

# WTC Health Registry



WTC Health Program  
Scientific/Technical  
Advisory Committee  
(STAC) meeting, NYC

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Director

# Registry Aims

- **Expand knowledge about the long-term health effects of the 9/11 disaster & gaps in health care**
- **Respond to the health concerns & needs of enrollees & others exposed to 9/11**
- **Maintain an updated Registry as a public health resource**

# History

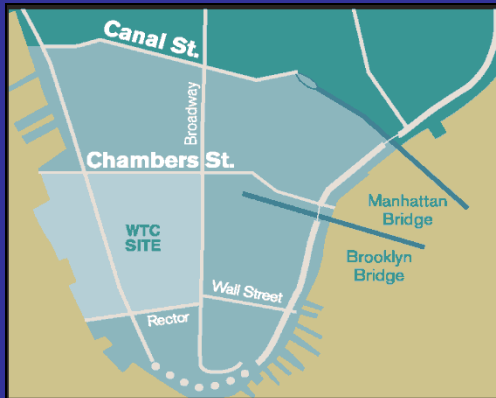
Largest US effort to monitor health after a disaster

- **2002: Launched as an exposure registry**
  - Funding from FEMA, ATSDR cooperative agreement
  - Input from scientific, community & labor advisors
- **2003-04: Wave 1 Survey**
  - 30-minute telephone interview on health and exposures
  - 71,437 enrolled, including >3,000 children
- **2006-08: Wave 2 Survey**
  - Course of symptoms, exposure clarification, emerging conditions, unmet healthcare needs
  - 46,322 adults participated (68.1% response rate)
  - 1,022 parent proxies responded (50.1% response rate)
- **2011-12 Wave 3 Survey**
  - All enrollees: launched July 2011 to adults & November to children
  - Course of conditions, emerging conditions, healthcare needs/use

# Eligibility Groups

## Highly Exposed by Time and Place

<u>Group</u>	<u>N</u>
Building occupants & passers-by south of Chambers St. on 9/11	43,487
Rescue/recovery workers & volunteers at the site (9/11/01 to 6/30/02)	30,665
Residents south of Canal St. on 9/11	14,665
Children & staff in schools (pre K–12) south of Canal St. on 9/11	2,646



**~400,000** were eligible across the 4 groups.

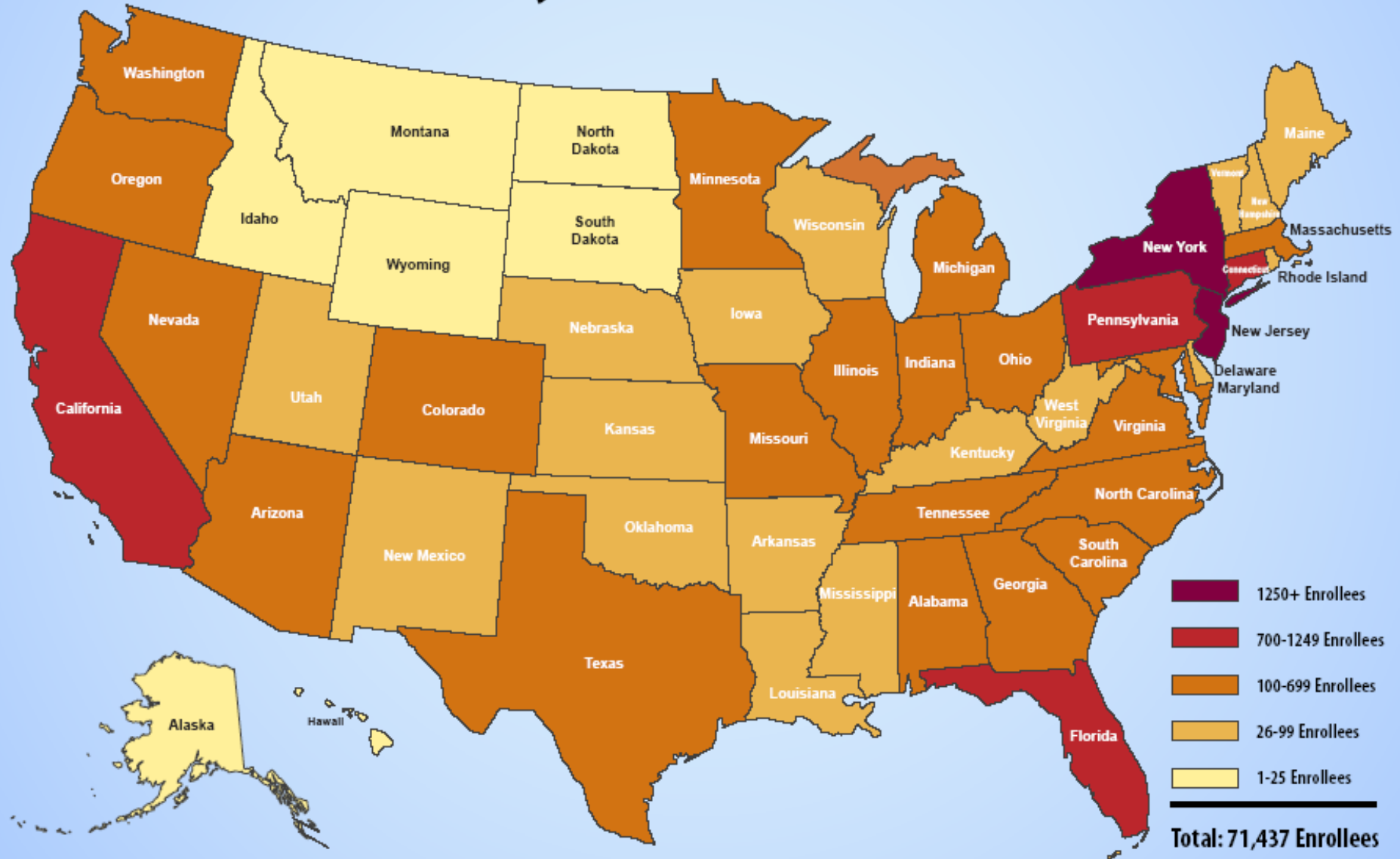
**Exposed persons *did not need to be ill* to be eligible for enrollment. Individuals may belong to more than one group.**

# Recruitment

- **List-identified (30% of enrollees)**
  - Lists of names from employers/volunteer organizations
  - Residents through publicly available directories
  - 273 lists with >135,000 potential enrollees
- **Self-Identified (70% of enrollees)**
  - Pre-registration WTCHR web site
  - Toll-free telephone numbers for inbound interviews
  - Extensive media awareness & outreach campaigns
  - Newspaper, bus, subway, ferry ads, brochure stands
  - Letters to parents of school children

# World Trade Center Health Registry Enrollment by State

Every State Affected



# Unique Strengths of the Registry

- **Published the only estimates of the number of exposed persons**
- **Follows and compares diverse groups directly exposed to 9/11**
- **Provides vehicle for external researchers to conduct WTC research**

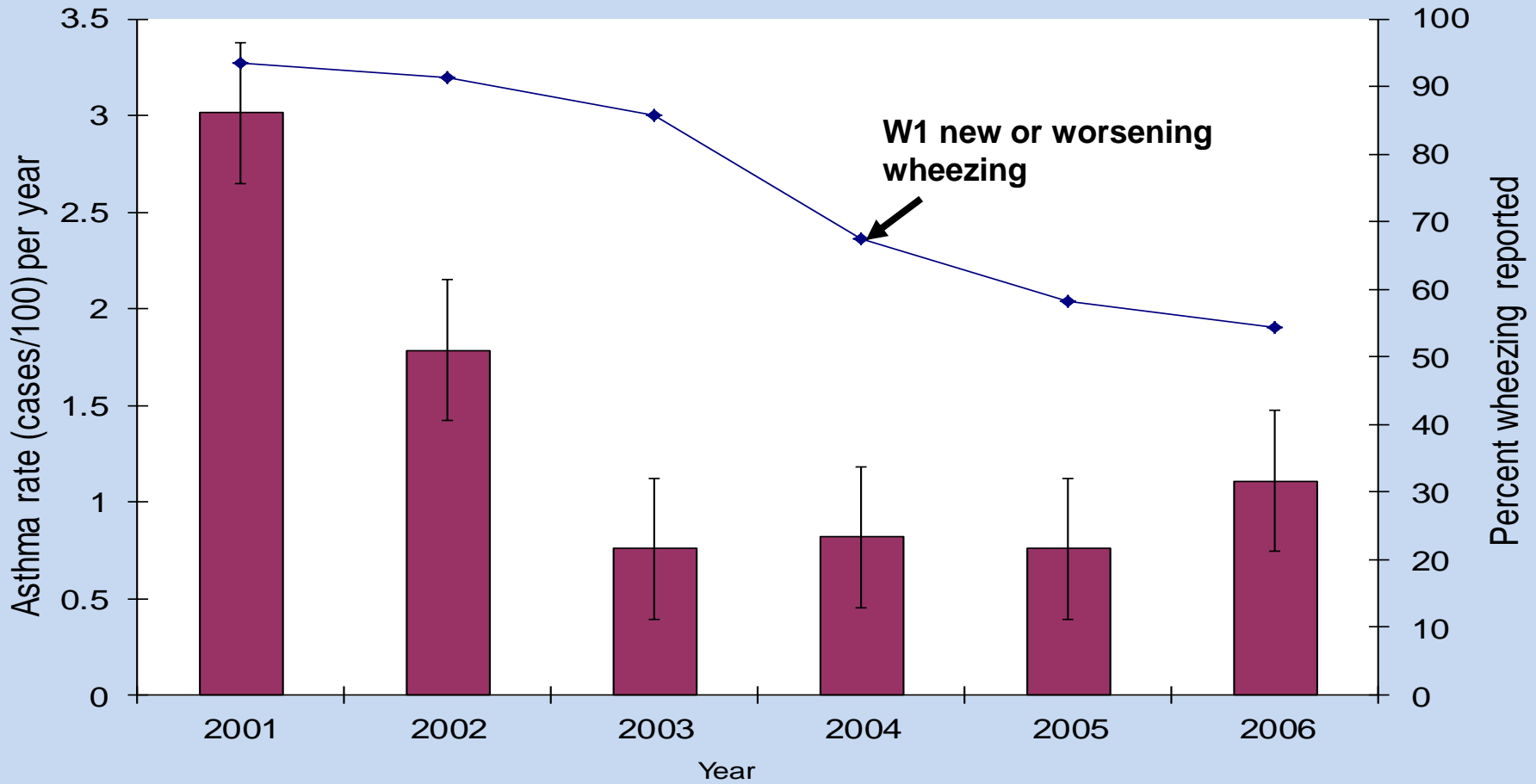
# Probable posttraumatic stress disorder (PTSD): adults

- 24% had new onset PTSD 5-6 years after 9/11 - US pop=4%
- Most with chronic or late onset PTSD reported:
  - Poor mental health in past month
  - No mental health care in past year
- Rates varied by occupation & training (7%-24%)
- Risk factors:
  - Caught in dust cloud\*, witnessed horror, and injured on 9/11
  - Heavy dust in home or workplace\*
  - Early arrival, longer duration of rescue/recovery work\*
  - Event-related loss of spouse or job, low social support
- Risk factors for new asthma after 9/11

Brackbill et al., 2009; DiGrande et al 2008; Perrin et al 2007



# Annualized incidence of post 9-11 diagnosed asthma: adult enrollees



Error bars: 95% confidence intervals

# Recent Findings (1)

## Common physical effects:

- Pulmonary function tests (oscillometry) showed lower airways disease among residents & area workers associated with symptoms, exposure
- Responders using respirators less likely to report respiratory symptoms/conditions than those reporting no or lower levels of respiratory protection
- Dust exposure & psychological trauma associated with elevated risk of non-fatal heart disease 2-6 years post 9/11. PTSD independently associated with HD.
- Persistent symptoms of gastroesophageal reflux disease associated with 9/11 exposures

# Recent Findings (2)

## Less common physical effect:

- Sarcoidosis after 9/11 associated with recovery work on pile

## Co-morbidity:

- Enrollees with co-occurring PTSD & asthma reported lower quality of life, more unmet healthcare needs than those with PTSD or asthma only

## Volunteers:

- Lay volunteers more highly exposed than affiliated volunteers and at greater risk for post 9/11 asthma & PTSD

## Mortality:

- Overall mortality below population rates, but elevated all-cause and cardiovascular mortality in “intensely exposed” survivors relative to those less exposed

# Ongoing Research: Matching to other health registries

## Matching to State Cancer Registries

- To what extent is there evidence of excess incidence of cancer among WTCHR enrollees?
- If so, are any of the WTC-related exposures or other identifiable risk factors associated with cancer incidence?

## Matching to Vital Records/National Death Index

- To what extent is there evidence of excess mortality among WTCHR enrollees?
- If so, are any of the WTC-related exposures or other identifiable risk factors associated with mortality?

## Matching to NYS Hospital Discharge Data:

To validate self-reported health conditions (e.g., heart disease)

# Selected Ongoing Research: Analysis of Wave 2 & 3 data

- **Unmet mental healthcare needs:** Which groups are underserved based on enrollees' perceived needs?
- **Treatment Referral Evaluation:** Have enrollees kept their appointments? Has their health status improved?
- **Injury:** What are long-term health effects of 9/11 injuries?
- **Alcohol use:** Is 9/11 exposure related to heavy drinking?
- **Pediatric asthma:** Is there persistent asthma?
- **Parent-child pairs:** Is parental PTSD related to stress symptoms and behavioral problems in children?
- **Late emerging conditions:** What is the course of symptoms and conditions 10-years post 9/11. Are there emerging conditions?

# Initial Cancer Study

## Methods

Compare numbers of incident cancer (observed cases) with “expected” cancer numbers

**Population:** WTCHR enrollees who were NYS residents on 9/11

**Cancer Data Source:** Linkage with State CRs through 2008

**Case Definition:** 1st primary invasive (or borderline bladder)

**Comparison:** NYS reference population rates

**Person-years:** Enrollment to whichever earlier:  
- cancer diagnosis, death, or 12/31/2008

## Timeline

Submit to peer-reviewed journal early 2012

# Wave 3 Survey Status

## ■ **Adult Survey**

- All 67k adults were sent a survey before 9/11/11
- 3 modes (web, paper, phone) and 3 languages
- 29,500 surveys completed to date (RR=44%)
- Rescue/recovery workers responding best so far

## ■ **Child Survey**

- Launched 11/01/2011 to parents of 1,200 children
- Separate parent and adolescent surveys
- Web (English) and paper (English, Spanish, Chinese)
- Respiratory outcomes, emotional & behavioral scales, parent's physical and mental health

# Wave 3 Adult Survey Content

- **Update Wave 2 items, including**
  - Physical health symptoms & conditions (eg asthma, CVD)
  - Mental health: PCL-checklist, K-6, diagnosed conditions
  - General health status/quality of life
  - Social support, life events, alcohol use
  - Health care utilization and unmet needs
- **New for Wave 3, including**
  - GERD, sleep apnea, pulmonary fibrosis, asbestosis
  - Medication and hospitalization for health conditions
  - Asthma control
  - Depression & anxiety assessments
  - History of trauma
  - Health insurance coverage



# Responding to Health Concerns: Treatment Referral Program

- **Objective:** Encourage eligible enrollees to seek care at HHC's WTC Center of Excellence at no cost to enrollee
- **Initial Focus:** Residents & area workers in NYC reporting
  - Unmet health care needs and
  - Physical symptoms and/or probable PTSD
- **Methods:** Personalized outreach and dedicated staff
  - >9000 enrollees to date, including ~4100 with PTSD
  - ~900 enrollees have made 1<sup>st</sup> appointment
- **Update:** Now refer to WTC Health Program; plan to include survivors outside the NYC area and responders

# Next Steps

- **Complete Wave 3 survey by March 2012**
- **Submit manuscripts to peer-review journals based on ongoing research, including cancer study and analysis of Wave 2 & 3 data**
- **Share new published findings with public & policy makers**
- **Apply for NIOSH continuation funding**