

TESTIMONY

of

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before the

**U. S. House of Representatives
Appropriations Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies**

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Washington, D.C.**

Good morning. I thank Chairman Obey and Ranking Member Walsh for this opportunity and for their continued support. My name is Lorna Thorpe, Deputy Commissioner of the Division of Epidemiology at the New York City Department of Health and Mental Hygiene (DOHMH). Thank you for this opportunity to discuss the health impacts of the terrorist attacks on the World Trade Center on September 11, 2001.

The Department has been monitoring these effects since October 2001, when it conducted a community needs assessment and learned that 50 percent of the people living near the World Trade Center site said they had experienced physical health symptoms related to the attack, and 40 percent reported symptoms associated with post-traumatic stress disorder.

As the concerns about the health impact of 9/11 become clearer to us, so does the need for a national program to assure that all potentially affected individuals across our nation receive the treatment they deserve. The attack on September 11, 2001, was an attack upon our nation, and it requires a national response.

Immediately following 9/11, the City's DOHMH began planning, in collaboration with the U. S. Agency for Toxic Substances and Disease Registry (ATSDR), a registry to help us track and better understand the potential short- and long-term health effects of that event over the next 20 years. As part of this federally-funded project, experts at the NYC Health Department and the ATSDR used the best available methods to estimate the number of people most likely to have been exposed to the World Trade Center (WTC) attacks and their aftermath. While by no means including everyone, we estimated that this number could total more than 400,000 people, including approximately 91,000 rescue and recovery workers and 300,000 building occupants, residents and passersby. Of those, more than 71,000 people voluntarily enrolled in the World Trade Center Health Registry, making it the largest disaster-related health registry in U. S. history. They represent a wide variety of persons affected by the 9/11 attacks— responders, volunteers, residents, students, area workers, children, etc.

Enrollees from the Registry are from every state, nearly every Congressional District, and 15 countries. In fact, more than 20 percent of the enrollees lived outside New York State on September 11. Many of them represent volunteers who rushed to New York City in response to the attack on our country. It is our responsibility as a nation to help identify and address any 9/11-related health concerns that threaten any of those who were exposed to this national disaster.

There is much we still do not know about the long-term effects of 9/11, but initial findings, based on information from New York City's three WTC Centers of Excellence, the WTC Health Registry, and from other published scientific research, make a compelling case for stable and long-term funding to address the health effects of 9/11 and the collapse of the WTC towers.

It is important to note that in the absence of a national program, the New York City Department of Health already has joined with local WTC medical experts to publish clinical guidelines for adults and soon-to-be published pediatric guidelines. These guidelines can be used by physicians to provide effective treatment for individuals who were affected by the WTC disaster, including those who do not live in the NYC metropolitan area.

9/11 Health Effects:

I would like to highlight some key study findings regarding 9/11 health effects. Studies have shown that most people directly exposed to the intense dust cloud, and many exposed less directly, reported acute respiratory symptoms in the days and months after 9/11, including cough, sinus congestion, and shortness of breath. Monitoring suggests that these symptoms resolved for many workers, but that symptoms continue to persist for some. A report from the Fire Department of New York (FDNY) indicates that as many as one in four firefighters (25 percent) who responded to the disaster still reported some symptoms five years after the attacks.

Findings from the WTC Health Registry, using the largest assembled sample of rescue and recovery workers, showed that respondents reported 12 times the expected rate of new asthma diagnoses two to three years after the attacks. Those who arrived at the WTC site on 9/11 or 9/12 and those who worked longer than 90 days were at highest risk for new-onset asthma.

Parents enrolled more than 3,000 children who were under the age of 18 on 9/11 into the WTC Health Registry. While this sample is not necessarily representative of all children exposed, parents of enrolled children reported twice as much new-onset asthma among children under five after 9/11 than found on average in that age group in the northeastern U.S. In particular, levels of asthma increased with reported levels of exposure to the WTC dust cloud. Now, a thousand of these children have aged into adulthood, and as some of them, and also others, leave New York City, those exposed individuals, too, would be well served by access to a national WTC treatment program.

Although little is known about the longer-term physical health effects that may be associated with the WTC disaster, including cancers and mortality, one FDNY study indicated that there were more new cases of sarcoidosis, which causes inflammatory lesions in one or more organs, most commonly in the lungs, among NYC firefighters in comparison to pre-9/11 levels. More studies on this are needed to verify these results, and the WTC Health Registry and other WTC Centers of Excellence are currently investigating post-9/11 diagnoses of sarcoidosis, as well as cancer, among enrollees.

In terms of mental health, many people suffered psychological distress as a result of the WTC disaster. Symptoms of post-traumatic stress were common in the first six months after 9/11. While these symptoms faded for most people, for others they have not, and post-traumatic stress disorder (PTSD) has developed.

Findings from a sample of nearly 30,000 rescue workers in the WTC Health Registry, checked two to three years after 9/11, indicated that PTSD levels were approximately three times higher than the rate found in the general population. The highest rates were found among those who had no prior training in or experience with traumatic situations. This group included many volunteers who came from around the nation to assist in the rescue and recovery effort. The Registry also has documented signs of serious psychological distress among survivors of collapsed or damaged buildings. Particularly because so many businesses had to move after the attacks, it is reasonable to assume that a number of these individuals may have left the New York City area following the attacks because of this experience.

9/11 New York City Mayoral Initiative

I'd like to say a few words about the NYC 9/11 Mayoral Initiative. In 2006, Mayor Bloomberg appointed a special panel to assess the City's response to 9/11 and the current state of services.

This assessment occurred at a time when private funding for 9/11 services, particularly from the American Red Cross, was coming to an end. That funding, which provided the first treatment for rescue workers and a small number of NYC residents at Bellevue Hospital, will be completely exhausted by June 2008.

Thanks in large part to the work done by this committee, the federal government has since appropriated funds to treat rescue workers through the WTC Medical Monitoring Program at FDNY and Mount Sinai, the future of this funding was highly uncertain as the panel began its assessment.

The panel identified two very specific service gaps:

- Treatment for lower Manhattan residents, area workers and students who were seeking privately-funded care in greater numbers at Bellevue Hospital Center.
- The end, in 2007, of a privately-funded program that acted as a payer of last resort for 13,000 individuals who needed mental health or substance abuse treatment for 9/11-related psychological distress. This included more than 4,000 rescue workers and members of their families who had sought services from licensed providers of their own choice rather than through FDNY or Mount Sinai.

In the absence of federal funding, Mayor Bloomberg accepted the recommendations of the panel to expand both of these programs. He also agreed to support these services through FY 2011 while continuing to advocate for sufficient federal funds to treat those dealing with the health impacts of 9/11, including the thousands of volunteers who came from all over the country to participate in the rescue and recovery operations.

In September 2007, the Bellevue program, now known as the WTC Environmental Health Center, expanded to two additional locations. In April of 2008, the NYC 9/11 Benefit Program for Mental Health/Substance Use will begin. All NYC residents previously enrolled in the privately-funded program and any residents of New York City who have symptoms of psychological distress related to 9/11 will be eligible.

In addition, Mayor Bloomberg has funded a variety of other initiatives, including studies matching the WTC Health Registry to cancer and mortality registries to determine whether rates of various cancers or death are elevated among people exposed to the WTC collapse, and a clinical research study of persistent respiratory symptoms reported among Lower Manhattan residents and area workers. The City also hired a World Trade Center Health Coordinator who has developed a one-stop shopping website for 9/11 health information and services. The website also posts up-to-date information on publicly- and privately- conducted research and study findings on health issues, including those based on the WTC Health Registry. This site can be found at: www.nyc.gov/9-11HealthInfo.

As illustrated before, the WTC Health Registry is a unique resource designed to monitor and systematically document the health impacts of this disaster over a 20-year period. Because of its size and diversity, the Registry can illuminate patterns and provide valuable guidance to potentially

affected groups, medical care providers, emergency planners and other policy makers. The continued investigation of WTC-related illnesses by the Registry is also important to assure the appropriate use of City, State, and Federal dollars for 9/11 screening and treatment programs. Attached, for your information, is a list of the studies and research that have been conducted or facilitated by the Registry.

The Registry has just concluded its second health survey of all 71,000 enrollees, and we expect to have preliminary results in the next few months. This second survey will help determine to what extent the reported respiratory and mental health conditions have persisted six years after the disaster and whether any new symptoms or conditions have emerged. It also will identify and help address gaps in medical and mental health treatment.

Initially established by a \$20 million FEMA grant, and later supported with approximately \$9 million through, thanks to this Committee, special 9/11 Congressional appropriations, the Registry received funding that will last through October of this year; we estimate that at least \$4.5 million per year will be required to maintain the Registry for the remainder of its 20-year life. Additional funding beyond the \$4.5 would be necessary to do any special research and analysis. Furthermore, it should be noted that the President's FY09 Budget does not include continued funding for this important health registry.

We are grateful to the New York City Congressional delegation and to the members of this committee for providing funding to support the critical medical monitoring and treatment programs at the Centers of Excellence and the invaluable epidemiological research conducted through the WTC Registry. We are equally thankful for Mayor Bloomberg's decision to expand the City's commitment to 9/11 health issues and provide physical and mental health screening and treatment for residents, area workers and students in the absence of federal funding. Working together with our elected officials nationwide, we are confident that we can improve medical and mental health care services to address the needs of first responders, recovery workers, residents and all those nationwide who experienced or may experience health effects related to the September 11, 2001 terrorist attacks and their aftermath.

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