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TOXIC SUBSTANCES AND DISEASE REGISTRY

convenes the

ELEVENTH MEETING

PEASE COMMUNITY ASSISTANCE PANEL (CAP) MEETING

March 24, 2020

The verbatim transcript of the Meeting of the Pease Community Assistance Panel held virtually on March 24, 2020.

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P R O C E E D I N G S

(6:00 p.m.)

WELCOME AND INTRODUCTIONS

**CDR MUTTER:** Okay, guys, let's go ahead and at least try to see who's on the line. I'm going to go ahead and read down the CAP list. So Andrea, I heard. Correct?

**MS. AMICO:** Yes, I'm here.

**CDR MUTTER:** Lindsey Carmichael?

**MS. CARMICHAEL:** Hey.

**CDR MUTTER:** Michelle Dalton was unable to join us today. Alayna Davis, I think you're on.

**MS. DAVIS:** Yes, I'm here.

**CDR MUTTER:** Thank you. Rich Dipentima, I think I saw you as well.

**MR. DIPENTIMA:** I'm here.

**CDR MUTTER:** Wonderful. Thank you. Senator Martha Fuller Clark? Okay. Robert Harbeson, he let me know he was not going to be able to join us today. Cliff Lazenby?

**MR. LAZENBY:** Yes.

**CDR MUTTER:** Thank you. Kim McNamara? Russel Osgood? Stefany Shaheen, I heard. What about Jared Sheehan?

**MR. SHEEHAN:** Yes, I'm here.

**CDR MUTTER:** Wonderful. Thank you, Jared. Mark Sullivan, I think I saw you on. Correct?

**MR. SULLIVAN:** Yes, here.

**CDR MUTTER:** Wonderful. And Shelley Vetter?

SV>> Hey.

**CDR MUTTER:** And for our technical advisors, Dr. Carignan? Okay. Dr. Clapp?

**DR. CLAPP:** I'm here.

**CDR MUTTER:** Thank you. Let's see. Dr. Durant? And Dr. Schaidler?

**DR. SCHAIDER:** I'm here.

**CDR MUTTER:** Thank you. Okay, so that's all for the CAP and technical advisors. Any other CAP and technical advisors that joined us? Okay, so let's go from ATSDR. I'm going to just go ahead and say your names since I have most everybody and if I didn't say your name, then I'll call you in a little bit. So I have Chris Reh, Frank Bove, Marian Pavuk, Tarah Somers, Lori Launi, Kimberly Dills, Pam Protzel Berman, Meghan Weems, Tarah Somers, Gary Perlman, Greg Ulirsch, Bharat Balyan, I hope I said that correctly, and myself Jamie Mutter. And I think we have Colonel Holifield on. Is that correct, sir?

**COL HOLIFIELD:** That's correct. I'm here.

**CDR MUTTER:** Wonderful. Okay and I know we have some great community members on, I believe, and so we won't go through all those introductions but welcome and thank you for joining us to those community members. Any other ATSDR/NCEH that I wasn't able to capture? Okay. So it sounds like I might've captured everybody on the phone. And let's see. So with that I just want to make a few general announcements before we get started, just as reminders. If you're not speaking, if you can please put your microphone on mute so we all don't hear what's going on in the background. I know for myself I have kids running around in the background, so I apologize for any of that excess noise but that's what we're dealing with these days. Also before you speak, it's really important in this format that you say your name before you speak, as we are still trying to do a transcript and so we know who says what for the transcriptionist. So if you can just remember to say your name before you speak, I would appreciate it. Also since I can't see body cues or nemetents, I'm not sure who has their, you know, question first. Let's just be patient with each other as we might stumble over each other a little bit tonight but that's okay. Audience members, we are excited to hear from you. We are excited to have you. There is a place on the agenda for audience comments. So we just ask you to wait until that time if you have comments or questions. With that, Dr. Reh, would you like just to introduce us and say welcome?

**DR. REH:** Sure. Thanks, Jamie.

**CDR MUTTER:** Yes, sir.

**DR. REH:** So we find ourselves in an interesting situation this evening with all of the everything going on with COVID-19. Most of us are now working from home. And I know many of you on the

line and in New Hampshire and I know some of the ATSDR people have kids out of school and we're all dealing with a new normal. Hopefully, it will be a temporary new normal. But it is what it is. I just want to recognize how much I appreciate the number of CAP members and the interest of the community for this work that considering everything that's going on and how our lives have been turned upside down that you've been able to make time for this very important meeting and this very important work and how appreciative we are that you have. For us, we carry on. Our mission has not changed. Our devotion to the work has not changed. We still feel that working with communities and with the Pease community to better understand PFAS contamination especially as it relates to drinking water and how it may impact communities. This is still important work for us and that has not changed. We have had to make some tough decisions and just the fact that we're not there in person meeting with you live in person like we normally are is one tough decision we've had to make. Another even tougher decision was to suspend sampling for the Pease Study. But it is important to remember that these are temporary things and we will hopefully soon be back to our original normal and back to completing this study. But, you know, as we start the evening, I want the takeaway message to be that this is still very important for us and the concerns of this community and of the communities across the nation that are affected by PFAS contamination is still very important for us. And even though the COVID work has distracted us to some extent, our mission is the same and our work is the same and we continue to push forward as best we can. So with that, Jamie, I'll turn it back over to you to start with the agenda.

#### ACTION ITEMS FROM THE MARCH 2020 CAP MEETING

**CDR MUTTER:** Great. Thank you. So we'll start with the action items from our last in-person meeting. So there's only a few. So these hopefully will go pretty fast. Can y'all hear me? I want to make sure I took myself off mute.

**UNSPECIFIED SPEAKER:** Yes, we can hear you.

**CDR MUTTER:** Okay, good.

**UNSPECIFIED SPEAKER:** Yes, we got it.

**CDR MUTTER:** That's all I need to do is talk for five minutes and then y'all didn't hear me. Okay, so the first action item was ATSDR will send the CAP the PFAS chapter and the AAP "Pediatric Environmental Health" Fourth Edition, Green Book. My apologies

that was sent so late. It was in my draft folder and I was looking to see when I sent it and realized it was still in my draft folder. So I sent that today. Apologies. So hopefully you all received that copy. Just please note that that's not to be shared or posted online. That's just for the CAP's reference. Any CAP member if you have questions as we go through these, please just unmute yourself and ask. I'm okay if I'm interpreted. So the next action item was ATSDR will relay the CAP message to AAP regarding suggestion for the Environmental Committee and the Committee of Infectious Disease to discuss vaccine effectiveness. So we just got -- Actually we've been asking this for a while and they had to go back and forth and ask people but we just got this response yesterday as well. And it says, "In response to the CAP request to consider concern of PFAS and lowered immune response and how that should be addressed in AAP guidance, the authors well water policy statement noted support for the conclusions of the December 2019 ATSDR's own update of the factsheet for clinicians. It says I believe they are planning to address this in the AAP's policy document but Dr. Hatcher at ATSDR wanted me to remind everybody that a policy statement at AAP can take up to 18 months. They also wanted me to share that AAP also shared that the council on Environmental Health is working on PFAS related information for a number of other AAP channels including PFAS related proposals for the AAP's annual meeting and a new page for [healthychildren.org](http://healthychildren.org), the academy's parents/family facing website. So that's the update I received. I can take back any questions if there are any. I'll just pause for a moment.

**MS. AMICO:** Hi, Jamie. This is Andrea. My question is does ATSDR and CDC work with AAP when they take on something like this? Do they consult with each other? Will you folks have any input or any ability to review what they say or do they working completely independently of anything that you guys are doing?

**CDR MUTTER:** That's a great question. Does anybody at ATSDR have that knowledge? If not, I can take that back.

**DR. REH:** So yes, this is Chris Reh. They work completely independently. They are a stand-alone professional organization. They do not consult with us when they develop the Green Book.

**MS. AMICO:** Thank you.

**CDR MUTTER:** Thank you. Any other questions on that action item? Okay, so the next action item is ATSDR will share the multisite study roll out plan with the CAP. Unfortunately, when I was trying to locate this, it came known to me that this is an internal document specifically for internal to ATSDR but the

question is if there was any specific question about the roll-out plan or any information that you need, we'd be happy to look into it and see. I know that Dr. Reh offered that at the last meeting but if you have any questions specifically about that document, it might be a moot point now since it's rolled out already and that was last September but I just wanted to pause for an opportunity if anybody has any questions about the roll-out document or Lori, if you had any other comments about that. Okay. So the last action item is ATSDR will research medical monitoring plans in Minnesota, California, and West Virginia. So we did look into this. So Michael Hatcher, Tarah Somers, and myself reached out to the regional reps, ATSDR regional reps and Appletree grantees and we weren't able to find any information on medical monitoring guidance. We weren't able to find it. So if the CAP has that information and wants to share with us, we'd be happy to receive it. We just weren't able to come up with it through our channels. So I will pause there and if there is any questions from the CAP that I can take about that. Okay, so with that, the action items are concluded. So that's great. And we'll move on to the Pease Study update. Frank, do you want to give a quick update on just recruitment up and to this point?

#### **PEASE STUDY UPDATE**

**DR. BOVE:** Well, actually I don't have it in front of me but I mean recruitment obviously has stopped. They were a couple of neurobehavioral tests scheduled for this Saturday but they had to be canceled. So that was unfortunate. We're working right now to try to figure out what the contractor can and can't do working with our contracts office. So that's what's going on there. There are certain tasks they might be able to continue doing but we have to work that out. I think that all of you got the latest information about how many people have been recruited into the study, right? Wasn't that sent out?

**CDR MUTTER:** Yes, that was sent out I believe last Wednesday.

**DR. BOVE:** Yes. As far as I know, that really isn't changed. So that's where we're at, at this point.

**CDR MUTTER:** Okay, so thank you for the update. Lori, do you want to go ahead and provide us a little bit of an update on the document I sent out today to the CAP and where we want to move forward when we're able to get back up and running?

**MS. LAUNI:** Yes, I'd be happy to share what we've come up with so far. The whole team got together here to brain storm ideas and



to come up with a strategic communication plan, which we're calling the Pease Recruitment push. We're kind of coming up with ways to rebrand, re-message, reach out. We were digging into areas maybe we haven't looked at before and just increase overall efforts everywhere, see who we could get involved. So this is what we shared as the overall plan. And with each sub-area of this plan, though, sometime there can be six, seven, eight different components to each little area or more and we had worked to the point of assigning people roles to work on this and we're moving this forward. So the objectives of this plan gained audience insights and understand the barriers, increase study awareness, increase participation in both like employees and children and the general population who has not been, is just not aware. So some of the tactics we looked at we were -- At this point we don't have -- We cannot really tap into like the community and get the feedback we'd like. We'd love to have, you know, some sort of session where we could survey everybody but that requires going through a lot of channels here and it's kind of prohibitive. And this is where I think the CAP really comes into play that can help us get kind of more a pulse and we're going to see if we could ask each member to and of course this is after social distancing is over. So we wouldn't want you do this before. But it would be more like when you go outside your immediate circle of friends and acquaintances and colleagues say for instance if you go in a convenience store and just a quick survey, have you heard of the Pease Study? Oh, would you participate? Why or why not? We're just trying to get really identify some barriers. We've heard some ideas but maybe we can just try and identify more and target those. And it's just a really good way to find out because you are right there and know better what's going on in your community. So with that, that's just like one of the things we're thinking. But then moving forward, the more we produce, more materials that can be distributed within the community, including yard signs and fliers. We want to increase paid messaging to geotarget the area, to really identify those that really could participate. Also, we want to do, we're going to increase more outreach to the media by hoping to get our professionals on there speaking on talk radio, maybe a local TV talk show, those type of things, just coming up with different ideas. Also, tapping into some local celebrities and politicians to have them talk about the Pease study more for us to appear at have the Pease study office members come to different events with their laptops and try and enroll people with REDCap on site. So those are some of the things we're thinking of. Now we've got these all kind of lined up. We've got strategies. We're going to continue this. We're going to continue the research on this while the study, while

the office itself may not be open, we're not stopping any of this work. So we're going to be continuing to move forward looking at all the possibilities going forward so that we are ready to start back up immediately when everything is ready to go. So that's kind of the -- That is the overall plan right now. I'd love to hear your feedback, get more ideas and just really, really increase outreach across the community.

**CDR MUTTER:** Thanks, Lori. And this is Jamie. So I sent in the email if we could have your feedback tonight or if we could have it no later than next week, I believe it was Tuesday, next week. But if any CAP member or technical advisor wants to speak up now, just remember to say your name before your comment. Thank you.

**MS. AMICO:** Hi. This is Andrea. I was just curious, do you guys have any plans to do any videos? I think a video of people going through the process or videoing people's testimonial, I just think that's a really powerful way to send messaging out to people and people relate to kind of short clips that they can watch on social media or on a website. So is that something you have considered?

**MS. LAUNI:** Yes, we have considered that and we are working along those avenues right now. We're thinking of doing a number of ways maybe to get something done quickly if we could reach out to a local community member and a news station where they could record this happening and we could use some stock footage of like a blood draw. And that way, that alleviates issues we may have with a participant actually going through a blood draw. But going through it to actually see what happens and it would get the message out to the community and then it could be shown over and over again on YouTube. So that's one thing we're also, you know, the idea of also speaking with other community members to talk about expressing what it meant to them to participate. So yes, we are really on that and that is one of the things we want to do. And also in the meantime while we're doing that and we can't really get out into the public right now, developing a short animation that at least we could post up right now until we can do some more live video. And we could probably do that very quickly. So we're trying to get all of that done. As soon as social distancing is over, we'll be able to do live video then.

**MS. SHAHEEN:** Hi, everybody. This is Stefany Shaheen. If we can maybe just step back. It feels to me a lot like this was the plan we had in place or was in the works prior to the reality we're all currently living in and it strikes me based on everything I read about the realities of COVID-19 and what the

next many months are going to look like. Obviously not as acute as what we're experiencing now. But given what we've seen with the blood drive shortages and how fearful people are, just period, I wonder if we need to reevaluate the whole outreach plan in the context of people's very legitimate fears that I don't think are just going to go away as soon as there's some arbitrary date where people think it's more safe to start going out again. And so I'm sure that is I know the data is evolving and people's tolerance is evolving and differs depending on who you are but have you all given thought to how do we think about what it's going to take to sell them there if the people participating in the study and the reality where they're afraid for their physical health, unrelated to what it takes to do the blood draw?

**CDR MUTTER:** Stefany, that's a great question.

**DR. REH:** So I'm sorry. I was talking and I was on mute. So it is a good question, Stefany. This is something we should probably kick around and come back to the CAP with. A lot of the issues that are emerging around the coronavirus, you know, are new to all of us and I think that that's what you said is a great pickup. And I think we're going to have to think about how what's happening today is going to impact and possibly change the way we recruit and communicate about the study.

**MS. SHAHEEN:** Yeah, I think it's -- I mean, it was a hard ask before just because it requires the blood draw and there's children involved. Now it feels an even hard ask because of how fearful people are. And I've been thinking about and talking through what the challenges are for just the blood drive right now and trying to get people to give blood. I mean, they're afraid. So, you know, that's a critical national shortage. This is, I think, sadly, for a lot of people who will feel elected, it won't feel like something they have to do. And so how do we think strategically about messaging and who we're going to partner with and how we're going to reassure people that this is going to be a safe and okay thing for them to do. I think it's an entirely new hurdle and I think we should reevaluate the outreach strategy, recognizing that through that lens.

**DR. REH:** Yeah, I very much agree and there are other parts of CDC who have experience with doing blood draws like the NHANES study and there's places where we can go to ask these questions. And so we're going beyond just having ATSDR people getting together and trying to figure out what's right but looking for some experts who can help us navigate this new normal. Thanks for asking that. That's a good push.

**MS. LAUNI:** And we will take that into consideration with this. As everybody is saying, it is an evolving situation but we will definitely look at this and the strategic communication plan through the eyes of risk communication and we will be working with you on that as we move forward.

**MS. AMICO:** This is Andrea. I'm just curious what kind of messaging do you want us to give to people today, because I know we got an email last week from Dr. Reh that, you know, the study actually completing the study is on hold and then we got another email that we're still allowing people to call and sign up? So do you want this big push from the CAP like through social media and stuff to continue to encourage people to sign up but, you know, the messaging is that we just don't know yet when the study will resume? So I didn't know if you could provide some clarity tonight about, you know, is there something in the next couple weeks that we can do, you know, a month out. I'm just trying to best understand the messaging that we can give to people and make sure that we're not -- Like for example, if you're still letting people sign up, do you have a certain date that you're booking appointments right now, because when they call they obviously book appointments? I'm just trying to figure that out so we know what to say.

**MS. LAUNI:** This is Lori. From my understanding and I think this is like we're all saying, it's still evolving what's going on and we're working with Abt but we were looking, they were considering calling in and not scheduling appointments but asking people to call in and taking their names and numbers and seeing if they're eligible, they would call back. Right now I'm working on communication, you know, some messaging and frequently asked questions to put on the Pease study page to address some of this. I do have to find out specifically what Abt will be doing but as soon as we know, we will put that on the webpage so that there can be more this can get out there but there's just so many decisions.

**MS. AMICO:** Okay. This is Andrea again. So just to be clear, if people call in today or tomorrow, Abt is collecting their contact information but they're not actually scheduling an appointment at this time?

**MS. LAUNI:** That is what I heard last Thursday.

**DR. REH:** So there's a lot of contractual procedures that go into answering your question, Andrea. And I'm not going to bore you with contractual procedures because I don't really know them as well as others within ATSDR and CDC. But what we are doing with our contract specialists is determining what are the things that

Abt can continue to do and what are the things that they cannot continue to do in this delay period. And so tied up in that is like for some of the exposure assessments, how do we report results. And in your case, when people call up, they can make an appointment or at least leave their information and express their desire to participate. We're working through those now. We should have an answer really quick and by really quick I mean within a day or so. But our desire is that the part where people can call up and express interest and that whole part of it is continuing.

**DR. BOVE:** This is Frank. Actually as of yesterday Abt was shutting down its call center. And again, this is what I was saying earlier that we're working out with the contracts office exactly what they can do and what they can't do. One of the issues is that we have delineated their tasks and the tasks are broad categories of work. And at one point the contracts office said if we can't do any part of that task, the whole task can't be done. So subtasks, you know, would not be performed if the any of the subtask had to be stopped. That's being worked out now. And so but as of this point, as far as I know, and again I may not have the most recent information either, the call center is not getting calls or not answering calls this point. So we have to work that out with the contracts office. Jamie or Lori and Chris, have you heard anything different?

**CDR MUTTER:** No, Frank. This is Jamie. I think from reading emails, I think that is true. What they did say is that they could do internal meetings, so we can continue to have our Thursday meetings internally with ATSDR staff but they couldn't do anything besides that at this time. That's why they couldn't join us on this call today as well.

**DR. BOVE:** Right, right. And so again, we're trying to work something out so that subtasks that aren't involving contact with people face to face could still be done.

**DR. REH:** Still be done, yes.

**DR. BOVE:** And that was the last I heard which was yesterday. I have not heard anything today.

**CDR MUTTER:** So as you can see, this is evolving daily. And so when we get the final information or even just an update we can provide to you, I can distribute that to the CAP.

**MS. AMICO:** Hi, this is Andrea again. So thank you for that and I certainly appreciate, you know, that this is things are changing rapidly every day. I'm just curious. I guess I'm not

understanding why Abt couldn't join the call tonight, though. I don't understand why they can't be on a call.

**DR. BOVE:** Because, as I said, it's underneath a task and some of the subtasks under that task they can't do. So what our contracts office was doing was telling them they couldn't any of the subtasks on that task, if that -- I mean, that's convoluted but that's -- That was the initial response. As I said, they're revisiting that and I think that some of these subtasks will be pulled out and Abt will be allowed to do it. One of the things that concerns both Marian and myself is making sure that the freezer maintains its temperature and that they check that but right now, that's up in the air because it's underneath another, it's underneath a task that they can't do. I don't know how else to make it clear. It's convoluted. But we're trying to free up, as I said, some of these subtasks that they can then perform and one of the key ones is making sure that even though the office is not functioning right now, at least the freezer is being checked and the specimens in the freezer are maintained.

**MS. AMICO:** Okay, thank you. This is Andrea. I have another question. Do you know how far out appointments have been canceled, folks that would've been scheduled for appointments this week, next week and beyond, how far out have people been notified that their appointment has to be rescheduled?

**DR. BOVE:** That is a good question. I don't know how far out.

**CDR MUTTER:** This is Jamie. I am going from memory, I think it was June but that's just from going from memory. I'd have to look back. Maybe I can do that while on the call and see if I can find that information.

**DR. PROTZEL BERMAN:** Jamie, check June 18th is what I had heard as well. So check that.

**CDR MUTTER:** Right. Thank you.

**MS. SHAHEEN:** This is Stefany. Is it safe to assume that we should just not be doing anything in the area of recruitment? I mean, I'm worried that if we, you know, even direct people to call, the situation is too fluid. They're not going to get good information or the information is going to change and it's just going to create frustration and then we'll lose them altogether. I think, I mean it feels to me like the message going back to the community right now is that enrollment in the study is on hold until it's safe for people to be together again. I mean, it just doesn't feel like -- Otherwise, we're all spinning wheels and we could be giving people bad information and then we lose them altogether.

**CDR MUTTER:** Yeah, this is Jamie. That's the way I see it but I'll let others comment as well. I don't think we should be doing active recruitment right now until we get the all clear.

**DR. REH:** Frank, what do you think on this?

**DR. BOVE:** Right. We probably shouldn't be doing active recruitment. I do think, you know, there's a lot of materials that we can develop in the meantime and get ready when the all clear is given. Maybe we can also again ask the CAP to check around and see if there are other obstacles besides COVID-19 that might be preventing people from in the past from participating although I'm not so sure you'll get a good answer at this point given that that's on everybody's mind. So that's what I think. I think recruitment would not make any sense at this point, where you have nothing to recruit them to. And so but we need to be able to hit the ground running once the smoke clears here.

**MS. AMICO:** This is Andrea. I agree with those points as well.

**MS. SHAHEEN:** And I think if we can also just frame this in the context of hitting the ground running recognizing that it's probably going to be foggy for a while even when the smoke theoretically clears because I think we're in unprecedented territory. So as we think about what it actually looks like to hit the ground running, let's be realistic about how the ground might still be shifting.

**DR. REH:** But I also think it's going to be important for us with the help of the CAP to think about and I think I'm reiterating your point to think about what the startup procedure is. Once we start getting on the other side of the COVID situation, how do we start back up and when do we do things. And, you know, right now we're spending a lot of energy on delaying and shutting down but at some point in the future we will be starting up and we need to think today about what that startup looks like so we don't miss opportunities when things get better.

**MS. CARMICHAEL:** This is Lindsey. I have a quick comment just going back to the shutting down piece. I'm assuming that we can hopefully have the ATSDR main landing page updated to indicate that if we are in fact sort of in a holding pattern that that's integrated into the site and any other materials out there that where if people are looking to register that they are notified that things are in a holding pattern.

**DR. REH:** Lori, you can do that update, right?

**MS. LAUNI:** Yeah, I'm working on that right now actually. I have it -- Yeah, I'm working on that. We were just trying to get, you know, clear on what is and isn't going on. So as soon as we have all of that, that's going right up there. So it should be in the next couple days. So, you know, top leadership will take a look at that. We want to make sure the messaging is the right messaging for the entire agency but definitely so that the whole community understands that this is just a pause and that it will reopen but this is temporary that the appointments will be canceled or postponed. We should say postponed.

**CDR MUTTER:** Lori, when that's posted, if you let me know, I'll send out an email to the CAP so they're aware.

**MS. LAUNI:** Okay, very good.

**CDR MUTTER:** Okay, any other questions, comments on Pease study?

**DR. BOVE:** This is Frank again. When the smoke clears, maybe that's a bad metaphor, I would like us to be ready with a media onslaught. I really do think that if we hit the morning talk shows, if we make sure that the local newspaper prints a story that we're up and running that maybe get the mayor of Portsmouth to participate in the study and make that public. Anything we can do right off the bat to get the word out that this study is back on and we want people to start coming in, that I think is what we'd have to do. So as I said, we have a time here to prepare for that kind of effort but I think that's what we should be doing.

**UNSPECIFIED SPEAKER:** I agree, Frank.

**MS. SHAHEEN:** I agree.

**MR. LAZENBY:** This is Cliff from Portsmouth City Council. I agree with what you just said but I do think it is important that we get some message, you know, even if part of the message is we're not yet clear on what the parameters are but that we are, you know, postponing things and have to delay some things so people are aware of that and then I think you're right. I think we can go through all those things and the other suggestions before about amplifying the message at a lot of different opportunities. And I suspect we're going to have a little bit of time to prepare for that because it seems like this will go for a while but I do think it would be helpful to just if in the very near term I know everyone is trying to, try and get some of that clarity that says, you know, we're postponing out to at least a certain date and, you know, to hold off on recruitment kind of things but that we plan to, you know, fire up the machine as soon as we can.



**CDR MUTTER:** Thanks, Cliff. Any other comments?

**MS. AMICO:** This is Andrea. I'm just curious, I think I had suggested in the email and I'm not sure if there's a barrier for ATSDR but have you folks considered creating a social media page that's run by you that's specifically for the Pease study, where you can also share updates, post videos, you know, things like that? I just think that might be another effective tool in the toolbox and I'm just curious if that's something you guys can do or if there's a limitation why you can't do it.

**MS. LAUNI:** This is Lori. I did check with the social media specialist who we work with and she says that we do not have that capability for our own social media page.

**MS. AMICO:** This is Andrea. Thank you. Is there a reason why? Is there more elaboration that you can give to that answer?

**MS. LAUNI:** Well, there are a number of reasons. One, we do not have enough people. One thing is we do not have enough people to make sure that it is taken care of and updated properly. There's a lot -- I think there's also some regulations with the whole Center and the Office of Communication that has some guidelines for that as well. But the whole possibility being just the amount of time spent watching the page to make sure that it's used properly, it takes a dedicated team.

**MS. AMICO:** Okay, thank you. This is Andrea again. Just another thought that popped into my head that we can jot down is that I know the editor of the "Portsmouth Herald" or the Seacoast Media Group. He had his blood tested and had elevated results and after we had a community meeting several years back he wrote an op-ed on that experience and how he had elevated results and what that meant. And so I hope that he's going to participate in a health study but he may be another person we could reach out to. And if he does participate, perhaps he could also write another op-ed. I heard from a lot of people that read his op-ed about the blood test results, so I think that really did resonate with our community. So just another thing to add for a list to kind of get more people, like you said, local celebrities. I don't know if I'd call them a local celebrity but certainly somebody who's known in the community and might just be another thing we could reach out. His name is Howard Altschiller and I'm happy to reach out and make that connection as the time, you know, as the time comes. I just wanted to add that to our list of things that we could be doing. And another thing that I wanted to update folks on, it's not going to happen at this point but you may recall on a prior CAP meet call I was contacted by someone who works with the Portsmouth Democrats and

they were looking to volunteer some time to help us spread the word. And so we had actually been in the beginning phases of planning like a canvas day where we were going to get some folks from the Portsmouth Democrats who were going to give us some time. There was some people in the CAP and we were going to message this out a few weeks ago but obviously things got put on hold because of COVID-19. But what we're hoping to do when things get up and running was to get a group of volunteers who would be willing to actually go out to the businesses on Pease and try to make a contact within each business and deliver some fliers and just ask people to post them, get an email and, you know, name contact for each business and be able to email them information and things like that just hoping to make that face-to-face contact and spread some actual literature there, if that would just be another way to get people in the businesses more aware of what's going on. So we did have people interested in doing that and I think they are still interested in doing that once we're beyond the social distancing. So that's something that Testing for Pease is working on and we hope that once we get and running other members of the CAP may be able to volunteer some time to do that and we'll kind of keep you posted as a future date comes in mind.

**CDR MUTTER:** Thanks, Andrea.

**MS. LAUNI:** If CAP -- I'm sorry.

**DR. REH:** Go ahead, Lori.

**MS. LAUNI:** Oh, I was going to say if CAP members do have ideas for I'm saying local celebrities or, you know, just in the community people that are known and well respected that you would like to, that you think may want to participate or, you know, you see a good reason that they would be somebody maybe we could that would want to help us in our media outreach, maybe if you could go ahead and maybe talk to them and then share the information with us and we could all work together and see what we can come up with, that would be really, really great.

**MS. AMICO:** This is Andrea. I have a question about that. So what do you envision doing with someone, you know, that we call "local celebrity?" I mean, are you envisioning making a video about their experience, are you looking for them, you know, to take pictures and, you know, kind of what did you envision by getting a local celebrity in and how would we use that to recruit more people? Just want to get a better understanding of how you would message that or put that out there that this person was participating.

**MS. LAUNI:** Yeah and that was the thing we're thinking of through that too of like different ways. Some way may be -- Some way we were thinking about it was like little short videos of like people in the community saying, yes, this is my study. I participated because blah. You know. It would be like short and quick but, you know, some recognition and just have like a whole series of people. It would be good. And we could use, you know, if they wanted to maybe a little bit longer. We could also -- Some people might -- You know, we could help do some outreach to the media. I have a media specialist and that's their job. They could reach out and say, oh, I think you should talk to so and so, you know, they'd like to share their story, they're involved in this study. So there's a lot of different ideas. And, you know, it might depend on the individual's story too, how it's crafted. But, you know, if you know somebody so we can think through that but one of the thoughts was, you know, to say this is, you know, this is my study and this is why it's important to me and, you know, have it kind of branded like that and you could have posters in different settings. So it's just -- These are some of the things we were thinking through.

**DR. REH:** I think -- This is Chris Reh. I think the comment that Frank made about the media onslaught and having that plan ready to go is a very good comment. And I could see where local celebrities and op-eds, like you mentioned Andrea, would be major components of really hitting the ground running when we get on the downhill side of this situation. So, you know, we're going to need to go back and think about what this onslaught is going to look like but to me, these are different tools in the toolbox and I think Frank said it really well.

**CDR MUTTER:** Any other comments, questions, concerns about the Pease study?

**MS. AMICO:** This is Andrea. I have another question. I was just curious, did you folks notice a difference with the electronic signs at Pease? Did we see like a substantial increase after that? I think Kim may have asked that question through an email or whatnot but I'm just curious if folks thought that was effective and if that's something else that we should consider? I think it's something that has to be requested and things like that. But should we consider that as another tactic once we get back up and running?

**CDR MUTTER:** This is Jamie. I think that when Danielle responded to Kim's question again, I'm going by memory, so I apologize, I think she said it was minimal, a minimal increase in recruitment. And remember, we had a problem with the dashboard, so we weren't able to get a number for that week. My opinion,

though, is that is something that's an easy get. It's free. And, you know, we should maybe try at least one more time. But that's my thoughts on that.

**DR. BOVE:** You know, I agree with that. I agree with that.

**CDR MUTTER:** Because Danielle did say that some people had mentioned when they made calls that they did see the signs, electronic sign, and that's why they called, at least I think she said two or three.

**DR. BOVE:** Right. But what will be important -- This is Frank, again. It will be important for visibility once we again hit the ground running to have that if it is free and it doesn't take much effort. So it's probably worth doing.

**MS. LAUNI:** Right. And if it's visible in multiple places, then it brings more attention to the study that just being at one. I think, you know, it's going to be more of a marketing thing and have that, like Frank was saying, onslaught to everywhere they start seeing the Pease study.

**MR. LAZENBY:** This is Cliff. I haven't driven out there in a little bit now but are they still out there and if so, maybe we should take them in? I'm not sure whether --

**CDR MUTTER:** No. Cliff, this is Jamie. They were up for a week and they were taken in I think March 12th, I believe. So they haven't been out there for a while.

**MR. LAZENBY:** Okay. Okay, alright.

**MS. AMICO:** This is Andrea. I have another thought or question. Not far from Pease we have a big traffic circle that kind of leads to a couple major highways in the area. ATSDR folks, you may be familiar with it. It's like near where you guys stay, like the roundabout diner and stuff. There's like a bunch of billboards right there and I'm sure that's really expensive but I didn't know if that's another thing is to think about is it possible to try to rent space on a billboard to recruit for the study because I feel like that's kind of a high visibility area. A lot of people travel that traffic circle to get to the major highways. It's not very far from Pease. I don't know if that's another thing to consider and look into the cost if it's doable.

**CDR MUTTER:** So this is Jamie. Since Lori's not responding, she may be on mute. So we can definitely look into it and see what that cost would be and if it's feasible.

**MS. LAUNI:** I'm sorry. I was on mute.

**CDR MUTTER:** I figured.

**MS. LAUNI:** Yeah, you know, I think we should just, we should, you know, put everything on the table, find out, and you know, we need to find out of course costs do matter but right now, you know, if anybody has any idea, please, please share them. Let's put them down and we can look at cost afterwards if something is doable or not. But please, please just keep the ideas coming.

#### QUESTIONS FROM THE AUDIENCE

**CDR MUTTER:** Thanks, Lori. Any other comments, questions on the Pease study? Okay. Going once. Going twice. Alright, let's move on. The next thing on the agenda is the questions from the audience. Do we have any audience members that have questions or comments that they'd like to share with the group? Any audience questions or comments? Okay. So the next thing we have is a break on the agenda. I'm going to propose that we might skip that break for right now since we're only an hour in. Is that okay with everybody?

**UNSPECIFIED SPEAKER:** Yes, that's a good idea.

**CDR MUTTER:** Okay, let's move forward then. Great.

**UNSPECIFIED SPEAKER:** Yes, push it out.

#### MULTI-SITE STUDY UPDATE

**CDR MUTTER:** Great. So if we could have an update on the multi-site study.

[ Multiple Speakers ]

**MS. WEEMS:** Do you want to give it or do you want me to give it?

**DR. BOVE:** No, you give it. you give it. Go ahead.

**CDR MUTTER:** So Meghan, maybe you can introduce yourself to the CAP.

**MS. WEEMS:** Sure, I'd be glad to. I'm so sorry I didn't have anything prepared but I will do my best. My name is Meghan Weems. I am the project manager for the multi-site study. And an update, so we are still working with OMB, the Office of Management and, oh gosh, I might have that wrong, Management and Budget, to have the multi-site study protocol approved so that we can go ahead and get moving on getting the study started. We

are working with an federal interagency group to address questions and work through any kind of concerns they have about the study design and the protocol. So that's really what we're spending a lot of time working on right now. We continue to meet with all of the sites. This week we're having one-on-one calls with each site to see where they are in their preparations and answer any questions or concerns they may have. That, I think, is a pretty good overview of what we're working on right now. Please feel free to add anything if I have missed anything.

**CDR MUTTER:** Thanks, Meghan. Any questions from the CAP on the multi-site study for Meghan or Marian?

**MS. AMICO:** Hi. This is Andrea. I just am curious if you are expecting any delays with OMB given COVID-19 and are we expecting that this will delay approvals of protocols and things like that?

**DR. REH:** This is Chris Reh. We've not seen any COVID-19 type delays from OMB. They still are working through our stuff with us and with the multi-site protocol and the related information.

**MS. AMICO:** Thanks. This is Andrea. So do you have an idea or a ballpark of when you may receive word that this has been approved or it sounded like it's still in interagency review? So I think I recall from the Pease process that sometimes that can happen a couple times, it can kind of go back and forth. Is this your first interagency review? Are you a few reviews in? Do you have any idea of where you're at in the timeline of things?

**MS. WEEMS:** Sure. I can answer that. This is Meghan again. Yes, so this is the first round where we're really kind of digging in an answering questions and kind of going back and forth. You're absolutely right that this is very much an iterative process and it can take a bit of time and a whole lot of back and forth. Unfortunately, I don't have any kind of indication of when, you know, a timeframe for this. We just -- You know, we just want to make sure that this is done, done well and, you know, done with the least amount of disruption for everyone. So we just at this point are answering questions, we're getting workgroups together and we're just kind of chugging along hoping that, you know, all of our work, you know, they'll see all of our work and we'll get approved sooner rather than later.

**MS. AMICO:** Thank you. This is Andrea. I'm just curious if you could tell me which agencies are part of the interagency review, please.

**MS. WEEMS:** I'm not sure. Yeah, Chris may be best to answer this. I'm not sure I have a full list of who's involved.

**DR. PROTEZEL BERMAN:** Yeah, Chris, I'm happy to answer this. This is Pam. If you'd like me to.

**DR. REH:** Sure, go ahead.

**DR. PROTEZEL BERMAN:** Sure. Andrea, so the groups, the other agencies that we have been working with on PFAS activities all along are the same ones that we've been providing information to and that includes our colleagues in HHS, the National Institutes of Health, National Institutes of Environmental Health Sciences, the Food and Drug Administration, DOD, Department of Interior. There's just a lot of different groups that are interested in PFAS issues. And so those groups have been -- We've been sharing information with them as well. So does that answer your question?

**MS. AMICO:** Yes, thank you.

**CDR MUTTER:** Okay, any other questions for multi-site? Okay. Thanks, Meghan. So we're going to move right on to the health consult update. I don't know if Greg or Gary are on the call to want to give a quick update on that for the public and private health consultations.

#### **PEASE HEALTH CONSULTATIONS UPDATE**

**MR. ULIRSCH:** Yes, sure. This is Greg Ulirsch. I'm one of the coauthors of the two consults along with Gary Perlman. I think most of the CAP members, or all of them, should have received embargoed copy of the Pease Public Water Health Consult last week and then it was officially released on the 20th, which was Friday. If you haven't had a chance to look at that, we got approximately 76 comments from the community, from a contractor, and from various agencies and those are all addressed in an appendix to the health consult. In general, the main conclusions did not change. There were some caveats based on some really good comments that we got from some community members about uncertainty especially in relation to the AFFF and what its constituents are and those have been included in the document. Any questions on the public water consult before I move on to the private water one?

**MS. AMICO:** This is Andrea. Can you just briefly summarize what the conclusions were?

**MR. ULIRSCH:** Sure. Again, the conclusions did not change. The first conclusion what we did was we separated the exposure out into two timeframes. Basically it was the demarcation of that

was in May of 2014 when the Haven well was taken offline. So basically we said that before that point we believe that harmful effects or the risk of harmful effects are possible especially for the developmental and immune effects and especially to young children and also to some adults, and that was the primary conclusion for that. After that point, because of actions were taken, we looked at the levels that were found in the distribution system especially in relation to the two daycare centers. The levels were below our health comparison values and there were a couple other PFAS there without health comparison values but they were very low and low parts per trillion. And we did look at that and we felt like the risk of harmful effects was low for that time period. And then the third conclusion related to breast feeding and we did get some comments on that from the public comment period. We basically said, and this goes along with the recommendations from CDC and the American Academy of Pediatrics and others, that the risks of exposure to PFAS are probably less than what the benefits are of breast feeding or saying it the other way, the benefits of breast feeding probably outweigh the risks of PFAS and that we encourage mothers to continue to breastfeed; however, we do understand that there is concern about this topic and that each mother should have their own choice and consult with their physician and we were available to do that if a mother desired to do so. So those were the three main conclusions. Those were the same ones, Andrea, as what went out last year. Again, the only caveat to that is the fact that we did receive some really good comments from community members about uncertainty and those kind of things were added into the document.

**MS. AMICO:** Thank you very much.

**MR. ULIRSCH:** Oh, you're welcome. Thank you. So as far as the private water health consult is concerned, we're very close to getting that cleared and we have reached out to the two towns. As you know, the town of Newington is the most affected with I think 38 of the 40 wells that were contaminated with Greenland having two wells contaminated. We reached out to them. Given the current situation with COVID-19, I think at least for Newington's sake, they feel like we need to get this out as soon as possible. So we're going to be following up with them to try to figure out some strategies to see if we can get this out and maybe do some kind of a call similar to this with the towns, maybe then follow up at some point when the metaphor for "the smoke clears" and we can get out there and actually meet with individual private well owners to discuss their results and their individual wells and get their health concerns. So we're going to have to work with the two towns to figure out what's



the best approach given everything that's going on right now. And of course, when this does occur, the roll-out plan would be exactly the same as it was for both the public comment and the final version of the Pease Public Water Health Consultation and that is that all the stakeholders will know two weeks in advance that the document will be coming out and then you will get an embargoed copy two or three days in advance of that release to the general public. So that we'll follow the same approach. Hopefully, that worked out well for the Pease Public Water Consult and we will attempt to emulate that again for the private well consult. Any questions?

**CDR MUTTER:** Okay.

**MR. ULIRSCH:** Okay, thank you, Jamie.

**CDR MUTTER:** Andrea, did I see you have a question?

**MS. AMICO:** No, I'm all set. Thank you.

#### **EXPOSURE ASSESSMENT UPDATES**

**CDR MUTTER:** Okay, great. Wonderful. I thought I saw your picture pop up. So with that, thank you, Greg, again. Let's move on to exposure assessment update. I had to piecemeal this together because Brad Goodwin is deployed for COVID and so he gave me very brief updates from his deployment. So I have -- Chris or anybody on the phone, if y'all have any updates to this, please let me know. I have sample analysis is in progress for Massachusetts, West Virginia, Delaware, and Washington sites. Texas has already had their interim meeting. New York has had their interim meeting. And Chris, can you confirm if Alaska has had theirs? It was scheduled for March, so I was not sure.

**DR. REH:** Yes, so Alaska and El Paso County, Colorado were delayed because of the COVID situation.

**CDR MUTTER:** Great. Thank you. The other thing he said is that data collection in Texas is complete. ATSDR has paused further sample collection at this time due to the COVID response. Chris, do you have anything to add to that?

**DR. REH:** No, I think that just about covers it. We've -- In the towns that we've been able to start and complete data collection, for some we got more than expected participation and for others we got less than expected and we're now starting to get the data back, get the results from the serum and urine testing and look at those. And the next steps at some point, hopefully in the near future, will be communicating those

results to the members of the towns that were the first ones off the bat.

**CDR MUTTER:** Thank you. Are there any questions for Chris on the exposure assessments?

**MS. AMICO:** Hi. This is Andrea. I was just -- I'm sorry, I was typing and trying to keep notes. So which sites have completed the gathering of the data? I heard Massachusetts and West Virginia.

**CDR MUTTER:** Delaware and Washington and Texas have all completed sample collection. Is that correct, Chris?

**DR. REH:** I know the first four is correct. I believe Texas, Lovett, Texas is also finished but I would have to go back and check but I'm almost positive.

**CDR MUTTER:** Brad said that Texas has completed data collection.

**DR. REH:** Okay, great.

**MS. AMICO:** So this is Andrea again. So there's only two sites that haven't had data collected yet and are currently delayed because of COVID-19?

**CDR MUTTER:** Would that be three? New York, Alaska and Colorado, Chris?

**DR. REH:** So New York, we were halfway through the recruitment when we had to shut down and put them on a delay. And then El Paso County, Colorado and Fairbanks, Alaska have not started. They're on a delay too. We've not had the opening meetings at those like we normally do when we kick these off.

**MS. AMICO:** Okay, thank you. And then this is Andrea again. I have another question. How do you plan to release the results? So I assume -- Are you waiting to get all the data at all of the sites and then you're going to release the results or as you get them in at these individual communities? I know Massachusetts was first. So are you planning to send those results and host a meeting in that community or, you know, what's the timing of the releasing of this information?

**DR. REH:** Yes, so it's difficult right now to say the timing but we expect it fairly quickly. But we're not going to hold all the samples and release them all at once. We're going to do them in order that we kicked off. So the Westfield residents will get their results first followed by the West Virginia and on and on. And so the last batch of results will come from Fairbanks, which will be the last one to kick off when we resume operations. The

results will be released -- We'll start off by releasing results in giving people their personal information and that will basically be done by letters, personal letters to them. And then there will be a report for each site. And so for Westfield, there will be a Westfield site report. For Lovett, Texas, there will be a Lovett site report. And then of course there will be an aggregate report from all the data from all eight sites that at some point in the future we will release.

**MS. AMICO:** Thank you.

#### **ATSDR PFAS SUMMIT UPDATE**

**CDR MUTTER:** Okay. Are there any other questions on exposure assessment? Okay, next up on the agenda is the PFAS Summit update. I don't have any further updates. As far as I know, this is still on hold. Chris, do you have any updates?

**DR. REH:** So we're still looking at ways that we can do the summit, one of the things or do a summit-like meeting. We're looking at different options. One of the things that we feel may have a lot of value is if we join up the summit-type meeting with one of our PI meetings where we're bringing in the principal investigators from all the multi-site sites together. But the bottom line is it's not off our radar. It's going to evolve to something different and we're working on what that will look like as we speak. But we're thinking about some options and there'll be some point in the future where we will be able to communicate what are the options we're looking at and how we're going to proceed with this.

**CDR MUTTER:** Thank you for the update. Any questions?

**MS. AMICO:** This is Andrea. I'm just curious if you're still planning to include the community in the planning of these different options that you're weighing.

**DR. REH:** So at some point in the process, yes, we will be including the community. Right now we're just conceptualizing what the options are and then going through our leadership as to what is possible and what's not.

#### **CAP CONCERNS**

**CDR MUTTER:** Okay. Thank you. Any other questions about the PFAS Summit before I move on to CAP concerns? Okay, with that I'm just going to open up the floor to the CAP for any concerns or

anything else you'd like to bring up. Okay, I'm not hearing anything. So if you're talking, you may be on mute. Don't everyone talk at once. Okay. Any CAP concerns we want to go on and talk about before we close out the meeting? Am I on mute? Can someone say something?

**MS. SHAHEEN:** No. We can hear you.

**CDR MUTTER:** Okay, great.

**MS. SHAHEEN:** I can hear you. I've already expressed my concerns. I think any attention we can turn collectively to the media blast when we can resume the study will be important.

**CDR MUTTER:** Okay, great. I just wanted to make sure I was not talking to nobody. Alright, I've done that before.

**MS. AMICO:** This is Andrea. So I'm just curious. You know, are you planning to send us some talking points or some messaging points that we can give to the community now about where things stand? I think that was something you said you guys would be working on but I just want to be sure because I would like to post updates and things like that but I don't want to word things the wrong way or so I'm just curious if there's some things that you can share with us the way that you want things phrased.

**DR. REH:** Absolutely.

**CDR MUTTER:** Didn't you say you were working on that, Lori?

**MS. LAUNI:** Yes. I'm going to work on that and I'll work directly with the communication team and Chris and all of leadership. And hopefully we can get something out fairly quickly to you.

**MS. AMICO:** Thank you.

#### **WRAP UP/ADJOURN**

**CDR MUTTER:** Great. And once that's gotten to me, I'll make sure to pass it on to the CAP so y'all can post that on your websites and how you see fit. Okay, any other questions, concerns? Okay, I do want to remind everybody that this is Jamie that I am deployed for COVID-19. So if I don't respond right away, I apologize but I am checking my email periodically through the day and will get back to you. It just might be a little bit delayed. So thank you for your patience with that. So I'm going to give one last call out before we close out the call. Anything

else? Alright, guys, thank you for your time tonight. Appreciate it. Stay safe.

**UNSPECIFIED SPEAKER:** Thank you.

**UNSPECIFIED SPEAKER:** Thank you.

**UNSPECIFIED SPEAKER:** Thank you.

**UNSPECIFIED SPEAKER:** Thank you, everyone.

**UNSPECIFIED SPEAKER:** Goodnight.

**UNSPECIFIED SPEAKER:** Bye.

**UNSPECIFIED SPEAKER:** Bye-bye.