

To Serve 9/11 Responders & Survivors

9.11



Shanksville



New York City



Pentagon

ADMINISTRATOR'S LETTER

THE WTC HEALTH PROGRAM IS MORE THAN JUST GREAT MEDICINE

Though the September 11th attacks occurred over a decade ago, many responders and survivors continue to experience physical and mental health symptoms as a result of their experience. Eligible individuals may not recognize that certain cancers, a chronic cough, difficulty sleeping, or frequent heartburn could be a 9/11 related condition. The WTC Health Program can identify these and other symptoms through regular monitoring. The first step in getting expert medical care is to know where and how to receive it.

The WTC Health Program strives to enroll new members and help current members understand their benefits. Community engagement efforts—from public campaigns to personal discussions—are critical to the success of our Program.

Spreading the Word

In 2012, outreach workers from the WTC Health Program's Clinical Centers of Excellence sponsored booths at local fairs, marched in parades, and developed public service announcements at sporting events. In addition to these community efforts, clinic staff have had countless in-person information sessions with firefighters, police officers, construction workers, trade unions, survivor groups, and other local organizations. The clinics' outreach teams succeed because they immerse themselves within the communities they serve.

In addition to the clinics' activities, the WTC Health Program has partnered with

eight community and union organizations to expand recruitment and education activities. These cooperative agreement partners have impressive achievements supporting responders and survivors, low income populations, and other groups who may benefit from the WTC Health Program. Our new partners began activities late in 2012 and we look forward to the contributions they will make during the next two years.

The most important endorsement of the WTC Health Program comes from you. If you know of a friend, colleague, or family member who may be eligible for the WTC Health Program, please help spread the word. **Ask them to call the WTC Health Program at 1-888-982-4748 or to visit our website at www.cdc.gov/wtc to download an application.**

The commitment of our clinics, partners, and members helps ensure the vitality of the WTC Health Program. Thank you for your support helping current and eligible members receive the care they need and deserve. ●

JOHN HOWARD, M.D.

Administrator,

World Trade Center Health Program



Pentagon photo courtesy of FEMA. Shanksville photo by vlashton, courtesy of Flickr.

Program Update

Enrollment Now Open for Pentagon and Shanksville Responders

Pentagon and Shanksville, PA responders are now eligible for benefits through the WTC Health Program. This change went into effect on May 1, 2013. For more information about the Pentagon and Shanksville, PA enrollment, please visit the Program's website at www.cdc.gov/wtc/pentagon.html.

Cancer Added to the WTC Health Program

The WTC Health Program published the addition of certain cancers to the list of covered conditions on September 12, 2012. Over 20 categories of cancers were added, greatly expanding needed services to our members. To see the full list and to learn more about cancer and the WTC Health Program, please visit the Program's website at www.cdc.gov/wtc/faq.html.

New Exposure Added for Breast Cancer Diagnosis

On April 17, 2013, the Administrator of the WTC Health Program announced new criteria for breast cancer coverage. Breast cancer was added to the Program in September; however this coverage only applied to those who experienced nighttime sleep disruption as a result of response and clean-up activities. Since that time, newly published scientific literature points to limited evidence that polychlorinated biphenyl, commonly known as PCBs, may increase the risk for breast cancer. PCBs were found in the dust at the World Trade Center site. Now eligible responders and survivors may be certified for the treatment of breast cancer if they've experienced nighttime sleep disruption from response or clean-up activities or PCB exposure resulting from the 9/11 terrorist attacks.

For more information about these program updates, please visit www.cdc.gov/wtc/faq.html or call 1-888-982-4748.

A SURVIVOR'S STORY

A FAMILY AFFAIR

Lillian Bermudez and two of her four children find asthma relief through the WTC Health Program.

Today Lillian Bermudez is a dedicated advocate for 9/11 survivors and their families. In 2001, she was a mother desperately trying to help her son breathe.

On September 11, 2001, Lillian and her family lived just a short walk from the Williamsburg Bridge. Lillian remembers the days following the terrorist attacks as being surreal—and steamy.

"Even though it was September, it was so hot that I had my windows open," she explains.

Without air conditioning, the heat inside her home was overwhelming. Still, she sensed something wasn't right with the air outside in the weeks following the attacks.

"You could see the dust and smell the debris... The air was moving."

Just one month later, her once healthy 12-year old son Mitch became ill. At first Lillian thought he had a cold, but after three days she suspected his symptoms were more serious.

"He was saying that his chest hurt and he couldn't breathe."

She became worried enough to bring Mitch to the emergency room. Soon after arrival he was rushed to the intensive care unit (ICU).

"I thought why are they taking him so fast? What's going on?"

Mitch spent three more days in the ICU as staff tried to open his lungs and stabilize his breathing. Lillian makes a heavy sigh as she recalls doctors explaining that Mitch had an asthma attack—one that could have killed him if she hadn't acted when she did.

Once released from the ICU, Mitch needed another five days in the hospital before he was well enough to go home.

Grateful that her son had stabilized, Lillian was still perplexed by his diagnosis.



No one in her family had ever had asthma before. She recalls a hospital social worker asking about smoking or other asthma triggers, none of which were in Lillian's home. People dismissed her idea that Mitch's asthma was related to the 9/11 attacks because the extent of the pollution was not yet fully known.

Months after Mitch first developed symptoms, Lillian's 9-year old daughter Amanda also developed asthma. It took years and several more hospital visits to manage the disease. With her concern firmly focused on her family, Lillian almost didn't notice her own shortness of breath.

"I felt a tightness, but I was more concerned for them."

Discovering Bellevue

For nearly six years, a local primary care doctor treated the family's asthma, but Lillian couldn't shake the suspicion that her children's sudden sickness was caused by the terrorist attacks. She began attending survivor meetings to learn what she could about 9/11 health effects. It was at one of these meetings where she met Bellevue doctor Joan Reibman, now Medical Director of the WTC Environmental Health Center. Dr. Reibman heard Lillian's story and encouraged her to visit their clinic.

"To this day I feel that my children are healthy because of Bellevue," explains Lillian. "They did a very thorough examination."

Mitch met with a psychologist, a medical specialist, and had extensive breathing tests. Doctors confirmed what Lillian had suspected all along: Mitch's severe asthma was likely related to pollution following the 9/11 attacks. Later Amanda and Lillian also enrolled in the Program.

Bellevue staff also "figured out what kind of medicine they needed, the right doses," and helped teach the family how to use the nebulizer, which improved their breathing. Lillian appreciates how "helpful, understanding, and patient" Bellevue employees were with her children and how supportive they've been of their care. Lillian reports that the Program contacts her regularly, helps track their progress, and reminds her when they are due for check-ups.

Lillian and her family still see their primary care doctor for routine needs,

"To this day I feel that my children are healthy because of Bellevue. They did a very thorough examination." — Bermudez

but they remain committed to the WTC Health Program for their 9/11 related care.

"They are experts on what's going on. [Dr. Reibman] knows what she's looking for... if something new is going on, she will find it."

Mitch and Amanda, now 22 and 19, are doing well. Regular medical care has effectively controlled their asthma. Lillian too reports that her breathing is better. She now only uses an inhaler as needed.

That hasn't stopped her from speaking out, however. Lillian remains an active speaker and educator about survivors' health issues, motivated by the children

she sees in her community with breathing problems.

"Because my kids got sick from 9/11 I know there are other people who got sick... I know that there are other people who are sick and don't know if it's from 9/11." ●

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 Van Orman at bse8@cdc.gov.

Asthma Fast Facts

- **What is asthma?** Asthma is a disease of the lungs that can make it difficult to breathe.
- **What are symptoms of asthma?** During an asthma attack, people may have coughing, wheezing, pain, or tightness of the chest.
- **What triggers an asthma attack?** Many things can trigger an asthma attack including: mold and dander, workplace exposures (like workplace dust and fumes); exercise, tobacco, and outdoor pollution.
- **What does asthma have to do with 9/11?** 9/11 related asthma is one of the top five conditions treated by the WTC Health Program and is often associated with other 9/11 conditions such as post-traumatic stress disorder (PTSD), gastroesophageal reflux disease (GERD), and other sinus problems.
- **What should I do if I think I have asthma?** All patients with a history of WTC exposures experiencing symptoms should be seen in the WTC Health Program for a complete medical evaluation and, if necessary, treatment.



In the News

Victim Compensation Fund (VCF) Information

The VCF provides compensation for any individual (or a personal representative of a deceased individual) who suffered physical harm or illness, or was 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.



To meet the VCF's filing deadline, you must complete and submit a registration within two years of when you first knew or should have known that you were injured as a result of September 11. **If you first learned of your injury before October 3, 2011, the deadline for submitting an application is October 3, 2013.**

For individuals diagnosed with a covered cancer before October 12, 2012, the deadline for applying to the VCF is October 12, 2014. **More information about VCF deadlines can be found at: www.vcf.gov/faq.html#gen4**



For more information, including how to apply, please visit the VCF website at www.vcf.gov.

Note: The WTC Health Program is a separate program from the VCF. This notice of the VCF application deadline is included in this newsletter because as a WTC Health Program member you may be eligible for VCF benefits.

A RESPONDER'S STORY

HEALING MIND AND BODY

Glenn Garamella experiences the WTC Health Program from a different point of view.

When it came to his own health, Glenn Garamella, like many caretakers, put others first.

As the Director of Special Programs at the Employee Relations Section for the New York City Police Department (NYPD), he's supported hundreds of officers and their families through bereavement, substance abuse, and treatment for post-traumatic stress disorder.

Glenn also knew about the WTC Health Program, having referred thousands of first responders for annual monitoring visits and for the treatment of 9/11 related diseases.

"I was doing the monitoring visits once and awhile. But I never really had time to do the follow-ups that I was sending my staff to do," he explains. "I was always swamped with work. I figured I'm fine. It's not a big deal."

After 25 years, Glenn retired from the NYPD but continued to work for a non-profit that supports police officers. As in his previous career, Glenn constantly met with officers and their families. He made referrals and gave talks—lots of them. In many ways Glenn's job was his voice.

It was during this time—nearly a decade after the 9/11 terrorist attacks—that nagging symptoms started to affect him. Glenn describes feeling tired all the time and not having the energy to play ball with his son. He had difficulty breathing and experienced coughing fits that wouldn't go away.

And in cruel irony for a man who talked for a living, he started to lose his voice. What began as recurring hoarseness soon developed into persistent laryngitis.

"I was never a crybaby when it came to pain but this was continuous and unrelenting, and it was progressively getting worse."

So in April 2011, he responded to his annual reminder call from Mount Sinai Medical Center and scheduled his belated monitoring exam. During his visit, Glenn's doctor surprised him.

"The doctor told me 'you know, you described these symptoms two years ago.'"

Shocked, Glenn reflected back and realized that his doctor was right. He had some shortness of breath and hoarseness, but explains "because it wasn't debilitating and I could still work, I didn't take it seriously."

At this point things were serious. Mount Sinai doctors ran a "gamut of tests." Eventually, he was diagnosed with asthma, sleep apnea, and throat cancer.



"The doctor told me 'you know, you described these symptoms two years ago.'" — Garamella

Mount Sinai doctors took the lead on treating Glenn's asthma and sleep apnea, and referred him to a hospital near his home for cancer treatment. (Glenn was diagnosed before cancer was added to the Program's list of covered conditions.)

Glenn had seven weeks of daily radiation sessions that left him unable to eat. Nausea, throat pain, and a liquid diet siphoned 25 pounds off his already lean frame. Glenn also opted for a modified

surgery to remove the cancer—a riskier option but one that doctors hoped would keep his vocal chords intact.

“I like to talk,” he jokes. “What can I say?”

Today Glenn’s voice is strong but retains a distinctive raspiness from his cancer ordeal. Despite his recent health challenges, Glenn says he feels blessed.

“I was lucky because they caught this early.”

“You are only doing half a job if you are just taking care of the body.”

Glenn caught his cancer early but other health issues had remained untreated for a long time.

The years leading up to his cancer diagnosis were marked by a change in his demeanor. Glenn describes being short tempered with this family. He was withdrawn and had lost a sense of “zest for life.” The mood changes, Glenn reported, were taking a toll on his family.

“They didn’t deserve my anger and mood swings that I was imposing my problems on them by not taking care of myself.”

Immersed in cancer treatment and unable to work, Glenn finally had the time to process the events of the last ten years. He had endured the loss of several family members and dear friends. And the memories of his 9/11 experience came into sharper focus.

“My job was taking care of families of police officers who died. A job I was proud to do,” he explains.

He was at the World Trade Center site caring for families of lost police officers for “two months, seven days a week, 15 hour days.” He was there when the first body was found. He saw both towers go down.

He eventually began to work with mental health specialists at Mount Sinai.

“It was easy to admit that I had cancer. It was really hard to admit that I had PTSD and depression,” he explains. “... I knew I was dealing with it for years I didn’t want to admit it.”

Since starting treatment, Glenn states that his “life has made a 180 degree turn for the better.” He reports that he’s been able to deal with painful things from his past, including his experiences during 9/11. And his relationships with his family—who were his biggest motivators—are stronger than ever before.

“I knew I couldn’t lead a happier life until I released these burdens.”

“It was easy to admit that I had cancer. It was really hard to admit that I had PTSD and depression. I knew I was dealing with it for years. I didn’t want to admit it.” – Garamella

Glenn recognizes, like many first responders, he was reluctant to take the time to address his physical and mental health needs. But he cautions other responders that, “you don’t have to wait for your symptoms to get bad,” before receiving care, “because it might be too late.”

Fortunately for Glenn it wasn’t too late. He credits his family and the Mount Sinai team, especially Garry Resnick and Dr. Michael Crane for supporting him through his healing. WTC Health Program staff, explains Glenn, “really have compassion and they understand what first responders have been through.”

“I was given a second chance through Mount Sinai. They literally saved my life.” ●

Each WTC Health Program member who provided a testimonial for this newsletter has signed a written consent form and waiver, which is on file with the Program. Any and all information provided during the interview, including any health infor-

Don’t Delay!

Putting Off Your Monitoring Exam?

Don’t delay! Yearly monitoring exams are an important part of your healthcare. A thorough exam can help find changes in your health that you might not be aware of and that may be corrected or slowed with early treatment. Regular exams also give tremendous peace of mind. They offer the chance to medical providers who are experts in 9/11 related healthcare.

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



mation, was done so solely for the purpose of WTC Health Program-related education and outreach efforts. At no time were the 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 Van Orman at bse8@cdc.gov.

CANCER AND THE WTC HEALTH PROGRAM

WHAT YOU NEED TO KNOW

Cancer was recently added to the Program's list of covered conditions. Learn what this change means for you.

I'm a member and I have one of the covered types of cancers, will I automatically get my treatment and medications covered under the Program?

By law all conditions, including cancer, have to be certified by the Program before you can receive treatment benefits.

How do I get certified?

Contact your Clinical Center of Excellence (CCE) and make an appointment with a CCE physician. Your physician must determine whether or not your cancer is one of the covered cancers and whether your exposures resulting from the September 11th, terrorist attacks are substantially likely to be a significant

factor in aggravating, contributing to, or causing the type of cancer for which you are seeking treatment coverage. If you do not know which CCE you are with, please contact the WTC Health Program at 1-888-982-4748.

Who makes the final decision?

The Administrator of the WTC Health Program reviews all WTC physician determinations and makes the final certification decision. Conditions are certified unless the Administrator decides that the condition is not a cancer covered by the Program or that the exposures resulting from the September 11th terrorist attacks are not a significant factor in aggravating, contributing to, or causing your condition.

I have one of the covered cancers and am certified to receive care from the Program, but I am already seeing a doctor for my cancer care. Can I still keep seeing my doctor?

All care paid for by the WTC Health Program must be provided by a health professional affiliated with the WTC Health Program through either a CCE or through the Nationwide Provider Network. If your current provider is affiliated with the WTC Health Program, then you will be able to continue seeing your doctor. If your current provider is not affiliated, ask the provider to contact your CCE or the Nationwide Provider Network to discuss becoming a WTC Health Program provider. ●

Updates to the WTC Health Program

The WTC Health Program has added the following types of cancers to the List of WTC-Related Health Conditions.

Malignant neoplasms of the following:

- Lip, tongue, salivary gland, floor of mouth, gum and other mouth, tonsil, oropharynx, hypopharynx, and other oral cavity and pharynx
- Nasopharynx
- Nose, nasal cavity, middle ear and accessory sinuses
- Larynx
- Esophagus
- Stomach
- Colon and rectum
- Liver and intrahepatic bile duct
- Retroperitoneum, peritoneum, omentum and mesentery
- Trachea; bronchus and lung; heart, mediastinum and pleura; and other ill-defined sites in the respiratory system and intrathoracic organs

- Soft tissues (sarcomas)
- Skin (melanoma and non-melanoma), including scrotal cancer
- Breast
- Ovary
- Urinary bladder
- Kidney
- Renal pelvis, ureter and other urinary organs
- Eye and orbit
- Thyroid
- Blood and lymphoid tissues (including, but not limited to, lymphoma, leukemia, and myeloma)

Other covered cancers include:

- Mesothelioma
- Childhood cancers
- Rare cancers

CONNECT WITH US

WWW.CDC.GOV/WTC OR CALL 1-888-982-4748

CLINIC LOCATIONS

FIND A CLINIC

The WTC Health Program has several clinic options 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 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

MOUNT SINAI SCHOOL OF MEDICINE

Selikoff Centers for Occupational Health

Telephone: 888-702-0630

Locations: Manhattan and Staten Island

NEW YORK UNIVERSITY

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, Garden City, and Brooklyn

UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY

Robert Wood Johnson Medical School Environmental and Occupational Health

Sciences Institute

Telephone: 848-445-0123

Locations: Piscataway and New Jersey

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/wtcmm

Locations: Brooklyn, Staten Island, Bayside, Brentwood, Middleton, 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

THE NATIONWIDE PROVIDER NETWORK INCREASES OPTIONS FOR CARE

- Love New York, but retiring in Florida?
- Live in Arizona but responded to the 9/11 terrorist attacks in New York City; the Pentagon; or Shanksville, PA?

Now you can receive benefits wherever you live in the U.S.

The Nationwide Provider Network provides medical monitoring and treatment for both responders and survivors who live outside of the New York City metropolitan area.

If you are eligible for the Program and you have a health condition related to the 9/11 terrorist attacks, you may be able to receive care near where you live. These services are provided by a nationwide network of healthcare providers coordinated by Logistics Health Incorporated (LHI) through a contract with the WTC Health Program.

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

Do you know someone who might be eligible for the WTC Health Program?

You can 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 *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

**HEALTH
PROGRAM** News

VOL. 2
SPRING 2013