

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

**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
WORLD TRADE CENTER HEALTH PROGRAM**

SIXTH MEETING

SCIENTIFIC/TECHNICAL ADVISORY

COMMITTEE (STAC) MEETING

June 4, 2015

The verbatim transcript of the
Meeting of the Scientific/Technical Advisory
Committee Meeting held on June
4, 2015, 10:00 a.m.

**WORLD TRADE CENTER HEALTH PROGRAM
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C O N T E N T S

June 4, 2015

WELCOME AND INTRODUCTION

DR. ELIZABETH WARD and DR. PAUL J. MIDDENDORF

CHARGE TO THE COMMITTEE - 'QUESTIONS FOR DELIBERATION'

DR. JOHN HOWARD

THE WTC HEALTH PROGRAM - STRUCTURE AND FUNCTIONS; RESEARCH TO CARE MODEL

DR. DORI REISSMAN

THE WTC HEALTH PROGRAM - ACTIVITIES, MEMBER SERVICES AND COMMUNICATION

MS. LAURIE BREYER

OVERVIEW OF WTC HEALTH RESEARCH

DR. TRAVIS KUBALE

WTC HEALTH REGISTRY: AN UPDATE

DR. MARK FARFEL

MENTAL HEALTH LESSONS LEARNED

DR. NOMI LEVY-CARRICK

PUBLIC COMMENTS

DR. PAUL J. MIDDENDORF

DISCUSSION OF 'QUESTIONS FOR DELIBERATION'

DR. ELIZABETH WARD

ADMINISTRATIVE ISSUES AND ADJOURN

DR. ELIZABETH WARD and DR. PAUL J. MIDDENDORF

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

PARTICIPANTS

(alphabetically)

THOMAS ALDRICH - COMMITTEE MEMBER
ROSEMARIE BOWLER - COMMITTEE MEMBER
ROBERT BRACKBILL, PhD – NEW YORK DEPARTMENT OF HEALTH SENIOR SCIENTIST
LAURIE BREYER - PROGRAM MEMBER SERVICES MANAGER
MARK FARFEL, ScD - WTC HEALTH REGISTRY DIRECTOR
ANTHONY FLAMMIA - COMMITTEE MEMBER
KIMBERLY FLYNN - PUBLIC COMMENT
ROBERT HARRISON - COMMITTEE MEMBER
JOHN HOWARD, MD - PROGRAM ADMINISTRATOR
CATHERINE McVAY HUGHES - COMMITTEE MEMBER
MARIAMA JAMES - PUBLIC COMMENT
VAYLATEENA JONES - COMMITTEE MEMBER
MICKEY KELLY - COMMITTEE MEMBER
TRAVIS KUBALE, PhD - NIOSH OFFICE OF EXTRAMURAL PROGRAMS
NOMI LEVY-CARRICK, MD - NYU SCHOOL OF MEDICINE MENTAL HEALTH DIRECTOR
STEVEN MARKOWITZ - COMMITTEE MEMBER
MICHAEL McCRAWLEY - COMMITTEE MEMBER
JIM MELIUS, MD - PUBLIC COMMENT
PAUL J. MIDDENDORF, PhD - DESIGNATED FEDERAL OFFICIAL
LILA NORDSTROM - COMMITTEE MEMBER
DAVID PREZANT, MD - PUBLIC COMMENT
DORI REISSMAN, MD - PROGRAM ASSOCIATE ADMINISTRATOR
WILLIAM ROM - COMMITTEE MEMBER
GLENN TALASKA - COMMITTEE MEMBER
LEONARDO TRASANDE - COMMITTEE MEMBER
ELIZABETH WARD, PhD - COMMITTEE CHAIR-PERSON
VIRGINIA WEAVER - COMMITTEE MEMBER

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

WELCOME AND INTRODUCTION

DR. MIDDENDORF: Good morning, everyone. I am Paul Middendorf and I am the designated federal official for the World Trade Center Scientific/Technical Advisory Committee. I'd like first to extend a warm welcome to each of our committee members, and want to point out that we have six new members for whom this is their first meeting. We are looking forward to hearing everyone's thoughts and ideas as we discuss things during the meeting. I also want to extend a warm welcome to the members of the public who are here with us in the room and also to those of you who are on the phone. We very much appreciate your interest in these proceedings.

Even though it has been almost fourteen years since the terrorist attacks, it's important for us to remember why we are here and set the appropriate tone for the meeting. To help set that tone, some of the members of the committee actually went to the 9/11 Museum yesterday. That was very enlightening and I think very helpful for the committee members, so we did that. But I think we should also take a few moments here and spend them in silence to remember those who were killed in the attacks on 9/11 and also those responders and survivors who have since died because of those attacks.

[Moment of silence.]

Okay, thank you very much. There are a number of administrative issues to deal with on the front end. First, I want to point out where the exits are. You can exit out of either side here, and then go through those sets of double doors. And if it's an emergency, we need you to go down the fire exits, you turn immediately to the left down the corridor, you get Stairwell C and we'll go down that way. If you need bathrooms, you can go out the double set of doors and turn to the left immediately, or you can go through both double sets of - double doors and go on down the hall. There are bathrooms next to the elevators.

For those of you who have signed up to provide public comments, they are scheduled to be in at 1:30 this afternoon and that's Eastern Daylight Savings Time. For those of you here, please come up to the podium when I announce you and we will give you five minutes to make your comments to the committee. Copies of the written public comments that were received have been provided to the committee before the meeting and they will also be posted in NIOSH's docket number 248-B, which is also available through the committee's website.

One thing I need to do is a roll call. For our roll call, I will call out the name of each member. Please indicate your presence for the record. So we'll start with Tom Aldrich?

DR. ALDRICH: Here.

DR. MIDDENDORF: Rosemarie Bowler?

DR. BOWLER: Here.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

DR. MIDDENDORF: Anthony Flammia?
MR. FLAMMIA: Here.
DR. MIDDENDORF: Bob Harrison?
DR. HARRISON: Here, on the phone.
DR. MIDDENDORF: Thank you. Catherine Hughes?
MS. HUGHES: Here.
DR. MIDDENDORF: Vaylateena Jones?
MS. JONES: Here.
DR. MIDDENDORF: Mickey Kelly?
MR. KELLY: Here.
DR. MIDDENDORF: Steve Markowitz?
DR. MARKOWITZ: Here.
DR. MIDDENDORF: Mike McCawley?
DR. McCAWLEY: Here.
DR. MIDDENDORF: Lila Nordstrom?
MS. NORDSTROM: Here.
DR. MIDDENDORF: Bill Rom?
DR. ROM: Here.
DR. MIDDENDORF: Glenn Talaska?
DR. TALASKA: Here.
DR. MIDDENDORF: And Leo Trasande is not here at the moment. And Liz Ward?
DR. WARD: Here.
DR. MIDDENDORF: And Virginia Weaver?
DR. WEAVER: Here.
DR. MIDDENDORF: Okay, thank you.
(Inaudible @ 00:03:37).

I'll point out the copies for this meeting are in the back, and for those of you who are on the phone, you can find copies of the agenda on the committee's website. Because this meeting includes issues related to research and several of our members have interest in doing research on World Trade Center-related matters, it's important that we manage the potential for conflict of interest, and each of our members has been counselled on the limits of their participation and may need to recuse themselves from certain discussions. And with that, I will turn it over to our Chair, Dr. Ward.

DR. WARD: Thank you, and I'd like to echo Paul's warm welcome to everyone, both the new and old members of the committee, those who will be presenting today and the members of the public who have joined us. When we get into the discussion parts of the meeting, I'd like everyone to use their—turn their name tent this way in order to indicate that they'd like to speak. That way we can keep—make sure everybody gets the opportunity to speak who would like to. I think it would be

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- good to go around the room just briefly and have everyone introduce themselves and say a little bit about what they do and their...and their connection with the issues before the committee.
- DR. MIDDENDORF: I'd also point out that if Bob Harrison wants to join the conversation, he can just let us know and then we'll put him in the queue.
- DR. WARD: Okay, good, so we'll start with Steve?
- DR. MARKOWITZ: Steven Markowitz, I'm an occupational medicine physician and epidemiologist, and I run now the Barry Commoner Research Center in Environmental and Occupational Health at Queens College, City University of New York. 2003 to 2011, I ran the Queens Clinic as part of the WTC Health Program, and now still involved with a research project which is based at Mount Sinai on World Trade Center asthma.
- MR. KELLY: Mickey Kelly, I am the Executive Director for Health and Safety with the Laborers' Union in New York State. Primarily in the City, I deal with Locals 78 and 79. A lot of our members were involved—involved in the recovery work, and I've been working with them since on the World Trade Center health issues.
- MS. JONES: I'm Vaylateena Jones. I'm a member of the World Trade Center Steering Committee. I'm a resident of Community Board 3. I got involved because I have young relatives, that are not so young right now, who had trouble breathing, and relatives that had to walk across the Brooklyn Bridge so that their children could breathe, and so that's why I'm here.
- MS. HUGHES: Good morning, my name is Catherine McVay Hughes. I'm also on the same Steering Committee with Val, the World Trade Center Survivors' Steering Committee. I'm also on the World Trade Center Health Registry. I was also appointed when there was the EPA World Trade Center Technical Advisory Committee before this committee was created, and I am also Chair of Manhattan Community Board 1, and I—our family of four is one block east from the World Trade Center site.
- MR. FLAMMIA: Good morning to everyone. My name is Anthony Flammia. I am a retired police officer from—with the NYPD. I was actually severely affected by 9/11, standing in front of the towers when it came down. I've spent over 300 to 400 hours at the site itself. I currently sit on the Board of Directors for the FealGood Foundation; also the Responders Remembered Park in Nesconset, New York. I have also extensively been down to Washington DC for many, many years getting the James Zadroga Act passed originally, and I am looking forward to serving on this.
- DR. BOWLER: I am Rosemarie Bowler. I am on the STAC Committee, the Scientific and Technical Advisory Committee, and I have done work and—both primarily with research but also treatment with persons involved to disasters for many, many years, and became interested very early on in 2002 in the police, and had access to learn about what was going on for them. I have since published, together with

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- colleagues, four or five papers on PTSD and related issues for the police in particular. Thank you.
- DR. ALDRICH: I am Tom Aldrich, I am a pulmonologist and Professor at Albert Einstein College of Medicine at Montefiore Medical Center. I have been involved in World Trade Center research, mostly involving respiratory disease, since soon after 9/11, and I've been on this committee since it formed.
- DR. WARD: Hi, I'm Liz Ward and I'm currently—run the Intramural Research Department at the American Cancer Society. Prior to that, I worked for 21 years at NIOSH, where I did research on occupationally related cancers. I have been Chair of the committee since its inception.
- DR. WEAVER: Good morning, I'm Virginia Weaver. I am an occupational medicine physician and associate professor at Johns Hopkins University. I've been on the Medical Advisory Board of the International Association of Fire Fighters for about 20 years, and so a fair amount of work with them relating to cancer risk in fire fighters.
- DR. TALASKA: Hello, I'm Glenn Talaska at the University of Cincinnati where I'm Professor and Associate Department Director of Department of Environmental Health. My research is mostly on cancer and cancer biomarkers and developing and utilizing those. I'm an industrial hygienist and toxicologist at UC.
- DR. ROM: I'm Bill Rom, I'm a pulmonologist and occupational medicine physician since 1975. I just finished 25 years of NYU Pulmonary Critical Care Medicine Division directorship, and now I work in the Public Health School at NYU and direct the William N. Rom Environmental Lung Disease Laboratory at Bellevue, and we do—hopefully we'll be doing studies in the future on World Trade Center respiratory health effects.
- MS. NORDSTROM: My name is Lila Nordstrom and I am the Director of StuyHealth, which is a survivor group that does outreach and advocacy work for young adult victims of 9/11, and I was a student on the day of the attacks and during the aftermath, which is sort of primarily who we seek to represent.
- DR. McCAWLEY: I'm Mike McCawley and I'm Interim Chair of the Department of Occupational and Environmental Health at the School of Public Health of West Virginia University. I also retired after 27 ½ years with the National Institute for Occupational Safety and Health in Morgantown where I mostly did the respiratory disease work.
- DR. WARD: Our—our first speaker today will be Dr. John Howard.
- DR. HARRISON: Hi, hi—hi, this is Bob Harrison, I just want—
- DR. WARD: Sorry, Bob.
- DR. HARRISON: Good. That's okay. I wanted—I was about to compliment everybody for how well I could hear them and then you all forgot about me.
- (Inaudible @ 00:11:25)
- DR. HARRISON: So first of all, I just want to thank everybody for the flexibility and allowing me to

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

participate by phone. I've been a member of the STAC for several years, and I (don't know @ 00:11:38) everybody really well, I appreciate that. I—I'm originally from New York, born on Long Island. I went to Albert Einstein (inaudible @ 00:11:47) that's my alma mater, and for the last 30 years I've been out in California where at UCSF I founded and direct the Occupational & Environmental Medicine Clinic. I diagnose and treat work and environmental diseases and injuries, and I do a lot of research both with UCSF and the California Department of Public Health.

DR. WARD: Thank you.

CHARGE TO THE COMMITTEE - 'QUESTIONS FOR DELIBERATION'

DR. HOWARD: Thank you, Dr. Ward, and good morning to everyone, and a special good morning to Dr. Harrison out in California. I'd like to welcome—

DR. HARRISON: Thank you, Dr. Howard.

DR. HOWARD: I'd like to welcome all of you here that are with us in New York and those that are joining us on the telephone. This meeting of the World Trade Center Health Program Scientific and Technical Advisory Committee is extremely important to all of us that work in the program. I'd like to welcome all the returning members, thank the Chair for her service and all of the returning members, and especially like to welcome Rosemarie and Anthony and Vaylateena and Mickey and Mike and Lila. Thank you very much for your service. It's not easy to get on the committee; it's a lot of paperwork. We appreciate you completing that paperwork and congratulate you on successfully doing so.

[Laughter]

My introduction is short because I want to preserve time for our program presenters, public input, and especially your comments and advice, and there's a lot of issues facing the program, and I'm asking the committee to consider four in particular. Now, these are not my issues. These issues are the result of a process within the program where we asked for important issues that we wanted you to address. So everybody in the program participated, essentially, in queuing up. Now, there are way more than 4 but we thought that giving you 29 to deal with at your first meeting would probably be a little much. So we chose four of the most important ones right now and we appreciate your comments and consideration on those four.

First, children exposed to 9/11 are aging, as we know. If research is not conducted on this cohort while they are still children—or, as Lila says, young adults—to what extent will the opportunity to discover relationships between the 9/11 exposure(s) and developmental milestones or other health effects be lost forever? What are the most important developmental and age-related health outcomes that should be targeted in such a cohort?

Second, World Trade Center researchers consistently indicate the need for

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

“external” referent groups for comparison of health outcomes with WTC exposed populations. How could the World Trade Center Health Program identify and develop robust and appropriate comparison groups to improve the validity and the interpretability of World Trade Center research, and provide potentially for a future post-disaster research model?

Third, the Centers of Excellence and the Nationwide Provider Program Network (sic) are required to provide benefits counseling to its members. Each of the CCEs in the nationwide program have staff and an internal process for triaging members to appropriate counseling, and have established a level of counselling provided within their own CCEs and the national, nationwide program. In an effort to streamline benefits counseling, the World Trade Center Health Program is working to identify gaps in the area of benefits counselling across the program, and provide recommendations for streamlining the process across all of our contributing centers. After reading the current program recommendations for streamlining benefits counselling which will be presented to you, what other recommendations would be helpful for you to provide to us?

And fourth, the “Research-to-Care” model, as you will hear about presented later on this morning, relies on strong linkages between health surveillance, research and clinical care to produce the outcomes of the logic model that you will be presented. Are there any missing linkages or other ways that the model might be improved?

Again, I want to thank each of you for your service, and have a great committee meeting. Thank you.

[Applause.]

DR. WARD: Thank you. Our next presenter will be Dr. Dori Reissman.

THE WTC HEALTH PROGRAM - STRUCTURE AND FUNCTIONS; RESEARCH TO CARE MODEL

DR. REISSMAN: I guess you all have what you need in front of you, inside the books. I’m here to talk with you today a little bit about the program structure and the logic model that was just mentioned, and I think it’s probably good that we have that early on because that is something where you really need to be awake for. Thank you.

Ah, okay, is there a pointer on this thing? Okay.

So, we’ll stay with this particular slide. We’re going to start with the actual program structure, and my role in this is, as the Associate Administrator in the program, which is now a division within NIOSH, and if you’re looking particularly at our organizational chart, for those of you who aren’t looking up at the screen, you will see that the gray boxes are boxes that exist within the Director’s office, and that was Dr. Howard. So as the Director of NIOSH, he is also the World Trade Center Health Program administrator, and this Advisory Committee—the STAC as we like to call it—is part of his particular discretion.

Along with that is the administrative rule-making component, and that’s why they

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

are shaded boxes because they are outside the division. Everything else is run within the division at NIOSH, and that includes things like any kind of research that is conducted that is extramurally funded, and other types of analytical projects that might be done either within the data centers or within the program itself using the data that we have as our administrative record, and we do program integrity work which has to do with how we report up our chains within government, for us sticking to what it is we say we're going to do, that we're actually doing it, what kind of quality is going on inside government, as well as the kinds of program goals that we are hoping to achieve and whether we are achieving that.

The aspect of operations is the rest of what you see in the program, and within those operations, we actually oversee the healthcare component of the program, and that's fairly complicated. It's not just the rendering of healthcare services but it's all the ways in which the authorizing legislation has required us to maneuver in order to certify health conditions and to look at the benefits, and to make sure there is no fraud, waste and abuse and things like that. And we have to pay our providers for the services that they render, and do that like a healthcare system would do anywhere. So we adjudicate claims and we pay those claims. We can't pay them directly, so we have a tortured system where we have to go through the Centers for Medicare & Medicaid to actually get to the Treasury. So in true government fashion, we have a tortured road but the job gets done. So, in our next slide—here we go—I'm going to talk about, now that you've seen who we are, what we are doing on the government side, how do we organize our program to actually address all the goals and things that we want to achieve? We are using a logic model, which is going to be the last slide, but that logic model is a—it's a way to capture the kinds of activities and efforts that are going on in the program, and it's a way to communicate a little bit about the strategy that we have put the program together with. One of the things I really want to highlight in this, just like this particular committee actually emulates people who were affected by 9/11, clinicians who take care of the patients that are in the program, and the researchers who have been also working with the other two, the clinicians and the stakeholders or the affected members. Those kinds of communities of practice, that's kind of like what I want to call it, really make a huge difference, and it makes this particular disaster, in a positive way, stand out from many other disasters that we have unfortunately endured, in that we have had the largest and longest-running cohort going that really is a bioinformatics laboratory. So we have information that we gather, we have health surveillance that we gather, and we have healthcare that is provided as a result of all of this, and within the benefit structure that we are allowed to administer as a federal healthcare program.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

One of the things that we really try to work with is as we learn information, we try to take that information and disseminate it back into our clinical program as much as possible. Part of this is done through research scientific meetings that actually were conducted in this room a couple of weeks ago, and other ways that we do it are through things on websites where we are working with some other products that I think Laurie will talk to you about in a little while. And those kinds of communication tools are incredibly important because it's not just for the people who were affected, but it's the scientific community, it's the practice community and how we're ready from a health and medical perspective going forward. So we're going to switch to the logic model now and this is a very, very busy slide, but part of that is the wow effect of yes, there is a lot that goes on in this program; and part of it is the fact that while this is two-dimensional and it looks as though it goes from left to right, it's actually a matrix and you would fold this up and you would constantly have different pieces, different boxes on here interacting with each other.

So if you start on the left, the way logic models typically run, you have a bunch of inputs here, everything within our program: the people who were affected, the actual Act that allowed us to provide services from a federal perspective, the Clinical Centers of Excellence, our program staff, data centers, the network of providers that we utilize across the country, the extramural researchers, and the Advisory Committee yourselves are all part of the inputs within our program. And if you look at the activities—and while this isn't all the activities, because you can't list everything, we've chosen some of the activities to highlight here, those being the fact that our extramural program undergoes peer review from a technical merit perspective, so you have high-quality technical science being conducted. You have high-quality provider networks who are selected by the Clinical Centers of Excellence. The excellence comes not only from the medical knowledge but from the long-term relationships that these providers have had with the affected individuals, and that really kind of matters in terms of the trust that has developed and the nuances that have been learned because of the volume of people that they have been working with for years.

High-quality patient care is another reason why these clinical centers were selected, and that kind of patient care has lots of different pieces of oversight within their own institutions as well as other federal components of that. You have medical quality indicators, things like how well do we care for asthma, for instance, in our program? How do we compare against other national metrics of the care of asthma? And our care is extremely high, so it's rated extremely well. Analyzing health surveillance—this goes to the components of the monitoring exams that have been collected on the responders and the survivors who have been certified for conditions. So in the monitoring component, it is a health

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

surveillance examination. It is something that has been followed now for ten years for some people, or more; and others who are still entering this process. So we have a time view of health burden on individuals, and to some degree we have also had the ability to look at how things are developing over time, so some of the latent things that occurred like the cancer issues that were brought before you early on as this particular committee first convened.

And then the translation activities that take the information from health surveillance and from science and turn that into products that help educate the clinicians and try and help educate the membership and the general public about the kinds of things that have been found here. You know, the public memory is very short, and I am sure you have all really seen that. Even as we face the reauthorization component within the Act to be able to continue the healthcare program and the research components of that, there's people out there now who don't have memory of 9/11 who might be making influential decisions, and this is just the life of something that goes on, and you have to keep that particular memory alive. So you need those products out there; you need them to be effective, and in our current generation of 30-second, you know, blips of time that you can listen to something, social media becomes incredibly important because nobody has the time to read a paper or even read a one-pager. You know, that's a little too long these days.

So when you look at our outputs, which is now the blue column if you have a color version, the blue column of the outputs was really how we designed our research program. We wanted to know, well, why in an acute, nasty event like this was, this devastating event with so much exposure, why did the acute health effects become chronic? What is it about the nature of the exposure or the nature of something that goes on with all of this that created chronicity?

Inflammation seems to be some common pathway in all of this; something with inflammation but we don't—our science doesn't really understand it, but we have been identifying some things along the way that have been helping us in terms of how we provide the care, and we need to continue to look at that component.

We also needed to understand what conditions were emerging, whether they were latent or they were right away, and they were linked with the exposures, because we didn't have the characterization of exposure the way you might have in a controlled experiment. We had a horrible disaster and things weren't measured early on, and it's never going to change. It's never going to be improved from that perspective, and all we have are proxy measures that have been done in the research to try and talk about what kinds of exposures happened. And it's only time that's going to prove us right or wrong in the assumptions that we have made in our political program to try and cover conditions, and the whole cancer piece that you all helped us with is a big piece

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

of that.

So when we look toward the future and we look towards how do we understand the aerodigestive conditions, the connectivity between respiratory and mental health and the wellbeing component of our population, and the fact that for people who were really grossly affected, it's taken so long for some of them to have any kind of retribution from either a workers' comp system that doesn't work so well or a victims' compensation system that takes a very long time to do what it needs to do, all these things have created a situation that blocked people from recovery. And so some of our research and some of the things that we need to be paying attention to really have to pay attention to that wellbeing, and what are the lessons from all of this that pertain to our future and how we get better ready for the future disasters that will, unfortunately, come our way.

If you look at our short-term outcomes, which is the sort of pinkish—the short and the intermediate outcomes—we have done a lot to recognize conditions and in recognizing them, once we recognize them and we can add them to the list through a highly bureaucratic process of rule-making, we get them on the list, we provide the care, we disseminate this information with our clinical centers. They work in partnership with us to try and identify the people who have been involved and get them into the proper care, get the right types of cancer screening and other types of program screening done so that we can identify people as early as possible and try and do at least secondary prevention, which is not perhaps preventing the exposure but preventing the illness from getting worse and worse, and causing really horrible disabilities, more than they already have.

Part of this is also educating our providers. You know, one of the things that we have been seeing among our clinical centers is that people do move on and some of the doctors leave, and sometimes they go to another clinical center which is, you know, great for the patient population but very hard for the center from which they came from because you have to train new people up. How do you train them? How do you imbue all of what has been learned over time, and how do you then move that into the world of training, like we have these grants with our Educational Resource Centers for Occupational Health. Those are the children of Occupational Health. We want to be able to train them for the next generation of being able to be smart about the kinds of exposure/disease linkages that we have appreciated, and the comorbidities and the kinds of lessons that we have had to learn that you'll hear more about later today with Dr. Levy-Carrick.

So moving through the intermediate outcomes, you can see that medical monitoring is there. We have had revisions probably numbering up to fifty of the types of monitoring that has been done, the nature of the questions that were asked and how we learned about them. The problem is you can't keep changing

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

the question and expect to have (inaudible @ 00:13:57) valid data. So sometimes you do the best you can early on and then you have to live with that, and you try and do what you can out over time. One of the things I think that we suffered from in terms of the Health Registry, and while it had a lot in terms of the exposure components and a lot of different types of exposure, we don't have comparison populations. We don't have comparison populations outside of this, but how could you have identified one? And that is something that I do believe is being asked of you to consider: are there ways in which we could think creatively about that? And that could help us with our intermediate outcomes and our science.

The long-term outcomes here, where it says, "Improve member health and wellbeing," wellbeing is an emerging area of science. It's been out in the Scandinavian literature for a while and other aspects of European literature. We are trying to do some work like that in NIOSH with Total Worker Health. There's aspects of that within our population that we could really hook up into. If you have workers who haven't been able to go back to work, what type of work rehabilitation has happened for them? If you have people who might not be signed up in our program as responders, they may still have been workers who fell out of their workforce roles. There's a lot of things that contribute to wellbeing and the interaction between disease and what actions people take in their life is a huge area of untapped question, if you will.

Improving our future disaster response is incredibly important, and we do have a couple of examples of where we've done that so far. At least through the program, the monies have been available through the New York City Department of Health and Mental Hygiene where they have been able to improve their web design capabilities and ability to quickly serve up surveys, and a good example of that is the looking at the registrants within the registry and being able to ascertain what happened to them in Hurricane Sandy, which was very devastating to this area. It was a quick way to get in there and get some really good knowledge that helped direct resources, and that kind of thing is an important contribution that has last (sic) beyond what our program is all about.

And now what I want to leave you with is this concept, again, of communities of practice, of the bioinformatics that we've been able to do in different ways. It's not perfect, it was something, but it has a lot to contribute and we can do more with it if we get good guidance around it. So I look forward to your deliberations and thank you for your attention.

[Applause.]

DR. WARD: So we have about five minutes if anyone has questions for Dr. Reissman. Steve?

DR. MARKOWITZ: So my questions actually relate or feed into the questions that we are being

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

asked to look at in the afternoon. One is you mentioned that the yield of the—of the screening and the monitoring pro—the monitoring and the treatment program, and the research, is useful for the providers within the World Trade Center Health Program who turn over. So what are the mechanisms actually whereby the practitioners within the WTC Health Program are learning what—and continue to learn—new information about WTC health effects? So within the Sinai, Stony Brook, etc., then FDNY, national providers, how do they keep—how do you ensure that they keep up on what we learn?

DR. REISSMAN:

Well, part of it is, as I mentioned, the research workshops that are here. There's people who do come to that that come from those institutions, and there is cross-fertilization among them, and the clinicians who are leading those particular treatment programs are also here. And in terms of ensuring, and this question of ensuring, do those clinical directors then go back and do in-services among their particular clinical staffs? I hope so. Have I ensured that? Have I made sure that that has happened? No, I haven't, but it is an interesting thought. I think there has been CME issues that have been offered in the past. We're working on a Medscape project now which Laurie Breyer may touch on, which is a specific type of introduction to the disaster and to let people, like in the national sphere, know a little bit more about what this was about, what is occupational and environmental medicine, what's the disasters, what are the health effects, what are we doing about it. So there's those components. I think there's also been website components where there have been videotapes made of researchers that are being put up on the website. Those are available for people to be downloading or looking at, and learning a little bit, with a little bit more interactive opportunities. This information is being fed into some of the Educational Resource Centers that are training occupational health doctors, who are the ones who often feed the Clinical Centers of Excellence, at least in the local area. So that's a beginning answer to your question.

DR. WARD:

Thank you. I think—

DR. ROM:

Another question—

DR. WARD:

Okay, one quick—more quick question.

DR. ROM:

Thank you, Dori, that was very nice. I have a question for you and John Howard. The federal government does an outstanding job of communicating a lot of their programs to the public and to Congress, and the US Global Change Research Program just produced the third National Climate Assessment, which was a lengthy document, and now a new one on the human health effects of climate change. I think it would be appropriate that the World Trade Center Health Program developed a document of all of its clinical programs and the research outcomes, and get this out as a federal document right away, because we're needing to educate Congress that there are now chronic health effects and that

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

this program shouldn't just die; that it needs to go on, and we need to demonstrate the productivity going forwards so that there could be a convincing argument to Congress that this should be an ongoing program. Are you doing that and if you aren't, when are you going to start?

DR. REISSMAN: We have been doing things like that. I wish it was quite as glossy as the ones you are referencing but it's not. We've had efforts to look at a five-year summary of—at least within the Zadroga Act—what has been accomplished both in the program in and of itself, the kinds of health conditions we've been seeing, the kind of research that's been conducted, what's been detected in terms of the health surveillance. So those products are something that, you know, we have been generating inside. The question is, you know, what is then disseminatable (sic) as a, you know, polished thing up on the website. I will take that point—and cogitate, so see if I can do something a little bit more that way. I don't know if there's something more you want to say? No? I guess I've said it, so I have committed.

DR. WARD: Thank you, and in the interests of time, we need to move on to the next speakers, thank you. Our next speakers are Jessica Bilics and Laurie Breyer.

THE WTC HEALTH PROGRAM - ACTIVITIES, MEMBER SERVICES AND COMMUNICATION

MS. BREYER: Actually, Jessica Bilics could not be here today. I am Laurie Breyer, so I will be speaking on behalf of Jessica Bilics and will do my best to represent her well, and the material that she's provided in the slides. So this presentation is really to talk about some of the Activities going on in the World Trade Center Health Program and provide you with some basic information about where we stand in the program as far as enrollment and certifications and any kind of policy activities that are going on, and then also provide a brief overview on what does "member services" mean, and the type of communication products that we are focusing on, developing or have developed already. So we'll start by looking at—what do I point at?

DR. MIDDENDORF: I don't think you need—we may be having a problem with the net.

SPEAKER: Could you use your cursor, maybe the cursor on your computer?

MS. BREYER: I don't have a cursor.

SPEAKER: Oh, you don't have it, okay.

MS. BREYER: I have a clicker that was working earlier, I think. All right, that worked. All right, thank you.

So we'll start with looking at enrollment. On here, you'll see that we've broken it down. This is as of May 2015. We currently have almost 72,000 people enrolled in the program total and then we've broken it down here by the three categories which are general responders, survivors and FDNY, and then we've also given a look at how many responders and survivors are enrolled in the Nationwide

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

Provider Network. So you'll see on here, the first category, general responders. We have about 39,000 people. And the term "general responders" in Zadroga is actually very broad. So typically we think of first responders, we think of police, fire, EMS, and in this category that includes non-FDNY fire fighters or EMS. It also includes police. It also includes very broad categories such as construction workers, for example, or even those who provided support services. And in this program that includes even Salvation worker-volunteers if they were in certain locations providing support to those who were doing rescue and recovery. So for this program, Zadroga, it's a very broad definition of general responders. "Survivors", and you'll see in the second column, that's the term used in Zadroga to include area residents, people who worked south of Houston and into—one and a half miles into Brooklyn. That's what's defined as the survivor catchment area or is also known as the New York City disaster area. It also includes people who went to school in the area, daycare, and even adult daycare is specifically mentioned in the Act, and those who were affected on 9/11, those in the buildings or those who were caught in the dust cloud on 9/11 in the New York City disaster area. And you can see we have approximately 8,100 people who are enrolled and categorized as survivors in the Clinical Center of Excellence. So the first three columns are the responders, survivors and FDNY who were assigned to a Clinical Center of Excellence in the New York or New Jersey area. The third category is FDNY. That's pretty self-explanatory, those individuals who worked with FDNY in rescue and recovery activities on 9/11 in the months that followed, and we have about 16,500 members enrolled in that category. And then we've broken out separately the Nationwide Provider Network. Now, responder and survivor in the Nationwide Provider Network are defined the same. Eligibility is no different but we just wanted to be able to make it an easy reference for people to see those going to a Clinical Center of Excellence versus those enrolled in the Nationwide Provider Network and receiving care across the country. So you can see we have about 8,200 individuals enrolled. That includes 7,600 responders and a little over 600 survivors, and that also includes Pentagon and Shanksville responders. They are enrolled in the Nationwide Provider Network as well.

The second slide gives you a better kind of image of where our members are dispersed. As you can see, the predominant number of members are being served in the New York City metropolitan area, New York, New Jersey, and those are the ones highlighted in yellow. So hopefully, I think you have a color-coded copy or a color copy in your booklet. And then you see we also have a large number of the pinks which you see are in Florida, Carolinas and Pennsylvania, for example. But as of the time of the making of this map in August 2014, there were only six congressional districts that did not have a member of this program,

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

either a responder or a survivor. So you can see this program largely affects—the largest number of members in this program are in New York and New Jersey, but we are diverse. We are all over the country and serving people across the country. And this map is also available online if anybody wants to go back and reference it, and we're hoping to update it soon, which it will be interesting to see if that changes.

As far as the top number of conditions we're treating, to give you an idea, this list is the top ten health conditions that we are treating as of March 2015. The conditions that we are able to treat were listed in Zadroga, in the Act—or since added through regulation or rule-making, I should say, since Zadroga. These are the top ten as of 2011, so post-Zadroga, and you can see a large number of these are aerodigestive and mental health. And many of the members in this program are treated for multiple conditions, so it's common that most of our members have more than one of these conditions that we're treating them for in the program. As many of you probably know, in late 2012 we also added cancer, with recommendations from the STAC, to the list of covered conditions for the World Trade Center Health Program. You can see as of May 2015, we have over 4,000 members that have been certified for a 9/11-related cancer. It's not in the top ten list yet because they've just been added in 2015, whereas the list I provided includes, you know, all the conditions that have ever been certified for the history of the program. And right now we have—we don't quite see the number of members being treated for cancer as we see in certifications. Because we added cancer late, a lot of people came in who had cancer at one point but may be in remission, and so therefore they want to be certified as it being 9/11-related but they're not currently needing treatment. But we have recently been seeing the number of treatments going up as well, and new certifications for cancer, so that's kind of a new development, and it'll be interesting to see, as time goes on, the increase in the number of certifications and treatment for cancer conditions that have been added.

Activities of the World Trade Center Health Program, as Dr. Reissman indicated, there's a lot that goes on outside of just providing treatment and care, and a lot of that is in the "policy", quote/unquote, world. So there's always—you know, we have the Zadroga Act that guides our program. We also have the regulations that guide the steps of the program, how we implement the program, and we're always updating our policies and procedures. The Zadroga Act also allows for the administrator to add additional conditions to the list of covered conditions in the Act. And as you can see on here, they can do that through a submission process and once we receive a submission from somebody—that can be anybody, a member of the general public, it can be somebody who has an interest in the program, who thinks that a condition should be covered as 9/11-

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

related—and when we receive that, that's considered a submission. If it's valid, meaning that certain criteria are established for the receipt of those submissions, then we call it a petition, which means it's a valid petition to be reviewed by the program to see if there's enough evidence to add it as a covered condition. And so far we have received seven of those. Two of those were cancer. In addition to those two, we had five additional valid petitions that include a request to add cardiovascular conditions, kidney, acoustic neuroma, primary biliary cirrhosis and autoimmune conditions. Of those five, four have been reviewed by the program and determined that there wasn't enough evidence to add those conditions to the list, and autoimmune is still being reviewed. All of these are available on our website. We try to be transparent. There's a link on the website that says "Petitions". We talk to the person that's submitting the petition and ask them if they want it redacted from any privacy information, for example their name or anything that may identify who they are. If so, we redact it and it's all placed on the website to be reviewed, including the information provided in support of that petition.

We also have created or produced and published several program policies that are also available online. That includes latency policy, time interval, medically associated conditions, cancer screening and workers' comp, and all of those policies are available online to be reviewed as well. We also have a policy and procedure manual which guides the program and is available online as well. Again, the goal of the program is to be as transparent in how we implement the program as possible.

And at this point, it was supposed to switch from Jessica to me, so now we'll go over to member services. My presentation is really just to orient you to what is considered member services. Dr. Reissman showed you an outline of the World Trade Center Health Program and our organization and so I'm just going to give you a brief orientation to what, you know, my team works on in our day-to-day operations.

So first I'm going to start with the goals of the member services and communication team. The first one is to coordinate outreach and education activities across contractors to ensure that those who are eligible for benefits are aware of the program and learn how to apply. The DC staff, you know, that help run this program—myself as the team lead for member services. I'm not in New York City, I'm not going door-to-door, I'm not trying to enroll people. So we have the Clinical Center of Excellence and they have outreach and education staff and they're out there hitting the ground, trying to make sure that everybody who's eligible for this program knows about it. We also wanted to make sure we had a diversity in our outreach so that we're trying to reach a diverse group of eligible members, and so we've also awarded six contracts to groups to do outreach and

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

education. And so between the Clinical Centers of Excellence and the contractors, you know, that's what's really getting out there in the New York City, New Jersey area and, as well, some of the program and outreach that we're doing nationwide. Some of our NIOSH staff has been responsible for Pentagon and Shanksville outreach though to make sure that we're hitting those populations as well. So we want to make sure that's coordinated so that we don't have people kind of going out and causing confusion if they're hitting the same people or reaching out to the same people. We want to make sure they provide consistent messages.

Second is we want to ensure that enrollment decisions are made in accordance with the law and that the enrollment process is accessible, transparent, and streamlined for the applicant. We want to make it as easy as possible for them to be able to apply to the program and provide information to support their application.

Third, we want to create communication products that provide clear, cohesive, and consistent messages that are branded and identifiable as World Trade Center Health Program. As I indicated, there are seven Clinical Centers of Excellence and the Nationwide Provider Network. And then on top of that, we have other programs. We have the World Trade Center Health Registry. We have the VCF. So a lot of times people are confused about what program you're talking about when you're out there talking to them. So what we want to do? We want to make sure that it's identified as we are talking about the World Trade Center Health Program and that includes, you know, providing guidance to all of our outreach partners and our contractors about, you know, when you're out there try to use the right branding, right? Try to use the right logo. Co-brand it, you know; put your clinic on it but put the World Trade Center Health Program on there as well, so we're identifying it as World Trade Center Health Program.

Fourth, we manage a public-facing website and call center so that way we're able to answer any questions and provide assistance to members. If you go to our website, you'll see we try to provide a lot of information about the program, we try to provide FAQs; we try to put it in plain language so it's understandable. The applications are on there and we also have an online application now. Same way with the call center, the call center is available for people who prefer to call and ask questions as opposed to going online. And we have call scripts there that mirror the information that's available on the website to make sure that we're providing clear and consistent information to individuals.

Next, we provide a mechanism for member concerns to be triaged directly to the program for resolution and tracking of larger systematic issues. Obviously, we want to make sure if somebody has a problem—whether that's the care they are receiving, if they have questions about what's covered, or they feel like they're

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

just not happy—you know, that they have a way to bring that to the program and we're able to address it and we're able to track to make sure that there's not any larger systematic issues related to member issues or concerns or problems that they're having in the program.

And then lastly, we want to streamline benefits counseling across the program and I'll talk about that later in a couple of specific slides since I know that's a question that's been asked of the STAC.

Quickly I just wanted to show this, you know, our responsibilities range in (sic) direct member services—again, that's outreach, enrollment and transfers—member assistance, and that, you know, complaints can come in from the clinics themselves will triage them up to us. They can come in from third party advocates who we deal with regularly. There's a control process if somebody sends a fax or letter or their congressional office sends it in. We have a call center, our World Trade Center inbox, and sometimes questions or concerns come in through CDC-INFO. We also handle appeals. My team has an appeal coordinator to help individuals through the process if they want to appeal denial of enrollment or appeal denial of a certification of a condition, all the way through how to submit the appeal, to a result from the federal official who is reviewing their appeal. Retention, again, that's once members are in the program, making sure that they are wanting to come back, that they're getting a good service, they feel like it's a benefit to them, and the call center. We also have communication, what I consider indirect member services, and again I mentioned that, the branding, the development of the communication products, translations. We want to make sure things are available to people who don't all speak English. You know, we have a large population of Polish, Spanish, and Chinese speakers, so we work to make sure that the materials are translated into those appropriate languages as well. Retention, again, we have a planning and development phase for what we want to look at, metrics for tracking retention. CMEs: Dr. Reissman spoke about, continuing medical education. We have a project with Medscape to create four products to disseminate to a large network of health care providers in the New York, New Jersey area as well as to our Nationwide Provider Network of doctors who are enrolled in the program. And then lastly evaluation, which again is looking at customer service and outreach, accessibility, and success.

So benefits counseling, this is one of the questions I know that's been asked of you. So what we're doing now, we have a work group that we're coordinating with the Clinical Centers of Excellence. They do the day-to-day benefits counseling. You know, members come in, they see the members, they treat the members, but they also help them with a variety of issues outside of providing them health care and treatment. And so when the contracts—when Zadroga was

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

passed and contracts were provided to the clinics, all of them were required to do benefits counseling and they all instituted their own program within their clinic on how they were going to provide benefits counseling.

So we started hearing some questions or concerns about whether that was being streamlined. You go into any clinic or the national program, you're getting the same level of service. So I had someone on my staff, we met with all of the clinics, the individuals who do benefits counselling and social work, and asked them, "What areas do you think that you provide benefits counseling in?" And there are seven main ones. There's program benefits counseling and that basically is what benefits can you get from the program? How can we help you based on what Zadroga allows us to provide, whether it's medication, whether it's, you know, care or treatment?

The second one is workers' comp counseling, so there's a lot of members of our program who may also have a workers' comp claim and so there may be some counseling on what they may or may not be available for.

Third is VCF assistance. I'm sure many of you are aware that the Department of Justice runs the Victim Compensation Fund and we work collaboratively with the Victim Compensation Fund, providing certifications that are authorized by the member for people who have been certified in our program, so they can use that in their processing of claims. And so we provide guidance to individuals on eligibility about VCF and refer them to the appropriate places to find more information for their VCF claims.

We also do external work-related or disability benefits counseling. If somebody has a disability, whether it's LODI or Social Security, being able to help them understand what benefits may be eligible for them. Social services assistance, we may have members who are having difficulty being able to get food because of their health conditions. They may have difficulty paying rent. We might try to get them in touch with social services agencies that will help them be able to get some of those services. Cancer care, obviously if they're certified for a cancer condition in this program we provide the treatment but they may have other needs sometimes, whether that's transportation getting to and from the clinic, we try to find them extra resources to help them get outside care that may not be covered by the program. And which feeds into the last one which is care for non-covered conditions. Many of our members are sick and they're being treated for multiple covered conditions but they also have other health conditions that may not be covered in this program at this time, and so helping them be able to figure out how they can get care for those conditions that we aren't able to pay for in this program.

So when we met with all the benefits counselors we tried to identify what everybody was doing at each clinic and where there might be gaps. In our

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

discussions with the groups we found that the extent and depth of services across the CCEs and the NPN is inconsistent. There's no program-wide definition of a minimum service threshold in those seven categories. So some CCEs, somebody may come in for workers' comp and they're going to refer them. They're going to say: here's a number. Go call this individual. Here are some attorneys who do worker's comp. You know, give them a list of resources and refer them. Some may actually provide counseling, sit down with them and say, well, let's see if you're eligible for workers' comp or you're not eligible for workers' comp. And then some go all the way to the point of assisting. So it's kind of a referral system versus a counseling system versus an assisting system, and different clinics do the different levels, differing on the different, you know, seven categories that I mentioned. So that's one thing we decided as a group that we would start developing. Second is there's no program-wide even working definition of benefits counseling. Third, there's no standardized or program-wide way of letting individuals know about the availability of benefits counseling at their clinic or the national program. And some people come in—every individual who walks in the door will get triaged for benefits counseling. In some cases they only may get referred to benefits counseling if the doctor or nurse hears them indicate that they were having a problem. The written materials distributed at the CCEs and NPN about benefits counseling is not consistent, so there's no World Trade Center Health Program information about benefits counseling that we've provided to them and so there might be different materials that they're getting when they go in for benefits counseling.

And lastly, it's unclear as to the qualifications of the staff performing benefits counseling, so their level of knowledge may be different. So we've come up with recommendations, again, in collaboration with the clinics and the staff that does benefits counseling, to try to move forward with streamlining it. The first thing that we came up with was a draft definition of benefits counseling which is listed here in your slides, which is it's a World Trade Center Health Program service provided by a benefits counselor, social worker, or other designated staff person who helps a member identify the benefits he or she may be eligible for, explains how to apply for those benefits. Benefits counselors also refer members to external benefits experts—again, we can't be experts in all of those seven categories—as needed to help the member access their benefits.

We recommended reinstating a monthly benefits coordination call so that anybody who does benefits counseling in the clinics, they can meet monthly and talk about problems they're seeing and any new issues that may be arising. The third recommendation is to develop communication products at the NIOSH level, so we would sit down with them, "What do you need? What are we missing?" and make sure that we create approved material with the clinics that is

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

the same for all of them. No matter which clinic you go to, if you have a workers' comp question you're going to get the workers' comp fact sheet. Also provide a benefits counseling handbook and training manual, again, since we may have different level of experience, from social worker to someone who's just coming in and learning about benefits counseling to help people, so the manual will help provide consistency. Benefits fact sheets that can actually be handed to the members so they can walk away with it if they don't want to sit down and talk with people.

And then also establish a network of benefit experts outside of the program that our benefits counselors can call. And lastly, establish some basic metrics to start tracking benefits counseling, how much is being done, what topics are we counseling on, and what level of service we're giving. So those are the current recommendations and I know the administrator has asked you with—coming up with any other recommendations that you think may help in as we move forward with the work group and benefits counseling and making sure we're streamlining it across the program.

And just really quickly—I know I'm running out of time—is the examples of communication products. We mentioned a few of them, Dr. Reissman in her presentation—on the left here you'll see this is just a screenshot of our web page and you'll see on there, there's a link for petitions, again, you can see that up on the top yellow banner. On the right-hand side is a screenshot of our newsletter we do. At one time we were doing two newsletters a year. Now we're doing one annual newsletter. It's going to be a little longer and provide more substantive information for members, almost like an annual report.

And one of the questions that was asked about getting our research out there, my team is really trying to work with the Office of Extramural Programs on—all the money that we've paid in research and all the products that have been developed, and how can we make that more readable to a lay audience, whether that's congressional offices or whether you're just a member of the public who says, "What's being done and what information are you learning from this disaster with the money that's been put into research?" So one of the things we're doing is we are looking at a fifteen years of research book to publish in 2016. I actually have an Emerson student who I have tasked to start going through some of the research and looking at similar type of books to see how would you organize that. Do you do it by year, 2001 to 2002, or do you do it by topic, for example breathing or respiratory issues? So we are looking are looking at publishing something similar to that in 2016.

And then also trying to make it accessible on the web through—I know many of you may know Dr. Max Lum, and he's really pushing to try to make it more accessible through social media and through our website through a new project

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

called Research Gateway. And you can see here is an example of one of the pages that we started. You see Dr. Hall, it has a very quick abstract and what question are you answering, and then it links it to several other social media sites. So it links it to his blog that he did on the NIOSH blog. You can click on it and you'll be able to see that. You'll also be able to click on it and see a one minute video with Dr. Hall explaining his research and the question he's trying to answer, and it'll click on Wikipedia which takes you to a 9/11 Health Effects Wikipedia page. So it's trying to make it more of a gateway of accessibility of research in a way that the public can understand.

And with that, hopefully I was brief enough and I'm happy to answer any questions you may have.

DR. WARD: Well, we probably don't have time for questions right now because I think it's time to move to the next speaker, but I hope you'll be available later in the afternoon when we discuss this question in case we have any specific questions.

MS. BREYER: I will definitely, thank you.

DR. WARD: Thank you. So our next speakers are Drs. Robison and Kubale.

OVERVIEW OF WTC HEALTH RESEARCH

DR. KUBALE: Good morning. I hope everyone can hear me. This is Travis Kubale. I'm the scientific program official for the World Trade Center portfolio, and Dr. Robison of course is the director of the Office of Extramural Programs, the department which I am a part of. Hopefully he'll be joining the call shortly but I'm going to go ahead with the presentation.

I want to—for new members and there are a couple of things for the returning members in the overview, I'm going to talk just a bit about the number of projects, give you an idea of how many projects we have, the project impact focus areas, populations served, the summary of the research funding. And then for the current projects, and these were some issues that came up in the February of 2014 STAC meeting, I do have a listing of our projects and the primary research contribution and also the STAC recommendation that we think those projects are addressing.

Just as a bit of background, the cooperative agreement research announcement for both the registry, World Trade Center Health Registry, and the research projects, both of those announcements, as everyone is aware, have expired. We will have a notice of intent to publish that will be published in mid-'15, we hope this summer, and that is to just put on notice that we certainly do plan future research activities pending enabling legislation so we want you to be aware of that. The number of research projects that we funded by year is listed here. In 2011, we had eight research contracts that were funded for three years, and then beginning in '11 and going through '15 we had cooperative agreements which were funded each year. In 2012 there were five two-year projects and six four-

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

year projects and that also included the World Trade Center Health Registry. In '13 we had six projects that were funded. Three were three-year projects and three were two-year projects. And in '14 we had ten projects, all of those were two-year projects. And in '15 we had our last call for one-year projects and there are currently seven recommended projects. We hope to have those processed and awarded by early July. So with those included, there will be a total of 42 research projects.

And just as a note, the World Trade Center Health Registry on its own, there are lots of activities and Dr. Farfel will be talking about, you know, the registry and those activities in more detail later on, but currently in our non-registry projects we have ten publications. Most of those are coming in, of course, from the projects that were awarded in 2011 and some of the two-year projects in 2012. The registry today has produced 58 research publications, and Mark will be giving some indication and description of those projects.

The funding by year is in the next slide. I just wanted to point out in FY '15 that total does include the seven recommended projects that have not yet been awarded. Our study focus areas, as probably you would expect, respiratory disease and mental health are the top two outcome areas. Cancer and cardiovascular disease, there are four studies each there. We do have three current studies, and again this does not include the recommended studies for FY '15, that involve both multiple outcomes and World Trade Center use. We have in the portfolio one autoimmune disease and I needed to make a note here, there is also another autoimmune disease that's currently being conducted by the World Trade Center Registry.

Our breakdown of population focus for responders, survivors, and both responders and survivors, you can see there are 27 of 35 for responders and then 8 of 35 that include survivors or responders and survivors combined. Project monitoring is very important for us and also communication. We do have and have done so since the very beginning of the portfolio, we have biannual grantee meetings that are in New York City. And this is a chance for the researchers to come together, all of the researchers in the portfolio, and talk about issues, progress, we look of course at compliance. It's a chance—it's really a site visit for us. The issues that are discussed—we have started publishing with the help of Laurie Breyer's team and Max Lum, publishing meeting proceedings that are available on the website so that we can make sure that we're tracking and that people are aware of what the early findings of the studies are as they progress through the cycle. We are also conducting, again with the Office of Communications' assistance, study impact videos where the researchers have a short 30-second video where they discuss in clear language, easy to understand, they discuss the impact and eventually the findings of their

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

studies. And those are available on our website locations and the videos will soon be hopefully there. They're not there as yet. When we were looking at how do we categorize the primary research contribution for our studies—and we have done that in OEP since the beginning and it is a mechanism that we use when we have the secondary review committee meeting, which is looking at program relevance of the portfolio or possible funded studies.

We wanted to come up with a way to sort of indicate to them where and how we were categorizing the portfolio and the contribution of each of the studies. When we talk about disease burden, these are studies of course that count disease cases, prevalence, incidence, and they also examine better methods to identify new disease cases and the conditions that affect the disease burden, and we did include surveillance studies in this category. When we talk about disease progression, these studies examine the changes in the individual disease status over time, over multiple clinic visits. Among the individuals who got sick, for instance, immediately after 9/11, what has happened to them? Did they get worse? Who was more resistant to getting better? That sort of thing.

There is also, we think—when we look for a mechanistic component in the disease progression, some of these studies include, for an example, an examination of the physiological mechanisms related to the primary outcome of interest and so we've flagged those in the upcoming slides as well. We also have some that focus on biomarker development. In these studies, the primary focus of the study is to generate data about disease biomarkers or to provide a foundation for future development of biomarkers.

We have also looked—and this came up in the last meeting—at treatment impact and embedded in some of the studies there is, at times, a treatment impact component. And an example would be, in some of our studies, they look at the influence of anti-inflammatory medication treatment. We have a study that looks at different methods to treat PTSD and that would be an example. So there are some examples in the portfolio that we think have a treatment impact component and we wanted, in this presentation for the committee, to, you know, provide that information again in the upcoming slides.

This next slide, we wanted to look at the STAC recommendations, the most recent STAC recommendations, and at least try to look at the portfolio and match where at least parts of the studies—or the studies were at least pertaining to parts of each of these recommendations. And in the upcoming slides I have numbered one through six for each study whether or not, you know, they address any of these or not.

I want to make one comment about number six, assessing the effect of World Trade Center exposure on gestation and early life. I had initially identified four studies and then when I was preparing the annotated bibliography for the

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

committee, and Dr. Anderson discovered that I had left out two respiratory disease studies of children that had been conducted by the registry and also a study by Christina Hoven that looked at exposure to mass violence and children's mental health. And so that four we think would quite possibly be a seven. Now we, in the bibliography, also found I think it was 19 additional studies related to children, some gestation and early life, that were really outside the portfolio but we thought the committee would need to be aware of those as well. Again, this is how we have categorized it for the committee.

These next few slides include the mental health studies that we have ongoing beginning in 2011. And on the far right-hand column we have the research contribution and then the STAC recommendation, numbered. I will say just a bit about each one of these—not each one of these but sort of as a whole, the mental health studies. Approximately six of the studies or about 60 percent are now reporting initial findings. And a couple of things that I think will be touched on later in more detail in future presentations, but one of the things that we're watching very closely is with mental health, there is reported evidence that there is still a very long-term impact due to the World Trade Center exposures and this impact is seen after, you know, ten years of time at least. And the symptom trajectories that they're reporting of active cases appear to be reflecting a combination of worsening symptoms and also delayed onset of cases, and sometimes this is even in spite of treatment. So there are some interesting initial results that we're watching closely in mental health in that area and I think there will be more on that in one of the upcoming presentations.

The respiratory disease studies, this is another large, of course, component of the portfolio. I would say just a couple of things. About 25 percent of these studies are reporting initial results and there's also some very interesting information that's starting to come out in this category as well that I think Dr. Aldrich and others will be talking about throughout the day in the discussions. But we're seeing reported new incidents of diagnosed obstructive airway disease at at least five years post-9/11, which was surprising. And we're also seeing that bronchial hyperreactivity, BHR, is tending to persist over an 11- to 12-year period, which is another interesting finding for this group of studies as well.

We have a couple of interesting things to point out in the cancer study category, and you all will be talking about the importance of external comparison groups and how to address that later in the discussion. I wanted to just point out that the 2014 study, it was initiated in 2014, the post-9/11 cancer incidence in FDNY fire fighters, is using—it's one of our first studies that's actually using an external comparison group. It's the three study, 30,000 member cohort, fire fighter study from NIOSH. The cardiovascular disease studies are still pretty much ongoing and are beginning to report initial findings. But again, half of these studies, as

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

you can see, are relatively new and were just funded.

We also have, in the biomarker category, we have Mike Marmer's study that was funded in 2013, and we're beginning to see some interesting findings there.

There are some—I will tell you, some very substantial hurdles that these researchers are dealing with in trying to get very good background or trying to sort out the difference between the exposure and just general background exposures. They're doing, I think, a very good job of that and making progress and we hope that we'll learn some interesting things from Mike's study, probably at the November meeting.

The other issue here that I wanted to point out—or study that I wanted to point out—is that we do have, of course, in the surveillance and multiple outcome category, the World Trade Center Health Registry. And as I said, to date from 2004, I think, to 2015, they have produced 58 publications, 107 scientific presentations, and then 16 technical reports, and they are very active in including external research or supporting external research as well.

Another interesting study in this category by Dr. Kim is "Health and Socioeconomic Sequelae of the WTC Disaster Among Responders" that was funded in '12 is starting to report some interesting findings, particularly as far as asthma is concerned. And about a quarter of the individuals that he has looked at in his study, after being diagnosed with asthma, had a greater risk of losing full-time jobs and there were a variety of socioeconomic factors that seemed to deteriorate that were related with this outcome. And again, all of these we put in the right-hand column the research contribution and also what we thought the primary STAC recommendation would be that the study is related to or addressing.

One last study, again, is the autoimmune study by Dr. Mayris Webber, and I apologize that the data is not there. That was a '14 study that was initiated in 2014. And there is one additional autoimmune project that is being conducted by the World Trade Center Health Registry to round out the portfolio. And that's all I have.

DR. WARD: Thank you. We do have about ten minutes for questions if anyone has any questions. Yes, Lila?

MS. NORDSTROM: For these studies specifically regarding youth, what definition of "youth" are you using? Are these studies that are being done on people that are children now, or what are the age ranges that you're looking at in these studies and who are you considering a youth in these studies?

DR. KUBALE: The internal studies or the portfolio studies that we were talking about there would be Dr. Trasande in one study, his current study, and two by Christina Hoven, and those are adolescents and I am trying to remember the exact age range. I think it's 14 to 18, I think, or 13 to 18 for roughly both of those studies.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

MS. NORDSTROM: Okay, great. Thanks.

DR. WARD: Any other questions? Okay then, we'll move onto our next speaker, Dr. Farfel.

WTC HEALTH REGISTRY: AN UPDATE

DR. FARFEL: I want to thank the committee for the opportunity to provide an update on the World Trade Center Health Registry. I think our last update was February 2014. And I did want to begin with a brief overview of the registry because I know there are new members on the committee and that I want to give the update on registry research and treatment referral activities.

So the registry is a cohort study designed to go 20+ years of over 71,000 people who were exposed to the events of 9/11, and we collect health updates and information on access to care, gaps in care every three to four years. We do additional data collection through matching to administrative databases for assessments of cancer and mortality and hospitalizations. And we also do additional data collection through in-depth study, some of which were mentioned by Travis earlier. Another core activity for the registry is to facilitate research by external collaborators or independent researchers. We have a number of those that I'll mention. And lastly and important part of the core is that we do respond to health needs and concerns of the enrollees and their family members, and we do quite a bit of active outreach for treatment referral.

Now the registry has diverse groups of responders. We have 30,000 responders in the cohort with, including fire fighters, police, construction workers, volunteers affiliated with organizations and unaffiliated volunteers. Among the non-rescue recovery survivors the largest group are the building occupants and passersby south of Chambers Street, 43,000, followed by residents south of Canal Street, followed by children and staff in schools in Lower Manhattan. So there are about 40,000 estimated persons eligible for the registry and we have 71,000. And the other thing to understand about this registry is that people do not need to be ill to be eligible, but to be in the exposed category. I saw a map earlier, an air map, based on the geographic distribution of our enrollees mirrors what Laurie Breyer showed you earlier. We happen to have most of our enrollees from New York City and New York State. We do have enrollees from all 50 states and more than 15 countries. We took a recent look just last month at the distribution by congressional district and we have rescue recovery workers in every congressional district across the country, and we have non-rescue recovery workers, survivor enrollees in all but a couple of dozen of the congressional districts across the country.

Brief history of the registry—registry was conceived shortly after 9/11 in New York City, and it was funded jointly by FEMA and ATSDR as a joint venture with the New York City Health Department. Registry has been housed in the New York City Health Department since the inception. Registry has had four waves,

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

surveys to date. The original wave one baseline survey of health and exposures was conducted in 2003/2004. Then we had health updates five to six years after 9/11. That's the wave two survey. Then nine to ten years post-9/11, which is our wave three survey. And both of those surveys had health updates on physical and mental health, potential emerging conditions. We had questions about quality of life, unmet healthcare needs. We've had several nested studies that were done through surveys. And the first was study of a basically understudied responder population, which are the Staten Island landfill and barge workers. That was done in 2010/11, followed by a Hurricane Sandy survey that was done six months after Hurricane Sandy among affected enrollees in 2013. And that survey actually demonstrated the registry's ability to respond to a subsequent event in a relatively rapid way. We fielded our survey five to six months after the hurricane. And then more recently, we're conducting our autoimmune disease survey, which I'll mention a bit more about in a moment. And our wave four survey was launched in April, and I'll give you an update on the status of that survey.

Travis had mentioned the scientific outputs of the registry. So briefly, I just wanted to mention that the 58 publications are mostly peer review publications and they do fall in the various categories that Travis had mentioned—adverse health outcomes, describing risk factors, disease course and progression, health burden. And they do cross the various eligibility groups and subgroups within the registry. We're aware to date of about 22 publications that were written by our external researcher collaborators across the 23 projects that were approved. We do have a commitment to present our findings at scientific meetings and conferences. There have been a large number of those, and that's how we do stay in touch with colleagues and others in the field. We've had 20 doctoral and master's theses through the registry based on registry data. Other scientific outputs include technical reports. There are three sets of clinical guidelines that were developed in collaboration with our clinical partners in the World Trade Center Health Program. We have a number of in-depth studies and surveillance projects, and there are public use data tools including our surveys. There are ways to analyze our wave one survey data online that are accessible to the public, and that is a requirement under the grant.

And just wanted to mention a few things about the strengths of the registry because we are unique in the diversity within the registry, size of the registry, and also the longevity of the registry. The scientific outputs are broad and deep, and the findings have informed 9/11 healthcare policy and disaster preparedness and response planning. We've now become a major source of new applications to the federal World Trade Center Health Program. We're a recognized platform for external research. And I should mention we believe it's a platform for cost

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

effective research because the registry's core function is to maintain the registry, to maintain the cohort, to maintain updated contact information, and we also make available cleaned data sets for secondary data analysis.

We have many ongoing collaborations with distinguished scientists and institutions. We have the high commitment, we believe, from the enrollees, and two quick points about that. We have about 1 percent loss to follow-up, about 800 enrollees at this point. And we have valid contact information for about 97 percent of enrollees. Another feature that I'd like to mention is that there are dedicated staff the registry. And we have lots of continuity and good staff retention. So we have people who are focused on cohort maintenance, the research functions, and treatment referral who are very experienced in those areas. You saw the slide earlier from Travis. And I just wanted to point out that registry research activities do address every one of the STAC recommendation areas.

I thought I'd give you just a few examples and then move on. You can read the rest in the handout. But under "investigation of potential emerging conditions" we've looked into sarcoidosis. We've looked into cardiovascular disease, cancer, and then currently autoimmune conditions. Under item two we have examined unmet mental healthcare needs in children and youth, for example. We're trying to improve the value of the World Trade Center Health Program data, for example, by collaborating with Mount Sinai and FDNY on a discussion of how to analyze our cancer data and report out in the future. We are collaborating with Mike Marmer's biomarker study that Travis mentioned. We have a number of registry studies and collaborations with regard to early childhood effects including publications on birth outcomes and collaborations with external researchers. And we're collaborating with, most recently with Dr. Gonzalez at Stony Brook on a study of treatment for persons with PTSD.

The next slide—you have that on your handout—just shows the range of research topics and in-depth study topics that we've addressed since 2006. And we feel like the research aligns well with NIOSH topics of interest including respiratory health, cancer, mental health, youth impacts, comorbidity, and cardiovascular disease. And on the slide there you'll see that there are little asterisks next to some of the topic areas. And those just reflect the areas in which we've published since the last update here at STAC. So we have published on asthma control, for example, diabetes, PTSD trajectories, comorbid conditions, adolescent behavior, alcohol use, smoking, Sandy-related PTSD, and we've had a conference presentation on cognitive impairment.

So I have about four slides that just touch on some of the findings, and I would just like to go over those. And I apologize that I have to be so brief and just to give you these little bullets, but that's about the best I can do today.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

So, for example, in the mental health area among adults, findings related to PTSD is that comorbid PTSD and depression is common. It's associated with unemployment, unmet healthcare needs, lower quality of life than either condition alone. We published on PTSD trajectories through nine years post-9/11, and we found a similar pattern of trajectories across eight subgroups of responder categories that we looked at. So that, for example, chronic, late onset, improving, and resilient patterns. When we looked at Hurricane Sandy survey data we found that for our enrollees who had 9/11-related PTSD, there was an elevated risk of Sandy-related PTSD. And then switching to the adolescents, Lila, you'd mentioned adolescents. There were behavioral difficulties documented six to seven years after 9/11 that were associated with exposures, respiratory conditions, 9/11-related injury or death of a family member, and PTSD in a parent.

We looked at some behavioral aspects. And enrollees with PTSD reported more frequent binge drinking than those without. And greater 9/11 exposure was also a risk factor. We found that smoking prevalence was higher among enrollees who had posttraumatic stress disorder symptoms and that PTSD was associated with reduced odds of quitting, and that was regardless of smoker type, whether you were a heavy smoker, a light smoker, or a non-daily smoker. And then a new area for the registry is the cognitive impairment. So cognitive impairment ten years after 9/11 is associated with 9/11-related PTSD. And there was an independent dose response relationship between cognitive impairment and 9/11 exposures.

Now, just on the physical health side mention a few things. Heart disease, intensive rescue recovery worker was associated with increased risk of heart disease hospitalization among men. And the risks were higher among men and women with PTSD at wave one. When we looked at asthma control in adults, most people who had asthma diagnosed early after 9/11 through 2004 had poor or very poorly controlled symptoms, and a dose response was found between the number of mental health conditions and poorer control of asthma. And with regard to diabetes, enrollees with PTSD were at elevated risk for developing diabetes six to eight years post-9/11 compared to those without diabetes. And then lastly, as a focus of Robert Brackbill's work more recently is the 9/11 injury is turning out to be a risk factor for chronic disease, and two examples here that Robert found was that persons with multiple types of injury were twice as likely to report a respiratory illness as those non-injured. And those with multiple types of injury and PTSD were three times more likely to report heart disease. And then back to children's health. Children's symptoms of respiratory symptoms six to seven years after 9/11 were associated with their dust cloud exposures. So just to give you a snapshot of many analyses that are underway at the

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

registry, I've divided them into three thematic areas—physical health, mental health, and evaluations and methods, and we have some analyses underway on some new topics for the registry including the cognitive impairment, respiratory hospitalizations, human remains exposure and PTSD ten years later, PTSD in early retirement, and provider knowledge. We have some additional analyses on topics that we published on previously but taking a look at a longer time course, and that includes GERD cancer mortality. We're doing our next follow-ups based on ten years post-9/11, and we're also taking another look at birth outcomes. In some of these studies we're beginning to employ newer methods, at least newer for the registry, in terms of linear growth models and looking at trajectories and doing mediation analyses.

I want to head next to the wave four survey. That's the one that's active now. It was launched in the end of March, and basically what we're trying to do is look at the potential emerging conditions and assess the course of conditions that were reported previously. We have a focus, as was mentioned earlier, on chronic health conditions. We've had new questions this time on mental health treatments and hospitalization. We continue to look at functional status, quality of life, and asthma control. Since asthma control requires a little bit of territory on a survey, we didn't want to make the core survey extended. So we separated that out as a separate survey that's going to go to about 15,000 people starting this summer. So who's in the survey? We distribute it to all of the adult enrollees. We have web and paper. We have three languages covered on the paper survey—Spanish, Chinese and English. And to date we've actually received more than 13,500 surveys, and the highest responding groups are what we had seen in the past, the responders, people who participated in our previous surveys. And we're actually ahead of the pace. We're about seven weeks in at this point and we're at the head of the pace that we were with regard to the wave three survey.

All right, so quickly I just want to give you a snapshot of nested studies. We have four that are in active data collection or analysis—the Hurricane Sandy survey, our respiratory follow-up study, autoimmune disease survey, and more recently a 9/11 injury study.

So the Hurricane Sandy survey was basically to look at the impacts of a subsequent disaster on physical and mental health of people who were already exposed to 9/11. We fielded web and paper surveys to all of our wave three participants who lived in the tristate area who also lived in the inundation zone. That was 4,300 people. And took a sample of 4,300 people not living in the inundation zone and tristate area. We had a 53 percent response rate. And to date we've published two papers, there's one accepted and there's a fourth in preparation, and the first paper was on injuries in the first week of Sandy, second

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

was on Sandy-related post-traumatic stress disorder, the third on household emergency preparedness, and the one that's active now is factors influencing evacuation.

The respiratory follow-up study builds on an '08 to '10 case control study of lower respiratory symptoms. Those are in residents and area workers done in collaboration with NYU Bellevue. The first study identified some risk factors for lower respiratory symptoms including dust cloud and home/work exposures. The objective of the following is to assess the longer term course of lower respiratory symptoms, lung function, quality of life, and PTSD comorbidity. So that study has completed data collection. We had a 74 percent response rate, and data analysis is underway in collaboration with our colleagues at NYU Bellevue.

The autoimmune disease study that Travis mentioned was to conduct surveillance of a potential emerging condition. We had heard concerns about this condition raised by our community advisors and also this was a condition that was discussed here I believe last year so we mailed web and paper surveys to all of our enrollees who had reported, self-reported an autoimmune disease at wave three. We received more than 2,000 responses for a 73 percent response rate, and what we're engaged in now is preparing to obtain physician confirmation through a short survey and then to analyze associations with 9/11 exposures.

The fourth study is the 9/11 injury study to better understand long-term consequences of injuries that occurred on 9/11. Right now we're in phase one, which involves in-depth interviews with about 40 enrollees with 9/11 injury, and that's in collaboration with Dr. Robyn Gershon at UCSF, and once we complete the interviews this summer we're going to do qualitative data analysis. And we'd like to use those findings to inform the development of a survey that we could field in future years of the injured enrollees in the registry.

Okay, just a point about the resource for external researchers. We do actively encourage external research proposals, and there are a number of options that can be mixed or matched. So you can collaborate with registry investigators, can request registry facilitator recruitment, or an independent study, and also external researchers can request de-identified data for secondary analysis. All of the applications are reviewed by registry scientists and representatives of our labor and community advisors. We've approved 23 studies to date and we have 11 that are currently in progress, and six of those are funded by the NIOSH research program. And some of those projects are actually active with members of the committee here—Dr. Rosemarie Bowler and Leo Trasande. Actually, the youth study that was mentioned, Lila, those studies are recruiting from about 14 up to age 20, I believe, in Leo Trasande's study; and Chris Hoven goes up to I think it's 23 or 24, slightly older.

And I wanted to come back to treatment referral because we believe that's sort of

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

the heart of the registry in the sense that we can show we care about enrollees. We're a long-term research study. And there's perceptions that research studies don't really care. So responding through the treatment referral program is a main avenue for us to do that.

And just a brief note about the history. We first had the phase one of this project in 2009 and 2011 in collaboration with HHC, and basically we encouraged our enrollees to make appointments, that was the survivors to make appointments at HHC, and about 1,100 appointments were actually made, and our approach was to use staff trained in motivational interviewing, nurses and social workers, to do the outreach. And they tried to address barriers to care that we all know about—lack of knowledge about the WTC programs or confusion, mental health stigmatization, for example. More recently we expanded the whole program, and so we now include responders living in and outside of the metropolitan area as well as out of state survivors, and have seen collaboration with the World Trade Center Health Program. So we've continued to have personalized outreach based on the most recent wave three updates and we've reached out to about 9,000 enrollees so far. And these are people who indicated 9/11-related mental or physical health symptoms in the most recent survey. We've retained our dedicated staff who trained in motivational interviewing. And to date about 2600 applications that had a registry brand on it were received by the World Trade Center Health Program. So basically we get a call from Reggie, who's here, every two weeks. He sends us an email and he gives us the counts from the back end so that we're able to keep track of that. I also wanted to note that we do have ongoing collaboration with both the VCF and the World Trade Center Health Program in the sense that we are offering enrollees copies of their wave one survey responses to help them document their presence at the site in order to qualify for Victim's Compensation Fund and the Health Program. So basically we have now sent wave one reports, we call them, either directly to the VCF or to enrollees to include with their World Trade Center Health application. And that's touched about 4,000 enrollees. So at the time the registry was initiated, Dr. Brackbill and Jim Cone were there at the time, there were no sort of known clear benefits; they just wanted to do this. But more recently there have emerged some benefits and one of them is the ability to obtain this additional documentation.

All right, I just wanted to end with some next steps. We have about a year and a few months left on the current funding cycle. So we're going to be focusing on completing that wave four data collection by early 2016, and that will include the asthma follow-up survey focused on asthma control. Going to be updating cancer and mortality assessments through ten years post-9/11. We're going to continue to submit manuscripts on all of those topics that were on the previous

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- slide. We're going to share the information. We're going to continue our treatment referral outreach collaborations with external researchers. And if the opportunity arises we will apply for continuation funding to take the registry hopefully 20 years post-9/11. Thank you.
- DR. WARD: Thank you. We do have about ten minutes for questions. Could the speakers identify themselves when they make a comment? Just because we're recording the proceedings for the transcript.
- DR. McCAWLEY: This is Mike McCawley. I have a question for you back on one of your earlier slides. And it's kind of a leading question, so I'll warn you to start with. Because I think what you were doing here was really good. But I'm wondering if there's a way that we could do more of it. You noted that under adolescent behavior the study was looking at 9/11-related injury or death of a family member and PTSD in a parent. Now, according to the Zadroga Act, the families of responders are not necessarily a part of the program. And here you're doing the right thing. How did you get away with it?
- DR. FARFEL: No. I mean, we do investigate other conditions that are not currently covered. That's part of the role of the registry and the whole research. So, for example, autoimmune diseases are (inaudible @ 00:25:44).
- DR. McCAWLEY: So we could—for instance, we could look at family members who potentially have been exposed to asbestos or dust coming home on clothing and those kinds of things?
- DR. FARFEL: I certainly think it's possible.
- DR. McCAWLEY: I haven't seen it proposed so far. I mean, it's one of the things that I think is kind of a glaring gap that whenever people did asbestos exposure they always looked at family members. There's not been, it seems like, a concerted effort here to look at family members for exposure to the World Trade Center dust. And that seems to be a major gap. But you're starting, it looks like, to fill in some of those gaps. Because the other major gap would be looking at families of PTSD people among this group.
- DR. FARFEL: Right. And we did have the opportunity to look at that because we had 250 what we call dyads, where both parent and a child were enrolled in the registry.
- DR. WARD: Can you speak into the mic, Mark? It's really hard to hear.
- DR. FARFEL: Yes. I'm sorry. No, I was just pointing out that, you know, we had some ability to look at that because we did have what we called the dyads, where we had a least a pair, one parent and one child, who were enrolled in the registry in the same household.
- DR. McCAWLEY: So in this particular case, this was from a dyad then. It was not necessarily from a child that was not otherwise.
- DR. FARFEL: Right, right. Our studies were focused on registry enrollees. That's correct.
- DR. McCAWLEY: Okay. Then the gap still exists for the families in which it's not a dyad. But

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- maybe it should be considered.
- DR. FARFEL: I mean, I think it's possible to reach other children in households. I know, for example, think Dr. Hoven's study and, Leo, I'm not sure about your study. But there may be an interest in other children in the household or not necessarily enrolled in the registry.
- DR. WARD: Steve?
- DR. MARKOWITZ: So Mark, thank you. That was a great presentation. Suppose there is another disaster and Dr. Howard asked you and Dr. Prezant and others how to proceed. And I'm thinking about one of the live questions 13-14 years ago, which was to what extent an interview based registry is useful as opposed to an exam based monitoring program, setting aside the treatment part of the World Trade Center Health Program, but just looking at the FDNY and clinical center based, exam based monitoring program. You're studying many of the same conditions and getting very useful research information out of it. My question is presumably a registry based system is more efficient, maybe cheaper? What do you think you've lost? Or how do you view the differences in terms of not doing, not having an exam based system in the registry as opposed to, you know, the other parts of the World Trade Center Health Program?
- DR. FARFEL: I think we, you know, we do recognize that we don't provide the treatment, so we don't necessarily have the clinical data. But we do do the matching with administrative databases to get more objective information. So we have published on cardiovascular disease hospitalizations where we're not relying necessarily on self-reported information, but we actually have some sort of more objective measure of that. I think really they both complement each other. You know, there's dialog between the registry and the clinicians. And I think that gives us some valuable information under the directions the registry should go. No, I'm just saying I think the two complement each other. And I think the dialog from the clinicians to the registry's been helpful in terms of understanding which potential emerging conditions, for example, to look at. And I think that's true both for sarcoid—I know Jim and Dr. Prezant had early conversations about that. And I think it definitely influenced the direction of our own in-depth studies. And we actually have, with our publications, in many instances we have a collaborator from the World Trade Center Health Program or an outside expert joining our papers. And of course we're a platform for clinical studies as well. And I think in terms of cost effectiveness, you know, I can tell you that you don't get much for 100 dollars these days, especially in New York City. But what you get is a whole, per enrollee for 100 dollars a year you get all of the research portfolio of the registry, plus the treatment referral, plus the other health promotion activities that we've done like the smoking cessation.
- DR. WARD: Okay. We've got four tents up, so we'll start first with Glenn.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- DR. TALASKA: Thank you, Mark. I have a question really more for the record than anything else. You listed a number of the scientific outputs that are here. And would you just address briefly how they're compiled, organized and then made available for the public and other researcher?
- DR. FARFEL: Well, we send all the PDFs of all the publications to Travis Kubale at NIOSH. So they're all available there. We have summaries of the research on the registry's website. We have brief blurbs. We also have document that we update every six months or so for NIOSH that reports out on all of the scientific outputs by category. So we have all the publications and then we have abstract or a summary of that. We also have a version that's publications with just a very brief blurb about each set of findings. And we're also making first author registry brief videos that we're posting on YouTube. So we've done five or six of those. And more recently Max Lum from NIOSH came to visit the registry and made another five or six, you know, one-minute brief videos. We also have videos that we've made with registry staff in different languages to encourage our enrollees to participate in the registry, kind of sustain their interest. And we also recently had permission from our IRB to have enrollee testimonials that we could share with other enrollees to encourage their participation.
- DR. TALASKA: And will that include the theses that you listed here? Will they also be made publically available in the same way?
- DR. FARFEL: I guess we could. They're public available through those universities. We could put out some sort of list of those. The three doctoral dissertations, you know, have actually been done by members of registry staff either for example at, you know, CUNY (or SUNY @ 00:32:51). But that would be an addition because there are a large number. And you know, the registry is very committed to staff development and professional development. And part of that is mentoring the thesis work that they do.
- DR. WARD: Lila?
- MS. NORDSTROM: Am I right that in order to participate in the registry you have to have participated in wave one?
- DR. FARFEL: Yes.
- MS. NORDSTROM: Given that there's sort of like been a change in awareness I think because of the World Trade Center Health Program and other programs in terms of people sort of knowledge that there is such a thing as World Trade Center-related health issues, do you see any future in which the registry is able to kind of like expand its study population in some way or in some way, you know, target people based on conditions that they have or things like that?
- DR. FARFEL: Yes. No, I've heard your first point before. There was some interest, and I remember the registry had, used to have public meetings and we would invite all the enrollees to the big auditorium at Pace University. And some people stood

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

up and said, you know, gosh, you know, we didn't really understand what the registry was or maybe didn't trust the registry because we're government. But now we know what you're doing. We'd like to join. And, you know, we just took names and said if we're ever reopened. But, you know, epidemiologically it'd be very difficult and very challenging to do. Because then you're dealing with all the issues of recall, if we were ever to have equivalent information on exposures and 9/11-related experiences. To begin asking those questions now 14 years later I think would be very challenging.

DR. WARD: Tom?

DR. ALDRICH: There must be some overlap in the people that you study and the people that are studied in other programs. And do you have any idea how much overlap there is? Is there any way to identify the overlap? And the reason I ask that is because, relevant to Dr. Markowitz's point, if there was a large number of people in this overlap group that would allow you to judge how effective a questionnaire based program is compared to an exam-based program.

DR. FARFEL: Well, Mount Sinai's cancer incidence paper I think had an, published an estimate. It was about 20 percent overlap between the registry and the Mount Sinai consortium. Of course the FDNY members who are in the registry, we happen to overlap for about 3,000 there. So that we do know. Are there ways to identify overlap? You know, there are ways to identify the number that overlap without necessarily identifying who they are. There's some issues around identifying that population. But it can be done. For example, we all submit to the New York State Cancer Registry, right, or the cancer incidence study. So the New York State Cancer Registry actually could, if we all worked out a mechanism, could identify the overlap.

DR. WARD: Rosemarie?

DR. BOWLER: Thank you. First of all, I continue to be very pleased and satisfied that you have been running the Health Registry. Because it's the only one in the world that has dealt with mental health issues. I was in Japan for a month, invited by the Department of Justice after the sarin attack. I was on Institute of Medicine panel and biological on, and chemical terrorism. And nothing has ever come of it. I think it's absolutely wonderful and so valuable that we have the Health Registry. And I agree with Dr. Markowitz and some of the other discussants here that the future, you need to look at the future. Hopefully you will be refunded. And the future should look a little bit different. I've really, as you know, in five papers now delved in with the issues. And what I've become very particularly interested in looking at the, truly at the risk factors over time. Particularly in my area is the first responders. So to do a little more than just questionnaires. For instance, you say they have cognitive impairment and you can't really say that. They report on five questions they have some problems with memory and concentration. I

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

looked at some of our epi data from Townsend, Ohio, and practically everybody said they had some concentration problems. The only point I'm making about that, this can be tested very easily, just like the exams. And I think we have cancer registries already and many others. The mental health issue needs to be emphasized more. And we can ascertain do they have it or don't they. As neuropsychologists, we've done studies to show if they have impairment. And I don't know. Maybe our police are really different that they all said, so many of them said they have cognitive impairment on those items. But I'd like to see that in a rigorous study. And these kinds of studies utilizing mental health cognitive issues, I mean, a person who has serious PTSD, from my having treated a couple of them and having done all this work for 20 years, that's a very serious illness and should be treated just as important as having cancer or asthma. Because it is to the people who have it and their families. So I would recommend, you know, you really consider that, the function of the registry as it continues and this incredible worldwide advance and advantage you have that you include some of that.

DR. FARFEL:

Yes. No, we agree, it's a unique resource. And I'll give you one example. So there are external researchers who are interested in looking in more depth at cognitive impairment, for example. And my point about the registry is we are a platform for recruitment. We can be co-investigators. We have the ability, since we have the self-reported, to recruit people into in-depth studies. So Jim Cone did the sarcoid case control study. So there was physician confirmation. We're doing the same thing with autoimmune disease. We do the same thing with cancer. You know, our studies are not based on self-reported cancer. So the extra added value of the registry is that we can offer the facilitated recruitment. Sort of we do the hard work of maintaining the registry, maintaining the addresses and the telephone numbers and the email addresses and keeping people engaged so that that will facilitate the recruitment. We have the datasets. We can identify the subsamples of interest to any external researcher. And if it's cognitive impairment, you know, we know what we have. But you're right. It's an early look. But we have through the questionnaires in some cases gone into more depth. And we're doing that with the cognitive impairment as well.

DR. WARD:

Sorry, we can take only one more question from Val. And then we need to break for lunch because we need to start promptly again at 1:00.

MS. JONES:

My question is similar to Michael McCawley's. What are you planning in terms of adolescents, whether they were children exposed or whether their parents have had any consequence from 9/11? Because I think that children experience quite a bit from their parents. You know, I think I saw PTSD with a parent who has now a respiratory problem. I think we've all seen the commercial of the kid, you know, taking care of his parent on TV with the respiratory problem. So just what

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- are your plans in terms of the adolescent age group, whether they were exposed or whether their parents have had any one of the major ten consequences?
- DR. FARFEL: Okay. So with regard to the adolescents, it's just a snapshot. So currently we're doing our wave four survey. And so people who were children at the time of 9/11 and have aged into adulthood and are now 18 years and older, they're included in the wave four survey. So we're continuing to follow the children as they age into adulthood. That's number one. Number two, we had a separate pediatric adolescent survey at wave three, which it was the 2010/2011 survey. So we have analyses underway of adolescent outcomes, behaviors, behavioral problems, risk behaviors, smoking and so forth. So that's kind of an active component of the research is analyzing the previous survey data. Then we're collaborating with Dr. Trasande on his study of physical health outcomes among adolescents and young adults. So he's inviting them in to do more in-depth clinical studies, clinical exams. And also we're collaborating with Dr. Chris Hoven at Columbia, who is going to the home to do mental health assessments of the adolescents and youth. So that's all going forward. And then in terms of the broader future of the registry, you know, as we go forward, if we're refunded and have the ability to do additional follow-ups, then we would continue to follow—So if we have a round five, by that time all of the children who are less than 18 today will have reached adulthood. And they will all be included in the subsequent study. So I hope that gets at your question. And then with regard to parents and children. So, you know, as I said earlier, we have identified, you know, several hundred of the pairs where we have the parent and the child are both enrolled in the registry. And so we have information. We can look at the parental PTSD and the effects on the child.
- MS. JONES: And, I mean, other than PTSD? You know, because there's like ten things there—like GERD, respiratory problems, etc.—that a parent can have. And I just believe a child in a home where a parent has a physical problem, most of these children these days realize a physical problem and very often have some kind of response to their parent's physical...
- DR. FARFEL: Yes. Well, you know, since we collect physical and mental health outcomes and symptoms, we have the ability to look at both. And, you know, what I think we've all been learning is comorbidity is the rule, not the exception, when it comes to 9/11 health, so.
- DR. WARD: Thank you very much and we'll break for lunch now. It's 12:10. And we'll be back promptly and ready to go at 1:00. Thank you.
- DR. MIDDENDORF: And just one quick note to the record that Dr. Trasande arrived during Dr. Farfel's presentation so we now have 15 members participating.

[Break.]

MENTAL HEALTH LESSONS LEARNED

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

DR. WARD: We're going to reconvene. We're reconvening a little late. So we're going to go ahead and have our next presentation on mental health lessons learned", but then hold any questions until after the public comment period, which starts at 1:30.

DR. MIDDENDORF: Before we get started I just want to make a note to the record that we have 14 members here at the table. Bob Harrison, are you on the phone? Not hearing Bob. We will check in with Bob Harrison again. Okay.

DR. WARD: Okay, our next presenter is Dr. Levy-Carrick.

DR. LEVY-CARRICK: Good afternoon. So thank you to the committee for the opportunity to share mental health lessons learned over the past four years. You know, I want to start by noting that this is amongst the most gratifying experiences one could imagine to work with colleagues whose professionalism and commitment to patient care is as extraordinary as that of the World Trade Center Health Program, clinicians and staff from the clinical centers to NIOSH. On the days, and in the month and years that followed 9/11 disaster, whether your rescue and response activities or—my, sorry? By returning to work and daily life, the population responded in ways that supported the narrative of a nation that wouldn't be paralyzed by the most spectacular of attacks on its iconic buildings and unsuspecting civilians. We seek to identify lessons learned as a way to honor the service and sacrifice that followed in the wake of the disaster, to serve our patients with the greatest efficacy and sensitivity, and this is an extraordinarily heterogeneous population in age, ethnicity, level of education, language, stage of life and a multitude of other factors.

My comments are meant to reflect lessons learned from the perspective of the clinicians engaged in patient care in these centers. While informed by personal experience as a mental health director and psychiatrist, this also reflects a meaningful dialog among all seven clinical centers within a mental health forum that's been meeting monthly since November of 2014 to support mental health coordination among all clinical and data centers.

Our objective is to promote a shared understanding of program values and to find areas for innovation and collaboration. There's six domains one can point to for lessons learned in ways in which the World Trade Center Health Program is supporting excellence in practice—patient engagement, psychopathology, mental health burden of chronic medical illness, program innovations, quality assurance, and promoting resilience and retention. They are somewhat arbitrarily chosen. They're not the only ones, but that's how I'll frame my discussion. Oh, somebody did that already? Okay.

So patient engagement. There's been an evolution of our understanding when and how we engage patients in treatment. Mental health screening is an integral part of every screening and monitoring visit. And this provides a context to

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

decreased stigma and decreased barriers to treatment. And so focus has moved beyond surveillance. We appreciate that screening and monitoring clearly are not the only points of engagement for mental health diagnosis and treatment referral. In fact, at all of our sites some patients are not interested or willing to start mental health treatment despite endorsing symptoms at the screening visit. Rather, at other times in the year, whether at a medical appointment, because of a registry phone call, or another life event, it prompts either an additional decompensation or a reorganization of priorities and an interest in coming for treatment, and patients will reach out for help at that point. And it's our ability to meet patients where they are, to be available for them when they're receptive that's one of the points of excellence in this program. There's also been an evolution in our understanding of what kinds of psychopathology fit reasonably into the scope of care of the World Trade Center Health Program, and I'll talk more about that over the next few points.

There's a lot more to explore and discuss about the scope of treatment and, you know, we appreciate that many people at highest risks for developing PTSD and depression, for example, are those with premorbid vulnerabilities that make for complex life narratives where 9/11 is one of many sources of distress. The clinicians amongst us feel that there are in fact both treatment modalities and planning that can balance these issues in a way that's both clinically reasonable and reflect shared values about the program's mandate. There's no one right action or one right actor. Rather this is about supporting transparency in the decisional logic applied and about supporting an organizational structure that provides patient specific disposition and treatment plans informed by a consistent understanding of shared values defined by the federal legislation. By having a mental health forum where these issues can be discussed in an open and constructive way, we'll continue to promote that dialog among all of the contributing clinical centers, and this points to another point of excellence in our program. I should add that it also provides a context to ensure that we're sharing knowledge amongst each other that's being gained around the cohort.

I know right at the beginning there was a question of how are we ensuring that there's ongoing education and feeding forward with the experiences, and I think, you know, our mental health forum was in a way modeled on the medical forum that started kind of right at the beginning of the Zadroga era. And so that context where we're getting clinicians with shared interests engaged and talking is another way of making sure that we continue to share and feed forward.

Now, we're sensitive to the fact that we, what we find depends on the questions that we ask. We rightly looked for PTSD after the disaster and we found it, but we're also appreciating that post-disaster mental health includes a broader range of symptom clusters than just that. Part of the evolution specifically includes a

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

growing appreciation that in the wake of the environmental ensued chronic and progressive medical illness carries with it the risk for a mental health burden. Whether conceived of as adjustment disorders because of loss of functioning for pulmonary issues or the implications of a new cancer diagnosis or side effects from medical treatment, commonly use of prednisone or albuterol, now also many of the cancer regimens, robust research is under way to understand these strong associations and comorbidities. We heard a lot about that in the morning. But meanwhile our efforts are focused on finding ways to integrate care and sensitive practitioners on both medical and mental health teams to these issues and thus to maximize the efficacy of treatment for each.

The education is happening within the mental health group and the medical group, but it's also happening across them, which is really very powerful, and this integration points to another point of excellence in our program. We're heartened to see also that there have been convergences in program innovations, even though the clinical centers do have different cohorts and do function somewhat independently. For example, various centers have developed monthly walk-in sessions focused on education and psychoeducation. Rather than clinical encounters, these programs are meant to decrease barriers to treatment by removing the stigma of a formal therapeutic frame. Supporting resilience by providing information in a consistent context that avails itself of the implicit esprit de corps of a people with a shared experience. While group psychotherapy is offered at each site, this activity serves a different purpose and a different cohort. Patients who attend are not necessarily interested or enrolled in additional mental health services but they can be referred if their needs or their interests change. Thus, as a context for clinical innovations and member engagement following terrorist attacks and environmental disasters, we're demonstrating another potential for excellence in our program.

An area of great challenge—great both because formidable and fascinating—is that of how to demonstrate efficacy over mental health programs. There are few elements that, while no means unique to mental health, do affect the way that we measure outcomes. First is that unless there's imminent danger we cannot mandate treatment. We can offer appropriate referrals, but we cannot engage patients who are not ready or able for a variety of psychosocial and economic reasons to confront some of their mental health issues.

So in terms of quality assurance our focus really needs to be foremost on ensuring quality of processes. We want to be sure the patients are appropriately screened and offered appropriate referrals. This goes back to our first point about being available for patients when they feel ready to engage. So in establishing a long-term relationship with a clinical center, we could again be a source of excellence of engagement.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

Second is a recognition that we're not only dealing with single incident trauma for which many treatments are often designed and that our patients may require different treatments over time. For example, first a course of individual treatment to gain skills for emotional regulation, then for social reengagement, some group therapy, and perhaps a year or two later for general support in adjusting to chronic medical conditions that have impacted their sense of self and self-worth, as well as possibly their adherence to medical treatment. So returning for more treatment is a sign of a program that's meeting the evolving needs of its patients, rather than one that can't cure their mental health issues with time-limited treatment. We have a long way to go to fully characterize these patterns of treatment engagement, understand where they reflect continuity of care, and also where they may point to areas that require programmatic attention.

Third, and related to all of this, is the recognition of the value of compiling quality longitudinal datasets, and we're still exploring how best to translate this into approved program efficacy. As recently as yesterday, during a hugely rich mental health forum meeting, we gained greater clarity about how identifying variable symptom trends can inform psychiatric service assessments. We further recognize that there are ways to utilize this information to identify those patients with the greatest comorbidities, which correlates with the greatest reduction in quality of life, and this can help focus outreach and retention efforts, ensuring that our patient engagement is commensurate with need. This is an exciting stage of program development and one that reflects how cooperation among data centers and clinicians and patients can create analytic synergies where attentiveness to our mandate and a commitment to quality programs share a common cause.

I titled this slide "Secondary Trauma" and of course yesterday decided to reframe and call it "Resilience and Well-Being." Last and certainly not least, we've become sensitive to the potential for provider distress. This is incredibly intense work. Listening to hair-raising exposure histories, to traumas survived, tragedies endured, to chronic symptoms and psychosocial collateral damage that has accumulated. We're starting to identify and articulate sources of caregiver fatigue by clinical and nonclinical staff. The intensity of patient engagement, but also the tensions of a dual world dilemma that can arise as function of working in a health program with a circumscribed mandate. We have learned that integrating certain routine meetings, not least one that promotes dialog and cooperation among the seven clinical centers, but also one among the clinicians themselves in each center can ensure that we serve our patients best by recognizing that this is very much a shared enterprise of stressors and of successes.

There's always more to say but I'll stop here by acknowledging and appreciating all my colleagues whose cumulative effort make this program the extraordinary undertaking it is, from the front desk staff that greet each person in the clinical

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

center to the clinical center leadership who juggle patient care research and administration. Continuity of care extends from the beginning to the end of a single visit, sometimes a very long screening or monitoring visit, sometimes a shorter follow-up, but also through dozens of visits over an accumulating number of years. I would add that Dr. Reissman's leadership in this has really been visionary and generous because it's a very dynamic program. We have had the opportunity to integrate our understanding to sort of think about what else we could do and bring that in and fold it in as we go along year after year in a way that also makes the staff feel like our observations, our cumulative knowledge is really feeding in in a way that's constructive and productive.

And so I'll end where I started. So we've all searched for meaning after 9/11. As a mental health program in partnership with our physical health program—and I would call that a very close partnership indeed—we strive to help our patients find meaning in their lives in this moment; to regain a sense of agency notwithstanding chronic stressors, medical mental health, and psychosocial variety of other sorts; to remain connected or to reconnect with social supports; to move forward even though they will never forget. And we search for excellence in this effort in the many domains I've outlined and more. I'm thinking we could talk about intergenerational transmission of trauma. We can talk about the different kinds of parental outreach that we could still do. There are many other sorts of things.

I'd be very happy to answer any questions. Thank you very much.

- DR. WARD: So it turns out we do have time for a couple of short questions before the public comments. Okay, we got Glenn and Anthony.
- DR. TALASKA: Anthony first.
- DR. WARD: Anthony first. Okay.
- MR. FLAMMIA: Thank you, Doctor. I know with responders, especially police officers, that many do not want to come in for treatment. And it's still today that I'm experiencing a lot of those responders that are just hiding in the closet. Has there been any outreach attempts via phone or technological means by either Skype, FaceTime, etc., which may be helpful for those wanting to come in for help? Do you think that method would be fruitful?
- DR. LEVY-CARRICK: Telepsychiatry is a relatively new and growing field. I know that the VA has done a series of trials around that. And I'm sure that we could look more closely at that. You know, I think we should never rule anything out. I think that the other side of that is that we are uniquely placed to do kind of specific sorts of outreach and peer outreach that we certainly want to make sure we're maximizing. You know, especially as I think people age and retire and move out of the city, I think that that's certainly a domain that can be explored in the years ahead.
- MR. FLAMMIA: Actually, I'm sorry. Do you think partnering in collaboration with the critical

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

incident response teams, with the Police Departments and the unions would be fruitful also for you to possibly get the members to get in? And I see it all the time with them not wanting to come in and they end up committing suicide. Do you think it would be fruitful to get together with the unions and to provide a possible outreach?

DR. LEVY-CARRICK: Yes, I mean, you know, to my understanding we do lots of collaborations. And absolutely, you know, to the extent that we—I think community involvement is different than clinical outreach and clinical engagement. And I think we should be clear that those are, they both need to happen together. I think one of the things that we also need to recognize is that the tone and the nature of the way we engage after a critical incident is different actually than what we're dealing with a lot of times now. There can be imminent danger, but I think we have to make people feel okay. I think part of what's happened is there is, there can be an accumulated shame. It builds with accumulated years since the trauma. And I think that, you know, by saying this can happen in a general way and trying to normalize it, I don't think gains much traction. At this point I think what we have to do is really normalize the idea that PTSD, if you really end up getting this disease, doesn't necessarily self-resolve and that we understand that all the little T traumas in our lives can become very big T traumas once you've experienced something so overwhelming. And so that, you know, to the extent that we can make sure that our messaging is one that's appropriately adapted to make people who are still suffering and not getting treatment and have shame as a barrier to treatment, who have ideas of what we're going to try and do, if we can get people to understand that we get that, whoever it is who wants to relay that message, whoever can relay that message I think is wonderful to include in this effort.

MR. FLAMMIA: Thank you.

DR. TALASKA: It's a closely related question. How has your experience so far allowed you to change and improve your traumatic exposure assessment over the period of time? Have you made changes in how the trauma is assessed in those exposures?

DR. LEVY-CARRICK: There are a couple of different ways to answer that question. I think there has been a clear effort to have some consistency in the kind of formal questionnaires that are used. I think the responders have a protocol that they're applying. I think a lot happens and I think we have a growing appreciation for how much happens in a clinical interview. I think, you know, the standard biopsychosocial formulation that we develop in a good comprehensive clinical interview serves us well. And it allows for capturing this really complex narrative and helping people really tease out what's going on, what's salient for them right now. When is it unresolved 9/11 trauma? When is it really about the fact that they can't, you

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

know, run after their kids in the playground? When is it just about, you know, the economic and financial burden that they're dealing with and, you know, shame, you know, piling on shame? All of that stuff needs to be talked through. And it's in the individualized treatment planning that we can then do as a function of that I think that is so powerful. You know, it's sort of what I said before. We get to hear what we ask questions about. People will not always offer. I mean, anybody who does a substance abuse history knows that, you know, if you just sort of don't ask, people aren't going to volunteer. And if you ask in a very general way they're not going to be specific. That's human. But the more that we do this, the more we can be attentive to making sure we ask the right 9/11 questions, but making sure also we write, we ask the right pre and post-9/11 questions and I think, you know. If that answers your question.

DR. TALASKA:

Oh, it's absolutely critical, yes.

DR. WARD:

It's 1:27. Do you want to take one more question or...?

DR. MIDDENDORF:

If there's another question we can take it, yes.

DR. WARD:

Is there another question?

DR. LEVY-CARRICK:

Okay. Thank you.

DR. MIDDENDORF:

We're going to start in with our public comments in just a minute. But I need to get some clarification. There's a form that's in the back that people sign in when they want to make public comments. But people can also sign up ahead of time. So I have a list of people who signed up ahead of time. And then several people put their name down on the list in the back. And I need to make sure that you really intend to make public comments or if you were inadvertently signing the, or thought you were signing the registration. So I'm just going to go down the list of names and just check. Dr. Prezant, I've already got you on my list, so you're okay. Terry Miles, are you interested in making public comments? No?

MR. MILES:

No.

DR. MIDDENDORF:

No. Okay, and the last name on here I'm not sure. I think it's Jim Melius. Did you sign the form back here? Okay, so I think we're okay then. Okay, great, because I've already got you on my list. Okay. So let's go ahead and start our public comments then. Each of our public commenters is signed up on a first come, first served basis and each of them will have up to five minutes to present. It's often surprising to people how fast five minutes can go by when you're talking on a subject of great importance to you. So in four minutes I'll let the commenter know that they have one minute remaining to allow them to kind of wrap up and make their final points. If you haven't finished at five minutes I'll have to rudely interrupt you and thank you for your comments and we'll need to move on from there. I also want to point out that you do have the option of submitting written comments to the docket to this committee. The docket number is 248B. And information on how to submit the comments can be found on the NIOSH docket

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

page. Last thing to do before we begin the comments is to make sure the commenters are aware of the redaction policy for public comments. The policy is in the federal register notice for this meeting. It's on the committee's webpage and there's a copy in the back if you want a look at it. The policy outlines what information will be kept and what information will be redacted before it's posted to the docket. So with that we'll go ahead and start, and Dr. Melius, you're first up.

PUBLIC COMMENTS

DR. MELIUS:

Thank you, Dr. Ward and others that, many of you I already know, and that I don't. Good to be here. I am Jim Melius. I am a physician working with the Laborers' Union. I am also chair of the steering committee for the Responders Medical Program and have been involved in these programs for a number of years. I want to make comments on a number of different areas within my five-minute limit.

First, just to clarify an earlier question—I think it was from you, Dr. Aldrich—about the sort of issue of overlap between the various programs, I think everyone has recognized it would be nice to understand the overlap. There are unfortunately apparently legal barriers to doing that. Initially with NIOSH, we saw with NIOSH, we thought we'd be able to do it and then now then with the City of New York with the registry, so we'll only—there's just limitations to what we can know from that overlap.

I think the one sign that is good in terms of the findings so far, as far as I can tell, in studies that have been done by the registry or by the medical programs, they all have had, you know, consistent results so I don't think, you know, there's a huge difference. But the way the recruitment went for the different programs is quite complicated and not easy to understand. I don't think we all completely understand it yet. I think it's also important to understand and look at the registry didn't start really until four years after 9/11 because of delays mostly at the federal end in getting the contracting done and so forth. There's no registry of actual people that worked at the site other than there were a few of the groups, particularly the Fire Department. Most other groups we don't know. And a lot of these programs started up in parallel. So the medical programs at Sinai, other places, started up at the same time as the registry. Our union recommended—we did a lot of outreach for our members, but it was to join the medical programs which we thought were more important for them. But there continues to be a lot of confusion. There are four or five different registries. The Workers Compensation Board has a registry, the 9/11 Museum now has a registry, there's the e-registry, and so people continue to get easily confused by this, and that's one of the problems with multiple programs. And I think the lesson going forward is, you know, start early in really doing—I don't know what you want to call it, but—a registry of those people that were exposed, done as early as possible,

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

getting lists of people, which I know the federal government has done in more recent instances. It certainly makes the follow-up a lot of easier and a lot better. The other, I think, important thing I'd like to emphasize is that in looking at the program there are—even though there is some overlap and there are programs, there's—limitations in terms of the numbers of cases and of people that become ill, particularly for less common illnesses. Dr. Prezant I think will talk a little bit more about that with his recent studies on autoimmune disease.

But one example that I ran across, this is surveillance by lawyers, a meeting with some of the lawyers involved with the Victims Compensation Fund. They asked me about cases of knowing this—it's been called Wegener's granulomatosis, now it's GPA or granulomatosis with polyangiitis, a mouthful, but—and were able actually come up with eight, seven to eight cases, I believe eight cases total. When we looked at them among the clinics, they were spread among five different clinics, so one case per clinic at the time, and three of them were outside the clinical programs altogether. They were being seen by private physicians. It was not considered a covered condition so people hadn't sought out the medical programs for them, or some of them had been in the medical programs and dropped out because their condition wasn't being treated. Now, in some work with the NIOSH program, we essentially got that condition covered. There's a fairly good literature on silica exposure and that disease, really robust, and which I was not aware of before I started looking into it, and there's also a very high percentage of those people with that illness have pulmonary involvement and therefore are really covered under that category rather than by the disease itself. So I think we have to recognize those limitations and when you're thinking about what should be covered or not covered take those into account.

Finally, I just want to say one of your questions has to do with benefits counseling, just to underline the continued importance of that for this group of people. I think we all know how difficult it is when people have developed significant chronic illness, cancer, lung disease, and how much help and how much assistance they do need. So even though it's, you know, 14 years down until the—after the event, people continue to get sick, people are getting sicker, and that kind of benefits counseling and help is still very badly needed, and needs to be supported in taking into account what these people have experienced. So I think I made my five minute limit, so thank you very much.

DR. MIDDENDORF:
MS. FLYNN:

Thank you Dr. Melius. Okay. Next on our list is Kimberly Flynn.
Good afternoon. I'm Kimberly Flynn and I chair the World Trade Center Health Program Survivors Steering Committee, which is the counterpart to the committee that Dr. Melius chairs for responders. As I'm sure you all already know, survivors, in Zadroga speak, are affected residents, students and area workers, and I make these comments of behalf of the committee. I'm going to

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

focus on question for deliberation one, and I'm going to start with a little bit of context.

On and after 9/11, more than 30,000 children 18 and under were exposed to unprecedented toxic pollution released in the collapse and burning of the World Trade Center. They were exposed throughout the New York City disaster area where they lived or attended school or daycare. Their health was placed at risk by an administration intent on reopening the area for business, a decision based on no scientific evidence. False assurances, telling parents that the area, its homes and schools, were safe, were issued repeatedly by federal and city governments and more amplified in the media in the days, months, and literally, for years following 9/11.

We know that children have an increased susceptibility to harm from environmental exposures, especially in critical periods of development. We know that unique behaviors are part of children's physiology. Their play close to the ground, frequent hand-to-mouth behaviors; these also serve to increase exposure compared with adults. We know that their exposures to World Trade Center contamination in their homes are likely to have been chronic and exacerbated by household characteristics such as carpeting and cleaning techniques. But while there were some mental health studies, because the government essentially stuck to its story that such exposures, such physical exposures, posed no problem, for the most part it does not seek to discover evidence of harm.

So 14 years later, we still know very little about how the WTC disaster has affected children's physical health. And because there was no World Trade Center pediatric program until 2008, only a tiny fraction of affected children, fewer than 100, are in the care of the World Trade Center Health Program. Through the years, there have been snapshots of physical health impacts, and I'm just going to cite one in the interest of time.

In 2007 the World Trade Center Health Registry released findings of a doubling of the rate for the northeastern US of new onset asthma in WTC exposed children under five years. This is for the registry's cohort of 3,100 children. Always, in every research study, researchers concluded that there is a need for further study, there is a need for greater understanding. We, the survivors, and Survivors Steering Committee, and our Medical Director, Dr. Joan Reibman, suspected and continue obviously to suspect that many impacts would be subtle and subclinical and would only be detected through clinical study, and that's what we all called for, for many years running.

So the good news is we are awaiting findings of the first in-depth clinical study of the WTC pediatric population, WTC Adolescent Health Study led by Dr. Leo Trasande. And that is examining respiratory and cardiometabolic health impacts,

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

as well as symptoms of post-traumatic stress. This study was launched with NIOSH support in 2013 and we hoped that it would be followed by a study of biomarkers of exposure in the same study cohort.

So the bad news is that time is now running out. We urge NIOSH to make WTC pediatric health, especially physical health, a priority before it becomes impossible to recruit an adequate subject pull from the rapidly dispersing pediatric population. We believe it is critical that the federal government commit to longitudinal studies that build on Dr. Trasande's research and the NIOSH funded studies of psychological health impacts by Dr. Christina Hoven, and both are based on the Health Registry cohort. Perhaps these PIs should collaborate. We believe that health impacts to multiple body systems should be examined and physiological mechanisms of disease as well. Studies that enhance the ability to monitor health risk, and that hold promise for informing early intervention to prevent disease, both physical and psychological, should have priority. And we may want to discuss some ways actually of supplementing the registry cohort, which is not truly representative of the more than 30,000 children who were exposed.

Finally, those who directly experienced 9/11 as children were not only the most vulnerable to harm but will also have the longest life expectancy within which to develop health problems as a result of their unprecedented WTC environmental exposures. We owe it to them to use every means available to provide them with the best science, preventative care and treatment. As this committee deliberates question one, it must have access to the best environmental health expertise, since environmental health is the greatest gap in our knowledge. For this reason, the Survivors Steering Committee has asked that Dr. David Carpenter, who directs the Institute for Health and Environment at the SUNY School of Public Health, be provided as an expert to this committee for the purposes of deliberating question one. We have sent his CV to Paul Middendorf, and we thank you very much for an opportunity to provide comments.

DR. MIDDENDORF:

Thank you, Ms. Flynn. Next on our list is Dr. Prezant, David Prezant.

DR. PREZANT:

My name is Dr. David Prezant. I'm the Chief Medical Officer for the New York City Fire Department and co-director of the World Trade Center Health Programs at the New York City Fire Department, the Director of the World Trade Center Data Center at the New York City Fire Department, and a Professor of Medicine at Albert Einstein College of Medicine. I'm representing the roughly 15,600 fire fighters and EMS workers at FDNY who are part of our World Trade Center cohort. This group has been committed from day one to helping others, not just at the World Trade Center, but in the aftermath of the World Trade Center. It is the only labor management group that is fully committed to a complete understanding of the World Trade Center disease with making available pre-9/11

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

health information, post-9/11 health information, with an over 96 percent participation in both medical monitoring, treatment and in IRB-sponsored research programs so that we capture our entire cohort. We only have about 5 percent of the cohort that has longitudinal dropout over this roughly 14 years, so our data is high-quality data. We also take great pride in the fact that we were the first, or among the first, to identify every major World Trade Center health-related disease outcome that has occurred since 9/11.

And the reason why I mention that is because today I'm talking about autoimmune disease and our other findings, World Trade Center cough, decline in lung function with persistence, the comorbidity issues between PTSD and lung function, between PTSD and depression, the increased incidence of sarcoidosis and cancer, which this group knows very well, have all been confirmed by the great work that has been done by our partners at the World Trade Center Health Registry, who presented earlier today, and at the non-FDNY World Trade Center Clinical Centers of Excellence and Data Center. That confirmation is critical and there has not been enough time for them to confirm our autoimmune findings, though their studies are in progress, but we anticipate similar confirmation. So what did we find? We found that there were 59 patients with significant autoimmune diseases. Now, this is not counting sarcoidosis, which you've already confirmed to be increased and which is already a World Trade Center-related covered condition. These 59 workers suffer from an assortment of autoimmune diseases which we hope will one day be recognized by the World Trade Center Health Program.

To help to define the science behind this we did a case nested control study which has recently been published. You have a copy of the publication as well as a slide presentation, which I don't have the time to go through today in its entirety, but I did want to highlight several issues. The study, the case nested control study, is a one-to-four, one case to every four controls. It tests the *a priori* hypothesis that acute exposure and chronic exposure is associated with an increased risk of new onset systemic autoimmune disease. We define acute exposure, as we always have, with based on arrival time, initial arrival time, at the 9/11 World Trade Center site. We define duration based on the months working there. In this study a median duration was two months. Now, our duration variable is not as high quality as our arrival variable; working one day in any given calendar month counts as a month's duration. But the typical fire fighter work chart would mean that they average per month somewhere between 7 and 15 days, many averaging 30, though we do not have complete duration data on that. We obtained information on the autoimmune diseases from our monitoring questionnaires which are done every 12 to 18 months, as well as from all our treatment exams and every one of the 59 cases was confirmed through looking at

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

the medical records from rheumatologists, most of which are either confirmed by serological blood studies and/or biopsy studies. There are only two cases, I believe, arthrologist (sic) cases, that—in spondyloarthritis that were not confirmed by a blood test but were confirmed by rheumatologic physician notes. Almost all of these patients have required very expensive therapy, which I'll get into in a moment.

The diseases of interest were systemic lupus erythematosus, which is SLE; antiphospholipid syndrome, APS, which is often part of lupus but for this case of controlled study were patients with APS that did not have lupus; systemic sclerosis; inflammatory myositis, specifically dermatomyositis, polymyositis and inclusion body myositis; Sjögren's syndrome; rheumatoid arthritis; spondyloarthritis; Wegener's; and Churg-Strauss. I should mention that these diseases are incredibly rare in a healthy male workforce. To see 59 cases of these diseases, all right, in people who couldn't possibly have had these diseases prior to 9/11 with the high-level manual labor that is required for both firefighting and EMS workers, where in New York City, these people routinely climb six flights of stairs carrying at least 40 to 100 pounds of equipment—these patients did not have this disease before. They didn't report this disease, and their work activity couldn't have made these diseases possible. These are all new onset cases in a healthy workforce of males, almost unheard of, and there is no study in the literature that could provide a comparable incidence or control for this, and that most studies are really about females or about juveniles, males who had rheumatoid arthritis at a young age.

So all cases were confirmed, all of the controls were confirmed not to have the cases, and what did we find? We found that there were, as I said, 59 of the cases. There's a slide, slide number 16, you don't have to turn to right now, that details the numbers of these cases. There were 22 rheumatoid arthritis cases which was the most number of any specific disease but there were also eight inflammatory myositis cases, dermatomyositis, polymyositis and inclusion body myositis; incredibly unheard of to happen in middle aged males. One of those—

DR. MIDDENDORF: Please wrap up, Dr. Prezant.

DR. PREZANT: All right. And the odds ratio that we found with the duration of median split of two months was 2.4. This means that we had a greater than double in chance if you were down there for two or more months. That is a higher odds ratio than was found for cancer in either our study or any of the other studies. Therefore, we really would like this committee to study this in depth and to make a recommendation to the World Trade Center Administrator on whether this disease, these group of diseases should be added. In final I would say that people who have no knowledge of these diseases think that they can be controlled with Motrin or prednisone, which essentially is of no expense. That is

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

not the case at all. It has been clearly proven most—best proven in rheumatoid arthritis that not only quality of life is improved by the modern biologic growth, but also joint erosion and in organ damage is greatly decreased by these drugs. These drugs, however, cost \$6,000 per month. And without the support of this program many of these patients, often started on therapy and shown to be successful, and then their insurance stops—

DR. MIDDENDORF: Please (inaudible @ 00:21:22) Dr. Prezant.

DR. PREZANT: —could not afford it. So thank you very much for your time.

DR. MIDDENDORF: Okay, thank you very much. The last commenter is Mariama James.

MS. JAMES: Good afternoon. I'm Mariama James. Thank you for hearing me. I just wanted to speak quickly as to the need for more intensive mental health care for pediatrics. I have three children that grew up around here [identifying information redacted] in the district, and I'm sure all three of them have been affected [identifying information redacted], because my [identifying information redacted] withdrew from their sports programs that they have very heavily participated in from early childhood. My [identifying information redacted] was a [identifying information redacted] from age like three, participating [identifying information redacted] and things of that nature. In middle school [identifying information redacted] had been on [identifying information redacted] teams. [Identifying information redacted] withdrawn from all of those. My [identifying information redacted] at one point was the only [identifying information redacted] in the summer [identifying information redacted] league at [identifying information redacted] league at [identifying information redacted]. [Identifying information redacted] withdrawn from that. And my [identifying information redacted] child, my [identifying information redacted] is the most heavily [identifying information redacted] impacted by this. [Identifying information redacted] began to [identifying information redacted] after 9/11. When [identifying information redacted] was in middle school, several of [identifying information redacted] fellow seventh graders either attempted or committed suicide at a local school. [Identifying information redacted] I also know of [identifying information redacted] local teenagers who have been in and out of institutions for years. And I only have to guess, I think, logically, that it is as a result of 9/11 because these are local teens. It's just too many to be sort of from nowhere. So I would just like to ask for further support of the existing program and an extension of the benefits that exist. Thank you.

DR. MIDDENDORF: Thank you, Ms. James. That's the end of our public comments, although we do have a few minutes. Let me just open it. Is there anyone else who would like to provide public comments? Okay. Not seeing anyone, I'll turn it back to Dr. Ward.

DR. WARD: Thank you, Paul. I wanted to set the stage for our discussion of the four questions that were posed to us by the program and note that I've talked to both Paul and Dr. Howard and I don't think anyone expects us to formulate complete

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

answers to these questions in the course of this meeting. There's a possibility that the committee can decide that we'd like to form workgroups to further work on any or all of the four questions. So we will open the floor to discussion, try to split our time so we have an hour for the first two questions. We'll try to split our time evenly. But let's try in the last five minutes to think about how we'd like to move forward and if we would like to form a workgroup on that particular question. Thank you. So if you turn in your book, if anyone hasn't found it, the questions for deliberation are under the "Questions for Deliberation" folder, as well as most of you received them by mail (beforehand @ 00:27:29).

DR. MIDDENDORF: I just want to do a quick check. Bob Harrison, are you on the line? Okay, I guess not.

DR. KUBALE: Who is that, Paul?

DR. MIDDENDORF: Bob Harrison. Okay, thank you.

DR. WARD: So the first question is with regard to children exposed to 9/11. I think you've all read it. And I'd like to begin with anyone who'd like to start the discussion.

DR. TRASANDE: So I'm going to need to recuse myself from discussion of comment one. So I'll step back.

DR. MIDDENDORF: Just for everyone's information, Dr. Trasande receives funding to do pediatric research on World Trade Center health populations, so because of the potential for conflict of interest he has had to recuse himself. To help the committee address that when you actually get into dealing with question one, we've arranged for Dr. Michael Anderson to provide some thought and input. And I'll introduce him. I think he'll be available at 2:30. So if we could actually get into question—

DR. WARD: Do you want to put off that discussion until later then?

DR. MIDDENDORF: Yes, I think we would need to.

(Inaudible @ 00:28:58),

DR. WARD: Okay. Okay, fine. Okay, so we'll move onto question two then until Dr. Anderson is available at 2:30. So question two has to do with the need for external referent groups and how external referent groups could be defined and to improve the validity and interpretability of WTC research. So any thoughts on this question?

DR. McCRAWLEY: Again, this is Mike McCawley. A couple of things: First of all, it occurs to me that depending upon what we want to look at we may need a control group specific to that. And so we may want to look at, not just a single external control group, but multiple external control groups for multiple questions. I will bring up one control group that I'm familiar with, and the interesting thing about it is the person who is most familiar with it is a former doctoral student of mine who is now an epidemiologist for NIOSH. So it kind of works that you've got some in-house expertise. We looked at people exposed to very high but very short duration, concentrations of dust from mountain top removal activities in southern West

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

Virginia, and a lot of the list of diseases that we've been talking about here were common in this population. And so it may be very interesting to take a look at what's happening in this population and where, in fact, exposures are still going on. So you can look at the short-term exposures, see what the levels are and see what kinds of disease they may correlate with, as well the level of stress in the populations surrounding these operations can be fairly high. And so we're also talking about stressful situations which may also be comparable to some extent with some of the World Trade Center populations. So I would bring that up simply as a group. And it's Dr. Laura Kurth in the surveillance branch in Morgantown that's...

DR. WARD:

Yes, and I wonder if there—and I don't know if anyone who's here from NIOSH could do that—but is there anyone who'd like to add—like elaborate a little bit more on why this question is being asked? Because I think one of my concerns about the question is kind of what you stated first, is that the—for every referent group, it really depends on the specific question that you're asking, and it also depends on how you're studying the exposed group. And so I see this as almost a very situational or study specific question, so if you're doing a registry-based study the answer is different than if you're doing a clinical study. But is there anyone who could elaborate on what you were hoping to get for this question?

DR. MIDDENDORF:

Travis, are you available to answer that?

DR. KUBALE:

Sure. Dr. Ward, I think the question originally came up in one of the early research meetings that we had in either late 2012 or early 2013. And one of the things then that NIOSH started doing was looking at the possibility, first among responders, and understanding that there's way more to it than just the first responders only and specifically even fire fighters. And the reason was that there was then a cohort that was a large cohort of fire fighters, the three-city study that had been conducted and was underway. And the thought was that there was a possibility with that to have a comparison population where, again, there were large city municipal Fire Departments that had at least reasonably close exposure scenarios. You could look at fire runs and there was a variety of information that you could get to address some of the exposure concerns. But they didn't have the World Trade Center exposure and so there was the thought that you would first use that to expand the comparison capacity for cancers. And there is a study, as I said earlier, with the FDNY that is currently doing that. Then there was also interest in what the rates generally among first responder fire fighters would be for PTSD and other respiratory diseases that you would likely see in a disaster. So that was the thinking. And the question would be is that something that, through contracts or other mechanisms, that the STAC would recommend that the program begin to look at and entertain, and with the possibility of expanding that of course to police as well as first responding fire fighters. So I

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

don't know if that helps address the question but that was the thinking.

DR. WARD: Thank you. That was helpful. And just for ease we'll go counterclockwise and start with Steve who I think was first.

DR. MARKOWITZ: Steven Markowitz. I had a few ideas actually. The Center to Protect Workers' Rights, which has a different name now, but the CPWR, has been conducting medical screening on construction workers since 1998. They have got over 20,000 enrolled and they screen them periodically. They have done their work near Department of Energy facilities and construction and renovation, so there is the potential that they had actually some DOE-related exposures above and beyond normal construction, but they have been screened over a comparable period with, to some extent, a comparable protocol. So for construction workers who were downtown, it may be useful at least to think about that. And the people who are on that are easily accessible and known to us.

Another thought I had is that, in place of an external control we could do what David did his paper, which is use internal controls. So you look at within the group that's exposed that was at Ground Zero, or any comparable disaster, you look at the ones who were least exposed and you compare the ones who were least exposed with those who were most exposed. And the disadvantage of that is those who were least exposed had some exposure, but the advantage of that is that they're all from the same group and so they're otherwise very similar, and the problem in World Trade was that the exposure assessment was not done well. And in future disasters—and there's nothing we can do about it now, 14 years later, but in future disasters—we want to be ready to do that right, and disease ascertainment now is excellent; identify cancers, heart disease, autoimmune diseases and the like. But to understand the exposure better we can't do that now. And so to better characterize exposure that would allow us to escape partly the need for an external group and be able to do the risk assessments within the group and compare the least with the most exposed. And then, lastly, let me just say that I think if we had a national blue collar cohort study, whether it was restricted to fire fighters and police or whether it was broader than that, that was ongoing, that used some of the same tools used in the World Trade Center Health Program and other tools, so that we understood what that group of workers looked like it would—and like for the physicians/public health people, the Framingham study which was a landmark study for heart disease. It started in the 1950s. It would be like the nurses study. A large group that's followed over time with the exposures that they already have and understand what goes on among them. It would be a big investment but probably not bigger than the money we've invested in understanding the problems of the World Trade Center.

So if we could think out of the box and undertake one of those cohort studies

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

then we'd have a reference group for whatever disaster is next, which will surely come.

DR. WARD: Thank you. Catherine?

MS. HUGHES: Great. I think probably one of the hardest cohort studies, or groups to find, would be the residential and the youth population. And I think even within the residential and the youth population there's a huge diversity, because you had the youth that lived down here but you also had a lot of youth that commute to go to the local schools, whether it's middle school or high school or the local colleges. And then in terms of the residents there's also a lot of people live and work in the same neighborhood, they don't necessarily commute out. And then you have the worker population that commutes in but they get to go home out of the impact zone from the World Trade Center attacks. And I think that has been a huge problem for the research studies up to now and it has prevented studies from happening in the first place. And then, as what was mentioned during the public comment, there was no systematic care at any center for children until 2008, and therefore because it was so spread out it was hard to share information unless you talked to friends at the playground.

DR. WARD: We'll go with the original tents and then get back to Rosemarie, with Rosemarie. Tom?

DR. ALDRICH: All right. Tom Aldrich. I think some of you may be aware that there is an effort to develop a control population but it's somewhat flawed. Our Fire Department has been following about 1,000 new hires after 9/11, that is people who were hired for firefighting or EMS work between 2003 and 2005, about 1,000. And so far we've looked at in that group in my opinion has a big disadvantage—two big disadvantages. One is it's several years later, a couple of years, well, let's see, three or four years later than 9/11. And the second disadvantage is it's a much younger group. So it's not going to be useful for comparison for cancers but it might be useful in other as a comparisons. We're looking at GERD and looking at the upper airway disorders, and looking at other—PTSD and other conditions that might plague fire fighters but not related to the World Trade Center exposure.

DR. WARD: Thank you, Lila.

MS. NORDSTROM: Thanks. I, more than maybe suggest a specific type of control group, I just wanted to kind of raise a sort of concern or point of interest that I think is especially important to people in the survivor community, but I think important generally, which is to make sure that we find control groups that include women and also control groups that include a variety of ages. I think a lot of the time when we talk about Fire Department control groups or things like that we're talking about industries that are heavily male, and in the survivor community we have women that are suffering from health conditions and we're not really able to do—we don't get as much information about how women's health has been

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

impacted by these events. And the same is true I think for people who were younger during the attacks who are maybe part of the adult population now but were not at the time. And maybe this partially relates to the first question as well, but we're not really sure how having been—exposed at like the age of 16, for example, impacts your health later down the line if we're using a control group that was all like professional men, so that was my—

DR. WARD:

Okay, and next is Rosemarie.

DR. BOWLER:

I understand the search—thank you—for a good control group. In the recent, last few years, I did an epi study in— of three towns in Ohio and very carefully controlled everything. We started out and the ATSDR, and EPA helped me. It was to study manganese. And we looked at even the US Census and matched them as closely as we could and still there were differences in the end, and I would like to say that certainly in New York is unique. We all know it's very special and different from most parts of America to find something like New Yorkers. And another point is we're certain, and maybe the Fire Departments are more similar in having medical clinic, but the Police Departments, I know, as a matter of fact, having been there, here locally, and then also in San Francisco I once considered to look at both of them, it's a very different model, very, very different. So it wouldn't do you any good to compare this kind of a difference that you would be finding. So it's very tricky. Maybe the residents, but even the residents, what is like New York City? No city in the world probably. So it's just it's very difficult, the controlled group. And I'd like very much, and that's what I would plan on using also, is the highest—since we have this incredible data, through the registry alone, so to use the highest—PTSD and then, I mean, it's still 11 percent in the police but there's a huge, couple thousand what we call "resilient" having no longer PTSD. Because having had this advantage of studying them already three times, so I would much rather see a controlled group like that, that is more similar so I would caution you.

DR. WARD:

Glenn?

DR. TALASKA:

I'd really just like to reinforce some of the things that Steven was talking about in terms of the control group and express to you how valuable it's been in my field of biomarkers, of exposure biomarkers, how important the NHANES CDC studies have been to establish what the median 95th percentile of exposures in the US population have been by studying 30,000 or 40,000 people for 200 biomarkers of exposure from metals through pesticides. That's an extremely valuable thing. And I think it points out one of the things Steven alluded to. One of the major weaknesses of course of the whole during 9/11 was the exposure assessment was very poor. And I've said this before, but one of the things that is most important is to improve our ability to respond and obtain exposures and have the strategy for a national response to exposures that we should be able to gather

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

data quickly. And it would be an extreme improvement and it would be testimony to the exposures that occurred in 9/11 if we did improve that. I do understand that NIOSH is developing an exposure response but we haven't heard much in the past four years about what the progress has been in that regard, and it would be nice for us to hear that from time to time to see how the changes in strategy have been undertaken.

DR. WARD: Thank you. Mike?

DR. McCAWLEY: Actually back to a question that Steven raised, NIOSH actually, in the late 70s and early 80s, did a blue collar worker study. And so that data should be in the files somewhere. And it probably might be worth someone going back and taking a look at to see what's there and bringing it back up and sort of summarizing it again. And in fact now it's almost 40 years later so it might be possible to go and look at a lot of death records too from that population.

DR. WARD: Any other comments? Bill?

DR. ROM: I think the NHANES is probably the best source of materials with questionnaires and serum and spirometry. I would add that NIH plans to do a 1 million-person precision medicine initiative to collect serum and plasma and questionnaires, and also will genotype everybody for future biomarkers of many different diseases, so that this would be a national control group that will be developed and will be already funded.

DR. WARD: Steve?

DR. MARKOWITZ: Do you know, Bill, will it have occupation environmental information collected by questionnaire?

DR. ROM: NIH is just putting out announcements for individuals to provide information on what cohorts they have. So they haven't even put out invitations for any grant proposals yet. But this will all happen in the next year or so, so occupational environmental exposures could be part of the questionnaires that they administer.

DR. WARD: Yes, I think that's a good point. We've been somewhat involved with that too at the American Cancer Society. And I don't know that the occupational and environmental community is being drawn into some of the discussions that are being had, so it would be good for you all to be alert to that. I think we've heard some pretty solid suggestions. Does anyone else want to speak to this, or do you think this would be a topic for a workgroup? Or do you think that the feedback we've provided is, if we write up—with the transcript of the meeting do you think there's further work that needs to be done or do you think that is sufficiently responsive to the NIOSH request?

DR. MIDDENDORF: Well, I think one of the questions for the committee is: Do you have more that you can provide, that you think there's more room to dig in here that would be beneficial to the program, or is this pretty much the extent of what's available?

DR. WARD: I think to me it really is almost a very basic epidemiological... It boils down to the

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

basic epidemiological principles about “how do you constitute a comparison group.” And the devil is always in the details. So you know in principle that you want your comparison group to be having the same level of clinical surveillance as your exposed group. The question is: Where do you find those people? And I think Steve had a nice concrete suggestion about one such group. But I’m not sure what we can say beyond that because, again, I think it’s study-specific if it’s cancer incidence. Now I do think we could have a subgroup to look at each of the major types of studies that’s going and talk about appropriate comparison groups. But I don’t think there’s much more we can say in generality than what we’ve already said.

DR. MIDDENDORF: Okay. Is that something that you feel like you can wrap here within this meeting? Or is it something that you need to have a workgroup kind of pull all the information together and provide a report back to the full committee, and then the full committee could further discuss it and then vote on specific recommendations?

DR. WARD: So what’s the sense of the group on that? Does anyone have any thoughts?

DR. TALASKA: Well, I almost think that we have to have a discussion to see what sort of things would be required and then try to help with some of the people that are participating in studies now. Because you do have to set it individually to whatever marker, whatever you’re looking at. It’s very specific so to be able to make specific recommendations you’d have to get down to very close nitty-gritty and that would take an interaction I think, don’t you?

DR. WARD: Right. And actually one topic that came up during the break is whether this committee might somehow have access to the meetings of the research groups that meet periodically. So it would give us more insight into what the different research studies are doing and maybe increase our ability to answer these questions.

DR. MIDDENDORF: Yes, I think what we all discussed was that we could do something like what we’re doing here. I’ll talk with the research group and see if we can’t put their meetings on the web, with telephone access to people on the outside so that our committee members would be able to then follow what’s going on at the meeting without having to travel. So that’s something I’ll follow up on.

DR. WARD: One thing we really didn’t discuss, and maybe if we have... we do have a few more minutes, is to talk about the question of controls for the community studies, because I think most everything that we came up with had to do with occupational groups.

MS. HUGHES: I mean, I wasn’t sure. I was just thinking a little bit more that maybe the schools, when your kid goes to school they have medical records that you have to fill out every year. So that could possibly be one location to get data, from the local schools of health forms that students have to put in. But it’s only as good as

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- what's required by that particular school or the local doctors.
- DR. WARD: Yes. Yes, I mean, I guess the other possibility that comes to mind is if there were some health systems or HMOs that covered a lot of people in the New York area you might be able to figure out which of their covered people were in this area versus other areas of the US. If there was some stable HMO or insurance covered populations that you could look at claims records and see what the incidence of health conditions was.
- MS. HUGHES: And there's one registry, I remember having had worked on it, which is the lead registry for children. So in New York State we helped pass a bill that children at ages 1 and 2 have to get tested. And so New York State, actually it's required that before you go to school it's on your health form that you're actually tested. So that's only one heavy metal, but it is one, and I know people were concerned about lead poisoning and mercury poisoning and other heavy metals after 9/11.
- DR. WARD: So, I mean, one thing we could do is we could put together the notes from this discussion kind of in an organized way, and then if we have volunteers for a workgroup to review those notes, then we could decide if that's pretty much all that we have to say on the topic and bring it back to the committee. Or if we read that and between now and then we think there are more areas that we could explore that that workgroup then continue to work on that. Does that sound like a reasonable plan? Paul?
- DR. BOWLER: Maybe you could give everyone in STAC to—once you have a list from a workgroup, to—see if the other members have anything to add on.
- DR. WARD: So let's talk about the rules for workgroups and for the full STAC because I think it's relevant.
- DR. MIDDENDORF: Yes. A workgroup needs to consist of fewer members than would constitute a quorum. So a quorum for the STAC is 10, so we'd need fewer than 10 members on any particular workgroup. And the purpose of the workgroup is to go out, generally get a lot of information, pull it together; put together a report or even potential recommendations. The workgroup does not have to operate in the same manner that the full committee does. It doesn't have to work in an open meeting. We don't take transcripts and all that sort of thing. However, anything that the workgroup does, it wants to bring back and wants to get to the administrator eventually, does have to be brought to the full committee. It has to be discussed in an open meeting with the full committee and just kind of parsed through. And then whatever recommendations the full committee wants to make are what would go forward.
- DR. WARD: Yes, and just to elaborate a little more, one of the things that I became aware of as we tried to work through the cancer recommendation was that, because the entire committee was involved in those deliberations, all of our communications essentially had to be in an open forum. So that meant that we couldn't even

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

email each other ideas or opinions, that that was not an acceptable way to proceed. And it's difficult so that we really were only supposed to be... We could collect ideas but we couldn't interchange ideas. And that's just part of the way the Federal Advisory Committee rules work, because everything has to be open. And so there is an advantage to deciding—well, plus efficiency and getting people who are really interested in a topic.

So if we take the workgroup approach we can iterate on email or have conference calls and then we'd come back to the open forum, so we're not doing anything hidden. Everyone on the committee gets to vote on the final recommendations. But the rules under which we can operate are a little bit more flexible, plus people can decide which of the workgroups they're most interested in and divide their energies appropriately.

DR. MIDDENDORF: So if the committee wants to form a workgroup, the things you'll need to decide on is, and vote on is, what will the charge be so that you actually give a clear charge to the workgroup about what you want them to do and what you want them to come back with. You need to identify the individuals. And you need to identify a Chair for the workgroup.

DR. WARD: Right. So does anybody want to make a motion to form a workgroup?

SPEAKER: And that would be for all four or...?

DR. WARD: No, this is just for this one.

SPEAKER: Just for this one. Okay. Thank you.

DR. WARD: Yes. Because if we do feel that we've wrapped up, that we've contributed all we can on a question, further work would not be needed, then there's no point in forming a workgroup. Yes. So is there a motion to form a workgroup on this?

DR. ROM: I would suggest that the chair summarize our discussion or discussions and send that to the full committee for any further comments and then finalize it, send it out to the committee and go from there and not have a workgroup.

DR. WARD: Well, that sounds reasonable to me. Do we need to make a motion and a second and vote on it? Or do we just...?

DR. MIDDENDORF: Since you're not actually requiring anything I don't think we need any vote.

DR. WARD: Well, that sounds like a good plan. Thank you. Good. So we're at 2:28 so I guess we're just about ready to begin discussion on the first question.

DR. MIDDENDORF: Yes. Dr. Anderson, are you on the line?

DR. ANDERSON: I am indeed. Thank you.

DR. MIDDENDORF: Good. Thank you. So I guess, Leo, this the time.

DR. TRASANDE: Yes. Yes.

DR. MIDDENDORF: Your time has come.

DR. WARD: No, no. He's not speaking. He's recusing himself.

DR. MIDDENDORF: Got you.

DR. WARD: Yes. Yes.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

DISCUSSION OF 'QUESTIONS FOR DELIBERATION'

DR. MIDDENDORF: Dr. Anderson is the chief medical officer at University Hospital Case Medical Center. He's an advocate for children's health on the national level and a recognized expert in pediatric disaster preparedness. Dr. Anderson has been selected to assist in guiding national efforts in this area. He is a consultant to the CDC and the Department of Health and Human Services National Disaster Medical System, and he was recently appointed to the National Advisory Committee on Children and Disasters. I just want to send a special thanks to you, Dr. Anderson, for taking time out of your busy schedule to be a resource to the committees. So thank you very much.

DR. ANDERSON: It's really an honor to be here. Thank you so much for the invitation.

DR. WARD: Does anyone have any comments or any questions for Dr. Anderson? Lila.

MS. NORDSTROM: Keeping in mind that most of the research that's getting done on youth and the effect of 9/11 is being done on people that were exposed when they were well under the age of ten. This is a question for Dr. Anderson, but maybe also for the rest of the committee. Is there sort of any evidence that shows that exposure at other ages where you're still a minor, but are not a small child has sort of differing impacts, is it worth studying people that were exposed as teens as a separate population or is it possible, if not, to include them in the larger study of children who've been exposed as we're doing them now? I mean, I think we said that the sort of maximum age of the youth studies is something like 23 or 24, which would mean that people were very young at the time of the attacks, but obviously there's a huge population of people that were exposed at the high schools and community colleges, and junior high schools in the area. So I'm wondering if that's a group that we should also be looking at.

DR. WARD: Dr. Anderson, would you like to comment?

DR. ANDERSON: Yes, I would, thank you. And I have a wonderful document that was sent me in preparation for the meeting. It's a summary that you all probably much better than I do. And I, first and foremost, need to complement not only the committee but the researchers that have put in the time in these studies. It's really impressive the breadth and depth of work that has been done on kids exposed during 9/11. So, first and foremost, kudos to the committee because, to be honest, I'm a pediatric intensive care physician. I've been more involved in sort of preparedness and response, sort of aka Sandy and how we evacuate large areas. So it's an honor to be here, once again. To answer the question point on from my work as a pediatrician and a pediatric advocate here at Case Western Reserve, I tend to think you would want those, quote-unquote, "kids," even though they seem sort of outside that age group and the young teens sort of lumped into the studies as much as possible. And, once again, my moderately cursory read, and obviously it's primarily in the world of psychological impact of

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

9/11, and then the respiratory impact of 9/11, I'm not sure there would be great value or merit in studying the group of young adolescents that you hypothesized. I think it seems to make more sense to me from an epidemiologic standpoint.

- DR. WARD: I can just answer it from the point of view of a cancer epidemiologist that, you know, there are some exposures, not necessarily those exposures that we talked about as really prominent in the World Trade Center where—and I'm thinking specifically of breast cancer—where it seems like the period of greatest susceptibility for breast cancer is between menarche and first birth. So there are some exposures where you will see a bigger response among people in that age group, and I think that's true for a lot of environmental toxins that there are certain ages where you're particularly susceptible to those toxins. Now, again, with the sample size we have the possibility of detecting any such effect. It may not be great, but at least conceptually there is a reason to look at people at all different life stages when they were exposed. It's just a question of is it feasible to do it.
- DR. ANDERSON: That's very great feedback. And just for my own education, what do you think that n is from the work that's been done already or what do you think the N is?
- MS. NORDSTROM: What? I didn't hear.
- DR. WARD: What would be the needed number? I think that's something we'd have to go back to the drawing board on.
- DR. McCAWLEY: He's asking what the sample size is.
- DR. WARD: No, but I'm saying...
- DR. McCAWLEY: Existing sample size.
- DR. WARD: Oh, what the existing sample size is...
- DR. ANDERSON: Right.
- DR. WARD: Rather than what is needed.
- MS. NORDSTROM: We know that there were 30,000 or more children sort of within the area. We don't really know sort of what specific group we're talking about.
- DR. WARD: And I think only 8,000 of them are registered.
- MS. NORDSTROM: It was a group that did not get reached very significantly in the registry phase because it was a weird time because they were either children or in college. So it is a group that really hasn't been widely studied as a whole, you know there's been certain pieces of the pediatric population that have had a little bit of study, but there really hasn't been a larger look at it.
- DR. WARD: And before we go to the Anthony let me make one more epidemiologist comment. I think that's kind of an interesting thought because if there was a way to get a better census on who those 30,000 people were, then at least for an outcome like cancer where we do have really good registries, you could do a study involving linkage with registries and that would not be a huge expense. So I think that is something to think about if you could a better census either through

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- school enrollment records and things like that. Anthony.
- MR. FLAMMIA: Thank you, Dr. Anderson, for taking this question. I wanted to bring up an issue. Actually, Mike McCawley had touched on it before in one of the presentations, and I wanted to bring this up. Being a police officer and bringing my uniforms home to my wife to wash, a secondary exposure. She was pregnant at the time. This exposure resulted in some developmental delays for my daughter with also an epilepsy condition. I'd like to have that looked at. And, Mr. McCawley, if you can expand on what you had said before to bring Mr. Anderson on board as to what we're discovering. I'd like to know if there is these studies out there for the disabilities and developmental delays as to secondary exposure.
- DR. McCAWLEY: Again, this is Mike McCawley. What we were talking about was, first of all, of course, in all of the asbestos studies there was take-home asbestos exposures, and that happened to all of the family members of the workers, and so we're concerned about that. More recently we've been doing beryllium exposures, and we found exactly the same thing with beryllium. Not only were people taking it home on their clothes, but they were taking it home in their cars because they were driving to and from work in these same clothes. And so anybody who traveled in the cars were being exposed. So this would include all the family members and the children, and even friends of the family in that particular case. And because we don't have a threshold above which, or below which disease does not occur for this particular set of compounds that may be in the dust, we can't say what's low enough to not call the population exposed, that may have this secondary route of exposure, and that would certainly be very true of the children.
- DR. ANDERSON: Right. Full transparency, I do feel as a pediatrician and an intensive doc, a little outside my element. We certainly, in the everyday clinical... obviously not speaking about Ground Zero, but in the everyday clinical world do have allergens that affect kids that are brought home by their parents. This is, obviously, much more of toxin exposure. If you ask my opinion as an advocate for kids, I think that would be well worth studying. My expertise in complete transparency is not in that sort of toxic exposure. So I would be a complete neophyte trying to explain exactly how we would study it. As an advocate for kids if we think that there is a sufficient N and a sufficient exposure to study, then I think the pediatric community would be behind that study. But as from my own individual expertise as an advocate that's a little outside my spectrum to understand the intricacies, to be honest.
- MS. HUGHES: Again, we're going back to lead and since I was the senior author Nypirg's Handbook to get—against lead poisoning and we know that workers in lead, because we hadn't covered lead based on all the studies, that that was something that they also found in their cars and their homes. And also talking

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

about lead, again, it was perceived as safe levels in your blood changed over time. So it used to be 50, then it went down to 25, then it went to 20, and then it went down to 14. So the levels of what was perceived as safe changed, and also what was the proper method to do the testing for lead in the blood. So those kind of parameters also had to be considered.

DR. ANDERSON: Can I just ask a structural question as a neophyte to the group? And I know a pediatrician who is probably more an expert than I am had to recuse himself, but what is the committee's interaction with the pediatric community? And by that I mean have bridges been built with the American Academy Pediatrics or with other advocacy groups that could either help add to the rolodex of experts to call upon or sort of help think about studies. And, of course, I'm not trying to restructure anything that the committee has done, just for my own education.

DR. WARD: Well, I would say we haven't—this is the first time, I think, that we've really been asked to comment specifically on the pediatric studies, to my recollection. And, really, I think, and it's unfortunate, the recusal rules are unfortunate because I think in some of our previous discussions having Leo on the committee was really helpful since he is probably one of the few experts in the country that are specializing in this type of exposure. So I guess that's the answer.

DR. ANDERSON: Yes, well, that's a spot-on answer. I guess, then my—what I can bring to the equation is, and I'm understanding more and more of the federal rules that I chair a federal advisory committee, which is sort of—and drinking from a firehose understanding those rules. If there are bridges that I can build with pediatric experts, as many of you know the American Academy of Pediatrics represents the great majority of pediatricians and pediatric specialists across this country, and I have several contacts of folks both within the toxicological world as well as the developmental world, that if the committee feels would be a benefit to start building some bridges, I would be more than willing to help with that.

DR. WARD: Thank you. Val?

MS. JONES: I'm looking at the question and since this is the expert on the line, I would like to hear the answer to that. "If research is not conducted on this cohort while they are children, to what extent will the opportunity to discover relationships between the 9/11 exposure(s) and developmental milestones or other health effects be lost?" And the second question is, "What are the most important developmental and health outcomes to target in such a cohort?" I think one of the things we did hear is we had somebody who said that her child had been very active in sports and activities, and then as a result or one of the outcomes she saw was that her child then at a point was not active in something they previously had, but anyway, I just wanted to hear the expert comment on the questions that are before us.

DR. ANDERSON: Yes, it's Mike Anderson again. I think from my 20,000-foot view answer, what I think was the first question, I'm sorry, it's not physically in front of me, I think it

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

would be a loss, if I understand the question, not to study the effects of this in children. Obviously, you know, some 14 years later they're aging. The second is if you were to ask me categories, and once again there was a very thorough review of some of the literature sent to me, I would imagine developmental disabilities and either the onset of things such as autism would be important. Too, there are some very good papers that, once again, the committee sent to me on the psychological effects of exposure at 9/11. I would think as a physician to others, and I know a colleague who said she was a cancer epidemiologist knows much more about this than I do, but I would think any potential oncologic effects of exposure would be important. And, although, the kids are aging out of this, I would also imagine, once again, some very good reports were sent on the respiratory effects be it asthma or lung diseases. So if I had to break it down into buckets as a pediatrician, those are the buckets that I would think about. And to the global question, once again, being a little new to this question, I think it would be a shame if we didn't study this cohort of children in the most effective way possible. The first question about how to find these kids, and I think you said that some 30,000 kids were exposed and, yet, only 8,000 made it into some registry. Obviously, from a practical perspective it would be a yeoman's task to get that done, but that doesn't mean it's not worth doing.

DR. WARD:

Thank you. Mickey.

MR. KELLY:

The person beside me just actually asked the question that I was going to ask. But I'd also like—there is a difference though between the developmental outcomes and establishing or recognizing what the developmental milestones are. So I think we need for the non-medical people to understand what would you determine to be the developmental milestones?

DR. McCRAWLEY:

Addressing the first part of it, I think that there are a number of compounds that we know were included in the 9/11 exposures like lead and cadmium, which we know from a toxicological point of view children are more susceptible to because they incorporate them, they absorb more of them for a given dose, usually by the oral route, so that there would be a potential for kids having a higher level of exposure relative to the same dose that's available on a surface, let's say. We know that children absorb 20 times more lead than adults do for the same amount taken into their mouths, for example. The problem is, is that most of our biomarkers that we would have to establish this relationship between the 9/11 exposure and the developmental effects that would occur are going to be long gone. Cadmium and lead might be the only two, or maybe dioxin where there's the long enough half-life, so that we're going to be able to see any remnants of exposure 14 years later. Lead would probably be gone, reduced—the blood leads would probably be reduced. The hope there would be there is an assay known as x-ray fluorescence where you can establish what the bone leads are,

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

and that might be something that we might want to look into that could be very useful. For the other ones, most of the more transient exposures that we had are probably not going to be detectable in these children 14 years later. There are a variety of things though that you can look at developmentally. You could look at how they mature sexually, and that's been done in Cincinnati looking at breast development, either faster or slower women or girls, and for men at the age that they come to puberty. That all can be looked at. There are a variety of these things that can be tested. But because, again, because of our exposure assessment being a couple hours late, it makes it much more difficult, much more difficult to establish those relationships.

DR. WARD: Let me just follow up on that for a second, and then get to the next person, because one thing I thought of when you were speaking is, you know, the typical developmental milestones that I think about as a mother is, you know, especially for young children, and it might be possible because I think pediatricians do keep pretty good records of developmental milestones. It might be possible to do a study looking at pediatric records to see when kids began... and this would be very young children when they began walking, etc. So just a thought. Bill.

DR. ROM: I think one of the striking findings was a nuance of asthma in children under age five, and so that needs to be followed up and validated. The second is what has happened to children who had suffered from PTSD. So a longitudinal follow-up of a cohort would be of great interest. A third thing, and I think this is a bit remote is what happens to these children as they have their own children. Are there any transgenerational effects? I doubt it, but I don't know. That's what science is all about. I would urge one piece of caution. I can just see some congressman saying, "Why should there be money funded for children and this happened 14 years ago? Are you going to find any kids because kids now aren't exposed?" So we have to have some caution, too, that we're doing follow-up of exposed children, and word things in the right way.

SPEAKER: Registry, you have that state the children's ages.

DR. WARD: So Val and Lila.

MS. JONES: Yes. Two things. I think one is looking at developmental in terms of, what you would say, somewhat like potential and activity, because I think the person that got up to speak was basically looking at the fact that their child, who sounds like now a teenager, is not participating in particular sports that they previously had been interested in. So I'm not sure how you would do that study, but I think a parent would probably know that my child used to be very interested in math, and now is a little dull or a little listless in that particular direction. I think that's one thing. I think the other thing is the whole concept of how you do the outreach. Because I think people are very cautious about their children and about having them participate in something where they're going to be, what we might call

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

“diagnosed” and what I would say the average person calls “labeled,” and then have to deal with the label. So that I think that some of it is about how you do the outreach and how you explain what you’re doing and what might be the consequences to that person’s child. Because I think in society that is exactly how you think about your child participated in something, is are they going to be labeled and is this going to have a negative consequence on them for school or for anything else? Because I know people who have children with special needs and it’s a whole learning experience for them how to deal with that and how to prepare for later on. So I think that that those are two things that we need to look at is that kind of thing and get parents involved. Because I think both of them really involves getting the parent to feel comfortable with the information and getting comfortable with the impact that it’s going to have on their child in their future.

DR. ANDERSON: It’s Mike Anderson in Cleveland. Could I follow up on that point?

DR. WARD: Sure.

DR. ANDERSON: I think that was very bright and very important. I think the entire... and I’ll take it just in a slightly different direction. The whole concept of, quote/unquote, “doing research” on children has really evolved at least in the 30 years that I’ve been an academic pediatrician. I think for many years we didn’t do research involving children because we saw them as too vulnerable and we go, “You can’t do research on kids, it’s just not a good idea.” I take the exact opposite approach. I think children are our most valuable asset to our nation. I think figuring out better ways to care for them and better ways to improve their health is really very important. I would agree with the previous speaker, however, you have to do it with the utmost of care and discretion in showing the families why it’s important. And to summarize the last two speakers, I think follow-up of the respiratory effects from 9/11 in my mind as a pediatrician would be very important because as most folks on the committee know most kids outgrow childhood asthma, but this toxic exposure can potentially create a different outcome where kids have respiratory diseases for longer. And the third point, once again, from scanning the summary that was sent to me, the continued follow-up of PTSD, you know, has time and a loving family brought about resolution of these symptoms or are these kids still affected as they enter young adulthood? I think those would be fundamental and really quite important questions.

DR. WARD: Thank you. Lila.

MS. NORDSTROM: I just wanted to speak briefly to the concern about finding members of this cohort. I think that Catherine actually sort of touched on this a little bit earlier. I think that this is maybe the population that we are of the survivor community, at least, that we are like most positioned to find because almost all of them were enrolled in school at the time. So unlike residents who could’ve lived on Duane Street, and

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

they moved away and no one knows who they were and never saw them again. I think a lot of, you know, we really have the ability to find out the names of the people that were children at the time. There's probably medical records for a lot of them. I think that this is probably one of the easier groups to do that with. Also, I noticed in my notes there's, actually, only I think like 3,000 children—or in the registry, I think we got that number wrong. But so I think that there's a lot more awareness now. And we're really talking about a population that are now adults, for the most part, I mean, I think the very youngest children who would've been exposed are in their mid-teens at the earliest right now. So we're talking about a population that, I mean, while I think it's important to include parents perhaps in sort of like figuring out what milestones their children may not like remember, they were missing or not experiencing or disturbed, or whatever. But I think that we're really talking about a population that we not only can find the information for, but probably reach, and are adults now and are people that we could interview as adults, and still sort of get valuable research out of them. So I think that that's less of a concern than it would be for the larger survivor population.

DR. BOWLER:

I fully understand the concern about children. That's very real. And yet, having done a cancer cluster with the health department in California for 1,000 children in the Valley with some pesticide spraying, I learned how difficult it is to study children. You need to have each year, I mean, some of the tests change every three months of age with a child to interpret them correctly. That's one aspect. You need a very large N of similar children, I suppose. But, also, the parental issue is a very big issue. If you have a mother who has PTSD herself, and if the kid had PTSD, and your kid had PTSD, it would impact this mother not only for her own PTSD but it's there are many, many factors, and it's not like doing biomarkers. Biomarkers, it's a great idea and I thought the only thing you have to be sure to have good diet questionnaires with the mercury, for instance, if there's any, but that's much easier than studying other aspects of it, the family constellation, what has happened. You can't really reconstruct it that easily. Plus, we, in that study, not only we have the mothers fill out questionnaires on the children, yes, and that was not as traumatic, but we also had the teachers rate the children, and they have good forms to do that. So it's a very complex, very comprehensive and difficult issue, but I'm sure worthwhile. Thank you.

DR. WARD:

I just wanted to briefly point out, and then we'll go to the other speakers, that there's a number of different groups we're talking about. And I think one group that people have mentioned several times during the day that it's probably not really constituting a group in any of the studies is children of people who worked at the site and don't live in the community. So I just wanted to point that out. So we've got kids that were enrolled in school, plus or minus living in the—and we've

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

got people with kids living in the community who might or might not, but have gone to school in the community, and then we've got this other group that might've had take-home exposure, and that group has not really been—it's not really included in any population that's been ascertained so far. So I just wanted to make that point. I assume it's within the purview of the committee. I mean, certainly, we have the identities of the adults who worked at the site who were exposed, but it's possible that we could learn something about that other group by studying people in the community or people who went to school here. So I just wanted to make clear that we have a third group on the table that really isn't included in any of the existing studies. Catherine.

- MS. HUGHES: Yes. I also wanted to say because there are some children in the World Trade Center Health Registry, it's even more important that the efforts are doubled with those that are in the Health Registry, and that the folks at the Health Registry really help the researchers to make that happen for those studies.
- DR. WARD: Several people have mentioned longitudinal follow-up of kids who had PTSD. Do we have any sense of how many kids are known to have had PTSD from the registry?
- DR. ANDERSON: This is Mike Anderson. I don't know. I'm looking through the data right now. I don't know if they—
- DR. WARD: Yes, because I guess that—but I would imagine that some kids had it and weren't, you know. Yes, go ahead, Robert. This is Robert Blackbill (sic) talking.
- DR. BRACKBILL: Brackbill. Robert Brackbill.
- DR. WARD: Brackbill, yes.
- DR. BRACKBILL: Yes. Well, when the registry did the first questionnaire, the enrollment questionnaire, they actually identified children on 9/11, but there were some children that actually had turned 18 at the time of the survey, and so they were asked the PTSD checklist questions. So they were adult questions, the PTSD. The children who were by through proxy, the parents had proxy for the children, answered a series of eight questions, which were not necessarily PTSD questions, they were actually stress symptoms, you know, such as not sleeping, etc. Okay? Those questions, I think, were used to identify, and people mentioned the study on asthma, I think was Polly Thomas. I think that's the one that looked at asthma. So and that study they used those eight questions. And I think it was somewhere around eight percent actually exceeded a threshold that was established. It was from PTSD-like. So it's not exactly PTSD.
- DR. WARD: And so has that work been published?
- DR. BRACKBILL: Yes, that's been published. That was, actually, in the study that has been mentioned, I think, regarding the association between dust cloud and asthma among children. In that same study we found that the children who exceeded the threshold for distress symptoms had a higher likelihood of having asthma.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- DR. WARD: Yes. So there is longitudinal follow-up taking place for that.
- DR. BRACKBILL: Yes. Yes, that same group has been followed, you know, too...
- DR. WARD: Yes.
- DR. BRACKBILL: Or those people when they turn adults, then, we have the posttraumatic stress or checklist questions, adult questions, for people who were children, and then who became adults and further surveys.
- DR. WARD: Okay. Thank you. Lila.
- MS. NORDSTROM: I just also wanted to stress, you know, I think it's obviously important that we do follow-up studies for what we've learned for respiratory and PTSD-related conditions. But I think a lot of the ways that we identify which conditions affect 9/11, affect the populations are through controlled groups that really don't have a lot in common with schoolchildren because through like responder groups or the groups that really experience these conditions first. So I think it's really important that we also study children and young adults who were affected as children for conditions that we haven't necessarily identified as 9/11-related yet, that we not just sort of pigeonhole our studies to conditions we know are already affecting the population, but maybe also find a way to look for other connections that maybe we're not necessarily finding in the populations that we're using to kind of mark what we kind of look for in these groups.
- MS. JONES: I want to piggyback on that just to be clear. I think that while there are obstacles, and I think we need to look at it holistically in terms of family when you look at children, looking at the entire family. I think that it's very important to do that. That's really my point, that I think that we're looking at some obstacles, but I think it's important to do that. And I think it's important to somewhat like Lila's saying is to expand what we're looking at in terms of much more looking at the family and much more looking at where young people are and expending some creativity in terms of getting people involved with their children. But looking at it much more holistically and looking at it, but I think that the person who spoke, I don't know that that was really what we would call PTSD, but when your child is not involved in certain kind of activities, say your child is not involved in extracurricular-type activities after school, is something to think about. And while that may not fit any particularly diagnosis, it's something to look at if this is a group that tends not to participate in anything other than what they have to participate in at school. But I think that it's a valuable population to look at, and that I just think it needs to come from a holistic point of view, a family point of view.
- DR. WARD: Well, my sense is there's a great deal of interest in this topic, and probably it's very broad. I think everyone who has spoken has basically given the same answer to the first part of the question, which is, yes, it's very important to study, and if we don't study it now we'll never be able to study it. I think that answer is clear. In terms of developmental and health outcomes, you know, people have

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

spoken specifically that we should definitely track the asthma and the PTSD long-term to see, you know, look at persistence, and so on. But we've also recognize that there may be effects that we haven't yet measured that we should be looking for, that we shouldn't confine future research to problems that have already been identified. I do think that there's probably merit in having a workgroup, because I think, really, this is a very broad question, but really the deeper questions are, given that we can't study all the populations and all the questions what would be the highest priority populations to study and within those populations what would be the most appropriate tools and techniques and questions to ask, which could be different for different populations. So I would think that a workgroup would be useful in this. I think especially if Leo is still, if he has to recuse himself from the workgroup as well. We need to think about it, and I think Paul mentioned the option that we can actually invite people who are not on the primary STAC committee to participate in the workgroup if we need a particular expertise that the workgroup doesn't have.

DR. MIDDENDORF: Yes, the committee and the workgroup can identify individuals outside the committee who have particular knowledge and expertise and ask them to consult with them or participate with them as they do their research to pull together the information they need.

DR. ANDERSON: And, once again, if you need a bridge to either academic societies or I'm sure the committee is well-connected and knows a lot of experts, but I think the American Academy of Pediatrics and several other organizations would stand ready to help in any way that we can.

DR. WARD: Great. So is there a motion to form a workgroup?

SPEAKER: So moved.

SPEAKER: I second it.

DR. WARD: All in favor?

DR. MIDDENDORF: Well, wait a minute. Why don't we identify what the workgroup charge is to...?

DR. WARD: Well, I guess, to formulate a response to the first question of the administrator, and to explore more deeply the population, to look at the question of the most important developmental and health outcomes to target, but also to better define what the potential cohorts might be, which isn't specifically asked in the question, but it's kind of assumed in the question that there's just a single—that there's a cohort as referred to, but in reality there could be multiple cohorts depending on how you define eligibility for the cohort and how you identify the cohort.

SPEAKER: Yes, because issues like age of exposure would be really important, you know, and there would be different timings for that depending upon how old they were at 9/11. Someone who was 14 at 9/11 would have a much different exposure than someone who was 1, and in terms of their uptake even. So I think we should include somebody who understands the toxicology of the exposures that

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

we have and could research the things that have been done already on humans and animals if they're going to be models for this for outcomes for developmental changes. And so somebody with that sort of bent should be on—one of our toxicologist should be...

DR. WARD: Developmental toxicology.

SPEAKER: Yes, yes. Yes, and...

DR. WARD: So Paul's typing.

DR. MIDDENDORF: Attempting to type.

SPEAKER: We're turning it into a long motion. Did you get all that, Paul?

DR. WARD: So one is always more articulate the second time around.

SPEAKER: So I made the motion that we have a workgroup to study this question that involves a subgroup, and I think that's what was seconded.

DR. WARD: Yes. Yes, Paul's just trying to write what the charge to the workgroup is. So Paul basically retyped the originally question, but I think the second question that we added, I think, which is important is define what we mean by a—this will be discussed in relation to specific cohorts, (age, sex, type of exposure category), which I think does leave open, and I think several people have said it in different ways. I mean, we have the children of people who were affected by 9/11 who are not in the existing community or school groups, and whether they could potentially be affected by the illness of their parent, whether they could potentially be affected by take-home toxins. I mean, we really need to look at the specific cohorts of children that could've been affected and maybe make some recommendations on which groups are the highest priority for studying and how they could be studied, and what outcomes to look out. So I don't know if we need all of that in our charge, but that's the sense of what I think we would do.

DR. MIDDENDORF: So is this essentially what the motion is, tell me what I need to write differently?

SPEAKER: Why don't you read it?

DR. WARD: The committee motions to form a workgroup to formulate a potential response to question one, what are the most important developmental and health outcomes to target in such a cohort. A part of this will be to identify sub-cohorts. And possibly, and recommend priorities for potential studies? Because, I mean, we can recommend 20 different studies, but I think it would be useful to recommend what we think are the highest priorities.

DR. MIDDENDORF: I think that goes with the first part of the question, is what will be lost.

DR. WARD: Well, no, because we already, well, I don't think we should frame it in what will be lost. I think we should frame it as what are the most important questions to study, both because they're important questions and because they're more feasible to study. Tom?

DR. ALDRICH: Yes, I hate to be negative on this, but 3,000 in the registry, that's a tiny amount. That's way too small to expect to find anything. And so I think if we're going to

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

study effects in children, we got to study something that can be studied. So look at the school records, identify a bigger cohort to study. I think it's totally out of the question that we're going to be able to find enough of a cohort of people who've taken home toxins to affect their children. We're just not going to be able to find those. So we shouldn't spin our wheels on hopeless endeavors.

DR. WARD: Well, I guess, I wouldn't say it's entirely hopeless. I mean, I'm not saying it's a high priority, but I think it could be done, for example, with the Fire Department cohort, right? You can look at children of people who were exposed to 9/11. Now, it may be that it's not a high priority, but again the two things that I've heard today, one is in relation to actual toxins, but the other is the psychological effects to children of having a parent who's been affected by 9/11 possibly psychologically, possibly physically, possibly very ill, and I don't think that's impossible to study. It may not be the highest priority, but it seems quite possible from my point of view to look at it at least in the Fire Department cohort. Virginia.

DR. WEAVER: So it does seem that in my four years on the committee that exposures and issues in children is the most glaring gap. We've heard a lot about workers, but we really haven't heard much about kids, and so I think the idea of a workgroup is an opportunity to expand on this gap and think about what options there are out there. Clearly, take-home exposures may be challenging from a research perspective, but they may be a hot issue when people actually start thinking about where their concerns lie. And so this is an opportunity for a working group to kind of lay out a range of concerns, a range of things that may be able to be addressed. Three thousand is a small number, but even, I don't know if the registry's done a descriptive study of what's actually been found in those 3,000. Something like that would be low hanging fruit, a way to start. So, clearly, more thought could go into this.

MS. HUGHES: I, also, just wanted to say with the children, it was as though the adult guidelines were created, and then years later finally the pediatric guidelines were created. We're on wave four for adults for the Health Registry and only on wave three for children. So there's always the children have been the last population that has ever gotten any attention and with healthcare as well.

MR. FLAMMIA: Catherine pretty much answered it, and I was thinking possibly through the World Trade Center monitoring program doing a survey because I've consistently over the past couple of years have gotten inquiries about it from responders serving as their advocate.

DR. MARKOWITZ: So I don't think we need to debate the narrative of this workgroup, but just come up with the language. So it's really what the most important developmental and health outcomes that would... phrasing includes priority-setting, and also it gives a non-defeasibility that Tom was concerned about. So what are the most important developmental and health outcomes to target, and in which cohorts of

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

children, and just leave it at that.

DR. WARD: Okay, Paul, type that.

DR. MIDDENDORF: What am I typing again?

DR. WARD: And in which groups of children; is that correct?

DR. MIDDENDORF: In, so take it out in such a cohort.

DR. WARD: Or how about in terms of the target in such a—or it could just be outcomes to target and in which groups of children. That's clear. Yes.

DR. MIDDENDORF: Right.

DR. WARD: Val.

MS. JONES: I was just going to say sometimes while things may seem like you're spinning your wheels, sometimes you spin them because it's the right thing to do, and to not try to find out what we can about children and their future and their potential, to try to find out what we can and do what we can is the right thing to do, even if we're spinning our wheels we can say, "We spinned (sic) our wheels in the right direction."

DR. WARD: Great. So we have a motion to vote on and we have a charge to the workgroup. So we're ready for a vote?

DR. MIDDENDORF: Do you want to read it into the record and make sure that...

DR. WARD: Okay. The committee moves to form a workgroup to formulate a potential response to question one, what are the most important developmental and health outcomes to target and in which groups of children?

SPEAKER: That's acceptable to me.

SPEAKER: Yes.

SPEAKER: Uh-huh.

DR. WARD: So we have a question from the floor.

DR. MIDDENDORF: Could you come up to the microphone, so it's in the record, please, Mark?

DR. FARFEL: The committee should be very well-informed and versed in all of the many, many outcomes that Leo Trasande is looking at, and Chris Hoven is looking at. Both of them are recruiting adolescents and young adults through the registry for intensive follow-up studies, I think would help answer your questions. The other input would be, of course, the pediatric surveys, the questionnaires that the registry has done, wave two and wave three, because there are additional measures that Robert Brackbill reminding me about, which includes the strength and difficulties, the questionnaire has things about different dimensions about peer-to-peer relationships and school behavior and prosocial behavior, lots of dimensions that we've looked at as well. So I think part of it is just knowing what's been done, what's currently being looked at because I think earlier someone had made a comment of the potential to do follow-ons to these in depth studies. So even to consider that you need to know what is being looked at currently.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

DR. WARD: Did we vote?

DR. MIDDENDORF: Somebody needs to say that this the motion, and somebody needs to second it.

MS. JONES: Can you just behind developmental can you put developmental, psychological?

DR. MIDDENDORF: I think that's incorporated.

MS. JONES: The motion.

DR. WARD: You want to add psychological to...

MS. HUGHES: Physical and mental.

MS. NORDSTROM: Yes.

MS. JONES: Behind developmental, psychological.

MS. HUGHES: Physical and mental.

DR. WARD: So you want to change developmental and health to physical and mental?

MS. HUGHES: Okay.

MS. JONES: I thought she said to...

SPEAKER: I think that's included.

MS. HUGHES: That's mental development.

SPEAKER: Physical and mental, yeah.

MS. JONES: Okay. Physical and mental is fine—

MS. NORDSTROM: Physical and mental development. Okay.

SPEAKER: Okay. Okay, I'm happy with that.

DR. WARD: Yes? Give your name, please.

DR. LEVY-CARRICK: It's Nomi Levy-Carrick. I'm the mental health director over at HHC. I would actually just note that to actually say psychological, developmental, and physical would actually be more accurate in a way and more specific, because we do think a little bit differently about the developmental disorders and neurologic disorders. We shouldn't; it's all on a continuum. But it does actually speak to the fact that when we're looking for autism spectrum things, learning disability things, it tends to be addressed differently than within the psychiatry-psychology realm. And so I think it will just identify key words and identify key literature probably more sensitively than if we just simply go for physical and mental.

DR. WARD: Thank you. So are we—discussion on that proposal? So change the wording to be more, I think, clinically accurate.

DR. TALASKA: Well, the sense of the motion was that the workgroup not be constrained at all, that they examine a wide area of things, and I think even though there are particulars that we could add, I think that... my sense in making that motion was that the workgroup not be constrained and they investigate all aspects of these potential situations, okay, and the sequelae of this exposure. Did you make the second with the same thing, with the same idea in mind?

SPEAKER: (Inaudible @ 00:51:37).

DR. TALASKA: Okay. So I think that's in the record now, and I think the workgroup will not be constrained. They will investigate all aspects that they deem relevant.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

DR. WARD: But Glenn, are you basically saying to accept the existing language?
DR. TALASKA: Yes. I'm saying that the motion was made without constraining and having a wide open sense of all the things that will be examined by the workgroup.

DR. MIDDENDORF: Good. So take out the psychological, is that what...
DR. TALASKA: No, leave it in. I mean, it's okay to leave it in, but I don't think we need to dance on too many angels. Let the workgroup do their work; on the heads of too many pins. Sorry.

DR. WARD: So can we vote on the motion as stated? I would like us to vote on the motion as stated, because then we have other things to talk about.

SPEAKER: I second that.
DR. WARD: Thank you.
DR. MIDDENDORF: Okay. So for the record the motion is the committee moves to form a workgroup to formulate a potential response to question one, what are the most important physical and psychological, developmental and health outcomes to target and in which groups of children. So I'll do a roll call vote. Tom Aldrich.

DR. ALDRICH: For it.
DR. MIDDENDORF: Please say yes, no or abstain.
DR. ALDRICH: Yes.
DR. MIDDENDORF: Rosemarie.
DR. BOWLER: Yes.
DR. MIDDENDORF: Anthony.
MR. FLAMMIA: Yes.
DR. MIDDENDORF: Bob Harrison. You e-mailed me saying you were on the line.
DR. HARRISON: Paul, can you hear me?
DR. MIDDENDORF: Yes, we can hear you now.
DR. HARRISON: Okay. Yes.
DR. MIDDENDORF: Okay. Catherine.
MS. HUGHES: Yes.
DR. MIDDENDORF: Val.
MS. JONES: Yes.
DR. MIDDENDORF: Mickey.
MR. KELLY: Yes.
DR. MIDDENDORF: Steve.
DR. MARKOWITZ: Yes.
DR. MIDDENDORF: Michael.
DR. McCAWLEY: Yes.
DR. MIDDENDORF: Lila.
MS. NORDSTROM: Yes.
DR. MIDDENDORF: Bill.
DR. ROM: Yes.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

DR. MIDDENDORF: Glenn.
DR. TALASKA: Yes.
DR. MIDDENDORF: Leo asked to abstain. Liz.
DR. WARD: Yes.
DR. MIDDENDORF: Virginia.
DR. WEAVER: Yes.
DR. MIDDENDORF: Okay. The vote is 14 to none, so the motion passes.
DR. WARD: We can either take a break or we can talk about the workgroup. Do you want to take a break? Let's take a break.

DR. MIDDENDORF: Dr. Anderson, we want to thank you very much for your participation. I think you're free to go now. Thank you, again, Dr. Anderson.

BREAK
DR. MIDDENDORF: Thirteen members at the table. Dr. Trasande is still recused. And Bob Harrison is on the phone.
DR. WARD: We'll resume by having a show of hands of people who would like to be on the workgroup that we voted to form right before the break. Okay. Just so everybody heard me, we're having a show of hands of people who would like to be on the workgroup that we voted to form right before the break. Bob Harrison, we can't see if you're raising your hand or not.

DR. HARRISON: Hi, Liz, I am not raising my hand.
DR. WARD: Okay, thank you.
SPEAKER: Can't we have Leo on the group as an expert?
DR. MIDDENDORF: No.
DR. WARD: However, we do have the option... we have two options. We can invite other experts. We also will definitely follow up on a suggestion that was made from the floor to get committee members acquainted with what is going on currently in terms of research on the children and young adults.

DR. MIDDENDORF: One of the things I will talk with the ethics counselor and legal counsel about is whether or not Dr. Trasande would be able to make a presentation on the research he has done, similar to the presentation that he did at the research meetings. (Inaudible @ 00:05:30) that'll give him a good baseline of where it is.

SPEAKER: I was suggesting that Julia or one of the other toxicologists also—
DR. WARD: Julia's no longer on the committee.
SPEAKER: Oh, sorry.
DR. WARD: She stepped off. I mean, I would like to have at least one physician on the committee.

SPEAKER: Why don't you get Dr. Anderson?
DR. WARD: Well, he kind of explicitly said that he's not, doesn't feel to be expert in this area. He's more involved in acute care. So, I mean, if anyone wants, if any of the physicians want to reconsider, who's on the committee, we do have the option of

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

looking for external experts. And, especially, probably we need someone who understands the mental health and the developmental and the psychological effects. So I would say we probably need at least one, you know, someone who specializes in pediatrics and someone who specializes in mental health effects in children and young adults.

SPEAKER: You know Sinai has a whole pediatric environmental group. So I'm sure there are people up there that might be useful.

DR. WARD: Okay.

SPEAKER: And it wouldn't be conflicted out. They're not part of the World Trade Center.

DR. WARD: Okay. Good. So I will volunteer as well. Because every group needs an epidemiologist.

DR. TALASKA: Hmm.

DR. WARD: Glenn says no.

DR. MIDDENDORF: Okay. We also need a chair for the workgroup.

DR. WARD: Right.

DR. TALASKA: I think we got one. She just volunteered.

DR. WARD: I'll do it. I'll do it.

DR. MIDDENDORF: Okay. Okay. Okay. So the workgroup is Glenn Talaska, Val Jones, Catherine Hughes, Lila Nordstrom, and Liz Ward, who will be serving as a chair. I missed Anthony, sorry about that. Anthony Flammia.

DR. MIDDENDORF: Okay.

DR. WARD: Good.

DR. MIDDENDORF: Done.

DR. WARD: Done. And the workgroup itself will deliberate on who additional... and we may be in touch with some of you to get recommendations for additional members with specific expertise, including Steve. Excellent. So I'll move onto question number three. So question number three is up on the board. So I don't think I need to read it. Can everyone see the question up on the board? So would anyone like to start this discussion off? Steve.

DR. MARKOWITZ: Well, you know, I thought the presentation earlier today that there was an excellent review of self-identification, really, of gaps, of problems, which was included in the PowerPoint. It seemed pretty thorough and self-critical. And then the response to that I thought was excellent. It's the PowerPoint slide "Current Recommendations." So I didn't have really much to add. I do wonder whether there was any attempt, actually, to poll kind of sort of informally poll members or beneficiaries, you know, participants in the program to see what their perceptions were about how useful the benefits were. But, otherwise, I thought it was excellent.

DR. WARD: So we've had a request to read the question for the record. So Paul will go ahead and do that.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- DR. MIDDENDORF: Okay. The question is, the CCEs and National Provider Network are required to provide benefits counseling to its members. Each of the CCEs and NPN have staff and an internal process for triaging members to appropriate counseling, and have established a level of counseling provided within their CCE NPN. In an effort to streamline benefits counseling, the program is working to identify gaps in the area of benefits counseling across the program and provide recommendations for streamlining the process across the CCEs NPN. After reading the current program recommendations for streamlining benefits counseling, what other recommendations would be helpful? Mickey.
- MR. KELLY: Mickey Kelly. Yes, I also thought that the presentation was very, very good. And I think it's very important that this is being done to streamline it because I work primarily with the construction workers in New York City. Last year when there was a deadline to apply or to make sure that you sign up for the medical program, I had latecomers coming in, people had not been involved. And this was 13-14 years on. A lot of those workers could not remember who they worked with because construction workers are pretty mobile. They travel around a lot, they worked down there for... some worked for two or three months, some are still down there working on the new projects. But the ones who were there from September through, basically, to May, some of them were there for a month, some of them were there for three months, four months, five months. And a lot of the time I have to help identify for them who they actually worked with. Luckily enough we have computer records for some of the unions, not all of the construction unions. And I think it might help if there was some kind of coordination between particularly construction workers and the World Trade Center health program, and we might be able to help them in moving things along, because the longer people are waiting to be certified for the program, it's stressful for them at that point, and maybe we can reduce that time there by offering a little more help to them that way.
- DR. WARD: Thank you. Anthony.
- MR. FLAMMIA: Yes. It's Anthony Flammia. Actually, I had posed this question to Dr. Carrick before in regards to the utilization of technology and doing this support, especially with the local outreach and also the national outreach, hearing problems as advocating for numerous responders nationwide. They often lack services and specifically psychological services, social workers, access to social workers and doctors. I'm actually proposing to expand the network of doctors and social workers for psychotherapy here and also nationwide.
- DR. WARD: Catherine.
- MS. HUGHES: I second what Dr. Markowitz and Mickey Kelley was saying. I think the key is to get them in the door rather than once they're in the door, because I think there's still is a resistance for people to go for care and for assistance.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

DR. WARD: Lila.

MS. NORDSTROM: I agree with Catherine and Mickey's points. But I also wanted to draw attention to something that's specific, I think, to the national program because I have a lot of experience dealing with national programs, and this is something that, I think, is feedback that they've gotten before. But there is a degree to which in terms of their benefits counseling there's a little bit of, what I kind of want a call, a culture clash where the program is administered by a company in the Midwest, and there was sort of like a tendency for things to happen really slowly with them, and because this is a program that is for all... it's exclusively for New Yorkers, basically. It's a program where every patient in the program is a native New Yorker or, at least, a long-time New Yorker, some kind of New Yorker. There was a huge turnoff factor with a lot of the people, at least, in the cohorts that I deal with who were dealing with a national program because they just like couldn't seem to get the information. There seemed to be a disconnect between how quickly and how easily they wanted to get information from people at LHI and how quickly they were able to provide that information, not just in terms of knowing the information, but also just how it was delivered. And so I just wanted that to be something that we keep in mind as we move forward. I think it's actually really an important part of outreach work to be able to send people to a program that they don't get annoyed with once they're finally dealing with it, because the national program causing you to deal with people all over the country. There were certain issues that we were seeing that were mostly just annoyances, but really were turning people off to even getting the kind of benefits counseling that they needed.

DR. WARD: Mike.

DR. McCAWLEY: I'm a little more familiar with the nuclear workers program. One of the things I wondering is how this program compares to that, and just having a chart one against the other to see what one program is doing and the other program is doing, would help us, I think, possibly identify gaps. And the nuclear workers program is, in fact, the NIOSH program.

DR. MIDDENDORF: Are you talking about the EEOICPA?

DR. McCAWLEY: Yes.

DR. MIDDENDORF: Yes. NIOSH deals with the dose reconstruction part of it. I don't think we do the benefits counseling. I think it's done by the Department of Labor.

DR. McCAWLEY: Yes. But those details are all pretty well set out, and just showing what details, because I know, for example, they have advocates there that are specific to individuals that work to help them get the benefits, and the NIOSH does run the advocates meeting, because I've been to some of those.

DR. MIDDENDORF: Okay. I can certainly get with the energy program and find out more about what they're doing. Laurie.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- MS. BREYER: I actually started my career 11 years ago with the EEOICPA program. So the Department of Labor set up resource centers for five districts across the country where a lot of the big DOE sites were, and so that's what they did. So they hire people from the local community to come in and train them about the DOL program and EEOICPA, the benefits under Part B and under Part E, and people who come into that office, they'd help them apply for the program, and then they'd give them resources and information about the program. They come back in and ask questions, if they had questions. But, yes, so we're centralized with a nationwide provider network that Lila mentioned was in Wisconsin, and the majority of the information that's provided is through phone calls, e-mails, and mailings, whereas the Department of Labor EEOICPA program and, again, that is through DOL's side of it, set up the resource centers across the country.
- DR. McCRAWLEY: You were the one who presented on the other thing. Is it possible to align the two programs up and show kind of line by line DOL does this, we do this, DOL does this, we don't do this, DOL doesn't do this, we do this?
- MS. BREYER: Yes, I'd be happy to put something together that would be helpful.
- DR. McCRAWLEY: Yes. It would give us something to compare to.
- MS. BREYER: To start with.
- DR. McCRAWLEY: It might automatically identify some gaps.
- DR. WARD: Just one question. Does the DOL program, is that actually a health program or is it more of a compensation program?
- MS. BREYER: It's both.
- DR. WARD: So they have a specific health program similar to the World Trade Center health program.
- MS. BREYER: They don't have clinical Centers of Excellence. It's more like the Nationwide Provider Network as I understand that side of it. I'm not an expert on DOL, but they do provide care, so if you do have a condition they get a card and they can go to certain doctors with that card under Part E. And I, actually, worked on Part B of the program, which is the dose reconstruction for exposure to radiation, but the Part E, chemical exposures and medical care, they can get that in addition to compensation. And my understanding is they had a network of doctors and someone would get a card, and they could go to those doctors. But it was even more limited as far as I understand for the healthcare and what we provide, but as far as treatment that's how I understood it worked. But I can find out more and refresh my memory. It's been six years.
- DR. MARKOWITZ: And there's a medical monitoring piece comparable to the WTC Health Program, that comes out of the Department of Energy, not DOL or NIOSH. I know all about that, so I can contribute.
- MS. BREYER: Probably know more than I do about that side.
- DR. WARD: And that was just Steve Markowitz speaking and say your name.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

MS. BREYER: Laurie Breyer.

DR. WARD: Thank you.

MS. JONES: I'm not sure this is an appropriate question. The translations, is that Spanish and Chinese? Is everything translated into Spanish and Chinese?

MS. BREYER: The majority of information is translated into Spanish, Chinese, and Polish, not everything that we do, but anything related to member benefits. Remember handbooks I provided? We have those in Spanish, Chinese, and Polish. The applications are in Spanish, Chinese, and Polish. The call center has a Spanish, Chinese, and Polish call prompt. But then the call line can answer, actually, any language. We have probably a list of 20 languages we've helped people with through our language line.

DR. WARD: Any other comments?

SPEAKER: So I just thought in terms of this specific question, Laurie, when you presented your current recommendations one that jumped out at me is the benefits eligibility assessment tool. It could be extremely valuable. And I wasn't sure the details of that. Is that going to be something interactive that's web-based that could be used by counselors as well as folks wanting to determine their own benefits on their own?

MS. BREYER: I don't think we envisioned it to be an online tool, but that's a good idea. I think what was envisioned is that anybody who came into the clinic for their first visit or it could be a second or third visit if they've never done one before, would get this checklist that would kind of go through, you know, are you having any issues with this, do you have questions about this. They would kind of fill it out, and then hand it back in when they checked in, and then it would go to the benefits counselors to see if that person needed any assistance in the categories on their checklist. But it could be an online tool as well, because then we could refer them to that and say at the end check this out, kind of assess yourself, and then see if you're may be able to get help at your clinic and here's who to call, give them the phone number.

SPEAKER: I'm just thinking if it was an online tool that was widely available it would allow people who are in labor unions, for example, to be able to help provide some initial assessment. It might just broaden the outreach available.

MS. BREYER: And I think that's a great idea.

DR. WARD: Any other comments? Maybe it would be worth summarizing the main points that we've gotten. I mean, one point I think was the importance of still reaching out to the populations that may be eligible for the health program, to identify any people who have not reached out and to encourage them, and specific recommendations were made about the Centers of Excellence, at least partnering with some of the local organizations such as unions or other organizations to help with outreach to their members. Anthony.

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- MR. FLAMMIA: To add that, currently there are several organizations out there that were awarded, I believe, a grant to do the outreach. I know with one of the foundations, a couple of the foundations are out there doing the outreach going from state to state and doing the outreach, most recently down in North Carolina and also California.
- DR. WARD: I mean, since that's going on, does the committee recommend anything in addition to that or are we satisfied that the current outreach efforts were adequate? How could that be improved, or should it be improved? I think Mickey was pointing to the opportunities within the construction field to improve the outreach.
- SPEAKER: So yesterday in one of the free local papers you see in the subway, I think it was AM New York, this is was this 9/11 health ad. So who was responsible for putting this ad out? I thought it was great. I'm just saying, I was just like going through and I was like wow.
- MS. BREYER: That was coordinated by Mount Sinai.
- SPEAKER: That was Mount Sinai.
- MS. BREYER: Mount Sinai paid for the ad, but coordinated with all the Clinical Centers of Excellence including the survivor program or the language that's on there. So they drafted it, graded it, shared it with the other groups, got it approved as a consensus, and then advertised.
- SPEAKER: Yes, because it was unusual because it said for breast, cervical, colon, and lung cancers. So that was the first time I actually saw an ad like that.
- DR. WARD: So, Mickey, you were specifically making, I think, a recommendation about...
- MR. KELLY: Yes, I mean, the outreach by, say, Mount Sinai is excellent. I know that one of the people involved with that who is just recently—I helped them get in touch with one of the other unions who they hadn't seen too many of their workers, and it's not a construction union. Not too many of their members they felt were not... she finally got to speak to somebody who's put her onto that. So that is all ongoing. They're not major problems, I think, but it's just that because I think everything is covered now under the way you've brought everything together, and it becomes something that is standard across all of the clinics. That's probably going to make it a lot easier, too, to get this information and get it out quicker.
- DR. MIDDENDORF: Yes. If I can make a quick point. I believe that there's a very big difference between the outreach efforts and benefits counseling. And benefits counseling is a subject of the question. So I think the committee needs to focus in on the benefits counseling at this point.
- DR. WARD: So, Lila was the point that you made earlier about the telephone services, was that in relation to benefits counseling or...
- MS. NORDSTROM: It's a broader point, I guess, but it definitely impacts the way that benefits counseling gets carried out for the national program, and it's something, I've

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

spoken to Laurie about it before, and it's something that's gotten better, significantly, over time, but it's definitely something that I think is important to keep in mind as we think of ways to kind of streamline the process for people in the national program. It's sort of, you know, it's difficult to deal with doing a lot of this work over the phone and not in person. So to have the additional problem of not really being able to communicate that effectively with the people that you're talking to can be problematic. And so it's something that I think should be a continuing focus of the way that the national program, in general, kind of focuses their efforts.

DR. WARD: Good. Well, I'm getting a... from everyone who's spoke, and I'm getting a general feeling that people... the answer to this question is that the committee really supports the efforts that are being made to streamline the program and make sure that there's greater uniformity at all the centers, and that there really isn't any major concern about what was presented, that people think it was a good plan. So would that be a reasonable consensus?

DR. MIDDENDORF: So I see a lot of heads nodding. So I'm assuming that means people agree.

DR. WARD: Yes. So we're good. We can move on to the next question. The next question is, The "Research-to-Care" model relies on strong linkages between health surveillance, research, and clinical care to produce the outcomes of the logic model. Are there any missing linkages or other ways that the model might be improved? Comments on that question?

DR. TALASKA: Just to reiterate, I think what both Steve and I said earlier would be to develop a better strategy for exposure assessment for emergencies of this nature again. Exposure assessment isn't in that particular model, but NIOSH, I know, is working on it, which I just really like to see the progress in that as we move along.

DR. WARD: Lila.

MS. NORDSTROM: I think, you know, at least in the survivor program we're almost operating on a modified "Research-to-Care" model because there isn't a monitoring program for survivors that we use as research before determining which conditions we'll cover in that program. There's monitoring programs for responders, and then we kind of cover people that have health conditions already in the survivor program. I think, ultimately, it would be preferable, certainly, and I don't know what the feasibility issues of this are, but it's definitely preferable for us to have some sort of research that expands beyond just what condition survivors are seeing in terms of studying what kinds of conditions—I mean responders are seeing in terms studying what kinds of conditions survivors might be experiencing, because the responder population is a very different kind of population, I think, in certain ways. We're talking about a lot of like police and firemen who were largely male and in good shape and good health, and so I think that there's certainly room and a need, maybe, for sort of a way to kind of broaden the survivor research in a

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

way that kind of allows them the same opportunities that responders get where there's research that kind of researches everything just to support, you know, to figure out what they need to support instead of just kind of backing into that system.

DR. WARD:

Val.

MS. JONES:

I think one of the things would be to... so I'm going to share this with other communities in terms of disasters, because I think one of the things we learned, or I know that I've heard—I don't even know a nice way to put it—was that people did not realize that they should've had something covering their face and their mouth. And when I think about in our area we had a fire recently, I think on Second Avenue or something, and one of the things I noticed in the paper after that was that people were talking about their breathing, and they were talking about the air. And I was just thinking that you they need to share this information about, you know, I think I read it someplace since that people should've probably had on some type of dust mask or something all with this dust cloud that was over everybody. And I think that needs to be shared, because I've seen this once or twice recently in these big fires in New York that people have talked about maybe the people in that building should have on some kind of dust mask. So I think that one of the things is sharing information, sharing the research that you find from the World Trade Center, share that in terms of a larger community.

MS. HUGHES:

Also, there was this book called Contaminated Communities, and there's a chapter that I did with Dr. Michael Edelman, and you can't compare the World Trade Center tragedy to any other exactly, but you sort of felt like you could insert yourself in of the other chapters where there was Chernobyl or something like that in looking at it from an environmental health perspective, not in terms of a terrorist attack. So there is parallels among a lot of these different incidents. So I totally agree with what Val said.

DR. MARKOWITZ:

So to address the question, I like the model. The model is all-inclusive. So it really kind of gives you... everything that I can tell that's important, every component is in this box, and there's some attempt, but fortunately not too much to relate within the overall table. And I thank Dori for not drawing arrows between the boxes because it wouldn't have clarified anything. So I have no criticism about the model. But what I really want to know is what happens to demonstrate what happens in those boxes. So, for instance, the long-term outcome of improved response for disaster. So what tools do we have from our experience now in the World Trade Center program if there's a disaster tomorrow, what tools are ready to use? Are we going to do the exposure sessions better because we have a tool to apply? Are we going to do the medical monitoring better because we know which questionnaires to use? Are we going to be able to set up the registry quicker because we have a protocol that we can use? So I'm looking

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- forward to a set of tools that comes out of this program that's going to be useful in the next disaster. Obviously, it'll need to be adapted, but it'll be starting from something, not starting from very little, which is what we have here after September 11th. So it's that kind of detail within the logic model where if this model drives us to produce those kind of products, then I think it'll be very useful.
- DR. WARD: It sounds like one consensus, and then I'll go to Glenn, is that this last box where a long-term outcome is improved response for future disasters, there's kind of a gap in having some specific products that would lead to that long-term outcome. Does that basically summarize it?
- DR. MARKOWITZ: I'm not saying there's a gap. What I'm saying is that as a general map of what's being done is fine, and then we want additional layers to this map whereby some of the details are filled out. That's not a criticism, that's just a target.
- DR. TALASKA: That was my point, too. And, actually, I see that Dr. Reissman is here, and we didn't get a chance to ask you any questions after your presentation, but that's what I think I would like to ask you is how are you incorporating an improved exposure assessment strategy into this whole program.
- DR. REISSMAN: There was an inter-agency group that had been convened probably back in 2004-ish, '05-ish, that got into the Emergency Responder Health Monitoring System, it's an acronym that is like ERHMS, which I didn't share with you all because there's just so much to say, but I didn't get into all that stuff. I didn't get into personal protective equipment technology and all the things that are going on with NIOSH with all that, with sensor technologies and all that. There are a lot of efforts within the agency that address long-term future disaster preparedness. They're not within the territory, so to speak, of this program. This program is funded specifically to provide healthcare, to provide certain aspects of research about health conditions. To some extent the future preparedness was my way of kind of pushing that envelope a little bit into where it kind of ought to be, too. But if you look inside the act in and of itself, it doesn't have a clear funding mandate to hit all of that, whether it will in the future or not I don't know. But the program evaluation piece, I think, is an important piece, and that is a legitimate thing that I think could be covered here. But if the committee would like, we could certainly follow up and provide some of the things that have contributed from NIOSH because there's a lot that's been done.
- DR. WARD: Catherine.
- MS. HUGHES: I have a question following up on Dr. Markowitz' question, which is also related to your response, Laurie, which is, first of all, if it's about healthcare you actually need to know the health assessment, so it's intertwined. And why are we putting that box under long outcomes versus intermediate outcomes? Because we're 14 years after, and isn't intermediate right now? If we add that box to the model.
- DR. REISSMAN: You mean the medical monitoring?

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- MS. HUGHES: Well, you know, improving the healthcare with the... you know, if we're going to talk about sharing best practices for healthcare, it goes back also to the environmental assessment strategy because you can't look at them in isolation because they're related in the emergency preparedness.
- DR. REISSMAN: Oh, sure, they definitely are. I mean, the idea of health surveillance and medical monitoring, the knowledge in that has been iterative over time. And then the findings that come out of that also back inform ways that things might've been designed better, but when you collect longitudinal information you can't keep changing it down the line because you don't have the continuity of information for scientific validity. So in certain ways the intermediate outcome concept is, what are some of the elements that we learned from all of this that could contribute toward future scales and future things you'd want to measure. Part of it depends, of course, what happens, you know, what's the pathway of exposure, etc. But we had all the pathways of exposure here that one could really have except maybe, you know, clearly radiation. But within all of this there is an iterative process that's built into program eval for both medical monitoring and for exposure assessment. The ERHMS concept took into account free disaster exposure worker registries, if you will, so that you know where an employer is with their potentially deployable force. This is different than a community registry because there's no money to really do that upfront ahead of time before something happens. But, at least, people who are being deployed to respond to something, they should be fit. They should have certain baseline measurements. There should be a certain understanding of what they're deploying to and what the environment should be in terms of protected, and what assessment should be happening during the time of the disaster. This is all built into that system, including suggestions for measurement tools or all of that. The problem with environmental health and the population at large is you don't know where something's going to strike, so what could you set up ahead of time other than a lot of the general preparedness strategies that happen throughout CDC and other agencies for general readiness and messaging and looking at individual behaviors, and what happens in group dynamics and who has leadership in the midst of a crisis, and that kind of thing. Does that help a little bit as to what you're getting at?
- MS. HUGHES: It's all right.
- DR. WARD: Anthony.
- MR. FLAMMIA: You touched on a few words that, actually, my antennas are going up. You're saying other agencies, you're saying deploy, you're saying response. I'm thinking in my mind I'm thinking FEMA, I'm thinking , I'm thinking NIMs, National Incident Management, I'm thinking other agencies, and comingling with FEMA and all these other response agencies to put these all together as a response

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

plan. Is that correct? Because you had mentioned some other things before, and it seems like it should be all tied in together with all of the collaboration and cooperation with all these other agencies. And to have a plan put together to respond to it.

DR. REISSMAN: Right. There is a national response plan. But what's in paper and what's practice there's often gaps.

MR. FLAMMIA: So do you think that in practice we should be doing something as far as readiness with the local law enforcement and local law enforcement agencies at the federal, state, and local level to comingle our assets together?

DR. REISSMAN: Yes, and that already happens. That already happens through Homeland Security and the Department of Justice.

DR. WARD: Michael.

DR. McCAWLEY: Looking at the logic model it's very informative just as it is on the page. But these are boxes that things are being done in. Right? If I understand you correctly.

DR. REISSMAN: Uh-huh.

DR. McCAWLEY: There's no way for us to judge what you think has been sort of successfully completed or is in interim stage or hasn't begun at all with those kinds of things. And it would be nice to have maybe a little extra coding on this model to let us know at what stage of whatever you'd like to tell us about each one of these titled things are at. If you just did it in a 0 to 5 scale that would, or a 1 to 5 scale that would be fine, you know, just put a little number next to it and say, "This one's good. Boy, this one really needs a lot."

DR. REISSMAN: Right. You're right on target. I mean, logic models are created most of the time for evaluation. The whole reason to put it all down is to show that you've actually thought through something. And then to go back and say, "Well, how did I do?" And to use that as a way for continuous quality improvement. So those are the next steps in part of this. I mean, I could go through right now and tell you one to five in many of the boxes. I don't know about all of the boxes, but it wasn't the purpose of today's...

DR. McCAWLEY: I understand. I'm asking you kind of can you go beyond...

DR. REISSMAN: I can occupy your whole day.

DR. McCAWLEY: Yes. But, I mean, and if there are boxes where you don't know, it's good for us to know that you don't know. So if you can go through and spend a little bit of time just putting a number there and tell us where you don't know, that way we can have a conversation back and forth about what kinds of things need to be looked at, and kind of continue on with this because it is a continual improvement cycle.

DR. REISSMAN: It is.

DR. McCAWLEY: It wouldn't be a bad idea, I think, personally, to sort of be updated on this on a regular basis because it gives us a framework in which to compare all of the other things that we're doing, because all of the other things we're doing, presumably,

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

- should fall into this model.
- DR. REISSMAN: It should. And you're right, the arrows can't be on here, Dr. Markowitz. We tried that at one point.
- DR. McCAWLEY: It's some kind of a one to five, even.
- DR. WARD: It sounds like in terms of answering the question that the program asks, that the committee basically thinks the logic model is fine, there's no missing linkages. It's just really, then, what do you with it. And, as you said, the next step is probably an evaluation process, and basically we'll wait. I mean, I think a number of people have said updates would be important, but I also think the next step would be to see what question the administrator wants us to... you know, there's a million questions that you could ask within this logic model and delve more deeply into, but we're really serving at the pleasure of the administrator to help give advice on things that are important to the program. So, in a sense, we can challenge you to ask us, you know, go deeper into the logic model and ask us additional questions that you would like to hear our advice on.
- MS. HUGHES: I have one last comment about community registries. Even when our building was closed and we weren't allowed to live there, we got every single bill. So if you really want to know who in the community is there, you can get that from the IRS from your taxes, you can get it from your local utilities whether it's Con Edison here in New York or Verizon on your landline or your Time Warner. If you really wanted to find out who is in that community or if you have to, you know, voter records are somewhat out of date. So there really, you know, and even your junk mail finds you. So I just want to put that in your bag, you know, next time if you have to create a community registry.

ADMINISTRATIVE ISSUES AND ADJOURN

- DR. WARD: I think we finished the business that we had on the agenda for today. Are there any additional comments about the format of the meeting or any other topic that you want to address in the last ten minutes? Paul.
- DR. MIDDENDORF: Well, if nobody else has any other thoughts or comments they want to share, I would just tell you that I'll speak for the program, and thank each of you very, very much for your time and your efforts, and your thoughts and advice. The program finds it very, very valuable, and safe travels. I hope each of you gets home safely. If you have any questions, comments, or concerns, feel free to contact me.
- SPEAKER: Was there anything particular about the data that we have to provide for itemizing our expenses and things that we should talk about?
- DR. MIDDENDORF: We can do that offline.
- DR. WARD: Well, thank you, everyone. I think it was a great meeting. And, especially, again, I thank the new members. It's exciting to have new people on the committee and

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

get some new insight.

[END MEETING]

**WORLD TRADE CENTER HEALTH PROGRAM
SCIENTIFIC/TECHNICAL ADVISORY COMMITTEE (STAC) MEETING
June 4, 2015**

G L O S S A R Y

ATSDR	Agency for Toxic Substances and Disease Registry
CCE	Clinical Center of Excellence
CDC	United States Centers for Disease Control and Prevention
CDC-INFO	Centers for Disease Control and Prevention National Contact Center (1-800-CDC-INFO)
CME	Continuing Medical Education
CUNY	City University of New York
DOE	Department of Energy
DOL	Department of Labor
EEOICPA	Energy Employees Occupational Illness Compensation Program Act
EPA	Environmental Protection Agency
ERHMS	Emergency Responder Health Management System
FDNY	Fire Department, City of New York
FEMA	Federal Emergency Management Agency
GERD	Gastroesophageal Reflux Disease
HHC	New York City Health and Hospitals Corporation
IRB	Institutional Review Board
LHI	Logistics Health Incorporated
NHANES	National Health and Nutrition Examination Survey
NIH	National Institutes of Health
NIMS	National Incident Management Systems
NIOSH	National Institute for Occupational Safety and Health
NPN	Nationwide Provider Network
NYPD	New York Police Department
ODAR	Office of Disability Adjudication and Review
PTSD	Post-Traumatic Stress Disorder
STAC	Scientific/Technical Advisory Committee
SUNY	State University of New York
VCF	Victim Compensation Fund
WTC	World Trade Center
WTCHP	World Trade Center Health Program