





#### Fall 2023

# The World Trade Center (WTC) Health Registry

Health registries help researchers and health professionals track and investigate illness and recovery related to disasters. The information they learn can help save lives and reduce health effects during future emergencies.

In 2003, the federal Agency for Toxic Substances and Disease Registry and the New York City Department of Health and Mental Hygiene established the WTC Health Registry to monitor the health of people exposed to the 9/11 disaster. It became the largest post-disaster registry in U.S. history. as more than 71,000 responders and survivors voluntarily enrolled. The Registry has been funded since May 2009 by the National Institute for Occupational Safety and Health (NIOSH). part of the Centers for Disease Control and Prevention, and regularly collaborates with academic and governmental entities, medical institutions, and the WTC Health Program.

The Registry periodically follows up with enrollees to track changes in their physical and mental health and in their health care needs. These periodic health updates from enrollees help us understand 9/11-related health effects, link enrollees to care and make sure that the Registry remains a valuable resource for our enrollees.





We invite you to learn more about the Registry by reading on about our work over the past 20 years and visiting us at nyc.gov/911health.

## A Letter to Enrollees

Dear Registry Enrollees,

On behalf of the entire Registry team, I would like to express our heartfelt gratitude for your participation over the past 20 years. Your valuable input has allowed for a fuller understanding of the health outcomes, unmet health care needs and other consequences of 9/11 among survivors and rescue and recovery workers.

Through your participation, we have been able to identify and track persistent and emerging health conditions and inform 9/11-related health care policies as well as future emergency preparedness and response. Your input has helped improve the lives of those impacted by 9/11-related health issues.

We recognize your commitment has required time and effort over the years, and we are profoundly grateful for your support. Your continued participation in Registry surveys and studies will allow us to gather crucial data, analyze trends and develop a deeper understanding of the health challenges faced by people exposed to the 9/11 disaster.

Your willingness to provide health updates has been the cornerstone of our research and outreach, ensuring our findings are relevant, comprehensive and reflective of the diverse experiences and needs of our community.

Going forward, we remain dedicated to our mission of tracking and promoting the health and well-being of 9/11 survivors. Your ongoing involvement remains important as we adapt our research to address new challenges and emerging health issues that may arise in the future.

Sincerely.

Mark Fafl

Mark Farfel, ScD Director

# Reaching Out to More Than 400,000 People







New York Post, November 23, 2004

After 9/11, there were concerns about the potential short- and long-term health effects of the disaster due to exposure to environmental toxins and witnessing traumatic events.

About 400,000 people who were exposed to 9/11, including those performing rescue or recovery duties, living, working, or going to school in Lower Manhattan at the time of the disaster, were eligible to join the Registry. We contacted potentially eligible groups through media campaigns and individual and community outreach. When enrollment closed in November 2004, more than 71,000 people had voluntarily enrolled in the Registry.

# **Putting Your Survey Answers To Work**

Over the past 20 years, the Registry has received health updates from enrollees through surveys and studies. Survey and study topics have included physical health, mental health, 9/11-related injuries, early retirement and COVID-19. Enrollee responses have helped the Registry publish more than 185 research papers that inform policies related to the WTC Health Program and emergency preparedness and response. The Registry also conducts personalized outreach to enrollees based on their responses to encourage them to enroll in the WTC Health Program and help them with the process.

The Registry plans on continuing its work to better understand the long-term physical and mental health effects of 9/11, emerging conditions, and gaps in care for people with 9/11-related health conditions. Some of the major topics addressed in the Registry's research papers include:

- Post-traumatic stress disorder (PTSD), depression and other mental health issues
- Asthma and other respiratory diseases
- Injuries sustained on and after 9/11
- Cancer and blood-related disorders
- Health outcomes in children and young adults who were affected by 9/11
- Enrollees' quality of life after 9/11
- Lessons learned from 9/11 and ways to better prepare for future emergencies
- Emerging conditions after 9/11
- Unmet health care needs
- Quality of life and functioning after 9/11



To read short summaries of our research papers, visit nyc.gov/911health, click on the Research tab and select Publications.

## **Read Our Health Materials**



These one-page health handouts have become one of our most popular ways of getting important health information to our enrollees. Topics include cluster, tension and migraine headaches; hearing loss; chronic obstructive pulmonary disease (COPD); breast and prostate cancer; sinusitis; and sleep apnea. To view these handouts, visit nyc.gov/health and search for health materials.

### Mail's Here









We want to hear from you! We believe everyone's voice should be heard, so we invite you to submit your stories and experiences related to 9/11 and feedback on our materials. We aim to create and share informative and relevant materials for you.

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

### **Need Care?**

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



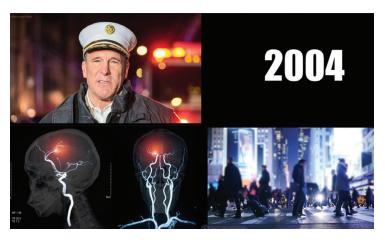
## **Holiday Cards**



The holiday season is a time for reflection and giving thanks. Every winter since 2008, the Registry has sent holiday cards to our enrollees to show our appreciation and help us stay connected during this time of year.

## 20 Years in 145 Seconds

To commemorate the Registry's 20th anniversary, we have created a video highlighting some of the work we have done over the past 20 years. The video also shows how our work has helped inform policymaking as we continue to better understand the long-term physical and mental health effects of 9/11. To view this video, visit nyc.gov/911health, click on the Research tab and select Research Videos.



#### 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 to people who are eligible at no cost to them, no matter where they live now. Apply online at **cdc.gov/wtc** or call 888-982-4748 to get an application in the mail.

# **Digital Data: From Publication to Video**

The Registry has created more than 60 short videos to summarize some of the findings published in our research papers for enrollees and the public. We have also produced more than 20 testimonial videos where enrollees speak about their personal experiences during and after 9/11 and the importance of participating in Registry surveys. Other videos provide information on 9/11-related programs, such as the WTC Health Program and the September 11th Victim Compensation Fund. To view these videos, visit nyc.gov/911health, click on the Research tab and select Research Videos.





















# **Stay Connected**

#### **Take Our Surveys**

Many Registry enrollees have responded to our surveys. The information enrollees provide helps us respond to their health needs and conduct research on 9/11-related health conditions. Registry findings also help inform health care policies, including federal support for the WTC Health Program.

#### **Read Our Previous e-Newsletters**

Read our previous e-newsletters for research findings, past 9/11-related updates and enrollee profiles. For more information, email wtchreletter@health.nyc.gov.

#### **Update Your Enrollee Contact Information**

Go paperless and receive Registry communications via email. To update your contact information, call 866-692-9827, email **wtchr@health.nyc.gov** or visit our Enrollee Contact page at **a816-healthpsi.nyc.gov/wtchr**.

#### **Use Our Health Data Tools**

Health data tools, including copies of our major and specialized surveys, are available. For confidentiality, personal information has been removed. To access our health data tools, visit nyc.gov/911health, click on the Research tab and select Health Data Tools.

### **Mission Statement**

With ongoing support from NIOSH, the Registry continues its mission to:

- Identify and track the long-term physical and mental health effects of 9/11 and gaps in care for 9/11-related health conditions
- Share findings and recommendations with enrollees, the public, the WTC Health Program and policymakers
- Respond to enrollees' health concerns and refer enrollees to the WTC Health Program
- Offer guidance to public health professionals on planning for future emergencies

To find this e-newsletter in English, Spanish, Simplified Chinese 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 **wtchr@health.nyc.gov**.