THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES AGENCY FOR TOXIC SUBSTANCES AND DISEASE REGISTRY

convenes the

TENTH MEETING

PEASE COMMUNITY ASSISTANCE PANEL (CAP) MEETING

September 5, 2019

The verbatim transcript of the Meeting of the Pease Community Assistance Panel held at the New Hampshire Department of Environmental Services, Pease Tradeport, Portsmouth, New Hampshire, on September 5, 2019.

C O N T E N T S

September 5, 2019

P A R T I C I P A N T S

(Alphabetically)

ALMOSARA, JOEL, USAF
AMICO, ANDREA, CAP MEMBER
ANDERSON, KAREN, CAP MEMBER
BOVE, FRANK, ATSDR
CARMICHAEL, LINDSEY, CAP MEMBER
DALTON, MICHELLE, CAP MEMBER
DAVIS, ALAYNA, CAP MEMBER
DIPENTIMA, RICH, CAP MEMBER
DURANT, JOHN, CAP TECHNICAL ADVISOR
HARBESON, ROBERT, CAP MEMBER
LAUNI, LORI, ATSDR (PHONE)
MUTTER, JAMIE, ATSDR
PROTZEL BERMAN, PAM, NCEH/ATSDR
REH, CHRIS, ATSDR
SCHAIDER, LAUREL, CAP TECHNICAL ADVISOR
SHAHEEN, STEFANY, CAP MEMBER
SHEEHAN, JARED, CAP MEMBER
SOMERS, TARAH, ATSDR
SULLIVAN, MARK, CAP MEMBER

P R O C E E D I N G S

(6:00 p.m.)

WELCOME AND INTRODUCTIONS

DR. REH: Are we all set? All right, thank you, everybody.

CAPT SOMERS: Is that really loud?

DR. REH: Is that really loud? Seems like it. Yeah, seems like there's a lot Of..

[Laughter]

So, thank you, everyone, for being here for the next meeting of the Pease CAP. This is, for us, at ATSDR, and I know for many here in the audience, an exciting time and an exciting meeting for us because something that's happened since the last time we were face to face is that the protocol for the Pease study with approved by OMB. And we are ready to move forward with the study. And so

[Applause]

I'm particularly happy because hopefully we don't have to spend a lot of time explaining why things are not going as fast as many rightly so would have liked them to have gone. And it's kind of pleasant to talk about something that we've all been working for. So, I want to introduce two people before we get to the housekeeping with Jamie. First, Karen Anderson is our new member of the CAP, and she's from the town of Newington. And so welcome, Karen.

MS. ANDERSON: Thank you.

DR. REH: Good to be here. Good to have you here. And then Pam Protzel Berman is here. She's part of the NCEH/ATSDR team. She works, she leads the office, she's the director of the Office of Policy, Planning and Partnerships. And she is the policy and partnership lead on Pat Breysse's team. And so we're very pleased to have her here. And also Kim from her team is also here today. So, with that, I will turn it back over to Jamie and let her do her usual stuff.

CDR MUTTER: That sounds good. Thank you. So, we'll start with the bathrooms are out this back door down the hallway to the right. Emergency exit are out this way right here and the door you came in. If we can have everyone turn their cell phones down onto silence, or off, that would be greatly appreciated. And just a reminder for the CAP members to put your name tents on end if you have a question or a comment. And if you could, say your name before your comment so our transcriptionist can accurately reflect your comment, that would be appreciated. So, with that, do you want to do introductions?

DR. REH: Sure.

CDR MUTTER: You want me to start?

DR. REH: We'll just go around.

CDR MUTTER: Okay, I'm Jamie Mutter with ATSDR. I'm the CAP coordinator.

MR. DIPENTIMA: Rich DiPentima, CAP member, Portsmouth.

DR. SCHAIDER: Laurel Schaider, Silent Spring Institute. I'm a technical adviser to the CAP.

MR. SULLIVAN: Mark Sullivan. I have a business here in Pease. Member of CAP.

MS. AMICO: Andrea Amico. Is this on?

UNIDENTIFIED SPEAKER: Yeah.

MS. AMICO: Okay, Andrea Amico, Portsmouth Resident, CAP member, and co founder of Testing for Pease.

MS. DAVIS: Alayna Davis, co founder of Testing for Pease.

MS. CARMICHAEL: Lindsey Carmichael, Portsmouth Resident.

MS. DALTON: Michelle Dalton, CAP member, and co founder of Testing for Pease.

Col AMOSARA: Joel Amosara from the Air Force Secretary.

MS. SHAHEEN: Stefany Shaheen, Portsmouth Resident, CAP member.

MR. HARBESON: Rob Harbeson, Pease parent, past chair of Great Bay Kids and CAP member.

MR. SHEEHAN: Jared Sheehan, CAP member, Pease Development Authority.

MS. ANDERSON: Karen Anderson, special project coordinator for the town of Newington and new CAP member.

DR. PROTZEL BERMAN: And Pam Protzel Berman, and I'm with the CDC, as Chris mentioned, and associate director for policy. And I do congressional relations and other work for CDC.

DR. BOVE: Frank Bove. I'm from ATSDR. I'm the PI on the study.

DR. REH: Chris Reh, associate director for ATSDR.

CAPT SOMERS: And Tarah Somers. I'm with ATSDR, Region 1, Boston office.

DR. REH: And the Abt folks, do you want to introduce yourselves?

MS. HUNT: Sure. Danielle Hunt. I'm the project director for Abt Associates.

MS. JEDDY: I'm Zuha Jeddy. I'm the project manager for Abt Associates.

[Inaudible]

DR. REH: And is there anyone on the phone?

[Inaudible]

Anyone else? Okay, so, let's get into it. Frank, do you want to start with an update on the Pease study?

DR. BOVE: Oh, we're not doing the action items?

DR. REH: Oh, do we want to?

[Inaudible]

I'm sorry.

ACTION ITEMS FROM THE JUNE 2019 CAP MEETING

CDR MUTTER: Okay, the microphone is not working. Right? Is it just me?

MS. CARMICHAEL: It doesn't sound like there's any amplification.

CDR MUTTER: They were working when we started, and now do we have it? Okay, great. Is that better?

UNIDENTIFIED SPEAKER: Yeah.

CDR MUTTER: Yay! Okay, so, so many papers, so many things going on. All right, some of the action items. The first one is regarding Dr. Woods from last presentation. ATSDR will work to communicate with Dr. Woods to follow up on questions asked regarding the Environmental Health and Safety Committee within

the American Academy of Pediatrics. Dr. Reh, did you have a quick update on that?

DR. REH: I do. And I'm going to read this because it's fairly lengthy, and I can't remember it. So, as you know, Dr. Woods was here with the CAP at our last face to face. He's from the American Academy of Pediatrics. And he's part of the AAP's Council on Environmental Health. And he went through a presentation on how the academy sets medical monitoring guidelines as it relates to children. And possibilities that we could explore with the AAP as far as medical monitoring guidelines. So, there's been two recent movements within AAP that I know will be of interest to the CAP, and are definitely of interest to the medical monitoring for PFAS. And AAP this year has published their pediatric environmental health fourth edition, which they call the green book. It was released this year, as I said, and this is the book of the AA, it's the AAP policy manual that helps clinicians to identify, prevent, and treat pediatric environmental health problems. So, it's basically all of their policies and upcoming approaches to setting policies related to environmental health hazards. Within the document, there is a new chapter on PFAS. We are working to get a copy of that. And we will definitely share it with the CAP once we have it. It's probably sitting in Michael Hatcher, who leads our environmental medical guidelines group, it's probably sitting with him right now, and it just hasn't made it to our inboxes yet. But we'll definitely share it. The chapter does not give a lot of clinical guidance for PFAS. But it does, as far as AAP is concerned, it provides a foundation for them to be more clinically focused, especially on recommendations for clinicians related to PFAS exposures. So, it's an important first step, a good first step towards getting this done. So, very glad to see

that happening. Also related to this, the AAP's Committee on Environmental Health has been collaborating with another committee within this group, the Committee on Infectious Diseases, and they are working on a proposed revision to the academy's drinking water from private wells and risk to children policy. So, again, a topic that we've discussed many times here within the CAP. And the committee has not yet received permission from the AAP board to undertake this revision. They are working through the proposal process for doing such a revision. So, it's not that the board has said no, we don't want you to do it. They have a process for recommending to go down a new avenue, and they're in the middle of that process. One of the Committee of Environmental Health's primary concerns for doing this revision was the need to address PFAS exposures. And so, again, another effort potentially within the AAP regarding medical monitoring guidelines. We've also talked, as you know, we've engaged the American College of Medical Toxicologists on them possibly considering medical guidelines for adults, and the AMCT has been in contact with AAP as a potential to work together on this. We're staying involved as best we can. Definitely more to come on this. So, that's the update.

CDR MUTTER: Okay, any questions on that?

MS. AMICO: I have a question. So, just, hi, this is Andrea. Sorry. One question I had when you talked about the AAP and the environmental committee collaborating with the Committee of Infectious Disease and talking about private wells and risk to children, I just wonder if there's a way to send a message back to them. Have they thought about looking into vaccine effectiveness? Because that, to me, would be an infectious disease issue.

DR. REH: Yeah, I think that's a good pick up, Andrea. And so we can definitely communicate that back to them.

MS. AMICO: Okay, thank you very much.

CDR MUTTER: Okay, so, I'm going to skip to an action item about Dr. Woods' presentation being posted on ATSDR's website. We're not able to post his presentation on our website because it's not our material and hasn't gone through our clearance process, but it's on the YouTube video from our last CAP meeting, and that is online, and that can be shared with whoever. So, the next one is for ATSDR. The CAP requested a summary of the historical reconstruction panel to include topic discussion and who was on the panel. That summary was sent out to the CAP on August 15th. The next action item, ATSDR will send the address of the Portsmouth Study Office to the CAP. That was done shortly after our last meeting on June 6th. The CAP asked for a new timeline on the Pease study. I think we'll delay and talk about that during the Pease study update. I think it will be more appropriate in that section. And the CAP requested to see the ATSDR map where ATSDR is doing PFAS related work. I sent that this morning. I waited as long as I could to see if we could get a more updated map that is currently getting updated with new sites. And so I sent what we have out there now. And once that is updated, I'll send you the link with the updated map. Okay.

[Inaudible]

The CAP requested information on the private well water health consultation related to the well location. It's the health consultation focused on wells within a one mile radius of the Pease Tradeport. And I will let Tarah answer that.

CAPT SOMERS: So, I went back and talked to Gary Perlman and Greg, who are writing the health consultations for the site. So, the private well data that we got was initiated by U.S. Air Force when they did the off base private well sampling. And they located all the drinking water wells within a mile of the Pease boundary. And my understanding is that that is all the wells that are in Newington and Greenland. So, basically, the wells that were that mile radius was what was started, but that included basically the wells that are in town. So, they offered sampling. They did door to door surveys in the neighborhood. And the property owners were interviewed, and data was collected on their water usage. They did a couple visits to follow up in case people weren't home the first time or didn't want to participate. And I think they did like up to six attempts to reach people. So, everybody who wanted to participate participated. But some people may not have participated. I think the question was like why a mile initially was the question. And they started with that, but that ended up encompassing all the wells. So, it's not the mile is kind of just, you know, not really a hard line when it's all the wells. Does that help maybe? I don't remember who asked the question.

UNIDENTIFIED SPEAKER: Yeah, I don't remember.

CAPT SOMERS: Sorry. And I was pretty sure that was what happened, but I went back and double checked. And that's, my understanding is that is still what happened. They started with a mile, and then that mile ended up capturing them all anyway.

UNIDENTIFIED SPEAKER: Meaning specifically in Newington.

CAPT SOMERS: Newington. And I think they were in Greenland too, there were a few. But not very many. It's mostly Newington.

UNIDENTIFIED SPEAKER: Okay.

MS. AMICO: I have a question. That data, because that's private well data

CAPT SOMERS: Right.

MS. AMICO: Will that be shared publicly, or will that be in the document, or will just like a summary of what you

CAPT SOMERS: Yeah, we don't like identify people's homes or that personal information in that level. No.

CDR MUTTER: So, a summary will be

CAPT SOMERS: I mean, it summarizes the data, and there will be, you know, we've done things in the past where we'll, you know, you can do things like group concentrations together so you know there were this many wells that had up to this amount, and this many between these amounts, you know, so you're not like necessarily identifying individual wells. We do that in all our documents, not just the Pease ones. We don't want to, you know, that's personal information. We don't want to give that out.

CDR MUTTER: All right, one last action item before we move on to what we all want to talk about. So, ATSDR will include the ATSDR PFAS summit on all future agendas, and we have done that. So, that is the end of the action items. And we'll move onto the Pease study.

PEASE STUDY UPDATE

DR. BOVE: Okay, so, yes, we have gotten OMB approval for the package. There were some stipulations that went along with that approval, which I think that we've been discussing with is this on? Yeah, talk into it. Okay, that would help. There were, there were some stipulations that were part of that, which we went

over with the CAP. And those included the usual things we would do in a study, which would be to make sure that there isn't any confounding factors that might explain any relationship we see with PFAS and an end point, which we would do. First, when we analyze the data, we put other risk factors in the model that are, that may affect the outcome. So, we already do that. And we also do other methods to look at bias. So, we pointed that out to OMB, and I think that they understood that we were, we're on the same page, that we do that normally anyway. The other issue was those findings where we might not have good statistical power. And so, but power is irrelevant once you start a study. What you have is a confidence interval. And the width of the confidence interval tells you how precise or how reliable, whatever term you want to use, the finding is. If the confidence interval is wide, it's not very precise, there's some, there's more uncertainty. If the confidence interval is narrow, there's less uncertainty, more precision, more reliable. So, that's what we do anyway. And that's what we will do. So, none of these stipulations really have any impact whatsoever on how we're going to analyze the data and how we're going to interpret the data. So, so, it's not an issue. What is an issue, but it shouldn't be, it's not a major issue, and it should have no problem getting through, is we're making changes to the consent form since then that need IRB and OMB approval. And these changes have to do with the stored blood from the Pease biomonitoring program. And we had a discussion with Dr. Chan and his staff a week or so ago, two weeks ago, and we decided together that Dr. Chan drafted a letter that will be sent out to those in the biomonitoring program explaining that if they want their blood stored at CDC, they need consent to it. If they don't want that, then the blood will be destroyed, because that's what the initial consent form for the biomonitoring

stipulated. So, we are, ATSDR is going to be consenting them. So, we will have on our consent form with a checkoff where they can say, yes, I consent to having the blood stored for possible further analyses. So, that change has to go through, as I said, it goes through our IRB, and also get OMG approval. They're aware of it. OMB is aware that we're making this change, so there shouldn't be a problem at all. And I think this is a good thing. We don't have any set plans for the blood. There are a couple of things we've been thinking about, such as additional PFAS that may, our lab may be able to evaluate in the next year or two or three, so we have the blood that we can look at. Also, if there's some finding that doesn't make any sense, if the trend with PFAS and a biomarker is just unclear, the dose response is a funny shape, it might be useful to analyze the blood for that. Where there may be a biomarker, we've just forgot, or not forgot, did not include, maybe because there was no evidence before that, or there's new studies that indicate that this might be an important thing to look at, we'll have this blood to be able to look at. And it's closer in time to when the exposures what happened when the Haven Well was shut down. So, it will be useful. So, that's one item that's changed. And, again, we need to get OMB approval for the consent form. But I don't think that's going to hold things up. So, the next steps oh, by the way, you did get the expert panel for the historical reconstruction document. They're continuing their modeling efforts. They've done some, what they call one dimensional modeling. I'm not a modeling expert. But that's an initial approach to looking at this and making sure that the data they have is accurate, working with the city on that. And they asked the Air Force for two different data items that I think they have in hand now. One is that there were monitoring wells installed near what's called Site 8 where a lot of AFFF

was used. And they wanted to get that data because that's important to, for their modeling. And the other, the other data item was groundwater measurements, elevation measurements that were taken in the spring. And that we have too. So, that modeling effort is going forward. So, the next steps. There's a slew of next steps that we'll be taking with our contractor, Abt, in the next few months. And so yeah, you're already set. Just briefly, and then Danielle, take it away. But there's going to be training of the staff. This letter that Dr. Chan wrote, and our consent form will be finalized. There's going to obviously be outreach and a community meeting held. And we're also finalizing with one of the labs that we'll be doing the analysis of the blood for immune endpoints. So, that's happening. So, there's a lot of different things happening. So, do you want to flesh that out?

MS. HUNT: Yeah, sure. Is this on? All right, okay, so, as Frank mentioned, and I don't know if you recall, we shared the community engagement plan with the CAP. That was kind of our process for working with the community and informing the community when the community meeting will take place. So, now that we have OMB approval, we're working with representatives from ATSDR and some individuals in the community to select a date for that community meeting. Some of the proposed times are through September and through the first couple of weeks of October. And that's just to coordinate across all schedules. So, at that point, we will hold the community meeting. I am meeting, Zuha and I are actually meeting tomorrow with Dr. Chan at the Department of Health, where we will be talking with them about the strategy for mailing out the recruitment letters. The strategy right now is that when the day of the community meeting, we would also be sending those letters out to the

participants of wave one, which is the biomonitoring study participants, so that they could then call into the call center that Abt has established, be screened into the study, and then we would probably give around two weeks after the community meeting to allow the letters to be sent, for people to receive the information, to call into the call center, be screened, and schedule an appointment, and then come in so that we would anticipate being able to start data collection around two weeks after that community meeting occurs. Excuse me. So, in the meantime, in preparation for the community meeting, we are scouting different areas to host that meeting. One of the questions that came up on some internal discussions that perhaps the CAP can provide some input in is approximately how many people we should expect to have come to the community meeting. We will do, we'll share information via multiple different outlets. We'll ask Testing for Pease to put it on your website. We'll get some information out to the newspapers over social media, et cetera. So, we will have that information out there. And it's open to all members of the community, even though we have different waves of recruitment, as you've seen in the protocol. This initial meeting will be open to everyone. So, I don't know, maybe we can just pause for a second to see if people have input on the approximate number of people, just based on other experience that you all have had.

MS. AMICO: I honestly am not sure. I feel like we've had pretty low attendance at our last CAP, several of our CAP meetings. I think the most well attended meeting we had was the parent meeting. It was like September of 2015 when a lot of the children got their blood test results back. It was like almost standing room only in this room. But, so, I honestly don't know what to say. I would love to say we could fill a room of like 2

or 300 people. I just, I'm not sure. I feel like, you know, it's been four years since people had their blood tested, so I would like, I mean, I hope we could plan for like maybe 100 or 200 and hope for the best, but I'm just not sure. I don't know if you guys have other thoughts. I just, I feel like even today with the announcement of the study, I would have hoped more people would have been here tonight to hear more information, and they're not, so, yeah.

MR. HARBESON: I just, kind to reiterate, or echo the same comments, I mean, at Great Bay Kids, I know when people got their blood tests back, you know, we easily had probably two water forums with like 100, you know, 50 to 100 people at each one. But there's been other meetings where, you know, similar to tonight, when I'm not seeing the same people here. And so I think there's going to be, you know, more active outreach required in this next step. So, kind of question mark.

MS. HUNT: Okay, that's what I was going to say. It sounds like there definitely needs to be a big push in the community in terms of outreach so that people are aware that the meeting is happening.

MS. AMICO: Yeah, I think the recruitment needs to be multi pronged. I know we've talked about this, Danielle, before, but it has to be many layers of trying to reach people. I think a community meeting is one way. But we need to get people to know about the community meeting, and that's going to require lots of different things like media, social media. I'm hoping the PDA can help reach out to people and let them know too. We'll do our part as well.

MS. SHAHEEN: Can I ask, is it possible to actually treat the community meeting as a screening opportunity as well? Because

asking people to come to a meeting, and then telling them they need to come back, we're going to lose people.

MS. HUNT: So, the way that the protocol is written, the waves are separate. So, that first wave is for the biomonitoring participants. So, they would, we want to exhaust that list because we already have, I mean, Frank can speak to this, but we already have that existing blood sample from them. So, we want to get as many people from that group as possible. So, that's really the first round. And so they will be the one getting the letters, and they will be the ones being invited to participate at the beginning of this study. We'll make very clear in the presentation to the community members that it is multistaged, and everybody will get a chance to call in. But the first round is the biomonitoring participants. I don't if, Frank, do you have anything more you want to say?

DR. BOVE: No, that's

MS. SHAHEEN: Well, before you go, so, if that's the case, why not just wait for the community meeting until after we've exhausted the first wave?

MS. HUNT: I think because as this is getting media attention, we want to raise awareness, and people who participated in the biomonitoring study need to know about it, but then they may have a neighbor or they may have a friend, there may be more questions generated if we only hold that community meeting for the biomonitoring participants, and we want to raise awareness early and keep the message going on throughout the study so that people would be ready and willing to participate when they have their opportunity.

MS. SHAHEEN: I guess my worry is that we've talked a lot to the community and engaged the community on a number of fronts. And to have yet another community meeting where they can't take action doesn't, it doesn't feel right to me. I mean, I'd rather I appreciate the need to enroll people in waves, and I completely understand why we would target the folks who have already given blood samples. But using a community meeting, generating interest in a community meeting, and then turning around and trying to generate future interests with those same people to come back and get screened feels like a huge missed opportunity. So, I mean, from my perspective, I'd rather have all the outreach effort early focused on getting those people in the first wave to show up and participate rather than try to create a ton of interest in a community meeting that is mostly informational and is still leaving them with things they have to do later. So, I don't know, I don't know if other people feel the same way, but I don't think a letter to the folks who have given blood already is going to be anywhere near sufficient to get them to reengage. So, I think every ounce of energy we have to capture this captive audience of people who at one point were interested should be targeted early, and trying to divert that with a broader community meeting feels like it may be wasted effort. I think 100% of our energy should be getting those people who we know have already participated, who have already been screened, to reengage initially.

MS. DAVIS: Is the community meeting going to be to recruit other people outside of the previous biomonitoring candidates?

MS. HUNT: At this point, the community meeting, it's an informational meeting. So, it's letting everyone in the community know about the study, know the process for the study, know the timeline for the study, know, let them know when they

can participate in the study, and what they can and cannot get out of the study. Those are kind of the main points that are covered during that meeting.

MS. DAVIS: So, in the letter that's going out to the biomonitoring participants, will that list the date for the community meeting, or is that something that will come later? Because like, you know, piggybacking on what Stefany was saying, it would feel, it would feel most efficient if we, in the letter, was able to state to the biomonitoring participants that there is a community meeting scheduled here if you would like more general information, but is there a different process for those candidates, or do they have to attend the community meeting? I think all those details need to be kind of ironed out.

MS. HUNT: Right, so, and Lori Launi is on the phone from ATSDR Communication. So, I don't know if Lori has anything to add to this. But, again, the process now is to have the information about the meeting go out to everyone so that it's not just a letter to the biomonitoring participants. That's the, that's the invitation to join the study. But the community meeting is, again, more of that information piece. So, we would provide information about enrolling at that study, at the informational meeting, as well as in a letter that would go out to the biomonitoring participants. But, again, Frank or Lori, I don't know if you have anything more to add.

DR. BOVE: Just to be clear, you don't have to be at the community meeting to be part of the study or anything. But the idea of the community meeting and all the other outreach efforts, including fact sheets to the schools, to the community groups, getting the TAP and the PDA involved, is to get the word

out about the study, and have a community meeting so we can explain the study to a larger audience. That was the idea. The recruitment was focused on a letter to the biomonitoring participants. That may not be enough. I agree. So, there needs to be other efforts as well in terms of outreach. So, the community meeting is not the only way we're doing this. Okay? But we thought it would be important. When we do a study, we thought it would be important to engage the community and let them know that we're doing a study in their community, number one, what we're going to be doing. And it seems to me we need to discuss this more. But it seems to me that we could have a sign up sheet of people who are interested in being contacted further about the study, or something of that sort, if you thought that the community if the community meeting was successful, and a lot of people showed up, and a lot of those people were going to be eligible. Okay? If we thought that that would the case, and a lot of the biomonitoring people were there, then, yeah, I think we could, we might be able to able to incorporate that in. But we need to have that discussion. But the key thing about the community meeting was to explain to the community that we're here, we're doing this study, they haven't been to these CAP meetings, this is what we're going to be trying to do, this is who's eligible, and so on. In addition to, as I said, getting the word out to the media so the media can say the same thing, and the community groups will have fact sheets on it.

MS. HUNT: And then in the past, we've met with different representatives. So, we met with some school, Kate Durocher, who was here at the last meeting, in person. We went and met with some of the school representatives. We've met with the Tenants Association Group, you know, we've met with different key groups in the area. So, we've talked about posting signs throughout

Pease. So, it's definitely a multi pronged approach in getting the information out there regarding the messaging of both the meeting, and then open enrollment when we get to the wave two and wave three as well.

MS. LAUNI: [Inaudible] And including through not only through social media and e mailing throughout the school system, we've formed a relationship with the school system to help with that, and with the tenant association. And we were going to participate in some of the community events to get the word out. So, it will be a multi pronged approach. So, it won't, it won't just stop at the meeting, like Frank said. It is information that's a recruitment with our materials will continue throughout to reach everybody.

MS. SHAHEEN: So, if I can just reinforce or ask, as you think about the recruitment effort, I think it's not enough to let people know about a community meeting and an information night. I think anytime they interact and learn about the study, we need to help them answer the questions, are they eligible, and can we get back to them so they can enroll in wave two. And so if collectively it makes sense to have the community meeting at the same time we're recruiting people in wave one to enroll, my plea is that anybody who comes here leaves here knowing A, if they're eligible, and B, we know how to then reach them, because I think the recruitment for this study is going to be much harder than we could imagine right now.

MS. HUNT: And we have talked about, we will have sign up sheets so that people can sign up. I know we've talked, Andrea, about the list that you have had, the e mail list of people that have written to Testing for Pease that have been interested in. So, we want to use all those mechanisms. We've also talked about

setting up a Pease specific e mail address on the CDC server. We need to still follow up on that. Where people could access it. So, we are we certainly don't want to miss anyone either, you know, we agree that it's going to be a challenge to get everybody into the study. So, we're trying to exhaust all the ways to reach them.

MS. DALTON: Yep. And this is Michelle. I just want to say, basically my point, I think, has been sprinkled around. But if there's any way to have the community meeting be both a proactive sign up, as well as an informational night, because with all due respect to everyone, we've been hammering the point of we're trying to get a study, we're trying to get a study for four years now, so I almost think that they are a little it falls a little deaf on their ears because we've been talking about it so much and kind of hyping it up that if they're saying, hey, we're having just another community informational night, we're not going to get the turnout that we want. So, if we have some sort of action that they can take when they're there, that's going to help drive recruitment as well.

DR. REH: So, when we do studies like this, the recruitment process is always the biggest load, and the hardest part. And that's not lost on us. And it's almost you've kind of gotten around this. It's almost, you know, you have to leave no stone unturned, and you have to find stones that you may have to turn over that you may not have known existed. And no community is the, you know, no two communities are the same. So, what is successful at one may not necessarily be successful at another. So, this is great feedback. You know, the CAP is providing some you guys know your community better than we do. We appreciate that. And this is some feedback we can take back and consider how we approach this better. But this is, you know, this is

where the heavy lifting begins. The recruitment is just so critical in studies like these. It can make or break them.

DR. SCHAIDER: Hi, this is Laurel. I had one follow up question. I agree with everything that's been said. I know this is a multi pronged approach. He said that you'd be sending out the letters to the biomonitoring study participants on the day of the community meeting. Is that

MS. HUNT: We are not. But that letter would be coming from the Department of Health. So, we're going to meet with them tomorrow to talk about the timing. But it was, when we had thought through the timeline, it was to be able to say at the meeting that those biomonitoring participants will receive a letter in the mail, and that it would be forthcoming. So, if we could send it that same day, then that was the goal.

MS. SCHAIDER: I was just wondering if there's an e mail list or something so that you can reach out to those participants ahead of time to let them know about the community meeting, to

MS. HUNT: Yeah, so we don't. That's a question for that I can ask Dr. Chan tomorrow when we meet with him because of the

UNIDENTIFIED SPEAKER: He's sitting behind you.

MS. HUNT: Oh.

UNIDENTIFIED SPEAKER: Maybe he can answer

[Laughter]

MS. HUNT: We don't have access to that information.

DR. CHAN: We may have some e mail addresses, but I don't, I don't know. It's certainly not complete. I don't know what the completeness of the e mail address is. We've been communicating

primarily through our biomonitoring group in the past through [inaudible]. This, you know, we've been, as you've heard, been working with Abt Associates and ATSDR around planning for recruitment and drafting a cover letter. This is the first I've heard about a community meeting, and so I'm finding these comments interesting, and a lot of good points are being brought up. But certainly we're happy to work with sending out letters, however, you know, or the timing of which however is best.

DR. REH: But even if it's incomplete and we only get 15% of the target audience, that's 15% that we got.

MS. DALTON: This is Michelle. One other question. Is there a way that we can snail mail a letter, a separate letter to them, letting them know about the meeting? If you don't have complete e mail addresses?

DR. CHAN: It's certainly possible. We're happy to discuss that. I'm just trying to think about timing in terms of, you know, workforce issues of doing the mailings. But we can discuss that.

UNIDENTIFIED SPEAKER: Okay.

DR. CHAN: If I can say, it sounds like a simple thing, just mailing that, you know, even just a snail mail letter, what we were talking about, you know, printing labels and sending out 1900, you know, mailings.

UNIDENTIFIED SPEAKER: Sure.

DR. CHAN: There becomes a few logistical hurdles to that.

MS. SHAHEEN: Yep. Okay. Again, I'm sorry if I'm having trouble. I don't understand why we're dividing the audience, because if we're going to if the goal of a community meeting is to spread the word and build some momentum for future recruitment, why

wouldn't we include all the people who are in the first wave to be part of that meeting and give them something they can do while they're here? Again, I think if they're the folks that were most engaged in the beginning, they went through the effort of having their blood screened, they're the ones we most want and need to get enrolled initially because they are a ripe audience of people. Why aren't, why aren't they part of the same cohort? I don't understand the bifurcation of the groups. I think they should be targeted as members of the community who are being invited to this meeting who are also eligible to enroll and who are part of the target audience for the first wave. And while they're here, whatever we need them to do in order to sign appropriate permissions, et cetera, they do while they're here. And we can explain to the folks who are maybe in wave two that they'll be eligible two weeks from now or three months from now. So, I don't mean to beat a dead horse here, and I don't want to take unnecessary time, but I think the most important function of the CAP at this point forward is helping with recruitment. This is where the rubber meets the road relative to how we go back to the community now and say, okay, here's your chance. Now we need you. Now we need you to come back. And before we do that, we've got to be smart about what we're asking them to do and give them something constructive and proactive to do. And the idea that we're sending a letter to the folks who are in wave one at the same day that we're having a community meeting that they should already be attending, and in that meeting, they should be doing something that helps us get closer to getting them enrolled, I'm missing it.

MS. HUNT: Well, I think there's a difference in the letter. So, what Michelle was proposing is an initial letter letting them know about the meeting, and an actual meeting is the information

meeting, and then the letter that would be mailed out that day is an invitation letter.

MS. DALTON: Why don't we do both? I mean, I'm sorry, why don't we combine them and just do one prior to whenever the meeting is?

MS. HUNT: Yeah, so there are some logistics. So, the way that we're doing recruiting is to have a call center available so that when people are calling in to determine their eligibility, they're actually calling our call center. And there's a screening form that they go through, and they set up an appointment to come into the office. Between calling and screening and then the appointment, they receive a participation kit in the mail that includes a urine collection cup along with other instructions so that when they come to the, to the appointment, they are supposed to be fasting for a fasting blood draw, and then they bring in their first morning void with them. So, there are things that have to happen from an implementation standpoint to where we can't just get everybody at that time and have a phlebotomy station set up, and, you know, be really enrolling people at that time. And from a screening perspective, we can think about ways that we might be able to screen people there. But, again, the way that the implementation is stood up is that they would be calling a number that's available in the evenings and the mornings, et cetera, where they would screen and set up that appointment, and then come into the office.

MS. SHAHEEN: But couldn't they, theoretically, if we sent out letters to everybody, not just the wave one folks, but including the wave one folks, couldn't the wave one folks' letters say if you call this number between now and the meeting, you could use

the meeting as an opportunity to go through screening? Because you could have done all that legwork ahead of time?

MS. HUNT: We would have to think through how that gets staffed up I guess is my point, because it would need to because our call center people wouldn't be there. You see what I mean? So, from an implementation standpoint, we can take it back and discuss it and see if it's possible. We, again, we're on the same page where we don't want to lose a captive audience. We want to get as many people enrolled as we can. So, we can certainly think through the logistics of that.

MS. AMICO: Yeah, I just, I think, I just want to echo what people are saying. We're already having a hard time getting people to show up. So, if we're going to get them to show up, we should really try to maximize that opportunity in every way. And I also think that we need to be doing outreach before the meeting as much as possible. Like, and not send multiple letters, and I think that's going to be confusing. So, I think we need to, we need to think this through and get it right the first time because I don't, I don't want to I already feel, I already know we're going to have a hard time recruiting. And so I just want to make sure that we're kind of maximizing our efforts and not expecting people to do multiple steps that they may not do.

MS. HUNT: Right, right.

MS. AMICO: Thanks for your consideration.

DR. BOVE: I mean, the key step they have to do is they have to call us once they get the letter. They don't have to come to a community meeting. They just need to call us. The idea of a community meeting, roughly around the time they're getting a

letter, is that they may not even know what the hell the letter is all about. So, you want to have something, an outreach effort, a community meeting, so get them to actually open the envelope and read the letter and want to do something with it. Okay? So, that's part of why I think the logistics is the way we were thinking. But, again, we can revisit this and figure it out. There absolutely has to be a lot of outreach done before we have a community meeting. You don't have a community meeting without an incredible amount of outreach. Right? Right. So, that has to happen. But, again, I think it's important for the community to know what this study is about. They haven't been to these meetings. All they have is a newspaper reporter. What they see on Testing for Pease. But a lot of people probably don't know exactly what this study is all about. They'll get and some of them will get a letter and still won't know what it means. And probably would like to have some way of talking. Now, the letter will say you can call this number to get more information. So, that's one way they can get it. And a community meeting is another. But there's no reason why we have a sign up sheet, and we can use that to further our recruitment efforts as well.

MS. SHAHEEN: I guess just to reiterate, it will not be enough to say to the community, come to this meeting and get more information about a study. They've been hearing about a study, in the paper, through social media, through individual meetings, through outreach, through e mail blasts for four years. So, we've got to collectively figure out how to message whether it's the meeting, whether it's other outreach, that there is something specific and tangible they can do when they come. Because just giving them more information I don't think is adequate. They've gotten a lot of information. It's not all the

specifics that we now have to share. But we've been talking about a study for four years, and it's been in the newspaper, and it's been in e mails, and it's been in personal conversations.

DR. BOVE: Right, but now it's actually happening.

MS. SHAHEEN: Right.

DR. BOVE: That's different.

MS. SHAHEEN: Right.

DR. BOVE: And also

MS. SHAHEEN: But it's only happening if they enroll. And we have to help them figure out how best to do that.

DR. BOVE: Right. And the recruitment effort is not going to be end with that community meeting. Okay? This is going to be an ongoing effort, which, you know, may take a lot of, a lot of different strategies, if we're not getting the numbers we're getting. For example, I'm not saying we'll do this, but there's been a situation with the EAs where we're doing door knocking. That may be, you know, I mean, something like that might have to happen. But before we go down that road, I mean, I think the community meeting is just one strategy. And, again, it's to get the information out there, to say that the study is happening, it's happening now, this is the eligibility requirements, this is how you can get, actually enroll in the study. And I think that's important. But that's also going to be said in the media outreach as well.

MS. DAVIS: Hi, this is Alayna. So, again, I feel like it's important that the biomonitoring group have notice about the community meeting so that they can attend. And then I feel that

at the community meeting, that there should be, if we do a sign up sheet, we should have two separate sign up sheets, one for biomonitoring participants, and one for new people. So, there will be two lines clearly labeled. And then at the biomonitoring section, that we actually have a checklist of their next steps if they haven't called the CDC yet. So, like a little piece of paper they can take, your next step, you know, this is the checklist, one, two, three, maybe just the first three steps or whatever. I mean, if that even, if they would even go that far at that point. But at least something they can take with them that if it's not discussed in the meeting, or if a lot of new people are showing up in the meeting and asking a lot of questions, that the biomonitoring participants know exactly what they need to do next.

MS. HUNT: Yeah, we have a card that we're getting developed by our creative services group, where, if interested, please call this number. So, it's a handout that people can take with them that has the number for the call in center to determine eligibility. That could be for those people that are showing up that haven't called yet. That's an easy takeaway. They don't have the handout or they don't have the presentation printed. They may not have written it down, but they can take that card with them and know. And then it would also be in the letter as well.

MS. CARMICHAEL: This is Lindsay. Can you remind me, Danielle? I remember our conversation a couple of months ago about some type of incentive, like an economic incentive for participants. Is there any more information that you can share with the group about that?

DR. BOVE: Yeah, I mean, for the child and the parent part of the study, the child's part of the study, it's a gift card of $25 if you do the blood test, I mean, you draw blood and urine, and do the measurements, the blood pressure measurements, the physical measurements, it's 25, 25 if you finish the questionnaire, and if you complete the questionnaire, and 25 for the neurobehavioral testing. For the adults, since there's no neurobehavioral testing, it's a $50 card, 25 for the physical measurements and blood draw and 25 for the questionnaire. So, yes, we have an incentive.

MS. HUNT: And then that's also part of the informational session as well, letting them know they can receive up to $75 for child participants and 50 for adult participants.

MS. CARMICHAEL: All right, thank you.

MS. AMICO: This is Andrea. I just had a question about how will this information for let's say people that can't make the meeting, the informational meeting, but they want to learn all this information, I'm assuming you'll have a website? And is there a way that people will be able to sign up online? Or it's the only way to kind of engage is to call that call center? Is that the only form? Is there another way? How are people going to if they're not going to make it to the meeting, how do we make sure they get the same information that was captured at the meeting?

MS. HUNT: Yeah, I don't Frank, do you want to talk about the, what's posted online?

DR. BOVE: Well, I'm not sure we've nailed that down yet. But the letter has the phone number. It also has, may even have our phone number. I'm not sure. The last time I saw it. But they'll

have a phone number for the call center that we'll give that to the media so that they'll have that as well, I mean, so, in all our outreach materials, that phone number will be given out.

MS. AMICO: So, phone is the primary way that people are going to, like if I'm not involved in this process and I'm a parent and my kids are now in third grade, you know, they're not on the daycares here anymore, there's not actively engaged here anymore, what am I going to tell them to do, call this phone number, and that's how you're going to sign up? That is the primary mechanism of how we're going to sign up is give a phone number and tell people that's what to do?

MS. HUNT: Because they'll be screened. When they call in, they'll be screened for eligibility at that point. So, it's not just an e mail. You know, an e mail wouldn't screen you. So, we're actually trying to get people to call in. That's how we're getting their contact information. That's how we're screening them. That's how we're sending them the kit. We're getting the appointment. That call is what is initiating enrollment into the study.

CAPT SOMERS: Okay. And, oh, sorry, I was just going to so, in Westfield, because we just kicked off the exposure assessment like within the last month, so just how it played out there is the same, similar way that people have to call. And, you know, we needed to get 400, well, we had to get 380 people to participate, to have the right statistical power for the exposure assessment. And we had the initial public meeting. And you're right, we had about, we had a pretty good turnout. We had about 160 people in that room who came to the initial meeting, largely through efforts of the community group that was there trying to push the information out to community members. We went

out there a couple times and hit like, you know, coffee shops and other establishments, and it was in the paper. So, we had about 160 people. And the message we had to sell at that meeting was we would like you to participate in this exposure assessment, but only if you get randomly selected, which is a harder message to sell than you can volunteer to be part of a study because there were many people who want to participate and we're not going to randomly select you. So, this is like, right, this is like a it's a hard message. So, we did the public meeting. We had a good turnout. And then the letters went out the next day, I believe, or that same

UNIDENTIFIED SPEAKER: That day.

CAPT SOMERS: Really close. Yeah, the same time period. And the call center opened. And I think in the first week, they had about 80 people call to sign up. And what they were signing up for is to come to an office that's in Westfield, and they were going to do the blood and urine collection and have them do like a questionnaire. And so they had about 80. And then there was the call center. Also, we had some phone numbers that were linked to those residences, the randomly selected ones, so we tried calling from the call center to those residents. That was kind of successful, because as you know now, like phones are linked to people, not to homes. So, to identify a residence and try to call a resident, you might not get a phone number because people don't have landlines, you know, it's the modern world. So, that was sort of successful. And they got some folks that way. And then it was like mid, or the beginning of August, there was some concern, because we had I think fewer than 200 people who had called the call center after they got the letter in the mail that said, you've been selected, please participate. We had less than 200 people. So, we made a decision to go out, boots on

the ground, and I had three teams of two people each, and we went to 900 homes and knocked on their door. And I'm not saying you're going to have to go to this extent, because this is like

DR. REH: But we are prepared to.

CAPT SOMERS: We are prepared to do it. And we went to 900 homes. We knocked on the door. If they were there, we chatted with them. Some people immediately said, not interested. I got your letter. Don't want to do it. We said, thank you for your time. Some people were interested. And what we did then is we gave them we had a flyer that we were going to hang like a door hanger, you know, it had the call in number on it, and if they were interested, we said, well, call this number. Or if you would like to give us your cell phone number, we will call you. And that call center is what was screening people to make sure they lived there long enough. Because there were still some requirements beyond just being randomly selected. And then if they weren't home, we left the little door hanger. And it was a pretty simple we can show you an example. It was a pretty simple message like, you know, exposure assessment, please call us, sorry we missed you kind of thing. And as of the start of doing collections, which was yesterday, right, blood and urine collections, we had over 400. I think we had 460 people who were called. So, we were able to get to the number that we needed through this type of outreach. And that was, like I said, a little bit harder sell because you had to be randomly selected. And there's no incentive. People are getting nothing. They're getting no gift cards.

MS. HUNT: So, I think one of the key issues, as well, which, again, we'll talk to Dr. Chan about tomorrow, is that for that initial list of 1,800 participants in the biomonitoring study,

we don't have a telephone number for them. We don't have their contact information because they didn't consent to sharing that information. So, that's why that has to be a coordinated effort with the health department, because they're the owners of that information, and they are the ones that can contact them. We cannot. So, that is, you know, a bit of a, you know, an obstacle that we have to overcome. And being able to reach them. And so that's why we're working closely with the health department, because they will be the ones that are able to send out that initial communication. And as soon as they pick up the phone and call us, as soon as they come to a meeting and give us their e mail address, as soon as they give us any sort of information, we can then contact them.

CAPT SOMERS: And I would just say, I think ultimately, I'm trying to remember how many letters were sent out, I think there were a little yeah, ultimately. They started with hundreds. I think it was about a thousand, 1,100. Yeah, it was about, I think it slowly increased. You know, they sent out the first wave of letters, and then they got a response, and they sent out more invitations to, you know, randomly selected homes.

DR. REH: The knocking on doors by far that community was the best way to

DR. BOVE: Yeah, the difference here, though, is we won't be knocking on doors because we don't have houses that we've picked out. So, it's a very Pease is unique because most of the other situations are residential situations. And so we're going to have a challenge. There's no question about it. And we're going to have to use all the tools we have, including, see what we can do with the PDA and the TAP to identify workers at the

Tradeport. And maybe even unions. That's, you know, to identify. So

MS. HUNT: Well, we talked. We do have the list of all the businesses on Pease. We've talked about putting it in there, a little quarterly paper going to their community events that they have.

DR. BOVE: Right. So, there's a whole bunch of outreach efforts that are going to be unique to Pease because of the situation here is different than almost any other situation. So, we're well aware of that. And that's all in the protocol. It was even in the feasibility assessment. So, so, we're taking all this feedback back. I think we were thinking about a room that would hold at least 100 people. We may want to expand that.

MS. HUNT: Yeah, we've got some various size options.

DR. BOVE: Yeah, we have various sites. So, I think that we'll have nailed down. And then we need to discuss all the options here that have been raised.

CAPT SOMERS: And we did at Pease, I'm sorry [inaudible] in Westfield, the exposure assessment, that initial meeting we had with the community to tell them about it and tell them how the process was going to work, we did have people when they came, like we do here, sign in with an e mail address. So, even if people are not randomly selected, because at that meeting, we wouldn't tell if you were selected or not, your residence, we have that list, and we've sent updates to the people who participated, like when we said, okay, the letters have been sent out. We sent them an update. Because there were some questions that came up at the meeting we couldn't answer then, so we told them we'd get back to them. We got answers. We sent

out an e mail. We told them when we were going to be out in the community. So, we did collect, you know, you could do outreach after it is, you know, if people voluntarily give you their e mails.

MS. DALTON: This is Michelle. I have a few, a few comments or questions. Is there going to be a website for this dedicated to this study?

CDR MUTTER: Is Lori on the phone?

MS. LAUNI: Yes, I am on the phone. We are working on that. We have our [inaudible] a final clearance with the communication team. And we're working with the website team to developer right now to get those on up and running, and hopefully we'll have them up by the end of next week.

MS. DALTON: Okay, great. So, the end of next week. And so information from the community meeting, or about the community meeting, will posted there beforehand?

MS. LAUNI: Yes.

MS. DALTON: Wonderful. And have you guys considered a sign up form on that website for people that want to learn more about it? Because I know nowadays, people are more apt to fill out a form and kind of be more distant rather than picking up the phone and calling to get more information. And you can gather information on a form as well and then have the call center as someone dedicated to reaching out to them to then try and recruit.

MS. HUNT: So, we have made that suggestion. So, I think there are just some internal things that would need to be worked out in terms of being able to collect personally identifying

information through the CDC website. But that's, yeah, we've talked about that possibility.

MS. DALTON: So, on the cards that you're going to be handing out at the community meeting, it's not just going to have a phone number on it, it's also going to have a web address of where they can get more information, sign up here, and a link to the form, and all of that good stuff?

MS. HUNT: Well, form being

MS. DALTON: On the website, but telling them that there is a form to sign up or learn more?

MS. HUNT: Yeah, so, what I would envision is if interested, they can include some of their contact information, and then we could follow up with them after that. But, again, we don't have like a screening form or anything like that. They would have to pull up the phone and call.

MS. DALTON: Okay.

DR. BOVE: You know, I mean, there are these, the personal identifying information issues, privacy issues that I think are part of the problem. But I think there is nothing wrong with getting an e mail address from somebody, or even a telephone number that we could contact them. That's not, I mean, I don't know.

CDR MUTTER: I do that with the Camp Lejeune registration. We just have to put a little blurb about PII on there and what we're going to use their e mail address for.

DR. BOVE: My agency rightfully worries about this issue. On the other hand, there are, I mean, sometimes we go overboard, and I think that, you know, from my own perspective anyway, and so I

think that we'll work something out here so that we can get information from the person without violating any privacy issues.

MS. DALTON: Yeah, and if they're voluntarily giving that information, that's different than taking their information. So, if they're voluntarily entering it in, with disclaimers, it should be okay.

DR. BOVE: We still have to protect that information.

MS. DALTON: Oh, of course it needs to be protected on the back end. But they're voluntarily giving it.

MS. AMICO: Can I just clarify? Why can't DHHS just give ATSDR the contact information? Aren't you partners? Like you're the federal partner of the state? I mean, people didn't consent to sharing their addresses?

DR. BOVE: No, they didn't. They didn't consent.

MS. AMICO: And there's no other way around? I mean, I just don't it's puzzling that they held this like gold mine of information that we all need to access to get people, and we just there's no other way around this?

DR. BOVE: They didn't consent to share that information. They didn't and they in the consent, their blood was supposed to be destroyed at the end of the program. So, I mean, so, the fact that the blood is still there is good. But, no, they can't do that.

MS. AMICO: But what is ATSDR and DHHS's relationship? My understanding is there is

DR. BOVE: We're friends.

MS. AMICO: You're friends?

DR. BOVE: No, seriously

MS. AMICO: I mean, you're obviously here doing a study and they're not. Right? So, I'm trying to understand the relationship that you guys have and why we can't find another way around this.

DR. BOVE: We analyze most of it, I guess, most of the PFAS samples. Right?

[Inaudible]

Oh, or maybe not most of them. Okay. Yeah. So, but that's the relationship. We are willing to help out. But we're separate entities.

[Inaudible]

MS. AMICO: Okay, thank you for clarifying that.

MS. HUNT: So, once they consent, you know, once this language is added into the consent, they are consenting to us having that information as well. And then once they physically call in and that's an actionable step on their part where they are then providing us

MS. AMICO: It's just all these steps that make me so nervous we're going to lose people. We've already lost people along the way. You know? So, it's just, if we can draw a straight line, it would be so much easier than this zigzag path. So, just trying to figure it all out.

MS. SHAHEEN: And if I can just piggyback on the points about more than just a phone line, I appreciate the need to protect personal health information. My company has to do the same. And

I'm responsible as the HIPAA compliant officer for making sure we do it. There's no reason why you couldn't set up a WordPress website that's hosted on Amazon, which is entirely HIPAA compliant, and be able to run people through a couple screening questions so they can determine eligibility without needing to call a phone number. It's 2019. People do it all the time. It costs $30 to host a WordPress website that can be built by me practically. It's so easy on an Amazon server. So, again, we are a healthcare provider as a company. And we do this, and we have people's personal health information about all kinds of things, and we have found a way to do it very cost effectively. So, I just would hope that forcing people to go through a call center isn't the only mechanism through which we can capture information.

MS. CARMICHAEL: Okay, so, this is Lindsay. I'm definitely going to sound like a broken record. But to Stefany's point and Michelle's points, a couple of other thoughts around that. So, obviously it would be wonderful if there's a way to build some type of functionality into the website to just capture some of the screening or pre screening information. I know personally if I am faced with a choice contacting a company about either picking up the phone and calling them or having an option to use a chat, that's, I'm always going to go the chat mechanism, or route. So, I don't know if that's kind of technologically beyond the capabilities of, you know, what's at our disposal. But I think we have to be cognizant of the fact that people just don't like talking on the phone today. I think culturally it's a different time than it was 10 years ago. And to the extent that we can make it as easy as possible for people to do things through their computer or their phone, I think, you know, we're

going to increase the odds of capturing people. So, I guess we've made that point. Thank you.

MS. DAVIS: One last quick question. Is the call center going to be open just during business hours, or at nighttime too?

MS. HUNT: It's going to have extra hours. So, people can call in the evenings as well.

DR. REH: So, with the transcript, Jamie will capture the main concerns and things and recommendations and comments. We'll share this back with the CAP just to make sure that they align with your concerns. And we'll also, at the same time, work with Abt and our ATSDR communications people to see what we can do to I mean, this is a very good fruitful discussion. We appreciate it.

MS. AMICO: I just have one question not really related to recruitment. In the beginning, Frank, you talked about the stored blood and trying to get consent. How much stored blood do we have? Like, how much is actually left? Volume wise? Nobody knows?

DR. CHAN: We don't have a complete record of the [inaudible] moving. There are some individuals that may have no blood volume left, and others that maybe only have, you know, half a milliliter. So, it's unclear, but it probably varies. But I don't think that there's a whole lot of blood sample left on the majority of individuals.

DR. BOVE: Right. I mean, there wasn't that much blood taken to begin with. But our lab, certainly for the PFAS measurements, our lab is pretty good. If there's some new PFAS that needs to be evaluated, we'll probably be able to do it. As for the biomarkers, it depends on the biomarker. There's some with a

very tiny amount of blood we can actually look at. There are other biomarkers we can't. So, it will, you know, but if there's no blood, there's no blood, we can't do anything about that.

MS. HUNT: And just as a final wrap up on the Pease study updates, I guess, is we have our staff who introduced themselves earlier today here. So, we have staffed up, the office is set up and ready to go. So, it's just a matter of getting the staff trained, which we started today, and we're going to continue over the next few weeks getting them trained throughout the protocol, and then having the community meeting and participants starting. So, everything else is coming into place, and we're really excited to get started.

UNIDENTIFIED SPEAKER: Sorry, just looking at the agenda.

DR. REH: Yeah, go ahead. Go ahead.

MS. SHAHEEN: As a punchline to that point, I hope you all will use us as a resource and see us not just, I mean, I don't think this discussion was us sharing concerns as much as brainstorming how we can best maximize the opportunity to reach out to people. So, please see us as a collective resource to help make that happen.

MS. HUNT: I see you as participants. Make that clear. We see you as participants as well.

DR. REH: And we're not going to wait for the transcript to discuss these issues.

QUESTIONS FROM THE AUDIENCE

DR. REH: No, that's true. That's true. So, are there any questions, before we go to break, are there any questions from

the audience? With that, let's take a quick break, maybe come back and reconvene at 7:40 or 20 till 8:00. Okay?

UNIDENTIFIED SPEAKER: Sounds good.

DR. REH: Thank you.

[Break]

MULTI-SITE STUDY UPDATE

DR. REH: Next, we don't have any housekeeping things we need to do. So we just go right into the multi-site study update, I'll -- do you want to give that or do you want me to do that?

DR. BOVE: No, no.

DR. REH: Well, bottom line up front, we're still on track to award the grants for the national multi-site study by the end of this month, which is the end of our fiscal year. As we've talked to you in the past, this is a national study that's based on the Pease protocol. So we're still on track to make those awards by the end of this month, probably in a couple of weeks. Of course, it would have to be by the end of this month. We had talked to you previously that we expect it to be around six awards, and grants and the total amount of first year money that will be rewarded when you think of all six, cumulatively will be about $6.5 million. We're still on track for that, about that number of grants and about that amount of money. So we're still pushing forward on this. We're hoping to have the research coalition, which will be all of the grantees and ATSDR formed and put in place. Again by the end of this month and starting in the next fiscal year, which starts October one for the federal government, we will start getting going with the multi-site, the national multi-site study. So, any questions on that?

MS. DAVIS: Hi, this is Alayna. So once the awardees are announced, then do you reach out to -- how do you reach out to communities to form CAPs and start organizing?

DR. REH: So that process will -- there will be a whole rollout plan associated with the announcement where we will have, we will lay out how we do that. And so similar with how we did the exposure assessments, that's a, that's a great example. There's a whole plan with how we talk to partners, how we talk to congressional representatives, how we talk to communities and CAPs, and so we'd be happy to share that plan once we have it together.

MS. DAVIS: But as of right now, there's nothing formed within any of the community because they don't even know yet.

DR. REH: That's right. That's right. So the there is a whole process within CDC and the federal government on how you award these grants. There are there is a peer review committee, two review committees that look at all the grants and they score them. And then the final scores are presented to the leadership of the agency awarding the grants and so that meeting where Pat and I saw the recommendations from the review committees happened two days ago and so we're getting very close to being able to announce who the awardees will be and then starting to work with those communities. But none of that none of that work can begin until we finalize who's getting the grants. Because, of course, it will tip the hat for those communities that may be receiving a great.

DR. PROTZEL BERMAN: Just add that the official notice will come from CDC's grants office. And that is, that's the very last thing that gets done before we do any rollout. Before we announce it or anything else. There has to be a formal notice.

DR. REH: Did that answer your question?

MS. DAVIS: Yeah. So I'm sorry to follow up on what you just said. So who do you -- who is the CDC announcing it to before the rollout?

DR. PROTZEL BERMAN: So they say they will make what they call a notice of award to the grantee. The first person to find out is the grantee themselves. So they will find out directly from CDC's grants office. Make sense?

MS. DAVIS: And then there's a formal announcement.

DR. PROTZEL BERMAN: Yeah. And then we'll have the other things that Chris was talking about. Yeah.

DR. REH: Okay.

MR. DIPENTIMA: Rich Dipentima how many potential grantees are there? I know there could be six awards, how many total applications?

DR. REH: We received 17 applications.

MR. DIPENTIMA: And who's the applicant from this region?

DR. REH: I cannot reveal that.

MR. DIPENTIMA: Can't reveal it.

MS. AMICO: I probably missed this part. I'm sorry for coming back late, but it's by September 30. Do you think that you anticipate it will be before then?

DR. REH: Probably so, seeing where we are in the process right now. Did you hear the part where Pat and I have seen the recommendations from the review?

MS. AMICO: That's when I was walking in.

DR. REH: Okay. So so so Pat and myself and the other leadership do not see who the grantees are or the applications until there's a review committee that goes through and reviews them and scores them. And then the review committee makes a recommendation to us. So we had, Pat and I had the meeting two days ago, where we saw the recommendations of the committee and we made some decisions, who will be the rewardees, and there's a -- probably in a couple of weeks we'll be making the announcement.

MS. AMICO: Okay. I'm sorry, what did I miss about this region? What was Rich's question in particular?

DR. REH: Rich was asking did someone from this region apply and who was it and I cannot answer that.

MS. AMICO: I see. Okay. Thank you.

DR. REH: Clever. Okay. All right. Moving on the exposure. Oh.

PEASE HEALTH CONSULTATIONS UPDATE

CAPT SOMERS: All right back to me for health consults. So I think it was the June meeting. We were hoping that the private drinking water health consult would be done in September. And once again, my powers of prognosticating when these documents will come out failed, and it's not happening in September. We're still hoping to do it this fall but I don't have an exact time yet. And it's in our internal clearance. We'll do the same rollout plan we discussed before where we'd send a letter to the residents of the private drinking water wells and let them know this document's been completed and invite them to like a public availability session like we did for a public availability session for the public drinking water health consult. And then we'd also we'd likely present also again to the Newington Select

Board, like we did, and we have reached out to Greenland as well. I don't know if we'll -- do we might do Portsmouth City Council again, but this one doesn't really impact them as much so I'll have to ask them if that was something they would like to have. And obviously, we'd share it with all the CAP members, and it will go out to like a public comment document. So there will be a chance for the public to comment. For the private drinking water consult, there are a lot of oh, yeah, sorry. Sorry, the public, yeah thank you. It gets confusing, I know. The public drinking water health consult, we got a lot of comments back from different sources. And so they're, I think they're nearly done addressing all those comments. And then the next process of that would be to finalize that as a final document with those comments. What we do in our documents, if you've ever looked at one of our documents is there will be a portion that where comments are from the public are included often not each individual comment. They're kind of grouped by theme because there's often like a theme of comments and then that will be addressed. We'll have an answer to those comments and then that's how we do that. So that's where we stand for the two health consults.

DR. REH: Karen.

MS. ANDERSON: And what I can update is Newington has been asked to host both a Selectmen's meeting public, as well as the Newington Greenland meeting.

DR. REH: Yeah.

MS. ANDERSON: And that has been received favorably by the board. And we're looking at I think the request was for a meeting with the Selectmen in November.

CAPT SOMERS: Yeah. We're hoping --

MS. ANDERSON: Meeting in December.

CAPT SOMERS: Yeah. That's our, that's our hope. Let's stay flexible. Stay flexible.

MS. ANDERSON: Okay.

CAPT SOMERS: So that's all the health consult news. Any questions for that? All righty.

EXPOSURE ASSESSMENT UPDATE

DR. REH: Okay. Exposure assessment update. We --

CAPT SOMERS: We kind of gave a little.

DR. REH: Yeah, we kind of gave a little but we've made great progress. So we're on track to launch in four of the eight cities. This year, we've already launched in three. So we launched in Westfield July 23rd, in the Berkeley County, West Virginia, July 24th. And in, I was just in New Castle County, Delaware, August 26th and we launched there. The furthest along, of course, is the Westfield site in as Tarah spoke to. We've, we've gotten over 400 participants. I believe it's around 460. Is that right?

CAPT SOMERS: Appointments? Yep.

DR. REH: Yeah. Yeah. And they've already as of yesterday, we started having participants come to the, to the office that we have set up and to start giving their urine and blood samples, so everything is proceeding as planned. We will be kicking off in Spokane, Washington, September 19. And I will be there to kick that off and, and then the other four sites will be kicked off after the first of the year at varying staggered paces, as

we I think have communicated in the past to the CAP. But because of the amount of work that's required at each community that we have staggered the approach and so we continue to move forward on this. Typically our lab has estimated that it will take about six to eight months to get results back from a given community once they receive the blood and the urine samples. Of course, that depends on how much backlog they have for the PFAS analysis, but we're certainly trying to move with a sense of urgency on this. And we continue to make great progress. Any questions? Yes.

MS. CARMICHAEL: This is Lindsay, just curious. I'm curious about the timeframe; the six to eight months. Is that because there's a dearth of labs that can do the type of analysis?

DR. REH: So our lab is doing the analysis and the reason we use our lab is that they developed the method and they can analyze the number of for the number of PFAS compounds that we need for the study. It's not a simple analysis. It's complicated in, in, you know, there's also -- they've got other projects they're working on too. Andrea.

MS. AMICO: Thank you. Hi, this is Andrea, thank you for that update. So you have 460 people in Westfield with appointments. How, what time frame are you looking to collect the samples? Like over what period of time?

CAPT SOMERS: They started September 4th, and they're going to the 14th. Right?

DR. REH: Right.

CAPT SOMERS: It's a little less than two weeks.

MS. AMICO: Two weeks to get 400 plus samples collected? Okay.

CAPT SOMERS: So there's office hours, it's staggered. So they have some -- you know, they start a little later. Some days they have some evening hours and there's some weekend time. So there, they staggered it. So to try to meet people's schedules where people are. It's not -- it doesn't take a terribly long amount of time for each individual as my understanding, you know, to come in, do the, you know, fill out the paperwork and then do the blood draw. It's not terribly time consuming, but you're right. It is a lot to do and just a few weeks.

MS. AMICO: Yeah.

DR. BOVE: Just keep it just keep in mind that for the study, we're asking for a fasting blood because we're looking at lipids, number one. And number two, there's a much more elaborate questionnaire because we're asking about health conditions for Pease, then they are for the EA's. And then there's the neuro behavioral test for the children and the parent also has to answer as well, parts of it. So that's there is a difference. In other words, if you're going to fast for eight hours, you probably can only or most likely get people in the morning to obtain blood. Whereas for the EA, they can get blood anytime of the day or night. And then the time the other time constraints. So what would probably take about two hours and in the Pease study would take, I don't know, how long.

CAPT SOMERS: I think they're asking about 30 minutes per -- I think so. I haven't been out there to see the process, but I think it was they're averaging that. And they had, I think, a couple of phlebotomists on staff every day, so they could try to stagger people to come in, you know, so they're, you're right. It's a lot in a few weeks, but getting it done.

MS. AMICO: Yeah. Can I go back and ask a question about the Pease study, now that you brought that up? How much time do we have to collect our data? Because we anticipate recruitment is going to be a problem. So I think there'll be this trickle effect, perhaps. So do we have a cut off like after six months, three years, if we don't hit the numbers that we need? We just we just analyze with what we have.

DR. BOVE: Well, I mean we have we want to reach our goals of 350 --

MS. AMICO: In what period of time?

DR. BOVE: Well, I think we're assuming it probably take at least eight months to get all you know if but it may take longer. We haven't really, as far as I remember set a -- or did we set a deadline?

MS. HUNT: We may have a deadline for the contract.

DR. BOVE: Contract. Right. That's all right. we've, we've said before that, yeah, we haven't set a strict deadline.

MS. AMICO: Okay, that's funny. Just to understand the differences, I guess. Okay. So going back to the exposure assessment, how will those results be reported back in a community type way? Like, yeah, obviously, you're doing this in a staged fashion. Are you going to wait to get to analyze all the results of all eight sites, which will obviously be over the course of two years to report back or will Westfield get a summary first, and then you'll do a big summary at the end?

DR. REH: Yeah.

MS. AMICO: And Westfield won't have to wait till the end.

DR. REH: So there will be three phases or three types of reports that will be reported out. First will be the individual results for the people participating and we try to get those back to them as soon as we can. Then second, there will be community reports. And you're correct. It will be phased based on when they are in in the time in the schedule. So, Westfield will probably get their report first and El Paso, Colorado, who we probably will be in that community in May, will get their report much later.

MS. AMICO: Okay.

DR. REH: And then there will be an overall summary report and probably some publications and scientific journals after that.

MS. AMICO: Okay. Thank you. And then my last question is, you talked about your lab doing the analyzing because it has the PFAS. How many PFAS will you be analyzing in the exposure assessment? And how is that different than what was analyzed at Pease?

DR. REH: I think it's 16. I think it's 16 different PFAS compounds. It's definitely 12 but I think we're up to 16 now.

MS. AMICO: So it's more than what the initial Pease biomonitoring was, which was also a good chunk of them was done through the CDC, but that was four years ago. Okay.

DR. REH: And so our lab is is continually and we had ATSDR are continually monitoring or trying to get as much information and intelligence may not be a great word to use on PFAS compounds that are being used. And our lab is continually working to add more PFAS compounds to their battery of compounds that they can detect in in in blood and urine. So you know, it would not

surprise me a year from now if where there are 16 today they may be at 20.

MS. AMICO: Okay. All right. Thank you. Those are all my questions.

DR. REH: Okay. Very good.

CDR MUTTER: You want me to me to go on to the next agenda item?

DR. REH: Yes.

ATSDR PFAS SUMMIT

CDR MUTTER: All right. And I'll look to Andrea to fill in some, if I miss anything. So we're talking about the national -- the ATSDR PFAS Summit. And we're both on the Executive Steering Committee. So that's why I pointed her out. So if you're not aware. ATSDR is holding a PFAS Summit, mainly focused on community engagement for community members. That will be held, I believe, February of next year. Our submission is still going through all the administrative hoops so it hasn't been finalized yet. Until we get that approval, we can't fully implement. We can just brainstorm and do some other kind of work. We've had many productive meetings. So we talked about potential agenda format, ideas for keynote speakers. process for soliciting interest from community members because it will be a invitation only conference. And we tried to prioritize topics for sessions, which was fun and stressful because there's so many topics that we want to, you know, squeeze into this but it was, it was a very good exercise that we that we did when we were at meeting. So the next steps will be finalizing a potential agenda that will be presented to ATSDR leadership. And one of the things I was excited to see and I didn't even know about this is that we will have a PFAS display design for the CDC Museum, which is

part of the Smithsonian Museum system. So that will be exciting that the community members that attend the conference can walk through the CDC museum and see a PFAS exhibit. So I thought that was pretty cool. Yeah. Andrea, Did I miss anything? Did I hit the big topics?

MS. AMICO: Yeah, I think you hit all the big topics. It is I think the community is excited about this. I know you haven't publicly really announced it, but I've been sharing it amongst my group and I'm one community member on the executive steering committee. There's also someone from North Carolina, Alaska, Hoosick Falls, New York. And I think they recently just added someone from Tucson, Arizona. So I'm very happy that ATSDR has invited community members to help be part of this planning and give our input on to how to make this as a successful event for the community. And I look forward to continuing to work collaboratively with you on this event. So thank you for the opportunity to be on the committee.

CDR MUTTER: Absolutely. Are there any questions?

DR. REH: You know, I just want to say this is an important summit for us and some of the discussion that we've had here today, exemplifies why it is important for the agency and for the mission that we have. And that is so much of our success model depends on a close relationship and working with communities and and it's not meant to always be happy and fun. And this is an opportunity for communities to tell us what's working and what doesn't work and to talk to us about how community engagement is evolving and what you see in your world that we may not see. And and so we we're taking this summit very seriously and because for us, it's an opportunity for us to learn from you. This is not going to be a meeting or a summit

where we're going to stand up in front of a bunch of community people and tell them what we're doing. And I just want you to understand that, that this is a real opportunity to change the way we that we work with communities or to reconsider some of our old traditions and think about if they are really valid anymore and if they're not what should be valid going forward? And, and so we appreciate the relationship we have with this CAP. Because, you know when when I think about the summit and as I was listening to some of the comments about how to recruit, you know, you guys have an experience that we don't necessarily have. That's very important for us to be successful in, in the Pease study and, and for all the other communities where we're doing work. And so we appreciate the input, it's very valuable to us, and this is going to be truly a chance for communities to come together and you know, what works in Arizona may not work in New Hampshire, and that's important to know and, and, and what we learned from Arizona and New Hampshire may help us in Washington State. And so we're very excited about this and very serious about it. Yes Michelle.

MS. DALTON: Thank you. Hi, this is Michelle. You had mentioned this is an invitation only summit. How many community members are you planning on inviting?

CDR MUTTER: Gosh, Andrea. What was it 100? It was the least half of the total amount. So 100 to 125 if I'm remembering that correctly.

MS. AMICO: I don't have my notes in front of me, but I recall like around two, I think they wanted 265 total and 40% of those were going to be community members.

CDR MUTTER: Right.

MS. AMICO: So round a hundred of more.

DR. REH: And we're looking at different ways of holding the meeting. Do we live stream it? Do we? Do we have like a YouTube video where people can watch and it's not going to be something where we're going to come together, have this summit, maybe produce a document and then walk away. You know, nothing's learned if we do this. We feel like this is a first step in better understanding and better engaging communities going forward. And again, this relationship here is one of the reasons we're doing this. This has been very productive for us.

MS. DALTON: Thank you.

CAP CONCERNS

DR. REH: Okay. Finally we're at CAP concerns.

MS. AMICO: This is Andrea. So I know that I bring this up at every single meeting and I know that you did talk a lot about some of the advances the AAP is making on not necessarily medical monitoring but on you know, different, two recent movements that they're doing which I think is great. Thank you very much for that update. I would just like to know is ATSDR considering revising their physician fact sheet that they or physician guidelines, I believe it was called. It's an 11 page document and I recall it's from 2017. I just didn't know. It seems like ATSDR is trying to work with other agencies to address the medical monitoring issue but I, I would like to know what ATSDR and CDC want to do to address medical monitoring or not want to do.

DR. REH: So, there's right now we have a revised version of the fact sheet, the physician guidelines that's starting to go through clearance at CDC.

MS. AMICO: Okay.

DR. REH: Now, it's based -- the revisions are based on comments that we received from external peer reviewers. We continue to look at different ways we can do this at ATSDR and with CDC in general. That's why we're engaging these other professional societies, because they can do things that may take us longer. I mean, that's just a fact and so that's why we're working more with AAP and the American, ACMT to utilize their expertise and their capability in trying to get to what you're, what you really desire. The stuff that we heard from AAP, leads us to believe and I think it's a it's a good belief that they're willing to go down the road to look at physician guidelines for children. We're not as far down the road with ACMT. But we continue to make progress. So it's definitely high on our agenda. I know you're going to continue to push it and rightly so. And I appreciate that because it keeps us keeps our eye on the ball on it too.

MS. AMICO: I guess I just want to make sure that ATSDR is working on this as well. It's not just we're reaching out to these agencies and seeing what they're doing. I am appreciative of that. And I'm glad that you're doing that too, because I think this is going to take more of a collaborative approach. But yeah, I wanted to make sure. Like I didn't realize there was a revised fact sheet, physician fact sheet. So that's something we can expect soon or I don't know how long that takes. But --

DR. REH: So it will have revisions. It's not going to have what you're looking for right now.

MS. AMICO: Okay.

DR. REH: Which you're looking for something if I understand you correctly, where it's something brand new, and kind of a further step. But we are continuing to push towards that.

MS. AMICO: So when can we expect to see this revised fact sheet?

DR. REH: Oh, I don't. That's difficult to say. There's a lot of clearance process that it has to go through and alignment with other federal agencies. So it's it's not as easy of a process.

CAPT SOMERS: I mean, I think this has come to our attention to with the exposure assessment roll out that when those letters go out to the four hundred more than, you know, community members that the importance of, you know, being able to talk with community members themselves when they get their letters, but also do some outreach to clinicians in those specific areas about what's out there currently for information. And so, it is something that's being discussed a lot to get out to clinicians and community members.

MS. AMICO: But I guess that's what I wonder. I mean, obviously, it's an issue that we we've it's something we brought up many times here and we will continue to push hard for it's a significant gap in our community and across the country. But as you go out and do these exposure assessments at eight sites, people are going to get results back and I know from personal experience, you're going to get these results, you're going to take them to your doctor, and they're going to have no idea what to say, what to do. So how -- what are you doing to get in front of that? I mean, I appreciate the AAP updates. That's huge. But what is ATSDR's doing like EAs? Like, what are you doing to get in front of that? What are you going to say to those community members in Westfield that have high levels in their blood? And

they go to their doctors and their doctors don't know what to say or what to do? What is ATSDR going to do to address that?

CAPT SOMERS: Yeah. And that's why we're having discussions on how to do this outreach to the community clinicians before the letters would roll out to community members.

MS. AMICO: You're not answering my question. What are you going to what are you going to say to those people? What are you going to say to those doctors in Westfield that are going to look patients in the face? How -- what are they going, what are they going to do? How are you guys doing eight exposure assessments across the country and you're going to hand out this data and you're going to have -- I'm just struggling with that. Like what? I don't understand. Am I missing something? What do you what do you what are you going to do?

CAPT SOMERS: You mean like what very specific guidance would ATSDR give to clinicians?

MS. AMICO: Yeah. well yeah, because they're going to be facing hundreds of people in their community with blood test results and maybe urine tests on chemicals that these physicians have never heard of. And they're not going to know what to do or what it means or what health effects people might be at risk for. And so I just don't understand. So you're going to arm people with results, but then you're not going to lead them to the next steps.

DR. REH: So there are we're looking at ways to communicate to the physician community in the communities where we're doing the exposure assessment, whether it's through training programs, webinars, you know, to talk to them about how do you communicate with your, with your patients who may have participated in this

study and come to you with this. A lot of the material around that's still in development. And how we actually do that is still in development too.

MS. DAVIS: So in six to eight months before the first people are going to go to the doctor is the question.

DR. REH: Yep.

MS. DAVIS: That's all we're kind of getting at here. We know everything goes slow.

DR. REH: Yeah.

CAPT SOMERS: Yeah.

MR. DIPENTIMA: Rich Dipentima. Again, I feel Andrea's pain because, you know, we went through this. We were four years ago. I mean, we had all this blood testing done and we had a significant number of people with significant high levels of PFAS' in their blood. And we had no no answer to give people, you know, we asked the question without knowing what to do with the answer. And that's an uncomfortable position to be in and I think that's the concern we have for this next round of testing. And obviously, you know, we're getting ahead of the science, in some ways by doing the testing before we know what the -- what to do with the results. And hopefully, you know, in part of this is why we're doing some of these studies in the first place is to come up with the answers to those questions that we don't have yet. So we're looking, we're looking for guidance on what to do when we have high results when we really haven't completed the science to get to those answers. And that's the frustration I think we all feel. And it's a very difficult position to be in particularly for parents and trying to put their physicians in a position of having to give reasonable answers to questions that

they don't have the answers to, and that's, you know, it's, it's a tough balance.

DR. REH: Agreed.

MS. SHAHEEN: So if I can just ask because we've, we've raised these questions now for months and we've there's, you know, the research has evolved and there are states that are ahead of where we are relative to putting guidance into the world, Minnesota, California, West Virginia. There's the C8 screening recommendations. So why does it have to be any more complicated than picking one of those.

DR. REH: And so our physician guidelines as they exist today are, are somewhat based on the C8 studies and their guidelines. And so and now whether we, we definitely are looking at what the other states are doing and seeing if there's something that we can add to what they're doing to ours.

MS. DAVIS: Well, the C8 was only PFOA and there are many communities that you're going to be --

DR. REH: Absolutely.

MS. DAVIS: -- doing assessments for that are more than PFOA.

CAPT SOMERS: That's a big challenge

MS. AMICO: Right. And to be clear, the C8 medical monitoring tool is very clear in what it's indicating physicians should do. If you're this age, you should test for these things. Right? The eight I just want to be clear the physician guidance from ATSDR does not even come close to that.

DR. REH: Right.

MS. AMICO: So I don't think that it's fair to say we're yes, I agree with what you're saying. You took the results of the C8 studies, and you help shape a document on what a physician -- kind of conversation a physician could have with a patient, but it's, it's not good enough. I don't I don't know how else to say it. It's not good enough. It's not helping people that have high levels in their blood, and they have had the opportunity to have a blood test, figure out what to do next. And I'm frustrated because we were down this road four years ago, and we've been raising this issue for years. And now you're going to do exposure assessments all across the country, and you're going to have frustrated people again, and I just, and yes, the science is evolving and we're trying to get out and ahead of the science but we have a lot of science now. Like, I just don't understand why this is so hard. I don't understand why we can't put together a medical monitoring protocol like the C8 did, based on the current science, and we can't give people some guidance on how to monitor their health and protect their family. It's just, it's, it's frustrating to me, but I'm going to bring it up at every meeting. We're going to keep pushing through because this is a huge gap. This is this is what we can give people today. Every new community because there will be more, every new community that finds their contamination. The first question they ask, how is this going to affect my health? What can I do to keep myself safe now and we can't answer that question. We can't and I feel we can. We just we need to keep pushing for it. So and with you folks having these exposure assessments coming down the pike, I want to see so much emphasis and so much attention paid to that because that is ultimately what you can give people as a result of participating in this exposure assessment. Not just I have a chart and my levels are really

high. What can I do with this information? And that's, that's where we're falling short and we need, we need to keep going.

MS. DALTON: On that note, Andrea had a question in there. Why hasn't it been done yet Or why can't it be done?

DR. REH: So, you know, there's certain things we can do and certain things we can't do. And we're trying to do the best we can with what we have. Now one of the things we can do is come to you and talk to you about what we're doing are the exposure assessments and what the rollout plan is, and the communications and how we're going to -- how we're going to address the concerns of the physician community in the in the communities that we're in. We can come and talk to you about that. And we will I think that's important to do. Because I think it's important to get your feedback on that. And right now in the current environment we're doing the best we can to develop the right guidelines within the rules that we in the regulations that we work with within ATSDR. I know that's not a satisfying answer.

MS. AMICO: No.

MS. SHAHEEN: Totally unsatisfying. And I know you're giving us the answer you, you need to give. But our job as a community advisory group, is to push in places where we know our community needs more, and to muster the political will, and the fortitude to get some answers. And this is one of those areas where I understand why you have to give us that answer. But it's not satisfactory. And it's not enough. And there are states like this, and this is for Dr. Chin's benefit here too. Minnesota, West Virginia, California, who have created guidelines, who have screening protocols, who are arming people with things they can do. Now, even if they do those things. we collectively

understand that it doesn't necessarily give them concrete answers, but it's something they can do. And so I think to Andrea's point, not only are we going to keep pushing, we've got to muster the will, whether that's through our own state Department of Health and Human Services, or collectively through some of these other states that are working on exposure assessments, to say to the scientific community, get together and get us a protocol. Because Minnesota's doing it. California's doing it. West Virginia's doing it. New Hampshire can do it. And we need to make sure that we arm people with steps they can take to monitor their ongoing health. That's our job. Our job is to make sure the study gets enrolled. And it's to make sure we can do something on behalf of our community that's been exposed to make sure they feel like they've done everything they can to ensure their health.

MS. AMICO: If I can just add to that too, I think in our community, we're going to face this again, as our study progresses. As people get the results back, you're going to retest people for PFAS here. Hopefully their levels are going down, right? But maybe they're going to discover they have thyroid issues now or high cholesterol or whatever. And so what are you going to do? Just report back and say, here's your results. And here's what we found, and then give nobody a forward step. Like what? What? It's so important to gather this information, but it's also important to be able to take this information and do something with it. And that's the part I'm not I'm not hearing what we're going to do with the information. How are we going to make this useful for folks? How are we going to help people protect themselves and monitor their health moving forward. So and I think you guys are doing a lot of work on PFAS. I'm so excited our study is approved. I can't wait to

get going on this. But it this these are the things that sit in the back of my mind. Like what happens when all these exposure assessment results come back? What happens when our results come back? What can people do with that? Because ultimately, that's, that's why we're here. That's why I showed up the very first meeting because I wanted to know what does this mean for my family? I don't think anyone can answer that for me yet. And I, we're moving along. But I feel like we're short-sighted right now. Like we need to keep keep looking ahead. And I'm frustrated that four years later, we're just we're still not looking that far ahead.

DR. BOVE: Well, I mean, the study will not result in a medical monitoring guidelines all by itself. So the problems that my agency has with doing this will continue to be the problems at the end of this study my from my that's my understanding of the problem. So the importance of the Pease study and the multi-site studies and other research has been done across the world on this is to add more evidence. Okay, so that any guidelines that get developed are based on good science. That's the idea. Right? And so that's what Pease will contribute. But you may have to explore other avenues to get what you want. Like you were saying.

MS. AMICO: Do we not? Do we not have good enough science now to do medical monitoring? I mean --

DR. BOVE: You're asking me personally, I agree with you.

MS. AMICO: Yeah, right. I think we know enough but do we know everything about PFAS? Absolutely not. No, I know. Do we know something? Do we just leave people in the dark until we have. I mean, to me, we could study this for years and years and years and years and years and years and years. What do we do today?

DR. BOVE: Right. We have plenty of information on PFAS. We have plenty information on PFOA. PFHXS, we still have limited information. This is what we said in the feasibility assessment. Nothing has changed a whole lot with PFHXS. And that's a key contaminant here. Okay. PFNA, same thing, maybe a little bit more than PFHXS. It depends on how you look at the evidence. So there's still some gaps that need to get filled. That's why it's important to do the study here. That's why it's important to do other studies and where AFFF has been involved. So you can look at PFHXS and other chemicals that were in that mix of chemicals that are part of the AFFF. Okay, so I you know, but I think there is enough evidence, and states have taken the move and maybe that's where it's going to have to, to come from. I mean, just you know, from a political standpoint, it may be difficult to get the federal agencies to move on this. You may have to go state by state, unfortunately, in this country, by state by state.

MS. DALTON: I'm going to piggyback off of that. This is Michelle. So the famous line, help us help you. If you guys are running into roadblocks or have certain parameters or guidelines, that is preventing you, or you're going through hurdles to try and get this physician guidelines out? What can we do as a CAP, as a community, as individuals to push this forward so that we can get something out there?

CAPT SOMERS: We've heard from many community members that this is a gap and clinician education about these contaminants and I think there is guidance out there from some places again, like C8, for example. And it's focused on only a few of those contaminants and I think from a clinician standpoint, and I'm not speaking for all ATSDR. As a clinician, it gets a little concerning if you put forth guidance like that, you can be

falsely assuring people since we don't know about these other contaminants. If you say just use C8, then you know, that's good if you've been exposed to the ones covered in C8, but I think it's just it -- the science is still really evolving and it is hard from a clinical standpoint, to come up with guidance that's going to cover this breath of contaminants for many we don't know, and you could be falsely reassuring or falsely alarming people. You know, it could go either way. I mean --

MS. DALTON: Sure absolutely.

CAPT SOMERS: -- assessments that people have exposures to these other ones that aren't, you know, yet fully understood.

MS. DALTON: What about the ones that we do have sufficient science for? I definitely don't want to be falsely, you know, alarming people or assuring people. But if there's enough science on some of them, why can't at least that portion be pushed out?

CAPT SOMERS: Well, I think that's the challenge, like when, you know, how do you sort out all these issues with?

MS. DALTON: And how can we help you guys sort those out and get those pushed through?

CAPT SOMERS: Yeah.

MS. DALTON: Is my point.

MS. AMICO: Tarah, it sounds like you're giving the chemicals the benefit of the doubt when you make an answer like that. Like we just don't know. So we're not going to do anything. That is just unacceptable. So you don't know. So you don't do anything. Where's the responsibility to take action with what you do know? With the full understanding that the science is evolving, we're

pushing through, but to sit back and do nothing. To let these communities have these results or not have these results. Just know their exposure but not know what to do next, seems irresponsible to me and to say we just don't know. We don't want to falsely alarm and we don't want to falsely reassure. To me that seems more detrimental and harmful to me than to put together a general guidance for people to decide what they want to do with their own health moving forward. So I completely disagree with your position on that.

MS. DALTON: So what can we do to help you?

DR. PROTZEL BERMAN: So I have a thought in the sense of problem solving. So you've mentioned a number of states that are doing certain things. Maybe it's worth taking a look at what those states are doing, just to be aware. How are they basing their decisions? What's it being based on? How are they making their guidelines? Are they consulting with medical groups within their state to do it? I mean, there's a lot of information that I know that Stephanie, you mentioned that it's happening already. But maybe that's something that the CAP could look at more closely, and investigate how those that are doing it. How are they doing it? What kind of approaches are they taking? I mean, I think about some work that you know, CDC has done in the past where we, you know, end up harmonizing or synchronizing guidelines for vaccinations, but we don't do it on our own. We do it in consultation with medical groups with pediatric groups and others. And I think that's what Chris and Pat were kind of thinking that, you know, as we know more, these groups, we work with these groups to come up with these but I think maybe a first step could be for us to see, take a closer look at what's happening out there. Just as something to do even though we've

all talked about the constraints that we have, we could get better educated about how others are doing it. So.

MS. SHAHEEN: I mean, I think we, we as a group, and in fact, we met before this meeting and have already done outreach to the Department of Health and Human Services here and have been looking at what other states are doing. So we are aware that this is one strategy for how to address this in New Hampshire. I think the issue Andrea was raising is, as exposure assessments are rolled out across the country, the same concerns are going to be experienced in other communities as the ones we've experienced here. And the ones we've experienced here are going to be raised again, when people get screened again. So I mean, certainly state by state by state is a way we have to do it if that's how we have to do it. But it strikes us that with federal funding on a new contaminant, and family of contaminants that is now getting all this attention, is there a better more efficient, more effective way to do that? And certainly, a federal agency with federal or national partners who can validate that these screening protocols are valid, is going to help us get further than fighting state pediatric association or medical society at a time. So I mean, we are not waiting, we're not going to rest on our laurels. We're not going to wait for the next 1800 families to get screening results to, to be in the same position we were in four years ago. We're going to find a way to make this work and give people some suggestions for things they can do. Recognizing they're not going to be exhaustive list, it's not going to be promises, not going to be giving people false assurances or falsely alarming them, but some action that they may choose to take should they want to take it, and Minnesota is doing it and California is doing it and West Virginia is doing it and New Hampshire is going to have

to do it. But state by state by state is absurd given the scope of this, what we now know about these contaminants and what we're going to learn. So you know, our goal is to -- I mean we were part of the call for the multi-site study. And as such, you know, we don't think about this is just Pease. This is we don't want this that families to go through the same thing that our families went through four years ago. We want to learn something. We want to have the struggle not be for nothing. We want to have help advance the ball. And so that's why we're here. And if we have to do it at a state level with our state pediatric society or medical society, then we will start there. But it seems like there's a better opportunity and a bigger opportunity, and you all are going to be facing the same questions for those families in Westfield that we're going to be facing again, however many months from now.

DR. PROTZEL BERMAN: Yeah. Appreciate that comment, Stephanie. We don't disagree with you.

DR. REH: And we struggle with the state by state approach too, especially on the regulatory front.

MS. AMICO: We've already seen that with the water regulation. So it's, it's not a good atmosphere to be in either when you live in one state and they say the level should be here and the state right next door says here. That doesn't feel good to a community member.

DR. REH: Absolutely.

MS. AMICO: So we absolutely need national leadership on this and I get it. This is uncomfortable for you guys. It's not something you typically do. I mean this nicely. I don't care. You have to respond to this issue that is rolling out across our country. If

you've never had to do it before, you've never had to address it before. I'm, I'm sorry, you haven't. But now you do. So you have to change your practice. You have to change how you're addressing the issue. It's not okay to just sit back and say, we don't do that or we're not comfortable with that, or we don't think there's enough science like, I just -- I want to push you guys to do approach this differently, because this PFAS contamination is not something ATSDR has ever had to address before. So you're going to have to do new things. You're going to have to think outside the box. You're going to have to respond to these communities. And you, you know, I know that I harp on this every single meeting but you're going to face this everywhere. So sorry.

DR. REH: Any other CAP concerns.

MS. SHAHEEN: I do want to just thank everybody for getting to this place where we have there has been progress. I think it's felt for a long time. Like, we're all collectively trying to push this huge boulder up the mountain and not getting as far as we want it. And in the last few months here, especially it has felt like progress. So thanks to everybody for their collective efforts. And certainly the voices that have been shared here are only a reminder of how much more we have to do, but not expressing a lack of appreciation for the progress that's been made. So thank you all for the effort.

DR. REH: Thank you.

MS. AMICO: I could just echo that. Thank you guys very much. I think I'm still in shock that our study's been approved. We're at this phase. It still just doesn't seem real. So I'm, yes, I know we push you hard on the medical monitoring stuff. And sorry, not sorry. But we're going to keep doing that. But in the

spirit of appreciation for everything else that we've come across, I thank you very much.

DR. REH: Andrea, I don't think you need to apologize. We're in this together. But we do have limitations to what we can do.

MS. AMICO: Yeah.

DR. REH: That doesn't -- I think your point about thinking differently is it is a good point and just because we have limitations doesn't mean we can't think differently. So.

MS. AMICO: Yeah, I yeah, just thank you very much. It's a huge milestone for us to be in this to be where we are tonight. And I think we're giving a lot of other communities across the country hope and we're inspiring people to take action in their own communities and, and speak out. And we're showing other people that, you know, communities can come together and identify problems and work towards solutions. And so not just on PFAS. So this has just been a remarkable experience. We have so much more work to do. But I think it's a good moment to just pause and say, like, good job, everybody. You know, we're changing the world. We're making a difference. And I know for me, I have two children that I worry about all the time. So this is this is huge for me. So thank you very much for everything that you guys have done.

DR. REH: All right. Thank you.