

**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**

FOURTH MEETING

**SCIENTIFIC/TECHNICAL ADVISORY**

**COMMITTEE (STAC) MEETING**

February 14, 2014

The verbatim transcript of the  
Meeting of the Scientific/Technical Advisory  
Committee Meeting held telephonically on February  
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STEVEN RAY GREEN AND ASSOCIATES  
NATIONALLY CERTIFIED COURT REPORTING

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### TRANSCRIPT LEGEND

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-- "^" represents indiscernible or indiscernible speech or speaker failure, usually failure to use a microphone or multiple speakers speaking simultaneously; also telephonic failure.

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JESSICA BILICS, SPEAKER  
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KIMBERLY FLYNN, COMMITTEE MEMBER  
ROBERT HARRISON, COMMITTEE MEMBER  
JOHN HOWARD, MD - PROGRAM ADMINISTRATOR  
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CAROL NORTH, COMMITTEE MEMBER  
MARY PERILLO, PUBLIC COMMENTER  
JULIA QUINT, COMMITTEE MEMBER  
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GLENN TALASKA, COMMITTEE MEMBER  
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**Committee Members**

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

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Professor of Medicine and Environmental Medicine, New York University School of Medicine  
Director, Division of Pulmonary and Critical Care Medicine, School of Medicine, New York University, New York City.

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***Occupational Physicians:***

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***Physician with Pulmonary Medicine Expertise:***

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Representatives of WTC Responders:

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Stephen Cassidy

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President, Uniformed Firefighters Association of Greater New York, Local 94 I.A.F.F. AFL-CIO

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2 Human Resources Analyst, Patrolmen's Benevolent Association of the City of New York, Inc.,  
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4 Guillermina Mejia, M.P.H  
5 Certified Health Education Specialist, Principal Program Coordinator, Safety and Health  
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9 ***Representative of Certified-Eligible WTC Survivors:***

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11 Kimberly Flynn,  
12 Co-Founder, Director, 9/11 Environmental Action

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14 Vice Chairman, Community Board 1 World Trade Center Redevelopment Committee, Lower  
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16 Susan Sidel, J.D.  
17 Resident of New York City and volunteer WTC responder.

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19 ***Industrial Hygienist:***

20 John Dement, Ph.D.  
21 Professor, Community and Family Medicine, Duke University Medical School, Durham, N.C.

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23 ***Toxicologist:***

24 Julia Quint, Ph.D.  
25 Research Scientist Supervisor II and Chief, Hazard Evaluation System and Information Service  
26 (HESIS), Occupational Health Branch, California Department of Public Health (retired), Oakland.

27 ***Epidemiologist:***

28 Elizabeth Ward, Ph.D. (Advisory Committee Chair-Person)  
29 National Vice-President for Intramural Research, American Cancer Society, Atlanta.

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***Mental Health Professional:***

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***Environmental Health Specialists:***

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***Designated Federal Official:***

Paul J. Middendorf, Ph.D., CIH  
Senior Scientist  
CDC/NIOSH/Office of the Director  
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## PROCEEDINGS

(9:35 a.m.)

### WELCOME AND INTRODUCTION

**DR. MIDDENDORF:** Well, good morning everybody, Happy Valentine's Day. Welcome to the meeting of the World Trade Center Health Program's Scientific/ Technical Advisory Committee.

Hopefully everyone has weathered the effects of Winter Storm Pax that's just gone through. It certainly caused us a few tense moments in the lead-up to the meeting. I am Paul Middendorf and I'm the designated federal official for the committee. I do want to extend a warm welcome to each of the committee members and the members of the public who are on the phone with us. We very much appreciate your interest in these proceedings.

Just to start out, I think it's very important for us to remember why we're here and set the appropriate tone for the meeting, so let's just spend a few moments 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.)

**DR. MIDDENDORF:** Thank you. There are a number of administrative issues to deal with on the front of our meeting so let's work through those initially. First I need to point out that we announced openings for five seats on the STAC last summer. Final selections for those positions have not been made yet so five of our members have had their tenure on the committee extended an additional six months through March 30<sup>th</sup>. We anticipate announcing the selections for those positions in the very near future.

We have also begun the process of soliciting nominations for six different seats on the committee, and those are scheduled to open on September 30<sup>th</sup> of this year. If you're interested in nominating someone, including yourself, please visit the committee's website to find the information on how to nominate someone. For those who are logged into the web portion of this conference, the committee's web address is on the screen.

For those of you signed up to provide public comments, those are scheduled to begin at 11:30 this morning, and that's Eastern Standard Time. Copies of the public comments that we received by yesterday have been provided to each of the committee members and they will also be posted in NIOSH's docket number 248-A, which is also available through the committee's website.

Let's go ahead and do a quick roll call. For our roll call, I'll call out the name of each member and ask you to let me know that you're on the line. I'll ask you to state whether or not there have been any changes in your employment or interest

1 that would affect your conflict of interest. If for some reason a member needs to  
2 leave the call, please let me know when you leave and when you return so we can  
3 be sure that we have a quorum for the meeting. For the STAC a quorum is, is ten  
4 members. And also I'll repeat the roll call after each of the breaks and after the  
5 lunch period.

6 So, Tom Aldrich?

7 **DR. ALDRICH:** ...and I have received a grant from the NIOSH program but I  
8 don't believe that affects my conflict of interest situation.

9 **DR. MIDDENDORF:** Okay. And Steven Cassidy and Valerie Dabas will not be  
10 participating in the meeting.

11 John Dement? Okay, I don't hear John on the line. Kimberly Flynn?  
12 Kimberly announced herself earlier. Kimberly, are you there?

13 **MS. FLYNN:** Hello? Paul?

14 **DR. MIDDENDORF:** Yes?

15 **MS. FLYNN:** Hi. Sorry, I couldn't get my mute off. My engagements have  
16 not changed.

17 **DR. MIDDENDORF:** Okay. Bob Harrison?

18 **DR. HARRISON:** I'm here and I don't have any conflicts or issues.

19 **DR. MIDDENDORF:** Okay. Catherine Hughes?

20 **MS. HUGHES:** Nothing has changed.

21 **DR. MIDDENDORF:** Okay. Steve Markowitz.

22 **DR. MARKOWITZ:** Present. I don't think it's a conflict but we were a  
23 satellite -- a site for Wisnivesky's asthma research project funded by NIOSH.

24 **DR. MIDDENDORF:** Okay. Is that new or different?

25 **DR. MARKOWITZ:** No, no. It's been going on for at least a year or so.

26 **DR. MIDDENDORF:** Okay. So it's part of the evaluation for your conflict of  
27 interest already.

28 **DR. MARKOWITZ:** Correct.

29 **DR. MIDDENDORF:** Okay. Guille Mejia?

30 **MS. MEJIA:** I still have the same employer; however, I am now the director  
31 of the safety and health department and I'm also the PR for the cooperative  
32 agreement.

33 **DR. MIDDENDORF:** Okay. And we've addressed your conflict of interest  
34 issues already.

35 **MS. MEJIA:** Yes.

36 **DR. MIDDENDORF:** Okay. Carol North?

37 **DR. NORTH:** I'm here. I don't think I have any change.

38 **DR. MIDDENDORF:** Okay. Julia Quint?

39 **DR. QUINT:** I'm here. My status hasn't changed.

1 **DR. MIDDENDORF:** Okay. Bill Rom?

2 **DR. ROM:** Present. No changes.

3 **DR. MIDDENDORF:** Okay. Susan Sidel.

4 **MS. SIDEL:** I'm here. Can you hear me?

5 **DR. MIDDENDORF:** Yes, we can hear you.

6 **MS. SIDEL:** Okay, all good.

7 **DR. MIDDENDORF:** Okay. Glenn Talaska?

8 **DR. TALASKA:** Present. No changes.

9 **DR. MIDDENDORF:** Okay. Leo Trasande? I believe he'll be joining us this  
10 afternoon. He said he wouldn't be available this morning. Elizabeth Ward?

11 **DR. WARD:** I'm here. No changes.

12 **DR. MIDDENDORF:** Okay. Virginia Weaver?

13 **DR. WEAVER:** Present and no changes.

14 **DR. MIDDENDORF:** Okay. I guess there's 13 members who are present. I'll  
15 ask John Dement, have you joined us?

16 **DR. DEMENT:** Yes, Paul, I'm on the line.

17 **DR. MIDDENDORF:** Okay.

18 **DR. DEMENT:** There are no changes.

19 **DR. MIDDENDORF:** Okay, great. Okay, so that's 14 members; we do have a  
20 quorum.

21 The focus of this meeting is on research needs for the World Trade Center  
22 Health Program. All the materials for this meeting including copies of our agenda  
23 and presentations can be got on the committee's website and, for those of you who  
24 are logged into the web portion of our meeting, the materials can also be  
25 downloaded by clicking on the right icon at the top of the screen that looks like  
26 three little pieces of paper. So if you click on that, you should be able to get to the  
27 materials and download from there, if you don't get them from the website.

28 Because the focus of this meeting is on the research needs of the program,  
29 and some of our members are researchers who potentially have interest in doing  
30 research on World Trade Center-related matters, it is important that we manage the  
31 potential for conflict of interest. So for each of those members, I believe, have been  
32 counseled on the limits of their participation. If I happen to see that someone has  
33 strayed into areas that are of potential conflict of interest for them, I will point out  
34 to them -- point that out to them, and then ask them to refrain from further  
35 discussion in that particular area.

36 An issue we need to address for committee members is how to make sure  
37 each of you has the opportunity to voice your ideas. Obviously we can't see hands  
38 raised or name cards turned on end so we need to work out a way to be sure that  
39 each of you has the opportunity to contribute to the meeting. So after a speaker is

1 finished and before the next speaker has been identified, if you would state that you  
2 have comments to make, Liz and I will both keep a sequential list of those who  
3 identified that they want to make comments, and then we'll recognize you in turn  
4 so you can have the floor.

5 I also want to remind you that you really do need to identify yourself before  
6 speaking so our transcriptionist can accurately attribute your contributions to the  
7 meeting.

8 The last things I need to review before turning this over to our Chair, Dr. Liz  
9 Ward, are the motions and voting procedures. When a member of the committee is  
10 developing a motion, I will type it so it's visible on the screen and each of you should  
11 be able to see it. When the Chair calls for a vote, I will have to do a roll call vote and  
12 will ask each of you in turn to say yes, meaning you are voting for the motion that  
13 has been put to the committee, or no, meaning you are voting against the motion  
14 that has been put to the committee, or abstain, meaning that you are not voting on  
15 the motion. If someone has been recused for a specific motion, I'll note that also.  
16 According to our bylaws a majority of those voting determines the outcome.

17 So with that, I will turn it over to Dr. Ward.

18 **DR. WARD:** Well, I will just add my welcome to the committee members,  
19 presenters and members of the public who are joining us today. And also thank  
20 Paul and other CDC staff who have organized and supported this meeting.

21 I think we have a very full agenda, had a little bit of a late start, so I'd like to  
22 move directly to Dr. Howard for his charge to the committee.

#### 23 24 **CHARGE TO THE COMMITTEE**

25 **DR. HOWARD:** Thank you, Liz. Good morning, advisory committee  
26 members and good morning to responders, survivors and members of the public.  
27 Welcome to the fourth meeting of the World Trade Center Health Program  
28 Scientific/Technical Advisory Committee. I especially want to thank each committee  
29 member for serving on the advisory committee. Your time and your advice to the  
30 Health Program are greatly appreciated.

31 The advisory committee has an important role to play in the World Trade  
32 Center Health Program. The Zadroga 9/11 Health and Compensation Act of 2010  
33 specifies three areas of contributions of the advisory committee to the program.  
34 First, the Act requires that the administrator consult with the advisory committee  
35 with regard to determining eligibility criteria for responder and survivor  
36 membership in the program. Second, the Act provides that the administrator may  
37 seek a recommendation from the advisory committee regarding whether a  
38 particular health condition should be added to the list of World Trade  
39 Center-related health conditions. And third, the Act requires the administrator to

1 consult with the advisory committee with regard to identifying research needs for  
2 the program.

3 It is this third area, consulting the advisory committee with regard to  
4 identifying the research needs of the World Trade Center Health Program, that I  
5 asked you to meet today.

6 Each year since 2011, NIOSH has solicited applications for scientifically  
7 rigorous research studies to help answer critical questions about the physical and  
8 mental health conditions related to the September 2001 terrorist attacks. From  
9 2011 through 2013, 79 research proposals were reviewed, and 32 percent of them  
10 or 25 meritorious projects, including the renewal of the World Trade Center Health  
11 Registry, have been funded.

12 The charge that I would respectfully give to the advisory committee today is  
13 to: One, identify critical research gaps relative to our understanding of the effects  
14 of exposure to airborne toxins, any other hazard or any other adverse condition  
15 resulting from the September 11, 2001 terrorist attacks; two, identify critical  
16 research knowledge gaps relative to the accurate diagnosis of World Trade  
17 Center-related health conditions; three, identify critical research knowledge gaps  
18 relative to the effective treatment of World Trade Center-related health conditions;  
19 and most importantly, four, provide advice on the priority ordering of the critical  
20 research needs identified by the advisory committee.

21 Thank you again for participating in the meeting today. I wish you a very  
22 productive meeting. Thank you for attending.

23 **DR. WARD:** So I think we'll move directly to the next presentation by Jessica  
24 Bilics, who will give us a brief update on the World Trade Center Health Program.

#### 25 26 **BRIEF UPDATE ON WTC HEALTH PROGRAM**

27 **MS. BILICS:** Hello. This is Jessica Bilics. This is the World Trade Center  
28 Health Program policies, staff and intergovernmental affairs.

29 It's been almost two years since the STAC last convened in March 2012. In  
30 these two years, the World Trade Center Health Program has had many changes.  
31 Some of these changes include the addition of more than 50 types of -- or categories  
32 of cancer, the addition of Pentagon, Shanksville, -- Shanksville, Pennsylvania  
33 responders to our membership and the completion of a variety of policies and  
34 procedures to help program providers determine World Trade Center-related and  
35 medically associated health conditions as well as policies and procedures for  
36 administrative requirements related to recoupment or reimbursements from  
37 workers' compensation or private health insurance.

38 I will not spend the limited time we have today on the details of these  
39 policies and procedures or the regulatory activities of the program. However, I

1 encourage everyone to spend some time on our website, specifically the policies  
2 and procedures page and the laws and regulations page, to learn more. You can  
3 access the website at: [www.cdc.gov/wtc](http://www.cdc.gov/wtc).

4 What I'd like to spend my time doing this morning is going over some data  
5 on the World Trade Center Health Program that may be of interest to you and be  
6 deliberated, as Dr. Howard requested, on research priorities for the future of the  
7 program. The data I will cover should be on the screen if you are participating via  
8 Live Meeting and are also available in a two-page document titled The World Trade  
9 Center Program Updates on the program's advisory committee web page.

10 The first four tables provide break-outs of the program's more than 66,500  
11 members by some basic demographics. The first table, table 1, breaks down the  
12 program's membership by four major member types: FDNY responders, non-FDNY  
13 responders, survivors and Pentagon/Shanksville responders. As you can see about  
14 two-thirds or 64 percent of the program's membership is made up of non-FDNY  
15 responders who responded to the disaster in New York City. Twenty-five percent  
16 are FDNY responders; 11 percent are survivors from New York City disaster area;  
17 and less than one percent are responders from the Pentagon and Shanksville,  
18 Pennsylvania sites.

19 Table 2 breaks down the program's membership by member types as well  
20 as gender. The program's members are about 83 percent male, 16 percent female  
21 and 1 percent unknown; however, the gender distribution varies within the member  
22 type. The three responder categories, the responders, FDNY and  
23 Pentagon/Shanksville in the table, all have about 85 percent or more males,  
24 whereas the survivor population is split almost evenly between males and females.

25 Table 3 provides the membership by member type as well as age categories.  
26 Now more than 12 years out from 9/11, about 70 percent of the program's  
27 members are between 40 and 59 years old. Some of you may have noticed and  
28 been surprised by the younger members in the program, particularly those in the  
29 responder and FDNY categories. Table 3 reflects the statutory eligibility criteria  
30 which includes not only traditional first responders but volunteers who may have  
31 been young people providing support services at the site as well as family members  
32 of FDNY.

33 Table 4 breaks down the member -- the program's membership by the top  
34 ten places of residence. Not surprisingly, 87 percent of members live in either New  
35 York state or New Jersey. There are also significant numbers of members in Florida,  
36 Pennsylvania, North Carolina and California. Most of the members living outside the  
37 New York metropolitan area are served by the program's nation-wide provider  
38 network.

39 As you all know, the World Trade Center Health Program provides

1 treatment for certified members as a variety -- for a variety of health conditions.  
2 The major categories of health conditions include obstructive airways diseases such  
3 as asthma, reactive airway dysfunction syndrome, World Trade Center-related COPD  
4 and chronic cough, upper respiratory diseases, upper airway -- such as upper airway  
5 hyperactivity, rhinosinusitis, nasal pharyngitis and laryngitis as well as interstitial  
6 lung diseases, gastroesophageal reflux disease, certain types of cancers, mental  
7 health conditions and musculoskeletal disorders.

8 Tables 5 and 6 show the number of certification categories per member.  
9 About 36,000, or 54 percent of the members, are not certified for any category of  
10 health conditions, which leaves 46 percent, or more than 30,000 members, certified  
11 for at least one health condition category. More than 30 percent of members are  
12 certified for three or more health condition categories.

13 Tables 7 and 8 list the top ten health conditions certified for all conditions  
14 and then for cancer conditions only. The top three certified conditions of all health  
15 conditions are GERD, with more than 2,000 members certified, sinusitis, with more  
16 than 1,500 members certified, and rhinitis with almost 15 members -- 1,500  
17 members certified as well.

18 Those top ten health conditions I just stated, the top condition is GERD,  
19 three are cancer conditions, three are mental health conditions, two are upper  
20 respiratory diseases and one is an obstructive airways disease.

21 Table 8 displays the top ten cancers certified within the program. As of mid-  
22 January, the World Trade Center Health Program had certified 1,930 cancers. Of  
23 this total, 320, or 17 percent, are for prostate cancer, and just over 300, or  
24 16 percent, are for non-melanoma skin cancer. The top ten certified cancers make  
25 up 80 percent of all cancers certified within the program.

26 That covers the eight tables provided in the document that I wanted to  
27 provide to the advisory committee for their discussion today. I'd be happy to try to  
28 answer any questions that any members may have.

29 **MS. HUGHES:** Yes, this is Catherine Hughes. Is this going to be posted on  
30 the website, this table?

31 **MS. BILICS:** Yes, it is a document that contains all eight tables and it is  
32 available on the advisory committee web page.

33 **MS. HUGHES:** So is it also available to the public is what I'm asking?

34 **MS. BILICS:** Yes. It's already posted on the web page in the STAC's advisory.

35 **MS. HUGHES:** Great, thank you.

36 **MS. BILICS:** And it's titled World Trade Center Program Update.

37 **DR. HARRISON:** This is Bob Harrison, thank you. Do you have a breakdown  
38 on the types of leukemia?

39 **MS. BILICS:** I don't have them by count. The regulation like -- I'm not sure I

1 have the regulations in front of me. The regulations do break down -- they include  
2 the tables of these cancers. I can probably find it.

3 **DR. HARRISON:** Yeah, I'm just thinking of, you know, how many were AML,  
4 ALL, CML or --

5 **MS. BILICS:** I don't have a specific breakdown for that level of detail right  
6 here.

7 **DR. HARRISON:** Okay.

8 **MS. BILICS:** We can maybe get it up on the website later.

9 **DR. HARRISON:** Okay, thanks.

10 **DR. MARKOWITZ:** Jessica, this is Steven Markowitz. I'm looking at the  
11 Power -- the transcript that was sent and looking through the tables that were  
12 numbered 1 through 8, and I can't see the reference to the chronic obstructive  
13 pulmonary disease that you mentioned.

14 **MS. BILICS:** I was just saying that of the covered different major categories  
15 of health conditions included that was in the statute, and included is in the  
16 obstructive airways diseases category is World Trade Center-exacerbated COPD as  
17 an eligible condition for coverage.

18 **DR. MARKOWITZ:** So in table 7, was the top -- was -- is the top ten covered  
19 health conditions --

20 **MS. BILICS:** Yes.

21 **DR. MARKOWITZ:** -- which starts with GERD and then goes to sinusitis and  
22 then rhinitis, right?

23 **MS. BILICS:** Yes.

24 **DR. MARKOWITZ:** Okay. So I don't know what total the member count is  
25 beyond the top ten but, you know, in that table it looks like, you know, 8,000 total  
26 or so. But if you go to table 5, it looks like there are some 30,000 members who  
27 have at least one covered condition or if I'm reading that correctly, they're certified  
28 for at least one covered condition.

29 **MS. BILICS:** Correct.

30 **DR. MARKOWITZ:** So I don't quite understand how it could be that 30,000  
31 members have a covered condition and we're looking at the top ten and the top ten  
32 seem to only include about 8,000 members.

33 **MS. BILICS:** I believe what's happening there is the 7 and 8 tables are  
34 actually those with claims since the program started so that's the ones that are in  
35 treatment. I believe that's the data.

36 **DR. MARKOWITZ:** Okay. So okay. Table 5 is not necessarily in treatment;  
37 it's certified.

38 **MS. BILICS:** No, it's for the whole program certified, yeah.

39 **DR. MARKOWITZ:** Great, thank you.

1                   **MS. FLYNN:** Jessica, this is Kimberly. Thank you so much for this  
2 information. A follow-up to Dr. Markowitz's question. Could you please clarify that  
3 the 35,966 members who are not -- who have no certifications are all in the  
4 responder monitoring program and that the survivor program is different?

5                   **MS. BILICS:** Yeah, so the difference between the two categories, the  
6 responder and the survivor committees -- or committees -- populations, are that the  
7 responders are eligible to be in the program regardless of whether or not they have  
8 a health condition related to the World Trade Center. They are allowed to have  
9 monitoring without being sick from any condition; whereas the survivor population  
10 statutorily has a requirement to -- that the members have to be -- they have to have  
11 a symptom initially to be screened to be determined if they are eligible, the certified  
12 eligible survivors. So in order to be in the program they have to be sick from one of  
13 the conditions.

14                   **MS. FLYNN:** Thank you.

15                   **MS. MEJIA:** Jessica, this is Guille Mejia. Can you tell me, do you have  
16 numbers in terms of the pending cases that need to be certified, how many are still  
17 pending that would add to these numbers?

18                   **MS. BILICS:** I don't have those numbers. I don't know if I -- anyone on our  
19 medical team -- I'm looking at the pending cases for certification -- any idea about  
20 how many they are? We can find out.

21                   **MS. MEJIA:** Okay, and when was the -- what's the date on these tables, in  
22 terms -- do you have a cut-off date for these numbers as of when?

23                   **MS. BILICS:** Tables 1 through 4 are through the 11<sup>th</sup> of February and tables  
24 5 through 8 are all through mid-January. I believe the date was the 8<sup>th</sup> of January.

25                   **MS. MEJIA:** Okay, thank you.

26                   **DR. WARD:** Before we close, will you and members of the medical program  
27 staff be available during our later discussions in the event that there are some  
28 questions that come up from committee members about these diagnoses or the --  
29 for the medical program?

30                   **MS. BILICS:** Yes, there will be some of us here at any time and we can grab  
31 folks from down the hall.

32                   **DR. WARD:** Okay, great.

33                   **DR. HARRISON:** This is Bob Harrison. I don't know whether we'll cover this  
34 later but one of the charges to the committee is the terms of research on effective  
35 treatment, and will we be covering that later or -- I guess I'm just trying to get a  
36 sense of how the covered conditions and suggest anything about how people have  
37 been treated or, you know, the numbers who remain in treatment, any questions or  
38 issues that have come up around treatment.

39                   **MS. BILICS:** There is a presentation from the clinical centers by Dr. Laura

1 Crowley later that will speak, probably, to some of your questions.

2 **DR. HARRISON:** Okay. Great, thanks.

3 **DR. WARD:** Okay. So I think we should move on and to the presentation by  
4 Dr. Robison and Kubale on Overview of World Trade Center Health Research.

5  
6 **OVERVIEW OF WTC HEALTH RESEARCH**

7 **DR. KUBALE:** Good morning, this is Travis Kubale and I'm the program  
8 official from the Office of Extramural Programs and assigned to the World Trade  
9 Center Health Program, and I'm here with Dr. Allen Robison who is the director of  
10 OEP. And Dr. Middendorf, as you know, has asked us to provide the committee with  
11 a brief overview describing the World Trade Center Health Program research  
12 portfolio, as Dr. Howard indicated, that was initiated in 2011.

13 Dr. Robison and I will describe the current research solicitation  
14 announcement and how STAC recommendations were incorporated. We will  
15 discuss the number of projects funded, and because this is a new and developing  
16 portfolio, we'll talk a bit about the publication status and estimated completion  
17 schedule. We will also briefly describe where the projects fit broadly within the  
18 primary research outcome and population focus areas that were discussed in the  
19 2011 STAC recommendation report. And finally we'll talk about where information  
20 concerning the current research, including the principal investigator contact  
21 information, project descriptions and results, can be obtained.

22 So Paul, the -- if we move to the third slide, Allen will talk a little bit about  
23 the funding announcement. Allen?

24 **DR. ROBISON:** Thank you, Travis. Can you hear me?

25 **DR. KUBALE:** Yes.

26 **DR. ROBISON:** Good morning, everyone. I just want to talk briefly about  
27 the World Trade Center Health Program research funding announcement that we  
28 developed in late 2011 and published in 2012.

29 Our first application was published in March 2012, and we received our first  
30 round of applications in May of 2012. As Travis mentioned briefly, we incorporated  
31 input from a wide range of experts including the Scientific/Technical Advisory  
32 Committee, the World Trade Center Health Program and others. That input is  
33 reflected in the announcement by identifying major areas of interest but not  
34 limiting the announcement to those six major areas of interest that are listed. We  
35 also identified relevant diseases or conditions but we did not limit applications to  
36 those nine or so diseases or conditions that are listed. We provided population  
37 focus, which is -- which by that, I mean we specifically talked about responder  
38 populations and community members or survivor populations.

39 We also listed contacts for the three data centers. And the reason for that

1 was to help stimulate collaboration and encourage collaboration by the applicants  
2 as they submitted their -- as they prepared their applications.

3 And then also in the funding opportunity announcement we provided  
4 guidance to reviewers on disaster science. And the way that's worded in the  
5 announcement, it's a little section called limitations of currently available data. We  
6 just advise the reviewers to be cognizant of the fact that research in this area is a  
7 type of research where there may not be a lot of pre-event information, so we  
8 equate that to the area of the -- the area that we call disaster science research.

9 Our goals in preparing the announcement were to stimulate meritorious, or  
10 as Dr. Howard said, scientifically rigorous investigator-initiated applications for  
11 research relevant to the World Trade Center Health Program, but we wanted to  
12 encourage collaboration, and we still pursue that -- those two goals with each round  
13 of applications that we receive.

14 We think it's been an effective and productive funding opportunity  
15 announcement based on the number and types -- the number and types of projects  
16 that have been funded.

17 And then before I close and turn it back over to Travis, I just want to say  
18 thank you to those committee members that are on the call, attending this meeting,  
19 who provided input and others who provided input. And I want to particularly  
20 thank the grantees on the phone and thank you for the great work that you're  
21 doing. So with that, I'll turn it back over to Travis. Thank you all.

22 **DR. KUBALE:** Thank you, Allen. The next slide we want to go to, the current  
23 research portfolio projects, as has been stated, is the result of solicitations that  
24 were conducted in 2011, -12 and -13. A 2014 solicitation was just completed, and  
25 the submitted projects are scheduled for scientific and technical review this spring.  
26 A final solicitation is planned for '15, and that will be the last solicitation until the  
27 program is reauthorized. Currently, as has been stated, the portfolio has 25 projects  
28 including the World Trade Center Health Registry, which has multiple projects and  
29 focus areas, and will be discussed in detail by registry staff in the next presentation.

30 In 2011 eight projects were funded, each with a three-year duration. Now,  
31 four of these projects have published initial results and the other four are expected  
32 to have results published late in the current calendar year. There are currently a  
33 total of seven publications for those four projects.

34 In 2012, 11 projects were funded, and like I said, the renewal of the World  
35 Trade Center Health Registry was included. Five of the 11 projects have two-year  
36 duration periods and the initial results we expect possibly late this calendar year.

37 Now, as a note, since the renewal in 2012, the World Trade Center registry  
38 has produced 15 research publications. These published studies focus on cancer,  
39 mental health and physical comorbidity, respiratory effects among World Trade

1 Center-exposed children, 9/11 healthcare utilization, behavioral and structural  
2 barriers to evacuation and cardiovascular disease hospitalizations related to 9/11.

3 In 2013, six projects were funded. Three of the projects have two-year  
4 duration periods and three are for three years. We are expecting and hoping that  
5 two of the two-year projects may have early results in early 2015.

6 The next slide is a listing of the eight studies by focus area funded in 2011.  
7 Three mental health studies were funded, and each of these studies has a post-  
8 traumatic stress disorder emphasis. Dr. Adriana Feder's study identifies and  
9 describes the distinct course of World Trade Center-related PTSD symptoms over  
10 time, and initial findings are published in two articles.

11 Dr. Evelyn Bromet has two studies, one examining post-traumatic stress  
12 disorder and physical illness comorbidity, and this study will also include a  
13 comparison of PTSD treatment approaches among clinics. Dr. Bromet is also  
14 implementing and evaluating a smoking cessation intervention program for  
15 individuals diagnosed with post-traumatic stress disorders.

16 As has been well publicized, respiratory disease conditions are prevalent at  
17 significant rates in both the responder and community populations. During the '11  
18 call, there was one respiratory disease study that Dr. Ken Berger is conducting to  
19 enhance the characterization of lung disease among individuals exposed to World  
20 Trade Center dust. And this study does include rescue and recovery workers as well  
21 as area residents, and initial findings have been published in three separate articles.

22 During the first call in '11, two cancer incidence studies were funded.  
23 Dr. Paolo Bonfetta's (sic) study included non-FDNY responders and a study by  
24 Dr. Prezant, David Prezant, included FDNY firefighters and emergency medical  
25 service workers. Initial findings for both of these studies have been published.

26 In addition there were two studies with a cardiovascular disease focus. One  
27 by Dr. Morabia is examining the overall CVD risk among responders and is also  
28 working to develop a specific World Trade Center heart disease risk score similar to  
29 that of the Framingham score for heart disease. Also Dr. Mary Ann McLaughlin is  
30 examining the long-term effect of particulate matter on pulmonary and  
31 cardiovascular disease risk.

32 Just as a note, females are included in all but one of these eight studies.  
33 The FDNY study has a low number of females but the seven other studies do include  
34 females.

35 The next slide. The next two slides, beginning with this one, list 11 studies  
36 funded in 2012. This slide is a listing of the respiratory disease studies that were  
37 added to the portfolio during the 2012 call.

38 As I said there were six of these studies. Dr. Tom Aldrich is examining the  
39 persistence over a ten-year period of bronchial hyper-reactivity easily triggered

1 airway narrowing among firefighters. The study will also assess the effectiveness of  
2 anti-asthma medications at resolving bronchial hyper-reactivity and a decline in lung  
3 function.

4 Dr. Charlie Hall is investigating the incidence of new obstructive airway  
5 disease cases over the first ten years following World Trade Center exposure, also  
6 among firefighters. Dr. Rafael de la Hoz is investigating how best to identify early  
7 indications of lung disease among World Trade Center's responders -- responders,  
8 workers and volunteers.

9 Dr. Sunderram is examining the role of nasal pathology or damage in World  
10 Trade Center responders and in the development of how it's related to the  
11 development of obstructive sleep apnea. He's also looking at the impact of the  
12 nasal pathology on the use of continuous positive airway pressure machines or  
13 CPAP machines.

14 Dr. Wisnivesky is studying the relationship between asthma morbidity and  
15 upper airway conditions among rescue and recovery workers. And Dr. Ben Luft is  
16 working to explain the potential mechanisms underlying post-traumatic stress  
17 disorder and respiratory disease comorbidity, also among responders.

18 Three of the six studies, Dr. Aldrich, Dr. Hall and Dr. Luft, are two-year  
19 studies and early results are possible by late in the calendar year. Four of these six  
20 studies do include females.

21 The next slide is a listing of the remaining five studies conducted in 2012. As  
22 you can see, there are three mental health studies. Dr. Adriana Feder is assessing  
23 the vulnerability to post-traumatic stress disorder among police and responders.  
24 Dr. Christina Hoven is assessing the prevalence of mental health disorders and high  
25 risk behaviors among World Trade Center youth exposed to 9/11. And she also has  
26 a second study, also of World Trade Center youth to assess the mental health  
27 service need, use and barriers to service. That is a two-year study and results are  
28 possible late this calendar year.

29 In '12, we also added two studies that have a surveillance or a  
30 multi-outcome focus. The registry, which we have talked about, was one. The  
31 second is a study by Dr. Kim which will describe the overall physical, mental and  
32 socioeconomic impact of the World Trade Center disaster on responders. All of  
33 these studies, all of these five studies, do include females.

34 The next slide is a listing of the six studies that were funded in 2013. Two of  
35 these studies have what we've labeled as a biomarker development focus.  
36 Dr. Emanuela Taioli is working to generate data on biomarkers of prostate cancer  
37 aggressiveness. Her study population is rescue and recovery workers.

38 And Dr. Michael Marmor is working on methods to determine if World  
39 Trade Center-related trace elements can be identified in individual autopsy tissues.

1 It's hoped that this work will provide a foundation for future development of  
2 biomarkers indicative of cumulative World Trade Center exposure.

3 The remaining four studies that were funded in 2013 each have a distinct  
4 focus area. Dr. Leo Trasande is studying the physical health effects among  
5 adolescents who had early life exposure to the World Trade Center disaster.  
6 Dr. Joan Reibman is working to identify the mechanisms most responsible for  
7 uncontrolled lower respiratory disease among survivors and responders. And the  
8 study will also examine best treatment methods for patients with persistent lower  
9 respiratory symptoms.

10 Dr. Mayris Webber is working to calculate the incidence of selected  
11 systemic autoimmune diseases in firefighters and emergency medical service  
12 workers. And Dr. Adam Gonzalez is comparing two methods of mind-body  
13 treatment for responders with PTSD, post-traumatic stress disorders, and lower  
14 respiratory disease.

15 All but one of these six studies include females. Three of them, Drs. Taioli,  
16 Marmor and Webber are two-year studies with initial results expected in mid-2015.

17 The next slide is simply a summary of the study focus areas. There are just a  
18 couple of things that I want to call your attention to. There are currently three  
19 studies in the portfolio that focus on World Trade Center youth. Two are mental  
20 health and one, Dr. Trasande's, deals with physical health issues.

21 The next slide gives a breakdown in the portfolio of the studies. Eighteen of  
22 the 25 focus primarily on responders; three of the 25, which include World Trade  
23 Center youth that I just mentioned, are survivors only; and four of the 25 include  
24 populations that have both responders and survivors.

25 And the next slide, I want to just point out that information about the  
26 research portfolio of projects can be accessed through the World Trade Center  
27 program website. On that site we will have updated, probably in the next several  
28 days, information about contact information for each of the PIs. We currently have  
29 study descriptions that are available on the website, if -- for people to see, and  
30 that's publicly available.

31 We will also be adding into a database research articles as they are  
32 published, and that will be searchable as well. I also wanted to point out that we  
33 have two research grantee meetings each year. In the '14 meetings, we will begin  
34 discussions, as I said, on preliminary results. The researchers will also begin  
35 organizing findings and identifying research gaps as well and providing that  
36 information to the program. The characterization or the categorization scheme that  
37 I talked about will also get a look at as well and I would imagine that there will be  
38 some modification there, too.

39 Scientific publications, like I said, there are currently seven publications that

1 are available from projects awarded in 2011. And currently the PIs will be  
2 presenting at several conferences in 2014, they include the American Thoracic  
3 Society Conference, the American -- the World Congress of Epidemiology, the  
4 American Heart Association and the American Association of Cancer Research.

5 And finally I just want to thank, from the staff and the NIOSH Office of  
6 Extramural Programs, the STAC committee members and also the very hard work  
7 that is being performed by the portfolio researchers. Thank you very much.

8 **DR. WARD:** Thank you for that informative presentation. We have a few  
9 minutes for questions.

10 **DR. MARKOWITZ:** This is Steven Markowitz; I have a question. I hope it's  
11 not an unfair question, but in Dr. Howard's charge to the committee, he listed  
12 several areas for us to look at. One was understanding the effects of exposure,  
13 secondly is research gaps on accurate diagnosis, a third is effective treatment, and  
14 I'm just wondering whether he's broken these projects down at all by those three  
15 factors, the extent to which they address more or less those three factors?

16 **DR. KUBALE:** You know, Dr. Markowitz, we have some information about,  
17 you know, how these projects would relate to that. I, you know, I would have to  
18 probably get back to you on some of the specifics of that. And, you know, maybe  
19 some of the committee members, Dr. Aldrich or Dr. Trasande would, you know,  
20 want to weigh in on that as well.

21 **DR. MARKOWITZ:** Actually, you know, let me just rephrase it. Do you think  
22 any of those three areas, the ideology of the diagnosis of treatment, it seemed  
23 when you reviewed the projects that they seemed to be covered, more or less, in  
24 the various projects, treatment, for instance, you mentioned a number of times.  
25 And from -- is it your impression that any of those three areas are perhaps under --  
26 are underserved in terms of the research, from your point of view?

27 **DR. KUBALE:** You know, I think the way that I would, you know, probably  
28 best answer that right now is that I think -- I think that there are several of the  
29 projects that we tried to point out that do have treatment relevance. I think that,  
30 because of the relative newness of the portfolio, it's hard for me to comment, you  
31 know, probably further on where the additional gaps would be, you know, at this  
32 particular time.

33 **DR. MARKOWITZ:** Okay. Thank you.

34 **DR. KUBALE:** I'm sorry.

35 **DR. MARKOWITZ:** It's not a problem.

36 **DR. HARRISON:** This is Bob Harrison. Could you just, Allen, just re-  
37 emphasize the current funding years for the projects that are already funded, when  
38 they're expected to end, when the new announcement goes out, and then when  
39 those would be expected to end? I'm just, just trying to get an overall perspective

1 on the time frame of the current funding on the projects.

2 **DR. KUBALE:** Um -- I'm sorry.

3 **DR. ROBISON:** No, go ahead, Travis, that's fine.

4 **DR. KUBALE:** Dr. Harris (sic), the projects that were funded in '13 -- or I'm  
5 sorry, in '11, there were eight of those, and they will end officially later this year.  
6 The projects that were funded in '12, some will, the two-year projects, will end in --  
7 at the end of '14, and the four-year projects will essentially be funded through the  
8 end of '15.

9 The six projects that were funded in '13, two -- like I said three of the  
10 two-year projects -- let's see, it will be FY '13 and '14, and the three-year projects  
11 will go into '15.

12 **DR. HARRISON:** The current projects that are funded end in 2015.

13 **DR. KUBALE:** Yes.

14 **DR. HARRISON:** And the new announcement that we're discussing in terms  
15 of recharge of priorities, that goes out this year and that -- those would end in --

16 **DR. KUBALE:** I'm sorry, I understand your question. That's a one -- those  
17 will be the '15 call, if there is a call, which we're assuming there will be, will be for  
18 one-year projects.

19 **DR. HARRISON:** Okay, for one year.

20 **DR. KUBALE:** Yes.

21 **DR. HARRISON:** And those would start in --

22 **DR. KUBALE:** The money would be allocated in '15. They would go into  
23 '16 but the money would be authorized and allocated for '15.

24 **DR. HARRISON:** Okay, gotcha. Thank you very much. That helps me 'cause  
25 I just wanted to -- and that would be, then, in terms of the -- from 2001, those  
26 would be research projects that would then be out potentially 15 years, just in  
27 terms of any kind of longitudinal evaluation or --

28 **DR. KUBALE:** Yes, you're correct. That's correct.

29 **DR. HARRISON:** We'd be talking 15 years.

30 **DR. KUBALE:** That's correct.

31 **DR. HARRISON:** Since 2001, okay. Thank you.

32 **DR. ROBISON:** And Bob, just to clarify, we've had one research funding  
33 announcement we've modified in each year to decrease the number of years, to line  
34 up with the projects. And then currently the next receipt date will be for one-year  
35 projects.

36 And then as we look ahead to another research funding opportunity  
37 announcement, we will incorporate input that we receive from the Scientific  
38 Advisory Committee members. We'll use information that we glean from the  
39 current projects that are funded, so we're, we're looking -- we're looking ahead to

1 that. Thanks.

2 **DR. HARRISON:** So can I clarify that, just one quick question? So then are --  
3 would you be asking us for our feedback and advice today on just the next  
4 announcement for one-year projects or also for potential reauthorization and  
5 additional research in subsequent funding announcements that could go beyond  
6 one year?

7 **DR. MIDDENDORF:** I think Dr. Howard is interested in getting information --  
8 this is Paul by the way -- is getting information and getting your advice extending  
9 out beyond the point of reauthorization.

10 **DR. HARRISON:** Okay. Thank you.

11 **DR. TALASKA:** This is Glenn Talaska. One of the areas where there was a lot  
12 of uncertainty was in the exposure and the ability to reconstruct the exposures from  
13 the, from the 9/11 -- the measurements that were done. Does that seem to be an  
14 area that's addressed? I realize that the Marmor study will be looking at the levels  
15 and autopsy samples, but still my thinking is there has been nothing that addressed  
16 strategies for doing monitoring under -- when circumstances like this might arise  
17 again.

18 **DR. KUBALE:** Glenn, is that a question for us? We would agree with your  
19 assessment.

20 **DR. TALASKA:** Okay, thank you.

21 **DR. WARD:** If there are no further questions, we'll move on to the next  
22 presentation, which is by Drs. Farfel and Stellman about the World Trade Center  
23 Health Registry Research Program.

24  
25 **WTC HEALTH REGISTRY RESEARCH**

26 **DR. FARFEL:** Good morning. Thank you for the opportunity to provide an  
27 update on registry research. This is Mark Farfel, the registry director, and I'm going  
28 to begin with a very brief overview, and Dr. Steve Stellman, the registry's research  
29 director, is going to focus on registry research since our last update, which was at  
30 the November 2011 STAC meeting as well as our plans going forward.

31 Next slide. Could I have the next slide, please?

32 **DR. MIDDENDORF:** Yeah, I'm working on it.

33 **DR. FARFEL:** The registry has a cohort study of more than 71,000 people  
34 directly exposed to the 9/11 disaster. And it was designed to last 20-plus years with  
35 periodic follow-up health surveys. We do collect additional data by matching with  
36 administrative databases, to assess cancer, mortality and hospitalization, and by  
37 conducting in-depth studies, such as our respiratory study, in collaboration with  
38 NYU-Bellevue. The registry is also a platform for numerous 9/11-related studies by  
39 external researchers, and Dr. Stellman will mention some of our active

1 collaborations.

2 One of the core registry aims is to respond to the health needs and concerns  
3 of enrollees and their families. Through our treatment referral project we do  
4 conduct extensive outreach to encourage enrollees to access monitoring and  
5 treatment through the World Trade Center Health Program.

6 Could I have the next slide, please? The registry has diverse populations of  
7 responders and non-responder survivors who were exposed to the disaster. We  
8 have more than 30,000 rescue and recovery workers enrolled in the registry,  
9 including thousands of firefighters, police, out-of-state responders, construction  
10 utility workers and volunteers.

11 The largest group of survivors is the building occupants and passers-by  
12 group, followed by residents and school children and staff. Approximately one in  
13 four of our enrollees belong to more than one eligibility group, and that's why the  
14 numbers total more than 71,000.

15 While most of our enrollees live in New York City, we do have enrollees  
16 from all 50 states and more than 15 countries.

17 And next slide, please. The registry was conceived here at DOHMH shortly  
18 after 9/11, and it became a collaborative effort funded by FEMA, ATSDR, CDC  
19 beginning in 2002. Our Wave 1 survey was conducted in 03-04, and addressed new  
20 and worsening physical and mental health symptoms and conditions and exposures  
21 on and after 9/11.

22 The first follow-up survey was conducted in 06-07, and our Wave 3 survey  
23 provided health updates approximately ten years post-9/11. These follow-up  
24 surveys included questions on the course of symptoms and conditions, new  
25 conditions, unmet healthcare needs, quality of life and had separate adult and  
26 pediatric surveys.

27 We collected data on Hurricane Sandy exposures and health outcomes six to  
28 12 months after the events among 4,300 enrollees living in inundation zones and a  
29 sample of enrollees outside of inundation zones, and this effort demonstrated the  
30 registry's ability to mount a rapid response to another event and to obtain good  
31 survey response from enrollees. And our Wave 4 survey is currently under planning  
32 for a 2015 launch.

33 Could I have the next slide? To date the registry has 43 publications in peer  
34 review journals that report on adverse health outcomes across all eligibility groups  
35 and subgroups, that address myriad conditions including some that Travis  
36 mentioned earlier: PTSD, respiratory heart diseases, cancer, mortality, GERD, co-  
37 occurring conditions and other topics such as access to care and respiratory  
38 protection.

39 We're also in continuous communication with scientific and clinical

1 audiences through presentations at conferences and scientific meetings. We've also  
2 produced a number of technical reports as well as three sets of clinical guidelines  
3 developed with our colleagues at the clinical programs.

4 Other outputs include our in-depth studies, doctoral and masters theses  
5 based on registry data and the public use data sets and data query tools that are  
6 posted on the registry's website.

7 Could I have the next slide? The registry publications appear in a range of  
8 journals, and here in this slide I've grouped them by type of journal. So they include  
9 the clinical/medical journals, journals focused on occupation/environmental health  
10 as well as mental health, public health/epidemiology and disaster-oriented journals.  
11 And our publications do include two papers, an editorial and two letters in *JAMA* as  
12 well as two papers in the *Lancet*.

13 Could I have the next slide? The publications -- the registry work is  
14 informing disaster response through the peer review literature contributions, the  
15 conference presentations, and studying the impact of exposure to multiple  
16 disasters. We also contribute through the facilitated external research that includes  
17 the studies of behavioral, organizational and structural aspects of evacuation of  
18 damaged and destroyed buildings at the World Trade Center site.

19 Could I have the next slide, please? The treatment referral project at the  
20 registry is actually one of the four aims under our current NIOSH funding. And the  
21 project was launched in 2008 in collaboration with a health and hospital  
22 corporations World Trade Center of excellence for residents and area workers, and  
23 it's now been expanded to include responders and out-of-state enrollees.

24 And we conduct what we deem personalized outreach to survivors who  
25 reported 9/11-related public health -- physical health and/or mental health  
26 symptoms as well as to responders with and without symptoms who did not report  
27 using 9/11 clinical services on the most recent survey. And our dedicated staff have  
28 social work and nursing backgrounds and are trained in motivational interviewing  
29 techniques so that they can encourage care seeking addressing attitudinal and  
30 access barriers.

31 There are many challenges to this project. We have hard to reach  
32 populations, for example, one of the subgroups with comorbid PTSD and depression  
33 and low social support. Others are concerned about mental health stigmatization or  
34 fail to connect their symptoms with 9/11.

35 And we have had some success motivating people either to make their first  
36 appointment, when we were linked to HHC's program. We're now applying to the  
37 World Trade Center Health Program, and we do continue to send applications for  
38 the World Trade Center health application to interested enrollees and follow up to  
39 see if they have applied and to offer assistance if needed.

1                   And before I turn this over to Dr. Stellman, I just wanted to highlight some  
2 of the registry's strengths that I believe will enable the registry to remain an ongoing  
3 source for 9/11-related long-term health impacts research.

4                   Could I have the next slide? And these strengths include the diverse cohort,  
5 the large numbers that we have of both responders and survivors, the scope and  
6 depth of the scientific output that have had a role in informing 9/11 healthcare and  
7 providing lessons learned for future disasters.

8                   We also have dedicated staff for core registry functions in the areas of  
9 research, surveillance, cohort maintenance and treatment referral. And we do have  
10 a strong commitment on the part of the enrollees, and for example, we have valid  
11 contact information for about 95 percent of our enrollees and relatively small  
12 numbers of withdrawals; it's just a little bit more than 1 percent, and small numbers  
13 of people currently lost to follow up. And lastly we do have increasing numbers of  
14 collaborations with distinguished external researchers.

15                  **DR. STELLMAN:** Good morning, this is Steve Stellman, the research director  
16 for the World Trade Center Health Registry. I want to thank you for this opportunity  
17 to acquaint the committee with highlights of registry published studies that have  
18 appeared in print since our previous appearance in 2011. I just have to emphasize  
19 that in the interest of time, I can only present the most salient features. All of these  
20 papers that I will discuss are in the open literature except for a new one by Dr.  
21 Brackbill on injury that was just accepted by American Journal of Epidemiology last  
22 week. After I discuss the published studies, I'll give you an outline of the registry's  
23 current research program.

24                  As you can see we -- the registry has now published 44 articles in the peer  
25 review literature and has five papers under review, and these sort into the thematic  
26 areas that are largely under discussion this morning, physical and mental health.

27                  As you can see on the right-hand panel, we have a number of other areas  
28 for which we have collected data and for which there is considerable amount of  
29 interest, and these are also the target of many of our studies, and I'll mention a few  
30 of these here.

31                  Next slide? Just as I mentioned, just as highlights of several studies, we had  
32 an article in collaboration with our colleagues at ATSDR, led by Vinicius Antao, on  
33 use of respiratory protective equipment. I'd like to point out, by the way, that this  
34 particular paper was one of a handful of nominees for the CDC's annual Charles C.  
35 Shepard Award for Science, so -- for which there are usually about a thousand CDC  
36 coauthored papers under consideration, so we're very happy to have been among  
37 the finalists.

38                  But we studied almost 10,000 rescue/recovery workers in that study. We  
39 found that protective equipment were used most often by construction utility

1 workers, and that correct use of RPE was associated with between a 20 to  
2 50 percent reduced risk of respiratory illness, and that fit testing and training were  
3 key to effectiveness. And so, although these may seem somewhat obvious and are  
4 consistent with the guidelines that NIOSH and other organizations have been  
5 publishing for years, it's really rather rare in the literature to find an actual  
6 evaluation of effectiveness.

7 What you also see on the slide is the clinical study that was conducted by  
8 Dr. Friedman using innovative technology, impulse oscillometry, which is particularly  
9 sensitive to distal airway dysfunction. We found that cases were more likely -- cases  
10 of respiratory -- lower respiratory distress were more likely to have abnormal  
11 spirometry than control but that a screening spirometry was relatively insensitive at  
12 distinguishing symptomatic or asymptomatic control, and that this oscillometry  
13 measurement was reflecting overall resistance to airway flow was more likely to be  
14 elevated in cases than in control.

15 Next slide. We've now published three separate reports on coronary heart  
16 disease, one on mortality, one on incidence and one on hospitalization. The first  
17 bullet here refers to our incidence study in which we reported that dust exposure  
18 and PTSD independently were predictors of elevated risk of nonfatal heart disease  
19 in our Wave 2 survey; that is, two to six years post-9/11.

20 The second bullet, this is our newly published study in the Journal of the  
21 American Heart Association based on linkage of respiratory data with the New York  
22 State SPARCS registry, which is a hospitalization database, which we found  
23 hospitalization for cardiovascular disease was 32 percent higher in women with  
24 PTSD and 82 percent higher in male responders with high exposure compared to  
25 low exposure.

26 Then in the last bullet, where we've also had a number of analyses of data  
27 on GERD or symptoms of GERD, which we call GERS, or gastroesophageal reflux  
28 symptoms. We found an elevated rate of GERS in our -- up to Wave 2 survey, and  
29 found that these were especially pronounced in people who had comorbid PTSD,  
30 asthma or both. So this has extremely important clinical implications for clinicians  
31 who may be dealing with one or another of these outcomes, and may not realize  
32 that all three of them may be associated with serious pathology.

33 Next slide? We've done the major study on mortality in the registry based  
34 on linkage with the New York City vital records and with the National Death Index of  
35 cancer based on linkage with the New York State cancer registry and the registries  
36 of New Jersey, Connecticut and a number of other states where the great majority  
37 of our enrollees live. The overall mortality in the registry population is considerably  
38 below the population rate, which in fact is what you usually find in the early years of  
39 a cohort study based on volunteer enrollment.

1 Cardiovascular mortality was in fact dose related to a 9/11 intensity score,  
2 so that the people with the highest exposure among the survivors had a hazard ratio  
3 of about 1.6.

4 In our cancer study we found overall no increased risk of cancer among  
5 people who did not perform rescue/recovery work. And among the  
6 rescue/recovery workers, although the overall death cancer incidence was not  
7 increased, we did report excess risk of three types of cancer, thyroid cancer,  
8 prostate cancer, multiple myeloma, and these were strikingly consistent with  
9 reports from two of the other reporting agencies, the fire department and Mount  
10 Sinai.

11 Next slide. Some of our other recent findings. We recently reported on  
12 evacuation modes and time in people who evacuated the two World Trade Center  
13 towers. And building on a previous external researcher, the work of Robyn Gershon  
14 from Columbia University, we divided different types of various evacuations  
15 according to structural and behavioral pattern. We found for example evacuation  
16 time was related to encountering smoke and poor lighting, structural barriers and  
17 behavioral barriers such as serious crowding and lack of communication.

18 We have conducted three follow-ups -- or three rounds of data collection  
19 and two follow-ups on our pediatric cohort. And in the younger children we  
20 reported our respiratory health associated with 9/11 exposures, which we found a  
21 prevalence of lower respiratory illness in 14 percent of the children, and the great  
22 majority of those reported a previous diagnosis of asthma among -- with clinicians.

23 We also have been looking at behavioral outcomes in children and  
24 adolescents as well, using some validated scales. And for example, in this study  
25 reported that, based on a question now known as the strengths and difficulties  
26 questionnaire, which taps into a number of emotional and behavioral domains,  
27 there was a three-fold increased risk for an abnormal score -- abnormal or  
28 borderline score on this outcome among children who also reported respiratory  
29 problems.

30 The third item on this slide refers to the study that I mentioned previously  
31 that has just been accepted for the American Journal of Epidemiology. There really  
32 has been very little research on the initial injuries that were sustained during the  
33 first hours and days of 9/11 exposure. And it turns out, at least in our study, we  
34 followed them forward now for a number of years, and that multiple injuries are  
35 strong predictors of subsequent -- not only subsequent PTSD but subsequent  
36 development of chronic diseases including cardiovascular disease and diabetes,  
37 particularly cardiovascular disease.

38 And finally, as Dr. Farfel mentioned before, the Hurricane Sandy  
39 phenomenon in New York City, which hit us particularly hard during the last days of

1 2011, raised the concerns that many people who already were dealing with  
2 9/11-related problems may have been re-traumatized, and so we sent out a survey  
3 to several thousand people in the registry, stratified by whether they lived within or  
4 not within the official FEMA inundation zone. Those data are still under analysis  
5 now, and the only preliminary finding that I'm able to report right now is that  
6 people with 9/11-related PTSD are about seven times more likely to screen positive  
7 for a Hurricane Sandy-related PTSD compared to people with no prior 9/11-related  
8 PTSD. But just keep in mind this is preliminary, unpublished findings that we expect  
9 to be able to submit for publication very shortly.

10 Next slide. To give you an idea of the manuscripts that are now in  
11 preparation, I've divided them into three areas here. We have two in-depth studies,  
12 that is a nested clinical study of respiratory disease, which is in the field right now,  
13 which is progressing very nicely. And then the Hurricane Sandy study that I just, just  
14 mentioned. Below on the left, several studies in progress include one on mortality  
15 related to substance use and then another study of reproductive health and  
16 potentially adverse birth outcomes such as low birth weight at gestational age,  
17 which we -- one study was -- which was done several years ago was only based on  
18 several years of data, and now we've linked the registry's data to New York City vital  
19 statistics for a 12-year period. So we have a much longer period of follow-up for  
20 those.

21 Over on the right we have a number of other studies in progress including  
22 the one on diabetes, one on the long-term time course of PTSD, which nowadays is  
23 popularly termed, trajectory study. We're also concerned with comorbidity of  
24 both -- as I mentioned before, comorbidity of physical and mental health outcomes,  
25 where we have one nearly completed manuscript on the comorbidity of PTSD and  
26 other mental health outcomes, particularly depression and anxiety.

27 We are working on one study on asthma control. We know asthma and  
28 other respiratory outcomes are a major 9/11-related outcome, and we have data on  
29 the extent to which people are using standard or recommended types of control  
30 approaches. I mentioned before that we are continuing to follow up our population  
31 for GERD. We're also concerned with unmet healthcare needs for physical and  
32 mental health, and we have several studies on alcohol abuse that are in progress.

33 Next slide. Research that is planned for the next two years the -- or two  
34 operational activities are the updating of our cancer and mortality databases.  
35 Cancer incidence database that I mentioned derived largely from about a dozen  
36 state cancer registries including New York State, New Jersey and Connecticut. And  
37 our mortality assessment, which is based on our local vital statistics and National  
38 Death Index.

39 Then we have an active study of adolescent behavior that is from -- goes

1 into several domains including internalizing behaviors, related to emotions,  
2 externalizing behaviors such as conduct and hyperactivity.

3 As part of our mortality studies, we're specifically focusing on PTSD and  
4 mortality, and then as we mentioned before our index study on rheumatoid arthritis  
5 and then there's a nested case-control study, which will unfold over the next year.

6 I also mentioned before our study -- we're looking at risk factors and one is  
7 smoking trajectories, and we're looking in particular at the impact of 9/11 on  
8 smoking habits, which are some interest by themselves but which, of course, are  
9 indicators and predictors of subsequent chronic disease.

10 Next slide. We are well along in our planning stage for Wave 4 survey. And  
11 I'm very pleased to note that many of the people on this committee have already  
12 made some valuable contributions to our -- to the planning process and to our  
13 thinking about what will go into the survey.

14 The objective for the survey will be to assess the course of conditions that  
15 we previously reported on, with a focus on chronic health, course of treatment for  
16 selected conditions, functional status of our enrollees and quality of life indicators,  
17 and then potentially new emerging conditions, which we're always looking out for.

18 The survey population is all adult enrollees who will be at least 18 years of  
19 age in 2015, and that in effect is about 99 and a half percent of the entire registry.  
20 The methods that we will use will be a web and paper survey, which worked very  
21 well for Wave 3, and we use, as is our policy, we always send out surveys in three  
22 language: English, Spanish and Chinese. And our current plan is to launch the survey  
23 early in 2015.

24 Next slide. Dr. Farfel also mentioned our linkages with external researchers,  
25 and this is something that we just simply can't do without, and we're very pleased  
26 with our relationships. This is a magnificent way to leverage the skill set and the  
27 resources in the registry and effectively tap into the very rich talent pool of  
28 researchers in the New York metropolitan area and elsewhere.

29 We have a -- excuse me? We actively encourage external research projects  
30 and, as Dr. Kubale mentioned before, there are -- have we lost our slide? Oh, okay.  
31 Dr. Kubale mentioned before that many of the external research -- that the grant  
32 funded proposals that NIOSH has funded are based on registry research. I'll just  
33 mention a few of those. We provide external researchers many different ways of  
34 collaborating with the registry: They can collaborate directly with us and just  
35 include us as if we were part of the research team; they can simply use our data as a  
36 public use database; or we have -- for several of these studies the registry can  
37 facilitate the recruitment of registry enrollees and once the recruitment is actually  
38 concluded, then the enrollees effectively are available to the external researchers  
39 for their approved projects.

1 We have a review committee that reviews applications similar to the way  
2 that most grant applications are reviewed. And to date we have approved 21  
3 studies from nine American and international institutions. Not all of these studies  
4 are in fact go into effect because many of them are contingent on funding for the  
5 individual studies and some of the funding sources -- sometimes investigators get  
6 funded and sometimes they don't. However, we are open as we possibly can with  
7 the making our data available.

8 The next two slides will show the 11 active external research studies that we  
9 have. And I think I'm just simply going to go down the list and mention the type of  
10 study and the investigator, because many of these have already been covered by  
11 Dr. Kubale.

12 So we have the first -- the first three -- first three bullets here are pediatric  
13 studies: the physical health study of Dr. Trasande at NYU and two mental health  
14 studies being done by Dr. Hoven at Columbia. The autopsy biomarker study by  
15 Dr. Marmor; the smoking cessation intervention by Dr. Kotov at Stony Brook; and a  
16 study of social integration and social support in police by Dr. Bowler at San Francisco  
17 State University.

18 Next. We also have a collaboration with the Center for Aging at the CDC led  
19 by Dr. Valerie Edwards, looking at cognitive functioning; another PTSD study among  
20 police responders by -- with Dr. Bowler at SFSU. A study with Dr. Berger, who is the  
21 oscillometry collaborator and is interested in developing normative scales for  
22 oscillometry for comparative purposes. And then a very innovative GIS study of  
23 respiratory conditions and exposures based on proximity measures with Dr. Antao  
24 at ATSDR. And finally the study of upper respiratory symptomatology in responders  
25 by Dr. de la Hoz at Mount Sinai.

26 Next. So with all of this activity going on, what are we actually doing? Well,  
27 we are continuing the analyses of registry data that I've outlined several of these  
28 slides already. As I mentioned we're working on the design and questionnaire for  
29 our Wave 4 data collection. We're working on the in-depth respiratory health study  
30 and the rheumatoid arthritis case-control study. We're updating cancer and  
31 mortality assessments. We will continue referrals to the World Trade Center Health  
32 Program that Dr. Farfel described. And of course, as we are doing now and we  
33 continue to do as we publish our findings in the -- all the literature, we will share our  
34 findings with the public and with policy makers.

35 Last slide. And once again, we gratefully acknowledge not only the funding  
36 but the advice and counsel of our agencies: NIOSH, ATSDR, the very talented and  
37 dedicated registry staff at the New York City Department of Health and Mental  
38 Hygiene and the many members of our scientific community and labor advisory  
39 committees, many of whom are represented on the -- this STAC as well.

1 Thank you very much and we're happy to field questions, if you like.

2 **DR. WARD:** Thank you. The floor is open for questions.

3 **MS. FLYNN:** Liz?

4 **DR. WARD:** Yes.

5 **MS. FLYNN:** Hi, it's Kimberly. Thanks very much, Steve, for that  
6 acknowledgment of the collaborators and partners that the registry has worked  
7 with, and I just -- following on that, I really do want to make a pitch to this  
8 committee for advocating a community-based participatory research process. And  
9 just to sort of name one example of how important that was, the paper that  
10 Dr. Friedman wrote, published in 2011, on impulse oscillometry, at one point in the  
11 CBTR process, where the registry was meeting with members of the community and  
12 also the medical director of the survivor program, Dr. Reibman, the registry was  
13 contemplating eliminating oscillometry from that study design. And were it not for  
14 the outcry among community members and Dr. Reibman, the registry may never  
15 have had these important results and this excellent paper. So it really -- it really  
16 does matter that there is a collaborative process and that that process includes  
17 members of the affected community.

18 **DR. FARFEL:** Are you expecting a response? All I can say is thank you again.  
19 We've got -- the study actually was planned before I came to the registry but I -- to  
20 this day, I do not understand why oscillometry is not a standard piece of equipment  
21 at every respiratory pulmonologist's arsenal. It just seems to be so highly sensitive  
22 and useful.

23 **MS. FLYNN:** Amen to that.

24 **DR. WARD:** Other comments or questions? Then I guess we'll move on to  
25 the next speaker, which is Laura Crowley, who will speak about the World Trade  
26 Center Clinical Centers of Excellence and the Data Centers' Research Needs.

27

28 **WTC CLINICAL CENTERS OF EXCELLENCE/DATA CENTERS RESEARCH NEEDS**

29 **DR. CROWLEY:** Hi, good morning. First of all I would like to thank you for  
30 the invitation to present on topics of interest for future research in the World Trade  
31 Center Health Program cohorts. And I'm affiliated with the responder program at  
32 the Mount Sinai clinical center but I have responsibility today to report on behalf of  
33 FDNY and survivor and responder programs. So I just wanted to start by describing  
34 the cohorts and a reminder of who each group is.

35 So as many of you know the FDNY program is a group of all active and  
36 retired fire department members who responded to the 9/11 attacks; the responder  
37 program includes workers and volunteers who responded to the 9/11 attacks; and  
38 the survivor program includes people who worked, lived or attended school, child  
39 care or adults in the New York City disaster area.

1                   The characteristics -- these are important characteristics within the groups.  
2                   Certainly we provide medical monitoring and surveillance to each of our cohorts.  
3                   We provide specialized World Trade Center treatment services for exposure-related  
4                   diseases in upper airway, lower airway, GERD, mental health and specific  
5                   musculoskeletal diseases and cancers. It's a unique group and a well-characterized  
6                   population at this point with high retention rates, and as everyone is well aware,  
7                   this is an unprecedented exposure and we do not have a control for comparison.

8                   So as a reminder the James Zadroga Bill on 9/11 intent was to support, in  
9                   terms of research, research on physical and mental health conditions that may be  
10                  related to the September 11, 2001 terrorist attacks; research on diagnosing World  
11                  Trade Center-related health conditions of such individuals in case of conditions for  
12                  which there has been diagnostic uncertainty; research on treating World Trade  
13                  Center-related health conditions for individuals in the case of conditions for which  
14                  there has been treatment uncertainty. And of course any emerging conditions.

15                  In moving forward, the World Trade Center Health Program responder and  
16                  FDNY and survivor programs agree that research should pretty much follow a  
17                  general direction, and think of it in kind of a three-prong approach in thinking about  
18                  each individual topic that needs to be explored moving forward. So we divided it  
19                  based upon mechanism, outcomes and progression of disease.

20                  So number 1, mechanism. This is the concept of particular scientific areas of  
21                  interest may be explained in terms of structure, interaction of their component  
22                  parts.

23                  Number 2 with the outcomes. Evaluating clinical and population-based  
24                  research that seeks to study and optimize the end results of healthcare in patients.

25                  And number 3, progression of disease. Where we evaluate disease states  
26                  and objective markers that place patients at risk for disease advancement. And  
27                  certainly we'll allow for early intervention for treatment and may promote  
28                  regression of disease.

29                  Let's move forward with mechanism. I'm just gonna view a snapshot of a  
30                  few published manuscripts, and you will see there are very many, that may fall into  
31                  each of these categories, and then we'll identify our thoughts moving forward for  
32                  each category.

33                  So many of you are familiar with the FDNY study that was published in  
34                  *Chest*. This was inflammatory biomarkers like GM-CS, CSS and MDC, that were  
35                  found to be elevated in the air flow -- in air flow obstruction.

36                  The next paper was published in the *Journal of Asthma* by the survivor  
37                  program by Dr. Joan Reibman's team, where they found an elevated level of  
38                  peripheral eosinophils in the World Trade Center patients found to have symptoms  
39                  of wheeze and peripheral abnormalities with air flow obstruction.

1                   In the responder program, Dr. Landrigan and Dr. Liroy found that World  
2 Trade Center dust was highly alkaline, and mice exposed to dust develop moderate  
3 inflammation and bronchial hyper-reactivity. And that was published in the EHP  
4 that we're on.

5                   We have a mental health study, led by Dr. Pietrzak and Dr. Southwick, that  
6 evaluated basically the dimensional structure and course of post-traumatic stress  
7 symptomatology in World Trade Center. And they found that the disaster-related  
8 PTSD symptomatology in World Trade Center responders is best represented by five  
9 symptom dimensions.

10                  We also have a study which, unfortunately, I don't have a slide today on, but  
11 it's a study that's about to be published by Dr. Luft's team, and presented at the  
12 American Psychopathology Association next month, in an abstract form. They  
13 provided an epigenetic linkage between PTSD and respiratory disease. They found  
14 specific genes associated with respiratory inflammatory cytokines, and this  
15 obviously could be very important in diagnostic and therapeutic impacts moving  
16 forward. So what does this mean? So I propose future mechanism studies, there  
17 are probably many but I'm going to name just a few.

18                  So number 1, what may be the impact of World Trade Center exposure on  
19 responders' DNA? Many are experiencing chronic health decline but the  
20 mechanisms remain unclear. It's critical for us to understand the relationship  
21 between exposure and changes to DNA and gene expression and further insight and  
22 development -- insight into the development of disease and treatment options is  
23 essential.

24                  Another example that may be worth exploring is we know from the current  
25 list of World Trade Center covered conditions, there's increased risk of sarcoidosis in  
26 hematological malignancy direct lymphoma. We could argue that these diseases  
27 are representative of a disruption in the immune system, suggesting maybe we  
28 could be taking a closer look at World Trade Center exposure in relation to diseases  
29 that alter the immune system, like hematologic disease, and seeing if there are any  
30 biomarkers to evaluate moving forward.

31                  Let's look at our next prong, outcomes. So this manuscript is published in  
32 the *American Journal of Industrial Medicine*, by FDNY, and it highlighted the need to  
33 evaluate the relationship between symptoms, pulmonary function tests and  
34 diagnosis and utilization of healthcare. In the *Lancet*, there is the publication by Dr.  
35 Juan Wisnivesky and Dr. Landrigan for the responder programs that evaluated the  
36 nine-year cumulative incidence of asthma, sinusitis, GERD, depression and PTSD,  
37 and found there's a 27 percent incidence of asthma, 32 percent with sinusitis,  
38 39 percent with GERD, and 31 percent PTSD, and 27 percent in depression. And  
39 we're still seeing spirometry abnormalities to date.

1                    In the *Journal of Occupational and Environmental Medicine*, Dr. Joan  
2 Reibman's team from the survivor program, five years out, on disaster residents and  
3 local workers are still seeing respiratory lung function abnormalities. And Dr. Luft's  
4 team for the responder program was able to identify a linkage between PTSD and  
5 respiratory symptoms in the *Journal of Psychological Medicine*.

6                    In *EHP*, Dr. Southwick's team and Dr. Stellman looked at the responder  
7 group and found that working in 9/11 recovery operations was associated with  
8 chronic impairment of mental health and social functioning. Psychologic distress  
9 and psychopathology in World Trade Center workers greatly exceeded the  
10 population norms.

11                    So thoughts on future of outcome studies. A couple thoughts came to  
12 mind, preliminary thoughts. Number 1, a need to assess overall health status and  
13 impact of World Trade Center exposure and how it's had on the individuals'  
14 occupation -- economics and psychologically, how they've been impacted, how their  
15 lives have changed. Very difficult end points to evaluate that we feel are definitely  
16 worth while. Thinking about and figure out a way to investigate.

17                    Number 2, how has exposure impacted cognition. Certainly that's an  
18 interesting question to answer, and may be considered in additional questions and  
19 adding additional questions to the monitoring program to explore further.

20                    Number 3, identify patient characteristics that maximize psychotherapeutic  
21 intervention for specific mental health conditions like PTSD.

22                    And Number 4, but definitely not lastly, utilize DC resource, that's a data  
23 center resource, to resume disease surveillance activities, to evaluate additional  
24 outcome measures, especially since the data's readily available for real-time analysis  
25 and can analyze those conditions that have been certified and are currently under  
26 active treatment.

27                    Moving to the next prong: Progression of disease. In *Chest*, we saw in Dr.  
28 Prezant's study with FDNY, it highlighted a relationship between pulmonary function  
29 test abnormality -- pulmonary function test improvement and lower respiratory  
30 system improvement. And basically recommended what we need to continue to  
31 follow spirometry in our cohort.

32                    In our survivor program, Dr. Reibman's team was able to confirm that PTSD  
33 high reversibility they were seeing in the population, but it reinforced the need for  
34 continued treatment. They were seeing improvements in populations but the -- this  
35 reversibility reinforced the need to continue to follow them very closely.

36                    In the responder program, Dr. Gwen Skloot with Dr. Paul Enright noted  
37 increased rates of spirometry even five years out post-9/11, and again,  
38 recommended need for monitoring.

39                    I'm going to skip to our thoughts on progression of disease, and skip the last

1 two slides in the interest of time. So advantage for the future. One example would  
2 be responders who experienced both medical and psychological sequelae are more  
3 impaired. This group requires further evaluation to determine best management  
4 strategy to optimize treatment.

5 Number 2 would be to investigate, and this is more in the physical health  
6 arena, these last two, investigate the impact of renal disease in the context of  
7 responders who now have multiple co-morbidities due to their exposure.

8 And number 3, consider identifying and characterizing those patients who  
9 have had significant difficult health decline due to their World Trade Center  
10 exposure, especially those with severe asthma and interstitial lung disease.

11 So, you know, we've mentioned studies that have been done, just a few, in  
12 each of the areas, general areas, of research that should be considered, and we've  
13 mentioned just a few of the studies that we think should be maybe considered in  
14 the future. Certainly this list is meant in no way to be comprehensive; it's only  
15 meant to give it a direction of future research, and we'd be more than happy to  
16 return and expand on the list of details after discussion with our lead World Trade  
17 Center Health Program clinicians, researchers, (indiscernible) members.

18 We would like to just round it off by saying a few things we'd like the group  
19 to consider is the time frame for any studies moving forward, the one-year,  
20 obviously, versus the future, the longer time frame; and addressing those  
21 populations that may be most vulnerable, like children; and thirdly, that these  
22 populations may provide and translate to disaster, future disasters, or even non-  
23 disaster populations in the public health arena.

24 Thank you again for the opportunity to present our thoughts.

25 **DR. WARD:** Thank you for your presentation. I noticed that we missed our  
26 11:00 to 11:10 break. Paul, do you think we should just go ahead and take it now  
27 and then resume discussion with Dr. Crowley?

28 **DR. MIDDENDORF:** Why don't we go ahead and ask Dr. Crowley any  
29 questions we might have, and then we'll take the break.

30 **DR. WARD:** Okay. Any questions for Dr. Crowley?

31 **DR. HARRISON:** This is Bob Harrison, thank you very much. It's just  
32 incredibly impressive. Did any of the research studies address the question whether  
33 early and aggressive treatment intervention make a difference in outcome?

34 **DR. CROWLEY:** Yeah, I mean, that's an excellent question, and certainly  
35 something that is definitely worth exploring, based in the physical and mental  
36 health arena, and I think in context of some of the potential proposals, certainly  
37 could be woven in, and I think that's an excellent suggestion.

38 **DR. HARRISON:** I don't know whether it's too late to do that, looking  
39 backwards over 15 years, but it's certainly one of the questions that I always have as

1 a public health, you know, official, is, you know, does getting people into early  
2 treatment for respiratory symptoms or potential psychological sequelae make a  
3 difference, you know, so that we really have to have the systems and infrastructure  
4 in place. When --

5 **DR. CROWLEY:** Right. I mean, we know from just a, from an asthma  
6 perspective, certainly folks who were left with prolonged disease without treatment  
7 are at risk for irreversibility. The Joan Reibman study that we mentioned early on  
8 about, you know, the reverse -- potential for reversibility is an important point  
9 because you have a chance to make an impact so that that doesn't become fixed  
10 airway obstruction.

11 **DR. HARRISON:** Right.

12 **DR. CROWLEY:** So I think there are ways to do it, and I think it's a good  
13 point.

14 **DR. HARRISON:** Yeah.

15 **DR. CROWLEY:** Thank you.

16 **DR. TALASKA:** This is Glenn Talaska. I have a very closely related question.  
17 And I was wondering if there's been investigation as to which levels of either your  
18 biomarkers or your clinical measurements are -- weren't associated with disease but  
19 were associated with reversibility, so as we move on and try to prove which levels  
20 which may be preventative in the future, that could be extremely useful, when to  
21 remove people from an exposure when a marker is being made during the course of  
22 that exposure.

23 **DR. CROWLEY:** Yes, and absolutely we would very much like to investigate  
24 something like that.

25 **MS. WALKER:** Dr. Crowley, this is Debra Walker from the World Trade  
26 Center Health Registry. I just had a question. You had mentioned about someone  
27 looking at patients who had severe chronic disease, that you were interested in  
28 looking at renal disease. Could you mention if you've seen patients who appear to  
29 be affected or an association with 9/11 exposure?

30 **DR. CROWLEY:** It's too early to tell. I think it's a question that is definitely  
31 ringing true in several of the investigators now. And I know Dr. Mary McLaughlin at  
32 Mount Sinai with her cardiovascular studies in looking at some of the laboratory  
33 markers felt like it was something worth investigating but it's too early for us to  
34 draw that correlation as of yet, but definitely worth investigating.

35 **MS. WALKER:** All right. Thank you.

36 **DR. WARD:** Okay, so if there are no further questions or comments from  
37 committee members, I think it would be wise to adjourn for our ten-minute break  
38 so that we can be reassembled and ready for the beginning of the public comment  
39 period at 11:30. Paul, do you want people to just leave their lines open?

1 **DR. MIDDENDORF:** Yes. I think that would be best.

2 **DR. WARD:** Okay. So my computer says it's 11:15; we'll try to all be back by  
3 11:25 to reconvene for the public comments.

4 **DR. MIDDENDORF:** Yes, and --

5 **DR. HARRISON:** Liz, this is Bob Harrison; before we do that could -- just  
6 moving ahead on the agenda, we're scheduled to take what your lunch break is  
7 really my breakfast break in a couple -- in about an hour and a half or something like  
8 that?

9 **DR. WARD:** Yes.

10 **DR. MIDDENDORF:** So it would be 12:15 our time which is about in an hour  
11 from now.

12 **DR. HARRISON:** About, about an hour from now, okay.

13 **DR. MIDDENDORF:** Yes. So we have probably -- four public commenters  
14 have signed up so we'll probably finish up around noon, and then Liz and the  
15 committee can decide whether or not they want to begin discussing the research  
16 needs at that point or if they want to just go ahead and break for lunch.

17 **DR. WARD:** Thank you.

18 **DR. MIDDENDORF:** Okay. So we're going to take ten minutes?

19 **DR. WARD:** Yes.

20 **DR. MIDDENDORF:** Okay.

21 (Meeting recessed from 11:15 to 11:30 a.m.)

22 **DR. MIDDENDORF:** We are now entering the public comment portion of  
23 our agenda. Each of our public commenters is signed up on a first-come, first-  
24 served basis. Each of them will have up to five minutes to present. I just remind  
25 everybody that it's surprising how quickly five minutes can go when you're talking  
26 on a subject of importance to you. So around the four-minute mark, I'll just let the  
27 commenter know that they have one minute remaining to allow them to make their  
28 final point. If you haven't finished in five minutes, I'll have to rudely interrupt and  
29 thank you for your comments, and I apologize to anybody that this happens to but  
30 we have to be fair to all our presenters and we also need to try and stay on time.

31 I do want to point out that you do have the option of submitting written  
32 comments to the docket. The docket number is 248-A. Information on how to  
33 submit those comments is on the NIOSH docket web page.

34 The last thing I need to do before beginning the comments is to make sure  
35 the commenters are aware of the redaction policy for public comments. That policy  
36 is in the Federal Register notice for this meeting. It's on the committee's web page  
37 and it's in the materials available for downloading. So the policy outlines what  
38 information will be kept, what information will be redacted before it is posted to the  
39 docket.

1 So with that, I'll ask Dr. Melius, are you available?  
2 **UNIDENTIFIED:** Did you say you have to do a roll call?  
3 **DR. MIDDENDORF:** Oh, yes, you're right. I do have to do a roll call, thank  
4 you. Let's do a roll -- a quick roll call. Tom Aldrich?  
5 **DR. ALDRICH:** Online.  
6 **DR. MIDDENDORF:** John Dement?  
7 **DR. DEMENT:** Online.  
8 **DR. MIDDENDORF:** Kimberly Flynn?  
9 **MS. FLYNN:** Online.  
10 **DR. MIDDENDORF:** Bob Harrison?  
11 **DR. HARRISON:** On line.  
12 **DR. MIDDENDORF:** Catherine Hughes?  
13 **MS. HUGHES:** (indiscernible).  
14 **DR. MIDDENDORF:** Steve Markowitz?  
15 **DR. MARKOWITZ:** Yeah, I'm here.  
16 **DR. MIDDENDORF:** Guille Mejia?  
17 **MS. MEJIA:** (indiscernible).  
18 **DR. MIDDENDORF:** Is that Guille?  
19 **MS. MEJIA:** Yes.  
20 **DR. MIDDENDORF:** Okay. Carol North? Carol, are you there?  
21 **DR. NORTH:** I'm here.  
22 **DR. MIDDENDORF:** Okay. Julia Quint?  
23 **DR. QUINT:** Here.  
24 **DR. MIDDENDORF:** Bill Rom?  
25 **DR. ROM:** I'm present but I'm also Macintosh so I'm -- I can only hear and  
26 cannot see.  
27 **DR. MIDDENDORF:** Okay. What I said earlier is that, for those that are on  
28 Mac, when we have a motion, I will copy it and paste it into an email and send it on  
29 so you can see it.  
30 **DR. ROM:** Okay.  
31 **DR. MIDDENDORF:** Susan Sidel?  
32 **MS. SIDEL:** Here.  
33 **DR. MIDDENDORF:** Glenn Talaska?  
34 **DR. TALASKA:** Here.  
35 **DR. MIDDENDORF:** Leo Trasande? Okay, I expect he'll join us in a half an  
36 hour or so. Liz Ward?  
37 **DR. WARD:** Here.  
38 **DR. MIDDENDORF:** And Virginia Weaver?  
39 **DR. WEAVER:** Present.

1 **DR. MIDDENDORF:** Okay. Has your flight been canceled, just by the way?

2 **DR. WEAVER:** No, it hasn't, so I'm still hoping.

3 **DR. MIDDENDORF:** Okay. If you need to leave, just let me know.

4 **DR. WEAVER:** I will, thank you.

5 **DR. MIDDENDORF:** So I'll ask Jim Melius, are you present?

6 **DR. MELIUS:** I'm present. Can you hear me, Paul?

7 **DR. MIDDENDORF:** Yes, we can hear you.

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9

**PUBLIC COMMENTS**

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**DR. MELIUS:** Okay, good. It's hard to tell. Anyway, I would like to first thank the committee for your -- certainly for your past efforts. I thought your assistance on the -- with Dr. Howard on the cancer issues was very, very helpful and I thought came up with a very good approach to dealing with a pretty difficult issue. So that's most appreciated by myself and many others involved here.

I was very involved in developing the legislation that initiated this program, and I wanted to make sure it's clear that the research portion of this was probably one of the most difficult parts to get into the legislation. Given all the other federal funding for research, it -- people were somewhat reluctant to -- we -- I found an additional pool of research funding, and we made the case that it was important for this unique population that I'm going, you know, medical research be done in a number of different areas and this needed to be supported over a period of time. I just think, given that difficulty, it's important that we keep the research focused on the World Trade Center populations, and although it is sometimes tempting to think of some of the other areas where this research is pertinent to and what can be very necessary and important research, really has to be funded, I think, through other sources.

Secondly, I'd like to particularly thank Dr. Crowley for her presentation. One of the things that disturbed me when I saw the initial agenda for this was there was no formal input from the clinical centers, who are the people essentially on the front line dealing with the many thousands of ill World Trade Center responders and survivors. Although some of those people were represented on the lead advisory committee, it seemed to me that there really needed to be formal input on that, and I want to thank Laura for doing an excellent job on something that she, I think, only heard about earlier and late last week, early this week in terms of organizing that presentation.

I think those items really are the heart of what needs to get done in this research, again, probably far too many questions given the amount of funding involved. But still, I think it's very important that we really start to focus on some of those issues that will provide the research that will, you know, hopefully yield a

1 long-term benefit to those thousands of responders and survivors who are ill.

2 One important area that I've not heard discussed today is a focus on what  
3 other conditions might be emerging in this population, and emerging conditions is  
4 actually included in the legislation for this research. We have lots of data being  
5 collected but the research review process tends to make it, I think, difficult for that  
6 data to be evaluated and explored in some ways. We have many responders and  
7 survivors who are ill who are concerned as to whether the conditions that they're  
8 now developing, whether it be kidney disease, autoimmune disease, others, might  
9 be related to their World Trade Center exposures and limited funding available  
10 through the clinics and to the data centers to evaluate that data.

11 I already talked to Dr. Howard. I think direct funding to the data centers  
12 may be appropriate, but for doing some of those exploratory work but I also think  
13 that the research program may be able to take up some of that slack, and I would  
14 hope that you would, you know, see what could be done within the research  
15 program to focus on that.

16 Finally, I would like to echo something that I believe Steve Markowitz said  
17 earlier. I think one of the other important areas that I don't think is being addressed  
18 in this very important underlying probably ongoing research that has taken place  
19 and will take place in this population is a better assessment of their exposures. You  
20 know, it's complicated, people did different tasks, but I think the tendency is to  
21 assume it's too complicated to understand, and I think that's a disservice, given  
22 some of the differences in the types of jobs, time people worked there, and I think  
23 other factors that could be taken into account in terms of evaluating the long-term  
24 impacts of this exposure and to identify higher risk groups. So I will end there. I  
25 think I'm under the five minutes so Paul didn't have to jump in. But thank you again  
26 for all your work on this.

27 **DR. MIDDENDORF:** Thank you for your comments, Dr. Melius. Our next  
28 public commenter is Heidi Alexander.

29 **MS. ALEXANDER:** Yes, I'm here.

30 **DR. MIDDENDORF:** Okay.

31 **MS. ALEXANDER:** Can you hear me?

32 **DR. MIDDENDORF:** Yes, we can hear you fine.

33 **MS. ALEXANDER:** Okay, great. First of all I want to thank you for all of your  
34 hard work in making the World Trade Center Health Program available, also to  
35 present my request, and then I'll give you some background of my situation.

36 I ask that toxic encephalopathy; that is, toxin induced brain damage, be  
37 added as physical injury to the list of illnesses treated by the World Trade Center  
38 Health Program. I recently came across a research paper presented by Dr. Grace  
39 Ziem, Z-i-e-m, at a conference in (indiscernible) entitled Medical Evaluation

1 Treatment Patient (indiscernible).

2 (extraneous interference from other participants)

3 And the treatment protocol for chemical injury, she testifies on her website,  
4 chemicalinjuries.net. (more extraneous interference)

5 It's [mcsbeaconofhope.com/ziem.html](http://mcsbeaconofhope.com/ziem.html). It's the research paper she  
6 presented. And her treatment protocol on her website, [chemicalinjury.net](http://chemicalinjury.net), where  
7 she recommends SPECT brain scans to detect the toxic encephalopathy, the brain  
8 damage, and (indiscernible) for six to ten months as part of her treatment protocol.

9 I'm impressed by her findings and I'm also mystified why this has been  
10 known for so many years and it's not been put in place for people in my position. I'll  
11 give you my facts for now.

12 I lived across the street from the World Trade Center and was in the toxic  
13 cloud. My apartment sustained considerable damage and contamination from the  
14 dust and smoke that infiltrated the entire area at the time of the towers' collapse  
15 and for months afterward. The office where I worked is also a few blocks away, on  
16 Broad Street. I was a self-employed computer programmer/technology consultant  
17 from 1985 up until the end of 2001. I was standing on the 14<sup>th</sup> floor terrace of my  
18 building where I lived on Albany Street and South End Avenue. That's catty-corner  
19 to the Trade Center site when the south tower imploded, and was blasted by a gust  
20 of vapor, and then immediately afterwards completely covered by the dust, and  
21 inhaled a significant amount of blackened air.

22 I was in that environment for several hours until evacuated by tug to Jersey  
23 City. I was very nauseous and had a severe headache at the time, and I went to a  
24 (indiscernible) house in New Jersey and I had difficulty breathing and burning lungs.

25 I was taken to the emergency room at the local hospital and had chest  
26 x-rays and was told to see a pulmonary specialist. Days later welts appeared on my  
27 face, arms and legs and skin that was exposed to the dust. I tried to continue  
28 working for my clients at the time but was so sick that I could no longer neglect the  
29 health issues that developed.

30 What I ingested from the dust and what was in the air that day circulated  
31 through my body causing extreme fatigue and affected various bodily functions for  
32 periods of time at random: the field of vision in both eyes went completely black  
33 only to return a few minutes later. Another time I lost hearing for several hours. I  
34 had difficulty breathing. My brain function slowed down to the point where  
35 everyday tasks appeared as a slow-moving slide show where I could see each step of  
36 a process, neglecting to perform the most important steps.

37 This condition worsened over the next few years. I eventually lost the  
38 ability to speak full sentences so that I couldn't think of words. For a time I lost  
39 coordination of my hands. This became evident when I tried to dial a phone where

1 the phone number was in mind but I wasn't able to touch the corresponding  
2 number on the keypad. Another time the lymph nodes in my groin area grew to the  
3 size of golf balls.

4 (extraneous interference)

5 Sorry?

6 **DR. MIDDENDORF:** Excuse me, would everybody except Ms. Alexander put  
7 your phones on mute, please? Thank you.

8 **MS. ALEXANDER:** In 2005, I developed a chronic sore throat and  
9 hoarseness caused by a condition diagnosed as silent acid reflux which I continue to  
10 experience to date. After five to six years of following a self-prescribed detoxifying  
11 practice, my brain function improved but not to the level I had prior 9/11. To date I  
12 have persistent thinking problems and poor thought retention where I struggle to  
13 keep more than one concept in mind at a time. I also found that I have difficulty  
14 learning new things which was never something I had trouble with as an ardent  
15 technology professional.

16 I have difficulty performing procedural tasks; that is, anything requiring a  
17 systematic approach. My thoughts become disorganized, leaving me unable to  
18 perform the task correctly, requiring several attempts, especially when the process  
19 requires the use of my hands.

20 This is completely disabling for a computer programmer with a brain as a  
21 tool of the profession. I would like to rehabilitate this part of my brain so that I can  
22 work again. I haven't been able to do so since 2001.

23 I found out about this protocol online just last week. I stumbled across the  
24 term toxic encephalopathy. I looked it up and ran across Dr. Ziem's research paper,  
25 and am mystified why this isn't being implemented. This has been out there for  
26 years and you people are going about this as if this is all new and unfounded. This is  
27 not new and there are treatment protocols in place.

28 I can't wait for your research to be gathered and analyzed. I'm sick now; I  
29 need help now. And then so I would like to add this toxic encephalopathy as  
30 physical damage. This is not post-traumatic stress disorder. This is quite physical. I  
31 had an MRI early on in 2003, and it showed that there was a --

32 (extraneous interference)

33 **MS. ALEXANDER:** -- (indiscernible) on the left side of my brain.

34 **UNKNOWN SPEAKER:** This is a smoker, right?

35 **MS. ALEXANDER:** I'm not a smoker. I was in good health before 9/11. I was  
36 a jogger, very active. Afterwards I can no longer jog. I can no longer exert myself  
37 because I can't breathe, all right? So that part I'm (indiscernible) just by avoiding  
38 those things. The brain damage I need help with. I can't find anyone who knows  
39 how to treat this sort of thing. Dr. Ziem's paper and her protocol is the closest thing

1 I'm finding to something that could be beneficial, and I urge you to take a good look  
2 at it and implement that as part of the program. Thank you.

3 **DR. MIDDENDORF:** Thank you very much, Ms. Alexander.

4 **UNKNOWN SPEAKER:** I, I didn't have that calcium test. That would have  
5 been a standard, right?

6 **DR. MIDDENDORF:** Excuse me, who is that speaking? Who is that  
7 speaking? During the public comment session, the only people who should be  
8 speaking are the public commenters themselves. Everyone else should be -- have  
9 their phone muted. Thank you.

10 Our next speaker is Mary Perillo. Mary, are you available?

11 **MS. PERILLO:** Yes, I am. I'm here.

12 **DR. MIDDENDORF:** Okay, great.

13 **MS. PERILLO:** Okay. My name is Mary Perillo. I just want to check that  
14 everyone can hear me?

15 **DR. MIDDENDORF:** Yeah.

16 **MS. PERILLO:** Okay. My name is Mary Perillo and I am a 9/11-affected  
17 lower Manhattan resident. I'm reading comments by the WTC Health Program  
18 Survivor Steering Committee of which I'm a member.

19 (extraneous interference)

20 **MS. PERILLO:** Excuse me?

21 **DR. MIDDENDORF:** Who is that speaking? Operator, could you find out  
22 who that is that's breaking in?

23 **THE OPERATOR:** Absolutely.

24 **DR. MIDDENDORF:** Thank you.

25 **MS. PERILLO:** Okay. The Survivor Steering Committee is presently  
26 comprised of representatives of Manhattan Community Boards 1, 2 and 3, and a  
27 range of community, labor, environmental groups advocating on behalf of  
28 9/11-affected individuals as well as residents, students and area workers. There's a  
29 wide range of knowledge gaps with respect to the science, biology and treatment of  
30 WTC-related illnesses. Therefore, NIOSH should approach closing these gaps by  
31 supporting a diverse portfolio of studies at different levels of funding including pilot  
32 studies, in-depth clinical studies, studies of disease mechanism and epidemiological  
33 studies.

34 It is especially important that the STAC recognize that input from the WTC  
35 Centers of Excellence is critical to developing the World Trade Center Health  
36 Program's research agenda since clinicians are likely to have the best sense of which  
37 conditions may be emerging as well as crucial perspectives on resolving diagnostic  
38 treatment and uncertainty.

39 The SSC has a number of recommendations regarding the World Trade

1 Center Health Program research priorities for the survival population.

2 Given the increase -- given children's increased susceptibility to harm,  
3 especially in critical periods of development, it is imperative that NIOSH continue to  
4 support -- continue its support for research into 9/11 physical and mental health  
5 impacts to those who were exposed to the disaster as children. Most important  
6 would be in-depth studies of respiratory, developmental and endocrine health  
7 impacts, and studies that explore avenues for early identification and intervention.  
8 This cohort is rapidly dispersing so we urge NIOSH to double down on its support for  
9 pediatric studies now.

10 Two, NIOSH should support longitudinal clinical research into the long-term  
11 9/11 physical and mental health impacts for survivors as well as long-term studies  
12 that explore the progression of the disease and treatment efficacy.

13 Because of the known difficulties of performing epidemiologic studies on  
14 small populations with ongoing treatment, we would like to suggest that alternative  
15 approaches, studying cancer in diverse survivor populations be explored. Possible  
16 approaches include nested studies as well as a case series approach to  
17 understanding the possible role of exposures, differences in presentation and the  
18 effects of comorbid conditions or additional risks.

19 Four, we recommend that blood samples be collected from WTC exposed  
20 survivors including those who were children at the time of 9/11. Samples should be  
21 banked for later analysis including the freezing of live cells from which DNA, RNA  
22 and proteins can be recovered. We anticipate that these samples will provide useful  
23 in at least three ways: As potential source of long-lived biomarkers of exposure to  
24 WTC toxins, useful in analyzing exposure-related health conditions in this  
25 population; as a source of protein markers of disease with potential use in  
26 diagnosing and understanding WTC-related disease; as a source of genetic material,  
27 which can be analyzed for evidence of enduring genetic and epigenetic alterations  
28 relevant to disease that may be still detected many years after exposure.

29 Five, because so little is known with respect to inflammation and other  
30 underlying mechanisms for WTC illnesses such as sarcoidosis, cancer and even  
31 asthma, it is critical that NIOSH support studies of underlying disease mechanisms.  
32 This would include both physical and mental health disorders with potential final  
33 common pathways. Again, this research provides for building blocks, for more  
34 effective treatments and early intervention, excuse me.

35 I would cite one final research need. The SSC believes that it is essential  
36 that NIOSH support research into the physical and mental health impacts to people  
37 exposed between Houston and 14<sup>th</sup> Streets. This population had been eligible for  
38 treatment at the WTC EHC prior to the passage of the Zadroga Act.

39 EHC clinicians observed the same physical and mental health conditions in

1 those who lived, worked or attended school in this geographic area as well as those  
2 in the current Zadroga catchment.

3 We refer you to our written comments for the complete list. The SSC is  
4 grateful for this opportunity to provide comments and appreciates STAC's  
5 consideration. Thank you.

6 **DR. MIDDENDORF:** Thank you, Ms. Perillo. Our next public commenter is  
7 Lila Nordstrom.

8 **MS. NORDSTROM:** Hi. Can you hear me?

9 **DR. MIDDENDORF:** Yes, you're coming through well.

10 **MS. NORDSTROM:** Great. Thanks so much. So I'm Lila Nordstrom. I run  
11 StuyHealth which is an organization that represents students who were impacted by  
12 9/11 and the 9/11 clean-up.

13 And I wanted to specifically urge NIOSH to fund studies of people that were  
14 exposed as children, like the people in my group and, you know, a lot of the children  
15 of survivors who lived in the area. We, you know, we don't really have a lot of  
16 information on what kinds of health issues are coming down the pike for people in  
17 our situation but we're going to be living with these health conditions for a really  
18 long time. And to be -- I think it's important that we -- that NIOSH start to fund  
19 studies that are going to help us identify, you know, what the early -- help us  
20 identify early what the health impacts are going to be on people in our -- of our  
21 generation, at Stuyvesant, specifically.

22 You know, we weren't even residents in the neighborhood but we -- we  
23 returned to school on October 9<sup>th</sup> when fires were still burning all around us, that  
24 barge that they took the debris to from the World Trade Center site was right next  
25 to our school building, and there were like more than 200 truckloads a day of debris  
26 that came by. They weren't watered down or anything because it was too cold.

27 Our vent system wasn't cleaned. It was used -- you know, the school  
28 building was used as a center of -- sorry, as a first responder base during the early  
29 days of the clean-up. And so we, you know, were promised when we returned that  
30 there would be, you know, that the school would be adequately cleaned but it  
31 wasn't. The vents were still filled with 9/11 debris, the carpets in the theater were  
32 not taken up or anything like that.

33 So we faced a sort of unique exposure but at a uniquely vulnerable time in  
34 our lives, and we're not the only school in the neighborhood that had a similar  
35 experience and, you know, specifically kids that lived in the neighborhood were  
36 down there a lot earlier than we were as well.

37 But we, you know, we are trying to keep track of the health conditions that  
38 people in our group are facing. We've already received word of a number of  
39 unusual cancers and very high rates of conditions that people in their early 20s

1 shouldn't really be facing, like very serious respiratory and acid reflux conditions and  
2 things like that.

3 And so we, you know, as people that are going to have to live with these  
4 conditions for, really, longer than any of the other survivors because -- or, you  
5 know, hopefully longer than any of the other survivors. It, you know, we're sort of  
6 in a unique position where we can look at what these conditions are going to be,  
7 you know, and catch them early because we were exposed so early.

8 So I want to ask that NIOSH start to, you know, look specifically at funding  
9 studies that focus on young people that were exposed as children. I understand  
10 there's already a study going on where something like 250 kids are being compared  
11 to a control group, and a study like that should really be expanded pretty rapidly  
12 because there were young people in a lot of different situations that were brought  
13 down to lower Manhattan after 9/11 for various reasons. I mean, there were four  
14 schools on our corner so it was a very student-heavy population. There were  
15 obviously kids that lived in the neighborhood. So I just want to urge NIOSH to  
16 consider focusing on -- or finding some focus for studies that focus on young adults  
17 that were exposed as children.

18 That's all I needed to say, if you want to give the time to --

19 **DR. MIDDENDORF:** Okay. Thank you very much, Ms. Nordstrom.

20 **MS. NORDSTROM:** Okay.

21 **DR. MIDDENDORF:** I want to apologize to the public commenters. Early on  
22 in the process it sounded like somebody was breaking into the line; I'm not sure  
23 who it was but I think our operator has been able to correct that for us. But I do  
24 apologize for that.

25 Liz, I'll turn it over to you. Where do you want to go from here?

26 **DR. WARD:** Well, we have a scheduled lunch break at 12:15. You know, I  
27 would suggest that we might want to talk about how we're going to approach the  
28 discussion of the research needs. I would think that it might be good to think about  
29 them in each of the areas that Dr. Howard suggested we group them under and kind  
30 of get a list of the main ideas that committee members would like to advance  
31 before we actually go to the motions stage.

32 I also wanted to say to the committee that we don't necessarily have a  
33 mandate to prioritize the suggested topics, you know, one by one. We can group  
34 them into grouping high, medium and low priority. And one question of  
35 clarification, Paul, when Dr. Howard asked us to prioritize, did he basically ask us to  
36 prioritize across all of the four categories or within each category?

37 **DR. MIDDENDORF:** He didn't specify. I think you could do it either way. I  
38 think it would be a little more helpful if you would categorize or group them into the  
39 high-low -- or high, medium, low, despite which category or type of research that

1 they might interact.

2 **DR. WARD:** Okay. So do the people on the committee feel that it would be  
3 helpful to try to first discuss these within each category and get the major ideas  
4 down before we try to prioritize them or does anyone have a suggestion for another  
5 way to approach the discussion? Okay, well, I would suggest that we proceed that  
6 way, then, and Paul, do you think it's reasonable that we break for lunch now and  
7 reconvene in 45 minutes?

8 **DR. MIDDENDORF:** I think that would be fine.

9 **DR. WARD:** Okay. So my clock has basically 11:59 or noon, so we'll plan on  
10 reconvening at 12:45.

11 **DR. MIDDENDORF:** Okay. I will put that information up on the web so  
12 everybody can see it.

13 **DR. WARD:** Thank you all. I look forward to talking again at 12:45.

14 (Lunch recess from 12:00 to 12:45 p.m.)  
15

16 **DR. MIDDENDORF:** I think it's time for us to get going again. We'll start  
17 with the roll call. Tom Aldrich?

18 **DR. ALDRICH:** I'm here.

19 **DR. MIDDENDORF:** Okay. John Dement?

20 **DR. DEMENT:** Here.

21 **DR. MIDDENDORF:** Kimberly Flynn?

22 **MS. FLYNN:** Here.

23 **DR. MIDDENDORF:** Bob Harrison? Bob back from his breakfast break?

24 We'll circle back for Bob.

25 Catherine Hughes?

26 (no response)

27 **DR. MIDDENDORF:** Steve Markowitz?

28 **DR. MARKOWITZ:** I'm here.

29 **DR. MIDDENDORF:** Guille Mejia?

30 **MS. MEJIA:** I'm here.

31 **DR. MIDDENDORF:** Guille, am I pronouncing your name close to accurate?

32 **MS. MEJIA:** It's pretty close.

33 **DR. MIDDENDORF:** Okay. Some day you'll have to give me lessons on that.

34 **MS. MEJIA:** Will do.

35 **DR. MIDDENDORF:** Carol North?

36 (no response)

37 **DR. MIDDENDORF:** Julia Quint?

38 (no response)

39 **DR. MIDDENDORF:** Okay, well we're missing a few people. I think we need

1 to wait a few more minutes before --

2 **DR. HARRISON:** Paul, did you hear that Bob Harrison is here?

3 **DR. MIDDENDORF:** No, I didn't.

4 **DR. HARRISON:** Okay, I'm here.

5 **DR. MIDDENDORF:** Okay. Back to Catherine Hughes? Carol North?

6 (no response)

7 **DR. MIDDENDORF:** I think we're about 50 percent here. Let's give it

8 another minute or two and I'll start all over again.

9 I'm hearing a lot of noise, possibly from a printer in the background, from

10 somebody. If somebody is typing and has something on in the background, so

11 please mute if you're not speaking.

12 (pause)

13 **DR. MIDDENDORF:** Okay, let's try this one more time. Tom Aldrich?

14 **DR. ALDRICH:** I'm here.

15 **DR. MIDDENDORF:** Okay. John Dement?

16 **DR. DEMENT:** I'm here.

17 **DR. MIDDENDORF:** Kimberly Flynn?

18 **MS. FLYNN:** Here.

19 **DR. MIDDENDORF:** Bob Harrison?

20 **DR. HARRISON:** Bob's here.

21 **DR. MIDDENDORF:** Catherine Hughes?

22 (no response)

23 **DR. MIDDENDORF:** Still not back. Steve Markowitz?

24 **DR. MARKOWITZ:** Still here.

25 **DR. MIDDENDORF:** Guille Mejia?

26 **MS. MEJIA:** I'm here.

27 **DR. MIDDENDORF:** Carol North?

28 **DR. NORTH:** I'm back on now.

29 **DR. MIDDENDORF:** Okay. Julia Quint?

30 (no response)

31 **DR. MIDDENDORF:** Bill Rom?

32 (no response)

33 **DR. MIDDENDORF:** Susan Sidel?

34 **MS. SIDEL:** Here.

35 **DR. MIDDENDORF:** Glenn Talaska?

36 (no response)

37 **DR. MIDDENDORF:** Leo Trasande?

38 (no response)

39 **DR. MIDDENDORF:** Liz Ward?

1 **DR. WARD:** Here.

2 **DR. MIDDENDORF:** Virginia I think was leaving. Two, three, four, five, six,  
3 seven, eight. We only have nine; we don't have a quorum yet.

4 **DR. TALASKA:** Did you hear me? This is Glenn.

5 **DR. MIDDENDORF:** Glenn, no, I did not hear you.

6 **DR. TALASKA:** Oh, okay, no, I'm here.

7 **DR. MIDDENDORF:** Okay, that's one, two, three, four, five, six, seven, eight,  
8 nine, ten. We have ten, Liz; we can proceed.

9

10 **DISCUSSION OF RESEARCH NEEDS AND**

11 **DEVELOPMENT OF RECOMMENDATIONS**

12 **DR. WARD:** Okay, great. So as we discussed before lunch, I think what we'd  
13 like to do is get the major suggestions down under each of the four areas that  
14 Dr. Howard proposed we discuss. And under the first item, which is to identify critical  
15 research gaps relative to our understanding of the effects of exposure, I think we  
16 should also include suggestions related to characterizing the exposure because that is  
17 (indiscernible due to extraneous input).

18 We are starting to hear some feedback from someone. We're having the same  
19 problem we had before. So Paul, could you ask the operator to check on that?

20 **DR. MIDDENDORF:** Yes, I will.

21 **MS. FLYNN:** Liz?

22 **DR. WARD:** Yes.

23 **MS. FLYNN:** This is, this is Kimberly. I don't know whether or not Dr. Crowley is  
24 back on the call but just speaking for myself, I would really benefit from an outline of  
25 some of the studies, you know, the, the kind of research needs and approaches that  
26 were not part of her PowerPoint presentation text but that she elaborated in her  
27 presentation. Would it be possible to request that?

28 The other point that I think we could benefit from hearing her elaborate more  
29 fully is the need for research resources to do analysis of all of the data pouring into the  
30 responder and survivor data centers.

31 **DR. WARD:** So, Paul, what's the situation with Dr. Crowley? Are you trying to  
32 reach her to see if she can rejoin us?

33 **DR. MIDDENDORF:** I sent her an email. We had asked some speakers to stick  
34 around and join us in the afternoon, if it's at all possible, in case there were additional  
35 questions. Dr. Crowley, are you online? Are you available?

36 **DR. ROM:** Dr. Rom just joined.

37 **DR. MIDDENDORF:** Okay. Thank you.

38 I'll ask again. Dr. Crowley, are you available? Okay, Kimberly, I think what we  
39 can do is we can ask again in a few minutes.

1 **MS. FLYNN:** Sure. Thank you very much.

2 **DR. MIDDENDORF:** Okay.

3 **DR. WARD:** I did try to take notes on Dr. Crowley's recommendations, and it's  
4 possible that, maybe between me and Ray, we could -- or me, Ray and Paul and  
5 whoever else, we could at least try to capture some of her major recommendations, if  
6 that would be helpful, and I think she did kind of divide them into the different areas  
7 that Dr. Howard mentioned. Maybe not; I don't know. But anyway, so the two things  
8 she -- I mean, if it's agreeable I can kind of read through them, and then, Paul, are you  
9 going to be able to put them on the screen?

10 **DR. MIDDENDORF:** Yeah, I will try to.

11 **DR. WARD:** Okay. So the first thing she mentioned was impact on DNA and  
12 gene expression. The second thing she mentioned was the increased occurrence of  
13 sarcoidosis and hematologic malignancies, and whether that -- those both reflected a  
14 relationship of the World Trade Center exposures to immune system disorders and  
15 potential research looking at those mechanisms.

16 She then, in her next section, talked about a more general assessment of  
17 overall health status and impact of World Trade Center exposures on occupational  
18 experience, income, economic and social well-being as a separate topic.

19 She mentioned the specific topic, which dovetails with one of our public  
20 presenters, on "has exposure impacted cognition"?

21 She mentioned a topic of examining patient characteristics that maximize the  
22 potential benefit of psychotherapeutic interventions. If I got any of these wrong,  
23 especially outside my subject matter or expertise, please correct them.

24 **MS. SIDEL:** Liz, what does that last one mean?

25 **DR. WARD:** I can tell you what I'm interpreting it to mean, but maybe one of  
26 our more psychologically experienced people could say it better. What I'm assuming it  
27 to mean are what are the resulting characteristics of patients who seem to benefit  
28 most from known interventions. But it could easily be rephrased or broadened in  
29 different ways, and specifically related to what are the interventions that have been  
30 employed and how effective are they and what populations do they seem to work best  
31 in. So that one could definitely probably use a little bit of, you know, discussion and --

32 **MS. SIDEL:** Right.

33 **DR. WARD:** But that's how I interpreted it.

34 And then the next one relates to how to better use data resources to -- for  
35 surveillance of health conditions related to the health centers, and then I think that  
36 specifically referred to the data resource centers at the World Trade Center program  
37 site.

38 I think there was -- the next topic I wrote down is pretty general, and she may  
39 have been more specific, but just was the whole question of understanding the

1 progression of disease. I guess that also would relate to whether it progresses or  
2 whether it actually improves over time.

3 So the next one, as I interpreted it, and this could be a little off, is looking at the  
4 medical and psychological sequelae of exposure among the more impaired individuals.

5 The next one is looking at the impact of renal disease in responders with  
6 multiple co-morbidities.

7 And then the next one, which may be related to one of the previous ones,  
8 characterize individuals with significant health impairment.

9 **MS. SIDEL:** I'm sorry, characterize?

10 **DR. WARD:** Characterize individuals with significant health impairment. But I  
11 don't think that -- I don't think it really means characterize individuals but I guess it's  
12 more of a descriptive study to -- of populations with significant health impairment.  
13 That could be clinical; it could be exposure status; it could be specific demographic; it  
14 could be a lot of -- kind of focus on the more impaired individuals and try to understand  
15 better who they are and what their needs are would be how I interpreted that.

16 **MS. SIDEL:** Okay.

17 **DR. WARD:** Specific question, which could be applied in a lot of the -- a lot of  
18 areas: Did early intervention make a difference in outcome? And there may be some  
19 specific areas where we would think that that would be most appropriate. There was a  
20 mention of a need for research to identify new conditions that may be arising in the  
21 population. Several people mentioned, including Dr. Crowley, the need for better  
22 exposure assessment or more exposure assessment studies. That was all -- those were  
23 my notes from Dr. Crowley's presentation.

24 **MS. FLYNN:** Thank you very much, Liz. This is Kimberly. Your notes are better  
25 than mine; I really appreciate it. I do want to add in to this list that Dr. Crowley also  
26 mentioned research into the impacts, the health impacts to vulnerable populations  
27 such as children.

28 **DR. WARD:** So Paul, there's a -- I'm in a little bit of a pause because I was  
29 looking at my notes, and now I'm trying to get back into the website so that I can look  
30 at what you're typing.

31 **DR. MIDDENDORF:** I'm sorry. I had mine on mute.

32 **DR. WARD:** That's okay. No, no, I'm saying I'm trying to get back in -- I  
33 somehow have lost the website where we can look at the documents you're looking at,  
34 so I have to find it again.

35 **DR. MIDDENDORF:** Does everybody else, who is into the meeting, actually see  
36 where I've been typing?

37 **DR. ALDRICH:** Yeah, I see it.

38 **DR. MIDDENDORF:** Okay. And a quick question for Catherine. Are you able to  
39 speak into the meeting now? I'm not hearing you so I'm assuming that you're not able

1 to speak into the meeting. I need to check on that again.

2 **DR. WARD:** So is everyone now able to see Paul's notes either through the  
3 website or through an email that Paul just sent?

4 **MS. SIDEL:** Yes. Thank you, Paul.

5 **MS. MEJIA:** Thank you, Paul.

6 **DR. WARD:** So Paul, if you would then add to that research on health impacts  
7 on vulnerable populations?

8 **DR. MIDDENDORF:** I'm sorry, say that again?

9 **DR. WARD:** A point that was just made on research on health impacts in  
10 vulnerable populations.

11 **DR. ALDRICH:** This is Tom Aldrich. I wonder if I could mention another area?

12 **DR. WARD:** Sure. That's, I think, what we should do now is look at the -- you  
13 know, kind of add to the list and make sure that -- and keep -- yeah, add to the list until  
14 we've gotten all of the major topics covered, and then go through and try to refine and  
15 combine. So go ahead, Tom.

16 **DR. ALDRICH:** Okay, well, I'm impressed with the -- there's three large cancer  
17 studies have remarkably similar results. Not everything -- not all the cancers have  
18 statistically significant increases but each of the three large studies showed significant  
19 increases over expected in at least some cancers. And all of them were only up to  
20 seven years post-9/11.

21 And I think in general we believe that cancer latency averages longer than that,  
22 something in the range of 20 years, so what we may be seeing is a leading tail of a  
23 bell-shaped curve. And if that's the case, then we're in for very large increases in  
24 cancer in the future. That may or may not be true but we should be thinking about that  
25 possibility.

26 And so I think that it's reasonable to expect, because of the inhalational route  
27 of exposure for most of these toxins, that head and neck, lung, esophageal cancers  
28 might be -- might emerge next. And those of course are extremely deadly and hard to  
29 treat, so early diagnosis is really important.

30 I think we should solicit proposals to evaluate biomarkers or other early  
31 detection techniques to detect free cancerous lesions or early cancers in order to treat  
32 them when they're potentially curable.

33 **MS. HUGHES:** That sounds really good. Catherine here. Can you hear me yet?

34 **DR. MIDDENDORF:** Yes, we can hear you now.

35 **MS. HUGHES:** Great. I liked the last comment. Thank you.

36 **DR. ROM:** I might add to Tom Aldrich's recommendation for biomarkers for  
37 early cancer detection. NIOSH could actually interact with NCI, who has a program on  
38 early -- called the early detection research network that funds about 35 PIs around the  
39 country for studying biomarkers in high-risk populations for early detection of lung

1 cancer, prostate cancer, GI or women's cancer. And that program is very collaborative  
2 and would probably be interested in the WTC registry. So that's a second for  
3 biomarkers for early detection of cancer recommendation.

4 I would add to that -- this is Bill Rom speaking -- that it would be very nice to  
5 develop biomarkers for asthma since we've gone from about 9 or 10 percent at  
6 baseline up to 27 percent in the Lancet article that Dr. Crowley cited, that there must  
7 be markers spilling over into the blood or other sources that could be looked at to  
8 correlate to these symptoms and meet the physical findings. And it may help us  
9 understand the etiology of asthma.

10 And I might add to that that microbiome might have something to do with that,  
11 and we haven't even discussed microbiome, but that might be something that's altered  
12 by World Trade Center dust and the GERD, asthma and sinusitis populations. And I'm  
13 not sure we've had any applications to look at that, but that might be another altered  
14 background setting that predisposes to these illnesses.

15 **DR. WARD:** That's great, and thank you. And I just wanted to interject a  
16 procedural thing -- this is Liz again -- that, as each of the speakers talks, I'm assuming  
17 that you're going to double-check what -- how Paul has captured your suggestions and  
18 make sure that they're -- I think Paul's doing a great job of condensing them, but make  
19 sure that they are captured accurately and that all the points are captured.

20 **DR. MIDDENDORF:** Yeah, I'm going to have to circle back with some of the  
21 folks, like Bill Rom, who I -- is not able to get into the website. So I'm going to have to  
22 email this out real quick.

23 **DR. WARD:** Okay, yeah, it is helpful for those who can to follow along on the  
24 website. I just -- I somehow had gotten myself out of it but got myself back into it, and  
25 so it's really helpful to follow along the suggestions.

26 So would anyone else like to add something to the list? I think Paul is sending it  
27 out again.

28 **MS. SIDEL:** I would. I'd like to add something to the list. It's Susan Sidel.

29 **DR. WARD:** Okay.

30 **MS. SIDEL:** Something that I think Dr. Melius mentioned earlier and that I've  
31 raised a few times is autoimmune diseases. There has been, I think, very little research  
32 on autoimmune diseases, and it's interesting because I -- I mean, obviously I'm not a  
33 doctor but I do know that it's accepted among hematologists that environmental toxins  
34 cause some autoimmune diseases or if you have a genetic predisposition to it, it'll make  
35 the autoimmune disease, you know, happen when it may not have otherwise, if you are  
36 exposed to something.

37 Now, and this is something that would have been interesting to ask  
38 Dr. Crowley. I wonder if part of the reason why something like autoimmune diseases  
39 are not covered is because the kind of doctors that would study it, I think, would be a

1 rheumatologist, and there aren't any rheumatologists that are involved in the program.  
2 I mean, that's not the kind of doctors that we have. And if that's the reason why, then  
3 do we reach out, you know, to specialists? I mean, how does that work? So it's like a  
4 two-part question because, I think it --

5 **DR. ALDRICH:** Tom Aldrich.

6 **MS. SIDEL:** I'm sorry, what?

7 **DR. ALDRICH:** I would just mention that one of the funded research projects is  
8 specifically to look at incidence of autoimmune diseases, and one of the cohorts  
9 relative to that would be expected in the population. So it's being addressed at least in  
10 one area. I think I saw something about rheumatoid arthritis in another study also.

11 **DR. WARD:** And who was speaking just then?

12 **DR. ALDRICH:** I beg your pardon, Tom Aldrich.

13 **MS. SIDEL:** Right, but the document that, you know, well, I mean, that's really  
14 good but is that enough? Because I mean, there was something that I was reading  
15 about asbestos out in Libby, Montana and how -- it's Montana -- and how exposure to  
16 asbestos, they're seeing a lot of lupus, which is usually something that affects women,  
17 you know, that are of child-bearing ages, and it's happening in a lot of men that are in  
18 their 40s. So I mean, it's just something that's a really broad subject, and the whole  
19 inflammation-cancer connection from the -- you know, from the fire department  
20 article, I just think that it's something that really needs to be looked into.

21 And also I have to say that, because I have one and I've just been fighting for it  
22 for years, and there's so much resistance at the program to even considering that what  
23 was going on with me could possibly have anything to do with my exposure. And, you  
24 know, it wasn't until I got a specialist involved to definitely say that it was, you know,  
25 before I could take that information back to the -- you know, back to the program and  
26 have it be taken seriously.

27 **DR. WARD:** So --

28 **MS. SIDEL:** So.

29 **DR. WARD:** Yeah, I think one thing we could do is, as we get the new  
30 suggestions in, is see if they really fit -- if they dovetail well with something that's  
31 already on the list. So I would say that this autoimmune diseases, we could combine  
32 that with the second suggestion on the list, to look at sarcoidosis and malignancy. But  
33 maybe the broader topic is immune system disorders, and that would include  
34 autoimmune diseases, malignancy --

35 **MS. SIDEL:** Oh, that's a good idea.

36 **DR. WARD:** Yeah.

37 **MS. SIDEL:** The other thing that to me, you know, talking with my doctor,  
38 especially since that woman was talking about it earlier, but a lot of people -- I've  
39 known a lot of people that have cognitive issues in the program, and it's usually

1 thought, you know, the doctors will say, well, it's because of PTSD. And it isn't. It's --  
2 something definitely happens to your brain from exposure to toxins. And I thought  
3 that that's something that would be really interesting to look into as well as the fact  
4 that we're not using EMDR to treat post-traumatic stress disorder. I mean, it's like  
5 there's so many -- there are so many techniques to deal with post-traumatic stress  
6 disorder and we're using, you know, like old-fashioned psychotherapy when there  
7 are --

8 **DR. ALDRICH:** What is EMDR?

9 **MS. SIDEL:** I forget exactly what it stands for but, you know, you sort of relive  
10 the -- it's like left-brain/right-brain, you kind of see -- they put little clickers in your  
11 hands and you kind of relive, you know, the painful experience, and you just kind of  
12 keep -- you know, you're going to do this with a therapist, and you kind of work  
13 through it until it doesn't -- you know, it's not as troubling. I'll look up the initials.  
14 Actually, let me just Google it.

15 **MS. FLYNN:** Hello? Can you hear me?

16 **MS. SIDEL:** Yeah.

17 **MS. FLYNN:** This is Kimberly. Hi. EMDR is eye movement desensitization and  
18 reprocessing. And at least one clinician in the Bellevue responder program has used it.  
19 I, you know, was lucky to catch a presentation a couple of years ago. So I'm not saying  
20 there shouldn't be research on it but, you know, it is a recognized modality.

21 **MS. SIDEL:** And there's another -- there's something else that they do at Mass  
22 General that's like the next step up from EMDR. I don't remember what it's called but  
23 maybe, Dr. North, maybe you might have more information about this. But I think  
24 we're using techniques that are kind of like old-fashioned and take a long time. And  
25 there's like there's shorter ways to deal with, you know, the trauma.

26 **DR. WARD:** Is Dr. North on the call yet?

27 **MS. SIDEL:** I guess not.

28 **DR. HARRISON:** This is Bob Harrison. I would like to add an idea or concept to  
29 the list, and that is research that focuses on practice or, you know, what NIOSH has  
30 called R-to-P, research to practice. Sometimes we call it applied epidemiology or  
31 applied public health. One of the things that has struck me, maybe coming out here  
32 from the west coast perspective but also as an occupational medicine provider, is that  
33 there's a huge amount of research that's incredibly valuable from these studies that --  
34 and there's been a lot written, you know, and really good summary articles, but I guess  
35 thinking it now, it's going to be, you know, almost 15 years out from this experience.  
36 You know, is there a way to integrate or apply the research findings and think about  
37 how it's affected the population that's in the registries or other potential worker  
38 populations. You know, this -- I see the research not only divided up into three  
39 categories that we're charged with, but there is, you know, basic biological

1 biomonitoring, etiological, epidemiological, but, you know, but I guess this other  
2 element is, you know, practice or public health impact. I don't know how that would  
3 be translated into research proposals but I would just throw that into the mix as, if  
4 there was an announcement that was put out that would encourage, you know,  
5 innovative proposals along that line.

6 **DR. MIDDENDORF:** I just want to interrupt for just a second. Dr. North is on  
7 the line but she's having trouble speaking. We're trying to get her access.

8 **DR. NORTH:** Can you hear me?

9 **DR. MIDDENDORF:** Yes, we can hear you now.

10 **DR. NORTH:** Oh, excellent. I've been trying six or eight times to interject and  
11 nobody heard me.

12 So regarding the mental health discussion, I had a couple of things that I  
13 wanted to add to the list, if that would be okay at this time.

14 **DR. WARD:** That would be great.

15 **DR. NORTH:** Great. Okay, well, the first thing relates to something other  
16 people have talked some about, which is the exposure issue. And 9/11 really was a  
17 different disaster from most past disasters in -- because of its scope and magnitude, the  
18 exposures may have gone a lot further than previous disasters. But I don't think we can  
19 necessarily assume the exposure zones for mental health problems will be the same as  
20 for other diseases. And so I think it's critical that that be further studied. That's my  
21 first item.

22 My second item is that often, for lack of a better method, diagnoses are not  
23 made and instead mental health problems are discussed in terms of symptoms, and,  
24 you know, we don't study cancer symptoms; we study cancer. And it would be good if  
25 we could -- if research could figure out a better way to assess full psychiatric disorders.  
26 'Cause it's not clear what these symptoms mean outside of disorders. They can be very  
27 nonspecific, so I'd like to see the field improve its ability in research there.

28 Hello? Did you hear me?

29 **DR. MIDDENDORF:** Yes.

30 **DR. WARD:** Yes.

31 **MS. SIDEL:** I didn't hear her. She cut out.

32 **DR. MIDDENDORF:** I think she finished, and then she was waiting for a  
33 response and didn't hear anything; is that correct?

34 **DR. NORTH:** Yes.

35 **MS. SIDEL:** Oh.

36 **DR. WARD:** And so this is Liz. I'm trying to figure out what the best way to kind  
37 of collate this information is since only Paul really has direct access to the document.  
38 So I guess, Paul, if maybe periodically, when you mail this out -- I think you're mailing it  
39 out to everyone regardless of whether they have access to the web version or not.

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**DR. MIDDENDORF:** Correct.

**DR. WARD:** And so Carol, if you would go into the text that Paul just transcribed and kind of edit your comments, that would probably be helpful, and in fact if everyone could do that, because I think Paul's capturing the bare essence but I think we will want to have a version of the document that has these points more clearly articulated. And then one of the things we'll probably want to do is take the email version of the document and start grouping things and collapsing and organizing. I do think that we may have gotten off-track a little bit with our plan to focus first on John's area 1 and then area 2. I'm actually having a little trouble sorting out which of the things in our list fall into the different categories. But I do think it would be important that we have some interactive mechanism for people to go in and edit their comments so that we can get this list to be as clear as possible.

**DR. NORTH:** Can we do it by email? 'Cause I can't get on the web.

**DR. WARD:** That's what I'm thinking. Probably the easiest thing is if everybody -- Paul, if this doesn't sound good to you, let me know. Let's say, if I made a point, I could take that point from the latest version of your document, rephrase it, if necessary, and send it back to you, and then you could insert it in the master document? Would that --

**DR. MIDDENDORF:** That sounds fine.

**DR. WARD:** Okay.

**DR. ALDRICH:** This is Tom Aldrich. I was struck by something Dr. North said and I think it's something that we should follow up on. The remote or the different geography that might apply to mental health issues as compared to, for the want of a better word, physical health issues, one example of that, that I think was very interesting, was the 9/11 dispatchers who were not within the footprint of the World Trade Center nor the original geographic boundaries but had significant PTSD issues. I don't remember any details about it but that's an interesting aspect of this that's got a little attention.

**DR. NORTH:** This is Carol North. That's a very interesting twist on the exposure issue. Because this disaster was so big, we've never even really thought about these things before.

**DR. WARD:** So it does sound to me -- this is Liz -- that we will want to coalesce around at least one research priority topic related to mental health issues and maybe fold in the issue of cognitive impairment? Dr. North, do you have a sense of how those might be -- if those should be combined, and if so, how, or if they should be separate?

**DR. NORTH:** Well, some of cognitive impairment is truly a psychiatric issue. Other cognitive impairment, depending on the situation, could be neurological or metabolic or otherwise medical, so it touches on both.

**MS. SIDEL:** The issue I'm concerned about with the cognitive is if it's thought of

1 as being part of like PTSD, it sort of diminishes the impact of it. Because there's  
2 therapy, like cognitive remediation, that people can do, and if it's not thought of as its  
3 own -- you know, as its own thing and it's like kind of wrapped up PTSD, then people  
4 aren't going to have access to the kind of therapy that's really going to help them  
5 function.

6 **MS. FLYNN:** This is Kimberly, and this issue of cognitive impairment came up  
7 recently in the survivor steering committee, because apparently lots of patients at the  
8 World Trade Center of our mental health center are complaining about cognitive  
9 issues: memory, attention, thinking, et cetera. And what the mental health director at  
10 the EHC who was present said to us, that made a great deal of sense, is that there  
11 should be a preliminary study. There needs to be, sort of as a first step, a full  
12 characterization of the problem, because indeed we don't know how much of this  
13 problem is a result of environmental exposures and how much of this problem is a  
14 result of psychological exposures to the disaster. So I don't know if I'm, if I'm, you  
15 know, capturing her expertise adequately but that was the point that emerged from  
16 our meeting.

17 **DR. NORTH:** I agree. I agree with you.

18 **DR. MIDDENDORF:** I just want to let everybody know that all of the emails that  
19 I send out and anything I get back in terms of an email will be compiled into a  
20 document and it will be posted on the website so that all this is public information.

21 **MS. HUGHES:** I have a question -- Catherine Hughes here. Are we checking  
22 that the treatments, such as for cancer, is effective or not or there may be more  
23 effective modes to treat the cancer? Would this be a study topic?

24 **DR. ALDRICH:** This is Tom Aldrich. The problem with that approach is that  
25 there are so few cases, that there's not going to be enough power in the study to  
26 determine different treatments. So I think we have to leave treatment differences for  
27 cancers to the cancer experts who are treating large numbers.

28 **DR. MARKOWITZ:** This is Steve Markowitz. I think there is a related topic,  
29 though, that probably is germane, which is that this is a big -- the World Trade Center  
30 Health Program is now a pretty big system, and someone should be looking at the  
31 healthcare utilization in the group and perhaps comparing it to the World Trade Center-  
32 exposed people who are not participating in the health program, to understand the  
33 patterns of how people are using this care, thinking ahead to the future disasters'  
34 problems, whether it makes sense to set up a new segregated health program or  
35 whether it makes sense to pursue a different kind of way of treating people. And  
36 related to that, not just on the treatment side but on the monitoring side, I think some  
37 research needs to be done on the utility and effectiveness of the current monitoring  
38 program. On the health -- on the WTC Health Registry side, we have, you know, a  
39 questionnaire-based approach; on the Health Program side, we have a physical

1 examination, an annual -- at least an annual offer of an encounter, although most  
2 people don't show up annually. And the question is, does -- what are the pros and cons  
3 of both sides, but specifically in the World Trade Center Health Program, what's the  
4 utility actually providing hands-on monitoring? That's not to speak in favor or against  
5 it, just we need to understand what we're getting out of it. So I would say that the  
6 research area would be both healthcare utilization on the treatment side and also, on  
7 the monitoring side, utility and effectiveness of the monitoring program as it's set up  
8 now.

9 **MS. SIDEL:** Well, one of the issues also with the monitoring program is that  
10 you're telling everything to a nurse, and she's interpreting what you're saying and  
11 putting it into your file, and if you don't -- there's a lot of times that information is like  
12 incorrect, it's sort of her version of what you're telling her. And so I've always  
13 wondered if it would be better to have some sort of a system where there was like an  
14 internet or people just had an iPad and they filled out all that information themselves,  
15 because at times it becomes congested when someone else is (indiscernible).

16 **DR. MARKOWITZ:** That would be a -- this is Steve Markowitz -- yeah, that  
17 would be the kind of question that could be looked at in this research area.

18 **MS. SIDEL:** Yeah.

19 **MS. MEJIA:** Liz, this is Guille Mejia. I just wanted to bring up something that  
20 Jim Melius had mentioned in his presentation which was that he was looking at  
21 focusing on emerging conditions. And so I think one area that we might want to look at  
22 is what are the non-covered conditions that are being reported by participants in the  
23 Health Program, and is there, you know, a pattern or trend or anything that can lead to  
24 maybe adding more conditions?

25 **DR. WARD:** Yeah, I think that's very well stated, and it's connected with one of  
26 the topics we've already captured. I think it's stated more clearly. I think we said  
27 something about new conditions, I think. But I think this really captures what we're  
28 trying to say. So Paul, if you could get that down.

29 **MS. FLYNN:** Liz, this is Kimberly with a follow-up comment, which is that it  
30 does appear that research resources are needed to do analysis of any emerging  
31 conditions that are, you know, in the database. My sense right now is that the data  
32 center has this information and does not have the wherewithal to conduct the  
33 analyses.

34 **MS. SIDEL:** This is a little bit far out, but I'm going to take a risk and bring it up  
35 anyway, is that, you know, because of the victims' compensation fund, attorneys are  
36 compiling tons of information on each of their clients' health conditions that are  
37 related to the World Trade Center, and that information is definitely out there. It's  
38 either going to go to the justice department or it could be compiled, you know,  
39 individually. But it's a lot of information because each person -- each client goes and,

1 you know, tells every condition that's related to World Trade Center (indiscernible) and  
2 it's pretty simple.

3 **DR. WARD:** Good. I think, I think one way to help reframe the discussion so  
4 that we're as responsive as possible to Dr. Howard's questions is to look again at his  
5 questions. And I think what he's asking us to do is to identify critical research  
6 knowledge gaps in each of these areas. So while I think it's tempting to look at specific  
7 courses of data or specific ways to do research, I think what we really should try to do is  
8 articulate as clearly as possible what the knowledge gap is that we're trying to address.

9 **DR. ALDRICH:** This is Tom Aldrich again. It seems to me that that that's been  
10 presented today is pretty good overview of the knowledge gap. My view is that -- I  
11 mean, there's only so much money for research, and there are gaps. To me the best  
12 way to approach this is to provide some guidance to areas that are -- that NIOSH or  
13 whoever thinks is important, but yet make the determination of funding dependent on  
14 the best quality research. So if it turns out that the best quality research does not  
15 match exactly with our list of needs, I don't think that's necessarily a problem. We  
16 should be supporting the best research that we can.

17 **DR. WARD:** Well, I think it's real -- you're addressing two areas of the process,  
18 and maybe someone at NIOSH would like to chime in. So I think our function as the  
19 scientific advisory committee is to suggest the priority -- or you know, the priority  
20 knowledge gap. And then there's a separate process that evaluates the quality of the  
21 proposal. So I think our recommendations might be used to help draft better requests  
22 for proposals. But I think there's a separate process that's going to evaluate the quality  
23 of the proposals, and so we're not in any way dictating which proposals will be funded.  
24 Paul, or someone else from the NIOSH grants program, would you like to step in?

25 **DR. KUBALE:** Dr. Ward, this is Travis Kubale. I would just agree that, there is a  
26 separate, you know, scientific and technical review process, you know, for that  
27 purpose. You're exactly right.

28 **DR. ROBISON:** This is Allen Robison. I would just add that the ideas and input  
29 that you come up with today, we will take that and use that as we move forward with  
30 subsequent funding opportunity announcements. Thanks.

31 **DR. WARD:** So with respect to the first area, maybe we should kind of review  
32 what, at least what I think are the major themes that are emerging, and then we can  
33 see what is missing. So I think one major theme that's emerging, that there seems to  
34 be a lot of interest in, is the question of the newly emerging conditions, that are not  
35 currently covered conditions but may be emerging in the population and could be  
36 identified by research, either using existing data, specifically using existing data  
37 sources. So that seems like, you know, something that the committee would want to  
38 recommend.

39 A second important area is doing research on mental health conditions related

1 to -- or doing more research on mental health conditions related to exposure and also  
2 the -- and one thing that came across very strongly there was the idea that the way  
3 we've been categorizing exposure in terms of chemical and physical toxins may not be  
4 appropriate for the exposures that impact mental health outcomes.

5 And also I guess the question that Dr. North raised about research, is there a  
6 way to do research, population-based research, where we would be looking at actual  
7 psychiatric diagnoses rather than symptoms. So that could all be -- those could be  
8 combined into one research topic on mental health outcomes related to World Trade  
9 Center exposures.

10 **MS. SIDEL:** What about the techniques they use for -- to treat mental health.  
11 You know, for example use the things like EMDR for post-traumatic stress disorder  
12 rather than just psychotherapy?

13 **DR. WARD:** Well, I think that might be more appropriate conceivably under the  
14 third, the third research area, which is critical research knowledge gaps relative to  
15 effective treatment of World Trade Center-related conditions.

16 **MS. SIDEL:** I see. Okay, thank you.

17 **DR. WARD:** And then the third area, I think, is -- was related to biomarkers of,  
18 specifically cancer but other potentially other chronic conditions related to World  
19 Trade Center exposures. And that captures a specific suggestion that Dr. Crowley made  
20 related to DNA and epigenetic effect. It captures a -- it captures what Dr. Rom talked  
21 about in terms of biomarkers related to asthma, potentially.

22 And the last -- the fourth kind of major area that I'm trying to -- you know, I'm  
23 trying to distill these into a smaller number of larger points, would be the whole  
24 question of immune system disorders, which would include autoimmune diseases and  
25 cancers of the -- relating to the immune system, like sarcoidosis.

26 So does anyone think that's a good synthesis of the four major topics we might  
27 want to identify under the first point?

28 **DR. TRASANDE:** Hi. Can I -- sorry to interrupt. This is Leo Trasande. I just  
29 joined.

30 **DR. WARD:** Hi, Leo.

31 **DR. TRASANDE:** Hi, how are you?

32 **DR. WARD:** Good.

33 **DR. MIDDENDORF:** Welcome, Leo.

34 **MS. FLYNN:** Liz?

35 **DR. WARD:** Excuse me, go ahead.

36 **MS. FLYNN:** I'm sorry. This is Kimberly, and Leo arrived just in time. I would  
37 suggest that we add health impacts, particularly physical health impacts, to the  
38 pediatric population.

39 **DR. WARD:** Good. And I would suggest maybe we broaden it a little bit to say

1 vulnerable populations, and that would be pediatric and also potentially the groups  
2 that -- well, I guess that could be pediatric but the study of children and young adults or  
3 people who were exposed to the World Trade Center at a relatively early age. There  
4 may be other vulnerable populations as well.

5 **MS. HUGHES:** Hi, this is Catherine Hughes. I think I'm the only residential mom  
6 on the committee. I think it can't -- it has to deal with the physical health, 'cause, you  
7 know, when they say they studied -- that there's been studies on the population, a lot  
8 of it has been mental, and there's been really a deficiency on the physical health for  
9 children. And I mentioned this at the last survivors' meeting. You know, we had the  
10 clinical guidelines, first for adults, went through iteration 1, iteration 2. Finally after  
11 much fighting, they got guidelines for children. I mean, it's been a battle to get children  
12 recognized in this entire process, and we've really done them a disservice over the  
13 years. So children have -- you know, they have to be there in terms of the physical  
14 health as well. That's all.

15 **DR. WARD:** Good. Good.

16 **MS. SIDEL:** You know, in the children's category, babies that were born during  
17 that time, I know of a few people that have concerns about, you know, their children  
18 that were conceived while one of the parents was working at the World Trade Center  
19 after the attacks. They have, you know, different issues that affect children that they  
20 had as well before, you know, 9/11, don't have.

21 **DR. WARD:** Okay, so that -- but I think in terms of, Paul, where you noted  
22 pediatric disease and other, I think what we want to do is maybe make that one little  
23 more broadly as effects -- health effects of exposure, World Trade Center, during  
24 gestation or early life, something like that. Then in parentheses, childhood and  
25 adolescence or something like that, so we're kind of broadening it.

26 And looking at the, at the web version, it looks like you have most of the points  
27 we've -- so under item -- under point 1, we really -- I mean, like the overall subhead is  
28 Dr. Howard's question, and then each of these areas is a separate kind of research  
29 recommendation. So newly emerging uncovered conditions is one research  
30 recommendation, and then more research on mental health conditions is the second  
31 recommendation. And they're all under item 1. Or they're all under, you know, his  
32 subhead 1.

33 **DR. MIDDENDORF:** Okay, I don't have that up, so.

34 **DR. WARD:** Well, I see it. Oh, you don't have the -- well, that's okay. You can  
35 just put a header like subhead 1 or something or...

36 **DR. MIDDENDORF:** Okay. So all of these go under his?

37 **DR. WARD:** His item 1, I think. Yeah.

38 **DR. MIDDENDORF:** Okay.

39 **DR. WARD:** What I'm thinking is maybe we should just -- we should see if

1 there's -- if this captures the major themes that we want to prioritize or if -- so and  
2 maybe what we could do is -- well, I guess you'll send these out, after you finish  
3 reformatting them, and then we can maybe look at them and see if we've captured  
4 everything and if we've got the wording close to correct.

5 **DR. ALDRICH:** This is Tom Aldrich again. I think one thing that isn't included in  
6 that list is exposure assessment.

7 **DR. WARD:** Okay.

8 **DR. ALDRICH:** I forget how that's based but the quantification of exposure.

9 **DR. DEMENT:** This is John Dement. I really second that one. It came about in a  
10 number of different discussions. It seems that early on we had a lot of exposure  
11 assessment that was really innovative, but later on it seems that we've sort of settled in  
12 on what was done before and not really looked at some issues of differences in the  
13 particularly higher-risk populations not yet identified. So I think that's really narrow  
14 and it really still needs to be up on this list. It really deals with etiology as well.

15 **DR. MIDDENDORF:** So how would you suggest I word this?

16 **DR. DEMENT:** Well, I think: expanded and integrated exposure assessment.  
17 And I really like the comments about the fact that we've principally looked at physical  
18 exposures and largely respiratory, but it really needs to be -- that concept needs to  
19 be -- needs to be broadened out. And I think it has some validation at least of some of  
20 the exposure assessment. It seems to be validated by the results that we've seen,  
21 particularly respiratory. But the network needs to be expanded out to some of the  
22 other health conditions.

23 **DR. WARD:** And I think what I would do is I would take that verbiage, that John  
24 just suggested, and make that a major bullet, and take cognition out of it. I think -- I'm  
25 not sure what -- you know, I think, I think we still -- I mean, I'm not -- I'm not sure if --  
26 well, I guess we can list cognition as a separate research topic, 'cause it sounds like we  
27 don't really -- I mean, we could, we could kind of group it under newly emerging  
28 uncovered conditions or under mental health conditions, even though Dr. North  
29 pointed out that the causes of problems with cognition could be either physical or  
30 psychological, or we could keep it as a separate topic. I'm not sure, you know, where  
31 it's -- maybe to me it makes the most sense to kind of group it as -- under the newly  
32 emerging for -- because it's -- I don't know how strongly it will stand alone as --

33 **DR. DEMENT:** Right.

34 **DR. WARD:** -- a major research theme.

35 **DR. DEMENT:** Right.

36 **DR. WARD:** But we can, we can talk about that. But I definitely don't -- I don't  
37 think it should be under the -- I think the exposure assessment is a very strong theme  
38 and it should stand -- I think it should stand alone.

39 **MS. FLYNN:** Liz, this is Kimberly. I'd like to just jump in on exposure

1 assessment. I just -- I guess I just want to reemphasize the point that, particularly for  
2 the survivor community, there is no reliable data set of environmental measurements.  
3 So I'm assuming that one would come at exposure assessment for that community  
4 differently. One suggestion is biomarkers of long-lived exposures, which I know is  
5 being done in the World Trade Center adolescent study by Dr. Trasande. So I don't  
6 know if you want to put -- okay, that makes sense, put it under biomarkers, but that  
7 would be a marker of exposure and not a marker of disease.

8 **DR. MIDDENDORF:** I'm going to try and send this out to everybody now so  
9 people have a chance to look at it. (pause) I sent it out. Hopefully people are receiving  
10 it. And what I sent out was the major themes and the grouping, one through six, under  
11 Dr. Howard's charge number 1.

12 **DR. WARD:** Well, it hasn't come into my in-box yet.

13 **DR. MIDDENDORF:** Okay.

14 **DR. WARD:** Has anyone else received it?

15 **MS. MEJIA:** Still waiting.

16 **DR. ALDRICH:** Not yet.

17 **DR. MIDDENDORF:** I re-sent it just to see -- make sure it wasn't caught off  
18 somewhere.

19 **DR. WARD:** I guess, Paul, in the worst case, if we can't receive it, maybe we  
20 can just read through them one by one, and those people who have -- I don't know why  
21 it's not coming in.

22 **DR. MIDDENDORF:** Yeah, Dr. North is again trying to get in but she's not able  
23 to be heard.

24 **MS. SIDEL:** I just got my email.

25 **DR. MARKOWITZ:** Yeah, I just got the email too.

26 **DR. MIDDENDORF:** Dr. North says: I'm trying to say that the exposure  
27 measurement should be specifically annotated to include a unique line of study for  
28 mental health.

29 **UNIDENTIFIED SPEAKER:** I agree; I think it's really interesting.

30 **DR. WARD:** Okay, so --

31 **DR. MIDDENDORF:** Okay, we're having some difficulties here. Both Dr. North  
32 and Dr. Talaska are having difficulty being heard. If the operator is on the line, please  
33 make sure that Glenn Talaska and Carol North are added to the speaking line.

34 **THE OPERATOR:** They have open lines, sir.

35 **DR. MIDDENDORF:** They do have open lines. Can you hear me?

36 **DR. NORTH:** Hi, this is Carol; can you hear me?

37 **DR. MIDDENDORF:** Yes.

38 **DR. TALASKA:** Can you hear Glenn?

39 **DR. MIDDENDORF:** Yes, we can hear you, Glenn.

1 **DR. TALASKA:** Oh, good, finally. God, I was yelling. I wanted to add that --

2 **DR. NORTH:** This is Carol; can you hear me?

3 **DR. TALASKA:** May I talk?

4 **DR. MIDDENDORF:** Yes, Carol, we hear you, too.

5 **DR. NORTH:** Thank you.

6 **DR. TALASKA:** This is Glenn Talaska. I wanted to just reinforce what Paul was  
7 saying about exposure assessment and the strategies that need to be developed as a  
8 result of the exposure assessment that was done after 9/11.

9 I think if everyone remembers, you know, one of the -- the exposure  
10 assessment that was done on -- during 9/11 was amazingly poor. And one of the things  
11 that would just be -- we really do need to develop a strategy coming out of what  
12 markers were measured and a critical review of what was done for the exposure  
13 assessment during 9/11.

14 John and I did that to a limited extent with the papers that we had but we did  
15 that in a period of a week. And a research study, which would look at that and try to  
16 integrate and make suggestions about which markers for which types of exposures,  
17 would be very useful, I think. It would be very -- well, it would be very useful if  
18 something like this ever happens again.

19 It certainly has been rolled in from the deep water horizon or the other  
20 disasters that we have, including hurricanes. We don't really have a strategy for doing  
21 that yet, and I think that's important. And it would include using or developing which  
22 long-term markers, which could be gotten from the autopsy studies that are being  
23 done currently, could predict or could be used to indicate which sort of shorter-term  
24 markers might be used to tell people when they've reached a critical level of exposure  
25 and should be removed from doing particular work. And that way, we could prevent  
26 the need. Thank you.

27 **DR. WARD:** I guess the question I have is -- I mean, I mean, I'm not sure, Glenn,  
28 that the way you phrased that, it kind of lends itself to a research funding proposal. I  
29 mean, it relates to a lot of these different areas, but it seems like it's more like writing a  
30 paper or a review. And I think what we're trying to do is come up with topics that really  
31 will benefit this population rather than the broader -- not that it's not important to use  
32 the information that we learned at the World Trade Center to benefit the broader  
33 fields but I think we're talking -- we're talking about doing research within the World  
34 Trade Center population. So I mean, I think what you're talking about fits in one of  
35 these broad categories but I'm not sure it would be a stand-alone priority.

36 **DR. TALASKA:** Well, no, I was really seconding what you -- what we were  
37 talking about. I could hear you; I couldn't talk. But what John Dement said --

38 **DR. WARD:** Okay. Okay, yeah, okay. And so one suggestion, just in the  
39 interest of trying to move, you know, to a -- unfortunately we have this one meeting

1 and we want to come up with final recommendations, and it's, you know, it's -- I want  
2 to make sure that we get to look at all of the four topics. So if we look at the email that  
3 Paul sent out, maybe what we should start doing -- one thing -- I mean, we could make  
4 a motion that these general topics would be the six priority areas we want to make  
5 recommendations on or we could make a motion that a specific additional area be  
6 added before we word-smith the final product, and maybe move on to the second  
7 area, because I think we'll want to do the prioritization after we've gone through all of  
8 the -- all of the four charge areas.

9 **MS. HUGHES:** I have a question -- Catherine Hughes. Should we also put them  
10 in priority order, like -- 'cause right now they're in order 1 through 6, and people might  
11 think that it's based on priority.

12 **DR. WARD:** Well, I guess we can. We could prioritize within each area, and  
13 then prioritize across the different areas, if the group would like to do that.

14 **MS. HUGHES:** 'Cause right now it's -- you know, it looks like biomarkers is  
15 number 3 but biomarkers is really important that it should -- you know, it looks like it  
16 should probably be moved up.

17 **DR. MIDDENDORF:** I'm going to suggest that at this point you just get out your  
18 ideas and what you think the specific, specific wording for each of these would be. And  
19 then at the very end, when you have all of the ideas or all of the specific topics that you  
20 want to address, then prioritize across all of the groups rather than just looking at each  
21 individual group. So at this point, let's just make sure that we get the wording in  
22 numbers 1, 2, 3, the way you want it, and then at the very end, go through and look at  
23 all of the topics and then prioritize.

24 **MS. MEJIA:** Liz, this is Guille. I'm looking at number 2 in terms of the research  
25 for mental health conditions, and you list two exposures, physical and chemical  
26 exposures. And obviously not being a researcher, is there any way to include the --  
27 maybe the visual and audio exposures that were experienced by different populations,  
28 in particular I'm thinking about our, as someone else mentioned earlier, the 911  
29 operators who didn't -- weren't physically at Ground Zero but certainly had to handle  
30 hundreds of calls coming in, and it would be interesting to see the impact that it has on  
31 this population.

32 **DR. WARD:** Yeah, and I think this one probably needs to be rephrased, and I  
33 would love it if somebody -- I mean, if somebody would make a recommendation for a  
34 rephrasing of this one that, you know, better captures the intent. I don't know if, Carol,  
35 you're on and can talk but you might be the best person to do that.

36 **DR. NORTH:** Well, I tried to write something. I'd sent it.

37 **DR. MIDDENDORF:** Yeah, the problem is I can't listen to what everybody is  
38 saying and type that in, and then go back and look at what you're sending back in  
39 emails; it just isn't working very well.

1 **DR. NORTH:** Now that I can talk, would you like me to read it?  
2 **DR. MIDDENDORF:** Yes.  
3 **DR. NORTH:** Okay. I got to find it here. Okay, exposures. That's what we're  
4 talking about, right?  
5 **DR. WARD:** It's number 2, the more research on mental health conditions in  
6 relation to exposure.  
7 **DR. NORTH:** Right. So you can't necessarily assume the exposures for mental  
8 health are the same as those for medical illnesses, so we need research to characterize  
9 disaster-related exposures --  
10 **DR. MIDDENDORF:** Wait, wait. Go slowly. Research to what?  
11 **DR. NORTH:** Characterize disaster-related exposures in relation to specific --  
12 **DR. MIDDENDORF:** Wait, wait, wait. I'm trying to type. I'm not that good a  
13 typist. Research to characterize disaster-related --  
14 **DR. NORTH:** Exposures.  
15 **DR. MIDDENDORF:** Okay.  
16 **DR. NORTH:** In relation to specific psychiatric disorders such as --  
17 **DR. MIDDENDORF:** Whoa, whoa, whoa. Okay.  
18 **DR. NORTH:** PTSD.  
19 **DR. MIDDENDORF:** Say it again, PTSD?  
20 **DR. NORTH:** PTSD, major depressive disorder, recognizing that exposures  
21 may --  
22 **DR. MIDDENDORF:** Wait a minute. Major depressive disorder. Okay.  
23 **DR. NORTH:** Recognizing that exposures may be different for different  
24 psychiatric disorders.  
25 **DR. MIDDENDORF:** Recognizing that exposures may be different?  
26 **DR. NORTH:** For different psychiatric disorders.  
27 **DR. MIDDENDORF:** I missed a for.  
28 **DR. NORTH:** So the bottom line, the knowledge gap is that we don't know how  
29 disaster-related exposures relate to psychopathology.  
30 **DR. ALDRICH:** This is Tom Aldrich. Doesn't that belong under item 6?  
31 **DR. WARD:** Tom, it could but I think the original intent was also to call for  
32 more research on mental health disorders in general, including the -- including the  
33 context of looking at both diagnoses and symptoms.  
34 **DR. ALDRICH:** Yes.  
35 **DR. WARD:** So and there will inherently be some overlap between some of  
36 these. I mean, there's going to be overlap between biomarkers and exposure  
37 assessment, but I think what we want to do is really identify where we see that a gap  
38 exists. And what I was sensing is that there's a gap -- there's a research gap in the  
39 understanding of the impact of the exposure on mental health disorders in general, and

1 then more specifically, there's a need to better characterize exposures in relation to  
2 risk of developing mental health disorders. And so --

3 **DR. ALDRICH:** I agree but I think those are separate topics. And right now in  
4 the document it looks like that whole issue of increased attention to mental health  
5 disorders has been eliminated and just gone down to potential to mental health  
6 disorder exposure or mental health -- exposure --

7 **DR. WARD:** Right.

8 **DR. ALDRICH:** -- as it relates to mental health. There are two separate issues,  
9 and I think the exposure part of it belongs as part of number 6.

10 **DR. NORTH:** Yes.

11 **DR. ALDRICH:** And yes, there will be overlap but that's okay.

12 **DR. NORTH:** And then the research on mental health conditions would include  
13 the point I made about symptoms versus diagnosis.

14 **DR. WARD:** Right, so I guess what we need is a separate -- we need a draft of a  
15 separate point on the mental health conditions research. And then we need to see  
16 how well the point we've already drafted on the exposure assessment for mental  
17 health-related exposures can be captured under exposure assessment.

18 **DR. ALDRICH:** I'd like to make a suggestion about item 1, okay?

19 **DR. WARD:** Okay.

20 **DR. MIDDENDORF:** Well, can we finish up on 2 and 3 -- on -- in the mental  
21 health?

22 **DR. WARD:** Yeah, 'cause I do think what we want to do is when we make the  
23 suggestions, we really want to make it framed as close as possible to how you'd like to  
24 see the sentence written.

25 **DR. ALDRICH:** I have that for item 1.

26 **DR. WARD:** Okay, but we want to finish up on -- I think Paul wants to finish on  
27 item 2 before we move on to item 1. Okay, to finish on item 2, I think we need a  
28 sentence from Carol on mental health research.

29 **DR. MIDDENDORF:** Do you want this to be like item number 3, or do you want  
30 it to be included in number 2?

31 **DR. WARD:** I guess at this point I would make the mental health research  
32 number 2, and then it sounds like the exposure assessment related to mental health is  
33 going to be a sub-bullet under the expanded integrated exposure assessment.

34 **DR. NORTH:** That would be fine.

35 **DR. WARD:** But --

36 **MS. SIDEL:** Can I just ask like why you wouldn't be more specific in 2, and just  
37 say like some of them -- you know, mental health conditions such as cognitive  
38 disorders?

39 **DR. ALDRICH:** I thought the concern about that was that cognitive disorders

1 may be mental health, may not be mental health. I mean, it's all about whether it's,  
2 whether it's a psychological injury or a physical injury.

3 **DR. NORTH:** Yes.

4 **DR. WARD:** That was the concern.

5 **MS. SIDEL:** But then maybe it should be just broken up into its own separate  
6 set, because that is a concern. But the way this is it's like they don't have to look at  
7 cognitive.

8 **DR. ALDRICH:** I was going to suggest that as part of number 1.

9 **DR. WARD:** That's where I was seeing it, and we can see it --

10 **MS. SIDEL:** Okay, that's good.

11 **DR. WARD:** -- more specific. I mean, it sounds like renal disease is another one  
12 that's --

13 **DR. ALDRICH:** Right, so look, under number 1, get rid of the second uncovered,  
14 because that's ambiguous.

15 **MS. SIDEL:** Yes.

16 **DR. ALDRICH:** Then we'll leave that one but the second one. No, leave that  
17 one. Newly emerging uncovered conditions that could be proven or disproven by  
18 research or existing data sources, for example, cognitive disorders, autoimmune  
19 diseases, renal diseases --

20 **DR. MIDDENDORF:** Okay, wait a minute.

21 **MS. SIDEL:** Excellent.

22 **DR. MIDDENDORF:** Such as --

23 **DR. ALDRICH:** Cognitive disorders, autoimmune disorders, renal diseases and I  
24 don't know, want to add in endocrine disorders? I mean, things that haven't been  
25 studied.

26 **DR. WARD:** That sounds good to me.

27 **MS. SIDEL:** That sounds really good.

28 **MS. FLYNN:** This is Kimberly, I'm not sure I can be heard, but --

29 **DR. WARD:** You can be heard.

30 **MS. FLYNN:** Thank you. I'm not entirely sure that these conditions can be  
31 proven or disproven by research on existing data sources. I think there would be, for  
32 some of these addition -- I mean, I know I've been piping up about the need to do  
33 analysis using existing data sources but cognitive disorders, we're not going to prove or  
34 disprove based on existing data sources.

35 **DR. WARD:** Yeah, so I think the current wording, unless it's changed, is  
36 research or existing data sources.

37 **MS. FLYNN:** Yeah, let's go with that.

38 **DR. MIDDENDORF:** Okay, so --

39 **MS. FLYNN:** Analysis or analysis of existing data sources?

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**DR. WARD:** Yeah.

**MS. FLYNN:** And the other thing I just wanted to roll in here, I am not sure of the extent to which Dr. North's excellent point about diagnostic terminology applies to children, number 1, for those who experienced the disaster as children, I guess; and in addition, I would say that there has been a lot of mental health research on children exposed to the disaster. I'm not saying there shouldn't be more. There should be more but the gaps, as Catherine has stated, are largely on: well, let's get this with the most critical gaps or on the physical health end. So maybe using the word adult in the mental health -- in Dr. North's point, you know, which would also cover potentially, young adults, but major depressive disorders, as I understand, it's not something that you would use as a child diagnosis. Please correct me if I'm wrong.

**DR. NORTH:** Sure you would.

**MS. FLYNN:** You would?

**DR. NORTH:** I'm not sure I understand the point. I think that both of my points would pertain to both adults and children.

**MS. FLYNN:** Really? Okay. But there has -- Dr. North, there has been a fair amount of mental health research on the impact of 9/11 to children. So I would obviously defer to your, you know, expert judgment on this but --

**DR. NORTH:** Well my, my points are not about whether there's been mental health research on adults or children.

**MS. FLYNN:** Okay.

**DR. NORTH:** Mine is specifically about the insufficient research on the meaning of exposures and on assessment of full diagnosis as opposed to symptoms.

**MS. FLYNN:** Okay. I, I understand what you're saying. I'm less familiar with the application of these very, very serious diagnoses, like major depressive disorder, to children, but, you know, I defer. And also we're talking about people who are adolescents now so maybe that makes more sense.

**DR. MIDDENDORF:** Okay, I'll give the people with Macs the opportunity to see what we're talking about. I sent out an email with the current wording. It's on the screen so we might want to give them a minute or two to get their email so they can weigh in.

**DR. WARD:** And I think, Paul, one thing that didn't get captured in this version is the objection to proven or disproven, and I would propose that maybe we could say: that should be further investigated or could be further investigated. Because I agree that most of the time we never really prove or disprove things.

**DR. MIDDENDORF:** I was going to bring that up.

**DR. WARD:** But I think other than that, it seems like this bullet is capturing something that we think is important.

**DR. ALDRICH:** I'm the one who suggested proven or disproven, and I think it's

1 being kind of wishy-washy to say it's going to be investigated. I mean, the goal is to  
2 prove or disprove something. We may fall short of that goal but I don't think we should  
3 hesitate to state that goal.

4 **DR. WARD:** What do other committee members think?

5 **DR. NORTH:** I agree.

6 **MS. SIDEL:** Yeah, I don't like being wishy-washy.

7 **DR. WARD:** Okay, so, so are we at the point where we want to go ahead and  
8 make a motion on the final wording for point 1, and then have a vote?

9 **MS. FLYNN:** Can I just --

10 **DR. MIDDENDORF:** Has everyone received their email? I think that's the first  
11 question.

12 **DR. ALDRICH:** Well, and add in endocrine diseases.

13 **MS. FLYNN:** This is Kimberly, what about the word discovered? I just feel that,  
14 you know, we need a little more wiggle room here than absolute proof. I offer that as  
15 an alternative. You may or may not like it.

16 **DR. ALDRICH:** I don't like it because it's -- it suggests that it's there to be found,  
17 and it might not be there to be found. That's why we need to include the possibility  
18 that we're going to find something in the negative.

19 **MS. MEJIA:** This is Guille, in terms of item number 1, I just want to make sure  
20 that what I had raised earlier in terms of ensuring that the non-covered conditions that  
21 are being reported by the participants in the health program are also captured in this as  
22 part of the emerging conditions?

23 **MS. FLYNN:** Yes, that's good.

24 **DR. WARD:** All right, so it should read newly emerging non-covered conditions.

25 **DR. MIDDENDORF:** Well, I was --

26 **MS. MEJIA:** But are reported by people in the program. That's the really  
27 important part 'cause it gives it credence.

28 **DR. MIDDENDORF:** Just tell me what words you want and where you want  
29 them.

30 **DR. ALDRICH:** Tom Aldrich again. I have a problem with that because the fact  
31 that people are reporting something doesn't mean it's World Trade Center-related, and  
32 to phrase it that way suggests that it is.

33 **MS. FLYNN:** I agree.

34 **DR. ALDRICH:** I mean, our purpose here is science so we should -- we  
35 shouldn't -- we should be critical.

36 **MS. SIDEL:** Okay, what about brought to the attention as, you know, as  
37 potentially World Trade Center-related?

38 **DR. ALDRICH:** I'd have to see how you phrase it.

39 **MS. SIDEL:** Okay, I have to -- I have to write it for a minute.

1                   **DR. WARD:** Well, I mean, maybe we should back it up a little bit and say  
2 something like investigate whether World Trade Center-exposed populations have an  
3 increased prevalence of conditions not previously recognized covered by the World  
4 Trade Center Health Program. Have an increased -- because I think that's really the  
5 sense, is that we want to know if, you know, by focusing on the things that emerged as  
6 World Trade Center-related conditions early in the course of studying what might occur  
7 in the population, we might be missing things -- diseases or conditions that have a  
8 longer latency. We could say investigate whether there are newly emerging conditions  
9 among World Trade Center-exposed populations.

10                   **MS. SIDEL:** I think that works and that's really what we're trying to do is  
11 investigate, and say, you know, just the word of and, you know, make the list of  
12 autoimmune disorders, cognitive disorders, renal diseases.

13                   **DR. WARD:** And it could be that that list is really including some conditions  
14 that have been raised as concerns but not adequately investigated.

15                   **MS. FLYNN:** Yeah.

16                   **MS. SIDEL:** Well, investigated by the World Trade Center because (multiple  
17 speakers) have them say that it's World Trade Center-related.

18                   **DR. WARD:** (Indiscernible) adequate -- you know, have not been fully  
19 investigated in World Trade Center-exposed populations?

20                   **THE COURT REPORTER:** Excuse me, was that Ms. Sidel speaking?

21                   **MS. SIDEL:** Yes.

22                   **DR. WARD:** And then it was Liz.

23                   **THE COURT REPORTER:** Right, yeah.

24                   **DR. MARKOWITZ:** This is Steve Markowitz. I actually don't think we should  
25 provide examples of conditions. I think the general category of newly emerging  
26 conditions would be sufficient. I don't know -- I mean, I think the hunches on these  
27 named conditions are hunches, and I don't -- to mention them seems like we're  
28 endorsing them as areas that need study more than other conditions that we haven't  
29 named. And I don't think that the researchers or that NIOSH need these examples.

30                   **MS. SIDEL:** Okay, the point of it was, though, that there are certain conditions  
31 that have been brought to our attention this morning, like Dr. Melius brought up  
32 autoimmune disorders. I think the fire department complained about autoimmune  
33 disorders. The woman that wrote the letter about her cognitive issues. So those are  
34 two specific areas that were thought of that, you know, I certainly would like to see  
35 them researched to see if they are in fact related to the World Trade Center. The rest  
36 (indiscernible) explore, you know, research cognitive, you know, problems and  
37 cognitive issues and autoimmune diseases and renal as possible World Trade  
38 Center-related.

39                   **DR. WARD:** This is Liz. I think maybe what we could do that might, and this

1 makes sense to me, is in this bullet really capture the broad theme of: make sure we're  
2 conducting research and surveillance to capture any newly emerging diseases, but then  
3 where we really as a committee feel that there needs to be more research, like if  
4 there's a specific area, like autoimmune diseases and immune system dysfunction, we  
5 could call that out as a separate bullet point or a separate point, but after due  
6 consideration that we really do think that particular area is more important than a  
7 variety of other areas that we could also highlight. 'Cause I do agree with Steve's point,  
8 that if we just make this look based on things that really have been mentioned during  
9 this call without kind of, you know, a more reasoned rationale for why we're  
10 mentioning these and not others, it's not really very helpful in setting the research  
11 direction.

12 **MS. FLYNN:** Yes, I agree.

13 **MS. SIDEL:** I agree.

14 **DR. WARD:** So, Steve, would you like to make a motion with final wording of  
15 this bullet number 1?

16 **DR. MARKOWITZ:** Well, the -- so Paul just sent around number 6.

17 **DR. WARD:** Okay. I haven't seen it.

18 **DR. MARKOWITZ:** Number 6.

19 **DR. MIDDENDORF:** Yeah, and it shows the two alternatives. One and two are  
20 the two versions that -- I guess the originating version, and then the one that it  
21 morphed into.

22 **MS. SIDEL:** Yeah, I would take out -- I would definitely take out cognitive  
23 disorders, autoimmune disorders, renal diseases. I would definitely undo number 1,  
24 because it's, you know, we don't have the research on those things because if we did  
25 have the research it wouldn't be an issue now. But it's an issue because it's affecting  
26 people, and there's no World Trade Center research on it.

27 **DR. MARKOWITZ:** Yeah, so that's -- this is Steve Markowitz. The number 1, if  
28 you just take out the examples, number 1 probably captures better what we mean.  
29 Uncovered -- you might want to specify that, you know, conditions that are currently  
30 not covered by the WTC program. And investigated by research or analysis, well,  
31 actually that's not either/or.

32 **DR. MIDDENDORF:** Are you suggesting an and, slash or?

33 **DR. ALDRICH:** Why not just go with number 2, adding the word uncovered  
34 before conditions? And leaving out everything after populations?

35 **DR. MARKOWITZ:** Yeah, that's fine.

36 **DR. MIDDENDORF:** Emerging conditions.

37 **DR. ALDRICH:** Uncovered conditions.

38 **DR. MIDDENDORF:** Well, one of the suggestions was to use the term not  
39 covered by the WTCHP.

1 **DR. MARKOWITZ:** That's better.

2 **DR. MIDDENDORF:** Okay. And what else goes away, just after populations?

3 **DR. MARKOWITZ:** Right, yeah.

4 **DR. MIDDENDORF:** Investigate -- so it would read: Investigate whether there  
5 are newly emerging conditions not covered by the WTCHP among WTC population.

6 **DR. ALDRICH:** I like it. It's vague, it's broad, that's good.

7 **DR. MIDDENDORF:** I want to send this out to everybody so they know exactly  
8 what it is. Is this the motion you're making? Is this the motion?

9 **DR. MARKOWITZ:** Sure, yes. This is Steve Markowitz. Yes, I'd make that  
10 motion.

11 **DR. ALDRICH:** Okay, this is Tom Aldrich, I second.

12 **DR. MIDDENDORF:** All right.

13 **DR. WARD:** And we have to vote.

14 **DR. MIDDENDORF:** I'm going to send it out to everybody so they can see  
15 exactly what it says. This is number 7 coming your way. I'm just going to point out that  
16 we have about two and a half hours left, and that includes time for a little break, here,  
17 fairly soon.

18 **DR. WARD:** Well, hopefully we're shaking out the process a little bit so we'll be  
19 faster on the others, hopefully. So let's see, everybody has 7.

20 **DR. MIDDENDORF:** Yeah, well, that's the question. Is there someone who has  
21 not received number 7 yet?

22 **MS. SIDEL:** I received it. Number 1 is so vague that like what are we -- what  
23 are we really saying? We're not saying anything, kind of. I mean --

24 **DR. MARKOWITZ:** No, actually -- this is Steve Markowitz -- I would disagree,  
25 actually, because if NIOSH were to set this as a research area and, you know, it would  
26 invite proposals that are going to have to plausibly address certain emerging conditions  
27 by way of methods or --

28 **MS. SIDEL:** Right, but the problem that we have with our proposal, and this is  
29 what I was talking about earlier, like for example with something like autoimmune  
30 disease, it's highly unlikely that any of the people that do these World Trade Center  
31 research projects is going to tackle autoimmune diseases because they're not, they're  
32 not rheumatologists. So that's why --

33 **DR. MARKOWITZ:** No, no, that's --

34 **DR. WARD:** I think we have -- we still have the options of calling out certain  
35 disease characters or certain diseases or groupings of diseases in another priority.

36 **DR. ALDRICH:** It's also -- it's just not true that they exist -- groups are not  
37 studying those things because they don't have expertise. There is an ongoing study of  
38 autoimmune disease in the FDNY cohort, and it's being run by epidemiologists with  
39 consultation from rheumatologists. And they are doing a really fine job.

1                   **MS. SIDEL:** I would -- okay, well, that's good. I'm really glad to hear that but I  
2 just meant like -- and you know, I'm not in the FDNY program; I'm in the, you know, the  
3 responder program, so I just know that people that have been really frustrated because  
4 they have had problems that are very likely World Trade Center-related, that they  
5 haven't been able to either get treated for it or even get a referral for it because it's not  
6 part of the program. And, you know, my thought is that the reason that some of these  
7 things aren't part of the program is because it's above the first level of (indiscernible).  
8 It's not necessarily their area of expertise.

9                   **DR. ALDRICH:** But my point is but the system, the system has worked. The  
10 prior -- the prior request for proposals was adequate to elicit that proposal even  
11 though there were no rheumatologists on any of the research staffs. And so this type  
12 of process is working.

13                   **MS. SIDEL:** Okay, but people --

14                   **DR. WARD:** Okay. I think we have a motion.

15                   **DR. MIDDENDORF:** Okay, first off, I need to ask, Julia, can you be heard now?  
16 Julia's been trying to say something and hasn't been able to get through.

17                   **DR. WARD:** I mean, I would say that we should call for a vote on this motion  
18 'cause I think we've heard a lot of the perspectives that we were expressing before, and  
19 it's really a question of whether the -- you know, this is -- I don't think further  
20 discussion is necessarily going to be productive. I think it's really a question of whether  
21 the majority of -- or you know, the committee, how the committee as a whole feels  
22 about this. I guess if we get a really divided vote, then we could have more discussion.  
23 But if there's, if there's (indiscernible) on it, we may need to -- we should move on to  
24 other points that may be equally or more important.

25                   **DR. MIDDENDORF:** Yeah, before we have a vote, though, I need to make sure  
26 that everybody has had a chance to be heard.

27                   **DR. WARD:** Right, right.

28                   **DR. MIDDENDORF:** And Julia is not into the meeting as yet. I'm assuming she  
29 can hear but she can't be heard.

30                   **DR. WARD:** Right.

31                   **DR. TRASANDE:** Paul, this is Leo. I'm just confirming I received 7.

32                   **DR. MIDDENDORF:** Okay, great. Is there anybody who has not received  
33 number 7?

34                   **DR. QUINT:** I've received 7 but I can't be -- can you hear me?

35                   **DR. MIDDENDORF:** Yes.

36                   **DR. QUINT:** Oh, can you hear me now?

37                   **DR. MIDDENDORF:** Yeah.

38                   **DR. QUINT:** Okay, it's Julia.

39                   **DR. MIDDENDORF:** Okay, great.

1                   **DR. QUINT:** The question I have is whether or not the uncovered conditions or  
2 the newly emerging conditions are being systematically captured. All I heard was that,  
3 you know, just discuss -- some things were discussed at meetings but I haven't -- is  
4 there a method now for capturing these uncovered conditions? Otherwise, you know,  
5 there's no -- what are we investigating?

6                   **DR. MARKOWITZ:** This is Steve Markowitz. You know, one of the ideas -- the  
7 proposal for a priority area that Dr. Melius made was to improve the surveillance -- the  
8 performance of the current -- the systems, the Registry and the Health Program. So I  
9 think that would, if done properly, that would address that issue. If there were more  
10 sensitive surveillance, then the signals from the populations would be appropriately  
11 detected, and that would provide some data for newly emerging conditions, which  
12 ones, which ones to pick.

13                   **DR. QUINT:** I agree, and so maybe we should add systematically document and  
14 investigate, because, you know, it's not clear that the surveillance systems are working  
15 adequately now, so the investigate newly emerging diseases doesn't have much  
16 meaning. And there's not a good feed in the system for that.

17                   **DR. WARD:** I think yes and no. I think the original intent was both to capture  
18 the opportunity of surveillance and the opportunity of research. So for example, you  
19 may not approach -- you may approach this in a surveillance way or you may actually  
20 propose to do a study looking at biomarkers that would reflect some newly emerging  
21 condition that you hypothesize for other reasons. So I, I think the -- what we want to  
22 do is -- I mean, to me the key -- the essence is the question of whether there are newly  
23 emerging conditions, and we don't necessarily need to be more specific about it being  
24 surveillance or other types of research.

25                   **DR. QUINT:** Okay.

26                   **DR. ALDRICH:** I agree with that. I think that if we make it too specific, that  
27 leaves out some innovative proposal that somebody's been thinking about, and if it  
28 doesn't happen to include surveillance, they will think they won't be able to get funded  
29 through this mechanism.

30                   **DR. QUINT:** Well, I guess I was concerned about how they identify them as  
31 emerging. What's the, what's the source of -- you know, anybody can say something is  
32 emerging but, you know, what is the source of that information? But okay, I won't  
33 pursue that.

34                   **DR. MARKOWITZ:** This is Steve Markowitz. I think that's a really good point,  
35 but I do think it's -- if there's a -- somewhere we're going to get to another  
36 recommendation about surveill -- improved surveillance.

37                   **DR. QUINT:** Oh, okay.

38                   **DR. MARKOWITZ:** And I think that would be -- that would answer, at least  
39 partly answer, that, you know, detection of emergents.

1 **DR. QUINT:** Okay. Great, thanks.

2 **DR. TRASANDE:** This is Leo. Can I ask a clarifying question, because I cut in and  
3 out for the past 45 minutes.

4 **DR. MIDDENDORF:** Please do.

5 **DR. TRASANDE:** Numbers 1 through 7 in various emails you sent, I assume  
6 number 7 is the -- is what we're debating now, and the other six have been voted on?

7 **DR. WARD:** No. We still need to vote on the others.

8 **DR. MIDDENDORF:** Wishful, wishful thinking, Leo.

9 **DR. TRASANDE:** Okay.

10 **DR. MIDDENDORF:** This will be the first vote we take.

11 **DR. TRASANDE:** Okay. Thank you.

12 **DR. MIDDENDORF:** The other emails were just trying to develop thoughts and  
13 ideas. And because there are numerous people who cannot see the, the web, because  
14 they have Macs and it's just not working, for them I'm just sending it out in an email so  
15 people can see exactly what the wording is, and also to try to keep them up to speed  
16 with summarizing the information that has been discussed. So, Liz?

17 **DR. WARD:** Yes.

18 **DR. MIDDENDORF:** Did you want to call for the vote? I think we had a motion  
19 and a second.

20 **DR. WARD:** Well, I mean, you know, I did -- I was prefacing the point that they  
21 may not be newly emerging but I think NIOSH probably will get the, the sense of what  
22 we're talking about. They don't necessarily have to be newly emerging. They could be,  
23 you know, just previously unrecognized or --

24 **MS. SIDEL:** That's a good way to put it.

25 **DR. NORTH:** Yeah.

26 **MS. SIDEL:** That would be more accurate because a lot of things, you know,  
27 has been around forever but it's just that nobody was talking about it or recognizing it  
28 or getting treated for it.

29 **DR. WARD:** All right, (indiscernible) unrecognized conditions associated with  
30 World Trade Center exposures that are not covered by --

31 (Interference)

32 **DR. WARD:** Okay, somebody's not muted and we're hearing their background  
33 noise. Hello? Okay.

34 **DR. MIDDENDORF:** So you're changing the motion; is that --

35 **DR. MARKOWITZ:** Yeah.

36 **DR. MIDDENDORF:** Okay. It was either Steve or Tom that --

37 **DR. MARKOWITZ:** That friendly amendment is accepted by the proposer.

38 **DR. MIDDENDORF:** Okay, so how does it read?

39 **DR. MARKOWITZ:** Can someone read it?

1                   **DR. WARD:** Investigate (indiscernible) that are previously unrecognized  
2 conditions associated with World Trade Center exposures but are not -- that are not  
3 listed as covered conditions.

4                   **DR. MARKOWITZ:** Yeah, they're not currently identified --

5                   **DR. NORTH:** Currently.

6                   **DR. MARKOWITZ:** -- identified as WTC-covered conditions.

7                   **DR. WARD:** Yeah.

8                   **DR. ALDRICH:** Could you make it previously unrecognized or newly emerging?

9                   **DR. QUINT:** You don't have to have newly emerging.

10                  **DR. MIDDENDORF:** Okay, so I didn't catch, quite, the tail end of the --

11                  **DR. WARD:** Steve, you're the original motion proposer, so why don't you  
12 propose the final language?

13                  **DR. MARKOWITZ:** Let's see, working still off what Paul sent as number 7,  
14 right?

15                  **DR. MIDDENDORF:** Yes.

16                  **DR. WARD:** Right --

17                  **DR. MARKOWITZ:** Okay, so --

18                  **DR. WARD:** So I think the part that's not that we're -- somebody proposed  
19 adding -- we were -- I think we were at investigating whether there are previously  
20 unrecognized conditions not currently --

21                  **DR. MARKOWITZ:** Right, right, okay. Set up an investigation --

22                  **DR. WARD:** But then someone else said, maybe we should say, and newly  
23 emerging, and somebody else said we don't need it. So I'm giving you the final call.

24                  **DR. MARKOWITZ:** So why don't we say: Investigate whether there are newly  
25 emerging or previously unrecognized conditions, health conditions, that are not  
26 covered by the WTCHP among WTC populations?

27                  **MS. SIDEL:** I think that's good.

28                  **DR. MIDDENDORF:** I need to hear it again. Investigate --

29                  **DR. MARKOWITZ:** Whether there are newly emerging conditions or previously  
30 unrecognized conditions.

31                  **DR. MIDDENDORF:** Okay, at one point -- last time you said health conditions.

32                  **DR. MARKOWITZ:** Yeah, I'm sorry, health conditions, that's right.

33                  **DR. MIDDENDORF:** Okay.

34                  **DR. MARKOWITZ:** Yeah. That are not covered by WTCHP among WTC  
35 populations.

36                  **DR. MIDDENDORF:** Okay. There was also a term -- somebody at one point  
37 suggested adding: previously unrecognized health conditions associated with WTC  
38 exposures not covered by the WTCHP among WTC populations.

39                  **DR. MARKOWITZ:** No, I think that's just -- that just obfuscates it.

1                   **DR. MIDDENDORF:** Okay, you want to take out associated with WTC  
2 exposures.  
3                   **DR. WARD:** I'm fine with that. I suggested it and I'm fine with taking it out.  
4                   **DR. MIDDENDORF:** Okay. So here's, here's what I have: Investigate whether  
5 there are newly emerging health conditions or previously unrecognized health  
6 conditions not covered by the WTCHP among WTC populations.  
7 I'm going to send this out in an email for those -- this will be number 8.  
8                   **MS. SIDEL:** Poor Paul.  
9                   **DR. WARD:** Poor us because we still have -- this is still on number 1.  
10                  **DR. MIDDENDORF:** Yeah.  
11                  **DR. ALDRICH:** You guys are doing great. Hang in there.  
12                  **DR. MIDDENDORF:** Has anybody received number 8 yet?  
13                  **DR. WARD:** I have not.  
14                  **DR. MIDDENDORF:** Okay.  
15                  **DR. QUINT:** Are your electronics frozen out east?  
16                  **DR. MIDDENDORF:** We're in a nice spot here in Atlanta, so I don't think that's  
17 our problem. I am going to resend 8.  
18                  **UNIDENTIFIED SPEAKER:** I just got it, Paul.  
19                  **DR. MIDDENDORF:** Has everyone received it?  
20                  **MS. FLYNN:** Not quite yet. This is Kimberly. I haven't received it but I've heard  
21 the language, and I think we should move forward on it.  
22                  **DR. MIDDENDORF:** Is there anyone who feels like they want to wait until they  
23 have the email?  
24                  **DR. TRASANDE:** I suggest we vote.  
25                  **DR. MIDDENDORF:** Okay, Liz?  
26                  **DR. WARD:** I think we should vote. So Paul, are you going to do the roll call  
27 vote?  
28                  **DR. MIDDENDORF:** Yes, I will.  
29                  **DR. WARD:** Okay.  
30                  **DR. MIDDENDORF:** Okay. Tom Aldrich? You can vote yes, no or abstain.  
31                  **DR. ALDRICH:** I vote yes.  
32                  **DR. MIDDENDORF:** Okay, John Dement. (pause) Okay, I'm going to pass on  
33 John at the moment.  
34                  **DR. DEMENT:** Hello?  
35                  **DR. MIDDENDORF:** Hello, John?  
36                  **DR. DEMENT:** Yes. I voted yes.  
37                  **DR. MIDDENDORF:** Oh, okay. We just couldn't hear you. Kimberly Flynn.  
38                  **MS. FLYNN:** Yes.  
39                  **DR. MIDDENDORF:** Bob Harrison.

1 **DR. HARRISON:** Yes.

2 **DR. MIDDENDORF:** Catherine Hughes.

3 **MS. HUGHES:** Yes.

4 **DR. MIDDENDORF:** Steve Markowitz?

5 **DR. MARKOWITZ:** Yes.

6 **DR. MIDDENDORF:** Guille?

7 **MS. MEJIA:** Yes.

8 **DR. MIDDENDORF:** Carol.

9 **DR. NORTH:** Yes.

10 **DR. MIDDENDORF:** Julia.

11 **DR. QUINT:** Yes.

12 **DR. MIDDENDORF:** Bill.

13 **DR. ROM:** Yes.

14 **DR. MIDDENDORF:** Susan. Susan?

15 **MS. SIDEL:** Yes, sorry.

16 **DR. MIDDENDORF:** Okay. Glenn?

17 **DR. TALASKA:** Yes.

18 **DR. MIDDENDORF:** Leo?

19 **DR. TRASANDE:** Yes.

20 **DR. MIDDENDORF:** Liz?

21 **DR. WARD:** Yes.

22 **DR. MIDDENDORF:** And I don't think Virginia's with us anymore. Okay one,

23 two, three, four, five, six, seven, eight, nine, ten, 11, 12, 13, 14 yeses. Zero noes, zero

24 abstain. Okay. Motion passes.

25 **DR. WARD:** So I would propose that the next one we talk about is mental

26 health research, and hopefully we have some suggested new language on that from

27 Dr. North that we can -- that Paul can email?

28 **DR. MIDDENDORF:** Okay, well, do you want to take a quick break or do you

29 want me to help out if we get the wording and I'll email it out, and then we'll take a

30 short break?

31 **DR. NORTH:** Good.

32 **DR. MIDDENDORF:** Yeah, we're set up for a break at 2:30; it's already after

33 2:30. Does that sound like a good plan, Liz?

34 **DR. WARD:** That sounds fine.

35 **DR. MIDDENDORF:** Okay. So we'll try to hammer out the language. Carol, do

36 you have some suggestions?

37 **DR. NORTH:** I would probably -- thought was what I sent you before. Is that

38 what we're on? I'm lost as to which document we're on.

39 **DR. WARD:** Okay, we're on -- I went back to the version 5 that Paul previously

1 sent.

2 **DR. NORTH:** Okay.

3 **DR. WARD:** Where we have the list of all the general suggested topics. And I  
4 was going to try to consider them in order. So if anybody has time during the break to  
5 look at any of them and suggest -- some of them -- clearly several of them need word-  
6 smithing. So if anyone wants to send any suggestions to Paul, they should.

7 **DR. MIDDENDORF:** I would prefer that they not email anything to me. I think  
8 that the suggestions need to be made verbally.

9 **DR. WARD:** Okay. Okay. So write them down so that you can read them off  
10 when we're back on the phone.

11 Okay, so we'll go ahead and take a ten-minute break.

12 **DR. MIDDENDORF:** Okay, and Carol is going to be thinking about wording for  
13 the mental health.

14 **DR. NORTH:** I'm working on it.

15 **DR. MIDDENDORF:** Okay, great. So what time are we returning?

16 **DR. WARD:** My clock says now 2:38, so I guess at 2:58, which is -- no, that's 20  
17 minutes.

18 **DR. MIDDENDORF:** Yeah, just do it 2:48?

19 **DR. WARD:** Yeah, so yeah.

20 **DR. MIDDENDORF:** Okay, 2:50.

21 **DR. WARD:** Okay. Thanks.

22 (Recess in proceedings, 2:38 until 2:50 p.m.)  
23

24 **DR. MIDDENDORF:** Let's begin. I've got 2:50, and we have just a little over  
25 two hours left. Tom Aldrich, are you there?

26 **DR. ALDRICH:** Yes.

27 **DR. MIDDENDORF:** Okay. John Dement?

28 **DR. DEMENT:** Yes.

29 **DR. MIDDENDORF:** Kimberly Flynn?

30 **MS. FLYNN:** Yes.

31 **DR. MIDDENDORF:** Bob Harrison?

32 **DR. HARRISON:** Yes.

33 **DR. MIDDENDORF:** Catherine Hughes?

34 **MS. HUGHES:** Yes.

35 **DR. MIDDENDORF:** Steve Markowitz?

36 **DR. MARKOWITZ:** Yes.

37 **DR. MIDDENDORF:** Guille Mejia?

38 **MS. MEJIA:** Present.

39 **DR. MIDDENDORF:** Carol North?

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**DR. NORTH:** Yes.

**DR. MIDDENDORF:** Julia Quint?

**DR. QUINT:** Yes.

**DR. MIDDENDORF:** Bill Rom? (pause) Come back to Bill. Susan Sidel?

**MS. SIDEL:** Here.

**DR. MIDDENDORF:** Glenn Talaska?

**DR. TALASKA:** Present.

**DR. MIDDENDORF:** Leo Trasande?

**DR. TRASANDE:** Yes.

**DR. MIDDENDORF:** Liz Ward?

**DR. WARD:** Here.

**DR. MIDDENDORF:** And Virginia is gone, so one, two, three, four... We have 13, and Bill, are you there? Okay. Well, we have 13, and so we have a quorum; we can continue on.

**DISCUSSION OF RESEARCH NEEDS AND DEVELOPMENT OF  
RECOMMENDATIONS (continued)**

**DR. WARD:** Okay. So Carol, did you have a proposed wording for item number 2?

**DR. NORTH:** I'm ready. That's an (a) and a (b); (a) relates to exposure. Characterize the disaster-related exposures that are associated with the development of specific psychiatric disorders. You want me to proceed to (b)?

**DR. WARD:** I think it would be good to do that.

**DR. NORTH:** (b) is diagnosis. Differentiate psychiatric disorders from symptoms and distress in relation to disaster exposures, comma.

**DR. MIDDENDORF:** Okay, wait a minute. I got a little slow there. Differentiate psychiatric disorders...

**DR. NORTH:** From symptoms and distress in relation to disaster exposure, comma, and develop efficient and effective methods --

**DR. MIDDENDORF:** I'm sorry, develop what?

**DR. NORTH:** Efficient and effective methods for diagnosis of disaster-related psychopathology in populations and individuals.

**DR. MIDDENDORF:** Okay. Do you want that as one motion or do you want these as separate motions?

**DR. NORTH:** I don't care.

**DR. WARD:** I think one thing we could do is we could combine -- I mean, we could have them as one motion and just have a, you know, a subhead such as research on mental health -- World Trade Center-related mental health disorders, and then we could have the two items included in that. And once anyone has -- I

1 think it would be better to combine it into one research area unless someone has a  
2 strong objection to doing that.

3 **DR. NORTH:** I separated them simply because they were -- responded to  
4 two different separate areas in the tasks that we were given in the original letter.

5 **DR. WARD:** Which -- what were the areas, then? The -- accurate diagnosis  
6 was -- okay --

7 **DR. NORTH:** The first was identify gaps on understanding the effects of  
8 exposure, and the second -- these are the charges. The second was, I guess, relative  
9 to accurate diagnosis.

10 **DR. WARD:** Okay. Very good point. So let's do that, then. Let's include the  
11 -- only the one on item 1, and the voting and listing now, and then when we move  
12 on to Dr. Howard's item 2, we can include the other one.

13 **DR. NORTH:** All right. Then I might mention that I didn't include anything  
14 on treatment because I didn't have strong feelings about it but other members may  
15 have some.

16 **DR. WARD:** Right. No, we haven't even started on two yet. And you're  
17 right, it probably better belong there.

18 Okay, so let's wrap up on the mental health research items for this list.  
19 Paul, do you want to read it over one more time?

20 **DR. MIDDENDORF:** Sure. What I have now is: Characterize the  
21 disaster-related exposures that are associated with the development of specific  
22 psychiatric disorders.

23 **DR. WARD:** My opinion would be that it might be better to keep that as a  
24 separate priority than to subsume it under exposure assessment, because it really is  
25 kind of a very unique observation that Carol is making, and she's also kind of saying  
26 that you may need to do a different exposure assessment, look at different  
27 psychiatric disorders, which it seems to me that that's enough of a unique concept  
28 to stand on its own as a research priority.

29 **MS. SIDEL:** Could I ask a question? This is Susan. I don't know really  
30 understand this because, because they think it's better -- I mean, we're asking them  
31 to look at other things. But they don't see that there's a reason to look at other  
32 things. And so I don't understand how this would change that.

33 **DR. WARD:** Well, this is a separate research priority. It's completely  
34 different from what we just discussed under item 1.

35 **MS. SIDEL:** Yeah, I know. I mean, I know that but it came out of the whole  
36 thing of cognitive, you know, dealing with cognitive issues.

37 **DR. WARD:** No, it didn't. I think it came out of -- I mean, I think I created -- I  
38 said that maybe they were interrelated but I think this is a -- this is a separate point  
39 that Dr. North was raising as a research priority.

1                   **DR. NORTH:** Yeah, certainly I didn't intend it for cognitive issues; I intended  
2 it for psychiatric illness.

3                   **MS. SIDEL:** Okay. All right. Then, then I, I just -- I just didn't understand it.  
4 'Cause we were talking about the cognitive thing. And I thought that that's what --

5                   **DR. NORTH:** No, I thought it diverged from that.

6                   **MS. SIDEL:** I'm sorry; I couldn't understand you. What?

7                   **DR. NORTH:** I diverged from that.

8                   **MS. SIDEL:** Oh, I see, okay. So where is that going to go?

9                   **DR. NORTH:** Either under exposures related to mental health or under  
10 mental health related to exposures.

11                   **MS. SIDEL:** So is it gonna be -- would that be part of 2?

12                   **DR. NORTH:** It could be.

13                   **MS. SIDEL:** Wait. I think it should be separate, then, because I think that  
14 the problem is that it's not being recognized, and so it's gonna have to be spelled  
15 out. Not as in, like somewhat -- something's gonna, you know -- if you're not  
16 schooled in that, it has to be pointed out.

17                   **DR. NORTH:** So I'm not sure I understand the question. Where are you  
18 suggesting we put it? Hello?

19                   **MS. SIDEL:** I think it should be separate.

20                   **DR. NORTH:** Okay. Other number?

21                   **MS. SIDEL:** It should be -- it should be raised as an issue. I mean, the issue  
22 was that they're not looking at cognitive issues that are not caused by PTSD; they  
23 were actually caused because something happened to your brain as a result of being  
24 exposed to toxins. That would -- I thought that the cognitive -- the woman that  
25 spoke today, that's what she was talking about, and I thought that we would be  
26 addressing that, that issue.

27                   **DR. NORTH:** Well, it's probably going to be more relevant to certain  
28 medical conditions. My point earlier was there are different kinds of exposures that  
29 would be pertinent to mental health conditions.

30                   **DR. WARD:** Can I say -- I mean, my suggestion would be that Dr. North  
31 make the motion -- at this point I don't think we can continue to -- I mean, I think  
32 we have to take these one by one, agree that they are a research priority, and then  
33 move on to the next research priority. Because otherwise we're not going to get  
34 past the first item in the agenda. So I think if Dr. North wants to make that as a  
35 motion, and then we have a second, then we could -- the committee could vote on  
36 it as whether we see it overall as a research priority, not necessarily ranking it as the  
37 most important but that it is one of the research priorities that this committee  
38 recommends as a critical gap in knowledge.

39                   **MS. SIDEL:** So you're basically saying that we're going to have like a laundry

1 list of things that are possible things that should be looked into, you know.

2 **DR. WARD:** Well, I don't think it's going to be a laundry list, 'cause I think  
3 we already have -- I mean, we're going back to version number 6 that Paul sent  
4 around, which has somewhere between six and seven teams. Now, the cognitive,  
5 cognitive health effects, I think, was originally subsumed as an example under bullet  
6 1, which we've already voted on, with taking out the bullets.

7 So I guess we still will need to discuss -- it's clear that Dr. North does not feel  
8 that cognitive issues belongs in the same priority area as the mental health  
9 research.

10 **DR. NORTH:** It might sometimes.

11 **MS. SIDEL:** But what mental health are they doing right now? I just don't  
12 understand it.

13 **DR. WARD:** It might sometimes but it might not sometimes so Carol, you  
14 have to decide if you want it in -- write a broader bullet that includes the cognitive  
15 research or, if not, then we have to handle the cognitive research as a separate  
16 bullet.

17 I don't know how many committee members feel strongly that that belongs  
18 on the list but I think we are going to need to take specific proposals for research  
19 gap areas one by one, but recognize that, you know, I was assuming that we were  
20 down to six or seven, that we were word-smithing.

21 **DR. NORTH:** We can't subsume all cognitive disorders in psychiatric  
22 disorders.

23 **DR. WARD:** We can't but we could -- I mean, if we wanted to --

24 **MS. SIDEL:** She's talking about a very specific thing. She's talking people  
25 that are actually found of having been exposed to toxins, that they're having  
26 cognitive issues.

27 **DR. WARD:** Because one person on a -- because one person in the public  
28 has testimony suggested that it's a research priority does not mean that the  
29 committee, as a whole, is going to --

30 **MS. SIDEL:** Okay, I --

31 **DR. WARD:** -- request it as a research priority. So I don't know how we get  
32 to the point where we have a substantive discussion on that but I do recognize that  
33 that was what the public -- the participant from the public was advocating for. I just  
34 --

35 **MS. SIDEL:** Right. I don't think it's just one person. I know a lot of people  
36 that have those issues. And I think it's very common and I think that usually people  
37 are told that it's part of post-traumatic stress disorder, and maybe it's not. And then  
38 it just doesn't get treated.

39 **DR. NORTH:** This is Carol, can I --

1                   **MS. SIDEL:** It's a cognitive issue.

2                   **DR. NORTH:** Can I respond to that? I'm thinking of psychiatric disorders in  
3 terms of exposure to trauma. I think that cognitive disorders in relation to exposure  
4 to toxins is a different set of conditions.

5                   **MS. SIDEL:** Right. I think that's what she's talking about, is as associated to  
6 toxins, not as being exposed to trauma.

7                   **DR. NORTH:** Right. That would not relate to my point.

8                   **MS. SIDEL:** -- and you know, she's probably had a neuropsych test. I know a  
9 lot of people that have had neuropsych tests. I know the NYPD does them. And,  
10 you know, the results are that people are damaged. They don't have the same  
11 brains that they went in -- that they went into, you know, they went to the World  
12 Trade Center with.

13                   **DR. NORTH:** Right. I don't conceptualize that as part of the psychiatric  
14 disorders I'm talking about.

15                   **DR. WARD:** Right, so what I'm saying is let's start on -- let's let Carol make a  
16 motion on the ones she's talking about, and maybe Carol can help us phrase one  
17 that Susan's talking about in more -- you know, in the appropriate technical  
18 language. And then we can take a vote on whether the committee feels that that --  
19 that it wants to recommend that as a research gap of priority.

20                   **DR. NORTH:** I'll be glad to help with that.

21                   **DR. WARD:** Okay.

22                   **DR. NORTH:** May I move that we vote on, I guess, acceptance of number 9  
23 as it is worded? Do I need to repeat it?

24                   **DR. MIDDENDORF:** Okay, it's actually motion number 2, and the wording I  
25 have is: Characterize the disaster-related exposures that are associated with the  
26 development of specific psychiatric disorders.

27                   **DR. NORTH:** That's it. Thank you.

28                   **DR. WARD:** Do I have a second?

29                   **MS. MEJIA:** Second. This is Guille.

30                   **DR. WARD:** So let's call for a vote.

31                   **DR. MIDDENDORF:** Okay. Tom Aldrich on motion number 2?

32                   **DR. ALDRICH:** Vote yes.

33                   **DR. MIDDENDORF:** John Dement?

34                   **DR. DEMENT:** Yes.

35                   **DR. MIDDENDORF:** Kimberly Flynn?

36                   **MS. FLYNN:** Yes.

37                   **DR. MIDDENDORF:** Bob Harrison? Bob, did you say something? I'll come  
38 back to you, Bob. Catherine Hughes?

39                   **MS. HUGHES:** Yes.

1 **DR. MIDDENDORF:** Steve Markowitz?  
2 **DR. MARKOWITZ:** Yes.  
3 **DR. MIDDENDORF:** Guille Mejia?  
4 **MS. MEJIA:** Yes.  
5 **DR. MIDDENDORF:** Carol North?  
6 **DR. NORTH:** Yes.  
7 **DR. MIDDENDORF:** Julia Quint?  
8 **DR. QUINT:** Yes.  
9 **DR. MIDDENDORF:** Bill Rom?  
10 **DR. ROM:** Yes.  
11 **DR. MIDDENDORF:** Susan Sidel?  
12 **MS. SIDEL:** Yes.  
13 **DR. MIDDENDORF:** Glenn Talaska?  
14 **DR. TALASKA:** Yes.  
15 **DR. MIDDENDORF:** Leo Trasande?  
16 **DR. TRASANDE:** Yes.  
17 **DR. MIDDENDORF:** And Liz Ward?  
18 **DR. WARD:** Yes.  
19 **DR. MIDDENDORF:** Okay. I'm assuming Virginia's still not with us. There  
20 were 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 -- Bob Harrison, are you still there? I'm not hearing  
21 Bob. We have 13 yeses, zero noes and zero abstentions. Okay.  
22 **DR. WARD:** Okay, so then, I think the next order of business would be to  
23 articulate a motion or a statement that we can vote on regarding research on  
24 cognitive disorders related to toxic exposures in World Trade Center populations.  
25 **DR. ALDRICH:** This is Tom Aldrich. I still think that's part of number 1, and if  
26 a researcher identifies cognitive disorders as an issue to study, they'll study it.  
27 **DR. WARD:** Well, I guess what we need to do is figure out a way to get a  
28 sense -- overall sense of the committee. So we've heard Susan advocating that it is  
29 an important priority on its own. And I think the way -- and we've also heard a  
30 number of people saying that, you know, it rightly belongs as a -- you know,  
31 something that could be under item 1. But I guess at this point we need a motion  
32 and a vote, because we have different viewpoints having been expressed on the  
33 committee, so I was thinking if we could have a motion to include it, then we can  
34 take a vote as to whether we want to include it. We can have a discussion and a  
35 vote as to whether we want to include it as a separate research priority.  
36 **DR. NORTH:** This is Carol. I would vote to put it as part of number 1, as part  
37 of the medical conditions, and I would like to make that motion.  
38 **DR. WARD:** And just to clarify, we won't call it out specifically but it will be  
39 understood that it would be one of the conditions that we include under item 1.

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**MS. SIDEL:** All right. This is Susan. I don't understand how it would be understood if it's not spelled out. Hello? Can you hear me?

**DR. ALDRICH:** I don't think it has to be spelled out.

**MS. SIDEL:** I'm, I'm confused. I mean are you saying that we need to have number 1, and then it'll say something about you're going to use the word cognitive disorders as caused by toxins? Or --

**DR. ALDRICH:** Number 1 stands as number 1, and it's one of many potentially previously unrecognized health conditions.

**DR. MIDDENDORF:** Allen stated that one of the things that will happen is that when they go to put together the funding announcements, they will look at the specific motions and then they'll also look at the transcript to try and get a sense of what the committee was intending with that.

**MS. SIDEL:** You know, I just give up. I mean...

**DR. WARD:** Okay, well, Carol has made a motion -- essentially it's kind of -- I guess it's hard to make a motion. I'm not sure the motion is actually vote-able in the way it was made. So I think maybe it is easier to just say, Susan makes a motion to include it as a separate priority area, and the, and the assumption we're voting on is that if it's not -- if that, if that does not get voted by the majority on the committee, then the sense of the committee is that it is included as one of the potential diseases to be studied under recommendation 1.

**MS. SIDEL:** So nobody on the committee thinks that something could happen to your brain from being exposed to toxins, so that the reason people are having cognitive issues is because of PTSD or because they're depressed?

**DR. NORTH:** This is Carol. No, I think that that's the reason to include it under number 1, to separate it from the psychiatric disorders --

**MS. SIDEL:** But I don't understand how you're going to include it. I mean, if you're not going to say it. If you're not going to say -- I mean, I don't understand -- I guess what I'm saying is like, what do you mean by include it? You're going to say the words cognitive, you know, issues as --

**DR. WARD:** No. I think that's not -- we're not --

**MS. SIDEL:** I mean, that sounds very vague because that's not inclu -- you know, not saying anything is not including it. That's like -- nobody reads the notes of what the committee meant.

**DR. WARD:** But I don't think aside from -- I mean, they're -- what we're trying to do is capture things that the majority of the people on the committee think are important, critical research knowledge gaps. And so far the only person who, who has advanced the viewpoint that that particular topic should be on the list of critical research knowledge gaps is you.

**MS. SIDEL:** All right, so then let's move on --

1                   **DR. WARD:** Is there anyone else who supports that or if not, we probably  
2 should move on.

3                   **DR. MARKOWITZ:** This is Steven Markowitz. Actually I would argue against  
4 any -- naming any particular condition at this point, given what we know. So it's not  
5 just cognition but I would make the same statement for renal diseases or whatever.  
6 They are subsumed under newly emerging conditions.

7                   **DR. NORTH:** I agree.

8                   **DR. MARKOWITZ:** What we need is a sensitive enough surveillance system  
9 to be able to pick up concerns like Susan's. If, if --

10                  **MS. SIDEL:** You know what, they're not really emerging conditions, though.  
11 They've been here for a long time and it's just been ignored. So there's a lot of  
12 people that have been suffering for a lot of years, and unless they have the money  
13 to go be treated by outside doctors, they're not being treated. Or I know people  
14 that are in the volunteer program as, you know, like that's the committee. I got a  
15 connective tissues disease covered as related to, you know, World Trade Center  
16 exposures, because I had the medical, you know, the medicals support it. And, you  
17 know, workers' comp, when all of them were in New York, they sent me to five  
18 different doc -- you know, rheumatologists. I couldn't find one to say that, you  
19 know, to disagree with my doctor who said that this is a result of my exposure. And  
20 I know a lot of other people that are -- have similar situations to mine. They just  
21 have finances to go on their own to a rheumatologist to be treated. And then when  
22 the -- when the volunteer program ends, in 2016, because they're gonna, you know,  
23 be out of money, then, you know, somebody like me, I'm not gonna have treatment.  
24 And it's not fair because it's, you know, the issue and -- at my very first appointment  
25 in 2002.

26                  **DR. WARD:** You know, the other point for everyone is a lot of the other  
27 bullet points -- or the other recommendations that we haven't gotten to talk about,  
28 there was one related to biomarkers; there was one related very broadly to immune  
29 system disorders, which would include autoimmune diseases, which, you know, I  
30 think there's a -- there's more support in the -- there may be more support in the  
31 community that that is a category of diseases that we really do need to call out as a  
32 research priority. There's one on vulnerable populations including those exposed  
33 during gestation, childhood and adolescence. And then there's one on exposure  
34 assessment.

35                  So I mean, from a viewpoint of efficiently doing our jobs, I would suggest  
36 that we table the discussion of cognitive disorders for now and move on to immune  
37 system disorders, and that -- well, we could move on to biomarkers --

38                  **DR. NORTH:** What about the other mental health issues?

39                  **DR. WARD:** Well, we need to take a vote on that, right.

1 **DR. NORTH:** The diagnosis statement that we haven't discussed yet?

2 **DR. WARD:** That one, I think, we want to -- we want to vote on when we're  
3 down to the second. You pointed out correctly that that's related to the accurate  
4 diagnosis, which is under the second --

5 **DR. NORTH:** Okay, that's the other thing.

6 **DR. WARD:** Yeah, no, I've been lost but I think that's where it belongs and  
7 I'm more -- you know, but I think, you know, our immediate order of business  
8 should be to finalize our recommendations in relation to area 1, and then move on  
9 to area 2 and hope that, that we've learned enough through this process that we  
10 can really narrow down the -- the second, third and fourth area more quickly, and  
11 come to consensus.

12 **DR. NORTH:** Good, I got it. I'm following that, thank you.

13 **DR. WARD:** It's also an -- you know, we also do have the option easily of  
14 saying, you know, putting in the committee recommendations that there was  
15 debate about whether research on cognitive disorders related to toxins should be  
16 included on the list. And you know, we can include those topics that we discussed  
17 but didn't come to consensus on for the sake of completeness.

18 But I suggest we move on and take a vote on the proposal for the second  
19 recommendation under category 1. If Paul will read it to us one more time. We  
20 have a -- we did have a second on that motion, I think.

21 **DR. MIDDENDORF:** On which motion? Oh, you mean the differentiate  
22 psychiatric disorders?

23 **DR. WARD:** No, no. We're -- I don't think we voted on the motion by Carol  
24 that belongs in this section.

25 **DR. MIDDENDORF:** Characterize the disaster-related exposures?

26 **DR. WARD:** Right.

27 **DR. MIDDENDORF:** Yeah, we have a vote, 13-0-0.

28 **DR. WARD:** We have? Okay, good, we're done with that one, okay.

29 Moving on, we're tabling cognitive discussion for now, and we're moving on to  
30 biomarkers.

31 **MS. FLYNN:** Liz?

32 **DR. WARD:** Yes.

33 **MS. FLYNN:** This is Kimberly. I don't know if this helps or not but would it  
34 be possible, before we move on to biomarkers, for perhaps Dr. Markowitz to frame  
35 a proposal around symptom surveillance?

36 **DR. MARKOWITZ:** This is Steve Markowitz. No, let's do biomarkers. We'll  
37 get to surveillance.

38 **MS. FLYNN:** Okay. So we gotta come back to symptom surveillance  
39 because that is at the bottom of many a complaint from survivors and responders.

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**MS. SIDEL:** It was supposed to be strengthened, I thought, like three years ago.

**DR. WARD:** Okay, so on biomarkers, has anyone had time to try to frame --

**DR. ALDRICH:** -- suggested wording for biomarkers -- this is Tom Aldrich.

**DR. WARD:** Okay. Go ahead.

**DR. ALDRICH:** This is possibly only a part of it because it doesn't include the issue about long-lived biomarkers as a measure of exposure, which, I think, maybe ought to be a separate thing because it's not -- it's more about exposure than about biomarkers so this is excluding that.

What I suggest is: Determine the value of biomarkers for early detection of precancerous conditions, comma --

**DR. MIDDENDORF:** Wait a minute. Early detection --

**DR. ALDRICH:** -- of precancerous conditions, comma, early cancers, comma, or other World Trade Center -- or other WTC-associated diseases.

**DR. MIDDENDORF:** You said associated, not related, okay.

**DR. ALDRICH:** Either one, it doesn't matter.

**DR. MIDDENDORF:** Well, these are your words.

**DR. ALDRICH:** Yeah, that's it.

**DR. WARD:** Okay, do we have a second on that motion?

**MS. SIDEL:** I'll second.

**DR. TALASKA:** Second.

**DR. WARD:** Any discussion?

**MS. SIDEL:** No.

**DR. WARD:** Okay. I guess we'll move to a vote?

**THE COURT REPORTER:** I'm sorry, could I get who seconded, please?

**DR. WARD:** Who seconded it?

**DR. TALASKA:** Glenn Talaska.

**THE COURT REPORTER:** Thank you.

**MS. SIDEL:** Oh, I -- whatever.

**DR. MIDDENDORF:** And Susan. Both of them seconded it, so.

**THE COURT REPORTER:** Okay, thank you.

**DR. MIDDENDORF:** So, are we ready for a vote? Okay, the wording on the motion is: Determine the value of biomarkers for early detection of precancerous conditions, early cancers, or other WTC-associated diseases. Is everybody ready for the vote?

**DR. WARD:** Yes.

**DR. MIDDENDORF:** Tom Aldrich? Tom, did you say something?

**DR. ALDRICH:** Oh, I vote yes.

**DR. MIDDENDORF:** Okay. John Dement?

1 **DR. DEMENT:** Yes.

2 **DR. MIDDENDORF:** Kimberly Flynn?

3 **MS. FLYNN:** Yes.

4 **DR. MIDDENDORF:** Bob Harrison? Okay, Catherine Hughes?

5 **MS. HUGHES:** Yes.

6 **DR. MIDDENDORF:** Steve Markowitz?

7 **DR. MARKOWITZ:** Yes.

8 **DR. MIDDENDORF:** Guille Mejia?

9 **MS. MEJIA:** Yes.

10 **DR. MIDDENDORF:** Carol North?

11 **DR. NORTH:** Yes.

12 **DR. MIDDENDORF:** Julia Quint?

13 **DR. QUINT:** Yes.

14 **DR. MIDDENDORF:** Bill Rom?

15 **DR. ROM:** Yes.

16 **DR. MIDDENDORF:** Susan Sidel?

17 **MS. SIDEL:** Yes.

18 **DR. MIDDENDORF:** Glenn Talaska?

19 **DR. TALASKA:** Yes.

20 **DR. MIDDENDORF:** Leo Trasande?

21 **DR. TRASANDE:** Yes.

22 **DR. MIDDENDORF:** Liz Ward?

23 **DR. WARD:** Yes.

24 **DR. MIDDENDORF:** Okay, 1, 2, 3, 4, 5, 6, 7, 8, 9... 13 yes, zero no, zero

25 abstain.

26 **DR. WARD:** Okay, so the next one on the list is immune system disorders

27 that cover sarcoidosis, malignancy, autoimmune diseases as a broad category. Has

28 anyone come up with better wording for that?

29 **DR. ALDRICH:** Let me ask, does the long-lived biomarkers, which I really like

30 that concept, but that's going to be a part of number 7, right, or the last one on the

31 list, the exposure assessment?

32 **DR. WARD:** I think that's what was proposed.

33 **DR. ALDRICH:** Good.

34 **DR. WARD:** So I mean, there is the question of whether we want to

35 highlight any specific disease category in these recommendations. We did highlight

36 mental health conditions. So I had a feeling that there was support from a number

37 of people on the immune system disorders; is that correct?

38 **DR. ALDRICH:** I personally think, to be consistent, we should say this is all

39 part of 1, and not talk about it separately.

1 **DR. WARD:** Okay, so is there anyone who disagrees with that perspective?

2 **MS. SIDEL:** I don't -- I don't understand what you mean by that. What do --  
3 what do you mean that it's all part of 1?

4 **DR. ALDRICH:** This would be one of those newly emerging health conditions  
5 that refer to in motion 1.

6 **MS. SIDEL:** But you're not going to say what it is?

7 **DR. ALDRICH:** No, because I think it's up to the researchers to focus on  
8 what they think are important, and convince us or convince the --

9 **MS. SIDEL:** Okay.

10 **DR. ALDRICH:** -- the review committee, whoever's going to be reviewing  
11 the applications, that they made a good case for it. And if it -- if someone makes a  
12 really, really good case that hang nails are associated with the World Trade Center,  
13 they should be funded. It's a matter of who can make a good case for something,  
14 not some preconceived idea about what's important.

15 **MS. SIDEL:** Well, there were preconceived ideas about what was important  
16 from the very beginning of the program, when they decided what they were gonna  
17 cover and what they weren't gonna cover. And just because something like  
18 autoimmune diseases wasn't on that list it wasn't because they didn't exist or  
19 because people didn't have them, it was because it wasn't something that was being  
20 checked and it wasn't being recorded.

21 **DR. ALDRICH:** But I just -- it was --

22 **MS. SIDEL:** And so it -- okay, but (indiscernible) --

23 **DR. ALDRICH:** -- (indiscernible) emerging -- newly emerging diseases.

24 **MS. SIDEL:** But it's not newly emerging; it's been there, and all I'm saying is  
25 that, with 13 years out and nobody has come close to dealing with this. The first  
26 time that it was -- that anything was ever like remotely close was the discussion of  
27 inflammation in the Dr. Prezant's article. And that was like, you know, when you  
28 discuss inflammation, you know, the underlying, underlying -- all of the  
29 (indiscernible) things that we had and, you know, that are associated with cancer,  
30 and it's, you know, it's a big part of autoimmune diseases. So --

31 **DR. ALDRICH:** Yeah, I think that, that work is being done. It's being done  
32 with the, the autoimmune surveillance program at the FDNY that's funded by NIOSH  
33 last year, and it is a late-emerging disease. It wasn't one of the early emerging  
34 things. Yes, there were some people who had polymyositis as a related condition --

35 **MS. SIDEL:** It was late because it wasn't recognized.

36 **DR. ALDRICH:** But a few cases out of many thousands is not something you  
37 can study. Now there are many cases and now they can be studied but it's not -- it's  
38 not a neglect that led them not to be studied. It's that they were -- they had not  
39 emerged in enough volume to be studied back then.

1                   And now they are being studied. And I don't think that we should -- you  
2 know, that's why I -- I kind of feel like cognitive issues are more -- are less  
3 recognized than autoimmune. Maybe that's because they're not related to World  
4 Trade Center but they're not -- autoimmune diseases are being recognized. They're  
5 not recognized to the point that they can be included in the Health Program. But  
6 the whole point of this research is to find out if they -- if they should or should not  
7 be included. And that's -- and research is being done. The research will be  
8 encouraged by item 1, research into cognitive issues, research into autoimmune  
9 diseases, research into all kinds of new areas, so --

10                   **MS. SIDEL:** But the thing is that we haven't had any new areas for a long  
11 time, a long, long time.

12                   **DR. WARD:** Let me just cut in, so we're -- we're just having a debate  
13 between two people in this and I guess I'd like to hear what other people think. At  
14 this point --

15                   **DR. MARKOWITZ:** This is Steve Markowitz --

16                   **DR. WARD:** Yeah.

17                   **DR. MARKOWITZ:** So, I think it's sort of a Catch-22, right? Some of these  
18 aren't looked at until it provides a strong enough signal but it doesn't provide a  
19 signal until it's looked at. So I think what we -- I think between the, the first priority  
20 we discussed, which was newly emerging and previously unrecognized. And then I  
21 think when we get to something, a proposal on a more sensitive surveillance  
22 system, so that it's more likely that problems will be picked up, like Susan's  
23 discussing. Between those, I think, then, it'll cover this issue.

24                   **DR. ALDRICH:** But won't there be a preamble to the list of priorities?

25                   **DR. WARD:** Here's the thing, any text that we want to convey has to be  
26 discussed and approved during this meeting. So if we want to talk about a  
27 preamble, we have to come up with draft text for the preamble.

28                   Now, I apologize 'cause I feel like we're not -- I mean, I don't think we, for  
29 various reasons including technical circumstances, I don't feel like we're in the  
30 most -- I think this meeting isn't the most conducive way to come up with the best  
31 set of recommendations, but within the technology constraints that we have, pretty  
32 much we have to agree on final text in the course of this meeting. So if anybody  
33 wants to propose a preamble, they should probably think about how they would  
34 want to word it while we're talking so that we can consider it as a committee and  
35 vote on it.

36                   **MS. SIDEL:** I just feel like it's redundant. We just, we just -- we're asking  
37 people to do what they're supposed to do. They're supposed to research new and  
38 emergent -- emerging things. It doesn't have to be said, but it's not being done.

39                   **DR. ALDRICH:** Yes, but we cannot --

1 **MS. SIDEL:** And it could be done.

2 **DR. ALDRICH:** We cannot point out things for study for which there is no  
3 evidence.

4 **DR. MARKOWITZ:** You know, I think actually we just have a -- this is Steve  
5 Markowitz -- we have a disagreement here. And I don't think we're gonna actually  
6 breach this. I don't think we're gonna solve this disagreement. So -- because the  
7 same points of view -- and I don't mean any disrespect here -- but are being  
8 repeatedly expressed. So I think either we formulate a specific proposal that can be,  
9 you know, we accept it or reject it or we move on.

10 **DR. WARD:** This is Liz; I agree.

11 **MS. SIDEL:** Well, is this a court for suggesting that more research needs to  
12 be done in the area of autoimmune diseases related to the World Trade Center?

13 **DR. NORTH:** I don't think we ought to single it out. This is Carol.

14 **DR. DEMENT:** This is John Dement. I think it's under item 1 in surveillance,  
15 as Steve has talked about as well.

16 **MS. MEJIA:** This is Guille. I also agree that it's covered under item 1.

17 **DR. TALASKA:** Glenn Talaska, the same.

18 **DR. WARD:** Okay, so, so unless, you know, unless Susan, you want to make  
19 a specific, you know, motion, and then we have a -- see if we have a second, and  
20 take a vote, I think we can table the issue 'cause it -- at least to me it doesn't seem  
21 like there's a great deal of support for calling this out as a priority research area.

22 **MS. SIDEL:** I don't think it's worth it for me to come up with a motion  
23 because it's not gonna get passed, so...

24 **DR. WARD:** Okay, thank you. So the next general area we have on the list is  
25 health effects of exposure to vulnerable populations with specific emphasis on  
26 children exposed during gestation, people exposed during childhood and  
27 adolescence. Does someone want to make a motion for the wording on that?

28 **DR. ALDRICH:** I think the wording -- the most recent wording is really, really  
29 good: Assess health effects of exposure on gestation and early life, paren,  
30 childhood and adolescence, end paren. I think that's perfect.

31 **MS. FLYNN:** And -- this is Kimberly. Would we include the biomarkers of  
32 exposure point here?

33 **DR. ALDRICH:** My view is that belongs after the next one.

34 **MS. FLYNN:** Okay.

35 **DR. ALDRICH:** The next one.

36 **MS. FLYNN:** Okay.

37 **DR. WARD:** I think that was the viewpoint I heard earlier from most people,  
38 that -- or from several people, that we should include it under the exposure  
39 assessment. So do we have a second on the motion for the item number 6?

1                   **DR. NORTH:** I'll second it. This is Carol.  
2                   **DR. WARD:** Okay. Paul, should we go to a vote?  
3                   **DR. MIDDENDORF:** Yeah, this is motion number 4. It is: Assess health  
4 effects of exposure on gestation and early life, in parentheses, childhood and  
5 adolescence.  
6                   I'll give people a second to think about that. And then I'll get to Tom  
7 Aldrich?  
8                   **DR. ALDRICH:** Is it WTC exposure or just exposure?  
9                   **DR. MIDDENDORF:** The wording only says exposure at this point.  
10                  **MS. FLYNN:** I accept the friendly amendment of World Trade Center  
11 exposure 'cause this is what this is all about.  
12                  **DR. WARD:** Yes.  
13                  **DR. ALDRICH:** With that amendment, I vote yes.  
14                  **DR. MIDDENDORF:** Was that amendment seconded?  
15                  **DR. NORTH:** I'll second, Carol.  
16                  **DR. MIDDENDORF:** Okay. So Tom Aldrich?  
17                  **DR. ALDRICH:** Yes.  
18                  **DR. MIDDENDORF:** John Dement?  
19                  **DR. DEMENT:** Yes.  
20                  **DR. MIDDENDORF:** Kimberly Flynn?  
21                  **MS. FLYNN:** Yes.  
22                  **DR. MIDDENDORF:** Bob Harrison? Catherine Hughes?  
23                  **MS. HUGHES:** Yes.  
24                  **DR. MIDDENDORF:** Steve Markowitz?  
25                  **DR. MARKOWITZ:** Yes.  
26                  **DR. MIDDENDORF:** Guille Mejia?  
27                  **MS. MEJIA:** Yes.  
28                  **DR. MIDDENDORF:** Carol North?  
29                  **DR. NORTH:** Yes.  
30                  **DR. MIDDENDORF:** Julia Quint?  
31                  **DR. QUINT:** Yes.  
32                  **DR. MIDDENDORF:** Bill Rom?  
33                  **DR. ROM:** Yes.  
34                  **DR. MIDDENDORF:** Susan Sidel?  
35                  **MS. SIDEL:** I'm sorry, yes.  
36                  **DR. MIDDENDORF:** Glenn Talaska? Leo Trasande? Liz Ward?  
37                  **DR. WARD:** Yes.  
38                  **DR. MIDDENDORF:** Okay. I'm gonna go back and check to see whether or  
39 not -- Bob Harrison, are you there? I'm hoping this isn't a problem with just not

1 being able to speak. Glenn Talaska?  
2 **DR. TALASKA:** I voted yes.  
3 **DR. MIDDENDORF:** Leo Trasande? Okay, I didn't hear anything from Leo or  
4 Bob.  
5 **DR. TALASKA:** You got mine, though, right?  
6 **DR. MIDDENDORF:** That was Glenn?  
7 **DR. TALASKA:** Yes.  
8 **DR. MIDDENDORF:** Yes, I got your yes.  
9 **DR. WARD:** So Paul, maybe you should ask if Leo or Bob are having trouble  
10 speaking, they should email you or something?  
11 **DR. MIDDENDORF:** Yeah, they -- usually they do.  
12 **DR. WARD:** Okay.  
13 **DR. MIDDENDORF:** So that's one of the things I've been monitoring.  
14 **DR. WARD:** Okay, so we have the last bullet or the last item on the list is  
15 related to exposure assessment. And I'm hoping that someone has some draft  
16 language.  
17 **DR. ALDRICH:** I have a suggestion for that. Unfortunately I don't think it's  
18 quite complete because it doesn't address the special issues or separate psychiatric  
19 exposures and it doesn't address the long-term, long-lasting biomarker issue, and I  
20 think those should be addressed. But aside from that, if we say: improved WTC  
21 exposure quantification: inhaled, topical, ingested, psychological or other.  
22 **DR. MIDDENDORF:** Okay, I'm gonna ask you to repeat all that.  
23 **DR. ALDRICH:** Improved WTC exposure quantification, colon, inhaled,  
24 topical, ingested, psychological or other.  
25 **DR. MIDDENDORF:** Okay.  
26 **DR. NORTH:** Could I make a suggestion -- this is Carol. We've got the  
27 mental health stuff separately. Could we take it out of this? Because psychological  
28 exposure is an odd conflict.  
29 **DR. ALDRICH:** Yeah, let's take it out and let's do a motion -- motion 6 that  
30 says something about the separate quantification of physical and nonphysical  
31 exposures.  
32 **MS. FLYNN:** This is Kimberly. Can I just -- can I please ask what's entailed by  
33 quantification in this instance?  
34 **DR. ALDRICH:** My view is that it's been extremely murky to understand how  
35 to quantify an individual's exposure, and that the only -- the only techniques have  
36 been extremely crude, and if some smart people can come up with better ways of  
37 doing it, that would be very valuable. This may be an impossible goal.  
38 **DR. WARD:** Yeah, this is Liz. I would suggest maybe we should substitute  
39 estimation.

1 **DR. DEMENT:** I would say assessment. This is John Dement.  
2 **DR. WARD:** Yeah, yeah.  
3 **DR. ALDRICH:** Assessment or metrics.  
4 **DR. DEMENT:** Yeah, or metrics, whatever. That's true because  
5 quantification has a connotation that you can actually put a numeric value to it and  
6 in a lot of cases you really can't.  
7 **DR. TALASKA:** That's right. And I think metrics or --  
8 **DR. DEMENT:** Yeah.  
9 **DR. TALASKA:** -- assessment would be better.  
10 **DR. ALDRICH:** Well, you know what? I'm thinking that since those last four  
11 words, and we're gonna get rid of psychological on that, the last three words refer  
12 to the word just before it. Somehow the word exposure should be just before it. So  
13 it should be improved assessment of WTC exposure, colon.  
14 **DR. MIDDENDORF:** I'm sorry, say that again?  
15 **DR. ALDRICH:** Improved assessment of WTC exposure, colon. Or estimate,  
16 if you prefer, and then get rid of psychological.  
17 **DR. WARD:** Yeah, and I'm not sure that we really need to specify the long-  
18 live biomarkers 'cause again, that's something that -- I mean, the investigators could  
19 propose to do to satisfy this knowledge gap.  
20 **DR. DEMENT:** Great point. It's a very cool idea though.  
21 **DR. NORTH:** Question. Exposure to what is implied here?  
22 **DR. MARKOWITZ:** Just about any agent. Just about any agent is what's  
23 implied.  
24 **DR. DEMENT:** Yeah.  
25 **DR. WARD:** So the three words -- just to repeat, the three words you have  
26 after the colon are?  
27 **DR. ALDRICH:** Inhaled, topical, ingested or other.  
28 **DR. WARD:** Okay.  
29 **DR. ALDRICH:** I don't think there was any intravenous.  
30 **UNIDENTIFIED SPEAKER:** There may have been some IM though.  
31 **DR. WARD:** Okay, so do we have a second for that motion?  
32 **DR. TALASKA:** I'll second it.  
33 **THE COURT REPORTER:** Who seconded?  
34 **DR. MIDDENDORF:** The question on the table is assessment of WTC  
35 exposure, colon, inhaled, topical, ingested or other.  
36 **MS. SIDEL:** Is this written down someplace?  
37 **DR. MIDDENDORF:** Sorry?  
38 **MS. SIDEL:** Is this -- did we -- is this written down?  
39 **DR. MIDDENDORF:** Yeah, you need me to send it?

1 **MS. SIDEL:** Yeah. I'm confused; I can't figure out which one it is.

2 **DR. MIDDENDORF:** Okay.

3 **THE COURT REPORTER:** I'm sorry, who seconded the motion, please?

4 **DR. TALASKA:** Glenn Talaska.

5 **THE COURT REPORTER:** Thank you.

6 **DR. WARD:** Okay, so Paul is sending out the, the task, and then once  
7 everyone has it, we can go ahead and have a vote.

8 **DR. MIDDENDORF:** And while we're waiting I will just point out that we  
9 have about an hour and 15 minutes, maybe an hour and 20 minutes, left.

10 **DR. ALDRICH:** While we're waiting, could somebody try to figure out how to  
11 phrase that next point, about the difference between exposure to physical agents  
12 and exposure to images or whatever it is that causes PTSD in people who weren't  
13 actually on the scene?

14 **DR. WARD:** I thought that was already covered in bullet 2, and we don't  
15 need to point it out.

16 **UNIDENTIFIED SPEAKER:** Yes.

17 **DR. ALDRICH:** Okay, cool. So no motion 6.

18 **DR. WARD:** Right. So that would enable us to move on to the second area  
19 that Dr. Howard asked us to comment on.

20 **DR. MARKOWITZ:** Liz? It's Steve Markowitz; I'm sorry to interrupt you but I  
21 do have a surveillance proposal.

22 **DR. WARD:** Oh, I'm sorry, Steve.

23 **DR. MARKOWITZ:** It wasn't on Paul's previous list.

24 **DR. WARD:** I know; that's why I forgot but it's still -- no, I still knew it, so  
25 yes, please.

26 **DR. MARKOWITZ:** But Paul, I sent it to you.

27 **DR. MIDDENDORF:** Okay, I just copied it in.

28 **DR. MARKOWITZ:** Okay.

29 **DR. MIDDENDORF:** If you want to read it off.

30 **DR. MARKOWITZ:** This is, you know, I welcome changes to the language  
31 here. Evaluate and improve the utility and use of current WTC data and activities  
32 for the purpose of access surveillance of health conditions in WTC exposed  
33 population.

34 **DR. ALDRICH:** That assumes it's all current data and not new data?

35 **DR. MARKOWITZ:** Well, no, we can, we can take out the word current. It's  
36 current -- yeah, current would be -- I mean, data that already exists, not future data.  
37 But since the question was raised, let's just take out that -- so it would, it would say:  
38 Evaluate and improve the utility and use of WTC data and activities for the purpose  
39 of access surveillance of health conditions in WTC exposed populations.

1 **DR. MIDDENDORF:** Okay, before we move any further on that one, let me  
2 ask if everybody has received the previous email? The improved assessment of WTC  
3 exposure, colon, inhaled, topical, ingested or other.

4 **DR. WARD:** Yes.

5 **MS. SIDEL:** And that's it? That's the whole thing?

6 **DR. MIDDENDORF:** That's it. That's everything.

7 **MS. SIDEL:** And what about -- I'm sorry, what's the point?

8 **DR. MARKOWITZ:** I'm sorry, is the question about the -- is the question  
9 here -- this is Steve Markowitz -- about the surveillance proposal?

10 **DR. MIDDENDORF:** We are back on the improved assessment of WTC  
11 exposure.

12 **DR. MARKOWITZ:** Okay, was that voted on already?

13 **MS. SIDEL:** No.

14 **DR. MIDDENDORF:** No.

15 **DR. MARKOWITZ:** Oh, okay. I apologize. I apologize.

16 **MS. SIDEL:** Sorry.

17 **DR. MARKOWITZ:** Go ahead.

18 **MS. SIDEL:** I'm sorry, Steve, I couldn't hear you.

19 **DR. MARKOWITZ:** No, no, no. We're back on the exposure, fine. So just  
20 strike the surveillance; we'll get to that.

21 **DR. MIDDENDORF:** Susan, you had a question about improved assessment?

22 **MS. SIDEL:** Yeah. Like what is that information going to do?

23 **DR. DEMENT:** This is John -- this is John --

24 **MS. SIDEL:** I mean, if you have that information, like what, what will that  
25 help do?

26 **DR. WARD:** John, I think you were trying to speak.

27 **DR. DEMENT:** Yeah, I, I think the idea here is that some innovative  
28 integration that some of these exposure assessment tools could give us a better -- a  
29 linkage perhaps even with the surveillance data to generate hypotheses.  
30 Exposure -- a better exposure assessment could definitely improve our ability to  
31 make causal links in this ideological research area so that was, I think, the core idea  
32 behind it.

33 **MS. SIDEL:** Okay, thanks.

34 **DR. TALASKA:** This is Glenn Talaska. I like that a lot because it's vague  
35 enough to include all the things we mentioned earlier. And it allows researchers to  
36 be innovative in addressing the weaknesses of the past exposure assessment that  
37 was previously done at 9/11.

38 **DR. WARD:** Okay, so are we ready to take a vote?

39 **DR. MIDDENDORF:** Did we have a -- I think this is the motion. We need a

1 second on it.

2 **DR. TALASKA:** It's already been seconded. I did it last time.

3 **DR. MIDDENDORF:** Okay, sorry. So yes, we're ready for a vote. And the  
4 vote is on the improved assessment of WTC exposure, colon, inhaled, topical,  
5 ingested or other. Bob Aldrich?

6 **DR. ALDRICH:** Yes.

7 **DR. MIDDENDORF:** John Dement?

8 **DR. DEMENT:** Yes.

9 **DR. MIDDENDORF:** Kimberly Flynn?

10 **MS. FLYNN:** Yes.

11 **DR. MIDDENDORF:** Bob Harrison? Catherine Hughes?

12 **MS. HUGHES:** Yes.

13 **DR. MIDDENDORF:** Steve Markowitz?

14 **DR. MARKOWITZ:** Yes.

15 **DR. MIDDENDORF:** Guille Mejia?

16 **MS. MEJIA:** Yes.

17 **DR. MIDDENDORF:** Carol North?

18 **DR. NORTH:** Yes.

19 **DR. MIDDENDORF:** Julia Quint?

20 **DR. QUINT:** Yes.

21 **DR. MIDDENDORF:** Bill Rom?

22 **DR. ROM:** Yes.

23 **DR. MIDDENDORF:** Susan Sidel?

24 **MS. SIDEL:** Yes.

25 **DR. MIDDENDORF:** Glenn Talaska?

26 **DR. TALASKA:** Yes.

27 **DR. MIDDENDORF:** Leo Trasande? Liz Ward?

28 **DR. WARD:** Yes.

29 **DR. MIDDENDORF:** Twelve yes, zero no, zero abstentions. Motion passes.

30 **DR. WARD:** Steve, I have a question on the proposed language -- this is Liz.  
31 When you say WTC data, are you really referring to WTC Health Program and  
32 registry data or -- it just seems a little bit broad, and I wondered if you wanted to be  
33 more specific or not?

34 **DR. MARKOWITZ:** I'm sorry, it would refer to both the health registry and  
35 the health program data.

36 **DR. WARD:** Well, I just have this one -- I mean, is it confined to that data or  
37 is it any data or is it new research data or -- I mean, I guess I was thinking it needed  
38 a little clarification. World Trade Center data is -- doesn't mean anything if you  
39 don't define it further.

1                   **DR. MARKOWITZ:** Okay. Yeah, so this -- so what I'm really after here would  
2 be more apparent with the World Trade Center Health Program and the clinics is the  
3 like, is that -- because the health -- the World Trade Center health registry at the  
4 health department actually -- surveillance is what it's doing already. But the clinical  
5 data or the data collected in the clinical program is underutilized for the purposes of  
6 surveillance. This was what, I think, Dr. Melius was striving at. And so the purpose  
7 here is to draw attention to it and to find ways of improving its use.

8                   **DR. WARD:** So then the friendly amendment would be, well, WTCHP data?

9                   **DR. MARKOWITZ:** Right, okay. That's fine.

10                  **MS. SIDEL:** But are you confident in the way that it's collected?

11                  **DR. MARKOWITZ:** I'm sorry, I couldn't hear that.

12                  **MS. SIDEL:** Are you confident in the methodology that's being used to  
13 collect it, that it's accurate?

14                  **DR. MARKOWITZ:** No, you know, I'm agnostic on that, actually, but I think  
15 that would be one of the things to look at is the quality of the data, how accurate it  
16 is.

17                  **DR. ALDRICH:** Why limit the investigator to Health Program data? Why  
18 shouldn't the investigator be free to use data of good quality from any source?

19                  **MS. SIDEL:** I'm just saying that this is your opportunity, maybe, to improve  
20 the methodology for collecting it. You know, like the things I was talking about in  
21 monitoring where you're talking to a nurse who's sitting there putting -- you know,  
22 inputting the information into a computer. And then a year later, when you go  
23 back, you have to think about that information because it wasn't put in correctly. In  
24 other words, if you did it yourself, it would be correct. So if --

25                  **DR. ALDRICH:** But that seems like that would be handled by this -- but what  
26 wouldn't be handled by this would be if some researcher had some innovative way  
27 to get to link the World Trade Center registry data with the Health Program data,  
28 and come up with something new by doing that, that would be concluded if we limit  
29 this to just Health Program data.

30                  **DR. WARD:** I have an idea. Could we leave the text as it is but then add:  
31 and/or develop additional surveillance methods or surveillance resources?

32                  **DR. ALDRICH:** I like it.

33                  **DR. WARD:** Like that? That could be an and, or an or, and/or develop.

34                  **DR. MIDDENDORF:** Where would that go?

35                  **DR. WARD:** It would just go at the end of this sentence.

36                  **DR. MIDDENDORF:** And/or develop --

37                  **DR. WARD:** Additional surveillance resources or data sources. That would  
38 include linking or other -- other data sets.

39                  **DR. MIDDENDORF:** So what is your wording again?

1 **DR. WARD:** I think that's good, and/or develop --  
2 **DR. MIDDENDORF:** Surveillance data sources --  
3 **DR. WARD:** Additional --  
4 **DR. MIDDENDORF:** Additional?  
5 **MS. MEJIA:** Or how about improved surveillance?  
6 **DR. WARD:** Improved surveillance data methods or sources? I think just  
7 improved surveillance methods would be fine.  
8 **DR. MIDDENDORF:** So the wording that we're looking at at the moment is:  
9 Evaluate and improve the utility and use of World Trade Center Health Program  
10 data and activities for the purpose of active surveillance and health conditions in  
11 WTC-exposed populations and/or develop improved surveillance methods.  
12 **DR. WARD:** Is there somebody who wants to make a motion that that  
13 language be adopted?  
14 **DR. MARKOWITZ:** Steve Markowitz. I would propose that.  
15 **DR. ALDRICH:** I'll second that. Tom Aldrich.  
16 **DR. WARD:** So I think we can go ahead and move to a vote.  
17 **DR. MIDDENDORF:** Do people feel like they need to see the wording on this  
18 before they can vote?  
19 **MS. FLYNN:** Do you think -- can you make sure that by the end of this  
20 meeting, we get a copy of all the wording that was approved?  
21 **DR. MIDDENDORF:** Yes, I can.  
22 **MS. FLYNN:** That would be really helpful. Thanks a lot, Paul.  
23 **DR. MIDDENDORF:** I just sent this out, so you should be able to see it in a  
24 minute or so, hopefully a little less.  
25 **MS. FLYNN:** I just got surveillance, thanks.  
26 **DR. MIDDENDORF:** Okay.  
27 **MS. FLYNN:** But like a cumulative list of all the things we've voted on.  
28 Great.  
29 **DR. MIDDENDORF:** Yeah, it's actually -- I've got that cumulative list here in  
30 a document that I'm gonna be sharing on the web. Unfortunately, you're not able  
31 to see it. But yes, I will send this document out.  
32 Okay, I guess we're proceeding to a vote. Tom Aldrich?  
33 **DR. ALDRICH:** Yes.  
34 **DR. MIDDENDORF:** John Dement?  
35 **DR. DEMENT:** Yes.  
36 **DR. MIDDENDORF:** Kimberly Flynn?  
37 **MS. FLYNN:** Yes.  
38 **DR. MIDDENDORF:** Bob Harrison? Catherine Hughes?  
39 **MS. HUGHES:** Yes.

1 **DR. MIDDENDORF:** Steve Markowitz?  
2 **DR. MARKOWITZ:** Yes.  
3 **DR. MIDDENDORF:** Guille Mejia?  
4 **MS. MEJIA:** Yes.  
5 **DR. MIDDENDORF:** Carol North?  
6 **DR. NORTH:** Yes.  
7 **DR. MIDDENDORF:** Julia Quint?  
8 **DR. QUINT:** Yes.  
9 **DR. MIDDENDORF:** Bill Rom?  
10 **DR. ROM:** Yes.  
11 **DR. MIDDENDORF:** Susan Sidel?  
12 **MS. SIDEL:** Yes.  
13 **DR. MIDDENDORF:** Susan, if you're responding, it's not coming through.  
14 **MS. SIDEL:** Oh, yes.  
15 **DR. MIDDENDORF:** Glenn Talaska?  
16 **DR. TALASKA:** Yes.  
17 **DR. MIDDENDORF:** Leo Trasande? Leo, if you responded, I didn't hear you.  
18 I'm still not hearing anything from Leo. Liz Ward?  
19 **DR. WARD:** Yes.  
20 **DR. MIDDENDORF:** Okay. That's 12 yes, zero noes, and zero abstentions.  
21 Motion passes.  
22 **DR. WARD:** Okay, so I think we're ready to move on to the critical research  
23 knowledge gap relative to the accurate diagnosis of WTC-related health conditions.  
24 And what I'd like to do, as much as possible, is for people to, you know, really try to  
25 propose topics that they think really are of significant and broad importance, and to  
26 try to propose them in words kind of along the same lines as the ones we've voted  
27 on. So if you can propose the final lang -- something close to the final language that  
28 we can move forward.  
29 So I think the first one that we should consider is the one that was already  
30 proposed by Carol North related to the psychiatric diagnoses. And Paul, I think you  
31 have that while you were putting it in the --  
32 **DR. MIDDENDORF:** Yes. The wording is: Differentiate psychiatric disorders  
33 from symptoms and distress in relation to disaster exposure and develop efficient  
34 and effective methods for diagnosis of disaster-related psychopathology in  
35 populations and individuals.  
36 And I am going to send that out 'cause it's long and complicated.  
37 **DR. WARD:** Okay, do we have a second? I assume that we can assume -- I  
38 assume that Carol has put that forward as a motion, and is there a second?  
39 **DR. MIDDENDORF:** Okay, I've just -- I've sent it out.

1                   **DR. WARD:** Okay, people need a minute to look at it and then we'll ask for  
2 a second.

3                   **MS. SIDEL:** My message has no content. Paul?

4                   **DR. MIDDENDORF:** Yeah, let me look.

5                   **MS. SIDEL:** Weird.

6                   **DR. MIDDENDORF:** The one I sent has content. Let me resend.

7                   **DR. ALDRICH:** I just got it.

8                   **MS. SIDEL:** Yeah, I got it. I have it, thank you.

9                   **DR. MIDDENDORF:** Okay.

10                  **DR. WARD:** Okay, and so do we have a second for that motion?

11                  **DR. HARRISON:** This is Bob Harrison, second.

12                  **DR. WARD:** Okay. Is there any further discussion on the motion?

13                  **DR. MARKOWITZ:** This is Steve Markowitz. Carol, could you just succinctly  
14 describe again the importance of this differentiating disorders from symptoms of  
15 distress?

16                  **DR. NORTH:** I'm glad you asked that because I wasn't sure that everything  
17 that I intend for this is getting across. And basically we know a lot about symptoms  
18 but we don't know enough about psychiatric disorders. Most of the studies have  
19 looked at symptoms and it's not clear what symptoms mean. They've used  
20 symptoms screeners rather than assess psychiatric disorders. And I think that it's in  
21 parallel to study of cancer. We don't study cancer symptoms; we study cancer. And  
22 I don't think we want to give psychiatric illness the short, short shrift. That's what I  
23 meant.

24                  **DR. MARKOWITZ:** So, I wonder whether you're discussing evaluating the  
25 clinical significance of symptoms and distress.

26                  **DR. NORTH:** Well, that could be a side sheet. But right now we don't have  
27 enough data about properly measured psychiatric disorders. Most of our data is  
28 about symptoms that we don't know what they really mean and we don't have the  
29 data on disorders to, to know what symptoms outside of that context means.

30                  **DR. MARKOWITZ:** How about evaluating the -- rather than symptoms and  
31 distress in relation to psychiatric disorders, to differentiate that -- I mean, I don't  
32 want to take much time here -- but --

33                  **DR. NORTH:** No, I understand what you're saying. We have way too many  
34 symptoms outside of diagnosis, and I think in the end what we're gonna care about  
35 is diagnosis.

36                  **DR. MARKOWITZ:** Right.

37                  **DR. NORTH:** We know that people are distressed; that's a given. But what  
38 we want to do is identify people with disorders that need treatment, and then give  
39 general interventions to the distressed populations.

1 **DR. MARKOWITZ:** So you want to understand the relationship between  
2 symptoms and distress on the one hand, and the development of psychiatric  
3 disorders?  
4 **DR. NORTH:** Well, we, we want to differentiate them because right now the  
5 literature doesn't.  
6 **DR. MARKOWITZ:** Okay.  
7 **DR. NORTH:** And that's a mistake.  
8 **DR. MARKOWITZ:** Okay, I understand.  
9 **MS. SIDEL:** I don't understand. Could you, could you explain that part again  
10 to me?  
11 **DR. NORTH:** Okay, most of the literature we have is about symptoms of  
12 PTSD.  
13 **MS. SIDEL:** Right.  
14 **DR. NORTH:** Symptoms of this and that.  
15 **MS. SIDEL:** Right, right, right.  
16 **DR. NORTH:** And it's just hard to know what that means or what to do with  
17 it. You don't have enough research that it's taking the effort to accurately diagnose  
18 and identify disorders for specific treatment.  
19 **MS. SIDEL:** But how -- but I don't, I don't see where the -- how does it get to  
20 a disorder? I mean, is that --  
21 **DR. NORTH:** Well, we have carefully defined criteria.  
22 **MS. SIDEL:** Oh.  
23 **DR. NORTH:** We just haven't used them.  
24 **MS. SIDEL:** So they're not like calling it by a name.  
25 **DR. NORTH:** Well, sometimes they mistakenly call it by name. They  
26 measure symptoms and they call it PTSD or depression when really it's not.  
27 **MS. SIDEL:** But what else would it be?  
28 **DR. NORTH:** What's that?  
29 **MS. SIDEL:** What would be symptoms -- like what would be -- what would  
30 be -- what would be a correct diagnosis?  
31 **DR. NORTH:** Well, PTSD or major depression. Those are the common ones  
32 that develop after disasters.  
33 **MS. SIDEL:** Right, and why wouldn't they be that?  
34 **DR. NORTH:** They don't. It's labor intensive; they haven't developed the  
35 efficient methods to do that, and so we often settle for symptoms of thus and such,  
36 and I think that's about as satisfying as measuring symptoms of cancer. I'd like to  
37 study cancer, not symptoms of cancer. These are difficult concepts but they're very  
38 important.  
39 **MS. SIDEL:** No, I, I understand the concepts, but I just don't see why they

1 don't think that they're already doing that because I think they -- I think that they  
2 think that they're doing that.

3 **DR. NORTH:** It could be. I'd like to see things be done differently so that we  
4 can advance knowledge.

5 **DR. WARD:** Does anyone else have any thoughts on this point or any  
6 questions about it? I'll tell you my point of view is that I don't feel that I fully grasp  
7 it but I think it's probably an important question, and it might result in some  
8 proposals that would be really able to address it, and it may not. I mean, it, you  
9 know, really is going to require people who both understand the nature -- and who  
10 understand the nature and importance of the question and can think of ways to  
11 address it.

12 But, you know, I don't -- I think we -- very few of us have expertise in  
13 psychiatric disorders, and I -- so I tend to want to defer to Dr. North's expertise on  
14 this. And again, I don't think it's really going to generate a lot of proposals but we  
15 might -- it might bring forth a really good and important proposal if we include it in  
16 the list.

17 **DR. NORTH:** I think because we have psychiatric expertise will -- many of  
18 them will understand it enough to generate proposals, and if judging the proposals,  
19 many of them will understand this enough to judge it well.

20 **MS. SIDEL:** Okay.

21 **DR. WARD:** I think that the proposal's been made and seconded. Am I  
22 correct, Paul?

23 **DR. MIDDENDORF:** Yes.

24 **DR. WARD:** So perhaps we should move to the vote so that we can consider  
25 the ideas in this topic -- in this area that we haven't even put on the table yet.

26 **DR. MIDDENDORF:** Okay. Motion on the table is: Differentiate psychiatric  
27 disorders from symptoms of distress in relation to disaster exposure and develop  
28 efficient and effective methods for diagnosis of disaster-related psychopathology in  
29 populations and individuals. So going to the vote, Dr. Aldrich?

30 **DR. ALDRICH:** Yes.

31 **DR. MIDDENDORF:** John Dement?

32 **DR. DEMENT:** Yes.

33 **DR. MIDDENDORF:** Kimberly Flynn?

34 **MS. FLYNN:** Yes.

35 **DR. MIDDENDORF:** Bob Harrison?

36 **DR. HARRISON:** Yes.

37 **DR. MIDDENDORF:** Catherine Hughes?

38 **MS. HUGHES:** Yes.

39 **DR. MIDDENDORF:** Steve Markowitz?

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**DR. MARKOWITZ:** Yes.

**DR. MIDDENDORF:** Guille Mejia?

**MS. MEJIA:** Yes.

**DR. MIDDENDORF:** Carol North?

**DR. NORTH:** Yes.

**DR. MIDDENDORF:** Julia Quint?

**DR. QUINT:** Yes.

**DR. MIDDENDORF:** Bill Rom?

**DR. ROM:** Yes.

**DR. MIDDENDORF:** Susan Sidel?

**MS. SIDEL:** Yes.

**DR. MIDDENDORF:** Glenn Talaska?

**DR. TALASKA:** Yes.

**DR. MIDDENDORF:** Leo Trasande? Liz Ward?

**DR. WARD:** Yes.

**DR. MIDDENDORF:** Thirteen yes, zero noes, zero abstentions. Motion passes.

**DR. WARD:** So the floor is now open for additional proposals in relation to critical research gaps relative to accurate diagnosis of World Trade Center-related health conditions.

And maybe on this one we should try to get indication of who, who has one that they would like to propose. How many people -- who would like to propose a specific point?

**DR. MARKOWITZ:** This is Steve Markowitz. I'd like to propose something.

**DR. WARD:** Is there anyone else who has something in mind that they'd like to propose? Okay. Steve, go ahead.

**DR. MARKOWITZ:** This -- I mentioned this before. It actually pertains to diagnosis and treatment. But it would be to examine the patterns of healthcare utilization in the World Trade Center Health Program and the utility of the medical monitoring activities of -- also of the World Trade Center Health Program.

The purpose of this is to encourage --

**MS. FLYNN:** Can you speak up louder, please? I can't hear you very well.

**DR. MARKOWITZ:** Sure. So the purpose of this is to -- is to take a rigorous look at actually what the World Trade Center Health Program is doing in terms of the treatment and also in terms of the medical monitoring so that we can learn, learn about these programs, maybe how they can be improved but also how they can be designed for the future.

**DR. WARD:** So Paul, have you been able to capture that?

**DR. MIDDENDORF:** Sorry, I was on mute. I only got the first part: Examine

1 the patterns of healthcare utilization --

2 **DR. MARKOWITZ:** Yeah, I just sent it to you, Paul. I don't know how quickly  
3 it'll come.

4 **DR. MIDDENDORF:** Okay. Yep, it's here. Okay.

5 **DR. MARKOWITZ:** And I welcome, you know, language which is more  
6 complete or more refined.

7 **DR. ALDRICH:** I think what's missing in this is your point that doing this will  
8 lead to improvement in design of future programs. But somehow that point has to  
9 get into this.

10 **MS. SIDEL:** Well, wait. Don't you mean how, how to improve this program  
11 like right now?

12 **DR. MARKOWITZ:** Yeah, for both purposes, actually.

13 **DR. ALDRICH:** Yeah, but I mean, you want to propose more than just an  
14 examination. An examination --

15 **DR. MARKOWITZ:** Right, right.

16 **DR. ALDRICH:** -- leading to the design of better.

17 **MS. SIDEL:** Well, monitoring the problem, because it takes so long, you  
18 know, you're in there for the whole day. Is that the kind of thing you're talking  
19 about?

20 **DR. MARKOWITZ:** That would be one aspect, sure.

21 **MS. SIDEL:** Because I think that more people would come if it was a more  
22 streamlined process. I think that's really good.

23 **DR. MARKOWITZ:** But, Tom, so what other verbs should be added to this?

24 **DR. ALDRICH:** Maybe after the, after the examine, examine the value and  
25 efficacy or something?

26 **MS. SIDEL:** Why don't you just say improve the efficacy of the monitoring  
27 program and --

28 **DR. ALDRICH:** Yeah, but you know what, the scientist doesn't have the  
29 opportunity to improve; he has the opportunity to suggest improvements.

30 **MS. SIDEL:** Right. Well, right. So that would be good.

31 **DR. ALDRICH:** Well, I agree but I mean, so what the scientist will actually do  
32 will be examine the value or examine the use or examine the quality or something.

33 **MS. FLYNN:** This is Kimberly. Would there be a possibility also of including  
34 language about barriers to care? Or is that already included in the notion of  
35 healthcare utilization?

36 **DR. MARKOWITZ:** Well, I think it would be -- that would be included in  
37 patterns actually.

38 **MS. FLYNN:** Okay. In patterns?

39 **DR. MARKOWITZ:** Yeah.

1                   **MS. FLYNN:** Okay, so then we should keep the word patterns.  
2                   **DR. WARD:** So Paul, I think the way you're capturing it is not quite the way  
3 it's intended.  
4                   **DR. MIDDENDORF:** Okay.  
5                   **DR. WARD:** Steve, can you see the screen?  
6                   **DR. MARKOWITZ:** Hold on.  
7                   **DR. WARD:** I think the value and efficacy was the, was the replacement for  
8 utility. So I think it was examine the patterns of healthcare utilization in the WTCHP  
9 and the value and efficacy of medical monitoring activity. I think that's what was  
10 intended.  
11                  **DR. MARKOWITZ:** Yeah, I'm sorry. I'm not seeing what Paul's written. So  
12 Paul, if you could read it, then I can get it.  
13                  **DR. MIDDENDORF:** Yeah, let me read it out. Examine the value and efficacy  
14 of patterns of healthcare utilization in the World Trade Center Health Program and  
15 the value and efficacy of the medical monitoring activities of the WTCHP.  
16                  **DR. MARKOWITZ:** Oh, that's fine.  
17                  **DR. WARD:** And I guess the thing that doesn't make sense to me is the  
18 value and efficacy of patterns of healthcare utilization. I mean, you don't look at the  
19 value and efficacy of a pattern.  
20                  **DR. MARKOWITZ:** Right, right.  
21                  **DR. WARD:** So I'm suggesting taking that out of there and just looking at  
22 examine patterns of healthcare utilization and the value and efficacy of the medical  
23 monitoring activities?  
24                  **DR. MARKOWITZ:** Yeah, that makes more sense actually, because we  
25 don't -- we're not getting into evaluating the efficacy of treatment; that would be a  
26 mistake. So I think the patterns in the first half and the efficacy in the second is fine.  
27                  **DR. MIDDENDORF:** I think I -- what I -- I copied value and efficacy from the  
28 first part into the second part. So the way it reads is: Examine patterns of  
29 healthcare utilization in the WTCHP and the value and efficacy of the medical  
30 monitoring activities of the WTCHP.  
31                  **DR. MARKOWITZ:** All right. That's good.  
32                  **MS. MEJIA:** This is Guille. I have a little friendly amendment to that. Is it  
33 possible for it to read: Examine patterns of healthcare utilization and delivery in the  
34 World Trade Center Health Program? So we're looking at the delivery of the  
35 healthcare as well as the utilization of it.  
36                  **DR. MARKOWITZ:** That's fine.  
37                  **DR. MIDDENDORF:** And delivery of what?  
38                  **DR. WARD:** Don't need the, of. I think you can just get rid of the, of.  
39 Healthcare utilization and delivery in.

1 **DR. MIDDENDORF:** Delivery of what?  
2 **DR. MARKOWITZ:** No, it's the delivery of healthcare. But if you just put  
3 utilization and delivery, it's fine.  
4 **MS. MEJIA:** Right.  
5 **DR. MIDDENDORF:** So the wording is: Examine patterns of healthcare  
6 utilization and delivery in the World Trade Center Health Program and the value and  
7 efficacy of the medical monitoring activities of the WTCHP.  
8 **DR. MARKOWITZ:** Yeah, that's good.  
9 **DR. MIDDENDORF:** Okay, so that's the motion; is it seconded?  
10 **MS. HUGHES:** Yes. Catherine here.  
11 **DR. MIDDENDORF:** Okay.  
12 **DR. WARD:** We're ready for a vote.  
13 **DR. MIDDENDORF:** Okay. Tom Aldrich?  
14 **DR. ALDRICH:** Yes.  
15 **DR. MIDDENDORF:** John Dement?  
16 **DR. DEMENT:** Yes.  
17 **DR. MIDDENDORF:** Kimberly Flynn?  
18 **MS. FLYNN:** Yes.  
19 **DR. MIDDENDORF:** Bob Harrison?  
20 **DR. HARRISON:** Yes.  
21 **DR. MIDDENDORF:** Catherine Hughes?  
22 **MS. HUGHES:** Yes.  
23 **DR. MIDDENDORF:** Steve Markowitz?  
24 **DR. MARKOWITZ:** Yes.  
25 **DR. MIDDENDORF:** Guille Mejia?  
26 **MS. MEJIA:** Yes.  
27 **DR. MIDDENDORF:** Carol North?  
28 **DR. NORTH:** Yes.  
29 **DR. MIDDENDORF:** Julia Quint?  
30 **DR. QUINT:** Yes.  
31 **DR. MIDDENDORF:** Bill Rom?  
32 **DR. ROM:** Yes.  
33 **DR. MIDDENDORF:** Susan Sidel?  
34 **MS. SIDEL:** Sorry, yes.  
35 **DR. MIDDENDORF:** Glenn Talaska?  
36 **DR. TALASKA:** Yes.  
37 **DR. MIDDENDORF:** Leo Trasande? Liz Ward?  
38 **DR. WARD:** Yes.  
39 **DR. MIDDENDORF:** That's 13 yes, zero noes and zero abstentions. Motion

1 passes.

2 **DR. WARD:** So is there anyone else who'd like to propose a research gap  
3 relative to accurate diagnosis of World Trade Center-related health conditions?

4 **MS. FLYNN:** This is Kimberly, and I'm afraid I'm not the ideal person to  
5 phrase this, but wouldn't examining epigenetic alterations relevant to disease play  
6 an important role in diagnosis?

7 **DR. MARKOWITZ:** Not really in diagnosis.

8 **MS. FLYNN:** Okay.

9 **DR. MARKOWITZ:** I mean, you know, in mechanism of the disease, sure,  
10 but not, to my knowledge, not in diagnosis.

11 **MS. FLYNN:** Okay.

12 **DR. WARD:** Okay, so I just looked back at Dr. Crowley's -- my notes from Dr.  
13 Crowley, and I didn't see any of the topics that she mentioned that specifically  
14 would fall into this category. I think one of the important points that she made, that  
15 we still need to capture but it maybe falls better under 3, is did early intervention  
16 make a difference in outcome.

17 **MS. SIDEL:** Early intervention does make a difference in outcome, but if  
18 you're not paying attention to something because you're just not paying attention  
19 to it, then you're gonna have a bad outcome, and that was the point of asking for  
20 research.

21 **DR. WARD:** I guess one of the things -- I mean, one of the things that  
22 people can propose to look at in the World Trade Center -- in the previous priority  
23 area is whether the -- these -- the selection of things that are being monitored for is  
24 appropriate or might be too defined to detect other conditions. I mean, that, that  
25 could be a topic under that last priority area.

26 **MS. SIDEL:** I think they've become so limited in air as digested, that other  
27 things are not considered. And they're not -- it's not a matter of that there aren't so  
28 many of them that they're being hit over the head with it. I mean, there's a lot of  
29 cancer but cancer happens because there's a lot of press about it.

30 **DR. WARD:** Well, I think that this --

31 **MS. SIDEL:** Like there are a lot of political factors that go into a lot of these,  
32 you know, decisions, and having -- you know, early detection is critical but it  
33 doesn't -- it's not going to happen unless you're recognizing things and you're  
34 looking for new things actively. And that's been my, my comment. And I said this in  
35 2011, and I think we're just, you know, going in circles, like we're just studying you  
36 know more parts of the same issues.

37 **DR. WARD:** I think we -- I think we think we covered that under the first  
38 priority under topic 1. So I guess, unless anyone has something additional to  
39 propose with regard to accurate diagnosis of WTC-related health conditions, we

1 should move on to research gaps relative to effective treatment of WTC-related  
2 health conditions.

3 **MS. FLYNN:** Well, Liz, I have one -- this is Kimberly -- I have one additional  
4 question, and again, it's not only you see a need for me to separate out the  
5 diagnostic and the treatment part, so forgive me if this is not relevant, but the  
6 whole issue of comorbidity, particularly between severe respiratory conditions and  
7 PTSD, does that -- I guess, my question is where in this scheme would that fall?  
8 Because this is something that has been raised by World Trade Center Health  
9 Program clinicians.

10 **DR. WARD:** I'm hoping some of our clinicians --

11 **DR. ALDRICH:** That's on the topic of several of the research grants, and  
12 there are a number of papers about comorbidity. There's lots more to be done. But  
13 it's not really a research gap, right? Hasn't that already been identified as a  
14 problem?

15 **MS. FLYNN:** It certainly has been identified as a problem. I think, and  
16 forgive me; I don't have this handy, but we had some language from, from survivor  
17 program mental health folks that talked about the effects of comorbid conditions  
18 and additional risks that talked about final common pathways. I don't know  
19 whether folks feel that this has received adequate attention or... Again, yes, if it's  
20 not -- if it's not a pressing gap, you know, I understand that as the standard for  
21 inclusion on this list. But it's not for me to say whether it's a pressing gap.

22 **DR. WARD:** I mean, I think -- I'm not sure where it would belong but I guess,  
23 if I was to try to articulate it, it would be, as a research gap, it would be  
24 understanding mechanisms underlying --

25 **MS. FLYNN:** Yeah, that makes sense.

26 **DR. WARD:** -- apparent --

27 **MS. FLYNN:** That makes sense.

28 **DR. WARD:** -- associations between, you know, underlying common  
29 pathways for certain -- for WTC-related conditions or something. Does any -- does  
30 anyone else feel strongly that that should be included somewhere?

31 **DR. MIDDENDORF:** Could you just repeat, repeat what the idea is again?

32 **DR. WARD:** I'm thinking that what we're trying to capture is underly --  
33 understand mechanisms underlying associations between WTC-related co-  
34 morbidities such as PTSD and respiratory disease. Understanding why these two  
35 conditions -- I mean, is it purely exposure-mediated or are there other -- is it  
36 something related to the mechanism or pathophysiology of these conditions that  
37 make them more likely to occur together. I think that's what Kimberly is getting at.

38 **MS. FLYNN:** Yeah, thank you.

39 **DR. WARD:** And you've got another -- I mean, do you get what she meant

1 and could you say it in another way, Steve?

2 **DR. MARKOWITZ:** No, no, no. I wasn't -- my concern about that, it's not  
3 that it doesn't have value but my concern about that is that it doesn't really  
4 contribute in a short-term way to the welfare of the World Trade Center exposed  
5 population. It doesn't kind of help us understand the clinical expression or the  
6 epidemiologic expression or early intervention in a way that I can see in the near  
7 future as helping people. That's, that's my problem with that.

8 **DR. WARD:** Okay, so does, does anyone else want to spend time working  
9 on this some more or should we just table it, put it in the parking lot as something  
10 that we don't have time to fully develop during this meeting?

11 Okay. I guess I haven't heard any sentiments that we should go forward  
12 with it. So the one thing that seems clear to me in terms of critical knowledge gaps  
13 relative to effective treatment of WTC-related health conditions is the concept of  
14 more research to determine whether early intervention makes a difference in  
15 certain outcomes.

16 **DR. ALDRICH:** It's hard to talk about early intervention when we're now 12  
17 and a half years out.

18 **MS. FLYNN:** Yeah.

19 **DR. WARD:** Well, it would have to be -- well, I mean, I guess it would have  
20 to be retrospective. I mean, it would have to be some kind of a retrospective study  
21 concerning people. I mean, people may have been diagnosed at one or two years  
22 post-exposure and some of them may have received an intervention. I don't --

23 **MS. SIDEL:** There's a, there's a gap between diagnosis and actual  
24 treatment. You know, you could be diagnosed when it was just a -- when it was just  
25 a -- you know, they were just doing diagnostic stuff and then it was a year or two  
26 before they opened up the treatment program. So for some people they -- if they  
27 didn't go to their private doctors to follow up on whatever happened in their, in  
28 their, I think it was called help for heroes appointment, there would be a big gap in  
29 treatment.

30 **DR. WARD:** Well, I guess, I mean, there may not -- may or may not be  
31 opportunities to look at it 'cause it's true, early intervention could require early  
32 diagnosis.

33 **MS. FLYNN:** This is Kimberly, and I guess the one example that I feel meets  
34 that standard is that Dr. Trasande is looking at cardiometabolic in disease in people  
35 exposed as children. And certainly if, if those start to show up, and one of the  
36 things he's seen in a pilot study is kids who have -- exposed kids who have high  
37 blood pressure but don't have, you know, the usual overweight -- you know, their,  
38 their weight is normal, they have high blood pressure. So he's looking at something  
39 like that, and certainly, you know, if this shows up in his study of, what, 250 exposed

1 kids, then that would provide a basis for early intervention to prevent, you know,  
2 chronic heart disease, et cetera, if I'm not mistaken.

3 **DR. WARD:** Yes. I think, though, the question is you want to -- I mean, I  
4 think where this might be most common is, is people who did or did not receive  
5 certain interventions for respiratory medicines or -- I mean, it does seem like it  
6 would be an important question to answer but it would require framing what, what  
7 the specific intervention was. And seeing whether the -- you know, the -- if  
8 everyone got treat -- if everyone who was diagnosed was treated pretty similarly,  
9 then I'm not sure you could study it. But if there are opportunities to compare  
10 people who were -- had similar conditions and some were diagnosed early and  
11 aggressively treated and others were maybe diagnosed but not aggressively treated.  
12 I mean, should we throw this open as a topic of research or do people think it's not  
13 likely enough to be approved and we don't want to put it on the list?

14 **MS. SIDEL:** The other thing is that even if you did get treated, it's not like  
15 you can be cured. It doesn't -- you know, it doesn't go away. It's just sort of  
16 managing symptoms.

17 **DR. WARD:** Clinicians? World Trade Center Program, what do you think?  
18 Do you want this in or do you want this not in?

19 **DR. ALDRICH:** This is Tom Aldrich. I favor not doing this just because we  
20 have more pressing issues about current treatments than about, about looking back  
21 at what happened 12 and a half years ago.

22 **DR. WARD:** Okay. So anyone strongly disagree with that? Okay. So then  
23 the question is --

24 **DR. MIDDENDORF:** I just do want to point out that you have the option of  
25 including it on the list and then giving it a low priority. That is one of your options.

26 **DR. ALDRICH:** Is this list exclusive; that is, no grant that addresses  
27 something that's not on this list will be considered?

28 **MS. SIDEL:** That's a good question.

29 **DR. MIDDENDORF:** No. What, what you provide to the, to the  
30 administrator will -- all of these things will be considered as part of a larger  
31 consideration. Information will be gathered from other sources as well. So this is  
32 just one avenue of gathering information about what the research needs are.

33 **DR. ALDRICH:** Okay.

34 **MS. SIDEL:** Can I raise something that's a new gap of knowledge or that's  
35 something that should be researched? Is that all right or are we past that?

36 **DR. WARD:** No, we're still on it. Ideally it's things related to types of  
37 treatment of WTC-related health conditions 'cause that's the -- that's the area of  
38 research gaps that we're, we're trying to flesh out now.

39 **MS. SIDEL:** Well, one thing that I'm concerned about, and I think it's gonna

1 get worse with cancer because the treatment is that side effects -- sorry about my  
2 dog -- side effects from medications. And I don't, you know, know if those things  
3 should get certified or if you can get treated for those or how that's going to work.

4 For example, Nexium causes -- hang on one second, sorry. You know,  
5 Nexium, which a lot of us take a couple times a day, you know, it causes  
6 osteoporosis; so do all the inhalers. I don't know if that's being monitored or  
7 tracked but it's something that can come up for people. It's a lot of side effects  
8 from a lot of medications, and I think, with the cancer drugs, that that's even more  
9 severe.

10 **DR. ALDRICH:** I think that's a really interesting concept because with --  
11 we've got a lot of things on the list of conditions associated with the World Trade  
12 Center, and maybe with all the drugs, we're bringing in a lot more conditions.

13 **MS. SIDEL:** Yeah, I don't think there's a way around it. I think that you  
14 create the conditions just because it just happens. But it's also interesting 'cause it's  
15 not something that, you know, when you're told -- when you're on Nexium -- note  
16 by the way, this could cause osteoporosis. You know, I found out about it on the TV  
17 commercial about Nexium. You know, 'cause it's just -- you just wouldn't think  
18 about it.

19 There's a lot of issues like that, and I think a lot of these medications, and  
20 especially for many of us who are on like multiple medications, it just compounds  
21 the initial effects of like one medication. And it's -- I mean, it's kind of like modern  
22 medicine but I think it, it's concerning.

23 **DR. ALDRICH:** Yeah, so that's all about risk benefit, right? So it's -- I mean, I  
24 think it would be very interesting to examine the risks versus benefit -- or the  
25 benefits versus drawbacks of taking World Trade Center-related medication.

26 **MS. SIDEL:** Well, and like what the options are because, if you're not taking  
27 Nexium and you can't do inhalers or you take nose spray that has, that has steroids  
28 in it, it's going to be bad for your glands, what are your -- what are your choices?  
29 There's not -- I mean, there are not very many other choices out there.

30 **MS. FLYNN:** So let's come up with the wording for this 'cause it seems to be  
31 a good idea. Can someone put -- articulate it well?

32 **MS. SIDEL:** Not me. I have cognitive issues. Let's see.

33 **MS. FLYNN:** How about studying the side effects of drugs that were  
34 administered to World Trade Center diseases? Of drugs administered to treat  
35 World Trade Center --

36 **MS. SIDEL:** Right.

37 **DR. ALDRICH:** I like it. Simple, the, the researcher can make with it -- make  
38 of it what he or she chooses.

39 **MS. HUGHES:** Yeah, and I remember some of the first responders also

1 complaining about -- in, in Washington.

2 **DR. WARD:** Okay, so do we have a motion for this?

3 **DR. MIDDENDORF:** Yeah, let me read it so that everybody is sure of what it  
4 is. Study the side effects of drugs administered for treatment of World Trade  
5 Center-related diseases.

6 **MS. FLYNN:** I like it.

7 **DR. MIDDENDORF:** So we need a motion and a second.

8 **MS. HUGHES:** Yes.

9 **DR. MIDDENDORF:** Yeah. Yes, you're submitting this as a motion?

10 **MS. HUGHES:** Yes, Catherine is.

11 **DR. MIDDENDORF:** Okay.

12 **DR. WARD:** And who is the second?

13 **DR. ALDRICH:** I'll second it. Tom Aldrich.

14 **DR. MIDDENDORF:** Okay. Are we ready for a vote, then? Tom Aldrich?

15 **DR. ALDRICH:** Yes.

16 **DR. MIDDENDORF:** John Dement?

17 **DR. DEMENT:** Yes.

18 **DR. MIDDENDORF:** Kimberly Flynn?

19 **MS. FLYNN:** Yes.

20 **DR. MIDDENDORF:** Bob Harrison?

21 **DR. HARRISON:** Yes.

22 **DR. MIDDENDORF:** Catherine Hughes?

23 **MS. HUGHES:** Yes.

24 **DR. MIDDENDORF:** Steve Markowitz?

25 **DR. MARKOWITZ:** No.

26 **DR. MIDDENDORF:** Guille Mejia?

27 **MS. MEJIA:** Yes.

28 **DR. MIDDENDORF:** Carol North?

29 **DR. NORTH:** Yes.

30 **DR. MIDDENDORF:** Julia Quint?

31 **DR. QUINT:** Yes.

32 **DR. MIDDENDORF:** Bill Rom?

33 **DR. ROM:** No.

34 **DR. MIDDENDORF:** Susan Sidel? Susan? Okay, I'm going to move on.  
35 Glenn Talaska?

36 **DR. TALASKA:** No.

37 **DR. MIDDENDORF:** Leo Trasande? Liz Ward?

38 **DR. WARD:** No.

39 **DR. MIDDENDORF:** Eight yes, four noes, zero abstentions. Okay, the

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motion passes.

Okay, Susan said you guys got disconnected?

**MS. SIDEL:** Yeah, I got disconnected, sorry.

**DR. MIDDENDORF:** Okay, did you want to vote on that motion?

**MS. SIDEL:** Yeah, what's the motion? How is it worded?

**DR. MIDDENDORF:** The motion says: Study the side effects of drugs administered for treatment of WTC-related diseases.

**MS. SIDEL:** Perfect. Yes.

**DR. MIDDENDORF:** Okay. Change that to nine yes and four noes. Motion passes.

**DR. WARD:** Okay, so let me just ask a question. Is the reason that we're not getting more ideas here in relation to treatment of respiratory diseases the fact that that's already the topic of a lot of research? Or is it just that the committee is getting tired?

**MS. SIDEL:** No, I think that it's been -- you know, I think it's, it's been a focus for, for all these years.

**DR. WARD:** Okay.

**MS. SIDEL:** I'm not -- not that there's probably not new things that are coming out but there's just so much work done on it, and I mean, it'll probably always continue but that's -- but that's one reason why we're not seeing any, anything new is because it's just -- there just keeps this focus going back on the stuff that's already been done, like some other nuance of it.

**DR. WARD:** Yeah, and I was probably being a little facetious but I think it is important that if, you know, we're really not coming up with a lot of recommendations on items 2 and 3, and I just want to make sure that the committee is, is considering these recommendations as thoroughly as they should because this is, this is our opportunity to influence the research agenda. And if we -- if there really are some topics that we haven't considered in the area of effective treatment of World Trade Center-related diseases, we should really take the time to think about them.

**MS. SIDEL:** Well, I brought up, you know, using EMDR to treat post-traumatic stress disorder, and then somehow that got turned into something else; I don't know what. But that's a really good treatment for PTSD, that they're not using it in the mental health feature at Mount Sinai anyway. I think that Kimberly said that they haven't (indiscernible) at Bellevue.

**DR. ALDRICH:** I do hear that there's a lot of controversy about what's effective and what isn't effective in treating PTSD, and shouldn't that be a focus?

**MS. SIDEL:** I just think that it's something that, that's out there and it's being used at -- you know, if it's being used at like other hospitals that are credible

1 and other credible programs, that maybe we should be able to use it. I know that a  
2 lot of volunteers, because they were -- because we were allowed to choose our own  
3 doctors, a lot of volunteers are seeing doctors that do EMDR, and the rate of -- just  
4 the success that they've had with, you know, coping with their PTSD has been, you  
5 know, tremendous, to the extent that you can see the change in people's  
6 personalities. You know, they go from being really angry all the time to being  
7 pleasant and sort of at peace. It's dramatic, dramatic changes, whereas --

8 **DR. ALDRICH:** If that is so dramatic, why isn't that the standard of care?  
9 And so, so shouldn't we be encouraging people to find out if it's really better than  
10 other treatments?

11 **MS. HUGHES:** This is Catherine. I may have a suggestion. I would -- I think  
12 this is important but I think it's broader than this. And I would say that there are an  
13 awful lot of treatments that are being explored for PTSD in various trauma settings  
14 but not enough work that is specific to disaster settings, and so I would like to  
15 broaden this to treatments in general for specific use in disaster populations.

16 And a second item that I think might be appropriate to include in this is  
17 better utilization of treatment in general, specifically for mental health. And that's  
18 it.

19 **MS. SIDEL:** Part of the problem with the mental health program is that  
20 there aren't a lot of people there that are really, really experienced. I mean, the one  
21 at Mount Sinai anyway.

22 You know, the first psychiatrist came to us straight out of school. And she  
23 was, she was wonderful. Our second psychiatrist came to us straight out of school.  
24 So they haven't had like a lot of like clinical practical experience. They don't have a  
25 lot of, you know, peers that have been practicing for a zillion years that can offer  
26 advice. It's just the way it is.

27 And I think that there's another -- a lot of volunteers because there wasn't --  
28 we were allowed to choose our own doctors. We, we have some different  
29 experiences, and I think that it's worth looking at, those experiences. It's not like  
30 everybody went to the same person that did EMDR, but a lot of people, you know, it  
31 definitely got around that it worked. And so --

32 **DR. NORTH:** So it's like (indiscernible) because there are other potential  
33 treatments like virtual exposure --

34 **MS. SIDEL:** Absolutely.

35 **DR. NORTH:** -- (indiscernible). I wouldn't want to single out one.

36 **MS. SIDEL:** Absolutely. Absolutely. I think you're right. I think absolutely.  
37 And I'm not saying that I know the best one but I'm just saying that there's definitely  
38 more out there than doing traditional like, you know, psychoanalysis and talking  
39 about your mommy. You know what I mean? It just -- that just takes forever and

1 doing it -- in the time that it's taking so long, you know, your life is ticking by.

2 **DR. NORTH:** Well, I don't think people generally -- that's not the state of  
3 the field, to use psychoanalysis for disaster-related PTSD.

4 **MS. SIDEL:** Well, that's what they're -- well, that's what they're doing.  
5 They've -- they have social workers who are talking to you about, you know, your --  
6 it's just like -- it's like traditional therapy, and I don't think it is effective.

7 **DR. WARD:** Well, Carol, could you give us some wording and propose a  
8 motion? Wording that Paul can get down?

9 **DR. NORTH:** Something to the effect of: To specifically investigate the  
10 effectiveness and utility of treatments for PTSD, specifically in disaster affected  
11 groups or individuals.

12 **DR. MIDDENDORF:** Okay, so what I have is: Specifically investigate the  
13 effectiveness and utility of -- wait, that's not right.

14 **DR. NORTH:** To investigate the effectiveness and utility of specific PTSD  
15 treatments in disaster-related settings.

16 **DR. MIDDENDORF:** Okay, you said, specific PTSD treatments? Are you sure  
17 you want that?

18 **DR. NORTH:** Well, --

19 **MS. SIDEL:** I think that's what it's about.

20 **DR. NORTH:** I don't want to -- I don't want to single any one out, but we  
21 want to test specific ones like, you know, if somebody has an interest in EMDR, if  
22 somebody has an interest in prolonged exposure, those specific therapies should be  
23 tested in disaster settings. They've been tested in more broad PTSD settings but not  
24 in disaster.

25 **DR. ALDRICH:** So get rid of the first specifically.

26 **DR. NORTH:** Yeah, it was overly long on specifics.

27 **DR. MIDDENDORF:** So the current wording is: Investigate the effectiveness  
28 and utility of specific PTSD treatments in disaster-affected groups or individuals.

29 **DR. ALDRICH:** Why not in WTC-affected groups or individuals?

30 **MS. SIDEL:** Right. That would be good.

31 **DR. NORTH:** Sure.

32 **DR. MARKOWITZ:** My only question with this one is, are we -- would it be  
33 setting investigators up to fail? Will there, will there be enough cases and will there  
34 be so that they'll be able to make, you know, significant -- or are we just planning on  
35 leaving it up to them?

36 **DR. NORTH:** I agree, and this is a problem because by now people are going  
37 to be really chronic and it's going to be much, much harder to treat. It would be far  
38 more interesting if we could be treating early on after. And this is why I was not  
39 enthusiastic about developing items specifically for treatment.

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**MS. SIDEL:** Well, you could continue the people that have had -- that have had EMDR, that went through the same disaster that got EMDR treatment.

**DR. NORTH:** This is really not as strong of a research design as we would like.

**MS. SIDEL:** Well, I mean, you can't -- it's like, you know, 13 years later so it's hard to be perfect but it would just show that -- it would maybe give some impetus for trying some EMDR or trying some other, you know, creative kinds of therapies at Mount Sinai's mental health.

**DR. NORTH:** I would be far more enthusiastic about trying to get people to treatment, who haven't come to treatment. So many people don't go --

**MS. SIDEL:** 'Cause they're not going to go to treatment because it doesn't work. This is what I'm telling you; it doesn't work. You know, you're sitting there with a social worker --

**DR. NORTH:** But there are people who have used the EMDR treatment that they could go to, and they haven't.

**MS. SIDEL:** Because maybe they can't afford it; they would have to pay for it. We don't offer EMDR treatment in the program. So they'd have to know about it and they'd have to have the resources to go pay for it.

**DR. NORTH:** But that's a utility issue, that the chance that people would go, is more interesting, scientifically.

**DR. ALDRICH:** Wouldn't that -- wouldn't investigators who wanted to investigate that be able to apply under this priority?

**MS. SIDEL:** You mean like have a grant that would pay for people to go?

**DR. ALDRICH:** No. I'm just saying this, this is one of the priorities, and an investigator who wants to do that study will look at this as a possible funding opportunity and have them compete for it. And if it's a good application, it might prevail. If it's not a good application, it's not gonna get funded.

**DR. NORTH:** That makes sense.

**MS. SIDEL:** All right, but still, all these people in the program that doesn't work and they're not getting anywhere with their lives 'cause they're just depressed and spinning. So well, they --

**DR. ALDRICH:** Look, we're all trying to -- we're all trying to help people, and some people don't get help and some people do. We do the best we can.

**MS. SIDEL:** Right, but if we have -- but if there's other ways to treat people that are stronger and better, that have more successful results, but --

**DR. ALDRICH:** And I don't --

**MS. SIDEL:** -- we should research it --

**DR. ALDRICH:** And I don't -- do not --

**MS. SIDEL:** -- well, we should be researching whether or not that's

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something that would be better for people.

**DR. ALDRICH:** That's why, that's why a priority like this should be in here. But it shouldn't be -- we shouldn't go in with the idea that one specific treatment's better than another, a specific unproven treatment.

**MS. SIDEL:** I didn't say that. I said any of the treatments; there's other treatments that they use, there's like cognitive something. There's another one that they use at Mass General that's like more advanced than EMDR; I don't remember the name of it. I'm not an expert at this stuff, but I'm just saying that there are other things that work and that I, I don't think that what's going on now will --

**DR. WARD:** Well, I mean --

**MS. SIDEL:** -- I mean, it's worth it to explore some things that could be an alternative.

**DR. ALDRICH:** I think we're all talking about the same thing. So this, this phraseology covers what we want to do, doesn't it? Can't we just accept this and move on?

**MS. SIDEL:** Well, what's the phraseology?

**DR. ALDRICH:** Investigate the effectiveness and utility of specific PTSD treatments in World Trade Center-affected groups or individuals.

**MS. SIDEL:** Well, I guess it's really vague. They could come up with anything. Like they could come up and say that what they're doing works.

**DR. ALDRICH:** That's the point. And if the science is good, then it will get funded. If the science is not good, it will not get funded.

**MS. SIDEL:** Okay.

**DR. WARD:** So I think we have the motion to -- who will propose the motion?

**DR. NORTH:** This is Carol. I guess I'm the one that proposed the wording so I'll move that we vote on the wording.

**DR. WARD:** Okay, and then do we have a second?

**DR. ALDRICH:** I'll second it.

**DR. MIDDENDORF:** Okay, so the motion on the table is: Investigate the effectiveness and utility of specific PTSD treatments in World Trade Center-affected groups or individuals. And going to the vote, Tom Aldrich?

**DR. ALDRICH:** Yes.

**DR. MIDDENDORF:** John Dement?

**DR. DEMENT:** Yes.

**DR. MIDDENDORF:** Kimberly Flynn? Kimberly, are you with us? I'm not hearing you so we'll move on to Bob Harrison? Bob, are you there? Not hearing anything. Catherine Hughes?

**MS. HUGHES:** Yes.

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**DR. MIDDENDORF:** Steve Markowitz?

**DR. MARKOWITZ:** Yes.

**DR. MIDDENDORF:** Guille Mejia?

**MS. MEJIA:** Yes.

**DR. MIDDENDORF:** Carol North?

**DR. NORTH:** Yes.

**DR. MIDDENDORF:** Julia Quint?

**DR. QUINT:** Yes.

**DR. MIDDENDORF:** Bill Rom?

**DR. ROM:** Yes.

**DR. MIDDENDORF:** Susan Sidel?

**MS. SIDEL:** Yes.

**DR. MIDDENDORF:** Glenn Talaska?

**DR. TALASKA:** Yes.

**DR. MIDDENDORF:** Leo Trasande? Liz Ward?

**DR. WARD:** Yes.

**MS. FLYNN:** Paul? It's Kimberly, I'm sorry. Yes.

**DR. MIDDENDORF:** Yes, okay. So that goes to 12 yes, zero noes and zero abstentions.

And I'll point out that we have about ten minutes left.

**DR. WARD:** Okay, so I would propose that we move from the generation of ideas under these three categories to see if there's any sort of priority setting that we can do at this point in time.

**DR. ALDRICH:** I think it's very clear that number 9 goes to the bottom.

**DR. WARD:** All right. I'm getting back into the site so that I can see what number 9 is.

**DR. ALDRICH:** It's the one that wasn't unanimous.

**DR. MIDDENDORF:** Number 9 is: Study the side effects of drugs administered for treatment of World Trade Center-related diseases.

**DR. WARD:** So is that the only differentiation we want to make at this point? Or do we want to indicate that some of these are -- the committee feels are especially high priorities?

**MS. FLYNN:** This is Kimberly. I feel that assess the health effects of WTC exposures on gestation and early life has to be a very high priority.

There are approximately 35,000 children who were exposed to WTC, and very little is known about the physical health effects on those children. In fact the first actual clinical study of physical health effects was not funded until 2013. So they are, you know, a vulnerable population and they are in fact the least studied of any WTC disaster population.

1 Also I would point out that this is a rapidly dispersing population, so really,  
2 certainly those of us in the survivor community feel that NIOSH has to make up for  
3 lost time and double down on this research.

4 **DR. ALDRICH:** One and three should be high priority.

5 **DR. WARD:** Okay, that --

6 **DR. MIDDENDORF:** Wait. Say that again?

7 **DR. ALDRICH:** I think 1 and 3 (indiscernible).

8 **DR. WARD:** So that could be a limited (indiscernible). We're getting some  
9 interference from background noise. Could whoever has it go on mute?

10 Okay, so why don't you put that in the form of a motion?

11 **MS. FLYNN:** Is that directed at me?

12 **DR. WARD:** I think, I think one person said, said -- let's see, one person said  
13 1 and 3 and then -- actually that's true. One person said 1 and 3, and another  
14 person said 4. So we could have one person make a motion to have all three be top  
15 priority or we could vote one by one.

16 **DR. NORTH:** This is Carol. I would like to add the exposure in mental health  
17 item as priority.

18 **UNIDENTIFIED SPEAKER:** [expletive deleted] you, no.

19 **DR. WARD:** Okay. So we --

20 **DR. MARKOWITZ:** Could we just vote as we go through each one and have  
21 each person say whether they think it's high, medium or low?

22 **MS. FLYNN:** Can you email the list around about where we currently --

23 **DR. MIDDENDORF:** I did that about two minutes ago.

24 **DR. WARD:** That might be the best thing to do given the limited time.  
25 Maybe we can just -- is it possible to just go through each of them and have each  
26 person say whether they think it's high, medium and -- or low and tabulate the  
27 results?

28 **DR. MIDDENDORF:** We can do that. How do you propose that we then  
29 consolidate that information?

30 **DR. WARD:** Well, we just make a table that says X number -- for, for item 1.

31 **DR. MIDDENDORF:** Okay, so all we're doing is we're identifying, say for  
32 motion number 1, five people thought it was high, two people thought it was  
33 medium and one person thought it was low. Is that what you're suggesting?

34 **DR. WARD:** Yeah, 'cause I can't see any other way to use the last nine  
35 minutes.

36 **DR. MIDDENDORF:** All right.

37 **DR. MARKOWITZ:** That would be my suggestion, yeah.

38 **DR. WARD:** Or if we need to make it simpler, we could just ask, you know,  
39 people whether they think it's high or not, and just do it high versus not high.

1                   **MS. FLYNN:** That might be quicker in the time remaining.  
2                   **DR. WARD:** Yeah.  
3                   **DR. MARKOWITZ:** Yeah, I think high versus not high makes sense.  
4                   **DR. MIDDENDORF:** Okay. How about if we just do it this way so that we  
5 get a -- kind of a yes or no vote. Just do motion number 1, and then how many  
6 people think it's a high priority; motion number 2, how many people think it's a high  
7 priority.  
8                   **DR. WARD:** Okay.  
9                   **DR. MIDDENDORF:** Then we get the same information that way.  
10                  **DR. WARD:** But you still have to go through all the names for each one, I  
11 think.  
12                  **DR. MIDDENDORF:** I'll do a roll call on each one for its priority.  
13                  **DR. ALDRICH:** You're gonna have to do that real quick.  
14                  **DR. MIDDENDORF:** Yeah. Okay. Motion 1, is this a high priority, Tom  
15 Aldrich?  
16                  **DR. ALDRICH:** Yes.  
17                  **DR. MIDDENDORF:** John Dement?  
18                  **DR. DEMENT:** Yes.  
19                  **DR. MIDDENDORF:** Kimberly?  
20                  **MS. FLYNN:** Yes.  
21                  **DR. MIDDENDORF:** Bob? Catherine?  
22                  **MS. HUGHES:** Yes.  
23                  **DR. MIDDENDORF:** Steve?  
24                  **DR. MARKOWITZ:** Yes.  
25                  **DR. MIDDENDORF:** Guille?  
26                  **MS. MEJIA:** Yes.  
27                  **DR. MIDDENDORF:** Carol?  
28                  **DR. NORTH:** Yes.  
29                  **DR. MIDDENDORF:** Julia?  
30                  **DR. QUINT:** Yes.  
31                  **DR. MIDDENDORF:** Bill?  
32                  **DR. ROM:** Yes.  
33                  **DR. MIDDENDORF:** Susan?  
34                  **MS. SIDEL:** Yes.  
35                  **DR. MIDDENDORF:** Glenn?  
36                  **DR. TALASKA:** Yes.  
37                  **DR. MIDDENDORF:** Leo? Liz?  
38                  **DR. WARD:** Yes.  
39                  **DR. MIDDENDORF:** One, two, three, four, five, six, seven, eight, nine, ten,

1 eleven, twelve yeses. So the motion was -- motion 1 is a high priority. And we had,  
2 what was the number, 12? Okay. Okay.

3 Motion 2 is a high priority. Characterize the disaster-related exposures that  
4 are associated with the development of specific psychiatric disorders.

5 Tom, is that a high priority?

6 **DR. ALDRICH:** No.

7 **DR. MIDDENDORF:** I'm sorry?

8 **DR. ALDRICH:** No.

9 **DR. MIDDENDORF:** No, I'm -- okay, thank you. John?

10 **DR. DEMENT:** No.

11 **DR. MIDDENDORF:** Kimberly.

12 **MS. FLYNN:** No.

13 **DR. MIDDENDORF:** Bob? Catherine.

14 **MS. HUGHES:** No.

15 **DR. MIDDENDORF:** Steve?

16 **DR. MARKOWITZ:** No.

17 **DR. MIDDENDORF:** Guille?

18 **MS. MEJIA:** No.

19 **DR. MIDDENDORF:** Carol?

20 **DR. NORTH:** I'll stick with my yes.

21 **DR. MIDDENDORF:** Julia?

22 **DR. QUINT:** No.

23 **DR. MIDDENDORF:** Bill?

24 **DR. ROM:** No.

25 **DR. MIDDENDORF:** Susan?

26 **MS. SIDEL:** No.

27 **DR. MIDDENDORF:** Glenn? Glenn? I'm sorry, what? Glenn?

28 **DR. TALASKA:** No.

29 **DR. MIDDENDORF:** Thank you. Leo? Liz?

30 **DR. WARD:** Yes -- oh, no. Sorry, no.

31 **DR. MIDDENDORF:** Okay. One yes, 11 no, zero abstentions.

32 Motion 3: Determine the value of biomarkers for early detection of  
33 precancerous conditions, early cancers or other WTC-associated diseases. Is this a  
34 high priority? Tom?

35 **DR. ALDRICH:** Yes.

36 **DR. MIDDENDORF:** John?

37 **DR. DEMENT:** Yes.

38 **DR. MIDDENDORF:** Kimberly?

39 **MS. FLYNN:** Yes.

1 **DR. MIDDENDORF:** Bob? Catherine?  
2 **MS. HUGHES:** Yes.  
3 **DR. MIDDENDORF:** Steve?  
4 **DR. MARKOWITZ:** No.  
5 **DR. MIDDENDORF:** Guille?  
6 **MS. MEJIA:** I'm going to abstain.  
7 **DR. MIDDENDORF:** Carol?  
8 **DR. NORTH:** Yes.  
9 **DR. MIDDENDORF:** Julia?  
10 **DR. QUINT:** Yes.  
11 **DR. MIDDENDORF:** Bill?  
12 **DR. ROM:** Yes.  
13 **DR. MIDDENDORF:** Susan?  
14 **MS. SIDEL:** Yes.  
15 **DR. MIDDENDORF:** Glenn?  
16 **DR. TALASKA:** Yes.  
17 **DR. MIDDENDORF:** Leo? Liz?  
18 **DR. WARD:** Yes.  
19 **DR. MIDDENDORF:** Okay, one, two, three, four, five, six, seven, eight, nine,  
20 ten yes; one no, one abstention. Okay, motion passes. That was motion 3.  
21 Motion 4: Assess health effects of WTC exposure on gestation and early life,  
22 childhood and adolescence. So Tom, is this a high priority?  
23 **DR. ALDRICH:** Yes.  
24 **DR. MIDDENDORF:** John?  
25 **DR. DEMENT:** Yes.  
26 **DR. MIDDENDORF:** Kimberly?  
27 **MS. FLYNN:** Yes.  
28 **DR. MIDDENDORF:** Bob? Catherine?  
29 **MS. HUGHES:** Yes.  
30 **DR. MIDDENDORF:** Steve?  
31 **DR. MARKOWITZ:** Yes.  
32 **DR. MIDDENDORF:** Guille?  
33 **MS. MEJIA:** Yes.  
34 **DR. MIDDENDORF:** Carol?  
35 **DR. NORTH:** Yes.  
36 **DR. MIDDENDORF:** Julia?  
37 **DR. QUINT:** Yes.  
38 **DR. MIDDENDORF:** Bill?  
39 **DR. ROM:** Yes.

1 **DR. MIDDENDORF:** Susan?  
2 **MS. SIDEL:** Yes.  
3 **DR. MIDDENDORF:** Glenn?  
4 **DR. TALASKA:** Yes.  
5 **DR. MIDDENDORF:** Leo? Liz?  
6 **DR. WARD:** Yes.  
7 **DR. MIDDENDORF:** Okay. That's 12 yes, zero no, zero abstentions. That  
8 motion passes.  
9 Okay, motion 5 is a high priority. Motion 5 is: Improved assessment of WTC  
10 exposure: inhaled, topical, ingested or other. Okay. Tom Aldrich?  
11 **DR. ALDRICH:** No.  
12 **DR. MIDDENDORF:** John Dement?  
13 **DR. DEMENT:** Yes.  
14 **DR. MIDDENDORF:** Kimberly?  
15 **MS. FLYNN:** No.  
16 **DR. MIDDENDORF:** Bob? Catherine?  
17 **MS. HUGHES:** Medium.  
18 **DR. MIDDENDORF:** Yes or no.  
19 **MS. HUGHES:** No.  
20 **DR. MIDDENDORF:** Steve?  
21 **DR. MARKOWITZ:** Yes.  
22 **DR. MIDDENDORF:** Guille?  
23 **MS. MEJIA:** Yes.  
24 **DR. MIDDENDORF:** Carol?  
25 **DR. NORTH:** Yes.  
26 **DR. MIDDENDORF:** Julia?  
27 **DR. QUINT:** Yes.  
28 **DR. MIDDENDORF:** Bill?  
29 **DR. ROM:** No.  
30 **DR. MIDDENDORF:** Susan?  
31 **MS. SIDEL:** Not sure. I guess I'll say no.  
32 **DR. MIDDENDORF:** Glenn?  
33 **DR. TALASKA:** Yes.  
34 **DR. MIDDENDORF:** Leo? Liz?  
35 **DR. WARD:** No.  
36 **DR. MIDDENDORF:** Okay. One, two, three, four, five, six yes, six no.  
37 Motion 6. I'm assuming everybody is okay with the shorthand way of doing  
38 our motions?  
39 **UNIDENTIFIED SPEAKER:** Yes.

1 **DR. MIDDENDORF:** Okay.  
2 **UNIDENTIFIED SPEAKER:** Yes.  
3 **DR. MIDDENDORF:** Okay. Motion 6 is: Evaluate and improve the utility and  
4 use of WTCHP data and activities for the purpose of active surveillance of health  
5 conditions in WTC-exposed populations and/or develop improved surveillance  
6 methods.  
7 Okay, so Tom Aldrich, is this a high priority?  
8 **DR. ALDRICH:** Yes.  
9 **DR. MIDDENDORF:** John?  
10 **DR. DEMENT:** Yes.  
11 **DR. MIDDENDORF:** Kimberly?  
12 **MS. FLYNN:** Yes.  
13 **DR. MIDDENDORF:** Bob? Catherine?  
14 **MS. HUGHES:** Yes.  
15 **DR. MIDDENDORF:** Steven?  
16 **DR. MARKOWITZ:** Yes.  
17 **DR. MIDDENDORF:** Guille?  
18 **MS. MEJIA:** Yes.  
19 **DR. MIDDENDORF:** Carol?  
20 **DR. NORTH:** Yes.  
21 **DR. MIDDENDORF:** Julia?  
22 **DR. QUINT:** Yes.  
23 **DR. MIDDENDORF:** Bill?  
24 **DR. ROM:** Yes.  
25 **DR. MIDDENDORF:** Susan?  
26 **MS. SIDEL:** Yes.  
27 **DR. MIDDENDORF:** Glenn?  
28 **DR. TALASKA:** Yes.  
29 **DR. MIDDENDORF:** Leo? Liz?  
30 **DR. WARD:** Yes.  
31 **DR. MIDDENDORF:** So that's 12 yes, zero no, zero abstentions.  
32 Motion 7. Seven is: Differentiate psychiatric disorders from symptoms and  
33 distress in relation to disaster exposure and develop efficient and effective methods  
34 for diagnosis of disaster-related psychopathology in populations and individuals.  
35 Tom, is this a high priority?  
36 **DR. ALDRICH:** Yes.  
37 **DR. MIDDENDORF:** John?  
38 **DR. DEMENT:** No.  
39 **DR. MIDDENDORF:** Kimberly?

1 **MS. FLYNN:** Yes.  
2 **DR. MIDDENDORF:** Bob? Catherine?  
3 **MS. HUGHES:** No.  
4 **DR. MIDDENDORF:** Steve?  
5 **DR. MARKOWITZ:** Yes.  
6 **DR. MIDDENDORF:** Guille?  
7 **MS. MEJIA:** Yes.  
8 **DR. MIDDENDORF:** Carol?  
9 **DR. NORTH:** Yes.  
10 **DR. MIDDENDORF:** Julia?  
11 **DR. QUINT:** Yes.  
12 **DR. MIDDENDORF:** Bill?  
13 **DR. ROM:** No.  
14 **DR. MIDDENDORF:** Susan?  
15 **MS. SIDEL:** No.  
16 **DR. MIDDENDORF:** Glenn?  
17 **DR. TALASKA:** Yes.  
18 **DR. MIDDENDORF:** Leo? Liz?  
19 **DR. WARD:** Yes.  
20 **DR. MIDDENDORF:** Okay. Nine yes, three noes, zero abstentions.  
21 Motion 8 was or is: Examine the patterns of healthcare utilization and  
22 delivery in the World Trade Center Health Program and the value and efficacy of  
23 medical monitoring activities of the World Trade Center Health Program.  
24 Is this a high priority, Tom?  
25 **DR. ALDRICH:** No.  
26 **DR. MIDDENDORF:** John?  
27 **DR. DEMENT:** Yes.  
28 **DR. MIDDENDORF:** Kimberly?  
29 **MS. FLYNN:** Yes.  
30 **DR. MIDDENDORF:** Bob? Catherine?  
31 **MS. HUGHES:** Yes.  
32 **DR. MIDDENDORF:** Steve?  
33 **DR. MARKOWITZ:** Yes.  
34 **DR. MIDDENDORF:** Guille?  
35 **MS. MEJIA:** Yes.  
36 **DR. MIDDENDORF:** Carol?  
37 **DR. NORTH:** Yes.  
38 **DR. MIDDENDORF:** Julia?  
39 **DR. QUINT:** Yes.

1 **DR. MIDDENDORF:** Bill?  
2 **DR. ROM:** Yes.  
3 **DR. MIDDENDORF:** Susan?  
4 **MS. SIDEL:** Yes.  
5 **DR. MIDDENDORF:** Glenn?  
6 **DR. TALASKA:** Yes.  
7 **DR. MIDDENDORF:** Leo? Liz?  
8 **DR. WARD:** Yes.  
9 **DR. MIDDENDORF:** Okay. One no and 11 yes. No abstentions.  
10 Motion 9: Study the side effects of drugs administered for treatment of  
11 WTC-related diseases.  
12 Tom, is this a high priority?  
13 **DR. ALDRICH:** No.  
14 **DR. MIDDENDORF:** John?  
15 **DR. DEMENT:** No.  
16 **DR. MIDDENDORF:** Kimberly?  
17 **MS. FLYNN:** No.  
18 **DR. MIDDENDORF:** Bob? Catherine?  
19 **MS. HUGHES:** No.  
20 **DR. MIDDENDORF:** Steven?  
21 **DR. MARKOWITZ:** No.  
22 **DR. MIDDENDORF:** Guille?  
23 **MS. MEJIA:** No.  
24 **DR. MIDDENDORF:** Carol?  
25 **DR. NORTH:** No.  
26 **DR. MIDDENDORF:** Julia.  
27 **DR. QUINT:** No.  
28 **DR. MIDDENDORF:** Bill?  
29 **DR. ROM:** No.  
30 **DR. MIDDENDORF:** Susan?  
31 **MS. SIDEL:** Yes.  
32 **DR. MIDDENDORF:** Glenn?  
33 **DR. TALASKA:** No.  
34 **DR. MIDDENDORF:** Leo? Liz?  
35 **DR. WARD:** No.  
36 **DR. MIDDENDORF:** Okay. One yes and 11 no. Okay.  
37 And motion 10 was: Investigate the effectiveness and utility of specific  
38 PTSD treatments in WTC-affected groups or individuals.  
39 Okay, Tom, is this a high priority?

1                   **DR. ALDRICH:** No.  
2                   **DR. MIDDENDORF:** John?  
3                   **DR. DEMENT:** No.  
4                   **DR. MIDDENDORF:** Kimberly?  
5                   **MS. FLYNN:** Yes.  
6                   **DR. MIDDENDORF:** Bob? Catherine?  
7                   **MS. HUGHES:** Yes.  
8                   **DR. MIDDENDORF:** Steven?  
9                   **DR. MARKOWITZ:** No.  
10                  **DR. MIDDENDORF:** Guille?  
11                  **MS. MEJIA:** Yes.  
12                  **DR. MIDDENDORF:** Carol?  
13                  **DR. NORTH:** No.  
14                  **DR. MIDDENDORF:** Julia?  
15                  **DR. QUINT:** Yes.  
16                  **DR. MIDDENDORF:** Bill?  
17                  **DR. ROM:** No.  
18                  **DR. MIDDENDORF:** Susan?  
19                  **MS. SIDEL:** Yes.  
20                  **DR. MIDDENDORF:** Glenn?  
21                  **DR. TALASKA:** No.  
22                  **DR. MIDDENDORF:** Leo? Liz?  
23                  **DR. WARD:** Yes.  
24                  **DR. MIDDENDORF:** Okay. One, two, three, four, five, six, seven yes, five no.  
25                  **DR. WARD:** I think that is a helpful metric that we can use. I think Dr.  
26                  Howard will find that helpful. Paul?  
27                  **DR. MIDDENDORF:** Yes, I'm, I'm here.  
28                  **DR. WARD:** Okay.  
29                  **DR. MIDDENDORF:** Sorry. Trying to do some quick cleaning here.  
30                  **DR. WARD:** Good.  
31                  **DR. TALASKA:** You're doing a great job, Paul.

### **ADMINISTRATIVE ISSUES AND ADJOURN**

34                  **DR. MIDDENDORF:** Well, okay. So what is the committee going to do?  
35                  What, what are you planning to do with this or how do you want to present this  
36                  information to Dr. Howard?  
37                  **DR. WARD:** Well, Paul, I mean, we could either draft a cover letter or you  
38                  could just -- I mean, you could circulate the list and the tabulations. And then unless  
39                  anyone has any questions, we could just provide that to Dr. Howard?

1                   **DR. MIDDENDORF:** Yeah, I think even if I send it out to folks, if they  
2 disagree with something that's on it, there's nothing that, that can be done about it.  
3                   **DR. WARD:** Yeah. So I would say let's just send it to Dr. Howard. We really  
4 don't have time to talk about -- and then first, there'll be the transcript, and  
5 certainly NIOSH staff could look at the transcript and, and help Dr. Howard identify  
6 the discussion points that are most relevant to his decision-making.  
7                   **DR. MIDDENDORF:** Yeah, and I will let you know that we have combed  
8 mightily through in great detail through the previous transcripts as we've been  
9 writing regulations. So the -- not just the information but what people say and how  
10 they say it are used to a considerable extent. So what you say in the meetings is  
11 valuable and is considered to be important.  
12                  **DR. WARD:** Good.  
13                  **DR. MIDDENDORF:** So --  
14                  **DR. WARD:** And it's interesting, I have read through the transcripts, 'cause  
15 it's one of my roles as the Chair to say that I believe they're accurate, and it is  
16 remarkable, sometimes it's embarrassing how you make, you know, you don't use  
17 the English language as well as you wish you did, but there really are some very  
18 useful discussions in those, in those transcripts.  
19                  **DR. MIDDENDORF:** Very much so. So the disposition from the -- what the  
20 committee intends to do, then, is for me to provide this document to Dr. Howard as  
21 the -- their report. Is that what you're telling me?  
22                  **DR. WARD:** I think so. That would be my recommendation.  
23                  **DR. MIDDENDORF:** How do people feel about that?  
24                  **MS. FLYNN:** Well, it sounds good.  
25                  **DR. MIDDENDORF:** Any dissensions?  
26                  **DR. TALASKA:** It's the product of our day.  
27                  **DR. MIDDENDORF:** Sorry?  
28                  **DR. TALASKA:** It's the product of our day.  
29                  **DR. MIDDENDORF:** Yeah. Okay. Well, since that is what I'm hearing from  
30 the committee, that is what I will do, and I will send a copy of this out to everyone  
31 so you know what it is and how it all turned out, exactly what happened.  
32 Transcripts will be available in a number of weeks.  
33                  I also want to thank each of you for muscling through this very difficult  
34 meeting. The promise of technology often doesn't measure up to what is really  
35 needed. And we struggled through, and I very much appreciate your hanging in  
36 there and muscling through it with me.  
37                  **MS. SIDEL:** Thank you for doing it.  
38                  **DR. WARD:** Thank you, Paul  
39                  **UNIDENTIFIED SPEAKER:** Thank you.

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**MS. HUGHES:** Thank you, Paul. Thank you, Liz.

**DR. ROBISON:** Hey, Paul, this is Allen. I would second that. And I've been listening, and Travis has been listening. It's very helpful to us to listen to the discussions and the sort of the struggles and challenges that you wrestle with in the time that you have to do this, so thank you.

**DR. WARD:** Thank you.

**DR. MIDDENDORF:** Well, with that, I guess we're closing the meeting?

**MS. SIDEL:** So if I'm unhappy about something, could I write a separate letter?

**DR. MIDDENDORF:** You can write something to the administrator at any time.

**MS. SIDEL:** Okay. Thank you.

**DR. MIDDENDORF:** Thank you, everybody.

**DR. WARD:** Have a good weekend everyone. Take care. Bye-bye.

(Whereupon, the meeting was adjourned, 5:10 p.m.)

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**CERTIFICATE OF COURT REPORTER****STATE OF GEORGIA  
COUNTY OF FULTON**

I, Steven Ray Green, Certified Merit Court Reporter, do hereby certify that I reported the above and foregoing on the day of February 14, 2014; and it is a true and accurate transcript of the proceedings captioned herein.

I further certify that I am neither relation nor counsel to any of the parties herein, nor have any interest in the cause named herein.

WITNESS my hand and official seal this the 9th day of March, 2014.

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**STEVEN RAY GREEN, CCR, CVR-CM, PNSC  
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