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 V

Herbert A. Perkins, M.D.

DIRECTOR, IRWIN MEMORIAL BLOOD BANK:
TRANSFUSION AIDS AND THE SAFETY OF THE
NATION'S BLOOD SUPPLY

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

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

Since 1954 the Regional Oral History Office has been interviewing leading participants in or well-placed witnesses to major events in the development of Northern California, the West, and the Nation. Oral history is a method of collecting historical information through tape-recorded interviews between a narrator with firsthand knowledge of historically significant events and a well-informed interviewer, with the goal of preserving substantive additions to the historical record. The tape recording is transcribed, lightly edited for continuity and clarity, and reviewed by the interviewee. The corrected manuscript is indexed, bound with photographs and illustrative materials, and placed in The Bancroft Library at the University of California, Berkeley, and in other research collections for scholarly use. Because it is primary material, oral history is not intended to present the final, verified, or complete narrative of events. It is a spoken account, offered by the interviewee in response to questioning, and as such it is reflective, partisan, deeply involved, and irreplaceable.

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

Interviews conducted 1993 by Sally Smith Hughes, Ph.D. for the San Francisco AIDS Oral History Series. The 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.

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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. A retrovirus was isolated in 1983, and by early 1985, diagnostic tests 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 determined, scientific teams in the United States and Europe raced to characterize it in molecular terms. Information about the molecular biology of the human immunodeficiency virus (HIV), as it was named, 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 have played 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 three interviewees in this series, Jay Levy and John and

Deborah 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 phases two and three of the oral history project, a series with AIDS nurses and a third with community physicians with AIDS practices, have been completed and serve to broaden the focus. 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 1,400 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 Library web page (http://www.library.ucsf.edu/).

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.

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

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

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., Caroline Hannaway, 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 third volume in a lengthy series, and most of the 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.

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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.

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:

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.

--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.

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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 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 UCSF, 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

October 1996
Regional Oral History Office

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VOLUME I

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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

VOLUME III

Arthur J. Ammann, M.D., Pediatric AIDS Physician and Administrator, UCSF
Paul A. Volberding, M.D., AIDS Oncologist at San Francisco General Hospital
Constance B. Wofsy, M.D., Authority on Pneumocystis carinii Pneumonia and Women with AIDS, San Francisco General Hospital

VOLUME IV

Donald P. Francis, M.D., D.Sc., Epidemiology and Virology at the Centers for Disease Control
Merle A. Sande, M.D., Infectious Disease Specialist; Professor of Medicine, UCSF-SFGH; AIDS Activities at San Francisco General Hospital
John L. Ziegler, M.D., Ph.D., Professor of Medicine, UCSF; AIDS Oncologist at the Veterans Administration Medical Center, San Francisco

VOLUME V

Herbert A. Perkins, M.D., President, Irwin Memorial Blood Centers

IN PROCESS

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 (On Hold)
Warren Winkelstein, Jr., M.D., M.P.H., The San Francisco Men's Health Study, UC Berkeley

INTERVIEW HISTORY--Herbert A. Perkins, M.D.

Herbert Perkins was interviewed because, as scientific director of San Francisco's Irwin Memorial Blood Bank, he had a crucial role in formulating and implementing policy regarding blood safety for San Francisco and the nation. He was at the center of the crisis that began to develop in late 1982 and early 1983, as evidence accumulated that the as-yet-unidentified agent of AIDS was transmissible by blood.

The oral history tells of Perkins's agonizing attempt to strike a balance between protecting blood transfusion recipients from infection and simultaneously preserving the volume of donated blood destined for hospitals in San Francisco. Somehow, demographic groups deemed to be particularly at risk for AIDS had to be identified and discouraged from donating blood and the public convinced that the blood supply was reasonably safe, even though a test for AIDS was not yet on the market.

Quiet-spoken and scholarly, with a Tufts medical degree and a background in hematology, Dr. Perkins did not welcome the almost constant swirl of controversy which enveloped him, Irwin Memorial, and blood banks across the country from January 1983 on when the possibility that the AIDS agent was infecting recipients of tranfused blood became the center of debate in the blood banking community. Perkins tells in the oral history of the rancorous process in which the blood banks, the gay community, the medical profession, and the general public each had a say in the procedures by which Irwin and other blood agencies were to screen potential blood donors, assess risk, test and process blood, and educate and inform the public. The turmoil for Perkins continues, in recent years centered in the court room, where he is called upon to testify on Irwin's behalf in cases concerning "transfusion AIDS", that is, AIDS allegedly acquired through blood transfusion.

The problems were not unique to San Francisco. The media has provided full coverage of "contaminated" blood in other areas of the United States and abroad, with the French blood banking AIDS "scandal" in 1993 perhaps receiving most attention.[1] One ironic effect of these tragic episodes is, as Perkins remarks, that the nation's blood supply is today safer than ever before; Irwin, and presumably other blood banks, was at the time of the interviews performing seven or eight screening tests on donated blood, as opposed to two in the early 1980s.

Irwin's legal battles affected the oral history in three ways. First, because of litigation, virtually every document related to AIDS

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[1] For coverage of the French situation, see: Jane Kramer. Bad Blood. The New Yorker, October 11, 1993, 74-95.

at Irwin Memorial had been pulled, given an identifying number (the CBBL number in footnotes to the oral history), copied, and made available to plaintiffs. At the time of the interviews, Dr. Perkins had twenty-five binders of documents in his office. A complete set will be held indefinitely at the law offices of O'Connor, Cohn, Dillon and Barr in San Francisco. Dr. Perkins not only made the information available to me but also allowed me duplicating privileges. I am very grateful, and believe the reader will readily understand, through content and footnotes, how access to the documents enhanced the oral history.

The court proceedings influenced the oral history in a second way, by repeatedly recalling to Perkins, whose lawyers had advised him to sit through every trial involving Irwin Memorial, the details and atmosphere of the years from 1981 through 1984, before a blood test to identify the AIDS virus, later named HIV [human immunodeficiency virus], was introduced in 1985. Because of this experience, which continued through and beyond the interviews, and because of ready access to voluminous documentation, the reader will find that Dr. Perkins had the facts at his finger tips.

The third effect on the oral history was that Irwin's legal counsel embargoed release of the transcripts for almost four years, until May 1997, when Dr. Perkins called to say that counsel had given him permission to make them available.

## The Oral History Process

Between June 11 and July 14, 1993, we met four times for interviews in Dr. Perkins's office at the blood bank. A genial and quietly humorous man, he approached the interviews seriously and with tremendous recall, for the reasons mentioned above. Dr. Perkins carefully reviewed the edited transcripts in 1993, which were then put on hold. Upon their release this year, he asked to see the transcripts again and made a few further changes and additions.

The blood bank controversy involved multiple worlds--science, medicine, law, politics, and, most poignantly, the hemophiliacs and other transfusion recipients who suffered and died, and continue to do so. In light of the media's sometimes sensationalist treatment of aspects of this history, as well as the emotional responses it engenders, we are fortunate to have this reasoned, balanced, and well-referenced account by a man who, because he was at the forefront of blood bank policy, shouldered, as he put it in the oral history, "a terrible responsibility."

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are

available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, and is an administrative division of The Bancroft Library of the University of California, Berkeley.

Sally Smith Hughes, Ph.D.
Research Historian, Senior Interviewer

September 1997
Berkeley, California

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 HERBERT A. PERKINS, M.D.

Date of birth Oct. 5, 1918 Birthplace BOSTON, MASS.

Father's full name LOUIS PERKINS

Occupation OWNER, WHOLESALE PAPER Birthplace RUSSIA

Mother's full name ANNA ROBINSON PERKINS

Occupation HOUSE WIFE Birthplace CHILE

Your spouse FRANCES M. PERKINS

Occupation Volunteer Research Assoc. Birthplace No. ANSON, MAINE

Your children SUSAN, DEBORAH, DALE, KAREN, RONNIE (5 DAUGHTERS)

Where did you grow up? BROCKTON, MASS.

Present community MENLO PARK, CALIF.

Education AB HARVARD 1940 (cum laude)

M.D. TUFTS Dec. 1943 (summa cum laude)

Occupation(s) PHYSICIAN (DIRECTOR OF RESEARCH, SCIENTIFIC DIRECTOR, MEDICAL DIRECTOR, EXECUTIVE DIRECTOR, PRESIDENT, SENIOR MEDICAL SCIENTIST, IRWIN MEMORIAL BLOOD CENTERS, SAN FRANCISCO)

Areas of expertise TRANSFUSION MEDICINE, BLOOD COAGULATION, TISSUE TYPING, AIDS AND BLOOD TRANSFUSION (EPIDEMICCOGY, TESTING)

Other interests or activities ASSOCIATE EDITOR, "TRANSFUSION" (1) FOUNDER AND CHAIRMAN-ELECT OF BOARD OF DIRECTORS OF NATIONAL MARROW DONOR PROGRAM

Organizations in which you are active AABB, ISBT, ASHI, ASH, AATB, AAAS, ASTP, CBBS, TRANSPLANTATION SOC.

# I FAMILY BACKGROUND, EDUCATION, AND EARLY CAREER

[Interview 1: June 11, 1993, San Francisco] ##[1]

## Family Background and Education

Hughes: I want to start with your upbringing and education.

Perkins: Well, I come from New England, born in Boston [in 1918]. I went to Harvard College [1936-1940], Tufts Medical School [1940-1943], trained in internal medicine at Boston City Hospital [1944-1949]. That was interrupted by three years in the Army of the United States in World War II. During my internal medicine training, I had a special interest in hematology, and my experience went progressively in that direction from that point on.

## Early Career

Perkins: We came to California in 1951 when I took a job for Kaiser Permanente up at Vallejo. I worked for them a year and a half and decided that that was not the way I wanted to practice medicine, being allowed too little time with each patient. So we came down to San Francisco [1953], and fortunately I was able to get on the staff at Stanford in the hematology clinic. I worked starting in 1955 on a very interesting problem. This was in the early days of trying to develop open-heart surgery, and the dogs that were being used as the experimental subjects were going through the procedure fine and then bleeding to death.

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

Dr. Frank Gerbode[1] at Stanford [Medical School], then in San Francisco,[2] was looking for a specialist in blood coagulation to help him unravel that problem. I was hired, and worked for three years [1955-1958] with Gerbode's group. Actually, within the first year, we solved much of the problem, and had begun to do the first human operations on the West Coast. The work led to my being invited to Washington University in St. Louis, where I spent a year [1958-1959].

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[1] For more on Frank Gerbode and the development of open heart surgery, see Frank A. Gerbode: Pioneer of Cardiovascular Surgery, an oral history conducted in 1983 and 1984 by Sally Smith Hughes, Regional Oral History Office, The Bancroft Library, University of California, 1985.

[2] Stanford Medical School moved to the Palo Alto, California, campus in 1958.

## II IRWIN MEMORIAL BLOOD BANK AND THE AIDS EPIDEMIC

### Positions

Perkins: I returned to San Francisco [1959] when the job opened up here at the Irwin Memorial Blood Bank [IMBB], where I was originally director of research [1959-1978], then medical and scientific director [1978-1987], and ultimately executive director and president [1987-1993], a position from which I've just retired [April 1993].

Hughes: What is your title now?

Perkins: I'm still on the staff full-time, so I need a title, and we decided to call me Senior Medical Scientist.

### Procedures to Ensure Safety of the Blood Supply

Hughes: Well, before we actually get into a discussion of the AIDS epidemic, please tell me what procedures were in place to ensure, or at least attempt to ensure, the safety of the blood supply.

Perkins: The procedures that were in place involved two areas. One was a medical history in which the potential donor was asked questions about conditions that were potentially transmissible, as well as questions to protect his or her own health. And the second part consisted of laboratory tests. In terms of infectious disease testing, in 1980, let's say, only two tests were being used by blood banks. One was a serologic test for syphilis, and the other was a test for the hepatitis B virus.

Hughes: That was the surface--

Perkins: The hepatitis B surface antigen test, right. It detects an antigen on the surface of the virus, so that when you get a positive test, you know the virus itself is there.

Hughes: The hepatitis B core antibody test wasn't developed yet?

Perkins: The core test was developed in, I would say, mid to late seventies. It was used in research, and in hospitals as a diagnostic test. It had never been suggested for use in blood banks at that point.

Hughes: I saw a reference in UCSF literature to the development of heat treatment of blood to kill viruses.

Perkins: The first thing I'm aware of is Jay Levy's studies which were done after HIV had been discovered, I think, in which he showed the virus was very sensitive to heat. But that was probably 1984. Or, you mean heating plasma to get rid of hepatitis? That was a mistake. [laughs]

This is an interesting story: Garrott Allen, who ran the blood bank in Chicago, decided that his stored plasma was not transmitting hepatitis, because the room where he stored it was so hot. He stored it at room temperature. Well, the temperatures in Chicago in the summer are eighty, ninety degrees. And he published this. I remember when I came here, we had a room in the basement where we kept the temperature at thirty-four degrees centigrade, and kept plasma for six months before we transfused it, hoping it wouldn't transmit hepatitis. As it turned out, this early method of Allen's was totally ineffective.[1] And he was the most disappointed man.

Heat treatment was being looked at in terms of the plasma derivatives, the chemicals that they fractionate out of plasma. You can't heat treat blood. In fact, you can't even heat treat plasma.

Hughes: Because it kills the cells?

Perkins: It cooks not only the cells, but also some of the plasma proteins, yes. So it's something that was developed, and I think actually came into use in this country in 1984 in terms of heat treatment of the clotting factor concentrates that hemophiliacs received.

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[1] J.G. Allen, et al. Homologous serum jaundice and its relation to methods of plasma storage. Journal of the American Medical Association, 1950, 144:1069.

Hughes: As a result of the AIDS epidemic?

## Transfusion Hepatitis

Perkins: No. Hepatitis was the big worry; it always was. Even through those early days of the AIDS epidemic, we were totally convinced, and probably correctly, that hepatitis was killing more people through transfusion than AIDS ever would.

Hughes: Simply because hepatitis was more prevalent?

Perkins: Oh, the numbers were immense. In the mid-1970s, several prospective studies were done that showed if you looked for hepatitis carefully, using laboratory tests, over a period of six months, 10 percent of people who got transfused developed hepatitis after a transfusion. And this was after we had the hepatitis B surface antigen tests. You go back into the fifties and sixties, and we were probably infecting 30 percent of those receiving transfusions.

Now, a lot of this was subclinical infection, and a lot of it resulted in disease later on that we didn't realize was even happening. But hepatitis was a worry; it always was.

Hughes: When did hepatitis C--I guess it was called non-A, non-B for a long time--become a worry?

Perkins: Proof that hepatitis was being transmitted goes back to the forties. The definition of non-A, non-B had to occur after we had a test for A and a test for B. The test for B came first; in about 1970, that became available. The test for hepatitis A antibody was developed several years later.[1] And only then could you talk about non-A, non-B hepatitis, because it was hepatitis occurring in people who were negative with those two tests. So we called it non-A, non-B in the mid to late seventies, and it wasn't until almost 1990 that hepatitis C was identified.

Hughes: So there are now three tests that are used for hepatitis?

Perkins: No, there are four, because the surface antigen test for hepatitis B was the initial one. Then all blood banks in about

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[1] S.M. Feinstone, A.Z. Kapikian, R.H. Purcell. Hepatitis A: Detection by immune electron microscopy of a virus antigen associated with acute illness. Science, 1973, 182:1026-1028.

1986, 1987, introduced surrogate tests for non-A, non-B hepatitis, one being the anti-hepatitis B core antibody [test], and the other being the ALT [alanine aminotransferase] test. The introduction of these tests was based on the evidence that came out in 1986 that this non-A, non-B hepatitis was not the benign disease we thought it was in previous years.

Now, there used to be all this talk about people who got hepatitis which was evidenced only by an increase in the serum levels of an enzyme called transaminase. This 10 percent figure, that 10 percent of transfused cases get hepatitis, was developed by showing that these enzymes appeared in the blood of patients about 10 percent of the time. But those patients didn't know they were sick; they were quite healthy;[1] they had no symptoms. And so nobody was that eager to do anything about it.

But by 1986, the evidence came up that 50 percent of these people developed chronic hepatic dysfunction, and that 20 percent of those went on to develop cirrhosis of the liver. So it was at that point that, not knowing what the non-A, non-B virus or viruses were, the decision was made to do surrogate testing for that disease based really on evidence that was collected back in the seventies.

Hughes: Was that the infamous study of the mentally retarded children?

Perkins: No, no. [You are referring to] the Krugman study at Willowbrook. I said there were two prospective studies in the seventies that showed that there was a 10 percent chance of getting hepatitis from a blood transfusion.

One was called the TTV [Transfusion Transmitted Viral] study,[2] and it was a nationwide, multi-center study in which patients were followed post-transfusion for six months with a blood test every three months afterwards. So it was a massive study.

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[1] R.D. Aach, W. Szumuness, J.W. Mosley, et al. Serum alanine aminotransferase of donors in relation to the risk of non-A, non-B hepatitis in recipients. New England Journal of Medicine, 1981, 304:989-994.

[2] Ibid.

There was a similar, much smaller study done at the National Institutes of Health [NIH] by Harvey Alter[1] looking at the heart surgery patients who got lots and lots of blood at that point, much of it from paid donors.[2] So those figures became available, as I said, in the mid-seventies, that 10 percent of transfused patients were getting hepatitis.

In the early eighties, papers were published from those studies[3] showing that when you went back to the donors of the patients who developed hepatitis as defined by these tests, you found a considerable fraction of them had positive tests for anti-core antibody, or had high ALTs. So as I said, that information was available, but nobody did anything with it, because they thought the disease wasn't a problem.

But in 1986, recognizing that the disease caused chronic problems, that old information was picked up and the surrogate tests begun. We of course had begun the core antibody testing earlier here at IMBB for another reason.

## First Awareness of the AIDS Epidemic

Hughes: When did you first become aware that there was a strange disease on the scene?

Perkins: Oh, I became aware of the disease later called AIDS in 1981, not too long after the papers in the MMWR [Morbidity and Mortality Weekly Report] in June and July.

Hughes: Did you pay attention to those reports?

Perkins: Oh, they intrigued me. You know, I'm an internist basically, which means I'm interested in all kinds of diseases, and strange diseases always interest me. I don't remember having any suspicion that this was going to affect blood transfusion therapy.

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[1] J.J. Alter, R.H. Percell, P.V. Holland, D.W. Alling, D.E. Koziol. Donor transaminase and recipient hepatitis. Journal of the American Medical Association, 1981, 246:630-634.

[2] Ibid.

[3] Ibid. and Aach, et al.

Hughes: Did you suspect that it was going to be a big problem?

Perkins: No, it was a rare, esoteric event in this population of gay men who did strange things to each other. As the year went on, there were all these speculations about something in their lifestyle that might be producing this condition.

But it was not until the report on AIDS in hemophiliacs, in 1982 in July, describing the three hemophiliacs who had Pneumocystis carinii pneumonia,[1] that I, and I think everybody else, began to say, "Hey, is there any possibility that this disease could be transmitted by a blood component, since the materials the hemophiliacs received were derived from human plasma?"

The debate went on. There were all these meetings that began to be called to discuss it, and they focused entirely on the hemophiliacs at that point. But those of us who were involved in blood transfusion therapy were certainly watching everything, and saying this certainly isn't any proof of anything, but we've got to keep our eyes open and look for more evidence.

The theories at the time were that it could be a new virus, but why haven't we found it? Or, it could be just the summated effect of the numerous viruses we knew the gays were getting--CMV [cytomegalovirus], EB [Epstein-Barr] virus, hepatitis, everything else--just the combined effect. Or third, it could be just exhaustion of the immune response apparatus from being battered with all these foreign proteins.

That fit hemophiliacs who were getting all this intravenous junk that was contaminated with a little bit of the anti-hemophilic factor they needed. It fit the intravenous drug users who were putting god-knows-what into their veins. It fit the gays who were being exposed to foreign proteins in the form of sperm from other gay men. It was as good an explanation as any.

But the worrisome hypothesis was, could it be a new virus, or a new infectious agent of some sort? I am not aware that anybody recommended then, or even looking back now, says something should have been done then until we had more information.

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[1] "Pneumocystis carinii pneumonia among persons with hemophilia A." Morbidity and Mortality Weekly Report, July 16 1982, 31(27):365-367. Hereafter, MMWR.

Hughes: Something be done to what?

Perkins: To protect the blood supply. Obviously, everybody was looking like mad for answers to these problems, and trying to see what was causing AIDS, and what we could do about it. And the number of cases was building up, and the evidence was increasing that this was a disease that might be totally lethal.

It was the UC baby that really told us, "Hey, we've got something here." Do you want me to go into that story?

## Irwin's Links with San Francisco Institutions

Hughes: Well, before you do that, what I'd like you to do is to establish some of the links that the blood bank had with institutions in San Francisco. The Department of Health, for example, looked upon itself as the coordinating center. Would you agree with that?

Perkins: They were responsible for the public health, no question about it. Our contacts with the Department of Public Health until the end of November of 1982 were reasonably minimal, mostly in relation to positive syphilis tests on the samples of some of our donors' blood.

Hughes: Which you had to report?

Perkins: Yes. In fact, they did the confirmatory tests for us in their own lab.

Hughes: Would that have been Selma Dritz' division [Bureau of Disease Control]?[1]

Perkins: I don't think so. I think it was a separate laboratory division.

Hughes: So you really didn't have much personal connection with the health department?

Perkins: I don't think I had ever met Selma Dritz until the end of November [1982]. I'm not positive about that, but I don't right now have any clear memory of having met her before.

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[1] See the oral history with Selma Dritz, M.D., in the oral history series, "The AIDS Epidemic in San Francisco: The Medical Response," Regional Oral History Office, The Bancroft Library, University of California, Berkeley. Hereafter, this series.

## Contacts at the University of California and San Francisco General Hospital

Perkins: Of course, we supplied blood to the hospitals, UC included. I was a member of its faculty; for twenty years, I was the mainstay of the hematology clinic there. I used to spend half a day a week. So I was in very close contact with people there, but I don't think specifically with the AIDS people. My appointment at UC is in medicine, and specifically in hematology. We had a regular hematology conference every week. I was there when people like Paul Volberding[1] were being trained. He was a resident in heme-onc [hematology-oncology] there, and I knew Paul from that moment on. When he went over to the San Francisco General [Hospital], he knew nothing about AIDS. I don't know that I had ever met Marc Conant before 1983. And through SFGH, I knew Don Abrams.

Mrs. P.: You will remember that Don Abrams gave a talk at a UC hematology weekly rounds about his patients with lymphadenopathy?

Perkins: I talked with Don about his series of gays with enlarged lymph nodes. This might have been 1983, but I can't be sure what year that was.[2] So I did have some contact with these people.

Nationally, people in blood banking read the same journals, they go to the same meetings. The annual meeting of the American Association of Blood Banks was where we exchange information every year. I had been heavily involved in research all along, first in blood clotting and then in tissue typing. I went to meetings where those things were discussed.

## Blood Bank Regulations

Hughes: Is it true that blood transfusion guidelines are set by the national blood organizations?

Perkins: Basically, policy in blood transfusion is set by these two booklets.

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[1] See the oral histories in this series with Paul Volberding, M.D., and Marcus Conant, M.D.

[2] These cases were first reported in 1982. See p. 16 of the oral history in this series with Donald I. Abrams, M.D.

Hughes: Can you give me the titles?

Perkins: This is the "Code of Federal Regulations." It's the Food and Drug's [Administration] regulations that govern blood banks. So this is our primary responsibility, to follow what's in here. And what's in here is fairly brief and simple, and not well-defined.

This is the "Standards for Blood Banks and Transfusion Services of the American Association of Blood Banks [AABB]." This is a fairly detailed outline of what is required of blood banks and of transfusion services, from the time of recruiting a donor to the time that blood goes into a patient and you follow up the patient. It contains a lot more detailed recommendations. Now, this has no legal force, except that we all want to be accredited by the AABB, which means we have to follow these standards. This [the FDA's regulations] has legal force. They can take away our license if they don't like what we're doing.

Now, we also have to follow the regulations of the state of California. Until very recently, they had their own regulations which were a little bit more detailed than the federal, not as detailed as the AABB standards. (About a year ago, they decided to use the AABB standards as state regulations, adding a few side paragraphs to it.) So basically, the AABB standards are really the most helpful documents in terms of deciding what the blood banks should be doing.

Now, these standards are developed by a committee of the AABB. I was on it for many years [1965-1981]; I was chairman of it for four years [1968-1971]. It includes people we select because of their particular experience in various aspects of blood transfusion and blood banking. It includes people who have nothing to do with blood banking, such as infectious disease experts. It includes liaison representation from the CDC [Centers for Disease Control], from the Food and Drug Administration, from other organizations. When a new edition or new changes are proposed, they're published by the association so that people can comment on them, perhaps change the mind of the committee. After that, the committee writes up the standards again, submits them to the board, the board approves them, and out they go.

Hughes: It's an annual review?

Perkins: At this point, new editions come out every eighteen months. They used to come out every two years, and it just wasn't often enough, because things were changing too fast.

More on Dr. Perkins's Institutional Connections

Perkins: In November 1982, I became a member of the board of directors of the American Association of Blood Banks, and I served on that board for four years. So that was another national contact I had, and another way of getting information faster than I might otherwise have done.

Hughes: I've read that Irwin was at the forefront of many of the changes in blood banking that occurred as a result of the epidemic. Do you think that was somewhat because you were on the AABB board and could transmit the information faster than other blood banks?

Perkins: I think we were at the forefront for two reasons: number one, because we were in San Francisco, where the concentration of AIDS cases was the highest of any major city in the country, and we knew we had to work fast, and we did. Most things happened here first. Second, being on the board, whenever the subject of AIDS came up, I was always asked to report what we were doing, so I could keep them informed.

Hughes: Did you have connections with the CDC?

Perkins: I had had contacts with the CDC as chairman of the standards committee for the AABB. I remember that we wrote our new malaria regulations with the advice of one of their people. So there were intermittent contacts in that way.

Hughes: But not with the people who became players in the AIDS epidemic?

Perkins: No.

Hughes: Did you maintain your ties with Stanford?

Perkins: No. Stanford moved to the Peninsula, and I was working here in the city. I joined the UC faculty, so that's where my world was.

Hughes: [laughs] Never the twain shall meet!

Mrs. P.: No, you had your tissue typing contacts down there.

Perkins: Well, that's true.

Mrs. P.: You had "Rosie's coffee klatch".

Perkins: I said one of my major areas of research was in tissue typing, and this was initially in collaboration with Dr. Rose Payne at Stanford. So I did a lot of work with Stanford at that point.

Hughes: At about the time that the epidemic was breaking?

Perkins: No, this started in about 1960 and went up through the seventies. So it had ended by the time the AIDS epidemic was breaking.

Now, I have good friends in blood transfusion at the Stanford Blood Bank, people I have known since they were fellows in training.

Hughes: You mentioned off tape Dr. [Edgar] Engleman.

Perkins: Yes. Engleman--he was a student at UC--gives me credit for introducing him to T and B cells. He's said that in several lectures where he knew I was present.

## Origins of Irwin Memorial Blood Bank

Hughes: What about contacts with the San Francisco Medical Society?

Perkins: The medical society and the blood bank have had a strange relationship, which has now been severed. The blood bank was started in 1941 by Dr. De Witt Burnham, Dr. John Upton, and Dr. Curtis Smith, who got permission from the medical society to use a room in the basement of Irwin Mansion at the corner of Washington and Laguna. The Irwin Family Foundation donated some money to help the blood bank get started, which is why we're the Irwin Memorial Blood Bank.

Hughes: This was something to do with the war?

Perkins: In part, because John Upton was trying to collect plasma to send to Britain. De Witt Burnham was an obstetrician who was sick of watching his patients die for lack of blood, so he wanted local blood. And Curtis Smith was a surgeon, and he wanted local blood. So yes, the war had a little bit to do with it. But blood banking had to wait until techniques had been developed whereby blood could be put into a bottle without clotting or turning into a solid gel which you couldn't transfuse; and so that the red cells wouldn't die in five days, as they used to. So it waited for the evolution of science to reach the point where blood storage was practical.

Hospital blood banks began in this country with Cook County in 1937. The first community blood bank was, to the best of my knowledge, Irwin, although there were other community blood banks started in 1941.

Hughes: What does that designation mean, community blood bank?

Perkins: It means it's not hospital-based; it's a central blood bank for all the hospitals in the community. This concept has evolved, and it's different in different parts of the country. Some hospitals have blood banks. UC has a tiny one but that's it in San Francisco. No other hospital here has a blood bank. You go to Boston, and a lot of the big hospitals have their own blood bank.

The Red Cross, which started in 1947 to develop a system of community blood banks, built up the system rapidly, and now provides the blood for half of the country. Non-Red Cross community blood banks like Irwin are fairly similar to those of the Red Cross, except they're independent. In the seventies, there was a lot of unfavorable publicity about blood banking. The charge was that they were using paid donors. Some were; we weren't. Another charge was the immense competition for donors that was leading to all kinds of squabbling and turning the donors off.

The national blood policy was established during the Nixon administration. One of the tenets of the national blood policy was to convert to an all-volunteer blood donor policy, and to work in coordinated regions, either with a single community blood bank or at least with a coordination of hospital blood banks. So community blood banks more and more took over from that point on, except in some areas where there are still hospital blood banks.

You were asking me about the San Francisco Medical Society, and we got off the track. Irwin was started, as I said, very informally using a room in the basement, with permission of the medical society. The relationship was formalized when Irwin was incorporated in 1951 before they gave up that building at Washington and Laguna and moved to this site [Masonic and Turk Streets], which was in 1955.

At that point, the relationship was formalized in the sense that the blood bank had its own board of directors, but this board of directors had to be approved by the board of directors of the medical society. Irwin's board of directors included representatives from the medical society; one-third of the blood bank's board were representatives of the medical society, the other two-thirds had to be approved by the medical society. Bylaws were written and changes in the bylaws had to be approved by the directors of the medical society. And that was it; that was the only impact the medical society had on the blood bank. They never had anything to do with policy or what we did or how we did it.

We did share this building. When we moved here in 1955--and this is before I joined--they set up a third entity called the Trustees of the San Francisco Medical Society, which owned the building. The trustees paid the utilities and things like that, and the blood bank and medical society each contributed their fair share.

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Perkins: Several years ago, the medical society decided to move out, sell us the rest of the building, and sever connections with us officially.

Hughes: And that was all? There wasn't any more to it?

Perkins: Totally amicable, if that's what you mean.

Well, you ask was that all? I'm sure one of the motivating factors was that the medical society was named as co-defendant in a lot of the lawsuits. It was easy to get them off the hook, because there was no evidence the medical society had anything to do with the blood bank decisions. But it was a nuisance. Secondly, we were supplying blood in eight counties; why be sponsored by the medical society of only one of the counties? Third, we'd gotten far beyond their understanding of the technicalities of blood banking.

## Early Contacts with the Gay Community

Hughes: Did you have contacts with the gay community prior to the AIDS epidemic? Had hepatitis, for example, been a connection?

Perkins: I was aware that we had some gay donors. I didn't know how many. We had some known gay groups to which we sent announcements of blood drives. There was an episode in the late seventies, let me say 1978, roughly around there. We used to send a community drive to the Castro area, and welcome all comers. When I reviewed the hepatitis B surface antigen reports from that drive, the levels were high. I told the director--I was not the director then--no more community drives in the Castro.

We looked at the hepatitis results from the other gay groups we had been going to, and they had no increase in hepatitis that we could see, and that continued until December of 1982. So yes, I was aware we were taking blood from gay donors.

## The UCSF Baby with AIDS, 1982

Hughes: Now, December 1982 was when AIDS was recognized in the baby at UCSF.

Perkins: That's the watershed, yes.

Hughes: You hadn't changed any blood bank guidelines prior to the baby?

Perkins: Because of AIDS? Absolutely not. Nobody had, and nobody had even suggested that we change. The discussions that were going on at the national level by the Public Health Service dealt entirely with the hemophiliacs and the manufacturers who provided factor VIII to treat them. We had some peripheral awareness of what was going on there, but that was about it.

Okay, in the latter part of November of 1982--and it may have been just one week before December, because I've got a letter from Selma Dritz that talks about what we had done in the prior week--I got a call from a CDC employee by the name of David Auerbach. Auerbach was visiting Arthur Ammann at UC, and Ammann, as I'm sure you know, was the pediatric immunologist.[1] Now, I knew Ammann well. We had talked about many things; we had worked together on problems that some of his babies get into with antibodies to a human protein called IgA [immunoglobin A], and we worked well together.

Hughes: When you say you had done work on IGA, you mean the blood bank had done some--?

Perkins: The blood bank actually was providing his patients with plasma from people who didn't have IgA in their plasma. There were other contacts I had with him related to pediatric transfusions. But he is not the one who called me. The one who called me was his visitor.

The visitor was there not to talk about transfusion AIDS, which nobody knew existed, but to talk about a woman and her three kids who might have AIDS. Apparently, Ammann mentioned to him that they had this baby with an immune deficiency that everybody had been puzzling over for months. The baby had a history of a lot of blood transfusions at birth. Was there any possibility of a connection?

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[1] See the oral history in this series with Arthur Ammann, M.D.

So Auerbach's question to me was, "This baby got blood from nineteen donors. Would you be willing to find out who those donors were, and give their names to Selma Dritz at the health department so she can see if any of them have appeared on her AIDS list?" I had to think a minute, because we'd never done anything like that in our lives. Donor confidentiality is one of the primary considerations in blood banking, but I felt this was so terribly important that I did supply the donors' names. And one of the nineteen donors was on her AIDS list.

So there we had it, and there were all these debates about what it meant. Pediatricians were saying, "This kid doesn't have an acquired immune deficiency; it must be congenital, because those are so common; and this kid doesn't have AIDS," because what the kid had was Mycobacterium avium infection, and that at the time was not on the CDC's list of what defines AIDS. Nonetheless, it was obviously a very important finding, and it was going to be made public very quickly. It did appear within ten days as a report in the MMWR.[1]

Press Conference, December 9, 1982

Perkins: The day before that report, UC decided they'd better hold a very limited press conference, because this could be sensational news, and they wanted it to go out in the right way. They invited to that press conference Dave Perlman,[2] George Duchek of the San Francisco Examiner, and someone from Medical World News. God, how do I remember this after all these years! [laughter] It's funny, the things that come back. I was there, Ammann was there, I guess the UC P.R. person was there--

Hughes: And Selma Dritz was there.

Perkins: Selma Dritz was there. They had a fellow there from BAPHR, Bay Area Physicians for Human Rights, Bob Bolan. That was my first introduction to BAPHR.

Following that conference, Selma Dritz and I talked about what we needed to do.

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[1] Morbidity and Mortality Weekly Report, December 10, 1982, 31:652-654.

[2] "Mystery of San Francisco baby with 'gay' disease." San Francisco Chronicle, December 10, 1982, p 2.

Hughes: Well, tell me what you said at the conference. Did you say any more than what you've already told me?

Perkins: Not really. "Here's a baby who has a lot of conditions that are suspicious of AIDS, who had received blood from a donor who clearly has developed AIDS." Incidentally, the donor was not only healthy when he donated, he was healthy for eight months after he donated. That, of course, raised the question, "Is this a disease that can linger on without showing any signs for a period of time?" The donor had, to his death, denied he was gay. His family denied he was gay, until they went through his effects after he died and then they had to admit he was. So I guess those were the facts we had at the time.

Obviously, the baby had raised the question, "Can AIDS be transmitted through blood?"

Hughes: Did that immediately occur to you?

Perkins: Oh, sure. As I said, from the time of the three hemophiliacs, we were looking for further evidence that AIDS might be transmissible via blood. And this was our first opportunity to see if we could find such evidence, and bingo. You could say it's coincidence that the baby had AIDS and also had been transfused, but it's not a coincidence you're going to ignore. Something had to be done.

## Actions to Protect Irwin's Blood Supply

Perkins: We did three things immediately. One of them was to stop the drives to the known gay groups. They had still been permitted to continue. The second was Selma Dritz and I agreed we've got to see if there's any more evidence we can come up with by comparing blood donor files against the AIDS list, if there were other examples that would prove the point that AIDS is being transmitted. So since the only way to do it was the other way around--she to give me her relatively small (at that point) AIDS list of maybe 100 cases to compare against the donor files--that's the way we did it. We started this in December. In fact, I had that data by the time I went to the January 4 meeting at the CDC in 1983.

I think we identified eleven former donors on that AIDS list.

Mrs. P.: There were thirteen recipients--

Perkins: Thirteen recipients still alive that we were able to get at, yes. And the question was, can we find any evidence of AIDS in these recipients? And the answer was no.

Hughes: And nothing much was known about the incubation period.

Perkins: Of course. Other than our case, which was really the first reasonable evidence that there might be a long incubation period, there had been a report which I guess I heard about in the January meeting in 1983. It was a CDC investigation of clusters of gay men that suggested the possibility that there was a somewhat prolonged incubation period which at the time, in early 1983, was considered to be two years. So that was the second thing.

The third thing was that I met Bob Bolan, and I got him and Ric Andrews, the president of BAPHR to talk to us, and to do two things: one was to talk within the gay community and get the gay press to write that, until we knew something more, gay men at risk for AIDS should not be donating blood. Now, one of the problems is, what's "gay men at risk"? And I'll come back to that.

The other thing that we wanted help with was, how do we set up a screening system to keep the gays at risk out of the blood bank, and will you help us do that? This was all before the January 4, 1983, meeting.

Hughes: Do I understand then that almost immediately after the episode with the baby, you began to think about procedures for excluding potential donors from high-risk groups?

Perkins: Yes.

Hughes: Was your attention focused almost exclusively on the gay community?

Perkins: Well, the IV-drug users were already excluded. Hemophiliacs were already excluded. We didn't have any Haitians, and anyway, they weren't even on our list of high-risk donors at that point. Yes, there were the gays we had to exclude. The question was, which gays? And that gets me to the issue I wanted to address. At the time of the January 4 meeting in 1983, what we were being told and what Selma Dritz was telling me was that the gays at risk are the fast-lane gays, the bathhouse boys, the ones with multiple anonymous partners.

Hughes: Which she knew from her epidemiology.

Perkins: Right. These were the kinds of cases being reported to her. And so my question to Selma and, through her, to the CDC was, "Okay, how do we define fast-lane? Is this a certain number of partners? What are we going to do? What can we put into a medical screening procedure in a blood bank that will exclude fast-lanes and not discriminate against all other gays?" And of course, nobody could answer that or was willing to answer that question for me.

If I may jump past the January 4 meeting, that question got answered for me later in January, because Selma called me to say that she had two reports of AIDS in gay men who had only two or three partners. These were not fast-lane by any definition. And that's what led us to the terminology ultimately used, which we'll get into.

## Bay Area Physicians for Human Rights [BAPHR] and Blood Donor Policy

Hughes: You mentioned Bob Bolan and the BAPHR. What was their response when you came to them?

Perkins: They wanted to be helpful. They were very much concerned. They said, "We get transfused too; we want safe blood." They did know we were going to have an interesting time talking to the rest of the gay community, which they assured us was an extremely heterogenous group, varying from the transsexuals and the protesters to the guys in the closet and what have you. And this was part of our problem in trying to address how we exclude people from donating blood who might be at risk.

The BAPHR people were extremely helpful and totally cooperative. I say that even though when we got to the press conference we had in February, their press release differed a little bit from ours, under pressure from the rest of the gay community.[1] There was very vocal debate within the gay community, and I know it spread across the country because

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[1] A Statement from the Blood Bank on AIDS. Irwin Memorial Blood Bank of San Francisco Medical Society News Bulletin, February 3, 1983 (CBBL 00482); Bay Area Physicians for Human Rights (BAPHR) Position on Acquired Immune Deficiency Syndrome Related to Transfusion, February 6, 1983 (CBBL 00484). Documents cited with a CBBL number were made available to plaintiffs in lawsuits involving IMBB. The are located in the law offices of O'Connor, Cohn, Dillon & Barr in San Francisco.

there's a memo somewhere in the file about my talking about the New York gays talking to the San Francisco people and trying to agree on what's a reasonable thing to do about blood donation.

Hughes: Say something about the general atmosphere in the city. Was the tension pretty much localized in the gay community?

Perkins: Oh, not once we had that report of a possible case of transfusion AIDS. Then there were write-ups in the national magazines, there were phone calls coming to me from all over the country, and much concern locally as well, sure.

Hughes: Were you used to handling that much publicity?

Perkins: I'd done some, but never in that emotional an atmosphere. I got used to it very fast.

Hughes: Please comment on your general method of handling questions from the press.

Perkins: I tried to be honest. The problem was, we didn't know much. I made statements then that, when you go back now eleven years later, you can say, "Well, gee whiz, why did he think the risk was as low as it was?" and so on. But this was what everybody was saying at the time. You read memos in which I tried to reassure people and argued that the hysteria was not justified. And that's what I thought at the time. And what I was being told. So what else can I say about the mood at the time? Maybe we should talk about the January 4 meeting.

Hughes: Well, Irwin and the other blood banks are accused of excluding fast-lane guys, but wanting the slow-lane gays to continue to donate; that one of your priorities was preserving the level of blood donation.

Perkins: Oh, absolutely. That's always a major priority. People die when blood isn't available. In 1983, we were dealing with a condition that we thought, and everybody else was thinking and publishing, including the Public Health Service, was a risk of transfusion AIDS of one in a million or less. We knew that if we lost 20 percent of our donors, people were going to be dying in this community soon. People do die because blood is not there in the quantities needed. Probably always a blood banker's worst fear is that he not have adequate blood to meet people's needs. So sure, we don't want to eliminate donors without reason. You've got to balance the benefits and the risks and decide what's best for the community, and always doing this with whatever advice we could get from all directions. But absolutely, preserving the level of blood donation was a major concern.

The other part of the picture was a feeling that we should eliminate those people who could be at risk for transmitting the disease. We should not necessarily--and this is December, January of 1983--eliminate somebody just because he was gay. That didn't mean he was at risk for the disease. That's what the data said at the time.

Now, when Selma came up with that phone call that said, "You don't have to be fast-lane to get AIDS," then that said to us, "We've got to get rid of the gays [as blood donors] essentially." And I say "essentially" because we left one loophole, and that was anybody who had been monogamous for two years, and his partner had been monogamous, and anybody who had been celibate for the past two years, could not possibly have AIDS and was free to donate blood. Gays with multiple partners were the ones at risk.

I don't know whether that wording came from us or from the BAPHR group or where, but we decided it was extremely suitable because, number one, it made sense. We were not telling the gay community, "We're discriminating against gays." We were only discriminating against gays at risk. Gayness per se was not the issue. Homosexual activity with multiple partners was the issue. And that's the terminology we elected to use.

Hughes: Now, when you say "we," do you mean Irwin?

Perkins: I mean Irwin, yes, with, as I say, the guidance of the BAPHR people. We felt these were the people who knew their community, who knew what would sell in the community. We felt they were the best people to advise us on what would work, and the best people to sell what we were doing to the gay community. As physicians, they were really concerned. And we had to use an approach which appeared logical and scientifically sound, because if the gays believed our policies were based on discrimination, they would feel justified in ignoring them.

So that wording, as I'm sure you are aware, appeared subsequently in the PHS [Public Health Service] and the FDA [Food and Drug Administration] recommendations. I don't know whether they copied it from us, or whether they heard it through the gay community, or they came up with it independently. But we had it first, anyway.

## The "One-in-a-Million" Risk of Transfusion AIDS

Hughes: Your friend, Randy Shilts,[1] made some accusations.

Perkins: [laughs] Lots of them.

Hughes: Some blood bankers, in trying to reassure the public that the blood supply was reasonably safe, talked about risk of acquiring transfusion AIDS in terms of one in a million. Could I quote from Randy Shilts?

Perkins: Sure.

Hughes: "The blood banking industry was insisting that because only one or two blood transfusion recipients with AIDS could be linked to donors who had full-blown AIDS, the chance of contracting AIDS from a blood transfusion was one in a million. After all, three million Americans are transfused with blood each year, they said. But Dr. Engleman calculated the odds differently. First, the blood bankers weren't counting the growing number of transfusion recipients who came down with AIDS from blood donated by someone with lymphadenopathy or pre-AIDS symptoms. Clearly, these people were also infected with the virus."[2]

Perkins: Yes, anybody who was infected with the virus would have been responsible for the case if it occurred. Well, go ahead.

Hughes: "The blood banks were playing semantics by not including them in the calculation."[3]

Perkins: No, that's not true. There is no question that the figure one in a million was based on the number of cases recognized versus the number of people transfused. The figure one in a million first appeared in an AABB memorandum in the summer of 1983.[4] It subsequently appeared in a publication from the Public Health Service called "Facts About AIDS",[5] which begins by saying, "This

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

[2] Ibid., p. 307.

[3] Ibid.

[4] "AIDS-Directed Donation," Draft, June 7, 1983. (CBBL 00739-00742).

[5] "Facts About AIDS," August, 1983.

is the most authoritative information we have on the subject of AIDS at the present time." That same document was republished in December, 1983, and again in April 1984, and it still said "one in a million."[1] So when Shilts talks about blood bankers, he's got to include the U.S. Public Health Service (CDC, FDA and NIH[2]).

Now, the argument in retrospect is, we should have realized this long incubation period and therefore there would be other cases coming along. But we also thought we were getting rid of the problem by excluding the gays. And so, I was very comfortable in 1983 with that one-in-a-million figure.

Now, to carry it one step further, my wife reminds me that there is a lovely article in the San Francisco Chronicle in September of 1983 at the time of the release of the report of the state task force on AIDS, which was chaired by Marcus Conant.[3] In that article, Marcus Conant is quoted as saying the risk of a blood transfusion is negligible. It's less than one in a million.

Hughes: Right. Well, the quote from Shilts goes on. Can you bear with me? [laughs] "Moreover, there may be three million blood units donated every year, but a typical patient is transfused with three, not one unit, increasing the odds further. Nor was it fair to figure in the transfusions of areas with no incidence of AIDS. The honest way to figure the odds was to use numbers from the major urban areas where the AIDS virus was prevalent. At San Francisco's Irwin Memorial Blood Bank, for example, officials figured they were losing between 7 and 15 percent of their blood for the lack of gay donors. If these people were donating in 1981 and 1982, this translates into a lot of blood potentially infected with AIDS years before anybody even knew the epidemic existed.

No, this one in a million rhetoric was bullshit, Engleman thought. Instead, he figured that a person's chance of

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[1] Ibid., December 1983.

[2] Centers for Disease Control, Food and Drug Administration, and National Institutes of Health, respectively.

[3] Consensus Conclusion and Recommendations of the California State Task Force on AIDS, September 1983 (CBBL 00946).

contracting AIDS from a San Francisco transfusion was more on the order of one in 10,000, maybe one in 5,000."[1]

Perkins: The risk was higher than that. This is looking back at things with current knowledge. There's no question we were talking about the risk of a single unit, and you have to multiply it by the number of units transfused. That would be self-evident; maybe it wasn't, but we were quoting the figures that other people used. We didn't know what the risk was. We thought the risk in 1983 was less than one in a million, and we reduced it below that, but we didn't know what it was. It's awfully hard to argue with retrospective reasoning. I still think that our reasoning at the time was logical, was correct, and was the same reasoning we were getting from the people we leaned on for advice, from the Public Health Service.

## Work Groups Formulate Recommendations for Prevention of AIDS, Centers for Disease Control, Atlanta, January 4, 1983

### Attendees, Format, and Discussion Points

Hughes: Well, let's discuss the January 4 meeting, because that seems to be an important event. What groups were represented?

Perkins: Well, there were obviously people from the federal government: the CDC, the FDA, the NIH [National Institutes of Health]. There were some representatives from blood banks, from the national associations, and I think as individual blood bankers. Probably Aaron Kellner from New York and I were the two that had been invited because of the areas in which we were operating. There were representatives of the gay community; there were representatives of the plasma fractionators, and of the National Hemophilia Foundation. Certainly there were well over 100 people in the room. And there was press.[2]

Hughes: Who had selected these groups to attend?

Perkins: Somebody in the CDC, I assume. I got a phone call from Harold Jaffe, who said he was from the CDC and that I was going to be invited to a meeting to discuss the potential of AIDS in the

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[1] Shilts, pp. 307-308.

[2] See "List of Invitees", January 4, 1993 (CBBL 00344).

blood supply. Then I got a letter, which I imagine you have seen as you went through the files.[1]

Hughes: The Rh-negative baby, was the event that precipitated this?

Perkins: Yes, there was no question about it. If we had not found that baby, it might have been another year before anybody took the risk real seriously, and then heaven knows how many more would have been infected.

Hughes: Could you say something about the atmosphere of the meeting?

Perkins: It was emotional. It was run in a little bit of a strange way. I came prepared to talk. I thought I had some interesting information. I had the information on the follow-up on the people who had also received blood from donors who later developed AIDS. The CDC had organized the program so they did most of the talking. They made formal presentations with slides and handouts in the morning. Then the afternoon was thrown open for general discussion. In the morning, we heard from Harold Jaffe on risk factors for AIDS, and some of the other studies. And we heard from Tom Spira on the suggested surrogate tests. And I don't know what all else. The agenda is in the book.[2]

Hughes: The format surprised you because you thought the meeting was going to be a bull session?

Perkins: No, I'm just saying I thought they would have had more people presenting information. It was a big audience, and it contained a lot of people with information, but few gave any formal presentations except the CDC people.

Hughes: Was that an attempt to control the meeting?

Perkins: I think they felt they had certain facts they wanted the group to have, and then they wanted the group's input on what should be done based on those facts. And obviously, what they wanted was a consensus that this is a disease that's of such-and-such a cause, in our best judgment, and this is what we should do. And they didn't get it.

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[1] William H. Foege to invitee, December 21, 1982 (CBBL 00298).

[2] Final Agenda, January 4, 1983 (CBBL 00347).

Perkins: Jeff Koplan, who moderated the meetings, summed it up with an expression of disappointment that we were not able to achieve any consensus at all.

Hughes: What points did the different groups make?

Perkins: The questions were, number one, is this an infectious disease? No agreement. Number two, if it's an infectious disease, is it transmitted by blood? Some yes, some no. The answers were all over the spectrum. We had people like Don Francis[1] who was saying, "This is an infectious disease; when are you blood bankers going to accept this?" That wasn't the issue. The question was, what were we going to do about the possibility that it might be an infectious disease transmissible by blood.

At that meeting, Aaron Kellner from the New York Blood Center made the suggestion that the three national blood bank organizations, through three blood banks in high-risk areas--New York, San Francisco, and Los Angeles--ought to go away from this meeting and work on approaches--just work on the assumption this is a disease transmitted by blood. Whether you accept it is or not is irrelevant; let's make the assumption this is a disease transmitted by blood, and act accordingly. And that's what we did.

Now, you can always find somebody who's saying that I said to do this, and somebody else who will say I said to do that, and that's exactly what did happen.

## Aftermath

Hughes: Well, what did you do that you hadn't already started doing? You'd already started trying to screen out the high-risk donors.

Perkins: Yes. We had just started discussions on how we were going to do that. As of January 3, we hadn't done any of that, other than stop the drives to the known gay groups. I came back to San Francisco, and I think on January 7 I sent out a memo to the staff adding a couple of questions to the medical history for potential blood donors that would look for signs and symptoms related to AIDS.[2] The AABB committee on transfusion-transmitted diseases met about the 6th. They came out with a statement that

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[1] See the oral history with Donald Francis, M.D., in this series.

[2] Herbert Perkins. Re: AABB on AIDS, January 7, 1983 (CBBL 00393).

was ultimately published as the January 13 joint statement of the three national blood bank organizations.[1]

Now, that was an AABB committee, but they had representatives from the Red Cross there, the Council of Community Blood Banks [CCBB], the American Blood Commission, the FDA, the CDC, the National Hemophilia Foundation, the gay groups. It wasn't a big meeting like the CDC meeting, but it was a meeting in which all the major players had representation.

Hughes: The AABB was the organizing group?

Perkins: Yes, they had a committee already established to advise them on this kind of a situation. So this committee was the milieu in which the statement was drafted, and then it was ultimately approved and sent out by the boards of all three organizations. This was, as we understood it, an authoritative statement that had had CDC and FDA input, et cetera. The statement made some additional suggestions about questions to be asked, and I sent out another memo adding to the questions we would be asking our donors.[2]

In the meantime, we were working on a total revision of our medical history questionnaire and approach to it, which evolved over the next month.

## Surrogate Testing

Hughes: Don Francis and maybe others at the January 4 meeting were asking for surrogate testing.

Perkins: "Asking for" are the wrong words. Tom Spira presented the data, and you've seen the handouts.[3] He presented data on something like twenty-four tests, and said, "These five tests look like the ones most worth investigating." And that's the way it was

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[1] Joint Statement on Acquired Immune Deficiency Syndrome Related to Transfusion, January 13, 1983 (CBBL 00435).

[2] Memo from Perkins to: "All Departments, Blood Centers, Physicians," January 19, 1983 (CBBL 00441).

[3] Sensitivity and specificity of tests identifying individuals at risk of transmitting AIDS, [n.d. but located with documents related to January 4, 1983 meeting] (CBBL 00381).

presented: These were the ones that were most worth investigating. It was not presented that, "We recommend you do this." Neither was the hepatitis B core antibody test picked up from the group. There were five tests presented as, "These are the ones that are most worth investigating." Those five tests were investigated.

Hughes: Why don't you name them, for the record?

Perkins: Sure. One of them was the antibody to hepatitis B core antigen. The second one was antibody to hepatitis B surface antigen. The third was the T cell helper-suppressor ratio. The fourth was the absolute lymphocyte count. The fifth was immune complexes.

## Current Interest in Transfusion AIDS

[Interview 2: July 2, 1993] ##

Perkins: At the present time, here in 1993, we are really at a peak of interest in the transfusion AIDS cases that were initiated back in 1982, 1983. This is for several reasons. One is the fact that the people who were infected then are just now coming down with AIDS in largest numbers. In San Francisco, the peak risk of AIDS from a transfusion was at the end of 1982, beginning of 1983. Our efforts to keep away the donors who were at risk did have a fairly profound effect; not perfect, but certainly the drop-off is obvious starting in 1983. In the country as a whole, the drop-off didn't start until after 1984. We hit our peak of reported transfusion-associated AIDS cases in 1989, and they've been falling off very rapidly since. In the country as a whole, they haven't yet started to fall.

Hughes: Now, is that because blood banks elsewhere instituted screening measures later than Irwin?

Perkins: No, they all started screening about the same time, but they certainly were less effective. I think part of what made Irwin very effective was the fact that we developed our screening approaches in collaboration with the gay community, particularly the gay physicians. We had their support from the beginning; we had their understanding, and I think it has been a community that understood the problem very well, and worked with us. Other parts of the country were denying they had a problem. It was very easy for gays in those areas to say, "This doesn't apply to me, because we don't have a problem." They did; they just didn't know it.

Hughes: So gays elsewhere continued to donate?

Perkins: I think so. I think this is the only explanation. Some people think that we got things under control faster here because we started [anti-hepatitis B] core testing earlier here. We began it in May of 1984. We have actually analyzed our data very closely to see how much impact that had on the increase in safety of the blood supply, and actually it was pretty minimal. It had almost all been accomplished before that period.

Hughes: Why would that be?

Perkins: Because the procedures we had to get the gays to exclude themselves were working.

Hughes: I thought there was a correlation between a positive core test and the incidence of AIDS.

Perkins: There was some correlation, yes, but by the time the core test was introduced, we'd gotten rid of most of the risk.

Hughes: Through self-exclusion.

Perkins: Through self-exclusion. You don't see another further sharp drop after introduction of the core test. There was some slow, progressive drop from then on.

Hughes: It was known by the time the high-risk groups were excluded that there was a latency period. Yet in 1983 you were not uniformly eliminating gays from donating, only the high-risk gays.

Perkins: No, we were eliminating any gay with multiple partners.

Hughes: Have you said enough about the correlation with the present problem?

Perkins: All I was trying to answer is, "Why is there so much interest in AIDS transfusion at this point?" Some of it is because larger numbers of people are suffering from this at the moment. Some of it is related to the trials in France of the blood bank officials who were accused of having deliberately transfused blood they knew was infected, or derivatives they knew were infected. People ask the question, "Well, could that have happened in this country?" And what they haven't really looked at is the fact that the French were found guilty because they weren't doing what we did in this country. So, even though that has directed interest at looking again at what we did back in 1982, 1983, and so on, in no way does what happened in France have any direct connection to what happened in this country.

Hughes: Has it been shown to be valid that indeed the French did delay instituting the HIV antibody test because they wanted to develop their own?

Perkins: Well, I don't know how you prove that. There's no question that they did delay introducing the test well beyond the period when it was available in this country, and when it would have been available to them from this country. What their motives were, I can't speak to. And there's also no question that the peak risk in Europe was not 1983-84 but 1985. So the transfusion AIDS cases were being accumulated all the way up until 1985, when only then did they begin to drop. So they were slow on it.

The Canadians now are going into an investigation of their blood industry, again saying the United States did it six to eight months before you [the Canadian blood industry] did; why did it take you so long? So we're, comparatively speaking, the good guys, but that may not be good enough. [laughter]

## More on the Aftermath of the January 4, 1983 Meeting

Hughes: Well, let's go back to the January 4 meeting, because it seems to me a lot of things flow from that.

Perkins: Absolutely.

### Debate over Donor Screening

Hughes: On the 9th, five days after the meeting, you wrote a document called "Update on AIDS for Blood Banks," which was based directly on that meeting, I understand.[1] You wrote, and I quote, "There was almost complete agreement that any policy which excluded all gay male blood donors was irrational, unscientific, unwise, and could jeopardize the nation's blood supply." Can you recreate some of the background for that statement?

Perkins: Sure. First of all, the article was written for the state blood bank association bulletin [California Blood Bank System], at the request of the editor of that bulletin, on what happened at the

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[1] Herbert Perkins. Update on AIDS for blood banks, January 9, 1983 (CBBL 00401).

meeting, and also what was going on. So you're correct on why it was put out that way.

The statement is correct in terms of what happened at that January 4 meeting. Nobody at that meeting came out with a recommendation that all gays should be excluded, except Alpha Therapeutics, which was one of the manufacturers of plasma derivatives, and they got pretty well shouted down. There certainly was no such recommendation made by any of the CDC people or FDA people or PHS people.

When the three blood bank organizations came out with a joint statement on January 13, I think there was reference to the fact that excluding all gays as a group could not be justified.[1] We came back from the CDC meeting with the information that AIDS was a disease of fast-lane gays, and we struggled for a few weeks to try to define "fast-lane gays" in a way that we could use as a screening technique for blood donors.

Hughes: Was that based on the evidence that the gays known at that point to have AIDS did have a large number of partners?

Perkins: It was based on the fact that all reported AIDS cases that had been well investigated had very large numbers of partners. I had that from the CDC, and I had it from Selma Dritz in terms of the local reports. However, some time later in January, Dr. Dritz called me and she said, "We have had now two reports of AIDS in gays who cannot be considered fast-lane in any sense. They've had multiple partners, but a relatively small number of partners." And to me, that solved the dilemma, because it said that we've got to reject any gay who has not been monogamous or celibate for a reasonable period of time. Working with the BAPHR people, we came up with this notion of homosexually active men with multiple partners as being the criteria for elimination.

Hughes: Go back a minute, please, to the January 4 meeting, because one of the groups represented there was the National Gay Task Force--do I have the name right?

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[1] The joint statement reads: "There is currently considerable pressure on the blood banking community to restrict blood donation by gay males. Direct or indirect questions about a donor's sexual preference are inappropriate." Ibid.

Perkins: I'm not sure who the gays were representing, but there certainly were several very vocal gays there.[1]

Hughes: What were they saying?

Perkins: Oh, they were saying, "You can't discriminate against us; we've been fighting to avoid this sort of thing, and it's not fair; it's not reasonable. There may be a subset of us who are at risk, but you can't eliminate the whole group because of a subset. You've got to define the subset."

Hughes: Did they color the outcome of this meeting?

## Debate over Instituting Surrogate Testing

Perkins: Well, if we had done what the gays wanted, we would have not excluded gays at all, and we would have done surrogate testing, because that was what they were begging us to do. They were saying, "Don't exclude people because they're gay; use a surrogate test; use the best test you've got. Exclude those that are positive from the test; let the rest of those donate." If we'd gone that route, we'd have infected many more people than we did.

Hughes: Why didn't Irwin institute one of the available surrogate tests?

Perkins: Because we would have infected many more people than we did. I'm sure that's true. And the reasoning is this: the issue of how effective the surrogate test would be in a blood donor population was the first thing we needed to find out about. What we had from the CDC at that meeting was evidence that some of these tests had a very high frequency of positives among people with AIDS--these were not people who donate blood, so we could forget them. They also had a very high incidence of positives among people who were in the so-called healthy gay control group. When we asked who were these healthy gay controls, we found out they came from two sources: they came from sexually transmitted disease clinics, and they came from people who had volunteered to be in AIDS studies.

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[1] The "List of Invitees" to the January 4, 1983 meeting includes Roger Enlow, M.D. and Bruce Voeller, M.D. of the National Gay Task Force (see appendix).

So we said, "Well, how representative are those two groups of the kind of gays that come to donate blood? These are not the bathhouse boys that don't believe in blood donation." So we went back with a determination to see if we could somehow find whether these tests would be useful as a method of screening blood donors. Our blood center did a study. There were studies done in New York, Albuquerque, and another one in Los Angeles by the Red Cross. All four of these studies resulted in a conclusion that the proposed surrogate tests would not be effective in a blood donor population.

Hughes: In the last interview, you listed the five surrogate tests that Spira mentioned at the January 4 meeting. Are you referring to the core antibody test?

Perkins: Actually, we looked at the core antibody test. We tried to look at the helper/suppressor ratio, without too much success, for reasons I can get into, but the [New York] blood center did a good study on that. We looked at absolute lymphocyte counts. Dr. [Girish] Vyas at UC looked at immune complexes. And I don't think any of us ever looked at anti-hepatitis B surface antibody, because that test demonstrates immunity to hepatitis B and has no advantages over the hepatitis B core antibody test.

Hughes: I saw reference to the $beta_2$--

Perkins: Serum $beta_2$ microglobulin test? That was not on Spira's list. That was never even mentioned as a possible surrogate test until after the meeting.

Hughes: But Irwin tested it?

Perkins: Yes. Actually, within a few months after the January 4 meeting, there were publications in the New England Journal of Medicine and Clinical Chemistry suggesting additional possible surrogate tests which could have more promise than any of the tests that

Spira had mentioned.[1] One of those was the $beta_2$ microglobulin test.

### Types of Surrogate Tests

Hughes: Do you think it's pertinent to say a little about each of these tests? Please bring in test sensitivity versus test specificity.

Perkins: Yes. To a person who runs the lab, there are two questions you ask about a new test. The first is, how sensitive is it? And that means, to what extent does it miss somebody who carries the disease? And the second is how specific is it, and that means to what extent does it react with people who don't have the disease? What you'd like, of course, is one that is 100 percent specific and 100 percent sensitive.

Hughes: Of course.

Perkins: It's an impossibility in a sense, because the more sensitive you make a test, the more likely it is going to be nonspecific in its results. You can have a test, let's say the core test, that is designed and works very well in a patient population, detecting somebody who has recently had hepatitis. That test will work very badly in a blood donor population where very few people have recently had hepatitis B, and the frequency of false positive will greatly exceed the frequency of true positives. So it's got poor specificity, and fair sensitivity.

So that's part of what we looked at, but remember, we were facing a dreadful disease and grasping at straws. If our studies showed any evidence that any of the proposed surrogate tests would have clearly reduced the risk, we would have used that test without any question.

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[1] R.J. Biggar, P.H. Taylor, A.L. Goldstein, M. Melbye, P. Ebbeson, D.L. Mann, D.M. Strong. Thymosin alpha-1 levels and helper suppressor ratios in homosexual men (Letter). New England Journal of Medicine, 1983, 309:49.

M.E. Eyster, J.J. Goedert, M-C. Poon, O.T. Prebel. A possible preclinical marker for the acquired immunodeficiency syndrome in hemophilia. New England Journal of Medicine, 1983, 309:583-586.

R.B. Bhalla, B. Safari, R. Mertelsmann, M.K. Schwartz. Abnormally high concentrations of beta-2 microglobulin in acquired immunodeficiency syndrome (AIDS) patents (Letter). Clinical Chemistry, 1983, 8:1560.

The test for hepatitis B surface antibody is one that would give roughly the same results as the core antibody [test], and in a sense, might be considered less useful because this is a test for an antibody which is protective against hepatitis B. So anybody who's got that antibody is not going to transmit hepatitis B. Whereas if you use the core antibody test, there's that little theoretical advantage that you might pick up a few more hepatitis B transmitters, even if you're not being very effective in picking up AIDS transmitters. So that's why people focused on core rather than surface antibody.

The absolute lymphocyte count turned out to be a very poor surrogate test, because lymphocytes get very low only in the later stages of AIDS. So that test was rather quickly disposed of.

Hughes: Lymphocyte numbers decrease because of the depletion of the T cells?

Perkins: Well, the helper cells drop; suppressor cells rise; and the total lymphocytes may not fall until quite late in the disease. So it's an insensitive test in terms of picking up healthy people that would be in early phases of the disease. And the immune complex test got nowhere.

The helper/suppressor ratio was the interesting one. This is the test that Stanford picked up and decided to use. This was a test which at the time was found only in very esoteric research labs and which required a very expensive instrument, highly trained people, and sera that were very difficult to get--all quite available at Stanford, because that's the area in which Dr. Engleman was doing all his research.

To my mind, the important study was the one done at the New York Blood Center. They took persons who presented themselves as blood donors but then confidentially admitted they were at risk for AIDS, and compared their test results with donors who said they were perfectly fine. The final result was that of those donors who said their blood was safe to transfuse, 3.6 percent had a low helper/suppressor ratio. Of those donors who said their blood was unsafe to transfuse, 4.3 percent had a low helper/suppressor ratio.

Hughes: Is that significant?

Perkins: No. It was not even statistically significant. So they concluded it would not be a useful test.

This was the early days in terms of helper/suppressor ratios. I was reading papers suggesting that sitting in the sun too long would give you a low helper/suppressor ratio, and I heard a paper on how simple rhinovirus infection, common cold, would lower your helper/suppressor ratio for three months, and so on. So this was the information I had as of June of 1983. This was before Stanford actually began its routine testing. I decided the helper/suppressor ratio was not a good test.

Now, we were still pursuing the lymphocyte subsets as a possible surrogate test. We had on loan from Becton Dickinson a new device that they had developed and they thought would be marvelous for blood banks. It was sort of an idiot-proof machine to do helper/suppressor ratios. It was very simple; so simple that when it went wrong, which was every five minutes, you had no way of figuring out what was going on. You had none of the diagnostic tools to correct it.

We and everybody else who had that instrument fussed with it for over a year, finally got it working about a year later, but with added instrumentation so you could do your own trouble-shooting. We actually began to use it in 1984 to follow people who were infected with AIDS, because it is useful for that.

Hughes: This instrument discriminated amongst the lymphocytes?

Perkins: Yes, this could give you helper/suppressor ratios, and at least until a couple of weeks ago, following the CD4 levels was the way you monitored the downhill course of somebody with HIV infection.

So we began actually in 1984 setting up to do helper/suppressor ratios on the people that were being recruited for the San Francisco Men's Health Study,[1] and did those for the next six, eight years. We were working closely with people at Becton Dickinson. The concept was okay, but separating the CD4 and CD8 [cells] did not really discriminate the at-risk from the not-at-risk people. We reasoned that there must be some subset of CD4 or CD8 that will do it better, if we knew which one was being knocked down in AIDS.

Dr. Noel Warner at Becton Dickinson was supplying us with other antibodies, and we were trying to find out if any of those would be useful. The long and short of it was that we never found any of them to be useful in the healthy blood donor population to discriminate the at-risk people.

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[1] For more about the San Francisco Men's Health Study, see the oral history in this series with Dr. Warren Winkelstein.

Stanford University's Blood Screening Process

Hughes: I have the distinct impression that there was some pressure felt at Irwin to duplicate Stanford's use of helper/suppressor ratios, simply to be competitive, that patients had been lost to Stanford for surgery because they felt its blood was safe.[1]

Perkins: Yes, but not on the surrogate test issue. It was the directed donor issue. In fact, somewhere in the files there is a letter from Dr. [Curt A.] Ries, who was then chair of the transfusion committee at UC, in which I informed him we were going to introduce core testing,[2] and he said, "Well, that's very nice, but that's not what we're asking for. We want directed donors."

UC was concerned because several patients were transferred from UC to Stanford to have their surgery because they wanted directed donors.

Hughes: Did Stanford emphasize the fact that their blood was safer than anybody else's in the Bay Area?

Perkins: No, I don't think so. And as a matter of fact, not all of the blood they were using was tested, because about 20 to 30 percent of their blood came from outside Stanford, and that did not have such testing. They were only testing what they collected.

You mentioned that we had knowledge that there was a latent period. Probably the only clearcut evidence that there was a latent period was the UC baby. If you accepted the UC baby as evidence of transmission, then we knew that donor was healthy for eight months before he came down with the disease. There were in addition, however--and we heard about this at the January 4 meeting--some epidemiologic studies of gay groups and contacts suggesting the possibility that there might be a latent period. In the March MMWR, the statement is made that there may be a latent period of as long as two years.[3] So that was information we had early in 1983. Once a test for antibody to the AIDS virus became available in 1985, it became possible to test stored blood

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[1] IMBB Scientific Advisory Committee minutes, November 21, 1983 (CBBL 00127-00128).

[2] Curt A. Ries to Herbert A. Perkins, January 20, 1984 (CBBL 01254).

[3] Morbidity and Mortality Weekly Report 1983, March 4, 1983, 32:101-104.

samples and show that AIDS had appeared in this country in 1977. Blood banks then excluded any potential blood donors who had engaged in risk activities since 1977.

We were working on the assumption that there could be a two-year latent period. In July, I think it was, you'll see a memo from me in which I upped that to three years, because I was getting that information.[1] The next year, it went up to five years.

## Irwin's Efforts to Screen out High-risk Donors

Hughes: You wrote an in-house memo dated January 6, 1983, in which you expressed doubt that the tests Irwin was applying were "doing anything useful."[2]

Perkins: I think you're talking about the thinking we were doing in terms of how do we evaluate whether any of these proposed surrogate tests will be useful in the blood bank setting? The memo from me is addressed to blood bank physicians and Dr. Ammann and Dr. Dritz, and I think my conclusion was that I can see how we're going to demonstrate the core test is feasible to do, but I don't see any way we can prove whether it's working or not in discriminating people at risk for transmitting AIDS.

And then there's a subsequent memo, I think a few days later, which just blithely ignores this and lays out a plan for doing just what I said could not be done.[3] In between the two memos, somebody, I don't know whether it was I or one of the others, came up with the notion that what we needed to do was to take the zip code areas that Dr. Dritz had already given me in which she'd rated the risk of AIDS based on number of AIDS case reports, and see if the frequency of positive core tests correlated with the frequency of AIDS case reports. And that's how we set up that trial we did in March, April, and May of 1983.

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[1] By word-of-mouth. [Post-interview note added by Perkins]

[2] Herbert A. Perkins to Selma Dritz, Art Ammann, January 6, 1983 (CBBL 00391-00392).

[3] Herbert A. Perkins. Interoffice memo to Procurement Laboratory and All Centers re Tests for AIDS, March 10, 1983 (CBBL 00525).

Hughes: Well, that correspondence or communication with Selma Dritz, as I remember, began before the January 4 meeting.

Perkins: Oh, yes. She gave the zip code AIDS risks to me originally in hopes that I could come up with an estimate of what percent of gay donors we had.

Hughes: Was the purpose to get an estimate of what kind of risk Irwin was facing?

Perkins: What the risk might have been, yes.

Hughes: It would have been a rather imprecise measure.

Perkins: Oh, terribly imprecise. And I had been asked to bring that to the January 4 meeting if I could come up with an estimate, and I told them at that meeting I just hadn't been able to do it. Subsequently, I did. There's a memo in there that comes up with the remarkable conclusion that only 1.9 percent of our donors were gay, and I wrote down, "An incredibly low estimate!!"[1] And it wasn't far wrong, damn it! [laughs]

Hughes: That 1.95 percent was based on Selma Dritz' figures?

Perkins: No, what they were based on was the proposition that, in San Francisco at least, the AIDS cases were all in males, so we could forget about the 45 percent of our donors who were female. Assume that all the donors at risk lived in San Francisco. At that time it seemed like a reasonable assumption; probably not now. Sixty percent of our donors lived outside San Francisco, so that gets rid of 60 percent of the males.

Hughes: You mean 60 percent of your donors with high risk?

Perkins: No, in general. I really should look at the memo, because I think it spells it out. In one sense, it's spelled out in the results of the core antibody trial, because you can see the same kind of figures showing up. [tape interruption]

Hughes: Dr. Perkins, I saw reference to the fact that on January 5, Irwin planned to survey all male donors for a period of two months, to try to determine how many high risk donors Irwin had.[2] It was a

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[1] Herbert A. Perkins to Brian [McDonough], January 11, 1983 (CBBL 00430-00431).

[2] IMBB Administrative Staff Meeting Minutes, December 27, 1982 (CBBL 00321).

different effort than the estimate based on Selma Dritz' estimates.

Perkins: Right. Except we didn't do it. Our new executive director, Brian McDonough joined us in November 1983, and walked right into this mess. He had called on a woman who was an expert in marketing to help him with some things, and she was a great one for running surveys. She suggested that a solution to the problem of what percent gays we had was to do a survey asking the question.

I am not totally sure why we never did. I have a feeling that the BAPHR people talked them out of it, saying that nobody would give an honest answer, that the survey would be meaningless. But the only concrete fact I have is that it never went forward. So I can't help you beyond that.

Hughes: Was the marketing woman Janelle Lynam?

Perkins: No, Janelle Lynam was director of donor recruitment. The marketing expert was Mary Joyce.

Hughes: Well, since I brought her in, erroneously, I would like to hear about a memo you received on December 15, 1983 from Janelle Lynam which stated, "If we implement surrogate testing, we would eliminate 7.3% of our donor population, according to your calculation. Based on a net draw of 120,000"--and that's per year?

Perkins: Yes.

Hughes: --"this would eliminate 8,760 of our donors. This would impact drastically on donor recruitment."[1]

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Perkins: That and the self-exclusion policy. See, in the beginning of 1983, we had a concern that we would be losing up to maybe 20 percent of our donors, if our wild guess about what percent were gay was correct. And then, to add on another 7, 8 percent loss through anti-core testing we felt was more than we could handle. By the end of 1983, we thought we had eliminated, for the most part, the gays at risk, so that we could then begin to consider again whether we would be willing to do core testing.

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[1] Janelle Lyman to Herbert Perkins, December 15, 1983 (CBBL 01202).

That question was directed to Janelle because it was at the end of 1983 that we made the decision to go ahead with core testing.

## Preserving Blood Donation Volume

Hughes: I'm playing with fire by asking this question.

Perkins: Go ahead.

Hughes: Please comment about the priorities of preserving the volume of blood donation, versus preserving the safety of the blood supply.

Perkins: Yes. What we're talking about here is human lives. There isn't any question that if blood is not available, many, many lives will be lost. So if you're in a situation such as we thought we were in 1983, where there is a remote possibility of a possible infectious disease being transmitted on a very rare occasion, and balance that with reducing the blood supply to the point where we know people are going to die, then obviously the greater risk is reducing the blood supply. One of my friends said very correctly that the most dangerous unit of blood is the one that isn't there when you need it.

Hughes: Now, does this policy perhaps explain the difference in viewpoint between the CDC and the blood bankers at that January 4 meeting? Some of the CDC people, Don Francis, for example, were calling for stringent elimination from blood donation members of the risk groups, and also for surrogate testing, because CDC's priority was attempting to ensure the safety of the blood supply. What I understand you to be saying is, you were thinking beyond AIDS. AIDS in a sense was a minor problem--well, it <u>was</u> a minor problem at that time, in comparison, for example, to hepatitis B--that it was a higher priority to ensure that you had enough blood for the needs of the community.

Perkins: Yes, I think you're absolutely correct. But it's not correct to say that the CDC felt this way, and the rest of the blood banks felt that way. You're probably correct about Don Francis, but he didn't speak for the CDC.

Hughes: Was there some sort of uniform voice from the CDC?

Perkins: No, there was not. The meeting was summed up at the end by the moderator, Jeff Koplan, who said, "It's really sad we can't reach a consensus."

Debate over Blood Screening Procedures

Perkins: Now, what the CDC felt, I can only go by what they finally put into writing, and that was in the March MMWR.[1] There, they proposed things that were exactly what we were doing. They said surrogate testing needed to be looked at, the tests needed to be evaluated.

Hughes: But nothing dogmatic.

Perkins: They never called on blood banks to do them. In any case, the CDC itself would not mandate; it would be the Food and Drug Administration. But what appeared in the Morbidity and Mortality Report--which was specifically indicated to be the position of the U.S. Public Health Service, which includes the CDC, the FDA, and the NIH--was repeated within weeks in correspondence sent from the FDA to the blood banks. And so at the end of March, we got correspondence stipulating what the blood banks needed to do to protect the blood supply.[2] That was what we were doing already.

Hughes: And the reason nobody was being dogmatic about instituting any of the available surrogate tests was because their validity was not established?

Perkins: Oh, I think everybody would agree their validity was not established.

Hughes: One could argue that a surrogate test that eliminated any risk might be worth instituting, but that doesn't seem to have been the argument.

Perkins: Oh, I don't know whether it wasn't the argument. The question was whether such a test would eliminate any risk. I'm tempted to repeat an old joke, in which a guy came across a friend walking around under a lamppost on a dark night, looking at the ground, and he asks, "What are you looking for?" The friend says, "I'm looking for a quarter." "Oh," he says, "Where did you drop it?" "Over there, across the street, where it's dark." He says, "So

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[1] Morbidity and Mortality Weekly Report 1983, March 4, 1983, 32:101-104.

[2] Director, Office of Biologics, National Center for Drugs and Biologics, FDA to AM Establishments Collecting Human Blood for Transfusion, March 24, 1983. IMBB binder 2, 1-5/83, CBBL 00551-00552.

why are you looking over here?" He says, "The light's better." [laughter]

And there's a certain similarity. Dr. Spira's data showed that the proposed surrogate tests would eliminate some persons at risk for AIDS who were almost certainly never going to be blood donors. The question was whether they would eliminate persons at risk among a blood donor population of public-spirited citizens giving blood for altruistic reasons, a far different population than those attending sexually transmitted disease clinics, or fast-lane gays volunteering to be in AIDS studies.

More important is the fact that a relatively useless surrogate test would increase the risk of AIDS transmission. Gays would continue to donate to get an "AIDS test" in the mistaken belief that their blood was safe if it tested negative.

Hughes: Yet, in terms of the gay population, that didn't really follow. My understanding is that [members of] the gay population, at least in San Francisco, were good blood donors. In fact, Irwin had mobiles going through the gay community. Of course, you stopped that.

Perkins: Right. There were good blood donors who were gays, there's no question about that. But we had instituted this self-exclusion policy which we were told and believed was working quite effectively, and later on, found evidence that it had worked quite effectively. That policy essentially did exclude all gays. The few that it didn't exclude were the monogamous couples and the celibates.

Now, where it didn't work was not because our terminology wasn't correct. Don Francis will say now, "We should have said, 'Have you had sex with another male?'" He's learned from all the things we've learned over the years.

Hughes: You mean one other male.

Perkins: Yes.

Hughes: Rather than multiple.

Perkins: Yes. When we talked to the people who had developed AIDS after being blood donors, or were found to be HIV-positive once we had the test, these were not people who would have been turned off from donating by that wording. These were people who looked at what we had written, "If you are homosexually active with multiple partners, you must not donate," and they said, "That's not me." And then when you catch them, they say, "Well, yeah, I

had fifty partners last month, and a hundred partners the month before." The wording just ain't gonna help them. We didn't know that then, but we know that now.

Hughes: You mean they were denying--?

Perkins: Denying--denial is exactly the word. I do not believe they were deliberately lying. They were so sure that they could not be at risk, they couldn't accept the fact that they could be at risk. They said, "This can't apply to me. I'm not at risk. Therefore, I can deny that I am homosexually active with multiple partners."

One of the real worries about the surrogate test was, if we introduced a surrogate test which was ineffective, these guys then clearly would donate, because now they had the test that would tell them it was safe to donate. If they were not safe, the test would pick them up. And besides, if they were not safe, they'd like to know it. They'd like to know what the result of the test was.

So one of our reasons for not doing the core test in 1983 was we felt the gays would continue to donate and come in even larger numbers. And that's why I said, and I really believe, that we would have infected more people.

## Relations among National Institutions Concerned with Blood Safety

Hughes: I'm going to pull you back to the January 4 meeting, I think for the last time. I was wondering if at that January 4 meeting there was any feeling amongst the blood bankers that the CDC was impinging on their professional turf.

Perkins: No. We have always worked very closely with the CDC. For example, the American Association of Blood Banks has a standards committee that writes detailed standards that go far beyond federal regulations on what blood banks should do. That committee, when it meets, always has a liaison from the CDC and a liaison from the FDA. We've worked well together over the years, and we have always wanted their input. Clearly, the CDC was worried. We were all worried--this horrendous thing. We'd seen epidemics before come and go, but this one wasn't going. The CDC's concerns were not only appropriate, but they were shared by all of us. I don't think that this was a them-versus-us situation, which so many people have tried to portray.

Hughes: Well, Shilts is one of them. He described tension, as he saw it anyway, between the FDA and the CDC, maintaining that the FDA resented the CDC invading so-called FDA territory.

Perkins: I'd love to know what his evidence for that is.

Hughes: Let me quote. "Privately in conversation with CDC officials, FDA officials confided that they thought the CDC had taken a bunch of unrelated illnesses and lumped them into some made-up phenomenon as a brazen ruse to get publicity and funding for their threatened agency."[1]

Perkins: And he thinks this happened at the meeting, or subsequently?

Hughes: Shilts makes the statement in a section dated July 27, 1982.

Perkins: I know that Dennis Donohue from the FDA was there at the January 4 meeting, and I know he spoke up, but all I remember him talking about was the prospects of a heated clotting factor concentrate which should be safe. I don't think he ever would have spoken out at that meeting in those terms. If he ever did privately, I have no idea.

I have worked closely with both CDC and FDA, certainly very closely in the last dozen years, and I've never had the feeling that they were at odds with each other. I'm talking research mostly, but a lot of the research was joint. We were working with both organizations at the same time.

## Funding Problems

Hughes: Well, there was of course a funding problem.

Perkins: Well, there's no question that the CDC was urgently requesting more funds to deal with AIDS. I know in early December 1982, there was a hearing in one of the congressional buildings, which I went to. I happened to be in Washington for an American Society of Hematology meeting, and somebody said that there was going to be a CDC report on AIDS and I ought to go, so I did. William Foege, who was then the head of the CDC, gave a talk. It was a good talk. He demonstrated the rapidly accelerating increase in AIDS reports in the U.S. I assume this was a presentation before Congress in an attempt to get more money for

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[1] Shilts, And the Band Played On, p. 170.

AIDS research and prevention. I don't think there's any question about that. It's no secret that all of the government agencies were beating on the president and Congress for more money all along, and still are.

Hughes: Well, one more quote from Mr. Shilts, and that will be the end, for this session, anyway! [laughter]

Perkins: I'll hold you to that one.

Hughes: Shilts wrote, "Privately, some blood bankers thought the CDC was overstating the possibility of transfusion AIDS to get publicity and, therefore, more funding."[1]

Perkins: Again, I don't know. I don't remember hearing that. I'm sure the CDC was looking for more funding. I can only talk about the people I was talking to. For the most part, these were the people in New York. We were communicating back and forth very frequently in those first three to six months of 1983. We went back from Atlanta determined to look at surrogate tests, and determined to set up some method of excluding people at high risk. We had not accepted the fact that AIDS was proven to be an infectious disease. We had not accepted the fact that it was proven that it was transmitted by blood. But we had accepted the fact that the evidence was sufficient to require that we go ahead on that assumption, that it could be possible, and that we'd act as if we had all that proof.

Hughes: So it's the difference between proof and assumption that you were working on.

Perkins: As far as I could see, that was our main quarrel with Don Francis. He was saying, "This is all proven." And I know some of the blood bankers said at that meeting, "It's not proven." And that's correct: it wasn't proven.

Hughes: Well, could it have been proven in your collective minds without isolating the virus?

Perkins: Probably not. Well, no, I won't say probably not; more cases would have proven it. But it didn't matter a bit whether it was accepted as proven. We wouldn't have done anything the least bit different. We went ahead on the assumption that it could be transmitted. And I can't say how we would have done things any differently, no matter how convincing the evidence was.

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[1] Shilts, And the Band Played On, p. 207.

## The Interorganizational Ad-hoc Working Committee on AIDS

Hughes: An offshoot of the same meeting, as I understand it, was the formation of the Interorganizational Ad-hoc Working Committee on AIDS.

Perkins: That's the fancy name for the fact that New York and we were working closely together, and that Los Angeles participated a little bit?

Hughes: Yes. The committee was to serve as a liaison between Irwin, Los Angeles, and New York blood services.

Perkins: Right. And it was really mostly New York and Irwin, because Los Angeles didn't do very much.

Hughes: Why?

Perkins: You have to ask them--I don't know. [laughs]

Hughes: And not because they didn't have an AIDS problem?

Perkins: They were third on the list of problems, after New York and San Francisco.

Perkins: No. When I say they didn't do anything much; they did what we were all doing to protect the blood supply, but in terms of research on surrogate tests, they did rather limited work.

Hughes: Committee members were comparing notes about surrogate tests?

Perkins: And screening techniques.

Hughes: So you were essentially sharing data?

Perkins: Yes. And by the June 6 meeting of the committee, at Irwin, I had all of the New York data on the surrogate tests.

## More on Donor Screening

Hughes: Here are notes on the January 5 survey that never happened, right?

Perkins: Never happened. The point that the BAPHR people were making to us is that you can't ask people, "Are you a homosexual?", because

everybody's definition differs. The guy who's bisexual would say no to that question. And if you ask if he's homosexual or bisexual, a guy who's primarily heterosexual will say no. So we finally learned that the only real thing to ask people is, "Have you ever had sex with another man?" That is not something that we felt we could have asked back in 1983. By the time we got around to asking it, blood donors had gotten a little bit used to being asked sexual questions as blood donors. As it was, many of our donors were insulted by our original indirect questions, and some would never return.

Hughes: There was a note to you dated February 10, 1983, from Paula Lichtenberg, and she was the secretary of the Coalition for Human Rights, which, was, and still is, a coalition of over fifty-two gay, and lesbian, and bisexual groups in San Francisco?[1]

Perkins: Yes.

Hughes: She wrote you in protest over what the coalition saw as a violation of Irwin's agreement in January of that year to ask no questions of donors related to sexual preference or national origin. What happened?

Perkins: Well, number one, we didn't have any agreement in January. I don't know what she's talking about. We had no direct dealings with that group until that letter and a subsequent face-to-face meeting with her and one other woman from the group. The AABB CCBC Red Cross statement that came out on January 13 [1983] did, of course, say it was inappropriate to seek out the sexual orientation of the donor.[2]

Hughes: Because it was a violation of individual rights?

Perkins: I wasn't on that committee, so I don't know, but I presume that's one reason. And another probably was that it wouldn't be effective.

This is what we struggled with, with the help of BAPHR: How do we accomplish what we're after without that kind of direct confrontation? And that's why we ended up with the rather indirect approach we took, in which we had a compound question that could be answered with a simple yes or no without admitting whether you were gay or not.

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[1] Paula Lichtenberg to Herbert A. Perkins, February 10, 1983.

[2] Joint statement of acquired immune deficiency syndrome related to transfusion, January 13, 1983 (CBBL 00435-00436).

Hughes: You mean whether you had had sex with one other male?

Perkins: We listed homosexually active men as one of the risk groups, and we said that the people to be excluded were those with multiple partners.

Hughes: And then subsequently cut it down to one partner.

Perkins: No. We excluded those with multiple partners, which meant excluding all those with more than one partner. I don't know whether it's coincidence or whether this was due to talk among the gays across the country, but when the Public Health Service, MMWR, and the FDA letters came out in March 1983, they used almost the same terminology. They said it a little bit differently; they said homosexual or bisexual men with multiple partners. We felt our wording was better because it included the heterosexual with occasional homosexual flings. So we left our wording as it was and did not change it when the FDA memo came out. And we sent it to the FDA, and they approved it.

Hughes: Which you had to do?

Perkins: Yes. Either we had to use one of the pre-existing brochures they had approved, such as the AABB one, or if we deviated from it, we had to send it to them and get it approved, so we sent it to them.

Hughes: And this applied how widely?

Perkins: To all blood banks.

Hughes: But not to the commercial suppliers?

Perkins: There was a separate mailing to commercial suppliers, which was a little bit different in its requirements.

Hughes: March 24, 1983, a directive from the Office of Biologics of the FDA advised all establishments collecting blood to decrease blood

collection from high-risk groups.[1] I was struck by the fact that the word "decrease" was used instead of "eliminate."

Perkins: Yes, I think it's a very good example of how difficult this problem was for the people making decisions. It certainly sounds like they're trying to avoid stigmatizing an entire group.

Hughes: The Food and Drug Administration could have been accused of being more concerned about loss of potential donors than about a safe blood supply.

Perkins: Well, I think they were more aware of donor loss as an issue than other agencies in the government, because they dealt with blood banks all the time. There's nothing they say there that specifically refers to that concern, however.

## Philosophy of Blood Donation

Hughes: Some of the literature that I've been reading has made a point of blood as a gift and as a means of binding the community together.[2] What happened to those concepts when receiving blood became recognized as a risk?

Perkins: Well, it raised a rather complicated issue. There was, of course, the original concern of paid versus volunteer donors. In the early seventies, the federal government got into the act and established the national blood policy, one of its goals being to create an all-volunteer blood donor system. This was based on evidence that those blood banks that used paid donors were

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[1] The statement reads: "Consistent with the recommendations of the American Red Cross, the American Association of Blood Banks, the Council of Community Blood Centers, and the Public Health Service Interagency committee..., the Office of Biologics is advising all establishments collecting blood for transfusion to institute additional measures designed to decrease blood collection from individual donors and donor groups known to be at increased risk for transmitting AIDS." Director of Office of Biologics, National Center for Drugs and Biologics, FDA to All Establishments Collecting Human Blood for Transfusion, March 24, 1983 (CBBL 00551-00552).

[2] Thomas H. Murray. The poisoned gift: AIDS and blood. A Disease of Society: Cultural and Institutional Responses to AIDS, Dorothy Nelkins, David P. Willis, and Scott V. Parvis, eds. Cambridge: Cambridge University Press, 1991, pp. 216-240.

transmitting a lot more hepatitis than those that did not. An all-volunteer system had occurred at Irwin long before this.

So the swing to an all-volunteer system continued. There was a further fight between what was in one sense a Red Cross philosophy that it was the community's responsibility to maintain an adequate blood supply, and the position then, and no longer held, by the American Association of Blood Banks that individuals who use blood had a responsibility to see that it got replaced. Those of us who were on the AABB side used a credit system whereby basically if you had given blood, you could receive blood at a discounted price. So that was an additional argument between total community altruism and altruism plus duty, if you will.

In actual fact, most blood donors, and this is true as far back as I can think here, even with that credit system, blood donors totally thrived on a sense of duty and pride and did not donate to get anything material for it. So then you ask the question, well, if people are donating only to help their fellow man, why in heck would anyone ever put their fellow man at risk by donating when he might possibly be at risk himself? If you asked me that question in early 1983, I would have said, "Of course they wouldn't," and I know better now. People who were donating for purely altruistic reasons who should have known better did continue to give blood. We didn't know that then.

Hughes: It's that denial issue.

Perkins: It's the denial issue, right.

Hughes: Also peer pressure.

Perkins: Well, when you donate with a group, then you have the worry that if you stop donating, people will be suspicious of why you stopped donating. And that was why approaches were developed that allowed people confidentially to let us know not to use the blood they donated.

## Irwin's Dialogs with the Pubic and the Media

Hughes: How had procedures changed when, presumably anyway, Irwin was being besieged by calls about the safety of the blood, what did you do about policy? Presumably, you had to train everybody here--well, everybody answering the phone here anyway--to present a unified approach to the public.

Perkins: Most of the questions were referred to me, unless they were fairly simple, obvious ones. The staff certainly had been told what we knew, and also very obviously were telling people in 1983 that the blood supply was "safe," that the risk of AIDS was extremely low. That wasn't true, but we thought it was.

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Hughes: Did you have any standard procedure for dealing with the media?

Perkins: Just to tell them honestly what we knew, and wish that what we knew was closer to the truth. There's no question that we were reassuring about the safety of the blood supply; we thought it was safe. Everybody who had anything to do with it, not just blood banks, thought it was safe. And it wasn't. And so we lost the public's confidence, and it's been very difficult to get it back, even though now we talk from considerable knowledge and good data, and then we were dealing with considerable ignorance.

## Cases of Transfusion AIDS

Hughes: When would you date the loss of public confidence? When did it begin noticeably?

Perkins: I think it really began in 1984, when the first headlines began appearing about people with transfusion-associated AIDS. In 1983, it hadn't really hit home. In retrospect, it appears that a lot of the gays began to believe us in early 1984, and that's why we had a very sharp drop in donations by people at risk at that point. That's assuming our current estimates are correct, these retrospective estimates.

Hughes: Well, here's an example of what we were talking about in terms of reassurance. It's a memo and draft of a statement that was to go out jointly from all the Bay Area blood banks to the media, dated June 24, 1983, that Brian McDonough sent out, who then was president of Irwin, as you know.[1] The statement was to go to the heads of the six Bay Area blood banks. The opening sentence is, "The Bay Area blood banks (identified below), after having examined the relationship between blood transfusion and the transmission of Acquired Immune Deficiency Syndrome (AIDS), have not found scientific evidence which indicates blood transfusion

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[1] Brian McDonough to [heads of six Bay Area blood banks], June 24, 1983 (CBBL 024051-02452).

from volunteer donors to be important as a means of spreading this disorder." Yet, approximately six months later, there were forty transfusion AIDS cases being investigated.[1]

Perkins: That could be right. I thought the figure was thirty-four.

Hughes: There may not have been forty known cases in June, but surely a sizeable proportion of that forty must have been known.

Perkins: That's exactly the problem. We had the UC baby, and we were told at the time of the January 4 meeting that they had two other possible cases of transfusion AIDS under investigation, and that's all we were told.

From that point on, we kept hearing rumors that the CDC had more cases under investigation. CDC published nothing. In June or so of 1983, around the time of this letter of Brian's, there was another AABB joint statement that mentioned something like twenty, twenty-four cases being investigated.[2] The problem is, an awful lot of people get transfused. So if you look at any large number of AIDS cases, you're going to find people who have been transfused. The question is, what's the evidence that there's any connection between the transfusion and AIDS in these people? The CDC and I were looking for evidence of AIDS in the donors to these people. I think I told you that I could find no further evidence of AIDS in recipients of donors who came down with AIDS, and the CDC wasn't finding any either.

But by the end of the year, they had gotten enough information on eighteen of those cases under investigation that they published it in January of 1984 in the New England Journal of Medicine.[3] In that report, they showed that most of these cases had a suspicious donor, a known gay or drug user or what have you. So it was not until that January 1984 paper that we

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[1] [Alfred J.] Katz, Executive Director, Blood Services, American Red Cross to executive heads, directors, medical/scientific directors, January 3, 1984. (From an unlabelled raw data folder belonging to Dr. Arthur Ammann.)

[2] Katz [Executive Director, American Red Cross] to Executive Heads, Directors, Medical Scientific Directors, Administrators. [ARC, AABB, CCBC] Joint Statement on Directed Donations and AIDS, June 22, 1983. (From an unlabelled folder belonging to Arthur Ammann, M.D.)

[3] James W. Curran et al. Acquired immunodeficiency syndrome (AIDS) associated with transfusions. New England Journal of Medicine, 1984, 310:69-75.

knew the CDC had anything more to talk about than that one UC baby.

I can remember in June of 1983 people calling on the CDC: "If you've got more data about AIDS transmissions, let's see them. Even if they're not complete, bring them out, let us look at them; give a sense of how much attention we should be paying to it." So yes, we knew there were more cases.

Hughes: Why wasn't the CDC getting the data out?

Perkins: Well, I guess they got it out as fast as they could, I don't know. See, they had to work through the blood banks which reported the transfusion-associated AIDS cases. Let's say they started with the report of AIDS in a transfused recipient. Then they had to go back to the blood banks and say, "Hey, can you find out who the donors were to this patient?" Then you get the donors to come in, let us interview them, let us test them, and this was done in case after case. I know that's very time consuming. Just trying to get these donors to come in; they're busy, "I'll get around to it, I'll see you next week," that kind of thing. And then the tests took time. But why the hell should I be excusing the CDC? Let them fight their own battles. [laughter]

## Washington Burns's Letter to the IMBB Board of Directors, January 1984

Hughes: I found a document written by Washington Burns--

Perkins: Oh yes, that's a lovely document.

Hughes: Good, I'm glad you like it. [laughter]

Perkins: You have to know Washington Burns.

Hughes: Well, I want to hear who he is.

On January 16, 1984, Washington Burns submitted what he called a "Rationale for Screening Blood Donors for Anti-core Antibody,"[1] He stated, "We," and I presume he means Irwin?

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[1] Washington Burns. Rationale for screening Blood donors for Anti-core Antibody, January 16, 1984 (CBBL 02475).

Perkins: I presume.

Hughes: "We are not providing the safest blood product possible when we withhold screening for anti-core. Morally and ethically we have the responsibility to provide the safest blood products possible to the community. I can no longer accept the arguments of increased cost or reducing the number of eligible donors. The blood community has merely swept this issue under the rug."

Perkins: That's a great quote. This document came to the [IMBB] board at the same time that I brought from the Scientific Advisory Committee a recommendation that we start core testing. Burns has been a good friend of this blood bank; he'd been on the board for many years; he was president of the board at one time. He tends to be a very quiet person who, every now and then, explodes in a way that's somewhat inappropriate. That's all I can say. He's embarrassed by what he wrote; he thinks it was incorrect, but it's no question he wrote it. He submitted it. And I've seen him speak out at board meetings on other subjects; like he's been sitting there holding everything in, and then suddenly it comes out and it's far more forceful than he intends. I don't agree with what he said. I certainly can't deny that he wrote it.

Hughes: Which part of it don't you agree with?

Perkins: Well, I certainly agree that we were morally and ethically required to produce the safest blood we possibly could. I don't agree we were sweeping it under the rug, absolutely not. And I think he would say the same thing if asked at this point.

Hughes: There is no correlation between this statement and your instituting the anti-core test?

Perkins: No. Irwin's Scientific Advisory Committee had been asked repeatedly to advise us on two issues. One was surrogate testing, and the other was directed donations. These were the sticky issues that had almost as much politics as science involved, and was one reason why the committee used to hate for me to bring these subjects up. They split badly on them, but until the December meeting, had a reasonably strong majority against doing either one.

At the December meeting, I think by a majority of one, they decided the time had come to consider core testing, and

recommended it to the board. So they did, and it was reported to the Irwin board[1] at the January meeting.

Arguments Pro and Con Anti-hepatitis B Core Antibody Testing

Perkins: I don't know whether I've gone over with you the reasons why we didn't do core in 1983 and we did do core in 1984?

Hughes: No, I'd like you to do that. [tape interruption] Dr. Perkins is looking at some notes that he made, presumably for his own use--

Perkins: No, I believe this was at the request of the [IMBB] board. They asked me to come to them with the pros and cons of instituting core testing, since the Scientific Advisory Committee had recommended that we consider it, but had not given it a very strong recommendation. So what would the arguments be for and against?

In 1983, we were in a situation where we had certainly no proof that we were transmitting disease. We had a serious problem in terms of keeping up the blood supply, if we were right that 20 percent of our donors were gay, and then we added into that another 7 percent or so eliminated because of core positives. So that was one of our concerns.

Concern number two was that almost everybody, and that includes Don Francis, will admit 98 percent of the core positives are not gay and had nothing to do with AIDS risk. We were appropriately very much concerned about the psychological trauma to a donor told he or she could not donate again because of a positive "AIDS test", despite our assurance that test was most likely falsely positive for AIDS.

Number three, we were concerned that having the surrogate test available, the gays would continue to donate. That was our worst fear at all.

As we went into 1984, we were beginning to see the first public reports of other cases of transfusion-associated AIDS. The public was getting disturbed a lot. You had on one side worried about hysteria in the donors because they were positive in the core test; on the other side, people who needed a

[1] Minutes of the [IMBB] Scientific Advisory Committee, January 10, 1984 (CBBL 01240-01241).

transfusion were terrified of receiving it. And the balance there had swung to the patients; patients' hysteria became more important than worrying about the donors' hysteria.

In terms of the adequate blood supply, we had gotten through 1983 quite nicely, and could afford it. The percent of our donors who were gay proved far lower than we had estimated, therefore, the loss of another 7 percent of our donors could be tolerated.

Hughes: Now, I understand that in tandem with this drop in donation, there was a concomitant drop in the use of transfused blood, that doctors were thinking twice before transfusing?

Perkins: I'm sure that happened then. I can't remember any good figures, but certainly, as you look at what's happened between 1982 and '92, there's been a fantastic drop in the use of transfused blood.

Hughes: Well, I know in the literature, there is talk along the lines of blood transfusion always has inherent risks; you physicians should think about it before you do it.

Perkins: Well, I've spent my life the last thirty-five years preaching that to physicians, so it's not just AIDS. [laughter] And the other thing, autologous donations had been available from this blood bank certainly since the beginning of the seventies and probably earlier. I can't find documentation earlier than that. But only with AIDS did people begin to take it seriously, and patients began to ask for it. So yes, there were these changes taking place.

At any rate, in terms of core testing, the situation had changed. We had no reason to believe that core testing would be any more effective than we had thought it would be back in 1983. But the New York Blood Center data had suggested it might be just slightly more effective, and as you say, if you could get rid of even one or two of these people, why not do it? If you could do it without risking increase of donations from the gay population. And we felt that it was probably reasonable to hope that once they had stopped donating, they would not resume again.

But frankly, I have to say that when we started core testing in 1984, I was not the least bit sure whether we were making the blood supply more safe or less safe. So we did it, and an awful lot of the reason we did it at that point was because of the fact that the public was so concerned, and wanted to be sure that we were doing anything that could make the blood supply safer.

Whether we were convinced or not, they were convinced that these surrogate tests would help.

Hughes: Are you convinced now?

Perkins: Now, at this time, I have a harder time convincing myself that surrogate tests would not have been helpful by 1984, because the core test, in retrospect, once we had an anti-HIV test to compare it with, turned out to be better for donors than we would have suspected, based on the data we had in 1983 (although far poorer than Spira's data would have predicted). Whether it was enough better to counter gays continuing to donate, I'm not sure at all. If the gays had continued to donate, even with the current knowledge of core's effectiveness as a surrogate test for AIDS, I'm not sure the blood supply would have been safer.

## The Risk of Transfusion AIDS Before 1985

Hughes: So you can't pin significant numbers of transfusion AIDS cases on that brief period between the beginning of surrogate testing and before the HIV test?

Perkins: No, I cannot. There was very little AIDS transmitted by transfusion in that period. The key evidence we have was published by Dr. [Michael] Busch, our scientific director, in the January 1991 issue of Transfusion.[1] That's the article in which he showed how he could make quite an accurate estimate of what the risk of transfusion-associated AIDS had been at any point back in time since the beginning of the epidemic. That's what I'm basing my figures on, along with one other paper we've published,[2] when I say things dropped in 1983 and 1984.

Now, in the first paper, Mike Busch looked at estimates at six-monthly intervals. The difference between the first half of 1984 and the last half of 1984 was very significant [the transmission figures dropped]. People have jumped to the conclusion that was because we started anti-core testing on May 1

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[1] M.P. Busch, J.J. Young, S. Samson, J.W. Mosely, J.W. Ward, H.A. Perkins, and the Transfusion Safety Study Group. Risk of human immunodeficiency virus (HIV) transmission by blood transfusions before the implementation of HIV-1 antibody screening. Transfusion 1991, 31:4-11.

[2] H.A. Perkins, S. Samson, M.A. Busch. How well has self-exclusion worked? Transfusion 1988, 28:601-602.

of 1984, so I had him go back and re-do his analysis in thirds instead of in halves, and most of the drop occurred in the first third before we started the core testing. That was when the newspaper headlines on transfusion-associated AIDS were coming out, and the gays really began to believe us.

So, God knows what surrogate testing might have accomplished. I don't know whether it would have made the blood supply more safe or less safe by 1984. I do know that the evidence at the time said it would make it less safe, at least in 1983.

Hughes: [tape interruption] Was there an obligation, when you had indication that the blood tested positive for HIV, to report to the state?

Perkins: You're talking about blood donors who are HIV antibody positive?

Hughes: Yes.

Perkins: Yes. Those names were and are reported to the state, but it's done as part of a general reporting of infectious disease testing. Hepatitis-positive donors are also reported to the state. So the state does not know why these people are being reported; they just know they're ineligible for blood donation. There is a California State Blood Donor Deferral Registry, which is constantly updated, and we get fresh tapes to plug into our machines every month or so.

Hughes: But nobody can tell why a person is ineligible?

Perkins: Nobody can tell why, right. That list actually includes people who were diagnosed with hepatitis by their private physician, and that kind of thing.

## New Technologies for Blood Screening and Testing

Hughes: Please comment on technology that was introduced because of the AIDS epidemic. You've mentioned the Becton Dickinson cell analyzer machine.

Perkins: Well, I think there's no question that the epidemic has influenced technology. Instead of two infectious disease tests, we're now doing seven or eight. I'm sure most of this would not have happened except for AIDS. I can't say that positively.

The human T-lymphotropic virus, HTLV, is a retrovirus which can be transmitted by blood transfusion, and in a very small percent of people, it can cause leukemia, or it can cause a spinal cord disease characterized by difficulty in walking. The test for HTLV was introduced and became a routine test in this blood bank before we knew most of that. The fact that we had a test, the fact that it was known that leukemia could be caused by this virus in extremely rare instances, was all it took to get that test introduced.

Hughes: Here, but not necessarily elsewhere?

Perkins: No, all over the country.

Hughes: Was that a blood agency dictum?

Perkins: It's not an FDA requirement, but I think the AABB recommends it. We started the core testing in 1984. In 1985, we got the test for anti-HIV. Now we have a much better anti-HIV test which reacts with HIV-1 and HIV-2. In 1986, we added another surrogate test for liver disease, the ALT test.

Hughes: What does that stand for?

Perkins: Alanine aminotransferase. It's a liver enzyme that leaks into the blood when there's liver cell damage. And then, of course, the hepatitis C test came along, and an upgrade, a second generation hepatitis C test, is now used. And then for certain patients, we test for anti-cytomegalovirus--newborns, marrow transplant patients, and other immunosuppressed patients.

Hughes: What does this testing add to the price of blood?

Perkins: The price of blood actually has not gone up as much as one would think. Every test certainly adds to our costs. We've been able to hold down costs partly because we used to dispense blood as a single unit; now we break it up into fractions, and we get income from each of the fractions. If you're talking about the price of red cells, I suspect it may have tripled in the last twenty years. That's not worth talking about. [laughter] We've also been helped at this blood bank by the fact that, even though doctors are transfusing less per patient, there are so many new procedures that require blood transfusion that the use of blood has increased overall.

Hughes: Even with things like the cell saver?

Perkins: Yes. Red cell use has pretty well plateaued, but platelet use is still climbing steadily at maybe 10 percent a year.

Hughes: What are the procedures that are particularly effective with platelet use?

Perkins: Organ transplants, and chemotherapy for leukemia and other malignant diseases, and marrow transplants particularly. These are all things that just wouldn't ever be done if blood was not available in adequate amounts.

Hughes: Anything else in terms of new technology, new techniques?

Perkins: Well, we're constantly working. That's one of the areas that we have spent a lot of effort on in our research labs in the basement, Dr. Busch particularly. There are new techniques which are not yet at the point where they can be useful in the blood bank. So many of the tests we do are for antibodies to the infectious agent. And those antibodies are not there when the infectious agent enters the body, so there's always that window period before the antibody appears when you may have somebody donating. So you'd like to test for the virus itself.

And such tests exist. There's the polymerase chain reaction [PCR] which allows you to take a single virus and turn it into a million copies of itself in about three hours, and then of course you can detect its presence, whereas you could never detect the presence of a single virus. The problem with that technology is that it is so exquisitely sensitive that it's almost impossible to test multiple samples without contaminating among the samples. You have to go through a lot of precautions, and to do it on a very large scale is difficult. It's very expensive and time-consuming.

Hughes: Is PCR in common use at the blood banks?

Perkins: No. It's a good research tool.

Hughes: But it's not practical--

Perkins: To screen blood donors it is not practical. We and others have been working to modify this test to bring it down to the level where it would be practical. I'm sure someday this will happen, but it isn't in sight yet. There's another approach which is even more exciting, and that is to sterilize blood so even though there are bound to be organisms in it, we'll kill them all.

Hughes: How?

Perkins: Well, this is being done routinely now for the plasma fractions, the clotting factor concentrates that the hemophiliacs get. So many hemophiliacs got AIDS through these concentrates, and now

they are totally safe from AIDS, and from hepatitis too. The decrease in hepatitis has been dramatic. In the sixties, your chance of getting hepatitis from a blood transfusion was about 25 percent. In the seventies, we got it down to 10 percent.

Hughes: How?

Perkins: By getting rid of paid donors for the most part, and by the hepatitis B surface antigen test. And now it's down to about one in 6,000.

Hughes: Again, how?

Perkins: Well, we got the hepatitis C test. We didn't have any test for that virus. We have the nonspecific core antibody, and ALT test, being used as surrogate for hepatitis. And we have tighter screening of donors. Screening out the gays helped on that too.

## Letter to the *New England Journal of Medicine*, February 1984

Hughes: In the New England Journal of Medicine article that you referred to of January 12, 1984, the CDC reported eighteen cases of transfusion AIDS. On February 21, you, Howard Goldman, Dr. Ammann, and Dr. Dritz wrote a letter to the editor of the New England Journal.[1] Do you remember that?

Perkins: No. [laughter] What did we say?

Hughes: I'll find it for you. [tape interruption]

Perkins: At the time that Curran wrote his paper that was published in the January 1984 New England Journal of Medicine,[2] we submitted a response in the form of a letter to the editor. We had been trying to get information published about our study of other recipients of donors who had come down with AIDS subsequent to giving blood. We had been unsuccessful in getting it published, either as a letter or as an article submitted to the New England Journal of Medicine, or to Lancet. We also submitted it to the

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[1] Draft to the editor, NEJM, February 21, 1984 (CBBL 02185-012870).

[2] J.W. Curran et al. Acquired immunodeficiency syndrome (AIDS) associated with transfusions. New England Journal of Medicine 1984, 310(2):69-75.

1983 AABB annual meeting to give a talk on the subject, and didn't get accepted there either. But then neither did Engleman's submission on the use of helper-suppressor T lymphocyte ratios to screen out donors at risk for AIDS. He has always complained about that.

Hughes: Were you given reasons for the rejections?

Perkins: In terms of the AABB meeting, they actually held a special session on AIDS where they let people get up and present what data they had.

Hughes: So they felt that was adequate.

Perkins: Yes.

Hughes: Do you remember if you presented some of that information?

Perkins: Yes.

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Perkins: The letter we submitted following Curran's article was rejected, I think probably in retrospect appropriately, because we had incomplete evidence that really didn't prove very much. With more follow-up, it became evident that some of the patients we were following were indeed infected with HIV.

Hughes: Another question relating to 1984: In September, Brian McDonough wrote a memo to the staff reporting the death from AIDS of a woman who had received multiple transfusions in 1982 at UCSF. Now, this was Irwin's first transfusion AIDS case?

Perkins: No, the UC baby was the first case. First case since the baby? No, I don't believe it was the first case since then. [tape interruption] Brian did something at the time that I thought was very stupid; in retrospect, I had to agree with him it was a very smart move. He told the press that we were going to have thirty more cases of transfusion-associated AIDS before the year was over. I thought that was a gross overestimate, and why tell them anyway; we didn't know it was going to happen. He said, "From now on, the press is not going to pay attention to any further cases that get reported."

Hughes: And was that indeed the case?

Perkins: Not quite, but it did calm down things.

Hughes: How did he arrive at that figure?

Perkins: I don't know.

Hughes: Did he pull it out of the air, do you think?

Perkins: Probably.

Hughes: But it turned out to be pretty accurate?

Perkins: Well, probably turned out to be an underestimate.

Hughes: Did you feel beleaguered at the height of the transfusion AIDS problem?

Perkins: Yes. We felt that we had a terrible responsibility. We felt there was an immense amount of hysteria out there which we thought was disproportionate to what the evidence indicated, and that we had a need to reassure the public, because we really thought the blood supply was not as dangerous as they thought it was. That's what all the evidence said.

Hughes: Was there any particular source that you thought was guilty of fanning the hysteria?

Perkins: No. The media always likes to make a story that the public will enjoy reading, and the public likes to be frightened and amused and all kinds of things. So sure, they were looking, and looking appropriately, to see whether they could find any evidence that things were worse than appeared on the surface. All we did was to tell them what we knew. We had a press conference on February 8, 1983, at which we had fifty people in the room.[1] We had every TV station, all the newspapers, the gay press, most of the radio stations--

Hughes: From across the country?

Perkins: No, from San Francisco.

Hughes: You got national coverage?

Perkins: Oh, subsequently, but at the moment, there was just the local press. That's where we issued our plans for changing our donor screening and the new donor form we were going to use.

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[1] See IMBB News Bulletin, February 8, 1983 (CBBL 00494-00495).

BAPHR's Statement on Donor Screening

Perkins: As I've said, the BAPHR people were there with us, and they had their own statement which didn't quite agree with ours.[1] That was all right.

Hughes: Had you known in advance that the statements would be different?

Perkins: The difference was that we were very specific that homosexually active men with multiple partners should exclude themselves, and they talked about how little was known about AIDS, and how people had to make up their own mind on who should be excluded, or who should self-exclude. I'm not sure we saw that statement before the conference. They were trying to come up with a statement that would be acceptable to the entire gay community, and they were telling us that there were groups out there on the left that were very adamant that there should be no mention of gays, no exclusion of gays, no discrimination against gays at all in blood bank policy. And BAPHR was not accepting that.

Hughes: The bathhouse crisis was occurring at this time?

Perkins: The bathhouse crisis was a little bit later, because I was on [Mervyn] Silverman's advisory committee [San Francisco Department of Public Health Director's Medical Advisory Committee] at that point, and I remember discussing it.[2] I sure in heck would not have been on his advisory committee before February of 1983.

Hughes: The bathhouse crisis runs from early 1983 to October of 1984, when they closed.

Perkins: Right. At our February conference that we and the BAPHR people had with the press, as I say, there was this difference between us. Subsequent to that we got the letter from the Coalition for Human Rights, which said we had reneged on our agreement and were going to be excluding gays as blood donors. We invited them in, and I remember Brian and I sitting down with two representatives from that group and explaining why we felt we had to do what we did. We felt they left convinced and willing to support us.

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[1] Bay Area Physicians for Human Rights (BAPHR). Position on Acquired Immune Deficiency Syndrome Related to Transfusion, February 6, 1983 (CBBL 00484).

[2] For more on bathhouse closure and surrounding controversy, see Mervyn Silverman's oral history in this series.

Hughes: And they did?

Perkins: I don't know what individual groups did. But as I say, the risk did fall off from that point on. Not as fast as I would have liked, and now that I have better figures, not as fast as I thought it was happening.

## Procedures for Self-exclusion from Blood Donation

[Interview 3: July 8, 1993] ##

Hughes: Dr. Perkins, last time you said off-tape that you wanted to talk about the procedures for self-exclusion.

Perkins: Yes. One of the obvious things we had to do from the moment we identified that child at UC was to develop a technique for removing from the pool of donors people who were at risk for transmitting AIDS, assuming that it could be transmitted by blood. We began with the elimination of drives to known gay groups, and our concern was really totally about the gays, because 98 percent of the AIDS cases in San Francisco were among known, self-identified gays.

When I came back from the CDC meeting, there's a memo dated January 7 in which I added a few questions for the nurses to ask in taking donor medical histories.[1] And there's a second memo dated a few days after the January 13 meeting, the joint statement from the three national blood bank groups which revised and added to those questions.[2] So in January, we were adding extra questions that the nurse was asking that were not on the donor history cards.

We were trying through January to devise an approach by asking the health department and the people from BAPHR to identify those people who would be at risk for transmitting AIDS. I think we discussed the fact that we started with the concept of the fast-lane gays but then switched to the notion that anybody with multiple partners would be at risk. So, with the help of the BAPHR group, we designed a form. We sent it out to a number

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[1] Herbert A. Perkins to All Departments and Blood Center Physicians, January 7, 1983 (CBBL 00399).

[2] Herbert A. Perkins to All Departments, Blood Centers, Physicians, January 19, 1983 (CBBL 00441).

of groups to look at to see if they had any questions, and ultimately got it printed up and ready for use.

In the meantime, we heard the FDA was going to come out with some recommendations, so we held off on printing the form. The FDA recommendations came out, I think March 24, 1983,[1] and I think our form was printed and in use by the middle of April.

Hughes: And did the FDA announcement make any difference?

Perkins: Yes. Because their announcement, together with the AABB transmittal memo that came to us after they saw the FDA announcement, added one thing that we did not have in our plans, which was to provide each donor in advance of donation with written information that he would have to read before donating, an information sheet, which was an excellent suggestion. We liked it and adopted it.

Hughes: Did you word-for-word adopt what they had suggested?

Perkins: Not exactly word-for-word. We certainly incorporated everything they had suggested. We had to send it to the FDA for approval. They approved it, except they objected to the fact that we were asking the donor to certify that he or she had told the truth. They weren't sure that was legal. But anyway, we ignored that, [laughs] and left it as it was.

We were trying to accomplish several things. We didn't agree with the joint statement that you could not in some way, perhaps slightly indirectly, get at the sexual preference of the person. We tried to do that in a way that would not make the person confess to the fact that he was gay, if he was. So the information sheet we had was basically similar to what other blood banks used, what the FDA or what the AABB had recommended, and the terminology that the PHS [Public Health Service] and FDA had used in terms of high-risk groups, with one major exception: they defined the risk group as homosexual and bisexual men with multiple partners, and we defined the risk group as homosexually active men.

It was a very deliberate difference, because we were doing what everybody later agreed was right, focus on the activity, not on the classification. Our BAPHR friends were saying people will deny they're homosexuals because they may be bisexual, or they'll

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[1] Director of Office of Biologics, National Center for Drugs and Biologics [FDA] to All Establishments Collecting Human Blood for Transfusion, March 24, 1983. (CBBL 00551-00552).

deny they're bisexuals because they have a wife and two kids, and so on. So we left it homosexually active males and the multiple partner concept, and the FDA approved that. We used it that way.

The other major difference was that we also put something on the donor history card, which a lot of blood banks didn't. They just used the information sheet. We had a section which was a single, rather complex question, because it listed all the possible factors relating to AIDS which might lead to a rejection, and then said, "Put down 'yes' if any of this applies to you." And that way, they could exclude themselves without necessarily admitting they were gay, and it was a form of confidential self-exclusion, if you will.

Hughes: Did you have a way of assessing how effective these new guidelines were?

Perkins: Only in the sense of asking our gay friends if they knew other gays who had stopped donating, and the feedback we got was that our gay contacts thought it was working, for the most part. In fact, it wasn't until February of 1984 that I had my first evidence that it wasn't 100 percent effective. I never believed that it would be 100 percent effective, but as I say, the impression was that this was working. And then in February of 1984, I got a call from one of the doctors working at San Francisco General with Andrew Moss, on the study of people who were at risk for AIDS. One of the study people had mentioned to this doctor that he had just donated blood at Irwin that morning.

The doctor called me up absolutely furious. He said, "What the hell is wrong with you people? Why are you accepting this guy? He's an admitted gay with multiple partners; he's in this study," and I ran for the donor card and picked it up, and the guy had checked 'no' to everything.

So I called the doctor back and told him that. Later in talking to the doctor I found that this guy was so convinced he could not be at risk for AIDS that he just wouldn't accept it. He couldn't psychologically accept it, and it didn't apply to him, so he put 'no'. So that's the denial phenomenon that we have increasingly recognized. Once we had an anti-HIV test to identify people who were infected, it was apparent that this was a major reason why people who were HIV-[antibody] positive were continuing to donate.

Hughes: In the past denial had not been a problem for blood banks?

Perkins: It certainly had not been recognized as a problem. In fact, I can't even think as I sit here of any other diseases where this

has been a problem. Now we ask people, "Have you ever had a venereal disease," and the histories are not always consistent. Whether that's denial or forgetting or thinking it's not important, I don't know. But for the most part, no, denial wasn't a problem.

Hughes: Of course, it makes a huge difference, doesn't it, when you're dealing with a lethal disease?

Perkins: It makes a huge difference. But what the bottom line effect of it is is that it almost doesn't matter how you word your question, because you're going to end up with them donating anyway: the guidelines don't apply to them. And in retrospect, that's a bit scary. The only answer we could see to it was education and more education.

I think what really probably had the greatest effect was when the notices began to appear in the paper about people who clearly had developed AIDS from transfusions, and then it was no longer a theory or a possibility; the gays began to believe it and stayed away. Our best calculations were, and this is based on Mike Busch's retrospective estimates of what the risk of transfusion-associated AIDS had been--we'd gotten rid of 86 percent of the risk by the time that we had the anti-HIV test. Now, that's a long way from 100 percent, of course, and that's March of 1985 I'm talking about.

## Evidence for Transfusion AIDS

Hughes: Is it accurate to say that, as of the December 1982 baby, you yourself were convinced that the suspected virus could be transmitted through blood?

Perkins: Convinced? No. I was certainly convinced it was a possibility. I was convinced we had to act as if we were convinced that it was.

Hughes: When were you really convinced, and why?

Perkins: You get to be 60 percent, 80 percent, 98 percent, 100 percent convinced--and I got 100 percent convinced in 1985. That's when the CDC got the same virus out of a donor and a recipient. But I certainly got well over 90 percent convinced in January of 1984 when the CDC came out with the evidence in the additional cases of transfusion associated AIDS.

Hughes: Would you say that was true of blood bankers in general?

Perkins: Oh, I think so, yes. All through 1983, everybody still was talking possibilities, and maybe toward the end of the year probabilities, because we did hear the CDC had more and more cases under investigation. The problem is, we didn't know what that meant.

Hughes: Right. Well, by December of 1983, there are forty under investigation.[1]

Perkins: The figure I remember is thirty-one. The January 6, 1984 MMWR has a CDC update on AIDS which refers to thirty-one patients with transfusion-associated AIDS, and the "transfusion-associated" is in quotation marks. And as far as I can remember, there was no previous reference to transfusion-associated AIDS in any CDC publication between the January, 1984 MMWR and the previous December 10, 1982 report on the child from UC. There was a joint report from the three national blood bank organizations in June or July of 1983, which mentioned that the CDC had something like twenty-four cases under study.[2] So those are the numbers that I remember.

At any rate, we're talking about when you get to believe in transfusion-associated AIDS. I think that I've told you before that an awful lot of people get transfused, so the fact that somebody who has been transfused has AIDS may not be cause and effect. What made it cause and effect was evidence of immune abnormalities in the donors to those patients. But as of January 1984, nobody had yet come up with a second case where both the donor and recipient had AIDS.

Hughes: The joint statement by the blood agencies dated January 3, 1984, says "As of December 8, 1983, the number of cases of transfusion-associated AIDS being investigated was 40." They were being investigated. It doesn't mean all forty were cases of AIDS.

Perkins: Right, but the issue is whether they resulted from the transfusion. We now know that there were many, many, many more than that. That's a very gross underestimate.

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[1] Joint Statement on Acquired Immune Deficiency Syndrome (AIDS) and Blood Transfusion, AABB, ARC, CCBC, January 2, 1984. (Raw data folder of Dr. Arthur Ammann).

[2] ARC, AABF, CCBC: Joint Statement on Directed Donations and AIDS, June 22, 1983. (Raw data folder of Dr. Arthur Ammann.)

Hughes: Surely, though, if you received numbers such as that, it would have made your ears perk up. These cases were adding slowly but surely to the growing evidence that AIDS could be transmitted by blood.

Perkins: Right. As we went through 1983, it went from possible to probable to almost certain, and by 1984, almost definitely certain.

As I said, one of the key events in setting up donor screening was that we held a press conference on February 8 of 1983 to introduce to the community the new approach we were taking to donor screening, the new donor card format. That was very widely attended. All the [local] TV stations, radios, newspapers, and gay press were there. The BAPHR group was with us, and they made a statement too, and we both had handouts.

Hughes: You said before that BAPHR's statement differed slightly from yours.

Perkins: It was not as specific as ours. It left it to the individual to decide whether he was or was not at risk, whereas ours was, we thought, quite specific on who should not donate.

Hughes: You mentioned BAPHR being focused on the definition of homosexual. But was BAPHR, along with other gay groups, also concerned about the issue of discrimination?

Perkins: Oh, absolutely. Discrimination was a major issue for them. But they had a greater concern for the medical aspects of transfusion than the non-physician gays.

Hughes: You made for me a suggested list of documents to prepare for the oral history, and on it you listed "Irwin's new protocol." Did you mean this self-exclusion protocol?

Perkins: Yes.

## Reactions of other Institutions to Irwins's Donor Screening Policy

Hughes: In this list you have the names of three other documents which I'd like you now to address, and one of them is the response from

the Kaposi's Sarcoma Research and Education Foundation.[1] [tape interruption]

Perkins: I said we had sent the mock-up of the donor card we proposed to use to various groups. One of them was the Kaposi's Sarcoma Foundation. We got a letter back from its executive director, Ed Powers I think, saying that he had no problems with it except for the fact that it made gays too prominent; we should change the order in which we listed the risk groups.

Hughes: Which you did?

Perkins: I think the order was changed, yes, as I recall. Whether it was in response to that, I can't say. Brian McDonough was handling most of the details of this new card. The Kaposi's Sarcoma Foundation, of course, was chaired by Marcus Conant, and he says he never saw the document at that time, which is too bad. I wish he had.

Hughes: Why do you say that?

Perkins: Well, then he couldn't be criticizing it now. [laughter] But we certainly sent it to the Kaposi's Sarcoma Foundation for the input of their experts, not for an opinion from somebody who was not an expert. So I don't know whether he saw it or not; he says he didn't.

Hughes: The second organization, which we've already covered, is the Coalition for Human Rights.

Perkins: I think we did discuss it. We met with them. I think we convinced them that we had to take the position we were taking, and they agreed to be supportive.

Hughes: And then you say [John C.] Petricciani.

Perkins: He's from the Food and Drug Administration.

Hughes: Right. He apparently made comments on the protocol.

Perkins: I've mentioned that; he's the one that wrote back and said, "Your protocol is fine, but we don't know that you have the legal right to make donors certify they've told the truth."

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[1] Later renamed the San Francisco AIDS Foundation. For the foundation and early history of the Kaposi's Sarcoma Research and Education Foundation, see the oral history in this series with Marcus A. Conant, M.D.

Hughes: Okay. You said last time that, aside from isolating the virus, increasing numbers of transfusion-associated AIDS cases would convince blood bankers that AIDS could be transmitted by blood. This is going back--this is probably repeating what we've already said. This is going back to that document that I just quoted from, about the possible forty cases of transfusion-associated AIDS. And in the same document, which is the joint agencies under Dr. Katz' signature, to blood banks January 3, 1984--.

Perkins: Well, Dr. Katz' memo is just transmitting the joint statement to the Red Cross. The AABB transmitted the same joint statement to its members.

Hughes: In the joint statement, and I quote, is the statement: "While epidemiologic observations associate a few cases of AIDS with transfusion, the hypothesis that AIDS is transmitted by transfusion remains unproven."[1]

Perkins: That's not a statement that I would have subscribed to by January 1984. I grant you that there was still some room for doubt, but it was so very, very, very likely that I would not have signed any document with that statement in it.

Hughes: Why was that statement made?

Perkins: Who made it?

Hughes: Well, let's look at it. [tape interruption]

Perkins: I can agree with the entire paragraph, because you didn't finish it. "--the most reasonable working hypothesis," they say, "is that of an infectious agent which occasionally can be transmitted by blood products."[2] So they're accepting it as the most reasonable hypothesis for the cause of AIDS.

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[1] Joint Statement on Acquired Immune Deficiency Syndrome (AIDS) and Blood Transfusion, AABB, ARC, CCBC, January 3, 1984. (Raw data folder of Arthur Ammann, M.D.)

[2] Ibid.

## Irwin's External Communication System

Hughes: Would you care to talk about the communication system which was set up between Irwin, the state, the hospitals, and the physicians for reporting donors diagnosed with AIDS?

Perkins: AIDS was a reportable disease. Any physician making a diagnosis of AIDS had to report it. The blood bank was never in a position of making a diagnosis of AIDS. We never had anybody here donating blood who had AIDS. (That's a correct statement until the recent change in the definition of AIDS by the CDC. Prior to that change, a diagnosis of AIDS required a symptomatic patient.)

Hughes: Well, I got this from a question in the minutes of Irwin's technical advisory committee.[1] [tape interruption]

Perkins: The technical advisory committee held a meeting I think every two months in which we brought in the supervisors of the transfusion services and the medical technologists from the various hospitals. We kept updating them on what was going on, allowing them to ask questions. It was probably one of the most important means we used to get information back to the hospitals, because not only did we talk to these people at the time, but minutes were written up, as you see. And copies of those minutes went back to the hospitals, with a copy going not only to the supervisor but to the director of the transfusion services.

For example, I do know that in June or July of 1983, when we got that joint statement which referred to twenty-four cases being under observation at the CDC for possible transfusion AIDS, that was made part of the minutes and sent to every hospital that we served, so they had that information. So this, in terms of written communication, was probably our most steady source of written communication to the hospitals.

In addition to that, I wrote an article that appeared in the March issue, I think, of San Francisco Medicine, the bulletin of the San Francisco Medical Society.[2] There were various other memos that went out at various times, but as I say, this was the most consistent way we kept contact.

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[1] Minutes of the Technical Advisory Committee, IMBB, February 14, 1984 (CBBL 01276-01278).

[2] Herbert A. Perkins. The risk of contracting AIDS from blood transfusions. San Francisco Medicine, March 1983, page 17.

Hughes: To whom did memos or announcements of any kind go?

Perkins: Normally, our announcements would go to directors of transfusion services, supervisors of transfusion services, the director of clinical laboratories, and the administrator of the hospital. So we'd have four copies of these memos going out to each of the hospitals we served. Our contact in general with the physicians in the hospitals was through the transfusion services. The directors of the clinical labs and transfusion services used to request that any information we had be transmitted through them, because they wanted to know what their physicians were being told. So it was their responsibility to pass on to their hospital staffs the information we were giving to them.

In addition, I gave numerous lectures and talks, and answered the phone numerous times, and that kind of thing.

Hughes: And all of that increased exponentially as the epidemic advanced?

Perkins: Yes.

## Reactions to Announcements of Transfusion AIDS Cases

Hughes: Well, on September 7, 1984, Brian McDonough wrote a memo to the staff, that we talked about last time, reporting the death from AIDS of a woman who was transfused at UCSF in 1982.[1] I'd like to quote from part of that memo: "The repercussions of this latest transfusion AIDS case will remain with us for a long time, I'm afraid. I don't believe there will be any easy or early resolution to this problem. More than likely, this negative publicity will spawn a decrease in blood donorship and an increase in requests for designated donations and auto-transfusions. We will support these two practices as much as possible." Was there any significance about this particular death, or was this a common reaction at that time?

Perkins: Well, every time there was a report in the newspapers, the number of donors dropped, obviously, and we got frantic calls from people who had been transfused and whatnot. This may have been the case of the nun, a Catholic sister, who was infected and died, and that caused a big sensation--a nun with AIDS.

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[1] Brian McDonough To All Staff, September 7, 1984. IMBB binder 1a, 2405-2605, CBBL 2503-02504.

Hughes: Did Irwin routinely take steps to counter bad publicity?

Perkins: I think I told you that somewhere around this time, or maybe even earlier, Brian had told the press that there would be thirty more cases of transfusion-associated AIDS before the end of the year. And as I say, to some extent, that did turn off the press interest when new cases got reported. This was just as predicted. I suppose the only things we did to counter this would be to explain over and over again what we were now doing to protect the blood supply, and to reiterate our faith that the blood supply was relatively safe at this point.

Hughes: Well, obviously, the general public was reacting. But was the medical community reacting in any sort of uniform way when these cases were announced?

Perkins: Uniform? No, except in the sense that--I don't know how to put this except to say they harbored a resentment that this problem had appeared, that it was complicating their lives.

Obviously, they had a tremendous compassion for the people who were infected. This was such a horrible situation, and every one of these cases is dreadful. But there's no question that it complicated the lives of every physician. We had started calling the hospitals when we had a donor reported who had come down with AIDS, and asking that physicians notify their patients who may have been infected by the transfusion. That met with a lot of resistance, resistance first on the part of the hospitals which said they didn't have the time or the personnel to look up who was the patient that got that unit of blood, and who was the physician responsible. We overcame that with arguments, and as long as the pressures weren't too great, they complied.

A lot of doctors, however, felt, "Well, why should I tell my patients? What are we going to do for them if they know? All we'll do is terrify them, make them miserable. Let's hope they're not infected and let's forget it." So there was a good deal of that attitude.

Hughes: Not only attitude, but performance? They did nothing?

Perkins: In many cases, they did nothing, reasoning that to terrify an eighty-three-year-old woman when nothing was going to happen to her [was unreasonable], and what were we accomplishing? We of course were looking at this as an extremely important research project, beyond the obligation we might have to notify recipients, because we were still looking for more evidence that AIDS was a transmissible disease and, if so, under what conditions was it transmitted, and how long would it take to come

down with the disease, and all the other things. So we were calling, cajoling, arguing with these people, and in most cases, getting their cooperation, getting the information, getting the blood samples we needed to test. In 1983 and 1984, all we could do with the blood samples was to do lymphocyte counts and helper-suppressor ratios. We still had nothing specific to test for. In those days, we were working very closely with Dr. Ammann, who was doing all of the immunologic tests on donors to patients with AIDS, and on recipients of blood from donors who later developed AIDS.

By at least late 1984, Dr. Jay A. Levy had his first crude test for anti-HIV antibody, and we would send him samples, and get test results.[1]

Hughes: Tell me something about that test, please.

Perkins: It was what's known as an immune fluorescence test. He would take cells from individuals infected with the virus, and incubate them with the serum that you're looking for antibody in, then wash the slide, and add a label that would indicate whether antibody was present. The label is fluorescent; you had to look under an ultraviolet microscope. And that's a technique which is now licensed and approved; it's a good technique.

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Perkins: It does have the problem that it requires a subjective determination by a technologist looking into the microscope and saying, "I think it's positive; I think it's negative." And if it's a borderline case, another person looking through the microscope might come up with another answer.

Now, when you work with the enzyme immunoassays, where you get a quantitative result, the intensity of the color that develops is given to you in optical density and the instrument gives you a very sharp end point. In a sense, it's no more accurate; it's just very arbitrary.

Hughes: When did tests such as that come in?

Perkins: Well, now we're talking about the test that became available in March, 1985.

Hughes: Well, getting back to McDonough's statement of September 7, 1984, his last sentence in this memo was, "Our greatest ally in

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[1] See the oral history in this series with Jay A. Levy, M.D.

fighting the negative consequences of this case,"--and presumably others--"is to provide accurate and complete information."[1]

Perkins: I think that's an important statement, and it's one thing we have tried to do at every step along the way. We've been wrong some of the time, but we've always told people what we had for data and what we thought the data meant. You talk to somebody like Dave Perlman[2] and he will agree that Irwin was always open, honest, to tell him whatever he wanted to know.

## Why People Give Blood

Hughes: Would you like to make a comment about why people give blood?

Perkins: That's not an easy question to answer. You know, the simple reason is they're altruistic; they do it to help their fellow men because it makes them feel good. I guess in a general sense that's probably the best answer. There's no question that it does help them to feel good; they feel very magnanimous. Their own personal esteem has risen because they've done this for their fellow man; they've suffered a little pain; they've taken a little time. There are those who get involved in contests to see who can give the most blood. So we have our very long-term donors who are struggling to reach that hundred-pint point, and certainly that's a motivating factor.

There are others who started donating because they were dragged in by a friend, or told to go by their parents, or it just got to be a habit. There are others who come in because they hear a pitch on the radio and think, "Oh, lord, somebody got shot down at 101 California." Large numbers of donors came in that day, believe me.

Hughes: What then are the implications when doubts are sown in the public mind about the safety of blood?

Perkins: That's a somewhat vague question, "what are the implications." Do you have anything specific in mind?

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[1] IMBB binder 1a, 2405-2605, CBBL 02503-02504.

[2] Medical reporter for the San Francisco Chronicle.

Hughes: Well, how does the donor react? He thinks he is doing something out of the goodness of his heart, and he finds that what he's contributing may not be pure and harmless.

Perkins: Right. Maybe we were a little naive in believing that anybody who was donating out of the goodness of his heart would not donate if he thought there was any risk to the person who's going to be receiving his blood. I am a little less confident of that after the last ten years than I was at the beginning of this whole episode, because people have very complex reasons for doing the things they do. We don't always understand the pressures they're under, and that's particularly true of the directed donors.

One of the inevitable effects of the transfusion-associated AIDS cases was for people to say, "Heck, I can do a better job of finding a safe donor than the blood bank can." Which again gets us to the directed donors.

## Irwin's Study of Surrogate Tests, March-May, 1983

Hughes: We talked last time about surrogate tests. There were some collaborations that you established with various institutions that I'd like to run through.

Perkins: Did we talk about the study we did here?

Hughes: You alluded to it, but didn't describe it.

Perkins: Well, we tried to set up to evaluate all of the various surrogate testing techniques that Spira had suggested at the meeting in January of 1983. We focused particularly on the core antibody test because it was a commercially available test, and it used techniques and instrumentation that basically we already had in-house, so it was a practical thing for us to look at. But we were simultaneously trying to set up the helper-suppressor ratio procedure--I think I told you about the instrument Becton Dickinson loaned us--and the absolute lymphocyte count. Dr. Vyas was working on immune complexes, which was one of the tests Spira had suggested. So we had at least three of these tests going simultaneously.

I set up a protocol--there are memos in there, the first one saying, "I don't know how we're going to learn anything from research on this test in terms of whether it will prevent transmission." Then the second memo just goes ahead and sets up

a protocol. The approach was to see if we could show a correlation between the frequency of core positive results and the frequency of AIDS reports in the different zip code areas in the city. The expectation was that the Castro would show the highest frequency of positive core antibody results, and upper Polk Street maybe second, and so on. We used the figures that Selma Dritz had given me, which were incorrectly specified as percent gay--she talks about the Castro being 100 percent gay, and upper Polk being 66 percent gay or something like that. Those are the figures we used for comparison.

We collected samples over a three-month period from our entire system, and then ran the tests as we could find the time. We ended up looking at it at a number of points along the way. Finally the study stopped, I think, when we had about 8,000 samples. We had planned to do 10,000 samples, and I think the last complete formal analysis is only 6,000-plus. But at that point, I had already decided this wasn't getting us anywhere, because we ended up showing no correlation of the kind I had anticipated. In fact, the Castro area, for reasons I don't understand, had a frequency of positive core tests lower than the rest of the city. We decided that we were wasting our time with that test.

Now, I was also influenced by the fact that the New York Blood Center data became available to me in June of 1983. We actually had a meeting here in which several people came out from New York, and one up from Los Angeles. We presented our data; the New York people presented their data. I was even more convinced by their data than I was by my own approach, which I thought was pretty indirect. They were comparing people who confidentially said, "I'm at risk for AIDS," with people who said, "I'm not at risk," and I think I've discussed this with you.

Hughes: Yes.

Perkins: So we concluded that test was not getting us anywhere, we lost interest in it, and I think by that time we were already beginning to work with the $beta_2$ microglobulin test, which was what we focused on for the most part at that time.

## The Acid Labile Alpha Interferon and Thymosine Alpha-1 Tests

Perkins: There were two other tests that subsequent to the January 1983 meeting had been suggested as surrogate tests. One was the acid

labile alpha interferon, and that test had been shown to turn abnormal in hemophiliacs who later developed what was to be known as AIDS. So it was for the first time evidence of a test showing up abnormal even before the symptoms appeared.

The other one was thymosine alpha-1. In both cases, we were dealing with complex tests that we didn't feel we could set up. But I contacted the investigators who had published the results on those tests, and they agreed to test samples for us. So we set up that arrangement. They told me they'd start when they got the NIH grants they were confident they were going to get, which they never got because the anti-HIV test came out first. I shouldn't say the test came out first, but Gallo's report [on the isolation of HIV in April 1984] came out first. So those never got off the ground, at least in terms of our samples.

## The Beta$_2$ Microglobulin Test

Perkins: The beta$_2$ microglobulin probably would have been a test to consider, but the problem was in 1983 and 1984, that the manufacturer who gave us materials for the test had a very lousy approach. This was the Pharmacia Company, and they make tiny plastic beads to which you can attach antigens or antibodies and use them in tests. The problem with the test was that you had to wash the beads, and every time you washed them, they floated out of the tube and you lost some. You could get any answer you wanted, depending on how carefully you washed.

So I fought with them, and they finally changed their test and in 1985 gave us a different approach that worked, by which time we had the anti-HIV test, so the beta$_2$ microglobulin test became less important. So there was a lot of wasted time, looking back at it, in terms of trying to develop surrogate tests, although beta$_2$ microglobulin is used still to monitor people with HIV infection.

Hughes: Well, in April of 1984, you wrote to Judy Wilber, who was at the microbiology lab at the health department, and you said, "I have compared the results of our two labs on the same 42 samples. Not only is there a disappointing amount of disagreement, but your lab tends to read samples considerably higher than mine, which is difficult for me to understand."[1] What are you talking about, first of all, and what was going on?

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[1] Perkins to Judy Wilber, April 16, 1984 (CBBL 01347).

Perkins: Well, this was the use of the bad test, the one that was not getting consistent results.

Hughes: The core test?

Perkins: No, my memory is that the tests that Judy Wilber was doing and I was comparing with were $beta_2$ microglobulin.

Hughes: Would it help to look at the letter?

Perkins: Yes. [tape interruption] This was definitely the $beta_2$ microglobulin test, because the letter mentions the technologist, Karen Clause, who was working on the $beta_2$ microglobulin test.

Let me get back to the subject of core testing. As I say, it's a lousy test, particularly for a blood bank. The problem is that it's a test that was developed to work with patients, where it works very well. When you're dealing with a normal population where most people are not core antibody positive, and you set the test to be extremely sensitive so you won't miss any, you pick up immense numbers of false positives. There still is no confirmatory test for core antibody, and there's no way to tell whether it's a false positive or true positive. [tape interruption] A false positive reaction is one which is positive even though there is no antibody to hepatitis B core antigen.

There's very strong reason to believe that about 50 percent of the positive core antibody test results we get are false positives, and the best evidence for that is based on the fact that if you repeat the test using a somewhat different technique with a radioactive label, radioactive immunoassay, 50 percent of them are negative. The problem is that the enzyme tag on the antibody you use is so huge that it tends to stick nonspecifically, and it's a real problem, but we prefer not to use radioactivity, so we stick with that approach.

## Assay Arrangements with Outside Institutions

Hughes: Apparently you had an arrangement with the Hemophilia Center of Central Pennsylvania for assays of acid labile alpha interferon.[1]

Perkins: That's what I was talking about, yes.

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[1] M. Elaine Eyster to Perkins, April 11, 1984 (CBBL 01339).

Hughes: Why them?

Perkins: The statement that this test becomes abnormal well before a person with hemophilia develops signs of AIDS was published by Elaine Eyster,[1] who was at this Hemophilia Center, working with Olivia Preble, who was at the Uniformed Services University in Washington, D.C. It was Preble who was doing the work, and Eyster was in charge of the project. I knew Eyster, so she was the one I talked to.

Hughes: You were sending sera, again for alpha interferon assays, to Kurt Osther at Wadley Blood Bank in Dallas?

Perkins: Right. They had set up an assay, not for acid labile alpha interferon, but for alpha interferon itself. It was an immunologic assay.

Hughes: What's the difference between the two?

Perkins: If you do an assay that is based on detecting a molecule using an antibody, you may detect the molecule even though the molecule is totally useless, because it is altered in some other part where it can't carry out its function. So you've got a measure of the presence of the molecule, but you don't have a measure of its activity. Nobody had ever claimed nor shown that alpha interferon by itself related at all to AIDS; it was just the acid labile form that was supposed to be, and don't ask me why. It makes no sense to me.

Hughes: Osther had done some work on this?

Perkins: He did a lot of tests, and he asked me to send him several thousand blood samples, which we did. I had no way of knowing what meaning it had, because we didn't know anything about the donors. They were all normal donors as far as we were concerned. So as far as I was concerned, it was just a normal control that he was running.

Hughes: Okay. One last question on surrogate tests. The minutes of the Irwin department supervisors meeting of December 20, 1983 state that: "It was the recommendation of some members of the FDA group that plasma pheresis centers do anti-hepatitis B core antibody

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[1] M.E. Eyster, J.J. Goedert, O.T. Preble, M.C. Poon. Acid-labile alpha interferon: A possible preclinical marker for the acquired immunodeficiency syndrome in hemophilia. New England Journal of Medicine 1983, 309:583-586.

testing. Dr. Perkins, as well as other attendees, objected to this recommendation, stating that if plasma pheresis centers would be required to implement this testing then so would blood banks. This could eliminate 6-7 percent of our donor population and cost a tremendous amount of money."[1]

Perkins: [tape interruption] In December 1983, the FDA scheduled a meeting of its advisory committee on the topic of surrogate testing. I was invited to attend to talk about my work of beta$_2$ microglobulin. Core antibody was discussed by Dr. [Johanna] Pindyke from the Greater New York Blood Program. T cell testing was discussed by Dr. Engleman. And then in the discussions, other data was presented. I had a chance to present my core antibody data following Dr. Pindyke's presentation. So this meeting pretty much had all the data that was available at the time relating to possible use of surrogate tests for AIDS. The general feeling was that the surrogate tests hadn't shown very much.

As the committee itself was debating, Dr. [James] Moseley said, "Well, we're really worried about the hemophiliacs. They're the ones that are being affected in large numbers by transfusion-associated AIDS. Maybe we should ask the plasma centers to test for core antibody. But definitely not the blood banks." Everybody agreed the blood banks should not be asked to do that.

And in the course of the discussion, I did make the statement that if these tests have been shown to be useless, and we're going to lose 8 percent of our donors and cost the patients money, why should we be doing them? I don't know who took those minutes, but that's not quite what I said. Usually it was Brian's secretary who didn't understand scientific things too well.

## Directed Blood Donations

### Initial Opposition

Hughes: Well, as you well know, one consequence of the scare over transfusion-associated AIDS was to increase the demand for

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[1] IMBB Department Supervisors' Meeting Minutes, December 20, 1983 (CBBL 01209).

directed donations. Would you like to say why you and other blood bankers were initially opposed?

Perkins: Yes. Let me go back a bit and say autologous donations are something we've always promoted, and I've got memoranda going back into the 1970s showing that. We certainly did use directed donations in situations where they were medically indicated, and these were primarily two situations. One was where we could not easily find compatible blood for the patient, and it was more likely somebody in the family would carry the same factors. And the second came out of the kidney transplant area, where actually it was here at UC San Francisco, they had shown that if you transfuse a patient with blood of the intended kidney donor, the graft survival is much better. So we were very actively using directed donors in both those situations. Just to do it at random at the request of a patient was something that we had always been against.

Hughes: Would you say why?

Perkins: That's what I'm about to say. Some of my best evidence was gained in the few months just before this became an issue. It became an issue in a lawsuit resulting from a transfusion that occurred in February, 1983, which was the famous Osborne case.

I haven't mentioned one other area, when we were looking for platelets for a donor and we couldn't get a good result with random platelets, presumably because the patient had formed antibodies, and you needed platelets of the patient's type. Then we would bring in family members and use the pheresis technique to collect a lot of platelets from a single donor. So we had a fair amount of information on family members who had donated blood. One of the things that struck me looking at that information was that they had a higher frequency of positive results for the hepatitis B surface antigen test than our routine donors, suggesting that family donors were not necessarily a better source.

The second bit of information came to me in the form of a phone call from one of my former fellows, Larry Kane, who had left about a year earlier and had gone down to Methodist Hospital in Houston, Texas. This was January of 1983, and they were getting directed donor pressure. They decided they were going to provide directed donor services. He said, "In the first fifty directed donors who gave blood here, two had syphilis in the infectious stage, and two are hepatitis B surface antigen positive."

My third concern was the very valid concern that if you ask somebody to donate for your mother or for you, they're more likely to donate when they know they shouldn't, and under a certain amount of pressure.

I can't remember if I had any other arguments, but those were the reasons--reasons that, of course, as far as most people were concerned, didn't apply to their family, might apply to everybody else's, but never to theirs. People are not as aware of the risk activity of their close relatives as they think. I have already pointed out that the parents of the donor to the UC baby denied he was gay until they went through his post-mortem effects. And so we had from time to time people who got extremely upset and emotional over the subject, and we developed a procedure for allowing them to give directed donations when we felt we were doing more harm than good by refusing to do it.

Hughes: There is a list of arguments pro and con directed donation.[1] Would you like to see it?

Perkins: Yes. [tape interruption] One of the major concerns was whether the use of directed donors would turn people off as regular donors, that they would hold themselves in reserve. And actually, in June of 1984, when we did start directed donations, the very first thing that happened was we got two calls canceling several large mobiles because participants scheduled to donate had decided they wanted to save themselves.

Hughes: For some hypothetical future need to give blood?

Perkins: Right. I think in the long run that probably it didn't make that much difference, because we got some additional donors as directed donors, although they don't return for the most part. You can call them up and say, "Now will you come and give to somebody else?" "Oh no, I'll only give for my father."

## Cost

Hughes: Did it make any difference that it required no expenditure on Irwin's part, that these were unsolicited donors who came in cost-free?

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[1] Anti-HBC Testing, n.d., January 1984? (CBBL 04478).

Perkins: No, unfortunately, that's not true. The logistics of keeping track of these units and making sure they get to the right place added more to our cost than we saved by not having to go out and recruit donors. You can see there was logistical confusion from all these individually donated units, and when we first set it up, it was an absolute nightmare. It literally took us many months to work out a system that would ensure that people got the directed donations they were intended to get.

It was worse for the hospitals than for us. The hospitals would get an order to cross-match six units of blood for a patient, so they cross-matched six units. And then they'd find out three days later that there were directed donations sitting in the refrigerator for that patient, so they had to work out a system whereby they always checked first to make sure there wasn't an autologous or directed donation. But it took a few bad experiences before that happened.

We started directed donations in 1984. We were the first community blood bank in the country that would do directed donations, and that was Brian McDonough's work. He was convinced that in the long run we'd probably get more donors out of it rather than lose donors. Above all, he said, "This is what the public wants; we should be giving it to them." My attitude back in those days was that, as a physician, you didn't do what a patient wanted if you knew it was bad for him. This is no longer true. [laughter]

Incidentally, the evidence we've accumulated since then is increasingly strong that directed donors are more likely to transmit disease, both hepatitis and HIV. I think some of that is because the groups that use directed donations most often are the minorities who don't trust the system, and they're the ones who are more likely to have infection, unfortunately. You get the Asians who have high hepatitis rates and the blacks and Hispanics who have a relatively high HIV rate compared to Caucasians.

## Other Directed Donation Programs

Hughes: Well, you certainly are right that Irwin was in the forefront of the community blood banks, but from what I read, Stanford as of June of 1984 had a designated donor program.

Perkins: Yes, and Cedars-Sinai down in Los Angeles had one in 1983, I think. We thought they were wrong. I still think it's a lousy

idea; I think it's wrong in general. But yes, I can't argue, if a person says, "What you say is okay, but it doesn't apply to my family," how do I know it doesn't apply to his family? They may be right; it doesn't apply to their family. In any case, I don't have any choice; it's now state law; we must allow people to give directed donations.

Hughes: When was the state law passed?

Perkins: Oh, probably five, six years ago.

Hughes: As a result of the epidemic?

Perkins: The pressure, yes. And there are quite a number of states around the country now that require blood banks to have directed donor programs. Basically, it's all part of this movement which says, "We're not going to let doctors tell us what's good for us; we're going to decide ourselves."

Hughes: And we know how you feel about that.

Perkins: No, I'm giving in. [laughter] I'm part of the new system now.

Hughes: Fighting and kicking all the way?

Perkins: Well, when I went to medical school, I was told you don't give somebody penicillin for a common cold just because he demands it, because penicillin has side effects and it won't do him any good. I guess nowadays you probably would prescribe it.

Hughes: Well, there was a report on January 24, 1984, of a meeting of the blood bank commission, and in it was noted that Stanford had added 100 new donors through its designated donor program.[1] You may not have liked it, but this again was increasing the pressure to move towards directed donation, was it not?

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Perkins: We accepted all requests for directed donations beginning in June 1984. The decision to do so was made several months earlier; I really think it was January or February. But I would have to check.

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[1] Minutes of the Meeting of the Blood Bank Commission of the Irwin Memorial Blood Bank of the San Francisco Medical Society (CBBL 01257).

## Requests for a Directed Donation Program at Irwin

Hughes: Are there other factors that went into the decision? We've mentioned Dr. Ries at UC who was head of the transfusion committee which was apparently pressuring for a designated donor program. Was this characteristic of the medical profession here in general?

Perkins: No, I think the UC group was very specifically driven by the patients they had lost to Stanford.

Hughes: So physicians weren't calling up and asking for a designated donor program?

Perkins: Physicians occasionally would call directly, but it would mostly be patients. As 1983 went along, we were more and more making exceptions to our "we don't do this" [directed donations] policy, because of extremely emotional people. In June of 1983, there was a joint statement from the three national blood bank groups saying directed donations are a very bad idea and you shouldn't offer them.[1] We took that to the Blood Bank Commission and got a ruling from them that Irwin should stop doing directed donations; no more exceptions.

That didn't last very long; it broke down again. There just was no way. I can remember one day when a policeman came in here in uniform and he was going to be a directed donor for his buddy, and when we said no, he reached for his pistol. He didn't bring it out, but--[laughs] This is how emotional people were on the subject.

So it may have been a wise policy to reject directed donations, but it became a totally impractical one.

Hughes: The minutes are filled with the debate.

Perkins: Oh, yes. We had people who were on the side of what's scientifically sensible and what's best for the patients, and people on the other side saying, "Well, this is what the people want; you better give them what they want."

Hughes: The people won out.

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[1] Recommendation regarding directed donations, AABB, ARC, CCBB. June 7, 1983 (CBBL 00739-00742).

Perkins: People won out. And most of the blood banks in the country thought we were terrible traitors.

Hughes: Well yes. You went to some meeting and reported that Irwin had just instituted the directed donor program, and I understand there was a very adverse reaction.

Perkins: Actually, Brian [McDonough] notified people fairly widely before we did it. We didn't want to spring it on the blood bank community.

Hughes: What about the legal challenges? I'm thinking specifically of an Orlando, Florida father who wanted designated donations for his eleven-month-old son. Do you remember that case?

Perkins: I guess I've lost it in the plethora of information. Directed donation certainly was a very emotional subject.

Hughes: Was the threat of litigation a factor in instituting directed donation?

Perkins: No. As a matter of fact, if you look at the pros and cons, one of the cons was that we might get into legal problems if we mislabeled one of those units.

## Directed Donation Procedures

Hughes: The procedures for making a directed donation were quite complicated. Did they really need to be quite that complicated?

Perkins: Oh, you ask me right now, I say no, but then I was sure that they did. They were quite complicated because we believed that we should not be accepting directed donations unless the patient, the patient's physician and the hospital approved what we were doing, so it required multiple signatures. We set it up so that directed donation had to be done well in advance of the planned surgery, so that there was plenty of time to carry out all of these activities. It remained complicated for some time, but got progressively simpler. And I will agree quite freely that it got most simple when we got into competition with Corus, that for-profit agency that was set up to provide the autologous and designated donors--for a horrendous fee, but they would provide custom service, and a very simple service.

Hughes: And they were located in the San Francisco?

Perkins: They were located in Sunnyvale, but they were actually providing blood all over the state. When we began to provide equally good service, they went out of business.

Hughes: Do you remember when that would have been?

Perkins: A couple of years ago.

Hughes: I remember that the prospective donor had to appear at Irwin twice, I think once to give a history and a second time to donate?

Perkins: No, the issue was that the donor had to have the right blood type for the patient. In many cases, the donors didn't know their blood type, and in other cases the patient's type hadn't been determined yet. So we tried to convince donors to donate, and we'll type your blood. If it's the right type, it will be designated for the recipient you want. If it's not the right type, we'll just put it in the general inventory and you'll be an altruistic donor to the community. Very few of them would accept that. They wanted to donate only if it was going to be used for their relative or friend. So we said okay, in that case, you're first going to have to come in and let us find out what your blood type is. So that meant they had to make two visits to the blood bank.

Hughes: There's a report in the minutes of the IMBB Technical Advisory Committee meeting of October 9, 1984 that requests for directed donations "went through the roof."[1] Do you remember that?

Perkins: Well, that's probably after a lot of newspaper publicity about transfusion AIDS, I'm sure. 1984 was the year for it.

## Anti-HIV Antibody Test

Hughes: The next subject is the antibody test.

Perkins: Oh, are we getting into 1985? I thought you were only interested in 1984. The antibody test became available to us in 1985.

Hughes: Well, how can I talk with you without talking about the antibody test? [laughter] As you well know, Irwin was the first blood

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[1] (CBBL 01574-01577).

bank in the nation to institute the HIV antibody test. Would you like to talk about the pros and cons of that test?

Abbott's Test

Perkins: Well, yes, it's mostly pros. We had been involved from the first of the year in doing field trials with various prototype tests for the HIV antibody, which people hoped to get licensed by the FDA. Some of these were absolutely terrible and ghastly, and some of them turned out to be very good. The first test to be licensed was the Abbott test, again using technology that we were used to, and since we were a good Abbott customer and since San Francisco had the reputation it had, they agreed we should be the first blood bank in the country to get the test.

Hughes: You mean San Francisco's reputation for high incidence of HIV?

Perkins: Yes. Plus our reputation for excellence, and for research and for various other things.

At any rate, we got the test. Now, it was predictable that the test would have a lot of false positives, and this is because it was the same kind of technology as the core test. But there was already a technique available to distinguish the false positives from the true positives, so that's been a godsend certainly all the way along.

Hughes: Is that the Western blot?

Perkins: Yes. That was available then. One of the things we didn't know at the time that we were doing those early investigations was that the Western blot will produce a band in about 15 percent of normal people. That means that if you use the Western blot as your initial test, you'll cull 15 percent of people as having antibody to HIV until you do any further testing. So it's a fine confirmatory test, but never should be done as the initial screening.

At any rate, with that backup we were able to demonstrate that most of the test results we got initially turned out not to be true positives. The real problem was we didn't know at that point what having a positive antibody test meant.

Let me go back to one of our basic concerns when the test came in. We were scared stiff that gays would come in and donate in order to get themselves tested, and we fought with the various

health department people to get something set up to prevent that. It wasn't until just a few months before we knew we'd have the test that the infectious disease public health officer in Oakland, Dr. [Bob] Benjamin, finally decided that we were making sense and got the attention of the state health department and finally the government. That's when the state decided to set up these alternate test sites where people could get anonymous testing. The reason they were set up was to keep gays from going to the blood banks.

### Alternate Test Sites

Perkins: When the test became available to us, since the alternate test sites weren't set up for several more months, a law was passed that said we couldn't give any of the donors the test results for three more months, or something like that. They wanted us to be able to tell them there will be alternate test sites available before you'll ever get the report from the test at the blood bank. So that was one of our concerns.

### Informing HIV-positive Individuals

Perkins: The second point is what in the hell do you tell the donor once you know he's antibody positive? Because we did not know then, as we do now, that anybody that's antibody positive is carrying the virus. We had the kind of data that Gallo had come up with in which he'd been able to culture virus out of maybe 30 percent of antibody-positive people. That said, presumably 70 percent don't carry the virus any more, they're immune, what have you. So if you look at any of the early literature we were handing out, and certainly this was literature we developed with the help of the CDC, because we were working with them by then, it says that we do not understand what a positive test means. It doesn't mean you're going to get AIDS, and this, that, and the other, all kinds of reassuring things that turned out not to be true.

Hughes: And there was a precedent for thinking this way, was there not? Am I right in thinking that the hepatitis B surface antigen didn't necessarily indicate that the virus was still there?

Perkins: No, surface antigen meant that the virus <u>was</u> there. If you had <u>antibodies</u> to the surface antigen, that meant you were immune. The virus was gone and you could not transmit it. If you had a

positive anti-core, it was either way; you couldn't be sure which it meant.

Hughes: So there was definitely a precedent for thinking that a positive test did not necessarily mean the virus was present.

Perkins: Oh, yes. And there were, thinking back, other situations where it was known that viruses persisted indefinitely, like the herpes virus that causes cold sores. So that having an immune response to a virus didn't necessarily mean that it was no longer present in your system. But we didn't know for several more years that the presence of antibody almost certainly meant the virus was present and AIDS would eventually occur--so we gave people partially reassuring information, and it turned out to be worse than we suspected.

So as of March, 1985, we could for the first time get an indication of what percent of our donors were at least capable of transmitting the virus.

Hughes: What did you find?

Perkins: In 1985, it was fifteen per 10,000.

Hughes: How did you react to that figure?

Perkins: I don't remember thinking, "This is more than I expected," or "less than I expected," or what have you. I think I just remember reacting, "Well, we've got a figure to deal with." We also had blood samples that we had put away for the Transfusion Safety Study from 1984, so we could go back and get earlier information. In June 1984, the figure was twenty-seven per 10,000. That's the beginning of some of the data that Dr. Busch used in going retrospectively to 1982 and beyond, to calculate the proportion of donations likely to have been infected with HIV.

Hughes: Abbott apparently air-freighted the first publicly released antibody test to Irwin?[1]

Perkins: If you say so. [laughs] I don't remember.

Hughes: There was nothing particular about that? Is it a fragile test?

Perkins: No.

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[1] Shilts, p. 539.

Hughes: Abbott was anxious to get it out in the field quickly?

Perkins: For all I know, it's always air-freighted. I don't know; I haven't even looked.

Hughes: It seems to me more expensive to send it that way.

Perkins: Presumably, and maybe it was an attempt to rush it over as fast as possible.

Hughes: You mentioned there were problems, but how bad were the problems with the first tests? How responsive was Abbott to attempting to get them corrected? Weren't there a lot of false positives?

Perkins: Oh, yes, but that wasn't something that called for correction.

Hughes: There was nothing that could be done?

Perkins: Oh, yes, there were certain things that could be done. It turned out that one of the reasons for false positives was that when a virus buds from the surface of a cell, it takes some of the cell membrane with it and coats itself with that, and you end up with antigens from the cell membrane coating the virus, which includes HLA antigens, the antigens we tissue type for transplantation, and lots of people have antibodies to HLA antigens. So if you have an anti-HLA of the appropriate type, it would always be positive and we'd have a false positive anti-HIV test.

## Genetic Systems's Test

Perkins: Now, if you went on to the Western blot, it would not be positive. But in the original screening it would, and you are immediately eliminated as a donor. So that turned out to be a problem which was recognized when Genetic Systems came out with its test, which was developed from the French virus, not from Gallo's virus. They used a cell line that didn't shed HLA along with the virus, so they had fewer false positives.

Hughes: How, biologically, does that work?

Perkins: I don't know how. I think it was serendipity, just plain luck. They happened to select a different cell line to do it with. Once Abbott recognized the difference, they were able to do the appropriate things to remove the HLA antigens from the preparation.

Nineteen eighty-six was when the Genetic Systems test was licensed. Not only did the evidence show that Genetic Systems had fewer false positives, but there was evidence that it was picking up some samples that were true positives that Abbott was missing. We latched onto that very early, and we switched to Genetic Systems.

Hughes: Was there any difference other than the fact that Genetic Systems' test had fewer false positives?

Perkins: Fewer false positives and more true positives; that's a better test. And the FDA and the Red Cross are now in trouble, because they did not recognize the difference between the two tests. The FDA never recommended that everybody go to Genetic Systems. The problem is that different panels of test cells may make a test appear better. If you select a group of samples that are positive by one manufacturer's test, and then you run it on another manufacturer's, it's likely to miss a few but your first manufacturer got 100 percent right, because you selected it by this test. Then you do the reverse, and you get the opposite. So you go nuts. And there's always a few borderline samples that will be picked up by one manufacturer and not by another.

We thought the evidence was good enough to switch from Abbott to Genetic Systems.

Hughes: And you switched quickly?

Perkins: We switched--I looked it up--August 3, 1986.

Hughes: My memory of a recent article in the Wall Street Journal was that [Senator John] Dingle's subcommittee was investigating hypothetical tardiness in switching away from Abbott to the Genetic Systems test.[1]

Perkins: Well, the only other choice was the Genetic Systems test.

Hughes: The article also criticized Abbott for not attempting to improve the test--.

Perkins: I'm sure they were killing themselves to improve it. When they found out we were switching, they sent six of their senior officers out here to argue us out of it, complete with charts, tables, slides, whatnot. We didn't go back to Abbott for about

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[1] Panel probes early Abbott AIDS test; Decision by Red Cross is questioned. Wall Street Journal, June 28, 1993, p. A7.

two more years, by which time they had a much better test than Genetic Systems did.

Hughes: Which is what you now use?

Perkins: We're still with Abbott, yes, with successive improvements in test specificity over the years. But that was one time when we saved ourselves some criticism, because we switched early. A lot of the blood banks, at least around here, watch what Irwin does and follow suit.

## Procedures for Determining HIV Test Results

Hughes: I think you should say for the record what the procedure was for establishing that a person was HIV-positive.

Perkins: Okay. The basic technique is what is known as an enzyme immunoassay. The principle of the test is, you start with a preparation of the virus, which is coated onto a solid surface. You incubate it with the patient's serum, and the theory is if the patient has antibody to any of the viral antigens that those antibodies will attach to this solid surface. And then you wash away any serum proteins that are not firmly attached to the surface.

Then, to answer the question, did antibody attach to the virus and if so, how much, you add a second antibody. It's an antibody made in an animal that reacts with human antibody, and it's got a big enzyme tag on it. If human antibodies attach to the virus, then this animal antibody with its attached enzyme will now attach to the solid surface. Again, you wash away the things that shouldn't stick.

Now you've got an enzyme coated on the solid surface, and the reason you use that enzyme is because you can add something that will change color, and the intensity of the color will depend on how much of the enzyme is there. So you end up with a colorless reaction turning yellow, and the darker the yellow, the more enzyme there, and by inference, the more animal antibody there, and therefore by inference, the more human antibody.

Then you have to establish how do you distinguish between a positive and a negative, because all the end results are yellow. The question is, how intense does the yellow have to be before it's a positive? And that sort of thing you do by testing lots of normals and lots of known positives. What you like to see is

two big peaks with a nice plateau in between you can draw a line down.

Which reminds me, when we did that core antibody study in 1983, we sent the results to Abbott and Abbott said, "This is marvelous, we've never seen so much data from a single lab on normal subjects." And then, "Oh, my goodness, we've got the cutoff in the wrong place!" [laughter] So that's how arbitrary this stuff is.

Hughes: And they presumably changed the cutoff.

Perkins: They changed it, yes. So having established where the cutoff is, it's all done by automated instruments and printed out on tape, and at this point, the results go directly up into the blood bank's main frame computer, once the tape's been checked. If you get a reaction with the color intensity dark enough to call it positive, then the next step is to repeat that test in duplicate, because all too often, you have made a technical mistake, generally in the form of a little splash coming from a positive sample into the well that's negative. When you run the test, every single plate has a bunch of known positive samples and a bunch of known negative samples, which have to give results in the right range before you can go ahead.

So a single initial reaction of positive doesn't mean anything. You repeat it in duplicate, and if one or both of the duplicates are positive, then it's repeat-reactive, and that's a positive, and that donor is finished forever [as a future donor], regardless of what the rest of your testing shows.

The next step is the Western blot, and the Western blot will give you one of three answers. There may be no band whatsoever, in which case the test result is negative and you know the first test result was a false positive. At this point in time [1985] we didn't know what to tell the donor. Now we can say, "It's a false positive, you don't have AIDS or HIV. However, unfortunately, you cannot donate blood."

Hughes: Why?

Perkins: Because the FDA says so.

Hughes: Why did the FDA say so?

Perkins: They're just leaning over backwards to be careful. Now, it is true that they've got an elaborate mechanism for reinstating such donors, which you can use at times. For example, last fall the Abbott test went a bit haywire, and the number of false positives

quadrupled for a number of weeks, apparently in donors with recent flu shots.

Hughes: Here, or everywhere?

Perkins: All over the country. So we have reinstated some of those donors. What you have to do is get two samples six months apart, make sure they're negative by all the screening tests, by Western blot and so on, and then you reinstate the donors. Anyway, that's one possible test result, negative.

Another result, you get all the classical bands that are typical of antibody to AIDS virus, and that's a true positive, no arguments.

The third possibility is you get one or two bands, and they're not typical of HIV; they're the sort you can find in these false positive Western blot reactions. They're also the sort of thing you can find in an infected person at a very early stage of antibody formation. So then you have to tell the poor sucker, "I don't know whether this is a true positive or a fake. Come back in three months and six months and we'll see." Because if it's a true positive, the test will give the true pattern in three to six months.

We know now from numerous culture experiments and polymerase chain reaction [PCR] tests that we have never been able to culture virus and demonstrate virus in those who are Western blot negative, nor in those who have a persistently indeterminate Western blot pattern which doesn't progress on to the typical positive pattern. Which most of them don't; most of the indeterminates stay that way.

## More on Informing and Counseling HIV-positive Donors

Perkins: Now, the next responsibility is, how do you tell these HIV-positive donors, and who helps them from there on in? One of the things we had to do was to set up mechanisms for informing them, for chasing them if we couldn't find them right away. They were informed of their test result with a certified letter that only they could accept, and told to call for an appointment to come in to the blood center. I think initially the letter was somewhat vague; it didn't say they had HIV. If they didn't respond to that letter, then they got a more definite letter. And if the certified letter didn't get delivered, then we tried it without a certified letter, because some people won't go to the post office

to pick up certified mail. If we still can't find them, we use things like the TRW credit company to see if they can find their current address.

So HIV-positives come in, they get counseled, both in terms of what it means to the rest of their life, in terms of what it means to their sexual partners, to notify their sexual partners, getting them tested, in terms of safe sex from here on in--

Hughes: Now, is this participation in counseling voluntary?

Perkins: Oh, we can't force them. If they don't come in, they don't come in.

Hughes: They may come in just to find out what the score is, and reject the counseling.

Perkins: Yes. But usually what happens is they come in, and people like Susan Samson, our manager of epidemiology, and a few others downstairs who have this ability, will spend several hours with them, gaining their confidence, letting them talk, everything totally nonjudgmental. Because one of the things the counsellors are trying to find out is, how did they get their HIV infection, and if they're in a risk group, why did they donate? And what can we do in the future to prevent donations by similar persons?

Then the next question is, okay, these guys may have donated before; what happened to the poor recipient who got their blood? So then we have to look up to see did they donate before? What blood components were made from those donations? To what hospital did those blood components go, and off go letters to the hospital saying, "Red cell unit No. __ was sent to your hospital on (date). The donor now has a confirmed positive test for anti-HIV. Please identify the recipient and have the recipient's physician notify the patient about the possibility of exposure to the AIDS virus." Plus much more.

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Perkins: We were doing this kind of lookback from the AIDS case reports from the health department starting in December of 1982, but with the HIV testing, the number of recipients that needed to be notified just multiplied exponentially for a while.

Fifteen HIV-positive per 10,000 means about fifteen a month, because we collect about 10,000 donations a month. So there were quite a number of HIV-positive. Each person may have donated an average of six to eight times before, with maybe a couple of components made from each donation, so when you start looking at

the number of recipients that need to be looked at, it gets up into the many thousands before you get through.

Now, when we went back and tested these transfusion recipients, on the average, we found that 50 percent of them were infected. The other 50 percent were transfused before the donor got infected. And the longer the period of time between detecting the donor's infection and the transfusion, the less likely the recipient was to be infected.

**Fear of Discrimination**

Hughes: Do you want to say something about the fear that the antibody test would be used as a mechanism of discrimination, particularly if it were made mandatory?

Perkins: Well, I don't have any special knowledge in that area, except that you're absolutely right, of course, gays had been very concerned about it possibly being made mandatory. I must confess, as the years go by, I get more and more on the side of those who want to make it mandatory. Yet, I'd like to see the gays get legislation that will protect them from discrimination at the same time. It gets very silly.

We have a law, for example, that says that you cannot tell a third party the results of an AIDS antibody test. That means--and we have had this situation: an antibody-positive donor had not told his wife. By law, we could not. We worked on that guy for six months, brought in a psychiatrist, and finally he did tell his wife.

Now, it probably didn't make any difference--I'm sure it didn't make any difference in this case; she wasn't infected. But he <u>might</u> have infected his wife in that six-month period.

Hughes: Is that one of your arguments for mandatory testing?

Perkins: That's an argument for being allowed to tell sexual partners without permission of the infected person. (Post-interview comment: The law was subsequently modified to permit this.) That's a different issue. If you're talking mandatory testing, under what conditions? I don't know. I think if somebody has raped somebody, then he ought to be tested.

Hughes: There is some movement towards increased testing, because at least until the Concord study, there was the argument that early intervention--

Perkins: Yes, we've been counseling everybody, you've got to know early if you are HIV-positive, because if you are, you need early drug treatment intervention. We're now back to the official line: we're not sure whether treatment should begin early or not. So early testing is important primarily for safe sex, I guess, which everybody should be using anyway.

Hughes: How much HIV-positive blood slips through all the screening procedures?

Perkins: There's no question that there is a window of time between infection and the appearance of antibody. That window of time has been progressively shortened as we've gotten better and better tests for antibody. The current test we use, which picks up both HIV-1 and HIV-2 antibody, detects IgM as well as IgG antibody, and IgM is the first antibody to appear after HIV-infection. So there's only a few weeks now at this point between infection and appearance of antibody.

The best guesses currently, and this was from the CDC and from the Red Cross, are one in 235,000 odds of HIV antibody negative donation being infectious.[1] That fits pretty well with the study we've been doing here where we've been culturing and doing PCR testing on donations that are screened negative, in other words, have normal history and negative tests, including a negative anti-HIV test. We've asked the question, can we identify virus in such samples by culturing it or by amplifying it by the polymerase chain reaction? We identified one such donor back in 1988, and none since.

Now, we haven't tested every single donor, but we've tested over 200,000 of these negative screened donors. So that's one-in-200,000, which is as I say pretty close to the estimate that is being offered nationally. I think blood in San Francisco now is as safe as it is in the rest of the country. That certainly was not true in 1983.

We still get an occasional report of a patient who was transfused since screening began who is HIV-positive, and almost always when we dig far enough, we find there are other risk factors. With that one in 235,000 odds on one side, and 4

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[1] R.Y. Dodd. The risk of transfusion-transmitted infection (Editorial). New England Journal of Medicine, 1992, 327:419-421.

percent of the town being HIV-positive, you'll likely find it was not the transfusion that did it.

## *Money* Magazine's Accusations Against Blood Banks, 1986

Hughes: Money magazine, in March 1986, made some accusations against the blood industry.[1]

Perkins: I read it at the time; I haven't seen it since.

Hughes: Well, one of the accusations--I think there were four--was that the blood industry had made exaggerated claims about the ability of the HIV antibody test to identify tainted blood. The test in those early days, I guess by common consent, was certainly not as accurate as it is now.

Perkins: Yes, but it was well over 99 percent accurate. I don't know what justifies that statement. Certainly I don't remember anybody claiming any more test accuracy than we knew. One would have to claim that it had totally prevented any transmission, and I don't remember anybody ever claiming that. I mean, the CDC has said repeatedly in authoritative statements [I have heard in the media] that the fight against transfusion-associated AIDS is essentially won, but this doesn't mean it doesn't still happen occasionally. And for the one person it happens to, it's just as devastating.

I thought Money magazine was going to accuse blood banks of making all our decisions for financial reasons. And the truth is that when we add a test, we just pass the charge on to the patients. If we're concerned about costs, it's patient money we're concerned about.

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[1] Andrea Rock. Inside a billion-dollar business of blood. Money, March, 1986, pp. 153-172.

## More on the Anti-HIV Antibody Test

[Interview 4: July 14, 1993] ##

### Irwin's Trial of Early Tests

Hughes: Dr. Perkins, last time we talked about the anti-HIV antibody test, and I have a few more questions. One of them is a comment which I got from the minutes of the [IMBB] administrative staff meeting of February 4, 1985, which stated, "The field trials are not going well. The reader must be off as we are having an extremely high percentage of false positives."[1]

Perkins: This was a test kit we were given to try. It was the very first one we worked with, and it was a very badly designed system. It gave us 6 percent positive test results which did not agree with what anybody was getting with any of the other tests; did not agree with what Jay Levy was getting with his immune fluorescence assay. We didn't believe any of the results, but there we were, stuck with 6 percent of the donors in this trial positive in the test, deferred forever as blood donors, and scared to death. We told them we didn't believe they were true positives. It was a very worrisome business.

Hughes: When you had a better test, did you go back and retest?

Perkins: Yes.

Hughes: How many different tests did you test?

Perkins: I would guess that by the time we began official licensed testing in March of 1985, that that was one of three tests that we had worked with in the preliminary phases.

Hughes: Do you remember what the other early ones were?

Perkins: The original one that gave us great trouble was a combined effort of Travenol, which is a Baxter subdivision, and Genentech down in South San Francisco. That was the bad one. I think we also did some preliminary trials with the Electronucleonics test. That was one of the early licensed tests. Then the third one, which was the first one licensed, was Abbott's.

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[1] IMBB Administrative Staff Meeting Minutes, February 4, 1985 (CBBL 02662-02663).

Hughes: And it was the first one licensed because it was the best?

Perkins: Yes.

Hughes: Did all the tests work on the same principle?

Perkins: Yes. Basically, they all lysed the virus, made an extract of viral proteins, and then coated them on a solid surface. And then you incubated your serum with the solid surface, washed it, added the indicator antibody, and saw how much uptake there was. So they were all enzyme immunoassays, all based on that concept. Now, that's not including the immune fluorescence assay that Jay Levy was using, which for many years nobody attempted to license, but now actually is a licensed test.

Hughes: I saw a reference to the fact that you were going to back up the Abbott test with the Western blot and Jay Levy's.

Perkins: Right. In those early days, Jay was interested in checking the positives to see if he could recognize them with his test.

Hughes: That meant a lot of work, did it not?

Perkins: Oh, yes! [laughter] All of this was a lot of work. A lot of work and a lot of worry.

Hughes: Anything else to say about problems with those early tests?

Perkins: No. We've talked about the numbers of positives we turned up, and some of our problems in knowing what to tell these people. But at that point, we were working very closely with the CDC, so whatever we told the donors was what we were getting from the CDC.

Hughes: Did you have enough tests to screen all donated blood?

Perkins: Once we began, we were able to screen all donated blood, and actually go back into inventory and screen that too.

## Establishing the Test Cutoff Point

Hughes: Well, the AABB statement of December 27, 1984 on the antibody test, includes a paragraph about the cutoff point in the "grey zone."[1] Who made the decision about where the cutoff should be?

Perkins: The manufacturer makes that decision. You get a printed pamphlet that tells you how to do the test, tells you where the cutoff is, and this pamphlet has been read and approved by the Food and Drug Administration. So if the test is licensed, it's licensed to use exactly as the manufacturer says, and you must use his cutoff.

Hughes: There's no input from outside sources before the literature is put out?

Perkins: Well, before the literature is put out, it's based on the field trials which are done in places like Irwin and others. Now, we don't help write any of the manufacturer's literature. All we do is give them the results we got on the samples that they asked us to test.

Hughes: I remember last time you said--I think we were talking about this test--that the Irwin findings did indeed indicate that a different cutoff should be stipulated?

Perkins: That was the test for anti-core. That was when we had done that trial of 8,000 donors in 1983. We never got into the debate with any of the manufacturers about where the cutoff was in the anti-HIV test.

Hughes: Was it a debate?

Perkins: Well, it's an arbitrary thing, where you set this cutoff. All I know is that the manufacturers based it on their field trials, and the FDA approved it, after testing with their panel of known positive and negative sera. I have to take that on faith. Now granted, once we get a positive in this screening test, then we go on to do further testing, such as the Western blot. And right away we found that most probably were false positives. But whether that was because of the cutoff or for some other reason, I can't answer.

Hughes: Well, we talked last time about how the sentiment of the times was that a positive test did not necessarily indicate current

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[1] "Anti-HTLV-III testing: A statement from the American Association of Blood Banks," December 27, 1984 (CBBL 02600-02603).

infection with the virus. There's quite a point made in Irwin's literature, which I'm sure stemmed from CDC directives--

Perkins: Yes, that's what I'm saying.

Hughes: --that this did not mean a diagnosis of AIDS. And yet, was that the interpretation of people who were told that they were HIV-positive?

Perkins: Well, it certainly could mean that they were infected, because we knew that virus had been isolated in something like a quarter or a third of people who tested positive at that point. We also knew that they could go on to develop AIDS. What we couldn't tell them is what their chances were. I don't remember actually how it worked. I don't know that we even went into "more likely than not" or "less likely than not." I think we just said that we can't tell you whether or not you are infected.

Hughes: Yes. I don't think you qualified it.

Perkins: I don't see how we could have, frankly. We didn't know. So they were left with this uneasy situation: the hope that maybe they weren't infected, but a dreadful fear that they did have a lethal infection. That certainly was a cause for immense panic in every case.

Hughes: In every case? Was that the reaction?

Perkins: Absolutely. Yes, it got quickly to the point where the people we were using to counsel these people needed their own psychiatrists to keep them going. I could always tell when they had told a recipient that he or she had been exposed, because they'd be white and shaky for the next two hours.

## Corporate Competition for a Successful Test

Hughes: I've seen references to the ferocious competition amongst companies to produce a successful test.

Perkins: I'm sure there was competition. I don't know if I ever used those words--

Hughes: No, it wasn't you.

Perkins: Competition, yes. There were probably at least half a dozen companies in early 1985 rushing to get a test licensed. The

first one licensed clearly was going to make a financial profit, and the ones left out might never recover their investment at all. So it very definitely was a very competitive situation, and remains constantly that. Abbott has probably, I don't know, 80 to 90 percent of the testing business in the country, and yet they're worried constantly that somebody else is going to come along and push them out of the way.

Hughes: Did the fact that Abbott was the first test to be licensed give it a real edge?

Perkins: They had two edges. First, it was the first test licensed, and second, their technology was already out in most of the blood banks. When we switched to Genetic Systems in 1986, we had to bring in new instruments and train people from scratch. But when we went to the anti-HIV Abbott test, we used the machinery we'd been using all along for surface antigen and for core antibody. All we had to do was instruct the technologists on a change in procedures; make sure they used the right reagents for the right test.

Hughes: So that would largely explain Abbott's domination of the field?

Perkins: Well, I hate to take away from the fact that Abbott had some very capable scientists who were doing an awfully good job in developing these tests. They were very good.

Hughes: Irwin's scientific advisory committee decided on October 29, 1984, that Irwin should not offer alternative testing sites, "as such an effort has great potential for getting out of control and causing severe problems."[1]

Perkins: I don't remember. Were we talking about setting up testing ourselves?

Hughes: It was a discussion in October of 1984.

Perkins: October of 1984 was long before we had prospects of the test coming.

Hughes: Well, it was in the wind.

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[1] Brian McDonough to [IMBB] Commission, November 12, 1984. "Implementation of HLTV-III testing" (CBBL 01602-01603).

## More on Alternate Test Sites

Perkins: Oh, yes. And Margaret Heckler [Secretary of Health and Human Services] said we'd have a test for AIDS antibody within six months [after the announcement of the discovery of the AIDS virus].[1] Six months was pretty well up by then. But clearly, we wanted alternate test sites so that the gays would not come back to donate in order to be tested.

I'd have to look at the memo to see whether it refreshes my memory at all. [tape interruption] All I can remember is that we certainly were concerned at that point about the issue of gays coming back to get tested, and that we felt some alternate mechanism should be set up. This memorandum implies that we decided that about all we could do was to educate the gay community that they must not come back, and explain to everybody as they came into the blood bank why they must not donate if they were at risk for AIDS.

Fortunately, as I say, the state did pick up the responsibility, and alternate test sites were set up, so it never did become a problem.

Hughes: But that took a while, didn't it?

Perkins: Well, it took a while, but it did not in any way endanger the blood supply, because what the state law said was that, until the alternate test sites were set up and people had had a chance to go to them, we could not give anybody the results of a test for anti-HIV. And we were telling people that up front: "We're not going to be able to give you results of any of these tests until next September," I think it was.

Hughes: Yes, six months hence.

Perkins: From March to September would be six months. And that meant that there was no incentive to come in to us when they knew the alternate test sites were set up in June or July, and they'd get their answers much quicker that way.

Hughes: Why was there the delay?

Perkins: To set up the alternate test sites? I'm not sure when the law was passed; I bet it wasn't passed until May or so. And it takes time to set up test sites. It certainly is not something you can

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[1] Secretary Heckler's announcement was made on April 24, 1984.

do right away. For one thing, you've got to bring in a bunch of people who are pretty doggone knowledgeable who can work with these people, counsel them appropriately. They have to be counseled twice: number one, do you want this test? Back in those days, there were a lot more reasons for not getting tested than there were for being tested. The pendulum has swung in the other direction now.

So those asking to be tested were counseled first as to whether they wanted the test, and then, once they got a positive test result, they needed to talk to somebody very knowledgeable. So it took a while to set that system up.

Hughes: The reason for not being tested was largely related to discrimination?

Perkins: Discrimination, and the fact that we had nothing to offer people who tested positive. At that point, we didn't even have data on what the risk was to sexual partners.

Hughes: In September 1984, you talked to Dean Echenberg of the health department's Bureau of Communicable Disease Control about setting up a mechanism for offering free testing to gays.[1]

Perkins: All I remember is we were doing our best to get the health department to assume that responsibility. I'm sure I did talk to him, but I don't remember the discussion.

Hughes: Well, I can tell you what his reply was, according to your memo. [laughter] "His [Echenberg's] reply was that they could not because they and all other public health agencies were agreed that testing gays for anti-HTLV-III should be discouraged at the present time. We will discuss it further with Jim Allen from the CDC when he comes to San Francisco next week."[2]

Perkins: What was the date of that memo?

Hughes: September 28, 1984.

Perkins: Oh, good. I've been trying to find out when Jim Allen started coming here. [laughter] Yes, I'd forgotten how vehement the public health officials were on that subject.

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[1] Herb [Perkins] to Brian [McDonough], September 28, 1984 (CBBL 02550).

[2] Ibid.

Hughes: And what was their main fear?

Perkins: What they were hearing was that gays had been denied their health insurance, life insurance, lost their jobs, lost their friends--this was a concern. There was no protection for those people.

Hughes: And that's the tenor of the CDC pronouncements of this era, too.

Perkins: Probably, yes.

Hughes: There's a lot of stress on the need for confidentiality.

California AIDS Task Force Statement on Testing, October 1984

Hughes: Do you want to comment on James Chin's draft statement on laboratory testing for the AIDS virus which was written, I presume, by him for the California AIDS Task Force?[1]

Perkins: He was head of the Infectious Disease Section of the State of California Department of Health Services. I don't know the draft to which you're referring. [tape interruption to consult draft]

Hughes: Do you know if the draft was indeed implemented much as it was originally written?

Perkins: I can't say I know that, but my best guess would be that it was.

Hughes: Was it sent to you for input?

Perkins: It was sent to me, because it's stamped, "Received, November 13, 1984, [IMBB] Scientific Services."

Hughes: Presumably, Chin wanted your comments.

Perkins: Not necessarily. See, I was not on that AIDS Task Force, but Dr. Silvia Hoag from the Oakland Blood Bank was, and she frequently asked my comments on things that she was asked to comment on. So I could have gotten it from her, rather than directly from Chin.

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[1] James Chin, M.D., to California AIDS Task Force, October 23, 1984, Draft statement on laboratory testing for the AIDS virus. IMBB binder 1a, 2405-2605, (CBBL 02553-02558).

Hughes: I see. So you didn't really have much connection with the task force?

Perkins: I was supposed to be on it originally. I was out of town at the wrong moment, so they appointed Dr. Hoag instead. But as I say, she always called me for advice anyway, so I had my input, I guess.

[skimming Chin draft] Look at this--such interesting statements: "...there is an urgent need to determine what proportion of exposed persons will develop asymptomatic infection with subsequent immunity to the AIDS virus..." How hopeful we were in those days! "...what proportion will develop only lymphadenopathy syndrome; and what proportion will develop irreversible and ultimately fatal AIDS."[1]

Hughes: [Donald] Abram's hope, remember, was that the lymphadenopathy patients whom he was studying would not go on to develop AIDS.[2]

Perkins: Yes. But we didn't know the answer to those questions.

The beauty of the test for antibody to HIV was that it at least gave us a handle to find out who had been exposed, and then we could start following them to see how many got into trouble. That takes time. Takes years, more years than we thought at the time.

## Blood Donation Deferral Lists

Hughes: Could I quote you something else from Chin's draft statement?[3]

Perkins: Yes.

Hughes: "Persons with a presumptive positive test will be placed on the individual blood bank's deferred donor list[,] and they <u>may</u> be placed on a blood donation deferral list that is compiled by the California Department of Health Services and distributed biweekly to blood banks in California and to American Red Cross Banks throughout the country." Why does Chin stress the 'may'?

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[1] Ibid.

[2] See the oral history in this series with Donald I. Abrams, M.D.

[3] Ibid.

Perkins: I don't know, because it was done. The list he's talking about was originally a hepatitis deferral list, and at the time, one could get from the list why the person was on the list. They were HBsAg positive, or a doctor had diagnosed hepatitis, or whatever it was. If they were going to add people who were anti-HIV positive, they didn't want to identify these individuals as anti-HIV positive. So the solution was to delete from the list all reasons why people were on it. They figured that the huge morass of hepatitis-positive people would protect the confidentiality of the few anti-HIV positives.

Hughes: Which it did.

Perkins: Which it did, it worked, and it still is being done. It's not being done exactly that way. This was written when? [looking through paper] This draft was written October 23, 1984, and of course we didn't even have the test for another six months. I think probably very soon after we had the test, this was being done. You didn't find a memo from the state on that subject, did you?

Hughes: Well, I can't say that I didn't find it; I didn't copy it, let's put it that way.

Perkins: At any rate, fairly soon after we began testing, we began putting the names on the state deferral list. Each deferred donor was also listed as deferred in his blood bank record.

Hughes: Well, do you have any more to say about the antibody test?

Perkins: Only that it's gotten progressively better over the years, and we now test for anti-HIV-2 as well as HIV-1.

Hughes: Using similar technology?

Perkins: The technology still uses the same Abbott equipment, but it's a slightly different approach in terms of the way the reagents are added.

Hughes: When a new test comes in, such as this, is it expected that the individual blood bank will be responsible for training its technicians in-house?

Perkins: Normally, what the manufacturer will do is either invite us to send a few supervisors to them, or they'll send a few trainers to us, to at least train a nucleus at the blood bank. So the manufacturer is responsible for our initial training, but once they have trained the trainers, then we're responsible for training the rest of our staff. And we will occasionally bring

manufacturers back at intervals. In regard to some of this recent criticism from the FDA about not documenting that we have retrained our people at intervals, we brought the manufacturers' representatives back in so that we could retrain them, and just didn't put it down in writing.[1]

Hughes: Does the FDA now stipulate a certain length of time for the retraining?

Perkins: The reason I'm hesitating is because their guidelines for all these things are about to come out in print. They inspect the blood bank first, and then we know what we're supposed to do.

I could add that at the current time, the frequency of HIV positives at this blood bank in our community donors is as low as in the rest of the country, in spite of the fact that we're operating in a high-risk area.

Hughes: Do you track the incidence in specific risk groups?

Perkins: When we get a positive, we try to find out why the person is positive. Is that what you mean?

Hughes: Yes, but you don't contribute directly to statistics on whether the incidence, for example, is rising among young gay men?

Perkins: No. The only relation we had was our involvement with the San Francisco Men's Health Study, and we didn't do the antibody testing for that. [tape interruption]

You could say that our AIDS research began with the UC baby in December of 1982, and our agreement with the San Francisco Health Department that we would check any new AIDS cases reported to them against our donor files. If we found anybody in the file, we then traced their recipients to see if any of them showed any signs of AIDS. That was done without any outside help or support, financially or otherwise, although the CDC was aware that this was going on. We thought we might have a chance to get some money from the city of San Francisco when they had some AIDS money for research there. It never came through. Selma Dritz recognized that we really needed a trained epidemiologist to be doing all this tracing and talking to people, that we doctors weren't necessarily the best people for that kind of thing.

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[1] See the following articles: Blood supplier to alter system after FDA rebuke, San Francisco Chronicle, June 18, 1993, A23. Irwin's licensing may be in jeopardy, San Francisco Examiner, June 18, 1993, C1.

Hughes: Could the city have provided you with an epidemiologist?

Perkins: Well, all the way along, we kept hearing the city was going to provide us with people. And they just couldn't; the city health department was overwhelmed. When the CDC got into the act officially, they gave the city of San Francisco--not Irwin--a contract, and then the city of San Francisco subcontracted with Irwin to carry it out. It was just a continuation of what we were doing already, but it was done through the city. We were anticipating getting some additional help through that contract that would put an epidemiologist in place, and that individual was always coming, except the city could never spare one.

Hughes: You mean the city was overwhelmed by work?

Perkins: Oh, they were overwhelmed, yes. The transfusion end of the epidemic was a minuscule amount of cases compared to the horrendous epidemic that was going on in the gay community, and the attempts to control that, and the bathhouses were a major source of controversy.

Hughes: Well, from talking with Dr. Silverman, I know that there was a budget surplus in those days.[1] Was there ever talk of hiring an outside epidemiologist?

## Irwin's Research on a Test for Healthy Carriers of AIDS, 1984-1987

Perkins: Well, we got our epidemiologist initially through an NIH grant, which was awarded to us and began May 1 of 1984. That's when I hired Susan Samson who's still running our epidemiology department downstairs. She was a one-lady department for a while.

Hughes: Which study is that?

Perkins: This was the grant from the National Heart, Lung, and Blood Institute to investigate a test for healthy carriers of AIDS.

Hughes: Do you want to talk about that?

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[1] See the oral history in this series with Mervyn Silverman, M.D.

Perkins: Sure. That was the first research grant or contract we ever got on AIDS.[1] At the time of the January 4, 1983 meeting of the CDC, when people started talking about, "We need to investigate surrogate tests, and we need to do this, that, and the other," several people spoke up, "Yes, but is there money? Does the CDC receive money that they could give the blood banks to do this research?" They laughed at us. They had no money they could spare for us. They were struggling to get more money out of Congress.

If you say there was a budget surplus in San Francisco, I don't care whether you talk of national, state, or city, but the money goes somewhere, and not always where we think it ought to go. So as I say, the first federal effort to supply money for the blood banks, or for anything related to transfusion AIDS, came in the form of a request for applications for research grants issued by the National Heart, Lung, and Blood Institute [NHLBI] in September of 1983. That was the first time that the federal government had said, "We want some research done in this area, and here's some money that people can apply for."

So we applied for that, and remember, this was the time at which we were trying to get all kinds of surrogate tests evaluated for us by outside people. And they replied in response to that same request for applications, and that's where Drs. Eyster and Goldstein were going to get their money.

So awards were given to all of us, and we were planning all of these studies. Then came word that the cause of AIDS had been discovered by Gallo,[2] and the NHLBI decided there's no point in going ahead with most of the surrogate test studies. They did want Irwin to go ahead, because of the rather broad nature of the approach we were taking, looking at donors to AIDS patients and recipients of donors and being able to compare AIDS antibody results versus surrogate tests.

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Perkins: Ed Engleman was another one of the winners of that grant, and he got his grant, that continued. But the others were strictly

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[1] For additional information on IMBB's AIDS-related grants, see the appendix in this volume, "HIV Related Grants and Contracts, 1984-1994."

[2] Luc Montagner and others at the Pasteur Institute have since been credited with this discovery. For more information on the race to isolate the AIDS virus, see the oral history in this series with Donald P. Francis, M.D.

evaluating new surrogate tests, so their grants were cancelled before they began.

We had that grant for about three years. It was the initial basis for setting up an epidemiology department here, and was the basis for a lot of the support for the $beta_2$ microglobulin work we subsequently did, and for a lot of our early studies of the anti-HIV test. But most of it went into the epidemiology of tracing the donors and recipients, getting them in, counseling them, getting blood samples. Art Ammann was doing immunologic tests for us [on this study], and we were doing the various infectious disease tests. Jay Levy was doing antibody tests with his technique as well.

At the same time, the CDC's interest in what we were doing was building up, and Jim Allen was sent out here to talk to us a number of times.

Hughes: That was your first contact with him?

Perkins: Yes. He was definitely set up to establish a collaborative agreement with the City of San Francisco Health Department and work with it and Irwin to do extended studies of the type we had already begun doing.

Hughes: He is an epidemiologist?

Perkins: Epidemiology, infectious disease, yes. He subsequently left the CDC and became [Health and Human Services Secretary] Louis Sullivan's right-hand man for AIDS; I forget what his title was. He was in the health secretary's office as the AIDS expert. He's now left the Public Health Service and is working for the American Medical Association [laughing]; I don't know what he's doing with them. He's an awfully nice guy, very knowledgeable, and very helpful.

We kept asking him for advice, and he'd say, "You people have all the experience. Nobody else is seeing all these transfusion-associated AIDS cases."

Hughes: And that was including New York?

Perkins: They were working with New York, but it's not the same situation. It's such a big, complicated mess, the numbers were huge. But I do know that the CDC had investigators working with the health department of that city; to what extent they were working with the blood bank, I don't know.

## Collaborating with the Centers for Disease Control

Perkins: So anyway, that evolved into a whole series of what they call collaborative agreements between the CDC and Irwin and other organizations with which they worked. These were not grants or contracts.

Hughes: Now, what's the difference?

Perkins: Well, the difference is, when you get a grant, you are given money to spend as you think fit to accomplish the goals that the grantor has approved. You get a contract; it says, "This is what we want you to do, and you do it." A collaborative agreement says, "You and I are going to sit down together and we're going to decide what we're going to do. We're Big Brother with the money, and we're going to have the most say." [laughter] So that's the way the CDC operated.

Hughes: So it's a skewed collaboration.

Perkins: Yes. To some people who might have been more concerned about building up a national reputation than I was at that point--I'd been around a long time already--it might have been something to resent a bit. If you look at most of the papers on transfusion AIDS that then came out, the lead author is a CDC guy. You'll find my name on the papers. The data is 60 to 80 percent Irwin data. They added in a little data from other blood banks. That didn't bother me. We got the data out; that was the important thing.

Hughes: You're implying that CDC's approach did offend some people?

Perkins: No, it could have, I said. If a very young man who had yet to establish a national reputation had been in my position, he could well have resented that kind of an approach.

Hughes: Does the CDC tend to have a heavy-handed approach to outside groups?

Perkins: I hate to use the word heavy-handed; I've had such good working relations with them all these years. They very definitely take the point of view that it's their responsibility; this is an epidemic, they're the ones responsible for helping to understand it, control it. They'll work with anybody they can and provide money as they must to get the job done, but they never delegate the responsibility to somebody else. The NIH will say, "You know, it would be a good idea if somebody would do research," and then they give you a big award, and their job is finished, except

to make sure you've spent the money wisely. So it's just that the CDC will never give up the responsibility, they won't go away and leave their collaborators unsupervised.

Hughes: So it's a difference in mandates.

Perkins: I think so. It's not a matter of style at all; it's a matter of what their responsibilities are. They are not an agency set up to provide research money to a research institute, university, or blood bank. It's not going to happen.

Hughes: I have heard that CDC epidemiologists were not fully trained, that they were given a crash course, six months or so, in epidemiology.

Perkins: It's not impossible. I really am not in a good position to comment; I don't know too much about the training of the people I've dealt with. People like Jim Allen came to me already thoroughly experienced. When Jim moved on to a higher office, John Ward took over for him, and I know John was a very young fellow, at a very early stage of the game. In fact, he subsequently went on to take some more postgraduate training; he interrupted his CDC career to do it. I never felt that I got less good service from John, however; he was an extremely bright guy and he had an awful lot of people to lean on back at headquarters. So I never saw it as a problem. It may be that to an epidemiologist, which I'm not, the CDC epidemiologists would have been regarded that way, but I think if you had talked to Susan, she would have given John high marks from the very beginning.

Hughes: Was there a difference in working with Selma Dritz, who was functioning as an epidemiologist, and Andrew Moss, and any of the other epidemiologists that you might have come into contact with?

Perkins: It differed, yes. I worked with Selma only at the end of her career, and I think she was fading at that point. I never found her particularly helpful. She knew what was going on, and she could tell me the statistics, that kind of thing, and she was supportive, but in terms of coming up with ideas or pointing me in new directions, that never happened.

I didn't have very close relations with Andy Moss. I'm aware of his study from the very beginning. We did hepatitis tests on all the people he was following for a couple of years at his request at blood bank expenses. But that's about the only contact I had with him.

Hughes: This was part of that census tract study that he did?

Perkins: I never heard it called that, but he had this study going with people with AIDS, neighbors, controls, and things like that. And we'd get all these samples blind. I later found out they included staff samples [laughs] that were retested over and over again.

## The San Francisco Men's Health Study, 1983-present

Perkins: The epidemiology group that I worked with mostly was Warren Winkelstein's and Jim Wiley's [San Francisco] Men's Health Study.[1]

Hughes: Well, talk about that. Who was involved, and what was each group doing?

Perkins: I'm trying to remember how it initially began. There was an AIDS research group at UC with members who were at least informally working well with each other, people like Marc Conant, Paul Volberding, Don Abrams, Andy Moss. This was sort of the in-group.

Girish [Vyas] is one of these people who is always on top of everything, and he's constantly calling the NIH, and he knows what's going on, what they're thinking about. He got word that a large nationwide prospective study was being set up involving gay groups in several high-risk areas, and thought this would be a marvelous thing for UC to get involved in. He ran into a roadblock because the group at UC that was doing AIDS research didn't want competition from Girish.

Being the kind of guy he is, Vyas didn't quit. He somehow latched onto Warren Winkelstein, who was the retired dean of the [University of California] School of Public Health in Berkeley, a highly respected epidemiologist. He had a contact with the Survey Research Center, a part of the School of Public Health there which does a lot of epidemiology and has a lot of computer facilities. So it was agreed that Warren would apply for participation in this nationwide study, and a group of principal investigators was set up. Girish was one, and I was one, and Jay Levy was one, and I suspect probably Art Ammann was involved, but he left the university somewhere in there [1985].

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[1] For more on this study, see the oral history in this series with Warren Winkelstein, M.D., M.P.H.

At any rate, the San Francisco Men's Health Study was set up as one of I believe five centers under contract with the National Institute of Allergy and Infectious Diseases. The goal of the project was to study the natural history of AIDS. Our study was a little bit different in that it was what the epidemiologists called population-based. The other four centers put ads in the newspaper and said, "Who would like to be in an AIDS study?" The people here felt that was going to result in a very biased group.

So they sent people from the Survey Research Center around knocking on doors in certain zip code areas they had selected. They tried to line up everybody in the selected zip code areas. I think actually we did get 60 or 70 percent. And they picked up ultimately 1,000 gays and 200 heterosexual controls who were neighbors of these gays.

We had been asked, and this was probably in 1983, whether we would do the helper/suppressor ratios for the study, because they knew we had this instrument [the flow cytometer] on loan from Becton-Dickinson. They also knew we were having problems with it. Nonetheless, by the time the study got funded, we had worked out those problems. So somewhere around the middle of 1984, I think, we began. The enrolled gays would come to a clinic, which was at Children's Hospital here in San Francisco; we'd get a blood sample; we'd separate out the white cells from the blood sample; run the helper/suppressor ratio, and then freeze the rest of the white cells and serum for future testing. We've still got the repository down in the basement, freezers full of stuff from that cell study.

Ultimately, we split off from the other five centers, because Warren had evidence that the gays were changing their behavior, and this was resulting in a decrease in the rate at which there were HIV-positive gays showing up in the group. He wanted to publish this information fast, and the other centers wanted to wait until they had their data so they could join in. He thought it was important to get the information out immediately to save lives, and we split off.

Hughes: Did that cause dissention?

Perkins: Oh, yes. We never did get funded as well as the other four centers. And we were constantly threatened with being cut off. I think the other four centers must still be going. They constituted the MACS study.

Hughes: So the San Francisco study was eventually terminated.

Perkins: The study has terminated; we have no more personnel on the study here. We do have, as I say, samples in the basement, and we're getting a few blood samples for a related study involving the same group of gays.

We got involved in many other ways. When Dr. Busch came here as scientific director, he was full of ideas of what to do with these sera, because they are marvelous samples, drawn every six months from people who ultimately became HIV-positive. These provided earlier samples to look at with our tests to see if we could have picked up the presence of HIV earlier with a better test, and polymerase chain reaction and other tests for the virus itself were investigated. So an awful lot of good work was done, and many dozens of papers came out from it. Eventually the NIH concluded that the study had accomplished its goal, and the money could be spent better elsewhere. I have no quarrel with that.

Hughes: You said earlier in this discussion that the Heart and Lung grant was the first one. Do you mean Irwin's first grant for AIDS, or the first grant that Irwin got for any type of research?

Perkins: Oh, no, we've had research grants ever since I came here in 1959.

Hughes: That's what I thought.

Perkins: I brought some with me. You have to understand, when I came here in 1959, I was an expert in blood clotting, and then Dr. Rose Payne at Stanford got me interested in white cell antibodies and tissue typing, and from that, we ended up being the organ transplant tissue typing center for northern California. We had a big grant from the National Institute of Allergy and Infectious Diseases to demonstrate the advantages of a central typing center for multiple transplant centers around the state. They supported us for a good many years.

## The Transfusion Safety Study, Initiated in 1984[1]

Hughes: All right, what research are we missing?

Perkins: The Transfusion Safety Study. It was led by a fellow named Jim Moseley who is a hepatitis expert from the University of Southern California. He envisioned a nationwide study looking at transfusion-associated AIDS, this being before we knew the cause

[1] To Dr. Perkins's knowledge, the study is currently phasing out.

of AIDS. The study was focused on the immunologic changes induced by transfusion, because remember, one of the theories for AIDS was antigen overload from all these foreign stimuli. And there were already some bits of evidence that transfusions in themselves are immunosuppressant.[1]

So this nationwide study was being set up, and it involved hemophiliacs, it involved chronically transfused kids with congenital hemolytic anemias, and it was going to involve blood donors. And then just as we were almost ready to go, along comes the announcement that the cause of AIDS has been found and a test is going to be available in six months.

So immediately, we all latched onto that and started saving serum samples from our donors. When the test became available, we would be able to find out who was positive, and we'll be able to see what actually happened to recipients of antibody-positive blood, because the blood will have been transfused. So the whole study was totally rewritten, at least the blood bank part of it, and we set up another repository to store donor serum samples. [laughs]

Every one of these studies involves consent forms; it involves going to the institutional review board--we used the UC Medical Center's institutional review board for all our research. It had to approve what we were doing; it had to approve our consent forms; it approved what we were telling the donors and the recipients.

So that was the beginning of the Transfusion Safety Study, initially just creating a repository to put away [blood] samples from July 1984 through January of 1985. I think we had 27,000 samples put away here, and about 200,000 around the country. And when the test became available, we had it set up, got these samples tested, got them Western blotted, recalled donors, told them if they were positive, found out who the recipients were, and started chasing them. So that went on and on for a good many years, and that study too is now fading out.

Hughes: Is that the study that included three epidemiologists who were funded by the grant?

Perkins: Where do you get three epidemiologists? My problem is that we've had such overlapping grants, I don't know who got paid by which.

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[1] H.A. Perkins. Transfusion-induced immunologic unresponsiveness, Transfusion Medicine Review, 1988, 2:196-203.

In fact, if you ask me right now today who's paying for whom down in this basement, I'm not sure. [laughter] [tape interruption]

Hughes: Then there was reference to extend the studies on transfusion AIDS under the CDC contract to include donors with lymphadenopathy, and also some controls.

Perkins: I'm not sure that ever even happened. Things get proposed and then they don't follow through. Our original CDC contract was to follow recipients of donors who had come down with AIDS. Then we got a CDC contract to study the donors, but before that we had an FDA contract to study the donors, right after the HIV antibody test came in. They were interested in getting some feedback, so there was the FDA one and then the CDC basically took it over when the FDA grant ended. We then had a CDC contract to study heterosexual contacts of individuals we had identified, because we had one of the few groups of HIV-infected people who weren't gay men.

Michael Busch

Perkins: A lot of the new research is Mike Busch's activities, and he's more basic, at the laboratory level.

Hughes: Was he brought in specifically because of his basic science orientation?

Perkins: Mike had been the chief resident in lab medicine at UC Medical Center, and we all liked him and thought he was a very bright guy. Irwin needed somebody to work with me. Probably Brian [McDonough] was still here, but I was scientific director, trying to run all these research programs, and be the medical director of the outfit. And so we brought Mike in, and we didn't really appreciate what we got, because he turned out to be an absolutely marvelous person. In addition to his M.D., he also had a Ph.D. in retrovirology.

## Other Research Efforts

Perkins: [The following discussion is based on a memorandum, "Contracts Update," April 28, 1993.][1] There is always some Universitywide AIDS Research [Program] money, and you can usually get a few dollars for new projects starting up. The American Association of Blood Banks has some small grants. I've already mentioned a big study that's been going on for years, trying to identify whether we can find anybody who's carrying HIV who passes through our screening, our testing and so on. That one's fading out at this point.

[looking through papers] This is the remaining active CDC collaborative study, relating to HIV-positive blood donors, and this is the heterosexual transmission study recently discontinued.

Then we had two major national studies which are just being discontinued: the Transfusion Safety Study and the [San Francisco] Men's Health Study, and now we have a big new study involving six blood banks: the REDS study, which is a prospective study of blood donors. This is the study that would be the basis of any work that gets done if a new virus suddenly appears, because we've got these huge repositories being built up of donor sera, which will be available for tests if there is concern about a new infectious agent.

Hughes: Which is something new for Irwin?

Perkins: Well, we've had repositories, but this is a new one. It started with HTLV [human T-cell lymphotropic virus], because that was the new virus at the time. Some research was done on that, and there were a lot of demographic studies being done on why people who were HIV-positive still donate. But the biggest purpose behind it was to set up for a new virus if one appeared.

There is another grant that Mike's assistant, Allen Mayer, got. What they're looking at is the nature of the virus [HIV] itself. They're trying to explain why some people are infected for years and nothing happens to them, and others get sick so readily. One possibility is that the virus mutates and becomes more virulent. We have this marvelous series of individuals where we know this donor transmitted the disease to those recipients; and how are the viruses the same, how are they

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[1] Mark Walker to Dr. Perkins, Dr. Michael Busch, et al., April 28, 1993. (Dr. Perkins' office files)

different, and what happens to the course of these different individuals. So they've got a grant on that.

I don't know if we can say much more about those early grants and contracts without actually looking at budgets. I don't know that you've seen all our publications.

Hughes: No, I haven't. [tape interruption]

You spoke of some of the research projects as winding down, and I wondered why.

Perkins: It becomes a matter of priority for money. There's always more you can learn, and yet, the urgencies change. As far as the federal government is concerned, the battle against transfusion-associated AIDS is essentially won. They're interested in funding us only to the extent that we can help in other areas where more widespread benefit may come out of the kind of research we're doing. I think it makes sense to say the Men's Health Study and the Transfusion Safety Study have basically accomplished everything they set out to do and then some. While they would continue to contribute something useful, the NIH point of view is, "Fine, submit a research grant application, and if it's good, we'll fund it."

Hughes: Have we said enough about the research in the early years?

Perkins: I really think so.

Hughes: Well, you said at our first meeting,[1] which was not recorded, "Most of what has been learned about transfusion AIDS has been learned in this building."

Perkins: Yes, I think that's correct. As I said before, the papers coming out from the CDC had CDC officials as the principal authors, but 60 or 80 percent of the data that prompted those papers came from Irwin.

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[1] May 19, 1993.

## The Lookback Program

### Origins

Hughes: I'd like to talk about the lookback program, which we have been talking about; we just haven't been calling it that. I suppose the lookback program began with the baby in December 1982?

Perkins: Yes, because when we started to look at other recipients of that donor, then that was the beginning of the lookback program in AIDS. It's interesting that for the country as a whole, lookback is something that began in 1985 with the anti-HIV test, when blood banks were faced with evidence that plus/minus one of their donors was positive, had been exposed to the AIDS virus, and they couldn't ignore that fact. Whereas we went out and tried to find evidence in the records of the local health department that we had a donor who was now infected. That's a policy that most blood banks have not used.

Hughes: Why?

Perkins: I don't know why. The AABB did come out with a statement that said if a blood bank learns that a previous donor has come down with AIDS, then it should investigate prior recipients and notify them.[1] It was just not made mandatory that the blood bank should try to find these cases by comparing the city health department's list of AIDS cases against the blood donor list. We have gone as far as putting in print our recommendation that it be done on a national basis.[2]

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Hughes: Was part of the hesitation on the part of other blood banks, let well enough alone?

Perkins: Well, it's a little hard for me to get inside their minds. To so many places, AIDS was a San Francisco problem, not their problem. They might have a few AIDS cases, but nothing that they had to

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[1] Transfusion-Associated AIDS: Interim recommendations for notification of blood collecting organizations and transfusion services. AABB, ARC, CCBC: Joint Statement, December 10, 1984.

[2] S. Samson, M. Busch, et al. Identification of HIV-infected transfusion recipients: the utility of cross referencing previous donor records with AIDS case reports. Transfusion, 1990, 30:214-218.

pay any attention to. And just as we didn't realize how big the problem was here, neither did they realize how big the problem was there, even though it was a lot less than we had. So now we're seeing the end result with every state, every city, small hamlets, all of their AIDS cases. I'm not trying to downplay the fact that this place per capita had more [transfusion AIDS] cases than anybody else, and it was more than any of us could have guessed with our wildest fears.

Hughes: I saw reference in the minutes of the Technical Advisory Committee meeting of February, 1984, to a discussion about procedures for keeping track of donors with AIDS, and for finding and notifying recipients.[1] Do you suppose that was the first, or one of the first, discussions of formalizing the procedure for what became known as the lookback program?

Perkins: You could be absolutely right. You know, you're talking of a meeting of supervisors of hospital transfusion services. Now, these were the people to whom we had been sending our requests: "Here are donor numbers of red cells we sent to you on such-and-such a date, and the donor now has AIDS." To some extent, there was a little bit of an attitude that, "Good lord, this is a lot of extra work; we don't have the people for this; Irwin's got a research project they want to carry out, but that's really not our responsibility." I will say that in spite of some of that attitude and some foot-dragging, they all came through, and I think rather quickly accepted the fact that this was far more than a research project, that they had a responsibility to their patients who were receiving this blood.

Hughes: But you did have to do some proselytizing?

Perkins: Oh, I definitely did. And Susan Samson was on the phone all the time beating them over the head, figuratively: "Why haven't you reported," and so on. She was very stubborn with them.

## Procedures

Hughes: Is it appropriate to ask you to describe the procedures?

Perkins: Oh, sure. Yes, both in the early informal days and nowadays as it's set up, any time we receive information that a previous donor is now infected with the AIDS virus, the first thing we do

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[1] IMBB Technical Advisory Committee Minutes, February 14, 1984.

is to pull that donor's records, check first to see if there's any reason why he should not have been accepted as a donor, and then find out what blood components were made from those donations, and where did those blood components go. Our records allow us to trace that all the way back.

Hughes: Has Irwin always kept a record of where blood components went, prior to the AIDS epidemic?

Perkins: Yes. We know to which hospital each component went. Now, that's as far as we know. We don't know what the hospital did with it, whether it was transfused or not, or who got it.

## Saving Donor Records

Perkins: One of the problems we've had with the hospitals is that frequently after ten years they threw away all their records. We still get an occasional request, "We'd like to find out what happened to a woman who was transfused back in 1979." Now, granted, the patient's medical chart is there, but you don't know what hospital record to look for, because the hospital transfusion services' record that says where that unit went is no longer there.

As experience has accumulated, hospitals have been saving these records. Our attorney has always told us, "You save that stuff forever," and we do.

Hughes: And that policy is a product of the AIDS epidemic?

Perkins: No. That particular kind of record we've always saved. I say "forever". If you ask me about 1947, I'm not certain I could find the record. [laughs] I've never tried to. But certainly when we've gone looking, no matter how far back we've gone, the records are there.

Hughes: I'm surprised it's not mandated that hospital records be kept.

Perkins: Well, what is mandated is they keep a careful record on each patient.

Hughes: But not how long that record is kept?

Perkins: Who ever thought that there would be a disease transmissible by blood that you wouldn't know about for ten more years?

Hughes: But now that there is one--

Perkins: Oh, now that there is, they've absolutely got no business throwing that stuff away.

Hughes: It is up to the hospital?

Perkins: Yes, as far as I know. I think they're keeping records currently; they'd be very stupid not to, because you can look awfully bad from what some records sometimes show up, but you look even worse when you can't find them. [laughter]

Hughes: You speak from experience?

Perkins: No, we've always managed to find those, thank heavens. But there will be times when you just cannot for a while, and then you find somebody's been mixing up the files. We used to have donor cards, five million cards, file after file after file. If you got one misfiled, god help you. Then maybe once every ten years we would have people going through the file, card by card, to make sure there wasn't anything out of order. So you could find the records eventually.

Hughes: Well, I think I pulled you away from the lookback procedure.

Perkins: So the hospital, unless it's an awfully long time ago, will have, in most cases, kept the records that say if the blood was transfused, and if so, who got it. So they then would be able to pull the medical record of the patient who received the unit and find out who the patient's physician was. So the normal course of events then would be to notify the patient's physician; and we had forms that we would transmit to the hospital. We would provide the hospital with information for the patient, information for the doctor, as well as information for the hospital.

Hopefully, the hospital would send that information on to the doctor, and then the doctor would then have to make the decision, am I going to notify this person, do I even know who this person is at this point, can I find the person?

Well, the first surprise that hit us was that over 50 percent of the patients were dead when we went looking for them, not from AIDS, but from the illness for which they'd been transfused. That bothered us, because we know medical procedures don't have that kind of a death rate. If we looked for a record on a heart disease patient, people who had heart surgery, 60 percent of them would have been dead. And what is this? The

operation is stated to have a 5 percent mortality, and 60 percent of them are dead?

But you start to think about it: the ones who are most likely to hit an [HIV-]positive unit are the ones who are getting a huge number of units of blood. So what we were finding was that massively transfused people (the ones who got into serious trouble) were dead. So in those early years, that was the end of the investigation. Now we have recognized there are sexual partners that need to be informed even if the patient is dead.

### Tracing Blood Recipients

Hughes: How would you trace a sexual partner if the original partner is dead?

Perkins: Well, let's say you sent a letter, and you got a letter back, "I'm sorry, my husband died."

A lot of our problems in those early days was convincing doctors that they should tell their patients that they had been exposed, and particularly this was before we had the test for anti-HIV. "So what am I going to tell the guy?" We would say, "But we need to learn; we need samples; we need to find out what this means." And that's when we got these complaints, "Well, why should we be doing your research?"

As I say, now things are quite different: doctors do accept responsibility; do tell their patients. In the beginning, we gave them options. We said, "You can tell them; you can ask us to come by; we'll send a counselor over to be there with you when you tell them, or you can send them over here and we'll tell them." In the beginning, most of them were sending patients over here and letting us tell them. Now, that almost never happens.

Hughes: What happened to physicians' psychology?

Perkins: I don't think it's psychology; I think it was knowledge. In the beginning, physicians didn't know what to tell these people. They felt totally lost.

Hughes: So it wasn't so much hesitation to tell somebody that he had a fatal disease, it was hesitation because physicians didn't know the scientific basis, or even the prognosis?

Perkins: Right. And they don't like dealing with all these uncertainties. They felt, well, if Irwin knows more about what's going to happen to this person, why not let Irwin handle it? And if I can get out of spending three hours comforting these people, why not let Irwin handle it? But as I said, physicians have gotten used to it now, and they've gotten knowledgeable, so they do it themselves, and that's as it should be. And there isn't that much notification any more. It's slowing down.

Also, part of what we sent to the hospitals was a plea that the recipients would allow us to enter them into our research studies, sign consent forms, and we asked the doctors to help us with that. So that's pretty much it. Sounds easy, but it involves an immense amount of record-keeping, particularly with the huge number of AIDS cases we've got: we have to keep track of everything, make sure nobody drops through the cracks, make sure that we follow up when the letter is returned "Address unknown."

## The National Blood Agencies' Policies

Hughes: Well, in June of 1985, the AABB, the Red Cross, and Council of Community Blood Banks agreed not to initiate a lookback program and not to notify blood recipients of past donors infected with HIV.[1] Do you know why?

Perkins: They were waiting for more information before recommending how to do it.

Hughes: Well, less than a year later, in April of 1986, the blood agencies reversed this decision.[2]

Perkins: Well, I don't think there's any question that it wasn't until 1986 that they came out with formal recommendations for lookback procedures.[3] I don't remember them having a policy recommending against lookback. I think it was more a delay until they were

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[1] C. Perrow and M.F. Guillen. The AIDS Disaster: The Failure of Organizations in New York and the Nation. New Haven: Yale University Press, 1990, pp. 40-41.

[2] Ibid., pp. 40-41.

[3] AABB: Guidelines for notification of recipients of blood or components from donors who now have a confirmed positive test for anti-HTLV-III, June 16, 1986 (CBBL 03381-03384).

sure how to handle it and had the opportunity to obtain advice from a wide variety of experts.

Hughes: Did Irwin ruffle any feathers by starting a lookback program, which could have put pressure on other blood banks to do something similar?

Perkins: No, I think they felt that was a San Francisco problem. It didn't put any pressure on them.

Hughes: Could New York ignore lookback?

Perkins: I don't know what New York did, now that you ask me. Very interesting that I can't remember. All my discussions with Dr. Pindyck in 1983 were always about donor screening and surrogate testing. I don't remember our discussing lookback; I'm sure she must have been aware of what we were doing. But whether they were doing something similar or not, I don't remember.

I'm thinking back to your statement that the blood agencies recommended against notification. I can remember all these arguments and fights about what does a positive [anti-HIV] test mean? What should we tell our positive donors if we call them in?

Hughes: Yes, what good is it. Also, lookback was an expense.

Perkins: Yes. We had money by then.

Hughes: But maybe not all blood banks did.

Perkins: No, they didn't. And there's no question that we have carried out more extensive lookback programs than anybody, and have done them with a lot of federal money, too, that other people didn't have.

## Funding for AIDS Research

Hughes: You mentioned the application to the city for money which you did not get. But in general, when Irwin asked for money, did it get it?

Perkins: Early on this was not true. Our funding from the Men's Health Study was so inadequate, we could not accept all the blood samples they wanted to send us. Later we received what we needed. If we had asked for more, could we have gotten more? I

guess the answer would be yes, providing we had a good idea of what to do with it. I honestly think money was thrown at us about as fast as we could tolerate in terms of our space and people, and what we might accomplish. But eventually money was not a problem for us; you're absolutely right. I've never before been in a situation where money was handed to me even before I asked for it. For the most part, I'd have to say that much of what we did in the eighties was not even initiated by us. It was CDC, NIH, or FDA saying, "Well, would you be interested in doing a study of such-and-such?" and we'd say, "Yes."

Hughes: So the story you tell in terms of funding is quite different from the one in most of the literature where there is great hand-wringing about the slow response to funding requests, particularly at the federal level.

Perkins: I would say slow too, because at the January 4, 1983, meeting, there was the suggestion for investigating surrogate tests. September of 1983, nine months later, the NIH said, "We'd like to offer some money for this purpose." The money was given in May of 1984, seventeen months later. That's slow. But once it got rolling, we did get funded. But yes, I have to say sure, the American public was concerned disproportionately about transfusion AIDS because it could happen to them, and much less about AIDS among the gays. There's no question about that. The gays are absolutely correct when they say they were discriminated against. Had AIDS been a disease of heterosexuals, it wouldn't have taken so long to get federal funding, or funding in general. There would have been a lot more money there. I agree completely with that.

Hughes: Why was it so slow?

Perkins: You mean in that specific instance?

Hughes: Well, whatever you care to comment on.

Perkins: Well, you see, the specific instance I cited is absolutely classical federal government. That's the way it goes. The staff gets together and they talk about, "Well, maybe we should do this," and then they form an advisory committee, and then they wait for a council to meet and approve the RFA [Request for Application] that they're going to put out, and then having gotten the approval in July, it takes them two months to write it and crank it up and get the OMB [Office of Management and Budget] to approve the use of paper, and that kind of thing. [laughter] If I see one more piece of paper on how this complies with the Paper Reduction Act of Congress, I shall scream. [laughter] All the paper that's been wasted saying that.

Hughes: Did Irwin from the very first case of transfusion-associated AIDS make a public announcement?

Perkins: Well, we had a press conference on December 9, 1982.

Hughes: All right, the second case.

Perkins: The second press conference was on February 8, 1983.

Hughes: And that was announcing the second case of transfusion AIDS?

Perkins: No, that was the announcement of what we were doing to prevent any further cases.[1] Did we ever just specifically make an announcement because we'd heard of a case? I don't think so. Seems to me they came the other way; they were in the paper first.

Hughes: In Shilts, there was a statement to the effect that Irwin "infuriated" (the verb that Shilts used) other blood bankers by admitting to cases of transfusion AIDS.[2] [tape interruption]

Perkins: You mean, like Brian McDonough's statement that there could be thirty more cases before the year's over, that kind of thing? Yes, there was no question we were trying to be totally open with the press. We never denied anything. But if you're asking whether, every time we got a report of a case of transfusion AIDS we called up the media and told them the answer is "No." In the first place, when you initially got a report, there was a lot of checking to do. Is it valid? Is it AIDS, or was it caused by something other than transfusion?

## Statistics on Transfusion AIDS Cases

Perkins: I do know that we had given out statistics repeatedly on where we stood on cases of transfusion-associated AIDS. Incidentally, although this is well past your time [1984 project cut-off year], there's another important event that happened in San Francisco related to this. And this relates to Mike Busch's estimates of what the true incidence of transfusion-associated AIDS was here. This was put together and was presented at the international AIDS

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[1] IMBB News Bulletin, February 8, 1983 (CBBL 00494-00495).

[2] Shilts, p. 514.

conference in Washington in May, 1987. It was in a poster, and it didn't get much attention.

It was also at the same meeting that the CDC issued its first estimate of what the risk must have been for the country, and they said they thought 27,000 people were what had been infected through blood transfusions.

Hughes: Did the two sets of figures agree?

Perkins: No. We think the CDC was grossly underestimating. We came back from that meeting, and Mike and I together sent out a memorandum to our hospitals with the new estimates. UC decided that it was going to send a letter to every patient they had transfused from the beginning of 1977 until March 1985, which they did. Then Kaiser decided it was going to do the same, and that got the media's attention. We had about fifty people from the press in here that day beating on us.

Lisa Krieger of the San Francisco Examiner was beating on me: "Why didn't you tell us about this? Here you've got this big estimate: you were saying one case of transfusion AIDS in a million [transfusions] back in 1983, and now you're saying one in 100." I said, "We could not have done the analysis that led to the one-in-100 estimates prior to 1987. We had presented the new figures publicly at the International AIDS Conference, and we did present it to our hospitals. We sent them our new estimates." So that got into the press, and as a result, the entire West Bay Hospital Conference hospitals sent letters out to all of their people who had been transfused in the time period from 1977 to March 1985.

Now again, this was not done elsewhere in the country. One more area in which we were ahead of the rest of the country.

Hughes: Did you approve of notifying recipients?

Perkins: Oh, yes. We couldn't do it, because we didn't have the names of the patients in the hospital. But UC did it, and came up with some very interesting facts. Things like, 10 percent of the people who got the letter didn't know they'd ever been transfused.

Notifying Transfusion Recipients

Hughes: Shilts made a statement in reference to a woman at Seton Medical Center who in January of 1985 was the hundredth American known to have contracted AIDS through blood transfusion. He says, "As part of a new policy of openness, Irwin was now publicly announcing each new case of transfusion AIDS."[1]

Perkins: Brian may have been doing this and I may just have not realized it.

Hughes: That date doesn't seem right to you?

Perkins: 1985? No. But we did have multiple previous contacts with the media with these cases. 1984 was the year when the front pages were often full of new stories about AIDS cases from transfusions.

Hughes: Shilts goes on in the next paragraph to say, "The Irwin policy of candor infuriated other blood bankers..."

Perkins: I don't know what his basis is. Maybe it did, I don't know. [laughs]

Hughes: Well, I should finish the sentence: "...infuriated other blood bankers who were still clinging to their one-in-a-million rhetoric, if not declining comment on the problem of transfusion AIDS altogether."[2]

Perkins: He may have information I don't have. I certainly don't remember getting into arguments with other blood bankers. I very much doubt they were sticking to the original estimates.

Hughes: Now, this recommendation is outside our period, but I think it's legitimate to discuss, because it applies to what was going on in these early years. In March of 1987, the Public Health Service recommended that certain recipients of blood components between 1977 and 1985 (when the test for anti-HIV became available) be considered at risk for infection with HIV.[3] Apparently, there

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[1] Ibid., p. 514.

[2] Ibid.

[3] Herbert A. Perkins to All Departments, March 19, 1987 (CBBL 03435-03436).

was a problem that the news was released before blood banks were notified. Does that ring any bells?

Perkins: No, I remember transmitting that CDC recommendation to our hospitals. I think it was that CDC recommendation that got Mike [Busch] going on figuring out what the risk must have been in San Francisco in those years.

Hughes: In the same memo, presumably written in response to the Public Health Service announcement, you say, "Although San Francisco must be considered to have been a high risk area for blood recipients prior to March 1985, we do not recommend that all recipients be tested."

Perkins: [pause] If I said that, I certainly changed my mind in a couple of months. [laughter]

Hughes: Why would you have said it?

Perkins: Well, I'm not sure that wasn't pulled out of context. [tape interruption to read memo]

What I was saying was that the arbitrary decision to notify everybody transfused from 1977 through March of 1985 was not appropriate. The decision had to be based on what the risks of transfusion AIDS were at various periods of time. There was no risk prior to 1979, as far as we could determine from our records, and each person had to consider the pros and cons of being tested. I think I still stand by everything that's in that memo.

In May, when we put out a more complete memo with a stronger recommendation for testing, I can't argue that either.[1] I think that that was the appropriate thing to do. But I think it needed to go along with the information of what the relevant risk was at different times.

Hughes: What had changed in those few months?

Perkins: Well, is there really a change in what these two memos are saying? I haven't reread them completely. Let's take a look. [tape interruption]

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[1] M.P. Busch to directors of clinical laboratories, directors of transfusions services, supervisors of blood banks: The risk of AIDS from blood transfusion updated April 25, 1987. Distributed May 13, 1987 (CBBL 03438-03445).

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Perkins: The memo to all departments from me on March 19, 1987 says that the decision to notify prior recipients must take into account what the relative risk was at the time they were transfused. I particularly objected to going back to 1977 because we had not seen a case of in this area from a transfusion prior to 1979.

The memo from Dr. Busch dated May 13, 1987, really asks the question: should previous blood recipients be tested? And then down at the bottom it says that we concur with the decision that individuals who received multiple transfusions during the high-risk period should consider being tested. We strongly encouraged physicians to be involved in the decision to test, and in the testing process.

So I think what we've done here in the May 13 memo, which is the one that went to the hospitals, is to give them a lot of background data, a lot of understanding of what the risks were at different times, and then say that the decision to be tested should be individualized. I think what happened, however, is that the hospitals found it a lot easier to do a general notification rather than an individualized one. I don't think our recommendations really changed between the March and May memos. I can understand why the hospitals might find it easier to send everybody a notice and let them discuss it with their physicians afterwards. Otherwise it would have meant looking up how many components each one got, what components they got. It was impossible for the hospitals to do it. I do accept that.

Hughes: Well, any more on lookback?

Perkins: Other than that it's been a fantastically big job, I can't think of anything else.

## Litigation

### Irwin's Record

Hughes: Well then, some questions on litigation. A recent article in the Chronicle reported that Irwin has been the target of fifty-three lawsuits from people allegedly infected with HIV via transfusions. Of those, twenty-four cases were dropped, eleven

were won by Irwin, four were settled out of court, and the rest are pending.[1]

Perkins: That's roughly correct. The figures keep changing. Of these fifty-five cases, three actually are not AIDS cases--or one is indirectly. It's a suit for slander in connection with an AIDS case. [laughs]

Twenty-four were dropped or settled. There are fourteen cases that we have won. Of these, three are currently on appeal, two at the appellate court level and one at the state supreme court level, the appellate court having agreed with us on the one that's being appealed to the supreme court. There's one case that was won and has now been reopened, and I don't know what they think they can do. We won the suit, and I'm sure that's going to be thrown out. So I guess the correct figure is that we've won fourteen.

There are four cases which actually have a trial date set at the moment, one of which is not an AIDS lawsuit; and there are eight cases in which nothing much is happening, and I'm not sure whether they'll ever get to trial or not.

Hughes: Can you say something in general about why Irwin won those fourteen cases? Or thirteen cases, because one was not AIDS?

Perkins: Yes, one of the cases, they sued us; we won. The transfusion took place in 1982 before anyone saw the risk. The child died, they sued us again, the court threw the case out. They then turned around and sued the blood bank and me personally because after the father had threatened the life of my attorney, I sent a notice around to the staff to keep their eyes open for any unusual occurrences. He thought that was slander, so he asked for a jury trial, and the judge wouldn't let it go to the jury. He threw it out. The family is still very angry, and I can't blame them for that.

Why did we win? There are two very simple answers. One is that we won because we weren't negligent, and we've been able to convince the jury of that by showing them all these documents which you've seen.

Hughes: Was the argument in general that Irwin was using accepted procedure for that given period?

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[1] Blood supplier to alter system after FDA rebuke. San Francisco Chronicle, June 18, 1993, p. A23.

Perkins: Yes. Now, you can listen to the plaintiff's side, and you can listen to our side, and you'll get a different story on why the jury voted as it did, because the other side of the coin is the legal interpretations and what the law of California says. The courts--and this has gone all the way to the Supreme Court--allow the state of California to include blood banks among health care providers. If you do that, then you have to judge a blood bank according to standard medical malpractice rules. You cannot allow a jury to make its own decision as to whether the blood bank was negligent or not; it has to make that decision based on testimony of expert witnesses who are the only ones qualified to say whether or not the blood bank did what it should have done.

Now, that means you're always going to end up with expert witnesses on both sides, some who said that Irwin should have done this, and some who said they should not have. It's true in general that Irwin has had better witnesses, more believable witnesses. But there have been people like Marc Conant and Don Francis on the other side, who certainly don't have to take second place to anybody. The attitude of the judge and jury in most of these cases has been, "These guys are saying what should have been done, but there's nothing in the record to say that that should have been done at that time." Anybody can get up after the fact and say, "This should have been done." A statement of an individual really doesn't set standard of care, which is what the legal decision is supposed to be based on.

Now, the plaintiff's side of this is that, well, all of the blood banks were guilty of negligence together, and therefore they were within the standard of care, because they did what the blood banks all said. To that I have to say, "Okay, then you have to say not only all the blood banks but the FDA and the CDC and the Public Health Service in general, because we did everything they told us to do. They were saying all the things we're now being told we were stupid for having said."

**Donald Francis's Argument**

Perkins: I honestly think that Don Francis is a very sincere guy, but I think he's emotionally wrapped up in this to the point where he's literally not even remembering things correctly; I'm sure he's wrong on some of these things. Look at the written record. The only thing that's in writing from Don Francis is a letter he wrote to Jeff Koplan, the moderator of that meeting in Atlanta on January 4, 1983. In that letter, he made two specific recommendations. One was that blood banks should do hepatitis

core antibody testing. No blood bank ever saw that letter until two years ago. The CDC didn't transmit his recommendation to anybody else.

Don's second recommendation was that the blood banks should exclude any individual, regardless of his sexual preference, who's had more than two different male partners a month for two years. Now, should we have followed that? I mean, everybody was saying something different, so why should one guy's claim--that I pounded on the table and said this--determine what blood banks should have done?

There hasn't been any question we've been helped by the court interpretations, which require us to be judged by the standard of care at that time, as outlined by expert witnesses, and do not allow jurors to base decisions on one person's statement of what should have been done--from a point of view ten years later.

Hughes: I'm amazed that you get the message through to the jury.

Perkins: I am too. Before the trials started we told ourselves that there's no way on earth that a San Francisco jury isn't going to find an institution guilty of having transmitted such a horrible disease. That's why Irwin made some of these early settlements. I must say my faith in the jury system has been amazingly turned around. They do a remarkable job. There will always be one stupid guy who didn't understand English anyway and was busy flirting with the kid who was brought in looking absolutely miserable with his AIDS. He'll be against us, but the other eleven are for us. And all we need for victory is a nine-to-three vote.

Hughes: Remarkable.

Perkins: Yes. We've still got outstanding cases. Who knows what's going to happen? (Post-interview comment: All AIDS suits were subsequently resolved with no plaintiff victories.)

**Dr. Perkins's Court Attendance**

Hughes: Have you testified in all these cases that have come to court?

Perkins: Not only that, but I've sat in court every day from the beginning to the end of the case.

Hughes: Out of choice?

Perkins: Because my lawyer said I should.

Hughes: So that you were informed.

Perkins: So that I was informed. It serves two purposes: one, it shows the jury that we care. But the other purpose is, I very definitely am a help to our attorneys, particularly at this point. A recent appeal that just went up to the Supreme court surprised us because we thought they'd quit at the appellate court level. Some other attorney, I don't even know who he is--he doesn't have a case against us as far as I know--wrote a letter to the court as friend of the court and made a number of allegations which stumped our attorney. He said, "This is trouble." He sent it to me and I said, "Oh, no, that isn't. Bing, bing, bing, here are all the reasons." The next thing I knew, I saw a rebuttal going up to the supreme court, rewritten in legalese, but it's my argument. And the supreme court refused to hear the appeal, leaving a decision in favor of Irwin.

Hughes: What were you able to do that the lawyer couldn't do?

Perkins: Oh, the argument was based on statements that could be easily proven incorrect.

Hughes: So you went back to the documentation?

Perkins: I didn't have to. I knew it. I've been living this stuff. That's one reason why we're in trouble with the FDA, because I wasn't around the blood bank for the last three years; I was in court all the time. So now Dr. [William A.] Heaton [the new IMBB president] can worry about everything else, and I'll continue to worry about the legal stuff.

Hughes: Is that all right with you?

Perkins: Oh, yes, that's mostly why I'm sticking around.

Hughes: You get a secret--

Perkins: Oh, no, I don't enjoy it, if that's what you mean.

Hughes: But it must be intriguing, nonetheless.

Perkins: It's intriguing and it can be satisfying, but I go into every one of these cases totally depressed. "Oh God, am I going to go through this all over again?" The things the plaintiffs' attorneys say are horrible. They'll get me up on the stand:

"This man was callously disregarding the safety of people, concerned only with the dollars they hold on to--" Mostly the juries don't believe that kind of accusation. But it's no fun hearing it.

Hughes: Yes, I can imagine it's not.

AIDS has had an impact on many aspects of medical care. Has it had any impact on the legal process?

Perkins: Obviously in certain specific rulings it has, but fundamental changes? I don't think so.

## Compensation for Hemophiliacs with AIDS

Perkins: One of the things that's still snowballing at the national level is the question of compensation for hemophiliacs with AIDS. I don't know whether it's snowballing now because so many hemophiliacs are only now developing AIDS from their infection in the early eighties, or whether the French trial has stimulated feeling. But clearly, the hemophiliacs are thoroughly organized. They have told literally all their physician members and associates that they must not testify for the manufacturers of clotting factor concentrates, asking them to testify for plaintiffs, and they're beating on Congress to come out with some kind of an indemnity policy.

Now, if the hemophiliacs get that, why not the blood transfusion recipients? And you go around in circles, because you can say, "Well, why should the poor person who went through this misery have to pay for it financially as well as with the absolute agony and misery of what he went through? Why not spread it a bit? Why not make the blood banks pay him?" they'll say. Well, if everybody infected by this blood bank got $200,000, we'd be out of business. Then those who sued later would be out of luck. That's not a fair way to do it.

One could say--and some people make this case--"Get rid of protection against implied warranty." Blood banks are protected against the standard manufacturers' problem, which is if you put out a defective product, you must pay for any harm it does. We have a state law that says blood banks are not providing products; we are providing a service, and therefore we cannot be held to a warranty of a product that we can't prevent from being unsafe. You could do that, but then who would be paying the bill? Current patients in the hospitals would pay. So if you're

going to spread the cost, you might as well spread it to the taxpayers as a whole. Let the government reimburse people.

But then if you do that, you know what the gays in this town are going to say: "We are innocent victims too!"

Hughes: And then the IV drug users. And the heterosexuals.

Perkins: Well, it's a mess.

Hughes: To what degree is fear of litigation an impetus for screening procedures?

Perkins: I don't know. I suppose it would be ridiculous to say it had absolutely no effect, but it goes beyond fear of litigation. The blood banks would like to do what the public wants or expects of them, provided they think it's safe and reasonable. Obviously, we have mother agencies too, like the FDA, determining what we do and don't do. My only concern about what the FDA is doing now is that they're putting all their pressure on not what we do but how we do it, and it's the 'what' that was the problem.

Hughes: What do you mean by that?

Perkins: What is the procedure we're going to use to prevent AIDS transmission via blood products? That was the decision that had to be made. The FDA's current actions do not give a hoot about that. All it wants is, when the decision has been made, that it be carried out appropriately. So they're not addressing the basic issue, which is the issue of who makes the decisions and how are the decisions made? The talk I gave to the AABB last year was on that subject.[1] [laughing] Oh, it will probably help get me in trouble with the FDA, too.

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[1] Herbert A. Perkins, M.D., "The Safety of the Blood Supply: Making Decisions in Transfusion Medicine," in S.J. Nance, ed., Blood Safety: Current Challenges, Bethesda, MD: American Association of Blood Banks, 1992.

Miscellaneous Topics

J. Garrott Allen

Hughes: I found a letter from J. Garrott Allen, professor emeritus of surgery at Stanford, who wrote on February 14, 1983, to Rudi Schmid, who had just become dean of medicine at UCSF. He said, "I don't know why it is that Irwin feels it must collect more blood than any other blood bank in the country to meet the needs of the population to which it is committed. Some years ago I calculated the figures for a number of communities and found that the mean number of units needed to supply these community populations was one unit for about every 20 people. Irwin, on the basis of their audited figures, drew 1 unit for every 10 people. Either it was due to enormous outdating, or blood was being sent beyond Irwin's area of assigned responsibility and never accounted for. Therefore I believe that there is every justification to request Irwin to restrict blood collection from the male homosexual population without causing shortages."[1]

Perkins: Garrott Allen is dead. He was a very famous surgeon and blood banker at the University of Chicago. His biggest claim to fame was his discovery that plasma that he kept at the hot summer temperatures of Chicago failed to transmit hepatitis, which turned out not to be true.

Hughes: Oh, you mentioned that.

Perkins: Anyway, he claimed in court that he had proved AIDS existed in 1970, and finally found his evidence--a letter from [Secretary of Health, Education, and Welfare] Eliot Richardson congratulating Allen on his new appointment as professor of surgery at Stanford.

After one year they pushed him into a back office. So he spent the next thirty years of his life writing letters. I guess we insulted him, because here was this famous blood banker who came to this area, and we never invited him to be on our advisory committee.

Hughes: Was that an oversight on Irwin's part?

Perkins: I wouldn't say so. I didn't think he had that much to offer, to be honest with you. But his gripe was not with me; it was with

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[1] Marcus Conant's "KS Notebook," 1983.

Bernice Hemphill.[1] He had an intense dislike for the woman who directed this blood bank for forty years, and I don't know what the basis of it was, except as I say that he may have felt he wasn't appreciated by people out here.

I want to get back to his claims: I think his figures are a little bit wrong, but it is quite correct that in 1982, we were collecting probably 5 or 10 percent more blood than we needed, and had probably for many years. The blood was shared with other blood banks who couldn't meet their own goals. And the money we received from other blood banks for that blood we sent was used to reduce fees to the local patients.

Hughes: Was the blood surplus a matter of good recruiting techniques?

Perkins: People were coming from all over the world to ask Bernice Hemphill how she did it, and that's literally true. She was a hard worker; that's how she did it. She pushed people very hard. Unfortunately, this plurality of blood didn't last. AIDS finished that; we've been in the hole ever since. But we collect about 120,000 donations a year, and the population we serve is about 1.5 million. Even then, you can't go by ratios, because you look at UC San Francisco and California Pacific Medical Center and the kind of referral business and tertiary care and the transplants they do, and blood usage is just far greater in areas like this. We supply blood for patients referred from outside our area of service.

We collect blood over a wide area of northern California, and we supply San Francisco by importing blood like mad from the north bay and northern California within our own system. You have to do that. The suburbs and the rural areas have to supply the big cities; the big cities can't do it alone.

Hughes: Is that explained by the fact that the tertiary centers are in the cities, or is donation better in the suburbs?

Perkins: Both. Donation is better in the suburbs, for many reasons. There is more feeling of community in the suburbs and small towns. In a city like San Francisco in which more than 50 percent of the population is minorities, it is very difficult to recruit donors. Donating blood is foreign to their cultures. All of the big industries that used to have large numbers of workers who would donate at our mobile drives have moved out to Contra Costa County and to the Peninsula. We're having a

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[1] See with oral history with Bernice Hemphill, M.D., Regional Oral History Office, The Bancroft Library, University of California, Berkeley.

terrible time recruiting blood in San Francisco. Most of the people who give in San Francisco don't even live here; fortunately, they come in from the Peninsula and Oakland, which are not our [recruitment] areas. That is fine, because when people in Oakland get sick, they come here to get treated.

Hughes: Yes, that's fair enough.

Perkins: So there is no question that the big cities are all in trouble. Places like New York survive on European blood.

## Safety Guidelines for Irwin Personnel

Hughes: We haven't talked about safety guidelines for Irwin personnel.

Perkins: OSHA? [laughs]

Hughes: Is that OSHA?

Perkins: Yes. Actually, it's both the state and the federal Occupational Safety and Health Administration.

Hughes: They stepped in right in the beginning of the epidemic?

Perkins: No. They've been around, but I don't know that they made AIDS a priority until probably the last few years, actually.

Hughes: Well, had Irwin set up employee safety guidelines for AIDS prior to that?

Perkins: The guidelines we set up were because of hepatitis, which is far more easily transmitted. Hepatitis B is a very easily transmitted disease. There's all this fight about health care providers who transmit AIDS to patients--you've got the one dentist [Acer]--but nobody understands that hepatitis B can transmit like mad. We have always had rules that you don't eat, drink, or smoke in the laboratory. Probably somewhere around the time AIDS appeared, we stopped letting people pipette liquids with their mouths.

Hughes: Because of AIDS?

Perkins: Well, I'd still say hepatitis, but AIDS was the precipitating factor. Certainly in terms of the use of gloves, AIDS was the precipitating factor. We've been requiring gloves probably for six or eight years. Interestingly enough, we've had a lot of

objection to it from the nurses in the blood collection department. They can't feel the veins as easily, so it's more awkward to get the needle in. We forced them into gloves because too many donors complained, "Your nurses aren't wearing gloves and I want them to wear gloves so their blood won't contaminate me."

Hughes: The other way around.

Perkins: So even though it's our nurses that are at risk from the people that they stick needles into, it's the people who get needled that want us to wear gloves.

Yes, things are getting stricter all the time. We now have regular meetings on safety of various kinds, and everybody has to be signed off as having attended, as having seen the audio-visual, what have you. The one on biohazards and blood safety that OSHA requires has to be seen annually by everybody that works for us.

Hughes: Policies such as these are a direct result of the AIDS epidemic?

Perkins: Oh, sure. We have a woman, Joanne Braddock, in human resources who's our safety officer in the sense of having to keep all the records to make sure that people get all the training exposures. [tape interruption]

## Changes in the Official Definition of AIDS

Hughes: As you well know, the CDC's definition of AIDS changed as time went on. How well did the definition keep up with what you were observing in the city?

Perkins: Well, it's not a matter of keeping up. Originally, the definition was fairly restrictive because they were trying to define an illness and follow it without any handle to hold onto. If they made the definition too broad, then you were going in a million directions and getting nowhere. But clearly, the first definition was far too restrictive, and we were saying things weren't AIDS that were. We've certainly gone well beyond that. But really, the only important thing is that a person is infected with HIV and has signs and symptoms of illness that are caused by it. Even today, not everyone infected with HIV will meet the definition of AIDS, because the definition is based on a low CD4 count, which is the new addition to the definition, in addition to specific opportunistic infections and tumors.

The current change in the definition, including the CD4 level as a definition of AIDS, totally threw us, because we had just been winding down our staff in epidemiology as we were phasing out these contracts. Suddenly we were getting three times as many people with AIDS reported to us who had been previous blood donors. So we've been scrambling with a lot of increased work because of that definition. We had actually called a meeting of our scientific advisory committee about six months ago and showed them the data and asked whether it was worth continuing the lookback program based on AIDS reports to local health departments because the work gets bigger and bigger, but the results were less and less productive.

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Perkins: The scientific advisory committee said, "Continue lookback for one more year, and then if it's not being more productive, we will probably recommend it be discontinued."

Hughes: Any other ways that the changing definition impacted Irwin?

Perkins: It doesn't really directly impact us, because all we are interested in is people who are infected from transfusions or donors who are infected. Whether they have AIDS or not is obviously important to them, but not to our research.

## San Francisco's Response to the Epidemic

Hughes: I think it's a fairly accepted fact that San Francisco's response to the epidemic was both faster and better coordinated than that of locations elsewhere, specifically New York. First of all, do you agree?

Perkins: Yes. Do you want to see my proof? [laughter]

Hughes: I want to know why.

Perkins: Some of it I think was because of the large number of gays and how well they were organized; they worked well together. And they had the support of people in the medical profession here; doctors weren't just turning their backs on them and saying, "We don't want to bother with you." People like Paul Volberding who came out of hematology-oncology and thought he was going to be an oncologist suddenly found himself the leader in clinical care of AIDS patients. The large groups that were intimately interested

in the epidemic were important too, and obviously, a supportive city government.

Hughes: So you had the three principal groups working together--government, the affected community, and the medical profession.

Perkins: We've had some superb directors of the public health system in San Francisco. Every time we lose one, I think, "Dreadful," then we get another good one. I'm very much impressed by Ray Baxter.

Hughes: Has Irwin always had a good working relationship with the health department?

Perkins: Yes. I was on Silverman's [AIDS] advisory committee. Dave Werdegar I knew through UC even before he came in. Baxter I had not known. The chairman of our board, Douglas Holloway, is also chairman of the Friends of the San Francisco Health Department, raising private money to help support the health department, and so he is friendly with Baxter.

## The San Francisco Model of AIDS Care

Hughes: What about the so-called San Francisco model of AIDS care? Are you familiar with that term?

Perkins: Hasn't it been used primarily for the San Francisco General clinics?

Hughes: Well, the way I understand it, it's an extended care model, one that extends from the medical community into the voluntary community.

Perkins: Yes. Of course, I don't really know in detail what goes on in other cities, but what goes on in this city is clearly incredible, starting with the hospitals and the clinics and the doctors in private practice, and then going on to the hospices and the Shanti [Project]. Incidentally, the chairman of our board is chairman of Shanti also. [laughs] So we're an inbred city.

## Formulating Local AIDS Policy

Hughes: Who at the local level was making AIDS policy?

Perkins: To the extent that there was policy, I suppose the focal point was Merv Silverman. But I'm finding it hard to deal with the term "AIDS policy", because people were really working independently in different areas and interrelating. There was no such thing as a single czar who was laying out a local line and everybody was following it.

Hughes: The health department, however, and I got this from talking to Drs. Dritz and Silverman, looked upon itself as the coordinating center of the AIDS efforts in the city. Is that apt?

Perkins: I think it's apt, but you have to look at it from their point of view. They're predominantly interested in epidemiology and prevention, not in clinical care. Granted that we have a city hospital [San Francisco General] that's part of the health department, but clinical care involved many other hospitals and health workers. From the epidemiology point of view, except for the special studies that people like Andy Moss were doing, yes, the health department was the focus. And from a prevention point of view, I suppose again you'd have to say they were certainly the focus of it. All the debates about closing the bathhouses were there at the health department, and the various pamphlets and whatnot that were being handed out, they played a role in. An awful lot of approaches to the care and support of AIDS cases were being done by gay groups and other groups, sometimes working independently, sometimes together.

## Impact of the Epidemic on Blood Agency Policy

Hughes: A lot of approaches were being done. Could you summarize how the HIV epidemic has influenced blood agency policy?

Perkins: I was afraid you were going to ask that. [laughter]

Hughes: Let's summarize our discussion.

Perkins: It's obviously had a most profound effect. To try to put it into a few words would be very difficult.

One of the problems of untangling the effects of AIDS is that it's occurred in a changing world. I have referred, for example, to the switch in control from the physician always telling the patient what to do to what's much more of a partnership at this point. And I think AIDS maybe helped accelerate that, but I'm not sure. Certainly what's happened in the response to AIDS has fit in very well with that switch.

We've been seeing, in fact for a number of years now, both physicians and scientists are getting very much downplayed and pushed down by the public that's saying, "You shouldn't be making all the decisions for me." The public has a right to at least participate in these decisions, and even if they don't understand everything, they don't trust us physicians to just go off and do what we feel is right. And I have no quarrel with that. I think that's quite appropriate.

Probably the most obvious thing that has happened to blood banks as a result of AIDS is the much tighter screening of donors that is done, and the greatly increased number of infectious disease tests. Some of these might have been in use by now, but I don't believe it would have happened nearly as quickly without AIDS. Obviously, when we brought [hepatitis B] core in, that was strictly for AIDS, no question about it--but the bringing in of core and ALT at the national level as a surrogate test for non-A, non-B [hepatitis] had been kicked around as a possibility since the mid-seventies. Granted, evidence accumulated that this [hepatitis] was a more serious problem than people had realized; I wonder if the introduction of core and ALT might not have been stalled another ten years if it weren't for AIDS.

The test for HTLV was introduced into blood banks with so little reason that most of us felt that it was probably not justifiable for anything but self-protection from litigation. But I think the accumulated data since it was introduced has proved that it was a good thing to do. So we've gotten to be a lot quicker to introduce new tests, but we've got to feel that they will benefit and not hurt. Every one of these decisions has got to be made after looking at both sides of the coin. We are now testing for HIV-2 even though there has never been anybody infected with HIV-2 by a blood transfusion. In fact, there's only been one HIV-2 positive donor identified anywhere, and she was identified with an HIV-1 test.

So we have very definitely ended up with the safest blood anyone has ever known by far, and the drop in hepatitis [transmission] is as dramatic as that in HIV, if not more so. You go back to the early fifties, sixties, the chance of getting hepatitis from a blood transfusion was somewhere between 25 and 33 percent. In the mid-seventies, we've got good studies showing your chance of getting hepatitis was 10 percent. Today, it's one in 6,000.

Hughes: What about other technologies, such as blood saving techniques?

Perkins: Those have been accelerated by AIDS, yes; thank you for remembering that. We've been pushing autologous transfusions as

long as I've been in blood banking, and yet nobody really listened until AIDS came along.

Hughes: Why wasn't hepatitis a worry to the public?

Perkins: Two reasons. One was that we didn't realize the seriousness of the liver disease caused by hepatitis C. We knew that some of the infected patients had fluctuating abnormalities in their liver enzymes for years, and there were jokes about getting transaminitis--well, what does it mean? So we didn't realize how serious the problem was.

The other reason was that the people who transfuse most of the blood never see a hepatitis case. That's the surgeons. Because when patients get hepatitis, they don't go back to the surgeons. That was the hardest thing I had to learn. It always struck me: why can't surgeons get this message? Here are the figures. Finally, one surgeon came up to me and said, "You know, I've been operating for thirty-five years; I've never seen a case of hepatitis." I looked at him and I said, "Well, how often do you follow your patients and see them repeatedly over a six-month period?" He said, "Never." I don't think I realized what the problem was until that surgeon told me that. But even then, it was still, "So what, hepatitis? Who dies of hepatitis?" Well, we've been saying for years that probably 3,000 people a year die of hepatitis in this country. When did 3,000 people a year die of transfusion AIDS? Probably never.

## Stigmatization of Minority Groups

Hughes: Had stigmatization of minority groups ever been a worry prior to the HIV epidemic?

Perkins: Well, what about down South years ago when they had blood for whites and blood for blacks, and never the twain should meet? You're right, today we've got the problem. What do we do about the fact that we know if we get an Asian donor in here, he's far more likely to transmit hepatitis than a white. If you get a black or Hispanic donor in here, he's more likely to transmit HIV than a white. But we need these donors; we need their blood types. Granted, we don't transfuse any blood that's tested positive, but if they're from high-risk groups, there's got to be an increased risk of some sort.

Hughes: Is Irwin now targeting these minority groups?

Perkins: Targeting? I don't know how to answer that question. We try to recruit minority donors, but we don't have a great deal of success. It's always there as a goal that we should, and we know we should. We've been helped far more by the National Marrow Donor Program, because that program has literally put its total focus in recent years on recruitment of minority donors. The program has more whites than it knows what to do with, and yet it does not have enough blacks, Hispanics, Asians, Native Americans, to meet the needs.

Hughes: Is that a cultural problem?

Perkins: Yes. But it's one we're getting increasing help with. There are a couple of very excellent groups. There is an Asian American Marrow Donor Program, a recruitment organization, and there is an African American marrow donor recruitment program in the Bay Area. They're really getting well organized, and we'll be able to pick up some blood donors through them because we work very closely with them.

## Physicians' Cautious Use of Transfused Blood

Hughes: Well, are there any other ways the epidemic has affected blood banking?

Perkins: The entire concern about blood transfusion, both at the patient level and at the physician level, is obvious. Physicians are being awfully good about not transfusing except when they have to. They've certainly gotten away from the cavalier use of blood for less than perfect indications.

Hughes: Now, are they thinking AIDS?

Perkins: Now they're thinking AIDS because that's what their patients are thinking. You pin them down, and they'll admit hepatitis is a bigger risk, but they're thinking AIDS. But there are other risks. I've got four slides with twenty lines on each slide about the risks of blood transfusion. We've got a lawsuit that's going to trial this summer where a kid got a bacterial infection from a platelet transfusion. As far as we know, there's no way to prevent these sorts of things. The estimate of such a risk is less than one in a million, but people sometimes do have bacteria in their blood when they're perfectly healthy.

Hughes: But I thought blood was filtered for microbial agents.

Perkins: No. Bacteria are smaller than blood cells. Besides, the only bacteria that get you into trouble are the ones that like to grow in the cold, and that produce what's called endotoxin, which is very poisonous stuff.

Hughes: So filtering wouldn't do any good.

Perkins: No. So we've had all these meetings about how we're going to identify such donors, or what we can do to treat such blood, and none of it's gotten anywhere so far. Which hasn't stopped people from suing; anybody can sue. I can't believe the amount of money that has been spent on this lawsuit.

## Impact of the Epidemic on Medicine

Hughes: Well, please comment on how the epidemic has affected medicine.

Perkins: I think it's had an awful lot of effects, including loss of some very good people from the health care professions for fear of being infected. Look at Lorraine Day, who was chief of orthopedic surgery at the San Francisco General Hospital, but she's left the field. She's terrified of being infected with AIDS. That's certainly a very harmful effect of the epidemic. I'm sure a lot of other promising people will never go into medicine because of their fear of AIDS, and it's not an unreasonable fear. The risk for the physician and surgeon of being infected is very real. AIDS is certainly pulling money away that could be spent to prevent other diseases, for research on other diseases.

But on the other hand, it's probably made us learn more about immunology faster than we ever would have in the next twenty-five years, so we're ahead of the game in that respect.

The epidemic has certainly changed my life. But then again, without all this excitement in the last ten years, I might be dead and buried. [laughter] It gets my circulation stirred up.

Hughes: Well, that seems to be a nice place to end. Thank you.

Transcribed by Shannon Page
Final Typed by Celeste Newbrough

TAPE GUIDE--The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984: Volume V

Interviews with Herbert A. Perkins, M.D.

APPENDIX

APPENDIX A: 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. |

[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:

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|---|---|
| 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, Barré-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 Medical Response 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.

## Chronology of Irwin Memorial Blood Bank [IMBB] Response to AIDS Epidemic, 1982-1985[1]

| | |
|---|---|
| January 1982 | - First case of transfusion-associated AIDS [TAA] reported. |
| December 1982 | - First reported incident of transfusion-associated AIDS.<br>- IMBB decided to eliminate all blood mobiles to gay areas/groups.<br>- IMBB met with gay groups to begin disseminating message that "homosexually active males" should not give blood. |
| January 4, 1983 | - proposals for screening out high-risk groups from donor pool. |
| January 7, 1983 | - IMBB added questions to the donor medical history form identifying symptomatic carriers of AIDS for deferral.<br>- IMBB and New York Blood Center began evaluations of surrogate tests for AIDS. |
| January 13, 1983 | - American Red Cross [ARC], American Association of Blood Banks [AABB], and Council of Community Blood Centers [CCBC] stated that evidence for TAA are "inconclusive" and "incomplete." |
| February 1983 | - IMBB further modified medical history forms and included questions of male homosexual activity as reasons for deferral.<br>- IMBB instituted "self histories" as a confidential means of encouraging more honest answers. |

[1]Based on IMBB document #CBBL 02175, ca. 1985, with additions by Sally Hughes.

March 1983 - Delayed by opposition from whole blood organizations, Centers for Disease Control [CDC] finally called for deferrals of high-risk donors.

April 1983 - Donor information sheet added to IMBB protocol; donors with multiple partners from high-risk groups excluded.

June 1983 - First announcements by national organizations that AIDS was a risk of blood transfusion - risk estimated to be one in one million.

July 1983 - IMBB further modified medical history process to clarify and strengthen questions of male homosexual activity as a reason for deferral.

April 1984 - Announcement of isolation of AIDS virus.

May 1984 - IMBB implemented hepatitis B core antibody testing as a surrogate test for AIDS as it was useful in identifying homosexually active males.

June 1984 - IMBB initiated "designated donor" program for friends and relatives to give blood for intended recipients.

- IMBB added confidential phone number for donors to call back if they have second thoughts about their donation's safety.

February 1985 - Designated donor program modified to eliminate extra charges to patients and allow donors to give in San Rafael, Vallejo, downtown San Francisco.

March 1985 - Definite Plans:

- Accept designated donors from out of town blood banks for patients from those areas.

- Further strengthening of medical history to eliminate all male bisexuals and homosexuals.

- Implement confidential process for donors to indicate that blood should or should not be used for transfusion before leaving donor site.

- Implementation of HTLV-III antibody testing as soon as FDA licenses test.

June 24, 1985 - IMBB added barcodes for confidential exclusion blood units.

July 1985 - Notification of test results for donors began.

June 1986 - First CDC report of patients infected with HIV from tested transfusion.

- IMBB established guidelines for "look-back" process.

December 1988 - IMBB became first U.S. blood bank to be successfully sued for negligence for supplying HIV-infected blood in 1983.

APPENDIX D: A Chronology of Events Related to the Management of the Blood Supply[1]

| | |
|---|---|
| June 1981 | First Centers for Disease Control (CDC) report on the disease |
| December 1981 | Blood suspected; three infants with IVDU parents |
| July 1982 | Three hemophilia cases; first CDC warning to blood industry |
| August 1982 | CDC asks blood banks not to accept high-risk donors; CDC recommends hepatitis B blood testing to Public Health Service (PHS) |
| December 1982 | First fully documented transfusion case by CDC |
| January 1983 | President of New York Blood Center denies evidence of transmission |
| March 1983 | PHS guidelines: persons from high-risk groups asked to refrain voluntarily from donating blood and plasma, but CDC's recommended hepatitis B blood screening is still not required |
| January 1984 | American Red Cross still minimizes transmission danger; New England Journal of Medicine article written by CDC scientists documents transfusion-associated cases of AIDS |
| March 1984 | New York Blood Center president still denies transmission; center still does not do the kind of testing CDC recommends |
| April 1984 | Retrovirus HTLV-III identified as responsible for AIDS; test to protect blood supply now foreseeable |
| December 1984 | 90 cases of transfusion AIDS; 49 Factor VIII hemophiliac cases of AIDS infection (clotting factor) |
| March 1985 | First blood test for AIDS (ELISA); blood banks begin screening but do not notify positive donors unless the more accurate and more expensive Western blot test is conducted on the ELISA-positive blood samples |

[1] From: Charles Perrow and Mauro F. Guillén. The AIDS Disaster: The Failure of Organization in New York and the Nation. Yale University Press, New Haven, 1990.

| | |
|---|---|
| June 1985 | Citing the possibility of making errors, the American Association of Blood Banks, American Red Cross, and Council of Community Blood Centers agree not to initiate a "lookback" program to identify blood recipients and notify them that their past donor(s) have now been found to be infected with HIV; no statute or regulation requires lookbacks |
| July 1985 | Notification of test results to donors begins |
| August 1985 | National Institutes of Health says blood screening has been successful |
| November 1985 | Thousands of people begin storing their own blood for future therapeutic transfusions |
| April 1986 | Blood agencies decide to reverse their June 1985 decision and proceed with the "lookback" program |
| June 1986 | First CDC report of a patient infected with AIDS from a blood transfusion that had been tested; blood test known to be sensitive only 95 percent of the time |
| July 1986 | Greater New York Blood Program tries to identify 700 people who since 1977 received transfusions of blood that might be infected |
| August 1987 | New York Blood Center claims it was the first to be on top of issue and denies knowledge of blood contamination by AIDS was available before spring of 1983 |
| May 1988 | Nearly 7,500 U.S. hemophiliacs believed to be infected with HIV |
| December 1988 | Irwin Memorial Blood Bank in San Francisco is the first in U.S. to be successfully sued for negligence in providing infected blood for a transfusion in 1983 |
| April 1989 | 900 hemophiliac and 2,300 blood-transfusion AIDS cases reported already to CDC; hundreds of lawsuits filed against blood banks |

**HIV RELATED GRANTS AND CONTRACTS**, Irwin Memorial Blood Bank, 1983-1994

## Men's Health Study

Department: S611
Title: The Natural History of Acquired Immune Deficiency Syndrome (AIDS) in Homosexual Men (San Francisco Men's Health Study).
Funding Source: Subcontract through UC Berkeley by National Institute of Allergy and Infectious Diseases (NIAID).

| Amounts: | | |
|---|---|---|
| 11/92 - 10/93 | $110,000 | |
| 11/91 - 10/92 | $278,137 | |
| 11/90 - 10/91 | $400,432 | plus $95,000 = $495,432 |
| 01/90 - 9/90 | $176,215 | |
| 7/89 - 12/89 | $442,877 | |
| 6/88 - 6/89 | $260,177 | |
| 5/88 - 6/88 | $ 17,134 | |
| 3/88 - 4/88 | $ 9,277 | |
| 2/87 - 2/88 | $ 91,000 | |
| 2/86 - 1/87 | $263,943 | |
| 1/85 - 1/86 | $147,052 | |
| 7/84 - 12/84 | $ 50,000 | |
| 12/83 - 7/84 | $ 65,961 | |

## Transfusion Safety Study

Department: S613
Title: Association of Blood Product as use with Immune Function Changes: Relation to AIDS - A Prospective Study.
Funding Source: Subcontract through The Regents of the University of California by the National Heart, Lung, and Blood Institute.

| Amounts: | |
|---|---|
| 7/01/92 - 5/30/93 | $56,814 |
| 11/16/91 - 06/30/92 | $74,510 |
| 7/01/91 - 11/15/91 | $44,708 |
| 12/11/90 - 07/01/91 | $36,280 |
| 7/01/90 - 12/10/90 | $29,041 |
| 7/01/89 - 6/30/90 | $72,751 |
| 2/15/89 - 6/30/89 | $32,985 |
| 12/01/88 - 02/14/89 | $32,329 |
| 7/01/88 - 11/30/88 | $67,687 |
| 5/01/88 - 6/30/88 | $36,953 |
| 3/01/88 - 04/30/88 | $13,897 |
| 11/01/87 - 02/29/88 | $27,795 |
| 07/01/87 - 10/31/87 | $27,796 |
| 03/31/87 - 06/30/87 | $51,689 |

07/01/86 - 03/31/87 $56,989
05/01/86 - 06/30/86 $10,181
07/01/85 - 04/30/86 $135,625
09/30/84 - 6/30/85 $37,613

**Universitywide AIDS Research Program**

Department: S615
Title: Comparison of in vivo HIV to tissue culture HIV isolates.
Funding Source: A grant from the Universitywide AIDS Research Program (University of California Office of the President).
Amount: 7/1/93 - 12/31/93 $26,553 includes subcontract to UCSF for $7,395.
7/1/92 - 6/30/93 $50,223 includes subcontract to UCSF for $16,430.
1/1/92 - 6/30/92 $26,553 includes subcontract to UCSF for $7,941.

**AABB Grant**

Department: S616
Title: Impact of Homologous Blood Transfusion on HIV Replication and Disease in Vivo.
Funding Source: A Grant from the National Blood Foundation.
Amount: 7/1/92 - 6/30/93 $30,000

Department: S616
Title: Adaptation of Capillary Separation to PCR Amplification for Blood Donor infectious Disease Screening
Funding Source: A Grant from the American Assoc. of Blood Banks Foundation
Amount: 7/1/90 - 6/30/91 $30,000

**Effectiveness of HTLV-III Antibody Screening**

Department: S618
Title: Effectiveness of HTLV-III Antibody Screening
Funding Source: Subcontract through UC San Francisco by the National Heart, Lung, and Blood Institute.

Amounts: 10/01/92 - 6/30/93 $119,006
9/30/91 - 9/29/92 $226,677
9/30/90 - 9/29/91 $588,699
9/30/89 - 9/29/90 $560,694
9/30/88 - 9/29/89 $533,975
9/30/87 - 9/29/88 $519,937
9/30/86 - 9/29/87 $508,538

**Heterosexual Transmission of HIV**

Department: S620
Title: Epidemiologic Research Study of AIDS/HIV Infection Heterosexual Transmissions.
Funding Source: Grant from the Center for Disease Control.
Amounts:

| | |
|---|---|
| 9/28/91 - 9/27/92 | $155,811 |
| 9/28/90 - 9/27/91 | $194,630 |
| 9/28/89 - 9/27/90 | $172,710 |
| 9/28/88 - 9/27/89 | $157,732 |
| 9/28/87 - 9/27/88 | $116,133 |

**Epidemiologic Study of HIV in Blood Donors**

Department: S621
Title: Epidemiologic Research Study of AIDS/HIV in Blood Donors.
Funding Source: Grant from the Center for Disease Control
Amounts:

| | |
|---|---|
| 10/15/92 - 10/14/93 | $94,958 |
| 10/15/91 - 10/14/92 | $55,592 |
| 10/15/90 - 10/14/91 | $47,478 |
| 10/15/89 - 10/14/90 | $55,525 |
| 10/15/88 - 10/14/89 | $53,870 |
| 10/15/87 - 10/14/88 | $51,554 |

**Reds Study**

Department: S626
Title: Blood Centers for the Epidemiological Studies of Human Retroviruses Among Blood Donors.
Funding Source: Subcontract through University of California, San Francisco by the National Heart, Lung, and Blood Institute.
Amounts:

| | |
|---|---|
| 7/17/92 - 7/16/93 | $279,927 |
| 7/17/91 - 7/16/92 | $334,866 |
| 7/17/90 - 7/16/91 | $358,713 |
| 7/17/89 - 7/16/90 | $ 34,799 |

**HIV Diversity**

Department: S628
Title: HIV Diversity/Pathogenesis in Donor-Recipient Clusters.
Funding Source: A subcontract through the University of California by the National Heart, Lung, and Blood Institute.
Amounts: 8/1/92 - 7/31/93 $177,943

**AMFAR Grant**

Department: S629
Title: Mother-Fetal Transfusion and Perinatal HIV Infection.
Funding Source: A Grant from the American Foundation for AIDS Research.
Amount: 7/1/93 - 6/30/94 $78,000

ADDENDUM TO HIV RELATED GRANTS AND CONTRACTS

Subject: Donors with reactive tests for Anti-HTLV-III (anti-HIV)

Funding Source: Food and Drug Administration

Amount: 6/6/85 - 1/20/87 $46,195

Subject: Laboratory detection of AIDS in Healthy Carriers
(This was the grant to evaluate possibly useful surrogate tests for AIDS. After the test for anti-HIV became available, the grant was awarded to study the results of that test as well.)

Funding Source: National Heart, Lung and Blood Institute

Amounts requested (and I believe granted)

| | |
|---|---|
| 4/1/84 - 3/31/85 | $161,750 |
| 4/1/85 - 3/31/86 | 158,992 |
| 4/1/86 - 3/31/87 | 169,998 |

JOINT STATEMENT

# TRANSFUSION ASSOCIATED AIDS: INTERIM RECOMMENDATIONS FOR NOTIFICATION OF BLOOD COLLECTING ORGANIZATIONS AND TRANSFUSION SERVICES

December 10, 1984

Recent reports linking the Acquired Immune Deficiency Syndrome (AIDS) and previous transfusions (transfusion-associated AIDS) make it advisable for blood collecting organizations and transfusion services to establish procedures to be followed when informed of blood recipients or donors who have developed AIDS. While laboratory tests may be available soon to facilitate the investigation of such cases, these tests are not generally available at this time. In the interim, there will be an urgent need for blood collecting organizations and transfusion services to assist public health investigators and other scientists in epidemiologic studies of transfusion-associated AIDS. The following guidelines are recommended for such investigations. The intent is to provide standardized procedures for collecting pertinent data while offering safeguards for the confidentiality of personal information obtained from donors, transfusion recipients, and other patients.

## I. IN THE CASE OF BLOOD OR PLASMA DONORS WHO DEVELOP AIDS WITHIN FIVE YEARS OF DONATION

A. Physicians in blood collecting organizations and transfusion services should urge public health investigators and physicians to ask all patients with AIDS if they have donated blood or plasma within the past five years. If such donations did occur, physicians in charge of the blood collecting organization should be informed of the donor's name and the date(s) and location(s) of donation(s).

B. All information should be handled with concern for patient-donor confidentiality. The transfer of information should be from the public health investigators, the patient-donor's physician, or from the patient-donor to the medical staff of the blood collecting organization; from there, information should be transmitted to the medical staff of the hospital transfusion service. At that time a decision should be made as to who will inform the recipient's physician. The decision to tell patients (or family members) that they have been transfused with products donated by individuals who later developed AIDS should be made by the patients' physicians. In most cases we believe it proper for the patient, or in special circumstances a guardian or responsible family member, to be informed. The patient-donor's name need be given only to the collecting organization where it should be available only to those senior individuals with a need to know for the limited purpose of fulfilling the notification obligation.

Irwin Memorial Blood Centers

**HERBERT A. PERKINS, M.D.**
**Irwin Memorial Blood Centers**
**270 Masonic Avenue**
**San Francisco, California 94118**

**Education:**

A.B., cum laude, Harvard College, 1940
M.D., summa cum laude, Tufts University School of Medicine, 1943

**Training:**

| | |
|---|---|
| 1944 | Intern, Third Medical Service |
| 1947-1948 | Senior Resident, First Medical Service |
| 1948-1949 | Chief Resident, First Medical Service (All at Boston City Hospital) |
| 1949-1950 | Bingham Program, Tufts University School of Medicine |

**Board Certification:**

| | |
|---|---|
| 1953 | American Board of Internal Medicine |
| 1978 | American Board of Pathology (Blood Banking) |

**Academic Appointments:**

| | |
|---|---|
| 1949-1950 | Instructor in Postgraduate Medicine<br>Tufts University School of Medicine |
| 1953-1957 | Clinical Instructor of Medicine |
| 1955-1958 | Hematologist, Artificial Heart-Lung Team |
| 1957-1958 | Assistant Clinical Professor of Medicine<br>Stanford University of Medicine |
| 1958-1959 | Director of Hematology, Jewish Hospital |
| 1958-1959 | Assistant Professor of Medicine<br>Washington University School of Medicine |
| 1959-1966 | Assistant Clinical Professor of Medicine |
| 1966-1971 | Associate Clinical Professor of Medicine |
| 1971-1996 | Research Associate, Cancer Research Institute |
| 1971-date | Clinical Professor of Medicine<br>University of California School of Medicine, San Francisco |

**Society Memberships:**

American Association of the Advancement of Sciences
American Association of Blood Banks
- Chairman, Standards Committee 1968-71
- Chairman, Committee on Organ Transplantation and Tissue Typing 1970-80
- Chairman, Scientific Advisory Committee 1972-73
- Board of Directors 1982-86

American Society for Hematology
American Society for Histocompatibility and Immunogenetics
- President 1985-86

California Blood Bank System
- President 1968-69

International Society of Blood Transfusion
Transplantation Society

**Professional Responsibilities:**

Irwin Memorial Blood Centers
- Senior Medical Scientist 1993 - date
- Director, National Marrow Donor Program Cell Repository and Cell Culture Laboratory 1987 -
- Executive Director/President 1987 - 1993
- Medical/Scientific Director 1977 - 1987
- Director of Research 1959 - 1977

National Marrow Donor Program
- Chairman, Board of Directors 1995 - 1996
- Immediate Past Chair 1997
- Treasurer 1987 - 1994
- Chairman, Finance Committee 1987 - 1994
- Chairman, Standards Committee 1987 - 1994
- Co-Investigator 1986

Asian American Donor Program
- Member, Board of Directors

Blood Research and Development Foundation
- Vice President 1995 - 1996
- Acting President 1996 -

Internation Society of Blood Transfusion
- Honorary Member, Biomedical Excellence for Safer Transfusion (BEST) Working Party

Editorial Boards
- Transfusion, Associate Editor
- American Journal of Hematology 1976 - 1995

**Honors:**

| | |
|---|---|
| 1942 | Alpha Omega Alpha |
| 1959 | Sigma Xi |
| 1981 | John Elliott Memorial Award, American Association of Blood Banks |
| 1986 | Owen Thomas Memorial Award, California Blood Bank System |
| 1988 | Visiting Professor University of California, San Diego |
| 1990 | Visiting Professor Emory University |
| 1991 | DeGowin Lectureship University of Iowa |
| 1992 | Emily Cooley Award American Association of Blood Banks |

**Publications:**

| | |
|---|---|
| Peer reviewed articles | 174 |
| Book chapters | 46 |
| Letters to the editor | 25 |
| Abstracts | 27 |
| Collaborative studies | 14 |

January 16, 1997

INDEX--The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984: Volume V

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