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

March 12, 2007
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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Statement of

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Co-Director WTC Medical Monitoring & Treatment Programs

New York City Fire Department

9/11 Health Effects:

Federal Monitoring and Treatment of Residents and Responders

March 12, 2008

Appropriations Committee

U.S. House of Representatives

Introduction

Good morning Chairman Obey, Ranking Member Walsh and Committee members. My name is Dr. David Prezant, and I am the Chief Medical Officer, Office of Medical Affairs, for the New York City Fire Department (FDNY). I am also a Professor of Medicine in Pulmonary Diseases at the Albert Einstein College of Medicine. Along with Dr. Kerry Kelly, who could not be here today, I am the co-director of the FDNY's World Trade Center Medical Monitoring and Treatment Program. Today I will update this committee about the health of our FDNY World Trade Center (WTC) rescue workers and about the monitoring and treatment program we have developed to meet the critical health needs of this population.

I would first like to thank this Committee and the Members of Congress who have shown their extraordinary support for our members and the FDNY's WTC Monitoring and Treatment Program. Federal support has been critical to our monitoring and treatment program, and I want to thank the committee for the support you have shown by providing funding for those suffering from the health impacts of 9/11.

We anticipate that current funding could last until June 2009, but the need for this funding—and a long-term solution that will end the uncertain cycle of annual appropriations-- remains strong, six-and-a-half years after 9/11. We need long-term funding to ensure that we have the staff, treatments and infrastructure for our members into the future.

As you know, the FDNY lost 343 members on September 11, 2001. The fall of the twin towers, and the collapse of the Seven World Trade building later that day, created a dust cloud composed of large and small particulate matter coated with combustion by-products. For three days, Ground Zero was enveloped in that dust cloud. The fires that continued to

burn at the site until mid-December created additional exposures and resulted in repeated dust aerosolization.

Nearly 2,000 FDNY rescue workers responded on the morning of 9/11, as did nearly 10,000 during the next 36 hours. And in the weeks and months following 9/11, virtually all of our FDNY first responders worked at the WTC site – amid the debris and dust resulting from the towers' collapse. In total, more than 11,500 firefighters and fire officers, 3,000 EMTs and Paramedics, and 1,000 FDNY retirees took part in the rescue, recovery and fire suppression efforts. As a group, FDNY rescue workers experienced more exposure to the physical and emotional hazards at the disaster site than any other group of workers.

FDNY Medical Monitoring and Treatment Program:

The FDNY WTC Medical Monitoring and Treatment Program is one of three Centers of Excellence for WTC Health. Because of the unique aspects of our program such as pre-9/11 health data for comparison and a 95 percent participation rate, FDNY has been able to analyze and publish data providing critical and unique insights about WTC health effects. On the anniversary of 9/11 last year, FDNY published an extensive report on these health effects which can be found on-line. See: http://www.nyc.gov/html/om/pdf/2007/wtc_health_impacts_on_fdny_rescue_workers_sept_2007.pdf)

Physical Health Issues

Because respiratory issues surfaced quickly for those working at the site, the FDNY initiated the WTC Medical Screening and Treatment Program in October of 2001, just four weeks after 9/11. Using federal funding appropriated by this committee, we evaluated more than 10,000 of our first responders from October 2001 through February 2002. Since that

time, we have continued to screen both our active and retired members. As of the end of February this year, we have examined 14,671 FDNY WTC rescue workers (95 percent of the cohort); 11,679 (75 percent of the cohort) have been examined at least twice; and 6,585 (42 percent) have received three monitoring exams.

Because the FDNY had extensive medical information on all of our members before 9/11, our Medical Monitoring and Treatment program can compare pre- and post-9/11 medical data. This enables us to observe patterns and changes among our members. For example, we have found a significantly higher number of firefighters suffering from pulmonary disorders during the year after 9/11 than in the five years prior to 9/11. On average, for symptomatic and asymptomatic FDNY-WTC responders, we found a 375 ml decline in pulmonary function for all of the FDNY-WTC responders and an additional 75 ml decline if the member was present when the towers collapsed. This pulmonary function decline was 12 times greater than the average annual decline noted five years pre-9/11. Over the past six years, pulmonary functions of many of our members have leveled off, improved or, unfortunately for a few, declined. More than 25 percent of those we tested with the highest exposure to WTC irritants showed persistent airway hyperactivity consistent with asthma or Reactive Airway Dysfunction (RADS). In addition, more than 25 percent of our full-duty members participating in their follow-up medical monitoring evaluation continue to report respiratory symptoms.

Disease Surveillance

In the first year after 9/11, the Fire Department identified 13 cases of Sarcoidosis, compared to only two to three cases per year before 9/11. While the numbers have leveled off -- we now see about four cases a year -- these Sarcoidosis cases continue to have more

serious clinical presentation than we were typically seeing prior to 9/11. This auto-immune disease can affect every organ system in the body, but is primarily a pulmonary disease. For most, it is stable disease with little impact on job or lifestyle but, for a few, it can be devastating with severe impairment, disability and, in rare cases, the need for lifesaving lung transplantation. Our preliminary analysis has shown no clear increase in cancers among our members since 9/11. Pre- and post-9/11, we do continue to see occasional unusual cancers that require continued careful monitoring. Monitoring for future illnesses that may develop, and treatment for existing conditions, is imperative. Federal assistance is needed to continue these programs.

Mental Health Issues

The need for mental health treatment for our members was apparent in the initial days after 9/11, as virtually our entire workforce faced the loss of colleagues, friends and family. Past disasters have taught us that first responders are often reluctant to seek out counseling, frequently putting others' needs ahead of their own. Many times, recognizing the need for help may not happen for years after an event. Our goals have been to reduce barriers to treatment so that members could easily be evaluated and treated in the communities where they live and work, and to develop enhanced educational programs to help identify early symptoms of stress, depression and substance abuse and address coping strategies.

Treatment

Because we started our medical monitoring program immediately after 9/11, we recognized right away the urgent need for early diagnosis and treatment. In the first ten months following 9/11, we treated 2,791 patients for WTC cough-related illnesses (sinusitis, asthma, bronchitis, and GERD) and 1,499 for mental health issues (PTSD, prolonged grief

and depression). Annually, over the next three fiscal years, we averaged 1,137 members for respiratory treatment and 2,354 for mental health treatment with very little year-to-year variation. However, in the following fiscal year (Fiscal 2006), the number of patients receiving respiratory treatment decreased to 793, while mental health treatment remained fairly stable at 1,970. We learned that the decline in respiratory cases was not due to a reduction in need. Rather, many patients decided to stop participating because they were having difficulty affording medications. In November 2006, this committee once again came through for us and appropriated federal funding, through NIOSH, for a treatment program that did include free WTC-related medications. With the ability to provide medications, respiratory patient treatment numbers have climbed monthly. We project that by the end of New York City's fiscal year on June 30, 2008, we will have seen 1,500 patients for respiratory treatment and 2,100 for mental health treatment. We also provide mental health counseling to affected family members (especially those related to the deceased), treating 645 family members last fiscal year.

With treatment, most of our members have been able to return to work, but more than 750 have developed permanent, disabling respiratory illnesses that have led to earlier-than-anticipated retirements among members of an otherwise generally healthy workforce. In the first five years after 9/11, we experienced a three- to five-fold increase in the number of members retiring with lung problems annually.

Funding

As you can see, the need for our monitoring and treatment programs and services remains strong. Current federal funding could last until June 2009 based on current projections, but a commitment to long-term funding is needed to ensure that we can continue

necessary treatment, monitoring and research into the future. As we know in environmental-occupational medicine, there is often a significant lag time between exposures and emerging diseases. The medical effects of asbestos, for example, may not be detected for 20 to 30 years after exposure. The actual effect of the dust and debris that rained down on our workforce on 9/11 may not be evident for years to come. Our current annual budget is $6 million for the clinical monitoring center and $3million for the data monitoring center. However, our clinical center has increased the number of exams it administers, and our data center now processes monitoring data and treatment data. We therefore anticipate that these costs will increase by $0.5 million to $1.5 million per year for the next five years.

We also need additional funding to continue enhanced diagnostic testing and focused treatment of FDNY first responders, addressing both physical and mental health problems related to World Trade Center exposures. Both our active members and our retirees face gaps in their medical coverage. Early diagnosis and aggressive treatment improves outcomes. This is only possible if burdensome, out-of-pocket costs (co-payments, deductibles, caps, etc.) for treatment and medications are eliminated. In January 2007, we spent nearly $120,000 on pharmaceuticals; last month we spent nearly $425,000 – a 3.5-fold increase. This growth is due solely to increased patient load. By 2009, we believe that our monthly pharmaceutical costs may be close to $750,000.

This fiscal year, our treatment budget is approximately $9 million. We expect that cost to rise by $1 million to $2 million per year over the next five years due to increased utilization and healthcare inflation. Long-term medication needs for respiratory disease and mental health illnesses require significant co-payments, taxing the resources of our members. In addition, most insurance plans do not adequately cover mental health treatment.

Thus, we expect that the cost for monitoring and treatment through the FDNY program will be on the order of $75 million to $80 million over the next 5 years.

Conclusion

The commitment to long-term funding, for both monitoring and treatment, must be made now to allow the FDNY WTC Health Center of Excellence to plan for the future in order to protect and improve the health of our workforce (both active and retired) and to inform lesser exposed groups (and their healthcare providers) of the illnesses seen and the treatments that are most effective.

Thank you for your past efforts, and your continued support of our members, patients and Department.

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Statement of

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March 12, 2008

Before the

House Appropriations Labor-HHS-Education and Related Agencies Subcommittee

"World Trade Center 9/11 Health Monitoring and Treatment Program"

Thank you Chairman Obey, Ranking Member Walsh, and members of the committee:

My name is Joan Reibman, and I am an Associate Professor of Medicine and Environmental Medicine at New York University School of Medicine, and an Attending Physician at Bellevue Hospital, a public hospital on 27th Street in NYC. I am a specialist in pulmonary medicine, and for the past 16 years, I have directed the NYU/Bellevue Asthma Center. I am pleased to be able to testify today on behalf of the workers, residents and students of downtown New York, and the clean-up laborers, all of whom were exposed to World Trade Center dust and fumes.

On the morning of 9/11 over 300,000 individuals were at work in the area, or in transit to their offices. Many were caught in the initial massive dust cloud as the buildings collapsed – these are the thousands whom we saw in video and still photographs coated in white, running for their lives. In the great outpouring of pride and patriotism after 9/11, many area workers returned to work one week later, the streets still covered in WTC dust, the massive WTC clean-up and rescue operation still in full force, and buildings incompletely cleaned or decontaminated.

As you know, Lower Manhattan is also a dense residential community; almost 60,000 residents of diverse racial and ethnic backgrounds live south of Canal St. (US census data). They are economically diverse; some living in large public housing complexes, others in newly minted coops. Lower Manhattan is also an educational hub; there are some 15,000 school children, and large numbers of university students. Some were locked in their buildings; others were let out and told to run. The dust of the towers settled on streets, playgrounds, cars, and buildings. Dust entered apartments, schools and office buildings through windows, building cracks, and ventilation systems. The WTC buildings continued to burn through December.

Each of these groups had potential for exposure to the original dust cloud, to the re-suspended outdoor dust that remained or was generated by the clean up, to indoor dust and to fumes from the fires that continued to burn. As pulmonologists in a public hospital, we sought to determine whether the collapse of the buildings posed a health hazard.

Our first step was to monitor the effect on the local residents. With funds from the Centers for Disease Control, and in collaboration with the New York State Department of Health, we looked at the rate of new respiratory symptoms in local residents after 9/11. It was the first such study, completed just over a year after 9/11. The results have been reported in three peer-reviewed publications (Reibman et al. The World Trade Center residents' respiratory health study; new-onset respiratory symptoms and pulmonary function, Environ. Health Perspect. 2005; 113:406-411. Lin et al. Upper respiratory symptoms and other health effects among residents living near the world trade center site after September 11, 2001, Am. J. Epidemiol. 2005; 162:499-507, Lin et al., Reported respiratory symptoms and adverse home conditions after 9/11 among residents living near the World Trade Center. J. Asthma 2007; 44:325-332).

We surveyed residents in buildings within one mile of Ground Zero, and, for purposes of control, other lower-risk buildings approximately five miles from Ground Zero. From an epidemiologic perspective, the exposed population was over sampled because at that time, this was the only study of the residents. Analysis of 2,812 individuals revealed that new-onset and persistent symptoms such as eye irritation, nasal irritation, sinus congestion, nose bleed, or headaches were present in 43% of the exposed residents, more than three times the number of exposed compared to control residents. New-onset and persistent lower respiratory symptoms of any kind were present in 26% versus 8% of exposed and control residents respectively; a more than three fold increase in

symptoms. This included an increase in cough, shortness of breath, and a 6.5-fold increase in wheeze (10.5 % of exposed residents versus 1.6% of control residents respectively). These respiratory symptoms resulted in an almost two-fold increase in unplanned medical visits and use of medications prescribed for asthma in the exposed population compared to the control population.

Our most recent analysis of the data also suggest that residents reporting longer duration of dust or odors or multiple sources of exposure had greater risk for symptoms compared to those reporting shorter duration. Data from the NYCDOHMH WTC Registry administered by the New York City Department of Health and Mental Hygiene, accrued after our study, further document adverse health effects in additional populations, including building evacuees and school children, and confirm our original findings. These data are provided in the testimony of Lorna Thorpe, PhD.

After 9/11, we began to treat residents who felt they had WTC-related illness in our Bellevue Hospital Asthma Clinic. We were then approached by a community coalition and together began an unfunded program to treat residents. We were awarded an American Red Cross Liberty Disaster Relief Grant in 2005 to set up a medical treatment program for WTC-related illness in residents and responders. A year later, we received additional philanthropic funding, and major funding from the City of New York to provide evaluation and treatment of individuals with suspected World Trade Center-related illnesses. This program, initially awarded $16 million over 5 years to Bellevue Hospital.

In 2006, Mayor Bloomberg appointed a panel to make recommendations about the sufficiency of resources available to those whose health has been affected by the September 11, 2001 terrorist attacks. The panel recommended that the Mayor expand the Bellevue program and seek federal funds to support it. Although the Bellevue

program has yet to receive any federal funding, the Mayor committed to implement the Panel's recommendation and added another $33 million in 2007, allowing for expansion of the program to two additional sites. But the City cannot afford to be the lone supporter of a treatment program to address this national problem indefinitely. For now,the WTC Environmental Health Center is funded by the City with a commitment that will average nearly $10 million per year over five years—but we need federal support to sustain and enhance the program over the long term.

We now have an interdisciplinary medical and mental health program that has evaluated and is treating over 2000 patients since 2006. With little outreach, we continue to receive over 200 inquiries each week; while most come from local people, we have received calls from individuals living in about 20 other states. These calls to our hotline (1-877-WTC-0107) result in 30 new patients each week, demonstrating an unmet need.

To enter our program, an individual has to have a medical complaint; we are not a screening program for asymptomatic individuals. To date, our patients are almost equally men and women, of diverse race/ethnicity and many, although not all, are uninsured. Some have never sought medical care, others have been seeing doctors for years, with a history of recurrent bronchitis, pneumonia, and sinusitis. These individuals have a complex of symptoms that include persistent sinus congestion (55%), asthma-like symptoms of cough (55%), shortness of breath (70%) or wheeze (39%), and acid indigestion (48%) for which they continue to need care more than 6 years after 9/11. Over 50% of our patient population has concurrent mental health issues, including PTSD, depression and/or anxiety. We have heard from countless individuals who were highly physical active – even training for marathons -- who now require daily medication to allow them to walk a few city blocks. While many of them can be treated aggressively as if they have asthma, the sickest among them show a process in their lungs that may

consist of a granulomatous disease – a type of inflammation that is like sarcoid or other interstitial lung diseases that, even after review by multiple pathologists have been hard to define pathologically, and have been described as hypersensitivity pneumonitis, alveolar destruction similar to emphysema, and often associated pulmonary arterial hypertensive changes. Some have pulmonary fibrosis, characterized as scarring or permanent damage in the lungs, and are now so sick that they are waiting lung transplants.

Many challenges remain. How can we determine whether an illness is WTC-induced? We have no simple test to determine whether any individual illness is related to WTC exposure. What we have is six years of clinical experience in Centers that have seen so many cases that we can now recognize a set of symptoms associated with the World Trade Center dust. Our tools are the history of exposure, the temporal sequence of illness and a particular constellation of symptoms that are by now sadly familiar. Armed with these tools, we can more effectively differentiate such cases from illnesses that are unrelated. The Registry provides us with the larger epidemiological picture and context that inform our daily clinical practice.

Why are some people sick, while others are well? We now suspect that while the level of exposure plays a role, so does individual susceptibility. This is similar to tobacco-induced disease: some smokers remain healthy, while for others, tobacco causes lung disease, cancer, and heart disease. Only through the existence of Centers will there ever be sufficient data collected to attack such medical puzzles.

What are these disorders, and will they respond to treatment? Will there be late emergent diseases, with cancers? For patients, these are the paramount questions and I wish I could clearly answer them. Without Centers, we will never have answers.

We now know, from peer-reviewed published literature as well as our clinical experience, that large numbers of residents and workers in downtown Manhattan and even Brooklyn were subjected to environmental insults on a large and unprecedented scale and that these insults had measurable medical consequences. These men, women and children will require continued evaluation, screening and treatment for years to come.

You, Chairman Obey, Ranking Member Walsh, Congresswoman Lowey and all the members of this committee have been very supportive of our efforts and we are very grateful. Our Center is funded by the City with a commitment that will average nearly $10 million per year over five years. But the actual cost of the program continues to rise significantly and is projected to cost an average of $15 to $18 million per year. Last year, for the first time, you made eligible for federal funding the people that we treat: the nearby residents, the local workers, the laborers hired to clean up the residents and offices, the schoolchildren and those who just happened to be in the WTC area on September 11 and immediately following. As you know, in FY 08 you provided $108 million for all those whose health was compromised by September 11 and its aftermath. We have not yet received any of these federal funds for treatment at the WTC Environmental Center at Bellevue. We have not been informed that we will receive any of these funds any time soon. It is my understanding that a study, taking over a year, may have to be completed before any funds are released. We have peer-reviewed articles demonstrating respiratory and mental health illness in residents and local workers. We have data coming from the Registry. We know these people are sick. A study is always helpful but its completion should not be a pre-condition to releasing funds this fiscal year. The Administration in its proposed FY 09 budget would make the residents, officer workers and students ineligible for any federally funded WTC health programs.

I thank you very much for your time and will be glad to take any questions. Joan Reibman, MD

Pertinent funding to Joan Reibman, MD.

2001-2002	CDC, World Trade Center Residents Respiratory Survey (Institutional P.I, Lin P.I.)
2001-2003	NIH, NIEHS, World Trade Center Residents Respiratory Impact Study: Physiologic/Pathologic characterization of residents with respiratory complaints (P.I.)
2004-2005	CDC, NIOSH WTC Worker and Volunteer Medical Monitoring Program (P.I.)
2005-2007	American Red Cross Liberty Disaster Relief Fund (P.I.)
2006-2011	New York City funding for WTC Environmental Health Center (Linda Curtis, Bellevue Hospital, PI)