Statement of

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H.R. 847, the James Zadroga 9/11 Health & Compensation Act of 2009

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Good morning, Chairman Pallone, Ranking Member Deal, 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 17 years, I have directed the NYU/Bellevue Asthma Center. I am pleased to be able to testify today on behalf of the local workers, residents and students of downtown New York who were exposed to World Trade Center dust and fumes.

I am very pleased to be here today to support H.R. 847, the James Zadroga 9/11 Health & Compensation Act of 2009, which will provide needed long-term funding for the monitoring and treatment for those members of the community exposed to toxic substances as a result of the 9/11 terror attacks. Many of these individuals, unfortunately, have become patients with long-term health needs related to respiratory as well as other physical and mental health illness.

First, I would like to thank this Committee and the Members of Congress who have shown their continuing and extraordinary support for our patients and our program, especially Congressman Nadler. The efforts in Congress resulted in an RFP which we applied for, and in September 2008, we were awarded funding for a 3 year program – $10 million each year – for three years.

Populations at risk

Let me now tell you about the people that we serve, the local workers, residents and students 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 local workers returned to work one week later, the massive WTC clean-up and rescue operation still in full force, and not all buildings completely 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 and college 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 dust, both indoors and outdoors, and to fumes from the fires that continued to burn.

Initial health effects in community populations

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. This first such study was completed just over a year after 9/11 and 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. 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 reported by 43% of the exposed residents, more than three times the number reported by control residents. An over three-fold increase in lower respiratory symptoms including cough, shortness of breath, and a 6.5-fold increase in wheeze (10.5 % of exposed residents versus 1.6% of control residents respectively) was reported. An almost two-fold increase in unplanned medical visits and use of medications prescribed for asthma in the exposed residents compared to the control residents was also reported. Residents reporting a 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, further document adverse health effects in building evacuees and school children, and support our original findings.

Current knowledge about health effects in community populations

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 potential World Trade Center-related illnesses. This program was initially awarded $16 million over 5 years to Bellevue Hospital. On the recommendations of a panel appointed by Mayor Bloomberg, the Mayor expanded the Bellevue program and in 2007 added another $33 million for 5 years, allowing for expansion of the program and the addition of two additional sites. In September 2008, we received our first federal funding under a grant awarded from the

National Institute for Occupational Safety and Health (NIOSH) providing three years of support. We are extremely grateful for the city and federal funding, but we need federal support to sustain the program over the long term.

We now have an interdisciplinary medical and mental health program that has evaluated and is treating approximately 3,500 patients. We continue to receive inquiries each week; while most come from local people, we have received calls from individuals living in about 20 other states. To enter our program, an individual has to have a medical or now, a mental health 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, some have been unable to seek care for lack of insurance, others have been seeing doctors for years since 9/11, with recurrent bronchitis, pneumonia, sinusitis, or unexplained shortness of breath.

As described in our most recent article, these individuals, residents, local workers, as well as clean-up workers and responders, have symptoms that include persistent rhinosinusitis (40%), asthma-like symptoms of cough (47%), shortness of breath (67%) or wheeze (27%) for which they continue to need care more than 7 years after 9/11 (Reibman et al. J. Occupational and Environmental Medicine, epub ahead of print April 10, 2009). One third of our population have lung function that is below the lower limit of normal; 40% have shortness of breath at a level that is consistent with significant activity limitation, 10% have the highest score on a standardized scale of breathlessness used for disability assessment. These are people who report that they were previously working and functional, and many report that they were highly physically active – even training for marathons -- and now require daily medication to allow them to walk a few city blocks. Over 50% of our population continues to have persistent post traumatic stress disorder.

Frequently asked questions

What respiratory disease are we treating?

We now believe that the exposure resulted in several respiratory diseases. The respiratory abnormalities have varied patterns. Most of our patients have irritant-induced asthma. Although we can treat this, these individuals may require prolonged courses of inhaled corticosteroids and bronchodilators, sometimes even oral steroids. Many will require these medications for years, if not for life. Others show a process in their lungs that may consist of a type of inflammation, a granulomatous process that is like an illness called sarcoid. Others have lung diseases that affect not only their airways, or breathing tubes, but also the air sacs that allow for the exchange of oxygen and carbon dioxide. Some have pulmonary fibrosis, characterized as scarring or permanent damage in the lungs, and are awaiting lung transplants.

How do we know whether an illness is WTC-induced?

We often hear, well these diseases are common in the population anyway, how do we know that these people became sick from WTC exposures. We have no simple test to determine whether any individual illness is related to WTC exposure. We now believe

we can recognize a set of symptoms associated with World Trade Center exposures based upon patients' reports of exposure, the temporal sequence of illness and a particular constellation of symptoms. The DOHMH WTC Registry provides us with the larger epidemiological picture and context that inform our daily clinical practice.

How many people in the community are sick?

We are asked this question repeatedly. We are asked this for health information, for budgetary reasons, and for planning issues. We cannot answer the question. Our program consists of a self-referred population, and so we cannot determine the prevalence of illness in the community. Unfortunately, there was no government-sponsored formal community screening program put in place in the immediate aftermath of the disaster. We are now faced with a nagging question that we will never be able to answer, how many are ill. The NYCDOHMH WTC Registry provides some information, and although this program did not begin until 3 years after the event, relies upon self-reported information and lacks a formal control group, estimates of burden of illness derived from this program suggest that between 3,000 to 9,000 adult community members (residents, building occupants, people in transit) have developed new onset asthma and 38,000 have developed PTSD (Farfel et al. J. Urban Health 2008; 85: 880). Perhaps this is one of the most important lessons we can learn for the future. All potentially exposed communities need to be screened if there is a risk of adverse health effects. If that system had been put in place, we might be better able to answer this burning question.

I would though like to point out to the Committee that the bill before you, H.R. 847, places a cap on the number of individuals that can newly enter the federally supported community program. The bill sets that number at 15,000 maximum along with the 3,500 current patients.

Why are some people sick, and others not?

The level of exposure clearly plays a role in determining who will or has become ill. However, there is also a role for 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 long term Centers will there ever be sufficient data collected to attack such medical puzzles.

Will there be late emergent diseases?

This is of course the question at the back of everyone's mind. Will there be a high rate of cancers in the adult community, will children with early life exposure have long term effects including cancers. Without long term Centers, and without centers that treat community members, not only adult responders, we will never have answers.

Many peer-reviewed published articles as well as our clinical experience, report that large numbers of community members – residents, students and local workers were subject to environmental exposures on a large and unprecedented scale and that these exposures had measurable medical consequences. These men, women and children will require continued evaluation, treatment, and monitoring for years to come.

Why do we need H.R. 847, The 9/11 Health and Compensation Act of 2009?

The bill before this committee today, provides much needed long-term stability for our program and for our patients. The bill provides long-term, sustained funding to monitor and treat those who are sick or who could become sick because of exposures related to the 9/11 attacks, and it funds critical research so that we can understand the long-term health impacts of the terrorist attacks. Importantly, the bill includes federal funding to provide long-term monitoring and treatment for residents, area workers and community members. The WTC Environmental Health Center at the City's Health and Hospitals Corporation is the only Center for treatment of this community.

Support for this program has been provided through philanthropy and predominantly by New York City, only just this fiscal year, have we received any federal funding for treatment.

The bill defines specific groups, including local workers and residents and delineates specific geographic areas that people must have been in on September 11 or immediately following to be eligible for treatment. These boundaries reflect the best data we have available at this time but also recognizes that we do not know the full extent of the health impacts of the disaster.

People who meet these criteria are "eligible" for treatment but then a doctor with experience treating WTC-related conditions must determine, based on a medical examination and on standardized questionnaires, whether or not a patient is eligible for treatment; and even then, that decision is subject to review and certification by the federal WTC administrator. These are tough standards but ensure that only those who are sick because of 9/11-related exposures will be treated under the WTC health program.

The bill caps the number of responders and community members who can get monitoring or treatment. Again, these limitations are based on the best available information about how many people could potentially seek treatment, and while we think they will be sufficient to provide treatment to anyone who may need it, there are reporting requirements in the bill so that Congress will be told if those caps are approached.

The bill also mandates the establishment of Quality Assurance and Fraud Prevention programs to prevent funds from being used for any purpose other than to monitor and treat those affected by the 9/11 attacks. The City also has its own incentives to contain costs because the City has agreed to be responsible for paying a percentage of the cost to treat anyone treated at a WTC Environmental Health Center serving the community members. Finally, the federal program will be secondary payor to both Workers Compensation payments and to applicable health insurance available to an eligible recipient with a WTC-related condition. Although I wish the program would be primary payor, as currently outlined, the program will provide a safety net for individuals who have inadequate insurance, or who do not have health insurance.

Research on diseases related to the 9/11 attacks is essential. The bill ensures that critical 9/11-related research continues. Long-term research is the only way that we're going to be able to develop a full understanding of the health impacts of 9/11. The Centers of Excellence have all contributed to research efforts. The research funded in the bill will make it possible for both patients and clinicians to have the necessary information to make informed decisions about health treatment and to make available the best science to determine what conditions qualify for treatment under this bill.

We need the full and predictable sources of federal funding which this bill provides. I urge you to support this bill to help us ensure first-rate care for all of those who desperately need it.

I thank you for the opportunity to testify today and would be glad to take any questions.

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)
2008 – 2011	CDC, NIOSH World Trade Center Non-Responder Program, New York City Health and Hospitals Corporation