

**TESTIMONY**

**Before  
The United States Senate**

**Committee on Health, Education, Labor, and Pensions**

**Hearing on  
The Long-Term Health Impacts from September 11:  
A Review of Treatment, Diagnosis, and Monitoring Efforts  
Washington, D. C.  
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**Presented By  
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Good morning.

Chairman Kennedy, Ranking Member Enzi, Senator Clinton and other esteemed members of the HELP Committee, I thank you for having invited me to present testimony before you today on the health consequences of 9/11 and on the urgent need to continue to provide proper medical services for the brave men and women who rose on that day to America's defense, many of whom are now ill as a consequence of their heroism.

My name is Robin Herbert, MD. I am an Associate Professor in the Department of Community and Preventive Medicine of the Mount Sinai School of Medicine, and I serve as Director of the World Trade Center (WTC) Medical Monitoring Program Data and Coordination Center at Mount Sinai.

In the days, weeks, and months that followed September 11, 2001, thousands of hard-working Americans from all across this nation responded selflessly – without concern for their well-being – when the nation and the federal government called upon them to serve. Unfortunately, many of these workers and volunteers have become seriously ill as a result of their response work, and we have documented in many that their illness appears to be persistent. It is therefore critical that we take stock of how we, as a nation, are caring for World Trade Center responders, and for others who have fallen ill, or may become ill in the future as a result of 9/11.

It is essential that we continue to provide aid and care for all those who were there for us – now and in the future. With your strong support – as a nation – I have no doubt we will.

### **Diversity of the WTC responder population**

Well over 50,000 people worked or volunteered in the aftermath of the attacks in and around the World Trade Center, and at the Staten Island landfill. An extraordinarily broad range of skill sets and occupational groups was required to mount an effective response to the terrorist attacks. Those who rushed in to perform rescue, recovery, restoration of services, and essential clean up included both traditional first responders such as firefighters, paramedics, and law enforcement officers, as well as a large and very diverse population of heavy machinery operators, laborers, ironworkers and others from the building and construction trades, telecommunication workers, other utility workers, transportation workers, sanitation workers and other public and private sector workers and volunteers. This extraordinarily diverse group toiled in search and rescue efforts that extended for days, weeks, and months, and engaged in critical service restoration for one of America's largest cities when it was in shock and on the brink of economic disaster. They sorted through the remains of the dead, and were witness, through many months, to horrors no one should ever have to face, or likely had ever faced, even if previously trained as responders. Even those not working directly on the pile – for example, responders who worked in manholes to restore communications, or to shut down gas lines to prevent explosions – sustained exposures both to airborne toxins and to the unexpected sight of human remains. Thus, when I use the term responders in my testimony, I will be referring to the large and diverse group of responders that performed rescue, recovery, restoration of services, and clean up in the service of our nation.

In addition to tens of thousands of men and women from New York, New Jersey, and Connecticut, approximately 2,300 responders from every other state in the nation are currently

registered in one of the WTC Medical Monitoring Programs. Particularly large numbers came from the states of Massachusetts, Ohio, California, Illinois, North Carolina, Georgia, and Florida.

### **The health consequences of 9/11**

The medical and mental health effects of the World Trade Center disaster have been well documented. I believe that there can no longer be any doubt that many people are sick, and that more will likely become ill in the future as a result of their work at Ground Zero.

In September 2006, we released a peer-reviewed paper in the medical journal *Environmental Health Perspectives*, detailing the findings from federally funded examinations of 9,442 WTC responders whom we and our partner institutions had examined between July 2002 and April 2004. I have appended this study for your review, and I would like to direct your attention to a few key findings:

- Among these 9,442 responders, 69% reported experiencing new or worsened respiratory symptoms while engaged in their efforts in or near Ground Zero.
- At the time of examination, up to 2 ½ years after the start of the rescue and recovery effort, 59% were still experiencing a new or worsened respiratory symptom, a finding which suggests that these conditions may be chronic and require ongoing treatment.
- One third of responders had abnormal breathing test results. One particular breathing test abnormality – decreased forced vital capacity – was found 5 times more frequently in WTC responders than in the general, non-smoking population of the United States. This is a most worrisome finding, that can be caused by a variety of conditions, including asthma with “air trapping,” and interstitial lung disease (or scarring disease of the lungs), the condition that has resulted in known fatalities among a few WTC responders.
- Findings from our program released in 2004 have attested to the fact that there also exist significant mental health consequences among WTC responders.

All of these findings are consistent with other independent study findings. They are replicated also in the spectrum of disease that we have seen among patients treated in the Mount Sinai WTC Medical Treatment Program:

- 86% of treatment patients suffer from upper respiratory conditions, such as chronic sinusitis;
- 51% suffer from lower respiratory conditions, including asthma and WTC cough;
- 32% have gastrointestinal conditions;
- 29% have musculoskeletal conditions; and
- 38% have been diagnosed with mental health conditions, including post-traumatic stress disorder, anxiety or depression, in addition to their physical ailments.

It is important to note that most patients in the treatment program actually suffer from multiple WTC-related illnesses, complicating their case management and their access to benefits.

### **Lack of medical insurance among WTC Responders**

More than 40% of the WTC responders in our treatment program are uninsured, and an additional 23% are underinsured, a situation that creates major barriers to access to medical services.

When I speak of the uninsured (those with no medical insurance) and the underinsured (those with insurance that may cover only in-patient care, or that may require payments of co-pays or have deductibles so high that our patients are functionally uninsured), I am talking about a wide range of responders. I am talking about poor workers: folks who cleaned buildings in the World Trade Center disaster area without, in many cases, adequate protection or training or insurance, often for fly-by-night operations that no longer exist. I am also speaking of construction workers, some of whom received insurance coverage for themselves and their families based on a certain number of days worked. But when these patients become too ill to work, or could no longer work as many days as they used to, their coverage often ended along with their paycheck. These difficulties are compounded for those responders who file for Workers' Compensation for their needed medical care, because filing for Workers' Compensation typically results in prolonged delays in accessing needed care due to case litigation and a complex bureaucratic maze. And there are others, countless tireless heroes, including thousands of volunteers as well, too numerous to detail here today. They put their lives on the line when they were needed, but now many of them find themselves in need. I invite all of you to speak with affected responders in our program, if indeed there is any doubt of their need.

### **The medical response to 9/11 – the critical need for Centers of Excellence**

To provide medical services to the men and women who gave of themselves at Ground Zero, this nation has provided funding to establish and operate Centers of Excellence. These Centers bring together specialists from many fields of medicine who work together to provide state-of-the-art care for the complex diseases that we are seeing in the responders. The Centers also have the capacity to track patterns of disease and to provide information on new and emerging illnesses.

The WTC Centers of Excellence were launched in late 2001 after initial reports were received of health problems in responders and volunteers. At that time the Congress provided resources for medical screening, and those funds became available in 2002. The WTC Worker and Volunteer Medical Screening Program was established as a regional and national consortium of Centers of Excellence that provided standardized, free, comprehensive screening examinations for WTC responders.

In July 2004, based on early findings from the screening programs, Congress authorized additional funding to establish an ongoing medical monitoring program for responders. This program too was organized as a network of Centers of Excellence. These Centers were selected by the National Institute for Occupational Health (NIOSH) through a fully competitive, peer-reviewed award process. This process established the World Trade Center Medical Monitoring Program which is funded through 2009. It provides baseline exams and well as follow up exams to WTC responders at 18 month intervals. NIOSH awarded funding to 2 sister programs of Centers of Excellence: one based at the Fire Department of New York (FDNY), and the other, a consortium of 5 Clinical Centers coordinated by a Data and Coordination Center at Mount Sinai Medical Center that serves all other responders.

Most recently, new federal funding for Treatment services which became available for the first time in 2006 has made possible a newly combined Medical Monitoring *and* Treatment Program. This program is again based in Centers of Excellence. It integrates all Monitoring and Treatment services and also supports a long needed expansion of services to provide care to a greater

number of responders than ever before. This new federal funding builds on generous but limited private support that had previously enabled some provision of treatment services to responders.

The Centers of Excellence currently provide the following complex array of services to the WTC responders:

- 1) Regular, standardized, comprehensive physical and mental health examinations to identify possible WTC-related illness in all responders.
- 2) Treatment for concurrent WTC-related physical and mental health illnesses. This care requires the close coordination of specialists from many disciplines, including: occupational medicine, pulmonary medicine, psychiatry, thoracic surgery and rehabilitation medicine. This array and coordination of services is to be found only in Centers of Excellence such as those that Congress and NIOSH have established.
- 3) Social work assistance to responders who have lost their ability to work or sustained other disastrous economic effects because of their WTC response work. Social workers teach responders how to navigate the Workers' Compensation system, access much-needed medical and mental health treatment, and to plan for the long-term security and needs of their families. Our social workers provide essential services to the sickest of responders – those who, unfortunately, are too ill to return to work despite state of the art medical care. For these responders, who typically have lost their jobs, their self-esteem, their income, and their ability to meet their basic expenses (rent, mortgage, food), social workers work directly with them and their families to advocate for vital resources.
- 4) Outreach to responders to ensure that they are not lost to follow up by regular phone updates, mailings, and educational programs. This sustained outreach will grow in importance as responders retire and relocate throughout the nation.
- 5) Linkage of clinical monitoring and treatment findings to public health data analysis for identification of disease trends. This is essential because we remain very concerned about the potential for diseases of longer latency to emerge among WTC responders. We know that responders were at risk of exposures to a wide range of toxic chemicals, including cancer-causing agents - such as asbestos, benzene, dioxins, PCBs, and PAHs - and to substances that can cause ongoing respiratory problems, such as highly alkaline, fine particulate dust that can cause permanent scarring of the lungs. Thus, it is important that the model of health service delivery for these heroes is capable of identifying newly emerging disease patterns that may include interstitial lung diseases such as sarcoidosis and cancers. We have been faced, as a nation, with an unprecedented attack with unprecedented consequences. We therefore need health service models that are capable of meeting the needs created by this unprecedented event: models that can identify and treat the ill, AND that also can identify emerging diseases in a group that unwittingly sustained exposures with unknown effects.
- 6) Dissemination of information learned from disease surveillance to responders, the public, and health care providers.

Major accomplishments of the Centers are these:

- 1) The Centers coordinated by Mount Sinai have provided baseline examinations for over 20,000 WTC responders including law enforcement officers, construction workers, communications workers, transit workers, building cleaners, and other public and private

sector workers and volunteers. Follow up examinations have been provided to over 7,440 WTC responders through the Mount Sinai Consortium.

- 2) The Mount Sinai Treatment Program alone has provided more than 14,000 medical and mental health treatment services to 3,700 responders.
- 3) The Mount Sinai Treatment Program alone has provided more than 7,700 non-mental health Social Work services primarily to assist the uninsured and the unemployed. They have successfully treated thousands of responders and returned many to active duty and productive lives.
- 4) The Centers have documented a very high incidence of both upper and lower respiratory disease in responders, much of which is persistent. They have documented a five-fold increase of certain abnormalities in pulmonary function testing.
- 5) They have documented high rates of mental health problems in responders, a proportion of which are persistent.
- 6) They are tracking the occurrence of rare diseases in responders such as pulmonary fibrosis and sarcoidosis. They have put into place an active surveillance system to monitor the appearance of cancer.

The two absolutely unique features of the Centers of Excellence are:

- 1) They have assembled a critical mass of medical expertise from many specialties – internal medicine, occupational medicine, pulmonary medicine, gastroenterology, and psychiatry, coupled with highly skilled social work units. This concentration of expertise enables the Centers to effectively treat the complex and multifactorial disorders of World Trade Center responders. Such sophisticated treatment is not possible in a private practice setting. Indeed, responders who have been seen outside the Centers have in some cases not been well managed medically and their medical care has not addressed the complexity of their problems.
- 2) The Centers of Excellence are linked to two Data and Coordination Centers (one at Mount Sinai and one at FDNY), which are staffed by public health specialists who are constantly monitoring patterns of disease and seeking new trends in illness. This highly sensitive system enables us to mount rapid responses to newly emerging problems, rapid responses that would not otherwise be possible. Additionally, the Data and Coordination Centers have developed unique expertise in conducting outreach and retention activities to ensure that no responder's needs go untended, that contact with the most ill responders is not lost, and that public health and medical information learned from the activities of the Data and Coordination Centers are rapidly disseminated to the responders, the public, and other health care providers.

### **Concluding Comment**

Our program of Centers of Excellence – the one that we, the legislative leaders, occupational medicine and other specialized medical experts, affected workers and their representatives, and health and safety experts have built together – has been designed and implemented to provide the greatest benefits and meet the demonstrated needs of our patient population. And our existing program of Centers of Excellence, and the lessons we have learned in the wake of September 11th, not only help to guide our ongoing response, but should be instrumental in helping guide future disaster response as well. By utilizing a Center-based approach, the program ensures

quality, experienced and standardized care across the country. We ensure that responders receive the best medical services on an ongoing basis, regardless of where they live now or may live in the future. We ensure the ongoing critical update of clinical monitoring and treatment services, because of the program's ability to identify disease trends by pooling information gleaned from almost 27,000 examinations and continually analyze that information. We ensure an ongoing public health response and education benefit, beyond the benefits to responders, health care providers, government agencies and policy-makers by informing future disaster preparedness and response.

As you are likely aware, federal funding for WTC-related treatment services is due to run out, likely before the end of this fiscal year. Federal support for the medical monitoring arm of our efforts, provided for the first five years of a 20 to 30 year needed initiative, may run out sooner than expected, because we are able to help more people now than we had initially anticipated.

Today, you can choose to continue to help thousands of those affected by 9/11 as we are best able: through a coordinated, experienced, expanded model of Centers of Excellence. We can help prevent death and disability, and improve life for many of those who gave so much. By providing responders with expert medical and mental health services, we can help them to stay in their jobs or begin to work again. We can help give them back their lives. We can provide them with some hope for the future.

Five years following the attacks on the World Trade Center, thousands of the brave men and women who worked on the rescue, recovery, and clean up efforts are still suffering. Respiratory illness, psychological distress, and financial devastation have become a new way of life for many. Also suffering, of course, are many WTC area residents, office re-occupant employees and students, for whom no appropriate systematic response is yet in place. I hope that my comments today will serve as a reminder of the long-term and widespread impact of this disaster, and of the need to continue to build on the successful model which gives these men and women the care they deserve.

Thank you.