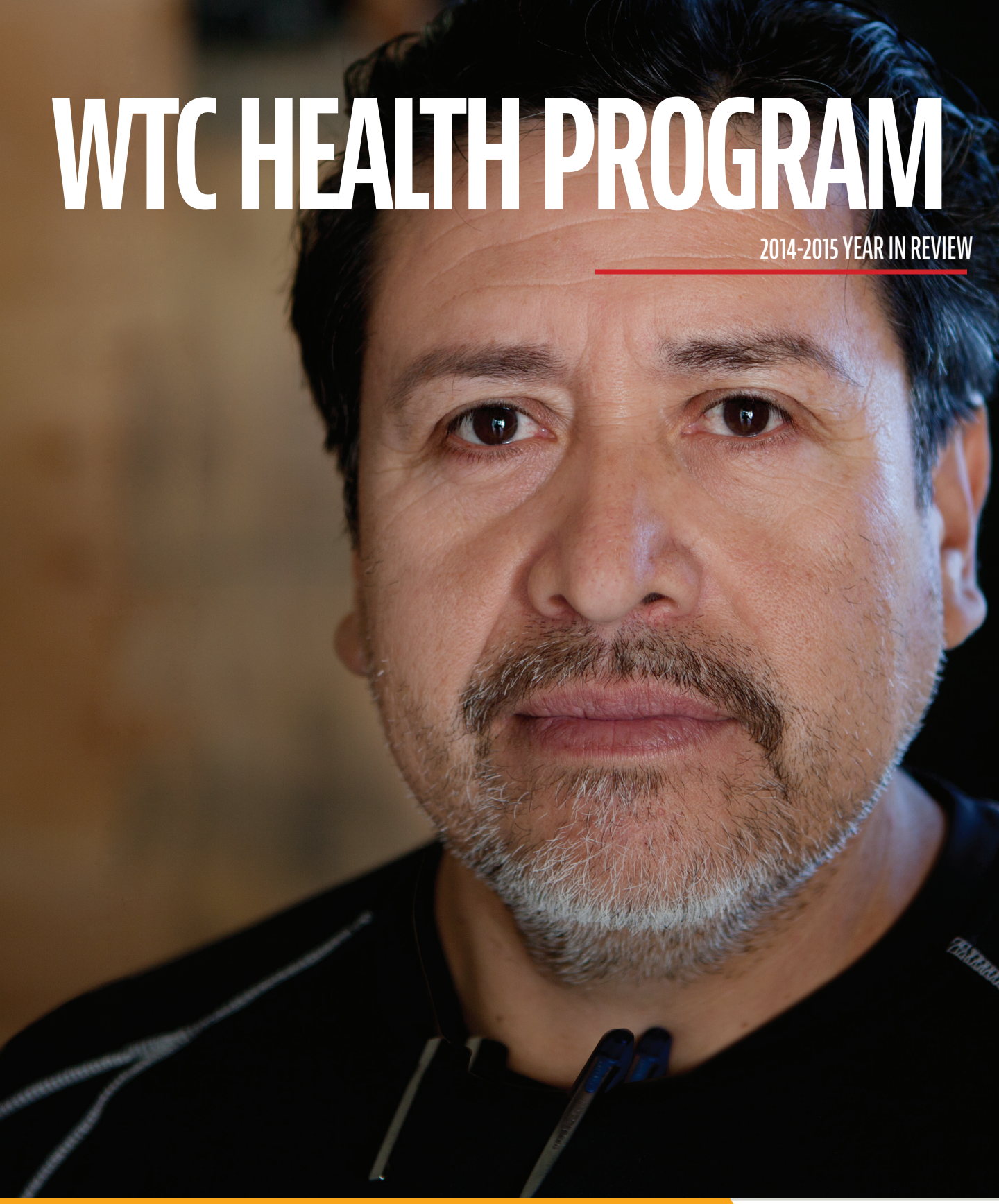


WTC HEALTH PROGRAM

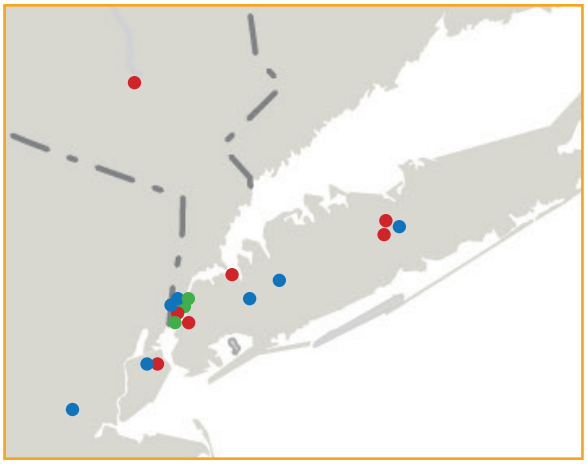
2014-2015 YEAR IN REVIEW

If you were there...We're here

Connect with us at www.cdc.gov/wtc or call 1-888-982-4748

Monitoring and Treatment
9.11
WTC Health Program

Finding Care



Nationwide Provider Network
Logistics Health Incorporated (LHI)

Not in the New York City Metropolitan Area? The Nationwide Provider Network (NPN) can help! The NPN provides quality medical monitoring and treatment for both responders and survivors who live outside of the New York City metropolitan area. Once you are enrolled in the Program, someone from the NPN will call you to discuss your healthcare needs and find local medical providers so that you can begin receiving benefits. The NPN has a large network of credentialed providers in a variety of specialties. For information about the NPN call 1-888-982-4748.

The World Trade Center (WTC) Health Program has several Clinical Centers of Excellence (CCE) for responders and survivors in the New York City metropolitan area and New Jersey. Some clinics have multiple locations and many can communicate in Spanish, Polish, or Chinese.

For a more detailed list, including a map, please visit the Program's website at www.cdc.gov/wtc/clinics.html or call 1-888-982-4748.

General Responder Clinical Centers of Excellence

ICAHN SCHOOL OF MEDICINE AT MOUNT SINAI
Selikoff Centers for Occupational Health
Telephone: 1-888-702-0630
Locations: Manhattan and Staten Island

NEW YORK UNIVERSITY SCHOOL OF MEDICINE
Department of Occupational and Environmental Medicine
Telephone: 212-562-4572
Location: Manhattan

NORTH SHORE-LIJ HEALTH SYSTEM
Telephone: 718-267-2420
Location: Queens

STATE UNIVERSITY OF NEW YORK, STONY BROOK
Telephone: 631-855-1200
Locations: Islandia and Mineola (contact main clinic first)

RUTGERS UNIVERSITY
Robert Wood Johnson Medical School Environmental & Occupational Health Sciences Institute
Telephone: 848-445-0123
Location: Piscataway, New Jersey

Fire Department City of New York (FDNY) Clinical Center of Excellence

FDNY Bureau of Health Services
Telephone: 718-999-1858
Locations: Brooklyn, Staten Island, Bayside, Brentwood, Middletown, Commack, and Manhattan

Survivor Clinical Center of Excellence

NYC HEALTH AND HOSPITALS CORPORATION (HHC) WTC ENVIRONMENTAL HEALTH CENTER
Telephone: 1-877-982-0107
Locations: Bellevue Hospital, Gouverneur Healthcare Services, and Elmhurst Hospital Center

Front cover photo by Terrance Williams, wundrstudio.com
Back cover photo of the painting "Trying To Remember the Color of the Sky on That September Morning" by Spencer Finch at the National September 11 Memorial Museum. Photo by Andrew Yianne, YiannePhotograpy.com

Letter from the Administrator

July 1, 2015, marked the fourth anniversary of the World Trade Center (WTC) Health Program. Established by the Zadroga 9/11 Health and Compensation Act, the WTC Health Program strives to provide excellence in 9/11-related healthcare and research. We reflect on another successful year by reaching out to you, our members. This special annual publication is our way of keeping you informed of important new research, helpful health news, and new Program resources. Key themes from this year's annual report to members include:

The need for 9/11 related healthcare is as urgent as ever.

The WTC Health Program now serves over 70,000 people, with over 3,600 new members joining the Program in the past year (July 1, 2014-June 30, 2015). Last year we approved over 8,000 new health condition certifications, including over 1,600 cancer certifications. Each certification represents a member who is now eligible to receive vital medical treatment. It also reminds us that thousands continue to confront 9/11-related health conditions over a decade after the disaster. For more details on enrollment and certification please see pages 6-7.

Research provides the critical link to improved diagnosis and treatment of 9/11-related conditions.

In addition to providing high quality healthcare, the WTC Health Program is committed to studying the health effects of the terrorist attacks. The Program funds a diverse group of researchers, including epidemiologists, health scientists, physicians, psychologists, and public health experts. They work to answer key questions about the risk factors and treatment of 9/11-related physical and mental health conditions. To learn more about research in the WTC Health Program—including how you can help—please see pages 4-5.

The WTC Health Program is committed to providing the highest quality healthcare for members.

This annual report offers a glimpse of the benefits available to you as a member of the WTC Health Program. Inside this publication you will meet Program staff, learn where to find Clinical Centers of Excellence, and discover new tools and resources, like the updated member handbook. And perhaps most importantly, you will hear from two Program members who agreed to share their stories of hope and healing. Stories like these recommit me to our mission and remind us all of the vital importance of the WTC Health Program.

Sincerely,
John Howard, M.D.
Administrator, World Trade Center Health Program

Photo by Shayla Mae, Flickr

Still Helping

A volunteer finds help for himself, encourages others, and moves the research forward.

On September 11th, Morris Paserchia witnessed the towers fall from his New Jersey home. His first instinct was "how can I help?"

Soon Morris was volunteering with the Salvation Army, assisting the city's Medical Examiner's Office. "I did whatever they needed me to do," he explains. From October 2001 to April 2002, Morris worked three days a week.

"I chose to work the night shift," he explains. "To me it was a cloak, out of respect to those who were missing or deceased."

Working the night shift also meant intensely long hours. "I brought my own boots," he remembers. "They essentially melted not from heat but just from wear." There were no respirators or masks.

The devastation around him was impossible to ignore. "The hardest part was when victims' remains came in," Morris recalls. He often worked out of a fire station on Liberty Street across from Ground Zero, known as 10 House. "There was nothing in 10 House . . except body bags and flags."

Getting Treatment

Morris is proud of his volunteer commitment, but his 9/11 experience took a toll on his health. He had trouble breathing and became deeply depressed. He sought help from his doctor, but still struggled with severe symptoms when he enrolled in the WTC Health Program.

"I was unable to pass any of the breathing tests. I actually passed out from a standing position."

Morris was diagnosed with asthma, rhinitis, depression, and PTSD. He credits the Program's competence *and* caring with giving him hope. "These people have both professional skills and compassion–a rare combination."

He explains that once in treatment, "I could tackle the emotional issues that were the real demons that haunted me." His providers were sensitive and supportive because they understood his experience.

Today Morris is breathing easier and better able to manage his depression and PTSD. He remains committed to regular medical monitoring for his own health, and for the health of others. Like a true volunteer, he hopes that others will benefit through his participation in the Program.

"This is not just about me," he explains. "The aggregate of the numbers is important to help all of the people who were involved."

"This is not just about me," he explains. "The aggregate of the numbers is important to help all of the people who were involved."

For Morris, the WTC Health Program helped him recover and he doesn't mince words when describing his appreciation.

"I don't know where I'd be without it. It saved my life."

To see Morris tell his story, visit the WTC Health Program website at www.cdc.gov/wtc/memberstories.html

Each WTC Health Program member who provided a testimonial for or is depicted in this newsletter has signed a written consent form and waiver, which is on file with the Program. Any and all information provided, including any health information, was done so solely for the purpose of WTC Health Program-related education and outreach efforts. At no time were members' WTC Health Program health records accessed. All portions of the article are based on statements made during the interview and are not based on official findings of the WTC Health Program. If you would like to share your story with others, please contact Melissa at wtc@cdc.gov

What You Can Do

Photo by Thinkstock

When you have an annual monitoring exam you may choose to share information about your symptoms with researchers who are studying 9/11-related illnesses. Participation in research is voluntary and anonymous—your identity is never revealed. You can also choose not to disclose your health information and still receive your monitoring exam and treatment for certified WTC-related health conditions. For more information, talk to your Program provider or call the WTC Health Program at 1-888-982-4748.

Photo by Thinkstock

9/11-Related Research

When the September 11th attacks occurred over a decade ago, little was known about the health effects of such a large disaster. What diseases might be linked to the toxic dust and debris that followed 9/11? Who was at risk? How would their need for treatment and quality of life change over time?

The WTC Health Program has been committed to finding answers to these and other questions.

In the past four years the Program has funded 34 research projects to learn more about the physical and mental health affects of the 9/11 terrorist attacks. Scientists study diseases like asthma and PTSD, which are common certifications in the WTC Health Program. Researchers are also investigating emerging concerns, like sarcoidosis, polymyositis, and other immune problems.

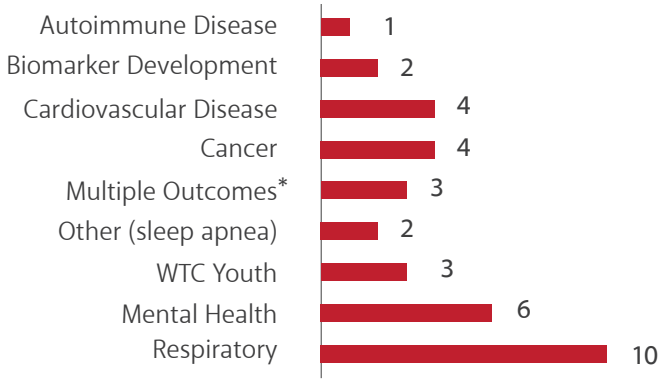
The Program draws from a network of researchers at medical colleges, public health organizations, Data Centers, and Clinical Centers of Excellence. These experts study a wide range of research questions, including how to:

- Identify and measure the body's response to 9/11-related exposures
- Link the amount of 9/11 exposures with specific health outcomes
- Identify patterns of illness (age, gender, etc.)
- Improve diagnosis and treatment

Scientists funded by the WTC Health Program meet regularly to share and review their research, keep up to date on emerging trends, and discuss ways to improve communication. The goal is to support a "Research-to-Care" model, so findings quickly benefit those with 9/11-related illnesses and protect those who are confronted with future disasters.

Areas of Emphasis

The table below shows the number of research projects currently underway for each of the areas of emphasis.



*This category includes the WTC Health Registry, a separate research project funded by the WTC Health Program.

Some Study Highlights

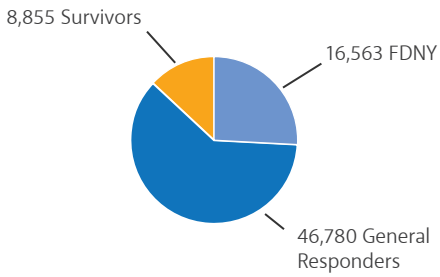
Below is a sample of research findings from the WTC Health Program.
Please visit www.cdc.gov/wtc/wtcresearch.html for more information about these projects.

- A modest excess of cancer cases was found among male firefighters.
- A greater than expected number of prostate and thyroid cancers were found among responders.
- More than one-third of adults surveyed by the WTC Health Registry reported unmet mental health care needs 10 to 11 years after 9/11.
- WTC dust may cause changes in small airways that result in chronic breathing problems. These changes may not be detected with a common lung screening test (spirometry).
- More severe PTSD symptoms were reported among responders with more severe WTC exposures and/or with additional WTC-related medical conditions.
- 9/11-related PTSD is a highly chronic condition. Tracking of life events and stress management training can improve mental health of 9/11-exposed populations.
- Compared with those who never worked at the WTC site, firefighters and emergency medical service workers who arrived earliest were at greater risk for nearly all health conditions, including almost four times the risk for GERD and rhinosinusitis, seven times the risk for probable PTSD, and twice the risk for probable depression.

Note: many projects funded by the Program are still collecting and analyzing data about 9/11-related health effects. More research findings are expected in the future.

Enrollment

The WTC Health Program serves over 70,000 members in every state in the nation. The following information offers a snapshot of the Program's impact over the past year (July 2014- June 2015).

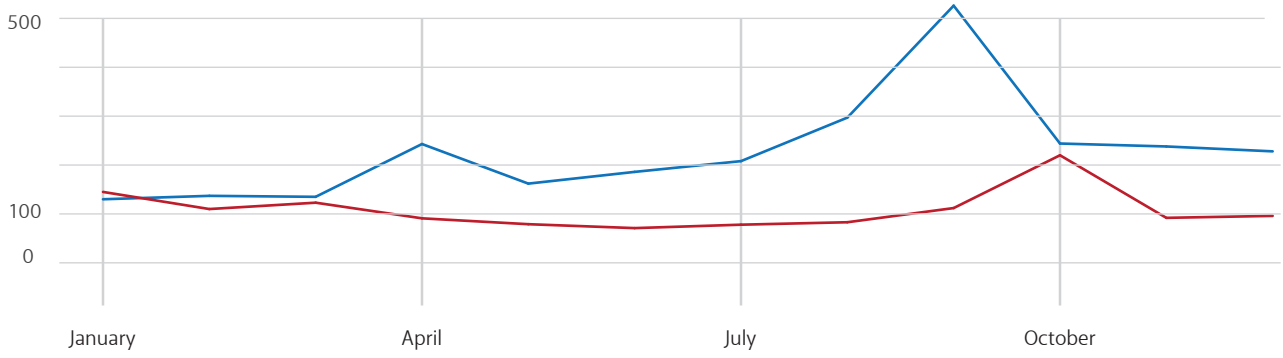


Total Program Membership by Category

As of 06/02/2015

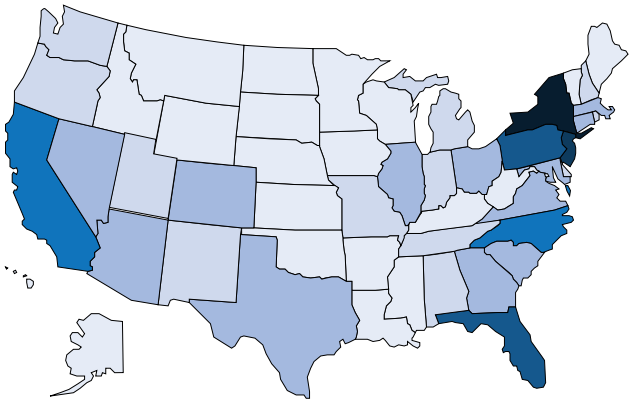
Enrollment Trends for 2014

The following chart shows newly enrolled members by month. The data represented is for 2014 but trends for 2012-13 were similar. Responders are represented by blue ▪ and survivors by red ▪



Total Enrollment by State

As of 06/10/2015



- >50,000 (NY)
- >5,000 (NJ)
- 1,000-4,999 (PA,FL)
- 500-999 (CA, NC, VA)
- 100-499
- 50-99
- 1-50*

*U.S. territories, armed forces have between 1 and 50 members

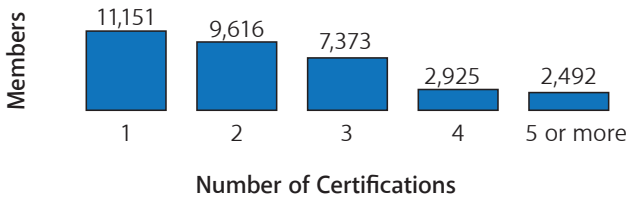
Certified Conditions

The WTC Health Program covers a specific list of physical and mental health conditions. The Program certifies, or approves, medical treatments for these conditions if they are deemed to be 9/11-related. The member handbook contains detailed information about the certification process, including a list of covered conditions. The member handbook can be read online or downloaded at www.cdc.gov/wtc/memberhandbook.html

Number of Members with One or More Conditions

As of 02/02/2015

Currently, the WTC Health Program has a total of 33,557 members with certified conditions. Many members have multiple certifications. The following chart provides a breakdown of how many members have one or more certified conditions.



Ten Most Commonly Certified Cancers

As of 6/11/2015

Non-melanoma Skin	1000
Prostate	888
Lymphoma	355
Melanoma of Skin	291
Thyroid	251
Lung/Bronchus	198
Breast-female	195
Kidney	193
Leukemia	176
Colon	164

Interested in learning more? Visit the Program at a Glance feature on our website (www.cdc.gov/wtc). This page is updated each quarter with the number of new member enrollments and certified conditions.

The Power of a Plan

How one survivor took control of her health and reconnected with her passions.

Florence Jones remembers the FBI agent saying "Don't look up and don't look back." She had just walked down 77 flights of stairs from the South Tower of the World Trade Center. The terrifying journey saved her life, but exposed her to smoke, jet fuel, and other toxins.

In the first few years after 9/11, she worked to address the emotional toll of her experience, including the loss of several colleagues. In time, physical symptoms also began to appear. She developed a cough that wouldn't go away. She endured multiple bouts of bronchitis, the flu, and walking pneumonia. During a routine check-up, her doctor found a spot on her lung. After years of suffering with chronic breathing problems, she was referred to the WTC Health Program.

A Team Approach to Care

Once at the clinic Florence knew she was in the right place. Her doctor heard her raspy voice and said "I could fill a room with people who sound just like you."

Florence explains that from the start the Program has taken a detailed interest in her health. "The monitoring program is very, very comprehensive. I was asked over 300 questions the first day I was there." Florence met with internists, a social worker, a psychiatrist, and had "every kind of test." She was diagnosed with asthma and acid reflux, neither of which she had before 9/11.

"When I left there I had a plan in hand," she explains. "All of these people worked together and set-up my subsequent appointments and tests." She learned how to use an inhaler and was prescribed additional medicines to control her symptoms.

Florence has since returned to her Clinical Center of Excellence every year, sometimes multiple times a year, to ensure her health remains stable. She notes that her providers recognize and treat symptoms that other doctors may miss, which she credits to their experience, caring, and team approach to care.

"You can move forward,"... "but you've got to make the first step."

"I know that my healthcare is under control. My symptoms are under control."

Having her symptoms under control gives her the energy and time to enjoy her life. Florence is extremely close with her family and wants to be there for her nieces and nephew. She also loves to travel and is now able to plan new trips.

She urges anyone who worked at or near the World Trade Center site to get help through the Program. After taking years to connect her symptoms, she knows that 9/11-related health problems won't go away on their own.

"You can move forward," she explains, "but you've got to make the first step."

To see Florence tell her story, visit the WTC Health Program website at www.cdc.gov/wtc/memberstories.html

Each WTC Health Program member who provided a testimonial for or is depicted in this newsletter has signed a written consent form and waiver, which is on file with the Program. Any and all information provided, including any health information, was done so solely for the purpose of WTC Health Program-related education and outreach efforts. At no time were members' WTC Health Program health records accessed. All portions of the article are based on statements made during the interview and are not based on official findings of the WTC Health Program. If you would like to share your story with others, please contact Melissa at wtc@cdc.gov

Making Your Own Plan

A yearly monitoring exam with the WTC Health Program helps you stay in charge of your healthcare. You will meet with a team of experts who will provide detailed medical tests, emotional support, and if needed referrals to specialists. Monitoring exams can provide peace of mind by confirming you are in good health or by finding changes that may be corrected or slowed with early treatment.

Call your Clinical Center of Excellence or the Nationwide Provider Network to schedule your free and confidential exam. If you have questions, please call the WTC Health Program at 1-888-982-4748.

Photo by Thinkstock

Health & Wellness

Eating and Drinking When Your Stomach Hurts

Gastroesophageal Reflux Disease or GERD is one of the most commonly certified conditions in the WTC Health Program. GERD can cause a painful, burning feeling in the chest, belly, and throat, along with nausea, vomiting, and trouble breathing. If you have these symptoms seek medical attention right away because they may be related to a more serious concern like a heart attack. If you are diagnosed with 9/11-related GERD know that providers with the WTC Health Program can help. They may recommend medication or they can discuss if some of the following tips can help manage your symptoms:

- Eat healthy and balanced amounts of different types of foods. Visit Choose My Plate at www.choosemyplate.gov to find more suggestions about healthy eating.
- Eat small, frequent meals instead of three large meals.
- Maintain a healthy weight.
- Avoid foods or drinks that may make GERD symptoms worse. Common triggers include:
  - chocolate
  - coffee
  - peppermint
  - greasy or spicy foods
  - tomatoes and tomato products
  - alcoholic drinks

For more information talk to your health providers at the WTC Health Program. If you are not sure who to talk to, call the WTC Health Program directly at 1-888-982-4748. Our help line can connect you with a Clinical Center of Excellence or the Nationwide Provider Network.

Source: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases www.niddk.nih.gov/health-information/health-topics/digestive-diseases/ger-and-gerd-in-adults/Pages/eating-diet-nutrition.aspx

Photo by Thinkstock

Alcohol and 9/11 Health

A recent study suggests that those affected by 9/11 may be at greater risk for binge drinking. In 2014, the WTC Health Registry published a study of over 41,000 people who completed their Wave 2 survey. They found slightly higher levels of frequent binge drinking compared to the general population (frequent binge drinking was defined as 5 or more episodes of binge drinking in the previous month). In addition, those with more exposure to the events of 9/11 and those with 9/11-related PTSD were at greater risk for binge drinking.

What is binge drinking?
Binge drinking is defined as 4 drinks within a short period of time (less than 2 hours) for women and 5 drinks for men.

Why is alcohol a concern for those with 9/11-related health conditions?
Most people who binge drink don't think it's a problem because they are not alcoholics, but alcohol use can worsen 9/11-related conditions by

- Triggering GERD,
- Aggravating sleep apnea,
- Making depression and anxiety worse, and
- Reducing the effectiveness of some antidepressants.

Source: Welch, A.E., et al., Frequent binge drinking five to six years after exposure to 9/11: Findings from the World Trade Center Health Registry. Drug Alcohol Depend (2014)

Source: Centers for Disease Control and Prevention
www.cdc.gov/alcohol/fact-sheets/binge-drinking.htm

Binge drinking also increases the risk of car crashes, violence, sexually transmitted diseases, accidents, liver damage, alcohol poisoning, and suicide.

Are you concerned about your drinking?
The doctors, nurses, and counselors at the WTC Health Program can help by providing you with resources and support. All care is completely confidential. Call your Clinical Center of Excellence or the Nationwide Provider Network to discuss what benefits may be available to you. If you are not sure who to call, call the WTC Health Program directly at 1-888-982-4748 to be connected with your health care provider.

Just Breathe

It may not seem like much but a three minute pause can help you deal with day-to-day stressors. Taking a few deep breaths or picturing a comforting scene can be just enough of a pause to relax the body and mind. You can also download a free three minute meditation from Oxford University at http://franticworld.com/free-meditations-from-mindfulness-for-health/

Thanks to the members of the Mental Health Forum for their support on this section.

Here for You

At the WTC Health Program we are always working to improve your member experience. In the past year we've launched several new tools to help you get information quickly and easily. You can also contact our member help line at 1-888-982-4748 with questions or concerns.

Do you have a question about the Program or your benefits?

Member handbooks are now available in English and will soon be available in Spanish, Polish, and Chinese. For a printed copy, please call 1-888-982-4748.
The member handbook can be read online or downloaded at
www.cdc.gov/wtc/memberhandbook.html

Interested in learning more about WTC Health Program members?

Our website www.cdc.gov/wtc now offers a Program at a Glance feature. This page is updated each quarter with information such as member enrollments and cancer certifications. (Flip to pages 6-7 for more information about program enrollment and certifications.)

Do you have a family member, friend, or co-worker who is not enrolled in the Program and may be eligible?

The Program now offers an online application system at https://oasis.cdc.gov/ to streamline the process of applying for benefits. (Note: current members do not need to reapply to the Program.)

WTC Health Program Pharmacy Benefits

The WTC Health Program offers prescription drugs to treat certified conditions with no out-of-pocket cost to you. When possible, the Program requires the use of generic and cost effective medications. Brand-name drugs with generic equivalents may be filled if your doctor documents that the brand name drug is medically necessary. If you have more questions please talk to your WTC Health Program provider or call the help line at 1-888-982-4748.

In New York

Reggie Pabon helps members and community groups out of his New York City office.

How do you help members of the WTC Health Program?

I help people one-on-one if they have questions about the Program or if they have a complaint or concern. I can also help people with their applications—if they have questions about how to enroll. The other big part of my job is doing community education and outreach about the Program.

What kind of support do you provide for people who prefer to get information about the Program in Spanish?

I work with people in either English or Spanish. Sometimes I assist the Clinical Centers of Excellence with Spanish-language information or to act as a Spanish interpreter for Latino members. I can also do community presentations in Spanish.

How can members reach you?

It's always good for members to share any questions or concerns with their Clinical Center of Excellence first. If they still have questions, then they can speak with me or someone in the Program by contacting the WTC Health Program at 1-888-982-4748 or emailing the Program at wtc@cdc.gov

Any helpful tips for members on how to get the most out of the WTC Health Program?

See your doctor regularly and notify your doctor of any symptoms you may have. The earlier a disease is diagnosed, the more likely it is that it can be cured or effectively treated. Also, there is a lot of good information on the FAQ section of our website and in the member handbook. Note: These pages can be found at www.cdc.gov/wtc/faq.html and www.cdc.gov/wtc/memberhandbook.html

What do you like best about your job?

I enjoy working with the dedicated team within the Program to provide WTC responders and survivors with the very best healthcare. I find it rewarding that I can make a difference in people's lives.

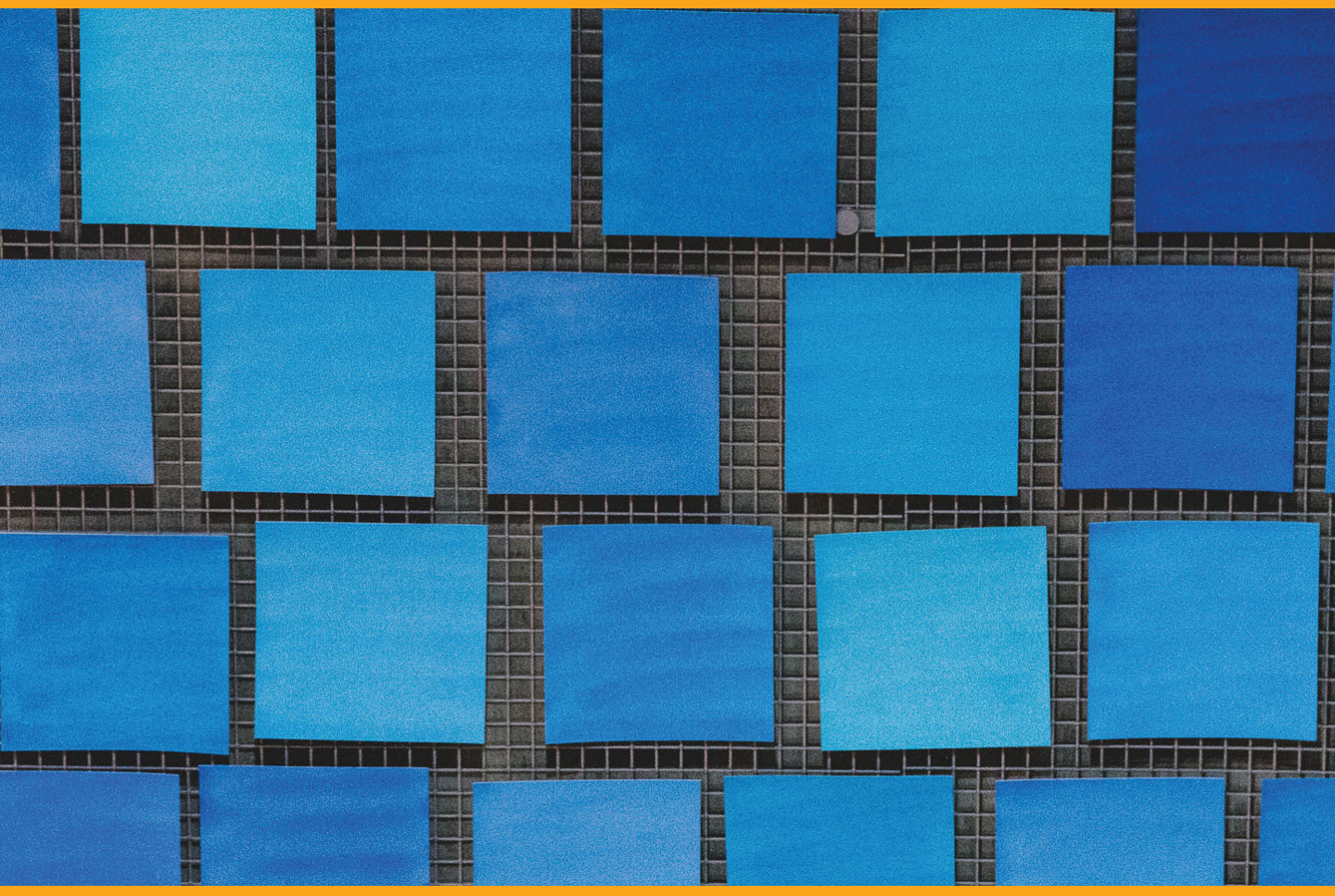



Photo by HD Zimmermann, Flickr