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HEALTH REGISTRY



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CENTER | **Health** 2017 ANNUAL
Registry REPORT

Dear Enrollees,

Over the past year, many of you provided valuable updates on your health by participating in World Trade Center (WTC) Health Registry surveys. Some of you also provided feedback on our work by participating in our focus groups. We are grateful for your support and will use your recommendations and input to improve our communications and share updated findings about the health of enrollees.

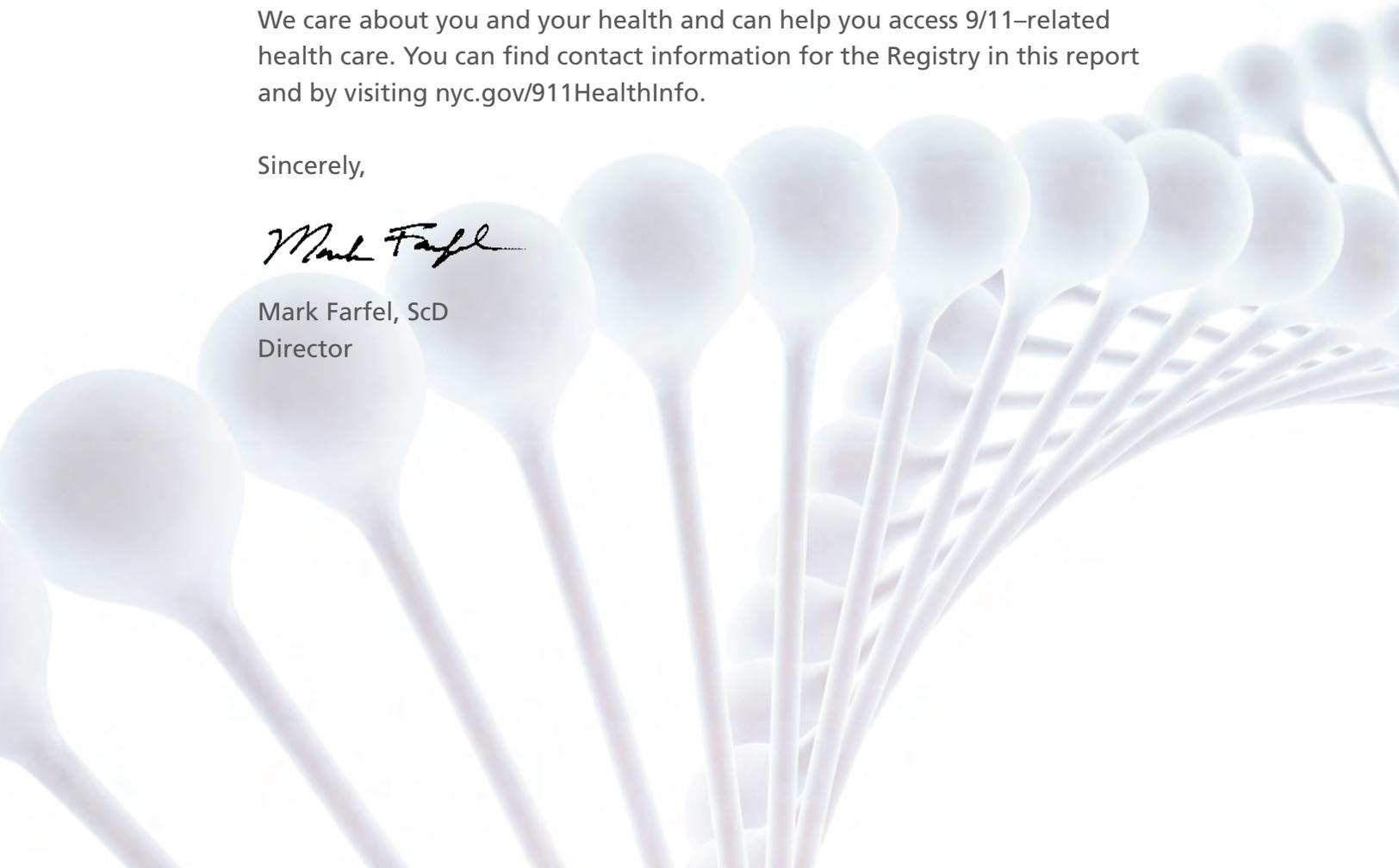
This year's annual report focuses on the health of adolescents and young adults affected by the 9/11 disaster. We have added new features to this annual report, including enrollee stories and comparisons to other populations to better explain our research findings. We hope these stories help us build a stronger sense of community.

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/911HealthInfo.

Sincerely,

A handwritten signature in black ink that reads "Mark Farfel". The signature is fluid and cursive, with a horizontal line at the end.

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.
- 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 or a loved one suffer from 9/11-related health problems? We're 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 **World Trade Center Health Program** at no cost to you. Since 2013, staff at the Registry's **Treatment Referral Program (TRP)** have reached out to more than 23,000 enrollees to tell them about the WTC Health Program and helped nearly 10,000 enrollees complete the application.

How do I know if I need care?

If you were exposed to the WTC attacks and have any of the following symptoms, you may need care: coughing, wheezing, shortness of breath, sinus congestion, stomach problems, frequent heartburn, depression and 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 www.cdc.gov/wtc/.

The federal WTC Health Program provides health care services for 9/11-related health problems at no cost to eligible responders and survivors. The James Zadroga 9/11 Health and Compensation Act of 2010 created the WTC Health Program.

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's been 16 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 www.vcf.gov or call 1-855-885-1555.





Adolescent & Young Adult Research Findings

Adolescence – the period from age 11 to 17 – can be a difficult period. The teenage years are full of physical and emotional changes and many teens experience a number of challenging situations, including anxiety, low self-esteem and peer pressure. It's not uncommon to feel overwhelmed and alone during these times. Experiencing a terror attack like the WTC disaster as a child can make adolescence even more difficult for both adolescents and parents.

Last year, we conducted several studies to look at the impact of 9/11 on adolescents. Two of these studies focused on parent-adolescent relationships.

We learned that family exposure to the WTC attack can affect school attendance and concentration in teens.¹

“We examined parent and adolescent mental health, adolescent behavior problems and adolescent unmet health care needs,” Lisa Gargano, a researcher at the Registry said. “We found that all these factors affected how adolescents functioned in school.”

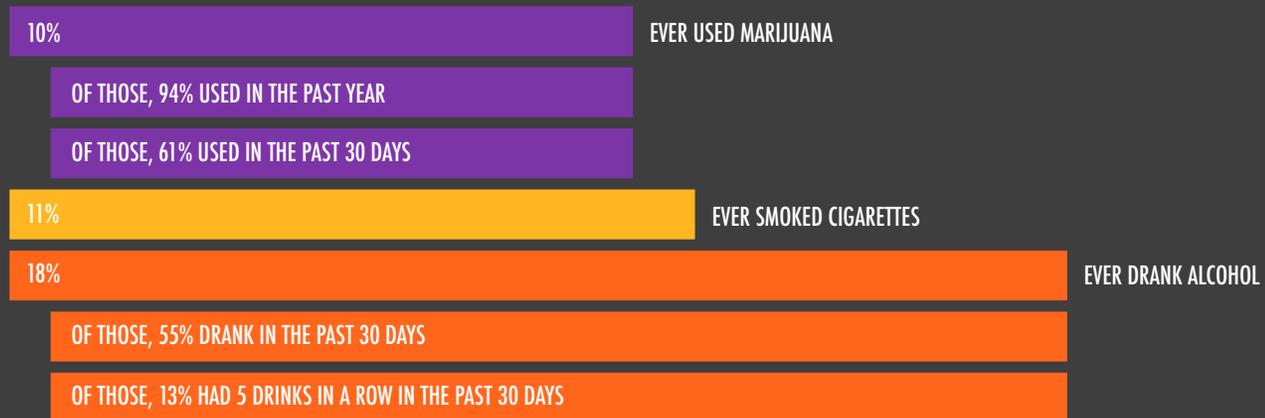
Even 10 to 11 years after the 9/11 disaster, adolescents who had 9/11 exposure were more likely to have behavioral problems.² Teens whose parents had posttraumatic stress disorder (PTSD) and at least one other chronic disease like asthma or heart disease were more likely to have behavioral problems.

We also examined the connection between the health of parents and adolescent health outcomes. If a parent reported 14 or more poor mental health days in the past month, their adolescent was more likely to have behavioral problems. We defined poor mental health as feeling sad, depressed, anxious or lonely. For more information about this research, visit nyc.gov/911HealthInfo.

Fortunately, the WTC Health Program can help adolescent enrollees and their parents address these health challenges. The WTC Health program can link adolescent enrollees and their parents to coordinated care for physical, mental and behavioral health problems. See page 3 for more information on how to seek care.

Adolescents Also Reported Substance Use, Asthma Control 10 Years after 9/11

Use of Marijuana, Cigarettes, and Alcohol³

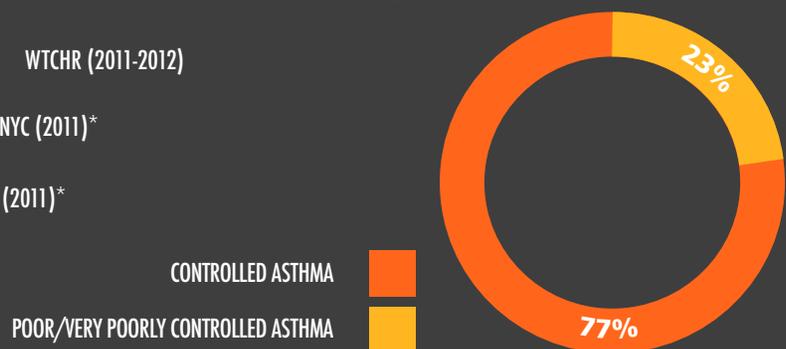


Asthma Diagnosis

Asthma Higher in Registry Youth Compared to NYC/US



Status of Asthma Among Registry Youth⁴



¹ Gargano, Lisa, Dechen T, Cone JE, et al. Psychological Distress in Parents and School Functioning of Adolescents: Results from the World Trade Center Health Registry. *Journal of Urban Health*. March 2017.

² Gargano, Lisa, Locke S, Brackbill RM. Parent Physical and Mental Health Comorbidity and Adolescent Behavior. *International Journal of Emergency Mental Health and Human Resilience*. February 2017.

³ Gargano, Lisa, Welch AE, Stellman SD. Substance Use in Adolescents 10 Years after the World Trade Center Attacks in New York City. *Journal of Child and Adolescent Substance Abuse*. May 2017.

⁴ Asthma Control in Adolescents 10 to 11 Years after Exposure to the World Trade Center Disaster. *Pediatric Research*. January 2017.

*Youth Risk Behavior Surveillance System



Young **Adult** **enrollees** Share **Their 9/11 Experiences**

Disasters have a powerful impact on those present during the event, as well as on family and friends. These stories show how the WTC attacks affected adolescent survivors and those whose parents or friends were survivors.* If you or someone you know have 9/11-related health problems, you're not alone. We're here for you. See page 2 on how we can help.

KRISTINA, NOW 31 YEARS OLD, 16 YEARS OLD ON 9/11

My childhood friend, Alyssa, went to school right in front of the towers. On 9/11, all I could think about was my parents. I remembered Alyssa only after I got home that day.

Later I found out that her school kept them indoors and let them out much later, by which time the towers had fallen. She came home covered in debris.

She was always scared after the disaster. I was naïve at the time, but I recall she had water bottles filled with clear alcohol. She drank a lot.

One time, I visited her where she lived with her mom. She was sleeping on the floor of her room [facing] the window.

She had written "Please help me" on the wall.

I was scared for her. The drinking continued until a point where she had delusions and blackouts. She

was also on medications for depression. She stood me up whenever we had plans, but would only call me when she needed me to do something. I mentioned her alcohol problem to her mother, but the news wasn't well-received.

Alyssa and I got into a huge argument. She denied her problem and we stopped talking. We patched things up later, but I haven't talked to her in years.

I heard she was in California, taking acting classes. She's doing what she always wanted to do, because growing up she always wanted to be an actress. I like to think she got the help she needed.

NICHOLAS, NOW 27 YEARS OLD, 11 YEARS OLD ON 9/11

On 9/11 I was in a Catholic high school called St. James. It's closed now. We felt a rumble but ignored it. Then we heard a second boom. Shortly thereafter, the principal dismissed us.

The black smoke and the big hole in the WTC were shocking, movie-like. That night I had nightmares. I was so scared of planes that I ducked down and hid, thinking they would hit us. When school reopened weeks later, we got gifts and cards of encouragement from countries like Scotland. It helped me feel like we were not alone.

I took a year off during my junior year of college at PACE University. I just couldn't function or do well in school. I had depression, anxiety, anger and frustration.

I got some counseling and was prescribed medications. I was able to complete my degree, but now I still can't function as well as I would like. I've been having thoughts about bombs, mass murderers and other random thoughts.

I didn't think it was about 9/11, but it now makes sense. I'm definitely interested in seeking help from the World Trade Center Health Program.

SADE, NOW 25 YEARS OLD, 10 YEARS OLD ON 9/11

I was in school when we heard the loud boom. "Oh, it's nothing. It's just God crying," my teacher in St. James elementary school joked.

Then, on the loudspeaker, we were told we were being evacuated underground. I was scared because my mom was pregnant with my sister and she worked right there on Broadway. Everyone came to pick up their kids. I was the last kid to get picked up.

My mom arrived at the school all red and out of breath. She has asthma. We lived in the Bronx and our trains weren't running. We walked all the way to the west side and caught the A train, which left us a long way from home.

Luckily, my mom had an extra mask, which she gave me to help prevent smoke inhalation. A lot of people were helpful that day. There was a small store that was giving water to people. My dad had an interview that day in the towers but cancelled it to take care of my brother who wasn't well. I'm so thankful he was home.

We didn't go to school for a couple of weeks, but when we did, things changed a lot at home. My mom was pressuring me to become more responsible and to help care for my younger sister.

I carried a pump with me to prevent my asthma from acting up. My mom got bronchitis a few times.

I had to grow up so fast. I felt it was not fair. Now that I am an adult and I have my son, I feel at times that something is going to happen and I get anxious. We still have asthma today, my mom and I. I'm happy to say I experienced this event with my mom. It's not something to be proud of, but we have that connection of how we survived.

JULIAN, NOW 23 YEARS OLD, 8 YEARS OLD ON 9/11

My mom, Myrna, survived the 1993 World Trade Center bombings. She remembered what that felt like and that informed her quick rush to pick me up. She had dust in her hair. She was crying.

I felt like 9/11 affected my mom more than it did me. She was paranoid all the time. She kept me really, really close. I had a curfew and a set bedtime. We disagreed a lot, especially because I couldn't go out and play with my friends.

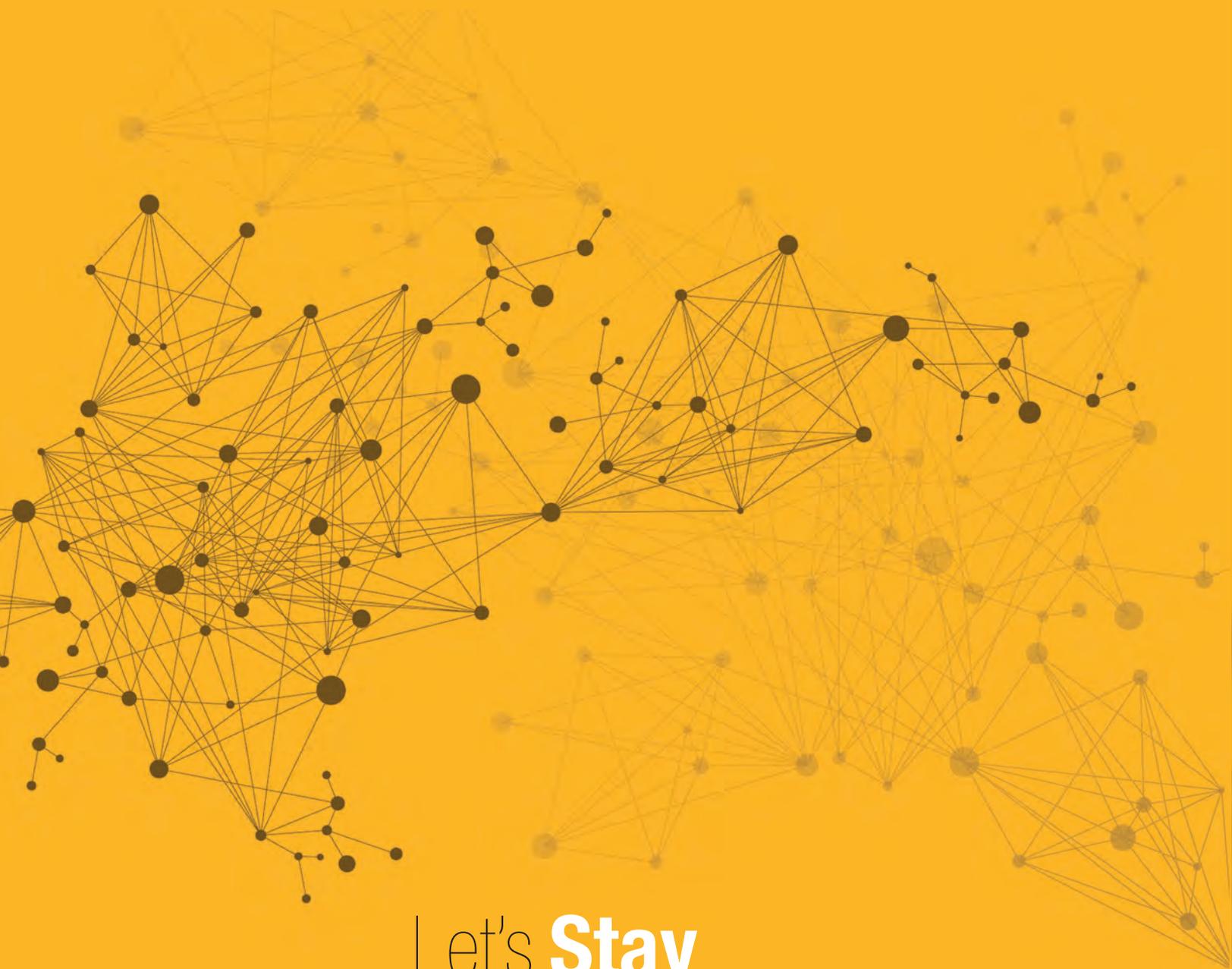
I hoped that maybe years later she would loosen the leash, but sometimes I had to show her I would be okay. She was able to return to work, but she suffered a lot of anxiety and panic attacks.

Now, 16 years later, she stops by the memorial at times, just to remember. She's okay now. She got therapy, and yeah, she still stays up until I come home.

As a grown man, I now have generalized anxiety disorder. I feel I got it half from my mom raising me with her anxiety, and of course other life issues that I've been through. I always look around – on the train, in stores, in offices – just to see who's around me, and I never get on a crowded train. I look for safety in open spaces.

Sometimes I think my anxiety is helpful because my job loves my perfection in the work I do, but sometimes I wonder if they think I obsess too much.

**The stories are reproduced here as told to Kimberly Mantilla, Registry Staff. All names have been changed to protect the confidentiality of the enrollees.*



Let's **Stay**
Connected

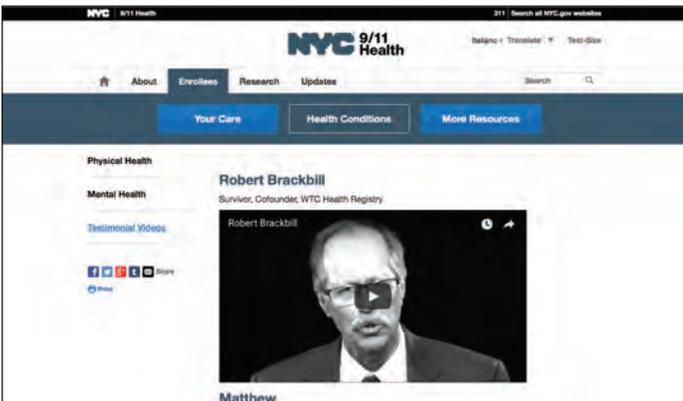
Learn More about Registry Findings and Recommendations

Thank you for your continued support of the Registry. 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, read updates on the Registry's recent findings or hear what enrollees are saying about the Registry, visit nyc.gov/911HealthInfo.

Our website also features:

Pages for Registry enrollees to update their contact information, read about their rights and learn more about available health care resources.



An interactive health data tool you can use to explore the information we collected during the first Registry survey in 2003-2004.

(All identifying information has been removed to protect confidentiality.)



Quarterly Newsletter

The Registry sends out a quarterly e-newsletter with the latest 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 wtdhr@health.nyc.gov.

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

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

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

Email: wtdhr@health.nyc.gov

Visit: nyc.gov/911HealthInfo

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