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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STAC meeting, February 14, 2014
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

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

- 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 (Wave 3)
- Diabetes
- 9-year time course of PTSD
- Comorbidity of PTSD, depression, anxiety
- Asthma control
- GERD
- Unmet healthcare needs
- Alcohol use

### In Progress
- Substance use related mortality
- Reproductive health: birth weight, gestational age
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
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 ≥18yrs 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
  - 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

- National Institute for Occupational Health and Safety
- Agency for Toxic Substances and Disease Registry
- Registry/NYCDOHMH staff
- Members of our scientific, community, and labor advisory committees