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convenes the

THIRTY-SIXTH MEETING

CAMP LEJEUNE COMMUNITY ASSISTANCE PANEL (CAP) MEETING

January 21, 2017

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TRANSCRIPT LEGEND

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P R O C E E D I N G S

(9:00 a.m.)

WELCOME, INTRODUCTIONS, ANNOUNCEMENTS

DR. BREYSSE: All right, good morning. I'd like to welcome everybody to the January 21st Camp Lejeune Community Assistance Panel meeting. This is a formal public meeting, so your comments are being transcribed and we're being taped, so remember, everything you say is now a public -- part of the public record. I'd also like you to speak clearly so that our transcriber can hear what you say and speak slowly if possible.

So a few housekeeping things. So there's microphones around the room. To speak with the microphone you push the button. When you're not speaking turn it off so we eliminate the feedback we might get from having one microphone pick up another microphone's signal.

The bathrooms are out in the hall on the right-hand side. You'll see we have a break scheduled at 10:30 so often we'll accommodate that. And I'd like to remind people to turn their cell phones off. And I'd also like to remind the public that this is an opportunity for the CAP to interact with ATSDR and other federal agencies. There will be an opportunity

later in the day for community members to express their concerns. We'd like you to hold those concerns until that time, if you could, please.

With that, I'd like to go around the room and begin by welcoming everybody. So my name is Patrick Breysse. I'm the Director of the National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry. So those are two different groups but they're related to one another. In this capacity I'm here as the head of the ATSDR. And we've been involved in Camp Lejeune for many years. And the camp -- Community Assistance Panel has been a vital contributor to work with you, and we get that input through this and other meetings.

So again, I'd like to welcome you all. I think we have a number of important things we'd like to talk about today. So with that short introduction I'd like to go around the room and ask people to introduce themselves for the record, starting with...

MS. MUTTER: Hi, I'm Commander Jamie Mutter with ATSDR.

MS. FORREST: Melissa Forrest, Department of Navy representative.

MR. GILLIG: I'm Rick Gillig, ATSDR.

DR. JOHNSON: Mark Johnson, ATSDR.

DR. BOVE: Frank Bove, ATSDR.

DR. CANTOR: Ken Cantor, a member of the CAP. I'm the technical expert and former National Cancer Institute person.

MR. WILKINS: Kevin Wilkins, CAP member.

MR. HODORE: Bernard Hodore, CAP member.

MR. TEMPLETON: Tim Templeton, CAP member.

MR. PARTAIN: Mike Partain, CAP member.

MR. ENSMINGER: Jerry Ensminger, CAP member.

MS. FRESHWATER: Lori Freshwater, CAP member.

MS. CORAZZA: Danielle Corazza, CAP member.

MR. ORRIS: Chris Orris, CAP member.

MR. FLOHR: Brad Flohr with the Department of Veterans Affairs Compensation Service.

DR. DINESMAN: Good morning. Dr. Alan Dinesman, medical officer with the Office of Disability and Medical Assessment with VHA.

DR. ERICKSON: Loren Erickson. I'm the chief consultant for health services, Veterans' Affairs.

MR. WHITE: And Brady White. I am the program manager for the family member program for Camp Lejeune. With the VA.

DR. BREYSSE: Fantastic. So the first item on the agenda is an update from the VA to provide us an update on their programs. So if I could turn it over

to the VA.

MR. PARTAIN: Actually, Dr. Breysse?

DR. BREYSSE: Yes.

MR. PARTAIN: If I may, there is a gentleman here, a former Marine, who has a medical condition and is going to have to leave, and he asked if we could have a minute to kind of pose a question or statement to the CAP. And I do understand that this is -- well, the CAP meeting, that there will be a public comment period at the end and the public meeting tonight, but unfortunately he's going to be unable to make it. Would that be possible?

DR. BREYSSE: So I think we can make an exception in this case, but I'd like to remind the rest of the public that if you can hold your comments 'til the end we'd appreciate it.

MR. PARTAIN: His name is William Retallic (ph). He is here. Do we have a microphone we can bring to him?

DR. BREYSSE: Actually you can go ahead and stay seated, sir.

MR. PARTAIN: If you'd introduce yourself for everybody.

MR. RETALLIC: Thank you very much. Is this on? My name is William Retallic. I was at Camp Lejeune,

1954-1955. I didn't become aware of any of this until 2016, and I've been avidly researching and trying to understand what's going on, because I have a lot of problems.

And I just came down here to ask one question. If our body is predominantly water, and I drink water from one of these bottles, and it permeates my entire system. Water goes to my brain, it goes to my lungs, it goes to my tissues, my nerves, bladder, everywhere. If I drank contaminated water, is it not reasonable to conclude that that water follows the same path and permeates our entire body? With that being the case, and you have identified liver cancer, bladder cancer and kidney cancer. And my concern and my question is what about prostate cancer? What about testicular cancer? What about penile cancer? What about any other malady, cancer, and the nervous system disorder that that water passed through on the way to excretion. And my concern is was any consideration given to that analogy?

And the other one is that DDT was commonly used at Camp Lejeune in hot, humid weather. In many evenings in the summers that I was here that was sprayed all over the place. So that's, that's all I have to say. I just could not understand why I have

all these other problems that are not on the list. I thank you for permitting me to speak.

DR. BREYSSE: Thank you for your comments, sir. And I'd like to just briefly try and address that. Recognize that your questions are, on the surface, seems simple but in reality are pretty complicated. But our goal at ATSDR is to identify -- you know, generate an evidence base that associates diseases with exposers at Camp Lejeune. And when we find that that evidence base is suggestive, or informs that relationship, we make that information known and we work closely with other agencies like the VA to see what that information means in terms of policy that they might develop.

So the, the evidence base that we've identified focuses on a range of conditions, and as new information comes available we'll gladly consider looking at a broader range of conditions. But right now the conditions that we think that there's strong evidence for, the conditions that we've already forwarded to the VA. But I can assure you in the future, as we learn more about these cancers and at other cancer sites, we will look very carefully at what that means, and advocate on behalf of the science that might affect the stakeholders like yourself. I

don't know if anybody else wants to add anything?

MR. PARTAIN: And Dr. Breysse, if I might add, one of the things that is currently ongoing with your agency is a groundbreaking cancer incidence study, which is using the National Cancer Registry -- or sorry, using the cancer registries across the states to help identify the occurrence of cancer among the Lejeune population. And once that study is completed, and we hope to be able to expand the list with the VA, and also hopefully in the future address the dependents and the civilian employees on the base as well.

MR. ENSMINGER: And everybody needs to understand -- this is Jerry Ensminger -- everybody needs to understand that science is not a quick thing. I mean, it moves at glacial speed, and that's just science in itself. And unfortunately in situations like Camp Lejeune not only is science slow, because that's the nature of it, you've also got people that are detractors from wanting science to find anything. And then it becomes a political football.

And believe me, I've been involved in this for 20 years. I've been kicked around quite a bit but I'm still here. You find it odd once you get involved in this thing that the United States Department of

Defense, who was created to protect us, has become strange bedfellows with people like the Halogenated Solvents Industry Alliance, for Christ's sake. So I mean, really strange. But that's the way it is, and all you got to do is just keep fighting. And I mean, I'll be fighting this. I'm under no illusions. I'll be fighting this until they run me through the crispy critter machine, so.

DR. BREYSSE: Thank you for starting us off with that prayer, Jerry. So again, I want to thank you for your service, and hopefully we'll do justice to your concerns as we generate as much data as we can in the future.

VA UPDATES

DR. BREYSSE: So with that I'd like to turn it over to the VA.

MR. FLOHR: Jamie, can you put up those slides?

DR. BREYSSE: I'd like to welcome CAP members, or tell those members, if you'd like to ask a question or comment, to lift your name tent up so we can call people in an orderly fashion.

MR. FLOHR: Okay. Good morning. It's very nice to see so many of you here today. I know it's an important issue for all of you, as it is for us. I think you may be aware, or at least I hope you are,

that on January 13th we published a final rule creating a presumption of service connection for eight diseases associated with the contaminated water. That rule has to be reviewed by Congress because it's over a hundred million dollars a year, and the Congressional Review Act requires Congress, or at least authorizes them, to review the regulation. In theory they could throw it back and say if this is too expensive. I doubt that's going to happen; I certainly would hope not. I've never seen that it has, but they do have that authority.

The eight diseases we published: leukemia, aplastic anemia, bladder cancer, kidney cancer, liver cancer, multiple myeloma, non-Hodgkin's lymphoma and Parkinson's disease. Although the rule was published on January 13th, it does take until the end of the Congressional Review Act review, 60 days, before it becomes effective.

Once it becomes effective then we will start working the claims that we have stayed. And since the Secretary announced his decision to create the presumptions, we have stayed over 1,430 or so claims for those eight diseases. Those are ones that we could not grant based on getting positive medical opinions in the individual case. So once the review

becomes -- or the reg becomes final and we can authorize benefits, we will start working those 1,400-plus claims right away. And then of course after that, any new claims we get we don't have to do anything except process them and work them, and grant them.

I wanted to give you the updated data you asked for through December. We've had over 18,000 unique veterans who have filed a claim. We have processed 18,016. We have 10,811 veterans who have active awards, not necessarily based on Camp Lejeune, but for something. They're getting compensation for something. The number of veterans receiving benefits are 60 percent of Camp Lejeune veterans are in receipt of some benefit, some compensation. 7,200 receiving benefits. Not receiving benefits, 40 percent. Active individual unemployed awards -- I don't know why we have this on here. That's not of interest to any of you, I don't think. But that's the veterans getting 100 percent, even though they are not rated a hundred percent, but because they have worked to their service-connected disability. Total completed claims, 23,958. Next slide, please.

These are for pension, nonservice-connected pension or service-connected dependency or indemnity

compensation awarded to subscribers. There is a count only of 960. Of these issue granted 117. Total active awards, 1080. Next slide.

It's hard to see this, isn't it? Big slide. The conditions are on the left side. Total claimed, total granted, percent of granted, total denied and the percent. You can see, if you can't see there, of the eight diseases we have creating presumption we have a fairly good grant rate of over 20 percent for each of those. What drags down the total numbers is the number of neural behavioral disorders. 2,747 have been claimed, and only about two percent of those have been granted. That is they have received a positive medical opinion enabling us to grant the claim. Overall the total primary disease categories, the 15 listed there, grant rate is 14 and a half percent. And miscellaneous conditions, again 37,000 miscellaneous conditions, only a two percent grant rate. And again, the end from last month or from the last meeting, I believe, on the number of those types of claims that we've received, and the top ten, and it contained migraine headaches, diabetes, hypertension, heart disease, things like that. Things that have not been associated, or at least that I'm aware of, with exposure to these contaminants. So those numbers

really drag down the overall rate, of the grant rate.

And I think that's the last slide. Thank you.

DR. BREYSSE: Would you like some questions now or --

MR. FLOHR: Sure, I'll take them.

DR. BREYSSE: Jerry?

MR. ENSMINGER: No, I'm waiting.

MR. TEMPLETON: I've got a couple questions. One, are we going to get a copy of that slide, with, with the data?

MR. FLOHR: Yeah, it's here.

MR. TEMPLETON: Okay, perfect.

MR. FLOHR: I sent this to...

MR. TEMPLETON: Perfect. And the other question on presumptives, is there some sort of a process or method for adding additional conditions down the road to, to the ones that are in presumptive?

MR. FLOHR: Of course. We can always add additional diseases to the list, once we receive evidence which -- showing there's some science to support it, we can add -- we can create a new presumption and add it to the list. Goes through the whole process, like this one, though, going through multiple levels of concurrence, going through OMB, going everywhere. Everybody's got to approve it

before it gets finalized. But if there is new evidence that we find that would support doing that, yes we would do that.

MR. TEMPLETON: Okay, thank you.

DR. ERICKSON: Brad, can I just -- can I just add --

AUDIENCE MEMBER: Excuse me. We're sitting back here, and we can't tell who's talking. Is there -- can you hold up a sign or something so we know who's talking?

DR. ERICKSON: I want to underscore something a little bit. This is Loren Erickson. I want to underscore something that Brad just said. Though the presumptions of these eight -- these categories is certainly historic, it was a long time in coming, and we feel that it's a major step, it's a good step, the book is not closed, okay? We will continue to work with our partners at ATSDR, with others in the community of medicine and science. We will continue to gather information as we can, as it becomes available.

The goal certainly is to refresh and update the list, okay. Not that anything comes off the list. I don't know that that would ever happen. But the idea is that science, and Jerry Ensminger's exactly right,

it moves at a glacial pace, which can be very frustrating, but it does move. And we do learn new things, and we're looking very much forward to these additional new studies, that Mike Partain just mentioned, from the ATSDR because we think those are going to further inform the policy changes that we can make in the future. So I just wanted to emphasize that. This, this rule that has now been published, that takes effect in the middle of March, is, is a starting point. It's a starting point only.

DR. BREYSSE: Lori.

MS. FRESHWATER: Thank you. I just wanted to say, you know, I've been a member of the CAP for a few years now. And this year -- I mean, this week was the fourth year since my mother passed away. And I just want to say thank you to the VA and to ATSDR because I do hope -- I know how hard this has been. I know how hard everyone has worked, and I think it's a cause for everyone to take a step back and really appreciate what was -- what kind of mountains moved here. And I hope the public understands that having this kind of justice is -- it took a lot for everybody. And I really just want to say thank you. And I hope everybody has had time to pat themselves on the back. And I know we have a lot of work to do, and we're not

going to slow down on that. But I just am very grateful to everyone, and I think my mother would've been too.

DR. BREYSSE: We'll do Jerry, Danielle, and then Mike.

MR. ENSMINGER: Brad, this is Jerry Ensminger. Brad, you started out your brief there with the health effects, and you said leukemias. Why did this final rule have the designation of adult leukemia? I have complained about this, and I see a possible confusion in the very near future, where some of your reviewers out there are going to say, oh, you have ALL. That's not a -- that's not an adult-type leukemia, and deny them. I made those comments during the comment period, and nobody addressed that. Why? Why, why the designation adult leukemia? One explanation I got from the VA was that: Well, they didn't want somebody who may have had leukemia as a child making a claim for that leukemia that they had previously. Give me a break. Anybody that had leukemia as a child is not going to get in the damn military, okay? They wouldn't be a veteran in the first place. So let's get adult off of there, okay? Because, if I'm correct, you're agreeing that this rule covers all types of leukemia, correct?

MR. FLOHR: That's correct, Jerry. The denominator adult came about through the concurrence process, when someone wanted to have it in there to ensure that it was for adults. I don't know why. It doesn't make sense to me either. But it is for leukemia that develops in veterans.

MR. ENSMINGER: Okay.

MR. FLOHR: Not in children.

MR. ENSMINGER: All right. We got that on the record.

MR. FLOHR: That's, that's where adult came from. Just I don't know, again, I'm not sure. It didn't make sense to me either.

MR. ENSMINGER: Now, got that out of the way. Scleroderma. The guidance Secretary McDonald gave to ATSDR, in the meeting last July with Senator Isakson, Senator Burr and Senator Tillis, was, when they asked ATSDR to assist the VA in putting together a list that would be covered by this presumption that he was going to propose, and he asked ATSDR to assist the VA in doing that. ATSDR issued a briefing paper which was posted officially. It was peer-reviewed, and Secretary McDonald's guidance was any health effect that had moderate or sufficient evidence for causation should be on that list. Scleroderma and end-stage

renal disease have the evidence. They've met the threshold. Why were they dropped?

DR. ERICKSON: In the three years that I've had with VA, I continue to be surprised at what I don't understand about civics, from my high school civics class. And what I share with you is more just realization that there are frequently many more cooks in the kitchen than I realized when it comes to getting something like this to a final rule that gets published.

Let me underscore that the ATSDR, as part of the Department of Health and Human Services, has played a unique and valuable role in providing us with the science, with generating their own studies, with contending with us on many of these scientific issues. And yet it's not ATSDR or DHHS's role to make presumptions. I'm building here; stay with me.

The agency known as Veterans' Affairs does have the authority to make proposals for new rules. In fact we drew upon the interactions we had with DHHS, ATSDR, quite heavily. In fact we had multiple meetings for several years, I now realize. And the issues on things like scleroderma were in fact discussed. You know, the science we -- I can't tell you how many times we talked to Frank Bove in

particular. I mean, it was -- I think we had lots of very good exchanges. And in fact we brought this forward in a way that it was initially packaged, and yet even we were not the final arbiters in this regard. The Office of Management and Budget had scientists as well, and has folks who were involved with reviewing proposed rules. And the three of us, ATSDR, VA and OMB also had discussions about what should be in the list that gets published in the final rule and where the line would be drawn. And I will not satisfy you or anyone in this room that the line was perfectly drawn, okay? I just -- I will tell you that the discussions were that -- came to the point where we certainly agreed on the eight that were published. We feel very good about that, and we went -- we went from zero to the Secretary talking about three to finally publishing eight. And those eight disease categories were not narrow, little categories. They were in many cases very broad categories. When it says the word leukemias, ALL, AML, CLL, CML, I mean, all these leukemias. So eight very broad categories, going from zero to eight for a comparison-based exposure is truly historic.

Again, the book is not shut but in order to have the rule published, when it was published, based upon

changes that were about to occur in Washington, D.C., we had to go with what we had. And again, the book is not shut. Minds are not closed. There will be additional opportunities to revisit some of these things, in particular areas that were not in the list of eight, but this was not totally under the control of ATSDR, and this was not totally under the control of Veterans' Affairs. And that's all I can tell you.

MR. ENSMINGER: Well, you just said a whole lot but it was a whole lot of dodging. I mean, what you just said you make it sound like ATSDR used all of their studies and all of their internal information to come up with this list. No, they didn't. Nobody does that. You know that. The National Academy of Science doesn't do that. They use studies that have been done by people all over the world, and the studies that they used to make that list were studies from all over the world. And those studies showed at least moderate evidence for causation for those two health effects. And I asked why they got dropped. And now I'll ask you, who dropped them? I want to know. The public has a right to know who dropped these things off there.

MR. FLOHR: Hey, Jerry, Brad. I don't believe end-stage renal disease was ever on the list, so it

wasn't dropped. It wasn't added; it wasn't dropped. Wasn't part of it.

MR. ENSMINGER: It's in the report.

MR. FLOHR: Not -- it was not --

MR. ENSMINGER: It's in that 69-page briefing document that was published.

MR. FLOHR: That's a briefing document. It was never in our regulation.

MR. ENSMINGER: I know that. That's what we've been -- that was what the VA Secretary asked for, was their recommendations for health effects to be included, and they submitted that, that briefing document.

MR. FLOHR: I know what he asked for. I was in that room with Senators Burr and Tillis and Isakson along with Pat. And they did a lot of work, and we worked with them in putting this all together. And when it came right down to it, it was looking at the science and what was more likely than not sufficient to propose a presumption. For example, bladder cancer originally wasn't on the list.

MR. ENSMINGER: Yeah, I know.

MR. FLOHR: And we added it subsequently to that. That's the way this has worked out. Some things will be added, some science, when looking at it more

closely, may not show that it's sufficient at this time. Doesn't mean it won't be in the future. In other words, we've got another really good study on scleroderma that was very supportive; we can always add it. But at this point we just, just couldn't.

DR. ERICKSON: One of the requirements that OMB had was that those studies, those manuscripts that would be considered in justifying the final rule hadn't been published. And the question is when was that document published by ATSDR?

MR. ENSMINGER: Well.

DR. ERICKSON: Okay, you mentioned the six --

MR. ENSMINGER: The briefing document?

DR. ERICKSON: No, the six -- the 60-page document that you said ATSDR, when was it published?

MR. ENSMINGER: Well, it was given to VA last September.

DR. ERICKSON: Okay, it was not published until a week ago.

MR. ENSMINGER: Yeah, it was published this past week.

DR. ERICKSON: Okay, again, OMB's requirement was that they would only look at published materials. Now, that's not to say that it didn't influence VA, but in terms of influencing OMB, it had not been

published at the time OMB was the gatekeeper.

MR. PARTAIN: No, not about the 2015 IOM report that was given to y'all, where kidney disease, there was language in there that said that the veterans should be given recommended -- the recommendation was made that veterans should be given the benefit of the doubt. That was a report that you guys commissioned, and received back, and that was published.

DR. ERICKSON: Okay, so this particular report, commissioned by VA for the Institute of Medicine, now called the National Academy of Medicine, was for them to review our clinical guidelines which describe how in fact we would view the execution of the 2012 Camp Lejeune law. So this was not related in any way directly, underscore the word directly, to the writing of presumptions.

MR. PARTAIN: And, you know, I cannot speak for ATSDR, and I don't mean to intercede on Jerry's behalf here, but this report that ATSDR has now published was given to you guys in the spirit of trying to cooperate to get this done, and it just seems like the job keeps shifting and the criteria changes. I've never heard of this requirement that it has to be published. Maybe that should've been informed to the CAP so we could ask Congress to put some pressure on ATSDR to

publish this list, 'cause we were asking for it.

MR. ENSMINGER: Well, it wasn't the ATSDR.

MR. PARTAIN: I understand that. But I'm just making the point that it just seems like the criteria is shifting here, Dr. Erickson. And you know, this document was created by ATSDR and reviewed studies and everything to assist you guys in developing the presumption list. And you know, kidney disease is listed on page 100 of the document. And, you know, there is -- you know, there is evidence for that, and in corroborating with the IOM report, and yet kidney disease was left off the presumption list.

DR. BREYSSE: So if I can jump in. So we at ATSDR support the VA in their movement to provide compensation for these eight conditions. We also have agreed to support the VA in the future by providing evidence as new studies emerge to help them inform any future decisions about compensation. And we will be revisiting these conditions in the future, as we think the evidence changes or if there's anything stronger that we can put on. But I'd like to make sure we move on, through fairness, to Danielle who's had her tent up for a while.

MS. CORAZZA: I'm going back to the numbers that you showed. I just had a question. The 1,430 claims

that are stayed, they are all one of these eight conditions?

MR. FLOHR: Yes.

MS. CORAZZA: Okay. And then the 4,749 claims that are pending, that's just a hodgepodge or that's also the eight --

MR. FLOHR: Hodgepodge.

MS. CORAZZA: Okay. So if it's there and assuming everything goes well in March, is there a goal for getting the 1,400 pushed through?

MR. FLOHR: It will be done immediately. They will start processing those claims right away.

MS. CORAZZA: Okay, thanks.

DR. BREYSSE: So were there other presentations you guys had hoped to make, or as we move the discussion forward I want to make sure we get everything covered in the time we have allotted.

DR. ERICKSON: Brady White has some update on the Camp Lejeune family member program, with some new numbers that we'd like to show the CAP.

DR. BREYSSE: Okay. So should we move on to that, and then we'll carry on?

MR. PARTAIN: Dr. Breysse, I do have another thing. I didn't get my question.

MR. ENSMINGER: I find it strange that we have an

agency here that was created and mandated by Congress to investigate human exposures, and study them, at Superfund sites, who gives basically not medical advice but exposure -- their professional exposure. And basically what you're saying is that anybody up the chain can just take that and say, well, yeah or no. Doesn't sound right to me. That's why people get angry at government.

DR. BREYSSE: Mike.

MR. PARTAIN: Yeah, my question, there were diseases that were left off the list, and, you know, diseases that we are seeing. And I do understand that science does have to progress. You know, at some point in time, you know, the CAP, which we're the community representatives for Camp Lejeune, for ATSDR, but there's going to be a time that we're not going to be here to voice opinions to, you know, to challenge what the VA has said. And I've noticed that there's --

MR. ENSMINGER: Or OMB.

MR. PARTAIN: -- or OMB, or whoever, you know, says something. Cancers such as male breast cancer, prostate cancer, esophageal cancer, you know, these are things that we are seeing at Camp Lejeune. I mean, like I mentioned before many times in the past,

we had the single largest male breast cancer cluster that's ever been identified, at 105 men. We have a study from ATSDR showing a suggestion that there is a possible early-onset of male breast cancer due to the exposure at Camp Lejeune.

My question to the VA is, you know -- and also too we have the public health assessment, the revised public health assessment, which now shows, from ATSDR, that there was indeed a hazard to expose -- exposure to contaminated water at Camp Lejeune. My question to the VA though is how are we going to address those cancers who, like for example, male breast cancer, renal, esophageal cancer, adrenal cancer, rare cancers that there are associations to the solvent exposure, but there's really not enough people who have come down with the disease to do studies or there's just not enough studies done, as in the case with male breast cancer. There's just a few studies that have been done on it. How does the VA propose to address that? Are you guys going to leave the SME process that you implemented in beginning of January 2013 in place? And what involvement is the public going to have now? I mean, is there going to be any type of dialogue to the community, so we can address these in the future? I mean, what's the plan?

DR. ERICKSON: You know, the plan is I tried to say -- and just -- I want to make sure everyone understands this. So this is an ongoing process. The partnership with ATSDR is ongoing. And just for everyone's sake, it doesn't only involve Camp Lejeune. It involves other exposures at other locations and other populations. This is a growing area of collaboration for us. And again, we value that relationship.

I think as it relates to the science, I think my colleague Frank Bove spoke to this at an earlier meeting. This, this question of how, how do you deal with the really rare diseases? You know, what would be those study designs? I mean, there are case control studies. There are a few different methods that can be used. But Mike, you'd be making an excellent point, that those particular diseases can be more difficult to study. There can be techniques, the use of particular statistical methods that will allow you to look at rare events, et cetera, but it's going to take an ongoing effort, ongoing effort as DoD works with ATSDR to complete the current studies, maybe to do additional studies. It'll take an ongoing effort as we work with ATSDR to see what else is being published.

Part of that collaboration and part of, I think, the challenge for us -- and when I say us, I'm talking about the team that is in this room, the public, ATSDR, VA, DoD -- is to identify what are those remaining gaps? What are those areas that we want answers for and how, how -- if we have to prioritize those within certain constraints, in that we can't study everything all at once with unlimited resources. But I think one thing the CAP has been particularly, you know, productive in helping us with is to focus a lot of efforts. I can't speak for ATSDR, but I'm guessing that you guys would say amen to that. Certainly the CAP has helped us.

I will tell you that the presence of four members of Veterans' Affairs here at this meeting is evidence of a commitment that we made to the Community Assistance Panel. We're not summoned to come here. We don't have an obligation to come here. We come here as invited guests. But we are invited to be a part of that team to find those solutions. And again, it's frustrating that things don't happen as quickly. It's frustrating to individual veterans and family members when perhaps their particular health issue has not been addressed with -- addressed as quickly as was hoped, but I can tell you that, you know -- as a

reminder, I'm a veteran myself. I served 32 years of active duty, went to war multiple times. I myself grew up in base housing at a number of military bases. My own children grew up in base housing. Now, not at Camp Lejeune because I was Army. But I get the outrage, okay? I understand the deep emotional concerns that are going with this. And yet it's our task to work through the science in a comprehensive way so that those rules that are made, those -- all of the decisions that are made are truly evidence-based, okay, are truly supported.

And again, to work with ATSDR is a privilege. It's an opportunity for us to pull upon the best and brightest who work in environmental health. And yet to realize that it's a broader team than just ATSDR and VA. It's a number of us that are involved.

DR. BREYSSE: We need to move along, but Jerry.

MR. ENSMINGER: Yeah. Yeah, I don't mind you guys coming up with something like a subject matter expert program, but for God's sake, if you're going to call them subject matter experts hire subject matter experts, because the evidence that we've got, these people are anything but subject matter experts, the lion's share of them. Hardly any of them are trained in environmental exposures. They didn't even major in

that, and they're not certified for that. Most of them are family practitioners. And when you've got people that say that they have reviewed all the meta-analysis for two decades' worth of well-conducted scientific studies and can find no evidence that TCE causes any kind of cancer, let alone kidney cancer, and denies two kidney cancer claims, with that rhetoric in it -- he didn't deny them, but that was his opinion, and the SME was never overruled by any claim reviewer I've seen. And that was in 2015. TCE was re-evaluated to be a known human carcinogen in 2011 and '12, by IARC and the EPA. And the strongest evidence for reclassifying it as a known human carcinogen was for renal cell carcinoma. Kidney cancer, for God's sake.

DR. ERICKSON: So Brad, you may want to respond to this as well. Again, we went from zero presumptions to three, that the Secretary mentioned, to eight that were published.

[Multiple speakers]

DR. ERICKSON: I'm getting there. I'm getting there. So the fact is this is historic. And this is the point I want to come to, Brad. The fact that we now have eight disease categories that are service -- that are presumed for service connection, actually

changes the pathway for those claims, as it relates to SMEs.

MR. FLOHR: Yeah, I wanted to respond to what Mike mentioned as well, but briefly, let me give you what is takes for service connection, for someone to be determined to be service-connected. There's three things, basically. One, there has to be evidence of a disability. Two, there has to be evidence of something in service: an injury, a disease, or in this type of situation, an exposure. And then the third element, which is the most difficult, is getting a medical nexus, or a link, from the medical profession between what the current disease is and what occurred in service.

We have a number of presumptions. We have 21 cancers presumed for radiation exposed veterans, atomic veterans, who were at the nuclear tests and places like that. We have presumptions for prisoners of war. We have presumptions for mustard gas. We have presumptions for Gulf War. We have lots of presumptions. What the presumption does, basically, is eliminates that last requirement, the third requirement, of having to provide medical link. That's what Camp Lejeune nexus does as well. It removes the requirement that there be positive

evidence of an association medically. It's presumed that it is. And as Loren said, we'll look at any -- all and any new studies, and if it looks like there's good evidence to support adding to the list, we do so. That's what we want to do.

MR. ENSMINGER: Yeah, but we've got veterans who are submitting doctors -- from their oncologist to the VA in support of their claims, and the subject matter experts are overruling them, and the guy has his -- is certified as a family practitioner.

MR. PARTAIN: Not only are they overruling them, they're actually challenging and writing these doctors to have them explain why they wrote their letter in the first place.

DR. BREYSSE: If I can jump in, so this is -- obviously this is an issue we've reviewed at, I think, every CAP meeting since I've been associated with it. So this -- it's obvious there's ongoing concern about the appropriateness of the subject matter expert review that you're hearing from the CAP. And it certainly is in everybody's interest to make sure that the subject matter experts utilize the best scientific evidence in making their decisions. And a decision that's based on a conclusion that there's no evidence of cancer from some of these chemicals is probably not

the best scientific available information. So I don't think we're going to get this any further today, but I think what you hear is there's still ongoing concern about that process. And I assume that process now is going to apply to diseases that fall outside of the presumption of service based on the rule. So I think that's --

MR. FLOHR: And you're right. That's --

DR. BREYSSE: That concern you hear from the CAP is going to persist, and, you know --

MR. FLOHR: What I can also say is that this whole process came about when we first briefed the Shinseki study on Camp Lejeune. We decided this was such a topic that it needed to have one office do claims processing. Louisville was selected. And after they started working claims, a group of people from VA went there to review the decisions that have been made, and they found what they felt were inconsistencies in one case versus another, when the evidence was pretty much the same. And that's when they created the subject matter expert. Is it the best? Who knows? Again, Secretary Shinseki’s plan, when we brief the new Secretary on Camp Lejeune, and I assume we will at some point, and he may decide we need to do something else. So we'll see what happens

there.

MR. ENSMINGER: It's like I said when I started. I don't have a problem with you having a subject matter expert but I don't want Ernest T. Bass being an expert.

DR. BREYSSE: Okay, Lori?

MR. FLOHR: I will review that.

MR. PARTAIN: So safe to say that the SME process is going to remain for non-presumptive service-connection patients?

MR. FLOHR: Right, for the time being anyway.

DR. BREYSSE: I'm turning to Lori now.

MS. FRESHWATER: So my concerns all along are with transparency with the SME program. You know, 'cause we've been doing this a while. So for those conditions that fall outside of the presumptions, with the SME program have there been any changes, improvements to transparency? Are we going to be able to have any access to who is making the decisions and the SMEs? 'Cause I really believe that that would be the kind of key to all of this, is just so people could know who is making these decisions, and if we could -- you know.

DR. ERICKSON: Yeah. So I'm going to make an introduction here. This is Dr. Alan Dinesman, and he

was with us at the last meeting. Yes, I thought you were. And he, he works, and he helped set up the office that does disability medical assessment. And just to make it clear for everybody that's here, with the presumptions taking effect the middle of March, a Camp Lejeune veteran who qualifies, according to the way the rule is written, for one of those eight diseases, are essentially fast-tracked through that claims process, okay. In other words, if the SME process is not sufficiently transparent, is not sufficiently accurate, whatever the concern is, at least for these eight broad categories, you know, that, that is not an issue. The SME issue is not for these now. The presumption actually makes it easier for the claims.

But as it relates to your concerns about transparency, we were going to save this for the due-out portion, but as is oftentimes the case, we sort of meld the VA update and the due-outs, and so Dr. Dinesman came prepared to talk about that, so it sounds like we probably need to move to that right now. And then we'll have Brady White talk about the family member program.

MS. FRESHWATER: Talk to Dr. Breysse.

DR. BREYSSE: Would that be your preference, to

do it now or would you rather wait?

DR. ERICKSON: Well, I mean, the -- you know, the griddle's hot, I mean.

DR. DINESMAN: There is a slide set. Do you have that? I'll go ahead and just speak to it. But there was a question about the SME training program. Understand first that all of the clinicians who are in the SME training program are C&P-certified. What that means is that they have been trained to look at disability cases, to work through the various aspects of reviewing literature and how to address the, I guess, medical/legal aspects of what we see with VA disability claims. So they are used to giving medical opinions. That's a general duty of all of the SMEs that we have, whether they be Camp Lejeune SMEs or just a compensation and pension examiners themselves.

We do have formal training sessions. Our last formal training session was in July. It takes place generally at Louisville, in conjunction with the regional office there. We have -- the last one in July was a four-day process where the first part of it was didactic training. And it was -- the didactic training is general principles.

You know, Camp Lejeune is an important topic but the environmental exposures themselves, as the general

topic, is what is discussed, you know, how to look at environmental exposures. We discuss things such as, you know, dosage, exposure time and how to go ahead and review some of the literature that's available. We go through kind of superficially some of the literature. We ask that the SMEs actually read through it on their own time, but we do go through some of the studies, just to kind of give some background. Again, these are individuals that are used to giving opinions, that are used to reviewing medical literature, and so we're not there to train somebody, and say, well, here is how you answer something. But just like any other expert opinion, here are the tools, and we'll provide them those tools that they can use to get started on it.

And then the last part of the training is actually hands-on experience. We do work together and review some cases, get a chance to discuss them and look over the cases as a group, and to kind of discuss the different thought processes.

MR. ENSMINGER: Well, and I got a question for you. Rather than calling these people subject matter experts -- when you tell me that you're having the whole training sessions while these people have been anointed as so-called subject matter experts, if

you're training them, they're not subject matter experts in anything. You know, he --

MS. FRESHWATER: Jerry, can I -- I don't want my question to get lost. Can we just go back to the transparency issue? Can you directly address how --

MR. ENSMINGER: What the hell?

MS. FRESHWATER: -- any changes you've made about transparency? Because I didn't hear any of that.

DR. DINESMAN: What do you mean by transparency? What are you looking for?

MS. FRESHWATER: Well, people should have a right to know who the --

MR. ENSMINGER: Who these guys are.

MS. FRESHWATER: -- subject matter expert is. People should have a right to know what went into these decisions. We've had a lot of trouble not being able to even get FOIA requests because of -- you know, I'm not going to be getting into all of that, but so are there any plans on trying to be more transparent about SMEs and who's making these decisions? I understand we can move all of the training issues and all of that to the due-outs, if you want, but I would like that direct answer about transparency, and why, if you are not going to let people know who the SME is, what is your justification for that?

MR. PARTAIN: And to tag onto Lori, and the whole issue of transparency, and I appreciate you trying to put the SME issue into a nutshell and describe what it is, but it's dressing on a cake that's not quite right. We've had to file a FOIA lawsuit with Yale Law School to get information about the SME program, and we're starting to get the documents from that and go through them. There are templates for SMEs to follow that -- for particular conditions. There are things that we're seeing in there, like one of those slides discusses how the purpose of the program is to create a legally defensible claim. And this is stuff that's not new to you guys. We've talked about it at other CAP meetings and what have you.

The problem remains, like Lori is saying, the heart of the issue is there is no transparency. It's forced transparency. And I'm a graduate student at the University of Central Florida, working on my master's thesis. If I was to go to Wikipedia and cut and paste a Wikipedia entry into something that I wrote for the university, I would be expelled from the program and humiliated, and probably never ever be able to try to seek a master's degree again, yet we have an SME who did that for a veteran in Atlanta. We have SMEs with conflict of interests. We don't see --

we don't know who they are in the files. And this is all, like I said, been addressed in the past. And rather than go through and gloss over the program, what it's doing, what have you, let's cut to the chase and get the answers, 'cause we've got a lot to talk about today, you know, and we're burning some time here.

DR. BREYSSE: Response to Lori?

DR. DINESMAN: Yeah, as far as the reports, the SME's name is on the report, and that is really, as far as what is supposed to be reported, is, you know, what we're able to do.

MS. FRESHWATER: Is that all of the claims? Because I had seen claims where the SME's name was not included.

MR. ENSMINGER: Yeah, that's true.

MS. FRESHWATER: I mean, I've seen that myself.

DR. DINESMAN: Yeah, I'd be happy to look at some individual cases with you.

MS. FRESHWATER: Will you make the commitment that, going forward, all SMEs' names will be on all denials?

DR. DINESMAN: The SME name should be on every single report. I've looked at -- you cannot --

MS. FRESHWATER: So I just -- I'm sorry, I just

really -- like --

DR. DINESMAN: No, please.

MS. FRESHWATER: -- I don't agree with –- really, you know.

MR. PARTAIN: Maybe it's on the report, but is it getting into the veteran's files so the veteran can see this SME report?

MS. FRESHWATER: No. What I want to know is, if you are making a commitment that every veteran who has a claim denied, will they be able to absolutely know the name of the SME who worked on their claim?

DR. DINESMAN: So the only way I can answer that -- I mean, it should be. When the SME does their opinion, they sign the form. The form has their name on it. Now, what happens after they sign that form, electronically in the records, as far as I know, it's, at least all the reports I've looked at, that I've done through the years, as a compensation of pension --

MR. FLOHR: It returns to Louisville, who requested the opinion. And then it goes in the veteran's claims file. It's available electronically, now that all our claims are electronic.

MS. FRESHWATER: So people who have been denied, and who would they go to in order to find out the name

of their SME now? If they've been denied and it doesn't -- it does not include the name, who should they go to in order --

MR. FLOHR: Most likely the medical opinion would not be sent to the claimant with the denial letter. So they would have to just -- they could ask, you know, for a copy of the opinion from Louisville.

MS. FRESHWATER: Okay, so, so going forward, everyone who -- in the past who has been denied and everyone in the future who is denied has that basic right to know -- because that's what I'm talking about --

MR. FLOHR: Absolutely, yes.

MS. FRESHWATER: -- with transparency.

MR. FLOHR: Of course.

MS. FRESHWATER: Because then, that person can say, well, my oncologist has this experience, put up against this SME when they appeal, right?

MR. FLOHR: Well, the oncologist, hopefully that report was submitted with the claim and not at a later date, but they can always submit new evidence, if they have a new oncology report. Always that reopens a claim with new evidence.

MS. FRESHWATER: But it's hard. It's hard for a veteran because most often they don't have money to

hire their own subject matter expert --

MR. FLOHR: I understand.

MS. FRESHWATER: -- as we've discussed over and over, so if they at least know who it is that -- you know. And just as a matter of principle, I think that anyone who is having a life or death decision made, oftentimes it's life or death, I think that person should absolutely be able to know who's making those decisions. And I think that would cut out a lot of friction between the community and the veterans and the VA, and, you know, it's always better to be open. And I think it would be helpful going forward. So thank you very much.

DR. BREYSSE: It sounds like a commitment to make that happen.

DR. DINESMAN: It is. And if I could also make just one comment on the specialty issue that is described in here. You'll say that so and so may have a report from an oncologist that says that there is an association. As a word of advice on these, for moving forward on some of these, a person's credentials do not always mean that they're able to provide an opinion that is well-supported. And so it's important that, if -- let's say this oncologist is talking about, saying, well, I believe this person's cancer is

due to, you know, an exposure, they need to be able to put down the scientific justification for that.

MS. FRESHWATER: Correct.

DR. DINESMAN: So just because --

MS. FRESHWATER: I'm just asking for a little transparency, right? You know? I mean, I'm not -- I don't think that there's going to -- I don't think we all have time to get into whether or not, you know, the oncologist has this or not, you know. We have two meetings later in the day, that I think will be allotted time for that kind of thing. But what I want is a level playing field. I want transparency so that they know who it is making these decisions. I'm a journalist. I want to be able to look into this person as far as their qualifications. I don't want to have to -- well, I mean, if you hide something, and I'm not making accusations, saying you're hiding anything, but if that's the way it feels, then people are going to, then, make an assumption, they're going to have a feeling that something not good is going on, right? Where if there's transparency, people tend to be able to say, okay, well, at least we know what we're dealing with here, and we can go forward on an appeal or what have you.

DR. DINESMAN: Makes sense.

DR. BREYSSE: Thank you, Alan. Maybe we should move on to Brady, make sure we have time to get that.

MR. WHITE: My name is Brady White, and I'm the program manager for the family member side of the law. I actually don't have slides. The CAP is familiar with most of the slides. I do have them available. We're going to be going over them in the meeting tonight, okay.

First I want to thank the veterans and their family members that are out in the audience. Thanks for being here. I know you're going to get a chance to ask questions later on, but as you know, tonight we're going to have more of a public town hall meeting. And at that meeting we're going to have somebody from the health eligibility center, who's going to be able to answer any specific veteran questions you may have. I'm also going to have somebody that we can contact for any family members, that has a question about their application or their claim, okay? So keep that in mind. So as everybody knows, we cover the health benefits for family members for treatment of one of these 15 conditions.

Just real quickly, for veterans to qualify for VA healthcare, they do not have to have one of the 15 conditions, nor do they need to have a service-

connected condition in order to qualify for health benefits. Okay, so that's very important to keep in mind.

On the family member side, there's basically two big buckets we need to verify. We need to make sure that the family member was a dependent of the veteran and that they resided at Camp Lejeune for 30 or more days during that covered time period. Okay, that's what makes them administratively eligible for the program.

Just want to highlight some new numbers for you guys. As of December 31 of last year we've provided healthcare to 39,123 veterans. 2,749 of those were treated specifically for one of the 15 conditions. And we treated 249 of those veterans for just the last fiscal year. And we've gotten some specifics for how they break out as far as those 15 conditions, and we can see those later on tonight.

For the family members, we've provided reimbursement for care. Remember, we provide the payment of benefits after all other health insurance, okay? So we, out of all the veteran -- or the family members that applied and got accepted, 243 of those are actively using the program, that we're providing benefits for. I've got 1,731 that actually applied

for the program, and 511 were deemed ineligible, and primarily because we couldn't show the resident at Camp Lejeune, we couldn't prove a dependent relationship or the veteran criteria didn't match.

So that's kind of highlights. We'll be going over some more later on this evening. At this point does anybody have any questions about the family member side of the program?

DR. BREYSSE: Thank you, Brady. I just want to remind everybody, so there will be a couple of opportunities tonight that you should take advantage. One there will be an open availability session where you can interact with the VA or ATSDR people one-on-one. And then there'll also be the public meeting, where you can explore any of these issues in a more question-and-answer format as well. So the whole day is designed to make sure that you guys have as much opportunity to get your questions answered and your service opportunities explored as possible. With that I'll come to the questions from the panel? I notice, Chris, you have your sign up?

MR. ORRIS: Yes. Thank you, Dr. Breysse. Brady, good morning. Thank you for being here today. You know I have several questions. One of those being I'm looking at ATSDR's list of conditions that they issued

strong evidence for causation, and in going through all of that every single one of those conditions is now a presumptive, or will be soon, at the VA, except for one. Now, I know a veteran cannot be born with a congenital heart defect, but ATSDR, it's pretty much established science, that congenital heart defects were caused by exposure to the water at the base. However, no single child that was born with a congenital heart defect at the base is eligible for the family member program. Of all that science, explain to me why.

DR. ERICKSON: Yeah, Chris, thanks for your question. Thank you for being such a strong advocate for, for the families in this regard. Chris and I were speaking a little bit earlier, and so I'm very glad that you had a chance to ask your question in public.

Allow me to speak broadly and then focus down directly on your question here. Veterans of all cohorts are concerned about the effects on their families. These intergenerational and multi-generational effects, or effects that would've occurred directly to family members. And to that end Veterans' Affairs is working very hard right now with other federal agencies, with the national academies,

to try and develop a roadmap, a research framework, which will allow us to more effectively look at those issues.

I will tell you that the Veterans' Affairs has entered into two new contracts with the national academies, one for the next Agent Orange study, which will have a major chapter on multigenerational effects; also the next goal for a health study is in fact almost nearly entirely dedicated to multi-generational effects.

And you say, well, what does this have to do with this, this issue right here? And the connection is that the science, the laboratory science, the new technologies, et cetera, are mentioned quite a bit. Most of us will hear words like epigenetics and talking about DNA, et cetera, and yet it's not always clear exactly what is the application and how do you trace what would be an effect on a developing child, whether it be direct exposure in utero, while the mother's pregnant, or an effect that would occur that would be handed down in the genes.

And in fact the national academies is going to give us what we've asked for, we hope, within two years. So that would be the framework, a research framework, a roadmap, which will enable us to

designate which part of the federal government, I suspect it will be the National Institutes of Health, will actually have the lead for nailing this down, because they of course do genetics work, et cetera. But what would those studies look like? How long would they take? What technologies would they apply? And so that's one thing. So I want you to know VA, we're on the case, we're working the issues broadly 'cause that's a big issue for all the veteran cohorts.

Now, specifically for Camp Lejeune and for Camp Lejeune family members, the current authorities given to the Secretary of Veterans' Affairs are limited to veterans. The current authorities are limited to veterans unless Congress provides some other additional authority. So Brady was just talking about one authority under the 2012 law that allows Veterans' Affairs to be in essence an insurance company for family members at Camp Lejeune, okay, a last payer. A very circumscribed, narrow authority that was given to the Secretary.

Another very narrow authority that relates to descendants of family members is the spina bifida program for Agent Orange. But that is, that is the limit. Those are the only small areas that the Secretary can currently work in legally, that he's

authorized to work in legally. So the solution to broadening the aperture on the 2012 law, to include things such as congenital heart defects for children who had been at Camp Lejeune, the solution set is to be found with the legislative branch, because, again, the Secretary doesn't have that authority. Do we have in the audience any Congressional staffers for any members of Congress? Is there anyone here representing? So I know at some of the meetings we can sometimes get people.

MR. ORRIS: I personally invited Walter Jones.

DR. ERICKSON: Okay.

MR. ORRIS: Who is a Congressman from this district, but he's not here.

DR. ERICKSON: Okay. But that's one of the solutions. I will tell you that in another week I and some others will be meeting with some Congressional staffers, to talk about multi-generational effects. And one particular area is, and I'm really surprised it didn't come up in the questions yet, so I'll throw it out, is dealing with the disconnect between the 15 conditions that are in the 2012 law, that include the family members, and now the list of eight that are in the presumptions. Okay, there are some overlap, there's some difference. Veterans' Affairs is not in

a position to rectify the disconnect because, again, our Secretary does not have the authority to change what are the benefits for the family members, but Congress can make that change.

MR. ORRIS: So, so just as quick clarification, you know, ATSDR has stated that there is a strong causation for congenital heart defects -- and especially when we're here in Jacksonville, this is where these babies died. You know, the cemeteries around here are full of Camp Lejeune babies. And there are a lot of them living. You know, myself, I was born at the base. I have a congenital heart defect. And when I talk with other people, and it's very hard to explain that disconnect, saying that, you know, no, there is no help. You will not get assistance with your copayment. There's nothing out there for any child who was born at the base with a congenital heart defect because -- why? The science is there.

And you talked about studies. The studies have been done. What is the VA -- specifically, Brady, what is your department doing to rectify the situation? You can go to the Secretary and ask for more authority. You can try to get the regulations changed yourself. What is your agency doing to make

sure that you're providing care for everybody that was affected at the base?

DR. ERICKSON: So just want to correct an error here. Brady certainly will talk to the Secretary. I can go with him. We could have multiple people in the room with the new Secretary. The Secretary would not have the authority to change the 2012 law.

MR. ORRIS: But he could ask Congress for that authority.

DR. ERICKSON: Yes, yes. But everyone in this room can do that as well. You see, that's sort of the message I'm giving everybody here, is that it is an issue. The voice from VA can be one of the voices that raises it as an issue, the same way that we're raising the disconnect between the list of 15 and the list of eight. But ultimately the solution set is found in new legislation that will update the 2012 law.

MR. ORRIS: But we can't even get the Congressman for this district to show up at this meeting. How are we going to do anything on the legislative side for that?

MR. PARTAIN: And thank you, Chris, and in fairness to a vet, that is something that the community, we need to do with our Congressional staff.

And I do believe Senator Burr, and I'm not -- I think maybe Senator Tillis's staff will be here tonight. Jerry was in contact with them.

MR. FLOHR: That's what I was going to say, Mike. Senators Burr and Tillis have been (indiscernible).

MR. PARTAIN: So but the Congressional offices have been following this, but Chris's point, we need to get together on that. And we need to -- and also you guys at the VA, if you see a gap or something like that, feel free to speak up too. I think that's what Chris was trying to say.

DR. ERICKSON: Lori.

MS. FRESHWATER: Yeah, just a reminder and, you know, going on what you're saying, it's not just North Carolina Congressional staffers and people, I mean, it's across the country. So people who are watching on live stream, people need to talk to their community. I mean, we really do need, as a community, to take responsibility for that as well, so everybody really does need to -- phone calls or writing works -- contact everyone, because we should be speaking up for, for Chris and for other family members, like myself, who, you know, whatever comes up down my road. We all should be standing up for each other, especially family members, because, you know, we are

kind of lagging behind, clearly, on what we're able to get. So yeah, everyone that's listening and everyone that's in the audience, talk to people in your state. Talk to your friends everywhere and start contacting your Congressional representatives.

DR. BREYSSE: Thank you, Lori. That's probably a good point to end this session. And I want to thank VA for --

MR. ORRIS: One more thing. I just to make clear that we're here in Jacksonville, and yes, the veterans were exposed, but so were their family members. Their family members ate, drank, bathed and lived on this base. And we need to have the exact same care that we give to our veterans as we give to their family as well, and that needs to be a priority.

DR. BREYSSE: Okay, great. So I think we have to move on. And Jamie, you're going to review the action items from the previous -- you know, Perri Ruckart's name is listed on the agenda, and she, due to a family matter, was unable to come at the last minute, so she wanted me to kind of welcome to you all, but we'll turn it to Jamie now to review the action items.

ACTION ITEMS FROM PREVIOUS CAP MEETING

MS. MUTTER: Thank you. Okay, so the first couple action items are for the VA. The first one is

the CAP wanted to know if there's a formal training for VA SMEs who review claims. I think that ties into the third question, so I'm just going to keep going. I think that's rolled into that question.

The next one is the CAP formally requests that the NRC report not be cited anymore in claims decisions.

DR. DINESMAN: All right, let me go ahead and address that, but before I do let me backtrack a little bit on, you know, the first one, the SME. There was a mention that many of the SMEs are family practice. If you go back and actually look at the ATSDR's training for environmental assessments, you will see that the majority of people that evaluate folks, at least initially, for a lot of these exposures are family practice. And so there are -- there is a disconnect when you talk about somebody who's a subject matter expert and their certification. And so people can be experts on something that they have studied intensively, regardless of what their, you know, specialty certification may be.

DR. BREYSSE: So, that's fine, but I think we need to --

DR. DINESMAN: Okay, let me go ahead and go -- let me answer that, the question on the NRC report.

So the NRC report is what I like to call a starting point, all right? So it is a -- it was a --

MS. FRESHWATER: We don't have time to go back through this. I know where you're going, but if you could directly answer her, what the action item is. We formally request that it not be used at all, so we don't need another explanation as to why you use it. I mean that respectfully. Please, just let us know if you're going to go and do what we've asked or not.

MR. ENSMINGER: No.

DR. DINESMAN: Well, as I said, it is a piece of the literature. We can't take out specific parts of the literature.

MS. FRESHWATER: Why can't you?

DR. DINESMAN: As a part of what we do, we either cite --

MS. FRESHWATER: Is there a law saying you have to use that report?

DR. DINESMAN: Is there a law saying we don't have to use the report? It's part of the literature. So we use what is available in the literature. Now, it doesn't mean that we have to rely on the NRC report as being the absolute authority on anything. It is just one piece of literature. And so as there's more and more scientific data that comes out, the SMEs

should be using the most current scientific data.

MS. FRESHWATER: But why put outdated science in there? Why not take it out? Why, why do you need it? I need -- we've asked you not to use it. You've not -- you've yet to give any justification as to why it's important to keep it in.

DR. BREYSSE: I think we've -- this has been --

DR. ERICKSON: Did ATSDR, in any way, reference the 2009 NRC report in their recently posted study? Was it mentioned at all?

MR. ENSMINGER: It wasn't a study.

DR. ERICKSON: Well, it was considered what's called a consensus literature review, okay.

DR. BOVE: One of the problems with this disconnect, I mean the two programs, is this NRC report. I mean, the 15 conditions that are gone in the law are based on the NRC report.

DR. ERICKSON: That's right. That's right. We read the review letter recently.

DR. BOVE: But since the NRC report there have been other reviews to the literature more extensive actually than the NRC report, and so that's why when we looked at the literature in the last few years, to come up with the report we just put on our website, we did not use the NRC report because there's more recent

information from IARC, from EPA, from the National Toxicology Program. And there are also studies that have been conducted since the NRC report, including our own studies that we're seeing. So that's why we don't use the NRC report, because we feel it's outdated. And we had some serious criticisms of that report that we've aired in the past.

DR. ERICKSON: So I want to say something very positive here. With ATSDR now publishing this very exhaustive work, and again, kudos to the team at ATSDR, and particularly you, Frank. This gives us something to -- a published, reviewed document, not, not a bootleg copy, okay, but a published document we've got that we can give to the SMEs that will obviate the need for them to reach back to the document that's seven years old.

MS. FRESHWATER: Okay, so just to be clear --

MR. PARTAIN: The problem with, Dr. Erickson, with all this on the NRC report, just to cut to the chase on this, the problem is that in the past it was selectively used as an authoritive [sic] statement in the denials, and it became quite apparent to us in the community that other reports were being disregarded. Studies were being disregarded. And as you mentioned the NRC report is a literature review; it's not an

epidemiological study. And the question, and the reason why this came back on the action committee, is because it is old scientific review. It has been discredited. There is -- it's been outdated. There are other studies, and we want to see these studies in the reviews. We want to see the revised public health assessment in future evaluations. We want to see the IOM report from -- for kidney cancer. We want to see ATSDR studies, mortality studies. Those are not mentioned in -- basically moored in the reports, but yet we consistently see the NRC report. And we're beating this dead horse over and over again in every meeting, and frankly I'm getting tired of it.

DR. ERICKSON: Yeah, so part of the dead horse is that you're right, we revisit history. And there's no question that the revisiting history can be instructive. But, you know, at this point I would make the recommendation that, again, as a team we move forward with the publication of the ATSDR document. As well referenced as it is, as well written as it is, this enables us to actually move past history. It enables us to move past the slights, the missteps, however you want to characterize the things that would've been done in the past.

You know, I'm not going to justify things that

have happened in the past, but in my current role, in the current role of the four that are before you right now as guests before the CAP, you know, we are looking for positive change. We are looking for transparency, as Lori has asked for. We're looking for those positive improvements in these processes. And the ATSDR published report, it took a little while to get it out there, is going to help in this regard, because as far as I'm concerned it's probably one of the best one-stop -- one-shop stops for a new SME, if you were thinking about getting somebody trained up.

DR. BREYSSE: Tim, you had a question?

MR. TEMPLETON: Yes, very quickly so we can move on here, a couple of them. To Dr. Dinesman, as far as SME names, they're not on the reports that get sent out to the veteran. Instead -- about the only place that you can find them, there's two ways, if you request a C-file, there in the case file, if you do a FOIA for that, you'll get the notes, 'cause they're in there; or if you happen to go on the HealtheVet site and search and look for the VA notes that are in your file, you'll find them there. But if you don't know that, you won't see them.

The letter that gets sent -- so that's one real quick, of two. For, for Brad, and I'll -- I have

another question. Will people need to refile on the -- for the presumptive? And then real quick, before you -- before I leave this, for Dr. Erickson, there was an article that was done in the *Military Times* recently and it described the process of coming up with additional Agent Orange commissions. And that they were told by you that they had to wait because they -- you guys were working on Camp Lejeune presumptions. And I'd like to get an explanation as to why VA seems to be only a single-carted agency. They're only dealing with one issue at a time. For as large an agency and well-funded as VA is, it seems a little odd for me to -- for us to be thrown under the bus. By doing that you're pitting veterans' groups against each other. So be very -- I would urge you to be very careful when you do that in the future. That's it.

DR. BREYSSE: So there were three questions embedded in that.

MR. FLOHR: Yeah. Brad, yes. Veterans who have previously in the past filed a claim for one of these eight conditions and been denied will need to file a new claim. And we'd encourage them to do that right away.

MR. TEMPLETON: Perfect, thank you.

DR. DINESMAN: And that was a good point that you had, Tim, on the name, the SME name. What you said was absolutely correct, thank you.

DR. BREYSSE: Dr. Erickson?

DR. ERICKSON: Okay. Oh, boy, I get this last one. You know, it certainly isn't the intent of Veterans' Affairs to ever pit one group against another, because all have served, you know, meritoriously in a variety of settings.

I will tell you that I don't necessarily want to leave the impression though that VA is replete to do all things all at once, okay? And there is no question but that there are priority missions that can shift based upon a variety of factors. And so some of those you know, some of those you may not hear about, but it's one of those things where we do the best we can for all the different veteran groups. We do the best we can to deal with the most immediate issues, those that need to get out.

I'm going to put this in a very positive way, and of course we do talk to the media all the time. Sometimes they correctly quote us, sometimes they don't. There is without a doubt that getting out the final rule for Camp Lejeune was one of Secretary McDonald's number one priorities. Through this last

year, you know, Brad and I were in his office nearly weekly. Updates -- you know, I will tell you myself, I went to the White House three different times, met directly with some of the most senior leaders, not, not the President, okay, but folks just below that level.

The Camp Lejeune issues, without a doubt, were front-burner, and were high flame, okay. So you know, I -- there's -- and so without making comparisons or trying to cause any kind of competition, I will tell you that the Camp Lejeune issue was absolutely front and center. Now, as it's been stated, that doesn't mean the results that have been met with, you know, perfect pleasure by everybody, but I will tell you that we feel that we've made some really good progress. We feel that a very concentrated main thrust was made, and we certainly took territory.

DR. BREYSSE: Jamie, how many more action items do we have to go through?

MS. MUTTER: We have about ten, sir.

DR. BREYSSE: So if we can try and get to those, and if we can focus on the action item itself as much as possible, that might help us get through.

MS. MUTTER: Yes, sir. So the next one is the CAP would like more information on the SME process,

and I can read through them, but I don't know if you want to elaborate more.

DR. BREYSSE: That's what we already touched on.

MS. MUTTER: We go with that? Okay.

DR. BREYSSE: It was what we already touched on.

MS. MUTTER: Next one for VA is there was a request from an audience member VA/VBA to do more outreach at the clinics such as posters, to get people registered for available programs.

MR. WHITE: Yeah, we took that, and we had actually been working on a poster for that very reason. So I brought a draft copy of it on a poster board over here. I was going to walk it around but I didn't want to look like a *Price Is Right* -- one of those ladies. So it's right there, and we're going to be sending that out to the VA medical centers and the clinics as well.

MS. MUTTER: Okay, thank you. So the next action item is for the DoD. The CAP reiterated a request that the USMC send a uniformed representative to the CAP meetings. If no one is sent to the next CAP meeting, the CAP requests a formal letter response to the CAP, signed by someone at Marine Corps headquarters.

MS. FORREST: Hello, this is Melissa Forrest from

the Department of the Navy. The Marine Corps remains committed to supporting the Agency for Toxic Substances and Disease Registry's Camp Lejeune health activities as well as the founding purposes of ATSDR's Camp Lejeune Community Assistance Panel.

In the past the Marine Corps has had representatives attend CAP meetings. Based on those past experiences we found that a uniformed presence detracted from the purpose of the meetings, which is forward-looking towards getting community input into current and ongoing health studies. Having a Department of the Navy CAP representative from the Navy and Marine Corps public health center, representing both the Marine Corps and the Navy, remains the most effective means of participation at the CAP meetings. Our Department of the Navy representative attends the CAP meetings, relays any questions or concerns back to the Marine Corps and Navy, and facilitates responses to any Department of the Navy CAP action items.

As an example, the CAP recently requested a tour of Camp Lejeune sites in conjunction with the CAP meeting in Jacksonville, North Carolina, and we have been able to accommodate this request through coordination with our DON representative on the CAP.

This response, as with all action item responses provided through the Department of the Navy representative, is the official Marine Corps response.

MS. MUTTER: Thank you. The next one for the DoD is the CAP formally requests that documents be released to the public as soon as they are available instead of waiting for all the documents to be ready to be released. The CAP would also like an explanation of the quality control process used in the document reviews.

MS. FORREST: The Department of Navy has completed its releasability [sic] review of documents identified by ATSDR as potentially relevant to their soil vapor intrusion public health assessment. On 17 January 2017 the Marine Corps provided ATSDR with an external hard drive containing the documents prepared for release.

The second part related to the quality assurance review. The quality control process used in the document reviews is as follows. First we determine which documents have been previously provided to ATSDR for release to the public, in order to prevent duplicate releases. Second, compare and reconcile documents listed on the master document index to those on the hard drive being provided back to ATSDR.

Third, review redacted and withheld documents, to ensure the appropriate FOIA, for Freedom of Information Act, exemption markings were made. Fourth, verify that documents previously marked FOUO, still requires such markings, and if not, properly remove the FOUO language. And fifth, conduct a final quality check for organization, appearance and functionality of the hard drive. This quality check and assurance process is conducted by several individuals and in order to ensure the most accurate and highest quality product is turned over to ATSDR.

MR. PARTAIN: One quick observation on the documents, and thank you for quickly working over the past three years to get this done, and I say that tongue-in-cheek. On the duplication of documents, I am concerned about that because there were numerous documents in the initial Camp Lejeune water and CERCLA files where they appeared twice. And one document had written comments on them that proved very -- you know, it points very important to what we were doing, and the other document had no comments on it. By arbitrarily saying the Navy and Marine Corps are removing duplicate documents, there's a concern in which, which version is being removed or not. I would prefer that -- you know, if they're going to designate

duplicate documents, go ahead and take those documents that have been so designated, and put them into a file labeled duplicate documents, so at least we can go look and see for ourselves. Not that we don't trust the Marine Corps but in the past the official statements and comments of the Marine Corps, leadership of the Marine Corps, have not matched what we uncovered in the document research.

MS. MUTTER: Thank you. Okay, the next action item is for the DoD. For the public meeting in Jacksonville, North Carolina, the CAP would like a base site tour to be made available to interested public meeting attendees. If it is not possible to accommodate a large group, then the CAP would like a tour for CAP members.

MS. FORREST: The Marine Corps is accommodating this request. As you are aware the tour is taking place today, 21 January 2017.

MS. MUTTER: Okay. The next action item is for ATSDR. The CAP requests that someone from the office of communications work with the CAP for planning, advertising the next off-site meeting. The response is ATSDR will follow the same template we used for the Greensboro and Tampa public meetings.

The next action item is the CAP asked that

Dr. Blossom's presentation be emailed to the CAP, and that was completed.

The next one is for ATSDR. The VA asked if ATSDR could share the addresses we have from the health survey with them. Response is -- was mailed to the VA on August 18, 2016. Unfortunately we are unable to share the addresses because the content from the survey said, quote, information from the survey will be used for research purposes only. All answers you give will be kept private to the extent permitted by law. We do not plan to share your information with anyone other than ATSDR staff and its contractors, end quote.

The next action item is for ATSDR. Request that the VA agenda items be placed at the beginning of the meeting, followed by a discussion on action items from the previous meeting. That has been completed.

And the last action item is for the CAP. In order to pursue getting -- I hope I'm saying this right -- an ombudsman for Camp Lejeune-related issues, the VA requested that the CAP provide a justification showing a specific need that an ombudsman would address.

DR. BREYSSE: So was the CAP able to provide a justification for an ombudsman to the VA or that's

something --

MS. CORAZZA: No. I think that was me, but I don’t think I ever wrote to that, so...

DR. BREYSSE: So we'll carry that action item forward?

MS. CORAZZA: Yes.

DR. BREYSSE: All right, so I have time for a break unless there's a question we'd like to jump in with now. Tim?

MR. TEMPLETON: Yeah, just real quick. I'm excited. I hear about this external hard drive. I'd like to get my hands on it as quickly as I can.

DR. BREYSSE: Rick, you wanted to say something?

MR. GILLIG: Well, Tim, we can't give you the external hard drive but we can load these documents up to the FTP site, as we did a couple years ago. So I've got a team back in Atlanta looking through the hard drive, and we'll get those uploaded as quickly as possible.

MR. PARTAIN: And resend us an email.

MR. GILLIG: And we will send you an email, and we will also resend the information for accessing the FTP.

MR. ENSMINGER: Define external hard drive.

MR. GILLIG: Well, an external hard drive is --

we've loaded the documents. It's a little widget. We've loaded all the documents on there, mailed that to the Navy. They looked through it. Those were the documents that they looked through and redacted. So it's just a hard drive like in your computer, except external.

MR. ENSMINGER: Oh. I thought it might have come from an external source.

DR. BREYSSE: All right, so I think it's time for a break so why don't we meet back here at 10:50. 10:50. That's 15 minutes from now.

[Break, 10:33 a.m. till 10:53 a.m.]

PUBLIC HEALTH ASSESSMENT UPDATES

DR. BREYSSE: So the next item on the agenda is a report back from ATSDR on the public health assessment updates, including the drinking water and the soil vapor intrusion update. So we'll turn to Rick Gillig to talk about the public health assessments updates.

MR. GILLIG: Okay, good morning, everyone. I'd like to update you with the soil vapor intrusion project first and then the drinking water public health assessment that was released yesterday.

So as you know, for the soil vapor intrusion project we have been compiling information for the last couple years. We have reviewed over 40,000

documents. We've completed pulling information out of those documents. We've put it into a SQL database. Currently we're in the process of standardizing that database. Once we standardize that database we can start doing data summaries and compiling results. We've had a considerable effort the last six months to geo-reference all the contaminant information that we pulled from the documents, and we completed that geo-referencing back in September. So it's been a long process but we are nearing the point at which we can start doing data analysis.

There was some mention earlier about the documents that were provided back to ATSDR from the Department of Navy. The Navy did redaction of documents. I've got a team back in Atlanta reviewing the hard drive that contains those documents, and we will upload those to the FTP site within the next couple weeks. We will forward all members of the CAP with an email, also information on how to access that FTP site. I know we have a couple of new members to the CAP. So we need to provide that information to all of you.

Is there any question on the soil vapor intrusion project? Jerry?

MR. ENSMINGER: No, I just got a comment for the

audience. And they're probably sitting back there wondering what the hell soil vapor intrusion is. So they understand and can follow along, all these contamination plumes that were down in the ground, a lot of them volatize and become a gas, and come up through the ground. And a lot of them are coming up into buildings that are located above those plumes. Most people think that the exposures at Camp Lejeune ended in 1985, slash, -87 time frame; they didn't. We have evidence that they were taking place as late as 1999, and that was through vapor intrusion into the buildings. So the saga continues. That's -- so.

MR. GILLIG: Any questions on the vapor intrusion project? If not, I'll move to the public health assessment, the re-evaluation of drinking water exposures. To my right I have Mark Johnson who was the lead author on that document. That was released yesterday. It's posted on the ATSDR website. This was an update from the 1997 document.

The reason for that update, we have completed -- several years ago we completed water modeling, which gave us information on -- gave us estimates of contaminant levels in the drinking water models across the base. So we use that information as part of our re-evaluation of exposures through drinking water. Do

we have any questions about the public health assessment?

DR. BREYSSE: I'll just say one thing for the members of the public here, we'll give a presentation of the findings at the public -- tonight during the public meeting. We've reviewed the findings of the public health assessment previously, and so we don't plan on going through those results right now, unless there's a specific question. But we will certainly have a more detailed presentation this evening for the benefit of the community.

MR. ORRIS: So I just have one quick question. I mean, we got the PHA late last night in the final form. And one thing, just for current accountability, I noticed that you're recommending that everybody who currently lives at the base should run their water from one to two minutes before drinking that water, for lead exposure. And I wanted to know have we communicated that to the Marine Corps? I'm sure the Marine Corps is aware of it. And has the Marine Corps trickled that down to the people who are drinking that water?

MR. GILLIG: Yeah, Chris, I, I can't answer specifically what the Marines are doing to address the lead contamination. I know they have a very active

monitoring program.

MR. ORRIS: Well, I mean, I live here. I live 30 miles from here, and I've never heard that you need to run your water for two minutes to drink from it.

DR. BREYSSE: Chris, that's a fantastic point, and we will -- we've today, in fact on Monday, to make sure -- that advice is given to them. But I will mention, though, that having spent a good part of my last year in Flint, Michigan, and dealing with other communities with lead problems, it's good advice for anybody, whether you have well water or you come from a municipal system, from, you know, Seattle to Saskatchewan, is to, when you get up in the morning, the water that’s been sitting in the pipes, to let it run for a minute or two, so you flush out all the water that's been stagnant over time. So that's just -- that's advice that we're finding is good public health advice wherever you are, whether you have a little bit of lead in your service lines or lead in your fixtures or not, that's just good advice. And so that's advice that our water health program at CDC is starting to communicate more broadly across the country.

MS. FRESHWATER: I would just add that, as someone who researches on line government, that it is

showing up in more and more places, and it's, it's really frightening, so I would just add that to Dr. Breysse's concerns.

DR. BREYSSE: Fantastic. Hearing no more questions or concerns about the public health assessments, we can now turn to updating our health studies, in particular the health survey and cancer study. We'll turn to Dr. Bove.

UPDATES ON HEALTH STUDIES

DR. BOVE: So the health survey, at this point we have it in clearance, and it's been in clearance now for about a month or so, and so it's going through that process. It may take some time but it's in that process.

As for the cancer incidence study, as you know, we're trying to get approvals -- in order to do this study you have to work with 50 state cancer registries, the cancer registry in Washington, D.C., the cancer registries in the territorial areas, the VA's cancer registry and the DoD's cancer registry. And each cancer registry has their own procedures, has their own way of get -- their own forms that you have to fill out, and their own IRB process. Some of them accept the CDC's institutional review board process, which protects human subjects in research, but other

cancer registries want to go through their own process, their own IRB process. And in some cases they have to have sign-off by the state commissioner to help. So it varies by state.

There's no national cancer registry, which is unfortunate. There is a national death index, so when we did our mortality studies it was easier to conduct those. But for the cancer study that we're doing now, we're working with all 50 states, state territorial cancer registries, the VA and DoD's cancer registry.

So right now we've submitted to 42 of the registries. We've submitted the forms. We've gotten approval from 11 registries so far. We've received partial approval from an additional four registries, and that just means that they're -- we're waiting for the commissioner, or in this case, I think these four, to sign off on it. So and we have 13 more registries who we want to submit forms to.

We understood, and I think we made this clear to the CAP, that this will require at least a two-year process to get the cancer registries on board, because there's no national cancer registry. So we're on target for that. And we're constantly reminding the registries that we've already submitted forms to, to please go -- get the process going.

A lot of these states, their institutional review boards don't meet monthly; they meet quarterly, so if you miss one quarter you have to wait for the next quarter. Some registries are saying, well, you're not asking for the data until the -- we're asking for the data actually at the end of 2018. So we want to get data from the cancer registries up to the end of 2016. There is a year-and-a-half gap between the time you -- we get the data from them and the time they finalize the data. So if you want 2016 data you have to ask -- wait until mid- to late 2018 to get that data, okay? So some registries see that, and they say well, there's no hurry, then, for us to approve the process. So we're trying to encourage them nonetheless to get on board and so on. So we're on track. And as I said, probably take another year or so to get them all on board, or most of them on board.

There are a few registries, one registry in particular, I think, that has a state law that will prohibit it from being part of the study. That's unfortunate. There are one or two other registries that are having difficulties staffing. So we'll have to figure out a way to work around that. We're hoping that's about it, though. We're hoping that most of the other registries will not have any problems with

what we're asking for.

We've worked with the national -- North American Association of Cancer Registries, which is the association covering all the cancer registries. We have close cooperation with them. They want to help. We've helped them on occasion, through projects of -- that they initiate, and so they really want to help us on this one.

So all the states know about the studies. We've presented to all the states at a convention last year, so we shouldn't have any problem. But, you know, these are difficult studies. There's only one other study that I'm aware of that used all 50 state -- or most of the 50 state registries, and that was a study where the researchers got consent from every last person, which we can't do in this case. So this will be kind of a unique study that tries to use the 50 state registries, and the others as well. So it's a unique thing, and we're hoping that we're successful.

MR. ENSMINGER: You done? What about funding?

DR. BREYSSE: So we heard late last week that the funding issue, you remember, was the VA -- the Department of Defense had agreed to fund the study, but we asked for a lot of the money for the cancer registry work up front rather than spreading it out

over a number of years. So there was an issue about whether we could get it all from them or not. And we -- and they resisted, but then we heard recently that they were able to do that. So we are going to get the money, so I think the funding issue has been resolved. And they resisted us 'cause it was a government budgetary restrictions about giving money to be spent for the next three years in this year, and so it wasn't a resistance in concept; it was just a resistance issue to go with the rules or in terms of governing, releasing resources, so we were able to overcome that.

MR. ENSMINGER: What state has the law?

DR. BOVE: I think it's Montana. What we'll do is this; once we go through this process, and if there are states that are -- we're having difficulty with, the first thing we're going to do is ask for help from, you know, as I said, NAACCR, it's called, the North American Association of Cancer Registries, to help us with those states, and try to work out some arrangement where we get the data we need.

If that doesn't work we'll let the CAP know what states we're having difficulties with and -- you know. But I think that -- but we want to go through this lengthy process, and see how many states we can get

without -- with the help of NAACR.

DR. BREYSSE: Ken?

DR. CANTOR: Frank, I wonder, going back to the health survey, I understand that you can't give any of the results or the conclusions from that, but could you provide just an outline of what was done, how big the population is and what kind of things we can look forward to when it is released?

DR. BOVE: I'm trying to remember a number. You know, we mailed it out to way more than 300,000 people. The list came from our own information we've gotten from the Defense Manpower Data Center, which we used to do our studies, and also those people who registered, for example, with the Marine Corps, so they have their mailing list as well. And so we used all of this information. And for the -- some people we couldn't get addresses, current addresses, for but we mailed it out to over 300,000 people.

We got responses back from like, I can't remember the exact number, but about 70,000 responses. If you combine both the Marine, the veterans, the dependents, and the people who were on the mailing list that may or may not have been at Lejeune but, you know, but were on that mailing list.

So we looked at -- we asked for the -- the survey

is a mailed survey so that the person filled it out. We asked about a number of cancers and other diseases, like Parkinson's, MS, lupus, scleroderma and so on, and also we left some area of blanks in the survey so people could fill in their own illnesses. We asked about pregnancy history, so we got that information and results of the pregnancy. So we asked all those questions. And we verified -- we went back and asked for medical records for the cancers, and as I said, the Parkinson's, lupus and sclerodermas, and for a restricted list, 'cause we couldn't get confirmation on everything. So that's what we did.

You know, there are limitations to a survey like this. Who participates and who doesn't is the key problem with any survey. When you do a mailed survey -- for example, the census, when they first do a mail-out for the census, they get a response rate pretty low. They have to go knocking on doors to get the, the rate up. So any time you do a mailed-out survey, you can expect a low participation rate, and it happened to us as well. We had about 25 to 30 percent participation rate. So these are problems with any survey and are problems with ours. But we're -- did what we could with the information. As I said it's in clearance. Do you have other questions?

DR. BREYSSE: Lori?

MS. FRESHWATER: Thank you. So going back earlier, when we were talking about people contacting Congressional representatives, this is another area where I feel like people can help by demanding that we have a cancer registry in this country. Not asking but saying that 49 of the states not have a cancer registry is -- it's not just, and it's not the right answer for public health.

So my question to you is, and I would ask anyone else that has input on this -- I know we've had very positive conversations I've had with the VA, and not to speak for them, but they seem supportive of the idea and feel like it would be helpful moving all of this forward. We also know in Washington that our -- there are forces that probably would not like a national cancer registry. So it is going to take a lot of public participation. So I would ask anyone who has any advice for the public or any of us that want to go forward and try and promote this as a cause, what -- you know, just give us some input on that, please.

DR. BOVE: Just so you know, this organization called NAACCR has been moving slowly but surely in that direction, trying to do pilot work to develop

something that could be national, okay. And they used our Camp Lejeune data as their first pilot thing, and it helped them a great deal. But it's extremely difficult. As I said, there are 50 state registries plus the Washington, D.C. registry. And they all have their different rules. Some have state laws that tell them what to do and what they can't do. And so we're going to have to break through all that and have a -- in order to have a national registry there would have to be a Congressional effort. But as I said, baby steps are being taken, at least. And we've been helping as much as possible in that process, using the Lejeune data for that.

MS. FRESHWATER: And you know, as a scientist, what -- can you just give us an idea of what people should -- if I were to call my Congressional representative and say we need a national cancer registry, but I'm not a scientist -- the purpose is so that the states can communicate with the data, right, and, and we can find areas where certain things show up and that kind of thing. Just kind of help me help the public know what to ask for, please.

DR. BOVE: Well, in almost any situation, I'm thinking for example of the study that was done with firefighters just recently, the last year or two, in

three cities. They had to use 11 or 12 different state registries. Almost any study you're going to do of a work force or an environmental situation, people move. They don't stay put. And Lejeune is an extreme example where people are all over the country, or all over the world in fact. So in order to do any kind of study you'd have to have access to quite a number of state registries, and you have to go piecemeal through this process, which takes quite a long time, a lot of resources, just to get this information.

Also it would help if the states, and they do to some extent do this, but we have cancer data that are published, national cancer data, that probably is inaccurate because there are probably a lot of duplication that, because of the states don't have a way of linking their data all together, to look for duplicates, we're probably posting -- I mean, not we, ATSDR, but the government's posting information that is probably problematic, okay? And so just for that reason alone, to have accurate incidence data for the cancers, and you can chime in on this, it would be helpful to have a national registry so those kinds of corrections can take place, because the people -- a person may get seen in one state and treated in another state. Now you have two states with the data,

and that gets counted, and it's duplicate.

DR. BREYSSE: So that's great. So if you're looking for some simple language, Lori, maybe I can impose on Ken, if Ken could draft from your fellow CAP members some simple language that they might use to communicate the need for a national cancer registry, as people might speak to various political parties or different levels of the government.

MS. FRESHWATER: That would be wonderful. I appreciate that very much. And just out of curiosity has anyone heard -- I know that former Vice President Joe Biden has this acute cancer what is it, the moonshot? Has anyone contacted that organization and what he's trying to do with the notion of a cancer registry? Is that something that people could do?

DR. BREYSSE: I'm not aware of any.

DR. BOVE: Again, an initiative is being taken by NAACCR, because they work with all of the state registries, the association they hold at a national conference every year and mini conferences. So that's the entity that's -- who would probably spearhead this effort, and basically have more information than I just gave you about the issues.

MS. FRESHWATER: Can you send me a link to them?

DR. BOVE: Well, it's N-A-A-C-C-R, so if you just

type that in, then you probably will come to their website. What we can finally -- I think I mentioned this before, but what we did, a year ago now, is we gave them all our Camp Lejeune data. They sent it out to, I think, it was over 40 states. They did the matching there. We didn't ask -- for the study we wanted this information connected to the Social Security Number of the person, so we can actually do this now, but in this case the pilot just was how many times did you -- how many states found hits, matches. And so we got that count data. It wasn't as useful for us but it was very useful for them, and so -- to start this process. So we're very much interested in helping them any which way we can. And CDC does fund all 50 state cancer registries, as far as I know, so we'll be involved.

MS. FRESHWATER: So that's great that someone else is -- you're saying they've already kind of started in that motion. Maybe we can kind of consolidate and work with them and get behind them to help push the rock with our shoulders, right? Okay, thank you.

DR. BREYSSE: Tim?

MR. TEMPLETON: Thank you very much. I'm trying to take us in a slightly different direction, so I

apologize. I heard, when we had the VA's portion of our program here, that they were talking about the NIH and for genetics and mutagenics, for studies, so I'm curious as to how, maybe just your guess, or some thoughts on how we might approach that. Do we need to approach them directly or would they -- would we approach them through the CAP, through ATSDR? To try and initiate some of those studies.

DR. BREYSSE: I think I'd defer to the VA about how -- what sort of interaction with the NIH you have or how we might facilitate that.

DR. ERICKSON: You know, at this time my encouragement would be to keep your powder dry, just for the moment. And the reason I say that is there are already members of Congress who have expressed interest in looking at toxic environmental exposures. They've passed some bills that have led to some generation of efforts already in this regard. I mentioned the two national academy studies that we have commissioned.

We really need the national academies to give us sort of an independent, authoritative -- I call it a roadmap, a framework, that allows us to then basically attach to the scaffolding, you know, all the elements that will enable those people that appropriate money

to do so in an organized and prospective manner. I'm actually very hopeful that we're going to get some traction on that, but the challenge right now is really one of education. There, there have been some, some very incredibly intelligent members of Congress who initially asked VA to just take it on entirely ourselves, and our response was, you know, we agree with wanting to do that, and we agree it needs to happen, but we don't agree that VA needs to own it. We think VA needs to be the collaborator, the same way that we collaborate with the experts at ATSDR. We want to collaborate with, with an agency that has pediatricians, 'cause we don't have pediatricians, and collaborate with an agency that has a deep laboratory bench of scientists who actually run those technologies on a regular basis, et cetera, because we think, in the end, that a whole of government approach, or at least bringing in other agencies that are truly the experts, will give us a better answer, a better product.

MR. TEMPLETON: Great, thank you. Thank you very much.

DR. BOVE: One thing that I just want to add to Lori, if you do look up the NAACCR, the project's called the virtual pooled registry, VPR, sometimes

called viper. And that's the project that I'm -- that I was talking about.

MS. FRESHWATER: Great, thank you.

MR. ORRIS: So Dr. Bove, quick question for you. I know ATSDR has many other affected communities that they're working with, doing a lot of research on cancer. One of them comes to mind is, you know that ATSDR handles the 9/11 exposures. And my question is, is there any way that we can start coordinating between all of these different agencies within ATSDR and these different studies to push forward this national cancer study, showing funding, et cetera, so that because -- you know, I know with specifically like 9/11 you're talking about 50-plus cancers from an environmental exposure standpoint, and I'm sure we can start tying some of these together to build this national cancer database.

DR. BREYSSE: So the -- while ATSDR helped establish the World Trade Center Registry, it's now run by the City of New York and administered through NIOSH, which is another part of CDC now. So we still, you know, have close contact with them, and we could certainly talk with them about any thoughts they might have about advocating on behalf of this effort to get a national registry, so we can certainly do that.

MR. ENSMINGER: So you guys are ATSD?

DR. BREYSSE: Yes. That's an inside joke.

MR. PARTAIN: Dr. Breysse, actually that reminds me of something that I forgot to ask about earlier, (cell phone music) after our brief musical interlude. Anyways, going back to the release of the public health assessment last night, being that there is some changes that's going to be discussed later tonight with the public meeting, is ATSDR going to approach the Marine Corps and the registry that they have compiled of like 235,000 Marines and their families to request that this updated PHA, at least a link, be disseminated to them?

DR. BREYSSE: We certainly can do that. We have a meeting with the DoD folks next week, and I'll make sure it's on the agenda.

MR. PARTAIN: And how many -- considering that in 2009, when the NRC report was released, it was in May, June, it was disseminated by the Marine Corps to everybody on the list within like two or three months. So hopefully this updated public health assessment, which is a very important document, will get out to the Marines and their families.

CAP UPDATES AND COMMUNITY CONCERNS

DR. BREYSSE: Pardon me for one minute, Jerry.

So I'm just going to move to a -- I think we're already entering into a broader CAP up -- you know, CAP question and answer period. We have a half an hour left. We reserved this last half hour for any residual CAP concerns that we haven't talked about, and we want to make sure we provide an opportunity for a public member or two to make a response or ask a question, recognizing that we can't possibly accommodate everybody who might want to speak right now, but that's the whole purpose of having the two hours this evening, to make sure we have plenty of opportunity for that. So I'll start off with Jerry.

MR. ENSMINGER: I just wanted to let the folks that are attendant here, the community, that we greatly appreciate what has been transpired here, with the VA and the approval, this rule-making. However, it only covers veterans. I've had several questions about -- people coming up to me out in the hall: Well, our families were there too. Yeah, I get it, okay? And, and believe me, this fight with this announcement is not over, by a long shot.

When the Marines that were married showed up in Camp Lejeune with their families, many of them were awarded -- or afforded housing aboard base. That veteran now, if he gets kidney cancer he gets his

benefits and compensation. Well, his family was exposed to the same contaminants and they don't get anything, except for payer of last resort for their healthcare. Is it right? No, it's not. That's our next goal.

Civilian employees is another issue that needs to be taken care of. There is a compensation act through the Department of Labor. It's called the Federal Employees Compensation Act, and the civilian employees can be a pretty quick fix. All we'd have to do is get Congress to provide them some money for the Camp Lejeune program, and that would be taken care of. So we hear you. We understand the injustice here, and we are going to pursue them. So bear with us.

DR. BREYSSE: So are there any other CAP questions or issues you'd like to raise or can we open it up to the --

MR. PARTAIN: Actually, Dr. Breysse, real quick, 'cause this may trump -- or not trump, nothing funny here, but may help some questions here. I've -- after the announcement on the 13th, I've had several spouses of deceased veterans contact us about, you know, they passed from kidney cancer, bladder cancer, and they're not aware that they may be entitled to potential benefits. And I don't know if there's a comment that

the VA can make real quick. Some people have indicated that they can't be here tonight, at tonight's meeting, so I want to go ahead and pose that and turn that over.

DR. BREYSSE: So is anybody able to respond?

MR. FLOHR: Well, Mike, are you talking about outreach?

MR. PARTAIN: Yeah, I'm not familiar with all the VA programs, but say a veteran dies of kidney cancer and has a surviving spouse, and the cause of death is due to kidney cancer.

MR. FLOHR: Right. Then they're entitled to what we call dependency and indemnity compensation. That's a service-connected death benefit, and that's payable to the surviving spouse and any children under the age of 18 or between the ages of 18 and 23 and are attending an approved program of education. All you need to do is file a claim.

DR. BREYSSE: So there's a microphone over here on the side. We have about a half hour. If people would like to ask a question, make a comment, feel free to do both. I'm sorry, I'm at a bit of a loss 'cause I have my back to the crowd. I'm going to see if I can stand up and move away, if you don't mind.

MR. MIRACLE: My name is Charles Miracle. Be a

miracle if this ever comes to effect. I was in the Marine Corps 1954 to 1957. I have a service number. I don't have a Social Security Number in that date. 1474262. I got out in '57. About two or three years later I begin to feel my arm as it went by my breast hurting, hurting very much. And today it still hurts and itches. Now, it's been 50, 60 years ago.

I was operated by a civilian doctor here in Jacksonville, become ill in Jacksonville. I have been -- I went to the VA. I was told by, I can't remember his full name, but it was Matt. Some of you folks might know him. He had a curly, handlebar mustache. I was told I was not a veteran. I'm a Korean veteran. I know that, but he wouldn't register me or do nothing for me.

Years passed. He went out of office, and I went to the VA again, and I was treated like a long-lost son. The VA has done me fairly well in medicine and a nurse, as of today. I have been to Fayetteville. The doctor up there didn't x-ray me, didn't check me, just looked at my scar, and said, oh, yeah, you have a scar. And I have papers right here to prove what she said.

I talked to my VA doctor two or three weeks -- or two or three months ago. I got the same statement.

But Doctor, why am I still itching and hurting in my breast? Now, some of you ladies, I don't know if any men know it, if you've got a breast problem, back then it wasn't mentioned. I'm a man. We didn't talk about our breasts. Nowadays people talk about their breasts, their nose, their ears, their pains. But anyway I still can't get an answer why I have a itching, a pain or what.

MR. PARTAIN: Something that a mammogram would probably solve.

MR. MIRACLE: Mammogram? No, they don't think -- no, you look good. I look good. I can show you, I look good. But I hurt. I'm a veteran. Been a veteran a long time. And I appreciate some of the work I've got, and I appreciate this man.

Many years ago when all this begin, with Jerome, I couldn't get any answer from anybody, Daily News, Camp Lejeune, the VA or anybody on trying to get up with anybody to help me.

DR. BREYSSE: So thank you, sir. Is there any advice we can give him about healthcare for his condition?

DR. ERICKSON: Mr. Charles Miracle.

MR. MIRACLE: Yes.

DR. ERICKSON: Get, get with me afterwards. Give

me some information, and we'll see what we might want to do. I mean --

MR. MIRACLE: The reason I've had permission to speak now is because today is my wife's 80th birthday.

DR. ERICKSON: Oh, congratulations.

MR. MIRACLE: And I'm giving her a special dinner tonight at five o'clock.

MS. FRESHWATER: Korean war veterans don't –– have known as the forgotten veterans sometimes, and I want to thank you for your service, and we'll never forget what you did.

MR. PARTAIN: Dr. Erickson, he did have a breast mass and surgery on that, so the concern would probably be to do a mammogram.

DR. ERICKSON: Yeah, roger that. I wanted to protect his privacy by not discussing it in public right now.

MR. PARTAIN: I know, but he's...

DR. ERICKSON: Thank you.

MS. MUSLER: Hi, thank you for allowing me to speak up here. My name is Patti Musler (ph). I'm from Ohio. I'm the daughter of a Marine veteran. He's 79 years old. He's living in Florida, and we believe he's suffering from a lot of the neural behavioral effects, which is not one of the

presumptive.

My question is -- I'm on the third part of the appeal. We're waiting for the hearing before the review board. It's not one of the presumptive now, but let's say he gets denied again, and then it becomes a presumptive later on, are we going to have to go through this whole four-year-now process again in order for him to get back into the, the system, to be re-reviewed, or is it just he's out of luck? Once you're denied, you're denied and that's it.

MR. FLOHR: Thank you. And thank your father for his service. You're right; neural behavioral effects are not going to be presumptive diseases. As we've discussed earlier today it might become part of it at some point in time.

UNIDENTIFIED AUDIENCE SPEAKER: Would you speak into the microphone, please?

MR. FLOHR: It might become one at some point in time, should we get sufficient evidence to show it should be added. But once he's been denied, then he would have to file a new claim. But he wouldn't have to file any medical evidence. Just file a claim, if it's presumptive it would be done very quickly and simply, and wouldn't have to go through a long review process.

MS. MUSLER: Okay, and then, God forbid, his health is not really good. God forbid, he passes, but my mother's still alive. Would we be able to reapply on her behalf, as a surviving spouse?

MR. FLOHR: If that was added to the presumptive list, then yes, she would be entitled to a dependent's indemnity compensation, yes.

MS. MUSLER: Okay. Thank you very much, and everyone that's here, thank you for your service. I have the utmost respect for all of you.

DR. BREYSSE: Next question, please?

UNIDENTIFIED SPEAKER: (Unintelligible) My husband died at the age of 28 years old. I'm fighting three types of cancer. I'm at the end of my ropes. My question is, one of the diseases that was on the paper, can I file on his behalf of that diseases. When I went to Duke University, they got three clusters of cancer. I've been fighting ever since my daughter was five years old. My daughter's 30 years old now, and she went to the doctor last week, and they found five clusters of tumors on her. So -- but before my husband could get a diagnosis of what he was going through, he passed away, so it wasn't put on his death certificate. What do I do?

MR. WHITE: Brad, do you want me to --

MR. FLOHR: So may I ask, was his cause of death one of the eight presumptions that we have now?

UNIDENTIFIED SPEAKER: No.

MR. FLOHR: It was not?

UNIDENTIFIED SPEAKER: No.

MR. FLOHR: Well, you could always file a claim for death benefits, but we'd have to review it. You'd have to have -- look at the medical evidence to find an association between what he had and his service with some medical evidence from medical professionals.

UNIDENTIFIED SPEAKER: This is what the doctor said. What he died of was caused by a chemical balance of water that he might have caught overseas at that time, because they did not know about the Camp Lejeune water, and that's what I'm told, and that's what is in contact with his paper. But it was never noted in his death records or anything like that.

MR. FLOHR: Well, you certainly have the right to file a claim. And VA has a duty to assist and help people who file the claims in developing all the evidence.

UNIDENTIFIED SPEAKER: Okay.

MR. FLOHR: If you could provide us names of doctors and whatever, we would try to get that information.

UNIDENTIFIED SPEAKER: Can you tell me where and what I go -- the VA office?

MR. FLOHR: Yeah.

UNIDENTIFIED SPEAKER: Okay. Okay. And thank you, also.

MR. WHITE: Well hold on. There was also another part to your question, I believe, that on the family member, and what kind of health benefits that the VA may provide. We've got a flyer on the table out here, just so everybody knows here in the room also, about where you can go to get more information for what the benefits are and how to apply for those benefits. But basically, if you have any of those 15 conditions and you apply for benefits, we should be able to handle the payment, so you won't have any out-of-pocket expenses for treatment of those 15 conditions.

UNIDENTIFIED SPEAKER: Okay, thank you. And he only (unintelligible) four years, so thank you.

MR. WHITE: You're welcome.

DR. BREYSSE: I'd just like to remind people, we're going to have a public availability session tonight, where representatives from the VA, ATSDR will be out there. If you have individual health questions, that might be the best opportunity to kind of bring that up. You're free to kind of talk now but

I think the goal is to make sure that these questions get answered, and if you have some private health concerns or family diseases you don't want to talk about in public, please take advantage of that.

MS. SMITH-DAVIS: Good afternoon. My name is Carol Smith-Davis, and I'm a dependent child of a honorably served Marine here at Camp Lejeune. I have several siblings that also were exposed to the water contamination; of course that’s why we’re here.

But my brother went into the Army when he got out of high school and served there honorably, and he has something that is presumptive on the list that -- from the water contamination. When he did the filing, they of course told him he did not rate any compensation because he was exposed as a family member, but he is an honorably served veteran that's not given compensation for something that is on your presumptive list.

So I'm just wondering, there seems to be a gap in the system. You know that we have had dependent children that have went into the military, and they're going to -- he can't be the only one. So there are going to be issues like this, and what are we going to do to resolve those veterans that have honorably served, maybe in other branches or in the Marine

Corps, that have these, these items that are on the list, that are not going to be compensated because they were exposed as children?

MR. FLOHR: That's a good question. He's a veteran. He was on -- a dependent on Camp Lejeune?

MS. SMITH-DAVIS: Born and raised like the rest of us.

MR. FLOHR: And I think he would still be covered by our regulations.

MS. SMITH-DAVIS: He got denied.

MR. FLOHR: Well, he couldn't be denied yet because the regulations just published.

MS. SMITH-DAVIS: But we -- so we put the claim in for later, and he was denied because they said he was a dependent. And so does he -- do he need to now put in an additional claim that needs to go to the VA and not family members program?

MR. FLOHR: Yeah, why don't you come see me after while?

MS. SMITH-DAVIS: I'd be glad to, thank you.

MR. PARTAIN: So Brad, if I understand you right in this case, her scenario is actually -- I've heard of this before. I briefly served in the Navy myself, and was born at Lejeune. So am I understanding correctly that, if -- and I used myself, for example -

- if I was born on Lejeune or a dependent upon Lejeune, and then went into the Navy, and then later came down -- God forbid -- kidney cancer, then I could be considered a service connected? Is that, is that a gray area? I'm sure that's a gray area.

MR. FLOHR: Yes. It's the first time I've been presented with that question. I'll have to think about that and see how -- what the law would provide.

MR. PARTAIN: Thank you for bringing that up, ma'am.

MR. ORRIS: So Brad, I mean, this would all be solved if we would just stop treating dependents as second-class citizens, and give the same compensation and coverage to everybody.

MR. FLOHR: We would be happy to do that, Chris, if Congress passed legislation allowing us to do that.

MR. WHITE: And I wanted to address that question, also, Chris, because, as the program manager of the family member program, let me assure you that everybody that works in this program, they go into it with the attitude of wanting to help and not hinder, and wanting to provide the benefits that you guys are entitled to, because of exposure that you should never have been exposed to. So I want to make sure that I correct them.

MR. ORRIS: Thank you, Brady.

MS. TINA: Yes, my name is Tina. I spent 24 years in the Marine Corps. I did the way (unintelligible) the VA back last year in May. I just found out today they pretty much put it on hold. It's for breast cancer. My question is, will I have to -- it's not a presumptive disease, but I'm also having preterm births and two miscarriages in the 80s, okay, so is the VA going to look at that, my lifestyle, no smoking, no drinking, will the VA look at that as part as, okay, is this going to be pertaining to the water contamination?

MR. FLOHR: Well, I'm sorry, but no, breast cancer is not on the list of presumptives, so we would have to have some evidence that would rise to the level of at least the disability resulted from your exposures at Camp Lejeune.

MS. TINA: So how do you do that, and then you don't come to me face-to-face? I have a nine -- a 93-year-old grandmother, no breast cancer, my mom, 80-something, no breast cancer, sister and aunts, 80-something, no breast cancer in my family. But I was here during that period. Breast cancer, preterm births. Five months, five months (unintelligible), and then two miscarriages. I don't drink -- well, I'm

not -- had a drink maybe. If I say I drank more than twice a year, that would probably be a overstatement. Never smoked. So I have no lifestyle issue regarding breast cancer.

MR. FLOHR: Sure. Well, ma'am, I'm sorry. You'd have to file a new claim, if you've been denied.

MS. TINA: I'm not looking at (unintelligible) put it on hold. Put stuff on hold.

MR. FLOHR: They shouldn't have put that on hold. We put -- we put on hold the ones who are presumptive. So let me get with you later, give me some information, and I'll see what's going on with your claim, all right?

MS. TINA: All right.

MR. PARTAIN: And ma'am? Ma'am, over here. Can you get with me before you leave too, please? Thank you.

MR. JACKSON: Yes, my name is Brian Jackson, and I grew up here in Jacksonville, North Carolina. I was -- it was mentioned earlier that other areas would be considered for exposure of contaminants. What I'm wondering is those other areas considering those communities outside of Camp Lejeune.

I grew up in a area, Bell Fork homes, and as I go through that area it is so many people that died of

cancer in that area. Yes, some of them were Montford Point Marines, so they were exposed to Agent Orange. But you look at their wives and you look at other people -- I go down my, my street, and I know four people that died of pancreatic cancer, which includes my brother. So I'm wondering, are you considering, 'cause, you know, I know there's been other areas of other bases that have had contamination, do you consider those areas outside of the base, and if you are -- if you do, what are you going to do about it? What's the remedies for that? Have you considered remedies for it?

DR. BREYSSE: I think that's a broader Department of Defense issue rather than a VA issue. So ATSDR's working with the Department of Defense on contamination on a number of military bases across the country where the primary exposure is to people off site of the base, and so I'd like to know more about where is this neighborhood?

MR. JACKSON: It's within a mile -- it's within a mile of -- less than a mile of -- it's at Fort Camp Knox, Knox trailer park. TT? You know, and then you start dealing with those neighborhoods around it. I got family members that have cancers that -- unexplained cancers that --

DR. BREYSSE: So this is an area close to Camp Lejeune.

MR. JACKSON: Yeah, it's close to Camp Lejeune.

DR. BREYSSE: Okay.

MR. JACKSON: Yeah, yeah it's close to it. I can talk to you later about it.

DR. BREYSSE: Why don’t we do that.

MR. JACKSON: And also, you know, I was a advocate so I wanted to mention that you could also file with some of the service organizations, 'cause one of the ladies mentioned about filing claims with VA as well as maybe you could touch on accrued benefits for the young lady that came up here first, said, you know, just in case her father did pass. And you know, if they filed a claim and that claim stays active, that her mother could also receive the benefit that had started with that, and then (unintelligible).

DR. JOHNSON: Just a follow-up question. The area that you were describing, the area you were describing, was that an area where there were private wells?

MR. JACKSON: No, not at that -- I know my neighborhood didn't have a well.

DR. JOHNSON: Okay, so they would've been on city water?

MR. JACKSON: Yeah.

DR. JOHNSON: Interesting, okay.

MR. ORRIS: Yeah, one more question. Is that near the ABC One-Hour Cleaner?

MR. JACKSON: It's on that side of the street though.

MR. PARTAIN: Yeah, one of the things I want to point out to you, as an advocate myself, you know, you've got to identify the source, or a source, or something that has either been deposited into the ground or migrated into the areas. Like in the case of ABC Dry Cleaner was one of the sources for contamination at Tarawa Terrace. The dumping that took place on the premise there migrated into, you know, the base housing area.

MR. JACKSON: Right.

MR. PARTAIN: So I'm not aware -- I've done a lot of research and reading through documents. I'm not aware of anything migrating out but that doesn't preclude the possibilities.

MR. JACKSON: Well, if they're -- if they're monitoring near Brynn Marr, then I'm sure that some of those exposures is going to Bell Fork Homes. Okay, we can talk later.

MR. PARTAIN: Yeah, we'll talk about it.

MR. JACKSON: All right, thank you.

MS. HILL: Good afternoon, my name is Ernestine Hill, and I'm here just to ask a few questions. My husband died 1998 with lung, throat and brain cancer. I fill out papers and sent them to D.C. Like they asked for all my husband's papers from the hospital, and I sent them to them. So what am I supposed to do now? Because I also received a letter -- I also received a letter from D.C., from the, what is it, the general -- judge advocate. And that was just before Christmas that I talked to him. So where do I -- who do I talk to over here?

DR. BREYSSE: You should talk to -- who can help her? Talk to Brad with more specific information about --

MS. HILL: Well, I can go ahead and talk with him right now?

DR. BREYSSE: Maybe wait for a break.

MS. HILL: Okay, thank you.

DR. BREYSSE: So how much time do we have left?

MS. MUTTER: We have seven minutes.

DR. BREYSSE: Okay.

MS. KRAMER: I'll make this as painless as possible. My name is Sarah Kramer. First I want to apologize because when it comes to my husband my

composure don't always hold. Here we go. I am the widow of United States Marine Corps Lance Corporal Carl Kramer. I'm a resident of Florida, and I came here today to get some long overdue answers, which I know I'm not going to get.

I have a couple of questions. First, the Department of the Navy, Camp Lejeune and the VA, you have stripped my life of everything. You've taken my husband and you've taken my home. How much more does the VA want from me? I have no more to give.

I have my husband's SME report. This report contained so many discrepancies it's as though a ten-year-old had wrote it. My husband was a United States Marine veteran. Your SME states that he also retired from the Army. My husband was talented, but to be in two branches at the same time, simultaneously, that's a feat he couldn't have pulled off, even though he'd argue with you.

Your SME states that I was denied because of my -- my husband's alcohol overuse. He didn't drink. Where you coming from? I didn't have the template that was sent in here earlier. What you give your SMEs to use in order to deny a claimant, you say you use BMI? You also said my husband had an elevated BMI, so you said he was a fat alcoholic. He had an

elevated BMI, alcohol overuse, the man didn't drink. Yes, he smoked cigarettes. And it was just told to me the other day, I don't know the correct word 'cause I wasn't in the corps or any branch, but back in the 70s, when y'all gave rations to these Marines and soldiers, didn't y'all also contain four cigarettes in there?

MULTIPLE SPEAKERS: Yes.

MS. KRAMER: Did you not? So you blame my husband for smoking? And the military supplied the cigarettes. Y'all make no sense.

One more thing, last month I drove a thousand miles to visit your Louisville regional office, and I really don't need this paper I got written in my hand. But the one thing I want to ask -- I have a letter from my husband's personal oncologist. His credentials are out the door. I did as much research, along with someone I had met in this room, on the credentials of your SME. Your SME is an internal medicine doctor with credentials that -- well, they're not very impressive. My husband's oncologist, in his opinion those chemicals caused his cancer. You still deny me. I heard Mr. Flohr say earlier --

DR. BREYSSE: What kind of cancer was it, ma'am?

MS. KRAMER: Sir?

DR. BREYSSE: His cancer?

MS. KRAMER: He had esophageal cancer, stage IV. He died ten weeks after he was diagnosed. A year later I lost my home. I heard Mr. Flohr say earlier that, when an oncologist -- that you want more studies. The VA, not you personally, Mr. Flohr, but the VA, you're challenging my husband's oncologist with a family practice doctor. That's ridiculous. Where do you guys -- three years. In a couple more months it'll be three years. I'm on disability. I struggle to live. I struggle to buy medicines, and you deny me DIC, and reimburse me the final expenses. I'm sorry, you paid me $300. I'm sorry that didn't work. Because you won't deem it's service-connected.

The other thing is I drove a thousand miles last month -- I don't need this. I drove a thousand miles last month, and stood outside of your Louisville regional office holding up a sign: Camp Lejeune widow. My sister was visiting at the time. She held up the other one: VA denies all Camp Lejeune claims. I wasn't out there 20 minutes, someone come out of your high-rise building and invited me in. And I know it was just to get me off the streets. But it didn't work very long 'cause I was back out there again.

Mr. Bob Clay. You know, the interesting thing

with your VA employee, me and my sister stood there and had a meeting with him, and I told Mr. Clay, I said, Mr. Clay, I got something to ask you. I said, I was at Camp Lejeune last month, and downstairs in my car, if you'll allow me to go down and get it, I have two bottles of water that I got from the tap water at Camp Lejeune. If I go downstairs and get it and bring it up here to you, will you drink it? That man slammed both hands, and my sister was there to witness it, and if that video camera behind his back was really filming me, it can prove it. He slams his hands down on the desk, and says, absolutely not. If it's not harmful anymore what's happening to these men and women and civilians on that base today? What's happening? Are they going to be in my spot in 30 years? Home -- well, I'm not homeless, but I've lost my home, everything my husband and I worked for. But why did Mr. Clay not want to drink that water? All he wanted to do was apologize.

DR. BREYSSE: I'm very sorry.

MS. KRAMER: I want my benefits. I deserve them, and I've proved it.

DR. BREYSSE: I encourage you to maybe talk to one of the VA reps to see if they may help you while you're here.

MS. KRAMER: They won't do me any good. They're just going to tell me what I want to hear.

DR. BREYSSE: I'm sorry.

MS. KRAMER: Thank you.

DR. BREYSSE: We have time for two more questions?

MR. JOHNSON: My name is Gregory Johnson. I served 22 years, aboard Camp Lejeune most of those years there. I am of the opinion that when a military person serves, their family serves. My wife served right along with me. When we leave the military, and we retire, our wives get recognized for the many years that they have stood by our sides during all that time and many deployments. And in that time -- and I just heard you all speak about it. No one has -- you kept saying that you're not going to recognize our children.

I lost my daughter to two of the eight cancers. She was diagnosed at 18 and died the day before her 21st birthday. I had letters from the oncologist that simply says in order for that cancer to have been as aggressive as it was, she had to have come in contact with those volatile compounds. Through their registry, through what they have and the things that you all have said here, what are they going to do? I

understand that you all have two billion dollars, but that's on the VA side of the house. That's on the medical side of the house. That's the doctors and the bills. Are they talking about what they're going to do about those who actually have lost dependent loved ones? People.

DR. BREYSSE: I think at least we heard this. Everybody acknowledges that that's a gap in what's being done right now. And everybody's been trying to figure out the best way forward to make that available. But it sounds like it's going to require Congressional action. So you were encouraged earlier, by members of the CAP and by the VA, to reach out to your Congress people and make this issue known to them. If they ask me about it, I will very clearly, if I'm asked to brief any staff or Congressman, I'll acknowledge this is a lesion, this is a hole in the program. And I think we all just have to commit ourselves. I know the CAP is committed to do what they can to address this problem. As Jerry said early on, from his perspective, they're not done, and they're not done exactly because of this.

MR. JOHNSON: Second concern --

MR. PARTAIN: Sir, real quick. My name is Mike Partain. I was born at the base, so was Chris here,

and Danielle and Lori were dependents on the base too. We haven't forgotten the dependents, and we had to -- you know, you take a journey one step at a time. And I do appreciate you coming up here and bringing this up, because it is the next step. Just out of curiosity, was your daughter born at the base?

MR. JOHNSON: She was not born at the base.

MR. PARTAIN: Okay, how old was she when she came aboard the base?

MR. JOHNSON: She was three years old, possibly.

MR. PARTAIN: Okay. And I would like to talk to you too later on. I know you've talked to Jerry, but...

MR. JOHNSON: I've heard you all mention 15 different types of illnesses. A question, was one of those 15 diverticulitis?

DR. BREYSSE: No.

MR. JOHNSON: Okay, just wanted to know, 'cause I had thought I had read something where it said that if you came in contact with those compounds it possibly would've been there.

DR. BREYSSE: All right, thank you.

UNIDENTIFIED SPEAKER: Hi, I just want a clarification. You had said that when a widow's husband passes away that she's entitled to benefits.

My dad passed away, and I was told that the claim dies with him, and we can't file on his behalf anymore, and my mom doesn't have nothing. And I don't know if that's true or not because he was in service, disabled at the time.

MR. FLOHR: No, that's not true. When a veteran dies, if -- and a claim is filed, then we will look at it, look at the cause of death, see how it possibly could be related to service. If he had one of the eight presumptive, then that's -- it would be automatically entitlement to death benefits.

UNIDENTIFIED SPEAKER: (Unintelligible) the death was a (unintelligible). But he had Crohn's disease that was affecting him very severely. And he was just going to get his (unintelligible).

MR. FLOHR: I see. Well, like I say, your mother, his spouse, can file a claim at any time. And we'll look at it. We'll develop it. We'll look at his service records. If you have any medical evidence from treating physicians that might -- would be willing to provide an opinion to us saying I believe the veteran’s disability resulted from something at his service somehow, we'll look at that as well.

UNIDENTIFIED SPEAKER: Okay, my cousin had mentioned that that was the better thing too, because

she had said one of the three of us kids has tons of medical issues wrong with us. And it showed up when we were teenagers. So we were talking about filing a claim for that. So would they still be able to try to do that or?

MR. FLOHR: You're talking about for, for --

UNIDENTIFIED SPEAKER: For the --

MR. FLOHR: -- for dependents?

UNIDENTIFIED SPEAKER: Yeah, for the dependent that was under 18 at the time that the disabilities started.

MR. FLOHR: Well, the VA doesn't have the authority to compensate dependents.

UNIDENTIFIED SPEAKER: Okay.

DR. BREYSSE: This is the same issue we just explored but --

UNIDENTIFIED SPEAKER: (Unintelligible) and there's a dependent thing.

MR. FLOHR: If the veteran -- if the veteran was alive, filed a claim and he was getting benefits, he would be entitled to additional benefits for spouse and children under the age of 18.

UNIDENTIFIED SPEAKER: Well, they have children that were disabled. I just read it in the book. It says if you're disabled before the age of 18 --

MR. FLOHR: Yes, but that's -- that's just to provide additional compensation for the veteran.

UNIDENTIFIED SPEAKER: Oh, okay. Thanks.

DR. BREYSSE: We have one last question or comment?

UNIDENTIFIED SPEAKER: To the CAP board, thank you. Thank you. My voice will tremor. I am a Parkinson's survivor, Camp Lejeune dependent. Anyway, but my question is about the SME, okay, because we're experiencing that with my husband. And being that subject matter expert is really difficult to get through to your -- to that person. I know that's one of the things we've had with our issue. I didn't realize I should've brought it to you all. But the problem is, is that my husband's got mononeuritis multiplex, and -- a neurological disease. However, in his claim it's requiring, and it's not a Camp Lejeune water, but it's his claim is requiring that he has fibromyalgia or, what's the other one? I think the other one -- I forget it right now and I apologize for that. But anyway his claim is saying that. And his doctor, who is very talented, very renowned within the United States, has said -- her words to me when I told her the VA denied it, were: I can't believe this BS. Don't they realize that in order to have this he's

already had the fatigue? He's already had the fibromyalgia. All of those things have already occurred in this individual.

But now, to try to go back and make all of this happen is another -- just one more huge process that has to be done. And almost -- to let you know, we're just trying to fight for life. He, he -- every two weeks (unintelligible) every month chemotherapy. Every week two to three doctor appointments.

MR. FLOHR: Is your husband a Gulf War veteran?

UNIDENTIFIED SPEAKER: Yes.

MR. FLOHR: Okay, that's what I figured. Congress did pass legislation creating presumptions for Gulf War veterans who have either an undiagnosed illness or what they call a medically unexplained chronic multi-symptom illness, and the law gives for an example, fibromyalgia, chronic fatigue syndrome and one irritable bowel syndrome, or functional gastro-intestine disease. And if he has one of those and served in the Gulf, then he should be service-connected for it.

UNIDENTIFIED SPEAKER: Yes, but again, because his record showed mononeuritis, and it didn't show the fibromyalgia, the chronic fatigue, which are all systems of mononeuritis, and that's what his doctor

was trying to say. If these panel experts were, her words not mine, true doctors, they would've known that this was automatically something that's already transpired in this individual.

DR. DINESMAN: Come talk to me on the break. Let me see if I can't help you out.

UNIDENTIFIED SPEAKER: Okay. And for all of you that are out in the audience, I certainly do encourage you. I know that I went back after the -- after the panel met in Tampa, and I met with each one of my Congresswoman and senators' offices. And I went there because, as dependents, we had to live aboard this base 30 days. Shame on them. I know I had so many friends that never lived aboard this base, but they were there. We played ball together. Our kids drank out of the water up there. Every activity back in those days was on Camp Lejeune. There was nothing in Jacksonville. Everything was aboard the base. We went to the base to do everything. So I strongly encourage you, it's going to take our voices for this to change. And it is one step at a time. Thank you, CAP. Thank you, VA. I know this is hard.

DR. BREYSSE: Well, with that, I want to thank you for your voices. They're crucial to what we do. And so this -- I'll adjourn our CAP meeting. And if

people are interested there'll be a public availability session from five to six. And the public meeting from six to eight. And Jamie?

MS. MUTTER: Yeah, I just want to remind the CAP and all you going on the tour, this is not open to the public but if you are going on the tour, and have been preapproved, you need to be there at 1:20, no later at the front gate.

(Whereupon the meeting was adjourned at 12:07 p.m.)

CERTIFICATE OF COURT REPORTER

STATE OF GEORGIA

COUNTY OF FULTON

I, Steven Ray Green, Certified Merit Master Court Reporter, do hereby certify that I reported the above and foregoing on the day of January 21, 2017; and it is a true and accurate transcript of the proceedings captioned herein.

I further certify that I am neither relation nor counsel to any of the parties herein, nor have any interest in the cause named herein.

WITNESS my hand and official seal this the 18th day of February, 2017.

_____

STEVEN RAY GREEN, CCR, CVR-CM-M, PNSC

CERTIFIED MERIT MASTER COURT REPORTER

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