



Shanksville



New York City



Pentagon

After the 9/11 Attacks **The World Trade Center Health Program** **and Disaster Response**

June 19, 2015

Training Objectives:

- 1) Identify patients who are eligible for care under the WTC Health Program
- 2) Identify exposure-related health risks associated with environmental exposures from the WTC site
- 3) Describe the lessons learned from the 9/11 disaster response

H.R.1786 – 114th Congress (2015-2016)

**JAMES ZADROGA 9/11 HEALTH AND
COMPENSATION REAUTHORIZATION ACT**

H.R.1786 – 114th Congress (2015-2016)

Short Title: James Zadroga 9/11 Health and Compensation Reauthorization Act

Introduced in the House: 4.14.2015

Sponsor: Rep. Maloney, Carolyn B. [D-NY-12]

Committees: House- Energy and Commerce; Budget; Judiciary

James Zadroga 9/11 Health and Compensation Reauthorization Act (Summary)

- Amends the Public Health Service Act to extend the World Trade Center (WTC) Health Program Fund indefinitely and index appropriations to the medical care component of the consumer price index for urban consumers. Makes funding available for:
 - a quality assurance program for services delivered by health care providers,
 - the WTC Program annual report,
 - WTC Health Program Steering Committees, and
 - contracts with Clinical Centers of Excellence.
- Amends the Air Transportation Safety and System Stabilization Act to make individuals (or relatives of deceased individuals) who were injured or killed in the rescue and recovery efforts after the aircraft crashes of September 11, 2001, eligible for compensation under the September 11th Victim Compensation Fund of 2001.

James Zadroga 9/11 Health and Compensation Reauthorization Act (Summary continued)

- Allows individuals to file claims for compensation under the September 11th Victim Compensation Fund of 2001 anytime after regulations are updated based on the James Zadroga 9/11 Health and Compensation Act of 2010.
- Removes the cap on payments under the September 11th Victim Compensation Fund of 2001.
- Adds the September 11th Victim Compensation Fund and World Trade Center Health Program Fund to the list of accounts that are not subject to budget sequestration.

The terrorist attacks on 9/11 at the World Trade Center (WTC), the Pentagon, and Shanksville, Pennsylvania, occurred more than 13 years ago, yet many of those affected by the disaster are still suffering from health effects today.

Clinicians, not only in these geographic locations but elsewhere in the country, may see patients who were exposed to toxins on that day or in the months that followed. Clinicians should be aware of the common health conditions that have been associated with hazardous 9/11 exposures and the benefits that may be available to their patients under the WTC Health Program.

In an effort to understand the hazardous exposures and health risks associated with 9/11, Medscape interviewed:

- 1) **Leigh R. Wilson, DO, MPH**, medical director, North Shore-Long Island Jewish Medical Center, Rego Park, New York
- 2) **Laurie I. Breyer, JD, MA**, with the WTC Health Program at the National Institute for Occupational Safety and Health (NIOSH) in Washington, DC.

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Can you tell us about the James Zadroga 9/11 Health and Compensation Act of 2010 (Act) and the WTC Health Program established under the Act?

MS. BREYER: The Act was signed into law by President Obama on January 2, 2011, and it was opened for participation on July 1, 2011. The law amended the Public Health Service Act, establishing the WTC Health Program, to be administered by the Department of Health and Human Services. This authority was delegated to NIOSH, a part of the Centers for Disease Control and Prevention.¹

MS. BREYER: The WTC Health Program allows for health screening and treatment of conditions that are determined to be WTC related. This means that a WTC Health Program physician has determined that it is substantially likely that the condition was caused, contributed to, or aggravated by the individual's 9/11 exposures. If the WTC Health Program physician believes the condition is WTC related, he or she will request certification (approval) from the Administrator of the WTC Health Program. The Administrator will either approve or deny the request based on information provided by the physician. If the condition is approved for certification, the member will be able to receive monitoring and treatment benefits for those conditions from the program.¹

MS. BREYER: The Act also reopened and modified the September 11th Victim Compensation Fund (VCF), initially operated from 2001 through 2004. The VCF is administered by the Department of Justice. The VCF provides monetary compensation to individuals as a result of a 9/11-related death, injury, or physical illness.¹

MS. BREYER: Before the passage of the Act, 9/11 responders were able to receive care through the WTC Medical Monitoring and Treatment Program. Nonresponders were able to receive care through the WTC Environmental Health Center's Community Program. When the Act was passed, the newly minted WTC Health Program worked closely with the previous programs to enroll eligible members into the new program and avoid interruptions in medical care. Current eligibility for the WTC Health Program is based on specific locations, defined as the disaster site(s), and the type and duration of activities conducted in the disaster site(s) during the time period starting on September 11, 2001, through July 31, 2002.

MS. BREYER:

These individuals include:

- Responders affiliated with the Fire Department, City of New York
- General responders: Those persons who worked at the disaster site(s) doing rescue, recovery, debris cleanup, or related support services for a specified amount of time from September 11, 2001, through July 31, 2002, below Canal Street in Lower Manhattan and/or at Ground Zero, the Staten Island landfill, or the barge-loading piers. Persons working with the Office of the Chief Medical Examiner, Port Authority Trans-Hudson Corporation tunnel workers, and vehicle maintenance workers are also covered under separate criteria.
- Survivors or community members: These include those caught in the debris, dust, or dust cloud on 9/11 and area workers, residents, students, and those in day care or adult day care in Lower Manhattan South of Houston St. or 1.5 miles from the WTC site into the northwest corner of Brooklyn. This group is referred to as "survivors" in the Act.
- Responders at the Pentagon disaster site in Arlington, Virginia, and at the plane crash site near Shanksville, Pennsylvania, are also eligible for the program if they meet the established eligibility criteria.

A full delineation of eligibility guidelines can be found at www.cdc.gov/wtc.²

When the Act initially passed, it covered certain health conditions in people who were at or near the disaster sites in NYC, Arlington, and Shanksville. Over time, the program has expanded the list of eligible health conditions based on emerging evidence from affected populations. Can you discuss this?

DR. WILSON: In the beginning, the program covered conditions that generally addressed direct irritant effects of the dust and some immune-mediated effects of the dust: sinusitis, rhinitis, asthma or exacerbation of preexisting lower airway disease, interstitial lung disease, and gastroesophageal reflux disease, as well as a number of other conditions.

DR. WILSON: In the early days, the bulk of the covered conditions were what the program refers to as aerodigestive disorders (airways and digestive), musculoskeletal disorders for responders, and mental health conditions. Over time, recognition that people were exposed to numerous known and probable carcinogens led to the addition of various types of cancer to the program. A list of all the conditions covered can be found on the website at www.cdc.gov/wtc.¹

When was cancer added, and why?

DR. WILSON: Recognition that people were exposed to numerous known and probable carcinogens enabled the program to provide diagnostic and treatment benefits for specific cancers. This recognition arose from comprehensive review of available scientific data, including 9/11 environmental sampling and authoritative reviews of research findings in humans and animal studies involving exposure to the identified substances. This provided sufficient evidence for the WTC Health Program Administrator to formally add numerous types of cancer to the list of covered conditions.

DR. WILSON: As new evidence emerged, the Administrator expanded the types of cancer covered, including those that had been originally excluded, such as pancreatic, prostate, and brain. Uterine cancer is one type that is not covered.³ With the addition of cancer coverage, the program incrementally added cancer screening benefits for colon, breast, cervix, and lung cancers. For this we are following the United States Preventive Services Task Force guidelines for tests that have an A or B grade recommendation. Certainly every cancer has its own latency period. The Administrator defined the latency period as the time elapsed from an individual's last day of qualifying 9/11 exposure to the date when the cancer is diagnosed.² The program began initial cancer coverage on October 12, 2012.³

How can you tell that 9/11 exposure was responsible for certain chronic diseases that were not diagnosed until years after 9/11 -- especially when the disease is prevalent in older populations?

DR. WILSON: We take an exposure and medical history that assesses the timing of the disease process and the timing and nature of the 9/11 exposures. For example, if an inflammatory aerodigestive condition first appears after 9/11, the program requires that the early symptoms emerge no later than 5 years after an individual's 9/11 exposure. The 5-year maximum time interval was chosen based on known pathophysiological changes associated with such diseases and factors used to set public policy. When such a condition existed before 9/11 exposure, we look for medical evidence that the 9/11 exposure aggravated the clinical course of the disease, such as an increase in severity of disease signaling a need to intensify treatment.

DR. WILSON: Exposure to 9/11 was also found to have co-occurring diseases involving upper and lower airways, gastroesophageal reflux, and disturbances in mental health. So, we also look for patterns of comorbidity when considering the impact of 9/11 exposure. For instance, gastroesophageal reflux must become manifest within 1 year after 9/11 exposure when it occurs by itself -- meaning that no airway disease is present. This type of evaluation should be performed by a physician with expertise in Occupational or Environmental Medicine.

Can you talk about the mental health needs of first responders, survivors, and those living around the WTC?

DR. WILSON: Absolutely. The entire 9/11 disaster was due to terrorism -- terrorism is a psychological assault all by itself, as no one was prepared for skyscrapers to collapse after intentional crashes of hijacked jets filled with jet fuel. These unprecedented events immediately caused massive death, destruction, and fear. Many aspects of society changed as a result of these events -- both locally and across the nation. For those surviving, many lives were ripped apart by loss, grief, and survivor guilt. For the people directly on-scene, the witnessing of sudden and dramatic death, injury, and dismemberment, and the sense of impending doom as the enormous dust cloud rushed through the streets, left many scars. Passions rose high, and risk communication was fragmented and faulty.

DR. WILSON: Many of those sickened never had any job training to deal with such hazards. People tried to clean up their homes, workplaces, and neighborhoods without adequate safety knowledge, and having to spend years fighting for scarce resources. Families felt helpless to protect their children, leading to developmental compromises and marital problems. The mental and behavioral health aspects of this disaster are complex and need ongoing attention, especially to engage in proper therapeutic regimens and adaptive lifestyle behaviors.

DR. WILSON: The program covers conditions including but not limited to posttraumatic stress disorder, anxiety disorder, depression, and substance abuse.¹ Those are among the most common mental health conditions that we are seeing, and blended approaches to care are extremely important. Many of the clinical centers have an on-site mental health professional who provides assessment, triage, and referral services to facilitate appropriate mental and behavioral health intervention. Cross-disciplinary case conferences and blended mental and physical health consultative services have been very successful in optimizing adherence to treatment regimens and improving health outcome.

***What does the WTC Health Program actually cover?
Are there specific eligibility criteria?***

DR. WILSON: The WTC Health Program provides members standardized medical monitoring, diagnostic evaluation, cancer screening, and treatment services for eligible conditions. Eligibility criteria revolve around the potential for hazardous exposure to the disaster sites in New York City, the Pentagon in Virginia, and the plane crash site near Shanksville, Pennsylvania. The WTC Health Program has a membership consisting of responders in all sites, and survivors from the NYC site, who comprise all those caught in the dust cloud on 9/11, who worked, lived, or went to school or day care in the area defined in the Act as the New York City Disaster Area from the date of the attack through July 31, 2002.¹

DR. WILSON: There are a few differences in benefits between the responder and survivor programs. Responders are entitled to monitoring regardless of whether they have any symptoms or are certified for any conditions. Additionally, the WTC Health Program is the primary payor of costs for responders. Survivors are only entitled to an initial health screening if they have a symptom they believe is related to a 9/11 condition. All responders and survivors who receive certification, or approval, for a diagnosed WTC-related health condition are offered annual medical monitoring and medically necessary treatment for the conditions that are certified by the WTC Health Program. Of note, survivors are required to use their own insurance as the primary payor for services, with the WTC Health Program covering co-pays and other costs not covered by their primary insurance -- to avoid "out-of-pocket" costs for these members.

DR. WILSON: To receive treatment benefits, a member must have their health condition certified by the WTC Health Program. This is a 2-part process, where we -- as the program physicians -- take a comprehensive exposure and medical history and make a formal determination that a diagnosed condition that is eligible for coverage meets the exposure criteria required by the WTC Health Program. This determination is then submitted for program review and approval. Members receive medically necessary care from program specialists for the conditions that are approved for coverage (ie, certified). Pharmacy benefits are included in the treatment benefits offered to members with certified health conditions.

Do survivors and responders have to go to particular doctors or clinics? If a member relocates their residence or is geographically mobile, how does the program provide ongoing care?

DR. WILSON: The Zadroga Act established both the Clinical Centers of Excellence (CCEs) and a Nationwide Provider Network (NPN). Eligible responders and survivors who live in the New York metropolitan area receive care at one of the CCEs. The CCE has been working with cohorts of members for a long period of time and are intimately familiar with the unique exposures, health concerns, and complex social benefit pathways associated with the 9/11 disasters. The law is written so that anyone could opt to go to one of the CCEs; however, travel expenses are generally not provided. Therefore, members living far from any of the CCEs opt to join the NPN, which then connects them with medical services close to their geographic location. CCE locations can be found online at <http://www.cdc.gov/wtc/clinics.html>.

MS. BREYER: Mobile populations and those living at a distance from the CCE are also offered program benefits through the NPN.² Logistics Health Incorporated currently manages the NPN for the WTC Health Program and provides an expert provider network with specialists in occupational medicine and all the medical disciplines, including psychiatry. Members assigned to the NPN may work with knowledgeable case managers to help them navigate their benefits and care needs; these case managers understand the unique exposures and health concerns of WTC responders and WTC survivors. The NPN also serves responders to the Pentagon and Shanksville, Pennsylvania, sites, as well as those responders and volunteers who traveled from across the country to assist in the rescue, recovery, and cleanup efforts at Ground Zero, the Pentagon, or the crash site at Shanksville, Pennsylvania, and then returned home after their response.

Can any provider participate in the WTC Health Program?

MS. BREYER: To participate as a provider in the WTC Health Program, a provider must be affiliated with a CCE and/or the NPN. Affiliation can be arranged by contacting a CCE or the NPN and setting up the appropriate business arrangements. The affiliation requires credentialing and formal agreements regarding service authorization, billing, reimbursement rates, and claims dispute resolution. Members are not expected to pay for any services rendered through the program, so providers should be cognizant of the service benefits and work with their CCE or NPN to ensure such understanding before services are rendered. Currently the NPN uses a large network of healthcare providers with a broad range of specialties, with provider availability across the country. Additional information about the WTC Health Program can be obtained by calling 1-888-982-4748 or emailing WTC@cdc.gov.

MS. BREYER: WTC Health Program benefits are only provided through the CCE or NPN and their respective provider networks. If a clinician is seeing patients outside of the New York City area - - say in Florida or Arizona -- who appear to have WTC-related conditions, it would be beneficial to provide that patient with information about the WTC Health Program. Program staff members can then help determine the best course of action for that patient, which might entail trying to add the patient's provider to the NPN or referring the patient to a clinician who is already part of the NPN.

What do you think are the lessons learned from 9/11 with regard to post-disaster health needs?

DR. WILSON: As an emergency is unfolding, it is difficult to address some issues when the focus is on the immediate rescue activities. Many first responders at the WTC site were much less concerned about their own personal health and more concerned about trying to recover any possible survivors.⁴ From the worker/responder perspective, this disaster highlighted serious problems with respect to the importance of worker safety and health, including proper training, needed equipment, lack of adequate exposure assessment (environmental sampling), inability to control site access, and inconsistent and inaccurate safety and risk guidance! From the community/survivor perspective, safety and risk guidance suffered from lack of adequate environmental data, consistency, and accuracy.

DR. WILSON: As a result of both the failures of the response and the nature of terrorism, multiple types and intensities of hazardous exposures were encountered, including physical, chemical, and psychological hazards. The resultant health effects have shown tremendous comorbidity between mental, behavioral, and physical health, which have significant and enduring clinical implications. Optimal disease control has required attention to these comorbidities. Many of our clinician-scientists have published on the differing trajectories of health over time in our disaster-exposed population. The comorbidities need more health services research to identify best practices and impacts of early intervention.

MS. BREYER: There are a number of important lessons learned:

- 1) It is important after a disaster like this that we ensure that all responders, including nontraditional responders involved in cleanup and recovery, are adequately trained and adequately equipped for disaster response activities;
- 2) There needs to be clear and immediate safety and risk communication with all who have been affected, including the responders, survivors, and community members;
- 3) We must identify, analyze, and monitor hazardous exposures in a timely manner in large-scale disaster events;
- 4) We must put remediation efforts into effect for populations surrounding an environmental disaster;
- 5) We must collect timely data on responder injuries and illnesses both during and after large-scale disaster events, including behavioral and mental health concerns;
- 6) We must identify and quantify the population at risk from hazardous exposure -- without this knowledge, follow-up study is scientifically challenged.⁴⁻⁹

If providers encounter patients who may be eligible for the program, what information or resources are available?

MS. BREYER: Providers should refer those patients to the WTC Health Program at 1-888-982-4748 or www.cdc.gov/wtc.

Additional Resources

[WTC Health Program](#)

[WTC Health Program: Frequently Asked Questions](#)

[Which Cancers Are Eligible for Coverage?](#)

[Eligibility Information and How to Apply to the WTC Health Program](#)

[WTC-Affiliated Clinics and the National Provider Network](#)

[NIOSH: Personal Protective Equipment](#)

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