

THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL AND PREVENTION
NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH

convenes

MEETING ONE

WORLD TRADE CENTER HEALTH PROGRAM

SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE

VOL. I

DAY ONE

WEDNESDAY, NOVEMBER 9, 2011

Jacob K. Javits Federal Building
26 Federal Plaza New York, NY

The verbatim transcript of the
Meeting of the Scientific/Technical Advisory
Committee held at the Jacob K. Javits Federal
Building, New York, New York, on November 9, 2011.

STEVEN RAY GREEN AND ASSOCIATES
NATIONALLY CERTIFIED COURT REPORTERS
404/733-6070

C O N T E N T S
November 9, 2011

WELCOME	8
ELIZABETH WARD, PhD, CHAIR	
INTRODUCTORY REMARKS	13
JOHN HOWARD, MD, WTC HEALTH PROGRAM ADMINISTRATOR	
PANEL OF WTC RESPONDERS AND SURVIVORS	18
RESPONDERS:	
JIM MELIUS, MD, DrPH, NYS LABORERS HEALTH & SAFETY FUND	
WILLIAM ROMAKA, UFA SERGEANT-AT-ARMS/H&S OFFICER	
MICKI SIEGEL DE HERNANDEZ, CWA DISTRICT 1; H&S DIRECTOR	
SURVIVORS: INVITED	61
TREATMENT PROGRAMS AND HEALTH REGISTRY:	
WTC HEALTH REGISTRY, MARK FARFEL, ScD	100
WTC ENVIRONMENTAL HEALTH CENTER/ HEALTH AND HOSPITALS CORPORATION	122
JOAN REIBMAN, MD	
FIRE DEPARTMENT OF NEW YORK CLINICAL CENTER FOR EXCELLENCE	145
DAVID PREZANT, MD	
STATE UNIVERSITY OF NEW YORK, STONY BROOK CLINICAL CENTER OF EXCELLENCE	175
BENJAMIN LUFT, MD	
MOUNT SINAI SCHOOL OF MEDICINE CLINICAL CENTER FOR EXCELLENCE	200
LAURA CROWLEY, MD	
UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY CLINICAL CENTER OF EXCELLENCE	218
IRIS UDASIN, MD	
NEW YORK UNIVERSITY/BELLEVUE HOSPITAL CLINICAL CENTER OF EXCELLENCE	230
DENISE HARRISON, MD	
LONG ISLAND JEWISH MEDICAL CENTER CLINICAL CENTER OF EXCELLENCE	252
JACQUELINE MOLINE, MD	
PUBLIC COMMENTS	244
COMMITTEE BUSINESS, ELIZABETH WARD, PhD, CHAIR	284

TRANSCRIPT LEGEND

The following transcript contains quoted material. Such material is reproduced as read or spoken.

In the following transcript: a dash (--) indicates an unintentional or purposeful interruption of a sentence. An ellipsis (. . .) indicates halting speech or an unfinished sentence in dialogue or omission(s) of word(s) when reading written material.

-- (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 A R T I C I P A N T S

1 Committee Members

2

3 Occupational Physicians with Experience in Treating
4 WTC Rescue and Recovery Workers:

5 Steven Markowitz, M.D.

6 Professor of Environmental Sciences and Director of
7 The Center for The Biology of Natural Systems at
8 Queens College, City University of New York, New York
9 City.

10 William Rom, M.D., M.P.H.

11 Professor of Medicine and Environmental Medicine, New
12 York University School of Medicine
13 Director, Division of Pulmonary and Critical Care
14 Medicine, School of Medicine, New York University,
15 New York City.

16 Occupational Physicians:

17 Robert Harrison, M.D., M.P.H.

18 Clinical Professor of Medicine, University of
19 California, San Francisco;

20 Chief, Occupational Health Surveillance and
21 Evaluation Program, California Department of Public
22 Health, San Francisco.

23 Virginia Weaver, M.D., M.P.H.

24 Director, Occupational and Environmental Medicine
25 Residency, Bloomberg School of Public Health, Johns
26 Hopkins University, Baltimore.

27 Physician with Pulmonary Medicine Expertise:

28 Thomas K. Aldrich, M.D.

29 Professor of Medicine and Director of The Pulmonary
30 Training Program, Albert Einstein College of
31 Medicine, Yeshiva University, New York City.

32

33

1 Representatives of WTC Responders:
2 Stephen Cassidy
3 President, Uniformed Firefighters Association of
4 Greater New York, Local 94 I.A.F.F. AFL-CIO

5 Valerie Dabas
6 Human Resources Analyst, Patrolmen's Benevolent
7 Association of the City of New York, Inc., New York
8 City.

9 Guillermina Mejia, M.P.H
10 Certified Health Education Specialist, Principal
11 Program Coordinator, Safety and Health Department,
12 American Federation of State, County, and Municipal
13 Employees, District Council 37, New York City.

14 Representative of Certified-Eligible WTC Survivors:
15 Kimberly Flynn,
16 Co-Founder, Director, 9/11 Environmental Action

17 Catherine McVay Hughes
18 Vice Chairman, Community Board 1 World Trade Center
19 Redevelopment Committee, Lower Manhattan World Trade
20 Center Redevelopment, New York City.

21 Susan Sidel, J.D.
22 Resident of New York City and volunteer WTC
23 responder.

24 Industrial Hygienist:
25 John Dement, Ph.D.
26 Professor, Community and Family Medicine, Duke
27 University Medical School, Durham, N.C.

28 Toxicologist:
29 Julia Quint, Ph.D.
30 Research Scientist Supervisor II and Chief, Hazard
31 Evaluation System and Information Service (HESIS),
32 Occupational Health Branch, California Department of
33 Public Health (retired), Oakland.

34
35
36
37

1 Epidemiologist:

2 Elizabeth Ward, Ph.D.

3 National Vice-President for Intramural Research,
4 American Cancer Society, Atlanta. (Advisory Committee
5 Chair-Person)

6 Mental Health Professional:

7 Carol S. North, M.D. M.P.E.

8 Professor, Department of Psychiatry, University of
9 Texas Southwestern Medical Center, Dallas.

10 Environmental Health Specialists:

11 Glenn Talaska, Ph.D.

12 Certified Industrial Hygienist, Professor, Department
13 of Environmental Health, University of Cincinnati,
14 Cincinnati.

15 Leonardo Trasande, M.D., M.P.P.

16 Associate Professor in Pediatrics, Environmental
17 Medicine and Health Policy, New York University;
18 Associate Attending in Pediatrics, Bellevue Hospital
19 Center, New York City.

20

21

22 Designated Federal Official:

23 Paul J. Middendorf, Ph.D., CIH

24 Senior Scientist

25 CDC/NIOSH/Office of the Director

26 Cincinnati, Ohio

27

28

29

P R O C E E D I N G S

(8:40 a.m.)

1
2 DR. MIDDENDORF: If there are any other
3 committee members, now would be a good time to
4 come up to the table, and I think we should
5 begin.

6 As this is the initial meeting of the World
7 Trade Center Scientific/Technical Advisory
8 Committee, it seems appropriate for us to take
9 a few moments to remember those who were killed
10 in the attacks on 9/11, and also those
11 responders and survivors who have since died
12 because of those attacks. So if we could just
13 take a few minutes to reflect on their
14 sacrifices, and do that in silence.

15 (Pause)

16 Thank you very much. I do have a few
17 administrative details that I need to go over
18 here at the beginning of the meeting. First
19 off, I want to point out where the emergency
20 exit routes are. If there is an emergency the
21 evacuation route would be through either the
22 door on this side or the open area on that side
23 (indicating). Go out to the corridor
24 immediately on the other side of the doors,

1 make your way down to the left and then go
2 through the glass double doors. And as soon as
3 you go out through the glass double doors, walk
4 to your left, go down to the end of that hall.
5 That's where the fire exit door is. That's
6 where the stairs are. So that's how we
7 (telephone connection interference).
8 I should also make another announcement that no
9 coffee or food is allowed here in the
10 conference center. Water and soft drinks
11 apparently are acceptable.

12 **WELCOME**

13 My first duty on behalf of the World Trace
14 Center Health Program is to extend a very warm
15 welcome to our newly-impaneled members. I
16 think we're looking very much forward to
17 hearing some very robust discussions, the many
18 perspectives that each of you will bring to
19 help develop recommendations that you will give
20 to the program administrator.
21 So one of the first things I need to do is take
22 a roll call, and what I'll ask each of you to
23 do is to identify yourselves. And when you do
24 that I also need you to identify whether or not
25 any changes in your job status or any changes

1 in your interest have occurred (electronic
2 interference) -- any changes in your interest
3 or changes in your job would have occurred
4 since you filled out the OGE-450 that would
5 impact your conflict of interest status.
6 So why don't we start with our Chair, Dr. Ward.
7 DR. WARD: No changes have occurred in my job
8 status or interest.
9 DR. NORTH: I'm Carol North; no changes.
10 MR. CASSIDY: Steve Cassidy; no changes.
11 MS. HUGHES: Catherine McVay Hughes; no
12 changes.
13 DR. HARRISON: Robert Harrison; no changes.
14 DR. ROM: Bill Rom; no changes.
15 UNIDENTIFIED: Status quo.
16 DR. QUINT: Julia Quint; no changes.
17 DR. TRASANDE: Leonardo Trasande; no changes.
18 DR. DEMENT: John Dement; no changes.
19 DR. WEAVER: Virginia Weaver; no changes.
20 MS. MEJIA: Guillermina Mejia; no changes.
21 DR. MARKOWITZ: Steven Markowitz; no changes.
22 MS. DABAS: Valerie Dabas; no changes.
23 MS. FLYNN: Kimberly Flynn; no changes.
24 DR. DEMENT: John Dement; no changes.
25 DR. MIDDENDORF: Okay. Dr. Talaska, are you on

1 the line?

2 (No response)

3 DR. MIDDENDORF: Dr. Talaska is a member of the
4 Committee. He will be participating at various
5 times by telephone, but he's not present at the
6 moment.

7 I also want to extend a warm welcome to the
8 interested members of the public, many of whom
9 are here in the audience, and we also will have
10 some folks on the phone.

11 I want to point out to you that there is time
12 on our agenda later this afternoon and early
13 tomorrow morning for members of the public to
14 speak to the Committee if you would like to.
15 If you're interested in presenting, you must
16 sign up out at the registration table which is
17 over in the corner. I also want to point out
18 that there are a limited number of slots. They
19 will be assigned on a first come-first served
20 basis, and each public commenter will be given
21 up to five minutes to present.

22 And also posted there is a copy of our
23 redaction policy, and you need to read that
24 before you sign up for making a presentation.

25 I also want to point out that there are copies

1 of our agenda for the meeting on the back
2 table, as are several other handouts. These
3 handouts are available not just here, but
4 they're available on the website for the World
5 Trade Center Health Program, so you can get
6 copies of those there as well if you happen to
7 be on the phone.

8 If we have any written comments which are
9 submitted while we're here, or afterward, if
10 they're submitted to the addresses identified
11 in the Federal Register notice, they will all
12 be posted in the docket. Our docket number for
13 this Committee is Docket No. 248. That's the
14 NIOSH docket page, is where you would find
15 those comments.

16 With that, I think it -- I'm done with my
17 administrative things and I will turn it over
18 to our Chair, Dr. Ward.

19 DR. WARD: I'd also like to add my warm welcome
20 to the members of the Advisory Committee, the
21 representatives of responders and survivors who
22 will speak to us today, representatives of the
23 Centers of Excellence who will speak later in
24 the day, and really to everyone who has --
25 attending this meeting. I think there are many

1 people in the group that have contributed a
2 great deal to our recognition of the health
3 conditions that are associated with the World
4 Trade Center exposures and whose hard work and
5 advocacy has led to passage of the Zadroga
6 Bill. So I want to recognize your
7 contributions.

8 This Advisory Committee will have several
9 functions. One is to give formal responses to
10 Dr. Howard's -- the questions that Dr. Howard
11 poses to us as World Trade Center
12 administrator. But I also think one of our
13 most important functions is to have discussions
14 here at the table where we're bringing together
15 a huge amount of expertise in the clinical
16 sciences and the epidemiology and public
17 health, all of the sciences that bear on the
18 questions about the health conditions that
19 we'll be discussing. And in a way, the sum of
20 the knowledge of this group will be greater
21 than the individual parts. So we are
22 emphasizing really the discussion part of the
23 function of the Committee, but at the same time
24 our agenda today is packed with a lot of
25 speakers and information.

1 Today is really a day to -- for us to gain
2 information, so we will have limited time for
3 discussion today. If members of the panel want
4 to ask a question or speak, please designate it
5 by raising your name card on end, but we may at
6 times have to move the discussion along in the
7 interest of hearing everyone who's here to
8 speak today.

9 So thank you very much, and we'll move on to
10 Dr. Howard.

11 DR. MIDDENDORF: Before Dr. Howard begins,
12 we're going to try to get rid of this buzz.
13 We're going to call back to the phone folks,
14 the conference line, and see if they can get
15 rid of that for us.

16 **INTRODUCTORY REMARKS**

17 DR. HOWARD: Good morning, everybody, and --
18 here on the Committee and to those of you that
19 came this morning. Thank you very much. To
20 all the responders and survivors and other
21 attendees, welcome to the inaugural meeting of
22 the Scientific and Technical Advisory
23 Committee. I want to thank each of you for --
24 (telephone/electronic malfunction).
25 (Conversation with Dr. Middendorf and the

1 operator in an effort to clear the line of
2 electronic interference.)

3 DR. HOWARD: I'm going to try this again. The
4 Committee has a very important role to play in
5 the World Trade Center Health Program. The
6 James Zadroga 9/11 Health and Compensation Act
7 specifies three general areas of contributions
8 from the Scientific and Technical Advisory
9 Committee.

10 One, the Act requires the Administrator to seek
11 advice from the Committee with regard to
12 determining eligibility criteria for responder
13 and survivor membership in the Program.

14 Second, the Act requires the Administrator to
15 seek advice from the Advisory Committee with
16 regard to identifying research needs for the
17 Program.

18 Third, the Act provides the Administrator may
19 consult with the Advisory Committee regarding
20 whether a particular health condition should be
21 added to the list of the World Trade Center
22 health-related conditions.

23 I want to provide you this morning some brief
24 updates on these three roles of the Advisory
25 Committee. With regard to eligibility

1 criteria, no modification of the statutory
2 eligibility criteria for responders or
3 survivors is planned at this time. Work to
4 determine the eligibility criteria for the
5 Pentagon and the Shanksville, Pennsylvania
6 responders has begun and is ongoing.
7 Information is being gathered to develop a
8 timeline of on-site response-related
9 activities, and exposure information is being
10 accumulated on airborne toxins and other
11 hazards present during the Pentagon and
12 Shanksville responses. And I've provided you
13 with an information sheet on the progress of
14 that project to date, and at a subsequent
15 meeting we'll be reporting to you and seeking
16 your advice on that particular project.
17 Second, research. A solicitation for research
18 proposals was announced on April 23rd, 2011 for
19 the award of research contracts in FY 2011 for
20 up to three years with annual budgets of up to
21 a half-million dollars. Four proposals
22 received funding in July, 2011, and four
23 additional proposals received funding in
24 September for the second round of the same
25 announcement, which is now closed. A brief

1 description of each of those funded projects,
2 all eight of those, has also been provided to
3 you and is a handout in the back of the room.
4 I encourage you to look at that.

5 A new announcement is currently being planned
6 for FY-12 funding. The solicitation process
7 for FY-12 funding research offered by the World
8 Trade Center Health Program will be open to all
9 qualified applicants, and will be competitively
10 awarded based on scientific quality criteria.
11 The objective is to support the best science in
12 areas that will be most meaningful in terms of
13 contributing to the scientific priorities of
14 the program. And here's where the Committee
15 comes in, in identifying, suggesting to the
16 Administrator what are those priorities, where
17 should research be funded and what are the best
18 priorities for the program.

19 Thirdly, with regard to petitions -- with
20 regard to petitions received to date requesting
21 that a health condition be added to the list,
22 the Administrator received a petition to add
23 cancer to the list on September 8th, 2011.

24 Pursuant to Section 33(12)(a)(6)(B)(i) of the
25 Act, the Administrator requested advice from

1 you, the Advisory Committee, on that petition.
2 That petition and the letter to the Chair is
3 also in your booklet.

4 Finally I just wanted to speak to you about the
5 concept of advice. As the Committee considers
6 any of the issues brought to it by the program,
7 it's important to keep in mind that the
8 Scientific/Technical Advisory Committee was
9 established by the Act to provide advice of a
10 scientific or technical nature to the
11 Administrator. Unlike the responder steering
12 committee or the survivor steering committee
13 with their broad representation across the
14 community of interested parties, the Advisory
15 Committee is not established as an advocacy
16 committee.

17 Six members of the Advisory Committee, though,
18 are representatives of the populations affected
19 by the terrorist attacks of September 11, 2001,
20 and have been seated on the Committee because
21 of their diverse experiences with concerns of
22 those populations of people rather than due to
23 their specific scientific or technical
24 expertise. The input of the affected
25 population is an important part of any

1 Committee deliberation as those views I think
2 ensure that any discussion of science is
3 grounded in the real world experience of the
4 populations affected. Ultimately, though,
5 articulating a scientific basis for any
6 Advisory Committee recommendation to the
7 Administrator will be of greatest value to the
8 program.

9 So on behalf of the World Trade Center Health
10 Program I welcome each of you to your service
11 on the Committee. I thank you for the time and
12 the effort that you will put into this
13 important activity. We appreciate your time.
14 We appreciate your interest and expertise.
15 Thank you very much.

16 DR. WARD: Thank you. We'll now begin the
17 panel of World Trade Center responders and
18 survivors, and I think the first speaker is Jim
19 Melius.

20 **PANEL OF WTC RESPONDERS AND SURVIVORS**

21 DR. MELIUS: That's why you're called the
22 technical advisory committee.

23 Anyway, I'd like to thank you for inviting me
24 today, thank NIOSH for holding this meeting and
25 for holding it in New York City where it's

1 convenient for many of the people that are
2 involved in this program. I'd like to also
3 thank all of you members of the panel for your
4 willingness to spend your time and efforts on
5 this Committee. It's a very important
6 committee and one that we do appreciate your
7 willingness to do this.

8 I work for the Laborer's Union which represents
9 construction laborers. Several thousand of
10 those laborers worked in the rescue and
11 recovery efforts at Ground Zero. But I also
12 work with several other -- many other unions
13 that -- really a very diverse group of people
14 that -- represent a group -- very diverse group
15 of people who worked in the rescue and recovery
16 efforts at Ground Zero. And as you'll hear in
17 one of the later presentations, it really is
18 very important to understand that this was a
19 large group, many different people doing it --
20 very hard to really sort of pinpoint or
21 characterize the people that were exposed, and
22 that diversity I think is very important to
23 your understanding of the program.

24 Organized labor in New York has been very
25 involved in this program right from the very

1 beginning. We -- early on we worked to get
2 funding to initialize the medical programs at
3 Mt. Sinai and elsewhere. We lobbied hard and
4 worked hard with our congressional delegation,
5 particularly Congressmen Maloney and Nadler, to
6 continue the funding for that, and we worked
7 very hard over many years with many groups here
8 in order to pass the legislation that
9 established your Committee, among other things.
10 We have a great deal -- feeling of ownership of
11 this program. We've been very involved. For
12 most of the time of the medical program I've
13 chaired what's called the steering committee,
14 which -- on the responder side, which for the
15 responder medical program is a group that meets
16 monthly of labor representatives and
17 representatives from the medical programs to
18 review and coordinate. On the program we've
19 had a great deal of input and we expect to
20 continue to have a great deal of input into
21 that. As you may know, in the legislation the
22 steering committee continues to meet on a
23 monthly basis, and we continue to play that
24 role.
25 Same on the side of the survivor community

1 representatives, there's a similar program that
2 started a little bit later but also has that
3 level of involvement.

4 One thing I think that's important -- I chair a
5 different committee sort of analogous to this
6 that has to do with compensation for our
7 nuclear workers in the United States. I chair
8 that committee, been on it for almost ten years
9 now, and one thing I think is very important, I
10 urge you to do, is to, one, ensure transparency
11 of your operations. I think that's very
12 important for the credibility of your decision-
13 making which -- and advice that you give. And
14 secondly, that you provide ample time and
15 opportunities for public input, meeting here,
16 but also to the extent possible, to hold
17 evening sessions, times that are convenient for
18 working people and -- to attend. I think it's
19 important not only for the input that you'll
20 get, but also for the openness, and I think it
21 will certainly help the credibility of the
22 decisions and advice that you give to the
23 Administrator.

24 One area that I just want to mention that I
25 think is probably the most urgent issue to deal

1 with -- I don't think we're expecting you to
2 deal with it today -- and that is the issue of
3 new World Trade Center-related conditions. The
4 listing that's in the legislation, been in
5 place for a long time, it's conditions that
6 were recognized relatively soon after 9/11 and
7 one that I think is pretty well established in
8 terms of follow-up studies. However, it's been
9 over ten years now, and I think there's a great
10 deal of concern, as well as I think now some
11 evidence, that there are other, more latent,
12 conditions appearing among this population,
13 certainly a great deal of concern about cancer.
14 And given that the funding for this program has
15 been difficult to achieve, it has not always
16 been very consistent over time, I don't think
17 that NIOSH has had adequate funding to set up
18 the kind of follow-up surveillance and follow-
19 up studies that are needed to fully detect
20 these new conditions on a very rigorous basis.
21 And I would certainly urge you, in terms of
22 your advice to the Administrator as well as
23 your review of the research program and so
24 forth, to ensure that this kind of function
25 gets fully funded and fully evaluated. People

1 are very anxious for answers, in particular
2 with cancer, but with other latent conditions.
3 And I think it's very important that this get
4 done in as expeditious a way as possible. And
5 that also that your advice to the Administrator
6 in terms of adding additional conditions to the
7 list of covered conditions also takes into
8 account not only the science and surveillance
9 that's underway and needs to be done, but also
10 you give a great deal of thought of what's an
11 appropriate way of making a decision on adding
12 conditions. We do not want to wait until 30 or
13 50 years from now when all the mortality
14 studies are done and we can look back and say
15 Well, gee, there was an increase of --
16 whatever, some type of cancer; lung cancer, say
17 -- so forth. And meanwhile, you know,
18 hundreds, if not thousands, of our union
19 members and people from the community have
20 suffered and many of them may have died from
21 this condition without compensation and without
22 recognition of these conditions. And I think
23 how to provide a fair and scientifically-based
24 decision approach to address these, to add
25 these -- evaluate and consider adding these

1 conditions to the list of covered conditions I
2 think is one of your most important functions
3 and one that I think you need to work very
4 closely with the Administrator on, and people
5 in the program.

6 So with that, let me stop here and let me
7 introduce the next member of our panel --
8 there'll be two other speakers, one from the
9 rescue workers' side and the other will be a
10 person representing other workers that were
11 involved in this. As you'll see, we overlap to
12 a great degree. But next person providing --
13 will speak will be Bill Romaka, who's the
14 health and safety director for the Uniformed
15 Firefighters' Association, which represents New
16 York City firefighters. And Bill will come and
17 speak now. Bill?

18 MR. ROMAKA: Good morning. I want to thank the
19 Committee first for all your work and for
20 coming together to try to help us make sense of
21 everything that's going on regarding what's
22 going on with the medical conditions of the
23 responders and survivors.

24 The first slide I have up there is a PowerPoint
25 presentation, just gives my -- who I am and the

1 committees and the conferences that I've been
2 attending to, and you all have that in front of
3 you also. If I could just figure out how to
4 work this -- I'm clicking on the right side.
5 Now I'm clicking on the left side -- there it
6 is.

7 The first responders -- I just want to -- these
8 are the people with the most-documented
9 exposures. That's what I wanted to present to
10 you who, for the most part, we're representing
11 today.

12 Okay, these are the related ailments that have
13 been covered in the World Trade Center bill,
14 the Zadroga bill. As you can see at the
15 bottom, we've also seen a lot of auto-immune
16 diseases and cancers, and those are the ones
17 that haven't been covered yet but that we're
18 trying to build the evidence for you to make an
19 informed, scientific decision.

20 Continued problems, the biggest complaint of
21 members in the World Trade Center medical
22 monitoring and treatment program is that when a
23 first responder is diagnosed with cancer in the
24 program they are told they have to seek
25 treatment elsewhere. Generally what happens

1 after this is the co-pays, the deductibles, the
2 loss of benefits contribute to the financial
3 ruin of what was once a contributing first
4 responder and their respective families.

5 You've got to remember, it doesn't just affect
6 the responder, it affects the families, too.

7 In the law enforcement responder cohort,
8 frustration and concern have been expressed
9 about the nature and extent of the data-
10 gathering as it relates to police officers
11 having cancer. Though the PBA has worked with
12 Mt. Sinai to identify members who have been
13 diagnosed with cancer to ensure the accuracy of
14 their reporting, to their knowledge Mt. Sinai
15 has not contacted NYPD to gain access to the
16 NYPD database so they could then do a complete
17 matching against the tumor registries, as does
18 the FDNY. This action would ensure a greater
19 level of accuracy.

20 For some time also the program did not accept
21 reports of cancer. Even now cancer is not a
22 covered illness, which is itself a deterrent to
23 report information about cancers. Many
24 responders with cancer have informed the PBA
25 that they do not wish to waste precious time by

1 participating in a monitoring and treatment
2 program that does not treat their disease.
3 They spend enough time in medical offices. In
4 addition, the PBA understands that 40 deceased
5 officers may not be included in any study by
6 Mt. Sinai, a decision that could skew the
7 results.

8 And so science -- we're talking about the known
9 exposure. Since 9/11 the FDNY has had almost
10 1,750 firefighters and fire officers retire due
11 to pulmonary disabilities. During this time
12 frame, based upon prior data and knowledge, the
13 predicted retirements related to pulmonary
14 disease was approximately 480.

15 Multiple myeloma -- in the Moline et al case
16 series "Multiple Myeloma in World Trade Center
17 Responders: A Case Series" reported in the
18 American College of Occupational and
19 Environmental Medicine in 2009, it shows that
20 this disease is showing in much younger, less
21 than 45 years old, exposed police officer first
22 responders in numbers that were approximately
23 four times the expected SEER cases in the
24 general population.

25 In NIOSH'S first periodic review of science and

1 medical evidence related to cancer in the World
2 Trade Center program, the authors' point about
3 cancers being prevalent in society was put
4 forth. What we have is, according to the
5 National Cancer Institute's SEER cancer
6 statistics review, the median age of cancer
7 patients at diagnosis for males was stated as
8 68 years old. In the recently published FDNY
9 cancer study appearing in The Lancet, the mean
10 age of first cancer diagnosis was 52.5 years.
11 Also in the fire department study big emphasis
12 is made on biological plausibility and the
13 likeliness of chronic inflammation. We have in
14 front of you the wording that comes from the
15 report. I hope that you can review it and
16 understand it because it is very scientific in
17 nature.

18 NIOSH and our government's history -- NIOSH has
19 a history of covering cancer under its Special
20 Exposure Cohort and Energy Employees
21 Occupational Illness Compensation Act once
22 provisions of eligibility have been met. Over
23 eight years it has paid out \$5 billion in
24 benefits to 52,600 claimants. Its provision
25 further states the following when it affects

1 medical care: An employee who meets the
2 statutory conditions of coverage is entitled to
3 prospective medical care required to cure, give
4 relief, or reduce the degree and period of
5 disability. Provider charges associated with
6 the treatment of an accepted medical condition
7 will be paid from the compensation fund and are
8 subject to a fee schedule.

9 Continuing on, the United States Department of
10 Veteran Affairs assumes that certain diseases
11 are related to qualifying military service.
12 These are called presumptive diseases. VA has
13 recognized certain cancers and other health
14 problems as presumptive diseases related to
15 exposure to Agent Orange or other herbicides
16 during military service. Source document is
17 attached and can be accessed.

18 Zadroga bill itself -- the mandate of the law
19 to include periodic reviews of a link between
20 cancer and exposure at the World Trade Center
21 sites suggests that there was reason to believe
22 that exposure to the toxins at the World Trade
23 Center site may lead to increases in the cancer
24 rates.

25 According to the language of the statute, the

1 program Administrator was required to review
2 the scientific data regarding cancers no later
3 than 180 days after the enactment of the
4 legislation. This language speaks directly to
5 the intent of Congress to have the basis for
6 inclusion be on biological plausibility of a
7 casual connection rather than on an exhaustive
8 scientific process which would be completed
9 when few, if any, responders would be alive to
10 avail themselves of the treatment component of
11 the law.

12 It also should be emphasized that this is very
13 much a unique event. Science analyzes
14 documents and compares. Science loses some
15 relevance when there is no similar comparison
16 to make. The exposure on 9/11 involved a very
17 unique synergism that may take decades to fully
18 analyze and understand. Unfortunately there is
19 no current comparison to help make sense of
20 this data in a timely fashion that might
21 actually help save lives.

22 Also it's important to know that New York State
23 legislation and the Governor have recognized
24 this uniqueness and approved a presumptive
25 accident disability benefit for all New York

1 State and City workers who were exposed at the
2 World Trade Center sites and have documented
3 exposures. This presumption already includes
4 cancer.

5 On May 24th and 25th of 2006 at the World Trade
6 Center Medical Experts Advisors Meeting the
7 cancer experts told everyone that the first
8 cancers to be seen would be the blood cancers
9 and the leukemias. This has been borne out by
10 the science and is available in the reports
11 that have been made to date.

12 Biological plausibility based upon what the
13 experts have predicted, what we are seeing,
14 should be the relevant factors upon which
15 policy is made.

16 Documented exposures with early scientific
17 evidence should support adding additional
18 conditions.

19 And I think it's important that you get the
20 human element about what we're talking about.

21 Here is a picture of one of our firefighters
22 who was at the World Trade Center site in 2001.

23 On the right is a picture of him at a
24 Washington press conference in 2009. He passed
25 away last year, leaving behind a wife and four-

1 year-old son.

2 Thank you very much for your attention.

3 I'd like to introduce Micki Siegel as our next
4 speaker for the responders.

5 MS. SIEGEL DE HERNANDEZ: Good morning, members
6 of the Committee, and I thank you for this
7 opportunity to talk to you today. I'm the
8 health and safety director for the
9 Communications Workers of America. Our union
10 represents a diverse group of workers: We had
11 members who were killed on that day, both in
12 the towers' collapse and also on the planes.
13 We represent a group of workers like the
14 Verizon workers, the Lucent workers, in the
15 telecommunications industry. We represent
16 traffic enforcement for the NYPD who were part
17 of the response, nurses at NYU downtown,
18 broadcast employees and technicians who brought
19 the vision of what was happening after 9/11 to
20 the rest of the world. And we also represent
21 workers who were in the area and who have been
22 affected by the contamination that was spread.
23 So I'm going to be presenting to you a photo
24 essay of sorts, with some comment about who we
25 refer to as the other responders. Bill focused

1 on the FDNY and the traditional first responder
2 population, and we -- this is a large group
3 that was part of the response afterward. So
4 I'm going to pick up on that and certainly echo
5 the concerns that Bill has raised, and we'll
6 continue that.

7 I want to mention to you that we start off
8 every steering committee meeting for the World
9 Trade Center health program in a similar way
10 that this meeting started. There are reports
11 made of responders who have died since the
12 month before, and we've never had a meeting
13 where that there wasn't something to report,
14 unfortunately. So this is not just academic
15 for us. This is something that we live with
16 every single day. The reports are often of
17 firefighters, sometimes police, but of other
18 unions as well who have already lost members to
19 World Trade Center-related diseases, and it
20 reminds us of why we're here and why we will
21 continue to advocate for proper health care.
22 So as Jim mentioned, the responder population
23 was very, very diverse. Public and private
24 sector actually heavily dominated by public
25 sector because of the -- of New York City

1 workers, protective services, police and other
2 -- the construction trades. There were
3 government responders at every level, telecom,
4 utility workers, broadcast employees, relief
5 organizations, volunteers, cleanup workers,
6 medical personnel, mental health counselors,
7 clergy -- and people were mostly from this
8 area, but came from around the country, as you
9 know, and also came from other parts of the
10 world. So these are not mutually exclusive
11 categories, but just to let you know how many
12 different types of people that were there.
13 This was also a heavily unionized work force.
14 I apologize for violating the rules of
15 PowerPoint that say you should only use three
16 or four bullets for a slide, but this is just
17 to make the point about how many organizations
18 were involved. And this is just a partial
19 listing, does not go into all the local unions.
20 So let me talk first just a little bit about
21 the exposures and what we refer to when we talk
22 about exposures.
23 So as you all know, and you've probably seen
24 these pictures of the dust cloud from the
25 towers' collapse. That cloud is just a

1 snapshot in time, continued to move through the
2 community and obviously well beyond the
3 boundaries of what became the Ground Zero site.
4 We actually don't know what the boundaries are.
5 That has never been established by any
6 scientific assessment.

7 This is what the streets of the city looked
8 like after some of that dust had settled and
9 continued to coat everything. It was blown
10 into buildings and continued to be moved around
11 in the outside community.

12 I put this picture in -- I actually took this
13 from the top of the Verizon Building, which was
14 at the north side of the site, but this was
15 taken approximately a month to six weeks after
16 the collapse, and you can still see the heavy
17 layering of dust, which I think is reflective
18 of how much the dust was -- was disturbed by
19 the activities that were going on and continued
20 to circulate around. It didn't end with the
21 dust cloud, I guess is what I'm saying.

22 What's also very familiar is that any of those
23 people who were caught in the dust cloud who
24 were either escaping, who were responders, had
25 an intense and overwhelming acute exposure.

1 There's -- there's no arguing with that fact.
2 The gentleman in the center is a member of the
3 operating engineers who happened to be working
4 that day. There were others there on that
5 first day, as well as the rescue organizations,
6 and you can see the firefighters helping him in
7 the back.
8 So the dusts were one type of exposures, and
9 then there were fires that burned for many
10 months afterwards. This was (telephone
11 connection interference).
12 Okay, so this shows you the smoke that
13 continued to burn, and again, this smoke
14 (phone connection interference) continued
15 to spread in the community. This is one of the
16 iron workers, and you can see the atmosphere
17 that was surrounding that site and
18 (phone/electronic interference). So there
19 were exposures from the dust, there were
20 exposures from the smoke, and then there were
21 also -- there was so much work going on on-
22 site, and individual work operations created
23 their own hazards.
24 This is a picture of an iron worker. He's
25 doing something called lancing, that is a high-

1 heat torch that can cut through rock and also
2 releases a variety of metal fumes. It's just
3 one example of one particular operation that
4 affects not only that particular worker, but
5 others surrounding them.

6 We're all familiar with the Pile and work on
7 the Pile, and you can see from the next few
8 pictures just the range of groups that are
9 there. In the foreground are MTA employees.
10 That's TWU Local 100. There's police, fire,
11 and lots of construction.

12 There's another example of a morning meeting,
13 getting set through -- to start some day's
14 work.

15 And again I just want to draw your attention to
16 the general atmosphere that was there. Again,
17 this was taken from above looking down on the
18 site from the Verizon Building.

19 There were lots of vehicles on site that also,
20 for some of them, created additional hazards
21 and -- diesel exhausts, different agencies and
22 different companies were using them. As we --
23 as I go through the next few pictures I'd like
24 you to also pay attention to the respirators,
25 or lack thereof, that various workers are using

1 because that -- that was an issue. It was
2 certainly not consistent. It was certainly not
3 something that all workers wore all the time,
4 and there was quite a variety. So we have a
5 dust -- there's a dust mask here which is not a
6 respirator and -- but that's what was given out
7 to many folks. Other vehicles here you can see
8 in working this crane, half-face respirator --
9 but again, it's not being used.

10 Remember, the backdrop of all of this was that
11 the government agencies were saying from the
12 very beginning not necessarily that it was safe
13 on site, but it was below levels of concern,
14 did not meet regulatory levels. So the message
15 was it's really not that bad. Right? There's
16 really not that much to worry about.

17 Obviously there are lots of hazardous work that
18 went on site. These are iron workers. This is
19 a track worker for the MTA. This is a 24/7
20 operation, so these were not 9:00 to 5:00 jobs.
21 People worked 12 hours, 14 hours, 16 hours,
22 seven days a week.

23 So that's the Pile, and people understand what
24 the Pile is. But then we talk -- we refer to
25 what is adjacent to the Pile, and there are

1 questions that are asked in the medical program
2 when patients come in, 'Did you work adjacent
3 to the Pile, or off the Pile?' And I think
4 that there are some misnomers that once you got
5 right off the Pile that there were -- it was --
6 they were safe areas, free of contaminants.
7 So I want to show you just a few other examples
8 of what we mean by or what could be present
9 adjacent to and off the Pile. So right
10 adjacent to the Pile was the Verizon Building.
11 It was heavily damaged. World Trade Center 7
12 collapsed against it. This is the east side of
13 the building. You can see the stream of water
14 coming -- the fire service was stationed there
15 to help put out that additional fire that
16 burned, and it caused a lot of damage as well
17 as contamination.
18 Subway system was damaged in the area, some
19 stations completely destroyed, and you have MTA
20 workers who then had to go into these locations
21 to perform cleanup operations. And again, here
22 we have a dust mask that really doesn't protect
23 against much. The subway.
24 Work was done on the street and in the general
25 area. These are splicers. Again, if you look

1 at the picture carefully, there's one guy
2 wearing a dust mask, one guy wearing a half-
3 face respirator, one guy wearing nothing. It
4 was a voluntary respiratory program because,
5 again, everything was, okay.
6 There were also lots of interior spaces, and
7 interior spaces have gotten no play in the
8 terms that they've been completely ignored as
9 far as the contamination inside of them. And
10 if you can imagine the contaminants that were
11 outside, in interior spaces they are confined
12 spaces, so as work was conducted people had
13 extreme exposures in some situations. So there
14 were manholes around the site and around the
15 neighborhood, so for both Verizon, Con Ed, the
16 electric utilities -- this one was covered just
17 because of falling glass from the buildings
18 above.
19 This is a picture of the concourse. Those are
20 MTA workers. As I mentioned before, damage to
21 the subway tunnels, and you can see the dust
22 just caked along the walls. This is some
23 interior damage I -- just because they are our
24 members, I happen to have pictures of what some
25 of that damage might look like, but there were

1 many other damaged buildings where many other
2 workers worked, and you can just see the degree
3 of dust that was in those spaces.

4 This is the cable vault. The reason -- there
5 was a lot of service lost, was because of what
6 happened to that cable vault at the Verizon
7 Building. That's not what it normally looks
8 like. It's a vast area. You can't really see
9 the extent of it, but this is where the hole
10 was broken on the sidewalk into the vault.

11 This is Engine 10/Ladder 10, the fire house,
12 and you can see the damage to that building.

13 And again, many, many buildings. These are
14 just a few examples. Basements in the area
15 where lots of workers go. To be honest with
16 you, we still have concerns to this day about
17 cleanup that may or may not have been conducted
18 in certain locations. And I bring that up
19 because in terms of exposures and chronic
20 exposures and when they could happen, we don't
21 know when they ended. What -- we know when the
22 site activities ended, but we really don't know
23 when exposures may have ended for other workers
24 continuing their jobs.

25 There was a lot of cleanup done in the

1 buildings by either unionized laborers of Local
2 78, by SCIU 32 BJ building personnel. And then
3 there were also day laborers who were hired by
4 contractors and subcontractors to go into
5 buildings, without training, usually without
6 protection, to clean those buildings. This is
7 a picture -- the guy -- second person from the
8 left, Alex Sanchez, has done a lot of advocacy
9 work since that time. He told me that he
10 worked at least ten buildings in six months.
11 Only two of them provided respiratory
12 protection. He cleaned the duct work of the
13 HVAC system, so you can imagine what was
14 brought in after the collapse and what his
15 exposures were like. And the reason he is such
16 an advocate is because he's very, very ill. So
17 another group of responders that has gotten
18 short shrift in all of this.
19 There were also off-site -- other off sites.
20 The Staten Island landfill operations, here's
21 some NYPD detectives sorting through -- 'cause
22 remember, this was also about recovering
23 remains. It was not just about a big cleanup
24 and getting rid of debris. We had barge
25 operations and so you had trucks driven by

1 Teamsters transporting that through the
2 neighborhoods to off-load to bring to the
3 Staten Island landfill. There were other work
4 locations like places where the vehicles were
5 brought that were contaminated, where they
6 needed to be maintained and worked on by
7 mechanics. You have the Office of the Medical
8 Examiner who had temporary morgues on-site and
9 also off-site, so many, many different
10 locations, and the exposure scenarios are vast.
11 So to conclude, a few recommendations to you as
12 a Committee. One, you really should consider a
13 much more thorough discussion about exposures
14 in a future meeting, and please solicit
15 information from a variety of sources,
16 including unions and others who have data
17 that's not public data that sort of brings some
18 of these issues to mind. The exposures are
19 important because they speak directly to the
20 development of disease.

21 When you are evaluating cancer and other
22 diseases you need to look at a variety of
23 evidence related to causation, as Bill
24 mentioned, biologic plausibility. You cannot
25 rely solely on published epidemiological

1 studies, although there have -- fire department
2 has a seminal study that came out recently.
3 But that will always be after the fact, after
4 workers have died. And as I -- as everybody
5 has said, we have concerns about ongoing health
6 issues.

7 We recommend increased efforts for continued
8 and more rigorous disease surveillance than is
9 currently happening.

10 And also we hope the Committee can advocate for
11 continued outreach for many diverse groups who
12 still have not been reached as part of medical
13 need and to bring into this program.

14 So thank you for the following folks for photos
15 that they contributed, and that's the end of my
16 presentation. Thank you.

17 Oh, one more thing. I'm going to pass out to
18 the Committee a packet that has been provided
19 by District Council 37. They are the largest
20 municipal union here in New York City and
21 represent a huge number of job titles, and
22 there's a video in here which talks about some
23 of their members who were involved in the
24 response. And I think it -- it's fascinating
25 in the sense that there are job titles you

1 would never ever have thought of that
2 participated. So thank you DC-37 and I'll get
3 that out to all of you.

4 DR. WARD: Thank you, and we'd like to invite
5 the speakers back to the table for questions
6 and comments.

7 DR. MIDDENDORF: And while you're coming to the
8 table, I apologize for the static, Micki,
9 during your presentation.

10 MS. SIEGEL DE HERNANDEZ: That's okay.

11 DR. MIDDENDORF: We're working with the
12 conference line folks to see if we can get rid
13 of that.

14 DR. WARD: Questions or comments for the panel?

15 DR. HARRISON: Is this on? There we go --
16 thank you. My name is Bob Harrison. I want to
17 thank all three of you for wonderful
18 presentations, particularly -- I'm from
19 California and seeing the photos and the
20 situations that the workers were in were really
21 eye-opening to me, so I want to thank you
22 particularly for sharing those.

23 I wondered if anyone would speak to your
24 suggestion about using biological plausibility
25 in addition to or separate from the

1 epidemiological evidence for cancer.

2 Particularly if you could speak about the type
3 of exposures that occurred and what we know
4 about the chemical constituents and the
5 biological mechanisms.

6 MS. SIEGEL DE HERNANDEZ: I think we probably
7 all have comments about this, and this is what
8 I think needs much -- much more discussion in
9 the future. The World Trade Center
10 contaminants, both the smoke and the dust --
11 very complex, hundreds -- hundreds of
12 materials. There have been estimates that --
13 reaching a thousand. And some of those
14 components are carcinogens, known carcinogens,
15 and there are others that, you know, have other
16 kinds of health effects. It was a very caustic
17 -- it was of a very caustic nature.

18 Bill mentioned synergism. There is nobody that
19 knows what the effect of all of those
20 components put together -- what that will be.
21 And the method of assessment that was conducted
22 in terms of exposures, the sort of one chemical
23 at a time or one contaminant at a time, based
24 upon some -- some known contaminants like
25 asbestos, to make a decision about the whole

1 mixture, we feel is a really inappropriate
2 method. So I think there's enough evidence to
3 look at some individual components that we do
4 know about, but I think that we really have to
5 also -- that the Committee really needs to
6 understand and -- what some of the limits are
7 about what we know about that mixture as a
8 whole.

9 MR. ROMAKA: So in other words, we're
10 advocating for biological plausibility based
11 upon what early scientific evidence shows,
12 'cause if you go with epidemiology by itself,
13 it's based on the SEER principle. The last two
14 letters of the SEER principle means end result.
15 So we're not going to be able to help anybody
16 by talking about after everybody's dead and
17 gone, so we'd appreciate that -- is an open
18 mind to using the science based upon what
19 experts have said and what the biological
20 plausibility is, just one-sided.

21 DR. MELIUS: Well, it's a long discussion, but
22 just briefly, I think -- at least I think of it
23 as one -- you know, what are the individual
24 components and the exposures, the known
25 carcinogens. Secondly, beyond that, you have

1 this -- the inflammatory response and diseases
2 that resulted from it, what does that say about
3 the possible development -- development of
4 cancer. And then third I think what's a fair
5 and appropriate way of assessing that, you
6 know, without waiting 50 years till mortality
7 studies are done 'cause we're talking about
8 people that need medical care in the short term
9 and -- do that. And frankly, our country
10 doesn't do that very well in the programs we
11 have established so far. I mean the nuclear
12 worker program -- we're actually compensating
13 people from the Manhattan Project, which is
14 World War II, so I mean it's sort of in some
15 ways pretty absurd. I'm glad we're doing it
16 finally, but it's -- but we need some way --
17 and I think, you know, what's the way of --
18 sort of the overall weight of the evidence that
19 provides a fair evaluation and there's some
20 plausibility in science to it, but at the same
21 time, you know, maybe not have quite as strict
22 a criteria that we would have for saying, you
23 know, pure causality or something in terms of a
24 regulatory sense or some other -- other venues.
25 So it's putting those together, but it is a

1 longer discussion but I think it's a very
2 important one to have.

3 DR. WARD: Then we'll go down the row of raised
4 name cards.

5 MS. SIEGEL DE HERNANDEZ: May I just add one
6 more comment, just to finish that? One of the
7 things that's striking in talking to members
8 who have cancer is that they're often -- have
9 more than one cancer, they have other diseases.
10 And when we look at epidemiological studies and
11 it's sort of rate by a particular cancer, it's
12 not looking at the whole picture and sort of
13 this issue of multiple diseases.

14 MR. CASSIDY: Yeah, I'd like to thank all of
15 you for your presentation, and I thought what
16 was powerful was -- I mean time heals all
17 wounds and ten years later a lot of people have
18 forgotten. Those -- those images that you
19 showed us again kind of have drifted from
20 people's recollections. But I do want to
21 remind everyone that a lot of first responders
22 and others who were affected by this pointed to
23 something that's happened throughout the
24 country and happened here in New York about
25 five years ago where second-hand smoke was

1 banned in restaurants and public parks because
2 second-hand smoke kills from cigarettes. So I
3 just want to remind everyone if you take a look
4 at those pictures, anyone who would trade
5 places -- I'll sit in any bar anywhere while
6 the waitress and somebody else is smoking
7 cigarettes, but I don't want to go back to that
8 Pile. And I think common sense has to play a
9 role in this, and I want to thank you for
10 pointing that out.

11 DR. WARD: Ms. Flynn?

12 MS. FLYNN: Many people here may not know that
13 you were the labor liaison to the EPA World
14 Trade Center Expert Technical Review Panel, and
15 so you know a great deal about the flaws and
16 inadequacies of the environmental measurements
17 taken, on the Pile and well beyond the Pile.
18 So in light of that knowledge, what is your
19 thinking about how to approach exposure
20 characterization and exposure assessment?

21 MS. SIEGEL DE HERNANDEZ: I try not to let
22 people know about that ill-fated panel,
23 Kimberly, so thanks for outing me. Again, this
24 is a -- it's a much more complicated answer to
25 that. I mean I think part of the discussion

1 that we need to have about exposures is an
2 understanding of what is not known, what data
3 is not available, what data that was collected
4 cannot give the answers that everybody is
5 looking for, and -- but what can we look at in
6 terms of figuring out exposures. So it's more
7 complicated than what you say -- what you were
8 asking about. I just think that in general, in
9 the community, there was some sampling that was
10 done on-site. As I said, it was one
11 contaminant type sampling, and compared to
12 occupational exposures -- occupational
13 standards that are not health standards. So
14 that was part of the problem.
15 Out -- once you left that Pile, virtually
16 nothing was done, or very little was done that
17 was applicable and that helps explain disease
18 that people are experiencing. And to me, the
19 biggest flaw in what happened after 9/11 was,
20 as people were trying to assess -- what little
21 was done to assess -- once people started
22 getting sick, and that happened early on --
23 right? The fire department was reporting on
24 World Trade Center cough in the beginning of
25 October, within a couple of weeks. Once people

1 started experiencing disease that -- then --
2 something wasn't jiving, something wasn't
3 matching between 'it's safe based upon this
4 measurement' and 'people should be okay, no
5 long-term health effects expected.' Well, that
6 didn't completely answer it, I'm sorry.

7 DR. WARD: So Paul just reminded me that we are
8 running short on time, so we'll take your
9 comment and we'll take the three tent cards
10 that were up initially, and then unfortunately
11 we'll have to move on.

12 MR. ROMAKA: Well, I just want to make the
13 point that -- okay, are we saying that --
14 you're down in here, you have this exposure,
15 are we saying that it's not going to cause
16 cancer? Are we saying that it was healthy for
17 you? Are we saying that it's possible that
18 it's going to cause cancer? Where is that line
19 that the Committee or that people are looking
20 for? We know that it wasn't healthy for you
21 when you look at Washington -- they went around
22 in space suits to clean that up. New York
23 City, that never happened. I think that you
24 just have to understand the difference between
25 the two and where do you want that line to be

1 drawn.

2 DR. MARKOWITZ: Just a couple of quick
3 questions. Micki, you said that you thought
4 there hadn't been adequate outreach to certain
5 groups, and that may or may not relate to
6 eligibility. I was wondering what you had in
7 mind.

8 The second question is both you and Jim
9 mentioned the need for more rigorous or more
10 extensive disease surveillance. Again, if you
11 had further thoughts, that would be of
12 interest.

13 MS. SIEGEL DE HERNANDEZ: I think there are a
14 lot of groups that still haven't been reached.
15 Certainly with the change in some of the
16 eligibility requirements and the extension of
17 the time frames there are even members of our
18 own unions who weren't previously eligible for
19 the program who are now eligible. So I just
20 think that it's something -- new people come
21 into the program all the time. You'll hear
22 that from the medical programs. And there are
23 many, many reasons for that. Outreach is one
24 part. We certainly have not reached out across
25 the country. I haven't even spoken about

1 national responders or some of our members who
2 moved out of this area. So there are
3 constantly new groups that we discover.
4 One thing that I didn't mention early on -- you
5 just reminded me, Steve -- is we don't know how
6 many responders were there. Nobody tracked
7 that. Employers -- many employers did not
8 track that. City agen-- the city doesn't know
9 who was actually sent down there. So we don't
10 have that answer. There are estimates about
11 how many people were involved. We don't know.
12 We don't know that denominator, as people call
13 it, so continued outreach is still needed.
14 I'm going to pass the mic to Jim for the
15 surveillance piece.

16 DR. MELIUS: That's actually part of it. But
17 in terms of surveillance, I think there needs
18 to be more resources put to case finding and
19 follow-up. I mean we have to understand that
20 in New York -- as well as I think many other
21 states, but in New York the -- there's less and
22 less reporting going to the cancer registry.
23 It's less complete -- probably it was 20 years
24 ago, lot more people being treated as
25 outpatients now. And I don't believe there's

1 reporting and I think there's actually some
2 good evidence of that from some of the
3 surveillance that the centers have done
4 already. It's a significant problem. So case
5 finding and follow-up I think is important.
6 Secondly, I think there's also -- as Micki
7 said, there are no lists, and one of the major
8 problems we have is that nobody knows who was
9 there. Fire department I think has some
10 records, police have some records. Most other
11 city agencies did not keep records -- do that.
12 Many private -- there were volunteers. It's
13 very, very -- very complicated, but there are
14 some. And I think looking at some of those --
15 our union, for example, kept records 'cause
16 people worked for contractors, and for their
17 pension and insurance benefits there's
18 reporting back, so we have fairly good lists of
19 people that worked there. And I think those
20 are -- not all those people participate in the
21 medical programs or the registry. And in fact,
22 many do not, and I think follow-up of those
23 lists is also another -- another possibility
24 where we need more resources for surveillance.
25 It's -- when you talk about sort of resource

1 versus sur-- I mean there's limited resources
2 and this is going to be I think a very 'what do
3 you focus on' 'cause there's so many issues
4 that need to be addressed and would -- but I
5 think on the surveillance side it just --
6 resources -- and Micki has a follow-up.

7 MS. SIEGEL DE HERNANDEZ: Specifically with the
8 issue about -- related to cancer surveillance,
9 I think there's an assumption that all the
10 answers lie in the programs if we only analyze
11 the data. You know, I know that many of our
12 members who have cancer are not in the program,
13 because everybod-- everybody knows it doesn't
14 provide health care and they spend -- their
15 lives revolve around their cancer treatment.
16 And so there are a lot of cases that are not
17 being captured, at least on the health program
18 side. That also speaks to continued outreach
19 and looking at other ways to try and understand
20 really the extent of disease -- not just
21 cancer, but other kinds of diseases that the
22 program is just not covering.

23 MS. MEJIA: Guillermina Mejia here. I just
24 have a brief question. Maybe you can -- can
25 you give us a brief account of how the current

1 covered conditions were identified so that we
2 have a little background information?

3 DR. MELIUS: You probably could turn to the
4 person next to you, he was as much part of --
5 Steve Markowitz -- but I think it's fair to say
6 they were -- and people in the audience here
7 and everyone else on the panel can -- I mean
8 they were identified essentially clinically.
9 It's what -- if people were providing
10 monitoring, there were people that were sick
11 within the -- from the responder program and
12 Dr. Reibman was seeing similar problems in the
13 -- within the community -- that. And at the
14 time that the -- funding for this program, for
15 the treatment part of the program, came in late
16 2006, really 2007 when it was implemented. And
17 before the time that was being implemented,
18 there was internal discussions within the
19 programs and it's just what -- basically they
20 determined what did they know clinically, what
21 did they have evidence from from what had been
22 published to date. I think obviously post-
23 traumatic stress, the resp-- I mean I think
24 they were all relatively straightforward, and
25 all of them were subsequently I think confirmed

1 from the follow-up studies that have been done.
2 I don't think -- but it was based mostly on
3 sort of clinical impression. But again, we're
4 talking, within the responder program, over
5 30,000 people that had received treatment as of
6 a year ago, it's probably more now, so it's a
7 very large number out of a relatively limited
8 population, so I think it's pretty
9 straightforward.

10 DR. WEAVER: Mr. Romaka mentioned the
11 presumptive accident disability benefit for New
12 York State and City employees, and noted that
13 it includes cancer. I'm interested to know
14 which employees are covered, whether it
15 includes fire and police department, and
16 whether it covers all cancers or specific
17 cancers. Thank you.

18 MR. ROMAKA: Right now the way it's written for
19 the most part people have to first of all
20 identify and get certified that they were
21 there, that they had an exposure. They have to
22 get signed off by their agency that this is
23 what happened. It covers all cancers, but
24 there is a different degree, depending on each
25 individual pension system, as to what cancer

1 constitutes a presumptive disability because a
2 presumptive disability for running into fires
3 is different than a presumptive disability for
4 being a police officer or being another worker.
5 And the Workers Compensation system is for
6 volunteers who weren't there also, so everybody
7 who registered with -- from the State, it
8 wasn't just firemen, police officers, it was
9 everybody who registered with the State. It's
10 up to the individual pension plans as to how
11 they feel that it should be treated, what --
12 what constitutes a disability.

13 I'd just like to add something -- a little bit
14 off the point, was the big problem that we have
15 when we compare the cancers and stuff. We
16 compare it to the New York State Tumor
17 Registry, and that's two or three years behind
18 all the time, which is a big problem for us
19 when we're seeing increased cancers now. We
20 had four firefighters diagnosed with non-
21 Hodgkin's lymphoma within a three-week period
22 and all with leukemia. That's not going to
23 show up until five years from now. They're all
24 problems when you look at just the science end
25 of it.

1 DR. WARD: I think we'll have to forego all
2 other questions, but if you have one last
3 comment, we can take that and --

4 MS. SIEGEL DE HERNANDEZ: My one comment about
5 the presumptive disability law is you should
6 also know that it's not something that was just
7 provided. It was something that the unions had
8 to fight for and it was in recognition that,
9 for many of these diseases that we are seeing
10 our members have, couldn't wait again.

11 Couldn't wait 20 years before it was proven a
12 hundred -- you know, 100 percent scientific
13 certainty, that the only way to treat people
14 fairly and give them compensation was to
15 presume that if they had those exposures, if
16 they participated in the response, that these
17 were the conditions that they should be
18 compensated for.

19 MR. ROMAKA: And there is a committee that's --
20 looks at that bill each year to see what needs
21 to be adjusted or fixed so that the right thing
22 is done for the intent of the bill. That was
23 made by government officials also, so it wasn't
24 just labor going up there saying 'do this.' It
25 was agreed to by all the interested parties.

1 DR. WARD: I think we unfortunately need to
2 move on. Thank you all very much.

3 MR. ROMAKA: Thank you very much.

4 (Pause)

5 **SURVIVORS**

6 MR. SPENCER: While we're waiting I'll just say
7 that we have two folks who are going to be
8 presenting from -- one from Florida and one
9 from California, and hopefully technology will
10 not fail us.

11 Ready to start? Okay. So on behalf of the
12 Survivors Steering Committee I want to thank
13 the Scientific/Technical Advisory Committee for
14 the invitation to make this presentation. We
15 hope it will help the Committee gain a better
16 grasp of the health problems affecting the
17 survivor community. We have a PowerPoint up so
18 folks can follow along.

19 I'm Rob Spencer, the labor co-chair of the
20 Survivors Steering Committee. I work for a
21 City workers' union called the Organization of
22 Staff Analysts. Our community co-chair,
23 Kimberly Flynn, is a member of the STAC.
24 The Survivors Steering Committee was created to
25 play an advisory role on the administration of

1 the Survivor Health Program and to represent
2 and gain input from the community of affected
3 non-responder stakeholders. It's the successor
4 to the Community Advisory Committee of the
5 World Trade Center Environmental Health Center,
6 which is the Clinical Center of Excellence,
7 serving non-responders. On the slide, by the
8 way, is some of the groups that have been
9 current or former members of the -- either the
10 Community Advisory Committee or the Survivors
11 Steering Committee.

12 Before we begin, the Steering Committee would
13 like to raise one procedural matter, that of an
14 imbalance on the Scientific/Technical Advisory
15 Committee in the number of representatives of
16 affected communities. We have requested that
17 the Administrator add an additional
18 representative of the survivor community to the
19 panel, and that this addition occur prior to
20 the second meeting of the body. The Survivors
21 Steering Committee has recommended a well-
22 qualified individual for that role, and we hope
23 that that recommendation will be given serious
24 consideration that it deserves.

25 Our goal here is to provide a brief overview of

1 the non-responder populations affected by 9/11,
2 their 9/11 exposures, and their health
3 experiences. This morning you'll hear from
4 individuals who were students, residents, and
5 area workers on 9/11. And you can see, this is
6 the morning of, and there is a slightly
7 different version of the dust cloud approaching
8 Chambers Street than Micki had in her
9 presentation, but it gives you some sense of
10 its sort of mode of force and how far it
11 traveled how quickly.

12 The collapse and burning of the World Trade
13 Center caused an unprecedented environmental
14 disaster. Toxic dust and smoke permeated
15 densely populated urban area. So you can see
16 in these slides some of the people who were
17 directly affected on the day by the initial
18 collapse cloud. And here you just see some of
19 the residual effects in stores, on streets.
20 I'm not sure I want that fruit and vegetable
21 stand's produce.

22 Fires then -- in addition to the effects of the
23 initial collapse cloud, the fires at the site
24 persisted for many months. And you can see in
25 these photographs -- these were taken anywhere

1 from a few days to several months after 9/11.
2 You can see that there's -- the persistent
3 fires created smoke clouds that hung -- a plume
4 that sort of shifted with the wind direction
5 and hung over lower Manhattan neighborhoods and
6 persisted.

7 And how did this deal with -- how did interiors
8 look after this event. Well, this is an
9 example of some buildings that border the World
10 Trade Center site. These are apartments.
11 Throughout the Ground Zero cleanup, World Trade
12 Center dust and contaminants entered buildings
13 through multiple routes. Many of the residents
14 of the affected areas were not evacuated, but
15 remained in their homes throughout. Some area
16 workers were brought back to the locations as
17 soon as two days after the attacks, and I know
18 that anecdotally from members of my own union.
19 On September 18th EPA Administrator Christine
20 Todd Whitman through my people declared the air
21 was safe, which put the health of tens of
22 thousands of people at risk. Residents,
23 students and area workers who had evacuated
24 returned to the area and were exposed to World
25 Trade Center smoke and dust, indoors and out.

1 The White House Council on Environmental
2 Quality, influencing EPA risk communications,
3 transformed statements of caution and concern
4 to ones that downplayed health risk. Revealed
5 by the EPA Inspector General's report in 2003,
6 these altered communications misrepresented or
7 concealed information that might have helped
8 protect thousands from the contaminated air.
9 On the tenth anniversary of 9/11 ProPublica,
10 working from documents obtained by the New York
11 Committee on Occupational Safety and Health,
12 revealed just how far this went -- and I think
13 this quote is particularly interesting: 'In
14 one instance, a warning that people should not
15 report to work on a busy thoroughfare in the
16 financial district -- Water Street -- was
17 rewritten and workers were urged to return to
18 their offices as soon as the financial district
19 opened on September 17th.'

20 The same day, the New York City Department of
21 Health issued an advisory: 'How should I clean
22 the dust in my apartment when I move back in?
23 The best way to remove dust is to use a wet rag
24 or a wet mop.' The advice for pregnant women,
25 which is on the slide, or young children and

1 area workers was sort of equally questionable.
2 In fact, and this is an important point, there
3 has been no comprehensive and scientifically-
4 valid assessment of indoor contamination ever
5 done.

6 After a lengthy struggle the EPA announced the
7 Test & Clean Program on May 2002 for residences
8 only in Manhattan south of Canal Street, purely
9 on a voluntary basis. Workplaces were
10 excluded, buildings were not treated as
11 systems, and tests in HVAC systems in
12 inaccessible areas that were most likely to
13 harbor contamination were not conducted.

14 Efforts by advocates to improve the program and
15 expand the boundary above Canal Street and into
16 Brooklyn were rejected.

17 The August 2003 EPA Inspector General's report
18 criticized the cleanup as flawed and
19 inadequate, and called on the agency to re-
20 examine the remaining risks to residents,
21 students and area workers in lower Manhattan
22 and in Brooklyn. After another lengthy
23 struggle the EPA created the World Trade Center
24 Expert Technical Review Panel -- that was the
25 panel that Micki was mentioning -- to examine

1 the first Test & Clean Program and to develop a
2 new program to address the remaining health
3 risks to survivors.

4 After months of meetings the EPA unveiled the
5 second program, which was essentially the same
6 as the first. It was deemed unacceptable by a
7 majority of the experts on its own panel, and
8 all of the labor and community representatives.
9 The Government Accountability Office conducted
10 a review -- when you look at this slide you'll
11 see the number of little bullet points in the
12 right-hand column there are little things that
13 they -- advice that they did not take, and
14 those are pretty significant, including testing
15 workplaces and so forth.

16 By 2004 the New York City Department of Health
17 had opened the World Trade Center Health
18 Registry. There was no input from affected
19 community or labor stakeholders into the design
20 of the registry and the wave one survey.
21 Criticisms included arbitrary boundaries not
22 based on any reasonable exposure criteria;
23 exclusion of affected neighborhoods, including
24 Chinatown and the lower east side; exclusion of
25 area workers who were not present below

1 Chambers Street on 9/11; carving out the entire
2 population of the borough of Manhattan
3 Community College; failure of the wave one
4 survey to assess survivors' exposure to indoor
5 dusts; failure of the wave one survey to assess
6 unmet health needs. These omissions and
7 failures of public health policy and exposure
8 assessment resulted in illness and the demand
9 from affected communities, initially led by
10 Beyond Ground Zero Network, for appropriate and
11 needed 9/11 health care for survivors. The
12 World Trade Center Environmental Health Center
13 is the outgrowth of those demands, met by
14 responsive public health professionals and the
15 New York City health and hospitals cooperation.
16 The individuals who will present after me this
17 morning will offer snapshots of the 9/11
18 survivor experience. We'll hear in order from
19 Mariama James, who's sitting here; Jo Polett,
20 who's here; Gail Benzman, who is on the phone;
21 Lillian Bermudez, who is at the far end of the
22 table; and Lila Nordstrom, who is also on the
23 phone.

24 So first up is Mariama James.

25 MS. JAMES: My name is Mariama James. I live

1 in Southbridge Towers with my family. That's
2 on Gold Street -- my building's on Gold Street.
3 I'm also a member of Community Board One,
4 formerly of the World Trade Center
5 Redevelopment Committee, presently on the Youth
6 and Education and Financial District
7 Committees.

8 On the morning of September 11th I was eight
9 months pregnant with my third child. I did my
10 usual commute from Gold Street to Queens, Long
11 Island City Queens, that's two trains and a bus
12 through the -- once I reached -- I was very
13 early that day so I went to hang out in the
14 engineering department, and through their
15 floor-to-ceiling bay windows I was able to see
16 the first plane hit. I immediately called my
17 children's school and contacted them, urging
18 them to close the school and let the children
19 get home. I was only thinking of traffic at
20 that point.

21 But by the time the second plane hit I could no
22 longer reach them and weren't sure if they were
23 -- whether -- if they were okay. Stayed at
24 work as long as I could in hopes of speaking to
25 them, and once that seemed futile I began

1 pretty much a walk from Queens back to lower
2 Manhattan.

3 When I arrived home I was covered in dust from
4 head to toe. My father, who had been
5 successful in picking up my children from the
6 Village, walking from Gold Street to Bleecker
7 Street in SoHo and back, was also covered in
8 dust, as were all three (sic) of my children.
9 At Southbridge Towers, the entire complex, we
10 had no power, no water, no phones. At daybreak
11 when the sun came out we were able to see that
12 our home was covered in the same thick dust
13 that was everywhere else in the surrounding
14 areas. Neighbors said that the building was
15 engulfed in the collapse cloud.

16 Soon we were told the dust was safe to remove
17 ourselves. At eight and a half months pregnant
18 I got down on my hands and knees and ripped up
19 my children's carpet -- the padding, the wood,
20 entirety. I cleaned the rest of my house as
21 well. My father was there to help with me as
22 well, and he vacuumed with a non-HEPA vac. We
23 used our wet rags and wiped up what we could.
24 Not long after 9/11 the City Health Department
25 put out an advisory to residents that stated,

1 in addition to cleaning with wet rag and mop
2 and throwing away any spoiled food, pregnant
3 women and young children do not need to take
4 additional precautions. And I think there was
5 just a quote in Rob's presentation a moment ago
6 with specific regard to pregnant women not
7 needing to do anything in particular.

8 My daughter was born on October 23rd. She was
9 diagnosed with asthma and sinusitis, things of
10 that nature, by the time she was ten months
11 old. And my other children, none of whom had
12 health problems before 9/11, developed the same
13 conditions -- which are now considered classic
14 World Trade Center illnesses.

15 For years all three of my kids took daily
16 treatments of Zyrtec, Allegra, Singulair,
17 Asthmanex, Albuterol, Rhinocort, Qvar and
18 Advair for allergy, sinusitis and asthma-
19 related symptoms and were eventually also
20 prescribed Prevacid for GERD that the doctors
21 said was caused by post-nasal drip from the
22 sinusitis problems.

23 There was no program to treat children who were
24 sick from 9/11. I had to be -- which is myself
25 -- to find a pediatric pulmonologist. For many

1 years she required them to come in once a
2 month, and then later, as they became better,
3 three times a month (sic).

4 We still keep steroids and nebulizer meds on
5 hand in my house, in the event that any
6 children -- any of the three children should
7 reach their what they call red level of asthma
8 action plans. They miss school often. At five
9 my daughter knew how to load the nebulizer and
10 administer treatment to herself.

11 In 2002 when my son's teacher and I realized
12 that he was having difficulty processing
13 instructions, we had him tested and he has
14 since been diagnosed with learning
15 disabilities. His sisters later followed in
16 being diagnosed with the same.

17 Our health care costs went through the roof,
18 averaging around \$820 a month because of \$50
19 co-pays for each med and \$50 co-pays for each
20 doctor visit. And as a result, I by myself
21 could not afford to go to the doctor, so I've
22 only recently begun to seek treatment.

23 All three of my children still have persistent
24 asthma, sinusitis and GERD, for which they are
25 now being treated at the EHC. And the last,

1 and I guess most important at this point, point
2 I'd like to make is that children are in many
3 ways the most vulnerable population exposed to
4 9/11 dust and smoke, yet they are the least
5 studied. It is absolutely critical that NIOSH
6 fund the pediatric study proposed by Drs. Leo
7 Trasande and Liz Fiorino which will test
8 hundreds of downtown children for World Trade
9 Center exposures and related symptoms. Years
10 ago we called for a program to screen the
11 area's children and we didn't get one. We must
12 have this study. Without it we have no clear
13 picture of the effects of 9/11 on the physical
14 health of downtown children.

15 MR. SPENCER: And next up is Jo Polett.

16 MS. POLETT: My name is Jo Polett. I'm a
17 patient at the WTC EHC and I live at 105 Duane
18 Street, a 52-story rental high rise located
19 seven blocks north of the World Trade Center
20 site. Constructed in 1990, the building has no
21 asbestos-containing material and no interior
22 source of lead.

23 On 9/11 dust from the collapsing towers entered
24 our building through windows, the louvers of
25 heating and air conditioning units, and the

1 building-wide ventilation system. In the
2 months following the attacks smoke-borne
3 contaminants from the fires that burned at the
4 site polluted the air and continued to enter
5 our homes.

6 On the morning of 9/11 I watched the towers
7 burn and collapse through the living room
8 window of my south-facing apartment. I spent a
9 week with friends in Brooklyn and returned to
10 my apartment once power and water had been
11 restored to the building.

12 Respiratory symptoms were common among my
13 neighbors, but we were assured by federal and
14 city officials that our symptoms would be
15 short-term, with no lasting consequences, so we
16 tried to ignore them. As the symptoms of some
17 intensified, it became hard to do that. I had
18 no history of respiratory problems, I was not
19 caught in the dust cloud and, because my
20 windows were closed when the dust cloud hit the
21 building, when I returned home I saw barely any
22 dust.

23 Yet by the end of October respiratory symptoms
24 that had begun to occur intermittently
25 following my return became persistent and

1 increased in severity. On November 20th I
2 consulted an occupational physician and was
3 advised to vacate my apartment until it was
4 professionally cleaned. A FEMA inspector
5 declared it uninhabitable and I was relocated
6 to a hotel on the upper east side.

7 I spent the next two and a half years working
8 with my fellow tenants to get our building
9 properly cleaned. Our efforts met with little
10 success.

11 By the end of November we'd learned that, even
12 if tenants who could afford to do so had their
13 apartments professionally cleaned, if the
14 ventilation system was circulating contaminated
15 air the cleaned apartments would be re-
16 contaminated. On December 3rd of 2001 we
17 brought in a certified industrial hygienist who
18 sampled the supply air diffuser or hallway vent
19 on the tenth floor. The sample was collected
20 by micro-vac and analyzed by TEM for asbestos.
21 The sample tested positive for asbestos at a
22 level of 550,000 asbestos structures per square
23 centimeter. Expected background for buildings
24 such as ours, constructed without ACM, is
25 usually below 1,000 structures per square

1 centimeter, though some studies show that in a
2 poorly-maintained building in an urban area the
3 level can be as high as 10,000 structures per
4 square centimeter. 105 Duane is a well-
5 maintained building, but in either case the
6 sampling result in asbestos level between 500
7 and 50 times expected background shows that the
8 ventilation system was contaminated with
9 asbestos from the World Trade Center. In
10 either case, the presence of additional
11 constituents of the collapse dust and smoke.
12 There is a supply air diffuser on every floor
13 of the building. Outside air is drawn into the
14 ventilation system through an intake vent at
15 the base of the building, and is then vented
16 into the hallways through the supply air
17 diffusers. That air enters apartments through
18 entry doors and is circulated out of apartments
19 through exhaust vents located in kitchens and
20 bathrooms. Sampling in July 2002 of the entry
21 doorframe of a fifth floor apartment yielded a
22 result of 123,000 structures -- asbestos
23 structures per square centimeter, indicating
24 that the ventilation system was circulating
25 asbestos and other WTC contaminants through

1 hallways and into apartments.

2 Sampling of the FAMCO unit of the living room
3 heating and air conditioning unit in that
4 apartment yielded a result of 37,000 asbestos
5 structures per square centimeter. That unit
6 had not been turned on since 9/11. Identical
7 sampling in an identical unit that had been
8 turned on since 9/11 showed a level of 16,700
9 asbestos structures per square centimeter.
10 That sampling was collected in my apartment in
11 January of 2002.

12 In addition to findings of trace amounts of
13 asbestos in the kitchen and bathroom exhaust
14 vents, the sampling report also noted the
15 presence of World Trade Center dust and debris
16 still visible on an exterior window ledge.

17 In addition to independent sampling results, my
18 building has EPA sampling results that also
19 confirm WTC contamination. My apartment was
20 one of the 222 residence (sic) in lower
21 Manhattan that EPA sampled for heavy metals and
22 dioxin during the first test and clean program
23 that launched in May of 2002.

24 The wipe sample result for lead on my bedroom
25 floor, taken in May of 2003, was 127 micrograms

1 per square foot. It was five times of EPA's
2 health-based benchmark for lead. The result
3 for antimony was 1090 micrograms per square
4 foot. EPA's health-based benchmark for
5 antimony was 627 micrograms per square foot.
6 The eight residences in my building sampled for
7 heavy metals and dioxins more than a year after
8 the collapse, four exceeded EPA's health-based
9 benchmark for lead.

10 Though EPA and the New York City Department of
11 Health responded to the inconveniently high
12 number of positive lead results in lower
13 Manhattan by attributing them to interior lead
14 paint in older buildings, there was no interior
15 source of lead at 105 Duane Street. And it is,
16 and was at the time, a known fact that there
17 was lead in World Trade Center dust.

18 Thank you, and please keep in mind that the
19 sampling results I've cited came from a
20 building that did not appear to be
21 significantly impacted by World Trade Center
22 dust, yet harbored contaminants in sufficient
23 quantities to cause lasting health effects.
24 MR. SPENCER: Next up will be Gail Benzman,
25 who's going to speak to us hopefully over the

1 phone from Florida. Gail?

2 MS. BENZMAN (via telephone): Thank you. Good
3 morning, ladies and gentlemen. My name is Gail
4 Benzman and I am a survivor of 9/11, even
5 though I was not physically in the area at the
6 time of the attack.

7 On 9/11 I had taken the day off to work on the
8 primary election. I was lucky. I watched the
9 planes hit from Queens. If not, I would have
10 been at a meeting within a block of the
11 collapse of the towers.

12 On 9/11 I was employed by the New York City
13 Comptroller's Office located at Chambers and
14 Center Streets. That night the mayor issued an
15 order that all non-essential city personnel
16 were not to report to work. On September 18th
17 EPA Administrator Christine Todd Whitman
18 announced that the air had been tested and was
19 safe. I received an order to report to work on
20 September 20th.

21 As I rode the subway to work that morning, at
22 each station as the train doors opened, the
23 smell of smoke became more intense. At the
24 City Hall stop the platform was black with
25 smoke. We all had to cover our faces as the

1 tears rolled down our cheeks and we ran up the
2 stairs. In the street was more smoke and the
3 smell of burning debris and chemicals. Dust
4 and debris were continually being blown through
5 the air and hosed off the buildings, coating
6 everyone and everything, as well as being blown
7 through the open windows of the buildings and
8 circulated by the ceiling fans.

9 Every morning, after we staggered through the
10 smoke and fumes, before we could begin to work
11 we had to clean our desks, papers, walls and
12 rugs. My reaction to the smoke and dust
13 particles was almost immediate. I had problems
14 breathing and my chest hurt.

15 On September 25th I spoke with the deputy
16 comptroller about the medical reactions I was
17 having -- constant coughing, swollen glands,
18 sore throat, pain in my sinuses, headaches and
19 constant pressure in my chest, as well as
20 nosebleeds. He informed me that the EPA had
21 tested the air and that there was nothing
22 wrong. If I felt sick, I should go home.

23 October 17th was my first of many 9/11-related
24 doctor visits. The list of medications
25 prescribed continued to grow -- V-Pack,

1 Claritin, Brobin (ph), Flonase, Albuterol,
2 Dioxin, Codeine, et cetera -- as did my
3 absences and time spent in bed. The
4 comptroller's environmental policy person
5 arranged for an appointment for me at Mt.
6 Sinai's Occupational and Environmental Health
7 Clinic.

8 On November 8th I was informed that I had
9 reactive airway disease and asthma, a
10 respiratory disease I never had prior to 9/11.
11 Additionally I have been diagnosed with chronic
12 sinusitis and GERD.

13 All the while the federal and city agencies
14 continued to say that there was nothing wrong
15 with the air, in every statement and at all
16 public hearings. Yet doctors, residents and
17 workers testified to new and worsening illness.
18 I had been advised to think about applying for
19 disability, but I had bills to pay, including a
20 mortgage, and I would no longer be able to
21 continue to contribute the time and money I
22 needed to my pension. Dr. Levin suggested I
23 file for Workers Comp. Most attorneys would
24 not accept my case since I had not worked on
25 the Pile. Finally a small firm accepted my

1 case in July 2002. After numerous hearings I
2 was notified by the Workers Comp that I had won
3 my case. My office was reimbursed for my
4 absences and the sick time was credited back to
5 me. I was also informed that I was afforded
6 lifetime medical. But in 2007 my case manager
7 disappeared. Messages left by her were never
8 answered, nor was anyone else ever assigned to
9 my case. Workers Comp stopped paying my drugs.
10 Since 2007 I have been paying for all
11 medications that my insurance has not paid for.
12 To avoid further exposure, I retired when I
13 finally could and left New York. I moved to
14 Florida on January 23rd, 2010. I still have
15 the same medical problems -- reactive airway
16 disease, chest pains, acute sinitis (ph),
17 reflux, and problems with my voice, although I
18 do not suffer as many attacks. Doctors in
19 Florida do not have much experience in treating
20 individuals with 9/11 health problems, even
21 though there are over 1700 of us now living in
22 Florida. After all these years I've learned
23 which medications work for me and which don't.
24 I have been to New York City only three times
25 since I moved. Every time I go I have had an

1 attack of asthma, shortness of breath, chest
2 pains and sinusitis. My most recent attack --
3 my most recent visit required me to be in a
4 lower Manhattan building, and I suffered one of
5 my worst attacks in a long time.

6 Since I was not at work below Chambers Street
7 on 9/11 I was not eligible for the World Trade
8 Center Health Registry. Although I now live in
9 Florida, I recently had my first thorough
10 examination at Bellevue's EHC.

11 Thank you for listening.

12 MR. SPENCER: Thank you, Gail. Next is Lillian
13 Bermudez.

14 MS. BERMUDEZ: Hi, my name is Lillian Bermudez
15 -- I get emotional. I live in Delancey Street
16 above Canal Street. I work for the New York
17 City Police Department. I am a senior police
18 administrative aide, and I have four children,
19 which two -- Mitch, who was 12, and Amanda, who
20 was 9 at the time of the 9/11.

21 A few days -- a few days after the 9/11 the
22 fumes and constant -- constantly coming through
23 my windows, my kids were complaining about the
24 smell, and the towers were still burning. I
25 could smell it, too, and it was very intense

1 and I wondered if it was dangerous. But of
2 course they said that the air was clean.
3 Neither of my kids had any health problems
4 before 9/11. So by the end of October 2001 my
5 son, who's been home from school for two days
6 coughing and sneezing, and I thought it was a
7 cold -- I thought he was suffering from a cold.
8 He had complaint of his chest hurt and I
9 thought that he was -- it was because of the
10 cold that his chest was hurting a lot. On the
11 third day, on a Sunday, when I saw that he
12 wasn't getting better I decided to take him to
13 the doctor at the Bellevue ER. When he was at
14 the triage nurse he check-- they checked his
15 oxygen blood level and asked for Mitch to be
16 taken in right away. As soon as they took him
17 in they put him in a bed, they started putting
18 IV on him and giving him oxygen. And I asked
19 them 'What's going on? What's wrong with him?'
20 They told me that he was having an asthma
21 attack. And I was shocked, because he never
22 had asthma before. That's the first time I
23 hear about it.
24 The next thing I knew, they're sending him
25 straight to ICU where the doctor was struggling

1 to get Mitch breathing under control. I stayed
2 there with my son on the ICU for three days
3 until he was better. The day after he was
4 admitted the doctor told me that if I waited
5 one more day and he would have died.

6 A social worker came to the ICU and started
7 asking me questions, whether there was dust,
8 pets, smoking in the apartment. We don't
9 smoke, we didn't have pets at the time, and if
10 -- and the -- in the apartment -- you know, and
11 the apartment was always kept clean, no matter
12 what. My kids had seen a pediatrician every
13 year and both been healthy. They were never --
14 I was never told that any of my children, you
15 know, had asthma at the time.

16 Because of the dust and fumes from 9/11 I have
17 -- my daughter -- no, before the fume from 9/11
18 she's -- they said that the air was clean and
19 it was not clean. Oh, God, I don't know where
20 I'm at. I am so...

21 (Pause)

22 Yeah, after -- I mean after the social worker
23 was drilling me, that's how I felt, I just kept
24 paying attention to my son who was having
25 problem breathing and the doctors could not get

1 it under control. I said that the dust -- the
2 dust fumes from 9/11 was not good. She kept
3 telling me yes, they said it was clean, that it
4 was nothing wrong with it. She kept resisting
5 -- and I kept -- I got too upset, you know, I
6 don't want to discuss it anymore, and I went
7 over to my son.

8 Mitch came out of ICU after three days, but he
9 was kept in the hospital for five more days so
10 they could keep giving him aburals, steroids
11 and oxygen. He was given a diagnose of asthma
12 and medicine, and we went home.

13 By 2002 my daughter Amanda was sick, and when I
14 brought her to the ER she was diagnosed with
15 sinusitis. The ER doctor gave her a pump, but
16 every time she got a cold it would get worse --
17 the sinusitis would get worse. Eventually she
18 was diagnosed with asthma also.

19 Even though Mitch stayed on the medicine from
20 the ER doctors, he continued to have severe
21 asthma attacks, and I would take him to the ER.
22 He was admitted to the hospital at least four
23 more times.

24 In 2007 I met Dr. Joan Wright-- Re-- oh, God --
25 and she told me to take Mitch and Amanda to

1 Bellevue World Trade Center Clinic to get
2 tested. They got the right kind of medicine,
3 and since then my kids have been doing great.
4 Now they can live like kids again.

5 If my kids have any more asthma or sinus
6 problems, the doctor there are there for them.
7 They know my children's history from 9/11, and
8 they know what to look for and how to get them
9 well because where my children live, they
10 didn't qualif-- and because where we live, they
11 didn't qualify for the health registry, either.
12 And I just want to say one thing that -- I am
13 not taking anything away from the first
14 responders. I am so glad and thank God that
15 they were there for us to be there to help out,
16 but we as to living in the residency have
17 problems also.

18 MR. SPENCER: Thank you, Lillian. Last up,
19 from California, is Lila Nordstrom.

20 MS. NORDSTROM (via telephone): Hi. Can you
21 guys hear me?

22 DR. WARD: Yes.

23 MS. NORDSTROM: Oh, great. Okay, good. So I
24 was a Stuyvesant student on September 11th in
25 2001. Our school was just three blocks from

1 the World Trade Center and on the day of the
2 attacks we were held inside the building until
3 about 10:30, just before the north tower fell -
4 - I think it fell at 10:38 -- so a lot of us
5 ran from the collapsing building the moment we
6 exited, but a lot of us did not get out of the
7 school until well after that time and exited
8 into a scene full of dust and debris.
9 Stuyvesant High School was in the dust cloud
10 and it was used as a command center for several
11 weeks after the attacks. But it was not
12 cleaned adequately prior to our re-occupying
13 it. The vents were not cleaned. There was no
14 fabric or drapery replaced. It had a very
15 cursory like mopping, essentially.
16 We returned back to Stuyvesant on October 9th,
17 2001. It was only three weeks after the
18 attacks. The area was essentially a war zone.
19 We had to go through National Guard checkpoints
20 to get into school, and there were still fires
21 burning at Ground Zero which burned for at
22 least a month after our return. Smoke and ash
23 were blowing into the school daily, and by the
24 end of each school day the smell of smoke was
25 really suffocating.

1 I'm a life-long asthmatic and up until that
2 point my asthma had been well controlled, but I
3 started having breathing problems immediately,
4 as soon as we returned to Stuyvesant. Coughs
5 and nosebleeds and respiratory problems became
6 really common in the Stuyvesant community.
7 To make matters worse, hundreds of trucks
8 carrying the dust and debris from the Pile at
9 Ground Zero passed by our school every day on
10 their way to the barge, which was moored just
11 outside of our building. The barge was facing
12 a community college as well, and a large
13 apartment complex. Their -- the trucks dumped
14 their loads next to our air intake system, and
15 environmental testing at the barge on several
16 days showed that levels of particulate matter
17 were higher there than they were at Ground
18 Zero, so -- and that was right outside
19 Stuyvesant's doors.
20 Stuyvesant students were minors at the time of
21 the attacks, and we had no ability to advocate
22 for ourselves and really no choice but to trust
23 that the Board of Education had made the right
24 decision to send us back. But the parent
25 association at Stuyvesant eventually discovered

1 that the City had really failed to disclose a
2 lot of relevant facts about the environment in
3 and around Stuyvesant, and they now maintain a
4 website where a lot of their failed attempts to
5 get the City to do further testing and cleaning
6 are archived, and that's a good resource for
7 finding out what -- you know, what information
8 was available at the time and what wasn't.
9 Stuyvesant alumni from that year are right now
10 in an age group with really high numbers of
11 uninsured people, and we're already facing
12 discrimination based on 9/11-related pre-
13 existing conditions on the open insurance
14 market. That's really problematic for us
15 'cause we are heavily dispersed nationwide at
16 this point. We live in a lot of different
17 states and not all of them offer the
18 protections that New York State does in terms
19 of pre-existing conditions when you're buying
20 private insurance. At the moment acid reflux
21 and coughs and respiratory problems are very
22 widespread with the Stuyvesant population.
23 There are anecdotal reports of cancers and
24 autoimmune disorders that are growing, but
25 there was no comprehensive study ever done of

1 the health impacts on Stuyvesant alumni, so we
2 don't have exact data.

3 As -- I've -- I have four cancers and two
4 autoimmune disorders were reported -- have been
5 reported to me by former classmates in the last
6 five years, but that certainly doesn't account
7 for the variety that -- you know, that could be
8 out there.

9 I just wanted to finish by reading a statement
10 by my classmate from that year, Amit
11 Friedlander. In 2006 he was diagnosed with
12 Hodgkin's lymphoma. He said: 'All through
13 college, which was 2002 through 2006, I
14 frequently came down with severe flu and cold-
15 like symptoms for a week at a time, and people
16 often told me that I looked sickly and like a
17 drug addict. I just figured I was tired and
18 sick and looked worn out because I was working
19 hard. Shortly after graduating from college a
20 physical therapist noticed a lump in my chest,
21 and the lump was diagnosed by doctors as
22 Hodgkin's lymphoma. I found out that many 9/11
23 responders were being diagnosed with Hodgkin's
24 and other blood cancers. And while I wasn't
25 one of the heroes working in the rubble at the

1 World Trade Center, I had significant exposure
2 to Ground Zero dust, smoke and debris. It is
3 also worth noting that every day there were
4 numerous truckloads of World Trade Center
5 debris going past the Stuyvesant High School
6 building and being unloaded onto a barge right
7 outside the school through late spring of
8 2002.'

9 Thanks.

10 MR. SPENCER: Thank you, Lila. So in closing
11 I'd like to thank Mariama, Jo, Gail, Lillian
12 and Lila, and also my co-chair -- my community
13 co-chair, Kimberly Flynn, for their hard work
14 in putting together this presentation. We hope
15 the Committee has found it somewhat helpful.
16 Thank you.

17 DR. WARD: And we'd like to take at least as
18 many as three questions for the panel. We are
19 running a little late so we'll have to limit it
20 to three.

21 DR. DEMENT: Seems like a recurring theme in
22 all the presentations -- at least most of them
23 -- is the issues for young children, in
24 particular present in the vicinity and
25 certainly outside of some of the zones that

1 were designated. I'd like to hear more
2 discussion about what is going on with regard
3 to looking at children, and maybe some comments
4 about what should be done.

5 MS. POLETT: I mean, we'd just say that parents
6 with affected children couldn't wait for the
7 WTC EHC pediatric program, so they're -- they
8 took them to doctors, you know, all over the
9 city. And that's such a concern because
10 they're dispersed, there's -- the large numbers
11 of them are not being tracked. There are very
12 few children in the World Trade Center Health
13 Registry. I think it's what, 2,000 or --

14 MR. SPENCER: Three.

15 MS. POLETT: -- 3,000, so we're really
16 concerned that there'll be no way to scope out
17 emergent illnesses. If you remember back to
18 the data in my building -- I mean obviously I'm
19 not concerned about the asbestos long latency
20 period, not a problem. I am really, really
21 worried about the children who are living in my
22 building now.

23 MR. SPENCER: One other interesting fact is
24 that it's become -- first of all, there were
25 several different pediatric populations. There

1 were those who were in sort of high school that
2 have now aged out into an adult population and
3 they're part of the -- could be part of the EHC
4 directly. There are people who were, you know,
5 much younger children who are still being --
6 could be treated at the pediatric program. But
7 one of the things we found that was very
8 difficult with is reaching out and finding the
9 people in the community, because in -- for
10 example, the Department of Education has not
11 exactly been forthcoming about facilitating
12 outreach to parents or to, you know, anyone who
13 was connected to this population at the time.
14 And it's only, you know, recently that there's
15 been any modest movement in this direction --
16 just pointing that out.

17 MS. JAMES: I would just first repeat again
18 that the study needs to be funded for
19 pediatrics, Dr. Trasande's study, Dr.
20 Loosfemio's (ph) study. But also to say that I
21 think that from the top there needs to be some
22 encouragement to pediatric physicians. Not all
23 of them take World Trade Center-related
24 illnesses seriously, even to this date after
25 they've been recognized. There needs to be

1 something from the Department of Health,
2 something from the national medical boards to
3 these doctors to not basically laugh it off if
4 you receive a patient -- a pediatric patient
5 that's complaining of multiple respiratory and
6 sinus diseases -- conditions.

7 MR. SPENCER: And the last thing I'd say on
8 that is that often parents seem resistant to
9 identifying, believe it or not, medical
10 problems as being tied to 9/11. And one -- my
11 community co-chair, who sits on your Committee,
12 would probably tell you she's run a pediatric
13 outreach project on behalf of the EHC and
14 sometimes getting people to sort of accept the
15 idea that these post-9/11 onset illnesses are
16 actually tied to that. For some reason there's
17 more of a stigma in some of these communities
18 to that than there would be that they just --
19 it just developed, you know. I don't quite
20 understand it, but there it is.

21 MS. POLETT: And the other problem that --
22 parents who brought their children back or
23 remained in their homes have a really hard time
24 with that, so as I think Rob said, there's
25 resistance. But the other problem is they're

1 handicapped by the misinformation they have
2 received. So a parent whose child was not
3 caught in the dust cloud or didn't occupy or
4 reoccupy an apartment with heavy dust or
5 visible dust just assumes that, you know,
6 whatever is going on with their child -- the
7 asthma, the sinusitis, the learning delays --
8 must have some other cause.

9 MS. BERMUDEZ: I just want to say that the only
10 reason why I found out about my kids being
11 affected with the 9/11 was because one day I
12 went to my -- to their doctor and she told me
13 they were having a meeting about the 9/11. And
14 me, I always thought that there was something
15 wrong with -- with the air and all -- you know,
16 all that stuff, and she told me about this
17 meeting -- I forgot the council person that was
18 supposed to be there, and I met some of the
19 Committee people there, and I just sat in the
20 back and I just listened to what they were
21 saying. But if it wasn't for that meeting I
22 would have never known that my kids was
23 affected with 9/11. I just thought it was just
24 -- they were sick. You know, a cold at the
25 first, but then when they started getting worse

1 and I realized he was getting worse, and then I
2 had started putting two together and I said
3 well, they were talking about that the air was
4 clean, and all of a sudden, you know, all these
5 things are happening and then it was talking
6 about no, the air is not clean. And I spoke to
7 some of the Committee members and they kept
8 telling me well, keep coming to the meetings
9 and we'll get more information about what's
10 going on. But if it wasn't for that meeting, I
11 would have been one of those parents that would
12 have known nothing about what was going on,
13 what was going on with my children. I mean all
14 of a sudden they come out with asthma; from
15 where, from what? And like I say, we were not
16 informed at all about anything about the 9/11.
17 And I have a -- and I met a couple of parents
18 and I told them about it. 'Oh, no, I couldn't
19 believe that; that couldn't happen.' I say
20 'Yes, I think you should start getting' -- you
21 know, getting more information and go on the
22 internet, there's a lot of information about
23 9/11. And because of that, more parents are
24 being aware, but there are a lot of parents out
25 there that are not aware and the children are

1 sick and not getting the right treatment that
2 they should get.

3 MS. FLYNN: Can you hear me? Yeah. There was
4 no official public health guidance for parents
5 of young children until 2009. That is the time
6 in which the New York City Department of Health
7 issued its guidelines for children and
8 adolescents exposed to the World Trade Center
9 disaster. And there was no funded pediatric
10 program for children suffering from 9/11-
11 related mental or physical health effects until
12 2008.

13 MS. HUGHES: I want to thank all of you for
14 sharing your stories with you, and as a fellow
15 mom, I really want to thank the parents and
16 it's been a really hard struggle for the last
17 ten years to get to where we are. And it'll be
18 interesting to see what this Committee will be
19 able to address, and we can't forget about the
20 children, too. Thanks. Thanks a lot.

21 DR. WARD: I think we will move on to taking a
22 short break for 15 minutes. I thank all the
23 members who spoke very much. I think it was a
24 very enlightening session. Thank you.

25 (Recess 10:37 a.m. to 11:00 a.m.)

1 DR. WARD: If everyone could take their seats.

2 (Pause)

3 DR. MIDDENDORF: Just a note to the record as
4 we reconvene that all the previous members are
5 currently at the table except for Dr. Rom.

6 When he returns we'll put a note to the record
7 that he has returned.

8 And I'll also ask if Dr. Talaska's on the
9 phone?

10 (No response)

11 Not hearing, I'm assuming that he has not
12 joined us as yet.

13 Before we get on with the rest of our program I
14 do want to remind folks that, if you aren't
15 aware, that today at 2:00 o'clock the federal
16 government will be conducting the first
17 nationwide test of the Emergency Alert System.
18 The test will last up to three and a half
19 minutes. During this period the regularly-
20 scheduled radio, television, cable and
21 satellite shows will be interrupted as the
22 system is being tested. So we're informing you
23 that this event will be just a test and not a
24 real emergency alert. My understanding is that
25 there may be sirens and things like that going

1 off as well, so it is not a real emergency. We
2 will -- if it's too loud, we'll wait for it to
3 be over and done with. If we can, we'll work
4 through it. So I just want to make sure
5 everybody is aware of that.

6 And a note to the record that Dr. Rom has now
7 returned.

8 DR. WARD: Then we'll begin with Dr. Mark
9 Farfel.

TREATMENT PROGRAMS AND HEALTH REGISTRY:

WTC HEALTH REGISTRY

10
11 DR. FARFEL: Are the slides cued up? So thank
12 you for the opportunity to speak for about 15
13 minutes about the World Trade Center Health
14 Registry. It's been mentioned a number of
15 times this morning already.

16 As I look around I see a number of you are very
17 familiar with registry activities and research
18 through service on the registry's advisory
19 committees, the science, labor and community,
20 and some of you have gotten recent updates on
21 registry research at the October WTC seminar
22 that Steve Markowitz helped organize. But I
23 know that others may not be as familiar, so
24 what I'm going to do this morning is just
25 briefly present on registry background and some

1 of the past findings, but really focus on
2 ongoing research and planned research. I think
3 that would be of interest to the Committee.
4 Let's begin with our registry aims. We have
5 three, and the first is expanding knowledge
6 about long-term health effects of 9/11 and gaps
7 in health care. And in a nutshell, we -- this
8 basically entails three approaches to the
9 research. One is we do periodic health surveys
10 of our enrollees; two, we do in-depth studies,
11 some collaboratively with external researchers,
12 and we also do matching to other health
13 registries such as the National Death Index.
14 The registry also responds to health needs and
15 concerns of enrollees and others who were
16 exposed. It was mentioned earlier the
17 pediatric physician guidelines, there was also
18 the adult guidelines, came out of this specific
19 aim of the registry. And we now also have a
20 treatment referral project that I'm going to
21 mention a little bit later that's part of the
22 core registry function under aim two.
23 Lastly, we expend quite a bit of effort
24 maintaining updated contact information, or an
25 updated registry, so that we can reach people

1 for the first two aims, and also so we can
2 serve as a resource for external researchers
3 doing 9/11-related research.

4 So briefly on the history of the registry, the
5 Health Registry was actually conceived shortly
6 after 9/11, and the registry was established at
7 the health department in partnership with ATSDR
8 in 2000 (sic). We're currently funded by NIOSH
9 and that came in the more recent years.

10 The first registry survey was in 2003 and 2004,
11 and at that time we had 71,000 exposed persons
12 enrolled in the registry, and including the
13 3,000 children that were mentioned earlier.

14 And they took a 30-minute telephone interview
15 which gathered information about physical and
16 mental health symptoms and conditions, new or
17 worsening conditions, and 9/11 exposures.

18 The second registry survey was 2006-2008, and
19 nearly 70 percent of the adult enrollees
20 responded to that survey, and we had just over
21 half of the parent proxies who responded for
22 their children who were in the registry also
23 responded to that survey. So the goals there
24 were to assess the course of symptoms and
25 conditions that had been reported on wave one.

1 We did get some exposure clarifications,
2 including asking questions about the intensity
3 of the dust cloud exposure, and we asked about
4 any new emerging conditions.

5 The wave three survey, which is the 10-year
6 follow-up, the 2011-2012 survey, is currently
7 underway. We did launch in July to the adults
8 and most recently to the parents of children
9 still enrolled. And our goals there are to
10 assess the course of conditions, emerging
11 conditions, unmet health care needs there.

12 So very briefly, the registry had four
13 eligibility groups that were individuals who
14 were highly likely to have been exposed, have
15 had high exposures to the 9/11 event or the
16 aftermath. And the largest group by far, the
17 building occupants and passersby of Chambers
18 Street on 9/11, and that includes occupants of
19 damaged and destroyed buildings and about 4,000
20 occupants of the twin towers; followed by
21 rescue/recovery workers and volunteers at the
22 site, and that includes several thousand of
23 NYPD, FDNY, Department of Sanitation employees,
24 as well as about 5,000 people who reported they
25 were there as volunteers. The third group is

1 the residents south of Canal Street, 14,665;
2 followed by children and staff in schools south
3 of Canal Street.

4 Now the numbers do add up to more than 71,000
5 because about one in four of the enrollees were
6 actually -- fell into more than one of the
7 eligibility groups. So the registry has about
8 17 percent of the estimated 400,000 people who
9 are eligible across the four eligibility
10 groups. And of course exposed persons did not
11 need to be ill to be eligible for enrollment in
12 the registry.

13 Just wanted to say a word about recruitment
14 briefly. We have two main groups, the first
15 that we call list-identified, which comprises
16 about 30 percent of the enrollees. These are
17 people who are recruited from lists of names
18 that were culled from employers and
19 organizations, or residents through publicly-
20 available directories, so there are a large
21 number of lists with a large number of
22 potential enrollees, and they were reached out
23 to by the survey vendor and assessed for
24 potential eligibility.

25 So this group, since it was recruited from

1 lists, is less likely to be subject to
2 selection bias compared to the remainder of the
3 enrollees that we call the so-called self-
4 identified.

5 These are people who responded to the extensive
6 media outreach and awareness campaigns --
7 subway and bus ads and so forth, letters sent
8 to parents -- and pre-registered or contacted a
9 toll-free number. And then those inbound calls
10 were handled and people were interviewed.

11 So we do take into account recruitment source
12 and registry analyses, and when we do look at
13 list-identified enrollees separately we do find
14 similar trends in findings.

15 Now this attack truly was an attack on the
16 United States, and this map reflects that the
17 registry has enrollees from all 50 states. We
18 actually have responders from all 50 states as
19 well. The majority -- we also have enrollees
20 from 18 countries. The majority of the
21 enrollees resided in New York City on 9/11. We
22 had about -- close to 90 percent in the New
23 York City metropolitan area. And then we have
24 enrollees -- large numbers of enrollees in
25 states like California, Pennsylvania and

1 Florida.

2 A few strengths of the registry to point out at
3 this point is that we do have published
4 estimates of the numbers of exposed persons,
5 and it was addressed earlier this morning that
6 these are just estimates, but we do have them.
7 The registry, as I mentioned earlier, is a
8 vehicle for external researchers to conduct
9 their own WTC research, or in collaboration
10 with the registry. We have about ten external
11 collaborations to date with local researchers
12 affiliated with local universities, including
13 Columbia, NYU, Cornell. We also have
14 collaborations with international researchers
15 from the United Kingdom. And the topics really
16 range quite widely, from looking at evacuation
17 procedures and understanding behavioral aspects
18 and structural aspects of building evacuation
19 to understanding the transmission of PTSD from
20 first responder parents to their children.
21 And I think first and foremost, you know, we do
22 have the diverse groups of enrollees that we
23 follow, with quite a number of subgroups in
24 there that I've alluded to. And each of these
25 main registry groupings that I just presented

1 has experienced a large burden of both physical
2 and mental health symptoms and conditions.
3 And I just wanted to show a couple of slides of
4 some of the more common conditions. I want to
5 begin with PTSD. I have one slide, and then
6 one slide on new asthma after 9/11. So we call
7 this probable PTSD because the -- our surveys,
8 which were self-report surveys, actually
9 screened for PTSD using the PCL checklist,
10 which was a 17-item checklist grounded in the
11 events of 9/11, so that's why we refer to it as
12 probable. So by the point of the second wave
13 of our survey in '06-'07, about one in four of
14 our enrollees had new-onset PTSD that had no
15 prior history of PTSD; about ten percent had
16 late-onset PTSD at wave two; and about ten
17 percent had reported PTSD or screened positive
18 at both waves one and wave two. Most of those
19 individual enrollees who had the chronic or the
20 late-onset PTSD reported poor mental health in
21 the past month, it was 13 days or more poor
22 mental health, and no mental health care in the
23 past year. And I think that last finding
24 really highlights the importance of ongoing
25 mental health services following a disaster and

1 the importance of understanding the barriers to
2 care.

3 And when we looked across rescue recovery
4 groups there was a range of prevalences of PTSD
5 from seven to 24 percent. It was lowest in the
6 police and it was highest in workers who were
7 least likely to have had any prior disaster
8 experience or training, such as sanitation,
9 construction, and the spontaneous volunteers.
10 Now what you see next under the risk factors
11 are some 9/11-related risk factors and others
12 for probable PTSD, so the 9/11 is being caught
13 in the dust cloud, witnessing horror, being
14 injured on 9/11; also heavy dust in the home
15 and the workplace, which has been mentioned
16 earlier today; for rescue/recovery workers,
17 early arrival, longer duration of
18 rescue/recovery work; and then event-related
19 loss of job or spouse and low social support.
20 So the ones I've highlighted in gold-colored
21 font are also risk factors for new-onset asthma
22 after 9/11. And for rescue and recovery
23 workers, delay in deploying a mask or
24 respirator after 9/11 was also associated with
25 new-onset asthma.

1 So let's turn to asthma, and this is the
2 annualized incidence of new asthma post-9/11 in
3 persons who had no history. And the asthma
4 rates were significantly elevated after 9/11.
5 They were highest in the first 16 months. The
6 rate in 2001, which was about three percent,
7 was six-fold higher than the general U.S.
8 population rate. And then you can see it
9 declined starting in 2003 to less than one
10 percent. And there was an increase in 2006
11 which we think is just attributable to the fact
12 that we were asking about asthma again in the
13 wave two survey, some recall.

14 The fact that so many of the people who were
15 diagnosed after 2003 had actually reported
16 symptoms of wheezing before 2003, we suspect
17 some of the late diagnosed asthma may actually
18 be 9/11 event-related asthma that was just --
19 had a late diagnosis.

20 By 2006/7 12 percent of rescue/recovery workers
21 and eight percent of other enrollees had new-
22 onset asthma, first time. And there was a
23 similar pattern in annualized incidents of
24 asthma among the children enrollees in the
25 registry.

1 I wanted to talk about some recent findings.
2 Some of these were actually presented at the
3 October WTC research seminar, but I wanted to
4 mention some of these. The first was a result
5 of a collaboration between the registry and NYU
6 Bellevue. It was a nested case controlled
7 study of residents and area worker enrollees
8 which were -- sort of tended to be more of
9 under-studied populations post-9/11. And the
10 oscillometry and PFT testing showed lower
11 airway disease among residents and area workers
12 that were associated with persistent symptoms
13 at waves one and wave two and exposure.
14 And we also, in the second finding reported
15 here, we looked at 9,300 rescue/recovery
16 workers who had worked on the Pile, and those
17 that reported wearing a respirator were less
18 likely to report symptoms and -- respiratory
19 symptoms and conditions than those that
20 reported no or lower levels of rescue -- of
21 respiratory protection. Predictors of adequate
22 respiratory protection we found were working in
23 the construction, utility or remediation trade,
24 having had prior respiratory training. And it
25 came up earlier that there was mixed degree of

1 respiratory protection on 9/11, and we actually
2 found in this study that 50 percent reported no
3 respiratory protection at all on 9/11.

4 And the third -- the third recent finding is
5 risk factors associated with heart disease, and
6 we reported dust exposure and the psychological
7 trauma was associated with an elevated risk of
8 non-fatal heart disease two to six years after
9 9/11, and that PTSD was independently
10 associated with heart disease.

11 Then the last bullet, we also found, looking at
12 about 37,000 adults, that persistent symptoms
13 of GERD, gastroesophageal reflux disease, were
14 common. It was actually reported by 13
15 percent, and that those symptoms were
16 associated with 9/11 exposures, independent of
17 both asthma and PTSD, 'cause it's known that
18 you can have elevated GERD symptoms when you
19 have asthma/PTSD, so it was important to look
20 at that independently.

21 Other recent findings was -- here's one case of
22 a less common physical effect. It was a nested
23 case-controlled study led by Dr. Jim Cone,
24 who's here, on sarcoidosis after 9/11, and that
25 was found to be associated with rescue/recovery

1 work on the Pile, and there were 43 biopsy-
2 confirmed cases. It was actually one of the
3 largest studies of sarcoidosis out there.
4 Back to the volunteers, I mentioned we have
5 5,000 volunteers in the registry, and the study
6 here compared the lay volunteers or people that
7 spontaneously arrived at the site, and compared
8 their health to the volunteers who reported
9 they were affiliated with organizations like
10 the Red Cross. And we found that the lay
11 volunteers arrived earliest and were at
12 greatest risk for post-9/11 first time
13 asthma/PTSD compared to the affiliated
14 volunteers.

15 Last one on this slide is a paper that was
16 recently published in the special Lancet volume
17 where we reported the initial results of the
18 registry's ongoing mortality study. The
19 overall mortality reported was below population
20 rates, but we did report elevated all cause and
21 cardiovascular mortality among the intensely
22 exposed survivors relative to those who were
23 less intensely exposed. And by intensely
24 exposed in that analysis were individuals that
25 had more than one injury on 9/11 and residents

1 who did not evacuate from the home, as well as
2 school children who were present in their
3 school in lower Manhattan on 9/11.

4 Wanted to now begin to talk about some of the
5 ongoing research that we have at the registry,
6 and fortunately we obtained consent from
7 enrollees to do matching to other health
8 registries -- that we obtained in 2003/4 at the
9 time of enrollment. So we have three sets of
10 matching activities that are ongoing. The
11 second one I'll mention first because that --
12 that I've mentioned we published the initial
13 study, but the matching to vital records and
14 the National Death Index to ask the question
15 'Is there evidence of excess mortality among
16 enrollees; and if so, are they related to 9/11
17 exposures?' That's ongoing, initial findings
18 published. The top is -- refers to matching to
19 state cancer registries, and we matched to
20 eleven that comprise about 90 percent of
21 enrollees, and we have a similar research
22 question that we're asking, but in this case
23 with regard to cancer.

24 The last item is matching to New York State
25 hospital discharge data, and we're looking to

1 that as an important tool to validate, again,
2 registry self-reported -- of outcomes, for
3 example, heart disease. And the good news is
4 the first installment has just arrived. We
5 haven't received all the data requested, but
6 now we're, you know, in a position -- hopefully
7 in 2012 -- to actually -- to begin working on
8 that.

9 We have a lot of analyses underway. I just
10 wanted to list some of those to give you an
11 idea what to expect in the future. Robert
12 Brackbill, who's the founding PI of the
13 registry, presented at the WTC seminar in
14 October on unmet health care needs. And I
15 think it's going to help us understand better
16 which groups have perceived unmet health care
17 needs. The registry also has done focus groups
18 with survivors to talk about their perceptions
19 of health care and access, so I think those two
20 together will help us understand better how to
21 conduct outreach to different populations that
22 are affected by 9/11. The referral evaluation
23 will also give us a handle on how many people
24 who scheduled visits actually kept them, and to
25 help us understand if health status has

1 improved.

2 We're also looking at injury on 9/11 and asking
3 the question about long-term health impacts.
4 We're asking questions about the relationship
5 between 9/11 exposures and heavy or binge
6 drinking among enrollees. We're asking the
7 question about pediatric asthma, so we're
8 looking at the wave two and we'll be looking at
9 wave three asthma data in children. We also
10 have almost 300 pairs of parent-child enrollee
11 data, and so we're looking at -- similar to
12 what was done by external researchers -- is
13 parental PTSD related to stress symptoms and
14 behavioral problems in children.

15 And then of course the whole wave three survey
16 that we're going to complete in March gives us
17 an opportunity to look at the continued course
18 of symptoms and conditions previously reported
19 in asking about new or emerging conditions.

20 Just a little bit more about the initial cancer
21 study that's underway now. The methods are to
22 compare incident cancer observed cases with
23 expected cancer cases. The population for the
24 initial cancer study are our enrollees, who are
25 New York State residents on 9/11. The source

1 of the cancer data will be linkage with state
2 cancer registries through 2008. We'll be
3 looking at the first primary invasive cancer or
4 borderline bladder. And the comparison
5 population will be New York State reference
6 population rates, and the person years
7 calculation will be based on the time of
8 enrollment into the registry to the time of
9 cancer diagnosis, death, or the end of 2008,
10 whichever is earlier. The timeline -- I can
11 tell you we're working hard to have a paper
12 submitted early in 2012 as possible, and we're
13 also -- of course it's hard to tell when there
14 may actually be a publication, but we're also
15 hoping that's as early as possible in 2012
16 because I know this Committee would find that
17 information helpful.

18 Just want to talk a little bit more now about
19 wave three, 'cause it is our ten-year follow-
20 up. We launched in July and by 9/11, the tenth
21 anniversary, all 67,000 adults in the registry
22 were sent a survey. And like wave two, we have
23 three modes. We're offering the web, paper and
24 telephone. And we're offering the surveys in
25 Spanish, Chinese and English. We have -- we're

1 approaching the 30,000 milestone, 30,000
2 completed surveys. The response rate is 44
3 percent. And it's interesting that among those
4 who responded to the wave two survey we have
5 over 50 percent of the surveys back. So that's
6 a high-responding group, which will give us a
7 third point in time for large numbers of
8 enrollees.

9 And as was the case in wave two, the
10 rescue/recovery workers are responding the best
11 so far, and we've started building outreach in
12 lower Manhattan with the help of our community
13 advisors, and we do plan to do door-to-door
14 outreach to try to boost the response of some
15 of the other groups, and local media outreach
16 as well.

17 Now the child survey was launched November 1,
18 and we now have 1,200 children who are below
19 the age of 18. And actually at this point, ten
20 years post 9/11, all of the children are
21 adolescents ten years and above. So we had a
22 separate survey booklet for the parent and one
23 for the adolescents. And for the first time
24 we're offering a web-based survey both to
25 parents and children. We thought that might

1 engender a better response than we had last
2 time. And we're offering the paper in three
3 languages.

4 And I just wanted to briefly mention some of
5 the new content for the child survey. We have
6 well-being on the adolescent survey. We have
7 school functioning, school engagement. We're
8 asking questions for the first time about
9 illicit drug use and use of prescription drugs.
10 And for the parents we're getting more
11 information on their own physical and mental
12 health status.

13 I thought you might be interested in just a tad
14 more detail on the content of the adult survey,
15 so we're getting updates on wave two items,
16 physical and mental health symptoms including
17 asthma and heart disease. On the mental health
18 side we're again having a PCL checklist for
19 probable PTSD, the K-6 scale for severe
20 psychological distress and diagnosed mental
21 health conditions. We're getting more
22 information on health status and quality of
23 life and functioning, social support, life
24 events and alcohol use. And then we're also
25 asking again about use of the WTC programs and

1 unmet needs.

2 What we've added new to the wave three survey
3 is more questions to get at GERD rather than
4 GERD symptoms. We're asking about sleep apnea
5 and other respiratory conditions. We're asking
6 more about medications and hospitalizations for
7 health conditions as an indicator of severity.
8 We've added asthma control both to the
9 pediatric and the adult survey. We have for
10 the first time scales for depression and
11 anxiety assessment. We're getting for the
12 first time a history of trauma 'cause we need
13 to take that into account in understanding PTSD
14 and depression. And we're getting information
15 on health insurance coverage.

16 But the survey length, since we're no longer
17 asking about exposure issues, we've actually
18 managed to still retain about a 20-minute
19 length survey.

20 I had mentioned earlier we have a treatment
21 referral program, and it's interesting and
22 worrisome that, despite multiple rounds of
23 outreach by the registry and certainly quite a
24 bit of outreach by the clinical programs, that
25 we have large numbers of enrollees who are just

1 not well-informed about the WTC clinical
2 programs. And so our treatment referral
3 program started through a subcontract to HHC's
4 Environmental Health Center, a World Trade
5 Center of Excellence. So what we were trying
6 to do is encourage the eligible survivor
7 enrollees to seek care at the Bellevue Clinic
8 at no cost to enrollees. And so our initial
9 focus was of course the residents and area
10 workers who were in New York City, and we
11 focused on those who had unmet health care
12 needs, as well as either physical symptoms
13 and/or probable PTSD, and we got guidance from
14 Joan Reibman about which symptoms, you know, to
15 put in that cluster. And we did personalized
16 outreach, which was different from what we had
17 done in the past. We had personalized letters
18 and telephone calls, and we have staff who are
19 trained as nurses and we have a pharmacist,
20 someone who's -- has a pharmacy background
21 leading the unit. And we've reached out to
22 more than 9,000 enrollees to date, including a
23 large number of people with PTSD symptoms. And
24 the good news is that about 1,000 enrollees
25 have actually made their first appointment at

1 the EHC center. And what's good news in there
2 is that some of those enrollees are enrollees
3 with PTSD. So it seems like we're learning
4 some new things about how to do successful
5 outreach to these populations, particularly
6 people who have the avoidance characteristic of
7 PTSD.

8 And now of course the program's referring our
9 enrollees to the WTC Health Program, and we're
10 planning to include survivors outside the New
11 York City area. And we believe that the
12 registry is an untapped source for WTC Health
13 Program outreach to that population, as well as
14 rescue and recovery workers.

15 So let me just conclude on some next steps and
16 priorities. We are going to complete the wave
17 three survey by March of 2012. This would
18 actually be a much more compressed time frame
19 than we've had in past surveys. We plan to
20 submit manuscripts based on ongoing research,
21 including the initial cancer study and analyses
22 of wave two and three data. We're going to
23 share findings with the public, enrollees and
24 policy makers. We do post-publications on the
25 website. And in order to keep all this going,

1 we're going to need to apply for continuation
2 funding from NIOSH. We are currently funded
3 under a three-year cooperative agreement and
4 we're anticipating that early in 2012 we'll be
5 writing that continuation application.

6 Thank you.

WTC ENVIRONMENTAL HEALTH CENTER/

7 **HEALTH AND HOSPITALS CORPORATION**

8 DR. WARD: Dr. Joan Reibman.

9 DR. REIBMAN: Good morning. It's my pleasure
10 to be here, and many of you I know and many of
11 you I don't know. And I would like to do today
12 is sort of, as the only clinical center for the
13 non-responders or the survivors, I sort of have
14 a heavy load to lift because I have a large
15 diverse population to talk about and so I'm
16 going to take a few liberties. But and I also
17 apologize for not giving you a handout.
18 Let me start by first giving you a little
19 definition that I think you're hearing
20 throughout the day that is a little confusing.
21 What you've heard is Health and Hospitals
22 Corporation. That's the corporation that
23 oversees the public hospital system in New York
24 City. There are a number of hospitals, one of
25 which is Bellevue Hospital, which you've heard

1 about today, too. Many of those hospitals have
2 academic associations. And so for example,
3 Bellevue Hospital's associated with NYU, which
4 is why you're hearing NYU Bellevue so much.
5 What I'd like to do today if I can figure out
6 how to do this and I do right -- is that what
7 it is? Yeah. I apologize for showing this
8 slide again. I do it for a purpose. One, to
9 remind you that, again, we think of lower
10 Manhattan as a financial area, but it actually
11 -- as you've heard today from so many people --
12 is a large residential area and also has a huge
13 working population. These -- the data of the
14 number of people who were down there around
15 9/11 comes from the World Trade Center
16 Registry. Again, I show that to you because it
17 strikes terror in the heart of the government
18 when they look at these numbers of potentially
19 60,000 residents, 300,000 area workers and
20 15,000 students who might have been exposed.
21 And when people start thinking about whether
22 these people are sick, it raises enormous
23 concern.
24 What I'd like to do today is a little bit --
25 talk about the problems with disaster exposure

1 science and the community at risk, the
2 background history of the World Trade Center
3 Environmental Health Center Program, the
4 clinical findings that we have, and certainly
5 touch on unanswered questions.

6 I don't need to go into this audience about the
7 basic tenets of environmental human exposure
8 science, except to say that when we think about
9 that, what you've been hearing today from
10 responders, from community members, is that in
11 fact those tenets are very difficult to do when
12 you're talking about what we're really talking
13 about today, which is environmental disaster
14 exposure science. And that's because the
15 systems are in disarray, politics and economics
16 complicate questions of potential health risk,
17 exposure assessment may not be feasible, and
18 disease assessment systems may not be
19 available. And so therefore you're hearing,
20 ten years later, many of the problems because
21 of these issues.

22 The first question for the community was did
23 World Trade Center dust or fume exposure pose a
24 health risk to the community, was really a
25 difficult question to ask. Again, you've heard

1 today about risk denied by the EPA, about
2 warnings that -- about procedures that were
3 told to the community and that local workers
4 returned soon after the event, and that the
5 concept of potential health risk to the
6 surrounding community was only accepted after
7 prolonged delay. And it took many, many people
8 working to get that word out that in fact there
9 might be a description -- a problem.

10 You've heard people ask about what were the
11 exposures, and I'm not going to go into them
12 except to show you that most of the details
13 about the potential exposures came from
14 academic institutions, as well as other sites,
15 and the key things were that there were huge
16 numbers of small and large particles that -- as
17 you've heard, the dust was very alkaline but
18 that there were many, many other components.
19 And as you're going to hear as people start
20 talking about biologic plausibility, that there
21 were huge other chemical constituents with
22 potential health risks.

23 So how does one do exposure assessment for
24 community members? And clearly for us it's
25 been complicated by the wide variety of

1 exposure possibilities -- the variable amount
2 of time in the area that people had, whether
3 they were there on 9/11, whether they were
4 evacuated, whether they did not evacuate,
5 whether they returned episodically to clean.
6 And there were no studies done immediately
7 after the event to assess exposure history --
8 assess exposure, meaning we had to rely a lot
9 on recall, which all of you know is limited.
10 So again, you've seen these pictures, but I
11 show them to you to remind you about exposure
12 and what it means to us when we talk about
13 acute exposures, we talk about dust cloud
14 exposure and -- and in our clinic we say 'Oh,
15 another dust cloud person.' These were people
16 who were heavily coated in the dust. But it's
17 not so simple because some of them had heavy
18 coating, some had less -- were less coated.
19 Some were there when the debris fell down
20 before the clouds -- before the buildings
21 collapsed. And there was also extensive dust
22 in the afternoon.
23 We talk about chronic exposures, which are much
24 more difficult to assess, including outdoor
25 exposures -- and this is a picture of the

1 workers returning on 9/11 -- on 9/17 when you
2 can see that the streets were still heavily
3 coated in World Trade Center dust. We talk
4 about chronic exposures to indoor -- and these
5 are pictures of people's apartments, these were
6 their furnishings. And we talk about the fact
7 that some residents were evacuated, many others
8 were not. But we do know that the chemical
9 composition indoor was similar to that outdoor.
10 And then we talk about gases and fumes.
11 But how do we put that all together for an
12 exposure assessment? Well, it's been very,
13 very difficult. Most of the time we just talk
14 dust cloud; it's the simplest way to look at
15 it. I take this picture from a publication
16 that's in press in a collaboration we did with
17 the World Trade Center Registry by Carrie
18 Maslaw (ph) where she tried to look at acute
19 and chronic exposures and do them by a
20 principal components analysis, putting all of
21 them in the mix. And what she basically
22 concluded is that both acute and chronic
23 exposures independent -- were independent risks
24 for persistent lower respiratory symptoms in
25 the residential and working community,

1 suggesting that what we're saying by just
2 saying acute exposures is inadequate, but we
3 don't really have a handle yet on how to look
4 at chronic exposures as well.

5 What do we do about disease assessment in the
6 community? Well, it's been very difficult.
7 Most of the -- really the -- we were alerted as
8 an academic community to this really by the
9 October 11th Pace University community forum
10 when many of us were asked to be on a panel,
11 and most of us had no answers. On that panel
12 were also members of the FDNY, also organized
13 labor, also Mt. Sinai representatives, and many
14 community members were in the audience, all of
15 whom were wearing dangling masks and coughing
16 and saying should we be concerned or should we
17 not, and we really had no answers at that time.
18 So we set out with the New York State
19 Department of Health to do a residents'
20 respiratory health study in October 2001. We
21 obtained funding by the CDC, and this was a
22 cross-sectional study of a control and exposed
23 population. We did an exposed population
24 surrounding Ground Zero. The control
25 population was -- not on this picture -- in

1 upper Manhattan. And we designed, implemented
2 and completed the study 16 months after 9/11.
3 It was a very difficult study. There were no -
4 - mailing systems were not working. We had to
5 go and do this by hand on site. We were lent
6 really a lot of effort by the community. We
7 were lent sites to do lung function testing, et
8 cetera. We over-sampled the exposed community
9 because at that point we were the first ones
10 out there to really be looking at the exposed
11 community, and we thought that this would be
12 perhaps used for later studies later on.
13 And basically simply what we showed was, not
14 surprisingly, that there was an increase in
15 respiratory symptoms -- whether it was cough,
16 wheezing, chest tightness, shortness of breath
17 -- in this population a year and a half after
18 the event, and that these symptoms remained a
19 year and a half after the event; that in fact
20 one could also document that these symptoms
21 were not just being reported, but they were
22 associated with unplanned medical visits, with
23 new use of fast-relief medicines -- Albuterol -
24 - and with controller medication in the exposed
25 population compared to the control population.

1 And furthermore that the risk of developing
2 these symptoms, whether they were new upper
3 respiratory or new lower respiratory or
4 persistent upper or persistent lower, was
5 associated with the persistence of dust or
6 odors in the home.

7 And so these were some of the early studies to
8 document that in fact there was a civilian or
9 community or non-responder or survivor
10 population, as they're now called, that was
11 also at risk for adverse health effects from
12 exposure to the World Trade Center dust and
13 fumes. And my pointer's not working, but as
14 you heard from Mark, many of these studies have
15 now been done and confirmed and supported by
16 the number of World Trade Center Health
17 Registry studies that have been done.

18 We then began a clinical program, first as an
19 unfunded pilot project with community groups --
20 actually Beyond Ground Zero Network and other
21 groups that are sitting in this room -- because
22 people came and said can you treat us, and we
23 actually didn't want to because we weren't
24 funded and we didn't have a place to treat
25 anybody, but we put people in our asthma

1 program and began a small pilot program. We
2 were eventually funded by the American Red
3 Cross Liberty Disaster Relief Fund in 2005 to
4 just do a treatment program, and in 2006 we
5 obtained funding from the City of New York for
6 a treatment program, and in 2008 we had our
7 first federal funding from CDC/NIOSH.

8 These fundings were to do treatment. That is,
9 we were never funded to do a screening of non-
10 symptomatic individuals. We were always funded
11 to do treatment for self-referred individuals
12 with presumed World Trade Center-related
13 illness. We worked with community members to
14 define geographic exposure boundaries. We
15 worked to define what kind of symptoms, and we
16 tried to stay inclusive because we didn't know
17 what to expect. We were initially not funded
18 to do isolated mental health but only physical.
19 Subsequently, with City funding, could we treat
20 people who also had mental health symptoms.
21 Our target populations were the non-rescue and
22 responder workers -- although, because of our
23 initial funding, we had a small population of
24 rescue and recovery workers. But really our
25 target population was residents, local workers,

1 students -- and because of who we are, we also
2 had a large number of cleanup workers.

3 And so we developed -- really working in
4 parallel to the responder programs -- a multi-
5 disciplinary treatment program providing
6 medical, mental health and social services.
7 And to date we have recruited nearly 6,000
8 individuals into this program, starting in
9 September 2005 to September 2008.

10 Just briefly, because our population differs
11 again from what you've been hearing about,
12 these are early population of almost 2,000, the
13 differences are we are -- have a large number
14 of women in our clinic. This is very different
15 from the responder populations. We have a very
16 mixed race ethnicity, which -- a large Hispanic
17 population. And consistently about 40 percent
18 of our population say that they were in the
19 dust cloud on 9/11.

20 Again, I don't have a pointer so it's hard to
21 show this, but basically what I'm showing here
22 is that when we ask our population what are
23 their symptoms, whether they are a resident, a
24 cleanup worker, a local worker, the symptoms
25 are those we have been hearing about over and

1 over -- cough, lower respiratory symptoms,
2 cough, wheeze, dyspnea, chest tightness, et
3 cetera. So the populations, regardless of whom
4 they are, are having the same symptoms.

5 One of the areas we became interested in was
6 what really were these illnesses. This is one
7 very -- one simple case, a 37-year-old
8 gentleman, previously healthy, not in the dust
9 cloud, developed shortness of breath, came into
10 our program, had wheezing, had spirometry shown
11 in the little picture on the right -- that was
12 classic for asthma. And so he's no problem for
13 us. We say he has asthma and we can treat him.
14 We know how to treat him. We feel very
15 comfortable.

16 However, not everybody presented that way. And
17 in fact, if you look at our lung function
18 distribution similar to the responder, what you
19 find is that in fact most people -- if you look
20 at spirometry pattern, most of them have normal
21 spirometry. Only a small number have an
22 obstructed pattern consistent with asthma.
23 Many of them have a reduced vital capacity;
24 that is, a slightly reduced lung volume. And a
25 small number have both an obstructed and a low

1 vital capacity.

2 So we weren't sure what that meant and how to
3 explain that, and there are a number of things
4 one can ask about, including are these
5 patients, like an asthmatic, just have retained
6 their lung function but they're hyper-
7 responsive, or are we not detecting the
8 abnormalities in the lung, do we need more
9 sensitive assays? Or are they not even lung
10 symptoms, that people have cardiac disease or
11 mental health? And all of those questions
12 remain of interest.

13 What I wanted to show you today is -- and this
14 is reinforced by the fact that if you look in
15 the firefighters -- and David will talk to you
16 more and more about this -- and if you look at
17 them in one point of time, they have normal
18 lung function. If you look at them
19 longitudinally you can see that in fact there's
20 a decline in their lung function. But we
21 didn't have that opportunity. We didn't have
22 the early lung function in these patients. So
23 we were just looking initially at one point and
24 now, later on, longitudinally.

25 So we tried to ask are there other techniques

1 we can use that might in fact be simple,
2 because we couldn't do methacholines on
3 everybody, but might be simple to identify are
4 there other ways we can look for abnormal lung
5 function. And as you heard Mark talk about, we
6 did a collaborative study with the World Trade
7 Center Registry looking at a technique called
8 impulse oscillometry, which is non-invasive,
9 which can be interpreted in a number of ways,
10 one of which is to say that it might suggest
11 that there's abnormalities within the distal
12 airways that might not be detected by
13 spirometry -- and I have a typo there, but that
14 was this morning. Basically what we showed
15 with the registry is that if you look in the
16 shaded boxes, that's one of the measurements of
17 impulse oscillometry in which you can see
18 consistently across BMI -- we put BMI in
19 because obesity is known to interfere with
20 measurements -- but consistently across these
21 groups that the patients who had symptoms,
22 compared to those who did not have symptoms, in
23 white, that the patients who had symptoms, in
24 gray, consistently had higher oscillometry
25 measurements, even if they had normal

1 spirometry.

2 So that suggested to us that this might be a
3 way to start to tease out some of the
4 mechanisms or some of the reasons why people
5 had these symptoms, even if they had normal
6 spirometry.

7 We have done this consistently in our
8 population in the clinic as well, but we didn't
9 have a control population. So working with the
10 registry allowed us to have a control
11 population and that was very beneficial to us.
12 And what you can see here is that the first box
13 on the left is an asymptomatic group, and this
14 is the measurement -- their oscillometry
15 measurement. And the other gr-- the other
16 boxes are -- all are clinic patients with
17 symptoms, and what you can see is that they
18 have, regardless of their spirometry pattern,
19 they tend to have higher oscillometry
20 measurements, even if they -- and even if they
21 have normal spirometry.

22 So this suggests to us that perhaps this is a
23 tool that we can use, in conjunction with
24 everything else, to try to figure out what are
25 some of the causes of some of the respiratory

1 symptoms in this population, and we think that
2 that's helpful.

3 One of the other things we have done in this
4 program is to look at pathologic findings,
5 because we felt we didn't fully understand the
6 disease. And so we did a case series of 12
7 patients who had clinically-indicated open lung
8 biopsies. This is not an easy thing to do. We
9 don't do this regularly. We don't like to do
10 it. These were patients who either had
11 abnormal CAT scans that we couldn't interpret
12 or had very severe lung function findings. We
13 ran these findings through four pathologists
14 and none of -- only one patient could they come
15 to a conclusion with a firm diagnosis. Most of
16 what they felt they could do was describe what
17 they were finding, which was a little bit of
18 patchy fibrosis or scarring in the lung; a
19 little bit of bronchiolitis or small airways
20 abnormalities, that is inflammation around the
21 small airways. Surprisingly, they described
22 emphysematous changes -- that is loss of
23 alveoli -- in all of the patients. And also
24 uniformly they identified intracellular
25 birefringing particles under polarized light

1 microscopy.

2 So here is one of these patients, and what you

3 can see is the CAT scan on the upper left.

4 Panel A is the -- is a high reso-- cut through

5 a high resolution CAT scan. It's basically

6 pretty normal. Panel B is an expiratory film

7 in what you can see is some areas which are

8 dark. That's air trapping; in other words, the

9 air is not being cleared out of the lung.

10 Panel C is one of the biopsies in which you can

11 see there is -- it looks a little lacier than

12 it should be, but then there's some little

13 areas of blue which are areas of inflammation.

14 Panel C (sic), there's an arrow pointing to

15 something that's a little difficult to see, but

16 it's a particle within a cell. And if you look

17 in Panel E, there's something that glows out,

18 and that's the particle that's in the cell.

19 Now most things don't glow. Certain things do

20 glow, and what we did do is send this to be

21 analyzed by scanning electron microscopy, and

22 what was -- been described in these patients is

23 that in the patients there is silica, aluminum

24 silicates, titanium, talc, and a variety of

25 metals which are unusual in human beings,

1 including steel, copper and chromium.

2 So that suggested to us again evidence that
3 these were in fact inhalational injuries that
4 could most likely be due to World Trade Center
5 exposures.

6 And what we also know now is that what we are
7 seeing is a diversity of respiratory illnesses
8 that include upper airway, include nasal,
9 sinus, cough, irritant asthma is what we call
10 the asthma now, airway damage including
11 bronchiectasis, sarcoidosis as you heard, and a
12 variety of interstitial lung diseases in a
13 small population, and that these depend on the
14 dose and clearly individuals' susceptibility
15 that we don't understand in these populations
16 because we know that not everybody is
17 susceptible to all of these.

18 Finally -- two other things -- finally, one of
19 the things we have been doing is looking
20 longitudinally at our population at lung
21 function. And surprisingly, what we have in
22 our early data that we had submitted is that in
23 fact overall what we are seeing in a population
24 sent to us for treatment is that there is
25 improvement in lung function in this group as a

1 whole; that the improvement differs depending
2 on the entering pattern of lung function --
3 that is, whether they started out normal and in
4 fact they get better, even more normal, which
5 suggests that the normal was a statistical
6 normal; that the low vital capacity group
7 improves; that the obstructive group improves
8 their obstruction; and the group who have both
9 obstruction and restriction in fact improve.
10 So that's very helpful to us.
11 Except as you see here, very quickly, if you
12 look at the group as a percent of predicted
13 where they should be, shown in the red bar, the
14 white is their initial, the shaded are their
15 follow-up, what you can see is that the normals
16 are normal, they get a little better, they stay
17 normal. The low vital capacity improves but
18 does not reach normal. The obstructed -- they
19 improve their forced vital capacity on the
20 left, that's their volumes, but they don't
21 improve their flow to normal. And the low
22 vital capacity again improve. The low vital
23 capacity obstructed group improve, but don't
24 improve to normal.
25 So what we are saying here is that although we

1 are seeing improvement in those who started
2 with abnormal patterns, they are not reaching
3 back to normal over time.

4 One other thing -- we looked at this, again
5 looking at longitudinal lung function, now
6 grouping our population as a potential exposure
7 category -- resident, local worker,
8 rescue/recovery, cleanup. And what you can see
9 in yellow is that surprisingly, although the
10 local workers improved their forced vital
11 capacity a little bit, it didn't reach
12 significance, and they didn't improve their
13 flow to an extent that reached significance --
14 suggesting that there's something about the
15 local worker population that's a little bit
16 different, that they're not responding as well,
17 and we don't really understand why that is.
18 We have also -- because our patients were
19 enrolled for physical conditions, not for
20 mental health, but underwent mental health
21 screening, again using the PCL, we looked at
22 who's at risk for probable PTSD in these
23 patients. And several things came out that
24 were interesting. One that, because we had
25 such a large population of women, that women

1 were at higher risk. Low income clearly puts
2 someone at risk, as shown in red. And also
3 shown in red being in a dust cloud puts someone
4 at risk. And having respiratory symptoms, both
5 upper and lower, puts someone at risk. And we
6 use a dyspnea score, which is a score of degree
7 of shortness of breath. And the greater the
8 dyspnea score someone had also puts someone at
9 risk for having potential PTSD.

10 Finally, you've heard a lot about children, and
11 we have a pediatric program which we have had a
12 lot of difficulty recruiting children into, for
13 a number of reasons that -- some of which are
14 known, some of which are unknown to us. What
15 I'm showing here is data I should not be
16 presenting because it's very, very, very, very,
17 very preliminary, but just because it's
18 interesting. But if we look at our first 80-
19 some-odd children in whom we have full data,
20 because our datasets are not closed yet, then
21 in fact we see a lot of -- a lot of girls. We
22 see a diverse race ethnicity, again with a 20-
23 some-odd percent Hispanic population. We see
24 that almost 40 percent of these children were
25 caught in the dust cloud; that about 20 percent

1 say they had a heavy volume of dust in their
2 clothing or hair. Many of them had dust in
3 their home, and 60 percent of them were in
4 school in southern Manhattan on 9/11,
5 suggesting that in fact this may -- this is an
6 important group to start looking at. These are
7 -- anyone who was 18 or younger on 9/11.
8 If we start looking at lung function -- and
9 again, lung function -- we have to use
10 different parameters for kids -- that in a
11 population who came to us, about 20 percent
12 said they had a new asthma diagnosis. The mean
13 latency was at -- of that was about three
14 years. And that if you just look very simply,
15 what's -- as a simple exposure -- again, dust
16 cloud, 'cause it's the simplest exposure
17 measurement you can do -- then in fact dust
18 cloud was a risk for an abnormal ratio of FEV-1
19 to FVC, that is flow, and also for an
20 obstructive pattern, suggesting again that we
21 need to look at these children much more
22 carefully; that there are issues that we
23 haven't teased out in them.
24 There are many, many unanswered questions in
25 the survivor population. There are a huge

1 number of medical questions. I didn't even
2 touch on cancer risk because our population is
3 a self-referred population. We can describe
4 what we're seeing. We can't give rates for
5 population rates. There are lots of questions
6 still in terms of the lung disease, what's the
7 long-term progression, what are the types, how
8 should we be treating these diseases, are there
9 autoimmune or connective tissue disorders, are
10 there neurological sequelae including
11 headaches, peripheral neuropathies; who's
12 vulnerable, who's not vulnerable, what are the
13 populations that are at risk? We don't know
14 the answer to those. Huge number of mental
15 health questions -- who's at risk for
16 persistent PTSD, what are the long-term
17 outcomes of PTSD, how should we be treating
18 PTSD in civilian populations, particularly when
19 they're associated with complex mental health
20 issues, multiple comorbid conditions and huge
21 socioeconomic stresses, and is there a risk for
22 cognitive defects in people who have persistent
23 PTSD? And as you've heard, we have a huge
24 number of unanswered questions in the children
25 -- what are their lung risks, are they

1 developmental, are there endocrinologic risks,
2 and what are their mental health issues?
3 And I'm stopping there, and I thank you very
4 much.

FIRE DEPARTMENT OF NEW YORK

CLINICAL CENTER FOR EXCELLENCE

5
6 DR. WARD: Now we'll hear from Dr. Prezant.
7 DR. PREZANT: Thank you for inviting me here
8 today. I'm going to take a little different
9 tact in my presentation. I'm going to try to -
10 - of course the temptation is to give you an
11 overview of our program, and there are certain
12 things that I will touch on that are overview
13 in nature. But I'd like to concentrate on
14 providing you with three specific issues.
15 One, understanding the unique exposure and the
16 unique fact that our cohort is not self-
17 referred and therefore is the only cohort that
18 can do true incidence and prevalence analysis.
19 The next thing I'd like to concentrate on is
20 showing you how that exposure has impacted on
21 health outcomes, including cancer.
22 And then finally, I'd like to make some brief
23 comments about where I think future research
24 should go.
25 You've already heard about the immense dust

1 exposure and the tragedy on that day. The New
2 York City Fire Department has approximately
3 16,000 rescue workers and recovery workers that
4 were exposed to the dust. This 16,000 group is
5 comprised of New York City firefighters and
6 officers, New York City Fire Department EMS
7 workers and their officers, as well as selected
8 pre-9/11 retirees that came in to help us with
9 our rescue/recovery effort.

10 We've heard about the dust exposure, that the
11 dust cloud is the largest exposure, and I'll
12 show you momentarily that we had 1,600 -- ten
13 percent to 15 percent of this workforce -- that
14 was there during the dust cloud.

15 We've heard that the dust is alkaline in
16 nature, and that much larger particles than
17 would be expected by physical science research
18 actually penetrated into the lower airways.

19 And important when we think about biologic
20 plausibility, that there was asbestos, silica,
21 fibrous glass, volatile organic carbons, PCBs,
22 dioxins, et cetera, that have all been shown to
23 be components of this dust.

24 Now if everybody was in the space suit that
25 someone else referred to earlier today, there

1 would have been no respiratory exposures, and
2 probably no systemic exposures. But as shown,
3 that was not the case.

4 Firefighters had the best respirator on the
5 planet Earth, a self-contained breathing
6 apparatus. However, it lasts for only
7 approximately 15 minutes. Thereafter, normally
8 in a fire we bring either new firefighters in
9 or, rarely, we bring new bottles in to the
10 firefighters that are there. Given the fact
11 that this was an attack on New York City, we
12 were unable to do that. And then we were
13 unable to get them P-100 respirators for
14 approximately a week or more. And after that,
15 the nature of this work is so hazardous that
16 these type of P-100 respirators that you see
17 here really are not conducive to communication,
18 they're not conducive to comfort, they're not
19 conducive to outdoor rescue/recovery work, all
20 right, in difficult conditions.

21 We know that large particles did get down into
22 the lower airways. We have many collaborative
23 studies going on at the fire department. One
24 of them is with NYU. And here was a
25 firefighter who developed acute respiratory

1 distress after having worked down at the World
2 Trade Center site for 20 of the first 27 days,
3 and became severely hypoxic, was taken to the
4 emergency room at Bellevue, was intubated and
5 was bronchoscopically lavaged. And as we
6 published with NYU, there were uncoated
7 asbestos fibers, degraded fibrous glass, and
8 fly ash particles, which are large elements of
9 pulverized concrete, down in the lower airways
10 and alveoli. This is stuff that normally, in a
11 low-density exposure, would be confined to the
12 nostrils and sinuses. But in this type of
13 exposure overwhelmed our normal respiratory
14 protective mechanisms and penetrated down
15 below. This is an isolated firefighter who was
16 extremely ill, all right.

17 However, we found the same thing, or similar
18 issues, on ambulatory, mildly symptomatic
19 firefighters which we published with an Israeli
20 collaboration in 2004. These are 39
21 firefighters who had induced sputum -- they did
22 not get lavaged, they did not require
23 intubation, they were walking, healthy
24 firefighters. They had their sputum induced.
25 They coughed up this sputum. It was analyzed

1 for dust particles, and in their dust particles
2 were very similar to World Trade Center dust,
3 and there was an exposure gradient -- which
4 I'll get to in a moment. Every one of our
5 studies, with rare exceptions, has demonstrated
6 an exposure gradient based on arrival time.
7 Understanding that there was dramatic
8 exposures, that there was symptoms occurring
9 from day one that were unusual for any type of
10 a fire, we started the first long-term medical
11 monitoring and treatment program, starting
12 monitoring on October 5th of 2001.

13 (telephonic/electronic interference) ...our
14 previous disasters, and we also knew that our
15 cohort, our patients, our members would be
16 asking repeatedly about late-emerging diseases.
17 And therefore we immediately set up to take in
18 information about things like cancer and
19 autoimmune diseases.

20 Typically in an environmental disaster -- I'm
21 sorry let me restart that.

22 Typically in an occupational exposure we count
23 the number of days exposed as an occupational
24 worker. We're able to say you were in a
25 particular area of the factory or the

1 sandblasting area or the quarry, and therefore
2 your exposure -- as long as you weren't wearing
3 respiratory protection -- was the same each one
4 of these days. Count up the days, count up the
5 hours, and you're able to get a very nice
6 exposure gradient that really is based on
7 duration. And if you have specific air
8 contaminant information, you can even express
9 it more than just hours, days, years. You can
10 even express it on the basis of the number of
11 particles or the amount of that chemical or
12 asbestos fiber that has been inhaled over time.
13 That is not the case in an environmental
14 disaster. If we were still looking for
15 modeling data based on the various different
16 amounts of chemicals and dust that were out
17 there and what the air quality demonstrated day
18 one, day five, day 15, people are in different
19 areas, some are crawling into crevices, most of
20 our firefighters were in fact crawling into
21 crevices -- they're being exposed to air that
22 was really more typical of day one. So any
23 type of complicated modeling will never answer
24 an exposure response gradient for this
25 workforce.

1 Rather, we found that initial arrival time is
2 the best exposure response gradient. Day one
3 in the morning, you're exposed to the dust
4 cloud and the collapse. And from a mental
5 health perspective, you're also exposed to the
6 most severe, life-threatening conditions, as
7 well as the loss of your coworkers. On
8 subsequent days -- day one, day two and the
9 beginning of day three -- there's still immense
10 dust cloud exposures to everyone, no matter
11 what they're doing.

12 The night of day three there were rains, but
13 that does not eliminate the dust exposure. The
14 dust exposure persisted for all the reasons
15 that you were -- that you heard about earlier
16 this morning, including persistent fires. But
17 for firefighters and certain other workers,
18 even day three, day 14, day 20, they're
19 actually crawling into crevices and having
20 exposures that might be similar to day one,
21 though in a much more isolated fashion.

22 Therefore, we found that doing this type of
23 gradient -- day one, day two, day three through
24 14, and after day 14 -- was our best predictor
25 of disease, and our best predictor of both

1 physical health and mental health disease.

2 Duration is a mild predictor, and most of our
3 workforce -- the median amount of months that
4 our workforce spent down there was four months.
5 And we do have, for some of our outcomes,
6 duration being a useful predictor. Because all
7 of our workers were down there -- you can see
8 from this graph, way over 80 percent of our
9 workforce was down there in the first week, we
10 are not able to do exposure gradients based on
11 the use, or lack of use, of a respirator
12 because they did not have a respirator in that
13 first week.

14 This will take too much time to go through, but
15 I just want to mention to you that we have a
16 variety of medical questionnaires that we
17 update. Our questionnaires have been used by
18 the other groups as well, as we have benefited
19 from their questionnaires. These are both
20 mental health and physical health
21 questionnaires that utilize the same PCL-17,
22 depression scores, et cetera. We do spirometry
23 and many of the other tests. And then these
24 move on to treatment referrals as needed.
25 All of this data is processed and is available

1 for analysis, and has been the basis of every
2 sentinel study produced after the World Trade
3 Center exposure via collaborations with Albert
4 Einstein College of Medicine, Montefiore
5 Medical Center, NYU, and to a lesser extent,
6 Robert Wood Johnson. This is a critical thing
7 that we are able to analyze this data. Why?
8 Because arguably we were the most exposed
9 workforce. But very clearly, we're the only
10 workforce that knows the denominator of those
11 people that were exposed. We have pre-9/11
12 data on every one of our workers, so we can
13 have an objective comparison. We know the
14 exact number of people that were down there so
15 that we can -- this is not a self-selected
16 group. And by analyzing this data, internally
17 and with outside collaborators, we are able to
18 provide analyses and information in a very
19 rapid approach and then seek corroboration
20 through the other data Centers of Excellence.
21 But it is also important because our individual
22 members, when they come in they ask two
23 questions, repeatedly. And that's why this
24 data is useful on a micro level as well as a
25 macro level. Our members come into our program

1 because they know they can get outstanding
2 medical care. The first question they ask,
3 'cause they're humans, 'How am I doing?' The
4 second question they ask is 'How are my buddies
5 doing?' And because of that we've been able to
6 work with their representatives, the various
7 different unions, to make it clear that
8 research is not a four-letter word. Rather, it
9 is the only way that we can provide people with
10 credible answers, and then adapt our treatment
11 protocols to meet their needs.

12 And the proof of this is the fact that this is
13 the most successful labor-management health and
14 safety initiative ever. We have provided
15 15,375 baseline medicals to a little less than
16 16,000 people that were exposed. This is over
17 98 percent compliance. We have over 95 percent
18 compliance with our second exam, over 90
19 percent compliance with our third exam. We
20 have already over 82 percent compliance with
21 our fourth exam, and that was just started in
22 2008. Give us another year and that will be
23 above 90 percent as well. Longitudinal dropout
24 is minimal in this workgroup, and we achieve
25 this without spending one dime on health care

1 advertisement. This has allowed us to be the
2 sentinel group for first demonstrating the
3 World Trade Center cough syndrome in September
4 2002, and demonstrating the exposure response
5 gradient that I've already discussed based on
6 arrival time; that the World Trade Center cough
7 syndrome is obstructive airways disease,
8 chronic bronchitis and asthma, along with
9 sinusitis and GERD.

10 We've published on several occasions both
11 cross-sectional and longitudinal analysis of
12 how their symptoms have gone over time. They
13 started with cough and sore throat as their
14 main symptom, and as you can see, those are the
15 -- at around 60 percent on year one. If we had
16 looked at this on week one, they would have
17 been over 95 percent.

18 By year eight, and this is true even in year
19 ten, the cough and sore throat have dropped
20 down to less than 20 percent. But the other
21 symptoms -- dyspnea, wheeze, sinusitis and GERD
22 -- remain in the 35 to 45 percent range.

23 We looked at lung function because we have pre-
24 9/11 lung function when we were able to
25 demonstrate very rapidly that there was a

1 tremendous drop in lung function in the first
2 six to 12 months. We then followed that up
3 with a seven-year study, began demonstrating
4 minimal longitudinal dropout, with the median
5 length of time being over six years in both our
6 firefighters, our EMS people. And even if we
7 break this down by active and retirees, we see
8 the same thing. In total we analyzed nearly
9 62,000 spirometries. This was done in
10 collaboration with Montefiore Medical Center
11 and Albert Einstein College of Medicine, and
12 there were -- and there were over 2,000 people
13 in this group that were present during the
14 early arrival time of this 13,000 people that
15 were studied.

16 Here's our findings. The dotted lines
17 represent extrapolated values for this group
18 over time. They don't come from the published
19 literature but rather from the pre-9/11 data
20 themselves in this group. They were dropping
21 at approximately 30 milliliters per year, which
22 is normal for a male population. Those are the
23 dotted lines. The blue line is what actually
24 happened in our firefighters after 9/11 over
25 the next seven years. There was an initial

1 drop of approximately 350 milliliters, and that
2 drop demonstrated an arrival response time
3 gradient, which I'll show you in the next
4 slide. Thereafter, as a majority, they did not
5 recover. Their lung function remained
6 persistently low, without recovery. This is in
7 contrast to what you'd see if there were normal
8 smoke inhalation, which we have over 30 years'
9 experience dealing with, and typically within
10 two months lung function returns to the dotted
11 line after normal smoke inhalation.

12 We see the same in the red line, which is our
13 EMS workers. It starts lower because they have
14 a lower health requirement for joining the
15 workforce, and it starts lower because there
16 are more females. In our firefighter workforce
17 it's about 96 percent male. In our EMS
18 workforce it's about 60 percent male. The red
19 line, though, despite the fact that this is
20 both males and females in EMS, despite the fact
21 that they have a little less exposure in terms
22 of their work tasks, demonstrates again a
23 dramatic decline in lung function -- a little
24 over 300 milliliters in the first six months --
25 and once again a persistent abnormality in that

1 decline in lung function.

2 People have said oh, this must be because
3 everybody's a cigarette smoker. The reality is
4 that in the New York City Fire Department there
5 are less cigarette smokers than there are in
6 New York City. New York City on 9/11 had over
7 20 percent of its population smoking. The fire
8 department had about 17 percent. And shortly
9 thereafter we initiated a very aggressive
10 tobacco cessation program, dropping tobacco to
11 about seven percent in the fire side, and this
12 was published in CHEST in 2004, the tobacco
13 cessation effort.

14 But here you can see the fact that tobacco is
15 not the major issue. The blue line this time
16 represents never smokers. The red line this
17 time represents ever smokers. You can see that
18 although at each time point lung function is
19 lower in the ever smokers, and that is a
20 statistically significant effect, in reality
21 the drop in lung function is predominantly in
22 nearly all due to World Trade Center dust, and
23 only minuscule impact of cigarette smoking.
24 You can see this because the red line is only
25 slightly lower than the blue line.

1 The exposure response gradient is demonstrated
2 in this group because if you look at that first
3 drop in lung function in the six to 12 months,
4 in this study averaging 372 milliliters, you
5 can see that there was the greatest lung
6 function in those people called here early,
7 which are people that were there in the morning
8 of 9/11, slightly less reduction in lung
9 function in those people who arrived in the
10 next day, and slightly less reduction in lung
11 function -- but still substantial -- in those
12 people that arrived for the first time at a
13 later time point.

14 Now this resulted in many people becoming ill.
15 This is not just a reduction in lung function,
16 as I can show you -- as I've showed you
17 already. There's a large amount of asthma,
18 sinusitis, GERD-like symptoms. And in your
19 main presentation, which I have had to excerpt
20 some of the slides and not show you, this is
21 also corroborated by diagnostic data, both
22 internally at FDNY and by self-reported
23 diagnostic data from their own physicians.
24 But we were very interested in looking at
25 whether these drops in lung functions and these

1 symptoms were due to obstructive airways
2 disease or due to restrictive airways disease.
3 Dr. Reibman presented some oscillometry data
4 demonstrating that it was obstructive airways
5 disease, for the most part, in her group. We
6 approached this in a slightly different area --
7 again collaborating with Einstein and NYU on
8 this issue. We looked at 1,720 people that
9 were referred for in-depth pulmonary function
10 testing. This would be bronchodilator
11 response, lung volumes, diffusion capacity.
12 And we found on the Y axis is the drop in lung
13 function after 9/11. If you are less than one,
14 you dropped lung function after 9/11. On the X
15 axis on Panel A is a bronchodilator response,
16 and this shows that the greater your drop in
17 lung function after 9/11, the more likely you
18 are to have a bronchodilator response; i.e.,
19 the more likely this is to be obstructive
20 airways disease rather than interstitial lung
21 disease. Likewise on Panel B, the greater your
22 drop in lung function, the more likely you are
23 to be hyper-inflated, to have big lungs. This
24 again is consistent with obstructive airways
25 disease rather than interstitial lung disease.

1 We looked at bronchodilator response correlated
2 with lung volumes, again demonstrating more
3 likely to be obstructive airways disease than
4 interstitial lung disease. We looked at chest
5 CAT scans, again demonstrating in nearly every
6 case that this was air trapping rather than
7 interstitial pulmonary fibrosis. And we looked
8 at methacholine challenge testing, again
9 suggesting obstructive airways disease more
10 likely than interstitial lung disease.

11 When we put all of these findings together in
12 that study we could find that there was some
13 evidence for obstructive airways disease in
14 about 60 percent of this group. Well, that
15 raises the point, the question, well, does that
16 mean that 40 percent had interstitial lung
17 disease, 'cause that is a substantial amount.
18 And that is not the case. For the 40 percent
19 we had no interstitial lung disease or
20 obstructive lung disease. Time will tell what
21 they have. In only 1.7 percent did we have
22 evidence for interstitial lung disease, so it
23 is very clear that interstitial lung disease is
24 incredibly rare after World Trade Center dust
25 exposure.

1 We do have a few cases of pulmonary fibrosis,
2 two of which have required lung
3 transplantation. We have 27 cases so far of
4 post-9/11 sarcoidosis, and we demonstrated that
5 sarcoidosis was the more likely disease that --
6 if you're looking at interstitial, though very
7 unusual. There was a blip of sarcoidosis in
8 the first year, and then a continued slight
9 increase, and this was published early on in
10 CHEST 2007. Sarcoidosis is slightly different
11 than we had in pre-9/11. Our rates are higher
12 than pre-9/11. Again, by having pre-9/11 data
13 we are able to show objectively change in
14 population rates for our cohort. But in
15 addition to the increased incidence, the
16 disease itself is presenting differently. It's
17 much more extrapulmonary, much more involving
18 rheumatologic problems, and that these problems
19 have required substantially different
20 medications. The vast majority of people pre-
21 9/11 did not require any medication for their
22 sarcoid. Post-9/11 31 percent have required
23 steroids, and nearly all of the rheumatologic
24 cases -- here it's shown as three bone cases,
25 but we now have almost ten cases. Almost all

1 of them have required either Methotrexate or
2 more expensive medications like Humira or
3 Enbrel.

4 The other groups have talked about post-
5 traumatic stress disorder. About 12 percent of
6 our workforce had probable PTSD in the first
7 year. About seven percent have it now on year
8 nine. However, what this slide shows is based
9 on arrival time. And what you can see in the
10 blue line at the top of your graph is the
11 incidence cross-sectionally of PTSD in those
12 who arrived in the morning during the collapse.
13 And here we have early on about 20 percent of
14 our group having PTSD and nine years later
15 about 12 percent. While in the other groups it
16 is far lower. In fact, this 20 to 24 percent
17 of PTSD in year one is almost as high as
18 survivors in other studies -- survivors of the
19 actual collapse or of other disasters, like in
20 Oklahoma.

21 This has resulted, both the lung and PTSD
22 issues, in over 1,700 retirees, 1,400 due to
23 lung/World Trade Center disability, for a
24 projected pension cost of \$826 million through
25 2008.

1 And this prompted both the large number of
2 respiratory problems, the mental health issues,
3 the exposure, the questions from our cohort --
4 'Will I be coming down with cancer?' -- has
5 prompted us to be the first to come out with
6 this early assessment of cancer outcomes in
7 firefighters. Our subsequent studies will
8 concentrate on EMS, but our first study
9 concentrated on our firefighters.

10 The study period was 1/1/96 to 12/30/2008, and
11 we started off requiring that everybody be
12 active on 1/1/96 so that we could have them all
13 be similar on that date -- active, not retired.
14 Because we would be comparing to U.S. data, we
15 concentrated on white, black and Hispanic
16 males. We required that they be working at
17 FDNY for more than 18 months, because if you've
18 only been there for a year it's likely that
19 you're a different type of person and also that
20 you've had very limited smoke exposure. And by
21 starting on 1/1/96 we had nearly everyone
22 exposed, but we had a small number of people
23 who were unexposed. We also required that they
24 be less than age 60 on 9/11 because even though
25 cancer is a disease of the elderly, we would

1 wind up with very few people above age 60 on
2 9/11 and therefore would not have good data for
3 comparison.

4 There's been a lot talked or mentioned about
5 matching. We have consent forms to match to
6 every registry. But unique to us is that we
7 have the Social Security number for our entire
8 workforce, and our IRB has allowed us to match
9 -- for the entire workforce, both pre- and
10 post-9/11 -- so that we are capable of matching
11 to people who were hired in 1980 and were never
12 at the World Trade Center because our IRB has -
13 - working with us, has appreciated our
14 demonstration that there would be no negative
15 impact to matching even without consent. And
16 the IRBs in the tumor registries that we have
17 matched to have agreed with that. So therefore
18 we are matching against our entire cohort, 100
19 percent Social Security numbers, 100 percent of
20 the cohort, whether they were there or not
21 there.

22 However, as also mentioned, with more and more
23 hematologic illnesses being diagnosed as
24 outpatients, these are not being reported to
25 tumor registries. If they're diagnosed as

1 outpatients in a hospital they are being. But
2 if they're diagnosed as outpatients in a
3 private office, although there are state
4 requirements that they be sent to the tumor
5 registry, they are frequently not. So we have
6 also endeavored to make certain that we can
7 supplement cases with those who are self-
8 reported, but only after confirmation with
9 pathologic data. And we keep these separate,
10 so when we compare to the U.S. SEER data, we're
11 only using those data from tumor registries so
12 that we're comparing like to like. But when we
13 compare exposed to non-exposed firefighters, we
14 use both tumor and self-reported cases. But
15 again, only self-reported cases that have
16 pathologic confirmation.

17 And we have these two comparison groups,
18 external to the U.S. population and internal
19 compared to unexposed firefighters. Our
20 internal comparisons will get better over time
21 because we will have more unexposed
22 firefighters over time as we supplement this
23 with -- with newer firefighters.

24 It's very important when you do these
25 comparisons to not only correct for age group,

1 gender and race, but to also correct for
2 calendar year, because this way you're able to
3 correct for both decreases and increases in
4 cancers that are occurring normally due to
5 other issues in the population. For example,
6 there's been a decrease in certain cancers, but
7 recently there have been reports both in the
8 U.S. and in the world of increases in thyroid,
9 prostate and melanoma cancers.

10 We look at observed cases divided by expected
11 cases, and we can also look at this as a ratio
12 found in the exposed to unexposed. This has
13 been quite controversial, but we've had
14 multiple inquiries about this and, after
15 discussing this, we always are able to come to
16 a conclusion that this, after answering
17 questions, is a reasonable statistical design.
18 One of the biggest issues with our data, and
19 with any data on cancer that will come from any
20 of the groups, is the impact of surveillance
21 bias on increasing the number of cancers that
22 we report. And this is a very reasonable
23 concern because our members are now in a
24 monitoring exam and therefore may -- we may
25 find more cancers than would be in the general

1 population. We may find even more cancers in
2 our unexposed group because our unexposed group
3 may not be as likely to participate in
4 monitoring, though we disagree with that and
5 because we have very good rates in our
6 unexposed group as well. But to address these
7 concerns we removed the -- we did one analysis
8 with all these cancers there, and then we did a
9 second analysis which we call the corrected
10 analysis where we removed any cancer that we
11 could have diagnosed in an asymptomatic worker
12 due to our monitoring exam. What we found here
13 is -- this was published in Lancet 9/3/2011 --
14 we found that in our exposed group, with 61,000
15 person-years, we had 263 cancers of all types,
16 and we would have expected in the general U.S.
17 population 238. This creates a ten percent
18 increase. But if we look at this as exposed
19 divided by unexposed, the increase is a 32
20 percent increase.

21 Now that's before correcting for surveillance
22 bias. If we correct for surveillance bias by
23 removing the cancers, if we remove the cancers
24 by just postponing their diagnosis two years,
25 essentially removing almost every one of those

1 cancers, we get -- instead of a 32 percent
2 increase, we get a 21 percent increase. And if
3 we removed every one of them we would get only
4 a 19 percent increase in the likelihood of
5 developing cancer.

6 Now we lose statistical significance when we do
7 that. You can see that the odds ratios drop
8 below one. And when we look at individual
9 sites we do not have statistical significance,
10 especially after we correct. But we have
11 trends that again argue, as talked about this
12 morning, for the possibility that there will be
13 an increased cancer signal in the blood-borne
14 cancers, the ones that you would have expected
15 to have occurred earlier. We believe that
16 after another year or two of additional data
17 these will rise to statistical significance
18 based on extrapolating what we currently have.
19 Now yes, some of these lose statistical
20 significance. I'm now back to talking about
21 all cancers, not just the individual sites.
22 Yes, when we adjust these analyses for
23 surveillance bias or for early versus late
24 diagnosis, it is absolutely true that some of
25 these point estimates lose statistical

1 significance. However, five of the eight
2 analyses still had statistical significance.
3 And every single one of them, as shown on this
4 figure, is to the right of an odds -- of a
5 points estimate of one point zero. And
6 statisticians, both our own as well as those on
7 the World Trade Center Cancer Expert Panel that
8 we convened, said that this was the most
9 important finding. Not whether a single
10 analysis has statistical significance, but
11 whether every one of your analyses has a point
12 estimate above the level one, and every one of
13 ours does.

14 We believe that this reflects the potential of
15 a biologic plausibility, though clearly more
16 study needs to be done studying additional
17 populations. We are already in progress with
18 nearly finishing our EMS population and
19 studying all of these groups for longer amounts
20 of time.

21 I again say to you that we need to be very
22 careful, especially in this area, in looking at
23 whether other centers are able to demonstrate
24 the same. It is easy for other centers to
25 demonstrate the same when it came to things

1 like obstructive airways disease, World Trade
2 Center cough syndrome, because the numbers are
3 so huge. In terms of cancers, the numbers are
4 small. This is not an epidemic. And therefore
5 knowing the entire population is critical in
6 obtaining excellent data.

7 Finally -- I'll close very rapidly, and I
8 appreciate your patience with me in addressing
9 the final issue I wanted to mention, is where
10 are we now in terms of research? The Zadroga
11 Act, as you know, has provided specific funding
12 for research. This increased funding will
13 allow us to do more than just case studies and
14 cross-sectional analyses. It was meant to
15 allow us to continue these analyses and to
16 continue our longitudinal analyses. It was
17 meant to stress collaboration that is already
18 ongoing, but to expand it further. It was
19 meant to add basic science studies, which we
20 could not do before, and fund those. And it
21 was to be all determined on the basis of peer
22 review.

23 The problems that require immediate solutions
24 may or may not be addressed by this. For
25 example, can disease surveillance or new

1 illnesses be done in this type of methods when
2 you don't yet know what the illnesses are? Can
3 time-critical research be done, even though it
4 has not yet been funded? And can peer review
5 be done effectively?

6 The problems with these issues do have
7 solutions. So can disease surveillance be
8 done, can time-critical research be done? I
9 believe it absolutely can be done, if we
10 continue to fund the data centers and the World
11 Trade Center Registry to do analytic work. The
12 data centers are in touch with the clinical
13 centers. They're in touch with the workers.
14 And they should be the ones that do the
15 analytic clinical and epidemiologic research
16 'cause they can do it most rapidly and most
17 efficiently.

18 This could be funded through specific research
19 awards through the data centers for trends
20 analyses and disease surveillance. It could
21 also be done through a project program grant
22 and awards that have been used in the past by
23 NIH to expand upon this proven research
24 process. All the information you're seeing has
25 been provided by the registry or these data

1 centers. We should be expanding on that
2 process, not abandoning it.

3 In addition, we could also use another process
4 called the Career Investigator Award to fund
5 both proven researchers as well as junior
6 researchers to continue in this effort. And we
7 should use isolated small awards, the RO1 award
8 process, only to look at mechanistic research,
9 to look at hypothesis-driven, mechanistic
10 research, and then when they find that, it
11 could be corroborated in a larger scale by the
12 data centers.

13 The awards need to be based on peer review.
14 But we have found that there's a potential
15 problem in the way peer review was done during
16 the BAA process which Dr. Howard talked about
17 briefly this morning in that there were eight
18 awards given. All of these awards are
19 certainly excellent awards and it is not my
20 duty to demon-- you know, to look backwards at
21 that. However, the process can be improved.
22 What happened was there was peer grading, but
23 the grades were not looked at in a study
24 section to then compare grades to normal those
25 -- normalize those grades for graders that

1 might have a more strenuous grading process
2 than others, and to prioritize it based on the
3 needs of the program or the program
4 administrator. Those things are typically done
5 using an NIH study section. They do not
6 require any budget, any large-scale budget
7 because it can be done by a conference call,
8 and is a critical part of any peer grading
9 process and should be added to this process at
10 the next available option. Peer grading should
11 continue, but a study section should be added.
12 On my last slide, just to summarize everything
13 into lessons learned, we now know that pre-
14 disaster health baselines, including pulmonary
15 function and mental health screening, should be
16 a requirement. We should protect workers by
17 training and educating them before the
18 disaster. There should be strict enforcement
19 of worker protection laws at a disaster site,
20 especially after the initial rescue effort.
21 All workers should be registered electronically
22 with electronic ID cards so that we know their
23 exposure, their times of exposures and their
24 durations. We should consider restricting
25 workers to minimum number of hours possible

1 during hazardous work environments. And we
2 should continue to integrate these programs to
3 have monitoring, treatment and research
4 together, and also in a collaborative fashion.

5 I thank you for your patience.

6 **STATE UNIVERSITY OF NEW YORK,**

7 **STONY BROOK CLINICAL CENTER OF EXCELLENCE**

8 DR. WARD: Next speaker is Dr. Luft.

9 DR. LUFT: We'll all take a deep breath -- a
10 lot of material, lot of data. I feel a little
11 bit at a loss where just at this point to
12 present what we do.

13 Let me introduce myself. My name is Ben Luft
14 of the -- director of the Long Island World
15 Trade Center Medical Monitoring Program. I'm
16 not an occupational medicine person. I'm
17 actually a molecular biologist who came to work
18 on the World Trade Center after 9/11. Actually
19 I spend most of my time in genetics and making
20 vaccines, some of which are in human trials in
21 Europe.

22 But after 9/11 we began to -- we saw the need
23 that there was -- that 9/11 occurred and as an
24 institution at Stony Brook we were preparing to
25 take care of the responders, people who had --
 actually survivors. We thought there would be

1 a great deal of people who would be coming out
2 to Stony Brook who were casualties, and
3 unfortunately there were very few and none came
4 out to Stony Brook.

5 Immediately thereafter what we did is we
6 decided to start a program to take care of the
7 responders. You know, we visited the World
8 Trade Center site. We saw the disaster there;
9 it was really quite dramatic. And our approach
10 at that time was that, being -- just from the
11 point of view of providing care is that we saw
12 that the actual toxicity there was really very
13 complex. It was a combination of both physical
14 -- I mean we've heard a tremendous amount about
15 the dust and the caustic nature of the odor and
16 the burning material, and I think that, in a
17 lot of ways, as scientists we can kind of grasp
18 that very quickly and that inhaling that will
19 cause a tremendous amount of injury.

20 But at the same time we knew that there was
21 going to be a tremendous amount of psychic
22 trauma, and that psychic trauma was, you know,
23 from this continuous danger that these people
24 were under, both to their life, their -- being
25 -- not only were they seeing their colleagues

1 killed, but they were be-- seeing them
2 dismembered. You know, they were finding body
3 parts and they were -- and this was not just
4 occurring over a very short period of time.
5 You know, usually when we think about being in
6 an event, it usually occurs -- you know, you're
7 in a car accident. It occurs in ten to 15
8 seconds and it's all over. Here people were
9 under continuous psychic trauma for a prolonged
10 period of time. And even as an internist, it
11 became evident to us that we were going to be
12 dealing with a very complex set of injuries.
13 And I think -- I wanted to emphasize that
14 because that's really how our program
15 developed, and a lot of the research that we've
16 been doing has evolved from that.
17 So if you look at the -- if you go to the first
18 slide, you look at the geography of what we
19 deal with. We're in Nassau and Suffolk
20 Counties. We're responsible for about 1,200
21 square miles of suburban area. We wanted to
22 set up two clinical centers, one in Nassau
23 County and the other in Suffolk County. And we
24 recently -- establishing a center in Brooklyn,
25 and these were Centers of Excellence that were

1 supposed to take care of both the medical and
2 the psychic injury.

3 We have a fairly large cohort size, around
4 6,000 patients, and we have an extraordinarily
5 high patient retention rate. About 84 percent
6 of our patients come back to us from year to
7 year. You know, that's basically our
8 monitoring program when we -- we have our
9 patients -- we have a very stable cohort that
10 we're able to study. And a very large
11 percentage of our patients take on treatment,
12 and I think that that's also a very important
13 thing. If you look at what our -- the number
14 of patients who come in for monitoring and the
15 percentage of their illnesses that we identify,
16 whether it's pulmonary or mental health or --
17 or gastrointestinal, that a very high
18 percentage of those patients accept care. So
19 we actually are almost -- it's almost
20 identical, you know, the ones -- cases we
21 identify, the same -- almost the same
22 percentage of patients go on to treatment,
23 which is very -- very important.

24 In our population we have two groups, of
25 course. We have the traditional responders,

1 and I think it's very important to realize
2 that. You know, when you hear about the fire
3 department or the police department, those are
4 very traditional type of responders, and about
5 50 percent of our patients are the non-
6 traditional responders. And when you look at
7 the disease rates among the traditional
8 responders and the non-traditional responders,
9 it can be very different. I think that that
10 really, you know, states the importance of what
11 was talked about when we talk about the
12 survivor program, the fire department and the
13 responders, that each of these groups have very
14 unique populations, and that the diseases may
15 be quite different from population to
16 population, how the disease actually manifests
17 itself.

18 And that was really very important to us 'cause
19 I'm talking to you as -- from the point of view
20 of a clinician, of a clinical scientist trying
21 to do research as to how diseases -- how
22 syndromes -- how patients are responding
23 syndromically.

24 You can see that if you look at it on a pie
25 chart of what the diseases are, it's very

1 similar to what you find amongst the different
2 populations in our treatment program. The
3 largest number of patients have upper airway,
4 that's in the blue, about 28 percent have upper
5 airway disease; 29 percent have lower airway;
6 and mental health disease we find in about 30
7 percent of patients.

8 Well, as I said to you initially, because we
9 began our program as a treatment program what
10 we began to do is we wanted -- and because we
11 had noted that these patients were exposed to a
12 very complex injury, we wanted to set up a
13 unique model for therapy. And the model that
14 we set up was a -- what we call a collaborative
15 care treatment model, which basically allowed
16 us to treat both the medical -- the mental
17 health and the medical disease concomitantly.
18 Actually our internists were initially trained
19 in some basic psychiatric -- and began to
20 perform certain psychiatric care, and they were
21 teamed up with a social worker who provided
22 care with both -- who are psychiatric social
23 workers. And so when the patients were seen,
24 they were seen by these -- this grou-- these
25 two individuals who were able to provide care

1 for both of these things concomitantly. And we
2 felt that this was an important way to be able
3 to treat these -- this particular patient
4 population, not really having a lot of data.
5 But this was our conviction, our -- we were
6 convinced that this was an appropriate way for
7 treating this particular disease syndrome.
8 And so what we were able to show was that by
9 doing this that this was cost-effective. When
10 we began to look at the cost per patient
11 actually it was quite reasonable and it was --
12 compared to other centers. It was
13 comprehensive. It decreased the obstacles to
14 care, the barriers to care. The patients were
15 much more accepting of mental health care, as
16 well as their physical health care. It
17 increased adherence to regimens, they would be
18 coming back often, you know, to being seen for
19 treatment. There was no stigma that was
20 associated with being treated by mental health
21 versus physical disease because basically you
22 were being treated in the same way. And I
23 think an important part was, like I said, it
24 really overcame a lot of barriers to treatment,
25 the personal barriers, personal prejudices,

1 providers lack of ability (sic). You know,
2 there was a question as to how many -- whether
3 you could get to a psychiatrist or a
4 psychologist. This allowed us to be able to
5 treat them very promptly. Various financial
6 barriers -- sometimes they wanted to keep, you
7 know, their mental health treatment secret. We
8 were able to take care of that. And geographic
9 barriers as well, they were able to come and do
10 really one -- one shop stopping -- one stop
11 shopping, as is familiar in the medical
12 parlance.

13 So this was really a very effective way of
14 being able to take care of these patients. And
15 I think that that was really what was
16 responsible for our high retention level and
17 our high, you know, adherence to treatment was
18 this particular model.

19 We really didn't have a scientific basis for
20 this, and so we began to do a study where we
21 wanted to really prove that this was really an
22 effective manner. And so we did a study which
23 I think -- which is going to be published
24 within the next month in Psychological
25 Medicine, and you have that -- the actual

1 manuscript attached to that. But we looked at
2 about 20,000 patient responders who were
3 followed in our World Trade Center medical
4 monitoring and treatment program, and we wanted
5 to see whether post-traumatic stress -- how
6 that was related to various medical conditions.
7 And for this particular paper what we did is we
8 only did it in response to respiratory disease.
9 So in this population we looked at 8,508 police
10 and 12,333 non-traditional responders who were
11 examined at the various World Trade Center
12 health programs. And what we were able to show
13 was that PTSD and respiratory symptoms were
14 correlated with one another, and that PTSD
15 statistically mediated the association of the
16 World Trade Center exposures with respiratory
17 symptoms.

18 I think this is a very important piece of
19 information. Although this was a study that
20 was only done cross-sectionally, it did
21 indicate, by using a variety of statistical
22 models, that PTSD itself, the psychological
23 condition, may actually mediate between
24 exposure and a physical manifestation of
25 disease.

1 Now this has, I think, very important
2 ramifications when you think about what the
3 compensation fund -- how they deal with mental
4 health -- actually mental health is really
5 pushed aside, but this may indicate that the
6 mental health condition plays a very important
7 or almost pivotal role as to how a physical
8 condition will manifest itself.
9 It also has -- very important in terms of
10 biological model. As I said before, my
11 interest is in molecular biology and genetics
12 and genomics. But there are some data that is
13 -- that exists currently that patients who have
14 PTSD, that they can have alterations in their
15 lymphocyte function and that perhaps those
16 inter-- and -- and actual infection disease
17 manifestations, actually -- and there was a
18 very nice paper that was published in the
19 proceedings of the National Academy of Science.
20 And so I think that this is an important piece
21 of information, that the link between PTSD and
22 respiratory symptoms is notable, it supports
23 our integrated medical and psychiatric
24 treatment of pa-- responders, and it con--
25 gives rise to being able to develop a

1 hypothesis to kind of look at the biological
2 linkage between the mental health and the
3 physical health. I think that this is an
4 important area that we -- we want to continue
5 to explore.

6 As I said, when we did this initial study we
7 did this as -- in a cross-sectional population,
8 and so there's a lot of provisos when you do
9 things cross-sectionally. It's much better to
10 do it longitudinally. It prob-- it real-- it
11 can nail down things. And so we actually
12 applied for one of the grants that was -- and
13 we actually were funded -- where we looked at
14 the burden of mental and physical morbidity.
15 And we worked with a psychiatr-- a psychiatric
16 epidemiologist, Evelyn Bromet, who has
17 extensive experience in disaster psychiatry and
18 mental health, and we're now currently doing
19 that.

20 And what we want to do now is we want to
21 identify the mechanisms responsible for the co-
22 morbidity. Psychiatrically we're going to be
23 looking for PTSD, anxiety, and depression, and
24 I think instead of being able to do the PCL,
25 which is a checklist and they're probable,

1 we're doing a SCID analysis on 5,000
2 responders.

3 But not only that, we're going to begin to look
4 at -- at other issues, such as quality of life.
5 This hasn't really been systematically
6 ascertained, because what our prejudice or what
7 our -- is that when patients have that
8 combination of a mental health disorder such as
9 PTSD and a physical disorder that they are much
10 less functional than a patient that has either
11 one of those things alone; and that it's not
12 just additive, but that this combination
13 actually has a synergistic impact in terms of
14 their quality of life and other indicators of
15 well-being.

16 So this is, as I said, part of this project
17 we're going to be looking at 5,000 responders.
18 We're going to be doing SCID analysis on each
19 of these responders. We're going to be looking
20 for various other parameters such as quality of
21 life parameters. And the other part of it is
22 we're going to continue to do our longitudinal
23 analysis looking at the second and third wave
24 data that has recently become available.
25 The other thing that we'd like to do is we'd

1 like to -- since we think that our site, you
2 know, had this collaborative model, it'll also
3 give us an opportunity to compare the outcomes
4 at our site at the Islandia site, which had
5 this partic-- our -- our particular strategy
6 for the care of patients with other sites that
7 had a different strategy, more traditional
8 strategies for care, and perhaps give us some
9 insight into how we should be taking care of
10 responders or individuals who are exposed to
11 these very complex set of mental health and
12 physical traumas.

13 The other aspect that we've become very
14 interested in has been looking at other types
15 of interventions. Now how do we -- you know,
16 one of the things that we've been very
17 interested in is that -- you know, we're now
18 ten years post to the event, and it's
19 remarkable the number of patients that are
20 still sick. You know, you would think that,
21 you know, they had this initial injury, it was
22 an environmental injury, it might have had some
23 impact on their lung function where they lost
24 300 milliliters of lung function and now it
25 seems to be leveling out. But there's a

1 tremendous amount of continued illness and poor
2 well-being. Patients continue to have a large
3 number of somatic and mental health complaints.
4 And so we want to look at various interventions
5 that we can do to be able to reverse that.
6 And one of the areas that we had noticed was
7 that patients who had PTSD, that they had a
8 higher incidence of smoking as well, and
9 perhaps respiratory disea-- and respiratory
10 problems as well. And so we wanted to -- we
11 developed an interventional study looking at
12 patients who have this combination of PTSD,
13 respiratory problems and smoking, and we
14 developed a program to -- an intensive program
15 for smoking cessation and seeing how that would
16 impact these various parameters; do they feel
17 better once you do that, do they improve in
18 terms of their mental health, do they improve
19 in terms of their quality of life and physical
20 functioning? And so we're going to be doing
21 this in a randomized clinical trial to look at
22 the effect of enhanced treatment versus
23 standard treatment on abstinence from tobacco.
24 So that -- you know, we feel that the
25 development of a powerful new intervention for

1 a difficult group of patients to treat may be a
2 way that we can really impact the quality of
3 life and the actual diseases in this patient
4 population.

5 Lastly, I wanted to mention another project
6 that we are doing at our site, and that's our
7 World Trade Center Oral History Project. This
8 is a project that we began about -- over two
9 years ago, maybe two to three years ago, I'm
10 not sure -- but we were featured on "60
11 Minutes" on 9/11; they did a half-hour program
12 on our oral history project. And the oral
13 history project was basically that, although
14 there was a tremendous amount of emphasis on
15 the physical and mental health issues that we
16 were dealing with in terms of the responders,
17 we felt that these -- it really didn't deal
18 with what was the impact of -- to them in terms
19 of their life, you know, and how they responded
20 in a very qualitative type of manner. You
21 know, what-- why they responded, what motivated
22 them, how they sustained themselves, what
23 sacrifices they made, how they were able to
24 overcome -- you know, where did they get their
25 sense of resilience. And we thought that that

1 was really a very important piece of
2 information, of qualitative information to --
3 for the responders.

4 Certainly it's not a scientific study in the
5 traditional terms, but certainly in a very
6 humanistic way, it is. And so we bas-- we've
7 now interviewed about 150 responders. We
8 document their perspective of the disaster. We
9 focus on their personal stories from their
10 perspective, the responder's perspective. We
11 highlight their motivations, their values,
12 their struggles, their resiliency. And we
13 expand our knowledge beyond the medical
14 effects. This has become a very important
15 resource, as I mentioned. You know, "60
16 Minutes" has utilized it, PBS had a documentary
17 of our program which also was shown on 9/11.
18 And it's been very useful in terms of
19 recruitment and retention, you know, among
20 patient populations. We've developed library
21 curriculums and educational programs for
22 schools. And the Library of Congress is now --
23 has agreed to provide us with a permanent home
24 for this project in their institution, to
25 maintain it in perpetuity, all of these

1 interviews, and we really -- we think it's
2 really going to be a very important piece of
3 information and also an important legacy to
4 this program as to who we took care of and why
5 we took care of it and why it was so important
6 to do so, and how we should do so in the
7 future.

8 So I've attached a copy -- I didn't want to go
9 into a tremendous amount of detail since I knew
10 that there was going to be a lot of data that
11 was there. I attached a copy of our manuscript
12 which goes into this mediational model, and I
13 think you'll find it very useful and
14 informative. But I do think that it's
15 important that we start to look at our data,
16 that we start to develop hypotheses and no
17 longer just deal with -- and then begin to test
18 it, you know, in an experimental manner.

19 And I think I'm going to end here since the
20 hour is late and I'm sure everyone's tired.

21 DR. WARD: Speakers back to the table for a
22 short period of questions or comments from the
23 panel -- yes, Steve -- oh, Valerie.

24 MS. DABAS: Hi, my question was for Mark
25 Farfel. You identified that a lot of the

1 cohorts that you identified in the monitoring
2 program with your -- came from employers. Were
3 you able to access the NYPD database for World
4 Trade Center responders?

5 DR. FARFEL: I don't have the exact number, two
6 or three thousand NYPD. Are you asking me how
7 we were able to outreach, at least through the
8 enrollment process?

9 MS. DABAS: On your fifth slide you had the
10 list of identified as 30 percent of enrollees
11 that you received the list and names from the
12 employers and their volunteer organization, and
13 I was wondering if NYPD was one of the ones
14 that you received?

15 DR. FARFEL: Oh, no, they -- I think the NYPD
16 are almost exclusively self-identified.

17 MS. DABAS: Okay.

18 DR. CONE: And from the roll call.

19 DR. FARFEL: Oh, that's Dr. Jim Cone from the
20 registry. Did everybody hear his answer? He
21 was saying that there was outreach through roll
22 calls at police stations.

23 MS. DABAS: I have a follow-up question to
24 that. The outreach through roll calls, once
25 those people came in, they were directly -- did

1 NYPD then provide a list, or was that once they
2 were -- the registry was announced at roll
3 call, those people then identified themselves?

4 DR. CONE: The people identified themselves
5 once they were approached individually or as a
6 group in the roll call. They also did the same
7 thing in the fire stations. We didn't receive
8 lists, but we did go to individual police
9 stations and attend roll calls to personally
10 recruit police officers. We signed up over
11 4,000. We also went to firehouses throughout
12 the city and did personal recruitment of the
13 firefighters.

14 MS. DABAS: Thank you.

15 DR. MARKOWITZ: My question's for Mark, and
16 also David. And I ask this as -- I'm not
17 authorized by this Committee to ask this, but -
18 - we haven't had a chance to discuss it yet,
19 but by March 2nd or thereabouts we need to
20 produce I think a recommendation guidance to
21 NIOSH about cancer. And Mark, we heard from
22 you that you hope by early January to have a
23 manuscript ready for submission, peer review;
24 and David, you're working on EMS and cancer.
25 My concern is that any manuscripts you might

1 have won't necessarily be ready by a March 2nd
2 date for us to review. So the question I have
3 is whether, when you complete your analyses and
4 they're ready for submission, whether you'd be
5 willing and able to share those with us so
6 that, if NIOSH -- if it's in accordance with
7 what NIOSH wishes, we can look at those data
8 and consider those in our recommendation to
9 NIOSH. I understand under the Act, NIOSH can
10 only use peer-reviewed publications.

11 Nonetheless, it's not clear whether we're -- we
12 have that similar restriction or not.

13 DR. FARFEL: First I just wanted to say we're
14 working as hard as possible to have something
15 submitted as early as possible in 2012, and so
16 there actually is a potential trajectory, given
17 the importance of this topic, that we may
18 actually have a manuscript that's in press or
19 been accepted by the March date that you gave.
20 And so I think -- let's -- let's cross that
21 bridge when we come to it and see what the
22 trajectory is, and we can certainly update the
23 Committee and NIOSH on the progress on that
24 submission. I think it's important, though, to
25 have the peer review aspect to the findings,

1 and that's certainly something that -- that's
2 been the case of every registry publication.
3 So I think let's just recognize that there is a
4 trajectory that may work; and if not, then we
5 need to communicate about the timelines that we
6 are on.

7 DR. PREZANT: I have to defer of course to Dr.
8 Farfel on what the registry can do, but I find
9 it impossible that the registry, or anyone
10 else, will be able to get you anything within
11 your timeline. I know the work it has taken us
12 to get the firefighter study to be completed.
13 We will show the same level of attention and
14 caution in doing the EMS data. I also know
15 that this month is November and therefore,
16 knowing both the analytic process as well as
17 the process that goes on at the Department of
18 Health, it is impossible for you to see any of
19 our studies by March. I mean I -- I just find
20 that to be an expectation that would be setting
21 you up for failure.

22 DR. ROM: I'd like to address a question to
23 David. For making cancer and respiratory
24 health effects assessments, I think it'd really
25 be important to know what's happening to the

1 1,700 folks who get disability retirements,
2 whether you're able to follow them up for both
3 of these diseases and examine them and what
4 have you.

5 DR. PREZANT: Our data includes the 1,700 that
6 have been retired. Our data, when we publish,
7 if you look at any of our publications, you
8 know, after 2004, have always demonstrated both
9 cross-sectional and longitudinal data. The
10 longitudinal data of course always has less
11 people in it than the cross-sectional data.
12 Cross-sectional data can be the entire cohort.
13 The longitudinal data suffers because people
14 have had to come for multiple, specific time
15 points in the exam, but we have not lost the
16 1,700 that have retired with disability. In
17 fact, they are very much in our cohort and they
18 -- and even -- and here's the point that I was
19 trying to make: For future respiratory
20 studies, mental health studies, et cetera, we
21 have to keep them, and we are. But for cancer
22 or mortality studies we only have to keep them
23 in terms of getting data that supplements the
24 registry's because we match with 100 percent of
25 our cohort.

1 DR. MARKOWITZ: The Chair has permitted me to
2 ask a short question, so maybe you could
3 produce a short answer. This is for David and
4 Joan. Do you believe that persistent
5 inflammation underlies the permanent reduction
6 in pulmonary function that you've seen? I
7 raise that because Bill and Micki this morning
8 made a strong plea on biological plausibility
9 in consideration of outcomes, and so I'm
10 heading in that direction.

11 DR. REIBMAN: I think we know very little about
12 the biology of what's going on in these lung
13 diseases. I think that -- let me back up a
14 little bit. And first I want to second
15 something that David said about research in
16 that I think the intent of the BAAs and the
17 research in the Zadroga Act was to allow us to
18 enhance our understanding and in fact ask
19 questions just like you're asking, which is
20 what are the underlying mechanisms, is there
21 ongoing inflammation, should we be treating and
22 pushing anti-inflammatory treatments in these
23 patients or is that futile. And I don't think
24 we know the answer to those.

25 I think that the other, analytic questions I

1 think that are equally -- or not equally, but
2 are also important, such as the continuing
3 analyses, longitudinal analyses, et cetera,
4 should be ongoing even without the support of
5 the BAAs.

6 So to get back to your question, which is do I
7 think that there is ongoing inflammation, I
8 think the interesting thing, for example, in
9 the biopsies show that there's in fact very
10 little inflammation that we can see. And in
11 fact, if you look at the airways themselves,
12 they don't look like asthma airways. They
13 don't have the mucous hyperplasia. They don't
14 have basement membrane thickening. They don't
15 have what's classically seen in asthma, and the
16 inflammation may not -- is not the same. But
17 that's that subgroup.

18 So what about the others who have the asthma-
19 like syndrome? And I don't think we can answer
20 that. I think we're starting to get some of
21 the biologic background on them, but I don't
22 think that's clear.

23 I think the other way to answer that would have
24 been a clinical intervention, but we don't have
25 that either.

1 DR. PREZANT: So to me, this is the value of
2 having a study section that's looking at the
3 various different grants that are submitted,
4 because one of the highest priorities should be
5 whether chronic inflammation is ongoing. We at
6 the fire department, in collaboration with NYU,
7 have now had accepted for publication three
8 papers looking at mediators of inflammation.
9 One actually was with Einstein Montefiore
10 that's already been published on alpha-1 anti-
11 trypsin. Another two were with NYU looking at
12 inflammatory biomarkers and then another one
13 looking at metabolic syndrome biomarkers. And
14 these are all preliminary studies 'cause
15 they're done on small numbers of patients, and
16 they also are done with blood that's drawn
17 within the first year and not years later. But
18 clearly those studies demonstrate that there is
19 an inflammatory mechanism, at least to the
20 initiation of this process, or to the
21 persistence of this process one year later.
22 In addition, in the study that I did show you
23 on particulates in induced sputum, we saw a
24 very big increase in MMP9, another mediator of
25 lung disease. So I think by having

1 prioritizations both in terms of the RFPs, the
2 BAAs, the award announcements, but also in
3 terms of the study section itself, hopefully
4 these additional studies can move forward.

5 DR. WARD: We should probably brea-- did you
6 want to make a response to that question or --
7 no. Okay.

8 I think we should probably break for lunch. As
9 you know, we are behind schedule so we're only
10 going to take 45 minutes and -- so what time
11 will we see everyone back? We'll see everyone
12 back at 1:50. Thank you all for your great
13 presentations.

14 (Recess taken from 1:05 p.m. to 2:08 p.m.)

15 DR. WARD: Let's begin the afternoon
16 proceedings. I would like to ask the speakers
17 to try to limit their presentations to 15
18 minutes. We won't cut you off at 15 minutes,
19 but we will give you a warning that it's
20 reached 15 minutes so that you can draw your
21 presentation to a close. And we'll get started
22 with Dr. Crowley.

23 DR. MIDDENDORF: Ms. Hughes has returned.

MOUNT SINAI SCHOOL OF MEDICINE

24 **CLINICAL CENTER FOR EXCELLENCE**

25 DR. CROWLEY: Good afternoon. So I'm going to

1 be speaking on behalf of the World Trade Center
2 Health Program at Mt. Sinai. Dr. Michael Crane
3 was going to be here today but unfortunately he
4 had a previous engagement at -- in Japan, so
5 I'll do my best to cover.

6 (Pause for technical problems)

7 THE COURT REPORTER: If you could start over,
8 I'd appreciate it -- so I can get her name.

9 DR. WARD: Yeah, but we are still getting a
10 pretty big hum up here.

11 THE COURT REPORTER: Still?

12 DR. WARD: Okay. Yeah. So we're ready to
13 start over, and if you wouldn't mind giving
14 your name again --

15 DR. CROWLEY: No problem.

16 DR. WARD: -- and start from the very
17 beginning.

18 DR. CROWLEY: Okay. My name is Laura Crowley
19 and I'm from Mt. Sinai. I work with both the
20 data coordination center and the clinical
21 center, and I'm going to do my best to describe
22 the World Trade Center Health Program. Dr.
23 Michael Crane could not be here today.
24 I don't see it moving forward, unless I'm doing
25 something wrong -- thank you.

1 Okay. So just as a basic introduction, it's
2 always good to review the exposures. I know
3 everyone's seen this list umpteen times, but I
4 feel like it's important to (inaudible) -- I
5 think I keep coming in and out so I apologize;
6 I'm not sure why.

7 So people have sustained a variety of exposures
8 -- smoke, dust, particulate matter, a variety
9 of toxins, asbestos, concrete, glass fibers,
10 polycyclic aromatic hydrocarbons and
11 polychlorinated furans and dioxins, to name a
12 few. I think it's important to reiterate this
13 list because a lot of what this expo-- this
14 exposure drives what we're facing today. And
15 the common effects to date that we know of are
16 respiratory and mental health consequences.
17 However, we're here today to also investigate
18 the long-term consequences and exposures of
19 late-emerging diseases.

20 Okay, so I'll do my best -- I'll talk really
21 loud.

22 Okay, so the population -- they're divided into
23 two categories, the traditional responders and
24 the non-traditional responders. We heard from
25 Dr. Prezant this morning about the traditional

1 responders, being the firefighters and
2 paramedics. We're going to speak about the
3 cohort that involves non-traditional, along
4 with law enforcement officers.

5 The non-traditional responders included
6 construction workers, the laborers, the
7 telecommunication workers, gas and electric
8 workers, transit workers, public sector workers
9 and volunteers.

10 Just a slide to describe our program. We've
11 been deemed the Clinical Centers of Excellence.
12 We have six centers and a data center. Our job
13 is to provide comprehensive clinical periodic
14 monitoring exams for all eligible responders,
15 and treatment for those with any World Trade
16 Center-related conditions. We're also tasked
17 with the job of disseminating information about
18 World Trade Center health effects to our
19 responders, the public, and all health care
20 providers. And we do this by collecting
21 standardized clinical information to identify
22 any physical and mental health consequences.
23 In addition to that, we analyze that data and
24 conduct a disease surveillance in our data
25 center.

1 The cohort -- this number's dated -- outdated,
2 but it's over 28,000, with the majority of
3 those being male at 86 percent. The median age
4 tends to be about 38, with 57 percent whites,
5 11 percent black, one percent Asian, three
6 percent other. We do have a population that's
7 unknown, depending upon if the person answers
8 the question or not, and 31 percent Hispanic;
9 83 percent are in a union. And the work
10 status, about 81 percent are employees, 11
11 percent are volunteer, and eight percent both.
12 Here's just a bar graph of the description of
13 the cohort in terms of occupation, and at the
14 bottom you can see that a majority of our
15 responders did come from the protective
16 services, or military, with it being over
17 12,000; and construction, almost 6,000; we had
18 1,700 in electrical or telecommunication;
19 transportation was 1,000; 4,000 in other
20 occupations; and about a handful, 477, in
21 unemployed or retired.

22 This slide's a little busy, but I think it's
23 helpful. It's helpful when you look at it on
24 the paper that you have in front of you.

25 Basically it trends the visits in numbers over

1 the years, and the really pretty key number is
2 the bottom number that shows that there's been
3 about 78,000 total screening and monitoring
4 program exams since the beginning of the
5 program, which is pretty amazing.

6 Publications -- I have about 19 slides' worth
7 of publications. I'm on a time limit so I'm
8 going to move as quickly as possible and not go
9 into the details for each publication. This
10 was published in the American Journal of
11 Industrial Medicine. It reviewed the health
12 effects of the World Trade Center site workers
13 and the lessons learned. This -- it was
14 published by Dr. Levin and colleagues. And
15 just a note -- I'm going to hit the highlights
16 of the science to date. There's many other
17 published articles out there which many of my
18 colleagues sitting around me have worked on
19 today, and I'll start with this one. But this
20 one really highlighted the importance of
21 advising our colleagues in the health care
22 profession to advise our health care
23 professionals of the importance of seeing
24 patients that had been exposed and how to
25 evaluate them clinically; how we were going to

1 capture all of those folks who were exposed;
2 whether or not there was going to be a
3 registry; how we were going to distribute
4 respiratory protection; that we needed rapid
5 mobilization of health care services; and make
6 sure we communicate effectively with our public
7 health agency regarding exposure hazards.

8 Another paper published in 2004 in the MMWR
9 reported a similar message about the importance
10 of provision of medical care for responders and
11 respiratory protection.

12 2004, Dr. Landrigan and Dr. Leroy published on
13 the health and environmental consequences of
14 the World Trade Center disaster with the
15 purpose being to examine the dust elements, and
16 found that it contained much of what I spoke
17 about in the beginning of the presentation.
18 And the pH of the dust was highly alkaline,
19 which attributes to much of the damage that is
20 seen in many of our responders to date. This
21 particular study looked at firefighters,
22 cleanup, community, pregnant women, and the
23 health effects in those populations and found
24 that they were seeing a high level of bronchial
25 hyper-reactivity, persisting cough, and

1 elevations in the level of -- you know,
2 frequently many of their patients were
3 reporting asthma as well.

4 In 2006 Dr. Herbert, Dr. Moline and Dr.
5 Landrigan and Dr. Levin reported on a five-year
6 assessment of our program, and they looked at
7 over 9,000 patients and found that exposure was
8 definitely related to an increase in
9 respiratory and pulmonary symptoms, and this
10 persisted -- at the time persisted up to two
11 and a half years after the attack, and we know
12 that it's persisted much longer because we're
13 all sitting around this table today.

14 This was a paper -- small study -- published in
15 JOEM in 2007, looked at air trapping and
16 reviewed the symptoms, much of the respiratory
17 symptoms we see in our patients, and looked at
18 it from a radiographic perspective. It was
19 performed by Dr. Mendelson and Dr. de la Hoz,
20 and revealed that air trapping explained a lot
21 of these PFT -- these pulmonary function and
22 breathing test abnormalities that we're seeing
23 in our population.

24 Again another small study by Dr. de la Hoz in
25 the American Journal of Industrial Medicine,

1 and it looked at a finding of vocal cord
2 dysfunction. So we're seeing a variety of
3 respiratory ailments, and this was one of them.
4 These patients presented with respiratory
5 complaints and were found on spirometry to have
6 abnormalities consistent with vocal cord
7 dysfunction.

8 2008 -- this was a comprehensive review. It
9 was done in the Mount Sinai Journal of Medicine
10 and really discussed -- you know, even under
11 circumstances where the program had limited
12 resources and in spite of all the challenges,
13 what they were able to accomplish. But also it
14 discussed, you know, in the absence of a prior
15 model, we were able to come up with a program
16 and see quite a few people in the midst of this
17 disaster.

18 2008, Dr. Stellman and colleagues published
19 Environmental Health Perspectives: The
20 psychological impact on World Trade Center
21 disaster workers, and found that 11 percent
22 were reporting symptoms consistent with post-
23 traumatic stress disorder; eight percent
24 depression; five percent panic; and 62 percent
25 had sustained a substantial stress reaction,

1 really showing that psychological distress and
2 psychopathology was exceeding what we found in
3 population norms.

4 2008, Dr. de la Hoz presented a paper in the
5 Journal of Occupational and Environmental
6 Medicine on reflux symptoms and disorders,
7 pulmonary disease in our workers. And it was a
8 small subset, 42 responders. Looked at
9 spirometry and upper endoscopy and 24-hour pH,
10 and found that there was a spectrum of reflux
11 disorders and spirometry, which was suggestive
12 of air trapping. And he associated reflux
13 findings and pulmonary disease in our cohort.
14 Again, all of this is consistent with, you
15 know, much of the diseases we're covering and
16 treating our patients for to date. All of this
17 literature drives much of the diseases and what
18 we're treating to date.

19 CHEST, this was a publication by Dr. Skloot and
20 colleagues about the longitudinal assessment of
21 spirometry, and it revealed elevated rates of
22 spirometry was found on both -- if a patient
23 ever returned for an exam, we saw abnormal
24 rates of spirometry in both first and second
25 exam, and that the most common finding was a

1 reduced forced vital capacity. This finding's
2 a bit different than what we see in the
3 firefighter cohort, but again, it just
4 highlights the fact that we're seeing
5 spirometry abnormalities in our cohort.
6 This was published in The Psychiatrist, and it
7 was -- it focused on iron workers, and it was
8 published in 2009 and revealed, again, that
9 we're seeing PTSD, panic attacks, depression in
10 this cohort. And Dr. Stellman's study
11 highlighted that this was consistent with what
12 we were seeing across the cohort.

13 Dr. Moline's here today so she'll probably go
14 into more detail about this, but this is a case
15 series of multiple myeloma, and she reviewed,
16 along with our colleagues, eight cases that
17 were observed and found that four of these --
18 the expected rate was 6.8, and we found eight.
19 Four of these were younger than 45, and this is
20 what was noted to be unusual. We did not
21 expect that.

22 I think -- this is a study about snoring and
23 obstructive sleep apnea. Dr. Udasin, who's
24 sitting next to me, will be talking a little
25 bit about the work they've done. Bottom line

1 is we've now deemed sleep apnea -- in the right
2 setting, with the right World Trade Center-
3 related conditions, deemed to be a -- now a
4 World Trade Center condition. Due to the
5 inflammation in the upper airway, some of our
6 patients are presenting with sleep apnea and it
7 is now a covered condition.

8 Dr. Moline also was involved in this study.
9 This is a study published by Dr. Wu. It was a
10 study that was a case report of seven
11 responders, and they looked in detail at the
12 histopathology and found that they were seeing
13 interstitial lung disease and described those
14 patterns that they were seeing. Also did a
15 mineralogic analysis and found aluminum,
16 magnesium, asbestos, calcium. And in addition,
17 an abnormal fi-- what was -- not abnormal; all
18 of this was abnormal. But they found an
19 unexpected finding of carbon nanotubes. So
20 interstitial lung diseases is also one of our
21 World Trade Center-related conditions as well.
22 Dr. Dalton and Dr. Ken Altman, separately,
23 conducted studies on chemosensory loss, and
24 basically found the prevalence of significant
25 chemosensory impairment in our group, which

1 certainly could be problematic for some people
2 in certain occupations.

3 This is a study I was involved in with my
4 colleagues. We looked at -- similar to what
5 the fire department had done, we looked at how
6 many cases of sarcoidosis we were seeing.
7 Sarcoidosis is a granulomatous pulmonary
8 disease, interstitial lung disease, and we
9 found that we had 38 cases and went on to look
10 at the incidence rates. When we compared them
11 to background rates, our incidence rates were
12 elevated, and we also found peaks of incidence
13 rates similar to what the fire department found
14 in the first and second year -- we found it in
15 year three and year four. He had found it --
16 Dr. Prezant's team had found it earlier, but we
17 were finding peaks earlier on.

18 This is Dr. Altman's study.

19 Lastly, this is a study that was published for
20 the 10-year anniversary in The Lancet. It was
21 conducted by Dr. Wisnivesky and Dr. Landrigan
22 and colleagues, and looked at the persistence
23 of many of these illnesses in the World Trade
24 Center recovery workers to date. And
25 unfortunately, we continue to see elevated

1 levels of asthma, sinusitis and gastro-reflux
2 disease, and this paper highlighted --
3 highlighted that.

4 Okay. So future scientific projects. I'm
5 going to describe the three projects that are
6 funded to date by NIOSH. We received funding
7 after applying for -- submitting our projects.
8 This is the first one, cancer among the World
9 Trade Center responders, and then enhanced
10 surveillance, exposure assessment and cancer-
11 specific rates. This -- this study -- to be
12 fair, this -- we've been doing this already,
13 and we've been conducting surveillance for
14 cancer. It's been an ongoing -- prior to this
15 funding. We've been validating, identifying
16 cases through exams, through a phone bank,
17 collecting for any physicians that tell us that
18 there's a case of cancer, and reaching out to
19 patients to get detailed medical records.
20 We've matched our population with the cancer
21 registries in New York, in New Jersey, and
22 Pennsylvania and Connecticut, and currently
23 we're waiting for a match from Florida and
24 North Carolina. Our group is working on
25 expected rates and observed rates, as is, you

1 know, the rest of the folks who described their
2 studies this morning and hope to, in the near
3 future, be able to discuss those in more detail
4 and have a publication.

5 This -- what's outlined here is a continuation
6 of that work that we've been doing. And
7 basically it outlines -- we know that there's a
8 latency between exposure and cancer development
9 for most human carcinogens. We need to follow
10 up this cohort, and our goals will be to
11 continue to identify and validate all cancer
12 cases in World Trade Center responders, link
13 exposure to cancer risk in these World Trade
14 Center responders, and identify the risk of
15 cancer.

16 DR. MIDDENDORF: Dr. Crowley, you're at 16
17 minutes.

18 DR. CROWLEY: Thank you. I'll be speedy. This
19 is a study -- Dr. McLaughlin is the PI on this
20 study. It's pulmonary function abnormalities,
21 diastolic dysfunction in World Trade Center
22 exposure. Basically a whole litany of tests
23 will be reviewed with the purpose to determine
24 if there's a risk of cardiopulmonary disease in
25 our folks who were exposed.

1 And Dr. Adriana Feder is the PI on this
2 project, trajectories of psychological risk and
3 resilience in World Trade Center responders,
4 with the purpose to examine the extent of
5 resilience, recovery and chronicity over the
6 eight years, and identify risk factors for
7 these patients. And hopefully all of these
8 studies will guide prevention efforts and
9 preparedness planning for disaster responders.
10 These are the goals of our program, many of
11 which are obvious, but it's really -- we want
12 to identify, treat diseases in early stages.
13 We want to report on trends of certain diseases
14 over time, continue surveillance of diseases
15 with long latency.

16 I would like to reiterate what Dr. Prezant and
17 Dr. Reibman highlighted this morning regarding
18 the importance of the data center being able to
19 continue to do disease surveillance. It's
20 something we were tasked -- hopefully we'll
21 continue to be tasked to do 'cause it's a very
22 important job; and obviously educate responders
23 to seek care if they developed any of these
24 illnesses.

25 In conclusion, I just think it's important to

1 reflect on how many people have been screened
2 and monitored -- over 30,000 since July 2002 --
3 and we've treated over 15,000. So you know, we
4 hope to continue to be able to help our
5 responders.

6 And that's it.

7 DR. MIDDENDORF: Just a note to the record that
8 Dr. Rom has returned.

9 DR. WARD: We'd like to take a few questions
10 for Dr. Crowley since both of our first two
11 speakers may have to leave before the panel
12 session would occur at the end of this -- at
13 the end of this section.

14 DR. DEMENT: The cancer study -- it looks like
15 it's just underway, so obviously no projected
16 time frame for the -- for your cancer study
17 being completed?

18 DR. CROWLEY: Actually I would say it's more
19 than underway. I think -- you know, we've been
20 approved for formal funding, you know, as of
21 the -- you know, now. But we've been doing it
22 for quite a while, so hopefully in the very
23 near future we will have a publication. It's
24 hard to give a firm date.

25 DR. DEMENT: I understand. Also your comment

1 about continued ability to do surveillance --
2 continue your work, basically. Is that -- I
3 mean do you have a -- what, a five-year
4 contract now?

5 DR. CROWLEY: Correct.

6 DR. DEMENT: Okay.

7 MS. FLYNN: I also want to follow up on the
8 question about data analysis. Just looking at
9 the presentations from FDNY, from you and from
10 Dr. Reibman, it's very clear that having a
11 robust data analysis is absolutely -- it's the
12 cornerstone of the knowledge base. So is there
13 any question of your ability to continue with
14 that work in the future?

15 DR. CROWLEY: I mean I think right now we just
16 want to be able to continue to do it. We want
17 to be able to continue to do disease
18 surveillance. I think Dr. Prezant's point this
19 morning in terms of the logistics behind, you
20 know, applying for each individual project -- I
21 would have to agree with him about the
22 logistics of. I think, you know, the data
23 center is set up to do disease surveillance and
24 we'd like to continue to do so.

25 DR. QUINT: I was wondering if you had any

1 plans to do biomonitoring of any of the cohort
2 at some point? There's some of the toxicants
3 that people had exposure to that are persistent
4 and could be compared to NHANES and I'm
5 wondering if there's any possibility of that in
6 -- sometime in the future.

7 DR. CROWLEY: Yeah, I mean we actually put in a
8 whole host of proposals to -- for -- we
9 submitted a bunch for funding, and hope that
10 around the corner there'll be another
11 opportunity for that because ideas like that,
12 and others, we hope to be able to explore.

13 DR. WARD: On to the next presentation.

UNIVERSITY OF MEDICINE AND DENTISTRY OF

NEW JERSEY CLINICAL CENTER OF EXCELLENCE

14
15 DR. UDASIN: So I'm going to be giving you the
16 advantages of being a small clinic, and so I
17 don't want to repeat what the large clinics
18 have done, but with being a small clinic --

19 (Pause)

20 The advantages of being a small clinic are that
21 we get to know our patients really well. We
22 don't have -- maybe we don't have to worry
23 about doing some of the other things that some
24 of the other clinics -- the data center -- has
25 to do. But now I'm going to say something

1 about our individual cases that may make the
2 Committee understand how difficult some of the
3 surveillance is between the time frame of when
4 we actually see patients with illnesses and
5 when they actually are able to be confirmed, so
6 to speak.

7 But this picture, to start my presentation, is
8 the Elizabeth fire trucks on the Staten Island
9 Ferry leaving to go to New Jersey -- leaving to
10 go to New York, rather, from New Jersey. The
11 Elizabeth Fire Company sent all 200 of its
12 firefighters to work alongside the firefighters
13 in Staten Island, and so I honor them by
14 putting this presentation up. And this is
15 actually Deputy Chief Workus, who gave us the
16 most -- the best picture of any of our
17 responders. And for those people who don't see
18 World Trade patients on a day-to-day basis, you
19 can see the chief's respirator is around his
20 neck. You can see the World Trade Center
21 debris all over his body. I actually used this
22 picture when I testified before the Energy and
23 Commerce Committee because I thought this was
24 the best picture of any of our responders. And
25 again, we are the only, outside of FDNY cohort,

1 that sees a lot of firefighters. We see the
2 Elizabeth people, we see other fire companies
3 in New Jersey.

4 And just to make things a little bit more
5 interesting about Elizabeth, this is the same
6 fire company that 30 years ago fought the
7 chemical control fire, which Dr. Melius was
8 involved with in NIOSH way back when. And so I
9 have original records on many of the same
10 patients that Dr. Melius saw way back 30 years
11 ago.

12 So we've seen more than 1,700 unique patients.
13 As a 'boots on the ground' kind of person,
14 since we've been seeing them since January of
15 2003, I've seen almost all of them for at least
16 one of their visits. Eighty percent of the
17 patients that we see in New Jersey are offered
18 some kind of treatment. That's a little bit
19 higher -- of course, some of the treatments
20 that we offer are things like nasal saline
21 irrigation and are not expensive treatment, but
22 we are pretty aggressive about preventive
23 health.

24 The next line is a typo that I fixed after I
25 made my 25 copies. What I wanted to say is

1 that most of our patients are civil servants,
2 if you will. Most of them have health
3 insurance, and that should say under-insured.
4 I thought I changed it -- it says 'uninsured'
5 but it should say 'under-insured' there, with -
6 - especially with respect to mental health.
7 Nobody's got good coverage for mental health,
8 and that's one of the things that I'm grateful
9 that our provider -- that our program actually
10 lets us refer to people that are actually good
11 at mental health, not the people that your
12 prescription -- that your insurance plan allows
13 you to see.

14 Different than the other clinics, our three
15 major counties that we see are Middlesex,
16 Monmouth and Staten Island, but we see all over
17 New Jersey, we see Pennsylvania -- we basically
18 go along 287 for those people who know the
19 northeast. We see a lot of people in upstate
20 New York who know that you can zip down the
21 highway 'cause if you drive through New Jersey
22 most people go at about 95 miles an hour on the
23 highways in New Jersey. So our cohort's a
24 little bit more spread out than the other
25 people.

1 Similar numbers except for the fire numbers,
2 but I'm going to also say that we see the Port
3 Authority Police, they're our biggest group,
4 and I'm hoping that when I go to the airport
5 that they're going to get me through the lines
6 'cause that's where I'm going after this, and
7 they promised me I don't really have to get
8 there four hours before the Israel flight
9 'cause they're going to get me to the front of
10 the line.

11 The Port Authority Police lost 37 of their
12 members out of a small department of 1,800
13 people. That means virtually everyone that was
14 in the Port Authority Police knew somebody that
15 died, and knew them really well. The Port
16 Authority Police are -- many of them were
17 physically there, 'cause many were stationed
18 downtown, right around here. If they weren't
19 stationed there they were stationed at a lot of
20 the other airports. The only place that the
21 Port Authority Police are stationed that's not
22 a terrorist target is Staten Island. And they
23 will make jokes about that, but every place
24 else they go is a terrorist target. We've seen
25 a huge number of mental health issues that we

1 take care of in our Port Authority Police, as
2 well as physical health issues.

3 We see a lot of New York City police officers
4 who live in Staten Island, New Jersey state
5 troopers, the various county and municipal
6 sheriffs, and as I said, we looked -- we had an
7 enormous group of people called 'other.' And
8 for those of you who know New Jersey, we have
9 lots of hazardous waste workers in New Jersey,
10 but we also have lots of OSHA inspectors who
11 live and work in New Jersey. We've seen a huge
12 number of OSHA inspectors in our population.
13 Similar numbers to everyone, high numbers of
14 upper airway conditions, lots of GI, lots of
15 mental health, lots of lower airway. I had a
16 student presen-- a student working for me this
17 summer and, interesting, while upper airway is
18 the highest number, the highest number of
19 prescriptions filled is actually GI, and that's
20 maybe a bit surprising that we do this. And we
21 actually have put in some funding to look at
22 our medication use and how it correlates with
23 exposure and illness. And I guess we're still
24 working on it because it didn't get funded yet,
25 but we're still working on it. But we are --

1 this is old. This is before the CSC people
2 came along. But we've been tracking our
3 prescribing patterns pretty carefully -- our
4 most used prescriptions and our most expensive
5 prescriptions -- and you can see the psych meds
6 are all on the most expensive prescriptions.
7 That Seroquel and Abilify and Cymbalta, all
8 that stuff costs a small fortune. But I want
9 to call everybody's attention to the fact that
10 number one, Nexium, is one of the highest -- is
11 our highest prescription that we write. I want
12 you to notice that number 13 is Omeprazole.
13 There's really no evidence-based reason why the
14 Nexium should work better than the Omeprazole,
15 but yet it does seem to work better in
16 practice. And I actually think that that
17 probably correlates well with the mental health
18 components because when people see the
19 advertising and they see the purple pill, maybe
20 they're more likely to get better. I'm not
21 real sure about that, but why the heck am I
22 using so much more Nexium than Omeprazole? I'm
23 just giving you this as my hypothesis here.
24 But the other thing is you see that there are
25 three proton -- four proton pump inhibitors on

1 that list, and gastro-esophageal reflux was not
2 originally a covered condition. And it became
3 a covered condition and it's huge. And in a
4 couple of slides I'm going to tell you some
5 reasons why I think it might be different in
6 many of our responders.

7 So highlighting what we've seen and done in New
8 Jersey, and I've been on many of the papers
9 that Laura just presented, and we had another
10 one about symptoms and spirometry that didn't
11 make the hot 19 that was on there, but that Dr.
12 Enright worked on with us as well.

13 But what I was really proud of was our sleep
14 apnea paper. Dr. Marroccoli and I were the two
15 clinicians in our group, and we were very, very
16 conscious of who we were referring to Dr.
17 Sunderram in the sleep lab to see who we were
18 referring. We were not merely referring people
19 with sleep apnea. We were referring people
20 with sleep apnea who had aerodigestive
21 illnesses, and Dr. Sunderram was the one that
22 noticed -- and all the rest of the people here
23 are the ones that helped us analyze the data.
24 But basically we found that in our population
25 the sleep apnea did not correlate with their

1 body mass index, and this was of course
2 contrary to popular belief, that being like a
3 big fat slob is what made you have sleep apnea.
4 And indeed in our population we do feel
5 strongly that there are other inflammatory
6 mechanisms. And we are also going to be
7 looking to, number one, expand this study; and
8 number two, look at the mental health issues
9 and sleep apnea. We were in the process of
10 improving that study as well.
11 Going to GI, though, we had an abstract that
12 our GI fellows were working on, and this is
13 about eosinophilic esophagitis, and this
14 condition is not well-understood and symptoms
15 are possibly inflammatory, possibly allergic,
16 we're not 100 percent totally sure. But the
17 people who get referred for this thing are the
18 people with intractable heartburn. And I was
19 discussing this last night with Dr. Harrison
20 when we were preparing our presentations, the
21 gastroenterologists have to be looking for this
22 pattern with the rings when you do this. And
23 maybe because we're a medical school and we had
24 the fellows on the teaching scopes, we saw a
25 lot of these, because the pathology diagnosis

1 is based upon seeing the eosinophils in the
2 high-power fields. But the reason why I'm
3 bringing this up and we presented this abstract
4 is we're still seeing this. This is responding
5 to steroids. This was our cohort.

6 The cohort of people that they reviewed -- and
7 this was, again, a Fellows presentation -- but
8 what was interesting was that three of the 45
9 patients that were referred to these Fellows
10 that they were involved with the care of had
11 eosinophilic esophagitis. Most of these people
12 were on inhaled steroids. And so I bring this
13 up as an emerging illness because I'm still
14 seeing this thing. We're seeing -- we can't
15 get our patients off of PPIs. I'm suspecting
16 in the field of gastroenterology that you will
17 be seeing other emerging illnesses. I think
18 this is an emerging illness. It's very -- it's
19 hard to report because my understanding is you
20 actually have to be looking for this to find
21 it. On the other hand, for many of our GERD
22 patients that are really hard to treat, many of
23 them might have it. Interestingly, a lot of
24 our patients who have this are police officers.
25 Again, though, we're a small clinic. We have

1 an awful lot of police officers, so I'm not
2 sure how to interpret that, but I wanted the
3 Committee to see that.

4 Now the other thing I want to say is a little
5 bit about our cancer cases. I have a medical
6 student who, when we see a cancer case, he
7 pulls out everything that he can find with what
8 did they do, where did they live, what other
9 exposures did they have, what's their job. And
10 some of these cases are on the road to being
11 confirmed, some of them are already confirmed.
12 But I'm just giving you this as a small clinic
13 -- raw numbers, not something that's going to
14 be published in a paper because of course we're
15 part of the consortium, but just something more
16 to think about. So we've seen four cases of
17 multiple myeloma. Two were reported. I was
18 one of the co-authors with Dr. Moline on the
19 multiple myeloma study. The 68-year-old and
20 one of the men in his 50s was included in that
21 study. They were in the table, not the 40-
22 year-olds. But interestingly, we've seen two
23 other people in their 50s with multiple myeloma
24 since that study. And so I suspect that the
25 other clinics might be seeing multiple myeloma

1 at some point and we may be able to report on
2 it.

3 We've seen five cases where I've seen the
4 pathology of non-Hodgkin's lymphoma. Four of
5 them were in law enforcement, one of them spoke
6 very eloquently on CNN, and we have another
7 case that I'm waiting for the pathology to be
8 confirmed. And you know, for all the talk
9 about, you know, when can you get a cancer
10 study, so I've seen the patient, comes into my
11 office, tells me about his non-Hodgkin's
12 lymphoma, so I first have to find the
13 pathology. Then I have to get the pathology
14 over to the nurse who works for Laura, and then
15 that person has to then match it up with all
16 the things she has to match it up for. So
17 it's, you know, not as easy as when the
18 patients are all contained in one place.
19 Two cases of CLL, one case of AML. The
20 myelofibrosis case is kind of interesting
21 'cause that patient had absolutely no other
22 exposure other than his exposure at World
23 Trade. And of course it's only one case, but
24 having trained under Bernie Goldstein, I look
25 at that diagnosis and I think you have to have

1 benzene to have myelofibrosis. So anyway --

2 DR. MIDDENDORF: Dr. Udasin, you're at 16
3 minutes.

4 DR. UDASIN: Oh, gee -- head and neck cancer,
5 we are seeing a surprising number of head and
6 neck cancers -- and I'm nearly finished -- and
7 some of our other cancers we're reporting on.
8 And that's basically what I have to say here --
9 and 16 minutes, that's not too bad. So I thank
10 you for your indulgence and I hope you're going
11 to continue to want to fund surveillance and
12 the other patient-related activities that we
13 do.

14 DR. WARD: Thank you. (Electronic
15 interference) presenter. Dr. Harrison? We
16 have to stop at 3:15 to allow for the public
17 comments to take place at the predicted time,
18 and then we'll continue this session
19 afterwards.

NEW YORK UNIVERSITY/BELLEVUE HOSPITAL

20 CLINICAL CENTER OF EXCELLENCE

21 DR. D. HARRISON: (Off microphone) of the
22 clinical program at NYU Medical Center at
23 Bellevue. Just -- I will start by giving a
24 quick overview of what we're seeing in our
25 patients, similar to what's been shown for the

1 other clinical centers. We are the smallest
2 clinic in the group, and we have a total cohort
3 registered and monitoring of over 2,200. And
4 of these we refer about 30 percent of our
5 patients to treatment. We have right now 630
6 patients who are referred for treatment.
7 Most of our patients are English-speaking, the
8 mean age is about 48, and again, most are male.
9 Just to go over the cohort -- you can see most
10 of our patients are white or Caucasian, 65
11 percent, with 9.6 percent black, four percent
12 Asian, and the rest 'other.' Most of our
13 patients, 89 percent, are employed, six percent
14 retired, four percent unemployed, and one
15 percent disabled. Of these, over 87 percent --
16 I mean around 87 percent are insured, with 13
17 percent uninsured. Most of our patients, like
18 most of the other centers, are -- where you see
19 a lot of -- 46 percent is law enforcement, 11
20 percent are in construction, and 15 percent
21 'other', and the rest break down into those
22 groups that you could see.
23 Again, one of the most common referrals for
24 treatment are for mental health disorders, and
25 this represents the range of mental health

1 disorders that we are seeing in our center.
2 Like most centers we see a high rate of PTSD,
3 followed by social stressors, and also for the
4 expected depression, generalized anxiety and
5 panic disorder.
6 Most of our patients are referred for lower
7 airway symptoms, and followed by upper airway,
8 GI and also sarcoidosis -- a small number for
9 sarcoidosis and interstitial lung disease.
10 This is a breakdown of the types of cancers.
11 Apparently -- these are patients within our
12 treatment program. The numbers are much higher
13 if we look at our total cohort, but not all the
14 cancer patients are referred for treatment. So
15 again we are seeing a lot of lung cancer
16 patients, followed by thyroid, others which
17 includes multiple myeloma, prostate cancers and
18 breast cancer.
19 So since mental health disorders are one of the
20 most common reasons for referral to treatment,
21 we decided to look at -- to do a systematic
22 review of treating post-traumatic stress
23 disorder in first responders. This study was
24 mainly done by Dr. Haugen and Dr. Evces, the
25 two psychologists in our clinical center. For

1 the purpose of this review they defined first
2 responders as paid professionals and volunteers
3 responding to emergencies, usually have high
4 levels of work demands, routine exposures to
5 both physical and psychological stressors, and
6 unique exposure recognized in revision to PTSD
7 in upcoming DSM-V -- that is experiencing
8 repeated or extreme exposure to adverse details
9 of the event. For example, in 9/11 workers
10 collecting body parts.

11 As expected, there was a lot of mental health
12 disorders found within these -- in the review
13 papers of first responders. This includes
14 depression, somatic or psychosomatic
15 complaints, chronic fatigue, difficulty with
16 alcohol, and post-traumatic stress disorder,
17 which was the focus of this review. Most of
18 the studies that are done on PTSD in first
19 responders are really small-scale studies.
20 There's no national representative large-scale
21 studies, and within the literature there's a
22 report of variable rates, range from seven to
23 19 percent in police officers and four to six
24 percent in volunteer disaster workers
25 responding to a disaster.

1 To estimate the prevalence of PTSD in first
2 responders we looked for comparison to the
3 military population because we thought that
4 population might more closely represent our
5 group. Specifically we looked at the National
6 Viet Nam Veterans Readjustment Survey which was
7 done in 1990, and looked at -- and it was a
8 good survey because it was nationally
9 representative and was done years post-
10 exposure. From that paper the inciden-- the
11 prevalence of PTSD was estimated -- full PTSD
12 was estimated to be around 15 percent, and
13 partial PTSD at 11 percent.

14 To get a further estimate on the prevalence of
15 PTSD we looked at -- from the Bureau of Labor
16 and Statistics in 2008 there was one thousand -
17 - 1.5 million patients that were registered as
18 first responders. So to get the estimate of
19 full or partial PTSD we multiplied that by the
20 -- the estimates from the veterans study. And
21 then we concluded that about 390,000 of first
22 responders nationally -- that there are about
23 390,000 first responders nationally with full
24 or partial PTSD. Of course this could be --
25 the numbers could be higher because this does

1 not include non-traditional first responders
2 like volunteers.

3 So we -- they conduct a literature review of
4 status of treatment outcome studies for PTSD in
5 first responders, looking at studies that
6 involve psychosocial treatment, pharmacological
7 treatment, and combined psychosocial and
8 pharmacological treatments. Inclusion criteria
9 for the study, the papers had to address
10 psychological or pharmacological intervention.
11 Subjects were first responders. Subjects had
12 primary diagnosis of PTSD based on DSM -- or
13 ICD-9 criteria. PTSD diagnosis or symptom
14 status was the chief study outcome. The
15 psychosocial treatment studies compared two
16 active treatment groups or one active treatment
17 group to a non-specific control or wait list
18 group. Pharmacological treatment studies
19 compared drug treatment to placebo or active
20 comparator.

21 So in total, a total of 845 articles were
22 reviewed. Of these, 21 were excluded because
23 they were not in English, and 84 -- 824
24 patients were considered for the study. 807
25 were excluded for various reasons

1 (telephone/electronic interference) treatment
2 study, some were not first responders, or the
3 PTSD was not a primary outcome. So they were
4 left with 17 articles for the review. Of
5 these, only two articles were randomized
6 control trials.

7 (NOTE: Electronic interference was present
8 throughout this presentation, with the sound of
9 dial tones and telephones dialing.)

10 So one of the -- this first article was done by
11 Difede et al in 2007 at Cornell University, and
12 involved a randomized control clinical
13 treatment trial for World Trade Center attack-
14 related PTSD in disaster workers. And they
15 looked at -- they randomized the participants
16 to two different treatment groups, what they
17 called cognitive behavioral therapy or what's
18 referred to as 'treatment as usual' therapy,
19 which is essentially referring the participants
20 back to their occupational physician or to
21 their primary care physician to address the
22 PTSD needs.

23 They also used two measurements to measure
24 PTSD. One was the CAPS, which is the gold
25 standard and is clinician-administered. The

1 other was the PCL, which is a self-administered
2 and is what we use in the treatment program.
3 And as you can see, there was -- when you
4 compare pre- and post-treatment data, the mean
5 scores for pre- and post-treatment, the drop in
6 symptoms were higher for the CAPS compared to
7 the PCL. However, if you include -- there was
8 a high dropout rate in the patients that were
9 treated with cognitive behavioral therapy, so
10 if you include them in the intend to treat
11 samples, the drop was not that significant.
12 Another randomized control study that was done
13 looked at the use of brief eclectic
14 psychotherapy for police officers with post-
15 traumatic stress disorder. These were Dutch
16 police officers, and they randomized -- 22
17 patients were randomized, either to brief
18 eclectic psychotherapy or they were -- this was
19 compared to -- a wait list was used for a
20 comparison that included 20 patients. And what
21 was interesting to note was that after four
22 sessions there was no significant difference
23 between the two groups. But post-test and
24 follow-up studies showed that 96 percent of the
25 patients that were in the brief eclectic

1 therapy had no PTSD and those 35 percent on the
2 wait list had no PTSD. And that was true also
3 for other PTSD symptoms.

4 What's interesting, too, at the bottom of the
5 slide, is when you look at resumption of police
6 work, that 86 percent of the patients at the
7 end of therapy that were treated with -- that
8 were treated with brief eclectic psychotherapy,
9 86 percent returned to work as compared with 60
10 percent that were on the wait list.

11 In summary, around 400,000 first responders
12 with PTSD symptoms, a review of 845 articles,
13 two randomized control of psychosocial
14 treatment, there was no randomized control
15 trials of pharmacotherapy or combined
16 treatment. CBT and brief eclectic
17 psychotherapy was evaluated, effect size was
18 large, and based on studies identified
19 treatment guidelines used our questionnaire.
20 Barriers to treatment research for first
21 responders due to status which -- we know the
22 people on active duty are associated with lower
23 levels of treatment, referral and engagement.
24 Stigma concerns, meaning negative evaluation by
25 peers or leadership. Changes in job status,

1 meaning that they're afraid that they might get
2 reduced. Changes in job duties or reduced pay.
3 And also it seems that first responder
4 organizations are unaffiliated with academic
5 institutions, unlike the Veterans
6 Administration health systems.
7 So recommendations for future treatments in
8 PTSD is to begin with treatment with the
9 strongest preliminary evidence for efficacy
10 with first responders as the CBT and BEP.
11 Psychosocial and pharmacological treatments
12 identified in non-random control trials should
13 be tested in random control trials. And
14 psychosocial and pharmacological treatments
15 represented in current treatment guidelines for
16 PTSD need to be studied, especially for those
17 evaluated with active duty military personnel
18 subjects with many similarities to first
19 responders. Also we need to focus on non-law
20 enforcement, as a majority of studies are
21 focused on law enforcement -- majority of
22 current studies focus on law enforcement. And
23 we need to assess duty status as a potential
24 moderator during and post-treatment. Duty
25 status has been known to be associated with

1 exposure to traumatic stressors, which may
2 complicate treatment, attenuate outcomes.

3 So the next common symptoms that we're seeing
4 in the treatment pro-- problems that we're
5 seeing in the treatment program is respiratory
6 disorders. And as you all know from the
7 previous presentations that respiratory
8 symptoms are common among World Trade Center
9 responders. Cough, dyspnea, wheezing are
10 common respiratory complaints, and there are
11 essentially two groups: World Trade Center
12 responders with symptoms and abnormal
13 spirometry, and World Trade Center responders
14 with symptoms and normal spirometry.

15 It was reported by Dr. Herbert from Mt. Sinai
16 using the clinical center consortium in 2006
17 that over 9,000 World Trade Center responders,
18 72 percent have normal spirometry results
19 despite respiratory symptoms.

20 A study that was done at NYU evaluated 174
21 patients with respiratory symptoms and normal
22 spirometry. This was done by Dr. Berger et al
23 from the pulmonary department at NYU, and they
24 looked at impedance oscillometry, which --
25 without going into details about, it's a way --

1 it's a simpler test to do -- some think it's a
2 simpler test to do than pulmonary function
3 test, and it's good for measuring distal airway
4 disease. And they also looked at the use of
5 oscillometry to look at resistance and
6 reactions in these patients, which are
7 measurements used to determine distal airway
8 disease. They also looked at what's called
9 frequency dependency of compliance, and
10 frequency dependency of compliance simply is
11 usually in normal people with no symptoms and
12 normal pulmonary function, when you increase
13 your respiratory rate there should be no change
14 in the compliance. For people with distal
15 airway disease, increase in respiratory rate
16 may cause a decrease in lung -- distal air-- in
17 compliance with distal airways. And this
18 testing was repeated after bronchodilation.

19 DR. MIDDENDORF: Dr. Harrison, you're at 15
20 minutes.

21 DR. D. HARRISON: Okay. I'm almost done. So
22 despite normal spirometry, mean resistance and
23 reactions were elevated, resistance and
24 reactions normalized after bronchodilators, and
25 so they determined that there was a need to

1 look at these alternative ways of measuring
2 lung disease in patients with World Trade
3 Center-related symptoms.

4 On the flip side, this was a study that was
5 done by Dr. Udasin, who just spoke, on
6 respiratory symptoms associated with lower
7 spirometry results during the first
8 examinations of World Trade Center responders.
9 They looked at over 18,000 responders with
10 dyspnea, wheezing and cough, and they found
11 that the mean FEV-1 and FVCs were lower for
12 participants who reported persistent
13 respiratory symptoms. Responders reporting
14 respiratory symptoms also had larger
15 bronchodilator response. The conclusion was
16 that responders reporting chronic persistent
17 cough, wheezing or dyspnea at first medical
18 examination were more likely to have lower lung
19 function and bronchodilator responsive compared
20 to those without symptoms.

21 Conclusions therefore that, similar to most
22 people with occupational environmental
23 exposures, World Trade Center responders
24 present medical conditions which may have
25 diverse etiologies. These include not just

1 respiratory and mental health conditions, but
2 other disorders such as GERD and sleep apnea.
3 The New York population allows for the study of
4 multiple diagnostic and treatment modalities
5 that can be applied to responders in future
6 disasters.

7 Thank you.

8 DR. WARD: I have seven minutes until public
9 comment, so are there any questions for Dr.
10 Harrison?

11 (No response)

12 Well, I think -- it seems like we shouldn't
13 start the next presentation, so we should --

14 DR. MOLINE: Oh, feel free to interrupt. It's
15 not a problem. I mean I can truncate my talk.
16 My talk's sort of split into two, so I'm happy
17 to start so you don't have to sit and waste
18 some time while we're waiting for public
19 comment, and then I can just continue after. I
20 don't mind. It's -- whatever you prefer.

21 DR. WARD: Okay, let's just take a very short
22 stretch break and be ready for public comments.

23 (Recess taken from 3:08 p.m. to 3:15 p.m.)

24 DR. MIDDENDORF: We do need to come back to the
25 table so we can get into the public comment

1 period.

2 (Pause)

3 DR. WARD: Okay, third call for Committee
4 members to come back to the table and --
5 because we'd like to start our public comment
6 period.

7 (Pause)

8 DR. MIDDENDORF: We need to move on. Okay,
9 we're going to begin, and a note to the record
10 that each of the Committee members is here at
11 the table except for Dr. Trasande. And let me
12 ask -- Dr. Talaska, are you on the line?

13 (No response)

14 And not hearing anything, apparently he's not
15 on the line at this point.

16 **PUBLIC COMMENTS**

17 So we do need to get into our public comment
18 period. Each of our public commenters has
19 signed up earlier today on a first come, first
20 served basis, and each of them will have up to
21 five minutes to present. It's often surprising
22 how quickly five minutes can go, particularly
23 when you're talking about a subject that you're
24 very passionate about. So what'll happen is at
25 four minutes I will politely say -- let you

1 know that you have one minute left, and we will
2 also be using these cards so that when you
3 start I'll hold up the five minutes, when it
4 gets to one minute left I'll hold up the yellow
5 card letting you know there's one minute. And
6 when your time is up, I'll bring up the red
7 card and I will have to rudely interrupt you.
8 I apologize for that up front, but it is part
9 of our requirements.

10 So I should also point out that you do have the
11 option of submitting written comments to the
12 docket for this Committee. The docket is
13 number 248 and the information on submitting
14 the comments is on the NIOSH docket web page
15 and it's also in the Federal Register notice
16 for the meeting.

17 And the other thing I want to point out is the
18 -- we do have a redaction policy for public
19 comments, and that was also published in the
20 Federal Register notice and was at the table
21 where you signed up.

22 So with that, I'll turn it over to Dr. Ward.

23 DR. WARD: Mariama James? And you can come to
24 the microphone at the table where the speakers
25 have...

1 (Off microphone discussion, not audible due to
2 electronic interference.)

3 DR. WARD: Okay. Alec Sanchez?

4 MR. SANCHEZ: Good afternoon. My name is Alec
5 Sanchez. I am a 9/11 responder, cleanup
6 worker. I would like to start out my testimony
7 by very much offering a moment of prayer for a
8 renowned leader to the 9/11 community. Right
9 this minute he's in the hospital, New York
10 (Indiscernible) Hospital, he suffered a stroke
11 -- Marvin Bethea, President of Unsung Heroes,
12 Helping Heroes, and one of our own.

13 (Pause)

14 I would like to recognize members of the STAC
15 committee. Mr. Chego (ph) and I have had the
16 honor to work with some of the familiar faces
17 in this Committee -- Steve Cassidy, Madame
18 Mejia, Madame McVay Hughes, Madame Flynn,
19 Madame Fidel (ph), thank you for your
20 commitment to the 9/11 community and to your
21 service to our country.

22 My name is Alec Sanchez, once again. I am a
23 9/11 cleanup worker. On September 11th I had a
24 very close encounter with terror. I was
25 standing a very short distance from this

1 building, and I witness the gate to Hell open.
2 On September 12th I get a call -- phone call
3 from my supervisor. Prior to performing
4 cleanup here at Ground Zero, I did janitorial
5 work for New York University. On September
6 12th I get a call and my supervisor, Major
7 Oliver, tells me 'Alec, get your team ready;
8 we're performing cleanup work at Ground Zero.'
9 I had two great news in 2001. I became a
10 father for the first time. And as a New
11 Yorker, being able to be part of the recovery
12 of my city, it was like winning the lottery.
13 9/11 changed the world. And it's very much
14 evident, just coming into this building here
15 today, how security has changed so much since
16 9/11. On 9/11 we encountered contamination
17 never seen at this level -- not in Hiroshima,
18 Nagasaki or Kuwait. Sadly a registry was never
19 put in place. New York City, unlike D.C., was
20 despair of the action taken at the Pentagon
21 where FBI tasked EPA for rescue, recovery and
22 cleanup to wear the personal protective
23 equipment. Here in New York City we
24 encountered a very casual sentiment to 9/11
25 contamination -- the air is safe to breathe.

1 Ten years later impunity for those elected
2 officials whose job is to serve and protect,
3 more than a thousand have died since 9/11 --
4 1,020, to be exact. There is no doubt in my
5 mind that we will surpass the number of 2,751
6 who lost their lives -- those innocent soul who
7 lost their lives on 9/11.

8 These last eight years Mr. Chego and I continue
9 to be on the front line on behalf of a
10 community afflicted by the maladies of 9/11
11 exposure. Through advocacy and political
12 activism, Mr. Chego and I have established a
13 relationship with the orphans, the widows, the
14 mothers, the fathers -- like James Zadroga,
15 Sr., a dear friend, who today is raising his
16 10-year-old granddaughter due to 9/11 exposure.
17 As a cleanup worker we were never trained or
18 licensed to perform our duties. Also we must
19 note no training in emergency management.
20 Today we have noted numerous of findings.
21 Nearly 70 percent of those exposed to 9/11
22 contamination have respiratory ailments,
23 gastric disease, post-traumatic stress disorder
24 also being recognized. Clinical studies have
25 shown pregnant women who were exposed had a

1 very low birth weight with their newborns. The
2 Lancet study recently I know all of you are
3 very familiar with.

4 Being in the front line nearly a decade
5 provides a whole lot of insight, seeing those
6 who were exposed to 9/11 contamination
7 deteriorate right before our very own eyes.
8 Example: Jack McNamara; we were sitting in
9 Senator Lieberman's office, and two months
10 after that --

11 DR. MIDDENDORF: One minute, Mr. Sanchez.

12 MR. SANCHEZ: Excuse me?

13 DR. MIDDENDORF: One minute left.

14 MR. SANCHEZ: Two months prior to that we were
15 sitting in Senator Lieberman's office and then
16 two months after that I reached to Mr. Chego
17 and asked him, 'Who is that gentleman?' He
18 said 'That's Jack McNamara', who very much
19 deteriorated before our very own eyes.
20 Let me speed it up so I can conclude. We cover
21 all the bases today. What I haven't heard
22 today is the economic aspect to all of this.
23 Under the Zadroga Act the crazy provisions in
24 the Zadroga Act provided by a political
25 establishment, the Republicans, who have turned

1 their backs on 9/11 responders since day one.
2 Every society honors and reveres those who go
3 to the front line. We have been --

4 DR. MIDDENDORF: Mr. Sanchez, hold on just a
5 second. Your five minutes is up, but before
6 you leave, since we have nobody else on our
7 list that is going to make any public comments,
8 let me throw it to the Committee -- would you
9 like to hear another five minutes from Mr.
10 Sanchez?

11 MR. SANCHEZ: Thank you so much.

12 DR. MIDDENDORF: It's unanimous.

13 MR. SANCHEZ: We have had a Republican
14 establishment that have turned their backs on
15 9/11 responders, as I mentioned. Every society
16 honors and reveres those men and women who go
17 to the front line. One of the crazy provisions
18 implemented by the Republican Party to the
19 Zadroga Act is \$2.8 billion being spread
20 throughout five years -- \$800 million is the
21 first five years, the remaining \$2 billion on
22 the sixth year. If we recognize these cancers
23 -- there's not enough money in place as it is,
24 but if we recognize these cancers, then -- and
25 we will recognize these cancers, by the way,

1 because we will continue -- our resolve
2 continues to be the same. We will fight to the
3 very end for those who helped lift a city, an
4 economy and a nation.

5 And one of the most proudest thing I ever done
6 in my life is serve at Ground Zero and watching
7 these men and women very much vanish right
8 before my very own eyes, and the children -- I
9 mean I am a single father of an amazing 10-
10 year-old. I wish I can say -- he is our
11 youngest advocate. Jack started advocating
12 along my side since he's five. But I witnessed
13 numerous of diaper change on the bus on the way
14 to D.C. and back. We must continue to strive
15 forward. We are a better country than this.
16 J. Edgar Hoover provided food for millions of
17 Russians. Ronald Reagan gave amnesty to
18 undocumented and put an end to the Cold War.
19 John F. Kennedy put a man in the moon. We are
20 better than this. We need to take care of our
21 own.

22 John Feal, President of the Feal Good
23 Foundation, an officer and a gentleman also,
24 tells me there's a code in the military, you
25 never leave yours behind. We have spent so

1 much money in Afghanistan and Iraq, \$360
2 billion to be exact, we couldn't come up with
3 \$10.7 billion to help those who helped lift our
4 city and our nation. This is not the country I
5 want my 10-year-old to grow in.

6 We shall never forget, and may God bless the
7 United States of America.

8 Thank you.

9 DR. WARD: ... the video that was submitted
10 earlier, or do we have another public...

11 (Discussion with off-microphone speaker)

12 DR. WARD: Oh, right. Well, I thought the
13 video was part of the public comment period.
14 That's my confusion.

15 (Discussion with off-microphone speaker)

16 DR. WARD: Okay, so we'll go to Dr. Moline
17 then. Dr. Moline?

LONG ISLAND JEWISH MEDICAL CENTER

18 CLINICAL CENTER OF EXCELLENCE

19 DR. MOLINE: Standing between you and Executive
20 Session, I will make my comments as 15-minute-
21 worthy as possible, I hope. It's a pleasure to
22 be before all of you, to be in front of many of
23 my former teachers, some of my former trainees,
24 some colleagues, and many people whose names
25 and papers I've read for many, many years.

1 It's a pleasure to be here presenting.
2 I'm going to be talking about some aspects of
3 the Queens World Trade Center Clinical Center
4 of Excellence, which was started by Dr.
5 Markowitz; and the Center for Biology of
6 Natural Systems at Queens College, and as of
7 July 2011 became a partnership with Long Island
8 Jewish Medical Center and is now the Queens
9 World Trade Center Clinical Center of
10 Excellence at Long Island Jewish Medical Center
11 Queens College. And if I could have my slides,
12 please?
13 The advantage of going last is that I don't
14 have to give you a lot of background or give
15 you much more, and I'll just give you some
16 numbers on the cohorts and means, and then I'd
17 like to talk to you about a research project
18 that's been funded while we're getting the
19 slides up.
20 And so there have been about 3,200 folks
21 registered in Queens. Of that, there are 2,885
22 in the total cohort and about 1,700 who are
23 actively involved in monitoring. If you can
24 see our -- a map of where most of our
25 responders live. Of note, Queens is the

1 borough with the largest number of World Trade
2 Center responders so it's critical that there
3 be a clinical center within the borough of
4 Queens.

5 And as of the end of September we had 443
6 unique patients in active treatment. These are
7 people who have been seen within the past 12
8 months, with about 350 in physical health and
9 200 in mental health, and many of those
10 obviously are in both, which brings us up to
11 our number.

12 Total number of exams is nearly 6,000 that have
13 been done since the inception of the Queens
14 Clinic in 2002. There have been 2,700
15 treatment visits, and almost 5,000 mental
16 health visits. And social work benefits have
17 been -- benefits, evaluations and advice have
18 been given to over 900 individuals.

19 Like many of the others, our patient
20 distribution is mixed. Law enforcement makes
21 up the bulk of patients that are seen in our
22 clinical center. We also have construction,
23 transportation, many unemployed, retired, and
24 in a variety of different trades.

25 As Dr. Crowley mentioned earlier, we worried

1 about multiple myeloma and my -- to talk a
2 little bit about cancers, and the reason that
3 this was -- we felt it was important to publish
4 this paper was not that the rate was so much
5 higher in the aggregate -- because the expected
6 rate, given the population size, was 6.8; we
7 saw eight that we counted at the time that we
8 were collecting the data -- but that there were
9 four people that were under the age of 45. And
10 for those of us who have been involved looking
11 at sentinel health events in our occupational
12 medicine careers, things strike out. And
13 sometimes very small numbers are what makes the
14 case, whether it's three cases of
15 hemangiosarcoma in one plant leading to the
16 connection between vinyl chloride and that rare
17 cancer, but it was very striking. Multiple
18 myeloma is not a disease of the young. It's a
19 disease -- it's actually the second most common
20 hematologic malignancy, but it's when you're
21 70, not when you're 40. And we had four folks
22 under the age of 45, and it just seemed unusual
23 so we wanted to alert folks of this. All of
24 them happened to be in law enforcement, which I
25 think is just a chance finding of our cohort,

1 and this was based on -- by way of history, I
2 was involved with the Mt. Sinai Medical Center
3 and was the director there until April 2010, so
4 this was during my tenure at Mt. Sinai, and
5 this was based on the clinical consortium.

6 But there were possible etiologies that we had
7 (telephonic/electronic interference) multiple
8 myeloma, whether it's with benzene exposure --
9 although usually it's a longer latency than the
10 other hematologic malignancies that are
11 associated with benzene, whether it's solvents
12 or many of the other toxicants that were seen,
13 or whether it's a cofactor of the mixed
14 exposure that people were exposed to.

15 In the manuscript, or in the paper, we also
16 described additionally cases where there were
17 one and (telephonic/electronic interference) in
18 the surveillance project that's being done by
19 the data center at Mt. Sinai and has been
20 reported on by other groups as well, whether
21 it's multiple myeloma or other cancers.

22 I wanted to talk about a project that's been
23 funded as part of one of the research projects
24 with Alfredo Morabia and Steve Markowitz at
25 Queens College, and this is the World Trade

1 Center heart project which is looking at
2 cardiovascular health impact, prediction of
3 incident cardiovascular events among World
4 Trade Center responders. And it's a cohort
5 study looking at the Framingham health -- the
6 risk factors, which are smoking, cholesterol,
7 blood pressure, diabetes; and treatment,
8 looking at the impact of exposure at Ground
9 Zero and also depression. It's following up on
10 much of the work that's being done looking at
11 co-morbidities, whether it's at Stony Brook or
12 at other centers, to see if there is something
13 unique about the World Trade Center exposure,
14 not just purely from an exposure basis.
15 So what is the evidence and significance? We
16 know air pollution is a risk factor for
17 cardiovascular morbidity and mortality. We
18 know that PTSD is an important risk factor for
19 cardiovascular morbidity and mortality. And so
20 the question is do they modify morbidity and
21 mortality above and beyond the established risk
22 factors for coronary artery disease or coronary
23 heart disease, which is the most prevalent
24 killer in the United States. There are -- the
25 first objective is to see whether this cohort

1 can use the Framingham health -- the Framingham
2 score to accurately predict the cardiovascular
3 risk for primary and subsequent cardiac events.
4 If any of you are interested in what your heart
5 risk score is, just Google Framingham health
6 risk, plug in your various factors that it will
7 ask you for, there are a variety of on-line
8 tools, and it will give you a percentage and a
9 percentage score. And actually in preventive
10 cardiology this score is used to determine
11 whether you should begin medications or at what
12 levels, and also to give you some semblance of
13 maybe what you should focus on in terms of
14 modifiable risk factors.

15 Leading to objective two, which is there a need
16 for a special score for World Trade Center
17 score for cardiac health; is there something
18 that's a cofactor between the exposures, as
19 well as the standard cardiac risk factors; and
20 are World Trade Center responders at higher
21 risk of cardiovascular disease than other New
22 York residents who weren't exposed to the air
23 pollution and the mental stress. So is there
24 something unique about these folks that we
25 might be able to add to? We plan to recruit

1 about 6,000 people, very ambitiously, who will
2 be undergoing their monitoring and exams both
3 at Mt. Sinai and at the Queens program. We
4 will be assessing the risk factors, looking at
5 the PCL score for PTSD which has already been
6 collected, and also looking at the dust
7 exposure which has already been corrected --
8 collected, and it will be integrated into the
9 usual clinical assessment so it will not
10 require an additional visit. There will be a
11 two-year follow-up. Power analysis has been
12 done which, given the prevalence of heart
13 disease and in an aging cohort, there is
14 sufficient power to determine if there is an
15 effect in terms of the primary or secondary
16 events. And there will be annual contact to
17 see if people have been hospitalized to
18 determine -- and these are heart end points in
19 terms of cardiovascular diseases, also looking
20 at SPARCS data for ER visits and medical
21 records. The investigator team includes Dr.
22 Morabia and Dr. Markowitz, as well as
23 colleagues from Mt. Sinai and the Mailman
24 School of Public Health at Columbia.
25 One of the things I wanted to talk about was --

1 and it's something that came up when Dr. Udasin
2 was speaking, the eosinophilic esophagitis made
3 me think -- you know, one of the true values of
4 the World Trade Center and the research into
5 it, and something I think we need to think
6 about, is that we can learn a lot about some
7 diseases that are idiopathic, or we thought --
8 or we classified as idiopathic, as a result of
9 looking at the World Trade Center cohort, and
10 maybe these diseases are not truly idiopathic.
11 The more we're learning about sarcoidosis, for
12 example, is that it's a dust-mediated disease
13 now. And there are studies from all three of
14 the major cohorts or the three groups, whether
15 it's the fire department, whether it's the
16 clinical consortium or the health registry,
17 that have all shown elevated rates of
18 sarcoidosis. I think research on the etiology
19 to find out what it was would be very
20 informative, and this is talking about looking
21 at some of the mechanistic causes for
22 sarcoidosis that could inform us to see are
23 there other things besides beryllium which
24 causes a sarcoidosis-like disease. Maybe there
25 were other metals there. Beryllium doesn't

1 seem to have been that big a factor, but maybe
2 it's aluminum. Should we be looking -- and we
3 know aluminum was there. Could it be other
4 metals that are there? And think about using
5 the information that we've gathered to fund
6 research that will look into the etiology of
7 sarcoidosis that would have far-reaching
8 implications above and beyond just the World
9 Trade Center responders.

10 Certainly it's important to think about
11 continued cancer surveillance, and urging that
12 all cases be considered as the studies and the
13 surveillance is being done that we not exclude
14 folks who are coming in to the monitoring
15 examinations who come with a diagnosis of
16 treatment of having a cancer. These are not
17 standard epidemiologic studies where you
18 exclude people who have pre-existing disease
19 when they come in. In a standard epi study you
20 would exclude them because that's -- you want
21 people free of disease at the time they come in
22 if you're doing a rigorously-conducted study.
23 This was not how any of these programs were
24 developed. They were developed as clinical
25 screening, evaluations, and to not count folks

1 who come in with diseases would be a travesty
2 to what was meant, the spirit by which people
3 came into these programs, and I think it's
4 important that we think about that in looking
5 at all the studies as we go forward.

6 And Mr. Sanchez also raised something -- we had
7 actually put in a proposal, that was not funded
8 in the latest round, looking at the socio and
9 economic impact of the World Trade Center among
10 responders. That's something that needs to be
11 done beyond what has just happened to folks
12 clinically. We've published many, many papers
13 on the health effects, haven't

14 (telephonic/electronic interference) looked
15 comprehensively at all the responders to see
16 what the true impact of the World Trade Center
17 has been in terms of economic loss, in terms of
18 disability, in terms of changing careers. And
19 this goes above and beyond those who have
20 clinical disorders. But that's something that
21 really should be funded, and I don't mean to
22 sound self-serving because that's our proposal,
23 to put it in there, but it's the type of
24 information that is really critical for folks
25 to get a full understanding of what impacts

1 (telephonic/electronic interference) of
2 disasters could be. And again, this does have
3 implications beyond just the World Trade
4 Center. But what happens when people respond,
5 and what can be the long-term sequelae in terms
6 of the overall impact on health, and that's
7 something that should be addressed.

8 So I think I -- in conclusion -- I'm the only
9 person who didn't get the Mr. Middendorf,
10 you've had 15 minutes, so I'm happy to conclude
11 and take any questions. Yes?

12 MS. HUGHES: On the second slide it said 25 had
13 deceased. I was just curious, was there any
14 trend among the people, the 25 who had
15 deceased, in your group you were looking at?

16 DR. MOLINE: We don't have the full information
17 on what they may have died of, and they may
18 have called in. But we can certainly look into
19 the cause of death, and I think that's
20 something that's also important. New York
21 State was collecting death information on all
22 folks. Certainly these should be collected --
23 the causes of death.

24 MS. SIDEL: I just had a quick question. I was
25 wondering when you were talking about seeing

1 disease in somebody that's 45 and it's a
2 disease that you usually see in somebody that's
3 70. Are you finding that with other diseases,
4 that people are like sort of almost prematurely
5 aging?

6 DR. MOLINE: Aside from the investigators
7 prematurely aging?

8 MS. SIDEL: No, I mean --

9 DR. MOLINE: That's a joke. That was a --

10 MS. SIDEL: -- that's exactly -- right.

11 DR. MOLINE: -- I'm sorry. For many of us who
12 have been doing this for ten years --

13 MS. SIDEL: I'm using that as a -- I'm using
14 that as a lay person, but what I'm trying to
15 say is that they're getting diseases that
16 usually old people get.

17 DR. MOLINE: It's actually -- it's a really
18 critical question, and that's one of the things
19 that I think we have to be alert for, and there
20 have been some concerns about things like
21 follicular lymphoma, which is again a cancer
22 that may not be so increased in number, but yet
23 is something that we see later in life.

24 You know, the cohort is actually -- as time
25 goes on with the monitoring program, people are

1 getting younger, if that makes any sense. When
2 we started it, the average age was 43. Now
3 over time, the average age has gone down to 38.
4 So people coming in actually -- the young-- the
5 people who were there coming in over time, so
6 it'll be important to see whether there are
7 those trends in terms of diseases and rates.
8 Apart from the lymphoma and the myeloma, I'm
9 not aware of any, but it's certainly something
10 that is critical to find.

11 MS. FLYNN: So thank you, Dr. Moline, and thank
12 you for the multiple myeloma study which we
13 read with great interest when it first came
14 out, very important work. And as a lay person
15 I would say yes, we do -- we detect the signal
16 in that study, and you have mentioned two ways
17 to proceed that sound like they should be on a
18 list of how this Committee could approach the
19 issue of emerging illnesses, especially
20 cancers, in a forward-leading fashion so that
21 we are able to sooner than later address the
22 emerging need in the population of sick
23 responders and survivors. And the two things
24 that I caught were, one, to not just look at
25 the issue of greater than expected frequency of

1 disease, but to look at all kinds of other
2 unusual, unexpected patterns. And the other
3 thing you said was that people should not be
4 excluded who enter the health program with a
5 pre-existing diagnosis.

6 Are there any other ways that you can propose
7 where we might lean forward and hope to capture
8 an emerging need sooner than later?

9 DR. MOLINE: I mean it sounds so simplistic,
10 but to approach everything with an open mind.

11 I think if you had asked all of us eight or
12 nine years ago if we would be expecting to see
13 folks coming in with persistent health
14 problems, we would have said no, it's going to
15 go away fairly soon, or we're going to have it
16 in ten percent of folks, not -- certainly not
17 in 30 or -- 30 percent of individuals who
18 remain affected, or to see drops in pulmonary
19 function that never come back in otherwise
20 healthy folks, as they saw in the fire
21 department. I think that, you know, having the
22 open mind and just being willing to accept that
23 there are issues that we need to look at
24 seriously.

25 One of the things that befuddles all of us,

1 which is how to work with existing regulations
2 and rules and data sequestration -- and there
3 are very strong rules that protect individuals'
4 privacy and we can't circumvent that by any
5 means -- but to be able to utilize whatever
6 resources we have, whether it's the registry
7 that has been done by the police department,
8 for example, and folks that may not have come
9 in with cancer to any of the programs because,
10 quite frankly, they're going to so many doctors
11 they don't want to go for another examination.
12 They're not counted, so they don't exist in any
13 of the studies. And we have to figure out a
14 way of looking at all folks that have been --
15 that have disease that is verifiable, and
16 include them in a comprehensive review of who
17 was there -- who we know was there -- and say
18 'What are we seeing across all?' I mean it's
19 easier said than done, because the datasets are
20 distinct, and they have to be distinct for a
21 variety of reasons. But for some of these
22 issues I think that it's important to go to
23 different data sources -- again, verifiable,
24 scientifically credible, whether it's working
25 with the health -- the cancer registries in the

1 region or whatever it might be -- but not to
2 miss out on folks who haven't come into the
3 programs because they've had many other reasons
4 why they wouldn't want to come into a program
5 for yet another examination.

6 DR. R. HARRISON: It strikes me that, in
7 listening to the presentation that you made, as
8 well as others, that there's been a tremendous
9 amount of research that's -- has shed and
10 potentially will shed even more light on
11 disease patterns and mechanisms, potentially,
12 of the disease in this cohort and that that's
13 tremendous benefit. I mean and the
14 publications are really, really impressive, and
15 I think we really have learned from the
16 research many things that will be valuable in
17 the application to other occupational cohorts
18 and environmental disasters in the future.
19 But there's a question that struck me that
20 might be worthy of further attention and I
21 wondered if I could get your reaction to it,
22 and that is the question -- really the bigger
23 question of has the program made a difference?
24 Has the application of probably what is the
25 largest medical monitoring and treatment

1 program that I've been aware of certainly in my
2 career made a difference in health outcomes,
3 whether that be -- has it improved the
4 management of occupational and environmental
5 lung disease, has it improved compliance with
6 medications, has it improved patient
7 satisfaction with care, has it improved access
8 to care? In learning about the resources that
9 we spent over the last ten years, it strikes me
10 there could be a number of interesting findings
11 or lessons to be taken away that I bet -- my
12 hypothesis would be that on a number of fronts
13 the answer would be yes. But not to know that
14 or not to take away from this historical
15 experience some additional lessons about -- you
16 know, it just strikes me that, you know, when I
17 hear the firefighter data that these
18 firefighters have been coming in, you know,
19 every year for eight years, that we see a
20 number in the consortium people who have been
21 coming in religiously every year, that's pretty
22 extraordinary and I think has some lessons in
23 terms of care in the American medical system
24 that's different in this experience than in
25 your general primary care setting. These folks

1 have gotten a chance to talk to occupational
2 and environmental health experts. So is there
3 -- are there some questions that could be
4 answered about that?

5 DR. MOLINE: I think they're great questions.
6 I think it's something we could certainly add
7 or amend to the application that we put in that
8 wasn't funded that was looking at the overall
9 impact, because they do go in line with how
10 they have -- what the overall impact has been
11 in terms of access, anecdotally. And from
12 working at the Sinai cohort, and now in Queens,
13 the access issue is -- for many folks this is
14 their only source of medical care. It is
15 certainly their only source of medical care for
16 folks who understand occupational and
17 environmental exposures. Countless folks were
18 placed on antibiotics in 2011. There was
19 probably a shortage of antibiotics in the fall
20 of 2011 in New York City from the number of
21 people who were placed on antibiotics for a
22 cough, who didn't have an infection but they
23 had reactive airways or the beginnings of the
24 World Trade Center lung issues that we still
25 see.

1 So access? Absolutely. Have we learned --
2 we've also learned that the treatment -- and if
3 you were to apply the NHLBI asthma guidelines
4 in terms of what's considered good treatment,
5 we'd all be considered horrible clinicians
6 because none of our patients are behaving, in
7 those who have World Trade Center-related
8 asthma, in a way that we would like in terms of
9 being able to have them under good control,
10 meaning needing a rescue inhaler less than once
11 or twice a week. They require it far more
12 often so it's a somewhat different disease. So
13 have we learned something from that in terms of
14 patient outcome and utilization? Yes.

15 Could we look at the fill rates and see if
16 that's made a difference in a program that has
17 covered the costs? I mean certainly we can do
18 that, and it's an important question to say 'If
19 you give people access to these medications and
20 they do in fact take them' -- first of all, are
21 they in fact taking them? Are they using them
22 correctly? One of the elements of all of our
23 treatment programs across the consortium has
24 been the nursing education component and the
25 sheer amount of time that people can spend with

1 a patient, which is different from a primary
2 care practice and the demands. So that has
3 also been of value, and does that mediate the
4 effect? I mean those are all important
5 questions to ask, to look at how has this
6 program made a difference. Certainly in terms
7 of access, there's no question.

8 You know, we've had philanthropic donations
9 that allowed people to even get to the clinic
10 because they didn't have the economic resources
11 for a subway trip, and have been able to
12 provide subway tokens or -- they don't have
13 tokens anymore; I'm dating myself -- but Metro
14 cards for folks because they couldn't otherwise
15 get to their treatment. And removing that
16 barrier, and particularly for folks with mental
17 health issues who need frequent visits, that
18 has often been the difference between them go--
19 becoming compliant and not compliant. And I
20 think those are critical issues to look at.

21 DR. R. HARRISON: I think that there ought to
22 be some way to capture that, what you just
23 said, either in qualitative or quantitative
24 terms. I think that's really, really important
25 because as we look back on this, funding a lot

1 -- will bring a lot of money, a lot of
2 resources into this, and I think there is a
3 question -- you know, what -- is this a good
4 thing to do, from a policy, from a care
5 integration point of view. Are we picking up
6 more people with hypertension and diabetes
7 because of this? Are people losing more weight
8 because they're coming in every year?

9 DR. MOLINE: Losing more weight? No. Are we
10 picking up more diabetes? Yes.

11 DR. R. HARRISON: Yes, I mean I'm just -- yeah,
12 I'm being facetious.

13 DR. MOLINE: But you know, one of the aspects
14 is -- you know, are we turning this -- the
15 programs are prohibited from doing any of the
16 primary care treatment. What we can do is
17 primary care health problem awareness, and
18 increase people's awareness of -- and certainly
19 we are identifying the newly hypertensives, the
20 out-of-control hypertensives, the diabetics,
21 folks with a litany of other medical conditions
22 and trying to urge them to get the medical care
23 and, as being in part of a program, show that
24 the rates may be different is a question. I
25 don't think we've been doing very well with the

1 weight, though.

2 DR. WARD: Would you like to come back up to
3 the table since we're having a more general
4 discussion, and then I think the next tents
5 were John and Julia.

6 DR. DEMENT: Thank you. My question has to do
7 with sort of the process and -- of how you
8 would take some of the leads. The sarcoid is
9 an interesting observation. Sort of the
10 current structure I think is something that
11 needs to be looked at in a lot more detail.
12 How would that occur in sort of the current
13 framework for how the centers work with the
14 care centers? I see it's not one of the
15 research projects -- one of the eight funded
16 research projects, so you know, your comment on
17 how that would go about.

18 DR. MOLINE: The sarcoid question, you know,
19 we've always -- it's been striking, and you
20 know from Dr. Prezant's paper it appear-- the
21 sarcoid was a different type of sarcoid than he
22 described earlier among firefighters even in
23 terms of the symptoms. How we would have to do
24 that would be, with the way things are set up,
25 is we'd have to apply and hope we'd get

1 funding. Or we'd have to find a donor to help
2 fund some of this research, and do it the way
3 that you'd do in a standard way -- which is in
4 many ways a shame that we're not able to easily
5 leverage data that has been collected and say
6 'We have 75 percent of it, but we can't do the
7 research without that last 25 percent.' And to
8 say you can -- or we should be looking at
9 issues, whether it's something about
10 sarcoidosis and trying to identify other
11 etiologies for it, or the factors that may have
12 caused it. I think that the structure as it's
13 set up now is challenging because there's this
14 very clear partitioning between what a clinical
15 center can do and what we would like to do.
16 And many times there's not the financial
17 resources, the staffing, to do anything except
18 provide clinical care.

19 DR. QUINT: Hi, I have I think what is a simple
20 question. I may have missed this, but is there
21 a gender breakdown in the people who are a part
22 of the folks who are being monitored? I don't
23 know if I remember --

24 DR. MOLINE: It's 86 percent male, 14 percent
25 female. It's been steady since 2002.

1 DR. QUINT: Okay. And have you seen any
2 differences between the -- based on gender? I
3 mean different problems or manifestation of
4 problems in women versus men?

5 DR. MOLINE: No, we haven't -- I don't think
6 anyone's looked at it specifically, but you
7 know, anec-- when we think about who we've
8 seen, it hasn't -- there hasn't been anything
9 that's popped out in terms of gender
10 differences. It would be important to see the
11 groups maybe differently.

12 DR. QUINT: Right. And the other question I
13 had, I don't know how many of the people are --
14 have continued to work. I guess I'm interested
15 in terms of the persistence of symptoms over
16 these many years, whether or not there are
17 other co-exposures, either community exposures
18 where people live -- 'cause there could be high
19 pollution which could exacerbate, you know, the
20 in-- you know, the initial WTC impact. Or
21 whether or not, you know, at work there are
22 other exposures that could cause the, you know,
23 symptoms to persist. You mentioned SES and I
24 just think that that's a fascinating thing to
25 look at, you know, not overall in terms of the

1 questions that you raised about the impact of
2 SES. But also we know that, for a number of
3 toxicant exposures, there's a SES pattern, so
4 I'm just -- was curious as to whether or not
5 there's been any look at the data to see if
6 there's any correlation between, you know,
7 where people live or where they work and either
8 severity of symptoms or if that could explain
9 in some way the persistence of symptoms.

10 DR. MOLINE: There hasn't been any work that's
11 been done yet. I think it's something that's
12 critical to look at. And as part of the
13 ongoing monitoring and examinations there are
14 questions about what people's exposures
15 continue to be, to see not only what was your
16 exposure, what were you doing on September
17 10th, what did you do during the time interval
18 that you were working at the World Trade Center
19 site, but what trade are you in and what job
20 are you in -- and we do have addresses and
21 there certainly should -- could be some geo-
22 coding of where people live and diseases and
23 see if there is, and maybe that will be one of
24 your recommendations, which is to also look at
25 whether we are seeing patterns of environmental

1 injustice that are mitigating some of the
2 health effects. Or is that also a co-factor as
3 socioeconomic status has declined as a result
4 of the World Trade Center exposures. Again,
5 those are critical things to look at to really
6 assess the impact. Because if somebody's
7 environment has changed because they can't work
8 at what they did before, their salary's gone
9 down and they're moving to an area that may --
10 as we know, many of the less-advantaged
11 neighborhoods tend to have higher rates of
12 pollution -- or local pollution.

13 DR. ROM: Jacquie and Denise. So we've heard
14 an awful lot today about cough and dyspnea and
15 wheeze, and then we've heard from Mark Farfel
16 about a real increase in new onset asthma, and
17 asthma aggravation also seems to be a major
18 disease outcome that we're seeing a lot of.
19 And then David Prezant presented a 12-year
20 decline of FEV-1 in one year, that he lost 375
21 mls in one year, and this -- that doesn't seem
22 to be recovered. So this all looks like the
23 monitory events leading to COPD, and what we
24 may have is a gigantic cohort of invalids ten
25 or 15, 20 years from now of people who are

1 short of breath and have the effects of all
2 this dust. And so should we be really focused
3 on this disease pathway now to try to identify
4 what may be causes and how do we intervene and
5 should we start thinking about this, 'cause
6 this may be a huge respiratory disease problem.
7 And what we've seen is cardiovascular disease
8 and stroke and diabetes and cancer, now COPD is
9 an emerging huge global problem, and we may
10 have a big problem or disaster in our back yard
11 with emerging COPD, and I'd like your comments
12 and thoughts about that.

13 DR. MOLINE: Sure, and then I'll happily turn
14 the mic over to Denise to answer this, but one
15 of the things we -- I was privileged to
16 participate in while I was at Mt. Sinai was
17 working with Maryann McLaughlin on a law
18 enforcement cardiac study, and we hope to be --
19 we've had several abstracts at national
20 meetings and are working on the manuscripts now
21 of 2,500 law enforcement officers and doing
22 fairly extensive coronary artery risk factor
23 and actual measurements. What we did find was
24 there was a fair amount of diastolic
25 dysfunction or right heart dysfunction, and so

1 the question is is that pulmonary in that I
2 think was the idea for the project that she is
3 now looking at. And there are other factors
4 'cause is it the stress related to being in law
5 enforcement that could be mitigating some of
6 these effects. So -- or is it something
7 pulmonary, because we know there are these
8 pulmonary issues. I think it's a group that is
9 in many ways invaluable for looking at can we -
10 - we've identified -- we know they had a
11 pulmonary insult. Some had symptoms that were
12 manifest, some might not initially have
13 manifest symptoms. Should we be doing
14 interventional trials that are preventive, and
15 I think that -- and thinking outside the box
16 again for looking at creative ways of maybe
17 intervening when there aren't symptoms -- that
18 you know they've had the exposure -- and seeing
19 over time if that will decrease it. We
20 certainly have the power in the numbers of
21 folks who had the exposures and who are being
22 monitored and you've had sequential pulmonary
23 function tests on many, many of these folks.
24 So I mean I think it's a critical issue. And
25 again that's something that could inform

1 medical treatment above and beyond just World
2 Trade Center responders. So in terms of bang
3 for the buck, to answer Dr. Harrison's point in
4 part, is to what have we learned and we've
5 spent a lot of money, and we -- but if we are
6 able to further medical knowledge in general by
7 looking at these very specifically-exposed
8 folks, then the money is very well spent, not
9 just in caring for these people who couldn't
10 otherwise get care, but in understanding or
11 helping others who have these similar disease
12 processes that are occurring more and more.

13 DR. D. HARRISON: We certainly know that a lot
14 of our patients continue to have a lot of
15 respiratory symptoms. What we don't know,
16 however -- and we know that, despite the
17 traditional treatment of some of these
18 symptoms, like cough, they're not responsive to
19 the steroid inhalers or to even systemic
20 Prednisone, so there is need to look into what
21 the etiology of this disorder is. And we think
22 that there's need for continued study whether
23 to look at whether it's a irritant-induced
24 pathway as well as early airway disease, and
25 surely more studies need to be done in this

1 area as to what the etiology is.

2 DR. WARD: Okay. So we'll thank you very much
3 for your presentations and the discussion, and
4 move on -- okay.

5 So the next thing on our agenda is we're going
6 to view the DVD that was submitted by District
7 Council 37, and Lee Clarke will give us a brief
8 introduction on that.

9 MS. CLARKE: My name's Lee Clarke. I'm
10 Director of Safety and Health for District
11 Council 37. DC 37 represents 125,000 New York
12 City -- primarily based in New York City --
13 government employees. Our job titles literally
14 range from A through Z, we're fond to say -- we
15 love saying that. But they are, they're
16 architects, engineers, housekeeping aides,
17 mortuary care technicians, clerical workers --
18 we represent them all.

19 We literally had thousands of our members --
20 our union building actually is right there, and
21 we were shut out for more than ten months. We
22 had thousands and thousands of our members
23 respond and who were right there when the Trade
24 Center fell. The members of DC 37 pretty much
25 characterize our sisters and brothers in the

1 private sector as well. So when you're looking
2 at this, you're looking also at the private
3 sector workers.

4 It's important I think for this Committee today
5 to go back a few minutes to the beginning of
6 this morning where you started to -- you heard
7 about the population, their titles and what
8 they do. And throughout the course of this
9 very long day people turned into cohorts and
10 numbers and letters and graphs and charts.
11 So with that, the minute -- the video isn't
12 very long. It may freeze. Just hit the 'play'
13 button again. And thank you to the Committee
14 for taking the time to view this.

15 I don't know if you get the sound with it. I
16 hope you get the sound with it. That's what
17 you need, is the sound.

18 (Pause)

19 DR. MIDDENDORF: For some reason it doesn't
20 seem to be... I don't know whether or not this
21 DVD player will work or not. Yeah, it -- I'm
22 more worried about the equipment than I am the
23 DVD itself.

24 (Pause)

25 Howard, who is with GSA, is going to take the

1 DVD and play it from the other room.

2 DR. WARD: Why don't we take a short break,
3 about ten minutes?

4 (Recess taken from 4:11 p.m. to 4:19 p.m.)

5 DR. WARD: Committee members come back to the
6 table. We'd like to start the video.

7 I've just been informed we need to conclude our
8 meeting by 5:00 because the building requires
9 us to leave, so we don't have unlimited time
10 here.

11 (Pause)

12 (Whereupon, DVD was played.)

13 MS. CLARKE: The video was made in 2002, right
14 before the upcoming holidays, and everybody in
15 that video, all those workers, were at Ground
16 Zero. Thank you.

17 **COMMITTEE BUSINESS**

18 DR. WARD: We're now at the last part of our
19 agenda, which is set aside for Committee
20 business. What time is it? Okay, it's about
21 4:30.

22 And so I guess the question is what -- I'd like
23 Paul's advice on what would be the most
24 immediate business that the Committee should
25 cover today and what we should defer until

1 tomorrow.

2 DR. MIDDENDORF: I think you might begin
3 discussing what issues are before the
4 Committee, and begin discussing how you might
5 begin approaching those issues. And to do
6 that, you might want to go back to Dr. Howard's
7 presentation first thing this morning in which
8 he laid out what he believes are the issues
9 before you.

10 DR. WARD: This is still a public session, so
11 anyone who wants to is welcome to come -- I
12 mean to stay.

13 So I think there were several issues that Dr.
14 Howard talked about this morning. I guess
15 we're going to discuss the Pennsylvania and the
16 Pentagon issues tomorrow, right? So that's a
17 specific -- we'll be getting an update, but we
18 don't need to make a recommendation?

19 DR. MIDDENDORF: What Dr. Howard said is that
20 there's nothing we can report on at this point
21 so he's not coming to the Committee to ask you
22 to address that. There is -- in your binder
23 that you received there's an update to let you
24 know where we are in that process.

25 DR. WARD: So there's two issues that I recall

1 discussing was the issue of what research
2 recommendations we would have for the next
3 round of funding, and also the consideration of
4 the petition with regard to including cancer,
5 or some specified cancers, as specified
6 diseases.

7 So in the half-hour remaining, perhaps we
8 should tackle -- or begin discussion on the
9 cancer issue, only because I think what we
10 heard today was that there are two studies
11 where the results are pending that -- but not -
12 - but not completed and not available for our
13 consideration that might, you know, really have
14 great bearing on any recommendations we would
15 make about cancer. So the question there is
16 how can we go about making a judicious decision
17 without the two pieces of evidence, 'cause I do
18 think -- you know, as an epidemiologist I wish
19 we had more defined cohorts, like the fire
20 department cohort where we have our denominator
21 and our numerator. But lacking that, I think
22 the information that's coming from the study of
23 the New York Health Registry and the Mt. Sinai
24 cohort is very substantial and important to
25 discussions about whether there is evidence,

1 even preliminary evidence, for increased risk
2 of multiple myeloma, non-Hodgkin's lymphoma,
3 and other cancers.

4 So does anyone have comments about how we
5 should proceed on that?

6 DR. ALDRICH: Let me just first say that I feel
7 that's cause for part of our cancer study. So
8 although I don't think that biases what I have
9 to say, I just want to make sure you know that.
10 It seems to me it's unlikely that there will be
11 more information in the near term, even if we
12 do wait for results from Sinai and the others
13 because there's going to be ongoing concerns
14 about surveillance bias and about the
15 denominator issue. And I don't think we're
16 going to have better evidence than we already
17 have -- and for several years to come. I don't
18 think we should delay making a recommendation.

19 DR. TRASANDE: I'm thinking about this a lot
20 because it seems to me perhaps the primal point
21 the STAC ought to consider right away. I'm
22 still struggling somewhat for almost a menu of
23 options the STAC could recommend to the
24 Administrator. I could see off-hand
25 recommending inclusion, not inclusion, or some

1 middle ground, and I'm still at a loss -- I
2 mean I struggle with the notion, just to start
3 with, of saying -- of recommen-- I'm looking,
4 like most of us on this Committee, for more
5 data and for more perspective. But at the same
6 time I think we need to be proactive and
7 precautionary; yet at the same time I think we
8 want to wait for more evidence, at least from
9 my perspective, before making a semi-definitive
10 judgment. And so I'm wondering what
11 specifically would be a middle -- if we were to
12 simply say 'there's not evidence at this time'
13 I think that could have a potential chilling
14 effect for the communities that are looking for
15 our perspective and our guidance. And I think
16 that that would be also something that I think
17 that Mr. Howard would not necessarily want us
18 to leave him with that suggestion. So I guess
19 I'm looking for some guidance on what -- and
20 maybe this is a bit of reflection back, and I
21 don't know if Paul wants to comment, or others
22 want to comment, about what might be some
23 guidance to the STAC of what would be helpful
24 advice.

25 MR. CASSIDY: I tend to agree with you. It's

1 complicated, but there are a lot of different
2 studies that are out there. The one point that
3 I would like to make about Dr. Prezant's study
4 is that it's a seven-year study through July of
5 2008. When 9/11 happened, I remember
6 specifically the stories being written six
7 months, a year after, 'It's going to take ten
8 years for cancers to show up.' So this is a
9 seven-year study. As the president of the
10 firefighters' union, I already know of several
11 firefighters who are sick and dying, are not in
12 Dr. Prezant's study because they got sick after
13 2008.

14 What I think, when I heard what Dr. Prezant
15 said, when I heard what others say, you know,
16 Dr. Prezant's study is about -- it's just about
17 firefighters, but it's really -- I think it
18 gets to the heart of the exposure. And so it
19 documents -- you know, he went into great
20 detail about the level of exposure --
21 firefighters who were there on day one, day
22 two, day three. And I think it -- you know, I
23 think that highlights something. I think we
24 should discuss what that highlights.

25 But then I -- you know, I think that because if

1 there's not a study of police officers or
2 construction workers who were working in the
3 same area that that doesn't mean that you can't
4 say 'well, one is transferable to the other'.
5 I mean I think we have to have a discussion
6 about what does one study say about others, and
7 does it say something about people who were not
8 working right there on the Pile but lived five
9 blocks away. I think what's been documented
10 today is that you could have severe exposure,
11 you know, living ten blocks away if your
12 building was contaminated and they were blowing
13 contaminated dust through your building. How
14 do we determine that?

15 So I don't think the level of exposure is
16 necessarily -- although I think it largely
17 revolves around how close you were to the site,
18 for what period of time and when you were
19 there. But I do think we need to talk about
20 levels of exposure in some way. And then I
21 think Dr. Prezant's study is really about
22 levels of exposure. I know it's about
23 firefighters, but I think -- I think, I
24 believe, it's about levels of exposure.
25 And then I think can this Committee then look

1 at that, because it seems to be the only
2 documents that are -- the only study that's out
3 there that has pre- and post-9/11. I mean you
4 can't lose 12 years' lung capacity in the blink
5 of an eye and think that it doesn't really mean
6 anything. It means something. Now what does
7 it mean? I don't know we should be discussing
8 it. But I think Prezant's study is more than
9 just about firefighters. I think it's about
10 levels of exposure, and I think we should talk
11 about whether or not we can come to some
12 consensus about level of exposure. And that's
13 my thoughts right now.

14 MS. SIDEL: I think we need to craft a
15 compassionate solution, that we can't just
16 leave people that are sick untreated while we
17 get the correct data. And you know, you're
18 scientists and so you have a certain
19 methodology for doing this, but you know, I'm
20 also aware that you have certain criterias for
21 risk assessment and that's something that, you
22 know, other studies like the National Academy
23 of Science are looking at how those things are
24 done. And so I think that there are so many
25 different factors that to do anything

1 definitive that isn't -- I think that we should
2 somehow craft a compassionate solution, and I
3 think that Dr. Prezant's study is really
4 important. But I don't know -- I mean what
5 else -- you know, how much better can it get?
6 I mean to have all communities that are sick
7 and to have that evidence? I mean it may take
8 a long time, because from what I heard today, I
9 think that a lot of the data has not been
10 compiled because of funding in the past, so a
11 lot of the Centers of Excellence haven't had an
12 opportunity to really compile data the way --
13 the way it needs to be compiled. That could
14 take a long time, and I think that people
15 shouldn't have to suffer because of a failure
16 to fund something.

17 DR. WARD: Now let me just make a comment. Now
18 what I heard today, specifically in relation to
19 the two cancer incident studies, is that the
20 data are for the most part compiled and they're
21 in the process of completing the analyses,
22 which would -- in my mind -- translate into a
23 six to 12-month time frame for us to have the
24 results. But it -- you know, I don't know if
25 others interpreted the comments the same way.

1 But I do want to hear from everyone who has
2 their tent card up. I think, Steve, you might
3 have been first.

4 DR. MARKOWITZ: That six to 12-month time frame
5 is probably right, and I think we have to, you
6 know, express our opinion, even if it's
7 provisional, but before then.

8 I have a couple of miscellaneous thoughts. One
9 is I'd like to -- not this afternoon, but I'd
10 like to seriously discuss the fire department
11 study, because it was positive in the sense of
12 showing cancer effect. It was -- unusual set
13 of results. It's what we have, and it was --
14 the quality was very good, so I think we need
15 to talk about that directly because that's what
16 we -- really what we have in terms of
17 epidemiology.

18 Secondly, I think we have to talk at some point
19 about what criteria we're going to -- we're
20 using to make judgments. And you know, the law
21 says -- and I'm puzzled about this --
22 'substantially likely to be a significant
23 factor in aggravating, contributing or
24 causing', so is that any different from the way
25 we normally think about causation? Because if

1 it is different, then we should be explicit
2 about that.

3 And finally, I think we have to -- again, I
4 don't expect to be able to do this today or
5 tomorrow, but -- take a very serious look at
6 exposure and about biological plausibility,
7 because there's more there probably than we
8 have in terms of epidemiology. And if -- if --
9 it's relevant to the case. I mean it's highly
10 relevant to the case and I think, again, we
11 have to look at those things directly, as fully
12 as we can, and see what we think about them.

13 DR. QUINT: Yes, I guess as a toxicologist I
14 don't usually rely -- wait necessarily for
15 epidemiological data, and I'm concerned about a
16 couple of things. I mean I know the fire
17 department study is pending, and we have a
18 cancer study that needs to be discussed. But I
19 think biological plausibility is something that
20 should be considered. It's what we go with for
21 many toxicants, such as the soup that people
22 were exposed to at 9/11. And I think that --
23 you know, we have cumulative impacts of many
24 carcinogens here, and we have latency, you
25 know, that -- it hasn't been long enough to say

1 that the cancers, some of the cancers, would
2 have developed from some of the chemical-- from
3 some of the exposures. So I think having set
4 the criteria for how we're going to make
5 decisions is important, because I've heard a
6 lot of emphasis placed on, you know,
7 epidemiological studies. And often it's -- you
8 know, if you have those studies, that's -- and
9 they're well-conducted and we don't have
10 confounders -- confounding, that's great. But
11 in the absence of those data, then I think we
12 have to look at what we know about these
13 particular exposures and, you know, bring to
14 the table the biological plausibility that
15 cancer could develop, and we haven't seen
16 cancers because either we don't have the power
17 to see them -- I don't know if somebody's done
18 a power calculation for some of these cancers,
19 but you know, we certainly haven't -- it hasn't
20 been long enough for some of them to have
21 developed, it seems to me. So I think that
22 that should be part of the decision-- part of
23 what we consider when we make a recommendation,
24 however we write it.

25 DR. ROM: I don't think we're there yet for

1 cancer and that's very troubling. My concern
2 with the FDNY paper is several-fold. One is,
3 no particular cancer came out, and I would
4 expect maybe lung or colon or some cancer site
5 to be increased, and that didn't come across.
6 It wasn't there. And we know that there were
7 carcinogens in the mixture. There was a lot of
8 asbestos. There was some benzene and there
9 were polycyclic aromatic hydrocarbons, so we
10 know that carcinogens were there. They may not
11 have been very high, but the exposures were
12 very intense to a lot of people. I don't want
13 to say I'm against compassion, we all have
14 compassion, but we are a scientific/technical
15 advisory committee, and we're going to have
16 critics out there of anything we say, and we
17 have to be on solid footing to -- before we say
18 anything so that the critics can be quelled.
19 So a 1.2 -- or a 20 percent increase is not
20 that impressive, I wouldn't -- everything below
21 two is a little bit bothersome. I like to see
22 threefold and fourfold. When you have eight
23 multiple myelomas and 6.8 are expected, you
24 know, I want to see 16 or 20 and then I feel a
25 little bit more confident and I'll stick my

1 foot out -- and my neck out. So I think we
2 need more data. And it's nice that there are
3 some studies coming down the pike, but I would
4 push NIOSH heavily that they are -- that the
5 Administrator's in a pickle and we need more
6 data. And there are research BAAs coming down
7 the pike and we should start thinking about how
8 these BAAs are going to generate data that's
9 going to answer some of these critical
10 questions. We need studies that address cancer
11 and we need studies that address asthma, and we
12 need some more of this science. And if there's
13 just four of these funded when there's like
14 eight or nine really good ideas and a bunch
15 that are on cancer or biomarkers or monitoring
16 or modeling, those might move up in the
17 priority list.

18 MS. DABAS: I have to say that I think we
19 should make some kind of decision when it comes
20 to cancers. For one, I think the fire
21 department has probably some of the best
22 information that we're going to get because
23 they have information on the responders prior
24 to 9/11 and after 9/11. Mt. Sinai's study is
25 not going to have the pre-9/11 information on

1 their people that they are gathering on. I
2 also know that Mt. Sinai has not done an
3 exhaustive search for responders with cancer.
4 One of the things that they are still doing,
5 and I believe haven't even done to date, is to
6 reach out to the NYPD to get the list of
7 responders to cross-check that with the cancer
8 registry. So I don't believe that their
9 specific study is going to come out within the
10 first quarter of the next year, which they've
11 said that it would but have backed away from
12 that timeline time and time again. And if
13 we're going to wait for Mt. Sinai to get to
14 that -- I also spoke to the WTC Registry, who
15 also haven't contacted the NYPD to identify any
16 members that were there so that they can also
17 cross-check their study with the cancer
18 registry. Mt. Sinai also had informed me on a
19 separate occasion that they will not include
20 the 49 police officers that have died of cancer
21 to date, which -- because they would not be
22 able to make a proper assessment of where they
23 were at the World Trade Center and how long
24 they were there for. I think that was going to
25 greatly skew their numbers. So to date I think

1 the fire department study might be our best
2 study.

3 The multiple myeloma as well, Jacquie Moline
4 did cite -- while she said the number of
5 occurrences was not high, the age of the
6 occurrences were. When you have people, six
7 out of the 16 of the multiple myeloma cases
8 were of men under 45 in a disease that shows up
9 at 70, that I think is a number that we need to
10 look at.

11 MS. MEJIA: Well, I don't even know where to
12 start, but all I can say is that I am not a
13 statistician. I am not an epidemiologist. I
14 am not a toxicologist. But I do know -- what I
15 do know is that we have a lot of members and a
16 lot of workers out there that have developed
17 cancers since 9/11. Now the question I have is
18 should all cancers be covered, and that's
19 something that I think we need to, you know,
20 discuss a little bit further because cancer is
21 cancer, and so we need to determine whether
22 we're going to cover one cancer versus another
23 cancer, or are we going to cover the entire
24 world of cancers. And so I do have that
25 question out there.

1 MS. SIDEL: I already touched on what I was
2 thinking, but one thing that I'm concerned
3 about is this whole thing with creating zones
4 and what day were you there, because you could
5 go into your apartment and have -- and get a
6 great big pile of dust in your face, and you
7 could have a predisposition toward something,
8 and it could have happened three months after
9 the fact. But those toxins don't get less
10 toxic -- I don't think, do they? I mean I
11 think that they are what they are. And so no
12 matter when you get them, you know, when they
13 get into your system they're going to do the
14 same thing. And every body -- and I mean body
15 -- is different, and I think that -- I
16 understand as scientists you want to find a
17 commonality. I think it's really hard and it's
18 unfair to a lot of -- I think that there's no
19 way to not exclude people that need to be
20 included.

21 DR. WARD: At this point there are many complex
22 questions, and I think -- you know, what you
23 said really kind of resonated with me because I
24 think -- you know, when you look at the
25 firefighters study and you look at the results,

1 and there were excesses for specific cancers
2 and there was a somewhat -- there was also an
3 excess for cancer overall, but it was not
4 large. And so you look at that and you say
5 okay, if you wanted to be compassionate and
6 cover some cancers, which one of those cancers
7 would you feel that there was enough evidence,
8 you know, to say was associated with the
9 exposure? And I think from those results it
10 would be very hard for most of us to say
11 there's one. I mean I'm certainly concerned
12 about the multiple myeloma because we've heard
13 about it in more than one population. Some of
14 the others, like thyroid and prostate, you
15 know, it's -- it would be hard to single them
16 out because again we know they are susceptible
17 to early detection -- whether there's detection
18 bias or not, those are cancers that are just
19 very susceptible to being detected when people
20 see a physician. So it's really -- even though
21 I think it is a strong study, there's not a
22 single pat-- there's not a single cancer or a
23 pattern that's kind of screaming that it's
24 causally related to the exposure. And so I
25 think that's the dilemma we face. Plus, of

1 course, the very complicated issues of what --
2 you know, the different exposed populations and
3 what constitutes high exposure and how do we
4 best characterize exposure in all these diverse
5 circumstances.

6 So we do have to close at 5:00 and I think --
7 does -- we can certainly mull these questions
8 over tonight and come back in the morning
9 refreshed, and hopefully come to some
10 completion. I doubt that we'll come to a final
11 conclusion, but hopefully we'll have some level
12 of consensus on a plan for how to proceed and
13 what criteria we should use, and kind of how to
14 frame the discussion tomorrow so that we make
15 the best use of our time together.

16 So I guess it's about time? Yeah. Well, thank
17 you -- oh, yes?

18 DR. TRASANDE: I'm just looking for the Chair
19 and Paul's guidance here with regard to whether
20 -- with regard to what our agenda is for tom--
21 for the half-day tomorrow. Is our intent to
22 focus on the cancer question? Are there other
23 questions of import that we're -- I mean I'm
24 just cognizant that we want to use our time
25 efficiently as well and respond -- I recognize

1 we have three core missions that Administer
2 Howard outlined here, and I just -- I'm only
3 asking that because I think we should try to
4 think about it rather than mull that and have
5 it be uncertain until the morning -- tomorrow
6 morning.

7 DR. MIDDENDORF: What I would say is that you
8 have a definite deadline on the cancer
9 petition, so that's something that you must
10 begin discussing tomorrow. You need to plan a
11 way forward, how you're going to address that,
12 and then come up with a recommendation by March
13 2nd that you can give to the program
14 administrator.

15 I think the research issue is something that is
16 on the table that maybe you want to start
17 thinking about just process, how you might as a
18 Committee begin addressing the issue as to how
19 you might develop recommendations for Dr.
20 Howard as the program administrator. But I
21 would not get into any details at this point in
22 time because of the potential for conflicts of
23 interest. That's something we're going to need
24 to deal with between now and when you start
25 getting down to specifics.

1 DR. WARD: So I think it would make sense that
2 when we reconvene that we first discuss the
3 cancer question, but that we agree in advance
4 that we'll have a certain amount of time set
5 aside for the research question because I think
6 it is important, after all we heard today, to
7 really identify some top areas that we'd like
8 to see addressed in the research agenda, while
9 all the discussion from today is fresh in our
10 minds.

11 DR. MIDDENDORF: That's -- why don't we say
12 8:15, just to make sure the people can get
13 through the door. Does that work for
14 everybody, 8:15 in the morning? Great. Have a
15 good evening.

16 DR. WARD: Thank you, everyone.

17 (Meeting adjourned at 4:59 p.m., to reconvene
18 at 8:15 a.m., Thursday, November 10, 2011.)
19
20
21

CERTIFICATE OF COURT REPORTER
STATE OF GEORGIA
COUNTY OF FULTON

I, Steven Ray Green, Certified Merit Court Reporter, do hereby certify that I reported the above and foregoing on the day of November 9, 2011; and it is a true and accurate transcript of the proceedings captioned herein.

I further certify that I am neither related to nor counsel to any of the parties herein, nor have any interest in the cause named herein.

WITNESS my hand and official seal this the 6th day of December, 2011.

STEVEN RAY GREEN, CCR, CVR-CM, PNSC
CERTIFIED MERIT COURT REPORTER
CERTIFICATE NUMBER: A-2102