

# World Trade Center Health Registry

Research, surveillance & treatment referral in response to the  
September 11, 2001 disaster in New York City



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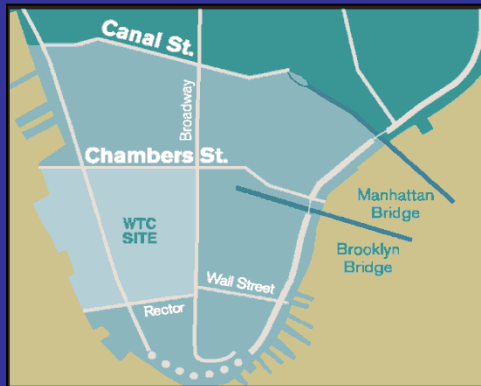
# Registry at a Glance

- Cohort study (20+years) of 71,434 exposed people with updates on health & access to care every 3 to 4 years
- Expanded data gathering for research
  - Mortality, cancer & hospitalization data obtained through matching with administrative databases
  - In-depth/clinical studies of selected subgroups
- Platform for independent & collaborative studies by external researchers
- Facilitation of 9/11 monitoring & healthcare for enrollees & their families in need

# Eligibility Groups

## Highly Exposed by Time and Place

<u>Group</u>	<u>N</u>
Rescue/recovery workers & volunteers at the site (9/11/01 to 6/30/02)	30,665
Building occupants & passers-by south of Chambers St. on 9/11	43,487
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.**

# History

## Largest US effort to monitor health post-disaster

- 2002 Launched as an exposure registry funded by FEMA/ATSDR
- 2003-04 Wave 1 Survey  
30-minute phone interview on health & exposures
- 2006-07 Wave 2 (68% adult response rate (RR))
- 2010-11 Wave 3 (63% adult RR)
- 2013 Hurricane Sandy Survey (52% RR)
- 2015 Wave 4 planned

Funded by NIOSH since April 2009

# Registry Scientific Outputs

- Peer-review publications: 43
- External researcher publications: 21
- Presentations-scientific conferences/meetings: 68
- Technical reports & clinical guidelines: 12
- Doctoral & master level theses: 17
- In-depth studies and surveillance projects: 10
- Public use data resources: 4

# Registry publications

## Clinical/Medical

- JAMA
- Lancet
- J Asthma
- J Am Heart Assoc
- Am J Gastroenterology
- Am J Respir Crit Care Med

## Occupational/Environmental Health

- Am J Ind Med
- J Occup Environ Med
- Environ Health Perspect

## Mental Health

- Am J Psych
- J Traumatic Stress

## Public Health/Epi/Disaster

- Am J Public Health
- Am J Epidemiology
- Soc Sci and Med
- MMWR
- J Urban Health
- Prev Med
- BMC Public Health
- Prehospital & Disaster Med

# Informing Disaster Response Through:

- Contributions to peer-reviewed literature
- Presentations at meetings/conferences, e.g., ATSDR meeting on rapid response registries, CSTE disaster epi
- Studying impact of exposure to multiple events, e.g., Hurricane Sandy survey
- Registry-facilitated external research

# Treatment Referral Program

- Aim: Encourage enrollees to seek 9/11 healthcare
- Model: Screen & treat model: post '05 London bombings
- Target: Residents & area workers reporting 9/11-related symptoms on Registry surveys & responders with or without symptoms
- Methods: Personalized outreach & dedicated staff trained in motivational interviewing to promote care seeking
- Outcomes: Major referral source for WTC Health Program:  
>1800 have applied or made an appointment
- Challenge: Hard-to-reach, vulnerable subgroups



# Registry Strengths

- Large, diverse groups of exposed people
- Depth & breadth of scientific outputs
- Findings inform 9/11 healthcare policy & disaster preparedness and response planning
- Dedicated staff for research, cohort maintenance, public affairs & treatment referral
- High commitment of enrollees
- Collaboration with distinguished scientists & institutions

# Registry Publications/Studies 2006-13

## Physical Health

- Asthma and other respiratory conditions\*
- Cardiovascular disease\*
- GERD symptoms
- Respiratory protection
- Sarcoidosis
- Skin rash\*

## Mental Health

- PTSD\*
- PTSD and co-occurring physical conditions\*

## Other Areas

- Alcohol use
- Birth outcomes
- Mortality\*
- Cancer\*
- Disaster response
- Unmet health care needs\*
- Injury\*
- Building evacuation\*

\* Publications since last STAC update 11/2011

# Respiratory

- Responders using **respirators** less likely to report respiratory problems than those with no/lower protection (Antao et al 2011)
- Pulmonary function tests (oscillometry) showed **lower airways disease** among residents/area workers associated with symptoms, exposure (Friedman et al 2011)

# Heart Disease & GERD

- Dust exposure & PTSD independently associated with elevated risk of **non-fatal heart disease** 2-6 yrs post 9/11 (Jordan et al 2011)
- **Cardiovascular hospitalization** was 32% higher in women with PTSD and 82% higher in male responders with high vs. low exposure (Jordan et al 2013)
- Persistent **symptoms of gastro-esophageal reflux disease** associated with 9/11 exposures (Li et al 2011)

# Mortality and Cancer

## Mortality

- Overall mortality below population rates, but **CV mortality** elevated in intensely exposed survivors vs. less exposed (Jordan et al 2011)

## Cancer

- No increased risk of cancer among those who did not perform rescue/recovery work (Li, et al 2012)
- Among rescue/recovery workers, there was an excess risk of **thyroid cancer, prostate cancer and myeloma**. No significant associations were observed with intensity of WTC exposure (Li et al 2012)

# Other Recent Findings

- **WTC tower evacuation time** was associated with number of reported structural and behavioral barriers (Groeger et al 2013)
- Respiratory symptoms associated with 9/11 exposures in younger **children** & behavior difficulties in **adolescents** (Stellman et al 2013)
- **Injury on 9/11** associated with elevated risk of heart & respiratory diseases with or without co-morbid PTSD (Brackbill et al, in press)
- Persons with 9/11-related PTSD were 7 times more likely to screen positive for **Hurricane Sandy-related PTSD** than those with no prior PTSD (preliminary finding)

# Ongoing Research

## In-depth Studies

- Follow-up respiratory study (nested clinical study)
- Hurricane Sandy impact on enrollees

## In Progress

- Substance use related mortality
- Reproductive health: birth weight, gestational age

## In Progress (Wave 3)

- Diabetes
- 9-year time course of PTSD
- Comorbidity of PTSD, depression, anxiety
- Asthma control
- GERD
- Unmet healthcare needs
- Alcohol use

# Planned Research 2014-15

- Cancer incidence update 10 years post 9/11
- Mortality assessment update 10 years post-9/11
- Adolescent behavior
- PTSD & Mortality
- Rheumatoid arthritis nested case-control study
- Smoking trajectories



# Wave 4 Survey

- **Objective:** Assess course of conditions reported previously, with a focus on:
  - Chronic health conditions
  - Course of treatment for selected condition(s)
  - Functional status and QOL
  - Potential new emerging conditions
- **Survey Population:** All adult enrollees  $\geq 18$  yrs in 2015
- **Methods:** Web & paper surveys; 3 languages
- **Timing:** Planned launch in early 2015

# A Resource for External Researchers

- Active encouragement of external research proposals
- Options:
  - Collaborate with Registry investigators
  - Registry-facilitated recruitment of enrollees
  - De-identified data for secondary analysis
- Applications reviewed by Registry & advisors
- 21 studies approved to date from 9 US & international institutions

# External/Collaborative Research Projects in Progress

- Physical Health Consequences of Childhood Exposure to the WTC
  - Dr. Leo Trasande, NYU Medical Center
- Impact of 9/11 on Youth: Mental Health, Substance Use and Other Risk Behaviors *and*
- Mental Health Service Need and Use among WTC Exposed Youth
  - Dr. Christina Hoven, Columbia University and NYS Psychiatric Institute
- Trace Elements in Autopsy Tissues from WTC Decedents
  - Dr. Michael Marmor, NYU Medical Center
- Enhanced Smoking Cessation Intervention for WTC Exposed
  - Dr. Roman Kotov, Stony Brook Medical Center
- Social Integration and Social Support among WTC Exposed Police
  - Dr. Rosemarie Bowler, San Francisco State University

# External/Collaborative Research Projects in Progress (cont.)

- Cognitive Functioning among Adult WTCHR Members
  - Dr. Valerie Edwards, Centers for Disease Control and Prevention
- PTSD among Police Responders
  - Dr. Rosemarie Bowler, SF State University
- Impulse oscillometry
  - Dr. Ken Berger, NYU/Bellevue Hospital
- GIS analysis of respiratory conditions & exposures among residents
  - Dr. Vinicius Antao, ATSDR/CDC
- Upper respiratory symptoms among responders
  - Rafael de la Hoz, Mt Sinai

# Next Steps 2014-2015

- Continue planned analyses of Registry data
- Launch & complete Wave 4 data collection
- Complete in-depth respiratory health study & rheumatoid arthritis case-control study
- Update cancer & mortality assessments
- Continue referrals to WTC Health Program
- Share published findings with public & policy makers

# Acknowledgments

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- Registry/NYCDOHMH staff
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