Verbatim transcript

Meeting of the Scientific/Technical Advisory Committee (STAC)
World Trade Center (WTC) Health Program

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CONTENTS

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Alijah James - Young Survivor Presenter
Jessica Petrow-Cohen - Young Survivor Presenter

Vittoria Fariello - Public Comment
Benjamin Chevat - Public Comment

Jordan Chanin-Albanese - Public Comment
Barbara Capparelli - Public Comment
Sacha Garcia - Public Comment
Taylor Banning - Public Comment
Rachel Lidov - Public Comment
Olivia Goodkind - Public Comment
Kimberly Flynn - Public Comment
David Prezant - Public Comment
Heidi Alexander - Public Comment

Wednesday, June 22, 2023

WELCOME AND INTRODUCTION, MEETING LOGISTICS

DR. CARREÓN-VALENCIA: I'm going to get started. I appreciate your patience. Thank you and good morning and welcome to the meeting of the Scientific/Technical Advisory Committee, also known as STAC. My name is Tania Carreón-Valencia, and I am the Designated Federal Officer for this Committee. I would like to extend a very warm welcome to all the members of the Committee that are joining us today, also to our presenters, the NIOSH staff that are also joining, and also to the public that is following the meeting via webcast.

It is a custom in our meetings to ask for a moment of silence to remember the people that were killed during the terrorist attacks of September 11, 2001. We also remember those responders and survivors that have died since then, as well as others who have died or suffered from terrorist attacks around the world.

[Moment of silence.]

Thank you. Before I hand the meeting to our Chair, I would like to remind you that the STAC is subject to the rules and regulations of the Federal Advisory Committee Act or FACA. For that reason, we develop meeting—minutes for our meetings. So please be aware it's being recorded, and you will see a block that says Transcription there, and it's also being recorded to produce the minutes that will be posted on the Committee's website in a few weeks. I have asked members of the Committee to refrain from communicating among themselves by text, email, or any other means regarding the matters that will be discussed at the meeting in the next two days. Member communication is part of the public record, and it will be added to the minutes of the meeting. There is also another FACA rule that relates to public comments. Members of the public can submit comments to the STAC to consider as it develops advice for the Administrator. And one way is for members of the public (audio break @ 00:06:05). We did not receive any comment, written comments by snail mail. Another way is to provide online comment on the NIOSH docket on the regulation.gov website and, as of

10:55 a.m. this morning, we have received one comment on the docket. Members of the Committee have been asked to monitor the docket and read the comments. The docket will close tomorrow at midnight. The other way to provide comments is to sign up to present at the meeting during the designated times for public comment. Today that will happen at 11:45 Eastern Daylight Time and tomorrow at 11:05 a.m. Eastern Daylight Time—Daylight Savings Time. And there are six commenters in each period who will have five minutes each to provide their comment. All comments will also be part of the public record.

So also, under FACA rules, we need to do a roll call of Committee members at the beginning of the meeting and after each of the breaks so we can ensure that we have a quorum. As I call your name, please unmute yourself and indicate your presence for the record, and if there are situations that would change your conflict-of-interest status since you last filed, filled out your OGE 450 form. And if you have to leave the meeting at any point, I ask for members to please let me know when you leave and let me know if you return. We need to make sure that we keep quorum at every time, and for the STAC, that is nine.

So, I'm going to start with our Chair. Liz Ward?

DR. WARD: Present, no changes.

DR. CARREÓN-VALENCIA: Sophie Balk?

DR. BALK: Present, no changes.

DR. CARREÓN-VALENCIA: Thank you. John Comiskey?

DR. COMISKEY: Present, no changes.

DR. CARREÓN-VALENCIA: Thank you. Chandra Davis.

MS. DAVIS: Present, no changes.

DR. CARREÓN-VALENCIA: Joanna Gaitens?

DR. GAITENS: Present, no changes.

DR. CARREÓN-VALENCIA: Mridu Gulati said she will join later. Mariama James? She will join later. Anita Jose? Indrina Kanth won't be able to join today. Michael Larrañaga?

DR. LARRAÑAGA: Present, no changes.

DR. CARREÓN-VALENCIA: Steven Markowitz might not be able to join. John Meyer? Debra Milek?

DR. MILEK: Present, no changes.

DR. CARREÓN-VALENCIA: Lawrence Mohr? I don't think he'll be able to join. Jason Ostrowe?

DR. OSTROWE: Present, no changes.

DR. CARREÓN-VALENCIA: Aarti Surti?

DR. SURTI: Present, no changes.

DR. CARREÓN-VALENCIA: Glenn Talaska? He might not be able to join. So right now, we have nine people, so we just barely made quorum. So, like I said, it's very important you let me know if, for any reason, you have to leave.
So we are ready to start so I turn it over to Dr. Ward. Thank you, Liz.

AGENDA AND ANNOUNCEMENTS

DR. WARD: Thank you, Tania, and I join you in welcoming everyone who's here to the meeting today, and I'll just turn the meeting over to Dr. Howard for his opening remarks.

OPENING REMARKS AND CHARGE

DR. HOWARD: Well, thank you, Dr. Ward, and good morning, everybody, and welcome to everybody, all nine of you, for the Fifteenth Meeting of the Scientific/Technical Advisory Committee for the World Trade Center Health Program. I want to thank each of you for taking time from your busy schedules to participate in the Committee and to offer your advice about the Administrator's charge to the Committee.
I have three issues about which I seek your advice. First is the youth cohort. In December of 2022, the Consolidated Appropriations Act of 2023 amended section 3341 of the Public Health Service Act to direct the Administrator, in consultation with the Secretary of the U.S Department of Education, to establish a new research cohort to conduct future research studies on the health and educational impacts of, quote, "exposure to airborne toxins, or any other hazard or adverse condition, resulting from the September 11, 2001 terrorist attacks, including on the population of individuals who were 21 years of age or younger at the time of exposure, including such individuals who are screening-eligible World Trade Center survivors or certified-eligible World Trade Center survivors," unquote.
The cohort may include individuals who were 21 years of age or younger

on September 11, 2001, who were located outside the New York City Disaster Area, and in Manhattan not further north than 14th Street; or anywhere within the borough of Brooklyn. Additionally, the cohort may include age-appropriate control populations as needed for research purposes. I propose an approach for establishing the youth cohort consisting of four phases, which will be explained in detail by Dr. Doug Daniels.

I seek advice from the STAC regarding four aspects, first, the proposed four-phase approach for establishing the youth cohort, including the sufficiency of community involvement; second, potential partnerships for establishing the youth cohort; third, ideas regarding outreach, recruitment, retention, and project oversight; and fourth, anticipated barriers to forming a cohort that can adequately support future research studies, for example, representativeness, insufficient statistical power, information biases, and selection biases, and any potential strategies that address those barriers.

To inform your recommendations, I have invited Dr. Joan Reibman, Professor in the Department of Medicine at the New York University Grossman School of Medicine and Medical Director of the Health + Hospitals World Trade Center Environmental Health Center, to present an overview of young survivors. The World Trade Center Health Program Survivors' Steering Committee, chaired by Ms. Kimberly Flynn, will provide you young survivors' views.

Second today is the Policy and Procedures for Adding Non-Cancer Health Conditions to the List of World Trade Center-Related Health Conditions. You will also receive an update on the revisions made to the Policy and Procedures following the STAC's recommendations at their meeting on February 9, 2023. The presentation by Dr. Doug Daniels will detail further revisions made to the Policy and Procedures in response to recommendations of the STAC, as well as substantive changes that include additional descriptions of the Bradford Hill criteria used in the Science Team's evaluation. I request the STAC's advisory recommendations and concurrence with the revised Policy and Procedures so that it can be finalized for Program implementation.

Third relates to peer reviewers. Dr. Carreón-Valencia and I would

appreciate the STAC's suggestions of peer reviewers for proposed additions to the List of World Trade Center-Related Health Conditions. Again, I thank you for your service for the Committee, on the Committee, and being here today, and have a great meeting today. Back to you, Dr. Ward.

DR. WARD: Thank you, Dr. Howard, and we'll move right on to the next presentation by Dr. Daniels.

YOUTH COHORT LEGISLATION AND PROGRAM'S PERSPECTIVES

DR. DANIELS: Thank you. I think Mia is going to start my slides, or am I going to share my screen?

DR. CARREÓN-VALENCIA: She is going to share that.

MS. WALLACE: I am going to share your screen.

DR. DANIELS: Okay. While Mia is bringing up the presentation, I just want to say most of—I have only a few slides and most of them are going to reiterate what you heard from Dr. Howard, and then we'll have a little bit of time for some questions. Mia, once you bring—yes, go ahead to the first slide, if you would please. Thank you.

So, as Dr. Howard mentioned, the Omnibus Bill in the late December, December 29 of 2022, provided us language for a very interesting project for the Program. And specifically, it's the development of a youth research cohort. And the language is, with the Administrator, in consultation with the Secretary of Education, will establish a research cohort of sufficient size to conduct future research studies of health and educational impacts of exposure to airborne toxins and other hazard or adverse condition, resulting from the September 11, 2001 terrorist attacks, including on the population of individuals who were 21 years of age or younger at the time of exposure, including such individuals who are screening-eligible World Trade Center survivors or certified-eligible World Trade Center survivors. So here, they've clarified the language in our research section, which is section 300mm-51 that we're looking at screening-eligible survivors, and we've extended it to screening-eligible survivors, not just those with a certified condition. So, next slide please.

So, in addition to that, they also provided us language with respect to

the population of interest. So, this also includes individuals who, on 9/11, were 21 years of age and younger, and were outside of New York City Disaster Area, and in an area not further north than 14th Street or Brooklyn. So, they've extended the area, and this is important from a research perspective because it gives us a gradient of exposure, right? So now we have a larger group of persons of interest to study. And it also allows us to enumerate control populations, age-correct control populations. So, the framers here provided us some clarification on who is interest of study and who can we enumerate into the cohort. Next slide please.

So, funding for this was also provided in the Appropriations Bill under the Supplemental Fund, and here it says: Amounts deposited into the Supplemental Fund under section (b) shall be available, without further appropriation and without regard to spending limitation under section 300mm–61—that's our funding section previously—as needed at the discretion of such Administrator, for carrying out the provisions of this title including 300mm–2—which is outreach and education—and 300mm–51, which is again research and, in specific, the youth cohort. So here they've called out the youth cohort. The funding from the Supplemental Fund, which is a ten-year fund, will be used for this project. And they also made is specifically clear in the language that the existing research funding would not be used during this time period. So we make a separation between research funding and funding for enumerating the cohort. So, next slide please.

So this slide is just basically summarizing what's just been said. So, they tell us we must—the cohort must be of sufficient size to conduct future research. Now, that's the guidance that we have, and this is going to be one of the tasks that we have to consider, moving forward, what is going to be considered sufficient size or, you know, for the cohort. Includes sufficient representation of individuals who were 21 years of age or younger, so they've defined youth to be 21 years of age or younger instead of 18 years of age or younger. And include individuals who are screening-eligible World Trade Center survivors or certified-eligible survivors. So that's the bare necessity of the cohort. Now, it also can include persons outside of the Disaster Area, the 14th Street. Again,

that provides us a lower-exposed group for comparison. And it also provides us the opportunity to enumerate control populations as needed for research purposes.

So, the next slide, okay. So we immediately set out, it was clear at the onset, that the Program is going to need participation from community members as well as our Advisory Committee on development of options for enumerating the cohort. So, as Dr. Howard has already presented, we set out with a proposal of four phases.

And the very first phase is immediately bring community on board to gather sufficient information from all stakeholder groups on options for establishing this youth research cohort. That was Phase I.

Phase II, we'll take the information that's gathered during Phase I and develop a set of options that we can move forward with establishing the youth cohort. So, we envision that there could be several ways to do this. I mean, it's going to be a very interesting project, and it's going to take a lot of thought and we'll have to consider several options in doing so.

The third phase would be to engage the community and stakeholders in ranking the options that we have developed in Phase III.

And then the fourth and final phase would be use the information gained in Phase III to select the preferred options, or option, for establishing the youth cohort.

So, what we've done is we're proposing this four-phased approach, and we've assembled some infrastructure within the Program to gather this information, and put the information in a usable format so we can have—for decision-makers down the road. So that's kind of how far we've gotten with this project thus far. So, next slide please.

So, what—again, we have done some things upfront to help us with Phase I. The first thing we've done is we've opened a docket. We have a Federal Register Notice for a request for public inform—Request for Information from the public, which was available in April. It's 120 days and will, of course, look—and we imagine that we'll continue that docket as we move through the process.

We have also opened up a Request for Information from prospective contractors. Again, it's not a solicitation. We're not looking to award a

contract here, but we're wanting information from those who have expertise in doing this, and that will help us, because we envision that some of the options will involve contracting, and this will help us build a Performance Statement of Work that will fit our needs.
And then the very last thing that we've been able to do is we developed a youth research cohort webpage which was avail—began, was created on June 6, and it is our intent that as we gather more information and move forward with the process, we'll be able to update this webpage in real time. So that will be an easy access point for communities and others to see how we're doing moving forward.
And I believe that might be my last slide. Yes. So please, if you have any questions.

DR. WARD: The floor is open for questions.

DR. BALK: Yes, this is Sophie Balk. Could you just—I'm having trouble understanding the cohort as it's described because it seems contradictory, "…who are located outside the New York City Disaster Area." What exactly is that? I know that there—I just can't access the link right now, but can—how was that defined? Because it seems contradictor, "…and in Manhattan not further north than 14th Street." Can you just, can you clarify that please?

DR. DANIELS: Right, so surely, thank you, and it's a very good question. So the New York City Disaster Area—and I don't have the dimensions or the map in front of me right now—but it is available on that website, the youth cohort website. But in essence, it's a smaller area. It's the northern part of Brooklyn and up to, I think, I can't remember the street, and I—

DR. BALK: Houston Street then?

DR. DANIELS: Yes, oh, Houston Street, thank you.

DR. BALK: Houston, yes.

DR. DANIELS: And so this, this new language enables us to extend past that area. It broadens the size of the available area for recruitment, if you will, for persons that were potentially exposed. So what that gives us is it's not only those people who would be eligible for the Program, those in the New York City Disaster Area, but we'll look, we'll be conducting research on persons who were potentially exposed to lesser amounts, and that gives us that gradient of exposure. At least that's what I believe was the

	intent of extending that. So yes, here's a great picture of the map. So you see the sort of pinkish area is the New York City Disaster Area, and then the purple area is the expanded view of what we're looking for for subjects to be recruited.
DR. BALK:	Thank you for that. Why the whole borough of Brooklyn?
DR. DANIELS:	Again, I'll defer that to Policy to answer. If they have one.
MS. BILICS:	That was what Congress gave us, so…
DR. BALK:	Did it have something to do with like the way the wind was blowing? But that's a big area. That's a huge area.
MS. BILICS:	We'd have to defer to Congress's rationale, which we don't have insight into.
DR. BALK:	Okay, thank you.
MS. BILICS:	Thank you.
DR. LARRAÑAGA:	This is Mike Larrañaga. I have a quick question. I'm curious about what the connection to the Secretary of Education is in Congress's…
DR. DANIELS:	Again, I really don't have the inner thinkings of those that drafted the language but I can imagine that they were concerned about adverse impact to educational or education of persons that were in school at the time of the terrorist attacks and so, in order to foster more research in that area, there was a need to coordinate with the Department of Education, both between the Program and the Department of Education for research—for the cohort that would support research moving forward. So, there has been some research in the area of education, a very little bit, it was by the Registry, but none others that I can recall. So, I think that was really what we're trying to do here.
DR. LARRAÑAGA:	Okay, thank you.
DR. BALK:	Is there any consideration of the people who were not yet born, or is that an entirely different process? In other words, the fetuses that were exposed.
DR. DANIELS:	Yes, we certainly did have—we do have—in our research portfolio, research involving *in utero* exposure. You know, that's not specifically called out in the new language for the cohort, and I guess that would be an area for discussion by the STAC and others, as we move forward. But we do have published research for *in utero* exposure during 9/11.
DR. BALK:	But just to clarify, are people who were not yet born in this cohort?

DR. DANIELS: That's not the way the language is currently written. Again, that would be an area for discussion, I believe. But currently it's just those aged 21 years or less is what the direction is. I don't know if Policy wants to weigh in here or not?

MS. BILICS: There is nothing necessarily excluding it from the cohort. There would be discussions of whether or not it would be best to include them, given that there's—research itself, that there's a separate section of the law, likely prohibits the research on *in utero*, people who were not meeting the eligibility criteria, which means that somebody had to be born prior to July 31, 2002, and meet exposure hours. So, they could have been *in utero* for part of that time, but had they not been born prior to the end of the exposure period and meet the exposure hours for enrollment in the Program, they would not meet the eligibility criteria for the research section of the law.

DR. WARD: So, this is Liz. I think this is an important point that we'll return to later, but we are at 11:30 and I want to stay on time, so I'd like to turn the floor over to Dr. Reibman for her presentation.

DR. CARREÓN-VALENCIA: Before we do that, I just want to acknowledge that Mariama James had joined the meeting and, Mariama, I just need to confirm and ask if there have been changes in your conflict-of-interest forms since you submitted your Form OGE 450?

MS. JAMES: No, there have not. Thank you.

DR. CARREÓN-VALENCIA: Thank you. Thank you so much for joining.

OVERVIEW OF YOUNG SURVIVORS

DR. REIBMAN: Okay, can you hear me? Okay, great. So, thank you very, very much for inviting me to talk to you at this meeting. It's really a pleasure to meet you, and also some of you who I've known before. What—oh, I guess I don't have, right, I don't have control. It's very unnerving. If you could please give me the next slide, please.

Let me start by telling you who I am, I guess, which is I'm at NYU and I'm also the Medical Director of the World Trade Center Environmental Health Center or the WTCEHC that started, that I started actually, first with research studies right after 9/11 and subsequently with a variety of

funding, and then eventually, with great excitement, to be included as a World Trade Center—in the World Trade Center Health Program as a Center of Excellence.

So what I'd like to do today is talk to you about a brief description of the community of those exposed at a young age in the New York City Disaster Area, and I know many of you know a lot about this but I thought I would sort of give you our perspective on it; talk to you about the WTCEHC as the survivor Center of Excellence, because I think that that will help us understand what information we can and cannot glean from the Program; our experience with recruitment of those exposed at a young age; what we know about the population exposed at a young age in the WTCEHC, and I think, importantly, that does not include those who were in the—the William Street Survivor Program or the National Program, and hopefully we will get that information, more of that information, soon; what, some of the thoughts we have about gaps in our knowledge about those exposed at a young age; and some of our experience and thoughts on recruitment of a cohort of those exposed at a young age. If I could have the next slide, please.

So I told you already that I am the founder and Medical Director of the Program and by training, I am really a pulmonologist. My background is really in asthma and before all of this began, I was studying the impact of pollutants on mucosal immune responses in the airway, and also many clinical studies in asthma through many programs, including the American Lung Association Asthma—Airways Clinical Research Centers. Next slide please.

And I just do this because I think it's important for all of us to remember the community that we are talking about, and this is like the aerial picture of the towers, which are surrounded by a very, very diverse residential and working community. And on the right side, I show you one of the dust clouds, really the first one, that it's traveling up West Street. And what it's reaching, is about to reach, is a bridge that goes across West Street, and on the right side is Stuyvesant High School, and on the left side would be the Borough of Manhattan Community College that you can't quite see, and the building that is about to be engulfed is a residential building that is going to be covered within this dust. And I

show you this one because it's an amazing photograph, that was an aerial photograph, and I forgot to put the source; I apologize for that. It's a detective who was flying in a helicopter. But I also show you because it helps us understand that we have no idea about the boundaries of exposure for the residents and local workers and the population in that surrounding community in terms of—and we have a number of boundaries that we've talked about, but the exposure may be different from any of those boundaries. Next slide please.

And to that point, and to the point that we were just hearing about, the area of exposure for the survivors has really varied over the years. When we began our first treatment program for survivors, we used—we were funded by the Red Cross, we called it the Red Cross Health Impacts Program—and actually we used 14th Street, river to river, as our boundary for geographic exposure. When the New York—when the World Trade Center Health Program was developed, the New York City Disaster Area was redefined. To show you this map that I have here, I guess I can't use a pointer. Sorry, it's very disorienting. But it's really the area west of Houston Street in Manhattan and also, as you heard about, an area of Brooklyn because of the way that the winds traveled. The World Trade Center Health Registry has used a different boundary, and either they've used Canal Street, which is the New York City Department of Health Registry, either below Canal Street or below Chambers Street. So, as we think about these populations of exposure, we really have a variety of populations that are, that have been studied, depending on the boundaries that we're talking about. And that makes it complicated to understand how many people we're really talking about, and the New York City—the World Trade Center Health Registry has estimated about 410,000 individuals exposed south of Chambers Street or in residences or schools south of Canal Street, that included about 300,000 local workers and commuters—unclear how many of those were less than 21 years of age—about 57,000 residents south of Canal Street, and, in the recent article by Doug Daniels, the estimate was at about 30% of these residents were assumed to be parents, and then about 15,000 students and staff south of Canal Street were in nursery or daycare, elementary, intermediate or high school but not college. So

again, our numbers of the populations exposed at a young age are really varied, to the large extent, depending on the boundaries that we're talking about. Next slide please.

If we think about these populations, we have to remember that they're very, very diverse populations. So, if we think about those who were on the West Side, we know that the residents from buildings there were predominantly—certainly not exclusively but predominantly—upper- and middle-income housing. And I show you the first picture, which is a very famous picture now, of a father and son. Many of those people were evacuated on that day and kept out of their apartments for some variable period of time. However, there were of course many middle-income and also some federally supported houses that were in that area.

East of that area was middle- and much—and many more individuals who were lower-income, including (residents @ 00:38:25) of public housing. So, I'm showing you pictures down below. That's the Alfred E. Smith Houses; those are public housing, NYCHA housing. They're east of—east, and I didn't put them on the map. Oh yes, I did, sorry. Smith Houses on the map there. I'm showing you, in Chinatown, which was often smaller houses and residences, they were not evacuated. And there is some very large housing projects such as Southbridge, again these were not evacuated. So again, how the exposure with experience was very different for those who were east of the site and those were southwest of the site. The ones who were not evacuated lost their electricity, they lost water, but we—but they were not evacuated. And the cleaning that was provided for them by the—subsequent—was very different from that that was provided to the west. So again, there's a lot of differences within the residential experience. Can I have the next slide please?

We think that there are about 50 schools in the World Trade Center Health Program Disaster Area, but there are of course many children of local residents who were not yet attending school. And then if you understand New York schools—they're very difficult to understand—many local children will attend local schools, and the World Trade Center Health Registry has called these "student residents." But many

children of residential will commute to distant schools, so they may have been exposed as residents but not as students. But again, there are many students of schools in the area who come from distant residences, which the World Trade Center Health Registry called "non-resident students" in their publications. So again, as we think about the student population, it's a very, very complex population that may have had very different exposures. If I could have the next slide, please.

And the schools themselves—excuse me, I'm sitting in a clinic so I might have some background noise—the schools themselves are very, very varied. So, for example, I'm showing you a picture here of P.S. 234. That's on Greenwich Street. Its windows looked right out at the towers. It's a fairly diverse school but often more middle-income, drawing some of the local apartments. But also, there was P.S. 89 on Warren Street, so again right there, and I show you a plaque from the parents to the teachers thanking them enormously for evacuating their children. There are intermediate schools right there. There are schools further downtown such as Trinity Place, but also schools that are further east such as the Alfred E. Smith School on Henry Street, which is P.S. 1, and also schools in Chinatown and the Hester Street School, the Sun Yat Sen Middle School. So, a whole variety of schools, with very, very different patient populations. Can we have the next slide please?

But there also are secondary schools, and I think you're going to hear from a lot of those students today, and they vary enormously. I showed you this cloud approaching Stuyvesant High School, and there's a picture of the students who are in Stuyvesant High School. Stuyvesant High School, as I'm sure you know by now, is a very elite school within New York City, but there are other schools such as the Murry Bergtraum High School, which is further east near Brooklyn Bridge, and those students were evacuated by the doors were put open and they were told to run, and you can see a picture of the students who stopped here looking at the towers collapsing. But there were other schools, the High School of Economics and Finance on Trinity Place, and its sister or brother school, the High School of Leadership and Public Services, also on Trinity Place. These are further downtown. Those students were initially locked in the cafeteria and then eventually evacuated to Battery

Park through the Staten Island ferry across the Hudson River, and then bused home later that evening. So again, there's a lot of variety in the schools, how these kids were exposed, and their experience. Next slide please.

One of the issues I had trying to understand the study of these young people, and we've had this issue as we've looked at our population, is how are we defining this youth population. And so you're going to have to go back and look at—and some of you probably know this much better than me, I'm an adult pulmonologist—but what are we calling "youth" and who's exposed at a young age? And I went back to the United Nations and WHO definitions where they define children as under 18 but then define young people as adolescents of 10-19, and youth 15-24, and the ILO and Commonwealth now calls youth a transition stage from childhood to adulthood. Having a 30-year-old myself, I would definitely call it a transition stage. The Registry, as you know, included children less than 18, and this proposal is less than or equal to 21.

And the reason I bring this up is again pertaining to a question that was raised earlier, which is as we think about these populations, they're not all the same, and their exposures are going to be different, and their exposures at various ages are going to have different implications. So, I think it's very complicated as we're thinking about this proposal, to really think about what ages are we really talking about. So, thank you. Next slide please.

So what I'm trying to show you is the complexity of those exposed at a young age, which is what I'm calling this group now, and due to the age of exposure, the type and severity of exposures, their race/ethnicity, their socioeconomics, their school level and type, and clearly also their underlying baseline health or vulnerability, all of which are going to play a role in how we look at these populations. Next slide please.

So, what is our experience at the World Trade Center EHC with those exposed at a young age? And I would love to tell you that I could include those in William Street and the National Program, programs that are now almost equaling our numbers, and I think that's going to be a very important group to look at, but I don't have those data on those

populations here. So, next slide please.

So, to understand how—this population, it's important to understand how we were created, and we really were created first as a result of a study we did on the respiratory health of local residents that we did in 2001, in collaboration with the New York State Department of Health and community members. And this resulted with a request from the community and a, just a community collaborative treatment program that we ran out of our asthma clinic, but eventually we obtained funding from the American Red Cross, which was to, again, a two-year funding and then from the City of New York, eventually federal funding, and then we were very excited to be included as the Survivor [Center] of Excellence under the World Trade Center Health Program from the James Zadroga 9/11 Health and Compensation Act. Next slide please.

But it's very important to understand that our program has a lot of differences and limitations, particularly when comparing to the Responder Program and comparing to the World Trade Center Health Registry. So, we began as a community collaborative multidisciplinary program with a focus on treatment, because that's what the community was asking for at the time, and sort of morphed into a surveillance program of community members, again because we didn't think we were going to be around very long. So, we really started as a treatment program and morphed into a surveillance program.

Second of all, we are for a self-referred population for those with symptoms. So, we are not a sample population of those with and without symptoms—very, very different from the Responder Program. Enrollment in the Program requires the presence of a certified condition. So, we are not a screening program for those without illness. And again, we have some limitations in our recruitment because the World Trade Center Health Program does not provide no-cost treatment to survivors, again in contrast to the Responder Program. We are the final payer after coordination of benefits to support no out-of-pocket costs for certified conditions, and our patients do not get paid work time off for either treatment or, for now, monitoring visits. So, we are a treatment and surveillance program, but we are for a population that, by definition, has to have symptoms. Next slide please.

From the very, very start, we incorporated services for the pediatric population. We hired general pediatricians. We had a pediatric pulmonologist, in fact one of the first hired at NYU. We had a specialist in developmental medicine. We had an environmental pediatrician, and we had child psychologists. So, these individuals we recruited onto our staff very, very early in order to offer services for the pediatric population. Next slide please.

We did a lot of the outreach to recruit this pediatric population. We had meetings with all the local pediatricians. We went to all the PTA meetings. We went to tons and tons of tenant meetings. We went to and attended the local fairs and events in the local neighborhood. As you will hear about later, we worked very, very closely with our community collaborators, who were very, very active in pediatric outreach, and we had a lot of advertisements on the radio, TV, local newspapers, and our most effective ones were always in the subway. We had a huge advertisement. "If you lived there, worked there, you deserve care," again trying to get the pediatric population. Next slide please.

However, despite our outreach and resources, we really had minimal enrollment in the Program, and we have thought about this a lot and although we have not studied the reasons, our assessment is that there—certainly we may not have reached everybody, there may have—we have made, we may have failed in our education outreach. But again, because you had to be sick, it may have been that many of the children were not sick. We also think that most children had insurance, even those of lower income had insurance, which differed from adults. So there was, in fact, less need for them to attend our program. We know, from talking to the pediatricians, that many of them felt that the—the local pediatricians felt that the illnesses were normal and were common childhood illnesses, and so they did not think there was anything unique to the World Trade Center exposure, and were loath to refer the children. And then, of course, from talking to the parents also, we know that there was a lot of complex emotion on the part of the parents. Many of them felt very, very guilty that they had returned to the community, that they had sent their children back to

local schools, that they had come back to apartments, some of which were incompletely cleaned, and so very complex emotional issues for many of the parents. So, I think there's a lot of reasons that we had low enrollment but that's the fact of what happened. Next slide please.

We did have some studies of our small population. Leo Trasande, who I think many of you know, reported on our first 148 patients, so a very small group, focusing on pulmonology and cardiometabolic findings. And his work on that little group led to research with a further study in collaboration with the World Trade Center Health Registry and he's reported on 400 individuals in that group, and showed that there were elevated serum dioxin levels, serum PFAS in World Trade Center children compared to controls, and that these associations were associated with lipid and cardiovascular outcomes, and he's published extensively on that. Next slide please.

But the enrollment has changed over time, and clearly the children are no longer children; they're now young adults. And so the enrollment has changed in our program for those who were exposed at a young age. And I show you here a slide of what we tried to put together in terms of what the enrollment has been over time in this group of those who were exposed at a young age, and I'm showing you, I'm cutting it off here at either 21 or 30 just for interest's sake. And what you can see in the pale purple are those who were less than 30 on 9/11 and on the pale, in the darker blue, those who were less than 21. And you can see there have sort of been waves of enrollment in the Program. Clearly at the time of the Zadroga Act, we had an increase, then we had a falling-off, and now we have had an increase in our numbers, and we can't explain this other than to look at it and see that that's what's happened. Next slide please.

Well, what do we know about those who we now have in our program? And these are data that we've included for those who were enrolled as of December 2022. Our total population is over 15,000 who are in the Program. Of those, we have about 2,000 who—or 15%—who were less than 30 on 9/11, or 638 who were less than 21. Again, this does not include those who are enrolled in the William Street or the National Program. Those programs now almost have as many as we have, so I

think that's a very important group to be looking at, but I don't have those data. In our group, which you can see is that we have 50% women. Again, that's at least in our whole population, very different from the responder population so, again, highlighting the need to understand the effect of exposures in women. We have very diverse race and ethnicity. Again, a little bit of differences if you include the older age group, but not that significant but, again, showing you that we have a very diverse population even in our program and, again, importantly, because we know that the neighborhoods, we're talking about are very, very diverse. Next slide please.

In our program, most of those who we have were actually enrolled in the older groups, so if you look at who's enrolled in our program by five-year spans, you can see that, in fact, most of the people enrolled are those who were older than 15, basically, on 9/11. So very, very few who really enrolled at a young age. And again, to address the question earlier, we can enroll people who were *in utero* on 9/11. I thought it was beyond July '22 ['02] but I could be wrong on that. So, we can enroll those who were *in utero,* but we have very, very few in our program at this point in time. Next slide please.

What are the exposures? Again, we have many who report having been caught in the dust cloud or one of the dust clouds that I showed you. About 42% say they were in the dust cloud, or 47%, they reported, or their parents reported. That's less than what we have in our total program where it's usually always 50%. But many of them were, in fact, in the dust cloud. We sort of cut coarse groupings of people as local workers or residents or students or cleanup workers or other people who were passing by. And again, most of these individuals in the younger group were exposed as a resident, although many also were exposed as students. And as we get into those who were exposed in the 30 or under, many of those were also exposed as local workers. Many of these were never smokers, and very, very few are current smokers. Can we have the next slide please?

What are they certified for in our program? And again, most, like we see in our whole group, are certified for obstructive airway disease, and so that would be asthma, probably not so much COPD in this group, but

really predominantly asthma. And about 30% in our younger group are certified for obstructive airway disease, and 19% in our less than 30 group. Many also are certified for upper airway symptoms, so that would be chronic rhinitis or chronic rhinosinusitis, and then again, some with GERD, and a small number with interstitial lung disease and with sarcoidosis, and I'm going to come back to the cancer group in a minute. Interestingly, we have very few—oh, we don't have very few but we have fewer with mental health certifications for PTSD than we see in the adult group. Here, we have only 10% of our younger group who are certified for PTSD, and a small number for anxiety and depression, and this is significantly lower than what we have in our adult population, or older populations. Next slide please.

So, what we, what I showed you before is that we do have the increasing number of these young adults who were, who are enrolling now with cancers. And if we look at the top cancer certifications in those who were exposed at a young age—here I'm including less than 30—breast cancer is the most common cancer we're seeing in that population. That's followed by thyroid, by Hodgkin's lymphoma, and non-Hodgkin's lymphoma. And this is similar to what we see in our adult population, where again, in our group, which is 50% women, breast cancer is the most common cancer that people are being certified for. We do have some rare cancers, including breast cancer in men, and also some rare mesotheliomas including peritoneal mesothelioma. We published our first version of these data in 2022. This is our data as of 12/2022. Next slide please.

If we look at these exposed at less than 21 or less than 30, we do see some differences, where those who were exposed at less than 21, we see thyroid is the main cancer. Again, the numbers are very, very, very small, followed by breast cancer, the Hodgkin's and leukemia. In contrast, who those who were exposed at less than 30, we start to see breast cancer as the main, most common cancer for which people are getting certified, followed by thyroid and lymphomas. So there are differences in this age group whether we cut them off at 21 or 30, so clearly the older population is coming in now with other cancers. Next slide please.

If we look by sex distribution, again we see differences. Again, not surprising but in the women, we're seeing breast cancer followed by thyroid and then the lymphomas. In the men, we're seeing thyroid, testicular cancer, head and neck cancer, and then the lymphomas. So again, there may be some differences in how these cancers are being distributed. But again, remember, these are people who are coming into the Program because they have a cancer and want to be certified for it, or there are cases in which somebody was enrolled for an obstructive airway disease, for example, and we identified a cancer and diagnosed it. But most of them are self-referred for their cancer. So this is only a description of what we are seeing in this program. It is not a prevalence, incidence, any of that. Next slide please.

So, there are a lot of knowledge gaps about World Trade Center exposure health effects in those exposed at a young age. We don't understand the mental health, how does their experience of a traumatic event incorporate itself into personality and behavior. We are talking a lot about cognitive issues in the adult population. We have very little information on cognitive issues or development issues in this population. We have very, very little information on reproductive health or endocrine disruption in this population, cardiovascular effects and, as I showed you, information on cancer types and behaviors. So all of these, I think, are very, very large gaps in this population that was exposed at a young age. Next slide please.

One of the things you hear talked about earlier and I would review again is, when we think about examining these knowledge gaps, it's really important to understand the sample size, and to understand the sample size that's appropriate for the outcome of interest, because each of these outcomes may require different-sized populations for study. For example, in the very lovely study published in the World Trade Center Health Registry on this younger group, that population may be appropriate for one outcome but may not be appropriate, for example, for a cancer outcome. As you all know probably better than me, the timing of the exposure in a lifespan may influence outcomes. Race, ethnicity, and other demographic characteristics are important. Are there vulnerable populations? And, very importantly, and included in

this new program, a control population is critical, something that we have lacked in our population. Next slide please.

But our experience in the World Trade Center EHC and the recommend—really informs our recommendations for recruitment. We know that this is a difficult population to recruit by standard means. It's an age group that's now focused on family, job, education. Many of them are not interested in looking back at the events of 9/11. It's a difficult population. Because of that, we will need new recruitment techniques using, again, many of the tools that were not available to us as we started this program, social media, digital studies, remote consent. All of these and more will probably need to be included. We will need recruitment and motivation incentives, and these may not be the same for each of the populations. For example, health benefits are important for some but not for the whole group. Many are clearly going to be interested in being involved in this as altruistic, because they're socially conscious, or they want to be involved in environmental studies, but that will get old. For some, it may be social networking, jobs and economic issues that may, in fact, make people want to be involved, or social connectedness may be very, very important. Fear, which I think was a motivating factor early on, may not necessarily be the main motivating factor now to recruit this population. And, in fact, it may be a factor to not recruit this population, as people may not want to face things that happened in the past. So, I think this is going to be something really important going forward, as we think about how to recruit this population. Next slide please.

I want to thank you for this, and I would open up to questions, but we had also, I think, organized a talk about—another talk—and unfortunately that talk got cancelled. So, I just want to talk to you a little bit more, if I could have the next slide, and—oh, sorry. First, thank the funding that's been involved in this all along, and that's the CDC and NIOSH contracts that have funded our World Trade Center Clinical Center of Excellence and the Data Center, and also the various grants that have been involved in this project. Next slide please.

And also, many, many thanks to many of the investigators that have been involved in many of these studies, and also to the community

organizations which we have worked very, very closely with throughout all of our work. You know—can I have the next slide please? Thank you. There was supposed to be a talk on community-based participatory research, and that talk got cancelled, but I want to say a few things about our experience with that, if you don't mind, very, very quickly. And if I could have the next slide, please.

When we think about community-based participatory research, and again many of you know much more about this than me, our goal to do it is really to achieve health equity, and the definition of health equity is—varies, by the CDC, which is a "state in which everyone has a fair and just opportunity to attain their highest level of health;" and the WHO, which "equity is the absence of unfair, avoidable or remediable differences among groups of people." And attaining health equity really requires the inclusion of affected stakeholders, the appropriate community. Can I have the next slide please?

So, the concept of community-based participatory research, again you know this more than me, has been around for more than 25 years, and there's an enormous literature on CBPR. Can I have the next slide please?

With a variety of definitions. But all of it includes the fact that it's a collaborative approach that equitably involves all partners in the research process and recognizes the unique strengths that each brings and begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. And that the active involvement of community members, organizational representatives, and researchers is important in all aspects of the research process.

And I will say—can I have the next slide please?—that our program really has had enormous community input throughout its whole history. And that, again you know this more than me, but community-based participatory research is a collaborative research approach designed to ensure and establish structures for participation by community affected by the issue being studies, representatives of organizations, and researchers in all aspects of the research process; and that it involves

co-learning and reciprocal transfer of expertise by all research partners, with a particular emphasis on the issues that can be studied, with shared decision-making power, and mutual ownership of processes and products in the research enterprise. And this program that you're seeing today, and that we've all been involved in, has really, I think, you know, used these definitions in its development, and we have had huge involvement of the community in all of these processes. Next slide please.

You know, I'm having a moment why I was going to do this. But again, you know all of these things, that in—that there are principles of community-based participatory research. Sorry, I lost my slide. I'm not even sure if you can still hear me. So…

DR. LARRAÑAGA: I can hear you.

DR. REIBMAN: You can hear me?

DR. WARD: We can hear you and we can still see your slides.

DR. REIBMAN: Yes, but I can't. I just lost everything. So if you just give me one moment, I have to sign back in here. I'm sorry. What happened here? I don't know. I'm having a complete block here. I'm going to… I'm having a moment of amnesia here. I really am having a moment of amnesia. So, I'm going to actually have to stop but I just want to—because I'm glad you can see my slides but I can't see them, and I really am having a moment of amnesia.

So, I just wanted to say here that these programs have really been involved with community groups and, going forward, we know that that involvement will continue, and I really can't see my slides so—and I just got locked out. So, I'm going to have to stop at this point because I can no longer pull this up. This is really—and I'm having a moment of amnesia.

DR. WARD: Well, thank you very much. That was a very informative presentation, and we really appreciate you putting your—all the effort into pulling all that information together for us. We have just a few minutes before lunch break, so are there any questions for Dr. Reibman?

DR. LARRAÑAGA: Hi, Dr. Reibman, thank you. This is Mike Larrañaga. If I understand correctly, the window is from 9/11/2001 to July 31, 2002. So, wouldn't the cohort population just, by definition, include anybody that was *in*

utero on 9/11?

DR. REIBMAN: I'm sorry, I'm just trying to get in and I'm having an issue here. Let me understand your question again?

DR. LARRAÑAGA: So, the—you said that you guys accept, that your team accepts those that were *in utero*. In the previous discussion, there was a question about that. But if the range for inclusion in the World Trade Center Health Program is 9/11/2001 to July 31, 2002, that's 10 months and 20 days, so wouldn't that include anybody that was in *in utero* on 9/11 by definition, the World Trade Center—

DR. REIBMAN: Yes.

DR. LARRAÑAGA: Okay.

DR. REIBMAN: Yes, we do include those who were *in utero*.

DR. LARRAÑAGA: Well, I under—yes, okay. Thank you.

DR. BALK: Hi, this is Sophie Balk. I'm a pediatrician. You listed the high schools and the middle schools and the elementary schools. Is there any way of finding out the childcare settings or the daycare settings that even younger kids were in on that day?

DR. REIBMAN: Are you asking—well, I, yes, there are lists of those. Some of those had been used in the past. I don't have them available now but yes, there are ways to do that. And, yes. Yes.

DR. BALK: Thank you.

DR. WARD: Dr. Reibman, you mentioned a couple of times the William Street and National Programs, and I think most of us, or at least I am not at all familiar with what those programs are or who they include. Are those programs for childhood survivors or what are they?

DR. REIBMAN: So, the National Program, and I guess I really think that NIOSH can answer these better than I can, the National Program is a program particularly for people who lived, worked or were in the area on that day who may have moved away.

DR. WARD: Okay.

DR. REIBMAN: And so many people moved to California, and so they can be included in that. They can still be in the Program now. Even though they live in California, for example.

DR. WARD: So, that would pertain to adults, any survivor, not specifically children.

DR. REIBMAN: Correct.

DR. WARD: Okay, thank you. Any other questions or comments? We still have about four minutes.

DR. MILEK: Debra Milek. Joan, do you anticipate any confounding from COVID, which has had the very significant mental health issues and certainly some physical issues with long COVID, going forward?

DR. REIBMAN: I think, absolutely, we have to consider COVID and long COVID, and you know, we have not actually—yes. Let me add to that and just say yes, I think we have to think about that. We have to include that in our analysis of anything that goes on, yes.

DR. MILEK: Okay. Similarly, similarly to what's happened since, is there consideration of climate change-related issues such as the wildfires that are now part of our world?

DR. REIBMAN: It looks like I've lost everything other than my phone at the moment. I mean, clearly we have to think about, you know, other exposures that people have had, and particularly as we're now so many years out and as we start thinking about health effects, and we do need to ask about those. But so, I think you have to include those. I think, you know, going forward not so many years out, that we do need to include other exposures, yes. I'm sorry, I've lost everything at this point and so I'm having my own amnesia. Yes, but happy to take questions.

DR. MILEK: I'll ask another question. Do you have spokespersons from the various communities who are well-recognized and able to recruit or attract?

DR. REIBMAN: We have many, many community groups. I mean, one of the absolutely amazing things about the Program has been the involvement of the community at all, at many, many levels. And so, we have—and many people who have been involved, from those who were students, to those who were residents, to those who were working in the area, and we've had enormous involvement of community, many of whom have also served as spokespeople.

DR. MILEK: I was thinking of more famous persons, for instance Jon Stewart and his ability to mobilize. Are there other people like that, that could bring forth people from the communities?

DR. REIBMAN: Yes. We've had a lot of people in all different—Jon Stewart has been much more for the responders, as I'm sure you know, but also has helped us. And we have many, many, you know, some people with high

	recognition who've also been involved in our program.
DR. MILEK:	Okay, thank you.
DR. WARD:	Well, we're now coming up to our—
DR. REIBMAN:	(Inaudible @ 01:14:30).
DR. WARD:	Thank you so much. We can—it's funny because we can still hear you and see you quite fine even though you're having so much trouble.
DR. REIBMAN:	I can't see—I can't see you. I'm having amnesia.
DR. WARD:	Thank you. This was really helpful and important, so thank you very much. And I think we're at the time for our lunch break and, Tania, did you want to make the lunch break announcement about not signing off?
DR. CARREÓN-VALENCIA:	Yes. First, I want to thank Joan for being here. It's my understanding that she'll be able to stay in the afternoon for at least for some time, to answer any questions that you may have during your deliberations. And with that, we will leave for lunch. We will come back at one o'clock. I ask members to please do not leave the Zoom room, just turn your cameras and mics off. And Joan, you may want to reset your whole computer but everybody else, please stay on if you want—if you can. See you at one then.
DR. WARD:	Thank you, bye.

[Lunch.]

DR. CARREÓN-VALENCIA:	Thank you, everybody. Welcome back to the meeting of the Scientific and Technical Advisory Board meeting for the World Trade Center Health Program. I want to welcome the members that are here with us and also the people on, that are following through the webcast. I will do another roll call to make sure that we have a quorum. So, I'm starting with our chair, Elizabeth Ward.
DR. WARD:	Present.
DR. CARREÓN-VALENCIA:	Sophie Balk?
DR. BALK:	Present.
DR. CARREÓN-VALENCIA:	John Comiskey?
DR. COMISKEY:	Present.
DR. CARREÓN-VALENCIA:	Chandra Davis?
MS. DAVIS:	Present.

DR. CARREÓN-VALENCIA: Joanna Gaitens?
DR. GAITENS: Present.
DR. CARREÓN-VALENCIA: Mridu Gulati?
DR. GULATI: Present from afar.
DR. CARREÓN-VALENCIA: Yes, thank you so much for joining. Mridu, could you tell me if anything had changed in your conflict-of-interest status since you last filed your OGE 450 form?
DR. GULATI: No.
DR. CARREÓN-VALENCIA: Thank you, and everybody, she's joining from Scandinavia, so thank you for being here today. Mariama James?
MS. JAMES: Present.
DR. CARREÓN-VALENCIA: Thank you. Anita Jose? Indrina Kanth? Michael Larrañaga?
DR. LARRAÑAGA: Present.
DR. CARREÓN-VALENCIA: Steven Markowitz? John Meyer? Debra Milek?
DR. MILEK: Present.
DR. CARREÓN-VALENCIA: Lawrence Mohr? Jason Ostrowe?
DR. OSTROWE: Present.
DR. CARREÓN-VALENCIA: Aarti Surti?
DR. SURTI: Present.
DR. CARREÓN-VALENCIA: Glenn Talaska? So, we have eleven members present and we have a quorum. Liz, the floor is yours.
DR. WARD: Thank you, and I'll turn the floor over to Kimberly Flynn for her presentation on young survivors' views.

YOUNG SURVIVORS' VIEWS

MS. FLYNN: Okay. Thank you very much, Liz, and I want to welcome everyone. So, am I—just, okay, now I think I'm seeing the screen. Hang on. I'm sorry. I'm having trouble. I'm apologizing; I'm having trouble getting a right view. All right. Close enough but not quite. Okay.
So, I want to welcome everybody to this presentation of young survivor views that is mostly going to be delivered by young survivors. It is organized on behalf of the Survivors' Steering Committee by myself and others. I have lots of help. There's going to be a full thank you slide at the end. Next slide please.

Okay. Today, I am—forgive me again, I'm having trouble actually getting this enlarged. I'm so sorry. Hang on. Okay. I'm going to revert a little bit to my own—okay.

Today, we hear from young survivors. So today is the beginning of a long process, the effort to imagine, plan, build, shape, and ultimately sustain a new youth research cohort. This effort will succeed or fail based on the quality of the World Trade Center Health Program's engagement with young survivors as equal, active, and valued partners. Young survivors are ready to engage. Listen to the quality of their ideas and the insights only they can bring to this endeavor. Next slide please.

So, I do want to hit on the characteristics of the 9/11 environmental disaster kind of out in the community. Everybody knows in Lower Manhattan, plane crashes, resulting collapse of the Towers. This created these massive dust clouds that filled the air, and left hundreds of highly populated city blocks covered with ash, debris, and harmful particles, including asbestos, silicon, metals, concrete and glass. The smaller particles penetrated into homes, schools and workplaces, and were never properly cleaned up. Fires within the debris pile burned into early 2002, releasing carcinogenic combustion byproducts. These contaminants were released throughout Lower Manhattan and beyond. In the weeks after 9/11, the plume moved with the wind direction and sat over every neighborhood, sometimes very close to the ground. Dust and smoke contaminants remained in Lower Manhattan and parts of Brooklyn for an undetermined amount of time after 9/11. Residents, local workers, and students, including more than 35,000 children, had the potential for acute exposures and continuing exposures from residual materials, indoors and outside, as well as exposure to toxic gases, smoke, vapors and combustion byproducts from the continuing fires. Next slide please.

I'm sorry, and now I can't tell that you have the next slide up, but you do. Okay, so this is a map showing you—it's a map of actually, that lighter blue is a map of the World Trade Center Health Program's New York City Disaster Area, and the red markers show where our presenters either lived or went to school.

And, with that, I am going to turn to our first presenter, Piera

Greathouse-Cox. Take it away, Piera.

MS. GREATHOUSE-COX: Can everyone hear me? Great. Hi, everyone. My name is Piera, I'm—

MS. FLYNN: Is Piera in the room?

MS. GREATHOUSE-COX: Say that again?

MS. FLYNN: Oh, I'm sorry. Piera, you're there, right?

MS. GREATHOUSE-COX: Yes.

MS. FLYNN: Okay.

MS. GREATHOUSE-COX: I think folks can hear me. I got nods.

MS. FLYNN: Right.

MS. GREATHOUSE-COX: I got some good-looking nods, yes.

MS. FLYNN: Okay. That's great. (Inaudible @ 00:06:52).

MS. GREATHOUSE-COX: I'm going to speak quickly, just to power through some content here, but my name is Piera, as Kimberly introduced me. I am enrolled in the World Trade Center Health Program, and I sit on the Survivors' Steering Committee.

On 9/11, I was 16 years old and living in an apartment with my father in the Financial District about two blocks from Ground Zero. When the planes hit the towers, I was in class at Hunter College High School on the Upper East Side. I didn't go home that afternoon or the next. My father and I stayed with a family friend in Queens for a week but returned home briefly a couple of days after 9/11. We walked south from Union Square through three miles of police checkpoints, the air growing increasingly acrid and chemical. Arriving at our building, we stood outside the front door and stared at the massive pile of smoking rubble. Fourteen flights up, our apartment was blanketed in a thick layer of dust and tattered office documents.

Within the next few days, our apartment was cleaned by a FEMA contractor, but we would continue to find pockets of dust and debris in unexpected places for months. We were also given a FEMA voucher for a HEPA vacuum, which we redeemed. That was the extent of our involvement with any federal remediation efforts.

Eighteen years later, in 2019, I was diagnosed with adrenal cancer. I have been living on the West Coast for the past two decades and was not aware of the World Trade Center Health Program. My mother, who still lives in New York, had seen ads for the Victims' Compensation Fund

and encouraged me to do some research. As I'd had what appeared to be a successful adrenalectomy and was symptom-free, I did not. I was ready to move on with my life.

When my cancer recurred in 2021, I finally took my mother's advice and enrolled in the World Trade Center Health Program. I have since undergone chemotherapy and immunotherapy, two additional surgeries, the most recent just last month, but the cancer has spread to my ovaries and various other spots in my abdominal cavity.

When I was approved for enrollment in the World Trade Center Health Program, I felt extremely relieved and grateful to have access to the care. But I'm just one of many 9/11-affected young survivors who need and deserve answers in the form of more research. The recently authorized cohort is incredibly important because it allows us to track the long-term health impacts of exposure to WTC toxins on the tens of thousands of children who lived or attended school in the Disaster Area. This is a population whose physical illnesses, which could look quite different from responder illnesses, are currently under-studied by the WTC Health Program. We need better information about conditions emerging in this population. The new cohort can help us meet this need, through more equitable inclusion in studies that satisfy the Health Program's evidentiary requirements for demonstrating causal association between health conditions and 9/11 exposure.

I'm here today to advocate for the government's full support of this cohort. Adequate financial resources and qualified experts with relevant experience are a must. It's also imperative that the Health Program solicit the active participation of young survivors and the personal experience only we can offer. Our insight and opinions need to be included now, and at every step throughout the process, a process which should have begun years ago, but much better late than never. Tracking people down and persuading them to participate 20+ years after the fact will be challenging especially if, like me, these people have moved out of state, weren't affiliated with the neighborhood or a neighborhood school, or didn't have any early-onset symptoms. It shouldn't have taken Stage IV cancer to alert me to the health impacts of exposure to 9/11's toxic chemical compounds. I didn't know about

the World Trade Center Health Program, but I should have. This cohort is an opportunity to ensure that other young survivors are familiar with the resources available to them. Reaching young survivors when they are well means they learn about the Program before they need it, before Googling "9/11 health" on a laptop becomes their best next step.

So, finally, we look to the new cohort to remedy the research inequity you'll be hearing all of us address throughout this presentation. The bodies the science has been attending to, primarily male, primarily middle-aged, are only some of the bodies that were present on 9/11 and during the many months of cleanup. In attending to the physiological impacts on people who were under 18, half of whom are female, we create a significant opportunity for improved outcomes among long-neglected survivor groups like women. In maximizing our ability to identify long-term trends among diverse populations, we can ensure that research keeps pace with the emergence of 9/11-related conditions, allowing us to better identify who is at risk, and develop targeted treatments. Quality longitudinal research won't just benefit young survivors like me. As the World Trade Center Health Program adds new conditions and develops more robust medical screenings, this research will provide potentially life-saving interventions to everyone whose health was harmed by the World Trade Center disaster.

As someone with a rare cancer, I'm fortunate to have my medical expenses covered. There are people who need and deserve access to the World Trade Center Health Program resources that I have, people who may be facing mountains of medical debt because they don't know about the Government's programs, or because their conditions cannot be certified due to inadequate research. Enrollment might just save their lives. We now have the authorization to pursue this research, so let's give everything we've got.

My thanks to the STAC for all your work, and everyone present for listening today. I hope I'm under five minutes. I will end here. Thank you so much.

MS. FLYNN: Thank you very much, Piera. Next slide please.

This is Piera on—in 2001, sorry, and currently. So next slide please and I will introduce our next presenter. Our next presenter is Lila Nordstrom.

MS. NORDSTROM: Hi, can everyone hear me?

MS. FLYNN: Yes.

MS. NORDSTROM: Got our nods, great. I know many of you. My name is Lila Nordstrom. I am a 9/11 survivor. I am a member of the World Trade Center Health Program and I'm also a former member of the STAC, as well as a member of the Survivors Steering Committee and the founder of StuyHealth, which assists and advocates for the 19,000 public school students that were impacted by the World Trade Center cleanup.

On 9/11, I was a student at Stuyvesant High School, which many of you know. That's three blocks from the World Trade Center. And my classmates and I fled just as the second building collapsed. Our building was converted into a command center during the rescue efforts, but our 3,000-person student body was sent back to that location less than a month after the attacks, on October 9, so we were there pretty early on.

In 2006, I founded StuyHealth because the young adults of the 9/11 survivor community, who were exposed to the World Trade Center cleanup as minors and didn't have the agency to make decisions about our health and our wellbeing, have unique needs and face unique health risks. And it's frustrating that so little of the World Trade Center Health Program's data is focused on this quite large cohort which, as Kimberly stated, is not just 19,000 public school students but is about 35,000 minors that were exposed and that, as a result, our 9/11 health needs are frequently overlooked or deprioritized.

As a former member of the STAC, I've been present for a large number of the conversations about the conditions that are missing from the World Trade Center Health Program's List of Covered Conditions. And, as I noted in my comments a few months ago, a frequent reason that new petitions get denied is insufficient data. So, as I've mentioned a few times to the Committee, when we discuss the best way to add new conditions, we have to remain mindful of what we came up against in the uterine cancer conversation, where previous medical biases meant that there was not much preexisting high-quality data on the condition in general, and that the World Trade Center Health Program's research cohorts didn't include enough women to get good data on how our community was being impacted by that condition. And then we also

need to remain mindful of what we continue to come up against in the autoimmune conversation, which is continually deferred because of lack of data. And alongside autoimmune issues, I see a lot of StuyHealth members complain of noncancerous reproductive health problems as well and, like with many of those who have autoimmune conditions, you're not going to find those complaints in the Program's data because a lot of these complaints are from people who don't actually qualify for the World Trade Center Health Program. Remember, there's no proactive monitoring for survivors that don't already have a qualifying condition. So, there's that, and then of course the fact that young people are not well-represented in the World Trade Center Health Registry either. So, they're absent from the major research cohorts that include survivors. I am in the World Trade Center Health Registry, and I am one of the only people that I know from Stuyvesant who actually made it into that study.

As I frequently remind the members of this Committee, though your mission here is to discuss the scientific rationale for adding new conditions to the World Trade Center Health Program's list, real people are sick with 9/11-related conditions right now, so there has to be a timely and appropriate way to support their needs that isn't solely reliant on a 20-year research plan, especially when it never gets underway, and especially when we're considering conditions like reproductive healthcare which, you know, are time-limited in the best of circumstances.

So, overall, we need to ensure that research on the 9/11 community is collected and considered in an equitable manner, and we know that the Program's research has, to date, primarily been focused on first responders, who are nearly 90% male and significantly older than many of the survivors now looking to the Program for health information and for care. And, as part of addressing the data disparities that put younger and female Program patients at a disadvantage, we have to actually start studying these long-ignored populations, and that's why it's so critical that we establish a new research cohort of people exposed as children.

It's also critical that we think about how to best reach these

populations, realistically though. We've already seen outreach efforts to this cohort stall in other forms because researchers refused to use accessible methods of contact like social media and traditional media, to reach out to younger cohort members or younger survivors, and instead were relying on out-of-date parental contact information and cold calls. I, like Piera, don't live with my parents anymore. I also live in California. I, you know, the contact information that would have been accessible to me when I was a student at Stuyvesant has nothing to do with my current contact information. Young people, in addition to being mobile, also are not—famously not—big phone-answerers so a plan regarding how to build this cohort should include stakeholders from it so that appropriate means of communication are being employed to try to reach out to this population. And then also, young people are working. So if you're asking them to spend time filling in surveys and participating in in-depth studies, there need to be incentives. I think monetary incentives that respect their commitment of time and energy would be appropriate to consider in this situation, and then, especially in light of the ever-shrinking access to insurance coverage that so many of us are experiencing, and the fragmentary nature of our healthcare, I think it would also be appropriate for those participating in this cohort to receive yearly screenings from the World Trade Center Health Program like those that are currently offered to World Trade Center Health Program members.

So, thank you so much for your time, and I appreciate you listening to young survivors talk about why it's so important that this program address our needs.

Kimberly, you're on mute.

MS. FLYNN: All right, please—thank you, Lila, very much. Next slide please. There we go.

Okay, so, very unfortunately, Winnie Yu is unable to attend today's meeting, and I'm going to read her statement.

"My name is Winnie Yu. I am 28 years old, and I was born and raised in Chinatown, New York City. On 9/11/2001, I was in class as a first grader at P.S. 124 on Division Street. I remember arriving at school for not too long before the news of the incident was shared. I wasn't sure what was

happening at the time but remember my teacher watching outside our classroom window as she spoke on the phone with the other school personnel. It's eerie. We had a pretty good view of the Twin Towers from our school but all we saw that morning was a grotesque cloud of smoke. I remember our teacher then herding all of us into our school cafeteria to join the rest of the students. We were instructed to huddle away from the windows and notified that our parents had been contacted to pick us up. My mom worked at the Empire State Building at the time. I remember she picked me up from school in a panic and brought me home. We sat as a family that afternoon, into the evening, watching the news as everything happened. Over the next several days, our school did not allow outdoor recess due to the dust and smoke present, and my parents rushed us home every evening after school. At that age, I didn't really understand the impact of what was really happening that day. All I could understand at that time was that my family, and everyone else in the neighborhood, was scared. Although I left New York for brief periods of time for work, I have for the majority of my life, including now, been based in Manhattan. I now work as a Doctor of Physical Therapy. Although I am fortunate to not have any immediate health impacts, my father was diagnosed with Stage IV cancer in 2016. As a healthcare worker, I strive to help improve the lives of others every single day, but have come to realize that there are sometimes factors that influence our health that can be beyond our control. Supporting a family member with terminal illness has not been easy. It takes a toll not only on the involved person but his entire support system as well. As a first responder in the hospital system during the height of the COVID-19 pandemic, I can wholeheartedly understand the urgency and need for supporting those who were at the frontlines during 9/11. But we must not forget everyone else that was also in the vicinity and exposed to the disaster. Implementation of a cohort that includes children who were living and/or going to school in Lower Manhattan on 9/11 would allow individuals like myself and my family to have a chance of being recognized as having long-term effects of this incident. Diseases and illnesses don't appear overnight. If we make the mistake of only capturing a snapshot of only a portion of the

population at one point in time, we run into the chance of neglecting hundreds, if not thousands, of individuals that may have been adversely affected. Children who are especially vulnerable to harm from environmental exposures have a very long time in which to develop 9/11-related health impacts. I know for a fact that many of my peers that were also in school or living in Lower Manhattan during 9/11 are still living in or frequently visiting New York City. I strongly encourage reaching out to local organizations that now can be easily contacted—excuse me—via social media, to connect with more young individuals that were located in Lower Manhattan during 9/11. Thank you for your consideration."

Next slide please. Okay, I am introducing Abishai, Alijah, and Armani James.

MR. ABISHAI JAMES: Hello?

MS. FLYNN: Hello.

MR. ABISHAI JAMES: Good afternoon, everyone, I am Abishai James, and I was 9 years old on 9/11.

MS. ARMANI JAMES: I am Armani James, and I was 5 years old.

MS. ALIJAH JAMES: I am Alijah James, and my mother was pregnant with me at the time. I was born in October.

MR. ABISHAI JAMES: We were living here in Southbridge Towers, four blocks east of Tower 1. I was at Our Lady of Pompeii, and when I became aware of the attacks, I was so worried, I went to my sister's classroom to make sure she was okay. Our grandfather, who also lived with us, came to get us at school and bring us home. When we arrived, our building had lost power. Our apartment was dark. My grandfather started pulling food from the refrigerator and sent me down the stairs with a bucket to get water.

MS. ARMANI JAMES: We waited and waited for our mother, Mariama James. We had lost phone contact with her hours earlier. When she arrived around 10 p.m., she was covered in dust like the rest of us. She had walked all the way from her workplace in Queens.

MR. ABISHAI JAMES: We didn't know it yet, but our grandmother had reported to work that day at Deutsche Bank, which is on the World Trade Center site, and we didn't know where she was at the time.

MS. ARMANI JAMES: 9/11 was scary. Our mother found soldiers with automatic rifles in the

stairwells. Our mother and grandfather were concerned about all the dust covering everything and in our—everything in our apartment. They started to clean immediately.

MR. ABISHAI JAMES: All of us developed health problems, a range of respiratory problems and GERD. This includes Alijah, who wasn't born yet.
Our first recommendation is that kids like Alijah, who our mother was pregnant with on and for more than a month after 9/11, need to be included in this cohort, since they were exposed to what their mother is breathing and ingesting.

MS. ALIJAH JAMES: My mother was advised to take us to a pulmonologist, and she took us to Dr. Leistner at NYU. She did tests on all 3 of us and I was diagnosed with asthma as well as other health program—health problems, sorry. When I was ten months old, oh, when I was ten months old, sorry. When I complained about my breathing and my stomach to my teachers, they would often, like pass it off as, like, you can't possibly have 9/11-related issues because you were born after. And I was constantly sent home for stomach issues, later seen as GERD. But Dr. Leistner understood that I was exposed to the same dust and smoke as the rest of my family, and the rest of our community.
Our second recommendation is that the cohort needs to be racially and ethnically diverse. It needs to reflect the kids who were in the Lower Manhattan—who were in Lower Manhattan on 9/11, some of whom look like us.

MR. ABISHAI JAMES: This is very important, otherwise the cohort will not be equitable. Cohorts that don't include groups in the population who were affected are biased and don't produce good science.

MS. ARMANI JAMES: Lots of people who experienced 9/11 as children still have PTSD, and some have anxiety and depression. The research needs to look at how mental health and physical health problems work together and affect each of us.

MR. ABISHAI JAMES: And we continue to be affected when we lose loved ones to 9/11-related diseases. Last year, both of our grandparents passed away from 9/11-related cancers inside of six months. It's retraumatizing. The impact should also be tracked.

MS. ALIJAH JAMES: A really good way that the World Trade Health Center Program could

establish trust with us would be to provide us timely mental healthcare. Lots of us need it. Right now, for lots of people in our age group, it's a priority.

MR. ABISHAI JAMES: Our third recommendation is that if you want to bring young people into the cohort as well as into the World Trade Center Health Program, then eliminating barriers to mental health would be the best step we could take. We would also ask that these clinics are flexible about virtual visits or visits outside of working hours because lots of us are working.

MS. ARMANI JAMES: We have participated in studies of 9/11 health, all three of us. Why? Because we want things to be better, for us, and better for everyone. Our final recommendation is that building community and solidarity is part of building this cohort—part of building this cohort. We think young survivors will embrace the goal of helping themselves and helping everybody, because we—because what will be learned from tracking and researching this cohort is going to benefit everyone.

MR. ABISHAI JAMES: Thank you.

MS. ARMANI JAMES: Thank you.

MS. FLYNN: Thank you, Abishai, Armani and Alijah James. Next slide please.
Okay, I am handing over the floor to Jessica Petrow-Cohen.

MS. PETROW-COHEN: Hi. Can everybody hear me?

MS. FLYNN: Yes.

MS. PETROW-COHEN: Right, wonderful. Thank you all so much for having me. My name is Jessica Petrow-Cohen, and on 9/11, I was in my third day of kindergarten at P.S. 3, which is a New York City public school in Lower Manhattan. I had just turned five.
The first sign that this was not a standard day of kindergarten was the presence of parents. My two moms, who had just hours before kissed me goodbye and promised to pick me up when school ended at 3:00 came rushing back into the building just a few hours later that morning. From the window of my kindergarten classroom, we could see the towers fall, and the fire and smoke that cloaked the city just south of us. As the school grew overcrowded with students and parents and teachers, we were brought up to the roof, where the air smelled of ash and burnt plastic.

In the days that followed, I asked my moms incessantly if there was another plane coming and if we were safe in the building that we lived in just ten minutes from the towers. I remember using crayons to write thank you cards to the firefighters at the station on our block. Outside the station's red garage door, there was memorials littered the sidewalk. So many of the heroes had died.

Twenty-two years later, I'm still a proud New Yorker. I live in Brooklyn now and I work as the Chief of Staff at a social impact tech startup as well as as a writer. In the past six years, both of my moms have been diagnosed with 9/11-related cancers. One of my mothers, Julie, was diagnosed with Stage IV ovarian cancer in 2017 and has recently transitioned to hospice care. My other mother, Maddy, was diagnosed with head and neck cancer in 2019 and is currently in remission. Both of my moms' care is covered by the World Trade Center Health Program. To say that this program has been monumental to my family is an understatement. The ability to access lifesaving drugs, treatments and, in the end stages of Julie's disease, palliative care measures without concerns over their cost has made managing her terminal illness more bearable. It is the extent of the impact that the World Trade Center Health Program has had on my family so far that brings me here today. It is this impact that makes me fiercely passionate about the necessity of the new youth research cohort.

As the daughter of two moms, one of whom has ovarian cancer, a women's cancer, the new youth research cohort's necessity is particularly prescient. Up until this point, there has been an overreliance on occupational cohorts such as 9/11 responder cohorts, that are primarily male. In fact, 87% of 9/11 responders were adult male, a biased sample population when used to draft policy that impacts women and children alike. It is imperative that there is a representative cohort of people exposed as children studied. This cohort must be 50% female and studied longitudinally to track the emergence of 9/11 health-related conditions that disproportionately impact women, such as women cancers.

Further, this cohort must be used to study the physical health impacts to children, the population most vulnerable to environmental toxins,

and currently the most understudied. The cohort should include a representative sample of New Yorkers under the age of 21 at the time of the attack, those who lived, worked, and attended school below Houston Street, across gender, age, race, and ethnicity. Critically, the cohort must include survivors before they become sick. While epidemiological studies have been relied on heavily until this point, in this case, epidemiology is often the science of "too late." While relying on data from previously exposed populations to determine what diagnoses will and will not be covered by the World Trade Center Health Program has resulted in 50+ cancers being covered thus far, it still leaves other survivors who are sick to suffer. Survivors who are waiting for research that won't be ripe for decades will be left to find and afford treatment on their own accord. Research must be sped up so that coverage can meet the 9/11-related health needs of survivors closer to emergence instead of after the fact.

Reaching a diverse and representative cohort of young survivors will require several key strategies put in place, first, outreach across multiple channels including social media, traditional media, email, and text message, as these are the channels most frequently used by this demographic. The use of a web portal or a mobile app to host all relevant information on the research cohort and provide participants with easy access to surveys, health data, and research findings, will also serve to engage—increase engagement of participants.

Finally, it is critical that the long-term benefits of this study be made clear to participants. The research cohort should receive ongoing updates on the findings of the study and the additional diagnoses receiving coverage as a result of this work. Ongoing engagement is dependent on a widespread and diverse population, understanding the imperative nature of the youth research cohort.

On 9/11, I was in my third day of kindergarten at P.S. 3. I'd spend the next several years afraid of planes in the sky, and fearful that my moms had been caught in a burning building if and when they did not answer their phone on the first ring. As it turns out, my fear was valid but misplaced. It was instead the silent killer, the environmental toxins released during the attack, that threatened my family's safety. With two

moms that have been diagnosed and one mom is currently dying from a 9/11-related illness, I say with the deepest conviction that accurate, representative research to inform the care and support of future survivors is critical. The new youth research cohort as an opportunity to collect exactly that. Thank you for having me today.

MS. FLYNN: Thank you very much. Next slide please. So I'm not going to go through all of these. I mean, I'm going to hit some of them. I really want to thank my labor colleague Rob Spencer for capturing the recommendations from, that are in the statements that you just heard, for collating and synthesizing them. I think that everyone can hear, I think that everyone can hear, that there's a lot at stake in getting this cohort right and, in fact, what is at stake is the Program's mission, which is to provide 9/11-related healthcare to those who need and deserve it, through 2090.

So, having said that, I'm going to briefly hit on some of the recommendations. Next slide please. Okay. We did this one. Next slide please. Okay.

So, adequate financial resources, obviously. And I want to, you know, make very clear, and I think it's indisputable, that young survivors are experts and they have not only highly relevant expertise, but they have the expertise that this effort is going to need in order to succeed. So, we think that means that the Program needs to give them something. The issue of free screenings to all those participating in the research cohort who are not current members of the Program, there's strong feeling about that, for obvious reasons. In addition, yes, money incentives, absolutely. It takes time and energy. It takes time and energy away from work and family and other concerns, so yes. And I also have to say, and it is a key principle of CBPR, that young adults that—the people for whom this cohort, well, the people that this cohort is comprised of—young adults should have cohort-related employment opportunities. So there need to be some jobs. Next slide please.

Oh boy, lots of struggle notes on this one. But, in any case, as I said, the insights and opinions of young survivors need to be included in every step of this process, from the ground up. As they say, nothing about us without us. I think the issue of the communication channels, I think the use of social media, I think that all of the recommendations that have

been brought to the issue of, you know, current technologies and how they are going to play a key role in reaching this cohort are musts to be followed.

And I guess, let me see, next—next page. Want to say something, actually, next page after that. Next page. That those points have been made multiple times about equity. Next page.

Okay, we're going to—I overshot, but all is not lost. So, one of the things I really want to raise up is that young survivors today have spoken for themselves but also for the communities that they are identified with. Young survivors, people in this age group in general in our country, they're identified with multiple communities. And so the notion that an entire community will be supported, an entire community will be helped with their participation in the cohort, with individual survivor participation in the cohort, is going to be a motivator. You heard Armani James say that's why the members of her family participate in the research, because they understand that it's going to make things better. It's going to make things better not only for them but for everyone.

So, in closing, you know, this cohort is really a major opportunity for a key course correction for the World Trade Center Health Program, and if this is achieved, if this is done well and done robustly and done into the long term, then the Program will be meeting the 9/11-related health needs of survivors through 2090.

So, with that, I just want to say we have lots of people to thank. I'm not going to go through the entire list, but I do want to thank Dr. Reibman. I also want to thank Piera's friend Tyler Pell, who made the (pack @ 00:40:00) for us. I have thanked Rob Spencer and want to thank him again, Mariama James and others, and I want to thank, absolutely, Dr. Tania Carreón-Valencia and Mia Wallace for every accommodation, for being so incredibly responsive and flexible, and for the quality of their work on this meeting.

Okay. I guess we're ready for questions?

DR. WARD: So, this is Liz. We only have about five minutes before the public comment but we're happy to see if anyone has any questions in that time. Or comments.

MS. DAVIS: I have a comment, or a question actually. I don't know if it could be

answered or not.

DR. CARREÓN-VALENCIA: Yes.

MS. PETROW-COHEN: You can but it's over.

MS. FLYNN: I'm sorry, I'm having trouble hearing. Is, Jessie, are you—Jessie, are you trying to speak? You got to unmute.

MS. PETROW-COHEN: Sorry, no. That was a mistake.

MS. FLYNN: Okay. Can someone repeat the question please?

MS. DAVIS: This is Chandra Davis. The only question that I was just curious about, and I'm not trying to stir up a hornets' nest by all means, because I feel that everybody deserves a chance with the World Trade Center Health Program whether you are a responder or a survivor. Everybody plays into this. But has World Trade Center Health Program put the funding aside to add another 30,000 to 50,000 or whatever number of survivors nationwide into the NPN program? Because as a responder myself, in the NPN program, we can't even get the healthcare that we need because we live outside the Tri-City—Tri-State area.

MS. FLYNN: I think that this question is, needs to be answered actually by the Program, and I hear you, Chandra, and I'm familiar with the issues around inability to access care in the Nationwide Provider Network.

MS. DAVIS: Like I said, I am not trying to stir a hornet's nest up. That's not my intention. I just have seen where things have been going and whatever, but like I feel that, you know, all the survivors nationwide, I mean yes. They deserve a chance for a monitoring exam and everything just like the—us as responders, because they were there too.

MS. FLYNN: Thank you. I appreciate that. And survivors are also in NPN. I think it's close to 11,000. And we are seeing the same kind of complaints that I understand responders are making.

MS. DAVIS: Yes.

MS. FLYNN: Very legit complaints.

MS. BILICS: This is Jess Bilics at the Program. The Program is aware of a lot of the issues that, Chandra, you're referring to and Kimberly is referring to. We are working through those. We're going through a transition in vendors for the NPN. We understand that it's been difficult. If anyone, Chandra, anyone else, if there are specific issues, please contact the Program directly.

In terms of setting aside money, the Program enrolls individuals on a first-come, first-served basis. That is what is dictated by the statute in terms of, you know, first-in, first-enrolled, etc. That is how the Program does its enrollment status.

DR. WARD: Thank you and, Tania, I think it—I believe it is time to start the public comments.

PUBLIC COMMENTS

DR. CARREÓN-VALENCIA: Yes, thank you, Liz. As I mentioned earlier, we have six people that have requested to provide public comments this afternoon. So, when I announce your name, please unmute yourself and turn your camera on. You will have up to five minutes to provide comment, and you will see the green light here which will turn into yellow and eventually red, which means that your time will be up. You all received a copy of the redaction policy for public comments, and this policy states that transcripts will be posted, and the names of the speakers will not be redacted. So, in making the statement, you may provide personal information. That usually won't be redacted either.

So, our first public commenter for today is Vittoria Fariello, and you have five minutes.

MS. FARIELLO: Thank you. Thank you so much for having me today. My name is Vittoria Fariello. I am a resident in Lower Manhattan, and I've lived here since 1998 along with my husband, and we've raised our four children here. On September 11, 2001, my husband and I lived just three blocks from the South Tower. We witnessed the horrors of that day in real-time. We saw the towers disintegrate before our own eyes, while people covered in soot ran down our street in the dust cloud. As we watched the destruction of the World Trade Center, we also saw the beauty and strength in our community, as neighbors and store owners ran out to help those who were running from the towers, not knowing whether they were putting themselves at risk. These are the same people who stayed to rebuild, who, along with the first responders, sacrificed their health and their lives to help our city and our country come back from the worst of tragedies.

My husband and I chose to stay in Lower Manhattan to help rebuild and contribute to our community, which has suffered so much. We opened our law firm here in Lower Manhattan so that our employees and our clients would participate in the local economy along with us. In 2001, we were young newlyweds and unaware of the potential toxins that existed in Lower Manhattan after September 11. Our first child was born in December of 2002, which means that I was pregnant by March of 2002. We know that at least as late as St. Patrick's Day in 2002, there were still flareups at the World Trade Center site. We had moved to Battery Park City in April of 2002, and every day I walked by the World Trade Center site to get on a subway to go to law school at first, and eventually to my job on the Upper West Side of Manhattan.

We have been blessed with four children, but our oldest has a disproportionate number of health issues, from allergies to intestinal problems of all sorts. We do not have a family history of these issues and our subsequent children do not exhibit many of these symptoms. We know how critical the early gestational period of pregnancy is. Everything a pregnant person breathes reaches the fetus, which is only just forming. In my mind, there is a strong correlation between the air I took in and the health issues our child now deals with on a daily basis, from difficulty digesting to intense seasonal allergies, as well as allergies to animals and specific foods. He is also far more likely than our other children to get sick. This deeply affects his quality of life, and may well put him at risk for other issues later on in life.

I strongly support a youth research cohort, and I ask that you please include in the cohort children that were conceived during the period when we know that the air was still contaminated, and that they have—and they likely have been exposed to harmful toxins while in the womb. So, thank you all so much for all of your work and your time, and thank you for hearing my testimony.

DR. CARREÓN-VALENCIA: Thank you very much for your comment. Our next commenter is Benjamin Chevat.

MR. CHEVAT: Yes, hi. Hopefully you can hear me. Thank you. My name is Benjamin Chevat. I—oh, I can start my video. Hi. My name is Benjamin Chevat. I'm an Executive Director of 9/11 Health Watch, a 501(c)(3) not-for-profit

created by the New York State AFL-CIO and its affiliated units. Our organization is dedicated to making sure that the goal of providing quality medical care and compensation for injured and ill 9/11 responders and survivors embodied in the James Zadroga 9/11 Health and Compensation Act of 2010 and its reauthorizations is met. Thank you for this opportunity to give public comments at this meeting with the World Trade Center Health Program's Science and Technical Advisory Committee discussion of the new youth research cohort being established by the World Trade Center Health Program.

First, I want to thank Senators Gillibrand, Schumer, former Representative Carolyn Maloney, Congressman Jerrold Nadler, and Congressman Andrew Garbarino for their efforts to get Congress to authorize the establishment and development of the new cohort. Their efforts to include the authorization of this new cohort as part of last year's Omnibus Funding Bill was key to finally allowing the World Trade Center Health Program the ability to do adequate research on the health impacts of toxins at Ground Zero on those in the local community of residents and those who were under 21 at the time of the attack and its aftermath.

As the leadership of NIOSH understands and has repeatedly stated, there is currently not a sufficient and representative cohort that can be provide an adequate scientific basis for research on the impact of toxins of this population.

Among the approximately 360,000 World Trade Center survivors were more than 35,000 people who were children at the time of the attack, who resided or attended school or daycare in the New York City Disaster Area. Children are extremely vulnerable, as we all know, to harm from both toxic exposures and psychological trauma, and there are continuing reports of health impacts, including those that are severe, in this population now that they are adults. However, the Program did not have suitable research tools to do the job needed, needed authorization by Congress to create this research cohort we are discussing today to study the impact of the toxins at Ground Zero. Now, through the senators' and representatives' efforts, it can.

Today's meeting is the beginning of the process to create the research

tool, and we look forward to hearing the discussion today. We want to applaud Dr. Howard and his staff for the outreach they've been conducting on this, seeking input from the community and calling the STAC meeting, for their—and their Request for Further Information. Our main concern, going forward with developing this cohort, are the challenges in recruiting this cohort after 22 years. We know that early attempts at this did not produce the numbers of possible cohort members that we need to see for this to be successful. Our suggestion, rather than initially relying on one vendor to assemble the cohort, is that the Program should hold a competition between possible vendors before embarking on a single contractor. This way, the Program could test different approaches and select the best methods based on real-world experience, or perhaps some small initial grants to try experiment with different outreach models, to see which would be more effective, to make sure that the population recruited reflects the exposed population, especially with respect to communities of color. This is something that we understand that NIOSH has had extensive experience with in the area of protective gear, and the recent NIOSH Mask Innovation Challenge as well as a crowdsourcing competition to improve respirator fit evaluations. While this would initially delay moving forward with assembling the cohort, it would allow for a more likely successful outcome by having a competition between vendors to test recruitment methods on the different populations.

We look forward to today's discussion. Thank you.

DR. CARREÓN-VALENCIA: Thank you very much, Ben. Our next presenter or commenter is Jordan Chanin-Albanese and you have five minutes.

MS. CHANIN-ALBANESE: Hello, my name is Jordan Albanese. Thank you for inviting me to speak on behalf of individuals under 21 years old during the time of 9/11. I was born, raised, and still currently reside in Lower Manhattan, and was present and have vivid memories of 9/11, being onsite at the time, and seeing people jump. I have been certified by the Health Program for multiple health conditions. I am here today to address the lack of data on young individuals who were affected by the toxins of 9/11.

At 17 years old, I showed levels of premature ovarian failure, in other words, premature menopause. We don't know how old I was when I

first started. My gynecologist at 17 failed to raise his concern at the time. It was when I switched doctors at 22 years old. My new gynecologist immediately sent me to a fertility specialist. I have no family history of any type of fertility issues and have gone through extensive testing. All of my doctors have stated that the only conclusion to cause this type of condition was based on my environmental situation and circumstances caused by 9/11. I was told at 22 years old I would never have children, and was handed a pamphlet on coping mechanisms and support groups to join. I didn't think this was an acceptable answer. I am a survivor and a fighter and have been through so much in my short life, while watching both of my parents for years suffer and continue to suffer from side effects from 9/11. I have also seen the lack of care my parents have received by the Program.

So from 22 to now 26 years old, I have gone through 11 successful egg-freezing surgeries, keyword "successful," and I've had multiple cancelled surgeries due to trial, errors, natural cycles, supplements, or injecting my body with five shots a day to boost my levels to be able to produce eggs, along with financial struggles because these surgeries cost thousands of dollars, which usually aren't covered by insurance, and this condition isn't in the 9/11 Health Program because of the large gap in their research on children affected. I know there are a lot of people out there with fertility issues whom have been silenced because it's not on the list. The latest surgery I had was Friday.

The average 22 to 30 years old would be able to retrieve eggs, between 20 to 30 eggs during one surgery period. I was able—since I have been in premature menopause, I only get one egg or no eggs. It's a very rough process mentally and physically. I currently have 11 eggs frozen, which I was told I would never have, because I didn't give up, and I will continue to do these surgeries, maybe even with the 9/11 Program if this cohort is approved. There is also no promise that these eggs will be viable when I'm ready to use them.

Where I live, my building was covered with debris from the towers, and my parents were told the parks were play—were safe to play in as a child, even with the dust cloud, which we all know was a lie. I was exposed to all these toxins for many years, and there's no answers from

the Program or the Government of the side effects because there's a limited number of people my age in the Program. There are also few people my age checking for fertility issues because they aren't ready to have kids. I am blessed to not have cancer, but cancer shouldn't be the only condition this program certifies and focuses on. I was lucky enough to catch my fertility issues in time to be able to do something. Others may not be so lucky.

I understand creating this cohort is key to getting answers and addressing the reproductive issues for survivors, especially young children before their bodies were even developed. I am willing to be one of the first ones to join the cohort, demanding answers, and hopefully spreading awareness to other survivors. This is a massive gap in our research which needs to be filled, and I'm demanding accountability and answers for what I have already gone through and what I may encounter in the future. Thank you for your time.

DR. CARREÓN-VALENCIA: Thank you, Jordan, and I apologize for mispronouncing your name. Our next commenter is Barbara Capparelli.

MS. CAPPARELLI: Hi, my name is Barbara Capparelli. My child who is now 25 was headed to her first day of Pre-K on 9/11 when we heard a huge reverberating boom. I assured her it was probably a truck backfire. For days, those streets and schools were closed, air thick, cars and playground equipment coated with dust. Still, they played outside. With a little bandana over her face, she cheered the rescue and recovery workers and vehicles headed to and from Ground Zero. We had our windows closed, with ACs on. She coughed for weeks at night, with the atmospheric inversion. We often visited the active recovery site. Schools and apartments were never cleared—cleaned in our hour—our area, nor the schools she attended later in Chinatown, nor the subways where the towers collapsed, with debris and fumes.

My child's Pre-K participated in the New York Academy of Medicine's Pediatric Respiratory Study of 32 daycares below 14th Street one year post-9/11. Her East 9th Street school showed 32.3% mutually exclusive statistics of increased impacts on children who either had asthma or never had but were still reporting symptomatic. The entire study showed over 43% mutually exclusive statistics. Geographically, we were

not deemed eligible to participate in the World Trade Center Registry. My child has since, for years, experienced paralyzing migraines, especially triggered by environmental and other chemical exposures; stomach problems; new allergies not related to family history; and found to have sinusoidal sphenoid polyp; mental health issues, including anxiety, depression, PTSD; difficulty sleeping; and menstrual issues.
The New York Department of Ed did not recognize 9/11 health impacts. Even the downtown medical providers didn't link the symptoms. I tried to figure out what was wrong with my child, went to countless medical appointments, causing school latenesses. Schools chastised the parents, that we should be more responsible. Latenesses and absences impacted her selection to choice schools.
She became a member of the World Trade Center Pediatric Program, Environmental Health Center at Bellevue, and now in the 9/11 Health Program as a federally certified survivor with physical and mental health impacts. After becoming a federally funded program, the boundaries to qualify were changed, so her peers with similar issues were not—were excluded from applying. Before the Program was federal, the World Trade Center Environmental Health Center held a conference on 9/11 health, with a panel dedicated to children's health. One presentation by a distinguished developmental expert told of symptomology already presenting, and of health impacts anticipated, in pediatric populations, including neurodevelopmental issues and anticipated behavioral. My daughter, over time, was diagnosed with ADD, NVLD and other.
Her high school—by high school, we realized many of her peers had IEPs. And the federal program hardly awarded research dollars to the boots-on-the-ground medical personnel who had been treating these populations, less so to study pediatric impacts. Most were funded—funding went to faraway academics with World Trade Center Registry data. My daughter attended a selective high school. Such a large school did not give attention to individual academic needs, hers being far away, travel time, added environment exposures, academic issues, and curtailed extracurricular participation on the robotics and sports teams because long days were too much. Superstorm Sandy blacked out our neighborhood for almost two weeks, triggering more mental health

traumas and reaction to molds. We all have been concerned about the endocrine impacts of 9/11. My daughter, as well as a male peer, developed extra breast tissue. She shied away from interactions with members of the opposite sex. Insurance wouldn't cover surgery, deeming it selective. They did not understand the psychological impacts on a teenage girl.

During the pandemic, my child with compromised health stayed away from New York City. Out-of-town colleges certainly didn't understand 9/11 health issues. Quarantining on a pretty empty campus increased mental health issues and continued physical health issues, her migraine, digestive disorders. Her graduate program at RIT suspended her, stating to come back when she felt better. She lost her campus housing, her campus job. Her educational career was terminated, and it caused such psychological trauma, she couldn't focus on applying to another program. She said to me, "I just want to be hospitalized." She bears the graduate school tuition bills without degree to pursue the level of employment she deserves. Her new part-time employment has already suffered from these issues, with frequent urgent care and hospitalizations due to respiratory and gastro issues, as well as anxiety and depression. I worry about my child and others her age far away from New York City and the 9/11 health experts at Bellevue. Thank you for recognizing this cohort.

DR. CARREÓN-VALENCIA: Thank you, Barbara. Our next commenter is Sacha Garcia.

MR. GARCIA: Hi. My name is Sacha Garcia. At the time of 9/11, I was about eight years old. I was currently going to school over on Bleecker and Carmine Street, and live and continue to live on Chambers Street by Stuyvesant High School. If you're aware with the address, that is very close. I am across the street from the field that was once a staging ground for people who worked on the pile, and I was right next to the route that the dump trucks used to bring debris to and from the barges over on Pier 25.

It wasn't very long before we returned home. Everything was still coated in dust. I remember going to Pier 40 to get cleared to come back home. And when we came here, we were told that luckily our windows were closed, but that did not exclude us from any of the health

complications that would arise. As was mentioned before, the playgrounds, soccer fields, everything was coated in dust at one point in time. There was a thin film that seemed to stick to everything.

And in a couple of years, we started to notice our neighbors coming down with something. Eventually, my grandparents would become ill as well. Whether it was some form of throat cancer, lung cancer, skin, brain tumor, the list got larger as time went on, and unfortunately my grandmother would pass away about ten years ago due to a brain tumor.

It would take about another five years for myself to start noticing health complications. I have noticed that I have an increasing number of moles that seem to pop up as compared to my peers, multicolored, black specks, you name it, and they're starting to pop up. Luckily, those have not progressed into anything but I will not lie, the fear of it becoming something worse lives in my mind at all times. For the last six months, I have been dealing with some form of abdominal complication that all signs point to something very serious but, unfortunately, from test after test, we still cannot diagnose it. And from lack of insurance, it is only getting harder to keep up with these. I do suffer from mental health illnesses related to 9/11, the major one being PTSD, which I have never been able to seek help for and, honestly, for the longest time, there has always been a bit of fear to addressing these sort of things, whether it was from stigma or, you know, thinking that I didn't deserve this kind of help because I wasn't a first responder or whatever it may have been.

As for concerns, I just want some research done. I feel like people my age have, to a certain degree, really been looked over as if we just somehow weren't affected. I know everybody likes to think that small children tend to be fit and near invincible, we have these incredibly strong immune systems, but there's no immune system on Earth that's strong enough to combat whatever we are facing here. And I would really like to see some serious research put towards mental health. I haven't been able to sleep right in almost 20 years. Any time there's a loud bang, I jump. I still get weird around sirens of any kind. I can't be in packed rooms. Subways scare me, and I am born and raised in New York City, but I have trouble getting on a subway because I just don't know

what's going to happen. I feel like I am constantly looking over my shoulder, for something I don't even really know.

And I do think that it should be mentioned that there is some power to, you know, word of mouth. If I had seen something about this on social media, I probably would have been a little skeptical, but it was friends and family who did know about this meeting today that really pushed for me to come and speak my mind, and I do really think that's important. People might see an ad on Facebook, and it might be helpful but, at the end of the day, we live in the age of AdBlock and someone might just glance over it. Family members saying, "Hey, I think you should speak your mind and what you experienced here," is very important. So yes, thank you for your time and thank you for hearing me out, and have a good day.

DR. CARREÓN-VALENCIA: Thank you very much. Our last commenter is Taylor Banning.

MS. BANNING: Hi, good afternoon. Can you hear me okay? I can't see myself, but my name is Taylor Banning, and Sacha, thank you so much for your comment. You are not alone, and I think I heard this somewhere. If there is a perception that 9/11 child survivors are silent, it's because y'all aren't listening. Because we are here.

So I was eight years old on 9/11. My sister was in my bedridden mother's room, born two weeks later. We lived in Gateway Plaza, overlooking the Twin Towers. We had family in the hotel between the towers, and that day I didn't go to school because we were going to see the family off. That morning, I woke up to rumbling, banging, my dog barking, and I sat up to see the plane fly into the building, into the first tower. The day that followed…is a flurry of horrific events, from being separated from my family at eight years old, from falling down choking, suffocating from the dust cloud, from being—from my aunt yelling at me that your parents are dead, and thank God they weren't. I fled my home. I've never been back to that apartment to this day. I'm thirty now. Our family did move back about six months later, to Battery Park City. I live here in Battery Park City now.

And, like many 9/11 children survivors who have spoken today, my experience has been isolating to the—isolating for me to the main population. I feel like so many people don't understand and cannot

understand, even adults, the people who were adults, 9/11 survivors, or my family do not understand the unique experience of having been a child that day. I now am coping with multiple 9/11 health issues: asthma, GERD, sinus infections. My mother has got—survived two 9/11 cancers. They've cut her open, carved parts of her out to keep her alive. We've lost so many members of our community to 9/11 illnesses, like long-time family friends, just watching them completely wither away. It's horrible and devastating, but the lack of knowledge about specifically the child cohort is really scary. I go to see my doctors and I have been pushing and pushing to get early cancer screenings, and they overlook the risk factors that I present because there isn't enough information about people like me.

We, I hope we will pursue this research project, and I hope that it is representative and expansive. It needs to be racially, ethnically, demographically representative. And I think one tool that could really help us reach so many young people could be providing support groups, a community network, even a registry, some way for us to connect to one another. I think that can help sustain engagement in this process. It is really triggering, as you can see, and really hard to show up to these things and do this. But I'm learning so much about the health impacts that have impacted other people who have spoken here today. This should not be the first time I'm learning about these things. So I really do hope this is taken on seriously and with care, and I do hope that we can connect with more child—more youth, 9/11 youth survivors, and support one another and learn more about what we're experiencing, to hopefully save more lives and keep us, keep us safe. Thank you.

DR. CARREÓN-VALENCIA: Thank you, Taylor, and this concludes the public comment period for today. I want to ask those commenting and also those that presented earlier on to please leave the Zoom room and join us and continue following via webcast. Kimberly, if you could stay in case there are questions from the Committee, we would appreciate that. I think I had said earlier that Dr. Reibman will be staying, but she wasn't able to after all. So, thank you very much and, Liz, the floor is yours.

STAC DELIBERATIONS

DR. WARD: Thank you. So, this, we have about, I think, an hour for our first discussion and you know, this is such a big topic and there are so many threads, I really thought it might be helpful for us to at least start our discussion around the four points in Dr. Howard's charge to the Committee. The one thing that's come up that I think doesn't fit in any of these categories is the issue of including people who were exposed *in utero*, and I suggest that we take that as point five at the end of—after we go through all the other four points. And I have kind of taken notes on things that might fit into each of these rubrics just so we can have an organization discussion.

But the first topic is comments on the proposed four-phased approach for establishing the youth cohort, including the sufficiency of community involvement, and it might be helpful if someone could show that slide again that shows the four phases, and then we'll go back to the screen where we can see people. I don't know if there's a way to simultaneously have that slide in the visual field without, you know, getting rid of all the Zoom people. But if there was a way, that would be helpful.

Tania, you're on mute.

DR. CARREÓN-VALENCIA: So, you want someone to write or take notes, is that what you're asking?

DR. WARD: No, no, what I was asking for, the first question that Dr. Howard asked us to address is give advice on the proposed four-phase approach for establishing the youth cohort, including the sufficiency of community involvement. And we only saw one slide, we've had one slide on that in the presentation, but we don't have that in front of us to discuss. So, either, just if we can put it up once and then take it down, or if there was a way to continue to show it while we have the discussion, that would be helpful.

DR. CARREÓN-VALENCIA: Yeah, we will put it up.

DR. WARD: Okay, good.

DR. CARREÓN-VALENCIA: Thank you.

DR. WARD: The other thing I wanted to suggest to the Committee at this point, I

think it's fine if people just speak as they want to speak, but if it, if the discussion gets more lively and people want to speak but they may worry about being able to chime in when they can get a turn, we can use the hand signal and I will make sure to—and Tania and I will make sure to keep looking at the hand signal. So, if you, I think that's under Reactions. So, if you want to raise your hand to make sure you get a word in edgewise, you can raise your hand and we'll make sure to get to you.

Okay, so we wanted to look at the four—the four-phased approach, and I wondered if anyone has comments on that. Is anyone speaking? I see… Okay. Is there, are there no comments on this topic?

DR. LARRAÑAGA: I'll ask a question. When we say "community members," you know, what does that mean?

DR. WARD: Tania, would you like to address that?

DR. CARREÓN-VALENCIA: So, in this case, will be the survivors, the young survivors that we have heard them. I think it's probably, also involves both people that are members and non-members of the World Trade Center Health Program that experienced the exposures. I don't know if somebody else would, from the Program, would like to address the question.

DR. DANIELS: This is Doug, and that's pretty much right. I mean, the intent here was to be as inclusive as possible, so it would be those enrolled and those not enrolled, those affected members of the community that have input on this process. So, it's pretty much open actually.

DR. WARD: Thank you. John, you have your hand up?

DR. COMISKEY: Yes, well, really like a question or I'm trying to just gauge the scope of this. This could be, number-wise and money-wise, huge. With—what are we talking about, 50,000, 100,000 people, of which, I don't—we are going to have some, you're going to have some people contract all kind of diseases, whether they were there or that. How do we consider that as far as, you know, how big this could actually grow? And how would anybody pay for it?

DR. WARD: So, so—

DR. DANIELS: Right. This is Doug again and yes, that's a very good question. The intent here is that, you know, we would develop a series of options, and those options would be costed out. And I'm assuming that, you know, there

will be some decisions will need to be made with respect of available funding. So that will be part of the decision process.

DR. WARD: So, this is Liz. Looking at this, my only comment is time, timeframe, because given the pace at which the Government typically moves, if you know, having a four-phased process without a timeline is a little worrisome to me. Does anyone have any comments on that?

MS. DAVIS: This is Chandra, but I can't make the little hand signal work on my laptop for some reason. But is there, like, when it comes down to the four phases, or actually five phases if we have *in utero* children that weren't born yet, is there a way to—whether it's STAC, whether it's the World Trade Center Health Program, whether it's NIOSH, whatever—develop, to develop a proposed timeline on when to meet goals of each of the five phases that need to be considered in order to make things happen, and then somehow, again, find funding for it? Because that's going to be a huge number, I mean a huge deal too.

DR. WARD: Well, can we just remind everybody that there is a specific appropriation for this research so—?

MS. DAVIS: Oh, sorry.

DR. WARD: And it's actually quite large, right? So, I don't know—I mean, it's true that this could expand and expand and expand, but there is quite a bit of available funding, both to do the developmental work and to actually conduct, you know, to develop the cohort. So, what was it, Tania, five—$1 billion was appropriated specifically for this effort?

MS. BILICS: So, this is Jess. Tania, I'll just take this question. The Omnibus did provide a billion dollars in funding. However, this is not the only activity which the Omnibus covers. It did not give a certain amount for the youth cohort.

DR. WARD: Okay.

MS. BILICS: It just required that the youth research cohort be established, using the billion dollars that were provided. But that billion dollars is also supposed to help the Program cover all other activities, including the healthcare for enrolled members and those members who have yet to be enrolled.

DR. WARD: Oh, that's interesting because I had misunderstood that. So, does, has the Program done any analysis of, you know, how much of that

Omnibus funding would be required just to maintain the projected expenses of the existing World Trade Center Health Program?

MS. BILICS: There are projections, yes, being used to predict the long-term funding needs of the Program outside of this program—outside of the youth cohort.

DR. WARD: Okay. So, presumably, those projections would be available to the Program at the time they start this process. Aarti, did you have, want to say something?

DR. SURTI: Yes, I just wanted to address some of the concerns around the fear that conditions that may be covered, and the number of individuals that may be covered may balloon to a volume that's unsustainable. Just wanted to reiterate that my understanding is that the youth cohort would help identify what conditions are strongly linked to the 9/11 exposure, and also just advocate that the youth in that area that was exposed are also entitled to benefits, as they were not, you know, they were inadvertently exposed to some of the environmental hazards and, as minors, did not have, like, the agency to make decisions around that.

DR. WARD: I think, you know, perhaps we're really broadening the discussion out too much. You know, I think this, like I said, this is a big topic and I think maybe it would be productive to kind of focus on the four questions that Dr. Howard asked in his charge, and then bring in whatever other topics we want to address, which would include the in-uterine exposures. But you know, if we, if—so essentially, we don't actually have a number of apparently the—of how much there, how much has been appropriated specifically for the youth cohort development. But we have this proposal by NIOSH that they take a phased approach and, you know, as people who've been on the Committee for a long time know, you know, the question of whether there's a way to study survivors who were youths at the time of the incident has come up before, and it's been very challenging in terms of how to define—like if, in a strictly epidemiologic sense, if you wanted to find a sampling frame, you know, we've had the discussion before of using the Department of Education in New York to, at least, as one sampling frame and that, those arrangements were made and were possible. But… Yes, so, and I think I lost my train of thought. But, you know, we've had—this is not

the first time the Committee has considered this issue, and the new funding kind of gives, I think, more of an opportunity for NIOSH to undertake, you know, a very serious look at this issue, and to develop, you know—and to do the research that was, you know, really prohibitively expensive under the framework of the existing research funding, given the difficulties of establishing the cohort and following a cohort, etc. So, you know, again, if we can sort of focus on, you know, aside from the comment that I made with respect to worrying about the timeline for the proposed four-phased approach, is there anything else that, you know, anyone thinks the Committee should say in their advice and recommendations regarding the four-phased approach?

DR. BALK: I have a question, Liz. When we're talking about options, are we talking about the Registry, a surveillance program, or treatment program? Or am I missing it completely?

DR. DANIELS: Yes, so this is Doug. So, when we're referring to options, we're referring to options to enumerate the youth cohort as described in the legislation, the statutory language. So that could be done in a number of ways. For example, it could be done under a contract. It could be done internally. It could be done by the Registry. There's several different options that could be available. But in addition to just simply the mechanics of enumerating the cohort, we want to be sure that we're enumerating the best cohort that we can with the funds that we have. So, we're looking for direction or advice, if you will, on, you know, the approach to be used for recruitment, mostly, in a way that would give us the best unbiased sample for moving forward with research. And, to be clear, this cohort is solely for research purposes. It's not for, you know, increasing or changing any of the existing requirements in the statutory language with respect to enrollment in the Program. This is solely for research purposes, right. So that's got to be the focus here when we start talking about options moving forward.

DR. GULATI: Hi, this is Mridu. I don't know if you can hear me. I don't have great reception.

DR. WARD: Hi, Mridu. We hear you.

DR. GULATI: I'm going in and out, so, okay. My one question is, I mean it seems like it's been a challenge to, it's been a challenge to recruit people. Is there a

way to create a very aggressive timeline to say that we really need to have *x* number of people for this (audio break @ 01:28:15) social media outreach. And then I assume there's a verification process of some sort after people say that they are, they lived in the area or, you know, how are we cross-checking that as well?

DR. WARD: Yes, I don't know if Doug wants to answer but you know, my impression is that at this point, everything is open. So, you know, it could be that the best way to recruit people is to have self-identification and then verification, as you said. It could be that you use a variety of sources like the Board of Education, and you know. It's going to be really tough to identify a standard, I think, epidemiologic framework for the population other the Board of Education because I don't think the residential information is that well available. But I think all of those options are kind of open to NIOSH, and what they're asking for here is, I think they're basically saying that this is a big question, and they don't know the answers to it, and they want to figure—they want to get… So this four-phased process is a way to get input from all of the possible expertise and stakeholders in developing what are the options for, you know, recruiting the cohort; what needs to be done to optimize participation once the cohort is recruited. You know, identification, recruitment, and then optimize participation. And NIOSH is willing to entertain that there may be more than one option on the table, and there, you know, and I think that's what this process is intended to do. Yes. Kimberly?

MS. FLYNN: Thank you very much, Liz. I, you know, I know that we went through this presentation very quickly and I know that we had a lot of recommendations but—and it seems like people may have been confused by, you know, putting all of this together and running—you know, rushing it out so quickly. So let me just say this. A cohort where, you know, a cohort of everyone in New York City or everyone who's currently living in Lower Manhattan is not useful to us at all, and no one is proposing that. Number one.

Number two, it seemed clear to us, but maybe we, you know, were making too many assumptions, that the same kind of verification is done by the World Trade Center Health Program of the place of

exposure, okay. The answer to the question, "Were you there?" okay? "I was there." "Where? And can you provide documentation?" So residential documentation is not impossible and, in fact, it is fundamental to the application for survivors to the World Trade Center Health Program. The school list, there was an attempt made. I'm going to say this and it's, you know, I know that the World Trade Center Health Registry was, in some ways, hamstrung by many, many, many different New York City Health Department regulations and requirements, but that was a failed effort. So, we are not proposing that this next effort be placed into the hands of the New York City Department of Health or the World Trade Center Health Registry. And by the way, and the Registry will tell you they have their own report, okay, that shows how very, very, very few young adults they were able to enroll, number one; and how very, very, very much money that cost. So, community groups actually, you know, did their own quick and dirty version, and yes, I know. When I say quick and dirty, yes, we didn't have an Institutional Review Board, etc., and so forth and you know, these are things that are going to have to be put in place. But we were able to maybe—I mean, I think we got like…

DR. CARREÓN-VALENCIA: Kimberly?

MS. FLYNN: Times the number of young people who were willing to fill in a survey. That's all I'm going to say.

DR. CARREÓN-VALENCIA: Yes, Kimberly—

DR. WARD: Jessica?

DR. CARREÓN-VALENCIA: Just want to say I asked you to stay to answer questions from the Committee so just please stay and do that. Please refrain from making comments. Thank you.

DR. WARD: So, my sense from the discussion on this first point is that it's hard to just discuss this first point alone without all the other issues that come up. But I do think, from the, you know—and what I was going to propose is rather than try to draft language for recommendations today as a group, maybe I'll take our discussion and summarize it verbally and then, overnight, I can try to summarize the discussion. But basically, I think we would—you know, we support the elements of this plan that, you know, cast a broad net for partners, for opinions, for ideas to

optimize this cohort. And our only concern would be that there—you know, that the Program set a timeline which will allow this to be accomplished in a reasonable timeframe because, you know, as many of the survivors have said, it's been a long time since 9/11 and the sooner we actually activate the process of developing this cohort, the sooner we'll have the research completed to have the information. So, I would say maybe we move on to the second point, unless anyone has any last comments on the first point in Dr. Howard's charge.

MS. JAMES: Hi, it's Mariama. I can't find my hand raise, I don't know what's going on here with my screen.

DR. WARD: I'm sorry, but go ahead.

MS. JAMES: I just wanted to, I guess, remind us all that Zadroga goes through 2090 so, although a number of us are in the Program, you know, have concerns about our own treatment at this, right now, we're not going to be here. These are the people that are going to be around in 2090 that are going to need that treatment, and they're not going to have it for them if the research isn't done to find out what their needs, the developing needs are. So that's like the purpose of this and it's not meant to be like a thing for fun because the way the bill is written is to cover people, you know, for a number of years. And there was (inaudible @ 01:35:27) these programs' lifetime in the math that the Zadroga Act would be in place. So, it's not like, you know, our treatment money funding versus theirs and where's theirs going to come from. It's all one big thing. One big pot.

DR. WARD: Okay, thank you. Joanna?

DR. GAITENS: Hi, thanks. So, I just wanted to say that, you know, I keep going back to what the charge to the Committee is, and that is, you know, to look at this proposed four-phase approach and then the sufficiency of community involvement. And so, you know, just looking at this in general, I'd, you know, I like the approach. I think that it does involve the community, but I guess the, you know, the—what's really lacking here, I think, are just some of the details to make sure that, you know, truly, the community involvement is sufficient. And so, for instance, you know, just even some of the wording like "gather sufficient information from educators, scientists, community members," of course it's going to

portend—it's all going to come down to, well, what information are we asking of them, and who exactly are those partners, to be able to really answer the question. But overall, I think the general approach seems, seems good, and like you said, I think that the timing of everything is going to be the big, one of the big challenges.

DR. WARD: Thank you. Debra?

DR. MILEK: It's, the message that I got from hearing our speakers, who were so eloquent, today was a sense of isolation and lack of awareness of other people experiencing the same issues and concerns. And I'm wondering if there is anything that—before we have the information—to be able to get an interest in people by letting them know that there are these concerns that they may not be aware of. It's a little chicken-and-egg, which came first, but I got a very strong sense of the people who spoke today really feeling all alone and not being aware of the circumstances. And so there must be many, many more people like that who wouldn't be open to recruitment if they didn't know more.

DR. WARD: So maybe, as part of this recommendation, we could add that. It will be important to figure out how to do outreach to the affected community as part of the—this process so that, a) there's awareness that it's going on, and b) that they have an opportunity to contribute their ideas to the process. So, there should be some outreach component to this process.

DR. MILEK: Right, and I think today's participants can probably give us some ideas as well.

DR. WARD: Right. And that really actually leads us to, I think very well, to the next question in Dr. Howard's charge, which is potential partnerships for establishing the youth cohort. And I think we can view that, you know, very broadly and kind of talk about the various constituents. And I think here, if we have specific recommendations, I think we can enumerate them.

Yes, go ahead, Chandra.

MS. DAVIS: I can't find my hand signal. I get it like—

DR. WARD: It's all right.

MS. DAVIS: So, I apologize.

DR. WARD: It's—just so everybody knows, it's, if you go down, you know, if you click on your controls, it's under the Reactions button.

MS. DAVIS: Oh, thank you. Didn't know that. But real quickly, as far as like outreach and things like that, to help reach the survivors, because they are nationwide. I mean, not everybody's, you know, in New York anymore. You've got a lot in California, in the Southeast, so on and so forth. And the reason why I say that is I know of two survivors personally that are my physicians in Nashville, oddly enough, that when they were looking up my records and said, "Oh, a 9/11 responder," you know, their eyes bugged out and they were talking about being in school then. They were in high school. And I'm going, "Wow, they lived up there. They were right there." I mean, they told me their own stories, and it was just heartbreaking. But again, like I said, these are physicians, and they don't even know about what's out there for the survivor community. So, I didn't know if there was a way to do like an outreach program and research similar to what was done for the responders, nationwide, whether it's a, you know, a couple of people that want to volunteer to help do it. I don't know how to be, how it could be done. But to set different community engagement opportunities at a meeting place, for example, in California, like three locations, because California is large, and be able to give people a chance to come answer questions, you know, get them enrolled. Get them the stuff that they need to enroll. Because my own physicians had no idea about anything, about there even was a program. So, I'm just trying to give some food for thought. You know, like I said, maybe (inaudible @ 01:41:03) similar to what they did for the responders many years ago, and do it nationwide, and then have community meetings in relation to, for survivors, or to develop the proper cohort for the youth.

DR. WARD: Thank you. I mean, I think it's obvious that one of the starting points would be to involve the constituents that participated in this meeting and have helped to put it together. I mean, there's, you know, there's the Stuyvesant—you know, there's lots of different groups that are already formed, and they're like the first, the obvious first level of stakeholders. But I think that's pretty obvious, and I guess the question is, is there any suggestion that goes beyond the groups and individuals that have already been identified by NIOSH?

DR. CARREÓN-VALENCIA: So, Aarti has her hand raised.

DR. WARD: Oh, thank you. Aarti?

DR. SURTI: Hi. I just wanted to acknowledge just the different categories of the youth survivors that were identified in the earlier presentation around students, residents who were not students, students who were not residents, and then people employed in Lower Manhattan, just to—each of those groups likely has a different geographic pattern, both in New York and outside of New York, and a different degree of exposure based on like time spent in and around the area. And another, echoing what was presented earlier, through some of our comments, so individuals have provided commentaries that it sounds like there was some influence or suggestions from loved ones, older loved ones in that youth's environment that encouraged them to participate or research the Program, and that might be another constituency to involve. And also, just want to acknowledge, as like we think about engagement and valuing people's time, in terms of compensation for that time as well.

DR. WARD: Great. And I think we are kind of—you know, I tried to attempt to break these questions into, you know, to address these questions one at a time. But I do think probably, unless there's anyone who has a suggestion about partnerships that we think has not, have not already been developed, we could move on to the next topic, which is ideas regarding outreach, recruitment, retention, and project oversight, which is a huge, you know, topic on which I think we can have more productive discussion.

Okay, so maybe the first theme that we are coming across is, you know, the fact that there's lots of survivors, young survivors out there, and it, you know, there's a need to kind of reach all of them with the fact that this is happening. You know, I think it's, you know, there are several phases of that. One is just awareness, and opportunities to become engaged in the planning process that NIOSH is preparing for. And then the second level would be once there is a plan for establishing the cohort and recruiting people, then you know, there's a need to actually, I mean, figure out how to get people enrolled and where—whether it's going to be a self-(identification @ 01:45:04) with the Registry or it's going to be a mixture of self-identification with verification, possibly with additional supplementation from lists like the Board of Education

lists. So, but at least in terms of outreach, there's a couple of different levels. One is there is this plan to do this study and the Program is seeking input from everyone who's affected, and just making sure people are aware of it; and then the next phase will be once the plan is actually made to do the study, there's a need to make sure that everyone who's eligible is aware of the opportunity to participate. So, anyway, you know, I think we are on the topic of ideas regarding outreach, recruitment, retention, and project oversight.

DR. LARRAÑAGA: You know, as far as recruiting goes, you know, there are, you know, with technology today, there are very simple ways—although it might be difficult because people are all over the country—but you can, to get people in communities online, forums and things like that. Has NIOSH considered that, like individual forums for these youth cohorts? And this, and I'll agree with the previous statement. These, the young people today communicate in very different ways than what we're used to. And if we don't communicate in the way that they are communicating, we will not reach them. So just, you know, has NIOSH considered, you know, forums or online groups for these, to attract these young people to?

DR. DANIELS: So, this is NIOSH, this is Doug, and yes. You're absolutely right. We have, we want to have a wide spectrum of avenues for recruitment. And so, we believe that all of those ideas that you just mentioned could be important. But, you know, we also understand the need to hear these things from the community because we do agree with all of your statements that were made that, you know, success or failure will depend on participation from those that are more affected, so. So, we're looking to you to help us, and we're looking to the community to help us as well, as we walk through these four phases.

DR. LARRAÑAGA: Thank you, Doug.

DR. WARD: Aarti? Aarti?

DR. SURTI: I think, in my experience, in terms of like youth and survivors, like, reaching out to another, a lot of it, I think it's from like individual conversations that occur within, like, groups of friends who are—who may be geographically co-located and some folks that might not be. So, I wanted to put a plug in for alumni associations because they'll capture

folks that are still connected based on graduation year. They have, like, regular gatherings.

It may circumvent some of the concern around addresses not being accurate from many, many years ago. And also calling out that some folk—many New Yorkers who have moved to other, larger cities often have social groups that encompass other people who've lived in that larger city, either that are found online through meetup groups or social circles, or just informally through other people who may know other folks that may encompass actually, like, a group of folks within an age who are off from New York but now live in maybe Nashville or L.A. or some other location.

And then, separately, thinking through engagement on social media or online more generally, I do want to acknowledge that I think the youth group, like, crosses generations. So, like the older end of the survivor group for youth may communicate using social media or the internet quite differently than probably the younger end of that group as well, both in terms of communication preferences and platforms through which they use. While a Facebook group may be relevant to one age spectrum of the cohort, that may not be as relevant to another one. And while I don't know how to use many of the other newer platforms like TikTok or something of that sort, I think that probably the younger end of the cohort may use other platforms.

DR. WARD: Yes, so I think we're all endorsing, I think, the recommendation that we've heard from some of the young survivors and others, that you know, that NIOSH be open to using a wide variety of media. And I really like the idea of tapping into alumni groups and other kinds of groups around, you know, around subcommunities because that may, I think, be the best way in the end to encourage participation is having outreach from peers who are aware of the study and are interested in participating. But I would think it's simply you would want to do a very broad-based—and I don't know if it's when you're trying to get input with the plan or whether you're actually launching the study, you would want to do a really broad-based media outreach because, you know, doing, just doing general media will inevitably get to Facebook and TikTok and Instagram and all the other things that people use. So

	certainly, you know, a very broad-based media outreach would be part of the plan. Again, what I'm not sure about is, you know, how to address the question of general awareness at this point in time versus, you know, putting a really big effort once the study plan is developed, to reach anyone who might be eligible to participate.
DR. MILEK:	Do we know how successful ads, PSAs, are in mass transit, since New York is such a heavily mass transit-dependent city?
DR. WARD:	That's an interesting point. I don't know if NIOSH has considered that one. These are the kind of ideas that we want to put on the table, I think, so you know, things that may not be obvious but could be really effective.
DR. MILEK:	I always read them. I don't know if younger people do but…
DR. WARD:	I would think so. I mean, what else are you going to do when you're in the subway?
DR. MILEK:	Right. And somebody's parents might read them.
DR. WARD:	Yes.
DR. GAITENS:	I thought one of the presenters mentioned that that was one of—am I imagining this, that they thought it was one of the most effective ways to reach the population of interest that they were looking at?
MS. JAMES:	I think that's correct. I remember seeing that in the prior presentation as well. Also acknowledging that some folks may have moved. So, I think it's—I mean, I don't know. I always read the subway ads but if folks are in other locations, they may not be able to have access.
DR. WARD:	Right.
DR. LARRAÑAGA:	So, this is Mike. One other idea is, like, an association type group, development of some—and one that comes to mind for me is the National Organization of Rare Disorders, or Rare Diseases, I think. And, you know, the reason that one comes to mind is because, you know, those people with those diseases, they share some sort of common frustration and common, like, difficulties in the medical system and things like that. And, you know, that might be a good model to recruit people to participate in something like that.
DR. CARREÓN-VALENCIA:	Liz?
DR. WARD:	Yes, I'm just thinking. Sorry. Tania, you want to speak?
DR. CARREÓN-VALENCIA:	Yes. So, Dr. Gulati is having issues connecting so she wants me to relay

this with you. So, her comment is, "Are there resources that were gained from COVID outreach that we could use?"

DR. WARD: Hmm. Interesting.

DR. CARREÓN-VALENCIA: And I don't know the answer to that. Maybe someone in the Program—

MS. BILICS: This is Jess. I'm not aware either. I was going to see if Geoff was still on. He might be aware. He was involved in some of the COVID tracking in our program early on. But, oh, Geoff, you are on. If you've got anything to add, please—sorry for putting you on the spot—but please go ahead and add. But I assume that our CCEs, Clinical Centers of Excellence, and their institutions would have insight into, you know, what outreach was done in their populations.

DR. CARREÓN-VALENCIA: Yes. Mridu says, "I would assume from CDC side would know, someone there from—would know, or also the New York Public Health Department."

DR. CALVERT: And this is Geoff Calvert with the Program. Jess, yes. I think it's a good idea too, but I can't think of anything off the top of my head that's specific for COVID outreach resources. Thank you.

MS. DAVIS: What about—

DR. WARD: Go ahead, sorry.

MS. DAVIS: What about physician education, people who see younger people or who have seen younger people, OB/GYNs, pediatricians? Educating them as to, you know, the concerns. Or even internists.

DR. WARD: So maybe work through medical associations?

MS. DAVIS: Right.

DR. WARD: So, one question I have, and I don't know if anybody who's present can answer it, but I think at some point—and this was worked on through the Registry, I'm not suggesting that we're going through the Registry again—but at some point, they had information from the Board of Education about students who were... And I don't know if they had like a large number but one thing that would be kind of interesting would be to see where those folks are living now, because they're probably reasonably—the kids who were enrolled in school during the time might be a reasonably good sample of, you know, at least a bit part of the survivor population. And if we knew, like, a lot of them migrated to Florida or, you know, where there are concentrations of survivors living

in specific geographical areas, then that might be a way to target outreach and recruitment efforts. I don't think it would be helpful to know where—I don't know it would be that—I mean, we do know where the adult survivors who are enrolled in the Program already live but I don't know if that would be reflective of the migration patterns of the younger group. But I think it may be actually only a small number of people from that Board of Education list that were actually traced. But it's worth thinking about.

MS. DAVIS: I do have a quick question. I can't—my emotion deal is not working on my screen. Anyway, so if you have survivors, adult survivors, already enrolled into the World Trade Center Health Program for the survivor side of things, would there be a way to reach out to them specifically to find out if they had kids at that time, young, little kids, raising a family or were pregnant or anything like that? Because then at least that way, there can be some kind of a sampling done because you've already got a lot of adults in the Program.

MS. BILICS: This is Jess again. Yes, things like that can be done, with proper clearance through the government channels, yes.

DR. CARREÓN-VALENCIA: I also have another comment from Dr. Gulati. So, she asked earlier on about using the resources gained from COVID outreach, but her comment also is about not just using those resources, but model social media outreach and materials based on what was used for COVID outreach.

DR. WARD: Okay. So, I think a couple of things have come up in the discussion, and I think one specific—several specific things had to do not so much with the outreach and identification of the cohort but how to encourage participation and retention, especially if it's a prospective cohort. And two of the things that I recall, one was, you know, providing compensation for the time and effort that people are putting into answering surveys and possibly even more. And the second one, which I think is worthy of the Committee commenting on if we care to, is the idea of offering some kind of medical health screening as part—as an incentive for participation. You know, from a point of view of an epidemiologist, screening is always a double-edged sword because you have the potential of identifying things that really turn out to be not a

problem, but you have to—you know, it takes a lot of—it's unnerving for the patient and it takes a lot of resources to follow up on things like one abnormal blood test. So, it's not, it's not an undertaking that one could take lightly but I think it's something that's been mentioned and maybe if anyone on the Committee wants to comment on it, it would be appropriate to do so.

Let's take a minute—

MS. JAMES: I think that the compensation matters to younger people.

DR. WARD: Yes.

MS. JAMES: There's been, over the years, there's been a number of these research studies, I think particularly out of Columbia, and they always include some sort of incentive, you know, to encourage the kids to do it, otherwise, you know, they get a piece of mail with a bunch of questions and they're not much interest I think, you know, a lot of the time.

DR. WARD: So, is there any disagreement that, you know, some form of reasonable compensation might be, should be considered, in terms of recruitment and retention? It's like something that we can certainly endorse?

Okay, I don't see any disagreement. We can—we'll go over these in more—you know, I'll try to write these up and we'll go over them one by one tomorrow, but that seems like something we would support. But what about the idea of medical screening? I think some of the survivors really, who spoke, really feel, you know, thought that would be a really good idea. Is that something the Committee wants to encourage the Program to consider or are we neutral or are we negative?

DR. CARREÓN-VALENCIA: So, here is another comment from Mridu. "How do we define screening? It's age-appropriate cancer screening, screening for diabetes and cholesterol?"

DR. WARD: Good question.

DR. CARREÓN-VALENCIA: I think we need to define screening first. Some of the concerns are rare diseases. And Aarti had her hand up.

DR. WARD: Aarti?

DR. SURTI: Yes. I understand some of the complexity around, like, what we're screening and what age and the can of worms that can get opened up if we're identifying things that are unrelated. And I also acknowledge that I think compensation is important for retention for certain members of

the cohort. But I did feel like, I do think surveillance and screening would be really compelling. I think, you know, for folks of my generation, like healthcare is expensive and hard to come by, and there is an interest in kind of understanding both with technology and not with technology, like what is happening to one's body, and I think that would be compelling both for people in the cohort and in terms of recruitment, identifying folks that are like the health—like the unexposed part of the cohort. Something of that vein may be appealing to folks too, just as healthcare sometimes is difficult to navigate for this age group.

DR. WARD: I guess the other piece, in addition to that maybe, would be for those survivors who are, you know, who participate who are uninsured, maybe you know, the opportunity to talk to a counselor about whether they're eligible for ACA insurance or Medicaid in their state. I mean, it does seem to me that that would be a benefit to people who are uninsured but who might have an opportunity to be insured if they knew, if they knew those programs existed.

DR. SURTI: That sounds amazing. So, I'll just say that I think, you know, going back to the two things that—compensation that you talked about, I think, you know, being able to compensate them for participating is great. The screening, I'm just a little bit more nervous about and, you know, because of---you know, it's going to depend on what we're screening for and, you know, the risks of doing screening in populations that aren't at, you know… It just, as everyone knows, can open up a can of worms. So, I'm a little bit more nervous about that one.

But one of the other things that someone had mentioned as far as retention goes is just being able to somehow connect with others, to be able to talk amongst the peers, their peers. And if there was some way, you know, that that could be facilitated, it may help keep them engaged and interested in the program.

DR. WARD: Great.

DR. CARREÓN-VALENCIA: Here is another question from Mridu. "What is the age range distribution of the youth cohort and estimated number?"

DR. WARD: Well, we've heard some people—wasn't there an estimate that approximately 35,000 kids were exposed? So, I guess that's the upper

band.

DR. SURTI: And then the age range, we're talking like 22 to 43, right? So, if they had to be 21 or younger at the time of 2001.

DR. WARD: So, is there anything else that we want to say about outreach, recruitment, retention, and project oversight?

DR. LARRAÑAGA: I think some sort of forum is necessary to connect these people—this group of people, so that they can communicate and reach each other. I think that would be beneficial for both recruitment and retention.

DR. WARD: Right. Anyone else? Okay, so our last question from Dr. Howard is the anticipated barriers to forming a cohort. And the funny thing is, I think he's kind of outlined the answer to his question in asking the question. I mean, yes, these are the anticipated barriers. He talks about representativeness, insufficient statistical power, information biases and selection biases, and any potential strategies that address those barriers. I mean, I think we've covered a lot of it and, you know, I think my concern as an epidemiologist, you know, one of the, you know—I think one, you go through the basic checklist, you know. Are---is there a framework for identifying the population, and how successful have you been in finding the people that could be recruited? And then, you know, but the real question is participation. I mean it's, you know, the concern in any study like this is that people who have medical problems or who suspect that they have medical problems related to their exposure may be more likely to participate than those who do not. And you know, typically in, you know, epidemiologic studies, we try to achieve response rates of 75-80% to kind of mitigate that. I don't think we're going to get that here necessarily just because, you know, the age of the cohort and the—you know, just where society is now in terms of people participating in research. So, I guess, you know, we should think about there is going to be a control cohort and you know, are there ways in which we can use the control cohort? Or are there ways that we could use other sources of information? So, for example, for cancer outcomes, you do have the opportunity to link with cancer registries. So, if there's concern about, you know… But again it's, you have really two things. You have the entity from which you're drawing the subjects, which we may or may not have a handle on. I mean, I keep going back to the

Board of Education rolls because that at least is one defined framework. But then there is the framework of the people who are actually enrolled in your study, and those two might not match up in terms of objective measures like cancer incidence.

Yes, I think it's a really tough—I mean, that to me is really the toughest question. If you can't—if you don't have a defined population from which you're drawing participants, or at least a portion of the participants, and you don't have a high participation rate, how do you ensure that your results are scientifically valid with, given the possibility of selection and participation bias?

Does anybody have any thoughts on that? Do we agree that that's the $64 million question?

DR. CARREÓN-VALENCIA: We have another comment from Mridu. "Are there other administrative datasets or like insurance, for example?"

DR. WARD: You know, I don't know of any. I think, I mean if you look at the popul—I mean, if you look at a subpopulation of young survivors that still live in the New York area, you might be able to do something with local resources. Like so much of our insurance is based on, is geographically based. Similarly, you might be able to look at birth certificate records and look at reproductive outcomes, maybe. But I think once you expand to the whole country, it's really hard. There's just so many systems.

But I think what—go ahead.

DR. SURTI: Oh, I agree with your concerns around the self-selection bias. Potentially one way to balance that risk out is around, like, the compensation or services offered in exchange for participation. I feel like folks that are ill or feel like they might be ill are more likely to participate without any sort of incentive, and potentially that incentive may even out like the cohort of folks that would participate.

And then my second question or comment is I forget if part of your concern was around identifying like a healthy cohort to exist beside the…

DR. WARD: It's not so much the healthy cohort; it's the—I think the legislation called for having kind of a control group in the cohort of individuals who were not exposed to 9/11. And I think that probably is really important because otherwise you don't know what the prevalence of the various

diseases would be in an unexposed cohort. You can look within the cohort and possibly come up with stratification on level of exposure based on interview data, but I think there is the opportunity to have a control cohort of individuals who were not exposed. But again it's, that's really going to be—we haven't even touched how hard it would be to identify a representative cohort of unexposed individuals. That are, you know, that are comparable. I mean, you know, your first thing that comes to mind is maybe people lived on Long Island. Well, are people living on Long Island comparable to people who live in Lower Manhattan? I mean, it's really tough.

Debra, are you speaking? I can't hear you.

DR. MILEK: I am speaking on mute, yes. There have been studies on pregnant women and children. Is there any way of having those researchers inform their study participants of possible follow-up establishment of a cohort?

DR. WARD: I would assume there probably is, but I think those cohorts were really small, or fairly small. So, but again, clearly there are investigators who have done a lot of work. I mean, again, I think it goes back to the involvement of the experts because, like for example, Leo Trasande has been one of the leading researchers in this area. So certainly, you'd want to go to him and say, "What are your ideas for iden—you know, recruiting, identifying, recruiting, outreach, etc.?" I think you do have to tap into the people who are already doing similar research.

DR. MILEK: Yes.

DR. WARD: For sure, yes.

DR. CARREÓN-VALENCIA: So, Liz, it's 3:17 so I have two comments from Mridu too here.

DR. WARD: Okay.

DR. CARREÓN-VALENCIA: But I think we could, I could read them when we come back from—

DR. WARD: Okay.

DR. CARREÓN-VALENCIA: From the break.

DR. WARD: Okay. So, we'll do a 15-minute break and be back at around 3:32.

DR. CARREÓN-VALENCIA: Sounds good.

DR. WARD: Okay, thank you.

[Break.]

DR. WARD: I think you're on mute, Tania.

DR. CARREÓN-VALENCIA: Yes. I'm waiting for a minute more to give people a chance to come back. Okay, well, it's 3:32, so welcome back, everybody, and also welcome back to those following via webcast. I'm going to make one last roll call for the day. Liz?

DR. WARD: Here.

DR. CARREÓN-VALENCIA: Sophie? She told me she wouldn't be able to come back after the break. John? He might not be back yet. Chandra?

MS. DAVIS: Here.

DR. CARREÓN-VALENCIA: Joanna?

DR. GAITENS: Here.

DR. CARREÓN-VALENCIA: Mridu?

DR. GULATI: Here.

DR. COMISKEY: John is here, sorry.

DR. CARREÓN-VALENCIA: Oh great, thank you, John. Thanks, Mridu. Mariama? We'll wait. Anita? Not here. Indrina? Not here. Michael?

DR. LARRAÑAGA: I am here.

DR. CARREÓN-VALENCIA: Great, thank you. Steven, not here. John, not here. Debra?

DR. MILEK: Here.

DR. CARREÓN-VALENCIA: Thank you. Larry is not here. Jason?

DR. OSTROWE: Here.

DR. CARREÓN-VALENCIA: Great. Aarti?

DR. SURTI: Here.

DR. CARREÓN-VALENCIA: Glenn is not here. Mariama, are you, have you joined? I don't see her now on the—on Zoom. So, we have nine, nine, so we just made quorum again.

MS. JAMES: I think I may have missed my name, but Mariama, present.

DR. CARREÓN-VALENCIA: Oh, great, thank you. I can see you there. Thank you. So, there's ten of you. Thank you so much. So, we are ready to go back.

DR. WARD: Great. So, what I was going to propose is we hear any last thoughts on the four elements in Dr. Howard's charge and then we turn to the question that's come up about our recommendations regarding inclusion of *in utero* exposures. And then if there's any other major topics that we think we should address, we can put them on the floor as well. So, any last thoughts on Dr. Howard's charge?

DR. CARREÓN-VALENCIA: So, I have this comment from Mridu, and she said there are sort of two parts. One, trying to recruit and see what diseases they have now, and two, what diseases will they have over time, and how do we do both? And then she said we have to rethink over time.

DR. WARD: Great. Okay, good. Okay, if there are no further thoughts, I know we had several people speak earlier about their view on including—well, we talked about the fact that the legislation, or the appropriation actually, just specified those that were under the age of 21 at the time of 9/11 and did not specifically include but also did not, as I can see it, specifically exclude people who were *in utero* at the time of the exposure. So, can we hear thoughts from the NIOSH folks about what they're currently thinking in terms of *in utero* exposures in this cohort?

MS. BILICS: This is Jess. I think we're going to have to do a further review about the legality of including individuals who were not yet born during the time of the exposure period for the Program's eligibility. That doesn't mean that that prevents you from giving any recommendations on it today, but we have to do further analysis of whether or not the Program could legally include those in the cohort and, if in the cohort, whether or not they could be actually researched in the research provisions in the statute.

DR. WARD: Okay.

DR. CARREÓN-VALENCIA: Mariama has her hand up.

DR. WARD: Mariama?

MS. JAMES: Those that were *in utero* and those that aren't eligible for the Program aren't necessarily the same though. There are children that were eligible—I have one myself—that were *in utero* who are eligible for the Program and certified with conditions and participating in the Program. So, they're not—it's not just one, that's not one catchment. Or *in utero* is not something that we can look at in, (it's gray @ 00:05:35), you know, in terms of should we include them, because some are automatically included. They're included in the bill. They were eligible.

DR. WARD: Yes, I guess I get a little confused about the relationship between included in the World Trade Center Health Program and included in this new research initiative because it seems to me that, at least from—

MS. JAMES: It comes down to by what month you were born—

DR. WARD: Right.

MS. JAMES: In 2002. Yes.

DR. WARD: Right. But I mean, even given that, it's kind of, you know, does who's eligible for the Program govern who's eligible for the research? It seems to me that they're slightly different questions.

MS. JAMES: (Inaudible @ 00:06:15) as well. I agree with you on that.

DR. WARD: Yes, yes.

MS. BILICS: And this is Jess again. I would just reiterate that, you know, the Program is further looking into whether or not the research component—not the cohort establishment but the research component of the law—would allow for research on individuals that would not possibly also be eligible for the Program. But I don't want to hinder any of the discussion related to recommendations related to people who were *in utero* for the full length of or part—through the exposure period—that would not also be eligible, meaning they were not born prior to July 31, 2002, and also meeting the exposure hours for eligibility.

DR. WARD: Yes, so I guess that really is an interesting question because you said something about meeting the exposure hours for eligibility. So, we haven't even talked about whether that's going to be a relevant criteria for enrollment in this cohort. I mean, I guess that's one of the considerations that NIOSH will have to grapple with as, you know, the cohort becomes further defined. Are you going to use the same definitions that you use for your existing survivor population, or are you going to have new ones, or different ones? But I think from—okay, so on that, but on the question of including, I get always, I always get a little confused on the timeframes but I think, in principle, most of the people who spoke earlier feel that people who were *in utero* at the time of the 9/11 would be inherently exposed due to their parents being, their mother being exposed. So, there's a strong, reasonable scientific rationale for including them in the cohort. Aarti?

DR. SURTI: I'm just, I'm in agreement with the last statement that you just made around the scientific rationale and, given some of the difficulty with recruiting folks in the younger cohort, gathering or…linking these efforts together may inform what inclusion criteria would be appropriate in the future. And given that there is some time sensitivity around prospective

cohorts, it may potentially benefit our future selves if we're having a similar conversation in five or ten years around who's included in the Program, to have information on folks *in utero*.

DR. WARD: Michael?

DR. LARRAÑAGA:: Yes, thank you, Liz. So, you know, if we don't study this group, how do we know if they need to be studied? And you know, if the exposure period for inclusion in the World Trade Center Health Program is 9/11/2001 to July 31, 2001 [2002], you know, at least for most of that period, children who were *in utero*, in my opinion, I would like to see them studied and be in this program so that we could understand how they were affected, or not. Either way, I would like to see that.

DR. WARD: Okay. Anyone have further comments on that, or anyone disagree? Okay. Were there any other issues that came up during the discussion that the Committee would like to provide advice on to Dr. Howard? I'll give everybody time to think.

Okay, I'm not hearing any. I'm not sure if we should—are you ready to adjourn, Tania, or are there any administrative issues we need to address? You're on mute, Tania.

ADMINISTRATIVE ISSUES

DR. CARREÓN-VALENCIA: Yes, sorry. No, unless you have any other comments or issues, no. No, my only administrative issue is that we will see you tomorrow at 11 a.m. again. But other than that, no, we can adjourn.

DR. WARD: Okay, and what I'll try to do is summarize our discussion and put it into PowerPoint slides for tomorrow so that you can, you know, tell me what I missed or what I got wrong, and then maybe we can adopt those as recommendations for Dr. Howard.

DR. CARREÓN-VALENCIA: Thank you and remember tomorrow there is also a discussion on the Policy and Procedures which I sent, and I also sent you a link to the flowchart. But if there's any information you need from me, please email me or Mia.

DR. WARD: Okay. Well, thanks, everyone. See you tomorrow.

[Adjourn.]

Thursday, June 22, 2023

INTRODUCTION

DR. CARREÓN-VALENCIA: Well, good morning. It's 11 a.m. so let's get started. Welcome to Day 2 of the Scientific/Technical Advisory Committee, or STAC, meeting. I'm Tania Carreón-Valencia, the Designated Federal Officer for the Committee. I would like to welcome again the members of the Committee that are joining us this morning. I also want to welcome the NIOSH staff and those people that are following us today via the webcast.

So, before we start, I want to do another roll call to ensure that we have a quorum. I'm going to start with our Chair, Liz Ward.

DR. WARD: I'm present.

DR. CARREÓN-VALENCIA: Sophie Balk?

DR. BALK: Present.

DR. CARREÓN-VALENCIA: John Comiskey?

DR. COMISKEY: Present.

DR. CARREÓN-VALENCIA: Chandra Davis?

MS. DAVIS: Present.

DR. CARREÓN-VALENCIA: Chandra?

MS. DAVIS: Present.

DR. CARREÓN-VALENCIA: Thank you.

MS. DAVIS: Sorry.

DR. CARREÓN-VALENCIA: Joanna Gaitens?

DR. GAITENS: Present.

DR. CARREÓN-VALENCIA: Mridu Gulati? I'm not sure she'll be able to join today. Mariama James? Well, I know Mariama is having some technical difficulties but is listening. Anita Jose? Indrina Kanth? Michael Larrañaga?

DR. LARRAÑAGA: Present.

DR. CARREÓN-VALENCIA: Steven Markowitz?

MS. JAMES: I'm sorry, I'm present, Mariama James. I couldn’t—

DR. CARREÓN-VALENCIA: Yes, thank you, Mariama, I know you are. I think I said John Meyer? Debra Milek?

DR. MILEK: Present.

DR. CARREÓN-VALENCIA: Thank you. Lawrence Mohr? Jason Ostrowe?

DR. OSTROWE: Present.

DR. CARREÓN-VALENCIA: I think I saw him joining. Yes, there you are. Aarti Surti?

DR. SURTI: Present.

DR. CARREÓN-VALENCIA: Thank you. Glenn Talaska? Okay, so we have ten members present, so we have a quorum. And of course, I want to remind you that as of 10:55 a.m., we have one new comment that has been added to the docket on Regulations.gov. So now we have two comments. The docket will remain open until midnight tonight.

And we will have another public comment period that it's starting now. Six persons have signed up to provide comment. So, when I announce your name, please unmute yourself and turn your camera on. You will have up to five minutes to provide comment, and Mia will post the dots on the screen. Once the dot is completely red, your time is up.

I want to remind you of the redaction policy which you all received. This policy states that the transcripts will be posted, and names and speakers will not be redacted. If, in making a statement, you reveal personal information such as medical information, that information will usually not be redacted.

So, our first person to comment this morning is Rachel Lidov. And hold on a second until Mia has those ready. Yes, thank you, Rachel.

PUBLIC COMMENTS

MS. LIDOV: Good morning and thank you for having me. My name is Rachel Lidov. I am a parent of a former high school student. I joined the Lower Manhattan—should I go on?

DR. CARREÓN-VALENCIA: I'm sorry. We'll start the clock again. I don't know where that is coming from. I apologize. I see everybody's muted. So please go on.

MS. LIDOV: Manhattan community to press for a science-based indoor cleanup. We fought… Go ahead? Okay. There was honking outside my window.

I am Rachel Lidov, a parent of a former high school student—I don't know where that's coming from.

DR. CARREÓN-VALENCIA: Rachel, everybody on the call is on mute—

MS. LIDOV: I joined the Lower Manhattan community to press for—

DR. CARREÓN-VALENCIA: So that noise must be coming on your…

MS. LIDOV: I joined the Lower Manhattan community to press for a science-based indoor cleanup—

DR. CARREÓN-VALENCIA: Your way. Sorry.

MS. LIDOV: And for health, for the right to healthcare and compensation.
It keeps blipping back at me. This is outrageous.

DR. CARREÓN-VALENCIA: I'm sorry, I don't know. Everybody's on mute and we hear you well.

MS. LIDOV: Yes, but why is it replaying?

DR. CARREÓN-VALENCIA: We can hear you well.

MS. GOODKIND: No one else can hear it, just continue.

MS. LIDOV: Hello, I'm—I don't know what to do and my time is getting used up.

DR. CARREÓN-VALENCIA: We'll restart the clock. Please go on. We all can hear you. We don't know whatever else you are hearing, okay?

MS. LIDOV: As a resident a few miles north in Manhattan's Morningside Heights, it was shocking to breathe the air wafting uptown. It was more shocking to attend early community meetings and to learn what the residents and workers and the students from other parts of the city were being subjected to. It only took a month or two for me to figure out—it only took a month or two for me to figure out we needed immediate action to create a registry of all those who were affected. It took us years to get any level of government to even consider our unified demand for it. While as a citizen I continue to be appalled that we cannot do better to protect today's children from emotional and physical harm caused by violence and national disasters. I am not surprised. And so, I wish to emphasize today my support to establish a full cohort of younger people affected by the WTC disaster that we sought for the last two decades.

Let me point out just two issues. We need to have people who can do this in real-time to make personal contact with those who have been left out. In September 2001, many of the young people were verging on entering adulthood. Some already were young adults. These people, now nearly of middle age or will be middle-aged in a few years. At the time of the attack on the WTC, the downtown community, the city, indeed the country, was in shock. And many government agencies who should have been protecting the pregnant women, babies, children, and

teens, and the very young adults were busy telling everyone there was nothing wrong with the outside air or the dust that was blown in to many buildings. And some were within months of being born.

When the CDC and the NYC Department of Health finally established a registry, many of these people had already scattered or were too young to realize their need. Many are in New York City, but many are all over the country. They are in country—other countries. Sending letters to family addresses from 2001 and 2002 will not do the job. Yesterday, the STAC and the Program heard from the people exposed as children, who are now adults, and who are advocating for a program, to include them in the research so that their needs might be met in the future. This is what we have fought for over twenty years.

NIOSH must address the knowledge gaps now. The first step is committing to this new cohort. We need longitudinal studies of the larger populations. Need I point out that the toll that a decade of cover-up of the dangers in smoke and dust deprived us of the opportunity to begin clinical studies? And yet, some dedicated community organizations, and individuals like Dr. Reibman, did begin that work through local hospitals. While the community supported those efforts, if they knew of them, we have never been fully successful in getting long-term commitment from the City or the federal government to fund them. There have been some attempts to survey the population but, again, will the effort now on the table be fully supported by NIOSH so that this can be done more methodically?

Epidemiologists have established scientifically sound methods for comparative studies of similar populations in urban areas, which can be applied to the destruction that occurred in the area immediately around the Twin Towers, to say nothing of the continuing upheaval in the surrounding environment that came with rebuilding across local—Lower Manhattan. Such studies could guide science and medicine to an understanding of the impact of environmental exposure and how to treat the affected, and why exposures should be reduced in the future, if not prevented, by those agencies whose mission it is to protect human health and the environment.

We owe it to the children in harm's way on 9/11 and to the months, in

the months thereafter to get answers that could help them now. These answers actually would help the entire 9/11 community, especially women, who are a minority of the responder research cohort. This work will take a long-term commitment from NIOSH. It is incumbent upon you and this Program to join with us to demonstrate the will to build and maintain the cohort that the young survivors themselves are calling for.

Thank you very much.

DR. CARREÓN-VALENCIA: Thank you, Rachel. And before I announce our next commenter, I see that Mridu Gulati had joined. Can you hear us, Mridu?

DR. GULATI: Yes, I can.

DR. CARREÓN-VALENCIA: Thank you. So now we have eleven members present. And I know you were having difficulties yesterday, so please continue communicating with me and I will relay your comments to the Committee. Thank you.

DR. GULATI: Thank you.

DR. CARREÓN-VALENCIA: So, our next commenter is Kendall Chapman. You have five minutes. Is Kendall present?

MS. WALLACE: No.

DR. CARREÓN-VALENCIA: No? Okay. Well, we'll move on. Olivia Goodkind?

MS. GOODKIND: Hi, yes.

DR. CARREÓN-VALENCIA: Okay, you have five minutes.

MS. GOODKIND: Okay. Hi, everybody. My name is Olivia. Three years ago, my father, Tom Goodkind, was diagnosed with 9/11-related stomach cancer after years of unanswered pain. He passed away three months before my college graduation. He was my best friend.

Since about the age of eleven, I've suffered from stomach pain. I ignored it for the majority of my life, as young people often do, until after my father's death when I decided to finally go to a specialist, who told me I had a digestive issue due to 9/11 that will eventually need surgery.

I was four years old during 9/11. It was my first full day of kindergarten at P.S. 89.

I remember the rattle of the building as the first tower fell. I remember running down the West Side Highway staring back at the fires behind me. And I remember the masks that were distributed being too large for

me. More than anything I remember the smell as the fires still burned and my parents were told it was safe to return home.

Now, as an adult, I fear for my fellow classmates who have moved on and away, as I fear for myself. Because as the time and distance goes on, it'll be harder and harder for them to recognize the effects of 9/11 and harder for them to prove they were there. And the truth of the matter is, when they might need help, those who were adults at the time who can prove that they were there will be gone. This study, this cohort, is essential. Thank you.

DR. CARREÓN-VALENCIA: Thank you, Olivia. Has Kendall joined, Mia? I don't think she has. So, the next person to comment is Kimberly Flynn. You have five minutes.

MS. FLYNN: I'm Kimberly Flynn and I make these comments on behalf of the Survivors Steering Committee. We thank the Program for holding a daylong meeting to begin the STAC's deliberation on its recommendations to the Administrator for planning of the new cohort but also, crucially, to begin engaging with young survivors who will make up that cohort and who will be critical to its success.

For those of you new to the STAC, I want to provide some context. What we saw and heard at yesterday's STAC meeting has not happened before. Young survivors showed up in numbers and spoke for themselves. Five of them delivered a presentation and young survivors will comprise the majority of speakers in both public comment sessions. Yesterday, all of them—and today, I would add—shared an extraordinary level of ideas, insights, and proposals for building the cohort. Some of these are in writing in the recommendation section of yesterday's PowerPoint and we strongly advise that all of you read through them.

But my main point is this: we, older survivors, are no longer talking about children's 9/11 research needs as we were in 2011 or 2015. The conversation has shifted. The World Trade Center Health Program is now in dialogue with young survivors who are talking about what needs to happen in order for them to have the answers they, and the whole 9/11 community, are entitled to. In addition, they are holding the Program accountable to address their research needs.

And yesterday afternoon, I got text messages from those who made

comments. All of them were wanting to know what's next. We of the SSC are proposing that the Program set up a meeting with them to continue the unprecedented dialogue that was started yesterday. As someone who was recruiting young survivors to speak in this meeting, I can tell you we gained momentum in the last week. We could easily have doubled the participation. We cannot allow this momentum to subside. Time is of the essence.

Now, for some corrections about yesterday. The youth research cohort is on a separate funding stream from the Clinical Centers in New York, New Jersey, and from the NPN. Next point: the youth research cohort we think will cost maybe $30 to $40 million over the long life of the cohort. Please keep in mind that the Program allocates approximately $16 million per year to research and that funding has gone overwhelmingly to studies focused on the largely male, male middle-aged or older, responder population. We are in no way opposed to research focused on responders. We are for it. We also benefit from it. But it doesn't tell us what might be happening to 9/11-exposed women, and it doesn't give us a view to help issues that may be emerging in people who were exposed at a much younger age.

We have been advised repeatedly over the years by the Program and its researchers that survivor research doesn’t get funded because there needs to be a cohort that is not based on a clinic population that is, by definition, already sick. A good research cohort has to be based on who was exposed and it would include some who have current health impacts and some who do not. That’s what this new cohort is. It's the research tool we have lacked all along. And, further clarification: no one is seeking to enroll 100,000 young survivors. We are probably looking more at 5,000 to 10,000, and please keep in mind that the Responder Data Center runs a cohort of more than 60,000 responders.

So, in closing, I want to emphasize again, because the youth cohort would be 50% female and followed longitudinally, it would track the emergence of 9/11-related women's reproductive health problems as well as conditions that are not unique to women. It would also track men's reproductive health problems. We learned yesterday for the first time that testicular cancer is emerging for young men in the survivor

program.

To paraphrase what Armani James said yesterday about the importance of research on young survivors, it will make things better for young survivors, but it will also make things better for everyone. So, for instance, as information flows from the new cohort about health impacts emerging in young women in their childbearing years, the program will gain an understanding of these types of impacts for 9/11-affected women generally.

It's the rising tide that lifts all boats, thank you. Did you (release @ 00:25:06) me? Hello?

DR. CARREÓN-VALENCIA: Yes, I'm sorry. Yes, thank you, Kimberly. Our next—well, before I move on, I also want to remind everybody that we have an RFI requesting comments from the public about the children's cohort. So that's the opportunity to post comments too. And this information has been shared with the STAC and it's on the website under the children's cohort session.

Okay, our next presenter is David Prezant. David, you have five minutes.

DR. PREZANT: Thank you for the opportunity to address the Committee. Can you hear me? Great, thank you. Thank you very much and I'll try to keep my comments short.

My comments are directed at the draft for the Policy and Procedures for Adding Non-Cancer Health Conditions to the List of World Trade Center-Related Health Conditions. I represent the Fire Department cohort as both its Director for the Clinical Center and Director for its Data Center. And as Chief Medical Officer for the New York City Fire Department, I also represent the Fire Commissioner's interest in this very important topic.

We are very much concerned that this draft would limit the ability to add new conditions to the health list, limit the ability in substantial ways.

It would appear to us upon reading this that there is a heavily weighted bias towards consistency amongst all the cohorts at the World Trade Center rather than the quality of the evidence. In fact, the Administrator first refers any new condition petition to the Science Team at NIOSH for its review. That makes perfect sense. The Science Team then classifies

the evidence as its quality, which also makes perfect sense, and has categories for the level of quality for a petition. It is there where we have a substantial problem.

It would appear that you could only move on, that the Administrator could only move a request for a new condition on to the STAC Committee, if the Science Team rates the quality of evidence as either Category 1: Substantial Likelihood or Category 2: High-Quality Evidence. And while on the surface that makes perfect sense, we should not be sending low-quality evidence to the STAC Committee for its review.

On the surface that makes perfect sense, but when you delve into the definitions in this draft for what would be high-quality or substantial likelihood, it appears that you would need evidence from all of the cohorts that to be Category 1 you must, and I quote, "Have available epidemiologic studies as a whole, must have examined both groups of the 9/11-exposed population, both responders and survivors?" That seems to be a requirement to get into Category 1.

Well, the research coming out of the survivor cohort has been hampered by many ways, not based on the quality of the physicians and scientists at the survivor level but based on other structural issues. So, it is going to be very hard to have substantial causal evidence reach a Category 1, Substantial Likelihood. Therefore, most of the provided evidence will be in Category 2 which would be the High-Quality Evidence. In Category 2, High-Quality Evidence, it again stresses—doesn't require but stresses the need to have either evidence from or extrapolatable evidence in both responders and survivors.

We know that the most scientifically valid evidence comes from closed cohorts with clear comparison groups. And that is the fire department and, to a lesser extent, the World Trade Center Health Registry. These are not survivor groups, and they are not the other groups, and to require evidence, high-quality or substantial, from all groups will limit the ability to add new conditions. It favors consistency rather than the quality of the evidence and we respectfully request that the draft be modified so that quality of evidence can be evaluated even when there is not complete consistency between all of the cohorts.

Thank you very much.

DR. CARREÓN-VALENCIA: Thank you for your comment. Our last presenter is Heidi Alexander.

MS. ALEXANDER: I'm here, can you hear me?

DR. CARREÓN-VALENCIA: Yes.

MS. ALEXANDER: Okay. I don't see myself, can you see me?

DR. CARREÓN-VALENCIA: Yes, we can hear you, go ahead.

MS. ALEXANDER: All right. My name is Heidi Alexander. I'm a survivor of the 9/11 attacks with high levels of exposure to the finely pulverized dust and fumes during the collapse of the World Trade Center Towers and as a Battery Park City resident living in the immediate vicinity of the World Trade Center site with continuous exposure during the eight and a half months of cleanup and for the following several years.

I've read through the World Trade Center Health Program research publications and notice the gap in the topic study concerning a form of rhinosinusitis, one of the covered conditions under the Program, that may offer insight into several symptoms considered to have diagnostic uncertainties as described in several World Trade Center-exposed research papers. Rhinosinusitis is generally regarded as an upper airway condition with symptoms of chronic post-nasal drip or stuffy nose. However, this condition causes much more serious injury when the sphenoid sinus is infected. The sphenoid sinus is one of the four pairs of sinuses that rarely becomes infected due to its inaccessible location deep into the middle of the head behind the other sinuses, separated by the brain and its anatomy by a very thin cartilage. An infection in this sinus causes inflammation at extent onto the surrounding anatomy, meaning the brain, the inner carotid artery, the pituitary gland, the optic nerve, the occipital nerve, and several others, causing symptoms that include ischemic stroke, permanent or intermittent loss of vision, permanent or intermittent loss of hearing, various neurological deficits, aphasia, meningitis, infertility, premature menopause, heart attack, cognitive deficits, among many other debilitating and chronic symptoms generally left untreated due to misdiagnosis or just plain ignorance. This topic needs to have priority as a dedicated research project that may help to develop better diagnostic and treatment protocols for this condition. Due to the relatively rare incidents of sphenoid sinusitis under normal circumstances, otolaryngologists generally do not request

an MRI or CT scan when the endoscope seems to do the job in incidences where sinus complaints exist.

This receded sinus cannot be viewed endoscopically and requires more advanced imaging in order to be diagnosed and treated in time to prevent chronic or permanent injury. The unique nature of the finely pulverized dust and smoke from the collapsing World Trade Center Towers created the perfect environment for infection of this type to be more prevalent among those exposed than are currently diagnosed, creating a core population for an in-depth research project into this type of rhinosinusitis.

There are hundreds of peer-reviewed medical research papers published on the NIH.gov PubMed website pertaining to the importance of early diagnosis of this particular form of rhinosinusitis to prevent the debilitating symptoms that become permanent injury. There's a significant number of MRI and CT scans of the sinus cavities from the 9/11 first responders and site workers available to retrospectively establish longitudinal study based on correlation of this type of rhinosinusitis with the other symptoms that may help explain the so-called diagnostic uncertainty and develop better treatment protocols.

This also highlights a gap in medical science. An otolaryngologist looks at the inside of the sinus for airway blockages and inflammation. They don’t look at the outside, which generally causes neurological problems. So you go to a neurologist, the neurologist would never look at the sinus cavity. So, who's looking at that space between the sinus and the brain? No one; no one I can find, at least, because this is what I suffer from.

I strongly urge the CDC and the World Trade Center Health Program STAC Committee to consider my suggestion for an in-depth research project on sphenoid sinusitis and its associated symptoms. In fact, a study can only be done retrospectively on this type of a condition because the symptoms don’t present themselves all at one, they present themselves over time. And so, by now you should have those who have this type of infection and their associated symptoms. Right now, yesterday there was a young woman complaining that she went into premature menopause. Well, I suggest she have her sinuses scanned and look at the sphenoid sinus because it presses up against

the pituitary gland causing infertility in a lot of people.
I don't know why this research isn't being done. It is a covered condition. It's just, I guess, maybe not widely known and I'd like to bring it to light so there is some research done. There's a lot of data that can be used.
Okay? That's what I have to say, thank you.

DR. CARREÓN-VALENCIA: Thank you, Heidi.

MS. ALEXANDER: You're welcome.

DR. CARREÓN-VALENCIA: I ask that those persons that provided comments now leave the Zoom Room and continue following the other webcast. Just want to make sure, did Kendall Chapman join us?

MS. WALLACE: No.

DR. CARREÓN-VALENCIA: Okay, thank you, Mia. So, before we proceed and I give the floor to Liz, I want to share the youth research cohort website page. So, you can see—I think you can see it now—the page has information about the Youth Research including legislation to proposed approach, the map we showed yesterday. And here is a Request for Information, or RFI, so anybody wanting to provide comment on the youth cohort can go to this website—it's on Regulations.gov, I believe—and provide comment. So far, we haven't received comments. And this is open until August 26th, so there's still plenty of opportunity to provide input.
And with that, I give the floor to Dr. Ward.

RECAP FROM FIRST DAY DELIBERATIONS

DR. WARD: Good morning, everyone. So, the next topic we're going to take on is a recap from the first day of deliberations. And I think as many of you who've been on the Committee know, the form in which we provide our recommendations to the Administrator is in a letter that I draft after the meeting and send it to Dr. Howard. And so, in preparing a recap, I kind of went through the content of our discussions and tried to prepare the text to capture those discussions for Dr. Howard that would then subsequently be put in the letter.
So, Geoff, if you would like to bring up my PowerPoint presentation. I propose that we go through the four areas and then the additional area

regarding the *in utero* exposures one by one. And as we go through this, I think it's important that we have a general consensus that this represents the views of the Committee. We should be aware of any additions or deletions that the Committee would like to make, and particularly if we've missed any particular points or you feel we've misstated the opinion of the Committee.

So, Geoff, you can move on to next slide. So, I'm not going to read through this. I'm going to take a minute and let Committee members read through it. And then everyone should voice any concerns that they have, and Geoff will be the editor to try to bring those concerns into the text.

Do we have any comments? Yes, John?

STAC DELIBERATIONS

DR. COMISKEY: Yes, so it's with respect to the timeline. Maybe we should make a recommendation with respect to the timeline—six months, one year—to be a little more specific there.

DR. WARD: And what do other people think about that?

DR. SURTI: I'm in agreement with that.

DR. LARRAÑAGA: I agree. I don't know if one year is a reasonable—or even six months is reasonable, but I agree with kind of recommending a proposed time.

DR. WARD: Any other thoughts on that?

DR. MILEK: I think if you don't recommend a timeline, it's probably the same as not having a timeline.

DR. WARD: Okay.

DR. MILEK: So, I'm for a timeline.

DR. WARD: So, does the Committee think a year is sufficient or too short? I mean it is a large process. My personal opinion is that six months would definitely be too short. Again, I'll throw out two possibilities: recommend a year or recommend 18 months?

DR. COMISKEY: I'm going to go back to the one year in a sense of, hey, if they need to extend that, okay, they have a rationale for that. But let's kind of try to hold them to that one year and certainly if things manifest, that could be extended.

DR. CARREÓN-VALENCIA: Is everyone in agreement with that?

MS. DAVIS: Yes.

DR. CARREÓN-VALENCIA: Okay, Geoff is making that suggested change in the text. Do we want to say "with extensions possible" or just say "one year"? It seems like "with extensions allow," that's kind of opening the door to a lot of extensions.

DR. GULATI: This is Mridu, sorry. I like the idea of there being extensions. I think maybe something about being able to propose some kind of process that would have to be accessed to allow extension beyond one year. I guess in terms of the—well, I guess it's already been so long—in terms of some of the other occupational cohorts, I assume that it certainly took more than a year for that to be established, as well, so I just want to make sure we're being reasonable.

But the other thing I wanted to mention was is there a way to not just talk about alternative options, but actually being specific in terms of leveraging either digital health platforms or social media or other alternative ways of recruitment. There are ways to do virtual recruitment through things like—there are also different methods and I think kind of emphasizing that, we should think about how to leverage some of those other platforms for both recruitment and retention would be helpful as well. That's at least my thought.

DR. WARD: Thank you, Mridu. I think we're going to cover the digital and other platforms—and we didn't use that specific phrase—under one of the other categories. So, let's wait and see if you think that's adequate. This is more specific to the phased approach. And I'll also say that the fourth phase is not completing the cohort, it's basically selecting the preferred option for establishing the cohort. So, there would undoubtedly be a period of years when the actual cohort would be recruited.

DR. GULATI: I was just going to say that I feel like sometimes to avoid going back to more dated methods, having those words foremost either something like—some kind of forward-thinking, technologically driven term or something like that might make it a little bit more first and foremost in there. That's the only reason I'm bringing it up. I'm sure they're going to have to actually use it, but I just want to ensure that so we're not going back to sending out letters.

DR. WARD: Right. Well, let's put that point kind of in the parking lot and see when

we discuss our draft on the recruitment and retention, if you still feel that we need to add something up here, we can go back and add it.

DR. OSTROWE: Might I suggest that we just leave it at suggested timeline to complete the four phases is one year, period? Because it's a suggestion, it's not a requirement, right? So, do they even need extensions with justification? Also, Liz, as you've noted, this entire process is going to take longer so I almost feel in a way that adding that additional language in there—which I'm not necessarily opposed to—would end up creating like additional bureaucracy and additional steps for people to do things. So, that's just my thought is maybe to leave it at suggested timeline to compete the four phases is one year.

DR. WARD: Yes, thank you. And Aarti has her hand up?

DR. SURTI: I'm in agreement with Jason regarding aiming for a more aggressive timeline and then anticipating that if that changes, we can address that in the future.

But I also wanted to ask the group if this is an appropriate place to deliberately state that we want the input of the youth like survivor cohort in order to like help shape some of the outreach effort. Similarly to what Mridu was saying about deliberately using technology, just a nod to including that group in designing some of the outreach and cohort structure.

DR. WARD: Great. And I am starting to see the point. It sometimes takes me a while. So, I suggest that we finish the sentence that Geoff is working on. And it sounds like there is a sense that we should just leave the phrases—we should just stop with one year. And I wanted to point out that under one of the other topics, there's a section on the Committee's advice regarding oversight. And when I typed up the notes, I realized that we hadn't really talked about oversight. So maybe we can segue that point about extensions and oversight into that section and not address it here.

Tania, you had a comment?

DR. CARREÓN-VALENCIA: Yes. I just want to know if Indrina Kanth had joined the room. Can you hear us, Indrina?

MS. KANTH: I can. Thank you so much, I'm sorry to be late.

DR. CARREÓN-VALENCIA: No, I just want to know, has anything changed in your conflict-of-

interest status since you filed your OGE 450 form?

MS. KANTH: No, nothing has changed.

DR. CARREÓN-VALENCIA: Okay, thank you and welcome.

DR. WARD: So, I'm thinking what we could do is before the line "Suggested timeline to complete the four phases," Geoff, you need to take out the word "with reasonable extensions" before we move on. But before that phrase I would suggest we add a sentence or two to capture the comments regarding the importance of engaging the survivor cohort and the importance of using digital and other media that's pertinent to that cohort.

DR. CALVERT: What was—digital?

DR. WARD: And using communication—Mridu, did you want to suggest language there?

DR. GULATI: Yes. You might even keep it broad like "leveraging innovative technologies to conduct outreach, recruitment, and retention." And that kind of keeps it broad.

The other thing I wanted to ask about, particularly given some of the comments, is how specific do we want to bring in funding in this statement? If there are indeed, as one of the speakers clarified, amounts that have already been put forth—or maybe saying something like, I don't know, maybe creating a budget or something like that. But I'm wondering about going back to that statement at the end.

DR. WARD: You don't think the statement at the end is sufficient?

DR. GULATI: No, no, I'm just wondering if there was already discussion about—during the public comments there was a comment about the fact that it is clear what the funding is available. That's all, I'm just looking at the projected budget, like how much surface area should we put on the budget at the end?

DR. WARD: Yes, and I think where your comment is coming from maybe that you weren't here at the early part of the meeting, so the STAC specifically asked the Program how much funding is available and they specifically said that they were not able to tell us at that time because the funds could be used for other—there were certain designated purposes for which the funds—other purposes for which the funds could be used and they hadn't sorted that out. So, we're basically encouraging the Program

before they go too much further to sort out the question of how much funds are actually going to be available for the youth cohort, putting it together and following it up.

DR. GULATI: Okay, all right, that makes sense. And just a comment: so, innovation technologies to conduct outreach, recruitment, and the retention. And, Liz, thanks, that's help. I'm still wondering if we could say that in a shorter way, the last two sentences.

DR. WARD: I guess what I was trying to do in the second sentence is provide a rationale for why it's important. I realize that it's almost self-evident why it's important, but sometimes it's helpful for the STAC to really belabor a point in order to get it across.

DR. GULATI: Got it.

DR. WARD: So, unless there's any further thoughts on this—and we can always return if somebody has a thought later and wants to go back—I suggest we move on to the second—

DR. BALK: Can I just ask, could you spell out RFI because I don't know what that means, and in the interest of transparency.

DR. WARD: Okay, Geoff, can you do that for us?

DR. BALK: Thank you.

DR. WARD: And as Tania has pointed out, if you go to the website, you can see the text of the RFIs that have been issued. I mean one thing that didn't come up yesterday, but I would almost be tempted to try to add it here somewhere, is that it's really important that the World Trade Center program make it known that these RFIs have gone out. I mean I know that there is a very connected and concerned community that is probably following this, but I'm afraid that some people may miss it, may miss the deadline and not—so I guess it would be important for the Program to really try to do outreach around the existence of these RFIs. Tania, is that part of the plan or?

DR. CARREÓN-VALENCIA: Yes, that's my understanding. And it was shared, it's on the website, it has been shared on social media. I don't know if somebody else from the Program can provide more input on that.

MS. BILICS: This is Jess. It's also been shared with both the Survivors and the Responders Steering Committees and asked to share with whatever networks they feel appropriate.

DR. WARD: Geoff is drafting a sentence for us. Do you think we should include that sentence? Is everybody in favor of including it or not?

DR. GULATI: Can we clarify that point again? I'm just—

DR. WARD: Sure. So, the Committee has been made aware that there are these Requests for Information that have been published in the Federal Register, specifically for ideas about how to form the youth cohort. And I was just saying that I worry sometimes that all of the interested parties may not see the requests and may miss the deadline. So, I was just thinking that we should add a sentence encouraging the Program to do reasonable outreach. And kind of what Geoff is saying here "Should do reasonable outreach to promote the availability of the RFIs."

DR. GULATI: Yes, that makes sense.

DR. LARRAÑAGA: I think it would be wise to include that.

DR. GAITENS: I agree.

DR. WARD: Okay, great. Okay, so in the interest of time, I think we should move on because actually the third response is the longest one. And the second one is relatively brief. Because I really feel like, in part, we're not in a good position to really provide extensive advice on this topic. So, it was advice regarding potential partnerships for establishing the youth cohort. So, we can take a minute and you can read what I drafted and I'm certainly happy to make additions to it or changes.
So, does anyone have specific suggestions for changing this now? There's also the possibility once you see what's discussed in the next topic that you may want to go back and change this one. But I think most of the—this question related specifically to partnerships and that's kind of a more diff… So, in the next point we talk about kind of outreach, and this is more specifically around identifying potential partners. So, I felt like there wasn't much more we could say about this, but does anyone have any suggestions for this? Or, like I say, if not, we can go back to it at the end and see if there's something that we should say that we haven't said.

DR. GULATI: Do you think that the existing—because I think somebody mentioned yesterday the existing occupational cohorts kind of leveraging people who are already enrolled—do you think that's actually so other first responders, etc., who are enrolled in other cohorts and perhaps

engaging their families and reaching out to their families? Because that's actually a pretty extensive network in and of itself. I'm wondering if that outreach, if this includes that.

DR. WARD: Good point. We couldn't rephrase it "partnership engaging responder and survivor cohorts" and—

DR. GULATI: I was going to say there's res—so engaging—so the other cohorts include not just the respon—well, I guess I'm just wondering beyond other occupational cohorts besides just the responder community.

DR. WARD: Yes, we could change that to "occupational."

DR. GULATI: Yes.

DR. WARD: Could you say, "to identify eligible participants and their family and communities"?

DR. GULATI: Or to help facilitate outreach.

DR. WARD: Good.

DR. GULATI: And then, I don't know, "engage their networks."

DR. WARD: "Through their networks" or something like that?

DR. GULATI: Yes, right.

DR. WARD: Okay, that looks good to me. Is everyone else in concurrence? Okay, great. I think we can move on to the next one and, again, I think at the end we can go back if anyone had any second thoughts about the first two.

So, this one actually goes on to a second page, and I have the opportunity to add something about project oversight at the end, but I don't know if we should read through both pages. Maybe we should read through both pages and then go back and have the discussion. So, we'll leave the first page out for a while and then we'll move on to the second.

I'll move on to the second page. And I'm sorry, typically I would have circulated this in advance, but I think the STAC rules prohibit it. So, I just—I'm sorry we have to do this all online.

DR. GULATI: Is there a way to show both of the slides at the same time? Or will it be too small or?

DR. WARD: You know, we could probably copy it into one page, Geoff, maybe go back into Word and just copy it into one page. Maybe that would be big enough to see.

DR. GULATI: That might be easier to edit it. I'm sorry; I don't mean to make this complicated.

DR. WARD: No, no, I think it's a really good point. I went to PowerPoint just out of habit, but it may have been better to leave it in Word because I think it could be large enough to read. Next time, there's always a good idea for next time.

DR. GULATI: So, I'm wondering, do—you are talking about the Board of Education records and the experience. I mean do we want to say something like sampling has—up until this point it's been inadequate to just use—I mean are we comfortable saying that and that we need to rely on other outreach and then subsequent verification?

DR. WARD: Well, you know, it's a hard thing to say. I think partly I kind of wish that the Program had talked more substantively about some of the information that was in the RFI because it articulated a little more clearly that they do still see a role for the Board of Education records. But at this point the Committee has very little to go on, so I mean we could say that—I mean I think the Board of Education records may be the largest and most systematic timeframe, but I think it's clear that we will miss a lot of people through the Board of Education records just because they would—or I guess we could say something like this: "The Committee notes that the Board of Education records will not include residents in the targeted age group who did not go to public schools and does not include children enrolled in daycare, so it will be important that the Program uses additional sources to identify."

DR. GULATI: Yes, I think it's important to say that the Board of Ed records are not enough. I'm not saying that they can do Board of Ed or a combination of both, but it should be the Board of Ed as well as a combination of other recruitment methods.

DR. WARD: Okay, so maybe we could add that right where the cursor is, Geoff.

DR. GULATI: I'm just wondering the first sentence is "recognizes that at this point is unclear whether the cohort will be...to ensure, it will be important to consider…" We could say "The STAC recommends that the cohort is developed using Board of Education records, as well as a combination of other recruitment methodologies" or something. So, we make a strong recommendation at the beginning because I think it's important that it

is a strong recommendation.

DR. WARD: Okay, so I think we could put that in right after the first sentence in the second paragraph, Geoff.

DR. CALVERT: Okay.

DR. WARD: So, I think we could say "The STAC believes"—

DR. CALVERT: Here?

DR. WARD: Yes. "The STAC believes it is important to use additional sources to the Board of Education records given that those records will include only children enrolled in public schools or in the public school system, and not residents attending private schools or children too young to be in school."

DR. GULATI: And you actually have in the next sentence "Multifaceted, national outreach using methods tailored to communication preferences." So, it could be "It is important to use multifaceted, national outreach methods"—because you have those words in the next sentence if you want to consolidate a little bit.

DR. WARD: Right. How about "To reach"—something like "To identify a truly representative population, it will be critical to do multifaceted outreach"?

DR. GULATI: Uh-huh.

DR. WARD: So, we can take out "If recruitment is."

DR. GULATI: Right.

DR. CALVERT: Here?

DR. WARD: Yes. You could say "To ensure that all these groups are represented in the cohort."

DR. GULATI: And not to just sort of beat a horse, I think we need to keep using terms like “social media” actively through here.

DR. WARD: Right.

DR. GULATI: And also, I don’t think—I mean if you're going to just do one example, I don’t know that PSA is, I mean I think it sounds a little dated—

DR. WARD: Right.

DR. GULATI: So, I would probably say social media campaigns.

DR. WARD: So, we put it after that "age groups," say, "such as social media campaigns."

DR. GULATI: Yes, I'm just thinking about even just eliminating that PSAs in the

subways because if you're only going to highlight one method, I don't know that that's the method that you want to highlight.

DR. WARD: Okay, I'm okay with that. Is everyone else okay with that? Okay, so we'll take that out.

DR. CALVERT: Take out this whole sentence?

DR. WARD: Yes.

DR. GULATI: I'm not saying not to do it. I just—

DR. WARD: Yes. Okay, so is everyone okay with that paragraph? Okay, so on to the third paragraph. And, Mridu, in the last sentence of this paragraph I was struggling to find the right words. I think the idea is to "develop online forums for survivors to communicate with each other," but I was struggling to—so if you have better words to suggest there, that would be great.

DR. GULATI: This is where having a document in front of you would be helpful.

DR. WARD: I know, I know. I wish that could be true.

DR. GULATI: Yes.

DR. WARD: Yes, I mean I was looking this morning at other types of forums. The only one I was familiar with was the Cancer Survivors Network and kind of—

DR. GULATI: There's the whole COVID—I mean this is what I was wondering about COVID. I mean there's all the survivor networks from COVID and I'm sure that the CDC, for example—

DR. WARD: Ah, okay.

DR. GULATI: Right? I mean some of them are listed on the CDC website pages as examples of patient support and they are partnering with a lot of research organizations post-COVID and things like that as well. So that's kind of what I meant yesterday about leveraging some of the knowledge from there. And that experience exists within the CDC.

DR. WARD: Okay, that sounds good.

DR. GULATI: So, I guess there's a difference between the Program—well, I guess there's the facilitation of online opportunities for survivors, but also partnering with existing groups within the survivor community. Which I think you kind of say anyway because you're talking about engaging survivors, but I think the COVID/long COVID cohorts and patient support groups are really large, good examples of how it's been done, and I

	think there are lessons that could be learned from that. And many of them are doing their research and recruitment and following their health longitudinally through those uses of those digital health platforms.
DR. WARD:	Yes, I think that's a great point and I didn't get it yesterday because I was thinking more of like COVID outreach regarding getting people to get vaccinated. I wasn't realizing that you were specifically talking about the digital platforms to engage with long-term survivors. So, if we could try to come up with a sentence maybe for the end of that paragraph. We could say, "Examples of this are partnerships are"—
DR. GULATI:	Or "Lessons learned can be derived from"—
DR. WARD:	Good.
DR. GULATI:	"Lessons learned can be derived from experience with COVID and long COVID communities, or long COVID survivors," whatever term would be appropriate to use.
DR. CALVERT:	Do we put "patients" here or—because "survivors," people might think of responders versus survivors.
DR. GULATI:	Whatever you think would be easier. Because I think these lessons are both learned both not only—I mean we now have the youth survivor cohort, many of whom have had COVID too, so they also know some of these things. So, the lessons learned are the researchers, the agencies, 9/11 survivor—everybody, the lessons have been learned by many.
DR. WARD:	Yes, I think we need to be more specific, though, in setting up digital platforms which become vehicles for research or something like that.
DR. GULATI:	Uh-huh. Let me see. All right, so what terms are you looking for? Let me think about this.
DR. WARD:	Something like if we say, "Affected persons where digital platforms have been used as vehicles for community and patient support, as well as vehicles for research"?
DR. GULATI:	It's not totally sounding right.
DR. WARD:	No. But sometimes you can only edit it when you see it.
DR. GULATI:	That's right.
DR. LARRAÑAGA:	Yes, I think better when I'm the one doing the typing.
DR. WARD:	Me too. I can't think when I'm not typing.
DR. LARRAÑAGA:	Yes, it's hard.

DR. WARD: Yes.

DR. GULATI: Well, we used some of these terms, I mean "leverage" keeps coming up, "where digital platforms have been leveraged," it's the same thing, "leveraged to conduct outreach, educate, and recruit patients." Educate both the—well, it can educate beyond the patient groups.

DR. WARD: So, Geoff, I think maybe the suggestion would be to say something like—okay, get those words down, but I think we're going to maybe move them.

DR. CALVERT: Okay.

DR. WARD: So, the line right above I think we could say, "Where digital platforms have been leveraged to conduct outreach, educate, and recruit; and as vehicles for patient support."

DR. GULATI: Oh, wait, is the vehicles—are we providing support or are we talking about—

DR. WARD: Or peer support, I guess. Or peer support?

DR. GULATI: Well, I mean is that within the scope of what we're being asked to do? I mean I think it'll help facilitate bringing those communities together, but is that within—are we talking about creating—I know for at least the COVID/post-COVID, I don't think they owned or created the platforms for patient support. They partnered with existing organizations that existed, which is different.

DR. WARD: Yes, so we could say, "Where partnerships to create digital platforms"?

DR. GULATI: No—well, let's see... the digital platforms would be used to conduct outreach, so they could use digital platforms to engage with the community. I wasn't thinking about it in terms of creating communities of support in there. I don't know if the CDC or NIOSH has done that before in a similar way with other programs. I mean that'd be great, but I don't know if that's—I think we're talking about setting up the cohort. I think that might be a little bit different.

DR. WARD: Okay. Let's take that out then and end with "recruit."

DR. GULATI: And I guess my limited knowledge, are we supposed to say "social media and digital platforms"? Let me think about that if you're supposed to say both words. Sorry, I didn't mean to interrupt somebody.

DR. LARRAÑAGA: Well, there are other platforms besides social media, so I think it would

	be appropriate to leave it.
DR. GULATI:	Oh, so you don't think we need to say "social media and digital platforms"? You think "digital platforms" is all-inclusive?
DR. LARRAÑAGA:	Well, you could leave "social media," but "digital platform" would include social media.
DR. GULATI:	Okay, great.
DR. WARD:	And we did mention social media in the previous paragraph.
DR. LARRAÑAGA:	And I think it would be wise to include social media because it's just so prevalent and it's become a communication method so I think it would be wise to leave it.
DR. GAITENS:	Can we move this sentence, though, up a little bit? Because it seems like we're mixing things in this paragraph. Because the middle of the paragraph we talk about "Since understanding the health effects of 9/11," and we're really starting to move towards the follow-up and the long-term retention. And that was the suggestion that was made about if there was an opportunity for survivors to communicate or some sort of support groups for these survivors, it would help with some of the retention. But the sentence we just added is really talking about more of the—I think it makes sense before that "Since understanding health effects."
DR. WARD:	Okay. Geoff, could you scroll up to the first paragraph? No, it is the second paragraph.
DR. GAITENS:	No, it's still in the third paragraph. It's just—
DR. GULATI:	I agree with you. You're talking about the last sentence?
DR. GAITENS:	Yes, just moving that last sentence up two sentences, I think, to before the "since" in that same paragraph. Sorry I keep pointing to my screen like you guys can see it.
DR. GULATI:	After the word "discussed" on the fourth line of the third paragraph, after the word "discussed"?
DR. GAITENS:	Yes, thank you.
DR. GULATI:	Yes, yes. But just to go back—and actually I want to kind of hear from NIOSH—is the Program able to support the creation of online support groups—or not support groups, like survivor communities? Were you able to do that on the NIOSH platform? Was that part of—I feel like that's kind of what's being suggested here.

MS. BILICS: This is Jess. I can't say for sure one way or the other, but I don't want what we would say yes or no in terms of ability to hinder anything you want to make as a recommendation. Because even if there are certain things we couldn't do, it doesn't mean we couldn't consider the recommendation in a different way.

DR. GULATI: Okay, all right, so here it's listed as kind of a suggestion. All right, got it, okay.

DR. LARRAÑAGA: One other alternative is to partner with an organization that already has that type of—

DR. GULATI: Right. Right, exactly.

DR. LARRAÑAGA: What keeps coming to my mind is the National Organization for Rare Disorders. Not that a lot of these would be rare disorders, but being a 9/11 survivor in the general population is rare, you know, number-wise. But it's just a suggestion.

DR. WARD: Yes, I remember that comment when I drafted this, and I was a little worried about implying that survivors or this youth cohort are medically compromised.

DR. LARRAÑAGA: Yes.

DR. WARD: Using an example of a disease cohort.

DR. LARRAÑAGA: What I was suggesting there is mainly there are organizations that have these types of membership communities already established. So, creating a new one within their platforms wouldn't be a great stretch. But I wasn't suggesting that one in particular, just as an example.

DR. WARD: Could we just add the sentence, and this could be done through partnering with existing organizations or something like that. Every—

DR. LARRAÑAGA: Yes.

DR. WARD: Right after—no, no, not—this one, please. This could be done…

DR. LARRAÑAGA: You know…

DR. WARD: Take that out there and put it at the very end of the paragraph.

DR. LARRAÑAGA: Yes, you could just do a comma and delete the first thing—or at the end of the paragraph.

DR. GULATI: Yes, the term profess—

DR. CALVERT: And what was—how did you want to complete this sentence? I'm sorry. Oh, existing…

DR. WARD: With existing partners, with partners, existing organizations…

DR. LARRAÑAGA: This could be done by partnering with existing organizations.

DR. WARD: Okay, that's good. I think that's sufficient.

DR. GULATI: I think the term "professional societies" came up yesterday, so I'm wondering in terms of (commuting @ 01:23:18)… I'm sort of thinking like internal medicine organizations. Nobody's a child any more.

DR. LARRAÑAGA: You could have put in parentheses, comma, e.g., and then—or do that, yes.

DR. GULATI: Yes.

DR. WARD: But here we're talking more about vehicles for the population to communicate with each other. And I'm not sure if professional organizations would be the right fit.

DR. CALVERT: You want me to take that out.

DR. GULATI: Well, hold on, I think you're talking about—I mean this is part of the massive campaign to reach out to the communities, so you're talking about educating large swaths of individuals. So, it's not necessarily to create support groups; it's part of the overall education and outreach.

DR. WARD: Well, we've kind of moved on to retention beyond—I mean we have talked about recruitment, and we maybe could put something up there, but I think now we're talking about ongoing follow-up and retention. And the specific point was made that one element in promoting retention would be to have some kind of online communities where participants could communicate with each other, as well as get information about new findings, etc.

DR. SURTI: Sorry. Just advocate the, like, the methodologies to recruit and retain don't have to be separate, like a social media campaign or an online community could both recruit and retain.

DR. WARD: Right.

DR. SURTI: But I think we're trying to separate out the—like I think we're trying to set, I think it's all about like harnessing like a community as opposed to like the actual actions that we want in terms of recruitment and retention, if that is a clear explanation. Because I think that if we're like engaging professional societies and alumni associations and like social communities that exist online, then we could get people to then like continue to be involved and also want to join those communities. Like those communities—

DR. GULATI: Yes, so I agree. Yes, so could you bring that up further, bring that message further up, right, in one of the earlier statements? Is that kind of what you're suggesting? It looks like targeted not just to the age group and offering compensation, but also targeted to other organizations including professional societies and things like that. Several options to facilitate including use of communication tools, but the communication tools are not just targeted to survivors, they're also targeted to—I mean that's where you might be able to put other organizations that connect with patients. Or am I completely off topic now? And I'll stop.

DR. SURTI: No, no, I'm in agreement with that. I think moving—like there are tools that need to connect with communities. Community stakeholders could be students, residents, educators, like family members of youth, or professional societies, which include medical and mental health folk. I think those are like potentially the group of people that are either survivors or closely connected to survivors and their health.

DR. LARRAÑAGA: Okay, so I've just been searching for types of associate. Maybe we replace that with "interest groups" instead of "professional society."

DR. SURTI: I don't think it has to be a replacement, it could be an "and."

DR. GULATI: Right.

DR. WARD: Jason, you have your hand up?

DR. OSTROWE: Yes, thank you. I mean the word that comes to mind is just "stakeholders," "stakeholder organizations." It sort of covers everything we're sort of talking about in my mind. Maybe that would make it a little bit more efficient.

DR. WARD: I think that's a good point.

DR. GULATI: That's perfect.

DR. CALVERT: And you want to move that up here?

DR. WARD: I think we can leave it where it is, I think. What does everyone else think? Or maybe it moves up, I don't know.

DR. GULATI: I feel like that should be moved up a little bit. I don't know what other people think.

DR. CALVERT: It seemed like people wanted to put it in this sentence?

DR. GULATI: Targeted to patient—targeted to survivor communities and other stakeholders, then we're about compensation for...options to facilitator

	recruitment.
DR. LARRAÑAGA:	You could say, "Including use of communication tools and stakeholder partnerships."
DR. GULATI:	Oh, that I liked. I like that. And then in terms of the compensation for time and effort of participating, when you sort of talk about retention at the end of the paragraph, maybe you could move that concept down there and then "Ways to retain would include compensation, facilitation of online support groups, and leveraging digital health platforms to make continued engagement over time easy."
DR. WARD:	So, if you're suggesting specific language, you better slow down so Geoff can follow you.
DR. CALVERT:	Yes.
DR. GULATI:	Sorry. I'm sorry.
DR. CALVERT:	So, yes, tell me where you want to put it and—
DR. GULATI:	I know, I'm sorry, I can't see you guys. It's hard to do this one. So, several options include use of—
DR. WARD:	Oh yes, you can't even see the text online?
DR. GULATI:	No, I can. I can, it just is very—
DR. WARD:	Oh okay, good.
DR. GULATI:	"Including use of communication tools to facilitate including…" Wait, that does—"several options to facility recruitment including use of communication tools…"
DR. WARD:	Yes, the phrase "targeted to the age group" was really connected with the communication tools.
DR. GULATI:	"And collaborating with existing stakeholders"—or you need another verb in there, including—hold on. There's "including use of communications tools, leveraging existing…" I hate that I keep using that.
DR. WARD:	I think it's okay. Remember, this is not a novel—
DR. GULATI:	Leveraging—
DR. CARREÓN-VALENCIA:	Science paper, it's…
DR. GULATI:	Okay, "existing stakeholder partnerships." Okay, and these can be targeted to—do you want to get rid of "targeted to the"—including use. We haven't said "survivors" yet—several options include use, the use of communication tools targeted to… Targeted to…

DR. CALVERT: Relevant age group?

DR. LARRAÑAGA: Then it would be "age groups."

DR. WARD: Yes, "age groups," right.

DR. GULATI: Yes, that's better. But we haven't actually said "survivors." Do we need to say it? I guess it doesn't matter. Yes. No, that's good.

DR. WARD: Well, I think with respect to the appropriateness of the media—

DR. GULATI: That's (inaudible @ 01:31:36).

DR. WARD: It's really the age, not the survivors so much.

DR. GULATI: Yes, that's true. And then where after partnerships the "and offering compensation for the time and effort of participating were discussed," I would delete—I would cut all of that, like put a period after "partnerships," and then cut the rest of the sentence and incorporate some of those themes in the end of the paragraph where we talk about ways to maintain to retain. "The long-term attention is critical..."

DR. WARD: I think with the compensation we probably are at a point where we could say, "The STAC recommends offering compensation for time."

DR. GULATI: Yes.

DR. WARD: You know we could make that a recommendation. Hi, Mariama, you have your hand up?

MS. JAMES: Is it possible to specify that we'd like to include local community-based organizations so that the program doesn't necessarily contract this stuff out to people all elsewhere that don't necessarily know—Lower Manhattan has a lot of its own community-based organizations, but we don't have to get one from Kentucky. And I know with the national program there's a lot of stuff like that where people that don't necessarily know anything about survivors or responders are involved in our care.

DR. GULATI: I think that's a good point to talk about engaging local communities. I think one of the things that's come up—and I think stakeholder partnerships is actually a pretty broad category—and so since—one of the things that's been consistently sad is that people have dispersed all over the country, but they were also sort of also suggesting to cast a broad net. But I am wondering if there's a way to emphasize the community engagement as well. I just also want to make sure that the stakeholders that they're trying to engage stakeholders across the

country to get people engaged. I think that was sort of why we were keeping it broad. I don't know what other people think.

DR. LARRAÑAGA: I mean you could specify that it's important to partner with local organizations, as well cast a wide net somehow.

DR. GULATI: Yes. Yes, that sounds good. Yes, put both.

DR. WARD: So, we could that in after "partnerships"?

DR. LARRAÑAGA: Oh, that's good, I think. Mariama?

MS. JAMES: Yes?

DR. LARRAÑAGA: What do you think about that?

MS. JAMES: No, I thought it was great, thank you. I'm sorry.

DR. WARD: Okay, so we need to clean up the last sentence. But I want to say I just did a time check, and we are scheduled to conclude this discussion in about ten minutes and I think we probably can get to the remaining parts if we try. And we do have to get to the next topic, which is the adding policy and procedures for non-cancer conditions. So, can we try to wrap up in the next 10 minutes and then move on to that topic? I think we're close. I mean we've gone through most of the text now. It's just the last paragraph of this section regarding medical screening.

DR. GULATI: Wait, I'm sorry, Liz, just the last sentence after "Long-term retention will be critical."

DR. WARD: Yes.

DR. GULATI: I think you could say "There are several ways to do this. One is we strongly recommend compensation." I do think that the digital health platforms are really going to help. So, I don't know if you can combine cleaning those sentences. I know we want to move on to the next thing. But the most important thing is probably compensation and digital health. Or do you want to put all three things in one sentence?

DR. WARD: Well, I guess the important thing is get the ideas in, even if it's not the smoothest editing.

DR. GULATI: Okay.

DR. WARD: Because I think we're running out of time to smooth the editing, but I think Dr. Howard will not criticize and he'll really want to make sure we are getting our points across. So maybe after "critical" we just say, "We believe it will be important to offer compensation for the time and effort of participants. The STAC believes that it will be..."

DR. BALK: Isn't that the last sentence of this paragraph?

DR. WARD: Yes, I think we were cleaning it up and moving it. It was suggested that it was so important that we move it up. But that's fine.

DR. BALK: Except that it also is relevant to the next paragraph, which, again, it talks about incentives.

DR. WARD: So maybe we should keep it where it is, because I really can't—we don't have time to do extensive editing, so let's keep it where it is. We could just say, "The STAC believes that offering compensation for time and effort will be critical to recruiting and retaining this busy population," or "This will be critical to recruitment and retention." How about that?

DR. GULATI: Sounds good.

DR. WARD: Okay, yes. And then we go on to the next paragraph about screening. We're basically saying we don't have enough—this is a big topic, and we really can't address it at this point, but we do think there's both risks and benefits. And then we raised the point yesterday about possibly facilitating—for those people that we contact for recruitment who say they have medical concerns and lack of access to healthcare; we might set up a mechanism to help them access insurance. I'd be happy to take that out or leave it in. I don't think it's a critical point.

DR. GULATI: I would love to be able to do that for everybody. I just don't know how—and it should be happening if they access, but I don't how it's going to be done across in a national stage when people are getting recruited from all over the country.

DR. WARD: Okay, let's take it out. Is that okay with everybody?

DR. GULATI: I do like the idea of suggesting that we'll connect them with some resources. If there's a way to say we'll provide some just overall resources as opposed to being specific because that is an incentive.

DR. WARD: So, it may be possible to connect them with resources, with local resources, or something like that?

DR. GULATI: I wouldn't say any more than that, if even that.

DR. WARD: So, it would be possible to do what? (Inaudible @ 01:40:14). No, I don't think what you're writing is... What was the sentence you were trying to get at?

DR. CALVERT: Are you asking me?

DR. WARD: No, I'm asking whoever it, I—

DR. GULATI: No, it's potentially connecting people with local resources—or providing information about local resources. I think that's probably it. Like people don't know what number to call and things like that, so... Not "may," providing information, providing information.

DR. WARD: For cohort mem—I think we should hard stop on the period, "risk and benefits," get rid of the next sentence or the next words, for people—"It may be possible to connect individual cohort members with—it may be possible to connect cohort members with—who have medical concerns and lack of access with local resources, with"—

DR. WARD: I think isn't the worry about making the actual connection versus just providing information about—

DR. GULATI: Yes.

DR. WARD: "It may be possible to provide information."

DR. GULATI: So, is somebody going to verify—I mean can we verify that this is—who's going to take a look at this and make sure that they actually can do this? I mean obviously I would love to—

DR. WARD: Honestly, I think we should take it out. It's too complicated and we don't have time, we're going to have to move on without completing review of the rest of the document. And this is a point we probably can return to later as the project unfolds.

DR. GULATI: Okay.

DR. WARD: We didn't say—I think it's too late to discuss project oversight. I think we should just take that out. Let's move on to the next page.

DR. MILEK: Can I make a comment about this paragraph?

DR. WARD: Yes.

DR. MILEK: The possibility of offering medical screening offers the possibility of detection or early detection of World Trade Center-related conditions. And this Committee has several people who have either designed and/or implemented World Trade Center surveillance programs. So, I think this Committee would do well to continue discussing the topic.

DR. WARD: I think that's implied, that we can't make a recommendation now, but certainly if the topic comes up later, we can discuss it when we have more details about what's being proposed.

DR. MILEK: But I'm less comfortable with offering medical screening only as an incentive.

DR. WARD: Okay.

DR. MILEK: I would like to know that there is a benefit to those participating, or a potential benefit.

DR. GULATI: Are you talking about medical screening and treatment? I'm sorry, just to clarify.

DR. MILEK: Medical screening in general offers the possibility of detection or early detection of World Trade Center-related conditions.

DR. WARD: Okay, Geoff, I suggest after participate, comma, and offers the possibility of early detection of World Trade Center-related conditions.

DR. MILEK: Even detection, if people have GERD—

DR. CARREÓN-VALENCIA: Where—

DR. MILEK: No, you're correct in putting it there. I'm just saying detection and possibly early detection.

DR. WARD: Right, so Geoff, I was thinking of putting that at the end of the next sentence, because we really mostly discussed it as an incentive. We said, "While we recognize that such an offering might encourage participation and offers the possibility of early detection of World Trade Center"—so at the end of the line where it says comma, it, "While we recognize that such an offering might encourage survivors to participate, and offers the possibility of early detection and treatment of potentially World Trade Center-related conditions, it would be premature to make a recommendation without knowing the nature of the screening (inaudible @ 01:45:11)." I think that's better.

DR. LARRAÑAGA: I like that.

DR. WARD: Okay, let's move on to the next page.

DR. CALVERT: Oh, let's see. I've got to go back to the PowerPoint.

DR. LARRAÑAGA: It would be the last, the—

DR. WARD: Number 6.

DR. CALVERT: Oh, sorry, yes, sorry.

DR. WARD: So, this is the paragraph about the youth cohort. And, again, we could probably write five or ten pages about this, but this is just to get the point across as succinctly as possible.

DR. LARRAÑAGA: I think it's quite well written.

DR. GULATI: I agree; it looks good.

DR. BALK: Can I just ask a question—because I had to leave the meeting early

yesterday—was there a discussion of like the next generation, like the parallel would be the DES grandchildren?

DR. WARD: No, there was no discussion on that point.

DR. BALK: Since the Program goes until 2090, should there be a discussion of that in here?

DR. WARD: Well, I suspect that that would not fall under the definition of the youth cohort in the congressional appropriation, which is probably relevant to our discussions. But does anyone else have any thoughts on that? Okay, so I think we should move on. I think that may come up later if the STAC is asked to provide any additional review and comment on the youth cohort, but it can certainly be addressed later but we don't really have time to address it now.

DR. CARREÓN-VALENCIA: There will definitely be opportunities for more comment for the STAC.

DR. WARD: Right. And certainly there's opportunities for individuals on the STAC to submit comments as individuals in response to the RFI. So, your being on the STAC doesn't preclude you from voicing your opinions in other things.

DR. MILEK: Do we want to offer advice on the inclusion, or do we want to support the inclusion?

DR. WARD: Of the next generation?

DR. MILEK: No, I'm sorry, of the first sentence, "Offer advice on the inclusion of youth *in utero*," or do we want to—

DR. WARD: Yes, we should support. I was trying to be as polite—I guess I said "offer advice" because typically we don't give advice unless the Administrator asks for our advice on a specific topic. So that's why I said "offer advice," because we're not responding to his request. That's just a... I mean we could say "support," I'm fine with that, "to support."

DR. GULATI: Yes, why don't we just "would like to offer"—you want to say, "would like to offer advice to support" or "would like to support" and then get rid of "offer advice"?

DR. WARD: I would say we could just say "support" since it's clear that that has come up in many—both in the public speakers, you know, it was an opinion that was voiced both by STAC participants and other participants, so.

DR. LARRAÑAGA: Could you delete "would like to" and just put "supports"?

DR. WARD: Sure. So, Tania, I'm assuming we don't need an indiv—a vote on this since it's kind of just advice rather than more specific recommendations, is that correct?

DR. CARREÓN-VALENCIA: That is correct.

DR. WARD: Okay. So, I'm sorry this process has been rushed and difficult because you haven't had this in front of you, but are we ready to conclude and move on? Is there any objection to moving on to the next topic? And I think, as you're aware from Dr. Prezant's—the Prezant's comments, this is an important topic as well for the STAC to have time to consider. Okay, so we'll move on to Dr. Daniels giving us an update on Policy and Procedures for Adding Non-Cancer Conditions.

UPDATE ON POLICY AND PROCEDURES FOR ADDING NON-CANCER CONDITIONS

DR. DANIELS: Wonderful. It's hard to follow. This has been an exciting dialogue, so now we have to shift gears. While Mia puts up our, my slides—I only have a few slides—but I want to remind everybody that we first provided the draft procedure to the Committee in February, and the focus of the revisions at that time were to clarify that a health condition can be added to the list based on if the STAC recommends the addition and provides a reasonable basis. So, this was aligning us with what we had learned from the cancer procedure.

So just to re—to clarify the STAC's role, the Administrator can involve the STAC at any point. It doesn't have to follow a classification or a categorization of the evidence. It can be at any point in the process the Administrator can go to the STAC. And then the Administrator can act on the recommendations if there's a reasonable basis, and that sort of addresses what we heard earlier about the STAC.

The second reason why we were revising the procedure was to clarify the evidence categories, and there are five evidence categories. And I just wanted to, while I'm talking about the evidence categories, I do want to clarify a statement that was made earlier that you don't have to have evidence in both groups, responders and survivors, for a decision of Highly Likely; that's Category 2. So just a point of clarification from what we heard earlier.

Now, if we could go to the first slide, Mia. So, the STAC reviewed our draft and made four important recommendations, and so now we're going to talk about our response to those recommendations. And while we were doing it, we made some other changes to the procedure and basically, the focus of those changes were to clarify the application of Bradford Hill criteria. And the Bradford Hill—those aspects of causation are really what we use to weigh the evidence of a causal association. Okay, next slide.

So, we'll just look at each recommendation, and I have on the one side the STAC recommendation lifted from the letter. But essentially, I'm just going to, for time reasons, I'm just going to give us a synopsis.

So, the first recommendation was that the STAC felt it was, it would be beneficial to expand the literature search for the first two categories, and that's substantially highly or substantially likelihood and highly like—High Likelihood, to include more than just the peer-reviewed epidemiologic studies from 9/11-exposed populations, as well as the U.S. Government authoritative scientific publications. And they wanted to extend that to limited. Now, what we did was we agree that, as we have found in practice, that the U.S. Government authoritative scientific publications tend to not be updated frequently. And so, we agreed that we needed to expand the literature, at our discretion, to include other important sources of information if we have a ranking of High Likelihood. Now, the intent here was that High Likelihood means that we're really close to reaching the threshold of Substantial Likelihood but we're missing, we may have some gaps in the literature, and we felt it was very important to expand the literature to hopefully fill those gaps. So, we didn't extend that expanded literature review to Limited Likelihood, and the reason being is that we felt that the gap between limited and substantial was significant to the point that it was unlikely that we would have a change in categorization based solely—up to substantial—based solely on extending the literature to the limited side. Next slide please.

So, the second recommendation we had was to clarify the meaning of "Substantial Likelihood," and the Committee provided us some language to do so. And essentially, we accepted that language and

made the change as recommended. So, next slide please.

The third recommendation was to add a table or a flowchart that clearly delineated the categories that will be used in various stages of the review process. And so, we set out to develop this flowchart. I think this flowchart actually has been developed in past meetings. But we've worked on it and during the process, we determined that, you know, it was impossible for us to feasibly create a flowchart that would cover all aspects of the procedure, and we felt that there was risk associated with putting a flowchart in the procedure that doesn't cover some of the intricacies of the procedure. So, we have developed the draft. We have provided it to the STAC, but we intend on using that for communication purposes so—and not included as a component of the procedure. The next slide please.

So, the fourth STAC recommendation was there was some—there was some ambiguity, I think, in the earlier draft that the Committee reviewed regarding the five categories, and the Committee recommended that we use the five categories of the weight of evidence; throughout the procedure we can do this. And we absolutely agree with that recommendation, and we did revise the Policy and Procedure to clarify and maintain those five mutually exclusive categories throughout the procedure. And next slide, if there is a next slide.

Okay, so this was the change that we hadn't discussed at the meeting in February. You know that the earlier version of the procedure removed—had a reference to “select Bradford Hill criteria.” For those, a little refresher, there are nine aspects of causal association that were first introduced by a Sir Bradford Hill I think in 1965, and they're still used today. It’s a great way of sort of weighing, a systematic approach of weighing the evidence. And we didn’t have them all listed in the procedure. So, the ones that I’m showing in the bullets, strength—we’ll start with strength, then consistency, and then we get to the first blue text. These are the ones that we didn’t explicitly address in the procedure prior.

So, specificity observed in the cause and effect. So, what that's dealing with is the premise that one cause and one effect is more evidence of a

causal association than many causes and many effects. And in reality, in practice, and we're dealing with, you know, very complex diseases and multi-factorial health conditions. So, specificity really doesn't play a large role and perhaps that's why it wasn't discussed prior. But, for completeness, we now added it to the procedure.

Temporality of the cause and effect, and essentially this is the cause must precede the effect. So, exposure must have occurred prior to the health condition of interest. It sounds simple enough and for—but it wasn't explicitly address, and yet, evaluations almost always look at this as an aspect of causation. So, and we do that when we're assessing all the characteristics of the exposure usually, which was addressed in the procedure but it didn't explicitly call out temporality, so we added that.

The next three were in the procedure, and that brings us to analogy. And analogy is, think of it as sort of a component of biological plausibility and coherence, which both of those were discussed previously in the procedure. And it deals with, you know, the studies with known facts about the biology of the health condition, coherence—in other words, it doesn't go against the grain of what we know about disease etiology. And analogy is what we often do where you take an established causal association and, through analogy, you say we have evidence of plausibility or coherence with the current knowledge through that analogy. So, for example, particulate exposure and air, you know, and air pollution and cancer, we would make the analogy that the exposures to dust at the World Trade Center are analogous to, and that relationship between that exposure and cancer is analogous to, air pollution and cancer, as an example. So, we just clarified that.

What's missing—I said there were nine—we only talk about eight, and what's missing is experiment, and experiment is dealing with an actual intervention. So, I would remove the exposure and I would see a reduction in the health condition. We can't do that. So, in essence, of the nine that Sir Bradford Hill spoke of, only eight really apply for us. And so that one's not listed in the procedure, although its omission is clarified in a footnote in the procedure.

So, next slide. Ah, that was it. So, I'm open for comment.

DR. GULATI: Hi, this is Mridu. Thank you for doing it. One question is about the inclusion of specificity, and I'm wondering if there's any concerns about bringing specificity back in there. And then the second question I have is I think one of the concerns that came up during the comments was that—and I think you clarified this—is that evidence has, for it to be considered highly, highly suggestive, that it would have to come across multiple cohorts of studies. I think Dr. Prezant had brought that up, is are you saying that that's not necessarily a concern in how the evidence categories are laid out now?

DR. DANIELS: Yes, so let me answer the last question first. So, I don't know if you have a copy of the procedure but on page 8, it talks about Category 2, which is the evidence supports a high likelihood of causal association. And in that, it states, "Available epidemiologic studies as a whole must have examined at least one group of the 9/11-exposed population." So that's one group. And so that is different from Category 1, which is the Substantial Likelihood, which Dr. Prezant was correct, it requires that we have investigated. It doesn't say that we have to see evidence but we have had to at least examined the health effect in both populations. So, Category 1, yes, both populations. Category 2, no, one population is all that's necessary.

And the thought there was that if we have evidence that is highly supportive but yet doesn't reach the Substantial threshold, that we would expand the literature search. And initially, the procedure expanded the literature search to just those authoritative volumes, those authoritative government records. But now we've made an adjustment to that. So, it allows us to look at all the research that's available that could help to fill the gaps that we're missing, let's say from not having more information on another population, as an example. So, the idea here is that we can get to the Substantial Likelihood threshold through that secondary literature evaluation if we're in the High area.

And the other point I want to reiterate that was brought up with Dr. Prezant is the STAC can be initiated at any point in the process. So, if the Administrator wants to seek STAC recommendations on adding a condition to the list, he can do so at any point, not based on the three—

the categories of evidence that we, the Science Team, does. So, it can be completely independent of the work done by the Science Team. I hope that clarifies things.

DR. WARD: I think the other point, Doug, is that there is no requirement for these recommendations, the addition of a new condition, to go to the STAC. It can go to, you know—I mean, the Administrator is, can take action based on, for the Category 1 and Category 2 determinations, without coming to the STAC. So, I think there might have been a misunderstanding on Dr. Prezant's point that the STAC was a necessary component of the process, and it's not. It's an option for the Administrator, as you say, at any point in the process, but not a requirement that it comes to us.

I have a question about what you said. So, for Category 1, I thought there had to be positive evidence in both populations, and I think what you said, if I didn't misunderstand you, is there has to have been studies in both populations but it's not required that they both provide positive evidence of association. Is that's correct?

DR. DANIELS: That's the way it's written now. I mean, it says is, "The evidence supporting a causal association for more than one high-quality epidemiologic study." So, we have consistent evidence across studies; that's number one. And the available studies, as a whole, most have examined both groups of the 9/11-exposed populations. So, what we're saying is for us to make a decision that we can rule out bias and chance completely, we really need more than just one population study.

Now, we understand that there could be a situation where you see it in one and not in the other, and that brings in some uncertainty. So, at that point, we have this other category, highly like—High Likelihood—which we have options in that, in that process, to relook at the existing evidence outside of the 9/11 population and fill those gaps and make a determination. Of Substantial Likelihood, sorry, excuse me.

And while I'm at it, I also—let's see. We wanted to talk—there was one question, I'm sorry, I didn't answer both questions prior. The other question about specificity. No, I mean, in all honesty, I don't think specificity is going to play a large role in any evaluation, you know, because we're dealing with these very complex exposures and health

conditions. So, but in the event that we did have some evidence of a more simple cause and effect, then it would play to an advantage. We at least, in our evaluations, we talk about uncertainty associated with the causal pathway. So, all of those complications are addressed and evaluated, ongoing. We just simply didn't explicitly call out specificity as an aspect prior, which opens questions as to why.

DR. WARD: Debra, you had a comment?

DR. MILEK: Yes, at the previous STAC meeting, we discussed the categories of Substantial versus High Likelihood, and—or Category 1 and 2. And I have difficulty with Substantial being higher than High, and in fact there is an article that CNN posted indicating that High is the highest, using an article from MMWR on COVID transmission. And in that article, in MMWR, Morbidity and Mortality Weekly Report, the highest category is High, followed by Substantial. So there seems to be an inconsistency in using High and Substantial.

DR. DANIELS: Yes, I mean, so my response is that we really don't see the inconsistency. I will say that all versions of the procedure have basically used these categories, and it's always, in the past, Substantial Likelihood has been related to the upper tier. So, we certainly take under consideration your comment about changing the order of terminology but, at this stage, you know, I guess I'll have to go back and discuss this with others.

DR. WARD: Yes, you know, it's interesting because I was, I did a presentation on the World Trade Center a couple of months ago, and I looked at the Zadroga Act, which I hadn't looked at in a while, and I think the Zadroga Act actually uses the term "substantial likelihood." It uses the term "substantial likelihood of a causal association." So, I think that may be where it came from. I don't, you know, the Com—the Program can verify that, but I think we need to go back to some of the earlier documents to see how this language evolved. I mean, I think it's unclear to most of us just from an English point of view. There's a big distinction between "substantial" and "highly" likely. And it may be that those terms are used differently in different disciplines and areas. But I think it would be fruitful to go back and look at the actual language in the Zadroga Act and sub—any other guidance that would suggest that these

terms are not appropriate.

MS. BILICS: This is Jess. Just to clarify what that language is, Liz, is it's the criteria for connecting an individual's 9/11 exposures to a 9/11 health condition. So, the language is that the 9/11—the individual's 9/11 health exposure, 9/11 exposures, have to be substantially likely to be a significant factor in aggravating, contributing, or causing the health condition.

DR. WARD: So, you're saying it's not an exact match but it still could be a carryover from that language.

MS. BILICS: Correct, yes.

STAC DELIBERATIONS AND RECOMMENDATION

DR. WARD: Thank you for the clarification. So, I can't remember if all of the Committee members who are present today were also present for our last discussion on this, but I wanted to go back to Dr. Prezant's point about, you know, is the bar set too high for Category 1. And I will say that in our last discussion, that was one of the major points, that did—you know, we, some of us felt that requiring that the effect be seen in more than one population was too stringent a requirement for Category 1. And others felt, you know, and others felt that, well, we accept that few things will actually meet the criteria for Category 1, which basically fast-tracks it, but that the—but we, but there is the opportunity for those findings that are highly likely to be considered as Category 2. So just to refresh everyone's memory.

Mariama, you have your hand up?

MS. JAMES: Thanks. Yes, I was concerned when reading the policy too, with the Category 1, for the youth cohort because with the youth cohort being nonexistent at this point, although it's being created right now, how will it ever be possible for it to be compared to any other cohort, or aligned with any other cohort? So that's means there's a potential—or at least I read it this way—potential for conditions to not be able to be added for the youth cohort because they haven't existed in the current survivor population or in the responder population, which is the whole purpose of the youth cohort in the first place. So, it's like a—unless I read it wrong, it seems like a big circle of confusion.

DR. DANIELS: Well, I guess I would respond this way. I would say we would consider the youth cohort as it's defined now, which is 21 years of age or younger, to be components of responders and survivors. And the current procedure recognizes responders and survivors. So… I don't think there would be, it would be necessary to make changes to address that specific subgroup of the 9/11-exposed population of interest here. So, I think the—

MS. JAMES: But the challenge is, if you're—if a certain condition has to have emerged out of the existing survivor cohort or out of the responder cohort first in order to, in order for it to be deemed highly likely that it can be added for the youth cohort, they would have to have seen some of the things that they're developing. But their cohort is being created because we haven't examined what they might be developing, and because the existing survivor cohort is, were already adults so they weren't in any type of developmental stages and certainly not *in utero*, and neither was the first responders. And then the, again, the first responders are largely male. We have a lot of young women that are in the youth cohort. So, I don't see it. I'm a layperson; I'm not a doctor like many of you. But I don't see how it's possible for an emerging condition connected to developmental stages to be found in the existing survivor cohort or in the first responder cohort.

DR. DANIELS: Yes, that's a very good point.

MS. JAMES: So, I don't know how things would be added for the youth.

DR. DANIELS: Right. I agree with what you're—I absolutely agree now with what you're saying. You're saying that, you know, because we have limited power to observe effects, especially given the fact that we have not, this—that you could say the youth population is underrepresented and understudied, therefore how would we have evidence of causation? And I agree with that. It's analogous to what we see with females, right? We have, we have…

MS. JAMES: Yes, exactly.

DR. DANIELS: Outcomes. Outcomes that are specific to females, we typically have less information on because we have more males that are being studied. And it's a—it's exact—it's the same issue. The procedure does provide an opportunity there for those outcomes through simply the

Administrator can act based on the evidence that we have, independent of the Science Team evaluation, as well as he can go to the STAC and seek recommendations for areas that perhaps we simply will never have sufficient research evidence to support a causal association but yet, the absence of that power, of that information, is reason enough to seek other remedies through the STAC or through action himself or herself.

DR. GULATI: So, this is—

MS. JAMES: That sounds great. My only concern then would be that, in the case of women and uterine cancer, it took ten years to determine all of that and put it into effect. And so, we'll be adding another ten years onto, potentially, the youth cohort having something added where they've already been waiting well over ten years to be recognized.

DR. GULATI: So, I guess, you know, what I'm—interesting, because you know, we're sort of limiting… Do we want to say something or make a recommendation that for certain populations that are not representative within these occupational cohorts that, I mean, if we actively make a recommendation that the, you know, things that do not meet the criteria of Category 1/Category 2, that we would encourage, you know, the Administrator to come to the STAC to talk about cohorts that may have not been representative before, or that just opens up—that opens up a lot. But I think there is no, to your point, there is no cohort like this.

DR. WARD: I think that's a good suggestion, but I had one clarification again. So if there was a strong study in a, in this, in the youth cohort that found an association between, you know, a particular outcome that is more likely to be—or a particular outcome, and that association either has not been studied or has not been observed in the older survivor population or the occupational population, would that, would that strong study in the survivor cohort be enough to meet Category 2, and then go on to high—go on to further investigation?

DR. DANIELS: Yes, in a hypothetical situation, if we have an established youth cohort which is 21 years of age or younger, that cohort itself will consist not only of survivors but responders who were aged 21 or younger.

DR. WARD: Oh, that's an interesting point. Okay, I hadn't grasped that yet.

DR. DANIELS: Right, so—and if they found evidence of a causal association then—and

it was strong enough, based on the weight of evidence, to classify it as Category 1, then it could be directly, substantially, we could reach an evidence rating of Substantially Likely, because it's a mixed cohort, right? So, it depends on the study design and who we study and what they found. But yes, it's hypothetically possible.

DR. WARD: But it's also possible that it could be in, it could reach Category 2—

DR. DANIELS: That's correct.

DR. WARD: And that would trigger the more extensive evaluation.

DR. DANIELS: Right.

DR. WARD: So, the youth cohort is kind of, a finding in the youth cohort is, basically has equal status with a finding in the survivor cohort in terms of the way—the different streams of evidence.

Mariama, are you—your hand is up. Do you still have another comment?

MS. JAMES: Yes, because now I'm confused about who the 21-year-old responders would be. Would those be people who were babies or *in utero* on 9/11 that are now responders and so they're qualifying for the responder cohort, or how did they fit into the youth cohort?

DR. DANIELS: Yes, there were responders who were aged less, 21 years or less, probably to age 18 on 9/11 who are actually in the Fire Service, as an example. So, and there were construction workers as well. So, there is about, in, just as a—give you an idea, there's about, I believe, 1,000 of our enrollees in the Program were not survivors, were in responders, on 9/11—and were, you know, 21 years of age or younger on 9/11. So, it's—

MS. JAMES: So, these are like the older Millennials, the better part of the youth cohort?

DR. DANIELS: Yes.

MS. JAMES: Got it, thank you.

DR. WARD: Any other comments or questions?

DR. GULATI: Yes, I'm just going back to, you know, with some of the challenges we talked about in terms of trying to recruit and retain a youth cohort that's, you know, busy. They're working; they've got lives. I don't know if everybody's reached the sandwich generation or not. But I'm wondering, you know, what the occupational cohorts being a little bit

more closed, are we going to be able to meet that high, you know, high threshold for strong evidence? And that's why I'm wondering, you know, just making sure that we review things that are, you know, those… Some of those studies that are harder to get, for example, and sometimes some peer-reviewed journals, etc. because of some of the challenges that are inherent to this, getting this cohort versus other occupational cohorts. So yes, I'm just—as long as things are considered and there's an openness to consider other studies that are some of the other survivor studies. I don't know if I'm making myself clear or not but…

I'm just worried about some of the challenges of the youth cohort and in terms of what bar we're actually setting for what a strong study means when we end up looking at the evidence with some of these emerging diseases.

DR. WARD: Mariama, did you have any comment?

MS. JAMES: I do, yes, sorry. And this is going, probably going back earlier into our discussion to but is it possible for—well, first let me, in the interests of, you know, full disclosure, I'm a member of both the STAC and the SSC, the Survivors Steering Committee. So, I was just wondering if the SSC could act as sort of like a springboard for the…

DR. WARD: Mariama, we lost your vocal.

DR. CARREÓN-VALENCIA: I think we lost her completely.

DR. WARD: Oh no.

DR. CARREÓN-VALENCIA: I know. Yes, I don't know what her question was. And we're getting close to the time so I…

DR. WARD: Look, Tania, I have a question. Is there a need for our concurrence or is this just informational?

DR. CARREÓN-VALENCIA: No, this, we need your concurrence. Yes.

DR. WARD: Okay. So, we have had extensive discussion both at this meeting and the last meeting, and it does appear that the Program has addressed the major concerns that we made in our recommendations. I know, as individuals, we all still have some questions about whether we would categorize Category 1 and Category 2 the same way as the Program has elected to but I think, you know, so I think it probably is reasonable to take a vote on whether there's a general concurrence on the policy,

	recognizing that there may still be some individual differences but that there has been extensive discussion within the STAC of many of the most important issues regarding this policy. So, I would make a motion that we have a Committee vote for concurrence on this policy.
DR. OSTROWE:	I second that motion.
DR. CARREÓN-VALENCIA:	Okay, I will take your votes then.
DR. COMISKEY:	May Chair make a motion or…?
DR. CARREÓN-VALENCIA:	Oh yes, that's—yes. So, you want to amend the motion?
DR. COMISKEY:	No, I don't, I was just curious. Thank you.
DR. CARREÓN-VALENCIA:	So that's the motion. So, we have a motion and a second, and is there any discussion? And Mariama is back.
DR. BALK:	Could you just talk about what policy we are voting on exactly?
DR. CARREÓN-VALENCIA:	Liz, can you formulate your motion again?
DR. WARD:	So, the STAC has now reviewed these, the criteria for conditions other than cancer several times, and the Commission—the Administrator is requesting that the STAC express concurrence with the policy as it's now drafted, recognizing that he has made changes in response to all of the recommendations that we made in the last meeting. So, I was making a motion that we have a vote so people could indicate whether they are in concurrence or not.
DR. CARREÓN-VALENCIA:	And we have a second from Jason.
DR. WARD:	Okay, so Tania was going to do a roll call vote for this.
DR. CARREÓN-VALENCIA:	Yes. Yes, so is there any discussion or—
DR. GULATI:	I'm sorry—sorry, I had one question, and I just wanted just to reiterate that there is, within this, there is the ability for the Administrator to raise the question on things that are—that point is emphasized, to raise things that potentially don't meet Category 1 or Category 2 in selected and appropriate circumstances.
DR. CARREÓN-VALENCIA:	Yes, at any point.
DR. GULATI:	Okay.
DR. CARREÓN-VALENCIA:	Okay, so if there is no other discussion, I will do a roll call for the motion. So, Liz?
DR. WARD:	Yes.
DR. CARREÓN-VALENCIA:	Yes. Sophie?

DR. BALK: Did you just call me?
DR. CARREÓN-VALENCIA: Yes, so do you support the motion?
DR. BALK: I would like to—yes, I would like to see it in writing, so I don't know what I'd do right now.
DR. WARD: You've, you've seen it in writing. Tania has circulated the document.
DR. BALK: Oh yes.
DR. WARD: And there is—yes.
DR. BALK: So, I'd like to see it again so what would you advise that I do?
DR. WARD: Probably abstain, right?
DR. BALK: Sure, okay.
DR. WARD: I mean, you have the option of abstaining or voting yes or no.
DR. BALK: Right.
DR. WARD: Yes.
DR. CARREÓN-VALENCIA: So, the document I shared it with you and it's also on the website. It's also on Regulations.gov—
DR. BALK: Okay.
DR. CARREÓN-VALENCIA: For you to look at.
DR. BALK: I'll look at it. Right now, I'm abstaining, thanks.
DR. CARREÓN-VALENCIA: Okay. John?
DR. COMISKEY: Yea. Yes.
DR. CARREÓN-VALENCIA: Chandra?
MS. DAVIS: Yes.
DR. CARREÓN-VALENCIA: Joanna?
DR. GAITENS: Yes.
DR. CARREÓN-VALENCIA: Okay. Mridu?
DR. GULATI: Yes.
DR. CARREÓN-VALENCIA: Mariama?
MS. JAMES: Yes.
DR. CARREÓN-VALENCIA: Indrina? I'll come back to Indrina. Michael?
DR. KANTH: Sorry, that's yes.
DR. CARREÓN-VALENCIA: Okay. Michael?
DR. LARRAÑAGA: Yes.
DR. CARREÓN-VALENCIA: Debra?
DR. MILEK: Yes.
DR. CARREÓN-VALENCIA: Jason?

DR. OSTROWE: Yes.

DR. CARREÓN-VALENCIA: Aarti?

DR. SURTI: Yes.

DR. CARREÓN-VALENCIA: Okay, well, with—six, seven, eight, nine, ten, eleven yes and one abstention, the motion is carried. Thank you very much for your vote and your confidence in the Program.

DR. WARD: Thank you, Tania. And I think we still have a few minutes for your peer review update and discussion.

PEER REVIEW UPDATE AND DISCUSSION

DR. CARREÓN-VALENCIA: Yes, thank you, and so as you know from reviewing the policy and from what we did during the uterine cancer review publication, the Administrator is—there's a decision to propose adding a condition to the List of World Trade Center-Related Health Conditions, there will be a publication of a Notice of Proposed Rulemaking or NPRM in the Federal Register. And so, this NPRM requests comments from the public but also the Administrator will conduct an independent peer review of the Program's evaluation of scientific and technical evidence supporting the addition of the condition. So, these peer reviewers are asked to review the evaluation of the evidence for the condition to the List within the context of the policy and provide a brief written report. So, the administration, the Administrator at this point would appreciate receiving suggestions from the STAC of subject-matter experts that can conduct such peer reviews. And I understand at this point we don't have any opened petition or suggestions for—or an open process—for adding conditions to the List but, nonetheless, this is a requirement. So, I will take your recommendations of peer reviewers that we can always call to help us on these evaluations. You can do that now, or you can send me an email later on. I'm opening now the floor for your suggestions.

DR. WARD: I have a question, Tania. As the Program now starts to review these non-cancer conditions, is there any way that the Committee can be alerted when you're looking for peer reviewers for a specific condition? Because it's really hard to find—these conditions are so specific that it's really hard to suggest general reviewers who would have the expertise

to evaluate a specific condition like whatever, yes.

DR. CARREÓN-VALENCIA: Certainly, and you might remember when we went through the process of adding uterine cancer, I requested the Committee's—

DR. WARD: Right.

DR. CARREÓN-VALENCIA: Recommendations, and those were the experts that we first approached. So, yes.

DR. WARD: Thank you. But certainly, if anyone has any recommendations to share with Tania now or later, I think they would be well-received. There may be some generalists who could be good reviewers regardless of the specific condition involved.

DR. LARRAÑAGA: Yes, so I mean, I guess I'd have to ask are we looking for epidemiologists, internal medicine, you know? It gets back to kind of, you know, this is the question.

DR. CARREÓN-VALENCIA: Any and all. I know, it's very broad, this point.

DR. WARD: Mariama?

MS. JAMES: I would like to recommend Dr. Peter Izmirly of Bellevue Rheumatology.

DR. CARREÓN-VALENCIA: Okay.

DR. WARD: Anyone else? Okay, well, we're just about at time. Were there any last administrative issues or closing remarks, Tania?

ADMINISTRATIVE ISSUES AND CLOSING REMARKS

DR. CARREÓN-VALENCIA: No, I want to always thank you all for your thoughtful review, discussion, and recommendations. Liz, thank you so much again for being—your leadership, for preparing the discussion for today, summarizing the points, and also of course for your leadership and keeping us on time. My extensive thank yous to Dr. Reibman, the Survivors Steering Committee, Mia, Doug Daniels, Geoff Calvert, and many people behind the scenes both in the Science Policy teams and Communication teams here at NIOSH that have helped us make this meeting take place. Thank you so much, all.

DR. WARD: Thank you, Tania, and I echo all of Tania's thanks and especially thank the members of the Committee for their patience and forbearance in this somewhat difficult meeting format. I really value all of your opinions and input, and think they are reflected in the comments we

prepared. So, with that, I guess we'll close the meeting.

DR. CARREÓN-VALENCIA: Yes, thank you so much.

[Adjourn.]

GLOSSARY

ADD	Attention deficit disorder
AFL-CIO	American Federation of Labor and Congress of Industrial Organizations
ATSDR	Agency for Toxic Substances and Disease Registry
CBPR	Community-Based Participatory Research
CCE	Clinical Center of Excellence
CDC	Centers for Disease Control and Prevention
COPD	Chronic obstructive pulmonary disease
COVID	Coronavirus disease
CT	Computerized tomography
DES	Diethylstilbestrol
EHC	World Trade Center Environmental Health Center
EPA	Environmental Protection Agency
FACA	Federal Advisory Committee Act
FEMA	Federal Emergency Management Agency
GERD	Gastroesophageal reflux disease
H+H	New York Health + Hospitals
ILO	International Labour Organization
MMWR	Morbidity and Mortality Weekly Report
MRI	Magnetic resonance imaging
NIOSH	National Institute for Occupational Safety and Health
NPN	Nationwide Provider Network
NPRM	Notice of Proposed Rulemaking
NVLD	Nonverbal learning disorder
NYCDA	New York City Disaster Area
NYCHA	New York City Housing Authority
NYU	New York University
P&P	Policies and Procedures
PFAS	Per- and polyfluoroalkyl substances
PSA	Public Service Announcement
PTSD	Post-traumatic stress disorder
RFI	Request for Information
STAC	Scientific/Technical Advisory Committee
WHO	World Health Organization

WTC	World Trade Center
WTCHP	World Trade Center Health Program

CERTIFICATION STATEMENT

I hereby certify that, to the best of my knowledge and ability, the foregoing transcript of the June 21-22, 2023, meeting of the World Trade Center Health Program Scientific/Technical Advisory Committee (STAC) is accurate and complete.

Elizabeth Ward, PhD
Chair, STAC