# HEALTH PROGRAM News

VOL. 3
SPRING 2014

To Serve 9/11 Responders & Survivors

9.11



**Shanksville** 



**New York City** 



Pentagon

## **PROGRAM NOTES**

# HEALTH MONITORING EXAMS: NOT YOUR AVERAGE DOCTOR'S VISIT

Regular health monitoring is a cornerstone of the WTC Health Program. Each year thousands of members receive their exam. A thorough check can confirm you are in good health or identify changes that may be corrected or slowed with early treatment. This peace of mind is valuable to many of our members, who tell us that health screenings are a major reason why they joined the Program.

What makes monitoring exams so beneficial? They provide high quality health care with no out of pocket costs to you. Monitoring exams use multiple tests and procedures to access how the events of 9/11 and its aftermath may still be affecting your health. Visits are detailed and include:

### Questionnaires

A **physical health** questionnaire reviews any symptoms you may have experienced, such shortness of breath, recurrent heartburn, or headaches. Similarly, a **mental health** questionnaire can help identify changes in your sleep, mood, or feelings of anxiety. Questionnaires help flag any new concerns or identify those that my have worsened since your last visit.

#### **Testing**

A **vital signs assessment** will record your pulse, temperature, or blood pressure to provide a snapshot of your overall health.

**Spirometry** measures how well your lungs are working. Many people who were in the dust cloud after 9/11 may now experience difficulty breathing.

**Blood and urine analyses** look for internal changes in your body, such as measuring your liver function, kidney health, or your blood counts.

A **chest x-ray** offers an important look of your lung function.

# Meetings with clinicians and other support specialists

With each monitoring exam, you will meet with a team of highly qualified physicians, nurses, and counselors who are experts in recognizing and treating 9/11-related illnesses and injuries.

During an exit interview you will receive any follow up information you need.

A benefits counselor will also help connect you to other resources and programs for which you may be qualified.

In addition to benefitting you, monitoring exams help others. Trends seen in monitoring exams can identify health conditions that other members may have and point to ways to protect populations during future disasters.

Call your Clinical Center of Excellence to schedule your free and confidential monitoring exam. If you have questions or need to find out which location to go to, please call the WTC Health Program at 1-888-982-4748.

## **Program Update**

## Mail Service Pharmacy Option for WTC Health Program Members

Want an easier way to refill your prescriptions? Walgreens now offers the WTC Mail Service Pharmacy with free shipping. Mail service delivers a 90 day supply of your medication to a location of your choice.

Visit www.walgreens.com/wtc or call 1-866-525-1590 for more information.

#### **Privacy Statement Now Available Online**

The WTC Health Program has published updated privacy guidelines. We ask all members to read the new privacy information online. Click on the WTC Health Program—Notice of Privacy Practices link at www.cdc.gov/wtc/policies.html.

If you have any questions, please contact the Program at 1-888-982-4748.

# New York State Workers' Compensation Board (WCB) Registry (WTC 12) Reopens

New York Governor Andrew Cuomo signed legislation late last year that extends and enhances workers' compensation eligibility benefits for World Trade Center workers. This new law:

- Reopens the registration for filing Form WTC-12 until September 11, 2014 for newly covered workers;
- Previously submitted registration claims will be reviewed and reconsidered by the Workers Compensation Board; and
- Adds qualifying conditions to the law.

Filing a WTC-12 form preserves workers' compensation rights for those who performed rescue, recovery, and cleanup operations after the World Trade Center attacks.

The law may also affect the classification of a WTC-related disability retirement benefit.

For more information, contact your retirement system or visit www.wcb.ny.gov/content/main/SubjectNos/sn046\_651.jsp.

## A SURVIVOR'S STORY

# STUDYING FOR MORE THAN AN EXAM

A thesis assignment helps to solve a healthy mystery.

"If you were in the affected areas after 9/11, get yourself to this program. It's really important."

For Lainie Kitt, a 9/11 community activist, this advice is personal. The WTC Health Program helped her regain her health following 9/11.

On that day, Lainie was working in lower Manhattan. "I was discussing my day with my co-worker when I heard this crazy loud explosion." The first plane had just struck the North Tower, only blocks from her office.

After 9/11, Lainie's office was closed for 4 years because of pollution. Yet just a week after the attacks, she was back at work, relocated to a building only two blocks away. Lainie explains that she's "never been out of [the] contaminated area."

### **A Slow Recovery**

Lainie's symptoms began 6 months after 9/11.

"My breathing was kind of labored. Loud noises, back firing of trucks, I would just jump. I wouldn't go on the subway."

During this time, Lainie was working, taking classes at the National Labor College, and writing a thesis. Her symptoms made it difficult to keep up with her demanding schedule. She sought medical help, but her regular doctors were at a loss. She now believes that for 9/11 survivors "ordinary doctors are not equipped to handle us. They're just not."

Lainie found a solution when doing research for her bachelor's thesis. She learned of a health monitoring program that helped those who lived or worked near the WTC site. Soon her academic interest became personal.

Lainie enrolled in the WTC Health Program, and found answers to her own 9/11 health problems. At the Bellevue Clinical Center of Excellence, she received a medical exam that checked her breathing, her digestion, and her emotional well-being. The "work-up was incredible," she



explains. "My own doctors didn't do anything like this."

Lainie was eventually diagnosed with asthma, GERD, post-traumatic stress disorder, and anxiety—conditions common to 9/11 survivors. The doctors at Bellevue have seen thousands of patients like Lainie and knew she was at risk. They were able to identify and treat her conditions. Today Lainie feels better.

Now, Lainie wants to ensure that others benefit from the WTC Health Program. "I'll take you there. I'll sign you up. I'll tell you what to do," she says with the passion of an advocate. "... But you've got to get the help, because this is not going to go away."

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.

## CANCER AND THE WTC HEALTH PROGRAM

## WHAT YOU NEED TO KNOW

WTC Health Program now covers cancer screenings. Learn what this change means for you.

# • What types of cancer screening are available through the WTC Health Program?

The WTC Health Program provides screenings and treatment for health conditions, now including colon and breast cancer related to 9/11. These screening tests may be available as a part of the health monitoring exam if certain requirements are met.

# What are the benefits of cancer screening?

Screening tests look for cancer before you feel symptoms from the disease. Screening allows for earlier treatment, which may slow or even stop the cancer from progressing.

# How does the WTC Health Program decide to screen for cancer?

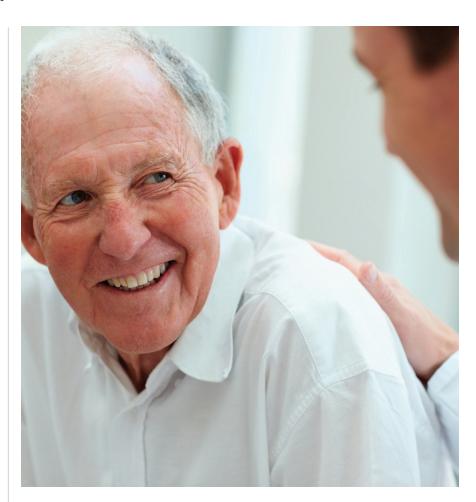
The WTC Health Program follows government screening guidelines set by experts who make recommendations about cancer screening and care.

# How often can I receive screening tests?

It depends on the test. Colon cancer screening is recommended to begin at age of 50 and continue through age 75. Women between the ages of 40 and 74 may receive a digital mammogram once every other year. The WTC Health Program may cover earlier or more frequent screening if you have a family history, a previous cancer diagnosis, or a condition that suggests a higher risk for breast or colon cancer.

# What is the risk from cancer screening?

Some procedures used to screen for cancer do present minimal risk, but for



most people the benefits of screening outweigh the potential risk. Talk to your doctor if you are concerned or have any questions about the procedures.

# What happens if I receive a positive result?

Your doctor will explain what the positive result may mean for future testing and possible treatment. The Program will cover additional screenings if you receive a positive result. The Program will also cover your treatment if the cancer is determined to be related to your 9/11 exposures.

# What happens if I receive a negative result?

Your doctor will explain what the negative result means in more detail. The Program will cover future screening as recommended by the government-screening guidelines.

# Can I still be screened through my personal physician who is not a part of the WTC Health Program?

You may choose to have cancer screening through your private physician. However, the WTC Health Program can only pay for care provided through the Program.

## A RESPONDER'S STORY

# "I HAVE ALL MY BASES COVERED"

An NYPD officer tackles cancer with added help from the WTC Health Program.

For the first few years after 9/11, Reggie Hillarie considered himself "one of the lucky ones."

As a young officer in the New York City Police Department, Reggie worked 6 months in the affected area, although he says, "Because I was a rookie I was only at the Trade Center for 11 days." After that, he worked to secure the site and manage the crowds that gathered nearby.

Reggie was then transferred to the Staten Island landfill to sort debris from the WTC site. He worked from October 2001 to July 2002 combing through dusty piles of rubble looking for remains.

"We were looking for anything—trying our best to help families find closure."

It took Reggie months after his work was complete to grasp what he experienced. Still, he felt lucky. He escaped major injuries. He was healthy and could look forward to his future.

#### A Lump in His Throat

In 2005, just a month after his first child was born, Reggie began feeling ill. Not wanting to expose his young son to what he thought was the flu, he went to see his family physician. As he left for the appointment, his wife reminded him, "Be

sure to ask your doctor about that lump!"

"That lump" turned out to be papillary thyroid cancer. Reggie was 34 years old. He had no family history of thyroid cancer. "I worked out. I was in great shape," he recalls. "I was one of the healthiest people in my family."

Surgery and radiation put his cancer into remission, but Reggie had little time to savor this milestone. Just a year later he was diagnosed with multiple myeloma, a blood cancer. Today this cancer remains stable, but he knows that will change. "Eventually," he explains, "it will get worse, but now it's stable."

### **Covering His Bases**

The WTC Health Program did not cover treatment for cancer at the time Reggie was diagnosed, but today he knows that "I have all my bases covered." Reggie has good insurance through his employer, but now his family won't have to face burdensome co-payments or prescription costs because he is a member of the WTC Health Program.

"When I got that letter that I was certified it was this great sense of relief . . . a big burden was lifted off our shoulders."

Today Reggie describes himself as

"grateful" for his family, his health, and the care he has received. He knows not to take signs and symptoms for granted, so he seeks every resource to stay

well. He wants to be there for his family. "It's not just about you," he explains when talking about his wife and now two kids. "It's about them."

He hopes his story will inspire other responders to "get checked."

"Be proactive about your life," he urges. "We have so many resources. There's no excuse." ●

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### **New Cancers Now Covered**

Members of the WTC Health Program may now seek coverage for several new types of cancers.

The Administrator recently announced a rule which revised how the Program defines rare cancers. As the result of this change, four specific cancers are now eligible under the revised definition of rare cancer for certification as WTC-related health conditions: malignant neoplasms of the brain, cervix uteri (invasive cervical cancer), pancreas, and testis. This rule also clarified the definition of childhood cancer to any cancer diagnosed in a

person under the age of 20 years old. This rule change went into effect on February 18, 2014.

These changes follow an expansion of cancer coverage late last year when the Administrator added malignant neoplasm of the prostate (prostate cancer) to the list of covered conditions. The rule which added prostate cancer went into effect on October 21, 2013.

More information about cancer coverage can be found online at www.cdc.gov/wtc/cancerresources.html.

## **PROGRAM NOTES**

## **NEW TESTIMONIALS NOW ONLINE**

Powerful new videos encourage those who qualify to seek care through the WTC Health Program.

The WTC Health Program has helped thousands regain their health following 9/11. This year the Program launched a media campaign to make sure that those individuals who may qualify for care, but are not yet enrolled, get the help they need and deserve. The campaign features videos of members telling their stories. Both responders and survivors describe how their quality of life has dramatically improved through the care they received through the WTC Health Program. Those featured include:

- Glenn, whose doctors caught his throat cancer early and helped treat his post-traumatic stress disorder;
- John, who can walk again without a limp after losing half his foot working at Ground Zero; and
- Lillian, whose children got care for their severe asthma triggered after 9/11.

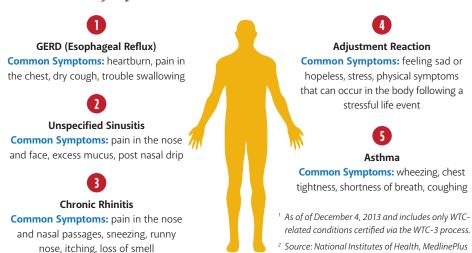
You can view these and other powerful testimonials at the WTC Health Program's website: www.cdc.gov/wtc/memberstories.

Were you moved by what you saw? If so, please share the videos to help us reach those individuals who may need care. •

## **PROGRAM NOTES**

# THE 5 MOST COMMON DIAGNOSES IN THE WTC HEALTH PROGRAM

The following are the most common certified conditions among WTC Health Program members<sup>1</sup> and their most common symptoms.<sup>2</sup>



#### VCF

## Update on the Victim Compensation Fund (VCF)

The VCF provides compensation for individuals (or representative of a deceased individual) who suffered physical harm or were killed as a result of the terrorist-related aircraft crashes of September 11, 2001, or the debris removal efforts that took place in the immediate aftermath of those crashes. It serves first responders as well as individuals who lived, worked, or volunteered in the areas near the WTC site. It also serves first responders at the Pentagon site and the Shanksville, Pennsylvania crash site.

In general, claimants who were diagnosed with a 9/11-related condition on or before October 3, 2011, needed to register by October 3, 2013. Those who are diagnosed *after* October 3, 2011, must register within two (2) years from the date of the diagnosis.

Special Note for Cancer: If you were diagnosed with one of the covered cancers on or before October 12, 2012, you must file a Registration Form by October 12, 2014. Those diagnosed with a covered cancer after October 12, 2012, must file a Registration Form within two (2) years of the date of their diagnosis. Prostate cancer was added to the list of covered cancers effective October 21, 2013, so those diagnosed before October 21, 2013, have until October 21, 2015, to register.

All claim forms must be filed by October 3, 2016. To learn more, go to www.vcf.gov or call 1-855-885-1555.

Note: The WTC Health Program is a separate program from the VCF, but as a WTC Health Program member, you may be eliqible for VCF benefits.

The WTC Health Program does NOT have any application deadlines.

## **PROGRAM NOTES**

# WTC HEALTH PROGRAM STAFF: WORKING FOR YOU!

Kecia Leatherwood offers tips on how to get the most out of your Program services.

Kecia Leatherwood is a member services specialist with the WTC Health Program. Kecia provides assistance when members have questions about their benefits or eligibility. Here is a glimpse of how Kecia and her team can help you.

# How does Member Services help people in the WTC Health Program?

We are involved with many different things to help current or potential members. We send out applications when requested. We answer questions that are sent to the Program's main e-mail address (wtc@cdc.gov). And when needed, we help people with their applications. For example, if we receive an application and it is incomplete, we contact the member to explain what is needed to complete the application. We also are the team that works with members when they have questions about benefits or transferring clinical centers.

### How can members talk to someone in the WTC Health Program if they have a concern?

We always encourage that members attempt to work out any concerns with their Clinical Center. However, if they feel that they need to speak to someone in the Program, they may contact the call center (1-888-982-4748) and ask to speak to me or someone from member services.

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

Yes! Here are my top five tips.

- **Review the Program website** to learn about the Program's benefits, as well as members' rights and responsibilities.
- **Prepare a list of concerns** when you go in for an appointment.
- Be willing to ask questions if you do not understand something your provider tells you.

Inform your medical provider of any symptoms that you have in order to help the provider determine if they are related to your 9/11 exposures.

**5 Bring your medical records** and any workers' compensation or line-of-duty injury paperwork with you to your appointment.

### What do you like best about your job?

Because I am not at a Clinical Center and I do not have the opportunity to work directly with members, I really like it when I have a chance to interact with members. It is one thing to be part of implementing the Program, and an entirely different experience when you actually have a chance to talk to someone who is receiving care through the Program.

## Member Services Handbook Available Soon

Have more questions? Member services handbooks will be available online in 2014 for both the NY/NJ Clinical Centers of Excellence and the Nationwide Provider Network. Handbooks offer detailed information about WTC Health Program benefits and policies.

### You'll find information about topics such as:

- When can I get my monitoring exam?
- How do I get a condition certified for treatment in the Program?
- How do I get prescription drugs?

- What happens when I need to change my Clinical Center of Excellence or move out of state?
- How does the Program handle privacy issues?
- Where do I go if I have a problem or a complaint?
- What are my rights and responsibilities?

Continue to check the WTC Health Program website for the release of the member handbook. All members are encouraged to download and review the member handbook when it is available. The handbook will be available at www.cdc.gov/wtc/memberhandbook.

# PROGRAM INFORMATION FIND A CLINICAL CENTER

The WTC Health Program has several Clinical Centers of Excellence for responders and survivors in the New York City metropolitan area and New Jersey. Some clinics have multiple locations for greater convenience and many can communicate in Spanish, Polish, or Chinese. For a more detailed list, including a Clinic Center 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: 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 Garden City

#### **RUTGERS UNIVERSITY**

Robert Wood Johnson Medical School Environmental & Occupational Health Sciences Institute

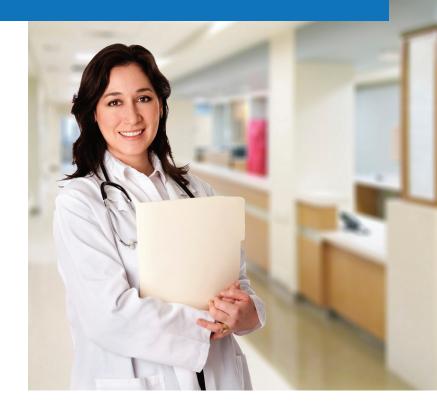
Telephone: 848-445-0123 *Location: Piscataway* 

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

For more information about the FDNY program or locations, please call the FDNY Bureau of Health Services at 718-999-1858 or visit the FDNY

Website: www.nyc.gov/html/fdny/insider/bhs/wtchp/index.shtml Locations: Brooklyn, Staten Island, Bayside, Brentwood,

Middletown, and Manhattan



#### **Survivor Clinical Center of Excellence**

# NYC HEALTH AND HOSPITALS CORPORATION (HHC) WTC ENVIRONMENTAL HEALTH CENTER

Telephone: 877-982-0107

Locations: Bellevue Hospital, Gouverneur Healthcare Services,

and Elmhurst Hospital Center

#### **Nationwide Provider Network**

Not in the New York City Metropolitan Area? The Nationwide Provider Program (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 health care 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 more information, please call visit the Program's website at www.cdc.gov/wtc/faq.html#mmtreat or call 1-888-982-4748.

For information about the Nationwide Provider Network call 1-888-982-4748.





## **World Trade Center Health Program**

Patriots Plaza I 395 E Street SW, Suite 9200 Mailstop P09 Washington, DC 20201

This Program is administered by the National Institute for Occupational Safety and Health.

## Recruitment

#### Can You Help?

Thousands of people may qualify for benefits under the WTC Health Program, but are not yet enrolled. Help inform your friends, neighbors, and colleagues that they may be eligible for important medical benefits. The Program serves the following groups:

- Fire Department of New York City members
- Other New York City responders (police, workers, volunteers)
- Survivors (people who were present on 9/11 or who lived, worked, visited, or went to school or daycare in the New York City disaster area)
- Responders from the Pentagon and Shanksville, PA

If you know someone in one of these groups, encourage them to visit www.cdc.gov/wtc and click the *Find Out How to Apply* button or call the WTC Health Program toll free 1-888-982-4748.

#### **Contact the Program**

For more information about the WTC Health Program call: 1-888-982-4748

Or you can visit the Program's website at: www.cdc.gov/wtc



**WORLD TRADE CENTER** 

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