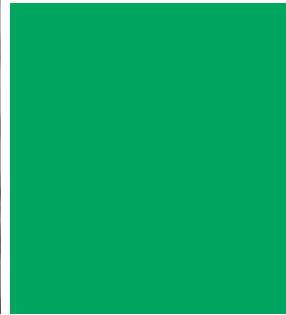
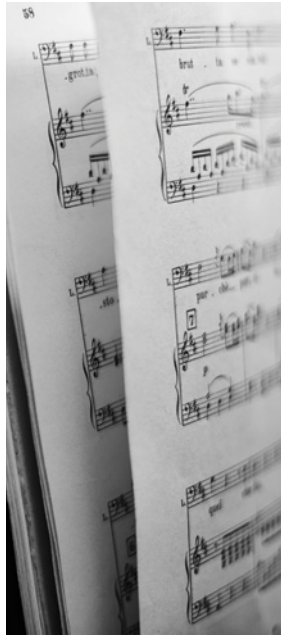
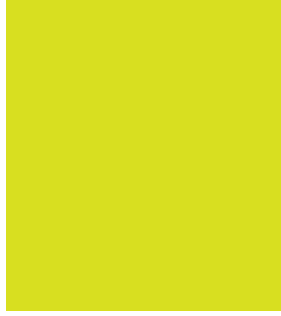
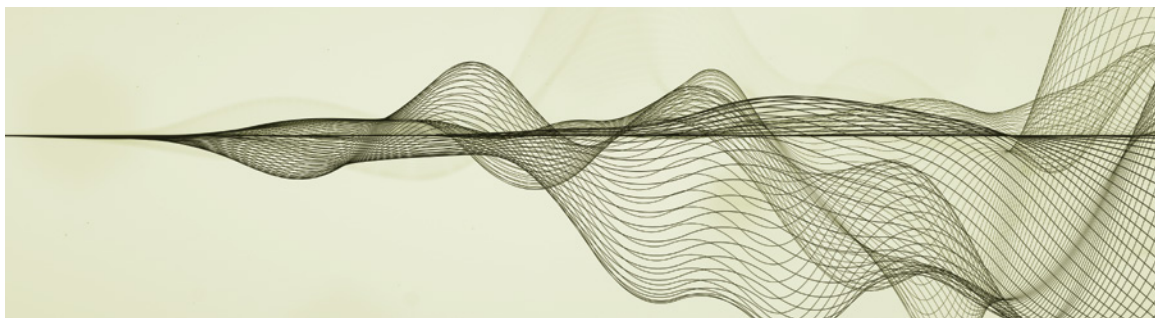


World Trade Center
Health Registry

2018 ANNUAL REPORT



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HEALTH REGISTRY



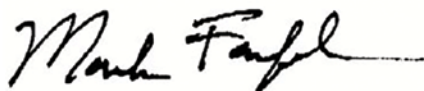
Dear Enrollees,

Over the past year, the World Trade Center (WTC) Health Registry conducted multiple studies on the health of 9/11 survivors and responders. This year's annual report shares new findings on topics we have reported on in the past, such as hearing loss, depression and quality of life. To help better explain these findings, we have included infographics and comparisons to other populations, including all New Yorkers.

This report also features stories from two enrollees who experienced hearing loss after the WTC disaster. They describe their experience on 9/11, the challenge of losing their hearing and their hopes for the future. By sharing these stories with other enrollees, we hope to build a stronger sense of community within the Registry.

We care about you and your health and can help you access 9/11-related health care. You can find contact information for the Registry in this report and by visiting nyc.gov/911health.

Sincerely,



Mark Farfel, ScD
Director



AT A GLANCE

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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 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 in planning for future emergencies.**



HOW TO GET CARE

Do you or a loved one 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-related health conditions. Treatment is provided through the federal **WTC Health Program** at no cost to you. The James Zadroga 9/11 Health and Compensation Act of 2010 created the WTC Health Program. Since 2013, staff at the Registry's **Treatment Referral Program (TRP)** have reached out to more than 35,000 enrollees about the WTC Health Program and helped nearly 15,000 enrollees complete the application.

How do I know if I need care?

You may need care if you were exposed to the WTC attacks 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, a loved one or someone you know may 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**.

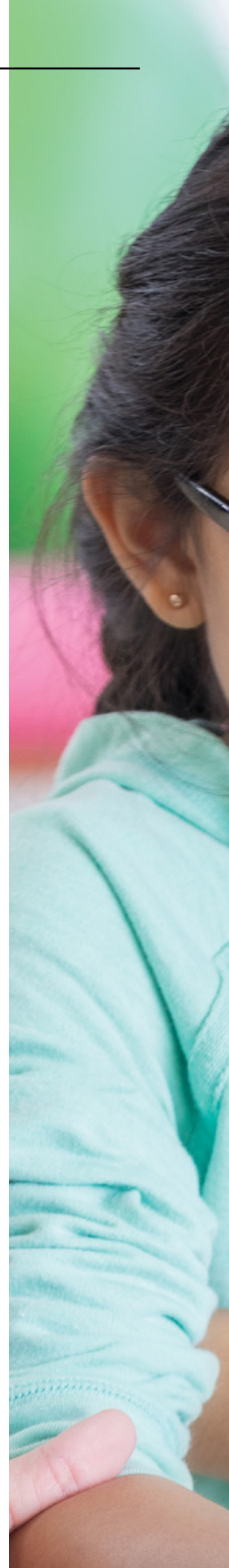
Can I reach the WTC Health Program directly?

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

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

The September 11th Victim Compensation Fund (VCF) provides compensation for any person (or personal representative of a deceased person) who suffered physical harm or was killed as a result of 9/11 or the debris-removal efforts that took place after the disaster.

Although it has been 17 years since the WTC disaster, you may still submit a claim to the VCF. The VCF was extended under the Zadroga Act, allowing those affected to submit claims until **December 18, 2020**. The Zadroga Act includes important changes to the VCF's policies and procedures for evaluating claims and calculating each claimant's loss. For more information, visit vcf.gov or call 855-885-1555.





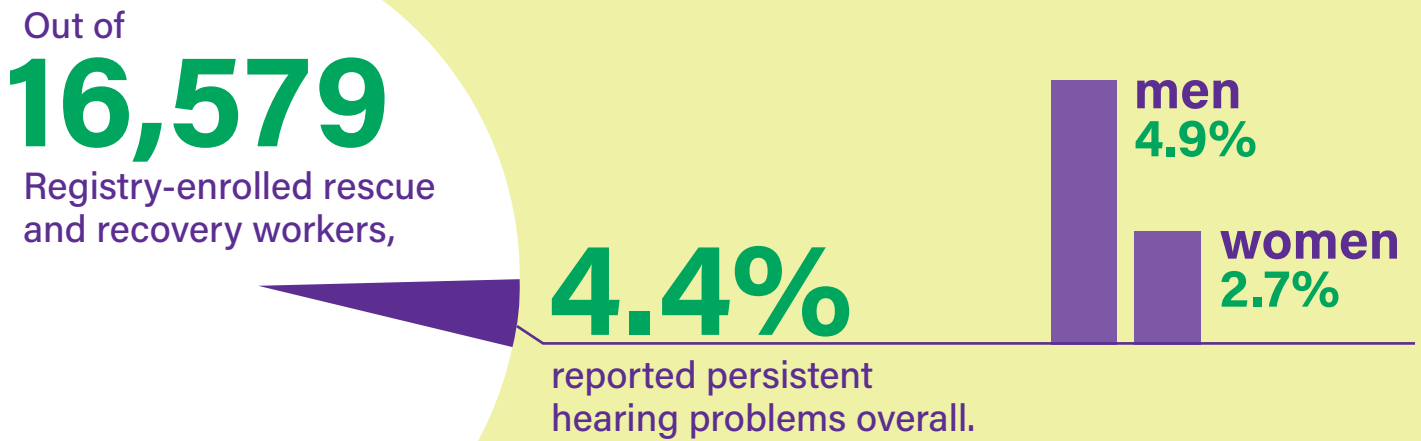
**Registry's
Treatment
Referral Program**
888-982-7848

**WTC Health
Program**
888-982-4748

**September
11th Victim
Compensation
Fund**
855-885-1555

RESEARCH FINDINGS

STUDY 1: AMONG 9/11 RESCUE AND RECOVERY WORKERS, MEN REPORTED MORE HEARING PROBLEMS THAN WOMEN¹



These findings led the Registry to partner with the New York City Fire Department on a study of hearing loss and hearing problems among firefighters and emergency medical service workers before and after 9/11.

¹ Stein CR, Lee DJ, Flamme GA, and Cone JE. Persistent Post-9/11 Hearing Problems Among World Trade Center Health Registry Rescue and Recovery Workers, 2001–2007. *J Occup Environ Med* 2017 59(12): 1229–1234.

STUDY 2: COMMUNITY SURVIVORS ALSO REPORTED HEARING LOSS²

A 2006 Registry study showed that exposure to the cloud of dust and debris on 9/11 was associated with reported hearing loss in civilian survivors.

A total of

8,418

enrollees surveyed in 2003 and 2004 were

SURVIVORS

of damaged or destroyed buildings.

Of these,

8.1%



reported hearing problems or hearing loss since 9/11.

What May Have Caused Hearing Loss or Hearing Problems



Exposure to toxic smoke and dust/debris



High levels of noise exposure



Head trauma from injuries



Ruptured ear drums

Responders and survivors of other disasters with similar kinds of exposure should check for hearing loss.

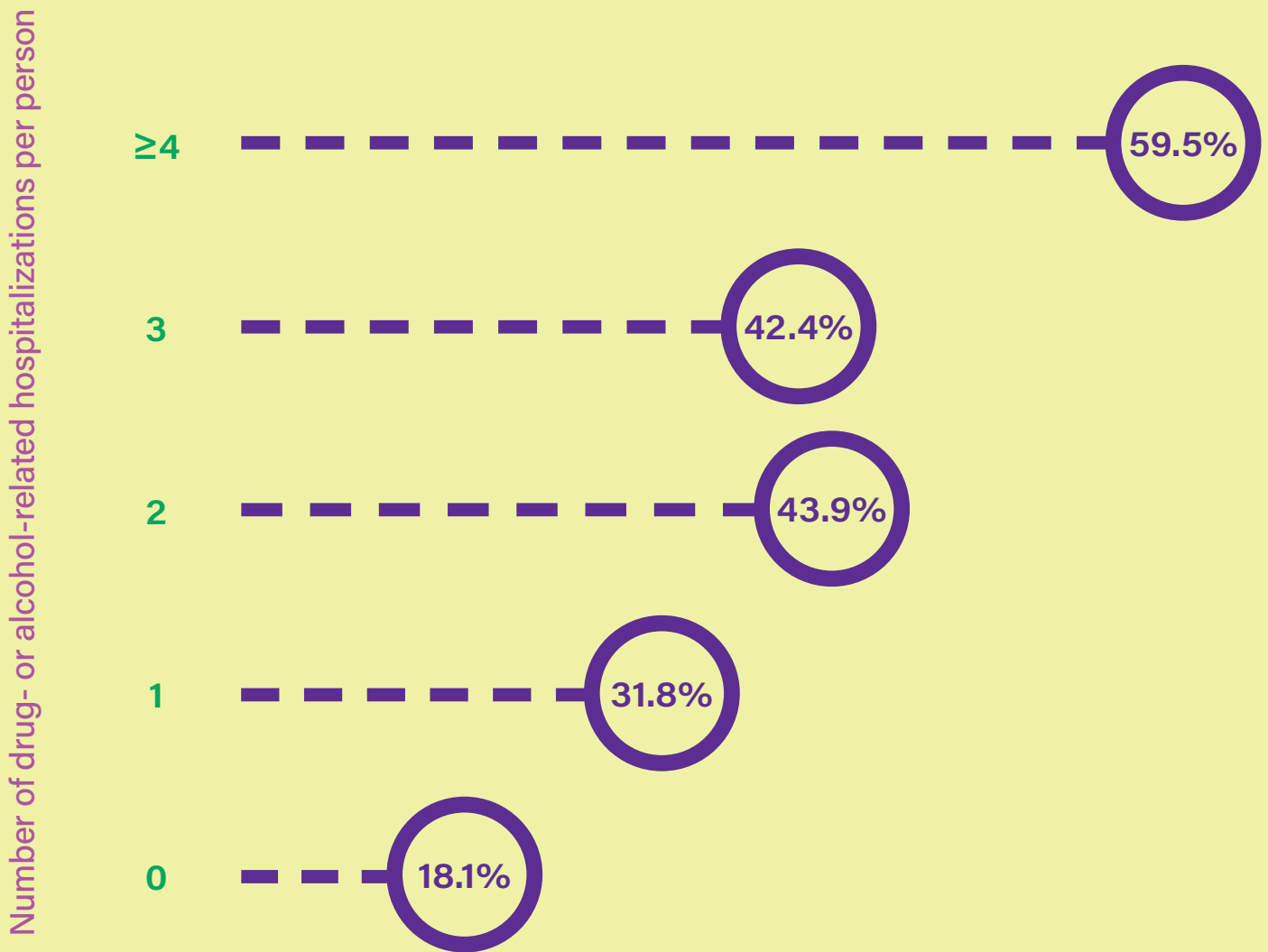
Hearing loss and hearing problems are not covered conditions under the WTC Health Program. However, the Registry continues to look into these health issues and share its findings with the WTC Health Program.

² Brackbill RM, Thorpe LE, DiGrande L et al. Surveillance for World Trade Center Disaster Health Effects Among Survivors of Collapsed and Damaged Buildings. *MMWR Surveill Summ*. 2006;55:1-18.

STUDY 3: ENROLLEES WITH POST-TRAUMATIC STRESS DISORDER (PTSD) WERE MORE LIKELY TO HAVE MULTIPLE DRUG- OR ALCOHOL-RELATED HOSPITALIZATIONS THAN THOSE WITHOUT PTSD³

The Registry reviewed the available data regarding drug- or alcohol-related hospitalizations among more than 40,000 enrollees that occurred between the time enrollees joined the Registry and the end of 2010.

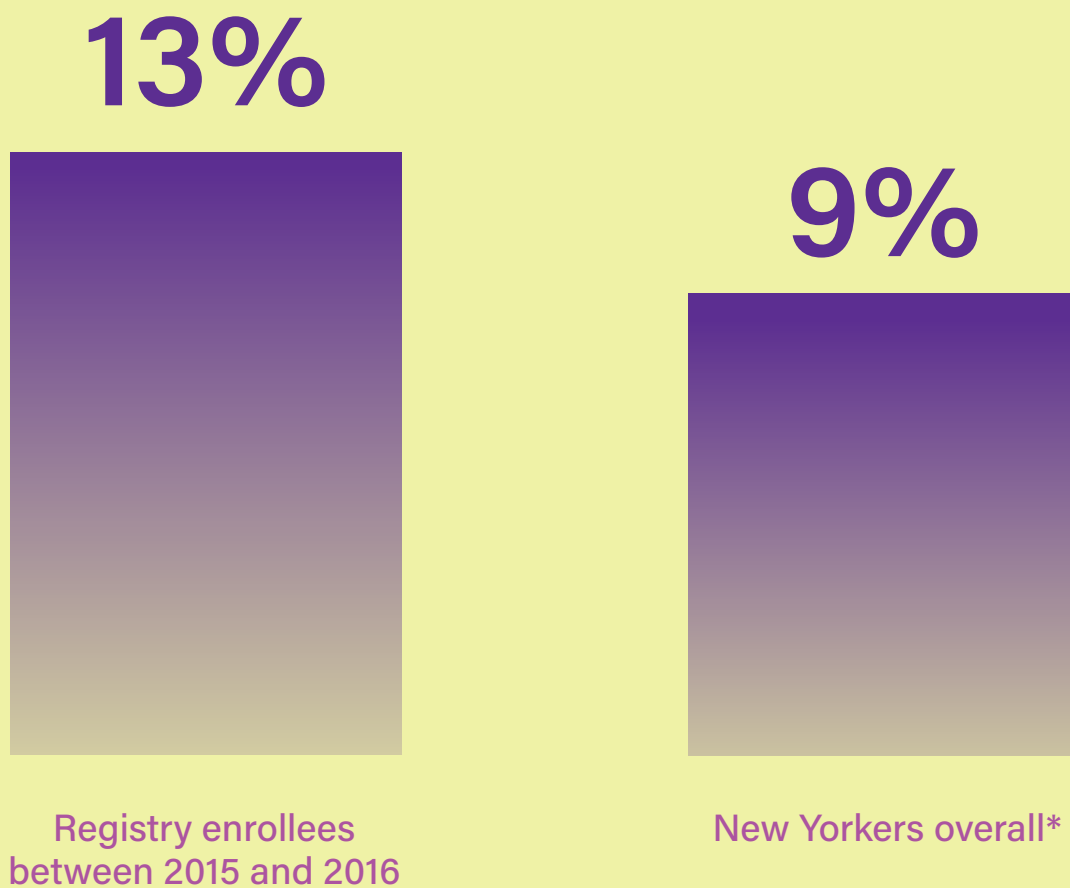
Percentage With PTSD



3 Hirst, Andrew; Sara A. Miller-Archie; Alice E. Welch et al. Post-9/11 Drug- and Alcohol-Related Hospitalizations Among World Trade Center Health Registry Enrollees, 2003–2010. *Drug and Alcohol Dependence* 2018 Jun 1;187:55–60. doi: 10.1016/j.drugalcdep.2018.01.028. Epub 2018 Mar 23.

STUDY 4: FIFTEEN YEARS AFTER 9/11, DEPRESSION WAS MORE COMMON AMONG REGISTRY ENROLLEES COMPARED WITH NEW YORKERS OVERALL⁴

Percentage With Depression



*Based on 2016 New York City Community Health Survey data.

⁴ Jacobson MH, Norman C, Nguyen A, and Brackbill R. Longitudinal Determinants of Depression Among World Trade Center Health Registry Enrollees, 14-15 Years After the 9/11 Attacks. *Journal of Affective Disorders*. 2018.

STUDY 5: EVACUATION EXPERIENCES AMONG ENROLLEES⁵

In this study, we interviewed 29 survivors about their evacuation experiences to identify some risk factors for PTSD, including lack of emergency response training. Many survivors who did not develop PTSD reported that they:

Followed a leader.

“I didn’t know what to do. I needed to be told what to do.”

Acted on their instinct.

“My gut said something was wrong and I’d feel safer outside.”

Stayed in a group.

“Because we stayed together we got out faster...”

Went into “survival mode.”

“It was just adrenaline... It kept me going.”

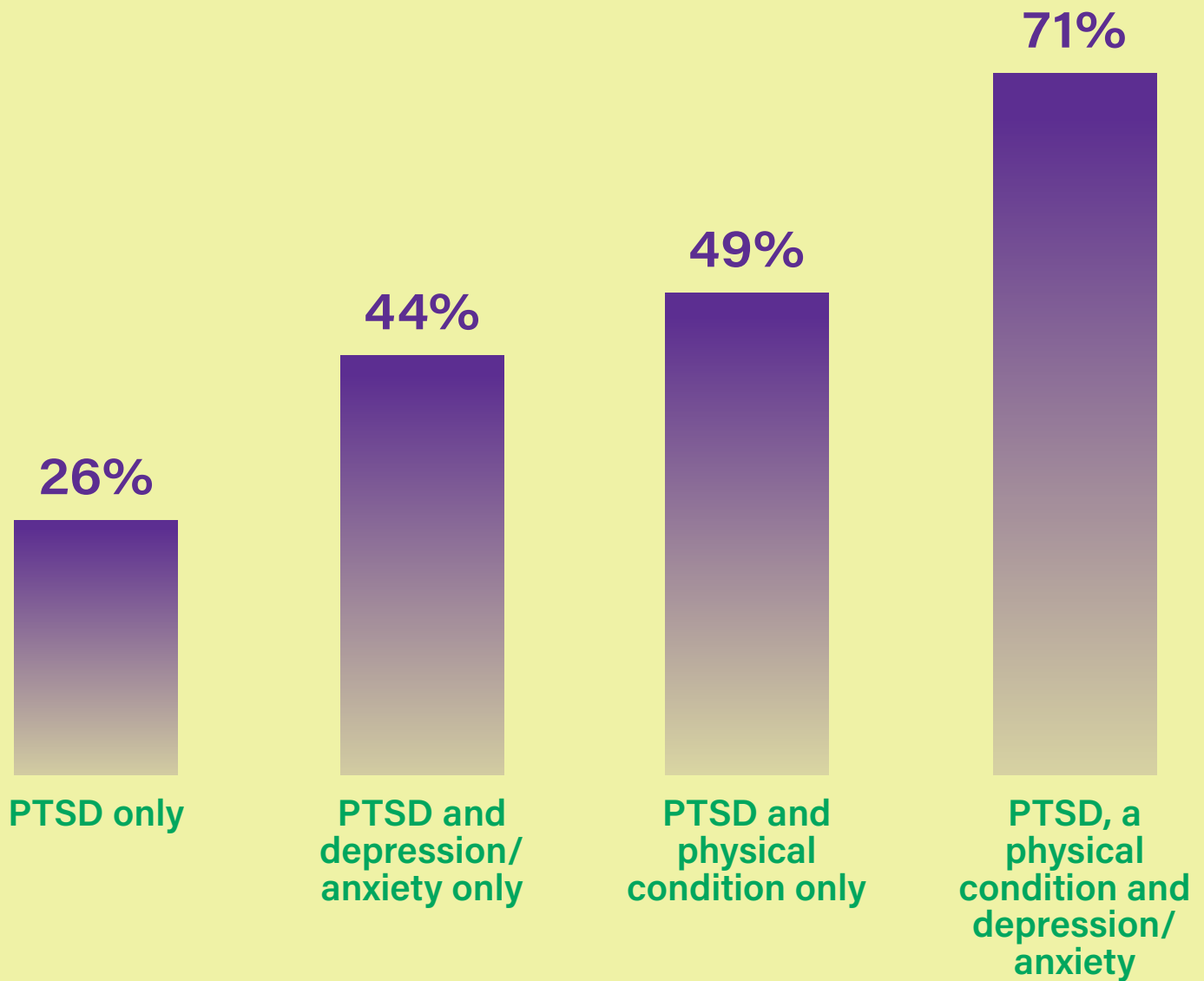
Used previous emergency response training.

“I had tremendous working knowledge from a fireman’s standpoint.”

⁵ Gargano LM, Hosakote S, Zhi Q et al. Resilience to Post-Traumatic Stress Among World Trade Center Survivors: A Mixed-Methods Study. *J Emerg Manag.* 2017 Sep/Oct;15(5):275–284. doi: 10.5055/jem.2017.0336.

STUDY 6: MANY ENROLLEES WITH PTSD REPORTED FAIR/POOR GENERAL HEALTH, ESPECIALLY THOSE WITH AT LEAST ONE OTHER CONDITION⁶

Percentage Reporting Fair/Poor General Health



⁶ Li J, Zweig KC, Brackbill RM, Farfel MR, and Cone JE. Comorbidity Amplifies the Effects of Post-9/11 Posttraumatic Stress Disorder Trajectories on Health-Related Quality of Life. *Qual Life Res.* 2018 Mar;27(3):651–660. doi:10.1007/s11136-017-1764-5.

ENROLLEE STORIES

Jay Alan Zimmerman's Silent Symphony

Musician, performer and WTCHR enrollee

I was at a film festival panel where artists with disabilities spoke about their challenges. Someone in the audience asked how I became deaf.

"I believe it's related to my exposure to the 9/11 disaster, but I really don't know," I said.

Suddenly, a woman in the audience started crying. She said, "Oh my God, I thought I was the only one who had worse hearing after 9/11."

I was so shocked. In that moment, I realized that being open about my hearing loss was one of the best choices I had made.

I searched online to see if there were any other World Trade Center survivors experiencing similar hearing issues. That's when I found the World Trade Center Health Registry's website. It showed that thousands of people had worse hearing after 9/11. Horrified, I became determined to help these people. It's hard to live with a disability, especially when you don't know the cause. I wanted the Registry to conduct research to help me and others. I contacted Dr. James Cone at

the Registry, which led to the survivor's hearing loss study.

It wasn't always like this. As a musician and performer, I relied on my ears. As I became deaf, I was in denial and hid it from those around me. In fact, my wife began learning sign language before I did.

I eventually turned to the classical musician Beethoven, who had also struggled with hearing loss. He wrote, "Let your deafness no longer be a secret even in your heart." Inspired, I took every hearing test available. Then, I asked myself what music was. I realized that the ears are only a channel that we hear through. The actual listening—to the rhythm, harmony and patterns—happens in the brain.

I'll never forget 9/11. In the thick cloud, I had no idea what was left of the world outside. The memory is fresh, even now, almost two decades later. I'm glad that something positive came out of my experience. I have a new approach to my art. No matter what happens, there will always be music.



Rolando* Hears Florida Calling

Department of Sanitation employee and WTCHR enrollee

I worked for the New York City Department of Sanitation in a shop on the West Side, south of 30th Street. Sometimes I worked with the welders and the blacksmiths. The work got very noisy.

For the first three months after 9/11, I worked in the shop where dump trucks full of debris and dust were sent from Ground Zero to be fixed. They were never washed. Even though we wore gloves and masks some of the time, I breathed in the powder.

I lived one block north of Canal Street. The police wouldn't let people go below Houston Street, so to make sure I didn't miss work, I lived in the shop for a couple of weeks.

Around mid-December, I started a shift at Ground Zero. Every day, I would wait at Murray Street and West Street in a truck full of tools and spare parts. There was a lot of debris, so trucks broke down often. When they did, we were called and would drive over to fix them.

I worked for a little over four months near Ground Zero, six to seven days per week, twelve hours a day starting at 6 a.m. Nobody wanted to go down there.

People began telling me that I had a hearing problem. I don't know when it started.

They would say, "You're not paying attention," and I would say, "You got me by surprise."

I have trouble hearing when I'm walking down the street and talking on my cell phone.

I tell them, "Look, call me tonight on my home phone. Then I'll be able to hear you."

I don't know if it's gotten worse. I took a test about 10 years ago and they told me I had a problem with my hearing. I never thought it was related to 9/11.

I've always had good health. I live on the sixth floor and walk up and down the stairs about three times per day. I try to eat my vegetables and fruit and keep in shape.

I ask people to repeat themselves and tell them I have trouble with my hearing. I'm not embarrassed. I don't try to hide it. I'm still in good condition.

I'd like to move to Florida and buy a condo near my brother and sister, who live in Tampa. And I can go fishing. I hear the fishing is good.

These stories are reproduced here as told to Lydia Leon, Registry staff.

*Name has been changed to protect the confidentiality of the enrollee.




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 on many 9/11-related health conditions and respond to your health needs and concerns. 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 or to read updates on the Registry's recent findings, visit nyc.gov/911health.

Registry Website

Our website also features pages for you to update your contact information, read about your rights and learn more about available health care resources.



The screenshot shows the 'World Trade Center Health Registry' website. At the top left is the 'NYC 9/11 Health' logo. At the top right is a 'Select Language' dropdown menu. The main heading is 'World Trade Center Health Registry' with the sub-heading 'Enrollee Update Contact Information'. On the left, there is a login form with fields for 'Email address:' and 'Password:', and a blue 'Login' button. On the right, there is a message: 'Registry enrollees with an active user account should log in to update their contact information.' Below this, there is a link: 'Forgot your password? Need a user account? Contact us at 866-NYC-WTCR (866-692-9827) or wtchr@health.nyc.gov'.

Videos

Hear from fellow enrollees and catch up on our latest findings.



Health Data Tools

Users can quickly and easily view registry surveys and access data. All identifying information has been removed to protect confidentiality.



Newsletter

Read the Registry's quarterly e-newsletter for updates on our research findings and other related news. **Sign up for the newsletter** by visiting nyc.gov/911HealthInfo/enroll.



Health Education Materials

To receive educational brochures about many 9/11-related health conditions, including asthma, GERD, sleep apnea and sinusitis, contact wtchr@health.nyc.gov.

World Trade Center Health Registry
125 Worth St., CN-6W
New York, NY 10013

Contact us for more information:



125 Worth St., CN-6W
New York, NY 10013



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



Email wtchr@health.nyc.gov



Visit nyc.gov/911health

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