



WORLD
TRADE
CENTER
HEALTH REGISTRY



9/11 and Beyond

Winter 2023

20 Years Later and We Are Still Here for You

It has been 20 years since the World Trade Center (WTC) Health Registry was established. It remains the largest post-disaster registry in U.S. history, with more than 71,000 responders and survivors who voluntarily enrolled. The Registry continues its mission to better understand the long-term physical and mental health effects of 9/11 and to identify gaps in health care for those affected. We also conduct outreach to help connect our enrollees to the WTC Health Program for 9/11-related monitoring and treatment.

We plan to continue the Registry’s work for many years with support from the National Institute for Occupational Safety and Health. I want to take this opportunity to acknowledge how important enrollee participation is to the continued success of the Registry. For that, we cannot thank you enough.

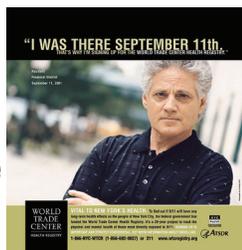
Sincerely,

Mark Farfel, ScD
Director

Enrollee Testimonials

Paul Hovitz: There From the Beginning

Paul Hovitz, a special education teacher, lived only a few blocks from the WTC towers. On 9/11, it took him nearly 24 hours to return from his job on Staten Island to his family at home to make sure they were safe, and thankfully they were.



After 9/11, Paul, who was already an active voice in his community, was determined to help Lower

Manhattan through the disaster. Twenty years later, Paul is still a leader and advocate for the health of residents in Lower Manhattan who were affected by 9/11.

Meet Paul as he discusses his story, including his battle with a serious condition possibly caused by his exposure to 9/11, at youtube.com/watch?v=JRqM9Dd_h-E.

Research Findings

Twenty Years and More Than 175 Research Papers

Over the last 20 years, information and data submitted by enrollees and partners have been critical in the Registry’s research. Since it was established, the Registry has published more than 175 research papers on 9/11 health outcomes.

The following findings are based on the Registry’s research:

- Up to 20% of adults developed post-traumatic stress disorder (PTSD) symptoms five to six years after being directly exposed to or injured by the WTC disaster. This is four times the average PTSD rate in the U.S.
- People who had the most significant exposure to 9/11 or 9/11-related PTSD were about twice as likely to binge drink.
- One in every 10 enrollees developed asthma within six years after 9/11. This is three times the asthma rate in the U.S.
- 50% of survey participants reported developing at least one physical or mental health condition after being exposed to 9/11.
- PTSD and intense dust cloud exposure were both linked to a higher risk of stroke by as much as four times the rate in the U.S.
- People who were injured on 9/11 and have 9/11-related PTSD are three times more likely to develop heart disease than people who were not injured on 9/11 or do not have PTSD.

9/11 Health

The Latest Health Updates

To make our latest research available to New Yorkers, the Registry creates short research and enrollee testimonial videos and posts them to nyc.gov/911health. Over the last two decades, the Registry has created and posted more than 50 videos, and more are currently being made.

The Registry's website is always being updated with new information, videos, health materials and recently published research papers for enrollees and the public. Visit nyc.gov/911health to read and download information on eligibility, how to apply for treatment of 9/11-related health issues, how to access data using our Health Data Tools and more.

Registry Highlights

 <p>9/11-Related Health Care for Enrollees and Their Families</p> <p>Need Care? Learn about eligibility and how to get monitoring and treatment for 9/11-related health problems.</p>	 <p>The Latest Registry Research Findings</p> <p>Health effects of 9/11 The Registry has a comprehensive list of 9/11-related research studies and findings.</p>	 <p>Where Enrollees Live</p> <p>Registry Enrollees by State The 9/11 disaster impacted hundreds of thousands of people. See where our enrollees live.</p>	 <p>Health Handouts on 9/11 Health-Related Conditions</p> <p>Health Info Find out the symptoms, treatment and prevention of 9/11-health related conditions.</p>
 <p>Why the Registry Matters: Enrollees Share Their Stories.</p> <p>Hear Their Voices Watch videos of our enrollees speaking about the Registry.</p>	 <p>Our Research Findings Have Shaped Policy</p> <p>9/11 Survivors Healthcare and Compensation You or a loved one may be eligible for healthcare, 9/11 compensation or financial assistance.</p>	 <p>Health Data Tools</p> <p>Use our data Survey data based on enrollee demographic, type of exposure or WTC-health related condition.</p>	 <p>Are You a Researcher Interested in 9/11 Health?</p> <p>Information for Researchers Find out how to collaborate with the Registry.</p>

The WTC Health Program

More Than 100 9/11-related Health Conditions

More than 400,000 people were exposed to the dust cloud created after the WTC disaster. Since 2002, the Registry has conducted five Wave surveys and multiple specialty surveys to collect data from its 70,000 enrollees. Some research findings have been used to inform federal policymaking, including the health conditions covered by the WTC Health Program.

For over a decade, the WTC Health Program has monitored and treated conditions caused by exposure to 9/11. The Program currently covers over 100 conditions. The 10 most common conditions are highlighted in the following illustration:

The 10 Most Common 9/11-related Health Conditions*

1. Sinusitis
2. Gastroesophageal reflux disease
3. Asthma
4. Various cancers
5. Sleep apnea
6. PTSD
7. Chronic respiratory illness
8. Chronic obstructive pulmonary disease
9. Anxiety
10. Depression

*cdc.gov/wtc/ataglance.html#top10Conditions. Data current as of June 30, 2020.

For more information on all covered conditions, visit nyc.gov/site/911health/index.page.

Health Equity: Keeping New York City (NYC) Healthy

To help improve health equity (where everyone has the opportunity to realize their full health potential), the Registry aims to make its information easily available to enrollees with limited English proficiency, or who have physical or mental disabilities. This includes translating our health materials and many videos into Spanish, Traditional Chinese and Simplified Chinese. We will also add non-English subtitles to existing videos, create survey questions to identify the needs of enrollees with limited English proficiency and make our website easier for people with disabilities to use.



Registry Highlights From Over the Years



2003

The Federal Emergency Management Association granted funding to the NYC Department of Health and Mental Hygiene (Health Department) to set up the Registry.



2006

The Registry's first publication, "Surveillance for World Trade Center Disaster Health Effects Among Survivors of Collapsed Buildings," cites the link between 9/11 exposure and hearing loss, stroke and PTSD.



2008

The Registry released findings from its 2003 and 2004 enrollment interviews. Notably, 67% of adult enrollees reported new or worsening respiratory symptoms.



2011

The Registry conducted Wave 2 and 3 health surveys to learn more about enrollees' physical and mental health 10 years after the WTC disaster, including new and emerging conditions.



2016

The Registry assessed trauma-related behavioral issues in adolescents and their mental health outcomes later as adults.



2018

The Registry began updating its website, redesigning outreach materials and increasing video production.



2020

Enrollees continued to report ongoing and emerging health conditions on the Wave 4 and 5 health surveys (conducted in 2017 and 2020, respectively).



2021

By the end of 2021, the Registry produced more than 170 publications and helped more than 7,000 enrollees access 9/11-related health care through the WTC Health Program.



2023

The Registry will continue to collaborate with Health Department staff and external academic researchers.

The Cohort Longitudinal Engagement and Retention (CLEAR) Forum

In late 2021, the Registry hosted a forum with partners from around the world to discuss the triumphs and challenges in managing long-term, health-related study groups. Partners enjoyed the forum and joined from the U.S., England and

Australia (including the Framingham Heart Study, Flint Registry, and Veterans Affairs' Airborne Hazards and Burn Pits Center of Excellence). The Registry has since hosted three more forums and is planning a fifth for early 2023.

Downloading the Latest Health Information

The Registry provides information to enrollees and the public about the long-term health effects of 9/11. Our health materials are one of our most popular sources of information and describe health conditions covered by the WTC Health Program. These materials help increase awareness of these conditions' symptoms and signs, methods of diagnosis, treatment, and prevention. To view these handouts, visit nyc.gov/911health and search for **health materials**.



20th Anniversary of 9/11

On September 8, 2021, the Health Department hosted a 20th anniversary of 9/11 town hall, which highlighted the Registry's ongoing work.

To watch a recording of the town hall, visit [youtube.com/watch?v=k-G_dUP-0s8&t=151s](https://www.youtube.com/watch?v=k-G_dUP-0s8&t=151s).



Joint Efforts

Since 2002, the Registry has worked with partners and research groups (including the NYC Fire Department, General Responder Cohort, and Cohort for Cancer and Mortality Studies) to learn from their data findings. The Registry has recently worked with NYC Health + Hospitals and is looking to work with the Mount Sinai Health System.

Mail's Here



We have kept our enrollees' needs at the top of our priorities. We want to hear from you. Your suggestions, comments and feedback are valuable as we aim to create and share informative and relevant materials for you.

Contact us by email at wthcr@health.nyc.gov or by phone at 866-NYC-WTCR (866-692-9827).

Centers for Disease Control and Prevention (CDC) Museum

The Registry was proud to be chosen as part of the David J. Sencer CDC Museum, which commemorated the 20th anniversary of 9/11. Research and referral work done by the Registry were presented in an interactive timeline. To view the 20th anniversary online commemoration, visit cdc.gov/wtc/history.html.



Enrollee Contact Information Update

Have you moved, changed your cell number or discontinued your landline phone? If so, you can update your contact information on our Enrollee Contact page at a816-healthpsi.nyc.gov/wthcr/.

Need Care?

If you are an enrollee and think you may have a 9/11-related health condition, email the Registry's Treatment Referral Program at trp@health.nyc.gov. A staff member will respond to help see if you are eligible.

Resources

The federal WTC Health Program provides monitoring and treatment, including medications for physical and mental health conditions related to 9/11. Services are offered at no cost to you, no matter where you live now. You can apply online at cdc.gov/wtc or call 888-982-4748 to have an application mailed to you.

To find this e-newsletter in Simplified Chinese, Spanish and Traditional Chinese, visit nyc.gov/911health and click on the **Research** tab, then choose **Publications** from the top menu, and select **e-Newsletter** from the drop-down. To contact the Registry, email wthcr@health.nyc.gov.