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RESEARCH TO CARE

COMMUNITY ENGAGEMENT ON 9/11 HEALTH

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The verbatim transcript of the

Plenary Session of the World Trade Center Health Program

Research to Care Community Engagement on 9/11 Health

held on October 21, 2017

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WELCOME & INTRODUCTION

DR. LUM: Good morning. I'm Max Lum. I work for NIOSH in Washington, DC and I've been grateful to work on the World Trade Center Program for the last five years. I grew up in New Jersey across the river. My first job was here in New York City with *Time* magazine, lived in the Village, attended the Village Gate, and it's always a pleasure for me to come back to New York City, not just to work, but also to visit. But today particularly it's a real pleasure to welcome you to this World Trade Center Health Program Engagement Meeting so we can talk about the research that has been undergoing by the World Trade Center clinicians and researchers, and how it applies to you, and what are the implications of the researchers. To accomplish that, we divided the session into three kind of distinct parts. The first part really has to do with the panel sessions, two panel sessions of our researchers talking for seven to nine minutes about the research that they are conducting and what the implications of that research is. That's the panel discussions.

The afternoon sessions are breakout sessions where there won't be formal presentations. They're really to answer your questions, starting off with your questions, ending with your questions, that's the whole purpose of the afternoon session. Because we've found that time is short for answering questions often, so we've set aside almost two hours this afternoon to really address particular questions that you have. And by looking at the preregistration questions that you gave us, there are plenty of questions to begin the dialogue this afternoon.

The final session, the third part of the meeting is really the wellness workshop, and that started in our minds as a breakout meeting/ breakout session, but it kind of morphed into a more complete workshop because we have a lot of information about wellness or resilience, and we thought it would be a good idea to share that information with you, what we have and what are the implications actually for your health and for all of our health, I think, in terms of these wellness sessions? And I'll be interested in your evaluation of the meeting, all three of these very discrete sessions.

If I could come back to the panel session that we're going to have, we are livestreaming the morning session panels on Facebook to the people that couldn't be with us here in New York today, that are around the US, and also in Europe. We've got some folks in Europe that are also tuned in because they're interested in what we're doing. This is a first for NIOSH, so we've got our fingers crossed here in terms of our ability to do this, but I think it opens up a huge opportunity for the Institute and for the World Trade Center Program for the dissemination of information. Because we're livestreaming, we're really asking your help this morning in the plenary sessions not to ask questions in the plenary sessions. We don't have the ability to capture you on tape and there's a confidentiality issue as

well. We ask that you please save your questions for the afternoon sessions; and to help you with that, in the folders that you have, we've put in index cards, and hope you'll write your questions down that you have. And we're asking you to do that not because we think you're going to forget your questions, it's because we would like to collect those at the end of the day, we'll have a box, and if you wouldn't mind sharing those with us… If your handwriting is as bad as my handwriting, feel free to print. We've given you a free golf pencil to—so it's your taxes in action right here. But I think it's important to capture your questions and hopefully they'll be answered this afternoon, but if they're not, we will hopefully, if we can work this out, put them on our website as frequently asked questions and provide you with some more detailed answers. The videos from this morning's plenary session will be available in a couple of weeks on the website and feel free to go back and review those.

We are offering CME, continuing medical education, for this session, if there are any health professionals in the audience. I think we had 24 people that were signed up for CME. Please see the registration desk to get the forms that you need which really have a link so you can get credit for the CME session.

The morning session, again, just the morning session, the plenary session is being simultaneously translated into Mandarin, Polish, and Spanish. If those are your first languages. We did prepare brief summaries, very brief summaries of what's going to be presented this morning. We'll have those summaries available in the breakout groups and they are available out on the table outside. We wanted to put them in your folders, but we were just too late getting it back from the printer, to be honest with you. So they're outside. Please take the ones that you're interested in. They're the summaries, again, of this morning's plenary session, and then we will have them in the breakout sessions.

All of this preparation for this, it goes without saying that we've had a lot of help inside of NIOSH really over the last three or four months in putting this together, but the real thanks goes to I think our outreach partners, and outreach partners are, you know, Mary Fetchet at Voices; and Kim Flynn for 9/11 EA, who has been burning up my server for the last month, which is a good thing, Kim, that's a good thing; and also John Feal, who I talked with last night about an interesting story that he has that I hope he might share with you later on in one of the breakout sessions; Liam Lynch from NYCOSH was helpful. We got a chance to attend one of the NYCOSH meetings to see how this might work for us. He's been very helpful in reaching out to his folks. And we had a very early meeting with Micki Siegel de Hernández, who really I think set us on the right course, and we appreciate those comments and have incorporated those in the design of our program. And I think real special thanks goes to NYU who provided us this particular beautiful site. I think you will really like the breakout rooms this afternoon. They're more intimate than this is, and they're tiered the same way, and I think will offer a good chance and a good opportunity to exchange views.

When I looked at this site—we looked at a whole bunch of sites really in New York. When we picked this site, it was Dr. Denise Harrison that I approached first, and she's a clinician here and seeing patients, and I went to her office, and I'm sitting there in her office, and the secretary was very nice, she said, "You're going to have to wait a while. Dr. Harrison is seeing patients." And the room was pretty filled up with folks waiting to see her, so I had a chance to talk to those folks, and you really get a feel of how important our medical staff is in terms of our members, and I certainly got that while I talked to Dr. Harrison and also had an opportunity to share some experiences with the patients. So at this point, I'd like to introduce Dr. Harrison, and if she'd come forward. Thank you. Denise Harrison is the Medical Director of NYU's World Trade Center Health Program and also serves as the Associate Medical Director of Bellevue/NYU Occupational Medicine Clinic. She's completed her residency in internal medicine, a fellowship in pulmonary medicine at NYU, and she works collaboratively, very collaboratively with other World Trade Center treatment centers to really monitor and treat World Trade Center health efforts for first responders. Denise, thank you.

DR. HARRISON: Good morning, everyone. Welcome to NYU. The World Trade Center Health Program Clinical Centers of Excellence, which includes the center here at NYU, centers at Mount Sinai, New Jersey Rutgers, Queens Northwell Health, Long Island Stony Brook, Survivors Program at Health + Hospitals/Bellevue, FDNY, the National Program welcomes you to this Research to Care Meeting.

I would like to personally welcome everyone in the languages represented here today. So in my best Google translator voice, bienvenido, welcome, huānyíng, fun ying, and in Polish, witamy. Welcome.

I know that in addition to researchers, medical and mental health providers, we also have quite a number of World Trade Center responders and survivors in the audience here today. While the researchers and healthcare providers are to be commended for their hard work, I would like to take this time, however, to especially thank the survivors and responders for their contribution to this program and to this community engagement event. We thank those of you that served at Ground Zero. We thank you for coming in regularly for your long monitoring and screening visits, even though there's no food provided. We thank you for checking the box that says, "Yes, I am willing to participate in ongoing research." We thank you for showing up for that research and we thank you for your patience with all of the annoying questions and follow-ups. We thank you for being patient for your certifications, medical reports, referrals, letters, and all the forms we have to fill out. In the words of one former President at Ground Zero, "We hear you."

The World Trade Center CCEs are here to provide an ongoing source of care and support for the next several years. We strive to provide a supportive environment where you can continue to not only receive care, but voice your concerns and

frustrations. In thinking about what I would like to convey about our program, what my vision for our CCEs are, I am reminded of what one patient said once in our clinic. After months of treatment for PTSD, it was decided, and he agreed, that he had completed treatment. During his termination session, after the goodbyes, he turned to his treating psychologist and says, "I feel like I've been kicked out of heaven." I know that this goal for all patients is not realistic, but we like to come close.

The World Trade Center Health Program has gone through a series of growth since it started many years ago and has undergone many name changes that I think reflects the growth and transformation that the program has undergone over the years. First, we were the World Trade Center Medical Monitoring Program, then we grew into the World Trade Center Medical Monitoring and Screening Program, then we grew even more into the World Trade Center Medical Monitoring, Screening, and Treatment Program, until we matured into what we are today, the World Trade Center Health Program, when the James Zadroga Health and Compensation Act of 2010 was established. All the current program operates as Clinical Centers of Excellence. I think the name change reflects the hard work the healthcare providers, administrators, and patients have done to attain a greater understanding of the health effects of 9/11 and to provide care in a comprehensive and supportive environment.

The World Trade Center Health Program, as you all know, is administered by NIOSH, which is part of the CDC within the Health and Human Services. Dr. John Howard is a three-term Director of the National Institute of Occupational Safety and Health. He took on the additional role of Administrator of the World Trade Center Health Program in September of 2015. He is a medical doctor, a lawyer, and a lifelong public health advocate. As the World Trade Center Administrator, Dr. Howard oversees the management of the World Trade Center Health Program. He has been involved in 9/11-related medical surveillance and treatment programs since 2001 and is a recognized expert in the field. Please join us in welcoming Dr. John Howard.

DR. HOWARD: Good morning, everybody, good morning. Come on, this is a health plan. Good morning, everybody.

AUDIENCE: Good morning.

DR. HOWARD: Thank you, thank you very much. It's a pleasure to be here in this beautiful surrounding. Thank you, NYU and everybody that—my god, there's even a balcony. Fabulous. Hi, up there in the balcony. You know, I hope this is the beginning of many of these community engagement events that we hold, so be sure, when you fill out your evaluation form, write, "We want to do this again," okay? Because that helps us spend the money for it, so be sure and do that. I want to thank all the people that Dr. Lum thanked, and especially Denise and everybody here at NYU for helping us get this beautiful setting. But, you know, more than that, I wanted to thank each and every one of you for coming, for all of

you that are on Facebook listening to us, and especially to the researchers that we're going to hear from today.

For those of you that are not familiar with research, it is a pain in the ass in several different ways. One, you have to get the money to do the research, and sometimes you have to fill out applications that are hundreds of pages long, and that's a difficult thing to do. And often you're turned down, and you have to try again to compete and get the money a second or third or fourth time. And then, when you do get the application approved by a funder, like ourselves, you have to get study subjects to participate, and that is also a very difficult thing to do. And then you have to collect the data, and then you have to write the report, and then you have to give the presentation. And you start all over again because one research paper does not prove very much. It's a body of knowledge that we need to move forward. So I want to thank each and every one of the researchers who work in 9/11 health, that come to us with an application, and the ones that we fund, because it's not an easy task.

We're very fortunate in the Zadroga Act, which many of you worked so hard—thank you very much for doing that. We have $15 million every year that we put out for research. And when you look at the length of the program in terms of how it's authorized to 2090, that's over a billion dollars of taxpayer money that is devoted to 9/11 health research, and we're just at the beginning of that research pathway.

And it's going to be extremely valuable for all of us to hear where we're at today, but also as we go through the years for a couple reasons. First, our research helps improve the care to our members, survivors and responders, but more than that, the research pushes our knowledge base forward so we're able to take those statutory health conditions that we were given permission to cover by the Congress and say, "Well, we have sufficient research to add another condition, to cover this new condition," but we have to have the science, and that's where the researchers and people like you that serve as study subjects come in. It is all of our role to push those frontiers, otherwise the program is static and it remains like it was when the bill passed in 2010. But for the next 75 years, we may learn a whole lot about the chronic conditions that arise from 9/11 exposures. So we're all a community of researchers, really, working towards the dynamism that we need for this program. So that's my way of explaining how valuable it is to hear from our researchers today. We are privileged in the program to fund all of the researchers who apply to us with good applications. We hope they continue to do that for the length of their career. We hope that you'll start recruiting other researchers to apply for our grants, to push the knowledge base forward. It's a tremendous opportunity that we all have to participate in research. And I want to thank the researchers today who are going to present their findings. It's an impressive activity that we have in front of us over the next 75 years, and I think that one of the things that I wanted to do today is to be able to thank all of you who got us to

the 75-year mark. It has been a struggle, to say the least, and some of you have struggled for years, and I thank you for that. But the program is in good shape. We have our challenges which we're trying to meet, and I want to thank everyone in the program who is here today for their work in the program because without them my job would be impossible. So thank you to all of the folks at NIOSH who are here today, thank all the researchers, thank all the members, survivors and responders, and I hope that you have a wonderful day. If you ever have a problem with the program, you know where to find me, reach out, send me an email, contact us. We want happy, healthy members. Thank you very much.

DR. LUM: Thank you, John. I can't wait to quote your comment about research in one of our newsletters, so I hope we have that permission to do that. If I could invite the first group to come up here, the first group of researchers, please, the first panel. I'll introduce you. Thank you. Thanks, thanks. So again, we thank you for coming, as John said, and also I meant to thank 9/11 Health Watch earlier, Ben Chevat, for providing us the food that's outside. So hopefully at the break there will be some left, but let me remind you we're not allowed to bring food and drinks into the auditorium. So I'd like to introduce the panel, the first panel's chair, and that's Dr. Jackie Moline. She's an occupational medicine specialist and Professor of Occupational Medicine, Epidemiology, and Prevention Internal Medicine at Hofstra/Northwell School of Medicine, and she obtained her medical degree from Pritzker School of Medicine, the University of Chicago. She completed an internal medicine from Yale University and her occupational and environmental medicine degree is from Mount Sinai School of Medicine.

PANEL DISCUSSION 1

DR. MOLINE: Good morning, everyone, and good morning, everyone out there on Facebook. We're thrilled that you're here. I have the pleasure of moderating the first session today. Our first panel discussion today will be covering what we know 16 years later from both acute and long-term health effects. We have a great panel here today and our panel will focus on physical effects among multiple populations that include survivors, including children, as well as responders. We'll be summarize ng some of the research that's been done among our cohorts or groups, along with the larger and different populations with the Department and the Health Registry. Now, the bios for everyone are in your packet and I'm just going to give a very brief title introduction. Joan Reibman is the Director of the NYU/Bellevue Asthma Center, Director of Health + Hospitals Corporation World Trade Center Environmental Health Center, and Associate Professor of Medicine and Environmental Medicine. I'd just like to—Joan and I have been participating in community fora since October 2001 when we attended one downtown, I think it was at Manhattan Community College, in the aftermath of 9/11, and these opportunities for the community and for the responders to have a voice and to

participate are vitally important. Dr. Laura Crowley is the Deputy Medical Director of the Selikoff Center of Occupational Health at Mount Sinai Hospital and Associate Professor of Environmental Health and Public Health. Next to her is Dr. Roberto Lucchini who is a Professor of Environmental and Public Health and Pulmonary, Critical, and Sleep Medicine at the Icahn School of Medicine at Mount Sinai. Dr. Mayris Webber is a Professor at the Department of Epidemiology and Population Health at Albert Einstein College of Medicine. Dr. Leo Trasande is going to be talking about the effects of World Trade Center exposure on adolescent lung and heart health. He's Associate Professor in the Department of Pediatrics, Associate Professor in the Department of Environmental Medicine, and Associate Professor in the Department of Population Health at NYU. And Dr. Mark Farfel is from the World Trade Center Health Registry where he is the Director, and that's part of the New York City Department of Health—and that is not Mark Farfel, that is Robert Brackbill, who is—we can change on the fly. Good thing I know him too since about 2001.

You know, we have a phenomenal panel here and I have a very hard job this morning which is to keep them on time so that they can impart some of their knowledge and wisdom to all of you about the program. You know, I've been a part of these programs since their inception, when we started the World Trade Center Worker and Volunteer Medical Screening Program at Mount Sinai, and saw our first patient on July 16, 2002 at Mount Sinai. And as the program has morphed and expanded, what I have been struck by is the amazing—what we've learned from the wonderful men and women that are our patients. I have the pleasure of leading the Queens, the Northwell World Trade Center Clinic now, so I've been part of this community now for 16 years, and not only do we learn from our patients, but we have the opportunity to learn from each other.

So without further ado, I'm going to give you the opportunity to learn from my colleagues here, but I do want to just give a shout out to the phenomenal support we've had over the years from Dr. John Howard and the amazing folks at NIOSH who have been integral partners in getting this program running, getting this program continuing, allowing it to morph into what it has become, and hopefully allowing our input to make it even better, and allowing your voices to continue to make it better in the future. So without further ado, I'm going to ask our first speaker, which is Dr. Joan Reibman, who is going to be talking about lower respiratory symptoms in the World Trade Center Survivor Program, to start.

DR. REIBMAN: So good morning. It's a pleasure to be here. It's actually pretty amazing to stand here for, I don't know, almost 16 years, I guess, and see many of the faces that we have grown up with as we have been working to understand the health effects in the community that was near the World Trade Center. And so today I have a very short period of time and I'm tasked with telling you a lot of information, so I'm going to try to tell it as a bit of a story and put it in context because, again, this is a very diverse audience and I want it to be clear.

So I'm the Medical Director of the World Trade Center Environmental Health Center for the survivors and community members, and my background, as you've heard, is really I began as an asthma doctor, asthma and environmental issues were my interest, and I've been at NYU and at Bellevue and at Health + Hospitals for many, many, many years, and I'm now a professor there.

What I would like to do is sort of start by giving you some definitions so that we're all talking the same vocabulary. And the definitions I want to give you are really, when we're talking about the respiratory system, we really think about it as one unit, but we break it up into upper and lower, the upper being your sinuses, nasal passages, and vocal cords, and the lower being your bronchi, the tubes in your lung that branch into many, many, many tubes and end up in small airways and in alveoli where you do gas exchange for oxygen and carbon dioxide. And it's important to understand that because that's how we talk about respiratory disease or respiratory illness in the population that was exposed to World Trade Center dust and fumes, whether it's the responder population or a community population. And when we begin to understand what's happened to the airways, we start with really the first thing which is symptoms, and symptoms are how somebody feels. They're not a diagnosis. Upper airway symptoms are postnasal drip, fullness in the face, facial pain, cough. Lower airway symptoms are cough, shortness of breath, chest tightness, wheezing. And what you notice from this list is that there's overlap, that you can have symptoms that are upper airway that are also lower airway, and that a symptom really only tells you a problem, it doesn't tell you a disease. It tells you that there's something going on that you have to figure out. So how do we figure that out? And that's not so easy and that's where the role of research comes in and that's where understanding disease mechanisms come in. We do physical exams, we do questionnaires, and we also do tests, and we do a lot of tests, and we ask people who are coming into our programs to do a lot of tests. And those tests include many, but one of the first ones we always do is something called spirometry where we measure lung function, and when we're doing that, that gives us a lot of information, but there are a couple of—actually three main things it gives us. One is how much air you can blow out. That's very important. The second is how fast can you blow that air out? Because you should be able to blow out almost all your vital capacity, that's vital because it's vital for your life, how much air you can blow out, you should be able to blow most of that out in one second. And if you can't, it means that there's an obstruction in there and that that may be something that is blocking that airflow. And the good thing about spirometry for research is that it's used a lot, we have standard values, it's relatively easy to do, it's noninvasive. But the bad thing is that the normal values are epidemiologic, they may not pertain to you as an individual, often we do it at one time point so you don't know where you're starting from or going to, and also it tells you mostly large airway function. It doesn't always tell you what's going on in those smaller airways. Also, it tells you a single point in time. So for example, in

a disease like asthma which is variable, you may not catch the abnormalities at the time that you're doing spirometry. So spirometry, which is our standard that we start with, is enormously helpful, but it doesn't tell us a whole story. So other tests you're going to hear about today that we can do are studies, for example, looking at twitchiness of the lungs, and we do that with what's called a methacholine challenge test. We take a chemical, we ask you to breathe it in, we measure your lung function, and that tells us how sensitive your airways are to external exposures, to other chemicals, for example, or just other exposures in the air.

So when we started our studies, we first had to understand what individuals—and I'm speaking here of community members, but clearly this pertains to others—had been exposed to, and how to describe the exposure, and how to link that exposure to symptoms and lung function. And although we never developed a perfect way to describe exposure in the community members, we've known now through studies we did with New York State Department of Health and then subsequently with the New York City Department of Health that we can think about exposures to community members as acute exposures, those that occurred on 9/11, as well as chronic exposures, those that occurred in response to the re-suspended dust and from the fumes from the fires that burned. And we now know that in fact, through these studies, that we can associate exposure with symptoms, so that gives us a dose response or an exposure response, and that's critical when we're talking about environmental health and understanding the impact of an environmental exposure. It's sort of the first thing you need to be able to do.

So then the question was: what was the disease? And early on we got clues from this from the fire department who described in fact airway hyper-responsiveness or twitchiness in the firefighters, and this made sense because, as we began to understand what was in that dust, we knew that it was caustic, that it had a pH of 11, and that that was going to in fact cause a burn, but there was something more to understand about that dust. And we knew that there were about 1.2 million tons of material that were deposited throughout Lower Manhattan and in Brooklyn, but for pulmonologists, you have to understand what is that dust made out of and also what's the size of that dust or the particles? Because size is important because it tells you where it's going to impact in the upper and the lower airways. And our dogma had always been that a particle that was larger than 5 micrometers was not going to get down into the deep airways and couldn't therefore do damage, but might in fact do more damage to the upper airways. But we knew that, in fact, a lot of the particles were bigger than that, they were smaller, and so what we understood was that some of that was going to get past the normal protective mechanism, the mucociliary escalator which would protect your lungs, and might in fact get into the small airways. But we weren't sure how to look at that, but we wondered—we got clues that, in fact, some of these particles were getting deep into the lung. The first clue was from a firefighter who was admitted to Bellevue

Hospital, got his lungs washed out, and we identified particles that were in fact large deep in his lungs, and this was published, this manuscript was published. We got additional clues from work done, again, in the firefighters by a woman aptly called Fireman, who many years later showed that sputum had particles, and we got clues from the survivor group when we did biopsies of some of these people and looked in the lungs themselves and saw particles within the lungs itself. But how could we look at this in a larger population and measure this?
So when we began studying community members, we did spirometry, we looked at how much air you could blow out, how fast, and many people had symptoms, but had normal spirometry. So we put in place another test that we didn't fully understand called forced oscillation and this test was a noninvasive test and it was pretty easy to do. You just had to breathe regularly and hold your cheeks, and what this technique did was to measure how airflow is distributed in the lungs, and when there's disease, the airflow is no longer uniformly distributed, and so if there was disease in the small airways, we could detect abnormal measurements. So we did this routinely in our population and what we found was in fact there were lots of abnormalities, but we didn't have normal, so we worked with the Department of Health, with the Registry, and we did a huge study, and we were able to show that in fact we could detect abnormalities associated with symptoms in people who had normal spirometry, suggesting that many of these people had small as well as large airway abnormalities.
I'm told I have to wrap up so I will move pretty quickly. But we now know that injury can be varied. We know that it depends not only on the size, on the components, but also on individual susceptibility. We also know that the damage can be heterogeneous, that it might present as asthma in one person and as a different disease in another person. And the question now, 16 years later, is what's happened to individuals who have these persistent symptoms? And the answer is varied. When we measured spirometry over time, we in fact saw improvement. In fact people seemed to be getting better in their large airway lung function. We haven't finalized our analysis of the small airways. We looked at causes and we looked at components of inflammation and we showed that in fact there's a variety of types of inflammation that we can see in our population, not surprising if you understand the asthma literature, but we showed that in fact some people had eosinophils as a type of inflammation that was associated with some of their symptoms, other people had elevation in different types of systemic inflammation that was associated with small airway disease. And then most recently with funding from the Centers for Disease Control, we've asked a number of people to come in, we have put them on a high-dose medication for asthma, we have asked did their symptoms improve or stay improved? And in fact what we found, almost 80 people participated in this pretty intensive study, and what we have found is that in fact, despite being on all these medications, some of them still had symptoms, lower respiratory symptoms. So we put these people through

a battery of tests, very detailed, we did extensive lung function testing, we looked for airway hyper-responsiveness, we did a vocal cord evaluation. And the data is still not published and not fully analyzed and we're still looking at it, but what it's beginning to suggest is that many of these people still have persistent twitchiness, twitchiness in their airways, twitchiness in their vocal cords, and also some abnormalities in their small airways. And this is very important for us because, as we talk about going in the future, this helps us figure out how do we need to now manage these individuals? What are the medical approaches that we can do? How do we target the treatments that we're going to need to do? And also tells us that there's more to learn and we need to think about how else to approach many of you who still have symptoms, although, as our data is also showing, many people are beginning to improve and have resolved their symptoms as well. So I hope I did that in a short time. Thank you very much.

DR. MOLINE: I told you I have the hardest job which is telling people when their time was up when they have such great information to impart, and I apologize in advance for having to start feeding you wrap-up messages, but we want to make sure all the panelists get their time.

So Dr. Laura Crowley is going to be talking about pulmonary health effects in World Trade Center responders. Dr. Crowley?

DR. CROWLEY: Thank you, Dr. Moline. Good morning. First of all, I'd like to thank you all, especially NIOSH, for the opportunity and invitation to speak today. I am under the direction of Dr. Crane, who is sitting to my right and Dr. Lucchini who is up on the panel now, and I'm with the Mount Sinai Responder Program. I'm going to do my best to follow Dr. Reibman and speak briefly about where we are with regards to lower airways disease. I do not intend to go over every publication that's been published to date regarding lower airway disease, because that would be an entire day, but really just touch upon how we got to where we are today and the pattern that kind of brought us here.

So there's certainly been a number of studies through the World Trade Center Program evaluating lung conditions in those exposed, and all of these have contributed in some way, shape, or form to what we know about lung disease in our responders and survivors today. The keyword is "all", and I'd like to pivot off of what Dr. Howard said in terms of needing more than one study to show evidence that there's disease in this population, and we've been fortunate enough to work very closely with our colleagues, both at the Survivor Program and with FDNY, to work together in research and show that certain diseases are cropping up in all of our cohorts.

So currently the World Trade Center Program covers several lung conditions – asthma, COPD, sarcoidosis, interstitial lung disease – and we'll certainly be talking more about these later today. However, the history behind how these conditions came to be covered conditions really should not be ignored. It certainly gives us perspective as to what has been done to date and it really sets the stage

for considering how we're going to move forward. So in taking a step back and reflecting on what Dr. Reibman said earlier, early on with exposure, we were seeing immediate symptoms, both upper and lower airway, specific to lower airway, as Dr. Reibman mentioned, cough, shortness of breath, wheezing, tightness in the chest, and certainly it was at this point when physicians were seeing these symptoms, it was like a red flag. So thinking about the research around that time, it was very symptom-driven, and in 2004, there was a group of physicians that banded together looking at about 96 ironworkers that worked at the site between September 11 and February of 2002. And it really had a pretty big impact because it showed that 77% of the patients were complaining of respiratory symptoms, with cough being the most common. In addition, there was the five-year study that was put out and published by Dr. Moline, Dr. Herbert, and Dr. Levin that similarly found elevated respiratory symptoms and abnormal breathing studies. Most of you are familiar with those tests that we do on a year to year basis to evaluate lung function, as Dr. Reibman described. So those objective tests became very important because they justified that what we were seeing from a symptom perspective could be acknowledged in a data way. So in the study that Dr. Moline published with Dr. Herbert, we picked up that forced vital capacity, which is a number that we look at on the breathing test, was noted to be abnormal in 24% of our patients. Forced vital capacity is basically representative of, when a patient takes a deep breath in, it assesses how well they're able to blow all that air out, and 24% of our patients were showing an abnormal value. So why was this important? Well, one, we had that objective data point along with symptoms. And two, it realized, you know what? These symptoms shouldn't be ignored and we really need to monitor these folks for long-term surveillance purposes to see if these numbers continue to decline, stabilize, or if there are any other conditions that may be associated with these abnormal parameters.
So in addition to the breathing test, we started to look obviously at chest x-ray, CAT scan, and evaluate the impact of what we were seeing in our patients with regards to those imaging studies. And in 2007, Dr. de la Hoz and his colleagues looked at CAT scans in our responders and found that we were seeing some abnormalities in the airways that are much deeper in the lungs. So it was at that point in time when we realized, well, certainly diseases more in the upper area, like asthma, bronchitis, and cough, were of concern because that was immediate and acute exposure, but then long-term effects, was that going to have an effect deeper down in the lungs, in the lung tissue? And we realized shortly after, with the research that the fire department put out, that there was a disease called sarcoidosis which shows that the lungs can get inflamed and have enlarged lymph nodes, was cropping up in the cohort. And it was around 2006 when we had a federally-funded program for a treatment program and it was at that point in time when we were categorizing diseases and figuring out which diseases could be covered. And we had asthma, bronchitis, chronic cough, and COPD, but with the

literature that Mount Sinai put out and the literature that the fire department put out actually before us, we were able to say, you know what? Sarcoidosis is probably one of those conditions we should put on the list. Shortly after, there was a publication by Dr. Moline and some pathologists, it was identifying that interstitial lung disease, which is a scarring of the lungs that can happen, was noted to be found in seven of prior healthy patients. That was concerning, we flagged it, and it was considered a covered condition. So this just goes to show you that, as time has progressed, the thought process behind research has evolved. So it starts out with symptoms, and then objective testing, and then we categorize the disease, and then moving forward, we've come to understand that comorbid World Trade Center disease plays a role as well. And it was in 2011 when Dr. Wisnivesky looked at our 27,000 responders and identified that we were seeing elevated cumulative incidence of asthma, sinusitis, GERD, kind of looking at the population as a whole in terms of all the different types of diseases that we were seeing and how it was impacting respiratory upper/lower, GI, and mental health.

So this kind of brings us to where we are now with research. So we have symptoms, objective findings, disease recognition, and now led to evolution of care in terms of inclusion of lower airway disease, and interaction of these conditions and comorbidities, and understanding the progression, and how some of these diseases may stabilize or progress, and how can best manage and treat. Currently, Dr. Wisnivesky is working at Mount Sinai on looking and assessing inflammatory and behavioral pathways linked to PTSD and increased asthma morbidity. Prior to that, he assessed how we can best monitor patients with asthma in our World Trade Center population and determine the best course of treatment and management interventions. Dr. de la Hoz, who is here today, will be speaking about his study regarding pulmonary disease and CAT scan and how it correlates to respiratory symptoms in our responders, breathing tests, and their occupational exposure.

So to attempt to sum up the importance of the program in a few lines would not really do it justice, but what we can say, it's important to note that the World Trade Center Program works to provide excellence in care for all our patients, to learn from our responders, survivors, and volunteers by studying World Trade Center covered conditions and how we can better monitor and treat these conditions, and certainly to use the lessons learned to maybe even understand areas of disease that remain a bit of a mystery and are less understood in clinical medicine to date. So with that, we and I extend a special thank you to all of the responders, survivors, and all of our partners at labor, and certainly of course Dr. Howard and NIOSH. Thank you very much and looking forward to an exciting day.

DR. MOLINE: Well, I'd like to thank Dr. Crowley for making my timekeeping job very easy. You know, you're going to hear a little more about this in the second session this afternoon from Dr. Markowitz and Dr. Prezant, which is how new conditions are considered to be added. And I know there have been a number of questions

regarding autoimmune conditions and when they're going to be added, and hopefully you'll learn the framework with which petitions are made to include new diseases. And, you know, this process happened in around 2010, 2011, which was—as you heard about the respiratory effects from Dr. Reibman and Dr. Crowley, that was an initial focus along with many of the mental health effects, but we used to say it was the -itises, meaning the inflammation, where people had bronchitis and sinusitis, and asthma doesn't have -itis, but we'll make it asthma-itis for today, but all these diseases that affected the upper and lower airway along with PTSD and some of the mental health sequelae. But then the questions started very early on, actually, in 2001 people were asking us about cancers, but the question really needed some science behind it. And so the next two speakers are going to be talking about how some of the research has gotten to the point where, in 2012, cancers were added to the covered condition list based on studies that were done. So the first speaker is Dr. Roberto Lucchini who is going to be talking about post-9/11 cancer among World Trade Center General Responder Consortium patients.

DR. LUCCHINI: Thank you, Jackie. Thank you. I would like to thank everybody for inviting me. This is a great opportunity. Thank you, Max, for putting it together, Tania and Dr. Howard and all these excellent, great colleagues. It's a pleasure for me to be here. So when we talk about cancer, of course we have to focus on carcinogens, so this is why we're here and this is why we're talking about cancer. So talking about the carcinogens is the most important point here that we have to focus on, all right? So we have a list of them and this is information that we have because of measurement that had been done on the settled dust. The settled dust is the dust that deposits after whatever happens, so you can collect this dust and you can do a lot of analysis, and that analysis is extremely, extremely important for our knowledge. This is the first, always, exposure assessment, it's called, exposure sciences, this is a very important field for us in occupational and environmental health because we are dealing with exposure constantly, so we need to know very well, as much as we can, what are we dealing with? So in terms of exposure, in terms of the analysis in the deposited dust, we have chrysotile asbestos, everybody knows about asbestos, and so I don't need to talk about this further, because it's a very powerful carcinogen. Unfortunately it was present in the buildings. When the building collapsed, a huge amount of asbestos came out and that became the exposure. Then we had—well, lead is another carcinogen according to IARC nowadays, then PCBs, polychlorinated biphenyls, and benzene, benzene is another important carcinogen we have known for many years in occupational health. And the list goes on with dioxin and diesel. So this is a mix of carcinogens that is unprecedented, so I think this is an important knowledge for us to maintain. Of course we are exposed to carcinogens, unfortunately, every day. We breathe carcinogens, we are exposed to them, but that was a particular story. That was a special moment where the people, the

responders, the workers, and the survivors, and the community were exposed to a high mix of carcinogens, and not only that, our knowledge about these carcinogens is based on the exposure to each one of them, right? So here we have a mixture, a co-exposure to different carcinogens, so the knowledge that exists about this co-exposure to a mix of carcinogens is not exactly the knowledge that we have based on each one of them. This is an important point to maintain. Before coming to this program in 2012, you can tell by my accent, I have been working for 20 years in Northern Italy in the area of Milan. In that area, in the Seventies, there was an outbreak of dioxin because of the first episode of a toxic cloud; it was an industrial accident. And in that case, it was the exposure to dioxin, just one chemical that happened to be a carcinogen too, and research in that case was very, very important. Even now, many years later, research is still going on, and it's very important also as an example of this kind of relationship with the community where it's important to maintain feedback between the researchers and the members of the programs. So it's important, this knowledge about the exposure, and it's important for us to study about the health effects. It's not easy. It's an important challenge. We have to collect data and we need to match data with registries, registries for many states, because we have to collect the numbers of all these cases of these cancers, so this is a very, very important challenge and it's a very important activity that is ongoing, basically. What we know, and actually I would say that, as Dr. Moline just said, the importance of this is there is a latency period before these cancers are actually identifiable. So before waiting for the latency period, it was very, very important for the program to recognize that cancer can be certified and treated by the program. So this is very, very important. It's important to continue with the research because we need to know the details, we need to know whether there are other emerging problems, but it's important that the program actually has this opportunity to treat cancers that are affecting the responders and the community. The first studies, I think three important studies came out in 2012, 2013. These are the first studies that came out from the firefighters, the Registry, and the General Consortium. These three studies were actually done in more or less the same time, but the data were updated to 2008, so now we need to update all this information, but already there, in 2008, it was already clear that there was an excess of all types of cancer, and especially of thyroid, prostate, but also some other cancers like melanoma not restricted to the skin and non-Hodgkin's lymphoma and multiple myeloma. So this was the first evidence that came out in those years, and now we are continuing to update these results, and it's going to be important to understand what's going to happen in the future. There is an important new study which has actually been funded and this study will be actually one merged cohort and this is going to be a cohort of FDNY, the General Responder Cohort, and the Registry. This is going to be a very powerful new study because the three cohorts will be merged into one, so this is going to be a better statistical power, kind of more uniform access to the

cases, and a better scientific approach, in a way, than before because it's going to be everything in one only study. And we are just starting now to collect data and to work on all the procedures, IRBs, and all the complicated, I would say, process that will make this happen. So I will stop here, so hopefully this is enough for now. And an important point I will say one more time, it's important that this program has cancer as a certifiable condition already, and it's also important that research is continuing to clarify and to give us more information and updates on what's going on in the long term. Thank you for your attention.

DR. MOLINE: Thank you very much, Dr. Lucchini. You know, he gave me a minute and 44 seconds of his, so I'm going to take his time. No, I just want to highlight one element which was, you know, sometimes identification of diseases starts with one person, and in about 2007, 2008, I happened to be seeing a patient who had multiple myeloma, and I didn't often see patients, I was administering the program, but we were filling in because we were short-staffed. And another one of my colleagues also saw a patient that day, and it was pure serendipity that we happened to see two people who were in their forties with multiple myeloma, which is a cancer that typically occurs in older individuals and not people in their forties. So we said, "This is unusual," and we began looking into it, and we ended up writing a case report or a case series where we looked at multiple myeloma incidence as a, "Is there something going on?" I highlight this to show that it came from one person, and then a second person, and then we canvassed the whole dataset to look for that. But now we know, in all the studies that have come forward, that in fact multiple myeloma is a covered condition. Now, yes, it would have been found five years later when all these studies were published, but really some of the kernel of that that allowed us to focus came from one individual presenting. And all of us in the World Trade Center health programs, as we treat all of you and all the responders and survivors, are looking to see what we might identify that can eventually lead to helping everyone else.

Our next speaker is Dr. Mayris Webber and she is going to be talking about post-9/11 cancer incidence in FDNY firefighters. And much of what we have been able to initially learn—they're often the first people out with the studies. They've got an amazing team, led by Dr. Webber and Dr. Prezant, but they have data that was collected pre-9/11 that allows us to understand how this event impacted folks, and they are often the first ones out with the work that is then confirmed as we look at the larger population. But without their integrity, without their perseverance, and without their amazing dedication, we wouldn't know what we know today. And I'd just like to salute everyone at FDNY and the research department for all that they have taught us in allowing us to better care for all of our patients, whether they're responders, survivors, and certainly members of the FDNY family. Without further ado, Dr. Webber.

DR. WEBBER: Thank you so much. Thank you. That was very kind. So we are lucky at FDNY because we had an occupational health service that was well in place for years

before 9/11, so it does give us a wonderful opportunity to understand more about a lot of issues, lung issues in particular, that were a focus of the fire department for decades.

But this morning, I'm going to talk to you about our recent cancer work. And as Roberto told you, because it's known that toxins were present at the World Trade Center site, we at FDNY were interested in looking at cancer rates in first responders soon after 9/11. In 2011, we published the first major study of post-9/11 cancer and reported that cancer risk was up to 10% higher in New York City FDNY firefighters versus other US males. In a more recent study, we compared cancer rates in New York firefighters, FDNY, to cancer rates in firefighters who worked in other major US cities. In this last recent study, we found no overall difference in cancer rates between the two firefighter groups, the New York firefighters versus those from the other major cities. However, there were some differences in specific cancers, both higher and lower. We found higher prostate and higher thyroid cancer rates and lower lung cancer rates in FDNY compared to the other firefighters. Both our original FDNY study from 2011 and the firefighter comparison study, which was published more recently, from cities outside of New York found small overall differences in cancer rates when compared to the US male population. Therefore, we can't yet conclude that the increase in cancer that we observed in our 2011 study in the New York firefighters was due solely to 9/11 exposure, as it might also be due to the hazards of firefighting itself. We continue to update registry information from various states, 10 or 11 states where some of our firefighters have retired to, so we continue to update both the FDNY data and the data from the other major cities. And also, just to let you know, that the average latency between smoking and lung cancer is about 30 years, and also cancer risk increases with increasing age. Therefore, our current studies will follow people far into the future in order to get the most comprehensive picture of the health consequences of the 9/11 tragedy. As for now, we recommend that you continue to come for screening to identify cancers at a stage that treatment is most likely to be successful and that the World Trade Center Health Program currently includes the following screening tests: colonoscopy, chest CT scans, mammography, Pap smears, and annual blood tests including blood cell counts which can be useful for hematologic or blood malignancies. And we thank you for your attention and really thank NIOSH very much for putting this together and for their continued support of our program.

DR. MOLINE: Thank you very much, Dr. Webber. You know, I think when we're looking at many of these studies, I think it's also important to look at not just the overall rates, but also subpopulations to see if there are increases in groups that are younger than we would expect in the overall populations that, when you take them as a whole, might not be elevated, but are looking at different rates. And I think there is a lot of research that is now ongoing to why rates of prostate cancer might be elevated, why rates of thyroid cancer might be elevated, because that’s been a consistent

finding among all the programs.

We're going to transition now to moving into an area that I think we haven't talked as much about in much of our work, and it's the impact of 9/11 exposures on children who are now teenagers. Very early on, there were some studies of women who were pregnant at the time of 9/11 to see if there was an impact on the babies that were born in mothers who had the exposures, and they did find that there were some alterations, there were decreased birthweights compared to what would have been expected. But now we're seeing the follow-up for 16 years later of those children and now young adults who may have been in schools, may have been in the community, who were affected by the—whether it was the dust cloud or in the days and months as they returned to their schools and returned to their homes while there was still dust and debris being cleared out in the area. So I'd like to welcome to the podium Dr. Leo Trasande who's going to be talking about World Trade Center exposure on adolescent lung and heart health.

DR. TRASANDE: Thank you, Jackie, for the warm introduction. Thank you to NIOSH and the organizers. I'm delighted to be here. There were tens of thousands of children who lived or attended school, depending upon how you define Lower Manhattan, on September 11 and in the weeks and months that followed. And as Jackie described, there are some substantial gaps in our knowledge with respect to what the effects of that early life exposure were and the implications now 10-15 years later. In many cases, these are now young adults as well as adolescents. And I'd like to draw some emphasis in particular on two aspects where there are some gaps in our knowledge, and one is in the impact of the chemicals that were in the dust cloud and in the dust and the fires that went on, in some cases, for months after the disaster. We had a substantial amount of research already accumulated with time looking at the psychosocial effects or the mental health effects of World Trade Center-related exposure, the trauma in these children. That’s actually quite, maybe not optimally described, but quite well described. And Jackie described, there have been studies in pregnant women and the children recently born showing effects, but it's the early life exposures in childhood where our knowledge is arguably the most thin. Now, the World Trade Center Health Registry, which Dr. Brackbill will describe in greater detail in a few minutes, documented the first warning signal in this regard, looking in particular at the development of asthma in children who were exposed to the disaster, and they found substantial, really frightening rates of asthma after 9/11 in the youngest children at the time of the disaster, that is, children less than five. We had the privilege of working with Dr. Reibman and colleagues, leveraging the clinically-referred population of children who came for health concerns related to 9/11 at Bellevue, and found some interesting and, unfortunately, concerning findings supporting effects as well potentially on lung function in the children who were exposed, but also with a clustering of cardiovascular-related or heart health-related risks. In particular, we found a relatively high rate of children with elevated blood pressure and a pattern

in which their lipid levels were a little bit distorted in a way that could herald the later life consequences for cardiovascular health. So that prompted us to seek funding from the Centers for Disease Control and Prevention to look at two populations together. I mean, when you're talking ten years out after the disaster and you haven't followed a population carefully every year or two years in the interceding period, you have the quandary that, the more you go out, the more there can be other factors that might explain the associations that you might have been able to control for or rule out if you had followed the population more carefully over time. So we recruited a population of young adults and adolescents from the World Trade Center Health Registry and we matched that population to a population of young adults and children who were New York City residents as well, but were not in the eligibility zone for the World Trade Center Health Registry, so they would be a reasonable comparison group for relatively less exposure. And I'll say more about why I mean relatively less as opposed to no exposure in a moment.

We haven't published all the findings as yet. I'll give a preview, to some extent, of those findings, but I'll emphasize the findings we have so far. We performed a battery of tests over about two to three hours, looking at lung function as well as measures of blood pressure and stiffness of the arteries, both in the arms and also deeper in the arteries near the heart. And the good news is that we're not seeing as much of the differences in direct lung function that we saw when we looked at a similar population that was clinically-referred. Now, we are seeing a persistence in asthma some 15 years out at a higher rate in the exposed population and in relationship to the dust cloud exposure in children who were exposed in early life. But moving on to the heart health risks, what we've not seen are substantial differences, in relationship to dust cloud exposure or even traumatic exposures, to direct measures of heart health, that is, elevations in blood pressure or measurements of the stiffness of the arteries. So that, in a way, is good news and reassuring for folks who are rightly concerned and maybe even scared about the implications in later life. Now, what we've also done is to try to get at the chemical exposures in greater detail. I mean, we're dealing with the reality that, in some cases, the recall of parents and children, even if it was based on the World Trade Center Health Registry, can be a difficulty. And insofar as you're imprecise about your exposure, it's harder to really identify effects that are really there. So what we've been able to do is actually leverage measurements of chemicals that were found in the dust in the serum of the these children, two types of chemicals in particular. We're focusing on Teflon-like chemicals and dioxins, the chemicals that are emitted through burning of various materials that occurred in the months and years that followed. And we have found some striking differences in the Teflon-like chemicals, and when we look at the chemical exposure as the marker of exposure, as opposed to the self-report description of exposure, we do start to see some associations, in particular with elevations in

cholesterol and lipid levels, that may be a signal for future health risks down the line. So this reinforces both the need for ongoing medical monitoring and care, but also the need for further research to continue, to follow-up in this population.

Now, I'll close by going back to what Jackie described before having me come up, and that is that there were some early effects in prenatally-exposed children, and to some extent we've actually not heard much from that population. And so I have the privilege of working with partners at Columbia Mailman School of Public Health to leverage two existing cohorts where one was recruited for another reason, so didn't have as much substantial 9/11 exposure, and then a population that was specifically followed with the intent of getting a population of women and children who were exposed, to get that kind of comparison, and that population is now about 15 years of age. So what we're doing is to not only leverage the existing data on their body mass and their growth as well as measurement of their cognitive function, but also bringing them in to evaluate their heart health. And that may actually be where we find an even stronger signal, because prenatal and early life exposures may be a time window of even more unique vulnerability. So in that regard, I have to tell you stay tuned because we've just had the privilege of receiving the funding to get started with that work. So again, thank you for the opportunity. We look forward to your questions and comments as the panel moves on. Thank you.

DR. MOLINE: Thank you very much. You know, I think that what Leo just said is critically important, which is that it takes many years to see this, and it's just amazing that we know that there will be now the 73½ years of additional funding going forward for the program with the dedicated research dollars that will allow us to answer some of these questions that have far-reaching implications, not only for the individuals exposed at 9/11 but also what happens in the aftermath of a huge environmental and occupational disaster.

So in the very early stages after 9/11, the CDC and the Agency for Toxic Substances and Disease Registry of the Centers for Disease Control and Prevention established the World Trade Center Health Registry, which was—and I'm going to hopefully not take any of Dr. Brackbill's time by describing this—but really a loud cross-section of different types of folks who may have come from different types of exposure to be followed, and thousands of people heard the call and answers. And we are so grateful to the folks from New York City and beyond who have participated in that Health Registry, and continue to participate in the Health Registry because, as Dr. Brackbill will tell us, I'm sure, we've learned so much from them. And it's also something that we can use as we are following the responder population, the survivor population, the firefighters, to see what the overall scope of the health effects were in the different populations.

So before I take any of his thunder away, I'd like to introduce Dr. Robert Brackbill, who will be discussing findings from the World Trade Center Health Registry.

DR. BRACKBILL: Many times when people come and begin working at the Registry, I'm the one

who sits down and tells the history. So I have to kind of be careful not to start, "October 2001…" blah blah blah, but anyway.

So, and I'm glad that Dr. Moline mentioned ATSDR because I was going to thank NIOSH for bringing us here, putting together this program, but it was the Agency for Toxic Substances and Disease Registry which found a way to fund the Registry back in July 2002.

And I want to say that I am here for Dr. Mark Farfel, who has unfortunately picked up something from his son and has to stay home sick today. He is a person who has made the Registry into a more customer service-oriented type of thing. He would talk about the Treatment Referral Program, which has been very involved with the World Trade Center Health Program and helping them get people enrolled and put their applications in.

So one of the first things that we do when we talk about the Registry to the public is we try to say what the Registry isn't and what the Registry is. The Registry is the largest post-disaster registry in US history, and now one of the longest-running in the world. It was launched 2002, as I mentioned, July 2002 it was funded, and it is housed in the New York City Department of Health and Mental Hygiene.

It is the mission of the Registry to understand the short- and long-term physical and mental health consequences of 9/11. We do this by tracking the health of 71,000 people exposed to the disaster. I just was thinking that 71,000 is more people than where I'm from, Harrisburg, Pennsylvania, which is like 55,000. And I was thinking about what stadium—is like Penn State stadium big enough to have 71,000 people? I don't know. Is there anything around here? Seventy-one thousand people, it's a lot, you know, and they've been like participating in this thing is just so important. I mean, it's just a public health enterprise of this very important magnitude for understanding the long-term effects of 9/11.

We also assess unmet healthcare needs, quality of life and functioning, and it's important for me to mention that quality of life is an important aspect, and I think a number of papers we've published recently, we've talked about quality of life in terms of how it's associated with particular conditions people have and how it has affected them.

Additionally, we collaborate with the World Trade Center Health Program and other researchers and share our findings to help inform the Health Program's policies. We are also planning for future disasters. And actually that was one of the aims of the Registry was in terms of understanding how to respond to disasters, even weather disasters such as hurricanes and that sort of thing. We actually periodically get calls from people to help with putting a registry together after some event.

Who makes up the 71,000 people we call enrollees? These are people who voluntarily enrolled in the Registry in 2003-2004 and completed our first major health survey. So that enrolment took place from September 2003 to November 2004, so it was about an 18-month period that we, through various media

campaigns and acquiring lists of people from different organizations, including Red Cross and that sort of thing, volunteers of the Red Cross or Salvation Army, lists that we tried to find people and call them up, and go through a consent and then get them enrolled on the Registry.

They were exposed to 9/11 but didn't have to be sick to be eligible for enrolment. Now, that's a very important thing when you establish a registry. You need to have the full cross-section of people who are not only sick but those who are healthy and remain healthy through the whole time that you have a registry. Having those sick and healthy people helps us get a fuller picture of the types and course of 9/11 health impacts.

Now this group on the Registry includes rescue recovery workers, survivors who lived, worked or went to school in Lower Manhattan, including children, tower survivors and Spanish- and Chinese-speakers, and also Polish actually. We found many Polish construction workers too who enrolled on the Registry.

They live in all 50 states and more than 15 countries. I mentioned that we have looked at—I'm not sure, I think we have somebody from every congressional district in the United States who is on the Registry, and I think that just showed it's a national registry, you know. And an international registry because we had people who were working in the towers who were from Canada, Great Britain, throughout Europe, Middle East, and those people are also on the Registry as well. We don't have many but there are some.

The Registry was closed for enrolment in 2004, and that's an important thing that it's a cohort. It's a closed cohort. We often get asked whether or not you can get on the Registry, enroll on it, but because it's a closed cohort for epidemiological purposes, to observe people over a period of time, you need to close it and then follow those same people for all the years afterward. But our findings are also relevant to others who are not in the Registry. That's an important point.

How many health surveys have we conducted? Well, we've actually, since enrolment, we've conducted three follow-up surveys. One we conducted, in the first one; Wave 2 we refer to as 2005-2006; the third follow-up survey in 2010-2011; and then most recently we had a fourth, 2015-2016. And each time we do a survey, we asked slightly different questions. We have some questions we ask every time such as questions on mental health, post-traumatic stress disorder for instance. We ask about symptoms in every survey. But then we also introduce new questions as time goes on, as we learn. We want to learn about other things.

The Registry does not provide clinical care but as I mentioned earlier, we do have a program where we try to help people get into treatment and get an application, and give them resources, information to do that. We do connect enrollees with the World Trade Center Health Program for monitoring and treatment, as I just said. Our Treatment Referral Team reaches out to thousands of enrollees who reported 9/11-related symptoms and conditions on our surveys. We encourage them to apply to the Health Program and offer help as needed.

Okay, now the findings. Cancer and respiratory findings—well, the Registry has published over 80 papers, and I think that's more, close to about 90 now, covering various findings. Summaries can be found on the website. You can go to our website. It's easy, just World Trade Center Health Registry, it will pop up and you can see up the top, Publications. With regard to cancer, the Registry has similar findings to responder and survivors. We also heard from Dr. Reibman and others about responders and how findings suggest that persistent lower respiratory symptoms may be due to injury of the small airways in the lungs. And we also have a collaborative respiratory study which she mentioned earlier that also looked at area workers and residents and reported ongoing lower respiratory symptoms on other registry surveys, but risk of having persistent symptoms with reported intense exposure to dust cloud. Dust cloud also remains an important exposure. Risk also increased with reported thickness of dust in the home or workplace. We've also followed up these participants about four or five years later to determine if they continued to have the same lower respiratory symptoms. The good news is that people in the study were largely improving as a group, although some continue to have lower respiratory symptoms, particularly those with post-traumatic stress disorder.

It is common for respiratory illness and mental health conditions to occur together in responders or area workers and residents. For instance, we found that 1 in 4 of the area workers and residents and passers-by, whom have either lower respiratory symptoms or post-traumatic stress disorder symptoms, had both conditions five or six years after 9/11.

We also looked at asthma, where we found an increase in asthma among enrollees in the first two years after 9/11. We found that about 1 in 3 participants with asthma had well-controlled symptoms a full decade after the attacks. Having cooccurring conditions such as PTSD or sleep apnea contributed to poor asthma control.

Children also experienced similar outcomes such as persistent symptoms, but then we also found poor asthma control among children. That was related actually to PTSD in their parents. Some also had a combination of respiratory and mental health symptoms and conditions.

One of the hallmarks of 9/11 health impacts is that it's not unusual for survivors and responders to have more than one physical health condition or a combination of mental and physical health conditions related to 9/11. Furthermore, having more than one condition generally has a greater impact on quality of life than any one condition alone. That's an important thing I think we're finding as the years go on, that there is comorbidity, that people have a combination of physical health and mental health and they exacerbate each other.

For the future, we plan to continue tracking health enrollees for years to come, under the Zadroga Act, including cancer and PTSD, and potential emerging conditions such as autoimmune conditions. We will keep you informed of our

findings even as we continue to work with our colleagues in the World Trade Center Health Program to build a bigger picture of 9/11 health impacts and ways to address them.

Thank you.

DR. MOLINE: Thank you very much. We have about fifteen minutes before the end of this session and I want to thank those of you who submitted some questions in for our panelists, and these are phenomenal questions and unfortunately there are so many on the health effects that we're not going to be able to address a lot of them, but I'm going to throw out a few of them.

But one of the questions was how can there be better communication about the research programs. Well, I think today is a first step and I think that as Dr. Brackbill said, in this internet age, there are various means that the government uses, and government officials use, like Twitter, that—and NIOSH has actually an amazing Twitter feed, and I all encourage you to subscribe to it, which will provide you with updates on the latest research happenings from not only the World Trade Center Health Program but occupational health and safety in general—but also the websites are available. And I am sure if you look in your packet, there will be the website for the World Trade Center Health Program, and much of the information about research is available on that website for anyone to look and see what has been done and what is currently underway that we will have the results for in several years. So I encourage everyone to avail themselves of these resources if you can get access to a computer.

So I'm just going to throw a couple of questions out to the panel, and there are a number of questions that are related to different topics. One of the questions is related to chronic cough, and people are having challenges controlling their chronic cough, and I wonder if maybe Dr. Reibman, you can talk about the challenges people have had with controlling chronic cough.

Actually, can you come up here? I'm going to call you up and you get to come back up here and allow the cameras to roll.

DR. REIBMAN: So cough—can you hear this? Cough is a symptom, and the issue, as we discussed earlier, is that a symptom can be due to many, many different things. And when we think about cough, we think about upper airway, postnasal drip. We think about actually acid reflux can give you cough. We think about vocal cord movement giving you cough, and we think about also lower respiratory.

So that's what makes cough such a difficult symptom to really deal with and why it's so important to do further tests—I hate to keep saying that—because it really is important to begin to understand what exactly is the etiology of that cough.

Unfortunately, something we can't figure that out, and at that point, that's why it's so critical to undergo care because there is often a trial and error of different types of interventions.

For example, if it's postnasal drip, we will do a lot of work on trying to maintain

and improve the sinuses and upper respiratory symptoms. If it's vocal cord, and one can have something called paradoxical vocal cord movement, where your vocal cords are just twitchy, they're more sensitive, and the treatment for that is we don't exactly know how to do it. We do a lot of voice therapy, for example, and also again, some of the inhalers that we'll use. And if it's respiratory or lower respiratory such as asthma, we have to then manage the asthma. So cough is a very difficult symptom that can be due to many, many different mechanisms.

DR. MOLINE: One of the other questions was actually—and I think this is critical for what we are learning, and I would actually like to ask Dr. Crowley to come up and try to answer this question, which is how and when do research and treatment recommendations interact? And I think what she tried to do in her discussion was tell you about some of the research that has been done so far, and how we're using this research to move forward with respect to treatment. Dr. Crowley?

DR. CROWLEY: Thank you. So I think that's well said. I think Dr. Moline answered the question for me. So basically, probably an example that I'm most familiar with is the sarcoid study that I happened to work on, and we utilized that as kind of a platform to investigate in our cohort how many patients had sarcoidosis. And as I described before, sarcoidosis is inflammation in the lungs. We can see scarring. So we have to do a deep medical record review, interview patients, evaluate their clinical records, their CAT scans, pathology to confirm a case, similar to how cancer handles—the cancer studies handle their case, but different, but it requires confirmation. And once cases are confirmed, then we can evaluate if that incidence level is higher than what's expected in the rate in the population.

So Dr. Prezant's team was able to identify sarcoidosis early on, that there was elevated incidence rates, and then we kind of followed. And after that, we had a conversation with our partners, our colleagues, and at NIOSH to say look, we are seeing increased rates of this disease in our cohort in multiple studies and we think it's worthwhile adding this as a condition. And so far, that's proved to be true, and we see this happening in multiple studies.

DR. MOLINE: Thank you. So I'm going to utilize all our panel in the next few minutes, and I'm going to transition now to some of the cancer questions. And Dr. Lucchini, I wonder if you can come up and talk about what types of cancer reviews and thoughts about cancer prevention in the program are being contemplated as we move forward.

DR. LUCCHINI: Yes. As I said before, there is a continuous work in this important activity here because we have to collect all the cases, we have to identify them, we have to do an intense work in terms of collecting data. There is a data center for the responders, for the general responder consortia, there's a data center for the survivors and the FDNY. So these three data centers constantly work on this important activity to collect the data, and constantly work on what we call cancer surveillance, which means is this particular condition, all cancer or specific types of cancer are this sort of exceeding what's the expected rate. Expected rate is

something that we observe in the general population and therefore we have to consider different areas, of course, in New York and other areas that are where the population is or the responders come from. So it's a very intense activity that goes on every day and this is the way we collect the information.

So the other point was the prevention part, and I think that you already heard about the important point here in terms of prevention, which is screening. Screening is fundamental in cancer. We have to participate to this program because the early intervention is fundamental. The identification of early stages of cancer is something very, very important because you can obviously make a huge difference. So that's why participation and constant feedback and communication with the researchers and then the respondents is fundamental here to make this happen and be proactive in prevention. It's the fundamental message.

Thank you, Jackie.

DR. MOLINE: So Dr. Webber, I'm going to ask you to come up and talk a little more about a concept that you touched on in your study, which is talking about latency. If you could just describe what latency really is and why it is so critical when we're studying cancers, and how that has impacted and will continue to impact many of the findings that we're seeing and why it also takes a while for us to perhaps identify diseases that might turn out to be World Trade Center-related.

DR. WEBBER: Thank you. So we were surprised to find out that there is very little information on human latency between particular exposures and in cancer outcome. So in an occupational setting, in general, people might work for two decades at mines. We know that certain kinds of miners are more likely to get certain diseases—black lung and other things. But occupational exposures in general are thought to occur at low levels over many, many, many years of work.

So the World Trade Center exposure is different. It was not really brief because for workers, they were at the site for many months, but it was not many decades, which is where most of the occupational latency information comes from. So we don't know—we do know more about smoking for example, and we know that the latency between smoking and lung cancer is, on average, 30 years. But human latency in general is not well-understood and not well-known. That is, the time interval between the exposure to the bad thing, be it smoking or air or dust, and cancer outcomes. Certain outcomes like coughing and respiratory diseases are obvious much sooner than cancer. So cancers in general are thought to take many, many years and maybe even decades.

So that's one piece of latency, and I wish I could tell you more, but we are hoping to learn more from the World Trade Center exposure because for people who were at the site, we know when they were at the site, and so we have a finite kind of exposure that you wouldn't have for people who worked over decades in mining or other fields.

The other piece of why it takes so long, just let me touch on what the cancer registries are. So every state is mandated, hospitals are mandated to report

cancer cases to their states. The states then cull through thousands and thousands of records. They verify, they get pathology reports, they look at cell types. So this information is very valuable in terms of being able to understand. So in New York State, men of a comparable age to our firefighters, what are their rates of lung cancer compared to what are our rates of lung cancer in World Trade Center-exposed individuals? So it's tremendously valuable to have this comparison, but it is a minimum of two years before you can get data from the states. So in other words, right now we can get information that is complete through 2015 through the states. So we are always a lag time of 2+ years getting state information to compare with information from our own group of firefighters and EMS workers that we follow.

So there is this low latency between the exposure and the outcome, and then there is another lag time of 2+ years before we have information from the states to compare with information from our exposed individuals in the various cohorts. Good enough? Okay.

DR. MOLINE: And I think that describes why Dr. Howard made his comment about how research is a challenge. You have to wait, and it takes a long time to amass the data.

I think our final question for this morning's panel is going to Dr. Brackbill. I'm going to ask—there's been some questions about what was in the dust and whether it's the root cause of the illness and what was in the air. And if you could just comment on some of what was known from being on the ground and being with ATSDR early on, if you could just comment on that and how it's been impacting much of the work that's been done in the research community since then.

DR. BRACKBILL: Okay, thank you. Yes, I think with—I think with the Registry when we thought about what was important to ask people, it came up that we should ask them about what happened when the buildings collapsed and the large dust debris cloud. And so we did ask, we asked questions, were you in the dust cloud, and where were you and how close were you to the building? Now of course when the buildings collapsed, Dr. Lioy many years ago collected samples of the dust around that area, and I can't recall exactly but it had a mixture of substances, primarily like things, gypsum and silicates and also things that come from plastics, and the various materials have all been described, toxicological kind of substances, even asbestos. But if you are in the—people who have said that they were in the area when the buildings collapsed and that they were enveloped in this dust cloud, and we did actually follow up with more questions to get at asserting intensity exposure, you know, whether or not you were covered with dust, you couldn't hear, you couldn't see, you had to get under a car, that sort of thing, in order to get out of the way, get away from the dust you might say, or it just enveloped you completely, that those intensity questions turned out to be very important in terms of trying—setting up an exposure level to the dust cloud. That has been, shows a dose response kind of association, which as we mentioned, dose response, high,

medium and no or low exposure for instance, with the likelihood of having respiratory symptoms, asthma and that sort of thing.

So I think that's, to me that particular exposure is—one more thing that's unprecedented about the 9/11 experience is that people, thousands of people were evacuating the buildings, firefighters were entering the buildings, people were evacuating, people were on the street, people standing around looking. The buildings collapse, they were caught in this dust cloud. You see pictures of course, people walking across the Brooklyn Bridge or going up to Brooklyn covered with dust. So that was the unprecedented, intense, overwhelming exposure where people breathed in this material, got into their noses, got into their lungs and it's remained there, and it's turned out to be one of the key acute exposures of people who were either civilians or responders on that particular day.

And of course, it's a continued deconstruction of the buildings after that, that people continue to get exposed to the various chemicals and the by-products of the fires and that sort of thing. But even if you don't know exactly—and that's one of the things about the 9/11 exposures is that we don't know exactly, from a personal level, we didn't have people wearing special kinds of sampling things, we could actually know what was in the dust, because the measures of exposures happened like weeks later, the actual exposure, what was in the air and that sort of thing. So what is known is from what people have reported basically in terms of when they arrived and whether they were in the dust cloud or not. I don't know if that kind of addresses that question. Thank you.

DR. MOLINE: Thank you. We're going to conclude this morning's session. I'd like to thank everyone. But before you all go, I'd just like to make two comments.

You heard some names earlier today. Dr. Paul Lioy, who collected the dust, went in and collected the dust, and we lost him a couple of years ago but through Dr. Lioy's perseverance, we learned much of what we know about the constituents of the dust. And I'd just like to remember him.

I'd also like to remember Dr. Steve Levin, who was one of the true advocates for workers throughout his career, and one of the founders of the World Trade Center programs. He passed on about five years ago.

I'd also like to thank Dr. Robin Herbert, who was instrumental in starting up the clinical programs when she was working at Mount Sinai.

And on a personal note, we are losing responders to World Trade Center-related health conditions every week, every day. One of my colleagues at Northwell Health, Dr. Mike Guttenberg, who was an FDNY EMS fellow, passed away this week from pancreatic cancer. And it hits home when it's one of your, as a physician, when it's one of your colleagues who responded, and I'd like his memory and the memories of all who have passed, both on 9/11 and in the years that have passed since then, let their memories be a blessing to all of us, and it inspires us as we continue our work going forward.

So I'd like to thank you all for your attention this morning, and I think Max is going to take it as we move forward.

DR. LUM: Thank you. Thanks to the panel and thanks to Jackie for moderating. I think you all just witnessed a very sentinel event, and that is six scientists that stayed within their time allotment.

And if you've been to these meetings, would you agree, I think that—and thank you very much for that, because I think the message is clear and got across.

So we're going to take a break. I think there's tons of food left. Please take a coffee break, and let's come back within, I think, fifteen minutes. And you have an evaluation sheet in your folder for this morning's session. It's very important, as Dr. Howard said, to fill this out. It helps us plan and also provide resources too. So give everybody, please, an A and give us your comments, and let's meet back here at 11:20. Fifteen minutes. Thank you.

(Break.)

DR. LUM: Could I ask the next group of panelists to come forward and take their seats.

And one of the points I heard someone make this morning was better communication of what we do, and I certainly, that plays into certainly my job and also how we should do this better. And I'm not suggesting this is the way we're going to particularly go, but I did mention that we are livestreaming this plenary session to our European friends and also in Asia. So I got a note back from the WHO that said we collected our people together and watched your session. It was very interesting. The live feed on Facebook is excellent quality. Congratulations. We need to do podcasts. So I think it's a good era for a communication person to be working in right now, but we need to figure out. You know, the idea is what can we do to reach larger groups of people, not only with the research we do but also in terms of what it all means. I think that's also the key. This whole idea of emergency medicine, disaster medicine, is a hot topic right now in the science field. But again, what does it all mean and are we doing this collegially with a larger audience, not just the American audience, not just a European audience. Do we have a larger audience to reach? And I think we do.

So again, thank you for coming back and there was a little bit of food left I noticed, but we're ready to go with our second panel. And again, after this panel, if I could just remind you to please fill out cards if you have questions for this afternoon, and we will eventually ask you to give us those cards if you want, please, so we know the kind of questions that you need answers for. We do have the questions that you put online during your preregistration, and they are quite numerous actually, and they are in your—a summary of those is in your folder if you'd like to look at those. And that will kick us off for this afternoon's session.

But right now we're going to talk, change a little bit and talk about chronic conditions in this area, a little bit about PTSD, a little bit about the science of adding conditions, and then Dr. Crane is going to have a tough job in trying to

wrap up, and so what does it all mean. And I think that's what we at NIOSH are constantly reminded of. Dr. Howard reminds me, what is all this for, what does it mean, the research we do? How does it translate into care? How does it eventually help the people that we're serving? And I think this is what the meeting is really all about.

Dr. Bromet was grateful enough to share this session. We appreciate that. And she is a distinguished Professor of Psychiatry and Preventive Medicine at Stony Brook. She graduated from Smith with a BA in history and Yale University with a PhD in epi—that's a nice combination, epi and public health and history—and a postdoctoral research at Stanford University on environmental influences on mental health. Over the past decade, she has collaborated with Stony Brook investigators on examining aspects of mental health among World Trade responders monitored at Stony Brook clinics and beyond. Thank you again, Doctor.

PANEL DISCUSSION 2

DR. BROMET: Well, thank you all for coming back after the break. It was, the last session was incredibly informative, and I think this session will also be just as informative. The last session, the last speaker, Robert Brackbill, ended on some notes that are going to reverberate in this session as well, which is that there was a psychological impact of the World Trade Center, as there has been after all tragic events of that magnitude. And we are going to talk about that because it's a complicated issue. It affects all of us differently. We each cope with it differently, and it's really important to understand it.

And the other comment that he made which you'll hear this afternoon is that mental health and physical health are two sides of the same coin. So to talk about one without talking about the other is really not adequate because our lives are affected by both. There's a mind-body connection, as you all know, as you all experience in different ways, and when something as horrific as the World Trade Center and other events—Chernobyl, Fukushima, I mean we've had a series of just horrible events occur—they affect our lives totally and our health totally. So that's what we'll be talking about.

Our first speaker is Sean Clouston, who is an Assistant Professor at Stony Brook, yes. And he's going to be talking about the issue of comorbidity which Robert Brackbill ended his talk on. So Sean?

DR. CLOUSTON: All right, yes. So, maybe it's worthwhile thinking about where we start. None of you are scientists so I'm trying to make this a little bit lively. At Stony Brook, we've had this really interesting relationship between different investigators and the responders themselves, trying to figure out what's going on for these people. Mental health is such a huge component of that. Most of our responders have

some symptoms. Even if they're not clinical symptoms, there's a little bit of symptoms, and that sort of pervades throughout and we're going to build on—Robert has talked about comorbidity here a little bit.

But I'm going to sort of go backwards and tell you a little bit about my family. So I was raised in a very loving household, but my grandfather was of course at the war and he had chronic PTSD. So as a kid, we were always told not to wake him up because he's come out and he'd punch you. (Laughs.) Which was sort of always a funny thing, to see someone as both a risk and a source of love.

I think what has happened at Stony Brook is that there has been this relationship, in a similar sort of way—not that similar I guess but there has been this sort of relationship between Evelyn and Ben, who would normally give this talk but he's currently in London because he just had a grandchild—where they sort of talk about the role of mental health, and we talk about how it gets embodied and how this sort of circularity between mental health and physical health occurs and what it means, right.

And so what has come out of it is that we try to understand why people are reporting having mental health problems, what it means for them, how they internalize it and then of course what does it actually do, right, if anything.

So you can sort of see this with maybe not a preliminary but one way that this plays out is through the cough, right. So PTSD is in itself a memory kind of disease, right. It contains flashbacks, it contains nightmares, which are memories of the event that are stressful. And then it contains emotional responses and behavioral responses and difficulties, right.

So, well, what can you think about with the coughing? Well, the coughing is, on the one hand, physical, right? You actually cough. There's a thing. We can see it. We can watch it happen. On the other hand, it's also mental. It's a reminder that you were somewhere that you had to cough, and so the cough brings around this sort of reminder of the event and then the reminder of the event of course can cause some coughing.

The thing with mental health is that these comorbidities are often kind of like this; they're non-specific, right, and they kind of get into the medical realm a little bit. So they can cause a misdiagnosis but they can also cause, we think, real disease, okay.

So in this discussion at Stony Brook, we have basically taken the view that the mental health is really a) it's real, we know that; but b) that there's really, people are reporting about something that going wrong for them, right, and therefore we should take their word and try and figure out exactly what's going wrong for them.

Now, one of the things that I think is interesting and certainly gotten us involved in this is that people with mental health problems, they take longer in the clinic, so they're more expensive. We have to talk to them more, so that's nice, we get to experience that. But they're also more complex patients. So like the cough, they have these physical symptoms and you have to figure out, like what is this? Is this

part of the mental health problem? Is this something different? Is it something new? What's going on? And these things can be chronic, right. Mental health problems are chronic. There are many people with chronic mental health problems in our clinics and so we're trying to figure this out both on the short term but also—what's happening for you today—but also in the long term, what's going to happen for you, to you or with you for the next twenty years.

So we started with, in our research, that something must be going wrong with these patients. They're reporting a lot of different symptoms. Something has to be happening. So that has led us to a couple of different types of research. Ben is heavily involved in epigenetic research. The idea here is that the mental health is causing some sort of genetic modification as to how your genes are actually regulated and used and expressed in everyday life. So there's transcripting that's changing, there's the ways that it's being expressed itself, all right. So we're focusing on trying to understand that. And we've got, I think, a paper coming out soon on that.

The next component of what we're trying to do is understand the sort of memory aspects. So about 35-40% of our responders at Stony Brook report having bad memory, and that it's getting worse. So we started looking into neurological conditions. The interesting thing with neurological conditions is that they can cause a bunch of nonspecific symptoms, right. So PTSD being located in the brain, it's not a long distance to the brain itself. And then the brain, if it's dysregulated, can cause all kinds of stuff to happen, often at low levels.

So we started doing cognitive research to figure out are people who are reporting memory problems, are they actually experiencing memory problems. What do those look like? Are they associated with the mental health? Are they associated with exposure? That kind of thing.

The other thing we noticed was that a lot of people, as part of, of course, mental health are also reporting being tired a lot. Fatigue is a terribly nonspecific symptom. You get tired for a lot of different reasons. You might be on treatment. You might be…sorry, I'm supposed to look for a yellow light but I realize that I don't actually know what—my red light is on, all right.

(Technical advice.)

I didn't know where to look. All right, there you go, okay. So we think that there might be nonspecific changes to physical functioning as well, right. So if you're getting tired, maybe you're also just not walking that fast. Maybe you're not getting up that fast.

The funny thing with this cohort, right, is that people are starting to get older. And the funny thing with age is that, you know, as we all get older, we rack up comorbidities and the mental health component is an important part of that comorbidity. And so what we're trying to do now is understand how are things changing for people as they get older. How are these comorbidities interacting? And is there something underlying all of that or is it sort of just what's expected?

Anyway, so I guess the point here that we're most interested in, and I think it will be reverberated throughout, is this sort of interaction back and forth between the mental health and the physical system, all right?

(Technical problem.)

DR. BROMET: So one of the comments that was made at the last session was what Dr. Webber was talking about, the latency period between exposure and getting cancer, which makes it very difficult because people get cancers. Twenty-five percent of the population gets cancer. And if there is such a long latency period, making that connection is not as straightforward as you would think. But that's not true for mental health. If you look at any disaster in the world, people develop a psychiatric reaction like that, and that's certainly what happened after the World Trade Center because it was such an intense and such a horrifying event that people, if they were going to get PTSD, got PTSD pretty much immediately. And there were surveys done, telephone surveys done, right after the event showing that severe symptom rates were pretty high.

But the fact is that a lot of people bounce back, which is what our next speaker is going to talk about, Adriana Feder. That's referred now by the word "resilience", but I like the old-fashioned term, which is we bounce back. So there are some of us, and I count myself among them, who have been through horrible experiences and took forever to bounce back. And there are some people who take even longer to bounce back. But the majority of people actually can handle and cope with things, and that is what Adriana is going to be talking about. So Dr. Feder? From Mount Sinai.

DR. FEDER: Thank you, Evelyn. So thank you to NIOSH for having me here, and for organizing this event.

So I am a clinician. I started out as a clinician and then I also became a researcher, but at Mount Sinai, I have been treating rescue and recovery workers who worked at Ground Zero and the landfill, etc., so WTC responders, since 2007. So I have a lot of experience talking to responders and helping them, trying to help with the things that the symptoms they're having and the experiences that they've gone through. And also, my research focus, as Evelyn, Dr. Bromet, mentioned is on resilience, on trauma and risk and resilience.

And so we have a program at Mount Sinai, based at Mount Sinai, myself and in collaboration with other researchers at Mount Sinai and also my colleagues at Yale, Robert Pietrzak and Steve Southwick, that started thanks to the funding from NIOSH a few years ago. And we started out trying to understand, looking at trajectories over time from PTSD symptom questionnaires that were collected at the monitoring program at the various, the five different Clinical Centers of Excellence and periodically, from responders coming for monitoring. And we noticed, like other groups of researchers, that some people had a more resilient or lower-symptom trajectory or had bounced back, and other people had worsening or more chronic trajectories. And so then what we decided to do was

apply for funding to NIOSH to look at what might be potentially protective factors as well. So we fielded a web-based survey to over 4,000—over 4,000 responders completed a survey over the internet.

And then we built up on that by obtaining funding to conduct a study of blood biomarkers to bring in a subgroup of over 300-350 responders to do more in-depth interviews and look at blood markers, including genetics, epigenetics that Dr. Clouston was talking about, and then also moving into try to get the whole picture with brain imaging and also intervention, trying to see if we can help improve PTSD symptoms in responders.

So there isn't enough time to talk about everything that we're doing in the program but I wanted to mention a couple of things. In our web-based survey and our trajectory studies, we confirmed findings from other groups that those who were having persistent and more severe post-traumatic stress symptoms like nightmares, memories, reexperiencing, tended to have more severe exposures. So they were more directly exposed to the attacks. Either they were there when they happened or they worked on the pile directly, or they might have colleagues or family members who were lost in the attacks. And also, subsequent stressful life events like losing a job or losing a family member or separation seemed to build up and make the trauma more difficult to cope with. And also, having medical problems, as we heard that mental health and physical problems, it's all one body—the brain is in the body as well—go together. So that also compounds.

And then from the web-based survey… Oh, one other thing I wanted to mention is that one thing when we brought the responders, between 350 and 400 responders who came in person, and we also looked at blood biomarkers, we found that childhood trauma, so more stressful childhood environments like abuse or neglect, compounds the experience of World Trade Center exposure together with some forms of genetic predisposition. For example, a protein, a gene that makes a protein in the blood that helps the stress, the hormones, stress hormones and the stress response in the body. So there seems to be a particular interaction between severity of childhood trauma, World Trade Center exposure and certain gene variants in the body that makes it more difficult for some people because they're at higher risk for PTSD; and then other people who have been lower exposed to trauma and also have the more protective genes are more likely to be resilient. So it's very complex and it takes a lot of time to study, and our colleagues in Stony Brook are also studying genetics, gene expression, epigenetics. So we will have, in the next few years, I anticipate we are going to have a lot of interesting and informative findings.

In terms of coping strategies, we also asked on the web-based survey, what are the three most common coping strategies that you have been using to cope with 9/11-related problems that you have encountered. And so we found, similarly to other populations who were exposed to severe traumas, that avoiding or not dealing with problems is not as helpful, although if you are very symptomatic,

sometimes that's what happens.

We found that accepting or being able to gradually coming to terms with having illnesses or the losses that came from 9/11 is important, and also trying to find a positive angle. Trying to grow, if at all possible, from the events. For example, you found new friendships with other survivors or responders or perhaps you, if you've been able to overcome some of the stress, you can share it with others or start a group or join a group to help others who are still struggling. So trying to positively reframe.

And then we also found that—and similarly, taking action. So instead of passively resigning oneself, to take action to deal with the problem, like getting help, getting medical care, going to monitoring, for example.

And we also found like in other survivors, other studies of trauma survivors, that a social support network is associated with better mental health and also being able to regain a sense of purpose and life. Those who had lower symptom levels over time were more likely to report that they had a better sense of purpose. Now, this particular study we can't say what's cause and effect. We just know that it goes together. And so some people need to, of course, access mental health treatment and even counselling, medication in order to be able to get to that point.

And finally, I briefly wanted to mention, right now we are fortunate to be funded by NIOSH to conduct a study of online writing therapy. This one is for responders, very broadly defined—police, firefighters, construction workers, Red Cross volunteers, a whole range of responders. And there are flyers outside and the best way to find out about the study is to log in to our webpage because that's how you enter the first steps of the study to be evaluated. And it's for responders who are still having significant PTSD symptoms. From our survey, we found of the 4,000 who completed the survey, we found that about a third of responders out there are still suffering from clinically significant PTSD symptoms. Perhaps not everyone full PTSD, but symptoms that are associated with impairment in their functioning at work or relationships, like distancing themselves from others or still having sleep problems, still being really disturbed by memories or when they are exposed to reminders of 9/11 and their work for the World Trade Center recovery. And so what we do is we pair them up—we first do an assessment online and over the phone. And I see that the light is red so I'll take half a minute. Five seconds. So we assign them with a therapist and they have writing exercises twice a week for eleven writing exercises over six weeks. And we are comparing two forms of therapy, one that focuses, incorporates their experience of 9/11 and coping, and the other one focuses on current stressors and problem-solving.

So anyways, there's a whole program of study that hopefully we'll have some more findings for you in the next few years. Thank you.

DR. BROMET: Thank you, Adriana. So I've worked in psychiatry my entire career. We don't have any biomarkers for diseases. We don't know how to do this personalized medicine you're hearing about, sort of matching somebody with certain symptom profiles to

the right kind of treatment. We're not even close. And so what we try and do is develop novel treatments that are a little bit eclectic, like they cover a lot of different issues—you can be on medications, you can do these psychological treatments—and hope that there is something in it that will prove to be valuable.

I don't know how many people, I'm not going to ask you, I don't know how many people here have ever had a period of depression, which is probably one of the most common, quote, "psychiatric problems" that there are, but I would bet most of you have. I certainly will admit that I have. And I decided on what kind of treatment I wanted for it. I don't know if something else would have worked better; it took a long time. But for the responders with PTSD that didn't go away right away, this issue of how do we—what treatments do we offer that are going to be beneficial. Well, according to the American Psychiatric Association, there are only three approved treatments and two of them are medications, and they're not even the medications that most providers are using.

So at our university, we did a trial with Adam Gonzalez—can you stand up for a minute, Adam—on a program that had been developed at Harvard, by a cardiologist actually, not by a psychiatrist. And it's a very interesting program and the nice thing about it is the people who enrolled in it really liked it. They didn't drop out, they didn't complain, they actually really were thrilled to be involved in it and felt that they benefited from it.

And so now, our next speaker is Lucia Ferri, who has inaugurated this program here in New York at NYU, and she's going to say a little bit about it.

DR. FERRI: Hello, I want to say thank you to everyone here for giving me the opportunity to tell you about this study, and to NIOSH for the support in conducting the study.

So I'm Lucia Ferri, I'm Assistant Mental Health Director of the World Trade Center Clinic here at Bellevue Hospital, and I am also a psychologist there so I see patients for mental health treatment in the clinic.

So our World Trade Center Environmental Health Center serves a survivor population, which is basically anyone who was not a first responder that was present on the day or in the months afterwards and had some kind of mental or physical health condition that come to our program for screening and treatment.

And to say a little bit more about our population, a large percentage of our survivors screen positive for mental health symptoms like PTSD, anxiety, depression and a number of other conditions. We find that these symptoms have persisted over the years, and they are also comorbid, as a lot of my colleagues have mentioned, with other medical conditions including respiratory illnesses, gastrointestinal illnesses, cancers and other conditions.

So in our population, about 33% of our survivor population in our program identifies as Hispanic. We've found that the Hispanic patients report higher rates of PTSD, anxiety and depression. that they report that these symptoms persist over the years, and they also have very high rates of respiratory illness and other medical health conditions.

Research has shown, and a lot of the research you've heard earlier today speaks to, the effects of PTSD, mental health and the relationship with physical health symptoms as well. So what we know is prolonged PTSD really results in a chronic stress response that can affect physical functioning as well, physical health as well.

There is little research on clinical treatments for Spanish-speaking individuals with mental health needs like the ones we see in our population. And due to the presence of both PTSD, anxiety, depression and other mental health symptoms along with the medical symptoms, we really strive to find treatments that can address both the mental health and the physical symptoms that our patients are dealing with over the years.

So in this study, we sought to assess the feasibility and acceptability of this mind-body treatment that has been used at Stony Brook with responder population to good effect, to really treat our Spanish-speaking World Trade Center survivors with chronic and persistent PTSD symptoms.

It's the Relaxation Response Resiliency or 3RP treatment program. It's a mind-body focused group psychotherapy treatment that has been shown to good effect at Stony Brook. It teaches patients to elicit the body's natural relaxation response. This relaxation response is proven to have positive effects on many mental and physical health problems including PTSD and respiratory symptoms in the research.

So we first translated the manual into Spanish, along with all the worksheets, and adapted it for use with our Spanish-speaking population. We then recruited 20 Spanish-speaking World Trade Center survivors with persistent PTSD symptoms who were interested in participating in the group psychotherapy. Participants were divided into four groups of four to six members each, and they met for eight weekly sessions of group psychotherapy that lasted an hour and a half each. Groups were led by a Spanish-speaking PhD-level psychologist.

At the first group psychotherapy, participants were provided with binders that included the patient manual, worksheets and weekly homework assignments that they utilized at each group session to read along with the group content and complete in-session worksheets and exercises, and then they had exercises that they had to do during the week at home and then report back.

Participants completed measures of PTSD, anxiety, depression, medical symptoms, life functioning, health promoting behaviors and mindfulness at three time points. It was a lot of questions. They first answered these questionnaires at baseline, which was before they started the groups, then at—oh, am I done already? No, okay. Sorry, then—

DR. BROMET: No, you have three minutes and twelve seconds.

DR. FERRI: Okay, then at exit, upon completing the group psychotherapy sessions, and at one-month follow-up. So let me tell you about the group quickly.

We had a diverse group of participants from the Dominican Republic, Puerto

Rico, Guatemala, Ecuador, Colombia, Mexico, Honduras, Bolivia. It's representative of our population; they come from all over. They all identified as Hispanic. The average age of our group members was 55 years old, and we did have 50% male and 50% female. They were exposed to the disaster as local workers, cleanup workers and residents. Seventy-five percent, or 15 of our participants, completed all the group psychotherapy.

And what we found is a decrease in symptoms of PTSD, medical symptoms, anxiety symptoms, perceived stress and depression between baseline and exit. Although this was not statistically significant, we did see a decrease in the scores. We also saw an increase in life satisfaction, which was observed between baseline and exit, and as well as one-month follow-up. What we did find statistically significant was the change in a measure of general health promoting behaviors. Participants reported an increase in physical activity and a significant improvement in stress management through the course of the group and by the end.

In open-ended interviews, they were asked about changes in their symptoms and health, perceptions of the group and overall experience, and all the participants reported that they benefited from this treatment program and they really liked it. They, all of them mentioned they really like learning the different breathing relaxation exercises. They also reported making positive changes to their diet and exercise routines as they learned in this program. They didn't love the homework, but I don't know who does. Many people did it and many didn't.

Okay. So okay, so overall, this study provides preliminary evidence for supporting the clinical effects of this group psychotherapy treatment. And before I end, I want to tell you a little bit about what we did in the treatment and how we—and what we thought it taught and was effective.

So it's really a treatment about resilience, a word that you've heard here from other speakers. And it's characterized by several factors that are actually themes and topics that we discussed in the group psychotherapy sessions. So group members learned about, one, awareness of the stress response, which is like a flight, fight or freeze response in the body and how it affects the body and its functioning. They also learned about the ability to bring about the relaxation response through a number of breathing relaxation exercises, other meditative techniques. We even did yoga, chair yoga. The ability to recognize negative thoughts. The ability to create adaptive thoughts and positive expectations. Also, developing a more optimistic and positive perspective by appreciating positive experiences on a daily basis that we actually reviewed in the groups. Increasing a sense of connectedness through social support, empathy and prosocial behaviors like acts of helping others or volunteering or sharing. And also, changing to healthful sleep, eating and exercise habits.

So overall, this treatment protocol had a positive effect on the participants. It was really well-liked. As it has shown efficacy, I look forward to continuing to use this

protocol as one of our treatments offered, and to really further investigate the benefits of this treatment in larger populations over time.
Okay, did it, thanks.

DR. BROMET: She did, and I screwed up the timer, so there we go. So essentially, what we've heard till now is that NIOSH and the researchers have pretty much focused on three issues. One is cancer, one is respiratory conditions, and the third is mental health, which is very broad—as are respiratory diseases. But we are all getting older, and there are other issues that have happened potentially as a result of the exposures, both the physical and the psychological, and the fact that they happened together at the World Trade Center.
So our next speaker is a very eminent occupational physician named Steve Markowitz, who is going to begin a dialogue about that. Before he starts, let me just mention that those of you who are interested in knowing more about this relaxation program should go to the roundtable at three o'clock where Adam and others will be leading the whole discussion about exactly what goes on in that training. Okay, sorry, Steve.

DR. MARKOWITZ: Hi, good morning, thanks. So I'm supposed to talk about how to think about adding additional conditions to the WTC covered list, which is really addressing causation, causation of disease. And disease causation is hard. It's hard for you to understand and it's hard for us to understand, so let me just start with that.
In fact, if you think about some new condition—forget WTC for the moment but if you think about some new health problem that you developed and you went to your physician for attention to that, and it could be pneumonia, it could be a fungal infection of your nail, it could be lupus or what have you—and you recall your visit to the doctor, my question is did causation actually ever come up? Was there any discussion with the doctor about why did I get this, why me? Why did I get this disease? What was the cause of this disease? And my guess is it didn't come up because what you spent your time talking about was diagnosis, what's the problem here, what's the nature of the problem, and also what the treatment is. What can we do about that problem? And that's right because that's actually our priority is diagnosis and treatment. And my guess, further, is that actually you didn't even realize the issue of what caused this with the doctor because you knew that the doctor didn't know, or you knew it wouldn't be a fruitful discussion. And in fact, my guess also is in the World Trade Center, if you discuss those issues with your non-World Trade Center physician, the answer is equally absent of any information. And that's because disease causation is hard because we spend most of our time talking about diagnosis and treatment.
In fact, if you think about the past medical history, you think about that form you fill out when you got to the doctor or what the doctor reviews in terms of symptoms, there is no equivalent exposure history. They don't talk about what you were exposed to, World Trade Center or otherwise. They don't go talk about your neighborhood, your home, what job you had or the like. And the price we pay for

that is ignorance, is that we simply don't know a lot about toxins and what they do. Now, I think it's useful to—switching now—I think it's useful to talk about how NIOSH looked at cancer, because NIOSH went through the review process with cancer and decided that cancer would be a covered condition. So let's just take a moment and review what considerations they looked at.

First of all, they looked at the epi studies that Dr. Webber talked about this morning and others, Dr. Lucchini, the epidemiology studies, and they looked at the results. And in fact, the results were, I would say, preliminary because not that much time has passed, and there was a modest signal of excess cancer. Some cancers, maybe it was exposure-related, maybe not, but there was a modest signal. So that's what the health studies of the workforce and survivors have shown us to date.

Secondly, NIOSH looked at cancers we would expect to occur as a result of known conditions. So we had inflammation of the esophagus as a WTC condition. We know that that can cause esophageal cancer. So we're going to cover esophageal cancer because it's related to inflammation; it's a secondary condition. And that makes a lot of sense.

And then they leaned on—and this is very important—the presence of known carcinogens at the World Trade Center site. So we know asbestos was there, and Dr. Lucchini mentioned this. We knew PCDs were there, dioxin and the like. Now, we knew that because there are decades of research on carcinogens which allow us to say that. You can go to NTP, National Toxicology Program, online. You can go to their report on carcinogens, and you can see their review of hundreds of carcinogens and what we know about them and whether they cause human cancer or not. That results from decades of work that's been achieved by the scientific community. Try doing that for autoimmune diseases. Try finding the report on autoimmune diseases by any authoritative government or nongovernmental agency and you won't find it because it doesn't exist. We don't have research as it applies to other outcomes besides cancer. And that's very important because it means we can't fall back on a body of knowledge that Dr. Howard mentioned, a body of knowledge to help make that decision about whether this condition could be World Trade Center-related or not.

And then finally, NIOSH used what we call plausibility and coherence, meaning did the toxin get to the site, to the target organ of concern, and does it cause biological changes that could cause cancer? And so we saw a lot of inflammatory conditions as a results of World Trade Center dust exposure, and we know that inflammation is a mechanism that can lead to cancer. So knowing those two facts, that WTC dust caused inflammation and that inflammation can lead to cancer, was important supportive evidence that cancer could be related to World Trade Center conditions.

So how much more time do I have?

DR. BROMET: None.

DR. MARKOWITZ: I have none, I have no time, so let me continue.

Oh, I just got two minutes. Mike Crane just gave me two minutes, thank you, thank you.

Okay, so in the workshop we'll discuss this further. But I'm thinking about heart disease and WTC, looking at kind of these same factors that NIOSH looked at. Do we have epi studies that show increase in heart disease? Well, there's some evidence from the World Trade Center Health Registry. That's one thing. Can conditions related to WTC cause heart disease? Well, PTSD does raise the risk of heart disease, so that's interesting. Were there known heart toxins at the World Trade Center site? Well, we know air pollution increases the risk of heart disease, though that leaves a lot of questions about how dust related to air pollution. And then finally, is there plausibility? That is to say, could that dust have gotten to the heart or caused inflammation that could lead to heart disease, on a long-term basis, not just in 2002 but in 2016? And that's a difficult question.

So that's application of NIOSH's criteria to a different condition, and you can see it's difficult. It's difficult in part because we don't have a lot of information, and that information will evolve.

My final point is, before Dr. Bromet cuts me off, is to emphasize, so the studies of the World Trade Center populations are key. The epidemiology studies, the surveillance work, the sentinel events that Dr. Moline mentioned before—it's key to us understanding and being able to cover conditions in the future, and we'll discuss this more at the workshop. Thank you.

DR. BROMET: So our next speaker is the Chief Medical Officer of FDNY, and he has done a lot of magnificent research over the years, but he taught me something that was really puzzling me for a long time. There have been other toxic disasters, and especially in the 20th century and early 21st century, horrible events that also had both physical and psychiatric consequences. And there were health surveillance programs set up just as many of you are part of the monitoring program for the responders or the Fire Department or others. You are filling out these mental health questionnaires and probably saying, God, do I have to fill this out again? I just filled it out the last time I came. And the answer is you do.

But what I asked Dr. Prezant about a year ago was how is it that the World Trade Center monitoring programs added mental health? Nobody had ever looked at mental health over time in disaster responders as part of a general medical surveillance program. Most of those programs were on cancer. Some of them broadened out a little bit to other medical problems, but never mental health. And the World Trade Center did. And Dr. Prezant said to me in his first email, very tersely, he said, "Because we cared." And I thought, what does that mean and how come nobody else cared before? And then I realized, from other conversations, that he was there at the time. He saw the emotional impact on himself, on the people around him, on the firefighters he was responsible for. So that answer was correct. And when you think about a lot of these other programs,

they were usually designed by researchers who weren't involved in the disaster. So they cared, but they didn't care in the same way and they didn't understand the full scope of what happened to people.

So I'm very happy to introduce Dr. Prezant and hear his talk on the future.

DR. PREZANT: Well, thank you for that lovely introduction and thank you for all that came here today. I'm certain it wasn't for the free food.

I'm certain it was because you care, and you care because this has impacted you, it's impacted friends and family and coworkers, and that's either because of direct exposures or because, as administrators, physicians, psychologists, researchers, it/'s impacted you in ways that many of us couldn't even begin to describe.

And when we're doing this, we have a unique challenge, and that unique challenge is to remember that we have two functions. The first function is obvious and that is to take care of the individual patient. That person who comes to us is looking for advice, is looking for treatment, and in many ways is looking for closure.

And I remember distinctly being at the bedside of a person who was dying from cancer, a firefighter, and his family was around him and he passed on. And he had many young children, and it was a very emotional event, as you could imagine. And the priest came in and said a few words. It helped a little. And then someone, I can't remember who, said, "You know, your dad was a hero because he died of cancer because he was there helping people on 9/11." There was no scientific evidence at the time that cancer was related to 9/11. There was no multimillion-dollar program paying for his cancer treatment. There was no World Trade Center logo over his bedside. But that family, for a moment—and I hope a moment that lasts forever but I know for that moment—that family had closure. That family didn't need scientific evidence. They didn't want scientific evidence. For them, Dad was a hero.

That was something that we gave to that family, and by now, covering cancer, that is something we can offer to every family—family of survivors, family of responders, family of patients that succumb to their disease, family of patients that don't succumb to their disease. It's more than about research and money; it's about taking care of human beings and their quality of life. That is our challenge.

At the same time, we have another challenge and that is a fiduciary responsibility to the federal government to say there is some science behind this. We hope that there's compassion. We hope, as Dr. Howard did for cancer, that there is compassion, that modest evidence can move us forward, because to not move forward is to miss an opportunity to provide the solace that I just mentioned, something that is invaluable. So we hope that there is comparison but there still needs to be some science because we have a fiduciary responsibility, because we need to have what I often call data-driven advocacy, right. Advocacy without data ultimately winds up being a program without credibility and a program that can't grow.

And one of the beautiful things about our program is that it has been based on data-driven advocacy. The clinical centers, the data centers, the researchers have provided clear evidence, for respiratory and mental health problems related to 9/11 and increasingly clear evidence for the same related to cancer. A modest increase in cancer only eight years after 9/11 is significant, and we are finding that our future studies are going to demonstrate, I think, that that level of data-driven advocacy and the confidence that the federal government had in our data is well-founded.

And it raises the question about what about something else. What about other issues? And we've been spending a lot of time on that, obviously. What we need is your compassion towards us as researchers, because it takes a lot of time. And I'm supposed to be talking about what it takes to do that today, and we'll learn more in the workshop, but we ask a lot of questions at the annual monitoring exam, and we ask them over and over again, and then we ask more, and people can get frustrated with that. But we're not looking for just one disease.

Let us postulate or think for a moment what it would have been if we did what would be a quick annual monitoring questionnaire on 9/11. The obvious thing to those of us who did care—thank you, Dr. Bromet—was mental health/PTSD and respiratory. And clearly as a lung specialist, respiratory is foremost. If that questionnaire was designed with just that in mind, we would have 150 lung questions and maybe 2 or 3 mental health questions, and that would be it. But we had a broader purpose. We wanted to ask questions about cancer. We wanted to ask questions about autoimmune diseases. We wanted to ask questions about potential toxic diseases like liver diseases, kidney diseases, etc. and therefore the questionnaire kept growing.

And when you come to answer that questionnaire, that is our beginning basis for picking up data. And then we do tumor matching and then we do treatment exams, and all of that data has to come together, and it has to come together in a way that is somewhat convincing so that we can move forward. And we are working very hard on that, but to get that data requires comparison studies. It requires that we look at control groups. The tumor registries provide us with the control groups for cancer studies. Looking at other workers with less exposure or no exposure provides us with control groups for many of the diseases, but these are control groups that are difficult to come by. There are always differences between controls and our own groups that make some degree of uncertainty, and that's why we need multiple studies.

And that's why the federal government has said, when we've presented what I believe to be overwhelming evidence that autoimmune diseases are increased, the federal government said, well, we need to see corroborating studies from the other groups, which actually is one of the strengths of our program. People initially said, well, you don't need to have a general responder group and an FDNY group and a survivor group, or maybe you just have one group and you just ask the

same questions of everybody and that will be perfect because there's more power in numbers. And these are people that don't really understand. There is more power in numbers but there is also more power in comparisons between different groups that then find the same evidence. That's what happened with cancer and we're waiting for that to happen in autoimmune, and I feel very confident that it will, and then we'll go on to the next and the next and the next.

But we're now getting an increasing challenge, and that increasing challenge is not just the comorbidity impact of all of these diseases together but there's an increasing challenge of two comorbidities that we all deal with in our own lives, that challenge each of us as individuals, and that is. unfortunately, aging and obesity. And many of the studies—I'm sorry, many of the diseases that we are looking at now, many of the questions that are being asked to us by our own patients, loss of memory, inability to exercise, increasing shortness of breath with activity, many of these are some of the same things that we see due to aging and obesity.

So what I want to do is provide you with confidence that we're looking at this. But what I also want to do at the individual level is empower you. Empower you to make a difference in your own lives, and that is to avoid future toxins, to continue to exercise and lose weight, as hard as that might be, and the biggest challenge—but which I know that at least I am capable of—is to never age.

DR. BROMET: I think I'm going to dye my hair after hearing that talk.

So we do collect chronic conditions as we age, and it is, it makes research on a population that's—we're all getting older. The investigators are getting older, the samples of people we're studying are getting older, and it becomes very confusing and very difficult. So as those of you who are participating in the studies, stay with us because the long-term picture might look quite different from the short-term picture, and there is no way to know that unless you stay with us through thick and thin, and really participate with your whole heart and not sort of take a questionnaire and say uh, I'm going to just put all this down so that I can get this over with. Actually, we want to know what you're really thinking and feeling and experiencing when you do fill out those questionnaires, because they matter enormously.

So our last speaker, and we'll probably go five minutes over, just to warn you — partly because I somehow screwed up this machine—is Dr. Michael Crane from Mount Sinai. And his task is the most difficult of everybody's, which is he's been asked to sort of pull this whole story together. So are you ready?

DR. CRANE: I'm ready.

DR. BROMET: Okay, well, we're ready for you.

DR. CRANE: So what a fantastic morning. What do you think of our panelists? Weren't they amazing? Incredible.

Absolutely incredible. It's just fantastic. And I have to say that because Dr. Bromet has a large weight that she's going to drop on my toe unless I say it, okay.

So that's what she's doing here. So I'm honored to be here amongst everyone, amongst our responders and survivors, and my fellow providers.

The modest title of my modestly titled talk is "What it all means". No problem. Seven minutes, I got it. I got it covered. But I think you've had hints about what it all means already, right? And the first hint, if you can think back that far, is what Dr. Denise Harrison said. Where is Denise? Where did she…? She's way in the back. Okay, if you have trouble remembering what she said, just turn around and look at her. It's okay. It'll come back, because she was fantastic. She's so eloquent.

But starting with that, we've had a group of people really tell us a great deal about World Trade. So let's start talking about what we actually heard. Well, this is a program about a disaster response program, as a categorization, and usually disaster response, you want to talk about the exposure obviously. You want to talk about acute and chronic. You want to talk about the populations, populations exposed. You particularly want to deal with the vulnerable populations to that exposure. You certainly want to talk about diseases, with an emphasis on mental health in disasters. And you want to also cover a myriad of other topics that will kind of fall out of trying to deal with those three.

So today we had wonderful talks about exposure, with Dr. Lucchini talking about the risk of cancer. Leo Trasande, who I think is just a marvel, kind of leading that charge about a really forgotten part of our population, the children, who are extremely vulnerable to this type of exposure, and his beautiful work, painstaking, detailed, beautiful work to show the risks that the kids are having to just one of the chemicals that goes down. So Leo, my hat is always off to you. Just continue the great work, just fabulous. And then our Dr. Webber, who works so hard with the Fire Department, doing a beautiful study. You realize that studies are kind of like baseball pitches, you know. Some are fast balls and some are sliders. Some go right in the dirt. This is a beautiful curve ball that Mayris is throwing, just a beautiful, gorgeous curve ball that's going to drop in the strike zone about fifteen years from now when the results come through and show that the difference between these two populations of firefighters in terms of outcome is the World Trade Center exposure. It's beautifully designed; it's well thought out. Thank you so much, Mayris.

We've had our doctors talking about illness. Dr. Reibman, my colleague Dr. Laura Crowley, Dr. Clouston and Dr. Brackbill really describing the population both in the CCEs and in the Registry, and talking about the illnesses. We've had people who have been doing population—I mean hypothesis-generating studies, like I think Dave Prezant's study about rheumatoid disease and autoimmune diseases—to generate new thinking about the illnesses that may be coming. And Dr. Reibman of course about the airway disease.

Dr. Markowitz talked about how we think about new conditions, and both Dr. Feder and Dr. Ferri just with us now talked about really exciting new approaches

to a terrible illness, PTSD, where people can actually start doing this and hopefully get relief of symptoms. I think this is fantastic work and I'm very, very excited about participating with both of you in the studies.

So we heard a lot of great stuff, right. So is that what it all means? Uhhhh…you kind of stop there and you say maybe, maybe there's a little something more.

So what I think it all means becomes clearer if you turn the title of today's program on its head. As somebody once said to me, if you really want to see the world, stand on your head. So it comes, Research to Care turns into Care to Research.

So David is looking at me—I said that already—and I'm just going to say it again. But it's not just the care, the medical care. What it is, I think, what it all means is the inspiration that responders and survivors gave to all of us, their courage, their unselfishness, their willingness to sacrifice themselves and share with the community, and to be the people who still say to me, day after day, oh Doc, I know you got treatments but really, save it for the guy who really needs it. Save it for the person who really needs it, Doc. That doesn't happen in a lot of places. It's the unselfishness of you, our populations. And quite frankly, that has inspired us. It has inspired us repeatedly. It has inspired us every single day. It has inspired us this morning. Your care that inspires our research, which then helps our treatment.

So what it all means, it means inspiration. And I'm hoping, I'm hoping that it's the type of inspiration that can carry us forward even when we have those moments that David and my dear colleague Jackie so eloquently described, of loss, and I hope which will carry us past the site of all these broken hearts.

So thanks very much, thanks for this honor. Thanks for being you.

DR. BROMET: So thank you. I understand we're on our own for lunch, and Dr. Lum is going to say something. I just want to reiterate what Dr. Crane said. Research isn't a we/they activity. It's really, it's an activity of all of us over a long period of time. So it's a commitment on both sides. So if you're involved in projects and you have thoughts or ideas or complaints, you need to express them. You need to take ownership of the studies that you're in, and communicate with the people who are doing the research. Because we all view it that way. We view it as a community effort, especially World Trade Center-related studies. So that's what I wanted to say.

WRAP-UP

DR. LUM: Thank you, all, by the way, for hanging in here. It's past 12:30.

Thank you. Thank you, Michael, for that summary. I know that's very difficult but I have said this before in PI meetings that we have with our researchers on a quarterly basis, and I truly mean it because of course I get to work with researchers at ATSDR when I was there, and also at NIOSH. And I think that Michael helped me understand, I think, in what he said about the difference in the

researchers here in New York, and that is passion. The passion that we hear in their presentations and the passion in their work is absolutely fantastic, and I thank you for that clarification there, Mike, very much. Thank you.
So I'll introduce another staff member who's really been helpful for us, with us, and I won't read Tania's bio because it's in your book, but Tania has been very instrumental in helping us work through that. She is the Science Advisor for the World Trade Center program, for the NIOSH part of it, and she is also Associate Professor in Cincinnati, and actually we've done some courses related to what we're doing here in Cincinnati, in her program, and her background is in epi and occupational medicine. But the thing that's really been absolutely great working with Tania is she's one of these people which I call the "but" people and the "but" people is the person where you are telling someone something and they say, "Yes, but…" And she has kept us very much on track with the yes, buts.
So she is going to tell us a little bit about lunch and the breakouts.

DR. CARREÓN-VALENCIA:

Yes. (Laughs.) Thank you, Max, for that wonderful introduction, and thank you all for being here. It has been an amazing morning. I want to thank again our panelists and moderators both in this session and the morning session.
I have a few housekeeping announcements before we break out for lunch. The lunch, of course, is a way to get some calories and energy for the afternoon session but also we want to take you, for you to take the opportunity to visit the tables of our wonderful partners. I know you will find some useful information that you can take home with you. When you go to lunch, you can use the NYU cafeteria here. There will be volunteers that can lead you to the blue path towards the cafeteria, and also our partners here at NYU have put together a list of nearby restaurants. You can find those lists outside on both sides of the registration table. Also, for those of you that parked here, NYU has graciously given us parking vouchers. So please look for me or go to the registration table to pick up one, and you will get free parking. Very nice, right?
And finally, I want you all please come back here after lunch at 1:30. We will have volunteers and NIOSH staff that will take you to the all different breakout sessions. So have a wonderful lunch and see you here at 1:30.

(Applause.)
(Participants leaving.)

[END SESSION]

G L O S S A R Y

ATSDR	Agency for Toxic Substances and Disease Registry
CCE	Clinical Center of Excellence
FDNY	Fire Department, City of New York
NIOSH	National Institute for Occupational Safety and Health
NYCOSH	New York Committee for Occupational Safety and Health
NYPD	New York Police Department
PTSD	Post-Traumatic Stress Disorder
WTC	World Trade Center