ASSESSING SEPTEMBER 11TH HEALTH EFFECTS

HEARING

BEFORE THE

SUBCOMMITTEE ON NATIONAL SECURITY, EMERGING THREATS AND INTERNATIONAL RELATIONS

OF THE

COMMITTEE ON GOVERNMENT REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED EIGHTH CONGRESS

SECOND SESSION

SEPTEMBER 8, 2004

Serial No. 108–283

Printed for the use of the Committee on Government Reform

Available via the World Wide Web: http://www.gpo.gov/congress/house
http://www.house.gov/reform

U.S. GOVERNMENT PRINTING OFFICE

98–999 PDF WASHINGTON : 2005

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CONTENTS

ASSESSING SEPTEMBER 11TH HEALTH EFFECTS

WEDNESDAY, SEPTEMBER 8, 2004

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON NATIONAL SECURITY, EMERGING
THREATS AND INTERNATIONAL RELATIONS,
COMMITTEE ON GOVERNMENT REFORM,
Washington, DC.

The subcommittee met, pursuant to notice, at 12 p.m., in room 2247, Rayburn House Office Building, Hon. Christopher Shays (chairman of the subcommittee) presiding.

Present: Representatives Shays, Tierney, Kucinich, Duncan, Maloney, Turner, and Ruppersberger.

Also present: Representative Nadler.

Staff present: Lawrence Halloran, staff director and counsel; J. Vincent Chase, chief investigator; R. Nicholas Palarino, Ph.D., senior policy analyst; Kristen McElroy, professional staff member; Robert Briggs, clerk; Andrew Su, minority professional staff member; and Jean Gosa, minority assistant clerk.

Mr. SHAYS. A quorum being present, the Subcommittee on National Security, Emerging Threats and International Relations hearing entitled, "Assessing September 11th Health Effects," is called to order.

Three years after the cataclysmic attacks on the World Trade Center, shock waves still emanate from Ground Zero. Diverse and delayed health problems continue to emerge in those exposed to the contaminants and psychological stressors unleashed on September 11. An effective response to that attack and future terrorist assaults requires a coordinated, sustained program to monitor, diagnose, research and treat those wounded.

Last October, this subcommittee convened in New York City, to discuss the rigor and reach of Federal, State and local efforts to assess the public health impacts of September 11. We heard hopeful descriptions of outreach networks and monitoring protocols, we heard criticisms of slow funding and arbitrary deadlines and we heard concerns about a patchwork of short term solutions to an admittedly long term set of needs Today, we revisit those issues asking what more has been learned about the health effects of September 11 and what yet needs to be done to understand and repair the physical and mental toil of catastrophic terrorism.

It is a complex challenge. As we will hear in testimony from the Department of Health and Human Services and the Government Accountability Office, Federal leadership and resources continue to play a critical role in helping public health and disability com-

pensation systems adapt to the demands of an urban battlefield. Make no mistake, the firefighters, the police, the emergency medical personnel, the transit workers, the construction crews and other first responders did not go to work on September 11, they went to war.

In the days and weeks that followed, those who labored and lived near Ground Zero, fought to survive against the subtle, prolonged assault on their bodies and minds. Many are still fighting. For them, and for future casualties in this all too modern war, the national public health response has to be vigilant and implacable as the enemy we face.

Our second panel of witnesses brings firsthand knowledge of the medical shadow still cat by the falling towers of the World Trade Center. We appreciate their time and insights. We look forward to the testimony of all our witnesses.

At this time, the Chair would recognize the gentleman from Ohio, Mr. Kucinich.

[The prepared statement of Hon. Christopher Shays follows:]

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AND INTERNATIONAL RELATIONS
Christopher Shays, Connecticut
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Statement of Rep. Christopher Shays
September 8, 2004

Three years after the cataclysmic attacks on the World Trade Center, shock waves still emanate from Ground Zero. Diverse and delayed health problems continue to emerge in those exposed to the contaminants and psychological stressors unleashed on September 11, 2001. An effective response to that attack, and future terrorist assaults, requires a coordinated, sustained program to monitor, diagnose, research and treat those wounds.

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Today we revisit those issues, asking what more has been learned about the health effects of September 11th, and what yet needs to be done to understand, and repair, the physical and mental toll of catastrophic terrorism.

It is a complex challenge. As we will hear in testimony from the Department of Health and Human Services (HHS) and the Government Accountability Office (GAO), federal leadership and resources continue to play a critical role in helping public health and disability compensation systems adapt to the demands of an urban battlefield.

Make no mistake, the firefighters, police, emergency medical personnel, transit workers, construction crews and other first responders did not just go to work on September 11th, they went to war. In the days and weeks that followed, those who labored and lived near Ground Zero fought to survive against a subtle, prolonged assault on their bodies and minds. Many are still fighting. For them, and for future casualties in this all too modern war, the national public health response has to be as vigilant and implacable as the enemy we face.

Our second panel of witnesses brings first-hand knowledge of the medical shadow still cast by the fallen towers of the World Trade Center. We appreciate their time and their insights, and we look forward to the testimony of all our witnesses.

Mr. KUCINICH. Good afternoon and good afternoon to the members of the subcommittee.

I want to thank the witnesses here today. I know this is an emotional topic for many of them.

It has been 3 years since the horrific loss our Nation suffered on September 11. Yet, while our Nation still grieves and mourns the families, friends and heroes we lost in that tragedy, hundreds of thousands, possibly even millions of New Yorkers carry an even more salient reminder, the lingering physical and mental wounds which persist to this day, but we cannot cure those wounds when we still know little about what caused them.

We know intuitively that rescuers, residents, workers and people in the vicinity of the World Trade Center breathed in dust, smoke, asbestos and toxic substances that day and for many days after the attack. We know that the psychological impact of that day would haunt those closest to the scene and mental health care would be needed.

Yet, the questions we ask in Congress today are simple but in some cases they are still not answerable 3 years later. Who became ill or may still be ill and doesn't know it, what harmful substances were inhaled and what toxic amounts, are these people receiving treatment, are we working together at all levels, Federal, State and local to provide the care and followup needed?

The picture that is slowly developing, and that has been confirmed by the work of GAO to be presented today, is of woefully inadequate funding and neglect in the medical care of those affected. According to GAO, thousands of New York rescue and recovery workers have not yet been screened. Many of them have not received the workers compensation they are due and many of them do not have any medical insurance at all.

GAO also notes that hundreds of New York firefighters have been forced to give up their livelihood, been placed on medical leave and had to end their careers due to lingering respiratory illnesses. There is even a new condition affecting hundreds of these firefighters coined the "World Trade Center Cough" which is characterized by an acute, persistent cough with severe respiratory problems. Much more needs to be found out and be done.

First of all, we need to know how widespread the problem is. There is no longer any monitoring of New York State employees as the program has been discontinued. The World Trade Center Health Registry Program to screen civilians closed its enrollment as of September 1, though only 55,000 out of an estimated 400,000 affected civilians were screened. Rescue and recovery workers have been slow to register and be screened due to lack of treatment options, boundary disputes, interagency disputes and other delays.

We need to act and act in unison for the long term. There is no plan to fund long term medical research into September 11 illnesses. We do not know what if any debilitating conditions may require years to appear such as cancer will end up being prevalent. Where the monitoring programs were designed to last 25 years, they are currently only funded for 5. Private and charitable donations are drying up and the current administration has been slow to act.

For example, Congress allocated $90 million for the September 11 health screenings last year but this money was only awarded to New York City medical institutions this spring. Of the $175 million appropriated by Congress for the New York State Workers Compensation Board, millions have been spent on processing claims and preparing for future terrorist attacks but almost none has gone to actual reimbursement to the Uninsured Employer Fund, established for worker and volunteer benefits. Moreover, not a single penny has gone directly for treatment of these injuries. If we can raise and dispense over $500 million in financial assistance to 100,000 for the September 11 Victim Compensation Fund, then we can do the same for those still suffering physically and mentally today.

No amount of money can alleviate the loss and pain many shared that day but we all need to give a better effort.

I want to thank both Chairman Shays and Mrs. Maloney for their persistent oversight efforts to keep the management of and funding of these programs in the spotlight. This cannot and must not be a partisan issue, it should not be a matter of misinformation or red tape. It would be unconscionable to abandon our responsibility to care for each and every one of those victims today and into the future.

Thank you, Mr. Chairman.

[The prepared statement of Hon. Dennis J. Kucinich follows:]

Statement of Rep. Dennis J. Kucinich
Ranking Minority Member
House Subcommittee on National Security, Emerging Threats, and International Relations

Hearing on "Assessing September 11th Health Effects"

September 8, 2004

Good afternoon, Mr. Chairman, and members of the Subcommittee. I want to sincerely thank all of the witnesses here today, as I know this is an emotional topic for many of them.

It's been three years since the horrific loss our nation suffered on September 11. Yet, while our nation still grieves, and mourns the family, friends, and heroes we lost in that tragedy, hundreds of thousands, possibly even millions of New Yorkers carry an even more salient reminder – the lingering physical and mental wounds which persist to this day.

But we cannot cure those wounds when we still know little about what caused them. We know intuitively that rescuers, residents, workers, and people in the vicinity of the World Trade Center breathed in dust, smoke, asbestos, and toxic substances that

day, and for many days after the attack. We know that the psychological impact of that day would haunt those closest to the scene, and mental health care would be needed.

Yet, the questions we in Congress ask today are simple, but still unanswerable, three years later. Who became ill, or may still be ill and doesn't know it? What harmful substances were inhaled and in what toxic amounts? Are these people receiving treatment? Are we working together at all levels – federal, state, and local, to provide the care and follow-up needed?

The picture that is slowly developing, and that has been confirmed by the work of GAO to be presented today, is of woefully inadequate funding and neglect in the medical care for those affected.

According to GAO, thousands of New York rescue and recovery workers have not yet been screened. Many of them have not received the workmen's compensation they are due, and many of them do not have any medical insurance at all.

GAO also notes that hundreds of New York firefighters have been forced to give up their livelihood, placed on medical leave, and had to end their careers due to lingering respiratory illnesses. There is even a new condition affecting hundreds of these men, coined "World Trade Center cough," which is characterized by an acute, persistent cough with severe respiratory problems.

Much more needs to be found out and to be done. First of all, we need to know how widespread the problem is. There is no longer any monitoring of New York State employees as the program has been discontinued. The WTC Health Registry program to screen civilians closed its enrollment as of September 1, though only 55,000 out of an estimated 400,000 affected civilians were screened. Rescue and recovery workers have been slow to register and to be screened due to the lack of treatment options, boundary disputes, inter-agency disputes, and other delays. We can't drag our feet any longer.

We need to act, and to act in unison, for the long term. There is no plan to fund long-term medical research into 9/11 illnesses.

We do not know what, if any, debilitating conditions that may require years to appear, such as cancer, will be prevalent. While the monitoring programs were designed to last twenty-years, they are currently only funded for five. Private and charitable donations are drying up, and the current Administration has been slow to act.

For example, Congress allocated $90 million for 9/11 health screenings last year, but this money was only awarded to New York City medical institutions this spring. Of the $175 million appropriated by Congress for the New York State Workers Compensation Board, millions have been spent on processing claims and preparing for future terrorist attacks, but almost none has gone towards actual reimbursement to the uninsured employer fund established for worker and volunteer benefits.

Moreover, not a single penny has gone directly for treatment of these injuries. If we can raise and dispense over $500 million in financial assistance to 100,000 people through the September 11 Victim Compensation Fund, then we can do the same for those still suffering physically and mentally today. No amount of money can

alleviate the loss and pain we all shared that day, but we all need to give a better effort.

I would like to thank both Chairman Shays and Mrs. Maloney for their persistent oversight efforts to keep the management of and funding for these programs in the spotlight.

This should not be a partisan issue, and it should not be a matter of misinformation or red tape. It would be unconscionable to abandon our responsibility to care for each and every one of these victims today and in the future.

Thank you, and I look forward to hearing the testimony this morning.

Mr. SHAYS. I thank the gentleman.

At this time, the Chair would recognize John Duncan from Tennessee.

Mr. DUNCAN. I have no statement, Mr. Chairman.

Thank you.

Mr. SHAYS. I thank the gentleman.

At this time, the Chair would recognize John Tierney from Massachusetts.

Mr. TIERNEY. Thank you.

I am going to waive my remarks so that we can get to the witnesses, but I believe Mrs. Maloney probably has some comments to make.

Mr. SHAYS. Before recognizing Mrs. Maloney, let me thank her for her persistent in encouraging us to look at this issue. We had a hearing in New York City which was very enlightening. I am sure this hearing will be as well. She has been in the forefront of this issue and we do thank her.

Mrs. Maloney, you have the floor.

Mrs. MALONEY. I really want to thank Chairman Shays for holding the second hearing on the health effects of September 11. Back in October, at the end of the first hearing, Congressman Shays promised to continue working on this topic and once again, you have shown that you are a man of your word. We have tabulated how many hearings have taken place and only five have taken place on the after effects of September 11 health effects and two were held by Congressman Shays. So my constituents join me in thanking you for your leadership on this issue.

It is a great pleasure for me to welcome many New Yorkers here today and many have been working extremely hard on problems since September 11. I am particularly interested in what the Government Accountability Office has found as a result of their research into the health effects of September 11 as well as the Federal assistance for September 11 workers compensation costs.

After reading the prepared testimony of our witnesses, there are still some basic questions that have not been answered. Three years after September 11, it seems that we don't even know how many people are injured or how many people still need medical care, or who in the Federal Government is even responsible for looking into it or taking account of it. I am interested very much in what GAO has to say about this.

I am also interested in hearing about what is known with regard to the high levels of injury and illnesses emerging as a result of the attacks. For example, the most comprehensive program to date is one that the New York delegation, led by Senator Clinton, had to fight extremely hard to fund, the national program offering actual medical screening exams coordinated by the Mount Sinai Center for Occupational and Environmental Medicine.

Preliminary analysis of the World Trade Center responders, both workers and volunteers in that program, 12,000 of them have shown, well over 50 percent required physical or mental health treatment and/or aid immediately. Even months after the September 11 disaster sometimes the illnesses did not come up. I just met a firefighter 2 weeks ago who showed no illness until he went to another fire and immediately lost his voice and had tremendous

problems breathing and can no longer serve as a firefighter. This did not show or come to action until 3 years later and the doctors think it is directly related to September 11.

I am also very interested in hearing from Dr. Levin, regarding the current state of the program. The Johns Hopkins December 2001 study which is reported in the GAO report found that among non-firefighters, among those who reported no previous history of lower respiratory symptoms, 34 percent reported developing a cough and 19 percent reported developing wheezing. I am also very interested in hearing about the NIOSH survey of Federal employees working near the World Trade Center that found that 56 percent of respondents reported having a cough.

What is astonishing to me is that of the 10,000 Federal workers who responded to the World Trade Center, GAO found that only 412 exams have been completed. When we have seen that up to 90 percent of firefighters have reported health problems immediately after September 11, why have less than 5 percent of the Federal employees who responded been examined for illness?

The one program we have that even attempts to track everyone is a phone survey that was supposed to track between 250,000 and 400,00 responders, area workers and residents, but only 55,000 have enrolled according to the report. There are so many challenges with this so-called registry that even some unions who had members working at Ground Zero, are telling their members not to participate due to privacy concerns.

All total, we have six different programs that are tracking in some way the health effects of September 11, some are as simple as a phone call or a mailed questionnaire, while others actually involve a doctor and a health exam. However, none include any treatment and no where can I see a Federal coordination among them. I find this outrageous that we repeatedly call the men and women who rushed to Ground Zero heroes and heroines. We describe it as a war zone but if they do not have health coverage or have lost their job because of their health, there is no health coverage available for them. This needs to be changed and it is a very, very important issue.

Instead of coordination, it looks like you have a number of different programs going in different directions with different ways of collecting and analyzing data. I don't think this is the way to treat the heroes of September 11.

I hope to hear from our witnesses from the administration who in the Federal Government is in charge, who in the Federal Government is worried about these people and who can the victims of September 11 turn to for help. We literally have thousands of rescue workers, area workers, local residents who are sick, yet we have had to fight every step of the way just to set up a program that monitors and documents they are sick. We still do not have treatment.

One possible avenue to receive some sort of compensation is the funding provided to the workers compensation. It is absolutely unbelievable to me with so much demonstrated need that GAO finds in its testimony that of the $25 million Congress appropriated for injured volunteers, only $456,000 has been spent and only 31 percent of their claims had been resolved by the State.

I hope to hear more about this from our witnesses today including what definition the State gave them for the term resolved. If you were to tell me that we would not provide care for the heroes who so selflessly gave of themselves on September 11, I would not believe you and I do not think the American people would believe you and I do not think the American people would believe you. Yet, we have individuals who are now so sick from their work at Ground Zero that they cannot work, have lost their health care and the Federal Government's response so far has been to turn a cold shoulder.

Quite simply, they deserve to be treated better. We give our veterans health care if they get wounded in battle. Why should our first responders and relief workers be treated differently? We lost more people on September 11 than we did on Pearl Harbor. This is the precise reason why Chairman Shays and I have introduced H.R. 4059, the "Remember 9/11 Health Act." This legislation is modeled after a program that gives free Federal health insurance to volunteer forest firefighters who get injured while fighting a forest fire, provides Federal health insurance to individuals who are sick as a direct result of the September 11 disaster. The Senate has passed a bill offered by Senators Voinovich and Clinton which sets up a similar program for all major disasters but the House has yet to act on it.

Immediately following the terrorist attacks, the most heart warming thing that happened was how all of America came together and tens of thousands of people came to lower Manhattan to help. I truly believe the most inspiring scene I have ever seen in my life was the bucket brigade of volunteers who went in and worked with the police and fire. Many of them have no health coverage, there is no way to help them now. We know the deep sacrifices of the police, the firefighters, the Port Authority made in terms of first responders who lost their lives.

The story is not told as often of the thousands who have suffered from health problems. We always talk about the people who lost their lives, we need to start talking now about the people who are suffering from health problems. We are not, in my opinion, living up to our end of the bargain. We are not caring for the health of our heroes and heroines of September 11. Unless we take the opportunity now to care for them, we jeopardize the future response to disasters. We cannot afford having first responders and volunteers second guess their actions as they respond to a disaster when they rush in to help others. They should at the very least know that the Government will be there to help them with health care coverage.

Again, I thank the chairman for his oversight and for his persist work to help the victims of September 11.

[The prepared statement of Hon. Carolyn B. Maloney follows:]

Statement of Congresswoman Maloney
Government Reform Committee
Subcommittee on National Security
Hearing on 9/11 Health Effects
September 8, 2004

Thank you Chairman Shays, thank you for holding this second hearing on the health effects of 9/11. Back in October, at the end of the first hearing, you promised to continue your work on this topic and once again you are showing that you're a man of your word.

It is my pleasure to welcome some friends from New York who have been working so hard on this problem since 9/11 and I am particularly interested in what the Government Accountability Office (GAO) has found as a result of their research into the health effects of 9/11 as well as the federal assistance for September 11th workers compensation costs.

It seems to me that after reading the prepared testimony of our witnesses that there are still some basic questions that can not be answered.

Three years after 9/11, it seems that we don't even know how many people are injured or how many still need medical treatment or who in the federal government is even looking out for them. I am interested in asking GAO about this.

I am also interested in hearing from them about what is known with regard to the high levels of injury and illness emerging as a result of the attacks.

For example, the most comprehensive program to date is the one that the New York Delegation, led by Senator Clinton, had to fight to fund - the national program offering actual medical screening exams coordinated by the Mt Sinai Center for Occupational & Environmental medicine. Preliminary analysis of WTC responders - both workers and volunteers - in that program - 12,000 of them in fact - show well over 50% required physical and/or mental health treatment and or aid immediately - even months following the 9/11 disaster. I am interested in hearing from Doctor Levin regarding the current state of this program.

From the GAO testimony, I am interested in the Johns Hopkins December 2001 study among non-firefighters which found, "among those who reported no previous history of lower respiratory symptoms, 34 percent reported developing a cough and 19 percent reported wheezing.

I am interested in hearing about the NIOSH survey of federal employees working near the World Trade Center Site that found 56 percent of respondents reported having a cough. But what is astounding to me is that of the 10,000 federal workers who responded to the World Trade Center, GAO found that only 412 exams have been completed. When we have seen that up to 90% of firefighters have reported health problems immediately after 9/11, why have less than 5% of the federal employees who responded been examined for illness?

The one program that we have that even attempts to track everyone is a phone survey. It was supposed to track between 250,000 and 400,000 responders, area workers and residents but only 55,000 are enrolled. There are so many problems with this so-called registry that even some unions who had members working at Ground Zero are telling their members not to participate due to privacy concerns.

All told we have 6 different programs that are tracking in some way the health effects of 9/11. Some are as simple as a phone call or a mailed questionnaire while others actually involve a doctor and a health exam. However, none include any treatment and no where can I see a federal coordination among them. Instead of coordination, it looks like you have a number of different programs going in different directions with different ways of collecting and analyzing data. Is this any way to treat the heroes of 9/11?

What I want to hear from our witness from the Administration is who in the federal government is in charge?

Who in the federal government is worried about these people? Who can they turn to for help?

We literally have thousands of rescue workers, area workers and local residents who are sick yet we have had to fight every step of the way just to set up programs that can monitor them. We still have done nothing to provide treatment.

The one possible avenue to receive some sort of compensation is the funding provided to the worker's compensation. It is unbelievable to me, with so much demonstrated need, the GAO finds in its testimony that of the $25 million Congress appropriated for injured volunteers, only $456,000 has been spent and only 31 percent of their claims had been resolved by the state. I would like to hear more about this from our witness, including what definition the state gave them for the term resolved.

If you were to tell me that we would not provide care for the heroes who so selflessly gave of themselves on 9/11, I would not believe you and I do not think the American people would believe you.

Yet we have individuals who are now so sick from their work at Ground Zero that they can not work, have lost their health care and the federal government's response is to turn a cold shoulder. Quite simply, they deserve to be treated better.

We give our veterans health care if they get wounded in battle, why should our fire fighters, police officers or relief workers be treated any differently?

This is the precise reason why Chairman Shays and I have introduced HR 4059, the Remember 9/11 Health Act. This legislation, modeled after a program that gives free federal health insurance to volunteer forest fire fighters who get injured while fighting a forest fire, provides federal health insurance to individuals who are sick as a direct result of 9/11.

The Senate has passed S.1279 offered by Senators Voinovich and Clinton, which sets up a similar program for all major disasters, but the House has yet to act on it.

Immediately following the terrorist attacks, the most heart warming thing that happened was how all of America came together and tens of thousands of people came to Lower Manhattan to help. We all know of the deep sacrifices the FDNY, NYPD and the Port Authority made in terms of first responders who lost their lives. The story that is not told as often is of the thousands who have suffered from health problems. Unfortunately, we are not living up to our end of the bargain and we are not caring for heroes of 9/11.

Unless we take this opportunity now to care for them, we jeopardize the future response to disasters. We cannot afford having first responders and volunteers second guess their actions as they respond to a disaster.

Mr. SHAYS. I thank the gentlelady. Let me say, your statement was outstanding. It was longer than we usually have in an opening statement, but frankly, she was using Mr. Tierney's time as well. I thank the gentleman for yielding because it was an outstanding statement.

The only reason I am making that preface is that I am going to be asking the witnesses to stay closer to 5 minutes since we are starting later in the day. At this time, I would ask if Mr. Turner has any comment or if I should recognize the witnesses?

Mr. TURNER. No.

Mr. SHAYS. Let me ask unanimous consent that all members of the subcommittee be permitted to place an opening statement in the record and that the record remain open for 3 days for that purpose. Without objection, so ordered.

I ask further unanimous consent that all witnesses be permitted to include their written statement in the record and without objection, so ordered.

I think the key point I heard in Mrs. Maloney's statement is how do you get the disparate pieces to fit together? How do we do that? I hope that is answered.

I would note our first panel consists of: Dr. John Howard, Director, National Institute for Occupational Safety and Health, HHS, accompanied by Dr. G. David Williamson, Director, Agency for Toxic Substances and Disease Registry, HHS; Dr. Janet Heinrich, Director, Health Care-Public Health Issues, GAO; and Robert E. Robertson, Director, Education, Workforce and Income Security, GAO.

Dr. Howard, you have the floor.

STATEMENTS OF JOHN HOWARD, DIRECTOR, NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH, HHS, ACCOMPANIED BY DR. G. DAVID WILLIAMSON, DIRECTOR, AGENCY FOR TOXIC SUBSTANCES AND DISEASE REGISTRY, HHS; DR. JANET HEINRICH, DIRECTOR, HEALTH CARE-PUBLIC HEALTH ISSUES, GAO; AND ROBERT E. ROBERTSON, DIRECTOR, EDUCATION, WORKFORCE AND INCOME SECURITY, GAO

Dr. HOWARD. My name is John Howard and I am the Director of the National Institute for Occupational Safety and Health which is part of the Centers for Disease Control and Prevention in the Department of Health and Human Services. I am pleased to appear before you today on behalf of CDC and am joined by David Williamson of the Agency for Toxic Substances and Disease Registry.

Mr. SHAYS. Before you proceed, I would note for the record we have Jerry Nadler from Manhattan. I would like to go on with the testimony but without objection, the gentleman is allowed to participate fully as any other member here. If you would like to limit your comment to a minute or so, I would be happy to have your statement. We started literally 25 minutes ago and we haven't heard from the witnesses.

Mr. NADLER. I think it is about 2 minutes.

Mr. SHAYS. Mr. Nadler is in the area affected and I welcome his statement.

Mr. NADLER. I appreciate your holding this hearing and allowing me to sit on the panel.

I appreciate your holding the hearing today regarding the health effects of September 11's terrorist attacks and those who live and work at Ground Zero.

As the Member of Congress representing Ground Zero, I have heard from far too many constituents with health problems because of exposure to contaminants in World Trade Center dust. For almost 3 years, I have been criticizing the Environmental Protection Agency's response and that of other Federal agencies to the terrorist attacks on New York City.

In March and April 2002, my office published a white paper documenting EPA's misfeasance and malfeasance in an August 2003 EPA Inspector General issued report documenting the EPA gave false assurances to the people of New York regarding the air we were breathing and that the EPA refused to take responsibility to decontaminate indoor spaces such as apartments, offices and schools despite the fact they are federally mandated to do so.

Earlier this year, residents, workers and school children filed a class action lawsuit against EPA in an effort to finally get the agency to do its job and do it right as well as to request medical relief. I am very sorry to see the EPA is not present at this hearing today. At the last hearing on this subject back in October, I asked EPA some questions and as far as I know, they have yet to provide any answers. The EPA has also yet to fully answer a Freedom of Information Act request submitted by myself, Representative Owens, along with the support of Democratic Leader Nancy Pelosi and Ranking Members John Dingle, George Miller, Henry Waxman and John Conyers. In order to fully address the issues under consideration today, we hope the committee would receive all the information requested by Congress.

I understand that the chairman and Representative Maloney want to focus more on the health registry and the new GAO report on some of the EPA issues. Frankly, we do not need EPA to be here to tell us people are sick as a result of exposure to hazardous substances on September 11. Many of the problems associated with the health registry stem from EPA failures in responding to the terrorist attacks. For example, EPA has never properly tracked the release of hazardous substances and characterized the site to determine who has been exposed, what they were exposed to and the full extent of how far the contamination spread. The EPA instead drew an arbitrary boundary at Canal Street which the health registry followed. Even today's New York Times points this out in a story on this very GAO report. According to the article, "There are still no definitive answers to what exactly was in the dust, how many people suffered because of their exposure." Again, this is because EPA never characterized the site consistent with Federal law.

The article goes on to say that "Although EPA warned people working directly in the rubble to wear protective masks, the agency maintained the dust settled over wider areas including only low levels of asbestos and generally was not harmful, a position the spokeswoman said the agency continues to hold." You simply can-

not separate the health effects of September 11 from EPA's response at the site.

I believe it is very clear what the Federal Government should do to protect the health of all those exposed to hazardous substances as a result of September 11. The EPA should follow its federally mandated procedures to characterize the site and the Federal Government should cover the actual medical treatment of those in need. We must do more than just a screening program. The victims of the terrorist attack are not just statistics.

The GAO report under consideration today provides more disturbing evidence to the extent that the health impact following September 11 and the gaps in medical treatment for those affected. According to the report, 90 percent of the firefighters and EMS workers at the site had respiratory ailments. Of the 332 firefighters in the study that reported "World Trade Center Cough" only about half have shown any improvement.

The GAO report also found that the people living and working in lower Manhattan experienced health effects similar to first responders and that almost 75 percent of respondents living near the site experience respiratory symptoms. The only assistance for these residents is the health registry which does not provide any actual medical treatment.

It troubles me that it has been almost 3 years since the attacks and we have made so little progress in helping people recover physically and mentally from the attacks. I am pleased this committee is continuing to look into the health effects of September 11 and I look forward to hearing from the witnesses and learning more about this GAO report so we can move ahead and try to make progress on this issue.

The first responders, workers, residents and all those affected by the attacks deserve more from the Federal Government. I stand ready to work with my colleagues in that regard and I again express my appreciation to the chairman, Mr. Shays, and the ranking member, Mrs. Maloney, for following up with this hearing.

Mr. SHAYS. I thank the gentleman and appreciate his statement.

Dr. Howard, you are going to start over again.

[Witnesses sworn.]

Dr. HOWARD. My testimony this afternoon is going to focus on the most recent CDC efforts to respond to the needs of workers and volunteers regarding the potential health effects of their exposures at the World Trade Center site.

Regarding baseline medical screening, in 2002, CDC's National Center for Environmental Health granted $4.8 million to the New York City Fire Department and $2.4 million to the New York State Department of Health to conduct baseline medical evaluations of firefighters and New York State employees who responded to the World Trade Center site in the course of their own jobs.

To assess the health status of the emergency services and rescue and recovery personnel who were not otherwise covered by the New York City Fire Department or the New York State Health Department, baseline medical screening programs, CDC awarded $11.8 million to the Mount Sinai School of Medicine, Center for Occupational and Environmental Medicine to establish the World Trade

Center Worker and Volunteer Medical Screening Program. In 2003, CDC supplemented this program with an additional $4 million.

Mount Sinai established the program by organizing a consortium of occupational health clinics both in New York City and across the Nation to provide medical screening services to workers and volunteers. Baseline screening began in July 2002 and as of August 4, 2004, 11,793 workers and volunteers have been screened.

NIOSH scientists, in collaboration with Mount Sinai, analyzed data from a subset of participants, about 10 percent of the sample seen at Mount Sinai between July 2002 and December 2002. These findings will be published this Friday, September 10, in two articles in the CDC Morbidity and Mortality Weekly Report and will describe the physical and mental health effects seen in World Trade Center rescue and recovery workers and volunteers.

With regard to long-term medical monitoring, in 2003, Congress directed and provided $90 million for FEMA to work with NIOSH to support long-term followup medical monitoring for World Trade Center rescue and recovery workers and volunteers, including current and retired New York City firefighters. In anticipation of receipt of these funds, NIOSH held a public meeting in New York in May 2003 to gather input regarding the content and the structure of this long-term medical monitoring program. On March 18, 2004, CDC awarded eight grants for a total of approximately $81 million to provide New York City firefighters and other rescue and recovery workers and volunteers with medical monitoring examinations at six clinical centers throughout New York City and over the next 5 years.

Importantly, the New York City Fire Department and the Mount Sinai School of Medicine provided funding to establish coordinating data centers to facilitate coordination and communication among the clinical centers and to assure quality control. Followup medical examinations will begin in October 2004 after appropriate hospital review committees have approved the clinical protocols.

CDC and ATSDR are also working to identify the health effects of September 11 on the people living, working or attending school in the vicinity of the World Trade Center site. In collaboration with the New York City Department of Health and Mental Hygiene, ATSDR has established a registry to identify and track the long-term health effects of tens of thousands of workers and community members who were the most directly exposed to smoke, dust and debris resulting from the World Trade Center collapse.

Launched on September 5, 2003, the World Trade Center Health Registry will interview registrants about their physical and mental health periodically over 20 years or more through the use of comprehensive and confidential health surveys. More than 59,000 have been interviewed and enrolled in the registry to date and they include rescue and recovery workers, office workers, residents, and school children from each of the 50 States. The registry will be maintained over time by the New York City Department of Health and Mental Hygiene and will provide an important picture of the health consequences of the events of September 11 and can be used to identify physical or mental health trends resulting from the exposure.

The New York City Department of Health and Mental Hygiene and ATSDR will communicate information to registrants and health care providers as well as posting information updates quarterly on the World Trade Center Health Registry Web site at www.wtcregistry.org. The upcoming October quarterly update will present for the first time health outcome data collected and analyzed via the registry.

In summary, CDC and ATSDR are committed to assessing the health effects resulting from September 11, 2001 World Trade Center disaster and to identifying the physical and mental health needs of affected workers, residents and community members.

I thank you for your attention. I am pleased to answer any questions you may have.

[The prepared statement of Dr. Howard follows:]

Testimony
Before the Subcommittee on National Security, Emerging Threats, and International Relations
Committee on Government Reform
United States House of Representatives

Assessing 9/11 Health Effects

Statement of
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For Release on Delivery
Expected at 12:00 noon
Wednesday, September 8, 2004

Mr. Chairman and members of the Subcommittee, my name is John Howard, and I am the Director of the National Institute for Occupational Safety and Health (NIOSH), 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. I am pleased to appear before you today to provide testimony on behalf of CDC and our sister agency, the Agency for Toxic Substances and Disease Registry (ATSDR).

CDC supplied extensive emergency assistance during the initial months following September 11th, providing technical assistance to the Federal Emergency Management Administration (FEMA) and to New York to better characterize acute exposures and to make recommendations for the development of a comprehensive protection program for the rescue workers.

My testimony will focus on the most recent CDC efforts to respond to the needs of workers and volunteers regarding the potential short-and long-term health effects of their exposures to the World Trade Center (WTC) site. I will report on the status of efforts to assess health effects from the September 11th attack on the WTC and the programs in place for monitoring health and providing assistance to victims.

Mr. Chairman, I would like to express my appreciation to you and to the members of the subcommittee for holding this hearing. HHS shares your concern for the community and for the workers who responded so courageously in our country's time of great need.

Assessing Health Status of WTC Responders

Since September 11, 2001, CDC has continually provided technical assistance and financial grant awards to local, state, and federal organizations to assess the health impact of the WTC disaster. Immediately following the attack, CDC provided much needed medical evaluation for the brave men and women who worked day and night in the rescue and recovery at Ground Zero. In collaboration with an informal network of occupational medicine specialists, CDC helped to facilitate the production of a guidance document to assist community-based physicians in the medical evaluation of patients exposed to this disaster; ultimately providing the groundwork for the creation of a comprehensive medical screening program. In addition, in 2001, CDC conducted a series of health hazard evaluations to examine the physical and mental health concerns of those working at or near Ground Zero. The results of these health hazard evaluations were reported to you during the Subcommittee hearing in October 2003.

Also reported to you during the previous hearing were the activities of the National Institutes of Environmental Health Sciences (NIEHS), at HHS' National

Institutes of Health, which has provided over $8.5 million since September 11 for a multi-faceted array of studies on the health consequences of the attacks. NIEHS grantees have identified the composition and structure of dust particles from the collapse of the buildings, and have determined particle size and the degree of penetration into the airways of those who were exposed. Researchers have also created a public database that includes both pre- and post-September 11 air quality data (http:wtc.hs.Columbia.edu).

Other NIEHS-funded researchers have conducted clinical and epidemiological studies to investigate respiratory abnormalities and post-traumatic stress syndrome in WTC-exposed population such as firefighters, ironworkers and community residents. Scientists have also identified the symptoms and duration of the "World Trade Center Cough", and determined that some dust particles from the attacks were small enough to penetrate into lung airways, producing caustic effects on the respiratory system. Other researchers have evaluated birth outcomes and conducted follow-up studies on the impact of prenatal hazardous exposures during the WTC attack. NIEHS grantees have sponsored town-hall style meetings to inform the public about study results and future planned studies and address residents' comments related to health consequences of the attacks.

Baseline Medical Screening

In 2002, CDC's National Center for Environmental Health granted $4.8 million to the New York City Fire Department and $2.4 million to the New York State Department of Health to conduct baseline medical evaluations of firefighters and New York State employees, respectively, who responded to the WTC site in the course of their jobs.

To assess the health status of the emergency services and rescue and recovery personnel who were not otherwise covered by the New York City Fire Department and New York State Health Department baseline medical screening programs, CDC awarded $11.8 million to Mt. Sinai School of Medicine's Center for Occupational and Environmental Medicine to establish the WTC Worker and Volunteer Medical Screening Program. In 2003, CDC supplemented this program with an additional $4 million. As of August 4, 2004, 11,793 workers and volunteers have been screened.

Mt. Sinai established the Screening Program by organizing a consortium of occupational health clinics to provide screening services to workers and volunteers living throughout the New York City metropolitan area and subcontracted with a national network of occupational health clinics for those workers and volunteers who responded from as far away as California and Washington State. In consultation with occupational health experts from NIOSH, Mt. Sinai developed the comprehensive medical screening program which began

in July 2002, and included medical and exposure assessment questionnaires, comprehensive physical examinations, lung function assessments, chest x-rays, routine blood and urine tests, and mental health screening. The program also provided necessary clinical referrals and occupational health education for workers and volunteers. Participants were recruited through a series of outreach efforts that included community and union meetings and mailings and articles distributed through the media.

NIOSH scientists, in collaboration with Mt. Sinai, analyzed a subset of the 11,793 program participants. The study analyzed data from 1,138 participants seen at Mount Sinai between July 2002 and December 2002. These findings will be published on Friday, September 10th, in two articles in the CDC Morbidity and Mortality Weekly Report (MMWR). The articles describe the respiratory symptoms and include the first published report on mental health findings for these WTC rescue and recovery workers and volunteers.

In addition to these efforts, HHS's Office of Public Health Emergency Preparedness is coordinating a screening program that parallels Mt. Sinai's. This program screens Federal responders who are not covered by the programs offered by the New York City Fire Department, New York State Health Department, or Mt. Sinai.

Long-term Medical Monitoring

In 2003, Congress directed and provided $90 million to FEMA to work with NIOSH to support long-term follow-up medical monitoring for the WTC rescue and recovery workers and volunteers, including current and retired New York City firefighters.

In anticipation of receipt of these funds, in May 2003, NIOSH held a public meeting in New York City to gather input regarding the content and structure of this program. The meeting was attended by individuals representing the medical community, city and state health departments, labor unions, employers, and other federal research agencies such as the Environmental Protection Agency and the National Institutes of Health (NIH). Participants identified a number of significant health concerns among the exposed workers, particularly, respiratory and mental health. CDC collected additional comments from NIH and mental health experts to develop strategies for assessing and monitoring workers to address long-term public health concerns and to learn valuable lessons about complex psychobiological impacts and long-term recovery.

Based on the information gathered, in March 2004, CDC awarded eight grants for a total of approximately $81 million to provide New York City firefighters ($25 million) and other rescue and recovery workers (approximately $56.5 million) and volunteers with medical monitoring examinations over the next five years. The other $9 million from Congress funded the expansion of the baseline screenings

(as discussed previously) and CDC/NIOSH operational costs. The grants provide for long-term monitoring at six clinical centers: the New York City Fire Department, State University of New York - Stony Brook, the Mt. Sinai School of Medicine, the New York University School of Medicine, the City University of New York's Queens College, and the University of Medicine and Dentistry of New Jersey's Robert Wood Johnson Medical School. The New York City Fire Department and the Mt. Sinai School of Medicine were provided funding to establish coordinating data centers. This will facilitate communication among clinical centers and assure quality control. Periodic analysis of the monitoring results will provide the information necessary to identify priorities and allow for the adaptation of monitoring protocols to accommodate the changing needs of the population and new medical innovations over time.

A steering committee was established to make decisions regarding the structure and content of the monitoring programs; thus, enabling the creation of a single coordinated examination protocol for all rescue workers enrolled in the program. Commencing this past April, the steering committee, composed of the principal investigators and labor representatives, has met one to two times per month and made major decisions regarding the structure and content of the program. In addition, the committee established multiple working groups composed of national experts who have provided technical advice on the recommended content and structure of the follow-up examinations.

The clinical centers are currently providing baseline examinations (as stated earlier, as of August 4, 2004, 11,793 workers and volunteers have been screened). Follow-up examinations will begin in October 2004 after appropriate hospital review committees have approved the clinical protocol. The creation of this coordinated program will allow for improved communication and information sharing across all of the diverse occupations involved in the WTC rescue, recovery, and restoration efforts.

Assessing Health Impacts on Workers and the Community

In addition to its activities to assess and address the health impacts on rescue and recovery workers and volunteers, CDC and ATSDR are working to identify the health effects of 9/11 on the people who were living, working or attending school in the vicinity of the WTC site.

World Trade Center Health Registry (WTCHR)

ATSDR, in collaboration with the New York City Department of Health and Mental Hygiene, has established a registry to identify and track the long term health effects of tens of thousands of workers and community members who were the most directly exposed to smoke, dust, and debris resulting from the World Trade Center collapse. The World Trade Center Health Registry (WTCHR) was launched September 5, 2003, thus beginning data collection. Extensive public outreach and media campaigns followed, focusing on reaching possible

participants throughout the New York metropolitan area and other areas where affected individuals may now reside. Registrants will be interviewed periodically over a period of 20 years or more through the use of a comprehensive and confidential health survey concerning their physical and mental health.

Participation in the health registry is voluntary and stringent safeguards are in place to protect the confidentiality of all information collected. Fostering a cross federal agency effort, both FEMA and EPA have provided funding to ATSDR for various aspects of the development, launch and maintenance of the Registry.

One year following the launch, more than 59,000 people have been interviewed and enrolled, establishing the WTCHR as the largest health registry of its kind in the United States. Registrants include rescue and recovery workers, office workers, residents and school children from each of the 50 states. Official enrollment for the Registry ended on August 31, 2004. The Registry will be maintained over time by the New York City Department of Health and Mental Hygiene.

The WTC Health Registry will provide an important picture of the health consequences of the events of September 11th. Registry information will be 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.

In addition, it will serve as a resource for future investigations, including epidemiological and other research studies, concerning the health consequences of exposed persons from all walks of life. These investigations and studies will act as a significant base for developing and disseminating important prevention and public policy information for use in the unfortunate event of future disasters. By assembling a broad range of data and information into a single database, the Registry also facilitates coordinated follow-up.

The New York City Department of Health and Mental Hygiene and ATSDR will communicate information concerning physical or mental health impacts to the public and to health care providers so those affected can make informed decisions about their health care. Information is posted quarterly and available on the WTC Health Registry Website (www.wtcregistry.org). For the first time, the upcoming quarterly update in October will present health outcome data collected and analyzed via the Registry.

Summary

Although there is certainly much more to learn from the tragedy of 9/11, CDC and ATSDR have succeeded in providing valuable assistance to the American people in time of need. Over the years since the WTC collapse, we have networked and collaborated with numerous researchers and health professionals across the country to develop and implement medical monitoring programs and to disseminate pertinent information to assist the exposed workers and volunteers

as well as the community-at-large. Our medical monitoring programs and the Health Registry will continue to describe the physical and mental health effects over time, some of which may not yet be discovered, and help to direct resources to those in need throughout the entire United States. Furthermore, our data will provide evidence to further guide public health response in the unfortunate event of future disasters. CDC and ATSDR are committed to the health and welfare of the brave men and women who worked so tirelessly to serve the people of the United States and to all of those who were exposed to the potentially harmful agents emitted as a result of this tragic moment in history.

Thank you for your attention. I am pleased to answer any questions.

Mr. SHAYS. Thank you very much, Dr. Howard.

Dr. Heinrich.

Dr. HEINRICH. I too appreciate the opportunity to be here today as you discuss the health effects of the September 11 terrorist attack on the World Trade Center.

Although people across the country were exposed to the emotional trauma of the attack, the residents and workers in the area around the World Trade Center as well as responders, not only experienced the event but also were exposed to a complex mixture of potentially toxic contaminants in the air and on the ground.

As noted before, almost 3,000 people were killed in the attack, although a majority of the estimated 16,000–18,000 people who were in the complex that morning were able to evacuate with minor or no injuries. An estimated 40,000 responders were at or in the vicinity of the World Trade Center site or the Staten Island Fresh Kills landfill.

Concerns have been raised about the short and long term physical and mental health effects. Under challenging circumstances, various government agencies and private sector organizations established several efforts to understand and monitor the health effects resulting from the attack. I will describe the variety of physical and mental health effects that have been reported across a wide range of people in the aftermath of this attack.

Even though most people did not require hospitalization immediately after the attack, thousands of people were treated for injuries including inhalation, musculoskeletal burns and eye injuries. In addition, thousands of responders were treated for injuries during the 10 month clean-up period. Despite the disaster site being considered extremely dangerous, and the more than 3.7 million work hours logged over this period, very few injuries resulted in lost work days. There was a concerted effort by everyone to work safely as well as a reluctance to leave the site.

A range of respiratory health effects including a new syndrome called World Trade Center cough and chronic diseases such as asthma were observed among people exposed to the dust and debris of the World Trade Center collapse. Studies present a consistent picture in findings regarding the conditions among those people involved in rescue, recovery and cleanup as well as those who lived and worked in the vicinity. Commonly reported conditions include wheezing, shortness of breath, sinusitis and gastroesophogeal reflux disease.

Almost all of the New York City Fire Department firefighters who responded to the attack developed respiratory problems and for some this has meant their careers ended as firefighters. While some responders have reported that symptoms resolved after a few months, many reported pulmonary symptoms 9 months or more after the attack.

In the weeks and months that followed, many people reported symptoms associated with post-traumatic stress disorder or PTSD with people living or working near the site reporting a higher rate. People near the site also reported more symptoms associated with depression, stress and anxiety.

The six programs established to monitor and understand these health effects vary in terms of which people are eligible to partici-

pate, methods for collecting information about the health effects, options for treatment referral and the number of years people will be monitored. These programs are not centrally coordinated but some are now collaborating with each other. Although five of the programs target responder populations, the largest, the World Trade Center Health Registry, is open to people living and working in the vicinity as well as responders.

The monitoring programs vary in their methods for identifying those who may require treatment and although none are funded to provide treatment, they provide options for referrals. For example, the New York City Fire Department Program offers a comprehensive medical evaluation and mental health screening. People needing treatment may obtain care from the fire department's Bureau of Health Services.

The Mount Sinai Program also provides a comprehensive physical and mental health evaluation. If a person requires followup medical or mental health services and is unable to pay for these, they may be referred to the Mount Sinai Health for Heroes Program which is supported through donations, or to other safety net programs.

The Federal Occupational Health and New York State programs also include medical evaluations as well as self-administered health and exposure questionnaires. Workers who require followup are referred to their primary care physicians.

Unlike the other monitoring programs, the World Trade Center Health Registry and the Hopkins registry obtain information obtained by questionnaire and does not include a medical evaluation and neither effort is affiliated with treatment. Health effects have been reported but the full impact is unknown.

The potential for additional long term effects remains, yet the monitoring programs may not be in operation long enough to capture information about new conditions and are not set up necessarily to coordinate data and findings.

We continue to hear the concerns about the lack of resources for adequate treatment of chronic conditions. People really must rely on the existing patchwork of services.

Mr. Chairman, I am happy to answer any questions you may have.

[The prepared statement of Dr. Heinrich follows:]

United States Government Accountability Office

GAO

Testimony

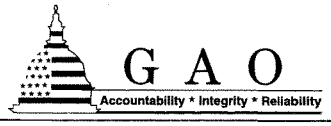
Before the Subcommittee on National Security, Emerging Threats, and International Relations, Committee on Government Reform, House of Representatives

For Release on Delivery
Expected at 10:00 a.m. EDT
Wednesday, September 8, 2004

SEPTEMBER 11

Health Effects in the Aftermath of the World Trade Center Attack

Statement of Janet Heinrich
Director, Health Care—Public Health Issues



GAO-04-1068T

September 8, 2004

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Highlights

Highlights of GAO-04-1068T, a testimony before the Subcommittee on National Security, Emerging Threats, and International Relations, Committee on Government Reform, House of Representatives

SEPTEMBER 11

Health Effects in the Aftermath of the World Trade Center Attack

Why GAO Did This Study

When the World Trade Center (WTC) buildings collapsed on September 11, 2001, nearly 3,000 people died and an estimated 250,000 to 400,000 people who were visiting, living, working, and attending school nearby, or responding to the attack, were exposed to a mixture of dust, debris, smoke, and various chemicals. In the months to follow, thousands of people who returned to the area to live and work, as well as responders who were involved in the search for remains and site cleanup, were also exposed. In addition, people in New York City and across the country were exposed to the emotional trauma of a terrorist attack on American soil.

Concerns have been raised about the short- and long-term physical and mental health effects of the attack. Various government agencies and private organizations established efforts to monitor and understand these health effects.

GAO was asked to describe the health effects that have been observed in the aftermath of the WTC attack and the efforts that are in place to monitor and understand those health effects. GAO searched bibliographic databases such as Medline to determine the pertinent scientific literature, reviewed that literature, and interviewed and reviewed documents from government officials, health professionals, and officials of labor groups.

www.gao.gov/cgi-bin/getrpt?GAO-04-1068T

To view the full product, including the scope and methodology, click on the link above. For more information, contact Janet Heinrich at (202) 512-7119.

What GAO Found

In the aftermath of the September 11 attack on the World Trade Center, a wide variety of physical and mental health effects have been reported in the scientific literature. The primary health effects include various injuries, respiratory conditions, and mental health effects. In the immediate aftermath of the attack, the primary injuries were inhalation and musculoskeletal injuries. During the 10-month cleanup period, despite the dangerous work site, responders reported few injuries that resulted in lost workdays. A range of respiratory conditions have also been reported, including wheezing, shortness of breath, sinusitis, asthma, and a new syndrome called WTC cough, which consists of persistent cough accompanied by severe respiratory symptoms. Almost all the firefighters who responded to the attack experienced respiratory effects, and hundreds had to end their firefighting careers due to WTC-related respiratory illness. Unlike the physical health effects, the mental health effects were not limited to people in the WTC area but were also experienced nationwide. Because most of the information about mental health effects comes from questionnaire or survey data, what is reported in most cases are symptoms associated with a psychiatric disorder, rather than a clinical diagnosis of disorder. The most commonly reported mental health effects include symptoms associated with depression, stress, anxiety, and posttraumatic stress disorder (PTSD)—a disorder that can develop after experiencing or witnessing a traumatic event and includes such symptoms as intrusive memories and distressing dreams—as well as behavioral effects such as increased use of alcohol and tobacco and difficulty coping with daily responsibilities.

Six programs were established to monitor and understand the health effects of the attack, and these programs vary in terms of which people are eligible to participate, methods for collecting information about the health effects, options for treatment referral, and number of years people will be monitored. Although five of the programs focus on various responder populations, the largest program—the WTC Health Registry—is open not only to responders but also to people living or attending school in the vicinity of the WTC site, or working or present in the vicinity on September 11. The monitoring programs vary in their methods for identifying those who may require treatment, and although none of these programs are funded to provide treatment, they provide varying options for treatment referral. Under current plans, HHS funding for the programs will not extend beyond 2009. Some long-term health effects, such as lung cancer, may not appear until several decades after a person has been exposed to a harmful agent.

GAO provided a draft of this testimony to DHS, EPA, HHS, and the Department of Labor. In its written comments, HHS noted that the testimony does not include significant discussion of ways in which mental health symptoms have changed over time. The evidence GAO examined did not support a full discussion of changes in mental or physical health effects over time.

Mr. Chairman and Members of the Subcommittee:

I appreciate the opportunity to be here today as you discuss the health effects of the September 11, 2001, terrorist attack on the World Trade Center (WTC).[1] When the WTC buildings collapsed on that day, nearly 3,000 people died and an estimated 250,000 to 400,000 people were immediately exposed to a mixture of dust, debris, smoke, and various chemicals.[2] These people included those living, working, and attending school in the vicinity as well as the thousands of emergency response workers who rushed to the scene. Also exposed to these substances were the thousands of responders[3] who were involved in some capacity in the rescue operations, search for remains, and site cleanup in the days, weeks, and months to follow and the thousands of residents, commuters, and students who returned to the area to live and work while the cleanup continued.[4] In addition, people in New York City (NYC) and across the country were exposed to the emotional trauma of a terrorist attack intended to instill fear and anxiety in the American population.

Concerns have been raised about the short- and long-term physical and mental health effects of the attack. Experts have stressed the importance of understanding the health effects related to the attacks and ensuring that these effects are investigated and that people needing treatment are identified. Under challenging circumstances due to the unprecedented nature of the events and the need for rapid response, various government

[1]A list of abbreviations used in this testimony is given in Appendix I.

[2]New York City Department of Health and Mental Hygiene and U.S. Department of Health and Human Services, Agency for Toxic Substances and Disease Registry, *Protocol for the World Trade Center Health Registry* (New York, 2003).

[3]For purposes of this testimony, the term responders refers to anyone involved in rescue, recovery, and cleanup efforts at or in the vicinity of the WTC site and Staten Island Fresh Kills landfill (the off-site location of the WTC recovery operation), including firefighters, law enforcement officers, emergency medical technicians and paramedics, morticians, health care professionals, construction workers, ironworkers, carpenters, heavy equipment operators, mechanics, truck drivers, engineers, laborers, telecommunications workers, and various federal, state, and local agency employees who assisted with rescue, recovery, and cleanup activities.

[4]For more information on exposures to these substances, see, for example, U.S. Environmental Protection Agency, *Exposure and Human Health Evaluation of Airborne Pollution from the World Trade Center Disaster (External Review Draft)* (Washington, D.C., 2002), and J.D. Pleil et al., "Air Levels of Carcinogenic Polycyclic Aromatic Hydrocarbons after the World Trade Center Disaster," *Proceedings of the National Academy of Sciences of the United States of America*, vol. 101, no. 32 (2004).

agencies and private-sector organizations established several efforts to monitor and understand the health effects resulting from the attack. You asked us to examine these efforts.

In this testimony, we describe (1) health effects that have been observed in the aftermath of the WTC attack and (2) efforts that are in place to monitor and understand those health effects. My colleague's testimony addresses workers' compensation for people who were injured while working during the attack or its aftermath.[5]

To describe the health effects of the WTC attack and the efforts to monitor and understand them, we reviewed the scientific literature related to efforts to identify, track, or treat the physical and mental health effects of the September 11 attack[6] and interviewed and reviewed documents from federal, state, and local agency officials, as well as medical and public health professionals and officials of labor groups. We searched 19 bibliographic databases such as Medline to determine the pertinent literature. The studies of health effects vary in study design, measures used, survey instruments, time periods, and populations studied, and thus in many cases the reported results cannot be directly compared. The federal, state, and local officials we interviewed were from the U.S. Departments of Defense (DOD), Education, Health and Human Services (HHS), Homeland Security (DHS), Justice (DOJ), Labor (DOL), and Veterans Affairs (VA); the Environmental Protection Agency (EPA); the New York State Department of Health; the New York State Office of Mental Health; and the New York City Department of Health and Mental Hygiene. The medical and public health professionals we interviewed were affiliated with the Association of Occupational and Environmental Clinics, the City University of New York's Queens College, the New York City Fire Department's (FDNY) Bureau of Health Services, the Greater New York Hospital Association, the Johns Hopkins Bloomberg School of Public Health, the Mailman School of Public Health at Columbia University, the Mount Sinai-Irving J. Selikoff Clinical Center for Occupational and Environmental Medicine, the New York Academy of Medicine, the New York University School of Medicine's Child Study Center, and the National Child Traumatic Stress Network. We also interviewed representatives of

[5]GAO, *September 11: Federal Assistance for New York Workers' Compensation Costs*, GAO-04-1013T (Washington, D.C.: Sept. 8, 2004).

[6]See the bibliography for a list of the scientific literature that we relied on in producing this testimony.

labor groups, including the American Federation of State, County and Municipal Employees District Council 37; the Communications Workers of America; the New York State American Federation of Labor-Congress of Industrial Organizations; and the Uniformed Firefighters Association.

We relied primarily on data from published, peer-reviewed articles and government reports and did not independently verify the data contained in the scientific literature or documents obtained from agency officials and medical professionals. However, we did review the methods used in the studies and discussed any questions we had about the studies with their authors. We determined that the data reported from these studies were sufficiently reliable for our objectives. We conducted our work from March 2004 through September 2004 in accordance with generally accepted government auditing standards.

In summary, in the aftermath of the September 11 attack on the World Trade Center, a wide variety of physical and mental health effects have been reported in the scientific literature. The primary health effects include various injuries, respiratory conditions, and mental health effects. In the immediate aftermath of the attack, the primary injuries were inhalation and musculoskeletal injuries. During the 10-month cleanup period, despite the dangerous nature of the work site, responders reported few injuries that resulted in lost workdays. A range of respiratory conditions have also been reported, including wheezing, shortness of breath, sinusitis, asthma, and a new syndrome called WTC cough, which consists of persistent cough accompanied by severe respiratory symptoms. Almost all the firefighters who responded to the attack experienced respiratory effects, and hundreds had to end their firefighting careers due to WTC-related respiratory illness. Whereas the physical health effects were limited to people in the WTC area, the mental health effects, although more pronounced in the NYC area, were experienced nationwide. Because most of the information about mental health effects comes from questionnaire or survey data, what is reported in most cases are symptoms associated with a psychiatric disorder, rather than a clinical diagnosis of the disorder itself. The most commonly reported mental health effects include symptoms associated with depression, stress, anxiety, and posttraumatic stress disorder (PTSD)—an often debilitating and potentially chronic disorder that can develop after experiencing or witnessing a traumatic event and includes such symptoms as intrusive memories and distressing dreams—as well as behavioral effects such as increased use of alcohol and tobacco and difficulty coping with daily responsibilities.

Six programs have been established by federal, state, and local government agencies and private organizations to monitor and understand the health effects of the attack. These programs vary in terms of which people are eligible to participate, methods for collecting information about the health effects, options for treatment referral, and number of years people will be monitored. Although five of the monitoring programs focus on various responder populations, the largest program—the WTC Health Registry—is open not only to responders—that is, those involved in the rescue, recovery, and cleanup efforts—but also to people living or attending school in the vicinity of the WTC site, or working or present in the vicinity on September 11. The monitoring programs vary in their methods for identifying those who may require treatment, and although none of these programs are funded to provide treatment, they provide varying options for treatment referral. Under current plans, HHS funding for the programs will not extend beyond 2009. Some long-term health effects, such as lung cancer, may not appear until several decades after a person has been exposed to a harmful agent.

We provided a draft of this testimony to DHS, DOL, EPA, and HHS. In its written comments, HHS noted that the testimony does not include significant discussion of ways in which mental health symptoms have changed over time. The evidence we examined did not support a full discussion of changes in mental or physical health effects over time. HHS and the other agencies also provided technical comments, which we incorporated as appropriate.

Background

Although people across the country were exposed through the media to the emotional trauma of the WTC attack, the residents, office workers, and others living, working, or attending school in the WTC area and the WTC responders not only experienced the traumatic event in person but also were exposed to a complex mixture of potentially toxic contaminants in the air and on the ground, such as pulverized concrete, fibrous glass, particulate matter, and asbestos. Almost 3,000 people, including some who were trapped above the impact zone and others who entered the buildings to assist in the evacuation, were killed in the attack.[7] The majority of the estimated 16,400 to 18,800 people who were in the WTC complex that

[7]National Commission on Terrorist Attacks upon the United States, *The 9/11 Commission Report* (Washington, D.C., 2004).

morning were able to evacuate, however, with minor or no injuries.[8] An estimated 40,000 responders were at or in the vicinity of the WTC site or the Staten Island Fresh Kills landfill, participating in rescue, recovery, and cleanup efforts[9]; conducting environmental and occupational health assessments; providing crisis counseling and other treatment; providing security; and assisting with the criminal investigation.

The responders included personnel from many agencies at the federal, state, and local levels, as well as from organizations in the private sector, and various other workers and volunteers. The agencies and organizations include HHS's Agency for Toxic Substances and Disease Registry (ATSDR), HHS's Centers for Disease Control and Prevention (CDC), the Department of Energy, EPA, DOJ's Federal Bureau of Investigation (FBI), DHS's Federal Emergency Management Agency (FEMA), HHS's National Institute for Occupational Safety and Health (NIOSH), HHS's National Institute of Environmental Health Sciences (NIEHS), the Department of the Interior's National Park Service, DOL's Occupational Safety and Health Administration (OSHA), HHS's Public Health Service Commissioned Corps, HHS's Substance Abuse and Mental Health Services Administration (SAMHSA), DOD's U.S. Coast Guard, DOJ's U.S. Marshals Service, the New York State Department of Environmental Conservation, the New York State Emergency Management Office, the New York State National Guard, the New York State Office of Mental Health, the New York State Department of Health, the Metropolitan Transportation Authority's New York City Transit, FDNY and emergency medical services (EMS), the New York City Department of Health and Mental Hygiene, the New York City Police Department (NYPD), the New York City Department of Design and Construction, the New York City Department of Environmental Protection, the New York City Department of Sanitation, the New York City Office of Emergency Management, the American Red Cross, and the Salvation Army.

Recognizing a need to monitor and understand the full health effects of the WTC collapse, officials from various organizations secured federal funding

[8]National Commission on Terrorist Attacks upon the United States, 2004.

[9]Department of Health and Human Services, "HHS Awards $81 Million for Five-Year Health Screening of World Trade Center Rescue, Recovery Workers," Department of Health and Human Services, *http://www.hhs.gov/news/press/2004pres/20040318.html* (accessed Aug. 9, 2004).

to establish programs to monitor the health of affected people.[10] FDNY sought federal support in order to provide comprehensive medical evaluations to its firefighters, and established its WTC Medical Monitoring Program (referred to here as the FDNY program). The Mount Sinai Clinical Center for Occupational and Environmental Medicine also sought federal support in the weeks following the attack to develop its WTC Worker and Volunteer Medical Monitoring Program (referred to here as the Mount Sinai program).[11] Through its Federal Occupational Health (FOH) services, HHS initiated a WTC responder screening program for federal workers (referred to here as the FOH program) involved in WTC rescue, recovery, and cleanup activities. Similarly, the New York State Department of Health established the medical monitoring program for New York State responders (referred to here as the NYS program) engaged in emergency activities related to the September 11 attack. In addition, two registries were established to compile lists of exposed persons and collect information through interviews and surveys in order to provide a basis for understanding the health effects of the attack. The New York City Department of Health and Mental Hygiene contacted ATSDR in February 2002 to develop the WTC Health Registry. ATSDR provided technical assistance to the New York City Department of Health and Mental Hygiene and worked with FEMA to obtain funds for the WTC Health Registry for responders and people living or attending school in the vicinity of the WTC site, or working or present in the vicinity on September 11. Separately, Johns Hopkins received a grant from NIEHS to create another registry

[10]FEMA provided funds appropriated for disaster relief and emergency response to the September 11, 2001, terrorist attacks to HHS through interagency agreements to support monitoring efforts. See Consolidated Appropriations Resolution, 2003, Pub. L. No. 108-7, 117 Stat. 11, 517; see also 2002 Supplemental Appropriations Act for Further Recovery from and Response to Terrorist Attacks on the United States, Pub. L. No. 107-206, 116 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. 2230, 2338; 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. 220-1.

[11]Initial medical screenings of responders conducted by this program were supported by funds appropriated to CDC for disease control, research, and training. See Department of Defense and Emergency Supplemental Appropriations for Recovery from and Response to Terrorist Attacks on the United States Act, 2002, 115 Stat. at 2313.

(referred to here as the Johns Hopkins registry) of WTC site workers who were involved in cleanup efforts.[12]

Varied Physical and Mental Health Effects Have Been Observed and Reported across a Wide Range of People

A wide variety of physical and mental health effects have been observed and reported across a wide range of people in the aftermath of the September 11 attacks. The health effects include various injuries, respiratory conditions, reproductive health effects, and mental health effects. Unlike the physical health effects, the mental health effects of the September 11 attacks were not limited to responders and people who were in the WTC area but were also experienced by people across the nation. Because most of the information about mental health effects comes from questionnaire or survey data, what is reported in most cases are symptoms associated or consistent with a disorder, such as PTSD, rather than a clinical diagnosis of a disorder. The most commonly reported mental health effects were symptoms associated with PTSD, depression, stress, and anxiety, as well as behavioral effects such as increases in substance use and difficulties coping with daily responsibilities.

Injuries

Although the total number of people injured during the WTC attack is unknown, data on hospital visits show that thousands of people were treated in its immediate aftermath for injuries, including inhalation injuries, musculoskeletal injuries, burns, and eye injuries. Unpublished data collected by the Greater New York Hospital Association from September 11 through September 28, 2001, showed 6,232 emergency room visits and 477 hospitalizations related to the attack in 103 hospitals in New York State and 1,018 emergency room visits and 84 hospitalizations related to the attack in nearby New Jersey hospitals. These numbers do not include injured people who may have been treated in more distant New York State, New Jersey, and Connecticut hospitals, in triage stations,[13] or by private physicians, and those who did not seek professional treatment. More detailed information on injuries is available from the four hospitals closest to the WTC and a fifth hospital that served as a burn referral

[12]The grant was funded by an appropriation to NIEHS to support research, worker training, and education activities. See Department of Defense and Emergency Supplemental Appropriations for Recovery from and Response to Terrorist Attacks on the United States Act, 2002, 115 Stat. at 2337.

[13]Triage stations are temporary facilities set up in the aftermath of a disaster where medical assessments of patients are performed to determine their relative priority for treatment, based on the severity of illness or injury.

center. According to the New York City Department of Health and Mental Hygiene, between September 11 and September 13, 2001, these hospitals treated 790 people, 2 of whom later died, for injuries related to the attack (CDC, 2002c). The most common of these injuries were musculoskeletal injuries—such as fractures, sprains, and crush injuries—and inhalation injuries. The majority of people with injuries were treated and released, although about 18 percent required hospitalization.[14]

In addition, thousands of responders were treated for injuries, a small proportion of which were classified as serious, during the 10-month cleanup period. The disaster site was considered to be extremely dangerous, yet no additional life was lost after September 11. Using data from five Disaster Medical Assistance Teams (DMAT) temporary medical facilities[15] and the four hospitals closest to the WTC site, researchers documented 5,222 visits by rescue workers to DMAT facilities and emergency rooms in the first month of the cleanup period (Berrios-Torres et al., 2003). During this month, musculoskeletal injuries were the leading cause of rescue worker visits and hospitalizations. Other injuries included burns and eye injuries. According to OSHA, despite logging more than 3.7 million work hours over the 10-month cleanup period, WTC site workers reported only 57 injuries that OSHA classified as serious because they resulted in lost workdays, yielding a lost workday injury rate of 3.1 injuries per 100 workers per year. This rate is lower than that seen in the type of construction deemed by OSHA to be the most similar to the WTC cleanup, specialty construction, which has a lost workday injury rate of 4.3.

Respiratory Health Effects

A range of respiratory health effects, including a new syndrome called WTC cough and chronic diseases such as asthma, were observed among people exposed to the WTC collapse and its aftermath. Many of the programs examining respiratory health effects are ongoing and have published only preliminary results. Nevertheless, the studies present a

[14]In an assessment of the cardiovascular effects of the WTC attack in eight hospitals in NYC, no significant increases in hospitalization for cardiac events immediately following the attack were found (Chi et al., 2003).

[15]The DMAT facilities were set up around the disaster site by FEMA's National Disaster Medical System, which was activated on September 11. The DMATs maintained a 24-hour presence at the WTC site for 2 months after the disaster. In addition to the DMATs, the National Disaster Medical System also includes teams of morticians, veterinarians, nurses, pharmacists, and management personnel.

consistent collection of conditions among those people who were involved in rescue, recovery, and cleanup as well as those who lived and worked in the WTC vicinity. The most commonly reported conditions include cough, wheezing, shortness of breath, sinusitis, and asthma. Many of the findings on respiratory effects published to date have focused on firefighters, and FDNY medical staff first described WTC cough, which consists of persistent cough accompanied by severe respiratory symptoms,[16] often in conjunction with sinusitis, asthma, and gastroesophageal reflux disease (GERD).[17] Several studies report on other WTC responders, such as the police, ironworkers, and cleanup workers, and a few studies report on the respiratory effects among people living and working in lower Manhattan.

FDNY Firefighters

Almost all of the FDNY firefighters who had responded to the attack experienced respiratory effects, and hundreds had to end their firefighting careers due to WTC-related respiratory illness. Within 48 hours of the attack, FDNY found that about 90 percent of its 10,116 firefighters and EMS workers who were evaluated at the WTC site reported an acute cough. The FDNY Bureau of Health Services also noted wheezing, sinusitis, sore throats, asthma, and GERD among firefighters who had been on the scene. During the first 6 months after the attack, FDNY observed that of the 9,914 firefighters who were present at the WTC site within 7 days of the collapse, 332 firefighters had WTC cough (Prezant et al., 2002). Eighty-seven percent of the firefighters with WTC cough reported symptoms of GERD. According to the FDNY Bureau of Health Services, symptoms of GERD are typically reported by less than 25 percent of patients with chronic cough. Some FDNY firefighters exhibited WTC cough that was severe enough for them to require at least 4 weeks of medical leave. Despite treatment of all symptoms, 173 of the 332 firefighters and one EMS technician with WTC cough showed only partial improvement. FDNY also found that the risk of reactive airway dysfunction syndrome, or irritant-induced asthma, and WTC cough was associated with intensity of the exposure, defined as the time of arrival at the site (Banauch et al., 2003). In addition, FDNY reports that one firefighter who worked 16-hour days for 13 days and did not use

[16]Severe respiratory symptoms are defined by the FDNY Bureau of Health Services as symptoms that are severe enough to require at least 4 consecutive weeks of medical leave.

[17]GERD occurs when the lower esophageal sphincter does not close properly and stomach contents leak back, or reflux, into the esophagus. When refluxed stomach acid touches the lining of the esophagus, it causes a burning sensation in the chest or throat called heartburn.

respiratory protection during the first 7 to 10 days was diagnosed with a rare form of pneumonia that results from acute high dust exposure (Rom et al., 2002). According to an official from the FDNY Bureau of Health Services, because one of the criteria for being a firefighter is having no respiratory illness, about 380 firefighters were no longer able to serve as firefighters as of March 2004 as a consequence of respiratory illnesses they developed after WTC exposure.

Other WTC Responders

Studies and screenings conducted among other responders—carpenters, cleanup workers, federal civilian employees, heavy equipment operators, ironworkers, mechanics, National Guard members, police officers, telecommunications technicians, truck drivers, and U.S. Army military personnel—have found respiratory health effects similar to those seen in FDNY firefighters. Some of the responders with existing respiratory conditions reported that symptoms worsened, and others reported that they developed new respiratory symptoms on or after September 11. The most commonly reported symptom was cough. For example, about 63 percent of officers from NYPD's Emergency Services Unit who were evaluated about 1 to 4 months after September 11 reported having a cough (Salzman et al., 2004). Other symptoms observed among responders included chest tightness, nasal congestion, shortness of breath, sore throat, and wheezing. Unpublished results from respiratory health assessments of WTC site workers—including truck drivers, heavy equipment operators, mechanics, laborers, and carpenters—conducted by Johns Hopkins in December 2001 show that among those who reported no previous history of lower respiratory symptoms, 34 percent reported developing a cough and 19 percent reported wheezing. While some responders reported that symptoms improved or resolved a few months after the attack, others reported that they continued to experience symptoms. For example, initial results from screenings of 250 participants in Mount Sinai's monitoring program show that 46 percent of these responders were still experiencing at least one pulmonary symptom and 52 percent were still experiencing an ear, nose, or throat symptom 9 months after the attack (Herbert and Levin, 2003).

People Living or Working in Lower Manhattan

Surveys conducted among people living or working in lower Manhattan show that these people experienced respiratory health effects similar to those experienced by responders, such as nose or throat irritation and cough. For example, a door-to-door survey conducted by the New York City Department of Health and Mental Hygiene in three residential areas in lower Manhattan between October 25 and November 2, 2001, showed that the most frequently reported symptoms were nose or throat irritation (about 66 percent) and cough (about 47 percent) (CDC, 2002a). A NIOSH

survey of federal employees working near the WTC site found that 56 percent of respondents reported having a cough (Trout et al., 2002). Other symptoms observed among those living or working in lower Manhattan include chest tightness, head or sinus congestion, shortness of breath, and wheezing. Some people reported that the WTC collapse and its aftermath exacerbated existing respiratory conditions, such as asthma, and others reported symptoms that developed after September 11, 2001. For example, a review of medical charts of children with existing asthma from a lower Manhattan clinic found that after September 11 there was a significant increase in asthma-related clinic visits among children who lived within 5 miles of the WTC site (Szema et al., 2004). Unpublished preliminary findings from a New York State Department of Health survey of NYC residents found that almost three-fourths of respondents living near the WTC site experienced new upper respiratory symptoms after September 11.

Reproductive Health Effects

For all measures of reproductive health studied except birth weight for gestational age,[18] no differences were found between infants born to women who were in or near the WTC on September 11 and infants of those who were not. The Mount Sinai School of Medicine conducted a study of the 187 pregnant women[19] who were either in or near the WTC on September 11. This study found no significant differences in average gestational duration at birth or average birth weight between infants of the women who were in or near the WTC on September 11 during their pregnancy and infants of the 2,367 women in the study's comparison group, who were not (Berkowitz et al., 2003). Additionally, no significant differences in frequency of preterm births (less than 37 weeks of gestation) or in incidence of low birth weight (less than 2,500 grams) were observed. Nor was an association observed between symptoms of posttraumatic stress in the mother and frequency of preterm birth, low birth weight, or small-for-gestational-age[20] infants. However, 8.2 percent of

[18]Gestation is the period between conception and birth of a baby, and gestational age is duration of gestation.

[19]Of the 187 women, 3 miscarried and 2 were unavailable for follow-up, leaving 182 women with live births. The last delivery occurred in June 2002.

[20]The term "small for gestational age" (SGA) means a fetus or infant is smaller in size than is expected for the baby's sex, genetic heritage, and duration of gestation. Birth weight below the population tenth percentile, taking into account gestational age, is the most widely used definition of SGA.

infants born to women who were in or near the WTC on September 11 were born with a birth weight below the tenth percentile for gestational age, compared to 3.8 percent of infants born to women in the study's control group. This difference was still statistically significant after variables such as maternal age, race/ethnicity, sex of the infant, and maternal smoking history were taken into account.[21] Because small-for-gestational-age infants are at risk for developmental problems, the Mount Sinai program includes a follow-up study in which researchers plan to obtain physical measurements of growth and perform assessments of early cognitive development.

Symptoms Associated with PTSD

In the weeks and months after the WTC attack, people living, working, or attending school in NYC and responders involved in the rescue, recovery, and cleanup reported symptoms associated with PTSD, as did people across the nation. PTSD is an often debilitating and potentially chronic disorder that can develop after experiencing or witnessing a traumatic event. It includes such symptoms as difficulty sleeping, irritability or anger, detachment or estrangement, poor concentration, distressing dreams, intrusive memories and images, and avoidance of reminders of the trauma.

People living or working near the WTC site reported a higher rate of symptoms associated with PTSD than did those living or working farther from the site. For example, researchers found that about 7.5 percent of Manhattan residents reported symptoms consistent with PTSD 5 to 8 weeks after the attack, with 20 percent of those living in close proximity to the WTC reporting symptoms (Galea et al., 2002a). Similarly, NIOSH surveys found that reports of symptoms consistent with PTSD were significantly higher among school staff in the WTC vicinity than among school staff working at least 6 miles from the WTC site (CDC, 2002a).

[21]Additionally, an unpublished study conducted by the Mailman School of Public Health at Columbia University found no differences in birth weight, length, head circumference, or Apgar scores (the Apgar is a test performed at 1 and 5 minutes after birth to determine the physical condition of the newborn). However, in this study, the gestational duration observed among pregnant women who lived or worked near the WTC during the 2 weeks after September 11 was shorter than that of those who did not (274.3 versus 275.9 days). Though this difference was statistically significant, its clinical significance is unclear. Researchers planned to assess cognitive and motor functions of the infants at a 1-year follow-up visit.

Some groups of people, such as children and responders, were found to have experienced traumatic reactions to the attack. For example, a citywide survey of a representative sample of NYC fourth to twelfth graders 6 months after the attack found that over 10 percent reported having symptoms consistent with PTSD. The researchers who conducted this survey noted that these symptoms were five times more prevalent than pre-September 11 rates reported for other communities (Hoven et al., 2002). Responders, many of whom lost colleagues, were also affected. Initial findings from the Mount Sinai program show that about 22 percent of a sample of 250 WTC responders reported symptoms consistent with PTSD (Herbert and Levin, 2003).

People across the nation also reported symptoms associated with PTSD. A nationwide survey comparing reactions in NYC to those across the country using a nationally representative sample of U.S. adults found that the prevalence of symptoms associated with PTSD 1 to 2 months after the attack was significantly higher in the NYC metropolitan area (11.2 percent) than in other major metropolitan areas (3.6 percent) and the rest of the country (4 percent) (Schlenger et al., 2002). Another nationally representative sample in a nationwide survey of U.S. adults shows that 17 percent of the U.S. population outside of NYC reported symptoms associated with PTSD 2 months after the attack (Silver et al., 2002). Although no baseline data are available on the prevalence of symptoms related to PTSD, typically about 3.6 percent of U.S. adults have a psychiatric diagnosis of PTSD during the course of a year.[22]

Symptoms Associated with Depression, Stress, and Anxiety

People living, working, and attending school in NYC and WTC responders, as well as people across the nation, reported symptoms associated with depression, stress, and anxiety. For example, in NYC, researchers found that about 9.7 percent of Manhattan residents surveyed 5 to 8 weeks after the attack reported symptoms consistent with depression (Galea et al., 2002a). Nine hospitals in NYC reported that from September 11 to September 24, 2001, the predominant symptoms related to the WTC attack were those associated with anxiety, stress, and depression (Greater New York Hospital Association, 2001). Data from these hospitals show that anxiety declined over the month following the attack but increased again

[22]Department of Veterans Affairs, "What Is Posttraumatic Stress Disorder? A National Center for PTSD Fact Sheet," www.ncptsd.org/facts/general/fs_what_is_ptsd.html, updated May 14, 2003 (accessed Aug. 16, 2004).

around the time that the first case of anthrax in NYC was announced in mid-October 2001. A NIOSH survey of people working in schools near the WTC site also reported symptoms of depression (CDC, 2002a). Among the responders, initial screenings from the Mount Sinai program show that nearly 37 percent of 250 program participants reported symptoms associated with anxiety, insomnia, and depression (Herbert and Levin, 2003). In addition, a nationwide survey conducted 3 to 5 days after the attack in a nationally representative sample of U.S. adults found that 44 percent of those surveyed reported one or more substantial symptoms of stress, including having difficulty concentrating, feeling irritable, feeling upset when something reminds the person of the attack, having disturbing thoughts or dreams, and having trouble sleeping (Schuster et al., 2001).

Behavioral Effects

The behavioral effects in the aftermath of the WTC attack included increased use of substances such as alcohol, tobacco, and marijuana. Increased use of alcohol and tobacco was identified through surveys of the general population conducted by the states of Connecticut, New Jersey, and New York in the 3 months following the attack (CDC, 2002b). In Manhattan, researchers found that almost 29 percent of people who responded to a survey administered 5 to 8 weeks after September 11 reported increased use of cigarettes, alcohol, or marijuana after the attack (Vlahov et al., 2002). According to these researchers, this increase in substance use was still evident 6 months after September 11 (Vlahov et al., 2004a,b).

The behavioral effects also included difficulty coping with daily responsibilities. Some NYC children and adolescents, family members, and other adults, including members of the response community, are still having difficulty coping 3 years after September 11. For example, an ongoing SAMHSA-supported youth mental health program in NYC is treating 220 children and adolescents who are having problems coping, such as having difficulties functioning in school. In addition, researchers affiliated with the New York University School of Medicine's Child Study Center's bereavement program for families of uniformed personnel killed in responding to the WTC attacks noted that the psychological and emotional reactions of children and adolescents directly affected by the attacks have diminished somewhat over time but that some children continue to be affected by the emotional state and coping difficulties of their parents. Of particular concern to these researchers are the widowed mothers, who are experiencing sustained distress at twice the level typically found in the general population and are having difficulty coping with their daily responsibilities, such as single parenthood, almost 3 years

later. Some responders, such as members of FDNY, also report having difficulty coping in the aftermath of September 11.

Programs Established to Monitor and Understand Health Effects Vary in Eligibility Requirements, Methods, Treatment Referrals, and Duration

The programs established to monitor and understand the health effects of the attack vary in terms of which people are eligible to participate, methods for collecting information about the health effects, options for treatment referral, and number of years people will be monitored. (See table 1.) FEMA provided funding for most of these programs through interagency agreements with HHS. These programs are not centrally coordinated, but some of them are collaborating with each other.

Table 1: Programs to Monitor Health Effects in the Aftermath of the World Trade Center (WTC) Attack

	Administrator	Eligible Populations	Participation	Monitoring Methods	Treatment Referral	Intended Duration and Federal Funding[a]
WTC Health Registry	NYC Department of Health and Mental Hygiene	Between 250,000 and 400,000 responders and people living or attending school in the area of the WTC or working or being present in the vicinity on September 11	As of 9/2004, 60,483 people were enrolled[b]	Telephone-based health interview; plan to re-interview subset of population in 2005	Provides information on where treatment can be sought; refers participants to LIFENET[c] for mental health services	Agency for Toxic Substances and Disease Registry intends to fund through fiscal year 2008 — $20 million total Environmental Protection Agency allocated in fiscal year 2004 — $1.5 million total
FDNY WTC Medical Monitoring Program (FDNY program)	FDNY Bureau of Health Services (FDNY-BHS)	About 11,000 firefighters and 3,500 emergency medical service (EMS) technicians	As of 4/2004, 11,770 firefighters and EMS technicians were enrolled	Medical examination and questionnaire; three follow-up examinations planned	Refers to FDNY-BHS	National Institute for Occupational Safety and Health (NIOSH) intends to fund through 6/2009 — $25 million total National Center for Environmental Health funded initial monitoring — $4.8 million total
WTC Worker and Volunteer Medical Monitoring Program (Mount Sinai program)	Mount Sinai's Irving J. Selikoff Clinical Center for Occupational and Environmental Medicine[d]	About 12,000 responders[e]	As of 8/2004, about 11,793 people were enrolled	Medical examination and questionnaire; three follow-up examinations planned	Refers to privately funded program available for responders	NIOSH intends to fund through 7/2009 — $56 million total NIOSH funded initial monitoring[f] — $15.8 million total
The medical monitoring program for New York State workers (NYS program)	New York State Department of Health	About 9,800 New York State employees and National Guard personnel	As of 10/2003, 1,677 employees received medical evaluations	Medical examination and questionnaire; follow-up on subset of 300 employees planned	Instructs participants to see their primary care physician or the state's occupational health unit	National Center for Environmental Health funded through fiscal year 2003 — $2.4 million total
WTC cleanup and recovery worker registry (Johns Hopkins registry)	Johns Hopkins Bloomberg School of Public Health	About 12,000 members from three unions[g] and the NYC Department of Sanitation	As of 6/2003, 1,337 workers responded to the mailed questionnaire	Mail-in health survey	Provides participants with brochures about health services; refers uninsured to Columbia University for mental health services	National Institute of Environmental Health Sciences (NIEHS) funded through fiscal year 2003[h] — $1.2 million[i] total

	Administrator	Eligible Populations	Participation	Monitoring Methods	Treatment Referral	Intended Duration and Federal Funding[a]
WTC responder screening program for federal workers[l] (FOH program)	Department of Health and Human Services' (HHS) Federal Occupational Health services	About 10,000 federal workers responding to WTC	As of 3/2004, 412 exams were completed and reviewed	Medical examination and questionnaire	Instructs participants to see their primary care physician	HHS intends to fund through 12/2005 — $3.7 million total

Sources: FDNY, HHS, Mount Sinai, New York City Department of Health and Mental Hygiene, and New York State Department of Health.

Note: Programs are ordered according to participation level.

[a]Except as noted, FEMA provided funds to the agencies listed below through interagency agreements with HHS to support efforts to monitor the health effects of the WTC attack.

[b]The WTC Heath Registry officials told us that they have generated a list of 185,000 potential participants gathered from various sources, including employers and registration via the Web or telephone. Registry officials told us that the registry will continue to interview and enroll people who are on this list after the registration period ends.

[c]LIFENET is a 24-hour mental health information and referral service provided by the New York State Office of Mental Health.

[d]Mount Sinai is the coordinating center for the five clinics in this program.

[e]People eligible to participate in the Mount Sinai program are those who worked primarily at or immediately adjacent to the WTC site, either during or after the disaster, including firefighters from outside NYC, police officers from NYC and surrounding communities, emergency rescue workers from a variety of organizations (including emergency medical technicians and paramedics), building and construction trade workers from the NYC metropolitan area and throughout the nation, members of the press and news media, health care workers, food service workers, structural and other engineers, and a variety of other public- and private-sector workers, and people who worked in the immediate vicinity of the WTC site restoring essential services, such as telephone services, electricity, and transportation, or performing services necessary to reopen buildings in the area, including cleaning and assessing the structural integrity of nearby buildings. The program excluded federal employees, FDNY firefighters, and, initially, New York State employees, who were all eligible for other programs. New York State responders were initially screened in the NYS program. The NYS program plans to follow 300 of these responders. All New York State responders are now eligible to participate in the Mount Sinai program.

[f]Initial medical monitoring conducted through this program was supported by funds appropriated to CDC.

[g]The International Brotherhood of Teamsters, the International Union of Operating Engineers, and the Laborers International Union of North America.

[h]Funds appropriated to NIEHS to support research, worker training, and education activities supported this grant.

[i]Includes funding for other activities, including Johns Hopkins' WTC Cleanup and Recovery Worker Health Assessment and community outreach.

[j]HHS officials told us that HHS is making modifications to the program and no screenings are taking place.

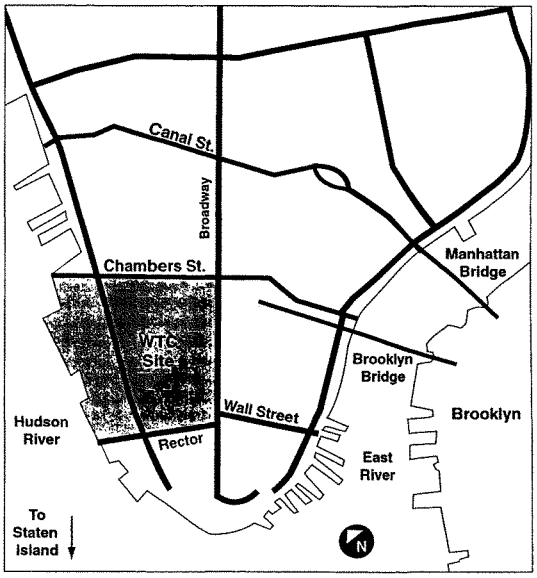
Program Eligibility

The six programs that have been created to monitor people who were exposed to the WTC attack and its aftermath vary in terms of populations eligible to participate. Although five of the programs focus on various responder populations, the largest program—the WTC Health Registry—is open not only to responders but also to people living or attending school in the vicinity of the WTC site, or working or present in the vicinity on September 11. Specifically, people eligible for participation in the WTC Health Registry include anyone who was in a building, on the street, or on the subway south of Chambers Street on September 11; residents and staff of or students enrolled in schools (prekindergarten through twelfth grade) or day care centers south of Canal Street on September 11; and those involved in rescue, recovery, cleanup, or other activities at the WTC site and/or WTC recovery operations on Staten Island anytime between September 11, 2001, and June 30, 2002. (See figure 1.) An estimated 250,000 to 400,000 people are eligible for the WTC Health Registry[23]; however, the registry was planned with the expectation that 100,000 to 200,000 people would enroll. Together the FDNY program and the Mount Sinai program cover more than half of the estimated 40,000 WTC responders.[24] The FDNY program is open to all 11,000 FDNY firefighters and all 3,500 FDNY EMS technicians, including firefighters and technicians who were not exposed. Some 12,000 other responders are eligible to participate in the Mount Sinai program. Responders who were government employees are eligible for participation in programs such as the FOH program, which is open to the estimated 10,000 federal workers who responded to the WTC attacks, and the NYS program, which was open to about 9,800 New York State employees and New York National Guard personnel who were directed to respond to the WTC disaster. In addition, approximately 12,000 members from three NYC unions and the NYC Department of Sanitation, whether they were responders or not, were eligible to participate in the Johns Hopkins registry.

[23]New York City Department of Health and Mental Hygiene and Department of Health and Human Services, Agency for Toxic Substances and Disease Registry, *Protocol for the World Trade Center Health Registry* (New York, 2003).

[24]Officials involved in the monitoring efforts acknowledge the potential for duplication across programs—for example, a responder could be enrolled in the Mount Sinai program, the Johns Hopkins registry, and the WTC Health Registry—but they have not determined the extent of duplication.

Figure 1: Map of Lower Manhattan Showing Canal Street, Chambers Street, and the WTC Site



Source: GAO adaptation based on WTC Health Registry Eligibility Map provided by New York City Department of Health and Mental Hygiene.

Concerns have been raised by community and labor representatives regarding the eligibility requirements for some of these programs, and while changes have been made to accommodate some of these concerns, others remain unresolved, particularly with respect to the WTC Health Registry. For example, the eligibility criteria for participation in the Mount Sinai program were initially more restrictive, covering responders who

had been at the site at least 24 hours between September 11 and 14, 2001. After discussions with labor representatives and CDC officials, the program expanded its eligibility criteria to include additional responders who may not have been there on those days but were there later in September. In contrast, community and labor representatives have been unsuccessful in their attempts to expand the eligibility criteria of the WTC Health Registry. These representatives have noted that the geographic boundaries used by the registry exclude office workers below Chambers Street who were not at work on September 11 but returned to work in the following weeks; office workers, including several groups of city employees, working between Chambers and Canal Streets; and Brooklyn residents who may have been exposed to the cloud of dust and smoke. Registry officials told us that they understand the desire to be included but they believe coverage is adequate to provide a basis for understanding the health effects of the WTC attack.

Monitoring Methods and Options for Treatment Referral

The monitoring programs vary in their methods for identifying those who may require treatment, and although none of these programs are funded to provide treatment, they provide varying options for treatment referral. Some programs refer participants to affiliated treatment programs, whereas others provide information on where participants can seek care. The FDNY program offers a comprehensive medical evaluation that includes collection of blood and urine for analysis, a pulmonary function test, a chest X-ray, a renal toxicity evaluation, a cardiogram, a hepatitis C test, and hearing and vision tests, as well as self-administered questionnaires on exposures and physical and mental health. Funds for the monitoring program do not cover treatment services. However, FDNY members who require treatment after being screened can obtain treatment and counseling services from the FDNY Bureau of Health Services and the FDNY Counseling Services Unit as a benefit of their employment. Similarly, under the Mount Sinai program, people receive a comprehensive physical examination that includes blood and urine analysis, a chest X-ray, a pulmonary function test, and complete self-administered as well as nurse-administered questionnaires on exposure, clinical history, and mental health.[25] If a person requires follow-up medical care or mental health services but is unable to pay for the services, he or she can be

[25]In addition, a standardized evaluation of nasal passages and upper airways is performed on a subgroup of 1,000 participants.

referred for care to other Mount Sinai programs such as the Health for Heroes program, which is supported through philanthropic donations.

The FOH and NYS programs also consist of medical evaluations of participants and self-administered health and exposure questionnaires. The FOH program conducted about 400 medical evaluations of federal workers. These evaluations included a physical examination, a pulmonary function test, a chest X-ray, and blood tests. Under the NYS program, the New York State Department of Civil Service Employee Health Service clinics or affiliated clinics conducted medical evaluations that included a physical examination and a pulmonary evaluation of almost 1,700 state workers. The questionnaires for both programs are more limited than the FDNY or Mount Sinai questionnaires; for example, they have fewer mental health questions. Under the FOH and NYS programs, workers who require care have been told to follow up with their primary care physicians under their own insurance.

Unlike most of the other monitoring programs, the WTC Health Registry and the Johns Hopkins registry do not include a medical evaluation, and neither effort is affiliated with a treatment facility or program. Instead, the programs collect information from participants solely through questionnaires and provide information on where participants can seek care. The WTC Health Registry questionnaire is generally administered over the telephone. The program provides all participants with a resource guide of occupational, respiratory, environmental, and mental health facilities in New York State, New Jersey, and Connecticut where people can seek treatment. Some of the services provided by these facilities require health insurance, whereas others are free of charge. If in the course of a telephone questionnaire, a person's responses to the mental health questions suggest that he or she may need to speak with a mental health professional, the person is given the option of being connected directly to a LIFENET counselor. The LIFENET counselor provides the person with information on where to go and whom to call for help with problems related to the WTC disaster. For the Johns Hopkins registry, the participants complete a mail-in questionnaire on physical and mental health. Responders who report mental health symptoms and agree to be recontacted may receive follow-up calls to refer them to mental health services. The referral process is facilitated by Columbia University's Resiliency Program, which provides free, short-term mental health services to affected people. The Johns Hopkins registry also provides participants with brochures about health services and programs they may find useful, including information about the Mount Sinai program.

Duration and Funding

The duration of the monitoring programs may not be long enough to fully capture critical information on health effects. Under current plans, HHS funding for the programs will not extend beyond 2009. For example, ATSDR entered into a cooperative agreement with the New York City Department of Health and Mental Hygiene in fiscal year 2003 with the intent to continue support of the WTC Health Registry for 5 years of its planned 20-year duration. Similarly, NIOSH awarded 5-year grants in July 2004 to continue the FDNY and Mount Sinai programs, which had begun in 2001 and 2002, respectively. Health experts involved in the monitoring programs, however, cite the need for long-term monitoring of affected groups because some possible health effects, such as cancer, do not appear until several decades after a person has been exposed to a harmful agent.[26] They also emphasize that monitoring is important for identifying and assessing the occurrence of newly identified conditions, such as WTC cough, and chronic conditions, such as asthma.

Collaboration

Although the monitoring programs began as separate efforts, some of the programs are collaborating with each other. In addition, there are other kinds of collaborative efforts, including those in which programs receive advice from various outside partners.

The WTC Responder Health Consortium is an example of collaboration between monitoring programs. It was established by NIOSH in March 2004 to coordinate the existing health monitoring of WTC responders initiated by the FDNY and Mount Sinai programs and to facilitate data sharing. It awarded $81 million in 5-year grants to six institutions to become clinical centers for WTC health monitoring. FDNY and Mount Sinai serve as coordinating centers under the consortium, and the other four institutions are coordinated with Mount Sinai.[27] Together, these institutions will

[26]For example, symptoms of lung cancer may not appear for decades after exposure.

[27]These four institutions are the Long Island Occupational and Environmental Health Center, the New York University School of Medicine, the City University of New York's Queens College, and the University of Medicine and Dentistry of New Jersey's Robert Wood Johnson Medical School.

provide follow-up health evaluations to a total of about 12,000 NYC firefighters and EMS technicians and up to 12,000 other WTC responders.[28]

Collaboration efforts have also been fostered between the monitoring programs and outside partners and researchers. For example, the WTC Registry has a Scientific Advisory Group that includes representatives from the Mount Sinai School of Medicine, FDNY, the Johns Hopkins University, Columbia University, Hunter College, New York Academy of Medicine, New York University, the New York State Department of Health, and the New Jersey Department of Health. The group has assisted the New York City Department of Health and Mental Hygiene and ASTDR in development of the WTC Registry protocol, selection of the eligible population, and analysis methods. It has been meeting with WTC officials quarterly since early 2002 to advise on such issues as data collection, study options, and guidelines for research studies to be done using the registry.

In addition, EPA convened an expert review panel in March 2004 to obtain greater input on ongoing efforts to monitor the health effects of workers and residents affected by the WTC collapse. The panel consists of representatives from federal and NYC agencies involved in air monitoring; from WTC health effects monitoring programs; and from academic institutions and the affected community. The goals of the panel include identification of unmet public health needs, gaps in exposure data, gaps in efforts to understand the health effects of the WTC attack, and ways in which the WTC Health Registry could be enhanced to allow better tracking of workers and residents.

Concluding Observations

A multitude of physical and mental health effects have been reported in the years since the terrorist attack on the World Trade Center on September 11, 2001, but the full health impact of the attack is unknown. Concern about potential long-term effects on people affected by the attack remains. The monitoring programs may not be in operation long enough to adequately capture information about new conditions, chronic conditions, and diseases whose onset may occur decades after exposure to a harmful agent, such as many cancers. Nevertheless, these programs are providing a more complete picture of the health impact of such events, and as they

[28]NYPD also applied to be in the consortium to provide monitoring for its officers who were responders to the WTC disaster, but was not able to secure funding to support its monitoring activities. However, NYPD responders are eligible for enrollment in the Mount Sinai program.

proceed they are also providing the opportunity to identify people needing treatment.

Agency Comments

We provided a draft of this testimony to DHS, DOL, EPA, and HHS. HHS provided written comments, in which it noted that the testimony does not include significant discussion on the ways in which mental health symptoms have changed over time. We relied primarily on data from published, peer-reviewed articles and government reports, and some of the researchers we spoke with emphasized that their studies are ongoing and they expect to publish further results. In the absence of these results, the evidence we examined did not support a full discussion of changes in mental or physical health effects over time. HHS and the other agencies also provided technical comments, which we incorporated as appropriate.

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

Contact and Staff Acknowledgments

For further information about this testimony, please contact Janet Heinrich at (202) 512-7119. Michele Orza, Angela Choy, Alice London, Nkeruka Okonmah, and Roseanne Price made key contributions to this statement.

Appendix I: Abbreviations

ATSDR	Agency for Toxic Substances and Disease Registry
CDC	Centers for Disease Control and Prevention
DOD	Department of Defense
DHS	Department of Homeland Security
DOJ	Department of Justice
DOL	Department of Labor
DMAT	Disaster Medical Assistance Teams
EMS	emergency medical services
EPA	Environmental Protection Agency
FBI	Federal Bureau of Investigation
FEMA	Federal Emergency Management Agency
FOH	Federal Occupational Health
FDNY	New York City Fire Department
GERD	gastroesophageal reflux disease
HHS	Department of Health and Human Services
NIEHS	National Institute of Environmental Health Sciences
NIOSH	National Institute for Occupational Safety and Health
NYC	New York City
NYPD	New York City Police Department
OSHA	Occupational Safety and Health Administration
PTSD	posttraumatic stress disorder
SGA	small for gestational age
SAMHSA	Substance Abuse and Mental Health Services Administration
VA	Department of Veterans Affairs
WTC	World Trade Center

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Mr. SHAYS. Thank you very much.

Mr. Robertson.

Mr. ROBERTSON. Good afternoon and thanks for the opportunity to be here.

I am going to switch gears a bit and talk about the Federal assistance provided to the State of New York to help the State deal with the workers compensation claims as a result of the terrorist attack.

Mr. SHAYS. Basically, we were talking about health effects and now we want to talk about compensation. There are really two streams of financing we are talking about. One is a stream of money for health needs and another to compensate for lost work.

Mr. ROBERTSON. Absolutely.

As you are aware, in the aftermath of the September 11 tragedy, the New York State Workers Compensation Board faced an unprecedented challenge in dealing with claims from workers or volunteers who were injured, became ill or died as a result of the terrorist attacks or the recovery efforts that followed.

To help the Board meet this challenge, Congress appropriated Federal funds totaling $175 million. These funds were provided through the U.S. Department of Labor for the board in three earmarked portions, $125 million was to be used for processing claims; $25 million was to be used to pay benefits to workers associated with uninsured employers; and last, $25 million was to be used to pay benefits to volunteers. I am going to divide my comments into two general areas.

First, I will talk briefly about how much of the Federal funds have been used and what they have been used for and then, I am going to talk about the status of the applications for compensation that the New York Board has received to give you some perspective on the number of claims the State is dealing with and what actions have been taken on them.

Starting with the use of claims, we found as of June 30, 2004, the New York State Workers Compensation Board had used about $49 million of the total $175 million appropriated for September 11 workers compensation expenses. If you look at how the funds within each of the three individual earmarked portions of Federal assistance were used, this is what you would find. From the $125 million portion available for processing claims, the Board used about $44 million to reimburse two State entities for benefits they had paid to September 11 victims or their survivors, those entities being the New York State Crime Victims Board and the New York State Insurance Fund.

In addition to these reimbursements, the Board used about $4.4 million of the $125 million to prepare for any future attacks. As an aside, I should note that we are continuing to gather information on whether or not the Board's use of funds in this particular earmarked category of Federal assistance is consistent with the Appropriation Act and the grant agreement covering the use of the funds.

Concerning the $25 million earmarked for paying benefits for workers associated with uninsured employers, we found the Board had not used any of these funds. However, the Board had used funds from its Uninsured Employer Fund to pay benefits for September 11 workers who worked for uninsured employers. It plans

to try to recoup these funds from uninsured employers before drawing upon Federal funds.

Finally, the Board has used about $456,000 of the $25 million earmarked for paying benefits to volunteers or their survivors.

I would like to move now to the status of September 11 claims. In that respect, the Board has indicated that as of mid-2004, it had received 10,182 claims for workers compensation and an additional 588 claims for volunteers that were related to the September 11 attacks. Ninety percent of the workers compensation claims had been resolved, meaning the Board had resolved all the issues that it could with the information available at the time.

Representative Maloney I am afraid I am not going to be able to go too much further than that in defining resolved.

Mr. TIERNEY. May I interrupt you for a second. Did you say 90 or 9?

Mr. ROBERTSON. Ninety.

The remaining 10 percent of claims were pending in that the Board was waiting for additional information, hearings were yet to be held or the claimants had not pursued their case after they filed initially.

Perhaps to head off future questions, I should point out that the Board does not track data on approval or denial rates of claims because, according to Board officials, the Board's core mission is to process individual claims, not their outcomes. While we can't say how many of the worker compensation claims were approved or denied, we can say that 42 percent of the worker compensation claims received were being paid or were in the process of being paid.

Turning to the status of the 588 volunteer claims, we see the Board had resolved a lower percentage of these claims in comparison with the worker compensation claims, 31 percent versus 90 percent.

The Board indicated that many of the volunteer claims were pending because the claimants were not actively pursuing their clams. Additionally, 85 volunteer claims were awarded cash or medical benefits.

Mr. Chairman, that concludes my prepared remarks. I would be happy to answer any questions at the appropriate time.

[The prepared statement of Mr. Robertson follows:]

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For Release on Delivery
Expected at 10:00 a.m. EDT
Wednesday, September 8, 2004

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Federal Assistance for New York Workers' Compensation Costs

Statement of Robert E. Robertson, Director
Education, Workforce, and Income Security Issues

GAO-04-1013T

September 8, 2004

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Highlights of GAO-04-1013T, testimony before the Chairman, Subcommittee on National Security, Emerging Threats, and International Relations, Committee on Government Reform, House of Representatives

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Federal Assistance for New York Workers' Compensation Costs

Why GAO Did This Study

In the aftermath of the September 11, 2001, terrorist attacks, Congress appropriated $175 million for the New York State Workers' Compensation Board (the Board) to assist with the resulting workers' compensation claims. These claims were filed by workers or volunteers (or survivors) who were injured, became ill, or died as a result of the attacks and the recovery efforts. Specifically, Congress provided federal funds to the U.S. Department of Labor (DOL) for the Board in three earmarked portions: $125 million for processing of claims, and $25 million each to reimburse the state Uninsured Employers Fund (UEF) for benefits paid (1) for workers associated with uninsured employers and (2) for volunteers. DOL transferred the funds to the Board using a grant agreement.

This testimony looks at the Board's use of the $175 million in federal funds and the status of September 11 workers' compensation claims. The testimony addresses: (1) how the federal funds have been used and (2) how many applications for compensation have been received and their status. In addition, we are continuing to gather information about whether the grant agreement and the appropriation act are consistent with the Board's use of the funds.

www.gao.gov/cgi-bin/getrpt?GAO-04-1013T.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Robert E. Robertson at (202) 512-7215 or RobertsonR@gao.gov.

What GAO Found

As of June 30, 2004, of the $175 million in federal funds appropriated to help pay workers' compensation expenses related to the September 11 attacks and recovery, the New York State Workers' Compensation Board had used about $49 million. From the $125 million portion available for processing of claims, the Board had used about $44 million to reimburse two state entities—the New York State Crime Victims Board and the New York State Insurance Fund—for benefits those entities had paid to September 11 victims (or survivors). In addition, the Board had used about $4.4 million of the $125 million to prepare for responding to any future terrorist attacks. For example, the Board paid for new computer backup systems and new off-site storage contracts to ensure access to claims data in case of a disaster. At the time of our review, the Board had not yet used any of the $25 million that is available to reimburse the UEF for benefits the UEF paid to workers associated with uninsured employers (or survivors). However, the Board had used funds from the UEF to pay these benefits and was first trying to recoup these funds from the uninsured employers before drawing upon federal funds to reimburse for any unrecovered expense. Finally, the Board had used about $456,000 of the $25 million that is available to reimburse the UEF for benefits the UEF paid to volunteers (or survivors).

The Board indicated that, as of mid-2004, it had received 10,182 claims for workers' compensation and 588 volunteer claims related to the September 11 attacks and recovery. Ninety percent of the workers' compensation claims had been resolved, that is, the Board had resolved all the issues that it could with the information available at that point. The remaining 10 percent of claims were pending, as the Board was waiting for additional information from claimants (such as medical evidence), hearings were yet to be held, or claimants had not pursued their case after initial filing. The Board officials noted that the status of claims was fluid: a resolved claim could change to pending if more information becomes available and the Board reopens the case. In addition, we were unable to report approval and denial rates of claims because, according to Board officials, the Board's core mission is to process individual claims and not track outcomes of claims decisions. For 52 percent of workers' compensation claims received, (1) a link had been established between the September 11 disaster and the resulting death, injury, or illness and benefits had been paid or were in the process of being paid, or (2) this link had been established but the Board had not authorized paying benefits. Of the 10,182 workers' compensation claims, 133 were associated with workers whose employers were uninsured. The Board had resolved 89 percent of these 133 claims. Of the 588 volunteer claims received, the Board had resolved 31 percent and 69 percent were pending. According to the Board, many of the volunteer claims were pending because the claimants were not actively pursuing their claims.

The Board provided oral comments on a draft of GAO's findings and GAO incorporated these comments as appropriate.

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss New York State's use of federal funds provided for workers' compensation expenses related to the September 11, 2001, terrorist attacks. In the aftermath of the terrorist attacks, Congress appropriated $175 million for the New York State Workers' Compensation Board (the Board) to assist with the resulting workers' compensation claims.[1] These claims were filed by workers or volunteers (or their survivors) who were injured, became ill, or died as a result of the attacks and the recovery efforts. Specifically, Congress provided federal funds to the U.S. Department of Labor (DOL) for the Board in three earmarked portions: $125 million for processing of claims and $25 million each to reimburse the state Uninsured Employers Fund[2] (UEF) for benefits paid (1) for workers associated with uninsured employers and (2) for volunteers.[3] DOL transferred the funds to the Board using a grant agreement. The federal funding provided to the Board is distinct from several other federal efforts to provide assistance to victims and survivors of the terrorist attacks. For example, Congress established the September 11th Victim Compensation Fund of 2001 to provide compensation for individuals (or their survivors) who were injured or killed as a result of the terrorist attacks.[4]

My testimony today focuses on the Board's use of the $175 million in federal funds and the status of September 11 workers' compensation claims. Specifically, my testimony addresses: (1) how the federal funds have been used and (2) how many applications for compensation have been received and their status. My colleague's testimony addresses the

[1]The law appropriating these funds was Public Law 107-117 (approved, Jan. 10, 2002).

[2]New York State requires employers to provide workers' compensation insurance. However, because some employers do not comply with this requirement, the state maintains an Uninsured Employers Fund to provide workers' compensation benefits for workers associated with uninsured employers.

[3]The law refers to "first response emergency services personnel"; however, for the purposes of this testimony we refer to these individuals as volunteers, that is, not associated with an employer.

[4]Benefits paid from the September 11th Victim Compensation Fund of 2001 are paid after deducting collateral sources, including (1) workers' compensation benefits received before filing for benefits with the Victim Fund and (2) future workers' compensation benefits to be paid to the children of the deceased.

health effects that have been observed in the aftermath of the September 11 terrorist attacks.[5]

We relied primarily on data provided by the Board to describe the use of funds and the status of claims. However, we were unable to report approval and denial rates of claims because, according to Board officials, the Board's core mission is to process individual claims and not track outcomes of claims decisions. In addition, the status of claims represents a point-in-time assessment that could change in the future. The Board officials told us that the status of claims was fluid: a "resolved" claim (that is, the Board had resolved all issues it could with the information available at the time) could change to a "pending" claim if more information becomes available and the Board reopens the case to consider the new information. To assess the reliability of the Board data we used, we requested information on Board systems for aggregating and reporting the data and Board policies for ensuring data quality. We reviewed the responses to our requests and determined that the aggregate data the Board had provided to us was sufficiently reliable for the purposes of providing descriptive information in our testimony. In addition, we reviewed relevant legislation, federal grant documents, and New York's policies and procedures for filing and processing claims. We interviewed Board officials, DOL officials, and representatives of selected worker and volunteer groups who filed September 11 claims with the Board. We conducted our review from February 2004 through August 2004 in accordance with generally accepted government auditing standards.

In summary, as of June 30, 2004, of the $175 million in federal funds appropriated to help pay workers' compensation expenses related to the September 11 attacks and recovery, the New York State Workers' Compensation Board had used about $49 million. From the $125 million portion available for processing of claims, the Board had used about $44 million to reimburse two state entities—the New York State Crime Victims Board (CVB) and the New York State Insurance Fund (SIF)—for benefits those entities had paid to September 11 victims (or their survivors). In addition, the Board had used about $4.4 million of the $125 million to prepare for responding to any future terrorist attacks. We are continuing to gather information about whether the grant agreement's statement of work and the appropriation act are consistent with these uses of the funds.

[5]GAO, *September 11: Health Effects in the Aftermath of the World Trade Center Attack*, GAO-04-1068T (Washington, D.C.: Sept. 8, 2004).

At the time of our review, the Board had not yet used any of the $25 million that is available to reimburse the Uninsured Employers Fund (UEF) for benefits the UEF paid to workers associated with uninsured employers (or their survivors). At the time of our review, the Board had used funds from the UEF to pay these benefits and was first trying to recoup these funds from the uninsured employers before drawing upon federal funds to reimburse for any unrecovered expense. Finally, the Board had used about $456,000 of the $25 million that is available to reimburse the UEF for benefits the UEF paid to volunteers (or their survivors).

The Board indicated that, as of mid-2004, it had received 10,182 claims[6] for workers' compensation and 588 volunteer claims related to the September 11 attacks and recovery. Ninety percent of the workers' compensation claims had been resolved, that is, the Board had resolved all the issues that it could with the information available at that point. The remaining 10 percent of claims were pending, as the Board was waiting for additional information from claimants (such as medical evidence), hearings were yet to be held, or claimants had not pursued their case after initial filing. For 52 percent of workers' compensation claims received, (1) a link had been established between the September 11 disaster and the resulting death, injury, or illness and benefits had been paid or were in the process of being paid, or (2) this link had been established but the Board had not authorized paying benefits. Of the 10,182 workers' compensation claims, 133 were associated with workers whose employers were uninsured. The Board had resolved 89 percent of these 133 claims. Of the 588 volunteer claims received, the Board had resolved 31 percent and 69 percent were pending. According to the Board, many of the volunteer claims were pending because the claimants were not actively pursuing their claims.

The Board provided oral comments on a draft of GAO's findings. GAO incorporated these comments as appropriate.

Background

The New York State Workers' Compensation Board administers the state workers' compensation program and processes claims for workers' compensation benefits. These benefits go to workers who are injured at

[6]In addition to these 10,182 claims, the Board received and cancelled 674 claims. The Board cancelled these claims for a variety of reasons, including the case had been entered into the claims database twice in error or the case was not related to the events of the September 11 disaster.

work or become ill because of workplace conditions and to survivors of workers who die because of their work-related injury or illness. New York State requires employers to provide workers' compensation insurance—either from the State Insurance Fund (SIF), a private insurance carrier, or self-insurance—to pay cash and/or provide medical benefits for workers who qualify for coverage.[7] Because some employers do not comply with this requirement, the state maintains a UEF to provide workers' compensation benefits for workers associated with uninsured employers. To administer the state workers' compensation program, the Board reviews claims to determine whether a worker is eligible to receive workers' compensation benefits. In simplified form, the workers' compensation claims process includes the following steps:

- An individual files a claim.
- An insurer can challenge the claim if it questions the validity of the claim.
- The Board resolves some cases without a hearing, while for others the Board holds a hearing or a series of hearings before a Workers' Compensation Administrative Law Judge with interested parties present, such as claimants, employers, and insurance carriers.
- The Board makes a final decision whether or not benefits are to be awarded to the claimant. For claims approved, insurance carriers, self-insured employers, or the UEF makes direct payments to the claimant.
- Either the claimant or insurer can appeal this decision. The appeal process involves successively higher levels of appeal; the highest level is the New York State Court of Appeals.

As a result of the September 11 terrorist attacks, Congress appropriated $175 million in federal funds to assist the New York State Workers' Compensation Board with the resulting workers' compensation claims. Specifically, the law provided the funds in three earmarked portions: $125 million "for payment to the New York State Workers' Compensation

[7]New York exempts the following businesses from the requirement to carry workers' compensation insurance: (1) a business owned by one individual with no employees that is not a corporation, (2) a business partnership under New York State law that has no employees, and (3) a business corporation owned by one or two individuals who own all of the stock and hold all of the offices and that has no employees.

Review (sic) Board, for the processing of claims related to the terrorist attacks"; $25 million "for payment to the New York State Uninsured Employers Fund, for reimbursement of claims related to the terrorist attacks"; and $25 million "for payment to the New York State Uninsured Employers Fund, for reimbursement of claims related to the first response emergency services personnel who were injured, were disabled, or died due to the terrorist attacks." The legislation provided no further explanation regarding the use of the federal funds. The law appropriating the funds gave DOL responsibility for distributing the funds. After researching various methods of transferring the funds, DOL provided the funds to the Board in the form of a grant.

Consistent with normal grant practices, before the funds were made available to the Board, DOL required the Board to complete a grant application that consisted of a statement of work, budget information, and other documents related to use of the funds. DOL approved the Board's grant application without making any changes. DOL awarded the grant to the Board and made the funds available for 4 years.[8] The grant agreement and the provisions of the underlying appropriation act together provide the legal framework for using the funds.

The grant agreement's statement of work, prepared by the Board,

- set out three broad categories of activities to be carried out: (1) administration, (2) mitigation—efforts to help mitigate the effects of future disasters, and (3) claims reimbursements to the Uninsured Employers Fund;
- requested flexibility to "transfer funds amongst the three pools of money," that is, the $125 million and the two $25 million portions;[9] and

[8]According to DOL, the Board can apply for an extension to use the funds beyond the 4-year limit.

[9]In the statement of work, the Board requested that the $50 million for reimbursements be transferred to the Board in its entirety. However, according to DOL officials, the Department of Health and Human Services' Payment Management System—which manages grant payments for DOL and other federal agencies—declined to make a $50 million advance payment, noting that the statute specified that the funds were available for "reimbursement." This action prevented the co-mingling of the $125 million with the other funds.

- listed the Board's intention "to use a portion of the disaster funds to assist other entities by creating a contingency account within [the Board's] funding structure that will allow the State to respond effectively to any unexpected needs as they arise, both in administrative and in mitigation efforts."

The following timeline summarizes the flow of federal funds to the Board:

- **Early January 2002**: Congress appropriated $175 million to DOL for the New York State Workers' Compensation Board.
- **Mid-January 2002**: The Board first contacted the New York State Department of Labor (NYDOL) and DOL's New York regional office for guidance about using the funds. NYDOL and DOL's New York regional office referred the Board to DOL headquarters for guidance.
- **April 2002**: DOL had determined that a federal grant agreement was the appropriate vehicle for providing funds to the Board. DOL notified the Board that the Board needed to submit a one-to-two page statement of work describing its proposed use of the funds before a grant could be awarded.
- **October 2002**: The Board submitted its complete grant application paperwork, including the statement of work, to DOL after consulting with the New York State Division of Budget.
- **November 2002**: DOL notified the Board of its decision to approve the grant, thereby allowing the Board to draw down funds to conduct activities consistent with the statement of work.
- **May 2003**: The Board made its first draw down of the funds.

As is the case with federal grants in general, DOL requires the Board to regularly submit reports to DOL for review. These reports specify the amount of federal funds the Board spent during the previous quarter of the year. These reports do not require the Board to indicate specifically how it had used the funds. In addition to these quarterly reports, DOL can access reports on funds the Board had drawn down but not yet spent.

The Board Used $49 Million for Benefits and Mitigation Efforts

As of June 30, 2004, of the $175 million in federal funds to help pay expenses related to the September 11 attacks and recovery, the New York State Workers' Compensation Board had used about $49 million. The Board had used about $44 million of the $125 million available for "processing of claims" (activities that the Board described in its statement of work as "administration" and "mitigation") to reimburse two state entities for payment of benefits those entities had made to individuals (or their survivors) who were injured, killed, or became ill as a result of the September 11 terrorist attacks. Specifically, the Board had spent about $28 million to reimburse the New York State CVB and $16 million to reimburse the New York SIF for benefit payments they each made to September 11 victims (or their survivors). The Board also had used about $4.4 million on mitigation efforts to prepare for responding to any future terrorist attacks. The Board had not yet used any of the $25 million available to reimburse the UEF for benefits the UEF paid to workers with uninsured employers (or their survivors). However, the Board had used funds from the UEF to pay these benefits and was first trying to recoup these funds from the uninsured employers before drawing upon federal funds to reimburse for any unrecovered expense. Finally, the Board had used about $456,000 of the second $25 million to reimburse the UEF for benefits the UEF paid to volunteers (or their survivors) who provided assistance under the direction of an authorized rescue entity.

The Board Had Used a Sizable Portion of the $125 Million for Benefits Reimbursements and Mitigation Efforts

The Board paid about $28 million of the $125 million to reimburse the CVB—a state agency that compensates crime victims—for payments in connection with individuals who were injured or killed during the September 11 attacks. The state determined that the September 11 attacks were a crime that qualified for benefits under the state Crime Victim Compensation Act.[10] According to Board officials, New York State temporarily designated the CVB as the first source of benefit payments for September 11 victims because state officials believed that this would be the most efficient way to deliver benefits.[11] Within a month of the attacks, the Governor issued two formal decisions suspending limits on the benefit amounts payable by the CVB and identifying individuals who would be

[10]NY Exec. Law 621 *et seq.* (McKinney 2004).

[11]For non-September 11 claims, the CVB is a payor of last resort and would pay only after payments from other sources, such as workers' compensation or Social Security, are deducted from the final award amount.

eligible for benefit payments from the CVB.[12] According to the Board, the reimbursement agreement between the Board and the CVB was established and approved by the New York State Assembly, the New York State Senate, and the Governor. Based on this agreement, the Board reimbursed the CVB after receiving documentation describing the nature and amounts of payments that the CVB had previously made to victims. The CVB requested reimbursement from the Board for payments to victims related to loss of earnings and support, loss of essential personal property, funeral and burial expenses, and medical expenses. According to the Board, the New York State Comptroller authorized the payments, and the New York State Division of the Budget reviewed and approved these payments. The Board said it did not anticipate the need to provide additional reimbursements beyond the $28 million already provided to the CVB because individual claimants are now going directly to the Board and not to the CVB.

The Board paid about $16 million of the $125 million to reimburse the SIF for workers' compensation benefits the SIF paid to September 11 victims employed by the state (or their survivors). The SIF—held by the New York State Department of Labor—is a fund that provides workers' compensation insurance to public entities and private employers who elect this coverage. Specifically, the Board reimbursed the SIF for workers' compensation benefits paid to state employees (or their survivors) who were injured or killed during the September 11 disaster. After the SIF provided documentation to the Board on benefits paid, the Board reimbursed the SIF to cover both payments already made to state employees (or their survivors) and projections of future benefit payments for these employees. These reimbursement payments were reviewed and approved by the New York State Division of the Budget. The Board did not expect to reimburse the SIF for many more September 11 claims because the deadline for filing had passed for injury and death claims. However, the Board indicated that the SIF might ask for reimbursement for a few new claims from state workers who become ill in the future, because such workers may file a claim when symptoms of a disease appear.[13]

[12]Executive Order 113.5, September 12, 2001, and Executive Order 113.31, October 10, 2001.

[13]New York workers' compensation law requires a claimant to file within 2 years after the accident or injury, or within 2 years after the death of an employee from a work-related accident or injury, whichever is later. For an occupational disease, the claim must be filed within 2 years after the disablement or after the claimant knew or should have known that the disease is due to the nature of the employment, whichever is the later date.

The Board used a significant part of the $125 million available for processing claims to reimburse the CVB and the SIF for benefit payments those entities made to victims. We are continuing to gather information about whether these reimbursements were authorized in the grant agreement's statement of work and whether the $125 million appropriation earmarked for "the processing of claims" was available for reimbursements of benefits paid. We are pursuing this matter further and will notify the committee of our findings.

Finally, the Board had spent about $4.4 million of the $125 million on mitigation efforts to help position the Board to respond to any future disasters. These funds were used for a multiyear project to ensure the Board has the ability to maintain operations, including access to all claims data, in case the Board's main data system fails. The Board used the funds to upgrade, purchase, and/or install computer systems; pay salaries and fringe benefits of staff working on the project; and cover travel expenses. For example, the Board paid for new tape and disk backup systems, new off-site storage contracts, and new image storage systems to ensure viability of Board data and operations. Finally, to enhance information security, the Board developed a security awareness program for all Board staff, and planned to test vulnerability of its systems. While these mitigation activities were undertaken to position the Board to recover more quickly from another disaster if one should occur, the Board acknowledged that these investments have benefited current operations as well. We are continuing to gather information on whether the $125 million earmarked for claims processing was available for these mitigation efforts.

The Board Had Not Used any of the $25 Million Available for Workers with Uninsured Employers

The Board had not used any of the $25 million federal funds available to reimburse the UEF for benefits the UEF paid to workers with uninsured employers (or their survivors). Congress appropriated these funds for the Board to reimburse the UEF—a fund maintained by the state that provides workers' compensation benefits for workers associated with uninsured employers—for payments made to September 11 victims. However, the Board had used funds from the UEF to pay these benefits and was first trying to recoup these funds from the uninsured employers before drawing down federal funds to reimburse the UEF for any unrecovered expense.

The Board Had Used Some of the $25 Million Available for Volunteers

The Board had used about $456,000 of the $25 million available to reimburse the UEF for benefits the UEF paid to volunteers (or their survivors) who were injured or killed as a result of the September 11 attacks. Congress appropriated the $25 million for "first response

emergency services personnel" and, according to Board staff, these funds were intended for individuals who had served as volunteers associated with the September 11 attacks. However, the New York workers' compensation law in existence prior to September 2001 did not include the term "first response emergency services personnel" and did not extend coverage to volunteers. To overcome this issue, the Chair of the New York State Workers' Compensation Board issued an official order that defined "first response emergency services personnel" as "[a]ll persons who, serving without compensation or remuneration, and serving under the direction of an authorized rescue entity or volunteer agency, provided services to deal with the emergency situation created by the September 11, 2001 terrorist attack on the World Trade Center."[14] This order also identified the types of groups that the Board would consider to be an authorized rescue entity and volunteer agency (including groups associated with the New York City police and fire departments) and thus designated which volunteers were eligible for benefits that can be reimbursed from the $25 million in federal funds.[15] Notably, volunteers are not covered by the state workers' compensation program because they have no employer and, thus, are not considered "employees." Therefore, compensation available to September 11 volunteers is limited to the $25 million appropriated by the Congress for reimbursement to the UEF.

While Most September 11 Claims Had Been Resolved, Many of Those from Volunteers Were Pending

As of mid-2004, 90 percent of September 11–related workers' compensation claims had been resolved, that is, the Board had resolved all the issues that it could with the information available at that point. For the subset of claims associated with workers whose employers were uninsured, the Board had resolved 89 percent. In addition to the September 11 claims for workers' compensation, the Board had resolved 31 percent of the volunteer claims received and 69 percent of these claims were pending.

[14]Order of the Chair #967, July 22, 2003.

[15]The Board did not establish a deadline for volunteers (or their survivors) to file September 11 claims.

Ninety Percent of September 11 Claims for Workers' Compensation Had Been Resolved

As of mid-2004, most September 11–related workers' compensation claims had been resolved, that is, the Board had resolved all the issues that it could with the information available at that point.[16] Specifically, 90 percent of the 10,182 claims received[17] by the Board had been resolved. Among the 9,124 resolved claims, 24 percent were death claims, while 76 percent were claims for an injury or illness. (For September 11 claims data provided by the Board, see table 1.)

For 42 percent of claims received, the Board had determined that a link had been established between the September 11 disaster and the resulting death, injury, or illness and benefits had been paid or were in the process of being paid.[18] For an additional 10 percent of claims received, the Board had determined that a link had been established between the September 11 disaster and the resulting death, injury, or illness, but had not authorized paying benefits. According to the Board, one of the reasons that benefits had not yet been paid, even though a link had been established, was that these employees had not missed more than 7 days of work on account of their injury or illness.

Ten percent of the claims received by the Board were pending. These claims were pending for a variety of reasons, including that the claimant was waiting for his or her hearing to take place; that no causal link had been established between the death, injury, or illness and the workplace; or claimants had not pursued their case after filing.

Some September 11 claims were challenged after initial filing and some were appealed after a decision had been made. An insurance carrier and/or employer can challenge a claim after a claim is submitted if they dispute the evidence provided by the claimant. For September 11 claims, insurers/employers challenged a higher proportion of injury or illness claims than death claims. Specifically, insurers/employers challenged

[16]The Board provided data on (1) the status of all September 11 claims (which do not include volunteer claims) and the time to process these claims as of July 5, 2004, (2) the status of September 11 claims for workers with uninsured employers and volunteers as of August 6, 2004, and (3) the time to process claims for workers with uninsured employers and volunteers as of May 14, 2004.

[17]The 10,182 claims received does not include September 11 claims for volunteers.

[18]While the Board conducted a special inquiry on this information for the purposes of our study, the Board does not aggregate information that would provide insights on the type of benefit received (i.e., medical or cash benefits) or the type of claim (i.e., death, injury, or illness).

about 27 percent of injury or illness claims compared with about 2 percent of death claims. According to the Board, with illness claims, symptoms can develop over time, and sufficient medical evidence may not exist at the time of filing to establish a link between the illness and workplace conditions. Independent of whether a claim is challenged, either the claimant or the insurer/employer can appeal a decision after the Board has resolved a claim. Of the resolved September 11 claims, 5 percent of the death claims were appealed and 6 percent of injury or illness claims were appealed.

Of the resolved September 11 claims, 36 percent were resolved with a hearing(s) and 64 percent were resolved without a hearing(s).[19] Of those claims with a hearing(s), 11 percent were death claims and 89 percent were injury or illness claims. The time to process claims with a hearing was as follows: 43 percent took less than 6 months, 22 percent took between 6 months and 1 year, and 35 percent took over 1 year. Of those claims without a hearing(s), 30 percent were death claims and 70 percent were injury or illness claims. The time to process claims without a hearing was as follows: 69 percent took less than 6 months, 21 percent took between 6 months and 1 year, and 10 percent took over 1 year.

Table 1: Status and Number of September 11 Workers' Compensation Claims (excluding volunteers), mid-2004

Status	Death claims	Injury-illness claims	Total claims
Claims received	2,195	7,987	10,182
Claims resolved	2,149	6,975	9,124
Claims pending	46	1,012	1,058
Claims challenged after initial filing by claimant[a]	33	2,121	2,154
Claims appealed after Board made its decision	99	422	521

Source: New York State Workers' Compensation Board.

Note: Data are current as of July 5, 2004.

[a]Claims challenged may be included in either claims resolved or claims pending.

[19]This does not include 26 individual claims that were resolved using a waiver agreement for which processing time was not available. In the case of a waiver agreement, a claimant has waived his or her rights to file a claim for workers' compensation and has entered into an agreement regarding his or her benefits.

Most September 11 Claims for Workers with Uninsured Employers Had Been Resolved

The majority (89 percent) of September 11 claims for workers with uninsured employers had been resolved. Most of these worker claims were resolved with a hearing(s) and took between 3 and 9 months to resolve. However, nearly a third of these claims took over a year to resolve. For those worker claims resolved without a hearing, most took less than 6 months to resolve. Eleven percent of claims from workers with uninsured employers were still pending. Common reasons that these claims were pending included that the claimant was waiting for his or her hearing to take place and that no causal link had been established between the death, injury, or illness and the workplace.

Some claims from workers with uninsured employers were challenged after initial filing and some were appealed after a decision by the Board had been made. Specifically, about 26 percent of these claims were challenged. Independent of whether a claim was challenged, 17 percent of the resolved claims were appealed after a decision had been made. For two claims for workers with uninsured employers, the claimants had received medical or cash benefits paid from state funds, and for one of these claims, the claimant was receiving continuing cash benefits. (For data on September 11 claims filed for workers with uninsured employers, see table 2.)

Table 2: Status and Number of September 11 Workers' Compensation Claims Filed for Workers with Uninsured Employers, mid-2004

Status	Death claims	Injury-illness claims	Total claims
Claims received	17	116	133
Claims resolved	15	103	118
Claims pending	2	13	15
Claims challenged after initial filing by claimant*	2	32	34
Claims appealed after Board made its decision	3	17	20
Claims that received medical or cash benefits	0	2	2
Claims receiving continuing cash benefits	0	1	1

Source: New York State Workers' Compensation Board.

Note: Data are current as of August 6, 2004.

*Claims challenged may be included in either claims resolved or claims pending.

Most September 11 Claims for Volunteers Were Pending

While the majority of all September 11 workers' compensation claims had been resolved, 69 percent of volunteer claims were pending.[20] According to Board officials, a high portion of the volunteer claims were pending because (1) sufficient medical evidence had not been provided to establish the link between the September 11 volunteer activities and the death, injury, or illness and (2) claimants had not pursued their case after filing. Board officials believe that some volunteers may not have pursued their case further because they had filed a claim before developing symptoms and, therefore, had little, if any, medical evidence to provide. According to Board officials, such volunteers had filed a claim so that they could pursue benefits at a later date if symptoms were to develop. (For data on September 11 claims filed for volunteers, see table 3.)

Table 3: Status and Number of September 11 Workers' Compensation Claims Filed for Volunteers, mid-2004

Status	Death claims	Injury-illness claims	Total claims
Claims received	1	587	588
Claims resolved	0	185	185
Claims pending	1	402	403
Claims challenged after initial filing by claimant*	0	14	14
Claims appealed after Board made its decision	0	0	0
Claims that received medical or cash benefits	0	85	85
Claims receiving continuing cash benefits	0	23	23

Source: New York State Workers' Compensation Board.

Note: Data are current as of August 6, 2004.

*Claims challenged may be included in either claims resolved or claims pending.

Ninety percent of the resolved volunteer claims did not require a hearing. The majority of these claims were resolved within 3 to 9 months of filing for benefits. The time it took to resolve the seven volunteer claims that required a hearing(s) ranged from less than 3 months to more than 6 months. A few volunteer claims were challenged after initial filing: while there is no insurer involved with a volunteer claim, the Board itself challenged 2 percent of these claims. The Board challenged these claims because, for example, it did not believe that a claimant had met the criteria

[20]The number of volunteer claims is not included in the total number of September 11 claims identified in table 1.

for being considered a September 11 volunteer or had sufficient evidence to support the claim. There have been no appeals regarding volunteer claims. For 85 volunteer claims, the claimants had received medical or cash benefits, and for 23 of these claims, the claimants were receiving continuing cash benefits.

Mr. Chairman, this concludes my prepared statement. I will be happy to respond to any questions you or other Members of the Subcommittee may have.

GAO Contacts and Staff Acknowledgments

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Mr. SHAYS. Thank you very much, all of you for your concise and helpful testimony. We will start by turning to Mr. Tierney to ask the first set of questions.

Mr. TIERNEY. Thank you.

Mr. Robertson, I want to pick up where you left off. You used the word resolved the claims, so can we explore that a bit and have you define that for us what exactly you mean by "resolved claim?"

Mr. ROBERTSON. I don't think you will like the explanation because, as I said earlier, I have given you all I have in terms of the definition which is basically the Board's definition. That is they have in essence acted on any piece of information they had and made any decision they could based on the information they had at that point in time. According to the Board, claims can go back and forth between resolved and pending depending on the information that is brought to bear.

Mr. TIERNEY. So they might not get resolved if they think a person has abandoned or neglected their claim?

Mr. ROBERTSON. That would go in the pending category.

Mr. TIERNEY. What items go into the resolved category, what is the range of decisions that end up being called resolved?

Mr. ROBERTSON. It would probably be easier to define pending and then anything else.

Mr. SHAYS. Mr. Tierney is going to have more than 5 minutes because we do need to understand this issue and you do not need to keep saying you don't think we are going to like the answer. You don't need to presume that. What you are doing is reporting on not what you are doing but on what someone else is doing. If you could help Mr. Tierney understand this point by point and the whole subcommittee, it would be helpful.

Mr. TIERNEY. We are not holding you responsible.

Mr. ROBERTSON. Let me say a couple things. Again, I think it is probably easiest to define pending and basically say anything else that is not defined as pending would be in the resolved category.

Mr. TIERNEY. That is only slightly helpful because it doesn't tell me at all any characteristics of the other things. If it is pending, it hasn't been acted upon, it is in resolved but it doesn't necessarily mean it has been acted upon favorably or any other way.

Mr. ROBERTSON. Absolutely, and as I said, the cases can go between pending and resolved based on the information.

Mr. TIERNEY. And they have no other breakdown of this at all?

Mr. ROBERTSON. No. It was very difficult for us to give a perspective on how the September 11 claims were treated because we didn't have information on typically what is the rate of approval and the rate of denial for the claims the Board normally processes and how the September 11 claims compare to that. We didn't have that data so that was one of the reasons it was very difficult for us to provide perspective on what those status numbers mean.

I would like to point out another factor that also limits or inhibits our ability to provide the perspective I think everyone wants in terms of the September 11 claims in comparison with the other compensation worker claims. The fact of the matter is that even if we had information on rates of denial and rates of approval, it could be that the very basic characteristics of the September 11 claims were so different from the typical worker compensation

claim that you would have to be careful in making that comparison.

This is a very long way of saying we have been frustrated in trying to provide perspectives on what was happening with these September 11 cases and the status of the cases.

Mr. TIERNEY. Any other ideas on how we are going to try to recapture some of that ground?

Mr. ROBERTSON. We are getting data and we do present some of the data in the prepared statement on specific types of claims—the volunteer claims—because those use specific Federal funds and the Board is following those in terms of providing information on how many have been awarded and how many weren't. In that respect we are getting more information.

Mr. TIERNEY. Dr. Heinrich, with respect to those workers who were injured and have not been able to return to their former employment, what did you say in your statement about what is being done for those individuals? Is anything being done and how are we doing?

Dr. HEINRICH. First of all, we don't have good numbers on all the people who were injured. I think the best of our information is for people who had musculeskeletal injuries or sprains. They were resolved fairly soon after the attack. The major issues really seem to surround people who have developed chronic conditions as opposed to injuries.

Mr. TIERNEY. Many of those people have not been able to return to work. I am interested in knowing what we are doing for that population of people.

Dr. HOWARD. The only thing I would say is I think we probably need to hear from the Mount Sinai people who are actually seeing these thousands of workers and former workers to give some reference point for that. I don't have any information from the CDC perspective. I would imagine if they are covered by workers compensation, there are rehabilitation provisions in the State Workers Compensation Act.

Mr. TIERNEY. They would be back in the resolved category?

Mr. ROBERTSON. Yes.

Mr. TIERNEY. Thank you, Mr. Chairman. Thank you for your courtesy.

Mr. SHAYS. At this time, we will turn to Mr. Turner.

Mr. TURNER. I want to thank you again for your efforts to focus on this issue. This is a very important issue as we all know not only for the heroes of September 11 but also for the victims of September 11 which through this process will be identified.

One of the issues that was clear when we had our hearing in October on this issue was the issue of misconceptions of how the agencies relate to one another and responsibilities as to how agencies relate to one another. I would like to ask that the hearing transcript of October 2003, pages 164 and 165 be admitted to this record.

Mr. SHAYS. Without objection.

[The information referred to follows:]

And to answer the question of who had access to what information. On September 12th we established, and it began the afternoon of the 11th, but we began our first of many, many conference calls with agency representatives from the Federal Government, from State government, from city government. Initially, actually, from the private sector as well because they were taking samples. And we exchanged sample results among that group and consulted on what to do next and what the implications of those samples were.

In addition to that, everyday the emergency operations committee that was established uptown, which had representatives from a broad base of Federal agencies, State agencies, city agencies had morning meetings at which, you know, data results were provided. Evening meetings to see if there was anything new to add. And downtown there was a daily meeting at which sample response results were provided and health and safety issues were also—everyday.

Mr. TURNER. So the analysis of this information, the dissemination of it, the reporting of it to the community was not solely controlled by one point or one agency?

Ms. CALLAHAN. Absolutely not.

Mr. TURNER. Mr. Gilman, in looking at the information that you had—Dr. Gilman, excuse me. If you look at the information that you have concerning EPA's indoor air monitoring and cleaning program, one of the misconceptions that I heard during panel one was that the EPA had a mandated responsibility to clean up all of the buildings and the apartments that were around the World Trade Center. And when I read your testimony it talks about a request that you received from New York City and your response, and a voluntary program where you went to individuals that were in the area and provided some services. And there may be some criticism or question as to the effectiveness of your program. But I just want to touch on the point of whether or not you were legally mandated to clean up the results of the World Trade Center collapse?

Dr. GILMAN. I will defer to Kathy in a moment, but I will say that under an emergency response and under the emergency response plan, different responsibilities get divided up among the different agencies. In the case of the indoor air, the initial responsibility went to the city of New York. Subsequently, the city asked the EPA to become more involved and ultimately to take over the testing and clean up program that was begun in May 2002.

Kathy, do you want to add?

Ms. CALLAHAN. That is absolutely accurate. And I think that in addition to that, the underpinning of our sort of statutorial authorizations is important. The Stafford Act is what defines sort of the agency's funding and statutory opportunities to respond to a federally declared disaster. And so EPA was operating under the Stafford Act.

In addition, EPA operates under the SuperFund law and the national contingency plan regulations that support that law in supporting its role within the Federal Response Plan and in support of the Stafford Act.

Mr. TURNER. Could you expand your answer related to testing, but specifically with the area of clean up. I mean, it is the same.

Your testimony was that both testing and clean up concerning the program was not something that EPA was mandated to do internally in individual dwelling spaces. Is that correct?

Ms. CALLAHAN. The National Contingency Plan and the SuperFund law, which is part of what we are responding under, authorizes EPA to undertake certain actions. But there are a lot of criteria that are applied in exercising the judgment so that we determine when we proceed on that authorization. And in a federally declared disaster, we do that in the context of a Federal Response Plan and the Stafford Act as well. And so it is not, per se, a directive to conduct certain activities. It is an authorization to conduct them given the agency's evaluation of the appropriateness in the response.

Mr. TURNER. Ms. Porter, when you talked about the different baseline medical screening and the data bases that were being created, we have a split that is happening between the New York Fire Department's baseline screening, what Mount Sinai is doing for those individuals who responded to the site, worked on the site but were not necessarily members of the fire department, and then we also have what the health department is doing with individuals that live in the area.

What is your assessment of the coordination of those programs and what advice might you have in that area?

Ms. PORTER. I think currently there is a steering group where, as you heard them testify, all Mount Sinai sits on the fire department's steering council as does the fire department sit on Mount Sinai's group. And so there is coordination.

Could there be better coordination? Always. And I think that as we construct the longer term program, we will actually mandate in the announcement a steering group that will be constituted and funded through that mechanism.

Mr. TURNER. Thank you.

Thank you, Mr. Chairman.

Mr. SHAYS. I thank the gentleman.

At this time the Chair would recognize Major Owens.

Mr. OWENS. Thank you, Mr. Chairman.

I would like to begin by getting some clarification from Mr. Clark, since they distributed the largest number of respirators. Can you clarify the terminology? There were some workers who said they never had anything for the first few weeks but paper masks. Is that a respirator, a kind of respirator? You mentioned half mask, full mask; there are two categories. Are there other categories? Do people mistakenly call it something else, the respirator?

Ms. CLARK. I can talk about what we provided. And we did this under the auspices of the New York City Department of Health.

We offered that we would take over the respirator distribution and fit checking and fit-testing eventually process for them. And we did so. Prior to that the New York State Department of Labor, Public Employee Safety and Health Program as early as the 12th were involved with handing out respirators.

I mentioned that as a group all the safety and health professionals on the site got together very early on, after the first couple of days, and determined that because the site was so unpredictable and we were not able to determine exactly what the exposures to

Mr. TURNER. It goes to refute the misconception that Federal EPA was mandated to undertake decontamination at or surrounding the World Trade Center. There is pretty exhaustive response in there by the EPA as to what their authorization responsibility is and their mandated responsibilities.

Getting to the issue of the different agencies and how they interact, one thing that was clear in that hearing in October is there appeared to be a lack of coordination both in registries and information being gathered in the processing of claims and assistance being provided.

I am hopeful that has improved since October and I would like your thoughts as to how the various interests and parties are working together to ensure we get a clear understanding of what resources will be needed, what resources are being applied, what information and data is being collected and how it is being handled and meshed together so we can have a clear picture of what needs to be done. Dr. Howard.

Dr. HOWARD. I do have a few thoughts on this issue. The short answer is I think we are better coordinated than we were but I think the long answer has to start with September 12, 2001, when response had to be immediate and oftentimes after a disaster, without existing programs in place, you make the best opportunities work for you.

I think that coordination wasn't the first item in the agenda in late 2001 and 2002. I think that is true in most disasters and I think I would like to make a relationship between that early response that was rapid and some of the money that came out of CDC very early went to States and grant systems that were already in place. That is how the New York Department of Health got money.

As 2002 and 2003 went on, the need for increased coordination was clear. When NIOSH received the $90 million from FEMA to do long term monitoring, one of the things we insisted on was coordination amongst the various medical monitoring programs, the Fire Department and Mount Sinai. We set aside money within that $90 million for coordination between those two entities and between the Government agencies.

I think we have grown in our understanding of coordination. From our department's viewpoint, the Department of Health and Human Services, our Office of the Secretary, the Office of Public Health Preparedness is the coordinator for our program, but we are not centralized in the traditional sense. All the programs are not one program because they attempt to deal with different populations situated in different ways and that have different needs.

I think the take home point I would like to make with regard to the coordination and centralization issue is that the biggest lesson I think we have learned from the establishment of these programs has been that emergency preparedness needs to include right now and in the future an aspect of medical preparedness also, not only the immediate need of taking care of people who are acutely injured and have acute illnesses, but also people who will develop chronic health effects.

I think that the Mount Sinai and other programs CDC has and HHS have funded have taught a very valuable lesson about the

value of including medical preparedness for chronic conditions that will develop from disaster responses. I would say my thoughts are that coordination has developed over time, we are much better coordinated now, 3 years later, than we were on September 12, 2001.

Dr. HEINRICH. I would like to add that there are institutions and organizations in place now as a result of our experience with September 11 that weren't there before. The States and certainly the city of New York have received money so that they are better prepared for major public health emergencies and bioterrorism. You have at HHS now the Office of Public Health Emergency Preparedness so that they really do have a mandated coordination role along with the Department of Homeland Security.

That is not to say that everything is rosy but at least you have people that are accountable for that coordination effort. Certainly in New York City we have seen that they practiced on a number of occasions coordination because of a public health emergency event, the anthrax incidents, for example.

Mr. ROBERTSON. My perspective is obviously a lot more narrow than my two colleagues. One of the points I wanted to make today in regard to the Federal assistance and how well it was used or well it wasn't used, is it seems to me now would be a terrific time, just talking about the narrow issue of Federal assistance, a terrific time for all of the players at the State and Federal level to get together and basically identify what worked and what didn't work.

This lessons learned type of evaluation, I think, is particularly important now in the world we live in because there is no guarantee that we are not going to experience another tragedy. I would encourage kind of a lessons learned analysis of how we use the Federal assistance for the worker compensation funds.

Mr. SHAYS. I think there is almost a guarantee that there will be future events. Some we will be able to detect and prevent and some we probably won't be able to, maybe not as horrific, God help us, but I go under the assumption that one of the reasons we are having this hearing is to make sure that we learn from the New York experience, in addition to helping our fellow countrymen.

At this time, the Chair would recognize Mrs. Maloney for 10 minutes.

Mrs. MALONEY. I thank all the panelists. I would like to say that your report, Dr. Heinrich, is probably the most thorough evaluation I have seen so far on the Federal response to September 11 health effects. Reading your testimony, it looks to me like 3 years after September 11, we still have no idea of the number of people who are ill or injured from the attacks. We still don't have that.

From reading your report, it looks to me that no one from the Federal Government or anywhere can give us a number as to how many people are ill because of September 11. It appears that no one is in charge. Is this a fair assessment?

Dr. HEINRICH. The no one in charge, I would agree with although as we have heard, there are new efforts to try to coordinate the programs that are doing the monitoring. I suppose we could say because most of these programs that are doing the monitoring come from CDC that one might expect that CDC would take a role in being accountable for all those programs. The fact of the matter is, you are correct. We don't know the exact number of people injured

as a result of September 11 or the number of people who now have chronic conditions.

Mrs. MALONEY. Dr. Howard, can you tell me who in the Federal Government is in charge of coordinating the health effects of September 11?

Dr. HOWARD. As I said, I can only speak for the Department of Health and Human Services. Certainly as Dr. Heinrich has said, our Office of the Secretary, the Office of Public Health Preparedness specifically, is our coordinator for all of our programs.

As our Secretary is fond of saying, we are one department. So all of the programs that emanate from the Department of Health and Human Services are coordinated. As I said also, that doesn't mean that each program looks like the other program. There are at least five programs that I know of funded by the Department to provide medical monitoring as well as the registry that ATSDR and the New York City Health Department administer. So it doesn't mean they are all centralized but they are coordinated.

I would also like to point out that there are coordinations that are occurring at the level that I think are also important, in addition to the Federal bureaucratic level. That is at the level of the users of the service, the registrants in the registry, the labor representatives of the workers, and the medical providers in the community. I think there is a lattice work of coordination going on there that I would say did not exist a couple of years ago but has developed over the last couple years.

Mrs. MALONEY. You are saying that the person in charge is Tommy Thompson of Health and Human Services?

Dr. HOWARD. As our Secretary would say and as my director would say, Dr. Gerberding, the buck stops with all of us in terms of the managers of all of our programs.

Mrs. MALONEY. One person has to be in charge.

Dr. HOWARD. As I said, the Office of the Secretary and the Office of Public Health Preparedness is the responsible entity within HHS.

Mrs. MALONEY. Can you give me the name of who is in charge?

Dr. HOWARD. The office is run by the Assistant Secretary, Stewart Simonson.

Mrs. MALONEY. Does he know or anyone in NIOSH or the Federal Government how many people are still suffering or still sick as a direct result of September 11?

Dr. HOWARD. I am not sure that anybody could give you an exact figure. The denominator of people exposed is very rough with a large margin of error.

Mrs. MALONEY. We have six different areas doing various monitoring and oversight according to Dr. Heinrich's report from the GAO. Someone should be pulling all of this together. At the very least we should know how many people are sick as documented in these six different programs.

Dr. HOWARD. I don't think it is hard to come up with an estimate based on the large margin error with the denominator of people exposed and the number of people that have entered the registry. We will be able to get an idea from the registry of a prevalence number of people exposed. My colleague who runs the registry may be able to respond a little to that.

Mrs. MALONEY. Yet we know in the registry, only 55,000 people have gone into the registry, so that is not in a sense an accurate number. Dr. Howard, since you said your agency is in charge. I want to get a number of how many people are sick and when are you going to get me that information? I think that is a legitimate question and something that should have been part of the GAO report but because we were not coordinated, they were not able to come up with the number.

I think 3 years after September 11, we should have a better assessment of people's health conditions that we can talk about. Because I represent New York, a firefighter just came to my office 3 weeks ago and when he went into a fire, he thought he was totally well and he lost his ability to speak. The doctors at the New York Fire Department are saying it is related to September 11. He can no longer operate as a firefighter. It is an illness that came out 3 years later that he didn't have at first. We have to have that some place and you say your unit is going to have that and coordinate it.

I want to know how many people are still sick based on the six registries we have going and when can he get us that information. I think that is a legitimate request.

Dr. HOWARD. I think we will have on September 10 the first peer reviewed report in CDC's MMWR which will have a subset, about 10 percent, of the participants that have been screened at Mount Sinai. We will have a prevalence figure, an incidence figure, of respiratory symptoms, muscle skeletal symptoms and others.

Mrs. MALONEY. Dr. Howard, that is just one. I am glad you will have that on September 10. I congratulate you and everyone who has worked on it but that is just one of the six different areas that GAO outlined that are pulling together this information. I am delighted we will have Mount Sinai's report on September 10.

What about the other five programs? When are we going to have their report combined together in one getting back to my initial question, who is in charge? Someone should be in charge of having this information in the Government and if that is the only thing that comes out of this hearing, I would be very happy to know there is one central point that Members of Congress can go to and the public and health experts to get this information.

Dr. WILLIAMSON. That is a very good question. I can respond with regards to the registry. One of the reasons the registry was established was because when you have these other five programs, there is one registry and five other programs, sets of health studies. Those sets of health studies are looking at very specific subpopulations of people who were exposed during and immediately after, a few months after the disaster.

We were hoping with the registry to be able to capture a cross section of everyone who was exposed not necessarily just subpopulations. We think the registry is going to give us the best idea of how many people actually were injured and/or ill resulting from the collapse of the World Trade Center Towers.

We are not going to have an exact number because we only have so many people who have registered and will be included in the registry but that is a much broader and more comprehensive snapshot than any of the other five sets of programs you are talking

about because it includes all of the people who were potentially and were exposed during and immediately after the collapse of the World Trade Center Towers.

Mrs. MALONEY. But it is just one of the six different programs and when you look at the other five programs, they have more people than the 55,000 in the registry. For whatever reason, the registry is not capturing the people. I think we have a challenge here and I think it is an important challenge. I think many health experts have talked about the unique disaster of pulverized glass, cement, toxins, antitoxins, all these chemicals.

What is that going to mean in terms of long term health effects for cancer and so forth and how can we be assured that the monitoring will continue for 20 years and maybe longer to really track this?

Dr. WILLIAMSON. I am not sure we can assure that we would be able to track it for over 20 years. On an annual basis, we are looking for being able to continue the registry as the registry was established a couple of years ago and hopefully we will receive additional funding in the fiscal year 2005 budget to increase our registry efforts but we can't explain whether or not we are going to be able to have the registry for more than 20 years.

We would like to be able to track as best we can not only the short term but the long term effects of the disaster. For as long as we continue collecting the data, analyzing it and find things in the data that indicate that we need to study more subpopulations, we are hoping to continue the registry.

Dr. HOWARD. That study over 5 years will provide very powerful indicators of the future need for funding.

Mr. SHAYS. Before recognizing Mr. Nadler, I want to make a point that haunts me a bit. I had some doctors who treat cancer patients, this was 10 years ago, and they came because they wanted me to get me to focus more on smoking. They said that 20 years after World War I, cancer rates went up almost perpendicular. The identical period of time, they leveled off and they just soared. That is unsettling because for a number of years, people thought they were safe and yet they weren't. That is why the monitoring issue is something I want to focus on long term.

At this time, the Chair would recognize Mr. Nadler for 10 minutes.

Mr. NADLER. Let me state for the record, regarding a comment made by the gentleman from Ohio a few minutes ago, at the last hearing when EPA was asked they stated they were not responsible, it would not be lead agency for cleaning up the area of having no responsibility for decontaminating buildings. EPA did say that in answer to a question of Mr. Turner's.

I then asked them in light of Presidential Defense Directive 62 issued in 1998 which specifically makes EPA the lead agency for dealing with the consequences of hazardous material discharges as a result of an enemy attack or any kind such as that, did they stand by their testimony given under oath?

They then said they were not lawyers and couldn't say yes or no to that question and would get back to us, which they have not done as of yet. I can't let that stand. The EPA ducked that question and clearly in my opinion under PDD 62 and the CERCLA law, is

responsible, is the lead agency and is still denying that responsibility.

That bodes ill for the future because no one is taking the lead responsibility at this point in the Federal Government for indoor cleanup or decontamination in case of a future attack or catastrophe. No one has taken it in New York at all. The city hasn't taken it, the State hasn't taken it, the Federal Government hasn't taken it. It has left residents to their own devices which is why I believe residents are slowly being poisoned today by toxic environments and improperly and inadequately cleaned up homes, schools, fire houses and offices to this day and for the next 20 years.

Mr. SHAYS. Could the gentleman yield for a second? We will go back and look at any part of the testimony and commitments made to respond because the agencies have not gotten back to us on certain issues and I need to make sure they have done it on all.

Mr. NADLER. It's in the transcript a few pages after page 164.

Mr. SHAYS. We will do that and I want to make sure we don't have it and have not been aware we have it. We will make sure that is followed up.

Mr. NADLER. Dr. Howard, following up Mrs. Maloney's question on how many people were affected, we have five programs basically for firefighters, police officers and different categories of first responders and then for residents and workers in the area, you have the registry. The registry, however, was limited by fiat to people who lived and worked south of Canal Street. What justification is there in terms of scientific validity of any information we get out of the registry for an arbitrary line at Canal Street?

Dr. HOWARD. I will let Dr. Williamson handle that one.

Dr. WILLIAMSON. The New York City Department of Health and Mental Hygiene as well as ATSDR put together a scientific advisory committee of a group of illustrious scientists from Columbia and Mount Sinai and Johns Hopkins as well as other institutions. Those people in conjunction with ATSDR and New York City Department of Health and Mental Hygiene decided.

Mr. NADLER. I don't care who decided, what was that based on other than arbitrary ruling? Was there a Star Trek type force field or a 3,000 foot high wall at Canal Street that prevented the toxins from going north of Canal Street or for that matter across the East River into Brooklyn? Do we have any scientific basis for believing that a registry with that geographic boundary has any validity at all?

Dr. WILLIAMSON. The CDC, ATSDR and New York City, along with the Scientific Advisory Committee took a look at the information provided by different groups including EPA, NASA and ATSDR.

Mr. NADLER. What is that information? I don't care who said it. I want to know what basis do we have for assuming that the south side of Canal Street might have been polluted but the north side of Canal Street was crystal pure and clear?

Dr. WILLIAMSON. The registry was set up not to say that some groups were exposed and others were not. It was set up to say what groups were most exposed.

Mr. NADLER. What basis do we have to assume that Canal Street had any scientific validity whatsoever? I am not interested in who

said it did. What basis do we have that there was something magic about Canal Street that said people who lived and worked south of it were at an appreciably larger risk and had to be looked at than people who lived across the street or a block north of it?

I know the answer to this question I am going to ask is no but I would like you to answer it. Did anybody do any scientific assessment of where the toxins went? Did anybody do sampling to say they went here and therefore this is where we will do the registry and not there?

Dr. WILLIAMSON. There were different outdoor and indoor air samples available and that information was taken into consideration.

Mr. NADLER. Did anybody do what the Inspector General of the EPA said should have been done which is to say, taking samples in a concentric circle going outward from the World Trade Center so you could say the problem is three blocks in this direction and 3 miles in that direction or two blocks? Do we have any scientific basis for assuming that the geographic limitation of the registry has any scientific validity at all, yes or no.

Dr. WILLIAMSON. I am not aware of that kind of detailed analysis.

Mr. NADLER. Are you aware of any scientific analysis other than an arbitrary, bureaucratic line?

Dr. WILLIAMSON. Only if taking into consideration the data we had at hand from the different agencies.

Mr. NADLER. The data that was in-hand was incomplete and showed lots of pollution north of Canal Street, in Brooklyn and all over the place. What was the basis for drawing a line for this registry at Canal Street or for that matter, the East River?

Dr. WILLIAMSON. I am not aware of specifically how the lines were drawn.

Mr. NADLER. Can you get back to us the information as to the scientific basis for choosing Canal Street, assuming there is a difference between north of Canal Street and south of Canal Street and that there is a difference between lower Manhattan and say Brooklyn Heights because all the satellite photos showed that plume going all across Brooklyn.

We know that ash was sprawling across Brooklyn into Borough Park and Brooklyn Heights and Coney Island and yet nobody in those neighborhoods or north of Canal Street is allowed to be in this registry which I maintain means the registry is incomplete. Chinatown was also cutoff. What was the basis? We know there was lots of pollution there.

What was the basis for saying nothing north of Canal, nothing in Chinatown, nothing across the East River? I am not interested in what bureaucratic agency said that's a good idea, I want to know what is the scientific basis for drawing such a line?

Dr. WILLIAMSON. Again, the point was not to exclude anyone. We have to collect as much information in as comprehensive a way as we can.

Mr. NADLER. With all due respect, that is rhetoric. Why was it drawn at Canal Street and not at say Chambers Street or in a 5 mile radius or a 2 mile radius around the World Trade Center? What basis was there for drawing the line that was drawn? What

was the scientific basis for drawing that line? I don't believe there was any.

I'd like to hear what the scientific basis for drawing that line is because if there wasn't a scientific basis, which I believe to be the case, then the registry is not including as many people as possible, it may be excluding 80 percent for all we know of the people who ought to be in it.

Dr. WILLIAMSON. It is a good question and I will try to get back to you on that but I must tell you that the registry was set up with some very specific things in mind in order to try to get as much information as possible given the resources and the time to reach so that we could answer the questions you are asking with the information we have.

Mr. NADLER. It is very nice, these conclusory remarks but why Canal Street and not Chambers Street, the scientific reason, not Howson Street but 14th Street, why not Chinatown, why not look into Brooklyn, not an arbitrary, bureaucratic answer but a scientific basis, what is different scientifically, what evidence do we have that there is a scientific difference between south of Canal and north of Canal.

Mr. SHAYS. Will the gentleman yield? I would like to resolve this now rather than later in part because I am wondering if we did get information that we had requested in the past.

I don't know if I would describe your analysis as bureaucratic. What I am hearing you basically say in the end, and I would like to pursue this and answer it one way or the other, it seems to me it was not based on any scientific knowledge. You made assumptions in order to begin the registry and to begin to start to get information. Are you aware that any of this was based on any scientific study that was done? I am not aware of any.

Dr. WILLIAMSON. I am not aware that it was based on any single scientific study. It was based on information that we got from EPA, that we got from NASA and with the constraints we had in order to try to get the registry up and running. With estimates of the numbers of people we thought we were going to be able to identify with the resources we had, we said this would be a good first cut at getting as much information on the people, we felt, not based on a particular scientific study but all of the information.

Mr. SHAYS. Let me give the floor back to you, Mr. Nadler, and allow you to pursue a little more but let me make this point.

I think the answer to the question is no and I don't think we need to wait for you to get back to us to say no. The answer is, it is not based on any scientific information. You all tried to do the best you could without scientific information, it strikes me. That is what I am hearing you say. I do think, Dr. Heinrich, you could maybe add some insight here and you have the floor, Mr. Nadler.

Mr. NADLER. Let me just say, I don't want to take anything away from officials who had to act in haste at the time. What bothers me is that I do believe, and I have been involved in this in some depth, that there is no valid reasons for those arbitrary lines and maybe it was a good first cut, as you said, but may be those lines should be expanded now.

In other words, if this registry is going to have validity and the registry is also funded for 5 years. It should obviously be funded

for the lifetime of all the people involved in it and it should also be expanded from the registry to provide health treatments for those who need we find need it.

Beyond that, the geographic boundaries, if we are to have any scientific validity, now that we have time, it is 3 years, there ought to be what the Inspector General said a year ago now or the white paper in my office said 2½ years ago, there ought to be detailed samplings, indoor and outdoor and concentric circles going out from the World Trade Center so we can see where the problem was, so we can have a better scientific estimate of where the people should be sampled, of where the registry should be expanded.

I will guarantee you it is a lot wider than Canal Street and what might have been a first bureaucratic cut based on somebody's estimate at the time but not based on valid science, which could not be based on valid science, because no one ever did all that testing. In all the hearings we have held and everyone has held, we know no one ever did the testing that needed to be done. The Inspector General said that and no one has done it since then.

It ought to be done now and the registry certainly ought to be expanded not only in terms of time so that we can see the effects beyond 5 years, if there are 20 year effects, which there will probably will be, but also geographically.

Mr. SHAYS. I thank the gentleman. If you want to make a comment, then I want to take the floor for my questioning.

Dr. WILLIAMSON. I would like to say again that is something that we hope the registry will allow us to do, to identify the areas and the subpopulations which need to continue to be looked at and to expand depending on the information that we get. The subpopulations right now that the other five studies are not looking at quite so much but the registry has information on, such as the residents and the school children, that is one thing the registry is going to allow us to do.

As far as expanding the registry boundaries, what we did was go through a very scientifically validated protocol from peer reviewers, so we got that approved and if we were to change the eligibility criteria or expand the eligibility criteria geographically, we would go back through a very scientific process of putting together a peer review.

Mr. NADLER. Excuse me. With all due respect, there was no scientific process. There may have been people who decided to OK what somebody decided but there was no valid scientific process and if there was, we have asked you to submit that to us which we have not yet seen.

Dr. WILLIAMSON. I am talking about justification for the protocols.

Mr. SHAYS. Dr. Heinrich, do you have any contribution to the dialog that has taken place in the last 10 minutes?

Dr. HEINRICH. I do think that in the scientific literature, we have seen some summaries now of the sampling of the air and there is more information now than there was when it was set up about what kinds of contaminants were in different geographic areas. I think what you have heard is that as they were establishing the registry looking at the resources they had at hand, they really had to make some assumptions about who would be the most likely to

have the largest exposure. At least that is what I have gleaned from the scientific reviews that we have done.

One issue I would like to bring up is that to the best of our knowledge, the registry doesn't necessarily have funds to carry it forward for all 5 years since much of the funding has already been expended.

Dr. WILLIAMSON. The registry only received initial startup funds.

Mr. NADLER. If I could just ask Dr. Heinrich, what you just said was very interesting. You said they made a decision as to where to focus based on the available resources most effectively which may very well be the case but that is backward. That is saying we have a certain amount of resources and therefore we can only do up to Canal Street.

Mr. SHAYS. Is that what you are saying because that is what it sounded like to me.

Dr. HEINRICH. There is no scientific justification for the specific boundaries that we were able to find.

Mr. SHAYS. I think we have to acknowledge that is the fact. I think we also have to acknowledge, given the resources available, there were intuitive decisions made but nothing scientific and I think we can agree on that. I appreciate my colleague's line of questioning.

I wrestle with this. Having been in the Twin Towers, thinking how tall they were, thinking of what was in them, the marble, the construction material, it was pulverized, the pressure and so on just pulverized all of that and it was smothering until well past December or at least to December.

So intuitively, I make an assumption that this wasn't good stuff and we would expect there would be some scientific explanation as to what was there and what wasn't. We know it wasn't done right away. We know workers like the firemen who raced up the floors, the workers that raced to the sight and we know they didn't wear masks, we know they didn't wear protective gear and we also know like some of the Gulf war syndromes, that they are sick. There are a lot of people who are sick.

What I am seeing is a Federal, State and local effort to deal with this and when Mrs. Maloney is asking the other very pertinent question besides the question asked by Mr. Nadler, she was basically saying who is in charge but you can tell me who is in charge at the Federal level, who is in charge at the State level and you can tell me who is in charge at the local level but the problem is we have them all mixed together.

We have the New York Fire Department, they have their system. We have the emergency medical and certain rescue in Mount Sinai. We have other Ground Zero responders at the registry. We have New York State workers who are being examined as separate. We have the people living and working in the area, they are under the registry. We have the Federal workers being examined separately.

I think what I would ask you to do is tell me how do we sort this out. I am not yet aware. My theory is this. If the witnesses don't tell us, we are ignorant of what needs to be done unless we find out from other sources. If they tell us what we need to do and we don't do it, the blame rests on our shoulders but right now, you are letting us off the hook. We need to know what needs to happen to

bring some sense to this. Who wants to start me out in this process?

Dr. HOWARD. I will be the brave one. I would like to suggest that the description you just gave of the very difficult nature of characterizing the exposures that existed for firefighters, other workers, volunteers, clean-up workers, rescue and recovery workers, from this mix of physical and chemical agents and combustion products represents what we in science call a mixed exposure which really strains the boundaries of our existing science in terms of understanding what the health effects are from mixed exposures.

I think often science proceeds too slowly for all of us but there is value in the fact that there are multiple different programs looking at this same issue, in different populations, granted, but they all will, over the next 6 to 12 months, be producing peer reviewed science articles as the one I referred to coming out this Friday in CDC's MMWR, that will help us answer the question that Mrs. Maloney raised and everybody is interested in: what is the prevalence of health effects on a chronic nature that comes from this population, albeit a sample of this population because we don't have the whole denominator.

I think what we need to concentrate on is making sure the existing programs we have are, and I agree with the committee's questions, coordinated well, they are speaking to each other, the people they are representing, the participants, the registrants and their representatives are fully involved in all the advisory committees for those programs and those advisory committees are coordinated.

Mr. SHAYS. The problem is committees create camels when they are trying to create a horse. Is there a recommendation from any of you of who should try to coordinate all this? Should it be New York State, the Federal Government? The Federal Government is providing most of the money it seems to me. Is that correct?

Dr. HOWARD. Through FEMA. FEMA provides most of the money; it comes to HHS, CDC, NIOSH, ATSDR and it goes out to the individuals.

Mr. ROBERTSON. The worker comp program is a State program. There was $125 million for processing the claims and then two pots of $25 million each, one for workers associated with uninsured employers and the other for volunteers.

Mr. SHAYS. I really believe there has to be one person in charge, maybe somebody who takes charge to coordinate and an agreement on the part of State and local governments. If it is the Federal Government, let them do it or the Federal Government needs to agree that it is the State, but one person basically looking to coordinate all this activity.

Tell me what steps should be taken to ensure that money and programs will be in place to look at the long term effects. This is running out, correct? So what do we do?

Dr. HOWARD. As I said previously, I think that the findings that will be coming from the programs already funded, from the registry, from the Mount Sinai program which will be funded for 5 years now, that data will speak louder than any of us at this table and I think it will give us a direction as to where we need to go in terms of continuing monitoring as well as research.

Mr. SHAYS. When is it going to give us that direction?

Dr. HOWARD. I would say very shortly. I would say since Mount Sinai has nearly 12,000 of its cohort participating, monitoring results—and Dr. Levin will speak to this on the second panel—will come out very shortly. As I say, the first report will come out this Friday. I think the report will be of concern.

Mr. SHAYS. But in the case of cancers?

Dr. HOWARD. That is a more long term thing and that is why I said the findings that come out that we have will inform us as we go through these periods of time.

Mr. SHAYS. We have one witness who has made some very helpful recommendations. I would like recommendations from all of you. What steps can we take to improve the process, how can we make sure this is better coordinated, and so on.

Dr. WILLIAMSON. I would certainly talk for the registry. One of the things we have done since September 11 is try to put into place a rapid response registry program so that we will be able to more quickly respond to emergencies. It is important to be able to identify the expertise that would be available on an as needed basis as quickly as possible to be brought to bear on the impacted emergency situation as quickly as possible.

We are in the process at CDC and ATSDR of putting together this rapid response registry program. This is one of the recommendations we have seen as a result of September 11 that we are trying to implement, we are hoping to be able to do things on a much quicker basis.

Dr. HEINRICH. Most of these programs are funded, I think all of them are funded, through different organizations, entities within CDC, and one approach might be that we ask CDC to be more proactive in its role for coordinating these programs. Certainly one effort it has already started it sounds like is having centers that have responsibility for coordinating the data because at a minimum, you would want somehow to be able to look at these findings across these various programs. It sounds like maybe you can do it for a couple now but not for all.

It is the Federal Government that has the money but you have to form a partnership with the people on the ground and I think that is what they are trying to do but the mechanism for that is the one they are using which is the cooperative grant program.

Mr. SHAYS. If there is ever a justification for a committee to write a report on recommendations, this is one of them because if everybody is doing their job to the best of their ability and in many cases, quite well, but they are all part of what I view as not a coordinated effort. Mr. Robertson, what happens when the $25 million in Federal funds designated for volunteers and workers comp has disappeared?

Mr. ROBERTSON. That is a great question and I think it illustrates some of the points you have tried to make. Basically, when those funds are used up, the benefits for those volunteers are used up. We probably should do more thinking in terms of trying to do some analysis now to figure out if and when those funds will run out and what we will do under those circumstances.

Mr. SHAYS. We need to get to the next panel. Is there anything you felt needed to be a part of the record that is not part of the record?

Mrs. MALONEY. I have one brief question. In your testimony, Dr. Howard, you talked about in collaboration "with informal network of occupational specialists, CDC helped facilitate the production of a guidance document to assist community-based physicians in the medical evaluation of patients exposed to the disaster." I want to compliment CDC on their response to SARS and sending out medical directives but I have not found one doctor who got this communication. I have had many cases reported to us where people went to doctors and were told they had asthma and then found they really had glass in their lungs.

If there is such a document that you provided, probably one of the leading authorities is Dr. Levin. Several of you mentioned he is going to be releasing this report on September 10 and I would say he is definitely considered a leader in the field. When I talked to him about this issue, he said he had not received any guidance from CDC on the health response to the World Trade Center disaster. So if you do have a document, I would like to have that as part of the record.

I would like to close with what I think is the most important aspect, that there is no health coverage for people we call heroes and heroines and we talk about how they selflessly gave their lives or injured themselves in helping others and yet they have no health coverage. I had one firefighter who 3 years later can no longer work. He said he saved two lives, pulled them out of the debris. Now his health condition is so terrible, he can no longer work and he has no health coverage. What are we going to do for health coverage?

Mr. SHAYS. Let us close quickly with that question and get on to our next panel. Is there a comment about health care coverage?

Dr. HOWARD. It is hard to quickly respond to that. Obviously health care provision is not contemplated in these medical screening programs. It is a large public policy issue and I have no expertise.

Mr. SHAYS. So the answer basically is they are not covered and this rests on whose responsibility? Is this a Federal, State or local responsibility? Is this something we need to be debating? The bottom line is you are putting on the record there is no health coverage?

Dr. HOWARD. My understanding is these are medical screening programs, and medical monitoring programs, not medical treatment programs, but in the case of the Mount Sinai program with which I am most familiar, referrals are made for medical treatment when appropriate.

Mr. SHAYS. To be continued.

Mrs. MALONEY. And we have put in the "Remember 9/11 Health Act" which would provide health coverage to those who were injured at September 11.

Dr. HEINRICH. Just one comment on that final point. Many of us learned in public health that there is something ethically wrong when you screen for disease, find it and then don't treat it. That is the dilemma we are in.

Mr. SHAYS. Let us end on that note because that maybe will get us all thinking about what we do about it.

Thank you. You have been an excellent panel. We appreciate your work in government and your effort to make this a better place and to help these victims. Thank you.

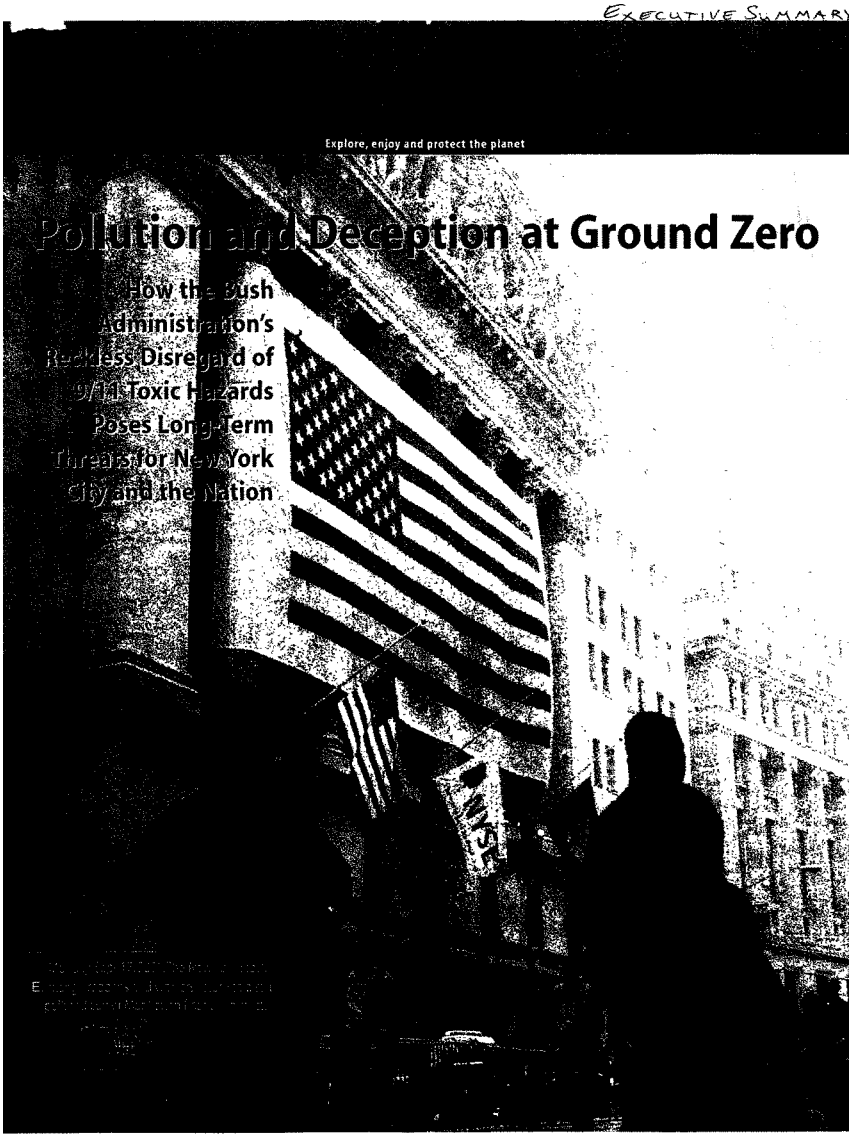
The Chair will now recognize our second panel. We have Dr. Stephen Levin, co-director of the World Trade Center Worker and Volunteer Medical Screening Program; Dr. Michael Lonski, director, training and program development, Life Matters; Dr. James Melius, administrator, New York State Laborers Health and Safety Fund; Mr. Stan Mark, esq., program director, Asian American Legal Defense and Education Fund; and Ms. Micki Siegel de Hernandez, health and safety director, Communications Workers of America.

Mrs. MALONEY. May I request we place into the record a report written by the Sierra Club, "Pollution and Deception at Ground Zero?"

Mr. SHAYS. Yes. Without objection, so ordered.

[The information referred to follows:]

EXECUTIVE SUMMARY



INTRODUCTION

Many hundreds of people in New York City are sick today because of exposure to the pollution from the September 11, 2001 attack on the World Trade Center. Some suffer from shortness of breath, loss of lung capacity, chronic coughing, throat irritation or irritant-induced asthma; some suffer from gastroesophogeal reflux disease. Many are so debilitated by their physical conditions that they can no longer do their jobs, and most of them no longer enjoy life as they used to. It is possible that many more illnesses will emerge in the coming years. People worry about cancer, weakened immunity, and reproductive effects, and many experts fear that these worries may well be justified. No one knows what tomorrow will bring for this exposed population.

If our federal government had responded to the crisis of the terrorist attack with proper concern for people's health, many of the exposures that caused these illnesses could have been prevented. In August 2003, the Inspector General for the federal Environmental Protection Agency ("EPA") released a disturbing165-page report documenting the fact that the White House Council on Environmental Quality blocked health risk information that EPA sought to release to the public following the September 11, 2001 attack. That, however, is only part of the story.

This report picks up where the EPA Inspector General's report left off. It shows how the federal government – EPA and other key federal agencies – failed to take important actions after the attack to prevent more exposures to contaminants. It demonstrates why the federal government's failures cannot be excused by ignorance or surprise, or by blaming workers who didn't wear protective masks. It documents how independent researchers found a group of toxic pollutants that cause cancer and other genetic effects, while EPA wrongly claimed that it did not detect the presence of these pollutants at all. It exposes the fact that a survey of federal employees, in a building several blocks from Ground Zero, showed that they were suffering health effects, yet the federal government did not disclose its own survey results to the public.

This report explains how the federal administration's reckless disregard for the toxic hazards generated by the attack had disastrous consequences for many people who served on the front line of terror response and lower Manhattan's recovery. Most Americans are not fully aware of the wide range of workers and community people who have been afflicted by Ground Zero pollution; this report describes these people, their unmet needs and the continuing risks that threaten them.

Finally, this report alerts the public to a danger that should be of national concern: This report finds that the Bush administration's new emergency planning documents – from the Department of Homeland Security and the Occupational Safety and Health Administration – make some of the administration's worst 9/11 response failures into standard operating procedure for national emergencies. In other words, the prolonged harm that resulted from lack of proper action at Ground Zero could happen again, in New York City or in another location in the United States.

People following news stories about the Ground Zero pollution may wonder whether federal agencies realized at the time that health warnings were needed, or whether those who got sick were just recalcitrant individuals who failed to follow safety directions. This report answers those questions.

- The Ground Zero health risk cover-up did not result from a poorly informed government. The World Trade Center attack involved the open, uncontrolled burning and demolition of two huge buildings – conduct that would be illegal in any state of the Union because of the known risks to human health. This report finds that the federal government ignored its own long-standing body of knowledge about pollution from incineration and demolition. The notion that EPA had to wait for test data before telling people that the pollution posed health risks is absurd. EPA should have issued a health warning, based on its own knowledge of pollution, before any test data came in.

- EPA failed to investigate and disclose toxic hazards properly. Oddly, EPA's website reports that it found no polycyclic aromatic hydrocarbons (PAHs) – cancer-causing chemicals generally released by combustion of mixed materials – "in any air samples," although four independent tests found them at elevated levels and even EPA's own research scientists reported in a scientific journal that they found them at levels that *Science* magazine deemed worthy of "the most serious kind of concern."

- The federal government failed to change its safety assurances even after it became clear that people were getting ill, and even after a survey of federal employees of a sister agency in the same building as EPA at 290 Broadway revealed that they were suffering health impacts – a survey that, this report finds, the federal government did not release to the public at the time. It was quietly published in a journal in 2002.

- Many Ground Zero workers did not have proper protection, especially in early weeks. This report explains that federal assurances of safety gave workers conflicting messages about the need for respirator masks, which are difficult and exhausting to wear.

- OSHA refused to enforce worker safety standards at Ground Zero. It wrongly claimed that it had no authority in national emergencies. It then continued this refusal long after the emergency had passed, and long after it became apparent that serious health and safety risks were occurring despite efforts by OSHA staff to advise safety.

- EPA and FEMA, in concert with New York City's own health department, told families that they could clean up the contaminated dust themselves with wet rags. In fact, they actually discouraged area residents from wearing safety masks.

The Bush administration's conduct is hard to understand given the fact that it had only recently learned some important lessons in a community contamination issue. Earlier in 2001, the

federal government had finally responded to families in Libby, Montana, who had long been trying to get their attention, after a *Seattle Post-Intelligencer* reporter had exposed EPA's prior inaction. The entire town – playgrounds, backyards and homes – was polluted by asbestos from a mine. EPA promised a full clean-up. It was too late for some families; many people had already died of asbestos-related illnesses. At the time, EPA Administrator Christine Todd Whitman told the community:

> I also want you to know what effect your experiences here are having on our work at the EPA. Because of what we've found in Libby, we are reviewing all of the scientific information about health risks posed by asbestos. We want to know if there are other problem areas out there. And if there are, we will take the appropriate steps to address them. I know it's small comfort, but your experience and your pain may help others facing similar situations.

Four days later, the September 11, 2001 attack occurred, releasing asbestos-contaminated dust over lower Manhattan and parts of Brooklyn. EPA ignored its own rules urging use of more modern asbestos testing equipment and failed to reverse course even when independent tests showed that it was failing to detect asbestos accurately. It failed even to alert the public that the dust was highly caustic.

At the very least, our federal government should have considered the pollution dangerous unless rigorous testing proved otherwise. It did not. Instead, EPA and OSHA – under the White House Council on Environmental Quality's direction – behaved as though they had never seen pollution before, as though they did not know their own regulations, as though they were unfamiliar with current scientific knowledge, and as though the asbestos disaster of Libby, Montana, had never happened.

The Bush administration declared that no expense would be spared in helping the affected communities to recover. Nevertheless, its action has fallen far short of the mark. It has resisted calls for proper cleanup of the toxic dust still present in homes and buildings even though over 2,700 children under ten years old live in the community around Ground Zero. Also, it has not provided adequate long-term health monitoring and care for the people exposed to the pollution. These failures have prolonged the harm to this "Ground Zero community" and impaired New York City's recovery from the attack.

Now, the Bush administration apparently plans to turn its missteps at Ground Zero into standard policy for any future national emergency.

- Its new occupational safety emergency planning document institutionalizes its failure to enforce safety and health laws for response workers.

- Its Department of Homeland Security emergency planning document solidifies the administration's insistence on centralized political control of all hazard

communications during an emergency – without providing strong policies to protect the public against false assurances.

This means that the Bush administration has learned nothing from the illnesses and hardships suffered by the Ground Zero community. Rather, it plans to perpetuate them in any future national disaster, anywhere else in the United States.

SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

Lesser Known Hazards from Ground Zero

The attack on the World Trade Center ("WTC") released toxic vapors and airborne particles that were hazardous to human health, including a toxic, caustic dust that settled on outdoor and indoor surfaces and often became airborne again through disturbances at Ground Zero.

- The Ground Zero fire emitted polycyclic aromatic hydrocarbons (PAHs), a group of chemicals including substances that cause cancer and may cause other genetic impacts that can affect children subjected to pre-natal exposure. PAHs generally are produced by combustion of mixed materials. (See below for details on EPA lack of disclosure.)

- Much of the WTC dust was as caustic as ammonia, and in some cases as caustic as drain cleaner. The federal government knew this, but did not tell the workers or the public. A carpenter and emergency medical technician, John Graham, comments:

> I was at all the safety meetings, but they never told us what was really going on. Now I'm a walking pharmacy. I have a chest infection, ear, nose and throat problems. . . . My tonsils look like strawberries – red and pitted. I guess drain cleaner would do that to you.

- Despite assurances that "most" WTC dust particles were too large to penetrate the lungs, evidence reveals that some did. The larger caustic particles also "burned" the nose, throat and upper airways, and some people inadvertently swallowed WTC dust.

What the Federal Government Already Knew About the Hazards

No one expects perfect safety practices immediately following such an unexpected and devastating attack. Palmer Doyle, rescue worker and recently retired firefighter from Coney Island Engine number 254, Ladder number 153, explains:

> During the first few days, we ran down there. I was there when the second building came down. I worked from 9:45 to 2:30 AM. I came back again at 9 AM and worked until very late. By Friday, you could see the shoulders sagging. We knew no more survivors were likely. By Sunday, the adrenaline was spent. Sunday was torture. But we rallied ourselves. We said, "Let me get something for the family to bury."

Unfortunately, the federal administration chose to respond in ways that further endangered human health. Its conduct prolonged hazards from the attack and promoted unsafe work conditions at Ground Zero that increased human exposure to pollutants.

The WTC disaster was new in scale but not completely new in character. The federal government already knew many of the dangers from uncontrolled combustion and demolition, but did not warn the public against them. Philip McArdle, Health and Safety Officer for the Uniformed Firefighters Association, points out:

> We talk about preparing for disasters, but if we don't use what we already know, when are we going to be prepared for a disaster? . . . The World Trade Center disaster was new in scale. But buildings have burned before. Planes have crashed and burned. Structures have collapsed in earthquakes. We've seen these kinds of hazards before, and we look to the agencies to tell us what the hazards are. These are things that federal agencies plan for all the time, so why weren't they ready?

In fact, EPA knew from the outset that uncontrolled burning of building materials releases toxic chemicals, and that cement dust typically is very caustic, because it has studied incineration, demolition, and the pollution and debris that they generate for decades. For example, following the catastrophic year of 1989, when both the California earthquake and Hurricane Hugo destroyed buildings and a steam pipe exploded in the Gramercy Park neighborhood of New York City, EPA produced a document called *Guidelines for Catastrophic Emergency Situations Involving Asbestos*, in which it warned of the potential for such emergencies to create asbestos contamination problems.

What the Federal Government Failed to Disclose or Find

- EPA misrepresented the meaning of asbestos test results by knowingly mis-characterizing its own technical detection limits as health standards.

- The White House Council on Environmental Quality provided misleading data to U.S. Senators Hillary Rodham Clinton and Joseph Lieberman in a letter which implied that only extremely few homes were contaminated by asbestos from the

WTC dust. (The senators were not dissuaded from pursuing their concerns about the need for proper testing and cleanup.)

- EPA did not find health hazards because it did not look for them, or failed to look for them properly.

  (1) As noted above, EPA did not report any testing of the WTC dust for harmful organic chemicals such as PAHs. In fact, PAHs were present at high levels, according to an independent test. Also, this Report discloses that private tests of dust from firefighters boots found toxic PAHs at levels 115 and 422 times higher than EPA's health-based criteria for soil cleanup.

  EPA's website reports that it failed to detect PAHs in the air in any air samples, yet a recently released study of "window film" in lower Manhattan after the attack found PAH levels at 10 times greater than urban background levels, and a new study analyzing the small dust particles gathered in EPA air samples revealed significant levels of PAHs. Also, EPA researchers themselves published a study of PAHs in air in late September and mid-October, finding levels higher than a serious photochemical smog episode in Los Angeles.

  (2) As has been reported before, EPA used an older, less effective testing method for asbestos in dust even though it had advised schools seven years earlier against using that technology. EPA did not change its method after independent tests found higher levels of asbestos using the newer method that EPA itself recommends for schools. Yet, the federal government used the newer method at EPA's own office building – and this Report finds that EPA ordered an asbestos cleanup of its lobby without even waiting for test results, based only on the presence of visible WTC dust.

  (3) EPA failed to test for the very tiny and more hazardous airborne particles that are likely to result from a hot combustion, as occurred at Ground Zero, even though this Report finds that it knew of the more precise equipment required to do so. Jimmy Willis, a 9/11 rescue worker and Assistant to the President for the Transport Workers Union observed:

> What EPA did was like using a colander with giant holes, and then saying, 'Look, there's no spaghetti.' It was a test to find nothing.

  Very small particles are more dangerous because they are more easily inhaled deep into the lungs and also tend to contain higher concentrations of toxic chemicals.

(4) EPA failed to conduct scientific sampling to determine the extent of indoor contamination from the WTC pollution. It even neglected to test most of the apartments in its limited cleanup program before cleaning them. This failure to measure WTC pollution in residences made it impossible to assure their safety.

- The federal administration failed at least a dozen times to correct its improper assurances of safety even after information and data on health risks became known and even after news began to emerge about people getting sick.

  By September 27, 2001, the federal government had test results confirming that the WTC dust was highly caustic – as caustic as ammonia, and in some cases as caustic as drain cleaner. The pH of ordinary urban soil generally ranges from 6.7 to 7.3, but the pH of WTC dust ranged from 9.0 to as high as 11.5. *This Report finds that EPA and OSHA did not warn the public about this in a press release or, apparently, even in directives to union health and safety officers.*

  This Report finds that the federal government was aware that area employees were at risk from WTC pollution by early 2002. A December 2001 survey of Health & Human Services employees at 290 Broadway found 65-69 percent suffered worsened cough, shortness of breath, and wheezing and 81 percent had worsened eye irritation just after 9/11; half still had symptoms three months later. An EPA report states that its employees too had health effects at that time. *Neither agency notified the public.*

- Both FEMA and EPA failed to warn residents that they should not just clean up the contaminated indoor WTC dust themselves – even though EPA has publicly denied this. Indeed, even after EPA launched an indoor cleanup program, it continued to assure residents that such cleanup was not really needed. The federal agencies failed even to give special instructions to prevent exposure of children and people with respiratory, immune system or heart disorders, who would be more vulnerable to the WTC pollution.

The desire to reopen Wall Street cannot justify placing civilian safety at risk. The EPA Inspector General's report stated:

> [W]e fully recognize the extraordinary circumstances that existed at the time the statement was made about the air being safe to breathe. It continues to be our opinion that there was insufficient information to support the statement.

The government has a higher duty to protect its citizens' health and safety. Civilians are not soldiers. They are supposed to be protected, not put in harm's way. And one of the most important jobs of the federal government in the event of an attack on a civilian target should be to control and limit the harm to human health and safety of that attack. Instead, the Bush administration's response to the September 11th attack furthered the danger to public health.

Speculative fear of public reactions does not justify suppressing warnings. Some may argue that there was a need to "soften" the message about pollution to prevent public panic. Yet, no one would advocate keeping silent about a fire in a building. People should be warned when they need to take action to protect themselves, and warning people about Ground Zero pollution would not have caused widespread, uncontrollable frenzy. Despite the myth of public panic, experts state that such conduct is rare, that people more consistently tend to bind together in the aftermath of disasters to restore their communities. Many disaster experts urge that treating the public with respect and forthrightness is the best approach. *Albany Times Union* columnist Fred LeBrun made this comment:

> Did Washington think we'd panic over the toxic possibilities, or that Manhattanites would stop breathing? Or that the cops, firefighters and rescue workers would stop sifting the rubble 24/7 for their comrades and other victims? Not a chance.

There is no question that the rescue and recovery work would have proceeded. But if proper warnings had been given, it would have proceeded more safely. Also, the emergency conditions of the first few days certainly cannot justify the continued suppression of health warnings that this Report documents occurred during the many weeks and months that followed the attack.

How the Federal Government Failed to Carry Out Its Own Duties

The federal government failed to carry out its own duties to protect the public from the toxic aftermath of the terrorist attack.

- The federal administration chose not to enforce worker safety standards at Ground Zero. OSHA has authority to enforce the federal Occupational Safety and Health Act, and primary responsibility for worker safety and health during national emergencies. Yet both FEMA and OSHA took the position, wrongly, that OSHA had no authority to enforce federal standards in emergency rescue operations.

  OSHA neglected to assert enforcement authority even after it became obvious that safety enforcement was failing at Ground Zero, and it continued to take no enforcement action long after rescue operations had ceased.

- The federal government failed to respond properly to the toxic release as a terrorist attack and illegal action. The President has broad powers to respond to pollution from terrorist attacks and to releases of hazardous substances, and these powers are delegated to EPA. EPA acknowledged as early as November 2001 that it had the lead responsibility to clean up buildings contaminated as a result of terrorism, but did not launch an effort until summer 2003, and that effort was highly flawed. This inaction left both families and workers at risk.

(1) Most residences in EPA's chosen Ground Zero "cleanup zone" (below Canal and Pike Streets) were not cleaned by trained environmental workers, and WTC dust very likely permeated some buildings outside the zone in Manhattan and Brooklyn.

(2) The FEMA-funded EPA indoor cleanup program completely excluded non-residential buildings, and it did not ensure that those workplaces were made safe.

(3) EPA even refused to clean the firefighters' contaminated firehouses.

Why the Federal Failures of Ground Zero Put the Nation at Risk

Most disturbingly, the Bush administration plans to make the mistakes of Ground Zero into policy for all future national emergencies. A future disaster could release toxic substances again. Most important buildings nationwide contain asbestos, lead, plastics, and other substances that could create hazards in a fire or collapse. For example, 84 percent of tall office buildings, 64 percent of short office buildings and 43 percent of transportation and government buildings in New York City contain asbestos. Nevertheless:

- The Bush administration is eliminating OSHA's enforcement role at all future national emergency sites. Under OSHA's new *National Emergency Management Plan*, the agency will not enforce safety rules, but rather will provide only technical assistance. The foreseeable result of this approach is insufficient protection for the hard-working and courageous Americans who respond to local disasters.

- Nothing in the Department of Homeland Security's new national emergency planning documents – the *National Incident Management System* or *Initial National Response Plan* – provides the assurance that the public should receive that the missteps of Ground Zero will not happen again in New York City or in some other town or city of our nation. Indeed, *Inside EPA* reports that the Bush administration is considering developing standards for toxic cleanup in national emergencies that may be weaker than Superfund standards, thus leaving communities at risk.

Based on the experience at Ground Zero, the Bush administration's new policies would dramatically increase the health risks to Americans unfortunate enough to experience future national emergencies.

Why the People Exposed to WTC Pollution Need Health Monitoring and Further Cleanup

If the Bush administration had provided proper warnings, it is likely that better precautions would have been taken in many circumstances, and that people would have been safer in several ways.

- Many rescue, recovery and emergency services workers were given inadequate safety gear and conflicting messages about the need to use it. Despite government assertions to the contrary, many of these workers did not receive properly protective masks in the early weeks. Also, federal assurances of safety and lack of consistent warnings reduced motivation to use the safety gear, which was difficult and exhausting to wear. Volunteers helping with cleanup or servicing the rescue workers did not receive proper advance warnings about the hazards and often did not have any protective gear.

- Residents were not given the information they needed to make informed choices about how to protect themselves and their families. Some had to make hard decisions about whether to evacuate and when to return. Also, following government instructions to clean up the WTC dust in their homes themselves brought them into close contact with the dust, much of which contained asbestos.

- City sanitation workers who cleaned up WTC street dust and managed the WTC debris needed better protective gear; also, privately hired, low income dust and debris cleanup workers – many of them immigrants – often received no protective gear at all.

- No government agency ensured that contaminated workplaces were properly cleaned before employees returned; some employees cleaned up their own work areas, and some employees reportedly were forbidden to wear masks on the job.

- Many small business owners cleaned their own spaces, and some who sought a proper environmental cleanup had trouble convincing the insurer of the need to cover the cost.

- Charities were not alerted in a timely way about the need for long-term medical monitoring and long-term healthcare. As a result, comparatively little charitable giving was directed toward such needs during the first two and a half years after the disaster.

Some of the dust left behind by inadequate cleaning likely still remains in homes and buildings, and may still present a health hazard, especially to children.

- Harder-to-clean areas in homes can present a special exposure risk to children. Young children play on carpets and bounce on upholstered furniture. Their toys roll under radiators and behind appliances. They may inhale the dust that is disturbed by such activities, or accidentally ingest dust that gets on their fingers.

- Less frequently cleaned areas – such as bookshelves, the tops of molding and under radiators – can "store" WTC dust and become sources of future unexpected exposures.

- Lead, a toxic metal, is present in much of the indoor WTC dust, putting any very young children who ingest it at risk of lead poisoning, which causes permanent brain damage.

The scale of public exposure to WTC pollution has created an urgent need for medical monitoring and care. The "Ground Zero community" includes a wide range of people who now are at risk of adverse health effects from exposure to WTC pollution. That community encompasses residents, area employees, building cleaners, sanitation workers, communications workers, plumbers and electricians, firefighters, emergency medical technicians and paramedics, police officers, volunteer rescue workers and others. Medical screening has revealed a disturbing trend of long-lasting lung ailments and other symptoms among many of these people. No one knows what the long-term or delayed health effects of exposure will be. They may include not only cancer but also effects on the immune and reproductive systems, and possibly other genetic impacts.

People exposed to the WTC pollution need long-term health monitoring and other help. The federal government, however, has utterly failed to meet this need. (The widely-publicized government-funded "World Trade Center Health Registry," provides no health services, and is probably too flawed even to satisfy the research purposes for which it was designed. *See* Appendix D of this Report.)

- The current WTC medical monitoring program is only funded for five years, even though cancers and certain other health effects may take from 10 to 30 years to appear.

- Many people who already suffer health effects from the WTC pollution have no health insurance or are under-insured.

- Some people who were harmed by the WTC pollution are too sick to work in the occupation for which they were trained, and are suffering economically.

Recommendations

The Bush administration must restore trust in its agencies charged with protecting health and safety and take action to mitigate the consequences of its own failure to provide proper warnings about the health hazards from Ground Zero. In particular, it must do the following:

- Take action *now* to prevent more harm from its failure to ensure proper cleanup of the WTC dust. A new cleanup must address both residential and non-residential buildings, and should include firehouses and emergency vehicles and equipment where needed.

- Fund long-term medical monitoring, treatment and assistance as needed to the people who suffer or are at risk from adverse health effects due to exposure to WTC pollution.

- Issue a retraction of its safety assurances; disclose and censure the top official involved in altering agency press statements to suppress 9/11 health warnings, to send a clear message that failing to warn the public truthfully about health hazards is unacceptable.

- Work with Ground Zero-affected communities, labor unions and environmental health advocacy groups to develop effective national policies and practices that promote truthfulness in the communication of health hazards and effective response actions.

- Abandon its plans to eliminate enforcement of federal safety standards for response workers and institutionalize political control of communications without providing strong policies to prevent issuance of false assurances of safety – actions that would transform the its missteps at Ground Zero into dangerous disaster policy for the rest of the nation.

Table II: Federal Help for People Made Ill by or at Risk from Exposure to WTC Pollution

Resident	None	None	None
Area Employee or Small Business Owner	None	None	None
Resident/Worker with Asthma or special sensitivity	None (except small scientific survey)	None	None
Downtown Cleanup Workers	Many qualified for WTC medical screening program (also some were screened by the nonprofit Mobile Medical Unit)	5 years only of medical monitoring	None
Transportation Services Worker	Provided to many – those who qualified for WTC medical screening program	5 years only of medical monitoring for those in WTC program	None; most workers' compensation claims delayed or denied. Some may have qualified for 9/11 Victim Comp. Fund
Communications Systems Worker	Provided to many – those who qualified for WTC medical screening prog.	5 years only of medical monitoring for those in WTC program	None; many workers' comp. claims delayed or denied
Emergency Services Workers	Provided to many – those who qualified for WTC medical screening program	5 years only of medical monitoring for those in WTC program	None; many workers' comp. claims delayed or denied; some may have qualified for 9/11 Victim Comp. Fund
Volunteer Rescue & Recovery Worker	Provided through WTC medical screening program	5 years only of medical monitoring	Funding for workers' comp. provided; may have had trouble qualifying for 9/11 Victim Comp. Fund
Firefighter and Police as Rescue & Recovery Workers	Provided through WTC medical screening program	5 years only of medical monitoring	9/11 Victim Comp. Fund for known harm; none for future illnesses that may arise

What Was Known, What Was Said

A comparison of known information on World Trade Center pollution and health effects with statements made or actions taken by federal administration

August 1, 1994	EPA advises schools not to use polarized light microscopy (PLM) analysis for asbestos testing, urging them to use the "improved" transmission electron microscopy (TEM). EPA explains that the new method identifies "thin asbestos fibers below the limits of resolution of the polarized light microscope."	In September 2001, the EPA uses the old PLM method to test for asbestos in the dust generated by the WTC disaster.
September 12, 2001	Regarding a White House request to produce fact sheets re asbestos, Dr. Ed Kilbourne tells the CDC, "We are concerned about even being asked to write a document for the public about reentry at this point," and warns, "We are aware of other potential toxic hazards in the WTC area about which you haven't asked." (Federal experts know the typical products of building demolition and burning of mixed materials.)	EPA's September 13, 2001, press release states that pollution tests "have been very reassuring about potential exposure of rescue crews and the public to environmental contaminants... the general public should be very reassured by initial sampling."
September 14, 2001	On September 13, 2001, Drs. Philip Landrigan and Stephen Levin of Mount Sinai warn that Ground Zero workers need training and "protective equipment." Dr. Levin warns that surgical masks do not protect against asbestos and urges use of a mask with a special filter. EPA data shows asbestos in dust ranging from 2.1 percent to 3.3 percent—above the 1 percent level at which material must be managed under asbestos standards. A Federal test of EPA's Region 2 office building lobby at 290 Broadway using the more sensitive TEM method finds asbestos. EPA does not even wait for these results; it conducts an environmental clean-up of its lobby based only on the presence of visible dust.	The White House Council on Environmental Quality changes EPA staff's September14 draft release, which had stated, "The concern raised by these samples would be for the workers at the cleanup site and for those workers who might be returning to their offices on or near Water Street on Monday, September 17 2001." This sentence is deleted. Instead, the September 16 release quotes OSHA saying, "Our tests show that it is safe for New Yorkers to go back to work in New York's financial district. The EPA office building testing and clean-up information is not made public at the time.
September 16, 2001	The EPA tells *New York Newsday* that its highest recorded asbestos reading for dust contamination was 4.5 percent.	*New York Newsday* quotes the EPA administrator as saying that "there is no reason for concern," based on airborne asbestos tests in the financial district. The stock market reopens on September 17; tens of thousands of workers return to work in the Ground Zero area.
September 18, 2001	More than 25 percent of the bulk dust samples that EPA had analyzed by this date showed asbestos at levels above the 1 percent threshold used by both EPA and the City of New York to define asbestos-containing material.	The EPA Administrator states that tests "show that the public is not being exposed to excessive levels of asbestos or other harmful substances. I am glad to reassure the people of New York that their air is safe to breathe..." A September 21 EPA press release entitled, "NYC Monitoring Efforts Continue to Show Safe Drinking Water & Air" asserts, "available results continue to show that rescue workers at the disaster site are not being exposed to hazardous materials."
September 27, 2001	The USGS gives EPA and other WTC response agencies its test results of WTC dust, finding that it is highly caustic. (EPA scientists disclose in a December 2002 report that the dust they sampled on September 12 and 13 was mostly gypsum and calcite, which "are known to cause irritation of the mucus membranes of the eyes and respiratory tract.")	The Federal administration does not issue a press release on the USGS findings and does not change its publicly released assurances about health risks from the WTC pollution.
September 28, 2001	*New York Daily News* columnist Juan Gonzalez reports that dust samples taken from within a block or two of Ground Zero by the New York Environmental Law & Justice Project showed asbestos at up to five times higher than the 1 percent definitional threshold for asbestos-containing material, and significant amounts of fiberglass.	On October 3, an EPA press release asserts that federal testing "found no evidence of any significant public health hazard to residents, visitors or workers beyond the immediate World Trade Center area." It states that "there is no need for concern among the general public, but residents and business owners should follow recommended procedures for cleaning up homes and businesses if dust has entered." The "recommended procedures" are for residents to clean the dust themselves.
October 5, 2001	*Newsweek* reports that tests of two private office buildings by an independent firm suggests that more asbestos was released than EPA tests indicated and discloses that EPA is using the older PLM testing method for asbestos in dust.	The EPA states that it has not seen the report and refuses to comment.
October 12, 2001	The Ground Zero Elected Officials Task Force provides sample results from two downtown apartments having asbestos levels in the dust nearly 460 times the EPA's allowable limit.	The federal administration does not change its publicly released assurances about health risks and it continues to support local City instructions that residents can simply wet mop and wet wipe their apartments by themselves.
October 26, 2001	*New York Daily News* columnist Juan Gonzalez reports that internal government documents reveal toxins in the air and soil around Ground Zero, sometimes at levels far exceeding standards.	In an unpublished letter the EPA Administrator tells the *Daily News* that the high benzene readings at Ground Zero are not in the 5 to 7 foot high "breathing zone" of the workers (ignoring the fact that they were digging and pulling much of the time).

November 26, 2001	Dr. Levin of Mt. Sinai reports early observations of new-onset asthma and reactive airway dysfunction syndrome (RADS) in Ground Zero workers and people who live or work within four blocks of the site—and his expectation that some people have symptoms for the rest of their lives	The federal administration does not change its publicly released assurances about health risks and it continues to support local City instructions that residents can simply wet mop and wet wipe their apartments by themselves
December 19, 2001	The Ground Zero fire is declared "out."	
	A survey of government office workers conducted in Dec. 2001 finds that half of the workers who reported shortness of breath or wheezing, still had symptoms nearly four months after the attack—**the government has knowledge** of health risks for area employees by early 2002, if not in December.	The federal administration does not disclose the results of this survey. It also does not change its publicly released assurances about health risks from the WTC pollution. (The survey results are quietly published in a scientific journal in July 2002.)
January 13, 2002	*St. Louis Post-Dispatch* reporter Andrew Schneider documents that private firms' tests are finding higher levels of asbestos than EPA. A senior EPA chemist is quoted as stating, "For every asbestos fiber EPA detected, the new methods used by the outside experts found nine. This is too important a difference to be ignored if you really care about the health of people."	The federal administration does not change its publicly released assurances about health risks. On January 12, *Daily News* reporter Russ Buettner quotes a Region 2 EPA spokesperson as stating that the EPA administrator never said the area was without risk, saying, "That's a mischaracterization of what was ever said."
January 31, 2002	OSHA notifies a labor union's law firm that indoor WTC dust should be "presumed" to contain asbestos unless tests prove otherwise, since asbestos was used in the towers.	
February 12, 2002	*St. Louis Post-Dispatch* reporter Andrew Schneider discloses that the United States Geological Survey reported to EPA that some WTC dust was "as caustic as liquid drain cleaner."	
March 24, 2002	Dr. Thomas Cahill of the University of California at Davis testifies on his air sampling results, which had shown very high levels of ultra-fine toxic particulates in the air from Ground Zero	The federal administration does not change its publicly released assurances about health risks from the WTC pollution.
April 18, 2002	EPA and a city agency, urged by the New York Environmental Law and Justice Project, test dust at a lower Manhattan residential loft building, using both PLM and TEM methods for asbestos. The PLM test finds no asbestos. The TEM method on the same sample reveals from 2 percent to 5 percent asbestos, up to five times the level for "asbestos-containing material."	EPA soon announces a residential clean-up program. It does not disclose the failure of the PLM method that it has been using. EPA Region 2 Administrator states, "While the scientific data about any immediate health risks from indoor air is reassuring, people should not have to live with uncertainty about their futures
September 11, 2002 to September 11, 2003	In September 2002, the CDC reports that up to 30 percent of employees surveyed in two workplaces near Ground Zero still had persistent symptoms four to six months after the attack.	The federal administration does not establish a program for cleanup of office and commercial buildings in lower Manhattan.
	In September 2002, The *New England Journal of Medicine* publishes Dr. David Prezant's study of "World Trade Center Cough	The federal administration does not expand the scope or increase the rigor of its residential clean-up program.
	In December 2002 the *American Journal of Industrial Medicine* publishes study by Dr. Steven Markowitz of WTC dust cleanup workers, "nearly all of whom" suffered new or worsened, long-lasting respiratory symptoms.	The federal administration continues to refuse the request to professionally clean firehouses and emergency equipment.
	In January 2003, Mount Sinai School of Medicine reports that 78 percent of more than 3,500 rescue/recovery workers suffered lung ailments in the months after the attack.	The federal administration does not change its publicly released assurances about health risks from the WTC pollution.
	In August 2003, the *Journal of the American Medical Association* publishes Dr. Philip Landrigan's findings that pregnant women exposed to WTC pollution were twice as likely to give birth to babies smaller than babies born to women not exposed.	
Oct. 27, 2003	Dr. Levin of Mount Sinai reports that Ground Zero workers examined now show roughly the same rates of illness as in 2002. He states, "We're finding that these problems are not going away."	The White House Council on Environmental Quality asserts, "we continue to stand by the information distributed in press releases regarding potential long-term health risks."

[Witnesses sworn.]

Mr. SHAYS. I would appreciate it if our witnesses could give their testimony in 5 minutes. We have some time restraints. We have some votes on the floor and testimony on the floor we need to participate in.

Dr. Levin, thank you.

STATEMENTS OF DR. STEPHEN LEVIN, CO-DIRECTOR OF THE WORLD TRADE CENTER WORKER AND VOLUNTEER MEDICAL SCREENING PROGRAM; DR. MICHAEL LONSKI, DIRECTOR, TRAINING AND PROGRAM DEVELOPMENT, LIFE MATTERS; DR. JAMES MELIUS, ADMINISTRATOR, NEW YORK STATE LABORERS HEALTH AND SAFETY FUND; STAN MARK, ESQ., PROGRAM DIRECTOR, ASIAN AMERICAN LEGAL DEFENSE AND EDUCATION FUND; AND MICKI SIEGEL DE HERNANDEZ, HEALTH AND SAFETY DIRECTOR, COMMUNICATIONS WORKERS OF AMERICA

Dr. LEVIN. I am Stephen Levin, medical director of the Mount Sinai-Selikoff Center for Occupational and Environmental Medicine and I am co-director of the World Trade Center Worker and Volunteer Medical Screening Program.

I want to thank Congresswoman Maloney and you, Congressman Shays, for inviting me to speak today about the health consequences of exposures during World Trade Center recovery efforts and what we see as the unmet needs of the people whose health has been affected.

Our Center for Occupational and Environmental Medicine at Mount Sinai has a long history of providing medical services to the working people of the New York Metropolitan area, their unions and their employers. We were well known to many of the workers who responded to the attacks on the World Trade Center Towers and to their unions and began seeing responders, evacuees, returning office workers and residents of lower Manhattan within a few weeks of the World Trade Center attacks.

It was clear to us almost immediately from this clinical experience that the exposures to the mix of respiratory irritants like pulverized concrete, hydrochloric acid mist and fibrous glass present in the air at and near Ground Zero caused respiratory problems, including sinusitis, laryngitis, asthma and bronchitis, acid reflux from the stomach known as GERDS and that the horrors that many had witnessed there caused stress-related psychological symptoms and depression.

Responding to the appeal of organized labor who were aware of the problems their members were developing and whose members made up the majority of the workers and volunteers involved in the rescue and recovery work, the cleanup and the restoration of essential services in lower Manhattan, the New York congressional delegation was successful in securing funds to establish two medical screening programs, one for New York City firefighters and another coordinated by our group at Mount Sinai for all other World Trade Center workers and volunteers, each to evaluate clinically some 12,000 World Trade Center responders.

We are grateful to the Centers for Disease Control and to the National Institute for Occupational Safety and Health for their sup-

port and their assistance in establishing these important programs whose mission it was to identify those who were ill as a consequence of their World Trade Center efforts and to make sure they were referred for appropriate care but not to provide that care since no resources were made available for treatment of World Trade Center related illnesses or for additional medical testing and individual responder might need. The firefighter and Mount Sinai programs have identified similar health consequences among World Trade Center responders, asthma, bronchitis, sinusitis, laryngitis, digestive problems. These illnesses are remarkably persistent.

We analyzed what was found clinically among 250 of the first 500 responders that we examined at the Mount Sinai program and we began seeing responders in August 2002 far too long after the event occurred and reported that nearly half of these men and women still experienced at the time of their examination at least one pulmonary symptom. By that, we mean wheezing, chest tightness, cough or shortness of breath and this was a minimum of 10 months after the September 11 event. Over half had persistent ear, nose and throat symptoms and over half had persistent evidence of psychological distress severe enough to warrant further evaluation by a mental health professional.

We recently updated our analysis to include the medical findings of over 1,100 responders seen in our program and that has been referred to several times today. It will be appearing in the MMWR in 2 days. I am not allowed to cite actual data from that figure until the report is released but I can tell you this. The results point to similarly high rates of persistent respiratory, digestive tract and psychological disorders in this larger group.

We know that we have examined only a fraction of the workers and volunteers whose health may have been affected by their World Trade Center efforts and there is reason to believe there are many who have not undergone screening examinations who have persistent World Trade Center related illnesses. Fortunately, funding has been obtained from the CDC and NIOSH for medical followup exams of the World Trade Center responders for the next 5 years and we will be able to bring in additional workers for their baseline examinations during this first year of the longer term program.

This program will give us an opportunity to evaluate the course of these shorter term illnesses and to some extent the response to various treatment approaches and to identify those who still need medical and psychological care for those conditions that occurred shortly after exposure but there remains the issue of long term consequences of World Trade Center related exposures. This witches brew of airborne materials found at and near Ground Zero where a number of carcinogens, cancer causing agents, including asbestos and the class of compounds known as PAHs, polycyclic aromatic hydrocarbons, the cancer causing chemicals in tobacco smoke.

If we are to detect the cancers that may develop as a result of these exposures encountered during the recovery effort at a time when treatment may be more effective, this group of responders has to be followed for at least another 20 plus years since such cancers most often occur at least 20 years after the onset of exposure to the cancer causing agent. I think our description of what hap-

pened after the World War I cigarette smoking experience is exactly what we are concerned about here.

This is an especially important issue for those who spent long hours without respiratory protection on the pile at Ground Zero where the fires burned until December 2001 and for the workers who cleaned up the office and residential buildings nearby Ground Zero, disturbing dust contaminated with carcinogens day after day for months, no warnings, no training, no masks.

Our screening pilot program has found many people who needed followup care for the physical and emotional problems they developed in the course of their World Trade Center efforts. Making sure they obtain adequate care has been a difficult challenge. For many, the workers compensation system should have been a resource but for all too many it has been an obstacle course of claims fought and delayed, almost impossible to navigate for these heroes whose tolerance for additional stress is often very limited. Many have no health insurance. At Mount Sinai, we have received limited funds from private philanthropic sources to provide care for these responders but it isn't enough to meet the need.

I believe that a public health response to a public health problem calls for Federal funding to pay for needed care. It shouldn't be left up to a badly fragmented health care system to ensure that the special testing people need and the medication these responders need will be made available. Our experience tells us it simply won't happen.

[The prepared statement of Dr. Levin follows:]

TESTIMONY OF STEPHEN M. LEVIN, M.D.

MEDICAL DIRECTOR
THE MOUNT SINAI – SELIKOFF CENTER FOR
OCCUPATIONAL & ENVIRONMENTAL MEDICINE

I am Dr. Stephen Levin, Medical Director of the Mount Sinai – Selikoff Center for Occupational and Environmental Medicine (COEM) and Co-Director of the World Trade Center Worker and Volunteer Medical Screening Program. I want to thank Congresswoman Maloney and Congressman Shays for inviting me to speak today about the health consequences of exposures during World Trade Center recovery efforts and what we see as the unmet needs of the people whose health has been affected.

The COEM has a long history of providing medical services to the working people of the New York metropolitan area, their unions and their employers. We were well known to many of the workers who responded to the attacks on the World Trade Center towers and to their unions, and we began seeing responders, evacuees, returning office workers, and residents of lower Manhattan within a few weeks of the World Trade Center attacks. It was clear to us almost immediately from this clinical experience that the exposures to the mix of respiratory irritants, like pulverized concrete, hydrochloric acid mist, and fibrous glass, present in the air at and near Ground Zero caused respiratory problems, including sinusitis, laryngitis, asthma and bronchitis, caused acid reflux from the stomach (known as GERDS), and that the horrors that many had witnessed there caused stress-related psychological symptoms and depression.

Responding to the appeal of organized labor, who were aware of the problems their members were developing and whose members made up the majority of the workers and volunteers involved in rescue and recovery work, clean-up, and restoration of essential services in lower Manhattan, the New York congressional delegation was successful in securing funds to establish two medical screening programs, one for NYC firefighters and another, coordinated by our group at Mount Sinai, for all other World Trade Center workers and volunteers, each to evaluate clinically some 12,000 World Trade Center responders. We're grateful to the CDC and the NIOSH for their support and assistance in establishing these important programs, whose mission it was to identify those who were ill as a consequence of their World Trade Center efforts and make sure they were referred for appropriate care - but not to provide that care, since no resources were made available for treatment of World Trade Center-related illnesses or for additional medical testing that an individual responder might need.

The Firefighter and Mount Sinai programs have identified similar health consequences among World Trade Center responders – asthma, bronchitis, sinusitis, laryngitis, digestive tract problems, as well as post-traumatic stress disorder and depression. And both programs have noted that these illnesses are remarkably persistent. We analyzed what was found clinically among 250 of the first 500 responders examined in the Mount Sinai program, which began seeing responders in August 2002, and reported that 46% (nearly half) of these men and women still experienced at least one pulmonary symptom (wheezing, chest tightness, cough, or shortness of breath) in the month before their screening examination, a minimum of 10 months after the 9/11 event. Over half (52%)

had persistent ear, nose and throat symptoms, and over half had persistent evidence of psychological distress severe enough to warrant further evaluation by a mental health professional. We've recently updated our analysis to include the medical findings among over 1,100 responders seen in our program, and this will be published tomorrow in the CDC's Morbidity and Mortality Weekly Report (MMWR). While I'm not allowed to cite actual figures until the report is officially released, I can tell you that the results point to similarly high rates of persistent respiratory, digestive tract and psychological disorders in this larger group.

We know that we have examined only a fraction of the workers and volunteers whose health may have been affected by their World Trade Center efforts, and there is reason to believe that there are many who have not undergone screening examinations who have persistent World Trade Center-related illnesses. Fortunately, funding has been obtained from the CDC/NIOSH for medical follow-up examinations of the World Trade Center responders over the next 5 years, and we will be able to bring additional workers and volunteers into the program for their first examinations during the next year. This medical monitoring program will give us an opportunity to evaluate the course of these shorter-term illnesses and to some extent the response to various treatment approaches, and to identify those who need still need medical and/or psychological care for those conditions that occur shortly after exposure.

There remains the issue of the long-term health consequences of World Trade Center-related exposures. In the witches' brew of airborne materials found at and near Ground

Zero were a number of carcinogens, including asbestos and the class of compounds known as PAHs, the cancer-causing chemicals in tobacco smoke. If we are to detect the cancers that may develop as a result of exposures encountered in the recovery effort, at a time when treatment may be more effective, this group of responders has to be followed for at least another 20-plus years, since such cancers most often occur 20 or more years after the onset of exposure to the cancer-causing agent. This is an especially important issue for those who spent long hours without respiratory protection on "the pile" where the fires burned until December 2001, and for the workers who cleaned up the office and residential buildings nearby Ground Zero, disturbing dust contaminated with carcinogens day after day for months – with no warnings, no training, and no masks.

Our screening program found many who needed follow-up care for the physical and emotional problems they developed in the course of their World Trade Center efforts. Making sure that they obtain adequate care has proven to be a difficult challenge. For many, the workers' compensation system should have been a resource; but for all too many, it has been an obstacle course of claims fought and delayed, almost impossible to navigate for these heroes, whose tolerance for additional stress is very limited. Many have no health insurance. At Mount Sinai, we have received limited funds from private philanthropic sources to provide care for World Trade Center responders, but it isn't enough to meet the need. I believe that a public health response to a public health problem calls for federal funding to pay for needed care. It should not be left up to a badly fragmented health care system to ensure that the special diagnostic tests and the medications World Trade Center responders need will be made available. Our experience

tells us that for too many, it just won't happen. People who risked their lives and health to do what they could for others should be taken care of for the health problems they've developed as a result. That's what we ought to do for heroes.

It's our view also that the residents of the surrounding community, the children who attended school in the immediate area, the people who returned – often too early - to offices in lower Manhattan, should have medical evaluations. We need too find those who are ill and get them into proper care. We're the most advanced industrialized country in the world, with vast resources and technical know-how, and we have the capacity to take better care of our people than the government has shown willingness to do up to now.

Thank you, and I'll be pleased to answer questions.

Mr. SHAYS. Thank you, Dr. Levin.

Dr. Lonski.

Dr. LONSKI. Thank you for inviting us to testify today.

The most helpful aspect of this hearing so far for me I have to say is that so many people have turned out today to try to continue to understand the after-effects of September 11 and how devastating the impacts are and how tenacious the impacts continue to be. For unless you live and work in New York or have a particular interest or involvement or a capacity or tolerance for understanding the depths of the painful after effects, you miss the fact that each report you have heard today from each of these agencies represents the personal experiences of thousands and thousands of people, active and retired, families and children, of people we have been able to reach out to through our organization and collaborate with other existing programs like Red Cross and Mount Sinai.

The fire, the police, the iron workers, the electrical workers, the New York City agency employees, family members, the National Guard, immigrant populations, there is a great deal of despair because the World Trade Center attacks forever altered the way many people see the world. The ensuing grief, trauma, stress, anxiety and despair worsened existing problems. It reactivated negative coping habits such as substance abuse, smoking and overeating. It overwhelmed peoples' abilities to control their emotional response and resulted in increased violence, depression and especially isolation.

Just check the corner newsstand to witness the breakdown in September 11 victims coping abilities, policemen setting bombs in train stations, firemen brawling with chairs, volunteers robbing banks, DWIs, extramarital affairs. People in New York are scratching their heads and wondering will it ever end? We are here to tell you from a mental health standpoint, this is just the beginning. In New York, September 11 was a mushroom cloud whose fallout is just now making itself known.

My name is Dr. Michael Lonski, Clinical Psychologist, Co-Founder of Life Matters. With me here today are Dr. Evelyn Llewellyn, also Clinical Psychologist, Co-Founder and Executive Director of Life Matters; Stephen Careaga, Executive Director of Firefighters National Trust who so generously underwrites much of our fire union endorsed work with active and retired first responders and families of the Fire Department of New York and board member, Lou Chinal, a September 11 survivor who retired from the Fire Department of New York after 29 years of service and who guides and serves us.

Life Matters is a not-for-profit organization created to meet the urgent need for counseling outreach and crisis intervention after the attacks. We teach people to understand, to cope and ultimately heal their trauma. We have embedded clinicians, trusted peers and support personnel in firehouses and social networks giving us the unique ability to quickly find and help people before they take actions that harm themselves or others. We have helped more than 30,000 persons remain healthy, productive and involved on their jobs and in their lives since the terror attacks. We continue to serve an estimated 15,000 New Yorkers a year. Let us put those numbers in perspective.

The Red Cross and the New York Psychological Institute estimate there are between 125,000 and 150,000 Manhattan residents alone who have fully diagnosable post-traumatic stress disorder. Mount Sinai researchers working with Ground Zero workers say more than 40 percent are suffering from mental health issues. A recent study by Smithers at Cornell's School of Industrial and Labor Relations found significant evidence of continued depression, stress, anxiety and grief and an increased risk for drinking problems among activity FDNY members post-September 11. So in 3 years, we have reached barely 20 percent of those who most dramatically need our help.

Let me explain what someone suffering from PTSD goes through and why this is a problem for us all. PTSD moves on a very predictable course from shock, to upset, to dysfunctionality. Key to their trauma is their perception that the world is not a safe place and that those in charge of protecting us have failed to do so. They are continually flooded with uninvited thoughts, flashbacks, day dreams and rivalry, nightmares and night terrors. Everything begins to look like a threat.

To protect themselves, they withdraw emotionally, buffer or medicate themselves or act out. They engage in negative behaviors to feel good, to feel alive or simply to feel anything at all. They become so preoccupied with warding off reminders that they lose their perspective of right and wrong. They fail to discriminate between external and internal triggers, judgment becomes impaired and anyone suffering from PTSD can become a time bomb.

Their explosions and implosions rock us all. Suicide, domestic violence, murder, divorce, criminal activity, inappropriate sexual activity, feared and actual debilitating disease and premature death. The loss of the talents and contributions of people who are otherwise vital and valued members of our society, that tragedy envelopes spouses, children, family and friends in the cycle of trauma, grief and loss is then renewed. We lose another generation and terror wins, no further attacks, just collateral damage from the original impact.

Those in need must understand that help is available and self help is possible. Those in power must commit the resources, financial and otherwise, required to prevent what uniformed first responders call a BLEVE, a boiling liquid expanding vapor explosion or be prepared to suffer in the fallout. We must rebuild victims' trust and help them reconnect with the world.

In our work, we continue to find ways to respect peoples' privacy and their integrity while reaching through their self protective isolation. Through flexible, tested and true, theoretically based, proactive outreach, education and support, we walk with them the paths of health, resiliency and hope. At issue is not just one man's unease but a family's ability to function and ultimately security for us all.

Thank you.

[The prepared statement of Dr. Lonski follows:]

LifeMatters
Health. Resiliency. Hope.

TESTIMONY
OF DR. MICHAEL LONSKI
DIRECTOR OF TRAINING AND PROGRAM DEVELOPMENT
LIFE MATTERS, INC.

AND DR. EVELYN LLEWELLYN
EXECUTIVE DIRECTOR
LIFE MATTERS, INC.

TO THE US CONGRESSIONAL SUBCOMMITTEE
ON NATIONAL SECURITY, EMERGING THREATS
AND INTERNATIONAL RELATIONS

SEPTEMBER 8, 2004

THE WORLD TRADE CENTER ATTACKS FOREVER ALTERED THE WAY MANY PEOPLE SEE THE WORLD.

THE ENSUING GRIEF, TRAUMA, STRESS, ANXIETY AND DESPAIR WORSENED EXISTING PROBLEMS. IT REACTIVATED NEGATIVE COPING HABITS SUCH AS SUBSTANCE ABUSE, SMOKING AND OVEREATING. IT OVERWHELMED PEOPLE'S ABILITIES TO CONTROL THEIR EMOTIONAL RESPONSES AND RESULTED IN INCREASED VIOLENCE, DEPRESSION AND, ESPECIALLY, ISOLATION.

JUST CHECK THE CORNER NEWSSTAND TO WITNESS THE BREAKDOWN IN 9/11 VICTIMS' COPING ABILITIES: POLICEMEN SETTING BOMBS IN TRAIN STATIONS, FIREMEN BRAWLING WITH CHAIRS, VOLUNTEERS ROBBING BANKS, DWI'S, EXTRA-MARITAL AFFAIRS.

PEOPLE IN NEW YORK ARE STRATCHING THEIR HEADS AND WONDERING, WILL IT EVER END?

WE'RE HERE TO TELL YOU, FROM A MENTAL HEALTH STANDPOINT, THAT THIS IS JUST BEGINNING.

IN NEW YORK, 9/11 WAS A MUSHROOM CLOUD WHOSE FALL-OUT IS JUST NOW MAKING ITSELF KNOWN.

MY NAME IS DR. MICHAEL LONSKI, AND I AM A CLINICAL PSYCHOLOGIST AND CO-FOUNDER OF LIFE MATTERS. WITH ME TODAY ARE DR. EVELYN LLEWELLYN, A CLINICAL PSYCHOLOGIST, CO-FOUNDER AND EXECUTIVE DIRECTOR OF LIFE MATTERS. STEPHEN CAREAGA, EXECUTIVE DIRECTOR OF FIREFIGHTERS NATIONAL TRUST, WHO SO GENEROUSLY UNDERWRITES MUCH OF OUR FIRE UNION-ENDORSED WORK WITH ACTIVE AND RETIRED FIRST RESPONDERS AND FAMILIES IN THE FIRE DEPARTMENT OF THE CITY OF NEW YORK. AND BOARD MEMBER LOU CHINAL, A 9/11 SURVIVOR WHO RETIRED FROM THE FDNY AFTER 29 YEARS AND WHO GUIDES AND SERVES US.

LIFE MATTERS IS A NOT-FOR-PROFIT ORGANIZATION CREATED TO MEET THE URGENT NEED FOR COUNSELING-OUTREACH AND CRISIS-INTERVENTION FOLLOWING 9/11.

WE TEACH PEOPLE TO UNDERSTAND, COPE AND ULTIMATELY HEAL THEIR TRAUMA. WE HAVE "EMBEDDED" CLINICIANS IN FIREHOUSES AND SOCIAL NETWORKS -- GIVING US THE UNIQUE ABILITY TO QUICKLY FIND AND HELP PEOPLE BEFORE THEY TAKE ACTIONS THAT HARM THEMSELVES OR OTHERS.

WE HAVE HELPED MORE THAN 30,000 PERSONS REMAIN HEALTHY, PRODUCTIVE AND INVOLVED ON THE JOB AND IN THEIR LIVES SINCE THE TERROR ATTACKS. WE CONTINUE TO SERVE AN ESTIMATED 15,000 NEW YORKERS A YEAR.

LET ME PUT THOSE NUMBERS IN PERSPECTIVE FOR YOU.

THE RED CROSS AND NYS PSYCHIATRIC INSTITUTE ESTIMATE THAT THERE ARE BETWEEN 125,000 AND 150,000 MANHATTAN RESIDENTS WHO HAVE FULLY DIAGNOSABLE POST TRAUMATIC STRESS DISORDER, OR PTSD.

MT. SINAI RESEARCHERS WORKING WITH GROUND ZERO WORKERS SAY MORE THAN 40 PERCENT ARE SUFFERING FROM MENTAL HEALTH ISSUES.

A RECENT STUDY BY THE SMITHERS INSTITUTE AT CORNELL'S SCHOOL OF INDUSTRIAL AND LABOR RELATIONS FOUND SIGNIFICANT EVIDENCE OF CONTINUEDDEPRESSION, STRESS, ANXIETY AND GRIEF – AND AN INCREASED RISK FOR DRINKING PROBLEMS -- AMONG ACTIVE FDNY MEMBERS POST-9/11.

SO IN THREE YEARS WE'VE REACHED BARELY 20 PERCENT OF THOSE WHO NEED OUR HELP.

LET ME EXPLAIN WHAT SOMEONE SUFFERING FROM POST-TRAUMATIC STRESS GOES THROUGH, AND WHY THIS IS A PROBLEM FOR US ALL.

PTSD SUFFERERS MOVE ON A VERY PREDICTABLE COURSE FROM SHOCK TO UPSET TO DYSFUNCTIONALITY.

KEY TO THEIR TRAUMA IS THE PERCEPTION THAT THE WORLD IS NOT A SAFE PLACE, AND THAT THOSE IN CHARGE OF PROTECTING US HAVE FAILED TO DO SO.

THEY ARE CONTINUALLY FLOODED WITH UNINVITED THOUGHTS, FLASHBACKS, DAYDREAMS AND REVERIE, NIGHTMARES AND NIGHT TERRORS.

EVERYTHING BEGINS TO LOOK LIKE A THREAT. TO PROTECT THEMSELVES, THEY WITHDRAW EMOTIONALLY, BUFFER OR MEDICATE THEMSELVES OR ACT OUT. THEY ENGAGE IN NEGATIVE BEHAVIORS TO FEEL GOOD, TO FEEL ALIVE -- OR SIMPLY TO FEEL ANYTHING AT ALL.

THEY BECOME SO PREOCCUPIED WITH WARDING OFF REMINDERS THAT THEY LOSE THEIR PERSPECTIVE OF RIGHT AND WRONG.

THEY FAIL TO DISCRIMINATE BETWEEN EXTERNAL AND INTERNAL TRIGGERS.

THEIR JUDGMENT BECOMES IMPAIRED.

ANYONE SUFFERING FROM PTSD CAN BECOME A TIMEBOMB.

THEIR EXPLOSIONS AND IMPLOSIONS ROCK US ALL.

SUICIDE. DOMESTIC VIOLENCE. MURDER. DIVORCE. CRIMINAL ACTIVITY. INAPPROPRIATE SEXUAL ACTIVITY. FEARED AND ACTUAL DEBILITATING DISEASE AND PREMATURE DEATH.

THE LOSS OF THE TALENTS AND CONTRIBUTIONS OF PEOPLE WHO WERE OTHERWISE VITAL AND VALUED MEMBERS OF OUR SOCIETY.

THAT TRAGEDY ENVELOPS SPOUSES, CHILDREN, FAMILY AND FRIENDS.

AND THE CYCLE OF TRAUMA, GRIEF AND LOSS IS THEN RENEWED. WE LOSE ANOTHER GENERATION AND TERROR WINS; NO FURTHER ATTACKS, JUST COLLATERAL DAMAGE FROM THE ORIGINAL IMPACT.

THOSE IN NEED MUST UNDERSTAND THAT HELP IS AVAILABLE AND SELF-HELP IS POSSIBLE.

THOSE IN POWER MUST COMMIT THE RESOURCES REQUIRED TO PREVENT WHAT UNIFORMED FIRST-RESPONDERS CALL A "BLEVE" (BOILING LIQUID EXPANDING VAPOR EXPLOSION) -- OR BE PREPARED TO SUFFER IN THE FALLOUT.

WE MUST REBUILD VICTIMS' TRUST.

HELP THEM RE-CONNECT WITH THE WORLD.

IN OUR WORK WE CONTINUE TO FIND WAYS TO RESPECT PEOPLE'S PRIVACY AND INTEGRITY WHILE REACHING THROUGH THEIR SELF-PROTECTIVE ISOLATION.

THROUGH FLEXIBLE, TESTED AND TRUE, THEORETICALLY BASED PRO-ACTIVE OUTREACH, EDUCATION AND SUPPORT WE WALK WITH THEM TO PATHS OF HEALTH, RESILIENCY AND HOPE.

AT ISSUE IS NOT JUST ONE MAN'S UNEASE, BUT A FAMILY'S ABILITY TO FUNCTION AND ULTIMATELY, SECURITY FOR US ALL.

LIFE MATTERS, INC.
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Dr. Evelyn Llewellyn

Co-Founder and Executive Director

In her work with victims of the 9/11/01 terrorist attacks and other deeply traumatic events, Dr. Llewellyn has helped thousands of families to identify, understand and cope with overwhelming stress, grief, anxiety and depression, and to regain emotional well-being even in the midst of crisis.

She is co-founder and Executive Director of Life Matters, a non-profit organization that teaches rescue, recovery and reconstruction workers and their families to find the internal and community resources to heal themselves and their families after disasters, and how to prepare for the possibility of future trauma. Life Matter's educational programs uniquely teach ***resiliency,*** the ability to recover after a stressful encounter and to make quick adjustments through coping; and ***hardiness,*** the capacity to continuously rise to life challenges and turn stressful experiences into opportunities for personal growth.

Life Matters works extensively with the Fire Department of the City of New York, which lost 343 members in the 9/11 attacks. A recent Cornell University study found that even three years after 9/11 City firefighters continue to struggle with significant amounts of stress, anxiety and trauma that to varying degrees impact upon their ability to function personally and professionally. Dr. Llewellyn's work focuses on mitigating the effects of this stress on first responders' wives, children and other family members who worry for their loved ones' safety while bearing the burden of holding the family together physically, emotionally and financially in the face of continuing stress.

In her outreach and education work, Dr. Llewellyn too often sees these family members – mostly women – grappling with debilitating illnesses, reactivation of terminal illnesses in remission, depression, sleeplessness, inability to concentrate, anxiety attacks, unexplainable aches and pains and, increasingly, negative coping behaviors including substance abuse and overeating. Their children are in some cases experiencing both behavioral and academic difficulties in school. She's seen these families struggle with DWI arrests, domestic violence, extramarital activities, emotional withdrawal and other negative behaviors, without understanding that help is available and self-help is possible. In the three years since its founding, Life Matters has become the trusted friend to thousands of first responder families throughout metropolitan New York.

Their extraordinary access among a population that traditionally shuns therapeutic interventions has won the praise and support of US Senator Charles Schumer, Congressman Jerrold Nadler, Congressman Christopher Shays, Congresswoman Carolyn Maloney, Assemblyman Joseph Lentil Clark and many others. As such, Dr. Llewellyn has been invited to testify on the mental health impact of 9/11 before the US Congressional Subcommittee on National Security, Veterans Affairs and International Relations in Washington DC on the eve of the third anniversary of the terrorist attacks.

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The Life Matters program is endorsed by the Uniformed Firefighters Association (UFA), which has tapped Dr. Llewellyn to help them to create an employee assistance program that addresses the unique needs for psychological and emotional support for firefighter wives and family members. The organization is supported by the New York State Crime Victims Board through US Department of Justice funds, Pfizer's Zoloft brand and by Firefighters National Trust, which provides relief for families of fallen firefighters.

In addition to her work with the UFA, Dr. Llewellyn has instrumental in creating a broad network of linkages with other counseling, outreach and support groups including the New York Disaster Counseling Coalition; the Mental Health Association- Life Net; The Coalition of 9/11 Families; September 11th Widows and Victim's Family Association; Clergy Crisis Responders; Ground Zero Fellowship; St. Vincent's Medical Center; Red Cross; City Crisis Team of New York; and Samaritans. In collaboration with the Lutheran Family and Community Services New Life Center, Life Matters has created a unique outreach program to serve the quickly growing but linguistically isolated Fujiansese population in Chinatown. The Chinatown Youth Leadership program trains high school students to identify key indicators of distress in their family, friends and neighbors and to connect them – and translate on their behalf – with social and medical services. The youth are all members of the growing Fujianese immigrant population whose dialect, Fuzhou, is not widely spoken even in Chinatown, and certainly not by mental health, physical health or social service providers.

As a result of her May 2004 presentation to 650 Critical Incident Uniformed and Civilian First Responders at the German Federal Congress of Emergency and Fire Chaplaincy and Crisis Intervention in Frankfurt, we are pursuing an international exchange of lessons learned and educational programs between American and German first responders.

A licensed psychologist in New York State, Dr. Llewellyn is a graduate of New York University's School of Education, Health and Nursing Professions and holds postgraduate certifications in Adult Psychotherapy and Psychoanalysis; in Eating Disorders from the Institute for Contemporary Psychotherapy; and in Critical Incident Stress Management.

For the last 25 years, Dr Llewellyn has worked in a multitude of settings with individuals from 18 months through 100 years of age. She has counseled children, adolescents, families and the elderly who have experienced traumatic and violent loss. In addition, she has worked with individuals experiencing learning problems, gender-identity issues, eating disorders and substance abuse.

She co-founded Life Matters in 2001 as a 501(c)(3) organization to provide and promote prevention and treatment of illnesses related to psychological and medical trauma, grief and loss. In her role as Executive Director she oversees the management of the organization and its implementation of key grants. Additionally, Dr. Llewellyn facilitates awareness and support efforts to the wives, children and families of first responders.

Dr. Llewellyn also is President of Shore Psych Solutions, which was awarded a method/process patent in May 2001 for a clinical documentation tool that is currently being adapted for handheld use by clinicians/peers and outreach workers in emergency response settings.

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Health. Resiliency. Hope.

Michael W. Lonski, Ph.D.

Co-Founder, Director of Training and Program Development

Psychologist Dr. Michael Lonski co-founded Life Matters as an outgrowth of his work with uniformed and civilian first responders after 9/11. He has emerged from his intensive work at Ground Zero, in firehouses and at fire scenes throughout the New York metro area as a recognized authority in Critical Incident Stress Management (CISM), Post Traumatic Stress Disorder (PTSD) and disaster response.

Dr. Lonski has served as a consultant to the Fire Department of the City of New York (FDNY) in implementing a pro-active model of mental health outreach, education, interactive stress management support and referral services. After 9/11 he was assigned to the FDNY Special Operations Command (SOC) and four impacted fire houses that together lost 103 or 30 percent of the 343 fire fighters who died in the World Trade Center attacks. He has been among the only psychologists to experience and share the realities of the rescue workers from the day the towers collapsed through the recovery efforts and at subsequent anniversaries and critical incidents. In the course of this work, he earned certification as a Level 1 HazMat Technician, enabling him to better understand firefighters on hazardous duty. Further, he is trained in Traumatic Stress Management and is an approved instructor with the International Critical Incident Stress Foundation for teaching Individual and Peer Crisis Intervention programs.

In his role as Director of Training and Program Development for Life Matters, Dr. Lonski is responsible for outreach, training and development and implementation of educational, self-help and intervention programs. In addition to Life Matter's signature resiliency program, The Psychological Third Alarm, a Uniformed Firefighters Association (UFA)-recognized program of mental health preparedness for first responders that is largely underwritten by Firefighters National Trust, Dr. Lonski has worked with the City of New York Employee Assistance Program, municipal and labor unions and the NYS National Guard to develop and train their workforce in a comprehensive crisis management and grief-counseling program.

He was instrumental in creating a Youth Leadership outreach program in Chinatown, which was heavily impacted by 9/11 and whose residents faced linguistic and cultural barriers to the delivery of mental health services. Teaming with the Lutheran Family and Community Services New Life Center, Life Matters trains youth leaders to identify key indicators of distress in their family, friends and neighbors, and to connect them – and translate on their behalf – with social and medical services. The youth are all members of the growing Fujianese immigrant population whose dialect, Fuzhou, is not widely spoken even in Chinatown, and certainly not by mental health, physical health or social service providers.

As a result of his May 2004 presentation to 650 Critical Incident Uniformed and Civilian First Responders at the German Federal Congress of Emergency and Fire Chaplaincy and Crisis Intervention in Frankfurt, we are pursuing an international exchange of lessons learned and educational programs between American and German first responders.

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Dr. Lonski was instrumental in forging collaborative relationships with New York Disaster Counseling Coalition; the Mental Health Association- LifeNet; The Coalition of 9/11 Families; September 11th Widows and Victim's Family Association; Clergy Crisis Responders; Uniformed Firefighters Association (FDNY), Lutheran Family and Community Services New Life Center; Ground Zero Fellowship; St. Vincent's Medical Center; Red Cross; Safe Horizon; City Crisis Team of New York; and Samaritans.

Further, Dr. Lonski has served as an advisory and trusted resource for NYS National Guard; the Stamford, CT Fire and Rescue Service; and the Federal Defender Office, District of Connecticut in New Haven, CT. He has been invited to testify on the on-going health effects of 9/11 before the US Congressional Subcommittee on National Security, Veterans Affairs and International Relations in Washington DC on the eve of the third anniversary of the terrorist attacks. He has been asked to contribute lessons learned to a book, edited by Dr. Yael Danieli of the International Society for Traumatic Stress Studies and Robert L. Dingman of the American Red Cross, entitled: *On the Ground After September 11:Mental Health Responses and Practical Knowledge Gained.* He is currently advising the Uniformed Firefighters Association (UFA) in creating a member assistance program that incorporates proactive mental health outreach and psychological preparedness for New York City firefighters.

He co-founded Life Matters in 2001 as a 501(c)(3) organization to provide and promote prevention and treatment of illnesses related to psychological and medical trauma, grief and loss. The organization is supported by the New York State Crime Victims Board through US Department of Justice funds, Pfizer's Zoloft brand and by Firefighters National Trust, which provides relief for families of fallen firefighters.

Dr. Lonski is a clinical psychologist licensed in the states of New York and Connecticut. He holds post-doctoral certification from NYU in Adult Psychotherapy and Psychoanalysis and from the Post-Graduate Center for Mental Health in Child and Adolescent Therapy and Analysis. For more than 20 years he has served as an organizational consultant and facilitator in hospital, day-treatment, private school and geriatric settings, and as counselor, coach and assessment consultant to Fortune 500 Employee Assistance Programs.

As Vice President of Shore Psych Solutions, Dr. Lonski was awarded a method/process patent in May 2001 for a clinical documentation tool that is currently being adapted for handheld use by clinicians/peers and outreach workers in emergency response settings.

Mr. SHAYS. Thank you.

Dr. Melius, you have a very long statement. I will be crushed if you don't get to your recommendations, so don't play a trick on me and use up all the other time and force me to not let you do your recommendations. I want to hear every one of your recommendations. Don't leave them out.

Dr. MELIUS. As I have been sitting here, I have been planning to skip most of the beginning of the statement and go directly to the recommendations.

Mr. SHAYS. We really appreciate your recommendations. Very helpful.

Dr. MELIUS. Thank you for holding this hearing and for your continued interest in this issue. I think it is important. Clearly in the absence of anybody at the Federal Government level, the agencies being in charge, it is a badly needed function. I really do applaud you for making this effort.

I represent people in the construction industry working for the laborers' union in New York. Throughout the country, I also work with our international union. I have also served many years as an advisor for the firefighters union around the country and have experience in dealing with other emergency incidents with them.

My testimony covers the involvement of the construction workers, what our exposures were, what some of our concerns were. As I said, I will skip that and go to the recommendations.

Mr. SHAYS. Your full statement will be in the record.

Dr. MELIUS. I would like to say that one thing that was very important to us as a resource in New York that without would have been a bigger problem to address and that was Mount Sinai Hospital. They really had the expertise and the capability to be of great assistance while these programs were being set up. We were able to refer many people there for treatment.

In my statement, I made six recommendations. I will go through each. They deal with both the World Trade Center medical followup as well as with followup for other incidents.

The first repeats a point that I think you already made. We need a comprehensive and rapid medical response for these types of incidents. We can't wait a year or two to get a program in place. We need to have people in a coordinated fashion there immediately. We need them there because we can't expect local governments, local construction companies, local agencies to have the expertise, the resources and the capabilities to deal with it. This needs to be set up and included in planning efforts for future disasters.

That program can't wait 2 years for setting up a medical program or a year. It needs to be set up as quickly as possible and needs to think about the need for monitoring. The issue Congressman Nadler raised, we need and should have had and in future incidents we need comprehensive environmental sampling that will think about the possible health risks for people involved. It is needed to help protect them and needed to be able to address who is at risk, what type of future medical programs do we need for those who have been exposed.

In my testimony, I mentioned some of the frustrations at the time in dealing with both this incident and getting environmental data, as well as with the simultaneous efforts going on with the an-

thrax incidents where people in the medical community or in my case representing workers involved, where it was very frustrating to figure out who to call to get information. That needs to be developed immediately after these incidents.

Three, we also need to recognize these programs need to go on for a long period of time. As I mentioned, I previously worked for both Federal and State Government and have been involved in other incidents usually involving fire departments and response to toxic exposure. One was the Elizabeth chemical control fire in New Jersey across from New York over 20 years ago where there was an immediate response but then nothing was done long term for the people involved.

It is difficult to budget that, to estimate what kind of resources may be needed but we have to have a mechanism in place whether through Homeland Security in these instances, through Health and Human Services, I don't know but there should be a program place that can fund those programs over the long term, provide the support and guidance needed to implement that type of program.

I think we have already heard some of the problems because people develop programs in response to the resources that were available rather than to projected needs. Because of that, we may never know the number of people that were affected or will be affected from the World Trade Center. This has to be done up front. People have to know full resources will be available.

That program has to also be comprehensive and include everyone. We can't make arbitrary decisions based on a street, where people worked on a site, whether they worked or whether they were a member of the general public that were exposed. It may take some time to sort out, some people may need different amounts of medical followup to different degrees but we need to have that comprehensive program in place that covers everybody.

My fifth recommendation is that we need to think about the future rights of these people. They need to be protected. This addresses issues related to the workers compensation. A lot of concern about the reluctance of our members and other union members to participate in the registry programs, is because we don't feel the rights of our members are being protected and some of that information may be used against them 10 years from now.

Mr. SHAYS. Give me a short example of how information can be used against you.

Dr. MELIUS. For example, if someone does an analysis of that data, especially given how incomplete it is, it only covers such a small number, and there is a report that says we found in a certain subpopulation no health effects.

What if one of our members who could fit the definition of that subpopulation applies for workers compensation? Their employer or insurance company may use the information in that registry to contest that claim. Also, it is not completely clear how their privacy will be protected in that registry.

Will somebody be able to go in and get information on them and other participants and somehow use that to discriminate against them in some way? We are particularly sensitive to that given some of the problems with the workers compensation system in New York as well as other States.

At the same time, it is important that we assure people there is a long term, comprehensive, compensation program for them. I applaud what you have done so far.

Finally is the treatment issue. The programs put in place must include more work on treatment. There needs to be resources for people to get treatment as well as some medical research and effort made to try to determine what are the best treatments. We don't know that for some of the conditions related to the World Trade Center. We need to learn more about that and provide resources.

In Mount Sinai and the other programs we are doing an excellent job of referring people but not everyone has complete health insurance, not every physician is as familiar with what kinds of treatment might be needed and there are limitations. People aren't getting the treatment they need because of that. I think that is a disservice to them.

Thank you. I will end there and be glad to answer questions.

[The prepared statement of Dr. Melius follows:]

COMMITTEE ON GOVERNMENT REFORM

SUBCOMMITTEE ON NATIONAL SECURITY,

EMERGING THREATS, AND INTERNATIONAL

RELATIONS

PUBLIC HEARING

SEPTEMBER 8, 2004

"ASSESSING SEPTEMBER 11TH HEALTH EFFECTS"

TESTIMONY OF

JAMES MELIUS, MD, DRPH

ADMINISTRATOR

NEW YORK STATE LABORERS
HEALTH AND SAFETY TRUST FUND

Thank you for the opportunity to testify to the subcommittee today. I am James Melius MD, DrPH, an occupational physician and epidemiologist. I currently work as the administrator for the New York State Laborers' Health and Safety Trust Fund and as Research Director for the Laborers' Health and Safety Fund of North America. Both of these organizations are joint labor management funds dedicated to improving the health and safety of construction laborers. Our union (the Laborers International Union of North America) represents hundreds of construction workers who worked at or around the World Trade Center site in the aftermath of September 11. Prior to working for these organizations, I spent many years working in occupational and environmental health for the National Institute for Occupational Safety and Health and for the New York State Department of Health. I have also served for over 20 years as Chair of the Medical Advisory Board for the International Association of Fire Fighters. Much of my professional career has involved evaluating the effects of toxic exposures related to emergency response situations. I have also acted as Chair of the Steering Committee for the World Trade Center Medical Monitoring program.

My testimony today will concern the medical follow-up of construction laborers and other workers involved in the response at the World Trade Center starting on September 11, 2001. As is well known, immediately after the collapse of the World Trade Center Towers, hundreds of construction laborers and other construction workers made their way to the World Trade Center site volunteering their skills to assist with the rescue effort. Like the many other rescue personnel at the site, these workers were exposed to the smoke, fumes, and toxic chemicals present in the air around the site. Many of these workers spent long hours at the site without the benefit of any respiratory protection.

Over the next several days, rescue and recovery work at the site was organized with four major construction contractors becoming responsible for different areas at the site, and procedures were developed to organize the removal of the material at the site. Hundreds of union construction workers were brought in to work at the site. Most were from the New York Metropolitan area, but some were from nearby states. Fire fighters and other rescue personnel continued to be present at the site to aid in the recovery of bodies.

Construction companies and their unions developed procedures to outfit the workers with respiratory protective equipment. These efforts took time, and due to the environmental conditions at the site and the difficulty of many of the tasks that needed to be done, it was often not possible for the workers to utilize the protective equipment at all times especially in the first few weeks after September 11. As a result, hundreds of construction workers continued to be exposed to the toxic materials in the air at the WTC site.

In addition to the work at the World Trade Center site, there was much other construction activity in the area around the World Trade Center. Nearby buildings were contaminated with dust and debris from the site. These offices and residences needed to be cleaned. There was much confusion about how stringent that clean up needed to be. This confusion and the lack of responsiveness by the responsible government agencies lead to unnecessary confusion and an unfair burden on the building owners and occupants. In some cases, the clean-ups were handled as asbestos abatement projects with stringent protection required for the workers while in other similar situations, the clean-ups were handled with minimal precautions potentially exposing the clean-up workers and building occupants to toxic materials present in the dust from the WTC collapse.

Our union and the other construction workers at the WTC site in cooperation with the construction contractors set up programs to provide medical evaluations and fit testing for respiratory protection for workers at the site. Throughout the first few months, we also had a staff member present at the site to monitor health and safety issues and address the health and safety concerns of our members. While this program addressed protection at the site, the program did not take care of workers who became ill because of exposures at the site. For this, we were fortunate to have a readily available resource with outstanding clinical expertise in occupational medicine at Mt. Sinai Hospital. Their occupational health clinic funded through New York State provided a place to refer our members who became ill at the site. We made many referrals to their occupational health clinic where our members received excellent medical evaluations and follow-up.

However, as Dr. Levin has already noted, Mt. Sinai was under great strain to respond to the many health issues related to the WTC. Mt. Sinai did not have the capacity nor the funding to respond to all of the people from the site who needed follow-up care. There were also many questions about the health effects from exposures at the site. What type of health problems might result from the exposures? Were there long-term health risks such as cancer? What we knew about exposures at the WTC site and about the type of work that construction workers were performing at the site indicated that there were very legitimate concerns about health risks. A long-term medical monitoring program needed to be implemented for this population.

Fortunately, the government, especially Congress, recognized this need, and funding for the medical screening program was made available. Later, additional funding for a longer-term program was also appropriated. Hundreds of fire fighters, construction workers, and other workers exposed at the site have participated in the screening program. The results available from the program to date (as summarized by Dr. Levin) underline the importance of the program for the long-term health of these people. We must provide long-term medical monitoring for them.

In addition to the medical health issues, the mental health of this population also needs to be addressed. Construction workers responding to the site were not used to working at a site where dead bodies or body parts might be discovered at any time. Witnessing the collapse of the building was traumatic for many who then responded by coming to the site to participate in rescue efforts. The psychological stress of working at the site was obvious to anyone who spent time there. Through various volunteer and professional groups, counseling was made available to people working at the site, and many of our members utilized these services. However, there may also be long-term consequences from this psychological distress. Follow-up is necessary to ensure that those experiencing longer-term difficulties are recognized and referred to proper care. This aspect has been incorporated into the medical follow-up program.

Although not directly related to the World Trade Center incident, our union members were also involved in responding to the anthrax contamination problems in the months after September 11. Members of our union decontaminated many of the buildings that were contaminated. Their possible exposures raised some questions about medical follow-up for terrorist incidents that will the basis for the recommendations that are outlined below.

Our members are very appreciative about the federal funding and assistance for the medical screening and monitoring programs for the World Trade Center workers. **This medical monitoring addresses an important medical need for these workers related to their exposures at the site that would not be adequately addressed without this program.** The National Institute for Occupational Safety and Health is doing an excellent job in overseeing the program. Mt. Sinai, the New York City Fire Department Medical Program, and the other medical centers involved in the program are all doing an outstanding job in providing expert medical and mental health monitoring of this population.

However, I have several recommendations to improve this program and future medical programs in response to similar incidents should they be necessary.

1. **We need the capability for a comprehensive and rapid medical response for workers responding to terrorist incidents.** We cannot afford to wait while the involved federal agencies decide which agency should bear the responsibility for providing a medical response, what type of procurement is needed, where is the funding coming from, etc. We cannot expect the local fire departments, construction contractors, and local government to bear the burden for developing and funding these programs. The terrorist disaster planning being done under the new Department of Homeland Security should have the overall responsibility, but the expertise of federal agencies such as NIOSH should also be involved.

2. **This national program must include an immediate medical response to address acute medical issues and to ensure that toxic exposures for these workers are identified and monitored.** This work site monitoring needs to be coordinated with environmental and public health agencies to ensure that the public and the involved workforce receive comprehensive and accurate information and advice on possible exposures from a terrorist incident. Access to appropriate medical information is also needed. I was very frustrated in the anthrax incidents to trying to find out about the availability of the anthrax vaccine and about certain medication recommendations for our union members who were involved in decontaminating buildings where anthrax spores had been released. Physicians and other health personnel should be able to rapidly consult with knowledgeable authorities about diagnostic and treatment issues.

3. **We must recognize that the medical programs for monitoring these workers and workers involved in future incidents must be supported for long time periods.** Health effects may not occur until many years after the incidents. Workers responding to these incidents must be reassured that their long term health concerns will be addressed. We will need more funding to extend the World Trade Center program over the many years that health effects may occur. We also need the flexibility to adjust the program over time. The components of the program will need to be adjusted, and it is very difficult to evaluate what future medical testing is appropriate for these populations. In the steering committee for the current medical monitoring program, we have struggled to develop a comprehensive program within the current budget limitations especially not knowing to what extent future funding will be available.

4. **The programs should include all workers exposed in the incident, and similar programs should be available for the exposed general public.** Although the World Trade Center program has been flexible in accommodating the workers who were exposed because of the World Trade Center incident, it is important to

note that many more workers were exposed than originally estimated. I was surprised by the large number of municipal and other workers who were assigned to duties immediately after September 11 that exposed them to smoke and dust from the site. People working or living in nearby buildings and students in buildings in the area were also exposed. The health needs of these people need to be addressed.

5. **Future rights for the participants need to be protected.** We have been fortunate with the program at Mt. Sinai in having a medical center that our members trust for its competent care for people with possible work-related illnesses. For the screening and monitoring programs, NIOSH, Mt. Sinai, and the other involved institutions have taken steps to involve representatives of the participating groups in the development and implementation of the program. Confidentiality and other issues are important to ensure that the rights of these workers are protected. For the participants that may develop an illness related to the WTC incident many years from now, we must be able to ensure them that their future rights to appropriate compensation are protected.

6. **We need to provide support for the treatment of workers that have developed an illness or will later become ill because of their WTC exposures.** We need more research on the respiratory and other illnesses that have become recognized among these workers. We also need funding for their treatment. The Workers Compensation Program in New York and other states does very poorly in providing support for occupational illnesses especially in the early stages of disease development. It may take months simply to get approval for payment for a medical test to evaluate the person's illness. Direct funding should be made available to support treatment, and more funding should be directed to research on the treatment of these illnesses.

In conclusion, I would like to thank the Chair and the Subcommittee for holding this hearing and for their continued interest in this subject. Many of our members rushed to the World Trade Center site immediately after the building collapse to assist with rescue and recovery efforts. They continued to work long hours at the site despite the very difficult working conditions. None of them thought about the long-term health consequences. If necessary, they would do the same thing again. However, now that the incident is past, they have legitimate reasons to be concerned about their health. I believe that they deserve a comprehensive, high quality, long-term medical program that addresses these concerns.

I would be glad to answer any questions.

Mr. SHAYS. Thank you very much.

Mr. Mark.

Mr. MARK. I would like to start with my recommendations.

My clients at the Asian American Legal Defense Fund as well as many of the community people I work with support the "Remembering 9/11 Health Act" and the fact that it would cover many of the people in the lower East Side and Chinatown who are without insurance or don't have the right insurance coverage. We feel that particular legislation should be passed.

In addition, I think it also addresses some of the concerns raised in the previous panel about coordinating efforts. One of the problems we had in my office was we believed that the funding for Mount Sinai would cover treatment as well but we understand that it did not. When we heard that, we felt it really undercut our efforts to try to get funding for our joint clinic work with many of the organizations and specifically partnering with Bellevue Hospital to address the health needs of people in the lower East Side and Chinatown.

I would also mention that at this point we are now engaged in this joint clinic. We can't wait for that coordination to take place, we can't wait for that funding to take place, so in the last 4 months or so, we have been going through 400 apartments and visited 400 families, we have done outreach tables in the summer months reaching thousands of people, trying to get people who were harmed by September 11 to participate in this clinic program. We have now booked many appointments for people to be screened and treated at Bellevue Hospital at the Asthma Center. There is at least a month's waiting list.

I am bringing this up as a point that studying the health impact shouldn't be limited to Ground Zero but that they extend way beyond Ground Zero and include communities of color in the lower East Side and Chinatown which have not gotten sufficient resources when it comes to health care.

My office is a civil rights organization. We represent many garment and restaurant workers on the Lower East Side and Chinatown who work in sweatshops. We also represent people who are South Asians and Muslims, who have been denied due process after September 11, and who have been detained preventatively and secretly. We also have had work in voting rights and on a weekly basis, we register people to vote at the courthouse, about 300 people every week, who are sworn in as new, citizens are registered to vote.

Since the September 11 attack, our Federal and local agencies have not fully addressed the public health emergency resulting from the collapse and fallout from the World Trade Center. Lower Manhattan residents in the neighborhoods adjacent to Ground Zero and surrounding areas such as Chinatown and the lower East Side witnessed the attack and now live and work in buildings that are contaminated or recontaminated with asbestos, mercury, lead, dioxin and other toxic compounds. Many have respiratory ailments and lung damage, skin rashes, gastronomical disorders and other illnesses, or express anxiety about their health and the health of their children. Many are under the care of doctors while others liv-

ing east of Ground Zero are still seeking health coverage and medical treatment for these illnesses.

Federal resources for treatment and long term studies must be made available immediately to address the unmet health needs of thousands of people who live and work in lower Manhattan. Furthermore, resources must be made available to strengthen the public health infrastructure in order to meet the threat of chemical or biological attacks such as anthrax.

The full scope of the public health emergency and the resulting environmental health impact have not been adequately addressed and acknowledged by the Federal and local government agencies. Government agencies did not conduct representative sampling which uses detection devices laid out in concentric circles from Ground Zero to collect air, dust and water samples to measure the fallout, its range and to gather data.

The Center for Disease Control did not issue health advisories urging health professionals to look out for the symptoms of illnesses resulting from the fallout. For months, the dust and stench filled the air throughout lower Manhattan and seeped into the homes and offices, factories and businesses. Trucks hauled debris from the fire at Ground Zero.

These trucks and dumpsters were parked on the streets on the lower East Side and Chinatown, along Henry, Clinton and Jefferson Streets and behind Stuyvesant High School. The debris was eventually hauled to the Freshkills Landfill. The World Trade Center dust circulated in the air and was blown throughout lower Manhattan and continued to make people sick. People who live and work in the buildings located in Battery City, John Street, Cedar Street, Liberty Street, Pearl Street and downtown Broadway have testified at public forums and hearings about their poor health and the lack of adequate testing and cleanup.

These residents continue to struggle with government agencies to test and clean their buildings still contaminated with dangerous heavy metals and toxic compounds that remain or spread through heat and air conditioning systems, elevators, carpets, window ledges and other common areas. Recontamination remains a serious concern since the clean up 1 year after September 11 was at best incomplete. Without full participation and cooperation to clean an entire building, this leaves the distinct possibility that recontamination would occur, even assuming the initial cleaning for some apartments was properly done for part of the building.

During 2002, at community town hall meetings, rallies and marches in New York City and Washington, DC, thousands of Chinatown residents assisted by a group known as Beyond Ground Zero Network, which my office is part of, had demonstrated and demanded that health care coverage, medical treatment and research studies must be at the top of priorities for our government agencies and institutions committed to rebuilding New York. Health care must be made a priority with adequate resources to cover long term treatment and studies for all people affected by September 11 including residents of Chinatown and the lower East Side.

Government officials and agencies must be held accountable for the delay in initiating full health coverage, treatment and studies covering the residents of Chinatown and the lower East Side.

Given the wide scope of harm and the shortage of resources targeted for health care and the research studies covering people of color living in Chinatown and the lower East Side, we need a stronger commitment from our leaders and institutions to make these resources available.

[The prepared statement of Mr. Mark follows:]

TESTIMONY

TO SUPPORT

HEALTH CARE AND MEDICAL RESEARCH FOR

RESIDENTS OF LOWER MANHATTAN

SUBMITTED

TO

THE HOUSE SUBCOMMITTEE ON
NATIONAL SECURITY. EMERGING THREATS
AND INTERNATIONAL RELATIONS

ON

SEPTEMBER 8, 2004

BY

STANLEY MARK
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Good afternoon. My name is Stanley Mark and I am the program director and a staff attorney at the Asian American Legal Defense and Education Fund (AALDEF), a non-profit civil rights organization located 9 blocks north of Ground Zero. I am here today for my clients who live or work in lower Manhattan including Chinatown and the Lower East Side. According to the 2000 Census, about 156, 000 reside in Lower Manhattan. More than 84,000 reside in Chinatown. To our detriment most of us who live or work in Lower Manhattan relied on the statements of the Environmental Protection Agency that the air was safe when it was not. I want to note for the record that there is a continuing failure by EPA to provide adequate testing of all of lower Manhattan. More specifically, the data from 2 medical studies illustrates the health impact upon residents of Chinatown and the Lower East Side, many of whom live and work north of Canal Street and east of Essex Street where Canal Street ends. These health impacts must be considered in assessing the full impact of 9/11 and the allocation of health care resources.

Asian American Legal Defense and Education Fund (AALDEF)

Founded in 1974 as the first Asian American public interest legal organization on the east coast, AALDEF conducts impact litigation,

community education, and policy advocacy in the areas of civil rights, immigrant rights, labor and employment rights, and voting rights. AALDEF represents garment and restaurant workers challenging sweatshop conditions, victims of anti-Asian violence and police brutality, indentured servants seeking political asylum, and South Asians and Muslims detained indefinitely by the Bureau of Immigration and Customs Enforcement without adequate due process. AALDEF also conducts free legal rights clinics for immigrant families seeking legal advice on a range of immigration and citizenship matters. In addition, AALDEF has assisted thousands of persons in becoming U.S. citizens and registering them to vote once a week at the U.S. District Courthouse in Manhattan. My clients include family members who lost loved ones at the World Trade Center and immigrant families seeking relief assistance after the 9/11 tragedy. By the way, Canal Street was an arbitrary boundary set initially by every federal relief program; it was much later that these relief programs expanded eligibility criteria to include the needs of people who lived or worked north of Canal Street.

Background

Since the 9/11 attack, our federal and local agencies have not fully addressed the public health emergency resulting from the collapse and fallout from the World Trade Center. Lower Manhattan residents in the neighborhoods adjacent to Ground Zero and surrounding areas such as Chinatown and the Lower East Side witnessed the attack and now live or work in buildings that are contaminated or recontaminated with asbestos, mercury, lead, dioxin, and other toxic compounds. Many have respiratory ailments and lung damage, skin rashes, gastrointestinal disorders and other illnesses. All express anxiety about their health and the health of their children. Many are under the care of doctors while those living further east of Ground Zero are still seeking health coverage and medical treatment for these illnesses. Federal resources for treatment and long term studies must be made available immediately to address the unmet health needs of thousands of people who live and work in lower Manhattan. Furthermore, resources must be made available to strengthen the public health infrastructure in order to meet the threat of chemical or biological attacks such as anthrax.

Lower Manhattan Residents

The full scope of the public health emergency and the resulting environmental health impact have not been adequately assessed and acknowledged by federal and local government agencies. For example, government agencies did not conduct representative sampling which uses detection devices laid out in concentric circles from ground zero to collect air, dust, and water samples to measure the fallout and its range and to gather data. The Center for Disease Control did not issue a health advisory urging health professionals to look out for the symptoms of illnesses resulting from the fallout. For months, the dust and stench filled the air throughout lower Manhattan and seeped into homes, offices, factories, and businesses. Trucks hauled debris from the fire at Ground Zero. These trucks and dumpsters were parked on the streets of the Lower East Side and Chinatown (on and near Henry Street, Clinton Street, and Jefferson Street) and behind Stuyvesant High School before the debris was hauled to Fresh Kills, a city landfill. The Word Trade Center (WTC) dust circulated in the air and was blown onto and in some cases into buildings, factories, schools, and tenements throughout lower Manhattan and continue to make people sick.

People who live or work in the buildings located in Battery Park City, John Street, Cedar Street, Liberty Street, Pearl Street, and downtown Broadway have testified at public forums and at hearings about their poor health and the lack of adequate testing and cleanup. These residents continue to struggle with government agencies to test and clean their buildings still contaminated with dangerous heavy metals and toxic compounds that remain or spread through heat and air conditioning systems, elevators, carpets, window ledges, and other common areas. Recontamination remains a serious concern since the cleanup one year after 9/11 was at best incomplete. Without full participation and cooperation to clean an entire building, this leaves the distinct possibility that recontamination would occur even assuming that the initial cleaning for some apartments was properly done for part of a building. In too many instances, residential buildings were not cleaned properly and residues of toxic compounds or heavy metals remain to exacerbate existing health problems. Office buildings downtown were not cleaned since the responsibility for such cleaning was placed upon landlords, most of whom did not clean their office buildings.

After the Environmental Protection Agency (EPA) announced that the air was safe within a week of 9/11, a family of four who resided in Battery Park City since 2000 returned to their home which was covered with dust from the collapse of the Twin Towers. Despite cleaning their home with wet rags and other cleaning agents as recommended by the New York City Department of Health, the entire family had continuing bouts of asthma and bronchitis as well as skin rashes, none of which existed before 9/11.

A young garment worker who lives in an apartment on Mulberry Street just below Canal Street contracted asthma and nasal congestion after 9/11. She had cleaned her apartment which was contaminated with WTC dust while she was pregnant. Her factory closed after 9/11 since her employer lost contracts due to street closings. Her son born after 9/11 needs a small oxygen tank at home to help him breath at times. She now stays periodically with her mother who lives on Jefferson Street in the Lower East Side and is being treated at the Asthma Clinic at Bellevue Hospital.

An attorney at a federal agency located in the Woolworth Building on Broadway was ordered back to work within days after 9/11. Despite his protests about the corrosive air and dust, his office reopened. Since 9/11, he has contracted asthma, bronchitis, and now has permanent lung damage.

For several months, a retired couple living on Baxter Street, two blocks north of Canal Street, lived with a stench that originated from the burning debris at Ground Zero . They cleaned their apartment but never had their apartment tested nor did their landlord suggest it. They developed headaches and a hacking cough that lasted for several months after 9/11. They are more concerned about the long term health of their grown children who no longer live with them in Chinatown but who experienced similar coughing and headaches since 9/11.

A woman who lived in an apartment on John Street approximately one and a half blocks from the World Trade Center site developed a hacking cough with sinus problems since 9/11. Her apartment had a blanket of

WTC dust which was cleaned by a private contractor whose workers did not wear masks. She had reentered her apartment after the cleaning but moved to midtown due to her illnesses; she remains sick and continues to see doctors about her health problems.

A young woman living in Chinatown and working in an office building south of ground zero developed a painful cough and bronchitis which only subsided after she moved out of Manhattan after consulting with a doctor. Her coughing returned when she visited her family in Chinatown.

After 9/11, a former law student intern at AALDEF went door to door in several housing projects in the Lower East Side using his cell phone to assist residents who no longer had phone service for weeks after the attack at the World Trade Center knock out phone service. He also brought food and water to the elderly and disabled. Based on his visits, he informed me that most people living in the housing projects wanted and needed health care. Within a few days, he developed a hacking cough which persisted for almost a year. He continues to live in Queens but remains concern about his health.

A middle age man saw the the planes crash into the World Trade Center while downtown and wanted to volunteer at Ground Zero but he was turned back by fire fighters and police officers who closed the streets downtown. He later fled when the WTC collapsed and went to his Brooklyn home. He has developed nose and throat problems and has a raspy voice from coughing up phlegm. He continues to have skin rashes whenever he runs out of medication. He tells his granddaughter that he is unhappy and feels depressed. He is being treated at Bellevue Hospital.

These are only a few of the thousands of people whose health are at risk. Furthermore data from two health studies confirm that respiratory problems such as asthma increased due to poor air quality after 9/11. These studies suggest that the scope of the health impact reaches beyond Ground Zero into all neighborhoods of lower Manhattan including Chinatown and the Lower East Side.

Health Treatment and Studies Covering Chinatown and Lower East Side

Since 9/11, AALDEF has worked jointly with organizations in the Beyond Ground Zero Network including Chinese Staff and Workers Association, National Mobilization against Sweatshops, Urban Justice Center, and Workers Awaaz to assist thousands of residents affected by the 9/11 tragedy; many of whom were not within the initial geographical boundaries or formal eligibility guidelines of relief programs administered by the Federal Emergency Management Agency, Lower Manhattan Development Corporation, and other private relief organizations. AALDEF has worked to obtain health care coverage for many clients and to escort them, most of whom do not speak English, to medical clinics for testing and treatment. Recently, the Beyond Ground Zero Network has initiated a joint clinic at Bellevue hospital to test and treat our clients who wish to be patients and possible research subjects in order to study the environmental health impacts beyond ground zero. AALDEF clients who are residents of Chinatown and the Lower East Side are experiencing more respiratory illnesses and suffer from rashes attributed to the 9/11 attacks. A young woman who worked with me to assist many residents to navigate FEMA, LMDC, and Safe Horizon programs became ill repeatedly with a range respiratory

problems due to 2 years of exposure to post 9/11 dust and air found in clients' homes and in various offices in lower Manhattan. She has since moved out of New York City for both family reasons and in order to ease her asthma and hacking cough; however, she remains deeply concerned about the long term effects of the polluted air that she inhaled for months after 9/11.

In several conversations during the last two months, I spoke with Dr. Allan Tso, a physician at the Charles B. Wang Health Center (a/k/a the Chinatown Health Clinic) and a co-author of the study conducted by Stony Brook University School of Medicine and the University of Pittsburgh School of Public Health. (See Clinical Deterioration in Pediatric Asthmatic Patients after September 11, 2001, Journal of Allergy and Clinical Immunology, Szema et al., March 2004 at pages 420-426). Dr. Tso asserted that his study reveals a statistical significance of asthma warranting further research and study. Their data consist of pre and post 9/11 information derived from the records of 205 Chinese American children with asthma. These children who live within 5 miles of ground zero had to visit their doctors more often for treatment and had to take more medicines for asthma one year after the 9/11 tragedy than the year preceding the World Trade Center attack. Tests were conducted to measure the children's air flow from their lungs within three months after 9/11. The test results indicate that their airways were narrowed and supports the hypothesis that their asthma became more severe after the 9/11 tragedy. As a result, the scope of the health impacts should be assessed at least five miles out or where there is a drop off in asthma.

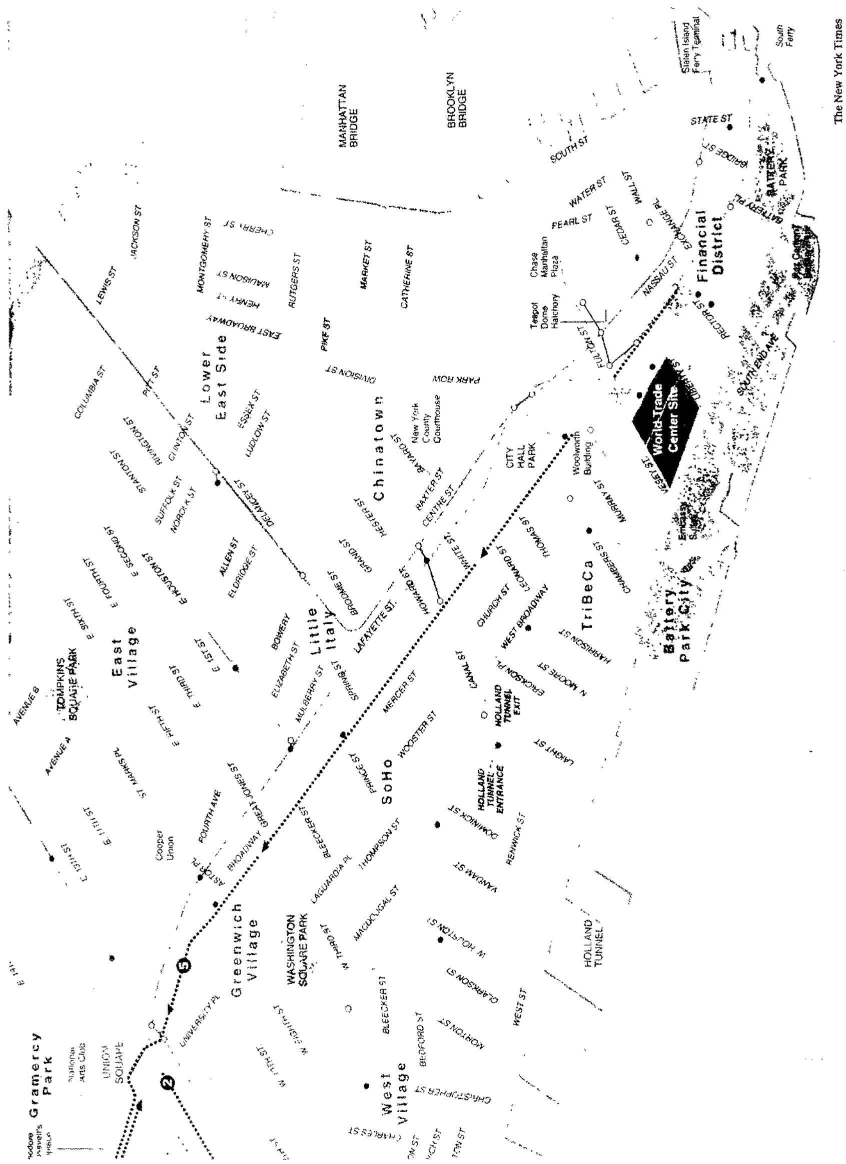
According to Dr. Joan Reibman, Associate Professor of Medicine and Environmental Medicine at New York University School of Medicine and Director of the Asthma Center, there was a sharp increase of reported respiratory problems (new onset cases) after 9/11 among families living in Chatham Towers, Chatham Green, and Smith Projects located in Chinatown and the Lower East Side. BGZ has been working with Dr. Reibman to initiate a joint clinic based at Bellevue Hospital to examine and treat our clients. She is about to publish a study covering the areas of Chinatown and the Lower East Side. Her data and study would show that the health impact beyond ground zero is significant and warrants further study and adequate funding to do it. It also strongly suggests that further environmental testing must be extended beyond ground zero. (See Health and Environmental Consequences of the World Trade Center Disaster found in Environmental Health Perspectives, Volume 112, Number 6, May 2004 where her study is mentioned.)

Conclusion

During 2002 at community town hall meetings, rallies, and marches in New York City and Washington, DC, thousands of Chinatown residents assisted by BGZ had demonstrated and demanded that health care coverage, medical treatment and research studies must be the top priorities for our government agencies and institutions committed to rebuilding New York. Health care must be made a priority with adequate resources to cover long term treatment and studies for all the people affected by 9/11 including residents of Chinatown and the Lower East Side.

Government officials and agencies must be held accountable for the delay in initiating full health coverage, treatment, and studies covering the residents of Chinatown and the Lower East Side. Almost 2 years later, the announcement of the Inspector Generals Report at the end of August of 2003 revealed the misconduct committed by the Environmental Protection Agency, and perhaps the White House as well as the responsibility for this delay. Since 9/11, our leaders and government agencies have failed to alert us about the public health emergency resulting from the attacks on 9/11 and have yet to acknowledge the full scope of the environmental damage and health risks created by dust and pollutants recirculated to and from homes, offices, and buildings throughout lower Manhattan including Chinatown and the Lower East Side. Given the wide scope of harm and the shortage of resources targeted for health care and research studies covering people of color living in Chinatown and the Lower East Side, we need a stronger commitment from our leaders and institutions to make these resources available. Otherwise, both the short term and long term health concerns among community residents will remain unaddressed despite the results of these recent research studies.

I would like to end my remarks by thanking this committee for this opportunity to present testimony and to inform this committee of my community's support for HR 4059. My clients support the passage of The Remember 9/11 Health Act (HR 4059) and cosponsored by Congressman Shays and Congresswoman Maloney. It provides for medical treatment for all whose health was harmed due to the 9/11 attack and covers the long term health impacts for up to 20 years. It also sets up a mechanism to coordinate efforts addressing future health emergencies. Thank you.


MANHATTAN BRIDGE
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BATTERY PL
Chase Manhattan Plaza
Teapot Dome Hatchery
NASSAU ST
Financial District
RECTOR ST
FULTON ST
SOUTH END AVE
World Trade Center Site
VESEY ST
Woolworth Building
CITY HALL PARK
MURRAY ST
CHAMBERS ST
TriBeCa
Battery Park City
THOMAS ST
LEONARD ST
WHITE ST
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UNIVERSITY PL
Greenwich Village
WASHINGTON SQUARE PARK
W THIRD ST
MACDOUGAL ST
LAGUARDIA PL
THOMPSON ST
BLEECKER ST
SoHo
PRINCE ST
WOOSTER ST
MERCER ST
BROADWAY
GREAT JONES ST
FOURTH AVE
ASTOR PL
Cooper Union
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ST MARKS PL
AVENUE A
AVENUE B
TOMPKINS SQUARE PARK
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ELIZABETH ST
SPRING ST
BOWERY
Little Italy
LAFAYETTE ST
BROOME ST
HOWARD ST
GRAND ST
ALLEN ST
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DELANCEY ST
SUFFOLK ST
NORFOLK ST
STANTON ST
RIVINGTON ST
CLINTON ST
COLUMBIA ST
PITT ST
LEWIS ST
JACKSON ST
Lower East Side
ESSEX ST
LUDLOW ST
HESTER ST
Chinatown
BAXTER ST
CENTRE ST
BAYARD ST
New York County Courthouse
DIVISION ST
PARK ROW
PIKE ST
EAST BROADWAY
HENRY ST
MADISON ST
MONTGOMERY ST
CHERRY ST
RUTGERS ST
MARKET ST
CATHERINE ST
Gramercy Park
National Arts Club
UNION SQUARE
The New York Times

Mr. SHAYS. Thank you.

Ms. Hernandez.

Ms. HERNANDEZ. Thank you for keeping this issue current as it has been for us since the beginning.

My name is Micki Siegel de Hernandez. I am Director of Health and Safety Programs for the Communications Workers of America and CWA District I which is the northeast district of CWA. I am also the Alternate Community Liaison to the EPA Expert Technical Review Panel, so I also bring a collective view from both residents and also labor groups in the area.

I am here today because of the effect the World Trade Center has had on our members. Many of our CWA members have developed September 11 related illnesses. We don't know what the future holds in terms of chronic disease. We believe there are still huge gaps that need to be filled in the government's response to assess the September 11 health effects.

Our members have been part of both the evacuation, we had 11 members who died in the collapse of the Towers, we have thousands of members who work in downtown Manhattan and we also had thousands of members who worked at Ground Zero. At Ground Zero, our largest group was the telecommunications workers from Verizon and some from Lucent who repaired the telecommunications infrastructure in New York City.

The report that Dr. Levin and also the GAO referred that came from the WTC Worker and Volunteer Medical Screening Program that looked at the sample of 250 of the first 500 responders, 44 percent of that group were CWA members.

The World Trade Center Worker and Volunteer Medical Screening Program is severely underfunded. There have never been Federal funds for treatment. It is a wonderful program but it stops.

We also don't know what kind of followup care our members are getting. The new Worker and Volunteer Medical Monitoring Program is only funded for another 5 years, so we are talking about approximately three exams for those workers who came for their baseline and again, there is no future. We need some early recognition and treatment of disease.

We also believe that the model in terms of the funding from the Federal Government is what should be adhered to. We believe the Consortium of Occupational Health Clinics should play the key role in that continued program. We have also had experience that when there is an employer-sponsored program, not only is it not as good in terms of quality but that information remains varied.

We have had that with two employer-sponsored programs, one is with ABC, we represent broadcast technicians at ABC. They did a company-sponsored program early on. We have never received any information about the health of our members who went through that program. With Verizon we also were negotiating with them to have our members be allowed to go to the World Trade Center Screening Program on paid work time. We thought it was that important. We spent many months negotiating and we thought we were getting close.

Coincidentally at about the time the World Trade Center program started, Verizon sent a letter home to employees saying they were going to institute their own program, employees could go on

paid work time to a number of clinics, not the Consortium of the World Trade Center, and they could go for a one-time free screening by the end of September. They would not be given paid work time to attend the World Trade Center Worker and Volunteer Medical Program.

We have asked Verizon since that time what has been the response, what has been the analysis done about their program. We have received no information. When we asked for the total number, not even the names just the total of CWA members who participated, Verizon's response was again this was not information that was tracked, it is embedded in each member's medical records and would require manual effort by a nurse to go through each of the 900 plus records to make this determination. When we asked for general reports or analyses of the findings, not individual medical records, the response was no such reports were prepared.

We also heard anecdotally from members that many of the workers comp cases were being controverted meaning that the employer just said no, we don't recognize this is the case, we don't agree this should be a workers comp case, that it is not work related.

We tried to get information from the Workers Comp Board to find out for particular employers how many of the cases being applied for were being automatically controverted. We never got that information.

Mr. SHAYS. I don't understand. Is that information not available or it is just not being shared?

Ms. HERNANDEZ. From the Workers Comp Board? According to what the GAO said this morning, the Comp Board claims they don't track information in that way. I find that hard to believe but we have never been able to get that.

We were able to go to one of the law firms that handled many CWA cases of our members and they did manual search and were only able to find some because of how the cases are applied for in certain parts. They were able to locate some cases only for New York City. Of 18 cases, Verizon cases that were illness related not injury, 16 of them were controverted, meaning the company just said no, we don't believe this is work related. These were for a combination of respiratory illnesses and PTSD.

We believe we need additional Federal funding for medical services. There is a great need for medical services. We do not support use of the funds for the World Trade Center Registry. We do not believe the registry is a substitute for a medical screening program, we believe it is diverting resources that could be put to better use.

We also believe that due to poor design, the registry cannot yield valid results, nor will it ever be able to answer the questions it claims it will be able to answer about the health of New Yorkers affected by September 11. Poor participation rates further erode the validity of the data collected. Without the statistical power as calculated in the registry protocol, the true extent of specific health effects such as asthma cannot be accurately determined. This can lead to a gross underestimate of disease in the population of affected workers and residents. There is also no apparent system in place for decisions about what research will be conducted using the registry data collected.

A couple of the recommendations would be adequate funding for the World Trade Center Worker and Volunteer Medical Program. In the event of future disasters, we need to have a system in place so there is an immediate system workers can turn to. We also need to broaden the scope of who we think of as workers that respond to an emergency not just workers like telecommunications workers but many public sector workers, transit workers at the site.

We do not believe additional funding should be provided to the registry as it is currently crafted and also would like to recommend for future emergencies, agencies not be allowed to get rid of laws that protect workers and the public as happened with several of the agencies in the September 11 response such as OSHA who was there on a consultant basis, the DEP who did not enforce their laws for cleanup of asbestos in buildings and so forth.

[The prepared statement of Ms. Hernandez follows:]

"Assessing September 11th Health Effects"

Testimony of
Micki Siegel de Hernández, MPH
Director, CWA District One Health and Safety Program
on behalf of the
Communications Workers of America, District One
Lawrence Mancino, V.P.
September 8, 2004

Presented to the:
Congress of the United States
House of Representatives
Committee on Government Reform
Subcommittee on National Security, Emerging Threats,
and International Relations
Christopher Shays, Chairman

Thank you for the opportunity to testify before this subcommittee to address the important issue of September 11th health effects. My name is Micki Siegel de Hernández and I am the Director of the Health and Safety Program for the Communications Workers of America (CWA), District One. CWA District One is CWA's northeast district. I am here today because of the deleterious effects the World Trade Center (WTC) disaster has had on the health of our members. Many CWA members have developed 9/11-related illnesses and we do not know what the future holds in terms of chronic disease. We believe there are still several gaps that need to be filled in the government's response to assess the 9/11 health effects and to care for those who have become ill as a result of their exposures.

CWA represents thousands of members who have been directly affected by the disaster, on 9/11 and in its aftermath. Eleven of our CWA members died in the collapse of the Towers; other CWA members were evacuated from the World Trade Center and surrounding buildings. Over two thousand CWA members worked at Ground Zero. Our members continue to work in offices throughout lower Manhattan and Brooklyn. Our members working in the Towers included Port Authority administrative employees and Verizon employees. CWA represents the nurses who treated the first victims of the disaster at the closest hospital to the WTC site, NYU Downtown Hospital. We represent N.Y.C. traffic enforcement agents, some of whom assisted in the rescue efforts on 9/11 and others who continued to redirect traffic around Ground Zero and in lower Manhattan. CWA members working in offices in lower Manhattan include: public sector administrative employees for the City of New York, Verizon and AT&T telecommunications employees, reporters for Dow Jones at 1 World Financial Center, and Board of Elections employees. The CWA District One office is also located in lower Manhattan.

At Ground Zero, our members included the news crews from ABC, NBC and other stations who brought live coverage of the disaster. Our largest group of members at Ground Zero were telecommunications workers employed by Verizon and Lucent. These telecommunications workers got Wall Street up and running, restored the 911 emergency network and restored the telecommunications network for lower Manhattan which was severely damaged by the attacks. These CWA members were a critical part of the restoration efforts and they worked in various locations throughout the site, on the street and in manholes, as well as, in the Verizon building located at the north end of the WTC site. This is the building that 7 World Trade Center collapsed against. It is this group of CWA members that have been most impacted by adverse health effects due to exposure to contamination.

EPA's politically motivated declaration of air safety had numerous, adverse repercussions for our members. For instance, many of our members returned to their offices prematurely, breathing the contaminated air outdoors and working in buildings without knowing whether they were properly cleaned or not. Three years after the disaster, no government agency has yet assessed the extent of contamination in workplaces or has provided oversight for workplace clean-up.

EPA's misinformation also led to employer decisions that left CWA members working at Ground Zero with inadequate protection from contaminants. Verizon initiated a voluntary respiratory protection program for workers at Ground Zero based on EPA's assertion that the outside air did not pose a threat to health, coupled with results of passive air monitoring for

asbestos inside the Verizon building that did not exceed OSHA standards. With a voluntary respiratory protection program, workers do not have to wear a respirator, respirators are not fit-tested to ensure a correct and adequate seal on the face, and the comprehensive respirator training required by the OSHA Respiratory Protection Standard (29 CFR 1910.134) is not required. As a result, many of our telecommunications members who were exposed to the dust and debris while working at Ground Zero have developed WTC-related health problems.

The preliminary report from the NIOSH funded WTC Worker and Volunteer Medical Screening Program released in January 2003 confirmed this. The interim report summarized data on a random sample of 250 of the first 500 patients examined under the auspices of the WTC Worker and Volunteer Medical Screening Program during the period of July 16 to August 29, 2002. The largest single group of workers in the sample by job/industry were telecommunications workers employed by Verizon and represented by CWA. This group of CWA members comprised 44% of the sample population on which the preliminary report was based. The report indicated the following: approximately 50% of the participants experienced persistent WTC-related pulmonary, ear, nose or throat (ENT), and/or mental health symptoms 10 months to one year following the terrorist attacks; and 78% of the participants reported at least one WTC-related pulmonary symptom that first developed or worsened as a result of their WTC-related efforts. Only about one-third of the sample participants had received any prior medical care for their symptoms and conditions before participating in the screening program.

Since that time, many more CWA members have gone for a screening exam at the WTC Worker and Volunteer Medical Screening Program. To date, 663 CWA members have been seen at one of the participating clinics. At the request of CWA District One, and approved by the Executive Committee of the WTC Worker and Volunteer Medical Monitoring Program, an updated summary analyses of the records of 551 CWA members employed by Verizon and seen by the WTC Worker and Volunteer Medical Screening Program will be provided to CWA after September 10th, 2004.

While the WTC Worker and Volunteer Medical Screening Program (now the WTC Medical Monitoring Program) has provided an invaluable service for our eligible members, it is still grossly under funded. No federal funds have ever been provided to this program for any follow-up medical treatment for those who are ill. It is of paramount importance that money be provided for treatment as part of the WTC Medical Monitoring Program. The Occupational Health Physicians who are part of the WTC Medical Monitoring Program have the training and expertise to understand and treat occupational diseases caused by environmental exposure to contaminants. Most primary care physicians do not possess this expertise. While our members are fortunate to have health insurance coverage, we do not know how many people did, in fact, seek and receive appropriate follow-up care. We also do not know how many people had their treatment delayed or were denied treatment altogether due to controverted workers' compensation claims. There may also be a small number of members who may have lost their continued health coverage, due to subsequent layoffs since 9/11.

At the current funding level, the WTC Worker and Volunteer Medical Monitoring Program can only provide periodic exams (approximately three) for the next five years for workers and volunteers who participated in the initial screening. Five years is clearly not enough time to

monitor workers for late emergent diseases, such as cancers. The program needs to be expanded to provide for long term surveillance. Early recognition and treatment of disease is crucial.

At the current funding level, not all Ground Zero workers and volunteers are eligible for the program. Workers in the vicinity of Ground Zero, such as office workers, and residents have never been eligible for the medical screening program. The program needs to be expanded to cover all affected workers and members of the community.

Evidence exists to support the need for expanded, more inclusive screening. One group of CWA members who were not originally eligible for the WTC Worker and Volunteer Medical Screening Program are the CWA-represented nurses at NYU Downtown Hospital. This hospital, located a few blocks from the WTC site, fell outside the initial geographic boundaries established as criteria for inclusion in the program. After several nurses began reporting breathing difficulties, CWA Local 1104 organized a respiratory screening for this group of nurses with the help of the SUNY-Stonybrook Long Island Occupational and Environmental Health Center. Prior to the physical screening date, questionnaires designed to obtain relevant occupational and health history were distributed to participating members. The screening was conducted on July 15, 2002; 114 members participated in the respiratory screening program. The results of the respiratory screening revealed that 32 participants had abnormal spirometry test results which indicate a decrease in pulmonary performance. The abnormal spirometry test results for 28% of the nurses tested is higher than what would normally be expected in this population of workers. Whether this was due to exposures to WTC contaminants is difficult to conclude with the limited nature of the screening and without funding to provide follow-up treatment and diagnostic medical care.

Out of concern for the health of CWA workers in offices in lower Manhattan, CWA District One also participated in a NIOSH Health Hazard Evaluation in 2002. The evaluation was conducted at the request of several unions with members in lower Manhattan to look at the physical and mental health symptoms experienced by office workers near the WTC site. One of the buildings selected for inclusion in the evaluation, which included some CWA public sector members, was 40 Rector Street. The evaluation found that workers at 40 Rector Street reported elevated rates of upper and lower respiratory and gastrointestinal symptoms, as well as, elevated symptoms of depression and Post Traumatic Stress Disorder compared to a similar group of workers in another area of the city. While this study was not conclusive and was based only on self-reported symptoms, rather than a medical exam, it does raise a red flag as to the health of office workers and highlights the need for a more thorough evaluation.

With hundreds of Ground Zero workers already ill and evidence that a proportion of other workers in the vicinity of the WTC site have also experienced physical health symptoms consistent with exposure to WTC contaminants, it is clear that additional funding for the WTC Worker and Volunteer Medical Monitoring Program is necessary. We strongly believe in the model of the WTC Worker and Volunteer Medical Screening/Monitoring Program. The consortium of occupational health clinics, under the coordination of the Mt. Sinai Center for Occupational and Environmental Health, are trusted by the workers and their representatives and this trust has been an important factor contributing to the success of the program thus far. There is the need for this type of government-sponsored medical monitoring program in order to

provide equal access to care, to centralize records to allow for epidemiological analyses, and to provide consistent, quality care by institutions possessing the necessary expertise. It has been CWA's experience that this is not the case when workers participate in employer-sponsored programs, which can serve to hide the true extent of illness in a population of workers.

After 9/11, CWA negotiated with the major employers to allow eligible CWA members to go for a medical screening on paid work time. (Originally, a screening was being coordinated with the NYS Department of Health, before the creation of the WTC Worker and Volunteer Medical Screening Program.) When funding was provided for the WTC Worker and Volunteer Medical Screening Program, negotiations were for time off with pay to participate in this program. Lucent and NBC agreed to allow eligible CWA-represented employees to go for a screening on paid time at the WTC Worker and Volunteer Medical Screening Program. ABC would not agree because they had provided a company-sponsored screening. No summary information about the results of ABC's-sponsored program has ever been provided to the Union.

Verizon's screening program is another case in point. After months of negotiations with Verizon, Verizon initiated its own voluntary medical screening program, which began at approximately the same time as the WTC Worker and Volunteer Medical Screening Program. On July 12, 2002, Verizon sent a letter to employees' homes telling them about Verizon's program. Employees could go to one of several participating health centers on paid work time for a free screening to be completed by September 30, 2002. In contrast, Verizon would not agree to allow employees to go to the WTC Worker and Volunteer Medical Screening Program on paid work time, even though this would have been at no additional cost to the Company. This served to discourage some people from participating in the WTC Worker and Volunteer Medical Screening Program.

Since the completion of Verizon's medical testing program, several verbal requests were made by CWA District One to Verizon for summary information about Verizon's medical screening program and WTC-related workers' compensation claims. Each time a request was made, CWA made it clear that the Union was seeking an overall analysis of the program results, and each time Verizon refused to provide information. Verizon repeatedly stated that information could not be disclosed because employee medical information was confidential, even though this was not what the Union was asking for. In March 2004, CWA sent a written information request letter to Verizon asking for summary health information related to the screening exams sponsored by the Company, none of which was confidential medical information. Verizon responded in a letter dated May 7, 2004. Following are Verizon's responses:

1. When asked for the total number (not the names) of CWA members who participated in the Verizon-sponsored medical screening program conducted for employees who worked as part of the WTC response, Verizon's response was, "The Company agreed to provide testing (on Company time) because the employees that participated in the WTC response were concerned about their health. There were 900+ employees that participated in the Verizon-sponsored medical screening, however the numbers were not tracked by Union affiliation, Company department and/or titles."

2. When asked for the total number (not the names) of CWA participants in the Verizon-sponsored WTC medical screening program who were advised to seek follow-up, diagnostic medical services, Verizon's response was, "Again this is not information that was tracked: it is imbedded in each individual's medical records and would require a manual effort by a nurse to go through each [of the] 900+ records to make this determination."

3. When asked for any general reports or analyses of findings (not individual medical records) regarding the Verizon-sponsored WTC medical screening program conducted by Verizon or any of the participating medical facilities, Verizon's response was, "No such reports were prepared."

4. When asked for the total number of WTC-related workers' compensation claims filed by CWA members who are or were Verizon employees, Verizon's response was, "Workers' compensation claims have not been segregated or tracked to identify claims specific to WTC related issues."

5. When asked for the names of CWA members who filed a WTC-related workers' compensation claim, the corresponding case numbers, and the current status of each case, Verizon's response was, "Since WTC-related claims were not tracked, it would be a manual effort to supply the information requested and over 6,000 claims are received annually."

6. Verizon concluded the letter by stating, "The purpose of the testing was solely in response to employees concerns about their health. The Company was not conducting a study nor did it track any of the specific information you are requesting above, either for the medical screening or the (if any) workers' compensation claims. Based on the number of participants involved in the screening and the number of workers' compensation claims received annually, the work effort involved would be enormous and would require the services of a nurse. Perhaps there is a better way to approach the information you are seeking. If you can identify the members (perhaps by doing a Union canvas) that participated in the screening and those that filed claims we can narrow down the search and we can determine the timeline to get the requested information to you."

In essence, no information whatsoever was provided by Verizon to CWA about the overall results of the Verizon-sponsored screening or WTC-related workers' compensation claims.

To compound this problem, CWA has some preliminary evidence that 9/11-related workers' compensation claims are being routinely controverted by Verizon. At the request of CWA in March 2004, one of the workers' compensation law firms used by CWA searched its records for claims filed by CWA members employed by Verizon. For New York City only, 20 cases were identified -- 19 for Verizon and 1 for Empire City Subway, a subsidiary of Verizon. Of these 20 cases, two were traumatic, injury cases. Only the two injury cases had been established. All of the other cases, 18 in total, were controverted. The 18 controverted cases were for claims of respiratory illnesses (12 cases) and for Post Traumatic Stress Disorder (6 cases).

The controversion of workers' compensation cases related to 9/11 is another reason we believe the WTC Worker and Volunteer Program needs to be expanded to provide follow-up, diagnostic care for workers. This would enable the occupational health physician's in the WTC Worker and Volunteer Program to determine the work-relatedness of the illnesses and to submit the necessary paperwork needed to support a workers' compensation claim, when appropriate. Due to the definition and nature of the present screening program, this is currently not possible. Currently, workers who are provided with a diagnostic referral must seek care elsewhere and it is the physician providing the follow-up care who must establish the work-relatedness of the illness.

For the reasons described above, CWA District One strongly believes that additional federal funding should be allocated to provide for medical services for workers and other members of the community affected by the events of 9/11. We do not support the use of funds for the World Trade Center Health Registry implemented by the New York City Department of Health and Mental Hygiene (NYC DOHMH) in collaboration with the Agency for Toxic Substances and Disease Registry (ATSDR). We do not believe the WTC Health Registry is a substitute for a medical screening program, rather, it diverts needed resources that could be put to better use. Due to poor design, we also do not believe the Registry can yield valid results, nor will it be able to answer many of the questions it claims it will be able to answer about the health of New Yorkers affected by 9/11. Poor participation rates further erode the validity of the data collected. Without the needed statistical power as calculated in the Registry protocol, the true extent of specific health effects, such as asthma, cannot be accurately determined. This can lead to a gross underestimate of disease in the population of affected workers and residents. There is also no apparent system in place for decisions about what research will be conducted using the Registry data collected (other than requirements for Institutional Review Board approvals) nor is there a process in place for the affected community of workers and residents to have a say in the decisions about research.

In conclusion, CWA District One makes the following recommendations:

1. Adequate funding should be provided for the current WTC Worker and Volunteer Medical Monitoring Program so that the program can:

    - Provide periodic (every 12 – 18 months) medical examinations for all affected workers and volunteers involved in the WTC rescue, recovery, restoration and clean-up efforts for a period of 30 years. (The 30 year timeframe is already a precedent in several OSHA standards, e.g., 29 CFR 1910.1020 Access to Employee Exposure and Medical Records and 29 CFR 1910.1001 Asbestos. The requirement for employers to maintain medical records for 30 years, and in some cases in addition to the duration of employment, is because of the long latency periods for certain diseases, e.g., mesothelioma.);

    - Provide treatment to those workers and volunteers in need of follow-up care, including mental health services;

- Provide periodic medical examinations and follow-up care for other workers, such as office workers, and residents in areas impacted by WTC contamination.

Additionally, funding should be provided for the continuation of the WTC Worker and Volunteer Medical Monitoring Program Data and Coordinating Centers (DCC's) for the maintenance of medical records, coordination of outreach and education activities, and for overall program quality assurance. To ensure program continuity, the WTC Worker and Volunteer Medical Monitoring Program should be provided by the current participating consortium of occupational and environmental clinical centers and the Mt. Sinai Center for Occupational and Environmental Health should continue to be the DCC for the other responders' program, (i.e., non-firefighter).

Funding should also be provided for research on the 9/11 health effects and treatment modalities.

2. In the event of future disasters, all workers who respond to the scene of an emergency, and who are involved in rescue, recovery, restoration and/or clean-up activities related to the emergency, should be included in medical monitoring and other benefit programs. Medical monitoring programs should also include affected members of the community.

3. A process should be established and a program developed for government-sponsored medical monitoring and surveillance for workers and affected members of the community in the event of future terrorist disasters. The WTC Worker and Volunteer Medical Monitoring Program should be a blueprint for such a program. The lessons learned and best practices from the current program should be used to fashion an emergency medical monitoring program for future incidents so that immediate medical care and surveillance can be provided, if needed. Leading occupational and environmental health centers and other institutions that can provide the appropriate services should be identified across the country. Other resources and experts who can be called upon as "consultants" for such an emergency medical monitoring program should also be identified, e.g., experts in biological exposures, radiation exposure, etc. Oversight of such a program should always include representatives of the affected groups (workers and/or residents).

4. Additional funding should not be provided for the continuation of the ATSDR/NYC DOHMH WTC Health Registry. Rather, this funding should be used to provide real medical services, as previously described.

5. For future emergencies, agencies should continue to enforce those applicable laws and standards within their jurisdiction necessary for the protection of the health of workers and the public. An emergency is not the time to relax or ignore standards, as was the case following the WTC disaster. Collaborative models, such as the one embraced by OSHA at Ground Zero, should not be allowed.

Thank you.

Mr. SHAYS. Thank you very much.

Mrs. Maloney, you have the floor for 10 minutes.

Mrs. MALONEY. Thank you all for your testimony.

Briefly with 10 words or less, I would like each of you to respond to this question. Has the Federal Government responded adequately and if not, what should they be doing or what needs to be done? Dr. Levin? Has the Federal response been adequate, yes or no, and very briefly, what needs to be done, your top priority in 10 words or less?

Dr. LEVIN. The Government's response has been a partial response. It has enabled us to identify illness among a small section of those who responded and were affected by World Trade Center exposures. What is needed is one, resources to evaluate those who were exposed who have not yet been examined, resources to provide treatment, additional testing when diagnostic work has to be done beyond what screening programs can do and we surely need to have in place a mechanism for a rapid clinical response, an evaluation response and a treatment response should there be disasters in the future that pose the same sorts of risks.

Dr. LONSKI. It has been mixed. The Federal Government's response has been frustrating for us as an organization. I think you heard today we are probably the only group represented today who does treatment, proactive treatment to not only directly with mental health stresses involved in ongoing work as uniformed and civilian first responders and civilian members after September 11 but we are the only organization that links between the Chinatown community, the Mount Sinais, the labor organizations and tries to get out the word to those people about the kinds of screening and help that are available behind the scenes.

Aside from the funding, we mentioned earlier through Firefighters National Trust which allows us to do the only educational, proactive outreach program for the Fire Department of New York in which we go out to active and retired members and help them, give them a tool to identify when they look at themselves and the people around them who they care about what you're looking for in terms of being operationally overloaded.

With that tool, those members can identify for themselves and others much better than us. There will never be enough professionals, never enough people from the counseling unit out there. Once they know what to look for, they can help each other get the help available but in terms of our Federal funding through the efforts largely of Mr. Ron Dickens who is the contract supervisor from the New York State Crime Victims Board, the Grant Division, not the Compensation Division, we were able to get two rounds of funding.

Unfortunately the frustration with that is the application process for the first grant began in October 2002. Those funds come from the Department of Justice. We were notified in April 2003 and this is for September 11 work, that we were approved for a grant. The first amount of money didn't come to us until July 2003.

Mrs. MALONEY. That is a challenge but you are over your 10 words.

Dr. LONSKI. What we need according to Mr. Dickens in helping that process along with Federal funds is to reevaluate the conven-

tional methods of getting moneys out to take out some of the middlemen like the New York State Crime Victims Board and allow the Federal Antiterrorism and Emergency Guidelines to give money directly to organizations like ours. That is recommendation No. 1.

Two, in terms of the linkage between stress and medical issues, there are so many studies going on that have been designed by the best minds.

Mr. SHAYS. You are losing me here because her question was much simpler.

Mrs. MALONEY. We will come back to mental health. My question is has the Federal Government response been adequate or not and if not, what should we be doing briefly, Dr. Melius.

Dr. MELIUS. It is not an adequate program. It is not comprehensive and nobody is in charge or can be held responsible for the program.

The program needs to be expanded. We all made recommendations on the way that needs to be done. The numbers of people covered need to be expanded, the agencies need to stop thinking of this as a scientific study. It needs to be scientifically based but it needs to be a program for the people that were impacted by the World Trade Center. That includes many who aren't included in the current program. Finally, it needs to consider the long term needs for treatment, followup, counseling and that needs to be made a part of the program also.

Mr. MARK. I would say that we must strengthen the public health infrastructure in order to deal with public health emergencies of the nature of September 11. In addition, I would say there has to be a greater Federal role in coordinating as suggested in your legislation by Government agencies such as HHS or other appropriate entities in order to make sure that the public health and the health of all the residents such as folks in lower Manhattan including the lower East Side and Chinatown, get the treatment.

Furthermore, I would say we need to continue to fund two studies that provide for treatment as well as research for people outside of the Ground Zero area. One is a study conducted by SUNY at Stoneybrook, Dr. Anthony Szema and Dr. Alan Iso and other co-authors, who showed a rise and spike in asthma among Chinese children within a 5 mile radius from Ground Zero. Those incidents that occurred at least warrant further research to show the full impact of September 11.

Furthermore, Dr. Joan Reibman had a sample of about 2,000 people in the Chatham Green, Chatham Towers and Smith Projects on the lower East side of Chinatown. She showed a spike in new incidences of asthma and respiratory problems.

So in both instances, the health problems that resulted from September 11 go way beyond the area downtown and Ground Zero. It extends to all areas and neighborhoods. I described that in my written testimony. You have to fund these institutions such as the hospital as well as the asthma center run by Dr. Joan Reibman and institutions like Charles B. Wang Health Center which helped address the needs of people in the local area.

I think there are other things mentioned in my testimony but I would say there has to be better coordination with an increased Federal role in making sure there are no gaps and that the response is an anticipatory mode as opposed to a reactive mode.

Ms. HERNANDEZ. The quick answer is no, there has not been an adequate response with a few exceptions. I would like to add that there has not been an adequate response at the State level either or at the city level.

Certainly to help the current problem, we need more funding for the World Trade Center Worker and Volunteer Medical Program that extends the boundaries to whoever needs it and includes residents. We need a greater role for the Federal Government in the coordination for this and for future events. We also need a characterization.

We still don't know how much contamination is left in downtown Manhattan. No workplaces have ever been assessed by any agency, so we need a scientific characterization to understand what kind of ongoing exposures may still be occurring.

Mrs. MALONEY. I want to note that all of your comments are encompassed in the "Remember 9/11 Health Act" that is offered by the chairman and myself. It covers treatment, continued monitoring throughout the life of a person, research to find out what these toxins mean and how to better prepare for them and coordination under Health and Human Services. I urge you to look at that bill and see if you can help us gain more support because we do need at the least to cover the health needs of the people who sacrificed their health coming to help others.

Dr. Lonski, the GAO recognized six entities who were providing health monitoring but mental health was not being monitored within any of these six programs. Is that correct?

Dr. LONSKI. I don't know. I do know that we are not wired to wait for the results of these scientifically based studies. What we know is what you know. We know all the personal stories, anguish and grief and the fears.

Mrs. MALONEY. How great is the need? If we are not monitoring, we have a sense from these programs how many people are sick because they are monitoring them, they are documenting their physical sickness is totally related to September 11. That is one purpose of these monitoring programs. They are scientifically documenting that people are sick, so we have a sense of what is out there. We need a better sense but there is no one documenting, according to the GAO report, mental health.

Dr. LONSKI. We reported statistics earlier from the Red Cross and the New York State Psychiatric Institute that estimate that up to 150,000 New Yorkers, Manhattanites alone have fully diagnosable PTSD, not talking about post traumatic stress, not talking about the New York Times Sunday study that links stress equals illness, not talking about the study that was in the paper the other day, $300 billion in costs of stress, health related stress issues in this country alone.

When we go into the firehouses, we don't argue. If we can be the front end engine to get out there and let those people know whether it is construction, Chinatown, wherever it is, there is still help available, we need to know once we get them that there is money

from the Federal Government, the State, the city, somebody can pay for the treatment. What kind of treatment? Somebody used the term mixed exposures in describing what happened at Ground Zero.

That reminded me of a couple of guys who recently got married after September 11 who worked in what they described as a sacred, toxic, waste zone for 7 months doing rescue and recovery. What does that mean to them? It means they are afraid to tell their wives they are afraid to have children with them because they don't know genetically what is going to happen to those babies and they don't know what is going to happen to them 5, 10, or 20 years down the road. I don't now how much of that is a medical condition brewing or how much is stress related.

We know there isn't enough money to pay for these guys to get the kinds of proactive medical screenings they are looking for. They are looking for a full body scan once a year so that if there is something percolating in their system, the experts can help them get help right now for it. Open the windows of opportunity to other populations.

Mr. SHAYS. I would like to ask a few questions.

First, I want to know who is getting help, who has such good coverage that they are not at the table? Tell me who they are? Is it the fireman? I believe that because there would be such a public outcry if all those who were impacted were not getting help. Some are getting help. I want to know who the some are.

Dr. LEVIN. I can speak for the Fire Department's program. I know it indirectly and I know they do provide care to the firefighters who have been harmed by their exposure there. We have in our program at Mount Sinai philanthropic sources to provide care to some individuals we have identified mainly through our screening program.

Mr. SHAYS. Are you choosing which lives and which dies? That is an exaggeration but are you helping everyone or just deciding who gets help and who doesn't?

Dr. LEVIN. We take on the responsibility of trying to assure that every individual we identify who needs care gets into care in some fashion, some through our supported programs, some through ordinary medical channels if they have insurance, some through workers comp in the relatively rare instances that these occupational disease cases are accepted by the insurers.

Mr. SHAYS. The workers comp issue, they are sick plus they can't work.

Dr. LEVIN. No. Some are working and ill, working with symptoms because if they go out because of their illness, the maximum they can get through a long and difficult process is $400 a week in New York State if they are declared totally disabled. Most of the people who went down to that Ground Zero area were making much more than that in order to pay their mortgage or rent. It is hard for them to accommodate to $400 a week. What they don't get is access to medical care and their medications.

Mr. SHAYS. Someone who has basically good insurance, the firefighters are getting their health care needs but are working on the job, still in the job.

Dr. LEVIN. Some.

Mr. SHAYS. And some are getting compensation. They aren't limited to $400 are they?

Dr. LEVIN. The firefighters have a different program entirely.

Mr. SHAYS. It strikes me that the firefighters, basically because they do work in this kind of stuff, this is not new experience as a general rule?

Dr. LEVIN. I would not agree with that. I don't think they would either even though they have fought many fires including some toxic fires. The breadth and seriousness of what they encountered down there often without adequate respiratory protection has yielded a rate of respiratory problems never before seen.

Mr. SHAYS. That is because rather than putting out a fire in the common sense, they were helping to do rescue and move construction material in some cases?

Dr. LEVIN. Day after day, 12–16 hour days on that pile.

Mr. SHAYS. What are the parallels and I have no right as a doctor given that I am not to make these analyses but I will tell you as someone who sat in on countless hearings on illnesses, the one thing that impressed me is when people are under stress, their system functions differently and may become more receptive to serous illness. There was huge stress here. Tell me who is getting help.

Mrs. MALONEY. May I ask a clarifying question? Dr. Levin, if someone is a firefighter and comes to you for help, his insurance and his job covers it but if they become so ill they can no longer work, don't they lose their health coverage?

Dr. LEVIN. Let us not talk about the firefighters who are in a very particular position. The construction workers are exactly as you said.

Mrs. MALONEY. Workers have told me they have become so sick that they lose their job and then don't have health benefits.

Mr. SHAYS. That is why I want to go there. It is easier to find out who is getting health care and maybe the compensation because there are less of them. Firefighters would tend to have a better shot.

Dr. LEVIN. Yes.

Mr. SHAYS. Who else?

Dr. MELIUS. I think the unionized construction work force would as long as they can continue to work. Once they stop working either because of economic down turn or because they are disabled, then they lose their health coverage after a period of time, so they become more vulnerable. The other factor depends on the health condition they have and the type of treatment, how much coverage they have, how much medication, how much of the medication is covered. Medication costs can get into the thousands of dollars per year that may or may not be covered depending on their health plan.

We have people that work in construction and other jobs with no health coverage and are certainly the most vulnerable.

Mr. SHAYS. The people who can come to the hospital to basically have their condition reviewed are workers not residents?

Dr. LEVIN. Right. The residents can come to our Center for Occupational and Environmental Medicine but cannot get access to that screening program that is federally funded.

Mr. SHAYS. But you do not take on the firefighters or you do?

Dr. LEVIN. The New York City firefighters have their own program and are not eligible to be screened in our program. They can come to us for treatment.

Mr. SHAYS. Their treatment is covered by their own plans?

Dr. LEVIN. If that is possible. Wherever that isn't available, we will provide care with no out of pocket expenses for them as we do for all the others who come to us in the treatment program because our mission is to provide care with no out of pocket expenses. We will accept insurance wherever we can get it to preserve the resources of the program.

Mr. SHAYS. You have very important points you want to make. Dr. Lonski.

Dr. LONSKI. I would like to echo what Dr. Levin said. If you think it is confusing to you about what is available, you should see what happens to these guys and their family members across the board when they try to go for help. They are afraid to go. Once they get into the system and start to file the paperwork as soon as it breaks down, there is almost an immediate feeling of what is the use. It is the same old nonsense over and over again. I would recommend to the extent that a clear communication can come out of these hearings about what exactly is available with all the six different surveys going on, how to get in, who is still eligible, what the filing dates are, that would be helpful because the people who are still trying to get help can't find their way through the morass and don't have the emotional stamina to put up with it.

Mr. SHAYS. We would have the returning soldiers from the Gulf war testify after the government would say no one is sick and their testimony was they were sick, and you could tell they were sick and they had documentation they were sick and were being told it was basically post-traumatic stress disorder and it wasn't physical. We then started to switch it so they went first and the Government came second. So we got through that hurdle and the Government finally acknowledged it.

There was enough pressure on us that we needed to deal with this issue. I am not feeling the pressure from the ill folks and maybe partly it is because it was the war in the Gulf, it was clearly a Federal responsibility, here because it is all three, it is being deflected.

Dr. LEVIN. I think what also is happening is that many people who do have insurance or have the capacity to pay out of pocket which is more limited, are seeking care through the regular general medical health care system. The problem that has been identified and talked about is the care people get from the regular medical system is very uneven. That is because physicians in our country are not trained in occupational and environmental medicine and have too little experience knowing how to deal with such.

Mr. SHAYS. The parallel to the Department of Veterans Affairs was out of the thousands and thousands of doctors there were only two that knew this kind of treatment. Our military was in their workplace, it was toxic, there were parasites, they were being given medicines they shouldn't be given, drugs they shouldn't be given and so forth.

First, we didn't properly monitor from day one and it would strike me any report this committee comes up with there should be

a Federal immediate response to any type of tragedy that comes in and tests the condition of the work environment. We understand why that didn't happen in this instance. We wanted to jump in right away but there needs to be a mechanism to do that. There needed to be absolute requirements on the workers that they have proper equipment and if they wanted to go in, people should have held them back until they had better equipment because in trying to save a life, they put their own lives in huge danger.

It seems to me you need to monitor and we need to sort out whether it is Federal, State or local but there needs to be the monitoring, Federal dollars maybe but constant monitoring of the condition, knowing the pool we are dealing with and then they need counseling, health care. Lord knows what it must be like for the families and individuals involved.

I am going to encourage my staff to do some additional homework on this without a hearing to try to make an assessment. I don't think we can get a report done before we adjourn but it will be my goal to make sure this subcommittee follows up on this because it simply has to happen.

Mrs. MALONEY. I wanted to thank you for your leadership and state at the very least we can followup on Dr. Lonski's recommendation that we come forward with a listing of what is available, where people can go which would be helpful. All of you pointed out we need treatment and I thank all of you for your work.

Mr. SHAYS. Dr. Lonski.

Dr. LONSKI. Our treatment request is for funding because in 3 weeks our Department of Justice grant will expire, in 3 weeks and there is no, as of yesterday morning from Mr. Dickens, there is no Federal funding available to organizations like ours direct or through grants.

Mr. SHAYS. When does other funding run out?

Mr. LEVIN. For the monitoring program, we will continue for another 5 years.

Mr. MARK. In the current registry, I believe there would be much greater participation if it was publicized that people would be given treatment as well and not wait 2 years later for its startup. I would add that any type of monitoring or response must include an educational campaign not only for doctors but come from the CDC, and also a campaign that actually tells people what is available and they will get treatment. That would be an incentive to step forward and participate in long term studies.

Ms. HERNANDEZ. I agree with what Stan said. We need a long term solution to this problem. One thing clear from the beginning is every step of the way has been frustration and piecemeal and if we can start pulling that together, I think that would go a long way to protecting the health of our workers and the residents.

Mr. MELIUS. I have nothing further.

Mr. SHAYS. I appreciate your getting us started with recommendations. We appreciate the testimony of all our witnesses on both panels.

If there is nothing further, we will adjourn.

[Whereupon, at 3:05 p.m., the subcommittee was adjourned.]

[The prepared statement of Hon. Edolphus Towns and additional information submitted for the hearing record follows:]

Statement of Rep. Ed Towns
Before the
Subcommittee on National Security, Emerging Threats and International Relations
Hearing on
"Assessing September 11th Health Care Effects"

September 8, 2004

I am very pleased that the Committee is holding this hearing. The citizens of New York have suffered enough, and I hope that we can help to ease their continuing pain and lend clarity to their continuing confusion. Many New Yorkers have experienced illness and suffering as a result of attacks on September 11th, 2001, and we need to explore the causes and potential remedies.

Although individuals working within blocks of Ground Zero have a higher risk of illness than those located at a farther distance, we must examine exactly how far-reaching the negative health effects are. I commend the New York City Department of Health and Mental Hygiene and FEMA for their efforts in establishing the World Trade Center Health Registry and their continuing work on behalf of the residents of all five boroughs. Over 40,000 people have signed up for inclusion in the registry, and as a resident of Brooklyn I draw comfort in knowing that steps are being taken to combat the adverse health effects stemming from the attacks. My efforts and those of my neighboring New York colleagues in Congress have served to raise awareness and spur improvements and initiatives.

In this regard, I want to call attention to the letter that was sent to HHS Secretary Tommy Thompson, in which myself and fellow New York Members Carolyn Maloney and Major Owens requested assistance in ensuring that the Department's Agency for Toxic Registry includes Brooklyn residents in the World Trade Center Registry.

The October 21, 2002 edition of *The American Prospect* addresses our concerns. The article entitled "Under the Plume" notes that the World Trade Center debris "blew for more than 30 hours" and "obscured the Brooklyn Bridge as well as many Brooklyn neighborhoods". Many residents of Brooklyn have suffered negative health effects as a result of exposure to the debris cloud. At least three Brooklyn hospitals reported increases in visits related to respiratory ailments.

I am optimistic that this hearing will serve to address the concerns raised by myself and my colleagues and I look forward to updates in the near future. I want to thank the Committee for holding this hearing. I will continue to monitor the progress of all of the agencies involved and urge that any and all health concerns be addressed as soon as possible.

Thank you.

UNITED STATES ENVIRONMENTAL PROTECTION AGENCY
WASHINGTON, D.C. 20460

DEC 3 2004

OFFICE OF CONGRESSIONAL AND
INTERGOVERNMENTAL RELATIONS

The Honorable Christopher Shays
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Shays:

Thank you for your letter of October 28, 2004, to Administrator Leavitt concerning the follow up from the October 28, 2003, hearing before the House Government Reform Committee, Subcommittee on National Security, Emerging Threats and International Relations.

We have provided a response to Congressman Nadler which addresses the concerns he raised at the hearing regarding the legal authority of EPA to act in the event of a terrorist attack (enclosed).

Again, thank you for your letter. If you have further questions, please contact me or your staff may contact Carolyn Levine, in EPA's Office of Congressional and Intergovernmental Relations, at (202) 564-1859.

Sincerely,

Charles L. Ingebretson
Associate Administrator

Enclosure

UNITED STATES ENVIRONMENTAL PROTECTION AGENCY
WASHINGTON, D.C. 20460

DEC - 3 2004

OFFICE OF
GENERAL COUNSEL

The Honorable Jerrold Nadler
U.S. House of Representatives
Washington, DC 20515

Dear Congressman Nadler:

I have been asked to respond to your question to Dr. Paul Gilman, former Assistant Administrator for the Environmental Protection Agency's (EPA) Office of Research and Development, during the October 28, 2003, hearing before the House Government Reform Committee, Subcommittee on National Security, Emerging Threats and International Relations, concerning the Environmental Protection Agency's legal authority to act in the event of a terrorist attack. I apologize for the delay in responding to you. We appreciate your continued interest in matters relating to lower Manhattan following the September 11th terrorist attacks.

Specifically, at the hearing you asked whether, in the event of a terrorist attack, it is EPA's responsibility pursuant to the Comprehensive Environmental Response, Compensation, and Liability Act (CERCLA) or Presidential Decision Directive 62 (PDD 62) to ensure the cleanup of releases of hazardous substances.

With respect to the EPA's authority under CERCLA, EPA is authorized under a variety of circumstances to respond to releases or substantial threats of releases of hazardous substances. The statute provides that the EPA is to give primary attention to those releases that may present a public health threat. Accordingly, EPA has considerable discretion in fashioning a response that will address the particular circumstance and the potential risk to the public.[1] If necessary, this authority can be used to address hazardous substances released to the environment by a terrorist attack.

[1]Responses to releases and substantial threats of releases are carried out under the National Oil and Hazardous Substance Pollution Contingency Plan (NCP). While the NCP gives EPA broad authorities to address the release and threat of release of hazardous substances, the NCP expressly states "[a]ctivities by the federal and state governments in implementing [the NCP] are discretionary governmental functions." The NCP "does not create in any private party a right to federal response or enforcement action [nor does it] create any duty of the federal government to take any response action at any particular time." 40 C.F.R § 300.400(i)(3).

Operating in concert with PDD 62 (discussed immediately below) is Homeland Security Presidential Directive (HSPD) 5, promulgated February 28, 2003, concerning the management of domestic incidents. Under HSPD-5 response to terrorism events is referred to as incident management. HSPD-5 provides, "the Secretary of Homeland Security is the principal Federal official for domestic incident management" and "the Secretary shall coordinate the Federal Government's resources utilized in response to or recovery from terrorist attacks, major disasters, or other emergencies." HSPD-5 also directed the Secretary to develop a National Incident Management System (NIMS), which provides a nationwide system for coordinating response and recovery efforts, and the National Response Plan (NRP), which integrates all Federal Government preparedness, response and recovery plans into a single all-hazards plan.

PDD 62, promulgated May 22, 1998, provides the general framework that governs the coordination of federal agency actions in the event of a terrorist attack, including an attack that involves the release or threat of release of a hazardous substance.[2] PDD 62 provides that "FEMA, the Lead Federal Agency for consequence management, is responsible for preparing for and responding to the consequences of a [weapon of mass destruction] incident with the participation of other departments and agencies including the . . . Environmental Protection Agency . . ., as necessary." Thus, while PDD 62 continues to exist, the NRP will provide the organizing structure for an EPA response.

Therefore, in the event of a terrorist attack, EPA would respond under the NRP pursuant to the annex entitled "Emergency Support Function (ESF) 10, Hazardous Materials." EPA is the primary agency for Federal efforts to support State and local governments in response to an actual or potential discharge and/or release of hazardous materials following a major disaster or emergency. In such circumstances, there may be a presidential declaration of a "major disaster" under the Robert T. Stafford Disaster Relief and Emergency Assistance Act (the Stafford Act). The Stafford Act provides for Federal assistance to State and local governments when a major disaster overwhelms their ability to respond effectively to save lives; protect public health, safety, and property; and restore their communities.

Under the NRP, in the event of a terrorism attack EPA may receive a task assignment from DHS and, if a Stafford Act event occurs, a mission assignment may come from FEMA, now within the Department of Homeland Security. However, under the Stafford Act, mission assignments are designed to be primarily for an initial short period of time, normally no longer than sixty days, and may be with or without reimbursement. Under the NRP, even without a Stafford Act declaration, EPA could respond under its own authorities and funding. In the case of the attack on the World Trade Center, EPA's actions were conducted in accordance with mission assignments from FEMA.[3]

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[2]PDD 62 reaffirmed Presidential Decision Directive 39 (PDD 39), which, among other things, specified that the "laws of the United States assign primary authority to the States to respond to the consequences of terrorism; the Federal Government provides assistance as required." Both PDD 39 and PDD 62 are classified documents. The quotations are from unclassified synopses prepared by the Department of Justice.

[3]EPA previously has corresponded with you on several occasions concerning the specifics of the response to the September 11 terrorist attack. The following letters are attached: February 22, 2002, letter from Administrator Christine Todd Whitman; April 25, 2002, letter from Regional Administrator Jane M. Kenny (referenced attachments not enclosed given their length); July 29, 2002, letter from Jane M. Kenny; and March 5, 2003, letter from Jane M. Kenny.

I hope this additional background information regarding the Agency's authorities and its appropriate role in the event of a terrorist attack is helpful to you. If you have further questions, please contact me or your staff may contact Carolyn Levine, in EPA's Office of Congressional and Intergovernmental Relations, at (202) 564-1859.

Sincerely,

Ann R. Klee
General Counsel

Enclosures

Table 1: Programs to Monitor Health Effects in the Aftermath of the World Trade Center (WTC) Attack

	Administrator	Eligible Populations	Participation	Monitoring Methods	Treatment Referral	Intended Duration and Federal Funding [a]
WTC Health Registry	NYC Department of Health and Mental Hygiene	Between 250,000 and 400,000 responders and people living or attending school in the area of the WTC or working or being present in the vicinity on September 11	As of 9/2004, 60,483 people were enrolled[b]	Telephone-based health interview; plan to re-interview subset of population in 2005	Provides information on where treatment can be sought; refers participants to LIFENET[c] for mental health services	Agency for Toxic Substances and Disease Registry intends to fund through fiscal year 2008 — $20 million total Environmental Protection Agency allocated in fiscal year 2004 — $1.5 million total
FDNY WTC Medical Monitoring Program (FDNY program)	FDNY Bureau of Health Services (FDNY-BHS)	About 11,000 firefighters and 3,500 emergency medical service (EMS) technicians	As of 4/2004, 11,770 firefighters and EMS technicians were enrolled	Medical examination and questionnaire; three follow-up examinations planned	Refers to FDNY-BHS	National Institute for Occupational Safety and Health (NIOSH) intends to fund through 6/2009 — $25 million total National Center for Environmental Health funded initial monitoring — $4.8 million total
WTC Worker and Volunteer Medical Monitoring Program (Mount Sinai program)	Mount Sinai's Irving J. Selikoff Clinical Center for Occupational and Environmental Medicine[d]	About 12,000 responders[e]	As of 8/2004, about 11,793 people were enrolled	Medical examination and questionnaire; three follow-up examinations planned	Refers to privately funded program available for responders	NIOSH intends to fund through 7/2009 — $56 million total NIOSH funded initial monitoring[f] — $15.8 million total
The medical monitoring program for New York State workers (NYS program)	New York State Department of Health	About 9,800 New York State employees and National Guard personnel	As of 10/2003, 1,677 employees received medical evaluations	Medical examination and questionnaire; follow-up on subset of 300 employees planned	Instructs participants to see their primary care physician or the state's occupational health unit	National Center for Environmental Health funded through fiscal year 2003 — $2.4 million total
WTC cleanup and recovery worker registry (Johns Hopkins registry)	Johns Hopkins Bloomberg School of Public Health	About 12,000 members from three unions[g] and the NYC Department of Sanitation	As of 6/2003, 1,337 workers responded to the mailed questionnaire	Mail-in health survey	Provides participants with brochures about health services; refers uninsured to Columbia University for mental health services	National Institute of Environmental Health Sciences (NIEHS) funded through fiscal year 2003[h] — $1.2 million[i] total
WTC responder screening program for federal workers[j] (FOH program)	Department of Health and Human Services' (HHS) Federal Occupational Health services	About 10,000 federal workers responding to WTC	As of 3/2004, 412 exams were completed and reviewed	Medical examination and questionnaire	Instructs participants to see their primary care physician	HHS intends to fund through 12/2005 — $3.7 million total

Sources: FDNY, HHS, Mount Sinai, New York City Department of Health and Mental Hygiene, and New York State Department of Health.

Note: Programs are ordered according to participation level.

[a]Except as noted, FEMA provided funds to the agencies listed below through interagency agreements with HHS to support efforts to monitor the health effects of the WTC attack.

[b]The WTC Heath Registry officials told us that they have generated a list of 185,000 potential participants gathered from various sources, including employers and registration via the Web or telephone. Registry officials told us that the registry will continue to interview and enroll people who are on this list after the registration period ends.

[c]LIFENET is a 24-hour mental health information and referral service provided by the New York State Office of Mental Health.

[d]Mount Sinai is the coordinating center for the five clinics in this program.

[e]People eligible to participate in the Mount Sinai program are those who worked primarily at or immediately adjacent to the WTC site, either during or after the disaster, including firefighters from outside NYC, police officers from NYC and surrounding communities, emergency rescue workers from a variety of organizations (including emergency medical technicians and paramedics), building and construction trade workers from the NYC metropolitan area and throughout the nation, members of the press and news media, health care workers, food service workers, structural and other engineers, and a variety of other public- and private-sector workers, and people who worked in the immediate vicinity of the WTC site restoring essential services, such as telephone services, electricity, and transportation, or performing services necessary to reopen buildings in the area, including cleaning and assessing the structural integrity of nearby buildings. The program excluded federal employees, FDNY firefighters, and, initially, New York State employees, who were all eligible for other programs. New York State responders were initially screened in the NYS program. The NYS program plans to follow 300 of these responders. All New York State responders are now eligible to participate in the Mount Sinai program.

[f]Initial medical monitoring conducted through this program was supported by funds appropriated to CDC.

[g]The International Brotherhood of Teamsters, the International Union of Operating Engineers, and the Laborers International Union of North America.

[h]Funds appropriated to NIEHS to support research, worker training, and education activities supported this grant.

[i]Includes funding for other activities, including Johns Hopkins' WTC Cleanup and Recovery Worker Health Assessment and community outreach.

[j]HHS officials told us that HHS is making modifications to the program, and no screenings are taking place.