



Testimony

of

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before the

**New York City Council
Committee on Civil Service and Labor,
Committee on Lower Manhattan Redevelopment and
Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and
Disability Services**

regarding

**Oversight: Examining the NYC World Trade Center Medical Working Group 2010
Annual Report on 9/11 Health**

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Introduction/Overview

Good afternoon. I want to thank Chairs Koppell, Chin, and Sanders, as well as the other distinguished members of the Council for convening this hearing examining the NYC World Trade Center (WTC) Medical Working Group 2010 Annual Report on 9/11 Health.

I also would like to thank the New York City Council for its vocal support of the James L. Zadroga 9/11 Health and Compensation Act, which became law earlier this year and which will provide steady funding for 9/11 health monitoring, treatment and research over the next five years.

My name is Dr. Carolyn Greene. I joined the NYC Department of Health and Mental Hygiene (DOHMH) in January 2008 and was appointed Deputy Commissioner for Epidemiology in April 2010 after serving as Acting Deputy since November 2009. I oversee the work of the WTC Health Registry and represent the Department on the WTC Medical Working Group, which is co-chaired by Deputy Mayor Linda Gibbs and Commissioner Thomas Farley

The WTC Medical Working Group was appointed by Mayor Bloomberg in 2007 at the recommendation of a special panel that he convened to address the health impacts of 9/11. I am pleased to serve with 15 other members who, in addition to the co-chairs, include representatives of NYC's three WTC Centers of Excellence, as well as scientists and 9/11 health experts from inside and outside of City government.

The WTC Medical Working Group meets three times annually to review the latest scientific research on potential health effects of the WTC attacks and issues an annual report summarizing its findings. Both the 2009 and 2010 WTC Medical Working Group annual reports were distributed to all members of Congress with Dear Colleague letters from New York Senate and House sponsors of the Zadroga Act as part of the City's advocacy efforts in Washington.

The WTC Medical Working Group also identifies priority topics to address at each of its meetings. Since last year's hearing, these topics have included long-term 9/11-related mental health conditions and cancer and mortality research.

Today I will briefly summarize findings from the WTC Medical Working Group's 2010 Annual Report on 9/11 Health, update you on the sunseting of the NYC 9/11 Benefit Program for Mental Health and Substance Use Services, and discuss the recommendations the WTC Medical Working Group made regarding cancer research, a critical concern for many.

Summary of WTC-Related Health Findings

The WTC Medical Working Group has reviewed nearly 250 studies published in the peer-reviewed literature from 2001 to 2010.

Although most studies to date have examined the short-term health effects on people exposed to the WTC disaster one to four years after 9/11, an increasing number have begun to describe and analyze health effects five to eight years after 9/11. These mid-term studies demonstrate that some WTC-related conditions have persisted, even among people who have received treatment suggesting that continued health monitoring and treatment is needed for many of the nearly 50,000 rescue and recovery workers, Lower Manhattan residents and office workers who to date have enrolled in the WTC Centers of Excellence. Fortunately, the Zadroga Act ensures that these services will be available at least through 2015.

Broadly speaking, the research, which is remarkably consistent across studies, indicates that the short- and mid-term health conditions associated with WTC exposure include post-traumatic stress disorder or PTSD; upper and lower respiratory symptoms, such as sinus problems and asthma; loss of lung function; and sarcoidosis, an inflammation that can affect any organ, but typically affects the lungs. The research also suggests that many WTC-exposed people have more than one of these conditions.

Results from the first two World Trade Center Health Registry surveys show that many people who were directly exposed to the WTC disaster report having developed post-traumatic stress symptoms. For some, these symptoms have resolved, but 10% of enrollees showed symptoms of chronic PTSD five to six years after 9/11. Job loss and trauma unrelated to the terrorist attacks before or after 9/11 was associated with greater symptom severity while lack of adequate social support was associated with reduced recovery.

Reports of some physical symptoms, including cough and sore throat, declined significantly in the first four years after 9/11 while others, including shortness of breath upon exertion, wheeze and nasal congestion, remained relatively stable. Among those reporting persistent respiratory symptoms, many also had below-normal lung function.

In the past year, the WTC Medical Working Group identified more than 60 articles published since the release of our 2009 report. The majority of these articles rely on previous findings or reports. For example, new research published in the *New England Journal of Medicine* examined firefighters and emergency medical service workers enrolled in the FDNY WTC Medical Monitoring and Treatment Program; it showed that declines in lung function first diagnosed in the twelve months after 9/11, persisted among many for at least six additional years.

Two articles contributed new findings related to suicide by analyzing New York City death records before and after 9/11. Despite widespread evidence of PTSD among all exposed groups, both studies concluded that suicide rates did not increase in the first four years after the terrorist attacks.

Findings about Children and Adolescents

Few studies have addressed the impact of the 9/11 attacks on child and adolescent health, especially physical health.

However, the WTC Health Registry has nearly completed analyzing physical health outcome data for children and adolescents five to six years after 9/11. We plan to share and discuss these preliminary findings with our scientific and community advisory groups in the near future, before submitting results for publication.

9/11-Related Mental Health Services

As I mentioned earlier, the Zadroga Act ensures that the thousands of people with WTC-related health problems will continue to receive integrated mental and physical health care over the next five years. This is important for the more than 5,300 people who enrolled in the NYC 9/11 Benefit Program for Mental Health and Substance Abuse Services, the vast majority of whom are now eligible for federally funded services.

Throughout the literature, we see that probable PTSD is the most common WTC-related health effect. The Registry studies I mentioned before indicate that rates of probable PTSD remained six times higher among people directly exposed to the WTC attacks than in the general population five to six years after 9/11. I use the term “probable” because this research is based on self-reported symptoms, not clinical diagnoses.

In 2008, the Department launched the NYC 9/11 Benefit Program to facilitate access to affordable behavioral health care and substance use services for those affected by the events of 9/11. This was a continuation of a similar program implemented by the American Red Cross in 2002. Between the two programs, there has been continuous treatment for mental health and substance use disorders available for those impacted by the WTC attacks regardless of their ability to pay.

As originally planned, the benefit ended in early January of this year, although enrollees have until March 31 to submit reimbursement requests. The Department has communicated consistently with enrollees regarding the end of this benefit and to assist in identifying additional resources when needed. Reminder letters went to enrollees in June and October last year with information about the WTC Centers for Excellence as well as how enrollees can access services through the public mental health system.

With enactment of the Zadroga Act, people with 9/11-related mental health conditions, including those who have had access to privately or publicly funded care since 2002, will continue to have access to federally subsidized care through at least 2015. The availability of integrated mental and physical health care for this population is especially important. As the WTC Medical Working Group noted in its 2009 annual report, 10-40% of people seeking care at the WTC Centers of Excellence have both mental and physical health conditions.

2010 WTC Medical Work Group Recommendations

The findings of the WTC Medical Working Group about cancer, other late-emerging conditions and mortality have not changed since our first report in 2007. Scientific research has so far not linked WTC exposure to any cancer or found elevated mortality rates among WTC-exposed populations. However, clinicians, epidemiologists and other researchers at the WTC Centers of Excellence and the WTC Health Registry continue to monitor the exposed population closely for any evidence of increased risk.

Cancer research efforts are still in their infancy because of the latency period or length of time it takes for cancer to develop after being exposed to something that may cause cancer. For example, previous cancer research suggests that it takes at least ten years for solid tumor cancers such as lung cancer associated with asbestos exposure to develop, and even longer for mesothelioma. Blood cancers have shorter latency periods.

In addition, science requires that researchers identify cases in an objective, unbiased manner. Many WTC cancer researchers, including those at the WTC Health Registry, are using state cancer registries to verify diagnoses within their cohorts. Currently, state cancer registries are able to provide verifications only through 2007. This is why most cancer researchers have begun to conduct preliminary cancer analyses only within the past two years.

Nevertheless, the WTC Medical Working Group recognizes both the challenges of cancer research at this early stage and the extraordinary interest among people who may have been exposed to known carcinogens released by the collapse of the World Trade Center. In response, our 2010 annual report includes a series of recommendations intended to assist researchers in their efforts to analyze the number of confirmed post-9/11 cancer diagnoses among exposed individuals using the best and most consistent methods possible.

These recommendations were based on the expert advice of nationally recognized biostatisticians, environmental health scientists and cancer epidemiologists who were convened by the Health and Fire Departments for a two-day analytic methods meeting last June. Researchers from the three WTC Centers of Excellence and the WTC Health Registry—all four of whom are tracking distinct cohorts of people exposed to the WTC disaster—attended the meeting, as did members of their labor and community advisory boards.

To help you better understand the challenges that these researchers face, I would like to briefly discuss several of the recommendations made by the experts.

First, the experts advised us to conduct what are known as internal comparisons. All of you are probably familiar with the expression that you should compare apples to apples and oranges to oranges. This also can apply to epidemiology. Comparing populations who were exposed to the WTC disaster to very similar populations who were not exposed is challenging, because it is difficult to find truly comparable populations. Instead, the

experts recommended that we compare people within each of our cohorts who were more highly exposed to those who were *less* exposed whenever possible because these “apples to apples” comparisons are likely to have greater scientific meaning.

Second, the experts suggested that we agree on a common way to classify WTC exposure across all of the studies that are being done by the different research groups. As I mentioned earlier, measuring WTC exposure is difficult because there are so many unknowns, but the experts advised the clinicians and scientists monitoring the four cohorts to work together with what we do know—such as whether or not someone was caught in the dust cloud, when they arrived at the WTC site, what kind of work they did and how much dust was in their home or office—to develop exposure classification systems for both the responder and non-responder populations. This way, the degree of exposure within and across these cohorts can be categorized more consistently.

Third, the experts told us that we should consider conducting formal cancer analyses no more frequently than every five years because of the long latency period between environmental exposures such as the WTC disaster and the development of most cancers. That said, during the interim periods, researchers will continue to monitor and track data in order to detect and share new developments.

These recommendations already have increased collaboration among the three WTC Centers of Excellence and the WTC Health Registry, and have resulted in the formation of a WTC Analytic Methods Workgroup. This workgroup includes representatives from each of these institutions, as well as labor and community stakeholders, such as the Uniformed Firefighters Association, the Communications Workers of America and 9/11 Environmental Action.

The WTC Analytic Methods Workgroup has been meeting regularly since July of last year and it has completed an exposure classification system for the responder population. In addition, the workgroup has established a cancer review board so that the clinicians and researchers monitoring the four cohorts can classify cancer cases according to a shared set of principles. These principles have been developed in consultation with one of our national experts who is affiliated with the Mount Sinai School of Medicine.

I and other members of the WTC Medical Working Group realize that these recommendations will not be satisfactory for people who want answers now. As a physician and a human being, I have tremendous compassion for those who receive a cancer diagnosis and for their families and friends; I also understand the intense desire to know what caused it.

As an epidemiologist, I also understand that science may never reach the point where we can say with any certainty whether an individual’s exposure to the WTC disaster is the reason that an individual developed cancer. A number of factors can contribute to the development of cancer which is, unfortunately, the second leading cause of death among all New Yorkers.

WTC Health Registry

In closing, I also would like to note that the Zadroga Act provides a steady funding stream for WTC research in general, and for the WTC Health Registry in particular. This is welcome news as the Registry is about to begin its third major survey of more than 71,000 enrollees this spring.

The *New England Journal of Medicine* recognized the importance of the Registry in a 2007 article titled “The Legacy of World Trade Center Dust.” The authors wrote “the actual causal contribution of the dust to future risk of disease can best be characterized through prospective epidemiologic investigations involving sufficient numbers of exposed persons, along with control groups. The [World Trade Center Health Registry], designed to track the physical and mental health status of this group of highly exposed persons for up to 20 years, could become the platform for the requisite investigation. Decades of commitment to the registry, as well as continued monitoring of responders, will be needed to gain the best information possible on the longer-term consequences of inhalation of the dust.”

As a result of the Zadroga Act, both the Registry and the monitoring programs at the three WTC Centers of Excellence are better positioned than ever to begin investigating any longer-term and late-emerging health effects of WTC exposure. This research and monitoring will provide a solid foundation for responsibly continuing—and possibly expanding—the care and treatment that this legislation guarantees for the next five years.

Thank you again for your support of the Zadroga Act, and for inviting me to testify today.