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COMMITTEE (STAC) MEETING

December 1, 2015

The verbatim transcript of the

Meeting of the Scientific/Technical Advisory

Committee Meeting held on December

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WELCOME AND INTRODUCTION

DR. MIDDENDORF: Good morning. Most of you know I am Paul Middendorf. I am the designated federal official for the World Trade Center Scientific/Technical Advisory Committee. It's been our tradition to spend a few moments at the beginning of each of our meetings in silence to remember those who were killed in the attacks on 9/11 and also those responders and survivors who have since died because of those attacks, but today let's take this time to also remember others who have been killed in and are suffering from terrorist attacks around the world including those in Paris and in Mali. So let's just take a few moments now.

[Moment of silence.]

Okay, thank you. As usual, I want to extend a warm welcome to each of our committee members and to the panel members who have graciously agreed to share their time and thoughts with the Committee on children's research issues. We're very much looking forward to hearing everyone's thoughts and ideas on this so we can get some good advice to the program. I also want to extend a warm welcome to the members of the public who are here with us and listening to us on the phone. We very much appreciate your interest in these proceedings as well. I do need to deal with a number of administrative issues on the front end. The first is the exits, in case there's a fire or whatever, go out through the glass doors and off to the right are stairs. One of the stairwells is labelled as a fire exit and that's the one you should take in case of a fire. Bathrooms are just down the hall next to the elevator or opposite the elevators.

We have not had anyone sign up to provide public comments, so if somebody is here who does want to provide public comments, please go outside and sign up with Mia. When we start those, I'll check again to see whether or not we've had anyone sign up. If we haven't then we'll just continue on with the meeting. Otherwise, we will have public comments if someone does sign up. We did receive some comments; they were received by November 27 in the Survivors' Steering Committee, and those were—that was sent out to the members. Hopefully you've had a chance to look at those.

For our roll call, I'll call out the name of each member. Please indicate your presence for the record and also state whether there have been any changes in your employment or interests that would affect your conflict of interest. After each break, I'll make a note to the file on the number of committee members so we can be certain that we continue to have a quorum. So let's do roll call as soon as I get a pen. Can you hear me now?

PARTICIPANT: Yes.

DR. MIDDENDORF: Okay. Just need to make sure the microphone is closer. I will point out to everyone that the microphones are constantly on; there's no way to turn them off. So committee members, if you want to make a comment on the side, make sure that your microphone is away from you. But let's do the roll call. Tom Aldrich?

DR. ALDRICH: I'm here on the phone.
DR. MIDDENDORF: Okay, you're on the phone. Okay, and Rosemarie Bowler?
DR. BOWLER: Here.
DR. MIDDENDORF: Anthony Flammia?
MR. FLAMMIA: Here.
DR. MIDDENDORF: Bob Harrison? I don't believe he's going to be able to make it. Catherine Hughes?
MS. McVAY-HUGHES: Here.
DR. MIDDENDORF: Val Jones?
MS. JONES: Here.
DR. MIDDENDORF: Mickey Kelly?
MR. KELLY: Here.
DR. MIDDENDORF: Steve Markowitz I don't believe is going to be here. Mike McCawley?
DR. McCAWLEY: Here.
DR. MIDDENDORF: Lila Nordstrom?
MS. NORDSTROM: Here.
DR. MIDDENDORF: Bill Rom?
DR. ROM: Here.
DR. MIDDENDORF: Glenn Talaska I don't believe is going to be here. Liz Ward?
DR. WARD: Here.
DR. MIDDENDORF: And Virginia Weaver?
DR. WEAVER: Here.
DR. MIDDENDORF: Okay. With that, I will turn it over to Liz Ward, our Chair.
DR. WARD: Good morning, everyone, and I'd like to—
DR. MIDDENDORF: Yes, it needs to be really close.
DR. WARD: —join Paul in welcoming everyone to the meeting. I think the first—
DR. MIDDENDORF: Dr. Howard wanted to say something.
DR. WARD: Yes, we wanted to introduce Dr. John Howard, who will make a few comments.

CHARGE TO THE COMMITTEE - 'WHAT ARE THE MOST IMPORTANT PHYSICAL, PSYCHOLOGICAL, AND DEVELOPMENTAL HEALTH OUTCOMES TO TARGET AND IN WHICH GROUPS OF CHILDREN?'

DR. HOWARD: Thank you very much, and I think I can be heard. Welcome, everybody. Thank you for taking time out of your very busy schedules to be here, and thank you for spending a day on this topic. I think your advice will be very helpful for the program. You know, we've talked about and around our younger members of our cohort and—but we never spent a day talking about what the research needs are and what you all can provide to us in terms of advice. So we're really thrilled that you're going to do this today and we look forward to all your recommendations and thoughts on this issue. The program has every expectation that you all will continue on as members and the program will continue on and provide coverage for our members.

Lastly, I just wanted to mention to you, a very sad note, the passing of one of our original members of the committee, Dr. Julia Quint, who was very helpful to the committee in their deliberations on cancer. She died recently in California and I'd like to note the tremendous help that she gave us as well as so many others. She volunteered her time in many worthwhile activities. I first met her when she was in—at the Department of Health in California, and she will be missed, and I think it's important that we note her passing here.

So thank you very much again for coming, and have a wonderful meeting today.

DR. WARD: Thank you, Dr. Howard. So I just, I wanted to set the stage for the meeting by just talking about the way the agenda is set up. I know you've all read it, but the idea is to really set the stage for our deliberations by hearing from many of the experts who have done studies in children and adolescents affected by the World Trade Center, but also to ask them directly for their thoughts and to give us their expertise on what types of research they believe would be most valuable at this point in time. I think a recurring theme throughout the day will be the fact that there are some outcomes that we very definitely want to study but because we're 15 years out from the exposure and also even the youngest children exposed are now in their mid-teens, we may not be able to study some of the things that we'd most like to study due to methodologic challenges. So hopefully the speakers will reflect on that as they give their presentations. And there will be an opportunity after all the presentations for the panelists to interact with the committee members and each other, so we're really hoping that this will be a very interactive session today.

And our first speaker is Dr. Phil Landrigan, who probably is known to many of you. He is both an expert on the World Trade Center exposures and an expert on the pediatric epidemiology and environmental health, so Phil?

WTC CHILDREN'S RESEARCH – OPPORTUNITIES AND CHALLENGES AND PERSPECTIVES ON THE CHARGE

DR. LANDRIGAN: Thank you, Liz. Good morning, everybody, and it's good to be here. Thank you very much and sorry that I delayed the meeting for a few minutes with difficulties with getting in through security, but we're here and it's all good. It's all good. So I'm going to draw, as Liz just said, I'm going to draw on the fact that I have a joint background, I started off my professional life as a pediatrician and then, in the course of my years at CDC, got involved in occupational and environmental medicine and did formal training in occupational medicine, and been involved in the medical response to 9/11 pretty much since the beginning because at Mount Sinai, we had on that day—and we ever since—had the largest program in occupational medicine in New York City and the Tri-State Area, so we've been deeply involved in the medical response really since day one.

And the real theme that I, the real message that I want to give you today or sort of the overriding theme is the idea that we should take the information that we've

gained, through great difficulty and a lot of work, from studying the diseases in the workers and the first responders who were exposed to 9/11, take that information and also take the information on exposure that was gained at great cost in the early days and weeks and months after 9/11, and use those two streams of evidence—the exposure science and the occupational medicine evidence—to guide whatever search we do for diseases in children.

There's a long history of this. Over the past 100 years, time and again, new occupational hazards have been recognized first in workers and then later, the same chemicals at lower levels of exposure have been found to cause disease in children. And the reason for this sequence of discovery, which has been repeated for lead, for mercury, for pesticides, for a number of industrial chemicals, has to do with several facts about working populations that make them unique and make them populations where it's relatively easy to do good-quality epidemiologic and clinical studies. The first is that occupational populations tend to be defined populations. You know who was employed, what job they did, how long they were there because in most instances at least, there are records; and as my late mentor Bill Rom's and my mentor Irving Selikoff said many years ago, when money changes hands, records are kept, and therefore you have a denominator and you know who's at risk and you even can grade that risk according to their job title and duration of employment.

Another reason about occupational populations is because records exist, it's possible – and not always, but often – to do good follow-up. You can trace them. You can use Social Security and other identification systems to trace people and find out what happened to them years, even decades, after their exposure and so it's possible to relate exposure to a place long ago to disease that's occurring today.

And finally, occupational populations tend to be – not always but more often than not – more heavily exposed than general populations, and I realize that children are more sensitive but still, dose response is dose response and the people who are most heavily exposed are most likely to get disease and most likely to get severe disease, and most likely to get disease sooner. And for all those reasons, the study of occupational populations has been a very important guide to children's environmental health over the years. So that's the prelude and that's why I subtitled my talk 'Lessons from occupational studies'.

So let me run through some material rather quickly, but it's all in support of that theme I just put before you. Everybody here was involved in 9/11 and has been in one way or another, so I don't need to dwell on this except to say that in addition to everything else that it was, the attacks on the World Trade Center were an environmental disaster on an unprecedented scale. Tens of thousands of people were exposed. We'll go through the data in just a second. These exposures have already caused respiratory, GI and mental illnesses as well as cancers in

thousands of persons and will almost certainly cause a lot more disease, disability, premature death in the years ahead. And the question is: where do children fit into this picture?

So here's some, a couple of pictures of the attacks, and I show this picture mainly to underscore the importance of the dust cloud. We know from our studies, and I'll show you the data in a few minutes, that there was a qualitative and a quantitative difference in illness response of all kinds between people who were caught, actually caught in the cloud, who are much sicker than people who were down there, who were exposed, but who were not actually engulfed in the cloud. And clearly, being caught in the cloud elevated risk in a very substantial way. I suspect the reason is simple physical chemistry that the levels of dust in the cloud were so high that when people took a breath, the dust simply overwhelmed the defenses that we all have in the upper airways that's supposed to filter toxic materials out, and the result was that actual chunks of dust went down in the lungs. And I was talking to Bill Rom not long after 9/11, maybe six months afterwards, and Bill was telling me about doing bronchoscopies in people who were caught in the dust cloud and actually getting what he called gravel—that was probably a bit of an exaggeration—but clearly, particulate matter of a large size out of the depths of the lung, which ordinarily never happens because the nose and the throat are very efficient filters, but it did happen to the poor folks who got caught in that. And then of course there was a great deal of dust in the weeks and months afterwards from the demolition, from the removal of materials, trucking them over to the West Side to put them on the barges to take them out to Staten Island and elsewhere, and even though attempts were made to cover it, the attempts we all know were imperfect and the result was that dust got through the neighborhoods. And this number, 400,000 people, I don't know if it's been revised, Mark, but that's the number that I have from the past and of course many thousands of these were children, children who lived in the buildings down there, children who were going to schools at all levels from nursery school through to Stuyvesant High School.

So the pediatric research has to be informed, as I said at the beginning, by several things. Very importantly, it needs to be informed by the hard-won data on environmental exposures. When I teach environmental epidemiology, I always tell the students that it's the information or the lack of information on exposure that is Achilles' heel of so many studies in environmental epidemiology. Just because a person is at a place at a certain time doesn't tell you very much about exposure unless there's really good exposure information on that person. If you're really going to do high-quality studies, you need to know what people are exposed to, and this unfortunately is going to be a recurrent difficulty as we confront the problem of children's exposure post-9/11. As I said already, we can be guided from findings from the adult workers, and then of course you have to weave

through that, knowledge of children's unique patterns of exposure, which basically means you've got to have people with pediatric expertise on the investigative team who are aware of these exposures, especially prenatal vulnerabilities, and the teams will have to be highly interdisciplinary or they'll probably not work. The pediatricians don't really know how to do high-quality epidemiology but the epidemiologists are not—most of them anyway—not deep dipped in pediatric knowledge, and the exposure side to bring the critical information on past exposures.

So why are children so vulnerable to toxic hazards? This has been laid out now, this has been well-understood for a number of decades but it's worth mentioning. First of all, children have unique patterns of exposure, patterns of exposure that are very different from those of adults. They breathe more air per pound of body weight per day, so anything that's in the air, children are going to be proportionally more heavily exposed; likewise, they drink more water and they eat more food. And then children engage in behaviors normally that most of us don't do, most of the time anyway, like roll on the floor, put our hands in our mouths—and all of that, all of those behaviors further increase children's exposures.

And then children, in a sense, are at double jeopardy because they're not only more heavily exposed pound for pound, they have greater sensitivity. One component of that sensitivity is that they're not as well able as we adults are to break down and get rid of toxic chemicals. If an infant is exposed to an organophosphate pesticide, just to take one example, the infant—that chemical is going to remain in the infant's bloodstream for 36 hours because the enzymes that we have have not yet developed in a newborn baby. You and I can break that chemical down in four hours. And if the chemical hangs around for 36 hours, it's a neurotoxic chemical, it has a lot more time to create havoc in the child's body. And then especially in early development, during the nine months of pregnancy and in the first 12-24 months after delivery, there are periods of susceptibility, windows of sensitivity that have absolutely no counterpart in adult life. We first learned this the hard way sixty-some years ago in the thalidomide tragedy when women in Europe took the medication thalidomide, intended to suppress morning sickness during pregnancy, during the first trimester—which it actually did—but unfortunately, it was learned belatedly that thalidomide was a powerful teratogen. It hindered the development of limbs in the embryo and fetus and there was an epidemic of 8,000 or 10,000 babies born in Europe in the span of three or four years without arms, without legs because their moms had taken thalidomide during pregnancy, and the mothers were untouched. It was the first demonstration of the fact that, first of all, the toxic chemicals can get across the placental barrier from the mother to the baby and number two, that the fetus has unique vulnerabilities totally unlike the adult, and that experience has been repeated many times since then: diethylstilbestrol, ethyl alcohol, lead, mercury,

pesticides, polybrominated diphenyls, brominated flame retardants.
Finally, kids have a lot of future life, and we now understand that most chronic disease—whether it's cancer, heart disease, dementia—develops through multiple stages over long decades, and if somebody is exposed to a toxic chemical early in life, they have a lot more time to ultimately manifest the disease that is the consequence of that early exposure. So you can summarize that in a single phrase when you're talking to your mother, saying that children are not little adults.
So what about environmental exposures after 9/11? A huge amount of work was done. The two people that really led the charge on this were Paul Lioy and his team from UMDNJ and Lung-Chi Chen and his group from NYU. There were others, but I think of them as the two that led the effort, and they actually got in on the ground, down there at Ground Zero, on the evening of 9/11 if you can believe it, and got dust samples. And those samples have proven to be a treasure trove of precious information on what materials were in the dust. That said, Paul and his colleagues will tell you that the knowledge that they have of exposures, especially in the first 24 hours and the first week after the attacks on the World Trade Center, is extremely incomplete. For example, we are completely lacking information on what gaseous exposures were present because we had no gas monitors. They picked up dust, which is particles, but the gases by definition boiled off into the atmosphere and are untested. There was probably hydrochloric acid there from the combustion of polyvinylchloride. There was probably benzene vapor from the jet fuel in the airplanes. There were almost certainly other toxic gases but what they were and what concentrations were present is unknown and, frankly, unknowable. I don't think there's any way that it can be re—they couldn't reconstruct it back then. I think it's even less likely that anybody could reconstruct it now.
But we do have fairly good information on what solid materials were there from that dust and from the other sampling modalities that were used. So there was high-altitude imaging. This was good because it provided useful information on where the plume went on different days. Most days it went southeast, as it did on 9/11 itself, but on the 12 September, it swung around to the west and then up to the north. That was information that is from the Earth Observatory at Columbia, Steve Chillrud and his team. Then the dust sampling that Paul and Lung-Chi did was to figure out what was in there and assess potential health hazards. There's a picture of Paul taking dust and what he's pointing at is you can see some collected dust—some settled dust up there in the lintel above that door. That's what they went after because it was the purest distillation that they could get of the material that had been emitted into the atmosphere when the buildings came down, and he's collecting it in that plastic bag such as he's holding in his hand, and he may have been one of the few persons in Lower Manhattan that week with

a proper respirator.

Here are the components, and I've put in red the first three, which are the three elements that I think are—at least at the present time—are the ones that we consider most important contributors to the disease that we're seeing. Asbestos I've put in red not because it's causing disease yet today but just because it is asbestos and will almost certainly cause cancer in the future, but it's not an acute respiratory toxin. And then the noxious combination of cement dust and glass fibers is probably what accounts for the bulk of the cough and the pulmonary function abnormalities and the other respiratory abnormalities, as well as the gastroesophageal reflux disease that we're seeing in the first responders. And the reason I say that is it has to do with the chemical composition of the two things. The glass fibers, these microscopic shards of glass from all the windows and from the fiberglass insulation, lacerated—created microlacerations in the inside of the trachea, the bronchi, all through the airways. And then superimposed on top of that, like salt in the wound, was the cement dust, extremely caustic, highly alkaline, pH of 10 or 11. If any of you have ever had the pleasure of making cement steps or something on a summer holiday and gotten raw cement on your hands, you know that it's incredibly desiccating. It just tears your hands up. Well, imagine inhaling that in powdered form into your airways in high concentrations, which was exactly what happened on 9/11 and thereafter. And what I think happened, and talking to pulmonologists like Bill, we seem to have converged on a storyline which is that the highly alkaline cement dust, aided and abetted by the glass fibers, caused punctate burns on the inside of the airways as it went down. Wherever a dust particle hit, it caused a pinpoint burn. Subsequently, inflammation developed around that burn and then in the succeeding weeks, the inflammation turned into a scar and over the months and years since then, the scar has contracted and that has resulted in a gradual diminution in lung volume in people who had that exposure, which I think is why we're seeing 42% of the first responder population today with abnormalities in pulmonary function. It doesn't mean they're all sick, they're not, but they have decreases in function, which is a harbinger—at least a possible harbinger—of future illness in these folks as they get older and their lungs naturally become smaller as these people age, as happens for all of us.

And then in addition, there were lots of other toxic materials there at the bottom of this slide, and probably the most important of those is the benzene because benzene is a known cause of cancer, leukemia and lymphoma, and it was present in large volumes in the jet fuel from the two airliners.

Here are other materials that were in the dust. I won't run through it but you can see it was a toxic combination.

This is a low-power microscopic view of one of those concrete articles that I was talking about.

Here's asbestos fiber. The story in asbestos, there was a lot of controversy, at least early on, about asbestos in the World Trade Center but I think we've pretty well sorted it out at this point in time. Asbestos was used in insulation up to about the fortieth story of the North Tower and it stopped at that point due to the work of my predecessor Bill Rom's mentor Irving Selikoff. Selikoff, it was reported to Selikoff in the summer of '71 I think by Ed Ferrand, who was the Deputy Commissioner of the Environment for the City of New York, that cars in Lower Manhattan were being covered by a white snow in July, and that white snow was asbestos. And what was going on was that workers were using a pressure hose to spray a slurry of asbestos and paste of some kind to stick it to the steel beams of the skeletal building, and some of it stuck to the steel beams and some of it shot out into the atmosphere and settled down in the nearby streets. There was also asbestos in the elevator shafts in both buildings all the way up to the top as best as we've been able to reconstruct. So there's a fair bit of asbestos in the building, 40 stories worth plus the elevator stacks, and some of the dust samples showed as much—some of the settled dust showed as much as 2% or 3% asbestos and we're only now at 15 years getting into the window of time when asbestos begins to cause cancer. So I'm deeply concerned that we're going to see asbestos-related malignancies in the years ahead.

There's Paul Lioy again, now collecting indoor dust. You can see dust again on the lintel there by his right knee. Here's a poignant picture of a child's high chair with dust on the tray in one of the nearby apartments. Here's chrysotile asbestos in an indoor sample.

Then there was air sampling, the goal of which was to measure time trends and build a composite picture, and the stuff that was collected in the air samples is roughly the same as that that was seen in the dust.

And this graph looks at two air monitoring stations, one right at Ground Zero, the solid line; the second a few blocks away at 290 East Broadway. And there's a couple of lessons here. The first is that clearly exposures were highest right after the attacks and declined with time, got back to baseline in the spring of 2002 some place, so five, six months out. It's also noteworthy that the levels are much higher at Ground Zero than at 290 Broadway, meaning that a lot of the particles were fairly heavy. They fell out of the air rather quickly and you didn't have to go very many blocks away before the levels were lower than at the site. It's also noteworthy that the first data on there, if you look over at the lower left, is September 16, which speaks again to the great absence of information on environmental contaminants in the first two weeks approximately after the attack.

Paul Lioy put this table together to try to make coherent sense out of the massive exposure information that he and others collected, and what he did was divide the periods of time after 9/11 into these four segments and then characterize the principal exposures in each of these four periods of time and the sources of the

pollution. So he had the first 12 hours then the rest of day one, day two through day thirteen and then day fourteen thereafter. And this is pretty well held up in the occupational studies that this gradation of exposure has correlated quite well with the severity and the prevalence of disease in the exposed workers.

So let's talk about the health problems now. We started seeing patients up at Mount Sinai. David Prezant started seeing patients at FDNY. People at Stony Brook, Rutgers, NYU Bellevue, North Shore-LIJ all started seeing patients early on and thanks to NIOSH, thanks to Dr. John Howard, thanks to the Zadroga legislation, we've had continuous funding to properly follow these different populations. And what we're seeing in our group at Sinai—and the firefighter pictures are pretty much the same, not exactly but close—27% with asthma, 40% with chronic sinusitis, 40% with GERD and I was going to say almost 42% with abnormalities in pulmonary function, of which the great majority are restrictive disease, and a clear dose-response gradient in all of these conditions. Also lots of comorbidity, which is the long way of saying that lots of these people, especially the most heavily exposed, had two or even three physical health problems, as you can see from the degree of overlap in these Venn diagrams.

And then we had the mental health problems, which are pretty much as common as physical problems: PTSD, depression and here are the rates. It's been striking all the way through that the Police Department, who comprise about 40% of our population at Sinai, have strikingly lower rates than others and whether that's because the cops just don't acknowledge stuff or it's because their battle-hardened, having been working the streets of New York before 9/11 I'm not sure, but there is a clear difference between police officers and others in the rates of these mental health conditions.

DR. WARD: Or pre-selection.

DR. LANDRIGAN: Or what?

DR. WARD: Or preselection.

DR. LANDRIGAN: Or preselection, yes. Preselection, experience and denial, all together, probably a combination of all the above. We love cops.

Okay, next. And again, there was a gradient, and again there's a lot of comorbidity and of course, I didn't have a slide that was big enough to show it but I could have put six circles on here. I could have put three physical conditions and three mental health conditions and you would have seen an awful lot of overlap. You have people who have asthmas, sinusitis, depression and panic disorder, the whole thing, and they're on twelve medications. There is no shortage of previously robust, healthy marathon runners, gym rats who are now afflicted with these multiple conditions. And this is all a guide to what should be looked for in exposed children because they're going to get, to the extent they were exposed, they're going to get the same stuff.

So here are the conclusions, that respiratory, GI and psychological symptoms are

prevalent, severe and persistent in the responders. They're not going away; that's clear. Some of the PTSD has gone away but not much else. Strong dose response for pretty much everything including the mental health conditions. I already talked about the combination of dust and glass causing the respiratory symptoms. Very high likelihood that new diseases may emerge in future years, especially certain malignancies, maybe certain forms of heart disease, maybe dementia, maybe accelerated dementia as a consequence of particulate exposure. There's an emerging literature in geriatrics that living in highly polluted areas increases rates of dementia maybe through vascular disease mechanisms. They're still in early stages of elucidation but it's something to keep an eye on. And that's why we've said repeatedly to the Congress and are saying it now, as the bill is still under debate down there in Washington, that assured long-term support is essential. We will not be able to continue to do the follow-up studies, we'll not be able to continue to provide care to the workers who serve this country if the Zadroga bill is not renewed, and in my opinion is should be renewed indefinitely and cover these men and women for as long as they live. They responded to a crisis the same way that military veterans respond and they should be treated equally.

So in closing, two final slides. First of all, what we don't know. We don't yet know about late effects, cancer, pulmonary disease, autoimmune diseases, other, dementia I just mentioned, heart disease. And we don't know precisely whether the conditions will be persistent, although at this point I think it's becoming clear that most will be persistent.

And now with the final slide on pediatric research, since that's our topic today, it's very clear that studies of children, as I've said two or three times already, need to be guided by the environmental information that Paul Lioy, Lung-Chi Chen and others collected. Reconstruction of exposure is going to be a key element. It's going to be very hard to say anything meaningful about disease in children unless we have some indication of their level of exposure. It doesn't have to be out to the third decimal point but there has to be knowledge of where the child was, how long the child was there and any information that we can piece together like a mosaic on chemical exposure would be very helpful. Absent that, it's going to be hard to say anything very meaningful, and that's a reality check that we'll just have to bear in mind as we go forward with any planning for future studies. Just as in the adults, there'll be dose-response relationships. The whole dose-response relationship may be set at a lower level because children are more sensitive than adults but there'll still be dose-response. It's a theme that runs all through biology and medicine. The adult studies are clearly going to provide important guidance but even as we think about the adults, we have to think about children's sensitivities and recognize the patterns may not be identical.

And the last point I wanted to make is that children exposed prenatally are a

group worthy of special attention. We had a phone call yesterday, a few of us, to reflect on that. There was a small cohort of about 187 pregnant mothers put together by Trudy Berkowitz. Trudy was—now long since retired—was an epidemiologist at Mount Sinai who was concerned about effects during pregnancy because she was the spouse of the head of OB at Mount Sinai. And so using her OB connections, she contacted all the obstetric practices in the Tri-State Area, got a list of about 190 women who were pregnant on 9/11 and within a half-mile radius of the towers. Twelve of the women were actually in the towers and got out. The others were in nearby. And she found that among those exposed women compared to women in Northern Manhattan, there was a doubling in the frequency of babies born small for gestational age. It was 8% in her group versus 4% in the unexposed population. She followed that population for a couple of years. Funding was not renewed. Trudy retired, and I don't believe that anybody has followed up that cohort but if that cohort could be reassembled, they might be a group worthy of further investigation.

And as we look at that group or any other group, we need to expect the unexpected. We know, we certainly have guidance from the exposure studies, we have guidance from the occupational studies, but kids are different and we may see stuff in children that we have not seen in adults, and therefore as any children are studied and followed in any future studies, we need to do it with eyes wide open and not narrowly focus on one or two outcomes. And that's it, thank you very much.

DR. WARD: Thank you.

PARTICIPANT: (Inaudible @ 38:53).

DR. WARD: I think we'd like to save it for later so that it can be more interactive. Thanks. Our next speaker will be Dr. Robert Brackbill, who will be talking about the Registry studies related to children.

OVERVIEW OF CHILDREN'S RESEARCH AT THE WTC HEALTH REGISTRY AND PERSPECTIVES ON THE CHARGE

DR. BRACKBILL: Hello. Thank you for inviting us from the Registry to speak about the children cohort in the World Trade Center Health Registry.

PARTICIPANT: We can't hear you, Bob.

DR. BRACKBILL: Oh, sorry. Got to get some microphone training here, I guess, right? All right, thank you for inviting us from the Registry. I actually was the principal investigator of the original protocol for the World Trade Center Health Registry. I was present downtown during the attacks and I was working in the Health Department at the time, and I think it was a month later that we began meeting and discussing, you know, how to put together such an entity as the Registry that would do follow-up studies. I want to mention Polly Thomas and I were sort of collaborators and probably worked alone on this project for a little while.

So I wanted to—so I have this thing here. Okay, so the objectives of my talk

today, I'm going to be sort of giving you some information about the population frame, you know, overview of the recruitment and enrolment methods, current status, some of the information about current status of the children's cohort, and then I'll summarize some findings, you know, on physical and mental health, that we publish findings, and I'll talk about some current studies that have not—they're in clearance and not been published yet. And a note on limitations, challenges for following a children's cohort and then have some ideas for some future research that we might be able to use the Registry to do.

First I wanted to talk a little bit about—let's see, did I miss—okay. So first I wanted to talk just a little bit about the types of groups that we're looking at, you know, at the time of 9/11 in considering a Registry and looking at, you know, inclusion of children. So we have, as Dr. Landrigan said, people who were in the vicinity, living in the vicinity of the World Trade Center site in downtown Manhattan, and children who were attending school in Lower Manhattan at the time of the attacks. We actually defined not—people didn't have to be actually in school that day but enrolled in the school, considering that exposure could sort of go on afterward. People on the street or in the buildings. There were some children that we found in our enrolment who participated, they were in their later teenage years, participated in the rescue/recovery; they were volunteers. And then we have children are exposed to family disruption, you know, parents losing their jobs, parents who were in the buildings, who were on the street and then of course relocation, you know, the schools closing or even the family had to relocate, the parents had to go to a different location to go to work. All those kinds of disruptions. And then born to mothers exposed to the World Trade Center disaster, I think Dr. Landrigan pointed that out. We actually have a cohort of—I'll talk about that a little bit—about 3,000 children who were born to mothers who are on the Registry that we have birth certificates and we're doing some analysis of that. And then a group that's exposed to the post-disaster media in itself, I think that had some traumatic effects as well.

So just some of the types of exposures that resulted from the disaster, you know, we've had Dr. Landrigan go through these and certainly we had the witnessing the events at the time, the media exposures, evacuation, panic, exiting the scene if you were in the vicinity. There might have been—not very many, I think it's mostly adults—were in the vicinity of the buildings sustained an injury in 9/11, primarily eye injuries, eye irritation, that sort of thing. And then of course the dust cloud is a key exposure that we've found in our analysis looking at adults as well as children. The proximal exposures, loss of parent, sibling, evacuation from home which I've mentioned, evacuation from school, then the restricted transportation. And then ongoing, re-suspended dust, which Dr. Landrigan actually talked some detail about that, the dust that was in ventilation systems, dust in the, you know, churned up by trucks and by all the deconstruction of the site, that sort of thing.

And then abrupt changes in children's social network and the media about the event. And the parents' health too is actually a consideration that we've actually found that PTSD in parents is associated with similar stress symptoms among children in the family.

Now this is just a little bit about what the population frame looks like, that this is from data from—I actually pulled data out from the census, 2000 census, and of course originally, we had identified 57,000 people who were south of Canal Street, about 24,000 households, and then you can see the distribution from census data, number of children who were south of Canal Street. That south of Canal Street of course composes the population frame for the Registry, and you can also see, given that there's been some concern about not including populations that were north of Canal in the Registry, you can see that the numbers increase a great deal and that the massive effort in trying to enroll the 50,000 children that are south of Canal Street would have been magnified, you know, by trying to reach out into neighborhoods north.

Just to point out that another—that in an epidemiological kind of study, you want to get the most coverage of your exposed population and the most highly exposed, and that way you can generalize for—like Dr. Landrigan was pointing out—occupational studies of high exposure, you can generalize to groups who, you know, that might have the same type of exposure/disease relationships.

Oh, uh-oh. Did somebody turn something off? No? The button's not working here. Oh, there we go, okay. All right. So recruitment, we're going to go over the recruitment and enrolment for the Registry. First of all, the eligibility criteria for children included having a—being a resident in Manhattan south of Canal Street on September 11, 2001; enrolled in a school south of Canal Street September 11, 2001; or work—we actually have children in the Registry who were in neither of those first two categories but who were volunteers, you know, like I said earlier, in rescue/recovery work and also who might have been on the street or in buildings on the south, this is the south of Chamber Street area close to the World Trade Center site on the morning of September 11, 2001.

So the types of activities related to recruitment of children you can break up into two categories: those that you might refer to as household-based enrolment, and so as I mentioned earlier, there were 24,000 households identified from census data and we actually got lists of people who lived in the area, you know, addresses and names from a company called Genesys, purchased these lists, and we used these lists to contact people in the households and we sent out actually twenty-some thousand letters to households, you know, talking about the Registry. You have to think that in the recruitment of children who were residents that you had to start with the family, identify the families and work through the adults mostly. And then of course the outreach in media, that was an enormous effort. You know, there was advertising, subway ads, I believe we put in these

pamphlets and other types of things and all the businesses, restaurants, that sort of thing in the area, we did presentations at community meetings. I went to maybe a hundred myself. I spoke to different groups, you know, who were represented, or groups who were represented in the community in downtown Manhattan. Posters, informational letters, etc. So there were about 1 million items and it just was a constant thing over an 18-month period of distributing this material. And we also went, we identified a resident in the enrolment interview, we got a roster of family members and were able to—and then set up, if there was a child in the family that we then set up a separate interview, you know, and the parent served as a proxy for a child who was younger than 18.

And then a separate effort, a school-based enrolment, so developed a list of 37 Lower Manhattan schools consisting of, you know, childcare centers, nursery schools, public, private schools K-12. And then in looking at these 37, most—public schools certainly—we tried to, we worked with the Department of Education. In fact, we had a protocol, of their reviewing the protocol in order to provide us a list of children in the schools, and this went on for a number of months back and forth with the Department of Education, and then finally I think I got the last bullet there that the Department of Education agreed that they would send a backpack letter to 12,000 families, you know, of children in public school. And you know how it is, a backpack letter comes home, you know, a kid gives it to you and ah, well, that was the best effort of us. And we actually got some lists from nine private schools.

So in the end of all this effort, we got 3,251 enrollees younger than 18. It's the largest World Trade Center-related disaster childhood cohort, 73% are residents, 23% were non-resident students. That is, they were students in schools south of Canal Street, enrolled but they were not—did not live in the area.

So this is somewhat of a—this is a summary of enrolment in the Registry and I wanted to show you this, you know, by age group and again I used census data here by age to give some estimate of the coverage by age group, and you can note that among the residents younger than 5 and also 5-9, that there was already 30% of children who were enrolled in the Registry who were resident south of Canal Street. And so that translates into almost one out of three kids were on the Registry of that age group. And then as you get up into the older age group, 15-17, a bit harder to reach, a bit harder to get—have the parents do the proxy interview, etc. The percentage then drops to 12% coverage in that group. The other thing to note there is that there is some variation by age group as who was in school in Lower Manhattan and who was not enrolled in school in Lower Manhattan. We'll mention that we have down there a bullet, overall coverage, a similar overall coverage for residents but actually it's a little higher for children than it is for residents.

So here, actually this is data that actually some years ago, Dr. Thomas and I were

working on the first pediatric paper. She and I put together a database of, you know, what schools we had in the Registry, what schools the children represented, and this is also reported in a paper by Murphy and myself, you know, on coverage, some of this information. But just looking at this, I ordered the schools by the number of enrolled children, starting with Stuyvesant High School with 422 and then the number in parentheses is the percent of the students in those schools who are enrolled in the Registry, and then on the right I have the percent of those students who are residents of Lower Manhattan. So a key sort of piece of information about these numbers is that you're looking at two sources of exposure there. One is the being enrolled in the school and the second is being a resident, and so it tells you a magnet school like Stuyvesant High School, that many kids would come from elsewhere, that they had exposure to coming back to school to whatever remained from the attack—I guess Stuyvesant was closed for some period of time, which of course is a disruption in life as well—but also being a resident or not resident is another, you know, exposure dichotomy.

But the other thing that's sort of important is that some of the elementary schools such as PS 89 or even PS 234, that we have a substantial number of children—I don't want to use the word 'substantial' but you know, the percentage of enrolment is like for PS 234 is about 38% and then it's as high as 72% for PS 89, and most of those children, you know, were residents.

So let's just go over data collection. It's somewhat complex and I could probably talk more about this later, but the Registry, you know, typically talks about, as it is a longitudinal study, we talk about data collection in terms of waves of data collection, and the first wave, Wave 1 was the enrolment wave which I think most of you know, you know, that the enrolment started about two years after 9/11, September 2003, and then it continued on to November 2004. So as we were enrolling adults, we also enrolled children, and this was done primarily through proxy interviews by parents and guardians and this was a, you know, an IRB sort of issue. I recall that actually we had a discussion with the Centers for Disease Control IRB board on whether or not we could allow, you know, could have adolescents do the interview themselves or have the parents, and they finally decided that they wanted us to have the parents do the interview by proxy even for adolescents. And there was, by the time that enrolment began, there was 600, about 600 children who were children on 9/11 who were interviewed, who did the interview themselves, and we asked questions, you know, exposure—self-reported exposure, physical and mental health conditions before and after 9/11, the same questions that adults received, and depending on which, you know, particular eligibility group they were members of.

And then Wave 2 was about two to three years later. In this case, you know, because of children aging, you know, getting older, we separated out the Wave 2 into two groups: children younger than 11, and we had parents complete the

entire survey for both themselves, we had parent questions, then we had also children-related questions, and we asked the parents additional information on 9/11 exposure and physical and mental health symptoms and conditions of the child, and questions on healthcare access and utilization; and then for the adolescent, the parent filled out a survey and then the adolescents filled out a survey. So you can imagine, you know, families getting these envelopes with two instruments inside, you know, and two envelopes inside, one for the parent to mail back, one for the child to mail back, and they had to figure out among themselves how they were going to do it and all this. So we had, in the end, we had some parents who sent back a survey but no adolescent and then we had adolescents send back but no parent. So you know.

And then Wave 3, again this was about four years later, we conducted a survey and in this case it was only adolescents because all the children in the older age groups of 9/11 had aged into adults, so they were part of an adult survey. And you can see that the questions become more extensive, especially around asthma control and functionality, ask about school functioning and behavioral issues and substance use.

So just to talk about some of the work, published work that's come out on the children, the first article is Polly Thomas, you know Dr. Thomas, we did, looking at primarily asthma and the key thing about this is that we look—well, first of all, you can see that two or three years, I have up there two or three years after 9/11, the age-specific asthma rates were higher than national rates. So we compared the asthma rates in this cohort to national published rates, I think from Health Interview Survey. And then also, more sort of important is that we looked at all the different self-reported exposures that I had mentioned earlier and we only found dust cloud associated with new asthma and there was a dose-response relationship in a sense because we broke dust cloud into two categories, one where we had a combination of no eye irritation, the other with eye irritation, and there was an adjusted odds ratio 1.7 with no eye irritation and 2.2, which suggests that dust cloud was a key factor in development of asthma among children.

And then a more recent article, Steve Stellman in 2013, in this case didn't focus on the asthma; it focused on respiratory symptoms that may be indicative of asthma or be associated with asthma. And again, looking at the ray of exposures that we have available, we found only dust cloud was associated with symptoms and we found a (inaudible @ 59:07) relationship for children 5-10 years old, and then it was twice—the prevalence was twice the rate among adolescents who were in the dust cloud versus those who were not in the dust cloud, although when we adjusted that and adjusted the odds ratio, it was not significant.

And then a study I mention here that was done on the mental health of children, this looked at behavioral problems and actually we had a scale in the wave—starting with Wave 2 called the Strengths and Difficulties questionnaire, and that

was a self-administered set of questions by adolescents giving a sense of how they were doing, you know, how they're doing in school, how they're getting along with their peers, how they're getting along with their parents. There were some questions on, like, positive things where you—are you kind of generous to other people sort of thing. And so we could score children, there was actually a way of scoring children into categories referred to as abnormal, normal or actually I think there was two abnormal categories.

PARTICIPANT: Borderline.

DR. BRACKBILL: Borderline, thank you. Yes. Abnormal, borderline and normal. And so we did find that, you know, that these behavioral problems as measured by the SDQ or associated with the direct 9/11 exposure, with injury and also death of a family member, and the key thing in this study was the parent—9/11-related PTSD. So that's one of the, I think, it's one of the significant advantages of the Registry is that we have both information on parents and on children, and we have information on parents who are in the Registry as well. And I might mention that there are about 1,000 parents who are on the Registry in the cohort and had children in the Registry, you know, who were enrolled during the Wave 1. The other thing is that adolescent-related PTSD associated with 9/11 exposure, we had some other—another variable, fear for personal safety among adolescents. And then a key thing, as I mentioned, a parent with 9/11-related PTSD was associated with the adolescents exhibiting PTSD symptoms.

So some work in progress, I mentioned, I put the first thing under physical health: birth outcomes. We have a study and it's actually in the last stages of clearance and will probably be submitted for publication soon, in which we developed a birth cohort, you know, based on batching of birth certificates, the City birth certificates, with mothers who—well, with women basically who are on the Registry, and we looked at births from 2003 to 2010 to mothers who are on the Registry. That's sort of the observation period, and we had about 3,200 births. Now there were multiple births for women, so women had more than one child during that period of time. And we looked at, you know, birthweight and gestation period as outcomes and with different types of 9/11 exposures. That's exactly what Dr. Landrigan was just talking about a minute ago.

Then we have another paper on asthma control, adolescent asthma control, and this is based on most recent data from Wave 3, and found about 23% of children who had asthma reported poor or very poorly controlled asthma, and we also found that some 9/11-related exposures were associated with the lack of asthma control.

We're also looking at unmet healthcare needs of children and this is, we're looking at this in a context of parental mental health and also school functioning and other factors that sort of relate to this, and has this as kind of a mediator, you know, between you know, what happened to people on 9/11 and then how they're

dealing with things in the future. This actually, this was—I don't know if any of you were at the principal investigator meeting, Lisa Gargano presented this data just at the meeting two weeks ago.

And then we have external studies, Registry-facilitated external studies, that is facilitated through recruitment using the Registry cohort, which is Leo Trasande's study focusing on precursors of mostly cardiovascular disease.

And then on the mental health side, we're looking at substance/alcohol use and again, you know, in the context of unmet healthcare need, we're looking at adolescents' mental health care needs and parents' mental health. And then we have external studies with Dr. Hoven, one is mental health service need, and one youth and young adults, and she'll be talking about this today and the 9/11 impact. Both are Registry-facilitated studies.

So the limitations of pediatric cohort, it goes without saying that you have a mother or father, you know, who's doing the interview for their child. It's a self-report by proxy, then—of exposure by proxy—and it's also self-report of health conditions. So this is filtered by a parent and what they observe about the child, especially younger children, the parent could obviously be, you know, not saying things that may not be of course true about their feelings, or can't really talk about how the child actually experienced 9/11 in a sense.

And most of the enrolled adolescents ended up through self-identification, and I talk about the effort of mass media campaign, advertising and all that sort of thing. That was to get people to self-enroll because it turns out that, you know, even with the lists that we had, that we had to use a major effort to get people to be aware of the Registry and then to go to the effort of calling 800 number and agreeing to do an interview.

Individual exposure, well, there, well, actually what I mean is just that we don't have the physical exposure. This is, as Dr. Landrigan said, you know, the Achilles' heel of World Trade Center research is that we don't have measures of physical exposure. Primarily for the Registry of course, it's self-report, and we have, of course, these experiences that people had with dust cloud, witnessing events, being in the vicinity of things but we don't actually have a physical measure of what they're exposed to. Some communities and demographic groups may be underrepresented. Actually I note in the—I did look at the race/ethnic group and found that, you know, Hispanics actually had a 57% coverage using census data denominator, and then Asians had a 15%, which would be expected in coverage. Whites are around 40% and then the other groups were—I can't recall what that number was. And then also we looked at the household income and found that families that had a household income of less than $50,000 or more than $50,000, it was about just an equal representation, 23%. And I think the low number of 23% for both was mostly due, because many people didn't report their income. I think about 70% of households

didn't report income.
So, and also we did not include children whose parents, siblings or others were killed in the attacks, and actually with the Registry, it's sort of looking at a bereavement kind of group, you know, which was not an eligibility group on the Registry. But we certainly, we asked parents and we asked children about if they did lose somebody, we do have that information but we didn't include children by definition who lost parents.
And then we had to mention of course the difficulty of trying to follow children and get parents to—with the complicated surveys and way of trying to collect the data, we had a low response rate and follow-up, in the 40% range, and of course as the samples become smaller, it gets more difficult looking at some of these combinations of types of things, the interaction of mental health and physical health for instance, comorbidities, that sort of thing.
So just some considerations for future research. I think a way of looking at this is looking at notable Registry sub-cohorts, you know, and I mentioned that, you know, that obviously the cohort is aging but we do currently have, as of today, we have 676 Registry enrollee children who are still under 18. So that is, you know, that's the group who were born—many of them were babies at the time, you know, three or four years old at the time of the 9/11. We have children who are adults who would be eligible for the next wave, and certainly we have Wave 4 ongoing right now and many of those children are, you know, completing surveys in Wave 4. And I wanted to mention that the IRB has requested that we re-consent children—I mean who were children that were actually enrolled in the Registry by their parents, and that we have about a 20:1 ratio between those we contact who re-consent versus those who say they want to withdraw. So it's about, you know, if we get a hold of somebody and ask them if they want to remain in the Registry, we have about 20:1 ratio between those who say yes. And as I mentioned before, about 1,000 enrolled parent-child pairs, and this is, I think, really key information to have, you know, information from all the—you know, if you put it all together over three waves, I think you end up with about 200 of these parent-child pairs and that's, in some cases, a substantial amount of data for looking at complicated mediation or interaction type of things between parent and children. And children in the 9/11 Registry have also specific populations, and then I mentioned that there was a study—I think Dr. Hoven did that early on—looking at children of rescue/recovery workers. So we can, through people on the Registry, identify their children for a separate study.
And then school-based sub-cohorts are highly represented. Now, that's something which I might have put at the top there because that was kind of a discovery I had when I looked at some of the schools in Lower Manhattan which I mentioned, which we have a fairly high coverage rate and we have also a high rate—you know, high percentage of residents. So you have, if you were to do

some kind of, sort of small analysis, cohort analysis, you would have a school in which—and that had, everybody sort of had the same exposure, you might say, and maybe you will actually go in the school and get some information about what happened at that particular school, for instance. So I think that that's something which we, I think this committee consider as a suggestion.

Then offspring of exposed children, you know, we can of course take children who are exposed and look at their children; that has potential. Children enrollees who lost parents, and I think I mentioned that earlier. Interplay between—and then some topics of interest I think is the comorbidity issue, especially between physical and mental health, because I think mental health is actually—you know, physical health is very important, and what Dr. Landrigan was talking about, but I think the trauma, especially among adolescents, of the parents losing their job, getting relocated, schools closed and all that sort of thing, and then the parents suffering from stress-related problems, I think that's something that's important to look at along the long term. And substance/alcohol use is an outcome of that type of, you know, situation in families. And then the clinical testing of children with respiratory problems, and I think to—and this is going on that also, I think to do more in-depth clinical testing would be very important, pulmonary testing, to understand the underlying mechanisms of any kind of deleterious effects.

So, thank you for listening and I acknowledge that Dr. Farfel has helped me, you know, put this together, focus on things, and I had several staff who helped me pull some of this data together, and of course the study is supported by ATSDR, CDC, etc. And we're hoping that the Zadroga Act gets passed soon so we can get on with it. Thank you.

DR. WARD: Thank you, Dr. Brackbill, that was very informative. Our next speaker will be Dr. Christina Hoven from Columbia University and she'll be discussing mental health research.

DR. HOVEN: What happened? Where did it go? That's what they say; Paul does everything. That true?

OVERVIEW OF WTC MENTAL HEALTH RESEARCH AND PERSPECTIVES ON THE CHARGE

DR. HOVEN: Thank you. So first I want to thank you all for inviting me here. I have been living and breathing children's mental health since 9/11, and it's a wonderful thing that you are devoting this day to the issue. I truly appreciate it. What I thought would be most helpful is if I give you an overview first of the approach that my group takes to research in general and, particularly, this problem of children's mental health post-9/11. So epidemiologists we try to always to do representative sampling so that in fact what we find has some meaning for a larger population, which means we generally also include matched controls. That is people who have not experienced what we're examining. We try always to do longitudinal design to follow people over time, so that we can understand things change over time, and impact from a disaster certainly has different ramifications over time.

To do this kind of work we always do what's called 'field-based research,' which is face to face interviews. So whereas the Registry has more than 70,000 people they couldn't possibly do the kind of face to face work that we do. We do smaller samples, but we go to people's homes or to the library if that's what they choose or some other neutral place and we conduct extensive interviews. We try to the extent possible to do comprehensive bio-psycho-social assessments. That means not only the interviews about the psychological well-being but also try, in most studies, to do a genetics brain scanning cortisol, whatever is reasonable as the examining biological markers. We take a developmentally-focused approach. These are children and it is an important developmental period, and we have learned over many, many years that if you don't consider what's going on in the home, the neighborhood, the school, or the work environment you're missing some very important dimension of a person's life. And to the extent possible we always include family members, most frequently the mother. As I said, we take a life course perspective and for children that means that children, of course, are at a very vulnerable developmental period and our understanding is that events at any one point in a person's life can have very powerful determining factors or influences on subsequent well-being and well-being during childhood often determines successful educational, occupational, and social functioning in adulthood, and that the context that I just mentioned influences how a child processes their experiences and understanding the consequences of events in childhood requires a bio-psycho-social assessment across the life course.

So I say all this because I think it's important for you all who are trying to figure out where we should go with the research focused on children. And I think it's important to understand where we have been and what we've been thinking in order to have a better perspective on where we might go. So I just put this up partly as a way of saying that this has been a major preoccupation for my group from the third day. I'm like Phil who was there on the first day. I was on the Board of Ed. On the third day after the 9/11, and as you can see this is a series over time of different investigations funded by different national institutes or for the first study, which was done pro bono, trying to understand what was going on with child mental health.

So the first study which was done, as I said, pro bono when it was started on the third day after 9/11. I was very fortunate to be invited into the chancellor's office and asked how we should understand children's mental health. Being an epidemiologist I said, 'Well, first of all, I don't want to just look at Ground Zero because that's not going to be the only effect of this event, it's just too enormous. I have to look at the entire city.' And I remember one of the discussions was, 'Okay, how many kids do you want?' I quickly calculated and said, 'Ten thousand,' and she said, 'Okay, you got it. What else do you want?' I mean, this was a board of education, as you know, in New York City was not the easiest

place to work, but for me they were wonderful. However, I then went back home after I said the 10,000 and I thought how am I going to sample 10,000 in New York City schools. I had known from previous investigations that as wonderful as New York City is we had no sampling experts anywhere. So I called the CDC, my friends at the CDC, right? I didn't know anybody, but I got to somebody, and I told them, 'I need help,' and the answer was, 'Listen, lady, we're the CDC. We do studies. We don't help people do studies.' I said, 'Listen to me, I'm working with the New York City Board of Ed and you are going to help me. You are not going to be able to do the study, but you are going to help me. So talk to whomever you have to talk to, but I need you here on Thursday.' This was a Monday. They called me back on Tuesday and they said, 'You're right, we're going to be there. Where do we go?' Anyway, it was a wonderful relationship and they helped me get this sample. We ended up getting only 8,000, that's all we needed. It was a marvelous arrangement with the CDC. Anyway, this is the most compelling slide from that collaboration.

As you can see here this is six months after 9/11, and I show it because it's the one and only representative sample of children after 9/11 that was done. It's very powerful. So if you look here on this right column you'll see US communities. These are very well known community studies that were done around the United States in like five years prior to 9/11, and they gave the rates here of these different disorders. Not being a trauma person prior to 9/11 I quickly dove into the literature and figured out what are the disorders I should look at, and then I talked to lots of people and I talked to a very famous person with childhood trauma. I gave him my list and I said, 'I'm going to look at agoraphobia,' and he said, 'Don't be ridiculous that has nothing to do with trauma.' I said, 'Well, you know you live in the flatlands of Los Angeles.' I said, 'This is New York City.' And I knew by then 750,000 kids every day in New York City took subways and buses and boats and cabs, and everything to get to school. So, anyway, I did agoraphobia. Anyway, if you can look over here. These are the community rates for these disorders. The first time I ran this analysis I was looking at these rates right here. These are the prevalence rates of these disorders, and after I had those rates and I saw how elevated they were I called my friend at the CDC and I said, 'Okay, I've run this analysis and this is what I found,' and I was very excited to know we identified all these elevated rates and nobody had ever looked at all these disorders. They only looked at PTSD and a little bit of depression, and I looked at eight disorders. You only have six there because the others are externalizing. And he said to me, 'Well, you know, Christina, this is really interesting, but I don't know what it means.' I said, 'What do you mean you don't know what it means?' He said, 'Well, you know the rest of the country knows that the kids in New York City are crazier than the rest of the country anyway.' So I said, 'Oh.' So I went back to the drawing board and now I divided it by exposure. Now you can see,

and it divided pretty evenly, so if you look at the mild exposure these kids actually look just like everybody else in the country, but as soon as you start looking at moderate exposure and severe exposure you start seeing something very, very different.

So the question was, you know, how did this work? So we have here exposure to trauma and we have children's mental health, and then we have parents and you had to assume that there was something going on with parents that might be disrupting the process of the children dealing with this. So then we looked at other things. This one here, for example, is gender looking at the difference between girls and boys, looking at grade group, and you can see that in fact what you would expect the girls were more significantly affected than boys, significantly grade group the younger they were the more affected they were, etc. So then we asked the question well, what about PTSD? Everyone's favorite disorder after a disaster. What's going on? And we were particularly interested in what happens with direct exposure, but then we looked at family exposure, we looked at prior exposure, and we looked at distance. Well, remember we took these kids they were a representative sample of the five boroughs, and in fact it didn't make a hill of beans whether you were a mile away, less than a mile away, or you way up in the outskirts of the Bronx. So that was a very interesting finding because no one had ever looked outside of a Ground Zero area or an epicenter of a disaster, and here we were looking at kids 15 miles away who were having exactly the same kind of response. I should add that when I gave the press conference right after this first paper came out I went back to my office and there was a stack of these little green pieces of paper from people calling me. I didn't think too much of it except I started looking at all these… why are they calling me? The first one I picked up was from Chile from the national television in Chile. I didn't do anything, I just put it down and I kept looking at all of them, and finally this person called back from Chile. I said, 'Why are you calling me?' She said, 'We want to come and interview you.' I said, 'Why?' She said, 'Well, because we're trying to do a study in Chile and the children can't do the survey because they think the planes are coming here.' This was in Chile. Now, I had these calls from all over the world, children all over the world had the same thing. They were watching the television. So you see here in New York we had high media exposure which was pretty high, but children all over the country were having this kind of reaction.

So then we asked the question, well, what do these children look like in this study if their family member was involved with the World Trade Center? It says 'in' and that's not correct. It's either they lost a family member or their parent was a first responder or they worked in the World Trade Center area, or there were no family members. You can see this difference. So even if the child lived up in the Bronx and the child had elevated rates of psychopathology those rates were more elevated if the parent was involved with the World Trade Center.

So then there was this question of how was this being transmitted. So I did a lot of talking to firemen and policemen, and first responders about what they were doing at home and without exception they all said, 'I don't take my work home. I leave it at the fire station,' or whatever, 'I don't talk about it.' But there's something going on besides just the child's knowledge that there's something happening. So I wrote a pilot study to NIMH to try to see if, you know, to develop some methodology for developing ways of getting the 9/11 exposed families. At that time that was still the Registry did not have a sample, and I was trying to figure out I could get at these families. So we designed the study to actually see if we could recruit them, we could do the in-home interviews and we could collect the biologics DNA from the parents and children cortisol and do fMRI. So we did all of these things and we found out that it was perfectly doable.

Then the question was how could we look at parental mental health and its relationship to child mental health considering exposure. So that study was a first responder study that Dr. Brackbill just referred to. I think some people at the CDC call that 'take home exposure.' I just want to run through some quick findings. There were significantly more symptoms for panic, PTSD, MDD, separation anxiety, conduct disorder, more psychiatric impairment, and significantly more substance abuse in those children of the first responders and the evacuees versus controls. And the controls, of course, come from the same geographic area who did not have a similar experience… have a first responder in the family. And this was adjusted for age and gender.

So the next thing was to try to figure out what was happening with need because the first study that we did with the board of education was actually attempting to try to identify what the need would be in New York City for child mental health services post-9/11. The state and the city departments of mental health were trying to figure out how to gear up services in schools and the community, etc. So I very much had that on my mind. So we wrote a grant to NIOSH and we said we wanted to look at two samples. One was the children of the first responders because we had asked about it, but we had not had that as one of our primary goals for that study, but we wanted to go back and examine the child service use, mental health service use. As you can see here, very interesting, you have for children with depression was associated with out of school mental health services and the adjusted odds here is 13. The higher proportion of children from minority and racial backgrounds had an adjusted odds of 2.5. So there was some really significant differences in that sample about service need. We did not have a lot of questions about it, but it was enough to make us wonder what was going on. This is the using the Registry data, and I think Dr. Brackbill mentioned that they had collaborated with us on this study. We were able to get the Registry data of the children and here what we were looking at over the three waves was just simply PTSD of those children who were ages 6 through 12 who were directly exposed to

9/11. There were 638 of them. What's interesting here… if you look here at this Time 1 survey, that's the Registry survey, you see that there's basically four groups jump out, and those are those dark lines, and you see 68%, which is the red line, basically are not doing too badly. They are, in fact, getting worse over time, but they're basically okay, and particularly at the Time 1, 68% of them are doing just fine. But then you have this other group that actually doesn't look so bad at Time 1. This is PTSD. But here they are at Time 2 and here they are at Time 3. So I don't know where they're going to be at Time 4, but you can see that there's a very clear escalation in PTSD symptomatology. And then you have this group that appears to remit, which is here, and it's this green line going down. Now they had the highest rates of Time 1. So they would probably be in that group of children that I showed you on the school survey where we had, I think it was 10.8% of the children had met criteria for PTSD. That's the same group here only this Wave 1 was collected a few years later, but you still had these elevated rates. And then there's this black line that's called… we called it the 'Chronic Mild PTSD' for they're here and they kind of stay here. They come down, but they're still here. And if you look over here at this little box here what you see is simply a dichotomous look of having or not having PTSD over the three waves of data. And, again, you see that green line coming down, but it's still fairly elevated here. So that's why we called it the chronic mild. And here's this group here, this very interesting group. Okay? Now, you would have no way of knowing that when you look at any one time point. That's the reason why you have to do longitudinal studies. Here's a same look at those trajectories and here what we've done is taking internalizing disorder and it's, again, the same 638. What we're looking at here, the relationship of the PTSD trajectories, these four trajectories that we just looked at, and we're looking at them in relationship to internalizing disorders and impairment. You see there's four distinct groups here again. The same ones from this last group here, those four lines. They're now translated here… you're now looking at these four different trajectories and this one here, number 2, is the increase in the PTSD severity, but what you see is not only the increase from the last slide in the PTSD severity, but you see the increase in generalized anxiety disorders. This is severe mental health that's taken from the K-6, agoraphobia, depression and impairment is way up here. Impairment is an overall assessment of a person's well-being and functionality that Dr. Brackbill had earlier referred to. So this not only is something to worry about who's got PTSD but the PTSD is actually going along with these other elevated problems. And here in number 3, if you look, this is the group that's called 'Remission.' Right? But they may be remitting as PTSD, but what you see are these very elevated rates of agoraphobia, impairment, and depression. So what is happening to the symptomatology of these groups or these individuals who, in fact, exhibit one set of symptoms at Time 1 or Time 2, and then Time 3 they're very different? So

that's the reason you need to follow people because it gets expressed differently over time and, of course, here's the trajectory 4. Can you see that? I can't see it. Anyway, it's what we called the 'Chronic Mild' and they're all also elevated.

So this is the stress and well-being study. Again, Dr. Brackbill referred to the study that we were doing in collaboration with the Registry. Here what we have done and what we continue to do is to attempt to take a random selection of 1,000 of the people who were under 18 at the time of 9/11, and we have been doing in depth assessments in their homes with the person and their parent, if possible. And, again, you can see here there's panic disorder and adjusted odds of 14. Separation, 6. Now, these are older people. You don't expect to have these kind of rates for separation. And there's the agoraphobia again. Here is the comorbid physical problems and the internalizing psychiatric problems, and it's twice what you we find in the controls.

There's another study that we have, a small study called the… we call it 'The Context Study.' It's also ongoing. It was just recently funded. Here what we asked to do having learned all these lessons was to go back and take the school study and see if we could actually make some sense out of why there were differences throughout the city and within different populations. So here you can see out of those 8,236, you can see among blacks, Hispanics, Asian, and mixed race and whites, you can see the differences in these different disorders. And, of course, they are all—although you see some significant differences between the groups, when it gets down to here having any anxiety disorder or any anxiety disorder plus depression. There aren't such great differences. But we're now in the process of doing neighborhood analyses and family analyses to see if we can sort out some of these differences because what it would tell us is which of these groups is particularly at elevated risk that we could think about what we could do about it. And here is a, I think, very interesting look at, again, the data from the school study, which we're just analyzing now thanks to funding from NIOSH. It's allowing us to actually understand some really interesting findings having to do with all of these symptoms. Now all of these symptoms are grouped. Here's PTSD, here's agoraphobia, separation anxiety, panic disorder, generalized anxiety, mood disorder, and conduct disorder. What you can see here is that there are people who stay at this very elevated rate. This was based externalizing symptoms and internalizing… externalizing and internalizing symptoms and looking at the comorbidity essentially across these symptoms. Here, again, are these different groups and how they play out over time. So it tells us something very interesting about these two lines here, this black and this red line particularly, it's something that we had not anticipated and did not really appreciate this level of comorbidity.

So moving forward I think the well-being through the life course in persons directly and indirectly exposed to 9/11 as children need to be studied. We now are more

concerned here with the life course and the well-being. As you can see we've added context to this. We now know a lot about exposure and you can't keep asking about exposure, you know, people forget over time what actually happened, but I think we know a lot from different samples. The Registry has asked about it repeatedly. We've asked it in all of our studies. We now have actually examined, as we always do, the parents' psychopathology in the home environment, and we're trying to understand that more in terms of the life course well-being.

So one of the questions was, where do you go from here? So I took it upon myself to draw up a few lists and one of them is who I think you should study, and that is the children who were directly exposed on 9/11, children whose parents were exposed on 9/11 which we called a 'take home exposure,' and that included evacuees, first responders, residents, and non-traditional WTC rescue and recovery workers, family members of children who were identified above and matched controls for all samples. So you really understand… you can make the kind of comparisons that you need to make.

What to study? For me, I know Dr. Landrigan would have a different list here, but for me it's the psychosocial well-being and I think Dr. Brackbill just said that based on their experience with the Registry it is in fact the mental health sequela to 9/11 that's probably going to have the most detrimental effect in people's lives long-term. So these, again, are based on our experience internalizing, externalizing disorder, substance use, comorbidities including the physical health comorbidities, suicidal behaviors. I mean, this is a population I do a lot of work in suicide and I can tell you this is a group that is at risk for suicidal behaviors. Functional impairment, you know how people do. You cannot have cancer, you cannot have depression, but your functioning is very much impaired, and we've saw that in those last few slides there where we saw elevated impairment, social impairment. Do people get married? Do they not get married? Do they get married seven times? What are they doing? What about education? Are they going to school later? We have some insights into that already, but it's a little premature for me to talk about it, but when people go to school, do they go to school? Do they go to graduate school, etc.? And all of that, of course, feeds into occupational attainment. Are people actually developing the kind of job skills and occupational lifestyle that they're capable of and want to pursue that are maybe too preoccupied with things related directly or indirectly with the 9/11? And the other is cumulative risk because we also know from PTSD, particularly, cumulative risk is critical for once you have a major exposure your likelihood of having a negative response to another exposure is dramatically increased. And then, of course, the living environment.

My slide is here, is how to study it? I would strongly endorse taking a life course perspective. Obviously, longitudinal represented in sampling is always critical.

And to think about comprehensive bio-psycho-social approach, which includes all of these things I've listed here some of which have been done and some of which have not yet been done, and I would advocate for their being done. And here because no one has been doing imaging, for example, and there has been no genetic work yet done in the child population I would suggest these four studies here would be particularly important using imaging genetics and epigenetics based on all of the data that I presented to you. Thank you very much.

DR. WARD: Thank you very much. I think it's time for us to take a break, ten-minute break.

[Break.]

PUBLIC COMMENTS

DR. MIDDENDORF: [I'd like] to get started again, and I just want to point out that we are at the time where we have to do public comments. It's one of the FACA rules that when you announce—publish the time for public comments you actually have to do them at that time. It's not one of the things that we can juggle. So, Dr. Beebe, we're going to have to wait a few minutes until after the public comments before we get to your presentation.

So, okay, Catherine was out in the hall. I'm just looking to see if we've got all our members here. We need Bill Rom and Catherine back. Tom, are you on the line? Tom Aldrich are you back?

DR. ALDRICH: Yes, I'm on the line.

DR. MIDDENDORF: Okay, great. Thank you. Let me go run and get the other two committee members.

[Moment of silence.]

DR. MIDDENDORF: Okay. We have all the committee members back. So we're going to do the public comment period now. And each of our public commenters has signed up on a first come, first serve basis and each of them will have up to five minutes to present. I want to point out that you have the option of submitting written comments to the docket to this committee. The docket number is 248C. Information on how to submit the comments will be found on the NIOSH docket webpage. I do want to make sure that the commenters are aware of the redaction policy before their comments. The policy is in the federal Registry notice for this meeting and on the committee's webpage. The policy outlines what information will be kept and what information will redacted before it's posted to the docket. So our first commenter is Kimberly Flynn.

MS. FLYNN: Thank you very much for the opportunity to give these comments which are on behalf of the World Trade Center Survivor Steering Committee which I chair. Although children are especially susceptible to harm from environment exposures 14 years after 9/11 we still know very little about the physical health effects of the World Trade Center disaster on the more than 30,000 children living or attending school or daycare in the New York City disaster area. While there is a substantial literature regarding World Trade Center related mental health impacts to children,

there is a paucity of research on physical health impacts or comorbid physical and mental health problems. SSC has urged NIOSH to move quickly to fill these major knowledge gaps by supporting a portfolio of studies that would investigate a range of biologically plausible health effects. And, of course, we continue to support the mental health studies as well.

The SSC's recommendations for the approach to WTC pediatric research going forward are: research into multi-system impacts. We believe that research should not only deepen the understanding of WTC respiratory illness but also examine a range of WTC physical health effects especially cardio, metabolic, endocrine, neurodevelopmental autoimmune, and cancer impacts.

Two, clinical, physical health studies, in depth clinical studies, and studies examining physiological mechanisms are needed. Moreover, some health impacts are subtle and subclinical, and may only be detected through clinical examination.

Three, developmental and longitudinal approach. And this has been remarked on multiple times and we'll reinforce that. Research, both physical and psychological should be grounded in an understanding of critical windows of development and developmental stages, and should ideally follow exposed children over the lifespan.

Blood banking. Blood banking from which DNA, RNA, and proteins can be recovered should be done for WTC affected children and should include freezing life cells. This is a resource that will yield many answers going forward, but we feel it's critical and it has to go forward now.

Biomarkers. Research should look for exposure biomarkers for substances that are persistent, obviously, and bioaccumulative and explore exposure illness relationships.

Early detection. This is a real priority for the SSC. Studies that enhance the ability to monitor health risk and that whole promise for informing early intervention to prevent disease or more severe disease both physical and psychological should have priority. In order to ensure that pediatric studies are fairly reviewed we urge NIOSH—we've actually asked for this before and we think it's now become very apparent that we need to get a separate World Trade Center pediatric study section with appropriate pediatric expertise. In addition, RFPs and the proposal review process should be informed by the understanding that 9/11 related health impacts were the result of disaster with all the complexity and uncertainty disaster ushers in. Reviewers must, therefore, take into account that much of WTC research is disaster science where a standardized body of preexisting medical data for study subjects does not exist. In addition, the absence of reliable and comprehensive environmental measurements makes quantifying exposures impossible. Now that doesn't mean that you can't characterize exposures at all and that you can't query exposures, and I know that

the researchers are doing that with questionnaires, but, again, the data set just isn't there. It is critical that these and other limitations in available data deriving from the unique nature of the WTC disaster or the negligence of the Environmental Protection Agency and other agencies not be allowed to become insurmountable barriers to enabling the research necessary for understanding and addressing the 9/11 health needs of those exposed children.

Finally, is the cohort question which we think is something very important for this committee to address and weigh in on? It is urgently necessary for NIOSH to work out strategies for ensuring access to a cohort for future studies. We have the following concerns and recommendations with respect to the vanishing pediatric cohort and the viability of subject recruitment efforts going forward.

First, the World Trade Center Health Registry Pediatric Cohort includes only some 3,000 people exposed as children. Given diminishing participation what can the Registry do to ensure the availability of this population for future research? Can the Registry address the issue of the importance of longitudinal research in the course of its communications to enrollees including its contact tracing efforts? Will the Registry commit to playing a long-term role in recruitment efforts for NIOSH-funded pediatric studies including studies by external experts?

Two, to quote—and this is the diversity issue—Heather Lipkind from a 2010 study supported by the Registry, 'The Registry is composed of a highly affluent population. Given the well-established salutary effect of affluence on children's health it is essential that all studies, including this cohort, address the demographics of household income and education level as well as those of race, ethnicity, age, and gender. Is the Registry cohort representative of the affected population of children? Biases should be addressed as study limitations in publications.'

Finally, are there ways—and we know we've heard from Dr. Hoven how difficult it can be to approach the board of ed., but nonetheless are there ways to supplement the Registry subject pulled by considering other sources of subjects drawn from the population deemed by the Zadroga Act to be de facto exposed? Is there a way to reach this population 14 years later? Are there research strategies that could adjust for the lack of Registry baseline survey data in non-Registry subjects? We just want to say, again, we believe that mental health impacts are very, very important to study, but we believe that studying physical health impacts is equally important and, frankly, we don't have the answers because we didn't have the studies. So in order to get those answers we need those studies and just to restate that this is a major priority for the Survivor Steering Committee and the communities of affected parents and children we represent. Thank you.

DR. MIDDENDORF: Thank you very much, Kimberly. Our next commenter is Rachel Lidown, Lidov?

PARTICIPANT: Rachel Lidov.

DR. MIDDENDORF: Lidov?
MS. NORDSTROM: Is she on the phone?
PARTICIPANT: She's on the phone. How are you going to…?
DR. MIDDENDORF: We can come back to her. Jo Polett…
PARTICIPANT: No, no, no, I mean she's on this call, but I don't know that she hears us.
DR. MIDDENDORF: Oh, no, she wouldn't be able to call in.
PARTICIPANT: So no one can testify via the phone? Oh, we've got it back on now, I'm very sorry.
DR. MIDDENDORF: Yes, to do it by phone I would have needed to know ahead of time.
PARTICIPANT: Oh, I'm so sorry. All right, fine. Maybe she can email it and somebody else can do it. I'm very sorry.
DR. MIDDENDORF: Okay. So Rachel Lidov is not here?
PARTICIPANT: No.
DR. MIDDENDORF: Jo Polett?
MS. NORDSTROM: She's emailed her comments to a list that I'm on, if that helps. I don't know if on the committee I can do that.
DR. MIDDENDORF: No. Is there somebody else that would be able to do that, a public commenter rather than a committee member?
MS. NORDSTROM: I mean, I don't know if anyone else on the list is actually present, but someone can take my phone.
DR. MIDDENDORF: Yes, could they do that?
MS. NORDSTROM: Yes, to read Rachel Lidov's comments publically.
DR. MIDDENDORF: Sure.
MS. POLETT: And then I can ask my one or two questions? Now I'm Rachel, and then I'll me later?
DR. MIDDENDORF: Okay.
MS. POLETT: Yes. I'm speaking for Rachel Lidov.
DR. MIDDENDORF: Okay. Please speak in the microphone.
MS. POLETT: Oh, okay. I'm speaking for Rachel Lidov and I'm speaking as a member of CSC on behalf of the over 20,000 students attending school in Lower Manhattan who were exposed over a long period to the dust and debris from the fall of the WTC Towers in 2001. Because the EPA and the New York City Health Department denied the health risks of these exposures most of these children and young adults did not participate in the World Trade Center Health Registry. It is now 14 years later and we still have no real answers on the physical health impacts to these exposures. And now I need a little technical assistance to make this thing scroll down.

[Technical assistance.]

MS. POLETT: Preliminary surveys NIOSH Stuy PA, Stuy Parents Association of students at Stuy and teachers at Stuy indicated that there were health effects. It would be foolish to assume that more serious findings are not going to emerge and irresponsible to take no action to reduce the impacts on this population. There can be no

question about the impact on younger children. Dr. Leo Trasande has had the opportunity to begin to demonstrate that there are respiratory and cardiovascular health problems arising from the WTC debris exposures. In order for these studies approved in 2013 and 2015 to be useful to the exposed children and young adults they must be extended over their lifetimes and expanded to include children who may not have been captured in the health Registry. At the very least in this day and age the technological tools exist to find and recruit young people who are or had been in Lower Manhattan and even western Brooklyn in the first years of the century to bank blood for further RNA and DNA research. Thank you for giving me the opportunity to provide these comments.

DR. MIDDENDORF: Okay. Thank you very much for reading that for us. And then you would like to go ahead and make your comments too?

MS. POLETT: Yes. I really just have…

PARTICIPANT: Can you talk into the mic, please?

DR. MIDDENDORF: Yes, talk into the mic, please.

MS. POLETT: Yes. I really have two questions. One, I'd like to hear a little more discussion on the panel later about which substances children are uniquely vulnerable to and which substance will have different health effects in children than they do in adults, and beyond that I appreciate Dr. Landrigan's instructions/warning that we have to study these children and we have to keep our eyes open because, I mean, it was an unprecedented mix of exposures and we don't know what we're going to see.

And then here's a question and that is, will the fact that dust cloud exposed children were most likely to be diagnosed with new onset asthma and other respiratory illnesses hold true for all other illnesses that may emerge? I mean, so far for the illnesses that have emerged across the cohorts dust cloud exposure is considered to be the heaviest exposure. And there's dose-response to that, but when I think about it and I don't know enough to think about it, and some of you on the panel do, but what I come up with is that dust cloud exposure was heavily the concrete and may have been proportionately less of the organic compounds that were borne on the smoke and to which resident children who reoccupied their homes were exposed for like six months after. So I'm just concerned that the chronic exposures won't be looked at and further that the chronic exposures… children chronically exposed are underrepresented in the Registry for reasons that you've heard about before the outreach was targeted to people living below Chamber Street and who were in the dust cloud. And we don't know, I mean, Kimberly brought up the question of income. We're concerned that the people east of Broadway who did not evacuate for any length of time are seriously underrepresented in the Registry, and those are people who I hope you can find, and I'm done. It just, I guess, that's it. So, I mean… I'll pause here.

DR. MIDDENDORF: Okay. Thank you very much.

PARTICIPANT: Paul, I have Rachel Lidov's statement.
DR. MIDDENDORF: It was already read.
MS. NORDSTROM: Jo read it.
PARTICIPANT: You read it? I didn't know you had it… Rachel… okay, very good. Thank you.
MR. FLAMMIA: Can you spell the last name, please?
MS. NORDSTROM: Rachel?
MR. FLAMMIA: I believe they just spoke, please.
DR. MIDDENDORF: Jo Polett. It's P-O-L—
PARTICIPANT: E-T…
DR. MIDDENDORF: —E-T-T.
MR. FLAMMIA: Thank you.
DR. MIDDENDORF: Thank you very much to our public commenters. It's always important for us to hear from the affected community. It helps give some perspective for us.
DR. WARD: Yes. We've been talking together and are going to make just a couple of changes in the agenda if it's agreeable to the forthcoming speakers. One adjustment is Dr. Landrigan has to leave before the panel discussion, and so we did want to give him the opportunity to take questions and specifically I thought some of the questions that Jo just raised would be relevant for Dr. Landrigan. We do really want to engage Dr. Landrigan in further discussions, and so at the end of this meeting we'll discuss our next steps whether it be another meeting of the whole STAC by phone or the workgroup that volunteered to work on this. We'll figure out how to keep Dr. Landrigan engaged. By the same token Dr. Trasande has not been here for the morning presentations, but he will be joining us for the panel discussion. So there will be a little disconnect, but it's hard to get this many very busy people together for this length of time. The other thing is we're queued up to have a short research presentation by Dr. Beatrice Beebe from Columbia University right after Dr. Landrigan takes questions. She wasn't listed on the agenda because initially we thought in the interest of time we wouldn't have time for all the presentations, but we're going to try to get through all of them. So, Phil, if you want to come back, maybe if you want to start by addressing Jo's questions, and then we'll see if there are any other questions specifically for you.
DR. MIDDENDORF: Phil, you can either go to the podium or you can sit down here at one of the microphones. Whatever's most convenient for you.
DR. LANDRIGAN: I think this is easier. So, first of all, thank you for your forbearance. We have—I don't know if John Howard is here at the moment, but our big NIOSH training grant the competitor renewal of our NIOSH training grant is due tomorrow for the next five years. So there's a few details to be attended to. So I thought this discussion over the past two hours-two and a half hours has been very fruitful. There's several themes that come up. One is the sharp contrast between the extremely well-characterized, I'm sure there's lots more you could do, but still the extremely well-characterized mental health situation with regard to the children of

9/11. It contrasted with the relative dearth of information on physical health. A second theme is the lack of any information on gene environment interactions, although, that is a criticism that largely applies as well to the adult population where genetic studies really haven't been done to any great extent. So just looking at those absences of information and research opportunities and potential collaborations either within or across the various institutions that are represented here I think the very fact that you convene this meeting and brought people together from around New York and beyond to think systematically about children's health issues is very important. So thanks for that. So refresh my memory. What were the specific issues that you really wanted me to drill down on?

MS. McVAY-HUGHES: Which are the substances that children are uniquely vulnerable to and which are the ones that are different that children are exposed to versus adults.

DR. LANDRIGAN: Okay. So the first issue is what are the substances to which children are uniquely vulnerable? I don't like to end sentences with a preposition. I would say pretty much all of them. Any toxic airborne material has the potential to cause more injury to children than adults for several reasons. Children breathe more air per pound of body weight per day, as I said in my presentation earlier today, which means the pound for pound they take in more air and, therefore, more of any toxic material that's suspended in the air. Children's airways have a narrower diameter than adults, and so the potential for airway injury goes up. When it comes to substances that get into the bloodstream and have the potential to cause neurotoxic or other systemic injury for virtually any substance you name whether it's benzene, organophosphate materials that might have been presented down there, dioxin, will get into children's bodies in proportionally greater amounts, and given the combination of greater exposure, greater vulnerability and great or huge longevity there's the potential for more harm. Offsetting that, of course, is the fact that, by and large, with exceptions, but as a general rule the children were less heavily exposed than the workers. I know that there were some children who were very heavily exposed. I'm not discounting that, but in terms of population exposure apart from the kids who might have actually been caught in the cloud, I think the general tendency is for the children to have been less exposed than the adults. But when it comes to the kids who were caught in the cloud, and there must be ways to… you already have a listing of some of them, at least, right? Christina? So that's a group in whom everything that we've seen in the adults has a high likelihood of happening… or of going on being present right today.

MS. POLETT: I mean, can I just… the other part of that first issue was which substances would have different health effects in children than they do in young adults?

DR. LANDRIGAN: It's hard for me to think of any one of the chemicals on the list that we've seen this morning that has qualitatively different effects in children than adults. I mean, I know there are chemicals out there that have qualitatively different effects.

Diethylstilbestrol causes cancer in girls who were exposed in the womb but not in their mothers who took the drug. Thalidomide cause birth defects in babies who are exposed to the womb but had no physical effects on their mothers. Some exposures that take place during pregnancy, during windows of exquisite sensitivity when the wrong exposure to the wrong chemical at just the wrong moment can have qualitatively different outcomes. But, by and large, the differences are quantitative that children are more sensitive, they'll have adverse effects at lower levels, but generally speaking the effects are not different in kind than the effects you see in adults.

MS. POLETT: (Are you talking @ 00:26:30) about endocrine disrupting chemicals?

DR. LANDRIGAN: I mean, maybe. Endocrine disrupting chemicals can certainly have developmental effects if exposure occurs during very early development which mainly means the nine months of pregnancy the practical problem here is how in the world today 15 years after the fact do we know what level of phthalate or bisphenol A or some brominated compound a baby in the mother's womb might have been exposed to on September 11, 2001. I think it's an unknowable question. The only possible way, now that you got me thinking about that, the only possible technology that I can think of to potentially capture that exposure takes advantage of a new technology that a colleague of mine, Manish Arora, has developed at Mount Sinai. Manish is a young scientist who has double training in dentistry and environmental science. He joined our faculty about three years ago. We built him a big new lab up at Sinai. His particular expertise is that he can take deciduous teeth, the baby teeth that a child sheds in the first grade or the ones that they shed when they're 12 years old, the molars, and he has a laser-guided technology for measuring foreign chemicals in enamel. His technology takes advantage of the fact that the enamel in the teeth is laid down in layers like the rings of a tree, the teeth begin to be formed in or around the fourth, fifth month of pregnancy. There's a particular line which indicates the moment of birth. There's some kind of a particular marker line called the neonatal line in the tooth so that he can separate the rings of the tree that were deposited before birth and the rings that were deposited after birth. We know when September 11 occurred. You always know a child's birthday, that's readily available information. And you can put the two together using his technology. And it might theoretically be possible to reconstruct exposures in a subset of the 9/11 children. A lot of families hold on to a child's baby teeth, and you can recover them. All you need is one tooth per child. So that would be a thought.

MR. FLAMMIA: Excuse me, Doctor. What is the technology? What's the name of it?

DR. LANDRIGAN: It's a laser-guided gas chromatograph-mass spectroscopy on a microscale so that he can get down to pretty much a nominal ocular layer within the enamel. It's extraordinarily sophisticated.

DR. WARD: So, Bill, your question?

DR. ROM: Thank you. A couple questions related to the lung.

DR. LANDRIGAN: Which one?

DR. ROM: First of all… you know, both ones. First of all, the scientists at USC have published that when you're exposed to PM2.5 as a young adolescent in school and in the community you have reduced lung growth over, say, five years until you're an older adolescent. Would you think the same thing might occur from World Trade Center dust and are studies to address that in progress or potential? A second question is, is that on the World Trade Center Health Registry we've learned that asthma incidents will be increased and that there's a substantial portion difficult to treat asthma. Will these individuals be at risk for COPD in later or adult life? And are there studies following this cohort or are there potential studies that could follow that cohort to answer that question as well?

DR. LANDRIGAN: Okay, so with re—excuse me, with regard to the first question impaired lung growth in children who were exposed to the WTC dust, so far as I know nobody's looking in that unless Leo Trasande is, and you would probably know that better than I since he's in your group. But I think especially for the kids who are caught in the cloud it's a very real possibility that their lung growth would be impaired. If they were caught in the cloud they inhaled the high concentrations of material that we saw in workers. There's every reason to think that they'll have suffered some injury that may prevent them from attaining full lung growth. When does it max out? Around age 21, give or take, right? They may never attain what would've been their genetically endowed full lung growth, and that's clearly something and it could be studied. We have the tools to do that.

With regard to the second question, the asthma and COPD, I know that in the adult workers who have asthma that our colleague at Sinai Juan Wisnivesky, whom I suspect you know, has been looking at that or planning to look at it. I don't know if anybody's looking at that in children. I haven't heard unless Leo's doing it.

MS. NORDSTROM: So I had a question. You talked a little bit about taking cues in research from occupational health studies that have been done already, and I wonder if you see any risks of overlooking health risks for women specifically in doing that because a lot of the exposed populations have been studied and has been heavily skewed males, particularly like responders or sort of the heavily male and also specifically like an usually healthy population to begin with, so do you see any risk in sort of overlooking some risks for other kinds of people that might emerge?

DR. LANDRIGAN: Yes. So with regard to women's health up at Sinai we're following 20,000 people, I think 21,000 of first responders, adults. Eighty percent are men because that was the nature of the workforce who was there, but that still leaves 20% women. So it's 20% of 20,000 which means it's a cohort of roughly 4,000 women whom we're following, and then when you add the women that are being followed by our compatriots at Stony Brook, North Shore-LIJ, Rutgers, and Bellevue the total

number of women in the responder cohorts in the neighborhood of approximately 5,000. So it's a big women's cohort. I think in the FDNY cohort that David Prezant is following it's relatively sparse because there are relatively few women in the fire service. But we've got 5,000 women on long-term follow-up, and certainly all of our studies, pulmonary, mental health, GERD, and everything else have looked equally at men and women. One of my colleagues, Susan Teitelbaum, who's an epidemiologist at Sinai, trained at Columbia, actually put in a proposal a couple of years ago through the Zadroga RFP process to look specifically at women's health and it came close, but did not get funded. It was not considered a priority, apparently.

DR. WARD: Yes, Catherine.

MS. McVAY-HUGHES: Yes, I just want to remind people as a resident of… I don't know how many of the people around this table or in the audience remember what it was like after 9/11 and one week later, then a month later, then two months later, so next to Stuyvesant High School was where the garbage barge was, and that's where everything… or a lot of the World Trade Center was removed. So where the ball fields are today that's where the EPA cleaning area was and right next to that is where 89's located. Clean-up, it wasn't like it was a magic wand that's suddenly on 9/12 the external… exterior or internal dust inside hundreds of skyscrapers were cleaned up. In fact, it took months, if not years, to get a lot of it cleaned up. So there was that ongoing exposure. I just remember how exteriors of buildings would be hosed down, and I don't think… and I remember being dripped on, you know, a couple months later. I remember looking outside of my apartment building and thinking, huh, it didn't snow. Oh, yes, that's the World Trade Center dust that's still on the roofs and tops of those shorter buildings than the building I live in. So I just wanted to follow up on this whole chronic exposures of people who live and work in the neighborhood, that it's not all about the dust cloud. And then you had demolition of buildings, and then even as late as, even though the fires were officially declared out—conveniently before the shopping holidays on December 19—there were still flare-ups like a coal fire on St. Patrick's Day in 2002. I could see it from my apartment. So I just wanted to put that in the record about the chronic ongoing exposure. And it was only recently that our local Council Member Chin applied funding to replace the seats in the auditorium at Stuyvesant High School and kids, my kids, went back to playing basketball at PS 89. So I just want to make sure that's in the record. And soccer, that was an important event to get the community to rally back together as well. Do you have a comment on this chronic exposure?

DR. LANDRIGAN: Yes. It's real. Absolutely. Yes. I mean, you described it far better than I could.

MR. FLAMMIA: Doctor, you had mentioned before about the baby boys exposed in the womb. Was there any studies done with females and/or responders that they brought home the dust to the family?

DR. LANDRIGAN: Not to my knowledge. I think it's a group that could be looked at. Yes.

MR. FLAMMIA: Thank you.

DR. WARD: So in the interest of time we're only going to take one more question, and then that'll be that.

MS. JONES: My question is basically about poverty. One of the things that recently came out is the community profiles and the Lower East Side in Chinatown area one of the things they noted is the fact that poorly maintained apartments, etc., have an impact especially on respiratory illnesses such as asthma. And one of the things that I remember because I am a resident of the Lower East Side and have relatives that are residents of the Lower East Side is I have some relatives that live in the Smith Houses which is about on Pearl Street, and I don't remember anybody coming and cleaning the apartments when it was over. So my question is, are we looking at that kind of thing? Are we studying that type of thing, the effects of…? I mean, right now New York City Housing Authority is saying they're having a hard time putting locks on doors let alone cleaning apartments. So my question is, are we going to look at that type of situation, the impact of, say, those people? Because I have relatives that their children… this is what got me involved. Their children had a hard time breathing and they live right there on Pearl Street which was not that many blocks away. And when I look at how they have looked at the community because of the way the community is shaped or the streets are done it's hard for me to tell if, say, the Smith Houses are included because in some ways it's not below Canal, it's not below Chambers. It's like east of these particular places. So my question is, are we looking at that type of situation? Because I know that they were definitely affected. I don't know if there was a dust cloud there, but I know that the dust in the apartments I think was a little tremendous especially, you know… so that's my question. Are we looking at that kind of a situation?

DR. LANDRIGAN: Yes. That's an important question. I'd have to really turn that one over to my colleagues in the Registry because it's the Registry that define the geography of what neighborhoods are included and not included. That's not the piece of it that I've been doing.

MS. JONES: But are you looking at income, poverty, housing situations, the fact that some areas were not dealt with the same as other areas. Some areas I remember hearing that some areas there were professional people that came in and cleaned whereas I don't remember anybody in Smith Houses telling me that somebody came and the cleaned the apartments at all, of those.

DR. LANDRIGAN: Yes. No, I mean, as somebody who's practiced pediatrics most of his adult life I've never seen a disease that poverty made better. I mean, poverty makes anything worse for all kinds of reasons. It increases exposure. It reduces access to medical care. It reduces access to services like cleaning services. There's always this noxious, terrible, negative interaction between poverty and pretty

much any environmental exposure, any human disease that you can imagine. But whether Smith Houses is included in the Registry you'd have to ask the Registry people.

DR. WARD: Yes, and I would suggest we do that during the panel discussion so that we can have both of our presenters finished before lunch. I thank Dr. Landrigan for coming today, and I hope that we can engage him further.

DR. LANDRIGAN: Thank you, Liz.

MS. POLETT: (Inaudible @ 41:14) asking my second question for Dr. Landrigan?

DR. WARD: Okay, but let's try to keep it brief.

DR. MIDDENDORF: And, if you would, come to the microphone and restate it so that they can hear it for the transcript.

MS. POLETT: Okay. My question, it's an exposure question. I just want you to think about whether the fact… the question is, will the fact that dust clouds exposed children when most likely to be diagnosed with respiratory illnesses hold true for all other illnesses that may emerge? I'm thinking about the dust cloud had this high proportion of concrete dust and maybe a much less proportion of the organic compounds to which children were exposed, children who re-inhabited the homes or who never left were exposed in the weeks and months that followed from re-suspended dust in their homes and from the smoke from the fires that kept infiltrating our homes.

DR. LANDRIGAN: So to answer that one a clear principle that's emerged from all the studies that we've seen, the studies of adults that we've done, the studies of firefighters that Trasande has done, the study of children's mental health that Dr. Hoven as done, in every one of these studies without exception there's a dose-response relationship with the most heavily exposed people being the most severely affected by any measure you choose to look at. And in that gradient of exposure time and again we've seen that people who are caught in the cloud are the most heavily exposed and the most severely expected. So I think as a general principle thinking about children's health, I think the children who were caught in the cloud would be the ones at greatest risk. Now, is it possible that there's going to be exceptions to that because of different distribution of different… particular environmental exposures? Yes, it's possible, and that's why I said at the beginning that any study that's done the investigative team that does it has to do it eyes wide open looking for the unexpected. But the general rule is heavier exposure produces more disease, worst disease, sooner disease.

MS. POLETT: I mean, I guess, I don't quite know what else (inaudible @ 00:43:53) it's twofold for me.

DR. MIDDENDORF: Jo, if you would please, come to the microphone so that we can get the question.

MS. POLETT: It's twofold. I mean, we're looking at the illnesses that have manifested today. It's clear that dust cloud exposure is the most potent cause of those illnesses, but what about illnesses that may manifest later? And then, I guess, I just want some

consideration of like the proportion of the different substances that were in the dust cloud, and then what came later on the smoke and look at the endpoints of those substances and maybe have some…

DR. LANDRIGAN: It's a reasonable point. The average exposure is clearly greater for people that were caught in the dust cloud, but there's a lot of variation around that average and there can be pockets of people, children who had unique exposures to put them at particular risk. I think anybody doing an epidemiologic study is always on the lookout for groups or subgroups of people within a population who may have had different exposures and who are at different risks. Any study of any exposed population is full of those kind of anomalies and smart epidemiologists pick up on them and recognize them for what they are, and it's often an important clue as to causation. I can think of a few examples which would take too long to recount here, but exposure is not uniform along a gradient. The exposure response gradient is an averaging trend with a lot of variation around the average.

DR. WARD: And I think, Jo, your point is being heard by the committee as well. So I don't think that there's a point in protracting this conversation, but I certainly think that it is an important point and we talked in the committee before about this scenario of, say, a toddler living in a contaminated apartment where there may be chronic exposures that cumulatively would be as significant as the exposure to the dust cloud. I think with the outcomes that have been studied the most, the respiratory disease and the mental health, the dust cloud is a surrogate. It's in a way a… I mean, it's a direct exposure, but it's also a surrogate for proximity to the event. But in some of the kids—some of the populations of kids we may be looking at very different effects that have to do with chronic exposures to lower levels. And I think the committee has that. Yes.

DR. LANDRIGAN: Yes. Has that. Right, thank you.

DR. WARD: Thank you.

MR. FARFEL: (Inaudible @ 00:47:11)

DR. MIDDENDORF: Come to a microphone.

DR. WARD: Microphone. Yes.

DR. FARFEL: Vaylateena, you asked about the Smith Houses. I just want to make sure I heard you correctly.

MS. JONES: Yes.

DR. FARFEL: You did ask about the Smith Houses. Yes. And I thought I heard you ask if the Registry has enrollees who live in the Smith Houses and the answer to that question is yes. And, as a matter of fact, in the various survey waves that Robert Brackbill talked about we've had outreach, door to door outreach to try to encourage people to fill out the Registry survey. So actually we have an outreach effort now in Lower Manhattan that does include the Smith Houses. We did that at Wave 2 and again at Wave 3 as well. Also you had asked do we have information about the home and the dust, and damage. I wanted to let you know

in the Wave 2 survey—Robert, correct me if I'm wrong—we had a module for residents where we asked a series of questions about was your home damaged and extent of the damage, and how much dust, like visible dust was noticed in the apartment. Was it a thin layer or a thicker layer of dust? So we had that type of information as well as the home damage. The Registry also conducted a more detailed study in collaboration with NYU Bellevue of people who had persistent respiratory symptoms, and it was a study of adults. But the questionnaire that went with that study got into a lot more detail, and I believe there's input from Jo and Kimberly, and others about the kinds of questions to ask there about the home exposures and the dust.

DR. MIDDENDORF: For the record that was Mark Farfel from the World Trade Center Health Registry.

DR. HOVEN: I just want to respond to your question about do we know anything about the first responders bringing home the dust and so forth. The first responder and evacuee study that I spoke about was taken from the Registry. We looked at their children, but we also assessed, in most cases, both parents because we like to interview the mother about the child, but in this case we wanted to interview the evacuee and the first responder which tended to be men. And so we have that information and we have all of the Registry information about the parents' exposure and what they brought home. We asked them those questions. So for that sample of children we do know what the first responders brought into the house. It's a small sample. It's not the Registry sample, but we do have detailed information.

DR. FARFEL: That's a psychological assessment only?

DR. HOVEN: No. We ask lots of questions about people's behaviors and well-being and you name it. I mean, we interview people for four hours. So we ask them a lot of questions.

MR. FLAMMIA: I think Dr. Landrigan's study basically articulated some other… different types of cognitive impairments and other things specifically with the baby boys as well. So I was looking for a physical aspect.

DR. HOVEN: Yes. We do ask about those physical questions.

DR. WARD: Let's hold this discussion because I really want to give Dr. Beebe and Dr. Szema a chance to talk. So let's hear from Dr. Beebe, and then we'll finish the presentations before lunch, and then we'll have one more presentation, and then the panel discussion. So let's move on. Okay. Thank you.

DR. BEEBE: Thank you very much for the opportunity to present here. Is this the right microphone or is this the right microphone? This one? The one I have here? Oh, both. You need both. Okay. So the particular group that I was interested in were the mothers who were pregnant and widowed on 9/11, and there were evidently 103. Not all of them lived in New York, of course, right? Some of the planes came from Boston, some were going to L.A. And I have yet to get an accurate estimate of exactly how many of those mothers were in New York. So, let's see. How does this work?

[Technical assistance.]

DR. BEEBE: So as you heard in many different ways children are the most vulnerable to the effects of trauma. It doesn't only impact the child directly, it impacts the child and the way the parent-child dyad operates. We have had relatively little research on the effects of trauma on infants and children until recently, particularly the work of Christina Hoven. But young children are underrepresented both in research, on reactions to trauma and planning for treatment. The young children that I was concerned with were babies who were in the womb on 9/11 and the siblings of those children.

So this is a called a 'Primary Prevention Project.' I don't know if you can see that in there, Primary Prevention Project. That was our goal, to find the mothers who were pregnant, widowed, their infants and their young children, and see if we could try and prevent difficulties. This was a clinical project. It was not a research project. We wanted to help the mothers mourn and provide a place where they could be heard. It's very interesting. But many of the mothers said things to us like, 'You can't help us. Our families can't help us. Our friends can't help us. No one can help us. I can't afford to think about it.' We found about 40 families and we followed approximately 30 of them, and this was a pro bono project. So this is not a research evaluation but this is one mother's experience of how the project helped her. So what we did is we did a video consultation where we videotaped the mother-child interaction. One camera in the mother's face, one camera in the baby's face. So it's a split screen so you can actually see the interaction. And then we discussed these videotapes with the mothers in the context of also discussing their own experiences on 9/11. This is the kinds of things that they wrote us. 'I learned to step back and let go a bit, and let him drive the bus, and my desire to protect and be everything for him I was trying too hard. Now it's much more organic.'

So now we have some preliminary research on how did the 9/11 trauma affect these mothers and babies by the time the babies were four months compared to our community sample. But just to step back a kind of research that informed our project has to do with the nature of mother-infant face to face communication. Babies at four months are very sociable and very interactive. Four months is a very fascinating time to study because the ability for face to face communication flowers at around that age, and you can predict infant development from the way that communication goes. So that face to face communication not only is it relevant to how the social brain is maturing but it sensitizes the baby to the temporal, emotional residence underlying all human relationships and it predicts attachment, cognition, physiological and emotional regulation, empathy in young adulthood.

At one year we assessed the security of the baby's attachment, and one year attachment predicts across the lifespan many different things including

psychopathology and adolescent development and dissociative symptoms. So this is some work of basic research showing how four-month communication predicts attachment. And this is another one. We use that research to inform what we were doing. Now this is a book that's coming out that shows exactly drawings of mother-infant interaction. I'm going to show you some of those to illustrate. Here's a secure interaction where the mother and the baby—they were all asked, 'Play with your baby as you would at home,' and you can see how mother and the baby are sort of delighted with each other. This is the second by second microanalysis. And here's another mother who is… this baby's going to end up secure. When her baby looks away from her, she lets the baby look away and she doesn't pursue him and she doesn't chase him. She just calms herself down and waits patiently for him. And then five seconds later he comes back to her. This is another mother—these are not 9/11 mothers, right, these are from basic research. This is a mother who has difficulty tolerating letting the baby take a break. It's very important to let a baby take a break because that's when they can reregulate their arousal. And she goes after him and chases him, as you can see. This baby ends up insecurely attached at a year.

So we looked at face-based communication in a preliminary study. This is not a published study. We found something very interesting. In some kinds of insecure attachments the mothers intrude. That's not particularly what these mothers did. And other kinds, for example, associated with depression the mothers withdraw. That's not what these mothers did. What these mothers did was something I haven't seen before. I call it 'Escalated Attempts to Engage.' I ended up talking about it as visual, vigilance, hyper-responsivity, urgent repair. So we've got findings such as the idea that when either the mother or the baby looked away they were more likely to come back to looking at the partner and the next second… the babies even twice as likely as my community sample. So there's no way to really take a visual break and reregulate your arousal. If the mother was touching the baby more positively these 9/11 babies were much more likely to look at their mothers in the next second which we call that a heightened responsiveness. If the babies became vocally upset the babies were much more likely to repair in the next second and become positive. So the babies themselves didn't tolerate staying distressed as sort of like 'I can't communicate my distress,' like 'I better not be distressed.' And if the mothers happened to have a more negative touch they were more likely to repair it in the next second. There's no room for the mother to have a more negative touch. So this urgent repair suggests an intense need for the partner with both risk and resilience implications. So the question for us now is what we're interested in is following these babies up into adolescence and how are they doing now. They're approximately 14 months [sic] old and they're siblings are high school or college. What we're interested in is, well, what was the role of that early mother and the communication, and infant

attachment in predicting how these babies are doing now, their quality of life, their social adjustment or their attachment, and what is the mother's own adjustment as the children reach adolescence and how is that affecting us? So that would help us understand the roots of social adaptation both strengths and difficulties in this strong ties group. We're very interested in this other potential control group that you mentioned about mothers who are pregnant on 9/11 but not widowed. That might be very interesting control group for this group, trying to think about what would need good control groups to compare these babies to. We do hypothesize that they will have difficulties, perhaps separation difficulties. Yes. So we need some research clarifying the effects of 9/11 trauma on the adolescent adaptation of these children of the mothers who were pregnant and widowed on 9/11. Thank you.

DR. WARD: Thank you.

DR. WARD: And now Dr. Szema.

OVERVIEW OF WTC RESPIRATORY HEALTH RESEARCH AND PERSPECTIVES ON THE CHARGE

DR. SZEMA: Thanks, Dr. Middendorf and the staff, for the opportunity to participate in today's discussions. By way of background I'm going to show a video of what kids in Chinatown experienced on 9/11. These are kids within Community Board 1.

[Video plays.]

DR. SZEMA: My new affiliations are with Hofstra North Shore-LIJ School of Medicine, Hofstra University, and the College of Engineering and Applied Sciences at Stony Brook. For the first study we were concerned about the plume in Chinatown. This is a satellite photograph of New York City. You can see in the upper left hand corner is Central Park, south is World Trade Center Towers. This plume is heading southeast directly into Chinatown on September 11th, 2001. This has been reiterated all morning that dust could have affected people individually depending on where they were located. And there were a variety of chemicals that were detected by Paul Lioy's group as in the bolt vest, mask including asbestos carcinogens, jet fuel as well as construction materials which maybe irritants because they're rich in calcium and affect the upper airways. Yet, there were also other gases and chemicals were detected as well, and these are all sources of lung injury.

The reason we were interested in the kids in Chinatown was that in the year before the kids in Manhattan who were ethnically Chinese in the 2000 United States Census actually had the very lowest rates of asthma in the entire city. If you can see here non-Hispanic whites were 11%, Puerto Ricans 28%, other Hispanics 16% whereas the Chinese were 6.8%. And we anecdotally were hearing reports that kids were coming in with new onset of asthma or worse asthma immediately after 9/11.

So our hypotheses were, number one, pediatric asthma patients exposed to the World Trade Center disaster may experience increased asthma severity. Number

two, some previously healthy children, may be newly diagnosed with asthma after September 11th, 2001.

Our study population comprised Chinese-American pediatric asthmatic patients who live in New York City. They received medical care at the Charles B. Wang Community Health Center which is located in Lower Manhattan's Chinatown which is approximately 1.5 miles from the World Trade Center. In this map you can see the World Trade Center on the lower left circle and the closest border of Chinatown is only blocks away from the World Trade Center. The star is the location of the Charles B. Wang Community Health Center.

So eligible subjects included patients younger than 18 years of age as of September 11th, 2001, who had established asthma and were already enrolled in an asthma Registry at the Charles B. Wang Community Health Center which was started in 2000. All patients included in the study were given diagnoses of asthma by a pediatric allergist. Patients younger than six years of age were given a diagnosis of asthma if they had two or more episodes of wheezing or coughing within a 12-month period and symptoms improved after asthma medication in the clinic. For the older children older than six years, they were given a diagnoses of asthma if they had wheezing, cough, or dyspnea, which is shortness of breath, on at least two occasions, and symptoms. Physical exam size and peak expiratory flow rates measured the speed of air leaving the lungs which improved after bronchodilator therapy or inhaler use. We only included subjects who had at least ten of the eleven study variables which included one… at least one clinic visit for asthma between September 11th, 2000 and September 10th, 2001, and at least one clinic visit between September 11th, 2001 and September 10th, 2002.

This was a retrospective chart review. There were 205 pediatric patients with established asthma from this clinic in Lower Manhattan's Chinatown. Clinical data were obtained for the year before and the year after September 11th, 2001. We used seven physicians. These were all allergy fellows trained in internal medicine or pediatrics, and they reviewed 319 patient charts from this established asthma Registry. Two hundred and five patients met the inclusion criteria. Data were extracted onto standardized study forms, and then entered into our study database.

Among the ten variables included number of visits to the MD for asthma, number of asthma medication prescriptions, use of corticosteroids, number of weekly doses of rescue inhaler, peak expiratory flow rates, age, height, and weight, which were measured three months pre-9/11 and post-9/11, as well as gender. We also included residential zip code and the MDs were blinded to the residential location of the children. We looked at peak expiratory flow rates in liters per minute. And the best value of three trials per visit was recorded at each doctor's visit. These peak expiratory flow rates were obtained from all patients who were able to consistently perform the maneuver.

The demographic characteristics indicated an average age of eight years. It was skewed to 65% male. The heights increased after 9/11. The weights before and after 9/11 indicate in this largely first generation Chinese-American population they're already acculturated and they're obese. We broke up the regions into Region 1 for kids living within five miles of the World Trade Center as well as Region 2 greater than five miles away. And as you can see in the next slide that these groups are matched in terms of age, gender, height, and weight.

What happened in terms of data? The asthma clinic visits and asthma prescriptions increased after 9/11. In this map you can see the twin towers on the left. The blue star is the Charles B. Wang Community Health Center. All the zip codes in red are zip codes within five miles of Ground Zero where these children lived. All the zip codes in tan are zip codes of these other children who also attended the same clinic but lived further away in zip codes more than five miles away.

The number of clinic visits in this diagram in Region 1 was statistically significant for increasing in Region 1 less than five miles away. So there were more asthma visits for children who lived within five miles of Ground Zero. In addition, in Region 1 asthma prescriptions increased and rescue inhaler doses per week was borderline clinically significant, statistically. So there were more asthma visits for children living within five miles of Ground Zero. The number of children with asthma also increased. So new diagnoses increased 66% in that year and pediatric asthma visits in total increased 48.8%.

This is shown graphically. If you compare control group in Flushing which is 11.9 miles away from Ground Zero, staffed by the same doctors at the Charles B. Wang Community Health Center who are salaried and had no incentive to under or over diagnose children. In the year after 9/11 the number of children with asthma decreased in Flushing by 10.9% and pediatric asthma visits decreased by 13.6% indicating they were out of this hot zone.

This is shown graphically in the next two slides. For peak expiratory flow rates we looked at the mean or the average percent predicted peak flow rates which actually decreased below 80% which is the normal cutoff for 6 months for those children exclusively living within five miles of Ground Zero.

As you can see in this slide prior to 9/11 in Region 2 in yellow if you lived greater than five miles away versus Region 1, which is in red living within five miles, these curves were the same. They had same peak flow rates. After 9/11 if you're in Region 1 in the red your peak flow rates went down for two quarters of the year whereas if you're in Region 2, more than five miles away in yellow, your peak flow rates were not affected.

So in conclusion, residential proximity to Ground Zero was predicted of the degree of decrease in asthma health. Exposure to World Trade Center disaster led to increased asthma severity. After September 11th, 2001, these children had more

asthma related clinic visits. These children received more prescriptions for asthma medications. Those children living within five miles had more clinic visits after September 11th, 2001. The increase in visits for children living further than five miles from Ground Zero was not significant. Mean percent predicted, peak expiratory flow rates decreased solely for those patients living within five miles of Ground Zero after September 11th, 2001. Asthma severity, therefore, worsened after September 11th, 2001 in pediatric asthmatic patients living near Ground Zero.

In our next study Debbie Lynn was at Cornell at the time, reported after 9/11 in 2005 and 2006 within the region of Chinatown there were still very high rates of asthma. She studied 476 second graders and the rates are about 21% in 2006. She used a standardized screening questionnaire called 'The Red Line' which yielded even higher rates, about half of the kids had asthma by questionnaire and when they underwent spirometry one-third of them had baseline airway obstruction.

So for this study we wanted to know are Chinatown asthma rates still higher than that reported for other ethnic groups in the 2000 census even years after 9/11. Number two, the rate of asthma in Chinatown is persistently high and did not decrease since the previous studies. For this study population we looked at 1,000 students attending the closest ethnically and socioeconomically homogeneous elementary school proximal to the World Trade Center. We used The Red Line standardized questionnaire for asthma. We conducted spirometry or breathing tests and we looked at air pollution data. The questionnaire was distributed to parents. We looked at demographic data including age, gender, weight and height, the presence of household smokers, use of asthma medication, diagnosis of asthma by a pediatrician, and whether they used alternative medicine including herbal remedies or burning with moxibustion. The spirometry required parental consent. In addition, students were required to have passive consent, meaning that on the day we did the test a student was able to opt out of the test even if the parents signed the consent form. Everyone got a KoKo Legend Portable Office Spirometer to do the spirometry. This spirometry was calibrated daily, adjusted for temperature, barometric pressure, age, height, gender, and race. For each student we did a minimum of eight forced vital capacity maneuvers performed to T3, acceptable flow volume within 200 milligrams for forced vital capacity and forced expiratory volume of 1 second, how much air can you breathe out in 1 second if you start from a total lung capacity. The value assigned to each student or participant was the largest acceptable value which was within 200 milliliters of a second value.

For outdoor air pollution, we used to two fine particulate sampler monitors deployed on the roof of the school. It was installed by the New York State Department of Environmental Conservation, measuring PM2.5, as Dr. Rom

pointed out, 2.5 micron-sized particulate mass samples collected continuously every three days.

We vacuumed the school. We were looking for air allergens as a source of allergic asthma. We used a dust-free vacuum collection system and sent it to INDOOR Biotechnologies in Virginia to analyze by enzyme-linked immunosorbent assay or concentrations of antigens or allergens including those for mouse, rat, cat, cockroach, three types of dust mite antigens, and dog.

We received 353 questionnaires from parents of children at an elementary school in Chinatown. We conducted spirometry on 202 students. For those living within one mile of Ground Zero the rate of asthma was 12.6%, only 4.8% for those living further away by self-report only. There were high asthma rates among children who actually engaged in spirometry with us. If you were between the ages of four and twelve years old, 29% of these children had an FEV1 less than 80% predicted. The average value was 72% which is abnormal, though, mildly abnormal at rest. For children greater than seven years old who were alive and living in Chinatown on September 11th, 2001, 17% of those kids had abnormal spirometry values with an FEV1 less than 75%.

For the outdoor air pollution levels collected on the roof of this school, it exceeded Environmental Protection Agency limits, which is this bar over here at 35 microns per cubic meter. This long, tall line is the Macy's Fireworks Parade in July. For indoor air allergens there were none significantly detectable. There were no dust mite antigens detected, no cockroach nor rat, and the amount of cat and mouse air allergen levels was minimal and not clinically significant.

So for study 2 our conclusions are: Number 1, Chinatown asthma rates are still higher than other groups, 29% versus the New York City Reference Rate of 13%. These rates indicate persistence of elevated rates as suggested by Dr. Lynn and colleagues. Air pollution levels exceed EPA standards and are unhealthy, more than 35 microgram per cubic meter per day. This may account for increased asthma incidents. It is possible that exposure to various toxins on 9/11, to hit number one, accentuated the effect of subsequent exposure to air pollution hit number two. Number three, the difference between parent-reported prevalence of asthma, which was 12.6%, and tested prevalence of 29% with spirometry corresponds to those data reported by the Harlem Children's Zone Asthma Initiative and suggests a high degree of unmet need for asthma treatment, and lower than necessary child well-being and health status.

For the next study we wanted to look allergy symptoms because they'd not been studied previously in this cohort of children attending school near the World Trade Center, which post-9/11 was a dusty construction site. In addition, impulse oscillometry or IOS, is a newer technique to measure the caliber of the small airways which form the source of airway resistance in asthma. And it is a measure of peripheral airways lung function. It provides geography or location as

opposed to proximal airways. And impulse oscillometry can also measure something called 'X5' which can measure airway hyper-responsiveness or twitchy airways. And that has not been studied in the context of those children alive on 9/11, although the Mount Sinai group looked at metal workers in Manhattan and Ground Zero. So we decided to look at these kids because it's more sensitive than spirometry. Furthermore, the specific chemical composition of this air pollution, this PM2.5, had not been examined.

So our hypotheses were, number one, allergy symptoms are common among children attending school near the World Trade Center. Number two, impulse oscillometry or IOS will show small airways function deficits as opposed to large or proximal, and it will also show airway hyper-responsiveness or twitchy airways not only among those children alive on 9/11 but also those born and raised in the area thereafter. Number three, the specific chemical composition of air pollution particles will yield harmful levels of lead. At the time we were concerned about lead as well as arsenic because kids drink apple juice. There is a lot of consumer information and consumer reports about getting arsenic from apple juice, and arsenic can be released from diesel exhaust as well.

Our study population, again, comprised of 1,000 students attending this closest ethnically and socioeconomically homogeneous elementary school proximal to the World Trade Center; 158 students completed both student and parental surveys, and of those 158, 129 completed impulse oscillometry. The inclusion criteria, you must have attended this elementary school, which was kindergarten through fifth grade, approved by the New York City Department of Education. Ninety-nine% of the children attending the school are Chinese-American. Special education students were excluded.

We used The Red Line standardized questionnaire from Harvard, impulse oscillometry, and we speciated air pollution data to look at specific chemicals in the air pollution. This is The Red Line questionnaire in English, example, some of the questions are like breathing sounds wheezing, it's hard to take a long breath, I can't stop coughing, etc. And there's a parental questionnaire that asks similar questions to see if there's concordance between the parental responses to symptomology in the kids as well as the kids. We had this translated in Mandarin Chinese.

This is the impulse oscillometer. It's a non-invasive test. It doesn't require effort on part of the kid which is very good compared to spirometry which is difficult to sometimes reproduce in very young children. And some of the measures we look at include the X5 which it measures twitchiness of the airways and the R5 minus R20 measure the peripheral airways narrowing. So this is a JAEGER MasterScreen Impulse Oscillometer. It was loaned to us from CareFusion Corporation. This required three trials. It only took 20 seconds each per trial to take 100 complete measurements. It's much more efficient than spirometry. The

way it works is there's a loudspeaker and just like I'm talking into this microphone the loudspeaker will deliver pulse-shaped pressure flow excitation to the respiratory system. And the over-impedance of the pulse is due to the resisted and viscoelastic forces of the respiratory system itself. This is reported as resistance, reactance measured in centimeters of water per liter per second. It's calibrated with a reference resistor of two centimeters of water per liter per second according to the manufacturer's instructions. These multi-frequency impulses were applied over 20-second trials to the airway through the mouthpiece during tidal breathing which is regular breathing. The children used a nose clip, as seen in the photograph, and we used three reproducible trials, twenty seconds each if they lacked artifacts from coughing, breath holding, swallowing, or vocalization. So they could not talk during this test.

So in terms of the questionnaire there is a very good correlation between what the kids were saying their symptoms were and what the parents were saying. In terms of the respiratory system resistance we saw that as well. The values for the R5 and R20, and the R5 minus the R20 suggest that the boys had higher values than girls, meaning they're more obstructed, and they were higher than the reference values which are available in the literature. The mean R5, X5, and R20 were given in centimeters of water per second and they were high. Boys were higher than girls, as seen here.

For the air pollution, again, we can see here is the EPA limit line in red. This time we compared the air pollution monitors in the Bronx as well as in Queens to the EPA standard values with our Manhattan Division Street School. And as you can see all locations exceeded the EPA limits at times. In particular, for Division Street can see that the blue lines exceed the World Health Organization recommendations as well as EPA limits. Although if you do a best fit line, over time the total amount of air pollution was going down even though sometimes it exceeded the limits. However, when we speciated it for specific chemical data for specific metals within the composition of the air pollution, antimony, in particular, kept on increasing and was above what's recorded as a normal limit. There were other detectable metals in the air as well as phosphorus, in particular.

MS. McVAY-HUGHES: What was the cross-street on Division Street?

DR. SZEMA: I'm not allowed to divulge the name of the school according to the New York City Department of Education. I can tell you it is the only school that faces the Manhattan Bridge. And when I was sitting outside the school I could count 100 diesel trucks per hour. That's all I'm allowed to say. And here's the Manhattan Bridge. Traffic during the time course that we studied the average Manhattan Bridge traffic increased consistently from year to year. So that would be the plausible source of the air pollution. In particular, statistically there was a very strong correlation or interdependence between antimony, chemical-laden SB, and phosphorus, and the amount of traffic over the bridge, but there is still also strong

correlation between all these other metals as well. Interesting we were in… you know, we were initially interested in arsenic because we expected kids to drink lots of apple juice laden with arsenic, and we're expecting arsenic for the diesel exhaust and we did not find higher levels of arsenic.
So conclusions, allergy and respiratory symptoms are common among those children, and confirmed by their parents, responding to this survey distributed among classrooms at the closest elementary school to the World Trade Center site. There was a strong correlation between responses from children and their parents. Frequent severe symptoms such as wheezing and chest tightness juxtaposed with use of allergy and asthma medications supports the concept, again, that these patients are not clinically well-controlled. So boys and girls in this cohort had increased values of air resistance at five hertz with boys having higher values than girls. Frequency dependence between resistance values of five hertz and twenty hertz suggest small airways dysfunction as the geographic location adds to their problem rather than central or proximal airways narrowing. Air pollution levels in this neighborhood are still high and contain detectable lead, vanadium and indium, and showed up antimony and phosphorus as well. So I believe there's probably a two-hit hypothesis in that if you were born or alive on 9/11 you were getting ongoing pollution, but if were born thereafter… at the time of the construction site you were still exposed to air pollution, and even now the air pollution across the bridge is increasing probably because you can go across without EZ Pass. So thank you very much.

DR. WARD: Okay. We're going to take our scheduled break for lunch and be back at 1:30.

[Break.]

OVERVIEW OF WTC RESEARCH ON 'OTHER' HEALTH OUTCOMES AND PERSPECTIVES ON THE CHARGE

DR. TRASANDE: Good afternoon. My name is Leo Trasande. I'm a pediatrician and epidemiologist at NYU School of Medicine. I had the privilege of serving on the STAC until very recently and am delighted to provide some broader perspective.

[Technical assistance.]

DR. TRASANDE: So my name is Leo Trasande. I'm a pediatrician and environmental epidemiologist at NYU School of Medicine. And I've conducted one of, arguably the only in-depth physical health studies of children exposed to the World Trade Center disaster. And I'm privileged to have served on the STAC until recently. I'm going to provide comments mostly on the theme of needing to shine the light away from what we already know about September 11 and its aftermath, and the exposures and their impact on children, and anticipating future consequences. Just to recap what we documented to date, our initial NIOSH funded studies were founded on preliminary findings from the Bellevue Environmental Health Center and the pediatric population who presented with clinical symptoms of concern. We had the opportunity under the—through the good graces of Joan Reibman

and her team to leverage questionnaire data that was meticulously collected, as well as physical health evaluations with everything from allergic symptoms to respiratory symptoms, as well as an in-depth pulmonary evaluation and screening laboratory values, including spirometry and oscillometry. And our findings from a modest self-referred sample of 150 or so, which were published in the Science of the Total Environment in 2013, documented a number of key findings, both confirming what's known from the Registry with respect to a high prevalence of asthma symptoms as well as respiratory symptoms in children who had dust cloud exposure as well as other exposures, but arguably and most importantly from the perspective of what we're doing now, documented two sets of themes. One is the importance of chronic exposures for a number of primary study outcomes. And secondly, the substantial prevalence of cardiometabolic conditions that are quite both plausible and were all too prevalent in this clinically referred sample.

So, for example, we found nearly one in third of the children who presented to that clinic had met the criteria for pre-hypertension, which is an alarm bell for the general pediatrician for the need to query more into diet and physical activity as potential predictors and modifiable behaviors for later hypertension and cardiovascular risk, especially in adult life. In particular, we were also concerned about chronic home dust exposures and their association with the combination of a reduction in HDL, the good cholesterol, and an increase in triglycerides. And that combination is a particular alarm from the preventive cardiologist. I'm not a preventive cardiologist. But the concern was substantial because that's actually an early marker of later life coronary heart risk. At least in adults and, in some studies, in younger adults as well.

And so we had the privilege of seeking out funding through a collaboration with the World Trade Center Health Registry to recruit 225 adolescents who were less than eight years of age on September 11th, 2001, and compare lung and heart health to a match comparison group recruited in a number of modes. And we've certainly faced some of the difficulties that the Registry has experienced with longitudinally following up those populations through questionnaires. We've recruited to date on the order of 180 adolescents who were exposed. That's probably our maximum at the current phase of the study, just due to some funding limitations in our ability to recruit from the exposed arm. And we continue to recruit a matched group of controls. And we are well over 180 towards our goal of 225 in that arm. And they're matched by sociodemographic factors in order to make sure that we have comparable populations.

In our early findings, which we presented two meetings ago at the investigators meeting, already suggest some substantial concerns consistent with those identified from a clinically referred population, suggesting there some generalizability in concerns about lung and heart health impacts of exposure.

One of the early findings that was striking was that our control, or unexposed comparison population being the correct, more correct epidemiologic term, was actually exposed in some cases to World Trade Center stress and dust in some cases, even though they didn't report being below the geographic, that is being in the geographic zone that counts for purposes of participation and eligibility in the Registry. And that was an early and striking finding that suggested our need to examine the two, the population in two ways. Examine them in an exposed and unexposed comparison group the way that we had originally proposed it, but also to examine differences in lung and heart health impacts based upon their actually self-reported exposure profiles. And more in the latter than in the former we found substantial associations so far in early data with decrements in lung volumes, as well as borderline associations with new onset asthma consistent with the Registry findings from Wave 1. And we've also seen increases in subclinical signs of peripheral arterial stiffness as measured by brach—reduced brachial artery distensibility in association with dust cloud exposure, controlling for psychosocial stress, which itself is an important and independent factor which we've evaluated throughout our studies to date.

So I think in this audience, given the previous comments, I can't re-emphasize enough the value of physical health evaluation in an in-depth fashion of exposed children in the aftermath of the disaster. One concern, which I have had for some time now and have only recently had the privilege of receiving funding from NIOSH to study, is persistent organic pollutant exposures comparing, leveraging the existing funding we had for the primary epidemiologic evaluation to examine dioxins and perfluoroalkyl chemicals in the two groups that we've recruited with our initial NIOSH funding.

My general concern about those exposures is that they are classically known as endocrine disrupting chemicals. And the implications of endocrine disruption are not readily identifiable through, especially given their subclinical manifestations and their—and the inability to evaluate that through questionnaires in particular. And so this is where there are limits to what the existing Registry platform provides in evaluating these kinds of exposures. It's not a knock on the design of the Registry intrinsically. It's just a reality of the biology and the approach to being able to evaluate it based on present technology.

In particular, beyond my concern about subclinical effects is a need to evaluate gene environment interactions and epigenetic effects, which has been elaborated by multiple previous discussants. So I won't dwell on that much further.

My overarching concern for this committee to consider is, regards the review process in particular for World Trade Center health research in particular. I've had the privilege of, for many years now, being on NIH review panels and can speak personally to what I like to call potential hidden biases that exist in the review process when, especially in the context of disaster related exposures,

there's an inclination to arguably—I don't know how one can really quantify this—but to focus on and rate proposals that evaluate known outcomes and outcomes for which the evidence is already there. And there can be more reticence in supporting funding for proposals where perhaps the population has been, is difficult to characterize because they're, the framework to evaluate that population hasn't existed heretofore.

I personally see a need to differentiate, if at all possible—I mean, I don't know how one really does that in practice, whether it's survivor versus responder or pediatric versus non-pediatric proposals. But I do have concern that in the same pool you will naturally as reviewers have an inclination to support proposals that are based on existing knowledge, shining the light where we know health effects exist rather than evolving our understanding towards populations where there are concerns but the framework for studying them is weaker intrinsically from the beginning. And that's something that's particular concern because many of these studies in children are so time sensitive. I can tell you that it took us a few years to get our initial pediatric study funded. That probably reduced our capacity in many ways both to recruit the population and also to evaluate its exposures. We had longer latency to our initial evaluation even though we are using and linking our data the World Trade Center Health Registry whenever possible.

So I raise these as concerns. I've outlined a few options for solution. I'm certainly not trying to subvert a rigorous peer review process for proposals. But I do think we have to lay out on the table the fact that pediatric research in the context of a disaster faces some unique challenges and may not be in the same pool and may not be comparable from scientific rigor to other proposals. So it's a concern that I will leave you with. And thank you for the privilege of commenting now on the outside as a non-STAC member. Thank you.

PANEL DISCUSSION WITH STAC

DR. WARD: So now what we'd like the panel members to do, those who are still here, is to join us at the table so that we can have some discussion both between you and the STAC and hopefully between you and each other so that we get—I mean, our intent is to really draw out some good ideas. And, you know, ultimately what the STAC is hoping to do is make some recommendations to NIOSH regarding budding pediatric research and certainly the specific recommendations that have been made by a couple of people around, you know, the possibility of doing a specific request for proposal or a special peer review process for these research studies I think would be in the realm of things that we could certainly, you know, recommend to NIOSH if appropriate.

But I think the other topics we want to focus on are going back to our original charge to the committee. So as we ask questions and discuss, I think we should kind of keep asking ourselves are these, is this line of questioning going to get us closer to addressing the issue before us or not? Because there are so many

interesting topics that we could explore. But I think ultimately the STAC wants to come back with some tangible recommendations to NIOSH.

And so I'll read our charge once more. 'What are the most important physical, psychological, and developmental health outcomes to target, and in which groups of children?' So I think that's a very broad charge. But, again, we really want to focus on that. But I do think it's perfectly appropriate and useful to talk about the process for generating research topics. So, for example, you know, should there just be a very broad call for research? Or are there some specific recommendations that we have around populations and outcomes that should, you know, that really provide the good opportunities for research so that we should be more specific? So with that I'll open the floor to questions and comments. Rosemarie.

MS. BOWLER: It would help me, Dr. Ward, if you would maybe further specify. Are you talking about a particular age group when you say children? Or is that one of the issue to discuss?

DR. WARD: And we thought about trying to lay out, you know, a more specific exposure characterization. And I think Dr. Brackbill kind of alluded to it most closely. I mean, there's lots of different ways you can categorize groups of children. You can categorize them by age. You can categorize them by what their exposure was. You know, the residents versus the school children. You can categorize them by whether they, if they were residents, did they stay in the area, did they go away from the area? There's also populations like the children of first responders that aren't included in the current definitions of potential study subjects, unless they happen to also be residents or schoolchildren in the area. So we're really talking about multiple ways to categorize children. And, you know, and I think the really complicated thing is we're not really thinking about what would be the ideal situation, what we—You know, it's what can we do now given that we're 15 years past the exposure and we don't have all of the records and the opportunity to observe children as they go through development?

MS. BOWLER: Well, I guess for myself I was thinking, if we are dealing with children and with children's intellectual development, for instance, cognitive development, the age group would be extremely important. Because like the scores are every three months there's a different score on the Wechsler intelligence scale for children if one were to use even one subtest. So that's why I asked that question. For the children, is there a specific age group?

DR. WARD: Yes. Well, I think that's for us to recommend.

MS. BOWLER: Okay.

DR. WARD: I mean, if we see, you know, that a particular age group or a particular outcome would be feasible and important to study, then that's really our charge to make those kinds of recommendations.

MS. BOWLER: So I would like to make that a recommendation, that we think about a particular

age group when we say children. When we said age at Wave 1 or at 9/11. And how far does it go, would be one example to look at intellectual development. It goes to 18 usually. And then even the adults every five years different norms, that we consider that in the recommending of…

DR. WARD: So not wanting to formalize the discussion too much, do you think it would be helpful to—I mean, Leo made the very nice point of not always shining, not shining the light where the light already is. You know, but I think one approach might be to focus a discussion around, you know, what really need, should be done in relation to the mental health research, given what's known? What should be done in relation to the respiratory disease research, given what's known? And we don't have to do it in that order. But then what are the other, you know, what are the research on other outcomes? Because I do think logically and I know I'm not educated enough with respect to, let's say, the respiratory disease studies to know. So what are the big unanswered questions? I mean, very often it's, you know, for those effects that have been characterized, how are they going to persist over the life course and so on? But I think that might be a useful way to approach the question that would get us a little bit closer to some recommendations. But what are your thoughts? Do any of the expert panelists have a way that they'd like to suggest framing the discussion?

DR. HOVEN: If you don't mind my ignorance, I would ask that you provide some framework for us to talk about this. Because I've heard a reference to RFAs and what you're going to do with the information. So, you know, what are we speaking to? Because the RFA as far as I understand is kind of floating around us, that would be used for this next year if in fact there is going to be funding. So I'm not sure what it is we're speaking to in terms of the task and the role and the responsibilities for this committee. And if I knew that, I could probably be more helpful to you.

DR. MIDDENDORF: Yes. Excuse me. I don't think we need to speak to a specific RFA. The question here is what can be done? Theoretically, what can we do given the situation we're in now? What is possible? Of the things that are possible, what are the priorities? What do we really need to focus on? And then the priorities can be determined by a number of different factors like, okay, if we don't do it now, this cohort is going to be so old that we won't be able to study these particular things anymore. Or if the power isn't, is there or isn't there now. So isn't there, so you may not want to study it. So you can think about looking at it in terms of prioritizing. That's what really is, needs to be done now is to prioritize. What type of children's research needs, or should be done now or you forever hold your peace; you're never going to be able to do it with this group?

DR. WARD: And I think that's a great clarification, so I'm probably jumping ahead a little ways. But I guess I'm reading into the request that this is something of interest, this is an area of interest to NIOSH. It's an area that they're considering, you know,

whether there's a more effective way to address it. And, again, I think our main responsibility is to respond to the questions posed by the administrator. But we can express opinions on issues like, you know, the need for possibly a different review or a separate review process for pediatric research. So we're not strictly limited to only address the question as Paul laid it out. We can go beyond that. But of course we're really providing advice to the administrator and he can do what he chooses with our recommendations found.

MS. JONES: I was going to ask… This is your study. Did all of your children's research—Brackbill? Under the data collection Wave 2 you have children younger than 11 and then adolescents, and it's done twice. You know, done there and then the next page in terms of men, you have adolescents and what was PTSD related. Is there something in that, in looking at adolescents versus looking at children younger than 11? For some reason you have Adolescent Survey 11-17. Is there something in that? Is there some purpose to that or some way that we should use that or think about that going forward?

DR. BRACKBILL: Well, you're talking about the…

DR. MIDDENDORF: Please use the microphone.

DR. BRACKBILL: Yes, I was looking for—oh, I got two now.

DR. MIDDENDORF: (Inaudible @ 00:24:18) Val, even though you're two feet away from Robert—

DR. BRACKBILL: Right. Yes.

DR. MIDDENDORF: People back there can't hear. So it's important to use the microphone—

MS. JONES: Okay.

DR. BRACKBILL: You're using that one. So I'll use this one.

MS. JONES: Do I need to say that again?

DR. MIDDENDORF: No, I don't think so.

MS. JONES: Oh.

DR. BRACKBILL: I guess I, or you're—I'm looking at what page you're looking at there, what slide. And I assume it's a data collection slide. So I think the questionnaires, you know, were split between children who were younger than 11 and, you know, sort of call them children, and then 11 to 17 were adolescents. And the reason for that split is because adolescents could answer the questions themselves and the parents answer the questions for children under 11. It was sort of a standard kind of separation, you know, according to like IRB and that sort of thing, Institutional Review Board kind of way of looking at children that the adolescents could answer these questions themselves. And parents would also answer questions about themselves as well as about their children. So that's why there's that separation.

DR. WARD: Catherine.

MS. McVAY-HUGHES: Yes. I have a question for Dr. Szema. So I'll just mention just for the record there are 90 major construction projects going on here in Lower Manhattan (inaudible @ 00:25:43) 1.5 square miles. So a major project is considered 25 million dollars or more. And one of the things that the community was very worried about after

9/11 was not only the ramifications, the health consequences due to the exposure of 9/11 and, but also during the rebuilding process, which brought, which brings in a lot of large vehicles along Canal Street. So are you able to on your study break out the contributing factors from the vehicular traffic, which probably has increased with increased density down here in the last 14 years, versus the original 9/11 exposure, ongoing exposure?

DR. SZEMA: The air pollution monitor data is tracked on a day-to-day basis. So you can look at the older data and the newer data. Obviously the newer data is just what's airborne. So it'd be unlikely to be related to 9/11. So the only way to do it would be go, to go indoor like the Smith Houses or go to houses that were never professionally cleaned and look at, vacuum up the dust and analyze the dust for asbestos and particles or the signature chemical, the chemical signature for (inaudible @ 00:27:05). I think, you know, one way of looking at it—and this brings importance of the age—is, you know, if you were alive in 9/11 or born in 9/11 or shortly thereafter or you lived near the pit, it'll break, it'll stratify different age groups so you can see how developmental problems are going to accrue in different age groups. So I think there really shouldn't be a particular age cutoff. Because the kids who were born on 9/11 are already 15. And, you know, it's more of were you there or are you living there? You know, do you have hit number one or hit number two or only hit number two?

MS. McVAY-HUGHES: Or do you think hit number two exacerbated the hit number one?

DR. SZEMA: Oh, absolutely. Yes.

MS. McVAY-HUGHES: Okay. Because it wasn't presumably a conclusion in your report—

DR. SZEMA: Right, right. So yes. If you were born on 9/11 or you were there, ongoing air pollution clearly is a risk factor for asthma exacerbation. So if you already had exposure on 9/11, this would be a contributing factor.

MS. McVAY-HUGHES: So then the one possible study is, if you have a sensitized population, the impact of ongoing environmental hits on a population could be something that could be studied.

DR. SZEMA: Right. There's an analogous study. Alan Gonzalez at Stony Brook had an R21 with me to look at the effects of Hurricane Sandy and mold allergy and allergic asthma in Long Island after the hurricane in the South Shore residents who were EMS workers and were exposed to that level. So he clearly found that, if you had two of these hits, then you were worse than versus one of them.

MS. McVAY-HUGHES: Right. So, because I know a lot of the mental health experts look at, you know, if you have one mental hit, then another mental hit. You know, a loss of a family member then maybe a loss of your home, compounded by a loss of your job. Something like this could also impact someone's physical health.

DR. SZEMA: In addition, yes. You're correct.

MS. McVAY-HUGHES: I mean, because people forget after 9… You know. So, because downtown as well, I know the World Trade Center Health Registry has done a couple, did a

study on the impact of Sandy as well.

DR. SZEMA: Right. So you know, even PTSD is associated with cytokine release and worsened asthma. So if you have identical twins, they both have the same mother and same genes, in civilian populations the kid with PTSD will have a higher risk of that. So I think there are a combination of factors that could, you know, affect the respiratory system.

MS. McVAY-HUGHES: Okay. And then, Dr. Brackbill, going back to the World Trade Center Health Registry, as someone who's lived down here for 27 years and lived a block from the World Trade Center site and doing out-, the question of doing outreach to the local schools. It wasn't clear from your data whether—there are two schools that are literally across the street or a block away. The two high schools. A High School, I think, of Leadership and the High School of Finance and Management or something like that. The majority of those children commuted in downtown from outside of the community. And I'm not sure if any of those students are in your Registry because they were not singled out. But they were really on the frontline. So even though Stuyvesant was right next to the barge on the east—well, it was literally right next to, you know, if you want to call it hit. So there was that. And then I remember also with these students, they were encouraged to come back with financial incentives as well. Like if you can come back, we will give you a gift certificate, you know, to the bookstore. Or if your attendance is better or something like that. I mean, so people, some of the folk, even though there was extensive outreach, there still are some gaps I guess.

You know, when people were coming back after 9/11, you had to evacuate. There was lots of forms to fill out. You were filling out your insurance forms or just trying to get your life back in order. Oh, you didn't even get your mail for a huge period of time. Like, so if somebody is going to be filling out a form, it was just another thing that people had to focus on. And I think someone else had mentioned, and I know the World Trade Center Health Registry's really important, but not everybody wanted to, you know, there was a—after having been lied to about whether the air was safe to breathe or not, there was some skepticism. And so I just want to talk about, just want to put that on the record.

DR. BRACKBILL: I guess you were first saying, asking whether any enrollees from the High School of Finance and Leadership? Yes.

MS. McVAY-HUGHES: How many?

DR. BRACKBILL: I don't have that number with me. I simply just showed a slide or the top six enrollment.

MS. McVAY-HUGHES: Right.

DR. BRACKBILL: I think it was maybe in the 20, you know, it was in the 23…

MS. McVAY-HUGHES: Okay. Because they're pretty big schools.

DR. BRACKBILL: Yes, yes. I greeted many of the high—I think high school students just typically lived out of the area, you know, because their main contact was through, you

know, these letters that went in their backpack, et cetera, you know. And I think there were some presentations in the auditoriums, that sort of thing. It just was difficult because the Board of Education didn't really let us go in and get lists of students. I mean, we requested that.

MS. McVAY-HUGHES: So that would be something that I would actually specifically put in your studies as limitations.

DR. BRACKBILL: Yes. Oh, yes.

MS. McVAY-HUGHES: That there was some bureaucratic hurdles.

DR. BRACKBILL: Yes. We've mentioned after some technical reports, coverage reports that, you know, outline, you know, all the various limitations and the whole process, you know, of trying to fulfill that mission of getting people enrolled, yes.

DR. SZEMA: I would agree that we would need to pull data sets, Dr. Trasande's, Dr. Brackbill's, because in Chinatown there are extremely low participation rates. It's the lowest ethnic group among all ethnicities in the WTC monitoring program. So, you know, you have less than 1% participation of the entire community. And that's a problem because you're completely neglecting an entire neighborhood.

DR. BRACKBILL: Yes, we actually had… Did you want to…?

DR. FARFEL: Just if you don't mind. While we're on that topic, yes. Because you had said neglected neighborhood.

DR. BRACKBILL: Yes.

DR. FARFEL: We do have Chinese speaking enrollees in the Registry.

DR. MIDDENDORF: Mark, if you would get up close to the microphone?

DR. FARFEL: Oh, yes. We do have the Chinese speaking enrollees. And actually, the Registry has a what we call a treatment referral program. So we're the only cohort that doesn't provide direct care, clinical care. However, a big component of what we do is making personalized outreach to enrollees who report symptoms on their surveys so that we can connect them to the World Trade Center Health Program. And actually, over the years we have become a major source of new applications to the World Trade Center Health Program, both to the survivor arm as well as the responder arm. And we are conducting intensive outreach to Chinese speaking people in the Registry. So they're getting called. So, for example, on our Wave 4 survey every single Chinese speaking non-respondent is getting a call from a Chinese speaker working with the Registry. And that's both Mandarin and Cantonese. So it's a population that we have always tried to make efforts to outreach to, including door-to-door outreach in the neighborhoods.

Now, you're correct in pointing out that given the boundaries of the Registry we don't include the entire section of Chinatown. That is correct. But for the enrollees that are in the Registry, they are subject to intensive efforts. And we do see that now the Registry's become an important source of Chinese language applications to the World Trade Center Health Program. You're correct. They are an underrepresented population. But with the Registry's outreach, the numbers

have increased. And it's also true for Hispanic, Spanish speaking enrollees. And there are other underrepresented populations where we've made a focused effort and seen an increase in the applications to the World Trade Center Health Program. So I just didn't want to leave that unsaid because there are lots of efforts on the part of the Registry to be able to reach the population, including having bilingual staff onboard at the Registry.

DR. WARD: Leo, did you want to comment on that?

DR. TRASANDE: Yes. Sorry. So while I applaud those efforts, I think what we're talking about is a slightly different question. I think what we're talking about is whether the popu—I think there's a presumption that the Registry might not, might be the only population in which to nest (these @ 00:36:41) studies.

MS. McVAY-HUGHES: It seems like there are three populations where you get children that were impacted from 9/11 health in general. One, the World Trade Center Health Registry, Dr. Szema's group that has longitudinal data, and the people that end up going to one of the World Trade Center health clinics that walk in. So that's a self-select group. And the problem is with World Trade Center Health Registry, it's all self-reported. And so the only two out of the three populations that actually have collected data is at Gouveneur's, at Bellevue for children, and Dr. Szema's group at Wang. Am I right?

DR. TRASANDE Can I build on that comment? So I think you're right. And I think the theme, an underlying theme of my intervention earlier on is that that only represents a subset of the entirety of the sample. And I think, again, within this hidden bias concern that I've raised is the notion that you are missing a large population that the presumption is you can't ever study them and/or you can't study them in a rigorous way. And I don't know how to address that. But I think this committee has to consider that as a real limitation. Otherwise, the sample that you're actually studying in those three subgroups is increasingly a subset of a subset of a subset of the entirety of the population. And the findings may have limited generalizability. It's not a knock on the Registry at all or the existing cohorts. But I acknowledge that our 180 or so is, if you take 30,000 as the denominator, it's at best 1.6%.

MR. FLAMMIA: Actually, Dr. Landrigan's not here to address the issue. He had stated in his concluding thoughts children exposed prenatally to 9/11 are also another group of special attention, open up the Registry—and that's what I'm getting at, and that's just to add to what Catherine said—born to mothers exposed to the World Trade Center disaster. That also should include the responders who went home to their loved ones. So, I mean, open up the Registry.

DR. WARD: Yes, so I guess what…

DR. HOVEN: Could I speak to the issue that Mark was speaking to? The sample that I'm drawing, the 1000 representative kids from the Registry, that sample at Wave 1 was, had a very reasonable level of Chinese, black, and Hispanic. It is the

Chinese actually, both Mandarin and Cantonese speaking, who have stuck with the Registry at higher rates than either blacks or Hispanics. So what I am trying to do is get a representative sample that looks more like Wave 1 than Wave 3. So my effort is great to get these Chinese, the black, and the Hispanic so that my sample, which I hope to be representative of Wave 1, is actually more like what the Registry has. So I just want to be clear that the Chinese are in fact the group that has stayed. Of the minority group, that is the one group that has stuck with the Registry better than any of the other minorities.

DR. WARD: So this is just a procedural thing. I'd like to try to respect the tent process as much as possible. And I wasn't able to keep track of everyone who has their tent up. So I suggest before we take any other comments we go down, just go counterclockwise.

DR. WARD: Lila and then—okay.

PARTICIPANT: Then Bill and then Mike.

DR. WARD: Yes. Let's hold off on raising any more tents until we get around the ones that are already up.

MS. JONES: What did you say? Raising any more what?

DR. WARD: Well, I said let's not keep raising tents until we get…

PARTICIPANT: Raising tents?

PARTICIPANT: That's what they're called.

DR. WARD: These are the tents. Until we get around to the people, so I don't… It's easier to keep track.

PARTICIPANT: Raise your hand.

DR. WARD: I should give people numbers. They not only have to hold up their tent, they have to hold their number.

MS. NORDSTROM: First of all, I wondered if I could reiterate my request of the Registry to get a table with demographic info for the pediatric population you do have so that we can see how that population breaks down. I noticed in the chart that had the breakdown of schools that one of the groups that seems to really have slipped through the cracks, probably not surprisingly, is non-resident students. They're, according to that census data, looked like there were more of them in the neighborhood than resident students even at the time. And that I think specifically looked like the population that you really don't have represented in the Registry is people who were teenagers. Because they would have been in college by the time you did the outreach. They would have had parents that lived outside of the neighborhood. They, you know, oftentimes, at least in the case of Stuyvesant, often had non-English speaking parents as well. So that would have been even harder to reach them.

And so I'm wondering if we can maybe talk about—and Dr. Trasande has been touching on this—but ways in which to make sure that that population is included in these studies. Because if we, you know, not only, you know, we want to make

sure that these samples are representative in terms of income level and ethnicity and other things that they may or may not be at the moment. But I also feel like it's important that we not only look at small children and then responders. Because those of us who were teenagers at the time of the attacks are going to be the first to kind of hit these health consequences. And if the research is all done on much younger children, it doesn't seem like it will have, it will happen in time to serve a purpose for us, which I would think ultimately is part of the purpose of doing the research is to help health outcomes going forward.

So I'm wondering if we can maybe talk about the feasibility of finding ways to expand this population so that there are people in this group that is very clearly missing from the Registry that can be brought into the process. Because they're much older than the small children that were living in the neighborhood.

DR. BRACKBILL: Well, of course, you know, I tried to describe, you know, that the enrollment and recruitment, you know, we had two sort of arms to that. You know, in the household and in the school. And I think the household of course is based on residents. So a resident was, you know, the group that we focused on. And it was through resident families that we found children. So I think by definition the children that we found through families, you know, tended to be younger children of course who lived, you know, south of Canal Street.

MS. NORDSTROM: Right.

DR. BRACKBILL: So, yes, there is that kind of you might say, you know, bi-. I don't really want to call it a bias. It was just the way it happened. And then the other activity of course, group activities was around schools and I think we did—and there wasn't a great deal of effort. I mean, I went through Stuyvesant High School personally myself maybe five times, talked to the principal, you know, spoke to the parent, you know, PTA groups, that sort of thing. So, I mean, it was a big effort, knowing that Stuyvesant was a key, you know, high school to try to get enrollment. Even the Stuyvesant had about 400 students enrolled, although that proportionally was a smaller, you know, percentage. But if you add up the number of students from the very big high schools, Murray Bergtraum and maybe even the Leadership High School as mentioned earlier, you might obtain maybe 600 or something like that, high school students. And that's 20% of the 3000.

So it's not really necessarily a small group to follow. And I'm sure that because of the nature of trying to just get people to enroll, if you don't, if you're depending on self-identification, you know, through advertising and that sort of thing, people calling in to request an interview, which is how we would find families, you know, of high school students because, you know, because like I said, we were enrolling residents and we were using that as our main kind of method, you know, of finding children. So if we could find a better way of identifying—I mean, if you got, you'd established your alumni, I mean, there wouldn't, you know, there's nothing wrong with that.

MS. NORDSTROM: Well, I'm just wondering…
DR. BRACKBILL: So that was just the cohort, there's nothing, you know.
MS. NORDSTROM: If there's a way to establish basically just…
DR. BRACKBILL: Yes.
MS. NORDSTROM: I mean, just because at the time that the Registry happened, everyone who would have been in high school on 9/11 was in college.
DR. BRACKBILL: Yes.
MS. NORDSTROM: That was a very difficult time to reach everyone because it's a very transient time in your life.
DR. BRACKBILL: Right. Right.
MS. NORDSTROM: And we're talking about 6000 or 7000 students that you don't have the kind of participation that you do for like an elementary school population.
DR. BRACKBILL: Right.
MS. NORDSTROM: But at least in the case of Stuyvesant and I know the schools across from the World Trade Center had very significant exposure because, you know, Stuyvesant went back to school on October 9. So even if we didn't live in the neighborhood, we were there for the entire cleanup.
DR. BRACKBILL: Right.
MS. NORDSTROM: So that's something that has, that I think is maybe a population that we could focus on figuring out how to, instead of just excluding them from the process because they weren't in New York City in 2006 when this outreach started, but could, we could figure out a way to maybe to do outreach again.
DR. BRACKBILL: Yes. Well, the outreach began I think to…
MS. NORDSTROM: To do outreach again to them in a way that is…
DR. TRASANDE: If you're asking about methods—
MS. NORDSTROM: Yes.
DR. TRASANDE: I think, you know, surveys are one thing. Nobody wants to fill out a survey. Right? If you park an asthma bus like the University of Maryland has right in front of Stuyvesant and with the alumni you say, oh we're, you know, here's your free impulse oscillometer. We're going to do, you know, a survey right on the iPad and it's going to be effortless and seamless. Then it, I think you're going to have higher participation on these. The reason we were (able @ 00:47:03) to get anybody to get through this insular Chinatown community was the parents said, 'Oh, my kids are going to get a free reading test. Let me go ahead and do it.' So.
MS. NORDSTROM: Right.
DR. HOVEN: I think if this committee, you know, wants to step back and think about the contribution that you can make as a committee, having learned all the things you've learned, one of the things is that in a future disaster—which you're going to have a lot to say about, you know, how to go about creating a Registry, et cetera—that you need to do it fast. So, for example, when I did my study six months after 9/11, I had a 92% compliance in the schools throughout New York

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City. It's an unheard of level. An unheard of level. I had 2300 kids from the schools in Ground Zero. Right? But it was six months later. The Registry, because of government bureaucracy, et cetera, et cetera, it didn't start recruiting until people were already saying, 'I don't want to hear about this anymore. Go away. Don't talk to me. Don't talk to my kids.'

So the Registry suffers from the delay, which was not their doing, but it's a fact. And that delay should not happen after the next disaster so that we're not sitting here two years from now saying, you know, we should have gotten the community, we should have gotten the schools, we should have, should have, should have. You can do it. You can figure out how to do it and make it available for the next disaster. Because there will be a disaster. And let's not repeat the same mistakes we had here.

DR. WARD: Bill, did you want to…?

DR. ROM: That was very well said. I think going forward one of the jobs of the STAC committee is to make recommendations to NIOSH. Hopefully that they'll be the next five years of the Zadroga Act and it'll be law. I think what we accomplish is we really have some very rigorous cohorts established. And we have some not bad exposure data. But we have a lot of adverse events and abnormalities that we're following. And I think a real focus should be on whether these abnormalities turn into disease entities. And being a pulmonologist, obviously I like lung stuff. But I'm really curious about things like asthma, or wheeze, or cough, or abnormal IOS, or even reduced FEV1, whether those are going to become disease entities, particularly COPD or fibrosis.

So I would be looking for technologies that would evaluate for disease status, particularly early detection, whether it's total lung capacity or quantitative CT or some kind of new functional MRI. But I would really focus on recommending biomarkers of serum, blood, buffy coat that might indicate lung abnormalities or PTSD or cancer. So that biomarker research would be a real priority for NIOSH. And I think for children, as they age and get older and as our clinic cohort ages in particular, cancer is going to be an increasing concern. We have about 600 cancers in our clinic patients at Bellevue. And much of this may be related to the persistent organic pollutants as much as the dust cloud. So working out those cancer relationships would be very important.

I'm not an expert on the mental illnesses, but I think that the methodologies look fascinating to me, whether it's some kind of structured interview or questionnaire. How you get all this data on mental problems, I think that's a real challenge on the methodology. I would love to understand more about how you get such great data.

And then on the review process, I personally think that NIOSH does a fairly good job. But reviews always seem to focus more on the knowns than the unknowns. And I think Leo has made a good point that we need to have reviewers

enlightened enough that they will consider novel approaches as well as an NIH study section that the strength of our investigators seems to be in epidemiology. They're all good epidemiologists rather than basic scientists like at the NIH. And so we're getting pretty good data. But I think NIOSH needs to make sure they have enlightened reviewers. Good luck. And I'd like the committee to comment on, or the speakers to comment on the thoughts that I've just mentioned.

DR. HOVEN: I'd like to speak to the issue of the biomarkers. Because as you saw on my list, I think that's absolutely critical. And I think we now have some important questions to ask of genetic data, of imaging data, and that we should be collecting that absolutely. I have previously proposed a genetic study and thought I was funded with the 36, but they funded at 35. So what could I do? I had an imaging study that I thought was funded at 37, but they funded at 35. So what can I do? But I think the biomarkers are critical and it's time we started collecting them. There's been a little bit, but I don't think there's enough. And I think we have to think about doing it in a large enough cohort. For example, my thousand. I think we have to get some real numbers and some real data.

DR. WARD: Any other comments from the panel? Okay. Go on to Mike's comment.

DR. McCAWLEY: Yes. I'm going to bring us back to the original charge. Because being a simple kind of person, I need simpler kinds of answers. So what I want to ask the panel to do is to go back and give me anywhere from one to three criteria for how you would prioritize what health outcomes we should look at and in which groups of children. I want priorities. And I want criterias or priorities from each one of you if you could.

DR. TRASANDE: So with no disrespect to my colleagues to my right, because this will come out naturally as controversial as best as I can frame it. I think to date the research agenda has focused on respiratory and mental health. And my argument is that we need to extend and think ahead. We've got a cohort of children that are aging into adulthood. Adults procreate. They have cardiovascular risks. As the children age into that era there are, it's common sense that one could think about the disease outcomes that are coming up ahead. And if the program is really trying to identify, document, and link exposures in early life to those types of outcomes, that has to be a major priority. I fully appreciate that we need to better characterize mental health, their developmental and pulmonary outcomes. My simple argument is that if we don't look where we don't know, we'll never find out. This is an inhalational lung injury, though with multi-organ system effects. There needs to be an interdisciplinary approach. So to disregard the pediatric influence on lung injury is to totally miss out on a data set that you're never going to be able to recapture. So I think it, you know, there should be funding quickly. It should be multi-institutional. And it should focus on, you know, novel technologies and biomarkers that will be able to elicit, you know, issues regarding the small airway, regarding inflammation, and the immune system effects. And, yes, they're all

related. I mean, you know, the PTSD/asthma correlation is, you know, well documented in the literature. And, you know, the kidney's going to filter whatever you inhale, et cetera. And you're going to get cancer with a latency of decades if there's really asbestos in the dust. So I think we have to pay attention to all the aspects of what we are exposed to.

DR. HOVEN: Very good question. I think my data demonstrated that you can utilize Registry data with an important child cohort and combine that data in a meaningful life course approach. And what we need to now start doing is looking at these comorbidities in the way that we started to look at them across the mental health and start looking at them as we see here in the association that I showed with the increased morbidity in physical health. And we need to start figuring out that relationship in a more profound way than we've been able to do separately.

So I would advocate for going forward with a large cohort that we look at, both the mental health and the physical health comorbidities, including collecting the biomarkers so that we can begin to understand these relationships. Because, as I showed you, we have this rising population with increased psychopathology. And we also have a rise in the comorbidity with physical health. And so what exactly is that relationship and how profoundly has it been affected by this 9/11 experience? Nobody can answer that. But the data can. And we've gone a long way to making that happen. And I think we just need to go forward with it now and collect the, collect that comorbidity data. And we can answer some of the most important questions that have been raised here today.

DR. BRACKBILL: Well, I think going back to what Dr. Landrigan was saying, that he's looking at occupational epidemiology for highly exposed populations and getting a sense of what kind of health problems they had from the exposure. You can look at some of the Registry findings in adults and sort of talk about what kind of things you might expect in children who are highly exposed. For instance, we do find that there is a relationship between PTSD and stress-related disorders and asthma. We find that, you know, there's kind of a, you know, talking about GERD and gastroesophageal reflux disease, that they all interact with other conditions. So those kind of things you find in adults. And then we also, you know, look at, you know, substance abuse, binge drinking among adults who were exposed in 9/11. I think you'd find that same thing perhaps in adolescents, you know, who experienced 9/11.

The only thing I might say is that you have to think in terms of like sort of age-specific types of vulnerabilities and hypothesize, you know, what kinds of mental and physical health effects you would have. You know, like looking at, we have the first cohort I mentioned earlier. We have children who were of mothers who were exposed to 9/11. And looking at birth outcomes, well, that group, you know, those kids born to mothers who were exposed to 9/11, you can do studies following up their behavioral experience in schools. You can look at school

absences, school functioning, that sort of thing in that same group. So you can look, you know, you can do longitudinal studies on that type of thing. And then as you look at, you know, different other age groups and their exposures you'd have other kinds of hypotheses.

But I think actually the emphasis on the comorbid conditions, which is now, you know, kind of is more of an emphasis in the adults, would also be the kind of things you'd want to emphasize when you look at, you know, follow longitudinally with children.

And to the extent that you think that you're missing the opportunity if you don't move fast enough, I think there's some truth to that. You know, you are looking at children who were exposed, you know, moving into adulthood. And you expect that these things carry forward. You know, some of these effects on their health and their function and that sort of thing. So your opportunity's not necessarily lost. Because we do have adults on our Registry and also in other cohorts who were children at the time of 9/11 that you could follow and you would follow over time, look at, you know, how it goes through their life course.

DR. HOVEN: Two more points I want to make. One of them is I don't think we should forget the children of the first responders and the evacuees. One of the groups that we don't hear much about is the evacuees. You know, that's a very special group. They were just people at work that day. And we have looked at their children and their children are very much affected, as are the children of first responders, whether they lived 100 miles away or 50 miles away. They took home that exposure. And those children are in fact different. And we can't forget that.

And the other thing I think it's important to remember, when we're looking at children and it's already 15 years out and we're talking about going forward, you have to be able and you have to know how to keep a sample. You have to be able to recruit it and you have to be able to keep them. Because you're in this together, you and the sample. And you have to know how to do that. So you need to be able to have good compliance, people agree to participate. And they need to continue to participate. And that's the nature of longitudinal work. You have to keep your sample. So you have to know what you're looking at.

DR. WARD: Okay. I know for sure, Rosemarie, you had your tent up. Val and Anthony, you had your tents up. Did you also have…?

MR. FLAMMIA: I'm good. I'm good.

DR. WARD: You're good? Okay. So we've got Rosemarie and then Catherine.

DR. BOWLER: Thank you. So I just learned more, which is always a wonderful thing being in the committee, from all of you. I've several reactions that we as a committee will need to deliberate. And what I'm hearing is we need to vote, what I'm identifying, we need to identify what it is that we're still needing to, what is missing from the current work we have done. Is it valid? Is it something we can recommend and use convincingly to ourselves in future disasters? So I think both looking at what

is missing now and then looking ahead, having something that's ready for other disasters. And I was on an Institute of Medicine committee ten years ago where we said this is what is needed. You know, or even 15 years ago. You know, we don't have good methods. We haven't even looked at the validity of most of our methods. So improving the methods we have and then dealing with recommendations for the future. So that's one part.

Then what I'm hearing is a lot of discussion of what I would think are important details of selection, representation, recruitment, what, you know, the SES. The many factors like that. That maybe those come after. Once we've decided sort of in general ways to look at our deciding on recommendations.

I also have done a child study in California with the Health Department. And that was 15 years ago. A pesticide problem in the Valley, McFarlane, which is like Delano. Was a cancer cluster. And we went in to study a thou—there were a thousand kids in the school. And I'm sorry to hear that you couldn't get the cooperation of the schools. Because we had. We had the mobile trucks right there on the school ground. We got like 90% of the kids to go through actual medical and psychological testing. It's very difficult to do with children actually. Because as I said earlier, the mental aspect is so important in their cognitive development, for instance. But later we actually went back and looked at the test scores they got in school. There's a lot that's available once you go in there and you have the permission of the parents. And the schools want to help you do that. I learned so how complicated it is to do child studies. Every three months of age is different. Gender is different. And so on.

So, okay, that's just sort of summarizing some of what I'm hearing. And then when we decide of what it is, not the issue to stuff around those children. Three major areas. One is the physical medical, that we have good representation. And I think that it's good we have had wonderful success and still do the Registry of studying the certain illnesses, particularly pulmonary and autoimmune and so on. And then we have mental health. And mental health is not just, it's not just, if we look at the children, it's not just the behavioral aspect of the child. But it's also very much the intellectual cognitive development. Because I suspect just like with adults where now we see that in the new DSM-V, along with PTSD is a criteria of cognitive dysfunction. So I think the same thing is going to come up with children that we see they will have more learning disabilities. It will be harder for them to achieve. So it's the cognitive, the behavioral as part of mental health, and of course the influence of family at home. We always did scales in the child study of the parents as well to see if the mother's depressive it affects the child. Of course.

And then the third major area is the exposure part. And that's also very interesting. The biomarker part. I think it's very tricky. After five years of doing environmental work in Ohio, we were hoping, on manganese exposure and

having the control town—Prior to that, we always thought great biomarkers, blood, manganese and blood, because it was manganese the exposure primarily. But it didn't turn out that way when we had the lower, much lower levels. And of course these are not low levels. But generally environmental exposures are much lower than the occupational exposures. And, yes, we can use that as a model and see maybe lesser effects in environmental studies than we see in occupational studies. And here of course in the Registry we have both. We have the first responder. We have occupational. And we have environmental. The people who just live there.

These are three very big different areas to have. The physical medical, the mental health cognitive intellectual development SES, and the exposure. Those are for us as a committee three areas that are huge. Because they've all disciplines out there. Everyone, all of us in different disciplines, we could say and think this is how it is. And the art is having it all together.

DR. WARD: Let me just interrupt for a minute, Rosemarie. I think we want to make sure to make the best use of the panel while they're here. So, I mean, I think it's okay to give either comments or questions. But let's see if we can engage with the panel on the questions.

DR. BOWLER: Okay. Thank you.

DR. WARD: Catherine?

MS. McVAY-HUGHES: Yes. So it seems like what I'm hearing from the panel, the four general areas of interest seem to be the pulmonology, the cardiovascular, the autoimmune, and the cancer. Those four categories in terms of physical health. And based on what we know about occupational health—you know, because I worked also on childhood lead poisoning way back when—if the parent comes home with contaminants on their clothes, it contaminates their car, it contaminates the laundry and the house. That there seems to be an interest also in doing a specific research on children of the first responders who were daily exposed for a period of time. And that instead of necessarily self-reported, that the focus should be on collecting real results from medical data such as the biomarkers in the bloods. Is that what I'm hearing? I just want to make sure. Okay. You're nodding your head, Dr. Szema. Okay. And Leo too? Okay.

MR. FLAMMIA: Actually, Dr. Landrigan brought up a good thing that's going on over his way with the doctor, the dentist that's doing those studies with the teeth. Might want to explore that as well.

DR. WARD: And Virginia has her tent up.

DR. FARFEL: There's a couple points. I'll just try and make quick highlights in response.

DR. WARD: Yes, sure. Sure.

DR. FARFEL: There's a theme that seems to be under the surface here about using high versus low response as a comparator. And the concern that I have about, or that is to say that looking at highly exposed populations tells you a lot about what's going

on in the lower ranges of exposure. Many of these chemicals are endocrine disrupting chemicals, which don't tend to follow linear exposure response relationships. I do want to flag that as a concern. I don't want to lead people away by, under the premise that high exposure no effect means no exposure at low effect. That's not necessarily the case based upon the literature.

You know, I think the theme of my comment, just responding to Catherine's inquiry, is my anxiety about going towards four categories or more is that I think we have to think about the life course of children as they evolve in the conditions that they develop. And, yes, there are a variety of organ systems that dysfunction across the life course. My suggestion to the committee would be to look at what's in the portfolio, look at how it matches with disease in organ categories, and consider what is not currently addressed by the portfolio as potential priorities. So I think that's the theme of my comment. Thank you.

DR. WARD: So, Virginia. Yes.

DR. WEAVER: So I want to make sure before you all leave that I have a good understanding or we have a good understanding of what research has been done to look at the developmental health outcomes, either intellectual or physical.

DR. HOVEN: I collect a lot of data about developmentally appropriate behaviors and so forth. And I also do an IQ test on all of the subjects. So is that what you're asking?

DR. WEAVER: So, yes, that's part of it. Now, nothing has been done in terms of puberty that I'm aware of unless…

DR. HOVEN: Well, yes. That's not exactly right. We start interviewing kids around the age of nine. And in then we interview them at all ages through adolescence. And we do a thorough assessment of pubescent stages.

DR. WEAVER: Okay.

MS. JONES: Okay. I think some of what I heard was trying to keep people. And the African Americans and Latinos have been a difficult population. I think there's a reality that Tuskegee did happen. I think for me, when you say ten years later you're asking me the same question you asked ten years ago, I kind of wonder what is this about. I can imagine that some people wonder is this experimentation? Because ten years later you should know a little more than you knew year one. And I think that a trust factor I would think would come up at that point. And I think that one of the things that was suggested was I think someone said that there was a truck outside and that people got a pulmonary test. Or they got something for answering these questions. It wasn't just answer these questions and you're getting absolutely nothing for it. You know, you're just answering questions and we asked these questions before.

So I think one of the other things, and when you go out to certain populations, is to ask certain populations what's comfortable to them. I'm not sure that a lot of times when people are poor—African American, Latino—I'm not sure that they're down to have people come to their house because they're being—If you're getting

certain kind of benefits, you have to answer all kinds of questions for people. And all kinds of things can be used for or against you for your benefits. That's a reality. So I think that one of the things, if you're talking about keeping certain populations, you want to find out from that population what is a comfortable way for you to get this information. And I think that's even part of the research is to find out what's comfortable for those individuals. Some people might be very comfortable going to the community center and may not be too comfortable with somebody in their house seeing what's in their apartment that they should or should not have.

So, and I think that one of the other things with the research that you, someone said even with the truck is that they get something. Whether it's people get some teaching, whether they get a spirometer when it's done. You know, what's in it for them other than they've answered some questions, they filled out a form, and somebody now has some more information on them? So I kind of think one of the things in, that's important going forward is looking at the methodology, looking at the people that you want to keep, looking at creative ways to do the research, especially if you, if it's a survey and you're asking questions.

And what is it that you give them in return? What do they learn, what do they get? What's in it for them? Because I don't think most people, especially people that are poor that are filling out forms all the time to get benefits, I don't think they very often see filling out a form and answering some questions as something that's going to benefit them. So if it's not explained how that's going to benefit them, the assumption is it's not going to benefit them. Especially if there's no benefits immediately given or stated that this is a benefit of what you're doing. So I just kind of think that one of the things to look at in terms of going forward is that population. And part of it is doing the research on what it is that will help who you want to keep, what will keep them comfortable.

DR. HOVEN: I'd like to respond to that. I think it was very well put. It's what I was referring to earlier about knowing how to get a sample and knowing how to keep a sample. I pride myself on almost always having at least an 85% compliance and an 85% longitudinal follow-up rate. That isn't easy to do. But one of the things we always do is we spend time appealing to people's better sense. And that is that there's something you, whether you're poor or you're this or you're that, you can contribute to science and to knowledge. And we have a spiel that we give to people and we believe it. That people have something they contribute to society regardless of who they are. And people internalize that and it becomes part of why they stay in our study.

We also give every person who contributes to our study something. Every family gets a health directory that we create for the region. And we give it to them. It's a very nice bound health directory. Has a lot of mental health referrals in it. But we also give them that book that they can keep. We also pay both the parent and the

child. Everyone that participates in our studies gets compensated. We're taking their time. We're intruding into their household. Or go to the library or the community center, wherever they want to do it.
But part of getting and keeping a sample is doing just what you said. You got to appreciate who you're talking to. You have to appreciate that you're intruding into their private time. And they have to feel that what you're doing is important. And if you don't believe it's important, you shouldn't be doing it. But if you believe it's important and you have people on your team who believe it's important, you generally can convey that to people and they want to stay in the study. So I applaud you for making the comments. And I agree with all of them. So I can applaud you because I agree with it.

MS. JONES: I have to say I like the fact that you are very concrete. And it's what I know about people, yes, you pay—you know, you said there was monetary, something was given monetary, something was given physical in terms of a book, in terms of information, and in terms of the attitude of the staff that went to do the surveys. In terms of what they had to say, their attitude, and their respect for the people that they were dealing with. I think respect goes a long way with a lot of people.

PARTICIPANT Done, I think—

DR. SZEMA: I have to make it to parent/teacher conferences on Long Island. So I'm available by email or cellphone if anybody has any questions.

DR. WARD: Thank you. Thank you very much.

PARTICIPANT: Good parent.

MR. FLAMMIA: Just to add to what you were saying. And for you to develop a best practices would probably be instrumental. Because the way you deliver it and the way you do it is best practice management to do it or serve as a model.

DR. WARD: Mickey.

MR. KELLY: I find that it's been very interesting today listening to all the presentations and from all the particular disciplines. And I've been educated. I do believe that what's up there on the board, everybody, there are people working on the physical aspects, on the psychological and the developmental. Think the most important word up there is 'target.' Because this discussion is arising because it was sensed that there is a population that hasn't been targeted. I'd also remove 'which' from that sentence because you have to include everybody, whether they're the young children, whether they're adolescents and now adults. And focusing on that now. But ask the members of the panel what do you think needs to be done particularly? I would say particularly in the physical realm of it, the physical health outcomes. Couple of the people in the, out here who've made comments on it. But that seemed to be one of their major concerns, that they don't believe that there's enough being done on the physical aspects or particularly for the survivor population.

DR. WARD: Great. Thank you.

DR. BRACKBILL: Actually, I'm not clear about what your question was.

MR. KELLY: Neither am I.

DR. BRACKBILL: Yes. Sorry. I just didn't really get, I didn't really hear a question. So I'm trying to answer.

MR. KELLY: Well, the question is do, when you had the members from the public leaving their comments today and one of the particular things that they said was they believed that there has not been a real focus on the physical outcomes for the children, the core population that we're talking about today. What do you think about that?

DR. BRACKBILL: I mean, I agree with that. I mean, I think, yes, I think physical health comes—it's after physical health comes, like I was saying earlier that we're finding among adults, especially the more highly exposed groups of adults, and we are finding physical outcomes. And I think the important thing is that these folks, you know, who, you know, had experienced 9/11 who were there, you know, they experienced a trauma as well. Psychological trauma. So, I mean, that's pretty much part of the physical outcome in terms of its manifestation. I think that's something important to keep in mind. So I think what we're seeing in adults, you know, is a manifestation of the combination of stress and physical outcomes and then behavioral things, you know, substance abuse. We should look at, be looking at that in children who were exposed to 9/11 as well. So, yes, I agree with that. But I think it should be thought out in a context, you know, of the whole, the system—the family, the environment, you know, the resources, that sort of thing. So I think we need to take, you know, sort of more of a system approach, you know, to how we're approaching this.

DR. HOVEN: Just a comment. I think our data showed this increase in physical health status and mental health status. One of the things we have been most recently doing is looking at these contextual issues. You know, what is in the home, what is in the neighborhood, what's going on in the school. Those are very powerful influences on a child. You go to a school that's, you know, that half of the teachers who are not fully certified or you have a violent neighborhood, it has a powerful impact on how that child processes everything. So I think it's a mistake to think you can look at any one of these things. You can look at physical health, you can look at mental health. And you don't have to take in the whole ball of wax. We're all made up with a ball of wax. So we don't walk around as a physical person or a mental person. We walk around as a person. And that means that our environment and everything that goes into it, whether it's our family or our school or our workplace, it's all important. And we have to figure out how to target those questions so that we get the most salient pieces of data. Then we can put it together and say what's going on in this person's life course?

So, you know, I don't have a simple answer. As I said, I've been trying to figure out what's going on with the outcomes of these kids since the third day after 9/11. And I've tried different things and I continue to try different things. And hopefully I

	can make a contribution to understanding it. But I want to go back to the point that you made about who stays in the study. And I think the Registry has done an excellent job of trying to keep everybody in the study. But people drop out at different rates. And the Registry doesn't have the wherewithal to do more than they're doing to keep that Wave 1 representation. My cohort is what is targeting Wave 1 representation, which is not perfect. It has a lot of blacks, a lot of Hispanics, a lot of Chinese, a lot of Koreans, a lot of whatever. And I think it's important, as you said, that we get that representation. And it certainly doesn't have it for the community. And that, I don't have an answer for how to do that. But the community was left out for a variety of reasons beyond the Registry's control. And I think, you know, if there's any way to make that up, we have to figure out how to do it. That's a challenge.
DR. BRACKBILL:	I want to make a comment about the Registry. I mean, we're talking about the, sort of the ongoing representation as a longitudinal study and then people—and there actually has been 1% of the registrants, you know, have withdrawn. I mean, it's less than 1000 I think at this point. That's 15 years later. But the other aspect I want to say is that, you know, the Registry has the capability of matching to other databases, and we have done studies in which we've matched to, you know, mortality, you know, national death index, cancer registry, and then also hospitalization data. So everyone, you know, practically everyone in the Registry, in the cohort we can, you know, get outcome information beyond, you know, what we get through self-report and help. And certainly we've been able to use, even though the exposure information we got at Wave 1 is limited and we had to ask further clarification on the next wave of data, than the exposure question in Wave 1, certainly with dust cloud. And we characterized that, you know, through where people were located, where they were in the dust cloud. We have that information. And what building they're in and certainly, you know, what their address was where they lived. That information is, you know, through other kind of matching and other sources tying and linking other sources, you can create, you know, more than what we have in terms of what people have responded on surveys. So we need to make that point.
DR. WARD:	Catherine?
MS. McVAY-HUGHES:	Yes. Following up on your last comment, when was the last time the Registry data was matched with the cancer registry?
DR. BRACKBILL:	Well, it's matched now. We just had a current match.
MS. McVAY-HUGHES:	Like 2014?
DR. BRACKBILL:	Up to, well, that's what's available. And then you have up until I think it's 2011 at this point.
MS. McVAY-HUGHES:	So that's four years lagging.
DR. BRACKBILL:	Cancer Registry is a determining factor, yes.
:	Right. Okay. So that means the cancer registry is four years lagging then.

DR. BRACKBILL: Yes.

MS. McVAY-HUGHES: Thanks.

DR. WARD: Lila?

MS. NORDSTROM: I think that the point that Val made earlier was really valuable. And I think it can sort of apply to kind of our larger charge here, where I think it's worth sort of—And this is something I think that Dr. Trasande had also been sort of driving at, which is that it's worth us being experimental when it comes to figuring out what our priorities are. I don't think that it's necessarily that valuable for us to sit around and sort of determine definitive kind of goals for research. Because we don't really, like, know what we're, what outcomes we're looking for here. This is an unprecedented event. This is unprecedented, an unprecedented type of research into an unprecedented type of exposure. And that being experimental whether it be in terms of how we do the outreach for region populations, but also what kinds of research we consider is maybe something that in this case is warranted. Because it's not this sort of a cut and dry like, you know, we lived in an asbestos town and then everyone had cancer and we're looking for one specific outcome of one specific kind of exposure or anything like that. I mean, we're really looking for kind of what we can find. And ultimately it's more valuable for us to try, you know, to try things that are unprecedented in a situation like this than to just sort of go, continue to go to the old standbys of looking for the same types of things we expect already to see. And I don't have a question. So that was just a comment.

DR. HOVEN: I would just like to say I think that's the importance of collecting the biomarkers on a large sample.

MS. NORDSTROM: Yes.

DR. HOVEN: So that you can begin to look at what's going on and you can do all kinds of exploratory work once you have those biomarkers. To think that the best way to do it is to go after a few people I think is not a good way to do science. That you need to have a large enough sample. You need to collect good viable samples and then you need to analyze them and see what's there. I mean, that's science. That's not looking for things. That's trying to find the truth.

DR. WARD: So just to clarify. It sounds, when I'm interpreting what you're saying, it almost seems like one approach would be almost like an NHANES type approach where you assemble a cohort, and then you really bring people in or have the opportunity for them to kind of go to a site, get blood drawn so biomarkers can be measured and tissues can be stored and then get, you know, card-, you know, a full range of cardiovascular and other kinds of outcomes looked at. But when we say large cohort really I think one of the 64 million dollar questions is, you know, is it from the Registry or is it, do we try to enroll new people? But it does sound like, you know, one approach would be really more like it. That would complement and supplement some of the more in-depth studies looking at psychosocial outcomes.

DR. HOVEN: I do think that that is the way to go. And I have talked to people at NIOSH that I

think that there should be, just as there are health services funded for in different places, I think there should be a child-focused center that looks in a comprehensive way over the life course of people who were under the age of 18 on 9/11 and, as you said, in an NHANES approach you do multiple different kinds of studies. And your commitment is to follow that cohort over time, for a very long time, and see what happens. And you need a lot of different kinds of data to do that. And I certainly would advocate that that's the best approach to do it. And I think it should be done sooner rather than later. Because people, you need to develop all kinds of techniques for following people when they start moving, when they start getting married, when they start going to live in London, when they start going to live in Hong Kong. You have to know how to do that. And you have to follow them and keep them in the group.

DR. WARD: Yes. Catherine.

MS. McVAY-HUGHES: Hi. I just want to point out, since we just passed, you know, a couple months ago the 14 year anniversary, if the Zadroga Bill gets renewed, we have the 15 year anniversary. And generally at the anniversaries—and this will be a big one—there's an opportunity for renewed focus. And people are going to want to know what the health impacts are, whether they're physical or mental. And I remember a couple years ago there was a conference on sharing data with just general people in the public, whether it was the World Trade Center Health Registry people or people in the clinic. And you could try to do that. And at the same time, in terms of getting the data, you could provide them with some, we have booths or stations that are private and you could get that testing on the spot during some lull points at that conference or something like that as well to draw people back into, to follow them to get them to focus on it again. Instead of, you know, shrinking the end number, you can actually try to bring it up again. Typically, except I would do it in August rather September when everybody's back in school and back at work.

DR. WARD: Yes. And, I mean, I have a question. So, I mean, I think there is general, there is some resistance to the idea of reopening the Registry, which makes sense. Because the, you know, the recruitment's been closed. The people who have entered have, you know, been entered with a set set of procedures. But I think one of the most compelling questions is whether the Registry population is sufficiently representative that, you know, studies done within that population really will satisfy the scientific questions or whether one, if one were to do let's say a major effort to put together a longitudinal study population, would it be wise to really start over again and rec-. Not start over again. I mean, certainly include the people in the Registry and kids. But to consider recruiting beyond that for this new study. What do you guys think about that? I know there's probably a socioeconomic bias compared to the overall population. And there's obviously some concern even about bias by people enrolling who believe their health is

affected. But what's your assessment of the potential bias?

DR. BRACKBILL: Well, I think when you're first saying was it a scientific thing, I mean, is the Registry scientifically valid for answering questions, I think the first thing I thought about was that we have, as far on the risk recovery side of things, we have multiple cohorts. We have the Fire Department and the police and then with Mount Sinai.

DR. WARD: No, I'm talking specifically about the kids.

DR. BRACKBILL: Yes, I know you are. But I'm just saying. But we find that the studies published on all three very different cohorts, the findings from all those three cohorts are almost identical in many ways. I mean, what they find. Even to the point of the estimated, you know, relative risk or whatever. So I think from that standpoint, I think there's a lot of, there's still, it seems to say that there's substantial credibility in terms of what the Registry has about adults. So if you want to try to, you know, generalize that through the children, I think you could to some extent. You know, I think you need to delve in a little bit more deeper into the—Like what I was trying to do today, you know, with the representation as far as census and age group, looking at some of the demographic characteristics and also the high schools where the schools are represented. I think there's some opportunity to take advantage there. And I don't think, you know, we have in some of our analysis. I think we're trying to develop a supplemental cohort at this stage. I mean, it could I guess be theoretically done. But you would miss out on the opportunity of recall, especially exposure recall. Because that would mean your key component of any study you do—and it's, we keep saying that over and over again—is exposure. And if you say that, well, we should have had this exposure information, you know, six months after 9/11 but we gather it two years later. You can imagine you're asking people about their exposure. It's 15 years later. You know, you'd have a problem in trying to, you know, to substantiate the recall. And you'd be basing it on primarily self-report too. So if someone could, you know, could find a way to link up exposure in some other way in a self-report, I think that would be—you know, possible.

DR. HOVEN: I have two comments. One, if you wanted to go down this route—and I certainly would not object—I know that the Registry is not as inclusive as it should be. We all know that. I think Robert's points are well taken that, you know, when you looked across the different samples you had very, very similar findings. So you have to believe that there is something going on here that's quite universal in the affected populations. Question is are there other people who bring something different to the table? And I think if you want to go down that road, you should think about creating a separate RFA and letting those people out there who can do this do it. Let them go out there and find that population for you. It's not necessarily anybody in this room. But there are people who've done this. It's not the first time that, you know, 20 years after an event people have come in and

said, okay, now we're going to study this. And they have to figure out who should be in that sample. You know, what's the inclusion criteria? What's the exclusion criteria? How do you get them in? Who do you want? What are the ages? I mean, it's a science. And if you wanted to go down that route, I would strongly advocate that you don't mix it up with what you're doing with the ongoing studies, but that you create a separate RFA and let people come forward who can do this and compete for the opportunity to do it. Perfectly valid.
Second of all, I don't think you should allow that to get in the way of trying to figure out how to put together the best cohort you can going forward with what we have. This is the best we have at the moment. Maybe we can do better, but we haven't done it yet. So let's stick with what we have and let's do the best job we can to try to understand the life course of these kids.

DR. WARD: And when you say stick with what we have though you're really talking about studies based on the Registry population.

DR. HOVEN: That's what we have. No, but you also have the World Trade Center health clinics.

DR. WARD: Right, right.

MS. NORDSTROM: There's two avenues for data.

DR. HOVEN: That's what we have. But it's in the Registry.

DR. WARD: And just a point of clarification. So the kids that were in your early study with the, that you got through collaboration with the Department of Education, those children cannot, can or cannot…

DR. HOVEN: That's a tragedy. That's a real tragedy and I am, I take full blame for that. I begged and pleaded with the Board of Ed to let me make that study longitudinal. They had no idea it was going to end up being the best study after 9/11 for kids. But they did let me do it. And when I was all done and I was sitting in my office analyzing the data, they called me up and they asked me some questions. And I said, you know, I can't answer them because you didn't let me make it longitudinal so I had no identifying information. And they said, ugh, we didn't realize. If that's what you meant, we would have let you make it longitudinal. It was all over. I had—

DR. WARD: Yes. I didn't mean to bring up a sad story. But I just wanted to…

DR. HOVEN; (Inaudible @ 01:40:21)

DR. WARD: I just wanted to make sure I understood. That is clearly another population that would have been quite valuable had it been possible.

DR. HOVEN: I had 92% compliance. Whoever heard of such a thing?

DR. WARD: Yes.

DR. HOVEN: (Inaudible @ 01:40:32) where you generally get 45.

DR. WARD: Yes. So, okay.

DR. HOVEN: But (inaudible @ 01:40:36). So, you know, the best we have now is what the Registry has and what the clinics have. And if you want to go forward and get

	another sample, so I have, I applaud you for doing it and I would encourage you to do it. Let's do the best we can with what we have.
DR. WARD:	And are all the clinics seeing pediatric cancer—I mean, not pediatric. Are seeing kids? Are all the clinics treating childhood community survivors or just a few?
DR. HOVEN:	Not that I know of.
DR. WARD:	So it's just NYU that are—the populations of children that are being assembled in clinics, that's just…
PARTICIPANT:	To my knowledge, and maybe Mark could answer this, I don't think—I know when there are some of the problems when they come to the Registry, they call me for a referral. And when I have my own cases and I need to refer, I have not been able to refer them to any specialized clinic at NYU or anywhere else. I have to make another entry.
DR. WARD:	I mean, we can follow up and try—I guess what I'm trying to come away from this meeting is just a clear sense of when we say let's use the cohorts that we have, I just want to make sure I understand the cohorts that we have.
MS. JONES:	Wait a minute. I think someone got up to the podium at one point and I thought he was saying that the Registry is planning to do outreach to different populations.
DR. WARD:	But only those that are enrolled.
DR. HOVEN:	I think that was Mark. I think he just ran off.
MS. JONES:	Oh, is that what he meant? Those that are enrolled.
MS. McVAY-HUGHES:	Can I also say we also have a third population, which was Dr. Szema's population, which is…
DR. WARD:	That's right, yes.
MS. McVAY-HUGHES:	Remember that was the third one?
DR. WARD:	Only a portion of it is kids that were in the area. I mean, so he's done a lot of studies now and some of them are of World Trade Center survivor kids and some aren't. So.
MS. McVAY-HUGHES:	It's the largest other one that I'm aware of.
DR. WARD:	Yes. Okay. So let's keep that on the table.
MS. JONES:	Could I just ask the—I don't know his name—
MS. McVAY-HUGHES:	Dr. Mark Farfel.
MS. JONES:	Mark.
DR. HOVEN:	Because, real quickly, that study is so important because it pre-dates 9/11. So the population that he was working on with, was a population that he had all this primary data, I mean, predating 9/11. Like the Fire Department, which also has that.
DR. WARD:	Okay.
MS. McVAY-HUGHES:	Right. Whereas the World Trade Center and the clinics do not. Anne's comment is really relevant.
DR. HOVEN:	Yes. Yes.
DR. WARD:	Yes. For some of his studies. I mean, again, it's presented (inaudible @

01:43:21).

DR. FARFEL: Was there a question for me? I'm sorry.

DR. WARD: Yes, there was.

MS. JONES: Right. You said earlier that you were going to do some outreach into different areas, and I think one of them was the Smith Houses. And so the question was, in terms of who we have, is that people already registered or…

DR. FARFEL: Yes. Yes, right.

MS. JONES: Oh, okay.

DR. FARFEL: So the context was sort of what Chris Hoven was talking about, is the Registry has a cohort, so many children and adults, and part of our job is to maintain the cohort, keep people engaged, have updated contact information. So a lot of the outreach we do is around maintaining the contact. And when I talked about the treatment referral project, that began as targeted to enrollees. Right? You would answer our surveys. We get up to dated health information. And then based on those answers, we'd reach out to people that have 9/11 related symptoms that makes, and/or unmet healthcare needs. And we contact them, encourage them to apply to the World Trade Center Health Program. And what I failed to say earlier is that the outreach for the treatment referral also included the children. Right? So we did try to link the children to the program as well.

DR. WARD: And we did have one question that we thought perhaps you could answer, one additional one, which is are all of the World Trade Center Health Program sites treating childhood survivors? Or is it just a few of the programs?

DR. FARFEL: What I understand is the children, the pediatric population' is taken care of at the Bellevue Center. And they may also include the group in—what's the other site?

PARTICIPANT: It's just Bellevue, Mark. Yes.

DR. FARFEL: It's just Bellevue.

PARTICIPANT: Yes.

DR. FARFEL: And I think I—don't quote me on this—but I think that the pediatric clinic population there is relatively small.

PARTICIPANT: It's about 168.

MR. FLAMMIA: Oh, but no new enrollees, correct?

PARTICIPANT: In children.

PARTICIPANT: Children, survivor children are the ones who are eligible. And that's a Zadroga issue. I mean, if the clinic could do differently, they would.

MR. FLAMMIA: It's just Bellevue you're telling me?

PARTICIPANT: Right.

PARTICIPANT: It's Bellevue is where the World Trade Center Pediatric Program is sited.

DR. WARD: I mean, I guess that's something we can talk about. It does seem like just getting, because if the program were expanded to other sites, maybe that there would be another way of developing a more robust study population. I don't know. Probably, I think we've all had enough discussion. We should take a break.

Because I'm losing coherence here.

DR. FARFEL: Yes, I think maybe—

DR. WARD: And I think we want to thank the panelists, the two that have left and the two that stuck with us. I think your comments have been really valuable. And, Christina, I really appreciated your comment that you made about, you know, yes, think about what would be in a more ideal but still realistic scenario, but also concentrate on focusing on doing the best with the populations we have now. I think that's a very nice guiding principle that will help the STAC as we deliberate on our recommendations. So that was really good. Thank you.

DR. HOVEN: Can I ask a question? The very good suggestion that was made that we get down as a permanent dictum that the work start immediately after another tragedy. You know, how is that going to go forward in other such really (inaudible @ 01:47:07) rules that would do an enormous favor to the first people coming after us the next time something happens? To have that wisdom embossed. How can that happen?

MR. FLAMMIA: That's actually what was said before about preparing for the future. So.

DR. HOVEN: Yes. But, I mean, like do we have a mode?

DR. REISSMAN: But why not hold a specific lessons learned discussion at a different meeting? Because I don't think that's this meeting.

DR. HOVEN: Oh no. Right.

DR. REISSMAN: Lessons learned that have been discussed here need to be embossed. They need to be written down. There is no question. But I feel like, you know, there's an important charge here. And the rest of the time needs to be devoted) to that.

DR. HOVEN: Right. Absolutely.

DR. MIDDELDORF: Go ahead, Dori. Dori, if you would, go to a microphone.

DR. REISSMAN: Just to answer that. I think we are interested in an after—

PARTICIPANT: Go to a microphone please.

DR. REISSMAN: Yes, after action. Yes. We are interested in the, what I'm calling after action or how do we find the lessons learned. And it's something that we've been doing. And we plan to do some of these things. Research translation issues, logistical translation issues. There's a bunch of thinking that is going on in and around that that's not STAC oriented per se. Doesn't mean it might not be in the future, but it's not STAC oriented right now.

DR. MIDDENDORF: And if we ever do want to go back and find out what the STAC has done or was said or been said at the meetings, we always pull it out of the transcripts. We have verbatim transcripts of every meeting.

DR. WARD: Break. Okay, let's take a fifteen-minute break.

[Break.]

STAC DELIBERATIONS AND DEVELOPMENT OF RECOMMENDATIONS

DR. MIDDENDORF: Okay, just a note to the record that all of the members are back at the table, except Rom, who has stepped out, and Tom Aldrich is on the phone, so we can

go ahead and continue.

DR. WARD: So we have reserved a little, about 45 minutes to talk about our conclusions and recommendations after the discussion today. And I don't know if we're at a phase where we—I guess I don't like that theme. I don't know if we're at a point where we can say that we have a clear—

PARTICIPANT: Shh out there. We can't hear our chair speak. Thanks.

DR. WARD: I don't think we're at a point where we can say we have a clear set of recommendations but I think we learned a great deal today and, you know, I think there are several concepts that have come across really clearly that are important. I think there is a—you know, we heard one perspective, largely at the beginning from Phil, which was very oriented towards, you know, using the occupational exposures and diseases as one guidepost for what to look for in children. And I think that has already been done in a lot of the ongoing studies which have focused on respiratory disease and focused on mental health outcomes, and certainly the results in the studies of children dovetail very nicely with the studies of exposed adults. But we also heard, you know, a great counterpoint to that from Leo at the end where he was cautioning us not to keep looking under the same lamppost that we've looked at before but to expand the breadth of the research to include other outcomes. And he was specifically calling our attention to health outcomes which become more prevalent in adulthood, things like cardiovascular disease, hypertension, metabolic syndrome, things that are actually very common conditions in the US population, but also may be influenced by childhood exposures. You know, the other, I think, really important dichotomy that came out was, you know, there is a point of view to really view the kind of exposure assessment paradigms that were used for the responder studies and some of the survivor studies, such as, you know, whether you were in the dust cloud, you know, whether you were on the site on 9/11 and, you know, proximate to that date. But the other possibility is, for children, we may need to look more broadly at exposure scenarios, so a child may have been highly exposed through living in a contaminated residence that was never effectively decontaminated, and that's a different mode. It's more chronic exposure but it could be cumulatively very large. And, you know, attention was also caused through the fact that, you know, the dust cloud is an important exposure for respiratory disease because that's the mode of entry but there may be other routes of exposures and other chemical contaminants that would be important for children and community residents. So I think we kind of assessed a lot of, you know—we kind of had some very important issues laid out very clearly in these discussions and I think that was helpful. It doesn't lead me, you know, particularly—it doesn't lead me to a particularly clear conclusion as to what the committee should recommend in terms of priorities. I do really like the comment that Christina made at the end where, you know, we might come up with—you know, in an ideal world, we'd like

to really see a longitudinal study that would have very comprehensive health assessments of a cohort of children, you know, over a period of time, but at the same time, we shouldn't do that at the expense of looking at everything that can be done with the existing study populations and cohorts because a lot of effort and expense has already been invested in assembling those cohorts and doing exposure assessments. So that's kind of my summary of what I've gotten out of the discussion so far. Any other…?

DR. BOWLER: Maybe a point of clarification in terms of biomarkers.

DR. MIDDENDORF: Microphone, please. Microphone, please.

DR. BOWLER: Sorry. You mentioned biomarkers and I think I didn't hear—the term 'risk factors' was sort of mixed up a number of times. The dust cloud being the dust cloud is a risk factor. It's not a biomarker.

DR. WARD: Yes, sorry if I confused those two. I wasn't intending to.

DR. BOWLER: And I think that's the hard thing, we don't have good biomarkers for it because we don't really know any of the exposure levels so it's tough. It's easier to talk of it as risk factors for a disease or an illness or dysfunction.

DR. WARD: Yes, and I still think—I mean, I do think—when I think of the dust cloud, I don't see it as a—it's a very particular exposure and it's also correlated with some other things like proximity to the site.

DR. BOWLER: It's very important and seeing those pictures today in the slides really brought that home to me too.

DR. WARD: Yes, but it does—I really do take the point, you know, that was made that it's very important for the outcomes that have been best-studied, but there may be other metrics of exposure that are later found to be correlated with other outcomes and we have to keep an open mind about that. I would certainly never do a study and not include whether a person was enveloped in the dust cloud as one of the measures of the exposure. It just may not always be the most important one, although it could be. I think that's what Phil was saying, it may be that it will transcend every outcome. Sorry, Lila.

MS. NORDSTROM: I just wanted to—and I've already forgotten what I was going to say—hold on, come back to me. I had a thought but I've forgotten it.

DR. WARD: It's that time of the day.

MS. NORDSTROM: That time of the day. (I just need a coffee @ 00:07:44).

MR. FLAMMIA: I also think at this point in the game, I mean, we've discussed a lot, we went over a lot of good information, a lot of stuff to consider. The other factor that I actually noticed in a lot of the conversations is the—not sure if the Zadroga Bill is going to be reauthorized. We're within days or possibly a week away, and there's some uncertainty. So, you know, it all comes down to money and how much they're going to do and how much they're going to fund the bill and how much money they're going to put in to do these studies. So I think possibly, maybe another meeting after this is all done and, like I said, we should know by the end of the

week or possibly next week.

DR. WARD: Yes, and I think, again, Paul and I have discussed our plans for the subsequent meeting. I think probably our next meeting will be by telephone rather than in person because we know we have a limited number of in-person meetings and, you know, we'll have to make a decision at the end of this meeting whether we want the workgroup, the smaller workgroup, to come together and, using the transcripts and the notes from this meeting, come up with something for the larger group or whether we want to have the next discussion with the larger group. And we'll also, you know, we may—we'll talk about whether we want to bring back or confer with any other external experts. Paul and I did basically extend an invitation to every person who was recommended by people on the workgroup and some of them could attend but some couldn't. But we essentially tried to bring in everyone who was recommended. So Lila.

MS. NORDSTROM: I just, as one point that I think I mentioned the last time that we talked about all of this, but I just wanted to sort of, like, bring it up one more time, as far as identifying—as sort of quantifying exposure in pediatric populations. That's one of the easier groups to determine the exposure levels in if it's a school-aged person because we know what the exposures in the schools were and then also how many days they were there and what days they were there, and also we have school records to show—you know, there are school health records that you have to have in order to go to school in the first place. So it's not as if—it's not like within the adult population where we would be just, like, starting from scratch and people would be like, 'Oh, I went to work three days a week,' you know, with the sort of vague answers. We have a pretty definitive sense of where a lot of the children in Lower Manhattan were and when and where specifically they were heading, which is to say that maybe it's—you know, I think Dr. Brackbill had talked earlier about how it's hard to sort of—in bringing in new populations, it's hard because sort of over time, there's a lack of exposure recall. People don't really remember their exposures that specifically. And I think with a pediatric population, we maybe have an opportunity to not have that be quite as dramatic an obstacle as it would be in an adult population because they sort of have to go where they're supposed to go during the day. So that was just something I wanted—we talked about it at the last meeting. I just wanted to reiterate that part.

DR. BOWLER: I have a question clarifying the schools. I mean, I don't know, in the local schools, were they open the days after the attack?

MS. NORDSTROM: Well, so they all opened on different days. A lot of the schools that opened later had mostly resident students so they obviously would be students that were living in the neighborhood already. But as far as those schools with the larger populations, they opened on specific days. Stuyvesant opened on October 9. That was less than a month later. That's why, you know, the clean-up being—happening right next to Stuyvesant was such a big deal because we know that

Stuyvesant students were there every day after October 9. And so because of that, we have a pretty clear sense for those non-resident students of what their exposures would have been and, you know, the extent of their exposures, because we know what was happening around them and what days specifically they were there.

DR. BOWLER: But they were then at home for a month, the kids?

MS. McVAY-HUGHES: No, actually what happened after 9/11 was the kids that went to Stuyvesant went to different schools temporarily. It wasn't as though—

MS. NORDSTROM: For only three weeks though.

MS. McVAY-HUGHES: Yes, but it wasn't that you didn't go to school.

MS. NORDSTROM: Yes, oh yes.

MS. McVAY-HUGHES: Because some of you went to Brooklyn Tech, some of you went to—

MS. NORDSTROM: We all went to Brooklyn Tech.

MS. McVAY-HUGHES: Okay, Brooklyn Tech I remember because one of my son's classmate's older brother was at Brooklyn Tech. Then you also had PS 234—

MS. NORDSTROM: Right. They were displaced.

MS. McVAY-HUGHES: Which is a block away on Chamber Street in Tribeca up on Greenwich. And they opened approximately the same time, I believe, as Stuyvesant.

MS. NORDSTROM: They actually didn't go back till February but they were mostly resident students so they—

MS. McVAY-HUGHES: But those were actually residents, where Stuyvesant was a lot of commuter students—

MS. NORDSTROM: Exactly.

MS. McVAY-HUGHES: Versus residents. But again, people always forget about the two local public high schools that were immediately next to the World Trade Center site, one block south and two blocks south, and the majority of those students commuted in, the high school learnership.

MS. NORDSTROM: And Murry Bergtraum also—

MS. McVAY-HUGHES: And Murry Bergtraum, was that even closed at all?

MS. NORDSTROM: I believe that it was.

MS. McVAY-HUGHES: Which is a couple—

MS. NORDSTROM: I'm not positive (inaudible @ 00:13:14).

MS. McVAY-HUGHES: Which is just right next to Brooklyn Bridge.

MS. NORDSTROM: Yes.

MS. McVAY-HUGHES: And then you also had BMCC, Borough of Manhattan Community College there, right there between Stuyvesant and PS 234. You also had the Pace students.

MS. NORDSTROM: Right, yes. But we know specifically what days those schools were open because that's a matter of record, so it's not as hard, for those populations, to sort of figure out what their starting exposure was as it would be for just random people.

DR. BOWLER: And isn't it true the highest exposure was the first—on the day and the few days after was the dust cloud, for instance?

MS. McVAY-HUGHES: It also depended—the folks today didn't really focus on the direction of the wind, but depending—and I think the reason why just not the immediate area was impacted in terms of youth population mentally was, depending on which way the wind blew, you could smell the World Trade Center. You could smell it in Brooklyn—

MS. NORDSTROM: Right. You could smell it every day at Stuyvesant for months.

PARTICIPANT: For months.

MS. NORDSTROM: And the clean-up was happening—you know, there was a day six months later where the globe from the middle of the World Trade Center was sitting—was parked in front of Stuyvesant while we all got to school. Things like that would keep happening so there was a certain amount of continual sort of mental health-related exposure that sort of was an ongoing part of the process.

PARTICIPANT: The traumas.

MS. NORDSTROM: Yes.

MS. McVAY-HUGHES: And then there was IS 89 too which is even—

MS. NORDSTROM: Right, which is across the street from Stuyvesant.

MS. McVAY-HUGHES: Which is across the street from Stuyvesant.

MS. NORDSTROM: Towards the World Trade Center side.

MS. JONES: I think what I heard more than anything was it sounded like comorbid physical and psychological seem to be an issue. And when it came down to most important in terms of children, there's no such thing as this one is more important than that one. What I got was it is important that we look at children, we look at responder's children, evacuee's children, children that went to school, children that were residents, and there's no way to pick out is one child's life or health more important than another one's. All of their lives are important. So that was really what I got out of it more than anything is that—I don't even like the idea of saying that one group of children is more important than another. I think if you're doing research, maybe you choose the group that you want to work with. But I think for me, as a committee, especially—I guess for me, especially when I read the paper and, you know, they're having a hard time passing or refunding Zadroga, I'm like, you've got to be kidding me. So I'm uncomfortable with any group being more important. The children's lives are important, children of responders, children that went to school, whatever. And for me, that's what I heard, is that all of their lives are important and in terms of what might be approaches—seem to be comorbid, you know, physical and psychological together. That was what I got more out of the day than anything.

DR. WARD: I think that's a good point and I think that is a theme that I certainly heard too. But I think one thing that we might want to think about is, you know, when you do a study, an epidemiological study, often you try to, well, pick out the most highly exposed group of children in order to see an effect because if you only have funds to study 500 children or if you would—and so, but I think that we all recognize that

it's tricky to know that but for—just as an example, you know, if you were trying to pick a sample of kids who were exposed by living here, you know, you'd want to look at what were the characteristics that would predict that their apartment was contaminated, right? And then you'd also want to look at the length of time they were here during, you know, like, the four to six month period. So ultimately I think in terms of priority-setting, even if we don't say, you know—if we don't target specific groups of kids in terms of categories of exposure, there still is an issue of, you know, what—would you target specific groups of children because they've had the high—they are bound to have higher levels of certain types of exposure that might be targeted to certain health outcomes? Because ultimately, we are going to want—I mean, anybody who's going to invest in a research study wants to do a study that has the best opportunity of finding an effect if it's there and sometimes level or type of exposure would be a consideration.

MS. JONES: I kind of think too what I heard was when you look at physical, there's one type of criteria probably—I'm trying to think of a good word for it—and when you look at psychological, it seemed like there were other things. You know, so, like, say physical, it might be closeness to Ground Zero, whereas when you look at emotional, it might be that your parent was a responder or your parent was an evacuee or whatever, that the physical and the psychological may have different kinds of risk factors—that's what I'm going to call it—they might have different kinds of risk factors that made it more risky.

DR. WARD: Other perspectives?

DR. BOWLER: Do you think physical—that's why I put a slash through it, physical/medical, medical emphasis, physical, the body, and mental, cognitive, as two different, two…

MS. JONES: Yes, I kind of think that, you know—I think, like one person was saying, the evacuees—I mean, children and especially adolescents respond to their parents. So, you know, a parent that was a responder, a parent that was evacuated may be different than, you know, a parent that went to work on 96 Street.

DR. BOWLER: Wouldn't that go then under psychological, the psychological, the environment would be the psychological, the parent who might be upset, depressed, whatever, dysfunctional at that time. And the physical is bringing home the dust and the clothes and she washes the clothes and they get exposure, the physical, that goes from I suppose exposure and then medical impacts. That's—

DR. WARD: Okay, Lila then Virginia.

MS. NORDSTROM: She can—Virginia can go first.

DR. WEAVER: So I guess I was somewhat reassured today that now that Leo Trasande has been funded to look at some physical aspects, I'm not seeing huge, gaping holes of things that are just not being evaluated at all, with the possible exception of maybe reproductive outcomes which may be—that's kind of why I was getting at the developmental health, to see what had been done on that front. I was

reassured that at least some questionnaire data had been gathered. But I guess reproduction is something that we tend to think about down the road. Other than that, it looks as if many of the pieces are in place to look at outcomes based on the groups that are currently being evaluated. But I think—the point Lila has been coming back to, is that there are gaps in the targets. More so than gaps in the outcomes, there are gaps in the targets. And I'm not sure we have a quick fix for that or an easy fix for that, both in terms of capturing groups, figuring out who would still want to be involved at this point. I mean, you know, 15 years out, you're sort of looking at some people who are just moving on and not wanting to be involved. But I think that that target is something to think about. My third thing that I think may be a gap is funding for clinical care. I had lunch with Dr. Szema today and, you know, he talked about the asthmatics and wanting to do more about their care because it seems that there are a number of these kids who have a lot of symptoms but they're not being treated, and wanting to work with the Zang Center, I think it was—

PARTICIPANT: Wang.

DR. WEAVER: Wang Center, thank you, to kind of have a center-based approach and being told that funding was an issue. So, you know, I think it's important to keep in mind, it sounds like we really just have NYU Bellevue as the treatment place for kids and they're specialists, they know what they're doing, I think it's appropriate, but I do think that to the extent that they could serve as physician extender—serve as, I guess, maybe experts for guidance for centers that are outlying, that are primary care, and to the extent that those centers could be funded to be able to better treat this, I would see that as another gap.

DR. BOWLER: Cognitive you didn't mention. Cognitive has not been studied very well with the exception of our colleague who says she studied the children in their group, but certainly in adults, we haven't looked at that at all. Not a single study other than with four questions and we have four—we have three. So it's an area we need to also target.

MS. JONES: I don't know if this was said, I'm not sure, but I think just going along with what you were saying, I think one of the other things that was stated at a point was the fact that it's just at Bellevue for children and that maybe one of the things to consider would be Gouverneur or whatever other places that, you know, are already setup in terms of providing services for adults, that maybe one of the things would be to extend those services to children at Gouverneur and the other—and any other sites that we have already.

MS. NORDSTROM: Also, I will say that for older children, they can actually get care through the World Trade Center Health Program so that's—but it also doesn't necessarily allow you to kind of, like, be in touch with what's happening in the pediatric populations in the same way, because people my age have never qualified for the pediatric program because, you know, we've always been too old. But one other thing that

I was just thinking about in terms of how we kind of, like, target this question or think about this question is that, at least from the perspective of people in my situation or my sort of, like, cohort situation where we're actually in the group that we're discussing right now, the kinds of studies and the sort of targets that we would like to see—or I can sort of speak anecdotally for me but—are things that really address the quality of life issues that we're going to have going forward, more so than just sort of, like—obviously there's an element of this that's just, in the interest of science, we want to know these things because we want to know about disaster science. But this is ultimately about making sure that—not just, like, that we get this information so that going forward, if this happens again, we know what to expect, but also that we target sort of conditions and things that are going to be the greatest quality of life challenges for us moving forward. So, you know, there are certain gaps in the types of—I mean, that's why I think it's so interesting what Dr. Trasande was saying about kind of, like, being experimental and thinking sort of more broadly than just sort of, like, strictly adhering to, you know, the scientific methodology that we've used before or whatever. Because I think it's important that we make sure to stay ahead of the kinds of unexpected quality of life challenges that people in our situation are going to end up having as a result of these events and of these exposures, and that not all of those are going to be predictable, but they're going to be, like, tangible to us in a way. So that's, I think, something for us to consider as we think about what kinds of research are going to be most beneficial, not just to science but also to the people that are being researched. That's it.

MR. KELLY: On the targeting issue, I think there's a—it's not that it's a problem but it's something that needs to be looked at, is the outreach that has been done in the past was done by contracted vendors. And in the case of Mount Sinai, they were one of the—and they have this same problem reaching out to people and something—maybe it needs to be tweaked so that it could be used to target the children because you need somebody to actually reach out. I mean, obviously the… Excuse me, I just… The people who do the—

PARTICIPANT: The Health Registry.

MR. KELLY: Registry, yes, the registry, there we go. The people who do—they do outreach in their fashion but then there are other people who actually specifically target specific groups. I know this is on the recovery workers end of it. I have a working relationship with one of the people who does it there and I'm trying to get her a list of workers from my unions, two of them specifically, I'm re-targeting them, who worked on them targeting by zip codes. And there's little blockages along the way. My IT guy says, 'Yes, I'll get it for you.' I haven't heard from him in a month. I'm probably going to go beat the [*expletive redacted*] out of him tomorrow. Pardon my… But anyway, but I need to get it, because between the two of us, we'll work out a way we can reach out to a good I would say maybe 35% to 40%

of the people who worked down there and who were the laborers are not in the programs at all. Some of them may not need to be, some of them don't want to be, but we have to sift through and find them. I think in this instance, within groups of—groups, took the word out, groups—children, we need to have that fine-tuned in order to reach out to them in the future.

MS. NORDSTROM: I definitely agree. I think that one of the reasons that my age group is so poorly represented in the registry has a lot to do with the sort of—not just the way that we were unreachable at the time but also the way that the outreach was done in the first place. The people that were conducting those initial interviews were at a call center in the Deep South. This is a group of entirely native New Yorkers who were forced to sit through three hours of slow talking. That's not something that is necessarily a great method for reaching, you know, young New Yorkers. But I think that you make a good point about that.

MR. FLAMMIA: You know, I see—just coming from the monitoring program myself, I've seen the upgrade of their information, the medical records, they're scanning them in, and the technology of having their whole portfolio in front of them of your health conditions, it's great. I think the collaboration should open up to—where other doctors can collaborate with the World Trade Center doctors. Also with the outreach, maybe open up a portal and have—everybody's technological today, even the younger generation and even us, the old generation—to open up a portal to get these questions and to do these surveys by a portal online instead of written. Because if you really sit down and do it—myself as a World Trade Center responder—you sit down, you're filling out pages of information. It's a pain in the neck. I'd rather do it on an iPad or a computer.

DR. WARD: I feel like I might be missing somebody but—yes.

MS. NORDSTROM: Rosemarie was—

DR. WARD: Oh, Rosemarie was—yes.

DR. BOWLER: I don't know if you—I mean, you didn't mention anything about cognitive issues, cognitive problems, and clearly you're a great example of a resilient person, very resilient, and we don't know and don't hear from those who are not. And to have cognitive problems, both for adults and for children, and recognizing it is—A, it makes—you know, they feel very—they know when they don't remember and they're middle aged, working memory or delayed memory problems. And the same with kids, they feel, 'I'm stupid. I can't learn.' And it may be connected to this, so that you can't really totally look from your position as a super resilient ex-kid—that those are very important too.

DR. WARD: I think Christina did mention that she does have some cognitive measures but I'm not sure if all of the results of that have been published and whether, you know, she's looked at the effects and—you know, without a real control group, you know, it seems like it's a difficult measure to look at. But, you know, it is interesting, she has collected a lot of data. I'm not sure all of it's been analyzed and published,

but that would be good to follow up on.

MS. McVAY-HUGHES: One idea that no one's talked about yet is if we can take what we've learned and try to make sure that the young people who were exposed in all of this, that their quality of life is not degraded in some way. So we can try to figure out what can be done to make sure that their life is going to be as good as it is, in terms of physical and mental health. And I think that should be something we consider.

DR. BOWLER: Do you mean maybe that we need to know more about different types of treatment – did they work, did they not work, and what treatments really have worked very well? I don't think we have any—a good knowledge of that as this point because there's a very large unmet—

MS. McVAY-HUGHES: That's exactly what Lila's referring to, looking at things that we haven't looked at before.

DR. BOWLER: Right.

MS. McVAY-HUGHES: And I think what we want to do is think of something proactively rather than having to solve the problem after the fact. And we're approaching the 15 year anniversary and, you know, there's got to, you know, be some smart doctors that can take care of that.

DR. WARD: Yes, I mean, I think that's—to me, that still gets back to the concept of really doing a longitudinal cohort study where you're assessing, you know, a wide variety of outcomes including physical outcomes, quality of life, you know, all kind—employment, education. You know, but you really—I think to draw any kind of really good conclusions from that, you'd need a control group that was very clearly an appropriate control group which is really difficult to define. But otherwise, you know, some of the things that you're looking at are pretty subtle differences and obviously there's a lot of risk factors including socioeconomic factors, you know, that influence all of these outcomes. So, you know, I mean, it is—it's a hard study—I think it's a hard study to do and could end needing to be large and expensive, which again, if that is really the best thing that we want to recommend, I think we can recommend it, but not, you know, exclusive to other opportunities that wouldn't necessarily require that level of resource.

DR. BOWLER: It doesn't necessarily have to be that expensive, because when you say subtle, sure, it's subtle. I have a friend from Harvard who did one paper showing that five points of IQ difference, maybe in one individual you don't even notice it, but you take a population, a large grouping, it's a huge difference. And that's what we have to gain by looking into that as well. If they have—starting out smaller and then adding onto it, if there's something there. But the quality of life definitely is affected, they have problems.

MS. JONES: You know, another thing is the groups that have dropped out. It sounds like when the person got up to the podium, that they are really going to do outreach to that group, so I'm not sure that it's, you know, necessary. But that's another group that I think about in terms of what is going on with that group, that they dropped

out, that they did not, you know, go to the next wave, that that might be another group to study if they don't actually have the outreach—you know, if outreach isn't successful.

DR. WARD: Yes, I mean, so that could be a specific recommendation that NIOSH could consider funding—you know, either that the registry—NIOSH could fund the registry to do additional follow-up to the people who dropped out from the study or could ask the registry for a proposal of how to follow up and improve participation in the subsequent waves. So that could be a very clear and defined, specific…

MS. JONES: With some creative approaches. I'm not sure what the approach was that they plan to take. You know, there may be some creative approaches—to ask for some type of proposal about some creative approaches to study the people that dropped out.

ADMINISTRATIVE ISSUES AND ADJOURN

DR. WARD: Well, I'm not sure how much further we can go today. I think we've all had to assimilate a large amount of information. And I do think—you know, I think it is probably reasonable to make a statement that—kind of along the lines of what Virginia said, that it does seem that, especially with the new wave of funded projects, that, you know, there is good work going on addressing some of the most important outcomes. And so it's real—what we're really looking for is what are the major gaps? And I think, you know, we clearly, from Leo and others, we have a sense of some of the gaps. And probably—you know, again, I guess it's really, for me, a question of how deeply do we want to dig? I mean, the cognitive, like—I just noticed you were still in the audience. I was looking for you out there. But I think, you know, for example, before we say that the… I mean, we have to decide on things like recommendations, like, should we put more study on cognitive outcomes, we would probably have to dig a little deeper and go back to Christina and go back to the literature and see, well, what has actually been published and done? I mean, that's kind of the approach of digging more deeply and getting more into very specific outcomes. So we really have a choice of the breadth and depth of comments that we want to make and what we think—you know, and I think we need to get a sense from NIOSH about what would be helpful to them given how they're planning to use the information. But I would say, in terms of shaping up a committee response, you know, it probably would be nice if we could kind of have some relatively broad themes and then we could also have a list of suggestions that are maybe a little bit more specific but less broad and less difficult to implement, like the specific suggestion about looking at the means of follow-up and ways of increasing study compliance in the registry. But I'm still not even 100% sure that we have the broad—we have a committee consensus or sense on broad outcomes that we would make recommendations about. Does anybody feel differently? Do you feel like we've…?

MS. McVAY-HUGHES: Well, I thought we said we were interested in pulmonology, cardiovascular,

	autoimmune, and cancers, like, for end points. I thought that was something that came up repeatedly.
PARTICIPANT:	Yes, I think it was, but we also mentioned comorbidities.
MS. McVAY-HUGHES:	And comorbidities, yes.
PARTICIPANT:	Yes, I think comorbidities has to be in there too.
DR. WARD:	Okay.
DR. BRACKBILL:	That's the physical health realm. The mental health realm is a whole big category, as big as those four.
DR. WARD:	Okay, so it was pulmonary, cancer, cardiovascular.
PARTICIPANT:	Autoimmune.
DR. WARD:	Hmm?
PARTICIPANT:	Autoimmune.
MS. JONES:	Autoimmune and cancer.
PARTICIPANT:	Did you want to put reproductive in there with children?
DR. WARD:	I think we have to keep that in mind. Maybe not immediately—
PARTICIPANT:	So that should be—
DR. WARD:	—But it's—it kind of goes through the…
PARTICIPANT:	Reproductive?
PARTICIPANT:	Yes, I think we have to keep the reproductive in mind. It kind of goes in the developmental health, the physical developmental health group, maybe not right now but depending on the age of the kids.
DR. WARD:	Yes, I mean, I don't think we've had a great deal of discussion about autoimmune disease. I don't think any of the presenters really focused on it and I don't think we've really discussed it. I know it's something that's been a really important issue in relation to the responder studies, but I don't think anyone has really presented a clear rationale for why that would be a priority in kids at this point.
MS. NORDSTROM:	It's something anecdotally we hear about all the time by the way.
DR. WARD:	From?
MS. NORDSTROM:	From people in my—we get contacted periodically with autoimmune issues that are all very rare. I don't know—I don't have the scientific data on that so I'm not—and I'm not a presenter. it's a topic of discussion that comes up a lot with us.
DR. BRACKBILL:	Yes, it come—
PARTICIPANT:	The Health Registry is studying autoimmune (inaudible @ 00:41:36).
DR. BRACKBILL:	Yes. Well, it comes under that category of comorbidity.
MS. NORDSTROM:	Yes.
DR. BRACKBILL:	Because if you're looking at psychological, now you have a stressor, and the stressors are known to cause dysregulation in the autoimmune system—well, the immune system in general.
DR. WARD:	Yes, I mean, I would feel a little more comfortable maybe, and maybe you can help us here—I mean, there's the immune system and then there's autoimmune disease. And, you know, I think—so allergy would be grouped under immune

system but then autoimmune disease, to me, is a more specific category that's different from allergies and… So what would you say—I mean, because I do want—whatever recommendations we make, I think we do need to have a scientific rationale for why we're making them.

DR. WEAVER: You know, I think allergy gets subsumed in the asthma category and we're not really thinking about World Trade Center exposures per se as being allergens or irritants. But I think autoimmune gets raised because of what's been reported recently in adults and I think with kids, given the life span of exposure, it's a real concern. Now, it's reassuring that the World Trade Center Registry is set up so that those rare cases can actually be collected, because I'm not sure that this is something that you would necessarily go out and start focusing on in a case-control study right now, but you want to have a network set up so that you're collecting information on it, so you're at least knowing.

DR. WARD: So you can write that paragraph. Because I think ultimately—I mean, I do think the thing about the mechanism probably would need a little bit more—you know, the mechanism and the life span, but I think a scientific rationale is there. We would just have to articulate it better.

DR. BOWLER: I also believe and think that not all of us are familiar with all of the studies that the registry has conducted, maybe in our subject area, but not in the others. I know there are a lot of medical articles, and I asked today, there are about 70 articles that have come out from the registry. What if we had—if we have to make recommendations on things like that? If we had just the first page, there's an abstract.

DR. WARD: We do, and actually Paul has circulated—there have been many summaries of World Trade Center literature circulated to the committee—

DR. BOWLER: Oh, I don't—

DR. WARD: One of which I looked at recently and it really is something along the lines of what you're saying. It's basically a compendium of all the studies and the outcomes and…

MR. FLAMMIA: Is that on the FTP that you go on with the password, with all the studies itself?

DR. MIDDENDORF: Yes.

DR. WARD: No.

DR. MIDDENDORF: I don't think that one is. I think it's been sent out by email to each of the members.

MR. FLAMMIA: But there's also a login to the FTP where you can…

DR. MIDDENDORF: Yes, those studies that are in there are the ones that Liz had found that would focus on this particular meeting.

MR. FLAMMIA: I think what we should—I think what I would propose is possibly to get them all in one spot.

DR. MIDDENDORF: Right.

DR. WARD: Well, yes, and I think—I mean, but I think that maybe the kernel of the issue is

that we are kind of endorsing the principle that it is important to look in children at all the effects that have been observed in adults and that a more, you know, a more thorough review be made of the existing studies to be sure that we've captured all of the health effects that have been documented.

MR. FLAMMIA: I'd like to see the sharing and the collaboration with CDC and NIOSH to have all that information available to us as a shared environment.

DR. WARD: Oh, you're saying in an FTP site as opposed to—

MR. FLAMMIA: Yes, it would be great just to have everything in one spot.

DR. REISSMAN: It's on the website.

PARTICIPANT: It's all there, I think.

DR. MIDDENDORF: Yes, I think it's on the website already and if it's not there, if there's things I've sent out to you individually—

MR. FLAMMIA: I think that's in bits and pieces and then you're going to have to search for it and then you're going to have to spend a lot of time to do it. I think for a tech guy to do it, to put it in in one spot, it would be so easy.

DR. MIDDENDORF: Yes, and there are many, many things on the FTP site in addition to those articles, things that were accumulated back when we were doing cancer, things that we've done in the meantime. But as Dori just pointed out, most of that is on our website, if not all of it.

MR. FLAMMIA: Yes, but just to show the transparency of the organization, just to have it in one spot. To go through the website, you've got to go through all the hyperlinks to get to it and it's just so archaic.

DR. WARD: Yes, I think one of the difficulties—I can't remember—is that sometimes the articles, there are restrictions on how freely we can put up the full articles because of publishing. Or can you put everything—can you put the full articles…?

DR. MIDDENDORF: I think we can put the full articles if it has limited distribution.

DR. WARD: So I do know that the—and we can work on it. I mean, I know that I found the latest tabulation by Travis really helpful and we can see what's feasible to do. But it is—I will admit that, you know, lots of times when Paul sends these things around, you know, it's hard to find the time to look at them. But if you look at them, they're really very helpful. And, you know, I do think that this is an excellent website. So, you know, we will make an attempt at this point because I think that's a very important issue about making sure we've seen the spectrum of research that's been done for the adults when we think about what might be important in kids. But I think it's pretty well there.

MR. FLAMMIA: I think from myself not—having a non-medical background, being able to read these studies just makes the picture clearer for me when you guys talk about it.

DR. WARD: Oh, well, yes. Well, having a non-medical background—I think some of these studies are difficult to read, you know, for all of us because they're complex studies.

DR. BOWLER: When were they last updated, the sum total list? Because there have been a lot

of articles published within the last year.

DR. WARD: It's pretty up-to-date.

DR. MIDDENDORF: Yes, fairly up-to-date. I don't remember when the last compilation was.

DR. BOWLER: So it'd be very helpful if—as new people, we could send that list. I've never seen it and I guess he hasn't either. Maybe you email us or ask us…

DR. WARD: We'll work on that.

DR. BOWLER: Thank you.

DR. WARD: Yes, and I don't know how much detail is in these books. I hope everybody picked one up. I haven't looked at mine yet but this is a summary from a research conference that was held two weeks ago?

DR. MIDDENDORF: Two weeks ago.

DR. WARD: And I think—

DR. MIDDENDORF: Yes, that's— that's the May version.

DR. WARD: Okay, but Paul also sent around information from that meeting that we had hoped could be made accessible to us through modern technology, but it was not.

MR. FLAMMIA: I would love to see it because it's just—you know, having the older stuff and the newer stuff all together, it's just connecting the dots all along the line. It would be so much easier.

DR. BOWLER: And could it be maybe organized either by illness or the medical part/

DR. WARD: I think that the compendium that Travis put together did have an index where you could… We'll look at what we have and we'll try our best without burdening the NIOSH staff too much, and get you…

MR. FLAMMIA: Thank you.

DR. MIDDENDORF: And by NIOSH staff, they actually mean me, so…

DR. WARD: Well, sometimes other people help you a little bit.

DR. MIDDENDORF: Occasionally.

DR. WARD: A little bit.

DR. MIDDENDORF: And that's no knock on you, Mia, you do a great job. Thank you for all your help. I think where we are is we need to start planning our path forward. It sounds to me as though we're going to need a workgroup meeting. One thought I had was asking each of the workgroup members to put together, say, three recommendations, draft three recommendations that they think need to be made and then send it to me and I will compile it for the workgroup meeting. I will then try to put together a workgroup meeting together—I will try to put together a workgroup meeting in January and that would be the earliest I can do it because there's a—well, no, the workgroup we can do—

DR. WARD: We don't have to announce it.

DR. MIDDENDORF: Yes, we don't have to do all the announcement and everything. But probably in early January after all the holidays and people can start to think about this again, so probably second week of January or so. But then my suggestion for the committee is that you use that as a way to iron out what recommendations you

	want to bring back to the larger committee, the full committee, to then discuss, think about, and talk about, and finalize in a full meeting that would be held probably about six weeks after that.
PARTICIPANT:	Okay.
DR. BOWLER:	Maybe with the holidays and everything, if you could push it out to the beginning of February, would give us more chance to read what we're getting and get ready for your meeting.
DR. MIDDENDORF:	Yes, I'm just concerned that the longer we put this off, the closer we get to a funding opportunity announcement, and it's more difficult for them to incorporate the thoughts and ideas that the committee comes up with and put it into the funding announcement. So that's why I'm pushing out the timeline.
DR. BOWLER:	Thank you, if you send us that other information—I guess he doesn't have it either and some of the other committee members do not have it.
DR. WARD:	And I guess the question is, I mean, at some point we'll have to—I mean, we may come to a point where we say, look, this isn't—this product isn't as complete or polished as what we wish it was, but it's probably the best this group can do together. Because, you know, I think we're all dealing in an area which is not our area of greatest expertise and, you know, we've brought in the experts and it may just be at some point we have to put down what agreements we come to and may not be able to get any further.
PARTICIPANT:	I thought for the working group to prepare for this actual meeting, that Travis had put together all those articles already.
DR. WARD:	He did.
PARTICIPANT:	Yes, he did, right. And that was in the summer, I believe, so maybe that just gets shared with the rest of the committee or…
DR. WARD:	Well, that's what we have to do. We kind of have to review because I know there were a number of different—there were different—there were probably, like, three or four different sets of information that were sent out at different times, but I think among that was all the information that basically we're calling for. And it's true, some of it may have gone out to the workgroup and not to the full committee. So I just think we need to revisit what we have, make sure it's up-to-date. But it's also a large volume of material and it's a lot to assimilate so…
PARTICIPANT:	(Inaudible @ 00:52:40).
MR. FLAMMIA:	Even an informal way to do it is possibly do, like, a shared Dropbox or shared Google account, where you share the files back and forth.
DR. MIDDENDORF:	Yes, I'm not allowed to use those.
MR. FLAMMIA:	Yes, that's what I figured, but you're bound by regulation.
DR. MIDDENDORF:	But yes, I've got the FTP site that we have used in the past and we've brought it back to life again for the workgroup, the research on cancer. So I will go back, I will look for everything that I have accumulated, and put it into the FTP site, and let you know exactly how to get to it and what the file name is—not the file name

but the folder name under the FTP site.

DR. BOWLER: Thank you.

PARTICIPANT: Thank you.

DR. WARD: Good. Well, thanks everyone. It's been, I think, a really productive meeting and I look forward to the next one.

PARTICIPANT: Thank you, Chair Ward.

PARTICIPANT: Thank you.

PARTICIPANT: Thanks.

PARTICIPANT: Thank you.

[END MEETING]

G L O S S A R Y

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

I hereby certify that, to the best of my knowledge, the transcript of the December 1, 2015 meeting of the Scientific/Technical Advisory Committee is accurate and complete.

1/4/2016
Date

Elizabeth Ward
Chair, Scientific/Technical Advisory Committee