

# **Testimony**

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**before the**

**House Committee on Government Reform**  
**Subcommittee on National Security, Emerging Threats, and International Relations**

**Assessing Sept 11<sup>th</sup> Health Effects: What should be Done?**

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**New York City**

Good morning. I am Dr. Thomas Frieden, Commissioner of the New York City Department of Health and Mental Hygiene. I want to thank Chairman Shays, the Committee, and especially Congresswoman Maloney, for holding these hearings in New York City to discuss the health affects of the World Trade Center disaster and what is being done to assess their impact. I am pleased to have the opportunity to be here, and in particular, to describe our progress with the World Trade Center Health Registry, which I believe will be key to understanding the extent of these health effects.

The immediate health effects of the tragic events of 9/11 include the deaths from the terrorist attack of nearly 2,800 New Yorkers, in addition to the passengers and crew of the two airplanes that were deliberately crashed into the World Trade Center towers. Our efforts now are focused on the many people who may experience long-term health problems as a result of the events of 9/11.

The World Trade Center Health Registry is a critically important effort to evaluate the short- and long-term health effects to both physical and mental health that may have resulted from exposure to the 9/11 disaster.

The Registry, a comprehensive, strictly confidential health survey of the most highly exposed people will be used to assess the possible long-term health effects of the disaster in different groups including those who were in close proximity to the World Trade Center site on 9/11/2001 and those who were exposed as recovery and cleanup workers, residents, and students in the ensuing weeks as the fires burned. Significant findings will be shared as soon as they become available, and reports will be posted on the Registry website every three months. We intend to track the health of persons who enroll in the Registry for up to 20 years. We hope to contact participants every three to five years to inquire about their health as well as to undertake specific, focused studies, resources permitting.

The World Trade Center Health Registry is unique, in that it is the only project that will allow comparisons across groups, and facilitate long-term follow-up of a large, population-based cohort that includes people with a wide range of exposures and health histories. It is our best chance to find out the true incidence and spectrum of health effects resulting from 9/11. Let me be clear about what the Registry is and what it is not. It *is* a systematic evaluation that should allow us to make conclusions about the health effects of 9/11, both for those who participate in the registry, and those who do not participate. It *is not* an attempt to identify and monitor every exposed person. It also *is not* a telephone diagnostic program intended primarily to find people with medical problems and provide care. Clinical evaluation of those most affected cannot tell us about rare effects, nor can it indicate the rate of illness. The Registry will be able to identify syndromes and conditions associated with exposure to the disaster, and help determine what is and is not associated with the disaster. The Registry provides the only comprehensive information available to put the clinical studies in perspective. We need both the detailed clinical evaluation that is provided by Mount Sinai, NYU, and others; as well as the comprehensive survey approach the Registry provides. This will provide information to support evaluation and treatment regimens. We will be able to identify who is at risk and what kind of exposure is more likely to put people at risk so that people can be identified and receive appropriate screening and treatment. Findings will be available to the participants, the general public, and the medical professions to help their evaluation and treatment of exposed persons at risk – whether or not they are in the Registry.

The Registry allows us a pivotal opportunity to evaluate the health of people who were closest to the site on 9/11 and in the subsequent months. It allows for understanding of various levels of exposure to dust, fumes, and debris, and provides information on both physical and mental health problems that may occur. The larger the number of eligible people who enroll in the Registry, the more valuable the project will be in terms of delineation of long-term health effects of 9/11 and identification of possible subgroups needing further evaluation and treatment. It will allow us to compare the health effects of people who worked for weeks on the burning pile, people who worked in office buildings in lower Manhattan during the Fall of 2001, and residents who returned to live near the World Trade Center site while the fires still burned, with those experienced by less-exposed persons, including those who were in lower Manhattan only briefly on 9/11 and never returned, or residents who did not come back until after the fires were out.

The Registry is the most systematic approach currently available to evaluate the possible health effects from 9/11. It does not depend on selected sub-populations, but rather encourages all eligible persons to participate. Findings from the Registry will allow us to put in perspective the important clinical data from medical evaluation studies conducted by Mount Sinai, the Fire Department, NYU, New York State, and others. The Registry will enable DOHMH to conduct targeted surveys and investigations based on the more general findings from the larger enrolled population. It may also facilitate the future development of effective treatment regimens for these possible health effects.

The Registry is a collaboration between the New York City Department of Health and Mental Hygiene, the federal Agency for Toxic Substances and Disease Registry (ATSDR), the Federal Emergency Management Agency (FEMA), and New York City community and business organizations. In July 2002, FEMA provided start-up funding for the Registry to ATSDR; ATSDR contracted with RTI (Research Triangle Institute) International to conduct outreach, data collection, and data management. During this period, DOHMH and ATSDR, with the assistance of a Scientific Advisory Committee representing a wide range of researchers and recognized experts from the scientific and medical community, have been designing this complex project that is unprecedented in size and scope. The development of the criteria, the questionnaire, and methodology for data collection all required extensive scientific peer and the human subject review required for all federally funded research to assure the protection of human subjects of research. The DOHMH is responsible for overall project management, oversight, and dissemination of findings from the Registry, in close consultation with our partners and our scientific Advisory Committee.

ATSDR has committed funding of \$1 million per year for project years two through five to support specific WTC Health Registry core functions, including database maintenance, location updates of 25% of registrants per year, and data analysis and reporting, including a quarterly report to be posted on the Registry website ([www.wtcregistry.org](http://www.wtcregistry.org)). We are also providing a resource guide to participants and others to help identify evaluation and treatment sources. However, ATSDR has not received and therefore cannot commit funding for follow-up and registry matching activities, which are essential to the goals of this project. Specifically, the following unfunded activities are vital to the WTC Health Registry's success: follow-up health assessments of at least a 10% annual sample of Registry participants via telephone interview or self-administered questionnaire; dissemination of findings, health alerts (if appropriate), and recommendations for referrals for medical screening, evaluation, and possible treatment; and matching with health databases such as hospitalizations, cancer registries, and the National Death Index. These activities would require a minimum of \$2 million per year more, beginning in calendar year 2005, for the intended 20-year life of the project. Without this funding, it will not be possible to fully evaluate the potential long-term effects of the WTC disaster.

The development of the scientific plan for the Registry has, from its inception, involved the collaboration of scientists from academic institutions both within and outside of New York City, including the City University of New York, Mount Sinai Hospital, Columbia University, the New York Academy of Medicine (NYAM), New York University (NYU), the Bloomberg School of Public Health at Johns Hopkins University, the health departments of New York State and New Jersey, the National Institute for Occupational Safety and Health (NIOSH), the federal Centers for Disease Control and Prevention (CDC) Injury and Environmental Programs, and the Oklahoma State Department of Health.

We are very pleased with the response to the Registry during the first 8 weeks of data collection. More than 10,000 people have completed the full telephone interview,

and another 5,000 have pre-registered on the Registry website or by calling the toll-free number; these numbers continue to increase each day. We also already have detailed contact information and will reach out to more than 25,000 others believed to be eligible.

Public awareness and understanding about the availability of the Registry is critical in order to enroll as many people as possible in the different exposure categories. It is important for people to know that the World Trade Center Health Registry has a federal Certificate of Confidentiality, which ensures protection of individual information from release by subpoena or Freedom of Information Act (FOIA) requests. We are grateful to the community organizations, businesses, and city, state, and federal agencies that have participated in identifying and recruiting people to be enrolled in the World Trade Center Health Registry. I also want to thank newspapers and other media groups, including our local TV news organizations that have contributed to increased awareness about the Registry. Potential registrants can pre-register by visiting our website, [www.wtcregistry.org](http://www.wtcregistry.org) or call 1-866-NYC-WTCR (1-866-692-9827)

I would like to thank Senator Clinton and her colleagues in the Senate and House for targeting a portion of emergency funds to be used for post-disaster health assessment. While hundreds of thousands of New Yorkers were exposed to the environmental effects of the disaster, we worked with our scientific advisors to devise a realistic definition of those who were likely to be the most heavily exposed, whom we are now inviting to join the Registry. The World Trade Center Health Registry will include a large representative sample of people who were in a building, on the street, or on the subway below Chambers Street on September 11, 2001; people living south of Canal Street; school children and staff from schools and day care centers located south of Canal Street; and people involved in rescue, recovery, clean-up, and other support services at the WTC site or the recovery operations on Staten Island from September 11, 2001 through June 30, 2002. The Registry will provide information about health effects for everyone exposed and will provide a basis for all of us to make public health and policy decisions related to the health effects of 9/11.

The World Trade Center Health Registry does not substitute for or replace the other World Trade Center-related studies and what has and will be learned from those studies about the effects of 9/11. Many of the measures that were included on the baseline Registry survey were derived from exposure and health measures found to be important from prior research conducted by NYAM, Mount Sinai, FDNY, NYU, NYSDOH, and Columbia University, among many others. The World Trade Center Health Registry, nonetheless, is unique in that it will include a high proportion of people in the highly exposed populations, will be more comprehensive (including study of multiple populations), and long-term, and will provide a foundation for conducting future World Trade Center-related evaluations.

We have recently published on the World Trade Center Health Registry website ([www.wtcregistry.org](http://www.wtcregistry.org)) our first report describing characteristics of persons interviewed during the first three weeks of data collection. Among the 6,313 individuals interviewed in September 2003, 83% were residents of New York State on September 11, 2001; 70%

were south of Chambers Street on the morning of 9/11; 28% worked at the World Trade Center recovery site on Staten Island or on the barges; and about 12% were residents in the area south of Canal Street. Many people among this first group of interviewees belonged to more than one exposure group. Although the largest portion of those interviewed in the first month live in Manhattan, more than 1,000 are from Brooklyn, and hundreds more from each of the remaining New York City boroughs have completed interviews.

The World Trade Center Health Registry is vital to our ability to put in perspective the information on health effects and to determine the spectrum of health effects from 9/11. It is critically important that people step forward to help develop this resource, which will help us and the medical community better respond to potential health care needs, as well as to respond to similar crises in the future. We also call upon our colleagues in Washington to provide support for the Registry in future years. In order for the Registry to be as useful as possible to determine the extent, need for treatment, and, possibly, treatment modalities for possible health effects from 9/11, as well as provide information that will be the most relevant to our response to any possible future acts of terrorism, we must have the resources available to operate this program at both the level and the duration planned.

The World Trade Center Health Registry, which is the culmination of planning that began shortly after 9/11, is the most recent of many health evaluations and activities conducted by the DOHMH in the days and weeks following 9/11. These include:

- **Syndromic surveillance**, a system to identify clusters of illness in hospital emergency departments and through ambulance calls. NYC's emergency department syndromic surveillance was developed in response to 9/11, but has grown and is now a disease outbreak health-monitoring program.
- **Inspection of food distribution and hand washing stations**, leading to immediate implementation of improved safeguards for workers. DOHMH also mandated shower and "hose-down" stations for workers.
- **Emergency department surveillance** for injuries to survivors on 9/11, in cooperation with CDC.
- **Rescue worker injury and illness surveillance.** For a month following September 11, 2001, more than 5,000 medical records at four Manhattan hospitals and five Disaster Management Assistance Team (DMAT) facilities located at the World Trade Center site were reviewed. Musculoskeletal conditions were the leading cause of visits, followed by respiratory and eye disorders. This system provided objective timely information that helped guide public health interventions following the 9/11 disaster.
- **Community Needs Assessment of Lower Manhattan.** DOHMH and CDC survey teams surveyed 414 persons in selected apartment units in Battery Park City, Southbridge Towers, and Independence Plaza in late October 2001. Some of the findings reported in January 2002 were that 50% of residents experienced nose, throat, and eye irritation; 40% had symptoms of post-traumatic stress syndrome.

- **Indoor air quality assessment.** In November and December 2001, in collaboration with ATSDR, samples were taken from 30 residential buildings in lower Manhattan and 4 residential buildings above 59<sup>th</sup> Street as comparison buildings. Samples were analyzed for airborne fibers, asbestos, and fibrous glass. Samples were taken inside residences, in common areas within residential buildings, and outside of the buildings. The air samples from inside the buildings showed no elevated levels of asbestos or fibrous glass. Settled dust samples were also collected and analyzed for asbestos, fibrous glass, and mineral components of concrete and wallboard. Analysis of interior settled dust samples for asbestos indicate that 18% of the 83 samples were above levels found in the background building. Upon reinspection, none were at levels requiring abatement. Asbestos was detected in 6 of the 14 (43%) outdoor samples. Only 2 of these were at levels requiring abatement. Professional abatement work was completed in this area. Fibrous glass was detected, as expected, in 40 of 85 (48%) indoor dust samples and in 11 of the 14 (79%) outdoor locations in lower Manhattan. Mineral components of concrete and wallboard were also detected at higher percentages in lower Manhattan than in comparison areas.
- **Assessment of mental health impacts.** The 9/11 tragedy has demanded a significant response from this Department to meet the intensified need for mental health and chemical dependency services. These are, and will continue to be, a significant long-term health affect of 9/11. In particular, post-traumatic stress syndrome and depression have been documented at very high rates in New York City. Although the prevalence of these disorders has decreased since the months immediately after 9/11, they have returned to baseline except in those directly affected by the tragedy – those who witnessed it, lost loved ones, worked on the rescue, or had their job status affected. In those directly affected, mental distress remains elevated.

In order to assist New Yorkers who were affected by the disaster, the Department implemented Project Liberty, a FEMA-funded crisis counseling program. Project Liberty contracted with more than 80 community-based agencies across the City, primarily mental health clinics with deep roots in their communities. Project Liberty providers employ outreach workers and crisis counselors who offer free individual and group crisis counseling and public education programs to help people return to their pre-disaster level of functioning. They refer people to mental health treatment if indicated.

We are proud of the way in which Project Liberty has served New Yorkers, and in particular how it has reflected the diversity of the City and focused on those communities that were most heavily impacted. Since the beginning of Project Liberty activities in October 2001, the program has assisted more than 900,000 New Yorkers affected by 9/11. Outreach efforts by Project Liberty providers were conducted in a broad spectrum of locations throughout the City, often in collaboration with community-based organizations, serving a population ethnically similar to the City as a whole. Project Liberty's public education campaign materials have been printed in Spanish, Chinese, and Russian, as well as in English.

FEMA made more than \$110 million available to the City through the New York State Office of Mental Health for Project Liberty, which is scheduled to end on December 31, 2003. We are hopeful for an extension of time so that ongoing Fire Department and Department of Education programs can be completed; without additional funding, we anticipate on the basis of claims submitted to date that essentially all of the remaining FEMA services funds for New York City's Project Liberty will be expended by the December 31 deadline, or shortly thereafter.

In conclusion, I want to again thank you for your interest and support. We are grateful for the federal financial support we have received for our bioterrorism and emergency preparedness activities, as well as the scientific guidance and expertise that federal agencies such as CDC and ATSDR have placed at our disposal. However, I cannot close without noting that there is much more that needs to be done to heal the City's wounds from that terrible event, and to ensure that we are prepared as we should be in the event of another attack. We are working hard to provide the best emergency preparedness system possible. The City continues to ask the Administration and Congress to provide bioterrorism and homeland security funding based on risk and consequence. We were the target of 2 of the 4 planes used on 9/11. We were the target of 4 of the 7 anthrax-laden envelopes sent in the Fall of 2001. And we are the target in most of the terrorist "chatter" which mentions a location now. But despite having more than half the nation's recent attacks and more than half the risk of future attacks, we receive less than one-fortieth of federal dollars to prepare and respond to terrorist attacks. In fact, per capita, NYC ranks a shocking 45th out of the 54 jurisdictions receiving bioterrorism funding.

The City has also asked the Administration and Congress for more than \$900 million to provide the necessary training, security enhancements and facility improvements, emergency preparation, and response equipment, as well as proper communications and information technology to New York City's five first responder agencies, including the DOHMH, the Police and Fire Departments, the Office of Emergency Management, and the Health and Hospitals Corporation, our public hospital system. DOHMH alone has requested more than \$100 million in financial assistance from the Administration and Congress so that we can upgrade the City's public health laboratory and provide equipment and resources to strengthen our capacity to respond to environmental threats. The Health and Hospital Corporation also has significant needs, and has asked for more than \$33 million in financial assistance to assure that our public hospitals can respond adequately to future threats. And as noted above, the WTC Health Registry – our best chance to know the health effects of 9/11 – has a large funding gap.

Thank for your interest and continued support. I will be happy to answer your questions.

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