



World Trade Center Health Registry 2008 Annual Report

About the Registry

Who We Are

The WTC Health Registry is the largest public health registry in U.S. history, tracking the health of 71,437 people directly exposed to the WTC disaster. It is a collaborative effort involving the New York City Department of Health and Mental Hygiene, the Centers for Disease Control's Agency for Toxic Substances and Disease Registry (ATSDR), and the National Institute for Occupational Safety and Health (NIOSH).

Our Mission

The Registry was developed to:

- Identify and track the long-term physical and mental health effects of the 9/11 attacks.
- Disseminate findings and recommendations to enrollees, others affected by the disaster and the public.
- Develop and disseminate disaster preparedness and public policy information for use in the event of future disasters.

Core Activities

We carry out our mission through the following activities:

- **Data Collection:** Gather data through periodic surveys, in-depth studies, surveillance and research collaborations.
- **Data Analysis and Distribution of Findings:** Analyze data and distribute findings through research, presentations, reports and scientific journals.
- **Maintain Enrollee Contact Information:** Ensure enrollee contact information is up-to-date to gather health data and to keep enrollees informed of the latest 9/11 health news and other 9/11-related studies.
- **Outreach and Referral:** Conduct outreach through phone calls, mailings, presentations and door-to-door visits. Refer enrollees with 9/11-related health conditions to WTC treatment programs and services.

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Acknowledgements

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A photograph of a city skyline at sunset, with the sun low on the horizon behind several skyscrapers, creating a lens flare effect. The sky is a mix of blue and orange.

Letter from the Director

Dear Partners and Enrollees:

I would like to thank our enrollees for their continued commitment to the Registry. Each completed survey provides important insights into the health effects of the WTC disaster.

This report includes information on the Registry's key activities and accomplishments for 2008, as well as details on recent findings about the health consequences of 9/11. The report also includes 9/11 resource and service information for those affected by the disaster.

In the pages that follow, you will find an overview of the Health Registry's core activities and recent accomplishments. Together we have:

- Completed the first follow-up health surveys of enrollees.
- Released new 9/11 health findings.
- Updated physician guidelines for evaluating and treating health conditions in adults exposed to the WTC disaster.
- Developed a web-based tool that lets users search quickly and easily for Health Registry statistics by multiple indicators, such as enrollee demographics, 9/11-related exposures and reported health conditions.
- Launched a smoking cessation program for enrollees.

We hope you find this report informative and helpful.

Questions? Need more information? Contact us at (866) NYC-WTCR (1-866-692-9827) or wthcr@health.nyc.gov, or visit nyc.gov/9-11HealthInfo.

Thank you for your continuing support.

Sincerely,

A handwritten signature in black ink that reads "Mark Farfel".

Mark Farfel, ScD
Director, WTC Health Registry



2008 Highlights

Follow-Up Health Surveys

We completed our first follow-up health survey of adult enrollees, with 68% responding. We also surveyed parents and guardians of enrollees under age 18, with 50% responding by the December 2008 deadline. We would like to thank all enrollees who responded and encourage those who didn't to complete future Registry surveys.

The follow-up surveys will:

- Help determine to what extent physical and mental health conditions have persisted six to seven years after the disaster, and whether any new symptoms and conditions have emerged.
- Identify and help address gaps in medical and mental health treatment.
- Help us better understand 9/11-related exposures.

Preliminary findings will be available in 2009.

New Findings

In 2008, we released the following new findings based on Registry data collected in late 2003 and 2004:

Psychological trauma and new respiratory problems were still elevated among all adult enrollees.

The findings¹ - published in the *Journal of Urban Health* - show that two to three years after the WTC disaster:

- 67% of all adult enrollees reported new or worsening respiratory symptoms.
- 3% reported they had developed new asthma - twice what is believed to be the baseline rate over that period.
- 16% likely had post-traumatic stress disorder (PTSD).
- 8% had severe psychological distress.
- The rate of new asthma was highest (6%) among rescue and recovery workers who worked on the debris pile on 9/11.
- The PTSD rate was highest among those injured on 9/11 (35%), as well as low-income (31%) and Hispanic (30%) enrollees.

Lower Manhattan adult residents had high rates of PTSD.

Published online in the *Journal of Traumatic Stress*, the study² shows that two to three years after the 9/11 attacks:

- One in eight lower Manhattan residents (12.6%) likely had PTSD, compared to a national rate of only about 4%.
- Residents were more likely to develop PTSD if they witnessed horrific events during the attacks. Minority residents, those caught in the dust cloud on 9/11, residents with lower incomes and those who were divorced, separated and widowed were also at increased risk.
- Residents injured on 9/11 (38%) reported the highest rates of PTSD.

¹ Farfel M, DiGrande L, Brackbill R, et al (2008). An Overview of 9/11 Experiences and Respiratory and Mental Health Conditions among World Trade Center Health Registry Enrollees. *Journal of Urban Health*, Vol. 85, pp 880-909.

² DiGrande L, Perrin M, Thorpe L, et al (2008). Posttraumatic Stress Symptoms, PTSD and Risk Factors Among Lower Manhattan Residents 2-3 Years After the September 11, 2001 Terrorist Attacks. *Journal of Traumatic Stress*, Vol. 21, pp 264-273.



Children had high rates of respiratory problems.

According to a study³ published in the June 2008 issue of *Environmental Health Perspectives*:

- Half of the 3,100 children enrolled in the Health Registry experienced at least one new or worsened respiratory symptom, such as a cough, between 9/11 and the interview in late 2003 and 2004.
- Children caught in the dust cloud on 9/11 were twice as likely to be diagnosed with asthma as those not caught in the dust cloud.

Updated Clinical Guidelines

In 2008, the Health Department released updated clinical guidelines⁴ for health care providers on how to treat adults exposed to the WTC disaster.

The guidelines incorporate the latest published information on physical and mental health effects of the WTC disaster, and updated recommendations for treating PTSD and depression. The guidelines also include information on free diagnostic and treatment services for 9/11 health conditions at the city's WTC Centers of Excellence.

The Health Department is planning to release clinical guidelines for pediatricians on how to treat children exposed to 9/11.

9/11 Health Online Data Tool

WTC Health Registry 2003/2004 baseline survey data are now available through the Health Department's user-friendly EpiQuery system.

The interactive tool allows users to sort Health Registry statistics by multiple indicators, such as enrollee demographics, eligibility category, 9/11-related exposures and reported health conditions. Users can also search for survey data based on rescue and recovery organization or agency, such as the FDNY, NYPD and DSNY. Data are grouped together to protect enrollees' confidentiality.

To access the data tool, visit nyc.gov/9-11HealthInfo, click on WTC Health Registry and then click on Interactive Data Tool in the drop down menu.

Smoking Cessation Program

Some studies show an increase in cigarette smoking among people directly exposed to the WTC disaster. In addition, research shows that smoking cigarettes can worsen respiratory problems. To help those affected by 9/11 become and stay tobacco-free, the Registry is offering smoking cessation services to enrollees who currently smoke.

For more information, call (888) WTC-QUIT (1-888-982-7848), email WTCHRCARES@health.nyc.gov, or visit nyc.gov/9-11HealthInfo, click on WTC Health Registry and then click on Cares Program in the drop down menu.

On the Horizon

We will be reaching out to enrollees with 9/11-related health conditions who may not be getting adequate medical care, to refer them to free or low-cost WTC treatment programs.

³ Thomas P, Brackbill R, Thalji L, et al (2008). Respiratory and Other Health Effects Reported in Children Exposed to the World Trade Center Disaster of September 11, 2001. *Environmental Health Perspectives*, Vol. 115, pp 1584-1590.

⁴ Clinical Guidelines for Adults Exposed to the World Trade Center Disaster (2008). *City Health Information*, Vol 27, pp 41-54.



9/11 Resources

Here are some key resources and services for those affected by 9/11:

WTC Centers of Excellence

The WTC Centers of Excellence offer:

- Free treatment and medication for 9/11-related health conditions.
- Treatment by health professionals specializing in 9/11-related conditions.
- Assistance with applying for 9/11-related benefits, such as Workers' Compensation.

The Centers of Excellence include:

- The WTC Environmental Health Center at Bellevue Hospital Center, Gouverneur Healthcare Services and Elmhurst Hospital Center
- Mount Sinai Consortium: WTC Medical Monitoring and Treatment Program
- Fire Department of New York (FDNY): WTC Medical Monitoring and Treatment Program

To find out if you're eligible or get more information, call 311 or visit nyc.gov/9-11HealthInfo.

The WTC National Responder Health Program offers free monitoring and treatment services to 9/11 responders who live outside the New York City area. For more information, call (877) 498-2911.

NYC 9/11 Benefit Program for Mental Health and Substance Use Services

This insurance-like benefit helps cover out-of-pocket costs for 9/11-related mental health and substance use treatment. It is available to New York City residents affected by 9/11. Coverage is retroactive to January 2, 2007, and continues through January 7, 2011. For more information, call (877) 737-1164 or visit nyc.gov/9-11mentalhealth.

9/11 Health Web Site

Visit nyc.gov/9-11HealthInfo for the latest information about:

- Free treatment for 9/11-related health problems.
- The impact of 9/11 on physical and mental health.
- Links to non-profit organizations.
- Signing up for an e-newsletter about 9/11 health.

9/11 Resource Guide

This guide contains detailed information about organizations, agencies and programs that are working toward getting those affected by 9/11 healthy. For more information, visit nyc.gov/9-11HealthInfo.

World Trade Center Health Registry
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If You Are an Enrollee

The Registry's Personal Visit Policy

Experience has taught the Registry that a personal visit from a member of the Registry's professional staff can sometimes help you complete a health survey or get information on services or access to a free medical test. **Home visits thus will be offered in some WTCHR research studies.** We want to make sure, however, that you're comfortable with our occasional door-to-door outreach. Our policy is that, before making any such visit, we will always contact you ahead of time, tell you why we'd like to visit and give you the opportunity to refuse. Refusing will not affect your status in the Registry or affect your ability to participate in future surveys. If you do not want our staff to **ever** visit you at home, please call (866) NYC-WTCR (1-866-692-9827), email wchr@health.nyc.gov or write to: The WTC Health Registry, NYC Department of Health and Mental Hygiene, 233 Broadway, 26th Floor, CN 6W, New York, NY 10279. For more information about the Registry's policy, visit nyc.gov/9-11HealthInfo and click on WTC Health Registry.

Update Your Contact Information

One of the challenges the Registry faces is maintaining up-to-date contact information - mailing addresses, email addresses and telephone numbers - for all 71,000 enrollees. If you are an enrollee, please remember to let us know if your contact information changes. Simply contact us at (866) NYC-WTCR (1-866-692-9827) or wchr@health.nyc.gov, or visit nyc.gov/9-11HealthInfo and click on WTC Health Registry. Thank you for keeping in touch with us.



nyc.gov/health

