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ONE HUNDRED FOURTEENTH CONGRESS
Congress of the United States
House of Representatives
COMMITTEE ON ENERGY AND COMMERCE
2125 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515-6115

Majority (202) 225-2927
Minority (202) 225-3641

MEMORANDUM

June 9, 2015

To: Subcommittee on Health Democratic Members and Staff

Fr: Committee on Energy and Commerce Democratic Staff

Re: Hearing on "Examining H.R. 1786, the James Zadroga 9/11 Health and Compensation Reauthorization Act"

On Thursday, June 11, 2015, at 10:15 am in 2322 Rayburn House Office Building, the Subcommittee on Health of the Committee on Energy and Commerce will hold a hearing entitled "Examining H.R. 1786, the James Zadroga 9/11 Health and Compensation Reauthorization Act."

I. BACKGROUND

A. September 11, 2001 Attack and Health Effects

The attack upon and collapse of the World Trade Center (WTC) buildings on September 11, 2001, exposed approximately 250,000–400,000 people in the surrounding areas to environmental hazards, such as asbestos, particulate matter, and smoke.[1] Based on data from the World Trade Center (WTC) Health Registry, approximately 90,000 responders from federal, state, and New York government agencies, private organizations, and volunteers helped in the rescue, recovery, and cleanup efforts following the attacks on the WTC. Additionally, approximately 435,000 community members were exposed to toxins polluting the WTC area following the attack.

As a direct result of the WTC attacks, these responders and community members face a variety of both physical and mental health problems. Physical health effects include respiratory ailments such as sinusitis, asthma, and WTC cough, which is persistent coughing accompanied

[1] U.S. Government Accountability Office (GAO), *HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders*, (July 2007) (pg. 7).

by severe respiratory problems, as well as skin, thyroid, and prostate cancers. Mental health problems include posttraumatic stress disorder and anxiety disorder.

B. Federal Funding and Spending Authorizations

In fall of 2001, Congress first appropriated funding to the Department of Health and Human Services (HHS) to screen responders for respiratory complaints. That grant program, run by the Centers for Disease Control and Prevention's (CDC) National Institute for Occupational Safety and Health (NIOSH), grew into the WTC Responder Medical Monitoring and Treatment Program and the WTC Environmental Health Program. From 2002 through much of 2011, these programs provided screening, monitoring, and treatment benefits for eligible responders, including firefighters, law enforcement officers, emergency responders, and for rescue, recovery, and cleanup workers affected by the WTC attack. Starting in 2008, survivors, comprised of residents, students, and others directly affected, were added to the programs.

Several sites of service for WTC responders and survivors in New York and New Jersey were funded through the WTC health programs. NIOSH also awarded grants to private and public entities to treat volunteers and responders living outside of New York City. In addition, the WTC Health Registry was created to track health data of those in the vicinity during and immediately after the attacks. The Registry, which enrolled more than 71,000 people between September 2003 and November 2004, continues to track those individuals as part of a longitudinal study to record and evaluate the long-term health effects of the WTC terrorist attack.

While short-term, discretionary funding has played an important role in monitoring and treating 9/11 survivors and responders, the WTC health programs have experienced difficulty ensuring the uninterrupted availability of services for responders and survivors. There have been instances where services were discontinued for months, and where responders living outside of the NYC metropolitan area have not been able to access funded health services in those communities.[2]

Serious concerns arose that urgently needed 9/11-related medical monitoring and treatment services could be discontinued without additional Federal support, in the form of a permanent program having dedicated long-term funding. As a result, the James Zadroga 9/11 Health and Compensation Act of 2010 (Zadroga Act) was signed into law on January 2, 2011.

II. JAMES ZADROGA 9/11 HEALTH AND COMPENSATION ACT OF 2010

A. Background

[2] See GAO, *Monitoring of World Trade Center Health Effects Has Progressed, but Program for Federal Responders Lags Behind*, (February 2007); GAO, *HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders*, (July 2007).

The Zadroga Act established, within HHS, the World Trade Center Health Program (the Program) and it reopened the September 11th Victims Compensation Fund (VCF) to address the September 11th health effects.

The WTC Health Program, which is administered by NIOSH, provides payments for medical monitoring, treatment and care of eligible responders and survivors who have been exposed to airborne toxins and other hazards. The Zadroga Act also supports outreach activities, uniform data collection, and research on WTC conditions.

B. WTC Health Program Authorization and Funding

The Zadroga Act authorized the WTC Health Program for five years, from FY 2011 to FY 2015. It allows for unexpended balances to be carried forward which, if available, could extend the Program through FY 2016. If the Program is not reauthorized by Congress, it will terminate in September 2016.

The Zadroga Act included mandatory funding for the Program, with an aggregate spending cap of $1.5 billion and a 10-percent matching requirement from New York City over the authorized period. Annual spending caps of $71 million (FY 2011), $318 million (FY 2012), $354 million (FY 2013), $382 million (FY 2014) and $431 million (FY 2015) were written into the Zadroga authorization. The Program also included caps on new enrollments of 25,000 each for those responders and survivors who were not enrolled in the previous grant programs prior to passage of the law.

C. Geographic and Medical Eligibility for Responders and Survivors

The Zadroga Act established geographic eligibility criteria for the WTC Health Program. These criteria applied to both new responders and survivors. Those who participated in the previous grant programs were grandfathered into the Program. Unlike the previous grant program, the law extended eligibility for the Program to responders to the Pentagon and Shanksville, Pennsylvania terrorist attacks.

The eligibility criteria are established for two major categories: responders and survivors. Responders include firefighters, law enforcement officers, emergency responders, and rescue, recovery, and cleanup workers who responded to the terrorist attacks at the WTC, Pentagon, or Shanksville, Pennsylvania site and meet certain time and place requirements. Responders also include a limited number of family members of firefighters who were killed at Ground Zero and received treatment for a mental health condition in relation to the WTC attack on or before September 1, 2008. Survivors include individuals present in the NYC disaster area on September 11, 2001, or who worked, resided, or attended school, childcare, or adult daycare in that area and meet certain time and place requirements. Responders are automatically eligible for medical monitoring without meeting any additional eligibility criteria. To receive treatment, however, responders must meet the medical eligibility requirement. Survivors are eligible for screening for a determination of whether the survivor has a WTC-related health condition.

The Zadroga Act established medical eligibility requirements. Notably, it included a list of WTC-related health conditions that are presumed to result from exposures to the WTC attack sites. The law further allows the Administrator of the Program to publish a rule to add health conditions to the existing list and it also provides that unlisted conditions can be covered if they are determined to be medically associated with a WTC-related health condition. The statutory list includes aerodigestive disorders (such as interstitial lung disease and cancer), mental health conditions ((such as posttraumatic stress disorder (PTSD)), and major depressive disorders, and musculoskeletal disorders for certain WTC responders. Although cancer was not included in the statutory list, 60 types of cancer were later added through regulation in 2012.

If a responder is determined to have a WTC-related health condition based on the medical monitoring received as the result of meeting the geographic eligibility test, that responder is eligible for medically necessary treatment under the Program. If a survivor meets the geographic eligibility test and is found to have a WTC-related health condition through the screening, the survivor is then eligible for follow-up monitoring and medically necessary treatment.

D. Clinical Centers of Excellence and a Nationwide Provider Network (NPN)

The Program provides monitoring, evaluation, and treatment services through a network of Clinical Centers of Excellence (Centers) and a Nationwide Provider Network (NPN). There are seven Centers located in the New York metropolitan area and they include: Fire Department of the City of New York; Health and Hospitals Corporation, WTC Environmental Health Center; Long Island Jewish Health System/Queens; New York University, Bellevue Hospital; State University of New York, Stony Brook; and Environmental and Occupational Health Sciences Institute, Robert Wood Johnson Medical School, Rutgers University. The Centers employ providers with specialized expertise in the diagnosis and treatment of WTC-related health conditions. Many responders and survivors rely on the expertise of those providers for the proper diagnosis and treatment of their WTC-related health conditions. The Centers also support outreach activities to enrollees and potential enrollees. The NPN includes a network to provide the Program benefits nationwide. Additionally, the Program includes data centers that support uniform data collection from the treatments provided to enrollees.

E. Program Coverage Requirements

The Program ensures that enrollees do not bear any of the financial costs related to conditions that resulted from their exposure to toxins as the result of the September 11, 2001 terrorist attacks. As of July 2014, the Program requires enrollees to maintain minimum essential coverage as defined by the Affordable Care Act. The Program acts as a secondary payor to workers' compensation (excluding any workers' compensation plan to which New York City contributes), private health insurance, Medicaid, or the Children's Health Insurance Program (CHIP). That means that the program pays any out-of-pocket costs not covered by an enrollees' other coverage for medical monitoring or treatment services for WTC-health related conditions. The WTC Health Program is a primary payor of costs of WTC-related health conditions for Medicare beneficiaries.

F. Research

The Zadroga Act also continued the grant program's focus on research. The Zadroga Act continued the WTC Health Registry that monitors the people exposed to the WTC terrorist attack. The Zadroga Act also requires NIOSH to continue to fund research into health conditions that may be related to the September 11, 2001 attacks as well as the diagnosis and treatment of such conditions.

In FY 2013, the Program funded six new research programs that addressed autoimmune health, cancer, respiratory health, and cross-cutting disease-related issues. This does not include existing research projects that were ongoing. Examples of those new projects include "Early Identification of World Trade Center Conditions" and "Prostate Cancer Risk and Outcome in WTC Respondents." Additionally, in FY 2013, 28 publications in scientific journals addressed the physical health effects, mental health issues, or both that resulted from exposures to WTC terrorist attack. While all of those publications did not result from the Program funded projects, some did.

G. The Scientific/Technical Advisory Committee (STAC)

The Zadroga Act also created several advisory committees to the WTC Health Program Administration. The Scientific/Technical Advisory Committee (STAC) was established to provide advice to the Program on the determining the eligibility requirement, to identify research needs for the Program, and to serve as a resource if needed for consultation on the determination of whether a condition should be added to the list of WTC-related health conditions. The Zadroga Act also created the Responder Steering Committee and the Survivor Steering Committee to provide advice on the implementation and improvement of the program.

H. Victims Compensation Fund (VCF)

The September 11th Victims Compensation Fund (VCF) was established after the September 11th attacks to compensate the families of those who lost loved ones in the attacks and individuals who suffered disabling injuries as the result of the attacks. It operated from 2001-2004. Title II of the Zadroga Act reopened the VCF for an additional five years. This hearing will not include an examination of this program.

III. ADDITION OF CANCER TO THE WTC HEALTH PROGRAM

As discussed above, cancer was not included in the statutory list of WTC-related health conditions. Instead, the Administrator was directed to periodically review all scientific and medical evidence to determine whether cancer should be added as a WTC-health related condition. Additionally, the Zadroga Act allows individuals to submit written petitions to add conditions to the list of WTC-related health conditions. In response to a petition, the Administrator is required to respond within 60 days in one of four ways: (1) request a recommendation of the STAC; (2) publish a proposed rule in the Federal Register to add the condition to the list of WTC-related health conditions; (3) publish in the Federal Register the Administrator's determination not to publish such a proposed rule and the basis for such

determination; or (4) publish in the Federal Register a determination that insufficient evidence exists to take action.

In 2012, 60 types of cancer were added in response to a petition submitted by Members of Congress.[3] Through regulation, the Administrator added those cancers after a determination that exposure to the September 11 attacks and their aftermath is "substantially likely to be a significant factor in aggravating, contributing to, or causing" the enrollee's condition. The Administrator reached this conclusion using a hazard-based, multiple-method approach which focuses on determining whether particularly hazards are associated with certain health conditions.[4] The Administrator continues to use this process in determining whether new conditions should be added to the list.

IV. SNAPSHOT OF THE WTC HEALTH PROGRAM

More than 71,000 responders and survivors are enrolled in the Program. Enrollees in the Program reside in every state across the country.[5] As of August 2014, a 9/11 Responder or Survivor resided in 429 of the 435 Congressional Districts.[6] More than 30,000 enrollees have at least one WTC-related health conditions, and over 3,600 have a certified cancer.[7]

Those WTC-related health conditions have resulted in disability and death and more is expected in the coming years. In fact, more New York City police officers have died as the result of the WTC-related health condition (at least 50) than died in the line of duty on September 11, 2001 (23).[8] More than 100 firefighters have reportedly lost their lives to WTC-related health conditions.[9] Additionally, more than 1500 active duty firefighters and EMS personnel and over 550 law enforcement officers were forced to retire due to WTC-related health conditions.[10]

V. H.R. 1786, THE JAMES ZADROGA 9/11 HEALTH AND COMPENSATION REAUTHORIZATION ACT

H.R. 1786, the James Zadroga 9/11 Health and Compensation Reauthorization Act (Reauthorization Act) would permanently reauthorize the Program. The Program is reauthorized at the amount of $431 million in FY 2015, and outlays in subsequent years would be indexed to

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[3] GAO, *Approach Used to Add Cancers to List of Covered Conditions Was Reasonable, but Could Be Improved* (July 2014).

[4] *Id.*

[5] World Trade Center Health Program, *WTC Health Program at a Glance* (May 11, 2015) (online at http://www.cdc.gov/wtc/ataglance.html).

[6] *Id.*

[7] *Id.*

[8] NYPD, *Memorial 9-11 Tribute* (2015) (online at http://www.nyc.gov/html/nypd/html/memorial/memorial_wtc.shtml).

[9] 9-11 Health Watch, *Help Remember All the Victims of 9/11* (April 16, 2015) (online at http://www.911healthwatch.org/help-remember-all-the-victims-of-911/).

[10] *Id.*

medical inflation. New York City would remain responsible for contributing 10 percent of the total Program costs permanently. The bill would exempt the Program from any sequester cuts. H.R. 1786 would also remove limits on the eligible number of responders and survivors existing in current law.

Additionally, the Reauthorization Act would make technical corrections to the law. The bill would clarify that funding for the Program can be used by the Administrator for several requirements already included in current law. These allowances include the quality assurance program for monitoring and treatment services under the Program, completion of the annual report to Congress, support of the steering committees, and contracts with the Centers. It would also explicitly authorize the Secretary to promulgate regulations for the Program. The bill would also clarify that the Centers would be contracted to provide activities to retain enrollees, and that Data Centers would be contracted to evaluate data on any newly identified WTC-related health conditions.

Further, the bill makes changes to the VCF. Committee jurisdiction on VCF-related matters resides under the House Judiciary Committee.

VI. WITNESSES

Panel One:

Dr. John Howard
Administrator
World Trade Center Health Program
Director
National Institute of Occupational Safety and Health

Panel Two:

Dr. Iris Udasin
Director of EOHSI Clinical Center & Employee Health
Robert Wood Johnson Medical School
Rutgers Biomedical and Health Sciences

David Howley
Retired, New York City Police Officer

Barbara Burnette
Retired, New York City Police Detective