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The San Francisco AIDS Oral History Series

THE AIDS EPIDEMIC IN SAN FRANCISCO: THE MEDICAL RESPONSE, 1981-1984

Volume II

Donald I. Abrams, M.D.	THE KS CLINIC, LYMPHADENOPATHY AND AIDS-RELATED COMPLEX, AND THE COUNTY COMMUNITY CONSORTIUM
Marcus A. Conant, M.D.	FOUNDING THE KS CLINIC, AND CONTINUED AIDS ACTIVISM
Andrew R. Moss, Ph.D.	AIDS EPIDEMIOLOGY: INVESTIGATING AND GETTING THE WORD OUT

Introduction by James Chin, M.D., M.P.H.

Interviews Conducted by
Sally Smith Hughes, Ph.D.
in 1992, 1993, 1995

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THE AIDS EPIDEMIC IN SAN FRANCISCO: THE MEDICAL RESPONSE, 1981-1984, VOLUME II, 1996, xv, 422 pp.

Donald I. Abrams (b. 1950), AIDS internist: work with Harold Varmus; early Kaposi's sarcoma cases at UC San Francisco (UCSF), lymphadenopathy in homosexual men; moving to the AIDS Clinic at San Francisco General Hospital (SFGH); defining ARC (AIDS-related complex); media coverage of discovery of HIV; County Community Consortium established, community-based clinical trials; AIDS medications; politicization of the epidemic. Marcus A. Conant (b. 1936), AIDS physician: dermatology specialization; clinical experience treating sexually transmitted diseases; establishment of Kaposi's Sarcoma Clinic and Kaposi's Sarcoma Study Group, UCSF; Kaposi's Sarcoma Research and Education Foundation (later SF AIDS Foundation); political activism around AIDS; transfusion AIDS and blood banks; funds for research; UCSF's reaction to AIDS patients; AIDS testing; 1992 international conference on AIDS; shifting AIDS activities to SFGH. Andrew R. Moss (b. 1943), epidemiologist: early AIDS epidemiology; competing with the Centers for Disease Control (CDC) and the SF Department of Public Health; AIDS epidemiology moves to SFGH; AIDS health workers study; case-control studies; research on AIDS in IV drug users, 1984; bathhouse issue; AIDS incidence study, 1983; San Francisco men's health study, 1983.

Introduction by James Chin, M.D., M.P.H., Clinical Professor of Epidemiology, School of Public Health, University of California, Berkeley.

Interviewed 1992, 1993, and 1995 by Sally Smith Hughes, Ph.D. for the San Francisco AIDS Oral History Series. Regional Oral History Office, The Bancroft Library, University of California, Berkeley.

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PREFACE--by David A. Lennette, Ph.D., and Evelyne T. Lennette, Ph.D.

As two young medical virologists working in Pennsylvania, we experienced first hand some of the excitement of medical detective work. We had our first glimpse of how personalities can shape the course and outcome of events during the swine influenza and Legionnaires' disease outbreaks.

On our return to California, we were soon embroiled in another much more frightening epidemic. In 1981, our laboratory began receiving samples for virologic testing from many of the early San Francisco AIDS patients--whose names are now recorded in Randy Shilts' book *And the Band Played On*. Our previous experience with the legionellosis outbreak had primed us for this new mystery disease. While the medical and scientific communities were hotly debating and coping with various issues during the following three years, we were already subconsciously framing the developments in an historical point of view. In San Francisco, dedicated junior physicians and researchers banded together to pool resources and knowledge out of necessity, and in doing so, organized part of the local medical community in a very unusual way. Once again, we were struck by how the personalities of each of these individuals shaped the course of events. Even before HIV was discovered, we knew we were witnessing a new page in the history of science and medicine.

The swine flu and legionellosis outbreaks were both very local and short lived. We now speak of them in the past tense. The AIDS epidemic, sadly, is still spreading unimpeded in much of the world. We know that it will be with us for a long time and that it is very unlikely that either of us will live long enough to read the closing chapter on AIDS.

Future generations will some day want to know how it all got started. The existing scientific reports and publications provide depersonalized records of some of the events, while newspaper articles and books give glimpses as summarized by observers. What are missing are the participants' own accounts and perspectives.

It is now more than a dozen years after the recognition of the AIDS epidemic in the United States. So much has happened and changed--already, some of the participants in early events have retired, records are being discarded and destroyed, and memories of those days are beginning to fade. We felt their oral histories had to be recorded without delay.

We had previously sponsored oral histories on virology with Dr. Edwin H. Lennette, David's father, and Dr. Harald N. Johnson, and were familiar with the methods and work of the Regional Oral History Office. We met to talk over the recording of the AIDS epidemic with Willa Baum, head of the office, and Dr. Sally Smith Hughes, medical history interviewer. After some discussion, we agreed that the events from 1981-1984 needed to be documented and we would fund it. This was a time when many crucial decisions on the clinical, public health, social, and political issues pertaining to AIDS were made with little scientific information and no precedents to rely on. The consequences of many of these decisions are still being felt today. With the discovery of HIV, however, the framework for decision making shifted to different ground, and a pioneering phase was over. Once we decided on the scope of the project, it was a simple task to identify prospective interviewees, for we worked with many of these individuals during those years.

Dr. Sally Hughes has shared our enthusiasm from the beginning. We are pleased that her efforts are now coming to fruition.

David A. Lennette, Ph.D.
Evelyne T. Lennette, Ph.D.

November 1994
Virolab, Inc.
Berkeley, California

SERIES INTRODUCTION--by James Chin, M.D., M.P.H.

As the California state epidemiologist responsible for communicable disease control from the early 1970s to the late 1980s, I had the privilege and opportunity to work with all of the participants who were interviewed for the San Francisco AIDS Oral History Project. I consider it an honor to have been asked to provide a brief introduction to the role that these individuals played in the history of AIDS in San Francisco during the early years. Before I begin, the following quote from Dr. James Curran, in a December 1984 issue of the *San Francisco Chronicle* sums up what has happened to all of the participants in this oral history project:

> I'd like to sound more upbeat about this, but there are some unavoidable facts we need to face. AIDS is not going away. Gay men don't want to hear that. Politicians don't want to hear that. I don't like to hear that. But for many of us, AIDS could well end up being a lifelong commitment.

The first recognized cases of AIDS were reported in the *Morbidity and Mortality Weekly Report (MMWR)* on June 5, 1981. I recall this report vividly. A few months earlier, the Centers for Disease Control (CDC) had begun sending an advance copy of the *MMWR* text to state health departments. The advance text of the June 5 *MMWR* had a lead article on the sudden and unexplained finding of five apparently unrelated cases of *Pneumocystis carinii* pneumonia in five young gay men from Los Angeles. The *MMWR* text was received in my office just before our weekly Tuesday afternoon staff meeting was to start. I handed the text to Tom Ault, who was responsible for the state's venereal disease field unit and asked him to have some of our federal- or state-assigned staff in Los Angeles assist in the investigation of these cases. I remember saying to him that it may not turn out to be much of anything, but it may be the start of something. I never imagined that that something would eventually develop into a worldwide epidemic of disease and death.

In the ensuing weeks and months, it became apparent that the mysterious illness reported from Los Angeles was also present among gay men in San Francisco. From 1981 to 1984, the numbers of AIDS cases reported from San Francisco rose almost exponentially--from a handful in mid-1981 to well over 800 towards the end of 1984. The impact that AIDS has had in San Francisco is unequaled on a per capita basis anywhere in the developed world. If the AIDS prevalence rate of about one AIDS case per 1,000 population that was present in San Francisco at the end of 1984 was applied nationally, then there would have been about a quarter of a million AIDS cases nationwide instead of the 7,000 that were actually reported. During the first few years of what was initially referred to as GRID (gay-related immune deficiency), there was general denial of the severity of this newly recognized mystery disease even in San Francisco. The enormity of the AIDS problem was first fully accepted by the gay community in San Francisco, and physicians and researchers in the city rapidly became the leading experts in the country on the medical management, prevention, and control of AIDS. In contrast to Los Angeles and New York, which also have had large concentrations of AIDS cases, the gay community in San Francisco has been more unified and organized in developing political and community support for the treatment and care of AIDS patients.

The epidemiology of AIDS, namely, that it is caused primarily by a sexually transmitted agent, was fairly well established by 1983, well before HIV was eventually isolated and etiologically linked to AIDS in 1984. Public health investigations in San Francisco, spearheaded by Selma Dritz in 1981 and 1982, provided much of the key epidemiologic data needed to understand the transmission and natural history of HIV infection. The more formal epidemiological studies of AIDS among gay men in San Francisco were carried out by Andrew Moss at San Francisco General Hospital (SFGH) and Warren Winkelstein at the University of California at Berkeley. All of these studies were helpful to Mervyn Silverman (who during this period was director of the San Francisco Department of Public Health) to support his decision in October 1984 to close the San Francisco bathhouses. Selma Dritz retired from her position with the health department in 1984, and Mervyn Silverman has moved on to become the premier HIV/AIDS frequent flier in his current position as president of the American Foundation for AIDS Research, which is now supporting studies internationally.

Jay Levy was an established virologist when AIDS was first detected and reported in 1981. His laboratory isolated and characterized a virus which he initially called ARV--AIDS Related Virus. He continues to play a prominent role in the quest to better understand the pathogenesis of HIV. Herbert Perkins was the scientific director of the Irwin Memorial Blood Bank in San Francisco during the critical period around 1982-1985 when data began accumulating to indicate that the cause of AIDS might be an infectious agent which could be transmitted via blood. Under his direction, the Irwin Memorial Blood Bank in May 1984 was the first blood bank in the country to begin routine surrogate testing of blood units for the AIDS agent using a hepatitis B core antibody test. He retired as director of Irwin Memorial in April 1993, but remains very much involved in defending the blood bank from legal suits arising from transmission of HIV via blood transfusions during the early years. Don Francis did not work in California during the early 1980s, but directed epidemiologic and laboratory studies on AIDS as the first head of the AIDS laboratory at CDC in Atlanta during this time period. Following his request to become more directly involved with field work and HIV/AIDS program and policy development, he was assigned to work in my office in Berkeley in 1985. Don took an early retirement from CDC in 1992 and continues to actively work in the San Francisco Bay Area as well as nationally and internationally on the development of an AIDS vaccine.

The clinical staffs of San Francisco General Hospital and the University of California at San Francisco established the two earliest AIDS clinics in the country, and in 1983, Ward 5B at SFGH was set up exclusively for AIDS patients. In the early 1980s, Don Abrams and Paul Volberding were two young physicians who found themselves suddenly thrust into full-time care of AIDS patients, a responsibility which both are still fully involved with. As a result of their positions, experience, and dedication, both are acknowledged national and international experts on the drug treatment of HIV and AIDS patients. Merle Sande, John Ziegler, Arthur Ammann, and Marcus Conant were already well established and respected clinicians, researchers, and teachers when AIDS was first detected in San Francisco. Their subsequent work with HIV/AIDS patients and research has earned them international recognition. The Greenspans, Deborah and John, have established themselves as the foremost experts on the oral manifestations of HIV/AIDS, and Constance Wofsy is one of the leading experts on women with HIV/AIDS. There is rarely a national or international meeting or conference on AIDS where most, if not all, of these San Francisco clinical AIDS experts are not present and speaking on the program. The number of HIV/AIDS clinicians and research scientists from San Francisco invited to participate in these medical and scientific meetings usually far exceeds those from any other city in the world. All of these individuals have made tremendous contributions to the medical and dental management of HIV/AIDS patients in San Francisco and throughout the world.

As of late 1994, more than a decade since the advent of AIDS in San Francisco, Jim Curran's remark in 1984 that "...for many of us, AIDS could well end up being a lifelong commitment" has been remarkably accurate for virtually all the participants in this San Francisco AIDS Oral History Project.

James Chin, M.D., M.P.H.
Clinical Professor of Epidemiology
School of Public Health, University of
California at Berkeley

September 1994
Berkeley, California

SERIES HISTORY--by Sally Smith Hughes, Ph.D.

Historical Framework

In 1991, Evelyne and David Lennette, virologists and supporters of previous Regional Oral History Office (ROHO) projects in virology and horticulture, conceived the idea for an oral history series on AIDS. They then met with Willa Baum (ROHO director), and me to discuss their idea of focusing the series on the medical and scientific response in the early years (1981-1984) of the AIDS epidemic in San Francisco, believing that the city at this time played a particularly formative role in terms of AIDS medicine, organization, and policy. Indeed San Francisco was, with New York and Los Angeles, one of the three focal points of the epidemic in the United States, now sadly expanded worldwide.

The time frame of the oral history project is historically significant. Nineteen eighty-one was the year the epidemic--not until the summer of 1982 to be officially christened "AIDS"--was first recognized and reported. The cause, human immunodeficiency virus (HIV), was reported in 1984, and by early 1985, diagnostic tests for HIV were being marketed. These achievements signaled a turning point in the response to the epidemic. Its science shifted from a largely epidemiological approach to one with greater emphasis on the laboratory. As soon as the virus was isolated, scientific teams in the United States and Europe raced to characterize it in molecular terms. Information about the molecular biology of HIV was in turn expected to transform AIDS medicine by providing a basis for treatment and prevention of the disease through new drugs and vaccines.

San Francisco continued to make important contributions to combating the epidemic, but by early 1985 it had lost its pioneering role. The AIDS test showed that the epidemic reached far beyond the three original geographic centers and involved large numbers of symptomless HIV-positive individuals, who were not identifiable prior to the test's advent. AIDS funding increased; the number and location of AIDS researchers expanded; research interest in the newly identified virus took center stage. San Francisco's salient position in the AIDS effort faced competition from new players, new research interests, and new institutions. The first phase of the epidemic was history.

Project Structure

Within the limits of funding and the years of the project (1981-1984), the Lennettes suggested eight potential interviewees whom they knew to play important medical and scientific roles in the early years of the San Francisco epidemic. (Both Lennettes have close connections with the local AIDS research community, and Evelyne Lennette was a scientific collaborator of 3 interviewees in the series, Jay and Deborah Levy and

John Greenspan.) I then consulted Paul Volberding, an oncologist at San Francisco General Hospital with an international reputation as an AIDS clinician. He and others in the oral history series made several suggestions regarding additional interviewees, expanding my initial list to fourteen individuals.[1] My reading of primary and secondary sources and consultation with other authorities confirmed the historical merit of these choices.

The series consists of two- to ten-hour interviews with seventeen individuals in epidemiology, virology, public health, dentistry, and several medical specialties. By restricting phase one to San Francisco's early medical and scientific response to the epidemic, we aim to provide in-depth documentation of a major aspect, namely the medicine and science it generated in a given location, at a given time, under near-crisis conditions. Like any human endeavor, medicine and science are embedded in the currents of the time. As these oral histories so graphically illustrate, it is impossible to talk about science and medicine without relating them to the social, political, and institutional context in which they occur. One of the strengths of oral history methodology is precisely this.

This concentration on physicians and scientists is of course elitist and exclusive. There is a limit--practical and financial--to what the first phase of a project can hope to accomplish. It was clear that the series needed to be extended. Interviews for phase two of the oral history project, a series with AIDS nurses, have been completed and serve to broaden the focus. Phase three, with community physicians with AIDS practices, is underway. The long-range plan is to interview representatives of all sectors of the San Francisco community which contributed to the medical and scientific response to AIDS, thereby providing balanced coverage of the city's biomedical response.

Primary and Secondary Sources

This oral history project both supports and is supported by the written documentary record. Primary and secondary source materials provide necessary information for conducting the interviews and also serve as essential resources for researchers using the oral histories. They also orient scholars unfamiliar with the San Francisco epidemic to key participants and local issues. Such guidance is particularly useful to a

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[1] A fifteenth was added in 1994, when the UCSF AIDS Clinical Research Center provided partial funding for interviews with Warren Winkelstein, M.D., M.P.H., the epidemiologist directing the San Francisco Men's Health Study. A sixteenth and seventeenth, with Lloyd "Holly" Smith, M.D., and Rudi Schmid, M.D., were recorded in 1995 when the UCSF Academic Senate allocated funds for transcription.

researcher faced with voluminous, scattered, and unorganized primary sources, characteristics which apply to much of the AIDS material. This two-way "dialogue" between the documents and the oral histories is essential for valid historical interpretation.

Throughout the course of this project, I have conducted extensive documentary research in both primary and secondary materials. I gratefully acknowledge the generosity of Drs. Arthur Ammann, Marcus Conant, John Greenspan, Herbert Perkins, Warren Winkelstein, and John Ziegler in opening to me their personal documents on the epidemic. Dr. Frances Taylor, director of the Bureau of Infectious Disease Control at the San Francisco Department of Public Health, let me examine documents in her office related to closure of city bathhouses in 1984. Sally Osaki, executive assistant to the director of the health department, gave me access to documents from former Mayor Dianne Feinstein's papers on her AIDS activities. I am grateful to both of them.

Dr. Victoria Harden and Dennis Rodrigues of the NIH Historical Office assisted by sending correspondence and transcripts of a short telephone interview with John Ziegler, which Rodrigues conducted.[1] I thank Dr. James Chin for his introduction to this series, which describes his first-hand experience of the epidemic as state epidemiologist at the California Department of Health Services where he was responsible for communicable disease control. I also thank Robin Chandler, head of Special Collections, UCSF Library, and Bill Walker, former archivist of UCSF's AIDS History Project and the San Francisco Gay and Lesbian Historical Society, for their assistance in accessing these rich archival collections.

The foregoing sources have been crucial in grounding the interviews in specifics and in opening new lines of questioning. A source to be noted, but untapped by this project, is the California AIDS Public Policy Archives, which is being coordinated by Michael Gorman, Ph.D., at San Francisco General Hospital.

Of the wealth of secondary historical sources on AIDS, the most pertinent to this project is Randy Shilts' *And the Band Played On*.[2] Although criticized for its political slant, it has been invaluable in providing the social, political, and ideological context of early AIDS efforts in San Francisco, particularly in regard to San Francisco's gay community.

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[1] Telephone interview by Dennis Rodrigues with John L. Ziegler, M.D., January 5, 1990. Tapes and transcripts of the interview are available in the NIH Historical Office, Bethesda, MD.

[2] Randy Shilts. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: Penguin Books, 1988.

Oral History Process

The oral history methodology used in this project is that of the Regional Oral History Office, founded in 1954 and producer of over 1,300 archival oral histories. The method consists of background research in primary and secondary sources; systematic recorded interviews; transcription, editing by the interviewer, and review and approval by the interviewee; deposition in manuscript libraries of bound volumes of transcripts with table of contents, introduction, interview history, and index; cataloging in national on-line library networks (MELVYL, RLIN, and OCLC); and publicity through ROHO news releases and announcements in scientific, medical, and historical journals and newsletters and via the UCSF web page.

Oral history as an historical technique has been faulted for its reliance on the vagaries of memory, its distance from the events discussed, and its subjectivity. All three criticisms are valid; hence the necessity for using oral history documents in conjunction with other sources in order to reach a reasonable historical interpretation.[1] Yet these acknowledged weaknesses of oral history, particularly its subjectivity, are also its strength. Often individual perspectives provide information unobtainable through more traditional sources. For example, oral history in skillful hands provides the context in which events occur--the social, political, economic, and institutional forces which shape the evolution of events. It also places a personal face on history which not only enlivens past events but also helps to explain how individuals affect historical developments.

The foregoing criticisms could be directed at the AIDS oral history series. Yet this series has several mitigating characteristics. First, it is on a given topic in a limited time frame with interviewees focused on a particular response, namely the medical and scientific. Thus although each interviewee presents a distinctive view of the epidemic, multiple perspectives on the same events provide an opportunity for cross-checking and verification, as well as rich informational content. Furthermore, most of the interviewees continue to be actively engaged in AIDS work. Hence, the memory lapses resulting from chronological and psychological distancing from events discussed are less likely to occur than when the interviewee is no longer involved.[2]

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[1] The three criticisms leveled at oral history also apply in some cases to other types of documentary sources.

[2] I discussed some of the advantages and disadvantages of oral history conducted with interviewees "in the heat of the battle", that is, while still engaged in the event being discussed, in an unpublished paper presented at the annual meeting of the Oral History Association, November, 1993.

An advantage of a series of oral histories on the same topic is that the information each contains is cumulative and interactive. Through individual accounts, a series can present the complexities and interconnections of the larger picture--in this case, the medical and scientific aspects of AIDS in San Francisco. Thus the whole (the series) is greater than the sum of its parts (the individual oral histories), and should be considered as a totality. To encourage this approach, we decided to bind several oral histories together in each volume.

Another feature of an oral history series is that later interviews tend to contain more detailed information because as the series unfolds the interviewer gains knowledge and insight from her informants and from continued research in primary and secondary sources. This was indeed the case in the AIDS series in which the later interviews benefited from my research in private document collections made available to me as the project progressed and by the knowledge I gained from the interviews and others connected with the AIDS scene.

A feature of this particular series is its immediacy, a characteristic less evident in oral histories conducted with those distanced from the topic of discussion. These are interviews with busy people who interrupted their tight schedules to look back, sometimes for the first time, at their experiences of a decade or so ago. Because many have not had the luxury of time to contemplate the full meaning of their pasts, the oral histories could be criticized for lacking "historical perspective." But one could also argue that documents intended as primary historical sources have more scholarly value if the information they contain is not filtered by the passage of years and evolving personal opinions.

The oral histories also have a quality of history-in-progress. With few exceptions, the interviewees are still professionally engaged in and preoccupied by an epidemic which unhappily shows no sign of ending. The narrators are living the continuation of the story they tell. Neither they nor we can say for sure how it will end.

Other Oral History Projects Related to AIDS

Oral history projects on other aspects of the San Francisco epidemic are essential for full historical documentation and also mutually enrich one another. Unfortunately, not enough is currently being done in this regard. Two local projects are Legacy, directed by Jeff Friedman, which focuses on the Bay Area dance community tragically decimated by AIDS, and Clarissa Montanaro's AIDS Oral History Project, which interviews people with AIDS. An installation, "Project Face to Face", directed by Jason Dilley and using excerpts from interviews with people with AIDS, was exhibited around the San Francisco Bay Area and in 1991 was part of the inaugural exhibit at the Smithsonian's Experimental Gallery.

AIDS oral history projects outside San Francisco include documentation by Victoria Harden, Ph.D., and Dennis Rodrigues of the NIH Historical Office of the contribution made by NIH scientists, physicians, and policymakers to the AIDS effort. Gerald Oppenheimer and Ronald Bayer at Columbia, with support from the National Library of Medicine and the Royal Marx Foundation, are conducting interviews with AIDS physicians in several cities across the United States. The New Jersey AIDS Oral History Project, sponsored by the University of Medicine and Dentistry of New Jersey, interviews faculty and staff involved in the epidemic and representatives of organizations providing AIDS support services. Rosa Haritos, Ph.D., at Stanford relied substantially on oral history in her dissertation on the controversy between the Pasteur Institute and NIH over the discovery of the AIDS virus.[1] In England, Virginia Berridge, Ph.D., co-director of the AIDS Social History Programme at the London School of Hygiene and Tropical Medicine, employs oral history in her research on AIDS policy in the UK.[2] And Maryinez Lyons, Ph.D., at the University of London, uses interviews in her work on the political economy of AIDS in Uganda.[3] In France, Anne Marie Moulin, M.D., Ph.D., Director of Research at INSERM, Paris, has relied on oral history in some of her work on the epidemic in France. The anthropologist, Paul Farmer, used interviews heavily in his work on AIDS in Haiti.[4]

Emerging Themes

What themes can be extracted from these oral histories? What do they convey about the medical response to AIDS in San Francisco? Was it unique, or are there parallels with responses to other epidemics? What do these interviews tell us about the complex interweaving of factors--social, political, economic, and personal--which shaped reactions to this epidemic, in this city, in these years?

The short answer is that it is too soon to attempt definitive answers. This is the second volume in a lengthy series, and most of the

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[1] Rosa Haritos. Forging a Collective Truth: A Sociological Analysis of the Discovery of the AIDS Virus. Ph.D. dissertation, Columbia, 1993.

[2] See: Virginia Berridge and Paul Strong, eds. *AIDS and Contemporary History*. Cambridge: Cambridge University Press, 1993.

[3] Maryinez Lyons. AIDS and the Political Economy of Health in Uganda, paper presented at a conference, AIDS and the Public Debate: Epidemics and their Unforeseen Consequences, sponsored by the AIDS History Group of the American Association for the History of Medicine, Lister Hill Center, NIH, Bethesda, MD, October 28-29, 1993.

[4] Paul E. Farmer. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press, 1992.

oral histories are not completely processed nor has the information they contain been fully assessed.

Furthermore, there is an inherent danger in reaching definitive conclusions on the basis of oral histories with only seventeen individuals. Obviously, this is not a statistical sampling. On the other hand, because these seventeen have been at the front line of the epidemic and in a city hit hard by the epidemic, their voices "count" more than their numbers might suggest. They also "count" because these individuals helped devise organizations and policies that have served as models for AIDS programs across the country and around the world. Thus, if used in conjunction with the traditional documentary sources, these oral histories "count" as rich historical sources on several levels.

Remembering these caveats, I will make some tentative suggestions about a few of the many themes which come to the fore as I put the first volume together. My thoughts will doubtless be modified and extended as I examine the oral history collection as a whole and assess it in the context of the existing literature on AIDS history.

--Professional and personal "preparation" for the epidemic:

Narrators invariably mentioned how their prior education and professional training and experience had prepared them for participation in the epidemic. Their training as oncologists or epidemiologists or infectious disease specialists "fitted them" in a deterministic sense to take notice when the epidemic was first recognized in San Francisco. Their interest piqued, they chose to become engaged because their professional knowledge, experience, and responsibility placed them in a position to contribute. How then to explain why others with similar backgrounds chose not to become involved? The interviews indicate that psychological makeup, humanitarian concerns, career ambition, sexual orientation, and simply being needed and on the scene also played a role.

--Organizing for the epidemic:

The oral histories describe at length, in detail, and on many levels how the academic medical profession in San Francisco organized to respond to the epidemic. The focus is on university physicians, but the oral histories show that it is impossible to talk about the medical response without at the same time mentioning its interconnections with the community physician, nursing, psychiatric, and social service professions, the gay community, and volunteer AIDS support organizations. Discussion of the coordinated medical system created in the early years of the epidemic, capsulized in the so-called San Francisco model of comprehensive AIDS care, permeates the oral histories. The complex process by which a community organizes to diagnose, investigate, and treat a newly recognized disease is detailed here, as are the spinoffs of these activities--the foundation of two AIDS clinics, an AIDS ward, and a specimen bank; funding efforts;

education and prevention programs; epidemiological and laboratory studies; political action at the city, state, and national levels; and so on.

--The epidemic's impact on the professional and personal lives of physicians and scientists:

A strength of oral history is its personal voice; its facility at putting a human face on history. The personal dimension makes history come alive and also helps to explain why events took the course they did. Its subjectivity is also an object of criticism. Hence the scholar's imperative to use oral history only in conjunction with the written documentary record.

Surprisingly, despite the flood of AIDS literature and the centrality of the medical profession in the epidemic, there are few accounts by physicians of the epidemic's professional and personal impact.[1] The physicians' voices which speak--at times poignantly, but always with immediacy--through these oral histories are a small corrective to the impersonality of most of the literature on AIDS.

On a professional level, the narrators describe commitment, concern, cooperation, camaraderie, and conflict as attributes of their engagement in the epidemic. Clinicians and epidemiologists confronted by what they perceived as a medical emergency described the prevailing sense of urgency and dedication of the epidemic's early years--to stop the insidious spread of disease, to discover its cause, to devise effective treatments, to establish community care arrangements. Narrators talked of concern for an articulate, informed, and youthful patient population, with whom some identified and for whom most felt great sympathy. They also spoke of the camaraderie and cooperation of the physicians, nurses, social workers, and community volunteers assembled at UCSF and San Francisco General to run the AIDS clinics and ward. But they also mentioned conflict--personal and institutional rivalries, funding problems, and run-ins with the university administration, city politicians, and gay activists.

On a personal level, the interviews recount the epidemic's impact on individual lives--of fear of a devastating and lethal infection, of stigma and homophobia involved in dealing with socially marginal patient populations, of exhaustion and burnout, and of growth in human experience and insight.

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[1] A few personal accounts by physicians do exist. See, for example: G. H. Friedlander. Clinical care in the AIDS epidemic. *Daedalus* 1989, 118, 2:59-83. H. Aoun. When a house officer gets AIDS. *New England Journal of Medicine* 1989, 321:693-696. The Oppenheimer/Bayer oral history project, mentioned above, also seeks to document physicians' responses.

--The epidemic as a social and cultural phenomenon:

These oral histories describe the complex interactions between disease and its social and cultural context. They indicate how the unique circumstances of San Francisco in the early 1980s--its large and vocal gay community, its generally cooperative medical and political establishments, the existence of a city budget surplus--shaped the response to the epidemic.

AIDS, like all disease, reflects social and cultural values. Implicit and explicit in the oral histories are evidence of stigma and homophobia, the politicization of the AIDS effort and those associated with it, and the tension between individual rights and social welfare.

The foregoing themes are but a few of those inherent in these oral histories. I hope that scholars will be persuaded to explore these further and to discover and research those unmentioned. To serve as a rich, diverse, and unique source of information on multiple levels is after all a major purpose of this oral history series.

Locations of the Oral Histories

The oral history tapes and bound volumes are on deposit at The Bancroft Library. The volumes are also available at UCLA and other manuscript libraries.

Note Regarding Terminology

In this series, both interviewer and interviewee occasionally use the term "AIDS" to refer to the disease before it had been officially given this name in the summer of 1982. "AIDS" is also used to refer to the disease which in recent years has come to be known in scientific and medical circles as "HIV disease." In these oral histories, the term "AIDS" has been retained, even when its use is not historically accurate, because it is the term with which readers are most familiar.

Sally Smith Hughes, Ph.D.
Project Director

March 1, 1996
Regional Oral History Office

LIST OF PARTICIPANTS IN THE SAN FRANCISCO AIDS ORAL HISTORY SERIES

VOLUME I

Selma K. Dritz, M.D., M.P.H, Epidemiologist, San Francisco Department of Public Health
Mervyn F. Silverman, M.D., M.P.H., Director, San Francisco Department of Public Health

VOLUME II

Donald I. Abrams, M.D., AIDS Internist at San Francisco General Hospital
Marcus A. Conant, M.D., AIDS Physician and Political Spokesman
Andrew A. Moss, Ph.D., Epidemiologist at San Francisco General Hospital

IN PROCESS

Arthur J. Ammann, M.D., Pediatric AIDS Physician and Administrator, UCSF
Donald P. Francis, M.D., D.Sc., Epidemiology and Virology at the Centers for Disease Control
Deborah Greenspan, D.D.S., D.Sc., Oral Manifestations of AIDS
John S. Greenspan, D.D.S., Ph.D., AIDS Specimen Bank, UCSF
Jay A. Levy, M.D., Virologist, UCSF: Isolation of the AIDS Virus
Merle A. Sande, M.D., AIDS Activities at San Francisco General Hospital
Paul A. Volberding, M.D., AIDS Oncologist at San Francisco General Hospital
Warren Winkelstein, Jr., M.D., M.P.H., The San Francisco Men's Health Study, UC Berkeley
Constance B. Wofsy, M.D., Authority on *Pneumocystis carinii* Pneumonia and Women with AIDS, San Francisco General Hospital
John L. Ziegler, M.D., AIDS Oncologist at the Veterans Administration Medical Center, San Francisco

Regional Oral History Office
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University of California
Berkeley, California

The San Francisco AIDS Oral History Series

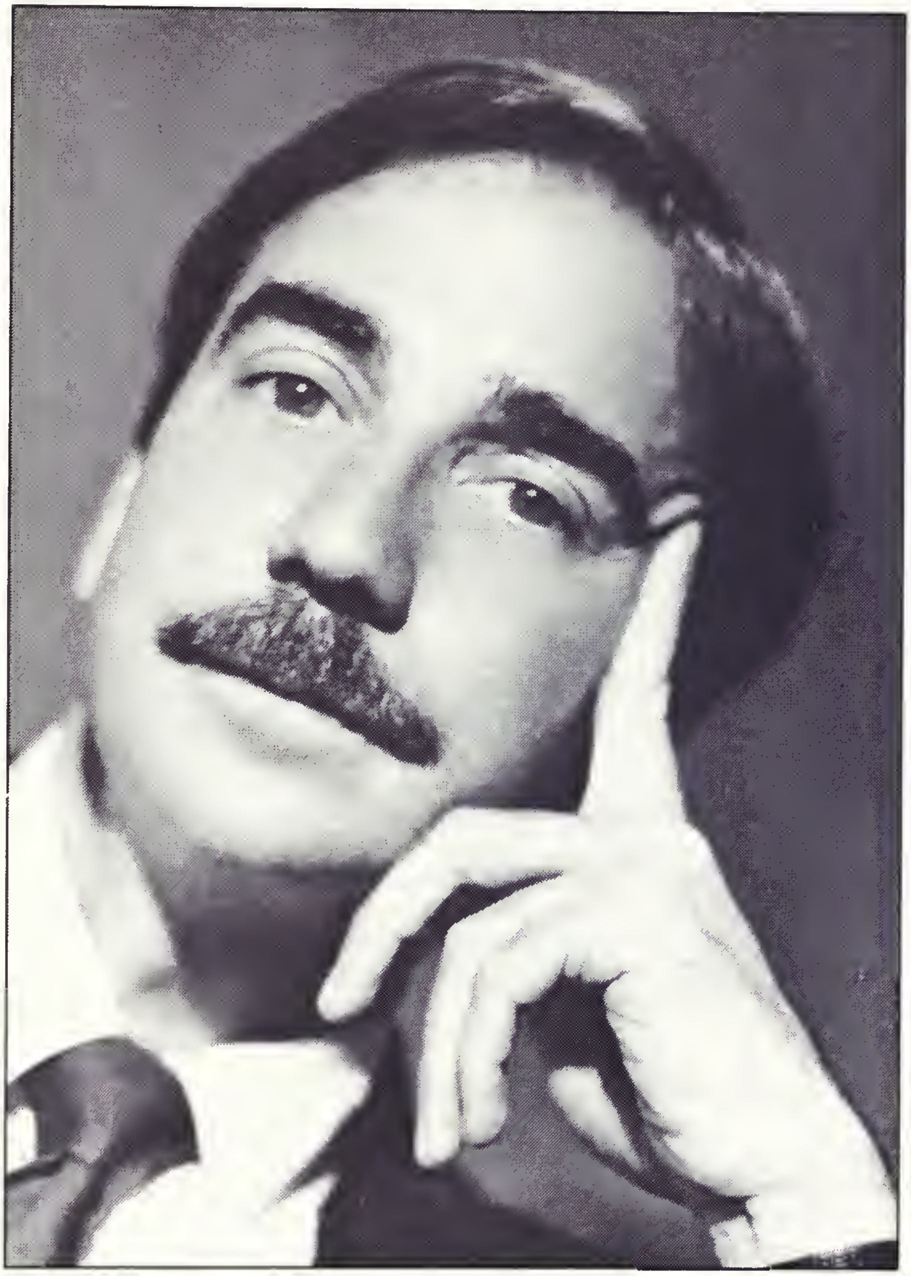
THE AIDS EPIDEMIC IN SAN FRANCISCO: THE MEDICAL RESPONSE, 1981-1984

Volume II

Donald A. Abrams, M.D.

THE KS CLINIC, LYMPHADENOPATHY AND AIDS-RELATED COMPLEX, AND THE COUNTY COMMUNITY CONSORTIUM

Interviews Conducted by
Sally Smith Hughes
in 1992



Donald Abrams

INTERVIEW HISTORY--by Sally Smith Hughes, Ph.D.

On several counts, Dr. Abrams was an obvious candidate for an oral history in the AIDS series. First, he is one of the three original members of the AIDS physician team at San Francisco General Hospital [SFGH] which in 1983 saw patients in the AIDS clinic and ward. Second, he took an early interest in lymphadenopathy--swollen lymph glands--which he observed while still a resident in a series of gay men as early as 1979, two years before the AIDS epidemic became manifest. As he explains in his oral history, only after 1981 was he able to recognize the condition as one associated with AIDS.

A third justification--if indeed another were needed--is Dr. Abrams' role in spearheading programs to accelerate research on and the availability of experimental AIDS drugs. He describes in the oral history how and why he founded the Community Consortium, an association of health care providers who treat the majority of people with HIV disease in the San Francisco Bay Area. The consortium serves as an interface between university physicians knowledgable about the latest developments in AIDS treatment, and community physicians and other health care providers in daily contact with patients. One of the consortium's greatest accomplishments is its community-based clinical trials program which enrolls patients to evaluate promising therapies for HIV disease.

Aside from discussion of these important topics and others, the oral history also reveals a personal struggle familiar to physicians, namely where to place the boundary between one's professional and personal lives. The problem is accentuated for Dr. Abrams, a physician whose basic science experience underscores his faith in the scientific method. But he is also gay, and AIDS in San Francisco was and remains a disease which overwhelmingly afflicts the gay community. What he discovered as a young physician at the outset of his career in academic medicine was that medical demands were often difficult to reconcile with those of the gay community and his own friendships. In the interviews, Dr. Abrams describes his close relationship with early patients and the gradual realization that to function as a physician, he could not continue to commingle the two sides of his life.

He also outlines his personal metamorphosis: from a young physician fearful about the impact of lifestyle on career advancement to an established physician with the courage to take a political stance on a national stage. The discussion does more than illuminate the tensions that most physicians face; it also illustrates how the epidemic almost inevitably politicizes those choosing to work at its front lines. The boundaries between medicine and society are once again shown to be interpenetrable.

The Oral History Process

Three interviews were recorded with Dr. Abrams in quick succession, all in November 1992. We met in his office on Ward 84, the administrative center of AIDS activities at SFGH. Warming to the process within the initial minutes of the first interview, Dr. Abrams spoke in detail of the "preparation" for the epidemic which by chance his education and training gave him. The observant reader will detect in the subsequent discussion of generally serious matters his conservativism, his compassion, and his sense of humor.

The edited transcripts of the interviews were sent to Dr. Abrams, who edited them lightly and supplied references. This oral history, particularly when read in conjunction with those of his SFGH colleagues and other archival material, provides a vivid picture of medical practice in the early years of the AIDS epidemic. It also speaks eloquently of the epidemic's impression on the life of an AIDS physician.

Sally Smith Hughes, Ph.D.
Senior Interviewer

Regional Oral History Office
The Bancroft Library
March 1996

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name DONALD IRA ABRAMS

Date of birth JUNE 1, 1950 Birthplace NEW YORK, NEW YORK

Father's full name SIDNEY ABRAMS

Occupation RETIRED/JOURNALIST Birthplace NEW YORK, NEW YORK

Mother's full name ROSALIE VITA BROKAW LAVIN

Occupation SALES Birthplace NEW YORK, NEW YORK

Your spouse N/A

Occupation Birthplace

Your children N/A

Where did you grow up? NEW YORK CITY AND CLEVELAND HEIGHTS, O

Present community SAN FRANCISCO

Education A.B. Molecular Biology Brown University 1972
M.D. Stanford University School of Medicine 1977

Occupation(s) PHYSICIAN, PROFESSOR

Areas of expertise AIDS

Other interests or activities TRAVEL, COOKING, GARDENING, AEROBICS, WEIGHT TRAINING, PHOTOGRAPHY

Organizations in which you are active COMMUNITY CONSORTIUM, AMERICAN ASSOCIATION OF PHYSICIANS FOR HUMAN RIGHTS, BAY AREA PHYSICIANS FOR HUMAN RIGHTS,

I FAMILY BACKGROUND AND EDUCATION

[Interview 1: November 12, 1992, San Francisco General Hospital] ##[1]

Childhood and Education

Hughes: Dr. Abrams, please give me a quick sketch of your family background and education up until the time you came to UCSF.

Abrams: I was born in New York and raised in Cleveland. We moved to Cleveland when I was four. My parents got divorced when I was ten; I'm the oldest of three children. I went to college in Rhode Island at Brown University, graduated in 1972, and then came to California at that time, went to the medical school at Stanford [1973-1977].

During my time at Brown University, I spent a summer [1970] working as a nurse in a hemodialysis unit in Amsterdam, and during medical school I spent a summer [1973] working in a pediatric hospital in Athens, Greece.

Hughes: How did those jobs arise?

Abrams: I just organized them. Stanford encourages fourth-year students to take time during their medical education to do other things, realizing that it is going to be their last spare time as a student. So I spent my fourth year living in London doing various rotations in seven different hospitals. I came back to Stanford, but moved to San Francisco because after living in London for a year, it was difficult to go back to Palo Alto.

Hughes: Were you getting an idea of what you wanted to specialize in?

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[1] ## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Abrams: Not really. When I left Stanford for the year to go to London, I was thinking that I wanted to be a psychiatrist. I had enjoyed my inpatient rotation in psychiatry at Santa Clara Valley Medical Center, and then spent the summer before I went to London in Boston at McClean's, Harvard's psychiatric hospital, working with borderline patients, and found that I was more accepted by the patients than by the staff. So I decided, well, there's something funny here.

My first rotation in England was at the Maudsley, which is their institute of psychiatry, and it seemed to me very unusual that psychiatric diagnoses didn't translate across the ocean, even though we both spoke English. Patients that we thought were psychotic, they would call depressed. Patients that we called schizophrenic, they would say were having an adjustment reaction. It just seemed to me that there was something amiss about not having something a little bit more objective to make a diagnosis upon; I was feeling uncomfortable.

Plus, I worked at this institute where patients were approached through psychotherapy--through Freudian, through Jungian, and through Melanie Kleinian approaches, or through electric shock therapy, or through pharmacologic interventions. Every different group had a different way of looking at the patient and a different treatment plan. That also got me a little concerned and confused, and I was looking for something that involved a little more science.

When I came back to the Bay Area, I moved to San Francisco, and I wound up doing my internship and residency in internal medicine [1977-1980] at the Kaiser Foundation Hospital here in San Francisco. That was a really important experience for me, because it's really where I learned medicine. Medical school at Stanford was fun and nice, but it was a little removed from reality.

Introduction to Lupus and Lymphoma, Stanford Medical School

Abrams: I have to give Stanford credit for teaching me a lot about two things which ultimately factor into the work that I'm doing now, and that is lupus and lymphoma. These two diseases are very highly referred to the Stanford University campus because of their expertise in autoimmune disease and lymphoreticular malignancies. Lupus, which is an autoimmune problem, and lymphoma, which is cancer of the immune system, focused me and gave me a background and appreciation for lymphocytes and disorders of lymphocytes.

Hughes: Had you actually done some research on those subjects?

Abrams: If I could go back to your question where you asked did I know what I was going to do: I still have in my typewriter case the essay that I wrote for Boston University School of Medicine that says, "What do you want to do with a career in medicine?" Right now, I'm doing exactly what I wrote in that essay that I wanted to do. However, from point A to point B, there were many veerings along the way.

When I left Brown and came to California to begin Stanford, I actually worked with an oncologist, Frank Stockdale, in his lab, and I am an oncologist now. However, I went through many tortuous turns to get here. I worked with that oncologist because I was interested in differentiation, in how cells become mature and different from each other, as well as how they become malignant.

I remember spending the summer [1972] before I started medical school working with Dr. Stockdale down at Stanford. I had to buy chicken breasts every week because I was trying to extract the main protein in chicken breast. I obviously did something wrong, because I always wound up with more weight of the protein than I had started with the chicken breast. [laughter] I remember Dr. Stockdale said it was a good thing that I was getting out of science and into medicine, when it came time for medical school to start and I decided to give up my lab career. So that was an abortive beginning of my research career. Then, once I started medical school, I was very much involved in that and didn't pursue laboratory research any further.

<u>Intern and Resident, Kaiser Foundation Hospital, San Francisco, 1977-1980</u>

Oncology Patients

Abrams: It was at Kaiser in San Francisco that I really learned how to be a doctor; I really enjoyed medicine and taking care of people. I did notice at that time that the patients that I was most interested in caring for were those who were at the end of their lives, particularly patients with leukemia and patients with solid tumors.

For some reason, and I think I've sort of worked out the reason in my own personal therapy over the past few years, patients who were dying held a lot of interest and fascination for me. My parents, from my birth to my second birthday, lost three out of four of their parents. So I think that that sense of loss and the fear of loss, especially of people that are close and loved, was probably subconsciously imbued in me by those experiences during my infancy. So when I try to think of what led me to pursue this career in oncology--but it was really AIDS--perhaps that has something to do with it.

In addition to being attracted to those patients, one of my role models or mentors, one of the doctors who I thought was very interesting and exciting, was the hematologist there at Kaiser, Lee Wilkinson. He was a thinker and a critical reader of medical literature, and I spent time with him when I was working in his clinic. I chose to work in his clinic one afternoon a week because I was interested in hematologic diseases, and particularly in lymphocytes, the building block cells of the immune system.

Lymphadenopathy

Abrams: In 1979 when I was a junior resident we started seeing a number of gay men who were referred to Dr. Wilkinson's hematology clinic because they had swollen glands. Nobody knew why their glands were swollen. They were being sent to make sure that they didn't have lymphoma or Hodgkin's disease. After I would do all the blood work that you normally do to determine why somebody has swollen glands, we sent a number of these men off to the surgeons for biopsies.

And one after another, their biopsies came back with the same picture under the microscope of very hyperactive glands, of lymphoid hyperplasia, particularly in the B cell area of the lymph node. That's a very nonspecific finding. Most of these patients were sexually active gay men with numerous sexually transmitted diseases and were using a number of the drugs that were popular in the community at that time. So we said, "Listen, we don't know why your glands are swollen, but you're living in the fast lane. Maybe you should slow down and not have so many partners, not get so many sexually transmitted diseases, give your immune system a break and don't use so many recreational drugs, and maybe your lymph nodes will go away."

We biopsied four or five of them. Then we started to see the pattern emerge and decided when we saw new patients with this syndrome that, well, we didn't really need to do a biopsy; they had this "gay lymph node syndrome," which is what it came to be called, after the "gay bowel syndrome" which had emerged in the mid-seventies.

Hughes: When did the term gay lymph node syndrome come into currency?

Abrams: I'm not sure if we actually started using it then or later, probably in '81. We didn't really know what to call this syndrome in 1979. We just saw these cases--

Hughes: But you were seeing a pattern.

Abrams: Yes. Kaiser being a place where cost effectiveness is the key, after we saw a number of these guys, then we saw the pattern and we didn't send them all for lymph node biopsies because that's expensive. We knew that chances are that they were just going to have this nonspecific benign reactive pattern.

What we didn't do, which is also unfortunately something that Kaiser is known for, is write up a description of this syndrome for the medical literature. Had we done that in 1979, that would have been throwing up a red flag that something was going on.

Hughes: Did you suspect some immune deficiency at that point?

Abrams: Lymph node enlargement implies that the immune system is hyperactive, and what we saw under the microscope was hyperactivity. So really we were thinking that their immune systems were overstimulated as opposed to deficient. In fact, that's what they were. These were the very earliest stages of HIV infection as we know it today.

Hughes: And it sounds as though you were operating under what later became known as the immune overload theory of AIDS causation.

Abrams: This was two years before we saw AIDS.

Hughes: Were you speculating immune overload?

Abrams: Yes, that these patients were having too many sexual partners. If they were taking in semen from each different person, then that was foreign proteins that their body was responding to. They had histories of gonorrhea, hepatitis, herpes, everything else, so that was a stimulation [to the immune system], and then they were using all these drugs. So that's what I mean: we told these patients to move out of the fast lane and see if their lymph nodes went away.

I really enjoyed working at Kaiser, and my desire when I finished my internal medicine residency there was to continue as a

Kaiser physician. I went to the chief of medicine at Kaiser, who was Jeffrey Fessel, who was a rheumatologist/immunologist, and told him that my desire was to stay on after I had finished my residency. By this time, I was a senior resident. Since Kaiser isn't a particularly academic program, I had not wanted to do a specialization, nor had I been particularly encouraged or directed to do so. So I was surprised when Dr. Fessel said, "Well, we don't really want to take people into the program who can't give to the program more than the program has given to them." I.e., if you want to work here on staff, you have to go out and learn something else besides what we've just taught you, so that you can make a contribution. That was a little bit startling. It was late in the year and I didn't know how suddenly to find a fellowship position or what I was going to do. I had always just assumed I'd stay on as a staff physician at Kaiser.

Plasmapheresis

Abrams: The next events also become relevant. I've always sort of been in the right place at the right time, is how I look at my involvement in this epidemic. I was interested, as I've said a number of times, in the immune system and lymphocytes and disorders of the immune system. Dr. Fessel himself was a specialist who believed that women with lupus, when they came in with a so-called lupus flare, needed to have their immune system suppressed with very high doses of steroids. And I always felt that that was a very dramatic and suppressive therapy, and that there needed to be another way to get around this.

So one day in November in 1979 it must have been, I was reading the *New England Journal* [*of Medicine*] in the classified column, and I saw that there was a doctor over at Children's Hospital, Peter Dau I believe was his name, who was advertising for a plasmapheresis fellow. Plasmapheresis was a relatively new technique in medicine, a little bit like dialysis, where the blood, instead of being filtered by way of membranes, is put through a centrifuge and the plasma gets removed and replaced with plasma from other people. So if there are antibodies in the patient's plasma, they get removed. It seemed to me that this technique had a lot of potential for some of these autoimmune diseases, for example, as a therapeutic alternative to lupus treatment with high dosage of very powerful steroids.

So I went over and I spoke to him and I said, "I'd like to do this fellowship, spend this year doing plasmapheresis training with you." He ultimately said I would be a good candidate. He said, "Just don't tell me in February that you're going to find another fellowship and leave me standing without a paddle." I said, "Oh, no, I don't have any desire or interest in looking anywhere else."

However, my mentor, the hematologist Lee Wilkinson, said, "There's another guy in the city that does plasmapheresis who's also a hematologist. Maybe you can go work with him and learn plasmapheresis but also learn to be a specialist in hematology." So he sent me over to talk to this doctor at Pacific Presbyterian.

Hughes: What was his name?

Abrams: I believe it was Harold Mielke. So I went and talked to him, and in fact, he said yes, he would be happy to train me as a hematologist, and so I'd have another skill as opposed to just learning this plasmapheresis.

Well, then I was sort of in a bind, and Lee Wilkinson said, "Well, why don't you go talk to my friend at the university, Curt Ries, who's also interested in plasmapheresis. He's on the faculty at UC, and he might be able to give you a better idea as to which one of these options you should choose--if you should go learn hematology and plasmapheresis with Mielke, or if you should go over to work with Peter Dau."

So I had an appointment with Curt Ries and his advice, if I recall, was to work with Dr. Dau in the one-year program and learn the plasmapheresis.

Hematology/Oncology Fellow, UCSF, 1980-1983

Abrams: Then in February of 1980, Lee Wilkinson came up to me in the hallway at Kaiser. I was making rounds, and he said, "Well, much to my better judgment, I've just recommended you for a position in the hematology/oncology fellowship at UC." I said, "What do you mean?" He said, "Well, I got a call from Curt Ries that they had somebody drop out of the fellowship, and they need somebody to take his place. You're interested in hematology and oncology, and you've talked to Curt about plasmapheresis. Why don't you go over and see what they say?" So I did, and they accepted me. And so I had to tell Dr. Dau, even though I promised I wasn't going to leave in February, that this was a real position in the fellowship program. So I just sort of fell into my specialty training.

My intent when I began in 1980 was to be a hematologist, because I thought oncology was basically following recipes and just giving patients various dosages of different chemotherapies, and it wasn't as intellectually stimulating as hematology. I particularly liked the interface between hematology and immunology that was afforded by the lymphocytes. I think that preference came from Stanford, where lupus and lymphoma are their main things. Throughout my professional career, the lymphocyte has been a focus. I don't go every day of my life saying, "lymphocytes, lymphocytes," but in talking to you about this now, it becomes clear to me that there was a unifying thread that probably originated at Stanford.

Hughes: Were you able to nurture that interest during your fellowship in hematology and oncology?

Abrams: Yes. Nineteen-eighty is when I started doing my hematology fellowship, and I started out right here at San Francisco General. I was very self-conscious because I thought, "Well, gee, now I'm in an academic center," and I had left that when I went to Kaiser from Stanford. I felt slightly inadequate because I hadn't been molded in this academic high-powered teaching thing. I found myself sort of threatened by some of the residents that I was supposed to be teaching because I figured, well, they were here at the university, and I was just a Kaiser resident.

But in fact, I also knew how to be a doctor. I had learned at Kaiser how to be a doctor, how to care for patients, and how to practice medicine, which I think you maybe don't learn as much at university centers, especially Stanford, where there's a little more focus on esoterica.

First Patient with AIDS

Abrams: I remember in May or June of 1980, my resident on the hematology consult service was a fellow named David Longworth, who's now at the Cleveland Clinic doing infectious disease. I was his fellow and he said, "They've asked us to see this guy with *Pneumocystis* pneumonia." I said, "Well, does he have leukemia or lymphoma?" He said, "No." So I said, "Well, why are they asking for a consult from hematology?" He said, "Well, just to see what we think he has." I said, "Well, they need to figure it out. If he doesn't have a hematologic malignancy or cancer, then what's the point in getting a hematology or oncology consult?" So he said, "Well, just because it's pretty interesting. It's a young guy who's otherwise healthy." Behaving as a typical fellow at the end of my first year of training, I said, "Why do we need to do this consult?"

But finally we saw the guy who was a youngish gay man and I started talking to him about habits. I said, "Well, do you use poppers?" I'm not sure that my residents or medical students really knew what poppers were or what I was talking about, but these are inhaled nitrites. The guy said, "Yeah." And I said, "Well, how often do you use them?" He said, "Well, every day." I said, "How much do you use?" I forget what quantity he said. I always was concerned about people that inhaled these substances, because I think that they're quite noxious.

When we walked out of the room, I said, "Well, clearly the guy has poisoned all of his alveolar macrophages," the cells in his lung that provide him with some immunity, "and that's why he has *Pneumocystis* pneumonia." I was very, I know everything, I'm just finishing my first year of my fellowship and I'm pretty glib about it.

And that was my first patient with AIDS. I didn't even realize it. I was even somewhat perturbed to have been asked to consult on the patient. I really missed the impact of the whole thing. To this day, Dr. Longworth reminds me of that.

Because AIDS came about as I was emerging into my professional career, and I didn't have a lot of experience, I missed the impact of some of the firsts that I actually saw, because I didn't realize that these things were unique, because I hadn't been practicing medicine for that long. So that was a disadvantage of my youth at the time.

Hughes: To a seasoned person, *Pneumocystis* in a young, otherwise healthy person would have stood out?

Abrams: Oh, yes. That's how we first became aware of AIDS, because in June of that same year the five cases from Los Angeles were published in the *Morbidity and Mortality Weekly Report*. Michael Gottlieb, though, wasn't all that seasoned either; he wasn't that much more advanced in his training than I was.

As part of the hematology/oncology training program, one needs to do laboratory work. My first year was clinical, and I really had no interest in working in a laboratory. I really enjoyed patient care and working with people. I had had the laboratory experience I described to you at Stanford. I had had laboratory experience at Brown that was okay; mainly I washed test tubes more than did any real science. So I didn't really know what I wanted to do with regards to working in a laboratory.

Bizarre Leukemias

Abrams: But during the course of my fellowship, I took care of a young woman, twenty-one or -two years old, who had a very bizarre leukemia, absolutely very bizarre. We had a lot of transference, counter-transference; we really bonded. I remember Valerie's death in the intensive care unit; I was involved in helping her have a smooth transition. Her mother was there, and it was really very touching, a very moving thing. Her leukemia was, again, very bizarre and unusual.

Shortly after Valerie died, her father, who was in the military, came to me and said, "You know, Don, I have leukemia now." And he had an even more bizarre leukemia. And I said, "This is too weird."

Hughes: Bizarre in what sense?

Abrams: Well, she had an erythroleukemia, and he had a megaloblastic leukemia. Leukemia usually means too many white blood cells, and these were leukemias of too many red blood cells in her case, and too many platelet precursors in his case. It was so strange and so unusual I said, "There has to be a virus here."

We had to do these presentations for a fellows' conference on Thursday afternoon over in the fellowship program, and normally it just involved doing a lot of library research and reading and making notes and making some transparencies. Usually it was on topics that emanated from a patient that you had seen, and it was a specific sort of field.

Harold Varmus' Lab, UCSF, and the Fred Hutchinson Cancer Research Center, Seattle, 1981

Abrams: But I decided I was going to give a talk on virus-induced malignancies, cancers caused by viruses. In an effort to help me figure out what kind of lab I was going to work in, when I gave this talk, Marc Shuman, who was the head of the teaching program, invited Harold Varmus, who is one of the microbiologists involved in retroviruses, to come listen to my lecture to see if there was any hope that I might work in his laboratory for the second year of my hematology/oncology fellowship.

Hughes: Did Harold Varmus mean anything to you at that point?

Abrams: Not really. [laughs]

Hughes: Just another doctor.[1]

Abrams: Yes. So Harold came to my presentation, and I think he thought it was a good presentation. I remember talking to him subsequently. We arranged a number of meetings, and he taught me about retroviruses. This man was the most brilliant person that I had ever talked to. He really knew what he was talking about in his field. But for somebody like me who was learning a whole new vocabulary, I would be able to follow him for the first three to five minutes of our discussion, and then it would go [schoop]. So I had to have a number of conversations with him until we decided that, okay, maybe I could work in the lab.

At the same time, there was a doc in the hematology program over at UC called John Klock, who I think had an interest in grooming me to learn how to do bone marrow transplants so I could help him someday, either at the university or ultimately he left the university. He knew that I was not that keen on doing laboratory research and, in a very kind and generous gesture, said, "When you finish your clinical year in June, how about taking time and spending a visiting fellowship month at the Fred Hutchinson [Cancer Research Center] Bone Marrow Transplant Unit in Seattle?" which is the most renowned transplant center in the nation. I said, "Well, that's a great idea." So he got me a position, gave me a stipend, and I was set to spend July working up at the Fred Hutchinson learning how to do bone marrow transplantation.

After giving this conference and having these meetings with Harold Varmus, we decided that when I came back from Seattle in August I would begin working in his lab, looking for increased expression of c-myc oncogene in human lymphoma tissues.[2]

Hughes: Was that a project he fed to you?

Abrams: Yes. Well, he put a postgraduate fellow from England in charge of teaching me the techniques. It was really Dave Westaway's project, and I was sort of his helper. It was another example of physicians working as laboratory scientists. Harold was a little leery about whether or not I could really produce.

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[1] In 1989, Dr. Varmus, with J. Michael Bishop, won the Nobel Prize in Physiology or Medicine.

[2] Dr. Abrams's project was titled, Oncogene activation in human B-cell neoplasms and Kaposi's sarcoma.

So in the meantime, here I am finishing my first year as a hematology fellow, which I really enjoyed, and planning a second year that was going to start with the month at the Fred Hutchinson Bone Marrow Transplantion Unit, and then come back and start learning about retroviruses. This was June, 1981.

So I get in the car to drive to the airport to go to Seattle, and I hear the end of a news story about an epidemic of cancer in gay men. I said, "Gee, that's pretty weird," and I switched around to hear if it was going to come on other stations, and it didn't, so I said, "Huh."

So I got to Seattle, I started working up there, and I said, "Hey, did anybody hear this story about this epidemic of cancer in gay men?" and they said, "No." I spent the month in Seattle, and Don Thomas was in charge of the bone marrow team that month. He got a Nobel Prize in medicine [1990] the year after Harold Varmus did. So within two months, I was working with two people who have now received Nobel Prizes; it's really quite amazing. I know both of them, and they're both really quite human and wonderful people.

Seattle is a real research factory. Every time a patient passes gas, he's put on a clinical research protocol. So I really learned how to do clinical research and what it means to adhere to a protocol. Plus, patients with bone marrow transplants have absolutely no immune system, and they're prone to get a disease called graft vs. host disease. Many people thought in the beginning that AIDS was a form of graft vs. host disease, because you get dermatologic manifestations, immune dysfunction, liver disorders, cytomegalovirus infection--everything that our patients with HIV get. It was an incredible experience being at Fred Hutchinson for that month. It was fabulous. I learned a lot about clinical trials research.

II THE AIDS EPIDEMIC

Early Kaposi's Sarcoma Cases at UCSF

Abrams: I came back, and Paul Volberding, who had just finished his fellowship in our [oncology] program, said, "Hey, I just saw my first case of this weird cancer, Kaposi's sarcoma, in this young gay guy over at San Francisco General. I know that you're not really overly enthused about working in this virology lab." Paul had also worked [in virology] with Jay Levy, but I don't think it was exactly what he lusted after. So I think Paul saw a little bit of himself in me, and knew that I was more interested in clinical things, and said, "Maybe you should help us." I'm not sure how far he had gotten towards putting together the KS [Kaposi's sarcoma] clinic, but he thought maybe I should become interested in Kaposi's as a clinical project.

Hughes: So there must have been more than one KS patient at that point.

Abrams: Well, maybe it was just his first one. He just told me about it, wanted me to be aware, and then subsequent discussions led to--

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Abrams: --working in Harold Varmus' laboratory, which is really another factory of thirty-five postdoctoral fellows and doctoral students from all over the world. They never had the experience of doing an internship and residency, so this was their commitment and their trial by fire. These people would stick around there all night long and run their gels, and do all their procedures, and play with their yeast and clones, and I didn't know what they were doing. I said, "I'm over this. I've done a fellowship and internship and residency and medical school, I am not that committed to bench research."

I was collecting malignant lymph nodes from patients with lymphoma, and also from patients with kidney cancers, and grinding up the tissues and learning to extract the DNA and to probe the DNA for the presence of genes from retroviruses to see if they were there in increased quantities.

While I was doing this, I also had a clinic a half day a week, because you have to continue to see patients as part of the training program. We were starting to see more of these patients--

Hughes: Now, just KS?

Abrams: No, also *Pneumocystis* [*carinii* pneumonia] and I'm trying to think how I got more involved in this. When did the KS clinic start?

Hughes: September 1981.

Abrams: I think I was right there at the very beginning. John Ziegler had just come [from the National Institutes of Health], bringing us all this expertise and interest about lymphomas. There was this clinical connection, because Paul was over here at San Francisco General and Marcus [Conant] was seeing patients in his dermatology clinic over at UC. These patients that were seen in the KS clinic were sent up for therapy to my clinic, because two floors above Marcus had the oncology clinic where I was in my training program. So I started to treat those patients with chemotherapy, including Bobbi Campbell, who was one of the first AIDS patients.

The patients would be evaluated by everybody [in the KS clinic] and then come up to me for chemotherapy. Then they started referring patients who had *Pneumocystis* to me for follow-up in my clinic. So I became sort of the AIDS provider early in the second year of my fellowship, when I was supposed to be working in the lab.

Hughes: Why was it logical to send you *Pneumocystis* patients?

Abrams: Well, people knew that I was interested in this new disease.

Hughes: So it wasn't because you were a hematology/oncology fellow.

Abrams: Well, that's part of it too.

Lymphadenopathy in Homosexual Men

First Cases, 1981

Abrams: Very early, in 1981 I noticed that a lot of these patients had swollen glands. And I said, "Hey, how long have you had these swollen glands?" And they would say, "Two or three years." So that's when I said [to myself], "I wonder if those people with swollen glands that I saw in 1979 are now these people."

So I called the CDC [Centers for Disease Control]. I remember, because I was working in Varmus' [molecular biology] lab. I said, "Hey, I think that there is this other group of people [with swollen glands] who have something less life-threatening than these infections and malignancies [of full-blown AIDS], and I think we need to study them because it might provide a clue as to what's going on here [with patients with Kaposi's and *Pneumocystis*]."

Hughes: When did you make that call?

Abrams: Well, the actual dates I don't recall, but it was before winter [1981]. I'll tell you why. One of the reasons that the CDC claimed that they didn't come out to look at my patient information was because there was a big snowstorm in Atlanta that was a surprise in December. So instead of coming to San Francisco, they went up to New York. They investigated records from Donna Mildvan and a number of other [AIDS] researchers in New York.

I had already sent them my definition of the syndrome, and an outline of a protocol to do an evaluation of patients with lymphadenopathy that I was submitting to REAC [Research Evaluation and Allocation Committee] at UCSF.

Hughes: Is this the protocol?[1] [hands document to Abrams]

Abrams: Yes. Where did you get that?

Hughes: Evelyne Lennette gave it to me.

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[1] "Evaluation of lymphadenopathy in homosexual men: a clinical study." [n.d.]

Abrams: So I sent this to the CDC, and they subsequently published an *MMWR* describing the lymphadenopathy syndrome, I think it was April of '82.[1] I wasn't referenced, and that sort of pissed me off.

I remember many people told me that they thought it was a fishing expedition, because I was throwing out a broad net and testing for many different things to see what the cause of this lymphadenopathy was. I said, "Well, how else are we going to do it; I don't have a hypothesis that it's this or that [cause]."

At this point in time, I was having a lot of phone conversations with David Purtillo in Nebraska, who was really intelligent. He was expert in what happens when people with immune deficiencies get infected with Epstein-Barr virus, the virus that causes mononucleosis and Burkitt's lymphoma. David had described this x-linked lymphoproliferative syndrome that only happens in men where some who get infected with Epstein-Barr virus develop malignancies, some die very rapidly of an immune deficiency, and some get lowered blood counts. So it seemed to me, well gee, this is a good model.

So David and I talked a lot, and he helped me with my thinking on this. He had a stroke and he died a month ago. But he was an early person that I talked to on the phone who taught me a lot.

Hughes: You knew of him through the literature?

Abrams: I think John Ziegler turned me on to this concept.

While I was working with Harold Varmus, I really got attracted to John Ziegler's thought processes and his enthusiasm and his new ways of thinking about causes of cancer, and so John sort of became my unofficial mentor. As Harold was my laboratory mentor, John Ziegler became my clinical mentor. I remember towards the end of the year in the lab when I was getting very frustrated and I felt like dropping the lab and just doing clinical stuff, John Ziegler felt very cautious about advising me to do that, because Varmus is this major star in retrovirology, and I should not jump ship to work with John...as my mentor in doing what? And so John was a little reluctant to advise me to do that.

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[1] D. Mildvan, V. Mathur, R. W. Enlow, et al., Persistent generalized lymphadenopathy among homosexual males. *Morbidity and Mortality Weekly Report* 1982, 31:19, 249-251 (May 21, 1982).

Designing the Lymphadenopathy Study

Abrams: I started my natural history study of patients with lymphadenopathy. I was connected with a lot of physicians in the gay community because I was a member of the Bay Area Physicians for Human Rights [BAPHR].[1] As an intern I joined that organization in its original year [1977], so I had a lot of colleagues in the community who had large practices of gay men who were previously healthy. I put the word out that I was interested in evaluating these patients: send them over to UC and I am going to do this protocol and get their blood and their semen.

At the beginning, I was working very closely with Larry Drew who did a lot of the cytomegalovirus studies, and I used to collect semen. I used to give the patients in the examining room a specimen cup and tell them, "I'd like a semen collection." They'd say, "Well, how am I supposed to get that?" I said, "Well, you figure it out." [laughs] They'd finish and I'd put my cups in the freezer and run over every afternoon, drop off six specimen cups at Larry Drew's office, and find that all of these people had cytomegalovirus in their semen. When we didn't know what the cause of this [syndrome called AIDS] was, we were looking at everything [as a possible cause].

I quickly in the lab changed my focus from patients with lymphomas and renal tumors to patients with lymphadenopathy and Kaposi's sarcoma. So I was sending a lot of my patients who were referred to me with lymph node enlargement for biopsies, and I would be in attendance when they had their lymph nodes removed. I would walk the lymph node over to pathology, and I would take half of it and freeze it in my freezer at Varmus' lab, and send the other half off for all sorts of studies.

Research on Oncogene Activation in Varmus' Lab, 1981-1982

Abrams: Then I would work on these specimens in Varmus' lab, looking for the same increased expression of the oncogene that I had been doing for the lymphomas. At one point I said, "Well, do you think I need to be in a more contained facility?"

I remember I was frightened working in the lab, because there were all these poisonous chemicals, there were these retroviruses

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[1] A predominantly gay organization.

flying around, and this phenol that we had to use that if you touched it, it burned your skin. It really made you feel terrible. One guy in the lab did have a lymphoma, a very bizarre T cell lymphoma, and he used to work on T cell lymphoma systems in chickens, and I just wondered if I was being put at risk here. They said, "Oh, no, really, there's no such thing as a retrovirus that causes diseases in humans, except in Japan." So I said, "Oh, well, okay."

Hughes: [Robert] Gallo's HTLV-I and HTLV-II.

Abrams: Yes. So that was a little cavalier. I was running around the lab with my specimens that I would collect from patients that I was evaluating, and I would try to extract DNA. DNA is one thing. But you really have to look at the RNA, and RNA is very delicate. If you touch any of the glassware with your fingers, then you leave RNase which will dissolve the RNA. So you have to be very clean and very precise, and I just couldn't be this obsessive. I spent four months trying to extract RNA from my specimens. Every time, after two weeks' preparation, when I'd look at the final film, there was nothing there. It really was very frustrating.

The lab felt like it was a doctor's office, because the clinic would keep calling [for me] and saying, "Well, they have a new patient for you to see, and here's a result of one of your lymphadenopathy patients." AIDS was a new disease, and I was being established as the central point person over at the UCSF campus who was clinically interested in this disease. Paul [Volberding] was [at San Francisco General Hospital], and I was [at UCSF]. So the lab got a little frustrated answering my phone calls. I remember that all these foreign postdoctoral fellows didn't really like being my secretary.

I was seeing so many patients with lymphadenopathy, I had to have two half-day clinics a week instead of just one, and that was cutting down on the time that I was spending in the lab. In the meantime, I was becoming very frustrated, because I realized that this amazing thing [the AIDS epidemic] was happening out there that needed investigation, and here I was twirling on little pipettes these invisible molecules [of nucleic acid]. I'm much more macro-oriented.

I was still working at Kaiser in the general clinic to make extra money during my fellowship. I would see patients with lymphadenopathy there as well. So I had my Kaiser cohort and my UC cohort.

I would sometimes collect lymph node specimens at Kaiser too. I would go with my vial of liquid nitrogen and pick up a surgical specimen from Kaiser and bring it back to put in my freezer.

Alarm over Presumed Kaposi's

Abrams: I remember one day I woke up--it was Christmas because I went to a Christmas party at Kaiser--and I had these four purple spots on my right hand. I said, "Yikes, what is this?" It was a weekend, because I was working in the emergency room at Kaiser.

I just kept looking at them and they weren't going away, and I said, "Jeez. This is very strange." So I immediately called Marcus Conant Sunday morning. I said, "Marcus, there's something going on here." I am a gay man, and we didn't know what this was, and I needed to reality test to make sure that I didn't catch this [Kaposi's sarcoma]. So I went over [to Marcus' office], and Marcus put my hand down on a velvet cloth and took a picture of the lesion, which got me very nervous, and said, "Well, if it doesn't go away in the next four or five days, come back and we'll have to do a biopsy."

I was completely freaked out. I had gone to a Christmas party the night before, and there was a woman there who had had a melanoma. She told me about a near-death experience and about the Center for Attitudinal Healing in Tiburon where they teach you how to cope with the fact that you're dying.

Everybody at this Christmas party said, "How are you doing?" and I said, "Well, I'm okay except for this." I showed everybody my four spots.

It was actually my partner who said, "Well, think about it. Did you spill something on your hand?" And then it dawned on me that when I carry the liquid nitrogen bucket, I don't have a top on it, and if the liquid nitrogen splashes, you get a little burn with a blister. I had on Friday gone to Kaiser to collect a lymph node, and I was carrying the open liquid nitrogen canister on my outstretched hand as I walked to my car. The liquid nitrogen splashed out, burnt me, and gave me these four spots on my hand.

Hughes: What a relief!

Abrams: Yes. It was pretty frightening because we didn't know what this disease [AIDS] was then, and here I was not only seeing these patients with it, but I was also grinding up and inhaling their DNA in the laboratory. So that was sort of a trip.

Suspecting a Retrovirus as the Cause of AIDS

Abrams: Well, ultimately what happened, the fact that I was so unable to do RNA work, and the fact that they didn't like me working in the lab because they didn't like being my secretary, and the fact that it wasn't for me anyway, I said, "Sorry, Harold, I'm over this." I learned retrovirology for the clinician par excellence, and I gave them little clinical conferences on this new disease and tried to get them excited about it. This is the time when I thought, well, maybe [the causal agent is] CMV [cytomegalovirus], maybe it's Epstein-Barr virus, maybe it's intestinal parasites, maybe it's ultraviolet irradiation, maybe it's nitrites--.

Then suddenly I said, "I bet you it's a retrovirus," and I tried to get them all excited so that some of them who had the technology and the laboratory expertise to examine these tissues that I was collecting might want to collaborate with me. But everybody had their projects and nobody could take the time.

Hughes: Was there a real rationale for your suspicion that it was a retrovirus?

Abrams: Well, just from what I had learned about retroviruses and what they do. It just seemed to me that if any disease was going to be caused by a retrovirus, this might be it. The fact that some people got lymphomas and some people got immune deficient was how retroviruses worked in certain animal systems too, depending on where the virus inserted into the genetic information. I forget what all the terms were now, but when I was deeply immersed in retrovirology, I just kept saying, "This is it." And that's what I was doing: I was looking in 1981.

Hughes: For a retrovirus.

Abrams: For increased expression--I didn't know how to culture or how to look for the retrovirus. I was looking for increased expression of a retroviral oncogene. The c-myc oncogene is what I was looking for, because that's the only thing I knew how to do. But I also was trying to stimulate people to think that maybe this [a retrovirus] has something to do, maybe this could be an explanation for this frightening, bizarre new disease.

Hughes: How did people react?

Abrams: Well, with interest, but everybody as I said had their own project. There was one guy, Paul Luciw, who subsequently went off to [the University of California at] Davis, who was across the bench from me, who always used to ask me questions about the disease. He seemed perhaps the most interested in it, and he subsequently has gone off into HIV-related retrovirology. But at that point, this lab had its focus, and everybody was doing their own project, and I was this clinician with this bizarre disease that I was interested in. It was too new. So I left the lab.

AIDS patients were developing cancers. My first fellowship year had been devoted mainly to hematology rather than oncology. The thought was that I should get my boards in oncology. To be eligible for them, the faculty decided that I needed to do more clinical work in cancer.

So I was happy, because I got to spend another year as a clinical fellow. While I was a fellow I was also doing my lymphadenopathy study, and I became the major referral point for all patients with AIDS at the university who were sent to my oncology clinic. With this added experience I would be eligible for my boards in oncology.

Hughes: There wasn't the term "AIDS" yet. How were you defining the syndrome?

Abrams: Well, we called it KS/PCP [Kaposi's sarcoma/*Pneumocystis carinii* pneumonia].

Hughes: So those two conditions were being referred to you. Anything else?

Abrams: Well, the lymphadenopathy was related to it.

Hughes: So those three conditions?

Abrams: Well, and the other opportunistic infections, although *Pneumocystis* was the most frequent.

Brian Lewis in the Cancer Research Institute at UCSF was my mentor at the time, and he applied for some fellowship funding from the National Cancer Institute.[1] Bruce Chabner at the National Cancer Institute approved a stipend for me so I could stay on for a third year of my fellowship. The reason people are

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[1] Brian J. Lewis, M.D., to Vincent T. DeVita, Jr., M.D., April 21, 1982. File "May 1983," files of the Associate Director, Division of Cancer Treatment, National Cancer Institute.

encouraged to go to labs is that once you start doing a lab project, you can usually get funding through the lab supervisor.

Decision to Focus on the Clinical Aspects of AIDS

Abrams: Now I was jumping ship, I was leaving a Nobel Prize-winning laboratory advisor [Varmus] to enter this unknown field of this new disease. Maybe it was going to disappear; maybe it was a flash in the dark. But it was very challenging, it was something that was affecting my community, and I was well suited and well educated to be able to make a contribution. So I wanted to.

And so I did an oncology fellowship year, managing patients with traditional solid tumors, but mainly being the AIDS fellow at UCSF for that year, 1982 to 1983.

Hughes: Did people think you were crazy?

Abrams: [laughter] I don't remember. Did they?

Hughes: Well, you went from a Nobel Prize-winner's lab to research on this unknown disease.

Abrams: Mike Friedman, who's now one of the program directors at the National Cancer Institute, was the director of our program at that time. He always advised me that patient care, which was my strong point, was not something that got people ahead at the university. I then started having maybe four half-day clinics a week, seeing my lymphadenopathy patients, seeing patients with Kaposi's sarcoma, seeing patients with *Pneumocystis*.

AIDS Medicine at San Francisco General Hospital

Carving Up the Turf

Abrams: One point that I need to make is that very early in the establishment of the KS Clinic, policy was made that patients diagnosed with Kaposi's sarcoma, even if they were seen in the KS Clinic on the third floor at UCSF, should not be referred up to me for chemotherapy any more. I had been giving all the chemotherapy. This new disease and particularly this new cancer were going to be Paul's [Volberding] field, his niche, in the program. And he couldn't rely on coming over to me, an [oncology] fellow, and looking at my charts to learn how the patients were doing with their chemotherapy; he needed to have first-hand experience. So a policy decision was made that all patients with Kaposi's sarcoma were to be treated at San Francisco General by Paul.

Hughes: Now, how did you feel about that?

Abrams: Oh, I was upset about that. I had worked here [San Francisco General], and I knew this hospital, and I knew the building where Paul was going to see patients, where they had this grubby elevator with graffiti all over it. I said, "My patients are very sophisticated, intelligent people that have a high socioeconomic status, and I think that herding them all over to San Francisco General to be treated in that place, which is not particularly wonderful, is sort of--I don't like it. These men need to have a choice."

This was an issue for a while, but it became clear to me that this was a professional/political issue, and that it wasn't my place to try to interfere. Some patients said that they were absolutely not going over [to the General] and they stayed with me. Alpha interferon was considered to be something new, modern, hopeful for perhaps curing the whole thing, so once Paul started doing clinical trials, it was a little easier to rationalize sending patients to SFGH for care. But in general, I found it upsetting.

Hughes: The process you're describing sounds to me as though it's carving up the turf. Was that indeed a fairly salient part of those early days, deciding who was going to do what in this very amorphous disease, with many disciplines feeding into the KS Clinic? Some of you were quite young, and you must have been thinking about where this disease was going to lead you in a professional sense.

Abrams: Well, I don't know. I was still a fellow and I was still naive and I didn't know about politics and academia.

What ultimately happened was I was seeing a lot of these patients with lymphadenopathy, and I had devised a three-page flow sheet that I used for every patient, where I would write everything about them. I would write down all their laboratory values, [the results of] their physical exam, and their [medical] history. I would collect all my information on every patient on this sheet so that I could ultimately collate it.

The patients came to see me in the oncology clinic. They were being billed for their visit to me as well as for all the lab tests I did because I had no funding to pay for their visits and tests. Patients with lymphadenopathy were generally well patients; they didn't have anything really wrong with them.

So I was very busy, and I saw a lot of these patients, sometimes six a day, and I would fill out my flow sheets on them, and they would have generated a UC Hospital chart when they came to see me. We also wanted one of our own clinic charts. That needed to have NCR [National Cash Register] forms filled out to go in with hospital chart and clinic charts so that the billing could occur and all this and that.

The Move to San Francisco General Hospital

Abrams: Because I was busy running around, I would fill out on my flow sheet all the information from every patient I saw as I saw them, put it in their chart, and when I had free time, I would write out their hospital note, and then put that in their hospital chart with the copy into our clinic chart. But sometimes I didn't have time to do them, and I developed a stack of these charts that I stored in a file drawer in my office.

I had been promised by the program that they would keep me as an instructor after I finished my fellowship in June 1983, and I would continue to do my research, seeing patients with lymphadenopathy and being the unofficial AIDS consultant at Moffitt Hospital.

I went away on a vacation; a patient called for a lab result regarding a stool specimen I had collected strictly for the study. The head nurse couldn't find the patient's chart in our clinic files, went back to my office, opened this drawer, and found all of my incomplete charts. "No, no, this is very, very bad. We're very sorry that we had to find all these charts that you hadn't filled out. How are we supposed to give these patients results?" Well, these were not patients with cancer or any life-threatening disease. They were participating in a natural history research study. They really didn't need to have their clinic chart generated immediately.

But I was found delinquent in filling out these charts. I got called into the chief's office at the Cancer Research Institute [at UCSF]. All the professors were sitting around the table, and they said that they needed to withdraw the offer to have me stay on as a clinical instructor. They felt that it would be better for me and my career if I joined Paul at San Francisco

General Hospital in his developing AIDS program, because the city obviously was going to focus its AIDS energies at San Francisco General Hospital. Paul was there, Connie [Wofsy] was there, they had a secretary, so there was infrastructure and support, and I would be better off over at SFGH.

Hughes: Now, were the charts the real reason?

Abrams: Well, [laughs] I think that they had lined up somebody else to be a clinical instructor. I think they wanted to have the husband of one of the nurses on the cancer ward come up from Stanford and have a position, and they could only appoint one clinical instructor in the program at UCSF.

Despite the fact that I was generating a lot of revenue, traipsing a lot of patients through the oncology clinic who didn't have cancer who in the best of possible worlds would not have been paying patients because they were undergoing a research evaluation, I think there was also some homophobia, to be honest. I think the concept of having all these gay men who were relatively healthy with this unknown disease sitting in the waiting room around all these patients with malignancies was disturbing [to them]. So I think they just thought that everything [on AIDS] should be centralized at one place [SFGH].

I've already told you how I felt about that. I just felt that this was a terrible affront to gay men to have to be herded to San Francisco General Hospital to wait for x-rays, sitting next to people that are chained and shackled and wearing orange prison uniforms. I thought that this was very, very bad. I said to Paul, "I will not come work in that clinic with that graffiti in the elevator." And Paul actually painted the elevator to get rid of the graffiti. Subsequently, we had to paint the elevators ourselves one Saturday afternoon after I was here for a while.

Well, once I got here I was with Paul and Connie and Roberta Gonzalez-Wilson, who was our secretary. She was the Girl Friday that did everything when we were just a small family. It was really wonderful. It was a much more pleasant esprit. We were all committed to what we were doing.

There was a little division of labor. Paul would take care of and be intellectually responsible for research programs in caring for patients with the malignancies. Connie, who was an infectious disease specialist, would care for patients with the opportunistic infections. We would all care for the patients, but our areas of intellectual and academic pursuit were distinct. Paul would be KS and lymphoma, Connie would be opportunistic infections, and I would be these AIDS-related conditions, including the lymphadenopathy syndrome. We called these things ARC [AIDS-related complex] back then.

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Abrams: I was one of the people that actually was on the conference call that made up the term ARC back in 1983.

These AIDS-related conditions became my area of expertise. At the beginning, the three of us did have the division of labor and turf clearly worked out--although Paul and I did collaborate in that we were the two oncologists here, so I helped him with the treatment of the KS and the lymphoma patients at the beginning.

Hughes: Was this a friendly division of labor?

Abrams: Yes, because we each had our area of expertise by then. Paul had seen these KS patients for a long time, was doing these trials; Connie was the infectious disease consultant. Although I knew how to treat these things [opportunistic infections], Connie had more expertise. I had defined ARC, so I was looked upon as the one who knew best what it was all about.

So yes, the friendly part is really what highlighted that period when it was Paul, Connie, and I. It was really wonderful.

In fact, UC soon realized that it had made a little mistake in giving up its clinical care of people with AIDS. I got a phone call shortly after I got over here [SFGH] saying that they were thinking of setting up a separate adult immunodeficiency clinic over there [UCSF]; would I be interested in coming back and heading it? Paul, Connie, Roberta, and I shared one office. Roberta overheard me say this and she took her silver pen with the purple stripe that lined the silver writing, and she wrote down what I said, and I hung it on my bulletin board. It said, "I'm no yo-yo. You just sent me over here [to San Francisco General], now you want me back [at UCSF]. I'm no yo-yo; I happen to like it here." And so I stayed.

Sometimes it really feels like I'm on a mission, and that it's not under my control, because I always seem to be at the right place at the right time, learning the right things, and being with the right people. It's almost magic.

Hughes: What did an AIDS patient encounter when he came to San Francisco General?

Abrams: Well, when I first got here, Ward 86 [the AIDS Clinic] was all we had, and in fact, only half of it was renovated. So we got off the elevator and turned left, and we had--well, I don't even remember if we had a front desk. The overwhelming memory that I have is that the whole right side of that hallway was like light fixtures hanging from wires from the ceiling, and chipped paint, and awful linoleum, and darkness, like it was off limits. It was something out of the Addams Family.

The other half of the hallway had been barely redone so that we had examining rooms. Then Paul, Connie, and I, and Roberta, our secretary, shared this one big office space where we just had little partitions up so that we could all have some sense of privacy. But it was not beautiful by any means.

Hughes: Where did the money come from?

Abrams: At that point in time, I think I was completely ignorant as far as administration and finance, and it was all [obtained from] the city and [by] Paul. There were 200 patients with the lymphadenopathy syndrome over at UC that I was following, plus a number of patients with AIDS that I had seen.

I figured when I left the university, no patient would want to schlep all the way across the city to be seen at San Francisco General. But it turned out that it was more important who was seeing them than where they were being seen. In fact, I really drained away a lot of patients from that clinic over there. When I became a faculty member and got to see financial information, I learned that my departure from that clinic really hit it. But they subsequently replaced seeing patients with AIDS with doing other things, and I'm not feeling sorry for them at this point in time. But it made an impact when I left.

Hughes: So San Francisco General became the AIDS center.

Abrams: Right, and I brought over a lot of patients who had third-party insurance, and who had been cared for over at UC. That really solidified it [AIDS activities at the General] when all [three] of us joined forces.

Ward 5B, the Inpatient AIDS Ward

Hughes: Ward 5B was, is, a unique place.[1]

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[1] For better continuity, the remainder of this section was moved from its original position later in the transcript.

Abrams: Now it's 5A. The AIDS ward moved to 5A in '84.

Hughes: It was not and is not a typical hospital ward, from what I've heard.

Abrams: It provided a target for the gay community to show their support and their care for their brothers who were sick. So even though it is dealing with a very terrible life-threatening disease, 5A or 5B has always had in a way a lightness.

Rita Rocket has come for five years every other Sunday and put on a brunch for all the patients, and she used to tap dance in the hallway. At Christmas a group called the Godfather Fund used to give a party, and bring people slippers and teddy bears and shaving stuff. There are various donations; there are flowers, there are plants--it always has a feeling of brightness and airiness that isn't present on the other wards of the hospital, because it's a focus of community attention and giving.

We used to say that our nurses were volunteer nurses, which gave the wrong impression. It made people think that they worked there without pay. But what we meant was that they chose to work there. So that also gave a different esprit than if nurses had been assigned there and didn't want to work there. The people there want to be there, often because they belong to a group at risk for HIV infection; they're gay men or women. I think it creates a sense of commitment to the patients that you might not get in other parts of the hospital.

Because these people have been working there for a long time, they become experts in care of these patients, and they can transmit information effectively to the house staff and to the new doctors that are just rotating through and don't know much about the disease or the dosages of the drugs. So it's really a nursing unit. The docs don't have much input and really can't take much credit for the success of 5B and 5A. And the nurses are very proud of that.

At the beginning, I was very involved and we used to have weekly conferences, talking about all the patients and reviewing how they all were. The learning curve was very steep at the beginning, because it was such an unusual disease and a new disease, and we didn't know anything, so we all took advantage of every opportunity we had to transmit information and to learn things from each other.

As I've become more involved in administrative programs and other research areas, I've become less involved in inpatient care. And now we have a full-time physician who oversees 5A, and two full-time physicians who oversee patient care and service consultations in the hospital for AIDS patients, so it has allowed me to become less involved than I was early on. When you're just finishing your training in medicine, you're really trained to take care of patients, and particularly to take care of inpatients. I think that as you grow older or are more removed from doing inpatient medicine twenty-four hours a day, it becomes a little more daunting. So one tends to withdraw and allow the younger people with more energy to do it.

I miss that, because whenever I visit inpatients, I know that they really appreciate it, and I know that all those patients that I used to see, the twelve a day, really appreciated it. I used to amaze Connie; I remember she always used to do these little reviews of charts, and she said, "Every day, Donald would have a note in his patients' charts."

I don't have that many inpatients any more, and when they're there, I know that my note doesn't really mean anything; it has to be the note from the house staff and from the attending of record. So one learns to withdraw when appropriate. But there are some aspects of patient care I miss.

Hughes: Well, comment on 5B/5A as a model for AIDS wards.

Abrams: I think it became clear that this was a good model and a good method for providing comprehensive care in one place. With nursing, with medical, and with the psychosocial support of the Shanti organization and the AIDS Health Project people, everybody all there on site, it really became a very efficient and compassionate means of providing inpatient care. Early in the epidemic, we just constantly were traipsing people from all over the country, all over the world, through 5B then 5A, and through the AIDS clinic upstairs, to see what it was like to have these facilities concentrated in one place for this patient population [with AIDS]. And the ward has been replicated, I think, all over the world.

The Nursing Staff of the AIDS Clinic

Hughes: You've mentioned the three physicians who were there in the beginning. What about the nursing staff?

Abrams: Well, Gayling Gee was the head nurse, and Gayling had always promised to get me over here full time. When I first came as a fellow to San Francisco General and worked in the oncology clinic, at that time there was no oncologist at the hospital. We just had outside consultant oncologists come to see the cancer patients. The fellows had to draw up our own chemotherapy in the clinic.

Gayling and I got along very well. Again, it was just when I finished my Kaiser residency and I was sort of young and feeling inadequate. Gayling was the nurse in the heme-onc [hematology-oncology] clinic, and she came over and worked with Paul in setting up the AIDS oncology program. She had always said that she wanted me to be over here full time, so she got that.

Tracy Moran was also one of our pioneer nurses. Tracy continues to stay as the clinical nurse specialist. Shortly after I came, we started getting nurse practitioners, and J. B. Molaghan was our first nurse practitioner. Actually, Gary Carr was hired before J. B., but J. B. started first, because Gary was on vacation or something. So that became the nuclear group.

Hughes: Cliff Morrison came later?

Abrams: Cliff was never in the outpatient clinic.

Hughes: Oh, we're talking about Ward 86.

Abrams: Right, Ward 86 is the outpatient clinic.

Cliff was on 5B, and he put together the inpatient unit. I came in July of '83, and I think the inpatient unit opened the same month.

Hughes: Yes, July, '83.

Abrams: That's another thing when I first got here that I was fighting against. I felt that having all the AIDS patients segregated on one unit was discrimination and homophobia. I had worked at UC and the AIDS patients were all over the hospital. Okay, sometimes they didn't get their trays brought in to them, but I thought you needed to have them dispersed so that the nursing staff would get used to it and realize that AIDS is just a disease, et cetera.

So I was sort of against this concept of putting everybody together, but the AIDS ward had all been planned and prearranged before I got here. And actually, it seemed to work pretty well, and everybody was happy with it. It provided a target for the gay community to make contributions to this focal point of the inpatient care. So I think it was ultimately obviously a wise decision, and it has served as a model.

But the inception of 5B was nothing that I had anything to do with, because I wasn't here yet.

Hughes: But you did work there?

Abrams: Well, when I first got here as a faculty person, I had a lot of patients whom I took care of in the outpatient setting. Being energetic and young and somewhat naive as to how things worked, I followed my patients into the hospital and also took care of them there. Which at the time was okay, because people were frightened of these patients, and they didn't know what to do.

One learns that when a patient gets admitted to the hospital, he's under the care of the medical team that's in charge of admitting patients that day, and that really the best I should do is be a social visitor, and not manage the care. But there were times when I first got here where I would have up to twelve patients in the hospital that I considered to be my patients, and I would follow them there, and I would spend a lot of time with them. So at the beginning of the ward, I was really a presence there a lot.

Hughes: And was that acceptable at that time?

Abrams: Sure. We were all learning about this disease, and I believed that you couldn't learn about it by just seeing the outpatient half of the disease and not the inpatient part. That allowed me to make many observations about toxicities of drugs and abnormal laboratory values that ultimately we did report on in the literature and made a contribution.

Drug Therapy

Hughes: What could you do, were you doing, for patients who were hospitalized?

Abrams: We've learned to follow patients earlier in what we now know is a continuum of HIV disease. At that point in time, we'd see patients coming in who never knew that they had AIDS, and they would present at the most extreme end of it. Now we can prevent those rapid cases from happening.

For the treatment of *Pneumocystis*, for example, the most common infection, we still use trimethoprim-sulfa and pentamidine. We have a few other drugs today as well, but I don't know that we've really changed treatment dramatically in the past ten years with regards to that condition.

We still use the same agents for the other infections. Fluconozole is something new that we didn't have back then; toxoplasmosis we treat the same; cryptococcal meningitis, most people would still use the same drugs we used then as well; KS, we've come back to using the same chemotherapies that we used at the beginning.

We didn't have our antiretrovirals, our AZT, ddI, and ddC at that point in time, but I'm a little unique in my feeling about those drugs compared to some of my colleagues. I still have a lot of patients who don't take those drugs, so in my opinion, treatment hasn't changed that much. I mean, it has, because of so many people taking the antiretrovirals and then the drugs that they need to protect against the side effects of the antiretrovirals--erythropoietin, G-CSF [granulocyte-colony stimulating factor], and all those others.

Some of my patients that I see today I first started seeing in 1981 with lymphadenopathy. We know the natural history of this disease is that by ten years after infection, 50 percent will have progressed [to AIDS], so that means 50 percent won't. So I do see a large number of people who are stable over a long period of time, who were stable before antiretrovirals came along, who chose not to take the antiretrovirals because they figured if it's not broken, don't fix it, who remain stable six years after antiretrovirals have been on the market.

So I have a skewed population and a skewed vision of the disease, because I have the opportunity of having so many patients who have been with me for a very long time. Now, that makes it more difficult when they get sick, because there's an even greater sense of loss.

Early AIDS Patients

Bobbi Campbell

[Interview 2: November 19, 1992] ##

Hughes: There are a series of early patients made famous, if that's the word, by Randy Shilts' book.[1] Would you talk about them, and any others?

Abrams: Well, I remember at the beginning of the epidemic that for Paul and myself and everybody who was working in AIDS, there were more doctors than there were patients, so we had a very intimate relationship with the patients. Even when the city had about fifty or sixty people diagnosed with AIDS, I still think that we knew each one of them individually.

Obviously, that couldn't continue as the epidemic grew in the city, but there is something very special about those interactions with the early patients, because the patients were pioneers in this new disease, facing completely uncharted waters. We didn't really know what was going to happen to them; we didn't really know what this disease was; we didn't know at that time whether we were at risk to get this disease by just taking care of the patients.

It was a very intense experience to bond with some of these people, and I remember particularly Bobbi Campbell, who was a nursing student in the school of nursing at the university [UCSF], who used to come over and get chemotherapy. Bobbi became the KS poster boy,[2] in his own terminology, and became one of the first people to be out about having AIDS and Kaposi's sarcoma.

He had a very mild case of Kaposi's sarcoma; he just had the so-called old man's variant of the disease, where it was confined initially to the soles of his feet. Although that's all he had, we felt a need to treat it, and so I believe I gave him chemotherapy every week. We saw each other a lot, and we really became very good friends.

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[1] *And the Band Played On: Politics, People, and the AIDS Epidemic.* New York: Penguin Books, 1988.

[2] Bobbi Campbell was pictured on a poster intended to raise interest in and money for research on Kaposi's sarcoma. He was the sixteenth diagnosed case of the disease in San Francisco.

Bobbi was also a member of the Sisters of Perpetual Indulgence, the group of [gay] men that runs around in nuns' outfits. He was involved in putting out one of the first safe sex brochures describing what safe sex was, even before the Bay Area Physicians for Human Rights put one out.

Bobbi and I really were very close. I still get Christmas cards annually from his mother and father, who are a lovely older couple who live up in Tacoma, Washington, and drive around in a van and go to square-dancing jamborees all over the country. Whenever they come to town, they make it a point to see me, and they keep me informed on everything, and have sent me pictures of the quilts that they've made.

Bobbi crocheted a pillow for me when I graduated from my fellowship program in 1983, when I moved from UCSF to San Francisco General. He crocheted it, and it said, "If I am not for myself, who will be for me? If I am for myself alone, who am I? If not now, when?" And he wrote, "Donald Abrams, M.D., oncology fellow," on the bottom of the pillow. I still have the pillow, and, in fact, I still end my talk on burnout with those lines, which are from Rabbi Hillel.

So Bobbi and I were friends. I was a nun for Halloween one year in his habit, and we were just--we were friends.

Simón Guzman

Abrams: Simón Guzman, who was another one of my early patients who is mentioned in Randy's book, was a Latino, and much different from me in background. He had a very severe case of Kaposi's sarcoma, unlike Bobbi Campbell. Simón was very disfigured. In fact, I see Simón every time I give a talk on KS. For me, one of the hard things is that the slides that I use for educating are generally of clinical material from my first patients.

Simón had the terrible swelling of his face, the edema that patients with Kaposi's sarcoma get. Whenever I show a slide of bad Kaposi's sarcoma lesions, it's Simón's face on the screen. So it's interesting for me that although he died over ten years ago, he's still there for me and I see him quite frequently.

Here was a man who was in the Latino community, whose family I think didn't know or didn't accept that he was even gay, who had this horrible disfiguring disease with these lesions all over his face, and then his face blew up like a balloon. It was at a time, I think, when the movie "The Elephant Man" was released, and there were a lot of similarities there, because he was so disfigured.

The thing I remember most about Simón was this diarrhea that he developed where he just produced volumes and volumes of diarrhea to the point where every time he came to see me in clinic on a weekly basis, he was always dehydrated. Finally we sent his stools off [to diagnostic laboratories] all around, and got back the report that was confirmed by the AFIP, which is the Armed Forces Institute of Pathology, and they said that he had cryptosporidium in his stool.

Again, as we discussed before, being young and naive and not having practiced a lot of medicine, I said, "Oh, well." So I read about it, and it was a veterinary pathogen that caused diarrhea in barnyard animals, particularly calves and young chickens. There were some reported cases in humans, but the literature was scant.

Anyway, it turned out that this case really was very historic and significant. I don't think it was the first reported case of cryptosporidium in a human, but it was the first case in a person with AIDS, and the CDC jumped on this and ran away with it, and reported it in the *MMWR*.[1] It was my patient, and I didn't get any acknowledgement on that one either. So it colored me early in my attitudes towards the CDC, that they seemed to run with my information and not give me any credit for it. It turned me off a little towards cooperating or collaborating with the CDC.

Hughes: Have other people had the same problem?

Abrams: Well, the head of the CDC is a political appointment, and I think under these past twelve years of Republican administrations, the heads of the Centers for Disease Control have not been the most enlightened people or the most cooperative. So hopefully, we might see some changes under Clinton.

Simón, I remember, had a friend whose name I can't recall. Simón lived in a trailer park, and I think this guy was either his neighbor or his roommate. They lived in the East Bay. This man was a tall, classic Latino, attractive Mexican man, and in the early part of the epidemic, I befriended many of my patients. Simón's friend used to come to San Francisco, or I used to drive over there, and we used to go out to eat. I used to see the

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[1] Cryptosporidiosis: assessment of chemotherapy of males with acquired immune deficiency syndrome (AIDS). *Morbidity and Mortality Weekly Report* 1982, 31:589-592 (November 12, 1982).

trailer park. I think it was after Simón died that we became friends.

Simón talked a lot to the nursing staff at UC Hospital about this disease and how awful it could be, because there was no treatment for the diarrhea. The man basically wasted away from having this awful disease where he just produced liters and liters of watery stool every day.

Hughes: Simón was a Kaiser patient, and there was a problem with getting Kaiser to pick up the bill when he was transferred to UCSF.[1]

Abrams: I think he was seen first in the KS Clinic, and then started coming to see me in clinic, and then was hospitalized at UC with the diarrhea problem and the swelling of his face. I think the fact that he was a Kaiser patient didn't become clear to us until billing problems occurred. As a fellow, billing was not one of the things I was particularly interested in.

As you mention this, it sort of rings a bell, but I think the issue was that when it came time for somebody to be responsible for Simón's care, Kaiser said, well, they never authorized the referral to us. I don't remember exactly; that seems like a scenario that might have happened. But now that you mention it, I remember some astronomical figure that UC claimed was owed to them for Simón's care. Whether or not it was ever collected, I don't know.

Hughes: So in general you weren't aware of the controversies over bills that weren't being paid by medical insurance companies?

Abrams: No, I was a fellow at this point in time. Even as a faculty attending, I don't know if that's something that I would pay much attention to. I would let my business people deal with it.

Mark Feldman

Abrams: There were lots of other patients early on that I really bonded to. I remember Mark Feldman particularly, who may also have been mentioned in Randy's book. He was an articulate, intelligent Jewish man, who was my first Jewish patient with the disease. He was my age, so I really related to him very strongly, because of

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[1] Marcus A. Conant, M.D., to Richard W. Sagebiel, M.D., October 6, 1981. (Conant's KS Notebook, 1981.)

our very similar backgrounds. I was seeing him at about the time the decision was made that the patients with KS should be sent over to San Francisco General and that I shouldn't be seeing them at UC. I think Mark was particularly interested in participating in Paul's first interferon trials, so he left UC and went over to San Francisco General, and I lost contact with him. But he made an impression on me. Before he left, he handed me two porno magazines for my examining room to help future patients collect their semen specimens for CMV testing.

Jim Howell

Abrams: I don't remember exactly how it came about, but I got to see somebody very involved in the Joffrey Ballet, Jim Howell, who was a very close friend of Gerald Arpino who's still the artistic director of the Joffrey Ballet. I always had been interested in ballet and dance, and Jim was another person for whom I used to make house calls when he was at home, and when he was dying.

I remember going over to his apartment when he was very close to death. It was a very spiritual, very sort of Zen-type event. The apartment was very clean and neat, and he was on a white mattress in the middle of the floor, wrapped in white sheets, and was sort of in extremis. It was a very powerful experience.

I stopped making house calls and being friends with every patient that I took care of as the epidemic progressed. But as we're talking about the early days, those are some of the names I remember.

Joe Schmall

Abrams: Joe Schmall was a patient who was very involved in the Castro Street Dog Show. He was the organizer, and he really loved animals. He was another person whom I was friends with and we used to go out to dinner. I remember the first time that I went over to his house, I was standing in his room, he was on the phone, and I saw that he had a cat on his bed. This was way before we knew what causes this disease, and I said, "Huh, another patient with a cat." I've never liked cats very much myself; I always think they carry bizarre viruses, and I knew that feline leukemia virus was out there.

Here I was in the house of this person who was very connected with pets and runs this dog show, and I was looking at the cat on the bed about twenty feet from me and thinking, "Uh-huh, another cat; I wonder if this is what the cause of the disease is?" And the cat lunged across the room at me and clawed me through my shirt and drew blood. I said, "Oh, great." I was convinced that this was it, that now I was going to have AIDS too.

Joe and Bobbi, they all followed me over to San Francisco General when I left UC.

Jack Cosner and Jay Schwab

Abrams: Other patients who had a major impact on me were Jack Cosner and Jay Schwab. They had moved from New Orleans up to Sea Ranch [on the Sonoma coast of California]. Jack was on the commission that restored the Vieux Carré, the French Quarter, in New Orleans. In fact, I was just in New Orleans and they have a plaque right in front of the cathedral there, with the names of the people who were on the commission. Jack was an architect, and so his name is on the plaque and he's immortalized. Every time I go to New Orleans, I see the plaque.

They also owned this fabulous restaurant called Jonathan's in New Orleans back in the eighties. Jack came to me with low platelets in 1982, and his lover Jay, who had been a banker in New Orleans, was felt to be well. But while I was treating Jack for his low platelet problem, and he was doing pretty well, Jay came down with *Pneumocystis*.

They were both in their mid-forties and very well connected and knew a lot of important people, very elegant, very lovely men who used to have me come up to Sea Ranch on the coast and visit with them. We also became very good friends.

A very dear friend of theirs shot himself in his bathtub in Bernal Heights [in San Francisco] in about 1983, I think, and left Jack and Jay his home. So when they came down to see me, they could stay in this house.

About this time, I had an emergency breakup of a relationship, and I needed a place to live. I knew Jack and Jay only used the house in Bernal Heights when they were coming to see me in the clinic, so I knew otherwise it was empty. They let me move into this house for a while. For a few months I lived there for free, and then they started collecting rent, and ultimately I even thought of buying this house.

Finally what happened is they both died, and there were two units in the building. Jay actually was dying in the house, and I was upstairs and he was downstairs. The point is that early in this epidemic, there was a very thin line for me between my life at the hospital and my private life. I was really constantly providing care for people who were my patients initially, who became my friends, and then who died.

Hughes: Did you find you eventually had to change that? I'm not meaning because of the sheer numbers. I'm thinking more of the emotional toll--.

Abrams: Yes, absolutely. Eventually that's what happened. First of all, with the sheer numbers, it became impossible to have that sort of a relationship. I think as a protective mechanism, I needed to withdraw and protect myself and shield myself from the intensity of those emotions, and from the constant living the life of being a care giver.

Defining ARC, AIDS-Related Complex

Hughes: Would you say you had a role in defining ARC?

Abrams: Yes. Well, with my awareness of the lymphadenopathy syndrome in 1979, pointing it out to the CDC in 1981, and then starting my prospective natural history study to define these patients and demonstrate that they did in fact move on to develop AIDS, I was regarded as one of the people who knew a lot about the pre-AIDS syndrome. And I called my patients persistent generalized lymphadenopathy, or PGL. Other people called them pre-AIDS. I thought, well, we don't really know if they are all going to go on to get AIDS.

I had this group of 200 men that I was evaluating, and I used to have meetings for them once every three or four months to tell them what was going on--sort of like what Marcus Conant continues to do.[1] I had this little coterie of patients and I would let them know that there was going to be a meeting at UC in a nursing

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[1] Dr. Conant holds a public meeting at UCSF once a month in which he presents the latest information on AIDS treatment.

school conference room. I would explain to them the results of the studies that I had done so far on them.

We had all hoped at the beginning of the epidemic that, like any illness, not everybody is going to have the same outcome. We used hepatitis B a lot as the model. We used to say, "Well, some people get infected with hepatitis B and die immediately of rapid liver failure. Some people get yellow jaundice and are sick. Some people get hepatitis and are less sick. Some people become chronic carriers of the virus and never even know they're infected."

We used to say this group of men with the lymph nodes is probably a lesser form of this Kaposi's sarcoma and *Pneumocystis* stuff that was killing people. But as we followed these people for a longer period of time, we saw, uh-oh, these people are getting AIDS.

Hughes: But some survive, is that not true?

Abrams: No. Time is the issue here. Most certainly have died at this point in time.

Those of us who lived in the epidemic areas--New York, San Francisco, Los Angeles--were aware of this other syndrome, these people with lymph nodes and low platelets who had something that was related to AIDS but not full-blown AIDS. We didn't know how to define it with a standardized term so that our colleagues in Cleveland or Milwaukee or other places where there wasn't a lot of this disease could recognize it.

In 1983, Jack Killen, who I believe at that time was at the National Cancer Institute, was put in charge of an NIH effort to try to get a handle on what is this syndrome. We had a number of conference calls where people from New York and Los Angeles and San Francisco, myself included, were involved in discussing what we were seeing and coming to a definition of a group of patients that would fit into this category.

The definition that we made had two entries from column A, which was a list of signs and symptoms, and two from column B, which was the list of laboratory abnormalities. Again, this was before we knew about HIV, so we didn't have positive HIV antibody results [from an AIDS diagnostic test].

We were on the phone, and somebody said, "Well, what should we call this?" Nobody knew. Then somebody said, "Well, how about ARC, for AIDS-related complex?" And everybody thought, huh, that's pretty interesting.

Now, the problem with the definition was that it never got published. When I started writing two, three years later about ARC as a historical term that we no longer use any more, finally that initial definition got published. But I don't think other than as a letter to those of us who participated in the conference call that the definition of ARC ever got widely promulgated. That made it confusing as to what ARC means.

Also, the definition was complex--two entries from column A, two from column B. People switched it and made it, instead of AIDS-related complex, AIDS-related condition, so it became a waste basket term that described anything that people felt was related to AIDS but wasn't AIDS. And this was again before we had HIV, so we couldn't call it an HIV-related condition. So we called it an AIDS-related condition.

Hughes: Well, you were quoted in Randy's book as describing it as "a Chinese menu approach."[1]

Abrams: Well, "two from column A, two from column B" is sort of that. I used to say that in giving lectures. But one thing that you learn in AIDS is cultural sensitivity. There were people in the audience who would get offended if I mentioned that the definition of ARC was a Chinese menu approach--two from column A, two from column B. So I learned very quickly how to be politically correct and what I could say and what I couldn't say without offending people. So I stopped using that analogy. [laughs]

Hughes: Did the CDC have a definition of ARC?

Abrams: The NIH came up with that definition. Because of my work in AIDS-related conditions, I subsequently was involved in the CDC group that came up with the reformatted definition--I can't remember if that was in 1985, '86, or '87[2]--the classification schema for HIV disease, which is group 1 is acute seroconversion, group 2 is asymptomatic, group 3 became PGL [persistent generalized lymphadenopathy] or lymphadenopathy, and group 4 became symptomatic disease [AIDS]--four different subgroups.

I was involved in the CDC workshops that put together a new definition of HIV disease, which eliminated the term "ARC" from the vocabulary by sprinkling ARC throughout these different

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[1] Randy Shilts. *And the Band Played On*, p. 356.

[2] Revisions of the case definition of AIDS were published in 1985 and 1987: Centers for Disease Control [CDC]. Revision of the case definition of acquired immunodeficiency syndrome for national reporting--United States. *MMWR* 1985, 34:373-375; CDC. Revision of the CDC surveillance case definition for acquired immunodeficiency syndrome. *MMWR* 1987, 36:3s-14s.

groups, which I think served to make it a little more precise. Although I used that CDC definition of disease stage a lot, and even to this day continue to use it, most people think the definition is too complicated. So I think now that most people just call it HIV disease, and stage people by how many CD4 cells they have. So that's what we've come to, a bit more reductionist.

Hughes: In 1983, March to be precise, AIDS became a reportable disease, but not ARC. Now, was that simply because it wasn't clear that people with ARC were going to develop AIDS?

Abrams: Yes, because there are a lot of things that can cause swollen glands or fatigue or fever, and in the absence of having actual documentation by the subsequent HIV antibody test, it was hard to really say how many people who would ultimately get AIDS we were dealing with. I think we used to estimate that for each AIDS patient there were about ten to twenty people with ARC out there. For a long time, when I lectured about lymphadenopathy, I had to convince people that this condition was somehow related to AIDS, and was not just something else that was going on.

So I think people were reluctant to start collecting information on this potentially much larger group that might or might not somehow be related to AIDS. Once the HIV antibody test was available, then people were more interested in expanding the reporting of AIDS cases.

Immune Thrombocytopenic Purpura

Abrams: The other group of patients that I helped define was the patients who had a low platelet problem, immune thrombocytopenic purpura or ITP. In 1982, the group in New York had published a paper on thirteen gay men who had the low platelet problem,[1] and then I, as somebody with an interest in hematology, became the focus for having those patients referred to my clinic. So I had not only the patients with lymphadenopathy but the patients with ITP as a group that I was interested in.

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[1] L. Morris, A. Distenfeld, E. Amorosi et al. Autoimmune thrombocytopenic purpura in homosexual men. *Annals of Internal Medicine* 1982, 96:714-717.

D. I. Abrams, D. D. Kiprov, J. J. Goedert et al. Human T-lymphotropic virus type III antibodies and development of acquired immunodeficiency syndrome in homosexual men presenting with immune thrombocytopenia. *Annals of Internal Medicine* 1986, 104:47-49.

I was contacted by Jim Goedert from the National Cancer Institute some time in 1983 or '84, asking me if I wanted to collaborate with him and Dr. [Robert] Gallo on looking at the blood of these patients with AIDS-related ITP--I don't know what we called it at that time--to see if they could find anything in this blood. During the course of the study, I sent them about thirty specimens from patients with this condition.

Goedert called me and told me that there were some interesting findings. He said there was evidence of a virus that Dr. Gallo had found in all of my specimens, but not in specimens from controls. Distinct evidence by an ELISA test was found in twenty-six out of thirty specimens, and then they did a Western blot test to confirm it in another four specimens that were borderline. I always sent controls when I sent specimens. I sent some of my own blood, and I think that was one of the negative controls, so that was nice.

Hughes: Was it a worry to you that it might not be negative?

Abrams: Sure. Whenever I sent out my blood as a control, I always was very anxious until I got the word back.

Discovery of HIV

Abrams: So I remember that Goedert called and said that this was really big, and that it was so big that it was probably going to be announced by somebody like [Secretary of Health, Education, and Welfare] Margaret Heckler within a few weeks. And then he explained to me that there is this virus, and da-da-da and da-da-da.

The Talk Show Slip

Abrams: I also remember that Peter Eisenberg, who's an oncologist, had a Sunday afternoon talk show on KCBS, and I had been asked to do one of these call-in sessions about AIDS on this talk show.[1] A caller whose husband had gotten a blood transfusion and was now sick asked what could be done in the future. And I said, "Well, I think that probably within the next few weeks, we might be hearing

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[1] According to Randy Shilts, it was April 15, 1984. (*And the Band Played On*, p. 447.)

some news that might make it so that there won't be any more cases of blood transfusion transmission of AIDS."

Peter Eisenberg was vaguely listening. I think he had just broken up with his girlfriend the night before and he wasn't a very engaged interviewer. He said, "Well, what do you mean by that?" I said, "I think we're getting close to hearing that the agent responsible for AIDS has been isolated." He said, "Oh." I thought I'd throw that out there to people, just because everybody was so down, and I took it personally that people were down on me about the bathhouse closures. I just wanted to put out a little hope, so I mentioned that. Peter said, "That sounds like a scoop. Is it?" But he didn't pursue it further.

Media Coverage

Abrams: As I was leaving the studio and Peter was thanking me for the interview, Cynthia Louie came up to me. She was this diminutive Asian woman who was wearing a Snoopy T-shirt. She said, "Dr. Abrams, I heard you say something about the agent responsible for AIDS being identified soon." I said, "Well, I can't say much more." She said, "Well, can you just say that?"

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Abrams: I said okay. She takes me to a little booth and puts a microphone in front of me and says, "Dr. Abrams, what is this about an agent?"

I said, "Well, I think we might hear in the next few weeks that the agent responsible for causing AIDS has been found." She said, "What do you mean by an agent? Is that like a virus?" I said, "Yes, it's a virus." And she said, "Can you tell me more about it?" I said, "Well, no, it's really not up to me." I don't remember what I said. This must be on tape somewhere.

I went home; I went to bed. The next thing I know, quarter to six in the morning, I get a call from some newspaper in Tallahassee, Florida, saying that they'd like more information on this AIDS agent. I said, "What are you talking about?" They said, "Well, it was announced on the news." I said, "What?" [laughter]

Then my cousin calls from New Jersey, she says, "Mazel tov! I said, "What?" She said, "I heard you on the radio announcing the cause of AIDS!" I said, "What!" She said, "Yeah, you said it's a virus!" I said, "Are you kidding?"

So I came to work and I said, "Oh, this is going to be a bad day." I walked onto the floor and I said, "No comment!" [laughter] Well, we had a media relations office, and I called them and I said, "This is what happened yesterday. I don't know what I did, but I just want to tell you, I can't make any comments on this."

And then Dr. Dean Edell[1] called, and he said, "Can't you talk to me, I'm a doctor too, and you should tell me what you're talking about," and I said, "No comment." I told media relations to refer everybody to the National Cancer Institute.

Well, by one o'clock in the afternoon, CBS National was calling our media relations saying that the National Cancer Institute doesn't know anything about what Dr. Abrams is talking about, so they either want me to withdraw my comment or say that the National Cancer Institute is not telling the truth. I said, "Jeez. This is really beyond my control."

Cynthia Louie, a little innocent woman in her Snoopy T-shirt who told me she was just doing a little local broadcast on KCBS, put it out over the CBS network. What I understand is that this episode may have caused the announcement of the discovery of the AIDS virus to happen a week sooner than NIH had planned it.

Hughes: They knew the word was getting out. [laughing] You never had any direct repercussions from the NCI?

Abrams: I think Gallo and I giggled about it at a dinner a few years later. But they probably think if you want something to be kept a secret, you don't tell Abrams. [laughter]

The Bathhouse Crisis

Mervyn Silverman's Meetings at the San Francisco Department of Public Health

Abrams: Now, the bathhouse issue was something that I did a flip-flop on. Merv Silverman [director of the health department] used to have meetings of all the AIDS clinicians and physicians and

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[1] Dr. Edell has a weekly talk show on medicine on National Public Radio.

epidemiologists in the city. I don't know if they still go on; I'm not involved any more, but I don't think they go on. At the beginning of the epidemic, it was a fascinating new thing. We didn't know what we were dealing with, and there were a lot of questions. So he used to bring together in a very constructive manner all these people to sit and meet and talk.

I remember with regards to the bathhouse issue that these discussions were facilitated. There was a woman and all these pieces of white paper hanging on walls, and she would write down things that people said, and tack them up on the walls all over the room. I knew from talking to my patients in clinic when I was still at UC that all of them seemed to go to the same bathhouse on 8th and Howard. I had this standard list of questions that I asked them: "Do you go to the baths, do you do this, and which bathhouse do you go to?" Everybody went to 8th and Howard. And it seemed to me, yikes, this is really pretty frightening.

Opposition to Closure

Abrams: As a gay man and somebody who didn't go to bathhouses, I felt that closing the bathhouses would be an invasion of people's rights and civil liberties. I was not particularly connected with the gay community in San Francisco. I was in my training program, I had been an intern and a resident and then a fellow, and I was in a relationship, and I was very fixated on my career and my work. I didn't really have a lot of time for politics. So I was sort of untainted and not particularly connected with any of the local gay political organizations, and I was acting as a free agent and as a clinician/scientist.

But still, as a gay man and as a member of a group of people that had been persecuted from time immemorial, I also thought that in the absence of knowing what AIDS is really caused by and being absolutely certain that closing the bathhouses would have very wide-ranging repercussions, I saw both sides of the issue. The gay community had achieved a lot of liberation and a lot of prominence in San Francisco over the seventies and on into the early eighties, and I thought that closing the bathhouses would really be a political setback.

So initially, I was against the concept. Somewhere along the line, Paul [Volberding] had this meeting of the bathhouse operators that I was invited to, so that we could all talk about the issue and what we felt about it.[1] I might have mentioned to

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[1] The meeting occurred early in 1984. (Shilts, *And the Band Played On*, pp. 421-422.

them that I thought all of my patients were going to bathhouses and one in particular. And then I remember the guy that made that awful comment: "Well, listen, Doc, we're all in it for the same thing. We get the money when they come to us, and you get the money when they come to you." And Paul and I just looked at each other with our mouths open.

First of all, we are salaried; we don't make money off treating patients. These people were dying, and we thought that that attitude was really quite cold and mercenary. That was a real shocker to hear a member of the [gay] community say that.

Supporting Closure

Abrams: Maybe that incident had an impact on me in that a year later when the same group was revisiting the bathhouse issue, and there was still a lot of political pressure from members of the community to keep the bathhouses open. But because I didn't feel connected or bonded to the community, it didn't impact on me and I was much more able on the second go-round to really see that this was a public health issue. We weren't doing anybody any good by keeping these bathhouses open and allowing this disease to continue to spread.

First we decided to use the bathhouses as possible educational venues, and Merv Silverman or Marc Conant said trying to educate people in the bathhouse [about safer sex] was like letting a child loose in a candy store.

By the second go-round, I was happy to stand behind Merv. Those who supported the plan had to be there when he signed the edict, or made the announcement in his office to close the bathhouses. He had all these gay people standing behind him. I think I'm right behind him in that [newspaper] picture.

I was in the early phase of my career and I wasn't really comfortable being openly gay, concerned that the university wouldn't want to keep me on or wouldn't promote me or something, so I tried to be more cautious, and I didn't align myself that much with being openly gay in the media or just in my life.

Hughes: But you were there in public on that occasion.

Abrams: Yes.

Hughes: Were there repercussions from the gay community when you and others supported bathhouse closure?

Abrams: Well, I remember particularly Neil Schram, who was the president of AAPHR, the American Association of Physicians for Human Rights, an organization to which I belonged; it's the national gay doctor group. It was an offshoot of BAPHR, the Bay Area Physicians for Human Rights, which I think I've mentioned before. Neil wrote a letter to the gay press saying that it was terrible that they closed the baths in San Francisco; the baths in Los Angeles were still open, and people should fight for their rights and civil liberties. I just said, "What's it his business? He's in Los Angeles." Neil and I subsequently developed this adversarial relationship which over the years has ceased to be because he actually agreed with us ultimately [about closing the baths], and his philosophies have become much more in keeping with my own.

But yes, at the time, there were probably people, if they knew that I was gay, who considered me to be a traitor to the community for coming out in favor of closure. But a lot of people maybe didn't even know I was gay. Until a few years ago when I asked patients questions about sexual histories, some patients would look at me and say, "Dr. Abrams, you certainly do know a lot about sexual practices of gay men." So I said, "Yeah, well, you know." So there are even members of my own community that don't appreciate the fact that I'm gay.

Hughes: Do you want to comment on making the deposition in the fall of 1984 supporting bathhouse closure?[1]

Abrams: I don't remember too much about it. I remember reading the deposition. I guess we did it in Merv's office [at the health department]? I don't remember. I remember one of my patients at the time was a policeman who went to a bathhouse and wrote a description of what he had seen there. I think that was in this deposition. I think I have a copy of it someplace in my archives. I did come across that recently and saved it, because I figured it was a good piece to save. But I don't recall the mechanics of what I did.

Hughes: Do you care to comment on the way that Dr. Silverman handled the bathhouse issue?

Abrams: Well, I think he was very diplomatic, and I think he really did the right thing for the community. The question was, did we do it a little bit too late? Had we become aware of the disease earlier while it was being spread silently by people who were infected during the seventies, that would have been the best thing to do.

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[1] Declaration of Donald Ira Abrams, M.D., in support of a temporary restraining order to close the bathhouses. October 10, 1984, Superior Court of the State of California in and for the City and County of San Francisco. (Dean Echenberg papers, San Francisco Department of Public Health, Bureau of Epidemiology and Communicable Disease Control, drawer: bathhouses, folder: 10-10-84 Declarations in Support, vol. 1.)

But of course we didn't become aware of the disease until '81, and then we fumbled around for [more than] a year before we could reach consensus.

But I think that's the only way that politically Merv could have--well, it's not the only way. He could have done it as an edict from his department, but I think Merv was very diplomatic and a consensus builder. I think he got flak ultimately from [Mayor] Dianne Feinstein because he was too slow in making this decision. Always from the outside it looks much easier, like it's a simple case of black and white. And in fact, it wasn't.

Hughes: There was a meeting in March 1984 where Volberding and others went to City Hall with the idea that Silverman was going to announce closure.

Abrams: Oh, I remember that; and then he didn't do it.

Hughes: The actual closure didn't occur until October 9.

Abrams: I forget what happened. You have to get that from Merv.

The HIV Antibody Test

Hughes: Say something, please, about the impact of the discovery of the virus and the subsequent development of the antibody test on the way you were looking at the epidemic, the way you were looking at the disease.

Abrams: Well, we had assumed all along that not everybody was going to respond the same way to whatever insult it was that caused this disease. When we discovered that the disease was caused by HIV and the technology became available to determine that people were HIV-positive, we said, "Oh, good, so here's this very large group of people which is going to be asymptomatic carriers, and here's this other group which is going to have swollen glands, and then here's the unfortunate group at the top of the pyramid who are going to have a devastating, life-threatening, fatal illness."

So we had the tool in 1985 to understand that we had a more expanded population of people which had been infected and affected, but we still weren't really sure whether everybody who was infected was going to progress to AIDS. After a while, and after doing further natural history follow-up, it did become clear that the progression was inexorable. We were now able to track patients much earlier in their illness.

The first patients we saw walked in in extremis with their *Pneumocystis* and died in a very short time, because we caught the very tail end of their illness. Now we were seeing people who were essentially well who had this laboratory marker [HIV positivity] telling us that we could predict what their natural history was going to be. So we got a whole new perspective on the magnitude of the epidemic by realizing that there were many, many, many more people out there who were well and just infected.

We now understood the natural history, that these people were going to progress through this ARC stage and then develop AIDS. The antibody test let us become aware that HIV disease was a real gradient or a spectrum, and it's not just AIDS and ARC and these static conditions; that it's a dynamic continuum, if you will.

As patients with HIV infection became identified earlier in their disease, it gave us the illusion that patients were living longer, even before we intervened with therapies, because we could start following patients not at the time they came with *Pneumocystis* or KS [Kaposi's sarcoma], but in an asymptomatic or early symptomatic stage. We got bonded to them or connected with them earlier. It seemed like the disease was having a more prolonged course, but it really was just that we were identifying people earlier.

When the test first became available, there was this whole issue then, "Well, should we recommend that people get tested, and is this some sort of a witch hunt to identify gay men?" Because it seemed like so many gay men, especially in San Francisco, were positive. And, "Are we going to keep lists of who's infected, and are we going to do case contacts so that people who are infected could notify their partners that they are infected?"

All of these issues came up, and we didn't have any real effective treatment. So again, this was a political issue, and there were questions, "Should we encourage people to go out and be tested? Why, if we don't have anything to offer them? Does the down side of being tested and having your name kept in some file exceed any potential benefits?" There was a lot of controversy in the community, and a lot of the gay community and the political forces felt that people shouldn't get involved in being tested because it was some sort of ploy to get your name on a list somewhere.

I don't know that I didn't disagree with that. I had traveled, and I knew that Arizona or Colorado or one of those states was collecting names of HIV-positive people. I didn't think that it was very necessary to collect names of those people or to recommend that everybody be tested. Subsequently, I've changed my opinions on the latter. Regardless of whether or not there is an effective treatment for the virus, I think that people who are infected should get into a relationship with a physician so that they can be monitored and take their life in their hands and control what they do.

Hughes: So you advocate testing.

Abrams: Yes, I think people should be tested, but it's easier said than done. As somebody who is in a group that's at potential risk for acquisition of the virus, I know what it's like to get tested, and the anxiety that it produces, even though I know that what I do is generally safe. Apparently, you can never be certain about anything. When the blood is in a test tube and no longer in my arm, the period until I get a result back that says I'm negative is a very high anxiety time. I can certainly empathize with people who would rather not have to go through that. There's a lot of denial out there, and a lot of people who are just fearful and don't want to know.

Hughes: Do you take the test yourself periodically?

Abrams: Yes. Unfortunately, too infrequently, like every two years.

Hughes: Why is that?

Abrams: Well, because of what I just said, that it's a very stressful and anxiety-producing event. I don't like to do it. It scares me. So that's why I can empathize with people who say that they'd rather not know.

Hughes: Is the counseling adequate that is supposed to accompany the testing procedure?

Abrams: I have no idea. I've never been. I've never gotten tested in one of those facilities; I usually do it in a very clandestine manner, which is again part of my issue and problem.

The County Community Consortium

Origin

Hughes: Would you explain how the concept of the County Community Consortium arose and who was responsible?

Abrams: Sure. I just wrote [Senator] Dianne Feinstein a letter telling her that she should recall when the concept of community-based clinical trials comes up in the Senate, that she is really the one who birthed, if you will, the creation of the first community-based clinical trials group in AIDS.

In February or March of 1985, she communicated to Paul Volberding that she thought it would be a good idea if there could be a meeting with the physicians caring for people with AIDS at San Francisco General Hospital and the physicians in the community, to bring them together. Now, what motivated her decision to do that, I don't know, and I would be curious.

Paul originally had a meeting in March, I believe, of 1985. I didn't go to it. I don't know if I was not invited or what, but after Paul came from the meeting, he said, "Gee, these are all your buddies from BAPHR--" Bay Area Physicians for Human Rights "--and maybe you should lead this group, these community physicians." I said, "Well, lead them? I'm not a community physician; what do you mean?" But I said, "Okay."

Communication with Community Physicians

Abrams: So that began a series of monthly meetings with me and twelve to twenty providers in the community, starting in 1985.

Hughes: And Paul dropped out?

Abrams: Paul dropped out, which was unusual. Paul doesn't like to relinquish control or responsibility very much, and so to have him hand something over to me was unusual. He tries to do that, but he likes to be in charge. I don't remember if he came to some meetings early on, but we generally had the meetings in the evening, and Paul has young kids. We met at the San Francisco Medical Society, and our original goals were to transmit information about this new disease, and to share information, to educate each other.

Hughes: Both ways?

Abrams: Yes. We were seeing about a third of all the patients with AIDS in San Francisco at San Francisco General, but that meant that two-thirds of the patients were being seen by these private doctors in the community. Being faculty of the university, having more time to travel and go to conferences, we often learned new things that we could share with our colleagues in the community. Whereas they, seeing a lot of patients day in and day out, were seeing new aspects and manifestations of the disease that they could come and talk about. So [mutual] education was our goal.

We were also, under Paul's leadership, doing clinical trials here in 1985 before there was ever an ACTG [AIDS Clinical Trial Group]. By then we had done trials of alpha interferon, gamma interferon, interleukin-II, isoprinosine, ribavirin, and suramin, before the government established its ACTG, just because we were very aggressive and Paul was really interested in trying to figure out how to treat this disease. We wanted also to have an opportunity to share with providers in the community what protocols we were conducting so that they could refer patients to our clinical research unit.

Limiting Numbers of AIDS Patients at San Francisco General

Abrams: The third original goal of the Consortium was to assure in a way that San Francisco General didn't become only an AIDS inpatient hospital. We're one of the teaching units of the university, and we didn't want all of our inpatients to have AIDS. We felt that if we were going to provide a good teaching experience, we needed to have a diversity of patients in the hospital. So we set an arbitrary cap of about thirty [AIDS] inpatients and decided that it would be good for the doctors at the county hospital, San Francisco General, to have good working relationships with the community physicians so that, should we get above thirty, we could call one of the docs at another hospital and say, "Will you admit this patient to your facility?"

Hughes: Who made the decision to put the cap on at thirty inpatients?

Abrams: Well, I think it was the department--us--and the department of medicine. Whether or not that was ever enforced, I'm not sure. I can remember on two occasions knowing that the census was high on the inpatient unit and trying to admit a clinic patient to another facility. But I think I only did that twice.

After meeting for about six months, the community doctors said, "Well, this is fine to refer patients to you for research studies, but we can do research studies in our own practices too, for problems that are more germane and basic to our clinical practice." So I said, "Well, for example?"

So they said, "Well, what do we do after somebody has an episode of *Pneumocystis* to prevent another one?" So I said, "Well, what do we do?" We took a survey, and everybody did something different, and everybody thought that what they did, worked. So in an effort to put a lid on all this data that was just going up in smoke, we devised a protocol. The group met every month, and we sat down with our next version of a study. I'd done a lot of clinical trials here by now, and I was also probably at this time on the UC[SF] institutional review board, the Committee on Human Research [1985-1988]. So I knew how to write a protocol and a [patient] consent form.

The First Study: *Pneumocystis* Prophylaxis

Abrams: I led the way in putting together our first study in 1986, which was to compare four different strategies as secondary prophylaxis after a first episode of *Pneumocystis*. These were no treatment, monthly pentamidine injections, weekly fansidar, or daily dapsone. We got the protocol up and running in July of 1986.

The difficulty was that the consortium was really no more than the doctors who came to the meetings, but there was no staff. There was no infrastructure. Paul designated one of our protocol specialists in the AIDS program, Zach Weingart, to help me so that when doctors called in to randomize patients on this trial, he could do the randomization.

We had in July of '86 a number of patients. I remember the first patient I randomized was Philippe Roy, one of our front desk clerks in the clinic. He had just had his first episode of *Pneumocystis*. He was seeing me as a patient, and so I put him on the trial. At that time, I didn't give patients anything after they had a first episode of *Pneumocystis*, and Philippe got randomized to the no treatment arm, so that was consistent with my clinical practice.

What we found in having this four-armed study was that a lot of doctors in the community had their own bias and their own practice. Doctors would call up and say, "Well, I'd like to randomize a patient," and then they'd be told, "Your patient is assigned to this treatment," and the doctor would say, "Oh, the patient doesn't want to be on the study." Really the doctor didn't want the patient to be on the study, because that wasn't the treatment he wanted to be assigned.

So we found that we needed to teach doctors in the community about clinical trials. It became clear to me as a research academician at the university that I was here because I was interested in clinical trials, and I had a mindset, as well as caring for patients, to be able to objectively put patients into clinical trials. But some of my colleagues in the community were doing private practice and patient care because they didn't have either the interest or the education to participate in clinical trials. So that was a learning experience.

Hughes: Were you skeptical that the community physicians could successfully run a clinical trial?

Abrams: A lot of these docs were gay men and women whom I knew from BAPHR. Bay Area Physicians for Human Rights is more of an educational-social group and doesn't have a strong scientific foundation. So I felt, well, this Consortium is like an arm of BAPHR. Now, I knew that they were interested in doing clinical trials and impacting on this disease, and I figured under my leadership here, under this new hat of the Consortium, we could make this work.

But as we started to do it, I did become a little more concerned that it might not be able to work because of people not really understanding randomization and not wanting their patients to be assigned to a no-treatment arm, and they gave everybody fansidar weekly without any evidence that it worked. So I saw this was going to be a long haul.

The Second Study: AZT

Abrams: But ultimately what happened was in September, 1986, the study that showed that AZT was better than placebo was terminated, and patients were told that if they wanted to take this new potential treatment, that they couldn't be taking other drugs. So interest in participating in our study disappeared because everybody wanted to have the opportunity to take AZT, and they weren't interested in preventing *Pneumocystis*.

Not to be daunted by this, we quickly sent off paperwork to our Committee on Human Research so that we could collect the data that the physicians were going to be sending to the AZT headquarters, and we could have a local database on patients put on the AZT treatment IND [Investigational New Drug].

That then became our second study. Really all that was was asking physicians to Xerox a piece of paper. It wasn't very intellectually challenging, but that's when I learned how minimal resources some people have in their offices, i.e., some people didn't have Xerox machines, some people didn't have staff to Xerox these papers, some people didn't want to spend the money to send me the copies.

So our second study sort of fizzled, and I was beginning to wonder, well, what are we going to be able to do? But the Consortium was growing, and there were sixty or eighty or a hundred people that were considered to be members of the Community Consortium.

We were already in the ACTG here at San Francisco General, and about this time the government put out a request for proposals to expand the ACTG. It was called an AIDS Clinical Study Group, ACSG. The proposal requested information on the infrastructure of our clinical trials group, a potential clinical trial protocol, and an educational component.

Applying for Grants

Abrams: So I called the NIH, and I said, "We have this group, the Community Consortium, in San Francisco. I realize that SFGH/UCSF is already an ATEU"--AIDS Treatment Evaluation Unit. "This is a group of community physicians and we want to do clinical trials in the doctors' offices." And they said, "Yes, that sounds like a good idea. Why don't you apply?"

In November of '86 the NIAID [National Institute of Allergy and Infectious Diseases] put out a small request for proposals to do viral studies in AIDS. I did all of my lymphadenopathy work without any financial support. We looked upon this as a way to look for viral co-factors in the lymphadenopathy syndrome.

I remember the deadline for this particular grant was like January 6, some ridiculous day. The RFP [request for proposals] came out in November, and the application was due January 6. We had just gotten a new epidemiologist in the program here, Palmer Beasley, who was a hepatitis B expert. He and I were going to submit this response to this proposal from the NIAID to study viral co-factors in the lymphadenopathy syndrome.

I had never written a grant before. I spent a lot of time and made a lot of collaborative efforts and made all of the office staff sacrifice Christmas and New Year's time. I sent them the application on time. They lost it. The NIH processed this, not as a response to their request for proposals, but as an investigator-originated RO1 grant, which meant that it went in a different pile, and it wasn't reviewed with the six other applications that came in for the RFP, but as one of hundreds of individual investigator-initiated RO1 proposals.

It was after the International AIDS Conference in Washington in July that I finally found out that this had happened, and I was really pissed off. Plus, it got a very low priority score because it was judged against this whole gemish of RO1s as opposed to against the small number of RFPs submitted by January 6. So I was pretty miffed.

For an April deadline, I submitted this other ACSG proposal to the NIAID. We proposed the infrastructure as well as for the Consortium to do a trial of inhaled pentamidine that was already being widely used in the community to prevent *Pneumocystis*. We also proposed under Connie Wofsy's direction our AIDS Provider Education Experience, or APEX, which was an educational program that we were putting together to train physicians in AIDS care.[1] We would bring physicians here to San Francisco General and have them get didactic lectures as well as patient experience in the clinic and on the ward.

So those were the three components of our submission, and I had heard from the grapevine that they thought this was an interesting submission. I remember meeting in Washington during the International AIDS Conference with the woman, Miriam, that was in charge of the program, and she wanted more explanation about the Consortium and how this proposal would work.

I thought that was encouraging. When I got back to San Francisco, our providers really wanted to start enrolling patients on the PCP prophylaxis trial even before we got funding from the government. Since we had heard that it might be looked upon favorably, I said, "Okay, why don't we start this?"

Gifford Leoung was in charge of that section of the proposal. Connie was in charge of the education one, and I was in charge of the overall grant plus the Consortium infrastructure segment of it, so it was a three-part application.

We started enrolling patients, and in four weeks we enrolled 200 patients on this *Pneumocystis* prophylaxis trial with inhaled pentamidine, because it was a drug that was being widely used, nobody knew what dose to use, nobody knew if it really worked. So we decided to study it to put a lid on the data that was otherwise going up in thin air.

We then found out that the government said that we were too novel, and that we got a low priority score, and they weren't going to fund us because it was too community-based. Really what they did through this AIDS Clinical Study Group application was expand the number of ATEUs and they made the current ACTG. The Community Consortium was a completely different deal, because it wasn't centralized or a university academic center doing research; it was research being done in community providers' offices.

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[1] For more on APEX, see the oral history in this series with Constance B. Wofsy, M.D.

So it was very different, and I was just pissed that they led me on originally and said, "Yes, this sounds good, submit it." So I spent from November until April writing grants for the government that year, and both of them were rejected. One was lost, and one was inappropriate to submit in the first place and got rejected.

Tony Fauci [director, National Institute of Allergy and Infectious Disease, National Institutes of Health] is a friend, and I called him. I said, "Listen. I am really pissed. This guy lost our grant application; he's incompetent. What's going on here? And on our second application, I think you really blew it. It is an important thing to involve community providers who care for the bulk of the patients with this disease."

So through our ACTG contract, the NIH came out and looked at the Consortium. They came to a few meetings, they saw what we were doing, they heard a little bit about the aerosolized pentamidine protocol and the success that it was having in enrolling patients. They gave me $100,000 through the ACTG to hire somebody. The Consortium was still essentially me meeting with these doctors from the community without any backup staff.

The Aerosolized Pentamidine Study

Abrams: Now we had this protocol with 200 patients on it, and no way to collect data or to assure the quality of the data. So I turned to John Ziegler at the university and I said, "What am I going to do?" He said, "Apply for this ACRC grant," AIDS Clinical Research Center. The Universitywide Task Force on AIDS[1] gave me an emergency $50,000 funding to hire Linda Wardlaw, who became the program director for the aerosolized pentamidine study. The study was very successful and it accrued 470 patients in eight weeks, and seventy-six different physicians enrolling patients at twelve different centers in three different counties.

It was really a model for community-based clinical trials, but it only was because there was nothing that the physicians had to do after making a telephone call. They just called, randomized their patient, and after that, all of the work was done in the respiratory care center where the patients were seen. Patients filled out a form, and the respiratory therapist confirmed that they got their treatment as allocated.

The drug company didn't want to support the study because it hadn't been involved in designing it.

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[1] Now called the Universitywide AIDS Research Program.

Hughes: Lyphomed?

Abrams: Yes. Subsequently, when they saw that it was big and doing well, they did come in to do retrospective data collection from the patients. Gifford Leoung was in charge of the program by then. Although that's considered to be a Community Consortium study, because we didn't get funding through the government, Gifford was in charge of the aerosolized pentamidine protocol aspect of the program, and I continued with the Consortium, and Connie continued with the APEX program.

Community-Based Clinical Trials

Personal Reaction to Activists[1]

[Interview 3: November 25, 1992] ##

Abrams: 1988 was the year that the Community Consortium began to have some input from the activist community. I think it would be good if I backtracked on my history of relationships with community activists.

This last decade has been my first decade being a professional, so there's a lot that I've learned. Being fresh out of medical school and in my residency program and my fellowship when I started working in AIDS, I thought I knew everything. Somebody who's young and energetic and has vision sort of knows everything, and there's nobody that knows any more.

As I mentioned previously, I had very positive, warm relationships with my patients. I learned a lot from my patients, but I also realized that my patients weren't doctors, for the most part. When in the mid-eighties lay people began to tell us how to do things, and what things we should be doing, I came back with a little resentment. I said, "Well, who are these people, and where do they think they get the knowledge? I've been to medical school, I've done a residency, I've been a fellow at the University of California, San Francisco, I've worked in these various research areas, I'm a member of the Committee on Human Research, so I know how to do things. Who are these people threatening me?"

And that's what it was: I was threatened by these people who were very smart and oftentimes didn't do anything else but read

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[1] See also: L. A. Simpson and D. I. Abrams. AIDS activism: The first decade. *San Francisco Medicine*, June 1992, pp. 22-23.

about their particular issue in AIDS, so they were very well informed. And it was a little frightening.

Plus, at this time I was not completely out and open about being a gay man, and these people often were a bit extreme in the way they behaved. That also was a conflict and something of a threat to me, because how come these people are there representing the gay community, and someone like me, who has all these credentials, has to be perceived as the enemy?

The Community Consortium and the Community Research Initiative, New York City

Abrams: This us-against-them mentality came to a head around the issue of community-based clinical trials in 1988. The Community Consortium had been established in 1985. We were a functioning group. We had enlarged to about 150, 160 members, health care providers, in the San Francisco Bay Area caring for people with HIV disease.

I gave a small presentation to Admiral [James] Watkins and the AIDS commission [National Commission on AIDS] when they came to town; I forget what year that was. In 1986 or '87, we had been visited by Mathilde Krim and Joseph Sonnabend from New York. Mathilde is one of the founders of AmFAR [American Foundation for AIDS Research]. They came to one of the meetings of the Community Consortium. And they were impressed by what we were doing with the physician community in San Francisco.

They decided they wanted to have something similar in New York, but Joseph Sonnabend is a bit of a fringe person. He practices in the Village; he's a little bit eccentric. He's a very nice man, but he has some views about medicine that are not widely held. And in New York, there are so many doctors and so many people caring for people with HIV disease, and it's a city with so many problems, that it's hard to bring the medical community together, much harder than we found it was to do here in San Francisco.

So what happened in New York, Sonnabend had a lot of connections with the PWA, People With AIDS, group there, and they decided to establish a community-based clinical trials center in New York that they called the Community Research Initiative [CRI]. In San Francisco, we became called the Community Consortium because nobody said County Community Consortium; everybody mixed up the three C's, and so we just dropped it to the Community Consortium. The "Community" stands for community physicians.

In New York, the "Community" in the Community Research Initiative was really the community of people with AIDS or HIV disease. Michael Callen, who's a famous person with AIDS--I hope he's still with us; I know he's been quite ill recently--also presented the Community Research Initiative to the presidential commission and they were very taken with the idea. This is about the time that I had applied to the government for a grant, and they gave us a low score.

Apparently, the presidential commission became enthusiastic about the concept of doing community-based clinical trials. In fact, some of the data that was reviewed by the FDA on our aerosolized pentamidine study was complemented by a study that had been done by the Community Research Initiative in New York. They looked more at the toxicity and side effects of the inhaled pentamidine, because they in fact had received some funding from the drug company. So that was felt to be the first victory of community-based clinical trials because we and the Community Research Initiative sort of joined forces.

The CRI became very well known because it solicited funding from the gay community directly. The Community Consortium had chosen, under my leadership, not to solicit funds from the gay community in San Francisco because the community was already overstressed in contributing to the multiple AIDS service organizations providing direct services to people with AIDS. And I've always felt that research should be funded by the government or by the American Foundation for AIDS Research. So we chose not to solicit by direct mail campaign, and therefore we're less visible than the CRI.

The Community Research Alliance, San Francisco

Abrams: In 1987 or 1988, activists in San Francisco began to hear of the CRI and decided that we needed to have a community-based clinical trials group in San Francisco. This is after we'd already done our aerosolized pentamidine study; we had our program; we were doing a number of different studies. They thought that they needed to set up something similar to the CRI, and in fact they did, and they called it the CRA, the Community Research Alliance.

We didn't understand why they needed to do this, or who their physicians were going to be, because we sort of had the corner on all the physicians caring for patients with HIV disease in San Francisco. The leaders of this Community Research Alliance--Martin Delaney and John James and Terry Beswick--felt that the Consortium was not answering their needs, that we were an elitist group of physicians only, and that we were shutting them out and shutting out their input. They wanted to come to our meetings.

From the beginning, the Consortium had been a very loose organization, and membership was health care providers. Members of the Community Research Alliance decided that they were going to start coming to our meetings. This was at about the time that ACT UP was born. The activist pressure made the Consortium solidify itself and made us establish bylaws and set up committees and really depressure me, because I was looked upon as the monolithic head of this organization without any input from any other sources.

By setting up an executive board and scientific advisory committee, and then incorporating the community into a community advisory forum that met with us on a monthly basis, we became a much more decentralized group, and the authority was shifted from me as an individual to all of these advisory committees. So it was really nice. We established a formal mechanism for having community activists and PWA input into our decisions and our research planning, even though we maintained in our bylaws that we were a group of health care providers in good standing.

The ironic thing is that many members of the Community Consortium are in fact gay men and women, and a number of them are also infected with HIV. One older doctor, who was one of the founders of the Bay Area Physicians for Human Rights, when we were having this conflict between, "Should we let the community at large into the Consortium or should we retain our doctors' club orientation?" said, "Donald, you know, we are the community. We are gay men and women, and some people are infected with HIV. So why do we have any less right to represent the community of people with HIV than the activists who are out there making noise and screaming?"

This began a period over the subsequent four years of increased communication between the Consortium and myself and the activist community. It's been followed by other groups--the ACTG and other organizations around the country--incorporating community advisory boards into their structure, by mandate now of the federal government. So rather than be "us versus them," everybody realizes that we're all fighting the same enemy. It's not each other; it's HIV.

I think everybody is quite impressed that the activist community really has a lot to offer, and it has shifted the paradigm, as they say, and has made people see things in a new light. They put a human face to the epidemic, and it's very hard to deny people when you see them right there. What they're demanding is their rights. Science, yes; I still am felt to be a proponent of the strict scientific method, and clinical trials, and statistical significance. But sometimes you have to bend a little just because of the circumstances.

So in 1988 we reorganized the Consortium and validated it. And then largely through the recommendations of the presidential commission and because Mathilde Krim was very excited about community-based clinical trials, both AmFAR and the NIH put out requests for proposals for funds for community-based clinical trials groups. And we did very well; we got large support from AmFAR as well as the government's largest contract from the Community Programs for Clinical Research in AIDS, or CPCRA.

AIDS Treatment Evaluation Units and the AIDS Clinical Trial Group

Abrams: The federal government's clinical response to AIDS is under the Division of AIDS of the National Institute of Allergy and Infectious Disease. The first program that they had, even before they called it the Division of AIDS, was the AIDS Treatment Evaluation Units, or ATEUs, which were established in maybe 1986 or 1987. I'm not exactly sure on the date. That was a federally-funded organization of tertiary care centers to do clinical trials in HIV disease.

We at San Francisco General in the AIDS program under Paul Volberding had already tested all of the drugs that they were considering testing by the time the first ATEUs were set up. The Community Consortium had also previously been established, and as I mentioned, the Consortium applied for an AIDS Clinical Study Group, ACSG grant, when the ATEUs actually were expanding. We didn't get it, because we were too community-based and not centralized enough, and what really happened is that this became the current ACTG, or AIDS Clinical Trial Group. When the first nineteen ATEUs, or whatever, were supplemented by an additional seventeen ACSGs, that became the ACTG. So that's the AIDS Clinical Trial Group, and that's how most of the intensive research in clinical treatment has been done until 1989.

The CRI and the Consortium, as part of our initial funding from AmFAR, put on a conference at Columbia in New York in July of 1989, where we had an incredible cast of characters--Tony Fauci, Sam Broder from the NCI, Ellen Cooper from the FDA. I sat next to Burton Lee, the president's doctor, at the dinner. We put together this fabulous all-inclusive group of people to tell everybody how to do community-based clinical trials.

Community Programs for Research on AIDS

Abrams: In October 1989, we got the funding to set up the CPCRA, the Community Programs for Clinical Research on AIDS. So that became the second research arm of the Division of AIDS of the NIAID.

Now they have a third thing called DATRI, Division of AIDS Treatment Research Initiative, and it's to do intramural research projects proposed by researchers. They contract out to various organizations. San Francisco General Hospital is an ACTG site, and UCSF is also a CPCRA through the Consortium. Since 1989, the Consortium has been funded by the government. We're one of seventeen groups doing collaborative studies in the community setting. In a way, it certainly funded an infrastructure. The Consortium has a full-time staff of seventeen, mainly research nurses that go out into doctors' offices in the Bay Area, enroll patients on clinical trials, collect the data, bring it back to our office. We send the data back to Minnesota to the Statistical Center, where it's analyzed.

Working with the federal government has been a little frustrating for us, because we are pioneers in this field, and we feel that a lot of the other groups that we work with need to be brought up to speed. Whenever you deal with the government bureaucracy, you sacrifice some of your freedom and independence, and in fact, some of your creativity, so that's been a little bit distressing. But they do butter the bread that we eat, so we try not to be too harsh on them.

The program has now been up and running for four years. Many feel the number of tangible accomplishments is not appreciable, although the program has recently been reviewed by an external review group which felt that it in fact should continue and has made some important progress.

The CPCRA has mandated to enroll previously underserved populations into clinical trials, and only about 50 percent of the people enrolled on CPCRA files are gay white men. Actually, I think two-thirds of the people on CPCRA trials are people of color or injection drug users.

Hughes: Is that deliberate policy?

Abrams: One of the mandates was to enroll previously underserved populations. Ironically, when we applied, and we are the sort of model organization for community-based clinical trial groups, there was a third definition of community, communities of color.

Many of the people on the review committee felt that the application from the Consortium in San Francisco, which everyone would have thought was a shoo-in, was in jeopardy because the San Francisco population with HIV continues to be 98 percent gay. We're known for not having that many people of color, and so people wondered if we'd be able to live up to the mandate of the CPCRA, that is, to enroll injection drug users and people of color. And we almost, I understand through clandestine means, didn't get funded. In fact, the CRI in New York did not get funded.

Hughes: For that reason?

Abrams: Well, I heard that their grant wasn't particularly well written. But that made a bit of hoopla, because they were felt to be the second founder of community-based clinical trials, and it was a major fragmenting issue that we got funded and they didn't.

Generating Scientifically Credible Data

Hughes: As you well know, one of the main objections to community-based trials was the fear that the data generated would not be scientifically acceptable. Has that proven to be wrong?

Abrams: Again, I think the Consortium did a lot to dispel that objection with the data that we generated in the inhaled pentamidine study, which did lead to FDA approval as well as a lead article in the *New England Journal*.[1] Much of the emerging data from CPCRA studies has not yet been published, but I think it's quite strong and will ultimately be appearing in the major medical journals.

Hughes: Is that data regarded as scientifically credible?

Abrams: Yes. In fact, one of my concerns about the NIAID using the same staff and the same mindset to govern both the ACTG and the CPCRA is that it's a bit too standardized and too rigid. I can understand why they feel a need to do it, to validate that community-based clinical trials can function. But by using the same staff in both arms of their program, it doesn't show a lot of expansive thinking or that they understand that there's really a difference between the ACTG and the CPCRA and what they do.

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[1] G. S. Leoung, D. W. Feigal, Jr., A. Bruce Montgomery et al. Aerosolized pentamidine for prophylaxis against *Pneumocystis carinii* pneumonia. *The New England Journal of Medicine* 1990, 323:12, 769-775.

Hughes: Have you been surprised how well they've worked in terms of generating reputable data? I think you will readily admit that you were one of the skeptics.

Abrams: Yes. Well, I think if you have money and you can set up an infrastructure and you can make things easy for the clinicians and their practice, then it can work quite well.

Hughes: You said that the ACTGs were created after the Community Consortium.

Abrams: Right. I told you how they started ATEUs and that our institution has been a member of the ACTG since its inception.

It's become a very huge and unwieldy organization in my opinion. I believe that the focus of the ACTG needs to be to continue to do early trials of promising new agents, because they have the setup to do high-tech studies and collect intensive data. Whereas, the community programs need to do later studies of agents that have already been used widely to refine what their usefulness is and look for clinical endpoints, not for laboratory test changes like T cell changes or virology. So I think we need to figure out how the two can complement each other.

I think right now, the ACTG is struggling a little, and they're in fact moving more towards the direction of the CPCRA. They're trying also to increase the numbers of women and people of color and injection drug users in their trials and to do studies that are more appropriately done in the community setting.

The activists also taught us that they're not happy with exclusionary mechanisms. The ACTG trials and pharmaceutically sponsored trials have standard criteria for patients who are eligible to enroll in the study. The reason for that is so that you can quickly generate data that you can say comes from a homogenous patient population, so you can really understand what this drug does, if it works, if it doesn't work.

Dextran Sulfate

Abrams: The activist community and the People With AIDS community have for a long time been pretty clever about obtaining drugs. First, there were the so-called alternative therapies--vitamin C, DNCB [dinitrochlorobenzene], and other therapies that were just available and out there. But then when drugs started to be tested in orthodox clinical trials, the community also found ways to obtain them.

For example, dextran sulfate is a drug that I was studying. Dextran sulfate has an interesting history. I was invited to a conference in Japan by David Purtillo, the guy who recently died that worked in Epstein-Barr virus. At this conference in Japan, he took me aside and introduced me to two young Japanese pharmaceutical people from Ueno Fine Chemicals who had this product, dextran sulfate, that they wanted me to consider investigating. This was in 1986, and AZT was about to become approved. First, they wouldn't tell me what the name of it was, because it was too top-secret, and they said it's something widely available in Japan.

They showed me that dextran sulfate prevented HIV from infecting susceptible cells. They had done this work in the test tube, but it hadn't been published yet, and they wanted me to do a clinical trial. They had two forms of the drug, an intravenous form and an oral form.

I said, "AZT is going to be approved as an oral agent, so I don't think it would be wise to investigate and develop an intravenous drug for this disease when the new standard is going to be oral. So why don't we look at your oral form? Plus, there's going to be this huge amount of enthusiasm for everybody to take AZT, and I don't know if we'll get people on this trial, especially if the results of your *in vitro* study are not published." So they got their study published in *Lancet*, and then I started working with them through the FDA to get an IND to study dextran sulfate.

Well, we had a small, thirty-patient phase I trial at San Francisco General Hospital. But while we were doing it, the community became aware that dextran sulfate was available in Japan, where it was sold in drugstores to lower cholesterol in the blood. So there became a large market, sort of the precursor of the current buyers club, which had already been established through the DNCB distribution network through the guerrilla clinics. They sold dextran sulfate. People would be calling me all the time to find out what dose they should be taking.

We had heard that a patient on our clinical trial, which was a dose-escalating study, who had been randomized to receive one of the lower doses, was buying dextran sulfate on the street to supplement the dose we were giving him to get to what he thought was the right dose. Here was a drug that nobody knew anything about, but everybody had their preconceived notions as to what was right and what was wrong. This was in 1986.

The Japanese pharmacies mentioned to the Japanese government that dextran sulfate was being widely sold and exported to Americans. Similar things had happened in the past with ribavirin and isoprinosine when we were studying those drugs in 1984. People went to Mexico where they were available over the counter, began to import them from south of the border, and sell them.

Now dextran sulfate was being imported, and interestingly, I had gone to the ACTG two separate times to give them an update on our clinical trial. The ACTG wasn't really doing anything very creative or new. I wanted them to consider doing a study with this drug. The people were very skeptical about the drug; they said, "Gee, the molecule is so big. Does it really get inside of the cell to do what it's supposed to do, yedda yedda?" I'm not a biochemist or whatever; I was just doing a phase I study and seeing that patients could more or less tolerate the drug.

Finally, a few things happened politically. I can't remember exactly who the congressperson was, but somebody demanded that dextran sulfate be tested by the ACTG immediately. And here I'd gone to two meetings previously and showed them this drug and the information and said, "Do you want to do it?" and it didn't get a high priority. At one meeting, they said, "We must have a protocol from you in two weeks for a phase I-II study of dextran sulfate that we need to do." I couldn't believe that I'd been talking about this for nine months, and suddenly it needed to be immediate.

At the same time, the Japanese government cracked down on dextran sulfate sales in pharmacies in Japan. I was accused of having masterminded that because I feared that sales of dextran sulfate on the black market would jeopardized the results of my clinical trial. I was told that the activist community was going to demonstrate at Japanese embassies all across the nation. I said, "I really don't think that's a good idea. You'll certainly scare off the Japanese."

I had learned a lot about working with the Japanese; I thought that they wouldn't tolerate major ACT UP demonstrations at their embassies nationwide. If the Japanese were ever going to consider throwing another drug in the ring to study, I thought that this would really be a turn-off. So I recommended against it.

Hughes: Did the activists listen?

Abrams: Well, I don't know. I think that there were some demonstrations. Certainly in the New York office of Ueno Fine Chemicals there were die-ins or whatever. People chained themselves to the doors and desks in the office, or so I recall hearing.

The bottom line in this story is that ultimately it was demonstrated that dextran sulfate is not ever absorbed by mouth. If you take the capsules as we were giving them to people in the NIAID study, none of it gets into the bloodstream. So none of the stuff that happens in the test tube when you mix dextran sulfate with the virus in cells could be reproduced in the body. It just doesn't get into the system.

I remember having dinner with my Japanese colleague, Ryuji Ueno from Ueno Fine Chemicals. They could never show me graphs of the pharmacokinetics of the drug. They said that dextran sulfate gets broken down into sugar or something, so you can't really measure how much of it is in the blood.

Finally when it became clear to me that the stuff wasn't even absorbed by the oral route, I asked Dr. Ueno, "How can this be sold in Japan over the counter as a therapeutic agent for people with high cholesterol when it's not even absorbed by mouth?" It's also used as a blood-thinning medicine.

He said, "Well, the difference between Japanese medicine and Western medicine is that in Japan we have many products that you can't measure in the bloodstream, but they work. If you take them long enough chronically, their activity becomes manifest, but you can't measure them by your techniques." I like different cultures and different ways of thinking, and I'm certainly open to that, but it was very hard to explain to my scientific colleagues. [laughter] And the drug didn't appear to do anything for T cells or for the level of virus in the body.

But here again the activists were demanding that everybody have access to this drug. And it was not without toxicity; people got bloody diarrhea and gastrointestinal distress from taking it. So I think it was a pretty good example of why it is not necessarily wise to distribute agents, as they go into phase II trials, to the general public.

Parallel Track

Abrams: This sort of planted the seed for what became the parallel track movement. I remember Tony Fauci came to a conference here in San Francisco that I was speaking at. I was backstage and I heard him say that, "We need to have a third track"--I forget what he called it--"for people who can't participate in the large clinical trials, who want to have a drug that seems to be safe and may be effective, who can't wait for the phase II trials to end." So he made this announcement, and everybody said, "What is he talking about?" The FDA said, "How can we do this?" The NIH said, "How can we do this?" Tony had been in cahoots with Martin Delaney or somebody and had decided to announce this.

Then I remember I was quickly called back to a meeting of the FDA's antiviral advisory committee in Washington where we had to walk through this whole gang of activists holding placards and demanding that we initiate this program. At this time I think I was felt to be slightly to the right of Attila the Hun in my thinking about how to do clinical trials. It's again because I just feel that there's a right way to do things and a wrong way. I felt drugs should be studied more completely before they were made more widely available. We should know if they are safe or have any activity before everyone gains access to them. But this was not a popular stance with the activist community who told me that they would prefer to make these choices themselves and didn't need me to be so protectionist.

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Abrams: I remember bringing to that meeting an example of our case report forms that we were using in the Community Consortium to collect data from physicians in the community. I said, "Rather than just distribute these drugs, we should make every effort we can to collect some information while people are taking these drugs in the expanded access program." That ultimately began the concept of expanded access and parallel track.

DdI was the first drug that was distributed along those lines. I am a member of the Bristol-Meyers Squibb antiviral advisory board, so I was privy to the information on whether or not the expanded access program was impacting on the standard or traditional clinical trials program. It seemed to me that people were choosing to get drugs on the expanded access program rather than participate in the large clinical trials. What we feared was that this was going to slow down the orthodox research that was going to tell us whether or not this drug did anything.

By this time, I was mellowing and becoming a little bit more responsive to the demands of the activist community. It's interesting because there is not one real activist community that represents every person with AIDS and HIV. I learned this from living with somebody who died of AIDS myself; he always resented the fact that ACT UP was his spokesperson. He said, "These people don't represent me or what I want. I don't want access to these drugs until people know if they work." The silent community of people with HIV and AIDS is not represented. But that's politics, and that's the way it is.

Activism at the Third International Conference on AIDS, 1987

Hughes: Why have you become more responsive to the activists?

Abrams: Well, I think I am an activist.

Hughes: [laughs] You're a closet activist.

Abrams: Well, I don't think I'm a closet activist. I have a videotape of me taking over the stage at the Third International Conference on AIDS in Washington. At that conference, many things happened while all the delegates from all over the world were meeting in Washington. If you remember, that's when there were riots going on in the streets, and the police in Washington were touching the AIDS activists with big yellow gloves.

The government made all sorts of proclamations about AIDS and HIV disease while we were all gathered there in Washington, but not related to our conference. AmFAR had a big dinner in a tent. I wasn't invited to it, but Reagan came and for the first time publicly said the word AIDS.

I can't remember the specifics that were going on, but the government was enraging people with their proclamations and announcements, because it looked as if the delegates at the international AIDS conference were sanctioning or devising these Machiavellian policies that were coming out of the government.

Hughes: Was the timing intentional?

Abrams: Well, I don't know. I wouldn't put anything past that administration.

I became involved in a group who wanted to express its dismay and dissatisfaction with being utilized in that fashion at this conference. So the day before the conference ended, we developed a statement and put it on top of a petition, and we circulated it among the remaining delegates at the conference. In less than twenty-four hours, we had 1,500 or so signatures.

Hughes: What did the statement say?

Abrams: I have it on tape, and at home on a piece of paper, but essentially: "We the delegates at the Third International Conference on AIDS object to the United States government's dissemination of policy on HIV in this manner while we're here. Be it so moved that in the future all of such proclamations and policies should be made in association with scientists, clinicians, social service groups, and people with HIV infection." Something like that.

A friend of mine, Jean-Claude Gluckman from France, was in charge of the closing ceremony at the conference. He is a real liberal activist type, and he knew that I had gotten these signatures. He signed the statement himself. It was interesting taking the petition around, because a lot of the people in the government, the various branches of the Public Health Service, felt that they couldn't sign it. But everybody was supportive of it. There were just a bunch of us getting signatures.

I said, "What good is this going to do if we can't let people know that this happened?" So at the closing ceremony, Gluckman told me when there was going to be some sort of shifting on stage. [C. Everett] Koop, Surgeon General, Otis Bowen, Secretary of Health, and James Mason, director of the CDC, were coming up onto the stage. Gluckman said that there would be a little bit of confusion so that I could come up at that point. In fact, I got to the front of the audience and my heart was really racing. I saw Gluckman on stage and he signalled to me to come on up.

So I went up and I took the microphone, and I said, "Secretary Bowen, Secretary--" I had a little opening statement, then I read our petition, and I said, "We collected 1,500 signatures in twelve hours." In my jacket and tie and with my credentials and everything, I was not going to stand for that. I walked off the stage in a rather defiant fashion, and I got a standing ovation that went on and on and on. I have it on videotape, because a friend of mine is a science correspondent for a national network and he filmed the whole thing. It was really quite exciting. I think that was the forerunner of people taking over AIDS conferences.

I think realizing that I'm an activist myself, not being ashamed of it, and also being more comfortable being gay in my career, and learning as much as I've learned from people with AIDS and HIV infection have all sort of tempered me a bit. I haven't completely tossed away scientific method and said, "Well, let's just distribute everything to everybody." And I still am on the FDA antiviral advisory committee. I was the only one that abstained just two months ago in voting in favor of rifabutin for prophylaxis against *Mycobacterium* infection. I don't think that the data warrants that everybody with less than 200 T cells should take this drug, because it doesn't prolong survival.

I've become a big stickler for survival as an endpoint [in drug trials], and I think that we really need to be aiming in this disease to find drugs that prolong people's survival. I don't really care if people's T cells go up for six months because if they still die at the same rate if they don't take the drug, then I don't see any benefit to taking toxins. So on that matter, I'm still on the other side of the fence of many of my activist friends who would much rather just have any treatment that they want.

Impact of the Alternative Therapies Movement on Drug Approval[1]

Hughes: Do you see the various events that you've been describing as having a substantive impact on drug approval in this country?

Abrams: Oh, yes. I think the alternative therapies movement and the AIDS activists have definitely had an effect. Importation for personal use has been allowed following the ribavirin and dextran sulfate issues. The buyers club industry is directly related to drug regulation, but it's something that has been developed under the nose of the FDA without them really putting much emphasis or attention on the whole thing.

The parallel track and expanded access programs are now legislated and validated, and accelerated approval is something that the FDA recently used to approve the drug ddC. Accelerated approval means that a drug, even before everything is known about it, can be approved on the basis of its impact on surrogate markers. If it turns out from continued clinical trials that the drug really doesn't have clinical benefit, then it can be acceleratedly withdrawn from the market as well.

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[1] See also: D. I. Abrams. Alternative therapies. In: *Information on AIDS and HIV Infection and Disease*. AMA Press, 1989, pp. 163-175.

In the past, when a treatment IND had come out for a drug to be used more widely before it was finally approved, it used to be that people who had had prior experience with the drug were excluded from participating in the treatment IND. Around the drug clarithromycin that was changed, because many in the activist community had access to this drug through foreign markets before it became available in the United States. They were taking it to treat a bad infection, and when it became available under the treatment IND, they were going to be excluded because they had previous experience, because they had the wisdom and the know-how to obtain the drug. So after arguing with the pharmaceutical sponsor, a subsequent treatment IND protocol was established for people with prior experience with the drug, and the FDA condoned that. So I think the FDA, with change in leadership and with wider exposure and dialogue with the activist community, and with their own advisory committees, has developed a new approach, or what seems to be a change from their previous "business as usual" attitude.

The Community Consortium petitioned the FDA two years ago [December 1990] to demand that information regarding studies on ddI and ddC be called in and evaluated quicker, because it seemed like those drug trials were just dragging on forever and we were not learning anything about them. They didn't exactly respond to that with a lot of speed, but ultimately both of those drugs were approved.

I think nobody could deny that the drug approval process is now quite quick. I think the onus really falls on the primary care providers in the community to figure out how to use these drugs in their patients. Things get approved so quickly that we don't really know how to use them. All the i's haven't been dotted and the t's crossed, and we really don't know how to best use these drugs in patients.

Hughes: Is it a function of the Community Consortium to get that kind of information out?

Abrams: Yes, absolutely. I think groups of doctors that have already had experience using these drugs in the expanded access and parallel track programs are a good resource for doing postmarketing studies to see how to use them. I don't think that's the sort of utilization of the highly specialized AIDS Clinical Trial Groups that we should be moving towards.

The California Law on Drug Approval, 1988

Hughes: Well, in 1988, the California state legislature passed a bill that allowed approval of drugs for life-threatening diseases that hadn't been approved by the FDA.

Abrams: Yes, I remember that.

Hughes: Do you remember having an opinion about the legislation?

Abrams: Yes, I thought that was ridiculous myself. Paul Volberding and I shared the concept that, what good does it do anybody if drugs are available here in California and not elsewhere? It just seemed to me like it was reduplicating the wheel. I didn't think that the FDA was that Draconian. Maybe it was a little more so at that time. But it just seemed a bit egocentric and provincial to think that California was in any way more special than other states. So what if we did a study that made drugs available for people in California and not the whole nation? It seemed like a silly waste of resources. I don't know of any drug that has been approved here and not approved elsewhere, but I don't follow whatever happened with that legislation.

Hughes: Did it perhaps have an effect on the drug approval process at the federal level?

Abrams: I couldn't say.

Trials of Immune Modulators

Hughes: Could you speak to the trial of alpha interferon at an early stage in the epidemic?

Abrams: Well, when I was still over at the university [UCSF], Paul had started an alpha interferon trial for patients with Kaposi's sarcoma; I had nothing to do with that. But I remember meeting with Paul and the drug company representatives, and it was at this time that I was investigating ARC and the AIDS-related complex group of patients. And we said, "Well, gee, if it seems like the drug is useful in patients with Kaposi's sarcoma, maybe it would be useful in patients with ARC." In 1983 when we started this protocol, we didn't even know that this was HIV disease. We just knew that these lymphadenopathy patients might be at risk to go on and progress to AIDS.

At first I was very protective of people with lymphadenopathy, because I was hoping that they were mounting a different response to whatever it was that was giving other people KS and *Pneumocystis*.[1] But as time went on I saw that there was a pattern: patients got white stuff in their mouth (this thrush or hairy leukoplakia), their T cells dropped, and then they got AIDS. I said, "Huh, maybe some of these people are at risk to go on and develop AIDS."

I set up what is probably the first trial in the country for patients with a condition that was not yet AIDS. Through collaboration with Abe Andes in New Orleans and Dan van Hoff in San Antonio, Texas, we put together a protocol for a small, placebo-controlled trial, and treated about eighteen people with lymphadenopathy with interferon versus placebo in a six-month trial to see what happened to their T cells and to their disease progression. It was a pilot study, and the first study that I'm aware of of an agent in patients with ARC.

With time it became clear to me that more and more patients were at risk to develop AIDS, so I became more agreeable to having these patients participate in clinical trials. So we did a trial then with isoprinosine, and we did a trial of ribavirin.

Hughes: Interferon was supposed to be a miracle drug, not just for AIDS but for a variety of problems. What was the rationale for using it to treat AIDS?

Abrams: Well, interferon is something that the body produces in response to a viral infection. It had been shown to have some activity against tumors, and Kaposi's sarcoma was a tumor that we thought was probably caused by a virus. There was some suggestion that interferon also was a booster of the immune system. So the rationale for using alpha-interferon was really quite strong.

We also did a small study of gamma interferon, very close to the beginning of the disease, and that was quite dreadful. I believe we hastened the demise of some of our patients who participated in that trial.

These interferons and interleukin were the drugs that we studied at the beginning before we knew about HIV. When we knew we were dealing with an immune deficiency and we were getting more sophisticated in knowing what was deficient, we used biotech products that we thought could boost the immune system. We knew

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[1] See Shilts, *And the Band Played On*, p. 598; "New Theories about AIDS," *Newsweek*, January 30, 1984, 50-51.

our patients had low levels of T cells; interleukin-II was [also] called T cell growth factor, so we figured, well, if patients are low in T cells, let's give them this T cell growth factor and see if we can boost their immune system.

The interleukin trial was a rather large study we did, the last of our immune modulators, and that also seemed not to be very helpful and potentially harmful to patients.

Ribavirin

Abrams: Ribavirin's an interesting story. Lawry Kaplan had just joined our staff then, and he was working with a group at ICN Pharmaceutical on the ribavirin protocol. I was the ARC person still, and I had been invited down to ICN Pharmaceutical by one of their people named George Banks. I was giving a talk down in L.A., and he whisked me away from this meeting to drive me down to Orange County to this spanking new, beautiful glass building where you needed all these cards to enter the doors. I systematically went from one vice president's office to the next, talking about ribavirin with them. They gave me that book over there, *Clinical Applications of Ribavirin.*[1]

I really didn't understand what was going on. I thought that, because I was the ARC person and they were doing one trial in patients with ARC and one trial in patients with lymphadenopathy--I wasn't sure exactly what the difference was, except I think the ARC patients were maybe more symptomatic--that they were looking to me for some consultative input.

Ribavirin was being widely imported from Mexico on the black market, and its price in Tijuana drug stores reportedly had gone up fourfold since the interest started to peak.[2]

Well, I was ushered at about four o'clock that afternoon into this huge, modern, beautiful office room that looked like a suite in a hotel, to meet with the president of ICN Pharmaceutical, a man named Milan Panic, whose name might sound familiar because

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[1] R. A. Smith, V. Knight, J. A. D. Smith, eds. *Clinical Applications of Ribavirin.* New York: Academic Press, 1984.

[2] For more on ribavirin and issues surrounding the black market in AIDS drugs, see Jonathan Kwitny's *Acceptable Risks.* New York: Poseidon Press, 1992.

he's currently the president of Yugoslavia. All these vice presidents, I had the impression, were standing behind me going like this. [gesturing "no"] Milan Panic said, "So, how can we help you?" I said, "Excuse me?" He said, "Well, why do you think we brought you here today?" I said, "Well, I'm not sure. I thought I was coming to help give you advice on your protocol."

He said, "You? Who are you? We have Paul Volberding, we have Michael Gottlieb, we have real doctors giving us advice. We brought you here to help you." I said, "To help me what?" He said, "We read in the newspaper that you would like to give all of your patients ribavirin." I said, "What?"

He said, "We read it in *USA Today*." I said, "You better reread that article because I doubt that I ever said anything like that." So he snapped his finger and told his secretary to get the article.

Then I recalled that there had been an article in the *USA Today* about Richard Rector, who was one of our first AIDS activists, who said that if ribavirin has any use, then everybody should be able to get it.[1] This was in 1985, I think. And I remember the bottom line was me saying, "We don't know whether treating these patients with early infection with this drug is going to help them or harm them. It needs to be studied." Milan Panic had read hastily, or perhaps because English was a second language, he had misread the article. I said, "I don't understand exactly what you're talking about. How would you help me?" Panic said, "We would like to sell you ribavirin to sell to your patients." I said, "What? I'm a member of an institutional review board at the University of California at San Francisco, and I conduct clinical trials. Why would I want to sell my patients a drug that is not approved and doesn't have any known efficacy, especially when they can get it in Mexico?"

He said, "How do you know that the drug that they're getting in Mexico is ribavirin?" I said, "Because they have side effects that are consistent with the side effects that we know come from ribavirin." He said, "I knew we should have gotten somebody in private practice." And I was dismissed.

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[1] Steven Findlay. "AIDS victims to study 2 experimental drugs." *USA Today*, October 22, 1985.

The *Wall Street Journal* wrote about that encounter.[1] Ultimately, ICN Pharmaceutical released its data from its lymphadenopathy or ARC trial where it showed major, major benefit from the drug compared to placebo in preventing patients from progressing. That data was presented at the International Conference on AIDS in Washington [1987]. It was really shot down because there had been some problem in randomization so that more patients who were much more advanced with regards to low T cells, et cetera, had been randomized to the placebo arm than to the ribavirin arm, so the results were really contested.

Ultimately, Paul Volberding appeared at the San Francisco Stock Market with Milan Panic at about the time that they were announcing the results of their study. Paul never really lived down that he chose to do that. But I find it quite remarkable that the man is now in power in his homeland.

Hughes: Well, that brings up the question of the availability of AIDS drugs. By that time, there wasn't much of a problem.

Abrams: What do you mean, there wasn't much of a problem?

Hughes: Well, companies saw that there was a market for AIDS drugs. I surmise that that was not true at the beginning of the epidemic when its dimensions were not certain. Was there a campaign on the part of the medical profession, or anybody, to try to interest pharmaceutical houses, and particularly the biotech firms, in developing drugs for AIDS?

Abrams: If there was, I wasn't involved. I think that once the drug companies realized the magnitude of the problem, they themselves got interested. I think some of them got a little turned off by pressures and demands from the activists, and concerned about having to release drugs to people before they were fully tested, and whether or not they would recoup any of their costs. I think that there have always been companies that are interested. Whether or not they weigh the liabilities and the potential benefits differently now, I don't know.

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[1] William Mathewson, Shop Talk. "He must have read the paper on the run." The *Wall Street Journal*, April 13, 1988, section 2, 31.

Suramin

Abrams: Then in 1984, it became clear we were dealing with this virus. The first article was published in *Science* or *Nature*, by Sam Broder, about this drug suramin. It worked in the test tube and they had given it to a few Africans. I remember Paul Volberding saying, "Let's go talk to this man and get this drug for our patients." So Paul and I got on an airplane. I remember it was very exciting; it was one of my first trips to Washington. We went to the National Cancer Institute and we met with Sam Broder, who's currently the director. We said, "Hey, we read your article; we'd like to have this drug available too. How can we get it? Can we participate?"

I guess we weren't the only ones; other people from around the country came. This was before the ACTG was set up by the NIAID, and the National Cancer Institute was taking the lead in doing the investigation. I think that's the pattern that's really subsequently been followed: Sam Broder and Bob Yarochan and his lab at the National Cancer Institute do the early phase studies on these potential antiviral agents, publish them, and then the ACTG does larger-scale clinical trials.

Paul and I flew to Washington, met with Sam Broder, and subsequently went back to Washington for a larger investigators' meeting that was at the National Cancer Institute. I don't remember exactly how loosely or strongly they were involved in sponsoring this trial, but we began to test suramin. We decided that we would have some patients with AIDS and some patients with lesser conditions, ARC, involved in the trial.

I remember when we first started the trial that, it looked like there were some problems with this drug. This was the first antiretroviral that we studied. I had one particular patient at this time who was quite well and had ARC and wanted to participate in the study. I actually tried to talk him out of it. I've always been a bit conservative, therapeutically. This man was very well; he was productive; he was an artist. I said, "I think I'd let a few other people who are more advanced in their disease take it first because it's a risk." In fact, he and his lover decided that he would take it. I believe he ultimately died as a consequence of this drug, and I really felt quite badly about that. After a while, we saw that many, many people with early Kaposi's sarcoma got dramatic flares of their Kaposi's sarcoma, and that people were getting all sorts of bizarre reactions, and then their adrenal glands started wiping out.

I remember once walking to the market in my neighborhood and this woman, who was an AIDS activist, who subsequently has gone on to be a Central American activist, came up to me and said, "Why can't everybody have suramin if there's a potential that it might help?" You know, the beginning of this mindset that everybody should have everything. I said, "Well, gee, because we don't know a thing about it. We don't know if it's going to kill people or if it's going to help people or what, so let's study it for a while." She said, "Oh, I think it's terrible; it's criminal; you're killing people by not allowing them to have access to it." After a time, it became clear that this drug was killing people. When we talk about expanded access, parallel track, and the speed of drug approval, I always point to the suramin story and say, "There but for the grace of God goes--." I mean, if this expanded access program had widely distributed suramin after the earliest trials, many unnecessary deaths would have occurred.

Then we had Rock Hudson flying off to France to get HPA-23. So we said, "Hey, what's this?" So Paul and I went to New Jersey to tell the people at Rhône-Poulenc, "Hey, we'd like to participate in this." All of these trials occurred before the ACTGs or the ATEUs were set up. We had already tested essentially every AIDS drug. We also became involved in the original AZT study that Burroughs-Wellcome did that led to approval of AZT in 1986. I believe it was after AZT was approved that the ATEUs were finally set up.

So we had really tested everything here at San Francisco General--alpha interferon, gamma interferon, interleukin-II, isoprinosine, ribavirin, suramin, HPA-23--gee, what else was there?

Compound Q

Hughes: Compound Q.

Abrams: Well, Compound Q is much later in the history. Compound Q is a Jim Kahn story. I have feelings about it, but I don't know much about it. Mike McGrath published that article in 1989, saying that Compound Q from the Chinese cucumber had some activity in the test tube protecting cells, including monocytes, from infection with the virus.[1]

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[1] Michael McGrath et al. GLQ223: An inhibitor of human immunodeficiency virus replication in acutely and chronically infected cells of lymphocyte and mononuclear phagocyte lineage. *Proceedings of the National Academy of Sciences* 1989, 86:2644-2848. Compound Q received considerable press coverage. See, for example: Gina Kolata. Early Tests

I have always said when I'm asked by newspaper reporters: "Gasoline works against the virus in a test tube. So does soap suds. Everything does. Just because something works in the test tube does not mean it works in people." That's really the hardest information to transmit to patients and their families.

So Mike and Jim Kahn started doing early phase clinical trials with Compound Q. This was the first drug that really blew the whistle on the underground market. Prior to Compound Q, most of the drugs that people experimented with in the community were very safe. In fact, it became almost the dictum that nontoxic equals effective. I tell people, "This is a bad disease, like cancer's a bad disease, and we have to use strong drugs." People get into this mindset that if something is mild and has no side effects, then maybe it's going to be effective.

Compound Q was different because it had to be given by vein, and it produced some serious side effects. Martin Delaney and the whole gang that organized the underground Compound Q trials said that the reason they were doing it was to monitor its use, because they knew that patients were going to be going to China to get the drug and were going to be injecting themselves. So they felt that they might as well do it in a monitored setting under physician observation--collect some data and do a parallel trial to what was being done here by Jim Kahn.

Apparently, they had involved some media personalities in setting up their underground Q trial, because they felt that this might in fact be the cure, and that this would be a story worth reporting.

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Abrams: The reporters were not supposed to divulge to anybody until the cure was announced that they were involved from square one.

Well, when patients started to die, the news broke, and I believe it was NBC News which reported that this Q trial was going on. People became aware of it, and the FDA now had to deal with it. Ultimately, the FDA said, "Okay, you should stop the trial, but if you apply for the right papers, we'll let you continue it." I was quite vocal against that, because I thought that that was not very strong protectionism, and it really opened the PWA community to being taken advantage of by people that wanted to do harmful things and sell them products. I was pretty vocal in the anti-underground Q movement, and didn't ingratiate myself with Martin Delaney and other people. But I just always speak my mind and say what I feel.

Promising for a new AIDS drug. *New York Times*, April 18, 1989, p. B6.

Here we are almost in 1993, and I don't know what the hell's going on with that drug. The community continues to use it; it's a large seller in the buyers' club. There's no data that I can see that suggests that it's very beneficial, even from my own group here at San Francisco General Hospital. I remain completely in the dark as to whether or not it has any benefit. If one wonders what the FDA should be doing as far as calling in data, I think Compound Q is probably one that we should get some information on and either bury it or approve it. It's ridiculous. The reason that the community did their underground trial was to get answers quicker, and I don't see that they're coming up with anything.

DdI

Hughes: You were at the meeting in which the FDA approved ddI in October of 1991.[1]

Abrams: Well, the meeting where the committee recommended approval of ddI was in July of '91. FDA approval came in October.

I think ddI approval was really historic and showed how things had changed. Approval was based on data from 170 patients enrolled in five different phase I studies. Phase I means you're looking for side effects and toxicity; phase II is when you look for effectiveness. Most studies of HIV disease now are phase I/II, where you get a little bit of efficacy information while you're testing for side effects.

The phase I studies were conducted at five different places, looking at two different routes of administration and twenty-four different dosages. So with 170 patients, you can see that there weren't too many patients who actually got the same thing. The phase I data was given a phase II spin, if you will, by comparing these patients to historical controls that had participated in other studies, including in fact my dextran sulfate NIH cohort. It was used as a control group that was felt to have gotten placebo for the whole time, because the drug wasn't absorbed. So they used what happened to T cells and p24 antigens as controls, which I thought was very interesting.

One of my problems is, I do all these studies with agents that don't have any effect, and then I never write them up. I say, "Well, who cares about a study of a drug that doesn't do

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[1] P. S. Arno, K. L. Feiden. *Against the Odds: The Story of AIDS Drug Development, Politics, and Profit*. New York: Harper Collins, 1992, p. 223.

anything? Let's just move on." A major problem that I have academically is that I need to understand that I still need to publish, even if something doesn't work.

Hughes: Publish for the sake of your career, or more than that?

Abrams: Well, for getting the information out there so people don't get stagnated and fixated that these drugs might still have some benefit, and also for my career, because these are studies that I did myself. I originated them intellectually, and I should take the credit for them. I would be the first author, and they can appear--well, I don't know where they could appear. I don't know if there's a journal for trials that fail. I could just about be the publisher or the editor.

Hughes: You were talking about ddI.

Abrams: Oh, yes. So they used historical control groups to give their phase I data a phase II spin.

We based approval for the first time on the impact of the drug on the surrogate markers, the CD4 count. Previously, approval had been based on disease progression and death. This was the first time that rises in the CD4 count were used to approve the drug.

Hughes: There's been recent criticism of using just one surrogate marker.[1]

Abrams: Sure. I'm one of the people that criticizes it.

Hughes: Were you critical of the way ddI was approved?

Abrams: Yes, I was concerned about it, absolutely. Especially since the CD4 cell count rises that we saw were not very dramatic.

The fourth thing that was quite historic with the ddI approval was that an ongoing trial that was blinded was partially unblinded for the purpose of bringing the information to this committee meeting. That was Jim Kahn's study of AZT versus ddI in patients who had been on AZT for longer than four months. What they brought to us was the graph of the CD4 cells in patients who had been on that trial for about six months. It showed us that people who continued on AZT had a continued decrease in their CD4 cell count, whereas patients switched to either of the two ddI dosages sustained an increase and a subsequent decline back to baseline. The difference between their T cells and the patients who continued on AZT was ten T cells. But it was clear that they

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[1] See, for example: Jon Cohen. Searching for markers on the AIDS trail. *Science* 1992, 258:388-390.

went up and then came back down, whereas the AZT patients continued to dwindle down.

So if we were going to accept that it was a beneficial outcome to have the CD4 cell count rise, it was clear that this happened in the patients switched to ddI and not the patients who continued on AZT. The fact that the study, which was ongoing and not even fully accrued, was unblinded with respect to that data for us again was a new first.

The fifth thing that's historical in the ddI approval was that approval was recommended for both children and adults at the same time.

Hughes: Now, was that due to pressure from the pediatric AIDS community?

Abrams: No, the largest single group of patients who participated in a protocol that was standardized was children. Phil Pizzo at the National Cancer Institute had the largest group of people that participated in a single protocol. In children, ddI seemed to have a good effect, both on CD4 cell count and neurologic function. It appeared that the data in children was perhaps even more convincing than in adults.

Hughes: Well, that was quite a breakthrough, wasn't it? My understanding is that women and children had not participated in these drug trials, that it had been predominantly white males.

Abrams: Yes, but who are the people with the disease? Now women constitute over 10 percent of the cases, but there aren't huge numbers of children. In ddI, the largest single subset of patients that participated in a trial was children, so that's why I think we could feel confident approving it.

Attitude about Alternative Therapies, and AZT

Hughes: How did you counsel patients who wanted to try unorthodox therapies?

Abrams: Although I'm viewed as being really conservative and rigid, I think I probably have more patients who do weird things than most people because I have not jumped onto the antiretroviral [drug] bandwagon. I don't think that these drugs are the end-all and the be-all. I don't necessarily believe that much in currently available, licensed products for this disease, so I'm always eager to see my patients do whatever they want that's going to empower them, as long as they're not suckered into something that's a complete scam.

I believe that maybe it will be serendipity that will cure this viral infection. I don't send my patients out to get products in health food stores or underground markets, but if they're using them, I don't condemn them. In fact, one of the early protocols that the Community Consortium did was called the HIV Alternative Treatment Database or Registry. Patients who were using self-prescribed drugs could come to their physician and say, "Here's a list of what I'm using," and they could be monitored using our case report forms as if they were participating in an observational database.

We knew that we wouldn't really see anything dramatic. AmFAR gave us $100,000 to do this project. We only enrolled thirty-seven patients, each one taking a different alternative regimen, so obviously we weren't going to see any pattern or trend. Our hope was, if there was something like N-acetylcysteine, which is now big and being widely used in the community and having a positive impact, that we could do a subgroup analysis and see that maybe something was happening therapeutically and that this drug warranted a traditional clinical trial.

I've always been interested in collecting information. Anecdotes don't impress me that much. We use this alternative treatment registry as a potential to collect some useful information on self-medicating patients. So I think my attitude about alternative therapies has been nonjudgmental and, if people are going to do this, it's reasonable to collect some data. Now we have a larger observational database that's run through the CPCRA. Whether or not any real information will be collected on alternative use is unclear. But I think that patients get a sense of empowerment if they take their lives in their hands and they do something that they think is helping them.

Many of my patients are on Chinese herbs and acupuncture. I don't know what else is really big right now in the community. I think the need to self-medicate with alternative therapy waxes and wanes with what's available through nonalternative means. Right now, with expanded access and even a new drug, d4T, currently available for patients who can't tolerate existing ones, people are less inclined to use alternative therapy.

Then there's the other population of patients, which I seem to attract, which has been suspicious about antiretroviral therapies from day one and just doesn't take them. I have a large population of patients which is free of antiretroviral therapy, because they know that I am not going to say: "[gasp] How can you not be taking this? You're not being treated."

I remain skeptical as to what impact we really have had on people's survival. I understand that some of these treatments raise T cells, and some of them cut down progression to HIV, but I haven't seen a good prospective and randomized study that shows that taking an antiretroviral impacts on survival. Even the study that I just reported to you, where patients switched from AZT to one of two dosages of ddI and their T cells went up, also had decreased disease progression, but the outcome was the same and the deaths were equal in all three arms, whether people switched off of AZT and raised their T cells and stopped their disease progression, or whether they stayed on it.

So the ultimate goal in this disease, if we can't cure it, is to prolong people's survival which I don't see we're doing right now. So that's been my attitude.

AIDS as a Chronic Disease

Hughes: Would you say that the shift in viewpoint from AIDS as an epidemic acute disease to one that is now viewed as a chronic disease had a medical impact?

Abrams: Medicine had something to do with it, because medicine came up with the HIV antibody test which allows us to identify patients much, much earlier in their infection. We don't see patients coming in in respiratory failure with *Pneumocystis* pneumonia like we did in 1981. Now we can identify patients who are HIV positive and have 900 T cells ten years before they're going to get sick. So of course it looks like a chronic disease, because what we're looking at is HIV infection and not end-stage immunodeficiency.

Hughes: You're not convinced that medications have had anything to do with AIDS chronicity?

Abrams: Right, absolutely. People come under care earlier; people alter their lifestyle; they don't abuse their bodies with drugs or chemicals; they get prophylaxis for *Pneumocystis*, which is the number-one opportunistic infection and one of the major causes of death. So I think those are the issues which are contributing to this perception of a chronic disease.

Publicity and Publication

Hughes: As you well know, many of the medical journals frown on any publicity before publication.

Abrams: I think that's changed by AIDS as well. People realize that in this public health emergency, information that's going to impact on how people are cared for needs to be disseminated before it's published. Look at the release of information about ACTG 019, the trial that Paul Volberding did which showed that asymptomatic people with HIV had decreased disease progression when they took AZT compared to placebo.

That trial was terminated, I believe, in August of '89; there was a press release; then it was reviewed by the FDA antiviral committee in December of '89 and was approved--increased labeling for people with less than 500 CD4 cells. Then the paper was ultimately published I believe in April of 1990.[1] In looking at what impacted most on sales of AZT, it was the press release in August. There was a little blip after the FDA meeting in December, and a minor blip after the April publication in the *New England Journal*, but the major change of practice occurred with the press release.

Hughes: Which obviously did not jeopardize publication.

Abrams: Right.

Hughes: Well, that is quite a switch.

Abrams: Well, the *New England Journal* announced it with regards to the Inglefinger rule, that they were liberalizing publication policies around AIDS because there was a need to disseminate information that may in fact impact on people's quality of life, if not lifespan.

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[1] P. A. Volberding et al. Zidovudine in asymptomatic human deficiency virus infection. *New England Journal of Medicine* 1990, 322:941-949.

Impact of AIDS on the American Health Care System

Hughes: Can you make a summary statement about the impact of the epidemic on the American health care system?

Abrams: Yes, it's easy, because I think AIDS has really demonstrated that our current system of provision of care to the American people is grossly inadequate. I think that most people who work in HIV disease really have abhorred seeing the inequities in the health care delivery system. Especially as we work with more and more disenfranchised people who don't have any resources, it's really awful.

Who knows what will happen with the new [Clinton] administration, but I think any sort of movement towards a national health care policy might be greeted with open arms by people working in this disease. It's just really underscored the inadequacies of our current system.

San Francisco and New York City: Responses to the Epidemic

Hughes: San Francisco is looked upon as a model for response to the AIDS epidemic. Why did this community respond more effectively than, say, New York or Los Angeles?

Abrams: Well, New York and Los Angeles are both very large communities. I've always said AIDS is one of New York's problems; it is not its only problem. New York has such a huge population and such a huge number of problems that the impact of the epidemic was not felt as dramatically as it was in San Francisco.

San Francisco at the end of the 1970s had a very large, very politically active gay community. Gay men in San Francisco are at a socioeconomic level above that of the general population. They were organized for achieving liberation and civil rights in the 1970s, and there was a large network of community organizations that could shift its priorities, once civil rights were perceived to have been obtained, to fighting a new disease that was decimating their people.

There were a lot of volunteers in the gay male community who were infected and dying. There was a lot of finances and a lot of support and a lot of political clout at City Hall. Also we had compassionate leadership in City Hall that realized that AIDS was a potential problem that could devastate the community.

In San Francisco, the power of the gay community is above and beyond what it is in New York and Los Angeles. The physicians working on the disease were often gay themselves, or were sympathetic to the cause. This model system could emerge. We like to say that it's not a gay disease, and that became a chant in 1986, but the reality of the situation is, in San Francisco, it is still pretty much a gay disease.

In New York, it isn't. It's 50 percent injection drug users, and there is not a "community" of injection drug users. The injection drug using population doesn't have an organized infrastructure and a community and a political presence that gay men do.

Now what we see is fragmentation in the organizations that have arisen. Every ethnic minority has its own AIDS service organization, its own AIDS education organization, and they're all competing for a very diminishing pot of funds. There was an article two weeks ago in the *San Francisco Examiner*[1] about the fact that San Francisco is no longer the model, that we're supporting a number of programs that are ineffective and duplicative, and that really we need to step back and revamp and re-evaluate exactly what's going on here.

I think the model is also threatened by the dwindling population of gay men with money who are either contributed out or dying. I think that's a major problem.

Politicization of the AIDS Epidemic

Hughes: How do you feel about the politicization of the disease and the players? You yourself have obviously taken, or been forced to take, a political role.

Abrams: Yes. I have mixed feelings about that. I hate to see the disease become a political issue, because it's a medical problem, just like abortion. It doesn't make sense that abortion is talked about by politicians, because it's a medical issue and it's a person's individual right to choose. I have a little that same feeling about AIDS; I don't like to see people make it into a political issue. I don't like the economic gerrymandering that goes on around HIV and AIDS.

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[1] Lisa M. Krieger. A rigorous journey. S.F. AIDS programs: The price of success. *San Francisco Examiner*, November 15, 1992, A13.

It's probably because I'm not very politically sophisticated and I don't really have a lot of understanding of how all these things work. But I think it's unfortunate, and I try to steer clear of politics when I can. But as you say, I have been forced, as everybody has, to be involved in politics and make political statements from time to time.

Hughes: Do you have any comment to make about the media's role in the epidemic?

Abrams: Well, the media have been our biggest friends and our biggest foes. We rely on the media, in the absence of any official government educational program, to disseminate the word about what AIDS is and what it isn't, and how HIV is spread and how it isn't. But the media likes to sell whatever it is they're selling, and oftentimes they choose to glom on to the most extremist pieces and sensationalize things that we would try to downplay. So they've been difficult at times, but they've been very useful at times as well.

Hughes: Well, that's the end of my questions. Thank you.

Transcribed and Final Typed by Shannon Page

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Berkeley, California

The San Francisco AIDS Oral History Series

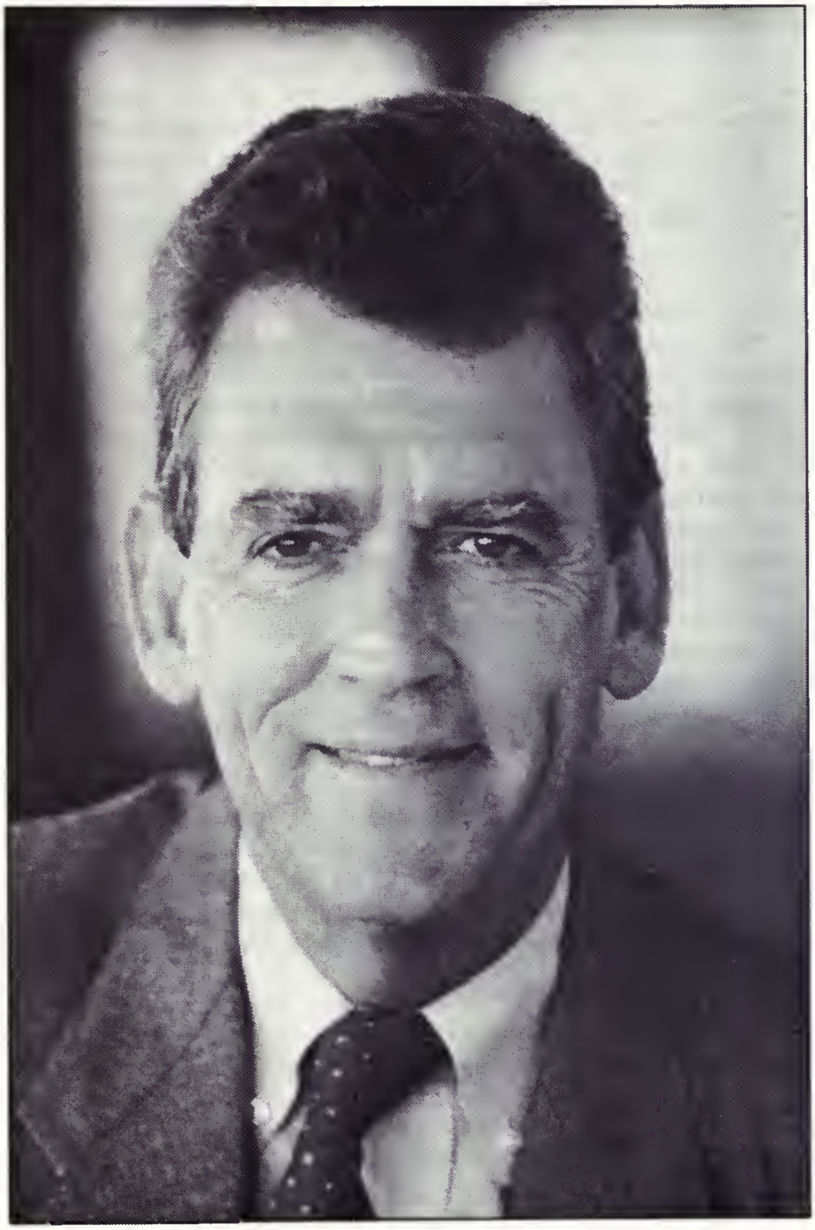
THE AIDS EPIDEMIC IN SAN FRANCISCO: THE MEDICAL RESPONSE, 1981-1984

Volume II

Marcus A Conant, M.D.

FOUNDING THE KS CLINIC, AND CONTINUED AIDS ACTIVISM

Interviews Conducted by
Sally Smith Hughes
in 1992, 1995



Marcus A. Conant, M.D.

INTERVIEW HISTORY--by Sally Smith Hughes, Ph.D.

As the inspiration and instigator of San Francisco's first coordinated medical response to the AIDS epidemic, Dr. Conant was an obligatory subject for an oral history. A professor of dermatology at UCSF with a large private practice in San Francisco, he became aware in April 1981 of two local cases of what later became known as AIDS. In these patients, it took the form of Kaposi's sarcoma, a skin cancer which heretofore had been seen in the United States mainly in elderly men and in patients receiving immunosuppressive therapy. Its untoward appearance in association with rare infections in young, apparently healthy gay men was being noted simultaneously by physicians in New York and Los Angeles. But the first published reports on the new syndrome did not appear for another few months.[1]

This oral history chronicles the city's earliest institutional and community responses to the epidemic from the perspective of one who was their prime organizer. One of Conant's first steps was to arrange for the establishment of a clinic, which met once a week at the University of California, San Francisco [UCSF]. The Kaposi's Sarcoma [KS] Clinic, as it came to be called, saw its first patients on September 21, 1981, a date establishing it as the first AIDS clinic in the world. Conant describes the assembly of a multidisciplinary health care team to diagnose, treat, and counsel patients with KS. The study group which Conant organized to follow the clinic was a magnet for anyone interested in the biomedical aspects of the epidemic--university and private practice physicians, health department and blood bank officials, epidemiologists and basic scientists, patients and an occasional journalist. The clinic and study group were in fact the center around which San Francisco's earliest medical response to the epidemic was organized.

Conant also describes his political activities at the local, state, and national levels. He tells, for example, of leading the group of university researchers who lobbied California Assembly Speaker Willie Brown to persuade the state legislature to allocate the first state funds for AIDS research--and of the university's mixed reaction to the group's unorthodox approach.

Conant also recounts private turmoil--the loss of patients and friends, frustration at the federal government's slow response to requests for AIDS funding, and the conflict produced by his dual identity as a physician and member of the gay community. He describes, for instance, his decision to support closure of city bathhouses and the enmity he earned from members of the community who saw the baths as symbolic of gay liberation. It was a time of personal anguish.

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[1] Centers for Disease Control. *Pneumocystis* pneumonia--Los Angeles. *MMWR* 1981, 30:250-252 (June 5, 1981); Kaposi's sarcoma and *Pneumocystis* pneumonia among homosexual men--New York City and California. *Morbidity and Mortality Weekly Report* [*MMWR*] 1981, 30:305-307 (July 3, 1981). In the summer of 1982, the puzzling new syndrome was named AIDS.

Some passages in the oral history suggest the persuasive oratory for which Conant is known, a talent instrumental to his continuing role as one of the medical community's prime political spokesmen on AIDS. But it is not sheer oratory which carries him. It is his deeply felt concern to assist people suffering and dying in this relentless epidemic.

The Oral History Process

Six short interviews were recorded between August and November 1992 in one or the other of Dr. Conant's two private dermatology practice offices in San Francisco. Our usual procedure was to meet over a simple lunch which we ate at his desk in the hour he had before seeing afternoon patients. Despite time limitations, Conant, a charismatic personality, was immediately committed to the discussion. But the difficulty in scheduling even these lunch-hour sessions meant that my list of interview topics was not completely addressed. To remedy this situation, I returned in 1995 after a gap of three years for two additional interviews. Like others in this series with heavy schedules, Conant edited mainly on plane trips, making only minor changes in the interview transcripts.

This oral history is important because it provides insight into the earliest days of the San Francisco epidemic. It presents unique information for a case study of a medical community's reaction to the appearance of a new disease. Readers may be interested to find parallels--and differences--between this response and those to epidemics in the past. They may also find clues as to how future scourges might be handled and the motivations which induce certain health professionals to commit themselves to their research and treatment.

Like the other oral histories in this series, this one clearly reveals the personal impact of this terrible disease on the health care provider. As Conant remarks, it should properly be called Horror or Awful, rather than AIDS. Yet his almost daily confrontation with its devastating effects in his patients is in part what moves him and others to extend themselves in ways previously unknown. It is a bonus that the voice central to the complex story partially revealed here is both humane and compelling.

Sally Smith Hughes, Ph.D.
Senior Interviewer

March 1996
Regional Oral History Office
The Bancroft Library

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Marcus A. Conant, M.D.

Date of birth 5/11/36 Birthplace Jacksonville, Fla

Father's full name Marcus Conant

Occupation Businessman Birthplace Jacksonville, Fla

Mother's full name Annie Long Conant

Occupation Housewife Birthplace Stark, Florida

Your spouse None

Occupation Birthplace

Your children None

Where did you grow up? Florida

Present community San Francisco

Education M.D., Dermatology

Occupation(s) Physician - AIDS

Areas of expertise AIDS
Herpes
Sexually Transmitted Diseases

Other interests or activities
Development of an HIV/AIDS Vaccine

Organizations in which you are active

I BACKGROUND, EDUCATION, AND EARLY CAREER, 1936 TO 1981

[Interview 1: August 6, 1992, Dr. Conant's office in his dermatology practice, San Francisco] ##[1]

Hughes: Tell me a little about your early life and education.

Conant: I was born on May 11, 1936, in Jacksonville, Florida. I was an army brat. My father [Marcus Conant] was stationed in Fort Lewis, Washington, and Fort Beauregard, Louisiana. I started school just about the time World War II began, so I moved around a great deal in my formative school years. When Dad was sent to Europe, we--my mother [Anne Long Conant] and my brother Richard--moved back to the home in Jacksonville, Florida, where I went to high school. I graduated from high school there and went to Duke University in Durham, North Carolina. I was at Duke for my undergrad training [1954-1957], my medical schooling [1957-1961], and my internship [1961-1962].

Medical Training, 1957-1967

Hughes: Was there anything particularly formative about those experiences?

Conant: Yes. Probably the most formative period was during medical school when I went to Europe. I was an exchange student in London for about nine months [1960]. That was important, because I think that was what made me realize that even though I was a fourth-generation Floridian on both sides of the family, which is a fairly unusual creature--you almost have to be a Seminole Indian to claim that--I probably could not live in the South. While I had been happy at Duke, or at least not unhappy, and I look back

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[1] ## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

at the time I was at Duke as really a good time, I certainly would never have been as studious as I was had I lived in New York or San Francisco.

In those days, there were no distractions in Durham, North Carolina. One could hike in Duke Forest; one could see a road show production of *Madame Butterfly* once a semester when it came through town. There were a few attempts at literary endeavors, but there was essentially nothing to do outside of your studies. So I worked hard and I was studious. It was a great period in my life in terms of building the foundation for my subsequent career.

But the time in Europe was good, both because of the time I spent in London, as well as the fact that my parents gave me the funds to buy a car and spend three months on the Continent. That certainly was the period when I realized that, Wait, there's a lot more to life than living in Jacksonville, Florida, or even Durham, North Carolina. There was a lot more than even medicine. Until that point, I had been on this track that I was going to be an internist; I was going to go to the National Institutes of Health [NIH] to do my two years of obligatory military training.

In those days, if you were deferred from the draft to go to medical school, you had to serve two years. It was called the "doctor draft." It really was discriminatory, because others were deferred or got out of the draft. But doctors, to get through school, signed up for this program, and then a lot of them had to serve. Well, I had already enrolled in a program at the NIH for young scientists. I was going to finish medical school, go to the NIH for two to four years of research, come back to Duke and do a residency in internal medicine, and be an internist, and in the mold of Gene Stead.

The man who was the chief of medicine at Duke in those days was Eugene Stead who I think by that time had trained thirty heads of departments around the country, a man of awesome stature and a man who drove himself as hard as he drove the students under him. One of the stories--and it's true--about Gene Stead was that he would make rounds every Christmas Day by himself. An intern of course was going to be working on one of the wards all day Christmas, and here would come the professor to make rounds on Christmas Day.

Well, the European experience almost made me rebel against that kind of idea--the idea of being so driven intellectually, in terms of, I'm going to go back and go through this internship and go back to Gainesville, Florida, or Jacksonville, Florida, and that's it. That's when I realized, Wait a minute. That's not what I want to do.

Decision to Specialize in Dermatology

Conant: I gave up the commission at the NIH, and I decided to go into dermatology instead of internal medicine because I perceived that I would have more time for me.

Hughes: Why?

Conant: I perceived dermatology the way the public perceives dermatology, as a specialty that's interesting, it can be a nine-to-five job, and you don't take care of very serious things if you don't want to. You can approach it so that you have time to move to San Francisco and go to the opera, and have a life.

And all of that is true. Many of my dermatology colleagues whom I respect and like, live what I consider to be a very civilized life in medicine, doing good and enjoying doing it, making a good living doing it, and yet not sacrificing themselves on this altar of self-denial.

Unfortunately, in retrospect, Gene Stead had already taken his toll. So I went into dermatology, but I have approached that career just exactly like Gene Stead demanded that you approach internal medicine. I have devoted my whole life to it.

Hughes: So it wasn't the AIDS epidemic that changed things?

Conant: Oh, no.

Hughes: The pattern was established.

Conant: The pattern was already established. It was really unusual because I went to Europe and said to myself, Oh, I want out of that, and I made a conscious decision to get out of it, but a very good decision. You know, you look back and you realize that a twenty-two-year-old kid was making decisions that influence you for the rest of your life. But that kid did all right. I'm pleased with the specialty that I chose. I'm ecstatic about where I've chosen to work. But the thing that I was running away from, this almost compulsive dedication to the medical profession, to the job, this all-consuming dedication, I didn't get away from.

Hughes: Well, you're not leading the life of the typical devoted specialist.

Conant: No, because in my case, I was lucky--lucky is the wrong word. I was fortunate that I was prepared. I had put in my time at the University of California [San Francisco], I had made my connections here, I was already a full professor, I had done the academic work, I had published, and then I was suddenly handed this AIDS epidemic. There are people who clearly could do what I have done as well or better. There are people who are certainly a lot brighter. But for other reasons, they couldn't do it: they had families that were too young; they had other commitments.

I had been practicing almost twenty years, and I was at a point financially where I could take the time off I needed to take to work on this epidemic. It was very fortuitous, and you realize that a lot of these kinds of things are just chance. You happen to be at the point where something happens, and if you're smart and lucky, you grasp that opportunity.

Residency in Dermatology, University of California, San Francisco [UCSF], 1964-1967

Hughes: Well, before we go on with UCSF, tell me why you came to San Francisco.

Conant: In the early sixties, there was a tremendous affection--I guess is the word--nationally for San Francisco. There still is, but there was this thing that passed through in the early sixties. In my mind, it was triggered by a Judy Garland album that came out, which was a two-record album. She sang "San Francisco, Open Your Golden Gate" on the record. And about the same time, Tony Bennett did "I Left My Heart In San Francisco." I had never seen San Francisco, except as a very small child, and I have very few memories. But it was just this wonderful, romantic place where one would want to go sometime. Not to live necessarily, but to go [to visit].

So I was returning from Guam in 1964 where I had been stationed. I actually had come to San Francisco for about five days before I went to Guam and had enjoyed it. I was coming back from Guam and decided, well, I would spend a week or so in San Francisco, because it would probably be the last time I'd ever do something fun. I thought, This will be the last time I'll have a chance to do that, because I'm going to go back, finish my military training, try to get a residency in dermatology in New York--I had decided then that I was going to live in New York--and make my career there.

While here, I called the university and asked if they had openings in the residency program. They did, and they had fortuitously just gotten a new federal grant to train young residents in dermatology who were interested in an academic career. So I interviewed with Bill Epstein and Howard Maibach, and they offered me a residency almost immediately. I still had three months' military service to do, so I went to Pensacola--actually, Eglin Air Force Base, Florida--finished my military training, packed my car, and moved to San Francisco. I completed my residency in three years, living right here near the university.

Then when I completed my residency, I had become very close to the woman who ran the [dermatology] clinic and the resident training program. She was an absolutely marvelous individual named Frances Torrey. Frances was one of California's first female physicians. She was from Maine originally, but as a small child of four or five she moved to California. She remembered the earthquake [of 1906]. She had lived here all of her life. And she had built this department and ran it very much as the matriarch of the department. All of the subsequent chairs of the department were beholden to Frances; there was no question about that.

Clinical Experience Treating Sexually Transmitted Diseases

Conant: Frances came to me during the last few months of my residency to tell me that she was going to retire, and that I was going to stay and run the clinic. I said, "Yes, Ma'am." [laughter] So I ran the clinic up there for about two years, and took over Frances' practice, and then built that practice into what's now my own practice. I have stayed right there ever since, and continued to teach at the university on a full-time basis, running the inpatient service, taking care of the hospitalized dermatologic consultations until 1981, when the AIDS epidemic began.

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Conant: I had been interested in sexually transmitted diseases. During my residency, I had worked as a volunteer one night a week at the Haight-Ashbury Free Clinic, which had opened during that period. This was the period of the flower children, and this was when the Haight rose and fell.

I was living right in the middle of the Haight. I was experimenting with drugs, like everybody else, to no detriment to me as far as I can tell. I guess with that recorded now, I can't run for president. [laughter]

Hughes: Maybe you didn't inhale.

Conant: That's right, I didn't inhale. Can you imagine that this country would want a president who lived through that era and who did not try marijuana? I mean, he would have to be the ultimate nerd.

But anyway, I lived in the Haight-Ashbury and experienced that, and loved it, though I always experienced it tangentially. I would smoke a joint on Saturday night, but by Monday morning at seven o'clock, I was at work.

Volunteer Physician, Haight-Ashbury Free Clinic

Conant: In my volunteer time at the Haight-Ashbury Clinic, I had started seeing patients with genital herpes. In those days, genital herpes was a disease that had been described, but was diminishingly rare. Less than 5 percent of sexually active adults in San Francisco had genital herpes in the mid-sixties. Today, that number is probably closer to 60 percent. So there was this epidemic of genital herpes that I saw in its infancy. Then for the next twenty years, a lot of my own academic endeavors went to trying to understand, treat, and popularize treatments for genital herpes.

What I learned from that was critical to what happened with AIDS, because to treat herpes, I used the model that I had seen used for other diseases. I came up here to UCSF and I asked Bill Epstein, the chairman of the department, if I could have the resources to open a clinic where we would have patients with herpes come up here to the university. I sat up here in this ivory tower and waited for somebody to catch the disease down there in the Haight and come up here for me to tell them, "Yes, that's what you have, and we can't cure it." I did that blindly for about fifteen years.

Then when AIDS began, as I've said before, literally one valley over, you've got the same thing: a sexually transmitted, viral disease. But the only difference is this one doesn't just recur and ruin your date. This one is there for life and kills you.

It suddenly dawned on me, and I think lots of others, that, Wait a minute. We can't just sit here in the university and wait for patients to catch this and come up here. We've got to get out in the community and get active and become involved. So as early as '82, it was real clear to me that the pattern we had followed for herpes, the pattern that I personally had followed, was not the appropriate thing to do with AIDS.

And it was that experience that clearly made me become socially active. That was the reason I started what became the San Francisco AIDS Foundation,[1] because we realized that we had to go into the community--that it was not going to happen from any other source. The government was not going to touch it [the epidemic]. The city was not going to touch it. The gay community was not going to touch it, because there was still this denial.

When we started what we called the Kaposi's Sarcoma [Researh and Education] Foundation, AIDS had not been named AIDS. We started the foundation in the spring of '82, and AIDS did not receive that name for another couple of months. When we started that foundation, one of the people that we asked to be on the board was Bob Ross. Bob is a fine man who is very active in the gay community and is the editor of the *BAR* [*Bay Area Reporter*]. The *BAR* is one of the big gay newspapers. We put him on the board expressly to try to educate him about the epidemic so that he would use the resources of his paper to educate the gay community.

It didn't happen. Mr. Ross, like many others in the community, for a prolonged period of time--this is really not criticism; this is documentation of what was going on--did not want to believe that this epidemic would not go away, that people had to change their behavior. I can remember on one occasion Bob Ross saying something to the effect that, "Well, it's not the people that just go to the bathhouses that get AIDS. It's the ones that don't shower after sex." And I said, "No, no, Bob, that's not right." And he said, "Oh, yes, that's right. I've heard that." You know, classic denial, classic rationalization, an attempt to find some easy talisman that's just going to make it all go away.

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[1] It was originally called the Kaposi's Sarcoma Research and Education Foundation, mentioned in the next paragraph.

II THE AIDS EPIDEMIC

Becoming Aware of the Epidemic

Hughes: Tell me about your first encounter with a Kaposi's [sarcoma] patient.

Conant: Well, I have a memory that may be flawed. I had a lovely little home on Ord Street that I loved and cherished and spent many years in, and I had spent a lot of money fixing up the kitchen. And like every construction project I've ever done, it took forever to get it done. I lived in this mess. So I remember with some clarity that the kitchen was finished, and I was working in this new kitchen, and there was a radio announcement that this doctor in Los Angeles had identified this pneumonia in these gay men. Now, that may be a false memory, but I can visualize opening the stove as I heard that. And if so, that would have been February of '81.

Hughes: Michael Gottlieb, February '81?

Conant: That's it.

Well, I didn't have that memory at first. It has literally come back, and it's really very strange how it came floating up, but I can remember thinking, Oh, Lord, I wonder what that is, and then it was gone.

Now, my first recollection of AIDS is the first of April of 1981. I learned through Jim Groundwater, who was a dermatologist here in town, that Alvin Friedman-Kien, who was a man I had known for years, was seeing cases in New York, and that these people had Kaposi's sarcoma, which was a dermatological condition. It was interesting on a number of levels. Al and I had been personal friends for fifteen or twenty years then. We both had worked on herpes, so our interests in dermatology were parallel in many ways. Al is much more a laboratory researcher than I am; I do more clinical work. He has done some very good laboratory work.

So I called him, and he told me that yes, they were seeing Kaposi's sarcoma, and that it was very interesting. It was in men who were very aggressive sexually and into anal-insertive fisting, which I wouldn't describe as mutilating, but certainly is a bizarre practice. Someone usually uses some drugs like amyl nitrite, gets high, and then one partner inserts his hand into the rectum of the other partner.

The interesting thing, which has never been explained, was that it was the insertive partner, not the receptive partner, who came down with Kaposi's sarcoma. I don't know how that's explained, unless it has to do with aggressiveness--people who are physically aggressive are often socially aggressive and maybe have more partners.

It was interesting to both of us also that the only explanation of Kaposi's sarcoma that had ever been given was that it was in some way associated with cytomegalovirus [CMV] in Africa. And cytomegalovirus is a herpes virus. So you can see the connection: we were both working on herpes, and here was this first-cousin herpes virus that [Gaetano] Giraldo had implicated as the cause of Kaposi's sarcoma in Africa, which had been seen in Africa the decade before as an epidemic.[1]

Hughes: Were you familiar with that research?

Conant: Oh, sure. Because of my interest in herpes, I had known about the CMV stuff.

And literally the day after Al and I spoke, I was giving dermatology grand rounds at the university, which would have been about April the first of 1981. I was speaking on herpes, had the five different herpes viruses listed, and was talking about cytomegalovirus. I mentioned that I had spoken to Al Friedman-Kien the night before, and there was this new group of diseases that he was seeing. I said, "Has anyone in the audience seen it?"

Jim Groundwater put his hand up and said, "Yes," and I remember the patient's name. It was Ken Horne. He was in the hospital ill. Also, the editor of the *Advocate*, which was another large gay periodical, was at Stanford and dying, or had just died

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[1] G. Giraldo and E. Beth. The involvement of cytomegalovirus in acquired immune deficiency syndrome and Kaposi's sarcoma. *Prog. Allergy* 1986, 37:319-331.

at Stanford, of the same thing. So the very first case was literally the day after I started looking for it.

Spreading the Word about the Epidemic, 1981

Conant: Now, it's also interesting, because I then distributed information saying I was looking for patients. The American Academy of Dermatology meeting that year that was held here was in fact the first meeting to open the new Moscone Center. [San Francisco Mayor George] Moscone and [San Francisco Supervisor Harvey] Milk had been assassinated in '78, just about the time the AIDS virus entered San Francisco. Two years later, the Moscone Center was built and opened in December of '81. The American Academy of Dermatology was the first meeting held there, and I wanted to distribute information about AIDS.

So I had financial support. I had never really done anything with drug companies before, so I didn't really know anybody, but I knew Ron Kulken, who was then the vice president of Neutrogena. When I had been a resident here, Ron had been a drug salesman. These drug salesmen would come around and try to convince you to use their product. Ron was a nice guy and I had gotten to know him well. Over the years, we had maintained our friendship. He was now vice president of Neutrogena.

I went to him and said, "I need some money because there's this new epidemic and I want to distribute some information at this meeting to teach doctors what it looks like." I was seeing someone at the time, Ernst Jansen, who was a graphic artist. So I went to Ernie and I said, "Will you print it if I can get the money to pay for the supplies? Ron Kulken's going to give us the money." Al Friedman-Kien and Jim Groundwater, as I recall, wrote the text, and we made up this little brochure. Now, again, this was long before it was called AIDS. [reads] "Funding provided by Neutrogena Corporation and Barnes Hind Pharmaceuticals--" I had forgotten that. "This brochure prepared by Marcus Conant, James Groundwater, and Alvin Friedman-Kien."

This was December of '81. [looking at brochure; see appendix for a copy] It's really amazing, because here's Ken Horne's lesion; here is a description of the disease. You could use this brochure today. We know a lot more now, but it does it.

Hughes: It's accurate.

Conant: It's all there.

Hughes: What was the reaction?

Conant: Well. It's fascinating. One of the nurses I worked with up at the university, Sally Edens, was nice enough to volunteer with Ernst Jansen, the man who printed them, to go down and hand them out. I was going to attend the meeting, so they wanted to stand at a table and pass them out. Ernie came to me that night and he said, "You won't believe this. Most of the people just took it and kind of shrugged and walked off. One guy said, `Homosexuals?! We don't have homosexuals where I come from!'" [laughter] So from the very beginning--

Hughes: There it was [homophobia].

Conant: And you know, I had perhaps lived in San Francisco too long. [laughs] I mean, everyone knows San Francisco has a large gay population, but I don't think that people understand how big it really is. The studies we've done on AIDS show we have 70,000 gay men in this town in a total population of 700,000 people. Now, if you figure people includes children, then when you eliminate out of the 700,000 whatever proportion are children--say it's 200,000 --then it's not 10 percent are gay, it's closer to 15 to 20 percent. It's a very large population.

The first apartment I lived in was in Buena Vista Park. I talked to the real estate man by phone and found this wonderful apartment I could walk over to from the university. He said, "Oh, it's a wonderful neighborhood. It's very quiet. Upstairs are these two old ladies." So I'm moving in, and upstairs are these two guys having this bitch-fight, screaming and yelling at each other. I think, These are the two old ladies upstairs that he was referring to? [laughter]

Hughes: That's San Francisco.

Conant: Yes, welcome to San Francisco.

The Kaposi's Sarcoma Clinic, UCSF

[Interview 2: September 10, 1992] ##

Educating the Physicians

Hughes: Dr. Conant, last time we discussed your first encounter with what was later to be known as the AIDS epidemic. After you realized that there were two KS patients in the Bay Area, what was the next step? How did you organize, both in a medical sense and also in terms of the community?

Conant: At that point, the biggest challenge was to make physicians realize that we had a new disease. Early in the epidemic, Kaposi's sarcoma was the most prominent condition, and certainly as a dermatologist, it was the thing that I felt I knew the most about and could recognize. But both of the cases in the Bay Area had been misdiagnosed or had not been diagnosed for a period of time, and consequently the patients were gravely ill by the time the diagnosis was made.

So what we saw as the first challenge was to create some forum where doctors in the Bay Area could send such a case for referral for the proper--what we hoped was the proper--evaluation and ultimate treatment of the patient.

There was a model for that. When I came here in 1964, the department of dermatology already had a number of specialty clinics. They had a patch test clinic, which Dr. Howard Maibach was running. They had an atopic dermatitis clinic, which Dr. Harry Roth was running. They had a number of other specialty clinics, a psoriasis clinic. There were these specialty clinics which met one morning a week in the dermatology area. We would go out in the community to dermatologists and say, "If you have a patient who has a difficult case of atopic dermatitis, we would welcome your sending the patient to us for consultation, and we will send you back information as to how we think the patient should be managed."

You see, the difficulty was that these patients with KS would go into a dermatologist's office, and he hadn't heard about this problem. He would reassure them that, well, he'd never seen anything quite like it, but it couldn't be too serious, not to worry about it.

Or he would take a biopsy, and it would go to a pathologist who was not accustomed to seeing Kaposi's sarcoma, and he would misdiagnose it as a dermatofibroma or as a benign angioma or some other condition. This was perfectly understandable when the average dermatologist would see one case of Kaposi's sarcoma in a lifetime. So the fact that this extremely rare disease was now popping up all over, the fact that people didn't realize what it was or would miss it or would misdiagnose it, is not only not surprising; it's surprising that the few who did immediately realize what it was, did so.

Be that as it may, I went to Bill Epstein, the chairman of the department of dermatology at the time, and I said, "I'm devoting most of my time to private practice, but I would like to take a morning a week and come over here and start a clinic where we try to get physicians in the community to send these patients with Kaposi's sarcoma." Dr. Epstein, to his great credit, has always been willing to entertain a crazy idea, and this was probably one of the craziest. He said, "Well, Marc, I can furnish you the space, and I can give you some nursing support. But we can't give you a salary. We just don't have the money." I said, "That's fine, I'll donate the time. But we need the space." So we got the [KS] Clinic set up.

Then what I did immediately was start writing to colleagues in the area and giving presentations at meetings, and saying, "If you see these cases, please send them to us." And send them they did.

Hughes: What made you think that there would be enough cases to make a clinic feasible?

Conant: Well, I'm sure it was my experience with herpes. For some reason, from the beginning of the epidemic, it seemed clear to me that this was not going to be limited. I think that part of it was my experience living in San Francisco, knowing that the gay community was sexually very active, and if there was anything new in that community that could be transmitted communicably, that it was going to spread like wildfire. It was just foolish to assume that it would not. All the diseases that we'd seen--syphilis, gonorrhea, amoebiasis--everything had spread through that community with tremendous rapidity. That was reason number one.

Number two was, from the beginning, the number of cases of this problem was beginning to increase. From the very beginning, New York saw a few, and then a few weeks later it had a few more, and a few weeks later, more. And the same was true here in San Francisco. Everywhere we looked, we began to be able to find it.

When I was a kid, my dad constantly played this game--he loved it--of handing you a penny, and saying, "Which would you rather have: a million dollars, or for me to double this penny every day for a month?" Of course, the kid would immediately say, "A million dollars." And then he'd make you sit down and calculate it out. You realize that if you take a penny and if you double that every day, the next day you have two pennies, and the next day you have four pennies. If you double that every day for a month, you have more than a million dollars. What you've got is an exponential curve. It's going up at an incredible rate. It doesn't have to double many times before the numbers you're dealing with are just astronomical.

And this epidemic, from the beginning, was doubling, and it was doubling in about six months at that point. So we realized, wait, if you've got two pennies today, you're going to have four pennies in six months, and you're going to have eight pennies in a year. Hang on, because the numbers before long are going to get just astronomical.

Recognizing a Syndrome

Hughes: You were still thinking of the problem just in terms of KS?

Conant: Michael Gottlieb recognized the first cases of *Pneumocystis* [*carinii* pneumonia] in February of '81. It was not really put together until later that year that we were both seeing the same epidemic. The first *MMWR* [*Morbidity and Mortality Weekly Report*] that began to put it together was in the summer of '81.[1] I and Friedman-Kien and Mike Gottlieb--this is when I first met Mike Gottlieb--went to a meeting which, as I recall, was in September of 1981 at the National Institutes of Health. We were all presenting the parts of the elephant that we were looking at, and it became really clear to all of us that we were dealing with the same epidemic.

Hughes: How did you realize it was the same thing?

Conant: Both diseases were occurring in gay men who were in the fast lane, if you will, had multiple sexual partners, and were living in New York, Los Angeles, and San Francisco. So not only was it gay men, but it was gay men whose behavior was exactly the same in both groups. Both of them were incredibly rare, new--if you will--conditions. *Pneumocystis* was as rare for the infectious disease specialists as KS was for us in dermatology.

By that time, we knew that the KS patients and the *Pneumocystis* patients were both immunosuppressed. We could do helper-suppressor T cell ratios, and when you looked at those, you found that their immune systems were depressed. So it was the same group of people in the same areas engaged in the same

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[1] Friedman, Feldman, Rothenberg, et al. Follow up on Kaposi's sarcoma and *Pneumocystis* pneumonia. *MMWR* 1981, 30:33, 409-410.

behavior with unusual diseases that indicated immunosuppression. So it then began to come together.

Hughes: What was the initial impetus for looking for immunosuppression?

Conant: Patients with *Pneumocystis* who had been described previously had all been immunosuppressed. Those patients included people at the end of World War II, for example, who were terribly malnourished, patients with cancer, patients who had had kidney transplants who'd been treated with corticosteroids. It was felt that *Pneumocystis* was a disease that was seen in the immunosuppressed host. So it became immediately obvious that, well, let's look at the immune status [of the KS and *Pneumocystis* patients], and sure enough, the minute you looked, they had an immune deficiency.

Measuring Immunosuppression

Hughes: Talk a little about the technology. I understand that the means to look definitively at immunosuppression was really a very recent event.

Conant: That's correct. We had known for years on clinical grounds that immunosuppression resulted not only in certain opportunistic infections, like *Pneumocystis*, but that the immunosuppression actually caused certain cancers to appear. For example, it was shown back in the late sixties or early seventies that if you took a patient who you immunosuppressed iatrogenically to give him a kidney transplant, that that person had a three times more common appearance of basal cell carcinoma, a thirty-six times more common appearance of squamous cell carcinoma, a 360 times more common appearance of lymphoma, and a 400 times more common appearance of Kaposi's sarcoma.

So it was already known that these diseases, including KS, were seen in the immunosuppressed patient. But in the late sixties, early seventies, we did not have the technology for measuring CD4 cells. Gideon Goldstein was the first person to isolate the CD3 receptor on lymphocytes, and other investigators immediately followed isolating the other receptors on circulating lymphocytes.

Hughes: Was this in connection with the AIDS epidemic?

Conant: No. This was prior to the AIDS epidemic. This was in the late 1970s that this work had been done. So by the time the AIDS epidemic had appeared, it was possible, using a flow cytometer, using certain technology, to look for these receptors which identified cells. We could at that point identify helper T cells, we could identify suppressor T cells, and we could count them.

But that technology had only been in place for about five years. It was just beginning. And the characterization of these receptors, the cloning of them, looking at the molecular structure, all of that has happened since the AIDS epidemic. So the technology was in its embryonic development at that point. If AIDS had happened twenty years earlier, we would have known the patients were immunosuppressed on clinical grounds, because of the diseases that they developed, but we would not have been able to characterize the immunosuppression, nor would we have been able to quantitate it.

We could now measure the drop in helper T cell number. Had this disease occurred twenty years earlier, we would not have had the technology that would have allowed us to determine who's got the virus and is doing very well, and who's got the virus and may be asymptomatic but is in a very perilous situation.

Hughes: Strides had also occurred in retrovirology.

Conant: Bob Gallo had isolated the first retrovirus, HTLV-1, only a few years before [1980]. And suddenly, here is a new retrovirus appearing almost miraculously. The technology was just there, and here within two or three years is another retrovirus. It's absolutely astounding. And then remember there wasn't just one new retrovirus, there were two. There's HIV-1 in Zaire and HIV-2 on the west coast of Africa. So not only did we in a very short period of time discover one new epidemic, we in essence discovered two new epidemics. It's just astounding.

Physicians Participating in the Clinic

Hughes: Well, go back if you will to the organizational aspects of the clinic.

Conant: I started the Kaposi's Sarcoma Clinic in the dermatology department.[1] Paul Volberding came to me almost immediately, within a month, and said that he wanted to be involved.

Hughes: Had you had any contact with him before?

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[1] The first clinic was held on September 21, 1981.

Conant: He actually sought me out. Paul had heard about this, as I recall, sought me out, and said that he wanted to be involved, and I welcomed his involvement. He and I became co-directors of that clinic for the remainder of its existence.

There were a couple of other people who were very important to the early days of that clinic. At the meeting at the National Cancer Institute [NCI] in Bethesda in September, I met for the first time Dr. John Ziegler.[1] John was still at the NCI at that point, and he had just been selected to be the assistant dean at the VA Hospital here in San Francisco. So he was planning to move to San Francisco. He had done some of the really early work on Kaposi's sarcoma in Uganda. John had gone to Uganda in the early seventies, had tried to treat and characterize some of these patients, and had published on that. John Ziegler was a very, very well-known and prominent young oncologist, and had actually received the Mary Lasker Award [1972], which is a very coveted award, a few years before that. So John joined Paul and me in running and organizing and overseeing that clinic.

The other person who was really essential was Don Abrams. Don came along as a young oncology fellow working for Paul, and immediately had the good sense to realize that he couldn't just follow us around, he had to carve out his own area of expertise. So he decided to take on all of these patients who appeared to be infected with the virus, had suppressed immune systems, but all they had [clinically] were swollen lymph nodes. So Don in those first years saw and characterized people with the generalized lymphadenopathy syndrome, and that was very important to building a network of physicians and individuals who could refer patients.

There were a number of other people at UC who joined the clinic. Remember, the idea of that clinic initially was, Let's study the patients and see if we can figure out what's happening. Well, we couldn't. We could characterize it, we could take pictures of it, we could tell people what it looked like, but we clearly couldn't answer, why is this happening?

But having the patients there as a focus of interest allowed us to invite people from other disciplines to come. The clinic, by intent, very quickly became a multidisciplinary clinic. It was not just a bunch of dermatologists seeing patients, or a bunch of oncologists treating cancer. I might add, too, that many of these people heard about us and came of their own volition. We didn't go and say, "Would you please come and join?" So early on there were lots of very bright people who realized, Hey, this is not

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[1] See the oral history in this series with Dr. Ziegler.

only a challenge, this is really, really interesting, and I should get involved.

Many were not academics. For example, Dr. Arthur Holliday. Dr. Holliday practices down near Los Gatos, and heard about this. He was a clinical instructor in medicine at Stanford, heard we were doing this, thought it was fascinating, and for almost two years drove up here once a week, donated all his time and got no income from it, did physical examinations on these patients, recorded their progress, absolutely essential work, total gratis. He never asked anything for it, and it was absolutely amazing.

Dr. Steven Mehalko. He's become ill himself.[1] He was in practice at Ralph K. Davies [Medical Center] at the time. But he too gave up a morning a week to come over here and see patients.

There were others. Dr. Selma Dritz attended. She was the epidemiologist who was in charge of AIDS [at the San Francisco Department of Public Health], tracking this new disease.

Seeing Patients[2]

Hughes: What happened to a patient who presented himself at the clinic?

Conant: Well, the clinic was held in the dermatology clinic area, and patients came in and registered almost as if they were a dermatology patient. But the front desk, of course, knew that they were there to be seen for an HIV-AIDS-related problem.

Now, most of the patients we were seeing there had Kaposi's sarcoma. After the clinic had been going for a few months, Don Abrams was seeing the patients with generalized lymphadenopathy up in the oncology clinic. Some patients we would see after they were hospitalized with *Pneumocystis*, but most of the patients we saw, at least in that first year, had Kaposi's sarcoma. So they were coming with a dermatological problem.

One of us would then examine the patient, take a complete history, the laboratory work would be drawn. And it wasn't just

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[1] Dr. Mehalko died of complications from AIDS on January 24, 1995. (*San Francisco Chronicle*, February 20, 1995, p. 18.)

[2] The following sections on the KS Clinic were moved for better continuity from Session 3.

me seeing the patients. Steve Mehalko was there seeing patients some, and Arthur Holliday was there seeing patients some.

Now initially, we had done it essentially as a clinic, and then we presented those patients to other consultants from the university who would come to the next hour. So we would see the patients ourselves actually from ten to eleven, and then we would present them to a group of consultants. Those would include Jay Levy and people from the GI [gastrointestinal] clinic and from infectious disease and from oral medicine, so that they would relate to the patient and see this new problem.

Now, what I found after a few months was the patients all began to look very much the same. They were thirty-five-year-old gay men with Kaposi's sarcoma. You couldn't present patients with the same problems to a group of people over and over; nobody's going to come to the meetings any more.

Invited Speakers

Conant: So after the first few months, we started inviting speakers to come. We would often show an interesting patient that we saw in the previous hour, but more and more over the next three years, the clinic meetings that are attended by the faculty got to be formal presentations on what was happening with the AIDS epidemic by someone either on our staff, or someone who came to visit.

To give you an example, Jim Curran came to San Francisco on one occasion. We invited Jim to come, and he stood up for half an hour and discussed what was happening at the CDC [Centers for Disease Control]. Hal [Harold] Jaffe did the same thing. Various people in our groups--Jay Levy, Paul Volberding, I, and others--would present formally what we were doing.

Probably one of the most significant meetings was one that we had in January, 1983. The first case of transfusion-associated AIDS had been described. Art Ammann had identified that case with Selma Dritz, who was the AIDS epidemiologist for the city, and Herbert [A.] Perkins at Irwin Memorial Blood Bank. This was a baby who had been born, I believe, at UC, certainly born here in San Francisco, who had received thirteen transfusions, as I recall. The baby developed an AIDS-associated condition, *Mycobacterium avium intracellulare*.

Clearly, here you had a baby who was dying of AIDS. To make a long story short, Dritz and Ammann found out that the donor of a unit, while healthy himself when he donated the blood, by the time the baby got AIDS nine to ten months later, the donor was dying of *Pneumocystis*. So we invited Herb Perkins, the head of the San Francisco blood bank, to come to the Kaposi's Sarcoma Clinic and present what the blood bank was doing to try to stop transfusion-associated AIDS.

It was those kinds of presentations that we were trying to engender in an effort to create a multidisciplinary clinic where you had specialists not just from dermatology, not just from infectious disease, not just from oncology, but you could have the epidemiologist, the psychologist, the nutritionist--everyone coming together to try to facilitate the exchange of information.

Pneumocystis Patients

Hughes: I found a letter dated November of 1982 in which you mentioned coordinating studies of KS patients very successfully, but you considered the work on the *Pneumocystis* patients less coordinated.[1] I wondered why that was, and what the significance was.

Conant: It's absolutely true that early in the epidemic here in San Francisco, the work on Kaposi's sarcoma was far better coordinated. Remember, we called that clinic the Kaposi's Sarcoma Clinic. I think it was a variety of reasons. Even though *Pneumocystis* was recognized by Mike Gottlieb before KS was recognized in New York, the cases of *Pneumocystis* were not as visible. Young men would come in critically ill, they would be diagnosed, but once they were discharged from the hospital, until they got ill again, they looked and often felt normal. So they would sort of fade back into the community.

Whereas once a patient had Kaposi's sarcoma, even if you X-rayed it or treated it with chemotherapy, other lesions usually appeared in a fairly relentless, progressive fashion. So these patients were, from the moment they were diagnosed, very visible. The disease was visible to them, and to every physician and clinician caring for them. So I think that was one reason.

Another reason the work on *Pneumocystis* was not as well coordinated was that we were actually recruiting patients with

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[1] Marcus A. Conant to Jeffrey Golden, November 24, 1982. (KS Notebook 3-12/82).

Kaposi's sarcoma to the KS Clinic. We were telling dermatologists, histopathologists, pathologists, and general clinicians, "If you have a patient with Kaposi's sarcoma, we want to see that patient." We were not doing that with *Pneumocystis*. We had not launched an aggressive attempt to go out and recruit those patients. So the failing was clearly ours. The next group of patients we actually went out and tried to recruit were the people with lymphadenopathy, and we were doing that because Don Abrams wanted to study that group of patients.

So part of it was because the [*Pneumocystis*] patients were not that visible, and part of it was because those patients were cared for by infectious disease specialists and then discharged back to their doctor, and there was no central place that was trying to collect them. From my point of view, we accrued a lot more information on Kaposi's sarcoma in the first two years than we did on PCP.

Hughes: Could also a factor have been that there wasn't one person particularly interested in *Pneumocystis*? Your primary interest, at least in the beginning, was of course Kaposi's sarcoma.

Conant: Yes. Well, I hesitated to say that. Obviously I am a dermatologist, and so it was the skin disease that I was the most interested in.

Hughes: Was there nobody trying to single out patients with *Pneumocystis* the way you were doing with Kaposi's?

Conant: Not to my knowledge. There were clearly people here in the community who were caring for these patients. Bob Fallot at Presbyterian Hospital was doing a great job. But Bob was doing it more as a traditional infectious disease specialist. You got sick with *Pneumocystis*, you went in to see him, he took great care of you, and he discharged you back to your doctor.

But to then do that next step where, "Let's create a clinic; let's bring these patients in; let's try to study them," no. But again, in their defense, remember that with *Pneumocystis*, a patient was sick in the hospital for two weeks, three weeks. He was treated, and then he was well. Whereas with Kaposi's sarcoma, we had the patient back every month. You had people like Jay Levy who wanted to collect samples. The patients continued to have the disease.

But this is true in science in general. Remember that often you have groups working on the same issue, but they may choose a disease that gives you the answer a lot quicker. Kaposi's sarcoma was just a lot more visible [than *Pneumocystis*]. And not only was

I a dermatologist, but Paul Volberding was an oncologist. He was a cancer specialist, and so was Don Abrams. So all of the people we had in the KS Clinic were cancer-skin people, and not infectious disease-lung people.

David Altman, the gastroenterologist at UC, came on board the KS Clinic very early and did some very interesting studies from the point of view of gastroenterology. But the GI [gastrointestinal] tract is not one of the primary sites attacked in HIV disease. Patients with HIV disease do get lots of gastrointestinal problems. But it's not like the lung or the skin, which were really the two target organs.

Helen Schietinger, Nurse Coordinator

Hughes: You haven't mentioned Helen Schietinger.[1]

Conant: Helen Schietinger was a wonderful addition to the clinic. I can't recall how long we had been going when we hired Helen.[2] But we finally, through the $50,000 from the American Cancer Society, had enough resources to hire a nurse.

The nurse's job was not only to provide comfort and aid for the patients that we were seeing, but on a more vital level to begin to coordinate a uniform attempt at collecting a uniform history from these patients, not just an incidental history as they came in, and to collect specimens because we were developing a tissue bank.

John Greenspan[3] and Dr. John Ziegler deserve the credit for coming up with the idea of the tissue bank. The notion was that as we began to see these patients, we would try to characterize the state of the disease at which we found them, what physical

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[1] See the oral history (in progress) with Helen Schietinger in the San Francisco Bay Area AIDS Oral History Project: The Nurses, a joint project of the Regional Oral History Office, University of California, Berkeley, and the Department of the History of Health Science, University of California, San Francisco. Hereafter, AIDS nurses series.

[2] Helen Schietinger became nurse coordinator at the KS Clinic in January 1982. (Michael Helquist. "What to expect at the KS Clinic." *AIDS and KS Foundation Newsletter*, vol. 1, no. 1, May 1983, 7.)

[3] See the oral history in this series with Dr. Greenspan.

findings that they had on examination, and then we would collect specimens in the form of blood, and I believe urine, and certainly biopsies from their Kaposi's sarcoma lesions. All of that information would be put on computer, and the specimens frozen to use for later research. The notion was that when we finally found the cause of this disease, we could identify what the virus or the bacterium or whatever's causing it looked like in early patients, what it would look like in people who were in the middle stage of the disease, what it would look like in the lymph node patients and the KS patients. So we started what became the world's first [AIDS] tissue bank, attempting to characterize these patients and then save specimens.

One of Helen's major jobs was to coordinate that effort. She did an absolutely superb job. Helen Schietinger was a major, major addition to all of the research efforts that were going on.

But she did something beyond that. Helen became a very, very active member of the activist community. It's hard, thinking back, to think of Helen Schietinger as an activist, because Helen was not the kind that would stand up and be confrontational or do things in the mode of, say, the current ACT UP [AIDS Coalition to Unleash Power]. Helen was a networker and a consensus-builder. She would attempt to build coalitions. And that's exactly what she did: she met people all over the city, and indeed all over the nation, and began to build networks to then define what is the appropriate evaluation of someone who's HIV positive or who had AIDS. What is the proper way to relate to people? Do you call everyone a victim, which was a big social issue at that time. Is everyone a victim of AIDS, or are they patients? Or as Bobbi Campbell wanted (and I think rightly so) to say, "I'm a patient as long as I'm in your office, Doctor. When I get out of your office, I'm a person with AIDS. I'm not a victim, and I'm not always a patient. I don't want to be a patient the rest of my life."

I had never thought of that until Bobbi came in and said, "You know, on the street, I don't want to be a patient. I want to be a person." And it's a very real point that I don't think any of us physicians think of.

Helen began to work with groups like that, trying to build consensus. She was the national [co-]chairperson of the gay and lesbian meeting [Second National AIDS Forum] which was held in Denver in 1983. So she had been working for us for less than a year when she was of such national prominence that she was asked to chair the AIDS activities for that meeting and put together an absolutely wonderful program, which I attended.

She left the clinic about 1985, I guess,[1] and has had a number of other jobs. She went to work with Shanti [Project] for a while [1983-1986], and then worked with the World Health Organization in Geneva [1988-1990], and now I understand that she's a private consultant in Washington, D.C. As a matter of fact, at the AIDS meeting in Amsterdam [July 1992], I was standing in this clutch of people trying to get in. The AIDS activists had disrupted the opening ceremony the first night of the meeting, and everybody was fighting like hell to get in, and activists were trying to infiltrate. It was your typical AIDS meeting. Suddenly this woman beside me said, "Marc," and I looked over, and it was Helen Schietinger. So Helen is still very much active and very involved.

Paul Dague and Psychological Services

Hughes: Well, another name closely associated with the clinic is of course Paul Dague.

Conant: I can only talk a little bit about Paul without crying.

I was going through a really difficult personal time in 1979, which was two years before the AIDS epidemic, and clearly was not handling it well, and clearly needed psychological counseling to process a huge, agitated depression. So I called a friend who was a psychologist and asked him for a referral to someone who he thought could handle me, and he sent me to Paul Dague.

So I actually first knew Paul in a doctor-patient relationship where I was the patient. I saw Paul weekly for about a year and a half. He taught me a tremendous amount. It was one of the finest experiences of my life. It got me grounded. I began to focus on what I was really all about, what my life was all about. I said, "Not only do I want to meet with you once a week, I really want you to give me references, and I want to read, I want to make this really a very productive time so that whenever it's over, it's something that I've got, and it was not just an exercise." So he recommended readings, and we read together, and it was really a very, very intellectually productive time.

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[1] Helen Schietinger resigned from the KS Clinic in 1983 to accept a position with Shanti Project. (Schietinger to Conant, April 27, 1983, KS Notebook 1983.)

A year later, AIDS began. I started the Kaposi's Sarcoma Clinic with Paul [Volberding]. We needed a psychologist for two very clear-cut reasons. We needed somebody there to talk to these patients when we told them what they had. The press was full of the "gay cancer," and it was a uniformly fatal disease, and it was the wrath of God being visited on these men, and yes, they were being punished for this behavior [homosexuality], which society said was wrong. And remember, too--this is often forgotten--gay men have the same mothers as straight men. So the straight men who believe that homosexuality is wrong were taught that by the same mother who taught her gay son. And what did she teach him? She didn't teach him that it was right; she taught him it was wrong.

So most gay men, at least in the early 1980s, were coming to an understanding of their sexuality, believing that it was wrong. They had to then overcome that. Now, different people overcame it in different ways, one of which was to become this flamboyant, very extroverted, screaming queen who everyone could identify immediately as gay, whether he was from some small town in Alabama or was walking the streets of the Castro. You finally say, "I'm just not going to deal with this feeling that I am some kind of evil, wicked person any more. I'm just going to totally flaunt it in front of society." So that was one way of doing it.

Another way was to intellectualize and go to therapy and deal with it, and really become very grounded and move on with your life. There are people who do that, but I know damn few of them. Because remember that these are seventeen-, eighteen-, nineteen-year-old boys who are suddenly having to confront hormones which are telling them to go behave in certain ways. Emotionally they want to do one thing, and intellectually they believe they should do something else. Now, that becomes very difficult.

So what a lot of people do is they just say, "Screw it, I'm going to move to San Francisco. I'm just not going to deal with whether it's right or wrong. I'm just going to get on with my life." So a lot of my patients in the early years of the AIDS epidemic had never really confronted their sexuality, other than just to go and act on it. And all of the things they had been taught as children, they had never worked through and brought to closure. They had simply said, "I'm not going to deal with that any more."

Suddenly, this man now has AIDS, and he's now dying, and society's saying, "It's your fault." All of that garbage that he's carried from his late teens comes roaring up: "Oh, my God, am I really this evil, wicked person? What have I done? Was

Mother right after all? Is society really right that I deserve this?"

The reason we needed a psychologist in this clinic was we doctors walked out of the room saying, "Yes, AIDS is what it is." And this man needed hours of counseling, not just a few minutes. He needed somebody who could work through not just the diagnosis of a potentially fatal disease, but all the stuff that he had there all of his life that needed to be processed, and all the other questions: how do you tell your mother? What are you going to do when your dad says, "You're a faggot," and slams the door and never wants to speak to you again?

And don't think that didn't happen. It happens less now. In the early days of the epidemic, it was absolutely astounding that young men were telling their parents they were gay and they were dying at the same time.

Hughes: You can't get much heavier than that.

Conant: You can't get much heavier than that. Well, that was Paul Dague's first job.

Hughes: Was he able to provide extensive counseling?

Conant: Yes. He was absolutely marvelous.

Hughes: But I would think the numbers would have overwhelmed him very quickly.

Conant: They did eventually, but in the early days, August, September, October of '81, we were talking about only a handful of patients. At that point we had Simón Guzman, we had Bobbi Campbell, we had just a very few people whom we were seeing. Some, I can visualize their faces but I've forgotten their names.

Paul had been in the clinic only a few weeks when the other reason we needed him became obvious. We needed him for us, because you had a bunch of young physicians, themselves in their thirties and forties, confronting their own mortality by daily seeing men their own age with a fatal disease. As doctors we all see young people die. But it was usually chance: the kid seriously injured on a motorcycle, the very rare case of some horrible disease that strikes down some young man or young woman in the prime of his or her life. But you could say, "That's not going to happen to me."

Now you're surrounded by men your own age who look just like you, who are as healthy as you are, who are dying. And remember, many of the doctors who came to AIDS early on were gay themselves. So here are these young gay men your age dying now of a disease that is associated with gayness, which is a characteristic you share. So suddenly, all of us in the clinic needed Paul Dague, not for what he was providing our patients, but what he could provide for us. How do we deal with our own mortality?

It was Paul Dague who conceived of the idea of going to the Shanti organization and bringing Shanti into the clinic. Shanti had been started by Elisabeth Kübler-Ross in Berkeley a few years before as an organization to provide aid and comfort to those who were dying. And Paul realized that that was what we needed.

That's changed. Today, you don't want to begin, nor do you need to begin, counseling a young man diagnosed HIV positive at this point about end-of-life issues. But when someone was dying with AIDS in 1981, the end-of-life issues were where you began because in those days, you couldn't even recognize the disease until they already had Kaposi's sarcoma, or *Pneumocystis*, or one of these life-threatening diseases. And remember, until 1987, no one with *Pneumocystis* survived for more than eighteen months.

So when we told someone, "This is *Pneumocystis*," what we were telling them is, "You have less than a year and a half to live." And that was pretty devastating, particularly for a thirty-six-year-old who had always been gorgeous, had perhaps always been the brightest kid in his class, who never really dated girls but was always just a very creative kid, who moved to San Francisco and got a wonderful job as a computer expert with AT&T, suddenly was making $40,000 a year (which in the early eighties was a lot of money) as a mid-level manager, was having no trouble sexually making out. He could go out to the Castro every night; he had money; he had a big car; he was dating. And suddenly, here these doctors tell him, "You're going to die." I don't think today they understand the impact of what this was doing in the early eighties, and why people like Paul Dague made such an important contribution.

It was less than a year after his arrival at the clinic, maybe two, that Paul walked in with a lesion. I was the one who had to diagnose Paul's Kaposi's sarcoma. That brings back almost impossible memories of someone that I had related to as closely as I did through the years we were together as my therapist, and I had to now change the role and become his physician as he then died of Kaposi's sarcoma.

Paul continued to work in the clinic with the disease, and with the disease progressing, seeing patients. One day Paul Volberding and I decided to put on the board all of the patients that we had seen who had AIDS. The list was probably less than fifty patients at the time. We listed all of them by initials and what had happened to them. You see, I was caring for some, and David Altman was caring for some, Paul Volberding was caring for some, and Don Abrams was caring for some. There wasn't any one of us who was caring for all of those patients. What we were trying to do was share all these patients we had seen together over time, and what had happened to them.

We get to "P.D." Someone says, "Well, what about P.D.?" And Paul says, "I'm okay." It was just overwhelming, that one of this list was sitting right there in the room with us, mindful of the fact that maybe half of them by that time were dead, and that we were saying, "No, he died of *Pneumocystis* two months ago, and no, he died of toxoplasmosis."

The last time I saw Paul, I went to his home, and he looked awful. Paul Dague died a terrible death. His Kaposi's sarcoma was rapidly advancing towards the end. He developed Kaposi's in his throat, and he literally choked to death on his tongue. So he was at this point having to sit up to breathe, and it was just a miserable, miserable, horrible death.

He was getting ready to fly to the Philippines. There was some charlatan in the Philippines at the time--and Paul knew he was a charlatan too, as did all of us--who claimed that by mystic healing he could reach inside the body and take out these tumors. With a twinkle in his eye, he looked at me and he said, "You know I'm not going to the Philippines for the cure. I'm going for the miracle."

What he was telling me was, "I know I'm dying. I'm going just because I have hope that there might be something out there that will do something." He knew and I knew that it was an act of desperation, but it was an act. And sometimes, even in desperate straits, the thing you have to do is to act. You must have hope. He had hope.

And then he came back and died shortly after he returned.

I don't remember the year that he died.[1] I went to his memorial service, and I don't go to services any more. The reason that I don't go to services is that I realized that night that what services are for is to break down, to cry.

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[1] Paul Dague died on January 20, 1984. (Counselor of Gays Dies of AIDS-Linked Illness. *San Francisco Chronicle*, January 21, 1984, p. 14.)

Services have a wonderful catharsis of letting go and letting you really get in touch with your grief, and letting you express it, and it's good for you and it's good for everyone there, and it's good to participate. At one level, I really wish that I could do it.

But I also understand that most people who go to things like that, one, if they just can't go to work the next day, it's okay; and number two, they don't have to go the next day and look into the face of another Paul Dague. Memorial services should mark an end. For me the AIDS epidemic is not yet over.

Demise of the Clinic[1]

Hughes: What was the ultimate fate of the KS Clinic?

Conant: We stopped it. We didn't run out of money; we ran out of a need to have it. A time came, probably about '85, when it became clear to all of us that San Francisco General was now up and going and had clinics that were caring for [AIDS] patients. My practice was taking care of lots of AIDS patients; we were busy as hell. There was now the annual international AIDS meeting; the first one was held in Atlanta in 1985. So meeting in the KS Clinic was unnecessary; it was no longer serving the purpose of facilitating the exchange of information, because that was now happening in journals and elsewhere.

But remember, whenever something like that happens, there is a paradigm shift. What had really happened was the realization that we're not going to fix AIDS by meeting together for a few months; that AIDS is going to be with us for the rest of our lives. When the Kaposi's Sarcoma Clinic stopped in '85, the significance there--although I'm clear I did not articulate this until later--was the realization on all of our parts that, Wait a minute, this epidemic is not something that we are going to be able to have a few meetings about, someone's going to run in one day and say "Here it is," and it's going to go away. The ending of the KS Clinic dates my acknowledgement that this disease is different. This was going to be with us.

Hughes: This is not toxic shock syndrome.

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[1] The following sections on the KS Foundation were moved for better continuity from Session 4.

Conant: That's right, this isn't toxic shock.

Kaposi's Sarcoma Research and Education Foundation

Hughes: Well, we've alluded on several occasions to the KS Foundation, but I don't believe we've actually talked about how and why it was founded, who was on the board, and its mission.

Conant: As with most of the things that were done, the KS Foundation was not my idea. It was Frank Jacobson's idea.

Hughes: Explain who he is.

Conant: Frank is another one of these wonderful people. Frank Jacobson was probably the most introspective attorney that I've ever known. He had an abiding interest in health policy issues, and he came to work as a young administrator with his law degree at the University of California. I was running the [UCSF] Utilization Review Committee, which I had run from 1972 until I resigned that position effective the thirty-first of last month; I resigned three days ago. Frank, as the young administrator with a law degree who was interested in health policy, was assigned as the administrative overseer of the Utilization Review Committee, which is the committee that is mandated to see if patients who are in the hospital need to be there, because otherwise the federal government is not happy about paying the bill. Frank and I became very, very dear friends, and our friendship persisted until his death. When I began the KS Clinic, Frank knew of it and was supportive of it, but he was very tangential to it.

Then in April of 1982, he came to me and he said, "Let's go to dinner." So Frank and I went to dinner at the San Remo Italian restaurant in North Beach. Over dinner he said, "Look, you've done a great job educating doctors here in the city about this disease. You're getting referrals; people are recognizing Kaposi's sarcoma; people are talking about it. But nobody's doing anything to stop it. We need some way to get out in the community." I said, "You're absolutely right. What do we do?" He said, "You start a foundation, you rent a storefront in the Castro, and you put in a hotline." He already had ideas. I said, "Great. How do we do that?" He said, "Well, we need money. We need 501(c)3 designation so we're a tax-free organization. If you'll put up the money, I'll get the 501(c)3."

Hughes: That's another instance where you reached into your pocket.

Conant: So I put up the money, and we created the foundation. Then we needed a businessman. The only person I knew who was a businessman who was reasonably successful, who knew a lot about personnel, was a young man named Richard Keller.

So on Mother's Day in May of 1982, Richard Keller, Frank Jacobson, and I had lunch at the Elite Cafe right down the street here in a booth which I look at fondly every time I go in the Elite Cafe. We sat there at that booth over lunch and we made plans for what this foundation was going to look like and what it was going to do, what it was going to be called, who was going to be on the board, and everything. The mission was simple; the mission was very easy: we were going to stop the AIDS epidemic, okay? [laughter] It was just like the clinic: there was no question in our minds as to what this was all about.

We picked the people who would be on the board--

Hughes: Who were they, and why did you pick them?

Conant: Paul Volberding, because of his visibility. Cleve Jones, because he was the administrative assistant to Art Agnos, who at the time was the most sympathetic assemblyman that we had; Lia Belli, because Frank Jacobson knew her, and she had a well-known name, and we hoped money. Lia did a very good job. Tom Horn, who is a gay attorney here in town; Bob Ross, the editor of the *BAR* [*Bay Area Reporter*].

Hughes: And Sheldon Andelson.

Conant: Oh, yes. Shelly Andelson lived in Los Angeles. Sheldon Andelson was probably the wealthiest gay man who was well known and had the highest visibility. He was a banker who in essence bankrolled West Hollywood. Jacobson came in to see me one day and he said, "Call Sheldon Andelson and ask him to be on our board, so that we've got some credibility." I said, "Who's Sheldon Andelson?" So he sat there and explained to me who Sheldon Andelson was. I picked up the phone and called Sheldon Andelson, and I said, "We're doing this, and I want you on my board." He said, "Sure." He actually came to San Francisco later, and we had drinks at the Redwood Room at the Clift Hotel. He's a very nice man.

Now, of all of those people, Frank Jacobson died of AIDS three years ago; Sheldon Andelson died of AIDS four or five years ago; Cleve Jones made it known during his campaign for supervisor that he's infected. As you know, he went on to do the [AIDS] Quilt Project. Volberding is still well; I am well; Mr. Keller is well.

Hughes: Tom Horn?

Conant: Tom Horn is well, as far as I know. Bobbi Campbell was later made a board member, and he was one of my first AIDS patients. He started the People With AIDS organization. Bobbi, of course, we knew had AIDS when he was named to the board, and he subsequently died of AIDS.

Another person who was named to the board because of his position as a gay leader was Billy Kraus. Billy Kraus was the aide to Congressman [Phillip] Burton, and Billy Kraus was one of the first openly gay men to be on the Democratic platform committee. He was an extremely bright and amazingly insightful young political strategist. He immediately saw where the power was and what the power would listen to. Just an astounding ability. Billy was on the board and was a major asset. I was his doctor. He walked in one day with a lesion of Kaposi's sarcoma. We lost Billy a couple of years later [January 5, 1986],[1] tragically for all of us. The day that Bill Kraus became ill, from my perspective, we lost him as a leader. He became so consumed with survival that he ceased to be effective as a leader, which is certainly understandable. It was a tragic loss.

We called it the Kaposi's Sarcoma Research and Education Foundation. We rented a storefront on the Castro. We put on a dog show shortly thereafter. [laughs] And we put in the hotline.

One of the volunteers who worked with Frank Jacobson, and actually probably knows more about that early foundation than I do, was Angie Lewis. Angie Lewis is a nurse at UC who was a dear friend of Frank's, and she and Frank would go down there at night and train the volunteers, get the phone lines in place, and get it all started.

I had a very selfish view of the foundation. For Marc Conant, the foundation was a platform from which I could go back to Washington and lobby for funds for research and for education. I was pleased that in the [gay] community we were publishing newsletters and that we had a hotline and that we were talking to people about insurance benefits. But clearly, what I wanted that foundation to do was to provide a platform where someone could speak to the country's leaders about the need for more research funding for prevention strategies, and it served that purpose.

Hughes: Is that the explanation for the National KS Foundation?

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[1] Randy Shilts. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: Penguin Books, 1987. p. 602.

Conant: That's right.

Hughes: Do you remember how soon the foundation adopted a national agenda?

Conant: Oh, we began trying to do that almost at once. The concept was to do pretty much what the United Way does. The idea was, AIDS is happening in every city, every city needs a foundation, and so we will start foundations in other cities. We can help them by furnishing them their own 501(c)3. We can umbrella them under our tax-exempt number. We can provide them expertise in how to set up; we can provide them all the printed material we have, and then they can go do it in their community. And for that assistance, they would pay X amount back to the national, like 5 or 10 percent of what they made, which we could then use for lobbying efforts on a national level, to go and do what we wanted to do.

We learned something very interesting about the gay community. One of the problems that the gay community has, as Ginny Apuzzo says, is that the gay community eats its leaders. The gay community has a real problem with following. It's certainly not true of all gay men. This is a sweeping generalization. But in this effort, we found that we could go to Sacramento, for example, and talk to them about a foundation, and they'd say, "Sure, please come help us, please give us everything you have, and please do this. But we don't want to give our money to you or to a national foundation."

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Conant: We started a San Francisco foundation, a Santa Clara foundation; we started a Sacramento group. In essence, each one broke into its own group. From my point of view, it was unfortunate. I would like to have seen a very powerful national foundation which could have addressed as a single voice many of these issues. You can begin to realize the significance that that could have had as the epidemic evolved, on a variety of levels. A national foundation with articulate spokespeople going back to Washington constantly saying, "We represent a million infected people. We want action here," is a lot more effective than one little group writing in and another little group writing in.

As a recent example, $20 million was appropriated to develop a vaccine, but it was given to one company. Now, if there was the powerful national voice of a foundation, then the leader or leaders of that foundation could have gone to Congress and said, "You're making a terrible mistake. You should give the money for vaccine development, that's wonderful. But don't give it to one company." That's what the vision was, that kind of voice. The problem was that the people coming together were caring, loving, wonderful people, many of them with very little experience in management, and all of them wanted to be in charge, wanted to do it. Consequently, we were just not able to successfully build a national foundation. We're pleased with the one we built here in San Francisco, which is great; but we failed in terms of trying to build a national foundation.

Hughes: Did you argue the advantages of consensus and coordination?

Conant: Oh, until I was blue in the face. As I was sitting here just now giving you the reasons, it's amusing because I can hear myself back there in that period in '83, '84, saying exactly the same thing over and over and over. There was this reluctance to join. Everyone wished to be autonomous.

We certainly had people from the gay community, and then from the community, who disagreed with what we were trying to do. And we dealt with that. As I say, unfortunately we failed, because sitting here today looking back, we would have been a lot more effective had we been successful.

Hughes: In 1983, the city gave the AIDS-KS Foundation $150,000 to spearhead with Shanti an emergency AIDS education program. In the *Chronicle*, September 22, 1983, Wendy Nelder, president of the San Francisco Board of Supervisors, stated, "We haven't seen results," and that Mervyn Silverman "had better be ready to have some answers."[1] Does that ring any bells?

Conant: Doesn't ring a bell. But I remember that there's been incredible criticism of educational programs all along. I don't think politicians have understood, and don't even understand today, that you could pour millions of dollars into educational programs to stop the AIDS epidemic, and you're not going to see results for years. The foundation was extremely effective in stopping it, and I'll tell you how in just a moment.

I don't remember the instance with Wendy Nelder; I can remember arguing with Wendy Nelder about AIDS, and making the comment later that "they don't call her Wendy for nothing." [laughter] But I think that that comment that you just read me from the paper reflects the fact that the city and the federal government and the state were all pouring money into this thing, expecting it to go away.

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[1] Randy Shilts. S.F. Wonders Where AIDS Money Goes. *San Francisco Chronicle*, September 22, 1983. (Gay/Lesbian Archives, AIDS folder, 8-12/83.)

Hughes: And it didn't go away.

Conant: It didn't go away.

To close the circle on all of this, it's important to look at the members of the board as to the role each of them later played in AIDS, three of them in particular. Paul Volberding went on to be the outstanding figure at San Francisco General in probably the most visible AIDS clinic in the world, to his great credit.

Cleve Jones and the AIDS Quilt Project

Conant: Cleve Jones went off to Hawaii for almost a year and meditated and came up with the idea for the quilt project, which I think has served a couple of very important functions. The quilt has been a visible reminder to people of the magnitude of the epidemic. You can't look at the thing spread out on the lawn in Washington and not sense its magnitude. But it has also been a way that people have been able to grieve, and that's been very important because the gay community doesn't have a family per se; the family is a very amorphous, disjointed, distant thing. Gay men have understandably been horribly saddened and emotionally devastated by this epidemic, and the quilt gives them a visible shrine that they can go to and stand and weep. And that's important. They brought bits of the quilt and hung them in one of the civic buildings in Amsterdam during the 1992 International Conference on AIDS. I can't tell you how many young gay men would come up to me in Amsterdam and almost tearfully say, "Have you been to the quilt?" I spent a couple of hours, looking. At first I looked to see how many names I knew. When I went to Montreal for the fifth international AIDS meeting, Gaetan Dugas's name was on one of the quilts, which was very ironic, but at that time I did not understand the significance of the quilt. But in Amsterdam in July, as I sat and watched young gay men standing there, walking around, I realized the quilt is like the flame at the Kennedy grave. This is where the faithful go to grieve, to remember.

And Cleve did that. It was his idea. Much to his credit. That's an amazing contribution that he made. He was a very young man when he was named to KS Foundation board. He was twenty-three or twenty-four at the time.

Frank Jacobson

Conant: Frank Jacobson is certainly one of the unsung heroes. He thought up the idea of the foundation; he thought up getting Shelly Andelson and Lia Belli on that foundation board. What Lia Belli brought to us was money and the ability to use her name and her home for fundraisers. That's no small contribution.

When we went to Los Angeles to meet with [California State Assembly Speaker] Willie Brown, where we had all these experts there talking about all this money we needed, we needed a bill written with a budget.[1] Frank Jacobson wrote that budget. So it really all ties in. Frank sat down there at the end of that table and did all the paperwork. We had all talked until we were blue in the face and walked out, and nothing would have happened. It's great to be a visionary, but if you don't have leaders around you who understand that vision and can transmit it to other people, you're useless. Frank Jacobson is certainly that leader, that person who really understood what had to happen to translate the foundation from a great idea to something that happened.

Frank's own personal life is fascinating, too. He and his wife Judith have one son, Justin, who is a wonderful young man. Justin is a sophomore at Lewis and Clark University in Oregon--very articulate, very bright, shares his father's interest in music, but wants to be a journalist. He was named Justin because Franklin was very much the attorney. Frank and Judith separated, and she now lives with a very interesting woman who is a minister. Frank and his lover both died of AIDS. So very much a San Francisco family. Bill Crisp, who was Frank's lover, died about two years before Frank did, and Frank died of AIDS--I gave the eulogy at his funeral--about two years ago, maybe three.

Probably during the period of time when we started the foundation and we went to Sacramento and got the funding, like most gay men, he probably was afraid he was infected. There wasn't an antibody test; you couldn't know. So many of the men--Cleve Jones, Frank Jacobson, Richard Keller--all of these people were involved in the caring. There was a personal commitment, because they probably knew that they were at least at risk of being infected, if not infected. But they didn't know [then for sure]. Only later did they learn that they had been spared or that they had in fact contracted the disease.

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[1] See pages 134-138 for discussion of this episode.

Naming the Disease

Conant: The disease wasn't called AIDS in the beginning. It was called the gay cancer, and then a few months later became known as GRID, Gay-Related Immune Deficiency Syndrome. The gay community went absolutely nuts over that, and so they changed it to Acquired Immunodeficiency Syndrome, and so AIDS was born in May of 1982.

Hughes: What was the prime objection from the gay community to GRID?

Conant: The feeling was that it was branding the gay community as having a disease, or being diseased.

Hughes: And yet, was that not the common perception?

Conant: Not only was it the common perception, but at that point in time when they were calling it GRID, if there were cases in heterosexuals, the number was preciously few.

Hughes: Remarkably early there were reports of heterosexuals with AIDS. [looks through notes]

Conant: I remember by September of 1982, there clearly were. At that point, the gay community would say, "Wait a minute, this isn't a gay disease, and we don't want to be branded as if we have a disease. You should call it something else." Roger Enlow and others objected very strenuously to the term GRID.

Hughes: And of course, they were right.

Conant: Yes, they were right.

I've always objected to the name AIDS. I would like it to be called something like Horror or Awful. The word "aid" to me is aid and comfort; it's support. I always think of the word "aid" as something very positive. I mean, "I go the aid of my brother in need." I think it's truly unfortunate that this was not called by its real name, which is Horror. Be that as it may, it is AIDS and will remain AIDS forever, I'm afraid.

Perception of the Disease

Hughes: The construction of the disease in the early days as a gay disease must have limited what sort of research was being done. An epidemiologist has speculated that one of the reasons that the first heterosexuals with AIDS were not investigated rigorously was because the CDC didn't want to do research on drug users.[1]

Conant: Right, that's true.

A fascinating part of this whole story is the resistance [to take action]. As we sit here today, four months before the presidential election, it is still true. I am told--I was not at this meeting--that during the Reagan administration, there was a meeting of government scientists and physicians, including the then-surgeon general, Dr. C. Everett Koop. One of the members of the Reagan senior staff came to the meeting and began the meeting by saying, "Gentlemen, I want it understood that it is the position of this administration that this disease is a law enforcement problem, not a medical problem."

And if you take that mindset and you really think about it, that this is a problem that is happening to people who are outside the law, they're engaged in behavior--homosexuality and IV drug use--that is not legal, and we are going to view it as such. The innocents, if you will, who happen to get the disease, like hemophiliacs or unborn children, are like people who are killed in the crossfire on a city street. You have the cops trying to subdue a gangster, and isn't it too tragic that someone got killed, perhaps even by the police's bullets, but that's just the way it is. If you have this mindset, that this is a law enforcement problem, not a medical problem, then it's not surprising that from the top all the way down there has been this constant resistance to do anything, to move.

Couple that with the fact that, who do you turn to for allies? Remember that the Congress of the United States is made up in great part by white middle-class males, many of whom have constituencies of not very bright people who require constant feeding and watering with little bits of information that are not true. [Senator] Jesse Helms and his constituency in North Carolina is a beautiful example. I have had a lot of opportunity to work with colleagues in North Carolina, because I went to Duke;

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[1] Gerald M. Oppenheimer. Causes, cases, and cohorts: The role of epidemiology in the historical construction of AIDS. In: *AIDS: The Making of a Chronic Disease*. Elizabeth Fee and Daniel M. Fox, eds. Berkeley: University of California Press, 1992, pp. 49-83.

I lived in the state for nine years myself. I continue to do a lot of research with Burroughs-Wellcome which is based at Research Triangle Park in North Carolina, so I'm there a lot and I know the state.

I ask my friends, many of whom are brilliant people, very liberal and very insightful, "Why do you keep electing Jesse Helms to the Senate of the United States?" And they say, "Ah. It's not us. We have a huge rural community in North Carolina, composed primarily of cotton and tobacco farmers, and Jesse Helms has them as a constituency. We in the liberal areas in the state cannot get him out of office." So you begin to realize that Jesse Helms is playing to this group of people in North Carolina who have certain views of the world and clearly need enlightening, but are not becoming enlightened.

I am reminded of an article I saw in the paper yesterday. Apparently, there was this poll taken of Americans asking, "Do you believe that God created the earth within the last 10,000 years?" And 40 percent said yes. Then the second question was, "Do you believe that God created the earth at some time older than 10,000 years?" Another 40 percent said yes. The final question was, "Have you heard of the Big Bang theory, and do you doubt whether the earth was `created' by a creator," and only 10 percent said yes. What we're up against is that kind of mindset in this country.

Political Advocates for AIDS

Conant: Let me frame it further. In the early days, finding leadership allies was one of our most difficult challenges.

Hughes: You mean in the political sense?

Conant: In Washington. In 1982 and 1983, I flew back to Washington on a number of occasions.[1] I can remember I was there three times in July and August of '83. What we were trying to do was to find people on Capitol Hill who would be sympathetic to this new disease. Most of the time, you'd go in to talk to them about it, and you'd see their eyes glaze over, and you'd realize, I'm wasting my time.

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[1] For an example of Conant's congressional testimony, see the draft in the appendix of a speech delivered on April 13, 1982, before Congressman Henry A. Waxman's committee on health.

So then we decided, well, as a strategy, wouldn't it be smart to identify gay congressmen, gay leaders, in Washington, go in with a private interview, close the door, and say, "We think this is something you will be very interested in, and we'd like to talk to you a little bit about AIDS."

Hughes: Were these people admittedly gay?

Conant: No.

Hughes: Did their constituents know that they were gay?

Conant: No. There's a huge number of gay men and lesbian women in Washington as administrative aides and legislative assistants. I think the American people would be astounded at how much of the power structure in this country is being controlled by people who they don't even think exist. There's this tremendous infrastructure of gay men and women in Washington; Washington has a very large gay community. Gay people are often very bright, very insightful, and they get good jobs doing great things.

And some of them are bright, insightful, and do horrible things. [laughter] I don't want to imply that all gays are just wonderful. You will remember that Roy Cohen, who was the administrative aide and prosecuting attorney for Senator McCarthy, was the strength of Joseph McCarthy. Roy Cohen, who was one of the most evil men in the history of this government, and died of AIDS himself a few years back, was known to be gay, would go to gay bars in Washington, and then would prosecute gay people the next day. I mean, he was an absolutely despicable man. But brilliant, absolutely brilliant.

The point is that there were then, and there are today, large numbers of very, very effective gay legislative aides, some at very high levels in Washington. So we went to lunch with these aides, and we said, "Tell us who we need to go talk to." They would say, "Well, I think you would find so-and-so very sympathetic, and you would find so-and-so very sympathetic," and so on. That kind of thing. There are networks. Otherwise, gay people could never meet other gay people. There have to be networks of how people find each other.

So we did. Ginny Apuzzo in New York did some of this; I did some of this. We would identify these people, and we'd go to their office and we'd close the door, and we'd say, "We're here to talk to you about AIDS." And to a man, the reaction was, "Why do you think _I_ would be interested?" I would say, "Well, so-and-so suggested that you might be very interested in this epidemic."

"Well, I don't know what you're talking about, and I'm not interested, and I'd just as soon you not bother me."

Hughes: So what did you do at that point?

Conant: [laughter] Felt sorry for him. Look at it: here's a strange doctor coming from California, where everybody's considered to be fruit and nuts anyway, and he's got the door closed and is talking about an issue which could perhaps lead to blackmail. I understand why this guy's upset or concerned or whatever, because the next thing you might say is, "That's right, and I'm going to go tell your constituency that you were very interested in this problem." It didn't work. So we didn't have friends in Washington, and we were having trouble finding friends in Washington.

Now, there were exceptions. Congressman [Henry] Waxman, who represented Los Angeles, was very sympathetic. His administrative aide--

Hughes: Tim Westmoreland?

Conant: Tim Westmoreland. That's exactly right. Well, you have done your homework. Tim Westmoreland was very helpful then, and has been just a knight through this whole thing; he's been a very good, positive force. Congressman [Ted] Weiss from New York, who represents Greenwich Village, also realized that AIDS needed urgent attention.

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Conant: Another friend in Washington was Barbara Boxer from the Bay Area. The reason I remember Barbara Boxer's involvement was Weiss had hearings in the summer of 1983 as to what we should do about funding for research for this new epidemic. [laughs] Some of that was wonderful. Mathilde Krim and I testified, and others, as to what was happening and what we needed and why we needed more money. Barbara Boxer came to those hearings and was very emphatic and very supportive.

And what we realized at that point was that there were two people we could go to: legislators who had gay constituencies, and women. To get the support of legislators with gay constituencies required that we have the gay constituency become more and more visible and begin to push their leader. If a gay community is totally closeted, the congressman or senator doesn't need to pay any attention to it. It's only significant if it's "out."

Women don't need to be concerned that if they appear interested in a disease that's killing homosexuals, they will be accused of being homosexuals. Of course, that was the major concern of the legislators in Washington: "Wait a minute, if I appear too interested in this problem, my constituents will wonder, am I gay? And if I'm [perceived as] gay, my political career is over."

The National Cancer Institute [NCI] Grant, 1982

Conant: We were fighting for money like crazy and it was not coming through. Paul Volberding had gone to great pains to put together a grant to support the research we were doing in the Kaposi's Sarcoma Clinic in late '82 and early '83. We submitted the grant to the NCI, the National Cancer Institute, with John Ziegler's help--remember he had come from there and he was very well connected there--and with indications from them that this would be funded.

And then politics raised its ugly head again. It looked initially that the way it would be funded would be that clinics such as ours, which had brought together the experts and the patients, would be given large sums of money to do research and find out what was going on. People, like Jay Levy that we had brought in, would then get the funding they needed, [in his case] to isolate the AIDS virus. There were lots of us working in different areas: Levy working to isolate the virus; Dan Stites and Art Ammann working on the immunology of the disease. We knew that if we could get $100,000 or $500,000, we could expand that work tremendously. That's what we were trying to do.

The NCI at the last moment in the spring of '83 decided, "Wait a minute, we don't want to give them the money. We want to get the money. We want them [extramural researchers] to work with us under our direction, but the National Cancer Institute will keep AIDS research as a federal project, and we will give out the money to people who will work with us," like the ACTGs [AIDS Clinical Trials Groups] today. So suddenly NCI said, "No, we're not going to give you money. We'll talk to you in a few months about doing collaborative investigations with us."

Whether it would have been better to have given the money to the universities, I don't know. I've often thought that probably it would have been, that it would have moved a lot faster, because you eliminate at least one level of bureaucracy, the federal bureaucracy, and then you're only dealing with the university bureaucracy. But be that as it may, that was not the way it was going to be, and of course, none of us had enough power to change that. We were begging for money, not begging for how we were going to be given the money, just as long as we could get it.

Funds from the State of California, 1983

Conant: At that point, I went to Harry Britt, who was one of the supervisors in San Francisco, was the gay supervisor, who ran for office to replace Harvey Milk after Milk's assassination [in 1978]. One of the people who was very, very pivotal in the discussions that immediately followed was Carole Migden. Carole Migden at the time was head of Operation Concern, which was a counseling community support group on Market Street. I had known who Carole Migden was because, as I mentioned, I had seen a psychologist [Paul Dague] because of a depression that I was having in '79, '80, and '81, and that psychologist had worked with Carole Migden at Operation Concern. So I knew who she was and that she was a shaker and a mover in the community, as she is.

Carole Migden has now gone on and become elected a supervisor herself some ten years later, but in those days, she was working with Britt. She was very worried about the AIDS epidemic. So in that sense, Carole was right there at the beginning. And they [Migden and Britt] decided, hearing from me and others, that there was just not enough money at the university to do AIDS research, and that the government had promised money, and now was pulling back. We had to get money from the state.

So Migden and Britt called [Speaker of the California Assembly] Willie Brown, who is from San Francisco, and persuaded the speaker that this problem was important enough to send one of his legislative aides down to San Francisco to meet with us and hear the problem. So in February of 1983, I had a meeting at City Hall with Britt, Migden, Joanne Murphrey, and I think there were a couple of other physicians in the room. Joanne Murphrey is a wonderful woman. She is one of the brightest people I've ever known. She said, "The Speaker's interested in this; tell us what the problem is." So I told her what the problem was, and why we needed money.

She returned to Sacramento, and within a week we heard that the speaker wanted me to bring together a group of scientists from UCLA and San Francisco and come up with a budget as to what was needed. We flew to Brown's office in Los Angeles, and I believe it was April of '83.

I took with me Frank Jacobson. That's a significant name, because Frank was a young attorney administrator here at UC, and was probably the only one of us that knew how to write a university grant. He did so, wrote the grant for the whole thing. Paul Volberding was with me; John Greenspan was there; Jay Levy was there; Andrew Moss was there; and leaders from UCLA attended as well. In the course of the day in the speaker's office we hammered out what we needed for a budget, and the number came in at $3 million.

Hughes: This was to cover research at UCLA and UCSF?

Conant: Correct. And at the end of the day, we presented the budget to Joanne Murphrey. She took notes and said, "Get back to me with a grant [application] of this much money." At that point the speaker, as he always does, "entered" the room. The speaker doesn't just "come by". [laughter] I have great admiration for Willie Brown. The speaker Makes An Entrance, and the speaker Entered The Room [spoken with emphasis]. Everyone was riveted by him. He is truly a charismatic man. He said that this was an important problem; it was a problem for his constituents in San Francisco, and that he was going to use the power of his office to get us the money. And true to his word, he got us every penny of the money.

That grant has been renewed annually for the nine years since. It grew until at its height, I believe it was $12 million a year from the state, for AIDS investigation and AIDS research. So over the ten-year period, almost $100 million has flowed from that original meeting at City Hall with Britt and Migden.

Hughes: Remarkable.

Conant: Yes, truly remarkable.

Hughes: Why was Willie Brown so receptive?

Conant: I've asked myself that a million times. Willie Brown is the consummate politician. He is a man who is very pragmatic, and I am certain he has a great deal of difficulty in his own personal life realizing he has to balance the needs of his constituents with his own political considerations and [with] what will and will not work in that environment. It's an amazing environment. That's part of it.

Willie Brown is also a truly brilliant man. He, too, saw early on that this epidemic was not just something that was going to go away. It was growing. Maybe his daddy doubled pennies on him early on. But for some reason from the beginning, he has seemed to understand. I guess the problem I have is not understanding why more people don't understand, don't see it [significance of the epidemic]. But Willie Brown clearly saw it early on.

The reason I don't believe that the speaker became involved for political reasons is because he's never used what he did for political advantage. When he speaks to gay groups, he clearly points out that he's been involved [in the epidemic] from the beginning. But he has not used it as a campaign issue, to say, "Look, I was there at the very beginning." He could well do that, and all of us who are beholden to him would agree. I would get up and say, "This man was there for you from the beginning, and if there's a hero here in Sacramento, he's it." He's never asked for that. So it was not purely political. There is something else motivating him--God bless him.

We would not have had that money without his help, because even though the budget problems are worse today than they were then, the state was not flush. It couldn't just start throwing that kind of money at this kind of a problem. So he went back and got us the $3 million. It was $2.9 million that first year; that was 1983. And then it grew to $12 million, and has generated $100 million in a decade.

Hughes: Was it fairly string-free?

Conant: Oh, yes, that's another whole wonderful story. [laughs] The university didn't want us to do it, amazingly, because of course we were going around the traditional university procedures. Early on I began to realize, look, we are going to get $3 million there, and it's a lot of money. And UC San Francisco is going to get $300,000 of the $3 million just for the clinic.

I called Julie [Julius] Krevans. Julie Krevans is an old friend, and I have tremendous respect for him as well. I think he's a truly brilliant administrator. I said, "What do I do?" He said, "Keep doing what you're doing, and keep me informed." I said, "All right, I'll do that." So that's what I did.

However, not all of the officials at UC were as sanguine about this matter. Dr. Conn [Cornelius] Hopper, who is vice chancellor in charge of health affairs--a title he did not hold at the time; he ascended to that position a couple of years later--but at the time, he was the senior health care administrator at UC

Berkeley.[1] He called me, and he was very distressed that we were doing this. Who did we think we were, going to the speaker to get money for university programs, and did I not understand that the university did not want to be beholden to the legislature, or if it did, the university wanted to control how it was. I said, "I'm sorry, but we've got an epidemic, and I'm trying to get money to fight the epidemic."

Hughes: There was another aspect, wasn't there? If the money came through the university, then it would control how it was disbursed.

Conant: That's true. And in addition to that, the university of course has overhead, about 50 percent.

At the meeting with Joanne Murphrey and the speaker in his offices in the spring of '83, John Greenspan--I remember it vividly--got up at the very beginning, while we were having the introductory comments about what we were doing, and said, "Gentlemen, I propose that any grant that's given by the legislature for AIDS have no university overhead." And of course, it was brilliant, because it meant that the legislature would look at it and say, "Well, we can fund AIDS research, and we can give them more money because we don't have to fund the university." And of course, that was one of the major reasons the university was not pleased with that.

But the university has more than been compensated for that. We didn't have AIDS budget hearings this year, but we've had them every year up until now. Assemblyman John Vasconcellos chairs the Ways and Means Committee, and John has always had AIDS budget hearings to look at the money: do we need more, do we need less, where should it go? Conn Hopper always comes to those and argues passionately for continuation of these funds. So while in the beginning he had certain reservations, he has certainly been converted and is a believer that this is probably not a totally bad process.

Hughes: Was that more or less the end of that? No further repercussions from the administration?

Conant: There were, but not direct. The university administration was never happy with me after that; I'm not sure they were happy with me before that. It was certainly not happy with me on a variety of levels, and for some reason, it and others could not believe that I was not getting paid anything. They kept thinking, Well,

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[1] In 1983, Hopper was Special Assistant, Office of Health Affairs, University of California Systemwide Administration.

he's getting this money for his own research or his own whatever. And it's true, the money gave me the opportunity to expand what we were doing tremendously.

It's really hard with the university mindset for them to understand the motivations of someone in private practice. I had my practice. I was making a very good living. I was at a point where I was ready to retire, I had made such a good living. And I could come over here and practice dermatology four or five days a week and make plenty of money, so I didn't need the income from the state. What I wanted to do was to stop the epidemic. And I can understand why it would be hard for someone who works for the university to realize, well, if you get grants, that increases your income.

I was even asked in Julie Krevans' office once what I was personally getting out of all of this. Julie Krevans didn't ask it; Sheldon Andelson, a gay banker leader from Los Angeles, who had been by that time made a regent of the University of California, said, "Well, what are you personally getting out of it?" I said, "Satisfaction." He said, "No, no, I mean money." [laughs] I said, "Nothing!" He said, "Oh, come on."

Transfusion AIDS

[Interview 3: October 11, 1992] ##

The UCSF Baby, December 1982

Hughes: Please tell me more about the baby at UCSF who died of transfusion AIDS.

Conant: I invited Herb Perkins to give a talk for the KS Clinic because the month before, the Centers for Disease Control had had a meeting in Atlanta. You see, what had happened was the first transfusion-associated AIDS case, this one that Ammann, Perkins, and Dritz had investigated, was announced on December 10, 1982, here in San Francisco.[1] Well, this was the first case of AIDS in which the only risk factor that this recipient had was a transfusion from somebody who had AIDS. Of course, there were a number of other diseases, like hepatitis B, that were known to be blood-borne, sexually transmitted infectious diseases. So there

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[1] David Perlman. Mystery of S.F. Baby with "Gay" Disease. *San Francisco Chronicle*, December 10, 1982.

was already a model for the fact that AIDS could well be a blood-borne disease. And remember that AIDS had already been seen in hemophiliacs who had received Factor VIII who had no other risk factors [for AIDS], and people who shared needles who were intravenous drug users who had no other risk factors.

So the fact that AIDS was now being seen in someone who had gotten a transfusion was not terribly surprising. It was almost the last step in what appeared to be inevitable.

The January 4, 1983 Meeting, Centers for Disease Control, Atlanta

Conant: The minute the baby was discovered, the CDC called a meeting to bring together the blood bankers, the people with AIDS or AIDS representatives, and people from the plasma industry which represented the hemophiliac community, to discuss what should be done. That meeting was held as soon as possible after the Christmas holidays, on January 4, 1983.[1]

Hughes: Did you go?

Conant: No. But Selma Dritz[2] and Herb Perkins went. Well, we heard from Dritz and others when they got back that there had been this huge fight, and nothing could be decided. That there was a consensus, if you will, that something should be done, but no consensus about what should be done. The blood bankers were hesitant to do hepatitis B core antibody testing, which was a surrogate marker for infection on donated blood, because it would raise the cost. They were also afraid that donors wouldn't come in if they knew that they might be tested for something that would show they had been exposed to AIDS, and the core antibody test might be interpreted as showing that.

The representatives from the gay community, particularly Roger Enlow, a physician from New York, didn't want donors

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[1] The CDC identified the meeting as the "Workgroup to Identify Opportunities for Prevention of Acquired Immune Deficiency Syndrome." For the agenda and related documents, see Irwin Memorial Blood Bank [IMBB] documents, CBBL binder 2, 1-5/1983, CBBL00347.

[2] See Dr. Dritz's account of this meeting in her oral history in this series.

questioned about their sexuality, because he didn't want gays scapegoated when they walked into a blood bank.

So here [at the CDC meeting] you had this one group, the gay representatives, saying, "No, no, it's not appropriate to ask people if they're at risk or what they had done that might put them at risk, but it's okay to do surrogate testing on everybody, and exclude those that have markers." And the blood bankers were saying, "Well, we don't want to ask people embarrassing questions, particularly if the gay community feels we shouldn't, and we don't want to do the core test because it's going to raise the cost of the blood." So in essence, they did nothing.

Debate over Blood Donation Screening

Conant: Now, when Perkins came to our clinic meeting, he reassured all of us that the blood bank here was going to screen out high-risk donors. We learned in retrospect that they didn't screen out the high-risk donors. They gave people an information sheet that in very vague terms talked about who should not give blood. It said things such as, "Homosexual or bisexual men with multiple partners [should defer donation]."[1] But it didn't say multiple means more than one partner since 1978. So lots of people interpreted that to mean more than one in the last month or two.

The donor guidelines were so vague that of course, no one wanted to admit to themselves that they might be infected with this new fatal disease. So they [the blood bank] gave people this information sheet which invited denial. I mean, the first thing you want to do is read that and say, "Oh, that's not me." So people were almost giving blood to prove to themselves that they couldn't possibly be one of the people infected with this new disease. It was almost a validation that you were okay, because you could get through the screening process.

Hughes: Why had the screening process been set up that way?

Conant: Well, because the gay community, the leaders like Roger Enlow, was telling blood bankers, "It's not appropriate for you to ask people their sexuality." I tend to disagree. I think people should have been told, "We have a new epidemic out here, and this blood that you give may be given to your mother, your brother, your friend.

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[1] See IMBB News Bulletin, February 8, 1983. (IMBB documents, CBBL binder 2, 1-5/1983, CBBL00494.)

If you've had sex with another man since 1978, please don't give blood today." I mean, I don't think that would have offended anybody had it been done appropriately.

I testified before the [John] Dingle committee in Congress two years ago now and pointed out that the blood banks had a wonderful opportunity as a national institution to educate people as early as '83 as to who should not give blood and why. That would have gone a long way to stopping the AIDS epidemic. They had free access to the radio and television and the press, and they could have said, "We're having to ask people who have engaged in these behaviors not to give blood, and this is why. And if you're engaging in those behaviors, for Christ's sake, consider using a condom."

You see, there was no national attention to the AIDS epidemic until Rock Hudson passed out in the lobby of a Paris hotel [1985]. Rock Hudson didn't announce that he had AIDS. Rock Hudson literally fainted in the lobby of a hotel, and he looked pretty bad, and the press came running over saying, "Why is Rock Hudson lying here unconscious?" It came out with a little investigative reporting that Rock Hudson had a serious disease.

<u>Suddenly</u> then, AIDS breaks on the national scene, but that's in the fall of 1985. That's three years after the blood banks knew that AIDS was already in the nation's blood supply, and that every blood banker could be on the local TV station every night educating people about this new disease.

So in my view, the blood banks not only let down the people receiving the blood by not screening it properly, they let down the people giving the blood by not taking this wonderful opportunity to teach them why we shouldn't take their blood, and why they were at risk, and what they could do [to prevent transmission].

But to go back to the clinic: that was the kind of information we were trying to disseminate. To follow up on that, Dr. Perkins told us, "We're going to screen out the donors, but we're not going to use the hepatitis B core test."

[tape interruption]

We thought from what Perkins had said Irwin was going to take a [donor] history and ask people more specific questions about their sexuality and about the behavior they engaged in. We felt that they still should do the [surrogate] testing. As doctors taking care of the disease, we knew that no matter how well they questioned people, there would still be people who would not be truthful. Either they were embarrassed or they would conceal their behavior, or some people just get drunk and do things that they choose to forget that they've done. After you practice medicine long enough, you realize you're being very, very naive if you assume that people are going to tell you the truth all the time.

About 75 percent of gay men in the city were hepatitis B core positive. So what we were saying was, "You do this test which can be done for less than $5 on every unit of blood, and if it's positive, throw out [the blood]. You will be picking up people whose behavior puts them at risk for hepatitis B, which is transmitted in exactly the same way that AIDS is transmitted."

Now, the blood bankers didn't want to do that, because they estimated--and probably rightly so--that they'd have to throw away 5 percent of all the blood that came in. We were arguing, "That's right, that's the 5 percent of people that are engaging in behaviors, either prostitution or homosexuality or IV drug use or whatever, that are putting them at risk for this new disease. So yes, Mr. Blood Banker, you're going to have to give up that 5 percent of your blood." They didn't want to do that.

David Altman came to me following the meeting with Herb Perkins and said, "Do you think Irwin ought to do more than screen donors?" and I said, "Yes." So I actually called Herb Perkins--and those memos exist, they've turned up--to say, "We're going to go to the press and tell them that we think you should be doing hepatitis B core surrogate testing." Irwin still didn't do it, so we went to the press. This group from the KS Clinic actually sent an open letter to the *San Francisco Chronicle*, which was published about February 3, 1983, and it's headlined, "Blood Bank Rebuffs UC on Test for AIDS."[1] It goes on to point out that while Irwin was considering doing a study of whether the hepatitis B core test could be useful, they were more concerned about [maintaining the volume of] the blood supply than they were about its safety, and that there was no great enthusiasm for doing the core test.

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[1] *San Francisco Chronicle*, February 4, 1983, A4. See also, draft of letter circulated to KS Clinic physicians: Marcus Conant and David Altman to Drs. Rudi Schmid, Girish Vyas, Paul Volberding, Steve Follansbee, and Andrew Moss, January 28, 1983 (Conant's KS Notebook, 1983); Irwin Memorial Blood Bank [IMBB] memo noting receipt of Conant's call, Fonna to HP [Herbert Perkins], 1/28/83 (IMBB documents, CBBL00469, CBBL binder 2, 1-5/83); "UC physicians want blood banks to screen donors for AIDS," *San Francisco Examiner*, February 3, 1983 (Gay and Lesbian Archives, blue plastic envelope labeled "1983").

But it was that kind of dialogue that we were attempting to get started in the KS Clinic. In many instances, I think we were successful. The bathhouse issue was another one that was widely discussed. Funding was widely discussed--just how to get the money for people like Jay Levy to do what they did. And then we were constantly bringing in patients to keep reminding these people that AIDS was not happening in a vacuum. AIDS was happening against the backdrop of more and more and more and more young men coming in with this new disease.

[tape interruption]

Hughes: At Stanford, Dr. Edgar Engleman, from an early date, had been screening blood for evidence of HIV infection.

Conant: Yes, that's right. Engleman started screening blood, I believe, in July of '83.[1] He didn't use the core test; he used the helper-suppressor T cell ratio. He was actually looking at the immune systems of people who were coming in to give blood, and if they were immunosuppressed, he would not use the blood. That was also going on, interestingly enough, at Tulane [University]. So there were enlightened blood bankers around the country who were in fact doing screening.

Hopefully, some investigative reporter or some student working on a Ph.D. one day will sit down and ask the question, Why did the blood industry of America choose for two and a half years to totally ignore an epidemic where all the data that they were receiving in their own in-house journals showed every month the number of AIDS cases going up, up, up, up, and they just sat there, and they didn't react.

As a matter of fact, it's even more startling than that, if you look at the data. The American Red Cross, which collects half of the country's blood, started working with Abbott Laboratory, which was developing the ELISA [enzyme-linked immunosorbent assay] test to look for AIDS in the blood in October of 1984. Now, the test was not yet approved, and so there were mistakes, but what they started finding was that they had people coming into the blood banks to give blood who were testing positive for HIV.

Now, the test was not approved until the following March [1985], so from October [1984] to March, the American Red Cross

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[1] In *And the Band Played On*, Shilts states: "By the end of May, Stanford University Hospital became the only major medical center in the United States to decide to start testing blood for evidence of AIDS infection." (p. 308)

did not change the policies. Instead of saying, "Wait a minute! We thought handing out these little information sheets telling people, `If you've had sex with multiple partners over the years, don't give blood,' was doing it. And now we've known for months that it's not doing it." You have to ask, why didn't they suddenly say, "Uh oh, we're not doing enough. We've got to do more." They didn't.

Hughes: You don't think that the economic argument is sufficient to explain their actions?

Conant: That it would cost too much to do core testing?

Hughes: Well, that, and also losing blood donations.

Conant: One would argue that if the purpose of having blood banks is to assure that everything is done to be as certain as possible that the blood is as free of any infectious disease as possible, then if that means throwing out some blood, then you've got to throw out blood. Remember that only between 5 and 7 percent of all Americans ever give blood. So while the resource is very valuable and very scarce, if one were really to push with appropriate advertising saying, "We're having to exclude this large number of people who heretofore have given blood, and we've got to ask others in society to give," then it's hard for me to believe that they couldn't get blood donors.

But it's true, they would have had to throw away a lot of blood. The federal code of regulations says that blood bankers are supposed to do whatever is reasonably possible to assure that they are preventing the transmission of infectious disease. Well, they weren't doing it.

Hughes: Why did it take so long to accept the idea that the epidemic was caused by a transmissible agent, and to forget about poppers and all the other things that the CDC and other people were looking at?

Conant: Well, that's a very good and very complex question, and there's not a simple and easy answer. I guess if there were, this whole terrible epidemic in America would not have happened.

We still have very well respected people, like Peter Duesberg, who claim that AIDS is caused by lifestyle, and that HIV is not the cause of AIDS, it is just a concurrent infection, a harmless infection, that people contract who live this kind of lifestyle and destroy their immune systems.

Now, Duesberg's theory is fascinating, and it points out that yes, it is true, we don't really understand how this virus that moves so slowly and doesn't seem to infect that many cells can ultimately kill you. But I think all of us accept that it does. Dr. Duesberg conveniently overlooks the children that have this disease, people who have not led what he refers to as a "profligate lifestyle" that's injuring their immune system or whatever. He goes so far as to say that he would let us inject him with the HIV virus to show that it's not detrimental. Now, many of us have offered, but he's not stepped forward. [laughter]

Debate over Blood Transmission of AIDS

Conant: The international AIDS meetings began in '85, so there were hundreds of people already identified around the country who could speak to this issue [of a transmissible agent]. Here in San Francisco we had a large group, L.A. had a large group, Boston had another group, New York had a large group. If the blood banking industry, the Red Cross, had called ten or twenty or 100 AIDS experts and said, "Do you really think this thing is transmissible?" the answer would have been, "Yes." "Do you think it's transmissible in blood?" "You bet."

Now, whether you would have gotten 100 percent agreement by January of '83, I'm not sure. I would have said yes at that point. But by May of '83 when the French were publishing that they had isolated the virus, LAV, people were still debating whether it was <u>the</u> virus, but everyone was focused on the fact that it's got to be a virus. So a point came somewhere in the spring of '83 where, in my mind, the overwhelming majority, if not 100 percent, would have said, "Yes, this is a blood-borne communicable disease." And clearly, the blood banks should have acted at that time.

So then you have to say, "Well, why didn't they?" Well, one, it was an old-boy network. If you were a blood banker, the only people you talked to were other blood bankers. They would go to blood banking meetings and they would talk to other blood bankers about, "We're doing the right thing, aren't we?" And they didn't bring these 100 AIDS experts to speak to the issue of transfusion-associated AIDS.

Hughes: At that January 4, 1983 CDC meeting, Don Francis yelled and screamed to institute core testing.[1]

Conant: That's exactly right. The CDC meeting in my mind is really a very interesting phenomenon. Of course, the blood bankers didn't call the meeting and say, "What should we do?" The blood bankers were there representing their vested interest, if you will. They had staked out their position. Their senior representative, [Joseph] Bove [of the FDA's blood advisory committee], said at that point that he didn't feel that the case [for blood transmission of AIDS] had been made, that he wasn't sure this one baby was strong enough evidence to change the blood banking industry of America. Maybe they would lose 5 million units of blood a year, or some incredible number of units of blood if blood banks institute core antibody testing. That was in January of '83.

Bove actually sent a memo, which I have in my files, in February of '83 saying there was no question in his mind that there would be more [AIDS] cases, and that "We must act together as blood bankers to keep the lawyers off our tail."[2] So it's pretty obvious that, while making public pronouncements including testifying before Congress that he wasn't sure yet that the case [of transfusion AIDS] had been proved, he was writing internal memos saying, "We've got to do what we can to buy time while we try to figure out what to do about this problem." You wished that he would have had the courage to step forward and say, "We've got to act to protect the blood supply, and act right now."

At the CDC meeting, you had Enlow and others representing the gay community, you had Bove and others representing the blood bankers, you had the plasma industry representing hemophiliacs, you had Don Francis and others representing the Centers for Disease Control, and Selma Dritz representing the local epidemiologists. But you didn't have anyone from the public. You didn't have anyone there representing the people who would ultimately get the blood.

Now, I'm sure had you asked a bunch of citizens, they would have said, "Well, the government represents us," or "the blood bankers represent us," or who knows. But you see, that's where the system really broke down. Everyone was representing their vested viewpoint, but you didn't have a consumer who was going to actually hold his arm out and get this blood put in him say, "Wait

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[1] See the oral history in this series with Donald P. Francis, M.D., D.Sc.

[2] See the appendix for a copy of Bove's memo, dated January 24, 1983.

a minute. I don't care if it costs another $5 a unit, and I don't care if you have to throw away more blood. I don't want the stuff if I think it's infected with the AIDS virus."

At the CDC meeting, Don Francis was sort of the conscience of America, but Don didn't have a group of citizen representatives there saying, "Wait, listen to that official [Francis] over there. We want more done than to go out of here today saying, `Yes, we all agree there's a problem, but we don't know what to do about it.'" After that, the CDC just washed their hands of it.

As Francis has testified in court, the CDC handed it to the blood bankers on a silver platter. They said, "Here's your problem; here's what you've got to do about it." And as criticism of the CDC, they didn't keep pounding on it. They should have called one of those meetings every month from then on and kept saying, "Okay, what are you going to do this month? The number of cases has now doubled since we last met. What are you going to do now?" They didn't do that. They in essence presented it to the blood bankers and then walked away from the problem.

Hughes: Why?

Conant: I've asked myself why I didn't do that. Why didn't all of us, who understood the problem, continue to create more hell? Unfortunately, I think the answer is there were so many bigger problems that we were addressing that it was just a matter of priorities. Yes, we knew that they were infecting people at the blood bank, but we didn't think there were that many cases of transfusion AIDS. Meanwhile, out in the Castro that night, there were thousands of men having sex without condoms. So if you really wanted to do something, that was where you had to go do it.

Deciding to Act at the State Level

Conant: I didn't go through that thought process at the time. I didn't try to prioritize it. But I think, looking back, what you realize is you put your energy one, where you think you have the biggest problem, and two, where you think you're going to have some chance of success. I flew back and forth to Washington God knows how many times in '83, and a few times in '84. And by 1984, certainly '85, I had decided I was wasting my time going to Washington, that I could fly to Washington from now until the cows come home, and Ronald Reagan and those nice people were not going to listen to me or anybody else.

No matter what strategy you use--you could be reasonable, you could be hysterical, you could be confrontational, you could be diplomatic--you could do anything you wanted to do. It was not that they didn't understand. They did not want to hear it. It's that simple. They did not want to hear it.

So then you realize, "Wait, if I start working at the state level here, perhaps we can create a model in California which will then serve as a model for the rest of the country." That's what Don Francis did. He requested that he be allowed to come to California [as CDC Advisor to the Department of Health Services, 1985-1989]. And I've never thought about this until just now as I said it, but it's really interesting that I certainly shifted all of my attention to Sacramento in '85, and Don Francis chose to request a transfer from Atlanta to California in '85.

So I think both of us, certainly without discussing it with each other, and I don't know if he and I realized that that's what we were doing at that point, decided nothing was happening on a national level; let's go out to California where maybe we can make a difference. I'm not sure we've made a difference in California, but at least that was where the energy was placed for the next five years, through the [Governor George] Deukmejian administration. I think the [Governor Pete] Wilson administration has washed its hands of the epidemic.

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Conant: A national policy on AIDS is needed. I don't quite honestly know why the American public does not understand that. Certainly many of us that are well educated work in large businesses, and those businesses are managed. You have managers, and those managers set priorities, they have goals, they look at their resources, they have time lines, they look at budgets--they do all the kinds of things that any businessman or any housewife does. You've got so much money, you've got so many mouths to feed, you've got to do it over such a period of time, and here's what we can afford to put on the table. That's just basic husbandry.

The way we have responded to the AIDS epidemic is we've thrown money at it. Congress has gone through periods when it's been very, very generous in terms of funding. But the money has gone into the system, and the system is without the leadership to say, "This much money needs to go to look for new antiretrovirals, this much money needs to go to look to treat the diseases that people get, this much needs to go to education, this much needs to go to prevention, and this much needs to go to vaccine development." And then you could take each one of those elements and break it down to how do you do prevention, how do you teach people what to do and what not to do, and how do you change behavior?

AIDS Vaccines

Conant: Take the issue of vaccine development, which concerns me a great deal right now. It's my view that if we don't get a vaccine, we're going to lose a tremendous part of the world's population to AIDS eventually. It's not going to happen overnight; it's not going to be like the Black Death where a third of the population of Europe is dead within two years. That's not going to happen.

But what is going to happen is hundreds of millions of people are going to die over the next decade if we don't find a vaccine to stop the disease. Now, in this country, all of the research right now is going to look at new antiretrovirals, like AZT and ddI and ddC, and that's grand. Except the cost of AZT right now is $2,400 to $2,600 a year.

Now, $2,600 a year is more money than is spent on many African villages for all of their health care for the <u>entire</u> year. We're spending more on one patient than whole villages can afford to spend for their total health care--not just AIDS--of every citizen in the village. So none of those treatments are practical in Thailand, India, China, Africa, and that's where the AIDS epidemic is clearly going.

The only thing that will stop the epidemic in those countries will be an effective vaccine. And the only countries capable of developing an effective vaccine are us, Canada, Germany, Great Britain, and France. If any other country does it, it's going to be by pure serendipity. It's just going to be luck.

Now, the United States can't afford to provide AZT to the world. But we could afford to develop a vaccine. We need it for our own people, it would be cost effective for us, and then we could provide the technology to other countries which could then themselves manufacture it in a cheap, effective way. So that's a goal, an ideal, that's not too hard to see how it could come to fruition.

The problem is that if we go at it as business as usual, we will wait until we have vaccines that are effective, say, in chimpanzees, and then we will start vaccine studies in humans, and then we will go around the world and try to isolate different strains of the AIDS virus to make the vaccine that will ultimately be the one that we will use in humans. Then we will begin to wrestle with the real ethical question of how do you give some people placebo when you know they could catch a fatal disease and die. Then we do field trials, first on a limited basis and then on a more expanded basis, and finally with God's help we will have an effective vaccine.

Now, what I have just described is a process that will take at least ten to fifteen years. By the time you finally get that vaccine, a large portion of the world's population is going to be dying of AIDS. If you want that vaccine faster, you're going to have to use a different paradigm.

Now, we've got the paradigm. We know what to do. When J. Robert Oppenheimer sat over there at Berkeley and came up with the idea for the Manhattan Project, working with [Enrico] Fermi and [Albert] Einstein and others, no one had ever seen if you could make a critical mass. Oppenheimer worked out on a piece of paper what he thought a critical mass would be, and then they persuaded Roosevelt to give them the money, and they cleared off a half a mountain in New Mexico, and they built Los Alamos.

At the time they were putting together the critical mass, a pile of uranium, to see if they could really make that stuff go critical, they were simultaneously designing the atomic bomb. They were looking at the detonating mechanism, they were refining the uranium--in other words, they didn't do it in serial steps like I just described. They came up and said, "This is the end product, a bomb that will do what we want it to do. Here are all the steps we have to take to make the bomb, and we're going to take them all simultaneously so that we can cut what will be a twenty-year development program down to four years." And that's exactly what they did.

If we accept today that a vaccine not only is essential but can be done, and I think most leading investigators do, we need the leadership to set up that kind of project right now, perhaps with Canadian and British and French cooperation, and we could make a vaccine. But without the leadership to do it, and the commitment to do it, and yes, the money to do it, without all of that to do it, it's not going to happen.

Hughes: Instead, we're back to the traditional linear approach with this bill--I'm not sure it's been passed--to finance the testing of MicroGeneSys' gp160 vaccine.[1]

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[1] "Agencies spar over vaccine trial," *Science* 1993, 259:752-753 (2/5/93).

Conant: What happened there--and again, with appropriate leadership, this shouldn't be happening--Bob Redfield, who's a wonderful AIDS investigator, is in the military. He's at Walter Reed [Hospital]. He has been working with MicroGeneSys to make the gp160 vaccine. He persuaded some congressmen to put this huge rider on to develop that one vaccine.

If that vaccine proves to be the one, if that works, we're home free. But the point is, what if it doesn't? We've spent all the money and all the time on a blind alley. Remember that when Oppenheimer and his team were trying to purify uranium, they were doing it in two or three different ways simultaneously, because no one knew which one was really going to work. That's exactly what should be done with AIDS vaccines.

Hughes: They may speed up the process of vaccine development, but it still has to go through the linear testing process.

Conant: That's exactly right. Now, that's where you need leadership. If you could simply bring in a man or a woman with vision who could sit down and say, "Mr. President, this is going to be very expensive, but the price we're going to pay for not doing it is not having markets for our children to sell our products to." We think of things in such isolation. Remember that if Africa, if Mexico, if India, if Thailand aren't there forty years from now, where are we going to find the expanding markets to maintain the standard of living in this country? We can't just sit by and watch the rest of the world die off.

Hughes: That's the economic argument. You would hope the humanitarian argument entered in there somewhere, too.

Conant: Well, you would. Today in Africa, there are 10 million people with AIDS. Now, on a humanitarian level, what are we doing as a nation to address that? As far as I can see, nothing. It's not discussed; it's not talked about; we're not sending freight trains full of condoms over there. We're not doing anything!

But bring that home: we're not even doing anything for our own people. You saw George Bush in the presidential debates on Sunday night say that if people would change their behavior, they could avoid catching this disease. That's only partially true. While it is true that this is a sexually transmitted disease, I think it would be very difficult to tell people, "If you quit having sex, you are not at risk of this disease."

Certainly there are all sorts of other diseases that can be ultimately traced to our behavior as human beings. Cervical cancer in women is almost entirely due to human papilloma virus, so if girls didn't have sex, they wouldn't have cervical cancer. Lung cancer is almost entirely traced to smoking cigarettes, and so if you didn't smoke cigarettes, you wouldn't get lung cancer. Automobile deaths are mostly from driving too fast, okay? And yet we don't tell these people, "We as a society feel that you should behave differently." If you can stop smoking, great, but we don't withhold care or compassion from people who are dying of lung cancer because they weren't wise enough not to smoke.

The argument that, well, if people just change their behavior, the AIDS epidemic will go away, and to some extent they are responsible for their own illness, just doesn't fit with the way we approach other diseases.

Funds for AIDS Research

[Interview 4: November 4, 1992] ##

Shift in Federal Strategy

Conant: There were several central issues of the period of time from 1981 to 1985. One was the failure of the federal government to step forward in a meaningful way. That happened because there was no responsible leadership, responsible meaning someone who was answerable to the president and to the American people. The NIH first said, "We will give money to investigators," and we geared up to that. And then they said, "No, no, we're going to control the money ourselves, and you will become the investigators for us. You will work, in essence, for the government."

So the first significant issue was this major change [in funding strategy]. From my perception, that happened for two reasons. One, the federal government had no one that they were accountable to. The NIH could do whatever they wanted to do. And number two, they began to realize that, "Wait a minute, AIDS is big business. AIDS is something where there are Nobel Prizes to be won and papers to be published and fame to be made, and we, the government, want to retain control over that."

The problem with that is that when the government retains control, it by definition slows down the process. There are very few examples where the government's been in control of something that has moved rapidly.

More on the State of California Allocation, 1983

Conant: Then the second major event was getting to Willie Brown and to the California legislature to get the funding here in the state of California. And that happened fairly quickly. There was a delay in the disbursement of the funds. But that doesn't surprise me terribly, because we're talking only of a matter of months. And you must remember that no one--except perhaps me in my foolishness--ever thought we'd get the money. Everyone else thought that that was just Marc Conant being crazy again. And number two was the university didn't want to have the money.

Hughes: Because of how you had gotten it?

Conant: Right, and the fact that the money was not coming through the usual channels. So they didn't want it, but of course, they weren't going to turn it down now that it was actually at their doorstep.

There was a lot of controversy and a lot of politicking. Investigators from other [UC] centers suddenly were calling in, saying, "Wait a minute, we deserve some of this money as well."

And then there was not a clear-cut allocation of the funds. When the funds were appropriated, it was, "Okay, here's this bundle of money, you distribute it." It was not a line-item budget where Dr. X will get this, and Dr. Y will get that. So in retrospect, I think that the delay [at the university level] is actually understandable, and probably did not cause that much damage.

Now, the infighting for the money was amazing, and the one that comes to mind is a doctor from UCLA. I believe his name was [David W.] Golde. He was an oncologist, as I recall. He had felt that all this exercise was so foolish that he didn't even go to the meeting with Willie Brown in Los Angeles. He was right there in Los Angeles, but he didn't come. He sent an underling who he then perceived was not advancing his cause as strongly as he would have himself.

So he then took it on himself to call Joanne Murphrey, who was Willie Brown's aide, and Willie Brown himself and others, and create a tremendous amount of havoc. I'm not privy to whether he was calling officials at UC Berkeley, but it would surprise me if he were not. And so I'm sure it was pressure like that that was also slowing down the process tremendously.

Hughes: You don't feel that there was an inordinant delay between passage of the money for AIDS research and its allocation by the university?

Conant: No. Remember, we were still in a mindset at that time where we thought that AIDS was going to be like toxic shock syndrome; if we could just get the money, we could find what was causing this epidemic and make it go away. So you're asking me the question a decade later when I now know that there's not going to be a quick fix for this problem.

I'm sure had you asked me that question in the summer of 1983, I'd have said, "Oh, my god, every hour is an hour wasted." But in retrospect, no, that delay does not seem inordinant, nor did it cause any damage.

Had it been that AIDS was a quick fix, if it had been like the Tylenol poisonings which were happening at exactly the same time, and we could have taken all the bottles of Tylenol off the shelf, then the delay would have truly been a tragedy. But unfortunately for all of us, AIDS is a much more difficult problem.

Hughes: Randy Shilts makes quite a point of Jay Levy's failure to get a fume hood so that he could work with retroviruses.[1] Do you think in that case the delay in funding made any difference?

Conant: Well, yes, I do. Again, it's hard to say a decade later. I'll tell you where that did make a difference. Had Jay Levy gotten that fume hood sooner, Jay Levy, rather than Bob Gallo, might well have been the person to first discover the AIDS virus.

Hughes: Yes, that's what I was wondering, because he was pretty close as it was.[2]

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[1] Shilts, pp. 173-174. Also see the oral history in this series with Jay A. Levy, M.D.

[2] Levy published a paper on the isolation of the AIDS virus in August 1984, confirming the previous work of the Montagnier team (published May 1983) and the Gallo team (published May 1984). Since Gallo et al. are now believed to have been working with the French virus, Levy claims that he was the second to isolate the AIDS virus. (F. Barré-Sinoussi, J.-C. Chermann, et. al. Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS). *Science* 1983, 220:868-871; R. C. Gallo, S. Z. Salahuddin, et. al. Frequent detection and isolation of cytopathic retrovirus (HTLV-III) from patients with AIDS and at risk for AIDS. *Science* 1984, 224:500-503; J. A. Levy, A. D. Hoffman, S.

Conant: Yes, he was very close. Had he had the funding immediately--one can never know. "Those saddest words of tongue or pen, the saddest of those it might have been." (Maude Muller) It might have been that Jay Levy would have been first.

Had Levy discovered the virus first, the significance to people with AIDS would have been as follows: we would have had the ELISA test to test the blood [for HIV] many months sooner. And so instead of 15,000 people infected by transfusion-associated AIDS, that number might have been considerably lower.[1]

Conference on Kaposi's Sarcoma and Opportunistic Infections, Sponsored by the National Cancer Institute [NCI] and Centers for Disease Control [CDC], September 15, 1981

Hughes: Is there a story to be told about the staging of KS? And I wonder if that ties in with a conference you went to at the NCI on September 15, 1981, where they were already talking about opportunistic infections.[2]

Conant: They were, yes. I'm not sure there's much to talk about, or at least to talk to me about, in regard to staging Kaposi's sarcoma, because I'm not clear that's even today been done and been done well. The reason for that is the skin is a very, very difficult organ on which to stage a disease, since it covers the entire body. It's very difficult to deal with the skin the same way you deal with, say, the liver, or the colon.

That meeting you refer to was held in September of 1981. It was very early in the epidemic. I had to finagle an invitation to that meeting. They didn't invite me. I found out that the meeting was happening, and I called someone (I cannot as I sit here recall who) and said, "I want to go to that meeting, and I'll pay my own way if I have to, but I want to be there." I then immediately received an invitation, and they paid my way, which points out that if you want something, you better go try to get it.

M. Kramer, J. A. Landis, J. M. Shimabukuro, L. S. Oshiro. Isolation of lymphocytopathic retroviruses from San Francisco patients with AIDS. *Science* 1984, 225:840-842.)

[1] Transcripts of a discussion of *Pneumocystis* patients which followed were moved for better continuity to the section on the KS Clinic.

[2] Shilts, *And the Band Played On*, pp. 93-94.

Al Friedman-Kien was there, [Vincent] Devita chaired it, and Mike Gottlieb, who had described the cases of *Pneumocystis*,[1] was there. So many of the heavy hitters were there at that first meeting. Paul Volberding couldn't go, but John Ziegler was still at the NCI, and it was at that meeting that I first met John. I knew he was coming to San Francisco, and invited him to join us here, and he did that.

The virologist [Werner Henle] that they had, who was internationally well known, was the guy who described Epstein-Barr virus, and his wife [Gertrude (Brigitta)]. They were both there.

Hughes: What actually happened at the meeting?

Conant: Not much.

Hughes: What was supposed to happen?

Conant: That's a very good question. I think, like many government meetings, they didn't have an agenda. They didn't have an outcome. The government often sponsors meetings just for process: "Let's bring everybody together and let them talk, and then we'll send them home and see if anything happens." It was certainly not clear to me that they had an agenda.

My agenda at that meeting was to meet as many experts as I could from around the country, and to begin to ask the questions about federal funding to get the studies that we were interested in here in place, and to start knowing who I had to talk to at the national level to get that done.

Hughes: Does the fact that you were not initially invited mean that they were unaware of what was going on in San Francisco in terms of KS research?

Conant: Probably.

Hughes: Hadn't you been in touch with the people at the CDC?

Conant: Oh, yes. I had actually taken the people at the CDC to dinner by that time.

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[1] *Pneumocystis* pneumonia--Los Angeles. *MMWR* 1981, 30:250-252 (June 5, 1981).

Attempting to Influence Washington

Conant: You know, it's not surprising. I have found through this whole epidemic that there is a very widespread myopic view in Washington--and this includes the NIH--that anything west of the Mississippi River is almost in a different country, and perhaps on a different planet. If you look at the whole history of the AIDS epidemic, what's happened in California has happened in California, and then the rest of the nation has responded to that, yet California has not been part of the decision-making process in Washington.

It's much like the election last night for president. By the time the California polls closed, the election was already decided. Now, we all went and voted, because one, we wanted to be recorded, and two, we had our own local elections to care about, but we were really totally superfluous to the presidential election. We would have had Mr. Clinton regardless of whether anyone in California ever moved themselves to go to the polls or not.

Well, it was the same way with AIDS, and it has been the same way with AIDS. California has had very, very little direct input into what's happened in Washington, and at the NIH, at a policy level for AIDS.

A period of time came about '86, '87, when I got real depressed and thought of moving, of quitting. I thought I couldn't do this any more. One of my job options, and I actually went so far as to interview back at NYU [New York University], was to give up my practice here, take a paid academic position at a university in New York, where I would prefer to live rather than Washington, with the idea of working half-time, say running the sexually transmitted disease clinic or dermatology clinic, and spend the other half-time in Washington as a junior member of some legislator's staff or as a lobbyist or as a consultant. It was my view that I was never going to get it done in California. I had to move back there and be part of that New York-Washington axis, and be able to get on a plane in the morning and fly to Washington and do a day's work, and then fly home in the evening.

In California, if you want to have an impact in Washington, you've got to take three days out of your life. Because by the time you fly back all night long, you're a basket case--I was doing that in '83. I'd fly to Washington and testify. I'd literally catch a flight out of San Francisco at the end of my day and take a red-eye overnight flight. I would fly to Chicago, because it was easier to fly to Chicago, change planes in Chicago, and then fly into National [Airport], take a cab across the Potomac [River], testify for two hours, and turn around and come back to California to try to see patients the next day. But I was still losing a full day in flight, and I was not as effective as I might have been when I testified, because I was bleary-eyed from being awake all night on a plane. I think I did that four or five times in the summer of '83.

The NIH at this point in time was dealing with AIDS as if it was a problem that they and the CDC were going to solve, and that these doctors in California at this medical center were kind of in the way--just the way the government views the citizens. [laughter]

Hughes: Two of the three original centers in the epidemic were in California. You would think that would have made some difference.

Conant: We had some of the country's leading scientists right here. We had the ability to really move. And we had other things, too. We had a community here that was supporting what we were doing. The gay community from the very first has been incredibly supportive of everything we've done. That's true not only here but in Los Angeles. We had a state government that was supportive of what we were doing. There were no political obstacles. And we didn't have the infighting that many of the centers on the East Coast have. Everybody was fighting over who was going to get the Nobel Prize.

California's Cooperative Approach to the Epidemic

Conant: One of the real strengths of the group, at least here in San Francisco, and I would hope in L.A., was that all of these strong personalities were able to meet and work together, and they weren't at odds with each other trying to see who was going to get the prize for being the first.

Hughes: How do you explain that? Why did it work here and not elsewhere?

Conant: Well, one would like to believe that California is a saner place to live than elsewhere. I don't know that that's all. I think we had a group of incredibly dedicated people who from the beginning realized that what was at stake here in terms of the quest for a way to cure this disease was far more important than anyone's particular career. That was articulated often.

I can remember a meeting I attended right at that period [1982]. It was a meeting called by someone at the university [UCSF], and it was to talk about how we in the university should deal with patients with this new disease, in terms of labeling their doors, and should they wear special red coats when they're rolled down to x-ray so nobody would touch them. You had in this room the whole spectrum. You had people who had never heard of the disease, you had people who had heard of it and didn't care, you had people who were ready to quit their jobs because they were so terrified. This was at the point where doctors were literally quitting and moving out of San Francisco, and nurses were quitting their jobs because they did not want to be near these patients. So we had reactions all the way from indifference to hysteria in this room full of people, and they were going to have to make decisions.

Well, I was called in, and I sat there, and the discussion started, and again the hysteria started. Hysteria has a way of raising the [emotional] level in the room. You could feel the whole level just going up and up and up. And you sit there thinking, Oh my god, this is just going to deteriorate into madness. It got to be my turn to speak, and I said, "You know, the most critical thing I think for all of us to realize is that whatever we do in this room today is going to influence what everyone does in the country. So we have a tremendous opportunity to really bring reason to a very, very charged issue."

It was amazing. It was like suddenly everybody said, "Oh, I see. I've got to act like an adult." And they changed--it was absolutely astounding--because someone pointed out that what they did was really going to make a difference, and they shouldn't indulge their own hysteria, fear, whatever. It was truly astonishing to watch it. It's like kids fighting and then mama tells one, "Now, you've got to be in charge," and the kid becomes very, very responsible. Well, I think that was one of the things that happened with physicians here.

Early on, because of the size of the gay community and the fact that lots of the physicians involved were themselves gay, the tone of those early meetings was, "This is <u>really</u> an important issue. This is more important than whether you're the first on the paper, or whether you get the Nobel Prize, or whether you get rich and famous. We're talking about something that's affecting the lives of people you love or you care about, or a whole community." Perhaps in other cities where there was not that sense of community, those kinds of pressures were not brought to bear.

Hughes: Certainly with the people that I've begun to talk to, I can't help but be struck by the personal commitment that the pioneers seem to have had.

Conant: And it was true.

Experiences Preparative for the Epidemic

Hughes: Dr. Volberding talked about how his experience with dying cancer patients prepared him for dealing with AIDS patients, and Selma Dritz apparently had very good rapport with the gay community.[1]

Conant: Extremely good.

Hughes: It was almost as though these people were in place and ready for this terrible epidemic. They had not only the scientific background but the emotional background for it. I like to think that personality has an impact on history.

Conant: Well, I had a discussion last night with an extremely bright woman whom I had the opportunity of hearing speak yesterday, and we were talking about fate. I had seen the epidemic of genital herpes that we've talked about. I watched how I responded to that and had a chance to critique that response and say, "Wait a minute, I wish I had that to do over again; that's not the way I should have done that." That experience directly molded how I responded to this epidemic.

But there was even more. If I had been a twenty-five-year-old physician rather than a forty-five-year-old physician when the AIDS epidemic began, I wouldn't have had the time to devote to AIDS that I have had for this decade. I was at a point in my life where I could say, "Okay, I'm making a good living. I can relinquish income to go work on this issue."

As a matter of fact, I had to actually pay for some of the early research. Again, as a twenty-five-year-old, I would not have had the money. The first fund raiser we had in the Castro was a dog show. [laughter] Honest to god, a dog show. Frank Jacobson decided that the KS Foundation would sponsor the dog show.

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[1] See the oral histories in this series with Paul A. Volberding, M.D., and Selma K. Dritz, M.D., M.P.H.

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Conant: We had our people passing the hat. I think we had the Sisters of Perpetual Indulgence raising money for us. Have you ever seen these guys in drag?

Hughes: I have. [laughs]

Conant: Well, I'm walking around the Castro in a three-piece suit and a tie, and here are the Sisters of Perpetual Indulgence. Early in the AIDS epidemic, I often felt like I was living in a Fellini movie.

We did not raise enough money to pay for the stage that had been put up to show the dogs on. [laughter] Dr. Conant had to reach in his pocket for $1900 to pay the difference between the cost of putting on this event and what we raised. Had I been twenty-five years old, not only could I not have done it, but that would have been the last fund raiser I ever did. [laughs] Because I would have said, "Wait a minute, this is getting too expensive."

Bringing Respectability to the Epidemic

Conant: I had been at UC for about seventeen years when the AIDS epidemic began. I had been very visible; I had been on every committee; I had been on the UCSF executive medical board [1974-1976]; I'd actually been asked to be chairman of the executive medical board and declined that; I was already a full professor; I was extremely well respected and liked. I could come out and deal with an issue that concerned gay men, and not have all of my peers and colleagues at the university totally distance themselves from me. In other words, I had paid my dues. I was part of the in group. It was not some young kid dealing with all those gay men, and, "Oh my god, I wish he wouldn't bring them to our hospital." It was in fact a respected member of the faculty who had the patients.

Again, had I been a twenty-five-year-old, if I had not been positioned by seniority and longevity [at the university] at that point, I could not have been nearly as effective. All of that came to bear for all of us. All of us were at points in our careers where we were ready for this new challenge.

John Ziegler had worked in Africa on Burkitt's lymphoma, had won the Lasker award for his research, and that very first year, 1981, took the job as associate dean of the VA [Veterans'

Administration] hospital here in San Francisco. So here you had this man whose whole career had been working on Kaposi's sarcoma in Africa, who moved to San Francisco in the first six months of the epidemic. Truly fate. John was extremely effective at bringing respectability to an epidemic that the university didn't want anything to do with.

As we've talked about before, the leaders of the university would have just as soon never touched AIDS, and that's absolutely clear. They viewed it as a disease that "those kinds of people" get: it's a sexually transmitted disease; "nice" people don't get sexually transmitted diseases; we should send it to the county hospital [San Francisco General]--which they did. The reason was not that the county had more space, but that people with STDs don't have any money and they ought to go to the county hospital and sit on a bench. That mentality was there from the very beginning.

The University's Reaction to AIDS Patients

Conant: People like John Ziegler were able to bring respectability--but not enough that it made AIDS a mainstream UC disease. The AIDS clinic at UC is still a very, very small clinic.[1] And at other UC campuses, like UCLA, they didn't have a county hospital to send the patients to. That's why Mike Gottlieb had to leave UCLA eventually; they did not support research on or the care of AIDS patients.

Hughes: Because UCLA did not want to deal with AIDS patients?

Conant: Yes. As a matter of fact, though I have never seen documentation of this, but it is a widely held belief amongst AIDS experts who were there at the time, there was a meeting held at UC Berkeley sometime in the early 1980s, probably in '82, where a decision was made that they would in fact move AIDS cases out of the university hospital to the county hospital, or to some other location. Here in San Francisco, it resulted in the AIDS clinic at San Francisco General. At L.A., it resulted in Mike Gottlieb leaving the university and going into private practice, because there was no place for AIDS patients.

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[1] The AIDS clinic at UCSF is officially and deliberately named the Adult Immunodeficiencies Clinic.

I do know the reasons why they chose to do that, because I was party to discussing with some university officials some of their misconceptions about AIDS patients. There were three things that they were worried about. One was, these patients don't have any money, so they will not be paying for hospitalization. Well, while the university hospital has been very generous in terms of taking care of indigent patients, they didn't want to create a clinic that would attract large number of patients that they perceived as indigent.

The second thing the university was worried about was the notion that, If those kinds of people with that kind of disease come here, other doctors will not send their patients here if it is known that we have AIDS patients in this hospital. It's like, if you're practicing in Fresno, are you going to send your patient to a hospital where they have leprosy patients?

The third thing was the concern that, We will not get medical students coming here as interns or residents if they perceive they might catch AIDS and if they perceive that there's so much AIDS in San Francisco that that's all they're going to learn. They're not going to learn heart disease or diabetes. They were planning to go back to practice in Billings, Montana, where there was no AIDS, and in those days they thought there never would be AIDS, because of course "those kinds of people" don't live in Billings, Montana. Their medical education here would have been superfluous.

Where I was involved was to confer with Mr. [William B.] Kerr who was and is the head of UC Hospital. We were collecting data at the San Francisco AIDS Foundation. When people would call in for information, we would say, "Do you have insurance?" We had written data that showed that 60 percent of the people inquiring about AIDS had private medical insurance. So the notion that these people were not insured we knew from the very beginning was not right. I was giving Mr. Kerr that data in an effort to try to convince him that UC should be more proactive in recruiting these patients.

Hughes: Were you getting through to Mr. Kerr?

Conant: No. [laughter] While UC has been very supportive of AIDS services at San Francisco General, I have been disappointed, and have publicly stated so on a number of occasions, in the response of the senior UC hierarchy--the faculty, from the dean right on down--to the AIDS epidemic. Now, some of that is just the reluctance of academics to become involved in the political process. The notion is that, I shouldn't go to Sacramento and try to lobby the legislature. And some of it, of course, is just a reluctance to acknowledge and deal with an epidemic that's happening in the city. Which is tragic.

Hughes: There's an ivory tower aspect to it, isn't there?

Conant: Right.

Hughes: We look the other way and somebody else will take care of the epidemic.

Conant: Or we'll just sit up here, and we'll study aspects of it, but we won't get down there with the people and become involved in actually trying to provide the solution to this problem.

Hughes: Which is <u>exactly</u> what you and your colleagues were doing.

Conant: That's exactly what we were doing. And that was the vision. We knew we were doing it, and we did it for that purpose. That's why we had the KS Clinic. The notion was, we are going to create this clinic and bring people from other disciplines together on a weekly basis and force a discussion of this issue, and try to disseminate information as quickly as possible.

Hughes: It also explains the passion, don't you think? If you're in an ivory tower, it's hard to feel the urgency of the epidemic.

Conant: No question about it.

Hughes: But if you're dealing with patients in dire straits on a daily basis--

Conant: And I did that, and consciously did it. I have tremendous respect for Jay Levy, but Jay's off in a virology lab all day long. You bring in to the clinic some twenty-eight-year-old boy, and he doesn't have to say a word; you can look at his face and tell he's terrified of what's happening to him.

You say to him, "Where are you from?" and he says, "Well, I grew up in Austin, Texas," and suddenly there's this human being talking to you. It's not "AIDS" or "Kaposi's sarcoma," it's your kid. And you can watch the faces of the people as they begin to realize this could be their kid. How you bring urgency to this thing is you force physicians to actually look this disease in the face. It's very effective.

The Interferon Trial at San Francisco General Hospital, 1982

Hughes: There were several interferon trials at San Francisco General, beginning in 1982. Could you tell me about them?

Conant: I can't. The person you need to talk to is Paul. As I recall, I'm on the papers, and I provided some of the patients for that trial and actually can remember seeing some of them.[1]

Paul [Volberding] and Don Abrams conducted that trial, as I recall, and that was clearly Paul's trial. And as I recall, he conducted most of that trial out at San Francisco General rather than at UC. So my participation in that trial was purely tangential.

It was a very interesting trial, because they were using massive doses of interferon, much higher than we use today. I believe one of the arms of that trial had ninety million units of interferon three times a week, which is just astoundingly high. A reasonable dose of interferon might be something like three million units three times a week.

Paul Dague, the psychologist that I loved so much, was in that trial. I can remember him coming to my office on Parnassus [Avenue] one day, and he described what the side effects were like. He looked up and he said, "I'd rather die of Kaposi's sarcoma than stay in this trial." I realized how really sick it was making him. It was just making him sicker than hell.

Hughes: Did the interferon come from Genentech?

Conant: No, it was not Genentech at that time, and I don't know. It's my recollection it was Schering.

Gaetan Dugas

Hughes: Do you care to say anything about Gaetan Dugas?

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[1] P. Volberding, M. Gottlieb, J. Rothman, S. Rudnick, M. Conant, M. Deresin, W. Weinstein, and J. Groupman. Therapy of Kaposi's sarcoma (KS) in acquired immune deficiency (AIDS) with alpha-2 recombinant interferon (IFN). *American Society of Clinical Oncology Proceedings*, 1983, 2:C[?]-206 {check pages].

Conant: Yes, I'll tell you something about him.

Hughes: You saw him in April, 1982 for the first time.[1]

Conant: Well, let me say first that when Randy Shilts found out that there was such a patient, Randy went nuts trying to get the name out of me as to who the patient was. Randy and I by that time had become close friends, and of course, I was trying to give him as much information as I could. But I wouldn't give him Gaetan Dugas' name. I can remember calling Randy one day and he said, "You don't have to tell me. I've got it." So I don't know where he finally got the name from, but he got the name.

The young man [Dugas] saw me after he had for a time been reported to the KS Foundation. The first I learned of him was when I was chairman of the board of the KS Foundation. We had a hotline which was well advertised in the [gay] community. If you wanted information about AIDS, then called Kaposi's sarcoma, you would call this number. That's the number where we would talk to them about insurance. We'd say, "Do you have insurance, and what kind is it?" Then we'd say, "If you don't have insurance, go get insurance right now." There are thousands of men today in San Francisco who are getting cared for because of that advice. That was probably the best advice we could have given. That [hotline] was Frank Jacobson's idea. He put that in place, and it was absolutely brilliant.

Well, this young man, this young Canadian, would come to San Francisco, and he would have sex. He was very perverse about it. He would do it with the lights out, and then after they had concluded the act of sex, he'd stand up and cut the lights on. He was covered with lesions of Kaposi's sarcoma. He'd say, "I have the gay cancer, and I'm going to die, and you probably have it too." And he would leave. I have talked subsequently to the man who he used to room with when he came here, an old friend of his who he would stay with. The friend would say that he was just absolutely obsessed with sex. He lived to have sex. That was the thing.

Tom Coates and Leon McKusick have taught us that there are people who are sexually obsessed, and that when they get stressed or frightened, what they do is they have sex. Now, think about that in terms of the AIDS epidemic. For those of us who have trouble dieting, when we get stressed, we go and eat. And for those of us who smoke, when we get stressed, even when we know we shouldn't, we go out and have a cigarette.

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[1] "Chronology of Marcus Conant's AIDS Involvement," unpublished document [n.d.] obtained from Conant's office staff.

These people, when they get frightened about dying of AIDS, go out and have sex as a way of dealing with it. And as I look back at that young man, unfortunately I think that was the pathology. It's hard to say that he was a wicked, evil person. He probably was truly obsessed with sex, was terrified of what was happening to him, and used sex as a way of dealing--as perverse as it is--with his own anxiety. He did see me in consultation on at least one occasion I can remember, perhaps two. The only thing that I can remember being struck with was how attractive he was. He was a stunningly beautiful man, just truly, truly one of those people whom you want to immediately hold, because he just looks so sweet.

I called Al Friedman-Kien in New York shortly thereafter, as memory serves, and I said, "I know he's here in town having sex because the hotline for the foundation is getting calls, `What can we do?'" Al said, "We've called the New York police. We can do nothing. There is nothing that can be done." There is no quarantine law; there is no way that anything can be done. In retrospect, the director of public health probably could have had him restrained. But of course, he was a flight attendant; he would have just left town.[1]

The Bathhouse Episode

[Interview 5: November 6, 1992] ##

Preliminary Events

Hughes: Dr. Conant, the bathhouse issue began to simmer in the first months of 1983. Do you remember when you first began to speak out publicly on the issue of closure?

Conant: The first recollection that I have was probably a talk I gave at the Harvey Milk Gay and Lesbian Democratic Club in the spring of 1983. That evening, I was invited to talk about AIDS issues in the community. I can remember it, because the talk, like many of my talks, got a lot of criticism. My message was, I've spent a lot of time in the last year criticizing physicians for not being interested in the epidemic, and criticizing Washington for not making the commitment that it needs to make. I think that the gay community needs to look at itself and see what role it's playing

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[1] Transcripts of the remainder of this session were moved for better continuity to the section on the KS Clinic.

in the transmission of this disease--what's going on in the gay community that is causing the epidemic to continue.

Bathhouses were clearly one of the foci, where people were going late at night, after having had a lot to drink, and having anonymous sex. That's what they were there for. And everybody was having a great time. The problem was that they were walking into bathhouses and getting infected.

I can recall about that same time seeing a patient who was a young Ph.D. scientist from the Peninsula [south of San Francisco], a very good-looking man with Kaposi's sarcoma who I was caring for. He had AIDS. He was sitting in my clinic on Parnassus. He was kind of impatient. I said, "I'm sorry I'm running late; I can tell you're impatient. What's wrong?" He said, "I wish you'd hurry up; I'm going to the bathhouses." My reaction was, "Wait a minute."

See, I was being a typical physician. We all in this society forget--and I think physicians are the worst--that when people are diagnosed with a fatal disease, all of the desires and longings and drives that they had the day before they were diagnosed are still there. Everybody believes that patients who are dying of AIDS are no longer sexual. I have patients that have sex the day before they die. I encourage them to do that. And people believe that women who have had breast cancer are no longer intimate or have longings to be intimate. We need to begin to relate to people and realize that those human, very human, desires don't go away because you have now had a label of "AIDS victim" stuck on you.

But being the typical doctor, it just never occurred to me that he was still out there having sex. He had Kaposi's sarcoma--AIDS, this horrible new, fatal disease. My line to him was, "Somebody must think you're smart, because they gave you a Ph.D. How come you're still going to the bathhouses?" He said, "There's nothing wrong with that. I probably caught it there, and so my view is, it's there and I'm going to have sex." I said, "Are you telling the people that you're having sex with that you're HIV-positive"--it wasn't even called HIV then--"that you have AIDS?" He said, "No. I figure that they ought to be smart enough to understand that there's AIDS out here, and that they can catch it. It's their responsibility as much as mine." I think that that, more than any other single event, called into focus for me the notion that someone needs to speak out.

About the same time--I can't remember if it was before or after as I sit here this afternoon--I went with Ernst Jansen to Santa Cruz to go to the beach and to ride the rides one beautiful summer day. We got on that rickety old roller coaster that they have down there. We were riding up this thing, and I'm terrified. I'm thinking, "I'm going to get killed right here for something I don't even like doing anyway." Then I said to myself as I rode along, "Well, if it weren't safe, `they' would probably close it down." As the thing went over the crest and started down that run, I thought, "I wonder who `they' are?"

And I thought of that patient going to the bathhouse. "Wait a minute, I'm the `they'. I'm the responsible authority in society, about whom society is saying, `If the bathhouses are not safe, `they' would close them down,' and I'm the `they'. I have a responsibility to speak out about this thing and to say, `They are not safe.'"

I can remember one presentation during this period of time in which I said, "What would you do if you were a young, beautiful kid from Iceland who had always wanted to come to San Francisco, and you were gay. You arrive here in San Francisco, you go to the Castro, you pick up the *BAR* [*Bay Area Reporter*], and you learn that there is this wonderful bathhouse south of Market. You're kind of frightened; you've heard about this disease, but the disease seems minor to your fulfilling your dream of a lifetime of an evening of mad sex with all these beautiful men in this bathhouse. You walk in, and there's a sign at the door that says, `Beware. It is not safe in here. There's a fatal disease.' At least that young man walking in the door would know what he was walking into." But at this time [1983] there was no sign. There was no warning. And I said, "Shouldn't we at least post a sign that says, `Enter at your own risk'?"

So that began the debate about bathhouse closure. The debate, as you know, went on for many months, culminating in a meeting with Merv Silverman, where Merv agreed to close down the baths.[1]

There was a great deal of debate surrounding that. It's got to be remembered that this didn't just happen in a vacuum. There was a lot of discussion with different groups. Merv Silverman had a meeting once a month in his chambers at the city department of health, and I had been on that committee [AIDS Medical Advisory Board to the Director of Public Health] from its inception. We had debated for months before, years before, the safety of the bars, the safety of the bathhouses, what should be done with

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[1] See the oral history in this series with Mervyn F. Silverman, M.D., M.P.H.

people who we knew were positive, who were going out and having sex--all of the various issues that arose.

I can remember telling Silverman a year or two before, "No, no, you don't have to close the bathhouses. If we do our job with education in the community, the bathhouses will close by themselves. People will understand it's just not safe to go in there." But by the time that young patient told me that he was going and having sex, it was clear that that wasn't happening, that the denial was there, and that people were not going to listen. So Silverman said yes, he would consider closing the bathhouses.

Meeting with the Mayor

Conant: Dianne Feinstein called me and invited me to have lunch with her. We went to Modesto Lanzone's and had lunch. I can remember saying to Feinstein, "Mayor, I want you to understand, and I hope you would agree to join me, that the day we cure AIDS, I'm going to be down there lobbying to reopen the bathhouses. I'm not opposed to the bathhouses; I'm not opposed to what goes on in the bathhouses. As a matter of fact, I think the bathhouses are a great idea. As a physician, I want to see the bathhouse closed because people are catching a fatal disease in there."

I was looking at her face and realizing, "Uh-uh, she doesn't understand what I'm talking about at all," because it was this look of, "He must be out of his mind if he wants to reopen the bathhouses."

Hughes: So it was a moral issue with her?

Conant: That's what I assumed. That's not fair to her, because she needs a chance for rebuttal.

Hughes: Well, maybe it was dual. You made the observation that because she was the daughter of a physician, she was open to a medical argument.

Conant: She may have had both feelings. That's certainly possible. Anyway, yes, it was my feeling at the time that there was a moral judgment there, that she thought bathhouses were wrong or immoral and should be condemned, and that if closed, that would probably be good riddance. And that was certainly not my view.

Anyway, as you know, it all culminated one crisp morning when we were sitting up at City Hall meeting with Merv Silverman, and he had decided to go meet with the gay community. He had gone to a meeting the evening before at what became the Valencia Rose out on Valencia Street with the owners of the bathhouses and a number of activists from the gay community, including the executive director of the San Francisco AIDS Foundation, which I had started. [laughs]

When the foundation found out that I was speaking out openly that the bathhouses should be closed, and that we had enlisted the support of Dr. Silverman to use the power of his office to say, "This is a public health threat; I'm going to close them," members of the foundation actually called the meeting with Silverman and the bathhouse owners that evening.

Well, Merv called me and asked me to attend. I said that I didn't want to attend that meeting, that I didn't think it was useful to go into a meeting with people you were about to put out of business to try to listen to their arguments, because I thought it would just lead to unnecessary fights. That's not a time you try to bring reason to the table. It seems a little Machiavellian. You've made a decision, you know what you have to do, and you don't then sit down with the condemned man's family to listen to arguments after you've already made a decision to execute him. I didn't go to the meeting, and Silverman did. He was very disappointed that I didn't come, and told me so.

Silverman Postpones Bathhouse Closure, March 30, 1983

Conant: The next day, we went to City Hall. The chief of police put a bulletproof vest on Silverman in my presence. I asked why I wasn't getting one, and he said, "Oh, this is just a precaution. You don't need this." We walked across the street from City Hall to the meeting with the gay activists, and there was this group of screaming, yelling people. This was not a meeting where one was going to find reason or middle ground. This was obviously a group of people who came with a preset agenda, and that was to dissuade Silverman from the action that he had committed himself to take. There were people dressed up as bathtubs with signs that said, "Out of the tubs and into the shrubs." They were arguing that sex would be far more dangerous in the parks than it was going to be in the bathhouses, which was really tangential to the primary thesis.

Carole Migden and I decided that it wouldn't serve any purpose to go into that meeting, so we left. And during that meeting, Dr. Silverman changed his mind and decided not to close down the bathhouses.

Hughes: Because of the strength of the protest?

Conant: I think so. I think the strength of the protest the night before from the bathhouse owners and that meeting of the gay activists clearly dissuaded him.

Now, you've got to understand Merv Silverman. I do, and I respect Merv. But he was not the right man at that moment in history. Merv Silverman is a man who truly likes to act when there's consensus. Merv Silverman, I've always said, comes from a point of view of the Peace Corps, where you sit down a group of very reasonable, highly motivated, idealistic people, and you all search eagerly for the solution to a difficult problem. I saw that over and over in the meetings that I had with him, where he was searching truly for consensus. Consensus in the true meaning of the word: not a majority opinion, but a point where everyone agrees on a position that they can adopt. Clearly, if you've made a commitment to close the bathhouses, and then you invite in the people who oppose that position and the bathhouse owners who are facing certain bankruptcy, you are not going to reach consensus.

Hughes: No. [laughter]

Conant: And so, as I saw it at the time and as I see it now in retrospect, while Merv Silverman was and is a wonderful man and a man I consider a friend, many of us have talents that we should use in certain places at certain times, and that was not the time that Merv Silverman should have been in that position. And I'm sure that it made him very uncomfortable to be in that position.

He backed off. It finally went to the courts, and the courts ruled that the bathhouses could stay open if they met certain conditions, which included that people could not have sex there unless they took certain precautions, which was not an unreasonable position for the courts to take.

Closure and Reopening[1]

Hughes: Closure actually occurred on October 9, 1984, and I believe the meeting when Silverman was expected to close the baths but didn't occurred on May 30.

Conant: That's right.

Hughes: What happened to his philosophy in those few months?

Conant: Oh, I don't think his philosophy changed at all. I think Merv Silverman was committed to closing the bathhouses. I think Merv Silverman's personal position to close the bathhouses probably antedated mine. I think he was waiting for consensus to act. He thought he had consensus in May when I finally came and said, "There are lots of leaders in the gay community who will join with me in supporting you to close the bathhouses. Carole Migden," and the list went on and on.

Merv thought he had consensus at that point. He certainly had consensus of a few of us. But when the other people in the gay community started speaking out against the closure, and the bathhouse owners did, he realized he didn't have consensus, so he stepped back from the position. Then he waited until the courts told him to act, you see. So all through the summer was the court hearings. The May to October delay, as I recall, was all because it was now in the courts.

So I don't see that Merv Silverman ever changed his position. I think Merv viewed that his role was to be a leader who didn't act until there was consensus, or a direction from the courts, or some other mandate to act. As I say, my criticism is, I think at that point in history--and we've had two or three of these crises in the AIDS epidemic--what you needed was a man or woman of courage and conviction who said, "This will be an unpopular step, but we must often take unpopular steps, and I'm going to take this one, which is to close the baths." Had Merv Silverman on May 30 of 1984 stood up at City Hall and said, "I hate to do this; the people around me, many of whom are gay, hate to do this; but we have a disease that is killing people, and I am closing the

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[1] See Conant's declaration in support of a temporary restraining order to close the bathhouses, 10/9/84, Superior Court of the State of Califorina in and for the City and County of San Francisco. (Dean Echenberg papers, San Francisco Department of Public Health, Bureau of Epidemiology and Communicable Disease Control, drawer: bathhouses, folder: 10-10-84 Declarations in Support, vol. 1.)

bathhouses of San Francisco," it is my view that the bathhouses of the world would have closed within a week--world-wide.

As it is, there are bathhouses still open today. I'm not sure that today, it's wrong. Here we are a decade later; gay men have sex world-wide; they know about safe sex; they really know what to do. So that young boy from Iceland that I mentioned a few minutes ago now knows he better use a condom or he's going to die. So I'm not certain that today even I would say that the bathhouses should be closed, because we have now been far more successful in education.

Clearly from 1984 until some time after Rock Hudson died [1986] AIDS was not yet even in the national consciousness. We didn't have an HIV antibody test [until 1984]. Nobody knew who was positive and who wasn't. In this early period, closure of those bathhouses would have been a dramatic education statement for the public that this epidemic is a serious problem.

Hughes: When bathhouse closure actually did occur in San Francisco in October of 1984, was it quickly followed by closure in New York and Los Angeles?

Conant: No. As I recall--and you really need to research this--when the courts finally acted, they only said that they would close the bathhouses if they didn't take certain steps.[1] And so of course, most of the bathhouse owners took those steps. So the bathhouses didn't close and go out of business; they died on the vine. They slowly couldn't make money, because people weren't going to pay ten bucks or something to go there and not be able to have a good time. In New York, the major bathhouses did the same thing. But again, it was a slow process of attrition rather than a dramatic public health statement.

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[1] Six of the fourteen bathhouses and sex establishments closed by Silverman's public health order opened the next day. The city obtained a temporary restraining order and the institutions were again closed. At the preliminary injunction hearing, the judge ruled that the establishments could remain open if they did not allow sexual activity and made specified changes in their physical structures. Mervyn F. Silverman. "AIDS--past, present, and future issues." In: *Charting the Future of Health Care: Policy, Politics, and Public Health*. Jack A. Meyer and Marion Ein Lewin, eds. Washington, D.C.: American Enterprise Institute for Public Policy Research, 1987, pp. 149-159, p. 157. Dennis J. Opatrny. "Judge disqualifies himself; sex clubs stay open, for now." *San Francisco Examiner*, October 12, 1984.

Hughes: As I understand it, Silverman closed fourteen sex establishments, and within hours six reopened. Seven weeks later, on November 28, a San Francisco superior court judge by the name of Roy Wonder ruled that the baths should reopen to achieve a balance between civil rights and public health. He also ruled that they had to be monitored every ten minutes for unsafe sex practices.[1]

Conant: That's my recollection, too.

Hughes: Randy Shilts maintains, just as you said, that it was a gradual attrition after that.[2] That yes, the baths were open, but people didn't want to go there anymore.

Conant: That's right, because they couldn't have a good time.

As an aside, an attorney friend here in town, Sarah Burgess, and I were talking about the bathhouse issue. Sarah recalled that a young male attorney friend of hers walked in to her office shortly after the issue of bathhouse closure came up and said, "That damn Marc Conant. I'm going to fight him to the wall, because he's trying to close the bathhouses." She said he did. He was one of the advocates to try to keep the bathhouses open.

But he told her years later, while he staked a great deal of his personal time in fighting the issue, that he never went to the bathhouses again. So you know, the whole issue in retrospect really was useful. It wasn't nearly as useful as if in fact Silverman had acted sooner to close the bathhouses. But looking back, I don't regret my stand, though it was very painful, because you hate to be vilified by the very people you're trying to help. It was a very painful experience, because I and others who joined me were portrayed as evil people who were moralistically opposed to the bathhouses--which was <u>not</u> true--and who were trying to injure the gay community. So it was a painful experience, but in retrospect it was probably the right thing to do.

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[1] Charles Perrow and Mauro F. Guillén. *The AIDS Disaster: The Failure of Organizations in New York and the Nation*. New Haven: Yale University Press, 1990, p. 29.

[2] Shilts, *And the Band Played On*, p. 498-499.

The Traitors' List

Hughes: One of the most vivid examples of that opposition, I believe, was the editorial by Paul Lorch [of the *Bay Area Reporter*]. He had what was later called a traitors' list on which you had the honor of being number six.

Conant: I didn't realize I was number six. Who was number one?

Hughes: [San Francisco Supervisor] Harry Britt.[1]

Conant: I knew that there was a traitors' list. Remember now, at this point Bob Ross was on the board of the KS Foundation, and Bob Ross owned the *BAR*. His editor, Paul Lorch, was writing awful things about me and the other people that Bob Ross was trying to work with. It was an absolutely bizarre schizophrenic period. I was also told that Lorch kept that list of traitors, and every time one of them would die, he would draw a line through the name. So when Billy Kraus died, Paul Lorch drew a line through his name on the list.

I wonder where Paul Lorch is today.

Hughes: Well, gay liberation was obviously paramount to Lorch; nothing else counted.

Conant: Well, that was true. A failing that you have in a democracy is that when something new emerges, the leaders you have are the leaders already in place, not the leaders who emerge. And the leaders that the gay community had in place were civil libertarians who had been fighting for civil liberties for a decade or more. There were no public health authorities, no doctors, no people with public health experience in leadership roles. So consequently, we were not listened to. Our advice was not sought. It was almost an anathema because the way we and they approached things was different. They were fighting for the rights of their people, and we were saying, "If you do this [oppose bathhouse closure], your people are going to die."

It would be much like a black leader shortly after integration having to tell black people that they had to sit at the back of the bus because it was good for their health. What a horrible position to be in. After years of persecution and fighting for integration, you get integrated and then one of the leaders stands up and says, "I'm sorry, folks, you've got to get

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[1] Shilts, *And the Band Played On*, p. 445.

to the back of the bus because you're going to die if you're up here at the front." You can see the difficulty that these leaders had. It was exactly that issue [in bathhouse closure].

Hughes: Did your medical colleagues who were gay support closure?

Conant: No. A couple of the major leaders here in the city who were gay-identified doctors with large gay practices argued up to that juncture that the bathhouses were to the gay community what the pubs are in England. They were a place where gay men went to kick off their shoes and relax and have dialogue and conversation and interact. I can remember one meeting the argument went something like that. Many of us said, "Baloney. They go there half-drunk, and they don't want any dialogue at all. They want to have sex." [laughter] They said, "No, no, no, between sexual encounters they stand around the bar and they talk about the major issues of the day, and safe sex." There was clearly a difference in perspective.

And probably both sides were right. There were probably people who went to the baths very single-mindedly just to have sex, and there probably were people who went there to talk about what they had read about in the *New York Times* that day. But there were many gay leaders, and probably the majority of gay physicians, opposed to the closing of the baths. When I think about that, the gay physicians that I think of were psychologists. They were not physicians standing at the bedside, watching men die.

Hughes: Which you were.

Conant: That's right. They were physicians and psychologists who were talking to gay men about why they left home, why they moved to San Francisco--they were dealing with different issues in the lives of these people. And to those of us dealing with AIDS, of course, the overriding issue was death. What could we do to keep these men alive?

Hughes: You had said, I think it was in reference to Bill Kraus' diagnosis, "We're all going to die."[1] "We" meaning the gay community. Was that really your feeling at that point?

Conant: Yes. I can remember saying that at the time. That may still be true. It's hard for people to understand. I'm being hyperbolic at this point.

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[1] Shilts, *And the Band Played On*, p. 488.

Jim Curran presented some data in Amsterdam this summer [at the International Conference on AIDS] that a gay man who does not practice safe sex universally and is a teenager, has a 25 percent chance of being HIV-positive by the time he's twenty-five, and a 50 percent chance by the time he's fifty. So we're still talking about, even today, losing large numbers of the gay community.

Instilling Safer Sex Practices

Hughes: Another one of the arguments put forward against closure was that by emphasizing locale, you diverted attention from the real issue, which was behavior, namely unsafe sex practices. What kind of validity do you think that argument had?

Conant: That's a very germane argument. And there's no question that gay men had to learn at that period of time that practicing safe sex, wearing condoms, was essential to their survival. The year before, I had actually marched in the only Gay Freedom Day parade I ever marched in. I marched all the way down Market Street from the Ferry Building to the Civic Center. We'd gotten one of the major condom companies to give us condoms. I was marching along with Ernst Jansen, my friend, and each of us had a huge bag over our shoulder with condoms. I'm throwing condoms to people thinking, What in the world would my mother in Gainesville, Florida, say if she saw Judge Long's grandson marching down Market Street throwing condoms at the crowd? She would have apoplexy. [laughter] And Judge Long, I'm sure, was rolling over in his grave.

The people picking up the condoms were cheering and screaming, and then blowing them up and popping them. This was not taken seriously. But we clearly knew at that point that people had to begin to use condoms if they were going to stop the transmission of the disease.

You see, I never felt strongly that the bathhouses had to be closed, though I thought that that was probably the most dramatic way to make the point. You could have begun with just the Department of Health putting up a red sign over the door, saying--

Hughes: Which they did do at one point. I think it was the summer of '84, only months before closure.

Conant: Yes, and after Silverman had backed off the first time. That could have been a first step. But the closure issue in my mind made a statement that, "Hey, wait a minute, we, the public health officials, feel that this is a big enough problem that we are going to tell you that we cannot allow unprotected sex to happen in a publicly approved, endorsed place."

Remember, if there weren't the homophobia and the suspicion that a lot of people just wanted an excuse to close the baths, then perhaps it could have been done [earlier] and the issue of civil liberties would not have been a major focus. But unfortunately, like Feinstein's reaction, the fear in the gay community was, "Wait a minute, they're just looking for an excuse to close these baths down, and they're going to take our rights away from us. This is their excuse. AIDS is going to go away soon; this epidemic can't possibly go on. They're all telling us that." And that's true, we were. And, "They're just looking for a reason to deny us what we want, and we're going to have to fight them." That was clearly the position they took.

Hughes: Do you remember talk about whether Silverman had the legal right to close the baths?

Conant: That discussion came up from time to time. My position on that issue was, the only way to find out if you've got the power is to use it. You'll find out very quickly. Because it was clear to everyone what was going to happen--the very thing that happened: you close the baths, and the courts reopen them immediately, and then you have to go through hearings. Any time anything happens, you get an injunction to stop it. That's the way society works.

Hughes: Couldn't Feinstein have closed the baths?

Conant: Yes.

Hughes: But she, for political reasons, chose not to.

Conant: Now again, the argument then, just like needle exchange today, is that no, only a physician could close the baths.[1] But you see, Feinstein either could do it or she could appoint someone else acting head of the Department of Health. She could appoint <u>me</u> acting head; say, "Merv, take two weeks vacation; Marc's going to be acting head, and we're going to appoint him to close the baths."

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[1] The *Chronicle* quoted the mayor as saying: "The closure and non-closure of the bathhouses is a public health issue not in the jurisdiction of the mayor." (*San Francisco Chronicle*, March 28, 1984, p. 1.)

Needle Exchange

Conant: Right now, the city is caught in exactly the same dilemma. No one wanted to be the person who would approve needle exchange. Clearly, if that is done, it will have to be done by a physician. The current director [Raymond Baxter] of the Department of Public Health is a Ph.D.; he's not an M.D. So it would have to be his senior medical officer who would have to do it. They tried to get around that by passing a bill in Sacramento, which the governor vetoed about six weeks ago, which would allow for needle exchange. So now we're back to the same issue as four years ago, which is the Department of Public Health here has got to bite the bullet and order that we will distribute needles to IV drug users in this city if we're going to stop AIDS.

Now, the argument that you get is, "Who really has the power?" and then the next argument you get is, "Will that person lose his medical license?" Well, all of those are germane arguments. I've told the mayor, [Frank] Jordan, if he wants to appoint me the physician at the Department of Health for two weeks, I will order that the needles be exchanged. If they want to try to take away my medical license for doing that in the state of California, I'd love to see that fought in the courts here. What we need is some bold leadership, because we're paralyzed on these rules which no one even understands. It doesn't matter how you interpret them; once it happens, it's going to be challenged in the courts anyway.

Sydney, Australia, has had needle exchange for the past five years with no adverse effects, and it's a city the same size as San Francisco, 700,000 people. There are 12,000 IV drug users in Sydney, Australia; it's a country that culturally is almost identical to ours. They have 4 percent of their IV drug users infected in Sydney, and we have 12 percent. They, with pride, point to the needle exchange program as one of the major elements in keeping the number of infected addicts down in Sydney. And here, we're back to this moralistic notion that if you give people needles, you're endorsing drug use. That's just stupid.

Continuing HIV Infection in the San Francisco Gay Community

Conant: In San Francisco today, we are infecting three men a day. And that's frightening. If there was any city in the United States where someone was shooting three people a day, the society would rise up in arms. They would go insane. And yet, here we are in a city of 700,000 people where today three men will die of AIDS, and three boys will get infected.

Hughes: Is the inaction due to homophobia?

Conant: Well, a lot of it is homophobia. It's really hard to sort out. There's more there than just homophobia.

In the six months following World War I, more people died of influenza in this country than died in all of World War I. We lost a half a million people in this country, I believe, in six months. If you look back at that period, there are monuments in almost every city in America to the brave young men who died on the fields of Flanders or wherever during World War I, and there's not a single monument to the victims of the great influenza epidemic of 1918. And if you look at the great authors of America who memorialized World War I--Hemingway, F. Scott Fitzgerald, and the list goes on and on--there are only two authors that even mention the influenza epidemic. Yet, all of those men and women were clearly touched by the influenza epidemic as much as they were by the war. So why is it that people confronting a new scary disease seem to almost block it out? They just can't deal with it.

So yes, there's homophobia, and that's a major problem. We're seeing that this week with Magic Johnson having to quit playing [professional basketball] because of the fear of the people he plays with that they will contract HIV from playing with him on the field, and yet those same men are clearly going out and having sex without condoms every night.

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Conant: They're afraid of catching AIDS, or they're afraid of dying of AIDS, or they're afraid that they'll be branded as gay if they get HIV infection. So there's a lot of homophobia, but then there's also just a lot of denial. People just don't want to deal with it.

So yes, at the time, I'm sure I was saying, "We're all going to die." And I still think that if we do not control this epidemic, it's going to be a major, major handicap for the gay community, and then finally all of society will be horribly impacted by this disease.

Hughes: Do you have the feeling that the gay community is letting down its guard, for one reason or another?

Conant: Yes. And there are figures that show that that's more than just a concern. You can measure it two or three different ways. The easiest is to measure the seroconversion rate. Where you've got really good population-based studies, the seroconversion rate can be measured as to how low it got. In San Francisco, it got down as low as 2 percent in the mid-1980s. Now it's risen to almost 4 percent. So that means that almost twice as many people are getting infected today as were five or six years ago. The reason that society relaxes with that is we're only talking about three [cases of new infection] a day, whereas in 1982 we were probably talking about hundreds a day. But it's still a significant increase. There's only one way you can catch rectal gonorrhea. So if rectal gonorrhea rates go up, then you know that people are having unsafe rectal sex and infecting their partners. There are all sorts of studies out there that can be easily looked at, and you see this rise [in new cases], suggesting that people are falling back to practices of unsafe sex.

Were I a journalist, the study I would do is take the archives of the *BAR*, the gay newspaper, and look at how many column inches in the back of the *BAR* are devoted to people advertising that they are for sale. In 1985, '86, '87, [such ads] got down to less than three pages a day. Now they're back up to five or six. People aren't going to pay to run an ad that they are for sale unless people are buying. [laughs] So the fact that the ads are there now, every week, week after week after week, with three or four times as many pages of models or whatever, tells me directly that people are out there having lots of sex. And then, of course, the rectal gonorrhea figures tell me that a lot of those people are having unsafe sex.

Hughes: Is anything being done about this increasing infection rate?

Conant: There are things being done, but not at an effective level. Remember that the problem, particularly when you're dealing with government agencies, is if you ask, "Is something being done?" the answer is always "Yes," and they point to all these programs. But if you turn around and say, "Show me the outcome. What have these programs achieved? Are they really effective programs?" Then you realize that no, nothing's being done, because you would only say yes to that question if in fact you were having an impact.

A few years ago, I looked at what was being taught in the school system that prided itself on teaching kids about HIV. What they were teaching the kids was that HIV is a retrovirus, an RNA virus--some amazingly interesting things from a biochemical and retrovirology point of view. I said to them, "Okay. In the curriculum, do you ever show a boy how to put on a condom?" "No, that's not in the program." See, in my view, it doesn't matter if the kid understands that it is a retrovirus. It's not information that he or she can use to stay alive. So the outcome of that program is really suspect, because the program is not geared at giving the kid information that the kid can use for survival.

AIDS Activities at UCSF

[Interview 6: November 12, 1992] ##

AIDS Clinical Research Center

Conant: AIDS Clinical Research Centers, founded initially here in San Francisco and in Los Angeles [1983], and then in San Diego [1985], were an attempt to fund patient evaluation to delineate the natural history of the disease. As I recall, we had a budget of about $300,000. That was to pay for a nurse, and that's where we got the money to pay for Helen Schietinger, for example, or continue her employment, and where we got money to pay for a nurse practitioner that we later hired.

We recruited a number of different patients who had different stages of disease. We were recruiting patients with *Pneumocystis*, patients with Kaposi's sarcoma, and patients who had the lymph node syndrome, and we were collecting specimens from those patients. We were doing biopsies, for example, on the KS patients, and collecting blood and freezing it down. We had established a tissue bank through the university and had placed it in John Greenspan's lab, because he had the space and the interest.[1] The notion of the tissue bank was that we would collect this group of patients, and we would very precisely try to define where they were in the course of their disease: how old they were, how advanced their disease was, and then we would collect specimens. Over time, we would follow those patients and collect additional specimens, so that we would have frozen down for later evaluation as we learned more about the disease specimens from people at different stages of the disease. To my knowledge, the place that that material has been the most useful has been in terms of developing vaccines. For example, Chiron Corporation is today using some of those specimens to look at the natural history of the disease.

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[1] For the history of the UCSF AIDS specimen bank, see the oral history in this series with John S. Greenspan, D.D.S., Ph.D.

So the AIDS Clinical Research Center was really trying to look at the natural history of this disease. What happens, for example, to someone with lymph node syndrome? Do they all get AIDS? Do some of them stay well? Do they all get sick over a period of time? We talked a great deal about trying to identify the co-factors. We were hoping that through taking histories on these patients, we could identify why some people were getting sick and some people were not.

For example, in men who were [HIV-]infected and had swollen lymph nodes, was it the ones who had used poppers who got Kaposi's sarcoma, or did poppers have anything to do with the natural history of the disease? We kept thinking that we would find co-factors--cytomegaloviral infection, frequency of sexual contacts, other sexually transmitted diseases, use of amyl nitrite--which would predict who was going to get sick and who wasn't. But unfortunately, no such co-factors were ever identified.

Hughes: Do you think that a co-factor is involved with HIV disease?

Conant: Probably. If you're in Bethesda with Dr. Gallo, you probably think it's herpes virus 6. If you're in Paris with Luc Montagnier, you think it's probably mycoplasma. If you're in the National Institute of Allergy and Infectious Disease with Tony Fauci, you might even think it's herpes simplex. So it's hard to tell. My guess, though, is that when we really do understand this disease, what we'll find is that HIV infection is itself such an overwhelming event that it will be the major machine driving this disease. And that yes, people who then get concomitant infections, and get monocyte activation by mycoplasma infection, they may in fact have a slightly increased rapidity of the course of their disease. So my guess is yes, a co-factor will play a role. I think the role is a minor one, not the major one that's been assigned to it.

Hughes: Was the KS Clinic distinct from the AIDS Clinical Research Center?

Conant: Not really. What happened was one sort of merged into another. The KS Clinic was essentially a volunteer operation. I volunteered my time; all of the doctors who came there and worked volunteered their time. Dr. Epstein volunteered the clinic space itself. But patients paid for visits to come there, if they had resources. If they didn't, we usually saw them on the side for nothing. Once we had funding from the state for the AIDS Clinical Research Center, then we could pay a nurse coordinator, pay a physician's assistant to do the examinations, pay for the clinic visits, pay for the biopsies. So it was a way that we could defray the cost of evaluating those patients. It was a natural extension of the KS Clinic.

Hughes: When did the focus of local AIDS research shift to San Francisco General Hospital?

Conant: I think the shift began about 1983, as we talked about on a previous occasion. A decision was made at UC Berkeley in the office of Conn Hopper [in the President's Office], it is rumored--though I do not know that this is the truth at all--that the university really didn't want a very high visibility in terms of taking care of AIDS patients. They wanted, if possible, not to have them in the university hospital. So at this institution [UCSF], the decision was made to care for those patients at San Francisco General Hospital. At UCLA, the decision was made to care for the patients at the VA Hospital.

Hughes: For similar reasons?

Conant: Yes, it was a Berkeley decision that then impacted on each one of the campuses. For example, Neil Flynn in Sacramento [at the University of California Davis Medical School] complained publicly that he wanted to increase his [AIDS] clinic, that he could fund his clinic with his research and patient fees. But the university would not let the clinic grow any bigger, because they wanted to contain the size of the AIDS visibility on the UC Davis campus.

For whatever reason--and it would appear that it was a university decision--Paul Volberding was transferred from this campus [where he was co-director with Conant of the KS Clinic] to San Francisco General to head up the AIDS activities there. And shortly thereafter, Don Abrams was transferred to follow Paul over there. From that point on, most of the clinical work--the seeing of patients and so on--was being done at San Francisco General. More and more, the Kaposi's Sarcoma Clinic, and indeed the AIDS Clinical Research Center here [at UCSF] became superfluous.

Adult Immunodeficiencies Clinic

Conant: Now, at my urging and with funds that I got for the university, UCSF started a clinic [Adult Immunodeficiencies Clinic] here on this campus to replace the KS Clinic, and to have a full-time, salaried person in the Department of Medicine providing care for patients with HIV disease who were admitted to UC. The first person, who's still there, that they hired for that was Dr. Harry Hollander. But UC San Francisco has continued to keep that as a relatively small presence. It has not grown to the size of the clinic that it could be in the epicenter of the hardest-hit AIDS city in America. Early on, they didn't even want to call it the

AIDS clinic. They called it the Adult Immunodeficiencies Clinic, instead of the Acquired Immunodeficiency Clinic, I guess in the hopes that people wouldn't figure out what it was all about. But it didn't take them long to figure out what it was all about. [laughs]

Hughes: Did all this upset you?

Conant: At various levels, yes. But I was pleased that the care was growing, that there was then an AIDS program at San Francisco General. That didn't upset me at all.

There were all sorts of politics being played as to who were going to be the major players: was it going to be Merle Sande at San Francisco General? Were we over here on this campus going to have any role in it? By that time, Rudi Schmid was the dean and firmly in place, and Dr. Sande was a very close friend of the dean's. And it was clearly obvious that the dean thought that this was an issue that Dr. Sande should oversee.

Hughes: In January 1985, you resigned as head of the AIDS Clinical Research Center. Is there a story?

Conant: No, not really. My feeling at the time was that we could not adequately run that clinic without decisive leadership from the dean, indicating that he wanted to keep an AIDS presence here. But there were all sorts of little battles going on. Dr. Levy was upset that a lot of the research had moved to County [SFGH] and that he was having trouble getting specimens. Dr. Greenspan had his agenda. Dr. Ziegler had his agenda. And there was no way that I was able to bring these people together as a cohesive working force. Everybody was splintering off in their own direction.

I went to the dean and said, "We need either a mandate from you that this is how this thing [AIDS activities at UCSF] will be coordinated or led. We need a leader that everyone can rally around, or otherwise the thing's going to be just terribly splintered." The response I got was indecisive, and so I felt that my effectiveness was at an end and it was time to move on and do something else.

AIDS Testing

Debate over Release of Test Results

Hughes: I think you wanted to talk about AIDS testing.

Conant: Yes. Let's talk about what happened when it became apparent that there was going to be an AIDS test.

Abbott [Laboratories] had started testing its kits in the fall of 1984 in blood banks around the country. It became obvious that the test was going to be released in the early spring of 1985. It was intended not so much to help with the diagnosis of HIV-positive patients. I mean, Abbott didn't come to us and say, "Would you like to use these tests early on to try to help you manage sick people?" The test was clearly to "protect the nation's blood supply" from infected people.

When it became obvious that the test was going to be used in blood banks, public health officials around the country began to openly threaten that once it was known that the test was available at the blood bank, that people who perceived that they might be infected with HIV would go to the blood bank to be tested. That would mean that the blood bank, of course, doing what blood banks do--if you walk in a blood bank they try to get blood out of you--the blood bank would take the blood from these people for transfusion, the test might not be 100 percent accurate, and they would miss [HIV-positive donors]. The test would attract more people at risk to the blood banks, and that would increase the number of transfusion-associated AIDS patients.

Now, quite honestly, if you think about it, it's a spurious argument, because the blood banks were telling physicians and the public that they were already taking detailed histories and screening out people who were at risk by asking them their sexual history, by asking them if they'd shot drugs, by asking them if they had traveled abroad, and other high-risk behaviors. In retrospect, we learned that the blood banks were not doing those things. They were not taking the history; they were giving patients information and then relying on the patient to understand that he or she should not donate blood, and self-defer.

The blood banks were concerned that [HIV-positive] people would get through their screening system. And so the blood banks, and the epidemiologists who were working with the blood banks, fought for two things to happen. The first was to have alternate test sites set up where someone who perceived that he was positive could go for an HIV test rather than go to the blood bank. They were then and are still called alternate test sites, and they're alternate to the blood banks. The second thing that they fought to do was that, if someone did come to the blood bank and did test positive, the blood bank would not tell the person that for a period of six months to a year. And they would make it known publicly that if they found out you were positive, they wouldn't tell you. They saw that as a way of deterring people from coming [to the blood bank for testing], because why go to find out if you're positive if you're not going to get told?

Well, I opposed that fairly vociferously, both publicly and privately, and can remember participating in a meeting in Sacramento in 1985 which became quite contentious. I can't recall who chaired that. I believe it was John Vasconcellos, but it may have been Art Agnos. All of us went trooping up to Sacramento, and we all sat around in the legislative seats feeling terribly important, being asked our views about what should be done about testing.

I can remember saying that I thought to find out that somebody was positive and not tell them was unconscionable. I did not see how they could justify the ethics of doing that. And I can remember the analogy that I used. If I was a young truck driver driving down the Bayshore Freeway and was in a terrible accident and nearly died, and received twenty units of blood and survived, and was able to return to my family and my wife, and perhaps she could get pregnant, that I would be so thankful that the blood bank had saved my life with those twenty units of blood that I would go to the blood bank and give blood once I had recovered. And if I had gotten infected with HIV from one of those transfusions, and when the blood bank tested my blood, found out I was positive, and didn't tell me, I went home and got my wife pregnant again with another child, and in that way killed my wife and my child, then I would sue the blood bank for every cent that it had.

It was prophetic, because exactly that thing has happened.

Hughes: Yes. It hadn't yet.

Conant: Well, there had been transfusion-associated AIDS cases. But there had not been situations where the blood bank found out donors were positive and did not tell people, who then went home and infected somebody else. During that window period when they weren't being told, the individual was infectious and infected someone else. I just don't see how the blood banks justified that.

Hughes: What was the response to your argument?

Conant: That the public health was more important than the individual; that the fear that so many of "those people" would come to the blood bank to find out if they were positive justified taking that position. So they took the position, as I recall, that they would not tell people testing HIV-positive for six months.

The next step in all of that was I argued, and argued publicly, that individuals should test and should find out if they were positive. I can remember using the argument that knowledge is strength, that was the philosophy that I generally espoused, and that the "ignorance is bliss" argument, that "if I just don't know it's not going to hurt me," was absolute foolishness, because the man who was not willing to find out that he was positive was going to eventually find out. It's not as if this was not a progressive disease. Why not find out now while you're well and while you've got all of your resources to handle the anxiety, and perhaps take steps to prolong your life, rather than waiting until you wake up on a gurney in an emergency room, dying of *Pneumocystis*? When's the best time to deal with the anxiety of learning that you've got a fatal disease?

It was another two years before the San Francisco AIDS Foundation started sponsoring public forums where they would have two people come and debate the issue. One was invited to debate the "you should be tested" model, and the other was invited to debate the "no, it's better to not do anything" model. Of course, I was always the one invited to come debate the "you should be tested" model, and while there were sympathetic people (and hopefully there were people there who took the advice and went and got tested), there were also boos and hisses and the perception that you were in some way betraying the community by arguing that people should find out that they were positive. So it was a very difficult time.

You realize that here we are now, eleven years into the epidemic, with a test that's been available since '85, and physicians are not widely suggesting that the general public be tested. We still don't have patients breaking the door down to find out if they're positive. We still today are seeing people whose first clue that they're positive is when they turn up in an emergency room with PCP [*Pneumocystis carinii* pneumonia]. The overall perception has been, "Oh, well, why bother? Why test? What can you do?" And yet, there's ample evidence that there's plenty you can do to prolong people's lives.

From the beginning, there has not been this public consensus, this wise view among clinicians and the general public, that widespread testing would be a beneficial thing.

Testing Indicates the Dimensions of the Epidemic

Hughes: What did use of the antibody test do to your perception of the breadth of the epidemic?

Conant: I think that beginning in March of '85, we began to understand how many patient cases there really were, because it immediately showed us that yes, there is what we have suspected all along: this great, huge base to this pyramid of asymptomatic patients.

The test became available in March of '85. The First International Conference on AIDS was held at the CDC in May or June of '85, just a couple of months later, and the next meeting was in Paris. The third meeting was in Washington, D.C. So we are now looking at 1987. At that point, we still didn't know how many people in the United States were infected because the Centers for Disease Control had not conducted a broad-based community testing program to determine how many people we have in this country that are infected. I can remember Jim Curran and Hal Jaffe promising us in Washington in '87, "By next year, we will have done, using the test, a community-based epidemiological study to answer once and for all how big is this epidemic."

Well, the next year came, and they didn't have the answer. The interesting thing is that the reason they didn't have the answer is that in the communities where they went to try to do the testing, no one would cooperate. In essence, they would go knock on the door and say, "I'm from the federal government. Do you think that you're at risk for AIDS?" And the person would say, "No." "Well, do you mind if we test you to see if you've got AIDS?" "You bet. I'm not going to let you test me." "Why is that?" "Well, one, I don't trust you. And two, I don't trust your test. If I test positive for some reason, I'm going to show up on some list. I will lose my insurance, I might lose my job, I don't know what would happen, so I'm not going to cooperate." So from that point forward--and we had seen this also in another instance--the CDC realized that they could not really do that kind of broad-based epidemiological study.

Today, six years later, all of the information we have about how big the epidemic is in the United States is based on indirect measurements: how many people who go into the military are positive, how many people who show up at blood banks are positive, how many people who go to hospitals and are tested blindly are positive. From that, they try to back-calculate the size of the epidemic in the United States. But because of the discrimination issue, the fear of discrimination regarding insurance and employment and housing and other things, we've never been able to really get a fix on how big the epidemic is using the test.

Hughes: Do other countries have a better system?

Conant: Oh, yes. For example, in some Scandinavian countries, they have done widespread testing and have a much better fix on how large the epidemic is in their communities.

Hughes: Did you and your colleagues rush to take the test once it was available?

Conant: Well, I think we'd all done other things first. A lot of us had been very concerned about being infected with whatever it was, even before we knew what it was. Randy Shilts has that great chapter in his book called "Night Sweats," where all of us would wake up at night in '82 thinking, Oh my god, am I going to catch this thing and die? Many of my colleagues and I knew that if you were infected, your helper T cell count was going to be low. We had been doing helper T cell counts on ourselves since '82. If our immune systems were still okay, it didn't mean that you had escaped being infected, but it certainly meant that if you were infected, there was no evidence yet of disease. So most of us had been doing that all along anyway.

Proposition 102

Hughes: Is there anything else on testing?

Conant: One other minor aside, which is something I'm proud of: in 1989, I had been made co-chair of the California AIDS Leadership Committee. That was the year that Mr. [California State Assemblyman William A.] Dannemeyer decided that he was going to use the test to identify people who were positive, and report them. He wanted to make testing mandatory and reportable, rather than voluntary and confidential. That was Proposition 102. Mr. Dannemeyer and the proponents of mandatory testing were never clear what they were going to do to people once they found that they were positive, but it was clear that it probably wasn't going to be terribly nice, [laughing] because they wouldn't tell what they had in mind.

Most of us tried to point out that most people who are infected got infected ten years ago. So they can't tell you all of their sexual contacts, because they don't know all of their sexual contacts. We have tried in California to educate the entire at-risk community, the gay community and the drug-using community, as a cohort [about safer sex]. In other words, a gay man in 1989 should know that if he's going to have sex with another man, there is a great likelihood that he's going to be exposed to AIDS, and that he should use a condom and take appropriate steps.

So because of that, even if you identified that Patient A was positive, and he told you, "Oh, two weeks ago I had sex with Patient B," and the state got hold of Patient B, Patient B already knew that he was at risk and would have taken the appropriate steps. So if he was positive, he probably had caught it months to years before; and if he was negative, it was because he was taking the appropriate steps. So it wouldn't serve the state's interest at all to do contact tracing. Furthermore, because the gay community so distrusted the state, how was it going to get Patient A to give you Patient B's name?

Mr. Dannemeyer said, "We will get a court order for him to do it." I can remember Don Francis saying, "Torture is no longer popular in this society. If an individual's not going to tell you, there's no way you can get him to cooperate. So it seems like a great waste of time."

So our committee [the California AIDS Leadership Committee] opposed the proposition. We had hearings, and in the end, we were successful in persuading Jonas Salk to speak out on it. It was actually the death knell for the proposition when Jonas came forward and said, "This doesn't make any sense." The public was moved by that argument, and that was the end of 102.

Had 102 passed, things would look quite different today. I think you would see widespread mandatory testing throughout the country, whereas we see much more of an attempt at confidential testing. I think the whole thing might have unfolded quite differently. There are many who still think that mandatory testing and contact tracing should be the way that the disease is managed. From my point of view, I still believe that if you're going to do that, you've got to put in safeguards for people in terms of insurance and employability before you expose them to the loss of insurance and a job. You don't tell someone, "By the way, you have a potentially fatal disease, oh and also, you just lost your medical insurance." People can't see that no one's going to cooperate with a system like that.

The idea of having a disease like AIDS in the United States, and dying of that disease without access to health care, is a terrifying prospect. No one in their right mind is going to come forward and relinquish their health care benefits for the good of the state or anybody else. You've got to then make it a desirable thing for them to do rather than a burden, and that's not going to happen.

Shortening the Drug Approval Process

Hughes: Could you comment on the impact of the epidemic on the FDA's drug approval process?

Conant: Well, it's certainly had a major impact, and in the most part, it's been a very good impact. But let's analyze it in terms of what's happened, and why it happened.

What's happened is that more and more the FDA is saying, "We will approve drugs for people with fatal diseases on very, very soft data, and we will continue post-marketing surveillance more intensely." In other words, "We'll continue to do the studies after people are using the drug, rather than have most or all of the studies completed before the drug is licensed." Now, that doesn't seem like a terrible unreasonable position, but it took a decade to get there. It took a decade to get there for one very simple reason: with the thalidomide scare in the early 1960s, there was a person at the FDA [Frances O. Kelsey, M.D.] who delayed approval of thalidomide.

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Conant: When it was then found that thalidomide caused terrible fetal abnormalities in Europe, Israel, and in other places where it was being used, this person, because she had slowed up the process, was suddenly a hero, and received a Congressional Medal of Honor and was much touted at the Food and Drug Administration for this type of caution which saved a disaster in this country. And it did.

But the message that went out from that was, the way to make points at the FDA is to move as slowly as possible, not to move rapidly. To be a snail rather than an innovator. So consequently, the paradigm was, "We will take as long as is necessary to be absolutely certain, not only of safety but of efficacy, before a drug is approved." So we were seeing companies having to take seven, sometimes ten years from the time they submitted an application to the FDA until the drug was finally approved. That's perfectly appropriate for 90 percent of the drugs, particularly when there are already drugs out there that are very effective [for treating the disease in question]. If you've got a drug that lowers blood pressure, and a newer drug that comes along which will be only a slight incremental increase in safety or efficacy over the existing drug, it needs to really prove its mettle against very strenuous criteria before you bring it to market.

But when you've got a disease like AIDS, where it's uniformly fatal and there is no [effective] drug out there, then concerns about, Well, I wonder what this drug will do to unborn children? don't make sense. These cases were 90 percent men, they were not going to get pregnant, most of them were going to be dead and not have unborn children, so those kinds of questions were really superfluous.

But the Food and Drug Administration was very, very slow. Ginny Apuzzo and I went to Washington in '83 and met with representatives from the FDA in the office of Undersecretary of Health and Human Services [Edward] Brandt. I can remember using the analogy: "We have at the FDA this process of drug approval which one would liken to a train moving at a certain pace from San Francisco to Washington. Even if you really fuel it up, it can only go so fast. What we need at this point is an airplane. We need to say, `We're not going to take the train this time; this is a big enough problem that we're going to take a plane and we'll be there in six hours instead of six days.' And that's what the FDA needs to do." That's now called parallel track [drug testing], and that seems like an appropriate term.[1]

That meeting was in '83, and we didn't see parallel track start happening until about 1988. So then the question has to be, what happened to make it happen, to make the FDA change? And I see two things happening.

The first was that Don Francis and I, working with individuals in Sacramento, and particularly the then-attorney general, [John] Van de Camp, were able to introduce legislation in Sacramento that said that the California Food and Drug Bureau could approve drugs for testing in California without going to the FDA. In other words, we introduced for the first time in America competitiveness in the regulatory agencies. You start having the regulatory agencies competing with each other.

Hughes: For any new drug?

Conant: Any AIDS drug.

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[1] For more on parallel track and other innovations regarding AIDS drugs, see the oral history in this volume with Dr. Abrams.

That immediately got the attention of the FDA, because the first person who applied under that new law was Jonas Salk for his vaccine which he saw as a treatment for AIDS rather than a prophylaxis. Representatives of the FDA flew out to San Francisco immediately and tried to persuade leaders here, including [Mayor] Dianne Feinstein and Paul Volberding, that we didn't want to go this route. Of course, the fear was, My god, what will we, the FDA, do if Jonas Salk has got a cure for AIDS and they then say, "They had to get approval through the California Food and Drug Bureau rather than the FDA. Look at the FDA, they were really slowing up the process." Then, unfortunately I guess for all of us, Jonas Salk's vaccine did not prove to be the magic cure. But for the first time, the FDA was really put on notice: Look, guys, if you don't change, we're going to find other ways to get drugs tested in this country.

The second thing that happened was Larry Kramer, to his great credit, started ACT UP. Larry Kramer of New York is a playwright and an activist, and a man who is HIV positive. He had started the Gay Men's Health Crisis back in 1982, and then made himself so unpopular with all of the people working at the Gay Men's Health Crisis that he was invited to leave. He remained, though, a very visible community activist and wrote a very famous AIDS play called *The Normal Heart*. Then he started ACT UP. In those days, ACT UP was very well focused. They were going to get out there, and they were going to demonstrate, and they were going to engage in civil disobedience to force the government to deal with issues like drug approval. They staged die-ins in the Food and Drug Administration building in Rockville, Maryland.

And sure enough, the agency moved, which is a really interesting thing if you think about it. What moved it was not doctors flying to Washington to discuss it intellectually, and it was not compassion for the tens of thousands of people dying of the disease, and it was not the insight of the leaders at the FDA, "Maybe we should look at doing this differently." It took activists in California saying, "If you don't do it, we're going to do it here." And it took community activists saying, "We're going to close down your operation." Then the FDA finally said, "Oh, well, maybe we should do something differently." So as much as one objects to having to engage in civil disobedience to get things done, the message that went out from the Vietnam War and from this is that, unfortunately in this society, that's a very effective way of advancing your agenda.

Drug Industry Interest in Developing AIDS Drugs and Vaccines

Hughes: What about the problem of interesting pharmaceutical houses in developing AIDS drugs and vaccines?

Conant: It's still a problem. Some of the problem is understandable, and some of the problem is clearly prejudicial. In terms of AIDS drugs, there have been only a very few companies--Burroughs-Wellcome being a notable exception, and Hoffmann-LaRoche and Bristol-Myers to some degree--which have devoted energies to bringing to market antiretroviral drugs.

In my mind, the budgets of drug companies have all gone looking for the magic bullet. They've all gone to see if they can't find the drug that's going to cure the disease. People infected with HIV develop a variety of different diseases as their immune system collapses--PCP, cryptococcal meningitis, toxoplasmosis--and there has been very little enthusiasm in the pharmaceutical industry to look for new drugs to prophylax against or treat those individual diseases. It's just not perceived, I think, as sexy. It's just not perceived as, that's going to really catch the attention of the market. And maybe it's perceived that the market is not large enough.

But for whatever reason, there does not yet seem to be the interest. Here we are, eleven years into an epidemic, and there is only one new drug to treat *Pneumocystis* [atovaquone], and it's not very effective. There are no new drugs to treat toxoplasmosis. So for these diseases that are killers, we have seen very, very little effort to bring new drugs to market. The two drugs that we have for CMV [cytomegalovirus] were both there when the epidemic began. Now, foscarnet was brought to market. It had not been fully investigated or fully studied, but the drug had been in existence for twenty years before the AIDS epidemic. So that's one shortcoming.

On the vaccine side, the fear of product liability litigation against the drug companies has been so significant that drug companies have been afraid that if they develop a vaccine, they're going to get sued. If someone catches AIDS socially, the person is going to say, "No, no, I didn't do anything that I could have done to catch the disease socially. I got the disease from your vaccine." So if we could indemnify the drug companies against that type of lawsuit, then we might get more enthusiasm for vaccine development.

The other is the perception of the venture capitalist that there's no money to be made in vaccine development. You see, the notion is that if you have a vaccine to stop the disease, people will only take the vaccine once, and not everybody will take the vaccine, only those people who perceive that they're at risk. So that's gay men and IV drug users; that's not very many people.

However, if you have a drug to treat the disease, those people have to take that drug every day, sometimes three and four times a day, for many years. So if you're looking at it purely as a market, there's more money to be made by letting people get sick with the disease than there is by preventing the disease. So let's put our money over here in developing a treatment rather than over here in developing a vaccine.

At the present time, there are a number of different companies developing vaccines, but mostly as immunotherapeutics, as treatments, rather than as prophylaxis.

Hughes: How much impact did the Orphan Drug Act of 1983 have on drug development?

Conant: It had an impact. Pentamidine, for example, was developed in an aerosolized form to prophylax against PCP. So the Orphan Drug Act did have an impact in terms of bringing drugs to market. The tragedy with that is that there doesn't seem to be a mechanism in that act to reward a company adequately for the risk it takes and for the amount of money it invests. But then once they had recouped their investment and made a reasonable profit, some of those companies made an absolutely obscene profit. So there was a tremendous amount of criticism simply because it seemed to be a good thing going bad at the end, and that there were companies that made too much profit.

It's a shame that the act was not tailored so that patients didn't end up being gouged. For example, foscarnet today, which has come to market, is a drug that is fairly easily manufactured and is not terribly expensive to make. But because of the unique patent privileges enjoyed by the company that makes it, they're charging $22,000 a year for treatment with foscarnet. So if you're going blind from CMV retinitis, and you can't take DHPG, and I treat you with foscarnet, the cost to you is going to be about $22,000 a year. Now, that's obscene.

Publishing on AIDS

Hughes: Did you ever have trouble getting AIDS papers published?

Conant: Yes, the only paper that I can remember having trouble publishing was a paper I wrote for the *Journal of the American Medical Association* where I chose to use the street terms for sexual practices which are not commonly practiced in middle America, so that the doctor would know what term to use that the patient might recognize.

For example, there were in the gay community at that time (and I think still are) some men who engaged in a form of eroticism where one partner actually inserted his hand and fist into the anus of the other partner. The term for that was "fisting." Now, you could call that "bracheo-anal eroticism," but chances are if you said to many gay men, "Have you ever engaged in bracheo-anal eroticism," they would say, "Huh?" at best, or probably just "No." [laughter] And it was my view that you had to use the terms that people were using, and that doctors needed to know what those terms were.

As I recall, in the article, I used the technical term, and then in brackets I put the lay term. The paper was rejected with a nice note saying that it was the standard of the *Journal of the American Medical Association* not to use that type of street language.

Hughes: Not even a suggestion that you might eliminate the street language, and it would be publishable?

Conant: No. [laughter] I don't think they wanted to deal with it at all.

Hughes: As you well know, there is the tradition in medical publishing that you don't talk publicly about your results until they're published. Peer review and the publishing process can go on for months and months, if not years. Was there any accommodation to the AIDS epidemic in the medical publishing field?

Conant: There were accommodations. For example, many journals, including the *New England Journal [of Medicine]* and the *Annals of Internal Medicine* and *JAMA* [*Journal of the American Medical Association*] and others, made it public policy and actually advertised the fact widely that if you submitted an AIDS article, they would expedite the publication; they would try to bring it to print faster than the traditional review process. That was a worthy effort.

The prohibition that was unfortunate was that the *New England Journal* and others continued to make it understood until very, very recently that if you presented something at a national forum, or in any other format than their publication, they would reject the paper. So up until about two years ago, people were hesitant to reveal data at an AIDS meeting if the paper had already been submitted to the *New England Journal*, because they knew that if it became known that they had discussed the data publicly, the *New England Journal* would reject the paper out of hand. I'm sure you understand, for a young investigator, having your name first on a paper in the *New England Journal* will essentially assure your career. You will be favorably looked at, for example, as an associate professor; you will be moved to another university; you will advance; you will be perceived as someone who has something worthy to contribute.

So for that reason, young investigators were understandably not only reticent, but they would not discuss their findings until they had been published.

Eighth International Conference on AIDS, Amsterdam, July 1992

[Interview 1: August 6, 1992] ##[1]

Hughes: Since you're just back from Amsterdam, I thought it would be well to summarize what the key themes of the conference were.

Conant: Unfortunately, there was a lot of science, and very few therapeutic breakthroughs. I think if one were to try to characterize this meeting--and each meeting has had its own flavor and its own characteristic, its own dynamic--you would characterize this one as a "me too" conference, where lots of people had repeated the studies that others had done in the last two or three years.

Growth of the Epidemic

Conant: But there were some themes that probably are worth noting. The first is the size of the epidemic. It is now estimated by Jonathan Mann at Harvard and confirmed, I think, by most experts that there will be one hundred million cases of AIDS in the world by the year 2000. As bleak as those numbers are, I think that the thing that is missed is that when the press records that, it's as if that's an end point. It's as if, "Oh, by the year 2000, there will be a hundred million cases, which is tragedy." But then no one says, "But two or three years later, if there is still not a

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[1] This section was moved from Interview 1 for better continuity.

vaccine to stop the further spread of this disease, there will be two hundred million." No one seems to understand that it's a moving target, that the epidemic keeps going until the necessary vaccine is developed.

The second thing, I think, is the spread of the disease to women. We have known since '83 that women were affected almost as equally as men, but no one in this country wanted to believe that. This disease was and is identified as a gay disease, with IV [intravenous] drug users being affected by the disease. The general population here in the United States I think still believes that they are immune from this disease.

Hughes: So it's a function of denial.

Conant: It's clear-cut denial. We are now seeing that over 10 percent of all the new cases of AIDS in the United States are in women. In some enclaves of the United States, for example in Brooklyn, New York, 10 percent of all of the women are HIV-positive. That's as high as some areas of subequatorial Africa.

So it is a totally unacceptable spread of the epidemic. The public health department should react immediately and with Herculean efforts to try to stop the epidemic, and there's nothing happening. Ten years later, there's no major attempt. There are these little cosmetic campaigns like AIDS awareness and "Just Say No," but none of it is having any impact. None of it is felt to really do the job, and I think if you talk to any expert, they will tell you it's cosmetic. It is purely an attempt by the government agencies to look as if they're doing something.

The Leadership Vacuum

Hughes: Why do you think there is this inertia?

Conant: Oh, I think the big problem is there's no leadership. Everyone that I talk to feels as if they are not empowered to do anything. If they understand the problem, they say, "But what can I do? It's up to `them' to do it," and the "them," of course, is the government. Ronald Reagan and George Bush have been unwilling to take any action at all.

Let me give you a further example. One of the talks I gave in Amsterdam was about this subject.[1] It was for the forum put on by the AMA [American Medical Association]. I pointed out that people keep waiting for the World Health Organization to do something. My idea of the World Health Organization is of an agency like the Department of Health and Human Services in this country, which will act if they get direction. If the heads of the governments of the world say, "We want this to happen, and we would like you to do it, and we will give you the money and the personnel and the guidance," then I think the World Health Organization could do a wonderful job.

But I think it's really naive, bordering on stupid, to think that they're going to formulate policy which is contrary to what the governments of the world want, and that they will get funding and can implement those policies without an international consensus as to what needs to be done. That international consensus is not going to emerge without George Bush taking some action, and George Bush will not even mention this disease. When he does mention it, he only mentions it in the context of children.

Hughes: Well, that's the gay stigma again, isn't it?

Conant: That's exactly right; it's the homophobia. We're so paralyzed by homophobia that we're willing to write off a large part of the next generation of heterosexuals to a disease whose transmission could be stopped with education.

Hughes: What about the likelihood of an effective vaccine in the near future?

Conant: I think that a lot of the papers in Amsterdam really point to the fact that we will be able to develop a vaccine. Many of us were very disappointed in the late 1980s when it looked as if a vaccine was not going to be possible.

One of the things that I did with [California Assemblyman] John Vasconcellos and some people from Genentech, Dr. Ammann and others, back in '86 or '87, was to try to identify why a vaccine had not been developed. We found that research was not happening. And when we went to companies like Chiron and Genentech and said, "Why aren't you working on an AIDS vaccine?", the answer we got

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[1] "Physicians at AMA Amsterdam news seminar offer panoramic view of their varied roles in pandemic." Medical News and Perspectives. *Journal of the American Medical Association* 1992, 268:1237-1246.

was [the risk of] product liability litigation. They were afraid that they would be sued if they did develop a vaccine.

I'll tell you a funny story. The example given by the attorney from Genentech was this: if you had a young man who, for all appearances and as far as his family was concerned, was a heterosexual, and he joined the army and we gave him the new Genentech AIDS vaccine as part of his induction physical, and six months later he developed AIDS, he and his attorneys would claim he got AIDS from that vaccine. Even if you said it's impossible to get AIDS from this vaccine, they would claim that he got AIDS from the vaccine. And the fact that he had sex with some of his buddies in the locker room in high school would never get mentioned; no one would ever believe that. This company would be liable for tens of thousands of dollars, if not millions, because of this societal perception. So they were unwilling to pursue the investment necessary to develop a vaccine until they could be indemnified in some way against that kind of liability.

California Legislation on AIDS Drugs and Vaccines

Conant: So in '87, I believe it was, we got legislation passed in California that did just that. And it did have some impact in helping to move California forward, in terms of protecting these companies.

We then went back the next year because we had been successful and got a bill passed to allow us to approve our own drugs in California. It was interesting, because that legislation was opposed by Dianne Feinstein, the then-mayor of San Francisco, and she was joined by Dr. Volberding at San Francisco General, both of whom felt that that was not an appropriate step to take. I think they were wrong in that judgment, and we were pleased that we were able to get the legislation passed. Both bills were an attempt to do an end run around federal legislation.

The reason they opposed that is they thought that if drug trials were going on in California without the supervision of the FDA, patients would be injured. There have been drug trials with the bill. We've done them, and to my knowledge no one has been hurt, so again, I think they were wrong in that judgment.

I characterized that second bill as an attempt to bring competition to the regulatory process. You see, the problem that you have if you have only one regulator and they have a monopoly on regulation is that they in essence can stop progress. There is no way that you can speed up the regulatory process. From 1983 until we got that bill passed in about 1988, many of us went back and forth to Washington constantly, meeting with people from the FDA, from Health and Human Services, members of Congress, trying to find ways of speeding up the drug approval process.

It never worked. All we got were very polite hearings. Secretary [Edward] Brandt, who was the Undersecretary for Health and Human Services in '83, said something to the effect that he had never met homosexuals before, that he was from Oklahoma where he didn't think they had any homosexuals, and that he wanted us to go home and to convince people to quit having that kind of sex and to help stop the spread of the disease.

Hughes: And that that would solve the problem.

Conant: Yes. This was an extremely bright man. He went on to be dean of the University of Maryland. He was not saying that because he was a stupid man, nor was he saying it to be condescending or to be pejorative. He was coming from a place in this country where that really was his perception of this universe. We've seen that over and over again. Dr. Perkins, the head of the blood bank here in San Francisco, states that he was told that everyone living in the Castro District of San Francisco was a homosexual. Now, he only had to go to the Castro and walk around for a little bit and he'd know that there are a lot of gay men living in the Castro, but not <u>every</u> man living in the Castro is a homosexual. So even people living here in San Francisco had erroneous perceptions and erroneous beliefs about the gay community.

There were lots and lots of people in Washington who listened, and listened politely, but were unwilling to change what the FDA was doing. Two things have changed the FDA and have resulted in the rapid approval of first ddI and then ddC in the last four months. The first was this bill that I mentioned that was introduced in California in '88. You see, the reason that bill had some impact was that though officials at the FDA were opposed, they were afraid that someone like Jonas Salk would come along and develop a vaccine to treat AIDS in California by short-circuiting the FDA. There was concern in Washington, "Wait a minute, if California in fact comes up with something sooner, it will be a terrible embarrassment. So we would begin the process of looking for ways of more rapid [drug] approval."

The other thing that people need to understand is the impact of political activism. As much as many of us disagree with some of the things AIDS activists have done on occasion, such as closing the Golden Gate Bridge one night, disrupting the opening of the opera, or any one of the number of things that have been done, they have been effective for getting medicine approved. They don't want these people lying down half-naked in the halls of the Food and Drug Administration. It's gotten to the point now that you go to meetings in Washington and they say, "What do the activists say about this?" Or more directly, "What does Martin Delaney [of Project Inform] think of this?" And so the FDA was very concerned at this point as to how they can assuage the anger of the activists.

Political Activism

Hughes: I understand that the activists were incorporated in the planning of the Amsterdam conference. Is that true?

Conant: They were. And *mirabile dictu*, a lot of the dissent and disruptions that had happened in previous conferences didn't happen. [laughter]

Hughes: There could be a correlation!

Conant: That's right, because the very people who had been disrupting the previous ones were now part of the process. They went out of their way to be cooperative. It was interesting: I was speaking to a senior scientist the other day who was a man from industry. My guess is he's had very little contact in the last ten years with AIDS patients or people affected with this disease--by that I mean gay men in San Francisco. He was saying that the conference had opened his eyes, because he had never worked with activists and seen the disease through their eyes. He indicated that he was wiser and better for the experience, so that's great.

A New Immune Deficiency Disease?

Hughes: Do you want to say anything about the rumors circulating at the Amsterdam conference about a new immune deficiency disease?[1]

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[1] Marilyn Chase. "AIDS meeting is dominated by reports of disease in HIV-negative patients." *Wall Street Journal*, July 24, 1992, B5.

Geoffrey Cowley. "Is a new AIDS virus emerging?" *Newsweek*, July 27, 1992, p. 41.

Conant: Only to say that I don't agree with either camp, the camp that says it's going to be a terrible problem like AIDS, or the camp that says it's no problem at all. The fact is, we don't know what this disease is. I can remember at the beginning of the AIDS epidemic, no one had any idea how big a problem it was going to be. I think that what must now happen is good science. We've got to go in, find out what this is, develop an antibody test if possible, see how widespread the disease is, and then see: do we have a problem? Is this what scientists like to call background noise? Is this a disease that's been there for years and has now just suddenly been found? Do we have a new disease? Either is possible.

You will remember that when AIDS began in this country, it was traced eventually to the area around Zaire and Uganda, and then almost at the same time, a similar, related virus was found in West Africa, HIV-II. So we have an example in the last decade of two closely related immune deficiency diseases being discovered within a period of two or three years of each other. So I think that yes, it's possible we've got a new disease. It's also possible we're just picking up people who are genetically immunosuppressed, and we'll have an answer sometime soon.

Combination Drug Therapy

Hughes: Well, anything else on Amsterdam?

Conant: Yes. In terms of treatment, clearly the move is going to be more and more toward earlier treatment with the antivirals that have been developed, and combining those. So I think we're going to see in the year to come AZT used in combination therapy with ddC and ddI. People keep talking about the newer drugs--the *tat* inhibitors and protease inhibitors, the drugs that inhibit glycolization. Those drugs will come on line, but unfortunately, we're looking at two to five years before they're available, because we're just in the very early stages of testing them. So even with the most rapid testing and the most favorable results, if every test gives the result you want, at the minimum we're looking at two years.

So then one has to say, "What do we have out there that's different from the drugs we currently have that is going to fill this gap for two to three years?" It's my guess that it's going to prove to be immunotherapeutics, that we're going to see vaccines used to generate antibodies in both healthy and infected patients, and those antibodies are going to be used to try to suppress the virus.

I think that's going to lead, interestingly enough, to another political fight. Drugs are approved by one branch of the FDA, and biologicals, which are what vaccines are, are approved by another branch of the FDA. There's already been an indication that the approval processes will be different. The biological branch has said that they're not going to use the same criteria to approve biologicals that are being used to approve drugs.

If criteria that are being used to approve drugs have been relaxed, drugs can go out to market quickly. That means that it will be much harder to bring a biological to market. My guess is that the activists, if they're doing their job, will pick up on this very shortly, and they will start petitioning the FDA to have the same standards that have been used for drugs used for biologicals. So if one wanted to guess what kind of political activism we're going to see in the next year, it would be that the activists will now focus on the biologicals and the early approval of gp160, gp120 vaccines for patient treatment.

Hughes: Well, thank you very much for the interviews.

More on Initial Awareness of the Epidemic

[Interview 7: August 15, 1995] ##

Hughes: Dr. Conant, please tell me how the phone call with Friedman-Kien in April, 1981 occurred in which he told you about an outbreak of Kaposi's sarcoma in gay men in New York City. Did he call you?

Conant: I can't remember if Al called me or if Jim Groundwater called me. The person who had made the contact was Jim Groundwater, because Groundwater had seen a patient here in town called Ken Horne, I believe his name was, who had Kaposi's sarcoma in his mouth. I still have a picture from that patient. In working up Ken Horne, Groundwater had discovered that there was another case at Stanford, a man who was one of the editors for the *Advocate*, which was a gay newspaper. He was at Stanford--I don't recall his name --and was ill.

Through some mechanism, Groundwater had discovered that Friedman-Kien was seeing a similar group of patients at NYU [New York University]. Now, I had known Al Friedman-Kien for years at that time, so I can't recall if I called Friedman-Kien or he called me. But it was Jim Groundwater who was the bridge between the two of us in that event.

Hughes: You weren't in regular contact with Friedman-Kien?

Conant: No, just sporadically. Al and I had worked on the same area, which was genital herpes. He had worked at it from an academic, scientific point of view, and I had worked at it from a clinical point of view. In other words, Al was spending most of his time in the lab; I was spending most of my time in the clinic. But genital herpes was clearly a subject we were both interested in, so we had served on committees together; we had been thrown together at scientific meetings.

But at that point in history, we weren't intimate friends where I was taking him out to dinner when I would go to New York, or staying at his home, or things like we are today. Since the beginning of the AIDS epidemic, I have stayed at his home and visited with him more frequently.

But that phone call, as I say, occurred from this office [on Parnassus Avenue in San Francisco]. I can remember sitting out front talking to him, and it was in March or April of '81. It was at the behest of Jim Groundwater.

Hughes: Do you remember what the gist of the conversation was?

Conant: Yes, some of it. I remember that Friedman-Kien said that they were seeing a group of these patients at NYU, that he had identified the patients, and that Bernie Ackerman had confirmed that they were in fact Kaposi's sarcoma. And Al was amazed by the fact that most of these men were into insertive sex, that they were into "fisting," where one partner would put his fist into the anus of another partner.

And it was the insertive partner who was coming down with AIDS. Al was questioning, "I wonder why it's the insertive partner?" You would think it would be the receptive partner who would get injured or hurt or more susceptible to disease, and in fact it was the assertive partner--the insertive partner. I suggested that perhaps the insertive partner was a more assertive person and went out and had sex with far more partners, and was just putting himself at greater risk.

Recognizing a New Disease

Conant: Then we both talked at that point about the fact that there had been an attempt to associate Kaposi's sarcoma with herpes viruses, and that Giraldo, who was an Italian investigator, had collected some specimens in East Africa, where Kaposi's sarcoma was very prevalent, and had tried to show that it was associated with some kind of agent. He had thought that it was probably CMV, cytomegalovirus, that was the etiological agent.

We're talking now about 1981. Giraldo had done his work in the late seventies. A lot of that work had come to a halt because Idi Amin [president of Uganda] had gone crazy with tertiary syphilis in the early 1970s and had run all the investigators out of Uganda. There was an American called, I believe it was [A.C.] Templeton, who was studying that group of patients, and John Ziegler, who finally joined us [at UCSF], was also in East Africa, studying that group of patients with Kaposi's sarcoma. That's how John got so interested in the whole subject and came to the AIDS epidemic.

Well, Idi Amin went crazy in the early seventies, became very xenophobic, ran everyone out of Uganda. All of that research sort of stopped. And of course, the problem in Africa was that follow-up was very difficult. Patients would be brought by their family for tens to hundreds of miles, treated in the clinic, and then they would return home and you never knew what happened to them. Did they die? Did they get better? Did they get worse?

By '82, it was obvious that what was being seen in Africa was not AIDS-associated Kaposi's sarcoma. The reason was that the African patients were treated very aggressively with chemotherapy --adriamycin, bleomycin, vinblastine. The great majority of them improved and went home in a better state of health than they had been when they came to the clinic.

When we used aggressive chemotherapy on our patients here in San Francisco, they died, and they died because those treatments were immunosuppressive and made them even more susceptible to *Pneumocystis* and other things. So it was clear just from response to the therapy, Wait a minute, these are different diseases.

In retrospect it's amazing, because recent work has now shown to a great degree of certainty that Kaposi's sarcoma is caused by a herpes virus, as Giraldo had expected. It's not CMV; it's being called Kaposi-associated herpes virus, or herpes virus 8. But there's fairly substantial evidence coming now from at least three different laboratories that it is in fact a herpes virus. So Giraldo's thesis was right; he just had the wrong agent.

Hughes: And of course, looking at the possible involvement of CMV was one of the emphases of the early AIDS research effort.

Conant: Yes. Larry Drew, for example, at Mt. Zion, did some of that early work.

Hughes: Was the purpose of the phone call with Friedman-Kien to alert you to look for similar cases on the West Coast? In other words, was there the concept that this might be something that wasn't just a New York phenomenon?

Conant: I can remember talking to Friedman-Kien about how many cases they had seen--I can't remember the exact number--but as I recall, it was fifteen to twenty cases by that time [March or April, 1981]. It indicated to me that, My lord, if you're seeing that kind of case load among gay men in New York, surely we're going to see that here. Groundwater has this case, and now there's the one at Stanford. So all of that began the notion of, We should start looking for the cases here.

I think by that time, Friedman-Kien and the other physicians who were seeing large numbers of gay men in New York were already looking for more cases. I think there were two or three sentinel doctors who already were looking for these cases in their practice, and that's when we began looking for them here.

Hughes: You mentioned fisting. Did that lead you to believe initially that the problem might be how these men were having sex, rather than the fact that they might be having a lot of sex?

Conant: Right. I think a lot of people, and clearly we were among them early on, started asking the typical epidemiological questions. I presented this material to grand rounds [about April 1, 1981], mentioned that I had talked to Friedman-Kien and that he was seeing cases in New York; Jim Groundwater had this case here in San Francisco. It led to a discussion of, What could this be? These cases were showing up amongst young gay men in New York, men in their thirties as opposed to their sixties, and now we knew of a couple of cases in San Francisco.

Marion Sultzburger was at the meeting. Marion was the dean of American dermatology and got up and said, "You've got a new disease. Homosexuality has been here since the time of Alexander the Great, and this disease hasn't been described before. So what you're dealing with is a new disease."

Considering Etiology

Conant: So then the question was, were gay men doing something that was putting them at risk for this new disease? And the same kind of model that had been used for toxic shock syndrome and Legionnaire's disease was used both by us and by the CDC. Hal Jaffe came out within three months, met with me and Bob Bolan and Mitch Koch and a number of physicians who either had large gay practices or who had gotten interested in this. I can remember Hal asking questions like, "Well, could we identify that these patients all went to one gay bar? Or these patients all engaged in some kind of behavior? Or these patients all did poppers?" And the notion was that there was something that they were doing that was putting them at risk for this new disease.

By the end of 1981, certainly by 1982, I think everyone figured it was an infectious disease, like CMV. But very early on, the question was, could it be either something they were doing, like toxic shock syndrome, where it was women who used tampons who were at risk for that disease, or was it a disease that was in one locale? Legionnaire's disease struck a whole bunch of people who had gone to one hotel in Philadelphia. So that was the initial thrust, that exact model of could it be something they're doing, like poppers, or some one place they're going?

And the question of fisting came up early on. Is that putting people at risk for this disease? But I think Marion was right, as he usually was. It wasn't any of those things; it was a new disease.

Recognizing KS and PCP as Part of a Syndrome

Hughes: Angie Lewis described the annual conference of BAPHR in June, 1981, which was the place where she first heard about the epidemic.[1] She remembered that you had introduced Friedman-Kien. Do you remember that, and how it might have come about?

Conant: I don't.

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[1] See Lewis's oral history in the series, The San Francisco Bay Area AIDS Oral History Project: Contributions of the Nursing Profession, 1981-1984, a project of the Department of the History of Health Sciences, UC San Francisco, and the Regional Oral History Office, the Bancroft Library, UC Berkeley. Hereafter, AIDS Nurses Oral History Series.

Hughes: Well, she said it must have been a rather hurriedly prepared presentation, because she remembers very clearly that he had hand-drawn slides. And of course, he would have been talking about KS, because am I not right in thinking that both of you at this very early stage in the epidemic were thinking almost entirely in terms of KS?

Conant: We were, except there was a National Institutes of Health meeting, and I believe it was held in September of 1981.

Hughes: That's right.

Conant: I went to that, and Friedman-Kien went to that. I remember that Al introduced me at that meeting to Mike Gottlieb, because Gottlieb had described the PCP cases. So we were aware that there was this parallel epidemic of *Pneumocystis* in the same population of patients. So while we were focusing primarily on KS, we were aware of the others.

Hughes: Do you remember the *MMWR* that came out on July 3, 1981 that reported PCP in patients with KS?[1]

Conant: That's right.

Hughes: What difference did that make, if any, that PCP was also appearing in gay men?

Conant: I think at least by September, we were all convinced it was the same disease.

Hughes: Was it the July *MMWR* that prompted you to think, Hey, there's much more going on here than KS. We have a syndrome on our hands.

Conant: No, I think it came earlier. Of course, it's very hard to reconstruct, but in looking back, I don't remember being surprised by that *MMWR*. We knew that Gottlieb had seen the PCP cases in February or so.

The interesting thing was that we divided them up. We had the KS Clinic, and then we had Don Abrams doing the lymphadenopathy. And we were treating *Pneumocystis* in the KS Clinic, but those patients were then just kind of lost to follow-up at UCSF. There was no clinic set up to follow the *Pneumocystis* patients. If you had come in with *Pneumocystis*, were treated, recovered, you went back to your doctor and you weren't followed.

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[1] Kaposi's sarcoma and *Pneumocystis* pneumonia among homosexual men--New York City and California. *MMWR* 1981, 30:305-307.

It was the KS and the lymphadenopathy that we were following early on.

Reasons for Involvement in the Epidemic

Hughes: Now, was that just a question of personalities and interests, the fact that there wasn't an ID [infectious disease] person that grabbed onto this disease the way you had grabbed on to KS?

Conant: I think that's right. There were ID people who came to the KS Clinic, Steve Follansbee being the classic example. But he was not at a point in his training where he had the luxury of opening a clinic and following those patients. He was still a young man. So I think you're right; I think it was in fact primarily interest. Don Abrams was an oncologist working out of the oncology clinic, not an infectious disease specialist, and men with swollen lymph nodes were something that an oncologist would appropriately follow.

So it was, I think, just as you suggest: more of an interest on the part of the clinician than an overall view of, Wait a minute, this is all the same thing, and we should have an AIDS clinic that's caring for all these patients.

The Duration of the Epidemic

Hughes: What were you thinking about the duration of this epidemic?

Conant: I'm real clear on that, and I can remember talking about this to Gottlieb and to others. I think all of us felt in those early years that this was going to be a disease like toxic shock or Legionnaire's disease, that we were going to find that, yes, it may be a new mycoplasma or something, or a CMV virus that's acting strangely, or something that people are doing. We're going to tell them to stop doing it, and it's going to go away.

It took all of us, I think, a long time, even after we intellectually knew that that wasn't the case, to emotionally accept, Wait a minute, this is not going away. This thing is going to be there. But in those early years, '81, '82, '83, probably for me up until '85 or so, I felt that this was something that if we could bring enough experts together (hence the KS

Clinic), and we could all share our experiences, that the answer would appear and that we would have an end to it.

Remember, I was the product of that generation that believed that we had conquered infectious diseases, and I believed it. I was wrong, and everybody else was wrong too. We all believed that sure, there were diseases like leprosy that we needed better treatments for, but that we understood infectious diseases and we could conquer those. And then suddenly you've got a new infectious disease that is totally mystifying, and still is in terms of the mechanism of action. How this disease really works, how it kills us, how it makes us sick, is still not fully understood fifteen years into the epidemic.

Hughes: If you had known that this epidemic is unfortunately with us to stay, would you have done anything differently in how you set up the KS Clinic?

Conant: Probably not.

One of the things that determined who was invited to participate in that clinic was the interest of the people that we talked to. You can set up a clinic, but if you're asking people to give up a morning a week and come at no pay and do something just because it's fascinating, you're going to get a very select group of people. So I think in the early period, we were very fortunate to have people, like Jay Levy, who were interested in coming and could come and could make a contribution, and John Greenspan, who set up the tissue bank. So had I known then what I know now, I am not sure that I would have tried to do the KS Clinic differently.

Political Influence

Conant: Now, I would have done some other things quite differently. Had I known then what I know now, I probably would have moved to the East Coast, and I probably would have made a huge to-do at whatever hospital I was associated with about them accepting blood from blood banks. Those are two things that come to mind that clearly in retrospect we could have done a lot more to get much more public attention to this disease.

Hughes: What would have been your motive for moving to the East Coast?

Conant: It has become painfully obvious that, if you live in San Francisco, which is a wonderful place to live, and the quality of your life is good, you have little or no influence on public policy, and you can't have. If you really want to be involved in public policy--decisions, direction, motivation of public programs--you have got to either live in New York, Boston, or Washington.

You've got to be able to get on a plane, fly to Washington, testify, and then maybe fly home and have dinner. From San Francisco, it's a three-day trip any way you hack it. You leave here and you spend most of the day getting there. You testify, and even if you get on a plane and come back that night, you're wiped out. So you're talking about three days out of your life as opposed to an afternoon out of your life.

I learned in '83, when I was trying to fly back and testify before Congress, that you just weren't there enough. The way you really had to do it was to haunt the Hill, really form a network and begin the process of really beginning to try to build a coalition of people who could influence public policy.

That's why I and Don Francis and others tried to do things to influence policy here in California. The notion was, Well, if you can't move to the East Coast and do it, at least you can go to Sacramento. You can create a program which can then serve as a model for the nation. And some of the things we did achieved that. Unfortunately, it was probably too little and too late. It was certainly not enough to stem the epidemic.

Personal Involvement

Hughes: Does this say something about how Marcus Conant perceived his primary role in the epidemic?

Conant: If Marcus Conant ever really examined it from that perspective. I think early in the epidemic, I was a man who in my career needed a challenge, was fascinated by the new disease, felt connected with the community that it impacted, and it was something really exciting and worthwhile doing. If someone had said, "Do you realize that this is going to totally change your life; that you are not going to retire at fifty-five as you had planned to; that you're going to keep working; that you're going to end up with probably the largest private AIDS clinic certainly on the West Coast, maybe in the country; that most of your waking hours are going to spent working on this?", I'd have said, "Now, wait a minute. Let's rethink this." [laughter]

But in actual fact, all of the things that happened you couldn't factor in at that point. It never occurred to me that every person who was a major friend at that point would be dead. By the way, you might as well stay that busy, because by the time you are sixty years old, you're not going to have anybody to go to dinner with unless they're involved with AIDS.

Early on, this was a real challenge, but a challenge that I clearly thought was going to get solved within a matter of a year or two, and life was going to go on as usual.

Hughes: AIDS was a natural thing for a dermatologist in San Francisco to take up? Because not everybody did.

Conant: No, I don't think it was a natural thing for a dermatologist; I don't think the specialty is important. I think there were some other elements that came to bear. One was you had to have the free time, which I had. A man who was trying to put three kids through college probably was so consumed trying to earn a living to educate those three kids that even if he wanted to, he didn't have the time to devote to this.

Another element was it had to be someone who was really interested in a new challenge. There are a lot of people who are very happy going along and doing business as usual and going home at five o'clock, As we talked about in the first interview, I volunteered to work at the Haight-Ashbury Clinic when I first moved here, just because I was fascinated by this new movement and the people there, and that there was a whole generation of kids who were behaving differently. So I think it takes that kind of personality.

And then, I think there are a couple of other elements. I think that one has to be fascinated by more than just your profession. I've gotten very interested in the medical-legal aspects. The transfusion-associated AIDS issue has afforded me an opportunity to spend a lot of time looking at the jurisprudence system in the United States, and that's been a fascination. I'm not sure everybody would be fascinated by spending the time doing that.

I got fascinated by the legislature and how it works, and how one exerts power there. It's not what you do; it's who you know. And does the person you know know how to really use power or not. We're seeing that in the current mayoral election here in San Francisco. We've got four interesting candidates, one of whom really knows how to use power [Willie Brown], and the other three are well-meaning, nice people [incumbent Frank Jordan, Angela Alioto, Roberta Achtenberg]. [laughter]

Hughes: We'll see what happens. [Brown was elected mayor]

Conant: And we'll see what happens; that's exactly right. From my point of view, there's hardly any question in terms of AIDS as to who could get the most done. It's probably not the gay candidate [Achtenberg], though she's extremely well-meaning; and it's not the current mayor [Jordan], though he's a very nice guy; and it's not the ex-mayor's daughter [Alioto], who also is well connected. It is the man [Brown] who has understood how power is exerted for the last twenty-eight years who, if you get him elected mayor, could probably get some things done. So that was a fascination.

Then the final thing that I was blessed with was I like to teach and I like to speak. I think those were necessary elements in terms of being effective in the epidemic. And of course, as you are effective, then the challenge becomes more seductive, and one gets more and more involved, and it feeds on itself. The next thing you know, it totally occupies your life.

Hughes: All good reasons, and it's ten after one.

Conant: We need to stop.

UCSF Faculty Club Luncheon, July 9, 1981

[Interview 8: August 16, 1995] ##

Hughes: On the second of July, you wrote a memo to five of your UCSF colleagues inviting them to lunch at the Faculty Club a week later.[1] You mentioned a "multidisciplinary task force" to investigate KS. I wondered at this very early date what prompted you to think that a multidisciplinary approach would be necessary?

Conant: Well, I think it was obvious from the beginning that what you needed was people who were seeing the disease from different aspects. So you clearly needed an epidemiologist. The GI [gastroenterology] people were already seeing disease, so David Altman, for example, expressed some interest. Since you had an infectious disease, there was the pulmonary problem. The cancer, Kaposi's sarcoma, was not only a skin disease, but was also systemic. So an oncologist, someone who treated the cancer internally, would be appropriate.

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[1] Conant to David Altman et al., July 2, 1981. (KSN 1981-2/1982)

So from the beginning, I had thought of this as a multidisciplinary approach, that it was going to take specialists from a variety of different specialties to answer the question. And of course, that's proved to be true.

What I would be interested in is who were those people?

Hughes: David Altman in gastroenterology was one. Jeff Brooks in infectious disease, Epstein in dermatology, Richard Sagebiel in pathology, and Julius Schachter, who I believe dropped out of the AIDS picture quite rapidly. Why was that?

Conant: Julius Schachter had done some of the work in Africa on the epidemiology of trachoma and eye disease, and was an internationally recognized authority on sexually transmitted diseases.

Hughes: Now, you mentioned oncology, and yet there wasn't an oncologist at the luncheon meeting.

Conant: That's right.

Hughes: Why was that?

Conant: I don't know. When you asked the question, I was thinking, I wonder who in the world I invited? And the only person I could remember inviting was Altman. So that's why I mentioned the GI. I don't remember the lunch, though. At that period in time, a lot of the business that we did about AIDS and Kaposi's sarcoma happened over lunches at the Faculty Club.

Hughes: Why these particular people? Had you had dealings with them before?

Conant: Yes. They were all very close friends and people I'd worked with for years, who I knew would probably be interested in this disease. Altman I think had already seen a case and we had talked about the disease. Bill Epstein was the chairman of the Department of Dermatology, so I clearly needed his support to get the space, to get the personnel, to set up a clinic. Without Bill's enthusiastic support, it could never have happened.

Hughes: Was the luncheon meeting the first time you had broached the issue to him?

Conant: No, I think I had gone to Bill before, had suggested that we have a clinic. And I think he had been enthusiastic. Bill Epstein, with all of his many faults, has always been enthusiastic about supporting new ideas or new approaches, and so I don't think there was ever any doubt in my mind that Bill would support that clinic.

Hughes: There was never any aura of, Why should the university bother with these rare diseases that are occurring in this fringe population?

Conant: Not among that group. That came later from the administration of the university.

Hughes: So I shouldn't read anything deep and heavy into the fact that an oncologist happened not to be at the luncheon meeting?

Conant: No.

Hughes: Those were the people you knew, so you invited them.

Conant: Those were the people I knew, and so those were the people I invited. When we got the clinic going, Paul Volberding came and joined us as an oncologist very quickly. There was really not an infectious disease person per se there. Brooks was a specialist in sexually transmitted diseases; Schachter was STDs; Altman was GI; and Epstein was dermatology.

Hughes: Oh, so I'm wrong about Jeff Brooks being infectious disease.

Conant: Well, he was in the Department of Infectious Diseases, but his real interest was sexually transmitted diseases.

Hughes: What actually happened at that meeting?

Conant: I don't remember. As a matter of fact, I don't remember the meeting, though I remember during the summer the process of trying to get the clinic started. My guess is that we proposed that we start the clinic, and Bill Epstein volunteered the space and a nurse.

Interest at UCSF in the New Disease

Hughes: Was anyone in the Cancer Research Institute in the Department of Medicine aware of what was going on at this stage?

Conant: Not to my knowledge. They became aware, because Volberding and Abrams joined the group and became part of all of this. But there were other oncologists who were not the least bit interested in seeing this disease.

You know, there's another whole subject that's really never been explored. This university had two of the leading retrovirologists in the world. Bob Gallo was sitting back on the East Coast at NIH, and here you had [Michael] Bishop and [Harold] Varmus. Both of them got Nobel Prizes [1989] for their work in retrovirology; neither ever did one thing involved with AIDS, except Harold Varmus chaired the committee that named the virus [HIV]. Harold Varmus' initials are Harold--I believe it's Israel --Harold I. Varmus.[1]

Hughes: Do you have any explanation for their lack of deep involvement?

Conant: When asked, they said that they thought that the time had not come for their level of expertise to be focused on this issue, that they thought it was still too early, that too little was known about the virus--but I have no idea. You would think that retrovirologists confronted with a brand-new epidemic would have been enthralled, or at least have someone in their lab focused on this. But in their defense, their interest had been retroviruses as oncogenes, as opposed to retroviruses as pathogens.

Hughes: Of course, in July 1981 it was certainly not a foregone conclusion that the causal agent was going to turn out to be a virus.

Conant: Or a retrovirus. Precisely.

Defining the Disease

Hughes: How integral was the CDC definition of AIDS to what you were doing? I understand that there was a difference between the CDC definition and the working definition.

Conant: I can't remember ever viewing the CDC definition as either a help or a hindrance. The only thing that it did early on, and in time that got stopped rather quickly, was the public got terribly confused about people who might be infected with this agent and people who had AIDS. You will remember that five years later, when the antibody test became available [1985], there was a tremendous counseling push to be sure that people understood that when you told them that they were HIV-positive, that they didn't interpret that to mean they already had AIDS and met the CDC criteria. Because there was a fear that people would commit suicide or do something inappropriate.

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[1] Varmus's middle name is Eliot.

That notion still persists until today, the notion being that people confuse the two conditions. I don't think most people confuse the two today at all. I think most people know that there is a state of HIV-positivity when people are infected and infectious, that it's progressive, but that they're not at the terminal stages of the disease. But you have arguments still that there needs to be counseling because the public doesn't understand that.

Hughes: What about even earlier than that, well before the virus had been isolated and the antibody test developed, when the CDC formulated a multileveled definition that was to determine a reportable case?[1] I understand that there were instances when it was quite clear that a person did have AIDS, but yet didn't really meet the CDC definition. [tape interruption]

Conant: We had patients in our clinic whom we knew had AIDS but did not meet the surveillance criteria. For example, I can remember a seventy-three-year-old man who used to go to the baths two or three times a week, and he had caught AIDS, and he was dying of AIDS, and he had Kaposi's sarcoma. But remember that the CDC definition said that it is a male under sixty years old with Kaposi's sarcoma. He didn't meet that criterion, so he was not counted; he was not reported to the CDC, and yet he clearly had AIDS.

But that didn't affect our treatment of the patient. We treated him the same way. We knew he had AIDS. But we also understood that if you've got a new disease and you don't have the cause, and you are trying to measure how common it is or how uncommon or if it's increasing, you need fairly explicit surveillance criteria. You've got to say that yes, people do fall into this or fall out, and then if you keep that definition tight and you see the cases going up, then, of course, you know that you've got an epidemic. If you just said, "Any young man with cancer," then people would have been calling in with all sorts of things, and it would have ended up all jumbled, and you wouldn't have had any idea was it really this disease [AIDS].

So if you say, "Yes, we know that Kaposi's sarcoma is very rare, and even very rare over sixty, but it's almost unheard of under sixty, so we'll count every case under sixty and we'll ignore every case over sixty, and that way we can really see, is this disease increasing or is this just a fluke."

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[1] Update on acquired immune deficiency syndrome (AIDS)--United States. *MMWR* 1982, 31:507-508, 513-514. (September 24, 1983)

Remember that early on with any epidemic, the immediate response of your critics is, "This disease has always been there. It's just now that people are starting to notice it." And of course, if you don't have a way of counting exactly, you can't refute that. Remember that at the Amsterdam AIDS meeting [International Congress on AIDS, 1992] a few cases were reported of individuals who were severely immunosuppressed who were not infected with the AIDS virus, and some said, "Oh, my god, a new epidemic." And others said, "Oh, no. Those people have been there all along. There have always been a few people who didn't have normal immune systems, and we're just collecting them."

There was a six-month period where the CDC had to come up with a very precise definition of who was going to fit into this new group, and they starting counting cases, and the case numbers haven't gone up. They've realized this isn't a new disease; this is just background noise. This is just stuff that was there, and we suddenly started to discover it.

Hughes: In one of our early interviews, you said that most patients who came to the clinic had KS, and that "most" surprised me. I thought that the only way that a patient could get to the KS Clinic was because of a diagnosed case of KS.

Conant: You're right, the vast majority had a case of diagnosed or suspected KS. But there was the occasional case that we saw in lovers or friends who came to the clinic. And then as Don Abrams started working on people with lymph node syndrome, he started bringing some of those cases down to the clinic. So the overlap occurred pretty quickly.

Hughes: How did you diagnose people who were obviously sick, and maybe their T cells were down, but they didn't have these marker diseases--KS and PCP and so on? Maybe they just had night sweats.

Conant: We were not seeing those cases. There weren't many of them. Remember that most people with AIDS, even when they're far advanced, still feel great up until the day they start getting PCP, *Pneumocystis*. So yes, there were in those days lots of men running around this town who were severely immunosuppressed, nobody knew it, and then the next thing you knew, they'd end up in an emergency room unable to breathe.

More on the Kaposi's Sarcoma Clinic

Paul Volberding as Co-director

Hughes: The first clinic was held on September 21, 1981. Can you remember, was Dr. Volberding actually in place as co-director from the time of that very first clinic?[1] [interruption]

Conant: Paul Volberding had come to me prior to the meeting at the National Institutes of Health [September 15, 1981]. We had talked about doing this clinic together. We then had talked a great deal more at that meeting at the National Institutes of Health. We even asked John Ziegler at that meeting to join us in help making the KS Clinic work. John Ziegler was still at the NIH at that point, and he was just coming here as dean.[2] So it was the opportunity to talk to him about, "When you come, we really want you to be involved."

So my recollection is that yes, Paul and I were clearly doing things in concert at that time. If the meeting at the NIH was the fifteenth of September, then Paul and I clearly were doing things in concert on the twenty-first, from the beginning.

Hughes: Can you picture that first clinic?

Conant: No. [laughter] I have pictures of some of those first clinics.

Hughes: Where are they?

Conant: Around here somewhere.

Hughes: Do you remember how many patients there were?

Conant: No.

Hughes: Where would the patient records be?

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[1] In a memo announcing the first session of the KS Clinic on September 21, 1981, Conant stated: "Dr. Paul Volberding has graciously consented to volunteer his time to serve in this clinic..." (KSN 1981-2/1982)

[2] In 1981, Ziegler became Associate Chief of Staff for Education at the Veterans Affairs Medical Center, San Francisco, and Professor of Medicine, UCSF. (Ziegler curriculum vitae in interviewer's possession.)

Conant: Sorry, I have no idea. I would assume the university has records, but I would bet you they can't tell you which patient who was registered at that time went to which clinic.

Hughes: It would just be registered as dermatology in general?

Conant: Bill James going to dermatology; that's right.

Multidisciplinarity

Hughes: Now, the clinic, as you well know, was established as a combined dermatology-oncology clinic. Was that a common thing to do in dermatology?

Conant: No. It was extremely common in those days to have specialty clinics in dermatology. We had a wart clinic; we had an atopic dermatitis clinic; we had a psoriasis clinic; we had a mycosis fungoides clinic; we had a patch test clinic, we had all sorts of specialty clinics. So it was perfectly normal to have a clinic in dermatology. The combination was rare, though there were times in my career where we would have a pediatric derm[atology] clinic, and you'd have a pediatrician and a dermatologist there. So it was not unheard of. It just wasn't common.

Hughes: What was the significance, if any, of having these specialists actually part of the clinic? Another way of doing it could have been to set yourself up as clinic director, and then consult with other specialists. I know you did refer patients around the hospital, but my understanding is that the main effort is physically located in one place, in the clinic.

Conant: That's right, and it evolved and changed over time.

Interest in Patient Profiles

Conant: In the beginning, with the very first patients that summer, everyone was so fascinated, some people hadn't seen one of these cases, that everybody was seeing every case. And then, of course, you would realize that after a few weeks, you'd seen it. There was nothing new to see or show.

I can remember a patient--his first name was Simón--

Hughes: Guzman.

Conant: Simón Guzman. We took him into a side room, because he had lesions between his buttocks. They were a mirror image--I have a picture of that, too. It's almost like an ink blot. I can remember John Ziegler talking about the significance or the lack of significance of that finding, and there must have been fifteen people inspecting this area, because everybody was so struck with the symmetry of this disease. Fifteen years later, none of us think anything about that, because everybody knows Kaposi's sarcoma is a symmetrical disease. But early on, that was not appreciated.

So the point I'm trying to make is that in the very early days of the clinic, everybody was seeing every patient. And then as the patient profiles became repetitive, Dr. Holliday or Dr. Mehalko or Don Abrams or I would see the patient, we would work him up, and we would only present a patient to the group if the patient presented with some unusual finding, or there was something that was unique about that patient.

The Kaposi's Sarcoma Study Group

Conant: As I remember, the clinic would meet from nine or ten in the morning until eleven or so.[1] And then from eleven to twelve was when all of the other people from the other disciplines would come, and we would have a formal meeting from eleven to twelve, where we might present a patient, we might present a follow-up on a patient, or we might ask one of the members of the group to present data that they were working on. I can remember at certain meetings Jim Curran from the CDC was here, and we had him present. You will remember that with the transfusion-associated AIDS issue, I invited Herb Perkins to come and present. We had Art Ammann present; we had Selma Dritz present; we had different people from different disciplines present.

At one point, we listed every case we had on the chalkboard. There was a point when you could do that because the numbers were small. We listed them by initials and when they'd first gotten their KS and what kind of treatment they had had, and what had happened to them. And of course, most of them had died. So we

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[1] As of October 1981, the KS Clinic met on Thursdays from 9 a.m. to 11 a.m., followed by the study group from 11 a.m. to noon. (Conant to Corrina Kaarlela, October 1, 1981. KSN 1981-2/1982)

were going down this list, and he had died, he had died, and he had died.

We got to P.D., and either Paul Volberding or I, whoever was chairing the session, said, "Who is taking care of P.D.?" Paul Dague, who was sitting in the audience and who was a psychologist, said, "That's me. Let me tell you what happened." So he told us about his treatment and what had gone on. It was extremely poignant, because one of the participants was reporting on himself and placing himself in this continuum of people who were still alive and who had died.

Numbers of Cases

Hughes: One thing that I have to keep reminding myself to keep track of is the fact that, for at least the first years, you weren't dealing with very many patients. That struck me as I was rereading your congressional testimony to [Henry A.] Waxman's committee.[1] I suspect it was the first time you appeared before Congress; it was April, 1982.

Conant: That hearing was held in Los Angeles. It was me and Mike Gottlieb.

Hughes: Do you know how many patients you were seeing at that point in the clinic? I'll tell you, because it was in the testimony.

Conant: April of '82? Let me think. We probably had no more than ten or twelve.

Hughes: You had twenty. I tend to think that there were floods of people coming to the clinic, but there were not, were there?

Conant: No, there were very few. But of course, the thing that was so scary was not how many were coming in, but the rate at which the numbers coming in were increasing. It's not how deep the water is; it's how fast it's rising around you that scares you to death, and it's the same thing here. You didn't have to be a rocket scientist to figure out what was happening and how bad it was going to get.

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[1] Marcus A. Conant, M.D. Testimony before Congressional Committee on Health. (draft) April 13, 1982. (KSN 1981-2/1982)

Remember, when we handed out that little brochure in December of 1981, there were ninety-one cases of AIDS in the world, in the whole world. And today there is what, 20 million?

Hughes: Hard to believe.

Campus Support

Hughes: I imagine when you were talking to non-medical people that your point--that the numbers are small but the significance is great--was a rather difficult one to put across. Did you have problems getting support from the UCSF administration? Not just funding, but it was clear from the very first that psychosocial support was going to be necessary. It seems to me that for anybody who wanted to find an excuse to not provide help, that one of the easiest things to say was, "You're only dealing with a handful of patients. How can you expect us to give you what you're asking for?"

Conant: You're exactly right. The hardest thing in the world is for people who don't think in numbers to think in terms of an exponential, and that's exactly what you're doing.

Hughes: Well, you had the support of your department, and you had the support of a core group, all of whom had a reason to be interested in the epidemic. But what about your other colleagues and what about the administrators in those very early days?

Conant: Well, it was a mixed bag. There were lots and lots of people on campus who were supportive, but not activist. For example, there were a number of gay colleagues in various departments who would come up almost surreptitiously, almost furtively, in the halls, and say, "I just want to tell you I think what you're doing for the [gay] community is a wonderful thing." But the commitment for them to then get their department involved was not there.

Now, at that point, it made sense. I never tried to attribute why they didn't do it. They may have had their plate full with other things. But there was a lot of support on campus that I perceived from gay colleagues who clearly favored what we were doing; asked me to give presentations at their departmental meetings, both here and at Stanford.

The opposition came at the highest levels, and not, by the way, from the chancellor. Julie Krevans was amazingly supportive all the way along. When Sacramento called me, for example, with issues about, "Would you be interested in state funding not coming through the traditional university channels?", I called Julie Krevans and said, "What do I do?" He said, "You just go ahead and do it, and just keep me informed." For a chancellor, that's amazing support.

Hughes: Why was he supportive?

Conant: I truly don't know the answer to that. As a matter of fact, there have been lots of people in this whole thing that I've never understood. It may be that there really are good people in the world. [laughter] I mean, who knows! But Julie was very supportive.

Rudi Schmid was not supportive. I've had this conversation about support with Rudi, and he doesn't understand his level of homophobia. He is not an evil man who is homophobic. The idea that there is a gay community and that colleagues that he respects may be gay is beyond the pale. He just cannot comprehend that. In '83 he became dean [of the UCSF School of Medicine], and we never got the support from his office that we should have had and could have had with a little more visionary leader.

Bill Kerr [chief medical center administrator] was ambivalent. Bill questioned seriously whether "these patients" should be here at UC. And yet Bill Kerr and I were old friends going back for probably two decades. We had known each other well. I at that point had the ability, and still do, to call his secretary and say, "I need to see him this afternoon," and I can get in there and see him.

Reluctance to Have AIDS Patients at UCSF

Conant: So it came to my attention that Berkeley and UCSF senior administrators were thinking of not allowing these patients to be at this hospital.

Hughes: Why?

Conant: There were three reasons given, and over and over and over again. Interestingly enough, these same reasons were given at Stanford. It is my impression that these three perceptions were the reason that the university finally made the decision not to have these patients here. Remember that the AIDS patients at UC were moved to San Francisco General. The AIDS patients at UCLA were moved to USC [University of Southern California]. That's why Mike Gottlieb ran out of AIDS patients. He had to stop being an AIDS expert at UCLA because there were in essence no AIDS patients at UCLA. They capped how many AIDS patients there could be at UC Davis. There could only be so many, and no more. And I am told, and do not have first-hand knowledge of this, that Stanford also made the same decision. They did not want AIDS patients in the hospital.

The perception was three-fold. One was, "Those kinds of people won't have any money." Perception number two was, "Our students are coming from all over the United States to learn about medicine, and all of our patients will have some weird disease [AIDS] which they will never see again when they go home to Minneapolis."

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Conant: And the third reason given was, "We don't want our referring doctors to know that we have `those kinds of patients,' because if it's known that UC is a magnet for `those kinds of people,' then our referring doctors will send their patients to our competition, because their patients won't want to be in the hospital with an AIDS patient."

Now again, in a more enlightened society, if you had had a dean that stood up and said, "This is the most exciting thing to happen to medicine since the time of William Osler, and follow me, guys, we're going to go up there and figure this thing out," and had led rounds once a week, and had been excited about it, and the University of California, San Francisco, had become the hub of where AIDS research not only was happening but was happening clinically, we could have probably done far more than we did. But the notion was, "We don't want those people here." So even though the university is walking distance to the Castro, they chose to move the AIDS Clinic to San Francisco General.

The UCSF Department of Medicine

Hughes: What about the role of the Department of Medicine? As you well know, in many locations, AIDS activities are centered in the Department of Medicine.

Conant: Again, it was very slow in coming. For Holly [Lloyd H.] Smith, who is an old and dear friend, who was the chairman at the time, AIDS was not one of his high priorities. When I finally went to the California Assembly and got the money for an AIDS clinic here at Moffitt Hospital,[1] Holly Smith supported that. That was Harry Hollander's clinic, and I think he started that about 1984. So the Department of Medicine came, but they came with the carrot of money to open a clinic, rather than the way Bill Epstein did, which was, "I'll put up the money for you to study this new disease."

Hughes: What was the interaction, if any, between the clinic, which is the Adult Immunodeficiencies Clinic, and AIDS activities at San Francisco General? Were they supposed to be collaborative, or were they set up as distinct, discrete entities?

Conant: They were set up as discrete entities, funded by different sources. The one at San Francisco General got its major support from the city; the one here at the university got its major support from the state. But there was a degree of collaboration between the two. This epidemic has not been characterized by medicine coming together and saying, "We have a challenge to all of us which we are going to work together to solve." People have in fact carved out empires and have held their territories.

Shifting AIDS Activities to San Francisco General Hospital

Hughes: When the shift towards San Francisco General began, which certainly was happening by 1983--that's when the AIDS Clinic opened at San Francisco General, and the ward a bit later in the same year--did you ever consider joining the exodus?

Conant: Oh, yes. As a matter of fact, I can remember numerous conversations with Paul Volberding about keeping his loyalty split between us up here at UC and Merle Sande down at San Francisco General. Remember, Dr. Sande was the chairman of the Department of Medicine [at SFGH]. If the whole thing moved, lock, stock, and barrel to San Francisco General, then Paul was clearly going to be under the thumb of Dr. Sande. I tried to persuade Paul of the wisdom of keeping a dual alliance between the two institutions, and that way would give him greater mobility in terms of making decisions.

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[1] On July 1, 1984, the "Adult Immunodeficiencies Clinic," in the UCSF Department of Medicine, opened at Moffitt Hospital, funded by the $100,000 Conant raised from the state legislature in Sacramento. (Conant to Howard Maibach, October 9, 1984. KSN 1/84-12/85.)

And initially, he tried to do that. I can remember on one occasion he said, "Why don't you just come down here, and you'll make my life a lot easier than my trying to be in both places at the same time?" So yes, we had those discussions, and had them directly, about the wisdom of my moving down there.

Hughes: Was this event upsetting to you?

Conant: No, not really. I can remember a point that I was upset that the leadership up here was clearly waning, and that, if we were going to run this clinic effectively over at the university, we needed to bring in someone in the Department of Medicine who was a strong leader, who could come in there and organize and run it and make it grow and flourish. I met with Rudi Schmid on two or three occasions regarding that, without any success.

And what was happening, of course, is it was fragmenting. Because as the emphasis got pulled more and more to San Francisco General, then you had situations where Dr. Levy perceived that the people at General were not working as closely with him as they should, and that he wasn't getting specimens, or John Greenspan perceived that there was not the cooperation that he should have. Of course, the only way to do that would be to have a full-time leader here who had the same kind of presence as the chairman of medicine.

Clearly, there were enough patients to have major AIDS clinics at both facilities. But the chancellor, the dean, Rudi Schmid, was not persuaded of the wisdom of doing that. So what we did was to hire Harry Hollander to run the Adult Immunodeficiencies Clinic, which never became a competitor to the clinic at San Francisco General.

Hughes: Because it didn't have the administrative support?

Conant: That's right. Or the charismatic leadership.

Hughes: Where was the decision made to shift many AIDS activities over to the General?

Conant: I have been told repetitively, and I do not know this from first-hand knowledge, that that decision was made in the [UC] President's Office at Berkeley, not at this campus, not at UCLA. It happened simultaneously at both places [ie. AIDS activities were shifted from UCLA to USC, and from UCSF to SFGH].

Hughes: Not necessarily by the president [David Saxon] himself?

Conant: That's right. My guess is that the decision was probably made by Conn [Cornelius L.] Hopper [Special Assistant to the President, Health Affairs].

Hughes: Do you have any comment to make about the name of the clinic here at UCSF?

Conant: Well, I called them the day they named it Adult Immunodeficiencies Clinic and I said, "Who are you trying to kid?" [laughter] I said, "It spells AIDS, but you don't want to call it AIDS." I got some silly story about how there were other adults with immunodeficiencies, and they wanted to serve that population. But you know, that's a clear example of people not wanting to face the reality of what's happening. "We can't call it the AIDS clinic, because we're afraid doctors won't send patients to this hospital if they know we have AIDS patients."

The Clinic as a Consultative Unit

Hughes: Now, one of the differences, as I understand it, between the KS Clinic and the clinic and ward that evolved at San Francisco General was that they were set up to provide ongoing care for AIDS patients, whereas the KS Clinic was designed for patient evaluation and research and not intended to provide ongoing care.

Conant: There's truth in that. The KS Clinic was clearly set up to see patients in consultation from private physicians in the community, with the notion that we would take histories, we would do examinations, we would draw blood, we would store specimens, we would take pictures, but the patient would go back to his or her doctor for their ongoing care.

Now, a time came when patients who didn't have a doctor [presented themselves at the clinic]. Patients heard about us and came off the street, or they would show up down in ambulatory clinic screening and say, "I have Kaposi's sarcoma, and they said there was this clinic up here at UCSF." So we ended up with a group of people for whom we were providing ongoing care. So again, it evolved. It started off clearly as a consultative clinic, which then grew into a clinic that ended up providing care.

For the other [dermatology] clinics that I cited, like the mycosis fungoides clinic, it was just that. Patients were flying in from all over the state for consultation as to what to do about their mycosis fungoides. We have a melanoma clinic right now that's the same thing. I have a patient from Oregon who sees me but goes once a year to the melanoma clinic at my urging for evaluations and state-of-the-art recommendations.

We saw the KS Clinic as a consultative clinic for the patient and his doctor, so what the patient got out of this was hopefully state-of-the-art information. What the doctor got out of it was a report back saying, "Here's what we see is wrong with the patient. Here's what we think you ought to do." And what the whole group of us, the interdisciplinary group, got out of it was that we had the opportunity of getting blood from this patient or a specimen or whatever.

But a time came when the KS Clinic did start growing into an ongoing clinic, and it was that base of patients that were then moved to San Francisco General.

Hughes: The consultative pattern of the KS Clinic was the more typical for dermatology, was it not?

Conant: Right. Precisely.

Hughes: Dermatology in general doesn't provide comprehensive, ongoing care, the way some other specialties would expect to?

Conant: It's split. For example, you have dermatologists who, say, take care of a patient with psoriasis. It ends up the doctor cares for that patient for thirty years and sees the patient once every two months. That patient will, in addition to his dermatologist, have an internist who does all the other stuff.

But you also have the patient who has never had a rash before and suddenly gets an itch. The internist sends the patient to the dermatologist, who does the necessary studies and says, "Your patient has scabies. I gave him a prescription for a cream, and I'm sending him back to your care." And then the dermatologist never sees that patient again. So it's split about 50-50.

Relations between the Clinic and Community Physicians

Hughes: With this system that you're describing, it seems to me that your relations with community physicians would be quite involved. You have to get patients from them. Sure, there are a few other routes by which they can arrive at the clinic, but most patients are referred by community physicians, right?

Conant: That's true.

Hughes: What responsibilities did you feel to the community physician who had to deal with a patient with a disease that at least in the early days he had never seen before?

Conant: I'm afraid that all we were providing early on was a pathology consultation, which said, "Yes, this really is this new disease; this is Kaposi's sarcoma." Then we would suggest therapists who would treat the patient. For example, we would say, "Dr. Volberding in the oncology clinic is treating these patients with adriamycin and bleomycin and vinblastine." And then the doctor might choose to send the patient to Volberding or to some other oncologist for treatment. So it was just as I described it: It really was a consultative service initially, generally with a letter back to the doctor.

Of course, then as it grew, and many patients started coming back to us, then we took over the patients' care.

Hughes: Did that cause any trouble with community physicians?

Conant: No, I can't remember any. As a matter of fact, it was my impression that people were delighted to let us take care of the patients. I can't remember any ill feelings from community physicians. Most of them were very supportive.

Patient History Confidentiality

Hughes: When I talked with Helen Schietinger, she expressed concern about confidentiality in reference to the extensive sexual histories that you were taking from clinic patients. These histories went into the patient's record, in code of some kind.[1] How did you feel about confidentiality?

Conant: Early on, it is true that the entire sexual history, and we were asking things like fisting, was going into the patient record. But a time came when Helen, or the person [Frank Baumgarten] who followed her as nurse-coordinator of the KS Clinic, persuaded us

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[1] See Schietinger oral history in the AIDS nurses series.

of the wisdom of keeping that sexual history separate. So we kept a separate chart of all those sexual histories.

But there certainly was a confidentiality issue. Fortunately, in San Francisco, it never materialized into anything. I can't think of anyone that was injured by that, but it had the potential.

The Clinic and Study Group--an Integral Unit

Hughes: Did the study group begin with the very first clinic on September 21, 1981?

Conant: It's my impression that it did.

Hughes: I've noticed in your correspondence that you used the term "clinic" in a very broad sense. You sometimes used "clinic" to include the study group. Does that usage indicate how interrelated the two were?

Conant: Yes, I thought of them as the same thing, and still do. The study group in essence was the whole group coming together to share knowledge. But I must admit that I have always referred to that as "the clinic."

Hughes: Would other people make more of a distinction between the seeing-patients function and the research-discussion function?

Conant: You know something, I can't answer that. I think William Osler would have understood exactly what we were talking about. But I don't know if today a distinction is made, that at the time you're actually seeing the patient, that's called "the clinic," and the time that you're actually talking about the patients is called something else. But certainly in my mind, I call both of them "the clinic."

Hughes: Although you sent out memos addressed to members of the "Kaposi's Sarcoma Study Group."[1] You used that term, too.

Conant: Yes.

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[1] See, for example, Conant to Kaposi [sic] Sarcoma Study Group, November 6, 1981. (KSN 1981-2/1982)

The Clinic as Center of the Early Medical Response

Hughes: For the first two years of the epidemic, 1981 through 1982, do you think it is accurate to think of the KS Clinic as the center of the early medical response to the epidemic in San Francisco?

Conant: Yes, no question about it. I don't think there was anything else that you could even point to. Now, there were clearly physicians in this city who were interested in this disease. Bob Bolan comes to mind; Jim Groundwater comes to mind. But I can't think of any other group or activity or focus--

Hughes: The health department?

Conant: It was the other way around. Selma Dritz was coming to us. Now, Selma was doing a great job tracing the cases of amoebiasis and counting the number of KS cases, but in terms of trying to understand what was going on, I think that it was coming from the clinic back to the city, rather than the other way around.

Hughes: When I talked to Merv Silverman,[1] he quite frankly allowed that his first real engagement in the epidemic was with the bathhouse issue, which doesn't--

Conant: --start until '83, '84.

Hughes: Right. He knew that the epidemic was going on, but his deep involvement began with the bathhouse issue.

Conant: I chaired the California Medical Society section in '83 in Anaheim. I was invited by the CMA to be the chair for the dermatology section. It had nothing to do with AIDS; I was a well known dermatologist, and had been teaching for a long time, and was recognized as a good teacher. So I was asked to chair the teaching section.

So we put on a program on AIDS at that meeting. That would have been the spring of '83. Merv Silverman was at that meeting and walked on to an elevator. It was the first time that I can ever remember shaking hands with and knowing who Merv Silverman was. Prior to that, I had always worked with Selma Dritz. So he's absolutely right; he came to it in '83.

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[1] See the oral history in this series with Mervyn F. Silverman, MD, MPH, director of the San Francisco Department of Public Health, 1977-1985.

More on the Study Group

Hughes: Angie Lewis told me that the very earliest meetings of the study group, after the clinic, were held in a conference room near the clinic[1]--on the same floor?

Conant: Yes.

Hughes: Was that room large enough to hold everybody when the interest in AIDS peaked?

Conant: Sure.

Hughes: Can you give me an estimate of how large that group might have gotten at its height?

Conant: Sixty at the most.

Hughes: Did people come from outside the city, and who were they?

Conant: Sure. Sylvia Hoag, who was a blood banker, came from the East Bay. There was a woman epidemiologist who would drive down from Sacramento on a weekly basis, and her name was--oh, dear, sweet woman. Can't remember her name. There were people coming over from the VA, there were people coming over from Ralph K. Davies [Medical Center]. Paul Dague, who was in private practice downtown, would come. So yes, there were people coming from all over, and everybody was welcome. Well, the blood bankers were invited once, and came once, and didn't come back.

Sylvia Hoag came because she was interested in transfusion-associated AIDS. But it was really not clear why some of them came. Some people were just mesmerized by this disease. Arthur Holliday is a straight physician who lives down in Los Gatos or somewhere down there [south of San Francisco]. He was clearly getting toward retirement; he was probably eight to ten years before he retired. He came up and volunteered a morning a week for almost three years. He called me; I didn't recruit him. I would ask him, but I've gotten just pleasant answers. I've never understood his motivation. Admirable, but I've never understood it.

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[1] See Lewis's oral history in the AIDS Nurses Oral History Series.

Support from Willie Brown

Conant: And Willie Brown. Willie Brown came to the AIDS epidemic in 1983 and made it clear that he wanted funding for the university to do this [AIDS research], that there would be no university fee [overhead] on top of those funds--the university generally takes 50 percent of everything. There would be no fee; the money would all go for AIDS. And in the first year, that was $3 million. The highest I think it got up to was $12 or $14 million one year. But the allocation was renewed annually, and still is, until now it has been more than $100 million that the state has put directly toward AIDS research as a direct result of Willie Brown's leadership back in '83.

Now, I can remember flying to Sacramento and standing in the airport thinking, What price is going to be extracted for this? I mean, I have great admiration for the Speaker, but I also understand that he is a very shrewd politician. I am standing there thinking, He has just given me, or the effort that I'm fighting for, $3 million. People don't just give you $3 million. Yet the Speaker has never asked for anything.

Now, when he decided to run for mayor, I actually called his office and said, "I'd like to do what I can to support you," and he has let me do that and I think has welcomed my efforts. How come he had that insight at that period?--in San Francisco, a black leader who gets the base of his support not from the gay community but from the black churches, where homosexuality is not approved of. What in the world would lead that man to make a move like that? Most shrewd politicians would stay as far away from that as they possibly could.

The real supporters we have had in Congress and in the state have either been politicians who are elected from almost exclusively gay areas--Waxman from L.A. and Weiss from Greenwich Village are two examples--or black men and women. And of course, the first group is self-evident. They got elected because their constituencies are gay. I think one of the reasons that black males and females have no problem with supporting AIDS funding is they will not be thought of by the public as gay or gay sympathetic. You have your average straight man who's out there fighting for AIDS, and he's afraid everyone's going to say, "Wait a minute. Why is he so interested in these people?" Whereas black men don't have that problem.

Hughes: That's interesting.

Conant: We must stop, dear heart. I hate to, but I will be happy to do an interview again any time.

Hughes: Thank you.

Transcribed and Final Typed by Shannon Page

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Berkeley, California

The San Francisco AIDS Oral History Series

THE AIDS EPIDEMIC IN SAN FRANCISCO: THE MEDICAL RESPONSE, 1981-1984

Volume II

Andrew R. Moss, M.D.

AIDS EPIDEMIOLOGY: INVESTIGATING AND GETTING THE WORD OUT

Interviews Conducted by
Sally Smith Hughes
in 1992, 1993

Andrew Robert Moss, ca. 1995

INTERVIEW HISTORY--by Sally Smith Hughes, Ph.D.

Epidemiology dominated AIDS science in the early years of the epidemic before the virus was isolated in 1983. Only then could laboratory science, armed with a tangible infectious agent, take off. Before this disciplinary shift, epidemiology held pride of place, its practitioners bent on identifying the factors determining the frequency and distribution of the new disease.

Andrew Moss was among the earliest of these AIDS epidemiologists, and not surprisingly, it is epidemiology that takes center stage in this account. He tells, among other things, of studies launched, funding sought, and rivalries engendered. Among the most pivotal of these early studies is his "AIDS incidence study" which uncovered terrifyingly high rates of infection in the Castro District, the geographical center of the city's beleaguered gay community. The medical, social, and political implication of his findings brought him into contact with gay activists, city and state politicians, and cemented his ties with medical and scientific colleagues at the University of California, San Francisco.

Moss's freewheeling discourse highlights the political and personal intrigues which inevitably followed. He is not loath to talk of personal foibles, turf battles, and the undercurrent of stigma and homophobia which shaped the development of AIDS activities in San Francisco and elsewhere.

Aside from Moss's highly contextual account of AIDS epidemiology, his reactions to the horrors of the epidemic and the problems it raises for him and for everyone it touches are one of the strengths of this oral history. While some may find his off-the-cuff remarks indiscreet, they also might represent a necessary personal distancing from the cruelty of the disease itself. Perhaps Moss expresses more explicitly an aspect of the epidemic which others prefer to gloss over: the self-protective mechanisms which those engaged in the epidemic devise in order to function as professionals and human beings. The foregoing is speculation; what is certain is that Moss's personal account reveals, in a way official documentation does not, the impact of the epidemic on human lives.

The Oral History Process

The first interview was recorded on September 30, 1992, in Moss's cramped office in Ward 95 at San Francisco General Hospital. The second interview occurred on March 18, 1993, while Moss had a brief respite from research in New York City on drug-resistant tuberculosis. A tall, disheveled man with an English accent and American phraseology, Moss spoke with intermittent cynicism and passion of his experiences. The transcripts were edited and sent to Moss, who made minor changes, offering further help, if needed. Because the transcripts were reordered for better chronology after his review and because of the frankness of some of his remarks, Moss agreed to a second review, again making few changes except for deleting one or two contentious remarks.

This oral history vividly reveals both the professional and human aspects of the epidemic, aspects not readily found in the biomedical literature. It provides a highly personal account of early AIDS epidemiology, and, like all human endeavors frankly documented, it also reveals human nature in its great complexity, tested by a disease which unveils the strengths and weaknesses of contemporary society.

Sally Smith Hughes, Ph.D.
Senior Interviewer
March 1996

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name ANDREW MOSS

Date of birth OCT 30 1943 Birthplace LONDON, ENG.

Father's full name LOUIS MOSS

Occupation CIVIL SERVANT Birthplace LONDON

Mother's full name WINIFRED MOSS

Occupation MEDICAL SOCIOLOGIST Birthplace LONDON

Your spouse DIVORCED

Occupation Birthplace

Your children WILLIAM, JESSE, NICHOLAS

Where did you grow up? UK - LONDON

Present community S.F.

Education B.S., MSc LONDON SCHOOL OF ECONOMICS
MPH, Ph.D. BERKELEY

Occupation(s) EPIDEMIOLOGIST / WRITER

Areas of expertise INFECTIOUS DISEASES

Other interests or activities LITERATURE, VISUAL ARTS, US WESTERN HISTORY

Organizations in which you are active INTERSECTION FOR THE ARTS, SAN FRANCISCO

I EARLY CAREER

[Interview 1: September 30, 1992, Dr. Moss's office, San Francisco General Hospital] ##[1]

Hughes: Dr. Moss, please tell me how you came to be an epidemiologist.

Moss: Epidemiology is my second career. I came to the United States [from England] in 1966 and went to Stanford and dropped out in 1968 and was a journalist and political activist until the mid-seventies. Then I went back to school at Berkeley and got a doctorate in epidemiology.

Hughes: Why in epidemiology?

Moss: I had originally been quantitatively trained, in statistics, and I didn't want to do statistics, but I wanted to do something quantitative. I looked at economics and city and regional planning, and somebody suggested epidemiology. They had fellowships, and I was a single parent, so I needed the money. So I did epidemiology because it was in my range and it was fundable.

I wasn't particularly interested in it. I certainly wasn't particularly interested in infectious disease epidemiology; nobody was in those days. There was not much infectious disease epidemiology taught at Berkeley.

Hughes: Because of the premise that the problem was solved?

Moss: Yes. The antibiotic era had removed infectious diseases as a major issue in Western countries. Infectious disease became a part of international health, more or less, until AIDS.

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[1] ## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

So I became a cancer epidemiologist, and I went to work near Stanford at a para-Stanford institute. Then I came to UCSF [University of California at San Francisco] in 1981 and did cancer epidemiology on testicular cancer and brain tumors and Hodgkin's disease.

II THE AIDS EPIDEMIC

Recognizing the Epidemic

Hughes: What was your first awareness of the epidemic?

Moss: I live in the Castro [District], on Liberty Street, which is right between Castro [Street] and Noe. That's four blocks from 18th and Castro. I have lived there since before it was gay, and lived there while it went gay. I was always very interested in what was going on in the Castro. I was an editor in the 1970s at Ramparts Press in Berkeley, and we published one of the early gay liberation books. So I'd had an eye on it all; it grew up right around me.

I bought my films at [former San Francisco Supervisor] Harvey Milk's camera store two blocks from my house, and my kids used to play the video games at the Spaghetti Factory. I took them to Cliff's [Variety Store] Halloween party before Halloween was gay. The Castro was a decayed Irish working-class neighborhood, and in the late sixties and early seventies, Cliff's Variety on Castro had a Halloween on a flatbed truck which was a kids' Halloween, and I used to take my kids down there. We moved there in 1974, and then had watched it go gay.

In 1981, I picked up somehow on my standard professional antenna the *MMWR* [*Morbidity and Mortality Weekly Report*] announcement,[1] and I somehow got the message that this was cancer. Kaposi's sarcoma was the manifestation that got people's attention in San Francisco, probably because [Marcus] Conant is a dermatologist, and that's the way he sees it.

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[1] Centers for Disease Control and Prevention. Kaposi's sarcoma and *Pneumocystis* pneumonia among homosexual men--New York City and California. *Morbidity and Mortality Weekly Report* 1981, 30:305-307 (July 3, 1981).

So here we are. It's presented as an infectious cancer, which is a very big deal for a cancer epidemiologist. But also it's presented as a gay disease in the Castro. So I started watching the Castro. My route to work those days was to walk down Castro Street to Castro and Market and take the bus. So I walked down Castro Street, and I read the covers of the magazines in the bookstores.

So some time in 1981, I think *Christopher Street*, one of the gay magazines, came out with a cover that said something about Kaposi's sarcoma, and I read it. I just gradually began to get the idea late in 1981 that there was this thing happening.

Hughes: You didn't come into contact at UCSF with people talking about it?

Moss: No. Our department, epidemiology, didn't have many infectious disease people in it. We didn't deal with the medical service, which is where there would have been cases. I don't think there was much talk at UCSF about it, really the core of UCSF, in 1981. UCSF has never really been very interested in AIDS.

Hughes: Why?

Moss: Well, there's a big process that goes on eventually whereby they decide they don't want to have AIDS patients at UCSF. That's why they're at San Francisco General [Hospital, SFGH], right? They pushed them down here for two reasons. One is the homosexuality issue, and the other is the infectiousness issue. It's hard to tell which is paramount. But the AIDS patients did end up down here, and the AIDS Clinic is here, and San Francisco General is the best AIDS hospital in the country as a result of that decision. Paul [Volberding] will blame it on Brian Lewis [associate clinical professor of medicine, Cancer Research Institute, UCSF], who was head of the cancer service at the time, not being interested in AIDS.

Hughes: Which is not true at San Francisco General?

Moss: Well, it's less true here. It's a complex issue.

Hughes: But perhaps that was true of every medical institution.

Moss: It might have been. Certainly of every first-line medical institution, because they're very conservative institutions.

Hughes: This institution is less so, at least that's my impression.

Moss: Well, [UCSF is] different, because it's on the West Coast and it's autonomous. It has its own universe. But I think it's quite conservative.

Hughes: I mean San Francisco General.

Moss: Oh, San Francisco General is very different. It's a very interesting institution. It's the left wing of the UC system, and it's full of all the left-wingers and oddballs and people who cannot exist within that kind of structured hierarchy up there [at UCSF]. It's a wonderful place; it's a great place, San Francisco General. Nick [Nicholas L.] Petrakis [professor emeritus, epidemiology and biostatistics, UCSF] said, "You'll like it down there; everybody who goes there likes it." And it's true. I do, and people do, because it's a different atmosphere from the very rigid UC atmosphere.

Key Players at San Francisco General Hospital

Moss: Anyway, the AIDS stuff was tolerable here. We have a very interesting chief of medicine, Merle Sande,[2] who is a very strange guy, because he is himself conservative--he's kind of a redneck--but he's a very, very smart redneck. He makes very interesting and uncharacteristic decisions. He presided over a lot of the AIDS stuff here and is responsible for a lot of the atmosphere here at SFGH but doesn't usually figure in the media history of AIDS, as Paul does. Paul kind of takes that role in the history.

Hughes: Why Volberding rather than Sande?

Moss: Well, Paul did it. He's Mr. AIDS. He built this whole enterprise here, basically, and he had to fight Merle at various times. He'd fight everybody. Paul was a very successful bureaucratic, medical, political turf-fighter. He emerged as the top AIDS doctor.

We all had to fight everybody all the time to do this. Everybody had to struggle ridiculously--with the UC bureaucracy, with the federal funders, with our own departments, with competitors--all the time. It was an incredible struggle to get funded, and then to hang on to the funds.

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[2] See the oral history in this series with Dr. Sande.

See, what happened with AIDS, at first nobody wanted it, and then everybody wanted it. First you had to fight to get in, and then you had to fight to hold on, and that's what happened to everybody.

Hughes: I pulled you away from your arrival on the scene at UC.

Moss: Well, I was a cancer epidemiologist, and I was doing all this stuff about brain tumors and whatnot, and I just picked this phenomenon [Kaposi's sarcoma] up from two fronts. One was the infectious cancer front, which is a big light bulb for an epidemiologist, and the other was the gay front, my neighborhood right here. I was very interested in what was happening in it. I was the only epidemiologist who was actually living in the epidemic in those days, right?

So I got very interested, and read the stuff in the gay press and whatnot, and I talked about it. And finally, somebody said, "Go and see Marcus Conant." By this time, it was early 1982. I went to see Marcus. I said, "Well, do you want an epidemiologist?"

They--I guess Paul--had been trying to put together research on AIDS. Somebody had told them--I think it was the NCI [National Cancer Institute]--"You need an epidemiologist, because you don't understand this stuff," which was true. So Marcus said, "Yes, we need an epidemiologist, and why don't you go and talk to the following people?" He gave me a list of people who were working at UC to put together a research group. It was Paul and Donald [Abrams] and Dan Stites, an immunologist.

Early in 1982, I met this group of people that was coalescing around a research project. Well, after much infighting, a product emerged which contained a subset of these people: Jay Levy, Larry Drew, John Mills, me--there were about seven or eight people who were the investigators on the original UCSF grant proposal to the National Cancer Institute which was put together in the middle of 1982. I met all those people during the first half of 1982. I went around and told them who I was and they looked at me--and I was an unpublished assistant professor with a Ph.D., which in a medical school is not very impressive.

But, they knew that they needed an epidemiologist, and it was me or Selma Dritz. Those were the options. Selma had gotten sucked into Marcus's process. Well, Selma was the city [San Francisco health department] infectious disease number two epidemiologist behind a man called [Irwin] Braff, and she had been given the job of reporting the cases to the CDC [Centers for Disease Control]. That's the way it worked, because AIDS is a reportable disease. So she was out there sort of futzing around trying to collect the cases and send them to the CDC, working with [William W.] Bill Darrow [research sociologist, CDC].

There were three epidemiologists assigned to the AIDS epidemic at the CDC, [James W.] Curran and [Harold W.] Jaffe and Darrow. Darrow was the one who did the footwork. He's a Ph.D. person from the old STD [sexually transmitted disease] division.

First International Symposium on AIDS, Mt. Sinai and New York University Schools of Medicine, July 1982

Moss: In July of 1982, I went to the first AIDS meeting, which was in New York at Mount Sinai. I went with Darrow to the Chelsea Clinic in Manhattan, and I watched him interview an AIDS patient, the son of surgeon, a very classy young gay man of twenty who had Kaposi's sarcoma. This was the first time that I had seen an AIDS patient. I hadn't met any in San Francisco. Darrow was trying to establish clustering amongst the AIDS patients.

Hughes: Had the elaborate, seventeen-page questionnaire been developed yet?

Moss: The CDC were probably evolving it at this point.

There were various agendas. They [the CDC] were doing a case-control study which came out in 1984, I think; the blood bank transfusion debate was at the end of 1982, beginning of 1983; and Darrow was doing a cluster study which was eventually the great Patient Zero study. In fact, he and Selma were running around trying to find [Gaetan] Dugas. I should give you a copy of a letter I wrote about this to the *New York Review of Books* saying it's all bullshit.

Selma, via her connection with the CDC and giving information to Darrow, was the other contestant for local epidemiologist, so it was between me and her. Now, she was much senior to me; she'd been around a long time, and she knew a lot of gay people because she'd done work on enteric disease.[1] After much discussion, they decided that they wanted to have me. I became the principal investigator for the epidemiology part of the [NCI] grant.

Hughes: Do you know why you were chosen?

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[1] See the oral history in this series with Dr. Dritz.

Moss: I was a UCSF faculty member and academic, and also, Selma didn't know what she was doing. At some level or another, Volberding and Conant must have figured that out.

Hughes: Did she want the job?

Moss: Oh, yes. She tried to stab me in the back. There was a big squabble about all this, one of many squabbles.

Early AIDS Epidemiology

NIH and CDC Involvement

Moss: The National Cancer Institute put out a request for proposals in the summer of 1982. It was the first invitation to write grant applications [for AIDS research]. This was the first federal response to the epidemic. So when this happened, it really caused the academic power struggles to define themselves, because you had to identify the principal investigator and the other investigators, and write the grant, and who got the money in the budget. So we started doing that over the summer. The deadline was August 1982, I believe. I got involved in this group just before it started to do that, so that was interesting because we all met each other and sat around and talked. A lot of this took place in Conant's KS Clinic, which was very interesting.

I started going to the KS Clinic and seeing all these unfortunate AIDS patients that Conant would bring out, kind of 19th-century style, and then shine lights in their mouths. He'd show you the [KS] lesions.

But that's how you got to see [AIDS] patients. Unless you were a dermatologist or one of the people who treated the PCP [*Pneumocystis carinii* pneumonia] patients, and there weren't very many, then you wouldn't see them unless you went to a conference and the patients got presented. And normally at conferences they don't present patients any more. But Conant brought in these people so you could see what AIDS patients were like--that makes it real to you.

I met the CDC people that came out here, Curran and Jaffe, and I drove them around in my hideous beat-up Volkswagen. Both of them said, "Well, I'm not really an epidemiologist," meaning, "I don't know what I'm doing." Which is true; they had no idea what they were doing.

Hughes: They didn't have formal epidemiological training?

Moss: They had the CDC kind of three-week course, or whatever it is they get. They were not formal epidemiologists. They were insecure about their ability as formal epidemiologists.

Hughes: But isn't epidemiology a prime purpose of the CDC?

Moss: The CDC didn't in those days give them a lot of training before pitching them in. Infectious disease epidemiology is sort of like, "Get in there and see what's going on!" Outbreak investigation--stamp it out. AIDS is a bit different.

See, the interesting thing about AIDS from a professional point of view is it's an infectious disease that looks like a chronic disease. It takes a long time [to develop]. You don't go and stamp it out. It's not like salmonella or something. You don't stamp out an outbreak by finding the infected chicken. Although that's what Darrow tried to do. That's what all that Patient Zero stuff was about.

It's like trying to visualize AIDS in the model of an infectious disease outbreak. It's quick; it spreads from person to person; you go in there and you find the prime cause, and you remove it. This is not the way AIDS works.

So the CDC epidemiologists didn't know what they were doing, and they in fact produced a crappy study. The very first CDC study published in the *Annals* [*of Internal Medicine*] was very peculiar. It found no relationship between AIDS and anal sex, for example, which every other study ever done does. So what's happening in 1982 is nobody knows what they're doing. We were all just running around trying to figure this epidemic out.

Hughes: Well, no one was sure that it was caused by an infectious agent.

Moss: I don't think that's true. I think that in 1982, when you started thinking about it, you'd say to yourself, "This is an infectious disease." That's what I think; that's what everybody did.

Hughes: Well, with hindsight, that's what you should have thought, but--

Moss: Well, everybody did. They all said, "Oh, this is an infectious disease." And that got fuzzed, because the National Cancer Institute, for some bizarre reason, got chosen to put out the grant. This is a very interesting story--why did the National Cancer Institute put out the first RFP [request for proposals]?

Well, the mythology is that NIAID [National Institute for Allergy and Infectious Diseases] didn't want it. Why not? Well, possibly because Richard Krause, the then-head of NIAID, was gay, and reputedly didn't want AIDS too close to home. Or possibly because they were jealous of their own turf. Or at that point they were like flu people who didn't want another disease. Or possibly because they were just stupid and out to lunch, which would be par for the course for a federal bureaucracy.

Hughes: Why was the NCI willing to take on AIDS?

Moss: Well, that would be interesting to find out. Who were the prime movers in the NCI? I don't know. Somebody made the decision at NCI [to deal with AIDS] because of Kaposi's sarcoma. But even at that point, people were realizing that this disease was not only cancer.

Hughes: Hadn't the link with PCP been made pretty firmly? So it obviously was not just a cancer?

Moss: Right. I think people thought it was an infectious disease.

Hughes: Nonetheless, there continued to be investigation of poppers, and there was also the immune overload theory of AIDS causation.

Moss: Yes, some. There wasn't much investigation of the immune overload theory in those days.

Hughes: But certainly the nitrites--

Moss: Poppers were a big thing. That suggestion never got resolved. It still floats around.

Hughes: The CDC pursued that lead.

Moss: They did reluctantly pursue it.

Hughes: Reluctantly?

Moss: Well, even Curran and Jaffe ended up not believing it. Harry Haverkos of the CDC invested his career in that, pushed very hard. He's still pushing on it.

Hughes: What's his rationale?

Moss: People take on an explanation in this business. It's very difficult to let your pet hypothesis go. Look at [Peter] Duesberg. He's never going to let his go.[1]

The AIDS Incidence Study, 1982

Hughes: A letter that Conant wrote to a Dr. Guy Everett mentioned that you had suggested as early as 1982 an epidemiologic study. Conant said that the study was delayed until the following year--

Moss: We didn't have any money. There was no money, period. You could not raise any money. Now, one reason is you can't raise money quickly. You can only raise money by going through the R01 [federal grant application] process, which in those days was a one-year turnaround--if you got the grant in the first place, which was rare. And then getting an R01 together and getting it funded normally will take a person about two years from idea to funding.

See, the other thing is that during 1982, it becomes clear to us that this disease is going to be a big deal.

Hughes: Now, why?

Moss: Well, from the epidemiological point of view, you begin to get the sense that this is a late-stage manifestation of an infectious disease.

Hughes: Why did you get that impression?

Moss: Well, we did a study. We started actually doing research in 1982. I made a decision in 1982 that my little group, which was cancer epidemiology, was going to do AIDS [research], without any funding. And bootleg it off our existing grants. Everybody made this decision. You had to make it; you had no choice. The soft money research business is a gambler's business. You have to gamble on a topic. Everybody who became an AIDS researcher gambled on AIDS, because you had to use your existing funds, which is illegal, or you had to lie, cheat, and steal--go out there and scrape up little tiny pots of money. You'd go whine at the foundations and they'd give you $1200. So we all did all that.

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[1] Duesberg maintains that HIV is not the cause of AIDS.

During the process of the grant-writing, you sort of commit. You say, "Okay, we're going to do it." So we committed. I said, "Okay, we'll do some research." So we decided to look at the data in San Francisco, a reasonable first place to start, which involved brutally ripping it away from Selma, who was of course protective.

Anyway, we went down to the health department and we sort of ripped it away from Selma, and we organized it. Dennis Osmond, my associate who's still here, and I went down there and we met with her and we looked at her data in her famous shoe box that had little cards in it.

Hughes: The box contained reports of AIDS cases?

Moss: Yes. Somebody calls up, says, "I have an AIDS case." She writes it down.

We organized the data into series, cases that met and didn't meet the CDC definition of AIDS--KS and PCPs and lymphomas. And we gave her series numbers for each of those categories, and counted them. Then we census tracted the data, and looked at the cases on the map and tried to figure out what had happened when and where. We did all this in the second half of 1982.

Hughes: This is leading up to the letter in *Lancet*?[1]

Moss: That's right.

But in the process, you get the sense of what's going on. That's why you do it. So it's real clear that you have something that's popping up amongst a whole bunch of homosexual men in the Castro. It's an infectious disease! That's what you have to gamble on.

So then you say, "Okay, these people have got some kind of infectious agent, but a lot later they're getting these strange things [opportunistic infections]." Well, if that's so, and it's infectious, maybe they've all got it. That was a reasonable assumption. That's a possibility. Or maybe not; maybe only some of them do, but you don't know.

Hughes: Now, were you thinking this was a new agent? There was a lot of talk about CMV [cytomegalovirus] as a possible cause of AIDS in those early days.

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[1] A. R. Moss, P. Bacchetti, et al. AIDS in the "gay" areas of San Francisco. (letter) *Lancet* 1983, April:923-924.

Moss: Yes, there was a lot of talk about CMV. Well, we didn't know what it was.

Hughes: But you had the premise that it was an infectious agent?

Moss: Well, it looked like an infectious disease outbreak. That's what it looked like to the CDC, too.

The CDC Cluster Study

Hughes: The cluster study that you mentioned comes along in the summer of '82.[1]

Moss: It's not published until quite a lot later. Darrow was at the same time going around San Francisco talking to all these guys, trying to put together the picture, trying to generate a cluster. It got given in talks, but it didn't get published until some time later.

Hughes: The cluster study must have reinforced the notion that it indeed was an infectious agent.

Moss: Yes, if you believed it.

Hughes: There were problems with that study, weren't there?

Moss: Well, the study's not true. The study's based on the assumption that if two people have AIDS, Darrow makes a link between them if there's sex between them. But he assumes that the time between the infection and the clinical disease is of the order of one year. His clusters are based on the assumption at that time that the latency period is about one year. So they're constructed to reflect that assumption, and that's not true. The probability of infectious disease occurring in a year or less is about 2 percent. So in point of fact, a lot of what he thought were transmissions were not transmission events.

So that cluster is not real. It's a cluster based on an assumption that was not true. It's a fantasy. They built the cluster; they found what they wanted to find, and fingered this guy Gaetan Dugas. People in San Francisco, and Darrow and Selma

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[1] A cluster of Kaposi's sarcoma and *Pneumocystis carinii* pneumonia among homosexual male residents of Los Angeles and Orange Counties, California. *MMWR* 1982, 31:305-307.

bought into it, constructed this cluster with Gaetan in the middle, on the basis of some key informants, some of whom we also interviewed.

Launching Epidemiological Studies

Moss: We also started at the same time talking to gay men, interviewing people with AIDS. That's the other thing we started doing in the second half of 1982. We started doing pilot interviewing, some background interviewing.

Hughes: The CDC's premise was false because the long incubation period wasn't realized then?

Moss: Yes.

Hughes: Why would Darrow pick one year as the latency period?

Moss: If you immunosuppress people for transplants, you have about a year until the KS shows up.

Hughes: So there was a logic to it. It just happened to be wrong.

Moss: Just happened to be wrong, yes. I got into a lot of trouble for pointing out that this was not true. It was the party line for a long time, but it's not any more.

Hughes: At that point did you realize that there was a long incubation period?

Moss: Well, no. We started deciding that it probably was longer in 1983.

By the end of 1982, things were getting very crazy. See, we had to write the grant. We had to actually start doing research. We had to keep our funded projects going.

Hughes: You mean the non-AIDS projects?

Moss: Yes. And we had to deal with professional politics, and try to raise money.

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Hughes: Did you predict where the epidemic might lead?

Moss: Well, no. We made various predictions, but not until we started doing some research. In 1983, we started making predictions of what was going to happen. But this was the pre-serology phase. Nobody knows how to model the infection. There are interrelated phenomena having to do with the infection rate and the length of the incubation period, and you can be a long way off with the modeling. You don't know whether it's a lot of people infected and a slow progression rate, or only a few people infected but they get the disease fast.

So we were just coming to grips with this in 1982, and beginning to get frenzied, because there's tremendous pressure when you have to start these things; there's tremendous turf pressure. You have to establish your niche and get the studies going, get people to cooperate with you, and beat the competition and all that. And in AIDS, you had to do this with no money and no prospect of any money. Also a very funny atmosphere around AIDS began to develop, because of the homosexuality and infection issues, which were the issues that made AIDS different from everything else.

Hughes: Are you talking about fear?

Moss: Yes. Two kinds of fear: fear of infection and fear of an anti-homosexual backlash, being caught up in that. Which was very real in those days. And also, nobody really knowing what was going on.

Hughes: Were you fearful for yourself?

Moss: Yes. We established a research group, and we said we'd commit; we'd do a case-control study of AIDS patients to look at risk factors, and then we'd do a prospective study, blah de blah, this that and the other.[1] We made all kinds of plans, which were in the grant. Writing a grant, which we submitted [to the NCI] in August [1982], gave me some ideas of what I was going to do, so then I started to do them. That's what you have to do.

I interviewed my first AIDS patient who was up at UC, who was a pathetic, emaciated late-stage dying AIDS patient with a teddy bear, a gay man with a little teddy bear, and barely able to talk. The nursing staff refused to go in there--very paranoia-inducing, because you don't know what the risk is. And then stuff about the blood banks and the transmission stuff beginning to come out in 1982, and things looking very serious.

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[1] For Moss's ideas concerning early epidemiological studies on AIDS, see Moss to Conant, June 23, 1982; Moss to Conant, July 12, 1982 (Marcus Conant's Kaposi's sarcoma notebook, 3-12/82; hereafter, KSN).

We did the incidence study based on Selma's data, and as we did that, it really became clear to me that this was a disaster. So I decided to cut the study at the end of 1982, and stop collecting data, and write it up, and also to take it around.

Hughes: Because you wanted to get the data out?

Moss: Well, yes. You looked at the data and you said, "Wow. This is a major disaster, and somehow it's not getting through. People are not getting this."

Beginning in January of 1983, I took on the road a presentation of the incidence data in San Francisco, and I began giving it to gay groups and all kinds of groups. What really got me into the AIDS business was that suddenly I had some data. I was the person who knew what was going on. I figured out how to get an approximate incidence rate, and it was 3 per 1,000. One in 300 gay men in San Francisco already had AIDS. You can see the graph in the *Lancet* paper; it's an exponential increase. So if 1 in 300 had already got this disease, that was a lot. You look at that and think, Where is this going to stop?

Hughes: And this was without really appreciating the length of the incubation period and the fact that probably there were many more people infected than people realized.

Moss: Well, that's what we thought. We thought, [the number of cases is] going up this fast; there's a lot more behind them. We don't know where this is going to stop. It's a big deal; people have to know about this.

Building a Base in the Gay Community

Moss: But at the same time, there was this tremendous problem about stigmatization, the beginnings of the stigmatization issue. It's in focus as this gay disease; it's a lethal infectious disease running around the homosexual population. They have all become Typhoid Mary, right? So wait a minute. Do you really want to go out there and say, "The gay men of San Francisco are collectively Typhoid Mary"?

All through the first years of AIDS is this feeling that you've got to be careful about this. You don't want to rush out there and shout, "The sky is falling, the sky is falling." On the other hand, nobody's paying attention.

Hughes: You mean even the gay community isn't paying attention?

Moss: Well, that's a complex issue. Some are, some ain't. Closeted gay men didn't want to hear about it--too dangerous. It's true that the gay activists were very good about AIDS. My side of that is: When we decided to do research on AIDS, we started two studies, the incidence studies and this case-control study. We charged into it, realized that to do this, we had to get into the gay universe to do the study and talk to people about what's going on. So we had to penetrate the gay community.

I recruited a lot of gay men into this working group that we set up to do these studies. Two of them are still working in our group. I hired two people very specifically, because-- Well, here's the thing. It began to be very clear right around then that this was going to be an urban issue because the city of San Francisco was better than the state or the feds in terms of dealing with gay issues. The little light bulb went on: Get the money [for research] from the city.

I had this realization, and Conant had it, and Paul Volberding had it, and we all started doing it in our own channels. To do this, you had to build up a gay base. They have to go to bat for you with the Democratic party politicians who control San Francisco.

So I started to build my own gay base. I hired two people to work the gay Democratic clubs--and even gay Republican clubs. There was even a gay Republican club in those days. I hired Louise Swig, who is an actual Swig, although she says she's the black sheep of the family, to work the Alice B. Toklas Democratic Club, which was then the biggest, and she was deeply involved in it. She was a powerful member of the Alice B. Toklas Democratic Club. We hired her to run the field work because in those days she ran field work for epidemiological studies.

And I hired Michael Gorman, who's here today, to work the Harvey Milk Democratic Club. Those are the two big gay democratic clubs in San Francisco. He also knew Bill Kraus, who was [Philip] Burton's gay aide, and the most powerful gay political person in San Francisco. We started to work gay political terrain, to talk about AIDS, to build support for doing research, and to raise money. That's what I did in 1983; I worked gay politics in San Francisco.

We had this data [from the incidence study] and Michael and Louise set up contacts with many, many gay organizations, and we just took it on the road.

Hughes: What was your reception?

Moss: Well, it's the beginning of the mushrooming of concern in the beginning of 1983. Everybody's starting to get the message. We were part of that. I showed my pictures and my maps and said, "Where gay people live, 1 in 300 of the men have AIDS, and it's going up real fast. It's a big deal, and it's going to get you."

I went to the Democratic clubs, I went to BAPHR (the gay physicians). I went down to San Jose; I talked to the Sons of Harvard, which is the gay Harvard alumni club. There's some journalism about this that has to do with the cover-up, for instance the Randy Shilts bubble, about the cover-up of AIDS by the city, published in *California* magazine about 1984. We went to the city also, to the gay-lesbian committee [San Francisco Coordinating Committee of Gay and Lesbian Services], which was chaired by Pat Norman. Michael and I presented the data to her group, and they were very unhappy about it, very, very unhappy about it. They didn't know whether to believe it or not.

Then rumors began to surface that we were inventing the epidemic for our own purposes. There was a definite constituency out there that felt that this epidemic was not true, that we were maximizing, overemphasizing it.

Hughes: This was a gay constituency?

Moss: Yes, a gay constituency. They thought that we wanted to close down the bathhouses--which we did; that was true. People were beginning to talk about that in the beginning of 1982, and so there was a backlash in the gay community: "Okay, this is the fag-bashers at work. We're being stigmatized; this is not what's really happening." So it was very tricky.

It's hard getting people's attention, too, when you're telling them that the Grim Reaper is upon you. People have very good defenses. They don't want to be told, "The Grim Reaper is at the door now. This is it. The worst thing in the world is happening now." That's what the message was. And it really was; it was the worst thing in the world. It was going to kill half of the gay men in San Francisco. One in two of the 1983 gay male population is going to be dead of AIDS by the time this is all over. That's about the same as the European Jews [under the Nazis]. So it was like saying, "The beast is at the gate."

People had very mixed responses. When we went to BAPHR, which is the gay physicians' organization, we were talking epidemiology, academic mysticism. They were saying, "What's he talking about?" I was too academic, too quantitative. On the same day, one of their members, a guy called George Riley, had been diagnosed with a KS lesion on his palate by Marcus. Riley got up and said, "I am going to sit in the corner and you can come and see this lesion if you want." Because most of them had never seen a KS lesion.

So I got upstaged by the disease itself. There was this very attractive, tragic young doctor with a flashlight, with his mouth open, showing everybody this palatal KS lesion. They didn't hear what I said. [laughs]

We gave the presentation to a sad gay organization in San Jose, kind of beleaguered. My talk was on the local TV with the maps and everything. They broadcast it, but the gay men didn't get it. Probably partly my fault. It's hard to know how to say, "The wolf is at the door." Although we did eventually all end up saying that. We sort of stared at the camera and said, "The sky is falling."

Releasing the Incidence Study Data

Hughes: Well, I understand that there was quite a controversy about if and when the incidence study data should be released.[1]

Moss: There was a big struggle over the data. We were running around giving talks on data. Michael was out working with the Harvey Milks and Louise was out working with the Alice B. Toklases, and I was going to all these gay fundraisers, Democratic fundraisers. A very interesting experience, because I'm a straight man. Although I've lived in the Castro for a long time, it's a separate world. The gay world and the straight world are separate. If you're a straight man in the gay world, you've passed through the mirror. You have to cope with the fact that everybody is homosexual.

All the researchers in the AIDS business started putting pictures of their wives and children on their desks so that people would not think they were gay. You get this homosexual panic: "Oh my God, they'll think I'm gay." You get seduced also, because they're very seductive, and especially seductive to straight men. You get a lot of charm. It's a very interesting experience.

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[1] Marcus A. Conant to Bill Kraus, March 4, 1983. (KSN.)

And you get to sit next to politicians. At the Alice B. Toklas Democratic Club, two people were waiting to give their pitches--me and [then-mayor] Dianne Feinstein. [laughter] Feinstein created her advisory committee on AIDS some time later.[1] At this point, she was listening to Marcus, I guess. Marcus was like a one-man advisory committee. At some point, he started talking to Feinstein.

At this point, [Mervyn] Silverman had not woken up to the seriousness of the epidemic. I went to see Silverman. He gave me the classic speech: "Why are you making a big deal about this epidemic? Breast cancer is more important than this." My department chairman [Nicholas Petrakis] said the same thing. [laughs] We're talking about the spring of 1983.

I had gone to the health department and had shown Silverman and Pat Norman the data; nothing happened. There was major ambivalence. So we were going around giving the data and working the gay political universe, and this epidemic was heating up very, very fast in 1983. I didn't know what to do about this; I gave this data and some people, like Pat Norman, wanted it squelched. Some people said, "This should be inscribed in letters of fire in the sky over the Castro."

Amongst them is Marcus Conant, who is really responsible for people actually dealing with what was going on in San Francisco in the early days. He's the single most responsible person, who did all this stuff really, pushed it very hard. He started [June 1982] an organization called the Kaposi's Sarcoma [Research and Education] Foundation, his own front. I talked to him all the time, and I'd go to his KS conferences.

Finally, I said, "I'm going to present this data to your organization." And I went and presented it to him and his board, which included Lia Belli. She dragged in her daughter who was sitting there eating candy bars and whining, and Lia's not paying any attention. I was trying to give them data and say, "Look, the sky is falling." Marcus got it, and he said, "This data needs to be made public."

Now, I wanted to publish it. Publication is a very long process. It takes six months to a year. Marcus said, "Too long.

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[1] The Mayor's Task Force on AIDS was established in fall 1984 to provide Mayor Feinstein with information on AIDS and to assist in the formulation of AIDS-related policies and programs. (United States Conference of Mayors. *AIDS Information Exchange*, vol. 3, #5, August 1986, p. 1. Feinstein papers in the possession of Sally Osaki.)

We've got to get this information out informally." Meanwhile, Randy Shilts got wind of it, and he wanted an exclusive; he wanted to have the story.

Hughes: You hadn't talked to him?

Moss: I didn't talk to him about it. But Marcus talked to him about it.

Hughes: Why didn't you talk to him?

Moss: Well, I didn't know how to deal with this information at the time. This was my first exposure to big-time media, big-time science, and serious crisis. And I knew that I was supposed to publish this. On the other hand, it was clear that it had to be gotten out immediately. Those two are incompatible; you can't do both of those things simultaneously.

Selma wanted the data. I now knew, because of jockeying for position in the grant process, that Selma had a knife in my back, because she thought I'd ripped her off. Selma was talking to Randy Shilts. There was a deal between them: She tells him all about this Patient Zero stuff and whatnot, and he puts her in the book and makes her famous.[1] She becomes a star. There's all kinds of deals that are going on between all the players. Everybody is playing; we're all players now at this point.

I didn't know how to handle this incidence study data. I had absolutely no idea what to do. So I basically let Conant make the decision. He said, "Give the data to me." Everybody wanted my data. I wanted it, Randy wanted it, Marcus wanted it, and Selma wanted it. And with good reason: It was extremely powerful data.

Anyway, Marcus got it, and we gave it at a big public meeting, I think at NYU [New York University], in New York early in 1983. (I don't know why all these meetings were in New York.) I gave the data to Marcus, and he put them in his talk and gave them in front of the press. I met Larry Kramer; Larry Kramer was at that meeting.[2] I still remember Larry Kramer, who was very morose listening to Marcus give my data.

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[1] Randy Shilts. *And the Band Played On: Politics, People, and the AIDS Epidemic.* New York: Penguin Books, 1987.

[2] Kramer is an early AIDS activist and founder of New York City's Gay Men's Health Crisis, a group of volunteers dedicated to AIDS education, patient assistance, and fund raising. (AID: Acquired Immune Deficiency. GMHC Newsletter, #1, July 1982.)

Hughes: Did those people appreciate the significance of the data?

Moss: Some did and some didn't, I think.

Hughes: Larry Kramer did.

Moss: Yes. I think people got it. At this point, people are getting the idea of what's going on, I think.

Hughes: Did you show the map [of AIDS incidence in San Francisco census tracts] that was eventually published in *The Lancet*?

Moss: Michael Gorman and Marc Conant showed the map at the press conference.

Hughes: How could the audience not get it, then?

Moss: I don't know the answer to that. People were getting it, but this stuff was happening now; the explosion of cases was on. Concern was rising exponentially all over the place; all kinds of information was coming out. This was the first AIDS boom, and we were all being carried along by it.

I went to England. I was sick of all this. Randy Shilts said, "Give it [the information] to me," so Marcus had a press conference in San Francisco. Michael Gorman, who was my associate, presented the data, and Randy called me up and interviewed me about it. I said, "Don't publish the maps." And they didn't; they didn't put the maps in the [*San Francisco*] *Chronicle* story.[1] But they published it, which was good.

Hughes: Why didn't you want the maps published?

Moss: Well, I had a funny experience with these maps. The maps have these lines around areas of San Francisco with a high incidence of AIDS. So I created this ghetto. This line showed where the homosexual ghetto of San Francisco was, where the disease was. So I thought, Wait a minute now, is this a good idea? I was very ambivalent about releasing the maps. A lot of people were very ambivalent about it, for all kinds of reasons. You don't want to say, "This is the ghetto where AIDS is." You don't want to label it.

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[1] John Jacobs. Getting Out Word on AIDS: A Life and Death Matter. *San Francisco Chronicle*, March 29, 1983. (Archives of the Gay and Lesbian Historical Society of Northern California, AIDS clipping file, folder, AIDS 1-5/83.)

The only reason for the maps was really because they define the area, allowing you to calculate incidence. It's not a real line. It was just a line where the incidence rate was above some arbitrary chosen level. Well, I'll see if I can dig out the actual working map some time.

Hughes: Yes, I'd like to see it.

Moss: I drew that line with a thick felt tip, and I thought: My house is inside the line. So what's going to happen? Are they going to put barbed wire around this line? Are they going to have a cordon sanitaire? See, at this point, we didn't know how infectious the disease was. And one thing that starts happening in 1983 is major infectious disease paranoia: Are we all going to get it? Is everybody going to get it?

Now, if it was as infectious as hepatitis B, then 5 to 10 percent of the medical staff would have died of AIDS, because that's the infection rate of hepatitis B. We didn't know it was only transmitted sexually and by blood. It could have been multiply transmitted. Everybody could have gotten it. For all we knew, the entire population of San Francisco could have been infected, or could have been threatened.

Now, if that had been true, then they would have put that fence around the Castro. They would have razed a six-block area around it, and left the gays inside it.

Hughes: In the late twentieth century, they would have done that?

Moss: Do you know about Ebola virus and Marburg virus? There are viruses that kill everybody. Now, suppose it [the infectious agent] is airborne, and you can get it by walking through the Castro. Now, how do you think people would have taken that?

Hughes: Well, there was a paper in the *Journal of the American Medical Association* by Oleske on the casual household transmission of AIDS, which apparently caused a real ruckus.[1]

Moss: Well, there were many ruckuses. There's a two-year period in 1983 and '84 when nobody knows what's happening, and the concern level has risen very high. And that's when this fear of stigmatization is going on. It makes everybody very paranoid indeed, because who knows who's getting it, and who knows what the political

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[1] James Oleske, Anthony Minnefor, et al. Immune deficiency syndrome in children. *Journal of the American Medical Association* 1983, 249:2345-2349.

consequence will be? What if it really is like pneumatic plague, where you breathe on people and they get it? Or TB [tuberculosis]? We didn't know whether that was the case. Nobody knew that. And it was a reasonable speculation that it could be at least as infectious as hepatitis B, and that would have been really bad.

So paranoia was very high, and I'm drawing this line [around the Castro], and I'm having paranoid fantasies about what might happen as a result of this line. Pat Norman had the same reaction. She gets scapegoated for this, but lots of people were having the same reaction: Wait a minute. I don't want to hear this. I'm just going to quietly leave town now, before you publish it.

Hughes: Was Dr. Conant still pushing to get the data out?

Moss: Conant pushed all the time to get things out. Conant early on figured out that the balance was way over on the side of public health. The civil rights issues were not going to be as bad. He could have been wrong. But he decided that the best strategy was to get everything out. He was right about it, he was right about my data, and he was absolutely right about the blood banks.

AIDS and the Blood Banks

Moss: The blood banks fucked it up disastrously. They didn't get it; they didn't react, and they lied. Joseph Bove [chairman of the FDA's advisory committee on blood safety and of the American Association of Blood Banks' Committee on Transfusion Transmitted Diseases] said, "The nation's blood supply is not compromised."[1] This is a lie, clearly a lie on the face of it.

Hughes: Well, comment on the blood bankers' motivation.

Moss: They're terribly afraid of anti-homosexual paranoia, but also it's money. They don't want to have to throw all the blood away or whatever--I don't know. You have to ask them. But the blood banks were at the other end of the spectrum from Conant in terms

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[1] See the appendix for a copy of Bove's memo, dated January 24, 1983.

of reacting [to the epidemic]. They really didn't react; they didn't deal with it.

There's a legal process in San Francisco with the local blood bank. You can't find out about it now because there are so many lawsuits that everything's buried. Selma consulted with [Irwin Memorial Blood Bank in San Francisco]; you should ask her what she told Perkins in 1983 about what they ought to do. In my opinion, the blood bank made the wrong decision. They made the severely wrong decision in 1983 about using hepatitis B core antibody testing as a surrogate [test for AIDS].

There's a famous letter written by UCSF faculty about this.[1] There are two versions of it. The first version says, "You should do hepatitis B core antibody testing as a surrogate test for AIDS." Then there was a discussion and he softened it in the second version.

Hughes: Conant softened it?

Moss: Well, everybody did. He circulated it. And the second version said, "You should explore hepatitis B antibody testing."[2] Well, they should have done it; Conant was right.

Hughes: Why the backpedaling?

Moss: Well, somebody told him, "Look, don't create hysteria, Marcus," or something. I don't know; you have to ask him. Big, important people signed that letter. The dean of the [UCSF] medical school, Rudi Schmid, signed that letter. Now, I don't know what went on between him and Marcus, but I'll tell you one thing, they hate

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[1] Memo: Fonna to HP [Herbert A. Perkins, M.D., medical director, Irwin Memorial Blood Bank (IMBB)], January 28, 1983; Marcus Conant and David Altman to Rudi Schmid [dean, UCSF School of Medicine], et al, January 28, 1983; Memo: Herb [Perkins] to Brian [McDonough, president, IMBB], January 31, 1983. (IMBB documents, CBBL binder 2, 1-5/83, CBBL 00469, 00467, 00472, respectively.)

[2] The exact wording is: "We recommend that the Irwin Memorial Blood Bank and other blood banks in New York and Los Angeles, where there is a high incidence of AIDS, investigate the feasibility of screening all donated blood for anti-HBc [anti-hepatitis B core antigen]." Draft letter by Marcus Conant and David Altman circulated for approval to Rudi Schmid, et al, and subsequently signed by David Altman, Marcus Conant, Rudi Schmid, Girish Vyas, Paul Volberding, Steve Follansbee, and Andrew Moss, January 28, 1983. (KSN, 1983.)

each other. Very big powers were now involved, not just us little assistant professors. It's big powers now in 1983.

Hughes: Irwin instituted the hepatitis B core antibody test as a surrogate test for HIV in May 1984.[1]

Moss: You'll have to ask Perkins.

Hughes: I suppose the letter was directed to Perkins?

Moss: Yes.

Hughes: How did he respond?

Moss: Well, they [Irwin] didn't do it [core antibody screening]. Basically, Conant was saying they needed to not take any gay male blood donors. That's what they should have done. Now, they said they had a "self-deferral" process. That's not true. Now, if they had done core antibody screening, they would have identified 90 percent of the HIV-infected gay men. Between this time [of the letter], January 1983, and when they started [HIV antibody] testing in 1985, they infected several hundred people. So they could have saved 90 percent of them. And this is in litigation now, so you can't discuss this with anybody, because there are 130-some lawsuits against the blood bank over this period of time.

Hughes: Stanford is held forth as the shining light because on July 1, 1983 it began doing helper/suppressor T cell ratios on donated blood.[2]

Moss: Well, there's a very strong guy down there, [Edgar] Engleman, who did CD4 counts for the [Stanford University Hospital] blood bank. Also there's an economic motive: Stanford has to protect its coronary artery bypass surgery.

Engleman is a very sharp guy. Sharp and powerful. There was nobody at UCSF or the blood bank that combined those attributes. So they blew it atrociously.

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[1] Herbert A. Perkins, M.D. Donated blood to undergo anti-HBc testing. Blood Bank News, *San Francisco Medicine*, May 1984.

[2] Minutes, [Irwin Memorial Blood Bank] Department Supervisors' Meeting, May 31, 1983. (IMBB documents, CBBL binder 2, 1-5/83, CBBL.) According to Shilts, Stanford was using the fluorescent activated cell sorter to test donor blood by the end of May 1983. (Shilts, p. 307-309.)

Hughes: Was the technology to measure helper/suppressor ratios available elsewhere?

Moss: Well, it was probably available here, sure, if they wanted to use it.

Hughes: It wouldn't have been a problem?

Moss: Well, it's very expensive.

More on the AIDS Incidence Study

Hughes: Well, let's go back to the incidence study. Randy Shilts reports that you called from London, "pleading that the study not be published."[1]

Moss: When Conant had the press conference (probably April), Michael Gorman gave our data. He was very flustered; he apparently dropped all his slides. Randy called me for comment, and he says that I asked him not to publish it. But we'd released it in the press conference, so that doesn't make sense. What I asked him not to publish was the maps, which the *Chronicle* didn't, which in my opinion was a good thing.

Hughes: Why did you publish in *The Lancet*?

Moss: It's quick. I sent it to them and they said, "We'll publish it as a letter." So I said, "Okay." It was not a publication that counted academically, but it did get out. That was quick; that was the right decision.

Hughes: So your decision was based on speed of publication.

Moss: Yes.

Hughes: Is there any more to be said about the census tract study?

Moss: The census tract information was used as a sampling frame for the San Francisco Men's Health Study in Berkeley. Other studies went on and built on it from a professional point of view. It definitely had a big effect. That study made *Playboy*. I'm in *Playboy* as a result of that study.

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[1] Shilts, p. 256.

Competing with the Centers for Disease Control

Hughes: [laughs] What was your relationship, if any, with the CDC?

Moss: Well, the CDC does what it wants. It's a 600-pound gorilla in infectious diseases. They were doing a case-control study which hadn't been published yet, but the data was being given out during this blood bank stuff around January 1983.

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Moss: They were also looking for the blood samples from the hepatitis B cohort study, which Don Francis had in Arizona. They were trying to get them and I was trying to get them. But of course, they got them. That is what both Curran's and Jaffe's careers are based on. They used those sera to reestablish that cohort study and turn it into an AIDS study, and it made them famous. If I had gotten control of it, it would have made me famous. So I was competing with them. This was not a good idea; they were much bigger than I was. At the time, it was not clear to me that you can't compete with CDC.

They were not going to do anything for me, and I was not going to do anything for them. But we were talking to each other in sort of a pseudo-friendly way, and that continued all through. The CDC competes with local investigators. Also, they were putting a lot of money into the [San Francisco] health department, but they wouldn't give money to academic institutions. Jaffe said, "Oh, well, we only work with state and local health departments." That's not true. In fact, with AIDS they stopped doing that, but it's their excuse. [tape interruption]

Establishing the Hierarchy of AIDS Researchers at UCSF

Moss: The thing that establishes the players at UCSF is the NCI grant process. So we have the struggle about the grant in the summer of '82. The first issue is, who should be the principal investigator [PI]? It's clear that it has to be one of the clinicians, because that's the way the medical school is; that's the top of the hierarchy. So that's either Volberding or Conant or John Ziegler, who was at the VA [Veterans' Administration Hospital], and an old Kaposi's sarcoma expert from Africa.

There's a lot of politics about that, and it was made clear to Conant that he was not sufficiently academic to be the PI, so it was either Volberding or Ziegler. Conant went around and polled everybody else in the group about who it should be. He came to talk to us all and said, "Well, who should be the PI?" And Volberding won. We voted for Volberding.

Hughes: Why?

Moss: Why did I vote for Volberding? Well, he was a UC person rather than a VA person.

Hughes: Is that a matter of prestige?

Moss: It's mysterious. There are three UC hospitals [in San Francisco], and their relationships are very complex.[1] But it's clear that the VA is low in prestige.

Hughes: Why would you care about that?

Moss: Well, I didn't particularly, but it was also a personality issue, what Ziegler's like versus what Volberding is like. Volberding was younger, and Ziegler was a kind of cold guy. Well, they're both, after all, oncologists, who are all totally cold people. However, Paul is very charming. I had only met him a couple of times, but I knew that I would prefer to have him than Ziegler. And evidently, that was the consensus, and he became the PI and that's what made his career.

Hughes: It's really as simple as that?

Moss: Oh, yes, it's as simple as that. If Ziegler had been the PI, he would have been in control of AIDS in San Francisco.

Hughes: Ziegler would have founded the AIDS Clinic and the ward?

Moss: No, because Ziegler's not really interested in clinical work. It would have probably been more scientific and less clinical had it been Ziegler. Ziegler is more in connection with the scientists. I don't know how it would have worked out. But people chose Paul, and it was, as it turned out, a good choice. He was very successful.

Hughes: He was very young.

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[1] Technically, there are four UC hospitals in San Francisco: Moffitt and Long hospitals at the UCSF Parnassus campus, San Francisco General Hospital, and the Veterans Administration Hospital.

Moss: He was extremely young. That was the down side. He was just out of his fellowship. Conant was a marginal person at UC; he'd really not been an academic doctor. Abrams was still in his fellowship. I was an unpublished assistant professor. Jay Levy was an outsider.

I went to talk to Harold Varmus about the grant at one point, because I knew him. I told him what was going on, and he said, "Well, any virologists in this?" And I said, "Oh, yes, there are two: Larry Drew at Mount Zion--" And he said, "Oh, he's not a virologist." By Varmus's standards he's not a virologist. "--and Jay Levy." He said, "Oh, yes, well at least he's a virologist."

Levy was a strange guy. He was an outsider at that point. He would fight with people and had a reputation, and people would go around saying, "Oh, he's only trying to keep his lab funded," and stuff like this. He was not perceived as being a hotshot. There were no hotshots in this proposal. And it took a while for any of the hotshots to get involved.

Hughes: Well, isn't that understandable?

Moss: It's a gambling phenomenon. The hotshots don't need it. They can wait and see how it plays out. The other thing is they can wait and see how infectious the disease really is.

Hughes: Do you think that went through people's minds?

Moss: Oh, yes. My chairman, Petrakis, said to me, "Well, when we started working with leukemia, nobody knew if it was infectious." He was basically saying, "We've been through this before." Yes, people were very cautious. And the reason it's marginal outsiders and young unpublished people [who become involved in AIDS research] is that the risk-benefit ratio for them says, "Do it," whereas for senior people it doesn't.

Hughes: And then you get the funding problems on top of that.

Moss: Then you get the funding problems on top of that.

Arthur Ammann was involved. He was the only big deal. He was the professor of pediatric immunology. He thought the maneuvering was all bullshit, a lot of it. He thought this was very diddly-shit.

I remember we had a meeting at Conant's private practice, which is a very un-UC thing to do. You don't have research meetings at somebody's private practice. And he kept us waiting, which is a totally un-UC thing to do; you don't keep these big deal people waiting while you talk with the patients.

We're in the waiting room, and we're talking about the grant. The whole budget for the grant is like $600,000 a year. Ammann turns to me and he says, "My pediatric center alone is $1 million a year," meaning, "I don't need this. Who are these people?"

I told Harold Varmus about Marcus, and I had a piece of Marcus's writing paper with his full name, "Marcus Aurelius Conant," and Varmus looks at me and says, "Marcus Aurelius Conant? Who is he?" Because in Varmus's terms, this is like a nobody, total nobody. Everybody on the grant except Levy is a total nobody in Varmus's terms, in terms of main-line top UC science.

Hughes: Had you approached Varmus with the idea that he might participate?

Moss: Yes, but not as directly as that. You don't go around to somebody like Harold and say, "Do you want a piece of this?" You tell him what's going on, and let him think about it. He got involved [in AIDS] because he was asked to chair the [AIDS] virus nomenclature subcommittee [of the Retrovirus Study Group of the International Committee on the Taxonomy of Viruses].

Harold said, "I'd have to retool my lab." His lab was not set up to deal with HIV. For a big-deal retrovirologist to retool a lab means start again.

One of his proteges, Don Ganem, finally got involved in AIDS, got involved in KS. People don't like to work with a full virus; it's dangerous. The molecular biologists like to work with a gene or chunk of it, the genome, but they don't want the whole virus in their lab. It's only part of the equation, you know.

Hughes: Was anybody else approached in biochemistry or virology?

Moss: I'm sure people were approached, but I don't know who. Ziegler would know; he's much more connected with the big scientists and everybody else. Or Levy. But Levy I think very much played his own game at this point. At that point, Levy was embittered about his career.[1] He hated all the big retrovirologists. The retrovirologists are a crazy bunch of people.

Hughes: Levy's lab was not tooled up to deal with HIV, was it?

Moss: No. But he decided to go for it.

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[1] See the oral history in this series with Jay Levy.

Hughes: But he had terrible funding problems.

Moss: Everybody had terrible funding problems. One hundred percent. We broke the ground; we sent it in [the grant application], and boom, nothing happened. Now the timetable was that the NCI would review it over a nine-month cycle, and you'd get the money God-knows-when. That's the standard timetable. This was the prize example of the federal government's refusal to respond to the urgency of the AIDS epidemic. That is to say, it was business as usual, and we got the normal timetable. So there was a famous investigation of the federal government's response by the OTA [Office of Technology Assessment], with the sort of things that they didn't do, and one of them was the NCI just ground drearily through the standard process. When my paper came out in 1983, we were just up to the site visit [for the NCI grant application]. One of the things I presented my data for was the site visit.

So anyway, you were asking about the players. Well, I met the players by the interactions around writing this grant.

Hughes: And also through the KS Clinic.

Moss: And through the KS Clinic, that's right.

Hughes: All these people you've mentioned went to the KS Clinic.

Moss: Yes, intermittently, depending on what was happening. That's Marcus's focus. Now, with the grant group, it begins to be a different focus.

Hughes: Which is what?

Moss: Well, it's around science, the UC machine, the clinical work, and, for me, doing epidemiology. The relationships develop between the grant players as we write the grant. I started talking to Dan Stites about epidemiology and this that and the other, and to Paul about the patients and so forth.

AIDS Epidemiology Moves to the AIDS Clinic at SFGH

Hughes: Were you as an epidemiologist between two camps, the clinical and the scientific?

Moss: Epidemiology is like Poland. There's Germany, and there's Russia, and there's Poland in the middle. If you're very lucky, you'll be autonomous for a while, and then one or the other of them will crunch you.

Hughes: [laughs] And what happened in this case?

Moss: Well, I went in with the clinicians. I went in with Paul.

Hughes: Was that a conscious decision?

Moss: I'll tell you what happened: [laughs] we had rental space on Gough Street, with another part of the department of epidemiology, Steve Hulley, who is now head of the division of clinical epidemiology at UC. And at the end of 1982, we started interviewing AIDS patients and key informants and whatnot, and I would bring them in to the office. Hulley got paranoid, and he threw us out. He said, basically, "I don't want you here with those AIDS patients."

So I had no space. Now, space is a serious issue at UC. Paul had just been given Ward 86 [the outpatient clinic at San Francisco General Hospital], and so there was Paul, Connie Wofsy, a nurse, and an administrator. That's all there was. He needed to fill it, so he said, "Why don't you come down to Ward 86 at San Francisco General?" So I made the major blind decision of my professional career, and just hurled us into Ward 86, the AIDS Clinic, in June of '83. Boom.

Hughes: All you needed was Paul's permission? You must have had to have approval from the administration.

Moss: We did not.

Hughes: No?

Moss: No, it's a funny system, UC. If you ask somebody, they'll tell you 'no'.

Hughes: So you just do it.

Moss: Oh, we just did it.

Hughes: Was that a good decision?

Moss: Yes.

Hughes: Did that location swing you towards the clinical people rather than the scientific?

Moss: Partly that. At that point we were trying to interview cases, get to talk to people with AIDS, and that's where they were. Very good advice for an epidemiologist is to get as close to the clinic as you can. That's my strategy.

Hughes: How does your Ph.D. degree work in a clinical setting?

Moss: Doesn't. All a Ph.D. does is get you the privilege of being on the faculty and being a principal investigator.

Hughes: But you must have been recognized for your skills in epidemiology; that's why you were there.

Moss: I was the only epidemiologist they had. Except for Selma, and I was better than her. See, it's the same thing. Well, for starters, most epidemiologists are dull. It's a dull field; they're not going to see it. For another thing, a senior epidemiologist is not going to take a chance. Only a junior person is going to take the chance. Now, I was a junior person, but I was a grown-up, because epidemiology was a second career. In 1982 I was nearly forty years old. So I knew about reality, and how to bluff, and how to appear as if I knew what I was doing when I didn't. So I acted like I knew what I was doing. And nobody else knew anything about it either.

More on the National Cancer Institute Grant Application

Moss: I made some bad mistakes. We got site visited by the NCI. With a big grant, they send out site visitors. So NIH sent out site visitors, a tedious bunch of infectious disease people. They had to round up infectious disease people who were not interested in AIDS, because everybody who was interested in AIDS has gone in for this grant. They put out this RFA [request for applications], and eighty applications came in. All nine medical institutions in the New York area put in applications, et cetera.

They had to find reviewers who were not from these places, so they rounded up this bunch of flu epidemiologists, and they sent them in as site visitors. So we did our first full-scale song-and-dance. Everybody does. The reason you do your little preliminary studies is so you've got something to present to the site visitors. "Here's my data." Everybody had their own preliminary data and their patients and this and that, and we all did our stuff. Very, very tense.

UCSF brought out the dean and chancellor--they brought all these heavies to address the meeting. We had it up at UCSF.

Hughes: Oh, not at San Francisco General? That's significant, isn't it?

Moss: Of course.

After we gave our presentation, the reviewers said, "Well, you wait in this room while we have a discussion amongst ourselves." It was sort of like an audition. So we went over to Dan Stites' lab. And Conrad Casavant, who was a gay man who worked for Dan, made leper jokes. (This was the year of leper jokes.) I don't remember the leper jokes specifically, but they were all about bits of flesh falling off of people, which turned out to be very ironic, because Conrad himself died of AIDS. Leper jokes because there's this leprosy feeling about AIDS. AIDS people are becoming--

Hughes: Untouchables.

Moss: Yes.

Hughes: What was Casavant's specialty?

Moss: He was an immunologist who worked for Dan Stites. He didn't know he was HIV-positive yet, because we didn't have the test, but he was worried even then, obviously. Well, he was a very sexually active gay man.

Oh, it was very creepy, especially if you were gay. Gay people were just terrified. Paul Dague was a psychologist who worked in the clinic. He was in line with this "cure your own cancer" type of approach, the power of mind over matter, and blah de blah. He came in one day and he touched his earlobe and he said, "I guess I'm going to have to put my theories to the test." Conant had just biopsied him and he had KS on his ear. He died horribly. He had a very bad, very unpleasant course, soon became wasted and emaciated and died of AIDS.

We were all sitting there waiting for the site visitors. Finally, somebody came up and said, "Oh, we want to ask Dr. Moss more questions," and I went away with them. And then they asked, "How did you establish the per-square-foot rental rate in the application?" I thought they were going to ask something important, something about what was actually going on. I couldn't believe that--these people were not with it.

Hughes: They didn't ask you anything about the science?

Moss: Well, it turned out that Selma had stabbed me in the back. The leading infectious disease reviewer was a guy called Arnold Monto, and she knew him. She got to him and told him, "Don't fund that guy."

Hughes: Why?

Moss: Why? Because Selma and I were competing for AIDS turf in San Francisco, and she was mad at me for working up her data. She thought I ripped it off, I guess.

Hughes: Well, did you?

Moss: It's a very interesting issue. It was public data. All data collected by a public agency is public data. She didn't own it. Now, I am a legitimate AIDS researcher and I say, "I want to look at these data." Now, in theory, they have to give it to me if there are no confidentiality issues and I am a competent researcher. In practice, they often don't give it to you.

Selma gave us access to the data, because she was not willing to block us. Some people in this business will use these bureaucratic obstacles just for their own turf purposes. The turf fighting in AIDS then and now is just as bad as anything else, and people are completely unscrupulous, motivated only by personal gain, and will use whatever they can to hold on to stuff.

Leaking the AIDS Incidence Study Data

Moss: But Selma didn't; she did give us the data, whereupon I ran with it. Now, I put her name on the paper; I put her name on three papers.[1] I treated Selma collegially, but she didn't like that. We actually leaked those [AIDS incidence] studies to Randy Shilts, via Selma.

Hughes: The leak was intentional?

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[1] Andrew A. Moss et al. AIDS in the "gay" areas of San Francisco (letter). *The Lancet*, April 23, 1983, 923-924. Andrew A. Moss et al. Mortality associated with mode of presentation in the acquired immunodeficiency syndrome. *Journal of the National Cancer Institute* 1984, 73:1281-1284. Peter Bacchetti et al. Patterns of survival in the acquired immune deficiency syndrome (AIDS). *Journal of Infectious Disease* 1988, 157:1044-1047.

Moss: Yes. I leaked nine copies of the study--one of my solutions to the publication problem. We did a preliminary version of it, stamped "confidential" on it, and sent it out to nine people, one of whom at least would be guaranteed to leak it.

Hughes: Who were the nine people?

Moss: They were mostly the gay legislative assistants and political people, and Selma. And Selma gave it to Randy, I think. That's the way it got into the *Chronicle*.

Hughes: Why did you choose to do it that way?

Moss: I don't remember. I was crazed; everybody was crazed. Everybody was grabbing at the data. Conant said, "Get it out." Okay. It didn't have any effect anyway because we presented it in New York at the meeting with Larry Kramer, and we did a press conference in San Francisco. I don't know why we did that; I can't remember.

Hughes: Now, you're talking about the report in the *Examiner*.[1]

Moss: Yes, and the *Chronicle*.

Hughes: Which was without the census maps.

Moss: Well, we had made the maps public at the press conference. I just asked Shilts not to publish the maps. But we leaked the actual draft of the *Lancet* letter to a bunch of people. So Shilts had the actual paper. And Selma felt very guilty about it, and I'm pretty sure she gave it to him.

Patient Zero

Moss: They had a deal. She did a lot for Randy. She gave him the name of Gaetan Dugas, Patient Zero. She or Bill Darrow broke confidentiality on that one and gave it [his name] to Randy, in return for which, and other favors, Randy made her a star in the book.

Hughes: Couldn't their motivation have been to stop the cycle of infection?

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[1] John Jacobs. Getting out word on AIDS: a life and death matter. *San Francisco Examiner*, March 29, 1983, A1.

Moss: In my opinion, no. It was clearly way beyond that. That had nothing to do with what was actually happening. That was ancient history even then. And that's just a story. For a while, Randy hung all his AIDS stuff on Patient Zero, and then he started sweeping that aside a bit, because he realized it was wrong.

Hughes: Dugas keeps appearing and reappearing in Shilts' book, having one encounter after another.

Moss: Well, he was a very sexually active gay man, who undoubtedly spread it around a lot, but he was not Patient Zero. He was too late in the epidemic.

Hughes: Do we know who Patient Zero is?

Moss: There's no Patient Zero. It's lots of people moving around from New York to San Francisco, and the rest of the world. If there was ever an original Patient Zero, it would have been back in the mid-seventies. But there isn't an original Patient Zero.

The National Cancer Institute Grant

Moss: The NCI gave me $30,000, and they didn't fund any of my research projects. They actually didn't give anybody much money. They gave something like $60,000 to most people. They gave me $30,000 to maintain contact with Dr. Dritz. This was specified in the pink sheet. It didn't matter, because at this point it had become clear to us that the amount of money the NIH were talking about was tiny, and we would have to go elsewhere.

The NCI grant was mostly legitimacy rather than money. See, by this point it had become clear the epidemic was a much bigger deal than even we had thought in the summer of '82 when we had written the grant. The amount of money NIH were talking about was peanuts, just vanished without a trace.

Hughes: You're saying that you could use the publicity of having an NCI grant to get more money?

Moss: Not publicity, but legitimacy in the university as the people doing the research.

Hughes: Right. And consequently legitimacy to other grant-giving groups.

Moss: Maybe. I don't know. It was mostly academic status: you get franchised; you're the people who are doing the research. You can hold the turf is what it comes down to. People won't come and say, "Well, I am the AIDS epidemiologist." That's the real body of it.

Obtaining Money for AIDS Research from the State of California

Hughes: Did you have a role in obtaining money from [California Assembly Speaker] Willie Brown and the state for AIDS research?

Moss: Yes, I did. Conant, once again, figured it out. He got to Willie Brown, probably through [Bill] Kraus. And Willie Brown, to give him credit, was the only politician outside San Francisco--I guess he wasn't really outside--who really responded. Amazing.

Hughes: Why did he respond?

Moss: Well, he had a big gay constituency. Also, he is a very smart guy. And for some reason or other, he figured out that this was not bullshit.

Hughes: This was a real epidemic, you mean?

Moss: Conant or somebody--Kraus--convinced him that this was serious. Everybody had been working on the gay legislative assistants, because they are the channel to mainstream politics. The San Francisco supervisors had their own, and [California State Congressman Phillip] Burton had his, who was Bill Kraus, who was a key person, and who of course died of AIDS himself.

Michael Gorman got to Kraus, and we had lunch with him and showed him our data, and he took it seriously. So somebody got to Willie Brown, and Brown said to Conant, "Bring your guys down here." So we all went down there to L.A.

Hughes: Who is "we"?

Moss: Conant rounded up the people on the NCI grant, and a bunch of other people whom Conant had defined as players. By this point, it was clear that he had a separate empire from Paul. He had other players, probably people doing research and his gay constituents in the research business. I don't remember who they were. But a bunch of us went down to Willie Brown's office.

So we're in Willie Brown's office in L.A., and we're sitting on the floor. We're talking to his staff people, and Brown himself is wafting around in the background. You know, he's very tall, and he's very black, and he wears these beautiful clothes. He had a suit with raised shoulders on it, and they looked like displaced horns. I saw him as Mephistopheles--an incredibly wealthy powerful black prince, like Othello.

Hughes: Do you think that was a conscious image?

Moss: Oh, yes. That's how he presents himself.

Brown said, "Write down your wish list." So Conant said, "Write it down!" So I sat there with a little pencil and wrote down, "I want to do study one, study two, study three." I think I asked for $150,000. Somebody came and picked up the requests, and we left.

Willie Brown went away and picked up $4 million of state money, lifted it up, moved it over, and dropped it on us: bang, four million bucks, like that.[1]

And the University of California started to scream, because Conant did an end run. You're <u>not</u> allowed to do this. You have to go through the university hierarchy, through the department, school, legislative office in Sacramento, university lobbyists, regents' approval, political process, right up the chain. Everybody has to sign off and take their cut, and you get the money. So Conant got four million bucks--the first serious AIDS funding. The state of California and Willie Brown did it, and Conant was responsible.

And the university said, "No, you cannot have this money." So there was a huge furor.[2] Everybody ran around, jumped up and down, all the politicians got into the act. Finally, there was a compromise. The university set up a process: we had to write grant proposals.

We're absolutely berserk at this point. We've moved into the AIDS Clinic; we've run out of money; I got stabbed in the back by Selma and the NCI. The same sorts of things happen to everybody [in the UC AIDS group]. So we're totally berserk.

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[1] The state appropriation to the university for AIDS research, 1983-1984, was $2.9 million. (William B. Fretter to J. Michael Bishop, et al., July 28, 1983. AIDS Coordinating Council Office, binder: AIDS Coordinating Council Historical Reports.)

[2] See: Randy Shilts. UC Assailed for Delay on AIDS Funds. *San Francisco Chronicle*, August 25, 1983, p. 10.

And the university said, "You must write grant proposals!" You know, another example of bureaucratic mindlessness. So we had to go and write actual formal proposals for this money, and then they'd give us the money. We more or less got what we asked for, but they delayed it. The first serious AIDS money arrived November of 1983, two and a half years after the announcement of the disease.

Hughes: Ammann didn't get any.

Moss: That's right. He got very pissed off.

Hughes: Six months later, the university asked him to reapply, and he was so fed up that at that point he took a position at Genentech.[1]

Moss: Oh, that's right. The senior people who are getting jerked around by this process didn't need the hassle, or the money.

Hughes: He went to the university administration and protested the grant application procedure.

Moss: Well, everybody felt like that, but we couldn't do anything about it. If we wanted the money, we had to follow university procedure.

So by the end of 1983 things are really crazy. The first media boom was on. Everybody was screaming about AIDS. The infection paranoia was very high. Health workers who had gotten needle sticks were getting sick. In England in the summer of 1983 was the first needle stick. It was really paranoid, and the university was saying, "Write a grant application." It made people insane. We all totally lost whatever faith we had left in the process.

Lobbying for Support from the City of San Francisco

Moss: We had gone to the city of San Francisco beginning in early 1983 and done a huge lobbying. One of these gay legislative assistants said to me, "You have to get a majority of the board of supervisors. Five out of nine. Line up five supervisors." So I worked the Democratic clubs and I got five supervisors, and the city made up its first AIDS funding packet in the summer of 1983. They gave me $60,000. Paul [Volberding] and Shanti and I and some

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[1] See the oral history in this series with Arthur Ammann, M.D.

other group were on there. [San Francisco Supervisor John] Molinari said, "I don't know what epidemiology is, but I'm going to give you your money."

Hughes: [laughs] How did you get to these five supervisors?

Moss: Well, Louise Swig and Michael [Gorman] worked the Democratic clubs. They went to them and said, "Dr. Moss says a very serious thing is happening, and can he please address the club?" So I addressed all the [gay political] clubs. I would tell them what was happening, and then show them the data.

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Moss: After the presentation, I'd say, "So you see. Now there's no money." If they believed you, they'd say, "What do you need?" That's the way they work; they're all politicians. They'd say, "What do you want?" I'd say, "I want Supervisor [Harry] Britt's and Molinari's support for my budget for AIDS epidemiology at the meeting of--" whenever it was. And you went through the process--the budget committee, this that and the other--and they took it over. The legislative assistants make a decision: "Okay, we're going to go for this." And they go back to their supervisors and say, "The Alice B. Toklas Democratic Club, which as you know can get 500 people to its meetings, would like you to support this, Supervisor," and the supervisors say, "Right." So they did.

We had to decide which principal avenue we were going to take, the Alice B. Toklases or the Harvey Milks. We went with the Alice B. Toklases.

Hughes: Why?

Moss: Louise was intimately involved with the Alice B. Toklases, knew all the people, the leaders. She got me in touch with them. Michael made the connection with the Harvey Milks, but he wasn't so connected with them. He knew Bill Kraus and he made that connection, but he wasn't so personally connected with the Harvey Milks.

There were ideological differences and temperamental differences between the two clubs. We may have been in bad odor with the Harvey Milks. They were more politically radical. They may have thought that Michael and I were bathhouse-closers, which we were. All this stuff, who controls the data, with Selma and Randy, was going around while this was going on. It was real politics. Pat Norman [director, Office of Lesbian and Gay Health, San Francisco Department of Public Health] was saying, "These people [Moss, Gorman, et al.] are troublemakers. Don't support them."

But, as it worked out, we got a majority of the board of supervisors, and they gave us $60,000. That's the first AIDS money I got, apart from a tiny foundation grant, and we got that in July of 1983, and it was the city that did it. It kept me afloat until November when we got the state money. So I got twice as much from the city of San Francisco as I got from the federal government [NIH], and much quicker and much easier, and the city was much more pleasant to deal with.

I spent six months doing this, and it was a real eye-opener. I went to meetings with lesbian dominatrixes dressed in leather. [laughs] Made my pitch. And I met all these AIDS patients. And at the same time, [at San Francisco General] I was dealing with all these people with AIDS and doing preliminary interviewing.

We had a key interviewer called Stewart Anderson, who was one of the very early AIDS cases, and one of the people that was chasing Dugas around, one of the people that gave Dugas' name to Darrow. Stewart was waiting for Dugas to come back to San Francisco so he could kill him.

Stewart was a Vietnam veteran, ex-marine medic, who had Kaposi's sarcoma. He did the first public health action on AIDS in San Francisco, which was late 1982. He went to the Star Pharmacy at the corner of 18th and Castro and he put up a Xeroxed picture of Bobbi Campbell's feet. Bobbi Campbell was an early AIDS case, who had Kaposi's sarcoma on the feet. He became the AIDS poster boy, and was on the cover of *Time*. I had seen this picture; it said, "Watch out: this disease is going around the Castro, and it will kill you." It's a famous local action piece.

Doing Epidemiology in the Gay Community in San Francisco

Moss: Stewart was a militant guy. His profession was building the back rooms of sex clubs, the actual orgy rooms. Stewart was an orgy room-builder, a carpenter by trade. I used to meet with Stewart down at the San Marcos bar. He was a fist-fucker. Have you heard about the fist-fuckers, the original high-risk group [for AIDS]? Well, Stewart was a fist-fucker. We talked to the fist-fuckers, with fist-fucking doctors. We talked to the bathhouse owners, the sex club owners, all kinds of very strange people. We did field research on pissing and bondage and sadism and masochism and all that stuff.

Hughes: Was data easy to get? Were people willing to talk to you?

Moss: Absolutely. They were all scared shitless by this point; they were definitely willing to talk. It was very interesting.

Hughes: Could you have done it without a gay entree?

Moss: Well, I wouldn't have. I mean, that's the way we operate in epidemiology, as it were. You're out there in the real world, you have to do the networking. Anyway, I liked it. It was partly prurient interest and partly exoticism. It was exotic: "Ooh, sexually transmitted disease of homosexual men; we're going to spend the next six months exploring the gay sexual underground." You can't beat that. It's better than cancer epidemiology, a very tedious field. Nobody ever finds anything out. I think a lot of people got involved in AIDS because of its exoticism.

Hughes: You mean from the sexual standpoint?

Moss: Yes. And homosexuality. That sense of crossing the boundary into the gay world.

The big event for me was in July of 1983 when we moved into the AIDS Clinic. I just picked up my group and moved into it. Volberding had Connie Wofsy and his administrator, Bobbie Wilson, down at one end of the clinic, as far away from the patients as possible. He put us right in the middle of the patients. He gave us two offices surrounded by the patients, examining rooms, at the other end of the corridor from him.

So why did he do that? It was like a hazing experience. It's like, "Oh, you want to be a real doctor? Try this!" It was absolutely terrifying. It was really terrifying. The maintenance people wouldn't come up there, and when they did, they'd arrive wearing white space suits. Nobody would go into the ward. "You went up <u>there</u>? To the sixth floor?" Strange.

It was great in another way, because the university didn't--nobody--bothered us.

Hughes: What sort of precautions were you using?

Moss: We weren't.

Hughes: Even with the fear, you weren't? Why not?

Moss: Denial. We were refusing to acknowledge how afraid we were. We all thought we were going to die. By the middle of the next year, 1984, we all thought we were going to die. Volberding thought he was going to die. He was going around saying, "Oh, my lymphadenopathy is bad today." He thought he had AIDS. He thought he had given it to his wife and his kids. Everybody did. I went to see my doctor five times.

Hughes: With what symptoms?

Moss: Everything--night sweats, peripheral neuropathy, white spots on the mouth. My doctor was gay, Fred Hartley. He was the Kaiser AIDS doctor. He died of AIDS; my doctor died of AIDS. That was the last straw. I found out and collapsed and somewhere around the summer of 1986 went to England. I ran out.

The AIDS Health Workers Study[1]

Moss: The next period, '83 to January of 1985, was like the true experience of terror, the thing itself for me, because that's the period when we were working up there in the clinic with the patients, and it was before the serology was developed. It was a period of maximum paranoia. Nobody knew who was getting infected. We started doing the serological testing at the end of 1984. I bled everybody in the AIDS Clinic--the very first serology we did on everybody in the AIDS Clinic and in the AIDS ward. We sent the samples to Jay Levy for testing. We didn't know how they were going to come back. We could have all been infected. I did that study in the end of 1984. It was a maximum paranoid moment. The serology came back negative, except for the gay men, who came back positive.

Hughes: Now, this is the study--

Moss: Health worker study.[2]

Hughes: Well, that must have made you feel better.

Moss: Yes. In January 1985, I tested myself, when I had seen how the results were coming in. All the heterosexuals were negative. It was a very difficult study to do. There were a lot of gay men

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[1] This section contains combined information from two separate discussions in this interview session.

[2] Andrew Moss et al. Risk of seroconversion for acquired immunodeficiency syndrome (AIDS) in San Francisco health workers. *Journal of Occupational Medicine* 1986, 28:821-824.

working in the clinic, and one-third of them were positive. And they're dead now. Philippe Roy, the receptionist, the Shanti social worker, Gary Starliper, and a whole bunch of people that worked there are now dead. We tested them and they were positive, and I had to tell them. I tested Don Abrams, and I told him, "You're negative." He was real happy.

We did two studies that were funded by the state and city and bits of federal money: a case-control study and a prospective study, and I also did this health worker study. Conant raised fifty grand to do the health worker study, for us to bleed everybody in the clinic. I had to break the rules on that. I did it without IRB [Institutional Review Board] approval and consent, which is illegal.

Hughes: Why did you do it without informed consent?

Moss: I couldn't get the funding. I had to use money stolen from somewhere else. I had to bend all the rules to do it. So I didn't have formal consent, or human subjects approval. How about that?

Hughes: [laughs] What's been the fallout?

Moss: None, zero. Paul Volberding said, "You didn't have consent, but it was a good study." It was; it relieved all the anxiety. We demonstrated that people in the AIDS Clinic were not dying of AIDS. It was a very important study. And it was the right thing to do.

At that point, like everybody else in the AIDS business, I thought, "Fuck the bureaucracy." Every time you went to them, all they did was throw an obstacle in your way. It's just amazing. Even in 1985, when the epidemic was an official cosmic disaster, they wouldn't cooperate. They'd make you do everything on their timetable according to their rules.

Controversy over Testing Sera for HIV

Hughes: Why were the French involved with one of your studies?[1]

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[1] Andrew Moss, D. Osmond, Peter Bacchetti, J.-C. Chermann, F. Barré-Sinoussi, et al. Risk factors for AIDS and HIV seropositivity in homosexual men. *American Journal of Epidemiology* 1987, 125:1035-1047.

Moss: That's a long story. Well, as you know, there were wars going on about the isolation of the virus. By early 1984, there was experimental serology available, and I went to [Robert] Gallo's group. I made contact with Stanley Weiss at a meeting and said, "I've collected all these sera from homosexual men in San Francisco. Would you like to test them?" He said, "Yes. We'll do it in Gallo's lab." I was going to have my serology done in Gallo's lab.

Jay Levy went bonkers. Just went absolutely berserk. UC basically tried to take the sera away from me. They basically tried to take my study away from me. They brought in the dean, and I threatened to call a lawyer, so I got into a huge power struggle to keep control of my study.

I did keep control of it, but got into terrible trouble with Jay--it was very bad for me. I was marked as a non-team player. Jay told me, "Don't send your sera to Gallo; he'll just rip you off." And then they tried to rip me off here. Jay did, basically.

Hughes: How?

Moss: Oh, he got the sera from my study from John Greenspan, who was storing the sera in the tissue bank.[1] Levy's group tried to do it themselves, and I said, "No." Jay wants control of everything he does. You just give him your stuff. He was doing what he had said Gallo would do to me. He might have put my name on the paper, or maybe not, so I said, "No." But as a compromise, I sent my sera to the French, who were more acceptable to Jay than Gallo. It was a stupid idea; it just ruined the whole study; held it up for a year. It was very destructive.

I kept control of the study. The health workers sera we sent to Jay. I sent my study of the gay men to France, to Pasteur, and it took forever, and they had to do the tests twice. It was really disastrous.

Hughes: Why did they have to do it twice?

Moss: Experimental serology is very dubious. You don't know what's going on the first time around.

Hughes: You mean they hadn't done much AIDS serology at that stage?

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[1] Marcus A. Conant to Paul Volberding, et al., June 27, 1984. (John S. Greenspan papers, 92-0123, carton 2-92, folder: AIDS Tissue Committee.)

Moss: This is the end of 1984. They had done practically none of it at that stage. This is right at the beginning of [AIDS] serology. I should have just gone ahead and sent the sera to Gallo. I could have probably done very well. But on the other hand, he might have ripped me off, like Jay said. But probably not; why would he bother?

Anyway, that was a disaster, awful.

Jay Levy and the Isolation of HIV

Hughes: Was Dr. Levy very much aware of the race that was going on to isolate the agent?

Moss: Well, Jay did a switch. In 1983 he was still saying, "No, it can't be a retrovirus."[1]

Hughes: Why?

Moss: I don't know. But at some point, he did a switch, and got the virus. But that's very mysterious. Retrovirologists all deal with each other; they all send each other stuff; they're all mad at each other. They're all claiming that the other has ripped them off, every single one of them. You can't actually find out what went on. But Jay managed to hang in there. He was number three in isolating the virus.

Jay's presentation is the NCI hates him, and he's an outsider, and Gallo's group blackballed him, and this that and the other. He hates them. But all these people hate each other. They all hate each other, all the time.

I think Jay just was too late. He probably switched a little too late. It's true that he was going around in 1983 saying, "It couldn't be a retrovirus."

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[1] See the oral history in this series with Jay Levy, M.D.

Case-Control Studies[1]

Moss: What we started to do was a case-control study of risk factors for AIDS. When the serology became available, it became a case-control study of risk factors for HIV. It took forever; it didn't get published forever. It was not a winner; I was not successful with that study.

But we used it in the bath-closing debate. It was the first data to show that risk of AIDS was associated with number of sexual partners. That bath closure issue blew up at the end of 1983.[2]

Hughes: The CDC hadn't come out with anything yet about the risk of having multiple sexual partners?

Moss: No. The CDC study is a crappy study.

Hughes: Why?

Moss: They picked the wrong controls. They picked controls that are too like the cases. All their controls were very sexually active.

Hughes: Oh, you mean because they came from the population attending VD clinics?

Moss: Yes.

Hughes: Who made the choice?

Moss: Well, CDC controlled the VD clinics. They did what was easier for them. They had a CDC person at the VD clinic in San Francisco. CDC funded large chunks of it. It's their clinic, or was.

Hughes: Didn't CDC know that they were biasing the study by choosing controls from a VD clinic?

Moss: They chose what was easy, using an institution that they controlled.

Hughes: Was this an honest mistake?

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[1] A later discussion of Moss's case-control study, recorded on March 18, 1993, is incorporated here.

[2] For more on the closure of San Francisco bathhouses, see the oral history in this series with Mervyn Silverman, M.D.

Moss: Well, I'm sure it was. They did not think it through.

We took two sets of controls for our case-control study. We took STD [sexually transmitted disease] clinic controls, and neighborhood controls that we picked at random. We used the census tract data to define an area, and we went through a process; we got very good controls.

Hughes: Because the CDC controls were suspect--

Moss: They weren't suspect. They were wrong. So you don't get good differentiation between cases and controls in the study.

Hughes: Do you want to look at a couple of the letters that I found?

Moss: Sure. [tape interruption]

Hughes: The questionnaire I just showed you was the one used in the AIDS incidence study?

Moss: No, we didn't use a questionnaire for that. That study was just counting cases.

The memo to Conant lists an agenda.[1] I asked him whether the CDC was continuing to interview people in San Francisco, and he said no. So I decided that we would do a case-control study ["A case-control study of men at high risk of AIDS"] in San Francisco to look for risk factors for AIDS. Having written a grant application, having committed to AIDS, I decided to start doing that.

The Questionnaire

Moss: At the end of 1982, we started developing a questionnaire. I got my gay informants together. Stewart Anderson was one of my first informants about gay sexuality and what we ought to be asking people about. I talked to a lot of people. I rounded up a working group, and we met in the evenings over on Gough Street in my office. I got a lot of gay men into it. Michael [Gorman], whom I hired-- How did I do that? I must have had him on brain tumor money. I was using my brain tumor study budget to fund

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[1] Andrew R. Moss to Marcus Conant, June 23, 1982. (KS Notebook, June 21-July 4, 1982.)

AIDS. That's what I did; that's what everybody did; I bootlegged it.

I hired Michael, and Wally Krampf, a gay doctor who still works with us and has a gay practice. I hired Louise Swig and other people that worked with us as interviewers and volunteers. We invited people to sit in on the discussions. I had an open process. Partly I wanted word to get out to the gay community about what we did, and I didn't want it to be seen as closed or secretive. Trying to win support in the gay community is what we were doing, and I figured since we were doing all this sexuality stuff that we should try and open it way out. So we did. We made it totally open. Anybody who wanted to sit in on these discussions was welcome, and a lot of people came.

We had this process of developing questionnaires whereby we iterated them. We started with something, and then we'd all take it out in the field and do one or two interviews, and then come back and discuss the questionnaire and change it. It takes a long time, but we worked through all the gay sexual issues.

I had key informants. I had my sadist, my masochist, and my water sports expert, and Stewart who was my fist-fucker expert. I had all these people that I would go to--it was great. My main motivation for being an epidemiologist is curiosity, voyeurism. A very big part of my motive was, Ooh, this is interesting. Let's have a look at this. The wall was down between the gay world and the straight world. You could peer into this taboo territory, where all this very extreme sex by heterosexual's definitions was going on. Homosexual sexuality in that era was almost a cult phenomenon; it was like a sex cult. It was very different from what goes on in the straight world, so we were penetrating into this weird world.

We were extremely thorough. We masked our prurience with Teutonic thoroughness, and investigated everything, and generated this gigantic questionnaire which asked about every possible sexual activity.

Hughes: Just sexual activities?

Moss: Mostly, not totally. Residence, history, places. We asked about places; we were very interested in where people did this. We were still under the epidemiological delusion that you could identify the place where transmission occurs. Of course, it's really going on everywhere, but we had this fantasy that you could identify place. Did we think in terms of tens or thousands of deaths at that point? I don't know. It's hard to reconstruct. Seeing what was going on in the bathhouses or the sex clubs, one strategy was to ask people where they had done their stuff.

It's probably the best case-control study of AIDS risk factors anybody ever did, because we got obsessive about it. Our coping strategy for the fact that we were so psychically out of our depth was Germanic thoroughness. [laughing]

It was a huge questionnaire; it took an hour to do the interview, and it covered every sexual activity and a lot of other stuff as well. It covered places and exposures and God-knows-what.

Hughes: Was it indeed more comprehensive than other questionnaires?

Moss: Yes, it's probably the best one developed for use in studies in gay men. It's definitely better than the CDC questionnaire, which we started off with.

Hughes: How much did you modify it as time went on?

Moss: Oh, we just went through a big development process. We took months to develop it. Dennis Osmond, Louise Swig, who was actually a field director for studies like this, and I piloted it. We were all obsessive about this particular part of the process, so we did it a long time. Also, it's how you get yourself into the issue, get yourself thinking about it.

We're doing it now with TB histories. You work yourself into what's going on--that's how you talk to your first patient. You get people of very varied backgrounds to comment, and you start with a draft questionnaire, and then you all go and interview an AIDS case. That's what we did.

So I interviewed my first AIDS case, an unbelievably creepy experience. I'll find notes on that: that will be worth reading. [laughs] It was an incredibly creepy and frightening experience, but also a bonding experience, a commitment experience. We all did it, we all came back, our eyes were opened, and we were exhilarated and terrified. We'd all done it, so we'd all get deeply into discussing what we were doing with studying this strange sexual stuff.

Quick-and-Dirty Studies

Moss: While we were going on the road with the AIDS incidence study, we were developing this case-control one. A census tract study is a quick-and-dirty study. I did it that way deliberately. I knew this would be a quick way of getting some data out. I did two things very quickly: the AIDS incidence study and a survival study, how long people diagnosed with AIDS lived. They were dying very rapidly. Peter Bacchetti and I finally did that study formally.[1] Eleven months was the average survival with AIDS in those days, eleven months from diagnosis to death. So that's another easy study that we were also doing. It wasn't so easy, but we were doing that too.

See, with no money, you have to do cheap studies. So I did cheap studies we could do with existing resources, and development work on this big case-control study, which was several hundred thousand dollars for the full study. We eventually interviewed 600 people in the case-control study, 300 AIDS cases, 300 controls.

Hughes: Give me an idea of what sort of questions in the questionnaire worked, and what sort of questions didn't work?

Moss: Well, you're trying to measure things, like number of sexual partners. You're trying to come up with how many sexual partners the person has had in the last week, month, year, ten years, lifetime. How do you group it? Zero-one, one-two, two-three, three-five? [tape interruption]

Institutional Indifference and Inertia

Moss: In 1983, when there was hysteria and no money [for AIDS research], you'd go to your department, and it didn't see it. UC didn't see it. The bureaucracy didn't get it, ever. It was just like they didn't care. Most institutions in this country, except where there is a threat of broad heterosexual transmission, in fact don't care.

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[1] A.R. Moss, G. McCallum, P. Volberding, P. Bacchetti, and S. Dritz. Mortality associated with mode of presentation in the acquired immunodeficiency syndrome. *Journal of the National Cancer Institute* 1984, 73:1281-1284.

Hughes: Surely by 1985, it was clear that heterosexuals were involved in the epidemic.

Moss: Well, yes. But the bureaucrats never really got very cooperative. My model of the federal government is that it is like a dinosaur. It has a very long spine and a very long neural system. You are down here at the end on the tail, and you're whacking away at the tail with a hammer trying to get its attention. The message goes all the way up to the head, and it gets processed, and the head slowly turns around and looks at you. But it takes quite a while, like years, for this to happen.

At UC it was different. You felt that at UC it was resentment: "You people are breaking the rules; you're getting all the money through the wrong channels; you're doing what you want; you're not playing the game. Who are you? You have no seniority. We're not going to do it your way. Get out of our face."

Hughes: In the case of the federal government, it has been argued that its slow response was partially due to the fact that a bureaucracy moves slowly.[1]

Moss: It's happening now with drug-resistant TB in New York.

Hughes: That involves a stigmatized group, too.

Moss: Yes.

Hughes: I'm trying to differentiate between the stigma and the inherent inertia in the federal response system.

Moss: It's hard to make that distinction, because the system is inherently so unresponsive. But I think it's true that there's definite reluctance to deal with this homosexuality issue. Eventually it came to seem normal. People go through this strange two-phase process where first they are afraid of it and they won't touch it and they won't do anything, and then they realize what they're doing and they overreact in the opposite direction. They then hurl money at you.

The way the system works is, they give you nothing for three years, and then they start hurling money at you. They'll hurl

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[1] For an analysis of the federal government's response to the AIDS epidemic, see: Daniel M. Fox. AIDS and the American healthy polity: the history and prospects of a crisis in authority. *The Milbank Quarterly* 1986, 64:7-33.

tens of millions of dollars at you, and all you have to do is catch it. But that's worse, because then everybody suddenly becomes an AIDS researcher. They're all trying to catch it. And then you have an enormous universe of mediocre AIDS researchers.

Hughes: And that's the situation now?

Moss: Well, we're into the third phase, when they start to cut budgets, when what you have is an enormous universe of mediocre AIDS researchers jumping ship.

Hughes: Can that pattern be tied in with the recession and the retrenchment of government?

Moss: No, it's normal. They expanded AIDS money very fast, to a level comparable with cancer--that's remarkable--and then they held it there. Also the research is not productive. The AIDS research universe has not succeeded.

Hughes: In what terms?

Moss: Any terms. There are no good drugs; there's no vaccine; there's no influential basic science.

Hughes: There's a lot known about the virus.

Moss: Yes, but not helping anybody.

Hughes: Can you really argue that? The vaccine people are building on the basic science.

Moss: It's not very impressive. It's normal science, as [the historian of science Thomas] Kuhn says. Normal science in America is a political bureaucratic process where it's not clear that it has to produce good results. Basically everything's measured by quantity. You do lots of drug trials but there aren't any new drugs--so it's churning. That's where we are now.

Hughes: But it is a difficult virus.

Moss: So what? Everything's difficult.

Hughes: There are degrees of difficulty.

Moss: I don't think it's a successful program. I think that it has been absorbed into the normal science system which doesn't really care whether it produces results or not.

Hughes: When did AIDS research become normal science?

Moss: I don't think there's a single point.

Hughes: The discovery of the virus?

Moss: No. Well, it's a funding issue. You just look at the funding trajectory. You can see where it levels off. At that point, you're doing normal science in Kuhn's terms, where the machinery of science is churning, but it's not clear that anything's coming out the end. [tape interruption]

Stages in the Epidemic

Moss: In my mind, this epidemic divides into time periods. The first one is up until July 1983, when we moved into the clinic. Then there's July 1983 to January 1985, which was when we were in the clinic sort of living in fear. Then after 1985 when the serology was available, we went into the just-doing-it phase, when we were no longer in a state of major paranoia and we didn't think there was going to be a huge anti-gay backlash. We did studies, and everybody here became suddenly the world's leading authority, a media star, and we all fly all over the world going to all these committee meetings. So we went in four years from being nobody to being the world's leading authorities, and that's a strange phase. For me, the second phase, the paranoid phase, was terrifying and very interesting, and after that, the phase of being an authority was a whole different experience.

Jerry Friedland did a lot of early AIDS work on drug users in New York, and he says, "Well, you're a pioneer." And we were pioneers, in the absolute literal sense. You were out there in unstaked territory, where nobody knew what was happening, trying to hack this stuff out. That's different from being an expert. We were pioneers and then we were experts. Being an expert is a bureaucratic process, where you are "them," really. You've now become "them."

TB is what I am interested in now. If you go to NIAID, the National Institute of Allergy and Infectious Disease Institute, and say, "Well, we want money for TB," they say, "We have to protect our AIDS research." Now, that's like all the breast cancer people in 1983 saying, "Oh, we have to protect breast cancer research."

So AIDS is now one of "them," not one of "us." So if you were one of the people in the pioneer era, you now have a divided soul because you've become one of "them." We have become "them."

But you remember when we were "us," when it was heroic. That's not how it is now. We are part of the big bureaucracy, and we're not doing a very good job, any more than they were when we were on the outside.

Hughes: How would you have it done?

Moss: You have no choice. You can't do it any other way. So the pioneers become irrelevant. You don't want pioneers now. You want organizational people. AIDS researchers had to make the transition if they wanted to go on doing AIDS research. Paul [Volberding] is the classic example. He successfully made the transition from rule-breaker to rule-enforcer.

Hughes: Does this development explain your switch to research on TB?

Moss: I've had enough of AIDS. I like the pioneer phase, although you have to recognize that pioneers become irrelevant when the schoolmarm arrives, or whoever it is in the movies.

Hughes: Well, what about epidemiology?

Moss: Well, epidemiology is a funny field. There are always interesting things to do. My line is that you can do whatever you like if you're an epidemiologist. You just call it epidemiology. I've done a lot of clinical research that most epidemiologists don't do, and so forth. I'll do anything that's interesting to me, that I can get away with. One of the features of the pioneer phase is that people let you, because nobody else would do the research. If you say, "Well, I'm going to do the clinical epidemiology of AIDS," they don't say, "Well, you're not a doctor. How can you possibly do that?" They say, "Great! Somebody's doing it."

Research on AIDS in Intravenous Drug Users, 1984

Reviewing Grant Applications to the National Institute on Drug Abuse

Hughes: Another transition seems to me to be when you moved into research on AIDS in intravenous drug users.

Moss: Well, the drug use research is very different. AIDS in drug users is not a big thing in San Francisco. We started in 1984, because of knowing what was going on in New York. Actually, the National Institute on Drug Abuse [NIDA], which funds drug-related research, had decided that it, not NIAID, would do drug-user AIDS research. Bureaucratic decisions were made that NIDA would fund it. I think the very first grants were in 1983, and I was a reviewer, because I had done drug-user related research. There were, I think, only three submissions. One was Don Desjarlais in New York, one was Herb Kleber at Yale, who became the drug czar, and I forget who the third one was.

We turned Kleber down. They were all crappy proposals. Like us, they didn't know what to do. Nobody knew what to do. But I funded Desjarlais. I was the reviewer. I said, "Well, this guy doesn't know what to do, but we should fund him anyway, because somebody ought to be doing something in this field." I was sensitized and alerted to this type of research, so I decided to do some drug-user research here.

In fact, Charlie Smart of the NIDA, one of the first bureaucrats to wake up to AIDS, came around trying to give people small grants to work on it. He had people write applications to NIDA for little teeny grants, $5,000 grants, to work on drug-user AIDS. He came to me because I had worked on drug use in the seventies. I was totally bummed out. I said, "I'm not writing any grants for $5,000, forget it. Give me $5,000, fine, but don't expect me to write a grant for it." So he went away.

Research in San Francisco

Moss: We had a gay male doctor working with us who, like a lot of gay male doctors, wanted to work in AIDS. But working with gay men was too close to home, so he decided he wanted to work on drug users. So we rounded up drug users, and in 1984 we started doing early serology on drug users, too. We did a drug user serology study.[1]

Hughes: Did your methodology change when you moved from one type of population to another?

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[1] R. E. Chaisson, A. R. Moss, et al. Human immunodeficiency virus infection in heterosexual intravenous drug users in San Francisco. *American Journal of Public Health* 1987, 77:169-172.

Moss: Yes. This we did through the drug treatment programs. Serological testing was available by the beginning of '85, and we got funded to do a big drug-user study. There were a lot of fears about stigmatizing gay men. I was one of the people who testified for California legislation that restricts the use of the HIV test. We thought it should be only done with specific consent. Being seen to be testifying for protection of their confidentiality enabled us to do research with gay men.

But with drug users, I thought that the test should be used. I thought they should be encouraged to take it, because there was no community public health enterprise; there was no way of doing anything like what was being done in the gay community. Education has worked, at least with the middle-aged gay cohort. I don't know if it's worked with young gay men; I don't think it has. That's another story.

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Moss: There was a big community enterprise involving public health staff that was working with gay men. There was nothing similar visible with drug users; you had to do something else. I thought we should do mass HIV testing, and I set out to do that in San Francisco. We are the only people who have done this, as far as I know. We decided to test as many drug users as we could.

The Medical Follow-up Program

Moss: I thought it was not legitimate to do testing unless you got them into medical follow-up, so we set up the medical follow-up. We set up a medical follow-up for the positives too. I couldn't get that funded by NIDA; they turned the application down. I got absolutely enraged with NIDA; had another big series of wars about this project. But we got state funding for the follow-up. The state has been very good to me. I am the second highest recipient of state AIDS funds after Connie Wofsy, who is number one, I think.

So the state funded the follow-up for drug users, and we went out and started bleeding drug users in the treatment programs. We did enormous politics--city politics and ethnic politics--and managed to eventually set up an HIV screening process in all the city-funded drug treatment programs in San Francisco. It took a lot of maneuvering.

In that program, we tested 2,351 intravenous drug users, which is probably more than anybody outside Baltimore. There are estimated to be 13,000 drug users in San Francisco, so we tested about one in four or one in five. We found out the main thing associated with HIV in drug users was intravenous cocaine use, not heroin. I went to NIDA and told them, but they didn't believe it; nobody believed it. The reviewers didn't believe it; we had to fight the paper into *JAMA* [*Journal of the American Medical Association*].[1] But it turned out to be true. It's cocaine injection that gives people AIDS.

We got several hundred drug users into medical follow-up, one way or another.

Hughes: Which consisted of what?

Moss: Well, first we set up a process like a longitudinal study. We'd see them every six months and do a physical examination, CD4 testing, interviewing, and clinical examination. Eventually, the AIDS Clinic set up a drug users' clinic downstairs, down below there on Ward 93, and they got steered into that. A lot of them ended up within the AIDS treatment system, at SF General or elsewhere. It was quite successful.

But then we stopped the project, got tired of it. It's very difficult working with users. It's very difficult to find doctors who want to do it. We had one very good one, Dick Chaisson, who wrote that *JAMA* paper, but after he left we never managed to find somebody who was comparably efficient and enthusiastic. We had a very good woman, Ann Williams from Yale, a nurse, who did it for a while and then she went back to Yale. I just got sick of it.

Hughes: You're saying that physicians don't like to work with drug users?

Moss: They don't want to. I don't blame them.

Hughes: How was it, dealing with drug users as opposed to dealing with gay men?

Moss: Depressing, because they're poor and generally fucked-up people. But it's not as bad as people think. There's a minority who are really violent, but most of them are actually fine. We ended up not minding it, and we carried on the study for a long time--six years.

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[1] R. E. Chaisson, P. Bacchetti, et al. Cocaine use and HIV infection in intravenous drug users in San Francisco. *Journal of the American Medical Association* 1989, 261:561-565.

The drug user study is a giant epic in its own right. Nobody believes that San Francisco is a place to do drug user studies, so it's been an uphill battle.

Hughes: Why?

Moss: They think it's an East Coast issue. Maybe it is an East Coast issue. It's certainly a bigger issue on the East Coast. Same with homelessness. People think that, Oh, San Francisco is where you study gay AIDS--and the East Coast is where you study poor people with AIDS, drug users and whatnot. So we have really been ghetto-ized as researchers. Although we have gotten funded to do all this--I shouldn't complain too much.

Screening the San Francisco Homeless for HIV and Tuberculosis

Moss: And now we've gone out to the homeless, which is a similar study. We're screening the homeless of San Francisco for HIV and TB. We've done about 1,500 of them, and we'll do a total of 3,000 or 4,000. We've set up our own follow-up and referral system for that, too. We do a little research. There's some serology, and we did a lot of collaborative research on drug users. But really these are public health interventions. I made the unilateral decision that it was a good thing to do, and got it funded as research when it's only partially research.

The medical students like the homeless project; it's politically correct. So we began to mobilize people, and we got into tuberculosis as a result, which is a very big deal now.

Comparing the Response of San Francisco and New York

Hughes: Please compare how San Francisco responded as opposed to how New York responded to the epidemic.

Moss: Well, San Francisco loves to pat itself on the back. I believe in some of that. I think that the gay political community responded brilliantly. They really did a great job of mobilizing in the early days. They were responsible for the fact that the city of San Francisco put out money and everything, and set up big prevention campaigns. They had access to and some control over the political machine. They were able to get the political machine to do things, to actually fund things.

Now, that's not true in New York. Nobody's ever been able to get it to do what needed to be done.

Hughes: Why is that?

Moss: It's ethnic politics; it's size; it's the fact that there are too many competing institutions in New York.

The other thing about San Francisco is there's only one medical school, and it has close relationships to the Department of Public Health. There's an integrated medical universe. It's like a fiefdom. You can get a lot done in San Francisco.

Hughes: New York has multi-fiefdoms?

Moss: Yes. But I don't think the undifferentiated propaganda about San Francisco is true. I think some things are true.

Hughes: Where would you disagree?

Moss: Well, the patting on the back about prevention amongst gay men.

Rising HIV Infection in Young Gay Men in San Francisco

Moss: It's clear that it's a failure amongst young gay men. We've failed, because they are getting infected. Well, that's terrible.

Hughes: Can the rise be correlated with a drop in educational programs?

Moss: I think it's a bigger issue. I think it has to do with the social dynamics of gay men, and what the younger generation is like, and what they believe about their risks and so forth, and a failure of anybody to try and intervene. Some people are working on it.

Hughes: Presumably, there was a young gay population in 1981.

Moss: They weren't that young.

Hughes: Is it younger now?

Moss: Yes, there's a big young contingent. But they may just be different. We are involved in studies on that.

Hughes: I read that there is a fatalism in the gay community, that some gay men think that getting AIDS is inevitable.

Moss: That's not the issue. It's a prevention issue. Young gay men are getting infected, and ten years into the epidemic they shouldn't be getting infected. It's stupid to live your life in such a way that by the time you're thirty, you have a one-third chance of being HIV-infected. Which is what's happening with young gay men.

Hughes: Do some gays have a feeling of fatalism, that one way or another they're going to come down with AIDS, so why not enjoy life to the fullest?

Moss: Well, that's a youth perspective. That's a perspective that's basically saying, "I'm not going to think about death." That's people not willing to see what's going on around them. If you see what is really happening, you wouldn't do that.

Hughes: Is the educational campaign effective?

Moss: No, I don't think it's functioning effectively. The seroconversion rate in young gay men is higher than in drug users now. Drug users are about 2 percent a year, young gay men about 2.7.

Closing the Bathhouses in San Francisco

Pressure for Closure

Hughes: What was your role in bathhouse closure?

Moss: Well, we got intimately involved in that because of doing all this sex research in gay men, and also this clinical research. The bathhouses were a big institution that was very much part of the whole matrix of gay life of San Francisco. Everybody went to the bathhouses. A lot of money moved through the bathhouses. The bathhouse owners were powerful people. The bathhouses were a business phenomenon.

As soon as Michael and I started talking about our data, people started saying, "Oh, you're going to close down the bathhouses." And we thought, Well, yes, we probably are. We are trying to close down the bathhouses.

Hughes: But that hadn't been your initial idea?

Moss: No, I hadn't thought about it in the beginning. But then we began to think about it, and we began to talk to people about what it was like in the bathhouses, and we did our sex research. Silverman eventually woke up to AIDS sometime mid-1983. Then he got the order--[Mayor Dianne] Feinstein began to lean on him--to shut down the bathhouses.

Now, Conant was advising Feinstein. He probably told her to shut them down. Conant was really going his own way on this. Various advisory committees got set up in '83-'84. Silverman set up his own advisory committee [Medical Advisory Committee on AIDS] on the bathhouses, because he didn't want to close them. Because he was afraid--he had this response which is that you're opening the gates of the concentration camp when you do that, fear of stigmatization. This was the paranoia response, the anti-gay backlash response. And 1984 is pre-serology. We still don't know who's at risk, and how much the risks are, and what happens if you allow it to spread widely in gay men, if it's going to mean it's going to spread to other people. Nobody knew this. It was not clear at all in 1984.

Hughes: Was it clear that the bathhouses were the center of the problem?

Moss: No, that was not clear.

Hughes: I thought that the interviews of patients at the KS Clinic and the AIDS Clinic indicated that that's where their encounters were.

Moss: Well, I'll tell you what we found in our study. We found that numbers of partners was clearly associated with risk, but that partners in bathhouses weren't clearly associated with risk. We couldn't demonstrate a clear association between bathhouses and risk.

Why? Well, it's a good question. It may be that in fact what went on in bathhouses was not the way most of it was transmitted; I don't know. So it was an interesting decision for me, because I was getting this data [on AIDS incidence in the gay ares of San Francisco] while Silverman was going through this process and assembling his advisory committee.

Mervyn Silverman's Advisory Committee

Moss: Paul [Volberding] and Donald [Abrams] and I were on the advisory committee. We would pile into Donald's Volkswagen Cabriolet and drive over there [the health department] for Merv's meeting.

This was when everybody was getting famous. I remember Paul saying, "Oh, do you go to these meetings?" You know, Are you in this loop as opposed to that loop, kind of thing. I don't know how I got into that loop, because Silverman I think felt that I had sandbagged him with our census tract study, in going to the media and saying, "Oh, my God, big trouble in San Francisco," before he woke up. Silverman was supposed to be at our site visit for the NCI where my data was presented. He didn't show up, because the Queen of England was here and it was more important to go see the Queen.

I don't know what Pat Norman had communicated to him, but he had not gotten it, the importance of the epidemic. Eventually he got it, but he had some idea that I had sandbagged him about it.

Anyway, eventually he put me on his committee, and we would go down there to the health department, where all this was being played out, and where Silverman would ask all the people on the committee about what we should do--whether we should close the bathhouses.

I remember at those meetings two things: one is pulling up the data from the risk factors for AIDS study, showing the relative risks associated with different numbers of sexual partners. Selma would say, "Well, how do we know it's a sexually transmitted disease?" There was actually no formal evidence that it was a sexually transmitted disease. No formal studies had shown that it was. The way you do that is to show that the risk varies with number of sexual partners.

Well, we had this data from our studies, so I put it on the board. I wrote down, "Number of partners in the last year, zero--ten--twenty--thirty--forty--fifty," with the relative risks, which go up very high. And it's very convincing. So the conclusion was: Oh, okay. Sexually transmitted disease--no doubt about it. That's a very powerful piece of data. Merle Sande said he was convinced by this data. And I thought it was very convincing, too. It does convince you that it's a sexually transmitted disease.

Decision to Suppress Data

Moss: What I suppressed was the fact that we had no evidence that there was risk associated with bathhouse use. My call was that they were dangerous, and that even if we couldn't show it, we probably were measuring something wrong. With these studies, it's hard to get to grips with some of this stuff--we may have been asking the questions wrong; bathhouse use may have been confused with number of partners; people may have lied.

So I suppressed it. I didn't show them that. We were all deposed as part of the bathhouse process.[1] These are classic documents of AIDS. I think I have them here. [tape interruption]

In the bathhouse process, including my deposition, I talked about this. Darrow was involved, and he was trying to get me to produce data. But it was not clear to me that we had any data to demonstrate the association of AIDS transmission with bathhouses.

Hughes: But you didn't tell people that.

Moss: I deliberately suppressed it. I decided that it was the correct thing to do to close the bathhouses, that it was clearly a sexually transmitted disease, and I would not report the fact that I couldn't demonstrate it from my studies. That's the decision I made. Everybody has to make those decisions.

Now, Silverman had to make the decision, and he asked us. At the first of these meetings I went to, I was the only person that thought the bathhouses should be closed. Silverman said, "Who thinks they should be closed now?" and I put up my hand.

Hughes: Was Selma Dritz there?

Moss: I don't think Selma was at these meetings. See, she worked for Silverman, and we were his outside advisory group.

Hughes: Who was on it?

Moss: Well, it varied, but there were two prominent groups: the AIDS doctors and researchers from UCSF and General (me and Paul and Donald and Merle Sande and maybe Connie [Wofsy]), and the gay doctors, mostly from BAPHR. Silverman really wanted to have a gay voice for closing the bathhouses.

But Silverman basically did well, because the Department of Health basically approached the issue of bathhouse closure in a

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[1] Declaration of Andrew R. Moss, Ph.D., in support of a temporary restraining order to close the bathhouses. Superior Court of the State of California in and for the City and County of San Francisco. (Dean Echenberg papers. SFDPH Bureau of Epidemiology and Communicable Disease Control, drawer: Bathhouses, folder: 10-10-84 Declarations in Support, vol. 1.)

formal way. They did the investigation, and they deposed everybody. The *Examiner* poll[1] showed a majority of gay respondents were for closing the bathhouses, and then he did it.

Silverman Delays Closure

Hughes: There was an occasion when everybody was expecting him to announce closure of the bathhouses--

Moss: It was a press conference [March 30, 1984].

Hughes: --and then he backed off.

Moss: We went to the press conference. We all piled into Paul's car. Paul had new shoes which the French would call à merde d'oie, goose-shit color, and he said, "You know how much these shoes cost? $260." Paul was becoming famous. And he was very happy, because he was like a star. He turned to Donald and me and he said, "We're making history," because he thought Silverman was going to announce the closing of the baths. We got there, and it was like--fizzle, no history. [laughs]

Hughes: Why did Silverman backtrack?

Moss: Well, he was getting pressure from gays who thought this was opening the doors of the concentration camps--the stigmatization issue again. People really thought that if you closed the baths, you were saying that gay men were responsible for spreading this plague. Remember, we still didn't know how widely it was spreading in the general population. So if you closed down the bathhouses, it was like ghetto-ization; you were lighting up the target. You were saying, "Homosexuals are responsible for this awful disease that is now killing your babies." That's what Silverman was afraid of.

So he wanted people out in front of him. He wanted us, the researchers, telling him, "Yes, this is scientifically correct, to close the bathhouses." He wanted the gay doctors saying, "Yes, even homosexual doctors say the baths should be closed." He wanted--he got--the gay community behind him. He can't have known

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[1] David M. Cole. Proposal to ban sex in baths gets most support in SF poll. *San Francisco Examiner*, April 8, 1984, p A1. This poll reported that 44 percent of those surveyed favored banning sex in the bathhouses, and another 36 percent favored closing them.

that the poll would come out that way, in favor of closure, but it did. At that point, he was in a very good position to close the bathhouses.

And then they had the investigation. They had Hal Lifton, a private investigator, round up all these reasonably gay-looking guys and put towels on them and send them down to the bathhouses to report on unsafe sex.[1] You should read their depositions about what was going on there. What was going on in the bathhouses and clubs was very dangerous. Everybody was fucking each other randomly. It was not a good idea in the middle of an epidemic.

In retrospect, closing the bathhouses was the right thing to do. As we found out later, at that point 50 percent of gay men in San Francisco were infected. So if you had anal sex with two or three other gay men, you were in a very good position to get infected.

Hughes: Were you saying that?

Moss: Well, we didn't know at the time how many people were infected. We didn't know what was going on. All I knew was it was a sexually transmitted disease. It was clear from my data it was a sexually transmitted disease.

Hughes: Well, you knew that because you had already published that *Lancet* letter.

Moss: No, I knew it from unpublished data in the case-control study. Well, we knew what we knew, which was parts of the story. Everybody knew parts of the story. But I think that Silverman made the right decision.

So far as we can see, the big change in behavior probably occurred in 1982. Our *Nature* paper shows seroconversion rates from various studies, and you can see that there's already a big drop in 1982 in new infection.[2] By 1984, the new infection rate was down a lot below what it was in 1982. So in fact, closing the bathhouses probably saved some lives. But it probably wasn't a determining influence on what went on. See, Silverman was

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[1] For a report on the inspection of gay bathhouses, see: George Bush to Mervyn Silverman, November 30, 1984. (Echenberg papers, drawer: bathhouses, folder: sex clubs/bathhouse.)

[2] Peter Bacchetti, Andrew Moss. Incubation period of AIDS in San Francisco. *Nature* 1989, 338:251-253.

probably right. I don't know. It [bathhouse closure] wasn't the critical issue.

Closure as a Political Rather than Public Health Decision

Moss: What happens in AIDS is that these initiatives become media events, and people see them as being the critical issue. "Close the bathhouses now, or the epidemic will spread." That's not the point. The bathhouses were just a part of it, probably a fairly influential part, but not the thing itself. The thing itself was the fact that gay men in San Francisco by and large were having a lot of sex with each other, everywhere--many venues and many different situations, in many different ways, including the bathhouses.

It's like needle exchanges. People get berserk about needle exchanges, but they're not the thing itself. It will not make any difference on a broad scale to what happens with drug users whether the needle exchanges are open or closed. It's a political issue. Same with the bathhouses: it was a political issue, not primarily a public health issue. I used to go around saying, "Do you know the three rules of AIDS? Well, the three rules of AIDS are: one, everything's political; two, everything's political; three, everything's political." I don't do this any more, because it is now obvious. At the time, it struck me as quite remarkable. But it is the way it is.

So the bathhouse bit was a political debate, much more than a public health debate, in which people were orienting themselves around what "should" embody in reality what the public presentation of homosexuality should be.

Mayor Feinstein's Role

Hughes: I understand that the bathhouse issue was what led to Silverman's demise as public health director.

Moss: Yes, Feinstein fired him. I think that's a very interesting maneuver. My analysis is that she fired him because somebody symbolically had to take the moral weight from the stigmatizing act of closure. By firing him, she made him carry the stigmatizing weight. He was the bad guy, although she was the person who actually forced it through.

Hughes: How did the mayor do that?

Moss: Well, she forced him to do it, basically.

Hughes: She didn't have any legal recourse.

Moss: I don't know how she did it, but I know she put a lot of pressure on Silverman, and I also know that she's very good at putting pressure on people. She really turned the screws on him to do it. She probably told him, "I'll fire you now if you don't do it," and then she fired him anyway.

Hughes: Well, I know that the health director reported to the city's chief administrative officer, not to the mayor.[1]

Moss: She probably did that to cut herself off from the AIDS stuff, to insulate herself. Well, that was an astute move, as it turned out. She was astute about AIDS. She got through all this with no egg on her face at all.

At first she just listened to Conant, and then during this bathhouse debate, somehow Conant stopped becoming her favorite, and people from here [San Francisco General Hospital]--Merle, Paul, Connie, Donald, and I--became her advisory committee on AIDS. We would go and talk to her, and she made it real clear. She said--well, Merle interpreted her to us, so he said, "She doesn't want to be blindsided. She wants to know what's coming along; that's what your job is." Which is very astute. She just wanted to know what was going to happen, so that she wasn't caught off guard.

Hughes: Did the committee perform that function for her?

Moss: Yes, we performed that function for her. She's a very rough woman. She'll say what she doesn't like. She whacks you around the head. She did it to me; I had her whack me around. She humiliates and degrades you in front of your colleagues, and you have the choice of either stomping out or taking it. What you do is take it, because if you stomp out, you're gone for good. [laughs]

Hughes: What was she on at you about?

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[1] Randy Shilts. Silverman Feeling Bathhouse Heat. *San Francisco Chronicle*, March 29, 1984.

Moss: I told her that the epidemic was going to peak and flatten out very soon. I persisted in telling her this, and she didn't want to hear it.

Hughes: Why?

Moss: She probably believed me; she just didn't want to say it, or have us say it. So she just whacked at me until I got the idea.

Hughes: And you shut up.

Moss: I shut up, yes. What I was saying was true. She's a tough lady.

Framing the Disease

[Interview 2: March 18, 1993, Dr. Moss's office, San Francisco General Hospital] ##

Hughes: Dr. Moss, I'm interested in the framing of the disease and how it determined your protocols.

Moss: Well, we all knew that in San Francisco it was a gay disease. It's still a 90 percent gay male disease in San Francisco. You couldn't frame it any other way. That's what made it interesting, I think, as well as biologically. The precedent was hepatitis B, really. The way AIDS works epidemiologically is not surprising; the risk groups are very similar to hepatitis B. There really weren't any big surprises in the early days in terms of epidemiology. What looks to be a virus that is mostly in homosexual men and drug users and blood transfusion recipients is not surprising; that makes sense.

Hughes: Because of the parallel with hepatitis B?

Moss: Yes. And lots of other blood-borne pathogens work in similar ways. It got weirder later because of the apparent absence of female-to-male transmission; it doesn't transmit very well heterosexually. But hepatitis B doesn't transmit that well heterosexually, and I don't think hep C does either. There were no big biological or epidemiological mysteries in the early presentation [of AIDS].

Hughes: As long as you were confining your thought to the infectious disease model. There was a lot of confusion about other possible factors.

Moss: Which other possibilities?

Hughes: Like poppers, and the immune overload theory.

Moss: But nobody seriously believed those.

Hughes: Are you sure?

Moss: Well, people who knew what they were talking about didn't seriously believe them. There are ideologically-maintained hypotheses that people want to believe, like [Peter] Duesberg's. Poppers were a micro-hypothesis. It accounts for a tiny bit of what's going on maybe. After the very first studies, it was real clear that it couldn't possibly explain very much of what was going on.

Hughes: The CDC spent a lot of time investigating alternative etiologies.

Moss: Jaffe and Curran rejected them very early. Harry Haverkos got vested in the popper hypothesis, kept it alive. Basically, people didn't have a whole lot of belief in it.

There was one bad study in New York by Michael Marmor which made it look like poppers had some serious influence. But it's clearly not true when you start looking at it. We looked at our study. There was just not a lot of relationship between poppers and AIDS. And that was very clear as soon as good studies began to get done.

But it's a irrational process. People cling to hypotheses in defiance of the evidence, like Duesberg. It doesn't matter what the evidence says. People decide for their own ideological or personal reasons that immune overload is what causes AIDS, although it's overwhelmingly clear that it's not, and it was from a very early point.

Hughes: Why was it clear that it wasn't immune overload?

Moss: Well, you couldn't find any data that said it was. Who was supposedly immunely overloaded?

Hughes: Gay men.

Moss: They're not immunely overloaded. What's immunely overloaded about gay men? Their CD4 counts are normal, as it turns out. They're not different in CD4 count from heterosexual men. When you look at the data, there is no immune overload. There isn't even in drug users. Recently, there have been some interesting things about drug users that are different--high beta-L microglobulin levels and immune activation. But you cannot ever find any solid data that says, Oh, yes, immune overload is a reasonable alternative hypothesis. Consequently, serious people dumped it very rapidly.

Hughes: So the fact that gay men had a lot of sexually transmitted diseases wasn't reflected in their immunology?

Moss: Well, not in their CD4 counts. What does immune overload mean? Nobody knows. The CD4 count was what people were measuring in AIDS, and it was the same in gay and straight men.

No, there's no evidence for immune overload in gay men or drug users. Drug users are immune stimulated. It is all turned up a bit, but there's no real evidence it does anything. The immune systems works, solid instinct does well.

So I don't think those theories were an issue for most people who were seriously examining these issues of AIDS etiology. But always with AIDS, there's the mythos that surrounds the science. It's true in any disease. There's the empirical stuff and the people working in empirical stuff, and then there's this penumbra of discussion, debate. There's the discourse of the disease.

And the discourse of the disease has an irrational component, and the irrational component is often bigger than the rational component. That's true in AIDS because of the fears and sexuality issues and the rapid spread and the politics. The irrational part of the debate is bigger. AIDS debates are almost never rational. You don't see people sitting around saying, "Okay, what is the right thing to do here? What does the evidence say? What is in the public interest? What would be best?" That isn't the way the debate works.

Hughes: The debate is more intense than with other sexually transmitted diseases?

Moss: There's no other sexually transmitted disease that's as important.

Hughes: Well, I'm thinking historically.

Moss: Maybe there is; there's chlamydia. Number two is chlamydia, and it's like this: There's no national crisis about chlamydia. Chlamydia is not in the newspapers every day. There's never been anything like AIDS. It's different. So it's a different discourse. The relationship between disease and the buzz of life is totally different, and it was from the beginning.

So AIDS was framed as a homosexual disease because it was a homosexual disease. In San Francisco, gay men were the only people in the AIDS outpatient clinic [at San Francisco General] until late 1983.

We watched for the first heterosexual AIDS case, and it was a pimp in the summer of 1983, just about when we moved in here [SFGH]. It was the first heterosexual AIDS case in San Francisco in very low-life people. Mrs. Proffitt was a prostitute and her husband was a pimp in the Tenderloin [district of San Francisco]. She didn't have AIDS. What she did have, although we didn't know it at the time, was HIV infection. Mrs. Proffitt, the mother of baby Proffitt, eventually years later got AIDS and died. She was an HIV-infected drug user.[1] Eventually drug users with AIDS began to show up in the AIDS Clinic. Somehow or other, they got there.

Caution about Presenting AIDS as a Gay Disease

Moss: The framing issue is important, but it's not my issue as a practicing researcher. The framing issue comes in when you start playing politics. Then it was very important for everybody. The light went on that the way you got funded in San Francisco was you play gay politics.

Hughes: Funded from the city?

Moss: Yes. That's where the money was. The state money was essentially the result of gay politics, too. And the lobbying with the federal government was gay lobbying. The people who were doing the politics of AIDS were gay from the start. We were all talking to Phillip Burton's legislative assistant, Bill Kraus. He was putting it into Burton's ear, and it was going to the Congress. And Conant was talking to Willie Brown, who was very attuned to his gay constituency. That's gay politics. And the stuff with the city is directly gay, right through the frame.

It was not a gay disease, but it was a gay lobby, I would say.

Hughes: Well, it was a gay disease in San Francisco! And wasn't that the way it was conceived of?

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[1] For more on the Proffitts, see the oral history in this series with Arthur J. Ammann.

Moss: There is no such thing as a gay disease. People are gay.

Hughes: Well, I'm talking about perceptions; I'm not talking about accuracy.

Moss: Well, when we started working on AIDS, it got very complex. When we went out in the gay community, everybody's flags were up instantly on labeling and stigmatization issues, so we had to be very careful to make it clear that we knew that homosexuality was an issue, and that we knew that it was not a homosexual disease, and we weren't saying it was. We were all walking around on eggshells.

Hughes: I realize that.

Moss: We were very sensitized to this stuff real early on. The people who succeeded in AIDS were people who could deal with the politics, and gay politics was a big part of it. We were quite sophisticated from a practical point of view about presentation of the disease at the beginning of this epidemic. We would give talks to gay audiences. Michael [Gorman] and I went to Pat Norman and presented our data. And then immediately this rumor started running around that we were doing something anti-gay, even though Michael is gay. We were trying to close the bathhouses; people thought this was homophobic. We were in that kind of minefield right from the beginning.

We were all incredibly oversensitized to the issue of positioning the disease. We backed away from it. We under-presented it as a gay disease for that reason. In the early days, we spent a lot of energy in toning, toning everything down, minimizing, so as to not freak people out.

Dealing with the Media

Hughes: What effects did that cautious approach have on conveying information to the gay community that it needed to protect itself?

Moss: Well, there's you, the researcher and human being, with your data and your little San Francisco process. And then there's the great world of the media. It doesn't matter what you do. It's what gets into the media that's important, because there's this tidal wave out there ready to fall on you and tell you what to think. And it did, with AIDS. The first big media cycle began then, in early 1983.

Hughes: And what was it about?

Moss: Well, I don't know, because we were in it. My study was one of the things that fed this media cascade. Then what happens is you lose control completely. There's a cascade from the local press, local TV, to the national press and national TV, and finally CBS News. Eventually, CBS News calls you up and you go on TV. It doesn't matter what you say. They will only put it on if you say what they choose to hear.

Volberding preemptively struck with the media, brought them in and told them what we thought was happening, and he prepared them. That was the right tactic.

Hughes: You mean he took the initiative.

Moss: Well, he had background sessions with reporters. The university is always kissing the ass of the media, because everybody knows that that's what runs things. So the university had these fellowships for journalists. Science journalists, like Randy Shilts, are the people who reap the rewards. The people who get famous are the science journalists, because everybody knows that's where the power is. Volberding had full-time press people at UCSF working on AIDS from very early on.

Jim Bunn, the Channel 5 reporter, practically lived here. Volberding just seduced him. Bunn finally went to work on AIDS for the WHO [World Health Organization]. Marilyn Chase from the *Wall Street Journal* was here all the time. I brought Laurie Garrett, who was the NPR [National Public Radio] AIDS person, who also became a big star, into the clinic.

More on the AIDS Incidence Study, 1983

Debate over Releasing the Data

Hughes: As I understand it, you agreed, I think it was under pressure from the gay community, to suppress temporarily the information you obtained in the census tract study.[1]

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[1] Shilts. *And the Band Played On*, p. 253-254.

Moss: Not at all. Here's the timetable: we decided to cut the study at the end of 1982, and we had preliminary data that we wrote up in 1982. In January 1983, we took it on the road.

Hughes: You cut it so that you could take it on the road? Get the information out?

Moss: You have to decide at some point that you have something to say, and this is enough data. So we took it on the road. I gave it to lots and lots of groups.

Hughes: Was the decision to cut the study based on scientific grounds, or was it, We've got a problem here, and we've got to get the information to the gay community?

Moss: Oh, yes, absolutely.

Hughes: The latter.

Moss: Yes. We thought it was a nightmare.

Hughes: So if it had been another disease, perhaps the study would have gone on longer?

Moss: I don't know. Those are intangibles. I just figured that the end of the year was a good time to cut it.

Hughes: Were you getting outside pressure to conclude the study and get the information out?

Moss: There was no pressure. That was an unfunded study; I just decided to do it. It was the other way around: we had to force the data out in the world; we had to force people to let us do the study. You never get pressure to do studies; you only get blocked from doing studies.

Hughes: I mean, once you had done the study, was there pressure to get the information out?

Moss: It was a mixed reaction. Basically they just didn't want to know. Some people said, "You've got to get this out." And a lot of people were in the middle. But we got negative reaction from the city from Pat Norman, who was the gay health aide [director of the Office of Gay and Lesbian Health] at the city health department. She was negative, and she didn't like it. It was clear she didn't know whether she believed what was going on.

But most people didn't give that kind of response. There was no kind of direct response about what to do about this data. Most people just listened to it and tried to absorb it. But Conant wanted it out. Randy Shilts found out about it, and he wanted control of it.

I went through a very strange evolution. I talked to many, many people in the political realm. What I really wanted to do was talk to people in the political process, like the legislative assistants and Kraus, because I wanted to get into that process. And we did. We talked to a lot of them about it, all the gay Democratic clubs and the legislative assistants and opinion-makers and the gay political appointees in the city--a gay judge, Herbert Donaldson, and the gay chairman of the board of permit appeals. Louise Swig knew all these people. She got us in to see all these influential gay Feinstein political appointees.

I was trying to get the information into that process, and it got in. And then it became a question, what do you do with it? You're in academic life; you're supposed to publish it. And that's a one-year delay from when you submit it to when it's published--about a year to get it out in academic life, during which time it ceases to exist. So that did not seem to be the right thing to do.

So we did two things. I took the data to Conant's foundation [Kaposi's Sarcoma Research and Education Foundation]. Conant had grabbed the lead in the public policy universe at that point and he had this foundation. So I presented the data to their board, which was composed of lots of politically active people. I asked Marcus, "What should we do with it?" The board said, "Get it out." Marcus basically said, "Give it to me."

I felt an enormous amount of competing, conflicting pressures about what to do with this data, whether to put it through a publication process and disappear it for a year, whether to present it publicly, whether to leak it to the media--I didn't know how to do this at that time. I had no experience with how the media works in relationship with science. The central fact of our lives was the relationship between the scientists and the press. I didn't know how to do it. We all learned that the hard way.

Leaking the Data

Moss: Anyway, what I decided to do was leak it. First we submitted it to *Lancet*, and we leaked it at the same time. We made nine copies of it, and we stamped "Confidential" on them, and we gave them to nine influential people, including Bill Kraus, Dana Van Gorder (Harry Britt's legislative assistant), Selma, and various other people. Michael Gorman will remember more of them; I don't remember who they all were. I knew Selma would leak it.

I was sort of saying, "Okay, I'm going to try and publish the study, but I will let go of it at the same time. I'm trying to do both things at once." So out it went. Randy did get it, and he used it to sell his book [*And the Band Played On*] to St. Martin's Press. I know that because I talked to his editor at St. Martin's Press.

Hughes: How did he use it?

Moss: He probably said, "Look what strange stuff is going on in San Francisco. They're covering it up." Something like that. For a while, he tried to entrepreneur a cover-up of the AIDS story, and then he sort of dropped it. It appears in *California* magazine the next year, but then he kind of dropped that.[1]

Anyway, I gave the data to Conant to present at this meeting in New York, and I rubbed my hands of it and I went to England.

Hughes: You went to England to get away from the problem?

Moss: Well, I just didn't want to deal with it. I did not know how to deal with the press. It was a crazy period, and this was the craziest part of it for me. I just said, "I'm getting out of here." I let go of it and left.

The *Lancet* Paper

Moss: *The Lancet* didn't publish the study. They said, "We're not going to publish it as an article, but if you submit it as a letter, we'll publish the letter." Which meant writing it off for publication credit. That's what we did; we said, "Okay, publish it as a letter."

Hughes: Why didn't *The Lancet* want to publish it as an article?

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[1] Nora Gallagher. Fear in San Francisco. *California Magazine*, March 1986, pp. 93-129.

Moss: Who knows? That was the old *Lancet* under the old editor, Ian Monroe; he made all the decisions himself. You had no idea what was going on there.

But the study was out, and when *The Lancet* came out, it was out legitimately, and it got picked up by various people. It became part of the media, this rolling wave, this rolling thunder phenomenon.

Hughes: How did the gay community react?

Moss: Well, my memory is that things were like crescendoing at this time. The epidemic was getting more important very fast. Silverman figured it out; everybody figured it out. In 1983, suddenly people got the idea that something bad was happening on a broad scale. And that realization had to be a media phenomenon. Randy would say that he did it, that he triggered the cascade that told everybody that this awful thing was happening to gay men in San Francisco and elsewhere.

Hughes: Do you buy that?

Moss: Do I? I don't know--I'm not sure what the timing was. Lots of things were happening. New York would probably say that they did it. Things were also happening in New York about AIDS. The CDC was running around with data beginning around then. In December of 1982 they started talking about their case-control study. A lot was in fact happening; this was just our little bit of it. You have to ask whoever made the decisions for CBS News. When did they decide that they would cover an AIDS story?

We were very stretched. Remember, spring of 1983, there was no research money. See, we were all doing this on nothing, and we had committed our careers to it. At this point, we were all in it. And there was no money, and there was also a very ambivalent response. There was this federal foot-dragging going on. Everybody had the sense that the powers that be didn't quite like this. The university didn't like it. They had made the decision to put [AIDS activities] over here at SF General. You couldn't get federal attention. There was this polarization between, Oh, my God, the sky is falling, on one hand, and on the other hand, There's nobody up there that gets the message. That's what's going on in 1983.

So I was crazed. I'm sure everybody else was crazed. Then we got kicked out of our space. The guy that I was working for decided he didn't want us bringing AIDS patients into the offices, told us to leave, right around the spring of '83.

More on the Bathhouses

Hughes: In the previous interview you said that the bathhouses were not particularly pinpointed as the main source of infection.

Moss: Well, it's in our study, you see. Eventually, I knew that going to bathhouses was not a major risk factor for AIDS.

Hughes: Why?

Moss: Because we investigated it in our study. We asked people about their bathhouse use, and they didn't have much of a different risk for AIDS than anybody else.

Hughes: Is that so?

Moss: Yes, that is so. I could show you the data.

Hughes: Then why the emphasis on shutting down the bathhouses, which you too were behind?

Moss: I had a complicated rationale for myself about it. Even at the time I didn't think that shutting down the bathhouses was a central thing to do in terms of AIDS prevention. And neither did Silverman, and that's why he was trying hard not to. The whole bathhouse issue got fetishized by both sides, and that's what happens. People have fantasies.

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Moss: The people involved were not just having a lot of sex in bathhouses; they were having a lot of sex in all kinds of places--back rooms of club bars and sex clubs and their own homes, the street--wherever they felt like it. A lot of sex was being had, including in the bathhouses. And a lot of anonymous sex was being had, including in the bathhouses. Location just didn't turn out to make a big difference in the people we studied.

The San Francisco Men's Health Study, 1983

Hughes: Was there any competition between the gay men's studies, yours and Winkelstein's?

Moss: I gave it to him. The NIH realized they ought to do something serious in about 1984, and they set up this five-cohort collaborative study of gay men called the MACS [Multicenter AIDS Cohort Study] Study which runs to this very day.[1] I got their RFP and the message that maybe you guys of San Francisco should apply for this. Obviously, we would have gotten it if we had.

I got the RFP via Girish Vyas, who runs the blood bank at UCSF. He called me and said, "There's this RFP. Why don't we apply, and why don't you be the PI?" I said, "I have to talk to the research group." So I took it to the rest of the group, which was the NCI grant group at UC, and they didn't want to work with Vyas. That was okay with me; I was state-funded at this point, and I had my cohort study going already.

So I took it over to Berkeley, where I had gone to graduate school, to Bill Reeves[2], who was the infectious disease epidemiologist, and I said, "You guys ought to do this study." He gave it to Warren Winkelstein, and Warren did it. It did become a competing study. It was an altruistic gesture on my part, a rare altruistic gesture, which resulted in me getting stabbed and stabbed. They were competition, and Levy went with them.

Hughes: How specifically did you get stabbed?

Moss: Well, Warren is a very nice guy and we are now collaborators. I have a good relationship with him. But I engendered a parallel study in San Francisco. In fact, there were three; the CDC had an epidemiological study too. Everybody had a cohort of gay men in San Francisco. Mine was the only one without federal funding. I ended up with a little study, competing with the CDC and the huge nationwide NIH collaborative study.

We did very well. But we did very well because we were in place and we were ahead of them, and we were pretty good epidemiologists. We did very good studies.

But I did do things that Levy for example would never have allowed. Most people who play this game know that you take a scorched-earth policy around your stuff. You don't let anybody doing anything like it anywhere near you because they're competition in your field.

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[1] See the oral history in this series with Warren Winkelstein.

[2] See: *William C. Reeves: Arbovirologist and Professor, UC Berkeley School of Public Health*, Regional Oral History Office, University of California, Berkeley, 1993.

But it doesn't always work to your disadvantage. Warren knew that it was a good gesture, and he's always been a friend to me. I made a friend by doing it. Nobody is going to get the Nobel Prize for epidemiology anyway; it's not that kind of competition.

So as a result of all these debates and the wars over serology, which were part of the big virus wars, these three groups fighting each other, I ended up sending the serology from my gay men's study to Paris. I went there and I met with them and they were interested. [laughs] I told my colleague in London this and he said, "Chermann's a lulu." And that is true; these guys were all so totally out to lunch.

Hughes: In what sense?

Moss: A lot of these big deal laboratory scientists are like crazed people. They have funny takes on reality. Anyway, it was just very hard to work with them, and it's hard working with the French anyway. It was not a success. We wrote some papers, but it was not good for me. Not a helpful thing to do in the long run. And I made an enemy of Jay, who has not ever been on my side. [laughs] It was really awful. I was sort of in Siberia for a while. But I was down here at SF General; we were in Siberia anyway.

And Paul was doing the same thing. Everybody was making enemies. By 1984, everybody knew AIDS was a super-giant-big deal; it was the disease of the century. The only way you could hold on to your research was by making enemies. You couldn't stay in the business unless you did. So I fought everybody. I fought Paul. You had to fight people for your turf all the time.

Hughes: What was Dr. Volberding trying to do?

Moss: He just wanted to control what we did. He invited us into the clinic in '83 because he needed somebody to fill up the space. Eventually, he decided that I was part of his empire. My position was that I was not part of his empire; I was part of my own empire. So we got in a big war, and I had to go through all this maneuvering. I had to play Merle Sande off against him and make deals with Merle. You have to align yourself with various power barons, go through the struggle. Everybody did it. Paul did it at his level. I did it at my level. Levy did it at his level.

AIDS Science in the Bay Area

Moss: One of the things that didn't happen in our group in San Francisco is we didn't develop good internal science. There was never any really good lab science. Levy would only do what he wanted. He has no interest in what anybody else wants. He was not going to have a big lab generating stuff for other people's projects.

Hughes: Which other scientists at UCSF were involved?

Moss: Nobody.

Hughes: You've said molecular biologists didn't want to be involved.

Moss: They didn't seem to.

Hughes: Who were the scientists here who might have taken an interest in AIDS?

Moss: This area's full of big scientists. There are more big biologists in the Bay Area than the rest of the world. There are plenty of scientists around here; just nobody was particularly interested.

Hughes: Was that because they were doing their own research, or was that the AIDS stigma? You know, why get involved with this stigmatized disease?

Moss: Both, and also positioning. If you're a big deal, you don't need a new disease. The only people that need a new disease are people who don't have turf already.

Hughes: Don't scientists need a disease that's becoming important?

Moss: Oh, but they didn't figure that out. By 1983 and '84, it was not so easy. If you wanted to get into AIDS in 1983 and '84, you had to deal with Levy, who was already doing it. Or if you wanted to do clinical research, you had to deal with Volberding. See, it was too late to get in then.

The molecular biologists could have, but there was nobody interested at that point; I guess nowadays people are. I don't know how they make their decisions. They're swimming in money. Their universe is different from ours. Issues are not presented to them because they're public health issues. Somebody has to present it to them somehow. It has to come from some group of clinicians, I guess. Who knows?

And as for virologists, the other group--Warren [Winkelstein] worked with this group--is the state health lab, which maintained an interest in AIDS.

Hughes: The Viral and Rickettsial Disease Laboratory of the California Department of Health Services?

Moss: Yes, Chip [H. W.] Sheppard and Mike Ascher. Earlier, there was a guy at Mount Zion called Larry Drew who was a CMV [cytomegalovirus] virologist, but he never really got to be a mainstream AIDS researcher.

Impact of the Discovery of HIV

Hughes: The epidemiologist played a central role in the early years of the epidemic. When the virus was discovered, it gave bench scientists a more important role. They now had something concrete that they could work on.

Moss: Oh, yes.

Hughes: What happened?

Moss: Well, they got a lot of money, was what happened. People started playing with the virus in the lab.

Hughes: Was there then less interest in an epidemiological approach to AIDS?

Moss: I don't know. 1984 was when the big epidemiological studies started, the MACS studies and all that, the same year that the virus was discovered. You could do much better epidemiology when you had the lab HIV antibody test. You could do real epidemiology. The discovery of the virus gave a big impetus to epidemiology, too.

Hughes: Explain how.

Moss: Well, you knew who was infected, so you could study infection. You didn't have to work from cases and controls that you didn't know whether they were infected or not. You had got the entity itself, as it were, from an epidemiological point of view.

Hughes: Were you surprised at the numbers that were infected?

Moss: No, because Gallo in his 1984 *Science* paper,[1] and the early French stuff, had quite high numbers of HIV-positive gay men. In fact, the first numbers published were too high. Fewer gay men were infected than you would have thought from the early studies, because the early studies were clinic studies, and they were done with clinical populations, like the STD clinics. You had very high estimates. In fact, the early estimates were too high in San Francisco.

Hughes: Because you were seeing a skewed sample?

Moss: Yes. But it did turn out eventually that 50 percent of the people in the gay community were infected.

What we were getting at this time was some sense of the relationship between infection and disease, and how long the incubation was going to be. It slowly became clear that that was going to be a very long period. And we were also getting a sense of what the prognosis was for infected people. All these things slowly became clear, and we did all that work. That's epidemiology.

We did all that research with the HIV test; you just do a different, much better kind of epidemiology. You do epidemiology with real tools instead of with just questionnaires. So the discovery of the virus was fine for us, and we had a pretty good few years in there.

Increased Funds for AIDS Research

Hughes: How was the money?

Moss: There was loads of money. Beginning in 1985 until last year, there was more money than people could rationally spend, much of it wasted. I think the crank-up began in 1983, but by 1985 the money was becoming available through the NIAID. And there were huge amounts of money. The budget for AIDS went from zero to the same size as that of the National Cancer Institute in about three, four, or five years. The fastest crank-up ever. Huge, huge

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[1] R. C. Gallo, S. Salahuddin, et al. Frequent detection and isolation of cytopathic retrovirus (HTLV-III) from patients with AIDS and at risk for AIDS. *Science* 1984, 224:500-503.

allocation of resources, far more than could be spent well. A very high proportion was spent on junk, which always happens.

It happened in the war on cancer in the 1970s. The federal funding agencies respond to the media. It goes media-politicians-funding agencies. They're told, "Crank it up. Don't tell me you don't know what to spend the money on. Spend the money!" So they start hurling out million-dollar chunks of it, just literally hurling it out, and all you have to do is catch it. So now Don Ganem says, "An anencephalic dwarf could get funded to work in AIDS." [laughter] As he starts to work in AIDS. So that's what happened. We knew it would happen eventually, and eventually it did happen.

It's terrible for the pioneers when this happens, because you're suddenly surrounded by people who know nothing about the disease; they're not competent, but have $5 million to spend. That's what happened. You're in their way. People who want to be real players then have to play in the million- and ten-million- and hundred-million-dollar universe.

So that's what happened with Volberding. You start off as a good-looking assistant professor of oncology, and suddenly you realize that if you want to go on doing what you're doing, you're in the hundred-million-dollar league, and you'd better develop big teeth and fangs very fast, and that's what he did. He went around the clinic saying, "We're playing hardball now." That became his mantra. He'd go around; he'd look at you and say, "It's hardball now," and stare through you. This meant, "I am going to have to override you, because my power struggles are more important than you." And they were.

Hughes: I took the comment about playing hardball to mean that he was rallying the ranks.

Moss: No. He was not interested in the ranks. He was interested in his own universe and power, and he succeeded. You might argue that he had to do what he did to become the leading AIDS clinician. He hung onto it, although many people were trying to knock him off. He fought a power struggle within NIAID and all that, and came out on top. It was not easy for somebody who's not a great scientist. He had to compete with people like [Thomas C.] Merigan of Stanford, or the clinical people at Harvard--[Martin] Hirsch, head of ID [infectious disease] at Harvard. Anyway, he had to compete with people who were very good at clinical research, very smart, and big-deal scientists. So he did. That's what happened. And he paid the price for it. <u>We</u> paid the price for it, in constant power struggles. And Levy did too, although Levy's a lab scientist and different. It's a whole different universe.

Clinical, Basic Science, and Epidemiological Approaches

Moss: Clinical science and lab science are different. They have different sets of people and different rules and different funding universes, and different personality characteristics.

Hughes: Well, say something about that.

Moss: Well, the lab people are easier to deal with usually. The M.D.'s are worse.

Hughes: Why?

Moss: It's just part of the whole M.D. business. Levy's not an easy person to deal with, and never has been. But that's the way it is.

A lot of the lab people are much easier to deal with, Paul Luciw and so forth. I've enjoyed dealing with the laboratory scientists. I rarely have enjoyed dealing with the clinicians. There are only a couple of clinicians I have enjoyed dealing with.

Hughes: And yet, if I understand what you did, you oriented yourself more towards the clinical side than the basic science.

Moss: Well, there wasn't any lab research at the beginning of the epidemic. It was the clinicians who had control. I don't know why I did that, but it was the right decision. It was just a feeling that that's where we would fit in better, and we did.

Hughes: It wasn't because of any particular philosophical inclination that you had?

Moss: Well, I think that we epidemiologists are willing to deal with patients. The lab people don't want to deal with patients. If they're M.D.'s, one of the reasons they're in the lab is they don't want to deal with patients. If you do epidemiology, you do have to deal with patients, and we were willing to do that.

The Epidemiology Component of the AIDS Clinic

Moss: It wasn't true for our studies; I very carefully made sure it was not true--but often, the clinicians' patients are the basis of epidemiologists' studies. And I was smart enough to know that that was a mistake. If I had let Volberding be a bottleneck over my studies, it would have not been a good idea. So we case-found from other sources, and we found our own AIDS cases. We brought people into the clinic rather than using his people.

But I used his clinic. I had to fight with Volberding because we used his clinic. We were competing with the clinical studies for resources.

Hughes: Did he object to you bringing patients into the clinic?

Moss: No, he liked that, because it was all stuff he could use to justify his operations: "This is what's going on in my clinic, and one of the things going on is all these epidemiological studies." We brought in loads of epidemiological studies, and that was good. But they became part of his mega-empire in a way. He claimed credit for them; everybody always claims credit for everything.

Also, the clinic got very full. We would compete for space and time there, and we would be marginal low status. We'd get forced out by the clinical studies, which were the bread-and-butter of the clinic. At various times, that got quite acute.

It was a difficult relationship, I have to say. Volberding finally threw us out. [laughs] Not out of the clinic, but he threw us out of the administrative space where we had our offices.

Hughes: When did that occur, and what was the reason?

Moss: Oh, '85, '86, something like that.

Hughes: Why did you move out?

Moss: Because Volberding wanted the space for his own operations. "It's my space; I need it." And it was; it was his space. We lasted a long time over there. It's pretty amazing.

It's very difficult for an epidemiologist to maintain space close to the clinical front end, because that's the valuable space. Everybody wants to be close to the patients. So you have to struggle for spaces. You're always getting pushed further away from the space that's near the ward or on the campus. It was very useful for us to be there. Volberding did me a big favor, and he knows it. He knows that it was very, very useful for me to be there all those years, and to do all these studies, have access to the clinic to do them all. So I guess he was pissed off that he didn't get more back for it or something; I don't know.

Hughes: Yet in a sense, he needed you in those early days.

Moss: Yes, he did, in the early days.

Hughes: More than just to fill up the space?

Moss: Well, legitimization, company, studies that were going on. It was useful for him to be at the head of an empire that was more than just clinical, that included an epidemiology component, when he started trying to write grants for program projects and cancer centers and all that stuff. At various times, we were the epidemiology component.

Hughes: How independent of him were you on a day-to-day basis?

Moss: Totally. I refused to accept dependency. Basically, our position was, "You can throw me out, but you'll have to go that far, and you won't look good if you do." [laughs] And I made deals with Merle. Volberding was involved in turf wars with Merle all the time. I positioned myself between them, and Merle protected me. We got the space from him because of Merle. Eventually, when we got pushed out of there, we moved in here [Ward 95, San Francisco General Hospital].

The Mayor's Advisory Committee on AIDS

Hughes: Do you want to say something about being a member [1983-1989] of the Mayor's Advisory Committee on AIDS?

Moss: Well, Merle suddenly appeared on the scene as a big player in AIDS, having at some point decided to buy in.[1] At some point, Merle decided that he was going to put a lot of chips on AIDS, which was the right decision for SF General, because it was the biggest thing to ever hit this hospital. Scientifically, it put this hospital on the map.

Hughes: Was this before other people here had gotten on the AIDS bandwagon?

Moss: I don't know when he did. This mostly had to do with the inpatient service [Ward 5B], which we didn't deal with all that much. I didn't really know what was going on over there in '83.

Hughes: Ward 5B.

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[1] See the oral history in this series with Merle A. Sande.

Moss: 5B, and the Department of Medicine. See, I was not in the department of medicine, so I wasn't in the loop.

But eventually, Merle invited me to be on this committee that was advising the mayor. Merle had staked that committee, I had a good relationship with the mayor, and he would convene it. It included Paul and the other UCSF AIDS clinicians, and the people from the health department--David Werdegar, who followed Silverman as health director.

Hughes: Selma Dritz had retired by then?

Moss: Yes. When did she retire?

Hughes: In '84.

Moss: She wasn't very visible during the bathhouse stuff. She wasn't on Silverman's bathhouse committee, which was mostly in '84. Merle was. I guess that was the progenitor of the mayor's AIDS committee meetings.

Hughes: Were there any members from the gay community, or nonmedical people?

Moss: No, it was a scientific advisory group.[1] It was not a community group.

Hughes: Was there anybody from UCSF?

Moss: Yes, we were all from UCSF.[2]

Hughes: I mean from Parnassus [Avenue, the location of the main UCSF campus].

Moss: I guess Levy came sometimes. Who was on the committee was who Merle invited at specific times.

Hughes: Oh, so it wasn't a committee with a fixed membership?

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[1] In September 1986, the Mayor's AIDS Task Force (one of several names for this committee) consisted of: "Dr. Werdegar and other senior staff of DPH [Department of Public Health], UCSF's AIDS specialists at SFGH, Commissioners Lee and Foster, and others." (Jeff Amory to Y. Clement Shek, September 17, 1986. AIDS Activity Office documents, SFDPH.)

[2] San Francisco General Hospital is jointly administered by the City of San Francisco and UCSF.

Moss: It was intangible. Same with Silverman's committees. You're on the committee as long as you're on the committee. [laughs] Jay may have come a couple of times, but usually, nobody from UC other than him.

Hughes: Except Conant, if you call Conant UC.

Moss: Yes, but Conant didn't come to these meetings.

Hughes: Why was that?

Moss: Well, I think that he had his own relationship with the mayor. It was a leadership struggle, for the prize of the mayor's ear. And Merle was asserting turf. Conant was not going to sign up as one of Merle's troops.

There were also internal dynamics at UC. Merle got himself into position as the head of the UC Task Force on AIDS.

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Moss: If you remember, Conant had been accused of end-running the university hierarchy. So they compromised and set up a universitywide committee, the University of California Systemwide Task Force on AIDS, that was going to spend the money which the state of California had allotted for AIDS research. Merle got himself appointed to be the chair of the committee [1983-1988].

Merle was a wonderful operator and manipulator and perverter of resources, and he just took this stream of funds and poured it into San Francisco General. I got funded out of that. My first big chunk of funds was Willie Brown money. Sande came by the next day and said, "How did you like all the money I got for you?" [laughs] Just letting me know; just a favor bank of some sort. "Pay me back."

Why did he get me all that money? Because Merle is an ID [infectious disease] person. He's much more attuned to epidemiology than Paul. Paul's not attuned to epidemiology at all; it's not something he even thinks about. Well, all infectious disease people do; oncologists don't. So Merle was interested in epidemiology, and he knew that you could get big bucks for epidemiology, and he did. He got all this state money, for me and eventually for Julie [Gerberding] and Connie [Wofsy]. We got millions of bucks of state task force money poured into this hospital. This was all Merle.

So he became a power in the UC system vis-a-vis AIDS. I guess that really what he was doing was operating as the UC representative to the mayor. How he dealt with the deans and all that up on the main campus, I do not know. Merle is an interesting character in many ways. And here he is dealing with AIDS and homosexuals, and total liberals, and the mayor, and a faculty here that's very left-wing; they're totally left-wing at SFGH. I think he did a great job, I must say.

So anyway, Merle convened the committee. And the way it worked was, every so often, at unspecified intervals, Merle said, "We're having another meeting of the committee. Will you come? I want you to talk about thus," something that you were doing that he thought the mayor ought to hear. Sometimes the mayor had set the agenda, and sometimes Merle just thought of something Feinstein ought to hear.

The mayor made it clear to him that the committee was there for one reason: so that she didn't get blindsided. I guess she felt that she was blindsided by the bathhouse stuff. So she told him, "Okay, Merle, I want to know before it happens." So we were all there to say what was going on, what was happening, where the epidemic was going. That was what she wanted to know.

Hughes: This was post-bathhouse closure?

Moss: For me it was. I don't know when Feinstein first switched from meeting with Conant to meeting with this group.

Hughes: Please comment on the sorts of issues that you dealt with on the mayor's advisory committee.

Moss: Well, I'll tell you one thing that happened to me fairly late in the mayor's advisory committee. I went in there and I said, "Well, this epidemic is slowing down. It's going to peak; it's going to plateau; it's going to turn down pretty soon."

Hughes: You were speaking on the basis of your epidemiological data.

Moss: Actually, from the city data. The mayor got absolutely berserk and irate and screamed at me.

Hughes: Why?

Moss: She didn't want anybody to say that. That's the way Feinstein works. I'd already seen her do it to the health director, Dave Werdegar; she screamed at him. She just flails people. To make it clear to you what she wants, that you're doing the wrong thing, she just tongue-lashes you. And you have to take it. The situational ethics is you're not allowed to give it back, get up and say, "You crazed bitch, I'm out of here." Even though that was what you wanted to say. All my colleagues were sort of holding me down, saying, "Shut up, shut up, shut up!" [laughter] Which I did; I shut up. On the way out, they all said, "Very good, Andrew." [laughs] It was very unpleasant, but it's the way Feinstein works.

Hughes: Why didn't she want to hear that the epidemic was going to plateau?

Moss: She was right. Politically speaking, you don't want to say the epidemic is over. For one thing, the money stops coming. It's not a good thing to say until you really think it's true. And it wasn't over; it was just flattened out.

Hughes: On the other hand, did San Francisco want the image of the AIDS mecca of the universe?

Moss: You would have thought no. At this point, there were two images going. One was the AIDS mecca of the universe, and the other was the city that knows how to combat AIDS. There's this tremendous mythology about the San Francisco "model". We brought the epidemic under control, and gave it all this good propaganda. We all ended up feeling pretty good about San Francisco.

Hughes: Is that a myth?

Moss: Yes, it's all myths, basically.

Hughes: Why do you say that?

Moss: Well, it's not myths. They're exaggerations. In terms of gay men changing their behavior, the studies of young men are real clear that things are by no means under control. It's still a disaster out there. We didn't know that, but it is. In terms of the San Francisco model, San Francisco is doing all right. I don't know. It's more complicated than that, is all.

AIDS Clinical Research Center, UCSF

Moss: The state money, the funds obtained in 1983 through Willie Brown, is very interesting. The university chopped up the state money. Ziegler also rose to prominence on the state money, but Conant was the original principal investigator. The biggest chunk of state money came to UCSF for the AIDS Clinical Research Center. And Conant got it originally.

Hughes: The AIDS Clinical Research Center at UCSF was the successor of the KS Clinic?

Moss: Well, briefly it was. It was Conant's empire, but he didn't know what to do with it. And that's where Conant blew it. I have a memory of some weird thing with computers, where he had this totally inappropriate idea of buying computers and selling them to us and taking a cut on the difference or something, like using the money as capital. He did some bad things, and he really got people pissed off at him.

Hughes: What was the center supposed to do?

Moss: Who knows? It was just a chunk of money. I guess his idea was that he was going to use it to treat his KS patients. What happened eventually was that he got replaced by Ziegler, and that became Ziegler's power base, this control over a lot of the state funds for AIDS research. And in fact, Ziegler still has control over the ACRC, AIDS Clinical Research Center, which became a little bitty granting agency.[1] It gives out little mini-grants at UCSF, and Ziegler still controls it almost ten years later.

Ziegler negotiated with Paul. He and Paul have these huge power struggles over how to spend this money. How it ends up is they just chop it up. "You get some and I get some and he gets some," and it's all negotiated out. And that's what it's about: it's about negotiating out the money, and the power that goes with it. All power in the university is based on the flow of money that goes through your operation.

Hughes: And space.

Moss: Well, if you have money, the university will give you space. But you're right, there are big struggles about space, too.

Volberding had space; he did very well in space. He must have figured out that it was good to be down at SF General because of the space there. He would have <u>never</u> got that kind of space at Moffitt [Hospital]; it couldn't be done. But he eventually got two whole floors in this building [Building 80].

Hughes: Amazing.

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[1] Ziegler was director of the AIDS Clinical Research Center from 1985 to 1992, when John S. Greenspan succeeded him.

Moss: It is amazing. But he's a good operator, Paul. He's definitely an excellent operator. All these guys are good operators. You'd better be, or you're not going to survive.

Assessing San Francisco's Response to the Epidemic

Hughes: Is it true that San Francisco responded better to the epidemic than other cities in this country?

Moss: The only city to compare it with is New York, and New York is a disaster. Everything's a disaster in New York. So yes, we did much better than they did. On the other hand, San Francisco's a smaller, more manageable place.

I think Feinstein was good about AIDS--much better than [Mayor Art] Agnos. Agnos dissolved the advisory committee and replaced it with a community advisory committee, i.e., an ethnic, share out the resources committee. He didn't care what was happening. He just wanted good political control of the spending.

Hughes: One part of the myth is that there was more cooperation in San Francisco than elsewhere. Yet the picture that you paint is of tremendous competition, turf battles, and back-stabbing.

Moss: Well, both things are true. The reason that it's better here is there's only one medical school, so you don't have to fight--inter-medical school fights are vicious. There's no quarter. And the relationship between the medical school [UCSF] and the city is good. Why? Feinstein is a UC sympathizer. Her father and her husband were UC faculty, so UCSF has a very good relationship with the city. Also everybody in the health department has a UC appointment.

Also, San Francisco is geographically small. From UCSF to City Hall is two, three miles. The Castro is right in the middle. From here [SFGH] to UCSF or City Hall is a mile and a half or less. You get everybody in one room. It's a mini-city, San Francisco. New Yorkers don't know that. They think San Francisco's a metropolis. They don't realize that it's 700,000 people. It's like a medium-sized town. The real truth is the gay community. The political organization of the gay community in San Francisco is very good, which really made a difference.

I would say that we, the outsiders, and low status academics at UCSF did a good job. We were on the ball. Volberding did a good job. For whatever I may say about him, I can't deny that he built a tremendous AIDS Clinic.

And Levy did a good job. Whatever I say about him, he was number three on the discovery of the virus.[1] That's not bad. So a lot of people did a pretty good job. And the people who were in the research groups at UCSF were able to deal with the community and deal with the city. Those of us who worked on AIDS were able to work with the other arms of the triad, and vice versa. The gay people in the city were able to deal with UC, and the mayor.

So all three arms were functional and were able to work with each other, and I think that really lubricated things. Even if UCSF as an institution couldn't. UC as an institution couldn't deal with the city and gay community, but the individuals who were working on AIDS could deal with it. And it's a loosely connected institution.

UCSF's Reaction to the Epidemic

Hughes: Was it a deliberate strategy of the UCSF administration to turn its back, hoping that individuals at the university would deal with the epidemic?

Moss: Well, who are the people? The people are the oncology people.

Hughes: The Cancer Research Institute [at UCSF]?

Moss: Yes. Brian Lewis, Paul's boss, didn't want to do it. I think Paul would say that Brian didn't want to deal with gay patients. Brian didn't want to have a clinic that dealt with them. I never knew any ID people [at UCSF] who got interested in AIDS. They just don't seem to care about it. They're bench people. They have their own interests, their own lab stuff. It's not a clinical ID group up there [UCSF]. So they just didn't get involved. The immunologists did; Dan Stites did. That was about it.

I don't know what happened at the high levels of UCSF. You definitely got the impression that there was a sentiment, "We don't want that [AIDS activities] here." And you definitely got the impression that there were two things involved: homosexuality

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[1] Dr. Levy currently considers his group to be the second to isolate the AIDS virus. (See the oral history in this series with Dr. Levy.)

and contagiousness. We don't want a ward full of faggots, and we don't want people catching this disease.

I suspect the latter. I think that experienced doctors know that you'd better watch out for new infectious diseases. Everybody may drop dead all of a sudden. So let them go over to San Francisco General, and see if they drop dead. And if they drop dead, it doesn't matter because they're only assistant professors anyway. There's plenty more where they came from. I think that was probably what happened; that's my guess.

And I think that's what my department chairman thought. Then when I would make noises, he would whine at me about how breast cancer is more important, which is his disease.

Hughes: Well, in fairness, breast cancer was and is important.

Moss: Yes, but what we're really talking about here is that people had forgotten how to deal with infectious diseases. If you stood back and looked at this epidemic, what you said was, "This is going to be a big deal." That's what we all went around saying. I would literally say that. I would tug people's coats, and say, "This is going to be important." And they'd look at me like, "What do you mean? Breast cancer is what's important."

But if you looked at [the epidemic], if you put the time into it, you could see that it was going to be important. It's being reported all over the world; it's [incidence is] going up incredibly rapidly; it kills everybody. It's clearly going to be a big deal.

Hughes: Why was your message about the significance of the epidemic so difficult to get across?

Moss: It's always difficult to get across. Social reality is an equilibrium-maintaining system. It's like the Russian dolls: if you try to change them, they will resist you. They have inertia and momentum. Society doesn't want to admit a new idea, especially a threatening new idea.

And also, it's bureaucracy, I think. All these things are bureaucracy. UC is a giant bureaucracy. You're really trying to get bureaucracies to do things; it's not easy. That was where the gay community was important in the city: they were able to move the bureaucracy. The same thing's happening now with this MDR TB [multi-drug-resistant tuberculosis]. You'll see: nobody will have learned any lessons from AIDS. I am doing this right now: I go around and say to people, "This [MDR TB] is going to be really important." And they look at me and they say, "Breast cancer is what's important."

Hughes: In the case of drug-resistant TB, you don't have a vocal, politically astute group that's affected.

Moss: Or as well-connected to the media. You don't have a well-organized, well-connected bourgeois constituency. That is the case.

Hughes: So what's going to happen?

Moss: Well, you don't have a Rock Hudson either. I don't know. Who knows? I guess it depends on how many deaths you are prepared to tolerate before you do something. The real difference here is the doctors will get it [tuberculosis]. That tends to move things around, I think.

AIDS as a Disease of Marginal Groups

Hughes: According to the recent NRC [National Research Council] report[1], AIDS will remain limited to marginal groups.

Moss: That's always been true. It's always been a poor people's disease.

Hughes: I don't think it's been perceived that way.

Moss: It hasn't been framed that way. This is a framing issue. A lot of people, including me, have been saying this for a decade.

Hughes: Saying what?

Moss: Any disease that's a drug user's disease and is infectious is going to be a poor people's disease. AIDS is a poor people's disease.

Hughes: But it's also a blood-transmitted disease, a sexually-transmitted disease.

Moss: Well, sexually-transmitted diseases are also poor people's diseases. It's been that way for decades. It's always been true that the poorest parts of New York have the highest AIDS rates;

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[1] *Wall Street Journal*, March 17, 1993, A14.

everybody knows that. Now, suddenly it's being reframed that way. Why are people now choosing to frame it that way and see it that way?

Hughes: Why?

Moss: I don't know. The *New York Times* is doing it.

Hughes: Well, the *New York Times* doesn't operate in a vacuum.

Moss: No, it doesn't. There are editors making these decisions. People decide they want to present AIDS this way. I don't know why, but they've made that decision.

Hughes: Could it simply be that time has gone by and AIDS hasn't spread into the heterosexual community to any great extent?

Moss: Maybe. You mean that's why they're framing it this way?

Hughes: I mean, they're looking at reality, and reality is that AIDS is a disease of marginal groups.

Moss: That's been true from day one.

Hughes: I know, but there was always the idea, it's sexually transmitted, it's transmitted by blood, why couldn't it move out into the heterosexual community?

Moss: Well, syphilis is totally a poor people's disease. Syphilis is gay men, junkies, and the poor, just like AIDS.

Hughes: You could be a cynic and argue that there had to be the potential of heterosexual infection in order to galvanize resources.

Moss: Well, all those things are true. Lots of people are playing it that way, and lots of people are playing it other ways. I think some knowingly and some unknowingly distorted the amount of heterosexual transmission. Many people distort everything about AIDS; it's political. Forty percent or 60 percent or whatever it is of AIDS funding has to go to women and children, regardless of the numbers of women and children with AIDS. That's the way the disease is handled.

Playing Politics

Hughes: How did you feel about becoming a political actor in the epidemic?

Moss: I liked doing it in San Francisco, partly because as a straight man among gay men, you get a lot of flattering attention, and partly because we all became media stars. It's great to become a media star. Nobody will complain about that.

But I don't like the institutional politics at the federal level, budget politics. I don't want to do it; I'm not good at it. Also, as an epidemiologist, I don't like working in a cloud of half-truths and simplifications. I'm not going to say that women and children are what is important about AIDS. I don't believe it.

So I've had it with AIDS. I don't want to do any more AIDS work. I am happy to be moving into something else. Simplifications are what work over time from the prevention point of view, but as an epidemiologist, I'm not going to have my priorities set by that huge political circus. I don't mind it when I can manipulate it, but when it's manipulating me, I'm not going to do it. But I've done enough AIDS anyway. I don't have to do any more AIDS. You probably need to do something different after twelve years of working on AIDS.

AIDS, a Worldwide Disaster

Hughes: How does the AIDS epidemic affect the American health care system?

Moss: It's affecting the entire world. It's just exactly what we said: it's a gigantic, world-class disaster. It's a new, lethal disease with no treatment, no vaccine, and not very good behavioral control that has spread all over the entire world. I think the reframing of AIDS after a decade is yes, it really is an awful disaster. It's a new scourge on the face of the earth that we do not have any control over at all. We're not affecting it. It's just gone it's merry way.

When you see what happens when AIDS and TB meet, it's just a hideous disaster. It's the worst medical disaster of the century. And nobody knows what to do about it. We're stuck with it. Our children are stuck with it. Our children are stuck with AIDS. It's going to change everything.

Hughes: Thank you, Dr. Moss.

Transcribed and Final Typed by Shannon Page

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APPENDICES--The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984, Volume II

APPENDIX I: AIDS CHRONOLOGY[1]--by Sally Smith Hughes

1968-1970	David Baltimore and Howard Temin independently discover reverse transcriptase, a marker for retroviruses.
1974	Charles Garfield founds Shanti Project to provide free volunteer counseling to people with life-threatening illnesses.
1976	Robert Gallo isolates T-cell growth factor (interleukin-2), allowing T-cells to be cultured in vitro.
1978	San Francisco Mayor George Moscone assassinated; Dianne Feinstein becomes mayor.
1980	Gallo demonstrates that retroviruses (HTLV-I and HTLV-II) can infect humans.
1981:	
February	Michael Gottlieb, UCLA, diagnoses *Pneumocystis carinii* pneumonia [PCP] in two homosexuals.
March	Gottlieb diagnoses another case of PCP in a homosexual.
	Sandra Ford, drug technician for Centers for Disease Control [CDC], officially notes increase in requests for pentamidine, for treatment of PCP.
	Constance Wofsy diagnoses CNS toxoplasmosis in gay patient at San Francisco General Hospital [SFGH].
April	Gottlieb diagnoses two more cases of PCP in homosexuals.
	Two Kaposi's sarcoma [KS] cases in San Francisco and Stanford announced at UCSF dermatology grand rounds.
May/June	Donald Abrams and others see cases of PCP in gay men at SFGH.
June 6 -	CDC's *Morbidity and Mortality Weekly Report* [*MMWR*] publishes Gottlieb and Wayne Sandera's report on PCP in 5 gay men.
June 8 -	First meeting of CDC Kaposi's Sarcoma/Opportunistic Infection [KSOI] Task Force, headed by James Curran. Purpose to characterize syndrome and determine frequency, risk, and etiology. Surveillance and case file for KS and PCP initiated.

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[1] This chronology is an ongoing working draft created to assist the oral history project; its focus is San Francisco and its accuracy contingent upon the many sources from which it was derived.

June (late)	First case of KS diagnosed in gay man at SFGH.
July	City of San Francisco establishes reporting and case registry system for KSOI.
July 3 -	First press report of syndrome appears in *New York Times*.
	MMWR reports Kaposi's sarcoma in 26 gay men.
July 13 -	First article on KS in *New York Native*.
August	CDC requires health departments to notify CDC of all KSOI cases.
Aug. 28 -	*MMWR* reports first heterosexuals, including first female, with KSOI.
September	CDC begins case-control study with 50 gay KSOI patients and 120 "healthy" gay ccontrols to determine factors in homosexual environment possibly causing KSOI.
Sept. 15 -	CDC and National Cancer Institute sponsor workshop on KS and opportunistic infections. CMV leading candidate for cause.
Sept. 21 -	First KS Clinic and Study Group held at UCSF.
October	Friedman-Kien et al. begin study of clinical course of KS in gay men.
November	Shanti begins to focus on psychosocial problems of people with KSOI.
December	First clinical descriptions of immunosuppression in IV drug users.
	John Ziegler, Conant and Paul Volberding receive $50,000 from American Cancer Society to support KS Clinic at UCSF; first grant awarded for AIDS.
	CDC investigators suspect that causal agent of AIDS is infectious but cannot provide irrefutable evidence. Others support "lifestyle" hypothesis.
	Reagan proposes massive cuts in CDC budget.
Dec. 9 -	Marcus Conant passes out flyers on KS at American Academy of Dermatology meeting in San Francisco.
Dec. 10 -	Durack at Duke suggests amyl nitrites ("poppers") might cause immune dysfunction.
	New England Journal of Medicine article links immune deficiency to T4 helper cell/T8 suppressor cell ratio.

1982:

Early 1982	Syndrome is named gay-related immunodeficiency disease--GRID.
January	First case of immune deficiency linked to blood products is reported in a hemophiliac. Helen Schietinger becomes nurse-coordinator of KS Clinic at UCSF. San Francisco health department makes first request for tax funds to support AIDS prevention and community services; Board of Supervisors appropriates $180,000 for AIDS programs.
March 4 -	*MMWR* lists four risk groups for AIDS--homosexuals, hemophiliacs, Haitians, and IV drug users [IVDUs].
April	Congressional subcommittee hearing in Los Angeles on AIDS, Henry Waxman (D-CA), chairman.
May	(Mother's Day) Conant, Frank Jacobson, and Richard Keller write articles of incorporation for Kaposi's Sarcoma Research and Education Foundation, predecessor of San Francisco AIDS Foundation.
May 15 -	Friedman-Kien et al. publish study showing promiscuity greatest risk factor for KS. Authors support immune overload theory of AIDS causation.
June 18 -	CDC reports cluster of PCP and KS cases in LA and Orange County, suggesting infectious agent is cause of AIDS.
June 26 -	UCSF Nursing Services sponsors conference, Kaposi's Sarcoma and *Pneumocystis* Pneumonia: New Phenomena among Gay Men.
July	CDC, FDA, and National Hemophilia Foundation representatives meet to plan risk evaluation of blood products for hemophiliacs.
July 9 -	CDC publishes first report of 31 cases of opportunisitic infections in Haitians.
July 13 -	First international symposium on AIDS, at Mt. Sinai Medical Center, New York, sponsored by Mt. Sinai and New York University schools of medicine.
July 16 -	*MMWR* reports first three cases of PCP in hemophiliacs, representing first cases of KSOI caused by blood or blood products.
<July 21 -	KS Foundation operates hotline for advice and referrals regarding AIDS, KS, and opportunistic infections [OIs].
July 27 -	CDC adopts "acquired immune deficiency syndrome--AIDS" as the official name of the new disease.

August	CDC asks blood banks not to accept high-risk donors; CDC recommends hepatitis B core antigen testing.
Aug. 13 -	National Cancer Institute [NCI] issues RFA for research on AIDS.
Sept. 24 -	CDC publishes first official definition of AIDS: a disease due to defect in cell-mediated immunity occurring in people with no known cause for immune deficiency.
	First? published use of term "AIDS", in *MMWR*. Rapid adoption of term thereafter.
October	KS Research and Education Foundation contracts with San Francisco Department of Public Health [SFDPH] to provide AIDS education services in San Francisco.
Oct. 29 -	UCSF Departments of Medicine and Dermatology and Cancer Research Institute sponsor program in medical education, Acquired Immunodeficiency Syndrome and Kaposi's Sarcoma. Almost 200 physicians and scientists attend.
November	*MMWR* suggests that hospital staffs caring for AIDS patients use hepatitis B precautionary measures.
December	Shanti makes first in series of contracts with SFDPH to provide counseling services and a housing program for people with AIDS [PWAs].
Dec. 1 -	House of Representatives votes $2.6 million to CDC for AIDS research.
Dec. 4 -	CDC presents Blood Products Advisory Committee with evidence of AIDS transmission through blood supply; no official action taken.
Dec. 10 -	Ammann, Cowan, Wara et al. report first case of possible transfusion AIDS, in *MMWR*.
Dec. 17 -	*MMWR* reports four cases of unexplained immune deficiency in infants.
Late 1982	Most investigators convinced that AIDS is caused by an infectious agent.
	Nation's first AIDS specimen bank established in UCSF School of Dentistry, coordinated by KS Clinic.
1983:	
Early	New York City health department establishes formal AIDS surveillance program.
	Beginning of bathhouse crisis. Formal AIDS infection control guidelines instituted at San Francisco General Hospital.

January Montagnier, Barre-Sinoussi, and Chermann at Pasteur Institute, seeking to isolate an AIDS virus, begin to grow cells from lymphadenopathy patient.

President of New York Blood Center denies evidence of transfusion AIDS.

Orphan Drug Act becomes law, giving exclusive marketing rights, tax breaks, and other incentives to companies developing drugs for rare diseases.

Jan. 1 - First outpatient clinic dedicated to AIDS (Ward 86) opens, at San Francisco General Hospital.

Jan. 4 - CDC national conference to determine blood bank policy re blood screening for AIDS; no consensus.

Jan. 7 - CDC adds heterosexual partners of AIDS patients as fifth risk group for AIDS.

Montagnier et al. find traces of reverse transcriptase in lymphadenopathy cell cultures.

San Francisco's Irwin Memorial Blood Bank [IMBB] adds medical history questions designed to screen out donors from high-risk groups.

Jan. 14 - National Hemophilia Foundation asks blood and plasma collectors to screen out high-risk donors.

Jan. 19 - Irwin Memorial Blood Bank adds more questions about medical history of potential donors.

February At Cold Spring Harbor Workshop on AIDS, Robert Gallo suggests that a retrovirus probably causes AIDS and presumes a variant of HTLV-I or HTLV-II.

Feb. 3 - Physicians from UCSF KS Study Group urge IMBB to use hepatitis B core antibody test to screen out blood donors with AIDS.

Feb. 7 - IMBB launches confidential questionnaire designed to detect potential blood donors with AIDS. Bay Area Physicians for Human Rights urges potential donors to refrain from donating if they have AIDS symptoms.

March CDC establishes clinical definition of AIDS in attempt to standardize epidemiological surveillance.

UCSF Task Force on AIDS created, mainly to establish infection control policy.

California requires reporting of AIDS cases, but not AIDS -Related Complex [ARC].

Public Health Service [PHS] recommends members of high risk groups reduce number of sex partners.

Mervyn Silverman, SFDH director, forms Medical Advisory Committee on AIDS.

Mar. 4 - *MMWR* first refers to "high risk" groups: gays with multiple sex partners, IVDUs, Haitians, and hemophiliacs.

CDC states that "available data suggests that AIDS is caused by a transmissible agent."

Mar. 17-19 New York University sponsors AIDS symposium.

Mar. 24 - FDA issues blood donor screening guidelines.

April Congressman Phillip Burton dies; Sala Burton eventually elected to his seat.

City of San Francisco and Shanti open hospice-type care center for neediest AIDS patients.

Conant, Volberding, John Greenspan, Frank Jacobson, and others persuade Willie Brown to ask for $2.9 million in state funding for AIDS research.

April 11 - Date NCI officials later cite as when NCI became committed to finding AIDS etiology.

April 14 - Irwin Memorial Blood Bank [IMBB] adds donor sheet designed to screen out donors at high risk for AIDS.

April 26 - Recall of San Francisco Mayor Feinstein, supported by White Panthers and some gay groups, fails.

May NIH announce $2.5 million for AIDS research. NCI and NIAID issue RFA [Request For Applications] for research on an infectious agent.

Heat treatment to reduce infectious agents in transfused blood approved by FDA.

San Francisco health department issues first brochure on AIDS.

Feinstein declares first week in May AIDS Awareness Week.

May 2 - "Fighting for our Lives" candlelight march in San Francisco to bring attention to AIDS; similar march in NYC.

May 6 -	*Journal of the American Medical Association* [*JAMA*] press release: "Evidence suggests household contact may transmit AIDS."
May 12 -	UCSF announces receipt of $1.2 million for AIDS research; Paul Volberding, principal investigator
May 20 -	Montagnier publishes discovery of "T-cell lymphotrophic retrovirus," later called lymphadenopathy-associated virus (LAV).
May 23 -	San Francisco Board of Supervisors votes $2.1 million for AIDS programs, $1 million of which is for out- and inpatient wards at SFGH.
May 24 -	Edward Brandt, Assistant Secretary of Health, declares AIDS research #1 priority.
May 31 -	Health department director Mervyn Silverman, backed by Feinstein and San Francisco Board of Supervisors, requires city bathhouses to post public health warnings about contracting AIDS.
June	UC issues guidelines to protect AIDS patients and health workers.
	San Francisco Men's Health Study begins to recruit participants.
	Feinstein chairs first U.S. Conference of Mayors Task Force on AIDS.
July	California legislature approves $2.9 million for AIDS research.
	Donald Abrams begins work at SFGH AIDS Clinic, bringing 200+ lymphadenopathy patients from UCSF.
July 26 -	12-bed inpatient Special Care Unit (Ward 5B) opens at SFGH--first dedicated AIDS hospital unit in U.S.
July 28 -	Universitywide Task Force on AIDS created to advise UC president on guidelines for and coordination of state-supported AIDS research at UC.
August	Willie Brown, Rudi Schmid, Conant and other AIDS researchers criticize UC for delays in releasing state funds for AIDS research.
September	At Cold Spring Harbor NCI meeting on human T-cell leukemia retroviruses, Montagnier et al. report LAV-like viruses in 5 lymphadenopathy patients and 3 AIDS patients, selective affinity of LAV for CD4 helper lymphocytes, and evidence of similarities between LAV and lentivirus causing equine infectious anemia. Gallo presents findings of HTLV-I in 10% of AIDS patients; doubts LAV is retrovirus.
	UC states that there is no scientific reason for healthy medical personnel to be excused from caring for AIDS patients.

Bureau of Infectious Disease Control, SFDPH, begins active surveillance of AIDS cases in San Francisco.

Sept. 13 - Montagnier sends Gallo sample of lymphadenopathy-associated virus [LAV].

Sept. 21 - UCSF Task Force on AIDS publishes infection control guidelines for health care workers caring for AIDS patients.

November - KS Research and Education Foundation contracts with State of California Department of Health Services to provide information and referral services on AIDS to other counties.

Mika Popovic in Gallo's lab discovers method for growing AIDS virus in T-cells.

San Francisco Department of Public Health asks for legal option to make baths off-limits to PWAs. Lawyers decide that medical uncertainties about AIDS prevent such action.

Jay Levy obtains six viral isolates from AIDS patients but decides not to publish until further proof.

December - Pasteur Institute applies for U.S. patent on diagnostic kit based on ELISA test for LAV antibodies.

Feinstein votes against live-in lover legislation, angering gay community.

AIDS Clinical Research Centers established with state funding at UCSF and UCLA to collect clinical and laboratory data.

National Association of People with AIDS formed.

Entry "AIDS" added to *Cumulated Index Medicus*.

Council of State and Territorial Epidemiologists passes resolution making AIDS a reportable condition.

Hospice of San Francisco contracts with SFDPH to include AIDS patients in its care of terminally ill.

1984:

January *Annals of Internal Medicine* reports case of heterosexual transmission of AIDS before overt manifestation of disease (hemophiliac to wife).

American Red Cross, American Association of Blood Banks, and Council of Community Blood Centers oppose proposal to screen out high-risk groups from blood donor pool.

Jan. 6 -	CDC updates its definition of AIDS.
Jan. 12 -	*NEJM* publishes CDC documentation of first 18 transfusion-associated AIDS cases.
February	Chermann in talks in U.S. states that French have discovered AIDS virus.
March	President of New York Blood Center continues to deny HIV transmission by blood.
	Larry Littlejohn, gay activist, sponsors San Francisco ballot initiative to close baths.
Mar. 2-4 -	19th Annual San Francisco Cancer Symposium, "Cancer and AIDS". Conant, Abrams, Wofsy, Ziegler, Volberding speak.
March 6 -	Blood industry task force meets on surrogate testing; blood bankers oppose it.
March 26 -	Government allots $1.1 million to develop AIDS antibody test to seven institutions, including Irwin Memorial and Stanford blood banks.
April	Feinstein issues first formal statement that Silverman should close baths. Silverman responds that he will formulate guidelines banning sex activity in baths that spreads AIDS.
	NIH applies for patents on Gallo's AIDS antibody test, a diagnostic kit based on Western blot technique.
April 9 -	Silverman and state and San Francisco health officials outlaw sex in bathhouses, rather than close them.
April 24 -	Margaret Heckler, Secretary of Health and Human Services, announces discovery by Gallo et al. of AIDS virus, that an AIDS test will be available soon, and that a vaccine will be available in 18-24 months. Gallo had not yet published his results.
May	Gallo publishes four reports and Montagnier one, in *Science*, linking AIDS with a new retrovirus which Gallo calls HTLV-III and Montagnier calls LAV.
	Board of Supervisor's president Wendy Nelder chides Silverstein for "shameful" delays in proposing sex guidelines for baths. Silverman replies that he is waiting for board to transfer authority to regulate baths from police to health department.
	Rock Hudson diagnosed with AIDS.
May 1 -	IMBB and other Bay Area blood banks begin testing blood for hepatitis B core antigen.

Summer	Silverman orders bathhouse surveillance for unsafe sex.
June	Board of Supervisors committee delays action on giving health department authority to regulate baths until after Democratic National Convention in San Francisco.
	IMBB adopts directed blood donation program.
July	Democratic National Convention in San Francisco.
August	After gay lobbying, Board of Supervisors tables move to give Silverman regulatory power over baths, killing his idea to promulgate sex guidelines for baths.
	Levy et al. isolate virus, ARV, which they claim to cause AIDS.
September	Chiron Corp. announces cloning and sequencing of ARV genome.
	Giovanni Battista Rossi in Italy isolates AIDS virus.
October	Feinstein forms Mayors Advisory Committee on AIDS.
	FDA approves Lyphomed's injectable pentamidine for PCP and gives it orphan drug status.
	Bureau of Communicable Disease Control, SFDPH, begins surveillance of average monthly AIDS bed census.
Oct. 9 -	Silverman closes baths and private sex clubs as "menace" to public health. Baths reopen hours later.
November	Gallo et al. clone HTLV-III.
Nov. 28 -	San Franciso Superior Court Judge Roy Wonder rules baths can remain open if monitored for safe sex practices every 10 minutes.
December	Montagnier et al. report cloning of LAV; they also report CD4 molecule as LAV receptor.
	Silverman resigns as director of SFDPH.
	90 reported cases of transfusion AIDS; 49 reported cases of Factor VIII hemophilia cases.
	CDC recommends use of heat-treated blood products for hemophiliacs; other specialists differ. Heat-treated blood products become commercially available.
	National Kaposi's Sarcoma Reasearch and Foundation renamed San Francisco AIDS Foundation.

Dec. 26 - Simon Wain-Hobson, Pierre Sonigo, Olivier Danos, Stewart Cole, and Marc Alizon at Pasteur Institute publish LAV nucleic acid sequence in *Cell*.

1985:

January Gallo et al. publish full nucleic acid sequence of HTLV-III.

Jan. 14 - Irwin Memorial Blood Bank prohibits males having more than one sex partner to donate blood.

February FDA approves Gallo's AIDS diagnostic kit based on Western blot technique.

Feb. 1 - Paul Luciw, Jay Levy, Ray Sanchez-Pescador et al. at Chiron publish ARV nucleic acid sequence.

Feb. 7- Dan Capon, M.A. Muesing et al. at Genentech publish ARV nucleic acid sequence.

March San Francisco County Community Consortium founded for community-based AIDS drug testing.

March 2 - FDA approves Abbott Laboratory's commercial test for AIDS. Red Cross contracts with Abbott, one of five companies supplying test, and in days phases in test. Britain and France delay testing six months to introduce their own antibody tests.

March 3 - IMBB introduces genetically engineered hepatitis B antibody core test.

March 4 - First International Conference on AIDS, Atlanta

March 6 - IMBB institutes anti-AIDS virus antibody test, the first blood bank in U.S. to do so.

March 14 - *San Francisco Chronicle* reports army study showing AIDS transmission through heterosexual contact.

Spring California legislature and Gov. Deukmejian approve bill banning HIV antibody testing without subject's written informed consent, except at test sites where testing is anonymous. Bill also bars employer and insurance company discrimination on basis of AIDS status. $5 million appropriated to establish HIV community test sites. Disclosure of test results to third party must be improved in writing by test taker.

April CDC drops Haitians from high risk groups for AIDS.

May US Patent Office awards patent on Gallo's antibody test.

Summer	AIDS diagnostic kits using ELISA become commercially available. California law mandates every county to offer AIDS test at public health centers; guidelines for preserving confidentiality.
June	American Association of Blood Banks, American Red Cross, Council of Community Blood Centers agree not to begin "look back" program to identify people who have received AIDS-infected blood.
	National Institute of Allergy and Infectious Diseases [NIAID] creates first AIDS Treatment Evaluation Units, predecessor to AIDS Clinical Trial Groups (ACTGs).
	California public health clinics begin testing for AIDS.
June 24	IMBB adds bar codes for confidential exclusion of blood units.
September	Mathilde Krim and Michael Gottlieb found American Foundation for AIDS Research [AmFAR], merging AIDS Medical Foundation of New York and National AIDS Research Foundation of Los Angeles.
	Martin Delaney and others found Project Inform.
October	Public's awareness of AIDS rises with Rock Hudson's death.
	Congress allots $70 million to AIDS research day after Hudson's death.
December	Pasteur Institute sues for share of royalties on AIDS antibody test.
	CDC first considers vertical transmission of AIDS virus; advises infected women to "consider" delaying pregnancy until more known about perinatal transmission.
	CDC contracts with San Francisco AIDS Foundation to develop materials for anonymous AIDS testing sites.
	Late in year Department of Defense announces that new recruits will be screened for AIDS and rejected if positive.
	Third UC AIDS Clinical Research Center founded at UCSD. Goals of three centers broaden to include rapid evaluation of new therapeutic agents.
	13-year-old Ryan White, a hemophiliac with AIDS, is barred from school in Indiana.
	CDC expands surveillance definition, in light of HIV antibody test.

KEY PARTICIPANTS
in San Francisco AIDS History, 1981-1984

Appendix B

*[1]Donald A. Abrams, M.D., AIDS clinician and member of original AIDS physician team at San Francisco General Hospital (SFGH); early research on AIDS-associated lymphadenopathy (swollen lymph glands); organizer of County Community Consortium.

*Arthur J. Ammann, M.D., pediatric immunologist at University of California, San Francisco (UCSF); conducted early studies of AIDS-associated immune deficiency in adults and children; reported first case of transfusion AIDS; currently head of a pediatric AIDS foundation.

Francoise Barré-Sinoussi, retrovirologist at Pasteur Institute and member of team which isolated AIDS virus.

Edward N. Brandt, Jr., M.D., Ph.D., Assistant Secretary for Health, U.S. Department of Health and Human Services, 1981-1984.

Conrad Casavant, immunologist in Department of Laboratory Medicine and associate director of Clinical Immunology Laboratory at UCSF; died of AIDS in 1987.

Jean-Claude Chermann, retrovirologist at Pasteur Institute and member of team which isolated AIDS virus.

*Marcus A. Conant, M.D., clinical professor at UCSF, and dermatologist with private AIDS practice; diagnosed first case of Kaposi's sarcoma in San Francisco; founder of first AIDS clinic (at UCSF); medical activist at local, state, and federal levels.

James W. Curran, M.D., M.P.H., epidemiologist and director of AIDS research at Centers for Disease Control (CDC), Atlanta, Georgia.

William Darrow, CDC sociologist.

Larry Drew, virologist at Mt. Zion Hospital, San Francisco.

*Selma K. Dritz, M.D., M.P.H., epidemiologist at San Francisco Department of Public Health (SFDPH); tracked early AIDS cases in San Francisco; addressed medical and community groups on AIDS recognition and prevention.

Gaetan Dugas, French-Canadian airline steward who was among first to be diagnosed with AIDS; sometimes mistakenly referred to as "Patient Zero" and held responsible for early dissemination of AIDS.

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[1] The asterisk indicates that the individual has been interviewed for the AIDS oral history series.

Edgar Engleman, M.D., medical director of Stanford University Hospital blood bank.

Anthony S. Fauci, M.D., director of AIDS activities at National Institute of Allergy and Infectious Diseases, later director of Office of AIDS Research, currently director of NIAID, National Institutes of Health (NIH).

*Donald P. Francis, M.D., D.Sc., epidemiologist and virologist at CDC in Phoenix and Atlanta; conducted early epidemiological and virological studies of AIDS; later became CDC advisor on AIDS to California Department of Health Services; current director of research on AIDS vaccines at a biotechnology company.

Robert Gallo, M.D., retrovirologist at National Cancer Institute, NIH, involved in controversy with Pasteur Institute over isolation of AIDS virus and patent rights to HIV test.

*Deborah Greenspan, D.D.S., D.Sc., clinical professor of oral medicine at UCSF; identified AIDS-associated hairy leukoplakia; instrumental in establishing infection control procedures in dentistry.

*John S. Greenspan, D.D.S., Ph.D., professor of oral biology and oral pathology at UCSF; organized and directs UCSF AIDS specimen bank; current director of UCSF AIDS Clinical Research Center.

Margaret Heckler, Secretary of U.S. Department of Health and Human Services, 1983-1985.

Harold Jaffe, epidemiologist with the AIDS program at CDC.

*Jay A. Levy, M.D., virologist and professor of medicine at UCSF; second to isolate AIDS virus; devised early AIDS diagnostic test and heat treatment to rid blood of HIV.

Luc Montagnier, virologist and member of Pasteur Institute team which isolated AIDS virus.

*Andrew R. Moss, Ph.D., M.P.H., epidemiologist at SFGH; conducted early epidemiological studies of AIDS in San Francisco showing high incidence in gay community; later work focused on AIDS incidence in drug users and homeless.

Herbert A. Perkins, M.D., scientific director (later president) of San Francisco's Irwin Memorial Blood Bank; involved in formulating national blood bank policy regarding blood screening for HIV; currently represents blood bank in legal cases associated with transfusion AIDS.

*Merle A. Sande, M.D., professor of medicine and chief of medical services, SFGH; chairman of AIDS advisory committees at university, health department, and state levels.

Randy Shilts, journalist who covered AIDS for *San Francisco Chronicle*; author of *And the Band Played On: Politics, People, and the AIDS Epidemic*; died of AIDS in 1994.

***Mervyn F. Silverman, M.D., M.P.H.**, director, San Francisco Department of Public Health; center of controversy over closure of San Francisco bathhouses; current director of American Foundation for AIDS Research.

***Paul A. Volberding, M.D.**, oncologist and chief of AIDS Services, SFGH; member of original AIDS physician team at SFGH; prominent AIDS clinician.

Girish Vyas, Ph.D., professor of laboratory medicine, UCSF.

***Warren Winkelstein, M.D., M.P.H.**, epidemiologist at University of California School of Public Health; director of early on-going epidemiological study of AIDS (San Francisco Men's Health Study); member of panel deciding in June 1994 to disprove expanded clinical trial of two AIDS vaccines.

*Constance B. Wofsy, M.D., infectious disease specialist at SFGH; member of original AIDS physician team at SFGH; authority on *Pneumocystis carinii* pneumonia and women with AIDS.

***John L. Ziegler, M.D.**, oncologist at Veterans Administration Medical Center, San Francisco; authority on AIDS-associated lymphoma and Kaposi's sarcoma.

DONALD I. ABRAMS, MD
CURRICULUM VITAE

DATE & PLACE OF BIRTH: June 1, 1950; New York, New York

OFFICE ADDRESS:
San Francisco General Hospital
995 Potrero Avenue, Ward 84
San Francisco, California 94110

HOME ADDRESS:
368 Valley Street
San Francisco, California 94131

TELEPHONE:
Home: (415) 648-6421
Work: (415) 476-4082

MARITAL STATUS: Single

EDUCATION:

1972	Brown University, Providence, Rhode Island. AB, Molecular Biology
1977	Stanford University School of Medicine, M.D.

CERTIFICATION:

1980	Diplomate, American Board of Internal Medicine
1983	Diplomate, Subspecialty of Medical Oncology

PRESENT POSITION:

1988	Associate Professor of Clinical Medicine University of California, San Francisco Assistant Director, AIDS Activities Division San Francisco General Hospital

POSTGRADUATE TRAINING & EXPERIENCE:

1977-80	Resident in Internal Medicine, Kaiser Foundation Hospital, San Francisco
1980-83	Fellow in Hematology-Oncology, University of California, San Francisco
1982-83	Assistant Research Physician, Cancer Research Institute, UCSF
1983-84	Clinical Instructor, Department of Medicine, Cancer Research Institute, UCSF
1984-88	Assistant Clinical Professor, Department of Medicine, CRI, UCSF

ACADEMIC HONORS:

1968-72	National Merit Scholar
1969	Ratcliffe Hicks Award & Francis Wayland Scholar
1972	Sigma Nu
1973-77	California State Fellow

AWARDS:

1986-89	American Cancer Society Career Development Award
1988	Community Service Award, Bay Area Physicians for Human Rights

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1990	Achievement Award, American Association of Physicians for Human Rights
1990	Assistant Secretary of Health's Award for Outstanding Accomplishment

COMMITTEES:

1983	Cancer Committee, San Francisco General Hospital
1983-84	Scientific Advisory Committee, AIDS Foundation, San Francisco
1984	AIDS Advisory Committee, San Francisco Department of Public Health
1985	San Francisco County Community Consortium, Chairman
1985-86	International Program Committee, Second International Conference on AIDS, Paris, France, 1986
1985-88	Committee on Human Research, University of California San Francisco
1986	World Health Organization - Program on AIDS, Consultant
1987-90	Organizing Committee, Sixth International Conference on AIDS, San Francisco, California, 1990
1987	Scientific Advisory Committee, AmFAR (American Foundation for AIDS Research)
1987-89	West Bay Hospital Conference AIDS Task Force
1987-88	Chancellor's Technical Advisory Committee on AIDS, UCSF, Chairman
1988	UCSF AIDS Coordinating Council
1988	Programme Committee, Fifth International Conference of AIDS, Montreal, Canada, 1989
1988	Ambulatory Care Committee, AIDS Office, San Francisco Department of Public Health
1989-90	UCSF 125th Anniversary Committee
1989	American Medical Association Diagnostic & Therapeutic Technology Assessment Reference Panel
1989	Center for AIDS Research (UCSF) Executive Committee
1989	Blood Borne Pathogen Committee, SFGH
1990	Antiviral Advisory Committee, Food and Drug Administration
1990	Protocol Evaluation Subcommittee, AIDS Clinical Trials Group, NIAID
1990	Board of Directors, American Cancer Society, San Francisco Unit
1990	Continuing Medical Education Advisory Committee, UCSF
1991	Keystone Center National Policy Dialogue on Expanded Access

MEMBERSHIP IN PROFESSIONAL ORGANIZATIONS:

1978-Present	**American College of Physicians (Fellow 1987)**
1984-Present	**American Society of Hematology**
1985-Present	**American Society of Clinical Oncology**
1987-Present	**California Medical Association**
1987-Present	**San Francisco Medical Society**
1988-Present	**International AIDS Society**
1989-Present	**American Medical Association**

EDITORIAL BOARDS:

AmFAR Directory of Experimental Treatments for AIDS and ARC, Co-editor
AIDS: An International Bimonthly Journal, Gower Academic Journals
AIDS Knowledgebase, BRS
Journal of AIDS, Raven Press

AIDS Section, Life Sciences
AIDS and STD's

INVITED JOURNAL REVIEWS:

American Journal of Medicine
Annals of Internal Medicine
Archives of Internal Medicine
Blood
Cancer Research
Gastroenterology
Journal of the American Medical Association
Journal of Clinical Immunology
Journal of Clinical Investigation
Journal of Infectious Diseases
Journal of Clinical Oncology
Journal of Laboratory and Clinical Medicine
New England Journal of Medicine
Science
Western Journal of Medicine

ADDITIONAL CLINICAL EXPERIENCE:

1970	Acting nurse on hemodialysis unit, Sint Lucas Ziekenhuis, Amsterdam, The Netherlands
1973	Pediatric extern, Aghias Sophia Hospital, Athens, Greece
1975-76	Clinical clerkships at the Maudsley, Queen Square, Hammersmith, St. Mary's, New Charing Cross and Guy's Hospital, London, England
1981	Fellow for one month at the Bone Marrow Transplantation Unit, Fred Hutchinson Cancer Research Center, Seattle, Washington

RESEARCH EXPERIENCE:

1971-72	Molecular biology of differentiation during myogenesis, Brown University. Advisor: John Coleman
1972	Myosin and myogenesis. Stanford University, Oncology Division. Advisor: Frank Stockdale M.D.
1981-82	Oncogene activation in human B-cell neoplasms and Kaposi's sarcoma, University of California, San Francisco, Department of Microbiology and Immunology. Advisor: Harold Varmus, M.D
1981-Present	Clinical study of Kaposi's sarcoma in homosexual men. University of California, San Francisco, Cancer Research Institute and Dermatology. Marcus Conant, M.D., John Ziegler, M.D. and Paul Volberding, M.D.

1981-Present	Clinical study of lymphadenopathy in homosexual men. Cancer Research Institute. Supported in part by funds from the Research Evaluation and Allocation Committee, University of California, San Francisco and NIH grant #1 UO1 CA 34980-01
1983-84	Clinical study of Apheresis in AIDS-related conditions: lymphadenopathy and immune thrombocytopenic purpura. Supported in part by funds from the University-wide Task Force on Acquired Immune Deficiency Syndrome award cycle November 1, 1983 to June 30, 1984.
1984-Present	Clinical trials of immune modulators and antivirals in AIDS and AIDS-related conditions. Principal investigators of ACTG Protocol 060 Oral Dextran Sulfate. Supported in part by NIAID N01-A1-62541
1985-Present	Community-based clinical trials through the Community Consortium of Bay Area HIV Health Care Providers. Supported in part by funds from the AIDS Clinical Research Center University of California San Francisco, July 1987 - June 1988; American Foundation for AIDS Research (AmFAR) [June 1988-July 1990] and NIAID [June 1988 - July 1989]. Awarded NIAID contract for Community Programs on Clinical Research in AIDS NO1-AI-95035 [Oct 1989 - Sept 1994]

PUBLICATIONS:

JOURNAL ARTICLES:

1982 **Abrams DI,** Dawson C, O'Donnell J, and Char D. Retinal findings in opportunistic infections of homosexual males. Audio J Rev Ophthalmo 8: August.

1982 Ziegler JL, Wagner G, Greenspan JS, **Abrams DI,** et al. Diffuse undifferentiated non-Hodgkin's lymphoma among homosexual males - United States. MMWR 31:277-279.

1982 Drew WL, Miner RC, Ziegler JL, Gullett JH, **Abrams DI,** Conant MA, Huang ES, Groundwater JR, Volberding PA, and Mintz L. Cytomegalovirus and Kaposi's sarcoma in young homosexual men. Lancet ii:125-127.

1982 Olson J, Feinberg I, Silverman S, **Abrams DI,** and Greenspan J. Serum vitamin B_{12}, folate, and iron levels in recurrent aphthous ulceration. Oral Surg, Oral Med, Oral Pathol 54:517-520.

1983 Ammann A, **Abrams DI,** Conant M, Chudwin D, Cowan M, Volberding PA, Lewis B, and Casavant C. Acquired immune dysfunction in homosexual men: Immunologic profiles. Clin Immunopathol 27:315-325.

1983 Moss A, Bacchetti P, Gorman M, Dritz S, Conant M, **Abrams DI,** Volberding P, and Ziegler J. AIDS in the "gay" areas of San Francisco. Lancet i:923-924.

1983 Jaffe HS, **Abrams DI,** Golden JA, Ammann AJ, and Lewis BJ. Complications of trimethoprim sulfamethoxazole in the treatment of AIDS associated *Pneumocystis carinii* pneumonia in homosexual men. Lancet ii:1109.

1983 Spector DH, Shaw SB, Hock LJ, **Abrams DI**, Mitsuyasu RT and Gottlieb ME. Association of human cytomegalovirus with Kaposi's sarcoma. UCLA Symposia on molecular and cellular biology.

1984 **Abrams DI**, Chinn E, Volberding P, Lewis B, Conant M and Townsend R. Hematologic manifestations of Kaposi's sarcoma in homosexual men. Am J Clin Pathol 81:13-18.

1984 Ammann AJ, Schiffman G, **Abrams DI**, Volberding P and Conant M. Acquired B-cell immunodeficiency disease. J Am Med Assoc 251:1447-1449.

1984 Valone FH, Payan DG, **Abrams DI** and Goetzl EJ. Defective polymorphonuclear leukocyte chemotaxis in homosexual males with persistent lymph node syndrome. J Inf Dis 150:267-271.

1984 Moon KL, Federle MP, **Abrams DI**, Volberding PA and Lewis BJ. Kaposi's sarcoma and lymphadenopathy syndrome: Limitations of the abdominal CT in acquired immunodeficiency syndrome. Radiology 150:479-83.

1984 Ziegler JL, Beckstead JA, Volberding PA, **Abrams DI**, Levine AM, Lukes RJ, et al. Non-Hodgkin's lymphoma in 90 homosexual men: Relationship to generalized lymphadenopathy and acquired immunodeficiency syndrome (AIDS). N Engl J Med 311:565-570.

1984 Stern RG, Gamsu G, Golden JA, Hirji M, Webb WR and **Abrams DI**. Intrathoracic adenopathy in AIDS and the diffuse, persistent lymphadenopathy syndrome: Diagnostic and clinical implications. Am J Roentgenol 142:689-92.

1984 **Abrams DI**, Lewis BJ, Beckstead JH, Casavant C and Drew WL. Persistent diffuse lymphadenopathy in homosexual men: Endpoint or prodrome? Ann Intern Med 100:801-808.

1984 Valone FH, Payan DG, **Abrams DI** and Goetzl EJ. Indomethacin enhances the proliferation of mitogen-stimulated T-lymphocytes from homosexual men with reactive lymph node syndrome. J Clin Immunol 4(5):383-387.

1984 **Abrams DI**, Lewis BJ and Volberding PA. Lymphadenopathy: Endpoint or Prodrome? Update of a 24-month prospective study. Ann NY Acad Sci 437:207-215.

1984 Ziegler JL, Bragg K, **Abrams DI**, Beckstead J, Volberding PA, Baer D, Wilkinson L, Rosenbaum E, Grant K, Silverberg I, McGrath I. High grade non-Hodgkins lymphoma in patients with AIDS. Ann NY Acad Sci 437:412-419.

1985 Moss AR, Bacchetti P, Osmond D, Dritz S, **Abrams DI**, Conant M and Volberding P. Incidence of the acquired immunodeficiency syndrome in San Francisco 1980-1983. J Inf Dis 152:152-161.

1985 Volberding P and **Abrams DI**. Ethical issues elicited by clinical care and research in AIDS. In: AIDS: The Emerging Ethical Dilemmas. The Hastings Center Report 15(4):16-18.

1985 Kiprov DD, Lippert R, Sandstrom E, Jones FR, Cohen RJ, **Abrams DI**, Busch DF. Acquired immunodeficiency syndrome (AIDS) - apheresis and operative risks. J Clin Apher 2:427-440.

1985 Stricker RB, **Abrams DI**, Corash L, Shuman MA. Target platelet antigen in homosexual men with immune thrombocytopenia. New Engl J Med 313:1375-1380.

1985 Lipkin I, Parry G, Kiprov D, **Abrams DI**. Inflammatory neuropathy in homosexual men with lymphadenopathy. Neurology 35(10):1479-1483.

1985 **Abrams DI**, Kiprov DD, Goedert JJ, Sarngadharan MG, Gallo RC, Volberding PA. Antibodies to human T-lymphotropic virus type-III antibodies and development of acquired immunodeficiency syndrome in homosexual men presenting with immune thrombocytopenia. Ann Intern Med 104:47-50.

1985 Greenspan JS, Greenspan D, Lennette ET, **Abrams DI**, Conant MA, Petersen V, Freese UK. Epstein-Barr virus replicates within the epithelial cells of oral "hairy" leukoplakia, an AIDS-associated lesion. N Engl J Med 313:1564-1571.

1986 Bottles K, Cohen MB, Brodie H, Jeffreys RB, **Abrams DI**. Fine needle aspiration cytology of lymphadenopathy in homosexual males. Diagnostic Cytopathology 2:31-35.

1986 Jeffrey RB, Nyberg DA, Bottles K, **Abrams DI**, Federle MP, Wall SW, Wing VW,Laing FC. Abdominal CT in acquired immunodeficiency syndrome. AJR 146:7-13.

1986 Nyberg DA, Jeffrey RB, Federle MP, Bottles K, **Abrams DI**. AIDS-related lymphomas: Evaluation by abdominal CT. Radiology 159:59-63.

1986 Bloom EJ, **Abrams DI**, Rodgers G. Lupus anticoagulant in the acquired immunodeficiency syndrome. JAMA 256:491-493.

1986 Kiprov DD, Lippert R, Miller RG, Sandstrom E, Jones FR, Cohen RJ, **Abrams DI**, Busch DF. The use of plasmapheresis, lymphocytapheresis, and staph protein-A immunoadsorption as an immunomodulatory therapy in patients with AIDS and AIDS-related conditions. J Clin Apher 3:133-139.

1986 **Abrams DI**, Volberding PA. Alpha interferon therapy of AIDS-associated Kaposi's sarcoma. Sem Oncol XIII Suppl 2:43-47.

1986 **Abrams DI**, Kaplan LD, McGrath MS, Volberding PA. AIDS-related benign lymphadenopathy and malignant lymphoma: clinical aspects and virologic interactions. AIDS Res 2(Suppl 1):S131-S139.

1986 Kaplan LD, Volberding PA, **Abrams DI** Treatment of Kaposi's sarcoma in acquired immunodeficiency syndrome with an alternating vincristine-vinblastine regimen. Cancer Treat Rep 70:1121-1122.

1987 Greenspan D, Greenspan JS, Hearst NG, Pan L-Z, Conant MA, **Abrams DI**, Hollander H, Levy JA. Relation of oral hairy leukoplakia to infection with human immunodeficiency virus and risk of developing AIDS. J Inf Dis 55:475-481.

1987 Kiprov DD, Simpson DM, Pfaeffl WA, Romanick-Schmiedl S, **Abrams DI**, Miller RG. AIDS and apheresis procedures - therapeutic and safety considerations. Blood Purification 5:51-56.

1987 Kaplan LD, Wolfe PR, Volberding PA, Feorino P, Levy JA, **Abrams DI**, Kiprov D, Wong R, Kaufman L, Gottlieb MS. Lack of response to suramin in patients with AIDS and AIDS-related complex. Am J Med 82:615-620.

1987 **Abrams DI**, Volberding PA. Alpha interferon therapy of AIDS-associated Kaposi's sarcoma. Sem Oncol XIV Suppl 2:43-47 (Reprinted).

987 Ayers MR, **Abrams DI**, Newell TG, Friedrich F. Performance of Individuals with AIDS on the Luria-Nebraska Neuropsychological Battery. Int J of Clin Neuropsych 9:101-105.

987 Ammann AJ, Palladino MA, Volberding P, **Abrams DI**, Martin NL, West R, Conant M. Tumor necrosis factors alpha and beta in acquired immunodeficiency syndrome and AIDS-related complex. J Clin Immunol 7(6):481-485.

987 Schneider PA, **Abrams DI**, Rayner AA, Hohn DC. Immunodeficiency associated thrombocytopenic purpura (IDTP): Response to splenectomy. Archives of Surgery 122:1175-1178.

1987 **Abrams DI**. AIDS update -1987. Advances in Alcohol and Substance Abuse 7(2):29-45.

1988 **Abrams DI**. The pre-AIDS syndromes. Infectious Disease Clinics of North America 2(2):343-351.

1988 Moran TA, Lovejoy N, Viele CA, Dodd MJ, **Abrams DI**. Informational needs of homosexual men diagnosed with AIDS or AIDS-related complex. Oncology Nursing Forum 15:311-314.

1988 So YT, Holtzman, **Abrams DI**, Olney RK. Peripheral neuropathy associated with Acquired Immune Deficiency Syndrome (AIDS): Prevalence and clinical features from a population based survey. Archives of Neurology 45:945-948.

1988 Moskovtiz B, Lane HC, Masur H, Lange M, England A, McKinley G, Volberding PA, **Abrams DI**, et al. HPA Cooperative Study Group. A clinical trial of tolerance of HPA-23 in patients with acquired immune deficiency syndrome (AIDS). Antimicrobial agents and chemotherapy 32: 1300-1303.

1989 Kaplan LD, **Abrams DI**, Feigal E, McGrath MS, Kahn J, Neville P, Ziegler J, Volberding PA. AIDS associated non-Hodgkin's lymphoma in San Francisco. JAMA 261:719-724.

1989 **Abrams DI**, Kuno S, Wong R, Jeffords K, Nash M, Molaghan JB, Gorter R, Ueno R. Oral Dextran sulfate (UA001) in the treatment of the acquired immunodeficiency syndrome (AIDS) and AIDS-related complex. Ann Intern Med 110:683-188.

1989 Mess T, **Abrams DI**. Clinical Manifestations of HIV Infection. Current Opinions in Infectious Diseases 2:54-60.

1989 Jacobson MA, **Abrams DI**, Volberding PA, Bachetti P, Wilber J, Chaisson R, Crowe S, Howard W, Moss A. Serum Beta-2 microglobulin decreases in patients with AIDS or ARC treated with azidothymidine. J Inf Dis 159:1029-1036.

1989 Krowka JF, Stites DP, Jain S, Steimer KS, George-Nascimento L, Gyenes A, Barr PJ, Hollander H, Moss AR, Homsy JM, Levy JA, **Abrams DI**. Lymphocyte proliferative responses to human immunodeficiency virus antigens *in vitro*. JCI 83:1198-1203.

1990 Leoung G, Feigal D, Montgomery AB, Corkery K, Wardlaw L, Adams M, Busch D, Gordon S, Jacobson M, Volberding P, **Abrams DI**, and the San Francisco County Community Consortium. Aerosolized pentamidine for prophylaxis against Pneumocystis *carinii* pneumonia. The San Francisco Community Prophylaxis Trial. NEJM 323:769-775.

1990 **Abrams DI**. Clinical manifestations of HIV infection, including persistent generalized lymphadenopathy and

AIDS-related complex. J Am Acad Dermatol 22:1217-22.

1990 **Abrams DI**. The relationship between Kaposi's Sarcoma and intestinal parasites among homosexual males in the United States. JAIDS 3(suppl.1):544-546.

1990 **Abrams DI**. Alternative therapies in HIV infection. AIDS 4:1179-1187.

1990 Kaplan LD, **Abrams DI**, Sherwin SA, Kahn J, Volberding PA. A phase I/II study of recombinant tumor necrosis factor and recombinant interferon gamma in patients with AIDS-related complex. Biotech Ther 1(3)i-ii, 229-236.

1990 Jacobson M, Bacchetti P, Kolokathis A, Chaisson R, Szabo S, Polsky B, Valainis G, Mildvan D, **Abrams DI**, Wilber J, Winger E, Hendricksen C, Moss A. Surrogate markers for survival in patients with AIDS and ARC treated with zidovudine. Brit Med J 302:73-8.

1990 Scitovsky A, Cline MB, and **Abrams DI**. Effects of the use of AZT on the medical care costs of persons with AIDS in the first 12 months. JAIDS 3:904-912.

1991 Greenspan D, Greenspan JS, Overby G, Hollander H, **Abrams DI**, MacPhail L, Borowsky C, Feigal DW. Risk factors for rapid progression from hairy leukoplakia to AIDS: a nested case control study. JAIDS 4:652-658.

1991 Hersh EM, Brewton G, **Abrams DI**, Bartlett J, Galpin J, Gill P, et al. A randomized double-blind placebo-controlled multicenter study of sodium ditiocarb (diethyldithiocarbamate) therapy in patients with ARC and AIDS. JAMA 256:1538-1544.

1991 Kaplan LD, Kahn JO, Crowe S, Northfelt D, Neville P, Grossberg H, **Abrams DI**, Tracey J, Mills J, Volberding P. Clinical and virologic effect of recombinant human granulocyte-macrophage colony-stimulating factor (rGM-CSF) in patients receiving chemotherapy for HIV-associated non-Hodgkin's lymphoma: results of a randomized trial. J.Clin.Oncol 9:929-940.

1991 Northfelt DW, Mayer A, Kaplan LD, **Abrams DI**, Hadley WK, Yajko DM, Herndier BG. The usefulness of diagnostic bone marrow examination in patients with human immunodeficiency virus (HIV) infection. JAIDS 4:659-666.

IN PRESS AND SUBMITTED:

1991 Northfelt DW, Kaplan LD, **Abrams DI**. Continuous, low-dose therapy with interferon-alpha for human immunodeficiency virus (HIV)-related immune thrombocytopenic purpura. Am.J. Heme. In press.

1991 **Abrams, DI**. Acquired immunodeficiency syndrome and related malignancies: a topical overview. Semin Onc 18 (11). In press.

1991 Slome LR, Moulton JM, Huffine C, Gorter R, **Abrams DI**. Physicians' attitudes toward assisted suicide in AIDS. JAIDS. In press.

1991 Moody DJ, Krowka JF, Rayner AA, Gemlo BT, **Abrams DI**, Stites DP. Absence of natural killer activity in NKH1A+ lymphocyte clones from individuals infected with AIDS-associated retrovirus. Submitted.

991 **Abrams DI**, Bihari B, Goosby E, et al. A placebo-controlled trial of the immune modulator, lentinan, in HIV-positive patients: A Phase I/II trial. In preparation.

991 **Abrams DI**, Pettinelli C, Power M, Buzas J, Kubacki JB, Grieco MH, et.al. A phase I/II dose-ranging trial of oral dextran sulfate in HIV p24 antigen positive individuals (ACTG 60). In preparation.

1991 Scitowsky A, Cline M, **Abrams DI**. Medical care use and cost of HIV infected persons without AIDS with T cell counts under 200/mm3. In preparation.

1991 **Abrams DI**, Feinberg J, Andes WA, Kisner JL, Golando JP, Volberding PA. A trial of alpha-2 interferon in a benign reactive lymphadenopathic syndrome. In preparation.

EDITORIALS:

1986 **Abrams DI**. AIDS-related lymphadenopathy: The role of biopsy. J Clin Oncol 4(2):126-127.

BOOK CHAPTERS:

1984 **Abrams DI**. Lymphadenopathy: The San Francisco experience. In: Friedman-Kien AE, ed. Epidemic Kaposi's Sarcoma and Opportunistic Infections in Homosexual Men. New York: Masson Publishing, 81-88

1984 **Abrams DI**. Lymphoproliferative diseases in homosexual males. In. Purtilo DT, ed. Immune Deficiency and Cancer: Epstein-Barr Virus and Lymphoproliferative Malignancies. New York: Plenum Press, 385-400.

1985 **Abrams DI**. Lymphadenopathy in homosexual men. In: Gallin J and Fauci A, eds. Advances in Host Defenses, Vol 5. New York: Raven Press, 75-97.

1985 Ziegler JL and **Abrams DI**. The AIDS-related Complex. In: DeVita VT, Hellman S, Rosenberg SA,(eds). AIDS: Etiology, diagnosis, treatment and prevention. Philadelphia: J.B. Lippincott Co., 223-234.

1985 **Abrams DI**. Asymptomatic lymphadenopathy and other early presentations of AIDS. In: Vaeth JM (ed). Frontiers in Radiation Therapy and Oncology, Vol 19. Basel: Karger Publishing Co, 59-65.

1985 Moss AM, **Abrams DI**, Conant M, Volberding P. Incidence of the Acquired Immunodeficiency syndrome in San Francisco. In: Vaeth JM (ed). Frontiers of Radiation Therapy and Oncology Vol 19. Basel: Karger Publishing Co, 14-20.

1985 **Abrams DI**, Mess T, Volberding P. Lymphadenopathy: endpoint or prodrome? Update of a 36 month prospective study. In: Gupta S (ed). AIDS Associated Syndromes. Advances in Experimental Medicine and Biology, Vol 187. New York: Plenum Press, 73-84.

1985 **Abrams DI**, Kiprov DD, Volberding PA. Isolated thrombocytopenia in homosexual men longitudinal follow-up. In: Gupta S (ed). AIDS associated Syndromes. Advances in Experimental Medicine and Biology, Vol 187. New York: Plenum Press, 117-122.

1985 Greenspan JS, Greenspan D, Lennette ET, **Abrams DI**, Conant MA, Petersen VH. Oral Viral Leukoplakia -

A New AIDS-Associated condition. In: Gupta S (ed). AIDS Associated Syndromes. Advances in Experimental Medicine and Biology, Vol 187. New York: Plenum Press, 123-128.

1985 Volberding PA, Wofsy CB, **Abrams DI**. Interferon and interleukin-2 therapy of Kaposi's sarcoma. In: Gupta S (ed). AIDS-Associated Syndromes. Advances in Experimental Medicine and Biology, Vol 187. New York: Plenum Press, 151-157.

1986 **Abrams DI**. Lymphadenopathy related to the acquired immunodeficiency syndrome in homosexual men. In: Cooney, TG, Ward TT (eds). Medical Clinics of North America, Vol 70 (3). Philadelphia: WB Saunders Co, 693-706.

1986 **Abrams DI**, Dilley JW, Maxey LM, Volberding PA. Routine Care and Psychosocial Support of the AIDS Patient. In: Cooney TG and Ward TT (eds). Medical Clinics of North America, Vol 70 (3). Philadelphia: WB Saunders Co, 707-720.

1986 **Abrams DI**. AIDS-related conditions. In: Pinching A (ed) Clinics in Immunology and Allergy, Vol 6 (3). London: WB Saunders, 581-599.

1986 **Abrams DI**, Volberding PA. AIDS-related Kaposi's sarcoma: Alpha Interferon Therapy in AIDS-related Kaposi's sarcoma. In: Silver HKB, (ed). Interferons in Cancer Treatment. Mississauga, Ontario: MES Medical Education Services, 67-73.

1986 **Abrams DI**. Issues of medical treatment of AIDS relevant to mental health practitioners. In: McKusick L, (ed). What To Do About AIDS. Berkeley: University of California Press, 12-24.

1987 **Abrams DI**. Clinical manifestations of AIDS: Hematologic Aspects. In: Cohen PT, Sande MA, Volberding PA et al (eds). San Francisco General Hospital AIDS Knowledgebase [computer data base]. Latham, New York: BRS, n.p.

1987 **Abrams DI**. AIDS-related conditions. In: Cohen PT, Sande MA, Volberding PA et al (eds). San Francisco General Hospital AIDS Knowledgebase [computer data base]. Latham, New York: BRS, n.p.

1988 **Abrams DI**. The pre-AIDS syndromes. In: Sande MA, Volberding PA (eds). The Medical Management of AIDS. Philadelphia: WB Saunders Co, 91-102.

1988 **Abrams DI**. The persistent lymphadenopathy syndrome and immune thrombocytopenic purpura in HIV-infected individuals. In: Levy JA (ed). AIDS: Pathogenesis and Treatment. New York: Marcel Dekker, Inc., 323-343.

1988 **Abrams DI**. Treatment results and outcome in HIV-related thrombocytopenic purpura. In: Andrieu J-M, Bach J-F, Even P (eds). Autoimmune Aspects of HIV Infection. London: Royal Society of Medicine Services Ltd., 185-190.

1989 **Abrams DI**. Acquired immunodeficiency syndrome. In: Goldsmith R and Heyneman D, (eds). Tropical Medicine & Parasitology. Norwalk, CT: Appleton & Lange Publications, 686-692.

1989 **Abrams DI**. AIDS Update - 1987. 7(2). In: Siegel L (ed). AIDS and Substance Abuse. New York: Harrington Park Press, 29-45.

1989 Kiprov D. Conant MA, Lippert R. Pfaeffl W, Miller R and **Abrams DI**. Therapeutic apheresis as a treatment modality in AIDS and AIDS-related conditions. In: Corless IB, and Pittman-Lindeman M.(eds). AIDS Principles, Practices and Politics. New York: Hemisphere Publishing Corp. 113-117.

1989 **Abrams DI**. Initial clinical trial of oral dextran sulfate for treatment of patients with symptomatic HIV infection. In: Mills J and Corey I (eds) Antiviral Chemotherapy, 2nd Edition. New York: Elsevier Publishing, 347-353.

1989 **Abrams DI**. Alternative Therapies In: Rapoza NP (ed). Information on AIDS and HIV Infection and Disease. AMA Press. 163-175.

1990 Hambleton J and **Abrams DI**. Hematologic Manifestations of HIV infection. In: Sande MA and Volberding PA (eds). The medical management of AIDS. Philadelphia: W.B. Saunders Co., 182-194.

1991 Macks J and **Abrams DI**. AIDS-related burnout. In: Volberding P and Jacobson MS (eds). AIDS Clinical Review 1992. In preparation

LETTERS:

1984 **Abrams DI**, Robia M, Blumenfeld W, Simonson J, Cohen MB, Hadley WK Disseminated coccidioidomycosis in AIDS New Engl J of Med 310:986-7

1984 Pearce RB, **Abrams DI** AIDS and parasitism. Lancet:i:1411

1986 McKusick L., Horstman W., **Abrams DI**, Coates TJ The psychological impact of AIDS upon the primary care physician Western J Med 144:571-752.

987 Ford PV, Lim AB, **Abrams DI**, Parker HG Utility of total body Gallium-67 scintigraphy in a patient with AIDS Related Complex. J of Nuclear Med 3:402-404.

987 Pearce RB, **Abrams DI**. Entamoeba histolytica in homosexual men. New Engl J Med 316:690-691.

987 Lipkin WI, Parry G, **Abrams DI**, Kiprov D Polyradiculoneuropathy, polyradiculitis, and CMV in AIDS and ARC. Neurology 37:888.

989 Wurtz RM, **Abrams DI**, Becker S, Jacobson MA, Nash M, and Mark SH. Anaphylactoid drug reactions to ciprofloxacin and rifampicin in HIV-infected patients. Lancet i:955-956.

991 Shuman M, Corash L, **Abrams DI** and Hittelman KJ. Retraction: Stricker RB, **Abrams DI**, Corash L, Shuman M. Target platelet antigen in homosexual men with immune thrombocytopenia. New Engl J.Med 1985 313:1375-80. NEJM. In press.

BSTRACTS:

982 Weintraub P, Koerper M, **Abrams DI**, Shuman M, Addiego JE, Jr., Cowan MC, Ammann A. Altered cellular immunity in hemophiliacs receiving prophylactic Factor VIII concentrate. Blood 60:224a.

983 **Abrams DI**, Lewis BJ, Beckstead JH, Casavant CH, Drew WL, Ammann AJ. Lymphadenopathy in homosexual men: Endpoint or prodrome? Proc Am Soc Clin Oncol 2:47.

1983 Lewis B, **Abrams DI**, Ziegler J, Conant M, Gee G, Silverberg I, Volberding PA. Single agent or combination chemotherapy of Kaposi's sarcoma (KS) in acquired immune deficiency syndrome (AIDS). Proc Am Soc Clin Oncol 2:59.

1983 **Abrams DI**, Volberding PA, Linker CA, Kiprov D, Moss AR, Sperling JA, Embury SH. Immune thrombocytopenic purpura in homosexual men Clinical manifestations and treatment results. Blood 62:108a.

1983 Volberding PA, Moran T, **Abrams DI**, Rothman J, Valero R. Recombinant alpha-interferon therapy of Kaposi's sarcoma in the acquired immune deficiency syndrome. Blood 62:118a.

1984 Shaw S, Spector D, **Abrams DI**, Gottlieb M. Characterization of HCMV sequences in Kaposi's sarcoma tissues from AIDS patients.

1984 Shannon K, Ammann AJ, Cowan M, **Abrams DI** Assessment of monocyte-macrophage antigen presentation in homosexual men.

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January, 1983

PLAINTIFF'S EXHIBIT
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AGENDA ITEM
B1

APPENDIX D

Report to the Board
Committee on Transfusion Transmitted Diseases

The major report of your Committee on Transfusion Transmitted Diseases has been issued as our recommendations to the Association. These few additional paragraphs are more my current views and concerns than a formal committee report. Nonetheless, because of my recent experiences I am anxious to share some thoughts with you:

The report that we have submitted to our members is, in my view, appropriate considering the data at hand. Since we met, however, an additional child with AIDS has been admitted to a Texas hospital. At birth the child had received seven transfusions, one of which came from a donor who now seems to have AIDS. This case increases the probability that AIDS may be spread by blood. Furthermore, the CDC continues to investigate the current cases aggressively and may even have a few more. While I believe our report reacts appropriately to the data at hand, I also believe that the most we can do in this situation is buy time. There is little doubt in my mind that additional transfusion related cases and additional cases in patients with hemophilia will surface. Should this happen, we will be obliged to review our current stance and probably to move in the same direction as the commercial fractionators. By that I mean it will be essential for us to take some active steps to screen out donor populations who are at high risk of AIDS. For practical purposes this means gay males.

The matter of arranging an appropriate screening program is delicate and difficult. We have had excellent cooperation from individuals in the gay community and our deliberations have been made easier by their knowledge and ability to help us. I have no doubt that they will continue to support us and, should we need to be more aggressive in this area, will help us do it in a way that is socially responsible.

Blood banks that wish to sell plasma for further fractionation already face the need to do something. Perhaps our Committee should prepare guidelines with suggested wording for them to use. We are reluctant to do this since we do not want anything that we do now to be interpreted by society (or by legal authorities) as agreeing with the concept - as yet unproven - that AIDS can be spread by blood.

All in all this is a knotty problem and one that we will not solve easily.

I want to make a few comments about the process by which our joint document developed. We spent a great deal of time and energy and did the best we could in attempting to reach a consensus. The difficulty was to get AABB, ARC, CCBC and all the other groups to adopt a postion which was acceptable to each other. It was impossible to have a small meeting; everybody wanted to attend. When we got the group together we were able to hammer out a statement that pleased the attendees. Unfortunately, the statement had to go through several iterations with our own Board and the Boards of the other involved organizations. In all probability these modifications resulted in a better statement, but the process of getting these changes incorporated and run back and forth through the three organizations was difficult. We have had a good start at working together on this and we hope to keep it up. The mechanism was a little less smooth when it came to releasing the statements and the public relations that went with it.

I hope that we are equipped psychologically to continue to act together. I have been in contact with ARC (Dr. Katz) and CCBC (Dr. Menitove) and believe that the three of us can, together, work out whatever new problems may arise. We plan frequent conference calls to keep each other informed.

I want to comment about the Committee. They worked well together and I was particularly pleased with the input of advisory members. Having individuals who are not associated with the blood banks nor a traditiona part of the blood banking community proved most useful to us. Their comments and suggestions were excellent. In a like manner, we were helped by participants from the National Gay Task Force. As we continu to react to the various challenges before us, I am sure that their help will be essential. Finally, let me acknowledge the help from the Central Office and, in particular from Lorry Rose.

No immediate end to the publicity is in sight and we will get continued calls for us to act more aggressively. We need to do whatever is medically correct. In addition, we may have to do a little more, since we are accused of burying our heads in the sand. We are not being helped by the spate of publicity about this illness, but will continue to react responsibility to whatever scientific and medical information we have.

Joseph R. Bove.

Joseph R. Bove, M.D., Chairman
Committee on Transfusion Transmitted Diseases
American Association of Blood Banks

JRB:tmf

1/24/83

CHRONOLOGY OF MARCUS CONANT'S AIDS INVOLVEMENT

April 21, 1981	Call from Alvin Friedman-Kien of N.Y. regarding Kaposi's sarcoma in gays.
April 22, 1981	Conant speaks at UCSF conference to dermatologists and asks about Kaposi's sarcoma. Jim Groundwater told of a current case he had. Conant thought a new epidemic had arrived in S.F.
July 2, 1981	Conant proposes a KS clinic in San Fran due to 6 cases having already turned up.
September 15, 1981	National Cancer Institute calls a conference on Kaposi's sarcoma and opportunistic infections in Washington, D.C. Conant is invited. (120 cases of Kaposi's sarcoma nationally)
October, 1981	Conant finds Dr. Paul Volberding (cancer chief at San Fran General Hospital) to assist on Kaposi's ("gay plague") cases and set up clinic and treat patients at San Fran General.
December, 1981	Conant uses his own funds (with Jim Groundwater) to put together a full-color brochure on Kaposi's to distribute at the American Academy of Dermatology convention in San Fran.
January 14, 1982	Conant views what had come to be known as GRID (Gay Related Immune Deficiency) as a "world-class disaster."
February, 1982	Doctors at the Kaposi's Sarcoma clinic were watching patients develop new aspects of Kaposi's.
April 1, 1982	Conant examines Gaetan Dugas (airline steward) who had been diagnosed with Kaposi's two years before and still appeared healthy.
April 13, 1982	Testified at congressional hearing regarding research funding for Kaposi's.
May, 1982	Conant ~~and Volberding~~ go to Tokyo to present data on Kaposi's.

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August, 1982	Conant and Volberding have agreement to open an AIDS outpatient clinic at San Fran General Hospital.
October 30, 1982	Conant organizes the first national conferences on AIDS.
January 7, 1983	Conant trying to engineer hepatitis antibody testing but Perkins (Irwin Mem.Blood Bank) argued against it (and said it would mark all gay men.)
March 17, 1983	Conant attends the New York University AIDS conference.
April, 1983	Conant was attempting to organize a national foundation for raising funds for AIDS research.
June 13, 1983	Jurors refuse to sit on a jury with a person known to have AIDS. Judge has to call Conant in to explain the spreading mechanism.
June 21, 1983	Conant meets with Thomas Donnelly, Assistant HHS Secretary for Legislative Affairs, regarding AIDS funding. Following the meeting, Conant wrote to President Reagan regarding the magnitude of the epidemic.
July, 1983	California state legislature approved $2.9 million in funds for AIDS research pursuant to Conant's efforts.
August 1, 1983	Testimony by Conant (heading the scientific testimony) regarding AIDS before Congressional subcommittees.
August 25, 1983	Angry with the Univ. of California withholding funds for AIDS research, Conant leaked a memo to the press regarding the serious public relations consequences of delaying funding.
October, 1983	The *Sentinel*, a San Fran gay newspaper, blasts Conants KS/AIDS Foundation, causing it to flounder nationally.

November 22, 1983	Conant attends the WHO (World Health Organization) meeting in Geneva, Switzerland to discuss AIDS. Serious discussion centered around transmission by blood but most countries chose to ban blood products from the U.S. The Dutch Red Cross was getting opposition from the gay community regarding screening. Britian echoed the American view that there was "no conclusive proof."
January 26, 1984	The San Francisco case load of AIDS surpassed 400.
February, 1984	Conant begins telling the gay community that they need to shut down the bath houses in order to help control the spread of AIDS.
March 28, 1984	Conant along with other doctors of BAPHRA (Bay Area Physicians for Human Rights) worked on a statement asking gay men to voluntarily stop going to bath houses.
March 31, 1984	Merv Silverman (San Fran Health Director) has a change of heart regarding closure of the bath houses and Conant and Mayor Feinstein believe that it may be linked to the mafia's association with bath houses in other cities.
April 4, 1984	Conant becomes labeled as a "traitor" by Bay Area Gays because of his support of bath house closure.
May 4, 1984	Announcement of HTLV-III isolates had been made and Conant proposed a symposium to develop an AIDS prevention media project.
October 9, 1984	Conant's private fears are "We're all going to die."
October 31, 1984	Conant learns of a drug developed at the Pasteur Institute in Paris called HPA-23 which reactivates a person's immune system.
January, 1985	Transfusion AIDS cases started reaching the press. A nun who contracted AIDS from blood in 1983 had died. Conant was involved with the Borchelt family and told them of the T-cell tests at Stanford and the controversy about hepatitis core antibody testing. He told the Borchelts to get an attorney.
January 24, 1985	Conant resigns from the UC Med. Center AIDS Research Clinic.

March, 1985	Conant's National Kaposi's Sarcoma/AIDS Foundation was defunct for lack of interest. Conant's receptionist, Jim Sheridan, dies of pneumocystis.
April, 1985	Don Francis and Conant agree that gay men should take an antibody test and that negative results should not have sex with positive results..

APPENDIX F

6/1/91

CURRICULUM VITAE

MARCUS A. CONANT, M.D.

I. HISTORICAL INFORMATION

A. Personal

1. Name: Marcus Augustine Conant
2. Date of Birth: May 11, 1936
3. Place of Birth: Jacksonville, Florida

B. Education

1. Duke University, Durham, North Carolina 1954 to 1957, B.S. (Zoology)
2. Duke University College of Medicine, Durham, North Carolina, 1957 to 1961, M.D.
    - a. Hammersmith Hospital, London, England, 1960, Exchange Student, OB/Gyn
    - b. London Hospital, London, England, 1960, Exchange Student, Elective Fellowship in Biochemistry

3. Duke University Medical Center, Durham, North Carolina, 1961 to 1962, Internship (Internal Medicine)
4. School of Aerospace Medicine, San Antonio, Texas, 1962 (Flight Officer)
5. University of California Medical Center, San Francisco, California, 1964 to 1967, Resident (Dermatology)

C. Military Service

1. United States Air Force, Andrews AFB, Guam; Elgin AFB, Florida, 1962 to 1964, Flight Surgeon
2. United States Air Force Reserve Officer, Hamilton AFB, California, 1964 to 1967, Flight Surgeon

D. Academic Appointments

1. Clinical Instructor, University of California Medical Center, San Francisco, California, 1967 to 1970

2. Assistant Clinical Professor, University of California Medical Center, San Francisco, California, 1970 to 1975
3. Associate Clinical Professor, University of California Medical Center, San Francisco, California, 1975 to 1984
4. Chief, Dermatology Clinic, University of California Medical Center, San Francisco, California, 1967 to 1970
5. Chief, Dermatology Inpatient Service, University of California, San Francisco, California, 1967 to 1980
6. Co-Director, Kaposi's Sarcoma Clinic, University of California, San Francisco, California, 1981 to 1985
7. Director, AIDS Clinical Research Center, University of California, San Francisco, California, 1983 to 1985
8. Clinical Professor of Dermatology, University of California Medical Center, San Francisco, California, 1984 to present

E. Awards

1. Recipient of UCSF Student's Outstanding Teacher Award, 1970
2. Recipient of the Bay Area Physicians for Human Rights Annual Award for Outstanding Medical Service, 1983
3. Recipient of the 1987 Chancellors's Award for Outstanding Public Service, UCSF
4. Recipient of the 1989 Vanguard Public Foundation Criollos Award
5. Recipient, San Francisco AIDS Foundation Leadership Award, 1991
6. Recipient, Harvey Milk Lesbian & Gay Democratic Club Billy Krause Leadership Award, 1991

F. Consulting Appointments

1. Consultant, U.S. Public Health Service Hospital, San Francisco, California, 1967 to 1968
2. Consultant, San Francisco General Hospital, San Francisco, California, 1967 to 1970
3. Consultant to the Director of Hospitals and Clinics, University of California, Medical Center, San Francisco, California, on Peer Review and Hospital Utilization, 1975 to present

4. Fifth Congressional District AIDS Task Force, 1983 to 1987
5. San Francisco City Public Health Aids Task Force, 1983 to 1987
6. United States Representative to World Health Organization meeting on AIDS, 1983
7. Consultant, California Assembly Ways and Means AIDS Committee, 1985 to present

II. TEACHING: University of California Medical Center, San Francisco, California

A. Inpatient Management Course No. 160.02, 1970 to 1978

B. Undergraduate

   1. Sexually Transmitted Diseases Elective, 1984 to present

C. Residents

   1. Consultant Dermatology Clinic, University of California, San Francisco, California, 1981 to present

D. Continuing Education

   1. Chairman, Kaposi's Sarcoma Clinic Conference, semi-monthly meetings, 1981 to 1985
   2. Numerous lectures and presentations to UCSF-Sponsored Courses on AIDS, 1981 to present

E. Visiting Professor Lectures

   See CME attached

III. UNIVERSITY COMMITTEE SERVICE: University of California San Francisco, California

A. Departmental

   1. Dermatology Advisory Board, 1967 to 1978
   2. Member, Visible Tumor Conference, 1967 to 1986

B. School of Medicine

   1. Utilization Review Committee, 1970 to present
   2. Quality Assurance Executive Committee, 1972 to 1984

3. Member, Executive Medical Board, 1974 to 1976
4. Chairman, Utilization Committee, 1973 to 1977
5. Medical Audit Committee, 1977 to 1979
6. Medical Ethics Committee, 1977 to 1984
7. Dean's Ad Hoc AIDS Committee, 1983 to 1986

IV. PROFESSIONAL ACTIVITIES

A. Membership in Scientific Societies and Associations

1. Fellow, American Academy of Dermatology, 1967 to present
2. Member, San Francisco Dermatological Society, 1967 to present
3. Member, Association of Military Dermatologists, 1967 to present
4. Member, Pacific Dermatologic Association, 1967 to present
5. Member, Board of Directors, San Francisco P.S.R.O., 1976 to 1979
6. Member, American Dermatological Association, 1977 to present
7. Member, International AIDS Society, 1988 to present

B. Committee Posts Held in Scientific Societies and Associations

1. Member, Officer Selection Committee, San Francisco dermatological Society, 1977
2. Member, Medical Ethics Committee, San Francisco Dermatological Society, 1974 to 1977
3. Chairman, Confidentiality Committee, San Francisco P.S.R.O., 1976 to 1979
4. Member, American Academy of Dermatology Committee on Health Planning and Quality Assurance, 1977 to 1982
5. Chairman, Medical Monitoring Committee, San Francisco P.S.R.O., 1979 to 1981
6. Consultant to AIDS Task Force of the San Francisco Medical Society, 1984 to present
7. Program Planner, California Medical Association Annual Meeting, Section on Dermatology, Anaheim, California, February 10, 1985
8. Member, California Medical Association's Task Force on Sexually Transmitted Diseases, 1985 to 1987

9. Member, American Academy of Dermatology's Committee on Sexually Transmitted Diseases, 1988 to present
10. Chairman, American Academy of Dermatology Committee on AIDS, 1989 to present

C. Service to Editorial Boards and Journals

1. Reviewer, Archives of Dermatology, 1971 to present
2. Reviewer, Journal of Western Medicine,1971 to present
3. Reviewer, Journal of the American Academy of Dermatology, 1980 to present

V. COMMUNITY SERVICE

A. Committees

1. Arts Council of Eureka College, 1980 to 1982
2. President, Board of Directors of the National AIDS/KS Foundation, 1982 to 1984
3. Chair, California State Department of Health Services Task Force on AIDS, 1983 to 1988
4. Co-chair, Episcopal AIDS Project, 1985 to 1988
5. Board member of the Health Policy and Research Foundation, 1987 to 1990
6. Co-chair, State Department of Health Services AIDS Leadership Committee, 1988 to present
7. Member, Board of Directors, International Bioethics Institute, 1988 to present
8. Medical Director, National Public Health Project Against AIDS, 1987 to 1990
9. Honorary Board Member, AIDS Emergency Fund, 1989 to present

B. Lectures

Numerous lectures to civic groups in California and elsewhere on AIDS and Kaposi's sarcoma, 1982 to present

See CME Attached

PUBLICATIONS
MARCUS A. CONANT, M.D.

1. Epstein, W., Conant, M. and Krasnobrod, H.: Molluscum Contagiosum: Normal Virus Infected Epidermal Cell Kinetics. J. Invest. Derm., January 1966, 46:91-103.

2. Conant, M. and Lane, B.: Secondary Syphilis Misdiagnosed as Mononucleosis. California Med., December 1968, 109:462-64.

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4. Ostler, H., Conant, M. and Groundwater, J.: Lyell's Disease, the Stevens-Johnson Syndrome, and Exfoliative Dermatitis. Tr. Am. Acad. Opth. and Otol., November- December 1970, 74:1254-65.

5. Conant, M. and Wisenfeld, S.: Multiple Glomus Tumors of the Skin. Arch. Derm., May 1971, 103:481-84.

6. Conant, M., Reed, W., and Harville, D.: Lamellary Ichthyosis of the Newborn. Arch. Derm., July 1971, 105:394.

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8. Conant, M.: Progressive Therapy for Herpes Simplex. Medical Opinion, July 1974, 3(7):10.

9. Conant, M. and Layzer, R.: Neuralgia in Recurrent Herpes Simplex. Arch. Derm., October 1974, 31:233- 37.

10. Conant, M.: Cutaneous Virology: Recent Advances Relating to Dermatology. Cutis, March 1975, 14(3):339-43.

11. Chappler, R., Maibach, H., Conant, M. and Aly, R.: Mucocutaneous candidiasis or Mucocutaneous microbiosis? JAMA, 1978, 239:428-29.

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13. Ostler, H., Okumoto, M., Daniels, T. and Conant, M.: Drug-induced Cicatrization of the Conjunctiva. Immunologic Diseases of the Mucous Membranes. Monograph, 1980, Masson, USA, ed. by Dr. G. Richard O'Connor, 150-58.

14. Conant, M., Volberding, P., Fletcher, V., Lozada, F. and Silverman, S.: Squamous Cell Carcinoma in Sexual Partner of Kaposi's Sarcoma Patient. The Lancet, January 1982, 1(8266):286.

15. Lozada, F., Silverman, S. and Conant, M.: New Outbreak of Oral Tumors, Malignancies and Infectious Diseases Strikes Young Male Homosexuals: The Kaposi's Sarcoma Puzzle. CDS Journal, March 1982, 10:39-42.

16. Webb, P., Conant, M. and Maibach, H.: Perforation of the Colon in High-Dose Corticosteroid Therapy of Pemphigus. J. Amer. Acad. Derm., June 1982, 6(6):1040-41.

17. McNutt, N., Fletcher, V. and Conant, M.: Early Lesions of Kaposi's Sarcoma in Homosexual Men: An Ultrastructural Comparison with Other Vascular Proliferations in Skin. Am. J. Path., 1983, 111(1):62-77.

18. Volberding, P., Gottlieb, M., Rothman, J., Rudnick, S., Conant, M., Deresin, M., Weinstein, W. and Groupman, J.: Therapy of Kaposi's Sarcoma (KS) in Acquired Immune Deficiency (AIDS) with a -2 Recombinant Interferon (IFN). Amer. Soc. Clin. Oncology Proc., 1983, 2:C- 206.

19. Ammann, A., Abrams, D., Conant, M., Chudwin, D., Cowan, C., Volberding, P., Lewis, B. and Casavant, C.: Acquired Immune Dysfunction in Homosexual Men: Immunologic Profiles. Clin. Immunol. Immunopath., 1983, 27:315-25.

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21. Colombe, B., Conant, M., Volberding, P. and Garovoy, M.: Susceptibility of Kaposi's Sarcoma and HLA BW44. Clin. Res., 1983, 31:340.

22. Groupman, J., Gottlieb, M., Goodman, J., Mitsuyasu, R., Conant, M., Prince, H., Fahay, J., Derezin, P., Rothman, J., Weinstein, W., Rudnick, S. and Volberding, P.: Recombinant Alpha-2 Interferon Therapy of Kaposi's Sarcoma Associated with Acquired Immunodeficiency Syndrome. Clin. Res., 1983, 31:408A.

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27. Moss, A., Bocchetti, P., Gorman, M., Dritz, S., Conant, M., Abrams, D., Volberding, P. and Ziegler, J.: AIDS in the "Gay" Areas of San Francisco. *The Lancet*, April 1983, 1(8330):923-24.

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51. Conant, M.: Questions from Mental Health Practitioners About AIDS. What To Do About AIDS: Physicians and Mental Health Professionals Discuss the Issues, ed. Leon McKusick, University of California Press, 1986.

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61. Friedman-Kien, A., Eron, L., Conant, M., Growdon, W., Badiak, H., Bradstreet, P., Fedorczyk, D., Trout, J. and Plasse, T.: Natural Interferon Alfa for Treatment of Condylomata Acuminata. JAMA, January 22nd, 1988, 259:533-538.

62. Francis, D., Anderson, R., Gorman, M., Fenstersheib, M., Padian, N., Kizer, K. and Conant, M.: Targeting AIDS Prevention and Treatment Toward HIV-1-Infected Persons: The Concept of Early Intervention. JAMA, November 10th, 1989, 262:2572-2576.

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IN PRESS

1. Lozada-Nur, F., Silverman, S., Migliorati, C., Conant, M., Abrams, D., Volberding, P. and Greenspan, D.: The Diagnosis of AIDS and AIDS-Related Complex in the Dental Office: Findings in 171 Homosexual Males. Am. J. Oral Med.

2. Ziegler, J., Conant, M. and Lutzner, M.: Kaposi's Sarcoma. Fitzpatrick's Textbook of Dermatology.

3. Kiprov, D., Conant, M., Lippert, R., Pfaeffl, W., Miller, R. and Abrams, D.: Therapeutic Apheresis as a Treatment Modality in AIDS and AIDS-Related Conditions. AIDS: Principles, Practices, Politics, ed.

Corless, I. Pitman Lindemann, M. Hemisphere Publishing Corporation, Washington, D.C.

4. Gilson, I., Barnett, J., Conant, M., Laskin, O., Williams, J. and Jones, P.: Disseminated Ecthymatous Herpes Varicella-Zoster Virus Infection in Patients with Acquired Immunodeficiency Syndrome. J. Am. Acad. Dermatol.

5. Conant, M. and Reveille, J., HLA-B Antigens and Peripheral Arthritis in HIV-Associated Psoriasis. New Engl. J. of Med.

SUBMISSIONS

1. Friedlaender, M. and Conant, M.: Ocular Findings in Kaposi's Sarcoma. New Engl. J. Med.

2. Wara, D., Martin, N., Abrams, D., Conant, M., Volberding, P., Ziegler, J. and Ammann, A.: Letter to the Editor. New Engl. J. Med.

3. Coates, T., McKusick, L., Morin, S., Charles, K., Wiley, J., Stall, R. and Conant, M. Differences Among Gay Men in Desire for Antibody Testing for the Probable AIDS Virus.

4. Greenspan, D., Greenspan, J., Hearst, N., Pan, L., Conant, M., Abrams, D., Hollander, H., Levy, J.: Oral Hairy Leukoplakia: AIDS Retrovirus Status and the Development of AIDS.

5. Mertz, G., Eron, L., Kaufman, R., Goldberg, L., Raab, B., Conant, M., Mills, J., Kurtz, T., Davis, L. and the Acyclovir Study Group: Prolonged Continuous Versus Intermittent Oral Acyclovir Treatment in Normal Adults with Frequently Recurring Genital Herpes Simplex Virus Infection. Am. J. Med.

6. Kizer, K., Conant, M., Francis, D. and Fraziear, T.: AIDS Prevention and Treatment: A Framework for Local Planning. Western J. Med.

7. Blair, M., Drew, W. and Conant, M.: Letter to the Editors. JAMA.

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9. Reveille, J., Conant, M. and Duvic, M.: HIV-Associated Psoriasis, Psoriatic Arthritis and Reiter's Syndrome: A Disease Continuum?

ABSTRACT PRESENTATIONS

1. Drew, W., Conant, M., Illeman, M., Blair, P. and Miner, R.: Isoprinosine Treatment of Human Cytomegalovirus Infection.

Presented to the Conference on Antiviral Chemotherapy, San Francisco, California, November 1985.

2. Ammann, A., Palladino, M., Volberding, P., Abrams, D., Martin, N., Wert, R. and Conant, M.: Tumor Necrosis Factor Alpha and Beta in AIDS-Related Complex and Acquired Immunodeficiency Syndrome. Presented to the American Federation for Clinical Research, May 1986.

3. Greenspan, J., Greenspan, D., Lennette, E., Conant, M., De Souza, Y. and Freese, U.: Unique Expression of Epstein-Barr Virus in AIDS-Associated Oral Hairy Leukoplakia. Presented to the International Conference on Acquired Immunodeficiency Syndrome, Paris, France, June 23-25, 1986.

4. Conant, M., Illeman, M., Glasky, A., and Drew, L.: A Double Blind Placebo Controlled Trial of Isoprinosine (INPX) in Volunteers Shedding Cytomegalovirus (CMV) in Semen. Presented to the Second World Congress on Sexually Transmitted Diseases, Paris, France, June 25-28, 1986.

5. Drew, W., Conant, M., Illeman, M., Miner, R. and Glasky, A.: Efficacy of Isoprinosine (IPNX) Against Cytomegalovirus Infection in Homosexual Men. Presented to the 26th Annual ICAAC Meeting, New Orleans, Louisiana, 1986.

6. Sacks, S., Conant, M., Connor, J., Douglas, J. et al.: Recombinant Alpha-2 Interferon Gel in the Treatment of Recurrent Herpes Genitalis. Presented to the Seventh International Congress of Virology.

7. Khoury, E., Greenspan, J., Conant, M., Chaisson, R., Garovoy, M. and Colombe, B.: B Lymphocyte]AIDS
Specimen Bank. Presented to the Fourth International Conference on AIDS, Stockholm, Sweden, June 12-16, 1988.

10. Francis, D., Warman, M., Padian, N., Fenstersheid, M., Shaah, R., Frazier, T., Anderson, R. and Conant, M.: Targeting AIDS Prevention and Early Treatment to Seropositive Persons: The Concept of Prevention/Treatment Center. Presented to the Fourth International Conference on AIDS, Stockholm, Sweden, June 12-16, 1988.

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POSTER PRESENTATIONS

1. Conant, M.: AIDS: A New Clinical Entity. Sixteenth International Congress of Dermatology, Tokyo, Japan, 1982.
2. Conant, M.: Intralesional Velban for the Treatment of Kaposi's Sarcoma. American Academy of Dermatology, December 1985.
3. Conant, M.: Kaposi's Sarcoma Look-Alikes. American Academy of Dermatology, December, 1985.
4. Conant, M.: Condoms Block the Transmission of AIDS- Associated Retrovirus. American Academy of Dermatology, December 1986; Silver Medal Award.
5. Lebwohl, M., Gordon, M., Conant, M. et al.: Recombinant Alpha-2 Interferon Gel in the Treatment of Recurrent Herpes Genitalis. Society of Investigational Dermatology, San Diego, California, May 1987.
6. Conant, M.: AIDS Infection Control Guidelines for Your Practice. American Academy of Dermatology, December 1987; Bronze Medal Award.
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TESTIMONY BEFORE CONGRESSIONAL COMMITTEE ON HEALTH
Congressman Henry A. Waxman, Chairman

APPENDIX H

Tuesday, April 13, 1982

By: Marcus A. Conant, M.D., Co-Director Kaposi Sarcoma Clinic
University of California Medical Center, San Francisco

Exactly one year ago, in April of 1981, we learned from our colleagues at New York University of an outbreak of Kaposi's sarcoma and pneumocystis pneumonia among male homosexuals in New York City. Within twenty-four hours we had confirmed that there was a case of this malignancy in San Francisco. My colleagues and I at the University of California in San Francisco were already deeply committed to a number of other projects but there were many aspects of this new outbreak that caught our attention and captured our imagination.

First, the disease appeared to be spreading from a point source in New York suggesting either some infectious agent or some common environmental factor.

Kaposi's sarcoma, an extremely rare form of cancer, had previously been seen in Europe among elderly Italians and Jews, and in equatorial Africa among young blacks. This again suggests that the disease may be transmissible and argues that there are certain individuals who are genetically susceptible to acquiring this malignancy.

Kaposi's sarcoma and pneumocystis pneumonia are known to attack individuals whose immune systems are not functioning normally, leading immediately to the question, "what was cutting off the immune system in these homosexual men?"

A virus of the herpes family, cytomegalovirus to be specific, had been implicated as a possible cause of Kaposi's sarcoma in Africa ten years before, but work in this area had progressed slowly because of political unrest in Uganda. Could a new form of this virus have emerged in this country?

We were therefore presented with a challenging scientific dilemma. What is causing this cancer, why is it occurring at this point in history, and why is it occurring just in the homosexual community? While the answers to these questions are not immediately apparent, even individuals not familiar with the techniques of studying these questions, will immediately sense that with enough study which of course requires enough brain power and enough money, the answers to these questions could be found.

Recognizing the size of the gay community in San Francisco and the unique geographical configuration of our City, my colleagues and I decided to establish a multidisciplinary clinic to study some of the questions that I have just raised. The clinic began as a handful of investigators last summer and has grown progressively to encompass representation from virtually every medical discipline at our University. We have defined for ourselves four tasks.

The first is to teach clinicians on the West Coast to recognize these diseases so that early diagnosis can be made and early treatment can be initiated.

The second is to study the spread of the disease and to bring new research techniques to bear to investigate the factors that have cut off the immune mechanisms of these patients, the viruses that they have acquired and the genetic makeup of each victim.

The third is to treat the patients. A variety of therapies immediately come to mind. Should the patients be treated with conventional chemotherapy to destroy the cancer; should they be given experimental interferon in an effort to poison the virus; or should they be given new experimental drugs such as Thymazine in an effort to stimulate their lagging immune system? All of these questions are being explored.

The fourth task is to provide emotional support to these unfortunate individuals. To be twenty years old and told that even though you feel well, you have a malignancy that may be fatal, can be a devastating emotional experience. Prompt and compassionate expert psychiatric assistance is needed to help these patients deal with their illness.

Work has progressed rapidly. We now have twenty patients that we are treating and studying. In this short time we have identified two new diseases occurring in this population.

We have found squamous cell carcinoma of the tongue in the lover of one of the patients suffering from Kaposi's sarcoma, suggesting that Kaposi's sarcoma may not be the only malignancy that we will see in these immunosuppressed individuals.

We have identified a new opportunistic infection, Cryptospirodiosis, which was until recently unknown as an infection of man.

We have identified cytomegalovirus in all of these patients and are preparing a paper for publication which shows that the virus appears to be in the cancers.

Work is ongoing in the areas of immunology and genetics in an effort to identify who is at risk and what happens to the patient's immune system.

Cooperation from federal and local agencies has been exemplary.

We were contacted by Dr. Harold Joffee from Dr. Curran's office at the CDC. They have kept us appraised of the findings of the CDC, and we in turn have notified them of new cases and new discoveries. The CDC initiated a contact control study last fall in an effort to identify the factors responsible for this new outbreak. The physicians in San Francisco have worked closely with this federal agency in this endeavor and they have kept us posted of their findings on a regular basis.

Dr. Selma Dritz, the physician epidemiologist of the City of San Francisco, is an active member of our clinic and we work closely together in our efforts to identify cases and teach health care providers to recognize the disease.

The National Cancer Institute, an agency of the federal government, recognized the importance of this problem last summer and sponsored an international meeting in Bethesda in an effort to bring together experts from all over the world and focus their attention on this newly emerging health problem.

The response from the private sector has been equally encouraging. Physicians and scientists at our institution have given freely of their time and resources to study this problem. Since this disease was new and unexpected, no funds had been earmarked for these studies and all of the work done to date has been on a voluntary basis.

> The American Cancer Society stepped forward with a $50,000 grant last month to furnish us the resources to hire a Nurse Coordinator who is desperately needed to coordinate the examinations, X-rays, investigations and treatment of all of these patients.
>
> The press has been restrained and responsible in reporting the facts of this problem. They have avoided inappropriate sensationalism which could have led to unwarranted fear and panic.
>
> Religious groups have approached us to offer assistance with the emotional needs of the victims and their families.

What is needed from the federal government in the months to come? The answer is simple and straight forward. Money in the form of support for our research and a continued participation of federal agencies.

Sizeable funds in the range of hundreds of thousands of dollars will be needed to study these diseases and answer the questions that I have just posed. The federal government through the National Institutes of Health, is the traditional and indeed only agency capable of financing research of this magnitude and complexity. Private agencies are often willing to help but they have neither the resources to make a meaningful contribution or the expertise to decide which of a variety of proposals has merit and which will probably lead down a blind alley.

And what will all this money buy? If we can answer the questions that I have posed about these new diseases, it will greatly expand our knowledge of the human immune system and of the role of viruses as a cause of cancer. Answers to these questions should help us understand the immune response to common viral diseases and why some individuals suffer from recurrent yeast infections while others appear immune to this annoyance. If we can understand the role of cytomegalovirus in the production of Kaposi's sarcoma, we may begin to understand how herpes simplex virus is related to cervical cancer in women with recurrent genital herpes.

We have heard that the funds to the CDS may be cut. This would indeed be shortsighted economy. If anything, we should learn from our recent past that our civilization will continue to be visited with plagues and pestilence. In the last ten years we have seen an epidemic of Legionnaire's disease among old veterans, and then toxic shock syndrome among young menstruating women, and now Kaposi's sarcoma among young homosexual men. With each of these epidemics, the CDC has been there to alert the public, to coordinate the studies and to support the scientists in the field. If the federal government thinks that Kaposi's sarcoma is the last plague that we will see, we are naive. If we think that we won't need the CDC when the next one strikes, we are indeed foolhardy.

How should funds for Kaposi's sarcoma and pneumocystis pneumonia be earmarked? I respectfully suggest that the Kaposi's sarcoma task force of the CDC be separately funded and its activities expanded. Further epidemiological information on this disease is urgently needed. This is a national, not a local problem; and the national agency charged with epidemiological surveillance can get us the necessary answers in the quickest and most economical fashion. Congress should direct that a national cooperative study of this problem be funded through the National Cancer Institute. In this way we can husband the tremendous intellectual resources available at teaching hospitals in major cities and avoid unnecessary reduplication of studies. If we do get the money we can begin to answer these questions that I have raised, but I can assure you that if we don't get the money, we can't.

Thank you.

from: John L. Ziegler papers, folder: KS Patients, AIDS History Project Archives, Special Collections, UCSF Library

During the past year an epidemic of an unusually aggressive and disseminated form of Kaposi's sarcoma has been seen in young gay men. All of them show evidence of immunological deficiencies. Some of the patients have developed secondary opportunistic infections such as pneumocystis pneumonia, as well as unusually persistent infections with herpes simplex and candidiasis. There are now over eighty patients with this disease. Most are in New York and California but there are a few patients from other states and in Europe. Over seventeen percent of the patients have died. In addition, over eighty cases of pneumocystis pneumonia have been reported in young immunosuppressed homosexual men without Kaposi's sarcoma.

The clinical and histological appearances are atypical and may be easily overlooked. Long delays in diagnosis have occurred. Multiple small reddish-purple or hyperpigmented brown macules, papules, plaques or nodules ranging in size from 2mm up to 2cm may appear on the trunk and on the extremities as well as in the mouth. The early persistent lesions may have an appearance similar to bruises, insect bites, pigmented nevi or dermatofibromas. There is no itching or pain. Localized or generalized lymphadenopathy with tumor involvement may be present and quite striking. Some patients present with lymph node and visceral involvement without any skin manifestations at all. Asymptomatic gastrointestinal involvement often exists as demonstrated by endoscopy or colonoscopy which has been difficult to diagnose by routine x-ray contrast examinations.

Examples of the kinds of skin lesions seen are illustrated in Figures 1 and 2. The most striking feature is the pink to purple color. A lesion of the oral mucosa is seen in Figure 3.


Figure 1


Figure 2

The histopathology of the skin lesions is shown in Figure 4. Mistakes in clinical and histopathologic diagnosis have occurred and have included hemangiomas and eruptive proliferative angioendotheliomas. In some cases it has been necessary to send the biopsy specimens to several pathologists before the correct diagnosis was made. Typical vascular slits and extravasated red blood cells are seen in the skin biopsy, shown in Figure 4. The histopathologic diagnosis of the diseased lymph nodes may be subtle and difficult to ascertain unless the characteristic histology of Kaposi's sarcoma is carefully considered.


Figure 3

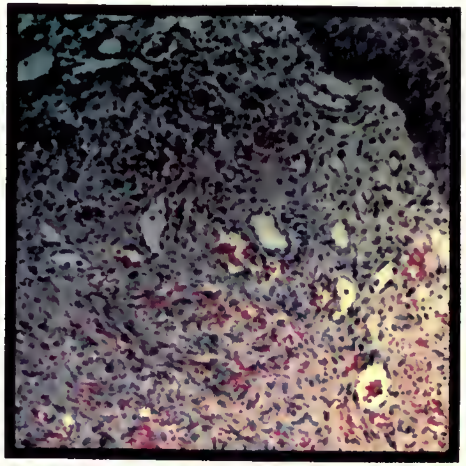
Figure 4

Doctor Bernard Ackerman in New York and Doctor Richard Segebiel in San Francisco have had extensive experience in reviewing these specimens and will be happy to examine material from suspected cases.

Please send slides to:

Dr. Bernard Ackerman
New York University
Medical Center
530 First Avenue
New York, New York 10016

Dr. Richard Segebiel
501 Health Science West
UCSF Medical Center
San Francisco, California 94143
Attn: Kaposi sarcoma study

The Dermatology Department at New York University (212-340-5314) or the University of California in San Francisco (415-666-2051) can refer you to specialists who have experience in evaluating this condition.

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CURRICULUM VITAE

Prepared: June 1992

NME: Andrew Robert Moss
crrent title: Professor in Residence, Dept. of Epidemiology and Biostatistic

UCATION:

62-66	London School of Economics, London, U.K.	1965	B.Sc., Upper Second Class Honors Economics and Statistics
		1966	M.Sc. (with distinction) Statistics
66-69	Stanford University	1968	Ph.D. qualifying examination in Mathematical Statistics
74-78	University of California Berkeley	1975	M.P.H. (Epidemiology)
		1978	Ph.D. (Epidemiology)

INCIPAL POSITIONS HELD:

69-72	Instructor in Statistics, California State Univ. at Hayward
73-78	Senior Statistician and Research Consultant San Francisco Unified School District
78-80	Assistant Director for Epidemiology, Northern California Cancer Program
81-91	Adjunct Assistant Professor, Adjunct Associate Professor, Department of Epidemiology and Biostatistics, UCSF
91-now	Professor in Residence, Department of Epidemiology and Biostatistics, UCSF

CILLARY POSITIONS HELD:

78-81	Lecturer in Epidemiology, Department of Epidemiology and International Health, UCSF
82-83	Associate Director, Mellon Program in Clinical Epidemiology, UCSF
83-now	Director, AIDS Epidemiology Group, San Francisco General Hospital
86-87	Visiting Senior Research Fellow, Department of Genito-Urinary Medicine, Middlesex Hospital Medical School, London
90-now	Head, Division of Epidemiology and Medicine at San Francisco General Hospital
92-93	Visiting Professor, Columbia University School of Public Health

HONORS AND AWARDS:

1964	Alyn Young Prize in Economics and Statistics, London School of Economics
1964-66	London University Scholarship in Statistics
1974-76	National Institute on Drug Abuse Predoctoral Fellowship, University of California, Berkeley
1976-77	National Institute of Mental Health Predoctoral Fellowship, University of California, Berkeley

MEMBERSHIPS IN PROFESSIONAL ORGANIZATIONS:

American Public Health Association, Society for Epidemiological Research AAAS;

PROFESSIONAL ACTIVITY (1986-NOW)

SERVICE TO PROFESSIONAL PUBLICATIONS

1986-1990	AIDS, An International Journal	Editorial board
1987-now	Journal of Acquired Immunodeficiency Syndromes	Editorial board
1989-1992	International Journal on Drug Policy	Editorial board
1991-now	Journal of Genitourinary Medicine(UK)	Editorial board

Occasional reviewer: New England Journal of Medicine, Science, Annals of Internal Medicine, Nature, Journal of Sexually Transmitted Diseases, British Journal of Addiction

OTHER PROFESSIONAL SERVICES

1983-89	San Francisco, Mayor's Advisory Group on AIDS	Member
1984-now	San Francisco Men's Health Study	Investigator
1986-87	McClellan Committee on HIV infection (Scotland)	Consultant
1987	Taylor Cttee on AIDS & Hlth Service Needs (Scotland)	Consultant
1988-90	California AIDS Leadership Commitee, Subcommittee on AIDS and Intravenous Drug use	Member
1988-now	Nat'l. Institute of Allergy & Infectious Diseases AIDS and Related Research Study Section No.2	Member
1988-89	New York City Department of Health, Expert Panel on HIV seroprevalence estimates and AIDS case projection methodologies.	Member
1989-now	Societal Institute of the Mathematical Sciences (SIMS) AIDS Project Advisory Committee	Member
1989	Dutch AIDS Cohort Studies	Site Visitor
1991	Food and Drug Administration Antiviral Committee Advisory Meeting on Surrogate Markers	Invited Spea
1992	FDA Antiviral Committee	Consultant

Occasional reviewer, Robert Wood Johnson Foundation, American Foundation for AIDS Research, Medical Research Council of Great Britain, Scottish Home and Health Department

WORLD HEALTH ORGANIZATION CONSULTING:

1989-90	Global Program on AIDS: Consultant on AIDS and Intravenous Drug Use: (a) On separation of function between GPA and MNH; (b) On HIV serology in surveillance of intravenous drug users
1989-90	Global Program on AIDS: Consultant on HIV staging and prognosis. Draft report on HIV staging
1990	Panamerican Health Organization: Consultant on HIV and intravenous drug use in Latin America
1990	Global Program on AIDS: Draft Guidelines on estimating number of drug users and HIV infection in drug users.

SCIENTIFIC AND PROFESSIONAL MEETINGS AND WORKSHOPS ATTENDED (1986-NOW):

INTERNATIONAL

Second International Conference on AIDS 1986	(Paper)
New York State International Conference on AIDS and Public Policy 1986	(Discussant)
Edinburgh International Workshop on AIDS & Intravenous Drug Use, 1986	(Panellist)
European Community Workshop on Epidemiology of HIV Infection in Europe, 1986	(Discussant)
National Institute of Allergy and Infectious Diseases Workshop on Pathogenesis of AIDS, 1986	(Invited speaker)
Fourth International Conference on AIDS, 1988	(Paper)
First Abbot HTLV-1 Technical Conference, 1988	(Invited speaker)
Fifth International Conference on AIDS, 1989	(Invited speaker)
Federation of Societies in Experimental Biology Annual Meeting 1989	(Invited speaker)
WHO Informal Consultation on Staging Systems for HIV Infection 1989	(Invited speaker)
WHO Consultation on Primary Prevention of Drug Abuse 1989	(Invited speaker)
Welcome Foundation International Seminar on Aspects of HIV Management in Injecting Drug Users, Madrid 1989	(Vice chair)
PAHO Conference on HIV & Intravenous Drug Use in Latin America, Buenos Aires 1990	(Invited spepaker)
Sixth International Conference on AIDS 1990	(Local org. cttee)
First International Conference on the Reduction of Drug-related Harm, Liverpool, 1990	(Invited speaker)
Seventh International Conference on AIDS 1991	
Psychosocial Repercussions of AIDS -- Sao Paulo 1991	(Invited speaker)
National Research Council of Italy, 1992 International workshop on Models and Methods of epidemiologic research in HIV infection	(Panel chair)

NATIONAL AND REGIONAL

New Jersey Meeting on AIDS & Intravenous Drug Use, 1986	(Invited speaker)
East Anglia Regional Workshop on AIDS (United Kingdom), 1986	(Invited speaker)

Medical Society for the Study of Venereal Diseases (United Kingdom) annual meeting, 1986	(Plenary speaker)
National Institute on Drug Abuse Technical review mtg. on natural history studies of HIV infection, 1987	(Invited speaker)
National Institute on Drug Abuse panel on five-year strategy development, 1988	(Panellist)
Comprehensive Care of the AIDS Patient 1988,89 workshops	(Invited speaker)
National Planning Meeting on AIDS modelling and Epidemiology, Washington DC 1988	(Panellist)
Third Montefiore Symposium on AIDS, 1988	(Invited speaker)
Santa Fe Institute Workshop on Modelling the Interaction of HIV with the immune system, 1988	(Invited speaker)
UCSF Workshop on Clinical and Epidemiological Aspects of the Polymerase Chain Reaction 1988	(Co-chair)
California Thoracic Society Advanced Course 1989	(Faculty)
Institute of Medicine Meeting on Surrogate Endpoints in Evaluating the Effectiveness of Drugs Against HIV 1989	(Invited speaker)
AIDS Clinical Trials; Symposium on Methodological issues, (ACTG)	(Invited speaker)
UCSF/OPRR conference: The Use of Human Subjects in research: AIDS as a model of complexity Feb 1991	(Invited speaker)
NIAID Meeting on Trends in Opportunistic Infections Associated with AIDS, April 1991	(Invited speaker)
Clinical and Molecular Epidemiology of Infectious Diseases, Napa 1992	(Discussant)

OTHER LECTURES, PRESENTATIONS, ETC.

1986-91 Extensive presentations in Health Departments, Community hospital and to community groups on AIDS; AIDS County Consortium Grand Rounds, Dept. of Public Health Grand Rounds, Invited Speaker New York State Health Dept., California Legislative analysts, Rand Corporation, California State Health Dept., etc. Presentations to French Senate, Tokyo Metropolitan Health Dept, Swedish MPs, Health Minister of North Rhine-Westfalia, House of Lord Select Committee on Science & Technology, Editor of Pravda, Annenberg Center, Bundesartzekammer (FRG), etc.Testimony to California Assembly Health Subcommittee on funding of AIDS research, 1986, Assembly Subcommittee on Education, 1988 Testimony to President's Advisory Committee on AIDS, 1988, 1989

UNIVERSITY SERVICE:

SCHOOL OF MEDICINE

Tenure committees for Dpt. of Medicine (1987,1990), School of Nursing (198
AIDS Research Coordinating Committee, 1987-now
Search committee, Department of Laboratory Medicine, 1988
Search committee, Department of Medicine SFGH (statistician) 1990
Search committee, Department of Psychiatry, 1991
Search committee, Department of Medicine, Division of General internal medi at SFGH (research director) 1992
Organizing committee IV International AIDS Conference 1990

mber, Committee on Core Curriculum for Clinical Research, 1990-now
mber, SFGH Department of Medicine Research-Community Advisory
Group on AIDS, 1989-now
mber, Committee on Merits and Promotions, Department of Epidemiology
and Biostatistics, 1990-now
ad, Division of Epidemiology and Medicine at SFGH, Department of
Epidemiology and Biostatistics, 1990-now
ecutive Committee, Center for AIDS Research 1990-now

HER
nure committee, school of nursing 1987
fection control consultant, Systemwide Task Force on AIDS, 1987

LIC SERVICE:

stimony to Office of Technology Assessment evaluation of Federal response t AIDS 1987; to various state and local gov't. committees 1983-1989; tensive speaking to local and community groups on public hlth. aspects AIDS including extent of epidemic, closing bathhouses, screening tests, needle exchanges (1989), on various aspects of AIDS and intravenous ug use and on homelessness 1986-91, etc.

EARCH ACTIVITY:

RESEARCH AWARDS

182-84	Principal Investigator, TESTICULAR CANCER AND PRENATAL DES EXPOSURE. R01 CA34188, National Cancer Institute.
183-84	Principal Investigator, A CASE-CONTROL STUDY OF ACQUIRED IMMUNE DEFICIENCY SYNDROME DISEASES. Universitywide Task Force on AIDS.
183-86	Principal Investigator, OCCUPATIONAL EXPOSURE IN ADULT GLIOMA PATIENTS. RO1 OH01557, National Institute of Occupational Safety and Health.
183-86	Co-investigator and principal investigator, epidemiology component, STUDIES OF ACQUIRED IMMUNE DEFICIENCY SYNDROME. P. Volberding, Principal Investigator. National Cancer Institute. U01-CA/AI-3420,
183-84	Principal Investigator, A CASE-CONTROL STUDY OF MEN AT HIGH RISK OF AIDS. State of California Universitywide Program on AIDS.
184-91	Principal Investigator, A FOLLOWUP STUDY OF MEN AT HIGH RISK OF AIDS. State of California Universitywide Program on AIDS.
187-now	Principal Investigator, HTLV-III INFECTION IN SAN FRANCISCO I.V. DRUG USERS. National Institute on Drug Abuse. RO1 DA04363

1988-now Principal Investigator, PROSPECTIVE STUDY OF INTRAVENOUS DRUG USERS WITH HTLV-III INFECTION. State of California Universitywide Program on AIDS.

1990-91 Principal Investigator, GENDER AND ETHNIC DIFFERENCES IN SURROGATE MARKERS FOR AIDS CLINICAL TRIALS. National Institute on Drug Abuse R01 DA07067-01

1991-now Principal Investigator, HIV AND DRUG USE AMONG THE HOMELESS IN SAN FRANCISCO. National Institute on Drug Abuse RO1 DA04363-05

1991-now Co-investigator and director, epidemiology and biostatistics core, SEXUALLY TRANSMITTED DISEASES COORDINATING RESEARCH CENTER; J. Schachter, Principal investigator. National Institute on Allergy and Infectious Diseases AI31499

1991-now Co-investigator and Principal Investigator at SFGH, THE MEN'S HEALTH STUDY. Warren Winkelstein, Principal investigator. National Institute on Allergy and Infectious Diseases AI82515

1991-now Co-investigator and director epidemiology and biostatistics core, CENTER FOR AIDS RESEARCH, P. Volberding principal investiga National Institute on Allergy and Infectious Diseases

ORIGINAL ARTICLES

1982 Haines AP, <u>Moss AR</u>, Whittemore A, and Quivey J. A case-control study of pancreatic carcinoma. Cancer Res and Clin Oncol; 103: 93-97.

✓ 1984 <u>Moss AR</u>, McCallum G, Volberding P, Bacchetti P and Dritz S. Mortality associated with mode of presentation in the acquired immunodeficiency syndrome. JNCI; 73: 1281-1284.

✓ 1985 <u>Moss AR</u>, Bacchetti P, Osmond D. Incidence of the acquired immunodeficiency syndrome in San Francisco. J Infect Dis; 152: 152-161.

1985 <u>Moss AR</u>. Occupational exposure and brain tumors. J Toxicol and Environ Health; 16: 703-711.

✓ 1986 Stites D, Casavant C, McHugh T, <u>Moss AR</u>, et al. Flow cytometric analysis of lymphocyte phenotypes in AIDS using monoclonal antibodies and simultaneous dual immunofluorescence. Clin Immunol Immunopathol; 38: 161-177.

✓ 1986 Coleman DL, Luce JM, Wilber JC, Ferrer J, <u>Moss AR</u>, et al. Presence of antibody to the retrovirus associated with the acquired immunodeficiency syndrome. Arch Intern Med; 146: 713-715.

✓ 1986 <u>Moss AR</u>, Osmond D, Bacchetti P, Gerberding J, et al. Risk of seroconversion for the acquired immunodeficiency syndrome

(AIDS) in San Francisco health workers. J Occup Med; 28: 819-822.

986 Moss AR, Osmond D, Bacchetti P, Torti FM, and Gurgin V. Hormonal risk factors in testicular cancer: A case-control study. Am J Epidemiol; 124: 39-52.

987 Chaisson RE, Moss AR, Onishi R, Osmond D, and Carlson JR. Human immunodeficiency virus infection in heterosexual intravenous drug users in San Francisco. Am J Public Health; 77: 169-172.

987 Moss AR. AIDS and IV drug use: The real heterosexual epidemic Br Med J 294: 389-390.

987 Moss AR, Osmond D, Bacchetti P, Chermann J-C, Barre-Sinoussi F, et al. Risk factors for AIDS and HIV seropositivity in homosexual men. Am J Epidemiol; 125: 1035-1047.

987 Lee PR, and Moss AR. A second opinion. AIDS prevention: is cost-benefit analysis appropriate? Health Policy 8: 193-196.

987 Hardell L, Moss AR, Osmond D and Volberding P. Exposure to hair dyes and polychlorinated dibenzo-p-dioxins in AIDS patients with Kaposi' sarcoma: an epidemiological investigator. Cancer Det Prev Supp 1: 567-570.

987 Moss AR. Epidemiology of AIDS in developed countries. Brit Med Bull, 44:1; 56-67.

987 Gerberding J, Bryant-LeBlanc C, Nelson K, Moss AR et al. Risk of transmitting the human immunodeficiency virus, cytomegalovirus and hepatitis B to health care workers exposed to patients with AIDS and AIDS-related conditions. J Infect Dis; 156: 1-8.

988 Moss AR, Bacchetti P, Osmond D, Krampf W, Chaisson RE, Stites D, Wilber J, Allain J-P, Carlson J. Seropositivity for HIV and the development of AIDS or AIDS related condition: three year followup of the San Francisco General Hospital cohort. Br Med J; 296: 745-750.

988 Osmond D, Bacchetti P, Chaisson RE, Kelly T, Stempel R, Carlson J and Moss AR. Time of exposure and risk of HIV infection in homosexual partners of men with AIDS. Am J Public Health; 78: 944-948.

988 Bacchetti P, Osmond D, Chaisson R, Dritz S, Swig L and Moss AR. Patterns of survival in the acquired immune deficiency syndrome (AIDS). J Infect Dis 157: 1044-1047.

1988 Moss AR. Predicting who will progress to AIDS: at least four laboratory predictors available. Br Med J; 297: 1067-1068.

1988 Moss AR, and Chaisson RE. AIDS and intravenous drug use in San Francisco. AIDS and Public Policy August 1988.

✓1988 Krowka JF, Stites D, Moss AR et al. Interrelationship of lymphocyte subset values, human immunodeficiency virus antibodies and HIV antigen levels of homosexual males in San Francisco. Diag and Clin Immunol 5; 381-387.

✓1989 Chaisson RE, Bacchetti P, Osmond P, Brodie B, Sande M and Moss AR. Cocaine use and HIV infection in intravenous drug users in San Francisco. JAMA: 261; 561-565.

1989 Krowka JF, Stites D, Jain S, Steimer KS, George-Nascimento C, Gyenes A, Barr P, Hollander H, Moss AR et al. Lymphocyte proliferative responses to human immunodeficiency virus antigens in vivo. J Clin Invest: 83; 1198-1203

1989 Osmond D, and Moss AR. The prevalence of HIV infection in the United States: a reappraisal of the Public Health Service estimate. AIDS Clin Rev: 1; 1-17.

1989 Moss AR, Bacchetti P. Natural history of HIV infection. AIDS;3:55-6

1989 Bacchetti P and Moss AR. Incubation period of AIDS in San Francisco Nature; 338: 251-253.

1989 Jacobson M, Abrams D, Volberding P, Bacchetti P, Wilber J, Chaisson RE, Crowe S, Howard W, Moss AR. Serum Beta-2 microglobulin decreases in patients with AIDS or ARC treated with azidothymidine J Infect Dis; 159: 1029-1036.

1989 Stites D, Moss AR, Bacchetti P, Osmond D, et al. Lymphocyte subset analysis to predict progression to AIDS in a cohort of homosexual men. Clin Immuno Immunopathol; 52: 96-103.

1990 Lemp GF, Payne SF, Rutherford GW, Hessol NH, Winkelstein W, Wiley J Moss AR et al. Projections of AIDS morbidity and mortality in San Francisco. JAMA; 2263: 1497-1501.

1990 Haas J, Bolan G, Larsen SA, Clement MJ, Bacchetti P, Moss AR. Sensitivity of treponemal tests for detecting prior treated syphilis during Human Immunodeficiency Virus infection. J Infect Dis; 162: 862-866.

1990 Moss AR. Laboratory markers as potential surrogates for clinical outcomes in AIDS trials. JAIDS; 3 (Suppl 2): S69-S71.

1991 Jacobson M, Bacchetti P, Kolokathis A, Chaisson RE, Szabo S, Polsky B, Vailanis GT, Mildvan D, Abrams D, Wilber J, Winger E, Hendricksen C, Moss AR. Surrogate markers for survival in patients with AIDS and with zidovudine. Br Med J; 302: 73-78.

✓1991 Feigal DW, Katz M, Greenspan D, Westenhouse J, Winkelstein W, Lang W, Samuel M, Buchbinder S, Hessol N, Lifson A, Rutherford G, Moss AR, Osmond D, Shiboski S, Overby G, Greenspan JS. The prevalence of oral lesions in HIV-infected homosexual men: three San Francisco cohorts. AIDS; 5: 519-525.

.991 Lang W, Osmond D, Samuel M, Krampf W, Moss AR, Winkelstein WW. Population-based estimates of zidovudine and aerosol pentamidine use in San Francisco: 1987-90. JAIDS; 4:713-716.

.991 Feigal EG, Bacchetti P, Murphy E, McGrath MS, Moss AR. HTLV-I/II and HIV co-infection in San Francisco intravenous drug users. J Infect Dis; 164: 36-42.

1991 Moulton JM, Stempel R, Bacchetti P, Temoshok L and Moss AR. Results of a one-year longitudinal study of HIV antibody test notification from the San Francisco General Hospital cohort. JAIDS; 4: 787-79.

1991 Osmond D, Shiboski S, Bacchetti P, Winger E, Moss AR. Immune activation markers and AIDS prognosis. AIDS; 5: 505-12.

1991 Crowe SM, Elbeik T, Ulrich P, Mills J, Moss AR. Lack of evidence of HIV infection in seronegative individuals at very high risk of infection. J Med Virol, in press.

1991 Lee T, El-Amad Z, Reis M, Adams M, Donegan EA, O'Brien T, Moss AR Busch MP. Low viral load does not explain reports of "silent" HIV infection. AIDS, in press.

1992 Wolfe H, Vranizan K, Gorter R, Keffelew A, Moss AR. Crack use and risk for HIV infection among San Francisco IV drug users. Journal of Sexually Transmitted Diseases 19, 111-115.

1992 Bacchetti P, Moss AR, Andrews JC, Jacobson M. Early predictors of survival in symptomatic HIV-infected persons treated with zidovudine. JAIDS, in press.

1992 Moss AR, Vranizan K. Charting the epidemic: IV drug use and HIV infection in San Francisco 1985-90. Brit J Addiction, in press.

1992 Katz M, Greenspan D, Westenhouse J, Hessol H, Buchbinder SP, Lifson A, Shiboski S, Osmond D, Moss AR et al. Progression to AIDS in HIV-infected homosexual and bisexual men with hairy leukoplakia and oral candidiasis: results from three San Francisco cohorts. AIDS, in press.

1992 Gorter RW, Vranizan K, Osmond D, Moss AR. Sex and ethnicity differences in response to HIV infection in intravenous drug users. AIDS, in press.

1992 Osmond D, Charlebois E, Sheppard HW, Page-Bodkin K, Winkelstein W, Moss AR, Reingold A. A comparison of risk factors for hepatitis C and hepatitis B viral infection in homosexual men. J Infect Dis, in press.

SUBMITTED FOR PUBLICATION

Bocellari AA, Dilley JW, Yingling C, Tauber M, Chambers D and Moss AR. The role of immune dysfunction in the neuropsychological and neurophysiological performance of HIV positive and negative homosexual men.

Dilley JW, Bocellari AA, Yingling CD, Chambers DB, Tauber MA, Osmond D, Moss AR. Early findings on the role of immune dysfunction in the performance of HIV positive intravenous drug users on neuropsychological and neurophysiological measures.

Moss AR, Vranizan K, Bacchetti P, Gorter R et al. Seroconversion for HIV in intravenous drug users in San Francisco 1985-90.

Lifson AR, Vranizan K, Busch M, Back A, Drew WL, Osmond D, Miner D, Bolan G, Bacchetti P, Moss AR. Serologic Evidence of Syphilis, Hepatitis B and cytomegalovirus in HIV-positive and HIV-negative intravenous drug users.

Lang W, Osmond D, Moss AR et al. Population-based estimates of AZT a pentamidine use 1989-90

Stempel R, Gorman M, Shiboski S, Moss AR. Behavioral changes in homosexual men: the San Francisco General Hospital Cohort 1983-92.
Miranda J,Hargreaves W, Moss AR, Wolfe H, Schoenfeld E. Prevalence of HIV infection among psychiatric inpatients.

OTHER PUBLICATIONS

1972 Moss AR. High School Revolutionaries, in The New Students. New York, Dutton.

1974 Cisin I and Moss AR. New Drug Use 1973. Reports of the Survey Research Center, George Washington University.

1975 Cisin I and Moss AR. Estimating drug use from sample surveys. Reports of the Survey Research Center, George Washington Univ.

1976 Moss AR. A note on transition probabilities and the concept of addiction. Drinking and Drug Practices Surveyor.

1977 Moss AR. The politics of methadone. In Rock P, ed. Drugs and Politics. Princeton, Horizon/Society.

1980 Cohen JB, Moss AR, Klinstein R. The epidemiology of hypertension. In Fair RG, ed. Proceedings of the Harvard Symposium in Ocular and Systemic Disease. St. Louis: American Society of Optometry.

1983 Moss AR, Bacchetti P, Gorman M, Dritz S, Conant M, Abrams D, Volberding P, Ziegler J. AIDS in the "gay" areas of San Francisco (letter). Lancet April: 923-924.

984 Conant M, Moss AR, Dritz S, and Schild D. Changing pattersn of sexually transmitted diseases over the past 15 years. In Friedman-Kein A and Laubenstein L, eds. AIDS the Epidemic of Kaposi's sarcoma and Opportunistic Infections. New York: Mason Publishing, Inc.

985 Moss AR, Abrams D, Conant M, Volberding P. Incidence of the Acquired Immune Deficiency Syndrome (AIDS) in San Francisco. In J.M. Vaeth, ed. Front. Radiat. Ther. Onc. Vol. 19. New York: S. Karger.

985 Moss AR. What proportion of HTLV-III antibody positives will proceed to AIDS (letter). Lancet July: 223-234.

986 Osmond D, Chaisson RE, Moss AR, Bacchetti P, Krampf W. Lymphadenopathy in asymptomatic patients seropositive for HIV (letter). N Engl J Med 317: 246.

987 Chaisson RE, Osmond D, Moss AR, Feldman HW, Bernacki P. HIV, bleach, and needle sharing (letter). Lancet 1: 1430.

988 Bacchetti P, Osmond D, Chaisson RE, and Moss AR. Survival with AIDS in New York (letter). N Engl J Med 318: 1464.

989 Moss AR. Coercive and voluntary policies in the AIDS epidemic. In Koenig B and Juengst ET, eds. The Meaning of AIDS: New York: Praeger Inc.

989 Coutinho R, Van Griensvan G and Moss AR. Effects of preventive efforts among homosexual men, in Adler M et al, eds AIDS 1989, Current Science, London.

989 Moss AR, Mills J. Laboratory predictors of progression to AIDS. Paper prepared for the WHO informal consultation on staging criteria for HIV infection. WHO/GPA, Geneva.

990 Moss AR. Introduction to the clinical epidemiology of AIDS. In A.G. Dalgleish and R. Weiss, Eds, AIDS and the New Viruses. Harcourt Brace Jovanich, London.

990 Moss AR. Prognosis in HIV Infection. WHO/GPA, Geneva.

990 Moss AR. Control of HIV infection in intravenous drug users in San Francisco. In Strang J and Stimson J, AIDS and Drug Misuse London.

990 Selwyn P, Moss AR. Draft Guidelines for National Programs to Assess the Extent of Drug Injection and HIV Infection in Intravenous Drug Users. WHO/GPA, Geneva.

991 Wodak A, Moss AR. AIDS in intravenous drug users. In Adler M et al, eds. AIDS 1990. Current Science, London, 1991.

MOST IMPORTANT RECENT PUBLICATIONS

1988 Moss AR, Bacchetti P, Osmond D, Krampf W, Chaisson RE, Stites D, Wilber J, Allain J-P, Carlson J. Seropositivity for HIV and the development of AIDS or AIDS related condition: three year followup of the San Francisco General Hospital cohort. Br Med J; 296: 745-750.

This is the standard reference paper on prognosis in HIV infection, written by me on the basis of the first three years of followup of our gay mens' cohort.

1989 Chaisson RE, Bacchetti P, Osmond P, Brodie B, Sande M and Moss AR. Cocaine use and HIV infection in intravenous drug users in San Francisco. JAMA; 261: 561-565.

This paper showed the importance of cocaine use in HIV infection in drug users. It was written by Dick Chaisson who was my fellow on the the basis of my NIDA-funded study of HIV serology in drug users. I am the senior author.

1989 Osmond D, and Moss AR. The prevalence of HIV infection in the United States: a reappraisal of the Public Health Service estimate. AIDS Clin Rev: 1: 1-17.

This is a collaborative paper with Dennis Osmond who has worked with me for many years: it was the basis of the downscaling of all official estimates of the number of HIV infected people in the United States in 1989.

1989 Bacchetti P and Moss AR. Incubation period of AIDS in San Francisco. Nature; 338: 251-253.

This is the definitive paper on incubation period in HIV infection, written in collaboration with Peter Bacchetti, the longtime statistician in our group.

1989 Jacobson M, Abrams D, Volberding P, Bacchetti P, Wilber J, Chaisson RE, Crowe S, Howard W, Moss AR. Serum Beta-2 microglobulin decreases in patients with AIDS or ARC treated with azidothymidin J Infect Dis; 159: 1029-1036.

This is the first paper on surrogate markers for HIV infection in AZT trials. It is an outgrowth of my work on prediction in epidemiological studies and was organized by me as collaboration between my group and investigators in the AIDS clinic. I am the senior author.

SEARCH IN PROGRESS:

We continue to study HIV infection in cohorts of homosexual men and travenous drug users. In a collaboration with The San Francisco Men's Health udy (W. Winkelstein PI), the San Francisco General Hospital cohort has been funded by NIAID for a four-year period to explore the changing clinical ectrum in AIDS. In addition, the joint cohorts will undertake a wide spectru collaborative laboratory research in AIDS virology.

In prospective studies in intravenous drug users we are examining ifferences in response to HIV in men and women, and in different ethnic oups. We will also examine the effects of HTLV-II in this population. In llaboration with Dr Constance Wofsy and others, the female drug users in is cohort will become part of a new cohort of HIV-infected women which will followed at SFGH.

In a new program we are extending our serological studies of intravenous ug users to the homeless in San Francisco. We have received three-year nding from the National Institute on Drug Abuse to examine HIV, TB, mental lness and syphilis in the homeless.

In a collaborative project with faculty of the AIDS Clinic we have tended the prognostic studies of laboratory markers in HIV infection ich were based on the San Francisco General Hospital cohort to clinical ials of antiretroviral drugs, the objective being to identify surrogate rkers for survival for early intervention trials.

The Division has become the epidemiological and statistical center for e coordinating center for research in sexually transmitted diseases which s recently been funded at SFGH with Dr J. Schachter as principal investigato anticipate an increasing research committment in this area.

Finally the Division has also become the epidemiological and statistical nter for the Center for AIDS Research, Paul Volberding principal vestigator, leading to a range of collaborations in clinical trials and her projects under way with CFAR investigators.

ACHING:

ARRATIVE

During 1986-91 the epidemiology faculty at SFGH maintained a largely informal program of consultation, participation in ongoing teaching activities at SFGH, and supervision of research by students and fellows. Six predoctoral students and three fellows have completed projects under my supervision since 1986, usually in collaboration with our ongoing studies of the epidemiology of HIV and AIDS in homosexual men and intravenous drug users. All the postdoctoral projects have resulted in papers published or submitted.

In 1991 the AIDS Epidemiology Group at SFGH took on formal status as the Division of Epidemiology and Medicine at SFGH and began the development of a formal teaching program in collaboration with the Department of Medicine. This program is aimed at meeting the clinical research training needs of fellows in the Department of Medicine and also of other interested departments.

In 1991 in collaboration with other faculty members in the new division I established a monthly research seminar, a weekly research clini which provides feedback on design and analysis for fellows' research projects, and an introduction to data analysis organized around teaching t use of statistical software packages (EPISTAT and EGRET).

At present we are exploring the relationship of our methodlogical teaching at SFGH with the proposed curriculum in research for all Department of Medicine fellows at UCSF.

In 1991 three fellows are working on projects with me: two Robert Wood Johnson clinical scholars (one in nursing) and a Fogerty International Scholar from Brazil referred from the program at Berkeley. The Division proposes to explore a formal fellowship program for 1991-92 or later. One medical student is also working in the group.

INFORMAL TEACHING

1987-90 TEACHING

1987-90	AIDS program research conference, journal clubs, (Discussions with house staff, graduate students)	2 hrs/wk
1987-90	Lectures in courses, SFGH grand rounds Clinical Epidemiology rounds, etc.	1 hr/wk
1987-now	Supervision of medical students projects	1 hr/wk
1987-now	Supervision of fellows projects	4 hrs/wk

1990-91 TEACHING

1990-91	Division of Epidemiology and Medicine Research Seminar at SFGH	2 hrs/mo
1990-91	Division of Epidemiology and Medicine Clinic at SFGH	1 hr/wk
	Ward conferences, rounds, seminars, lectures	2 hrs/wk
	Supervision of fellows and medical students	4 hrs/wk

1991-92 TEACHING

1990-91	Division of Epidemiology and Medicine Research Seminar at SFGH	2 hrs/mo
1990-91	Division of Epidemiology and Medicine Clinic at SFGH	1 hr/wk
1990-91	Division of Epidemiology and Medicine introductory course in data analysis at SFGH	1 hr/wk
	Ward conferences, rounds, seminars lectures	1 hr/wk
	Supervision of fellows and medical students	4 hrs/wk

REDOCTORAL STUDENTS SUPERVISED 1986-91

985-86	Lucille Johnston (Pharm D) (Beta-2 microglobulin and symptomatic CMV infection)
987-88	Robert Stempel (Dr. Ph) (Behavior change in HIV-infected homosexual men)
987	Charles Theuer (Med II) (Tuberculosis and HIV infection)
987	Jonathan Sheldon (Middlesex Hospital Medical School,London) (Clinical staging for HIV infection)
988-9	Katherine Kocurek (Med IV) (Progression to AIDS in HIV-infected homosexual men)
988-9	Sarah Hawkes (University College Medical School, London) (Health status of HIV infected intravenous drug users)
988-now	Dennis Osmond (Ph.D.) (Hepatitis C in homosexual men and intravenous drug users)
990	Michael Seefried (Univ. of Heidelberg Medical School) (HTLV1/2 and HIV coinfection in intravenous drug users)
991-now	Mark Sigueiros (Med II) (Referral success in TB screening)
992	Randal Jeffords (Med IV) (Previous HIV testing in the homeless population)
992	Rene Pacheco (Med II) (Compliance in TB prophylaxis)

POSTDOCTORAL FELLOWS' RESEARCH PROJECTS SUPERVISED 1986-91

1986-87	Richard E. Chaisson M.D. (Mellon Clinical Epidemiology Fellow) (HIV seroconversion in intravenous drug users)
1986-87	Mark Jacobson M.D. (Infectious Diseases Fellow) (Surrogate markers predictive of clinical response to antiretroviral therapy)
1987-89	Ellen Feigal M.D. (Epidemiology Fellow) (HTLV1/2 in intravenous drug users and homosexual men)
1989-now	Andrew Zolopa MD (Robert Wood Johnson Clinical Scholar) (HIV, tuberculosis and syphilis in the homeless)
1989-91	Anne Williams RN, PhD (Robert Wood Johnson Clinical Nursing Scholar (HIV and STDs in intravenous drug-using women in followup)
1990-91	Fabio Mesquita MD (Fogerty International Scholar) (HIV Prevention in intravenous drug users in Santos)
1991-now	Jordan Tappero MD (Dermatology Fellow) (Epidemiology of Kaposi's sarcoma)
1991-now	Louise Pilote MD and Jacqueline Peterson MD (Robert Wood Johnson clinical scholars). (Compliance in tuberculosis prophylaxis)

TOTAL HOURS OF TEACHING DURING 1990-91	**280**
TOTAL HOURS OF TEACHING DURING 1991-92	**280**

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Sally Smith Hughes

Graduated from the University of California, Berkeley, in 1963 with an A.B. degree in zoology, and from the University of California, San Francisco, in 1966 with an M.A. degree in anatomy. She received a Ph.D. degree in the history of medicine from the Royal Postgraduate Medical School, University of London, in 1972.

Postgraduate Research Histologist, the Cardiovascular Research Institute, University of California, San Francisco, 1966-1969; science historian for the History of Science and Technology Program, The Bancroft Library, 1978-1980.

Presently Senior Editor on medical and scientific topics for the Regional Oral History Office, and Research Historian in the Department of History of Health Sciences, University of California, San Francisco. Author of *The Virus: A History of the Concept*, Sally Smith Hughes is currently interviewing in the fields of AIDS and molecular biology/biotechnology.