



World Trade Center Health Registry

2019

Annual Report



NYC
Health
WORLD
TRADE
CENTER
HEALTH REGISTRY

A NOTE FROM THE DIRECTOR

Dear Enrollees,

This year, the World Trade Center (WTC) Health Registry continued to study the long-term impacts of 9/11 and to link enrollees to care. This report shares new findings about the relationship between 9/11 and stroke, confusion and memory loss, pulmonary fibrosis, and early retirement.

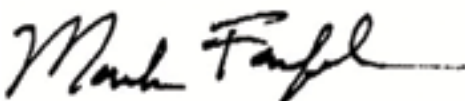
The report also includes enrollee stories that describe their experiences and some of the ways they have coped. These enrollees contacted us and shared their stories after receiving the Registry's e-newsletter and materials about health conditions.

In the spring of 2020, we plan to launch our next big survey. Enrollee responses will allow us to continue to track the health impacts of 9/11 and identify gaps in health care that affect 9/11 survivors and responders.

We care about you and your health. To learn how the Registry has helped enrollees access care for 9/11-related conditions — and how it can help you too — watch Manuel's video at nyc.gov/911health. The website also features more Registry videos, updated research summaries, e-newsletters and health materials.

Thank you to all of our enrollees for participating in the Registry over the past 17 years. We hope you continue to stay involved.

Sincerely,



Mark Farfel, ScD
Director

AT A GLANCE

4



How to Get Care

5



Research Findings

10



Enrollee Stories

11



Let's Stay Connected

The Registry's Mission

With ongoing support from the National Institute for Occupational Safety and Health, the Registry continues its **mission** to:

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

HOW TO GET CARE

Do you suffer from 9/11-related health problems? We are here to help.

The WTC Health Registry cares about your health and would like to support you. Our mission includes helping enrollees and others obtain care for specific 9/11-health related conditions. Treatment is provided through the federal [WTC Health Program](#) at no cost to you.

How do I know if I need care?

You may need care if you were exposed to the WTC disaster and have any of the following symptoms: coughing, wheezing, shortness of breath, sinus congestion, stomach problems, frequent heartburn, depression or anxiety.

How does it work?

If you believe you have a 9/11-related health problem, please call the **Registry's Treatment Referral Program** at **888-WTC-7848** (888-982-7848). When you call, one of our multilingual staff members will ask you questions about your health problems. Depending on your needs, eligibility and how you were affected by 9/11, we will refer you to the WTC Health Program for Survivors or the WTC Health Program for Responders.

Can I reach the WTC Health Program directly?

Yes. Call **888-982-4748** or email wtc@cdc.gov. For more information about the program, visit cdc.gov/wtc.

Can I still get compensation for my 9/11 injuries or a loved one's death?

Yes. Although it has been 18 years since the WTC disaster, you can still submit a claim to the September 11th Victim Compensation Fund (VCF). The VCF is authorized until 2090, but you may need to meet specific registration and claim filing deadlines based on your circumstances. For more information, visit vcf.gov or call **855-885-1555**.

PROGRAMS

Registry's Treatment Referral Program
888-982-7848

WTC Health Program
888-982-4748

September 11th Victim Compensation Fund
855-885-1555

RESEARCH FINDINGS

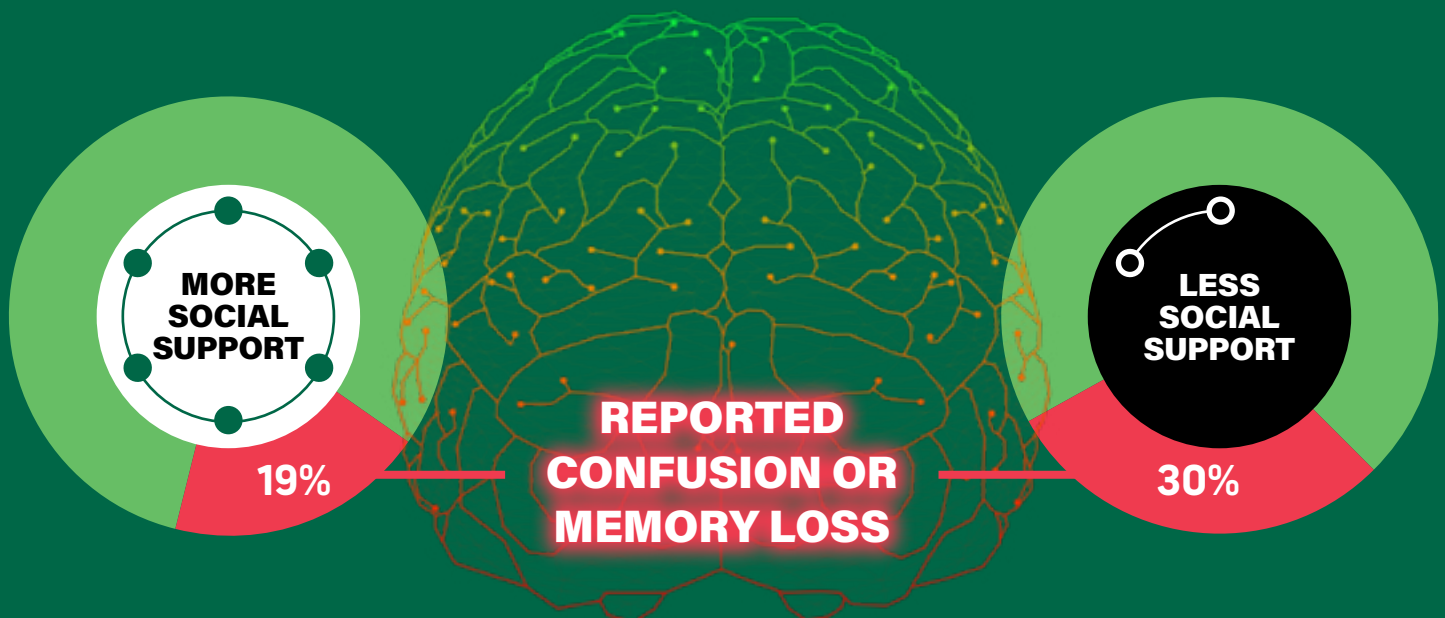
Over the past year, the Registry has published numerous research papers as part of our mission to understand and share findings about the health impacts of 9/11. On the next few pages, read about the findings from five of our studies.

STUDY 1

Having More Social Support Was Associated With Experiencing Less Confusion or Memory Loss Among Enrollees¹

This study is the Registry's first publication about this subject. The findings are based on enrollees' answers to the following question in the 2016 survey: "During the last 12 months, have you experienced confusion or memory loss, other than occasionally forgetting the name of someone you recently met?" About one in five enrollees between the ages of 36 and 64 in the study sample responded "Yes" to this question.

The Registry is still learning more about this topic. So far, we have found that enrollees who had more social support were less likely to experience confusion or memory loss than enrollees who had less social support.

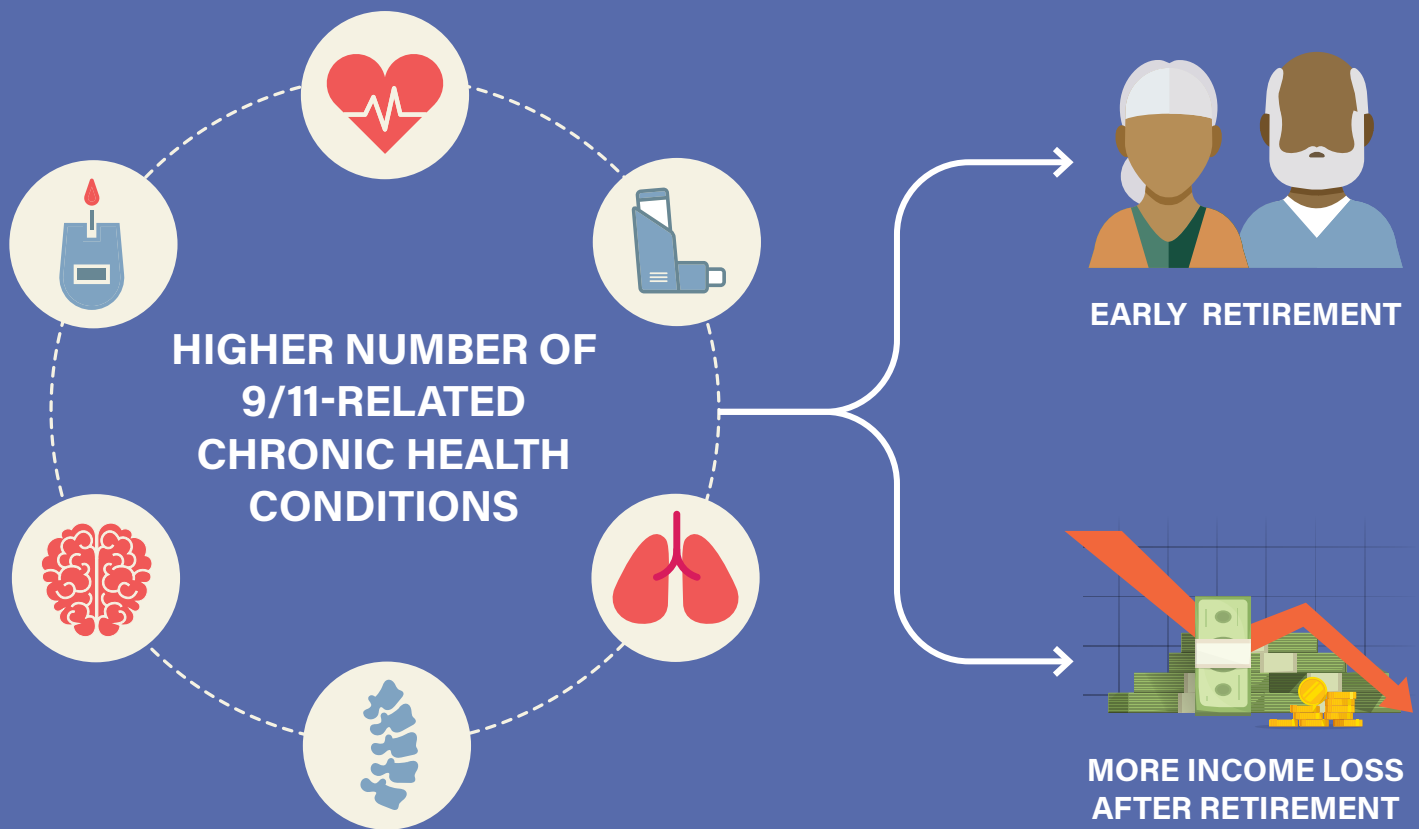


¹ Seil K, Yu S, Alper H. A Cognitive Reserve and Social Support-Focused Latent Class Analysis to Predict Self-Reported Confusion or Memory Loss Among Middle-Aged World Trade Center Health Registry Enrollees. *International Journal of Environmental Research and Public Health*. 2019;16(8):1401. doi.org/10.3390/ijerph16081401

STUDY 2

Residents and Area Workers With More 9/11-Related Health Conditions Were More Likely to Report Early Retirement²

The Registry studied retirement trends among people who lived or worked near the WTC site on 9/11. Those who had more 9/11-related health conditions were more likely to report early retirement (before age 60) than those who had fewer or no 9/11-related conditions. Those with a greater number of 9/11-related conditions were more likely to experience substantial income loss (a decrease of over 50% in income) after retirement.

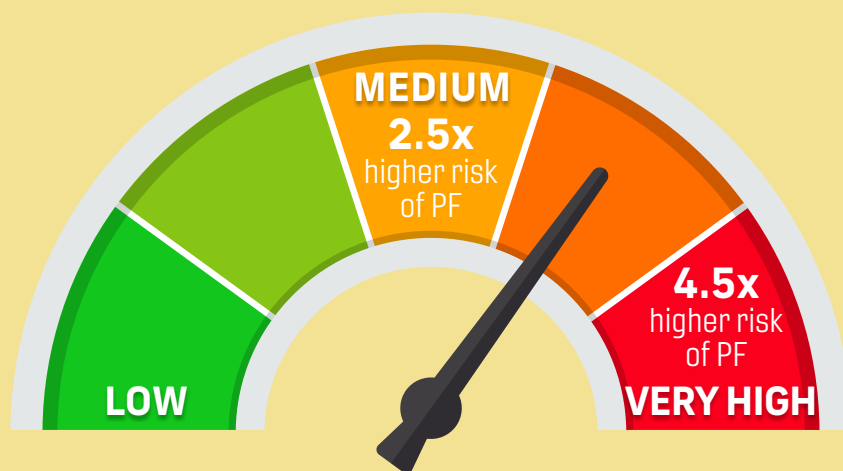


2 Yu S, Seil K, Maqsood J. Impact of Health on Early Retirement and Post-Retirement Income Loss among Survivors of the 11 September 2001 World Trade Center Disaster. *International Journal of Environmental Research and Public Health*. 2019;16(7):1177. doi.org/10.3390/ijerph16071177






STUDY 3

WTC Dust Exposure Increased the Risk of Self-Reported Pulmonary Fibrosis Among 9/11 Responders³

This is the Registry's first study exploring the association between level of WTC dust exposure and receiving a pulmonary fibrosis (PF) diagnosis from a physician. Pulmonary fibrosis is a rare lung disease that occurs when lung tissue becomes damaged and scarred. This condition makes it more difficult for lungs to work properly. Of the 19,300 responders included in the study, 73 reported receiving a diagnosis from 2004 to 2015.



WTC DUST EXPOSURE
was categorized from low to very high based on the following factors:

 Date of arrival at the WTC site		 Location on the morning of 9/11
 Total days worked at the WTC site	Specific time periods of work on the debris pile at the WTC site	 Presence in the dust cloud on 9/11

The risk of having PF was 2.5 times higher among those with a medium level of WTC dust exposure and 4.5 times higher among those with a very high level of WTC dust exposure, compared to those with low exposure.

³ Li J, Cone JE, Brackbill RM, Giesinger I, Yung J, Farfel MR. Pulmonary Fibrosis Among World Trade Center Responders: Results From the WTC Health Registry Cohort. *International Journal of Environmental Research and Public Health*. 2019;16(5):825. doi.org/10.3390/ijerph16050825

STUDY 4

Many People Injured on 9/11 Experienced Reduced Physical Health 15 Years After 9/11⁴

The Registry found that suffering a physical injury (burn, laceration, head or musculoskeletal injury) on 9/11 and having PTSD after 9/11 was associated with reduced physical and mental health functioning. These findings suggest physical injuries and PTSD have a long-term impact on quality of life.

Below are some questions included in a 2016 Registry survey to assess reduced physical health. We plan to continue asking these questions in the next survey:

- 1 How does your health now limit you in doing certain activities during the day? If so, how much (per activity listed)?
- 2 In the past month, have you had any problems as a result of your physical health?
- 3 In the past month, have you had any problems as a result of emotional problems (such as depression or anxiety)?
- 4 In the past month, how much time have any problems affected your social activities (like visiting friends, relatives, etc.)?

⁴ Brackbill, R, Alper, H, Frazier, P, Gargano LM, Jacobson MH, Solomon A. An Assessment of Long-Term Physical and Emotional Quality of Life of Persons Injured on 9/11/2001. *International Journal of Environmental Research and Public Health*. 2019;16(6):1054. doi.org/10.3390/ijerph16061054

STUDY 5

Intense Dust Cloud Exposure and PTSD Were Associated With Elevated Risk of Stroke⁵

This study included 42,527 enrollees and explored the association between WTC dust cloud exposure, 9/11-related PTSD and experiencing a stroke. The risk of having a stroke was higher among enrollees with intense dust cloud exposure and/or PTSD than those without. PTSD can increase the risk of stroke even in the absence of other common risk factors such as cigarette smoking, hypertension or diabetes.



Registry enrollees who had
**INTENSE WTC DUST
EXPOSURE ON 9/11**
HAD A 20% GREATER



LIKELIHOOD OF STROKE
than those without WTC dust exposure



Registry enrollees
who had
9/11-RELATED PTSD
HAD A 64% GREATER



LIKELIHOOD OF STROKE
than those without PTSD

⁵ Yu S, Alper H, Nguyen AM, Brackbill RM. Risk of Stroke Among Survivors of the September 11, 2001 World Trade Center Disaster. *Journal of Occupational and Environmental Medicine*. 2018;60(8):e371-e376. doi:10.1097/JOM.000000000000136

ENROLLEE STORIES



9/11 Led Paul Margolis Back to the Work He Loved

Paul Margolis first picked up a camera at age 9 and has followed his passion for photography ever since. He is now a documentary and fine art photographer, a writer and a lecturer.

"I was just three blocks from the World Trade Center on the morning of September 11. I photographed the towers from Broadway until I ran out of film. Then I ran back to my office to get more film. I spent the next few hours photographing the survivors trooping away from Ground Zero, then went home and didn't go out again for the next three days. The tragedy of 9/11 inspired me to return to documentary photography, which I had mostly stopped doing. It made me realize the fragility of what we often take for granted, and that I had neglected doing the work that I loved. For the next year, I photographed New York City advertising that used the images of the Twin Towers."

Paul's work has been exhibited in the United States, France and Israel.

This story is reproduced here as told to Registry staff.

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Contact us for more information or
to update your contact information:



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Email wtdhr@health.nyc.gov.



Call 866-NYC-WTCR
(866-692-9827).



Visit nyc.gov/911health.

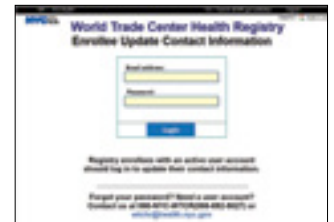
LET'S STAY CONNECTED

Many of you have spent time responding to some or all of our surveys. Your survey responses help us conduct research about many 9/11-related health conditions and help us respond to your health needs. Registry research findings help inform health care policy, including federal support for the WTC Health Program. This would not be possible without your participation.

We take seriously our commitment to transparency. To learn more about how the Registry uses your survey responses, to read updates on the Registry's recent findings or to hear what enrollees are saying about the Registry, visit nyc.gov/911health.

Update Your Contact Information

Go paperless! You can receive Registry communications via email. To update your contact information, call 866-692-9827, email wtdchr@health.nyc.gov, or visit nyc.gov/911health.



Videos

Hear from fellow enrollees and catch up on our latest findings: "I hope others seek help when they need it, because it is there for them." —Manuel, Registry enrollee



Health Data Tool

Use this interactive tool to explore the information we collected from the Registry's first survey in 2003 and 2004. All identifying information has been removed to protect confidentiality.



E-newsletter

Read the Registry's quarterly e-newsletter for updates about our research findings, the latest 9/11 related news and interviews with fellow enrollees. If you would like to send us your input, email us at WTDCHRELetter@health.nyc.gov or visit nyc.gov/911health.



Health Materials

To view materials and fact sheets about 9/11-related health conditions, including asthma, GERD, sleep apnea and sinusitis, visit nyc.gov/911health and search for **health materials**.



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