



MOUNT SINAI
SCHOOL OF
MEDICINE

TESTIMONY

before

The United States House of Representatives

Committee on Energy and Commerce

Subcommittee on Health

Hearing on

HR 847 "James Zadroga 9/11 Health and Compensation Act of 2009"

Washington, D.C.

April 22, 2009

Presented By

Jacqueline Moline, M.D., M.Sc.

Vice Chair and Associate Professor

Department of Community and Preventive Medicine, Mount Sinai School of Medicine

Director

World Trade Center Medical Monitoring and Treatment Program at Mount Sinai

Good morning Chairman Pallone, Ranking Member Deal, Members of the Committee, and other Representatives, I would like to thank you for inviting me to present testimony today.

My name is Jacqueline Moline, MD. MSc. I am Vice Chair and an Associate Professor in the Department of Community and Preventive Medicine and also an Associate Professor of Internal Medicine at the Mount Sinai School of Medicine in New York City. I am a board certified specialist in Occupational Medicine and in Internal Medicine. I serve as Director of Mount Sinai's Clinical Center of Excellence within the World Trade Center Medical Monitoring and Treatment Program. This Center is the flagship of a regional and national consortium that has been supported by a series of grants from the National Institute for Occupational Safety & Health (NIOSH) since early 2002, and that through February 28, 2009 has diagnosed and treated nearly 27,000 WTC responders in the New York metropolitan area and across the United States.

I am here today to testify in strong support of HR 847. I will discuss the health status of the 9/11 responders and the current extent of WTC-related illnesses in these brave men and women. I will discuss with you the critical need for continuing to provide medical care for the responders. I will emphasize the importance of stable, long-term federal support for the Centers of Excellence, where the necessary expertise and unique experience have been developed to provide the complex, high-quality medical follow-up and treatment that the 9/11 responders need and so rightfully deserve. In my view, HR 847 represents the best vehicle for meeting the continuing medical needs of the 9/11 responders and for ensuring that these needs will be reliably met in the years ahead.

The Diverse Population of 9/11 Responders

In the days, weeks, and months that followed September 11, 2001 an estimated 60,000 to 70,000 people from across the U.S. responded selflessly – without concern for their own lives or well-being – when our

nation needed them. Workers and volunteers, they included traditional first responders - firefighters, law enforcement officers, paramedics, the National Guard - and the not so traditional, including a large and highly diverse force of ironworkers, operating engineers, laborers, telecommunications workers, transit and sanitation workers, building cleaners and more. Many more volunteered their services, helping out however they could. They came from across America – tens of thousands of men and women from New York, New Jersey, and Connecticut, and from every state in the nation. They toiled for days, for weeks and months in and around Ground Zero, the Staten Island landfill and adjacent areas -- engaged in rescue and recovery operations, the restoration of critically needed essential city services, and debris removal and clean up. Their hard work and bravery got New York and our nation back on its feet, and we owe them tremendous gratitude.

The Exposures

Much has been written about what these heroes were exposed to: it was a complex and unprecedented mix of toxic chemicals. The combustion of 90,000 liters of jet fuel created a dense plume of black smoke containing volatile organic compounds - benzene, metals, and polycyclic aromatic hydrocarbons. The collapse of the Twin Towers and then of a third building (WTC 7) produced an enormous dust cloud – filled with pulverized cement comprising 60 to 65% of the total dust mass. Trillions of microscopic glass fibers and glass shards, asbestos, lead, polycyclic aromatic hydrocarbons, hydrochloric acid, polychlorinated biphenyls or PCBs, organochlorine pesticides, furans and dioxins were also included. Levels of airborne dust were highest immediately after the attack, at estimated concentrations of 1,000 to > 100,000 $\mu\text{g}/\text{m}^3$ according to the US Environmental Protection Agency – creating the thick airborne “soup” as a bright sunny day turned into night. The high content of pulverized cement made the dust extremely caustic, with a pH similar to lye (pH 10–11). Fires burned both above and below ground until December of 2001, exposing

thousands of workers to noxious chemicals. Rubble-removal operations continued until May 2002 repeatedly re-aerosolized the dust, creating continuing (intermittent) exposures over many months.

In addition to these extraordinary physical exposures, the 9/11 responders suffered extreme psychological stress. Responders lost friends and family in the attack, and were frustrated by the fact that there were few survivors found. During the desperate search and rescue operations, thousands of them came upon human remains. Stress was compounded by fatigue as these dedicated workers remained at the site, working for hour upon hour, day after day. Among those most affected are the non-traditional responders - those not previously trained for any emergency, let alone a disaster of the scale posed by 9/11.

Centers of Excellence

Mount Sinai, through its Center for Occupational and Environmental Medicine that had been in place since the 1970's and was the largest center for occupational medicine in the New York metro area at the time of the attacks, took a leading role in medically evaluating and treating affected workers and volunteers in the wake of 9/11. This work began within days after the attack, many months before any federal program was in place. Our dedicated physicians and staff designed and developed what stands today as the federal government's flagship health response to 9/11, a model based on the experience and expertise of academic physicians with specialty training in occupational medicine, surrounded by a team of specialists in disciplines ranging from pulmonary medicine, to psychiatry and rehabilitation medicine as well as nurses, social workers and support staff. We have been proud to work as a partner with all of you – legislators, federal agencies, and importantly the stakeholders, the affected responders and many organizations that represent them to provide a program that brings experience and excellence in its provision of service. We have striven to assure to the best of our ability the same quality of care for every responder, and have developed a consortium to make it easier for patients to be seen in areas that are convenient for them.

Our regional consortium of Clinical Centers of Excellence – Mount Sinai School of Medicine, SUNY Stony Brook, Queens College/Center for Biology of Natural Systems, University of Medicine and Dentistry of New Jersey and Bellevue Hospital, together with a national program for responders that until recently we coordinated and is now contracted through Logistics Health International, has provided, as of February 28, 2009, over 46,858 monitoring examinations to 26,651 responders in all 50 states. Mount Sinai alone has provided over 30,758 of those medical evaluation services – to 17,367 responders. Since the New York and New Jersey Metropolitan area consortium treatment programs began, we have provided nearly 90,000 physical health, mental health, and social work services consortium-wide¹. At Mt. Sinai alone, we have provided 63,548 treatment services - some through our privately-supported program, before federal funding was in place; 38,475 of these have been provided since federal funding began in the fall of 2006.

Much of what we know today about the health effects of the attacks on the WTC has been learned through this program and our sister program at the Fire Department of New York. Our physicians have diagnosed and carefully documented diseases in responders and linked these conditions to exposures sustained at the World Trade Center. We provide expert integrated medical, mental health and social work treatment that is, unfortunately, needed by tens of thousands of affected responders, and we provide this wide range of services regardless of patients' ability to pay. We remain constantly vigilant for newly emerging diseases and for trends of illness in the 9/11 responder population.

Demand for our Medical Monitoring and Treatment Program remains strong. Even now, almost 7 and a half years after 9/11, an average of approximately 150 new eligible registrants join the program each month.

¹ Most of the clinical centers began treatment programs for WTC responders with philanthropic funding. The first such program was initiated at MSSM in January 2003.

Health Effects

9/11 responders developed adverse health effects in 2001, and many continue to suffer. In addition, there have been social and financial impacts resulting in those whose health has been affected, adding to a list of loss and devastation for many responders, magnifying the health problems they face.

Respiratory conditions, including both upper and lower respiratory diseases, were prominent among the health effects that we began to see in responders as soon as our program began in 2002. We documented the health effects in responders from 2002-2004 a report published in 2006 in *Environmental Health Perspectives*, the respected peer-reviewed medical journal of the National Institute of Environmental Health Sciences. That report highlighted the following observations:

- New or worsened upper respiratory symptoms were experienced by 63% of program participants;
- New or worsened lower respiratory symptoms were experienced by 47% of participants, conditions such as asthma, RADS and COPD;
- Over one-quarter of responders had abnormal pulmonary function test results;
- Decreased forced vital capacity, a particular breathing abnormality, was found 5 times more frequently in non-smoking WTC responders than in the general, non-smoking population of the United States.

Mental health consequences also afflict a large percentage of 9/11 responders enrolled in the monitoring program. A paper that we published in 2008 in *Environmental Health Perspectives* documents, among over 10,000 Medical Monitoring patients, the presence of post-traumatic stress disorder (PTSD) in 11% of responders and depression in 9%, up to five years after September 11th. These rates are comparable to rates of PTSD among our veterans returning from Afghanistan.

Although many responders have shown signs of recovery, physical and mental health problems persist to the present time in a substantial proportion of the 9/11 responders. Rates of disease among responders who have returned for follow-up examinations, or who are coming in for the first time, have remained consistent and disturbingly high. A paper published in *Chest* in February 2009 compared pulmonary function tests, an objective measure of lung function in responders who have had two monitoring evaluations. The rate of breathing test abnormality was still close to 25%, much higher than the rates of disease in the nation as a whole, and certainly higher than we would expect among workers who are performing physically demanding work.

Statistics among patients actually in treatment in the New York/ New Jersey Consortium Clinical Centers – as evident by a six month snapshot of conditions seen among 4,398 patients between July 1, 2008 and December 31, 2008, highlight additional concerns:

- Gastrointestinal conditions affected 53% - most cases of GERD or gastro-esophageal reflux disorder.
- 35% were affected by mental health problems – including PTSD and major depression.
- Lower respiratory conditions affected 46% of patients.
- Upper respiratory conditions affected 69%.
- Social disability was unfortunately common, with over 22% of responders being unemployed/laid off, or on sick leave/disability during the observation period.
- 21% had no medical insurance at some point during the period.
- 64% suffered from multiple WTC-related covered conditions.

Because most of our patients are being treated for more than one WTC-covered condition, it is critical that they receive this care in Centers of Excellence where providers understand the complexity of the physical

and emotional needs of the responders. A majority of patients in our program receive treatment on an outpatient basis, but we have also had several inpatient admissions for conditions such as asthma attacks, complicated sinus surgeries, and for treatment of the mental health consequences, such as severe depression and attempted suicides.

These medical findings in the 9/11 responders fit with scientific understanding of the exposures that the responders sustained at Ground Zero. These findings are consistent also with the results of studies undertaken by the FDNY, the New York City Department of Mental Health and Hygiene, the Bellevue WTC Environmental Clinic and other independent researchers. The percentage of individuals afflicted by physical and mental health problems has been remarkably consistent across the various published studies, whether they are examining firefighters, construction workers, police officers, or office clean-up workers. Some responders have, of course, recovered. Many have been helped by the treatments that the Centers of Excellence provide. But the persistence of WTC-related physical and mental illness in thousands of responders nearly 7.5 years after the attack is no longer in question.

The possibility is real that new conditions – diseases marked by longer latency – will also emerge among the 9/11 responders. We know that responders were exposed to carcinogens such as asbestos and benzene, as well as neurotoxins, and chemicals toxic to the respiratory tract in concentrations and in combinations that never before have been encountered.

Longer term conditions we might see could include cancers, auto-immune disorders, and pulmonary fibrosis. The future health outlook for responders still remains uncertain. The long-term consequences of such unique exposures are not yet fully known. Because physicians and scientists have never before studied an unprecedented mixture of toxicants like this-- which resulted from the attack and collapse of the

most computerized office tower complex in the world, with vast numbers of compounds and potentially toxic agents inside released at Ground Zero. It will take decades to determine any collective tally of exactly what the health effects might be. It is for these reasons that all of us in the Centers of Excellence must remain constantly vigilant.

I'd like to describe for you two of my patients, who suffer from health consequences that are similar to so many others in our Centers of Excellence. Mr. H. is an ironworker who had actually retired in 1999. He returned to Ground Zero in September 2001 to provide assistance, since he had a skill set that was essential to the rescue and recovery effort. He stayed at Ground Zero for 3 months, working long days. Mr. H. had childhood asthma, but he had never had significant symptoms in over forty years of work as an ironworker. That all changed after the exposures he sustained at the WTC site. He now has severe asthma, has been hospitalized twice for asthma attacks, and takes multiple medications to treat not only his asthma but new onset sinus problems and GERD. Mr. S, a carpenter for a NYC agency, was in good health before he worked at the WTC site. He served there for 45 days. He was never bothered by dust, which was a daily part of his job. He developed severe GERD, reactive airways, rhinosinusitis, and anxiety. He was unable to work in a dusty environment anymore, and thus could no longer work as a carpenter. He lost his health insurance. He fell behind on his bills. He had difficulty obtaining care through his worker's compensation insurance, which controverted his claim, and he could not afford his medication or necessary tests. This program has provided him the care he needs, and his health is now stable. While it is not back to normal, and he can not work any longer, he has improved with comprehensive care, and can now take care of his family, and himself.

Conclusion

The medical findings in the 9/11 responders that I have summarized this morning, and most importantly, the persistence of WTC-related illness in a substantial proportion of the responders, underscore the critical importance and the urgent need for stable, predictable, multi-year federal support for a medical program for the responders. The complexity of these conditions and the difficulty of their treatment strongly support the need for provision of this care in the setting of an established medical monitoring and treatment program that is based in Centers of Excellence, and led by experienced physicians with specialty training in Occupational Medicine. Through the years that these programs have been in existence, we have identified countless health problems, and saved lives. We have developed relationships with our patients- and they trust us to provide them with the best care we can, and trust that we will be positioned to determine the magnitude of health problems they collectively face, and what we should be looking out for. HR 847 will accomplish these goals.

Data coordination is a second very powerful reason to sustain the Centers of Excellence model for provision of medical care to the 9/11 responders. The Centers of Excellence are highly skilled and experienced in the medical tracking and epidemiological monitoring of the responders' health as well as in overseeing the quality and in monitoring the outcomes of the care provided to the responders. Through the work of the epidemiologists, statisticians, and data base experts in our WTC Data and Coordination Center at Mount Sinai we have tracked medical trends and patterns of disease in responders. We have assured, as best we are able, uniform quality in services for all program participants. We have assessed the efficacy of our treatments. All of the data collected through the Data and Coordination Center are analyzed. Key findings are regularly disseminated to the medical community, policy-makers and the public through publication in major, peer-reviewed biomedical journals. This dissemination of findings and recommendations for diagnosis and treatment permits us to share our knowledge and to optimize medical

care. This shared knowledge and experience provides invaluable guidance in preparing for disaster planning for the future. Again, HR 847 can do this.

All of this good work would be impossible in the absence of Centers of Excellence. These Centers of Excellence are a national treasure. They are providing state-of-the-art medical care to the men and women who risked everything for all of us in a time tantamount to war. Our goal is to provide the best care possible to these men and women, and not have to worry that we won't be there for them if they still need care for their WTC-related diseases. This bill, *HR 847 "James Zadroga 9/11 Health and Compensation Act of 2009*, will ensure that the work of the Centers of Excellence can continue. Passage of HR 847 will ensure that the heroes of 9/11 are never forgotten.

Thank you.

I am pleased to answer any questions