ANSWERING THE CALL: MEDICAL MONITORING AND TREATMENT OF 9/11 HEALTH EFFECTS

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OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. The meeting is called to order. The hearing today is on “Answering the Call: Medical Monitoring and Treatment of 9/11 Health Effects,” and I now recognize myself for an opening statement.

Today the subcommittee is meeting to discuss an issue of great importance, medical monitoring treatment of 9/11 health effects, which is the first time that the subcommittee is meeting to hear about these issues. We had originally intended to hold this hearing last Tuesday on the anniversary of the 9/11 attacks, but due to the funeral of our colleague, Paul Gillmor, the hearing was postponed until today.

Now, it is hard for me to believe that it has been 6 years since the attack on the World Trade Center and the Pentagon. It was an event that affected our country deeply and continues to have an impact on all of us, especially those who participated in the rescue, recovery, and restoration effort.

It is important that, as a Nation, we recognize the extraordinary sacrifice of everyone who responded to the terrorist attacks and worked tirelessly in the hours, days, weeks, and months after 9/11 to help those in need and to begin clearing the site of the tragedy.

From first responders, to iron workers, to crisis counselors, Americans from across the country put their lives on hold and rushed to the site of the World Trade Center on the day of the attack and stayed for months after in order to assist with the recovery effort. I happened to be at this site the Friday after President
Bush visited, and I was amazed to see firefighters from all over. As we were listening to the President speak, I was standing next to a fire truck from Hialeah, FL, with all the firefighters from Hialeah. And I asked them how the truck got there, and they looked at me like I was an idiot and said well, of course, we drove it up from Florida. And to me, it was just amazing to see the turnout and the fact that so many people came.

It's been estimated that more than 40,000 people responded to the crisis and participated in rescue, recovery, clean up, or restoration of essential services. And we are clearly indebted to them for their efforts.

Now, 6 years later these brave men and women who helped lift our Nation up from one of its darkest hours are now in need of our help. Many of those who responded to the attacks on the World Trade Center have since been plagued by health problems. One of every eight responders has experienced symptoms of post-traumatic stress. They have developed asthma at 12 times the rate of other Americans. Nearly one in five has a respiratory or gastrointestinal illness as a result of their exposure to toxins.

I have seen the impact firsthand. More than 1,000 responders are currently receiving health services through the monitoring and treatment clinic in my home district in Piscataway, NJ. Furthermore, residents, workers, and students who were in the area at the time of the attack are also experiencing high rates of health problems. And I want to thank you, Mr. Engel, Mrs. Maloney, Mr. Nadler, Mr. Fossella.

One of the things that the New Yorkers, I think, have been particularly adept at pointing out is that not only do we need to be concerned about first responders, but the people who lived and worked at the site, of which there may be as many as 400,000 or more from what I understand who also may have been impacted. And we will hear about that today.

Unfortunately, for too long the concerns of the first responders have been ignored here in Washington, and that has to change. As chairman of this subcommittee, I am not going to let these issues be ignored any longer. I want to be sure that there are accessible health programs in place for responders and adequate funding for those programs. We are here today to ensure that those who are suffering from health problems have access to the monitoring and treatment services they are entitled to as a result of the conditions they endured at Ground Zero.

And I think we should be honest about the task in front of us. It is a big undertaking for us to ensure that adequate care is provided for those in need, but that is a responsibility we must fulfill. The cost of screening for and treating these illnesses is estimated at $8,000 annually per person, and it is expected to increase in the coming years. This cost should not be borne by the thousands of responders, workers, and health professionals who risked their health to do their job.

And, of course, it is not just our job in Congress. The Bush administration has an important role to play here as well. Unfortunately, for the past 6 years, the administration has been dragging its feet, in my opinion, on this issue. It is sad to say, but I think that many of those who came to our aid in the days after 9/11 feel
as though Congress and the President have failed to live up to the promises that have been made over the last couple years to not leave them behind.

And this is the first year that the administration proposed funding in its annual budget in the amount of $25 million for the healthcare needs of World Trade Center responders. The House does not think that was enough, and we doubled the President’s request to $50 million in our budget.

The administration said the initial $25 million was only the beginning and that it would propose additional funds once it had a comprehensive plan in place. That comprehensive plan has yet to appear, but in a draft plan developed by the administration, they acknowledge that the current cost estimate for the program is nearly $200 million a year and that it is possible the cost could reach $712 million annually based on what they gave us.

And that’s why I joined with members of the New York congressional delegation and sent a letter to the Health and Human Services Secretary Mike Leavitt 2 weeks ago asking that they finalize their plans immediately. We need a comprehensive plan in place so that we can help treat and monitor all of the people whose health was impacted by 9/11. We also sent another letter to new OMB Director Jim Nussle, asking that he live up to his predecessor’s promises and request the necessary funds to continue the process of helping these workers. And I would ask that these letters be made part of today’s hearing record.

In conclusion, today we will be hearing from a variety of people about the medical monitoring and treatment of health effects caused by the exposure to traumatic events and harmful materials. It is my hope that this hearing will shed some light on the problem and help us begin rectifying the situation. My idea is that we develop a legislative proposal that all of us can support. I know that the New York delegation put together different proposals. Obviously we want to look at those and we do need to develop legislation in my opinion so that the people who had their health affected by the 9/11 attacks are monitored and treated.

And again I just wanted to thank the witnesses. I know many people have been trying to have this hearing for some time. Unfortunately our schedule with S-CHIP and PDUFA and everything else has made it difficult for us to do it until now. But I do want to thank all of you, and now I recognize Mr. Deal for his opening statement.

OPENING STATEMENT OF HON. NATHAN DEAL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF GEORGIA

Mr. Deal. Thank you, Mr. Chairman. First of all, I would like to ask unanimous consent that Mr. Fossella, a member of the full committee, be allowed to participate in this hearing today.

Mr. Pallone. So ordered.

Mr. Deal. And thank all of the witnesses who will testify and members of the subcommittee for their presence. Certainly the tragedy of 9/11 and the aftermath of that event are going to be with us for a very long time, and today we simply deal with one of those manifestations of that aftershock.
While some would criticize the administration for not having done enough, in reality, the reaction and the outpouring of Federal dollars for this event has been unprecedented in American history. Truly the event itself, however, was unprecedented in American history, and none of us wish to diminish that.

The question is whether or not we have the information upon to make good decisions as to where we go from this point forward. One of the real concerns that I have is in the GAO report. It finds that much of the information relating to the health effects are unreliable, and the comments that despite the efforts of HHS to require the necessary information that much of that information is still incomplete. So to those who will testify today who are in a position to make that information available to us and to the administration, I would certainly call upon them to use their best efforts to do that.

All of us are reminded frequently of this event. In fact, last week when I was being interviewed by reporter from my local newspaper, in the conversation, he reminded me that he was at Ground Zero immediately following the event as a part of a voluntary group from my church who came to assist with the efforts of helping people in their time of need. So our country has reached out. The question is are we now following up on those efforts. And thank you, Mr. Chairman, for having the hearing so we can make those inquiries here today. I yield back.

Mr. Pallone. I recognize Mr. Engel who, like the other members of the New York delegation, has been very much out front on this issue. Thank you, Eliot.

OPENING STATEMENT OF HON. ELIOT L. ENGEL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Engel. Thank you, Mr. Chairman. I want to thank you for holding this hearing. You and I had discussed this several months ago, and I requested this hearing and said that I thought it would be a good idea. And you responded very positively then, and I thank you for the hearing now.

Six years, Mr. Chairman, as you pointed out, have passed since terrorism struck at the root of our Nation’s soil on September 11, 2001. As devastating as that day was, there are few days I’ve been more proud to be an American than on 9/11. Now, within minutes of crashes into the Twin Towers, New York’s first responders mobilized to save those trapped in the World Trade Center. First responders putting themselves in unspeakable danger, and too many lost their lives that day.

Within days, as you pointed out, Mr. Chairman, over 40,000 responders across the Nation descended upon Ground Zero to do anything possible to help with the rescue, recovery and cleanup. I remember those bittersweet days. I was in New York City when this happened. I was born and bred there, and remember seeing Americans lined up around blocks to donate blood. I remember the chaos as no one knew quite what to do, only that they had to do something, anything to help our Nation rise up from assault by the terrorists.
And the past 6 years have not been kind to many, so many of the first responders who put themselves in harm’s way. It is estimated that up to 400,000 people in the World Trade Center area on 9/11 were exposed to extremely toxic environmental hazards, including asbestos, particulate matter, and smoke. Years later, this exposure has left a significant number of first responders with severe respiratory ailments including asthma at a rate that is 12 times the normal rate of adult onset asthma.

Also common are mental health problems including PTSD and depression. This has all been well documented in scientific, peer-reviewed published work regarding the long term health effects of 9/11 by Mount Sinai Hospital, the Fire Department of the City of New York, and the World Trade Center registry. People who have been exposed are not only first responders but people who live in the area. And frankly, I think the behavior on the part of the Federal officials borders on the criminality when we in New York were assured that the air quality was OK and we were assured that we could go to the World Trade Center area and were assured by Christine Todd Whitman that we had nothing to fear. That all turned out to be false.

While these illnesses should sadden all of us, I am frankly outraged that 6 years later our Nation has really failed to provide the first responders with anything more than a fragmented and unreliable health care monitoring and treatment program that forces those who fearlessly volunteered for our country to fight within a myriad of bureaucracy to receive care that should be a given, and yet it is a struggle.

The nonpartisan Government Accountability Office has criticized the U.S. Department of Health and Human Services for its failure to provide consistent availability of services to Federal responders through the World Trade Center Federal Responder Screening Program. Despite starting in 2003, service stopped between March 2004 and December 2005. It resumed again in March 2006, but suspended key services between April 2006 and March 2007. It is truly shameful.

GAO has also noted that those brave volunteers and first responders that came to help New York from other parts of the country have not had regular access to screening and monitoring. After years of starts and stops, there are only 10 clinics in seven States where responders can receive services. It is just unconscionable. We can and must do better. I was proud to join with my New York City colleagues, lead by Representatives Maloney, Nadler, and Fossella, who is here with us this morning, and so many others last night in introducing the 9/11 Health and Compensation Act.

This comprehensive bill would ensure that everyone exposed to the Ground Zero toxins has a right to be medically monitored. And all that are sick have a right to treatment. It would also rightfully provide compensation for loss by reopening the 9/11 Compensation Fund. No more fragmented health care. No more excuses. We must and shall do what is right.

In conclusion, let me just say I still feel great sorrow in our remembrance of the tragedy of 9/11 and obviously will never forget what happened that day. But we must look forward and right the wrongs our Nation has perpetuated against our own heroes and
provide them with the care and compensation they so desperately need and deserve.

Mr. Chairman, I urge all Americans to pause and reflect on the tremendous loss of life that day and how so many sacrificed so much for their fellow Americans and make sure that our future actions are driven by these memories, and also remember that potentially still hundreds of thousands of people are being exposed to these toxic substances every day. And the Federal Government cannot wish that away. We need to respond, and we need to respond now. Thank you, Mr. Chairman.

Mr. Pallone. Thank you, Mr. Engel. Our next opening statement is from Mr. Ferguson. Again we have two New Jersey people here today, one from each party, and I constantly remind everyone that we in our State, had a lot of people that died and were seriously wounded, and a lot of first responders as well. And we also have one of the treatment centers here. One of the witnesses today is from one of the monitoring treatment centers. So again we obviously are very concerned about this as well, in our State. So, Mr. Ferguson.

OPENING STATEMENT OF HON. MIKE FERGUSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. Ferguson. Thank you, Mr. Chairman. Thank you very much for holding this meeting. I want to thank Mr. Deal as well and member of the subcommittee and certainly the witnesses for being here today to address this very important issue regarding medical monitoring and treatment of September 11, 2001 health effects on residents and first responders.

Addressing this issue is long overdue, and I am glad that we are giving it attention that it really does deserve. And the more that time goes by, the more we are learning about the after effects and the health effects of those who selflessly went to attend to this disaster. I am sure that we are going to be able to gain some valuable information from treatments and health effects from some of our witnesses today. I am pleased that we are having this hearing, and my hope is that the subcommittee will be able to use some of this information to help address some of the needs of the families who are suffering.

In addition, we need to find out what went wrong with some of the information and some of the air quality information surrounding lower Manhattan and why better information wasn’t made available in a more timely way. Of course, as the chairman referenced, this issue hits very close to home for many of us on the subcommittee. I know Mr. Fossella is here as well.

In our district, we lost 81 people on the attacks of September 11, 2001. And to save others, approximately 40,000 first responders answered the call, including many from New Jersey on September 11 and the weeks and months that followed, helping to try and find survivors. We have firefighters and police officers and construction workers and utility workers, all folks who were working tirelessly day and night on the pile in the hopes of finding one more survivor. These men and women didn’t think twice about running into burning buildings or climbing through rubble to help save the lives of
others, and we owe them the very best information that we have to assist with the health challenges that they are now facing because of those sacrifices.

Dr. David Present, the chief medical officer for New York City’s fire department has been studying the health effects on firefighters since September 11, 2001. In a recent interview with Katie Couric, he said this about the health effects of breathing the air at Ground Zero. I quote, “the biggest problem was that it was pulverized building materials that wind up having a very high alkalinity, almost like lye, all right, or Drano, that when you inhale or swallow it, it’s burning your entire nose and airway and stomach.”

In a study that was published in many of the leading medical journals, Dr. Present concludes that working on the pile for an extended period of time decreased an individual’s lung function by an average of 12 years. Six years later, those same heroes who risked their lives need our help. And we have to be there to answer their call. We need to make every effort to find out what is causing their illnesses and what can be done to treat them.

There is no reason that with today’s medical technology that we shouldn’t be able to get some proper treatment to those who made these sacrifices. In the future, we have to work to ensure that our first responders are not put in further unnecessary jeopardy than they are already placing themselves by their own choice. Our first responders were heroes on September 11, and we owe them our very best efforts today. Mr. Chairman, I want to thank you again for holding this hearing. I yield back.

Mr. Pallone. Thank you. The gentlewoman from Tennessee.

OPENING STATEMENT OF HON. MARSHA BLACKBURN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TENNESSEE

Mrs. Blackburn. Thank you, Mr. Chairman, and I thank you and Mr. Deal for holding the hearing. And I also thank our members from both sides of the aisle who have been so involved with this issue and continuing to keep the pressure on with this issue. I think that we all know what transpired September 11, and we know that we have to be very vigilant going forward in how we protect our Nation and also how we protect those who are going to respond to any tragedy that we do have.

There are lots of lessons learned, and, as you’ve heard in the opening statements, there is attention to what should be those lessons learned from members of this panel. And, as my colleague from New Jersey just stated, you had approximately 400,000 people that were exposed to the environmental hazards, the asbestos, the smoke, the particulates, 40,000 first responders that were there on that day.

Now, there is very little solid, quantifiable data from which we can operate as we look at the environmental factors and what the first responders were exposed to during those cleanups. What we do know is the damage that is there. Its detrimental physical effects, chronic respiratory, gastrointestinal conditions, anxiety, and other mental health problems. And these have severely impacted the lives of those that were at Ground Zero.
For example, the city health department reports rescue and recovery workers now develop asthma at a rate 12 times that found in the general population. Among children that were exposed to the toxins, 53 percent reported breathing problems in the 3 years after 9/11. New York City officials estimate 120,000 workers and volunteers and 550,000 other people may or may eventually need treatment.

And I do commend the State of New York and the U.S. Department of Health and Human Services for establishing 9/11 programs and resources to treat, track, and provide information about scientific research and services for people who have developed health problems as a result of the attack.

However, the GAO does state that the Federal Government has had difficulty ensuring uninterrupted availability of services for our Ground Zero responders. We have to be certain that Federal and State bureaucracy does not prevent responders from receiving the medical treatment and the tracking that is necessary for meeting the demands of their illnesses.

I look forward to hearing from our witnesses today. I welcome our witnesses and thank them for their time in preparing the testimony for us. And again, Mr. Chairman, I thank you and the Members who have been so diligent in continuing to keep the pressure on about the issue, and I yield back.

OPENING STATEMENT OF HON. VITO FOSSELLA, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Fossella. Well, thank you very much, Mr. Chairman and Mr. Deal, and thank you for allowing me to participate this morning on this panel. My colleagues, Mr. Ferguson, Mrs. Blackburn. Of course, Eliot Engel has been a true champion. Indeed, I think in Staten Island alone, we lost 78 fireman on that day. Twenty-two percent of all firefighters and more than 240 people were killed, probably the heaviest toll of any county per capita in the country.

And we still see the effects 6 years later. There is the old saying that time heals all wounds, and I think in this case, time exposes more wounds. And I thank you at the outset, Mr. Chairman, for shedding light on this issue, for ensuring that we never forget those who not just sacrificed on those days, but who continue to suffer. And I thank those in Congress and the executive branch for helping New York to rebuild the city, but I think there’s a fundamental obligation to call upon our Federal Government to help people rebuild their lives.

And at the outset, let me thank some individuals. I thank the panel, Mr. Howard. We will also hear from Deputy Mayor Edward Skyler, who is here on behalf of the mayor, who has truly been a good partner in helping us get the resources we need and, by extension, the fire department and the police department and Mt. Sinai
and all those who are trying to ensure that New York doesn’t shoulder disproportionately the burden here.

Because we have to remember September 11 wasn’t just a New York problem or a New York/New Jersey problem. It was an American problem. It was an attack on America, and I think America has a responsibility to respond in kind.

I would like to thank my colleagues in the New York delegation, Mr. Nadler, but especially Mrs. Carolyn Maloney who has really been spearheading these efforts to date. People in the labor community in particular, Dennis Hughes in the AFL/CIO who has helped us coordinate and shepherd this legislation through.

And I remind everyone that this is why we place so much emphasis on preventing another terrorist attack because one more exorbitant cost of terrorism is the individuals that we continue to have to help and treat.

Again the message is never forgetting. We know so many successes, but the successes have been measured in small steps rather than giant leaps as critical needs continue to be unmet after 6 years. We have encountered obstacles along the way, but as mentioned with Congresswoman Maloney, we have restored $125 million. Of that, $75 million was dedicated for treatment, the first ever Federal dollars to be directed for that purpose. We were able to get Dr. Howard to help coordinate and oversee the Federal response. And in addition, as Mr. Pallone mentioned, we included $50 million for the federally funded 9/11 health clinics in the Labor-HHS appropriations bill.

In addition, as was mentioned by Mr. Engel, we introduced legislation last night that ensures that everyone exposed to the Ground Zero toxins has a right to be medically monitored, builds on the Center of Excellence, and expands care to the entire exposed community and provides compensation for loss by reopening the 9/11 Victims’ Compensation Fund.

And for those, Mr. Deal and Mrs. Blackburn, also asked some, I think, very pointed questions of where is the information, what do we need? I can tell you, as someone who lives in Staten Island and sees young guys in particular who used to run a 6-minute mile, 7-minute mile, now have difficulty walking up a flight of steps. I could point to those individuals with specificity, but the data is just overwhelming, whether it is from Mt. Sinai or the fire department, that this is a major problem, a major undertaking that demands a Federal response. And I think the Federal Government has an obligation to be at the table with us helping to coordinate, shepherd, and provide for long-term plan for all those who are affected.

With that, Mr. Chairman, I thank you very much for holding this hearing. I yield back.

Mr. Pallone. Ranking member, Mr. Barton, for an opening statement.

OPENING STATEMENT OF HON. JOE BARTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. Barton. Thank you, Chairman Pallone. I was downstairs at the Oversight Subcommittee hearing on monitors for nuclear equipment coming into this country. I appreciate you holding this hear-
ing today. I appreciate my colleagues on both sides of the aisle from New York being involved with it.

Before I talk about the specific hearing, I think it would be appropriate that we all contemplate our dear colleague Paul Gillmor who passed away several weeks ago. Paul was a distinguished member of this committee, and was chairman of the Environment and Hazardous Material Subcommittee in the last Congress. He took a leave of absence from the committee this Congress so that some of the more junior members of the minority side wouldn’t have to be bumped off of the committee. So we are going to miss him, and we wish the best to his family in their time of sorrow.

As far as the hearing today, I think it is important. We know what happened on 9/11/2001. Firefighters, police officers, ambulance crews, and all of the other first responders were exposed to health hazards because of the attacks on 9/11.

Federal funding has been provided to Government agencies and to private organizations to screen and monitor responders for illnesses caused by that catastrophe. This hearing is going to provide some oversight for those programs. Many who responded to the disaster and then needed help themselves have been beneficiaries of various worker compensation, health insurance, and other Government coverage.

Some say that what has been done is not enough. I don’t really know where to draw the line. I don’t know whether the entities that are legally obligated to provide or pay for health care monitoring or treatment have done all that they could to help the victims of 9/11.

I know that we have appropriated Federal money and that we will continue to do so. I know that Federal dollars have been spent for the responders who responded on 9/11. Again I’m not sure exactly the effectiveness of those programs and the legality of some of those programs and what needs to be done. So I look forward to the hearing.

Before I yield back, Mr. Chairman, I do think that, since this is the Health Subcommittee, we should mention something that has yet to be done, and that is a reauthorization of our S-CHIP program. Members on both sides of the aisle realize the importance of S-CHIP. I am introducing a bill today to authorize a clean bill at existing levels with a slight increase for inflation until we can work out the details of a new S-CHIP program. I would hope that my friends on the majority side would join us in reauthorizing for a short term the existing S-CHIP program because, as we all know, if we don’t do something in the next 2 weeks, the program legally expires on September 30, the end of this month.

So while we wrangle over the details of any new improvements or expansions in the program, if any, we at least ought to keep the existing program going. And I would hope that we could move that extension fairly quickly while we tackle the bigger issue.

If the Democratic leadership in the House wants to accept the Senate bill, I do hope that this subcommittee would hold a hearing on that bill, a legislative hearing, where it would be open. We could look at the details and then have a markup subsequent to that so that we could actually make some changes in the bill before it went to the floor.
With that, Mr. Chairman, I yield back.

Mr. PALLONE. Thank you, Mr. Barton. I appreciate your ongoing interest in S-CHIP, and I am about S-CHIP-ped out today. So I am not going to comment any further. The gentleman from Arizona.

OPENING STATEMENT OF HON. JOHN B. SHADEGG, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ARIZONA

Mr. SHADEGG. Thank you, Mr. Chairman, and with your permission, I will insert my written statement in the record. I simply want to make some brief comments which may be a little bit different than others have made. I want to commend you for holding this hearing.

And I want to recognize that, while the focus today is the technical issue of the care, treatment, and monitoring of the first responders who have been victimized, I think it is important to remind everyone at the dais and in the audience and elsewhere that we are talking about the victims of a vicious attack on America by radical Islamists who seek to kill us and who are out there and who want to keep going in their efforts who make their designs clear every day.

That the people who are suffering—we all kind of internalize the numbers of those who were killed that day, and then we can extrapolate from that all the families that were affected by that attack. But as my colleague from New York Mr. Fossella pointed out we don't really know the number of victims. The issue we are looking at today demonstrates there are more victims being manifest every day by this attack on America.

And I think it is important for those watching this hearing who are considering this effort to recognize that this is not a health problem, though it is a Health Subcommittee. This is the Nation's response to an attack by its enemies. And we can all be critical and say we should have responded this way or that way, or we should not have responded this way or that way.

But at a minimum, I would hope that we can all come to agreement that when this Nation is attacked and there are people who suffer, whether it is the loss of life and the impact on the families, or whether it is ongoing health problems that manifest themselves months later or years later, that is something we need to be concerned about as a nation. That is a cost of failing to do what is necessary to defend ourselves. And we have an obligation to each of the people who are suffering as a result of those attacks today because that is a part of our national defense. That is a part of us standing together as a nation.

I will just conclude by pointing out when the 9/11 attacks occurred, my daughter was in college. She now works on the Senate side, and I talked to her a few days after the event. And she said that she and many of her friends in college were going down to the local blood bank to donate blood for the victims. That is the spirit that we had as a nation when the attacks occurred. That is the spirit which we should have or try to have as a nation in responding or figuring out the best way to respond to those who hate us and want to kill us. And that is certainly the spirit we should bring to this hearing and to doing the right thing by the people who are being victimized by this attack now years later.
And with that, I yield.

Mr. PALLONE. Thank you. Thank you for those remarks. We are done now with our opening statements, and any other statements will be accepted for the record at this time.

[The prepared statements follow:]

PREPARED STATEMENT OF HON. JOHN D. DINGELL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. Chairman, thank you for holding this important hearing today. I also want to thank the witnesses who are here to discuss the health effects of the World Trade Center collapse on first responders and workers.

One week ago marked the sixth anniversary of the attacks against our Nation. Nearly 3,000 people perished as a result of the attacks, and many who participated in the clean up, rescue, and recovery efforts continue to suffer from lingering physical and mental health problems directly linked to their work in downtown New York City. While Congress has taken some initial actions to deal with this issue, adequate screening, treatment, and monitoring services for all of those brave men and women throughout the Nation who came to New York to work in the cleanup has been lacking.

It is incumbent on our Nation not to forget these responders who placed their own well-being aside to help others. The administration’s fiscal year 2008 budget request of $25 million for the current World Trade Center responder programs fell far short of the amount appropriated in either 2006 or 2007. Over the long term, we must find a way to care for our heroes who answered the call and subsequently suffered severe health problems. In the short term, we must provide enough Federal resources to sustain the current monitoring, screening, and treatment programs in New York.

I would note with particular concern the intermittent services provided by the World Trade Center Federal Responder Screening Program. The program, now run by the Federal Occupational Health Services, provides Federal responders to the attacks with screening and referrals to health clinics. However, the program suspended examinations from March 2004 to December 2005, and again from January 2007 to March 2007. This program encompasses Federal employees all across the country that came to New York in response to the attacks. As new health 9/11 effects continue to emerge from latent conditions, it is especially important that all Federal employees who were exposed to the environmental hazards resulting from the WTC collapse be screened for problems.

Another area of concern is the failure to screen and monitor those non-Federal workers who reside outside of New York City. While the National Institute for Occupational Safety and Health has made two separate attempts to contract with entities to provide service across the country, only a very limited number of places in the country have services.

It is imperative that as Congress continues to work on these issues, we not forget the service our first responders and workers provided in those dark days following September 11.

I want to thank Chairman Pallone for holding this important hearing, and I look forward to receiving the testimony from our witnesses.

PREPARED STATEMENT OF HON. HENRY A. WAXMAN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Chairman, thank you for holding this important hearing today.

Last week the Nation marked the sixth anniversary of the terrorist attacks of September 11. As a nation, we mourned all those people who lost their lives on that day in the attacks on the World Trade Center and the Pentagon, and the passengers who died on United Airlines flight 93 in Shanksville, Pennsylvania.

But we also remember those people who continue to suffer from the attack on the World Trade Center—the men and women from all over the country who came to lower Manhattan to help clear the debris and to rebuild the site. Last week, Chairman Towns, chairman of the Subcommittee on Government Management, Organization, and Procurement of the Oversight Committee, held his third hearing on the impact of 9/11 on New York residents and first responders. We have also had a number of hearings over the years in the National Security Subcommittee of the Oversight Committee on the health effects of the 9/11 attacks.
We know from these hearings that Congress needs to craft a long-term solution to the problem of how we will identify, treat, and compensate those people who are suffering from 9/11-related illnesses. The current patchwork approach is clearly inadequate. That is why I am pleased that we are having a hearing today in this subcommittee. This is the subcommittee with legislative jurisdiction over the care of the first responders and others who continue to suffer because of the 9/11 attacks. The involvement of this subcommittee is critical to moving forward on this important issue.

I would like to commend my colleagues from New York, Representatives Maloney, Nadler, Fossella, who have worked together, across party lines, to develop a comprehensive approach to monitoring, treating, and compensating people who were exposed to the potentially toxic effects of the World Trade Center site. I look forward to working with these members and this subcommittee to make sure that all of the 9/11 victims are taken care of.

I thank the witnesses for coming today.

PREPARED STATEMENT OF HON. ANNA G. ESHTOO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Chairman Pallone, thank you for holding today's hearing on the Federal response to the health problems faced by first responders, construction workers, residents, and others living and working at or near the World Trade Center site following the September 11, 2001 attacks on our country.

In the haste to respond to the destruction of the World Trade Center buildings, the impact on public health was underestimated and diminished.

In the early days after the attacks, the Federal Government failed to provide the public with sufficient warnings about potential risks. After the collapse of the two World Trade Center towers, the EPA told the public in a September 18, 2001 announcement that the air was “safe” to breathe. The EPA Inspector General later concluded in an August 2003 report that “[EPA] did not have sufficient data and analyses to make such a blanket statement.” The IG report also said, “The White House Council on Environmental Quality influenced, through the collaborative process, the information that EPA communicated to the public through its early press releases when it convinced EPA to add reassuring statements and delete cautionary ones.”

Regrettably, as the GAO has reported, there have been additional missteps in the operation of federally-supported programs that monitor 9/11 related health problems and treat victims.

In one case, a screening program was suspended for 5 months earlier this year when there was a change in the agency overseeing the WTC Federal Responder Screening Program. Diagnostic services under the same program were suspended for 11 months because of a contracting problem.

Finally, the GAO notes that affected individuals living outside the New York metropolitan area have found it difficult if not impossible to participate in screening and monitoring programs due to a lack of nearby providers participating in the program. Getting treatment has been even more challenging.

Although my congressional district is 3,000 miles away from Ground Zero, this aspect of the public health aftermath of the 9/11 attacks has affected some of my constituents.

The Urban Search and Rescue (USAR) team based in Menlo Park, California, was one of many to respond in the days after September 11th. Although members of the team were in New York for a relatively short time compared to others who worked on “the Pile” some have experienced respiratory and other ailments in the ensuing years.

For my constituents and for other first responders from the around the country who answered the call after 9/11, I believe we need a new comprehensive framework that provides the screening and the treatment they deserve, similar to the legislation that my colleagues Representatives Maloney, Nadler, and Fossella have recently introduced.

Today, we’ll hear from the witnesses who are attempting to address the health issues that have emerged after 9/11. I look forward to hearing their thoughts on getting the services and care to those who need and deserve them.

Thank you, Mr. Chairman.
Thank you, Chairman Pallone and Ranking Member Deal.

As many have noted, our world changed forever 6 years ago, when our Nation was attacked. Thousands of innocent people died and our national security was shaken to the core. We will never forget those who lost their lives in New York, at the Pentagon, and on a Pennsylvania field. We will never forget the heroes—the first responders—who rushed to Ground Zero with no thought but to help with the recovery. In my State of Utah, the Salt Lake Urban Search and Rescue Team—also called Utah Task Force One—sent 62 people to New York City on September 18, 2001, to comb through the rubble of the World Trade Center. The team included specialized firefighters, search dogs and handlers, two physicians and several structural engineers. The Salt Lake City and Salt Lake County Fire Departments contributed, as well as the Rocky Mountain Rescue Dog organization. The Utah task force is one of 28 teams that participate in the national Urban Search and Rescue Response System. It’s impossible to honor the victims of 9/11 without also making a commitment to our first responders who run toward danger while others try to escape it.

Since the attacks, many rescue workers have reported an increase in illness as a result of exposure to toxic materials and debris, during their hours on the pile, amid the dust and soot. Many agency officials will provide testimony here today, confirming that we need to continue to examine the health exposure and work to make available physical and mental health screening programs, which should be available to all exposed first responders.

I also believe that Congress should continue to support critical programs that improve access to emergency medical care. For my part, I have introduced legislation to reauthorize the Emergency Medical Services for Children (EMSC) Program. This program is designed to improve emergency medical services for our children. For more than 20 years, the EMSC program has improved emergency care facilities that treat sick and injured children across this country. Through grants to States and to accredited medical schools, the EMSC program has driven “best practices” in the care provided to kids every day at the scene of an accident, en route to the hospital and in the E.R. and other critical care facilities. These efforts also translate into better care for children when natural or manmade disasters strike. When disaster strikes, we all want the best care possible for these small patients—I am working to preserve this program dedicated to improving emergency medical care for our children.

I look forward to the testimony today and with that, I yield back my time.

Thank you Mr. Chairman.

Mr. Pallone. We will now turn to our witnesses, and the first panel has one person, Dr. Howard. First of all, welcome. Dr. Howard is the director of the National Institute for Occupational Safety and Health with the U.S. Department of Health and Human Services. Let me mention that you may, in my discretion, submit additional brief and pertinent statements in writing for inclusion in the record after your comments. And I welcome you, and if you will begin your statement. Thank you, Doctor.

STATEMENT OF JOHN HOWARD, M.D., DIRECTOR, NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. Howard. Good morning, Mr. Chairman, and members of the subcommittee, and Mr. Fossella. I am pleased to report on the progress that has been made in addressing the health needs of World Trade Center responders and volunteers.

In 2002, the Department first funded medical screening for World Trade Center responders and volunteers. By 2004, medical evidence showed that periodic medical monitoring was indicated, and a monitoring program was added. In late 2006, treatment serv-
ices were added because a significant portion of the responders and volunteers were experiencing physical and mental health problems. Both monitoring and treatment services are provided to those responders and volunteers in the New York City/New Jersey metropolitan area by Centers of Clinical Excellence at a consortium of five medical centers in New York and New Jersey, coordinated by the Mount Sinai School of Medicine, and at a clinic center at the fire department of New York City.

These clinical centers have enrolled over 36,000 responders and volunteers in medical monitoring and have referred more than 7,600 of those responders for treatment of physical health ailments and nearly 5,000 for referral for mental health conditions. Even today, World Trade Center responders and volunteers are still coming forward to enroll in the federally funded monitoring and treatment program.

In addition, over 1,300 current Federal workers who responded have been medically screened by the Department’s Federal Occupational Health. And 700 nationwide responders have received an initial monitoring examination by contractors of the Mount Sinai Data Coordination Center. Just over 400 nationwide responders have received medical diagnosis and/or treatment from the Association of Occupational and Environmental Clinics supported by generous and continuing funding from the American Red Cross.

Finally, in collaboration with the New York City Department of Health and Mental Hygiene, the Department of Health and Human Services funds the World Trade Center health registry. The registry tracks the health of 71,000 responders, residents, office workers, students, and school staff, passersby, those in the area of the World Trade Center on September 11, 2001. The registry’s findings provide an important picture of the long-term consequences of September 11 on the health of not only those who responded and volunteered, but also on those living and working around the World Trade Center site.

Thank you, Mr. Chairman. I would be pleased to answer any of your questions.

[The prepared statement of Dr. Howard follows:]

STATEMENT OF JOHN HOWARD, M.D., M.P.H.

Good morning, Chairman Pallone and other distinguished members of the subcommittee. My name is John Howard, and I am the 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 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 subcommittee for holding this hearing and for your support of our efforts to assist those who were affected by 9/11. I am pleased to appear before you today to report on the progress we have 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.

Since February 2006, I have served as the HHS WTC Programs Coordinator. Secretary of Health and Human Services Michael O. Leavitt determined that there was a “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. Since receiving this assignment I have traveled to New York City (NYC) and
Albany, New York, to assess the status of the existing HHS programs addressing WTC health effects, and meet with those we serve. Participating in these dialogues has enabled me to better understand the needs of those affected, and the steps we can take to meet those needs. As the HHS WTC Programs Coordinator I work to coordinate the existing programs and ensure scientific reporting to provide a better understanding of the health effects arising from the WTC attack. Today, I will focus my remarks on the progress we’ve made toward these tasks.

**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).

In 2004, NIOSH established the national WTC Worker and Volunteer Medical Monitoring Program to continue baseline screening (initiated in 2002), and provide long-term medical monitoring for WTC responders. In fiscal year 2006, Congress appropriated $75 million to CDC to further support existing HHS WTC programs and provide screening, monitoring and medical treatment for responders. Since these funds were appropriated, NIOSH has established a coordinated WTC Responder Health Program to provide annual screenings, as well as diagnosis and treatment for WTC-related conditions (e.g. aerodigestive, musculoskeletal, and mental health) identified during monitoring exams. The WTC Responder Health Program consists of a consortium of clinical centers and data and coordination centers that provide patient tracking, standardized clinical and mental health screening, treatment, and patient data management.

To date, the WTC Responder Health Program has screened approximately 36,000 responders. The New York City Fire Department (FDNY) manages the clinical center that serves FDNY firefighters who worked at Ground Zero. As of July 31, 2007, FDNY had conducted 29,203 screenings, including 14,429 initial examinations and 14,774 follow-up examinations. The Mt. Sinai School of Medicine's Center for Occupational and Environmental Medicine coordinates a consortium of clinics that serve other response workers and volunteers who were active in the WTC rescue and recovery efforts. These clinics have conducted 21,088 initial examinations and 9,101 follow-up examinations. Of the 36,000 responders in the WTC Responder Health Program, 7,603 have received treatment for aerodigestive conditions, such as asthma, interstitial lung disease, chronic cough, and gastro-esophageal reflux, and 4,868 have been treated for mental health conditions.

In conjunction with these activities, CDC-NIOSH has funded the NYC Police Foundation’s Project COPE and the Police Organization Providing Peer Assistance 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 participating in the WTC Responder Health Program, which will enable us to better understand and treat the long-term effects of their WTC exposures.

**WTC Federal Responder Screening Program**

In fiscal year 2002, the HHS Office of Public Health Emergency Preparedness (OPHEP)—which is now the Office of the Assistant Secretary for Preparedness and Response (ASPR)—received $3.74 million through the Federal Emergency Management Agency (FEMA) to establish the WTC Federal Responder Screening Program to provide medical screening for all Federal employees who were involved in the rescue, recovery or clean up efforts. Current Federal employees in this program are screened by the HHS Federal Occupational Health (FOH), a service unit within HHS. FOH has clinics located in areas where large numbers of workers are employed. As of August 31, 2007, FOH had screened 1,331 Federal responders. In February 2006, CDC-NIOSH and OPHEP (now ASPR) signed a Memorandum of Understanding to monitor former Federal workers via the WTC Responder Health Program. Since then, former Federal workers have been enrolled in the WTC Responder Health Program and served by the Mt. Sinai Data and Coordination Center and national clinic partners.

**Nationwide Scope**

HHS is working with its partners to ensure that the benefits of all federally-funded programs are available to all responders, across the nation. Those responders who selflessly came to the rescue of NYC from throughout the country at the time of the WTC disaster should receive the same high quality monitoring and treatment as those who reside in the NYC Metropolitan Area. Enrollees in the WTC Responder Health Program who are not located in the NYC Metropolitan Area, receive mon-
itoring and treatment via a national network of clinics managed by QTC, Inc. and the Association of Occupational and Environmental Clinics (AOEC), respectively. To date, 698 responders outside of the NY Metropolitan Area have been screened by the WTC Responder Health Program.

Achieving such nationwide coverage for WTC responders is challenging; however, we are committed to serving all responders, regardless of their location or employment status. I am actively working with the medical directors of the WTC Health Program, the WTC Federal Responder Screening Program, QTC, Inc. and the AOEC to ensure that the services available to responders are uniform across programs.

**WTC Health Registry**

In addition to the WTC Responder Health Program, the Agency for Toxic Substances and Disease Registry (ATSDR) maintains the World Trade Center Health Registry. In 2003, ATSDR, in collaboration with the New York City Department of Health and Mental Hygiene (NYCDOHMH), established the WTC Health Registry to identify and track the long-term health effects of tens of thousands of residents, school children and workers (located in the vicinity of the WTC collapse) and those participating in the response effort who were the most directly exposed to smoke, dust, and debris resulting from the WTC collapse.

WTC Health Registry registrants will be interviewed periodically through the use of a comprehensive and confidential health survey to assess their physical and mental health. At the conclusion of baseline data collection in November 2004, 71,437 interviews had been completed, establishing the WTC Health Registry as the largest health registry of its kind in the United States. The NYCDOHMH launched the WTC Follow-up survey in November, 2006. As of August 31, 2007, 39,703 adult paper and web surveys had been completed for nearly 60 percent response rate (58.7 percent). NYCDOHMH has begun a third phase of the follow-up survey to reach the registrants through direct interviewing by telephone, as well as initiated a separate mailed survey of registrants who are younger than 18 (approximately 2,200).

The WTC Health Registry findings provide an important picture of the long-term health consequences of the events of September 11th. 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 recently published reported findings on 9/11 related asthma and posttraumatic stress disorder (PTSD) (Environmental Health Perspectives, 8/27/2007; and American Journal of Psychiatry, 2007; 164:1385–1394) among rescue and recovery workers. Newly diagnosed asthma after 9/11 was reported by 926 (3.1 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 WTCHR was 12.4 percent, a rate four times that of the general U.S. population. By spotting such trends among participants, we can provide valuable guidance to alert Registry participants and caregivers on what potential health effects 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 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. The findings will permit us to develop and disseminate important prevention and public policy information for use in the unfortunate event of future disasters.

**FUNDING**

I want to reaffirm the Department’s commitment to work with the Congress to provide compassionate and appropriate help to responders affected by the World Trade Center exposures following the attacks.

As you know, the Department of Defense, Emergency Supplemental Appropriations to Address Hurricanes in the Gulf of Mexico, and Pandemic Influenza Response Act of 2006 (P.L. 109–148) provide $75 million for the treatment, screening, and monitoring of the responders. With less than one month remaining in the fiscal year (FY) we are confident this funding will last at least until the end of fiscal year 2007.

The President’s fiscal year 2008 budget requests $25 million for World Trade Center responders and in May 2007, the President signed the U.S. Troop Readiness, Veterans’ Care, Katrina Recovery, and Iraq Accountability Appropriations Act of 2007 (P.L. 110–128), which included an additional $50 million to support continued treatment and monitoring for World Trade Center responders. This funding will be
awarded, as needed, to support continued monitoring, care, and treatment of responders through fiscal year 2008.

From July 1, 2006, through June 30, 2007, the Federal grantees have reported to NIOSH spending approximately $15 million total for treatment for World Trade Center related illnesses. This includes $6 million from American Red Cross funds and $9 million from the $42 million total Federal grants awarded in October 2006. Of this $9 million, the grantees have actually “drawn down” only $2 million in payments on the Federal grants.

Over $90 million in appropriated funds remains available—including the balance of the treatment funds appropriated in fiscal year 2006 and the $50 million appropriated in fiscal year 2007—before adding the $25 million included in the President’s fiscal year 2008 budget request. HHS is gathering additional financial data from the Federal grantees in order to better understand the healthcare cost issues of the responders. Additional data will help inform our policies, ensure that the current program operates efficiently and effectively, and maximize the available resources to meet responders’ medical needs. HHS will continue to monitor the work of the grantees as part of the fiscal year 2009 budget process.

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. We have had great success in expanding our monitoring program to include treatment, which has encouraged more responders to enroll and receive needed services. We will continue to forge ahead in providing coordinated medical monitoring and treatment services, supported by the recent $50 million appropriation. 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. While we have made much progress, we must continue to gather and analyze data that will enable us to better understand the health effects we have observed so that we may better treat those affected. I appreciate your support of our efforts and look forward to working with you in the future as we continue to serve this deserving population.

Thank you for the opportunity to testify. I would be happy to answer any questions you may have.

Mr. PALLONE. Thank you, Dr. Howard. I am going to recognize myself for some questions.

You are familiar with the letters that myself and the New York delegation have sent to both Secretary Leavitt and Office of Management and Budget? Have you seen those?

Dr. HOWARD. I think I have seen letters to the Department. I am not sure I have seen those you——

Mr. PALLONE. OK. Well, I mean essentially if I could summarize the concern, I mean the concern is that the administration had promised a comprehensive plan to deal with this. As you know, the New York delegation has submitted legislation which, I guess, could be intended to put together a comprehensive plan. But we were supposed to get something like that from the administration.

We continue to be concerned about the level of budget requests that come from OMB, so we sent a letter to OMB. And the concern I have, and I guess the criticism is that the administration would appear to be dragging their feet. We don’t have a comprehensive plan.

We have budget requests that seem to be inadequate. I did get a draft, I guess, that I mentioned in my opening statement that has the figure, that the current cost estimate for the program is nearly $200 million per year. And yet there is an acknowledgement in the draft that it could cost as much as $712 million annually. And yet the President’s budget for fiscal year 2008 request is only $25 million. And I know that one of the administrators for this task force resigned, and no new person has been appointed.
So I guess the question would be, one, what is happening with this comprehensive plan? Are we still getting it? Is it being held up because you don’t have a person to replace the person who was the chair of the task force? And when are we going to get some real cost estimates because I think you would agree that the $25 million wasn’t adequate.

Dr. Howard, Mr. Chairman, let me start with the beginning of that list of questions. I think all of them are extremely important. I don’t think there should be any doubt in anyone’s mind that Secretary Leavitt of the Department of Health and Human Services is dedicated to this program and ensuring that these individuals who are being monitored and treated are not abandoned. That will not happen on his watch.

I think one of the more serious issues with regard to developing a comprehensive plan, a multi-year plan, as opposed to a day-to-day operational plan, which we do in NIOSH every day with the grantees.

The biggest problem with that, I think, from the point of view, not being a budget accountant et cetera, is being able to project over time what the true costs are. Right now on the monitoring side, it is very easy to do. We know that it costs $1,150 to monitor an individual. You tell me the number of individuals you want monitored. We do the math, and it comes out. Right now, we have 37,000 under monitoring, $1,150 per year. That’s about a figure of $43 million. Easy to figure out. March that out to how many years you want.

On the treatment side, that is the real conundrum. We put out the money for the treatment services in October 2006. It took a few months for the grantees to get capacity up and running. Probably around February or March, the grantees really started treating individuals. So we have a very limited amount of time right now to assess from an actuarial sense the costs of treatment because each individual is generating different costs, and there are different costs associated with treating physical health effects and mental health effects.

So that is an extremely unstable number, and I think again from my point as a physician—I am not a professional in this area—but I think it challenges people who are looking at projecting costs through the years.

Mr. Pallone. I only have 5 minutes even though I am the chairman. I just really want to know if you are agreeing with me that there is a problem. The GAO report, that is the next panel, they agree that there is a problem. But I just want an answer to simple questions. Is the administration still going to give us a comprehensive plan so we don’t just have to operate ad hoc? When? Is there a problem because there is nobody in charge of this anymore because the person resigned? And I mean just answer that. Are we going to get a comprehensive plan, yes or no?

Dr. Howard. I would like to answer all three. Yes.

Mr. Pallone. OK, when?

Dr. Howard. We are developing comprehensive plans.

Mr. Pallone. Can we have a date?

Dr. Howard. The task force that Dr. Agwunobi reported to the Secretary in April. The conundrum, I think, we have, which I think
has to be recognized is that we don’t have solid cost estimates to do a comprehensive long-term plan at this point in time.

Mr. Pallone. But can you give me an approximate date?

Dr. Howard. In October at the end of this grant period for the treatment program, we will have exact numbers from the grantees about what they have spent in this first grant year. That will be extremely helpful for a comprehensive plan.

Mr. Pallone. So can we get this comprehensive, in the next few months?

Dr. Howard. Well, that I will take back to the——

Mr. Pallone. Yes, I would like to have it, if possible, right after October 1. And then is there going to be a new person appointed to head this task force?

Dr. Howard. The Secretary at this time—I am co-chair of that task force, so I am stepping in from the day-to-day operational standpoint to be able to fill that role.

Mr. Pallone. So you don’t know then?

Dr. Howard. The Secretary will designate a chair at some point.

Mr. Pallone. All right, well why don’t you take it back to him that we would like that person sooner rather than later?

Dr. Howard. Yes, sir.

Mr. Pallone. OK. Mr. Deal.

Mr. Deal. Thank you. Dr. Howard, talking about the treatment side of the issue and whether or not appropriate funds are available, just looking at your written testimony, I believe there is like $90 million in appropriated funds that remain available, including the balance of the treatment funds appropriated in the fiscal year 2006 and $50 million appropriated in fiscal year 2007, and that is before adding the $25 million that was included in the President’s fiscal year 2008 budget. I assume that is correct since it is in your testimony?

Dr. Howard. Those numbers are generally correct. The $90 million, because we have monies for monitoring, and then we have monies for treatment. So the $90 million is on the monitoring side, which was appropriated in 2003. The fifth year of that is coming up in fiscal year 2008. Otherwise, the numbers are perfectly correct.

Mr. Deal. OK, so there is money that has already been appropriated that is not currently been expended. But the projection is it will be expended over the next several years?

Dr. Howard. There is no doubt in my mind that medical treatment will be expend all the money that we have. The issue is the timing. As I mentioned to the chairman, we are looking at right now at the end of this fiscal year, September 30, we are looking at the certainty that we will have enough money to fund monitoring and treatment fully for anyone who needs it as of the end of this fiscal year.

When we look to that fiscal year 2008, which I think is where you are looking, looking at approximately maybe $24 or $25 million carried over from fiscal year 2007, plus the $50 million that the Congress generously appropriated us in the Iraq supplemental. So that is nearly $75 million. That is not counting the money that is currently in consideration by the Congress, which I think on the House side was $50 million.
So we are entering fiscal year 2008 with funds, and again we will continue to monitor this very closely. The Department keeps a very close eye on this because, as I said, the Secretary's intention is that these patients are not abandoned. They do not run out of money. The programs will continue.

Mr. DEAL. Now, as I understand it, most of the money and the programs that you put in place go to grantees to carry out various functions of the overall picture. Is that correct?

Dr. HOWARD. Yes, sir.

Mr. DEAL. And one of the criticisms that apparently GAO has made is the lack of documentation. Do you depend on those grantees to furnish the numbers and the documentation to you? Is that part of the grant function?

Dr. HOWARD. Yes, sir. A grant is an unusual vehicle, and it is money given to grantees. They decide how to spend it. There are some deliverables that are attached, but the data really depends on the good working relationship between the funder, the Federal Government, and the grantee. It is not exactly like a contract, which is a little tighter deliverable.

Mr. DEAL. And in order to make projections for future needs, it would seem that you would need the kind of demographics and the data that the grantees presumably would have access to, but it appears in the GAO report that maybe that information is not being funneled back up through the system.

Dr. HOWARD. No, I would say the grantees are bending over backwards to provide us with as much data at any time we ask. The issue is that within large hospital medical centers, it is not so easy to get actual cost accounting data from systems in any health care system. So you are talking about five large medical centers in the New York/New Jersey area. So our grantee, which is providing the services, must access large systems to be able to do that.

And as you know and we all know, sometimes health billing isn't in real time. So there may be some lag, if you will, in getting that data. So we are working on setting up alternative systems so that we are able to set data in real time. Because that is the question, as the chairman asked, as my Department asked, as others in Congress asked. What is your cost estimate? We want to know that with some certainty.

Mr. DEAL. But it appears though that the effort to determine who is out there and who has needs as a result of this event of 9/11, the screening process is the largest search screening process that has ever happened in the history of this country in terms of outreach, is it not?

Dr. HOWARD. Exactly right. We have never undertaken, to my knowledge, in the Federal Government this kind of process, either on a registry side with 71,000 registrants that the city is doing for us, or on the clinical side, the monitoring and treatment. We have never run this kind of system.

And if I could add, sir, the 40,000 figure that is often quoted, an early figure in 2001 and 2002 for the denominator of responders and volunteers, is often used. But as you see, we are nearly up to that 40,000 figure in registered, enrolled responders and volunteers right now.
It gives us some pause that that may not be the accurate total denominator. And in fact, the city Department of Health, utilizing estimation method with Research Triangle Institute in North Carolina has a number, an estimated number, mathematically estimated, but around 90,000.

So somewhere between this 40,000 of enrolled individuals that we have now in our program and this theoretical 90,000, we will find out exactly how many because, as some of you have noted, we do not know exactly how many people responded to the World Trade Center disaster. We have no census track for those individuals.

Mr. DEAL. Thank you. Thank you, Mr. Chairman.

Mr. PALLONE. Mr. Engel.

Mr. ENGEL. Thank you, Mr. Chairman. Dr. Howard, you heard my opening statement. I am wondering if you could respond to the criticism by the GAO that HHS has failed to ensure the uninterrupted availability of screening services with Federal responders. They have also commented that you failed to truly provide screening and monitoring to people in other areas of the country who came to Ground Zero. And, as you know, GAO said that NIOSH has only been able to establish a network of nationwide providers with 10 clinics in only seven States.

Do you believe HHS has acted appropriately in providing services to responders? Because the evidence would seem not.

Dr. HOWARD. I am certainly not going to dispute the fact that historically, as we have gone through establishing these programs for responders that are not physically in the New York City/New Jersey area, that we have had significant challenges. But right now, I think we are on a good trajectory with a contract through Mount Sinai for a large nationwide provider of monitoring services called QTC.

So indeed, sir, I would agree that GAO has pointed out historically a lot of fits and starts that we have had with both the Federal screening program as well as the nationwide program. We have done a lot of work lately, and I am hoping that we are on the final trajectory to make sure that those individuals have monitoring and treatment services. Now, the treatment services, as I mentioned in my statement, are not federally funded. The generous support of the Red Cross through AOEC supports treatment.

Mr. ENGEL. Let me ask you this, Dr. Howard. In September 2006 Secretary Leavitt established an internal task force on what you said to provide him with an analysis of the data and options on how to address the health effects at Ground Zero.

In April of this year, the task force briefed the Secretary on eight options that could be undertaken. We in Congress have yet to hear about these various options. Can you please tell us what the eight options are and if a decision has been made on a long-term comprehensive plan to care for those who are sick from 9/11?

Dr. HOWARD. Well, I think that all of us know the ways health care is provided in the United States. I think we could all probably sit down and make a list of Medicare, Medicaid, the VA system, in addition to our own grant system through our Centers of Excellence. Those are the kind of ideas that were put in front of the Secretary. There are not any hidden ideas. There is no magic bullet
here. And all those types of systems that are the systems by which health care is provided are ones that the Secretary is considering.

Mr. Engel. And let me ask you a funding question. In July, the New York Times reported on an internal HHS document, which estimated yearly cost for the current World Trade Center Medical Monitoring and Treatment Program at $195 million per year. It also says that the costs will probably rise to $428 million per year. Let me ask you. How much do you anticipate that the Medical Monitoring and Treatment Program will cost per year?

Dr. Howard. First of all, as I emphasized to the chairman, a lot of costs right now are highly speculative. You have to start out with some assumptions. If we start out from the grantee data, and this is grantee data that we have. We don't have our own independent data.

We rely on the grantees, but if the grantees are spending about $8,000 per patient per condition that they are treating, pharmacy costs, diagnostic costs, treatment costs. You multiply that times the number of people that are under treatment right now, which is about 12,000, you get to the figure of about $90 or $100 million. So you build on those kinds of figures that the grantees are producing.

By October, I am hoping that we will have more solid estimation, but even for treatment at $100 million without hospitalization—you have to add then hospitalization costs—you can see that health care in America is not cheap whether it is for responders or anyone else.

Mr. Engel. Well, let me ask you one final question with the chairman's indulgence. You mentioned Mount Sinai. I know we have people from New York City in the next panel. How does the manner in which Congress is currently funding the World Trade Center Medical Monitoring and Treatment Program, its piecemeal, its year-to-year funding, how does that affect the ability of grantees like the New York City Fire Department, Mount Sinai and others to collect medical and cost data? And how does it affect NIOSH's ability to administer the program in general?

Dr. Howard. Sir, I think it is a challenge. Institutions would like consistent funding more than year to year despite my personal assurances and the assurances of my Department that the programs are not going to go away. If you are a CEO of Mount Sinai or another medical center and you are looking at space considerations, infrastructure development, they would like some idea that the program is more than just that year. I think that is a real challenge. We have to constantly reassure them the program is not going away despite the current year-to-year funding. But it is a challenge, sir.

Mr. Engel. Thank you, Doctor. Thank you, Mr. Chairman.

Mr. Pallone. Thank you. Mr. Ferguson. I'm sorry. I apologize. Mr. Barton goes first.

Mr. Barton. Well, Mr. Ferguson was here before me. I don't mind.

Mr. Pallone. No, I think the rules are since you are the ranking member, I am supposed to call on you first.

Mr. Barton. Well, thank you. I will try not to take my entire 5 minutes. Is the problem, the health problem with the World Trade
Centers in New York, is it a scope problem? It’s just the catastrophe was so large that it has overwhelmed the healthcare system? Or is there something unique about the problem itself from a health standpoint at the collapse of the Trade Center Towers?

Dr. Howard. If I understand your question, sir, I don’t think that it is overwhelming. We have responded, and when I say we, the entire family of grantees have responded I think magnificently to the challenge of developing infrastructure to be able to see this number of individuals in a monitoring program and then refer those who need help to treatment. We have some backlogs it is true, but I think the response from infrastructure development is extremely positive.

On the issue of the uniqueness of the problem, I think we have an entire body of data very consistent from multiple investigators published in multiple peer review medical journals that looks at a very limited number of conditions. Chiefly those of the respiratory system, upper and lower respiratory system. Chiefly that of mental health issues, post-traumatic stress disorder, anxiety, depression, some musculoskeletal disorders, some gastrointestinal disorders.

That is really what we have seen consistently in elevated concentrations in these populations. So it is not a scope that we cannot deal with. One of the issues with regard to respiratory conditions is we don’t exactly know what the nature of the respiratory condition is in many cases, and we don’t know what the course is going to be. We don’t know exactly how to treat them. So I think that is a medical challenge.

Mr. Barton. But this WTC cough, is that just a colloquialism that is used in New York but it is not a unique condition caused by the specific type of environmental hazard at the Trade Center?

Dr. Howard. Well, the World Trade Center cough was a name that was acquired very early in the course of this disaster. It really refers to one particular type of symptom that an individual manifests. But lung disease in general, lower lung disease in the lower part of the respiratory track always seems to have cough as a symptom. So there is nothing specific or unique about it.

Mr. Barton. There is not a unique disease or condition associated with that specific location?

Dr. Howard. We don’t know that for sure because a lot of conditions that result in fibrosis of the lung, called interstitial fibrosis of the lung, you look at a medical textbook, there are 200 causes of it. Each one can be unique in terms of the cause. So in that sense, we are not far enough along the medical research line to be able to answer your question fully.

Mr. Barton. OK, in terms of legal liability, is there a specific problem between the Federal responders, the non-Federal responders, the city of New York, in terms of legal liability for work-related occupational accidents or conditions that resulted as a result of responding to that disaster?

Dr. Howard. Sir, I am not sure I am qualified to address that issue.

Mr. Barton. Well, that appears to be one of the primary issues that we are trying to—at least the people that come into my office, the private contractors have an indemnification problem. They claim that they went and did the work and were told by the city
officials that they would be indemnified. And now after the fact, they are finding they have not been indemnified, and there are some potential lawsuits. And there are requests for some Federal legislation to indemnify them. I thought that was one of the primary reasons we are holding this hearing, but maybe I am mistaken in that regard.

Dr. Howard. There are indeed lawsuits that are pending against the city and its contractors, but I don’t know any——

Mr. Barton. But I mean is there a generic Federal OSHA regulation on that?

Dr. Howard. Not to my knowledge.

Mr. Barton. OK. Thank you, Mr. Chairman.

Mr. Pallone. Thank you. Let me just mention we have three votes coming up, and we have about 10 minutes left. So Mr. Ferguson will ask questions, and then we will recess Dr. Howard and come back maybe half an hour or so. And we will have a few more questions. Mr. Ferguson.

Mr. Ferguson. Thank you, Mr. Chairman. Thank you, Dr. Howard, for being here. Your written statement appears to say that there are millions of dollars in funds that are still available under some of the Federal health programs. Is that a correct interpretation of your written testimony?

Dr. Howard. Right, as I have indicated, we will probably know for certain at the end of the grant period, October 30, 2007, how much money we will have expended and how much we will have that will be carried over to fiscal year 2007. Right now, we are estimating about $20 to $24 million will be carried over. We have $50 million from the Iraq supplemental. So already we have on hand $74 million. So we are not going to enter 2008 without funding.

Mr. Ferguson. What is your best estimate as to when we will know if that is going to be sufficient to meet some of the health treatment requirements and challenges that these victims are facing?

Dr. Howard. Exactly, and this is the question that everyone wants to know, and my answer is often inadequate because what I say is with time, as we gain more experience with the true cost, the average cost per patient for treatment, we are going to be able to give you a better number. Right now, it is hovering around $8,000 per patient.

If you are seeing about 25 percent of the monitored patients that are in treatment, then you can estimate those costs. But they are relatively unstable right now. I would like to see some more time take place at least until our grant period at the end of October, maybe towards the end of the fall, until we have some more stable numbers.

You can calculate any estimate at any time, but the stability of that estimate from actuarial level is often elusive.

Mr. Ferguson. What is being done in terms of R&D on new treatments for some of these ailments? It seems like some of the ailments that first responders and others are dealing with are new and more difficult than perhaps other health challenges that have typically been faced by a large number of people. What sorts of new treatments are being developed? What are you aware of in terms of those efforts underway?
Dr. Howard. We have no funds right now targeted specifically to research. All of our funds that we have appropriated go to monitoring and treatment. The grantee institutions, many of them are academic medical centers, and they have been very creative in looking at their clinical findings and trying to figure out the best ways to treat.

But specifically, they do not have money to spend in research per se, and that is something that we hope in fiscal year 2008 to be able to utilize some of the already appropriated money to be able to give to the grantees to engage in research activities per se.

Mr. Ferguson. That was going to be my next question. What is—do you have any specific recommendations at this point, or are those sort of informal conversations you are having with folks? I mean are we going to need to reprogram funds? What is your sense of how that can happen? It sounds like you believe it ought to happen.

Dr. Howard. Yes.

Mr. Ferguson. Do you have any further—kind of any more specific recommendations at this point, or are you developing those now?

Dr. Howard. Well, within the day-to-day measurement structure that we do, our own plan that I administer, we are trying to set aside targeted funds so that grantees can look into some issues with regard to what is the exact nature of the respiratory conditions and how are they best treated.

But we don’t have money appropriated by the Congress specifically for that purpose; although, everyone that I have talked to within the Department, within Congress, of course, is very attuned to that issue. And I think the grantees might be, Mt. Sinai and others that are here on the other panel, might be best to ask about their efforts because they have done heroic efforts with very little money thus far to move the medical science along.

Mr. Ferguson. Just in closing, Mr. Chairman, it seems like that might be an area that we really would want to examine further if we are experiencing these very significant health problems, if these folks are experiencing these very significant health problems. Perhaps we should also be looking at new and different ways of treating them in addition to just simply plowing resources into the current treatments that we have which may or may not be as effective as they need to be. Perhaps some of our efforts should be focused on some different and better treatments and some research into, perhaps we can take this terrible situation and create some good from it in terms of finding new treatments for ailments and illnesses and symptoms that maybe we otherwise wouldn’t have an opportunity to find.

Dr. Howard. Exactly, and in my subcommittee of the Secretary’s task force, the Science Subcommittee, we have recommended a number of studies along those lines. So that is a very important point that you are making.

Mr. Ferguson. Thank you. Thank you, Mr. Chairman.

Mr. Pallone. Thank you. Dr. Howard, we are going to take about a half an hour recess to vote on the floor, and then we will have some questions when we come back. We won’t have a second round though. We will just go through everybody. Everybody will
have a chance, and then we will go to the second panel. Thank you. The subcommittee is in recess.

[Recess.]

Mr. PALLONE. The subcommittee will reconvene.

Dr. Howard, we left off with Congressman Fossella asking questions.

Mr. FOSSELLA. Thank you, Mr. Chairman, and thank you again, Dr. Howard, and thank you for all you have done. I know in your capacity you have been very vigilant and a very bright light, I think, within efforts to try to reconcile what we have been trying to reconcile for 6 years.

And I could just characterize, maybe if you will for lack of a better phrase, the perception that—and I speak this on a personal level, and perhaps I speak for others—is there is a sense that we are constantly sort of dragging folks to the table. From securing just less than 2 years ago the Federal funding for treatment, to your appointment, to Dr. Agwunobi’s

I guess there is a perception that—I won’t say perception. There is an understanding that we would love for, in this case, the executive branch to be more out front leading the charge. And what has happened in the last 6 years from the private sector to the health care centers to the Centers for Excellence to the mayor’s office is just an understanding of this is too big and too important to wait for an answer and wait for the cavalry to come. So they have been doing the job.

For example, we talk about the inability to truly estimate, and we are always going to have disagreements on the margins and whether the number is 50,000 or 51,000, 52,000. But I find it curious as to how New York City could estimate what treatment would cost.

The mayor, if my understanding is correct, has committed $100 million until 2011. Why is it that the Federal Government can’t come forward and say this is what we are going to commit until 2011 for the sake of argument? I recognize the nuances of the annual appropriations process. But wouldn’t it be so much better if the cavalry came in and said whatever it is going to cost over the next 2, 3, 4, 5 years, until we get a sense of reliable data, it is going to happen?

And along those lines, April 3 is our understanding pursuant to the letter Mr. Pallone cited. Did the task force provide recommendations to HHS regarding what they have determined to date?

Dr. HOWARD. With regard to the latter question, the task force was divided into two groups, a finance group and a science group. I headed the science group, and we made recommendations to the Secretary from both of the subcommittees, from the finance side and from the science side.

A lot of the science issues we are trying to operationalize, looking at research opportunities to move the science forward with the current grantees. From the finance side, I think again despite those issues of policy that you talked about, the Department is extremely interested in the stability of cost estimates so that they are able to be able to project beyond just this last 6 months that we have. I know that is a big issue in the Department.
Budget people, which I am not one, want some certainty in those budget estimates. With regard to the policy options that you mentioned, they are beyond my task, and I will certainly take that back to the Department.

Mr. FosSELLA. Well, because I think there has been a vacuum in a way, and it is being filled in different ways. It is an ultimate collaboration, especially, I think, reflecting the legislation we introduced last night. And we would love to have a comment from sort of HHS as to whether they would support, let us say, that legislation. Have you had a chance to review the legislation or at least an outline of it?

Dr. HOWARD. No, I haven’t had a chance to read the legislation, and, of course, the administration’s position on legislation is decided at a level different than my own.

Mr. FosSELLA. Well, we would love again some dialog. If the goal—and you heard it in a bipartisan way here from those who just declare it as an emergency and it demands a national response. To me, national dictates a Federal response.

And it would also free up personnel and people at the city level, the municipal level. There is more litigation taking place. Why can’t we get these individuals out of the courtroom, get the lawyers out of the courtroom and settle this case?

I do think that with a strong Federal commitment, a lot of that would find its way to a swifter conclusion if there was a notion that the city of New York would not have to shoulder so much a burden. And likewise and most importantly again I get back to the insurance of monitoring and treatment that Mr. Ferguson brought up, and I think you would concur, the notion that research—why should we be 6 years later just talking about whether we should be providing funding for research? I mean it is a shame.

One just quick question. Do you think—and maybe you have answered it, but if there is any other way you can answer it that will elaborate—the biggest problem adjustment the Department would recommend at this time to improve the health monitoring treatment program? You talked about the grantees. You talked about more data, more information.

Is there any other thing that we should be doing in a legislative mechanism to free up flexibility at your end to get the answers or solutions we are looking for?

Dr. HOWARD. From the scientific side, I have always said that the money that we have had to date goes to monitoring services and now treatment services because it is small amounts of money, and we are always trying to make sure that we have enough to get from year to year.

We have not expended any significant amount of money on real research into the causes of some of these diseases or their best treatments because we have been trying to shepherd the money for services. So I think that is one area that we have spoken about already that, from my point of view as heading the Science Subcommittee that made recommendations to the Secretary, this is a really important issue. Otherwise, we are not going to know exactly what the contours of the problems are and how best to treat these people.
Mr. FOSSELLA. Mr. Chairman, again I would like just on a personal level thank Dr. Howard. He is very passionate about what he does, and again I said the bright light because you have been terrific in helping us all shepherd through this. And we would love to get more folks seeing it your way.

Thank you, Mr. Chairman. I yield back.

Mr. PALLONE. Thank you. Thank you, Dr. Howard. We are done with your questions.

Dr. HOWARD. Thank you.

Mr. PALLONE. And we appreciate this, and I know this is going to be an ongoing concern so. I will just repeat again we do want a plan from the administration, and we also would like to see someone appointed as the head of that task force as quickly as possible.

Dr. HOWARD. Thank you.

Mr. PALLONE. If you will send that back. Thank you. And I will ask the second panel to come forward please.

Thank you all for being here today. Let me just introduce everybody. Starting on my left is Mr. John Vinciguerra from the fire department of New York, although it says that you actually live in New Egypt, New Jersey. That is a long commute. And then we have Dr. Iris Udasin who is associate professor of environmental and occupational medicine at the University of Medicine and Dentistry, New Jersey, the Robert Wood Johnson Medical School. It is always a lot to say all that. She is actually from the clinical center that is in my district in Piscataway. Thank you for being here, and thank you for all that you do. And then we have Dr. Robin Herbert who is associate professor of the community and preventative medicine at Mount Sinai School of Medicine in Manhattan. And we have Ms. Cynthia Bascetta, who is director of health care issues for the Government Accounting Office for the GAO. Dr. Jim Melius who is administrator for New York State Laborers. And Mr. Edward Skyler who is the deputy mayor for administration in the city of New York, representing the mayor of New York.

So let me mention again that each witness has 5 minutes for their opening statement. Obviously your written statements will be submitted for the record. So we would like to have you keep to the 5 minutes if you could. You may, if you wish, submit additional brief and pertinent statements in writing for inclusion into the record later as well. And I will start with you, Mr. Vinciguerra. Thank you for being here, and thank you for all that you have done.

STATEMENT OF JOHN VINCIGUERRA, FIRE DEPARTMENT OF NEW YORK (RETIRED), NEW EGYPT, NJ

Mr. VINCIGUERRA. Good morning. Thank you for having me. I was glad to hear the testimony from Dr. Howard. It was nice to sort of be reassured that the money is not going to be running out tomorrow. I would just like to read my testimony and take any questions you might have.

My name is John Vinciguerra. I am 39 years old and a father of four. On January of this year, I was forced to retire as lieutenant with the fire department, New York City, EMS command, due to
the lung damage that I sustained during the World Trade Center disaster rescue and recovery effort.

It was one of the saddest days of my life when I had to turn in my badge and end an 18-year career. Prior to becoming ill, I was in good health, able to carry equipment and victims both up and down many flights of stairs. I love to be able to help people and felt I had one of the best jobs in the world.

September 11 started like any other day. I picked up an overtime shift on the night tour. Left work early that morning. I went home, hopped into bed, tried to get a nap because I had the rest of the day off. Wanted to have time to spend with my family. My wife came up and woke me up to tell me what was happening. We watched the second plane hit the towers on TV. I was wide awake in an instant.

Along with my wife, who was also an EMT, we grabbed our gear and drove to the city. I was told to report to my station just over the Brooklyn Bridge, began transporting equipment and personnel back and forth to Ground Zero. I worked at the World Trade Center site for many days, both on the piles as part of the bucket brigade, treating people who were injured at the site and supervising EMS crews from around North America.

I averaged twice a week doing 16- to 24-hour shifts each time until about January 2002. At that point, it was just too difficult to be there anymore.

While I do truly feel blessed to be here and be able to talk to you, and I know there are many others in much worse condition than myself, I also know that this has affected me in three major ways, both physically, mentally, and financially. As far as physically, like many others, I developed the World Trade Center cough. I was given medication by the fire department doctors, which was changed by my private doctor. When my breathing continued to deteriorate, another medication was added. I continued to work and watch my lung volumes drop on my annual physicals and became more and more run down but wanted to try to work through it.

On April 30, 2005, that came to an end. After suffering at home for 24 hours hoping I just had a bad virus, I was taken to Robert Wood University Hospital in Hamilton. I was hospitalized for severe respiratory distress and admitted to the ICU in it. A scan in my lungs revealed a spot, and the oxygen profusion in my body was so poor that they thought I had a pulmonary embolus, which is a blood clot on my lungs.

Unfortunately, this was not the case. What was happening was that the scarring in my lungs from breathing in all the toxins had become so bad that I was no longer able to move enough air, and my body was suffocating. I was also told that I know had high blood pressure, and I had stopped breathing several times during the night.

I was loaded up with steroids, antibiotics, and many other medications, and discharged a few days later. I currently cannot walk up a flight of stairs without running out of breath. My lung volumes run between 30 to 60 percent of what they should be. I cannot run and play outside with my children. I need to be cautious when temperature or humidity changes. I am very sensitive to
dust, pollen, and pollution, and I spend most of my time indoors with a hepa filter that is my best friend.

I have to take at least seven medications a day every day that cause both fatigue and weight gain. Due to my sleep apnea, I now have to wear a mask over my face at night that blows air into my nose to keep my airway open. Every time I put it on, I feel my ears pop as if I am on an airplane. And it has also greatly diminished my sense of smell, but it is much better than the prospect of suffocating in my sleep and stopping breathing.

Since becoming ill, I have been diagnosed with anxiety and depression, both related to post-traumatic stress disorder. I have tried medications, but the side effects only seem to make matters worse. Luckily for me, I have a strong marriage, and my wife has been there for me. But the stress this has put on me, my marriage, and our family is enormous.

After I first reported of my illness to the city of New York, my claim was denied. I was told that since more than 2 years has passed since September 11, I was no longer eligible for a Worker's Compensation claim. As you could imagine, I was despondent. The thought of being left on my own. I felt that I had done all I could to help this city and this country in its time of need, and now I was being abandoned.

Fortunately, the New York media was relentless in reporting both my case and the plight of others in similar situations. Legislation was introduced and passed in New York to extend the deadline to file for a claim. Fifteen months after becoming sick, as legislation was taking effect, on July 26, my case was finally approved on appeal. This event lead the way to me being retired and the end of my career. It was not how I pictured that it would end, and it is certainly a disappointment to me.

Financially, here there is a light at the end of the tunnel, but things are going to get worse before they finally get better. Since it took 15 months for my case to get approved, I was responsible for all my doctors' visits and medication copays. I was not working and was unable to pay all the bills and continue to put food on the table. I was forced to sell my home to try to keep my head above water, and it didn't take long for the creditors to start circling.

Even now, it has been over 2 years since I first became ill and a year since my case has been approved. But the New York City Law Department has still not paid the bills that have accumulated. My original pulmonologist told me a year ago that he would not be able to see me anymore because he has not been paid and still has not been paid to this day.

In May 2007, I applied for Social Security disability. After following up with several phone calls, I was told in August that despite all the documentation and the fact that I was forced to retire from my respiratory problems, I would have to be sent for an anxiety evaluation. And the earliest appointment that was available was the end of September, the end of this month.

On top of all this, although I was granted a pension, I will not come off payroll for the fire department until September 26 of 2007. Then I will have to wait until November to get my first pension check, and when that does come, it is only going to be a partial
payment until they get the numbers spooled up, and they can adjust them.

Since I have a biweekly pay mortgage, I am trying to work with my bank so that I won’t be missing too many payments. I have also tried to take a pension loan, but since I am so near to retirement, it is not considered a disbursement. Since it is a disbursement, I can’t take it until after my retirement date.

After that, it won’t arrive—they won’t cut the check until after my retirement date and will take another 30 to 45 days to arrive on top of that. I also looked to refinance my current mortgage, but due to late medical bills, the banks want over 10 percent for a new mortgage. It would be a long time before I recover financially.

While I feel good that hearings such as this are taking place and it is comforting to know that so many people are concerned with me and my fellow recovery workers, there still remains much to be done. More money is needed, not just for monitoring, but for treatment of symptoms and conditions that are discovered. Financial assistance needs to be provided for those in need of help, whether temporary or permanently. An advocate should be appointed to help cut through the red tape that is facing not just the responders but also the residents and school children that were affected. Because what good is a program if the people that need it most don’t know it is there and can’t get it to work for them?

Also the World Trade Center Captive Insurance Fund should be abolished and replaced with a compensation fund or another program that will put money to use where it is needed. It is disgraceful that the lead administrator is being paid $300,000 a year to run a hostile fund that is throwing tens of millions of dollars at lawyers to prevent giving financial support to those it was created for. Thank you very much for your time and consideration.

[The prepared statement of Mr. Vinciguerra follows:]

**STATEMENT OF JOHN VINCI GUERRA**

My name is John Vinciguerra. I am 39 years old and a father of four. January of this year I was forced to retire as a Lieutenant with the FDNY EMS command due to lung damage sustained during the World Trade Center disaster rescue and recovery. It was one of the saddest moments of my life when I had to turn in my badge and end an 18 year career. Prior to becoming ill I was in good health and able to carry equipment and victims both up and down many flights of stairs. I loved to be able to help people and felt I had one of the best jobs in the world.

September 11, 2001 started for me like any other day. I had picked up an overtime shift on the night tour and left work in the early morning. I went home and climbed into bed to grab a quick nap. My wife came and woke me up to tell me what was happening. Along with my wife who is also an EMT, we grabbed our gear and drove to the city. I was told to report to my station just over the Brooklyn Bridge and began transporting personnel and equipment back and forth to ground zero. I worked at the WTC site for many days on the pile as part of the bucket brigade, treating people who were injured at the site, and supervising EMS crews from around North America. I averaged about twice a week doing 16–24 hour shifts each time until January of 2002. After that, it was just too difficult to be there. And while I truly feel blessed to be here and able to talk to you, and I know that there are many others in much worse condition than myself, I also know that this event has affected me in three major ways, physically, mentally, and financially.

Physically, like many others I developed the “World Trade Center Cough”, and was given medication by the FDNY doctors. This was quickly changed by my private doctor. When my breathing continued to deteriorate, another medication was added. I continued to work and watch my lung volumes drop at my annual FDNY physicals. I became more and more run down but wanted to work through it. On
April 30 2005 that came to an end. After suffering at home for 24 hours hoping I just had a bad virus, I was taken to Robert Wood University Hospital in Hamilton NJ. I was hospitalized for severe respiratory distress and admitted to the intensive care unit. A scan of my lungs revealed a spot, and the oxygen perfusion in my body was so poor that they though I had a pulmonary embolus, or blood clot in my lungs. Unfortunately this was not the case. What was happening, was that the scarring in my lungs from breathing in all of the toxins had become so bad that I was no longer able to move enough air, and my body was suffocating. I was also told that I now had high blood pressure, and I had stopped breathing several times during the night. I was loaded up with steroids, antibiotics, and many other medications, and discharged a few days later. I currently cannot walk up a flight of stairs without running out of breath. My lung volumes run from between 30 percent to 60 percent of what they should be. I can not run and play outside with my children, I need to be cautious when the temperature or humidity changes. I am very sensitive to dust, pollen, and pollution, and I spend most of my time in my room with a hepa air filter which is my new best friend. I have to take at least seven mediations a day that cause both fatigue and weight gain. Due to my sleep apnea I have to wear a mask at night that blows air into my nose and keeps my airways open. Every time I put it on it causes my ears to pop as if I were on an airplane, and it has greatly diminished my sense of smell. But it is much better than the prospect of suffocating in my sleep.

Mentally; since becoming ill, I have been diagnosed with anxiety and depression. Both related to post traumatic stress disorder. I have tried medication but the side effects only seemed to make matters worse. Luckily for me I have a strong marriage and my wife has been there for me. But the stress that has been put on me, our marriage, and our family is enormous. After I first reported my illness to the City of New York, my claim was denied. I was told that since more than two years had passed since Sept 11, 2001, that I was no longer eligible to file a workers compensation claim. As you could imagine, I was despondent at the thought of being left on my own. I felt that I had done all I could to help the City, and this country in its time of need, and now I was being abandoned. Fortunately the New York media was relentless in reporting both my case and the plight of others in similar circumstances. Legislation was introduced and passed in New York to extend the deadline to file a claim. Fifteen months after becoming sick and as legislation was taking effect, in July 2006 my case was approved on appeal. This event led the way to retirement and the end of my career. This was not how I pictured that it would end and is certainly a disappointment to me.

Financially; here there is a light at the end of the tunnel, but things are going to get worse before they get better. Since it took fifteen months for my case to get approved, I was responsible for all my doctors visits and medication co-pays. I was not working, and I was unable to pay all of the bills and continue to put food on the table. I was forced to sell my home to try to keep my head above water. It didn’t take long for the creditors to start circling. Even now it has been over two years since I became ill, and a year since the case has been approved, but the New York City Law Department still has not paid the bills that accumulated. My original Pulmonologist told me a year ago that he would not be able to see me anymore because he had not been paid and he still has not been paid to this day. In May 2007 I applied for Social Security Disability. After following up with several phone calls, I was told in August that despite all of the documentation and the fact that I was forced to retire for my respiratory problems, I would have to be sent for an anxiety evaluation, and the earliest appointment was the end of September. On top of all of this, although I was granted a pension, I will not come off of payroll for the FDNY on September 26, 2007, then I will have to wait until November 2007 to get my first check from the pension department. And when it does arrive, it will only be a partial payment (less than half) for the first 3 to 6 months until the final numbers can be adjusted. Since I have a bi-weekly pay mortgage, I am trying to work with my bank so as not to miss two payments. I tried to take a pension loan, but since I am so near retirement, it is now considered a “disbursement” and I cannot take it until I retire. On top of that, it needs to be sent out as a check and will not arrive for 30–45 days. I also looked into refinancing my current mortgage, but due to the late medical bills, the banks want over 10 percent for a new loan. It will be a long time before I recover financially.

While I feel that it is a good thing that hearings such as this are taking place, and it is comforting that so many people are concerned with me and my fellow recovery workers, there still remains much to be done. More money is needed not just for monitoring, but for treatment of the symptoms and conditions that are discovered. Financial assistance needs to be provided to help those in need whether temporary or permanently. An advocate should be appointed to help cut through the
red tape that is facing not just the responders, but also the residents and school children that were also effected, because what good is a program if the people that need it the most don’t know it is there or cannot get it to work for them. The WTC Captive insurance fund should be abolished and replaced with a compensation fund or another program that will put the money to use where it is needed. It is disgraceful that the lead administrator is being paid $300,000.00 per year to run a hostile fund that is throwing tens of millions of dollars at lawyers to prevent giving financial support to those it was created for. Thank you very much for your time and consideration.

Mr. Pallone. Thank you so much really. I would like to ask Dr. Udasin to go next if you would. Is there a concern?

Ms. Udasin. Yes, I had some slides.

Mr. Pallone. You have some slides?

STATEMENT OF IRIS UDASIN, M.D., ASSOCIATE PROFESSOR, ENVIRONMENTAL AND OCCUPATIONAL MEDICINE, UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY, ROBERT WOOD JOHNSON MEDICAL SCHOOL

Dr. Udasin. Chairman Pallone, Ranking Member Deal, and honorable members of the Energy and Commerce Health Subcommittee, I am Iris Udasin, associate professor at UMDNJ, Robert Wood Johnson School of Medicine, and New Jersey principal investigator of the World Trade Center Medical Monitoring and Treatment Program.

I am board certified in internal and occupational medicine. My experience includes more than 20 years of practice as a real doctor, diagnosing and treating occupational and environmental illnesses. I have personally examined approximately 1,000 patients who responded to the tragedy.

The complex mixture of contaminated material present at the site has resulted in an unprecedented incidents of illness. Submitted with my testimony is a magnified dust particle, up there, that was collected at the site. Scientists from my institution were involved in characterizing this material. Even 6 years after the tragic event, our patients present with significant respiratory and gastrointestinal illnesses complicated by mental health disorders. In order to fully appreciate the diseases in this population, I direct your attention to the photographs of Deputy Chief Lacey Wirkus and the other members of the Elizabeth Fire Department that responded to this tragic event.

These photographs illustrate the roots of exposure and explain the mechanism of illnesses sustained by the population. Though the individuals in this photograph and the next one had respiratory protective equipment, the masks became weighted down by contaminated material and perspiration and did not offer sustained protection.

As depicted in the picture, there were huge amounts of dust and smoke debris on his face, clothing, hair, and skin. The material was absorbed by breathing, skin contact, and ingestion, as workers were contaminated even as they ate and drank at the site.

Most of our patients continue to work today despite suffering from conditions such as asthma, bronchitis, sinusitis, laryngitis, and gastroesophageal reflux. They have persistent shortness of breath, wheezing, cough, chest pain, sinus pressure, sore throat, in-
digestion, heartburn, decreased exercise tolerance. Many suffer from post-traumatic stress disorder and depression. Some have lost or limited health insurance benefits or financial hardship from loss of income. Uninsured patients clearly need the services of the medical monitoring and treatment program as they have minimal or no medical care. However, despite the fact that the majority of patients seen in New Jersey are insured, at least 60 percent are either untreated or undertreated for complicated medical and mental health illnesses.

Furthermore, typical health insurance has insufficient coverage for mental health. In order to correctly diagnose World Trade-related illnesses, health professionals spend several hours evaluating the medical, occupational exposure and psychological histories and perform detailed physical and mental health assessments. These assessments require more time than insurance typically allows for these encounters.

Specialized testing may be needed to appropriately diagnose our patients who have unusual presentations of asthma and other respiratory illnesses. Many community physicians do not have access to these tests or may lack of the knowledge of the unique aspect of diseases in this population.

The diagnostic dilemmas we face can be appreciated by the following patient presentations. Patient No. 1 is a 31-year-old man who presented with a dry cough, sore throat, anxiety, and decreased ability to exercise. He was being treated for anxiety and had a nasal spray that didn’t work and an asthma medication that he took occasionally. Further examination showed the presence of severe sinusitis and asthma.

His respiratory symptoms have improved after sinus surgery and proper treatment of the asthma. His anxiety level has improved but still requires prescription medication. His exercise tolerance has returned to baseline.

Patient 2 is a 46-year-old with severe coughing and heartburn. He took several cough medicines and nasal sprays with no relief. His examination and baseline breathing tests were normal, but his methacholine challenge test was diagnostic for asthma. And his endoscopy showed gastroesophageal reflux. He responded well to treatment but requires five prescription medications.

Patient 3 is a 39-year-old previously healthy man who was extremely short of breath and had a chronic cough. His original diagnosis was pneumonia, which did not respond to antibiotics. Biopsy of his lungs showed sarcoidosis. He currently takes three prescription medications but is disabled from his work as a New York City police officer.

Once the diagnosis is made, treatment can be complicated and frequently require several prescription medications. Even in patients who do have insurance, many have prohibitive copays or insurance constraints which prevent them from receiving brand name medications. Beyond the above conditions, there is concern about the possibility of life-threatening, long-term, chronic illnesses such as pulmonary fibrosis, sarcoid, cancer, and heart disease. The monitoring program provides the opportunity for early detection and intervention to potentially lessen the severity of these illnesses.
It is our goal to improve the treatment of acute and persistent health problems, enabling a decrease in future illness and disability and hopefully more productive lives. As a concerned physician, I implore you to support the 9/11 Health and Compensation Act and continue the funding by NIOSH of a program which allows experienced physicians to treat these complicated illnesses as well as provide adequate diagnostic testing and prescription medications. We want to continue to provide physical and mental health care for those people who willingly took care of all of the rest of us.

Thank you for the opportunity to appear before the committee.

[The prepared statement of Dr. Udasin follows:]

TESTIMONY OF IRIS G. UDASIN, M.D.

Chairman Pallone, Ranking Member Deal, and honorable members of the Energy and Commerce Health Subcommittee. I am Iris G. Udasin, M.D., associate professor of Environmental and Occupational Medicine at University of Medicine and Dentistry of New Jersey-Robert Wood Johnson School of Medicine and New Jersey Principal Investigator of the World Trade Center Medical Monitoring and Treatment Program. I am board certified in internal medicine and occupational medicine and serve as director of employee health for the University, and course director for the medical student course in clinical prevention. My experience includes more than 20 years of clinical practice as a "real doctor" diagnosing and treating occupational and environmental illnesses. I have personally examined and treated approximately 1,000 patients who responded to the tragedy at the World Trade Center.

The complex mixture of contaminated material present at the WTC site has resulted in an unprecedented incidence of illness. This material was highly alkaline, leading to the absorption of large particles of cement, glass, asbestos, and other fibrous materials as well as toxic gases from combustion. Submitted with my testimony is a magnified picture of a dust particle that was collected from the WTC site. It is noted that scientists at EOHSI (the Environmental and Occupational Health Sciences Institute, a joint project of UMDNJ and Rutgers University) were involved in characterizing this toxic material. Even 6 years after the tragic event, at least two thirds of our patients present with significant respiratory and gastrointestinal illnesses complicated by mental health disorders. In order to fully appreciate the diseases that are now prevalent in this population, I direct your attention to the photographs of Deputy Chief Lacey Wirkus and some of the other members of the Elizabeth, New Jersey Fire Department that responded to the tragic event. These photographs (see appendix) illustrate the routes of exposure to the toxic material and help to explain the mechanism of the illnesses sustained by the responders. Chief Wirkus donated these photographs for the purpose of representing all of the responders who included construction workers, communication workers, law enforcement, health care workers, as well as all of the paid and volunteer rescue and recovery personnel. Though the individuals in this photograph had respiratory protective equipment, you can see that the masks became weighted down by the contaminated material and did not offer sustained protection from the toxic material. As depicted in the picture, there were huge amounts of dust and smoke debris on his face, clothing, hair, and any other unprotected skin. The work was physically demanding, but these workers persisted, working shifts of 12 hours of more in the days that immediately followed the tragedy.

The toxic material was absorbed by breathing, skin contact, and ingestion, as workers were contaminated even as they ate and drank at the site. This population continued to work at the site, and most of them continue to work today despite suffering from conditions such as asthma, bronchitis, sinusitis, laryngitis, rhinitis, and gastroesophageal reflux. They have persistent symptoms including difficulty breathing, shortness of breath, wheezing, chronic cough, chest pain, head congestion, sinus pressure, sore throat, indigestion, and heartburn. Some patients present with decreased exercise tolerance and fatigue, which potentially could disable them from sensitive law enforcement, fire fighting and construction work. Many of our patients suffer from post traumatic stress disorder and depression. Some of our patients are now not able to work, or are working at lower status jobs. Many have lost or have limited health insurance benefits as they are not able to work at their chosen jobs, or were forced to take early retirement.

Uninsured patients and those without prescription benefit plans clearly need the services of the WTC Medical Monitoring and Treatment Program as they have mini-
mal or no medical care. However, despite the fact that the majority of patients seen at our New Jersey site have at least some health insurance and do have primary care physicians, at least 60 percent of our patients are either untreated or under treated for complicated and comorbid medical and mental health illnesses. Furthermore, typical health insurance covers mental health issues separately and often has insufficient reimbursement rates, rendering mental health care extremely difficult to afford. In order to correctly diagnose these illnesses, it is necessary for the health professionals to spend significant amounts of time simultaneously evaluating the medical, occupational, exposure, and psychological histories, as well as performing a detailed physical and mental health examination. These medical monitoring assessments can take several hours to result in proper diagnosis of our patients, far longer than what insurance covers for typical community encounters. In many instances additional testing is necessary; including spirometry with flow volume loops, x-rays, and laboratory testing. Often specialized testing such as methacholine challenge testing, rhinolaryngoscopy, endoscopy, and overnight polysomnography is needed to appropriately diagnose our patients. The purpose of these specialized tests is to identify and treat unusual presentations of asthma and other respiratory illnesses which are described in the examples below. Many community physicians do not have access to these tests, while our UMDNJ specialists have built up a substantial hands-on knowledge of the unique aspects of routine diseases in this population. Additionally, because of the atypical presentations of our patients, it is difficult to assess these combination of conditions, even for physicians with extensive experience in the individual conditions.

The diagnostic dilemmas faced by examining physicians can be appreciated by the following patient presentations:

Patient 1 is a 31 year old man who presented with a dry cough, sore throat, anxiety, and decreased ability to exercise. He was being treated for anxiety and had a nasal spray that didn’t work and an asthma medication that he took occasionally. Further examination showed the presence of severe sinusitis, as well as asthma. His respiratory symptoms have improved after sinus surgery and proper treatment of his asthma. His anxiety level has improved, but still requires prescription medication for his anxiety and asthma. His exercise tolerance has returned to previous levels.

Patient 2 is a 46 year old man with severe coughing and heartburn. He had been on several prescription cough medicines as well as numerous nasal sprays with no relief. His physical examination was normal, as was his baseline breathing test. However, his methacholine challenge testing was diagnostic of asthma or reactive disease, and he responded well to prescription strength asthma medication, but does require three asthma medications on a daily basis and one medication on an as needed basis. He was also diagnosed with gastroesophageal reflux, and requires prescription strength medication.

Patient 3 is a 39 year old previously healthy man who was extremely short of breath and had a chronic cough. His original diagnosis was pneumonia. He received several courses of antibiotics without relief. Biopsy of his lungs was consistent with sarcoidosis. He currently takes three prescription strength medications, but is unfortunately disabled from his work as a police officer. Once the diagnosis is made, treatment is also complicated and frequently requires the use of several prescription medications. This is clearly a burden to patients who do not have prescription drug coverage. Even in patients who do have coverage, many have prohibitive co-pays, or have insurance constraints which prevent them from receiving brand name medications which might better treat their illnesses.

Beyond the common upper and lower respiratory conditions that affect the majority of our patients, there is concern about the possibility of life-threatening long term chronic illnesses such as pulmonary fibrosis, sarcoidosis, cancer, and heart disease. The monitoring program provides the opportunity for early detection and intervention to potentially lessen the severity of these illnesses. It is our goal to improve treatment of the acute and persistent health problems seen now in our patients, enabling a decrease in future illness and disability and hopefully more productive lives.

In order to continue to allow experienced physicians to treat these complicated illnesses as well as provide adequate diagnostic testing and prescription medications that are needed, as a concerned physician I implore you to continue the funding of the program by the National Institute for Occupational Safety and Health. We continue to provide physical and mental health care for those people who willingly care for all of the rest of us.

Thank you for this opportunity to appear before the subcommittee.
The General Appearance of the Bulk Dust

Analyses by Millette, MVA, in Lioy et al, EHP, 2002
Mr. Pallone. Thank you, and again thank you so much for all that you have done. Next we have Dr. Robin Herbert from Mount Sinai. Thank you.

STATEMENT OF ROBIN HERBERT, M.D. ASSOCIATE PROFESSOR, COMMUNITY AND PREVENTATIVE MEDICINE, MOUNT SINAI SCHOOL OF MEDICINE, NEW YORK, NY

Dr. Herbert. Thank you. Chairman Pallone and other esteemed members of the committee, thank you so much for inviting me to testify today. I want to thank the New Yorkers on the subcommittee, Congressman Weiner, Mr. Engel, and other members from New Jersey, Congressman Ferguson in addition to the chair. Finally I would like to extend my thanks to Congressman Fossella as well as Congresswoman Maloney and Congressman Nadler and the entire New York delegation for their steadfast support of World Trade Center responders.

I direct the data and coordination center of the World Trade Center Medial Monitoring and Treatment Program. This is a consortium of five clinical Centers of Excellence in New York and New Jersey. The WTC Monitoring and Treatment Program diagnoses, treats, documents, and tracks the illnesses that have developed and the workers and volunteers who responded to 9/11.

We perform this work along with our sister Center of Excellence at the New York Fire Department. In the days, weeks, and months that followed September 11, 2001, more than 50,000 hardworking Americans from across the United States came to serve selflessly without concern for their health and well being. These responders included both traditional responders, such as firefighters and law enforcement officers, as well as many non-traditional responders, such as members of the building trades, utility workers, building cleaners, and a vast array of other working groups. And when I talk about responders, I am talking about this broad array of workers and volunteers.

In the months after the terrorist attacks, concerns grew about the potential health effects among the responders. In 2001, as we began to see individuals who appeared to have developed illnesses after performing World Trade Center response work, Congress authorized funding to establish a medical screening program to identify possible World Trade Center related illnesses among responders.

That funding lead to creation of a program that provided free comprehensive medical examinations to over 11,400 World Trade Center responders in the New York, New Jersey, and throughout the Nation. Between 2002 and 2006, as the monitoring and health needs of responders became clearer with the support of Congress, the medical monitoring program consortium, coordinated by Mount Sinai and the Fire Department of New York program, expanded and most recently in fall of 2006, received Federal funding to add comprehensive treatment services.

Thus with your support over time, the programs have evolved into comprehensive, highly skilled centers of excellence for monitoring and treatment of World Trade Center responders. The goals of these monitoring treatment program Centers of Excellence are one, to provide free comprehensive monitoring examinations at regular
intervals for responders. Two, to provide medical and mental health treatment for all responders with World Trade Center related illnesses, regardless of ability to pay. And three, to document and track diseases possibly related to exposure sustained at the World Trade Center.

With Federal support, the Mount Sinai coordinated Center of Excellence has provided initial comprehensive medical and mental health monitoring examinations to over 22,000 responders. Over 6,300 responders have received 47,000 medical and mental health treatment services through our New York and New Jersey consortium Centers of Excellence since 2003.

Demand for these programs remains great today. Even now, 6 years after September 11, about 400 new responders register on a monthly basis via the Mount Sinai phone bank to participate in the program. And in August 2007, 771 new participants signed up for the program.

In September 2006, last year, our consortium published a paper in the highly respected, peer review journal “Environmental Health Perspectives.” This detailed our findings from 9,442 responders who we examined between 2002 and 2004. Key findings included—and this paper is appended to my testimony—46.5 percent reported experiencing new or worsened lower respiratory symptoms during their response work, and 62.5 percent had new or worsened upper respiratory symptoms, with overall rates of upper and lower symptoms at 68.8 percent.

At the time of examination up to two and a half years after the rescue and recovery efforts, 59 percent of responders were still experiencing upper and/or lower respiratory symptoms. One-third of the responders had abnormal breathing tests, and these are objective tests. And among non-smokers, the rate of abnormal breathing tests was double what was expected.

These findings are very similar to what has been reported by the Fire Department of New York who have reported on symptoms in addition to diseases. For example, they reported that 40 percent of firefighters had persistent lower respiratory symptoms and 50 percent has persistent upper respiratory symptoms more than a year after September 11.

I would also like to quickly, if I may, go over by about 1 minute, present a snapshot in time of what we have been seeing with our consortium clinics in the 3 months from April to June 2007 in a treatment program. During that time period, the consortium saw 2,323 patients in 4,693 visits. And this is now the treatment program, not the monitoring. So these are the people who are sick, who are cared for by Dr. Údasin and my other colleagues.

Among that group, 40 percent were treated for lower respiratory conditions. The most common group of conditions were asthma and an asthma-like condition called RADS. Thirty percent had those conditions. Fifty-nine percent had upper respiratory conditions. Thirty-six percent of our patients in treatment had mental health problems, including post-traumatic stress disorder in 21 percent and depression in 15 percent.

We also frequently found social and economic disability among our patients. More than 30 percent of our previously healthy responders were either unemployed, laid off, or on sick leave or dis-
ability. And 28 percent had no medical insurance at some time period during the 3 months.

We still have two major unanswered questions about World Trade Center responders and what their health outlook is. Number one, we do not know and we need to know if the respiratory, gastrointestinal and mental health problems that we are currently observing will continue to persist. If so, for how long and with what degree of severity and associated disability.

Second, we need to know if new health problems will emerge in future years in responders as a consequence of their exposures to the uniquely complex mix of chemical compounds that contaminated the air, soil, and dust of New York City and the aftermath of September 11.

I would like to close by saying that we are very appreciative that we have had resources provided to serve the brave men and women who responded to the disaster. We are very honored to be able to provide treatment and monitoring. We do believe that these services need to continue into the future. Thank you very much.

[The prepared statement of Dr. Herbert follows:]
TESTIMONY

Before
The United States House of Representatives
Committee on Energy and Commerce, Subcommittee on Health

Hearing on
Answering the Call: Medical Monitoring and Treatment of 9/11 Health Effects

Washington, D. C.
September 18, 2007

Presented By
Robin Herbert, M.D.
Director, World Trade Center Medical Monitoring and Treatment Program
Data and Coordination Center
Associate Professor, Department of Community and Preventive Medicine
Mount Sinai School of Medicine
Good morning.

Chairman Frank J. Pallone, Ranking Member Deal, and other esteemed members of the Committee on Energy and Commerce Sub-Committee on Health, I thank you for having invited me to present testimony before you today on “Answering the Call: Medical Monitoring and Treatment of 9/11 Health Effects”.

My name is Robin Herbert, MD. I am an Associate Professor in the Department of Community and Preventive Medicine of the Mount Sinai School of Medicine. I serve as Director of the World Trade Center Medical Monitoring and Treatment Program Data and Coordination Center (DCC) based at Mount Sinai. The World Trade Center Medical Monitoring and Treatment Program is supported by grants from the National Institute for Occupational Safety and Health (NIOSH). The program is a consortium consisting of the DCC and five Clinical Centers of Excellence in New York and New Jersey, with a National Program across the United States, that diagnoses, treats, documents, and tracks the illnesses that have developed in the workers and the volunteers who responded to 9/11.

Also with me is my colleague Philip Landrigan, MD. Dr. Landrigan is a Professor and Chairman of the Department of Community and Preventive Medicine of the Mount Sinai School of Medicine. In his capacity as Chairman of Community and Preventive Medicine at Mount Sinai, he oversees the World Trade Center (WTC) Medical Monitoring and Treatment Program Clinical Center of Excellence at Mount Sinai as well as the World Trade Center Data and Coordination Center.

Today, I shall present a summary of our medical findings in the 9/11 responders. I shall comment also on the critical need for continuing support for Centers of Excellence that have the expertise and the hard-won experience that is essential to sustain high-quality medical follow-up and treatment for these brave men and women.

The Diverse Population of 9/11 Responders

In the days, weeks, and months that followed September 11, 2001, more than 50,000 hard-
working Americans from across the United States responded selflessly – without concern for their health or well-being – when this nation called upon them to serve. They worked at Ground Zero, the former site of the World Trade Center, and at the Staten Island landfill, the principal depository for WTC wreckage. They worked in the Office of the Chief Medical Examiner. They worked beneath the streets of lower Manhattan to search for bodies, to stabilize buildings, to open tunnels, to turn off gas, and to restore essential services.

These workers and volunteers included traditional first responders such as firefighters, law enforcement officers, paramedics and the National Guard. They also included a large and highly diverse population of operating engineers, laborers, ironworkers, building cleaners, telecommunications workers, sanitation workers, and transit workers. These men and women carried out rescue-and-recovery operations, they sorted through the remains of the dead, they restored water and electricity, they cleaned up massive amounts of debris, and in a time period far shorter than anticipated, they deconstructed and removed the remains of broken buildings. Many had no training in response to civil disaster. The highly diverse nature of this workforce, and the absence in most of the groups who responded of any rosters to document who had been present at the site, posed unprecedented challenges for worker protection and medical follow-up.

The 9/11 workforce came from across America. In addition to tens of thousands of men and women from New York, New Jersey, and Connecticut, responders from every state in the nation stepped forward after this attack on the United States and are currently registered in the WTC Medical Monitoring Programs. Particularly large numbers came from California, Massachusetts, Ohio, Illinois, North Carolina, Georgia, and Florida.

The Exposures of 9/11 Responders

The workers and volunteers at Ground Zero were exposed to an intense, complex and unprecedented mix of toxic chemicals. In the hours immediately after the attacks, the combustion of 90,000 liters of jet fuel created a dense plume of black smoke containing volatile organic compounds -including benzene, metals, and polycyclic aromatic hydrocarbons. The collapse of the twin towers (WTC 1 and WTC 2) and then of a third building (WTC 7) produced an enormous dust cloud. This dust contained pulverized cement (60-65% of the total dust mass), uncounted trillions of microscopic glass fibers and glass shards, asbestos, lead, polycyclic aromatic
hydrocarbons, hydrochloric acid, polychlorinated biphenyls (PCBs), organochlorine pesticides, furans and dioxins. Levels of airborne dust were highest immediately after the attack, attaining estimated levels of 1,000 to > 100,000 µg/m³, according to the US Environmental Protection Agency. Firefighters described walking through dense clouds of dust and smoke in those first hours, in which "the air was thick as soup". The high content of pulverized cement made the dust highly caustic (pH 10–11).

The dust and debris gradually settled, and rains on September 14 further diminished the intensity of outdoor dust exposure in lower Manhattan. However, rubble-removal operations repeatedly reaerosolized the dust, leading to continuing intermittent exposures for many months. Fires burned both above and below ground until December 2001.

Workers and volunteers were exposed also to great psychological trauma. Many had already lost friends and family in the attack. In their work at Ground Zero they commonly came unexpectedly upon human remains. Their stress was compounded further by fatigue. Most seriously affected by this psychological trauma were those not previously trained as responders.

Answering the Call: The medical response to 9/11 and the critical need for Centers of Excellence

To provide medical services to the men and women who gave of themselves at Ground Zero, this nation has provided funding to establish and operate Centers of Excellence. These Centers bring together specialists from many fields of medicine who work together to provide state-of-the-art care for the complex diseases that we are seeing in the responders. The Centers also have the capacity to track patterns of disease and to provide information on new and emerging illnesses. Much of what we know about the health effects of the attacks on the WTC has been learned from the federally funded Centers of Excellence, including the World Trade Center Medical Monitoring and Treatment Program Center of Excellence coordinated by the Data and Coordination Center based at Mount Sinai (MMTP) and the Center of Excellence coordinated by the Bureau of Health Services of the Fire Department of New York (FDNY). The program coordinated by Mount Sinai consists of the Data and Coordination Center and a regional consortium of Clinical Centers of Excellence which include: the Environmental & Occupational Health Sciences Institute at
UMDNJ-Robert Wood Johnson Medical School in New Jersey, the World Trade Center Medical Monitoring and Treatment Program Clinical Center at Mount Sinai, the State University of New York Stony Brook/Long Island Occupational and Environmental Health Center, the Bellevue/New York University Occupational and Environmental Medicine Clinic, and the Center for the Biology of Natural Systems at Queens College in New York. In addition, there is a National Program providing services for responders who reside elsewhere in the United States.

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

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

Federal funding for Treatment services which became available for the first time in 2006 has made possible a newly combined Medical Monitoring and Treatment Program. This program is again based in the Centers of Excellence. It integrates all Monitoring and Treatment services and also supports a long needed expansion of services to provide care to a greater number of
responders than ever before. This new federal funding builds on generous but limited private support that had previously enabled some provision of treatment services to responders.

The primary goals of the Monitoring and Treatment Program are:

1. To provide free, comprehensive Monitoring Examinations at regular intervals for responders;
2. To provide medical and mental health treatment for all responders with WTC related illnesses, regardless of ability to pay and;
3. To document diseases possibly related to exposures sustained at the World Trade Center;

Thanks to federal support, over 21,000 WTC responders have received an initial comprehensive medical and mental health monitoring examination through the NY/NJ and National Consortium coordinated by Mount Sinai, and 8,489 responders have also received at least their first follow-up or comprehensive medical examination. Demand for this program remains great. Even now, six years since 9/11, about 400 new participants register to receive baseline screening examinations each month. Astonishingly, in August 2007, 771 new participants registered through our Phone Bank.

Our WTC Medical Treatment Program has also been active. We launched this program in 2003 with support from philanthropic gifts. Philanthropic support provided the sole financial base for the treatment program from 2003 to 2006. Since September 2006, we have begun to receive support for this program from the federal government. To date over 6,300 responders have received 47,000 medical and mental treatment services through this program.

In addition to the NY/NJ and National Consortium of Clinical Centers of Excellence coordinated by Mount Sinai, over 15,000 firefighters have participated in a parallel federally funded Center of Excellence coordinated by, and based at, the Fire Department of New York Bureau of Health Services (FDNY) in New York.

Health Effects Among WTC Responders

Documentation of medical and mental health findings in 9/11 responders followed by timely
dissemination of this information through the peer-reviewed medical literature are essential components of our work. Documentation of our findings enables us to examine trends and patterns of disease and to assess the efficacy of proposed treatments. Dissemination of our findings and our recommendations for diagnosis and treatment to physicians across the United States permits us to share our knowledge and to optimize medical care. Such documentation and dissemination would be well nigh impossible in the absence of federally funded Centers of Excellence.

In September 2006, the Centers of Excellence that comprise our consortium published a paper in the highly respected, peer-reviewed medical journal Environmental Health Perspectives, a journal published by the National Institutes of Health. This report detailed our medical findings from examinations of 9,442 WTC responders whom we and our partner institutions had assessed between July 2002 and April 2004. I have appended this study to my testimony for your review, and I would like to direct your attention to a few key findings:

- Among these 9,442 responders, 46.5% reported experiencing new or worsened lower respiratory symptoms during or after their work at Ground Zero; 62.5% reported new or worsened upper respiratory symptoms; and overall 68.8% reported new or worsened symptoms of either the lower and/or the upper respiratory tract.

- At the time of examination, up to 2 ½ years after the start of the rescue and recovery effort, 59% of the responders whom we saw were still experiencing a new or worsened lower or upper respiratory symptom, a finding which suggests that these conditions may be chronic and that they will require ongoing treatment.

- One third of responders had abnormal pulmonary function test results. One particular breathing test abnormality – decreased forced vital capacity – was found 5 times more frequently in non-smoking WTC responders than in the general, non-smoking population of the United States.

- We found that the frequency and severity of respiratory symptoms was greatest in responders who had been trapped in the dust cloud on 9/11; that frequency and severity were next greatest in those who had been at Ground Zero in the first week after 9/11, but who had not been caught in the dust cloud; and that frequency and severity were lower yet in those who had arrived at Ground Zero after the first week.
These findings fit well with our understanding of exposures at the site and thus lend internal credibility to our data.

- Findings from our program released in 2004 have attested to the fact that in addition to respiratory problems, there also exist significant mental health consequences among WTC responders.

**External Corroboration of our Findings**

The peer-reviewed article that we published one year ago in *Environmental Health Perspectives* gains further credibility by virtue of the fact that the findings we report in it are consistent with findings on 9/11 responders that have been reported by highly credible medical investigators outside of our consortium. The FDNY has published extensively on the burden of respiratory disease among New York firefighters. They have seen a pattern of symptoms that closely resembles what we observed. Forty percent of FDNY firefighter responders had persistent lower respiratory symptoms, and 50% had persistent upper respiratory symptoms more than one year after 9/11. FDNY noted that rates of cough, upper respiratory irritation and gastroesophageal reflux were highest in those firefighters who had been most heavily exposed on 9/11. FDNY physicians have also noted reactive airways disease, and highly accelerated decline in lung function in firefighters as well as in other responders in the year following 9/11.

Our findings receive further corroboration from reports released recently by the New York City Department of Mental Health and Hygiene from the WTC Registry that the health department has established with support from CDC. These reports noted increased rates of asthma and of post-traumatic stress disorder.

**Current Medical Findings in 9/11 Responders**

To provide a “snapshot” that portrays in near real time the patterns of illnesses that we are currently seeing in 9/11 responders, we have recently performed an analysis of responders whom we saw for treatment in our federally funded consortium Centers of Excellence in the 3-month period between April 1, 2007 and June 30, 2007. During this time, 2,323 patients were seen in 4,693 visits. Findings among these responders who sought medical treatment included:
Lower respiratory conditions in 40%. This includes asthma and the asthma-like condition known as reactive airways disease (RADS) in 30%. Other lower respiratory conditions include chronic cough (7%) and chronic obstructive pulmonary disease (5%).

Upper respiratory conditions in 59%. This includes rhinitis (chronic nasal irritation or "runny nose") in 51%, chronic sinusitis in 20% and chronic laryngitis in 5%.

Gastrointestinal conditions in 43%. Most of these were cases of gastro-esophageal reflux disorder (GERD).

Mental health problems in 36%. This includes PTSD, in 21% and depression in 11.6%.

Musculoskeletal conditions in 9% with treatment sought most commonly for lower back problems.

Social disability was also commonly encountered. More than 30% of previously healthy responder patients were either unemployed/laid off, or on sick leave/disability during the 3-month time period of observation. Twenty eight percent had no medical insurance at some point during this period.

Future Health Risks and Unanswered Questions

Two major unanswered questions confront us as we consider the future health outlook for the brave men and women who responded to 9/11:

1. Will the respiratory, gastrointestinal, musculoskeletal and mental health problems that we are currently observing in responders continue to persist? For how long? And with what degree of severity and associated disability? These questions are especially important in the case of those responders who sustained very heavy exposures in the dust cloud on 9/11, in those who served in the first days after 9/11 when exposures were most intense, and in those who had prolonged exposures in the weeks and months after 9/11.

2. Will new health problems emerge in future years in responders as a consequence of their exposures to the uniquely complex mix of chemical compounds that contaminated the air, soil and dust of New York City in the aftermath of 9/11?
Responders were exposed to carcinogens, neurotoxins, and chemicals toxic to the respiratory tract in concentrations and in combinations that never before have been encountered. The long-term consequences of these unique exposures are not yet known.

Concluding Comments

Six years following the attacks on the World Trade Center, thousands of the brave men and women who stood up for America and who worked on rescue, recovery, and clean up at Ground Zero are still suffering. Respiratory illness, psychological distress and financial devastation have become a new way of life for many.

The future health outlook for these responders is uncertain. The possibility is real that illnesses will persist; at least in some, and that new conditions – diseases marked by long latency – will emerge in others.

Only continuing, federally supported medical follow-up of the 9/11 responders through Centers of Excellence that are equipped to comprehensively evaluate responders, to document their medical findings, and to provide compassionate state-of-the-art treatment will resolve these unanswered questions.

Thank you. I shall be pleased to take your questions.
Mr. Pallone. Thank you, Dr. Herbert. From the GAO, Ms. Cynthia Bascetta.

STATEMENT OF CYNTHIA BASCETTA, DIRECTOR, HEALTH CARE ISSUES, GOVERNMENT ACCOUNTABILITY OFFICE, WASHINGTON, DC

Ms. Bascetta. Thank you, Mr. Chairman and members of the subcommittee. I am pleased to be here today to discuss the implementation of federally funded health programs for responders who served in the aftermath of the World Trade Center disaster.

As we all know, these responders were exposed to numerous physical hazards, environmental toxins, and psychological trauma, and it is clear from numerous studies that these exposures continue to exact a toll for many of them 6 years after the attack.

My testimony is based on our July 2007 report which was done for Mr. Fossella, Mrs. Maloney, and Mr. Shays, and four previous testimonies in which we discussed the different programs set up for various categories of responders and highlighted that the World Trade Center Federal responder screening program had accomplished little and lagged behind programs for other responders.

Today, I would like to focus on the status of three things: NIOSH’s awards for treatment to the World Trade Center health program grantees, the services provided for Federal responders, and NIOSH’s efforts to provide services for non-Federal responders residing outside the New York City metro area.

First, last fall NIOSH awarded and set aside funds totaling $51 million from its $75 million appropriation to pay for treatment services, the first time Federal funds were awarded for this purpose. About $44 million was for outpatient treatment, and about $7 million was set aside for inpatient hospital care. Most of the funding went to the fire department and the New York/New Jersey consortium.

In addition to outpatient care, Federal funds paid for 34 hospitalizations of responders so far. NIOSH is now planning how to use the $50 million emergency supplemental appropriation made in May 2007 to continue support for treatment in fiscal year 2008.

Second, we reported this July that HHS has had continuing difficulties ensuring the uninterrupted availability of services for Federal responders who have been eligible only for one-time screening examination. The provision of these screening examinations has been intermittent. HHS suspended them from 2004 to December 2005, resumed them for about a year, then placed the program on hold and suspended scheduling exams from January to May 2007. The last interruption occurred because interagency agreements were not put in place in time to keep the program fully operational.

In addition, the provision of specialty diagnostic services associated with screening has also been intermittent. Responders often need further diagnostic tests from ear, nose, and throat physicians, cardiologists, and pulmonologists. And the program had referred responders and paid for these diagnostic services; however, because the contract with the new provider network did not cover these services, they were unavailable from April 2006 until the contract was modified in March 2007.
NIOSH has considered expanding the services for Federal responders to include monitoring examinations, the same follow-up physical and mental health exams provided to other categories of responders. Without this follow-up, health conditions may not be diagnosed and treated, and knowledge of the health effects caused by the disaster may be incomplete.

Third, NIOSH has not ensured the availability of screening and monitoring services for non-Federal responders who reside outside the New York City area, although it recently took steps to expand their availability. Similar to the intermittent service pattern for Federal responders, NIOSH’s arrangements for a network of occupational health clinics to provide services nationwide were on again, off again. NIOSH renewed its efforts to expand the provider network, however, and in May of this year completed about 20 exams.

Mr. Chairman, despite HHS’s recent consideration of ways to add monitoring for Federal responders and to improve the availability of screening and monitoring services for Federal and non-Federal responders nationwide, its efforts remain incomplete.

Moreover, the start and stop history of the Department’s efforts to serve these groups does not provide assurance that the latest efforts to extend screening and monitoring services to these responders will be both successful and sustained over time.

As a result, we recommended in our July 2007 report that the Secretary take expeditious action to ensure the availability of health screening and monitoring services for all people who responded to the attack on the World Trade Center, regardless of their employer or their residence. To date, HHS has not responded to our recommendation. That completes my statement. I would be happy to answer your questions.

[The prepared statement of Ms. Bascetta follows:]
SEPTEMBER 11

Improvements Needed in Availability of Health Screening and Monitoring Services for Responders

Statement of Cynthia A. Bascetta
Director, Health Care
IMPROVEMENTS NEEDED IN AVAILABILITY OF HEALTH SCREENING AND MONITORING SERVICES FOR RESPONDERS

What GAO Found

In July 2007, following a re-examination of the status of the WTC health programs, GAO recommended that the Secretary of HHS take expeditions action to ensure that health screening and monitoring services are available to all people who responded to the WTC attack, regardless of who their employer was or where they reside. As of early September 2007 the department has not responded to this recommendation.

As GAO reported in July 2007, HHS's WTC Federal Responder Screening Program has had difficulties ensuring the uninterrupted availability of screening services for federal responders. From January 2007 to May 2007, the program stopped scheduling screening examinations because there was a change in the program's administration and certain interagency agreements were not established in time to keep the program fully operational. From April 2006 to March 2007, the program stopped scheduling and paying for specialty diagnostic services associated with screening.

NIOSH, the administrator of the program, has been considering expanding the program to include monitoring, that is, follow-up physical and mental health examinations, but has not done so. If federal responders do not receive monitoring, health conditions that arise later may not be diagnosed and treated, and knowledge of the health effects of the WTC disaster may be incomplete.

NIOSH has not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC area, although it recently took steps toward expanding the availability of these services. In late 2002, NIOSH arranged for a network of occupational health clinics to provide screening services. This effort ended in July 2004, and until June 2005 NIOSH did not fund screening or monitoring services for nonfederal responders outside the NYC area. In June 2005, NIOSH funded the Mount Sinai School of Medicine Data and Coordination Center (DCC) to provide screening and monitoring services, however, DCC had difficulty establishing a nationwide network of providers and contracted with only 10 clinics in seven states. In 2006, NIOSH began to explore other options for providing these services, and in May 2007 it took steps toward expanding the provider network.

NIOSH has awarded treatment funds to four WTC health programs in the NYC area. In fall 2006, NIOSH awarded $44 million for outpatient treatment and set aside $7 million for hospital care. The New York/New Jersey WTC Consortium and the New York City Fire Department WTC program, which received the largest awards, used NIOSH's funding to continue outpatient services, offer full coverage for prescriptions, and cover hospital care.

To view the full-product, including the scope and methodology, click on the link above. For more information, contact Cynthia A. Baccarella at (202) 512-7114 or baccarela@gao.gov.
Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss our work on the implementation of federally funded health programs for individuals affected by the September 11, 2001, attack on the World Trade Center (WTC). Tens of thousands of people served as responders in the aftermath of the WTC disaster, including New York City Fire Department (FDNY) personnel, federal government personnel, and other government and private-sector workers and volunteers from New York and elsewhere. By responders we are referring to anyone involved in rescue, recovery, or cleanup activities at or near the vicinity of the WTC or the Staten Island site. These responders were exposed to numerous physical hazards, environmental toxins, and psychological trauma. Six years after the destruction of the WTC buildings, concerns remain about the physical and mental health effects of the disaster; the long-term nature of some of these health effects, and the availability of health care services for those affected.

Following the WTC attack, federal funding was provided to government agencies and private organizations to establish programs for screening, monitoring, or treating responders for illnesses and conditions related to the WTC disaster; these programs are referred to in this testimony as the WTC health programs. The Department of Health and Human Services (HHS) funded the programs as separate efforts serving different categories of responders—for example, firefighters, other workers and volunteers, or federal responders—and has responsibility for coordinating program efforts.

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1 A list of abbreviations used in this testimony is in app. 1.
2 The Staten Island site is the landfill that is the off-site location of the WTC recovery operation.
3 In this testimony, "screening" refers to initial physical and mental health examinations of affected individuals. "Monitoring" refers to tracking the health of individuals over time, either through periodic surveys or through follow-up physical and mental health examinations.
4 One of the WTC health programs, the WTC Health Registry, also includes people living or attending school in the area of the WTC or working or present in the vicinity on September 11, 2001.
We have previously reported on the implementation of these programs and their progress in providing services to responders, who reside in all 50 states and the District of Columbia. In 2005 and 2006, we reported that one of the WTC health programs, HHS's WTC Federal Responder Screening Program, which was established to provide one-time screening examinations for responders who were federal employees when they responded to the WTC attack, had accomplished little. 1 HHS established the program in June 2003, suspended it in March 2004, and resumed it in December 2005. In September 2006, we reported that the program was registering and screening federal responders and that a total of 507 federal workers had received screening examinations. We also reported that the National Institute for Occupational Safety and Health (NIOSH), the component of HHS's Centers for Disease Control and Prevention (CDC) responsible for administering most of the WTC health programs, had begun to take steps to provide access to screening, monitoring, and treatment services for nonfederal responders who resided outside the New York City (NYC) metropolitan area.

In September 2006 we also testified that CDC had begun, but not completed, the process of allocating funding from a $75 million appropriation made in fiscal year 2006 for WTC health programs for responders. 2 This was the first appropriation specifically available for treatment for responders. We reported that in August 2006 CDC had awarded $1.5 million from this appropriation to the FDNY WTC Medical Monitoring and Treatment Program and almost $1.1 million to the New York/New Jersey (NY/NJ) WTC Consortium for treatment-related

1See, for example, GAO, September 11: HHS Has Screened Additional Federal Responders for World Trade Center Health Effects, but Plans for Awarding Funds for Treatment Are Incomplete, GAO-06-102T (Washington, D.C.: Sept. 8, 2006). A list of related GAO products is included at the end of this testimony.


3See GAO-06-102T.

4In general, the WTC health programs provide services in the NYC metropolitan area.


6See GAO-06-102T.
activities. We also reported that CDC officials told us they could not predict how long the funding from the appropriation would support four WTC health programs that provide treatment services.

My testimony today is primarily based on our report issued in July 2007.1 As you requested, I will discuss the status of (1) services provided by the WTC Federal Responder Screening Program, (2) NIOSH’s efforts to provide services for nonfederal responders residing outside the NYC metropolitan area, and (3) NIOSH’s awards to grantees for treatment services.

To assess the status of services provided by the WTC Federal Responder Screening Program, we obtained and reviewed program data and documents from HHS, including applicable interagency agreements. We interviewed officials from the HHS entities involved in administering and implementing the program: NIOSH and two HHS offices, the Federal Occupational Health Services (FOH)2 and the Office of the Assistant Secretary for Preparedness and Response (ASPR).3 To assess the status of NIOSH’s efforts to provide services for nonfederal responders residing outside the NYC metropolitan area, we obtained documents and interviewed officials from NIOSH. We also interviewed officials of organizations that worked with NIOSH to provide services for nonfederal responders residing outside the NYC metropolitan area, including the Mount Sinai School of Medicine in NYC and the Association of Occupational and Environmental Clinics (AOEC)—a network of university-affiliated and other private occupational health clinics across the United States and in Canada. To assess the status of NIOSH’s awards to grantees for treatment services, we obtained documents and interviewed officials from NIOSH. We also interviewed officials from two


2FOH is a service unit within HHS’s Program Support Center that provides occupational health services to federal government departments and agencies located throughout the United States.

3ASPR coordinates and directs HHS’s emergency preparedness and response program. In December 2006 the Office of Public Health and Emergency Preparedness became ASPR. We refer to that office as ASPR throughout this testimony, regardless of the time period discussed.
WTC health program grantees from which the majority of responders receive medical services: the NY/NJ WTC Consortium and the FDNY WTC program. In addition, we interviewed officials from the American Red Cross, which has funded treatment services for responders. In our review of the WTC health programs, we relied primarily on information provided by agency officials and contained in government publications. We compared the information with information in other supporting documents, when available, to determine its consistency and reasonableness. We determined that the information we obtained was sufficiently reliable for our purposes. We conducted our work from November 2006 through July 2007—and updated selected information in August and September 2007—in accordance with generally accepted government auditing standards.

In brief, we reported in July 2007 that HHS’s WTC Federal Responder Screening Program had had difficulties ensuring the uninterrupted availability of screening services for federal responders and that NIOSH, the administrator of the program, was considering expanding the program to include monitoring but had not done so. We also reported that NIOSH had not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area, although it had recently taken steps toward expanding the availability of these services. As a result of our assessment of these programs, we recommended that the Secretary of HHS expediteously take action to ensure that screening and monitoring services are available for all responders, including federal responders and nonfederal responders residing outside of the NYC metropolitan area. As of early September 2007 the department has not responded to this recommendation. Finally, we also reported that NIOSH had awarded and set aside treatment funds totaling $51 million from its $75 million appropriation for four NYC-area programs.

\[\text{Footnotes:} \]
\[\text{NIOSH} \text{ provides funds in the program through cooperative agreements, but refers to award recipients as grantees. Therefore, in this testimony we use the term grantees when referring to NIOSH's award recipients.} \]
\[\text{In previous reports we have also referred to this program as the worker and volunteer WTC program.} \]
Background

The tens of thousands of individuals who responded to the September 11, 2001, attack on the WTC experienced the emotional trauma of the disaster and were exposed to a noxious mixture of dust, debris, smoke, and potentially toxic contaminants, such as pulverized concrete, fiberglass, particulate matter, and asbestos. A wide variety of health effects have been experienced by responders to the WTC attack, and several federally funded programs have been created to address the health needs of these individuals.

Health Effects

Numerous studies have documented the physical and mental health effects of the WTC attacks. Physical health effects included injuries and respiratory conditions, such as sinusitis, asthma, and a new syndrome called WTC cough, which consists of persistent coughing accompanied by severe respiratory symptoms. Almost all firefighters who responded to the attack experienced respiratory effects, including WTC cough. One study suggested that exposed firefighters on average experienced a decline in lung function equivalent to that which would be produced by 12 years of aging. A recently published study found a significantly higher risk of newly diagnosed asthma among responders that was associated with increased exposure to the WTC disaster site. Commonly reported mental health effects among responders and other affected individuals included symptoms associated with post-traumatic stress disorder (PTSD).

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8There is not a definitive count of the number of people who served as responders. Estimates have ranged from about 40,000 to about 91,000.


10Bianco et al., “Pulmonary Function.”

11Wheeler et al., “Asthma Diagnosed.”
depression, and anxiety. Behavioral health effects such as alcohol and tobacco use have also been reported.

Some health effects experienced by responders have persisted or worsened over time, leading many responders to begin seeking treatment years after September 11, 2001. Clinicians involved in screening, monitoring, and treating responders have found that many responders’ conditions—both physical and psychological—have not resolved and have developed into chronic disorders that require long-term monitoring. For example, findings from a study conducted by clinicians at the NY/NJ WTC Consortium show that at the time of examination, up to 2.5 years after the start of the rescue and recovery effort, 50 percent of responders enrolled in the program were still experiencing new or worsened respiratory symptoms.10 Experts studying the mental health of responders found that about 2 years after the WTC attack, responders had higher rates of PTSD and other psychological conditions compared to others in similar jobs who were not WTC responders and others in the general population.11 Clinicians also anticipate that other health effects, such as immunological disorders and cancers, may emerge over time.

Overview of WTC Health Programs

There are six key programs that currently receive federal funding to provide voluntary health screening, monitoring, or treatment at no cost to responders.12 The six WTC health programs, shown in table 1, are (1) the FDNY WTC Medical Monitoring and Treatment Program; (2) the NY/NJ WTC Consortium, which comprises five clinical centers in the NY/NJ

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12. In addition to these programs, a New York State responder screening program received federal funding for screening New York State employees and National Guard personnel who responded to the WTC attack in an official capacity. This program ended its screening examinations in November 2003.
area; (3) the WTC Federal Responder Screening Program; (4) the WTC Health Registry; (5) Project COPE; and (6) the Police Organization Providing Peer Assistance (POPPA) program. The programs vary in aspects such as the HHS administering agency or component responsible for administering the funding, the implementing agency, component, or organization responsible for providing program services, eligibility requirements, and services.

The NYU WTC Consortium consists of five clinical centers operated by (1) Mount Sinai-St. Luke’s and Roosevelt Center for Occupational and Environmental Medicine; (2) Long Island Occupational and Environmental Health Center at SUNY, Stony Brok; (3) New York University School of Medicine/Wellcome Hospital Center; (4) Center for the Biology of Natural Systems at CUNY, Queens College; and (5) University of Medicine and Dentistry of New Jersey Robert Wood Johnson Medical School, Environmental and Occupational Health Sciences Institute. Mount Sinai’s clinical center, which is the largest of the five centers, also receives federal funding to operate a data and coordination center to coordinate the work of the five clinical centers and conduct outreach and education, quality assurance, and data management for the NYU WTC Consortium.

Project COPE and the POPPA program provide mental health services to members of the New York City Police Department (NYPD) and operate independently of the NYPD.
<table>
<thead>
<tr>
<th>Program</th>
<th>HHS administering agency or component</th>
<th>Implementing agency, component, or organization</th>
<th>Eligible population</th>
<th>Services provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>FDNY WTC Medical Monitoring and Treatment Program</td>
<td>NIOSH</td>
<td>FDNY Bureau of Health Services</td>
<td>Firefighters and emergency medical service technicians</td>
<td>• Initial screening</td>
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<td></td>
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<td>• Follow-up medical monitoring</td>
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<td>• Treatment of WTC-related physical and mental health conditions</td>
</tr>
<tr>
<td>NY/NJ WTC Consortium</td>
<td>NIOSH</td>
<td></td>
<td>All responders, excluding FDNY firefighters and emergency medical service technicians and current federal employees¹</td>
<td>• Initial screening</td>
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<td>• Follow-up medical monitoring</td>
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<td>• Treatment of WTC-related physical and mental health conditions</td>
</tr>
<tr>
<td>WTC Federal Responder Screening Program</td>
<td>NIOSH*</td>
<td>FDH</td>
<td>Current federal employees who responded to the WTC attack in an official capacity</td>
<td>• Onsite screening</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Referrals to employee assistance programs and specialty diagnostic services¹</td>
</tr>
<tr>
<td>WTC Health Registry</td>
<td>Agency for Toxic Substances and Disease Registry (ATSDR)</td>
<td>NYC Department of Health and Mental Hygiene</td>
<td>Responders and people living or attending school in the area of the WTC or working or present in the vicinity on September 11, 2001</td>
<td>• Long-term monitoring through periodic surveys</td>
</tr>
<tr>
<td>Project COPE</td>
<td>NIOSH</td>
<td>Collaboration between the NYC Police Foundation and Columbia University Medical Center</td>
<td>New York City Police Department (NYPD) uniformed and civilian employees and their family members</td>
<td>• Hotline, mental health counseling, and referral services; some services provided by Columbia University clinic staff and some by other clinicians</td>
</tr>
<tr>
<td>POPPA program</td>
<td>NIOSH</td>
<td>POPPA program</td>
<td>NYPD uniformed employees</td>
<td>• Hotline, mental health counseling, and referral services; some services provided by trained NYPD officers and some by mental health professionals</td>
</tr>
</tbody>
</table>

Source: OPM analysis of information from NIOSH, FDNY, FDH, FDNY, FDNY, NYC WTC Consortium, the NYC Department of health and Mental Hygiene, the POPPA program, and Project COPE.

Note: Some of these federally funded programs have also received funds from the American Red Cross and other private organizations.

¹In February 2006, ASPR and NIOSH reached an agreement to have former federal employees screened by the NY/NJ WTC Consortium.

²Until December 28, 2006, ASPR was the administrator.
The WTC health programs that are providing screening and monitoring are tracking thousands of individuals who were affected by the WTC disaster. As of June 2007, the FDNY WTC program had screened about 14,500 responders and had conducted follow-up examinations for about 13,500 of these responders, while the NY/NJ WTC Consortium had screened about 20,000 responders and had conducted follow-up examinations for about 8,000 of these responders. Some of the responders include nonfederal responders residing outside the NYC metropolitan area. As of June 2007, the WTC Federal Responder Screening Program had screened 1,005 federal responders and referred 281 responders for employee assistance program services or specialty diagnostic services. In addition, the WTC Health Registry, a monitoring program that consists of periodic surveys of self-reported health status and related studies but does not provide in-person screening or monitoring, collected baseline health data from over 71,000 people who enrolled in the Registry. In the winter of 2006, the Registry began its first adult follow-up survey, and as of June 2007 over 36,000 individuals had completed the follow-up survey.

In addition to providing medical examinations, FDNY's WTC program and the NY/NJ WTC Consortium have collected information for use in scientific research to better understand the health effects of the WTC attack and other disasters. The WTC Health Registry is also collecting information to assess the long term public health consequences of the disaster.

Federal Funding and Coordination of WTC Health Programs

Beginning in October 2001 and continuing through 2003, FDNY's WTC program, the NY/NJ WTC Consortium, the WTC Federal Responder Screening Program, and the WTC Health Registry received federal funding to provide services to responders. This funding primarily came from appropriations to the Department of Homeland Security's Federal Emergency Management Agency (FEMA), as part of the approximately

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[Page 9] GAO-07-133RST
$8.8 billion that the Congress appropriated to FEMA for response and recovery activities after the WTC disaster.\footnote{See Consolidated Appropriations Resolution, 2003, Pub. L. No. 108-7, 117 Stat. 11, 517; 2002 Supplemental Appropriations Act for Further Recovery from and Response to Terrorist Attacks on the United States, Pub. L. No. 107-205, 115 Stat. 820, 894; Department of Defense and Emergency Supplemental Appropriations for Recovery from and Response to Terrorist Attacks on the United States Act, 2002, Pub. L. No. 107-117, 115 Stat. 2250, 2259, and 2001 Emergency Supplemental Appropriations Act for Recovery from and Response to Terrorist Attacks on the United States, Pub. L. No. 107-38, 115 Stat. 220-221.} FEMA entered into interagency agreements with HHS agencies to distribute the funding to the programs. For example, FEMA entered into an agreement with NIOSH to distribute $60 million appropriated in 2003 that was available for monitoring.\footnote{The statute required CDC, in spending such funds, to give first priority to specified existing programs that administer baseline and follow-up screening; clinical examinations; or long-term medical health monitoring, analysis, or treatment for emergency services personnel or rescue and recovery personnel. It required CDC to give secondary priority to similar programs coordinated by other entities working with the State of New York and NYC. Pub. L. No. 109-148, § 2013(c), 119 Stat. 2984.} FEMA also entered into an agreement with ASPR to administer the WTC Federal Responder Screening Program. A $75 million appropriation to CDC in fiscal year 2006 for purposes related to the WTC attack resulted in additional funding for the monitoring activities of the FDNY WTC program, NY/NJ WTC Consortium, and the Registry.\footnote{U.S. Troop Readiness, Veterans’ Care, Katrina Recovery, and Iraq Accountability Appropriations Act, 2007, Pub. L. No. 110-38, ch. 5, 121 Stat. 112, 126 (2007).} The $75 million appropriation to CDC in fiscal year 2006 also provided funds that were awarded to the FDNY WTC program, the NY/NJ WTC Consortium, Project COPE, and the POPPA program for treatment services for responders. An emergency supplemental appropriation to CDC in May 2007 included an additional $50 million to carry out the same activities provided for in the $75 million appropriation made in fiscal year 2006.\footnote{\textsuperscript{5}} The President’s proposed fiscal year 2008 budget for HHS includes $25 million for treatment of WTC-related illnesses for responders.

In February 2006, the Secretary of HHS designated the Director of NIOSH to take the lead in ensuring that the WTC health programs are well coordinated, and in September 2006 the Secretary established a WTC Task Force to advise him on federal policies and funding issues related to responders’ health conditions. The chair of the task force is HHS’s Assistant Secretary for Health, and the vice chair is the Director of NIOSH. The task force reported to the Secretary of HHS in early April 2007.
WTC Federal Responder Screening Program Has Had Difficulties Ensuring the Availability of Screening Services, and NIOSH Was Considering Expanding the Program to Include Monitoring

HHS’s WTC Federal Responder Screening Program has had difficulties ensuring the uninterrupted availability of services for federal responders. First, the provision of screening examinations has been intermittent. (See fig. 1.) After resuming screening examinations in December 2005 and conducting them for about a year, HHS again placed the program on hold and suspended scheduling of screening examinations for responders from January 2007 to May 2007. This interruption in service occurred because there was a change in the administration of the WTC Federal Responder Screening Program, and certain interagency agreements were not established in time to keep the program fully operational. In late December 2006, ASPR and NIOSH signed an interagency agreement giving NIOSH $2.1 million to administer the WTC Federal Responder Screening Program.67 Subsequently, NIOSH and FOH needed to sign a new interagency agreement to allow FOH to continue to be reimbursed for providing screening examinations. It took several months for the agreement between NIOSH and FOH to be negotiated and approved, and scheduling of screening examinations did not resume until May 2007.68

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67 The program previously suspended examinations from March 2004 to December 2005. See GAO-06-837T.
68 The agreement was a modification of ASPR’s February 2006 interagency agreement with NIOSH that covers screenings for former federal employees.
69 Before an agreement between NIOSH and FOH could be signed, the agreement between ASPR and NIOSH required several technical corrections. The revised ASPR-NIOSH agreement extended the availability of funding for the WTC Federal Responder Screening Program to April 30, 2008.
Figure 1: Timeline of Key Actions Related to the WTC Federal Responder Screening Program

- **March 2003:** FEMA and ASPR enter agreement to establish WTC Federal/Responder Screening Program with ASPR as the administrator
- **April 2003:** ASPR and FDH enter agreement for conducting screening examinations
- **June 2003:** FDH begins screening examinations
- **January 2004:** FDH places program on hold
- **March 2004:** FDH conducts last screening examination
- **April 2005:** ASPR and ATSDR enter agreement to identify and contact local responders and establish a database of names
- **July 2006:** ASPR and FDH enter agreement to expand clinical services and provide referrals for specialty diagnostic services
- **October 2006:** ASPR opens Web site for federal responders to register for screening examinations
- **December 2006:** FDH resumes examinations for current federal employees
- **February 2007:** ASPR and NIOSH reach agreement for screening former federal employees
- **April 2006:** FDH stops scheduling and paying for specialty diagnostic services
- **December 2006:** ASPR transfers administrative of the program to NIOSH
- **January 2007:** FDH places program on hold
- **March 2007:** FDH resumes scheduling and paying for specialty diagnostic services to previously screened responders
- **May 2007:** FDH resumes scheduling of screening examinations

Period during which program was conducting screening examinations
Period during which program was scheduling and paying for specialty diagnostic services

Source: GAO analysis of information from ASPR, FDH, NIOSH, and FDAA.
Second, the program's provision of specialty diagnostic services has also been intermittent. After initial screening examinations, responders often need further diagnostic services by ear, nose, and throat doctors; cardiologists; and pulmonologists; and FOH had been referring responders to these specialists and paying for the services. However, the program stopped scheduling and paying for these specialty diagnostic services in April 2006 because the program's contract with a new provider network did not cover these services. In March 2007, FOH modified its contract with the provider network and resumed scheduling and paying for specialty diagnostic services for federal responders.

In July 2007 we reported that NIOSH was considering expanding the WTC Federal Responder Screening Program to include monitoring examinations—follow-up physical and mental health examinations—and was assessing options for funding and delivering these services. If federal responders do not receive this type of monitoring, health conditions that arise later may not be diagnosed and treated, and knowledge of the health effects of the WTC disaster may be incomplete. In February 2007, NIOSH sent a letter to FEMA, which provides the funding for the program, asking whether the funding could be used to support monitoring in addition to the on-site screening currently offered. A NIOSH official told us that as of August 2007 the agency had not received a response from FEMA. NIOSH officials told us that if FEMA did not agree to pay for monitoring of federal responders, NIOSH would consider using other funding. According to a NIOSH official, if FEMA or NIOSH agrees to pay for monitoring of federal

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Note: The WTC Federal Responder Screening Program serves current federal employees who responded to the WTC attack in an official capacity. In February 2006, ASPH and NIOSH reached an agreement to have former federal employees screened by the NY/NJ/WWC Consortium. We refer to that office as ASPH throughout this figure, regardless of the time period being discussed.

In April 2006, FOH contracted with a new provider network to provide various services for all federal employees, such as immunizations and vision tests. The contract with the new provider network did not cover specialty diagnostic services by ear, nose, and throat doctors; cardiologists; and pulmonologists. Although the previous provider network had provided these services, the new provider network and the IHEC contract officer interpreted the statement of work in the new contract as not including these specialty diagnostic services.
NIOSH has not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area, although it recently took steps toward expanding the availability of these services. Initially, NIOSH made two efforts to provide screening and monitoring services for these responders, the exact number of which is unknown. The first effort began in late 2002 when NIOSH awarded a contract for about $100,000 to the Mount Sinai School of Medicine to provide screening services for nonfederal responders residing outside the NYC metropolitan area and directed it to establish a subcontract with AOEIC. AOEIC then subcontracted with 32 of its member clinics across the country to provide screening services. From February 2003 to July 2004, the 32 AOEIC member clinics screened 598 nonfederal responders nationwide. AOEIC experienced challenges in providing these screening services. For example, many nonfederal responders did not enroll in the program because they did not live near an AOEIC clinic, and the administration of the program required substantial coordination among AOEIC, AOEIC member clinics, and Mount Sinai.

Mount Sinai's subcontract with AOEIC ended in July 2004, and from August 2004 until June 2005, NIOSH did not fund any organization to provide services to nonfederal responders outside the NYC metropolitan area. During this period, NIOSH focused on providing screening and monitoring services for nonfederal responders in the NYC metropolitan area. In June 2005, NIOSH began its second effort by awarding $776,000 to the Mount Sinai School of Medicine to provide screening and monitoring services to nonfederal responders outside the NYC metropolitan area.

According to the NYC Department of Health and Mental Hygiene, about 7,000 nonfederal and federal responders residing outside the NYC metropolitan area have enrolled in the WTC Health Registry.

Around that time, NIOSH was providing screening services for nonfederal responders in the NYC metropolitan area through the NYU WTC Consortium and the FNNW WTC program. Nonfederal responders residing outside the NYC metropolitan area were able to travel at their own expense to the NYC metropolitan area to obtain screening services through the NYU WTC Consortium.

In early 2008, AOEIC applied to NIOSH to use its national network of member clinics to provide screening and monitoring for nonfederal responders residing outside the NYC metropolitan area, but NIOSH rejected AOEIC's application for several reasons, including that the application did not adequately address how to coordinate and implement a monitoring program with complex data collection and reporting requirements.
Sinai School of Medicine Data and Coordination Center (DCC) to provide both screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area. In June 2006, NIOSH awarded an additional $788,000 to DCC to provide screening and monitoring services for these responders. NIOSH officials told us that they assigned DCC the task of providing screening and monitoring services to nonfederal responders outside the NYC metropolitan area because the task was consistent with DCC’s responsibilities for the NY/NJ WTC Consortium, which includes data monitoring and coordination. DCC, however, had difficulty establishing a network of providers that could serve nonfederal responders residing throughout the country—ultimately contracting with only 10 clinics in seven states to provide screening and monitoring services. DCC officials said that as of June 2007 the 10 clinics were monitoring 180 responders.

In early 2006, NIOSH began exploring how to establish a national program that would expand the network of providers to provide screening and monitoring services, as well as treatment services, for nonfederal responders residing outside the NYC metropolitan area. According to NIOSH, there have been several challenges involved in expanding a network of providers to screen and monitor nonfederal responders nationwide. These include establishing contracts with clinics that have the occupational health expertise to provide services nationwide, establishing patient data transfer systems that comply with applicable privacy laws, navigating the institutional review board process for a large provider network, and establishing payment systems with clinics participating in a national network of providers. On March 15, 2007, NIOSH issued a formal request for information from organizations that have an interest in and the capability of developing a national program for responders residing...

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8Contracts were originally established with 11 clinics in eight states, but 1 clinic discontinued its participation in the program after conducting one examination. The 10 active clinics are located in seven states: Arkansas, California, Illinois, Maryland, Massachusetts, New York, and Ohio. Of the 10 active clinics, 7 are AESC member clinics.
9According to NIOSH and DCC officials, efforts to provide monitoring services to federal responders residing outside the NYC metropolitan area may be included in the national program.
10Institutional review boards are groups that have been formally designated to review and monitor biomedical research involving human subjects, such as research based on data collected from screening and monitoring examinations.
outside the NYC metropolitan area.¹ In this request, NIOSH described the scope of a national program as offering screening, monitoring, and treatment services to about 3,000 nonfederal responders through a national network of occupational health facilities. NIOSH also specified that the program’s facilities should be located within reasonable driving distance to responders and that participating facilities must provide copies of examination records to DCC. In May 2007, NIOSH approved a request from DCC to redirect about $125,000 from the June 2006 award to establish a contract with a company to provide screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area. Subsequently, DCC contracted with QTC Management, Inc., one of the four organizations that had responded to NIOSH’s request for information. DCC’s contract with QTC does not include treatment services, and NIOSH officials are still exploring how to provide and pay for treatment services for nonfederal responders residing outside the NYC metropolitan area. QTC has a network of providers in all 50 states and the District of Columbia and can use internal medicine and occupational medicine doctors in its network to provide these services. In addition, DCC and QTC have agreed that QTC will identify and subcontract with providers outside of its network to screen and monitor nonfederal responders who do not reside within 25 miles of a QTC provider.² In June 2007, NIOSH awarded $800,000 to DCC for coordinating the provision of screening and monitoring examinations, and QTC will receive a portion of this award from DCC to provide about 1,000 screening and monitoring examinations through May 2008. According to a NIOSH official, QTC’s providers have begun conducting screening examinations, and by the end


²QTC is a private provider of government-outsourced occupational health and disability examination services.

³Some nonfederal responders residing outside the NYC metropolitan area may have access to privately funded treatment services. In June 2006, the American Red Cross funded AIDC to provide treatment services for these responders. As of June 2007, AIDC had contracted with 46 of its member clinics located in 27 states and the District of Columbia to provide these services. An American Red Cross official told us in September 2007 that funding for AIDC to provide treatment services would continue through June 2008.

⁴As of June 2007, DCC identified 1,131 nonfederal responders residing outside the NYC metropolitan area who requested screening and monitoring services and were too ill or lacked financial resources to travel to NYC or any of DCC’s 10 contracted clinics.
of August 2007, 18 nonfederal responders had completed screening examinations, and 55 others had been scheduled.

In fall 2006, NIOSH awarded and set aside funds totaling $51 million from its $75 million appropriation for four WTC health programs in the NYC metropolitan area to provide treatment services to responders enrolled in these programs. Of the $51 million, NIOSH awarded about $44 million for outpatient services to the FDNY WTC program, the NY/NJ WTC Consortium, Project COPE, and the POPPA program. NIOSH made the largest awards to the two programs from which almost all responders receive medical services, the FDNY WTC program and NY/NJ WTC Consortium (see table 2). In July 2007 we reported that officials from the FDNY WTC program and the NY/NJ WTC Consortium expected that their awards for outpatient treatment would be spent by the end of fiscal year 2007.⁶⁵ In addition to the $44 million it awarded for outpatient services, NIOSH set aside about $7 million for the FDNY WTC program and NY/NJ WTC Consortium to pay for responders' WTC-related inpatient hospital care as needed.⁶⁶

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⁶⁵In August 2007 a NIOSH official told us that NIOSH did not expect that all of these funds would be spent by September 30, 2007.

⁶⁶In addition to funding from NIOSH, the FDNY WTC program and the NY/NJ WTC Consortium received funding in 2006 from the American Red Cross to provide treatment services. In September 2007 an official from the American Red Cross told us that it was the organization's understanding that most of the clinics in the NY/NJ WTC Consortium had expended the American Red Cross funds but that one of the Consortium's clinics was expected to request a no-cost 6-month extension up to the end of calendar year 2007. The American Red Cross had already granted a similar extension for the same period to the FDNY WTC program.

⁶⁶Of the $54 million remaining from the $75 million appropriation to CDC, NIOSH used about $35 million to support monitoring and other WTC-related health services conducted by the FDNY WTC program and NY/NJ WTC Consortium. NIOSH awarded $9 million to the WTC Health Registry to continue its collection of health data.
Table 2: NIOSH Awards to WTC Health Programs for Providing Treatment Services, 2006

<table>
<thead>
<tr>
<th>WTC health program</th>
<th>Amount of award</th>
<th>Date of award</th>
</tr>
</thead>
<tbody>
<tr>
<td>NY/NJ WTC Consortium</td>
<td>$20.0</td>
<td>October 25, 2006</td>
</tr>
<tr>
<td>FDNY WTC Medical Monitoring and Treatment Program</td>
<td>18.7</td>
<td>October 25, 2006</td>
</tr>
<tr>
<td>Project COPE</td>
<td>3.7</td>
<td>September 19, 2006</td>
</tr>
<tr>
<td>POPPA program</td>
<td>1.5</td>
<td>September 19, 2006</td>
</tr>
<tr>
<td><strong>Total amount of awards</strong></td>
<td><strong>$44.0</strong></td>
<td></td>
</tr>
</tbody>
</table>

Source: NIOSH

*Amount is rounded to the nearest $0.1 million.

NIOSH will provide $1 million annually to Project COPE beginning in September 2006 through September 2008, for a total award of $3 million.

NIOSH will provide $500,000 annually to the POPPA program beginning in September 2006 through September 2008, for a total award of $1.5 million.

The FDNY WTC program and NY/NJ WTC Consortium used their awards from NIOSH to continue providing treatment services to responders and to expand the scope of available treatment services. Before NIOSH made its awards for treatment services, the treatment services provided by the two programs were supported by funding from private philanthropies and other organizations. According to officials of the NY/NJ WTC Consortium, this funding was sufficient to provide only outpatient care and partial coverage for prescription medications. The two programs used NIOSH's awards to continue to provide outpatient services to responders, such as treatment for gastrointestinal reflux disease, upper and lower respiratory disorders, and mental health conditions. They also expanded the scope of their programs by offering responders full coverage for their prescription medications for the first time. A NIOSH official told us that some of the commonly experienced WTC conditions, such as upper airway conditions, gastrointestinal disorders, and mental health disorders, are frequently treated with medications that can be costly and may be prescribed for an extended period of time. According to an FDNY WTC program official, prescription medications are now the largest component of the program's treatment budget.

The FDNY WTC program and NY/NJ Consortium also expanded the scope of their programs by paying for inpatient hospital care for the first time, using funds from the $7 million that NIOSH had set aside for this purpose. According to a NIOSH official, NIOSH pays for hospitalizations that have
been approved by the medical directors of the FDNY WTC program and
NYU WTC Consortium through awards to the programs from the funds
NIOSH set aside for this purpose. By August 31, 2007, federal funds had
been used to support 34 hospitalizations of responders, 28 of which were
referred by the NYU WTC Consortium’s Mount Sinai clinic, 5 by the
FDNY WTC program, and 1 by the NYU WTC Consortium’s CUNY
Queens College program. Responders have received inpatient hospital
care to treat, for example, ashen, pulmonary fibrosis, and severe cases
development or PTSD. According to a NIOSH official, one responder is
now a candidate for lung transplantation and if this procedure is
performed, it will be covered by federal funds. If funds set aside for
hospital care are not completely used by the end of fiscal year 2007, he
said they could be carried over into fiscal year 2008 for this purpose or
used for outpatient services.

After receiving NIOSH funding for treatment services in fall 2006, the
NYU WTC Consortium ended its efforts to obtain reimbursement from
health insurance held by responders with coverage. Consortium officials
told us that efforts to bill insurance companies involved a heavy
administrative burden and were frequently unsuccessful, in part because
the insurance carriers typically denied coverage for work-related health
conditions on the grounds that such conditions should be covered by state
workers’ compensation programs. However, according to officials from
the NYU WTC Consortium, responders trying to obtain workers’
compensation coverage routinely experienced administrative hurdles and
significant delays, some lasting several years. Moreover, according to
these program officials, the majority of responders enrolled in the program
either had limited or no health insurance coverage. According to a labor
official, responders who carried out cleanup services after the WTC attack
often did not have health insurance, and responders who were
construction workers often lost their health insurance when they became
too ill to work the number of days each quarter or year required to
maintain eligibility for insurance coverage.

*Pulmonary fibrosis is a condition characterized by the formation of scar tissue in the lungs following the inflammation of lung tissue.

*The NYU WTC Consortium now offers treatment services at no cost to responders; however, prior to fall 2006, the program attempted when possible to obtain reimbursement for its services from health insurance carriers and to obtain applicable co-payments from responders.
According to a NIOSH official, although the agency had not received authorization as of August 28, 2007, to use the $46 million emergency supplemental appropriation made to CDC in May 2007, NIOSH was formulating plans for use of these funds to support the WTC treatment program in fiscal year 2008.

Concluding Observations

Screening and monitoring the health of the people who responded to the September 11, 2001, attack on the World Trade Center are critical for identifying health effects already experienced by responders or those that may emerge in the future. In addition, collecting and analyzing information produced by screening and monitoring responders can give health care providers information that could help them better diagnose and treat responders and others who experience similar health effects.

While some groups of responders are eligible for screening and follow-up physical and mental health examinations through the federally funded WTC health programs, other groups of responders are not eligible for comparable services or may not always find these services available. Federal responders have been eligible only for the initial screening examination provided through the WTC Federal Responder Screening Program. NIOSH, the administrator of the program, has been considering expanding the program to include monitoring but has not done so. In addition, many responders who reside outside the NYC metropolitan area have not been able to obtain screening and monitoring services because available services are too distant. Moreover, HHS has repeatedly interrupted the programs it established for federal responders and nonfederal responders outside of NYC, resulting in periods when no services were available to them.

HHS continues to fund and coordinate the WTC health programs and has key federal responsibility for ensuring the availability of services to responders. HHS and its agencies have recently taken steps to move toward providing screening and monitoring services to federal responders and to nonfederal responders living outside of the NYC area. However, these efforts are not complete, and the stop-and-start history of the department’s efforts to serve these groups does not provide assurance that the latest efforts to extend screening and monitoring services to these responders will be successful and will be sustained over time. Therefore we recommended in July 2007 that the Secretary of HHS take expeditious action to ensure that health screening and monitoring services are available to all people who responded to the attack on the WTC, regardless
of who their employer was or where they reside. As of early September 2007 the department has not responded to this recommendation.

Mr. Chairman, this completes my prepared remarks. I would be happy to respond to any questions you or other members of the subcommittee may have at this time.

Contacts and Acknowledgments

For further information about this testimony, please contact Cynthia A. Bascetta at (202) 512-7114 or bascettac@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this statement. Helene F. Toiv, Assistant Director; Herman Bozzolo; Frederick Caison; Anne Dievel; and Roseanne Price made key contributions to this statement.
Mr. Pallone. Thank you, Dr. Melius.

STATEMENT OF JAMES MELIUS, M.D., ADMINISTRATOR, NEW YORK STATE LABORERS

Dr. Melius. Chairman Pallone, other members of the subcommittee of Health, I greatly appreciate the opportunity to appear before you today. I have been involved with health issues at the World Trade Center since shortly after September 11. Over 3,000 of our union members were involved in the response and cleanup activities on site, and I would add that includes many not only from New York, but also our members from State of New Jersey who came over to assist and who worked at the site.

For the past 4 years, I have served as chair of the steering committee for the medical monitoring and treatment program and have been involved in oversight in working on outreach and other activities with Dr. Herbert and others with the New York City Fire Department on this program.

I believe that they have already—the physicians involved in these programs already talked about some of the medical problems that people are experiencing. And given the focus of these hearings, I like to sort of briefly mention two other issues regarding why it is so important that there be Federal support for this medical monitoring and treatment program.

One would expect—what are some of the other potential sources of funding that could pay for this? Well, one possible source of health insurance coverage; however, I think it is important to know that all health insurance plans exclude coverage for work-related injuries and illnesses. This is a basic part of health insurance. It extends even to the Federal Medicare program. They do not provide coverage.

If an insurance company finds that a person is applying for what they believe to be a work-related health problem, they will deny that claim or certainly raise questions about that claim. So we cannot rely on it, for that reason, to provide coverage for everybody who has become ill by this program.

We have also found that, as this program has evolved as people have sought treatment, that this use of health insurance today has put a great strain on the health insurance plans that cover these particular responders. In the case the city of New York has borne much of the cost through their health insurance plan to date. The various labor unions in New York, who operate either their own health insurance plans or provide partial coverage such as pharmaceutical coverage for their members, have also experienced severe financial strain from having to cover the medical costs for many of the responders.

Another alternative to provide coverage is Worker's Compensation, but I think, as we have already heard today in a very difficult example of how problematic it is for many of these responders to obtain Worker's Compensation coverage. It is long delays in getting that coverage. The coverage is often incomplete. The coverage often questions the need for follow-up medical treatment and can involve many, hearings, administrative proceedings, and especially long delays. Three, 4, 5, years or more before people can initially receive coverage under Worker's Compensation is not unusual.
To rely on Worker’s Compensation for coverage for these responders also shifts the burden for the cost to their employers and to the insurance companies involved. We have already heard the concerns about the contractors involved who thought they were indemnified for working at the World Trade Center site, for responding so quickly, and certainly the New York City itself, which is self-insured in regards to Worker’s Compensation cost would end up picking up these very large and very significant medical costs if we try to rely only on Worker’s Compensation coverage to cover all the health care needs.

I believe that we need a comprehensive solution to address the health needs of these rescue and recovery workers. We cannot rely on a fragmented system and should not rely on a system that utilizes private philanthropy, like the Red Cross, health insurance, line-of-duty disability retirement, and Worker’s Compensation to support the necessary medical monitoring treatment for the many thousands of people who have become ill because of their World Trade Center exposures.

If we rely on this fragmented approach, we will inevitably leave many of these ill and disabled rescue and recovery workers without the needed medical treatment and will only worsen their health condition. I think testimony we have already heard on this panel, I think, illustrates the problems with a fragmented system that is not responsive to the needs of these responders.

In my testimony, I have laid out what I think should be the key points in any Federal legislation that would provide comprehensive coverage that should extend not only to deal with the health issues but also to provide compensation for people who have become disabled because of their exposures at the World Trade Center.

I believe that the legislation introduced last night by Representatives Maloney, Nadler, and Fossella and others really addresses all of these goals and provide the comprehensive framework needed to address these serious medical problems and would lay the basis for both comprehensive coverage as well as the long-term coverage that is required.

I really want to thank Representative Fossella for your efforts, I think, on behalf of all the labor unions who represent people involved in this response. We greatly appreciate your efforts as well as those efforts of Representatives Maloney, Nadler, and the rest of the New York delegation to help address this. And I appreciate, Mr. Pallone, your efforts in holding this hearing. And hope we can move forward to get a comprehensive legislation that is so badly needed. Thank you.

[The prepared statement of Dr. Melius follows:]

TESTIMONY OF JAMES MELIUS, M.D.

Chairman Pallone and members of the Subcommittee on Health. I greatly appreciate the opportunity to appear before you at this hearing.

I am James Melius, an occupational health physician and epidemiologist, who currently 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 on the Federal Advisory Board on Radiation and Worker Health which oversees part of the Federal compensation program 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 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 3 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. 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 other physicians involved in the medical monitoring and treatment program for World Trade Center responders have already presented the medical findings from their respective medical program for these responders. The pulmonary disease and other health problems among both fire fighters and other responders are quite striking and quite worrisome. All of the medical programs have done an outstanding job in establishing their respective monitoring programs and in providing high quality medical examinations for many thousands of rescue workers and responders. These programs also recognized the problems that many of their participants were having paying for medical care for the conditions diagnosed in the medical monitoring programs and have made efforts to help the participants in obtaining necessary assistance. Given the focus of these hearings, I believe that it will be helpful to examine the reasons why so many of the participants need assistance for paying for their medical treatment.

**HEALTH INSURANCE COVERAGE**

The people who worked in the initial response to the September 11 disaster and the later recovery activities represented many different types of workers. On the public safety side, there were fire fighters, police, and emergency medical services workers. The response and recovery activities also included construction trades workers, utility workers, sanitation workers, transit workers, cleaning workers, and NYC municipal workers from many agencies. Many other people just volunteered to work at the site especially in the first few days after September 11th. Despite the diversity of backgrounds and job duties, these different groups are showing very similar patterns of illness. The pulmonary changes found in fire fighters have also been demonstrated in the rescue and recovery workers being monitored in the Mount Sinai medical program. Most recently, an independent study conducted by medical researchers at Penn State University of NYC police officers responding to the WTC disaster reported similar respiratory findings among the group that they examined. The other types of medical and mental health problems documented among WTC responders also appear to be similar across all groups of responders.

However, given the diversity of this workforce, it is not surprising that their health insurance coverage might be quite variable. I will provide a general overview.

All city workers are covered through the city’s general health insurance plan which provides basic health insurance which provides basic health insurance coverage and some pharmaceutical coverage. The pharmaceutical coverage is often quite limited with high deductibles and co-pays. These health plans require that the participant work a substantial number of days each quarter or year in order to maintain eligibility. An ill construction worker can easily lose their coverage by missing too many work days. Utility workers have general medical coverage including some pharmaceutical benefits. Cleaning workers (people who cleaned the residential and commercial buildings around the WTC) often worked for contractors who offered no health benefits at all. The majority of the people in the
Mt. Sinai treatment program up to now have had no health insurance coverage or very limited coverage.

All health insurance plans exclude coverage for work-related injuries and illnesses. Even Medicare has an active program to identify and recover payments for work-related services. While it is recognized that there may be uncertainty about whether a condition being diagnosed is work-related or not, this consideration could easily lead to the denial of health insurance coverage for many people with WTC-related health conditions. New York State does have in place mechanisms for health insurance providers to be reimbursed for medical expense payments incurred for conditions that are ultimately determined to be eligible for workers’ compensation coverage. However, these mechanisms are administratively complicated and do not necessarily prevent the health insurer from denying reimbursement for WTC-related health expense.

Another problem with health insurance is the limitations on coverage of many of the health insurance plans that cover the participants. This is especially critical for pharmaceutical coverage. Treatment for many of the WTC-related conditions (asthma, mental health problems, et cetera) requires substantial medication costs. These costs can commonly range from $5,000 to nearly $15,000 per year for participants. Many of the plans covering WTC participants have high deductibles or co-pays. Co-pays and deductibles can easily cost the participants with high medication costs several thousand dollars per year. These costs can severely strain the finances of a person with a moderate income especially if they have other health care costs and are missing significant time from their work due to illness. For those without any health insurance, the financial impact is even greater. Another potential problem is that many of these insurance programs have lifetime caps for each participant. Although these caps seem high ($500,000 to $1 million or more), they can easily be exceeded with a long term serious illness.

The medical and pharmaceutical costs for WTC-responders have also severely strained the health insurance plans for many of the responder groups, especially those providing pharmaceutical coverage. These funds are already stressed by the rapidly rising costs of health care. Those plans with a significant number of members who worked at the WTC response and clean-up have found that the overall medical and pharmaceutical costs for their plans have significantly increased due to the large number of participants with WTC-related medical costs. This has even led some to consider cutting back on their benefits for all members in order to absorb the costs for the WTC group.

WORKERS’ COMPENSATION COVERAGE

One alternative to health insurance coverage for WTC-related conditions is workers’ compensation insurance. Workers’ compensation is supposed to be a no fault insurance system to provide workers who are injured or become ill due to job-related factors with compensation for their wage loss as well as full coverage for the medical costs associated with the monitoring and treatment of their condition.

Similar to health insurance, the WTC program participants are covered by a variety of state, Federal, and local programs with different eligibility requirements, benefits, and other provisions. Most private and city workers are covered under the New York State Workers’ Compensation system. New York City is self insured while most of the private employers obtain coverage through an outside insurance company. Uniformed services workers are, for the most part, not covered by the New York State Workers’ Compensation system but rather have a line of duty disability retirement system managed by New York City. A fire fighter, police officer, or other uniformed worker who can no longer perform their duties because of an injury or illness incurred while on duty can apply for a disability retirement which allows them to leave with significant retirement benefits. However, should a work-related illness first become apparent after retirement, no additional benefits (including medical care) are provided, and the medical benefits for even a recognized line of duty medical problem end when the person retires. Federal workers are covered under the compensation program for Federal workers. Coverage for workers who came from out of state will depend on their employment arrangements with their private employer or agency. However, volunteers from New York or from out of state are all covered under a special program established by the New York Workers Compensation Board after 9/11.

The major difficulty with these compensation systems is the long delays in obtaining coverage. For example, the NYS Workers’ Compensation system is very bureaucratic. The insurer may challenge every step of the compensation process including even diagnostic medical testing. This challenge usually requires a hearing before a Workers’ Compensation Board (WCB) administrative judge to evaluate the case, and
this hearing may often be delayed for months. Even once the case is established, the insurer can still challenge treatments recommended for that individual even for a medication that the individual may have been taking for many months for a chronic work-related condition. Thus, it may be many years before the case of a person with a WTC-related condition is fully recognized and adjudicated by the compensation system. Meanwhile, the claimant may not be receiving any medical or compensation benefits or may have had their benefits disrupted many times.

In order to alleviate some of the problems for WTC claimants, last year New York State implemented some new programs that were designed to improve coverage for WTC responders by providing medical coverage and salary compensation for responders while their WCB cases were being evaluated. However, these provisions must be initiated by the insurer carrier, and there is uncertainty as to who would be responsible for reimbursing these costs if the claims are ultimately denied. To date, these provisions do not appear to be widely used. There was also legislation passed last year that allows more New York City workers to obtain disability retirement benefits for WTC-related conditions. Currently, there is an advisory task force in place that is examining how best to implement this legislation. Finally, there was a bill passed allowing people who worked at the WTC site to register for Workers' Compensation benefits. Potential claimants were given a year to submit a registration form to the Board that makes them eligible to apply for benefits should they later develop a WTC-related health condition. Prior to that, claimants who later developed a WTC-related medical condition were not eligible to file claims because they were judged to have missed the filing deadline required by law. In addition, New York State has just passed broad workers’ compensation reform legislation that makes many changes in the current system. Once implemented, this legislation could help to alleviate some of the delays in the current system. However, it will be some time before all of these changes assist WTC claimants. Meanwhile, claimants continue to face long delays and many hurdles in obtaining workers’ compensation coverage for any conditions resulting from their WTC exposures. It is not clear that the recent changes in the system will adequately address these problems.

I would also add that depending on workers’ compensation and disability retirement systems to cover the medical costs for the monitoring and treatment program places the financial burden on the employers and insurance companies. New York City is self insured and thus would pay directly for all claims. The private employers involved will also have greater costs either by directly paying for claims if they are self insured or through higher premiums due to an increase in their experience rating.

COMPREHENSIVE SOLUTION

A comprehensive solution is needed to address the health needs of the 9/11 rescue and recovery workers. 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 encourage medical institutions from providing that care.

This is a critical time for the federally funded treatment programs. Their funding will soon run out, and Federal officials are already proposing sending letters informing the participants that they must seek alternative arrangements for their care. Attempting to provide this care through some sort of voucher system as is currently being considered by the Department of Health and Human Services would also be disruptive. 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. 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.

We need Federal legislation that accomplishes the following:

- Provides long term medical monitoring program for all WTC responders and other workers exposed in the aftermath of September 11, 2007
• Supports long term medical treatment for those participants who have developed WTC-related medical conditions at no cost to the participants. This program should cover WTC-related medical conditions that are currently recognized as well as those which might emerge in the future.
• Provides that monitoring and treatment at Medical Centers of Excellence that have the expertise and experience to provide high quality medical care.
• Extends that high quality medical care to WTC responders from throughout the United States.
• Provides for the collection and analysis of these medical data in order to track the health of the participants and to detect emerging disease patterns.
• Establishes a medical monitoring and treatment program for residents, students, workers, and other people who were exposed to WTC contaminants in the aftermath to the September 11 attacks.
• Provides for appropriate compensation for those who have become disabled from their WTC-related illnesses.
• Provides administrative mechanisms that provides prompt and timely determinations and allows the proper oversight and management of the program.
• Provides for meaningful input and participation from representatives of the affected groups in the development and management of the program.

The legislation just introduced by Representatives Maloney, Nadler, Fossella, and others addresses all of those goals and provides the comprehensive framework needed to address the serious medical problems being experienced by thousands of people in the aftermath to the September 11 terrorist attacks. 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 are only two examples of this problem. We have left those people to suffer, often without proper medical care and facing financial hardship due to their illnesses. We should learn the lessons from these past mistakes and make sure that we provide comprehensive medical monitoring, treatment, and compensation for those potentially impacted by the WTC disaster.

I would strongly urge you to take immediate steps to ensure that there is adequate Federal funding for the current medical monitoring and treatment programs and to open up these programs or similar programs to the affected residents and to other affected workers. I would also urge you to support the Maloney-Nadler-Fossella legislation to provide a comprehensive approach to give WTC workers and residents access to long term medical monitoring and treatment for their WTC-related medical conditions and compensation for their losses.

I would be glad to answer any questions.

Mr. PALLONE. Thank you, Doctor. Mr. Skyler.

STATEMENT OF EDWARD SKYLER, DEPUTY MAYOR, ADMINISTRATION, CITY OF NEW YORK, NY

Mr. SKYLER. Good afternoon. I want to thank you, Chairman Pallone, Ranking Member Deal, Congressman Fossella and Congressman Weiner as well as Congressman Engel who was here earlier, and other members of the committee for convening this hearing for those who are still suffering from the effects of the September 11 attacks.

My name is Edward Skyler, and I am the New York City deputy mayor for administration. And as the 5-year anniversary of the attacks approached, Mayor Bloomberg asked me to co-chair a panel of experts to determine what must be done to fully address the health impacts of 9/11. The mayor accepted all 15 of the panel's recommendations.

I have shared the report with your staff over the last 7 months, and over that time, we have been working to put them into action. In particular, the city has been working closely with New York's congressional delegation, especially Representatives Maloney,
Fossella, and Nadler; and Senators Clinton and Schumer to incorporate these recommendations into legislation that establishes a strong and comprehensive Federal response.

And that is why I am here today. On behalf of Mayor Bloomberg and the city of New York, I have come to express our strong support for a piece of legislation that accomplishes much of what our panel recommended, the James Zadroga 9/11 Health and Compensation Act of 2007. The bill is named after an NYPD detective who spent hundreds of hours at Ground Zero and later died too young at the age of 34 from respiratory failure.

If adopted into law, it will provide the Federal funding needed to care for those who are sick or who may become sick. The bill would continue vital research that would help us better understand the health impacts of these attacks, and it would reopen the Victims’ Compensation Fund, which will enable the city to get out of the courtroom and focus its energies on helping those who continue to struggle with the aftermath of 9/11. In short, it recognizes fully and finally that providing health services to people who are physically injured and emotionally traumatized by an act of war and terror against the United States is in fact a national obligation.

We have estimated that more than 400,000 people were potentially exposed to environmental hazards and psychological trauma of the attacks. The gross national cost to treat those people who are sick or who could become sick as a result of 9/11 is $393 million per year. That estimate covers the entire potentially exposed population, including the thousands of rescue workers and others who came to our city to help in our time of need from all 50 States.

We also estimate that the cost merely to sustain the current treatment programs in the New York City area at their present levels and to implement the remainder of the panel’s recommendations is at least $150 million a year—not allowing for inflation, increased incidence of disease, or the emergence of new disease.

The funding that this bill will provide is needed for two critical and interrelated purposes. First, to treat those who are sick or who could become sick as a result of 9/11. This bill provides the means to treat anyone anywhere in the country who was affected by the attacks. A core element of that treatment is sustained funding for the three Centers of Excellence that collectively monitor and treat the more than 36,000 responders, residents, and others.

Those Centers of Excellence are the FDNY World Trade Center program, WTC Monitoring and Treatment program coordinated by Mount Sinai, and the World Trade Center Environmental Health Center at Bellevue Hospital, which is the only treatment program currently open to residents and other non-first responders. I should note the fire department recently opened a treatment center on Staten Island in Congressman Fossella’s district to better provide services to those who are injured as a result of the attacks and make it more convenient for them by supplying those services in their home borough.

Second, this bill ensures that the critical 9/11 research continues. Long-term research is the only way we are going to be able to develop a full understanding of the health impacts of 9/11. The Centers of Excellence have all contributed to the research efforts, including studies released by clinicians at all of them.
The city’s health department has also partnered with the Federal Government to establish the World Trade Center Health Registry, the largest of its kind, which includes over 71,000 people from every State in the country and from almost every congressional district. More than a quarter of the people in the registry, almost 20,000 individuals, are from outside New York State. This reflects the large number of people from throughout the country who came to New York’s assistance after the attacks.

Two large studies released last month based on registry data continue to show how serious the health impacts of 9/11 are. They were referred by Congressman Fossella earlier today, which is the 3.6 percent of 25,000 previously asthma-free rescue and recovery workers who developed asthma after working at the site, which is 12 times the national average. And the 12 percent of rescue and recovery workers, about one in eight, who developed post-traumatic stress disorder after working at Ground Zero. The national average is about 4 percent.

This bill will provide the necessary resources to fund all of these services, but while we wait for Congress to act and the executive branch to act, the city is not waiting to make sure that the people get the health care they need. In fact, in response to the report, the mayor increased city spending for 9/11 health-related programs six-fold to more than $27 million in the current fiscal year. And in the absence of long-term Federal support, he committed $100 million to these programs through fiscal year 2011.

Nevertheless, all of these programs remain in danger of being discontinued unless they receive a full and reliable and sustained source of Federal funding which this bill provides.

Finally, let me talk about how this bill will fulfill another core recommendation of our panel. The urgent need for Congress to re-open the Victim Compensation Fund. Between 2001 and 2004, under the leadership of Special Master Ken Feinburg, the fund provided compensation to nearly 3,000 families of those who were killed or injured on 9/11 or in the immediate aftermath of the attacks. It was a fair and efficient process that provided a measure of relief to victims’ families.

Now, it is imperative that the fund be reauthorized to take care of those who are not eligible to benefit from it before it closed in 2003. The fact that their injuries and illnesses have been slower to emerge should not disqualify them from getting the help they need. Even if we provide them health care, many of these people have suffered other losses. Some can no longer work or are in financial distress. They shouldn’t be forced to go to court to get compensation. That not only compounds their pain, it would result in costly and protracted litigation that is distracting us from our primary mission of giving real help to those in need.

The fundamental point is that compensating people who were hurt on 9/11 shouldn’t be based on a legal finding of who is to blame. We all know who is to blame: 19 savages with box cutters. I am here today because New York City would rather stand with those who filed suit than against them in a courtroom, but we need your help to do that.

There is no reason why people injured on 9/11 should now have to go to court and prove liability. Proof of harm should be enough
to receive fair and fast compensation. What is more, reopening the fund would send a clear message that if, God forbid, America suffers another terrorist attack, the private sectors and our first responders could respond with the same kind of determination that we saw on 9/11, knowing that their Government will always stand with them.

If we leave the issue of compensation to the courts and the tort system, we risk bankrupting those who responded—either the individuals or the companies. We simply shouldn’t be so callous to those who responded in the Nation’s time of need.

In sum, the James Zadroga Act represents a vital lifeline to the men and women who risked everything and helped lift our Nation and our city back onto its feet during its time of need. That is why it has gained the support of New York State’s entire congressional delegation. That is why Speaker Pelosi, who met with Mayor Bloomberg and me last week, expressed her support of it. And that is why Mayor Bloomberg and his administration are pledging to work with Congress to do everything possible to make it a reality.

Thank you for your attention. I would be happy to answer any questions you might have.

[The prepared statement of Mr. Skyler follows:]

TESTIMONY OF EDWARD SKYLER

Good morning. I want to thank Chairman Pallone, Ranking Member Deal, and the other distinguished members of the Committee for convening this hearing about those who are still suffering the effects of the September 11 attacks. I also want to take this opportunity to thank Speaker Pelosi for coming to New York last week on the eve of the sixth anniversary of the attacks. Speaker Pelosi met with Mayor Bloomberg to discuss a number of critical 9/11-related issues, and she expressed her support for addressing the urgent and unmet health needs that I will talk to you about today.

My name is Ed Skyler, and as New York City’s deputy mayor for administration, I’ve been directly involved with the city’s response to 9/11-related medical conditions. As the 5-year anniversary of the attacks approached, Mayor Bloomberg asked me and our city’s Deputy Mayor for Health and Human Services—Linda Gibbs—to chair a panel of experts to determine what must be done to fully address the health impacts of 9/11.

The mayor accepted all 15 of the panel’s recommendations—I gave congressional testimony about them in February—and over the past 7 months we’ve been working to put them in action. In particular, the city has worked closely with New York’s Congressional delegation—especially Representatives Maloney, Fossella, and Nadler, and Senators Clinton and Schumer—to incorporate these recommendations into legislation that establishes a strong and comprehensive Federal response.

That’s why I’m here today. On behalf of the city, I’ve come to express our strong support for a piece of legislation that accomplishes much of what our panel recommended, the James Zadroga 9/11 Health and Compensation Act of 2007. This bill is named after an NYPD detective who had spent hundreds of hours at Ground Zero, and later died at the age of 34 from respiratory failure. If adopted into law, it would provide the Federal funding needed to care for those who are sick, or who may become sick.

The bill would also continue vital research that will help us better understand the health impacts of the attacks, and it would re-open the Victim’s Compensation Fund, which will enable the city to get out of the courtroom and focus its energies on helping those who continue to struggle with the aftermath of 9/11. In short, this bill recognizes, fully and finally, that providing health services to people who were physically injured and emotionally traumatized by an act of war against the United States is in fact a national obligation.

We’ve estimated that more than 400,000 people were potentially exposed to the environmental hazards and psychological trauma of the attacks, and that the gross national cost to treat those who are sick or could become sick as a result of 9/11 is $395 million per year. That estimate covers the entire potentially exposed popu-
lation, including the thousands of rescue workers and others who came to our city from all 50 states.

We also estimated that the cost merely to sustain the current treatment programs in the New York City area at their present levels and to implement the remainder of the panel’s recommendations is at least $150 million a year—not allowing for inflation, increased incidence of disease, or the emergence of new diseases.

The funding this bill would provide is needed for two critical, interrelated purposes: first, to treat those who are sick or who could become sick as a result of 9/11. This bill provides a means to treat anyone, anywhere in the country who was affected by the attacks. A core element of that treatment is sustained funding for three “Centers of Excellence” that collectively monitor and treat more than 36,000 responders, residents and others.

Those Centers of Excellence are: the FDNY World Trade Center program; the WTC Monitoring and Treatment program coordinated by Mt. Sinai and the World Trade Center Environmental Health Center at Bellevue Hospital—the only treatment program currently open to residents and other non-responders. I should note that the Fire Department recently opened a treatment center in Staten Island—in Congressman Fossella’s district—to provide better services to those who were injured as a result of the attacks.

Second, this 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—including studies released by clinicians at FDNY, Mt. Sinai and the Bellevue program.

The city’s Health Department has also partnered with the Federal Government to establish the World Trade Center Registry—the largest effort of its kind in history—which includes over 71,000 people from every state in the country and from almost every Congressional district. More than a quarter of the people in the Registry—almost 20,000 individuals—are from outside New York State. This reflects the large number of people from throughout the country who came to New York’s assistance after the attacks.

Two large studies released last month based on Registry data continue to show how serious the health impacts of 9/11 are. One shows that 3.6 percent of 25,000 previously asthma-free rescue and recovery workers in the Registry developed asthma after working at the World Trade Center site—12 times the national average. And a second study shows that more than 12 percent of rescue and recovery workers—about 1 in 8—developed Post-Traumatic Stress disorder after working at Ground Zero.

The James Zadroga 9/11 Health and Compensation Act will provide the necessary resources to fund all of these services—but while we wait for Congress to act, the city is not waiting to make sure that people get the health care they need. In fact, in response to the Panel’s Report, the Mayor increased city spending for 9/11 health related programs six-fold in the current fiscal year, to more than $27 million. And, in the absence of long-term Federal support, he committed nearly $100 million to these programs through FY 2011. Nevertheless, all of these programs remain in danger of being discontinued unless they receive the full and predictable source of Federal funding which this bill provides.

Finally, I’d like to address how this bill will fulfill another core recommendation of our panel: the urgent need for Congress to reopen the Victim Compensation Fund. Between 2001 and 2004, the Fund provided compensation to nearly 3,000 families of those who were killed or injured on 9/11 or in the immediate aftermath of the attacks. It was a fair and efficient process that provided a measure of relief to victims’ families.

Now it is imperative that the Fund be reauthorized to take care of those who were not eligible to benefit from it before it closed in December 2003. The fact that their injuries and illnesses have been slower to emerge should not disqualify them from getting the help they need.

Even if we provide them health care, many of these people have suffered other losses. Some can no longer work. Some have lost their homes. They shouldn’t be forced to go to court to get compensation. That would not only compound their pain; it would also result in costly and protracted litigation that ultimately would distract us from our primary mission of giving real help to those in need.

The fundamental point is that compensating people who were hurt on 9/11 shouldn’t be based on a legal finding of who is to blame. We know who is to blame—19 savages with box cutters. I am here today because New York City would rather stand with those who’ve filed suit, rather than against them in a courtroom. There is no reason why people injured on 9/11 should now have to go to court and prove liability. Proof of harm should be enough to receive fair and fast compensation.
What’s more, reopening the Fund would send a clear message that if—God forbid—America suffers another terrorist attack, the private sector and our first responders could respond with the same kind of determination that we saw on 9/11, knowing that their government will always stand by them. If we leave the issue of compensation to the courts and the tort system, we risk bankrupting those who responded—either the individuals or the companies. We simply shouldn’t be so callous to those who responded in the nation’s time of need.

In sum, the James Zadroga Act represents a vital lifeline to the men and women who risked everything, and helped lift our Nation back onto its feet during our time of greatest need. That’s why Mayor Bloomberg and his administration are pledging to work with you all and do everything possible to make it a reality.

Mr. Pallone. Thank you. I thank you all. I am going to start with the questioning.

My view, and I think most of you, if not everyone here, sort of shared the same view, although I don’t want to put words in your mouth, is that if we had a situation where every one of the first responders, or even those who were not first responders that might have been victims because they live or work near the World Trade Center—but at least let us focus on the first responders, if we had a system where all the first responders could go to a specialized treatment center, where they have the expertise like what UMDNJ or Mount Sinai do, and they could be screened and monitored, and they could be treated there by those experts who have the expertise, and the Government was paying for it because there wouldn’t be any gaps because of your private insurance, if you have it or don’t, that would be the best situation.

But the problem with that, of course, is that for ideological reasons or whatever, our system doesn’t work that way. Everything is done stop-gap, and you have to rely on private insurance and who has and who hasn’t. So if we set something up like that, although it might be the ideal—there are all the ideological problems that go with it. So what I would like to know is how far do you think we need to go?

In other words, we obviously need a comprehensive plan. Would you argue that this comprehensive plan should allow everyone who is either a first responder or a victim in some other way to go to one of these centers? That they should be fully covered by the Federal Government without any recourse to private insurance? Is there any other way to help people like Mr. Vinciguerra without having to go that far?

I mean, this is the committee of jurisdiction that would have to report out that legislation, and we have some bills out there that are sort of similar to that. But we also have to think about what is possible to get passed here.

And so I guess I would just like to ask a basic question about is that the way we need to go? Is there some way to continue to rely on private insurance, or let people go to their individual doctors, or is this really what we are talking about? And I know it is sort of a broad question. I am not sure we have time for everybody to answer it, but I would like to at least ask that of Dr. Udasin, Dr. Herbert and the GAO person in that order and then we will see. If we can start that way.

Dr. Udasin. Well, I would like to answer that question by saying that most of the patients in New Jersey actually have private health insurance, and so many came in with either incorrect diag-
noses or they couldn’t get the medications that they needed because the insurance company said you had to have this medication, not the one that actually works for what is wrong with you. I am no expert on figuring out how to fund a program, but I feel like the people that were there that did the kind of work that Mr. Vinciguerra did need the kind of medical care that we are able to provide for them.

Mr. PALLONE. And if they can’t go to your center, then there is a danger that they won’t get the specialty care, correct?

Dr. UDASIN. That is correct, and we do work with physicians all over the—actually we work with physicians all over the country. And we do give a lot of medical advice to people who can’t get into our centers, and at the very least, it is making the diagnosis that is so complicated that takes such a long time figuring out what people need. And that is actually where the trouble is, in my opinion, that a lot of people that do have correct health insurance are coming in with the wrong diagnosis. And that is what I feel like we can do for them is at least get them started on the path to the correct treatment.

Mr. PALLONE. See, that is, Dr. Herbert, my concern is that if you look at Mr. Vinciguerra, he went to Hamilton. Did they necessarily know what the problem was? It seems to me that if they are not going to one of your centers and then they are not being able to get the full monitoring and treatment over a long period of time under somebody that has the expertise, they are going to have incomplete care. And then you get into all the insurance problems.

Dr. HERBERT. I agree exactly with what you said and with what Dr. Udasin said. The other features of this kind of system are the ability to track symptoms, physical findings, breathing test results from the monitoring examination so that we can identify disease and symptom patterns over time, A. And, B, in the treatment programs, we have a real-time system to capture not just the single billable diagnosis that you are going to find from a private physician but all of the conditions for which that responder is being treated.

So I think without this kind of center, A, you would lose the ability to provide the highly specialized treatment that the responders need. And, B, you would lose the opportunity to identify the patterns of disease going forward in time, and you would lose the responders as a group. And that would be a huge loss.

Mr. PALLONE. And I will ask Dr. Melius because my time is actually up, but the problem that I see is that when you talk about the insurance, unless the Government is actually saying we are going to pay for your screening and treatment at one of these centers, there is going to be just a gap. There is no way for private insurance to make up the difference. Or is there some way for us to still rely on private insurance to pay for some of this?

Dr. MELIUS. The answer to that is twofold. One is I don’t think it is fair or appropriate to rely on private insurance because that cost is getting then passed back either to the victim or his fellow workers who are part of the same plan or to the employer who is having to provide that.

Second, I don’t think it works. It leads to fragmented care. Mr. Vinciguerra, I think, was a good example of the problems that that
causes. And there are countless other examples like that in this program. People that delay treatment, don’t get the right medications, uncertainty about whether it is covered or not.

And I really think the only way to provide timely comprehensive care is to do it through the system that is proposed in the legislation, that sets up the Centers of Excellence, that tracks people, provides the care at Centers of Excellence or in coordination with Centers of Excellence, and assures that people get the best care as early and in as timely a fashion as possible.

Mr. Pallone. And I agree with you, but I mean the problem is when you try to move a bill like that, you are basically saying you want a Government sponsored plan, paid-for plan for these people. And the question is can we accomplish that.

Dr. Melius. Well, this is, I think, extraordinary circumstances.

Mr. Pallone. Right, thank you.

Dr. Melius. Yes.

Mr. Pallone. Mr. Deal.

Mr. Deal. I would sort of like to follow up on that. Does anybody know how many of these responders have been provided care and benefits under their Worker’s Compensation plans? Yes, Mr. Skyler?

Mr. Skyler. I would just point out from the city’s perspective, worker’s comp actually doesn’t apply to members of the uniform service, such as police department and fire department. So, as a matter of course, the 50,000 or so police officers and firefighters wouldn’t get any care through their worker’s comp system.

Mr. Deal. So you don’t have any worker’s comp system for your uniformed officers?

Mr. Skyler. Not for our uniformed officers. It only affects the civilian cohort of the workforce.

Mr. Deal. So what benefits do they have then if they are injured in the line of duty?

Mr. Skyler. They have different benefits provided by pension plans, and there are different levels of care depending on the agency. For example, the Bureau of Health Services was a part of the fire department set up before 9/11 that monitored firefighter health before 9/11. They used their data to compare against the patients that came in after 9/11.

Mr. Deal. So that is why Mr. Vinciguerra had such a hard time is because the normal processes that would be in place in most instances that I am aware of across the country, apparently you didn’t have those for a uniformed person injured in the line of duty?

Mr. Skyler. No, I would submit and I think the doctors on the panel would agree that the fire department Bureau of Health Services is one of the Centers of Excellence that has gotten Federal funding that we want to see funding continued for. The advantage——

Mr. Deal. Well, I know you wanted the Federal Government to pick up the tab. My concern is when you have got local folks who should be covered by some kind of local policy, why is not that the first line of resources?
Mr. Skyler. Well, it has been the first line, and the mayor put up money despite a lack of Federal long-term commitment on this issue—$100 million over the next 3 years.

Mr. Deal. If a fireman is injured in my hometown, he is covered by an insurance policy. He has got a retirement benefit plan. Why does a man like this gentleman here have such difficulty in New York?

Mr. Skyler. I believe Mr. Vinciguerra actually has been treated by our Bureau of Health Services. One of the gaps that was exposed was a lack of prescription drug care, which we have remedied since the panel's report came out.

Mr. Deal. Mr. Vinciguerra?

Mr. Vinciguerra. Yes, if I may, the reason I think there is some confusion is I worked for the EMS division of the fire department, and it is sort of considered a civilian component even though it is a uniformed service now. It works under compensation, not the pension component.

Mr. Skyler. Well, Dr. Melius's testimony here says that depending on a Worker's Compensation disability retirement system to cover the medical cost for the monitoring and treatment programs, placed a financial burden on the employers and the insurance companies.

Mr. Deal. Well, yes, that is true. Any time you write an insurance policy or create a system, when you have a claim that comes forward, whether they be of the magnitude we are talking about here or even minor claims that same statement could be true. Let me ask specifically about how we are spending money.

Ms. Bascetta, in your testimony, I am looking at the portion where you talk about the contracts that NIOSH has entered into for those outside of the metropolitan area. And you say in June 2005, they began a second effort by awarding $776,000 to Mount Sinai School of Medicine to provide screening and monitoring for non-Federal responders residing outside the metropolitan area.

And then in June 2006, they awarded an additional $788,000 to provide screening for these first responders. And you conclude the paragraph by saying that they ultimately contracted with 10 clinics in seven States and that as of June 2007, 10 clinics were monitoring 180 responders. That is an awful lot of money for a very few people. Am I reading this wrong?

Ms. Bascetta. No, you are correct. The system wasn't working well at all, and in fact to update that, NIOSH has gone to a different system with a different contract with QTC, I believe. Dr. Howard referred to that, and they have piloted it. They have done about 20 exams under that program, but the first program did not work well at all.

Mr. Deal. OK. Well, let us go to more recent. You say here in June 2007, NIOSH awarded $800,600 for DCC to coordinate provisions of screening and monitoring exams, to provide 1,000 screenings and monitoring examinations through May 2008. And they began the screening process, and by the end of August, 18 non-Federal responders had completed screening and 33 others had been scheduled. Here again, that appears to be a lot of Federal dollars for a very few people that are being affected by it. I mean we
would be better off to take that amount of money and give all those people that amount of money in cash, wouldn’t we?

Ms. BASCETTA. It is a very good question. Again that is the same program that you were just referring to. The money was there, but the administrative logistics were not in place to serve the people well. And it didn’t happen.

Mr. DEAL. And yet we are going to be anticipating the same kind of funding or even at greater levels for this fiscal year, are we not?

Ms. BASCETTA. Yes, but those funds were for screening and monitoring, and the discussion that we were just having was about treatment, which is actually where even more of the funds would be required. The screening and monitoring are a smaller proportion, and they are known costs. Once you get the mechanisms in place to do the screening and monitoring, then you know per person what that is going to run.

Mr. DEAL. But using that same logic, if the cost per person just to do the screening and monitoring is so exorbitant and out of kil- ler it seems to me, then we would expect the treatment phase of it to be even more exorbitant, would we not? I mean why is it costing so much to do so little for so few?

Ms. BASCETTA. Well, I don’t think we know at this point what the full treatments costs are going to be. One of our findings was that HHS has just last year begun asking for the actual cost data from the grantees. Last year was also the first year that there was Federal money awarded to grantees, and prior to that, it was all philanthropic funds from the Red Cross. So there wasn’t a requirement for the grantees to be reporting actual cost data.

We would hope that one of the lessons learned from this situa-
tion is that in the future the requirements for screening and mon-
itoring, who is responsible for that, where the funding streams will come from, how those programs will be administered, and how the various funding streams for treatment would be made available to pay for treatment if that were necessary, would be planned in advance to avoid this kind of situation after the fact.

Mr. DEAL. Well, I don’t mean to diminish the importance of what we are all talking about here by my questions, but I do think that we can’t just simply all say take a simplistic answer of let the Federal tax payer pick up the burden. Let us forget about asking the private insurers to contribute. They have been paid premiums for that, but it is too cumbersome to do that. Let us forget about the Worker’s Compensation system because it takes too long to go through system.

I can assure you that every injured employee in this country who has a Worker’s Compensation claim would tell you yes, the system does take a while. But just to say let us forget about that and throw up our hands and ask the Federal Government to pitch in millions, perhaps billions of dollars, I think, doesn’t show the kind of responsibility that I think all of these responders showed when they responded to the emergency before them.

I think there is a responsibility at every level for us to make sure that we are doing what is best for the people who need the help and that we are not just throwing dollars out there that don’t seem to wind up in the right place. That is the concern that I have.

Mr. PALLONE. Mr. Engel.
Mr. Engel. Thank you, Mr. Chairman. Let me just say before I ask my question in view of some of the comments that my friend Mr. Deal has been making. The President talks a lot about America being attacked on 9/11 and talks a lot about it being as part of the overall fight on terror. He mentions Iraq and everything else and that the United States of America was attacked.

Well, we in New York don't believe that we were attacked simply by random. New York was obviously a symbol of the country, and the terrorists wanted to hit us hard. Therefore, we believe that the Federal Government has an enormous responsibility above and beyond. It is not just simply worker's comp or private insurance plans.

Sure, it would be helpful, but the bottom line for me is that the Federal Government needs to be responsible. We were attacked. New Yorkers were killed and maimed and injured, and the Federal Government needs to have a response. And I think pushing it off on private companies or whatever—and I am not trying to absolve them of responsibility, but the bottom line for me is again that the Federal Government needs to step in.

Mr. Skyler, let me just ask you. I don't know if you were here when I gave my opening statement, but I talked a lot not only about first responders but about other New Yorkers and people from the metropolitan area who were exposed to these poison toxins, people who live within the area, residents, students. These people who were exposed to the toxins of Ground Zero are not eligible for the federally funded World Trade Center Medical Monitoring and Treatment programs.

We have just introduced a bill lead by Mrs. Maloney, Mr. Fossella, Mr. Nadler, but many of us also co-sponsored and signed on, which would help the entire exposed community. I am wondering if you could give us some of your insights on how that bill would help and why it is so necessary.

Mr. Skyler. Absolutely, and I think the bill addresses one of the fundamental challenges, also something that Congressman Deal essentially stated, which is that we have different populations, and we have different systems that handle different populations. But we have the same health effects caused by the same disaster, an environmental disaster, and I am not aware of one on American soil that was greater than this one. It is an environmental disaster, not just a terrorist attack.

But we have populations where different standards apply depending on what their pension benefits are, depending whether they are on worker's comp or not, depending on what union they are in sometimes, depending on what resources that union has available, depending on where they live.

So one of the things that the report recommended was to establish an enhanced funding for a World Trade Center environmental health center in Bellevue Hospital. It is a hospital in New York City, Manhattan, that anybody can go to, whether you are a resident—and there was no treatment program available for residents before this was established—whether you are a firefighter or police officer, whether you are a worker, whether you worked in the cleanup as a contractor or whether you worked in the building cleaning up the interior of a building that was damaged.
Anybody can walk in there and get care, and we have had about 1,600 people go in. And that is a gap that needs to be filled. There are other gaps throughout the populations that we have also sought to fill, but that was a huge one that nobody had focused on. And we are gratified to see that Congresswoman Maloney's bill, the Zadroga Act, which I am here to support, actually identifies that population as one deserving funding.

Mr. ENGEL. Thank you. I think that is very important. Dr. Herbert, let me ask you something specifically about the Mount Sinai program. Many of the responders who are now in medical monitoring programs, these are run by their employer, the fire department or the police department. And a lot of the problems are mental health related, and due to the presence of these issues among the population, might it not be possible that some of these workers fear sharing this information with their employer due to potential adverse work consequences and things like that?

Now, let me ask you about the Mount Sinai program. Should you be assisting in helping in monitoring those employees who may be uncomfortable with being monitored by their employer?

Dr. HERBERT. Thank you for asking that question. To clarify with respect to the two federally funded monitoring and treatment programs for responders, distinct from the additional program that Mr. Skyler spoke about, one is employer based, the program for New York firefighters or employees of FDNY is based at the Bureau of Health Services.

The other federally funded program does exactly what you have suggested might be important. The way the program works is that we have exposure-based eligibility criteria. Any responder can choose the Center of Excellence that he or she prefers to go to, and the examinations are highly confidential. We are very well aware that we are collecting very sensitive information. We adhere to all pertinent HIPA regulations. So, in fact, I think it is very important, and it is one of the reasons that I believe—we have had enormous success in combining mental health screening and treatment with physical health screening and treatment in a group of workers who probably would not seek mental health care.

Mr. ENGEL. Let me ask you this. You have your program, the fire department's medical monitoring program, the World Trade Center Health Registry, the World Trade Center responders, Fatality and Investigation program, and Project Cope to name a few. All these programs seem to be working within their own silos. Are there any plans to merge data, save resources, share expertise, to examine the overall health effects related to the World Trade Center rather than just limited populations?

Dr. HERBERT. Yes, indeed there is, and we think that is very important. Presently, the New York/New Jersey consortium group of clinical centers and the FDNY programs use virtually identical questionnaires for the follow-up visits and the monitoring program.

Because of a number of privacy issues, it is sometimes difficult to actually have the same data systems, but we are collecting virtually identical data. And so we will be able to compare the experiences of different groups of responders, and that is essential.

We, in the Mount Sinai consortium, and Dr. Prazant at the FDNY program are also working very closely both with the World
Trade Center registry and with the New York State fatality investigation. So we agree that it is critical that resources be used in as prudent as possible so there is not redundancy.

Mr. Engel. Thank you. Thank you, Mr. Chairman.

Mr. Pallone. Mr. Fossella.

Mr. Fossella. Thank you, Mr. Chairman. I thank the panel again for your testimony, particularly Deputy Mayor Skyler. And this gets back to the overarching issue of the city of New York has stepped in to fill this breach, and many of us feel that it should have been the Federal Government stepping in immediately to help fill the breach. And the panel is consisting of people who have had to deal with the first responders and others, Mr. Vinciguerra from day one. And I used it before Dr. Howard as we are waiting for the cavalry.

And there are some legitimate concerns, I guess, one could point to if they are looking in after the fact and say where are the problems? And I think we have a responsibility to ask those questions to make improvements. But if I believe the Federal Government was up front early on, perhaps we could avoid asking those questions today because we would have had them at the table.

If I am not mistaken, with respect to some of the issues that have been raised, for example, workman's comp is designed through actuarial tables and doesn't necessarily take into account the scope and size of this catastrophe, the thousands and tens of thousands. 400,000 people thought to be affected would be one of the largest cities in this country, larger than the population of Minneapolis is, for example, people who have been affected by this.

So the system design does not, I think, take into account that radical number. And, in fact, some of the money we secured last year was helping the workman's compensation system facilitate and minimize the delays of those who partitioned the program.

Second, this is not totally unwarranted or unprecedented. After Pearl Harbor, there were programs that were put in place to help sailors who were called in to respond and came down with certain illnesses. So the Federal Government recognizing, although it took place in Hawaii, that this was a national catastrophe and demanded national scope.

Similarly, we can make that argument that flood insurance should be held by everybody or homeowner's insurance. But we know that major hurricanes, tornadoes, fires, other, FEMA steps in some way, shape, or form to help people through that system.

And finally there are those, we have noticed—and I would like to ask the deputy mayor for maybe expounding a little bit on this—we kept emphasizing that although it took place in New York City, this is a national problem in scope. You mention that there are 20,000 people who don't even live in New York City, again this would be larger than many towns and cities and villages across this country, 20,000 people.

So if you were a firefighter from Hialeah, FL, as Mr. Pallone said, or came in from New Orleans or California, and then went back to work and now suffering, common sense would dictate that that individual would show the similar signs of ailments and illnesses and manifestations of those diseases, let us say, or illnesses as someone who lives in New Jersey or Staten Island, New York.
And yet that person is probably on his own right now, and we don’t even know whether that person becomes eligible for satisfaction under workman’s comp.

So, Deputy Mayor Skyler, can you expand or illuminate, elaborate if you will, on the number who do not live within New York City?

Mr. SKYLER. The World Trade Center registry, through their modeling, estimated—and a lot of what we deal with in this subject is estimates—there are 410,000 people that qualified for the World Trade Center Health Registry, and that is based on where they lived, where they worked, where they were that day. We estimate that of those 410,000, 45,000 of them live outside not only New York State but New Jersey, which I believe has the second most members in the registry.

Of the 410,000 that we estimate, we had over 71,000 people signed up, we believe, of the 410,000 that qualified. And about 10,000 of them live outside New York and New Jersey. And at least one of them lives in Congressman Deal’s district in Georgia. There is literally at least one person in almost every congressional district in the country.

So it is absolutely a national problem, and it is not just because New York was attacked because of its symbolism, because it is the financial and media center of the country. But people come to New York. Sometimes they live in New Jersey. Sometimes they live in Connecticut. Sometimes they are there for the day. Sometimes they are working there for a couple months or visiting.

We have a population that is, to some extent, always changing, and people relocate. And we also had a great amount of people that came from all over the country to help when we needed. And this is a recovery that just wasn’t a couple of days or weeks. It was months.

So we believe that the Federal Government has a responsibility to help the city take care of its own. The city has stepped up. The city takes care of its firefighters. We take care of our police officers. We have done the best we can. What we are asking for is some Federal assistance so we have the long-term funding in place not only to maintain the great levels of care that we have established in our centers of excellence, but make sure that people that aren’t parts of those populations also get the care they need.

If you were hurt because of 9/11, it shouldn’t be just because you worked for the city or responded. If you were hurt because you lived across the street and breathed in the air potentially, then you also should be deserving the same assistance. And we have been hard at work. Since this panel report came out, there is only, I believe, two or three of the 15 recommendations that fall outside of the city. They are essentially requests for the Federal Government to help.

One is the Victims’ Compensation Fund, which I mentioned before, that Speaker Pelosi voiced her support for earlier. I am not sure whether she supports the whole James Zadroga Act. I would refer you to her office, but she voiced support for the Victims’ Compensation Fund.

The second is getting long-term funding from the Federal Government. The rest of the report was the city government taking a
hard look at itself and saying it wasn’t doing a good enough job explaining to the city workers what resources were available, coordinating services, encouraging people to get checkups, establishing communications within city government, and establishing protocols so that we have emergencies that have environmental impacts, whether it is Deutsche Bank building or the steam pipe explosion, that we have environmental professionals on scene that can help guide the emergency response.

So we have tried to learn from this disaster and do what we can do to improve our response. But what we are also saying is we are in need of a Federal commitment so that the people that were hurt don’t have their care jeopardized by the fiscal stability or health of New York City. In tough times, programs get cut back.

We would like to see an established program, a sustained commitment, so that people that were hurt continue to get the care they need. It is possible that some of these illnesses—doctors could speak better than I could—will improve over time. It is also possible that things will get worse. We don’t know. There are a lot of illnesses that we would not have a sense at this point of whether they will materialize. And we are talking about hundreds of thousands of people here, and it is unlike something that the country has ever experienced. And it is impossible for the health insurance mechanism, as set up now, to absorb it and care for it properly.

Mr. Fossella. Thank you, Mr. Skyler. Thank you, Mr. Chairman.

Mr. Pallone. Sure. I have to apologize to Mr. Weiner because he was supposed to go next because Mr. Fossella is not on the subcommittee. I apologize. Your turn.

Mr. Weiner. Well, I am gratified then that Mr. Fossella did such a good job in his time. I thank you, Mr. Chairman. I think that it is very important that we address fully Mr. Deal’s concerns because we want this effort to be one that is bipartisan. There are a lot of people who are not living with these issues day to day like we are who perhaps don’t understand the nuance and raise similar questions.

And perhaps, Mr. Skyler, you can expand a little bit on this notion that the programs that have been set up for the fire department, for example, take a State program, the disability insurance program, and say we as New York City residents, we are going to do even better. We are going to provide them even better care. We are going to step in and provide better care.

I don’t think that the failure of the fire fighters to go through the disability program is any way the shirking of New York City’s responsibility. It is taking on in addition. I just want to make sure that is clear for the record.

Mr. Skyler. Right, the level of care provided by the Bureau of Health Services, the fire department, is the gold standard. And if we can provide every person that was affected by these attacks with that level of care, we would be in a lot better shape than we are currently.

Mr. Weiner. And I think it is also worth noting one of the tools that many of the medical community have to determine what is going on is the monitoring that went on of firefighters long before September 11 that allow people to look at healthy 20-year-old lungs
and 23-year-old lungs that look like they should be on a 70-year-old person. That is one of the reasons that that is available.

I think it is also important that we understand that what we are suggesting here is exactly what Congress—and I don't know the record of my colleagues on the committee or Mr. Deal—I know Mr. Fossella and Mr. Engel's on this. We looked at a very similar problem when we created the Victim's Compensation Fund. We said well, how do we deal with what could be long-term lawsuits that go on ad infinitum. How do we deal with a community that has so many victims coming from so many places? How do you deal with them expeditiously, compassionately? How do we deal with this when the Victim's Compensation Fund was created?

And with that in mind, I just want to ask—and I will just go one by one on the panel—is there any doubt based on either your experience, your friendships with other people, your research that you write, is there any doubt in your mind—I will go from left to right—that people today are dying from 9/11-related illnesses? Why don't we start to the left, just a quick yes no. Is there any doubt in your mind?

Mr. VINCIGUERRA. Yes, people are dying.

Mr. WEINER. Doctor?

Dr. UDASIN. Yes.

Dr. HERBERT. I agree with Dr. Udasin.

Ms. BASCETTA. There is a large part of peer-reviewed literature that documents the health effects.

Mr. WEINER. Doctor?

Dr. MELIUS. Yes, absolutely.

Mr. WEINER. Mr. Skyler?

Mr. SKYLER. I am not a doctor, but clearly there is tremendous amount of harm that was caused by the attacks.

Mr. WEINER. And the Victim's Compensation Fund was created for people who died from the attacks. So the only question is Congress's instinct and Congress's desire to try to figure who the universe of people is, set up rules and parameters, and then go out and take care of them. The only thing that the city is asking is that the one parameter, December 2003, be changed. And that we know now that there is a whole universe of people who themselves didn't know that they were dying from September 11 related diseases and figuring out the correct place to place that December 2003 date.

We are asking essentially—what the city is asking, what residents are asking us to do—and what the residents of 40 or so States or all 50 States who are asking who are in this additional group, to do what all of us voted for. And at the time, those 2,800 or so that were in the known class of people that had died at the time, they had insurance. They had lawyers. They had someone to sue. They had a lot of people to sue, and we made a decision, you know what, it is probably better for everyone involved that rather than fighting in the courts for perhaps the better part of a generation over this, let us figure out what our responsible role is. And it had broad bipartisan support in its institution.

And I should say something else. If the Federal Government says no, Congress says no, we are not going to do any of these things we are going to do what we can. All of the people who are here testifying are going to keep doing their good work. We are going to
keep advocating. We are going to do what we can to embrace one another. We are going to try to figure out a way to take care of these people.

The question is: Is this the best way to care for people who are dying because of their heroism or their simple presence on September 11 at a certain place? Is that the way we want to respond as a Congress and as a people? Up to now, the American people, through their Congress, have said no, we don't believe that we want to respond. And we let people kind of go fend for themselves. If they are fortunate enough to have good insurance or to have been further away from the plume or to be a firefighter that has good monitoring, if that is where—Congress could wind up being there.

But I want to make it clear that what we are suggesting here and what sponsors of the bill are suggesting and what Mayor Bloomberg is suggesting is not this cosmically different way of looking at the problem. It is the same way that Mr. Deal and I and others in this Congress looked at it after September 11. We were attacked. Let us figure out a smart, compassionate, comprehensive way to deal with it.

We are not rewriting everything here. We are not reinventing the wheel with this legislation. The mayor’s desire to reopen the compensation fund, all of our desire to do that, is trying to figure out a way—and let me just end—I know I am a little bit over time.

If you are concerned, as I know so many of my colleagues are about the courts being clogged up with lawsuits and that us using the courts as the way we solve even the most basic disagreement about interpretations—and I know many of my colleagues on the judiciary committee have that feeling. Well, the Victims’ Compensation Fund is a way, in the words of Mr. Skyler, to get us working together rather than fighting one another.

It would be a shame if we are all sitting here in 10 years talking about and reading about the horrible lawsuits going on as families sue the city of New York which desperately wants to try to provide help. And I think the questions that Mr. Deal asked are exactly the right ones, and that we have to embark on trying to explain to people what we are doing here is not transformative. It is just tweaking a system that we have already created.

The city has taken on an enormous amount of responsibility. Whoever the next mayor is is going to have to deal with those responsibilities as well, but it is imperative that we, the Federal Government, take this opportunity to continue the job that we began. And I want to commend Mr. Fossella and Ms. Maloney, Mr. Nadler, Mr. Engel, and the chairman, Mr. Pallone, for helping us get to that place and for all of you for testifying here.

Mr. Pallone. Thank you. Let me say before we conclude that this was just a beginning. This was not a legislative hearing per se. I mean we didn’t have a piece of legislation before us, but it is my intention, and I think I can hear that there is a bipartisan concern that the current system is broken in terms of handling the health concerns of both first responders as well as other people that may have been impacted because they lived or worked in the vicinity of the World Trade Center.
So it is our intention to follow up on this and come up with some legislative initiative. But I think you can all see that even though, on a bipartisan basis, we realize that the status quo doesn’t work as well as we would like, that it is difficult to figure out exactly how to put something together.

So we are probably going to rely on all of you and follow up with phone calls and other things to help us out as we proceed, but we do intend to try to put something together legislatively.

And let me just say also that the Members, as always, can submit additional questions for the record to be answered by all of you. The questions should be submitted to the clerk within the next 10 days, and then we would notify you about those questions. So you may get some follow up in that respect.

And without objection, this meeting of the subcommittee is adjourned. Thank you all.

[Whereupon, at 1:30 p.m., the subcommittee was adjourned.]