EXAMINING THE CONTINUING NEEDS OF WORKERS AND COMMUNITIES AFFECTED BY 9/11

HEARING

OF THE

COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS

UNITED STATES SENATE

ONE HUNDRED ELEVENTH CONGRESS

SECOND SESSION

ON

EXAMINING THE CONTINUING NEEDS OF WORKERS AND COMMUNITIES AFFECTED BY 9/11, INCLUDING S.1334, TO AMEND THE PUBLIC HEALTH SERVICE ACT TO EXTEND AND IMPROVE PROTECTIONS AND SERVICES TO INDIVIDUALS DIRECTLY IMPACTED BY THE TERRORIST ATTACK IN NEW YORK CITY ON SEPTEMBER 11, 2001

JUNE 29, 2010

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EXAMINING THE CONTINUING NEEDS OF WORKERS AND COMMUNITIES AFFECTED BY 9/11

TUESDAY, JUNE 29, 2010

U.S. Senate,
Committee on Health, Education, Labor, and Pensions,
Washington, DC.

The committee met, pursuant to notice, at 2:40 p.m. in room SD–430, Dirksen Senate Office Building, Hon. Tom Harkin, chairman of the committee, presiding.
Present: Senators Harkin, Merkley, and Enzi.
Also Present: Senator Gillibrand.

OPENING STATEMENT OF SENATOR HARKIN

The CHAIRMAN. The Senate Committee on Health, Education, Labor, and Pensions will please come to order.

I welcome everyone to this important hearing.

Nine years ago this September—we all remember that day, and we all remember exactly where we were and what we were doing when that happened—two airplanes flew into the World Trade Center, burst into flames—3,000 people killed—watched those building come down. All of our lives were changed forever.

We’ll never forget the images burned into our memories of people running in terror, covered from head to toe in gray ash. But, we’ll also never forget the brave heroes who were running in the opposite direction—the police, the firefighters, the doctors, the emergency responders, bravely rushing toward the cloud and the chaos. And we’ll never forget the volunteers from all across America who spent weeks at the site digging and hand-sorting through smoldering debris, frantically looking for survivors first, and later for remains to give closure to the thousands of families who lost loved ones.

One, a young man whom I knew as a kid, his folks—his dad was a minister in Iowa—was one of those lost in the Trade Center. And also—I’m sure I can speak for many—a lot of our firemen and emergency responders came from my State to go there to do what they could to help out.

On 9/11, terrorists, determined to kill thousands of innocent people, showed us human nature at its very worst. But, the response to those attacks showed us not just the better angels of our nature, but truly astonishing examples of courage and selflessness and self-sacrifice.
On 9/11, in the days, weeks, and months that followed, many thousands of people came to offer, as I said, their assistance and expertise. Since those initial days, our Nation has responded to the tragedy in a myriad of ways, both here and abroad, obviously.

This committee is especially interested in learning about the long-term health effects of the World Trade Center attacks. As we all know, now, and some advised at that time, the enormous rubble pile at Ground Zero emitted a toxic brew of gases and fine particulate matter for months after the attack.

In the immediate aftermath, the city and Federal Government tried to do its best to protect those who came to serve, although we know there was also misinformation that was given out about the safety of the dust at the World Trade Center site. In the years that followed, we set up programs to address health needs that we couldn't prevent, and I am proud that the Appropriations Subcommittee, that I chair here, along with Congressman Obey on the House side, has worked closely with the New York delegation to meet those needs.

But, our work is not done. We're learning that the health effects of the 9/11 disaster are far more extensive and more wide-ranging than many people initially thought. A wide variety of health effects have been observed in responders and volunteers, local residents, and community members. These conditions include respiratory and gastrointestinal problems, as well as mental health effects. We'll hear from one such individual today.

There have been many reported mental health effects, including depression, anxiety, and post-traumatic stress disorder.

In addition to these documented short-term health effects, we're concerned about the potential long-term health effects, including the possibility of higher rates of cancer. It is critically important that we continue to study and address these health impacts, both for the sake of the workers and community members affected, so that we can apply the lessons we've learned to other disasters, whether it's the Gulf Coast oilspill or some crisis yet to come.

So, today's hearing is an important step in our continued response to this crisis. It's about keeping faith with those directly impacted by the 9/11 attacks, and meeting their needs.

I applaud Senator Gillibrand for her tireless leadership and advocacy in this area.

I, again, also thank two members of the New York delegation who I've asked to join us up here today, Congressman Jerry Nadler, a long-time friend of mine, one of the senior members of the House and of the New York delegation, representing the 8th District of New York; and also, Representative Carolyn Maloney, another long-time friend of mine and a representative of New York's 14th District. They obviously, along with Senator Gillibrand, have been involved in this for, well, since 9/11. And we thank you for that leadership, and welcome you to our committee.

Senator Gillibrand introduced one proposal, the James Zadroga 9/11 Health and Compensation Act of 2009, that's currently before this committee.

More generally, I commend her and our two colleagues from the House for their relentless efforts to address the needs of the heroes and the victims of that day.
The committee looks forward to hearing from Senator Gillibrand today, and learning more about her bill. I also look forward to getting an update about the progress of the various programs that currently serve the needs of those exposed to the World Trade Center site, and how we can best continue to meet those needs.

So, I thank the witnesses for coming today.

And I will yield to Senator Enzi.

STATEMENT OF SENATOR ENZI

Senator Enzi. Thank you, Mr. Chairman, and thank you for holding this hearing.

On September 11, 2001, terrorists killed nearly 3,000 people in New York, Virginia, and Pennsylvania. The destruction of the World Trade Center created a huge toxic dust cloud. Emergency responders, recovery workers, and others who breathed in the dust, developed lower and upper respiratory conditions, sarcoidosis, reactive airway dysfunction syndrome, worsened asthma, pulmonary fibrosis, post-traumatic stress disorder, and other conditions. There are continuing concerns that latent illnesses might appear decades from now. We are here today to talk about the programs for these 9/11 health conditions.

Shortly after the attack, my wife and I visited Ground Zero. We were deeply moved by the heroism of the emergency responders and the recovery workers from all over the country. They kept their promises, did their duty, and saw things through to the end. They deserve the same from us.

In October 2006, I sent four members of my staff, along with staff from the offices of Senators Burr, Clinton, Coburn, Kennedy, Murray, Voinovich, and Schumer, to gather facts from the Fire Department of New York and a number of the other city departments, Mount Sinai Hospital, the victims, and others.

In March 2007, Senator Clinton and I held the first Senate hearing on the long-term health impacts of 9/11. Drs. Herbert, Kelly, Melius, and Stellman explained the medical and scientific issues to the committee. After the hearing, a bipartisan Help Committee working group was formed. It was led by Senator Clinton’s and my staff, and joined by the offices of Senators Burr, Brown, Coburn, Dodd, Gregg, and Kennedy. One goal of the working group was to try and learn more about the program run by the Centers from Disease Control through the National Institutes of Occupational Safety and Health, or NIOSH.

We were especially impressed by the caregivers’ expertise and devotion to their patients, by the patriotism of the construction companies and workers, and by the fire department, the police, and union outreach, on post-traumatic stress disorder and mental health. There are a lot of good people doing a lot of good work.

At the same time, the working group had difficulty obtaining basic facts about the NIOSH program. We learned that NIOSH received $475 million in earmarks from the Appropriations Committee from 2002 through 2010, then sent those funds to grantees for monitoring treatment. When the bipartisan working group looked at a sample of about $111 million that NIOSH sent six grantees from 2004 to 2007, they saw that neither NIOSH nor the
grantees could produce detailed expenditure reports to show how funds were spent. Several grantees could not furnish copies of annual financial status reports, known as FSRs, that they were supposed to send to NIOSH. One grantee told us they could not document how the earmarks were actually spent, but they’d be glad to go back and, “assign costs,” retroactively to the spending.

Preparing for today’s hearing, Help Committee staff again asked NIOSH to explain how the funds were spent. NIOSH did not answer, or make a good-faith effort to try to answer, the committee’s questions.

Senator Gillibrand and I spoke last week, and we agreed to ask the Governmental Accounting Office to account for those funds. I appreciate that these programs were set up under extraordinary duress, and I’m inclined to give the grantees the benefit of the doubt here. But, it does not build confidence in the program when NIOSH can’t answer basic questions about how it spent half a billion dollars. I’ll have some questions for Dr. Howard about this. 9/11 victims deserve better.

Having said that, NIOSH programs are just one piece of the puzzle, a second task of the working group was to inventory all of the 9/11 programs, plus health and compensation systems that were already in place, to see how all the pieces fit together.

We learned that the Federal Emergency Management Agency, FEMA, used some of its 8-and-eight/tenths-billion dollars in 9/11 funds for screening and recovery, and for mental health counseling and assistance to hospitals, under the Stafford Act.

A Victims Compensation Fund, VCF, administered by Ken Feinberg, paid out more than $7 billion to families of those killed on 9/11, and about 2,000 workers with 9/11 health claims.

Congress appropriated $50 million for the New York State Workers Compensation system to respond to claims filed by volunteers, that are not typically eligible for compensation. New York State extended its filing deadline until September 11 of this year.

The full extent of the Department of Health and Human Services programs is unknown. Through 2007, it looks like HHS administered between $778 million and $1.01 billion worth of 9/11 health programs through the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, and the National Institutes of Health, and NIOSH.

Within the NIOSH program, grantees can sometimes recoup payments when patients are entitled to workers compensation, disability, private health insurance, or public entitlements. Going forward, we’ll also want to understand how NIOSH programs dovetail with coverage under the new healthcare reform law.

And earlier this month, a judge tentatively approved a $712-million settlement for the 9/11 health claims. These funds will come from the World Trade Center Captive Insurance Company, an entity created by Congress specifically for this purpose.

I hope this hearing will help us understand how all these pieces fit together, so we can make sure heroes get the help they need, and the community and taxpayers get the well-administered program they deserve.
I thank the witnesses for coming, and look forward to their testimony, as well as Senator Gillibrand.

The CHAIRMAN. Thank you, Senator Enzi.

I note there’s a vote in the House, so our guests have to leave here.

Well, we’re joined today by an outstanding set of witnesses. We’ll have three panels. The first panel will be Senator Kirsten Gillibrand, the junior Senator from New York. And we welcome our esteemed colleague, here, who is sponsoring this important bill. And I thank the Senator for her great leadership in this area, first as a Senator, and then previously as a member of the House of Representatives, for all that you’ve done to meet the health needs of the people who were affected by the disaster on 9/11.

So, we thank you for being here. Your statement will be made a part of the record in its entirety. Please proceed as you so desire, Senator Gillibrand.

STATEMENT OF SENATOR GILLIBRAND

Senator GILLIBRAND. Thank you very much, Chairman Harkin. I’m extremely grateful for your leadership and for convening this hearing.

I want to thank Ranking Member Enzi for his hard work over these years, working with Secretary Clinton, and doing so much hard work and analysis to ensure that the men and women who need these funds are provided for.

I’m very grateful that you’ve taken the time to bring this committee together to discuss the legislation to provide health treatment and victim compensation to the affected first responders and survivors of September 11.

I want to thank our witnesses—Dr. John Howard, the director of the National Institute for Occupational Safety and Health; Dr. Jim Melius, the administrator of New York State Laborers’ Health and Safety Trust Fund, and chair of the Steering Committee for the World Trade Center Medical Monitoring and Steering Program; Dr. David Prezant, our chief medical officer for the Fire Department of New York City; Lieutenant Marty Fullam of the Fire Department of New York City; and Margrily Garcia, a patient at the World Trade Center Environmental Health Center—for providing testimony on today’s bill.

We obviously can all agree that we, as a nation, have an undeniable moral obligation to provide treatment for individuals who are sick and dying because of the terror attacks at Ground Zero. The responders and the survivors living in the area were told by the Federal Government that the area was safe. They removed debris and recovered victims with little to no safety equipment to protect their lungs from the toxic ash that invaded Ground Zero for months. They tried to return to their normal lives, as best they could, because that is what the Nation asked them to do.

I chose to have one picture today for my testimony. And this is just a sense of the kind of contamination that was in the air that the men and the women who were present when the towers collapsed—you can see the amount of film on their clothing, on their faces. That film was present in the air for months afterwards. And
so, this is something that people who worked on the pile, day in, day out, breathed in, with very little protective equipment.

And for the communities living in the area, there was absolutely no protective instructions provided. Community members were told, “Go ahead, clean your apartments. You can use a mop and plain old water.” And for them to breath in these toxins, day in, day out, from their furniture, from their carpets, was something that has been devastating to their long-term health. In particular, there were many children in daycare centers, in schools, that were sent back to school very quickly, who didn’t have the benefit of real environmental cleaning. And that’s one of my primary concerns.

Just this week, I spent time with those parents. I met with those community leaders. I met with those men and women who are now struggling with these diseases. And as a parent with a child who has asthma, I know how difficult it is for young children when they do have grave respiratory illnesses, such as asthma.

This tragedy is obviously beyond our comprehension. And our failure, as a nation, to confront it should offend all of us at the very core, to make sure that we provide the healthcare that these families and first responders and survivors desperately need.

My legislation will fulfill this moral obligation to these heroes and those who have sacrificed their lives for our country, and all the victims who are ill and dying, because of the worst terrorist attack in our history.

Building upon the Centers for Excellence, S. 1334 establishes formal—formal—eligibility requirements, and provides health benefits through a national network of providers.

It also addresses some of Senator Enzi’s main concerns. This new bill will provide a level of accountability and transparency in the disbursements of funds that we have not seen up until this time with the current program. It terminates the six billing systems created in the chaotic aftermath of September 11, and will establish a third-party administrator who will set the rates, track expenditures, and enforce eligibility requirements.

It also creates a dedicated line of funding so the victims can receive the consistent and 9/11-specific care that they need for the illnesses that have been created.

Additionally, it would ensure that survivors are compensated for their losses that they’ve experienced as a result of these health problems connected to Ground Zero, by reopening the Victims Compensation Fund.

I also have, for the record, Senators, about 20 letters from community groups throughout our State and—that are very, very moving—not only from our Governor, but from children who have lost their parents. You know, one in particular, this is a letter from Jennifer McNamara, who lost her father. You can see the difference between this brave, very able and fit firefighter from 2001, and how diminished, because of his health conditions, he was by 2009. So, these letters are an important part of the record, and I do hope you’ll have the opportunity to look through them. They’re from community organizations, from schools, from all the advocates who are living this every day.

The CHAIRMAN. We'll make those a part of the record.

Senator GILLIBRAND. Thank you.
Senator GILLIBRAND. As we debate this bill, let us all remember the lives of those we’ve lost, and the thousands of survivors who are living and working in the area, and the tens of thousands of responders that came from every single congressional district in our wonderful country. We must establish efficient programs to provide for their care and treatment, and fulfill this moral obligation to them all.

The horrific damage of 9/11 did not end when the buildings came down. For thousands of Americans, the horror and the pain began weeks, months, and sometimes, years later. We must never forget the way these men and women have sacrificed for our country.

Thank you, Mr. Chairman. Thank you, Mr. Ranking Member. I’m happy to answer any of your questions.

[The prepared statement of Senator Gillibrand follows:]

PREPARED STATEMENT OF SENATOR GILLIBRAND

Thank you very much, Chairman Harkin and Senator Enzi, for convening this hearing. I am incredibly grateful that you have taken the time to bring the committee together to discuss this incredibly important issue and my legislation to provide health treatment and victim’s compensation to the affected first responders and survivors of September 11th.

Thank you to our witnesses Dr. John Howard, Director, National Institute for Occupational Safety and Health, Centers for Disease Control and Prevention, Department of Health and Human Services, Dr. Jim Melius, Administrator of the New York State Laborers’ Health and Safety Trust Fund and Chair of the Steering Committee for the WTC Medical Monitoring and Steering Program, Dr. David Prezant, Chief Medical Officer, Fire Department of New York City, Office of Medical Affairs, Lt. Martin Fullam, firefighter, Fire Department of New York City, and Margrily Garcia, a patient at the World Trade Center Environmental Health Center, for providing testimony today on this bill.

I hope we can all agree that we as a nation have an undeniable moral obligation to provide treatment for individuals who are sick and dying because of the terror attacks at Ground Zero. The responders and survivors living in the area were told by the Federal Government that the area was safe. They removed debris and recovered victims with little to no safety equipment to protect their lungs from the toxic ash that invaded Ground Zero for months. They tried to return to their normal lives because that was what our Nation asked of them to do.

Now years later tens of thousands of these Americans are sick and dozens perhaps hundreds are dying. Just this week, I spent time with parents who had children enrolled in daycare centers in the area. These children are now suffering from horrible asthmatic conditions and could experience other horrible health effects that we have only begun to discover.

This is a tragedy and our failure as a nation to confront it is an outrage. My legislation would fulfill our moral obligation to the heroes who have sacrificed their lives for our country and all the victims who are dying from the worst terrorist attack in our history.
by creating a fully transparent system that establishes a long-term health program with proper oversight and accountability.

My legislation would create a fully transparent system that establishes a long-term health program that our heroes and community survivors can rely on.

- It would terminate the six billing systems created in the chaotic aftermath of September 11th and establish a third party administrator, who will set reasonable rates, track expenditures and enforce eligibility requirements.
- The legislation would require an annual program report to Congress. And 3 years after enactment, the Government Accountability Office would be required to report to Congress on the cost of the program.
- This bill would create the needed statutory infrastructure to fulfill our moral obligation with a program that is efficient, effective, and diligent with taxpayer funds.

My legislation also tightens the eligibility criteria that an individual has to meet to be covered by this program.

- There are specific times that a responder or community survivor would have had to have been in Lower Manhattan. Individuals would only receive assistance if they are diagnosed with a condition from the list of covered ailments, such as Chronic Respiratory Disorder, interstitial lung disease, and Post Traumatic Stress Disorder (PTSD).
- A physician with experience in WTC-related diseases would have to make the determination that the disease is related to exposure on or in the aftermath of 9/11.
- These eligibility guidelines ensure that all who were exposed to the toxic cloud are able to receive the medical treatment they require. Those eligible are not just responders, but also community survivors who lived, worked, or attend school in the affected area.

I would like to submit more than a dozen letters of support from Members of Congress, elected officials, local community organizations, businesses, labor, and others from New York City and across the country that are asking the Senate to move forward on this important bill. As we debate this bill, let us think about the lives of these heroes—the thousands of survivors living and working in the area and the tens of thousands of responders that came from every single congressional district in the country to serve our Nation. Listen to the stories of Lt. Martin Fullam and Margrily Garcia, who you will hear from today.

We must establish efficient programs to provide for their care and treatment, and fulfill our moral obligation to these heroes.

The horrific damage of 9/11 did not end when those buildings came down. For thousands of Americans, the horror and the pain began weeks, months and sometimes years later. We must never forget the way these men and women have sacrificed for our country.

Thank you and I look forward to answering any of your questions about my legislation and hearing from the expert witnesses today.

The CHAIRMAN. Well, Senator Gillibrand, thank you very much, again, for your leadership on this issue, and for a very impassioned
statement, and for the legislation that you’ve introduced. Like so many of us here, I know you have a lot on your schedule today, too, that you have to do. And so, we thank you for appearing here. Without further ado, we——

Senator GILLIBRAND. Thank you, Mr. Chairman. Thank you, Mr. Ranking Member.

The CHAIRMAN [continuing]. Excuse you, and we’ll get on to our next panels.

Thank you very much, Senator.

Senator GILLIBRAND. Thank you.

The CHAIRMAN. Now we go to panel two. And that’s Dr. John Howard, director of the National Institute of Occupational Safety and Health, and the coordinator of the World Trade Center programs, board-certified in internal medicine and occupational medicine.

You were just here, now that I think about that. So, you must like it here.

Welcome back, Dr. Howard. And again, your statement will be made a part of the record in its entirety. Please proceed.

STATEMENT OF JOHN HOWARD, M.D., DIRECTOR, NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH, CENTERS FOR DISEASE CONTROL AND PREVENTION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ATLANTA, GA

Dr. HOWARD. Thank you very much, Mr. Chairman, and Ranking Member Enzi, and other distinguished members of the committee.

Thank you for inviting me here today. I’m pleased to say, at the outset, that Secretary Sebelius and President Obama are committed to ensuring that rescue and recovery workers, residents, students, and others suffering from the health consequences related to the World Trade Center disaster have access to the monitoring and treatment that they need. In fact, the President’s 2011 budget more than doubles the funding for care and monitoring of the 9/11 heroes.

First, let me tell you a little bit about the World Trade Center Responder Health Program, which provides monitoring and treatment services for responders who were involved in the World Trade Center disaster. This program consists of a center at the Fire Department of New York City, and at five medical centers in the New York/New Jersey area, which provide these services to responders.

In addition, there are two data-coordination centers, one at FDNY and one at Mount Sinai, which provide patient data management. As of March 31, 2010, a total of 48,613 responders are enrolled in the New York/New Jersey metropolitan area program; 15,000 at FDNY; 32,000 at the other five academic centers, combined.

CDC also supports the New York City Police Foundation’s Project Hope and the Police Organization Providing Peer Assistance, or POPPA, which provides psychological health services to World Trade Center police responders. The cooperative agreements for the grantees in the New York/New Jersey area will be extended to July 2011, next month.

Second, through the National Responder Contract, medical monitoring and referral treatment services are provided to about 4,000 responders who came to New York City from States like Wyoming
and Iowa and other States, and returned to their home, and now live outside the New York/New Jersey metropolitan area. CDC will announce a solicitation for a new national responder contract soon, and expects to award that contract in September.

Third, since 2008, when Congress appropriated funds to provide screening and treatment for residents, students, and others who were affected by the World Trade Center, CDC has offered these services to eligible members of the community. As of March 31 this year, about 4,500 individuals are enrolled in the community program.

Finally, CDC funds the World Trade Center Health Registry, operated by the New York City Department of Health and Mental Hygiene, which follows a cohort of about 71,000 people who performed 9/11-related rescue and recovery work, or who lived, worked, and attended school in the vicinity of Lower Manhattan on September 11, 2001.

This is the largest post-disaster health registry in U.S. history. The registry goals are to identify the long-term physical and mental health effects of the 9/11 disaster, disseminate findings and recommendations to registrants, the public, and the scientific community, share information about 9/11 resources and services, and inform health policy and disaster response planning.

The registry has published several peer-reviewed scientific articles, among—these are two that were published in 2007—one finding that newly diagnosed asthma, after 9/11, occurred at a rate that is 12 times the norm among adults in the United States, and another that showed the overall prevalence of post-traumatic stress disorder among responders enrolled in the registry was four times the rate of the general U.S. population.

By spotting these trends among registrants, the registry can provide valuable guidance to alert those affected by the World Trade Center disaster, and healthcare providers, of the potential health effects that might be associated with their exposures, and the need for early medical intervention.

Since 9/11, HHS and CDC has worked with our partners to best serve those who served their country, as well as those in nearby communities affected by the terrorist attacks. HHS and CDC will continue to provide medical monitoring and treatment services to responders, regardless of their location, as well as to residents, students, and others most directly affected by the World Trade Center attack.

Thank you, Mr. Chairman, and I'm happy to answer any questions.

[The prepared statement of Dr. Howard follows:]

PREPARED STATEMENT OF JOHN HOWARD, M.D.

Good afternoon, Mr. Chairman, Ranking Member Enzi, and other distinguished members of the committee. Thank you for inviting me to testify today. I am Dr. John Howard, Director of the National Institute for Occupational Safety and Health (NIOSH), which is part of the Centers for Disease Control and Prevention (CDC) within the U.S. Department of Health and Human Services (HHS). CDC's mission is to promote health and quality of life by preventing and controlling disease, injury and disability. NIOSH is a research institute within CDC that is responsible for conducting research and making recommendations to identify and prevent work-related illness and injury.
Mr. Chairman, I would like to express my appreciation to you and to the members of the committee for holding this hearing and for your support of our efforts to assist those who are at risk or have experienced adverse health outcomes from their 9/11 exposures. I am pleased to appear before you today to report on the progress HHS has made in addressing the health needs of those who served in the response effort after the World Trade Center (WTC) attack on 9/11, and those in the affected communities and HHS efforts to improve the existing program.

In September 2009, I began my second term serving as the HHS WTC Programs Coordinator. Health and Human Services Secretary Kathleen Sebelius and CDC Director Dr. Thomas Frieden emphasized the “critical need to ensure that programs addressing the health of WTC responders and nearby residents are well-coordinated,” and charged me with this important task.

This Administration is committed to ensuring that rescue and recovery workers, residents, students and others suffering the health consequences related to the World Trade Center attack have access to the monitoring and treatment they need. The President’s 2011 Budget will more than double the funding for the medical care and monitoring of these 9/11 heroes.

Significant activities have been implemented and continue to evolve through key partnerships with academic and clinical centers of excellence in occupational and environmental health.

WTC RESPONDER HEALTH PROGRAM—MONITORING AND TREATMENT

Since 2002, agencies and offices within HHS have been dedicated to tracking and screening WTC rescue, recovery and clean up workers and volunteers (responders). HHS has allocated more than $1 billion for recovery-related efforts since September 11, 2001.

In 2010, Congress appropriated $70.7 million to CDC to further support existing HHS WTC programs and provide screening, monitoring and medical treatment for responders and others in affected communities. Since fiscal year 2002, Congress has provided approximately $475.8 million for WTC screening, monitoring, and treatment activities, and grantees have spent approximately $263 million. Since these funds were appropriated, NIOSH has established a coordinated WTC Responder Health Program to provide periodic screenings, as well as diagnosis and treatment for WTC-related conditions (e.g., aerodigestive, musculoskeletal, and mental health) identified during monitoring exams. Current spending rates indicate that there are sufficient resources to provide health care treatment and monitoring for World Trade Center responders and non-responders through fiscal year 2010. The fiscal year 2011 President’s Budget requests $150 million for the WTC program. Based on current spending rates, the fiscal year 2011 Budget request is expected to provide sufficient funds to fully continue and manage the WTC program.

The WTC Responder Health Program consists of a consortium of clinical centers and data coordination centers that provide patient tracking, standardized clinical and mental health screening, treatment, and patient data management.

As of March 31, 2010, more than 52,667 responders from across the country and 4,583 non-responders have met the eligibility criteria and have enrolled in the WTC Health Programs. Most of the enrolled responders reside within the greater New York City-New Jersey (NY/NJ) Metropolitan area; however, 4,054 enrolled responders reside across the United States, including Federal responders who were integrated into the NIOSH program in fiscal year 2008. Of responders and non-responders, 50,662 have received an initial health examination, and responders are offered follow-up monitoring examinations annually. Over the past year, 25,280 monitoring examinations were conducted, and 15,889 enrollees received treatment for WTC-related health conditions.

The New York-New Jersey consortium—five clinical centers of excellence—(non-FDNY Responders) provided data on its program as of March 31, 2010. According to the data provided, these clinics have conducted 27,682 initial examinations and 12,071 monitoring examinations during the past year. During the same year, there were 7,578 patients in treatment.

According to data provided by the FDNY program, they have conducted 15,307 initial exams and 9,934 monitoring exams in the past year. FDNY provided health care for 4,993 treatment patients.

In conjunction with these activities, CDC/NIOSH has funded the NYC Police Foundation’s Project COPE and the Police Organization Providing Peer Assistance (POPPA) to continue providing mental health services to the police responder population. The availability of treatment for both physical and mental WTC-related health conditions has encouraged more responders to enroll and continue partici-
Many rescue and recovery workers traveled from other States to New York City to participate in the response efforts and following their service, have returned to their States of residency. Initially, these responders were offered monitoring exams through facilities that were subcontracted by Mount Sinai Medical Center. Responders referred for treatment from these monitoring exams were referred to the philanthropically funded Association of Occupational and Environmental Clinics (AOEC). AOEC was funded by the American Red Cross to ensure the delivery of needed treatment services for the WTC responders located outside the catchment area of the FDNY and NY/NJ Consortium. As the philanthropic funds for treatment were expended, monitoring and treatment services were combined into a national services contract that included the Federal responders. An $11 million contract was awarded to Logistics Health Incorporated (LHI) on May 31, 2008 to ensure that monitoring and treatment services would continue without interruption. HHS is working to award a new responder contract in early September and will continue to work with its partners to ensure that the benefits of all federally funded programs are available to eligible responders across the Nation by ensuring that responders do not face an interruption of services and can easily transition between funded programs. As of March 31, 2010, of the 4,054 responders residing outside the NYC-NJ metropolitan area that have enrolled in the WTC Responder Health Program, 2,067 had completed monitoring exams. These responders, including current and former Federal employees, receive monitoring and treatment services via a national network of clinics.

**COMMUNITY PROGRAM**

From September 11, 2001 until 2008, HHS/CDC provided health care services solely to WTC responders. However, in the Consolidated Appropriations Act, 2008, Congress appropriated funding “to provide screening and treatment for first response emergency services personnel, residents, students, and others related to the September 11, 2001, terrorist attacks on the World Trade Center.” As of March 2010, 4,583 non-responders were enrolled in the program; 1,208 received monitoring exams and 2,629 received treatment for WTC-related health conditions.

**WTC HEALTH REGISTRY**

In addition to the WTC Responder Health Program, CDC/NIOSH maintains the World Trade Center Health Registry (WTCHR). It is the largest post-disaster exposure health registry in U.S. history and follows a diverse cohort of 71,437 directly affected people who performed 9/11-related rescue/recovery work or lived, worked or attended school in the vicinity of Lower Manhattan on 9/11/01. The goals of the WTC Health Registry are to identify the long-term physical and mental health effects of the 9/11 WTC disaster; disseminate findings and recommendations to enrollees and others exposed, the public, and the scientific community; share information about 9/11-related resources and services; and inform health care policy and disaster response planning. Specific aims are to: (1) Expand knowledge about the long-term health effects of 9/11 by continuing the WTCHR research program; (2) Conduct community activities to respond to the physical and mental health concerns and specific healthcare needs of enrollees; and (3) Maintain the Registry as a valuable public health resource for future research.

CDC and the Agency for Toxic Substances and Disease Registry (ATSDR) have supported the WTCHR for 6 years, and over $20 million have been invested to date. In addition, Registry data are used to identify trends in physical or mental health resulting from the exposure of nearby residents, school children and workers to WTC dust, smoke and debris. Two journal articles published findings on 9/11-related asthma and post-traumatic stress disorder (PTSD) among rescue and recovery workers (Environmental Health Perspectives, 8/27/2007; and American Journal of Psychiatry, 2007; 164:1385–94). Newly diagnosed asthma after 9/11 was reported by 926 (3.6 percent) workers, a rate that is 12 times the norm among adults. Similarly, the overall prevalence of PTSD among rescue and recovery workers enrolled on the WTC Health Registry was 12.4 percent, a rate four times that of the general U.S. population. By spotting such trends among participants, CDC/NIOSH can provide valuable guidance to alert Registry participants and caregivers on the potential health effects that might be associated with their exposures.

The WTC Health Registry also serves as a resource for future investigations, including epidemiological, population specific, and other research studies, concerning
the health consequences of exposed persons. These studies will permit us to develop and disseminate important prevention and public policy information for use in the unfortunate event of future disasters. The findings can assist those working in disaster planning who are proposing monitoring and treatment programs by focusing their attention on the adverse health effects of airborne exposures and the short- and long-term needs of those who are exposed.

CONCLUSION

Since 9/11, HHS has worked diligently with our partners to best serve those who served their country, as well as those in nearby communities affected by the tragic attack. HHS will continue to provide medical monitoring and treatment services to responders, regardless of their location, as well as to residents, students and others most directly affected by the WTC attack. This commitment is reflected in the fiscal year 2011 Budget request of $150 million for the World Trade Center Program, which is a doubling of the fiscal year 2010 levels. Likewise, the WTC Health Registry continues to paint a picture of the overall health consequences of 9/11, including the effects experienced by the residents, school children and office workers located in the vicinity of the WTC. HHS is also working to increase program accountability and fiscal management in fiscal year 2011 through improved data collection and analysis. Thank you for this opportunity to update you on our progress. I am happy to answer any questions you may have.

The CHAIRMAN. Dr. Howard, thank you very much.

As administrator of the World Trade Center programs for many years, you’ve had intimate knowledge of what’s been going on. Again, just sum up, looking back—What would you say has worked well? And what do we need to do now to make any improvements?

Dr. HOWARD. Well, I think what’s worked well is the partnership that we have with local institutions in New York/New Jersey that are closer to the population, understand the population better, are best able to provide medical services.

The national program—I think we’re fortunate in the contractor that we have that’s been able to reach out to a network of health providers so that we don’t lose any of these providers that are now returned to their home States.

I think one of the areas that—speaking on behalf of the grantees, stable funding is an important issue. These are medical institutions that have many healthcare programs; and obviously having some stable funding, as opposed to year-by-year funding, is an issue—I think, that is one area that I think could improve.

The CHAIRMAN. I don’t want to detract from the importance of this hearing, in terms of applying what we need to do for the World Trade Center—the victims—but, I have had a number of emails into my office, and actual phone calls, and others, from people concerned about the workers in the Gulf, and respiratory problems, and saying that we ought to be mandating that people who work down there have to wear respirators. Yet, every time I turn on the TV, I see people down there going about in T-shirts with no respirators or anything like that. And I don’t know that much about this, but I’m just wondering, What lessons did we learn from 9/11 that we should be applying to the Gulf crisis?

Dr. HOWARD. Well, I think this is a very important question. And, indeed, from the experience in the World Trade Center response, I think there are three lessons that we learned that we are applying in the Gulf oilspill. First of all is, have a list of who the responders are, some basic demographic information, some idea of what jobs they’re being assigned to.

One of the issues in the World Trade Center is that we’ve had a continuing problem identifying those who were actually involved
in the response. So, having the roster of individuals involved is something that we're doing now. And in the oilspill response to date, we've rostered over 20,000 workers. In other words, we know who they are, where they're working, and we can find them at any particular time.

The second big issue is exposure monitoring—real-time exposure monitoring. So, we now have a number of organizations, including governmental organizations, as well as contractors—OSHA and NIOSH being two of those governmental organizations, EPA being another one—and a number of contractors that are out looking at real-time exposure assessment—air monitoring, air sampling, for instance. So, we're able to create a picture of what the exposures are for individuals who are working now in the oilspill. We didn't have some of that real-time exposure.

Then the third lesson that we learned is to be able to actually collect health surveillance information on the responders while they're working. So, we're preparing a symptom survey that we're going to administer to response workers who are currently working in the Gulf oilspill, to be able to understand, What symptoms are they experiencing? We know about folks who are seeking medical attention, who go to the medical clinic or are transported to an emergency room. We know what their issues are. But, we don't know the general worker response issues with regard to, Are you feeling any symptoms? So, those symptom surveys are going to be done during the response. So, those are three lessons I think that we learned from the World Trade Center.

The fourth lesson has to do with, Where do you go from here, after the response is completed? So, having some information about what the exposures were, having some information about what the symptoms were during the response, we can better manage, implement, a chronic health effect survey and decide whether or not—What kind of study do we need to do on these individuals over time to look for chronic health effects?

So, I think the World Trade Center—one of the positives from this terrible, terrible tragedy is that we've learned how to manage the health effects of disasters better than we did when we walked into the World Trade Center.

The CHAIRMAN. Well, that's very encouraging.

Thank you very much, Dr. Howard.

I'll turn to Senator Enzi.

Senator Enzi. Thank you, Mr. Chairman.

In your testimony, I think you mentioned that the New York Fire Department conducted 15,307 initial exams, and then 9,900 monitoring exams, in the past year. That number is a little confusing. Could you—since there are 16,000 firefighters, wouldn't most of those have had some initial exams, even well before the Trade Center?

Dr. Howard. Well, of course, I'll let Dr. Prezant speak more directly to that. But, New York City firefighters, like all firefighters, are subject to fitness-for-duty exams, which are usually annually. So, those firefighters would have had annual exams. In fact, one of the real positives with the cohort of FDNY responders is that we have, if you will, predisaster medical information. So, when we're able to—when we're looking at a health effect after 9/11 in that co-
hort, we're able to compare it better with a predisaster health effect.

Senator ENZI. Thank you.

Healthcare payers generally require providers to furnish detailed information about patients, their treatments, their costs. There's a consensus that this type of information is needed. It's the foundation of all the delivery system, quality, and payment reforms. From the documentation that I have from you, it looks like you require grantees to report how much they spent, but not how they spent it. Why is that?

Dr. HOWARD. Yes, Senator, what you're seeing is exactly what we require in the grant mechanism. And what we're doing now, and have been doing for the last year and a half, is to obtain more granular detail about fiscal management categories—actually, service categories. We're asking the grantees now to give us more granular data about the service type that they're charging, to be able to get to, if you will, what your question gets to, which is health-claims-level data. This is not exactly that kind of vehicle—cooperative agreement isn't that kind of vehicle. But, we're moving toward that. We've implemented some of those requirements in the last extension. We're implementing many more in the current extension, which will start next month.

So, we, like you, are looking at some of those financial status reports, where we're looking at how much funds are obligated, how have they been spent. And we're seeing that we don't have enough information to do sound fiscal management.

Senator ENZI. It's been quite a while. One argument for authorizing those programs through the Help Committee was that we could assure accountability and transparency. That way, victims would know that they were getting the best care, and taxpayers would know that the funds were being used effectively to help victims. What procedures have you used to assure the accountability and transparency over the 475 million you've already received?

Dr. HOWARD. Senator, I think that's another excellent question. And I would separate it into two phases.

In 2002 and 2003, I would say that we were in an emergency provision phase, if you will. We received money from FEMA and we weren't exactly sure what was going on with these responders or community members, in terms of their health. And we quickly got out the money, with very little strings attached to it.

As we then did the 5-year cooperative agreement, which started in 2004—some of the FSRs that we provided to you are based on that 5-year period of time—in those, toward the end of that period of time, in 2007 and 2008, we began looking at technical assistance visits to each of the grantees to try figure out, “Let’s look at the books, and figure out whether we can help you with fiscal management, and provide more assistance.” So, that phase, we began to actively implement some of the issues that you’ve identified.

And now, as we get to 2008, 2009, and 2010, we have placed that burden on the grantees, to do sounder fiscal management, in terms of, basically, quasi-claims-level data.

Senator ENZI. It seems like a lot of people can fall between the cracks, though, between one program and another program.
The Congressional Budget Office expects most 9/11 victims to continue to receive care from providers other than the Centers of Excellence or the World Trade Center Health Program. Do you know why patients are choosing to go to other providers?

Dr. Howard. I assume you’re talking about responders choosing to go to outside of the Federal-funded programs?

Senator Enzi. Yes.

Dr. Howard. I'm not 100 percent sure about that, Senator, so I would have to get back to you on that.

Senator Enzi. OK. And another thing, since my time's expired, I'll have you get back to me on how that NIOSH program has recouped from, say, workers compensation, disability, private health insurance, public entitlement, and the other benefit delivery systems that——

Dr. Howard. Sure. And I'd be happy to answer that. If I could have a minute, I'll get you the specifics on that.

Senator Enzi. I'll just send that to you in writing.

Dr. Howard. OK, great.

Senator Enzi. Don't answer it now. I've got several other questions, too, but that will take care of it.

Go ahead.

The Chairman. Thank you, Senator Enzi.

Senator Merkley.

STATEMENT OF SENATOR MERKLEY

Senator Merkley. Thank you very much, Mr. Chair.

And thank you for your testimony.

First, I congratulate Senator Gillibrand for bringing this bill forward to try to create a solid framework into the future, to provide for both the healthcare needs of the community and the responders.

One thing I want to have you comment on is—this is separate from the settlement structure—but, my understanding is, the settlement structure does not provide for the future healthcare of those who are not currently sick and those who have not filed a lawsuit. Could you comment on that?

Dr. Howard. I wish I could, but I'm not an expert on the settlement. I've never read it. And so, I wouldn't be able to do that. However, I certainly would be happy to try to get that information to you.

Senator Merkley. OK. Well, I'll just note that that’s my understanding. And that’s part of the reason that this bill is necessary.

I was wondering if you could comment some on the difference between the health effects of those who were near or in the toxic cloud the first, say, 48 hours, and those who were exposed over a longer period of time, later, and whether you see significantly different patterns of health problems.

Dr. Howard. Well, again, I’m going to ask Dr. Prezant, who is quite familiar with the cohort of FDNY responders, and has published a number of different studies in that area.

You know, certainly in the overall cohort of responders, we see probably at least three major areas where health effects are persistent; first, in the psychological stress reactions that Senator
Harkin has referred to already—we see persistent post-traumatic stress disorder.

The second category would be in respiratory effects, both upper and lower respiratory effects. Some of them short-lived, some of them are intermediate, and some of them have persisted for many, many years. As Dr. Prezant reported, with a number of other researchers recently, in April, the New England Journal of Medicine, some of those effects have lasted 7 years since the disaster.

And then, the third area is upper gastrointestinal, or gastrointestinal esophageal reflux disease; we see quite a bit of that.

Those are the major chronic health effects we’re seeing in the population.

Senator MERKLEY. Thank you.

Thank you, Mr. Chair.

The CHAIRMAN. Dr. Howard, thank you very, very much.

Time compels us to move on to our next panel.

Thank you very much for your leadership, and for being back with us again today.

Now, we have our third panel. And this panel, I’ll introduce in order.

Dr. James Melius. He’s the administrator of the New York State Laborers’ Health and Safety Trust Fund and chair of the Steering Committee for the World Trade Center Medical Monitoring and Steering Program. Dr. Melius is an occupational health physician, an epidemiologist by training, and has years of experience with occupational and environmental health issues.

Next is Dr. Prezant. He is the chief medical officer for the New York City Fire Department, and the codirector of the New York Fire Department’s World Trade Center Medical Monitoring and Treatment Program. Dr. Prezant is also a professor of medicine and pulmonary diseases at the Albert Einstein College of Medicine, and the principal investigator for the New York City Fire Department’s Data Center, which conducts analysis of the health effects of the World Trade Center attacks on firefighters.

Then we have Lieutenant Marty Fullam. Lieutenant Fullam devoted nearly 30 years of his life to the New York City Fire Department. In the days and weeks following the September 11 terrorist attacks, he worked with his fellow firefighters, at Ground Zero, to rescue survivors and restore order. In 2005, doctors diagnosed Lieutenant Fullam with a rare autoimmune disease called polymyositis and he underwent a lung transplant last year. Lieutenant Fullam lives on Staten Island with his wife Tricia and his three daughters.

Finally, we have Margrily “Maggie” Garcia. Ms. Margrily Garcia, from the Bronx, New York City, was forced to evacuate her office building near the World Trade Center on September 11. In the weeks following the attacks, she developed a persistent cough and eventually sought out treatment at Bellevue Hospital’s World Trade Center Program.

Thank you for being with us today, Ms. Garcia. And we look forward to also hearing your story.

So, from left to right, we’ll start with Dr. Melius.
Again, all of your statements will be made a part of the record in their entirety. And I'd ask you to sum up in 5 minutes or so, if you could; I'd appreciate it.

Dr. Melius.

STATEMENT OF JIM MELIUS, M.D., DrPh, ADMINISTRATOR, NEW YORK STATE LABORERS' HEALTH AND SAFETY TRUST FUND AND CHAIR OF THE STEERING COMMITTEE FOR THE WTC MEDICAL MONITORING AND STEERING PROGRAM, ALBANY, NY

Dr. Melius. Thank you, Chairman Harkin, Ranking Member Enzi, Senator Gillibrand. I greatly appreciate the opportunity to appear before you today at the hearing. I will summarize my written testimony today.

I've been involved with the World Trade Center health issues since shortly after the attack occurred. As you indicated, I've been closely involved with all the medical programs that are currently in place for those workers, and working with NIOSH on that.

The pulmonary disease and other health problems among firefighters and other rescue, recovery workers, and community residents are quite serious, and are affecting a large number of people. In fact, I believe over 20,000 people have received treatment through the federally funded treatment programs. Others have received treatment elsewhere.

I believe that all of the Centers of Excellence, the clinics involved, are doing an outstanding job of providing high-quality medical care for the thousands of people that are affected by these exposures. And I believe that these programs have all been very effective in providing that care and keeping people at work, helping them to get better, as best we can, given the current status of our medical knowledge and care.

We also know that these medical problems are likely to persist for years, and require chronic monitoring and treatment. The toxic exposures that were experienced by people, as you see in this picture, were complex. We really don't understand what the long-term consequences will be. We certainly can expect that there may be other diseases emerging in the future. So, it's not only critical that we provide medical care and treatment and monitoring, but we also track these people over time to see what occurs and what we can learn from that so that we can provide better treatment in the future and prevent more people from becoming ill and disabled.

I believe that the current medical programs, and the way this is set up through the medical Centers of Excellence, provides the most effective and efficient approach to provide these people with expert medical care by physicians experienced in detecting and treating these conditions, and in a setting where their long-term health can be tracked. This combination of long-term health tracking and expert medical treatment, I believe, is essential to provide the best long-term medical care for these individuals, which I believe they all truly deserve.

These medical programs also require Federal support. As I testified in a previous hearing—I believe the subcommittee, 3 years ago—health insurance, and even health insurance under the healthcare reform that's recently been passed, and workers com-
pensation programs, will not provide the comprehensive reimburse-
ment that will cover these conditions and provide the support for
this care.

We need a comprehensive solution. I believe that the bill, Senate
1334, that Senator Gillibrand and others have introduced, provides
the framework for that treatment. It includes a number of improve-
ments. It institutionalizes a number of important improvements in
the program. It addresses the issue that Senator Enzi raised for re-
imbursement through more of a fee-for-service system so we can
better track and monitor treatment costs—a number of other
changes that I’ve listed in my testimony.

I also would add—the question I think Senator Merkley in-
quired—the Victims Compensation Fund is also a very important
part of this legislation. The recent settlement that was passed—
and I’ve read the settlement, and I’ve seen the press releases, dis-
cussions of it—this settlement does not cover medical costs. It will
not provide for—there’s no provision in it—in fact, they have stated
that they will be dependent on the federally funded program, or
some similar program, going forward, to provide medical care for
all of these people that are included in the settlement; simply deals
with economic losses, or future economic losses, for these people.
So, despite the settlement, and those other issues with the settle-
ment, we’re going to continue to need this program.

We’re approaching the ninth anniversary of this event. We’ve
known about the potential health consequences from these expo-
sures for most of those 9 years, seen the number of people who’ve
become ill, disabled, and dying from their World Trade Center con-
ditions continue to increase. Many of these people are truly heroes
for what they did. And all were initially reassured by the Federal
Government that the air was safe to breath.

We should now do our duty to these rescue and recovery workers
and community residents whose health has been damaged by the
World Trade Center exposures, and pass legislation that would pro-
vide long-term comprehensive medical and compensation programs
for these people. I urge you to do this as soon as possible.

I thank you, and I’d be glad to answer questions.

[The prepared statement of Dr. Melius follows:]

PREPARED STATEMENT OF JAMES MELIUS, M.D., DrPH

Honorable Chairman Harkin, Ranking Member Enzi, and other members of the
Senate Health, Education, Labor, and Pensions Committee. I greatly appreciate the
opportunity to appear before you at this hearing.

I am James Melius, an occupational health physician and epidemiologist, who cur-
rently works as Administrator for the New York State Laborers’ Health and Safety
Trust Fund, a labor-management organization focusing on health and safety issues
for union construction laborers in New York State. During my career, I spent over
7 years working for the National Institute for Occupational Safety and Health
(NIOSH) where I directed groups conducting epidemiological and medical studies.
After that, I worked for 7 years for the New York State Department of Health
where, among other duties, I directed the development of a network of occupational
health clinics around the State. I currently serve as chair of the Advisory Board on
Radiation and Worker Health which oversees part of the Federal compensation pro-
gram for former Department of Energy nuclear weapons production workers.

I have been involved in health issues for World Trade Center responders since
shortly after September 11. Over 3,000 of our union members were involved in re-
response and clean-up activities at the site. One of my staff spent nearly every day
at the site for the first few months helping to coordinate health and safety issues
for our members who were working there. When the initial concerns were raised
about potential health problems among responders at the site, I became involved in ensuring that our members participated in the various medical and mental health services that were being offered. For the past 6 years, I have served as the chair of the Steering Committee for the World Trade Center Medical Monitoring and Treatment Program. This committee includes representatives of responder groups and the involved medical centers (including the NYC Fire Department) who meet monthly to oversee the program and to ensure that the program is providing the necessary services to the many people in need of medical follow-up and treatment. I also serve as co-chair of the Labor Advisory Committee for the WTC Registry operated by the New York City Department of Health and as a member of the Community Advisory Committee for the medical program serving the community residents and workers affected by 9/11 exposures. These activities provide me with a good overview of the benefits of the current programs and the difficulties encountered by responders seeking to address their medical problems and other needs.

I believe that Dr. Prezant will testify in more detail on the medical problems experienced by the fire fighters and other responders. The pulmonary disease and other health problems among fire fighters, other rescue and recovery workers, and community residents are quite serious and are afflicting a large number of people. All of the federally funded medical programs have done an outstanding job in providing high quality medical care for the many thousands of people affected by these exposures. I believe that the expert medical care being provided is helping many of these ill people continue to work and be active which would not be the case if these programs did not exist.

These medical conditions are likely to persist for years and require chronic monitoring and treatment. As the recent study of NYC fire fighters demonstrates, the pulmonary capacity lost due to the WTC exposures does not appear to recover. Post traumatic stress disorder, another common condition in this population, is often very difficult to treat and requires years of treatment for some individuals. We also have to be vigilant for the emergence of new WTC-related conditions. The WTC exposures were complex and unlike any that have been studied in the past. It would not be unexpected for other WTC-related conditions to become apparent as time goes by. The collection of medical data on these populations allows us to track their health and identify new health problems due to their 9/11 exposures at an early stage when (hopefully) we will be able to avert more severe illness.

Given the need for long-term medical monitoring and treatment, the current programs provide the most effective and efficient approach to provide these people with expert medical care by physicians experienced in detecting and treating these conditions and in a setting where their long-term health can be tracked. The close link between the health monitoring or tracking and medical treatment is essential to provide the best long-term health care for these individuals.

These medical programs require Federal support. As I have testified at a previous hearing of this committee, health insurance (including Medicare) does not provide reimbursement for the treatment of work-related injuries or illnesses. Workers’ compensation systems are slow and are not designed to handle complicated cases where people have multiple health problems and whose medical needs and treatments may constantly change over time. Despite attempts by New York State to facilitate claims for people with WTC-related illnesses, these claims still take years to get adjudicated and often not in a satisfactory manner that would support the long-term health care needs of the claimants. Community residents often face similar problems with their health insurance, and many of them lack health insurance coverage at present or are covered by policies with high co-pays and other costs for them.

A comprehensive solution is needed to address the health needs of the 9/11 rescue and recovery workers and community residents. We cannot rely on a fragmented system utilizing private philanthropy, health insurance, line of duty disability retirement, and workers’ compensation to support the necessary medical monitoring and treatment for the thousands of people whose health may have been impacted by their WTC exposures. This fragmented approach will inevitably leave many of the ill and disabled rescue and recovery workers without needed medical treatment and will only worsen their health conditions. The delays and uncertainty about payments would discourage many of the ill rescue and recovery workers from seeking necessary care and discourage medical institutions from providing that care. We will also lose track of these people and the ability to monitor their long-term health.

S. 1334

Senate bill 1334 the James Zadroga 9/11 Health and Compensation Act of 2009 provides the comprehensive framework needed for the long-term health monitoring and treatment for the workers and community residents whose health has been af-
fected by their WTC exposures. The legislation builds on the current medical monitoring and treatment programs and adds appropriate oversight to ensure that the program is properly administered. These additions include:

- Certification by NIOSH for all new people enrolling in the program.
- Certification by NIOSH for the diagnosis of a WTC-related condition making that person eligible for treatment in the program. Note that this diagnosis requires two steps—the finding that the individual has the medical condition (on the list of WTC-related conditions) and then that, in his or her case, that condition is related to their WTC exposures.
- Basing the medical care at Centers of Excellence to ensure that physicians experienced in treating WTC-related health problems are providing this care.
- Reimbursement through a fee for service system that will help to better track and monitor treatment costs.
- Requirements for the development and use of approved treatment protocols where appropriate by the medical care providers in the program.
- Implementation of quality assurance programs.
- Implementation of a Federal program to detect fraud, duplicate billing, and payments for inappropriate services.
- Implementation of a method for adding new WTC-related health conditions after scientific review.
- Requirements for uniform data protocols within the program.
- Continuation of the national program to provide monitoring and treatment for individuals living outside of the New York City region.

These and other provisions in S.1334 will help to maintain the high quality of the program and ensure that the Federal support is properly administered by the participating medical centers and providers. It will also stabilize the funding for the institutions providing the care.

**VICTIMS COMPENSATION FUND**

The legislation would also reopen the victims compensation fund (VCF) which will provide fair compensation for economic losses for people whose health has been damaged by the WTC exposures. This is especially important for the many individuals who are disabled and unable to work and who are now unable to support their families. The VCF as administered immediately after 9/11 had a limited time period for application, and many people did not become ill until after they were no longer eligible to apply.

Recently, another possible source of compensation was announced. This is the proposed settlement of the lawsuits for health damages filed against the city of New York and other parties involved in the rescue, clean-up and recovery efforts. While we do not yet know the full details of that settlement, it is clear that this settlement does not provide a comprehensive solution. The lawsuits involve approximately 10,000 to 11,000 individuals including at least a few thousand without current health problems. We know that many more people have been documented to be ill due to their 9/11 exposures. The Federal medical programs have recognized over 20,000 people in treatment for WTC-related health problems. Many of these would not be covered by this settlement. Secondly, the settlement as announced does not include provisions for ongoing health care. Thus, even for those people who accept the settlement, there would be the need for current medical programs.

**CONCLUSION**

S. 1334 and the similar House bill H.R. 847 provide a sound and effective approach for supporting the long-term health care needs of the workers and residents whose health has been damaged by their exposures in the aftermath of the WTC terrorist attack. Discontinuing or disrupting this high quality, coordinated medical treatment would only exacerbate the health consequences of the 9/11 disaster. Most of the participants in the monitoring and treatment program have medical conditions (asthma, mental health problems, etc.) that should be responsive to medication and other treatments. They need expert medical care by providers who are experienced in providing care for WTC patients. Their health status needs to be tracked to detect illness in those who are not yet sick and to monitor for possible new conditions related to WTC exposures. The Centers of Excellence fulfill both of these functions. Hopefully, many of these people will gradually recover and not become disabled due to their WTC-related medical conditions. To the extent, that we can prevent worsening of the medical conditions and prevent many of these people from becoming too disabled to work, we can not only help these individuals, but we can also lower the long-term costs of providing care and assistance to this population.
The continued stable funding provided by this legislation will ensure that these excellent medical programs will continue to provide this badly needed care. Too often in the past, we have neglected to properly monitor the health of groups exposed in extraordinary situations only to later spend millions of dollars trying to determine the extent to which their health has been impacted. Agent Orange exposure in Vietnam and the current compensation program for nuclear weapons workers (EEOICPA) are only two examples of this problem. We should learn the lessons from these past mistakes and make sure that we provide comprehensive medical monitoring for those potentially impacted by the WTC disaster.

We are approaching the ninth anniversary of this terrible event. We have known about the potential health consequences from these exposures for most of those 9 years and have seen the number of people who have become ill, disabled, and dying from their WTC conditions continue to increase. Many of these people are truly heroes for what they did, and all were initially reassured by the Federal Government that the air was “safe” to breath. We should now do our duty to these rescue and recovery workers and community residents whose health has been damaged by their WTC exposures and pass legislation that provides long-term comprehensive medical and compensation programs for these people. I urge you to do this as soon as possible.

Thank you. I would be glad to answer any questions.

The CHAIRMAN. Thank you very much, Dr. Melius.

Now, we'll turn to Dr. Prezant.

Dr. Prezant, welcome.

STATEMENT OF DAVID PREZANT, M.D., CHIEF MEDICAL OFFICER, FIRE DEPARTMENT OF NEW YORK CITY, NEW YORK, NY

Dr. Prezant. Thank you. Good afternoon Chairman Harkin, Ranking Member Enzi, members of the committee, and Senator Gillibrand.

My name is David Prezant, and I’m the chief medical officer for the New York City fire department.

The FDNY World Trade Center Medical Monitoring Treatment and Data Analysis Programs are operated under a cooperative agreement with NIOSH. And the Senate and the House have generously provided funding so that FDNY could do this needed monitoring and treatment, and analyze our results, develop treatment protocols, and share this information with other healthcare providers throughout this Nation, so that our experience could be used to help their patients, as well as ours.

Our patients have chronic World Trade Center-related medical conditions that require long-term healthcare commitments impossible to achieve when the funding is provided year to year, and will run out on or about June 30, 2011.

Currently, our annual budget for monitoring, treatment, and analysis is nearly $35 million. Without continued funding, we will have to stop clinical services on or around late spring or early summer of 2011. This has been a constant battle for us, the end of each fiscal year.

Clearly, we need a long-term solution, and we hope to receive a commitment from the Senate, the House, and the President that matches the commitment FDNY firefighters and EMS workers and many others made on 9/11, the day our Nation was attacked, 2,751 innocent victims were killed, the day 343 FDNY first responders made the ultimate sacrifice. That day began a 10-month-long rescue/recovery effort during which nearly every FDNY member was exposed to World Trade Center dust and chemicals, risking their life and health.
Every FDNY firefighter and EMS rescue worker in our program suffered intense exposure, with health effects that could be objectively quantified because our program had the foresight to collect pre-9/11 health data, including breathing tests, on each and every one of them. Nearly 16,000 FDNY rescue workers took part on the rescue and recovery efforts—roughly 11,500 firefighter and fire officers; nearly 3,000 EMTs and paramedics; and nearly 1,000 FDNY pre-9/11 retirees that came in to help us.

Arrival time at the World Trade Center site, the initial day of arrival, has been the best predictor of health outcomes in both our cohort and the other cohorts. Nearly 2,000 of the 16,000 workforce, 15 percent, arrived during the morning of 9/11, during the collapse or immediately thereafter; 54 percent arrived during the remainder of that day; 14 percent on day 2; 15 percent during the days 3 through 14; and the rest thereafter. Most spent an average of 4 months working at Ground Zero.

Everyone received a pre-9/11 health exam. But, as of March 31, 2010, 15,307 of the 16,000 have received a first post-9/11 FDNY monitoring exam for an amazing 96-percent compliance rate—unheard of in any medical monitoring program. You asked, Why not 100 percent? Well, 343 could not receive a post-9/11 exam, because they were killed that day in the attack on our Nation.

Annually, we provide over 10,000 monitoring exams. And overall, since October 1, 2001, we have provided over 73,000 monitoring exams. Retention rates have been excellent, and define this program as the most successful labor management healthcare initiative in our history.

Ninety-four percent have received a second World Trade Center monitoring exam. Eighty-six percent have received a third exam. We just started a fourth exam, and already 74 percent have received that exam. And each year, these rates improve. And we are already starting, shortly, a fifth and sixth exam.

Disease surveillance is a critical part of this program. We don't just do monitoring. We look at the data, and we try to provide the best healthcare possible, based on what is—our findings show.

In the first year post-9/11, the average annual decline in pulmonary function for symptomatic and asymptomatic exposed FDNY rescue workers was 372 milliliters. That is 12 times greater than the annual decline in pulmonary function that we saw in each of the years before 9/11. Normally, our workers drop about 27 milliliters per year.

And in those who were most affected—most symptomatic, the decrease in pulmonary function was 600 milliliters, or 10 percent. Why was this decrease occurring? Because of asthma, reactive airways disease, chronic bronchitis. We've documented, in the New England Journal of Medicine, just recently, in April 2010, that over the next 6 years, pulmonary function did not return to normal. This drop was persistent and has not improved, despite time and treatment.

More than 30 percent of the members who participated in World Trade Center medical monitoring exams have upper and lower respiratory disease. We've shown an increase in other diseases, not just asthma, but sarcoidosis, which affects an increasing number of our workers; pulmonary fibrosis, luckily only in a few of our work-
ers. And we are closely monitoring for other diseases, such as cancer.

Seventy-six percent of our workers have reported psychological problems—12 percent with PTSD, post-traumatic stress disorder; 20 percent with chronic depression.

Overall, we have treated nearly 9,000 members for chronic respiratory or mental health issues. And nearly all of our patients have benefited from this treatment. But, despite this treatment, 1,300 FDNY rescue workers have had to file for respiratory disability—objective disability benefits, not based on symptoms, but based on clear declines in pulmonary function.

These healthcare findings, they really don’t speak to the heart of the matter, to what our patients are suffering on a daily basis. And if I could just have 1 more minute, I’d go over that with you briefly.

On 9/11, when the Twin Towers were burning, FDNY firefighters ran into those buildings. By the time the second plane hit, most realized that this was not going to be just a fire; this was an attack. And yet, they continued to run in. I have a patient who told a younger firefighter, “You go left, I’ll go right.” That younger firefighter died. And that older firefighter, because of that decision, feels he was responsible for that firefighter’s death. He woke up every night screaming for the first 6 months. And now he wakes up screaming less, but still so often that his wife sleeps in a separate room. That’s not the way things should be.

We have firefighters who have suffered severe trauma. One firefighter was rescued by a unit that went in specifically because they heard his distress on a radio signal. They found him lying in a pit. His skull was hanging off of his head. They put the top of his skull back on his head like a helmet, they picked him up and carried him out of there. He was the sickest firefighter during the first weeks after 9/11; intubated, dying several times, being brought back to life. Because of our treatment program, he is alive today. He still has symptoms, he still has some problems with asthma and PTSD and vertigo from his head trauma, but he is alive today. And he’s watched his two children grow. And that’s because of our treatment program.

Then, we have firefighters—a few, thankfully—who have suffered pulmonary fibrosis and the only treatment for pulmonary fibrosis is lung transplantation. Without new lungs, they would be dead. We’re lucky today that two of those firefighters have survived. One of them is here today, Lieutenant Martin Fullam, who will share with you his story in just a moment.

In summary, this program needs to continue for all the patients I’ve talked about today, for every FDNY rescue worker, for all the others exposed to the World Trade Center. This legislation will provide, hopefully, long-term funding so that they can receive health benefits.

Most importantly, I’m proud to say that this legislation will allow FDNY, New York City, and all of America to fulfill the commitment we made to each of those heroes on 9/11, to help those lucky enough to survive, and to help those who helped us survive.

Thank you.

[The prepared statement of Dr. Prezant follows:]
Good morning Chairman Harkin, Ranking Member Enzi and members of the committee. 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 World Trade Center (WTC) Medical Monitoring and Treatment Program. I am delighted to be here today to support this legislation, which will provide needed long-term funding for the monitoring and treatment of WTC-exposed responders and specifically for FDNY first responders. Many of these responders, unfortunately, have become patients with critical health needs related to physical, respiratory and mental health illness.

I would first like to thank this committee and the members of the Senate and the House of Representatives who have shown their extraordinary support for our patients, especially those from the New York delegation—Senators Gillibrand and Schumer and our New York members of the House of Representatives.

The FDNY WTC Medical Monitoring, Treatment and Data Analysis Programs are operated under a cooperative agreement with the National Institute of Occupational Safety and Health (NIOSH). This funding that the Senate and House have generously provided has helped the FDNY to provide needed monitoring and treatment, an ability to analyze our results, develop treatment protocols and share this information with other healthcare providers so that our experience could be used to help other patients with similar WTC-related problems. These patients have chronic WTC-related medical conditions that require long-term healthcare commitments—impossible to achieve when the funding is provided year to year and will run out on or before June 30, 2011. Currently our annual budget for monitoring, treatment (physical and mental health) and our data center is nearly $35 million. Without continued funding, we will have to stop clinical services in late spring to early summer of 2011. Clearly, we need a long-term solution—a commitment from the Senate, the House, and the President that matches the commitment FDNY firefighters and EMS workers made on 9/11, the day our Nation was attacked and 2,751 innocent victims were killed—the day 343 FDNY first responders made the ultimate sacrifice. That day began a 10-month long rescue/recovery effort during which nearly every FDNY member was exposed to WTC dust and chemicals, risking their life and health.

I am often asked, how many have been exposed, how many are in the monitoring and treatment program and will there be funding left to allow this program to continue? The FDNY-WTC Center of Excellence, its clinical and data center components, is uniquely capable of providing this information because, as a group, our exposure was the most intense and our group is the only one with pre-9/11 baseline health data. So, the effects of WTC exposure on the health of our members can be objectively measured. The following data will help to answer these questions and allow you to better understand the FDNY's WTC-related healthcare needs.

- Nearly 16,000 FDNY rescue workers took part in the WTC rescue, recovery and fire suppression efforts—roughly 11,500 firefighters and fire officers, 3,000 EMTs and paramedics and 1,000 FDNY retirees. So far, arrival time at the WTC site has been the best predictor of health outcomes. Nearly 2,000 members—or 15 percent of our workforce—arrived in the morning on 9/11. 54 percent arrived during the remainder of that day, 14 percent on day two, 15 percent during days 3 through 14, and the rest thereafter. Duration, total time spent at the site, has also been an important predictor of health outcomes, but not as important in our group, probably because of their extensive exposures during the first week.
- As of March 31, 2010, 15,307 FDNY WTC-exposed rescue/recovery workers (active and retired fire and EMS personnel) have received at least one FDNY WTC monitoring exam for a 96 percent compliance rate.
- Retention rates in our program remain extremely high. In the past 12 months (6/1/09 to 5/30/10), we provided 9,922 monitoring exams to active and retired WTC-exposed FDNY firefighters, EMS personnel and officers. By the end of the year, we will again achieve over 10,000 monitoring exams and overall since 10/1/01, FDNY has provided over 73,000 WTC monitoring medical exams. As of 5/31/10, retention rates have been excellent:
  - 94 percent have received a second WTC monitoring exam.
  - 86 percent have received a third exam.
  - 74 percent have received a fourth exam.
  - Each year the above rates improve and already many have received fifth and sixth exams.
• Disease surveillance is a critical part of our program. In the first year post-9/11, the average annual decline in pulmonary function, for symptomatic and asymptomatic FDNY-WTC responders, was 372 ml, or 12 times greater than the average annual decline noted 5 years before 9/11. And in those most affected, the decrease in pulmonary function was over 600 ml or 10 percent of their lung capacity. Further testing has indicated that the predominant problem is obstructive airways diseases such as airway hyperactivity, asthma, Reactive Airway Dysfunction Syndrome (RADS) and chronic bronchitis. In April 2010, we reported in the New England Journal of Medicine (see appendix and attachment) that over the first 7 years post-9/11 (9/11/01 to 9/10/08), for the majority of our members, the drop in pulmonary function identified in year 1 has persisted with no significant improvement. Time and treatment has only prevented further decreases. More than 30 percent of the members who participated in follow-up WTC medical monitoring exams continue to report upper and/or lower respiratory symptoms.

• Sarcoidosis is an auto-immune disease that can affect any organ but primarily affects the lungs. In the first year after 9/11, FDNY identified 13 Sarcoidosis cases, as compared to an annual rate of only two to three cases per year in the 15 years 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 saw prior to 9/11. Before 9/11, they were nearly always asymptomatic. Now the majority of the Sarcoidosis cases we see have objective evidence of airway obstruction and a few have disabling systemic inflammation involving joints, bones, muscles and other organs.

• Unrelated to Sarcoidosis, we have also seen several cases of pulmonary fibrosis, one of which has been fatal, and two of our patients have received lung transplants—both are doing well. As this is nearly always a fatal disease, with lung transplantation the only available option, we are fortunate that very few have come down with fibrotic lung disease. However, in the 15 years prior to 9/11/01, FDNY saw no such cases.

• In a mental health study, 76 percent of our FDNY-WTC firefighters reported at least one psychological symptom post-WTC. The most frequent symptoms reported are insomnia, irritability and anxiety, and 12 percent met criteria for Post Traumatic Stress Disorder (PTSD). PTSD rates remain elevated and we are now seeing more cases of chronic depression.

• Since 9/11, the FDNY WTC Medical Monitoring Program has provided treatment for WTC-related physical health (majority being asthma, rhinosinusitis, GERD) and mental health (majority being PTSD, depression, prolonged grief and anxiety) conditions to over 9,000 members. In the past 12 months (6/1/09 to 5/30/10), our program provided WTC-related physical health and mental health treatment to 4,241 and 1,770 members, respectively. This year, we are on track to equal those numbers.

• Nearly all of the patients in our treatment program report improvement in symptoms. Many have been able to return to work but others have had to retire with documented disability based on serious reductions in lung function. Between 2002 and 2010, over 1,300 FDNY firefighters have qualified for disability benefits, primarily due to lung disease but with some due to other WTC-related conditions (mental health, chronic rhinosinusitis, etc.). Annually, we have been averaging 150 cases per year, as compared to 49 cases in the 3 years before 9/11.

• In addition to publishing nearly 40 peer-reviewed medical articles on WTC medical conditions (see appendix), the FDNY distributed a summary data publication to every FDNY-WTC member, a copy is available online (see appendix) and also coauthored with the NYC Department of Health and the other Centers of Excellence clinical guidelines for the treatment of respiratory and mental health conditions related to World Trade Center Exposure that is also available online (see appendix).

These numbers only begin to express the real healthcare needs of our exposed members and patients. They provide the basis for understanding the extent of this disaster and our future funding needs, but they do not speak to the heart of the matter—to the special commitment that was made on 9/11 between those in need of help and those who could provide the help.

On 9/11, when the Twin Towers were burning, FDNY firefighters ran into those buildings. By the time the second plane hit, most realized that this was not just a fire, but a terrorist attack; our members were the first to enter this urban war zone. In a tower that morning, one senior firefighter told a young firefighter to search the right hallway while he searched the left. At the time he could not have realized that he would come home and the younger man would not. But, because he is my patient, I can tell you that there are still nights when he wakes up screaming in a cold sweat reliving that decision. Thankfully, this happens less often than before we started treatment, but still too often to claim a medical victory.
One fire officer was buried in the first collapse and was rescued by a group of firefighters who, without a second thought, ran in to pull him out. Many of the members of that unit are my patients today. They have asthma and sinusitis that prevents them from being firefighters or from living anything that resembles the life they once took for granted. But, like every patient I have, they all shared a common commitment that remains unshaken, no matter how ill they are or might become. They would never have done anything different that day. In fact, they would all do it again and only wish they could have done more. They were the lucky ones because that morning their efforts were rewarded. They found that fire officer with the top part of his skull hanging off to the side and barely breathing. One of those firefighters told me that “we had no choice but to push it back on as if it was his helmet, pick his heavy ass up and run for our lives.” He got to the hospital alive, but was suffering severe head trauma, and airway and lung injuries. The next few days were tough ones for him and his family. He was saved many times over. I spoke to his wife and tried to explain to her how critical his condition was and what decisions she needed to make. She looked up at me and said I can’t think straight, I am counting on you and the others here to make those decisions. Thankfully, he eventually recovered. He continues to have a daily cough, vertigo, headaches and a host of other problems. But, the treatment that this program provides him has gotten him back on his feet and he remains hopeful that the monitoring and treatment that we have promised him will continue. He also remains angry that each year he is told that Federal funding may not be renewed and if so our program and the other WTC programs will have to severely curtail their programs, eventually even close their programs and that his medical needs may be ignored. All he wants is to remain well enough to see his children and grandchildren grow and prosper in a safer world because of the sacrifice he and others made that morning on 9/11.

Others were not so lucky. They could not be rescued. But, it was not for lack of effort or commitment. Nearly every FDNY member suffered significant and repeated exposures and they were not alone in these efforts. Members of the Police and Sanitation Departments, and construction and communication workers, and others helped in every way possible. A perfect example are the two firefighters who required lung transplants after working at Ground Zero, trying in whatever way they could to find someone. Without new lungs, they would in all likelihood have had less than a year to live. I have seen both of these men struggle with their illness over the years since 9/11, learning how to breathe with limited reserve and on constant oxygen. Despite knowing that death was around the corner, they remained outwardly unemotional and completely stoic about their fate. That is until the day each was notified that donors had been found. Joy, fear, tears mixed with a grateful understanding that none of this would have been possible without the FDNY WTC Treatment Program. Both are now doing well with substantial improvements in their quality of life—in fact, one no longer requires supplemental oxygen.

This program needs to continue for all of the patients I have talked about today, for every FDNY WTC rescue/recovery worker and for all the others who were exposed at the World Trade Center site. This legislation will provide long-term funding so that the FDNY and the other Centers of Excellence can continue monitoring and treatment programs for our exposed workforce (both active and retired firefighters and EMS workers), and use lessons learned to inform lesser exposed groups (and their healthcare providers) of the illnesses seen and the treatments that are most effective. Most importantly, I am proud to say that this legislation will allow the FDNY, New York City and all of America to fulfill the commitment we made to each of these heroes on 9/11—to help those lucky enough to survive and to help those who helped us survive.

Thank you for your past efforts, and your continued support of our members, patients and Department and I urge you to support S. 1334.

APPENDIX—FDNY WTC PUBLICATIONS


The CHAIRMAN. Thank you very much, Dr. Prezant.

Now we turn to one of those heroes, and one of those victims.

Lieutenant Fullam, again, we sit here in awe of you, and what you and your fellow firefighters did on that day and the weeks and
months afterward. I know you’ve had a rough time of it, health-wise. So, we really appreciate your extraordinary efforts, both then and now, to come to this hearing. Thank you.

STATEMENT OF MARTIN FULLAM, FIREFIGHTER, FIRE DEPARTMENT OF NEW YORK CITY, NEW YORK, NY

Mr. FULLAM. Thank you very much, Senator.

The CHAIRMAN. Please proceed.

Mr. FULLAM. Senator Harkin, Senator Enzi, and Senator Gillibrand, thank you for having me here, and my wife. We’re very honored to be here today. I just want to give you a story—my story of what happened to me, 9/11 and afterwards.

My name is Martin Fullam. I was a first responder to 9/11. I’m here to support any legislation that would guarantee medical care for those whose lives have been significantly altered by the events of that day. My life, as well as that of my family, has been significantly affected by that day, and remains a struggle today.

Nothing prepared us for the scene that awaited us in Lower Manhattan on 9/11. I responded that day, participating in rescue efforts, and subsequent days in search capacity. The hope of rescue grew grimmer with each passing day.

We were covered in dust, soot, powder—you name it. We had some face masks, mostly paper types, but nothing could adequately equip us, with the intake of dust we were subjected to.

The days grew into weeks, and we continued to be assigned in a search capacity. We took breaks, but—and weren’t solely detailed at Ground Zero, but rotated back there until February or so.

Some guys were immediately sick, and we all went for medical monitoring. I experienced the typical cough and upset stomach that many felt, and tried to get on with my life, as best I could, but it wasn’t until early in 2005 that some signs, that seemed insignificant, grew to be noticed. My muscles ached horribly, and my breathing became greatly compromised. My wife arranged for a specialist in New York University Hospital to see me. He phoned the next day, after my appointment and lab tests, and immediately admitted me. Blood counts for toxins were “exponentially” higher than the normal range. After several weeks of hospitalization, it was confirmed that I had polymyositis and autoimmune disease. Unfortunately, what could be aching muscles for some, for me led to a loss of 60 pounds, a breathing capacity of 50 percent, an inability to walk or even sit up in bed, all within 5 weeks’ time.

The doctor was sure of his diagnosis, but had never seen it hit someone with such vengeance. When he learned of my history at Ground Zero, he was no longer surprised.

Treatment followed, which allowed for my release, but weakness and compromised lung capacity have always followed. Intermittent spurts of improvement showed, but, overall, my health declined. When my lung capacity suddenly dropped another 30 percent, I became a candidate for a lung transplant, which occurred in March 29, 2009.

The hope of a better life, post-transplant, has faded, as—40 pills a day, each with their own side effects, and a compromised immune system that kept my body constantly fighting against attack.
My life has been altered, and has not been my own since I’ve gotten sick. I can no longer spend time with my family in the capacity I used to. There are some days I can’t drive the car or go somewhere for a bit, and other days where I can’t leave the front porch. Plans can’t be made, as we never know if it’s a day I can handle, or not. I’m not available for my wife or kids, and I know that there’s nothing I can do about it. My wife has left her job to take care of our needs at home, and there’s not been a normalcy for us since I’ve taken ill.

I’ve left a job I love because I can no longer perform it. Ironically, performing the job is what caused my illness in the first place. But, I’d do it again.

There’s not a person who will forget what they were doing on that day. The memories are especially etched in those who lost loved ones and those who battled the thick of it, hoping to provide the rescue and search services for which the people of New York depend on their firefighters for.

It was nothing short of a war zone. Being a firefighter put me in the thick of the scene that day, and many firefighters that followed. We never questioned our orders or our actions. We answered a call that day, as we do every other day an alarm sounds for us. It’s what we do. When lives are in danger, we run in when others are running out. Our training prepared us to react as we always do, but nothing could have prepared us. It always affects a firehouse when a rescue is not successful. It has left its mark in the lingering sick from that day. We didn’t forget to answer our call that day.

I pray for those who have the opportunity to pass legislation to care for us, the lingering sick, that you will answer the call, and pass the necessary legislation that will allow us to live as best we can, without the additional hardship of financial worries and medical bills. We responded for those in need, and we are counting on you to do the same.

Thank you for your time.

[The prepared statement of Mr. Fullam follows:]

PREPARED STATEMENT OF MARTIN FULLAM

INTRODUCTION

My name is Martin Fullam, a first responder to 9/11. I’m here to support any legislation that will guarantee medical care for those whose lives have been significantly altered by the events of that day. My life as well as that of my family has been significantly affected by that day and remains a struggle today.

9/11

Nothing prepared us for the scene that awaited us in Lower Manhattan on 9/11. I responded that day participating in rescue efforts and subsequent days in search capacity. The hope of rescue grew grimmer with each passing day. We were covered in dust, soot, powder . . . , you name it. We had some face masks, mostly paper types, but nothing provided could adequately equip us with the intake of dust we were subjected to. The days grew into weeks as we continued to be assigned in a search capacity. We took breaks and weren’t detailed solely to Ground Zero, but rotated back there until February or so.

MEDICAL HISTORY

Some guys were immediately sick and we all went for medical monitoring. I experienced the typical cough and upset stomach that many felt, but tried to get on with life as best I could. It wasn’t until early in 2005 that some signs that seemed insig-
significant grew to be noticed. My muscles ached horribly and my breathing became greatly compromised. My wife arranged for a specialist in NYU Hospital to see me. He phoned the next day after my appointment and lab tests and immediately admitted me. Blood counts for toxins were exponentially higher than the normal range. After several weeks of hospitalization it was confirmed I had polymyositis, an autoimmune disease. Unfortunately what could be aching muscles for some, for me led to a loss of 60 lbs., a breathing capacity of 50 percent and inability to walk or even sit up in bed all within 5 weeks time. The doctor was sure of his diagnosis but had never seen it hit someone with such a vengeance. When he learned of my history at Ground Zero, he was no longer surprised.

Treatment followed which allowed for my release, but weakness and compromised lung capacity have always followed. Intermittent spurts of improvement showed, but overall, my health declined. When my lung capacity suddenly dropped another 30 percent I became a candidate for a lung transplant which occurred in March 2009. The hope of a better life post-transplant has faded as I face 40 pills a day, each with their own side effects and a compromised immune system that keep my body constantly fighting against attack.

PERSONAL

My life has been altered and has not been my own since I’ve gotten sick. I can no longer spend time with my family in the capacity I used to. There are some days I can drive in the car and go somewhere for a bit and other days where I can’t leave the front porch. Plans can’t be made as we never know if it’s a day I can handle or not. I’m not available for my wife or kids and I know there’s nothing I can do about it. My wife has left her job to take care of our needs at home and there’s not been a “normal” for us since I’ve taken ill. I’ve left a job I loved because I can no longer perform it.

Ironically, performing the job is what caused my illness in the first place . . . but I’d do it all again. There’s not a person who will forget where they were or what they were doing on that day. The memories are especially etched in those who lost loved ones and those who battled the thick of it, hoping to provide the rescue and search services for which the people of NY depend on their firefighters for. It was nothing short of a war zone. Being a firefighter put me in the thick of the scene that day and many days that followed. We never questioned our orders or our actions. We answered a call that day as we do every other day an alarm sounds for us . . . it’s what we do. When lives are in danger, we run in when others are running out. Our training prepared us to react as we always do, but nothing could have prepared us for the day that awaited us that Tuesday morning. No one expects to witness the hell we faced. It always affects a firehouse when a rescue is not successful. The strangers we respond to leave their mark when we are too late. 9/11 had the double effect of rendering us helpless in rescuing not only the strangers, but our own. It further has left its mark in the lingering sick from that day. We didn’t forget to answer our call that day. I pray that those here who have the opportunity to pass legislation to care for us, the lingering sick, will answer their call and pass the necessary legislation that will allow us to live as best we can without the additional hardship of financial worries and medical bills. We responded for those in need and are counting on you to do the same.

The CHAIRMAN. Well, Lieutenant Fullam, thank you very much for that very poignant statement. Thank you again, in so many ways, for your life and your dedication. You know you represent a lot of firefighters in this country. Thank you.

Ms. Garcia, welcome to the committee. We have your statement. Please proceed.

STATEMENT OF MARGRILY GARCIA, PATIENT, WORLD TRADE CENTER ENVIRONMENTAL HEALTH CENTER, NEW YORK, NY

Ms. GARCIA. Hello and good afternoon, Chairman Harkin, Ranking Member Enzi, and members of the committee.

Thank you for inviting me to speak with you today. And thank you, to Senators Gillibrand and Schumer of my home State of New York, and all who support the James Zadroga 9/11 Health and Compensation Act.
My name is Margrily Garcia. I'm a patient in the survivor program at the World Trade Center Environmental Health Center Program that's run by the New York City Health and Hospitals Corporation.

I'm here today because I got sick from the aftermath of 9/11. My health changed for the worst since then, because of all the dust and chemicals that I inhaled.

Over 4,700 people are now being treated at the World Trade Center Program, and thousands more in the fire department and responder programs. We have similar health issues, but need different treatments that, with expert, reliable care, we'd all have an excellent opportunity of living healthier, longer lives.

The doctors in our communities were unable to properly diagnose us, and we suffered greatly for it, because they didn't have research and exposure of treating thousands of people who were affected by 9/11, like the WTC program.

Please listen to my story, as I am just one example of thousands who were affected by the same tragedy, and who are here with me now in my heart.

On that day, I was a healthy 28-year-old woman employed as a paralegal at a firm on 90 Broad Street, about a 10-minute walk from the World Trade Center. My coworkers and I evacuated shortly after the North Tower collapsed. All transportation was shut down, so we headed to a coworker's apartment in Brooklyn, to stay together and be safe.

I was covered in dust and soot from head to feet as we crossed the Brooklyn Bridge, just like that picture, with no mask. A week later, we all reported back to work in Lower Manhattan, determined to do the right thing during a time of national crisis. I'm unable to describe the sights, horrible smells, and constant dust we all endured for so long. I worked for 4 more years at this location.

Shortly after 9/11, I developed a persistent cough that lasted months, and then years, to which doctors found no cure or temporary relief. My health deteriorated and became impaired so badly that I was forced to move back in with my mother for help. I often visited the hospital ERs and doctors' offices.

At my family's urging, I finally called the WTC clinic at Bellevue Hospital, in September 2006, which now has sites at Gouverneur Health Services and Elmhurst Hospital Center, and I have been a patient there ever since.

I had to visit the ER again, the day prior, so I was exhausted and weak for my appointment. I feared that I was going to die if I didn't find help immediately. And God answered my prayers with the WTC program.

There I was diagnosed with both chronic asthma and sarcoidosis, a kind of scarring that can affect many different organs in the human body, especially the lungs. This disease increased among firefighters who responded to the WTC disaster in the first year after 9/11, compared to previous years. Sarcoid affected my heart, which had been scarred so badly that there were disruptions in my heartbeat causing less oxygen to get into my lungs, and worse. I was living with the possibility of sudden death. I had to have a pacemaker defibrillator implanted, which had to be surgically ad-
justed three times in a single year to ensure it would indeed save my life.
I'm sorry.

The CHAIRMAN. Take your time, take your time, Ms. Garcia.

Ms. GARCIA. Most recently, I had sinus surgery, due to chronic sinus inflammation from all the irritants we breathed on 9/11. My sinus CAT scan revealed that nasal polyps were blocking my airways, and my ENT doctor described my CAT scan as an example of a worst-case scenario, which he asked permission to use in his seminar, alongside a picture of my face.

I am but a shadow of the woman I was, and I continue to adjust to this new me, this new normal that is now my life. Even my wonderful new husband and I must bend to endless hardships of my chronic illnesses, including fatigue and getting sick almost constantly, in one way or another.

I will require a lifetime of specialized care, monitoring, and treatment, like so many others sickened since 9/11.

I am here today, because Federal funding must be reliable so that care is always available for us. Our very lives depend on it. Not just year by year, but anyone whose health was affected by the terrorist attacks on our Nation. The various WTC healthcare programs we are hearing about today cater to our special medical needs. So, please show support for the responder, firefighter, and the community programs comprised of people who were once strong and brave, and are not so anymore.

In our numbers, even if we have weakened bodies and voices, I pray with all my heart, though scarred, that you hear and see us as loud and strong advocates for the bill you are considering today. Collectively, we are the firefighters, police officers, other responders and rescuers, those who helped clean up the area, those of us who lived, worked, and went to school in the area, made it known that we still refuse to let the terrorists win. We went back to our workplaces and our homes and our schools because you said it was safe to do so and we believed that our city and our country needed us to do just that. We proudly reported to duty. We knew it was the right thing to do then. And we humbly ask you today to please do the right thing for us now.

Thank you for your time.

[The prepared statement of Ms Garcia follows:]

PREPARED STATEMENT OF MARGRILY GARCIA

Hello and good afternoon, Chairman Harkin, Ranking Member Enzi, and members of the committee. Thank you for inviting me to speak with you today. My name is Margrily Garcia, a patient in the survivor program at the WTC Environmental Health Center, known as the WTC EHC, that's run by the New York City Health and Hospitals Corporation.

I am a patient there, and I am here today, because I got sick from the aftermath of 9/11. I also express my gratitude to Senators Gillibrand and Schumer of my home State of New York, and to all who are here today in support of the James Zadroga 9/11 Health and Compensation Act. I honestly feel Dr. Joan Reibman, the Medical Director of the WTCEHC, could better explain why we in the Survivor program got sick on that day. I don't know all that she knows but I do know that I am one of the people who has suffered great health loss since that day.

I am a shadow of who I use to be before 9/11. The person who I've become started changing soon after 9/11, because of all the dust and chemicals that I inhaled, the trauma and fear endured that day, and the uncertainty of the days thereafter.
I am told over 4,700 people are now being treated at the WTCEHC, and tens of thousands more are in the Fire Department and Responder programs. I certainly don’t know all of them, but I have seen many sitting next to me at the WTC clinic at Bellevue Hospital. We all have similar health issues but we’re still very different. Some of us are sicker than others and I pray equally for all alike. It is my fear each day to not be well or get worse. With expert reliable care, all of us have a dramatically better chance of living healthier longer lives.

Through no fault of their own, doctors in the community don’t know what our doctors know with their thorough research and specialty care. I went that route and for years I only got sicker. We need these programs and doctors who are better qualified to offer the special medical treatment that we need and deserve as upstanding members of this country. We benefit from their knowledge and expertise from the years that they have of treating thousands of people who were there that life-changing day of 9/11.

I ask you to hear my story as just one example of those thousands who obviously are not physically here today, but each and every one of them are here with me in my heart.

I was born in New York City and raised in the Bronx. It was friends and family there who first heard of the special treatment program at Bellevue Hospital Center for people who worked, lived, or went to school in Lower Manhattan on September 11, 2001. They urged me to check it out because they had become increasingly concerned about my constant debilitating cough and just how much my health had changed after 9/11.

On that day I was a healthy 28-year-old woman employed as a paralegal at a firm on 90 Broad Street, about a 10-minute walk from the World Trade Center. My co-workers and I evacuated from our office shortly after the north tower collapsed. We decided to head to a co-worker’s apartment in Brooklyn, because we wanted to stay together, and we thought we would be safer there. All transportation was closed down, and I had no means of getting home to the Bronx on that fateful day. I was covered in dust and soot from head to feet as we crossed the Brooklyn Bridge. A week later, I, like thousands of other New Yorkers, returned to my job in Lower Manhattan determined to do the right thing during a time of national crisis. Getting to and from work so soon after the horror of that day was challenging. No one can truly accurately describe the sights, horrible smells and constant dust we all endured for so long. Our hearts broke everyday as we tried to resume our normal lives and daily routine in spite of the remembrance of many lives lost that day.

Within just a few weeks I developed a persistent cough, which was surprising and confusing to me because I had rarely been sick before the terrorist attacks, other than a brief cold or flu. No allergies, no ill health of any kind that could explain why I suddenly was getting so sick. Everyone else in my office looked OK to me at the time. My health deteriorated so badly throughout the years after 9/11 that I was forced to move back in with my mother because I simply could not manage my life on my own anymore. My primary care doctor had diagnosed me with bronchitis and asthma but I didn’t respond very well to the medications she prescribed. I felt like hospital emergency rooms and doctors’ offices had become my second home. By September 2006, my constant coughing had become disruptive and disturbing to my co-workers at my new job, threatening my ability to keep my job and the private insurance that paid for my ever-increasing doctor and ER visits.

At my family’s urging I finally called the WTC EHC at Bellevue Hospital Center in September 2006, which now has sites at Gouverneur Health Services and Elmhurst Hospital Center, and have been a patient there ever since.

I was coughing so hard the day I called, the woman who answered the phone advised me to immediately come in that same day but I couldn’t. Instead I made an appointment and advised my superiors at work of that appointment. I was afraid that my constant illnesses would compromise my employment because I had missed so many days already by calling in sick. I’m still constantly afraid of losing my employment due to my illnesses. Being here today was a sacrifice to my job but I’m happy to be here and make your acquaintance. Because so many others cannot, I want you all to know who I am and how I came to be here to share my story with you. I had to visit the ER later that same week because my coughing would not stop, I was in serious pain because of it, and my asthma was out of control. Despite lack of sleep and pure exhaustion, I was determined to keep my appointment at the WTC clinic, which helped people with symptoms similar to mine who hadn’t responded to prior medical treatment. I’d had enough and I thought that I was going to die if I didn’t receive immediate help soon.

I found out my condition was even more severe than that of many other WTC-exposed patients they had seen. After a series of tests, they diagnosed me with both chronic asthma and sarcoidosis, a kind of scarring that can affect many different
organs in the human body. I learned that rates of sarcoidosis increased among fire-
fighters who responded to the WTC disaster in the first year after 9/11 compared
to previous years.

In my case, though sarcoid is more typically found in the lungs of WTC patients,
it was my heart that had been scarred. It was so bad that there were disruptions
in my heartbeat that was causing less oxygen to reach my lungs, and worse, I was
living with the possibility of sudden death. I had to have a pacemaker/defibrillator
installed to help save my life. Worse I had to have this surgery done three times
in a year for necessary adjustments to ensure that the pacemaker/defibrillator
would indeed save my life.

Most recently I had to have sinus surgery which I’ve been told is not uncommon
for many of us who suffer from chronic sinus inflammation due to all the irritants
we breathed in. He showed me my sinus CT scan and explained that no air was
entering through my nose because of all the nasal polyps blocking my airways. The
ENT doctor was impressed with how bad my case was and asked permission to take
a picture of my face and show it with the CT scan in a seminar he was conducting
as an example of a worst case scenario. I was not impressed. In fact, I was very
sad and concerned that yet something else was very wrong with me.

Sadly, I am a medical phenomenon. I now return every 2–3 months for a checkup
with several specialists, sometimes more often, and my visits to the ER have consid-
erably dropped off since I became a patient at the WTC Clinic almost 4 years ago.

My health became permanently impaired at a young age and I know I will never
be like I was before 9/11. I continue to adjust to this new me, this new normal that
is now my life. I know I am blessed with people who love and support me. I am
happy to say that now my life includes the man I married on May 29th of this year.
All newlyweds have their challenges but he and I must continually adjust to the
debilitating physical and mental hardships that face anyone with chronic illnesses,
including the fact that I so easily get winded and am almost constantly sick in one
way or another.

In addition, I’ve had to sacrifice leisure time; time that I can spend with loved
ones for medical time. As you all know time is very precious to us all especially
when you’re sick and time is threatened and becomes critical. However, I’m hanging
in there, and my husband and family members are hanging in there with me. But
we all know that my scarred heart and asthma will require a lifetime of specialized
care, monitoring, and treatment.

We all take some comfort in knowing that the program that helps me has been
partly funded from 2008 through 2011 by a grant from the Federal Government. I
am here today to support the 9/11 Health and Compensation Act because federally
funded monitoring and treatment must be reliable and always available for us be-
cause our very lives depend on it; not just year by year but for anyone whose health
was affected by the terrorist attacks on our Nation. I need to know and trust that
my government will protect and help us live better productive lives.

The WTC healthcare programs you are hearing about today are very similar in
how they go about caring for us who are sick. The responder programs are mostly
overwhelmingly men, good strong brave men who did the right thing that day and
the days and months after. Many of those men are not so strong anymore. We of
the community did the right thing too. Many of us men, women and children are
not so strong anymore either. However, in our numbers, even if we have weakened
bodies and voices, I pray with all my heart that you hear and see us as loud and
strong advocates for the bill you are considering today.

Collectively we are the firefighters, police officers, other responders and rescuers.
We are the people who soon came after to help in the clean up and we are certainly
those who lived, or worked, or went to school in the area. We are the same people
who not only were going about our normal lives; we still refuse to let the terrorists
win. We went back to our workplaces, and our homes, and our schools, because we
were told it was safe to do so, and we believed that our city and our country needed
us to do just that.

We proudly reported to duty. We knew it was the right thing to do then and we
humbly ask you today to please do the right thing for us now.

Thank you kindly for your time and patience with me.

The CHAIRMAN. Thank you, Ms. Garcia. Well, congratulations on
your wedding.

Ms. GARCIA. Thank you.

The CHAIRMAN. Is your husband with you?

Ms. GARCIA. No, he’s not here with me now.
The CHAIRMAN. Oh, I thought I’d recognize him, and congratulate him, too.
Ms. GARCIA. Thank you. Thank you.
The CHAIRMAN. Well, a very sad story.
Let me start with you, Ms. Garcia.
We’ll start a round of 5-minute questions, here.
Tell us more about the differences between receiving treatment through your primary care doctor versus going to the Bellevue program. Tell me again, in your own words, Why is it important for you to see the doctors in that program?
Ms. GARCIA. The providers at the World Trade Center program were the only doctors that were able to control my uncontrollable asthma at the time. I had this obnoxious cough that was literally destroying my life. I was looked upon almost as a leper in public places. It was very difficult to go to work, because I was disrupting everybody. There was just no cure. They gave me all the medications under the sun, and nothing was helping me, nothing at all. I was in constant pain—chest pains, back pain. And I was continually going to the ER, often, because of all of the wheezing and my asthma.
Once I started going to the World Trade Center program—my ER visits has decreased and my asthma has been more manageable.
The CHAIRMAN. Very good. Well, I hope everything’s going to be OK. I hope you’ll continue to improve.
Ms. GARCIA. Thank you.
The CHAIRMAN. Lieutenant Fullam, again, your story is one that touches us all, because you were part of that picture I saw in New York that day, when everyone was running away from the cloud, we saw the firemen going into it.
Tell me again—I don’t need any numbers or anything like that, but, How about your fellow firefighters that you’ve seen up there? Are more and more of them—how have they reacted? Have you seen increased illnesses among those people that were there that day?
Mr. FULLAM. Yes. Well, yes. A good number of my friends have cancers and different types of diseases. There’s four or five other guys who have the same disease I have, polymyositis, which, typically, 1 out of 100,000 people have. But, I believe right now there’s six or seven firefighters out of 16,000 that have that disease, when, typically, the population—1 out of 100,000 is struck. So, that’s where they get the presumption from that disease.
The CHAIRMAN. I also wonder about a lot of the firefighters who came from Wyoming or Iowa and all over the country, that came there. I must admit to you, I haven’t checked with them. I don’t know if there’s a registry of them.
Mr. FULLAM. I wouldn’t know that.
The CHAIRMAN. I’m going to find that out, because I have a feeling—
Well, Dr. Prezant, do you know that?
Dr. PREZANT. Yes, Dr. Howard referred to the national program. The national program has a treatment and monitoring program for firefighters and every other exposed World Trade Center responder, no matter where they live in the country. And also, they were originally eligible to participate in the World Trade Center Registry.
The reason I ask that is because I remember talking to some of our firefighters from Iowa who went there at that time—after they returned—and they were thrown into actions. A lot of them worked tirelessly for 2, 3, 4 weeks, and then came back home. And it seemed—and I can’t say this for sure—but, it just seemed to me that they were just told to go into the mess there, and do what they could. And I am not certain they had a lot of protections.

Dr. Prezant. Yes.

The CHAIRMAN. So, I’m just wondering if we have a good handle on who those, from around the country, were that came there at that time. And you’re saying we do.

Dr. Prezant. We have a good handle, but I will say that it took a while to get those programs up and running. That’s one of the lessons learned from 9/11, that we have to take care of our first responders, no matter where they are.

The CHAIRMAN. Are we hearing, around the country, about illnesses and stuff, from some of those firefighters who came from around the country, Dr. Melius?

Dr. Melius. Yes. I also do work with a firefighters union, and at national meetings I’ve gone to—actually I have talked to a number of these firefighters who have come in. A number of them have become ill, a number of them with very serious illnesses, similar to what’s been experienced by the New York City firefighters. So, we know that.

There has been some outreach to them. But, we need to do more, because many of them are not aware of the programs.

The CHAIRMAN. Yes.

Dr. Melius. Particularly those that, on their own, individually, volunteered to come in, particularly in the initial few days afterwards, because there was no listing kept of them. Those that were on an organized basis that came in under a Federal program, we have listings; we know where they came from. But, those individuals that came in, which there were many, we just don’t know. Nobody kept track. And so, there really is a need to do continued outreach to let them know about these programs, and to get them in for care.

The CHAIRMAN. OK. Thank you very much, all of you. Thank you.

Senator Enzi.

Senator Enzi. Thank you, Mr. Chairman.

I’ll continue with Dr. Melius.

Currently, NIOSH sends funds to New York providers for monitoring treatment. I’m not sure if you’ve seen Senator Gillibrand’s bill, but under sections 3001 and 3006, NIOSH would send funds to New York providers for monitoring and treatment. Does that basically codify the current practice?

Dr. Melius. Yes, it basically codifies the current practice at the centers. It’s a little bit different, in that it essentially ties the funding to the individuals, rather than, through this grant mechanism, to the centers, but would direct most of the care through the Centers of Excellence, allow additional Centers of Excellence to be established, if they meet certain criteria, including centers in other parts of the country, where there are a significant number of re-
sponders, and medical centers that have the expertise to help those people.

So, essentially, it does. It also, as I mentioned in my testimony, would also change the reimbursement methods so it’s tied to the individual—more of a traditional fee-for-service kind of system, which would provide for better accountability, and able to follow up on—some of the questions that you were asking Dr. Howard, early, would be answered.

Senator Enzi. Thank you. I’ll follow up on one of those questions that I asked, and that he suggested that I ask you, and that’s, Why has it been so difficult to document the half a billion dollars in NIOSH grant money that was spent?

Dr. Melius. The current program is funded through grants. And grants provide, essentially, broad categories of funding for different services. So, there’s essentially a broad category for, say, pharmaceuticals, and for others, so, you break it down—those sort of broad categories.

But, for identifying individuals receiving those, they have to set up a separate system to track those, which has—as Dr. Howard testified, have been put into place, but they weren’t in place initially. There was uncertainty about how the program would be funded, going forward. So, there was some hesitation doing that. Dr. Howard—NIOSH—also tried to set up a contract to provide this sort of fee-for-service reimbursement system, and the administration decided not to do it.

Actually, after the contract had already been announced, and there were people prepared to compete for that contract, it was pulled back, and the only part that went forward was for the national program.

Dr. Melius. Correct. There are provisions to identify people getting services from more than one program for the same problem, and sort of simple things like that, because we have all the individuals being followed. The individual medical care that they get, the services, is much harder to track, under the current system. We need a new system to do that as we go forward.

Senator Enzi. OK. Thank you.

Dr. Prezant, first, I want to salute the Fire Department of New York, and you, for your leadership and service. You hosted a visit of the HELP Committee staffers, last Congress, and really helped us to get up to speed on the medical and scientific issues.

And the last time you spoke with us, about 650 firefighters had to go on permanent disability because of the World Trade Center cough. Are more of your firefighters becoming incapacitated because of the cough? Or is the number holding fairly steady?
Dr. Prezant. Thank you for your question. First off, when we call things “the World Trade Center cough,” we use that term broadly to represent all of the respiratory diseases that are affecting our members, both chronic bronchitis, asthma, what some people call “reactive airways dysfunction syndrome,” sarcoidosis, pulmonary fibrosis—they all have manifested themselves as “World Trade Center cough,” and as “severe shortness of breath.”

In terms of the initial numbers that I gave you, there are people that were still in the pipeline that had not been awarded disability, and there are still new people coming forward with disability. So, as of earlier this year, there was a total of approximately 1,300 FDNY rescue workers, mostly firefighters and a few EMS workers, who have received permanent respiratory disability benefits.

Senator Enzi. So, the number has doubled in just the last year.

Dr. Prezant. That is correct. Prior to 9/11, we averaged less than 30 cases per year, for respiratory disability, out of a department that’s approximately 15,000 in total membership. And since 9/11, on an annual basis, we average approximately 150 cases. So, that’s a huge increase in the number of cases, starting to level off, for the first time, this year.

Senator Enzi. I’ll change the subject to mental health. This committee is in charge of that, too. Can you share with the committee how the department and the unions attack the stigma that’s associated with seeking treatment for mental illness?

Dr. Prezant. Well, our patients are no different than the military. They are incredibly proud of the service they provide this country—and the city, in particular. They’re used to sacrifice. And, as you can see from Lieutenant Fullam, not only are they used to sacrifice, but they hold themselves with incredible pride and a stoicism that leads to barriers to mental health care.

But, we have fought very hard to overcome that. We have, currently, nearly 2,000 people each year in mental health treatment through our programs. We’ve opened up five centers outside of fire department facilities that we rent in nonfire department locations, noncity buildings, so that there would be no stigma to going into that building. We have reached out to every firehouse with peer counselors, retired firefighters, who go in there, and they’re not there to do psychotherapy or to provide medication, they’re there to say that it’s safe to come forward. And we use that as a system.

Could we do better? Each year we could do better, and that’s what we strive for.

Senator Enzi. How are those numbers holding? Are they increasing?

Dr. Prezant. They’re steady. We’re running between, as I just said, a little less than 2,000 per year, and not decreasing at all. We have about 12 percent with PTSD. And we are finding exactly what the psychiatrists told us to expect, that when you have chronic PTSD, you will develop increasing numbers of people with depression. They get depressed because their PTSD is not getting better. And so, now we’re having to rev up to treat a second mental health illness.

Senator Enzi. Can you also tell me about the difference between the fire department program and what the police do with their Project COPE.
Dr. Prezant. Project COPE is a mental health outreach program, as well. Because the police department has a much greater workforce, and other issues associated with a greater barrier, because each one of their officers carries a gun, they’ve decided to completely separate their mental health program from their physical health program. And COPE is a sort of similar peer-type group that reaches out to policemen, but in a completely non-NYPD, non-official way. There’s a linkage, but it’s very unofficial. This way, they try to deal with the barrier that’s much greater in their workforce than our workforce, because of the issue of carrying a gun.

Senator Enzi. Thank you.
I do have some other questions, but I’ll submit those in writing.
I appreciate you letting me go a little longer, there.
The Chairman. Thank you, Senator Enzi.
I have a follow-up question for Dr. Melius. There’s still people who are coming forward now, who you hadn’t seen before. Now, again, I think some people might say, “Well, they’re taking advantage of the program. They’re coming into this program to get their healthcare needs taken care of.”
Would there be some reason why people might not have come forward before now, who were around Ground Zero, or who may have been in that area, in the weeks and months afterward? Is there any reason why they might not have come forward before now?
Dr. Melius. I think that there are several reasons. Some is knowing about the program. Despite all the publicity, I think there are people that are not aware, particularly in other parts of the country, I think, more than in New York.
Second, I think that, as Dr. Prezant just said, people don’t like to go to the doctor, particularly working men do that. And so, they’re reluctant to go forward and seek care, they don’t want to know that they might have a problem. They’re concerned that it might affect their current job in some way—lots of excuses. So, they’re reluctant to get examined to find out. And that’s common in general medicine, it’s common in this program.
Third, many of them are seeking care through their own personal physician. And they discover they’re not getting better, and—over time—maybe their condition is getting a little bit worse. And so, that’s the reason they come forward. They know about the program. They say, “Well, I’ll finally come forward. And, maybe if I go to these special centers, maybe they can improve my treatment, and I’ll be able to work better and feel better.”
There are others—actually, well, just approached by another one of the building trades business agents recently. He had a group of veterans. They were operating engineers that knew about the program, but felt that—they met, I believe, on a monthly basis, as sort of a military veterans group within the union—they felt that, really, it was for other people. Their patriotic duty was, “Let it take care of the other really sick people first.” So, here it is almost 9 years later, and they’re just deciding that, “Well maybe we really should go in and get checked out. Some of us are having symptoms, but—and, you know, we’ll finally go forward and take advantage of this program.”
It’s surprising that we’re continuing to see, in the General Responder Program, 250 new people come in monthly, seeking care. And many of these are sick and need treatment. So, it’s not a population that’s just trying to take advantage; they need the program, and it’s important to them.

The Chairman. As a follow-up to that, Dr. Prezant, I have one more question, and that is, What factors explain why one person got sick and another one didn’t? And, in these kinds of cases, how do you know that the exposure is the cause of the symptoms? And why are people just getting sick now? So, there are kind of three. Why are people getting sick now? How do you know that it was due to the exposure? And why does one get sick and someone else didn’t?

Dr. Prezant. Well, I wish I could tell you why one person gets sick and another person doesn’t.

The Chairman. But, you did testify that the severity, I think you testified, was that, depending on how near to Ground Zero you were in the days, hours, right after.

Dr. Prezant. Absolutely. We’ve clearly shown that initial arrival day and where you were and duration of work down there, are all factors. But, if you match two people with exactly the same arrival time, exactly the same duration of exposure, you will find that one has gotten sick and one has not.

That does not dispute the World Trade Center as the cause, because—I refer to the same issue with cigarette smoking. We know, and we have fully accepted, the major illnesses caused by cigarette smoking. But, we all have, thankfully, a relative or a friend who has smoked tremendously, and has not gotten ill. And we also have, unfortunately, relatives and friends who have smoked very little and have gotten ill. There is a genetic/environmental interaction with every disease. And that doesn’t negate the environmental interaction. It just, once again, tells us that we are human beings. We are not robots.

Now, in terms of, How do we know this is World Trade Center disease? Well, at the fire department, we are lucky to have documented exposures on every person. We still have people coming in now for treatment, when they haven’t before, because of their stoicism. But, we know that they were at the World Trade Center, and we have cumulative evidence from decades of dealing with firefighters—our medical database goes back to the early 1980s—and we have not seen these diseases. We have a handful of firefighters with asthma each year before 9/11; after 9/11, we have overwhelming numbers. We never saw pulmonary fibrosis or polymyositis before 9/11; now we do. So, that’s the basis for us understanding that this is World Trade Center-related.

The Chairman. Dr. Melius.

Dr. Melius. Yes, just to follow up on that.

The Chairman. Yes.

Dr. Melius. I think it’s important, as Dr. Prezant said and has shown in his studies, but there are also many other scientific studies showing that large numbers of people are getting sick. I mean, this is not something that’s occurring in just a few people.

The Chairman. Right.

Dr. Melius. It’s large numbers.
Second, I think it's also important—you know, people's exposure differs. And even though we see the picture here—what happened immediately after—even within the community of people living further away, there were people that had very high exposures. Their apartments or their workplaces weren't cleaned. They lived with that dust, breathed that dust for months.

So, many, many people had long-term and heavy exposures. And I think that accounts for what we've seen.

Dr. Prezant. A major strength is the fact that you have essentially four different groups: the fire department, the World Trade Center Consortium of New York/New Jersey, the World Trade Center Registry, and the Environmental Health Center at Bellevue. All of them have slightly different types of populations and slightly different types of exposures, and all of them are showing the same thing.

The Chairman. Well, listen. Thank you all very much.

I would yield to my colleague from the House, not for purposes of a question, but for any statement or observation that he would want. Again, a distinguished member of the House, a senior member of the delegation. And it was in his district in which this occurred.

And then I'd ask Senator Gillibrand if she'd like to also close up with any comments or observations.

Congressman Nadler, welcome.

STATEMENT OF U.S. REPRESENTATIVE JERROLD NADLER

Mr. Nadler. Well, thank you very much, Senator, for the privilege of allowing me to sit here, and to make a statement, and for holding this hearing, at Senator Gillibrand's request.

Let me say, we've been involved in this for a long, long time, since immediately after 9/11. And we've held a number of hearings in the House and in New York, and we've seen all of this.

It is unquestionably the case that there is a massive exposure, that people have gotten sick, that people who don't know they're sick yet, will get sick. We also know—in connection with the last question you asked—that certain diseases have different latency periods. We've seen most of the respiratory diseases. We're starting to see the cancers. We'll see the cancers much more. They have latency periods, I understand, of 8 to 15 years, generally, so that you wouldn't expect people to come in with the cancers. We know there were millions of carcinogens in the atmosphere, everything from benzene to God knows what. So, we're going to see the cancers. We're starting to see a few of the soft-tissue cancers now; the blood cancers will come later. So, those are also reasons why people didn't come forward earlier.

This legislation is completely necessary, for any number of reasons, one of which is, we cannot depend on the annual appropriations process. We have done rather better in the last few years, in the appropriations process, than prior to that. But, we have still had occasions, within the last few months, when some of the institutions have had to send out notices to affected populations that, "You're not going to be served after June 30, because the appropriation didn't come through in time." It's unfair to put people through that. It's unfair to rely on who may be sitting in these con-
gressional seats 5 years, or 6 years, or 8 years from now, to make sure we keep getting the appropriations. And we've got to put it on a systematic basis.

We owe a tremendous moral debt, because it wasn't simply that the terrorists did this, it's also that the Federal Government misled people and told them that it was safe to work in these areas, when it wasn't, and enforced the OSHA laws at the Pentagon but not in New York. So, there's a tremendous moral debt owed to people.

And finally, God forbid there's another natural disaster or another manmade disaster, we have to want first responders to be able to go into these and—places, and rescue people, and clean up, and—first responders and contractors—and not worry about, Will this put their businesses and their families at risk 5 and 10 years later?

So, it's imperative we pass this legislation. I want to commend Senator Gillibrand and Senator Harkin. And I want to commend all the people who've testified today, who've been active in this for so many years.

I want to commend, in particular, Dr. Howard, who I would say has been the one official in the executive branch of government—of the Federal Government—who's been responsive.

And so, thank you.

[The prepared statement of Mr. Nadler follows:]

**PREPARED STATEMENT OF CONGRESSMAN JERROLD NADLER**


Thanks to Senator Gillibrand's hard work and attention to this matter, I am pleased that we are making progress on this legislation in both the House and the Senate. Just last month, the House version of this bill, of which Congressman Maloney and I are sponsors, was favorably reported out of the House Energy and Commerce Committee. And in July of last year it cleared the House Judiciary Committee, of which I am a member. All of this movement means that we are now within reach of providing justice to the thousands of first responders and survivors who are sick because of their unnecessary exposure to the toxic dust of 9/11.

As we all know, the collapse of the World Trade Center propelled hundreds of tons of asbestos, nearly half a million pounds of lead, and untold amounts of glass fibers, steel, and concrete into a massive cloud of toxic dust and smoke which blanketed parts of New York City and New Jersey. Fires burned for many months, emitting a host of deadly substances into the air.

In the days and weeks after 9/11, thousands of workers and volunteers selflessly came from across the country to help. They worked harder and longer than they had ever worked before, and under unfathomable conditions. And they did not ask questions, because there was a critical job to be done.

We warned then that the air was not safe and that our courageous first responders were not being afforded proper protection from dangerous toxins as they worked on and around the pile. But the Bush administration and the EPA lulled us all into a pro-
foundly false sense of security by irresponsibly and dangerously de-
claiming that the “air was safe to breathe.”
And, devastatingly, as a result, many people toiled for months on
that toxic pile at Ground Zero without proper protection. They were
unnecessarily exposed to hazardous toxins because of what the gov-
ernment said and did—or did not do.
And now thousands of them are sick.
The truth is stark: the government failed its bravest citizens.
After its own inaction and malfeasance caused irreparable harm,
the government has failed its citizens for 8½ long years, because
it has failed to fully pay the debt owed to those citizens.
We must now ensure that the Federal Government provides long-
term, comprehensive health care and compensation to all of the
first-responders and survivors affected by 9/11, in a way that is not
subject to annual politicized fights for budget dollars.
I don’t have to tell you that every day that our sick responders
and survivors have to wait to receive the health coverage and fi-
nancial restitution that they need and deserve is one day too many.
I want to thank the responders and survivors for their all of their
hard work and patience in this struggle; I want to thank Senator
Gillibrand for championing this issue in the Senate, and Congress-
woman Maloney for her continued leadership in the House.
Let’s pass this bill.
Thank you.
The CHAIRMAN. Thank you, Congressman Nadler.
Senator Gillibrand.
Senator GILLIBRAND. I just want to thank you, Chairman Harkin,
for holding this hearing. This is so important to the first respond-
ers, to the community survivors, and to everyone in New York and
throughout the country.
You know, we have first-responders from every State in the
Union. And we have people suffering from these grave illnesses at
every corner of our country. So, just, on all of their behalves, thank
you for holding the hearing.
Thank you, Congressman Nadler, for your leadership and advo-
cacy throughout this. It’s been extraordinary.
And thank you, to all of you, for testifying and being part of de-
velling a record so that we can move this legislation forward so
that we can finally make sure that families and firefighters and
first responders have the healthcare and the reimbursement for the
costs they’ve suffered that is so desperately needed. It is our moral
obligation. And because of your advocacy, we will find a way there.
So, thank you so much. Thank you for your testimony.
Thank you, Mr. Chairman.
The CHAIRMAN. Thank you, Senator Gillibrand, and for your per-
sistence in working with this committee, and with both Senator
Enzi and me, to make sure that we had this hearing to get the
record made. And thank you very much for your leadership on this
crucial issue here in the U.S. Senate.
And again, I thank all of our witnesses.
Lieutenant Fullam, again, thank you. Thank you, thank you. I
can only hope that your health continues to improve, and you get
better.
And, Ms. Garcia, again, same for you. I hope your health continues to improve and you enjoy many more years of married life to that new husband of yours.

Ms. GARCIA. Thank you so much.
The CHAIRMAN. Thank you all very much.
The record will be held open for 10 days for additional questions. And with that, the committee will stand adjourned.

[Additional material follows.]
ADDITIONAL MATERIAL

PREPARED STATEMENT OF SENATOR DODD

Mr. Chairman, thank you for calling today's hearing and allowing the HELP Committee to more closely examine this critically important issue. This Nation suffered an immeasurable tragedy on September 11, 2001.

We will never forget the thousands of people who died on that day. And we cannot allow ourselves to forget about the thousands more—including first responders, area residents, workers, students, and others—who still feel the effects of those attacks and are sick and getting sicker from exposure to the mix of toxins released from the collapse of the World Trade Center (WTC) Towers. As today's experts will testify and the published, peer-reviewed research in our leading national medical journals shows, the rates of asthma, the WTC cough, decreased lung function, sinus problems, posttraumatic stress symptoms, and many other health effects are on the rise.

In my own State, thousands of residents dropped what they were doing in the days after 9/11 and showed up at the WTC site to volunteer in any way they could. Firefighters from Connecticut communities nearest to New York, including Fairfield, Greenwich, Norwalk and Stamford—responded quickly on September 11 and several hundred responders from Connecticut were officially sent to help in the rescue and recovery efforts. More than 800 residents in my State are enrolled in the World Trade Center Health Registry and several dozen are participating in either the FDNY WTC Medical Monitoring and Treatment Program and the WTC Environmental Health Center at Bellevue Hospital Center.

The Federal Government has an obligation to help the heroes of 9/11 as well as all others who were exposed to dust and debris, including residents and children. That help should include mental and physical health considerations as well as access to the Victims Compensation Fund. It is important, especially as it pertains to children, that we are properly identifying and treating their physical and mental health needs. Countless children who were not at the WTC site continue to live with the impact of having lost a mother, a father, a grandparent or a sibling. Their needs must not be overlooked.

As the Chairman of the Subcommittee on Children and Families and the author of legislation creating the National Commission on Children and Disasters, I am particularly concerned about the needs of children and ensuring that programs receiving Federal resources are adequately monitoring and caring for the most vulnerable in our population. In my questioning, I look forward to discussing the response of the Federal Government and city of New York to children and 9/11.

For more than 2 years, I was part of a bipartisan HELP Committee effort led by former-Senator Clinton that included the late-Chairman Kennedy, Ranking Member Enzi, and Senators Burr and Coburn. Our purpose was to craft a bipartisan health and compensation program for those who are suffering potentially life-long health effects of 9/11. I am disappointed that this effort did not result in legislation. It is something I deeply regret. However, I am
a proud cosponsor of Senator Gillibrand’s legislation, the *James Zadroga 9/11 Health and Compensation Act of 2009*. I hope to see action on this legislation soon.

**Prepared Statement of Senator Casey**

Thank you, Chairman Harkin, for calling this important hearing. I would like to thank Senator Gillibrand for her testimony, and also extend thanks to all of the panelists for their work, their sacrifices, and their testimony here today.

September 11, 2001, was a day of horror and tragedy for America. We still feel the loss of the thousands who died that day, in New York, at the Pentagon, and in Pennsylvania. We have spent the last 9 years honoring their sacrifice and ensuring that their memories will not be forgotten.

However, we have another commitment that we must remember, and that is our commitment to those who still live with the scars of that awful day—the rescue workers, the recovery workers, and the people who worked, lived, or went to school near the World Trade Center. The dangers that they faced that day endure. Many of them have suffered health effects since that 9/11. Some of them have died as a result; others are severely incapacitated. We owe these Americans our gratitude and our help.

The health effects of 9/11 may not follow “traditional” paths for similar illnesses. Individuals were exposed to many different substances, some in large quantities on 9/11, and some in smaller doses over the days and weeks and months that followed. Fortunately, the programs that were created in the immediate aftermath of 9/11 have tracked and monitored the health of these individuals, but it is clear more must be done.

As a cosponsor of Senator Gillibrand’s bill, I believe that we must guarantee a steady source of support for our valiant first responders and community members. I applaud the committee for scheduling this hearing and thank the witnesses for their testimony today.

**Prepared Statement of Michael R. Bloomberg, Mayor, City of New York**

Thank you Chairman Harkin, Ranking Member Enzi, and the other distinguished members of the committee for convening this hearing on S. 1334, the James Zadroga 9/11 Health and Compensation Act. I also want to particularly thank Senator Gillibrand for introducing this legislation to establish a sustained, long-term 9/11 health program.

Passing this bill would, at long last, fully engage the Federal Government in resolving the health challenges created by the attack on our entire Nation that occurred on 9/11. The destruction of the World Trade Center and the attacks on the Pentagon were acts of war against the United States. People from every part of the country perished in the attack, and people from all 50 States took part in the subsequent relief and recovery efforts. And that makes addressing the resulting and ongoing health effects of 9/11 a national duty.

This legislation achieves what WTC responders, area residents, and other survivors of the 9/11 terrorist attacks have long been seeking—sustained funding to treat those who are sick, or could become sick because of 9/11; continued research on potential WTC health effects; and the re-opening of the Victim Compensation Fund so that those harmed as a result of 9/11 are fairly compensated without having to show that anyone but the terrorists were at fault.

Before detailing the virtues of this legislation, I’d like to review some essential facts about the scope of this problem and the efforts the city has made to address it. Four years ago, as the fifth anniversary of 9/11 approached, I directed city agencies to undertake a thorough investigation of the health problems potentially cre-
ated by the terrorist attack. The report published 6 months later established beyond question that many people suffered physical and mental health effects as a result of the World Trade Center attack and its aftermath.

They include firefighters and police officers, community residents, schoolchildren, and owners and employees of neighborhood businesses, and also construction workers and volunteers from across America who contributed to the heroic task of clearing the debris from the World Trade Center site. The report made clear that the ultimate scope of these health effects is still unknown; that they must continue to be studied; and that those who are sick or could become sick must be monitored and treated with the best possible care.

S. 1334 achieves those aims, but New York City has not waited for Federal funds to address this issue. For instance, the city funded the launch and expansion of the WTC Environmental Health Center at our Health and Hospitals Corporation (HHC) before receiving any Federal dollars; and we’ve launched a number of public outreach campaigns about 9/11 health problems and how to get help.

WTC CENTERS OF EXCELLENCE AND THE WTC HEALTH REGISTRY

The Federal Government has been an important partner in this area. The annual appropriations that Congress and the President have made over the last several years have funded the World Trade Center program at Mount Sinai, as well as the longest-running health response to the attacks—the FDNY WTC Medical Monitoring and Treatment Program.

The FDNY Center of Excellence provides monitoring and treatment to the firefighters and other FDNY personnel who participated in WTC rescue, recovery and clean-up. With the help of Federal appropriations, the Program has provided specialized WTC health care to thousands while generating leading research on the health impacts of 9/11. Lacking long-term funding, however, the Program faces perpetual uncertainty about its ability to continue providing clinical services.

In addition, the HHC WTC Environmental Health Center was awarded in 2008 a 3-year grant for $10 million a year. This funding is critical to allowing the program to continue addressing the physical and mental health needs of community members.

Finally, short-term Federal grants enabled the establishment of the WTC Health Registry (WTCHR), which this bill will continue to fund on a permanent basis. The Registry is a partnership between the city and the Federal Government that is the largest effort of its kind in history. It includes more than 71,000 people from every State in the country who reported being exposed to the aftermath. Over 20 percent of the people in the Registry are from outside the New York Metropolitan region. This reflects the number of people from throughout the country who were in New York at the time of the attacks or who came to New York soon after.

Efforts by the Registry, FDNY, Mt. Sinai, the HHC WTC Environmental Health Center and the reports generated by the Medical Working Group—which we convened to keep us all abreast of the newest research and resource-needs for 9/11 health issues—are central to the city’s core approach to this issue: dedicating resources based on the latest science and medical research. And the data shows that 9/11 health issues continue to be a serious problem.

Registry data confirm continued high levels of reported post-9/11 asthma and Post-Traumatic Stress Disorder (PTSD) among Registry enrollees 5-6 years after the attacks. Adverse respiratory health symptoms, while most frequently reported by rescue and recovery workers, have also been reported by Lower Manhattan residents, office workers, and passersby on 9/11, and more than 20,000 directly exposed adults may have received new asthma diagnoses since the event. PTSD levels were high at baseline and remained elevated at the time of the last survey in 2006-07.

The Registry will soon launch the third major health survey of all enrollees, 10 years after 9/11. This survey is the only tool that gathers critical health information from a diverse group of individuals exposed to the WTC disaster—including rescue, recovery, clean-up workers, Lower Manhattan community members, office workers and children. As has been reported, however, the Registry is facing funding shortfalls that threaten its ability to carry out the survey—highlighting the need for sustained, long-term funding.

S. 1334 provides for the long-term sustainability of the city’s Centers of Excellence and the efforts of the WTC Health Registry. It would establish much-needed year-in, year-out Federal support for monitoring, screening, and treatment of health-related problems among eligible 9/11 responders and community residents. As part of this, the bill would maintain the WTC National Responder Program, providing monitoring and treatment for the many men and women who came from across the country to help in WTC rescue, recovery and clean-up operations.
In addition, the bill funds essential ongoing medical research, including the WTC Health Registry, so that we can better understand what the health impacts of 9/11 are, and what resources we need to address them. Finally, the bill reopens the Victim Compensation Fund so that people who were harmed by the terrorist attacks can get compensation fairly and quickly without having to prove that the city, the contractors, or anyone else but the terrorists were at fault.

The bill’s provision for the long-term future of the centers of excellence is critical. While Federal funds have supported important research and treatment efforts, the uncertain and fragmented nature of that support has needlessly jeopardized the future of these programs. Passage of this bill would make that future secure.

To ensure that funding goes only to those whose conditions are due to 9/11, the legislation includes important controls and cost-containment standards that the city fully supports. In addition, the bill makes the city responsible for paying 20 percent of the cost of care provided at our public hospitals and clinics. This is a significant obligation, but we accept it. It will give us a powerful incentive to work with Federal health officials to ensure that expensive and finite medical resources only go to those who truly need them.

Less than 3 months from today, we will observe the ninth anniversary of 9/11. Too much time has passed without action on this legislation. Let’s work together to ensure that those who survived the attacks, and those who risked their lives to save others, receive the health care that they deserve.

PREPARED STATEMENT OF ANN WARNER ARLEN

A PERSONAL ACCOUNT OF 9/11 HEALTH EFFECTS

My name is Ann Warner Arlen. I live a few doors south of Houston Street on Sullivan Street, west of SoHo. Before September 11, 2001, the World Trade Center was just a short walk south.

My apartment has a garden, part of an open core at the center of our block. On September 11 my back was to the garden when I heard the roar of the first plane go over our block, sounding too low, gunning its motors, followed by a crash.

In the street a group of us watched the towers burn. When one of the towers turned grey and slid down the horizon, people screamed. A man appeared at the edge of the group, eyes red, face chalky with dust, trying to speak. Finally he said he had been in a building where people jumping from the towers fell so close by he could identify them. He wanted to tell the families so they could know. He came to my place to call his own family. On the TV the second tower went down.

The next day the air was filled with the dust. Going to an emergency community meeting at Bleecker and West Broadway, I had a bandana around my nose and mouth, yet was grinding the dust and grit between my teeth. The following day the dust was still in the air. The police had Houston Street cornered off. An officer gave me a mask.

After that the thick black smoke rising from the World Trade Center during the day settled as a pall over the Downtown area at night. The central core of our block held the smoke in place, allowing it to seep into the rear-facing apartments. Every morning for 3½ months I woke to an apartment filled with smoke, head aching with sinusitis and chest bubbling with bronchitis. With so much death so close by, it seemed not to matter.

A combustion-scientist friend described the smoke as a combination oil fire, crematorium and mass burn incinerator. During the day, when the smoke lifted, the smell of burning flesh persisted. It was a relief when someone wrote about it or mentioned it. That was rare. I felt that we were carrying around inside of us the people who had been vaporized, and that it was a good thing.

Two years later, in October 2003, I did jury duty in the Supreme Court building on Foley Square, in a courtroom facing the WTC site and still smelling of WTC smoke. Court workers who had offices were running air purifiers. As we jurors were seated, our eyes began to redden and noses ran. My sinusitis and bronchitis returned and got steadily worse. Following jury duty, after many weeks, the bronchitis became acute, and my doctor sent me for a chest X-ray. The radiologist made an initial diagnosis of obstructive lung disease. My doctor said that such a diagnosis was not uncommon in tall people, and that in any case she would not recommend a pulmonary function test because there would be little to be done about it anyway. She prescribed Mucinex for the mucus in my chest, and it helped.

After that, when I got a cold or sniffle, I often got bronchitis. To keep it in control, I worked hard to build my immune system, with success. However, that was of no avail last December when an uncontrolled construction dust situation in our building (an 1875 tenement building with lathe and plaster,
not wall board) triggered an abrupt attack of the bronchitis, sinusitis, and aching chest, which rapidly developed into respiratory illness. This time I was able to go to the Bellevue World Trade Center Environmental Health Center, was given a pulmonary function test and relevant lab and other tests. I was impressed with the staff and with the facility itself. I was grateful finally to be evaluated by this “center of excellence,” experienced in 9/11 exposures, their symptoms, consequences, and treatment. The unique experience of these centers seems to me necessary if the consequences of 9/11 exposures are to be properly addressed and their cascading health consequences prevented.

PREPARED STATEMENT OF JOAN REIBMAN, M.D., ASSOCIATE PROFESSOR OF MEDICINE AND ENVIRONMENTAL MEDICINE; DIRECTOR, NYU/BELLEVUE ASTHMA CENTER; MEDICAL DIRECTOR OF HEALTH AND HOSPITALS CORPORATION, WTC ENVIRONMENTAL HEALTH CENTER

Good morning, Chairman Harkin, Ranking Member Enzi, 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, Medical Director of the WTC Environmental Health Center, 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 18 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 S.1334, 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 the Senate who have shown their continuing and extraordinary support for our patients and our program, especially Senator Gillibrand and Senator Schumer. 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 3 years.

POPULATIONS AT RISK

Our program serves, the local workers, residents and students and children 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 falling debris and the initial massive dust clouds 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 1 week later, the massive WTC cleanup 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. (U.S. 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 over 15,000 school children, and large numbers of university and college students. Some children 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.

Each of these groups had potential for exposure to the initial dust, the resuspended indoor and outdoor dust, and the gas and fumes from the fires that burned at least through December 2001.

INITIAL HEALTH EFFECTS IN COMMUNITY POPULATIONS

Exposure assessments inform us as to components of the dust and fumes. However, the only way to really assess health risk is to study health effects in exposed populations. As pulmonologists in a public hospital, we sought to determine whether the collapse of the buildings posed a health hazard soon after the event. 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

We surveyed residents in buildings within 1 mile of Ground Zero, and, for purposes of control, other lower-risk buildings approximately 5 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 percent of the exposed residents, more than three times the number reported by control residents. An over 3-fold increase in lower respiratory symptoms including cough, shortness of breath, and a 6.5-fold increase in wheeze (10.5 percent of exposed residents versus 1.6 percent 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 were 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. These data have now been replicated and expanded with publications from the New York City DOHMH WTC Registry, which has monitored a cohort of over 71,000 individuals recruited after 2003. The Registry's data document reports of new onset, and persistent respiratory symptoms and asthma diagnoses in local workers, evacuees, residents and school children, as well as in the responders. The data also document reports of extensive mental health symptoms in all populations.

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 a program 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 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, now called the WTC Environmental Health Center (WTC EHC), was expanded to include three sites: Bellevue Hospital, Gouverneur Clinic, and Elmhurst Hospital. In September 2008, we received our first Federal funding under a grant awarded from the National Institute for Occupational Safety and Health (NIOSH) providing 3 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.

The WTC Environmental Health Center is an interdisciplinary medical and mental health program that has evaluated and is treating approximately 4,700 patients as of June 2010. We continue to receive inquiries each week; whereas most come from local people, we have received calls from individuals living in about 23 other States. To enter our program, an individual has to have a medical or mental health complaint; we are not a screening program for asymptomatic individuals. To date, our patients are almost equally men and women and of diverse race/ethnicity. Forty-six percent are uninsured. Some have never sought medical care before entering the program, others have been unable to seek care for lack of insurance, and many 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, have symptoms that began after 9/11 and that remain persistent at the time of enrollment in the program. Symptoms include persistent rhinosinusitis (40 percent), and asthma-like symptoms of cough (47 percent), shortness of breath (67 percent) or wheeze (27 percent) for which they continue to need care more than 7 years after 9/11 (Reibman, et al. J. Occupational and Environmental Medicine, May 10, 2009). One third of our population have lung function that is below the lower limit of normal; 40 percent have shortness of breath at a level that is consistent with significant activity limitation, 10 percent 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 were highly physically active—even training for marathons—and now require...
daily medication to allow them to walk a few city blocks. Over 40 percent of the population in the WTC EHC score positive for PTSD symptoms and nearly 50 percent have complex mental health symptoms, including PTSD combined with depression and anxiety.

The persistence of respiratory and mental health symptoms in WTC-exposed resident and local worker populations is also supported by additional epidemiologic studies: a follow-up of our first resident study (Lin, et al., International J. Occupational and Environmental Health, 2010;16:44–52), and the most recent publication of the larger WTC Registry population (Brackbill, et al., Journal of the American Medical Association, 2009;302:502–16).

HOW DO WE ASSESS WHETHER AN ILLNESS IS WTC-INDUCED?

We are often asked how 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 have epidemiologic data to suggest adverse health effects, but how do we apply that information for an individual. We assess attribution based on the presence of exposure, temporal sequence of symptoms, and a particular constellation of symptoms. Studies from all the WTC programs, most of which show consistent findings, provide us with the larger epidemiologic and picture and context that inform our daily clinical practice.

WHAT MEDICAL ILLNESSES ARE WE TREATING?

We now believe that at this time, the most common, although not exclusive illnesses resulting from WTC dust and fume exposure involve the upper and lower respiratory tract. The respiratory abnormalities have varied patterns. Many patients have chronic rhinosinusitis. Most of our patients have irritant-induced asthma, some have unremitting cough. 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 have received, or are awaiting lung transplants.

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 screening program for community members in the immediate aftermath of the disaster. We are therefore faced with the nagging question of how many people are ill. The best information that we can avail ourselves of comes from the NYCDOHMH WTC Registry. Estimates of burden of illness derived from this program suggest that 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 potential risk of adverse health effects. If that system had been put in place, we might be better able to answer this burning question.

WHY ARE SOME PEOPLE SICK, AND OTHERS NOT?

The level and type of exposure clearly plays a role in determining who will or has become ill. We continue to learn about this from ongoing studies. 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 of Excellence 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. We just completed a 2-day meeting with many outside cancer epidemiology experts to discuss the best way to examine this ques-
tion. Without long-term Centers of Excellence, including Centers that treat community members, and without funding for this research, we will never have answers.

WHY DO WE NEED S. 1334, THE JAMES ZADROGA 9/11 HEALTH AND COMPENSATION ACT?

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. We now know that all these years later, these men, women and children have persistent symptoms and will require continued evaluation, treatment, and monitoring for years to come.

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 the WTC Environmental Health Center has been provided through philanthropy and New York City, with Federal funds available only for the last 2 fiscal years. The short term and uncertain funding stream makes fiscal planning difficult and prevents continuity of care, the hallmark of quality care for chronic conditions.

The bill takes care to define eligibility for the community program. There are specific geographic areas that people must have lived, worked, or attended school in on September 11 or within a defined time-period to be eligible for treatment. These boundaries reflect the best data currently available, but we also recognize that we do not know the full extent of the health impacts of the disaster.

People who meet these criteria are “eligible” for treatment. Eligibility is again reviewed by a doctor with experience treating WTC-related conditions. Using standardized questionnaires and a medical assessment, health professionals determine whether or not a patient is eligible for federally reimbursed 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 and that can newly enter the federally supported community program. The bill sets that number at 15,000 maximum along with the 4,700 current patients. 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 community member with a WTC-related condition. 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 submit testimony today.

Pertinent funding to Joan Reibman, M.D.:
2001–02: CDC, World Trade Center Residents Respiratory Survey (Institutional
P.I, Lin P.I.)
2001–03: NIH, NIEHS, World Trade Center Residents Respiratory Impact Study:
Physiologic/Pathologic characterization of residents with respiratory complaints
(P.I.)
2004–05: CDC, NIOSH WTC Worker and Volunteer Medical Monitoring Program
(P.I.)
2005–2007: American Red Cross Liberty Disaster Relief Fund (P.I.)
2006–011: New York City funding for WTC Environmental Health Center (Linda
Curtis, Bellevue Hospital, PI)
City Health and Hospitals Corporation

RESPONSE TO QUESTIONS OF SENATOR ENZI, SENATOR DODD, SENATOR CASEY, AND
SENATOR FRANKEN BY JOHN HOWARD, M.D.

SENATOR ENZI

In your verbal testimony, you indicated that, beginning in 2004, NIOSH installed
procedures to account for how 9/11 health funds were spent.

Question 1a. Please provide a copy of each version of those procedures, and iden-
tify their respective effective dates.

Answer 1a. Beginning in 2004, NIOSH implemented the World Trade Center
(WTC) Responder Health Consortium program by announcing a Request for Applica-
tions (see Attachment 1) and awarding eight cooperative agreements to support six
Clinical Centers and two Data Centers. Appropriate procedures to account for ex-
penditure of funds were put in place for these awards by placing requirements in
the award documents (see Attachment 2), which included standard procedures for
submitting annual progress reports, plans for the next year with a budget request,
Financial Status Reports that are due 90 days after the end of the budget year, and
Cash Transaction Reports that are due 45 days after the end of each Federal fiscal
year. There are also references in item 8 of Attachment 2 to OMB administrative
guidelines, HHS Grant Administration Regulations at 45 CFR part 74 and 92, and
other HHS, PHS, CDC and NIOSH grant administration policy statements, which
the grantees agreed to comply with as a condition of their awards.

Beginning in 2007, the program was authorized to provide funding for the treat-
ment of WTC-related health conditions detected through the screening and moni-
toring exams, and NIOSH added requirements to the Notices of Award to imple-
ment quarterly reporting of information on responders participating in the program
(see Attachment 3). After discussions between NIOSH and the Consortium mem-
ers, quarterly reports were adopted to provide more information to NIOSH on the
number of participants and the overall costs of the monitoring and treatment com-
ponents (see Attachments 4 and 5, respectively), which were used to evaluate the
status of the program.

Question 1b. Please provide a copy of each cooperative agreement, grant, contract
or other like instrument between NIOSH and any grantee, vendor or other
counterparty regarding 9/11 health matters.

Answer 1b. The latest award documents establish the current relationships be-
tween NIOSH and all of the components of the WTC Program (see Attachment 6).

Question 1c. Please indicate when Mt. Sinai or another party acted as a sub-
grantor, provide copies of subgrant procedures and agreements, and identify their
respective effective dates.

Answer 1c. The Mount Sinai School of Medicine funded the National Responder
Monitoring Program through a subcontract, within their grant budget, from 2005 to
2008. Mount Sinai was responsible for providing monitoring services for responders
outside of the NY–NJ metropolitan area and issued contracts to several clinics and
to QTC, Inc. to conduct the monitoring exams. Mount Sinai used their institutional
procedures to establish those contracts, which were required to be in compliance
with the standard award provisions mentioned in the answer to question 1a.

Question 1d. Please identify and provide contact information for the NIOSH em-
ployees responsible for administering the procedures and agreements.

Answer 1d. Kelley Durst, MPA, Associate Director for Planning & Performance,
National Institute for Occupational Safety and Health, Centers for Disease Control
and Prevention, 1600 Clifton Road, NE, Atlanta, GA 30333; Mailstop: E–20; Phone:
404-498-2500; Fax: 404–498–2573; Email: KDurst@cdc.gov.
**Question 1e.** Please identify and provide contact information for all grantee, vendor or other counterparty employees responsible for administering the procedures and agreements.

**Answer 1e.** Contact information for Principal Investigators of the grants and the Project Manager of the contract is provided in Attachment 7.

**Question 1f.** Please provide a detailed breakdown of how the $475 million appropriated to NIOSH for 9/11 health purposes was spent. If you cannot provide a complete answer, please explain each information gap, and furnish as complete an answer as you can.

**Answer 1f.** Awards for 9/11 health purposes, plus Federal operating costs, account for $461 million of the $476 million appropriated, as shown in the attached table (see Attachment 8). The remaining $15 million is unobligated and is available to provide supplemental funds to the awards if needed to ensure that the planned objectives are met and to cover potential cost increases of patient care. Unobligated funds that remain at the end of fiscal year 2010 will be carried over to fiscal year 2011.

**Question 2.** Please provide a detailed breakdown by grantee or vendor of sums that the NIOSH program has recouped from workers compensation, disability, private health insurance, public entitlement programs and other benefit delivery systems.

**Answer 2.** To date, three of the Clinical Centers have recouped a total of $136,220 funds from workers compensation as shown in the table below. The Community Program has filed claims for recouping funds from private health insurance companies, but no funds have yet been reported to NIOSH.

<table>
<thead>
<tr>
<th>Institution</th>
<th>Recouped Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mount Sinai School of Medicine</td>
<td>$127,386</td>
</tr>
<tr>
<td>City University of New York (Queens)</td>
<td>$5,812</td>
</tr>
<tr>
<td>State University of New York (Stony Brook)</td>
<td>$3,022</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$136,220</strong></td>
</tr>
</tbody>
</table>

**Question 3.** Please list all lung transplants and other high-cost inpatient procedures performed within the NIOSH program since 2002.

**Answer 3.** Two FDNY responders have received lung transplants. No other procedures of that high cost have been performed in the program, but there have been numerous lower cost inpatient procedures for both physical and mental health conditions.

**Question 4.** Please list how many patients are being treated for what type of 9/11-related conditions within the NIOSH program now. For each common condition, please identify the usual treatment regimen and itemize the regimen’s costs. Please explain whether there are any specialized treatments that only the Centers for Excellence can provide.

**Answer 4.** The number of responders who were treated for 9/11-related conditions within the past year are displayed in the table below. The number of total patients is greater than the sum of the patients in the health condition categories because many responders have more than one type of health condition. Similar types of health conditions have been observed among the 2,629 patients who were treated in the Community Program within the past year. No data are currently available on the costs associated with these categories because that level of detail on cost information was not required as part of the quarterly reports. However, starting this year, the grantees have agreed to begin developing systems to provide that type of information by next year.

<table>
<thead>
<tr>
<th>Number of Responders in Treatment from April 1, 2009 to March 31, 2010</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Condition Category</strong></td>
<td><strong>Number</strong></td>
</tr>
<tr>
<td>Upper Airway</td>
<td>7,201</td>
</tr>
<tr>
<td>Lower Airway</td>
<td>6,552</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>6,258</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>1,009</td>
</tr>
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</table>
Number of Responders in Treatment from April 1, 2009 to March 31, 2010—Continued

<table>
<thead>
<tr>
<th>Health Condition Category</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health</td>
<td>4,601</td>
</tr>
<tr>
<td>Total Patients</td>
<td>13,260</td>
</tr>
</tbody>
</table>

The special aspect of the Centers of Excellence is that they have a unique group of doctors who have gained a tremendous amount of experience by serving a group of patients who had an unprecedented exposure. The doctors understand the needs and concerns of this group and are able to work collaboratively in teams to provide more comprehensive services, which increases the likelihood of improving the health of responders because they know what to do and what not to do. Below is a list of the main features of Centers of Excellence.

- Utilize an integrated, centralized-provider approach instead of a multiple, separate-provider approach to create a comprehensive suite of health services to an assembled cohort of responders.
- Conduct specialized physical and mental health assessments designed to identify acute and emergent morbidities associated with the unprecedented exposure from the WTC 9/11 attack.
- Use scientifically guided treatment approaches to address the complex synergy between physical and mental health diseases that are exhibited by WTC responders and others affected by the 9/11 attacks.
- Maintain electronic linkage with a Data Center to enable a systematic collection of high-quality data for disease tracking and surveillance system, analyzing and interpreting the findings, and integrating the information into the monitoring and treatment program activities.
- Communicate with patients in numerous languages.
- Assist with workers’ compensation, insurance, pension and disability claims.

SENATOR DODD

Question 1. How many residents of CT are participating in the WTC National Responder Health Program to monitor and treat responders outside of the NYC metropolitan area? Can you provide the committee with State-by-State data of participants?

Answer 1. As of June 2010, out of over 4,000 responders who are enrolled in the National Program, 3,279 are currently participating and the distribution of these responders by State is given in Attachment 9. There are 40 responders from Connecticut who are participating.

Question 2. How many participants in the WTC Response Program are children?

Answer 2. No children are enrolled in the WTC Responder Program, 53 are enrolled in the WTC Community Program, and nearly 3,000 children and adolescents participated in the baseline survey of the WTC Health Registry.

Question 3. It is my understanding that there are very small numbers of children receiving treatment or monitoring the national program or at the Centers of Excellence in New York. Why is that? What is being done to track longitudinally the physical, and in particular the mental health of children who were at Ground Zero or affected by the loss of a loved one because of 9/11? Why has so little research been done on children?

Answer 3. In an effort to promote the pediatric services offered at the WTC Environmental Health Center (EHC) in New York City (the lead Center in the Community Program), the WTC Health Registry has sent information about these services to all of its enrollees. In addition, the WTC EHC and the NYC Department of Health and Mental Hygiene recently sent information about how to get care for 9/11-related pediatric care to more than 15,000 downtown parents. The WTC EHC provides possible reasons (see below) to explain why so few parents of WTC-exposed children have enrolled them in 9/11-specific health care program of the WTC EHC, despite extensive outreach efforts.

- The WTC EHC is the only program that is able to treat children affected by the collapse of the World Trade Center towers. The six Centers of Excellence in New York (Fire Department of New York, Mount Sinai School of Medicine, State University of New York at Stony Brook, City University of New York at Queens, New York University at Bellevue, and University of Medicine and Dentistry of New Jersey)
and the National Program focus on adult rescue workers and responders and were developed from occupational clinics for adults.

• Parents with private health insurance may prefer to initiate or continue their children’s care with a community pediatrician. It may be that children eligible and in need of WTC EHC services are far more likely to be insured than adults would be. Having insurance means that the child is likely to be under the continuing care of a local pediatric provider—be that a pediatrician, child health clinic, school health clinic, or a community health center. Many of these pediatric providers may not recognize the presence of a WTC-related illness in their patients. As such, the provider does not see the benefit of referring the child to the WTC EHC.

• In the months and years following 9/11, many families moved out of Lower Manhattan. Children in schools may have transferred or graduated. Identifying and locating these children is challenging.

The World Trade Center Health Registry enrolled nearly 3,000 children and adolescents under the age 18 in its 2003–4 baseline survey. Findings from the survey were reported in the following publication: Thomas PA, Brackbill R, Thalji L, DiGrande L, Campolucci S, et al., Respiratory and Other Health Effects Reported in Children Exposed to the World Trade Center Disaster of 11 September 2001. Environ Health Perspectives 2008; 116:10. The investigators reported that half (53 percent) of the children had at least one new or worsened respiratory symptom at some time after 9/11, including shortness of breath, cough, sinus problems, throat irritation, or wheezing (5.7 percent has new asthma diagnoses). Additionally, eye irritation or eye injury on 9/11 was reported in 22 percent of children, and injuries (sprains, lacerations, burns, broken bones, or concussions) were reported for 3 percent. In 2008 the Registry completed its second survey of the physical and mental health conditions among 2,000 children and adolescents who remained under age 18; analysis is currently underway. The Registry plans a third survey of children and adolescents in 2011.

There are several barriers to conducting research among children, including:

• In order to do research on children, parental consent would have to be granted. Parents want to protect their children from further harm by excluding them from research studies. Parents want their children to move past 9/11.

• Parents believe their children are healthy and therefore there is no reason for them to participate in studies.

• Several schools refused to participate in the study, not wanting to perpetuate the focus of 9/11.

SENATOR CASEY

Question. How have the 9/11 World Trade Center programs in existence helped to track, and provide care for, children and youth who were affected that day? What sort of long-term commitment needs to be made to understand how children and youth have been impacted; how do the 9/11 programs discussed today help to do that?

Answer. The WTC Environmental Health Center (EHC) in the Community Program has a pediatric component dedicated to the assessment and treatment of WTC-related conditions in children and adolescents. Children who enroll in the EHC program enter it as a treatment patient. That is, the child has a WTC-related medical, developmental, and/or mental health problem requiring treatment. All new pediatric patients undergo an initial medical and mental health screening, which is different from the adult program because it is enhanced to include pediatric needs. The EHC offers a wide range of pediatric services including assessment and care by a pediatrician with WTC expertise, a pediatric pulmonologist, or a developmental pediatrician. In addition, children can undergo psychotherapy or psychopharmacologic evaluation and treatment, as needed, with pediatric psychologists or psychiatrists. The recruitment of specialists with these skills who are able to work together in a coordinated manner is a major advantage to treatment. The EHC also offers art therapy and child life services to pediatric patients.

Because there were so many unknowns in the pediatric population, the EHC expanded their inclusion criteria to include children whose mothers were pregnant during the above-referenced time period. Also included are children of sickened responders/rescue workers and/or children who lost a parent, both parents, or other custodial care taker on 9/11. Although the WTC EHC offers a comprehensive program that includes medical treatment, mental health and developmental treatment programs, there has been a low response to date. However, as news of the program spreads and local pediatricians gain trust in the program, it is anticipated that the program will continue to grow.
The WTC Health Registry does not provide direct healthcare services, but the Registry does the following activities related to children: (1) routinely surveys the health of children and adolescents enrolled in the Registry to determine if changes in their health may be attributable to 9/11; (2) disseminates its health findings and recommendations to enrollees, and to the public and policymakers; (3) informs enrollees of 9/11-related services, resources and health promotion programs; (4) develops and provides data resources for, and responds to inquiries from, enrollees and the public; and (5) developed and disseminated Clinical Guidelines for Children and Adolescents Exposed to the World Trade Center Disaster to physicians and parents in New York City and to college health centers throughout the Northeast.

SENATOR FRANKEN

Question. Dr. Howard, in your testimony, you discuss the mental health needs of survivors of the 9/11 tragedy, noting that the effects can linger for years. What type of mental health infrastructure do we need to have in place to respond appropriately to the acute and long-term effects of such events?

Answer. CDC/NIOSH is committed to providing programs and services to help meet the on-going and long-term health needs of those directly exposed to smoke, dust, debris and psychological trauma in the September 11, 2001 WTC attacks. NIOSH currently addresses the psychological trauma and mental health needs of program participants via the WTC Health Program, NYC Police Foundation's Project COPE and the Police Organization Provided Peer Assistance (POPPA).

- The WTC Program provides monitoring and treatment for both physical and mental health conditions attributed to WTC exposures and embraces a comprehensive model to address the issues that influence long-term recovery of those affected by this disaster. The WTC Clinical Centers work to identify program participants who are suspected of having mental health conditions related to WTC exposures and intervene as early as possible to minimize adverse health impacts over time. Program participants complete standardized mental health symptom surveys as part of their (annual) medical monitoring exam process. The surveys are scored and reviewed by healthcare staff and used to guide decisions about further mental health evaluation or referral for mental health treatment services. A program participant may also be referred for mental health treatment services as part of the treatment program, should such health complaints or requests be presented to the program provider (physician, nurse or social worker). The WTC Program gathers information to describe the rates and trends of conditions experienced by program participants. Analysis of individual case reports, data from monitoring programs and the WTC Health Registry report that certain mental health conditions are cited consistently: anxiety, depression or post-traumatic stress disorder (PTSD).

- The NYC Police Foundation’s Project COPE and the Police Organization Provided Peer Assistance (POPPA) also provide mental health services, such as counseling and support groups, to the police responder population.

NIOSH and CDC recognize that mental health conditions can be persistent in a small percentage of the WTC Health Program cohort, and may require long-term monitoring and treatment.

LIST OF ATTACHMENTS

1. Request for Applications for the World Trade Center Responder Health Consortium in fiscal year 2004
2. Terms and Conditions for procedures in the first-year awards for six Clinical Centers and two Data Centers
3. Additional Terms and Conditions that established Quarterly Reporting
4. Quarterly Monitoring Report
5. Quarterly Treatment Report
6. Award documents for all current components of the WTC Program: NYC Responders, National Responders, NYC Community members, and WTC Health Registry
7. Contacts for each cooperative agreement, grant, and contract that make up the WTC Program
8. Table of funds spent by fiscal year for each cooperative agreement, grant, and contract that make up the WTC Program
9. Table of participants by State in the National Responder Health Program
ATTACHMENT 2.—COOPERATIVE AGREEMENT TERMS AND CONDITIONS OF AWARD FOR 2004 TO 2009

The cooperative agreement is an award instrument establishing an “assistance” relationship (in contrast to an “acquisition” relationship) between NIOSH and a recipient, in which substantial NIOSH scientific and/or programmatic involvement with the recipient is anticipated during performance of the activity. The purpose of NIOSH involvement is to support and/or stimulate the recipient’s activity by acting as a “partner,” while avoiding a dominant role, direction, or prime responsibility. The terms and conditions below, elaborate on these actions and responsibilities, and the awardee agrees to these collaborative actions with the NIOSH Scientific Program Administrator to achieve the project objectives. It is anticipated that these terms and conditions will enhance the relationship between the NIOSH staff and the principal investigator(s), and will facilitate the successful conduct and completion of the study. These agreements will be in addition to, and not in lieu of, the relevant NIOSH procedures for grants administration.

1. The awardee(s) will have lead responsibilities in all aspects of the study, including any modification of study design, conduct of the study, quality control, data analysis and interpretation, preparation of publications, and collaboration with other investigators, unless otherwise provided for in these terms or by action of the Steering Committee.

2. The NIOSH Scientific Program Administrator will serve on the Steering Committee as non-voting members; he/she or other NIOSH scientists may serve on other study committees, when appropriate, but if other NIOSH scientists are identified, they will also be non-voting members. The NIOSH Scientific Program Administrator (and other NIOSH scientists) may work with awardees on issues coming before the Steering Committee and, as appropriate, other committees, e.g., recruitment, intervention, follow-up, quality control, adherence to protocol, assessment of problems affecting the study and possible changes in protocol, interim data and safety monitoring, final data analysis and interpretation, preparation of publications, and development of solutions to major problems such as insufficient participant enrollment.

3. Awardee(s) agree to the governance of the study through a Steering Committee. Steering Committee voting membership shall consist of the Principal Investigators (i.e., cooperative agreement awardees), and the Chairperson. Meetings of the Steering Committee will ordinarily be held by telephone conference call or in the metropolitan New York Area.

4. Awardees will retain custody of and have primary rights to their data consistent with current HHS, PHS, and NIOSH policies. The collaborative protocol and governance policies will call for the continued submission of data centrally to the coordinating centers for collaborative databases, one for the firefighter and one for the other responder cohort; the submittal of copies of the collaborative datasets to each principal investigator upon completion of the study; procedures for data analysis, reporting, and publication; and procedures to protect and ensure the privacy of medical and genetic data and records of individuals. The NIOSH Scientific Program Administrator on behalf of NIOSH, will have the same access, privileges and responsibilities regarding the collaborative data as the other members of the Steering Committee.

5. Awardees are encouraged to publish and to publicly release and disseminate results, data and other products of the study, concordant with study protocols and governance, and the approved plan for making data and materials available to the scientific community and to NIOSH.

6. The NIOSH reserves the right to terminate or curtail the study (or an individual award) in the event of (a) failure to develop or implement a mutually agreeable collaborative protocol, (b) substantial shortfall in participant recruitment, follow-up, data reporting, or quality control, (c) major breach of the protocol or substantive changes in the agreed-upon protocol with which NIOSH cannot concur, or (d) human subject ethical issues that may dictate a premature termination.

[Editor’s Note: Due to the high cost of printing, previously published materials will not be reprinted in the hearing record. Please refer to the Web site provided to access these documents.]
7. Payment for health screenings will be based on an email from the Data and Coordinating Center, DCC approving the submitted data. These emails must be retained for the annual audit of the health screenings charges and must be maintained for the annual audit review. No other documentation shall be required to justify the health screening charges.

8. These special terms of award are in addition to and not in lieu of otherwise applicable OMB administrative guidelines, HHS Grant Administration Regulations at 45 CFR part 74 and 92, and other HHS, PHS, CDC and NIOSH grant administration policy statements.

ATTACHMENT 3.—ADDITIONAL COOPERATIVE AGREEMENT TERMS AND CONDITIONS OF AWARD FOR 2007 TO 2009

Additionally, the Reporting Requirements have been augmented as follows:

Principal investigators for this program are required to provide a quarterly report on patient and conditions. The report shall be submitted to the Data and Coordination Center (DCC) and the Center for Disease Control (CDC), Grants Management Office, noted below. The content of the report will be defined by the DCC and NIOSH no later than close of business Tuesday, November 14, 2006. The report due dates are as follows:

Due Date: February 1, 2007
Covering the period: October, November, and December

Due Date: May 1, 2007
Covering the period: January, February, and March

Due Date: August 1, 2007
Covering the period: April, May and June,

Due Date: November 1, 2007
Covering the period: July, August, and September
**ATTACHMENT 4.—QUARTERLY MONITORING REPORT**

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<thead>
<tr>
<th>Clinical Center:</th>
<th>World Trade Center - Monitoring Program</th>
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<td>Quarterly Report - Dates: MM/DD/YYYY - MM/DD/YYYY</td>
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<tr>
<td>7/1-9/30</td>
<td>10/1-12/31</td>
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<table>
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<table>
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<tr>
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<td>Visit 2 (First Follow-Up)</td>
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<td>Visit 3 (Second Follow-Up)</td>
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<tr>
<td>Brief health questionnaires for patients not returning for visit this 18 months</td>
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<table>
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<table>
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<th>Employment Status @ time of visit</th>
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</thead>
<tbody>
<tr>
<td>Currently Employed</td>
</tr>
<tr>
<td>Unemployed/Laid off</td>
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<tr>
<td>Extended Sick Leave/Disability</td>
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<tr>
<td>Retired</td>
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<tr>
<td>Other</td>
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<tr>
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<td>TOTAL</td>
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<table>
<thead>
<tr>
<th>Occupation @ time visit</th>
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<tr>
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</tr>
<tr>
<td>Law Enforcement</td>
</tr>
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<td>Civilian Public Sector</td>
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<td>Technical and Utilities</td>
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<td>Transportation</td>
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<td>Cleaning/Maintenance</td>
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<tr>
<td>Volunteer</td>
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<tr>
<td>Firefighter (excludes New York City)</td>
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<td>Healthcare</td>
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<tr>
<td>News Agency</td>
</tr>
<tr>
<td>Office/Administrative/Professional</td>
</tr>
<tr>
<td>Federal Employee</td>
</tr>
<tr>
<td>Other</td>
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<tr>
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</tr>
<tr>
<td>TOTAL</td>
</tr>
<tr>
<td>Insurance Status (at time of visit)</td>
</tr>
<tr>
<td>------------------------------------</td>
</tr>
<tr>
<td>Active</td>
</tr>
<tr>
<td>Blue Cross/Blue Shield</td>
</tr>
<tr>
<td>Gold</td>
</tr>
<tr>
<td>HIP</td>
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<tr>
<td>Other Managed Care/PPO</td>
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<td>Other Managed Care/HMO</td>
</tr>
<tr>
<td>Other Private</td>
</tr>
<tr>
<td>Medicaid</td>
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<tr>
<td>Medicare</td>
</tr>
<tr>
<td>No Third Party Coverage</td>
</tr>
<tr>
<td>Declined Information</td>
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<tr>
<td>Line of Duty:</td>
</tr>
<tr>
<td>WTC-related LODI claim filed</td>
</tr>
<tr>
<td>Patient able to receive care through WTC-related LODI claim</td>
</tr>
<tr>
<td>Workers' Compensation</td>
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<tr>
<td>WTC-related WC claim filed</td>
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<tr>
<td>Patient able to receive care through WTC-related WC claim</td>
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<td>WC claim status unknown</td>
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<table>
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<th>Conditions (diagnosed/suspected)</th>
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<th>2nd Quarter</th>
<th>3rd Quarter</th>
<th>4th Quarter</th>
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<tr>
<td>Lower Airway</td>
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<td>Musculoskeletal</td>
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<tr>
<td>Mental Health</td>
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<td></td>
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<tr>
<td>Other</td>
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<td>TOTAL</td>
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**ATTACHMENT 5.—QUARTERLY TREATMENT REPORT**

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<th>Clinical Center:</th>
<th>World Trade Center - Treatment Program</th>
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<td>Quarterly Report - Dates: MM/DD/YYYY - MM/DD/YYYY</td>
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<td>TOTAL Participants</td>
<td>1st Quarter</td>
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**Employment Status at time of visit**
- Currently Employed
- Unemployed
- Sick Leave
- Disability
- Regular
- Retired
- Not Recorded

**Occupation at time of visit**
- Construction
- Law Enforcement
- Civilian Public Sector
- Technical and Utilities
- Transportation
- Catering/Maintenance
- Volunteer
- Firefighter (excludes New York City)
- Healthcare
- News Agency
- Office/Administrative/Professional
- Federal Employee
- Other
- Not currently employed
- Not Recorded

**Insurance Status at time of visit**
- Astra
- Blue Cross/Blue Shield
- CIGNA
- HIP
- Other Managed Care/PPO
- Other Managed Care/HMO
- Other Private
- Medicare
- Medicaid
- None
- No Third Party Coverage

**Details Information Line of Duty**
- Patient not covered by LODI
- LODI claim filed
- LODI claim denied
- LODI claim established
- LODI claim established, settled or closed and medical care authorized
- LODI claim established, settled or closed and medical care NOT authorized
- LODI claim status unknown
- Not Recorded

TOTAL
ATTACHMENT 6.—AWARD DOCUMENTS FOR ALL CURRENT COMPONENTS OF THE WTC PROGRAM: NYC RESPONDERS, NATIONAL RESPONDERS, NYC COMMUNITY MEMBERS, AND WTC HEALTH REGISTRY

ATTACHMENT 7.—CONTACTS FOR THE COOPERATIVE AGREEMENTS, GRANT, AND CONTRACT THAT MAKE UP THE WTC PROGRAM

<table>
<thead>
<tr>
<th>Grantee/Contractor</th>
<th>Program</th>
<th>Address</th>
<th>Principal Investigator/Contact</th>
<th>Telephone</th>
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</thead>
<tbody>
<tr>
<td>Fire Dept. City of New York</td>
<td>Clinic Center</td>
<td>Office of Medical Affairs, Rm. 2–E4, 9 Metrotech Center, Brooklyn, NY 11201.</td>
<td>Kelly, Kerry J. <a href="mailto:kellykj@fdny.nyc.gov">kellykj@fdny.nyc.gov</a></td>
<td>718–999–1933.</td>
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<tr>
<td>Fire Dept. City of New York</td>
<td>Data Center</td>
<td>Office of Medical Affairs, Rm. 4W–1, 9 Metrotech Center, Brooklyn, NY 11201.</td>
<td>Prezant, David J. <a href="mailto:prezand@fdny.nyc.gov">prezand@fdny.nyc.gov</a></td>
<td>718–999–2696.</td>
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<tr>
<td>Mount Sinai School of Medicine.</td>
<td>Clinic Center</td>
<td>One Gustave L. Levy Place, Box # 1057, New York, NY 10029–6574.</td>
<td>Crane, Michael <a href="mailto:Michael.crane@mssm.edu">Michael.crane@mssm.edu</a></td>
<td>212–808–7625.</td>
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<tr>
<td>Mount Sinai School of Medicine.</td>
<td>Data Center</td>
<td>One Gustave L. Levy Place, Box # 1057, New York, NY 10029–6574.</td>
<td>Landrigan, Philip, <a href="mailto:Phil.landrigan@mssm.edu">Phil.landrigan@mssm.edu</a></td>
<td>212–824–7018.</td>
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<tr>
<td>Research Foundation at SUNY, Stony Brook.</td>
<td>Clinic Center</td>
<td>W. 5510 Melville Library, Stony Brook, NY 11794–3362.</td>
<td>Luft, Benjamin J. <a href="mailto:Bluff@notes.cc.sunysb.edu">Bluff@notes.cc.sunysb.edu</a></td>
<td>631–444–8219.</td>
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<tr>
<td>UMONI—Robert Wood Johnson Medical School.</td>
<td>Clinic Center</td>
<td>170 Feilnguyen Road, Room 115, Piscataway, NJ 08854.</td>
<td>Udasin, Iris G. <a href="mailto:usasin@ehsi.rutgers.edu">usasin@ehsi.rutgers.edu</a></td>
<td>732–445–0123 x 612.</td>
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<tr>
<td>Queens College of CUNY...</td>
<td>Clinic Center</td>
<td>230 W. 41st Street, New York 10036.</td>
<td>Markowitz, Steven B. <a href="mailto:smarkowitz@qc.cuny.edu">smarkowitz@qc.cuny.edu</a></td>
<td>718–670–4184.</td>
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[Editor's Note: Due to the volume of documents submitted with this attachment and the high cost of printing these documents were not printed in the record, but are maintained in the committee files.]
Senator Enzi: 1-e, Grantee/Contract Contact Information—Continued

<table>
<thead>
<tr>
<th>Grantee/Contractor</th>
<th>Program</th>
<th>Address</th>
<th>Principal Investigator/Contact</th>
<th>Telephone</th>
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<tr>
<td>New York University Medical Center, Bellevue</td>
<td>Clinic Center</td>
<td>550 First Ave., New York, NY 10016.</td>
<td>Harrison, Denise Joy</td>
<td>212–562–4572.</td>
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<tr>
<td>Logistics Health Incorporated (LHI)</td>
<td>National responder Contract.</td>
<td>328 Front Street South, La Crosse, WI 54601.</td>
<td>Sarah Parins</td>
<td>866–284–8788 x 1116.</td>
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ATTACHMENT 8.—TABLE OF FUNDS SPENT BY FISCAL YEAR FOR EACH COOPERATIVE AGREEMENT, GRANT, AND CONTRACT THAT MAKE UP THE WTC PROGRAM

WTC Awards & Program Operations

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<th>Fiscal Year</th>
<th>Obligated</th>
<th>Expenditures</th>
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<td>$3,574,116</td>
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<td>FY05</td>
<td>3,591,898</td>
<td>3,591,898</td>
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<tr>
<td></td>
<td>FY06</td>
<td>5,110,214</td>
<td>5,110,214</td>
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<tr>
<td></td>
<td>FY07</td>
<td>3,629,079</td>
<td>3,629,079</td>
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<td></td>
<td>FY08</td>
<td>5,631,557</td>
<td>5,631,557</td>
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<tr>
<td></td>
<td>FY09</td>
<td>25,513,854</td>
<td>25,513,854</td>
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<td></td>
<td>FY10</td>
<td>29,436,738</td>
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<td>Total</td>
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<td>Fire Department of NYC (OCC)</td>
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<td>FY05</td>
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<td>FY08</td>
<td>4,851,185</td>
<td>4,851,185</td>
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<td>3,313,199</td>
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<td>-</td>
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<td></td>
<td>Total</td>
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<td>$19,743,363</td>
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<tr>
<td>Mount Sinai School of Medicine (CC)</td>
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<td>$5,225,000</td>
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<td>FY05</td>
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Mount Sinai School of Medicine (OCC)
### WTC Awards & Program Operations—Continued

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<th>FY05</th>
<th>FY06</th>
<th>FY07</th>
<th>FY08</th>
<th>FY09</th>
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<th>Expenditures</th>
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<tr>
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<td>1,200,000</td>
<td>3,720,794</td>
<td>11,421,282</td>
<td>6,744,826</td>
<td>11,806,362</td>
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<tr>
<td>FY05</td>
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<td>1,200,000</td>
<td>1,200,000</td>
<td>3,720,794</td>
<td>11,421,282</td>
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<td>1,200,000</td>
<td>1,200,000</td>
<td>1,200,000</td>
<td>3,720,794</td>
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<td>11,421,282</td>
<td>11,421,282</td>
<td>11,421,282</td>
<td>11,421,282</td>
<td>11,421,282</td>
<td>11,421,282</td>
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<td>6,744,826</td>
<td>6,744,826</td>
<td>6,744,826</td>
<td>6,744,826</td>
<td>6,744,826</td>
<td>6,744,826</td>
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<td>FY10</td>
<td>11,806,362</td>
<td>11,806,362</td>
<td>11,806,362</td>
<td>11,806,362</td>
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</tbody>
</table>

| Queens College of City University of NY       |          |          |          |          |          |          |          |           | $716,914  | $716,914    |
| FY04                                          | $716,914  | 621,144  | 621,144  | 1,714,239 | 2,336,371 | 2,006,172 | 3,146,637 |          |           |
| FY05                                          | 621,144   | 621,144  | 621,144  | 1,714,239 | 2,336,371 | 2,006,172 | 3,146,637 |          |           |
| FY06                                          | 621,144   | 621,144  | 621,144  | 1,714,239 | 2,336,371 | 2,006,172 | 3,146,637 |          |           |
| FY07                                          | 1,714,239 | 1,714,239 | 1,714,239 | 1,714,239 | 1,714,239 | 1,714,239 | 1,714,239 |          |           |
| FY09                                          | 2,006,172 | 2,006,172 | 2,006,172 | 2,006,172 | 2,006,172 | 2,006,172 | 2,006,172 |          |           |
| FY10                                          | 3,146,637 | 3,146,637 | 3,146,637 | 3,146,637 | 3,146,637 | 3,146,637 | 3,146,637 |          |           |
| Total                                         | $10,688,590 | $6,709,289 |          |          |          |          |          |           |           |

| NYU School of Medicine, Bellevue             |          |          |          |          |          |          |          |           | $762,409  | $762,409    |
| FY04                                          | $762,409  | 706,355  | 706,355  | 1,295,337 | 1,295,337 | 1,385,008 | 2,010,394 |          |           |
| FY05                                          | 706,355   | 706,355  | 706,355  | 1,295,337 | 1,295,337 | 1,385,008 | 2,010,394 |          |           |
| FY06                                          | 706,355   | 706,355  | 706,355  | 1,295,337 | 1,295,337 | 1,385,008 | 2,010,394 |          |           |
| FY07                                          | 1,295,337 | 1,295,337 | 1,295,337 | 1,295,337 | 1,295,337 | 1,295,337 | 1,295,337 |          |           |
| FY08                                          | 775,715   | 775,715  | 775,715  | 775,715  | 775,715  | 775,715  | 775,715  |          |           |
| FY09                                          | 1,385,008 | 1,385,008 | 1,385,008 | 1,385,008 | 1,385,008 | 1,385,008 | 1,385,008 |          |           |
| FY10                                          | 2,010,394 | 2,010,394 | 2,010,394 | 2,010,394 | 2,010,394 | 2,010,394 | 2,010,394 |          |           |
| Total                                         | $7,508,073 | $4,483,266 |          |          |          |          |          |           |           |

| Logistics Health Incorporated (LHI)           |          |          |          |          |          |          |          |           | $11,000,000 | $9,434,495 |
| FY08                                          | $11,000,000 | 5,200,000 |          |          |          |          |          |           |           |
| FY10                                          | 5,200,000   |          |          |          |          |          |          |           |           |
| Total                                         | $16,200,000 | $9,434,495 |          |          |          |          |          |           |           |

| Project COPE/NYC Police Foundation             |          |          |          |          |          |          |          |           |           |           |
### WTC Awards & Program Operations—Continued

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<th>FY08</th>
<th>FY09</th>
<th>FY10</th>
<th>Total</th>
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<tr>
<td>POPPA/Police Resiliency Maintenance Program</td>
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* For health screening of WTC responders before the current monitoring and treatment program.
## WTC National Responder Locations

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RESPONSE TO QUESTIONS OF SENATOR DODD, SENATOR CASEY, AND SENATOR FRANKEN BY JIM MELIUS, M.D., DrPH

SENATOR DODD

Question 1. Do you believe residents should be included in any health program authorized by Congress to treat individuals and families suffering physical or mental health effects of 9/11?

Answer 1. Yes, people living, working, and going to school in the area around the World Trade Center were exposed to the same WTC dust and smoke as the rescue, recovery, and cleanup workers at the WTC site. Some of these residents, workers, and students had very intense exposures to the so-called dust cloud at the time when the buildings collapsed. Others spent weeks and months in workplaces or residents that were never properly cleaned and, as a result of this, were exposed to significant amounts of dust. Maintenance workers in downtown buildings often had to try to clean these buildings without proper respiratory protection and were often exposed later when doing maintenance work in areas of their buildings that still hadn’t been cleaned even many months later.

In general, studies have found a higher rate of illnesses in these residents, workers, and students similar to those found in the rescue and recovery workers. These illnesses include asthma and other respiratory diseases. Acute symptoms such as eye irritation, cough, and other respiratory symptoms were reported to be significantly elevated in these residents in the time period immediately after the attack. Later studies conducted by the NYC Department of Health and by Bellevue Medical Center staff reported on many downtown residents (including children) and workers with serious respiratory disease including asthma as a result of their WTC exposures. Studies by the NYC Department of Health and other academic institutions have also documented a high rate of Post Traumatic Stress Disorder (PTSD) among downtown residents after 9/11. For many of these people, these symptoms are chronic and require intense medical treatment.

Question 2. According to the 2009 WTC Medical Working Group of NYC Annual Report on 9/11 Health, "Few studies addressed the impact of WTC exposure on child and adolescent health, especially physical health." Why is that?

Answer 2. There are several reasons why there are few studies available addressing the effects of WTC exposure on child and adolescent health. Most of the early studies focused on the health of the rescue and recovery workers who, in general, had the highest exposures to the WTC dust and smoke and thus very high rates of respiratory disease and other illness. More scientific effort has recently shifted to focus on the community near the World Trade Center including children and adolescents. The WTC Registry operated by the New York City Department of Health has reported on their initial survey results on children and is currently planning a follow-up survey. The Bellevue Program for WTC residents and workers has also expanded their services to include pediatric services.

There are also difficulties conducting research on children and adolescents. Many of the children exposed in 2001 have now moved to other areas to attend college and for other reasons. This makes it more difficult to track them and enroll them in studies. There are also additional ethical safeguards in place for research involving children which adds to the time required to conduct studies of children and adolescents. Despite these difficulties, I expect that more studies on children and adolescents will be conducted over the next few years.

SENATOR CASEY

Question 1. For those who rely on 9/11 World Trade Center health programs, how would the legislation introduced by Senator Gillibrand help to guarantee that they are taken care of not just today but tomorrow? Has our country made a long-term commitment to helping the people served by these programs? What are the benefits of funding these programs not just for 1 year but for several years at a time?

Answer 1. Senator Gillibrand’s legislation would provide stable long-term medical care for people who have become ill as a result of their exposures following the WTC terrorist attacks in 2001. Many of them have developed serious chronic diseases including respiratory illnesses and Post Traumatic Stress Disorder (PTSD) which will require many years of monitoring and treatment. In addition, we do not know what other illnesses such as cancer may emerge among this population. This legislation will ensure that they receive long-term high quality medical care that will help to reduce the long-term effects of these illnesses on them and their families.

Immediately after September 11, President Bush and Congress stated their commitment to help everyone harmed by this terrorist attack. Unfortunately, the fund-
ing for the WTC medical programs has been intermittent. Often it was only included in emergency appropriations. While long-term support for the program has been stated, supporters of the program have struggled from year to year to obtain the necessary funding.

A long-term funding commitment would ensure that the programs can provide high quality medical care to these patients over the longer term. The institutions will be able to commit to hiring the medical staff needed for the programs. This has been difficult with just year to year budgeting. Administration functions will also be improved with more stable funding and staffing. The legislation also includes provisions for improving the administrative efficiency of the program through better funding mechanisms for the medical care and improved ability to utilize long-term contracts for pharmaceutical coverage and other medical expenses. Most importantly, the patients being cared for in this program will be assured that their medical care will continue to be available.

Question 2. From a health care systems perspective, in your opinion does investing in the World Trade Center health programs—which as many of the panelists have testified are tailored to meet the needs of those harmed by 9/11—offer a better return on investment than just providing funding to individuals directly to seek out care from providers who are not specialists in this area? If so, how?

Answer 2. My initial training and experience was in primary medical care, and I understand the benefits of using primary care practitioners for general medical care. However, this is a special situation where much of the medical care for these WTC patients is specialized. More importantly, their illnesses are not routine. Their illnesses do not always respond to medical treatment in the expected manner, and we don’t know what future illnesses might occur among these patients. For these reasons, there is considerable benefit to provide their medical care by a more concentrated group of providers who focus on just these WTC patients and thus have more experience in the diagnosis, management, and treatment of these patients.

While there may need to be some adjustments for patients living in other parts of the country, I believe that limiting most medical care to these Centers of Excellence will provide higher quality medical care that will benefit these patients. We also know from experience that most primary care physicians are uncomfortable treating these patients and often have difficulty when trying to do so. Many of the patients recently enrolling in the program do so because their health has continued to get worse while under the care of their primary care provider. This is not necessarily the fault of the provider but rather a reflection of the difficulty of diagnosing and treating these patients.

Question 3. Can you comment on how many people who live outside of New York City are being helped by the 9/11 World Trade Center health programs?

Answer 3. Currently, over 4,000 rescue, recovery, and clean-up workers living outside of the NYC area have received monitoring exams, and approximately 1,000 have received medical treatment through this program including over 675 in the last year. The program for rescue and recovery workers living outside of the NYC area was slow in getting implemented. Now that a more comprehensive program is available, I expect that the number of people obtaining care through this program to continue to increase especially as many of the older patients retire and move out of the New York City area.

Question. Would it be correct to summarize Senator Gillibrand’s bill, S.1334, as providing for the extension and coordination of existing programs to ensure they are administered most efficiently and effectively? Would it also be correct to say that the legislation doesn’t create any new categories of beneficiaries and that it has adequate safeguards to prevent fraud and abuse?

Answer. Yes. In establishing the medical programs as long-term monitoring and treatment programs, the legislation also helps to improve their administrative efficiency. The program administrator (NIOSH) will have to establish standardized procedures for enrollment and for approval of treatment for WTC-related medical conditions. There will also be better criteria and procedures for adding additional providers to the program. Better quality assurance programs will be required, and there will be better oversight of the medical programs. Long term funding will also enable the Federal Government and the Centers of Excellence to establish longer term contracts for pharmaceuticals and other medical services for the programs. These longer term contracts should be more cost-effective.

The legislation does not create any new categories of beneficiaries. The enrollment criteria and treatment criteria mirror those currently in place for the responder and
community medical programs. Under their current funding agreements with
NIOSH, the Centers of Excellence could expand the list of covered conditions. The
legislation restricts changes to enrollment criteria to require that the program ad-
ministrator approve all changes and also limits additions to the list of covered condi-
tions.

The legislation also includes provisions to prevent fraud and abuse. All of the
Centers of Excellence are required to have in place internal safeguards against
fraud and abuse and must institute quality assurance programs. The Centers must
also utilize treatment protocols developed for the program, and only treatments that
are deemed medically necessary can be reimbursed. These and other provisions
should safeguard against fraud and abuse.

RESPONSE TO QUESTIONS OF SENATOR CASEY AND SENATOR FRANKEN
BY DAVID PREZANT, M.D.

SENATOR CASEY

Question. Why is it that, after 9 years, there are people who haven’t yet been
given assistance?

Answer. At the FDNY program, we have offered assistance in terms of monitoring
and treatment to 100 percent of our cohort and over 95 percent have accepted it
in one form or another (monitoring or treatment or both). For a voluntary program
such a high rate of service is unheard of. The only thing that prevents continued
high rates is the uncertainty raised by year-to-year funding.

SENATOR FRANKEN

Question 1. EMS workers are the backbone of our emergency response system in
this country. How does the Center of Excellence communicate with health care pro-
viders to ensure that survivors are getting the care they need?

Answer 1. Our outreach to FDNY EMS has been as successful as to FDNY fire.
The services they receive are identical. Mt. Sinai and the national program are re-
sponsible for other EMS personnel. Our service to them has been to publicize our
results and findings and treatment protocols so that everyone can benefit from our
experience.

Question 2. Can you also please discuss whether there’s a deadline for monitoring
the long-term effects of the 9/11 exposure and treatment these workers receive—in
other words, what do you think EMS workers’ health needs may be 10, 20, or even
30 years from now?

The timeline for EMS should be no different than for others with exposure. Asth-
ma and PTSD are early outcomes but cancer and interstitial lung diseases like as-
bestosis and pneumoconiosis (from dust) take 10 to 30 years to develop. Therefore
the follow up should be at least 30 years.

RESPONSE TO QUESTION OF SENATOR CASEY BY MARGRILY GARCIA

Question. You spoke about your experiences on 9/11—and the challenges that you
faced that day and in the months and years that have followed. What are your
greatest fears related to your health at this point? How do the 9/11 health programs
help you minimize or face those fears?

Answer. My greatest fears related to my health at this point are the probable and
continual deterioration of my life from now on. I’m afraid of just getting by and not
improving, of having to always visit a specialist for one medical problem or another.
I fear of falling into that small but fatal percentile where a procedure, surgery, or
prescription side effect may go wrong and make me feel or get worse.

Thus far I’ve had three operations to fix my pacemaker/defibrillator which the
leads came out twice within 6 months when I was advised that it would be about
10 years for me to change my battery or be otherwise operated on. My life depends
on a battery-operated machine inside of me that can malfunction at any time. What
happens to me if I don’t reach the hospital in time?

I had the sinus operation in late February to remove nasal polyps completely
blocking my nasal airways, and was promised to feel relief for at least 5 years only
to be recently informed that I have nasal polyps again 3 months later which means
sinus congestion and horrible constant headaches. I have to suffer with a nasty odor
that exists in my nose from the polyps if I don’t rinse it and have to use a nasal
steroid (Nasonex or Flunisolide) to find temporary relief. This also means more un-
comfortable experiences at the ENT clinic where the doctors fill my nose with bad
tasting fluids (local anesthetics and decongestants) to numb my nose and throat
while they stick a tube with a camera to see deep inside my very sensitive nose.
I force myself to go to listen to their advice to take the medicine that I need that would avoid having another surgery. I sit there very nervous thinking that if I sneeze while the tube is in my nose that perhaps it may puncture something inside which is connected closely to my brain. Every time I visit the WTC clinic and their affiliated doctors I'm afraid of what news I will receive, but I am also relieved because if anything is wrong I have trust that they will proceed with caution and expertise. In assistance, I observe and try to keep track of any changes in my body to report in case something else is wrong and we can detect it early before it becomes too late. I wonder who lives like this. Who worries about their lives daily like I do? I hate feeling so tired everyday as if I were an old lady whose body is about to give out. I'm a recently married woman who wants to have kids and form a beautiful family. My life is crucial because I am significant and precious and worthwhile to my family and country. I keep my family together. I am the loving leader who my siblings look up to and my mother depends on to help her with everything. I make my job run smoother because I perform my job with diligence and excellence. Something I am very proud of and yet my job is another one of my greatest fears. I have my Family Medical Leave Act (FMLA) form promptly filled out yearly but that isn't enough to ease my concerns of losing my job, never getting a promotion because of my absenteeism, or looking for a new job because who wants to hire a sick person? Due to my illness I sacrifice personal time or paid time off (PTO) from work for medical appointments and when I don't have PTO available then I don't get paid for the day which I must miss for my well-being and therefore I miss out financially as well. This isn't fair to my employers or me. I'm still responsible for my bills so I feel shortchanged somehow.

Not to mention that when I first discovered that my illnesses were WTC-related no attorneys would help me. They said I wasn't first responders or belonged to the recovery crew that I wasn't a police officer or firefighter and so they could not help me. I felt worthless and alone. Sometimes I still do because I don't know how I could survive without the help and specialized care of the WTC program. They didn't turn me away when I called them for help and, in fact, the doctors and staff embraced me as a patient and continues to help me get better each day. I'm not saying that I'm cured although I wish I were but I am truly grateful to rely on such superior care. I used to cough consistently and roughly which caused me much distress at work and health wise because I disturbed my co-workers with my asthma and coughing. They thought I was contagious and I can see their apprehension when my co-workers were near me. They wouldn't even disguise their hostility when I first started at my current job. I was and still am quite miserable. I was always wheezing and suffered from chest pains, back pains and headaches. It is very difficult to concentrate in front of a computer all day and try to control a massive continuous headache almost every day. My eyes also hurt in conjunction with the headaches, and allergies, and I can't stand it. I'm also seen by a neurologist who advised me to keep a headache journal to describe when my headaches occur, how often and how painful.

I visited the clinics and emergency rooms quite often in a year which made my employers frown and uncomfortable. I felt ashamed of my cough which would never go away. Today it's more manageable thanks to the care that I receive at the WTC program at Bellevue Hospital. Life feels more manageable but I'm not out in the clear. The WTC program helps give me hope that there are doctors who know how to treat me and understand my symptoms and diseases even when I don't fully understand them, although I keep myself informed so that I can ask the right questions for the treatment provided and alternatives available for options. I don't know what I will ever do without the WTC program should it ever not be available to me and thousands of others who need this program to survive. I hope we never have to find out.

I need help to exist and I'm no longer ashamed to seek it. I am no longer invincible and I need assistance for my body to match the strength of my soul and spirit.

I thank you Senator Casey for your question and concerns. If I may be of more service to you please do not hesitate to ask.
CHAIRMAN HARKIN, RANKING MEMBER ENZI, MEMBERS OF THE COMMITTEE: I want to thank you for holding this hearing today on S.1334, the James Zadroga 9/11 Health and Compensation Act, introduced by Senator Gillibrand and Senator Schumer. I am proud to work with Senator Gillibrand to champion the health needs of World Trade Center responders and survivors. As the sponsor of the House counterpart, H.R. 847, I am pleased to see movement on this side of the Capitol.

On September 11, 2001, thousands of people tragically lost their lives. Nearing 9 years later, we know that thousands more have lost their health.

Within hours of the collapse of the World Trade Center, fire fighters, police officers and EMTs labored alongside construction workers, volunteers, and others without regard for their own health or safety. All were told by the government that the “air was safe to breath.”

Unfortunately, we now know better. The cloud they worked in was a poisonous cocktail of thousands of tons of coarse and fine particulate matter, pulverized cement and glass, asbestos, lead, and other toxic pollutants. To the mix were added 24,000 gallons of burning jet fuel and plastics which created a dense plume of black smoke containing a specific combination of toxins probably never seen before and hopefully that we will never see again.

And all of this went into the mouths, throats, and lungs of tens of thousands of first responders and survivors.

Although most of these people live in the New York/New Jersey area, at least 10,000 people came from across the country to help in the aftermath of the attacks. They hail from every State in the Union and nearly every congressional district.

Now, nearly 9 years later, we continue to see the deadly effects of those toxins. There are numerous peer-reviewed, scientific studies showing that the exposures at Ground Zero are causing people to become very ill. Their illnesses include respiratory and gastrointestinal conditions such as asthma, interstitial lung disease, chronic cough and GERD (gastroesophageal reflux disease), and mental health conditions such as post-traumatic stress disorder.

S. 1334 helps the sick by improving medical monitoring and treatment to WTC responders and survivors who were exposed to Ground Zero toxins. To do this, it will build on the existing monitoring and treatment programs by delivering expert medical care for these unique exposures at Centers of Excellence. The bill also provides compensation for those who suffered economic loss by reopening the September 11 Victims Compensation Fund (VCF).

Press reports this morning indicated that Senator Enzi will say that the existing programs to help the WTC responders and survivors are enough and that we do not need this bill.

Nothing could be further from the truth. Our bill would authorize these programs into law and ensure that they have guaranteed funding. The bill would eliminate gaps in coverage in the current program that have too often resulted in 9/11 first responders and others getting notices that their care is coming to an end, as we saw last year in New Jersey and this year with New York City’s program to provide mental health care for those affected by the attacks.

The solutions we have offered in H.R 847 are neither easy nor inexpensive, but they are part of our country’s moral obligation, as the wealthiest country in the world, to care for those who respond to an act of war. We must take care of the people who took care of us following 9/11. It is the least we can do as a grateful nation.

Thank you.

CAROLYN B. MALONEY,
House of Representatives.
DAVID A. PATERSON, GOVERNOR,  
STATE OF NEW YORK,  
EXECUTIVE CHAMBER,  
ALBANY, NY,  
June 29, 2010.

Hon. THOMAS HARKIN, Chairman,  
Committee on Health, Education, Labor, and Pensions,  
S–428 Dirksen,  
Washington, DC 20510.

Hon. MICHAEL B. ENZI, Ranking Member,  
Committee on Health, Education, Labor, and Pensions,  
S–835 Hart,  
Washington, DC 20510.

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: I write to thank you for convening a hearing to consider the James Zadroga 9/11 Health and Compensation Act of 2009 and express my strong support for this critical legislation. The importance of the continued monitoring and treatment of the World Trade Center responders cannot be overstated. This bill will guarantee a Federal commitment to funding for the long-term health and mental health care needs that many of the affected individuals now require.

Immediately following the attacks on our country on September 11, 2001, our Nation made a commitment to ensure that those responders from around the country who were directly affected by the events of 9/11 get access to the care they need, making this legislation not only a New York priority, but a national priority. It is critical to continue the much-needed research into World Trade Center-related illnesses.

I commend Senator Gillibrand for her determination in securing a hearing for this crucial piece of potentially life-altering, legislation. It is with utmost sincerity that I reiterate my support for the James Zadroga 9/11 Health and Compensation Act of 2009.

Yours truly,

DAVID A. PATERSON.

THE UNITED STATES CONFERENCE OF MAYORS,  
WASHINGTON, DC 20006,  
June 28, 2010.

Hon. TOM HARKIN, Chairman,  
Health, Education, Labor, and Pension Committee,  
U.S. Senate,  
Washington, DC 20510.

Hon. MICHAEL ENZI, Ranking Member,  
Health, Education, Labor, and Pension Committee,  
U.S. Senate,  
Washington, DC 20510.

DEAR MR. CHAIRMAN: On behalf of the United States Conference of Mayors, I am writing in support of S.1334, James Zadroga 9/11 Health and Compensation Act of 2009. This legislation is a critical first step to providing long-term and sustainable funding for a permanent monitoring and treatment system for thousands of first responders and others who became sick and are getting sicker from exposure to toxins released in the aftermath of the 9/11 attacks.

During our 78th Annual Meeting in Oklahoma City, the mayors of this Nation unanimously supported a policy resolution calling for legislation that would permanently fund a monitoring and treatment program for Americans who can prove they were exposed to the WTC (World Trade Center) disaster and to permanently fund WTC-related health research to ensure appropriate use of Federal funds for monitoring and treating WTC-exposed Americans. In addition, the mayors called for legislation that would re-open the September 11th Victim Compensation Fund.

We applaud Senator Gillibrand for her commitment to this issue and believe this legislation is a necessary measure to ensure that 9/11 rescue and recovery workers who risked their lives will receive the proper long-term medical care and support they deserve.
If you have any questions, please feel free to contact conference staff Crystal Swann at 202–861–6707 or via email at cswann@usmayors.org. We appreciate your consideration and thank you for your support.

Sincerely,

TOM COCHRAN,
CEO & Executive Director.


Dear Senators: On June 29, 2010, it was my honor to travel to Washington, DC and watch the HELP Committee hearing entitled “Examining the Continuing Needs of Workers and Communities Affected by 9/11.” I am a patient at the World Trade Center Environmental Health Center at Bellevue Hospital and would like to submit my profile (attached to this email) to be part of the record of that hearing.

I survive the attack on the World Trade Center on 9/11 and strongly support continued funding of the Centers of Excellence which provide medical and mental health treatment for those affected by the 9/11 attack.

I hope that, when you read my story, you will agree that all efforts must be made to ensure that those impacted by 9/11 are guaranteed care well into the future.

Thank you for your hard work and consideration.

Sincerely,

Susan Herr.

World Trade Center Environmental Health Center Patient Profile:
Susan Herr

“I can't walk and carry a balloon at the same time,” says Susan Herr, who survived the collapse of the World Trade Center on September 11, 2001 but who, almost 9 years later, finds it difficult to do many of the things that most people take for granted.

Susan, a Long Island commuter, worked as a computer programmer on the 68th floor of the south tower. She decided to evacuate not long after the first plane hit even though building management had announced that it was safe for workers who had been leaving to return to their desks. The elevator got her as far down as the 43d floor, where she entered the stairwell. “But I had a panic attack and couldn't walk down any further than the 19th floor so I got back into an elevator.”

Susan was descending to the lobby when United Airlines Flight #175 slammed into the building. “At first it was impossible to get out because of the surge of people pushing back inside who were trying to protect themselves from the falling debris.”

Once she was able to exit onto the plaza, a policewoman instructed Susan to run east. After cutting her leg on fallen debris, Susan headed uptown. Two other details about her terrifying journey that morning still stick in her mind: “I couldn't believe it when I heard someone say the Pentagon had been hit, and all around me people were throwing their cell phones down on the street.”

Susan made contact with her family for the first time around 1 p.m. when she finally arrived, covered in a light coating of dust, at her sister-in-law's office in the Madison Square Garden building. Her parents and her brother and sister had no idea if she was OK or not. She found out that her brother, an off-duty NYPD cop, was trying to get back into the city to help. “The Long Island Railroad had stopped running so I didn't get home until much later that evening.”

Working from home and staying in touch with a close-knit group of colleagues helped Susan make it through the next few weeks. Although she didn't have to return to work in Lower Manhattan for more than a year, her nerves and recurring nightmares prevented her from sleeping well. Her family physician prescribed sleeping pills.

Susan began to have other health problems in 2002. She learned always to bring water or candy with her everywhere she went to soothe a cough that just wouldn't go away. “Any excitement or over exertion would set it off,” she says. Walking, even breathing, became increasingly difficult although she never had smoked. And when her parents decided to move, she decided she couldn't face living alone after what she had been through, so she relocated with them to upstate New York.

Around the time things got really bad in 2008, Susan, who now works for the U.S. Military Academy in West Point, received a mailing from the World Trade Center (WTC) Health Registry about the WTC Environmental Health Center's services for people who worked or lived in Lower Manhattan. She made an appointment.
Doctors at the WTC Environmental Health Center diagnosed Susan with asthma and prescribed medications that have reduced the frequency of her coughing and made it easier to breathe. But what really worries Susan is the future. "I'm going to be 54 soon," she says. "What will happen when I'm 64? We just don't know how being down there that day is going to affect our health in the years to come."

Susan feels so strongly about the importance of the health monitoring and treatment offered by the WTC Environmental Health Center that she's willing to make a two-hour drive each way. "Based on what they're seeing in other patients"—more than 4,600 Lower Manhattan community members have sought care at the WTC Environmental Health Center—"my doctors know what to look for in me."

Unlike many of the patients served by the WTC Environmental Health Center, Susan has private insurance. This means that her health care would continue even if Federal funding for the program ends, but she would have to rely on local providers who may not have the expertise necessary to treat WTC-related respiratory illness or identify emerging conditions.

That's why Susan plans to visit members of Congress with a strong, but simple message of support for the 9/11 Health and Compensation Act: "Even though I wasn't a first responder, I was still a victim." My country let me down once by letting the World Trade Center get hit. I hope it won't let me down again by closing the clinic.

KATHY GOPICCHAN
OCALA, FLORIDA 34473
July 8, 2010.

Hon. TOM HARKIN, Chairman,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Hon. MICHAEL ENZI, Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.


DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: I am Kathy Gopichan and I currently reside with my family in Florida, where I am now working as a nurse. On 9/11, I was living in Queens with my husband and two young children. At that time, I was working for Time Warner Cable and attending school at Borough of Manhattan Community College (BMCC), 5 blocks North of Ground Zero. When the second plane hit, I had been inside Fiterman Hall, a school building directly adjacent to the WTC, for a class. As the building shook violently and the ceiling started to collapse in on us, I ran outside. Then I saw bodies flying out of the WTC, debris falling, people screaming and running, and choking on air full of airplane fuel and horrible smelling smoke. I was disoriented by the crowds, dust and smoke. I spent the next 2 hours "in shock" as I tried frantically to get to my baby, who was at the babysitter's on 23d Street.

I was so traumatized that I had to cancel my semester and was unable to work. I was also unable to sleep, "jumping awake" in our apartment which was right near LaGuardia Airport, where we heard planes overhead around the clock. This had never been a problem before 9/11.

Soon after 9/11, I was diagnosed by a local doctor with heart palpitations and anxiety. Although I had no previous respiratory or other health problems, by April 2002, my health had deteriorated. I started wheezing, which progressed to bronchitis and then pneumonia. I have also been plagued by migraines and insomnia, eventually I was diagnosed with sleep apnea and irregular heartbeat.

Several years ago, when my husband had been laid off, our family moved to Florida, hoping for better work prospects. Both he and I were able to find jobs, but I later lost mine due to too much time sick. I was unable to use my husband's benefits because the insurance company deemed my conditions to be pre-existing. We have been paying all medical expenses out-of-pocket until we simply could no longer afford to do so. It was my husband who learned about the WTC EHC from a friend whose union held an information session. I usually spend some of the year with my extended family in Queens, NY so I made an appointment. I was diagnosed and am now being treated for WTC-related asthma, headaches and PTSD. The family is con-
sidering a move back to New York, so that I can continue to receive the right kind of care. I am trying to visit soon for a follow-up appointment.

The treatment I received at the WTC EHC was very good. The doctors are experts in recognizing the 9/11 health problems and knowing the right medications for the overlap of symptoms from the type of exposures that I had. No one else understood or connected the dots of my health symptoms. I get care for my body and my mind. After 9/11, I struggled for years with improper care and struggled trying to have a decent life for myself, my husband and my children. I feel very lucky that I FINALLY have this program.

9/11 survivors like me are asking for your help to protect the program which enables us to get our lives back.

Gratefully,

KATHY GOPICHAN.

JULY 8, 2010.

Hon. TOM HARKIN, Chairman, Committee on Health, Education, Labor, and Pensions (HELP), U.S. Senate, Washington, DC 20510.

Hon. MICHAEL ENZI, Ranking Member, Committee on Health, Education, Labor, and Pensions (HELP), U.S. Senate, Washington, DC 20510.


DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: On September 11, 2001 my daughter Alexia, who was 1 1⁄2 years old, was at my mother’s house in Lower Manhattan, on Mulberry Street between Houston and Prince Streets. At that time, my mother was my main source of childcare and though I left for work that day, I never made it there because my supervisor called me to tell me that I shouldn’t come in to work. As the terrible events began to unfold, a crowd had gathered at the corner of Lafayette and Prince from where the towers could be plainly seen.

When the towers collapsed, the dust rolled into our neighborhood, and the air reeked of fumes from the WTC fires as they burned for many, many weeks. Throughout the year my mother continued to be my main source of childcare, with my daughter often spending the night at her house. We had been told that the whole area was safe. Within a few months of 9/11, however, Alexia started to develop symptoms of asthma for the first time. It seemed that every time she had a cold, it would turn into difficulty breathing. The first few times the doctors said that she was too young for them to diagnose her with asthma. By the time she was 3 years old, she was given that diagnosis and we ended up at the pediatrician’s office every few months because she was having difficulty breathing.

Alexia started Pre-K at 4 years old and unfortunately missed many weeks of school either because she’d had an asthma attack or because the cold weather put her at risk for one. At that time, I got a call from the school district—the staffer said she was very concerned about Alexia’s attendance and then suggested I take her out of school and not re-enroll her until she was 6 years old, and legally required to be in school. I was horrified at this suggestion, Alexia had missed a lot of school but she had also made important strides, had friends and loved school. I didn’t take her suggestion. Alexia struggled through although she continued to miss school.

The worst crisis occurred when Alexia was in the first grade—she was hospitalized for an entire week with asthma and pneumonia. It was terrifying. Afterwards she was put on Singulair year-round. Other parents I was friendly with expressed concern that they thought Singular was only a seasonal drug for allergies but when I raised this with the pediatrician, my concerns were brushed aside. The doctor described it as “a great pill that had hardly any side effects.”

A year and a half later, the Singulair suddenly stopped working, and Alexia had several severe bouts of asthma. At the same time she was having nightmares and although I never made the connection at the time, when I was researching Singular online later, I found out that other parents were reporting nightmares, depression and suicidal behavior while their children were taking Singular. I got Alexia off the medication and we struggled with her asthma day by day. We were once again in and out of the offices of overbooked pediatricians who had little time to do more than triage.

I knew that my child’s troubles began after 9/11, so when I heard about the Bellevue WTC Pediatric Program, I brought Alexia in. It was such a life-saver. Finally
we had a doctor someone who thoroughly examined Alexia, and understood the origins of her asthma. And I found out that the drug Prednisone was not supposed to be given more than a couple of times a year. She had gotten it more than a couple of times just in the past few months. Now Alexia has ongoing care from doctors familiar with her condition and has preventive medicine which keeps her healthy and doesn’t cause side-effects.

I urge you to do everything in your power to preserve this essential program for my child and for so many children who, like her, have experienced serious health problems from breathing the toxic 9/11 dust and smoke.

Thank you for your consideration.

Sincerely,

MARIA MUENTES,  
New York City.

JULY 9, 2010.

Hon. TOM HARKIN,  
731 Hart Senate Office Building,  
Washington, DC 20510.

Hon. MIKE ENZI,  
379A Russell Senate Office Building,  
Washington, DC 20510.

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: My name is Lillian Bermudez. I am a Lower East Side resident and am now a senior police administrative aide with the New York Police Department. I have two children who developed chronic respiratory illnesses as a result of the 9/11 disaster.

On 9/11/01 we were living at 296 Delancey Street (where we still reside) which is in Lower Manhattan near the Williamsburg Bridge. My son, who was 12 years old on 9/11, had no prior respiratory problems.

In October 2001, he had been home from school for 2 days, suffering with a cold, or so I thought. When he was not better on the third day, I brought him to the Bellevue ER. When the triage nurse measured his 02 blood level, it was so low that my son was immediately admitted to the Bellevue ICU. He remained there for 3 days, as doctors struggled to get his breathing under control with IV medications.

I was truly shaken when the doctors told me that if any more time had been lost getting Mitch medical attention, Mitch could have died. The doctors questioned me extensively about dust, pets and smoking in our apartment. I told them we had no pets and no one smoked and I always kept the apartment clean. My kids had seen a pediatrician every year and both had always been healthy.

What had changed at home and in our neighborhood was the smoke and dust from 9/11. The doctors said, no, that wasn’t it, because “the EPA said the air was safe.” (For the same reason, the only cleanup our building got was when the NY City Housing Authority wiped the window sills.)

Mitch was released from the ICU but they kept him in the hospital 5 additional days so his condition could be monitored. He was given a diagnosis of asthma and sent home. Although he continued to take the asthma medicine they prescribed, he continued to get severe asthma attacks that were so bad that he had to be admitted to the hospital several more times. I was getting desperate.

Also, my daughter, Amanda, had been affected. She was 9 years old on 9/11. She had no prior respiratory problems. A number of months after 9/11, I had to take Amanda to the ER, where she was first diagnosed with a sinus infection and put on antibiotics. A few months later, the same thing happened. This time, the ER doctor gave Amanda a pump, but she always ended up getting bad sinus infections whenever she got a cold.

Then, in 2007, I contacted the office of city council member Alan Gerson and his staff told me about the Bellevue WTC Clinic. I brought Mitch and Amanda to Bellevue and they were thoroughly evaluated. They got breathing tests and for the first time, they were put on the right set of medications.

I credit the Bellevue WTC doctors with giving my kids the kind of treatment they need to lead normal lives. My son and daughter have been doing great. Now, they can live like kids again. If the program is ended, where will they go? If my children have any more asthma or sinus problems, the doctors at Bellevue WTC are there for them. They know my children’s history from 9/11, they know what to look for and how to get them well.
Please do everything you can to make sure that this essential program will be there for the people whose health was harmed at such a vulnerable age, and for all the sick survivors of the 9/11 attacks.

Sincerely,

LILLIAN BERMUDEZ,
New York City.

BARBARA CAPORALE,
NEW YORK, NY 10009,
July 9, 2010.

DEAR ESTEEMED SENATORS HARKIN AND ENZI: My name is Barbara Caporale, and I am a Lower Manhattan resident and the parent of a child entering the 8th grade in the fall. For the past 13 years, we have lived on East 5th Street in the Lower East Side, approximately 2 miles from the World Trade Center site, inside the original "frozen zone," set up by the police and the National Guard to secure downtown in the weeks after 9/11.

On 9/11, I was walking my daughter to her first day at a daycare/preschool when we heard what we thought was an incredibly loud backfire. After dropping her off, I returned home, where I watched the buildings collapse from the roof of my building. I filled the bathtub with emergency water, scrambled to buy supplies at the grocery for myself and my parents, and then picked up my child in a taxi. She rode on top of our supplies.

The air in the Lower East Side of Manhattan quickly became thick with smoke and grit and smelled like a mixture of an electrical and chemical factory fire and crematorium. Cars, buildings and playground equipment were coated in dust, and were never cleaned in our area.

Two days later, I was forced to return to work when the mayor declared the zone from 14th street to Houston Street re-opened. As a parent, I was extremely anxious about sending my child back to her daycare and about my own return to my work-site, but I couldn't afford to lose my job. It was evident that things weren't "back to normal" as the Mayor deemed them to be, nor was the environment safe as the EPA declared.

Like many others in our community, I did not have the means to take my child out of the city to escape the smoke and the dust.

In a semblance of normalcy, and to relieve stress, the children played in the neighborhood playground, where they cheered the rescue vehicles from many States, coming and going, all coated with debris. It was surreal. There was dust and grainy grit on the playground equip. My daughter and I wore little cowgirl bandannas to cover our noses and mouths.

We live on East 5th Street, in the Lower East Side, four blocks above Houston Street on the top floor facing south towards the World Trade Center site. The smoke and dust plume would infiltrate our apartment. My daughter and I could not breathe in our apartment for most of the 3 months while the fires burned, particularly at night with the atmospheric inversions. We would wake up every few hours, coughing. It was much worse for my child.

Over the months, she began to develop mold and extreme chemical and smoke sensitivity. She also started to suffer from migraines which forced her to be immobile due to the pain and nausea. To this day, migraines that are often crippling make it impossible for her on many days to do homework.

She also developed shortness of breath. In 2002, my daughter was diagnosed with "respiratory syndrome" by her pediatrician and was prescribed Singulair and Flonase.

My daughter was a participant in a Pediatric Respiratory Study of children enrolled in daycare centers below 14th street, which was conducted by epidemiologists from the New York Academy of Medicine, 1 year post 9/11. It showed that in an age range of population with an expected asthma rate of 7 percent of asthma, approximately 40 percent of parents reported their child either having respiratory syndrome, coughs and wheezing without ever having an asthma diagnosis, or reported their child having asthma with increased intensity.

Our area never got a proper environmental cleanup. After the months of running our air conditioner after 9/11, I saw that it was contaminated with WTC dust, and I never used it again, though I could not afford to replace it.

Before 9/11, my daughter had no health problems. After 9/11, my daughter who was an early dancer, active and dexterous, began to exhibit an obvious lack of spatial awareness, and would bump into things and people. My child had been a very early speaker and is very intelligent with an amazing memory. But I began to notice
as her school career was advancing, that she was not able to focus as well on her work, and that she was experiencing memory problems. After a series of neurological tests revealed some cognitive issues, we were advised to make her an appointment for a developmental evaluation at the WTC Environmental Health Center.

She gets sick more often since 9/11. After a recent illness, which kept her out of school for a week, and another recent prior one, she was given an inhaler last month, to see if this would help her headaches and coughing.

She is stressed by the constant “war on terror” reports on TV, from which I try to shield her, (but now that she is older, she needs to watch current events). She experiences anxiety when we encounter subway stations closed for “police activity, and then NYPD’s ‘backpacks are subject to search’ announcements.” Otherwise she is a creative, beautiful, and lovely child, who suffers bouts of sadness and feeling overwhelmed.

So many children continue to suffer health problems as a result of the 9/11 attacks. Please help our children get proper diagnosis and treatment by fully funding the World Trade Center Environmental Health Center Pediatric Survivors program.

Thank you.

Respectfully,

BARBARA CAPORALE.

MARY PERILLO,
NEW YORK, NY 10006,
July 9, 2010.

Hon. TOM HARKIN, Chairman,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Hon. MICHAEL ENZI, Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.


DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: I am a resident of the closest residential building to the World Trade Center (WTC)—we are right across the street. From the beginning, in the first days after September 11, the EPA, incredibly, was saying that the air was safe, but my neighbors and I knew that it couldn’t possibly be safe to be inside our apartments.

In our building where the most windows had blown out, we had massive piles of WTC debris, which was composed of items ranging from seven-foot pieces of metal down to dust particles measurable in microns or fractions of microns. Four tenants had dust samples taken from their apartments tested for asbestos, and it was found in all of the four apartments. The amounts were between 1.8, and 3.3 percent by bulk analysis—all exceeded the EPA’s safety threshold.

At that point, I start trying to get to any government agency that would help us, to test indoor air in our building in hopes that that would effect an asbestos clean up for the building. I was also hoping to find some official guidance, or even a set of standards for safe re-occupancy. Finally, someone from the New York City Department of Environmental Protection (DEP) came to the building and met with a few of us tenants and representatives from the building’s management company. He said he was coming to the building to do some tests, but he did none. He wouldn’t tell us why, he just said he “wasn’t allowed.”

So then I called, wrote and/or visited FEMA, HUD, NYC DOH, NYS DEC, EPA, OSHA, the New York State attorney general’s office Bureau of the Environment, Pace Environmental Law Clinic and NYCOSH. This was essentially my full-time job for 6 weeks. After that, I did this for a few hours a day, and after that for a few months and sporadically through summer 2002. None of these agencies or organizations could or would test our homes.

We fell through the cracks. We are not first responders, our apartments are not public spaces, and we don’t own our apartments. There was nobody to protect us or even provide us with accurate information about the toxic dust and debris sitting in our homes, several feet deep in places.

At one point I had a conversation with an inspector at the Department of Health and asked him, “So what you’re telling me is that the EPA won’t test because they know what they’ll find?” And he said yes.
So as you can see, by that exchange, sometimes individuals at these agencies tried
to help, at least by speaking the truth off the record. But EPA and other agencies
would not allow them to give us the help we needed. So the pattern was that they
would make an appointment—the first one took 6 weeks to make—and then at 4:55
p.m. the night before, somebody else would call from the relevant agency or depart-
ment and cancel the appointment, telling me they were not allowed to do any test-
ing.

My next appointment—yes, I kept trying anyway—was for the 30th of November.
At that time they sent me an e-mail canceling and stating: “Upon further review,
 it was determined that the address in question is located in the hot zone.” Of course,
I’ve been telling them that from day one. And that New York City Office of Emer-
gency Management (OEM) would “coordinate re-occupancy,” and that an inspection
would not be conducted “until the building is cleared for re-occupancy.” And who
would clear us?

All this time, my neighbors and I were spending long hours in our apartments
searching for important keepsakes and personal belongings, cleaning up by literally
shoveling the WTC dust into plastic bags—and many of us were experiencing scary
symptoms we had never had before. For me, it started with nosebleeds and breath-
ing problems.

So following the letter about OEM, I turned to whatever individuals I could catch
on the phone or in person, at any agency, who would talk to me. Individual OSHA
workers were probably the most helpful and ending by truthfully acknowledging
that the conditions in our homes were a threat to our health but always stating
“But you didn’t hear that from me!” Looking at the OSHA and NY COSH’s Web sites
I found workers instructions because I figured if I’m spending 8 hours cleaning up
in there, I am a worker.

I went out and bought my P-100 respirator, because of what I had been reading
in the press, and what I had known from the tests we had done in our building.
There was knee deep debris in my apartment which testing showed was nearly 2
percent asbestos and an OSHA person had told me I need a respirator to be in THE
NEIGHBORHOOD at all.

After 5 months of one agency passing me off to the next to the next to the next,
just to make sure that things hadn’t improved, I tried it again in February 2002.
First I called the EPA Region II offices. I was connected by the receptionist to
somebody in Air Quality who told me that I had to speak to somebody in the City
Department of Health. They gave me the numbers of the city Department of
Health—which were new numbers. EPA didn’t used to give me numbers, then at
the DOH Environmental Inspection Bureau, an Inspector Stable told me I had to
call the DEP. At DEP I left three messages—with three different people, asking for
a callback about questions about standards.

After about six visits to my apartment, I would wake up coughing the morning
following the visit. I headed to the doctor and was told that I had something that
could be described as “spontaneous asthma” and was given one of those inhalers.
A week after that, I coughed myself into an emergency room in St. Vincent’s. In sub-
sequent years I developed GERD and still get out of breath coming up the subway
stairs.

But in 2001, once I got proficient with NY COSH and OSHA’s recommendations
for workers and bought the P100 respirators the reaction subsided somewhat. But
what that meant is every time we walked into my apartment, I’d need to don a
Tyvek suit with hood and boots, latex gloves, respirator and goggles. And I’d need
to see if I could use the wash station at the site, on the way out to try not to track
this where I was staying. But I couldn’t afford to get new Tyvek each day. My studio
and equipment was destroyed, I had no source of income. I finally found out in 2002,
that I wasn’t changing the cartridges on the respirators frequently enough.

Anyway, to try to save the possessions, to try to save our artwork, to try to save
our livelihoods, we had to be amateur Tier II OSHA workers.

We went to try to get professional help cleaning the apartments. Estimates were
$19,000 to $26,000 for EACH apartment. This is not something most of us could af-
ford. The Red Cross offered us between $1,000 and $2,000 for cleaning an apart-
ment that required asbestos remediation which costs approximately $20,000.

The landlord wanted us back in and paying rent and wanted us to sign a wavier
that named clearance levels for moving back into the building—but, as I said, we
couldn’t get any State or Federal agency to give us numbers. The city was telling
us to clean up with wet mops and wet rags. It was unconscionable.

Finally some brave souls took up our cause. Between Congressman Nadler who
brought the EPA Ombudsman Hugh Kaufman to hold a hearing in NYC in 2002
and shine a light on the EPA leaving the residents and workers and responders in
Lower Manhattan in the dust, and State Assembly Speaker Sheldon Silver, who
forced the agencies and utilities to sit down and meet with us to come up with a plan to get us back home (not to mention, what I understand to have been closed door meetings between an unnamed State assistant attorney general and lawyers for EPA). EPA was forced into doing a proper testing and remediation for our building using DEP contractors.

But what about the rest of the neighborhood? What about all of Lower Manhattan? What about 10 years of heavily contaminated Deutsche Bank next door? Roof-tops that were NEVER cleaned? What about the schools in the area whose kids came back way too soon?

And what was the motive of Christine Todd Whitman, and other top officials in the EPA for lying to the public and for not doing their job? Now is the time to make this terrible betrayal right. The Federal Government needs to take responsibility for abandoning us after we were attacked at home by terrorists on that horrible morning.

Thanks to Senator Gillibrand we have a new champion in Washington who does see that we should not be abandoned by our own government and that we should have access to health care for our WTC-related illnesses.

We are now turning to you to make sure that the federally funded WTC health programs needed by responders and survivors are there for us now and in the future.

Sincerely,

MARY PERILLO.

JULY 9, 2010.

Hon. Tom Harkin,
731 Hart Senate Office Building,
Washington, DC 20510.

Hon. Mike Enzi,
379A Senate Russell Office Building,
Washington, DC 20510.

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: As a 9/11 survivor, I am writing to state my strong support for S. 1334, the James Zadroga 9/11 Health and Compensation Act of 2009, that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

I strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11.

H.R. 847, the House of Representatives’ version of this bill, has passed both the House Judiciary and Energy and Commerce committees, which is a significant step towards achieving justice for the survivors and responders of 9/11.

I live three blocks south of the World Trade Center (WTC) site. On September 11, I was caught in the dust cloud. After 5 months of being displaced from my building, I moved back into my apartment. Even after being away, I saw upon our return that there were many reservoirs of toxic dust from 9/11 that permeated my home, my building and my neighborhood. The EPA conducted no testing of our building, in spite of the fact that it had deemed buildings in the immediate vicinity (where conditions seemed identical to ours) to be contaminated. To this day I am not certain of the degree to which my apartment and the rest of my building have been cleaned of World Trade Center dust. I still worry about reservoirs of dust in behind my heater and in the air ducts.

Although I had pre-existing asthma, my asthma became more severe after 9/11. Subsequent tests at the Bellevue WTC Clinic showed that my lung capacity was only 43 percent of normal. During this time I also suffered from severe acid reflux. I am now on five medications for my ailments. I am very fortunate to be getting specialized treatment at the World Trade Center Environmental Health Center (WTC EHC) at Bellevue, from doctors trained in recognizing and treating WTC illnesses.

The director of the WTC EHC, Dr. Joan Reibman has established the only center of excellence to treat Lower Manhattan residents, area workers and students who are now sick from their 9/11 exposures. Dr. Reibman was one of the first in the medical profession to establish a link between the 9/11-related exposures of inhabitants who were not first responders, and their subsequent illnesses. The WTC EHC is consistent and thorough in its methods for treating all illnesses related to 9/11, both psychological and physical, and currently depends on limited funds from the city’s coffers.
Today there is no cure for my condition, and it is medically necessary for me to be properly monitored and maintained on medication in order for me to stay healthy. In addition, it is essential that those of us who are sick have the benefit of being followed by doctors at centers of excellence who will be able to recognize any trends among the population of WTC-affected non-responders. The bottom line is that unless the Federal Government is willing to fund WTC-related health care for residents, I will one day cease to get the care I need from Bellevue. The events of 9/11 have made me a victim of a crime. The negligence of the EPA, and its failure to tell the public about the true nature of the toxic smoke and dust from the WTC disaster, meant that those in proximity were subject to ongoing health risks that could have and should have been prevented. Now my health is suffering. I ask the Federal Government to provide this much-needed support for those of us who were harmed as a result of this attack on our Nation. I am sincerely grateful for your time and attention in support of this bill.

Sincerely,

ESTHER REGELSON,
New York, NY 10006.


Hon. Tom Harkin,
U.S. Senator,
Hart Senate Office Building,
Washington, DC 20510.

Dear Senator Harkin: Thank you and your distinguished members of the Senate for allowing me an opportunity to tell my 9/11 story and to let me express the importance of passing the James Zadroga Bill (H.R. 847) with bipartisan support by the ninth anniversary of 9/11.

My name is Marvin Bethea, and I was a healthy NYC Paramedic dispatched to the World Trade Center (WTC) on September 11, 2001. Everyone in this room remembers exactly where they were when first hearing about 9/11. I arrived after the second tower had been struck. There was total chaos at the scene.

I was a block away treating patients in a bank. As I was about to evacuate the patients from the bank, someone yelled, "the tower the tower!" As I looked up, I saw, and then heard the rumble of the tower beginning to fall. I told everyone to take cover in the bank. I knew I was going to die. I just asked God to let it be quick. In my 23 years in Emergency Medical Service (EMS), I have had a gun put to my head twice and been shot at once. Nothing compares to the tower falling down, NOTHING!!!!

We went from day to night. Normally at night, you can see a little. Imagine being completely blind, hearing this loud noise getting closer and closer to you until the noise was on top of you while being hit with debris from all over and having dirt (which we know now was toxic) being poured down your throat. Everyone was able to finally get out of the bank and head north. Damn, I would have loved to have joined them, but I knew I had a job and duty to do, so that is what I did with honor.

Finding my paramedic partner after the first tower collapse, I assisted him in loading injured people in our ambulance. I stayed at the scene to treat other injured people. A woman came out of the second tower bleeding and crying. She collapsed in front of me. As I helped her, I told her, "you are going to make it." At that point, I heard the rumble again; it was the second tower collapsing. Luckily for us, the Hilton Millennium was right in front of us. As we dove into the hotel, we were covered in debris. Again I asked God to let it be quick. Once again my life was spared. As a black man, you couldn't tell what race I was due to all the dust that had covered me.

I could go on and on about what we saw that day, but I am sure all of you have heard numerous horror stories about that day. I was healthy and happy before 9/11. After losing 16 people I knew from the police, fire and EMS departments that day, I am not healthy and I am not happy. You see, the stress of 9/11 became too much, and on October 16, 2001 at 41 years old, I suffered a major stroke which left me paralyzed. I said if I can survive the collapse of two towers, I can beat a stroke. I recovered and went back to full duty as a paramedic 3 months to the day.

I was taking two medicines (for ulcerative colitis) before 9/11. Now I currently take between 10–15 medicines depending on how I feel. My diagnoses are Post Traumatic Stress Syndrome (PTSD), major depression, asthma, sinusitis and sleep apnea. I had to stop working January 2004.
I pray to God every day I don’t develop any other health problems because if I do, the workers comp systems will make my life “A Living Hell” about the claim. If you found what I just said offensive then maybe you will get the sense that myself and so many of the people here (at the hearing) find it offensive the way we are being treated.

You called us “Heroes and Treating Us like Zeroes.” Our elected officials and government said “We Will Never Forget” and yet we constantly see a case of what I refer to as Political Blindness. For those of you who don’t know what “Political Blindness means—Look the Other Way.” Tell me if I am wrong, but I feel like so many other responders do, that the government and the workers comp system want us to die so they can say “Well We Just Got Rid of Another One of Them.” At times, I wish I had died on 9/11 so I wouldn’t have to be victimized twice by this horrific event.

Opening the 9/11 Fund will not give me my health back, hell it won’t even make me whole. I want the fund to assist my fellow responders who are trying to get their lives and families back. Give us back some of our dignity. Do you have any idea what stress does to a person who can’t provide for his or her family, let alone themselves? I was fortunate to have received something from the fund initially. However, I am incurring medical expenses that are not covered by my insurance (dental work). Believe me, I am grateful that I have insurance, but you must remember that it is no fault of my own that I am unable to work anymore. I don’t have the option of if I need something, just working a few extra shifts to get it. I have to just make do. Fortunately, I have friends who have helped me get some of the things I needed done. Not everyone has that option.

It would be great to just be able to receive the benefits we are entitled to. I did not say “entitlement”, as some Members of Congress have referred to the fund, as if 9/11 victims will be receiving something we do not deserve. When I personally witnessed a Member of Congress refer to H.R. 847 with such a negative spin, I felt worse than someone calling me the N word. Why not just kick me to the curb and spit on me? I am not here politically grandstanding either.

This reminds me of when I was trying to obtain my workers compensation benefit. The lawyer representing my employer’s insurance carrier said to the administrative law judge, “Your Honor, how do we know that Mr. Bethea was actually down there and if he was, what was he doing there?” Mind you, my employer had already acknowledged I was down there because, in May 2002 for National EMS Week, myself and five others from my department were presented plaques from St. John’s Hospital of Queens (Division of St.Vincent’s Hospital my employer) and a citation from NYC City Council for our heroic work on 9/11. The event was on television and in the newspaper, so how do you come to court to raise an issue that you know is false? The rage I had at that moment I just wanted to climb across the table and do my best to stomp the attorney and to spit in his face. That type of rage troubles me because I am not a violent person, but you can only be pushed so far.

I urge the government to instruct all agencies, State and Federal, to work with us to help us get what benefits we are entitled to and to stop trying to find every sleazy way not to give us our benefits. I could go on and on about the James Zadroga 9/11 bill H.R. 847, but I won’t.

I just want to say tis; it has been almost 9 Years. Can you imagine the outrage this country would have had if it took me 9 years to respond to the WTC? Not only would the public have wanted my job and my medical certification, they would have wanted me charged criminally for breach of duty and to prosecute me to the fullest extent of the law. Those were the standards I was held to every day, so why shouldn’t our government be held to the same standards? Were the men and women of 9/11 any less heroic than our soldiers fighting overseas today? The answer to that is NO. As a matter of fact, many of the soldiers I have met say they enlisted because of what happened to us on 9/11.

Put your political parties and differences aside and let’s unite as one as we did on 9/11. As John Lennon said, “Come together right now over me”. Thank you for giving me this opportunity to speak. God Bless each and everyone one of you and God Bless the United States of America.

Sincerely,

MARVIN E. BETHEA,
NYC Paramedic,
St. John’s Hospital of Queens.
Hon. TOM HARKIN, Chairman,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.
Hon. MICHAEL ENZI, Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.


DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: On behalf of the Community Advisory Committee (CAC) of the World Trade Center Environmental Health Center (WTC EHC), we write in strong support of S. 1334, the James Zadroga 9/11 Health and Compensation Act of 2009, a bill that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly urge you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest possible protections for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has now passed both the House Judiciary and Energy and Commerce committees, a significant step towards achieving justice for the survivors and responders of 9/11.

As we know you recognize, 9/11 was an attack on our Nation that targeted civilians, many of whom were exposed to toxic dust and smoke from the collapse and burning of the WTC. In addition, along with many 9/11 responders, many people who lived, worked, or attended school in Lower Manhattan at the time of the attacks have become ill as a result of the Federal Government’s false assurances that “the air is safe” and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government help to provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster.

The Zadroga Act would guarantee 10 years of Federal funding to specialized WTC-related medical programs. The continued availability of specialized medical care at these programs from health professionals who have developed expertise in treating 9/11-related illnesses is critical.

The WTC EHC is the center of excellence serving the health needs of non-responder survivors of the 9/11 attacks. It was formed in direct response to the emergence of serious 9/11 health effects in the community.

In 2007, the Community Advisory Committee of the WTC EHC was formalized.

It is made up of representatives of advocacy and community-based organizations, labor unions, three New York City community boards, individual patients at the WTC EHC and advocates for those who were affected by the WTC attacks and who were exposed to environmental contaminants in its aftermath. A broad base of over 30 organizations is currently represented on the CAC. Many of those organizations have separately submitted letters of support for S. 1334 as well.

We therefore especially ask that, as you consider S. 1334, that you protect the “Survivor Program,” currently based at the WTC EHC, so that it can continue to meet the needs of more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a result of their WTC exposures. Many survivors, including children, are now struggling to recover their health, and others may develop WTC-related illnesses in the future. They urgently need your help.

It is particularly important to remember that the concentration of a group of affected patients in one program facilitates the identification and treatment of 9/11-related illnesses and provides a special base of knowledge not duplicated elsewhere. The survivor program offers a window on the health conditions suffered by those in the survivor community and insights on the unmet health needs of these populations.

The WTC EHC CAC strongly urges you to do all you can to ensure that this important legislation passes your committee, the Senate as a whole and is brought to President Obama for signature.
Nearly 9 years after the attacks, we urge you to help make a just Federal health response to 9/11 a reality.

Sincerely,

KIMBERLY FLYNN,
Community Co-Chair.

ROBERT SPENCER,
Labor Co-Chair.

CITY OF NEW YORK FIRE DEPARTMENT,
BROOKLYN, NY 11201–3857,

U.S. Congress,
Senate Committee on Health, Education, Labor, and Pensions,
428 Senate Dirksen Office Building,
Washington, DC 20510.


DEAR SENATE COMMITTEE MEMBERS: I am grateful for the opportunity to submit this letter on behalf of the New York City Fire Department (FDNY) in support of S. 1334. This bill provides absolutely essential long-term funding for the monitoring and treatment of our members who took part in the rescue and recovery at the World Trade Center (WTC) site following the terrorist attacks of 9/11.

In the months following the attacks, nearly every FDNY member suffered significant and repeated exposures to WTC dust and chemicals, risking their life and health. For almost a decade since, the FDNY World Trade Center Medical Monitoring and Treatment Program has allowed the Department to provide vital treatment to and monitoring of our affected members. Because we are the only group with pre-9/11 baseline health data, the FDNY is uniquely capable of measuring the effects of WTC exposure on our members.

Congressional funding has been the linchpin of these efforts. It has allowed us to continue our monitoring and treatment, and also to analyze our results, develop treatment protocols and share this information with other healthcare providers caring for patients facing similar exposures. But without legislation ensuring sustained funding, the program’s future remains uncertain.

On a personal note, I was at Ground Zero at the time of both collapses. Many friends and co-workers of mine lost their lives that day. Many others continue to suffer with respiratory illness and other conditions—both mental and physical—requiring ongoing, extensive treatment. I know first-hand how our members responded on 9/11, how they have been affected, and how critically important our treatment and monitoring programs have been to them.

Congressional funding has been the linchpin of these efforts. It has allowed us to continue our monitoring and treatment, and also to analyze our results, develop treatment protocols and share this information with other healthcare providers caring for patients facing similar exposures. But without legislation ensuring sustained funding, the program’s future remains uncertain.

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Our first responders demonstrated their commitment to serve the public on 9/11. Now, we need Congress and the President to make a long-term commitment to them. As always, we sincerely appreciate all of your past efforts and your support of our members.

I strongly urge you to support S. 1334.

Sincerely,

SALVATORE J. CASSANO,
Fire Commissioner.

June 27, 2010.

DEAR SENATOR GILLIBRAND: I am writing with regard to my husband Kevin J. Cassidy. I am Rose Cassidy. The two of us met in 1970. Kevin had recently returned from service with the U.S. Army. He had taken the test to become a NYC Firefighter in 1972. A goal of his since childhood and that is all I heard him talk about doing. The list was then frozen for 5 years. He almost gave up but in the fall of 1977 he was called to Join the Fire Department.

He worked in the Bronx for 13 years. Most of his time was spent in Ladder Company 48. Due to his promotion to Lieutenant he transferred to work in Brooklyn with Ladder Company 104. While going into work the evening of May 31, 1991 he responded to a fire call (while still off duty) and saved a mother and her three children. This was done without the aid of a mask, radio, or hose line.

On March 10, 1998, Kevin was promoted to Captain. He eventually settled into Engine 320 in Bayside, Queens. On September 11, 2001 I arrived at work and the girls told me to watch what was happening on TV. The first Tower was on fire. I
immediately called Kevin at home. He just jumped into his car and was off to help. He made the last bus to take staff down to the site. They made it there before the collapse of Tower 1. The rest is history. We heard almost nothing from him that week as they struggled with events they never had to deal with. My daughter Jean who was living at home wouldn’t sleep until her dad was home. Kevin was a healthy and fit man. It was in 2003 on a routine Fire Department physical that they detected microscopic blood in his urine. At first they thought they were Kidney stones but the CT showed a mass. Kevin had a nephrectomy on his right side. His tumor was a mix of renal cell carcinoma papillary and collecting duct type. Collecting duct type is a rare and usually aggressive cancer. In November 2007 Kevin had a change on his CT of his Chest. There were two enlarged lymph nodes. This is one of the most common metastatic sites for Renal Cancer. It was through the out-of-the box thinking of his oncologist that Kevin had Chest surgery to remove these nodes. There is no known chemotherapy to date to treat this type of cancer. This bought him time until on 8/30/2009 he lost the battle with this disease.

I know the emotional and physical impact dealing with cancer has on a family. I have lost my life partner, my girls their father, his mother wondering why her son died before her, and many others in the family affected by the loss. Just a few days before Kevin passed away we were consulting with an oncologist in Chicago. We were looking for that needle in the haystack that might make a difference. When that oncologist said to him, I guess with what we know now you would have done things differently. Kevin quickly replied, “Absolutely not, we had brothers and people down there that needed help.” I am requesting that the victims from 9/11 be allowed to be treated and compensated for the many ailments the exposure to such toxic dust and fumes from that day caused. We know that some of the ailments were immediate such as Asthma but many others do not show up until years later as in asbestos exposure. My concern is for all who were at Ground Zero.

Sincerely,

Rose Cassidy.

COMMUNITY BOARD NO. 1,

Hon. Tom Harkin, Chairman,
Committee on Health, Education, Labor, and Pensions,
U.S. Senate,
Washington, DC 20510.

Hon. Michael Enzi, Ranking Member,
Committee on Health, Education, Labor, and Pensions,
U.S. Senate,
Washington, DC 20510.

Re: S. 1334/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009”

Dear Chairman Harkin and Ranking Member Enzi: We are writing in strong support of S. 1334, the “James Zadroga 9/11 Health and Compensation Act of 2009,” that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath. We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has passed both the House Judiciary and Energy and Commerce committees, which is a significant step towards achieving justice for the survivors and responders of 9/11.

9/11 was an attack on our Nation that targeted civilians. In addition, many 9/11 responders and New Yorkers have become ill as a result of the Federal Government’s false assurances in the aftermath of the attack that the air was safe and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government provide specialized care for everyone whose health was harmed as a result of the WTC disaster, responders and survivors alike.

The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs that provide the right kind of treatment for the people who lived, worked or attended school in the area, as well as the heroic responders who came to their rescue, for their 9/11-related illnesses. The continued availability of medical
care from health professionals who have developed expertise in treating 9/11-related illness is critical.

On behalf of Community Board One, which represents the Lower Manhattan community in which the World Trade Center site is located, we urge you to protect the “Survivor Program,” currently based at the World Trade Center Environmental Health Center (WTC EHC), so that it can continue to meet the needs of the more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a result of their WTC exposures. Many survivors, including children, are now struggling to recover their health, and others may develop WTC-related illnesses in the future. They urgently need your help.

Nearly 9 years after the attacks, we urge you to help make a just Federal health response to 9/11 a reality.

Sincerely,

JULIE MENIN,
Chairperson.

CATHERINE McVAY HUGHES,
Vice Chairperson.

COMMUNITY BOARD NO. 2, MANHATTAN,
NEW YORK, NY 10012–1899.
June 24, 2010.

Hon. TOM HARKIN,
Chairman,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Hon. MICHAEL ENZI,
Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Re: S. 1334/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009”

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: We are writing to state our organization’s strong support for S. 1334, the “James Zadroga 9/11 Health and Compensation Act of 2009,” that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors and responders of 9/11.

As we know you recognize, 9/11 was an attack on our Nation that targeted civilians. In addition, along with many 9/11 responders, many New Yorkers have become ill as a result of the Federal Government’s false assurances that “the air is safe” and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster, responders and survivors alike.

The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs that provide the right kind of treatment for the people who lived, worked or attended school in the area, as well as the heroic responders who came to their rescue, for their 9/11-related illnesses. The continued availability of medical care from health professionals who have developed expertise in treating 9/11-related illness is critical.

Our organization represents Lower Manhattan, from 14th Street to Canal Street, 4th Ave/Bowery to the Hudson River, an area that was impacted by the dust cloud and was for many days under the plume emanating from the fires at Ground Zero, but was nonetheless excluded from the Environmental Protection Agency’s 2002–03 clean up. Scientists from the University of California at Davis took readings from the roof of the Federal Building at 209 Varick Street in our district and found higher concentrations of particulates than in their reading from the Kuwait oil fires during the Gulf War.

As representatives of the Lower Manhattan community, we especially ask that you protect the “Survivor Program,” currently based at the World Trade Center En-
environmental Health Center (WTC EHC), so that it can continue to meet the needs of the more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a result of their WTC exposures.

Many survivors, including children, are now struggling to recover their health, and others may develop WTC-related illnesses in the future. Lives have been restored and saved by the uniquely qualified and knowledgeable medical team at the survivor’s Center of Excellence that began at Bellevue, under Dr. Joan Riebman’s medical direction and leadership, and that has expanded to include Gouverneur and Elmhurst hospitals. They urgently need your help.

Nearly 9 years after the attacks, we urge you to help make a just Federal health response to 9/11 a reality.

Sincerely,

JO HAMILTON,
Chair, Manhattan Community Board 2.

JASON MANSFIELD,
Chair, Environment, Public Safety and Public Health Committee,
Manhattan Community Board 2.

CONCERNED STUYVESANT COMMUNITY.

Re: S. 1334/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009”

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: On behalf of Concerned Stuyvesant Community, I am writing to state my organization’s strong support for S. 1334, known as the James Zadroga 9/11 Health and Compensation Act of 2009, that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has passed both the House Judiciary and Energy and Commerce committees, which is a significant step towards achieving justice for the survivors and responders of 9/11.

As we know that you recognize, 9/11 was an attack on our Nation that targeted civilians. In addition, along with many 9/11 responders, many New Yorkers have become ill as a result of the Federal Government’s false assurances that “the air is safe” and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster, responders and survivors alike.

The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs that provide the right kind of treatment for the people who lived, worked or attended school in the area, as well as the heroic responders who came to their rescue, for their 9/11-related illnesses. The continued availability of medical care from health professionals who have developed expertise in treating 9/11-related illness is critical.

Our organization represents parents of students, students, and faculties of Lower Manhattan schools who were exposed during this disaster and its aftermath, many continuously through today.

Reminder that as Students/Faculty—they had no option but to return to their school after as short as a 3-week stay elsewhere—after false reassurances of safety, due to inaccurate reports on the cleanup. A toxic brew of materials both in schools through the ventilation system and outside with a hazardous debris barge dumping operation of the discarded material right next to the schools continued the dust and debris exposures through nearly the end of that school year. That churning of toxic dust was constant over 9 months and was not properly cleaned to this day.

As a Lower Manhattan community-based organization, we especially ask that you protect the “Survivor Program,” currently based at the World Trade Center Environmental Health Center (WTC EHC), so that it can continue to meet the needs of the more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a result of their WTC exposures. Many survivors, including children, are now struggling to recover their health, and others may develop WTC-related illnesses in the future. They urgently need your help.
Nearly 9 years after the attacks, we urge you to help make a just Federal health response to 9/11 a reality.

Sincerely,

LORI PANDOLFO.

9/11 ENVIRONMENTAL ACTION,
NEW YORK, NY 10025,

Hon. TOM HARKIN,
Chairman,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Hon. MICHAEL ENZI,
Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.


DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: On behalf of 9/11 Environmental Action (EA), I write in strong support of S. 1334, the James Zadroga 9/11 Health and Compensation Act of 2009, a bill that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly urge you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest possible protections for the survivors of 9/11. H.R. 847, the House of Representatives' version of this bill, has now passed both the House Judiciary and Energy and Commerce Committees, a significant step towards achieving justice for the survivors and responders of 9/11.

As we know you recognize, 9/11 was an attack on our Nation that targeted civilians, many of whom were exposed to toxic dust and smoke from the collapse and burning of the WTC. In addition, along with many 9/11 responders, many people who lived, worked, or attended school in Lower Manhattan at the time of the attacks have become ill as a result of the Federal Government's false assurances that “the air is safe” and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government help to provide WTC-specialized care for those health was harmed as a result of the WTC disaster.

9/11 Environmental Action is the community-based organization of residents, school parents and occupational safety and environmental health advocates that formed in April 2002 to spearhead the downtown community's fight for full disclosure of WTC hazards, and proper testing and cleanup of WTC indoor contamination by the EPA. In addition, 9/11 EA has long advocated for federally funded medical monitoring and health care for everyone whose health was harmed by WTC dust and smoke.

In the course of our work downtown, we can attest that in the weeks and months after 9/11, residents, school parents and others were left to struggle on their own to protect themselves and their children from unprecedented toxic exposures, including hazards that had contaminated homes, schools and offices. Moreover, as people became sick from those exposures, they had no access to accurate environmental health information, appropriate health guidance or proper medical evaluation or care.

The “Survivor Program” based at the WTC EHC is the center of excellence serving the health needs of non-responder survivors of the 9/11 attacks. The continued availability of specialized medical care at these programs from health professionals who have developed expertise in treating 9/11-related illnesses is critical.

We therefore especially ask that, as you consider S.1334, that you protect the “Survivor Program,” currently based at the WTC EHC, so that it can continue to meet the needs of more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a re-
sult of their WTC exposures. Many survivors, including children, are now struggling to recover their health, and others may develop WTC-related illnesses in the future. They urgently need your help.

Nearly 9 years after the attacks, we urge you to help make a just Federal health response to 9/11 a reality.

Sincerely,

KIMBERLY FLYNN.

June 28, 2010.

Hon. KIRSTEN GILLIBRAND,
478 Russell Senate Office Building,
Washington, DC 20510.

SENATOR GILLIBRAND: The events of 9/11 caught everyone by surprise. Men and women from all over the area, rushed in to help those who had been impacted by the planes, the fires and the collapses. The workers who stayed, those who spent days and weeks and months on the site of the horror, have been and are continuing to show a variety of terrible health symptoms from exposure to the site. These people did not hesitate to help when they were needed, and stayed to show the world that they believed in our country and the future of our way of life. They are now being punished by the toxins they were exposed to for their noble efforts.

My husband, Lt. Peter J. Farrenkopf, spent 30 years loving his job with the FDNY, and on that horrible day, he was on duty at the Marine Division at the Brooklyn Navy Yard, and with the fire boats was one of the first responders. He continued to return to the site for weeks. there was not even a question about his being there, because in his heart it was the right thing to do. He was diagnosed in July 2009 with glioblastoma, a brain cancer which is like a freight train . . . very fast and just impossible to stop. He was dead in 3 months. After watching my dear husband become ill and die at the age of 56, I would do anything to help people who find themselves in the same or a similar position.

The fact that men and women from the tri-State area (and many points elsewhere, remember how they kept coming??!!) are only NOW becoming ill from the toxins released on that day is strong statement that we need to continue to provide for these heroes. They were on the front lines for our people, our city and our country, when it counted. We canNOT allow the funds for their monitoring, diagnosis and treatments be stopped. We must make sure our commitment to this cause is for the long haul, and that the WIC 9/11 ZADROGA BILL is passed.

Thank you for your time.

Sincerely,

JANET BELLUSCI FARRENKOPF,
Ulster Park, NY 12487.

FEDERAL LAW ENFORCEMENT OFFICERS ASSOCIATION,
LEWISBERRY, PA 17739,

Hon. KIRSTEN E. GILLIBRAND,
U.S. Senate,
Washington, DC 20510.

DEAR SENATOR GILLIBRAND: As the National President of the 26,000 members of the Federal Law Enforcement Officers Association (FLEOA), as well as your New York State constituent, I am writing to express our members’ sincere appreciation for your introducing the James Zadroga 9/11 Health and Compensation Act of 2009. Our membership is unified in its support for this important bill, and we are optimistic that you will make all efforts to move this legislation forward.

FLEOA has met with numerous Members of Congress to support H.R. 847, and we are encouraged by its favorable vote out of full committee. In working with our New York Coalition partners, in particular the Sergeants Benevolent Association, we stand ready to educate any reluctant members of the Senate on the importance of your bill. Our message is clear: there are 50 stars on our flag, and an attack on one of them is an attack on all of us.

In addition to those of us still working in New York, FLEOA has numerous members who were first responders to Ground Zero and are currently residing in other States. Indeed, this is a nationwide problem, and with the passage of your bill, all first responders will have access to medical screening and treatment. It is painfully clear that the harmful toxins we were exposed to are finally taking their lethal toll
on our health. We are counting on you to champion our cause, and we are prepared to support you with our full resources. Please do not hesitate to contact me, or Andy Quinn, our Washington, DC representative, at 202–680–0447.

Respectfully,

J. ADLER,  
National President.

PATRICIA HESS,  
STONE RIDGE, NY 12484,  

Hon. KIRSTEN GILLIBRAND,  
478 Russell Senate Office Building,  
Washington, DC 20510.

DEAR SENATOR GILLIBRAND: I have a story that should be told, in fact, that needs to be told. My name is Patricia Hess and I am a widow. I lost my husband Robert Hess just 2 months ago. We had been married for 18 years and we had four wonderful children together. Our daughter Kimberly—17, our twin sons Robert & Brian—12, and our joyful youngest Connor—9, were the pride and joy of Rob’s life. The hole left by his absence is still gaping and raw and I’m not sure how I will fill it.

Rob was a New York City Fireman for almost 25 years. He worked his way up through the ranks, achieving the grade of Lieutenant. He loved the FDNY. It was his second family and he was proud to serve the city he had called home. I was the wife of a New York City Fireman and so I was always prepared for the worst; that call in the middle of the night, the knock on the door by men dressed in blue with somber faces. It was a reality I dealt with, always prepared for the worse and praying for the best each time I heard about a terrible blaze or a fireman killed in the line of duty.

Rob responded on the morning of September 11, 2001. To be honest, I had thanked God every day that he was not among the first on site or our family would not have had him to love for all the years since that horrible day. He arrived at Ground Zero just after the collapse of Tower Two and remained on scene for the next 20 hours. He was there to witness Building Seven crumble to the ground. We lost many fine people that day, many friends, and Rob carried that loss with him in the ensuing years.

For the next 2 months he worked in midtown Manhattan, riding on Engine 26. This engine had been on site during the collapse of both towers and was covered with a thick coat of dust and some debris. It was miraculous that the driver of Engine 26 survived and was rescued. Over the course of the first 2 weeks of Rob’s tour in midtown, Engine 26 remained covered in the dust of the once grand World Trade Center. He, like all the other proud and loyal FDNY members did not know that this dust would later cause them much hardship; he only knew he had to help.

When the World Trade Center Monitoring Program began, Rob, being a prudent person, registered right away. Over the past 4 years he was screened for any emerging health issues. He had semi-annual cat scans of his lungs. In February 2010 when he went for the first of his two annual scans it was discovered that he had a carcinoid tumor in his right lung airway. On April 23 he went to NYU hospital to have it removed, along with 2/3 of his lung. We were told it was a fairly routine surgery and had every confidence in the doctors and the outcome. Four days after the surgery Rob began having difficulty breathing. It was determined he had pneumonia and he was placed on a respirator. On Sunday May 2, despite heroic efforts from the medical team at NYU that went on for nearly 35 minutes, my husband died at 6:07 p.m. of coronary arrest. His death has been attributed to his service during the response to the terrorist attacks on the World Trade Center.

I am writing to you to say that without the World Trade Center Monitoring Program my husband would have likely died a horrible cancer-related death, never understanding how 9/11 had impacted his health. Rob was one of the fortunate ones, he acted quickly and he was able to register to receive the screenings. Had he not, the tumor would have grown and spread. It is sad to say that other first responders, as well as residents from the neighborhoods surrounding Ground Zero, have not been as fortunate to receive this kind of monitoring. It is also sad to think that many who have become, or who will become ill, will never know if the events of September 11th are the real culprit.

The James Zadroga 9/11 Health and Compensation Act of 2009 can help ensure that these people—fathers, mothers, sons and daughters—are given the same chance at life that my husband Robert Hess was. While one can never really understand why someone survives or not after a life altering surgery, the fact of the mat-
eter remains that the monitoring program helped to identify the cancer and gave Rob a fighting chance. Every first responder as well as the people who lived and worked surrounded by a cloud of toxic dust, and every man and woman who spent months doing cleanup at Ground Zero should be given this same opportunity.

The James Zadroga 9/11 Health and Compensation Act will do exactly that, provide screenings and treatments to those impacted and adversely affected by the events of September 11, 2001. It will also help those who suffer with the emotional and stress related problems that we often see in soldiers who experience combat. I know of no one who experienced first hand the World Trade Center’s destruction that wouldn’t say they had been in a combat zone. As we protect our military, so too should we protect all of our citizens.

My husband never hesitated to answer the call to duty, he served with pride and honor. He valued what he did and he brought value to the FDNY through his presence. My family is left with a void. My children will not have their father at birthdays and graduations. Our holidays will be less joyful without his booming laughter. My daughter will not have her father to walk her down the isle on that special day. And me, well I will go to sleep at night with an empty space beside me and an even emptier space in my heart.

Please Senator, for my family and all the others who might be facing this terrible situation in the years to come, please pass the James Zadroga 9/11 Health and Compensation Act.

Thank you,
PATRICIA HESS.

JENNIFER McNAMARA,
BLUE POINT, NEW YORK 11715.

Thank you Senator Gillibrand, and all the co-sponsors of this bill for giving me the opportunity to submit a statement today and for the fight you have taken up on behalf of sick 9/11 Responders.

My name is Jennifer McNamara and I am the widow of FDNY Firefighter John F. McNamara. On August 9, 2009, John, only 43 years old, died of colon cancer. John worked over 500 hours at Ground Zero, had no genetic predisposition to cancer, did not smoke, and drank only socially. He was strong and in good health—just look at the pictures. When he was diagnosed, we were expecting our first child, Jack, who is now 3 1/2.

Upon diagnosis in June 2004, John’s cancer was considered to be end Stage 4. It had infiltrated other organs, and there was little chance he would survive. John had no warning that he was sick—just sudden and severe stomach pain one day. I firmly believe, as did John, that if his health had been monitored, he would have had a chance at surviving the cancer.

From almost the first moment he was diagnosed, John became an advocate for other sick 9/11 Responders. He teamed up with John Feal and also helped to found the NYC Firefighter Brotherhood Foundation. He knew that without medical monitoring and medical assistance, many people who responded on 9/11 and in the days after would get sick and die. He knew many would be unable to afford the proper medical treatment. He knew this because he met these people—ironworkers, construction workers, private EMS workers; all who never knew their own bodies had betrayed them until it was too late.

Until the day he died, no matter how sick he was, John advocated for proper medical care for 9/11 Responders. He believed in the Zadroga bill. He attended press conferences in the rain after chemo sessions, allowed videos to be made of him in the hospital, traveled to Washington, and talked to any reporter who asked.

John’s message was clear—9/11 Responders need medical monitoring and care; nobody else should die because of a late diagnosis or because they can’t pay for medications. I can’t say it more clearly; this bill must be passed before there are more widows like me and more children without a parent.

I have taken up John's battle because I promised him on his deathbed I would. I have taken up his battle because I must now be the voice for my dead husband. I beg you to listen to the stories of sick 9/11 Responders. Understand the hell that they and their families go through. Understand the heart-wrenching choices they may sometimes have to make because they have no access to medical monitoring and care. Most of all, understand that the fear you hear in their voices is real. They have seen what happens to people who don’t have medical monitoring and care. Just as nobody in this country should go hungry, no 9/11 Responder should be sick or die because they didn’t have medical access.
Vote on this bill and pass it quickly, for there is little else you can do to thank those Americans who, being told it was safe, toiled in the weeks and months after 9/11. They took care of this country, now is the time to take care of them.

Sincerely,

JENNIFER K. McNAMARA.

Hon. KIRSTEN E. GILLIBRAND,
U.S. Senate,
531 Dirksen Senate Office Building,
Washington, DC 20510.

DEAR SENATOR GILLIBRAND: On behalf of the National Association of Police Organizations (NAPO), representing 241,000 rank-and-file law enforcement officers from across the United States, I would like to advise you of our support for the “James Zadroga 9/11 Health and Compensation Act of 2009,” S. 1334. This important legislation would ensure that first responders and community workers who risked their lives responding to the 9/11 terrorist attacks on the World Trade Center (WTC) receive medical monitoring and treatment so they can maintain, or regain, their good health.

Nearly 9 years after the attack on our Nation, we continue to mourn the 84 Port Authority personnel, including 37 members of the Port Authority Police Department, 23 New York City Police Department officers, 11 New York State and Federal Law Enforcement Officers, 343 fire fighters, and over 2,200 civilians who lost their lives. While the Nation remembers those we lost, those who responded to the WTC continue to suffer from the physical and mental traumas endured that day and in the days following. According to the Mount Sinai Medical Center study on 9/11 health effects, 70 percent of the first responders at Ground Zero suffer from chronic lung ailments.

As the health risks associated with exposure to the WTC site become more manifest, it is imperative to ensure that workers in the rescue and recovery effort are properly monitored and treated for exposure-related diseases. By establishing the World Trade Center Health Program within the National Institute for Occupational
Safety and Health, S. 1334 would make certain that there is a federally funded program to give medical monitoring and treatment to WTC responders, who were exposed to the toxins at Ground Zero. Additionally, this legislation would provide for research into conditions, such as cancers, that may be related to the WTC site.

NAPO appreciates all you are doing to support those who have fallen ill due to their response and subsequent exposure at the WTC. We look forward to working with you to fight for the passage of this bill. If you have any questions, please feel free to contact me, or NAPO’s Government Affairs Director, Andrea Mournighan, at (703) 549–0775.

Sincerely,

WILLIAM J. JOHNSON,
Executive Director.

NEW YORK COMMITTEE FOR OCCUPATIONAL SAFETY AND HEALTH (NYCOSH),
NEW YORK, NY 10038–3331,

Senator TOM HARKIN, Chairman,
U.S. Senate Committee on Health, Education, Labor, and Pensions,
428 Senate Dirksen Office Building,
Washington, DC 20510.

Senator MICHAEL ENZI, Ranking Member,
U.S. Senate Committee on Health, Education, Labor, and Pensions,
428 Senate Dirksen Office Building,
Washington, DC 20510.


Dear Chairman Harkin and Ranking Member Enzi: We are writing in support of S. 1334 which would provide medical monitoring, treatment, and compensation to rescue and recovery workers as well as to local workers and residents who are ill as a result of exposure to the toxic substances released in the aftermath of the attack on the World Trade Center on September 11, 2001.

Tens of thousands of workers responded to the emergency and were exposed to a wide variety of toxic substances, including carcinogens, as were additional thousands of people who lived, worked, and attended schools in the area surrounding the World Trade Center. People were exposed to WTC-derived toxic substances outdoors and indoors, on that day and for uncounted months afterwards. We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has passed both the House Judiciary and Energy and Commerce committees, which are significant steps towards achieving justice for the survivors and responders of 9/11.

NYCOSH is a non-governmental membership organization representing 200 labor unions and over 350 safety and health activists and legal and health professionals dedicated to the right of every worker to a safe and healthful workplace. For 9 years, we have been working with workers who worked on and under the pile at Ground Zero, workers who worked to clean up the adjacent community, and residents whose health has been adversely impacted as a result of their exposure to these toxic substances. Clinically diagnosed conditions include lower and upper respiratory illnesses, gastrointestinal problems, and psychological trauma. We are also greatly concerned about the prospect of late-emerging diseases such as cancers. The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs that provide the right kind of treatment for the people who lived, worked or attended school in the area, as well as to the responders who came to their rescue, for their 9/11-related illnesses. The continued availability of medical care from health professionals who have developed expertise in treating 9/11-related illness is critical.

Passage of S. 1334 would provide on-going funding for the World Trade Center Medical Monitoring and Treatment Program, the World Trade Center Environmental Health Center, and the FDNY WTC Medical Monitoring and Treatment Program, which have provided vital and expert services to those who suffered toxic exposures after the attack on the World Trade Center. We attest to the capabilities of these medical “centers of excellence” to provide needed medical services to the af-
fected communities. We strongly support Federal funding over the long term for these essential medical services.

Respectfully,

JOEL SHUFRO, PH.D.,
Executive Director, NYCOSH.

ORGANIZATION OF STAFF ANALYSTS,
NEW YORK, NY 10010,

Hon. TOM HARKIN, Chairman,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.
Hon. MICHAEL ENZI, Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.


DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: On behalf of the Organization of Staff Analysts (OSA), I write in strong support of S. 1334, the James Zadroga 9/11 Health and Compensation Act of 2009, a bill that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly urge you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest possible protections for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has now passed both the House Judiciary and Energy and Commerce Committees, a significant step towards achieving justice for the survivors and responders of 9/11.

Nearly 9 years after the attacks on the WTC, the Federal Government has yet to make an appropriate long-term, consistent commitment to the health care of responders and survivors.

As we know you recognize, 9/11 was an attack on our Nation that targeted civilians. In addition, along with many 9/11 responders, many New Yorkers have become ill as a result of the Federal Government’s false assurances that “the air is safe” and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster, responders and survivors alike.

The Zadroga Act would guarantee 10 years of Federal funding to specialized WTC-related medical programs. The continued availability of specialized medical care at these programs from health professionals who have developed expertise in treating 9/11-related illnesses is critical.

OSA is a union representing 4,700 active and 1,500 retired professionals in the public service, all of whom work in some capacity for the city of New York in 1 of the more than 50 mayoral agencies or in one of the city’s affiliated employers, including the NYC Health & Hospitals Corporation and the NYC Housing Authority. The vast majority of our members perform central office functions for their employers and, since the vast majority of city agency central office locations are in Lower Manhattan, OSA members were exposed to the dust cloud on the way to work, at work, or while evacuating from work locations on 9/11. In addition, many were recalled to their work locations in buildings downtown within weeks of 9/11, some as early as a few days later. Some of our members were also enlisted in cleanup activities, whether their own offices or, as in at least one case we’ve been told of, volunteering to move dust-encrusted vehicles from Lower Manhattan locations to piers on the Hudson River. And, they have also suffered mental health impacts from the trauma of 9/11.

For these reasons, since 2001, we have taken an active interest in the provision of adequate healthcare for those impacted by 9/11, especially those who fall into the category of survivors, as do our members as area workers.

We therefore especially ask that you protect the “Survivor Program,” currently based at the WTC Environmental Health Center (WTC EHC), so that it can continue to meet the needs of more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a result of their WTC exposures. Many survivors, including children, are now
struggling to recover their health, and others may develop WTC-related illnesses in
the future. They urgently need your help.

OSA has participated in the WTC EHC’s Community Advisory Committee since
its inception. It is especially important to remember that the fact that a con-
centrated group of affected patients is being seen in one program facilitates the
identification and treatment of 9/11-related illnesses and provides a special base of
knowledge not duplicated elsewhere, offering a window on the health conditions suf-
furred by those in the survivor community and insights on the unmet health and
mental health needs of these populations.

OSA therefore encourages you to do all you can to ensure that this important leg-
islation passes your committee, the Senate as a whole and is brought to President
Obama for signature.

Nearly 9 years after the attacks, we urge you to help make a just Federal health
response to 9/11 a reality.

Sincerely,

ROBERT SPENCER,
Director of Media Services and Labor Co-Chair,
Community Advisory Committee,
World Trade Center Environmental Health Center.

LORI HALPERN PANDOLFO,
BROOKLYN, NY 11218–4314,
June 27, 2010.

Re: S. 1324/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of
2009”

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: As a parent of an affected
Stuyvesant HS Alumna, and former PA co-president along with Linda Lam, I felt
it my duty to speak not only on behalf of Concerned Stuyvesant Community, but
also on behalf of myself in this matter here today. I have remained active by attend-
ing meetings and maintaining membership on community advisory to the NYC De-
partment of Health WTC Health Registry studies and activities. With that partici-
pation, I gained knowledge of the programs and the needs of affected students, resi-
dents and workers.

My own daughter is a cancer survivor who escaped the area along with her class-
mates during one of her first days of high school and was returned to attend school
in the area, much too soon, and continuously, after only a short 3-week break with
false assurance that the school was cleaned properly and the area was safe for
health. It turned out differently for her and all other local students, including
BMCC, a college nearby. As you can easily imagine, I am overly concerned about
health, having experienced the turmoil and anguish caused by life threatening high-
ly aggressive pediatric cancer treatment of my young child, prior to the events of
9/11. Having been exposed to any sort of toxins still is a tremendous source of anx-
iety to me and my family. That is why monitoring and treatment, available to all
those affected by 9/11 is of paramount importance to me. Both the organization I
represent on the community advisories and I myself, support the survivor treatment
programs to be funded by the proposed Zadroga bill.

This group is especially vulnerable to being overlooked as they were adolescents
and are now young adults. While their exposures should be considered within the
pediatric guidelines, their care and monitoring happen as young adults—without
specialized attention to this group, the link to 9/11 can easily be lost over even the
short 8 years already passed. It bears repeating that “they don’t know what they
don’t know.” If these students have used denial as an effective healthy tool to move
forward from this experience, they may not, and most importantly, their doctors will
not, know about associating illnesses that crop up over a lifetime with their expo-
sures in this event if there is no real data gathered or disseminated.

Adults are more likely to continue care under the original/same practitioners they
were seeing at the time of the event, while these students will be sure NOT TO
since they age/aged out of the care of their original pediatricians. This loss of coordi-
nation may lead to misdiagnoses and improper care in our population, especially
over the longer term. I am hoping and believe that the programs being funded will
capture this transition and account for it at every point of change, leading to better
coordination of care.

The 10-year limit and limit on the number of treatment slots remains a concern
while the bill moves forward and is reconciled.

I appreciate your help in strengthening and supporting the bill as it evolves to
become law and will serve our community.
Thank you for the opportunity to express my views.
Very truly yours,

LORI PANDOLFO.

PORT AUTHORITY POLICE BENEVOLENT ASSOCIATION, INC.,
ENGLEWOOD CLIFFS, NJ 07632–1805,
June 28, 2010.

Hon. KIRSTEN E. GILLIBRAND,
U.S. Senate,
531 Dirksen Senate Office Building,
Washington, DC 20510.

DEAR SENATOR GILLIBRAND: On behalf of the 1,558 members of the Port Authority Police Benevolent Association, I would like to advise you of our support for the “James Zadroga 9/11 Health and Compensation Act of 2009,” S. 1334. This important legislation would ensure that first responders and community workers who risked their lives responding to the 9/11 terrorist attacks on the World Trade Center (WTC) receive medical monitoring and treatment so they can maintain, or regain, their good health.

As a first responder to the World Trade Center myself, I know firsthand the conditions that we were exposed to as we worked on the pile, day after day, week after week and month after month. I have personally suffered health impacts and it seems like another one of my members develops a new health condition clearly related to our work at the site every week.

As the health risks associated with exposure to the WTC site become more manifest, it is imperative to ensure that workers in the rescue and recovery effort are properly monitored and treated for exposure-related diseases. By establishing the World Trade Center Health Program within the National Institute for Occupational Safety and Health, S. 1334 would make certain that there is a federally funded program to give medical monitoring and treatment to WTC responders, who were exposed to the toxins at Ground Zero. Additionally, this legislation would provide for research into conditions, such as cancers, that may be related to the WTC site.

Again, on behalf of all of our members, I thank you for supporting this bill to provide relief to our members who are suffering as a result of their work in the rescue effort and cleanup of the WTC site. If there is anything that we can do to support this effort, please feel free to contact me at (201) 871–2100.

Very truly yours,

PAUL NUNZIATO,
President.

PUBLIC EMPLOYEES FEDERATION,
AFL–CIO DIVISION 199,
NEW YORK, NY 10008–1212,

Hon. TOM HARKIN, Chairman,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Hon. Michael Enzi, Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Re: S. 1334/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009”

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: I am writing to state my division’s strong support for S. 1334, the “James Zadroga 9/11 Health and Compensation Act of 2009,” that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11. H.R. 847, the House of Representatives version of this bill, has passed both the House Judiciary and Energy and Commerce Committees, which is a significant step towards achieving justice for the survivors and responders of 9/11.
9/11 was an attack on our Nation that targeted civilians. Along with many 9/11 responders, many people who lived, worked, or attended school in Lower Manhattan at the time of the attacks have become ill as a result of the Federal Government’s false assurances that “the air is safe,” and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government help to provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster.

The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs that provide the right kind of treatment for the people who lived, worked or attended school in the area, as well as the heroic responders who came to their rescue, for their 9/11-related illnesses. The continued availability of medical care from health professionals who have developed expertise in treating 9/11-related illness is critical.

My union, the New York State Public Employees Federation, AFL–CIO, is the union that represents the 59,000 professional, scientific, and technical employees of the government of New York State. About 500 of our members came from all over the State and responded to Ground Zero and the aftermath of 9/11. Several thousand of our members work in offices adjacent to or within walking distance of the World Trade Center site. My union is one of many that represent non-responder State workers whose health has been and continues to be negatively impacted by the events of 9/11. Most of the members of my division work at 90 Church Street, an office building next to Ground Zero.

As members of the Lower Manhattan community, we especially ask that you protect the “Survivor Program,” currently based at the World Trade Center Environmental Health Center (WTC EHC), so that it can continue to meet the needs of the more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a result of their WTC exposures. Many survivors, including children, are now struggling to recover their health, and others may develop WTC-related illnesses in the future. They urgently need your help.

Nearly 9 years after the attacks, we urge you to help make a just Federal health response to 9/11 a reality.

Thank you.

Very truly yours,

ILANYE LONGJOHN,
Council Leader, PEF Division 199.

PARTNERSHIP FOR NEW YORK CITY,

Hon. Michael Enzi, Ranking Member,
Committee on Health, Education, Labor, and Pensions (HELP),
U.S. Senate,
Washington, DC 20510.

Dear Senator Enzi: On behalf of New York City’s business community, we are writing to urge your favorable action on S. 1334, the James Zadroga 9/11 Health and Compensation Act of 2009. This legislation would provide a comprehensive long-term solution to address the serious health problems that WTC responders and survivors are facing as a result of 9/11 hazardous exposures.

The Partnership is a nonprofit organization that represents international business leaders who are headquartered in the New York City metropolitan region. Our members are responsible for 7 million jobs throughout the country and contribute more than $740 billion to the national GDP.

The terrorist attack of 9/11 was an unprecedented act of war against this country, targeting both our economic and political capitals. The impact for those who were directly exposed to the attack or participated in emergency response and recovery is still reverberating, with tens of thousands of Americans suffering physical and mental consequences.

In November 2001, we issued a study that quantified the immediate cost of the attack for New York City, in economic terms, at $83 billion. The Federal Government and the insurance industry combined to cover most of these losses, allowing for the recovery and rebuilding of the areas of Lower Manhattan that were destroyed or damaged in the attack. New York City was grateful that the American public recognized that this was a national challenge that required and deserved Federal assistance.

Tragically, there are significant additional costs that continue to mount as a result of the direct consequences of the attack on the physical and mental health of
rescue workers, construction crews, and people who lived and worked in the area that was contaminated as a result of the attack. Our Partnership offices are a few blocks from the World Trade Center and we, like most New Yorkers, were committed to reopening America’s financial district quickly so that the country would not suffer the economic blow that the terrorists hoped to inflict. At the time, we were not aware of how toxic the residue of the attack would be.

People from all over the country who participated in rescue, recovery and early rebuilding efforts were exposed to contaminants that have and will result in premature death and lives of suffering. We urge you to enact S.1334 and insure that victims of the fallout from the attack will be properly monitored and receive the best health care that this country can deliver.

Sincerely,

KATHRYN WYLDE, 
President & CEO.

Valery Roberts, 
Mahopac, NY 10541, 

Hon. Kirsten Gillibrand, 
U.S. Senate, 
Washington, DC 20510.

DEAR SENATOR GILLIBRAND, My name is Valery Roberts. My husband Tommy was a member of The New York City Fire Department for 29 years. He worked in Washington Heights and Harlem. The Fire Department was his life and he looked forward to every tour. He said “It was the best job in the world.” When 9/11 happened he worked tirelessly at the site with his men never taking his own health into consideration. The trauma, depression, sadness and loss of lives were overwhelming but still they kept searching. He lost many friends that day.

In January 2007 Tommy retired from the department he loved and looked forward to a long and happy retirement. We looked to the future to enjoy and do all the things we put on hold when he was working. He kept his hand on the job by becoming a peer counselor to help and guide men and women on the job.

In September 2008 Tommy was diagnosed with esophageal cancer with metastasis to the lymph nodes and liver. Our world was shattered. This was a man who was never ill, ran two marathons and had NO history of cancer in his family. His parents are 90 and 91 with no major health concerns. He went for his physicals annually and was always given a clean bill of health. His last physical was April 2008. The prognosis was with palliative treatment, we could go on indefinitely. We were thankful for the health care we had knowing that he would receive the best care and would not have to worry about “how are we going to pay for this.” The effect of his illness on our family was daily. We have three daughters 32, 27, and 26 who faced the prospect of loosing their father. The father who was always there for them, who they idolized and loved with all their heart. For me the thought of not having the love of my life by my side, not realizing our hopes and dreams was devastating. His illness took its toll. The tests and treatments were grueling but he faced them with dignity praying for a cure.

Tommy lost his battle August 12, 2009. He was 58. Our family’s hearts are broken and dreams shattered. He will never see his girls get married, never know his grandchildren and never enjoy the retirement he worked so hard for. My life partner is gone and my days are empty.

If not for the health plan coverage we had, our days would have been filled with worry as to how to pay for his care instead of focusing on enjoying what time we had left and treasuring everyday. The costs would have been prohibitive and insurmountable. That is why I respectfully ask you to vote for and pass the 9/11 Health and Compensation bill, so that every other family faced with a devastating illness receives the best medical care possible and spend every minute without worrying how to pay for it.

Respectfully, 

Valery Roberts.
SOUTHBRIDGE TOWERS PARENT AND YOUTH ASSOCIATION, INC.,
NEW YORK, NY 10038,
June 24, 2010.

Hon. TOM HARKIN, Chairman,
Committee on Health, Education, Labor, and Pensions,
U.S. Senate,
Washington, DC 20510.

Hon. MICHAEL ENZI, Ranking Member,
Committee on Health, Education, Labor, and Pensions, U.S. Senate,
Washington, DC 20510.

Re: S. 1334/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009”

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: On behalf of South Bridge Parents and Youth Association, I am writing to express our full and continued support of the H.R. 847 bill, S. 1334 and the “Survivor Program.” The World Trade Center Environmental Health Center (WTC EHC). We appreciate your past and future support of long-term, consistent Federal funding so that the Center can meet the growing health needs of Lower Manhattan residents, families and children, exposed to toxic smoke and dust on and after 9/11.

We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has passed both the House Judiciary and Energy and Commerce committees, which is a significant step towards achieving justice for the survivors and responders of 9/11.

South Bridge Parent and Youth Association is a not-for-profit advocacy organization that serves the many families residing at Southbridge Towers, a nine-building complex with 1,690 apartments, and also families in the adjacent Seaport and Financial District neighborhoods. Our mission is “To Enhance the Childhood Experience and Maximize the Quality of Life for All,” and our focus is on issues and events centered around education, health, community and recreation that directly affect our community.

Many New Yorkers (students, residents, office workers and responders) have become ill as a result of the Federal Government’s failure to provide proper environmental cleanup and its false assurances that “the air is safe” upon the attack on our Nation’s innocent civilians. It is therefore imperative that our Federal Government provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster, responders and survivors alike.

9/11 had a massive, lasting impact on our area. As the terrifying events unfolded, the first thought for many of us was how to get to our children. Many of the kids in our area, as well as adults, arrived back home coated in white dust. Because there was no real evacuation in our neighborhood, most residents remained in our buildings, which had been totally engulfed in the dust clouds when the Towers collapsed. We had no power, water or phones but at daybreak on September 12th when the sun shone brightly again, we could see that the interior of our home was also covered in that same thick white dust. Health officials soon told us that it was safe to remove. With no truthful information on the dangers of inhaling that dust, we, like countless numbers of residents, embarked on our own cleanup.

The experience of my own family was typical. In the days immediately following 9/11, I myself cleaned our apartment, along with my elderly father, who vacuumed up what we now know was toxic WTC dust, without the right kind of vacuum filter. At 8 months pregnant with my third child, I got down on my hands and knees and pulled up the contaminated carpet in my children’s room.

It was not until 2003 that the Environmental Protection Agency (EPA) offered residents a cleanup on a voluntary basis. Many people did not even know any cleanup was happening because the program was so poorly publicized. And the cleanup was so late in coming and so haphazard, that participation was low. My apartment’s “professional” EPA clean up didn’t occur until March 2003. Everyone knows that just cleaning a fraction of apartments in a building means that it probably won’t take long for recontamination to occur. The whole building cleanups we all needed to clear out the toxic dust once and for all were never carried out.

After being forced to deal with the WTC environmental fallout ourselves, we found that we were likewise on our own to struggle with the health effects. Speaking for my own family, we had to search long and hard to find specialists, including a pediatric pulmonologist, who could correctly diagnose and treat the health problems we developed as the result of our WTC-related exposures.
All three of my children, including the baby born just 1 month after 9/11, were prescribed daily treatments including Zyrtec, Allegra, Singulair, Asmonex, Albuterol, Rhinocort, Q-Var and Advair for allergy, sinusitis and asthma-related symptoms. Additionally, all three have been prescribed Prevacid for GERD. We keep steroids, a nebulizer and associated medications on hand in the event that any of the children should reach the red level of their “asthma action plans.” They miss more school than average healthy children in their age groups. At 5 years old, my youngest knew how to load the nebulizer with treatment and to administer that treatment to herself.

For years, I struggled to shoulder the costs for my family’s 9/11 health care, which averaged $840 a month, on top of what our insurance covered. Like so many others in our neighborhood, my family is staggering under the burden of WTC medical expenses, for which the Federal Government should bear responsibility.

Those who are sick as the result of 9/11 need and are entitled to the right kind of care. As the Center of Excellence for non-responders, the WTC EHC provides optimum, specialized care with a commitment to continue to meet the medical needs of the community as those evolve. Because its patients are being closely tracked over time, any new patterns of disease will be detected, making possible the early intervention needed to maximize the chances of recovery. This effort requires and must receive sustained Federal support.

Moreover, early detection is crucial when it comes to children, who are especially vulnerable to the effects of environmental pollutants, and who may develop different health problems than adults. Thousands and thousands of children, including very young children, were exposed to WTC smoke and dust in their homes, schools and playgrounds— wherever they turned. Therefore it is critical that the Bellevue WTC Pediatric Program receive the funding it needs in order to meet the needs of affected children, now and going forward.

Our community has the strongest possible stake in the preservation and expansion of the WTC EHC so that it will always be there for our children, our families and our neighbors. We wish to thank you for all your efforts to ensure that the people of Lower Manhattan, as well as all the brave responders, get the help they need to recover from 9/11.

Sincerely,

MARIAMA JAMES,
Chairwoman.


Hon. TOM HARKIN, Chairman, Committee on Health, Education, Labor, and Pensions (HELP), U.S. Senate, Washington, DC 20510.

Hon. MICHAEL ENZI, Ranking Member, Committee on Health, Education, Labor, and Pensions (HELP), U.S. Senate, Washington, DC 20510.

Re: S. 1334/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009”

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI: I am writing on behalf of 105 Duane Street Residents Association to state our strong support for S. 1334, the “James Zadroga 9/11 Health and Compensation Act of 2009,” that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has passed both the House Judiciary and Energy and Commerce Committees, which is a significant step towards achieving justice for the survivors and responders of 9/11.

Our building is a 52-story residential high rise located seven blocks north of the World Trade Center site. On 9/11 toxic dust from the collapsing towers entered our homes through windows and through the ventilation system. In the months following the attack, smoke-borne contaminants from the fires that burned at the World Trade Center site polluted the air and continued to enter our homes. The air
smelled bad and the dust made us cough but the Government assured us that our homes were safe and that we would suffer no long-term health effects.

Yet in the almost 9 years that have passed since the attack on the World Trade Center, it has become clear that many of the people who lived and worked in the surrounding communities have developed long-term respiratory and other health effects as a result of exposure to World Trade Center dust, fumes, and smoke. In the months and years following the attacks, as more and more WTC-impacted residents and workers required medical care, we found that our illnesses were often not properly diagnosed or treated by our physicians. We received antibiotics for irritant-induced bronchitis, or inhalers for breathing problems that required additional therapies. It was not until the WTC Environmental Health Center opened in 2007 that residents and local workers who survived the attacks could receive specialized and effective medical care from a team of physicians who understood the range and complexity of the physical health effects we incurred as a result of our exposures.

As we know you recognize, the attack on the World Trade Center was an attack on only New Yorkers that targeted civilians. It is therefore imperative that our Federal Government help to provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster.

The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs that provide the right kind of treatment for the people who lived, worked or attended school in the area, as well as the heroic responders who came to their rescue, for their 9/11-related illnesses. The continued availability of medical care from health professionals who have developed expertise in treating 9/11-related illness is critical.

As residents of Lower Manhattan, we especially ask that you protect the “Survivor Program,” currently based at the World Trade Center Environmental Health Center (WTC EHC), so that it can continue to meet the needs of the more than 4,700 residents, area workers, and students, including people now residing in 23 States, who survived 9/11 but who are now sick as a result of their WTC exposures. Many survivors, including children, are now struggling to recover their health, and others may develop WTC-related illnesses in the future. They urgently need your help.

Nearly 9 years after the attacks, we urge you to help make a just Federal health response to 9/11 a reality.

Sincerely,

JO POLETT,
105 Duane Street Residents Association.

Re: S. 1334/H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009”

DEAR CHAIRMAN HARKIN AND RANKING MEMBER ENZI, On behalf of StuyHealth, I am writing to state my organization’s strong support for S.1334, the “James Zadroga 9/11 Health and Compensation Act of 2009,” that would provide medical monitoring, treatment and compensation for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pensions Committee, with the strongest protections possible for the survivors of 9/11. H.R. 847, the House of Representatives’ version of this bill, has passed both the House Judiciary and Energy and Commerce Committees, which is a significant step towards achieving justice for the survivors and responders of 9/11.

As we know you recognize, 9/11 was an attack on our Nation that targeted civilians. In addition, along with many 9/11 responders, many New Yorkers have become ill as a result of the Federal Government’s false assurances that “the air is safe” and its failure to provide proper environmental cleanup. It is therefore imperative that our Federal Government provide WTC-specialized care for all whose health was harmed as a result of the WTC disaster, responders and survivors alike.

The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs that provide the right kind of treatment for the 9/11-related illnesses of not only the heroic responders, but for people who lived, worked or, like ourselves, attended school in the area. The continued availability of medical care from health professionals who have developed expertise in treating 9/11-related illness is critical.

Our organization represents former students who attended school in Lower Manhattan on 9/11 and during the World Trade Center clean-up. As representatives of
over 400 students who attended school just blocks from the WTC site, we especially
ask that you protect the “Survivor Program,” currently based at the World Trade
Center Environmental Health Center (WTC EHC), so that it can continue to meet
the needs of the more than 4,700 residents, area workers, and students, including
people now residing in 23 States, who survived 9/11 but who are now sick as a re-
sult of their WTC exposures. Many survivors, including children and young adults
like ourselves, are now struggling to recover their health, and others may develop
WTC-related illnesses in the future. We urgently need your help.

Nearly 9 years after the attacks, we urge you to help make a just Federal health
response to 9/11 a reality.

Sincerely,

LILA NORDSTROM,
Founder.

INTERNATIONAL UNION, UNITED AUTOMOBILE, AEROSPACE &
AGRICULTURAL IMPLEMENT WORKERS OF AMERICA + UAW,
WASHINGTON, DC 20036,
June 29, 2010.

DEAR SENATOR: On behalf of over 1 million active and retired members, the UAW
urges you to support and cosponsor the James Zadroga 9/11 Health and Compensa-
tion Act of 2009 (S. 1334), sponsored by Senator Gillibrand. This bipartisan bill
would provide medical monitoring, treatment, and compensation to emergency re-
sponders, recovery, and clean-up workers, as well as to community members suf-
fering serious illnesses as a result of hazardous exposures from the 9/11 terrorist
attacks. The companion bill (H.R. 847) has been marked up in two House Commit-
tees, and the House is expected to take up this legislation shortly.

Tens of thousands of workers rushed to the World Trade Center (WTC) site to as-
sist in rescue and recovery operations following the 9/11 attacks. At the site, they
were exposed to a toxic mix of dust and fumes, as were residents and others near
Ground Zero. Now thousands of these individuals are suffering from serious res-
piratory diseases and other severe health problems. S. 1334 would provide a com-
prehensive, long-term solution to these health problems by establishing the World
Trade Center Health Program, under the direction of the National Institute for Oc-
cupational Safety and Health (NIOSH).

The program would build on the current medical programs to provide high quality
care through the Clinical Centers of Excellence in New York City. Additional clinical
centers would be designated to provide monitoring and treatment for those who re-
side outside the New York area, but whose medical conditions are due to exposure
at the WTC site. Individuals who meet the eligibility criteria would receive moni-
toring and medical treatment for WTC-related health conditions at no cost. In addi-
tion, S. 1334 would reopen the September 11th Victim Compensation Fund to pro-
vide compensation for economic damages and loss for those who were not previously
eligible or became sick after the original December 22, 2003 deadline, with awards
determined by a Special Master.

To control costs, the bill caps the number of program participants who can be
added. The program may take on up to 15,000 additional responders and 15,000 ad-
tional community members. The bill establishes the patient’s health insurance as
the primary payer for non work-related conditions and offsets costs for work-related
conditions through workers’ compensation payments. In addition, it provides for cost
sharing by the city of New York. Moreover, the bill would limit the overall legal li-
ability for construction contractors and the city of New York for 9/11-related health
claims to the funds available in the WTC Captive Insurance Company and coverage
under liability insurance.

The 9/11 attacks were attacks on our entire Nation. Compelled by a moral obliga-
tion, the United States has acted to compensate and care for the injured and the
surviving family members of those who were killed. The UAW believes the same ob-
ligation should now lead Congress to meet the needs of 9/11 rescue, recovery, and
clean-up workers, as well as area residents who became ill because of their exposure
to WTC hazards. We urge you to support and cosponsor the James Zadroga 9/11

Sincerely yours,

BARBARA SOMSON,
Legislative Director.
MARY C. VAUGHAN,  
Mahopec, NY 10541,  

TO: SENATOR KIRSTEN GILLIBRAND: My husband, Battalion Chief John J. Vaughan, retired from the New York City Fire Department in January 2003 after working for 35 years. He loved his job, served proudly and never wavered when he was called for duty. The devastating events that occurred on September 11, 2001 did not change his determination or deep responsibility he felt towards his co-workers and people of New York City. John worked tirelessly (as well as many other members of the FDNY) during the rescue and recovery effort. He spent over 6 straight months at the World Trade Center site. My husband unfortunately passed away on October 26, 2009. After working 35 years for the NYC Fire Department, he was only able to enjoy his retirement for 5 short years.

John was always physically active during both his career and during retirement. During his career, John was instrumental in revitalizing the FDNY Boxing team. He, trained, boxed and sparred with the team as well as the countless hours behind the scenes organizing and planning upcoming events. His commitment to being physically fit continued into his retirement. He always found time to walk daily and ride his bicycle over 50 miles per week. John was rarely sick, never spent one day in a hospital and never, ever complained.

His life changed dramatically in January 2009 when he was diagnosed with Mesothelioma. John went for his annual FDNY World Trade Center Medical at the Bureau of Health Services. He was told by Fire Department doctors to follow up with further evaluation because of extreme irregularities in his left lung. John was never the same. He was now extremely fatigued during the day. He was no longer able to ride his bicycle. Although he fought to keep walking right into the latter stages of his illness, I know it was only out of his sheer grit and determination to prove to himself (and me) that if he went down, he would go down fighting. I mentioned my husband never, ever complained. After serving 2 years in Vietnam as a paratrooper in the Long Range Reconnaissance Patrol, I guess nothing else he would encounter in his life would compare. However, this illness from 9/11 was too much for him to bear. He spent his days curled up on the couch, sometimes in too much pain to even feed himself. His day mostly consisted of moving from place to place in the house, trying to find a position that would alleviate even some of his pain. He lost over 80 lbs of body weight. John went from a physically fit solid man to a thin, frail, dying man. We all know the effects of lung cancer are not pretty. Nobody should have to watch another family member waste away knowing that there is no hope of recovery, only death. My husband John is survived by myself, two daughters, Mary and Jo-Ann, his son John (who is also a Battalion Chief in the FDNY that I fear may also become physically disabled from his exposure during 9/11), his daughter in law, Janine, and his granddaughter of 15 months, Tara. He is thought about and missed every day.

I write this letter to you, Senator Gillibrand, so that other members of the FDNY do not need to suffer the way my family already has. I know that if my husband had the choice, he would not have changed one thing he did during and after the events of 9/11. He served, he did what was expected of him, and would not have hesitated if called to do it again. That's the way he was. I sincerely request that you help pass the "9/11 Health and Compensation Act" to protect those who have sworn to protect others. Thank you.

Sincerely,

MARY C. VAUGHAN.

WORLD TRADE CENTER RESIDENTS COALITION (WTCRC),  

Hon. Tom Harkin, Chairman,  
Committee on Health, Education, Labor, and Pensions (HELP),  
U.S. Senate,  
Washington, DC 20510.

Hon. Michael Enzi, Ranking Member,  
Committee on Health, Education, Labor, and Pensions (HELP),  
U.S. Senate,  
Washington, DC 20510.

Dear Chairman Harkin and Ranking Member Enzi, we the WTCRC, fully support S.1334, the “James Zadroga 9/11 Health and Compensation Act of 2009” that would provide medical monitoring, treatment and compensation
for responders and survivors whose health has been impacted by the 2001 terrorist attack on the World Trade Center (WTC) and its aftermath.

We strongly encourage you to pass this bill out of the Health, Education, Labor, and Pension Committee considering H.R. 847 bill that was passed by the House of Representatives Judiciary and Energy and Commerce committees. The Zadroga Act would guarantee 10 years of Federal funding to specialized medical programs to care for all whose health was harmed as a result of the WTC disaster.

9/11 was an attack on our Nation, targeting civilians. Along with 9/11 responders, people who lived, worked, or attended schools in Lower Manhattan have become ill as a result of the Federal Government’s false assurances that “the air is safe” and its failure to provide proper environmental cleanup. We believe that the Federal Government has a responsibility to fund WTC specialized care to help all of those affected. It is the right and honorable thing to do!

WTCRC—World Trade Center Residents Coalition is a grass roots non-sectarian humanitarian organization founded in the aftermath of 9/11 in Lower Manhattan. Our umbrella organization dealt with issues of access, landlords, cleanup and now health and downtown rebuilding. We reach out via our list server to around 30,000 downtown Manhattan residents directly and through various tenant associations, condominium boards and other resident groups. We collaborate on community events and work closely with downtown environmental activist groups and 9/11 health-related groups. We strive to help protect the community responders and non-responders from contaminants, campaigning for proper 9/11 cleanup and now residents, workers and student monitoring, on-going studies and treatment programs.

We advocate for 9/11 medical centers of excellence where exposure data can be collected and the best treatment regimes administered. We strongly support cleanup and recovery worker issues and the families of our bravest, who laid down their lives to save others. We embody the spirit of giving back, protecting our community, and also helping others less fortunate.

WTCRC is a founding member organization of the WTC Environmental Health Center Community Advisory Committee (WTC EHC CAC) and its members are active participants. We are also active members of the Community Advisory Board to the WTC Health Registry, and provide residual input and guidance into the Department of Health’s In-Depth Respiratory Study and research of WTC Health Effects based on the Health Registry cohort. Invited onto the CAC, which advises on the implementation of the World Trade Center health program for residents, we actively supported the campaign to expand the Bellevue WTC Program to two additional sites. Dr. Reibman’s team has been key, from the beginning they have been the only experts researching, documenting and treating the complex interactions of 9/11 health effects in the downtown resident population. Before the creation of the WTC EHC, residents with no or limited access to private health care had nowhere else to turn to for help. Even those who had access to good private health care were misdiagnosed and did not receive appropriate treatment.

Many residents reported back to us that their physicians baffled by their complex symptoms, did not make the 9/11 connection. There are residents who got sick after 9/11 either caught in the dust cloud, returning to contaminated apartments breathing the stench from the burning fires or the dusty air, while the recovery program was in full swing. Some of those got sick months or even years later from chronic indoor exposures, the EPA clean and test programs were wholly inadequate! Many felt like lab rats being fed a toxic daily gumbo of contaminants, while government agencies that should have protected us stated the air was safe! Some residents are still in denial about their health issues, some avoid discussing their WTC-related symptoms with their doctors fearful that they might get labeled by their insurance carriers as 9/11 liabilities. All affected need to know there is somewhere they can go to get treated with the most knowledgeable physicians in the field, safe from reprisals. They need and are entitled to the same quality of treatment that is offered at the Mount Sinai Center—the WTC EHC provides this!

The WTC EHC has our full support to treat the 9/11 unmet health needs in our communities. The WTC Clinics are trusted 9/11 centers of excellence from their long-standing community relationships. The current patient population of >4,700 is growing on a daily basis and is increasing as the advertising and outreach program continues. WTC EHC needs to be federally funded to continue to track and treat their current patients and to allow service expansion to include future new patients and treatment specialties as the need arises. Regardless of patients ability to pay, the best expert medical and mental health should be offered for 9/11-exposed responders, residents, students and workers who were victims of this horrific terrorist attack on our Nation. The WTC EHC, where an established treatment program provides all services under one roof, where patients are tracked through the program
and treatment protocols are revised as needed, we believe is the most cost-effective means to provide the best care now and in the future.

We are a very diverse community united in our commitment to this legislation. We call on Congress 9 years after the attacks to make a just Federal health response to 9/11 a reality. Let's do the right thing. Let's provide a brighter future for all those that were exposed on 9/11. The horrific events of 9/11 bonded us together—we will never forget, we stand tall, risen from the ashes, hopeful but guarded about a brighter future. In these very difficult times there are funding requirements that just have to be met!

We would like to thank you for your continued tireless support of the 9/11 victims health needs.

Yours faithfully,

CRAIG HALL,
WTCRC President.

[Whereupon, at 4:13 p.m., the hearing was adjourned.]