

**JAMES ZADROGA 9/11 HEALTH AND COMPENSATION ACT OF 2010
PUBLIC MEETING**

MARCH 3, 2011

Jacob Javits Federal Building
26 Federal Plaza
New York, New York

TRANSCRIPT LEGEND

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-- (sic) denotes an incorrect usage or pronunciation of a word which is transcribed in its original form as reported.

-- (phonetically) indicates a phonetic spelling of the word if no confirmation of the correct spelling is available.

-- "uh-huh" represents an affirmative response, and "uh-uh" represents a negative response.

-- "*" denotes a spelling based on phonetics, without reference available.

-- (inaudible)/ (unintelligible) signifies speaker failure, usually failure to use a microphone.

P R O C E E D I N G S

(10:15 a.m.)

1
2 **DR. HOWARD:** The Department of Health and Human Services
3 is holding this meeting to hear about your concerns and
4 issues with regard to the new James Zadroga 9/11 Health
5 and Compensation Act. We're holding the meeting at the
6 request of several members of the New York State
7 Delegation in the U.S. House of Representatives --
8 Representative Carolyn Maloney, Jerrold Nadler and Peter
9 King. Unfortunately they're not able to be with us
10 today because there are important votes in the House
11 today in Washington, but their staff is going to be here
12 listening to your input.

13 So as you know, the -- the 9/11 Act was signed by the
14 President on the 2nd of January. Title 1 establishes
15 within the Department of Health and Human Services the
16 World Trade Center Health Program. And Title 2, as you
17 probably know, amends the September 11 Victim
18 Compensation Fund and is administered by the U.S.
19 Department of Justice.

20 So today what we wanted to do was to provide anyone
21 interested with five minutes of the spoken word, but the
22 written word is always available to you, and we
23 encourage you to go to our web site at NIOSH.gov, just
24 enter the word "docket" and you can enter as much of the

1 written word as you want. And we encourage you to do
2 that. That docket's going to remain open at least till
3 April 29th, and can be extended, so -- so please avail
4 yourself of that if you -- if you don't want to speak
5 today or -- or don't get a chance to speak today.
6 Transcripts from the -- from the meeting will be
7 developed and will be available publicly, so it's
8 important for me to make a little bit of a disclaimer
9 here. If you're making a comment orally today and --
10 and you give your name, no attempt will be made to
11 redact the name from the written transcript and it'll
12 appear in the transcript. So if you reveal, you know,
13 personal medical information, that information is very
14 difficult to redact, and so I encourage you not to --
15 not to reveal things that you don't want everybody to
16 see in public. So keep that in mind.

17 So as I say, we're here to hear the spoken word, but
18 please avail yourself of the electronic docket as -- as
19 we go through the next few months and your thoughts
20 mature and you hear more information that you'd like to
21 comment on.

22 Just one last sort of disclaimer. This is an input
23 meeting, so we're interested in hearing your input.
24 It's not an output meeting from us. We're still in the
25 process of understanding the bill and making plans for

1 implementation, so this is an opportune time to hear
2 from you. We want to maximize that time today. So if
3 anyone's interested in the current programs,
4 representatives will be here in Rooms D and C for that.
5 I'd now like to introduce our moderator for today that
6 will keep us all on time, our five-minute limit, Larry
7 Elliott from NIOSH, who works in our Cincinnati
8 facility. And Larry will explain more about the fire
9 exits and our schedule for today.

10 Larry?

11 **MR. ELLIOTT:** Thank you, Dr. Howard. Good morning,
12 ladies and gentlemen. We certainly appreciate your
13 presence here today, and your participation. Thank you
14 for coming. We had prepared this meeting with the
15 thought that there would be a large, large crowd who all
16 wanted to speak, so we posted in the Federal Register
17 notice and in the handouts that have been given you that
18 we would -- in order to allow everyone an ample
19 opportunity to have their voice heard, we would limit to
20 five minutes.

21 I have this fancy little machine right here that, when I
22 turn it on, gives you a green light; four minutes in
23 it'll give you a yellow light; and then when the red
24 light comes on I'll get a hook out. Doesn't look like
25 we're going to have 70 speakers at this point in time

1 this morning, so if we go through the complete roster of
2 those who've signed up and somebody wants to speak
3 again, or somebody else decides they want to speak at
4 that point, then we'll continue by allowing you to speak
5 a second time, or a third time if you wish, but we're
6 going to keep the five-minute clock going on you.
7 Some housekeeping issues -- safety. We know that
8 there's no planned building evacuation here today, but
9 in the event of an emergency the loudspeaker will come
10 on. If there's a need to evacuate the building, the
11 Fire Warden will tell us over the loudspeaker to exit
12 the building. Don't use the elevators. There are a set
13 of stairwells and we can lead you to those stairwells.
14 The restrooms, they are located -- if you go back out
15 the hallway and across from the elevators you'll see the
16 restrooms. There are also a couple of small restrooms
17 over on the side of this room -- on that side over there
18 (indicating).
19 I think that covers all of my business at this point, so
20 if you haven't signed up to speak and want to do so,
21 please see the ladies at the back and they'll get you
22 signed up, and we'll be ready for our first speaker here
23 in a moment.
24 Any questions before I sit down? Yes, ma'am?
25 **UNIDENTIFIED:** (Inaudible)

1 **MR. ELLIOTT:** Microphone's not working? Thank you. So
2 we'll -- if you're up here and you're using the mic, I'd
3 ask you to adjust it, move it around. Let's see if we
4 can get a clear recording.

5 So I'm going to call the first -- this one works. I'm
6 going to call the first three names off so -- you may
7 already know who you follow, but we have Jim Ryder
8 first, then Rhonda -- and I'm -- I apologize if I mis--
9 Villamia, if I mispronounce your name, please allow me
10 to try to get it right -- and Jennifer Spano. Those are
11 the first three, in that order, so we'll go with Jim
12 Ryder, please.

13 **MR. RYDER:** Good morning, gentlemen. I'd like to thank
14 Dr. Howard and Mr. Elliott for taking the time to be
15 with us here today. I'd like to thank everybody in the
16 audience for coming. If you're in the back and you
17 can't hear me, please let me know.

18 **MR. ELLIOTT:** Readjust your --

19 **MR. RYDER:** Testing one, two -- can everybody hear me in
20 the back? Can you hear me in the back?

21 Okay. Again, I'd like to thank Dr. Howard and Mr.
22 Elliott for having us here today. This is a very
23 important day. I'd like to take a moment to introduce
24 myself and everybody else with my board, if I may. Does
25 the clock have a pause?

1 Thank you. I'd like to take a moment of your time,
2 gentlemen, to introduce our documentation to you. I'll
3 describe us to you in a moment.

4 It is my understanding after a brief conversation with
5 Dr. Howard that there are other people from the federal
6 government that are here. We have more of these; if
7 anybody else would like these, you're welcome to them.
8 At the end of the day, if we have any leftovers, if
9 there's anybody else in the audience that would like
10 them, we'd also.

11 If I can also take another moment, before we start, to
12 introduce the FealGood Foundation Zadroga Bill Action
13 Team, known fondly as the Zad Team -- if you can stand
14 up. It's pretty much all the people you see in front of
15 you in red. We've spent -- our team has -- has
16 responded down to Washington, DC to pursue the passing
17 of the Zadroga Bill at least 100 times -- or close to
18 it. And if you counted us individually as how many
19 times we went there, it's well over 1,000 times that
20 we've been to DC.

21 We know this building very little. We know the Senate,
22 the Russell, the Caine* and all the other buildings very
23 well. And as we progress with this bill, I can assure
24 you that the FealGood Foundation will begin to know this
25 building very well, as well. We are determined. We are

1 pursuant (sic). We are vigilant and we don't waver.
2 We're here for a reason, and that is all of the 9/11
3 first responders like myself, as well as the families
4 that live down there, the children that learn down there
5 and the employees that had to pursue (sic) from there on
6 9/11. Thank you, gentlemen.

7 My name is Jim Ryder. I'm a New York City police
8 officer. I retired in July of 2005. From then till now
9 I've spent a lot of time in my doctor's office because I
10 have a heart ailment that they can't identify. When I
11 sleep, I wake up 70 to 90 times a night because of sleep
12 apnea, and that is the least of my concerns.

13 My greatest concern, as a parent, is my four children.
14 I would like to be here for them as long as I can, not
15 having realized that when they were born. 9/11 changed
16 me, as I'm sure it changed everyone else here. The
17 FealGood Foundation Team is aware of that. We are just
18 like you. If you give us your faith and your time and
19 your efforts, I'm sure we can make a difference here
20 like we made a difference in DC.

21 There are many concerns that we have about Ground Zero
22 and the health of those who were down there. There were
23 toxins floating around that none of us could identify.
24 The federal government, gentlemen, told us that the air
25 down there was safe. We all know that not only was that

1 a fallacy then, it is a gross statement now. There is
2 no way that anybody in their right mind would know that
3 it is not of great concern. Because of what happened
4 down there with those buildings, and because those
5 buildings fell, there were toxins in the air. If you
6 can just use your imagination with things like asbestos,
7 cocaine from the DEA vault, computers that were crushed,
8 buildings' cement and other things, these toxins were
9 deadly. These toxins did not belong in our bodies, but
10 they got there.

11 Our concern as the Zadroga Action Team is there is a
12 list of cancers that were -- I apologize, somebody moved
13 my paperwork. There was a list of cancers that were
14 affected -- or people were affected by these cancers --
15 and I'm mumbling here so give me a second.

16 (Pause)

17 Let me just start the pitch about cancer again, if I
18 may. I apologize for that.

19 Cancer is a type of disease that will get into your
20 system through the air. We're aware of that, and we're
21 aware that people are suffering with that type of cancer
22 -- or those types of cancers. And if I may, I'd like to
23 tell you about those types of cancers -- as we know
24 them, and we're not doctors.

25 Skin cancer, lung cancer, lymphoma, liver cancer, colon

1 cancer, thyroid cancer, testicular cancer, leukemia,
2 melanoma, brain cancer, kidney cancer, bone cancer,
3 throat cancer, breast cancer, stomach cancer, laryngeal,
4 tongue, rectal, esophageal, myeloma, pancreatic,
5 sarcoma, tonsillar, sinus and nasal, gall bladder,
6 neurological, cervical, eye, adenocarcinoma (sic) of the
7 esophagus, digestive, gastrointestinal, muscular, anal,
8 ovarian, mesothelioma, parotid, small intestine,
9 skeletal, parathyroid, penile, pituitary, urethral,
10 bladder, genitorany -- I'm sorry, I'm saying that wrong,
11 genitorinary (sic) and gynecological. Boy, I didn't
12 think I was going to get through that list, and I'm not
13 a doctor.

14 Our concerns about these cancers, ladies and gentlemen,
15 is they attack -- when the Twin Towers were attacked and
16 those buildings fell and those toxins became airborne,
17 those deadly toxins were breathed in by myself and
18 everybody else that was down there. I spent four years
19 myself, and I'm one of the lucky ones, because I can
20 look you in the eye today and say I don't have cancer.
21 But a good friend of mine, Tony -- who's sitting in this
22 audience -- and I just went and sat in the hospital with
23 a friend who does have cancer, and has children. And
24 he's struggling to look us in the eye and say "You're my
25 advocates. I need you to fight for me because cancer is

1 not covered."

2 Gentlemen, we need to expedite the coverage of cancer.

3 We need to open our eyes and realize that these toxins

4 were there. We were there. Our bodies are required to

5 breathe. And if a gentleman goes on that pile and

6 scratches his leg and three months later has got a sore

7 on his leg that goes from his knee to his heel, and that

8 sore is still there today, there is a concern -- there

9 is a genuine concern -- of these types of cancers that

10 are getting into people's bodies, we know full well that

11 they did, and how is it that they're affecting -- or

12 they are affected by these cancers.

13 It is therefore not surprising that a record number of

14 cancers have been reported along the 9/11 community.

15 People are going to the site and Centers for Excellence,

16 and they're telling people that they can't breathe,

17 they're waking up, they have sleep apnea, they have GERD

18 and they have all the other disease that are not easy to

19 deal with. But then they're also telling them they have

20 cancer. "Go out the door, go find yourself a doctor;

21 that's not covered." That's not covered, but we know

22 full well, gentlemen, that these people stood down

23 there, breathed in those toxins, and it damned well

24 should be covered.

25 The addition of cancer to this list needs to be tracked.

1 We use -- need to use technology that is afforded to us
2 today because of the likes of Steve Jobs and Bill Gates,
3 two men that are my fans. I'm a tech guy. I'm a geek,
4 and I know that the technology's there to track it.
5 And the last thing I'll say, because the light is red,
6 is: In the case of cancer we cannot wait for science as
7 usual. Thank you.

8 **MR. ELLIOTT:** Thank you, Jim. And if you didn't get
9 finished, we'll try to get you back on.

10 Next we have Rhonda.

11 (Pause)

12 **MS. VILLAMIA:** Thank you. My name is Rhonda Villamia.
13 For nine months I volunteered at the World Trade Center
14 site with the Red Cross, Salvation Army and St. Paul's
15 Chapel. Aside from providing care to the responders and
16 workers who came into our respite centers for meals,
17 rest, supplies, showers, or simply to vent, I did
18 perimeter runs around the pile/pit in ATVs, bringing
19 supplies and nourishment to those who could not leave
20 their posts. I also served at the respite tents right
21 beside the pile/pit. Of the 26 World Trade Center
22 covered conditions on the NIOSH list, I have 12. In
23 addition to these 12 I have thyroid disorders.
24 I have been a simultaneous -- I have been a simultaneous
25 focus group interpreter for Hispanic marketing research

1 since 1982. As my physical and psychological health has
2 increasingly deteriorated, I have had to incrementally
3 reduce my workload to the point that I can no longer
4 work.

5 I am part of a group of responders who traveled to
6 Washington with the FealGood Foundation to help put a
7 face to the staggering statistics in order to have our
8 leaders understand the importance of the Zadroga Bill.
9 I have been advocating for the health care needs of the
10 9/11 community over the past three years, initiating
11 dialogues with the directors of the World Trade Center
12 Monitoring and Treatment Programs, and serving on the
13 World Trade Center Registry Community Advisory Board. I
14 come before you now not only as an individual with
15 concerns, but also as a voice for the consensus of
16 issues we are raising here today in an effort to
17 communicate priorities for the implementation of this
18 Act. It is for this reason we have created the Zadroga
19 Action Team.

20 We urge NIOSH to ensure that there is an agreed-upon,
21 consistent quality of medical care provided to all
22 participants in the World Trade Center health program.
23 We are particularly concerned with the following:
24 All data centers should operate in a fully transparent
25 manner, using standard protocols to capture data on

1 patient medical history. In order for medical
2 understanding of World Trade Center illnesses to keep
3 pace with the emergence of new health effects,
4 comprehensive health data must be kept for each
5 participant. This includes intake, monitoring and
6 treatment visit data, as well as data from non-World
7 Trade Center doctor visits. Medical monitoring exam
8 data and treatment doctor data should include
9 information on all symptoms and diagnosed conditions,
10 whether or not they are deemed to be World Trade Center-
11 related.

12 Data from mail home questionnaires and monitoring visit
13 interviews should be immediately printed out so that the
14 patient can confirm the data has been captured
15 accurately. Ideally, errors caught on the first review
16 should be corrected on the spot. There should be a two-
17 week period for participants to review the document for
18 any additional errors, which would be corrected prior to
19 the document being entered into the official record.

20 Doctors' evaluation findings should be done
21 electronically, not handwritten, and provided to the
22 patient at the end of the visit. Any unusual medical
23 conditions the patient may be experiencing on the day of
24 the appointment should be noted in the record.

25 Neglecting to do this could not only skew the patient's

1 results -- for example, giving a false positive -- but
2 it could also skew the data used for the research at
3 large.

4 Psychological evaluations should be done early in the
5 appointment so that disturbing emotional feelings that
6 may be triggered can be addressed while the patient is
7 still at the medical center.

8 Due to the 9/11 community's unique exposure to the
9 unprecedented toxic brew, the mandate -- and the mandate
10 of this research and monitoring program, patients should
11 be given blood tests that are more sophisticated in
12 evaluating toxins, inflammatory and autoimmune
13 conditions. Blood and urine tests should include
14 screenings for cancers, where such tests exist.
15 Patients should be able to choose their treatment
16 doctor, and have a reasonable process by which to change
17 doctors. Patient records within the monitoring and
18 treatment program should be cross-referenced when the
19 doctor's evaluating the patients' conditions. Currently
20 in the treatment program, patients' non-World Trade
21 Center-related conditions are recorded, but they are not
22 analyzed or included in the research, nor are they
23 referenced in the monitoring doctor's report.

24 Doctors and staff must have a comprehensive
25 understanding of the documentation necessary to qualify

1 participants for disability claims, or any other benefit
2 for which the patient may be eligible. And they should
3 provide these documents in a timely manner.

4 Thank you for treating us with dignity and respect.

5 **MR. ELLIOTT:** Thank you, Rhonda. Next we have Jennifer,
6 who'll be followed by Catherine Hughes, and then David
7 Perezant -- Prezant.

8 **MS. SPANO:** Hello. I am Jennifer Spano. I worked at
9 Ground Zero for approximately nine months with the
10 Salvation Army, first as a volunteer and then as an
11 employee. I was a shift supervisor for the respite
12 center that serviced all Ground Zero workers, and that
13 was one of the community's hubs during the rescue,
14 recovery and cleanup operations at the World Trade
15 Center site.

16 (Pause)

17 Should I start over, Dr. Howard?

18 **MR. ELLIOTT:** Yes, why don't you start over.

19 **MS. SPANO:** How is this?

20 **MR. ELLIOTT:** Yeah, we're going to start over.

21 **MS. SPANO:** Hello. I am Jennifer Spano. I worked at
22 Ground Zero for approximately nine months for the
23 Salvation Army, first as a volunteer and then as an
24 employee. I was a shift supervisor for the respite
25 center that serviced all Ground Zero workers and that

1 was one of the community's hubs during the rescue,
2 recovery and cleanup operations at the World Trade
3 Center site.

4 Post-Ground Zero I volunteered with several
5 organizations, including family groups and groups of
6 former Ground Zero volunteers. Immediately following
7 the closing of the site we stayed together as a
8 community, and we have remained together as one
9 community until this day. I have since been introduced
10 to and equally bonded with other members of the 9/11
11 community, such as survivor groups.

12 After finally acknowledging and seeking help for my
13 PTSD, I gathered myself together enough to enter a
14 graduate program in Washington, DC. Shortly I will be
15 receiving my graduate degree. While living in
16 Washington I would join the FealGood Foundation whenever
17 they were meeting in DC in order to participate in their
18 grand effort to pass the Zadroga Bill. Once I returned
19 to New York I would travel with them on bus trips to
20 Washington to walk the halls of Congress, advocating for
21 our bill.

22 I stand before you today to relate our community's
23 concern about the implementation of the Act. I will now
24 read some of the concerns listed in the Zadroga Action
25 Team's document.

1 We urge NIOSH to ensure that there is an agreed-upon,
2 consistent quality of medical care and treatment
3 provided to all participants in the WTC health program.
4 We are particularly concerned with, one, participant
5 accommodation. Although the literature states that the
6 exam takes three hours, this does not accord with
7 reality. The exam takes close to five hours, and is an
8 all-day event. People cannot necessarily return to
9 work, as they have promised their employer. Please
10 communicate clearly the accurate duration of the exam.
11 There should be late-night and Saturday appointments at
12 least once a month in order to accommodate those for
13 whom it is too burdensome to take off of work. There
14 should be ample staffing so that optimum service can be
15 provided. We expect something more than a bare-bones
16 program. We ask that enough resources be provided to
17 fund a first class program.

18 Two, tracking conditions. Each data center must
19 maintain a centralized database with all monitoring data
20 and diagnosed conditions. That is, whether or not the
21 participant's condition is deemed to be WTC-related and
22 whether or not the diagnosing doctor is a WTC health
23 program clinician. From this data, data centers must
24 produce periodic reports on illness incidence and
25 prevalence for conditions emerging among the

1 participants. Participants need to know which
2 conditions are manifesting in significant numbers within
3 the community. Updated incidence and prevalence data
4 for cancers and other serious conditions diagnosed in
5 the population should also be presented in graph form,
6 and shared with participants -- whether upon request,
7 when they come in for appointments, or in the
8 newsletter.

9 Three, scientific analysis. If the Centers of
10 Excellence will only evaluate and record those symptoms
11 and diagnosed conditions on the covered list, their data
12 will be flawed and inadequate. This does not meet the
13 standard of scientific rigor. Further, this flawed data
14 will produce flawed scientific research and undermine
15 the effort to identify new conditions as WTC-related.
16 This does not serve the needs of our community.

17 Four, the difference between programs. The survivor
18 program is very different from the responder program. A
19 survivor community participant is required to have a
20 WTC-identified symptom in order to be enrolled in the
21 treatment program. Then they get yearly revisits for
22 monitoring. On the other hand, responders are monitored
23 and then accordingly sent for treatment. We want the
24 survivor community to be monitored in the same way that
25 the responder community is. We want one list of

1 conditions for the whole 9/11 community. Right now the
2 Act is structured so that if a condition is added for
3 responders, then it is added for survivors. We want to
4 make sure that the reverse is also carried out such that
5 survivor conditions can be added of their own accord,
6 with responders following.

7 Five, exclusion barriers. In the certification of
8 residents, students and area workers who are sick from
9 being exposed to WTC dust and smoke in the geographical
10 area between Houston Street and 14th Street, the
11 treating physicians should have the discretion. The
12 process for certifying prospective participants must not
13 create a barrier to care.

14 Six, covered conditions. We implore you to consider
15 PTSD as an illness that stands on its own.

16 Thank you for listening.

17 **MR. ELLIOTT:** Thank you, Jennifer. Now we'll hear from
18 Catherine Hughes, then we'll have David Perezant, and
19 then Rich Volpe.

20 **MS. HUGHES:** Can you hear me okay? Good morning, does
21 that work? Okay. Good morning? Okay, great.

22 Good morning. I am Catherine McVey Hughes, the vice-
23 chairperson of Community Board One. On behalf of
24 Community Board One I'd like to thank Representatives
25 Maloney, Nadler and King, the primary sponsors of the

1 James Zadroga 9/11 Health and Compensation Act of 2010,
2 for requesting that NIOSH host today's public meeting to
3 receive comments on implementing the provisions of the
4 Act.

5 In addition we would like to thank NIOSH for its prior
6 support of the 9/11 health issues for both the responder
7 and survivor's communities, and for being here today.
8 The World Trade Center lies in the heart of Manhattan
9 Community Board One, and many of us who were here when
10 the towers were attacked are still living and working
11 here. Some of us volunteered as first responders, and
12 many of us continue to work or to attend school downtown
13 in the aftermath of September 11, 2001 terrorist
14 attacks.

15 CB-1 has strongly supported the James Zadroga Health and
16 Compensation Act for many years, and we were very glad
17 when the bill finally passed at the very end of the
18 federal legislative session at the end of 2010. Today
19 we would like to raise some concerns about how the bill
20 will be implemented, including the World Trade Center
21 medical monitoring-- World Trade Center program administrator
22 who will be appointed, and the other issues regarding
23 medical monitoring and treatment for survivors,
24 education, outreach, clinical data collection and
25 analysis, research on health conditions, and expansion

1 of the diseases and conditions covered.

2 Under the 9/11 Health and Compensation Act, a World
3 Trade Center medical program administrator will be
4 appointed to run the World Trade Center health program
5 to be established within the Department of Health and
6 Human Services beginning July 1, 2011. I believe that
7 the appointment of Dr. John Howard would ensure
8 continuity of leadership and the implementation of the
9 legislation. Dr. Howard is currently the director of
10 NIOSH and coordinator of the World Trade Center health
11 programs, and over the years Dr. Howard has met with and
12 carefully listened to the concerns of the diverse
13 coalition members of the survivor community. In the
14 short term, an important part of the medical monitoring
15 and treatment of survivors is the continuity of funding
16 of the World Trade Center health centers while the
17 legislation is being implemented. Continuity is
18 important to the well-being of the patients and the need
19 to retain specially trained, dedicated doctors and
20 staff, especially funding for the pediatric program,
21 including keeping a pediatrician, a pulmonologist, a
22 child psychologist and development doctor. It is
23 important to continue the healthy dialogue that the
24 World Trade Center EHC Community Advisory Committee has
25 had with NIOSH for several years. The education and

1 outreach component of the World Trade Center EHC for the
2 survivor community will be a critical component of the
3 delivery of health care for the next five years.
4 Although the legislation does not go into effect until
5 July 1, 2011, money spent on outreach now would be much
6 more effective if some funding were available prior to
7 the upcoming 10-year anniversary of the terrorist
8 attacks. Only now are some members of the survivor
9 community beginning to understand the correlation
10 between their exposure to World Trade Center
11 contamination and its health impacts. Community-based
12 education and outreach is a key to success, especially
13 to diverse community that is somewhat cynical after all
14 they've been through after the past nine and a half
15 years. I want you -- to point out, this is the EPA
16 building, right here, for region two, right across
17 through the shades there.
18 We request that there is a special emphasis on outreach
19 to children that have become adolescents or young
20 adults. On September 11, 2001 about 25,000 children
21 were living or attending school in lower Manhattan in
22 close proximity to the World Trade Center, but they
23 comprise only a very small portion of the World Trade
24 Center health registry besides the World Trade Center
25 health registry findings that there's not as much

1 research as we'd like about the impact of 9/11 on
2 children, a particularly vulnerable population. The
3 limited studies that have been performed, such as those
4 cited by the New York World Trade Center Medical Working
5 Group, 2010 annual report on 9/11 health, suggest that
6 elementary school children could be more at risk of
7 respiratory illnesses.

8 We are also concerned about the conditions that may
9 affect survivors more because of gender -- we're worried
10 about gender and age may not adequately represent the
11 responder population that has been studied. Therefore
12 we urge the science advisory committee to take steps to
13 address the unique needs of children as adolescents and
14 women. To date, most studies have focused on first
15 responders, and not others who continue to live and work
16 downtown in the aftermath of September 11th attacks.

17 There's no monitoring program for survivors and women in
18 the World Trade Center health registry. It was
19 voluntary for people who lived, worked or went to school
20 in the area of the World Trade Center disaster.

21 Therefore any disease that is included for responders
22 should be included for survivors as well. How the data
23 collection analysis portion of the survivor program will
24 be implemented is also important.

25 The diseases and conditions covered in the recent

1 legislation need to be expanded. At this time the 9/11
2 Health and Compensation Act does not include cancer in
3 the list of World Trade Center-related health conditions
4 defined diseases. The addition of cancer to the list of
5 approved diseases needs to be expedited, especially
6 those cancers that are strongly correlated to
7 environmental exposure through the inhalation, ingestion
8 and other exposure to carcinogens.

9 We are concerned with the long lag time between disease
10 diagnosis, data collection, research and approval. For
11 example, the most recent data on the New York State
12 Department of Health cancer registry web site is from
13 2007. A three-year delay in information relating to
14 cancer is not acceptable since such a gap in medical
15 knowledge could be the difference between life and
16 death.

17 Thank you very much.

18 **MR. ELLIOTT:** Thank you, Catherine. And now we'll have
19 David.

20 **DR. PEREZANT:** Thank you for the time to speak today.
21 Can people hear me? Dr. David Perezant, New York City
22 Fire Department. Good to see my friends out in the
23 audience, and nice -- and good to see you, Dr. Howard,
24 as well.

25 When 9/11 occurred we realized here in New York City

1 that we needed federal assistance, but that this
2 disaster, this emergency, this attack was on us. It was
3 on us, the citizens of New York City, the people of New
4 York City, firefighters, cops, community, et cetera.
5 We grouped together and we developed a local health care
6 response to this problem, and we have been thankful to
7 NIOSH for their assistance every step of the way. And
8 we are glad that NIOSH will continue in that role in the
9 Zadroga legislation.

10 What we are afraid of is that now an immense federal
11 bureaucracy will steal patient care dollars. This was
12 never meant to happen. There is not an unlimited pie.
13 There is a specific amount of money that was put in the
14 Zadroga Bill that cannot be increased, and therefore
15 every administrative dollar takes away from a patient
16 dollar.

17 Now I'm not naive. I run a large program. I understand
18 that you can't have a program without excellent
19 administration oversight, and I applaud you -- all
20 right? -- for thinking about how to achieve that,
21 because it will only make patient care better. So naive
22 I am not.

23 However, I am extremely concerned that in your effort to
24 achieve this -- all right? -- it will wind up becoming a
25 bloated, expensive bureaucracy, a bureaucracy that

1 spends a fortune on compliance and audits -- all things
2 that need to be happen, but they can be happened at a
3 proper level rather than at an extreme level, stealing
4 patient care dollars.

5 Specifically, I am immensely concerned about the
6 administrative contract proposal that went out last week
7 with very little knowledge to any of the participants.
8 An administrative contract proposal that,
9 understandably, needs to be written in a broad way, but
10 that, if interpreted the way it is written, it
11 specifically states that 290,000 contract hours per year
12 can be spent on administrative oversight issues.

13 Now that is a huge amount of money. If we were to just
14 do some simple multiplication at \$100 an hour, that
15 would be \$29 million per year. If we were to do it at
16 \$50 an hour, that would be \$15 million a year. And both
17 of those costs per year -- all right? -- exceed the
18 costs of every -- of nearly every one of the clinical
19 centers and of each of the data centers. It also
20 exceeds the cost of what is allocated for the data
21 centers in the current Zadroga Bill.

22 Now that makes no sense, so there's -- needs to be some
23 happy medium. I understand that it can be said to us
24 that that contract proposal merely set up parameters and
25 that there's no intention to come anywhere near those

1 hours. But I've never seen a contract proposal that
2 doesn't come near, or even exceed, the hours. So I am
3 very concerned. Because let us not be mistaken, this
4 money is not going to come from a different pot. This
5 money is coming from patient care dollars. And while we
6 are all here, while we are all here worrying about every
7 little thing, behind the scenes this is an effort that
8 can dramatically change health care.
9 And there are other examples of this, because this is a
10 local health care emergency and it is a local response,
11 with federal assistance. For example, outreach,
12 retention, getting new patients, keeping patients --
13 that is a local response. That cannot be nationalized.
14 That cannot be outsourced to some company that sits
15 somewhere. We have clear knowledge that when we call
16 patients and remind them of appointments, if it doesn't
17 come from a 718 or 212 phone number exchange, they often
18 don't even pick up the phone. All right? That's an
19 example of how outreach and retention must be local.
20 We also have clear knowledge that even when we outsource
21 it local to our own patients, if they don't recognize
22 our phone number, they won't even call up the phone --
23 pick up the phone. So there's a -- there's a certain
24 amount of distrust that needs to be understood in this
25 program.

1 And then finally, any concept of removing research from
2 the data centers needs to be eliminated. Research is
3 not a four-letter word. Research is not guinea pigs and
4 experiments. Research is being able to answer the very
5 question that was raised here today, and is: Is cancer
6 a problem? All right? And I can tell you that science
7 will have that answer for you. And I can tell you that
8 science will have that answer for you a lot sooner than
9 you may think. All right? And it is only because the
10 clinical centers, the data centers and the science are
11 married that every one of our patients is getting state
12 of the art care -- all right? -- and has a chance for
13 real, honest disease surveillance.

14 I thank you.

15 **MR. ELLIOTT:** Thank you, Dr. Perezant. Rich Volpe,
16 followed by T.J. Gilmartin, and then Keith LeBow.

17 **MR. VOLPE:** Good morning, everybody. First I'd like to
18 thank Dr. Howard and Mr. Elliott for taking time out of
19 their busy schedule. I'm not going to take a lot of
20 your time. I don't want to reiterate everything that a
21 lot of people here are saying.

22 I was a New York City detective. I spent over six
23 months down at Ground Zero working on the pile, doing
24 escorts, working with the Port Authority, all different
25 -- I was on every aspect of the location.

1 My concern is there's a lot of people like myself that
2 are diagnosed with illnesses that are not being
3 recognized by whoever the people are doing these
4 studies. Prior to 9/11 I was a healthy -- healthy
5 person. I went to the gym five to six times a week,
6 didn't spend much time with doctors. After 9/11, now
7 I'm seeing nephrologists, I'm seeing pulmonologists, I'm
8 seeing endocrinologists, I'm seeing pulmonologists, I'm
9 seeing ENT doctors -- I have all different ailments. My
10 main ailment is kidney disease, which is going to
11 eventually lead me into full kidney failure. My disease
12 is not being recognized, and my concern is that it's not
13 going to be.

14 All I can say here is ask you, Doctor, and everybody
15 involved here to please look outside the box and realize
16 that there are a lot of different ailments out there
17 that we're not -- that we're not recognizing. And
18 that's my only concern.

19 I appreciate your time.

20 **MR. ELLIOTT:** Thank you, Rich. T.J. Gilmartin?

21 **MR. GILMARTIN:** Good morning. Good morning, Mr.
22 Elliott; Dr. Howard, thank you. I'm going to be two
23 minutes here. My name is T.J. Gilmartin. I'm 31 years
24 working with the cement union, building high rises in
25 Manhattan. And the two points that I want to make about

1 being in the construction business, I know every
2 fluorescent light bulb has mercury in it. I haven't
3 heard anything about this. Everybody's saying that
4 cancer's not part of this. I know the federal
5 government recognizes mercury as a cancer-causing agent.
6 You had 220 floors of fully-lit merc-- fluorescent light
7 bulbs in all those buildings. I mean -- so that -- it
8 just baffles me when the federal government can turn
9 around and say that mercury is cancer-causing, you can't
10 be near it. You had two towers at 110 stories each that
11 came down, 50,000 square foot floors each, trading
12 floors with full fluorescence like these (indicating) --
13 how much mercury is that, all breaking at one time? You
14 know, so there's your relation to cancer.
15 And the only other point I want to make relates
16 something to what the doctor's saying, you know, in the
17 realm of these fakes, everybody that's latching onto the
18 9/11 Zadroga Bill. All of a sudden, everybody was down
19 there -- you know, whatever. I just hope somehow that
20 they set up some kind of commission -- I mean all this
21 money's being spent from the federal government, borrow
22 a -- borrow an FBI agent or something, or a couple or
23 two; pay them out of our money and get these fakes, you
24 know, and the frauds out of this money.
25 That's all I have to say. Thank you.

1 **MR. ELLIOTT:** Thank you, T.J. Now we have Keith LeBow
2 and Mike -- or excuse me, Marc Brandell and Ann Baumann.
3 **MR. LEBOW:** Gentlemen, thank you for having me here
4 today. Like Mr. Ryder said earlier, one of his friends
5 has an issue with his skin. I'm one of those people.
6 As you can all see, I rubbed the dust into my leg when I
7 was standing on the pile. That was only the beginning
8 of my problem. My biggest problem, though, is the heal-
9 - is the medical program itself, Health Care for Heroes.
10 It's not health care, and it's not helping heroes.
11 We get to a certain point with our illnesses, and they
12 turn around and they tell us "Well, we can't figure out
13 if it's 9/11-related or not." They cut you loose.
14 They leave you to go -- and go somewhere else.
15 Now they did this to me in August. I am now probably
16 several years behind. I have to start all over again,
17 and this is costing me not only time, it's costing me my
18 health. I've been told by doctors that I have very
19 little time left. I have maybe three years now. I was
20 told two years ago, a week before my birthday, I'm lucky
21 if I make it to 50. I'm going to make it to 48 now, I
22 know that much is sure because I've got three months to
23 my birthday. But I don't know if I'm going to make it
24 to 50 because I have to stop what I'm doing and
25 constantly go to the doctors and have the doctors re-

1 diagnose the same thing that they were doing for the
2 Trade Center program. This puts me back several years.
3 This is not going to help me.
4 I need help now. I've gone to Dr. Melius and pleaded
5 with him to help me. I -- my prayer -- my pleas fall on
6 deaf ears. I'm getting nowhere. I mean I -- I'm now
7 going to have to find a way to start paying for all of
8 these doctors that I can't afford to get them to help
9 me, to try to save my life.
10 Now I know I'm not the only one this is happening to. I
11 know that both Bellevue and Mount Sinai pick and choose
12 who they want to help. When you -- like I said, when
13 you get to a certain point, they just throw their hands
14 up and use the statement "We can't figure out what's
15 wrong with you; we don't know if it's 9/11-related."
16 And that's the end of your care.
17 Some-- there's got to be some kind of oversight
18 committee that will actually protect everybody involved
19 because, you know, I don't want to be another fatality.
20 I want to live. I want to be an old man. You know, I
21 want to grow up, I want to have kids. With this going
22 on now, that's not a possibility. That's already been
23 taken away from me.
24 I was a volunteer there. I spent the first 100 hours on
25 the pile. If I knew then what I know now, I would have

1 stood and let the buildings hit me because I can't take
2 much more of this. I -- I wake up in the middle of the
3 night, my bed full of blood. My nose -- it's just
4 pouring from my nose. I get violent headaches. I was
5 told that I recently had either a stroke or a seizure in
6 my sleep that almost took me out. In the past three
7 weeks I've been to the doctor's four times and then to
8 the ER four times 'cause I can't breathe anymore. And
9 I'm having people tell me "There's nothing wrong with
10 you." They're looking at the -- they're looking at the
11 outside of me. They're not looking at what the hell I'm
12 going through on the inside.

13 I -- there were days I can't even get out of bed, and I
14 -- I know I'm not the only one with this. There's a few
15 people probably here today that it's so bad, to move is
16 excruciating pain.

17 I had somebody rec-- a doctor recently want to put me on
18 -- he wanted to put me on methadone. There's no way I'm
19 taking that stuff. That's a life destroyer. My life is
20 gone enough; I don't want to go any further.

21 But you guys, please, we have the Bill now, it's an Act.
22 We got to have the right thing, the right people in the
23 right places to actually take care of all of us because
24 without this, people like me -- you're going to see us
25 more and more and more in the papers. There's going to

1 be more deaths, and they're not going to -- they're not
2 -- nobody's going to accept responsibility. They're
3 just going to say "Well, hey" -- I mean look at Cesar
4 Borgia, he was told all he had was a chest cold. He had
5 cancer and died of lung cancer, and that was done by
6 Bell-- by Mount Sinai. I mean to have somebody say to
7 you "Please help me, please" over and over again, and to
8 ignore them, and be a doctor? That's not the oath of
9 Hippocrates. That's the oath of hypocrisy right there.
10 That's turning around and saying you won't -- you won't
11 allow harm to come to another person, but then turn
12 around and stab them right in the back.

13 We need help now. Thank you.

14 **MR. ELLIOTT:** Thank you, Rich. Now we have -- or Keith,
15 I'm sorry, Keith. And now we have Marc.

16 **MR. BRANDELL:** Is this good? Everybody can hear me?
17 Closer? Better? Okay.

18 First I would like to thank Mr. Elliott and Dr. Howard
19 for taking their time to hear us today, and everybody
20 else for coming.

21 My name is Marc Brandell, and I'm the supervising
22 pharmacist of Madison Avenue Pharmacy. I'm here to
23 speak to you today about New York City and the Mount
24 Sinai Hospital responder patients and how the Zadroga
25 9/11 Bill Health and Compensation Act may affect them.

1 Madison Avenue Pharmacy is one of two independent
2 pharmacies that currently fill prescriptions for the
3 World Trade Center responders that are seen at Mount
4 Sinai World Trade Center treatment and monitoring
5 program. We've been serving this unique population
6 since 2003. In fact, it was called the Healthy Heroes
7 program and was solely funded by Bear Stearns. We were
8 the only pharmacy filling prescriptions for the World
9 Trade Center responders at Mount Sinai.

10 When we first started supporting this program, we filled
11 approximately ten prescriptions a month. As the program
12 has grown over the years, we now fill over 3,000
13 prescriptions a month. In fact, we fill prescriptions
14 for over 25 percent of the 16,000 responders that are
15 undergoing treatment. This is an impressive number
16 considering that these patients have the option of
17 filling their prescriptions with us or at a local retail
18 chain that has over 250 locations in the New York City
19 vicinity.

20 Madison Avenue Pharmacy is located one block from Mount
21 Sinai Medical Center. This close proximity has forged a
22 strong relationship between our pharmacy and the medical
23 center for nearly 11 years prior to the 9/11 tragedy.
24 This relationship was built on an outstanding service,
25 our knowledge and commitment to the patients and other

1 health care providers. When the responder study started
2 in 2003 and the hospital needed a pharmacy to fill
3 prescriptions, we were the hospital's first choice. As
4 a member of the community, we felt supporting this
5 important effort was our obligation, and we were only
6 too happy to help.

7 So, after seeing their doctors at the hospital, the
8 patients from the study would literally walk across the
9 street, they would fill their prescriptions. As the
10 program expanded over the years, so have our services.
11 Now if the patient can't make their appointment to see
12 the doctor, we pick up the prescriptions from the
13 hospital and fill them. If the patient is unable to get
14 to the pharmacy to pick up their prescriptions, we mail
15 them directly to the patient's home. We do not charge
16 for this service, and we currently mail over 50 packages
17 a day.

18 We run a 100 percent transparent pharmacy benefit
19 administrator -- let me reiterate that, a 100 percent
20 transparent pharmacy benefit administrator -- to
21 electronically adjudicate all prescription claims that
22 are filled for the Mount Sinai World Trade Center
23 treatment and monitoring program. The administrator
24 that we have contracted with to process these
25 prescription claims has the ability to meet and exceed

1 the pharmacy processing and reporting requirements that
2 are outlined within the Zadroga Act. This includes the
3 transmission of data to a data center in any format that
4 is required.

5 When the program was developed it was designed as a
6 study to the effects -- to study the effects of the
7 toxic dust on the responders. As a result, medication
8 compliance became critical to the findings of the study.
9 This prompted us to start a program that we -- that
10 where we now call patients to remind them to fill their
11 prescriptions.

12 To sum it up again, along with our standard pharmacy
13 services, Madison Avenue Pharmacy picks up prescriptions
14 from the hospital, calls patients to remind them to
15 refill their prescriptions, mails out prescriptions to
16 patients who are unable to pick them up, and runs a 100
17 percent transparent pharmacy benefit administrator that
18 has the ability to meet the challenges of the changing
19 market. And we do all this for a reimbursement rate
20 that is less than the New York State Medicaid
21 reimbursement rate.

22 The standard of needs of the patients through constant
23 and open communication, coordinating and meeting with
24 Mount Sinai Medical Center staff, picking up and mailing
25 prescriptions, as well as other pharmacy services such

1 as respiratory aids, home health aids and surgical
2 supplies, has resulted in a level of care and services
3 that these patients have come to rely on -- and frankly,
4 one that they deserve.

5 The James Zadroga 9/11 Act -- Health and Compensation
6 Act of 2010 requires a competitive bidding process in
7 order for a pharmacy to secure a pharmacy services
8 contract. While we understand the bid process is a
9 necessary tool, we are very concerned that a small
10 independent pharmacy such as Madison Avenue Pharmacy
11 does not have the national experience necessary to bid.
12 With all the services we provide, we have proven that we
13 can compete -- and surpass -- with the nationally
14 recognized pharmacy benefit managers such as Medco,
15 Express Scripts and CareMore. We feel strongly that
16 excluding us from a pharmacy service contract would have
17 a negative an unnecessary impact on these patients.
18 With the passage of this bill into law, these patients
19 may lose their relationship with Madison Avenue
20 Pharmacy. Instead of continuing to be serviced by a
21 pharmacy that these patients know and trust, they'd be
22 subject to an impersonal, mail order telephone customer
23 service representative who is employed by an uncaring
24 pharmacy benefit manager that cares more about wealth
25 care than health care.

1 In closing, we ask that you give the small, local,
2 independent pharmacies that have already proven
3 themselves to this community the opportunity to continue
4 to serve its patients. We have and will continue to
5 support and care for them in a way that nobody else can
6 or will.

7 Thank you.

8 **MR. ELLIOTT:** Thank you, Marc. Ann Baumann, and then we
9 have Glen Klein, Alex Sanchez and Anthony -- Flammia?

10 **UNIDENTIFIED:** Flammia.

11 **MR. ELLIOTT:** Flammia?

12 **UNIDENTIFIED:** Flammia.

13 **MR. ELLIOTT:** Sorry, I apologize for butchering that
14 pronunciation.

15 **MS. BAUMANN:** Okay, my name is Ann Baumann -- all right,
16 I'm short. Is that better? Okay.

17 My name is Ann Baumann. I am the outreach coordinator
18 for Tuesday's Children, the First Responder Alliance,
19 and a senior vice president of the FealGood Foundation
20 for the past six years.

21 With that said, I deal with many responders, including
22 my own husband, NYPD police officer Christopher Baumann.
23 He was a first responder and he was hurt severely on
24 that day. He never returned after the 11th. His issues
25 mound every day.

1 One of the issues that we had in my family really quick
2 was that my husband, after 9/11, tried to shoot a plane
3 down in the front of my house with a loaded revolver as
4 soon as the planes started to fly again -- I think that
5 was on the 15th. Shortly after that, he tried to kill
6 himself, twice. Shortly after that the family structure
7 collapsed. Not only my family, but it's in families,
8 and my 11-year-old son tried to kill himself, tried to
9 throw himself off of the school building. They caught
10 him climbing up the building.

11 Obviously they were diagnosed with PTSD. I deal with
12 over a thousand responders between the FealGood and
13 between First Responder Alliance. I cannot tell you, I
14 cannot count on my hands, how many of them have had to
15 go -- be taken away, grown men and grown women, taken
16 away by a police officer because they, too, at 4:00
17 o'clock in the morning, have decided that they also want
18 to kill themselves.

19 We urge NIOSH to advise the U.S. Department of Justice
20 that post-traumatic stress be included. In 2006 the
21 Surgeon General recognized PTSD as a physical injury
22 because of the stress that it causes mentally and
23 physically on the body -- heart, there's a hand-- the
24 heart, just -- you're fatigued, the neurological. The
25 yet-to-be-appointed special master of the Victim's

1 Compensation Fund should recognize PTSD as a separate
2 compensatable (sic) condition.

3 There's many other diseases that I do have the
4 unfortunate opportunity to deal with. One of them is
5 kidney disease. Kidney disease can lead to cancer,
6 resulting in kidney failure and need for dialysis and
7 kidney transplant. This we know: that heavy metals are
8 filtered through the kidneys. This is a fact we all
9 know about. Therefore it's not surprising that we have
10 seen an increased rate of incidence in kidney ailments
11 within the 9/11 community.

12 Another ailment is neurodevelopmental disorders.

13 There's a results -- study linking in utero exposure to
14 mild and moderate neurological development problems.

15 Thyroid disorders -- it starts out as a diagnosis and it
16 ends ending up in cancer in -- in exuberant amounts, and
17 I only deal with about a thousand of these people.

18 Neurological disorders, immunological disorders,
19 inflemary (sic) and connective tissue disorders, the
20 blood disorders and the skin diseases are popping up
21 like crazy. It's not just one, it's -- it's -- it's not
22 just one person. It's an over-exuberant amount.

23 Ten minutes -- ten years in five minutes; this is hard,
24 definitely.

25 All right. Current research gaps that -- that we have

1 come to recognize is that research non-covered
2 conditions emerging at increasing rates are including
3 research reproductive abnormally -- abnormalties (sic)
4 such as early sterility, infertility, early menopause,
5 early gestation pregnancy, and low birth weight in
6 babies. It's affecting a lot more than anybody's aware
7 of.

8 And now I'm at my end because I see my little red light.
9 We know from various 9/11 organizations, including
10 family groups, that as we approach the tenth anniversary
11 more people are coming forward for the first time
12 looking for services. Some organizations are now seeing
13 a different population surfacing than their primary
14 target, and it is changing. It changes weekly. Example
15 is the media who worked at various sites, people who
16 live outside the New York metro area, and people who
17 live locally, but -- they're all now seeing problems
18 with their families.

19 Much of this new population is looking for mental health
20 services through som-- though some are looking for
21 medical services as well. Sorry about that. We're
22 concerned that the Act will not meet the needs of this
23 population, and we will consider them part of the 9/11
24 community, and we want to make sure that their needs are
25 addressed, because it is severe.

1 The outreach for the clinical centers and data services
2 should utilize programs conducted by trusted community
3 and labor-based groups with established rapport with
4 these 9/11 responders and the populations of the
5 survivors.

6 And I thank you for your time, and have a good day.

7 **MR. ELLIOTT:** Thank -- thank you for those comments,
8 Ann. And now we'll hear from Glen Klein, followed by
9 Alex Sanchez, Anthony Flaminia (sic) and Steven --
10 Cholinski?

11 **MR. KLEIN:** Good morning. Thank you for being here.
12 Thank you -- thank you, everybody, for being here. My
13 name is Glen Klein. I'm a retired NYPD detective. I
14 was assigned to the emergency services unit on 9/11. We
15 lost 14 of our guys on that day. I was at Ground Zero
16 for over 800 hours, and I retired in 2003 due to 9/11-
17 related illnesses. I had planned to do 30 years. I
18 left a job that I loved dearly because of 9/11-related
19 illnesses.

20 About four years ago while seeking assistance I found a
21 group called the FealGood Foundation, which I know
22 everybody here is familiar with. They asked me to
23 become a board member, and I did. I'm currently still a
24 board member, and I spent hundreds of hours in
25 Washington, DC fighting to get the Zadroga Bill passed.

1 I'm also part of the Zadroga Action Team -- which for
2 those of you who came late and don't know what that is,
3 basically the best way to explain it is we're going to
4 be an oversight to the oversight. We're going to make
5 sure that all the money that is allotted to us by the
6 government is used correctly, and is not squandered away
7 on a hospital that needs a new parking garage.
8 Couple of the other issues are the attribution of
9 illness to World Trade Center exposure. We ask NIOSH to
10 use the same approach as the New York City uniformed
11 services for everybody -- NYPD, the FDNY, sanitation,
12 and the survivor group, the civilians that lived down
13 around Ground Zero and the students who went to school
14 down there.
15 In 2005 Governor Pataki signed into law the World Trade
16 Center Presumption Bill. The bill states that if you
17 were healthy before 9/11 and you worked at Ground Zero,
18 any of the morgues, the barges, the Staten Island
19 landfill, and you became sick later on, it is presumed
20 that your illness was from your exposure to toxins at
21 any of those sites, until proven otherwise by a medical
22 professional. The onus is supposed to be on the medical
23 professional, not the sick responder or the sick
24 civilian who lives down around Ground Zero. We feel
25 that the guidelines -- or similar guidelines should be

1 in place for everybody.

2 As a side note, and I don't know if this has anything to
3 do with NIOSH, but as a New York City police officer,
4 and I'm sure there are other ones here in the audience,
5 that presumption bill that was signed into law in 2005
6 by Governor Pataki is something that is not being
7 adhered to by the NYPD medical unit over at One Lefrak
8 Plaza, and we need to get something done about that.
9 They continually deny police officers disability
10 pension, and hundreds of sick police officers are denied
11 over and over again by the medical board. This has to
12 stop.

13 The next issue that I'd like to bring up is the next
14 generation exposure, our children. We need to have
15 research on the incidences of affected children of male
16 responders whose partners conceived one or two, or even
17 several, years after the men were exposed to the toxins
18 at Ground Zero. We're hearing of many cases of children
19 -- responders -- I'm sorry, responders of chil--
20 children of responders with asthma, sleep apnea, ADD and
21 severe ADHD, which is near and dear to my heart because
22 I have a 6-year-old son at home with severe ADHD. My
23 son has been on at least six different medications, and
24 not a day goes by when my wife and I don't get called by
25 the school about his behavior. There's no history of

1 ADD or ADHD in my family whatsoever. It may not be
2 because of Ground Zero, my exposure to Ground Zero, but
3 it may be, and it needs to be looked at. I know I'm not
4 the only case.

5 And the next important issue is participant care and
6 communication. There needs to be an intercommunication
7 among the Centers of Excellence. They need to share
8 information. At the very least, this makes for more --
9 more thorough medical monitoring. Presently an illness
10 that is covered at one Long Island center may not be
11 covered at Mount Sinai or Robert Wood Johnson in New
12 Jersey. The same goes for prescribed medications.
13 People are covered at some clinics and they're not
14 covered at other clinics. There needs to be one
15 standard of care for all the treatment centers, and that
16 includes LHI, which treats the out-of-state responders.
17 We also need a national information sharing system to
18 better serve the responders who came to New York to
19 assist us on 9/11, and those who moved out of state
20 after 9/11. We have no way of knowing how many of these
21 people may have died already because of their exposure
22 to 9/11, and they might not even know that they died
23 because of exposure to 9/11. This system, if put in
24 place, would be vital in saving lives of those who no
25 longer live in New York and are being treated by

1 hospitals outside of New York.

2 And I thank you very much for your time.

3 **MR. ELLIOTT:** Thank you, Glen. If -- just a note here,
4 if you haven't signed up and you would like to speak,
5 please see the ladies in the back of the room and get on
6 the speakers' roster.

7 Now we'll hear from Alex Sanchez, followed by Anthony,
8 and then Steven. Thank you.

9 **MR. SANCHEZ:** Good morning, ladies and gentlemen, and
10 thank you for being here today. First and foremost I
11 would like to thank Dr. (sic) Elliott and Dr. Howard.
12 Dr. Howard, you have truly live up to your name these --
13 after all these years, our 9/11 czar under the Bush
14 administration and once again director of these programs
15 under the Barack Obama administration.

16 My name is Alex Sanchez. I am a 9/11 responder. On
17 September 11th I witnessed the gates of hell open. I
18 was a very short distance from where we're standing
19 today when the City of New York and our country came
20 under attack. Two days afterwards, on September 13th,
21 my coworker, Monroe Cheko*, who is here today, and I
22 performed cleanup work in skyscrapers surrounding the
23 pit, ten buildings altogether. Many of these buildings
24 are considered on site, One, Two, Three World Financial
25 Center.

1 Today we suffer from permanent total disability from the
2 State of New York. At the mere age of 37 we were
3 diagnosed with disease that we couldn't work any longer.
4 These past seven years Mr. Cheko and I have been
5 advocating and educating two administrations, members of
6 the House and the Senate, on behalf of the men and women
7 who rushed to the front line to uplift a city and
8 economy and a nation.

9 What we would like to see is the same quantity and
10 quality of health care that we have been receiving at
11 Mount Sinai these past eight years. No program is
12 bulletproof, but we really believe these programs are
13 very close to that.

14 As a director of United We Stand, which is a non-profit
15 organization -- we are not a non-profit organization.
16 It's merely two citizens, responders, attending to calls
17 of other men and women who have been -- have come in
18 direct contact with September 11th pollution and are
19 sick, very much guiding them and -- and providing
20 support.

21 The lack of information is as bad as no information
22 whatsoever. My coworker and I truly understand that
23 many who have been affected by September 11 pollution
24 have yet to receive compensation -- worker's
25 compensation. Under this recession, many of the sick at

1 times don't have the \$4.50 to go to the appointment and
2 see their doctors. We would like to see the program go
3 back to its roots and provide transportations for those
4 who are sick. This way, if you do not have the \$4.50 to
5 go see your doctor and keep an appointment, you won't be
6 able to miss out on your medical treatment.

7 We also would like to see a suggestion box at every
8 doctor's office. I mean we cannot fit 30,000 people
9 here today, so we can have patients write their names --
10 or do not write their names -- and very much come up
11 with suggestions so we can make this program much
12 better.

13 We also would like to see ID cards with medical history
14 provided in them. Many, many patients do not live near
15 Mount Sinai or other Centers of Excellence, and they
16 have to go to other hospitals. And many of these
17 doctors very much do not know where to start when a
18 responder or -- or a resident or someone who very much
19 was exposed is sick and they do not know what they're
20 going through.

21 Another issue is many of these cancers are a reality to
22 9/11 responders. For seven years we have been walking
23 the halls of Congress. Many of the men and women who
24 started this journey are no longer with us. And they're
25 no longer with us today due to cancer. It's very hard

1 to look into the eyes of spouses and children, and know
2 that their parents and their loved ones are not here
3 because they were exposed and have died due to cancer.
4 Cancers are a reality among 9/11 responders and those
5 who have been exposed.

6 I would also would like to thank President Obama for
7 signing this bill. I would also would like to pay
8 tribute to James Zadroga, Sr., an officer and a
9 gentleman, raising his granddaughter due to September
10 11th pollution; NIOSH, the AFL/CIO, (unintelligible)
11 valentine, Mount Sinai for continuing to respond to the
12 needs of responders; the FealGood Foundation, John Feal;
13 Unsung Heroes Helping Heroes, Marvin Bathel*. These two
14 gentlemens (sic) are my hero and my champion. Not only
15 do they provide and assist responders, but they have set
16 the blueprint so citizens like Mr. Cheko and myself can
17 go out there and continue to do the same for a group of
18 men and women that very much gave it their all. 9/11
19 Environmental Action, Community Board One, DC 37, Lee
20 Clark; and last but not least, Suzanne Montee, my
21 mentor, we would never have gone upon this journey
22 without meeting this woman.

23 Thank you so much. We will never forget, and may God
24 bless the United States of America.

25 **MR. ELLIOTT:** Thank you, Alex, for those comments.

1 Anthony?

2 **MR. FLAMMIA:** Good morning, gentlemen. Good morning,
3 everyone. My name is Anthony Flammia. I was a police
4 officer with the New York City Police Department,
5 highway patrol unit. I, as many others, responded to
6 this tragic day and fallout from this tragedy, not
7 realizing what we were going into but responding to all
8 in need that day. My service at Ground Zero was for
9 over 200 hours, with various assignments within the
10 police department, which exposed me and others to the
11 toxic site which brings us here today, standing in front
12 of you.

13 I am asking you to listen, and take into account what we
14 all have been through and have suffered due to the
15 exposure. As a result of the attacks and subsequent
16 exposure, I was medically retired from the police
17 department on September 8th, 2008 due to my injuries
18 sustained at the World Trade Center in 2001. My
19 injuries include GERD, reactive airway disease,
20 obstructive sleep apnea, sinusitis, rhinitis, various
21 kidney dysfunctions, costochondritis, various
22 musculoskeletal disorders, and other minor skin
23 conditions; constant feeling of sickness, numbness and
24 disorientation; and finally, post-traumatic stress
25 disorder with delayed onset, which is so severe that I

1 often black out from when I -- from -- when I go from
2 point A to point B and not realize how I got there.
3 My injuries started off with mild symptoms, and many
4 issues came on more severe as the years went on. The
5 World Trade Center monitoring center needs to be
6 patient-centered and developed in a way that promotes
7 the well-being of the patient, and all should be treated
8 with dignity and respect.
9 We are concerned that integrative treatment and
10 alternative medicine will not be covered in this Act.
11 Many have developed chronic illnesses, and have reached
12 the point where their health is no longer improving.
13 They have reached the maximum medical improvement.
14 Alternative therapies have reported that the pursuit of
15 integrative medicine has improved their health and
16 quality of life with these alternative therapies.
17 A stand-fast commitment must be made to research funding
18 for the treatment for the World Trade Center illnesses.
19 Gentlemen, I offer the following explanation for you all
20 to think about. The medical and scientific communities
21 have not seen anything like the fallout from 9/11 in
22 history. Medically, we need to think and treat outside
23 of the box, and reach beyond the current band-aid
24 approach. In the current system first responders are
25 treat-- are being treated for symptoms. In many cases

1 the root causes are not being addressed. Toxic
2 exposures, complications from medications, and
3 structural abnormalities are going untreated. There is
4 a need for an integrative medical monitored approach.
5 This is not a self-administered or alternative approach.
6 The integrative model looks at the patient in a
7 comprehensive manner. Signs, symptoms, medical history,
8 extensive blood work and tests, medication history
9 supplements lifestyle, diet and mental state. It is
10 needed to put together a successful treatment plan that
11 targets the root causes of illnesses and advocates for
12 the patient. The integrative model embraces the
13 traditional medical model and opens up to additional
14 treatment options such as medical acupuncture,
15 nutraceuticals and nutrition, osteopathic manipulations,
16 detoxification programs, and injection therapies. We
17 need to look at how various medications are interacting
18 with one another, and their compounded side effects and
19 complications.
20 Many first responders are on up to 40 medications daily.
21 That's unacceptable. This is not helping them to
22 improve their health, and it's a huge financial burden,
23 especially when their regular insurance would cover the
24 medications. These therapies have improved many of my
25 other conditions, as well as has offered some pain

1 relief. As I progressed and completed my treatment, I
2 feel better than when I came into the doctor's office on
3 a -- when I do go to the doctor. These treatments
4 relieve several of my physical and overall mental
5 symptoms. It is not acceptable that we are told at the
6 Centers of Excellence that they are offering some
7 alternative means of treatment, and there are only a
8 couple of slots open for responders.
9 On the advisory panel we were told some methods are
10 being explored and offered. A couple of spots for a
11 thousand people -- not acceptable.
12 Please accept these explanations and re-evaluate the
13 current treatment at the Centers of Excellence to direct
14 some of the funding for this.
15 Thank you, gentlemen.
16 **MR. ELLIOTT:** Thank you, Anthony, for those comments.
17 Steven Choinski? Followed by William Moore, then
18 Michael McPhillips.
19 **MR. CHOINSKI:** Thank you. I came here originally -- I'm
20 a member of the FealGood Foundation. I have nothing --
21 I'm sorry, I'm sorry -- I have nothing rehearsed; this
22 is all from the heart. Okay?
23 I came here to take notes. I didn't know I was going to
24 speak today. All I was -- I was going to put my suit
25 and tie on and shave (indiscernible). Thank you.

1 Okay. In all seriousness, from the heart -- okay? In
2 1982 I went to college and I graduated from Brockport
3 State, I was a social work major, and I worked with
4 outpatient Viet Nam veterans, and I'm going to get to
5 9/11 and a little correlation here. Okay? I sat at a
6 little table, I was a little social worker in front all
7 the head of psychiatry and all the medical -- and I did
8 a term paper on Agent Orange. And they all said oh,
9 they're never going to pay out for the veterans. We're
10 never going to pay out blah, blah, blah, blah. And I
11 sat at the end of the table, I was a little -- little
12 puke there, and I said oh, your little bureau-- your
13 little liberalism ideas as a little college student is
14 never going to pass.

15 Ten years later I'm driving in my police car around
16 Manhattan and I see this zipper -- VA Administration,
17 federal government settle large lawsuit with Viet Nam
18 veterans for \$55 billion -- whatever the amount is. Ten
19 years later they paid out for these people. A lot of
20 them suffered and they died, and it was just the idea of
21 how long they had to wait to get treated.

22 Now I have no cancer, not at all. I have no ax to grind
23 with cancer. These people out here with cancer, my best
24 friend in the police department, Rich Ruggerio, who
25 cannot make it today, he's very sick, has cancer. He

1 had throat cancer. He's in recovery.

2 Okay, my point is I get on this FealGood Foundation bus
3 every day for the people who can't make it on that bus,
4 who are already sick or died. I sit next to widows and
5 orphans from every trade -- construction workers to
6 firemen to policemen to cleanup workers, whatever they
7 are. I get on that bus and I get sick when I come home
8 because that -- those kids that don't have a mom and dad
9 could be me tomorrow. They need treatment.

10 Last I heard there's this place called Sloan-Kettering.
11 It's one of the finest cancer hospitals in the world.
12 They said they're ten years ahead of everybody else in
13 the world. Anybody who knows anything about cancer
14 comes here, stays in the hotel across the street and
15 goes to Sloan-Kettering because we are the leaders of
16 the world. And this is not a knock on Sinai, I love
17 Mount Sinai. I think it's one of the greatest places in
18 the world to get treatment. I live in Long Island and I
19 come to Mount Sinai 'cause I want to live, because I
20 have my own issues with illnesses. But that -- it's not
21 about me. This is about people with cancer I'm trying
22 to speak for.

23 Okay? I just lost my train of thought for a second, I'm
24 sorry.

25 So that's what I want. I want Mount Sinai to

1 coordinate, along with the federal funding, to get
2 Sloan-Kettering involved. And then when we do come out
3 with this list of cancers -- and like the detective that
4 was up here before and he talked about cancers that we
5 don't know about, or minute, they're coming out -- we
6 were all poisoned down there, everybody who worked down
7 there, from A to Z, was poisoned. We were poisoned. We
8 had paper masks or no masks at all and that's why we
9 were poisoned, because we didn't stand a chance. Okay?
10 Let's not learn the hard way through example, through
11 life and history like Viet Nam veterans. Let's get the
12 aid, let's get the money, and let's help these people
13 with cancer before they all perish. Let's give them
14 help what they need now and let's -- let's get Sloan-
15 Kettering going, and let's Mount Sinai and -- and the
16 doctors of the world and the administrators of the
17 world, and let's get the money to the buck and let's get
18 it going.

19 Thank you. Thank you.

20 **MR. ELLIOTT:** Thank you, Anthony, and now we have Steven
21 -- or that was Steven, sorry. Now we have William --
22 William Moore.

23 **MR. MOORE:** Good day. Thank you for letting me speak.
24 My name is William Moore. September 11th, 2001 was a
25 horrific day of -- for America. According to the 9/11

1 commission report it was a day of unprecedented shock
2 and suffering in the history of the United States. To
3 address the uncertainty about the short and long-term
4 effects on our country and the rest of the world,
5 miscalculated steps were taken to minimize our exposure
6 and vulnerability to our country. These miscalculated
7 steps were supposedly taken to protect us as a nation.
8 This protection would require individual sacrifice, some
9 knowingly and some not. Many on that day were willing
10 to make that sacrifice, and others had no choice.
11 Many believed that on that day, and the weeks following,
12 we came together in unity as a strong nation. But as
13 time passed over the years, we have found out that our
14 government did not come together for us. That is why
15 some of us are here today. These miscalculated steps
16 have yielded severe consequences. Findings of these
17 miscalculated steps have been exposed in many reports,
18 including the 9/11 commission report and the EPA's
19 inspector general's report. Mandated environmental
20 studies were interfered with and manipulated. Accurate
21 investigation was prevented in both timeliness and
22 access.
23 Many of us affected by the consequences of this
24 miscalculated steps have mistrust in the handling of the
25 Zadroga Bill funding. Plausible deniability is a

1 primary reason. Scientific research shows potential,
2 suggestive and probable causation for health effects to
3 all the body systems and dysfunction of all the organs
4 of those exposed by the toxic cocktail created by the
5 collapse of the World Trade Center buildings. Yet
6 presented by New York City's update reports, disease-
7 wise only one and a half body systems have been
8 associated with health effects caused by the World Trade
9 Center toxic exposure. This includes the respiratory,
10 and only a portion of the GI tract, the upper GI system.
11 Through one of the centers -- through the centers of the
12 ex-- Centers of Excellence established by New York City
13 and the federal government, evaluation and treatment is
14 provided to us only for these two systems. We're
15 referred to our health -- our own health care providers,
16 utilizing our own insurance or out of pocket funds for
17 other system ailments and treatments. As we all know
18 that the City of New York is a defendant in a class
19 action suit due to its mishandling and mismanagement of
20 the World Trade Center 9/11 events, so is it any wonder
21 that minimal health effects have been identified through
22 the screening and treatment programs that were sponsored
23 by New York City. Minimal effects -- minimal health
24 effects means minimal liability.
25 Identification of specific ailments has less impact than

1 a detected systemic disease which affects multiple
2 organs and systems. The program screening and treatment
3 program design is flawed and needs to be redesigned to
4 screen, evaluate and treat all potential and probable
5 cause health effects from the exposure, and adjustment
6 should be made for the purpose of compensation as well.
7 Those suffering from other than permitted ailments lose
8 twice -- once for proper health care and once for
9 compensation.

10 As it was already explained, we have a lot of scientific
11 evidence that shows that the exposures that we had to
12 the different chemicals and heavy metals can yield
13 severe consequences with our health. All I'm doing is
14 urging others as myself to petition for redesign of the
15 program and refunding the removed \$4 billion for the
16 Zadroga Bill that was basically stolen from the till.
17 Just like the health bill is being recreated, we can go
18 back for that Zadroga bill to be recreated so we can get
19 back that \$4 billion.

20 I thank you for your time.

21 **MR. ELLIOTT:** Yes, thank you, William. And now we have
22 Michael McPhillips, followed by William Gromer and
23 Nehemiah --

24 **UNIDENTIFIED:** (Unintelligible)

25 **MR. ELLIOTT:** Okay, you did it. Very good. You got it.

1 Yes, sir. Thank you.

2 **MR. MCPHILLIPS:** Hello, my name is Michael -- Captain
3 Michael McPhillips. I'm a disabled retired port captain
4 who worked for New York Waterway. New York Waterway is
5 a privately-held company that carries approximately
6 60,000 commuters daily from all parts of New Jersey to
7 New York City. I was the port captain in charge of the
8 evacuation and support operation on 9/11 and the days
9 thereafter. At 8:47 a.m. on September 11th I received a
10 phone call from a deck hand informing me that a plane
11 had hit the World Trade Center, and that one of the
12 towers was on fire. After grabbing certain staff
13 members, I immediately took a boat to the World Trade
14 Center and upon arrival began directing the waterway
15 evacuation. I also worked with New Jersey Transit to
16 set up the two triage areas and the one decontamination
17 area on the Jersey side of the river.

18 In the days that followed I was in charge of New York
19 Water-- in charge of waterway transportation for the New
20 York National Guard, and we also went down to the site
21 every day with family members of the deceased. I was
22 fortunate enough to be able to serve, you know, my
23 country and be part of the largest water evacuation in
24 recorded history of the world. I would not trade that
25 honor for anything.

1 However, I became disabled in September 2003 and was
2 forced to retire. It was not until 2006, after a series
3 of tests and much research, I became aware that my
4 illness was directly related to 9/11. I got sick, and I
5 just thought I was sick like everybody else.
6 I've had the privilege of being able to support the
7 FealGood Foundation in its effort to get the Zadroga
8 Bill passed. I've traveled to Washington more than a
9 half a dozen times over the last three years to help
10 advocate for this bill. Now that it is passed, we have
11 created the Zadroga Action Team to advocate for the
12 proper implementation of that Act. We urge NIOSH to
13 ensure that there is an agreed-upon, consistent quality
14 of medical care and treatment provided by all
15 participants in the world health program.
16 There needs to be consistency of treatment.
17 Participants who are communicating identical symptoms
18 during the monitoring process at each Center of
19 Excellence must be treated the same in consistent
20 manner. Disparities among treatment offered by
21 physicians at the various Centers of Excellence must
22 end. Disparities in the determination of program
23 eligibility based on reported symptoms and conditions
24 must end. Participants need to be treated holistically
25 at one center. The practice of referring patients back

1 to their own doctor for certain symptoms and ailments
2 rather than being treated at the center must be
3 considered.

4 There needs to be consistency in evaluation. There
5 should be a consistent standard for evaluating symptoms
6 and ailments needs to be established and followed by all
7 Center of Excellences and administrative programs.

8 There should be timely reporting of test results.

9 Centers of Excellence must inform participants of test
10 results in a timely manner, enabling participants to
11 access treatment without delay. Most medical
12 practitioners provide test results within seven to ten
13 days. Sometimes it'll take weeks and weeks to get it
14 from the World Trade Center.

15 There must be research for first responders' children
16 and spouses who now have illnesses resembling those of
17 the responders. I have two kids. They both have
18 asthma. One has sleep apnea, and they suffer from all
19 sorts of illnesses.

20 The covered conditions -- PTSD, again, (indiscernible)
21 standard cite, in 2006 the Surgeon General declared it
22 as a physical illness. It must be considered like
23 everything else.

24 Transparency, we have to have transparency in
25 everything.

1 You know -- you know, we all stepped up to the plate
2 when we were asked to on 9/11 and the days thereafter,
3 and now we ask you to help us make sure that everyone in
4 the 9/11 community is given the best care possible.
5 Thank you.

6 **MR. ELLIOTT:** Thank you, Michael. William Groner. And
7 after William we have Nehemiah, then Susan Sidel and
8 Reggie Hilaire. And we have no further sign-ups after --
9 -- after that. So again I would encourage anyone -- you
10 know, we could take a break, but anyone who wants to
11 speak may want to sign up, so...

12 You may proceed, William.

13 **MR. GRONER:** Hi. I'll -- I'll stick around afterwards
14 for specific questions.

15 Mr. Elliott, Dr. Howard, thank you for hosting this
16 forum. Dr. Howard, it's very nice to see you again
17 since we met many, many years ago. You showed an early
18 interest and sensitivity to the plight of the
19 rescue/recovery workers back I think in 2002 when we
20 first met and we talked about cancer, and I'm so happy
21 that you're part of this program.

22 My name is Bill Groner and my firm, Worby Groner
23 Edelman, in White Plains started this litigation back in
24 2003. We then joint-ventured with Napoli and Bern and
25 have -- and now represent over 10,500 first responders

1 and cleanup workers.

2 I have been tasked -- I took it on myself to take care
3 and review and study and analyze the medical side of
4 this, and I've done so for seven years. I've studied
5 the medical periodicals, the peer-reviewed articles, Dr.
6 Perezant's great work, as well as cataloguing the
7 illnesses seen by our -- our cohort of over 10,000
8 clients.

9 One of the most difficult parts about this litigation
10 and representing these clients is the one question that
11 I could never answer. And that was: What about the
12 future? What about the unknown? What about the
13 illnesses that may develop? Who's looking into that?
14 Who's protecting us? Who's involved? Who cares? And
15 certainly a great moment was when Zadroga was passed,
16 just the health and monitoring side, because I felt for
17 the first time somebody will be in charge of looking at
18 this. Somebody will look ahead of the curve.

19 And by the way, I want to thank Congressman Maloney,
20 Congressman Nadler, Ben Chabot, the FealGood
21 organization, who just did fabulous work in getting this
22 thing passed.

23 What I'd like you, Dr. Howard, to focus on -- and I've
24 come up with about five things in my mind of issues
25 about future illnesses that I hope that you look at.

1 First of all, unfortunately the medical community needs
2 to be -- is conservative by definition. They need to
3 see the illnesses develop for years and years before
4 they start discussing it, before they talk about
5 relationships. I mean just the first study came out
6 multiple myeloma where they only had eight in the study
7 last year. We've known about more than that in our data
8 pool for many years. By definition the medical
9 community -- it takes some time. They have to get grant
10 money. They have to do the study. I hope that you can
11 be more aggressive than that. I hope that you have a
12 standard about looking at illnesses that, if they're
13 suspicious, we don't have to prove it beyond a
14 reasonable doubt. If they're suspicious, you will look
15 at them.

16 Five -- five groups that I want to talk about real
17 quickly. First one is cancer. All we can talk about
18 cancer now is epidemiologically, what's the incident
19 rate of the cancers. Studies will come out in -- over
20 the years. We don't have years. We need to jump on
21 this right away. My biggest concern is that if you're
22 only relying upon the cancer incident rate from the
23 Centers of Excellence, that's not all the cancers. We
24 have a number of cancer clients who are going to other
25 institutions. Somehow that data needs to be pooled.

1 You need to be aware of it. If there's greater
2 incidence of multiple myeloma that Mount Sinai's seen
3 from Ground Zero, you need to know that now. And I
4 would like to continue -- or start a dialogue and
5 continue that dialogue.

6 Second, interstitial lung disease. I have hundreds and
7 hundreds and hundreds of clients with nodes, nodules,
8 granulomas -- this is scar tissue of the lungs --
9 suspicious CAT scan findings. I don't think there --
10 it's being paid attention to. If it's the precursor to
11 interstitial lung disease, it needs to be looked at. I
12 mean a five-year Mount Sinai study showed abnormal FVC,
13 higher than they thought, and that's precursor,
14 potentially, possibly, to interstitial lung disease --
15 has to be looked at.

16 Third, idiopathic diseases. There are unusual diseases.
17 People were healthy beforehand, and they're not now, and
18 they're across the board. We have a couple of clients
19 with IGA nephropathy, severe kidney disease, that no one
20 is taking seriously. It's suspicious. You should look
21 at these things. There's many idiopathic diseases --
22 thyroid diseases, cardiac issues, dermatological issues
23 -- that people are not necessarily relating. I pray
24 that you do that.

25 Two other quick ones -- sleep apnea, I see the studies,

1 they say maybe it's not related. But you know what, I
2 have hundreds and hundreds of clients with sleep apnea.
3 I understand that you -- generally it's felt you have to
4 be -- a high body mass index, you have to be overweight,
5 maybe it's related to sinus. But we have clients that
6 don't have chronic rhinosinusitis, they're not
7 overweight, and they have sleep apnea, and they're on
8 oxygen. This needs to be studied.

9 The last group is GERD. GERD is looked at as sort of a
10 casual disease, take some Nexium, no big deal. But GERD
11 can cause Barrett's esophagus. We have a lot of clients
12 with Barrett's esophagus. That's a precursor to
13 esophageal cancer.

14 What I pray that you do is you look at these diseases,
15 you study them, and you educate all of these first
16 responders about symptoms -- if you have them, go to the
17 doctors; you educate the doctors -- this could be Ground
18 Zero-related, here's what you have to do; and you work
19 on early detection. These people need to know they can
20 go to sleep at night knowing you're thinking about
21 preventing future diseases.

22 Thank you.

23 **MR. ELLIOTT:** Thank you, William. We -- before we have
24 Nehemiah come up we're going to take a ten-minute break
25 -- a comfort break, if you please -- and we'll be right

1 back at ten till.

2 (Recess taken from 10:44 a.m. to 10:58 a.m.)

3 **MR. ELLIOTT:** Thank you. Thank you for coming and
4 commenting. Please take your seats so that we can be --
5 get started again, please.

6 (Pause)

7 All right, if we can restart here, we're going to
8 restart with Nehemiah Bar-Yehuda.

9 **MR. BAR-YEHUDA:** It's -- that doesn't -- does it? Ah,
10 okay, okay.

11 So as you know by now, my name is Nehemiah Bar-Yehuda,
12 and as you know also, I have an Israeli accent, so if
13 you don't understand me -- we speak fast in Israel --
14 please ask me to slow down. Okay?

15 I start with a few personal note and then I'll read from
16 my written testimony.

17 I start with -- from -- with some personal note, and
18 then I'll read from my written testimony.

19 Since I'm -- was in high school in kibbutz in Israel,
20 besides teaching yoga and doing body/mind work for -- to
21 (indiscernible) people, has been to see a social need
22 and to respond out of the box what society doesn't do.

23 So the first charity, after serving in Israel, in
24 America is serving those who serve, which give holistic
25 medicine to detoxify the body. By now the two thousand

1 and six hundred of the people, many of them are sitting
2 here, including John Feal and many of his people,
3 including the first people who testify, Rhonda Villamia
4 and Jennifer Spano -- they give me permission to mention
5 their name -- the person who speak after me, and they
6 all claim the benefit and they come to volunteer for us
7 because we don't get the money so we need volunteers.
8 We are self (indiscernible) as volunteer. I work -- I
9 volunteer as a body work therapy in -- across the street
10 from the pit and the cafeteria. Those of you who worked
11 there remember. And then in St. Paul Church until they
12 closed it.

13 And I straight away saw that people were coughing and
14 the press was not reporting, except for one article by
15 Sanchez, I think was his name, from The Daily News. So
16 I realized here is a need. I realized that the most
17 neglected as outcome of this tragedy is going to be the
18 pollution, before anybody was talking about it. I've
19 seen it in Agent Orange. I've seen it in -- commando
20 people who were -- in Israel who were doing -- in deep
21 water, toxic water. It takes years for society to
22 recognize the problem. But here, unfortunately, the
23 problem was in the lungs, so it come fast, they had to
24 respond fast. That problem number one, I realize.
25 Problem number two I know, they are going to work on the

1 symptom and if it's medicine, which is great, but they
2 are not going to detoxify the system because it's not --
3 it's out of the box. So I look for protocol and I
4 research with three of my friend in charity, and we
5 found a protocol that cleanse the system -- the lungs,
6 the body, and support the immune system. People told me
7 -- good people, told me, nobody from the fire department
8 are going to come to you, because of the effect. The
9 captains are telling one another, they inviting us with
10 -- behind the back of the fire department to the fire
11 houses and a thousand and two hundred people, which is
12 close to ten percent of the people who were there from
13 the fire department, have been treated by us.
14 Now, we are not perfect of a organization, and our
15 mission is to help people recover from both the physical
16 illness and the psychological stress of 9/11. Our main
17 program are Ayurvedic herbal formulas which were
18 developed by world-renowned Ayurvedic doctor, Pankaj
19 Naram, who has worked with Mother Theresa and the Dalai
20 Lama. Ayurveda, for those of you who don't know, is the
21 ancient medical art and science of India over 5,000
22 years.
23 Our programs are supervised by Western MDs, led by our
24 chairman of the board, distinguished integrative
25 psychiatrist Dr. Richard Brown of Columbia College of

1 Physician and Surgeon, and gives over -- who -- who is
2 teaching Columbia College and give over 200 medical
3 conference talks a year all over the world.
4 Our Ayurvedic -- our Ayurvedic herbal formula are meant
5 to be integrated with whatever medical
6 protocol/pharmaceutical one is doing. Which mean we are
7 not alternative. We are not fighting with medical
8 profession. We want to work together. Okay?
9 A study was done of our herbal program by Dr. Kathy
10 Falks of Mount Sinai College of Medicine and Dr. Jim
11 Dahl, then senior researcher at Phoenix House, one of
12 the top drug treatment program in the U.S. This study
13 was published in the peer-reviewed journal, Alternative
14 Therapies in Health and Medicine. You can see it on the
15 front page of our -- you can -- link on our web site.
16 In this study our program participant reported that Dr.
17 Naram's herbal formula that we distribute for 9/11
18 toxicity were 32 percent more effective for them than
19 any other treatment they tried. There's a statistic way
20 of questioning and writing it by scientific, and it was
21 done this way -- this way, and it's a huge statistical
22 difference, 32 percent, including emotional challenges.
23 Why it works? Because our approach was -- you have to
24 deal with the root cause. You have to cleanse the body
25 of toxin. It's not enough to treat the symptoms. You

1 better do it be-- many people came before they had
2 cancer and maybe they don't have cancer because of it.
3 If they have cancer, they still -- we still can help
4 them and so in all these conditions.
5 We have a -- the first person who came to us, when he
6 came to us he was the first fireman. He was our guinea
7 pig when we start -- start -- tried. We had -- he had
8 30 percent lung capacity, but now he has more than 70
9 percent. Some firemen came back to force. They were
10 retired and they came back. Now one of them is now
11 captain -- became captain.
12 Our other main programs are Breathwork and Meditation
13 workshops -- one of them is going to be given this
14 weekend and next weekend in Staten Island -- taught by
15 Dr. Brown. Dr. Brown has taught these workshop all over
16 the world, to health professional as well as people
17 affected by trauma, as natural disaster, Viet Nam war,
18 Afghanistan and so and so. In emotional trauma it did -
19 - he helped them with their physical and emotional, in
20 addition to those who serve the 9/11 community.
21 Dr. Brown and his wife work together integrative --
22 she's integrative psychiatrist also, Dr. Patricia
23 Gerbarg. They have gathered research done in peer-
24 reviewed journals and are conducting research that
25 demonstrate that the techniques that they teach in this

1 course have dramatic effect in both reducing the symptom
2 for the worst kind of trauma, raising lung capacity, and
3 helping the enormosity (sic) of the psychological
4 process such as -- and psychological post-traumatic
5 stress.

6 The experience of the 9/11 community that trust us and
7 come to us without any advertisement, without -- we have
8 research, but we still don't have the money for blind
9 test research -- shows that our work should be
10 researched and financially supported by the Zadroga Bill
11 as an important contribution to helping the 9/11
12 community heal from both the physical illness and the
13 psychological trauma associated with 9/11 illness.

14 To close, people from 9/11 who were volunteering get our
15 herbs for free with the amount of funds that's been
16 given. Our cost by (unintelligible) give it for the
17 resident is \$30 a month, one dollar a day.

18 With a fraction of the \$4 billion, small fraction, for
19 research to prove the efficiency of program like us and
20 other program -- I don't want to claim exclusivity -- in
21 addressing the root cause, thinking out of the box,
22 y'all commission and all other organizations involved
23 can save so many life that it's worthwhile testing and
24 funding.

25 Thank you. I appreciate it. And the person who talk

1 after me is also one of our recipient, please.

2 **MR. ELLIOTT:** Thank you, Nehemiah. Susan Sidel, and
3 then we'll have Reggie Hilaire.

4 **MS. SIDEL:** Hi, I'm Susan Sidel. How are you? Okay,
5 can you hear me? No, I don't want to hold it.
6 My name is Susan Sidel, and -- you can't hear me.
7 Closer to my mouth? Is that better? Okay. All right.
8 Thank you.

9 My name is Susan Sidel, and before 9/11 I was an
10 attorney -- an entertainment attorney. Now I'm
11 disabled, totally and permanently. I have brain damage.
12 I have a connective tissue disease. My back is falling
13 apart. My lungs are -- actually have improved because I
14 -- I was in -- I did take the herbs that Nehemiah is
15 talking about. I started them in 2009, and also I did
16 the Breathwork, and you can ask Dr. Crane*, because he's
17 my doctor and he has all the -- all the data.

18 I have two things that I wanted to talk about. One is
19 all this talk about medical research linking toxins to
20 the World Trade Center. And the second thing I want to
21 talk about is the New York State Worker's Compensation
22 volunteer program.

23 The first thing I want to talk about is -- let's talk
24 about the -- the studies that are out there. And you
25 know, my father is a -- well, he's retired now, he's 88,

1 but -- but he was one of the very first OSHA engineers.
2 He had to be certified when OSHA came into being. He
3 went to MIT -- had to go back to school and, you know,
4 learn all about OSHA. And in his study I found this
5 little book called The Rapid Guide to Hazardous
6 Chemicals in the Workplace, and it's a really easy
7 booklet. You look up the chemical and it says, you
8 know, what happens when you're exposed to it. And it
9 talks about different kinds of exposure, you're exposed
10 through the skin, you're exposed through the nose, you
11 know, did you drink it. So for example, mercury. There
12 was a gentleman that was talking about the light
13 fixtures in the twin towers, so in this book, Fallout by
14 Juan Gonzalez, he won a Pulitzer for the research that
15 was in The Daily News, I think there's some -- I think
16 he says that there's -- there were 500,000 fluorescent
17 lights just in the twin tower buildings alone, so that's
18 a lot of mercury.

19 So this book -- this is from 1984 -- it talks about how
20 mercury causes brain damage. And in this book, which is
21 like a new book that NIOSH puts out, along with the CDC,
22 it says the same thing. So I don't understand the
23 disconnect between the way the whole program is run and
24 what you're calling research. Because this is your --
25 not -- I'm not -- I don't mean you, I mean the

1 government, so it's not you personally, please. I mean
2 I don't understand the disconnect because it's well
3 established what toxins -- certain toxins can do to
4 people physically. And if I were running the program
5 from the very beginning, from day one -- and I realize
6 that you were hindered by the Bush administration --
7 what I would have done is I would have made a list of
8 all the chemicals that were down there and all the
9 potential health hazards that could come as a result.
10 So for example, the three cognitive tests that I've had
11 that show that I could never have gone to law school
12 with the brain that I have now, I could never have
13 passed the New York Bar with the brain that I have now
14 because I have so much brain damage, you know, from
15 exposure probably to mercury and lead -- that would have
16 been figured out at the very beginning, and maybe that
17 would have been something that could have been treated.
18 I have a connective tissue disease that took two years
19 in Worker's Comp court to prove. And the way that that
20 got diagnosed was not through Mount Sinai; it was
21 through -- I had to go to a private doctor because it
22 wasn't on the -- back in those days it wasn't on the
23 list of conditions that were -- I don't think
24 musculoskeletal issues were even on the list generally.
25 I think that was added later because I remember talking

1 to Dr. Herbert about it and, you know, connective tissue
2 disease falls under that. So I have like a positive
3 ANA, and sometimes I have a positive anti-DNA. It's
4 like well-established that, you know, you can have a
5 connective tissue disease -- sometimes it happens from -
6 - hereditarily, but usually with women it would affect
7 you -- you'd find out in your early twenties. For me,
8 it happened to me in my mid-forties. So the other way
9 that you can get a connective tissue disease is from
10 exposure to toxins. I mean that's not -- that's not new
11 information.

12 That's like very well-established that -- so when I was
13 listening to this gentleman here, he sounds like his
14 symptoms are very similar to mine. But because he
15 didn't go to a rheumatologist and have that panel of
16 labs done where they test -- you know, they don't just
17 do a complete blood count. They do -- they -- they do a
18 rheumatological panel and they're testing for like your
19 -- you know, your anti-ANA and your anti-Ro and your
20 anti-DNA, and they're testing like your IGG and your IGA
21 and all those other immunogammaglobulins -- I'm so not a
22 doctor and I did bad in science. But you know, there
23 are tests that could be done. And you know, the doctors
24 at Mount Sinai are -- are not expert rheumatologists,
25 nor should they be.

1 And what I don't understand is, this is America, and you
2 know, we have so many brains here, and especially in New
3 York, why aren't you -- why aren't you engaging Sloan-
4 Kettering to help with cancers? Why aren't you engaging
5 Hospital for Special Surgery to look into
6 musculoskeletal issues and -- and autoimmune diseases?
7 You know, why aren't you getting the biggest brains in
8 the country involved in this?
9 I'm from Boston originally and I have a friend that was
10 also a volunteer. She drove down from New Hampshire,
11 and she has to drive to Worcester, Massachusetts --
12 which is not a nice place -- to go to a hospital, one of
13 the Centers of Excellence, that, you know, is -- I think
14 it's affiliated with U. Mass., which is -- has a really
15 good public health program. But you know, my question
16 is why don't you have Harvard's public health program
17 involved? I mean they're like the number -- you know,
18 they're like tops. I don't understand why we're not
19 getting the best and the brightest involved.
20 And the other thing that I wanted to talk about just
21 really quickly is with the Worker's Compensation program
22 because with my treatment there's been such a delay
23 fighting my doctors, fighting Dr. Crane, you know,
24 fighting my doctors at Hospital for Special Surgery,
25 that it has hindered my health. And I know that they

1 got \$15 million from the federal government and there's
2 about 1400 and -- I think 1400 or so volunteers --
3 unpaid volunteers, sorry, that are in that program. Why
4 are they fighting these claims? That -- that bill that
5 created that fund, we're supposed to be treated
6 expeditiously and compassionately. That has not been
7 the case. I mean sometimes they're -- they're good at
8 things, but for the most part it's not the case. And
9 why hasn't there been an accounting to see how much
10 money is spent fighting claims versus -- versus just
11 treating them? Because if I'm winning all those cases,
12 then what's the point of -- of taking me to court, you
13 know, three times and doing a bunch of IMEs? It's a
14 waste of money.

15 Thank you.

16 **MR. ELLIOTT:** Thank you for those comments, Susan. Now
17 we'll hear from Reggie Hilaire, followed by Barbara
18 Horn, then Darcia Hemphill. Reggie?

19 **MR. HILAIRE:** Hi, good morning. Can anybody --
20 everybody hear me?

21 All right. Thank you, Dr. (sic) Elliott, Dr. Howard,
22 for this forum. I'm a New York City police officer. I
23 was appointed -- I was hired in September 2000,
24 graduated from the Academy May 2001. I spent over 850
25 hours at Ground Zero on Staten Island. In 2005, at the

1 age of 34, I was diagnosed with thyroid cancer in June
2 of 2005, and then multiple myeloma, a blood cancer, in
3 December 2005.

4 At the time, I didn't know anybody that worked down
5 there that had cancer. 2011 I know of 13 MOS -- that
6 means members of service -- of the New York City police
7 department with cancer, and two unfortunately passed
8 away.

9 When you're dealing with cancer you're not dealing with
10 -- you're -- you're being thrown at everything, and the
11 least on your mind is "Oh, I have to notify the City, I
12 have to notify Mount Sinai." But because I had so much
13 time on my hands because I was out sick, I went on the
14 computer and I was like okay, let me notify Mount Sinai
15 and let me notify the New York City's World Trade Center
16 health registry. I told them that I have cancer. I
17 have thyroid. I have multiple myeloma -- just to cover
18 -- just to let them know, to let everybody know.

19 I'm being treated for both cancers at Sloan-Kettering,
20 which if you know in New York City, that's the best
21 place in the world to go. I told my hematologist about
22 my work down there, and months later -- I have to go
23 every couple of visits, every couple of months -- he
24 comes to me and like "You're a cop?" I said yeah. "You
25 worked at Ground Zero?" I was like "Yeah, I did; why do

1 you ask?" "Well, I'm seeing other patients with blood
2 cancers." So I asked him "Do you think there's a link?"
3 Like "I don't know, it's too early to tell."
4 I support everybody's help with the Zadroga Bill as
5 great, but when I downloaded the law and I read it, I
6 was kind of shocked because in order for a cancer to be
7 added, we need published evidence. However, I hope I'm
8 not reading it wrong, other conditions and interested
9 parties can petition the administrator to add this -- a
10 condition to the list. I have a problem with that
11 because it's -- it seems we're separate and unequal.
12 People with cancer -- the guys I know have cancer, the
13 last thing on our minds was to -- to notify everybody.
14 However, I'm very concerned about people down the line -
15 - other cops, other firemen, other first responders
16 regardless of what they -- how much they did or what was
17 their affiliation, would they be afforded the same
18 rights? However, I'm not trying to say we're different
19 or special than anybody else. We all worked down there.
20 We're all brothers, sisters together. However, cancer -
21 - we're -- we feel like that we're the stepchild. We
22 know, we're hearing people with cancer. However, our
23 burden of proof is different.
24 I propose that it shouldn't be separate and unequal. We
25 should have the rights -- the rights. My union knows I

1 have cancer. My union introduced me to other people
2 that have cancer. Why can't -- and the police
3 department, the medical division, knows of myself and
4 others. I believe, like other speaker have said, we --
5 we have a small window of opportunity, about five years,
6 before Zadroga has to be re-funded. Being a New Yorker,
7 being a cop, I'm being very cynical. I don't know we're
8 going to get re-funded at this point. I feel everybody
9 should be proactive. The unions should tell the
10 administrator, this is -- our members have this. The
11 administrator should go to the -- to the departments,
12 the fire department, the NYPD, to ask you guys, ask the
13 agencies "Hey, you guys are seeing anything? Are your
14 members sick?" I just feel it's very slow. We need --
15 as a cancer survivor, I feel like I'm proactive. This
16 caused me to be proactive. We have a small window of
17 opportunity to do this before members die and other
18 people have cancer. We're not even thinking about it.
19 The doctor -- the medical community is not even thinking
20 about cancer. When I tell them about this, everybody,
21 they're like "Well, we're not sure." The red light
22 should go on. We should think outside the box because
23 this is unprecedented. There's no medical evidence --
24 just, again, be proactive. We should be afforded the
25 same opportunities to petition the administrator, either

1 us as victims, as first responders, or our unions or our
2 agencies or anybody, because right now I just feel the
3 letter of the law is -- the administrator goes by the
4 letter of the law. It's not fair.

5 And thank you very much.

6 **MR. ELLIOTT:** Thank you, Reggie. And now we'll hear
7 from Barbara Horn, followed by Darcia Hemphill, and then
8 Dr. Margaret Dessau.

9 **MS. HORN:** Good morning. Can I be heard? Closer? Just
10 right? Okay. Do this (indicating) in the back if my
11 voice goes down.

12 I'm going to go off-script just for a moment because
13 this is a poem that I have heard read, and read
14 sometimes when we remember September 11th. It's by Jane
15 Stanton Hitchcock. It's a quote, really.

16 (Reading) A violent act pierces the atmosphere, leaving
17 a hole through which the cold, damp draft of its memory
18 blows forever.

19 So I think we're feeling that draft. My name is Barbara
20 Horn. During the 9/11 recovery I served my country as a
21 volunteer at St. Paul's Chapel. St. Paul's Chapel is
22 where George Washington and members of Congress walked
23 to immediately following the swearing-in of our first
24 president. This is the house of worship where they came
25 to pray for the strength and courage they needed to

1 govern our brand new nation.

2 St. Paul's Chapel is also the place where thousands of

3 recovery workers walked to day after day, night after

4 night, as they cleared the wreckage and recovered the

5 remains of those who perished at the World Trade Center.

6 This is the house of worship where they came to pray for

7 the strength and courage they needed to continue their

8 labor of love at the site of the first attack on our

9 nation's shore.

10 I am part of the Zadroga Action Team. I'm also a

11 veteran of the lengthy and ultimately successful

12 lobbying efforts for the 9/11 James Zadroga Health and

13 Compensation Act. It is due to the efforts of the

14 veterans of 9/11, some who are here today, some who are

15 too sick to attend, and some who have suffered and died

16 because of their 9/11 service, because of them and the

17 Congressional delegates who heeded their cries -- that's

18 what brings us all here today.

19 It is my fervent desire to see that there's no more loss

20 because of the 9/11 attacks. I do not want one more

21 survivor or one more responder to die because of what

22 the terrorists did here.

23 Therefore I urge you, NIOSH, who have been given the

24 sovereign duty to implement this law, to consider the

25 following:

1 First and foremost, help the children. We must do our
2 utmost to bring to bear every resource and remedy to
3 alleviate the suffering of the children because of their
4 exposure, or their parents' exposure, to the toxins that
5 filled the streets and air of our great city and the
6 surrounding areas. We must do everything possible to
7 care for them. If we don't help our children, what good
8 are we?

9 Next, I applaud -- I applaud the fact that the Zadroga
10 Act emphasizes the importance of having established,
11 ongoing avenues of communication with all those being
12 monitored and treated at the World Trade Center
13 treatment and monitoring programs. I would like to
14 propose the following model to be used as the primary
15 avenue of communication that will put teeth into this
16 part of the Act. The models are above and beyond --
17 these models are above and beyond the steering
18 committee. The steering committees do good work, but
19 their work is primarily administrative in nature. I
20 believe a direct line of communication to the
21 participants is what truly will bring about a patient-
22 centered health care model.

23 I recommend the adoption of a community advisory council
24 for each Center of Excellence. This council would
25 consist primarily of participants at the respective

1 center. Some of the benefits for the participants would
2 include appreciating being part of the program, listen
3 to and having your opinions valued, understanding how to
4 be an active participant in their own health care, and
5 recognizing that collaboration with their, our,
6 providers through patient center care leads to better
7 self-management of chronic conditions -- uh-oh, yellow.
8 Okay, the benefits for the health care organization
9 include learning what the priority concerns are for the
10 patients, which may not be what the health organization
11 selects; hearing directly from the consumers, the
12 patients; transforming the culture toward patient-
13 centered care -- it's top-heavy right now; developing
14 programs and policies that are relevant to the patients'
15 needs. This all will improve customer satisfaction,
16 which leads to stronger patient loyalty and strengthens
17 community relations.

18 The very last thing, for the resear-- further, I would
19 also suggest there be a coalition of these councils and
20 these individual councils would send members to the
21 coalition, and the coalition would have -- would have an
22 overview of what's happening at all the centers, would
23 strengthen and passionately promote the things that are
24 working and would swiftly yet thoughtfully address the
25 problems that could come up. We could see them, we can

1 track them.

2 Lastly, please, for the research component of the

3 program, I urge you to adopt something called the

4 community-based participatory research. It's called

5 CBPR. It's the new thing, the cutting edge in the

6 health care world, and see -- I -- two sentences, if I

7 may. May I? Thank you.

8 CBPR is research conducted as an equal partnership

9 between traditionally-trained experts and members of the

10 community. The community participates fully -- fully,

11 fully, fully -- in all aspects of the research process,

12 including the conception, the design, the analysis and

13 dissemination of the research. This research will

14 engage the community as a partner in collaboration with

15 the scientists. And mounting research shows that when

16 this happens, guess what? The research actually

17 produces better results that are more fully embraced by

18 the community. It is a truly win/win approach.

19 I thank you very much.

20 **MR. ELLIOTT:** Thank you, Barbara, for those comments.

21 Darcia Hemphill?

22 **MS. HEMPHILL:** Hi. Good morning, everyone. Can you

23 hear me?

24 Okay. Good morning. Can you hear me now? Hi, my name

25 is Darcia -- oh, hold it.

1 My name is Darcia Hemphill -- oh, yeah, 'cause I'm too
2 tall. Thanks, better.

3 My name is Darcia Hemphill. I'm here today in behalf of
4 my husband, Milton Hemphill, who was a victim of 9/11
5 and he wasn't a police -- wasn't from the police
6 department nor from the fire department nor a first
7 responder. He was a worker around the area and also a
8 hero, 'cause he saved a lot of life that day, too. And
9 -- I mean you're talking about someone that was very
10 healthy -- healthy, physically fit and he's
11 (unintelligible), doing all kind of things -- running
12 New York City marathons -- and was diagnosed like in
13 2005 with sarcoid disease. Having problems now. He was
14 in the ICU three weeks ago for two weeks, and he's --
15 his condition is deteriorating and we never asked for
16 help. We didn't know how nor where to go and -- I mean
17 I'm glad for one person that really, really make me come
18 to this meeting today so I could really approach you to
19 know why is not -- why this information is not out
20 there? Why is a lot of people not knowing where to go,
21 what to do? And wha-- he'd been registered with the
22 9/11 registry in 2005 since we start -- he started
23 symptoms earlier, but we didn't know -- they couldn't
24 find what was wrong with him, and he was diagnosed after
25 surgery with the disease. Right? And why is not people

1 knowing where to go, what to do, or why is not a lot of
2 information out there for us to know what to do?
3 I called Bellevue Hospital because -- I mean I'm close
4 to Mount Sinai but I'm not allowed to be there. I don't
5 know why is only for certain people to only go there or
6 why is only certain group can go there, and why we have
7 to go all the way to Bellevue Hospital just to get check
8 and wait so many -- I have to wait till May for him to
9 be seen and he's not good right now, you understand what
10 I'm saying? He have an appointment until May. I mean
11 he's deter-- his condition is very deteriorated right
12 now.

13 He -- he had acute kidney failure recently, and have
14 other illnesses. So I'm trying to find out what is it,
15 Dr. John, that we could do, where could we go, how could
16 we be part of this because we weren't -- we didn't
17 approach anyone and we really need the help. And I know
18 a lot of people's out there right now that's got sick --
19 got -- got sick after that, and they probably don't even
20 know what to do, like myself, right now. And I got a
21 family, like childrens (sic), and I mean we don't know
22 what to do.

23 Thank you very much.

24 **MR. ELLIOTT:** Thank you, Darcia. You may want to speak
25 with -- there's some of the NIOSH representatives here

1 that you might want to speak to -- and the program
2 folks. You may want to speak with the program folks to
3 find out how to get enrolled.

4 Dr. Margaret Dessau, and then we'll have Bruce Edwards
5 and Mary Fetchet.

6 **DR. DESSAU:** Good morning, Mr. Elliott, Dr. Howard. My
7 name is Dr. Margaret Dessau. I'm a retired
8 pulmonologist --

9 **UNIDENTIFIED:** (Unintelligible)

10 **DR. DESSAU:** My name is Dr. Margaret Dessau. I'm a
11 retired pulmonologist affiliated with Columbia
12 University, a native New Yorker. I lived in Tribeca for
13 34 years. I was here on 9/11, facing it, seeing the
14 horrific thing, and then I was right opposite the barge,
15 so I was exposed and the whole neighborhood was exposed
16 for a lot longer than often many of the first
17 responders. Yet there was no outreach, really, at all
18 to the residents, no epidemiological investigation. I
19 only found out about the possibilities through the
20 downtown express, found out about CB-1, Catherine
21 Hughes, who got me involved. I volunteered, because of
22 my specialty, with the World Trade Center registry with
23 Dr. Jim Cohen to see if I could help, and discovered
24 through that about the sarcoid connection.
25 Epidemiologic data, which is statistics -- I'm a

1 scientist; I'm also a humanist -- it takes years. There
2 are multi-factorial agents, there are pre-existing
3 conditions. I worked in compensation for reviews, so
4 I'm familiar with the system. I was in this building 30
5 years ago doing comp reviews, you know, so I understand
6 the difficulty.

7 But I think, just listening to Ms. Hemphill, it -- it's
8 heart-wrenching. And when I was in the committee --
9 first of all, only 20 percent of those who registered --
10 there was never an outreach to the community. Many
11 people didn't know about it, like myself; questionnaires
12 to get a baseline. When I asked Dr. Cohen why is there
13 no study going on for studying carcinomas of all kinds,
14 particularly respiratory, lung carcinoma, he said well,
15 there was no funding for it. I said don't you thi-- and
16 also there was no database starting at the time zero. I
17 said "Well, it's not too late." But you know, we just
18 could do what we can do.

19 On a personal note, my husband and I are athletes, very
20 active, marathoners, skiers, everything, and perfectly
21 healthy until -- my husband was a non-smoker, and then
22 in January '09 he was diagnosed with stage 4 lung cancer
23 and he died four months later. And I just can't help
24 believe there's a connection.

25 And we learned after World War I about mustard gas, and

1 from World War II after the Nagasaki and Hiroshima
2 explosions about all these toxic exposures. We should
3 at least learn from a terrible experience, with our new
4 scientific, technological data handling, we should be
5 able to get some scientific data out of this. I'm
6 sorry...

7 **MR. ELLIOTT:** Thank you, Dr. Dessau. Bruce Edwards?

8 **MR. EDWARDS:** I'd like to thank Dr. Howard and Mr.
9 Elliott for holding this meeting for us. It's very
10 important.

11 My name is Bruce Edwards, and I was a 9/11 responder. I
12 worked as an electrician at the Verizon building at 140
13 West Street. I spent the better part of 18 months at
14 Ground Zero, and in 2007 -- late 2007 -- I was diagnosed
15 with stage 4 non-Hodgkin's lymphoma. I spent the better
16 part of two years battling the disease, and I just feel
17 victimized twice. The first time by the disease itself,
18 and the second time by lack of treatment I was afforded
19 at the medical monitoring systems.

20 They were willing to treat my sinus conditions and the
21 depression and all the other things that were brought on
22 by the disease, but nothing for that particular disease.
23 And Jim Ryder mentioned that -- previously that they
24 just show you the door if you have cancer, and I feel
25 very -- I don't agree with that.

1 All my doctors agree that my -- my cancer was 9/11-
2 related, and I would -- I would hope that NIOSH would
3 follow that -- that thinking.

4 On another item, I know it's a very small model, but I -
5 - I arrived at Ground Zero on September 14th. I was one
6 of eight men in my crew. And Bob Ciano, one of my men,
7 he's passed on from cancer and I'm currently in
8 remission. So I know it's small, but that's 20 percent
9 of my crew that has been seriously affected by this.
10 And as Mr. Gronan (sic) noted that we're not included in
11 these studies. The cancer just gets pushed aside, and
12 it's really, really affecting our lives.

13 I appreciate NIOSH's current efforts, but I hope that
14 they will be expanded for responders like myself and
15 others, and they will include this current criteria.
16 Thank you.

17 **MR. ELLIOTT:** Thank you, Bruce, for those comments.
18 Mary Fetchet, and then Wanda Ortiz, and Diane Stein
19 after that.

20 **MS. FETCHET:** It's nice to see familiar faces out there
21 in the audience. I wanted to begin by thanking Dr.
22 Howard and Mr. Elliott for the time to speak today, and
23 to be able to pull together this community and listen to
24 their concerns. I think that's just critical.
25 My name's Mary Fetchet and my husband Frank is here with

1 me today. We lost our 24-year-old son, Brad, on 9/11
2 and -- he was on the 89th floor of Tower Two, worked for
3 (indiscernible) and Woods and was 24 years old at the
4 time.

5 Just to give you a little background information, Brad -
6 - Brad had just graduated from college and hadn't --
7 hadn't been in -- in the job that long, but I was at the
8 time working as a clinical social worker in an out-
9 patient mental health clinic about a half-hour north of
10 our home in New Canaan, Connecticut. And I used to
11 attend a conference with -- about victims of crime, and
12 they had high profile cases -- like the Unabomber's
13 brother was there and some -- some of the victims.
14 But they had this woman that lost her daughter in
15 Oklahoma City speak, and on a large-screen TV they
16 showed the events of that day unfold, and the video
17 actually ended with her walking through the memorial and
18 talking about that her friend Susan sat here, or her
19 friend Tom sat there, and that they had -- the nursery
20 was here. And so I was so compelled, not just by the
21 images and the video that day, but by her message that
22 the attacks in Oklahoma City expanded well beyond the
23 families that were directly affected. They had a higher
24 incidence of depression, anxiety, suicide, spousal
25 abuse, job loss, and many other disorders, and it

1 rippled through the broader community.

2 And so of course this was before Google, but I did a lot

3 of research then. You know, I don't know that I thought

4 about it as a terrorist event, but I did think about it

5 -- that this was a community that was impacted by a

6 horrific event and that there were people that had to

7 respond, not just to the loss that was suffered that

8 day, but to the devastation within their community.

9 And so the Friday before 9/11 I thought as much as I'd

10 like to work with victims of trauma, it's not going to

11 happen here in Connecticut and I threw the materials

12 out, and then 9/11 happened. So I'm seeing Barbara sort

13 of nod. You know, many people don't even know that

14 background.

15 But when I started going to the family assistance center

16 I was looking through those lenses and I saw people

17 coming in from around the country and around the world.

18 They were shouting out the need for interpreters, you

19 know, of languages I had never heard of. Of course you

20 saw the volunteers and the rescue workers that came to

21 help our families, and I'm learning over the years that

22 many of the people that survived actually responded in

23 setting up and helping with families that were coming in

24 from around the country and around the world.

25 So my journey began there. I started having weekly

1 support groups in my home, you know, and then I opened
2 an office later. The first people that I hired were
3 social workers because I knew that if -- I could either
4 choose to run the organization or to listen to the
5 stories and help the people that had survived. And it's
6 funny, we're actually going through the process of
7 forming our business plan with this busy year ahead with
8 the tenth anniversary, and I pulled out our first
9 brochure, which was an advocacy group providing
10 resources and support to the victims, families,
11 survivors and all those impacted by the terrorist
12 attacks on September 11th.

13 And so what I've seen over the years is this -- it
14 wasn't just our family. The woman from Oklahoma was
15 exactly right. The people that responded that I met
16 early on at the Taj Mahal -- you know, I recognized at
17 that point that they probably at some point would need
18 psychological help, but I never dreamed that there would
19 be this long list of medical problems that so many
20 people here today that are representing the people that
21 can't be here today are -- are trying to convey to you
22 the real needs that they have.

23 As an organization we have now three offices in New
24 Jersey, Connecticut and Washington, DC, and we're
25 working with the Pentagon families and survivors. But

1 what I'm seeing first-hand is people coming forward as
2 the woman spoke today. People -- women now that are
3 single parents, they've lost their loved one due to the
4 cancer that their spouse had.
5 We're also seeing women that are living with, and
6 families that are living with, people that have chronic
7 illness. They're having respiratory problems, constant
8 calls to the hospital, constant doctor visits, problems
9 related to their PTSD, the nightmares that they're
10 having. These families are really ill-equipped to deal
11 with what they're seeing.
12 We're having survivors, many of them who are not
13 registered, that either lived or worked in the area.
14 And for many of them, their coping skill is to move
15 away. You know, I think if they're -- they're not faced
16 with being reminded of the event up in Maine. But the
17 problems that we're seeing as they're dealing with both
18 psychologists and medical doctors that have no clue
19 about the impact of 9/11.
20 So I do think that there's going to be, you know,
21 intergenerational issues. There is going to be this
22 rippling effect, not just today but in the many years
23 and the generations to come. I think there's going to
24 be the need for people to have treatment that -- that
25 we're thinking -- listening to what their needs are and

1 integrating that into our programs.
2 We have to give them information. We have to give them
3 support, and we have to give them services in our own
4 communities. I think that's really a unique way that
5 we've dealt with our families. You can't expect
6 somebody living in Maine to have to come to the New York
7 area for treatment. We have to educate service
8 providers outside the area.
9 And I think we have to look at -- I think my fear with
10 the tenth anniversary, the attention of the tenth
11 anniversary, we're going to see and have to deal with
12 many more people that are coming forward for the first
13 time. And so I think it's unpredictable the number of
14 people that unfortunately this event has impacted.
15 And so I think that you've seen today, not just hearing
16 the stories, you know who the organizations are that are
17 providing support, and I would just ask you, rather than
18 reinventing the wheel, support our organizations, many
19 of them who are in the room today, that understand this
20 population. Trust is so huge, so I think that you have
21 to really try to help support the existing organizations
22 that have worked with these populations from the very
23 beginning. And we have to, as organizations, then be
24 able to inform the Centers of Excellence that are
25 providing the concrete support.

1 I can say on behalf of all the families, we've been
2 notified five times of our son's remains and -- I'm
3 sorry -- but I remember when we were notified for the
4 first time in November of 2001. And I remember going to
5 St. Paul's and bringing a card and my roses, 'cause it
6 was the only gesture that I could make to thank the
7 people that came -- that left their own families, you
8 know, at a time that we were trying to bring our
9 families together, and the bravery and heartwarming
10 response that these rescue workers and the people that
11 survived -- you know, I can never thank them enough.
12 And I just pray that you will help them through this
13 difficult time, and that you will listen to what they
14 say. And you know, I think it's very short-sighted if
15 we can't help the people that were so brave, that not
16 just helped our families but helped our country.
17 So thank you.

18 **MR. ELLIOTT:** Thank you, Mary. Wanda Ortiz? Then we'll
19 hear from Diane Stein.

20 **MS. ORTIZ:** Hello, good morning. My name's Wanda Ortiz.
21 I do not speak English very good, but I try. Everybody
22 here, I have the same thing problem. Everybody is sick
23 because I working in the Ground Zero. I am -- I working
24 in the area Ground Zero, I working cleaning office in
25 the building, the company Tanco*. Now I'm very sick. I

1 have the 75 percent of my body not working good. I have
2 the asthma, fibromyalgia, GERDs, and the presumed
3 neurological problems. Every day I need nine different
4 medicines. When they -- I eat, I need the medicine for
5 my stomach. My life is no good in this moment. I have
6 two small kid. Sometime never I go again can I go to
7 the tree because I have the lot of problem in my body,
8 in my leg. That's why the doctor say this is fibro--
9 now I have -- I have (unintelligible) -- my asthma.
10 Never get out -- out of my house on the medicine.
11 Everybody come back when they forgot the cellular. Me
12 come back when I forgot the medicines. Now is very hard
13 because '97 -- 1997 I had two different job. Now in
14 2001 October and December, never -- is very different
15 because in 2002 (unintelligible) working is very
16 (unintelligible). I go to the emergency room. My
17 asthma don't allow long-distant working because that's -
18 - now -- it's different, everything.
19 Okay, thank you.

20 **MR. ELLIOTT:** Thank you, Wanda, for those comments.
21 Diane Stein, and then we'll hear from William Gleason,
22 followed by Troy Rosasco.

23 **MS. STEIN:** Hi, can -- can anybody hear -- can everybody
24 hear me?

25 Okay. My name is Diane Stein, and I'm a resident. I

1 live in Independence Plaza, which is a large apartment
2 complex, about 3,000 or so tenants, and it's located
3 around six blocks from Ground Zero. And it was also --
4 we were right next to where they were bringing the
5 debris removal barges after -- you know, remov-- after
6 9/11, for months and months afterward.

7 And this past Saturday I attended two funerals for
8 people in the community who both -- each died of cancer.
9 One lived in Independence Plaza. She was only 62, which
10 is not all that old. And the other gentleman lived
11 right across on 125 Cedar Street, which is right next to
12 -- their building was like blown away from -- you know,
13 from all the debris and he had -- he was diagnosed -- he
14 had pancreatic cancer, which originally started with I
15 think feelings of GERD and wasn't diagnosed as quickly
16 as it might have -- might have been.

17 And we'll never know if these were -- if these incidents
18 were 9/11 related, and that's one of the problems is,
19 you know, hearing a lot of anecdotal reports from
20 neighbors, but there's not a lot of -- there's no real -
21 - I don't think there's a really great mechanism in
22 place right now for connecting the dots -- excuse me.
23 A number of my neighbors are not in -- on any of the
24 databases. Many people in the area have not registered,
25 are not included in the World Trade Center health

1 registry. And also a number of people -- people who
2 have been reporting sick, they're not going -- they
3 haven't gone to the centers -- World Trade Center
4 environmental health centers. And some of them -- they
5 say oh, they want to -- they have their own doctors,
6 their own pulmonologists. So meanwhile, you know,
7 there's not a lot of -- not a lot of pulling together of
8 the data.

9 I mean yesterday I was talking to somebody who was
10 telling me oh, his -- his asthma has returned. He
11 hadn't had an -- asthma since childhood and it's
12 returned with a vengeance, and his pulmonologist, who's
13 located downtown, was telling -- was telling him that he
14 did see a spike in -- in pulmonary, you know, problems
15 with people who are living down there.

16 But we -- we -- so we just need a better way to reach
17 out and communicate and monitor and educate and outreach
18 to the community about what's going on and communication
19 between the medical professionals.

20 And I also wanted to add -- I think somebody had
21 mentioned before and I wanted to reiterate a concern
22 that the NIOSH administrative outsourcing will take away
23 funds available for treatment and the research and
24 medication that's badly needed by people.

25 And finally I want to just express my appreciation for

1 Mr. Elliott and Dr. Howard for holding this hearing.
2 And I'm very -- you know, very grateful for the efforts
3 of everybody who's been involved in -- in shedding light
4 on this environmental and other issues related to 9/11,
5 and passing the Zadroga Bill. I want to thank Dr.
6 Howard, who's -- Dr. John Howard, who's been there with
7 us from the beginning, and who's also listened to the
8 concerns of the community and -- and John Feal, the
9 FealGood Foundation, and John Stewart -- all the Johns --
10 -- 9/11 Environmental Action Community Board One,
11 Representative Carolyn Maloney, Senator Schumer and
12 Senator -- and Senator Kirsten Gillibrand, who worked
13 tirelessly to get this -- the Zadroga Bill passed. And
14 finally -- and I'm sure I've probably left out people --
15 it's like the academy awards -- but I want to thank
16 Representative Gerald Nadler, who's also been with us
17 and listened to the community and -- and urged for the
18 passing of this -- bills from the beginning.
19 So thank you very much.

20 **MR. ELLIOTT:** Thank you, Diane. William Gleason? Then
21 we'll have Troy Rosasco and the Reverend Terry Lee.

22 **MR. GLEASON:** Crib notes, helps. My name is William
23 Gleason. I'm an FDNY EMS lieutenant. I have lung
24 disease. I've lost 49 percent use of my lungs thanks to
25 9/11. I have GERD. I have been operated on and had

1 surgical procedures more than 20 times post-9/11. And
2 my life is only about 25 percent of what it was prior to
3 9/11.

4 I still would have gone, even knowing. We would have
5 used a little bit better caution. My job was to save
6 lives.

7 I lost 141 friends on that day, and I've lost many more
8 post-9/11. I sent people to Ground Zero to work. I
9 supervised people there. I've watched them get sick and
10 I've watched them die.

11 We have a moral obligation to help the rescuers. We
12 also have a moral obligation to help the residents down
13 there who were exposed. Worker's Compensation is a
14 short-term, not a long-term, health care program. And
15 unfortunately, the rescuers are trapped in that system.
16 The disease and mortality tracking, the Centers of
17 Excellence or the City Department of Health needs to
18 take the lead. If you go to CDC, New York State and
19 even the City Medical Examiner's web site, all three
20 have different statistical numbers. No one is on the
21 same page there.

22 The Centers of Excellence need to share information in
23 health care and trends that will better produce patient
24 outcomes. For the established World Trade Center
25 rescuers who participate with a Center of Excellence, I

1 recommend that an insurance program be instituted to
2 cover all of their health care needs. Health care would
3 be 100 percent coverage with no deductible. This would
4 address the issues of reporting medical problems and
5 treatment to the Centers of Excellence, and also resolve
6 conflicts between Worker's Compensation and their health
7 insurance that can cause unnecessary patient care
8 delays.

9 Our health problems sometimes blur the lines between
10 what is 9/11-related and what is not. The money
11 normally spent by the employers and the government for
12 the health care and the Worker's Comp can be used as a
13 source of funding for this insurance. The program could
14 be administered by an agency such as Medicare, that
15 already has the resources established to help keep costs
16 down.

17 We need help. Studies and research are important.
18 Unrestricted access to health care will save lives.
19 It's a matter of honor.

20 I do this because I feel I have to. The best patient
21 advocate is a patient, and I'm a patient. So I'm asking
22 you -- I'm actually begging you, please help us. I'm
23 watching friends die. I sent them there.

24 Thank you.

25 **MR. ELLIOTT:** Thank you, William. Troy Rosasco, and

1 then Reverend Terry Lee.

2 **MR. ROSASCO:** Thank you. First I'd like to thank Dr.
3 Howard and Mr. Elliott for having this public meeting.
4 It's very helpful to all of us.

5 Secondly I'd like to thank all those people in the room
6 who were so important. I don't think any of us would be
7 here today without those who pushed so hard for the
8 Zadroga Act, especially the FealGood Foundation, so I
9 thank you all.

10 I want to be short today and re-emphasize a couple of
11 themes I've heard already this morning. And those
12 themes are as follows: There are two particular areas
13 of illness that I think are not being treated correctly
14 here. Let's take for -- first, cancer. It's absolutely
15 imperative that cancer be made part of the NIOSH
16 program. We all know that in the rush of the lame duck
17 session we weren't able to get every single detail of
18 the Zadroga Bill on there that we would have liked. Now
19 it's up to an administrative agency, of which you are
20 the people who will implement the Zadroga Act, and now
21 it's up to you to implement it correctly and to do the
22 right thing. And the only way you can do that is to
23 include cancer, and the cancers we've been talking
24 about.

25 I can't understand how the federal government would not

1 include cancer as part of this program when so many
2 other governmental agencies have already done so. I won
3 my first nasopharyngeal cancer case for a Verizon worker
4 back in 2003 through the New York Worker's Compensation
5 board. I had an NYPD officer in my office yesterday who
6 is out on the WTC presumption bill for colon cancer.
7 Now if that's good enough for other governmental
8 agencies, it should be good enough for the federal
9 government. And there is absolutely no reason why these
10 cancers that we know can come about from the toxins that
11 everybody knows were cancerous down there should not be
12 covered.

13 In addition, there's not a client that doesn't come into
14 my office who does not include, as part of their
15 illnesses, post-traumatic stress disorder. Whether or
16 not they've been treated for it or not is a different
17 story. As we all know, sometimes it's hard to bring
18 those who are suffering from post-traumatic stress
19 disorder to treatment. But nevertheless, that outreach
20 has to be done for those people with post-traumatic
21 stress disorder. We know enough. We don't need any
22 more research on post-traumatic stress disorder. It
23 goes back to World War I when they called it shell
24 shock. A hundred years of research is out there. Do
25 not make the first responders and victims of 9/11 wait

1 for years and years and years of research to get them
2 the help they need today.
3 Do the right thing. Take the leap of faith. It doesn't
4 take rocket science to sit there and understand that
5 there's a causality here between those people who were
6 perfectly healthy prior to being down at Ground Zero,
7 fresh kills, various and sundry other places along the
8 debris route, and then got seriously sick the way they
9 are. You need to do the right thing. You're the
10 administrative agency that can do the right thing. We
11 have the law now. Please do so.
12 I say that in all due respect. I know your intentions
13 are absolutely correct, but we cannot sit by and wait
14 for research studies and to study it forever while
15 people die in front of us.
16 Thank you.
17 **MR. ELLIOTT:** Thank you, Troy. Now we have Reverend
18 Terry Lee, and then we have four more folks who have
19 signed up. And so our plan is to go ahead and hear
20 those four folks, since they may have been here for a
21 while, before we take a break for lunch. And we may
22 only take a short break for lunch.
23 So Dr. Lee -- or Reverend Lee.
24 **REV. LEE:** Thank you. Good afternoon. My name is
25 Reverend Terry Lee. I am the pastor of the Byways and

1 Hedges Youth for Christ Ministry located in Brooklyn,
2 New York, migrated in this country 1989, couldn't find a
3 job. I began to volunteer in the community. On 9/11 I
4 was serving as a clergy liaison with the NYPD in
5 Brooklyn South. But on the day of 9/11, seeing all
6 these police officers responding to Ground Zero, I cried
7 out to God and I said what can we do? I rushed down to
8 the precinct. They said "Reverend, please pray." We
9 began to offer counseling to the local precincts and we
10 were called also by the Mayor office OEM, Office of
11 Emergency Management, to sign up into the program as a
12 clergy crisis responders.

13 And from then we began to go down to Ground Zero to
14 volunteer our time. I spent days, nights, weeks, months
15 at Ground Zero as a immigrant volunteering my time. I
16 worked in the morgue blessing the body parts. I worked
17 in the piles searching with rescuers. I've seen
18 hundreds and hundreds of clergy, a rabbi, people from --
19 priests -- from the faith-based community, immigrants
20 who responded.

21 Now in Brooklyn there is no type of outreach in
22 Brooklyn. Nobody knows where to go and who to go to. I
23 thank God for the FealGood Foundation. And when I heard
24 about them we all went to Washington, D.C. and stand for
25 this bill to be passed. There is no outreach in the

1 community. We need to know why, and how can we help.
2 There are people out there that are dying. Many people
3 from the immigrants community, also. We are looking
4 forward for your help and for your support. Let us
5 reach the unreachable. Let us reach out and touch the
6 untouchable.

7 Right now I've been going to Mount Sinai. I develop
8 asthma. My wife complaining every night with her
9 husband. She can't get her proper sleep because I'm
10 wheezing and I'm snoring, I'm turning in my bed. My
11 daughter, she's going through the struggle.

12 We have work to do as immigrants. I love America.
13 America is a place where we can come as immigrants, and
14 from holding the door to owning the building, from
15 packing the bag in the supermarkets to owning the
16 supermarket, from being a delivery man who delivering
17 the food from the restaurant to owning that restaurant.
18 I want us to continue to work together.

19 We're at war against the enemy. Churchill recognizes
20 that. And Churchill call a group of men together, and
21 Churchill says "The enemy is about to harm us. If we
22 come together, the enemy would have a harder task
23 harming us together. But if we don't come together, the
24 enemy will harm us separately."

25 We want to thank all of you that are in the fight and

1 making sure that we get the resource that is available.
2 But let us remember, those families that have not been
3 reach, don't know who to go to, who to call. They are
4 dying, and they are waiting on us. Let us reach out and
5 touch. God bless you.

6 Thank you.

7 **MR. ELLIOTT:** Thank you, Reverend Lee. Now we have
8 Barbara Caporale.

9 **MS. CAPORALE:** Hi, my name is Barbara Caporale and I'd
10 like to thank you for holding these hearings and -- and
11 celebrate the passage of this Bill. I am currently
12 doing pediatric outreach for the survivors of the World
13 -- of the World Trade Center environmental center
14 program. Prior to that I was doing outreach for DC-37
15 members, for municipal workers. And prior to that I did
16 outreach and organizing for the affected/neglected town
17 hall which we held at St. Peter's which forced the City
18 to recognize the fact that health care for -- for
19 workers and residents needed to be funded and the
20 programs needed to be set up to continue to this point
21 now where we have federal funding finally, thank you
22 very much.

23 Prior to that, I was community organizer for Rebuild
24 Spotlight on the Poor Coalition, which was an emergent
25 organization begun after 9/11 of over 25 community-based

1 organizations and legal advocacy groups that worked for
2 social, economic and environmental health justice for
3 the monies that were given and the programs that were
4 set up to help New York City recover after 9/11.
5 Primarily I am a resident and a mother in the original
6 frozen zone located below 14th Street in New York City,
7 which is also the boundary of the LMDC* small business
8 retention grants.
9 Firstly, I request that Dr. John Howard be the
10 administrator of this program as he is most familiar
11 with the programs and the excellence of care, the
12 players and the people, and has come to this city
13 innumerable times to hear from us about our symptoms and
14 about our needs, and has been very responsive and
15 supportive in addressing this on our behalf. And I
16 thank you, Dr. Howard. I hope that happens.
17 Secondly, I hope that this bill helps -- that -- that
18 all the different administrative details in this bill
19 really respects the existing programs and how they are
20 being run, the medical directors and the administrators
21 of it, and that they don't get tied down in lots of
22 minutiae and paperwork that take them away from the main
23 -- the main -- the main mission, which is to provide
24 treatment to those who are impacted and -- and need
25 that.

1 I don't know if I -- I mentioned that I was also
2 community-based participatory research outreach liaison
3 during the World Trade Center expert technical panel
4 hearings for community and labor, which allowed the
5 rescue and recovery workers and the -- the community
6 workers and residents to express their health impacts.
7 And unfortunately that panel process was ended
8 prematurely by the USEPA before it fulfilled its mission
9 to determine the extent of health impacts from 9/11,
10 both geographically and symptomatically, and also to
11 establish a proper cleanup protocol which would have
12 alleviated a lot of our problems of -- of -- of being --
13 our symptoms being reactivated and re-exposed during
14 this whole demolition, construction, rebuilding process.
15 Regarding the outreach that is under this, I hope that
16 you will respect the Centers of Excellence and their
17 community advisory committees, and the people that have
18 been in place, who know the populations, who are
19 familiar with the needs -- yet unmet -- and not just
20 issue a general RFP to anyone who has the ability or
21 staffing to be able to write a grant to do outreach.
22 And thirdly -- I mean lastly, I will tell you that I --
23 I coined the phrase "affected/neglected", and I'm very
24 concerned that I still, according to this bill, am part
25 of the population that is still affected and neglected.

1 This bill is written with a boundary line at Houston
2 Street. The original frozen zone was 14th Street. My
3 child was in a day care, and I will submit into the
4 record the New York Academy of Medicine's pediatric day
5 care study one year after 9/11, which shows in her
6 school alone 32.3 percent mutually exclusive statistics
7 of children who had never been diagnosed with asthma or
8 who had some kind of respiratory symptom one year later
9 in a population that nationally would be seven percent.
10 The entire study of all the day cares shows 41 percent
11 mutually exclusive information -- I'll give you that.
12 I also want to show you the Department of Health's
13 clinical guidelines for childrens (sic) and adolescents
14 exposed to World Trade Center disaster. I'm very
15 concerned about the children in this area between
16 Houston Street and 14th Street. That is the catchment
17 that has been recognized by the existing World Trade
18 Center environmental health center program. It is the
19 catchment that was reached out to in a letter from the
20 Department of Education, the Department of Health and
21 New York City health and hospitals population.
22 Unfortunately, this letter -- the mailing with the DoE
23 did not get to many households that -- that have these
24 populations. And our pediatric outreach just went into
25 full effect at this, you know, late fall.

1 So I am concerned about this 60-day waiting period and
2 I'd like to know, does that mean for people who are not
3 currently patients in these programs as the Centers of
4 Excellence, or does that mean people who do not fit into
5 one of the criterias (sic) that are listed as, you know,
6 the area of -- you know, all the different qualifying
7 criteria, because I think that the population between
8 Houston Street and 14th Street -- first of all, 60 days
9 is too long for anybody to wait for medical care.
10 Secondly, if it's only for that -- you know, for anyone
11 outside of those qualifiers, I'm asking you to take into
12 consideration the way that the intakes do at the Center
13 of Excellence, and they look for a symptom and they look
14 for exposure, and they understand the populations.
15 These populations are in the data that shows that
16 survivors and responders have similar symptoms, and
17 they've already been included in studies but the
18 populations have not been outreached to. I'm very
19 concerned about our children. I'm also concerned about
20 the children of our first responders and others who --
21 who lost a loved one during -- after 9/11. The mental
22 health qualifications for pediatric program never set a
23 geographic boundary. You can see how upset our
24 responders are and the fight that they've been through,
25 and you can know that their children have mental health

1 impacts, as do the residents in the survivors' program,
2 their children, especially after we had to fight for so
3 many years for recognition. So I'm hoping that this 60-
4 day and the -- and the zone is -- is made an exception
5 because it's -- it's just too long a period and that we
6 need to include the area that had been recognized in the
7 original federal boundaries, which is Houston to 14th
8 Street.

9 Thank you very much.

10 **MR. ELLIOTT:** Thank you, Barbara, for those comments.

11 Robert A. Grochow?

12 **UNIDENTIFIED:** Grochow.

13 **MR. ELLIOTT:** Grochow.

14 **MR. GROCHOW:** Good morning. I'd like to thank Mr.
15 Elliott and Dr. Howard for allowing us to speak here
16 today and share with you certain information that we may
17 have that's relevant to you.

18 My name is Robert Grochow. I am an attorney. Our
19 office, along with my partner, Greg Canata*, has been
20 honored to serve as one of the plaintiffs' lead counsel
21 in the federal litigation, and we are here to just
22 briefly touch upon what we feel should be the inter-
23 relationship between the health aspect of the bill and
24 the victim compensation aspect of the bill. And I know
25 that today there are many, many injured people in the

1 audience, victims of 9/11. I see several of my clients
2 here. I'm honored to represent Alex Sanchez, who I
3 believe spoke earlier, and Manny Cheko for many years.
4 And the -- before I get into the interrelationship, I
5 just want to share two short conversations we've had
6 over the years with some of the directors of the
7 programs at Mount Sinai. One came after I had the
8 opportunity to speak to some of their patients, and I
9 asked the doctor -- and this goes back many years --
10 what can you tell us statistically -- and this was
11 probably back in '04 or '05 that I had this conversation
12 -- about the injuries that we haven't seen yet? And
13 quite frankly, cancer wasn't really on the radar screen
14 as early as '03 and '04 for -- for most people. As you
15 know, cancers generally have a -- a time gap before
16 they're actually going to start showing up, sometimes
17 ten years, sometimes 12 years, sometimes 15, 18 years.
18 And I said to the doctor, what can you compare this to?
19 And she said "Well, we were involved, to an extent, with
20 the telephone company" -- it's now called Verizon; it
21 wasn't in those years, I believe it was in the '70s or
22 '80s when the entire building went up in flames, and
23 many, many people were injured in that building. And
24 toxins, some of which are the same toxins that leaked
25 into the air following the 9/11 attack, from the

1 interior workings of the telephone company building
2 caused significant damage to their employees. I said
3 "Well, are you going to draw a comparative study between
4 all the people in the phone company building and the
5 9/11 people?" And the answer was a shocking "We'd like
6 to, but most of them are dead."

7 So that is a really, really somber thought to think
8 about. And as I look out into the audience and as I
9 meet with my clients on a daily basis, and as we have
10 said in court, we unfortunately feel that many of our
11 clients are dying a slow and uncomfortable death. And
12 the -- the inter-relationship between the health fund
13 and the victims is -- this -- this brings this to light.
14 When the victims' compensation fund aspect of the bill
15 receives its regulations by the special master, or
16 regulators from the Department of Justice in Washington,
17 I would hope and urge that the medical community play an
18 integral role in association with the federal
19 regulators, and not stand back. And that you give them
20 guidance as to the manner in which they should formulate
21 what injuries should be included. For my money, it
22 should be an open door. All injuries -- yes, obviously
23 subject to some causality, but all injuries should be
24 the first step. They should not come out with a menu
25 and say you either fit into this menu or you don't fit

1 into this menu. Because if you do, the fear that has
2 been echoed by virtually everybody in this room is
3 what's going to happen to the cancers? So if the
4 medical community and the health aspect of the bill does
5 not recognize certain injuries such as cancers -- I mean
6 the asthmas are almost a given, I assume. The COPDs,
7 the RADs, are a given. But if asthma (sic) is going to
8 be the sticking point, then let the medical community
9 come forward and educate the federal legislators. And
10 if you educate them only based upon the scientific data
11 that is available today, we fear that you will be
12 leaving out those cancers that the medical community has
13 not yet actually formally recognized as being causally
14 related to the World Trade Center because it takes so
15 many years for that to happen. And by the time that
16 happens, the fund will be closed. The health benefits
17 may be shut down. We don't know what the -- Washington
18 is going to do in the future.

19 So I urge that there be this open communication and
20 influence by the health portion of the Act on the
21 victims' compensation portion of the Act.

22 Thank you for your time. Thank you.

23 **MR. ELLIOTT:** Thank you for those comments, Robert.
24 Mike Kenny. I think I pronounced that one right.

25 **MR. KENNY:** Good afternoon. Thank you for having me

1 here, Mr. (sic) Howard, and to the good doctor.
2 I'll tell you a little bit about myself. Forty-nine
3 years ago I came into this world kicking and screaming.
4 I hope to go out that way, just better be with my boots
5 on. Today is my birthday.

6 (Applause)

7 On September 10th I was a jaded New Yorker. I was
8 working on Rikers Island. After the towers came down I
9 started loading scout packs, sending emergency equipment
10 down to the site. I worked for the Department of Design
11 and Construction. I spent seven months at the site,
12 overseeing the site and the cleanup, rescue and
13 recovery.

14 Today I'm a vice president in Local 375. We have over
15 7,000 members, and many of our members, working for
16 different agencies -- Department of Design and
17 Construction, New York City Transit Authority,
18 Department of Transportation, Department of Buildings,
19 Department of Environmental Protection, and Department
20 of Health -- were down at the site. Some of those
21 members have lost kidneys, testicles, lumps in their
22 throats, lot of illnesses that's not on the chart.
23 It was an honor for me to go down to the site. I never
24 expected I would ever be in a location like that and
25 doing the job I was doing. We heard the doctor before

1 speaking about mustard gas. One night when I was down
2 there, it was a Sunday night, we had chillers that were
3 covered -- were packed with freon that went on fire.
4 That's mustard gas. That is mustard gas. I had a
5 battalion chief yelling and screaming at me on a Sunday
6 night to find some argon gas 'cause argon gas will
7 smother out and stop a freon fire. Very hard to find,
8 Sunday night, argon gas. We ended up covering it with
9 sand, putting it out. But that fire was right there.
10 Mayor Giuliani said the fires were out in January. Man,
11 I seen every color smoke coming out of that hole. I
12 seen steel being lifted that was melted and bending.
13 Those fires were going a lot longer than January.
14 By winter 2002 I could not get out of bed. I didn't
15 care about Christmas. I didn't care about the holidays.
16 I was a mess. I had actually left the site April 13,
17 2002 with a broken collarbone and not the man I was when
18 I went down there. I'd gone back to work in September
19 because I was a mess, but I needed to get back to work.
20 I needed to climb out of that hole.
21 I did every single thing I could do to try to get
22 healthy. I went to the New York detox, spent hundreds
23 of days there detoxing. Serving those who serve, I took
24 those pills. Mount Vincent's World Trade Center health
25 center, I went to. Red Cross, I went to -- life net

1 counseling, I went to it. I did everything.
2 Okay, I'd like to tell you some of my illnesses that are
3 not on this list. I have sores all over my body that
4 ooze out nightly. My wife changes the sheets every day.
5 Now I have skin cancer -- which is coming from these
6 sores, if you ask me, but I'm not a doctor.
7 I'm a big guy, kidney stones. Kidney stones are
8 painful. Give me that morphine, give it to me 'cause I
9 don't want to feel it. All right? What do they tell
10 you to do? Scream, and catch the stone so it could be
11 examined. What comes back? Non-organic material. My
12 urologist tells me I'm crazy. How is it getting into my
13 system? Seven months at Ground Zero might have
14 something to do with it.
15 I have a little prepared speech here, bear with me.
16 Thank you for letting me come here. We urge NIOSH to
17 ensure that there is agreed-upon, consistent quality of
18 medical care and treatment provided to all participants
19 in the World Trade Center health program. Okay?
20 What we would like to see. The World Trade Center
21 health program needs to be patient-centered. The visits
22 should be designed in a way that decrease stress and
23 promotes the well-being of the patient, as much as can
24 be possible during a medical visit.
25 Participants should be treated with dignity and results

1 -- and respect.

2 Follow-up appointments. Some participants require

3 multiple appointments because they need to see their

4 regular doctors as well as specialists.

5 Participants request that multiple appointments be

6 scheduled on the same day, to avoid making multiple

7 trips, should that -- and this should be accommodated.

8 When follow-up appointments are required by specialists,

9 the staff should take care of such appointments for, and

10 communicate their necessity to, the participants ASAP.

11 Let us know what's going on.

12 Schedules should be coordinated to best meet the needs

13 of participants. For me, still working with the City of

14 New York, I get 12 sick days a year. I go to the doctor

15 for World Trade Center medical monitoring, that's six

16 right off the bat, guaranteed. I get the flu, that's

17 another three, and what do I have left? I have nothing

18 in the bank, and my boss doesn't want to hear about it.

19 They well forgot 9/11 ten years after the fact.

20 If participant's medical issue is urgent, a follow-up

21 appointment should be scheduled without delay. We have

22 to wait months aft-- after we're told to get an

23 appointment.

24 There has to be enough staff to monitor follow-up

25 appointments.

1 Once the appointment is set, verbal communication should
2 be made to the participant. I schedule my appointments
3 six months in advance. I schedule three appointments.
4 When it comes time for me to go to my appointments, I
5 get a cancellation every time for one of the doctors
6 'cause of schedule conflicts. I try to put it all
7 together so that I'm not taking time off from work.
8 I need a referral to go see a specialist, is required
9 for every time I go see that specialist. I've already
10 seen the specialist. Why can't I just schedule and
11 appointment and go back and see the specialist?
12 Once a participant has been referred by a treating
13 doctor, participant should be able to make follow-up
14 appointments directly with the specialist. Currently
15 the scheduling of all appointments has to be done
16 through the treating doctor. So it's an overlap that
17 wastes my time.

18 Bedside manner. Our community was involved in an
19 unprecessident (sic) environmental and psychological
20 incident, and we are battling significant physical and
21 emotional conditions. I do better when I ad lib. I
22 hate to read from the scratch.

23 We ask that doctors and staff demonstrate the
24 appropriate sensitivity and compassion when dealing with
25 our unique community.

1 There should be a benefit coordinator who would be
2 responsible for assisting participants in obtaining the
3 benefits for which they may be eligible -- disability
4 benefits, Worker's Comp benefits, scholarships for the
5 kids maybe.

6 In this way participants do not discover about these
7 benefits after the fact.

8 The last thing is consider PTSD an illness that stands
9 on its own.

10 Now I'd just like to tell you a little story about -- I
11 was down lower Manhattan the day of the Deutsche Bank
12 fire, and I was with my son. He's 16, so he was 12. He
13 wants to go closer to the fire. I want to run. I don't
14 want to be nowhere near. Street was like a frozen zone.
15 Car was parked in the frozen zone. I couldn't get out
16 of there. I took him over to -- near 17th, try to spend
17 some time. The smoke, the smell. I was going on a two-
18 week vacation down to the beach after that. That first
19 week I was miserable. I couldn't put it all together.
20 Later on I'm in Chinatown when Air Force One decides to
21 fly over the Empire State Building all the way down to
22 the Statue of Liberty. I swear to God, I thought my
23 world was going to end that day. It took me to then to
24 connect the dots and figure it out, that this is serious
25 stuff that I'm dealing with. And how do you go around -

1 - when I was raised not to ask for help, but now I
2 realize I need to ask for help. And that's why I'm
3 here, asking for help from you guys. You guys have the
4 power to do it. 9/11 happened tomorrow, I'd be down
5 there, knowing everything that I know now.
6 Got some other little notes here that I just want to
7 look at before...
8 That's pretty much all I've got to say. Thanks so much
9 and I hope you guys really do the right thing. We're on
10 the road to recovery. This menu of options you have,
11 you should treat us like a patient, take care of
12 everything. You know what? My kidney stones are, in my
13 eyes, directly related to my time down at Ground Zero.
14 But to be told at the treatment center "Oh, you've got
15 to go see your own doctor for that." You know what?
16 I'm taking these steroids they're giving me and my bones
17 are getting weak and my bones are starting to break,
18 they should be all treated together. You've got to look
19 at it as a patient. Get us well. Get us healthy again
20 so that we can be there next time you need us.
21 Thank you.
22 **MR. ELLIOTT:** Thank you, Mike. Keith, we're going to
23 hold you just a moment, Keith. We've got two others
24 that haven't spoken. You spoke once, so if you wouldn't
25 mind having a seat.

1 Joel Kupferman, and then Kimberly Flynn.

2 **MR. KUPFERMAN:** Thank you very much for having these
3 hearings. I'm Joel Kupferman. I'm the executive
4 director of the New York Environmental Law and Justice
5 Project. I'm the environmental justice committee head
6 of the National Lawyers' Guild. I was the environmental
7 counsel for the firefighters' union after 9/11. And
8 it's -- I guess this is an emotional moment for me after
9 all I've gone through with 9/11, and I think the
10 important thing is that we really thank you for letting
11 these people speak.

12 But after two, three weeks and the first five, six
13 months, a lot of the information I got about 9/11 --
14 besides grabbing the samples there -- were from my --
15 the phone calls that came to me after 5:00 o'clock from
16 a lot of City workers and city staff people that were
17 scared to speak out to their bosses, to the Mayor, to
18 everyone else, who were basically told "If you keep on
19 complaining about what you have or what you saw, what
20 you were exposed to, you're going to lose your job."

21 Okay? We've got to remember that. Okay?

22 So when you're doing your science research and trying to
23 figure out what's out there, you have to put it in
24 historical context that the city did not want to hear
25 from these people. The city, up until now, has spent

1 \$500 million or so from the captive fund to deny their
2 claims. Okay? The city health department refused to
3 follow the law. We pointed out that under New York
4 State health law, there's something called the New York
5 State lung disease registry, and it states (reading)
6 Report of occupational lung disease. Every physician,
7 health facility and clinical laboratory in attendance on
8 a person with clinical evidence of occupational lung
9 disease, as characterized in Section 22.5 of this Part,
10 shall report such occurrence to the State Commissioner
11 of Health within ten days. Such report shall be on such
12 forms prescribed by the State Commissioner of Health.
13 This was even -- it had a whole list, and basically said
14 that people exposed to toxic dusts or toxins, it had to
15 be reported. The worst violator of this was the New
16 York City health department and Health and Hospitals
17 Corporation. Okay? So when you're looking at these
18 figures, you have to point out that it was an under-
19 count and why there was an under-count.
20 I fortunately got down to the site on behalf of a -- a
21 cop, the union delegate, they got me down, it was
22 concerned about people exposed to -- and we grabbed
23 samples. And those samples we sent to two labs, and we
24 found five percent asbestos. And moreover, we found 90
25 percent fiberglass, and that was something that we kept

1 bringing up in the beginning and it was -- seemed to be
2 ignored. But after a little bit of research we found
3 out that fiberglass is tiny, needle-like particles,
4 probably causing much of the reported irritation and
5 pain in the eyes and respiratory system. Fibers are
6 usually coated with a thin later of formaldehyde-
7 containing resin. Long-term health damage is also
8 associated with fiberglass. The national toxicology
9 program lists respirable-sized glass fibers as
10 reasonably anticipated to cause cancer. And the
11 international agency for research in cancer lists
12 certain other glass fibers as possible carcino--
13 carcinogenic to humans. So we have the fiberglass
14 issue, that I think was basically, then and now, you
15 know, brushed under the rug.

16 Then we just went by DEC reports -- DEC handed out -- I
17 wish you could see this -- a poster that talked about
18 the bad chemicals that people are exposed to. I'll send
19 you -- okay. It's a poster, and it basically says: PM-
20 10 wanted for -- and this is what the DEC said back then
21 -- description, PM-10 is the generic name for
22 particulate matter less than ten microns in diameter.

23 Crime: PM-10 can reduce visibility and make it
24 difficult to breathe. It has been linked to cancer and
25 heart attacks. Cause: PM-10 comes from burning fuel in

1 power plants, factories, cars and trucks, as well as
2 dust blowing from roadways, fields and construction
3 sites. EPA -- it's well documented that fires burning
4 at the -- at 9/11 lasted for weeks and weeks and weeks.
5 I fortunately became the attorney for the firefighters,
6 and I represented a lot of the workers and residents in
7 lower Manhattan. And one of my concerns, besides the
8 fiberglass and the under-count in cancer, is your
9 boundary lines; that your boundary lines in the
10 catchment area is arbitrary. One of the places that I
11 was sent to was the cancer house in Brooklyn, in
12 Redhook, dealing with -- with post-9/11. A lot of these
13 trucks that went down to the -- to 9/11, carried the
14 World Trade Center dust back into their fire houses.
15 One of the firefighters pointed out to me that the dust
16 from 9/11 didn't just go over -- let me just -- can I
17 finish? Okay. Didn't just go over the East River, went
18 under the East River. And the fact that it was carried
19 by trucks through Brooklyn to Freshkill -- okay? That
20 dust was -- is so bad and not covered, that firefighters
21 from their fire house had to put fires out in the truck.
22 The embers were still burning. Those -- those trucks
23 went to Freshkill.
24 We were contacted by the detectives association, you
25 know, to ask in the beginning why the detectives were

1 not given masks and the FBI agents were. So -- short
2 three minutes -- I'm really concerned, after putting up
3 a fight to get information out to all those people out
4 there about the cancer risk and everything else, that
5 just going forward -- I'm in contact with people down in
6 the Gulf Coast -- that people are scared to speak out.
7 And also speaking to a lot of the firefighters, they
8 were scared to speak out. And also a lot of their -- I
9 think their illness has come from the angst that they
10 weren't allowed to speak out, and I think that's really,
11 really important for you to put it, you know, into it.
12 And also that you should really be wide in terms of
13 receiving information, that you shouldn't rely on the
14 people that were paid to tell everyone out there that
15 there was no problem, and then got paid to gather the
16 evidence. All right? I think it's really wide and it
17 was really inspiring this morning with someone talking
18 about community-based information. You have to listen
19 to these people, and you have to make sure your phones
20 are open past 5:00 o'clock to actually hear these people
21 that are not scared to speak and told that they're going
22 to lose their jobs or their going to lose their -- their
23 homes for speaking out. So I urge you to keep this wide
24 open, you know, view.
25 And also to seek all the records, to look at Worker's

1 Comp and look through all those filings that people did.
2 Okay?

3 And also the undercounted population 'cause I represent
4 a lot of immigrants, incl-- including doing cases in
5 this building here. They're scared to speak out to
6 anyone. So you've got to -- really got to go out of
7 your way to make sure that they can speak and that
8 they're protected.

9 So thank you very much.

10 **MR. ELLIOTT:** Thank you, Joel, for those comments. Now
11 we have Kimberly Flynn, and after Kimberly we'll break
12 for lunch, and then we'll come back to finish up.

13 **MS. FLYNN:** Can everybody hear me? Close, close, close,
14 okay.

15 I'd like to thank Dr. Howard for all of his years of
16 service to 9/11 survivors and responders, and I'd like
17 to thank NIOSH for the opportunity to testify.

18 I'm Kimberly Flynn and I serve as community co-chair of
19 the community advisory committee to the World Trade
20 Center Environmental Health Center, the WTCEHC. This is
21 the World Trade Center of excellence that serves the
22 residents, students and area workers. Known as the
23 survivor program in the Zadroga Act, the environmental
24 health center operates at three clin-- operates at three
25 sites, at Bellevue, Gouverneur and Elmhurst Hospitals,

1 and currently cares for a patient population totaling
2 more than 5,000.

3 In the weeks and months after 9/11, not only were
4 residents, school parents and others left to struggle on
5 their own, to protect themselves and their children from
6 unprecedented toxic exposures, but it is also the case
7 that as people became sick from those exposures they had
8 no access to accurate environmental health information,
9 effective and timely testing or cleanups, appropriate
10 public health guidance, or proper medical evaluation or
11 care. The negligence of the EPA and other federal,
12 State and local agencies constitutes a massive failure
13 of our government to take the legally-prescribed actions
14 that would have protected the very people who would come
15 under attack from suffering still more harm from the
16 health hazards released in that attack.

17 The EHC was formed in direct response to grassroots
18 activism, outreach and advocacy by community and labor
19 groups, working to address these globally-denied health
20 impacts to the community. The community brought its
21 unmet health needs to Dr. Joan Reibman at the Bellevue
22 asthma clinic, and Bellevue responded to the community's
23 needs when no one else would. From the beginning the
24 WTCEHC recognized the importance of working closely with
25 the diverse community and labor groups representing the

1 affected neighborhoods as a partnership to ensure that
2 the WTCEHC's 9/11 health services would meet the needs
3 of the population it serves.

4 The WTCEHC rests on the foundation of New York City's
5 municipal hospital system. Patients receive
6 environmental and mental health treatment from an
7 interdisciplinary, highly skilled team of specialists
8 with established expertise in WTC illness.

9 In addition, and crucially, translation services,
10 benefits counseling and other critical services are
11 offered, enabling patients to access care easily. An
12 expanded network of community, labor and advocacy
13 organizations is now working in partnership with the
14 WTCEHC as its community advisory committee to ensure
15 best fit between the services it provides and the
16 evolving health needs of the diverse affected
17 populations in the community.

18 The overriding goal of this collaborative work between
19 the EHC and the CAC has always been improving health
20 outcomes for the affected lower Manhattan residents,
21 students and area workers. And all regulations should
22 be formulated to strengthen the EHC as the New York City
23 survivor Center of Excellence under the Act, and to
24 maintain the ease of access to care and the standards of
25 effectiveness the patients currently benefit from at

1 WTCEHC.

2 We understand that NIOSH is considering contracting out
3 a wide range of functions and responsibilities to
4 information technology contractors such as Northrop-
5 Grumman, who are on a list approved by the Centers for
6 Disease Control. We would appreciate clarification on
7 which functions and what the rationale is for
8 outsourcing these functions. When there are scarce
9 resources for the medical program, we ask is this the
10 most effective and appropriate use of government
11 dollars.

12 In addition we are concerned that the outsourcing of key
13 administrative functions may disrupt the patient center
14 delivery of services, the development of a community --
15 of community and labor-based outreach techniques, and
16 the establishment of a data center that operates on a
17 community-based participatory research model.

18 And I just want to add a few other concerns. The terror
19 watch list requirement we believe may serve as a
20 potential barrier to care, and I have to say, as
21 somebody who's done a great deal of outreach over the
22 years, that explaining to residents who were harmed
23 because they came under attack by terrorists on 9/11
24 that their names will be given to the Department of
25 Homeland Security so that they can be checked against a

1 terror watch list, and it can be determined that they
2 are not terrorists, is a really, really tall order. I
3 can tell you that the people that I have explained this
4 to thus far were confused, to say the least, and -- and
5 many of them had an immediate negative response.
6 Also we are concerned that there may be some changes to
7 the enrollment process that will end up posing a barrier
8 to care for the diverse community of survivors served at
9 EHC.
10 On the subject of a survivor data center, we support a
11 survivor data center as an active disease surveillance
12 initiative which is fully staffed and funded, and fully
13 integrated with the work of EHC. We believe it's
14 essential that we conduct population surveillance for
15 WTC impacts on downtown residents, local workers and
16 students, and we think it's especially critical because
17 the vast majority of the populations currently being
18 monitored are adult white male responders. We need to
19 know more about the impacts to women. We need to know
20 more about those exposed as children and seniors. And
21 we need obviously for new emerging conditions to be
22 captured by the data center.
23 Protective public health policy actually rests on an
24 understanding of impacts along the dose response
25 continuum. We need to know how little it takes to cause

1 harm, especially in the earliest years of life and in
2 the womb.

3 Which brings me to the needs of children, of those who
4 experienced 9/11 as children. Due to their development,
5 behavior and physiology, children are more susceptible
6 than adults to being harmed by exposure to 9/11 -- to
7 all environmental toxics (sic). It is unacceptable that
8 those who were most vulnerable to harm, both
9 psychological and environmental harm from WTC exposures,
10 have actually been the least studied.

11 The New York City Department of Health and Mental
12 Hygiene estimates that some 30,000 children were living
13 or attending school in lower Manhattan on 9/11. And
14 though there has been far too little research, a growing
15 number of studies have documented serious and lasting
16 9/11-related physical and mental health impacts on
17 children and adolescents. In October 2008 DOHMH WTC
18 health registry found that post-9/11 asthma prevalence
19 in children under five years of age who lived or
20 attended school in lower Manhattan was more than twice
21 the already high rates for the northeastern United
22 States. Studies also document age-related mental health
23 impacts for a range of ages, including increased post-
24 9/11 alcohol or substance abuse among affected
25 adolescents.

1 There is an overwhelming need for research to fill the
2 gaps in understanding 9/11 health impacts to children
3 and adolescents. And there is an overwhelming need for
4 outreach to this population and their parents. It is
5 essential to track and treat the cohort of people
6 exposed to the World Trade Center disaster as children.
7 Because children have much of their lifetimes ahead of
8 them, it is critically important that this population be
9 linked with care and monitored over the long term so the
10 trends and emergent diseases can be recognized, studied
11 and, of foremost importance, treated as quickly as
12 possible.

13 We will be sending you much longer testimony in writing.
14 Thank you very much.

15 **MR. ELLIOTT:** Thank you, Kimberly, for those comments.

16 We now will have a -- a break of 30 minutes. We'll be
17 back at 1:15. We'll take a short lunch here.

18 For those folks who are on the phone, when we come back
19 from lunch we will entertain comments from the phone
20 participants, and we have one more individual signed up
21 on the sheet here.

22 (Recess taken from 12:50 p.m. to 1:28 p.m.)

23 **MR. ELLIOTT:** Excuse me, if you'll take your seats we're
24 about ready to restart. We have one sign-up -- one
25 individual in the room signed up yet, and then we have

1 individual or individuals on the phone to provide
2 comment, so...

3 (Pause)

4 **MR. ELLIOTT:** All right, let's -- let's restart if we
5 can, and Operator, are you on line? Or do we have the
6 folks on the telephone ready to make presentation?

7 **THE OPERATOR:** Yes, I do.

8 **MR. ELLIOTT:** We're having trouble hearing you,
9 Operator, so we're --

10 **THE OPERATOR:** Is that better?

11 **MR. ELLIOTT:** Yes. If you -- if you have any influence
12 over the volume, if you could turn it up a little more
13 that would be helpful.

14 **THE OPERATOR:** I'm up all the way. I'm up all the way.

15 **MR. ELLIOTT:** Okay. Then we're going to have to have
16 somebody here turn you up because we can't hear the
17 phone, so our -- our technical staff here in the room
18 are working on that.

19 So at this point why don't we go ahead and -- we have
20 one more individual here in the room, Paul Stein. Paul,
21 would you like to come up front and give your comments,
22 and then we'll go to the phone lines. So Mr. Stein, and
23 then to the phone.

24 **MR. STEIN:** Thank you, Mr. Elliott, Dr. Howard. My name
25 is Paul Stein. I'm the health and safety chair emeritus

1 of the New York State Public Employees Federation,
2 Division 199.

3 Is this better? Okay. My -- my union had many first
4 responders, as well as many workers working in the area
5 of Ground Zero, and a number of them did suffer
6 significant health effects and are -- are sick and
7 injured at the present time.

8 First of all, I'd like to endorse Dr. John Howard as
9 administrator of the World Trade Center health program,
10 not simply because we know from past experience that
11 he's a skilled administrator and a fine physician, but
12 because he's a compassionate human being and a
13 compassionate physician. And despite the necessity of
14 talking about all the different diseases and all the
15 coverage that -- that needs to be -- be covered in terms
16 of -- of health care, we're basically talking about
17 human beings. We're talking about human suffering. And
18 Dr. Howard has always shown himself to care about the
19 individual, not just about the disease. So we hope that
20 Dr. Howard will be appointed as the administrator.
21 As I sat through the session this morning, it was very
22 heartbreaking to listen to all of the individuals
23 talking about their suffering as a result of the public
24 service they rendered, or as a result of living
25 downtown, or as a result of -- of working downtown. And

1 it was compounded -- the heartbreaking nature of the
2 testimony was compounded by the fact that people had to
3 come here today and practically beg to be helped. These
4 people deserve -- you know, people deserve coverage.
5 They're -- they're hurting. They deserve -- they
6 deserve coverage.

7 And to my mind, we should absolutely do everything we
8 can within the confines of the laws and the health care
9 system we have, and this hearing is an important part of
10 that process, to expand the comprehensiveness of the
11 coverage of the Zadroga Act through regulations, through
12 administrative action, and ultimately I hope through
13 further legislative action, through amendments and
14 extensions to the bill.

15 But at the same time, to me, there's a certain elephant
16 in the room here that -- that hasn't been mentioned, and
17 I think it's always worth mentioning when we're talking
18 about health care, and that's the fact that we're
19 fighting over the coverage to a large extent because it
20 involves money, it involves funding. And in these
21 economic times especially, and in these political times,
22 it's very difficult to get -- get funding for health
23 care coverage.

24 But it should be pointed out that if we had universal
25 single payer health care coverage, along the lines of

1 the Medicare system, perhaps, that we wouldn't have to
2 be fighting about how it's going to get paid for because
3 everyone would be entitled to coverage. That doesn't
4 mean we wouldn't need to be here today. I want to
5 stress that. Because the people who are injured as a
6 result of 9/11 have very special needs. Because of the
7 nature of the illnesses and how they came about, we have
8 needs for Centers of Excellence. We have needs for
9 coordination of medical coverage. We have needs for
10 coordination of data collection. We have needs for
11 coordination of research. And a universal health care
12 system, by itself, would not guarantee any of those
13 things. So I want to stress that nothing I'm saying
14 about this larger issue undercuts the need for what we
15 are doing here today.

16 But at the same time, as an activist and as someone very
17 concerned with health care and as someone who
18 previously, in my professional career, was concerned
19 with the quality of health care coverage in this -- in
20 this country, I think it's very important that while we
21 fight for all the things we are fighting for today and
22 to expand -- to expand coverage and comprehensiveness in
23 the bill, at the same time we need to go forward and
24 fight for true universal health care, which will mean
25 that in the future -- in the future we will not have to

1 be fighting over the money, who's going to pay for --
2 for coverage for particular illnesses when different
3 disasters arise, whether it's terrorism, whether it's a
4 natural disaster, whether it's -- whether it's let's say
5 an explosion at a chemical plant which can cause all
6 sorts of horrible health effects over a -- very wide
7 areas.

8 So I'd like to end on that note. What we're doing here
9 is very important. But in order to ensure it in the
10 future, we wouldn't have to work as hard to get coverage
11 for people who are well-deserving of it, that we need to
12 think about the underlying health care system and work
13 toward universal single-payer health care. But again,
14 for -- for situations, for disasters like 9/11, at the
15 same time we have to make sure in the future that we
16 have Centers of Excellence, coordination of medical
17 coverage, coordination of data collection, coordination
18 of research, to make sure that the unique aspects and
19 the unique nature of the diseases that arise will be --
20 will be properly and -- and appropriately addressed.

21 Thank you.

22 **MR. ELLIOTT:** Thank you, Mr. Stein. Now we'll go to
23 those on the phone line, so if the Operator will allow
24 the first person to speak, and that person -- and
25 anybody thereafter -- if you would please state your

1 name clearly and if you feel we -- we would like you to
2 spell it for us, if you would. So please go ahead,
3 Operator.

4 **THE OPERATOR:** Our first person is Mickie Singleday*
5 Hernandez; your line is open.

6 **MS. HERNANDEZ:** Hi, can you hear me?

7 **MR. ELLIOTT:** Yes. Yes, we can hear you. Thank you.

8 **MS. HERNANDEZ:** My name is Mickie Seigle-Day* Hernandez,
9 and I'm the health and safety director for the
10 Communications Workers of America in District 1. On
11 behalf of CWA District 1, I want to thank NIOSH and Dr.
12 Howard for the opportunity to provide input at today's
13 public meeting. I'm sorry I could not be there in
14 person, and I will be submitting detailed comments about
15 the statute to the docket, but I wanted to make a brief
16 statement today.

17 On 9/11 CWA had 13 members who died as a result of the
18 attacks. We also -- our union represents workers who
19 were responders, as well as area workers in the vicinity
20 of Ground Zero. So all of these programs that we're
21 talking about here affect us.

22 Our CWA members who were responders included
23 telecommunications workers from companies such as
24 Verizon, and their name has been mentioned a couple of
25 times today; AT&T, Lucent -- well, what was then Lucent,

1 traffic enforcement agents and supervisors from the
2 NYPD, New York City sanitation workers; nurses from the
3 closest hospital, NYU downtown; and news crews from
4 media and broadcasting companies like ABC, NBC and
5 others. Our CWA members in the area affected by the
6 collapse worked for the Port Authority in the towers,
7 additional telecommunications workers, public sector
8 workers for New York City agencies, Guild members who
9 were reporters for The Wall Street Journal and other
10 publication. In other words, we have -- we represent an
11 extremely diverse group, many of whom are sick and all
12 of whom were, and continue to be, affected by the events
13 of 9/11.

14 So as everybody knows, those members of Congress who
15 were in opposition and fought against the passage of the
16 Zadroga Act repeatedly characterized the Act as an out-
17 of-control slush fund for greedy people wanting to get
18 free health care. Of course nothing could be further
19 from the truth. But in order to get the bill passed,
20 there were many compromises that had to be made to get
21 past these unreasonable and, in my opinion, immoral
22 objections.

23 Our union has been part of the fight to establish a
24 long-term World Trade Center health care program, all
25 these many years before any program existed, and we're

1 thrilled that the Zadroga Act was finally passed. But
2 we're not happy with all of the changes that were made
3 in the bill as part of the necessary negotiations.
4 However, now we must all live with these changes and
5 NIOSH is tasked with drafting regulations for the
6 statute's implementation.

7 So as NIOSH interprets the statute and drafts the
8 regulations that will become the standard operating
9 procedures for the program, I'd like to offer some
10 guiding principles.

11 First I would like to implore NIOSH to draft regulations
12 that maintain as much as possible the essence of the
13 current medical program, which is to provide
14 compassionate and specialized health care and other
15 services, like benefits assistance, to those who were
16 affected by the events of 9/11, provided by Centers of
17 Excellence. And the regulations should improve upon and
18 expand the care offered.

19 I ask that the mandated changes to the program be
20 implemented in ways that do not set up a gauntlet of new
21 barriers to care, for patients or for the providers
22 providing that care.

23 I ask that the regulations be implemented in a way so
24 that no patient finds themselves losing the care they
25 have been eligible for, have been receiving, and so

1 desperately need.

2 I ask that the language in the statute for adding new
3 conditions be interpreted broadly, so that the proof
4 needed for adding diseases like cancer and other
5 illnesses is not solely based on published statistical
6 analyses of what is essentially incomplete data, so we
7 are not forced to wait 20 years down the line for an
8 answer that may never come as more and more people
9 become ill and die, and too many people already have.

10 I ask that the regulations maintain the medical programs
11 as patient-centered programs, and that there be
12 continued and expanded collaboration with patient
13 representatives and patients themselves.

14 I ask that with all the new certifications and reporting
15 requirements that patient confidentiality is maintained.

16 I ask that the data centers be able to continue and
17 expand their important disease surveillance activities,
18 and have the funds to do so.

19 In closing, I ask that we use this opportunity and time
20 to build on and strengthen the current program to
21 provide the best possible care for all those affected by
22 9/11.

23 Thank you.

24 **MR. ELLIOTT:** Thank you, Mickie, for those comments. Do
25 we have anyone else on line that would like to make

1 comment?

2 **THE OPERATOR:** Yes, we do. We have Steven Petrovich.
3 Your line is open.

4 **MR. PETROVICH:** Yes, good afternoon, Dr. Howard. I'm
5 sorry, I can't talk very well. I was a responder and
6 chaplain at Ground Zero, and the past year I've been
7 under hospice pallia-- palliative care, and I'm home-
8 bound and I ask doctor to please consider -- I've been
9 paying out of my pocket every month to be -- have
10 someone come to help me at home. I'm 59 years old and
11 my whole Workmen's Compensation check must go towards
12 paying someone to help me. And I have been told by my
13 doctors that there's nothing more than can be done for
14 me, and that's why they put me on the palliative care
15 program. And I -- I'm in Ohio and many of the doctors
16 really do not even know how to treat us here. And I
17 just ask Dr. Howard if you would be so kind, please, to
18 take into consideration us who are home-bound and are
19 very sick, that maybe we could get some kind of -- more
20 discounted care we could afford 'cause we have to pay
21 out of pocket to get help. And I would hope that --
22 there's many other people, I'm sure, in my position
23 also. And I would like to say thank you to you for all
24 you've done for (unintelligible). God bless everyone.
25 Thank you.

1 **MR. ELLIOTT:** Thank you, Steven, for those comments, and
2 I believe, if I can, I'd like to just quickly summarize
3 because you come across -- rather difficult for us to
4 hear, but being a home-bound individual, you're seeking
5 Dr. Howard's support for additional medical support in
6 home health care. Is that correct?
7 **THE OPERATOR:** I'm sorry, I just cleared his line. If
8 you'll press Star-1 again I'll reopen his line.
9 **MR. ELLIOTT:** Okay. Well, we'll go ahead and go to the
10 next individual on line.
11 **THE OPERATOR:** I have Steven's line reopened.
12 **MR. PETROVICH:** Hello?
13 **MR. ELLIOTT:** Hello, Steven.
14 **MR. PETROVICH:** Yes, I was just saying that I have to
15 pay out of pocket because I'm just on Social Security
16 and they don't pay or send someone to the house, so I
17 have to pay someone to come and help me in the mornings
18 to get up and to help me with my meals and medicine, so
19 I was just asking if there could be some type of
20 provision for those of us who are --
21 **MR. ELLIOTT:** Thank you. We understand that now. I
22 appreciate you coming back on line to clarify for us.
23 Thank you.
24 **MR. PETROVICH:** Thank you.
25 **MR. ELLIOTT:** Next individual on line, Operator?

1 then they'd be paid for 100 percent. The fact that he's
2 in Ohio, that puts him in the Tommy Thompson program
3 that is -- I've not heard good things about. And you
4 know, that's a problem, because I -- I think this was
5 like a really drastic case of somebody who desperately
6 needs, you know, home care help. And the fact that he's
7 paying out of pocket and doesn't even know that his
8 medications should be paid for 100 percent, and he
9 should be having home care paid for, you know, but
10 that's the disconnect here.

11 Thanks.

12 **MR. ELLIOTT:** Thank you, Susan. Now back to the on--
13 on-line folks, is there anyone else that would like to
14 make a comment by telephone?

15 **THE OPERATOR:** We do have a person; Denise Villamia,
16 your line is open.

17 **MS. VILLAMIA:** Yes, good afternoon, Dr. Howard and
18 everyone else there. I'm so sorry, I'm just very
19 emotional after hearing the last caller, so I'm going to
20 try to get myself together to get through what I have to
21 say.

22 I want to thank Steven first for his service, and I'm
23 very sorry that you're going through what you're going
24 through, and my heart goes out to you and my prayers
25 will, too.

1 My name is Denise Villamia. I'm in Florida right now so
2 I can't be there personally, but my sister Rhonda spoke
3 earlier. We were both volunteers down at the World
4 Trade Center at Ground Zero. We were citizens who
5 responded to the attack on the World Trade Center. I
6 volunteered through the Red Cross and then the Salvation
7 Army.

8 Prior to my setting foot at Ground Zero I was a vibrant,
9 healthy, happy and joyful individual. I'm a social
10 worker by profession within the New York City public
11 school system, and currently I'm on an unpaid leave of
12 absence due to my worsening medical conditions. I've
13 traveled several times with the FealGood Foundation to
14 Washington also in order to advocate for the passage of
15 this bill. Subsequent to my stepping foot at Ground
16 Zero I have developed, in this order, vitiligo, which is
17 a disease of the skin pigmentation; asthma and reactive
18 airway disease; post-traumatic stress, depression and
19 generalized anxiety disorder; GERD and IBS; moderate
20 obstructive sleep apnea; fibromyalgia; autoimmune
21 antiphospholipid antibody syndrome, which is a blood
22 disorder; lupus and Hashimoto's Disease, along with
23 chronic fatigue syndrome.

24 In the research that I've reviewed for myself as a lay
25 person, not a doctor, I have seen that for certain

1 vitiligo and fibromyalgia can be triggered by exposures
2 to traumatic events and/or exposures to chemical toxins.
3 I have also read in research that vitiligo,
4 fibromyalgia, lupus, chronic fatigue syndrome and
5 antiphospholipid syndrome along with Hashimoto's Disease
6 all have in common that they are disorders in which the
7 immune system is attacking its own body, or the person's
8 own body.

9 I have been involved at Mount Sinai program since 2003,
10 and it's only recently that they've offered me treatment
11 for the GERD, the sleep apnea and the asthma, and only
12 because I had to strongly advocate for this and jump up
13 and down to be heard. And right now I'm about to lose
14 my health insurance because of the leave of absence and
15 not being paid, and I eventually will have to quit my
16 job. While I'm so grateful for these programs at Mount
17 Sinai and what I am getting, it isn't good enough. It's
18 -- it's not enough just to cover -- cover the covered
19 treatments or the covered conditions or the identified
20 conditions. Any and all immune system and inflammatory
21 conditions should also be evaluated further, and treated
22 through the program and under the new funds.

23 I went to Ground Zero with no thought of the after-
24 effects. I should not have to go outside the treatment
25 program to be seen by a rheumatologist, a hematologist,

1 an endocrinologist on a regular basis. These specialty
2 doctors should be part of the covered treatment
3 specialists that all participants can have access to.
4 I just want to say that the person that I was before
5 9/11 no longer exists. I have had to learn to live with
6 this new chronically ill person that I've become, and I
7 just want to be able to enjoy my life again as best I
8 can. Please, Dr. Howard, I beg of you to help me and
9 the participants do this, all responders. Please help
10 all of us and treat us for all our symptoms.
11 Thank you.

12 **MR. ELLIOTT:** Thank you for those comments, Denise. Are
13 there any more people on the line that would like to
14 give comment?

15 **THE OPERATOR:** Once again, to make a comment, please
16 press Star-1 on your touchtone phone.

17 (Pause)

18 At this time there are no commenters on the phone.

19 **MR. ELLIOTT:** Anyone else in the room that would like to
20 provide comment today?

21 If not, we're going to wait around for 15, 20 minutes,
22 and if you want to come up and talk to Dr. Howard or
23 myself or some of the program representatives, that
24 might be a good thing to do at this time, so -- one last
25 call for any comments in the room or on the line.

1 **MS. ZUNIGA:** Hi, my name is Marina Zuniga. I used to
2 work in the 9/11 for six months all around and we don't
3 has protection when we're going to clean because
4 everybody say that nothing happen, everything was okay.
5 And I know a lot of people work with me, about 300, with
6 my group, and everybody's very sick. I used to have
7 cancer before. I have asthma, reflux, my eyes, pain in
8 my bones, and I don't need the -- they say that we are --
9 -- has to treat me yes only for five years more, and I
10 don't think so that is good for everybody because
11 everybody's very, very sick. Some people that I know,
12 they die by cancer. They are very sick. They can't
13 come today because they are very bad condition, and I
14 would like to tell to somebody help us, because we need
15 help. Believe me, we don't have tomorrow, we don't
16 know. Everybody's difference -- different kind of
17 sickness, every day different, everybody's different and
18 sick. And I went to the Bellevue Hospital. I went to
19 the treatment. They gave me lot of pills. They gave me
20 lot of medicine, but is not enough. I don't feel good.
21 Every day I feel very, very bad, mental problems, and I
22 don't know what can I -- I guess I -- each day I say
23 thanks God for the (unintelligible) that they gave me
24 because I'm not feel good. And it's a lot of people is
25 like the same like me. They can't come to over here.

1 They -- someone is outside because they have -- scared
2 to come and sit in here because they don't have papers
3 and I'm feel very sad for them.

4 Thank you.

5 **MR. ELLIOTT:** Thank you, Marina, for those comments. I
6 appreciate you coming up at the last hour here.
7 Any further comments from those in the room?

8 (No responses)

9 We're going to wait another five minutes. We'll see.

10 (Pause)

11 **MR. ELLIOTT:** I believe we have one more caller on line
12 who'd like to comment, so if we could hear that caller
13 now -- and if there's anyone else in the room that would
14 like to identify themselves as wishing to give a
15 comment, please do so.

16 Operator, if we could have the caller on line.

17 **UNIDENTIFIED:** I'm here, are you -- can you hear me?
18 Hello?

19 **MR. ELLIOTT:** Yes, we can hear you.

20 **UNIDENTIFIED:** Then -- well, I'm -- I'm hoping that
21 maybe by my calling I'll open up some more discussion
22 because I'm one of the shy people and the most -- I'm
23 feeling the most intimidated about calling 'cause I -- I
24 hear about all these people that are really, really --
25 and are right on the edge of -- have just gone through

1 so much and --

2 **MR. ELLIOTT:** Could you speak up a little bit more and
3 give your name, if you please? I'm sorry to interrupt
4 you, but we're having a little bit of trouble hearing
5 you so if you could be a little bit more -- louder and -
6 -

7 **UNIDENTIFIED:** Should I start over --

8 **MR. ELLIOTT:** -- tell us your name.

9 **UNIDENTIFIED:** -- or should I just go on? I just -- I
10 wanted to say that I'm one of the shyer people and
11 feeling one of the -- I am one of the ones who feels the
12 most insignificant because I haven't -- my experience,
13 although horrifying for me, 9/11, has just been as bad
14 throughout the whole last ten years. And I'm -- from
15 that moment that it happened until now, I feel so
16 insignificant and so small that why should I bother you
17 with what my problems are. But nonetheless, I'm going
18 to go ahead. It's taken me all this time to have the
19 nerve to call because I don't feel like I'm one of the
20 forgotten ones, and I know there's lots of people out
21 there that are because I know there are these incredibly
22 substantiated first responders and people that are
23 horribly sick, and that makes me feel like I shouldn't
24 even bother, but I am going to bother.
25 I live on Ground Zero and that day 18 windows of mine

1 blew out. I had six feet of rubble in my loft, and I --
2 I and my son and my partner, who's no longer here, spent
3 the year and a half -- it took 18 months to come home
4 after that day, digging in here, trying to find things.
5 And as it turned out, it all got put in storage and then
6 I couldn't afford the storage bill.
7 My situation is ten years later things are falling apart
8 physically. I've been pretty sick. I'm homebound. I
9 couldn't come today. I'm so glad you had some kind of
10 call-- listening service available. But I think it's
11 very important for people like me, who I don't have the
12 energy to fight anymore -- I tried and, you know, just
13 tried to stand up for myself and I just got rolled over,
14 run over pretty much by the systems and the process. It
15 was really nobody's fault. It's the process just got so
16 hard.
17 Just trying to find a therapist, you know, they -- you
18 had to go -- Red Cross said you had -- can go to a
19 therapist, but you've got to go find someone who will
20 take you on and be willing to wait the nine months it
21 took to get paid. So my life has been like that. I
22 have no money. I'm on disability. I'm getting food
23 stamps and meals on wheels -- thank God there's those
24 services. But I -- I had a thriving business here in my
25 loft. My windows are on Liberty Street. I'm above a

1 fire station. And there's no hel-- I go -- everywhere
2 I've asked for help, they always say "Well, do you have
3 a disease?" Yeah, I've got lots of things wrong with
4 me, including I sleep about 20 minutes a night, but
5 nothing -- you know, I'm not dying of cancer and I don't
6 ha-- I have a lot of things that are probably not going
7 to make me live that much longer, but I -- I have spent
8 months and months in hospitals for different things, but
9 none of it is substantiated. I even went to the lawyers
10 and -- about the -- the bill, and none of it is like,
11 you know, directly substantiated by what I went through
12 9/11. And I -- I just want to put a voice in for those
13 of us that haven't made a voice very loud and very
14 clear, and I don't want to take any more time, but I
15 think it's really important that somehow those of us who
16 are more of the silent ones have some -- get some help.
17 If nothing else, someone to listen to us because that's
18 the biggest problem, just getting someone to hear us.
19 Anyway, I thank you for doing what you've done, and I
20 hope it serves a lot of people. I'm sure it will. It
21 would be nice if something was possible for me because I
22 know there has been much -- I mean I have no money now
23 so even my disability check goes to paying part of my
24 rent, so -- and I can't go to doctors a lot of times.
25 I'm on Medicaid and Medicare, so I do have that now, but

1 that just came, so I haven't had that -- you know, I had
2 to wait till I -- quite a while, after 65, for that to
3 come. So I'm -- I'm -- you know, I'm an elder disabled
4 person who needs help.

5 And I'll thank you for the help you've given and I'll
6 say good-bye. Thank you.

7 **MR. ELLIOTT:** Thank -- thank you for that comment. We
8 have one more comment here from somebody in the room,
9 Sta--

10 **DR. HOWARD:** Stan, be -- go ahead up there. I just was
11 going to deliver some information about the victim's
12 compensation fund for our record so that, if you're
13 interested, I have a phone number and a web site, which
14 I just checked. It's 9/11 -- that's 9-1-1, just enter
15 the numbers 911 dot fund, f-u-n-d, at usdoj dot gov.
16 That's 911.fund@usdoj.gov. And I have a phone number,
17 too; 202-616-7900. That's 202-616-7900. We'll put that
18 on our WTC web site on the NIOSH site and our -- our
19 docket will list that number and web site. So thanks,
20 Stan. Sorry for the interruption.

21 **MR. MARK:** That's okay. My name is Stanley Mark. I'm
22 an attorney with the Asian-American Legal Defense and
23 Education Fund. I am one of the cofounders of the
24 Beyond Ground Zero Network that helped initiate and set
25 up, in partnership with Bellevue Hospital, a clinic that

1 would treat and track survivors, mainly folks from lower
2 Manhattan, and including Chinatown and lower east side.
3 I'm interested in today in just giving a very brief
4 statement indicating our support for combining the
5 clinical centers with the data centers that are
6 mentioned in the Zadroga Act. We feel that is very
7 critical to do so in order to further studies of people,
8 particularly folks living in the lower east side and
9 Chinatown, that may or may not have included in other
10 studies. However, we will be submitting, at some point
11 later on before the April deadline, comments, either as
12 a individual organization or as part of Beyond Ground
13 Zero Network or part of the community advisory
14 committee.

15 Thank you.

16 **MR. ELLIOTT:** Thank you, Stan. Anyone else who would
17 like to provide comment today, for the record?

18 (No responses)

19 We encourage you to provide your written comments to the
20 NIOSH docket. Those will be considered and factored
21 into our deliberations, so please use that avenue of
22 communication as well.

23 Anyone else who would like to speak today?

24 (No responses)

25 Anyone on the phone?

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C E R T I F I C A T E

STATE OF GEORGIA
COUNTY OF FULTON

I, STEVEN RAY GREEN, being a Certified Merit Court Reporter in and for the State of Georgia at large, hereby certify that the foregoing pages, 1 through 166, constitute, to the best of my ability, a complete and accurate transcription of the proceedings and were accurately reported and transcribed by me or under my direction.

I further certify that I am neither related to or counsel to the parties herein nor have any interest in the outcome of the above-styled proceedings.

This certification is expressly denied upon the disassembly and/or photocopying of the foregoing transcript, or any portion thereof, unless such disassembly/photocopying is done by the undersigned and original signature and official seal are attached thereon.

Witness my hand and official seal this 16th day of March, 2011, in Atlanta, Fulton County, Georgia.

STEVEN RAY GREEN, CCR, CVR-CM
CERTIFICATE NUMBER A-2102