THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

AGENCY FOR TOXIC SUBSTANCES AND DISEASE REGISTRY

convenes the

THIRTY-THIRD MEETING

CAMP LEJEUNE COMMUNITY ASSISTANCE

PANEL (CAP) MEETING

December 4, 2015

The verbatim transcript of the Meeting of the Camp Lejeune Community Assistance Panel held at the Grand Hyatt Tampa Bay, Tampa, Florida, on December 4, 2015.

STEVEN RAY GREEN AND ASSOCIATES
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C O N T E N T S

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TRANSCRIPT LEGEND

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-- (sic) denotes an incorrect usage or pronunciation of a word which is transcribed in its original form as reported.

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-- "uh-huh" represents an affirmative response, and "uh-uh" represents a negative response.

-- "*" denotes a spelling based on phonetics, without reference available.

-- "^" represents unintelligible or unintelligible speech or speaker failure, usually failure to use a microphone or multiple speakers speaking simultaneously; also telephonic failure.

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

(alphabetically)

BOVE, DR. FRANK, ATSDR
BREYSSE, DR. PATRICK, NCEH/ATSDR
CANTOR, DR. KEN, CAP TECHNICAL ADVISOR
CLANCY, DR. CAROLYN, VHA
CLAPP, DR. RICHARD, CAP TECHNICAL ADVISOR
CORAZZA, DANIELLE, CAP MEMBER
ENSMINGER, JERRY, CAP MEMBER
ERICKSON, DR. RALPH LOREN, VHA
FLOHR, BRAD, VA
FORREST, MELISSA, DEPARTMENT OF NAVY
FRESHWATER, LORI, CAP MEMBER
GILLIG, RICHARD, ATSDR
HODORE, BERNARD, CAP MEMBER
ORRIS, CHRISTOPHER, CAP MEMBER
PARTAIN, MIKE, CAP MEMBER
RUCKART, PERRI, ATSDR
STEVENS, SHEILA, ATSDR, CAP LIAISON
TEMPLETON, TIM, CAP MEMBER
UNTERBERG, CRAIG, CAP MEMBER
WHITE, BRADY, VHA
WILKINS, KEVIN, CAP MEMBER

P R O C E E D I N G S

(4:00 p.m.)

WELCOME, INTRODUCTIONS, ANNOUNCEMENTS

MS. STEVENS: Okay everyone, welcome and thank you for coming to today's Camp Lejeune CAP meeting. For the next -- from now until 8:30 we will be having a meeting discussing -- you should have an agenda, if you -- when you first walked in the door. The agenda, basically we're going to have the welcome and introductions, following by the previous action items from the CAP meeting. Updates from health assessments, then we'll have updates on health studies. We'll break for about 40 -- or for 15 minutes, and then we'll have a briefing from Dr. Cantor on TCE, Veterans Affairs updates, CAP updates and concerns, a follow-up of the summary items that came from today's meeting. And then for the folks that are here and new to our meeting in our -- and joining us, we're going to have an opportunity for you to ask questions for about 30 minutes. And then we'll wrap up and adjourn the meeting.

My name is Sheila Stevens, I am the Camp Lejeune coordinator for this meeting. I work with the Agency for Toxic Substances and Disease Registry, and, and I work directly with the CAP members that are sitting

around the table, and other members that are participating in the meeting. If you need to go and use a restroom, exit door is over -- I'm pointing over towards it, the exit sign. There's a women's and a men's bathroom off to the right. Yeah, my right. You're -- that way. Just point to where I'm pointing at.

I also -- if you've lost your phone, I have a cell phone here. It belongs to one of our CAP members. Lori Freshwater, come on down; you're the next contestant.

So also I would like to take the time to recognize a few people in the audience that are here. We have Michael -- what are you saying Jerry? I want to first also -- I want to recognize a few folks that are in the audience right now. Michael Simonia[ph], and I'm just butchering your name; I am so sorry. With -- oh, my goodness; I'm sorry. We'll get back to that one. And I have Stephanie Germon with Kathy Castor, Congressman Castor's office. I have Digna Alvarez with Senator Bill Nelson's office. And Michael, come back and I'm going to recognize you again after the break so I have your information correct.

UNIDENTIFIED SPEAKER: Congressman ^ office.

MS. STEVENS: Thank you. Sorry about that.

UNIDENTIFIED SPEAKER: No problem.

MS. STEVENS: So, next one I introduce -- okay, also, if you have a cell phones on right now, please turn them off. Take a moment and turn your cell phones off.

And the next thing I want to do is I want to introduce the Director for the Agency for Toxic Substances and Disease Registry. He's also the Center Director for the National Center for Environmental Health, which is part of the Centers for Disease Control and Prevention in Atlanta. Please welcome Dr. Patrick Breysse. [applause]

DR. BREYSSE: No, no need to clap. So I want to add my welcome to everybody here today. It's thrilling to see such a large contingency from the community here as well. Hopefully you'll find this an informative day. That's what our goal is.

The purpose of the Agency for Toxic Substances and Disease Registry, ATSDR, is to address community concerns about chemicals and hazardous chemicals in their environment. And obviously Camp Lejeune is one of the more important sites that we're addressing through ATSDR. We hopefully will spend some time talking about the work that we're doing, and you'll be

informed by that.

I'd like to go around, start by asking for a moment of silence. So the shooting in California over this week hit us very close to home at ATSDR and NCEH. They were environment health professionals. Many of the people killed were from the Department of Environmental Health in the county out there, and these are colleagues that many of our colleagues at ATSDR and NCEH had worked with before. And it's awful when this stuff happens but it's even worse when you think that the people who are doing important environmental health work in the country were killed as a part of this disaster. So if people wouldn't mind, just us taking a moment for that. (moment of silence) Thank you very much.

So I'd also like to just say a few personal notes that I think one of the things that the tragedy in California, and the other tragedies around the world, reminded me is that it’s the one thing that we can anchor ourselves on, it's the one thing that we can use to keep us from going insane in this crazy world we live in, and that's a commitment to civility. And I think, as a civil society, that's what separates us from a lot of this madness around us. So I'd like to remind people today that there's a commitment to be

civil towards one another. And we can have disagreements, and we can talk about those disagreements but we're going to insist on civility, and I remind people in the audience as well that there will be time for you to participate, and if you could hold off until that time is available, we would appreciate it.

So I'd like to now go around the room and ask people to introduce themselves so everybody -- we get on the record who's here and people in the audience can see who we have here. And why don't we start over on my right with Brady.

MR. WHITE: My name is Brady White. I am with the VA. I am the program manager for the family members side of the Camp Lejeune program.

DR. ERICKSON: My name is Loren Erickson. I'm the chief consultant for post-deployment health. Our office works many of the environmental health issues that involve veterans, to include all the Camp Lejeune issues.

To my left, at the moment there's a gap, but shortly Mr. Brad Flohr from the VBA will be joining us as will Dr. Clancy, who has been the interim undersecretary of health for a year, and is now the deputy undersecretary of health for organizational

excellence. And so they'll be joining us here shortly.

MS. FORREST: Melissa Forrest. I am the Department of the Navy representative for the CAP.

MR. GILLIG: My name is Rick Gillig. I'm the branch chief for the central branch in the division of community health investigations at ATSDR. And this is the branch that is responsible for doing the public health assessments, one on ground water and one on soil vapor intrusion.

MS. RUCKART: Perri Ruckart, ATSDR, epidemiologist. I work on the health studies.

MS. STEVENS: Again, my name is Sheila Stevens. I'm with the Agency for Toxic Substances and Disease Registry, and I also have an announcement that Chris Orris, one of our CAP members, is on the line and listening and participating in this meeting.

DR. BREYSSE: As Sheila said, my name is Patrick Breysse. I'm the Director of ATSDR and the National Center for Environmental Health.

DR. BOVE: My name is Frank Bove. I'm an epidemiologist with ATSDR, and I work on the health studies.

DR. CANTOR: My name is Ken Cantor. I'm an environmental epidemiologist, retired from the

National Cancer Institute, and consulting with NCI on a part-time basis at the moment.

DR. CLAPP: My name is Richard Clapp. I'm an epidemiologist, member of the CAP.

MR. ENSMINGER: My name's Jerry Ensminger. I'm a member of the Camp Lejeune CAP.

MR. PARTAIN: My name is Mike Partain. I'm also a member of the Camp Lejeune CAP.

MR. TEMPLETON: Tim Templeton. I'm a member of the Camp Lejeune CAP. I was stationed at Camp Lejeune as a Marine, 1984 to 1986.

MR. UNTERBERG: Craig Unterberg. I'm a member of the Camp Lejeune CAP and I lived on Camp Lejeune from 1974 to 1976.

MS. FRESHWATER: Lori Freshwater. I lived on Camp Lejeune as a dependent from 1979 to 1983.

MS. CORAZZA: Danielle Corazza, member of the CAP, and I was born on base and was there from '80 to '86.

MR. WILKINS: Kevin Wilkins. I'm an ex-Marine and member of the CAP.

MR. HODORE: Bernard Hodore, CAP member.

DR. BREYSSE: Thank you very much. Are there any announcements we need to make, Sheila, at this point?

MS. STEVENS: Just, for those folks that are

participating tomorrow in our public meeting, the meeting -- we'll have some people here at 9:00 o'clock. We'll have some tables set up if you have questions or just want to talk to subject matter experts or other members who participate in this meeting. We'll have tables set up. That'll start around 9:00 o'clock. And then from 10:00 to 1:00 will be the public meeting. It'll be in this room, just like -- and it'll be in a little different setup, but that's a three-hour meeting that you're welcome to join us tomorrow. And hopefully you've registered for that meeting. Thank you.

ACTION ITEMS FROM PREVIOUS CAP MEETING

DR. BREYSSE: So with that, I'd like to move onto the formal part of the agenda. So Ms. Ruckart, if you can lead us in a discussion of the previous action items from the previous CAP meeting -- action items from the previous CAP meeting.

MS. RUCKART: Sure. I'm going to start off with some action items that are for the VA. So the first one is for VHA CBO. The CAP requests that the VA website encourage families of veterans to sign up to be administratively eligible for the family healthcare program.

MR. WHITE: Yeah, this is Brady, and we made sure that on our website that folks -- it's very clear that they do not have to have one of the 15 conditions in order to apply for the program.

UNIDENTIFIED SPEAKER: Can you say that one more time?

MR. WHITE: Sure. In order to apply for the program for benefits as a family member, you do not need to have one of the 15 conditions. You can -- if you were at Camp Lejeune during the covered time frame for 30 or more days, and you were a dependent of a qualified veteran, you can go ahead and sign up for the program.

MS. RUCKART: Okay. The next item is for VBA. The VA -- there was a request that the VA should acknowledge IARC, EPA and NTP findings on TCE carcinogenicity. Training for SMEs should include the cancer classification of these compounds, for example, that these agencies stated that TCE causes kidney cancer, so that reasons for denial don't include that it's unclear whether TCE causes kidney cancer.

MR. WHITE: Did you say that was for the VBA?

MS. RUCKART: Yes.

MR. WHITE: Okay. Any questions for them, we may have to postpone until Brad gets here.

MS. RUCKART: Okay.

MS. FRESHWATER: When is Brad going to be here?

DR. ERICKSON: Momentarily, I hope.

MR. WHITE: Well, perfect timing.

MR. ENSMINGER: I thought I smelled sulfur.

MS. RUCKART: Okay, we're going to ambush them as soon as they get here.

DR. BREYSSE: Dr. Erickson, you have such strong powers.

DR. ERICKSON: Hey, listen, I was going to have to start tap dancing here so you know. Brad, we have a question for you.

MR. FLOHR: Yes.

MS. RUCKART: I'll let them get seated.

DR. ERICKSON: So this is Brad Flohr and Dr. Clancy, and I'd provided introductions prior to them being here. But yeah, it's great to see you guys.

DR. BREYSSE: So as you're getting yourselves settled, maybe introduce yourselves to the crowd.

MR. WHITE: If I could just mention, I'm having a difficult time hearing some of you. I'm hard of hearing so I'm sure probably some of the other folks in the audience may have a difficult time as well, so make sure you're speaking into the microphone.

DR. BREYSSE: Does that include me?

MR. WHITE: Pardon me?

DR. BREYSSE: Are you having [laughing], I fell for it.

MS. FRESHWATER: Dr. Breysse, I heard somebody back here say yes.

DR. BREYSSE: I fell for it.

MS. FRESHWATER: People back here are saying they're having a hard time hearing us too. So I don't know if we have any more microphones but we're kind of short over here.

DR. BREYSSE: Well, there's one over here that can be moved if they're not -- well, I guess they're plugged in. That might be hard. We'll try and get something at the break.

UNIDENTIFIED SPEAKER: Somebody texted me. They're listening online and they can't hear the audio either.

DR. BREYSSE: We've had that problem before. So the online audio should be fine? So if anybody can hear online? How do we verify that they can hear? So we have a, right here, that is showing that it's coming through.

UNIDENTIFIED SPEAKER: I'm not saying it's not coming through. I'm just saying ^.

DR. BREYSSE: Okay.

MR. ENSMINGER: Tell them to try to turn their computer up.

DR. BREYSSE: So, if we still have a problem at the break we'll try and address it, but it appears like we have audio. So we'll pass the microphone off to the left. We have some handheld microphones. Jona, I think they need more microphones over in this area. So, Brad.

MR. FLOHR: Yes, sir.

DR. BREYSSE: Welcome. Can you introduce yourself?

MR. FLOHR: Yeah, hi. I'm Brad Flohr. I'm a senior advisor in compensation service with VA.

DR. BREYSSE: Dr. Clancy?

DR. CLANCY: Good afternoon everyone, and our apologies for being late. It was a horrendous traffic signal we got stuck at. I'm Carolyn Clancy. I'm the chief medical officer and, as of today, a deputy undersecretary for health at the Veterans' Health Administration.

DR. BREYSSE: Congratulations.

DR. CLANCY: Thank you.

DR. BREYSSE: And I'm sorry we don't have a tent for you but --

DR. CLANCY: I could make one.

DR. BREYSSE: -- we'll fix that when we can.

UNIDENTIFIED SPEAKER: We can hear online.

DR. BREYSSE: Okay.

DR. CLANCY: Terrific.

DR. BREYSSE: So do we want to go back to the question at hand? And the question that was asked, Brad, people punted. They said we can't answer that 'til Brad gets here. So that's why it was perfect that you walked in when you did.

MS. RUCKART: So it's that portion of the meeting where we go over the action items from last time, and this one was for VBA. It was a request that the VA should acknowledge IARC, EPA and NTP findings on TCE carcinogenicity. Training for SMEs should include the cancer classification of these compounds, for example, that these agencies stated that TCE causes kidney cancer, so that reasons for denial don't include that it's unclear whether TCE causes kidney cancer.

MR. FLOHR: As I recall, after the last couple of meetings this was brought up, and we went back and talked to our office of disability medical assessment, to make sure that that -- they understood that that was in fact -- kidney cancer is causative -- or TCE is causative for kidney cancer. So hopefully that's

changed.

MS. RUCKART: Okay. The next item is for -- oh, do you --

DR. CLANCY: I was just going to say, the office of disability and medical assessment -- assessment, excuse me, actually is under Veterans' Health Administration, so I will confirm that that was followed through on.

MS. RUCKART: Okay. The next item is VHA item as well -- or a VHA item. The V -- the CAP would like the VA to take steps to make Camp Lejeune a presumptive using the IOM report for Camp Lejeune.

DR. CLANCY: Can you say that again?

MS. RUCKART: Mm-hmm. The CAP would like VA to take steps to make Camp Lejeune a presumptive using the IOM report for Camp Lejeune.

DR. ERICKSON: Yes, I --

DR. CLANCY: Go.

DR. ERICKSON: May I take that? Again, this is Loren Erickson. The IOM report, I believe, that's being referred to is the review of the clinical guidelines, that we asked them to review. I will assure you that the work group and the task force at VA has studied that very carefully; however, that particular decision is what we call pre-decisional at

the present time. In other words, I cannot speak for my big boss, in terms of what his decision is, is that it is shortly forthcoming, but I can tell you that we did look at that very carefully. We did consider that very carefully.

MS. RUCKART: Okay. The next item is for VHA as well. The CAP would like the VA to conduct more education and outreach to VA clinicians on Camp Lejeune.

MR. WHITE: I'm sorry, could you repeat that?

MS. RUCKART: Mm-hmm. The CAP would like the VA to conduct more education and outreach to VA clinicians on Camp Lejeune.

MR. WHITE: Okay. Yeah, that's part of my presentation about showing exactly what we've done since the last CAP meeting. But we have done additional outreach. We've trained some additional individuals. We've got some online training that's available 24/7. So I believe we tackled that.

MS. RUCKART: Okay. The next item is for VBA. The CAP would like information on the number of male breast cancer claims, how many were determined diagnostically to have the condition, and how many were approved and how many denied.

MR. FLOHR: We did that review about the end of

last year, and we sent that report to Senators Burr and Hagan and Nelson, so I figured that you had all had gotten that report. In fact I talked about that the last time, I believe.

I've got it with me. We reviewed 206 claims files where breast cancer was an issue; that is, it was identified in our systems by a diagnostic code that would indicate breast cancer or something similar to that. 117 of those were from males; 89 were from females. They were identified by searching our database using our unique diagnostic code. They're identified as decisions made on claims. Of the 117 identified breast cancer claims filed by males with service at Camp Lejeune during the period of water contamination, only 47 actually had a diagnosis of breast cancer.

Sixteen of those claims were granted. Now, this is, again, the end of last year, representing a grant rate of 34 percent. Of the 89 identified breast cancer claims filed by females with service at Camp Lejeune, only 73, which is significantly more than the males, 73 actually had a diagnosis of breast cancer. 31 of those claims were granted, representing a grant rate of 42 percent. And I'm sure I gave this to you last time, or at least one of the last meetings.

MS. FRESHWATER: I don't have that, and I don't -- also those senators don't call me. They might call some of the people at the table, so giving it to them doesn't mean I get it. So if you could --

MR. FLOHR: Yeah.

MR. PARTAIN: Brad, the information was given out, and I believe that part of the question, and I'm not sure if it got garbled somewhere, was an update since then, as far as after -- because I believe that statistic's over a year old.

MR. FLOHR: Yes, they are, and I don't recall getting any due outs to.

MR. PARTAIN: Okay. 'Cause we did have these numbers.

MR. FLOHR: Yeah, that's what I thought, yeah.

MR. PARTAIN: And what I was getting at is if there's any updates since then. And just out of curiosity, would the -- the 117 cases, the other, what, 70 that were -- I mean, I'm just a little confused how someone comes in with male breast cancer to the VA, and only 47 end up with a diagnosis. I mean, what kind of other things were -- how were they misdiagnosed, I guess?

MR. FLOHR: Well, you said when we -- we may -- rather than a claim for breast cancer, it may have

been a claim for gynecomastia. But we don't have a unique diagnostic code for gynecomastia in our rating schedule.

MR. PARTAIN: What about a non-cancerous tumor? 'Cause there were quite a few of that.

MR. FLOHR: That as well. We do have a non-malignant -- not necessarily breast cancer but a cancer of that body system. So although we pulled them for granted and denied breast cancer, there were other conditions, gynecomastia, nipple discharge, things like that, that were -- were identified by a unique diagnostic --

MR. PARTAIN: A disorder of the breast code or something?

MR. FLOHR: Yes. A made-up code.

MR. PARTAIN: Okay. Okay. And thank you.

MS. CORAZZA: So I think part of the reason that question was asked is because we've noticed some of the other claims numbers going down, and so we wanted specifically to know if those were going down also. That approval -- I'm sorry, the granted percentages.

MS. FRESHWATER: Right, like why is the male breast cancer lower than the female breast cancer on approvals?

MR. FLOHR: I'm not a clinician or -- so I can't

tell you why --

MS. FRESHWATER: I know but I'm saying this is why we keep asking, to try and get some sort of idea of why.

MR. FLOHR: It's, it's -- basically it's because when we get a medical opinion, which we get to determine if someone has a disease that's caused by contaminated water, and if we get a negative opinion, then it's going to be a denial in most cases.

MS. FRESHWATER: So the new numbers won't take into consideration the new study. Would that be right?

MR. FLOHR: I'm sorry?

MS. FRESHWATER: The new -- when we get new numbers, since Mike is saying these are the old numbers.

MR. FLOHR: If you want new numbers, that can be a due-out today. I mean, I can't give them to you today 'cause I don't have --

MR. PARTAIN: Yeah, it'd be nice to have an update.

MR. FLOHR: Okay.

MR. PARTAIN: To see where we're at. And on a side note, the -- I mean, we have a pretty large public contingent here tonight. I know a lot of

people do have questions they'd like to ask. Unfortunately we're not really set up to do that here now. But either -- are we going to do a public answer at the end or?

DR. BREYSSE: Yeah, there'll be -- but we have a whole public meeting scheduled for tomorrow.

MR. PARTAIN: That's what I wanted to bring up. You know, if you can hold your questions or if you can get with us at the break or something, if you need to have a question or something like that. Also the VA, Dr. Clancy, I'm assuming you guys are going to be here tomorrow for questions and things like that. And I do know there are a couple people here tonight that can't be here tomorrow, like one family who's going to be undergoing dialysis tomorrow and cannot be here. So, you know, they have some questions. I'd like to see if we can get them addressed too. But I just wanted to take a second to bring that up.

MR. TEMPLETON: While we were on this topic, I had an exchange with Mr. Flohr a few meetings ago, talking about the diagnostic codes and so forth. But Dr. Clancy, since you're here, I'd like to confirm that VHA actually does use ICD-9 or ICD-10 for their diagnostic codes; is that correct?

DR. CLANCY: Yes. We just transitioned to ICD-10

as of the end of the fiscal year. So it's coming into October 1 --

MR. TEMPLETON: Right.

DR. CLANCY: -- we made that switch.

MR. TEMPLETON: And the exchange, and I'll shut up real quick, but the exchange had to do with the transposition between the ICD codes --

DR. CLANCY: Yes.

MR. TEMPLETON: -- that are used and the codes that are used by VBA.

DR. CLANCY: Yes, so what you're saying is in updated numbers we're going to need to be extremely attentive to that issue.

MR. TEMPLETON: Yeah.

DR. CLANCY: Yeah, got it.

MR. TEMPLETON: 'Cause unfortunately it sounds like that some of them may be getting missed during that transition process --

DR. CLANCY: Yes.

MR. TEMPLETON: -- from ICD to the VBA system, that maybe there are some errors that are involved there?

MR. FLOHR: No, Tim, that's -- we do not use ICD codes. We have a unique set of diagnostic codes. We have approximately somewhere over 800 unique

diagnostic codes in VBA's systems to identify diseases and disabilities, injuries, musculoskeletal, cardiovascular, whatever. But we don't identify them through ICD.

MR. TEMPLETON: Right, but I guess, the whole point, and again, I'll shut up real quick here, but the whole point was that when it comes to you it either comes from private physicians or it comes from the VHA, that are in the ICD -- that those codes are in ICD, and somehow they have to get translated over to something that VBA uses for their purposes.

MR. FLOHR: Well, not exactly. If someone files a claim, let's say, for a low back condition. They injured their back in service and they've got pain and whatever. And we can do an examination to determine how severe it is, 'cause we know it happened in service. We need to know how severe it is, not whether it occurred in service, because we have that through their service medical records. And we give an examination, and we have a unique diagnostic code for low back disabilities. It's -- our code's 5295. It has nothing to do with ICD codes. We don't need an ICD code. We -- that's just how we identify it, and we determine the severity and assign an evaluation. But the examiner might put an ICD code on the

examination, but it's not something that we actually use.

DR. CLANCY: I'm going to take that as a due-out, though, 'cause now I'm really curious, so thank you for the question. And for -- I don't -- I won't go into the long drama about the switch from ICD-9 to -10, but you can tune in to many places to hear people yelling about it. What I will say is that it vastly expands the number of diagnoses, so even when Brad was just describing what other codes might be thought of as breast cancer or similar and related to that part of the body. ICD-10 has got a zillion and one entries for things, including such things as in-laws were visiting, believe it or not.

MS. RUCKART: Okay, the next item is for the VBA. The CAP requests that the VA stop using the NRC report as a reference or decision authority when processing claims.

MR. FLOHR: I had that conversation with the medical examiners when we came back from the last CAP meeting. I made it a point to say, do not use that solely as a basis for a denial of a claim.

MS. FRESHWATER: Well, can you define solely? Like you're still using it. What weight are you giving it if you're using it?

MR. FLOHR: By solely I mean don't use that as the only reason for denial.

MS. FRESHWATER: Can they use it for 90 percent?

MR. FLOHR: I have no idea.

MS. FRESHWATER: Can we get clarification on that, please?

MR. PARTAIN: And Brad, I mean, I don't want to get into another round of semantics like we did back in May, but when you're dealing with the NRC report, you know, it is an old study, 2009, and there have been significant advancements and studies that have been completed since then.

The weight of what Lori was asking is concerning what weight is the VA placing with the NRC report. Frankly I would question whether -- why that should be even a part of the review. 'Cause you say that one -- not one report should be considered. I mean, when you're looking at scientific evidence, you're looking at the weight of the evidence, the body of the evidence, not just one or two reports. But and -- well, as Jerry's reminding me here, the NRC report wasn't even a study. It was a review of scientific literature.

MR. FLOHR: Right.

MR. PARTAIN: And there were some fundamental

flaws with that report, including, as we've mentioned in the past, the fact that the peer reviewer was cherry-picking the peer review, and a former executive of -- was it Honeywell?

MR. ENSMINGER: Honeywell, Limited.

MR. PARTAIN: Honeywell, Limited, who is a major TCE contaminator in this country. And the fact that the VA is using the report in any capacity at this point is a concern from the community. I mean, and we've got letters from other epidemiologists. We have a letter from one of the former directors of ATSDR, back in 2010, stating that there was a hazard at Camp Lejeune and contradicting the findings of these reports -- of the NRC report.

So going back to the question, if the report is going to be used, I think the VA needs to articulate in what manner, and also what counterpoints are being provided to these SMEs in the use of this report. Are they aware of the limitations, the shortcomings, the problems with that report?

DR. ERICKSON: Mike, maybe I can jump in. I don't, I don't do the claims evaluations, though I have a lot of contact with this disability group that does these medical assessments. And what they would tell you is that they have an ever-growing

bibliography, which includes, for instance, the study that's on the screen, okay, in terms of this bibliography is growing as new studies are published in the peer reviewed literature, as they're made aware of new information. And I think to a person they would tell you they're not relying upon the NRC report as the basis of their claims today. They have an ever-dynamic and ever-evolving fund of information that is that body of knowledge that you were talking about.

MR. PARTAIN: And on that point, Dr. Erickson, the bibliography --

DR. BREYSSE: Mike, can I interrupt, please? We have a lot of other former action items to go through. Can we go through that? If we have time, we come back to this issue or?

MR. PARTAIN: Okay. Let me make just one point with this bibliography, and I'll end right here with the bibliography and this case in point. Yes, the bibliography's important. Hopefully Wikipedia's not part of that. But that bibliography should be public and made available to the public so we can see what they're saying. And I know I've asked for this in the past but I would like to have a copy of that bibliography of what's being relied upon by the SMEs.

Thank you, Dr. Breysse. I'm sorry about --

MR. ENSMINGER: Well, I want to go back to Dr. Erickson for a minute, on the IOM report and the review of it. Who did the review?

DR. ERICKSON: Okay. Just so I know which one we're talking about, is it the most recent IOM study?

MR. ENSMINGER: Yes, yeah.

DR. ERICKSON: Where the IOM was asked by VA to review the VA clinical guidelines?

MR. ENSMINGER: Yes.

DR. ERICKSON: Okay. Okay, good. So VA commissioned a study with --

MR. ENSMINGER: IOM.

DR. ERICKSON: -- IOM, and said, you know, we have a list of clinical guidelines that we provide to our clinicians that help us to execute, to carry out the wishes of Congress, as stated in the 2012 law, which you know very well, the 15 conditions, et cetera. And the goal of the clinical guidelines, of course, were to describe to the clinicians how they would approach being able to fill the requirements of that legislation.

Realizing that, you know, our best efforts needed to be peer reviewed, needed an external independent body to look at what we were doing, we asked the IOM

to look at that, and in fact commissioned them to do a study to respond back to us to tell us, you know, are we on target? Did we get this right? If we need to change it, what things do we need to change? And they actually then published, you're right, in this last year, a document -- and in fact I held that document up --

MR. ENSMINGER: No, I, I have the report.

DR. ERICKSON: Okay, very good. And so at that point, then VA is put back into the response mode, where VA then needs to bring our SMEs, our subject matter experts, together and say, okay, IOM is making recommendations to us. How can we take those recommendations and rewrite our clinical guidelines so that they're better, so that they take into account what the IOM is recommending that we do?

I will tell you that there was a committee of SMEs, a work group. They have done this. This document has been rewritten. It's in final ^ right now, but because it's pre-decisional, I cannot show it to you today. Okay, and this is, this is a bureaucratic thing, and I'm sorry, but I will tell you that it's -- we have taken to heart every word of the IOM report.

MR. ENSMINGER: Well, I remember whenever you

announced that you were forming this task force to do this review of the IOM report and make recommendations, I remember asking you if you would consider including, like for Camp Lejeune -- I know every situation and every issue that the VA deals with, you don't have a community assistance program or group. But we do, and I asked you to include some of our experts in that task force, on that review, and you didn't do it. I mean, we got two of the best, most renowned epidemiologists in the world sitting here.

DR. ERICKSON: Right, and Mr. Ensminger, this is a clinical document.

MR. ENSMINGER: Well, that's fine.

DR. ERICKSON: This involves -- well, but a clinical document involves physicians who touch patients, who make diagnoses.

MR. ENSMINGER: So this was all done by physicians?

DR. ERICKSON: This was primarily -- yes.

MR. ENSMINGER: You said subject matter expert.

DR. ERICKSON: Well, which is a very broad term. But again, this is --

MR. ENSMINGER: Yeah, I'll say.

DR. ERICKSON: Well, but it's a clinical

document. Well, it is. But it's a, it's a clinical document.

DR. BREYSSE: I think we need to move on; otherwise we're not going to get close to getting through this section.

MS. RUCKART: Okay, our next item is also for VBA. The CAP requests more information, such as a breakdown of miscellaneous conditions with the claims.

MR. FLOHR: I actually have -- I do have that for you. The top ten that make up miscellaneous conditions, by a very large number, is diabetes. Then there's hypertension, colon cancer, a kidney condition -- not cancer but another condition -- high blood pressure, depression, heart conditions, sleep apnea and erectile dysfunction. Those are the top ten.

MS. RUCKART: Okay.

MS. FRESHWATER: Can you be more specific about the kidney?

MR. FLOHR: I'm sorry?

MS. FRESHWATER: The kidney. You're saying anything that's not diagnosed as cancer --

MR. FLOHR: Not cancer but a chronic renal disease or whatever.

MS. FRESHWATER: So you're familiar with Willy. We've been working together with Willy Copeland down

in Georgia, right? He has end-stage renal disease.

MR. FLOHR: No, I don't know.

MS. FRESHWATER: Okay, well, we've talked about it, but anyway that's where he would fall into a miscellaneous as opposed to -- do you see what I'm saying?

MR. FLOHR: Sure.

MS. FRESHWATER: So that's what -- that would cover him.

MR. FLOHR: I think so, yes.

MS. FRESHWATER: Okay.

MR. TEMPLETON: Brad, can we get a copy of that? And is there a number for each one of the top ten that you had there?

MR. FLOHR: Yeah, for example diabetes is 1,246.

MS. FRESHWATER: Brad, he's called -- he called in. He's a double amputee. He was a police officer. He's been on the news now down there in Georgia. Do you remember now?

MR. FLOHR: I really don't.

MS. FRESHWATER: Okay, that’s all right.

DR. BREYSSE: I think we can come back to that but we need to move along. And Brad, can you get the numbers off line?

MR. FLOHR: I'll send it to Perri, when I get

back to the office on Monday.

MR. PARTAIN: Actually, Brad, and just the numbers, before we move on, the cancers, the 15 conditions that are on the healthcare law, are they included in this breakdown too? 'Cause I'd like to see the number of kidney cancers, leukemias, liver cancer, bladder cancer --

MR. FLOHR: That's right. Those are the normal --

MR. PARTAIN: Okay, 'cause I'm not sure --

MR. FLOHR: -- claims that we track. And you've seen the report I've given --

MR. PARTAIN: No, I just want an update on that.

DR. BREYSSE: Remember at the end of the list, there's miscellaneous? So this is just breaking down what was -- there's a huge number of cases of miscellaneous, and you guys asked, what does that encompass?

MR. PARTAIN: Okay.

DR. BREYSSE: And so I think Brad is being clear about that.

MS. FRESHWATER: I think we were curious as to how many toe fungus cases were reported.

MR. FLOHR: I have the most recent Camp Lejeune report as through November as well.

MR. PARTAIN: Okay. Thank you.

MS. RUCKART: Okay, the next item. The CAP requested clarification on the maximum copay amount per day for healthcare and per prescription for the VA. And that -- I have information that Brady has that to go over when he gives his presentation.

MR. WHITE: I am going to be going over that in my presentation, but real quickly, for inpatient care, for Camp Lejeune veterans, what we're talking about here, they don't have any copayments for a Camp Lejeune condition. But they would pay normal VA copays for care that's not related to one of the 15 conditions, okay. And then if you break that down, for inpatient care it's ten dollars a day, plus $1,260 for the first 90 days. For outpatient care, it's $15 for primary care, $50 for specialty care. And I'm running through these a little quickly but it'll be on the slide, and I think you guys are going to get a copy of that after this. And then outpatient medication, it's eight dollars per day for a 30-day supply for veterans that are in priority group 2 through 6.

DR. BREYSSE: Brady, can we do this tomorrow, if we're going to do it tomorrow? I'm really --

MR. WHITE: Okay, yeah.

DR. BREYSSE: -- worried about the time.

MR. WHITE: Absolutely, I'm just trying to answer the question.

DR. BREYSSE: Yeah, I appreciate that.

MS. RUCKART: Okay. And the CAP requested that Brady White give his PowerPoint presentation from the Greensboro meeting at the meeting in Tampa. So he'll do that tomorrow.

There was a question for the VBA. How frequently are Camp Lejeune veterans submitting information the first time for claims and benefits so that their requests are not required to go through further SME review. They wanted numbers.

MR. FLOHR: I'm sorry, the question was how many times do we make a decision on a claim without getting an SME/VHA review? Those numbers I don't have. Our data folks are looking into that. They might be able to do that but they're going to have dig deep in that. And as soon as I get that I'll give it to you.

MS. RUCKART: Okay. There was a request, this is for you, Brad, to check if denial letters are following the CAVC criteria for fully articulating the decision.

MR. FLOHR: We've got some notice letters from Louisville, and yes, they do. They are very, very

in-depth, provide all the information about the decision, how it was made, how it was arrived at, how they can appeal it. Talks about very, very --

MR. TEMPLETON: Is that after a certain date or?

MR. FLOHR: That's current. I don't know if it's changed.

MR. TEMPLETON: Okay.

MR. FLOHR: Everything has changed. I mean, we're going through transformations. We're doing electronic claims processing now. Almost 99 percent of all claims we do are electronic, which I never thought I'd see that in my career. We've done that really, really quickly. So now everybody can -- like right now we have Camp Lejeune in Louisville; we have radiation cases in Jackson, Mississippi.

At some point in time, this is called the national work queue, we can send claims to any regional office, not just where a veteran lives. One office may have more ability to do claims than another office, may be backed up. And eventually I believe we'll be able to do more targeting of specific types of claims, environmental exposure type claims. We'll have PTSD experts and TBI experts in one regional office or another. All those people are in one office. They're specially trained people, really good

folks. So that's down the road. That's not now but it's down the road.

MS. RUCKART: Okay, the next item was for both VBA and VHA. The CAP reiterated their request to have a presentation at the public meeting tomorrow on the difference between VBA and VHA, and what each covers.

MR. FLOHR: We're prepared to do that.

MS. RUCKART: Okay. The next item is for VHA. There was a request for the VA to provide at the Tampa meeting the budget for the Camp Lejeune family member program and how much has been spent so far, and I believe Brady will discuss this during his presentation.

This is an item for the DON. There was a request to put together a process on how to release the documents to the CAP that have already been released to ATSDR. The CAP wanted to know if there was a way to grant access specifically to the CAP members while the issue of public release is being worked out. A suggestion was made for the CAP to view the documents at Camp Lejeune in a secure room where they did not have any access to electronic recording devices.

MS. FORREST: As outlined in the general charter, the ATSDR community assistance panels, or CAPs, are non-statutory groups that provide a mechanism to

exchange information with the affected community and to obtain input from the community. CAP members are not special government employees, consultants or experts to ATSDR. Therefore the CAP members are considered members of the public for purposes of access to government documents.

Since all DoD unclassified information must be reviewed and approved for release before it is provided to the public, any access to documents, whether in a secure room or otherwise, is not permissible until the formal review process under FOIA is completed.

MR. ENSMINGER: Thank you for that lecture. I mean, but that still doesn't answer the question. You know, how long are you people going to take reviewing these documents so that they can be released to the public? I mean, your legal people have had long enough.

DR. BREYSSE: Do you have a time limit?

MS. FORREST: Do I -- I think I would have to know specifically which documents --

MR. ENSMINGER: All the documents that they're working on the public health assessment, on the vapor intrusion, that we've been asking for for years. That's what we're talking about. Now, where are they?

MR. PARTAIN: The Marine Corps and the Navy did not have a problem releasing documents. Matter of fact ATSDR, in their water modeling, enclosed several DVDs of the documents. They didn't -- this did not become an issue with these FOIA requests until we started putting together the documents and making a sensible storing, and asking questions. And it is -- I mean, the latest trove -- and when we started, we're talking probably 8,000 documents or so that, when I got involved in this back in 2007-2008, and my understanding we're up to, what, 45,000 documents that were disclosed to us last year. And now over a year later, and we still don't have any release or any type, you know, even a partial release of these documents.

Many of these documents go back to the 1980s. The Navy has been in possession of these documents for over 30 years in some cases. Now granted there are documents that are coming out today, but the thing is, what are you people doing? This information is not a national security; it's a national tragedy, the fact that you people poisoned a million Marines and their families over a 38-year period on the base. We have a right to know what transpired on the base. We have a right to know what was in our water. And we have a

right to these documents.

MR. ENSMINGER: And what was in our air.

MR. PARTAIN: And I'm sorry, what was in the air and the soil, too, in the case of the child daycare building -- center, in building 712 that was the former pesticide shop, that they put the kids in in 1966.

DR. BREYSSE: All right. So Melissa, is there anything additional you can add?

MS. FORREST: I can't add anything additional at this time. I mean, to me this sounds like maybe something that -- I know ATSDR and the Navy, we do program review meetings. It sounds like something that needs to be worked out between the two agencies on exactly what point in the process --

DR. BREYSSE: So --

MS. FORREST: -- because I -- because if I'm not -- I just wanted to finish and say I mean, as far as I understand, ATSDR is getting all of the documents --

DR. BREYSSE: Yes.

MS. FORREST: -- from the Navy that they need to conduct --

DR. BREYSSE: So we have the documents, and the CAP has asked for us to show them to them, and the

Navy said we can't because they haven't been released. And then I believe the CAP then FOIA'd the documents. And they're waiting to hear --

MS. FORREST: Has, has the CAP FOIA'd the documents, all of the documents?

MR. PARTAIN: We've been asking for these documents for the past year. I know every CAP meeting I bring it up.

DR. BREYSSE: Is it an official FOIA request or is it just a CAP request?

MR. PARTAIN: I don't know what the FOIA -- at this point we've got 45,000 documents. We don't even know, really, what's out there. All we got is the index that you --

MR. ENSMINGER: Well, the point is this. When ATSDR gets their study done, and their assessment, is a better word, and they want to issue that assessment, they can't issue it without the supporting documents to back it up. And if we don't have our hands on it, it'll go right back to the way it was with the water. We found things in the water documents that ATSDR overlooked.

DR. BREYSSE: So if we can make it an action item for us to revisit with the Navy the time frame and the conditions under which those data can be released,

it's clear to me, when we publish our report all the documents that we cite have to be made publicly available, and I believe the Navy knows that. But there's probably going to be many other reports that we don't cite that won't be released as a matter of fact at that point, that I think, the CAP is still going to want to see. So I think that that's -- we can do our best to talk to the Navy through the APOW process but we'll do that.

MS. FORREST: If I'm understanding --

MR. PARTAIN: With all due respect to you, and thank you for being here, but the fact that the Marine Corps does not have a uniformed officer representing them here at this table, and has withdrawn because they consider themselves a distraction to our proceedings, is an insult to the community. And I do want to note that here now. [applause]

DR. BREYSSE: And the thing is -- I think we need to keep this on a more professional plane. I appreciate the enthusiasm of the audience, but if we can hold back on that and, and I think we've discovered that this is probably something we still need to work on.

MS. FORREST: Yeah, and I want to make sure I understand the full complexity of the action item,

'cause we just talk about all documents, all documents.

MR. PARTAIN: Well, Camp Lejeune is a Superfund site, and under CERCLA these documents should be in the administrative record that is publicly available, and for some reason they're not. And case in point, and I'll leave off at this point because we're kind of -- to avoid beating a dead horse, but the case in point is the presence of 1.5 million gallons of fuel in the aquifer at Camp Lejeune.

Okay, up until 2009, we did not have a clue. The Marine Corps/Navy was telling Senators Burr and the Congress that they -- according to their inventory records they lost 30- to 50,000 gallons of fuel, which was the truth, 'cause their inventory records did include -- indicate that.

What they weren't telling us and Congress was that there was a password-protected electronic portal with 1,500 Navy documents detailing the loss of 1.5 million gallons into the ground at Hadnot Point. That's the kind of stuff that's a problem.

Now, and not criticizing ATSDR, but as Jerry mentioned, when they went through the public health assessment, and we did a presentation of this back in September of 2014, they missed a lot of stuff. They

missed a lot of information, and critical information, including the presence of benzene in the water, that ultimately forced ATSDR to withdraw the public health assessment ^ 2009.

MS. FORREST: But to help me formulate this action item, you are saying -- I understand, you know, the process --

MR. ENSMINGER: Ask Rick Gillig. He'll give you what the documents we're talking about.

DR. BREYSSE: Well, we have a large library of documents that the Navy made available to us for our ongoing public health assessment. Those are the documents that the CAP has asked to have access to.

MS. FORREST: For the public health assessment --

DR. BREYSSE: We have a list, and we could give that to you, I assume, Rick? Tell me if I'm saying something wrong?

MS. STEVENS: Rick is right here.

MR. GILLIG: The list has been provided to Scott Williams. Scott Williams is serving lead on this. We talk to Scott at least once a week about the status of releasing those documents. And I know Scott's working on it.

MS. FORREST: Yes, I know they're working on reviewing them. They have to be reviewing them.

MR. UNTERBERG: Melissa, it seems like you raised at the beginning somewhat of a legal issue on why you can't release it. Who is your internal counsel that's dealing with it? Is that someone we can talk to? 'Cause I find it hard to believe that you guys don't have situations where you enter into confidentiality agreements and NDAs with non-consultants and non-employees, and we could have a legal discussion about that prohibition, 'cause it sounds like you're saying we're public, and there's no way to get around giving us the documents from a legal perspective.

MR. ENSMINGER: Well, the eastern area counsel's office is the ones that are doing this review, supposedly, so.

MR. UNTERBERG: Could we have a specific name? I'd like -- I'm an attorney, I'd like to talk to them, 'cause I think there should be a solution.

MS. FORREST: I will have to get back to you with a name, for you to speak with. There are multiple lawyers who work with different aspects of this.

MR. UNTERBERG: Fine.

UNIDENTIFIED SPEAKER: You can tell 'em we'd like it released this week.

DR. BREYSSE: Perri?

MS. RUCKART: Okay. The next item is also for

the DON. There was a question about the need to clarify for the building 133 vapor intrusion investigation, what was the justification for using the industrial standard versus using different screening methods if that building was classified as an administrative building.

MS. FORREST: I apologize. It's a little long but we wanted to clear up two different possible confusing items related to the term industrial. So the Environmental Protection Agency industrial or non-residential risk-base screening level was the proper screening level for building 133, an administrative building. The difference between industrial, or non-residential, and residential is the amount of time spent at the location. The EPA industrial, non-residential air risk-based screening value is based on a person being at that location for 250 days per year, an example of five-day work week, two weeks of leave per year, for eight hours per day.

The EPA residential air risk-base screening values are based on exposure conditions for 350 days per year for 24 hours per day.

Please note that at the time of the building 133 vapor intrusion investigation in 2013 the EPA risk-based screening levels were classified as industrial

and residential. Since that time EPA has renamed the industrial screening level as non-residential. This change in terminology did not affect the screening level values and therefore does not change the conclusion of the 2013 building 133 vapor intrusion investigation. For clarification, industrial health-based values, such as those set by the Occupational Safety and Health Administration, or OSHA, were not used in this evaluation. It was EPA screening values.

MS. RUCKART: And the last action item. There was a request that we invite Dr. Sarah Blossom of the University of Arkansas to the Tampa CAP meeting to discuss immunotoxicology. She was invited. She couldn't attend today. And we are going to invite her to our next meeting.

MS. FRESHWATER: Just to be clear, she was available for the meeting, and then we had to change the date. But she was available for the original meeting, and we're very much looking forward to working with her.

DR. BREYSSE: And we're committed to getting her here.

MS. RUCKART: Pardon?

DR. BREYSSE: And we are committed to getting her

here.

HEALTH ASSESSMENT UPDATES

DR. BREYSSE: So the next item on the agenda is an update on the health assessments, soil vapor intrusion, drinking water re-analysis. Rick, can you walk us through that?

MR. GILLIG: Sure. First I'll go through the soil vapor intrusion project. As I mentioned last time we got together, we have contractors on board. We have nine total contractors on board. These contractors are reviewing that library of documents.

I think I talked before about 22,000 documents that we had narrowed it down to. We wanted to review those and pull out data. We have actually found a number of duplicate documents out of those 22,000; that's not surprising. I think we've identified around 1,500 duplicate documents. So we're just over 20,000 documents that we're going through. We're going through those documents to pull out information on soil vapor, soil gas, shallow ground water, and that's ground water 15 feet or more shallow; ambient air and indoor air.

We're pulling more than just the sampling results. To really make sense of this data we have to

have information on the location of where the contaminant -- or where that sample was taken. In many cases it's not near a building. We're more interested in what's close to the buildings. But again, we're collecting all that information as well as the date of sample collection. That'll give us an opportunity to do both spatial and temporal analysis of the data.

So at this point we're continuing to go through those documents. We've gone through about -- we've gone through over half a million pages so far. Unfortunately we have over two million pages, so it's a long, drawn-out process. It's going to take a lot of time, even with nine people doing it full-time. Any questions?

MR. PARTAIN: Well, we would love to be able to help you in the CAP.

MR. GILLIG: We would love to have the help.

MS. FRESHWATER: Can we get -- is there any current testing going on on the base? I'm not sure if this should be for Melissa or you. But are we testing anything on the base currently, for vapor intrusion?

MR. ENSMINGER: I can answer that. I sit on the restoration advisory board for Camp Lejeune. And yes, there's continuous testing, constantly. They got

contractors on there, left and right. Now, whether you get to see the results, that's another story. But they're taking the tests.

MS. FRESHWATER: Well, because I was on base in October, and I went to TT-2 for the first time since I went to school there, and I was really surprised at the density of the housing. It was a different place. I mean, the housing -- they've just stacked houses on top of each other on TT-2, and it's on top of plumes that we know are there.

So I know this seems like -- I don't know, it just seems obvious to me that we should know that those houses are being tested, if they're sitting on top of plumes on TT-2. So who do I found out -- like how -- is that information that I need to send in a FOIA for?

MR. ENSMINGER: Yes.

MS. FRESHWATER: Really?

MR. ENSMINGER: Yes. But I can tell you right now that those -- the construction of those homes, the homes were not constructed over the plumes, and those houses that are even near a plume -- well, I can guarantee you that all of them have a vapor barrier under the slab to stop any kind of vapor intrusion from coming up into the living quarters.

MS. FRESHWATER: And what about the school and the daycares? I mean, I hope so because, remember, we found all those daycare centers operating out of houses? And now that's the thing I was going to ask about --

MR. ENSMINGER: What daycare center?

MS. FRESHWATER: They are operating daycare out of houses on TT-2.

MR. ENSMINGER: Well, but they're all new construction. All those houses are new construction, and they took precautions when they built those. They got vapor barriers under the slabs.

MS. FRESHWATER: So you're saying they don't need to be tested, Jerry?

MR. ENSMINGER: Yes.

DR. BREYSSE: But Lori, we can find out if they are testing, where they're testing, and if -- we can see if that -- at least that general information can be made available to you.

MS. FRESHWATER: And that particularly, like I said, the houses, we have those addresses. We gave them to Rick. So we have the addresses. Did the Defense Department ever come forward and give us the addresses? Do you remember, we requested from the Marine Corps the addresses for the daycares?

MR. GILLIG: They gave us some addresses. Some of the information we can release. Other information they ask that we not release, and it's their policy not to release it, I believe, for safety concerns.

MS. FRESHWATER: Did you tell them that we were able to get it through a Jacksonville Daily News reporter?

MR. GILLIG: No, I did not tell them that.

MS. FRESHWATER: Well, I'm telling them now that we got the information very easily. I mean, I found it through a nutrition program, a document online, about whether these daycares were giving the kids proper nutrition during the day. And here I am wondering, you know, what -- because, Jerry, I mean, the houses are -- the houses are everywhere. They cover the whole place now. I was really shocked.

And Tim and I found stuff about the school. And so I would like to know -- I would like an update, have they tested that school, because that school, when you look at it on a map, it's a lot different than when you are actually there, and you're standing by a yellow school bus and you're looking at the ditch where the tanks were, you know. And again, I'm not a scientist. I'm coming at this from my perspective. But it's kids so why not just know what's going on?

DR. BREYSSE: We'll see if we can find out for you.

MS. FRESHWATER: Thank you.

DR. BREYSSE: Rick, can you remember to do that, help with that?

MR. GILLIG: Yeah, that's all I have on the soil vapor intrusion. But Tim, you have a question?

MR. TEMPLETON: I do, just piggyback on the question for Melissa: the documents, release of documents. Do you have any update on a release of additional documents for us?

MR. GILLIG: Unfortunately I do not have an update.

MR. TEMPLETON: Okay. You know I ask this every meeting.

MR. GILLIG: I expect it every meeting, Tim.

MR. TEMPLETON: There you go. All right.

MR. GILLIG: Not a problem.

MR. PARTAIN: And just to make sure, Rick, no new documents have turned up since we've last asked?

MR. GILLIG: No new documents have turned up.

MR. PARTAIN: Okay. Just want to make sure.

MR. GILLIG: So that's all I have on vapor intrusion. I'd like to talk about the next project, the drinking water reevaluation. As you know we

discussed in the last meeting, and we actually handed the document out to you all in the last meeting. We gave the document to the CAP. We gave the health assessment to five peer reviewers, and we also provided it to the Navy.

We received comments, about 26 pages of comments. We've been going through and addressing those comments. I have a copy of the revised document here. We will put this into clearance next week.
Dr. Breysse has asked that we do a concurrent review, which means it'll be an abbreviated process.

We're going to get together on January 13th in a room, all the reviewers. We're going to discuss it, reach an agreement, this is what we're going to go out with. It'll then go through CDC clearance and out for public comment. We expect it out for public comment in February. It'll be out for public comment, probably for at least 60 days.

MR. ENSMINGER: All right. Of the -- how many pages?

MR. GILLIG: The comments, 26 pages.

MR. ENSMINGER: How many of them came from the CAP and the five peer reviewers?

MR. GILLIG: I would guess probably 18 or so.

MR. ENSMINGER: Really?

MR. GILLIG: From the CAP and the peer reviewers?

DR. BREYSSE: No, he wanted to know how many -- of those pages came from the CAP versus how many came from peer reviewers, correct?

MR. ENSMINGER: No. I want to know how many -- well, let me ask you straight out. How many came from the Department of the Navy? How many pages?

MR. GILLIG: I would guess it was eight pages or so.

MR. ENSMINGER: Oh, really.

MR. GILLIG: And many of their comments were reflective of what the peer reviewers commented on.

MR. ENSMINGER: Okay.

MR. PARTAIN: Rick, for the benefit of the audience, can you explain what the document is that we're talking about?

MR. GILLIG: Sure. I'm talking about the public health assessment, which is an evaluation of exposures to the drinking water. So we evaluate the exposures and the health impacts that are associated with those exposures. We also make recommendations in the document. So we're looking at VOC contamination as well as lead contamination in the drinking water.

We're relying very heavily on the modeling that Morris Maslia did. Morris underwent an eight-,

ten-year effort to do the modeling, and we're basing it on that information.

DR. BREYSSE: So the public health assessment is our way of estimating what we think the health impact would be if you drank the water or were exposed to the contamination over a period of time, and based on known risk relationships about how much causes how much disease. And so that's our way of looking back in time, because we're investigating things today. And the water contamination obviously occurred many years ago.

MR. ENSMINGER: Well, it occurred many years before you even issued the first one.

DR. BREYSSE: We're trying to do better.

MR. GILLIG: Any questions on the drinking water project?

MR. ENSMINGER: No.

UPDATE ON HEALTH STUDIES

DR. BREYSSE: So the next item on the agenda is an update on health studies. Perri and Frank?

MS. RUCKART: Sure. Okay. I want to start off by just summarizing the results of our male breast cancer study. This was published in the iournal *Environmental Health* in September of this year.

There's some slides there so you can follow along with me. That's its official title. Okay.

So we conducted a case control study. This is to evaluate whether residential drinking water exposures at Camp Lejeune were associated with an increased risk of male breast cancer among Marines.

The cases and controls came from Marines who were in the VA's central cancer registry. We call that the VACCR. And -- or they call it the VACCR. The VACCR contains information on eligible Marines who were diagnosed with or treated for cancer at a VA clinic.

And this study was prompted by community concerns that the drinking water exposures at Camp Lejeune may have caused male breast cancer. Although we included male breast cancer in the mortality studies done at Camp Lejeune, we couldn't really evaluate this because of small numbers of deaths due to this cause. So to be eligible for this study, the male Marines had to be born before January 1, 1969, and be diagnosed with or treated for a cancer at a VA medical facility from January 1, 1995 to May 5, 2013. We also needed to be able to identify the Marines' tour dates and location.

And we chose these dates because VACCR started collecting data on January 1, 1985, and May 5, 2013 was the date -- was the latest date for which the

complete VA cancer registry data were available when we conducted the study.

We didn't include Marines born after January 1, 1969 because they were too young to serve during the period of drinking water contamination at Camp Lejeune, meaning they were not at least 17 years of age by the end of 1985.

And this was a data linkage study that did not involve contact with the participants. So for each case and control we obtained data from the National Personnel Record Center, that's NPRC, in St. Louis, on their military personnel file, so we could identify which of the cases and controls were stationed at Camp Lejeune before 1986.

So VACCR initially identified 78 cases of male breast cancer. This was based on primary diagnosis and histological confirmation. To minimize the possible selection biases and ensure that the controls were similar to the cases, we selected controls from cancers that are not known to be associated with solvent exposure.

So the controls and cases both came from the VA cancer registry, and the controls included non-melanoma skin cancers, bone cancers and mesothelioma cancers of the pleura and peritoneum.

So we needed to know where the people were at Camp Lejeune and what they were exposed to, so ATSDR conducted extensive water modeling to reconstruct the residential drinking water exposures at the base before 1987. This was necessary because there was very little measured data for the period of the drinking water contamination.

And although we know that exposures to contaminated drinking water likely occurred during training and elsewhere on base, we didn't have information on that, so we were only looking at their residential exposures. And I just want to point out that the water modeling is a unique feature of our Camp Lejeune studies. Other studies that evaluated these associations didn't have monthly estimates of the contaminants at the residences.

So we combined the water modeling results with information abstracted from the personnel records and information from base family housing records and information on where units were barracked to assign contaminant-specific residential exposure levels to each case and control who were stationed at Camp Lejeune.

So in terms of analyzing the data, we calculated odds ratios and 95 percent confidence intervals in the

main analysis. So an odds ratio compares the risk, or odds, of disease among those exposed. So in this case the risk of male breast cancer in Camp Lejeune Marines, and we compare that with the risk among those unexposed. That would be the risk, in this case, for Marines at Camp Pendleton.

An odds ratio greater than 1 indicates a higher risk of the disease among those exposed compared to those who are unexposed. We calculated 95 percent confidence intervals for the estimates, to give us a sense of how uncertain we are of the actual risk. So a wide confidence interval indicates there's a lot of uncertainty about the risk and that the estimate's not very precise. So we have an estimate, that's a number, and we're -- a number greater than 1 would indicate that there's a higher risk at Camp Lejeune than -- because that's just an estimate, we have some kind of limits around that, an upper and lower limit, and that gives us a sense of what the actual risk could be.

So to interpret our findings, we use two criteria: one, the size of the odds ratio, how large it is, greater than 1; and an exposure-response relationship. So what I mean by that is a monotonic exposure-response relationship occurs when the risk of

the outcome increases with increasing levels of exposure. So meaning those who have -- who were exposed to a low level have a number, and those who were exposed to a higher level of contamination have a higher risk. That would be an exposure-response relationship.

And the confidence intervals were only used to indicate the precision of the estimates. And we don't use statistical significance testing to interpret our findings.

We also compared how our findings matched up with findings of other studies of male breast cancer and breast cancer, to evaluate what we did.

We also conducted exploratory analyses using proportional hazard methods and hazard ratios to evaluate whether being stationed at Camp Lejeune and the cumulative exposures to the contaminants were associated with earlier age at onset of male breast cancer.

So what did we find? Our study results suggested possible associations between PCE, DCE and vinyl chloride at Camp Lejeune and male breast cancer. These results took into ^ -- took into account, age at diagnosis, race and service in Vietnam. However, the results were limited because of wide confidence

intervals and only two or three cases with high exposures. For PCE there was a slight monotonic exposure-response relationship, meaning there was slightly higher risk with increasing levels of the exposure.

So the OR for high -- the high category of exposure to PCE was 1.20, and I want to just point out this is similar to odds ratios observed in the Cape Cod study for PCE in drinking water. That was for female breast cancer. Also that Cape Cod study found increased risk at higher levels of PCE exposure, so that's in line with what we found.

The odds ratio that we found for PCE of 1.2 was within the range of estimates observed in occupational studies of solvents and female breast cancer.

The exploratory analyses found an earlier onset of male breast cancer among those stationed at Camp Lejeune compared to other bases as well as among those exposed to higher cumulative exposures to TCE, PCE, DCE and vinyl chloride.

So these results provide additional support to what we saw in the main analysis. I just do want to point out that we only found something with TCE in terms of earlier onset. We didn't find something with TCE and risk of male breast cancer in the main

analysis.

So every study has limitations so I just want to point out what they were in this study. As I mentioned, the findings were based on small numbers of exposed male breast cancer cases, and that resulted in the wide confidence intervals. We were unable to include seven cases of male breast cancer in the analysis because we had no information about where they were stationed. That's very critical. We needed to know if the cases were at Camp Lejeune or another base, so we could see about the risk. Only about 25 percent of veterans reported using the VA healthcare facilities; therefore, we likely missed some cases, and that underestimated -- and that would underestimate our sample size. While missing cases who were diagnosed at non-VA facilities reduced the power of the study, it's unlikely that this limitation led to selection bias because veterans at Camp Lejeune were no more or less likely to get care or treatment at the VA than Marines from other bases when this study was conducted because there were no laws enacted or anything at that time.

As I mentioned it was a data linkage study. We didn't interview any of the participants to find out more detailed information about where they were on

base or other activities, so it's likely that exposure misclassification occurred, meaning we weren't, you know, exactly sure of their exposures. We had to just use the records we had available to us. However, we feel that this wouldn't really differ between cases or controls. And wouldn't really affect the results.

It's possible that confounding by unmeasured risk factors could've affected the findings in the study, that could've affected the odds ratio in another way. So what I mean by that is we know that the BRCA1 gene mutations and family history of breast cancer and other occupations affect the results but we just were unable to get any information about that.

So if there are any questions I can take them now.

MR. PARTAIN: Perri, I have a question. When you're talking about the chemicals, TCE and PCE, DCE, vinyl chloride, when you're looking at the risk assessments, were they evaluated individually as a chemical or as a toxic cocktail that they were drinking?

MS. RUCKART: So both ways. We looked at each chemical separately, and then we looked at something that we just called total VOCs, where we'd add up the levels of all the contaminants a person was exposed

to.

So we looked at -- we had information from the personnel records showing when they were stationed at the base. And so we were obviously here only looking at those at Camp Lejeune. So we would know when they were stationed on base and their unit. Then we match that up with information we have about which -- where the units were stationed. And then we matched that up with the water modeling to find out the levels of contamination, and we gave the monthly levels for all the tours of duty. And then for TCE that would be, you know, one measurement, and then PCE, et cetera. And then we have that catch-all where we added them all up, the total limit -- total levels.

MR. PARTAIN: And because I just -- you know, the point I was trying to understand, you know, the effects of one chemical is bad, but when you're adding three others or four together and putting them into a cocktail that they're drinking, bathing, breathing, you know, that -- I mean, how is that reflected in the study, I guess, is probably a better question.

MS. RUCKART: So if you -- I have here the published article. So when we have the tables here, we show what the odd ratios were for each of the chemicals. But really, the measure that we have that

we call TVOC, the total chemicals all together, it didn't show anything different or add anything different than looking at each chemical separately. We did look at it but it didn't really change things. It wasn't like so much higher for that. Actually it was just in line with what we saw of PCE and TCE. It didn't really add anything.

DR. BREYSSE: But the reality, Mike, is you're asking a very complicated question, as I'm sure you know. And the science, epidemiology science isn't well situated in the absence of a clear mechanistic information that allows us to group things, so maybe it's not all the VOCs; maybe it's just three of the VOCs. So rather than just -- you know, we could've gone through an exercise where you just go fishing, but that's usually not how we proceed. But so when we group things toxicologically -- you know, in these studies, there's usually a toxicological basis in terms of a mechanism of action that would allow us to group things, and we're just not there yet. And that's a limitation in this arena and lots of other regions. We're not just -- epi's not well situated to address what you're asking.

MR. PARTAIN: Well, until we find the -- you know, the biological triggers, then you can't really

answer the question. So certainly when you're being exposed to three human carcinogens, something's going on. And I would postulate that possibly, you know, being exposed to one carcinogen, and then three, there's going to be different risk factors involved.

MS. RUCKART: You know, I do want to add, I forgot to mention that we did look at just, besides the individual chemical exposures and then the total chemical exposure as a level, as a number, we looked at just being stationed at Camp Lejeune versus being stationed at other bases, because, as I mentioned, we didn't have information about people who didn't have residential exposures but still had exposures from elsewhere on base. And that odds ratio was actually lower than the individual chemical exposures, but that kind of gets at what you're talking about a little bit too.

MR. PARTAIN: Oh, I know we see it on the back end from the VA, where you have a veteran's exposed to a chemical, and then they smoked or they were obese, and somehow or another obesity and smoking caused their cancer rather than -- or caused their kidney cancer rather than PCE or what have you, and that's why I asked that question.

Now, if I heard you right, you said that the

study itself was correlating with the Cape Cod study, as far as the same factors?

MS. RUCKART: Well, that study was looking at PCE, and so I'm saying our findings for PCE were in line with that study. That's also a drinking water study of the residential exposures. And then our results for PCE were also in line with occupational studies that looked at the --

MR. PARTAIN: Now, didn't the Cape Cod study also have a findings of male breast cancer as well?

MS. RUCKART: They found odds ratios of, I think, 1.2.

MR. PARTAIN: No, but didn't they have male breast cancer --

MS. RUCKART: Oh, not male breast cancer, no. Female breast cancer. Female.

MR. PARTAIN: Now, are you talking about the Aschengrau study? 'Cause I believe there were some male breast cancers identified in that study? No? Well, okay. But I thought I'd heard that too.

And you said the occupational studies, that what you were finding there was in correlation with -- was there any particular studies that -- I'm not familiar with the occupational ones.

MS. RUCKART: Right. So there is a few studies

that looked at solvents and female breast cancer, and they had different measures, not, you know, necessarily the odds ratio. But so for PCE they had measures ranging from 1.09 to 1.48, that's standard incidence ratios. And then SMRs, so that's mortality ratios, ranging from 1.14 to 1.66 for PCE, and ours was 1.2, so it's in line.

MR. PARTAIN: Okay. So it seems like the body of evidence is still going in the same current. Would that be fair to say?

MS. RUCKART: I would say they're consistent.

MR. PARTAIN: Okay.

MR. TEMPLETON: I do have one question. Was it factored in the age of -- of when the individuals were exposed?

MS. RUCKART: Not when they were exposed but the age that they were diagnosed. However, I mean, in a sense you could say the age that they were exposed is somewhat related to -- well, how old they were when they joined, and most people join kind of right away. And then we know obviously our levels take into account when they were there. So I mean, in a sense that's tied into how old you were, when you would join, when -- where you were stationed. So we have the individual levels.

MR. PARTAIN: One last question, Perri. What was the average age of diagnosis? I know male breast cancer's typically seen in men who are 70 years of age or older. Do you have an average age?

MS. RUCKART: Let me see here. I don't know off the top of my head but let me check here. All my pages are out of order.

DR. BREYSSE: Can we get that back to him, maybe, and we'll move ahead?

MS. FRESHWATER: Well, I could ask a question --

MS. RUCKART: Oh, I'm sorry, I have it now.

MS. FRESHWATER: I was just going to ask, Brad, this is what I was saying earlier. Can we -- will this be now included in the -- in the bibliography, so to speak, that we were talking about earlier, for male breast cancer cases? Like immediately?

MR. FLOHR: The study?

MS. FRESHWATER: Yes.

MR. FLOHR: It is.

MS. FRESHWATER: It -- okay. Good.

DR. ERICKSON: Yeah, in fact when this first came out, in fact there was a lot of discussion about the results and what they meant.

MS. FRESHWATER: Okay, great.

DR. BREYSSE: Perri, I think we need to move on.

Let's get that number to them.

DR. CLANCY: Can I ask a quick question? I'm just curious. Tim's question intrigued me. Not an area I know well, but what is the latency between exposure and diagnosis found in other studies?

MS. RUCKART: So with our study, the latest they could've been exposed was the end of 1985. Then the cancer registry began on 1995, so it's at least -- it's ten years. But the Cape Cod study, it was about -- they had some different measures. They looked at 11 years or 15 years, so we were lining up with them. It was in the same ballpark, I would say.

DR. CLANCY: Thank you.

DR. BREYSSE: Cancer incidence study?

DR. BOVE: I have a bad cold so I apologize. Just a little background on the study. It's a new study. We had conducted studies of deaths due to cancers and other diseases. We looked at Marines and we looked at civilian workers, and those were published last year. And we decided that it would be important to look at cancer incidence because deaths due to cancer -- cancers are survivable. And so just looking at deaths does not give you a full picture of the situation.

So instead we're going to -- we're embarking on a

multiyear study, because it's going to take that long, and we're going to use data from all -- as many state cancer registries as we can get to participate. There are 51. There are 50 state cancer registries, plus Washington, D.C. has a cancer registry, as well as the VA registry and the Department of Defense cancer registry as well. So we're going to try to use as many of those as possible, and look -- and evaluate the cancers that occur to Marines as well as civilian workers.

So in the process of getting started with the study we developed a protocol, which goes through how we're going to do the study. We had that peer reviewed by independent peer reviewers, outside peer reviewers. We went through our agency clearance process, including a review of human subjects, to make sure there was confidentiality and privacy, it's protected. And so we've done all that at this point.

So the way we're going to conduct the study initially is to use staff internally to contact each state cancer registry, and go through their approval process. And we figure that's going to take at least two to three years to do that, based on what other researchers have found when they've tried to do some similar study; although this study will probably be

the most ambitious, if we can get most of the cancer registries to participate. So we're planning to do that.

We're waiting to see what our budget looks like. We're waiting for Congress to pass its budget. And then we'll see who internally will be available, because their program is cut, for example, or diminished. We're going to use those staff to start contacting the cancer registries.

So that's where we are at this point. So we've done all the clearance processes. We're ready to go; we're just waiting for the budget. So any questions about?

DR. ERICKSON: Can I just make a comment? VA's had a lot of really great interaction between the scientists at ATSDR and our scientists. And I just, for the record, I just want everyone to know we really look forward to this study launching and getting the results and what's going to come from this. And I don't want it to be lost on everyone here. This is a very big deal in terms of the enormity of, you know, contacting that many registries. I mean, the man-hours, the expense, the blood, sweat and tears, this is a big deal. And I, you know, I salute you, Frank, and your team.

MS. FRESHWATER: Maybe we'll get a national cancer registry out of it.

DR. BREYSSE: The health survey?

MS. RUCKART: Okay. So for the health survey, that was a massive effort involved sending surveys out to over 300,000 people and asked about upwards of 60 conditions. So we're finally at the point where we're wrapping up the final report, and we plan to start that in our clearance next week. And we're also going to ask for that kind of flat review, where all the parties have it for a certain amount of time and review it. And then we meet and we can hopefully get that cleared as quickly as will be possible.

MR. TEMPLETON: Is there a rough estimate of when it might come out?

MS. RUCKART: I don't know. Pat, if you want to speak to that. If we started it in clearance in December, when do you think it would be available?

DR. BREYSSE: Sorry?

MS. RUCKART: If we start the health survey in clearance in December, when do you think it would be available?

DR. BREYSSE: In December? Well, I'm relatively new but we will expedite the review, like we've done all our documents. So we can do it in two or three

months instead of six months is probably not unreasonable.

MR. TEMPLETON: One other point, just for the benefit of the people in the room and that are also watching, there's no more entries that are being taken for that survey, correct?

MS. RUCKART: That's correct because, I mean, we've already finished analyzing the data, and we're just putting the finishing touches on the final report. It's just, you know, obviously a passed that point at this date.

DR. BREYSSE: All right. Any other questions or concerns about the updates on the health studies that we're working on? So right now we have a break scheduled. But we have a short presentation on TCE. I suggest we do that. If, Ken, if you're willing?

DR. CANTOR: If I could get this loaded quickly.

DR. BREYSSE: Let's take a break, then, if we got to load it up. Okay, I thought you were ready to go. So right now, we got back on time. My clock's just miraculously turned to 5:30. So at 5:45 we're going to start up again. Fifteen-minute break.

(Break, 5:30 to 5:50 p.m.)

DR. BREYSSE: If people can take their seats. Ken, you all already to go? (pause) So I'm not --

I'm not usually used to eating dinner so late, so I want to get us and keep us on time. Ms. Freshwater.

MS. STEVENS: Please, take your seats. Please, take your seats.

DR. BREYSSE: Ms. Freshwater. Ms. Freshwater.

MS. FRESHWATER: Yes.

DR. BREYSSE: Please take your seat.

TRICHLOROETHYLENE PRESENTATION

DR. BREYSSE: All right, we have a short presentation on trichloroethylene, otherwise known as TCE, by Dr. Ken Cantor. Ken?

DR. CANTOR: Thank you. So I'm going to talk about ten or 15 minutes on some relatively new findings from my colleagues at the National Cancer Institute. One or two things. First of all, I'm going to be talking about rather some biological effects of TCE, that maybe -- that we think are related to lymphoma. There are some other studies with kidney cancer as well. This is a set -- this is basically one study, and it's led to multiple publications on different aspects of the effects of TCE. I am sorry that Dr. Blossom, is that her name, is not yet here because I'm sure she'd have many comments on what I'm going to...

MS. FRESHWATER: We'll make sure that she sees it before it goes down on the live stream. You know, I'll make sure that she has an opportunity, or Tim, if you could let her know to maybe try and watch this part.

DR. CANTOR: She may well be familiar with these studies. First of all, I'd like to thank my colleagues at NCI: Dr. Nathaniel Rothman and Qing Lan, who are the -- at, at NCI and Dr. Roel Vermeulen, who are the principal investigators of this study.

Okay, so why was this study done? First of all, to study the early biological effects of TCE at airborne exposures in levels below the U.S. occupational standard, which is a hundred parts per million as an eight-hour time weighted average.

And also it provides an insight into the carcinogenic mechanism of TCE exposure, especially for non-Hodgkin's lymphoma and for kidney cancer.

So the studies design -- is everything showing up there? I'll read what isn't showing -- showing up on the left but not the right; I'll read it. First of all, 40 factories in Guangdong, China were screened to identify those factories that use TCE with none to minimal use of other chlorinated solvents.

So the idea was to focus on TCE without the

potential confounding effects of other exposures. And of those 40, six were chosen, and from those six, 80 workers were chosen from those with almost exclusive exposure to TCE.

And elsewhere, six -- 96 unexposed controls were enrolled from three other factories. There was extensive monitoring for TCE, personal monitoring, and blood and urine samples were collected after extensive exposure. All these workers had worked for at least six months in these places.

So this is an example, this photograph, of one of these working places. They were small places, you can see the workers having direct exposure to these -- to TCE, which was used as a metal cleaning agent in these settings.

Okay, so the first thing that was looked at was white blood cells, particular types of white bloods cells. They looked at white blood cells from the myeloid lineage and then from the lymphoid lineage.

The immune system of all of us is extraordinarily complex. The basic cells are white blood cells but there are many different types. And so I'm going to show you the results from the myeloid lineage and the lymphoid lineage of these white blood cells.

Okay, so on the left of your -- of this graphic,

are the results from the myeloid lineage. I only have one marker that can point to the -- and I'm using it on the right-hand screen, so if you'll just bear with me there. So from the myeloid lineage, from granulocytes, monocytes and also some platelets, there was no association with increasing levels of TCE.

And let me just go back and tell you in each set of results there are three columns. The first are workers with no exposures. Those are from the control factories with no TCE. And what they did, they took the workers in the exposed factories and they divided them into two groups according to the median level of TCE, which was 12 parts per million. So the red column in each set are people who were exposed to less than 12 parts per million, and the third column is people who were exposed to more than 12 -- 12 or more parts per million of TCE. So you can see, for the myeloid lineage, there's no decrement or increase as you increase the level of TCE.

On the other hand, for lymphocytes there was a systematic decrease of the lymphocyte count with increasing levels of TCE. So for those with less than 12 you see some slight decrease, and for those with more than 12 parts per million you see a greater decrease. And this was true for every different type

of lymphoid cell that was looked at.

And we see here the basic types of lymphoid cells are T-cells and B-cells; they looked at three types of T-cells, and in each type there was a linear decrease with increasing levels of TCE, as well as for B-cells as well as for natural killer cells, NK-cells, in the last group.

In addition to this they looked at -- so they looked also for a type of signaling chemical in the serum called cytokines, and they also looked for antibodies in peripheral blood of these unexposed and exposed individuals.

So cytokines are cell signaling molecules that aid cell-to-cell communication in immune responses. And the three types that were looked at here are simply called CD27, CD30 and IL-10. The s before the CD simply means soluble CD27, and so on. In many cases these molecules are found attached to cells but these were ones in the circulating system. And they also looked at two types of antibodies, IgG and IgM.

And so for the results of these, in each case there was a significant linear decrease with increasing levels of TCE for -- and for each of them: for CD27, CD30, IL-10, IlG and IgM. And these are all statistically significant.

So the conclusions of this are that TCE exposure results in alterations in multiple types of immune markers. It supports the biological possibility that TCE may cause non-Hodgkin's lymphoma. And all of the effects were seen in exposures less than 12 parts per million, which is only about one-eighth of what the current U.S. occupational standard is. So it raises concerns about that standard, of course. And this has had impact both on the IARC evaluation of TCE and also the EPA risk assessment of TCE exposures.

DR. BREYSSE: Ken, can I ask you a favor? So there's a lot of lay people in the audience.

DR. CANTOR: Yes.

DR. BREYSSE: Can you give a -- maybe give just a two- or three-minute overview that maybe just wraps us up, for the audience members who probably don't know what a cytokine means and things?

DR. CANTOR: Okay. So --

MR. ENSMINGER: Yeah, dumb it down.

DR. BREYSSE: No, I wasn't saying that.

DR. CANTOR: So we're looking at immune system function basically, on the one hand. We're also looking at effects that have been linked in other studies with non-Hodgkin's lymphoma. So before frank non-Hodgkin's lymphoma is observed, you often observe

a decrease in these lymphocyte counts, that we -- that we've seen. So things that affect immune function, for example -- well, there are many diseases that, that affect immune function, HIV, for one, which is a precedent for lymphoma, among many other diseases. Or kidney transplant patients, for example, and other people with compromised immune systems, often later in their life, will have -- show up with a diagnosis of lymphoma. So that's the importance of that. The cytokine -- the cytokine evidence is just another measure of immune function behavior.

DR. BREYSSE: So lymphoma is a cancer of the immune system.

DR. CANTOR: Correct. Yeah.

DR. BREYSSE: Right. And these are potentially markers that, if somebody was looking for an early precancerous indicator, that might be in the future, clinical relevance?

DR. CANTOR: It's very early relevance that this could be related, yes.

DR. BREYSSE: So the Holy Grail is to try and find some early changes that occurred before frank cancer appears.

DR. CANTOR: Exactly.

DR. BREYSSE: And so if this basic science

research leads to that, it could be a huge boon to people who were exposed to chemicals, who are at an increased risk for this type of cancer, so that they can have some screening that might protect them or identify them before they become too sick.

DR. CANTOR: Right. It's not clear at this point whether this decrement in levels would be adequate for a prescreening concern, but certainly it's in that direction.

DR. BREYSSE: Sure.

MR. TEMPLETON: I've got a --

DR. CANTOR: Okay, let's see, I think that's -- so this is a list of five articles. I've just put it in here for the use of anybody who's going to use this set of slides, including ATSDR, VA or --

DR. BREYSSE: So we have two questions over here.

DR. CANTOR: Yeah. Okay, so --

DR. BREYSSE: Danielle's using the -- raise your tent to indicate.

MS. CORAZZA: I just wanted to know the time of exposure. So these workers, how long was it before these changes in the markers?

DR. CANTOR: They, they had been working for at least months.

MS. CORAZZA: Months, okay.

DR. CANTOR: Yeah, months, but at these relatively low levels, you know, 12 -- and, and --

MS. CORAZZA: So my question, like if you were in vitro, and I admit that was 35 years ago for me, would this be -- if I had this blood work, is it plausible that those -- that the effect would be long-term or is it within a certain amount? I'm just curious. We don't know yet?

DR. CANTOR: I can't -- someone smarter than me could answer that. I, I would doubt that you would see it now. I don't know what the recovery period would be for that.

MR. ENSMINGER: In other words does the exposure suppress the bone marrow temporarily or your lymph glands temporarily or does it -- is it permanent damage? You don't know?

DR. CANTOR: I don't -- I don't know the answer to that, especially at these levels. The, the other -- the other thing that has not been done is that a lot of people at Camp Lejeune obviously were exposed, not to airborne, but to ingested. And these are two very different types of exposure, for a few reasons. One, when you ingest something, it goes first to the liver, through the circulatory system. And the liver has a lot of the enzymes that would modify these, these

compounds; whereas if you were exposed to airborne TCE, it goes directly into the blood stream, to affect every organ, as TCE.

MR. TEMPLETON: So the subjects here were acute -- it was a -- or it was a chronic low level exposure that these guys were.

DR. CANTOR: Correct. Chronic at --

MR. TEMPLETON: Talking about -- go ahead.

DR. CANTOR: Chronic at eight hours or however many hours these workers were working per day, yes.

MR. TEMPLETON: Okay. Got it. You were talking about the cytokeens[ph] --

DR. CANTOR: Cytokines.

MR. TEMPLETON: Cytokines, sorry about that. Is there any correlation or any type of study that was done on, let's say, B-cell switching or some of the other mechanisms that have to -- that have to do with the changes between lymphocytes?

DR. CANTOR: In this particular study? At this point, no. They may have the samples or they may have the data that --

MR. TEMPLETON: Okay.

DR. CANTOR: -- that's there. There are at least -- there's at least one publication that's still in process from this, and I'm sure they're thinking of

others to do as well.

MR. TEMPLETON: The main reason why I ask, I have low IgM and IgG, so there you go.

MS. FRESHWATER: And tell him what you did.

MR. TEMPLETON: Oh, yeah, I worked with trichloroethylene, with the pure -- I worked with pure trichloroethylene in electronics repair. We cleaned circuit cards with them. But then of course --

MS. FRESHWATER: Closed building.

MR. TEMPLETON: It was in a closed structure where we had fumes, but that was in addition to drinking the -- our -- the best water in the world.

MS. FRESHWATER: Dr. Cantor, I have a question, and I'm just looking more for your kind of -- and anybody could answer -- more of a -- just your opinion, and I'm not asking for like a scientifically sound answer to this, but I'm really fascinated with immunotherapy for cancer, and I -- you know, I've been reading a lot about it, and our immune system reaction, which is an allergic reaction and inflammation, and how it's all tied in, and now how they're kind of reversing it and actually injecting children with leukemia with a version of the AIDS virus and having success with it. Do you know about that case?

DR. CANTOR: I'm not familiar with that, no.

MS. FRESHWATER: I can't remember the hospital but they --

MR. ENSMINGER: Now what?

MS. FRESHWATER: They changed the AIDS virus slightly, and they actually inject it into the cancer patient, the leukemia patient, a child, and it made her almost die but she didn't die. And it made the body attack the cancer. So I mean, it -- this is like a big deal obviously.

So what I'm asking is could -- like we've all suffered a great deal from what happened to us. So I'm always looking at ways to find where our research and our science can be helpful for, you know, other areas. So the more we find out about what -- how our bodies react to these exposures, the more it's going to help -- like a rising tide situation -- all boats, right? I mean, this is important stuff that we're talking about, I think. And to have this control group seems, to me, to be a good thing.

DR. CANTOR: Yeah, absolutely. I think this line of research will open a lot of doors to a lot of the questions that you're asking me. I, I don't have all of the answers.

MS. FRESHWATER: I mean, instead of just always

looking at what's made us sick, you know, to be able to look at, as this -- as this immunotherapy -- these drugs advance more and more, it seems to me that it could help us look at what makes us well too.

MR. ENSMINGER: Duke University just did a -- not just, they've been working on this for quite a while but they took the polio virus, and they used it on brain cancer, and it was successful, very successful.

MS. FRESHWATER: Multiple cases, Jerry, now.

MR. ENSMINGER: Yeah. But as far as this thing with leukemia and AIDS, I don't -- I've never heard that one now.

MS. FRESHWATER: Well, just because you haven't heard it doesn't mean it's not true.

MR. ENSMINGER: No, I know.

MR. TEMPLETON: Dr. Breysse, I do have one quick --

DR. BREYSSE: Sure.

MR. TEMPLETON: -- thing that I do want to make here, and it ties right into this. It's an excellent presentation. I think it's not only timely but very informative for us.

I want to speak kind of a little bit more directly, even though I'm not a scientific person, on this, is that I have a feeling that there are probably

a large number of people within the Camp Lejeune exposed community that have low levels of IgG and IgM, and it's possibly due to the exposure.

Now what that does for them, they don't -- they may not have non-Hodgkin's lymphoma today, but what that could be doing for them is causing them to be sick on a regular basis, and it's something that is extremely difficult for doctors to chase down. It took 27 years for my doctor to finally figure out what my -- what the problem was. Of course other people know what my problem is, but anyway.

DR. BREYSSE: Thank you. So I just want to make sure I didn't miss anybody. So studies like this can lead to, you know, understanding mechanisms of disease that, down the road, might be diagnostic or testing methods. This science is clearly not there yet, but pursuing this kind of research is crucial to helping communities address exposure-related concerns as well as workers. And so at ATSDR we follow this research very carefully, and we support it with our own studies whenever we can.

MS. FRESHWATER: Thank you for that, Dr. Cantor.

VETERANS AFFAIRS UPDATES

DR. BREYSSE: Everybody ready? Now comes the

best part of the agenda. Updates from the VA.

MR. FLOHR: I think we're on the agenda tomorrow, right, myself and Brady, to talk about VBA and VHA and differences?

DR. BREYSSE: Yeah.

MR. FLOHR: So that would be our updates, I think.

MS. FRESHWATER: But we're not talking about general, like, bureaucratic stuff, though, right? We're looking for updates on -- for the presumptions and all of that. Do you have any information on that?

MR. FLOHR: Information on that, it's currently we are looking at that very closely. We had a phone call, the Secretary did, with Senator Tillis the other day, that I was part of.

UNIDENTIFIED SPEAKER: We cannot hear you.

MR. FLOHR: Oh, sorry. We've been working very closely, we have, with Dr. Breysse and his staff. We met with them on two occasions, and they did a lot of work. The first time we came down, Dr. Clancy and Loren and myself were very impressed with what they provided to us. The second time we met it was a much larger document. But it's just a document which talked about various studies that have been done, IARC, NTP, things like that.

So then we put together basically a group to look at the issue and to determine what recommendations, if any, we wanted to make to the Secretary, and he's been provided with an options paper. And he has not yet signed it, although personally I think that's going to be fairly soon, when he makes an announcement.

MR. ENSMINGER: I got some questions.

DR. CLANCY: Well, could I just add to that before, and then we'll take questions? Let me just say that the work our colleagues did at ATSDR and the work we did together was a serious game changer. So I know many of you are aware that there was an announcement last summer that we're going to declare a presumption for three conditions. Not that that's unimportant but that's a very small number of veterans who served at Camp Lejeune. And it is fair to say that the recent work with ATSDR has vastly expanded our thinking. If you like football metaphors, the ball has moved way, way down the field.

We still have some additional steps to take. The process is not complete. But I'm here on behalf of the Secretary to say thank you and how much we appreciate the work, and that we are close.

MS. FRESHWATER: I, I appreciate --

MR. ENSMINGER: Hold it hold it. I asked for

these questions first.

MS. FRESHWATER: All right, Jerry.

MR. ENSMINGER: On 16 July there was a meeting with Secretary McDonald, Senator Isakson, the chairman of the senate VA committee, Senator Burr and Senator Tillis, and various staff. In that meeting Secretary McDonald announced the creation of a presumptive status for Camp Lejeune. In that meeting he never mentioned three health effects.

MR. FLOHR: Yes, he did.

MR. ENSMINGER: No, he didn't.

MR. FLOHR: I was there.

MR. ENSMINGER: No, he didn't.

MR. FLOHR: Yes, he did.

MR. ENSMINGER: Then why did he ask Dr. Breysse to assist the VA in creating the health effects that would fall under the presumption?

MR. FLOHR: That's not actually what he asked Dr. Breysse to do. He asked him to assist in determining the duration of exposure that might be pertinent to creating a presumption. He specifically told the senators -- I was right behind him --

MR. ENSMINGER: Whoa, whoa, whoa. Wait a minute. Wait a minute. You also said, Brad, that he never said anything about stopping Camp Lejeune claims from

being processed.

MR. FLOHR: That's true, and it wouldn't make sense if we did.

MR. ENSMINGER: He did.

MR. FLOHR: He did not. I was there, again.

MR. ENSMINGER: I'll tell you what, you've got a bad memory.

MR. FLOHR: No, I don't.

MR. ENSMINGER: I've got this from two other senators, okay?

DR. BREYSSE: But the point is looking forward. I think we've moved beyond that meeting and --

MR. ENSMINGER: Well, in that meeting he also said he wanted this done in weeks, not months. Are you denying that?

MR. FLOHR: He said he would do it as quickly as possible.

MR. ENSMINGER: He said he wanted it done in weeks, not months.

MR. FLOHR: I don't remember that. I remember he said it may be months, but that's not always possible.

MR. ENSMINGER: Yeah, no kidding. Well, what's this I hear about this was sent over to OMB, and it got kicked back because you didn't have a cost analysis on it?

MR. FLOHR: No. We haven't done costing. There was supposedly -- I don't know if it occurred -- there was a meeting scheduled this morning with OMB. You know OMB has to approve everything. Nothing goes forward without OMB approval.

MR. ENSMINGER: And the Secretary said he wanted this in the Federal Register before the end of this calendar year. Well, folks, you got about 26 days.

MR. FLOHR: We have -- as I said, we have drafted a cost analysis; we have drafted a preliminary regulation, a proposed rule, that as soon as the Secretary signs off on what he wants to do, it's ready to go forward.

MR. ENSMINGER: He hasn't signed off on this?

MR. FLOHR: But it has to go through concurrence.

MR. ENSMINGER: The Secretary has not signed off on this?

MR. FLOHR: He has not announced his decision yet.

MR. ENSMINGER: Really?

MR. FLOHR: Really.

MR. ENSMINGER: That's not what I heard from Senator Tillis. I heard that this was at OMB, already approved.

MR. FLOHR: Well, I don't know. But there was a

meeting today with OMB. I don't know what happened.

MR. ENSMINGER: You don't know that this was in OMB.

MR. FLOHR: No.

DR. CLANCY: The Secretary's working very closely with OMB and with the Congress, because obviously all partners are going to be required to not just say this was great work, it was great work, but to say we're going to declare a presumption and we've got the resources behind it to make it a real commitment to all the affected veterans. We're very close. We're not ready to make that announcement just yet.

MR. ENSMINGER: What's the holdup?

MR. PARTAIN: Let's put a human face on this. I mean, we have quite a few people here. In the audience, by show of hands, how many of you were service men or women aboard Camp Lejeune or are -- have a service woman or man on Camp Lejeune that is now deceased or has cancer, please raise your hand.

MS. FRESHWATER: Look behind you.

MR. PARTAIN: Now, those of you who have your hands in the air, just -- we'll take out one cancer. Everyone keep it up real quick, 'cause I want to see. Okay, there's quite a few people here. Of these families that are here, how many of y'all have had

kidney cancer in your family? Keep your hand up, please. We got one, two, three, four, five, six, seven. Yeah, kidney cancer is the big boogieman here with TCE, and we got seven people here, or seven families, or whatever you want to say, that have kidney cancer on it. Matter of fact one of these people sitting behind me earlier today gave me a stack of bills that they're being charged copays for their kidney cancer treatment by the VA, even though the 2012 health law says they're not supposed to. The veteran in question has both kidney cancer and bladder cancer. It's not toe fungus. And he has no kidneys. They were removed for cancer. And they gave him service connection for bladder cancer and denied him his kidney cancer. What is going on?

MR. FLOHR: I talked to his wife right here during the break, and I asked her to --

MR. PARTAIN: I asked her too.

MR. FLOHR: -- I asked her to contact me with his name and information. It doesn't sound right to me but I don't know.

MR. PARTAIN: Okay, and we have another veteran widow sitting behind me who's now getting bills from the VA. Her husband died, Mr. Burpee[ph], we talked about him in May. And he went through appeal and was

denied and denied and denied. And now they're getting bills from the VA, requesting copay for kidney cancer.

But the kidney cancer, I mean, EPA recognized TCE as a human carcinogen due to kidney cancer. We got seven kidney cancers sitting right here in a meeting in Tampa, Florida. And these are all -- by the way this -- everyone here is local. Anyone not local from Tampa? I mean, I'm sorry, central Florida, I'll expand that out, 'cause we're a driving state. I live in kind of Orlando-ish, but I grew up here, okay. But, you know, most of these people are coming from just hearing about this in the media and through efforts of ATSDR to get out there. Florida has got -- we have 20,000 people registered with the Marine Corps, okay? So these are the faces of the delays. You know, the gentleman that spoke to you, he is undergoing treatment. He is undergoing issues because of his cancer. Weeks, not months.

DR. BREYSSE: If I can add, I've been impressed over the last couple months with the commitment to make this work on behalf of the VA. And being new to the federal government myself, I know that we can't always make things happen as quickly as we'd like. It's quite frustrating, but I'm certain and I'm convinced that this compensation program is coming,

and it'll be supported by the science, and the information that we provided them will be used to come up with a logical scheme for a compensation program. I'm confident that's going to happen.

MR. ENSMINGER: Well, that's fine, but, you know, when I -- we deal with real people. I mean, we talk to them on a daily basis, and weekly basis. You guys look at numbers. You're not in direct contact with these people. You are here now, but we work with this daily. I'm getting emails and phone calls every day. And this is very frustrating, and it's very difficult. What do I tell them? That the Secretary is taking his time? You're telling me right now that the Secretary has not signed off on this. Is that your words right now?

DR. CLANCY: The process is not complete. When the Secretary signs off, it will be because he's got full confidence that everything is ready to go, that the commitment is real. I -- we all have the highest respect and appreciation for what you do every day. And I hear you. And I hear the frustration loud and clear. If I could wave a wand and make it faster, that would be done.

MR. ENSMINGER: You know, we keep hearing -- I'm sorry to cut you off, Dr. Clancy, but we keep hearing

different things. We keep hearing different things from the VA. Oh, yeah, this is at OMB. It's being taken care of.

MS. FRESHWATER: And it's kind of put us on the spot, because people are now coming and saying, but the letter in August, and, and so --

MR. ENSMINGER: So I'm going to go back and I'm going to check with my senators.

MS. FRESHWATER: They're just waiting for us to die.

MR. ENSMINGER: -- because my senator -- one of my senators spoke with Secretary McDonald on Tuesday.

DR. CLANCY: Yes.

MR. FLOHR: Yeah, we were there.

MR. ENSMINGER: And I'm going to find out.

DR. BREYSSE: All right. Bernard has been patient.

MR. HODORE: Hello, Mr. Flohr, I have a comment from one of the statements from the VA, and it states, the most important risk factor for the development of prostate cancer is increasing in age. Clinically diagnosed prostate cancer is more common in African-Americans than Whites or Hispanic males. It is most likely that a veteran age and ethnicity are the greater risk factor in his prostate cancer

developed than his brief exposure potentially while stationed at Camp Lejeune. Can you back up that statement, sir?

MR. FLOHR: I cannot. I'm neither a clinician nor a scientist. And that sounds like something that a medical professional looked at, looked at all the evidence and made a decision on that basis.

MR. ENSMINGER: Well, I've seen some --

MR. FLOHR: I think we all know, though, that if males live long enough we would all develop prostate cancer some day or some time or another.

MR. HODORE: But it says African-Americans than White or Hispanic.

MR. FLOHR: I have no information on that.

DR. BREYSSE: I think that's a true statement, but I think the question now becomes is how do you tease out, and the challenge we've debated extensively in the past, you know, personal risk factors versus exposure-related risk factors, and the difficulty teasing that out, I think, is why we've now come to the situation where the model going forward is likely to be some sort of presumption. So we don't have to weigh those things. So those are challenges that we've talked about extensively in the past. And I recognize your frustration, and it's hard to be told

that your prostate cancer is 'cause you're old and you're African-American, and not because of what you did as a Marine, but I think we're trying to get beyond that now. Is that fair?

DR. CLANCY: Yes, and that is actually the value of a presumption. What I will tell you from my prior job, which did not have anything to do with VA but had a lot to do with the evidence for is it a good idea to screen for prostate cancer. When the U.S. preventive services task force, this is an independent group that makes recommendations, looked at recommendations, and they looked at the question of whether there was a greater risk for African-American men, would that affect how often or how early they should start screening and so forth. They could not at that time, so this would've been within the past two to three years, find evidence to back that up.

Many doctors have the impression, from their patient panels and the patients that they see, that it's more common in African-American men. But this task force combed through all the evidence that they could find. Now again, as I'm thinking about it, it's probably more like three years. They couldn't find the evidence at that time, but I'd be happy to take a further look, just on that specific question.

MR. HODORE: Thank you, ma'am. Thank you.

MR. ENSMINGER: And Dr. Clancy --

MR. UNTERBERG: Yeah, I'm fairly new to the process. And when I got involved this year, and I started reading -- and I'm sure this has been discussed before -- but I started reading about the different acts, the family act, there's these 15 presumptions that were -- that had been approved. So I was very confused when I started reading about we're trying to make those presumptions apply again. So could you explain? Could you explain, I mean, is it just dollars? Are the disability amounts going to be a lot more? Why? We've already decided those presumptions apply for paying medical benefits. Is it a legal process? Could you explain to me why those are not carrying over and have to be revisited now?

DR. CLANCY: The law that was passed was to provide medical care --

MR. UNTERBERG: I understand. Yeah, I understand.

DR. CLANCY: -- for veterans. What is being discussed --

MR. UNTERBERG: Is disability.

DR. CLANCY: -- and we're in the very final stages, is for disability benefits.

MR. UNTERBERG: But for three of the 15. So the government --

DR. CLANCY: No, no, no, no.

MR. UNTERBERG: -- for all 15?

DR. CLANCY: It will be a bigger list than that. And again, due to the really fine work of ATSDR. So your work encouragement, very candid feedback, combined with terrific science, I think, has actually moved the process along and expanded our thinking dramatically in the past few months. So I'm very optimistic. I'll leave it at that.

MR. UNTERBERG: Okay, but so you had to revisit those presumptions for this other -- for disability? Is that what you're saying?

DR. CLANCY: What we're looking at is a greatly expanded list, again, based on the scientific work that ATSDR did and that we went over with them in some detail, which, of course, takes a little bit of time of itself.

DR. BREYSSE: Lori?

MS. FRESHWATER: So my question, I know, will be about a process that I can't even wrap my head around, but why can't we do this in an incremental way? So if we have one that you're -- you've kind of felt like you can say, without a doubt, this is -- we're going

to decide upon this kidney cancer, for example. Why not go ahead and do that now, just so that you can show some movement? Why does it have to be all announced at once? Why does -- because it could mean the difference, 30 days, or this, that, and the other makes a huge difference to these people, so if it's going to be -- do you see what I'm saying? Like if it's going to be -- if it's all being held up to be done together, why not do it incrementally?

MR. FLOHR: Well, I don't think -- it's not really being held up for that reason. Whether it's one or whether it's a hundred, they have to go through rule-making. They have to be published in the Federal Register and become rules that we follow. It's the general rule-making process for federal agencies. So we have to write regulations, again, whether it's for one or ten or a hundred, and ask for public comments. We receive comments from the public. And then we're required by law to provide that. And then we have to go back and look at their comments, and we have to address each of their comments in the final rule-making. So it's just not that easy.

MS. FRESHWATER: No, I wasn't saying -- I know it's not easy. I'm saying I can't even imagine --

MR. FLOHR: And it's not that fast either.

MS. FRESHWATER: -- how not easy it is.

MR. FLOHR: It's not that quick.

MS. FRESHWATER: I know what it's like to file taxes, so you know. But what I'm saying is, what I get from the veterans, like a lot of the questions I ask are on their behalf because this is what I'm hearing them say. Well, why -- they said three -- they're desperate. They're desperate because their families are burdened by the fact that they have these bills. And they're, as we have mentioned, behind us, you know, so it's difficult to talk about because somebody passed away without knowing that they had left their family in a safe place.

MR. FLOHR: I completely understand, Lori.

MS. FRESHWATER: So, so -- they're -- I know, and I'm not trying to, you know, guilt you or be emotional or any of that, but I'm just letting you know that I'm conveying the desperation that we're getting, 'cause that's our job as a community assistance panel. And so when they say, well, why can't they just give us the one that they're sure of? Why are -- I just really want you to understand that, you know --

MR. FLOHR: I do understand. And I'm sorry, Jerry, but I have veterans I talk to all the time. I had a veteran and his wife in my office just the other

day. He's a Vietnam veteran, talking about his claim. And I meet with them, and I understand their concerns, and I know them and I share them. I can't tell you this is going to be a lightning fast process. It's not. But the Secretary has promised to make this happen as soon as possible.

MR. UNTERBERG: Brad, without changing the rules, couldn't you make the presumption process easier for the ones that you're close to doing? Could you make your people who -- the people that are deciding whether the presumption's accurate, couldn't you instruct them that these certain conditions should, more likely than not, be presumed?

MR. FLOHR: That's what we've done. That's what we've done in our work group, based on our meetings with Dr. Breysse and his staff. We have looked at all the evidence --

MR. UNTERBERG: But has there been an increase in approvals?

MR. FLOHR: I'm sorry?

MR. UNTERBERG: Has there been an increase in approvals since you did that?

MR. FLOHR: No. No. I don't think so. But we're not denying those claims. We are still processing the claims. It wouldn't make sense not to

because the rule-making process does take time.

MS. FRESHWATER: I don't think that's true, actually. I, I will try and get the cases, because I try and document everything I say, but I do believe people have been denied since this announcement.

MR. FLOHR: Oh, they have been denied but our, our instructions --

MS. FRESHWATER: Their appeals have.

MR. FLOHR: -- our instructions to Louisville is if one of the 15 conditions in the healthcare law, if, after getting medical opinions, reviewing the evidence, it would be a denial, then we're not going to deny them. We will send a letter to the person saying we are not making a decision yet on this claim as -- while we're going through this process. So we're still granting them when we can, which, if we were going to just stop doing them, it could be a long time before someone who now, under our current procedures, we could grant their claim, it wouldn't be -- we wouldn't be able to do that. That would be -- not be good for veterans and their families.

MS. FRESHWATER: Well, I haven't heard anyone who's gotten that response. So I would ask that if anyone has gotten that response, you know, to the public that are watching, not in this room, to please

contact the CAP at our g-mail and let us know because we have not had any word of anyone getting that response. All we keep hearing are people still being denied, denied, denied, and it's so frustrating --

MR. FLOHR: This is still a fairly recent development as well, I mean, since July, and we're -- and then...

MS. FRESHWATER: So but you know -- but have those responses gone out? Do you know that for sure?

MR. FLOHR: Yes, I do.

MS. FRESHWATER: So I just need to find people that -- do you have a percentage or do you have like any --

MR. FLOHR: No, I don't. I could get that, probably, from Louisville.

MS. FRESHWATER: Okay.

MR. FLOHR: Yes.

MS. FRESHWATER: Again, just so I can bring that back to the community who's asking.

MR. FLOHR: Sure.

MR. HODORE: Thank you. I have one more question, Brad. I'm getting time and time again that a lot of these claims, these subject matter expert doctors, these veterans have nexus letters. They have doctors, oncologists' records and stuff, and these

subject matter experts come right back and deny their claim. They overruled the oncologists on certain cases.

MR. ENSMINGER: Most cases.

MR. HODORE: In most cases. Time and time and time and time again; it just keeps happening.

MR. ENSMINGER: Well, let me give you an example, Dr. Clancy. We have a veteran in the audience who was denied for kidney cancer. He was approved for hypertension. The VA's subject matter expert, in his write-up, stated that he had done a comprehensive review of the meta-analysis that had been done on several decades' worth of very good studies on TCE, and could find no evidence that TCE causes cancer. That denial was written in January of this year, and I gave that to Brad Flohr, and it was sent back to Louisville, and you know what they did? They took all that erroneous language out of his decision and still denied him.

MR. PARTAIN: Now, the problem with the SME issue, you know, and we've been --

MR. ENSMINGER: I mean, that's the problem. I mean, when you even come back and point out the mistakes, and they blatantly come back and just throw it back in your face, and say, okay, here, we've took

all the erroneous wording out of this, but he's still denied. So here, jam it.

MR. PARTAIN: And the whole problem with the SME issue is point-blank, no transparency. We don't know what's going on. The reason why we found out about the SME issue is because of veterans coming to us with their denials, and we started reading denials and seeing similar language, similar errors. And for example, over the summer, Channel 6 out of Orlando did a story about a veteran in Melbourne, Florida who has non-Hodgkin's lymphoma, and the SME was copying, cut-and-pasting, Wikipedia into his denial. And the only thing that was missing is they took the word, not, out which supported the doctor's conclusion, but everything else matched the Wikipedia article.

The issue about the bibliography that I asked about earlier, the literature review, we were told no at first, as far as getting this information out. We've been asking for it. We've been asking for transparency. We did a FOIA request. We recently got back a disk on the FOIA request on the training materials for the subject matter experts. And most of it -- a lot of it was Dr. Walters running interference including they put a blank over the label that she used to describe the CAP member that made the request.

We don't know what she said but it looked like it was pretty long. She said the requester is a blank, and it has a blank black block on there from the FOIA request. And then she also goes on to say that all the people who were involved in this do not need to be subjected to the personal attacks and vicious attacks that I've undergone from the community, meaning us. Now, we're not calling you guys names; we're not making fun of you all. We are here to resolve this problem.

And you talked nicely about ATSDR and the progress that's being made. Great. I'm happy for that, but include the community in this as well. Include the experts that we know, like Jerry mentioned, with Dr. Clapp and Dr. Cantor. And more importantly, this SME process, get it out in the public so the public can understand it. Get the materials that they're using, the training materials, and show that to the public so everybody can understand how an SME can take a treating doctor, who is a specialist, an oncologist in their field, and totally refute their nexus letter, if they're a veteran, when they're not even qualified to do so, is beyond me.

And, you know, Jerry mentioned about a veteran,

here, I was talking about earlier. The veteran has bladder cancer, kidney cancer. They gave him service connection for his bladder cancer but nothing, and they denied him for his kidney cancer. But yet the weight of evidence is out there that kidney cancer is tied to TCE, and we're still going round and round and round, and chasing our tails in circles. That's where the frustration's at.

DR. CLANCY: I hear you.

MR. ENSMINGER: And I have another question. Once this is -- once this presumption is official, is the VA going to go back and look at all these denials that --

MR. FLOHR: Absolutely.

MR. ENSMINGER: Well, I believe the Secretary said he would do that. So how far back are you going to go?

MR. FLOHR: As far back as we can identify people in our system, that have filed claims over the years.

MR. ENSMINGER: And you're going to approve them? And -- well, how far back are you going to grandfather their benefits?

MR. FLOHR: As a general rule, regulations, when they're published, are effective the date they are published. So whether we need to go back earlier than

that, that's something to be discussed further. Don't know.

MR. PARTAIN: So a veteran who's been arguing a claim for the past four years, and received denial after denial, bogus, you know, citations from Wikipedia on their denial, they're get -- their presumptive service, say it's announced in January, their claim matures beginning in January, and they lose the four years that they've been trying to fight this? Is that what I'm hearing?

MR. FLOHR: That depends, Mike, again. If -- generally, effective dates of rules would apply to claims filed on or after the date of publication in the Federal Register or claims still pending or on appeal.

MR. PARTAIN: Okay, 'cause, I mean, that's where, you know, we are hearing from veterans who have been, you know, denied. After the meeting on July 16th, I got an email from a veteran here in Tampa, or sorry, a widow here in Tampa, whose husband has been denied several times. He died of prostate cancer at the age of 45. He spoke -- she spoke to somebody at Louisville, just this -- I believe this week or last week, and she has a name and phone number who she spoke to, and said, oh, your claim is denied but we

can't tell you, and release the information until the Secretary releases the presumptive service connections. So that's what's going on.

MS. FRESHWATER: I have a question for Dr. Clancy.

DR. BREYSSE: Lori, can Tim go? He's been waiting patiently.

MS. FRESHWATER: Oh, I'm sorry, Tim. Sorry, sorry.

DR. BREYSSE: He's got his tent up.

MR. TEMPLETON: I've been very... I have hopefully into a little bit of a side track, interesting question. Given what Dr. Cantor has given us, as far as the presentation goes, and also the collective scientific evidence that we have up to this point leading into this, could we come up with a battery of tests, let's say, for immunoglobulin, that's one that would detect -- that's one that would detect this, if we were to do an immunoglobulin test on Camp Lejeune veterans or family members that happen to come our way, we allow them to have medical care. Now, of course, it's only, you know, no copay for the 15 conditions, but when they present themselves to the VA, can we have a battery of tests to ascertain whether their immunoglobulin levels are improperly

low, et cetera, with some of the others?

DR. BREYSSE: That's a medical screening issue. I don't know who would address that.

DR. ERICKSON: Well, let me give this a shot here, just for the public. I served 32 years of active duty in the U.S. Army. In fact two of those years were here at McGill Air Force Base. And so I'm within a long walking distance of where I used to live down here, and so it's good to be back down in Tampa.

I've been with VA for two years. The fact that the four of us would show up today and tomorrow, I want you to know, is not evidence that we think we're perfect, but in fact evidence that we want to improve. We want to make things better. You know, the -- Tim, you know, you and I were talking earlier, and what you have just said is a very constructive interaction, that I would want to have more of, because you've touched on something that is -- is, I mean, for me as a scientist and a doctor, it excites me. As a veteran it excites me.

Now, Dr. Cantor, you know, two thumbs up. It's early work, by his own admission. If it could lead to a screening test, if we could determine what the cut-offs were, in terms of screening and such, yeah, this could be something that could be very, very

viable, in terms of how we could best take care of Camp Lejeune veterans and such. But to be able to say, right now tonight, that we're ready to do that is just -- it's a little early.

MR. TEMPLETON: That's great. Thank you very much.

MS. FRESHWATER: And also, not to say that this would be why you would make any decision, but it would save money if you catch things earlier.

DR. ERICKSON: Can I say something else? And, you know, I was telling my wife this earlier, before I left home early this morning, and you guys are going to say, you know, this Erickson losing his mind, okay. Stay with me, folks. Working at VA, working within a couple blocks of the White House, it's been like a civics lesson for me. When I first showed up, I thought, my gosh, everything moves at the pace of a glacier, you know. Where is the urgency? You know, where is the ability to just make that change, you know, reach out and do something that would immediately help a million veterans at a time?

There are laws; there are rules and regulations. We're bound up in lots of things that go ten and 20 years back. A lot of the stuff that we deal with that deals with that word presumption is actually -- goes

back 20 years to Agent Orange law. And the Agent Orange laws were in fact the starting point for modern day presumptions. And they set in motion some of those calendar dates, some of those timelines that are required, some of those processes that are required.

Now, I will be the first to say I'm not satisfied, as a veteran, as an American, as a VA employee, that the timelines, you know, are what they should be. I want them to move faster. I think we've been moving this particular issue very fast. I spoke with a few of you at the break and before. I wish tonight we were telling you a whole lot more than we can but, because we're not the boss, we can't tell you certain things. But I will tell you that, as a veteran, we've made tremendous steps forward in this regard. We just don't have the ability to talk to you directly about it tonight.

MS. FRESHWATER: No, I understand. I appreciate you being here. I appreciate ATSDR. I appreciate that I live in a country who is making any effort to be open about this at all, because there are many countries in the world who poison people and don't ever make an effort to fix it. So I am someone who is very grateful for this process, and I hope I've made that known at every meeting, and that includes the VA.

My question for Dr. Clancy is going back to the SME program. I only met you today but you seem clearly like a straight-forward person and a common sense kind of person. Does it make sense to you to have a subject matter expert deciding cases for the VA, who also has a business that works for industry, deciding cases?

DR. CLANCY: I think the question is what is the business and is there an obvious conflict of interest?

MS. FRESHWATER: It is.

DR. CLANCY: Well, I have been told, and I don't know as many of the details as you do, to be honest. I have been told that this has been reviewed by our ethics folks. But I want to say one thing in response to a lot of the comments here. There's no question that we have to do a better job at being transparent with how we're doing business, and we're committed to doing that. I will also say, in the weeks versus months, you know, earlier -- early in this calendar year we got a report from the Institute of Medicine on C-123, the people who flew in those airplanes, and I actually think we all believed, including the Secretary, that we could just like have that out in a week. It wasn't quite that quick. It wasn't all that long, though. I mean, it was a matter of several

months. And when we put that out we were very, very confident that we had checked every last detail, that we weren't missing people, and that we had strategies in that instance to be able to find people who would benefit and so forth.

So that's the kind of leadership that this Secretary has brought, and we're continuing to push forward. I hear the frustration, but I also recognize that you all do phenomenal work in bringing this to our attention.

MS. FRESHWATER: But I just want to go back to the SME program.

DR. CLANCY: Yeah.

MS. FRESHWATER: I found, in my investigation on my own, that several of the subject matter experts had side businesses. And if you're telling me that there's been an ethics investigation, I'd like to know what I need to ask for it, to FOIA, because I'd like to have a look at it, because it's very difficult for me, when I see veterans being denied by someone who works for Dow Chemical. It's not right.

DR. CLANCY: Well, I'm not altogether sure, right at this very second, that we're talking about the same person, but I'd be happy to follow up with you on that.

MS. FRESHWATER: I would really like that because I'm -- and I have no problem with this person, or these people, actually, there's several. I have no problems, personally. I think -- I'm not trying to get them kicked out of the VA or --

DR. CLANCY: No, I get that.

MS. FRESHWATER: -- I'm sure they're professional, good people. But this is not the right position for them if they want to work for industry. You can't work for the people who use the chemicals, and then decide that the veteran is not -- shouldn't get disability because they have cancer from the same chemical. You know, it's just not -- so I just really want to impress upon you that that's something -- that's the kind of thing that -- it is frustrating because, if it happened in, I'm venturing a guess, in a legal profession or corporate America, that kind of conflict of interest would not -- would be immediately divulged. There would be an openness about it.

And we had to find out about it on our own, and I'm a journalist, so I -- you know, I was able to find it out. But the SME program is a big deal. And I -- as Mike said earlier, we've just had no access to any of it.

As far as the timeline, I just want to say I do

understand. I really do. And I -- what I am, to bring it back to the positive, I think that, hopefully, what we're doing here will help the many, many veterans from Iraq and Afghanistan that, in the next years are going to be needing --

DR. CLANCY: Yes.

MS. FRESHWATER: -- the same kind of help.

DR. CLANCY: That's exactly right.

MS. FRESHWATER: So whatever pain we're having to go through, I'm really hoping that we're setting a framework that those veterans won't have to go through this kind of thing, because those veterans are going to come back with problems. I mean, the military, the Army has admitted that they were exposed to chemical weapons, and all kinds of stuff that you all know a lot about. So, you know, hopefully what we're doing here is going to make -- because you're going to be -- you're going to have a lot of them coming, unfortunately, so.

DR. CLANCY: Without question.

DR. BREYSSE: Thank you, Lori. Before -- Danielle, we have a question here that we want to address first.

MS. STEVENS: So this question is actually from Chris Orris. He asked me to pass this on. He said,

please ask the VA what they are doing to add congenital heart defects to their list of covered illnesses.

MR. ENSMINGER: That is for the healthcare law.

DR. BREYSSE: In your conditions that you're provided healthcare is congenital heart -- are congenital heart defects being considered for inclusion?

MR. ENSMINGER: That's something that we're working on as an amendment.

DR. ERICKSON: That's exact -- that's part of the civics lesson is who -- whose job is it, and that's Congress's job. And just so everyone knows, the issue of congenital heart defects related to these chemicals we've talked about, there can't be a presumption for that because the children are not veterans.

DR. CLANCY: Not without a law change.

MR. ENSMINGER: And by the way, we're reviewing all the health effects on that law and some of the stuff that's -- can't be determined. You know, that was made up from the NRC report.

DR. ERICKSON: No, it was.

MR. ENSMINGER: Yeah.

DR. ERICKSON: You're, you're, you're exactly right.

MR. ENSMINGER: And, you know, just to show you how great that NRC report is, a bunch of stuff in that law is crap, okay?

DR. ERICKSON: Jerry, let me engage you. Listen, for all of you that are here, Jerry and I, we gave Senate testimony two months ago, and there was actually an issue that we both agreed on, and that was really cool.

MR. ENSMINGER: Just once in our lives.

DR. ERICKSON: No, no, but here's perhaps another area of agreement, and I want to exploit this, you know, even though you're a jarhead, okay? All right.

MR. ENSMINGER: How's come you got away with 18 years in the Army. You said you only served 18 years? What they do, kicked you out?

DR. ERICKSON: Thirty-two. Thirty-two years.

MR. ENSMINGER: Oh.

DR. ERICKSON: Thirty-two years. So but here's what I want -- where I want to go with this. For the veterans in the crowd here, you probably remember your first time going to the range and being familiarized with a variety of weapons. And, you know, your first shot group was probably spread all over the place, may not have even hit the, you know, the Canadian Bull, if you remember the Canadian Bull. Anybody remember

that? Okay. And yet as you got better, you brought the shot grouping together, okay. I'm the first to tell you, and you know this already 'cause you just picked up this point, the initial law, as written, is not perfect. It needs to be amended.

MR. ENSMINGER: Yeah.

DR. ERICKSON: And for us to work together in this regard is another fruitful avenue for us. The ATSDR helping us with science, our engagement with you as CAP members, because there are disconnects. There's no question there are disconnects. And yet different parts of the solution are going to belong to different people, okay. We've talked about certain members of Congress, some of them are going to have to help us amend that law for some of those parts of the problem. We agree on that.

MR. ENSMINGER: Yeah, and I mean, and, you know, all this talk about cooperation and all that is fine, but it's just like the point that I made earlier about that decision where this so-called subject matter expert said that they had done that comprehensive review of the meta-analysis of well-conducted -- two decades' worth of well-conducted studies and could find no evidence that TCE caused cancer. We brought that back to the VA. We did. We brought it back to

Brad. He sent it back. They cleaned it up, sent it back, denied. I mean, you want to talk about cooperation? Let's talk about cooperation. I mean, when that kind of stuff happens, that is a slap back in my face saying, here, tough. You know, but we beat this long enough.

MS. FRESHWATER: But it also goes into the TBI, the subject matter -- I know you're aware of the -- that there was a big problem with the subject matter experts who were not qualified to be -- or they were examiners actually to examine TBI. Where was that, Brad? Was it in Oregon?

MR. ENSMINGER: No, Minnesota.

MR. FLOHR: Minnesota.

MS. FRESHWATER: So the other thing -- you know, so this is kind of an infection, so to speak, that is going beyond Camp Lejeune.

And just one more final point, another thing that confuses the veterans is they'll have the same doctor. One person will have that doctor as an examining doctor, and then another person will have that as a subject matter expert. Which are they? You know, and they're making decisions that seem to make absolutely no sense. It can't be explained, you know. So that's it. Danielle?

DR. BREYSSE: You had your tarp up and I interrupted you.

MS. CORAZZA: No, I was just going to say I feel like really the spirit of this is that, I guess and VA said this. I want to say when I came onboard in January with the CAP, that the process was to be erring on the side of the veteran, and honestly I don't think we can look at any of the people that have come to us with their issues and say, this is a clear case of, hey, the VA erred on the side of the veteran. I don't think that has been the case to-date. I agree there's a lot of movement forward, but that is still not a true statement from my personal perspective, and I think most of the CAP would agree with that.

And then secondary, Dr. Erickson, I don't know who we should address, but like with the IOM stuff and some of the clinical screening and medical screening, I just wanted to -- for the record, like scleroderma testing is very expensive, and the VA doesn't offer a complete ANA panel. As a veteran they didn't offer it to me. They definitely -- it's not really listed under family -- the family member program, 'cause you have to have a diagnosis, but that's really, again, like a nebulous thing, so some of that, I think, could be worked on, and I would love to be involved in maybe

some of those discussions, so.

DR. CLANCY: We'd be happy to follow up with you on that. I'm not all that clear that an ANA panel is actually a good screen for scleroderma, because it's --

MS. CORAZZA: Well, it's not but gastroparesis on its own, which is one of the only other things --

DR. CLANCY: Yeah.

MS. CORAZZA: -- is also not a clear standing, per the VA head rheumatologist at VCBAMC as a differentiator either. And so as a family member, that was -- my exposure came from that. And the VA is like, well, we don't -- you know, you have both but you don't have it. So I think some of that needs to be massaged.

MS. FRESHWATER: And I think like Willy Copeland has all the symptoms of scleroderma. He has end-stage renal failure, lost both legs in a VA hospital, and now he's being forced to pay for private nursing home. And he has all the symptoms of scleroderma, and I can't get him a work-up. And so he doesn't have kidney cancer so he can't get disability. But the doctors have told him that -- his quote was that they said it looked like he had moonshine in his blood.

MR. ENSMINGER: Moonshine. Could I make a

suggestion? Could we possibly, like the afternoon before the next CAP meeting, have a meeting with just representatives of the VA and the CAP, without ATSDR? At the facility, but, you know, they -- they'd facilitate the meeting, the meeting area, within the campus down there. And we could meet that afternoon before, and discuss issues with you guys that we -- you know, things that come to our attention, and you can tell us some things maybe we don't know.

DR. CLANCY: No, I think that would be a great idea. We would appreciate it, if you've called the press, if you let us know ahead of time.

MR. ENSMINGER: Excuse me?

DR. CLANCY: I said, if you notify the press, if you could tell us ahead of time, we would like to know that.

MR. ENSMINGER: Oh, okay. The press can't -- they won't let the press in there.

DR. CLANCY: Oh, you mean on the CDC campus.

MR. ENSMINGER: Yeah.

MS. FRESHWATER: Can we have Sheila there?

MS. STEVENS: So just, I do have a date for that next meeting. If we have the CAP meeting itself I'm planning on March 24th to Thursday. And so if we were to have a meeting prior, that would be the 23rd, which

is a Wednesday. So we would have the ATSDR/VA meeting on Wednesday, and I would find a location on our campus for that meeting and --

DR. BREYSSE: It would be a CAP/VA meeting.

MS. STEVENS: Yeah.

DR. BREYSSE: Not ATSDR/VA meeting.

MS. STEVENS: No, we're talking about having a separate meeting but the actual CAP meeting would be March 24th.

DR. CLANCY: And we'll stay at the CDC Hilton.

MR. PARTAIN: With this meeting --

MR. WHITE: Mike, sorry for interrupting. Can you hear me? I don't have a name thing to fold up here. Did I hear you mention earlier that there was a veteran here that was denied healthcare coverage for one of the 15 covered conditions?

MR. PARTAIN: No, he wasn't denied healthcare coverage; he's being charged copays.

MR. WHITE: Okay, well that's -- I'm going to have -- if that person can come talk to me afterwards, tomorrow, part of my presentation is going to be veteran eligibility, and copays are --

MR. ENSMINGER: Well, he's got a -- he's going to be here.

MR. PARTAIN: And the other one, they're being

billed, the veteran is deceased, and they're receiving bills now for items -- prescriptions for kidney cancer.

MR. WHITE: Okay. Yeah, if they could come talk to me 'cause we definitely need to get that cleared. If a veteran was at Camp Lejeune, and it's a very easy process for them to go through to prove eligibility, they should not have any copayments for treatment of those 15 conditions. They are made a category, priority 6 veteran, and copayments shouldn't even be entering into the picture. So we need to clear that up.

DR. CLANCY: So just one quick question on that, Mike. Is the veteran being charged or is his or her insurance being charged?

MR. PARTAIN: I believe the veteran.

DR. CLANCY: Got it, got it. No, just very important information.

MR. PARTAIN: Yeah, I've got --

DR. CLANCY: That's all, thanks. And Brady can help.

MR. PARTAIN: Now, on this meeting that Jerry's talking about beforehand, I would like to see -- 'cause a lot of times we bring in the denials, especially when there is precedents and things like

this about Camp Lejeune, the veterans do contact us and they give us these denials, and that's how we found out about this SME process. And when we discuss them, we're always put the wall up, which I understand. We can't talk about privacy.

Is there a form that you can provide us, that, when we do have these veterans' cases, we can have them sign off on it so that we can talk to you about the claim and get into the dirty and the specifics, like the Wikipedia, for example, when we have this meeting or discussion? That way we can come prepared. I mean, get y'all's form? I mean, we can't make the form 'cause we don't know the rules and regs. But I'm sure you've got some type of disclosure form that we can get signed by the veteran.

DR. BREYSSE: Is there a HIPAA release form of some kind that would allow them to advocate on behalf of the veteran and discuss their medical --

MR. FLOHR: I don't know that there's a specific form, Mike.

MR. WHITE: Yeah, there's a release of information form that they can sign that we can talk to you about healthcare issues.

MR. PARTAIN: Is there any way you can get a copy of it ahead of time so we can start working on that on

our end?

MR. WHITE: Yeah, I can send it out to the CAP. If you can make that an action item for me so I don't forget.

MS. FRESHWATER: Melissa, can we sign one of those for the documents?

MS. FORREST: I'm sorry, I didn't -- I missed what you were saying.

MS. FRESHWATER: I was making a joke.

CAP UPDATES AND CONCERNS

DR. BREYSSE: So we're going to transition now into the CAP updates and concerns, since it's 7:00 o'clock, keeping us on time. And I think we may have addressed some of these in the last hour, and if we can save some time, I'm happy to do that, but I give you guys the floor.

MR. PARTAIN: Well, I've got my questions.

DR. BREYSSE: Why don't we just go down the line and see. So we'll wait 'til, you know, Jerry comes back, and we'll come back to him. But Ken, or Richard, do you have anything you'd like to raise from your perspective? Okay, Mike?

MR. PARTAIN: No, I'm good, thank you.

DR. BREYSSE: Tim?

MR. TEMPLETON: Very good.

DR. BREYSSE: Craig?

MR. UNTERBERG: Me? Sure. Sheila had asked me to introduce myself. This is my first meeting. I just joined the CAP, and I'm very happy to be here and helping out with the CAP and with the community. I'm an attorney in New York City.

I was diagnosed this year with kidney cancer. I lived on the base from ages two to four, and my brother also lived on the base, was born there and had a tumor. So we've been affected greatly by living on the base.

My reason why I got involved is I applied for my medical bills to be paid, and I, as a lawyer, I was very precise about what I submitted, and I got denied. I think they asked me for electro bills and moving invoices from 1974, 1976, I mean, things I could never produce. So I figured if I got denied others would be denied. And so I wanted to help out. And so that's why I'm involved.

DR. BREYSSE: Thank you. Craig, do you have any additional items you want to raise for anybody around the table?

MR. UNTERBERG: Oh, no.

DR. BREYSSE: Lori?

MS. FRESHWATER: I guess this would be for you, Melissa, now that I've got our dialogue going again. Where do I go to find out information about current sites on the base? Because when I was on base, there's a site where there was radiation. There were dogs dug up, the old carcasses, radioactive, and supposedly been remediated. I won't go through the whole thing 'cause it is late.

But when I went to the site it's -- the vegetation is thick, years thick, and there's no fencing around it. I know radiation. I'm doing a case in St. Louis, so I've made it my business to learn about it. And so where do I go to ask a question like why is that -- why is that site not marked? Why is it so -- why is it right on the edge of a parking lot? I have pictures. I'm not going to put them up because I don't want to be accused of --

MS. FORREST: Is this part of an environmental clean-up site, a former environmental clean-up? Okay. The first place for you to start is a similar board to this, the restoration advisory board, because there are officials from Camp Lejeune who participate on that board, and they'll talk with you about, not just sites that they're doing current investigations on, but ones that have been closed. That's your best

avenue to get answers related to environmental clean-up sites.

MS. FRESHWATER: So I could ask them about any of the sites.

MS. FORREST: I can't guarantee that they -- you know, what information they'll be able to provide you.

MS. FRESHWATER: But you're saying that's their purview.

MS. FORREST: That's the forum to ask questions. That is intended to be very similar to this, to allow for community participation in the environmental clean-up program.

MS. FRESHWATER: Okay. 'Cause when I was in St. Louis, and I was walking around a contaminated creek bed, I was not allowed to get into someone's car because she was fearful of what might have gotten on my shoes, and she had kids. So the fact that this site, which I know had quite a bit of radiation dug up, and it doesn't look like -- it was -- nothing was done, to me, maybe it was. We still don't know where the soil is.

No, Jerry, it's -- they don't have the records. But anyway, and so it's right across from a brand new mess hall, the enlisted mess hall that's named after two Iraq war heroes. I could very easily see those

guys wandering onto this lot, right, just to see what this old building is that's still there, that was there in the 40s, when they were experimenting on beagles and shooting them up with radiation to see how long they lived, and beta buttons and barrels. So, you know, I'm also concerned for the Marines that are still there.

And a lot of these sites were very dangerous. It wasn't just the stuff that went into the water. There's a bunch of sites that have different kinds of contamination.

MS. FORREST: And they have a very large environmental clean-up program on Camp Lejeune. It's very involved.

MS. FRESHWATER: I understand, and I appreciate everything they've done, but when I saw that lot --

MS. FORREST: Yeah, definitely start with the restoration advisory board, going through that. If you don't get the answers, you know, you're not getting the information, I can try and reach out to a contact at Camp Lejeune to --

MS. FRESHWATER: Okay. All right, thank you.

DR. BREYSSE: Anything else, Lori?

MS. FRESHWATER: No, thank you.

DR. BREYSSE: Danielle?

MS. CORAZZA: No.

DR. BREYSSE: Kevin, you've been your normal talkative self. Bernard has left. What are we going to do without the magical Jerry Ensminger?

MS. CORAZZA: Oh, he's walked out for a second. Go ask him does he have anything to say; we're going home. We're going to bed.

MR. WHITE: Okay, while we're waiting, I wanted to address something, Craig, you mentioned earlier. And without getting into your specific situation, I'd like to talk to you afterward about it. But for the family member side, one of the key challenges we've had with this law, the way it's been enacted is we have to prove that a family member was stationed, or with a veteran that was stationed at Camp Lejeune during the covered time frame. That's been one of the biggest challenges that we face.

Now, one of the ways we have helped overcome that is we have worked closely with the Marine Corps, and they have actually a whole bunch of records dating from the early days of veterans that were stationed at Camp Lejeune and assigned to base housing.

So what they've done is they've digitized those records, and we have access to those. And our Office of General Counsel has agreed that we can do this,

that as long as we can show the family member, and I'm going to go over this more tomorrow in my presentation, but I know some of the family members may not be here, as long as we can show a family member has a dependent relationship with the veteran, the veteran was stationed there, and if we can show that the veteran was assigned to base housing, then we can show that the family member was on base.

Now, without that it gets to be very challenging. And, you know, I'll be the first to admit. So help us, you know, figure out what kind of records we can help show that a family member was on base, if they're not in the housing database. That's a really key challenge for us.

DR. BREYSSE: So Jerry, we were doing CAP updates, and we wanted to make sure everybody had a chance. Is there anything additional you wanted to add?

MR. ENSMINGER: Just that my favorite Chihuahua, Tigger, if I wanted to declare him a subject matter expert, doesn't really make him a subject matter expert.

DR. BREYSSE: Thank you very much.

MS. CORAZZA: Brady, I just wanted to add, I actually found some really good information on my

mom's military records, the beneficiary forms have all of the previous base addresses listed on them. So for family members that was a random -- but it had my dad's Social and her Social, and all of the addresses that the two of them have had -- and their units, which is helpful in some historical re-creation.

MS. FRESHWATER: Do you accept report cards, because I -- like I -- no, I have all my report cards.

MR. WHITE: Yeah, that would show that you went to school on base but not necessarily that you resided on base, right?

MS. FRESHWATER: Right, okay.

MR. WHITE: You can live off base and unfortunately you would not be covered because of the way the law is written.

MS. FRESHWATER: I was okay.

SUMMARY OF ACTION ITEMS

DR. BREYSSE: So I'd like to turn to Jona Ogden now to review the action items. Now, pay attention carefully so in case we're attributing something that we expect to be done, and you don't think that's what we heard or if we missed something, now would be the time to catch it.

MS. OGDEN: So for the VA, Dr. Clancy, I have

that you're going to make sure TCE is listed as positively associated with kidney cancer. The VA, Brad, you're going to update the breast cancer claims acceptance statistics. Again, Dr. Clancy, you're going to look into the ICD code issues. VA, Brad, you are going to look into what does solely use the NRC report mean. What weight of evidence are you putting on the NRC report, and we're going to look into making the bibliography of the studies used for determination public.

MS. FRESHWATER: Can I add something? I'm sorry.

MS. OGDEN: Yeah.

MS. FRESHWATER: I just want to add to that action item, Brad. Don't get mad at me but could I get some justification as to why we're still using the NRC report?

MR. FLOHR: I don't know. Again, it's about the third time now I've had to say this. I'm not a clinician; I'm not a scientist. I don't use it.

MS. FRESHWATER: No, I'm asking you to ask them.

MR. FLOHR: Ask who?

MS. FRESHWATER: The subject matter experts.

MR. ENSMINGER: The NRC report is not a scientific study. It was a literature --

MR. FLOHR: Well, we will take it back to the

disciplinary medical assessment office.

MR. ENSMINGER: So it should be out of -- it should be out of the formula.

MS. FRESHWATER: Why not just get rid of it, right?

MR. ENSMINGER: How about that?

MS. FRESHWATER: Instead of talking about it at every meeting.

MR. ENSMINGER: Let's just -- let's drop the NRC report from the formula.

MS. CORAZZA: It did get taken off one of the VA websites since the last meeting.

MS. OGDEN: Okay, and VA, also, provide a list of the miscellaneous diseases and the numbers to the CAP. VA, Brad, specifically, how many claims aren't requiring the SME review. ATSDR, revisit with the Navy the time frame for when the reports can be released to the CAP. Rick and Scott Williams are going to connect and we will follow up on that. DoD, Craig requested that you get the name of your advising attorney or attorneys to him.

MS. FORREST: Can you go back to the one on the documents?

MS. OGDEN: For when they can be released to the CAP?

MS. FORREST: Yeah. What exactly do you have there?

MS. OGDEN: Revisit with the Navy the time frame for when your reports can be released to the CAP.

MR. ENSMINGER: Not reports.

MR. GILLIG: Is that a follow-up item for the Department of Navy?

MS. OGDEN: No, no, no, no. That's ATSDR and the Department of Navy. So we're going to work with them.

MR. GILLIG: We've been working with them for a couple years.

DR. BREYSSE: This is specifically about can we help the CAP know when they can expect to be able to see the documents that we're reviewing.

MR. GILLIG: So work with the Navy to identify a date.

DR. BREYSSE: Yeah. At least find out what's being done and how long it will take to make it so those reports can be publicly available.

MS. FRESHWATER: 'Cause we're public.

MS. FORREST: Yeah, I had taken down that the CAP wants to review all documents provided to ATSDR for their consideration in updating the PHA, regardless of whether ATSDR uses or cites the documents in the final report.

MR. ENSMINGER: That's good.

DR. BREYSSE: Yeah, those are the documents we're talking about.

MS. FORREST: Yeah, I took that, and then so then you wanted to know -- you have that request, so does the CAP have to provide an official FOIA request for these documents, or what do you -- what has to be done so that you can get these documents. That's how I captured it.

MS. OGDEN: Perfect.

MS. FRESHWATER: And just to put on the record one more time, at each meeting, we would like to request the Marine Corps send a representative from the Marine Corps to one of our meetings, to the next meeting, please. And it's not that we don't love you.

MS. OGDEN: Okay, and I also have that ATSDR is going to invite and notify Dr. Blossom of when our next meeting is. ATSDR, find out what current SVI vapor intrusion testing is being done and where at Camp Lejeune. ATSDR, get the average age of the male breast cancer cases in the ATSDR male breast cancer study. So we wanted the age, Perri.

MS. RUCKART: We did that. That's in table 1 of our published journal article.

MS. OGDEN: Got it. The CAP, specifically, Tim,

send Dr. Blossom a link of the live stream for Dr. Cantor's TCE presentation. VA, Dr. Clancy, connect with Bernard to examine his personal claim. The VA, we were interested in the percent -- the CAP was interested in the percent of people who have gotten letters letting them know their claim is pending while the new rules are being developed. Is that right wording? Yeah? Okay. VA, CAP is interested in transparency in the SME process, and provide Lori what she needs to FOIA the ethics review of the SMEs. VA, follow up with Danielle about the sclero --

DR. BREYSSE: Can I just talk about that? That's really not very accurate, to say they want more transparency. I don't think that's specific enough to be an action. I think that was more of a --

MR. PARTAIN: Transparency with the SME program.

DR. BREYSSE: -- yeah, just more of a comment that the SME program should be more transparent.

DR. ERICKSON: I think there was an accusation about unethical behavior or something.

MR. ENSMINGER: Well, it's not only that, but when you got -- you got these SMEs that are writing opinions that are included in these people's -- well, if they're approved they don't really care. But all

these denials? I mean, these people are refuting what these people's own doctors are saying. So they're actually making life and death decisions that will affect these people's lives and their families. And the veteran -- we have a right to know who these people are that are making this, these decisions, and so we can check them out and find -- vet them and find out what their qualifications are. Don't you think? I mean, really?

MS. FRESHWATER: We have veterans fundraising to be able to find doctors to refute the SMEs, because the oncologist was overturned. So they're having -- so they have no money but they're trying to get someone else to, then, refute the SME. I mean, that's -- you know, that just doesn't make any sense.

MR. PARTAIN: And we also have records where a doctor -- I mean, a veteran gets a nexus letter from a doctor, a treating doctor, that connects their cancer to Camp Lejeune, and then their doctor receives a letter from the VA demanding that they do a, you know, an explanation to how they came to that conclusion, which, I mean, if you're going to ask a medical doctor to do that, there's going to be a charge, a significant charge, to do that. And, you know, these treating doctors, in the past, with other VA issues,

the nexus letters, from my understanding, weren't questioned. And why are they being questioned now with Camp Lejeune? And, you know, it's disturbing. It's intimidating to both the doctor and the veteran, that if the treating doctor's going to write a letter and then be challenged on it by the VA -- and that's some of the transparency -- transparency statements that I was making, because it seems like everything -- you know, when we try to get something going, to help the veterans, the rules change. And it's like the game -- as the game keeps going, the rules keep changing to whatever, you know, is best for the VA rather than the veteran. And that's the impression we get. You know, that's what we're hearing back from the veterans.

MS. FRESHWATER: I unearthed some VA slides that said give the veteran the benefit of the doubt. And it was previous to the SME program. And then after the SME program came in, everything changed. And so I can show you the timeline.

And I -- just to answer you, I have not called anyone personally. This is not a personal thing. I am not saying anyone's acting unethically. I think that the system is unethical right now.

DR. ERICKSON: Yeah. Let me make a comment. I

know there was concern earlier about home pictures being posted and, you know, names of SMEs and this kind of thing. There was a bit of threatening actions that were out there on the web. And I'm not accusing anybody; I'm just saying that there --

MS. FRESHWATER: No, you should address that to me directly, 'cause I did it.

DR. ERICKSON: Okay.

MS. FRESHWATER: And I did not put anything up that wasn't on the internet. And I didn't put anyone's home. What I said was this is somewhere that they registered a business, that -- where they were giving decisions to people, they were saying a veteran --

DR. ERICKSON: Right.

MS. FRESHWATER: -- can come hire me to help them get a better decision, and then denying our veterans.

DR. ERICKSON: Right, right. So, and what I -- because we're having sort of an honest discussion here, I mean, and the fact that workplace violence is a real occurrence, and, you know, we've had this issue within our system, we need to work together in a professional way, in a respectful way.

And so what I think might -- you know, just an idea I'm going to kick over, and I haven't discussed

this with Dr. Clancy. As there are these specific cases that are viewed as being egregious, you know, you've talked about individuals who submit their claim, and there's a specialist who has a letter that's included and how it gets handled and such, perhaps we need an ombudsman or some type of parallel track that the CAP, you can help us with, because I -- you know --

MS. FRESHWATER: But Brad Flohr served as that person, and he didn't help us --

DR. ERICKSON: Well, okay --

MS. FRESHWATER: -- and I'm sorry, it --

DR. ERICKSON: Stay, stay, stay with me on this. Stay with me on this. If, if we get nine out of ten correct, you're not going to hear from the nine; you'll hear from the one out of the ten. But to have a more formalized process as opposed to just saying send it to Brad, okay, this is what I'm implying is that we could have internal processes at VA that provide peer review checks and double-checks, our own quality assurance, if you will, of the process for the SMEs.

But then to have a feedback, in particular, from Camp Lejeune families and veterans, that perhaps you as CAP members, because you're -- like you said,

you're hearing all these stories. You're getting sent things. Having that somewhat formalized back to us, you know, I think would go a long ways because then I think we -- you know, and Mike, you're exactly right. We need to find out what is that piece that allows us to talk so that, you know, we don't break any laws about HIPAA, et cetera. But to get past those stories, to get past the mistakes or the misunderstandings, to get past the emotional indignation, and help us make the program what it needs to be.

MS. FRESHWATER: I -- here's what --

DR. CLANCY: Lori, I want to --

MS. FRESHWATER: Let me just answer this really quickly, Dr. Clancy, please. I did not write anything I wrote emotionally, and I only did it after -- and I've not mentioned a name here, to prove the point that I am not being personal.

But there was a doctor who called into the CAP meeting in Greensboro, and I asked directly, Jerry asked directly, what is your business, this other business that you have. And we were told it was none of our business.

So I said, well, I'm a journalist so I'll just find out. And I just went and found out. And I

didn't go do anything that anyone else couldn't have done. I found -- you know what I mean? So it was after trying to talk with her and being condescended to and being treated as if we weren't deserving to know what her conflict of interest may be, because at that point I didn't -- you know, no one had any -- no one had made up their minds.

So I just want to say I -- going forward I would love to have this kind of process, but I stand by everything I did, and I don't -- I didn't disclose anything that would put anyone in any danger. I'm a very professional, military brat, you know. So I just don't want that -- I want that on the record, and I want you to know that I did what I did only after running into brick walls.

DR. BREYSSE: Can I suggest that the SME process, and if we're still at that point during your first meeting together, might talk about how to operationalize what Dr. Erickson just suggested?

DR. CLANCY: Yes, that's what I was going to suggest. And also to see I wanted to follow up with you about the people specifically you were concerned about.

MR. ENSMINGER: And your peer review coordin- -- or your SME coordinator, you need to take a look at,

and you know why.

MR. FLOHR: I need to make a comment about the SMEs too. These are subject matter experts provide medical opinions in claims. They do not make decisions in claims. That is a piece of evidence that is used by the claims processors in Louisville to make a decision on a claim.

MS. FRESHWATER: And we have asked you repeatedly to show us one case where the people ruled against the SME. And you have not given us one example where an SME said deny this claim, in my opinion, I would deny it, and it came back, no, we're going to approve it anyway.

MR. ENSMINGER: And they reversed it.

MS. FRESHWATER: Not one time. We've asked you every meeting, Brad, show us one time when the SME didn't win.

MR. PARTAIN: And in June I sat in Donald Burpee's appeal over at Bay Pines, and the judge --

MR. FLOHR: Well, we have granted a number of claims based on their opinions, a number.

MR. PARTAIN: Okay. Brad, in June I sat at Bay Pines when Donald Burpee did an appeal. The VA judge sat there and basically said that, without, you know -- that the VA has gotten an SME opinion, and

until Mr. Burpee could produce something similar to that, there's no way he could reverse the claim.

MS. FRESHWATER: They are putting much more weight on the SME decisions than what either you know or what you're admitting to.

MR. PARTAIN: While they may not be making the decisions, their write-ups are extremely clear that the decision cannot be made -- you know, well, I should say, the decision is made in the write-ups.

MR. FLOHR: And that is the job of the adjudicator. That's what that means, to adjudicate a claim. It means to review all the evidence, determine the credibility of all the evidence and determine the weight of the evidence.

MS. FRESHWATER: Can you show me, again, one case where the SME's decision wasn't followed?

MR. ENSMINGER: Was overruled by the --

MR. PARTAIN: And just like in the training, the training PowerPoints that we got from the VA, the purpose of the SME program is to make a basically a legal proof -- a legal claim -- I can't remember the wording on it now.

MR. FLOHR: It's to provide a medical opinion.

MR. PARTAIN: Well, not a medical opinion, but it's -- there was a slide in there that discussed

this, and I forgot the exact word of it, but it's to provide -- sorry, my brain is just frying right now. I'm getting tired. But I'll find the slide and send it to you. But basically in laymen's term, the slide -- the purpose of the wording in the slide was to create a claim that is legally defensible. Okay, that -- an SME being a medical review's one thing, but what's end up happening, and it may not be the intent of the VA, is that the SME program and the reviews that are coming out, and we're seeing it in the denials, there is just no way that they can make a decision contrary to what the SME is finding. And it just -- you read through them, and, you know, you see it. But that's -- I want to give time to the families to ask questions but one --

MS. FRESHWATER: But there's also inconsistencies with the fact that some of the denials have the SME name on them and other denials don't. So some people get to know who their SME is, then other veterans don't. Then the veterans go on Facebook and they're like, well, why didn't I get to know my SME's name? And it's not just me. The veterans are looking up the SMEs' names, when they get them, and they're trying to find out -- why wouldn't they? They want to know what their qualification is to overrule their oncologist.

And they can't find any.

MR. PARTAIN: And the point of everything here, I mean, we -- between now and May, I mean, I will step out and come in, there's a distinct change in tone here, that I'm hearing from the VA. I hope it's something that matures into a relationship with the community so you can build back that trust. That trust is not there. It is not with the veterans. And what you guys say we take with a very small grain of salt because, it just -- we've seen it time and time again.

I appreciate your words, Dr. Erickson. I appreciate your words, Brad. And I hope this is a new direction that we're going. Time will tell, and I -- keep talking to us. Okay?

One off thing, those of you here in the audience that are from Florida, before you go, I would like to get your contact information, 'cause I do work with Senator Nelson's office quite a bit and some of the Congressional offices here. And it's important that I know who you are too. And this is our opportunity to do so.

DR. BREYSSE: Okay. We have two more action items we want to go through. Then we'll open it up to the community.

MS. OGDEN: So quickly, the first one is that the next meeting in Atlanta at CDC, we are going to have time for the CAP and VA sole discussion. And the VA is going to provide the CAP with a form needed to speak on behalf of a veteran for a claim.

So that's all I have. If I've missed something, how about you find me after we open it up for the community members.

QUESTIONS FROM AUDIENCE MEMBERS

DR. BREYSSE: So we have some handheld mics which we can take around the room. So now we're transitioning to the part of the agenda where we take questions from the audience. So we have one.

MS. CALLUN: My name's Kim Callun. I was in utero at the base, and lived there until I was two years old. My dad was a Marine. I'd list for you all the ailments I've had throughout my life but I don't need any competition with the rest of the people here. They're extensive. They continue and they're ongoing. I have compromised immune system which has caused lots of other problems along the way.

I've been partnering with members of the CAP to do some research. And in-artfully I'll call it my dead baby research, but I say that bombastic term for

a reason. Chris Orris, whose name has been brought up here today, member of the CAP, accidentally came upon some graves in New Bern cemetery. He was there, and he started noticing a lot of baby graves at that cemetery, which happens to be a Civil War cemetery, part of the national cemeteries throughout our land.

I have a list, this is my dead baby research, of 373 graves there for babies that were born and died on the same day or born and died within 30 days. And I have a list from other Jacksonville cemetery -- not cemeteries but funeral homes, which gave us an additional 120 names, mostly from 1951 through 1955, a few from 1950, which suggests that the contamination at the base may have been farther back than we even know, and we've, you know, talked about.

The more eyes on the case that we have, the better. We need any of you that were stationed at Camp Lejeune or know people that were stationed at Camp Lejeune to go out. If you're near a national cemetery, go and look around. If you happen to start finding a lot of baby graves, for babies born and died on the same day, if they have a designation of the Marine Corps, that's great. Take a picture. Even if it doesn't have a Marine Corps designation, take a picture anyway, because there's been, let's say, some

shadiness in the listing of the dead babies that I have on the listings from various cemeteries, trying to hide the fact that these were babies that were from the Marine Corps or born on the base to Marine --

MS. FRESHWATER: We have, we have proof that many of the babies were Marine babies, and their grave stones actually say Army or different services.

MS. CALLUN: Or the listing with the cemetery lists Army or a rank insignia that is indicative of the Marine Corps and not of the Army or Navy or whatever.

So I ask you, especially the people in the audience, if you know someone, have them contact me directly so I can further the research. We want to find out and we want to talk to these people. They can contact me at my email directly, callunzo, c-a-l-l-u-n-z-o at aol.com, or if they feel better about contacting CAP, I'll have that information forwarded to me. But I'm working on it so we don't put burden on the people on the CAP that are already working on other things. I ask you contact me directly. Again, my name is Kim Callun, and I'll be happy to help you out that there.

MR. ENSMINGER: And you can put that on our website, The Few, The Proud, The Forgotten, on the

discussion board.

MS. CALLUN: That's fine with me.

MS. FRESHWATER: I mean, I think the babies should have the right designation. They're Marine babies.

DR. BREYSSE: Thank you, Kim.

MS. CALLUN: My second thing is a question I wanted to ask this. This is about the presumptive list, is do we know -- is melanoma included on that list? We don't know that? The reason I ask is 'cause when Perri did her slide show, she specifically did a comparative analysis for the male breast cancer with diseases that, she said, were non-contamination-caused. And among those, what stood out to me, she said non-melanoma skin cancers, which then makes me presume that melanoma is caused by one of the contaminants. And I specifically have had melanoma, not once but twice, in addition to leukemia and other diseases. So I was just wondering if that's included. If not, why not? And have we any -- do we have any studies relating to melanoma among family members or Marines?

MS. RUCKART: Well, I think this is a question for the VA, but I will say that when we looked at cancers that we could use as comparison cancers, that

were not associated in the literature, it's with solvents in general, first of all, not just necessarily the ones at Camp Lejeune. And it's just what's in the literature. We had our -- we started out with a much larger list, and we vetted it with a lot of other scientists to get it down to that point. But I just wanted to make a case that we were looking at just solvents in general, not limiting it to the ones just found on Camp Lejeune.

MS. CALLUN: Well, I've had discussions with my oncologist, and she has read literature and done research that, you know, some of the diseases that I've had, including melanoma are linked to some of the chemicals that I was exposed to on the base.

MR. ENSMINGER: When these people just talk about literature, they're talking about studies. That's for all of you out there. They're not talking about magazines and stuff. But when they refer to literature, they're talking about study reports, okay?

MS. RUCKART: Published articles in scientific journals.

MS. CALLUN: I have one more point of clarification. I don't know if I made it clear. My partner just let me know. But I'm looking for people specifically, not only to go to the cemeteries, if you

see, you know, something that looks awry at a cemetery, contact me with a picture or a listing of what it says. But also if you know somebody that's had miscarriages after miscarriages or babies that were born and died within a 30-day period of their birth date, those are the people I want to talk to also. Thank you.

DR. BREYSSE: Thank you.

MS. CALLUN: And thank you for all the work that you've done, all of you, both the CAP and the ASTDR and the VA.

DR. BREYSSE: Can we get the microphone to the back right?

SUE ANNE: My name's Sue Anne (inaudible). I was the wife of a Marine for 48 years. And he was stationed at Camp Lejeune; that was his main station.

He was a heavy equipment mechanic, and he worked with these chemicals constantly. They washed -- these chemicals. For four years, before he passed away in February, we have had requests from the VA to help us, because not only did he have three very rare cancers, he also had cardiovascular disease which was not prevalent in his family, ever.

He was a smoker up until about 12 years ago when he quit. And all of a sudden these diseases. The

first cancer he had was in 1980. The second cancer he had was squamous cell, which you live in Florida, everything gets squamous cell but not on the palm of your hand. He was also in Okinawa. And he was working on all the equipment coming out of Vietnam from the jungles.

And we've been fighting with the VA for many, many years. In July of this year, I received a denial on every single claim, saying that none of them are related. And I'm about at my wit's end at this point, but I'm glad I came 'cause I needed to speak with some of you -- someone, because I'll fight this until the day I die. (applause)

And I don't know who to blame other than the Marine Corps or the government or whoever, but they never ever gave my husband anything to protect himself from the Agent Orange on these so-called generators and things coming out of the jungles. When we inquired about this five or six years ago, they said, oh, no, everything's completely washed down, and it was not. There was live hand grenades still in some of these things. So I'm fighting two battles, not only with Lejeune for the various cancers that he's had, which two of them are considered very rare, I'm also fighting back from the Vietnam era, so I will

take anybody's help I can get. Thank you.

DR. BREYSSE: So I'm very, very sorry for your loss. Is there somebody here, Brady, who can speak to her about helping out or...

MR. FLOHR: About Okinawa?

DR. BREYSSE: I'm sorry?

MR. FLOHR: About Okinawa?

DR. BREYSSE: No. Is there someone here who can speak to her afterwards and see if you can give her some assistance?

MR. FLOHR: Sure.

DR. BREYSSE: Okay.

UNIDENTIFIED SPEAKER: Hi, this is my first meeting. I'm so glad to be here, and I just want to say thanks, especially to the CAP for fighting on behalf of the community. So grateful. Also especially to Jerry and Mike, who I've just really resonated with so much of your words tonight. Thank you so much.

I traveled from out of state, representing my family. I have over 20 service members in my family, including many Marines and multiple Marine generals. And I was affected and so was my brother. So this is interesting and very insightful, and I'm so glad I'm here.

And one thing I expected when I came here, and I traveled a long way, was a lot of information and to, you know, be in community with so many other people similar to myself.

However, one thing I did not suspect when I came here was to be harassed by the media. And the guy from Channel 8 news asked me some very personal questions out of the gate, which made me feel extremely uncomfortable. And then he went around talking to different people, including this gentleman and those audio guys, and continued to video and take pictures under the table. And I just -- there's a time and place for the media, and I am so grateful to everybody in the CAP that talks to the media, and that speaks up on behalf of -- and rallies on behalf of all of us, but I'd like to keep some -- I never anticipated just being harassed by, by this guy tonight. He threw out a business card: Love to hear why you don't think I should be here. Now, I have no problem if the media comes to these meetings. That's great. But they should not be taking pictures and taking video of people like this amazing family or everybody else sitting around here unless we have written consent, and we know that coming into these meetings.

So for whatever that's worth, I'm fine if a reporter sits in the back and takes notes and prints articles and papers because I agree with everybody in the CAP, that we need to tell as many people as possible, and tell millions and millions of people. But what I don't agree with is taking pictures and video of everybody in the audience, and then this reporter sneaking around, and telling this gentleman and these audio guys and everybody else here to send him pictures because he's been asked to leave.

So I'd like to set a precedent -- already, he's already put an article on there today, that if any pictures or video get posted by this guy about this meeting, that the CAP ask that they be removed. It's great to have articles but I don't think pictures and videos are welcome. We didn't sign waivers. I think it's irresponsible and it's unprofessional.

And then moving forward, I think for other CAP meetings, it would be really helpful just to know that media are going to be present and are going to be asking you very personal and invasive questions. Thank you. (applause)

DR. BREYSSE: Thank you for that feedback. I apologize. I don't know -- can I -- I'll get some more detail from you about that?

MS. STEVENS: Is there anybody on that side?

MS. MASON: Hi, I'm Sharon Mason. I'm from York, Pennsylvania. This is the first time I'm here present. I sat in on, I think, two of the meetings from afar. And I don't even know where to begin. My dad, he was in Camp Lejeune, and he had on here that he was a lance corporal. And it was the 27th of November, 1963. He was very proud. He always talked about his country, very proud Marine.

He passed away in 2011, coronary artery disease. And not long after he passed away I received a phone call from the VA telling me that we had a pretty large sum of money to pay back for him with the Agent Orange.

I didn't get one call; I got two calls. Then they called me back, and they changed how much it was by thousands and thousands. It's interesting; I didn't get a call 'til he was dead.

So I'm not real happy right now with the VA, and I went through a lot of years with my mom and dad. My mom just passed away last month. She had scleroderma, CREST syndrome. It's an acronym. She had every one of them. She had a liver transplant at age 50.

I'm a nurse almost 30 years now. I've taken care of my mom and my dad for over 20-some years. That's

pretty sad, okay?

I feel like none of you at the VA are intending any of this. We have a problem with leadership, not just in companies with America right now, and I feel like it's gotta start there. Where's the accountability? Where are we -- there's people's lives at the end of this. I feel like there's people in the VA -- and I've had the problem about putting in claims and them turning around and then denying them back and forth a million times, and I feel like there are people that are doing tasks, and they think there's a quota, and there's just going to keep denying. Maybe they'll give up.

Well, I'll tell you, I'm bitter right now. This whole meeting has been very difficult for me because, you know, my brother actually has problems. He was in vitro. The way that we got information about where they were stationed there was he was born in the naval hospital. So we were able to find out then what the address was. And right before my mom died, I finally got -- that they found that they were residents there. You know, a little too late.

So I'm hopeful, and I really hope that the people sitting here really, really mean what you're saying, and you're going to go back and you're going to do

everything in the world you can do to help us. We've all been through so much, and I'll tell you, I found out by accident that there was even pollution at Camp Lejeune. I found out last December, while I was at a meeting, a corporate meeting, with OSHA. And they said to me, well, you know, Camp Lejeune, the water pollution. And I went, what? And I went and researched it, and I have felt like a victim ever since. And I don't feel like people are listening, you know? And I'm in Pennsylvania and the VA clinic finally came into York, Pennsylvania. They're not asking, did you live in, you know, Camp Lejeune? There's nobody there that's even talking about this. So if you think that the word's out, it's slow. I mean, I had to found out by accident.

And the sad thing is my dad died in 2011. He was very service-connected. He should've been a hundred percent connected for years and years and years, but he wasn't. He kept fighting it and going back and doing this thing where he had to have a lawyer, over and over. And then after he dies, we get called to -- here's a check? I mean, come on.

So please help. I just -- I could go on for days but I needed to -- I had to get this out because we have to help these people. There's a lot of us. This

isn't even -- there should be more people. There should be rooms and rooms of people. The word's not out there. What can we do to help get it out there? I'll help and I'll go to the cancer banks or whatever. I'll do whatever I can do to help get this out there, because there are poor souls out there that need help. And they keep getting papers. I have the papers here. I have to, then, send in one page refilled out for my mom for every diagnosis. She has like four or five of them on your 15 list. So I have to go back to a doctor to have them refill it out.

And see, the doctors, they use ICD-9 or -10. So on the form they have the place that says ICD-9 or -10, so they put that there. But I'm hearing here that y'all don't use that at the VA, so why would it be on the forms, you know? I think that things get set up, and people have good intentions, but the people maybe aren't doing the research to even make a form right.

But at that, I'm done; I got it out. And I just want to thank everyone on the CAP, because I'll tell you what, you've been fighting this a long time. I've only known a year, only a year, and you guys have been at it for years. Thank you. Jerry, thank you. That's all I can say. I'm done. (applause)

DR. BREYSSE: Thank you for your story.

MR. ENSMINGER: Thank you. I would -- I want to address one point. When Dr. Breysse took over ATSDR, we requested that we move our CAP meetings away from the CDC, and start getting around the different areas of the country to involve the communities, the affected communities. And to allow these meetings to be open, because at the CDC, you have to preregister; you have to go through security, and you have to do all that.

And we readily invite the media to come to these meetings so that they can take our messages and our stories, and share them in your areas here. And so just a head's up, these meetings are public. The media is invited, yes, to take pictures, and maybe we should've posted that on the door. We will do so tomorrow because the media's going to be there tomorrow. And if you don't want to get your picture taken, then don't come. But I'm not trying to be rude or anything, but that's the reason for this. And believe me, I've been at this for 19 years.

MS. FRESHWATER: The media needs to be here.

MR. ENSMINGER: I've been at this for 19 years. Without the media I would be nowhere today. They are truly the watchdogs of our democracy. And they are

the music that politicians dance to. No, I'm serious.

MS. FRESHWATER: But Jerry, I think we could talk to them beforehand and just -- because television journal --

MR. ENSMINGER: I'm not going to talk to the media.

MS. FRESHWATER: I'm not saying you.

MR. ENSMINGER: This is a First Amendment right, and, you know --

MR. PARTAIN: One thing about the media --

MS. FRESHWATER: Jerry, I'm just saying --

MR. PARTAIN: One thing about the media -- Lori, hold on --

DR. BREYSSE: We got a lot of people who want to ask questions.

MR. PARTAIN: I want to say one thing real quick. On the media, with Channel 8 specifically, when I first approached them in 2007, after I was diagnosed with breast cancer, the response from Bob Hike(ph) was basically, what does this have to do with Tampa Bay? It is incredibly hard to get the media to even pay attention to this. The only reasons why stories appeared in Florida were because male breast cancer was unusual, and a lot of the first cases of male breast cancer with Camp Lejeune came out of Florida.

I understand the media. They have the five-seconds-or-less-state-your-case before the conversation's terminated, but all you have to do is say, if you don't want to talk to them, say no thank you. That's all you have to do. They're not rude. Yeah, they may be pushy, but like Jerry said, without the media's involvement, a lot of you wouldn't have known about this meeting today, wouldn't know about Camp Lejeune, and I can tell you for sure, without the media, we would be nowhere near where we are right now.

MS. FRESHWATER: Mike, can I just say, as a journalist, like I -- I just, I agree with all of that but there's no reason that we could not just say to a television crew that there is a sensitive -- a lot of sensitivity to this event, and just at least -- so people feel like they have that right to say no, and they're not hounded.

DR. BREYSSE: So I will speak to the press tomorrow. We'll put a note on the door so people know the press is there. And anybody should know that if you don't want to be interviewed, you just say I don't want to be interviewed. But I really want to get to some of the other hands that have been up, 'cause I saw many hands, and we have a limited amount of time.

MS. MCPHERSON: Good evening. My name is Jodi McPherson. My husband is Ian Collin McPherson. He is one of three members of his family that have passed. He passed to prostate cancer at 45 years old. His PSA was 1,500-plus from the time he was diagnosed.

He had sexual incontinence, he had urinary problems from the time I met him in 1985. He was still in active reserve. I've been denied six times over 12 years. And like this beautiful woman back here -- and I will be here for you and I will get your number when I leave -- I will not give up 'til the day I die, which this is killing me, by the way. I would like you to know that, and many of us.

I am the one that Mike talked about earlier, that had been denied six times, that called up to Louisville. First I called Bob McDonald's office, and I got Michelle. She's one of his personal secretaries. She said she would help me. She called up to Louisville. They said they'd call me back in a week, which they did. I was grateful, talked to Kyle. He's a second supervisor there, there's one of two supervisors. And he told me, well, we can't do anything about your claim now because it's been denied. But we can't notify you because it's on hold. So Michelle had told me if I had any problem with that

to give her a call back with the decision. So I gave Michelle a call back, and she said it's not coming from my director's office. The hold is not from Bob McDonald. So I want to know who's got the hold on it, because Kyle suggested I go to the courts because of how many times I've been denied. Okay, I can't go to the courts without a proper denial.

Now, my husband suffered for many, many years. He was conceived --

MR. ENSMINGER: And he was born there, right?

MS. MCPHERSON: Yeah, conceived there, born there, raised there, 105 --

MR. ENSMINGER: And then went in the Marine Corps.

MS. MCPHERSON: Yeah. 1053 East Peleliu, Tarawa Terrace I. His father was the Lieutenant Colonel R. T. McPherson, who is, like I said earlier, deceased. He went in the Marine Corps; he served very, very valiantly, went over to Lebanon, you know, got medals, meritorious service, everything, humanitarian service, did his job.

And when he came back, he had a rash covering his entire body as he left Camp Lejeune. And the doctor asked him have you ever been in touch with any chemicals around here? Well, you know what he was?

Corrosion control specialist, aircraft structural mechanic. Worked on C-123s, C-130s in Tennessee, Ohio. He was at El Toro. He was at Okinawa. And I can't pronounce, Fuji-something base in, in Japan.

MR. ENSMINGER: Camp Fuji.

MS. MCPHERSON: Yeah. Has been around Agent Orange and every solvent and chemical in this country.

And I've been denied. And you know what the SME, who I don't know his name -- thank you, Lori -- you know what he told Kyle the reason for my denial? Past risky behavior. That's why I've been denied: past risky behavior. And what I'd like to do, Brad, if it's okay with you, I'd like to set up a three-way call and I'd like to find out what that risky behavior is, because I'll tell you, I married the man directly out of the Corps. He went in at 17. He had to have his lieutenant colonel father sign him in.

So I want to know what past risky behavior he did before he was 17 years old, because they accepted him as a Marine. When he joined they accepted him and they took responsibility for him.

I want to also let you know I'm over $500,000 in debt and had to declare bankruptcy. I've lost my home, and I'm living with my daughter. My husband was too valiant and too brave and too good of a man,

husband, father, son to have me have to go through this with my child, who, by the way, and I don't know how many other people here have a child with a problem, but she was never on base, and she's got autism.

I want to know when the presumptives are coming out, and I want to know why prostate cancer was not listed in the right frame. Prostate cancer is associated with TCE. ATSDR has come out and said it. I want to know why it's not even in the presumptives. And I also would like to know, as far as prostate cancer goes, when a man dies at 80, most the time, like everybody said, like we all know, he most likely will die with it. But my husband died of it at 44 years old, very aggressive.

Well, he didn't catch his cancer within one year of his last date of service. That was my first denial. My second denial was that the science, the NRC report, didn't quantify properly about prostate cancer. Now I'm being told an SME has decided, because my husband was risky.

So I would like to get to the bottom of this, for not just me but for this nice lady back here, for the gentleman that talked about prostate cancer either, or earlier, for Mr. Burpee, for everybody that was in the

past audiences that has had prostate cancer problems or a spouse, where they've left completely without answers. So if you would, I would like to get with you later.

MR. FLOHR: Sure.

MS. MCPHERSON: Thank you very much. And thank you, Jerry, Mike. Mike, I got involved with you seven years ago, and God bless you, God bless you both.

Because, and as far as the press goes, I understand your not wanting to be on camera, but seven years ago I did an article. There are still people coming up to me trying to explain that they would've never found out about this. And one gentleman caught his kidney cancer in time because he read an article done by *Tampa Bay Times*.

UNIDENTIFIED SPEAKER: I think my quote was misinterpreted. I'm fine with the press and the media. I, I think I stated that several times. And Jerry, I completely agree with you. We need the press and the media. I think it's been misinterpreted, kind of a cell phone situation. I just -- I think people should know about it coming into it because I was surprised to see the camera here. So we need the press and media, but you need to inform people. And then I think, also reminding the press -- I mean, this

guy was like harassing me, this Channel 8 guy. So that's just not right. Anyway, any press and media are good.

MS. MCPHERSON: That's all I had. I appreciate it and thank you.

DR. BREYSSE: Over here to my left.

MR. SHUMARD: Thank you, my name is Tom Shumard. I served in the United States Marine Corps from age of 17 until Camp Lejeune, a beautiful place of lots of Southern charm, cross-country bicycling up and down the hills, sailing, a beautiful coast. It's a great place to visit, just don't drink the water.

I spent half of the day in the friendly city, Bradenton, which is where I live now. I spent about 38 years here in the city of Tampa, which is like the Emerald City when I come up here now, lots of over-passes. And I'm always humbled -- my wife has come with me a couple times to the clinic in Bradenton, and to Bay Pines, and I'm always humbled to be in the presence of other people and their families that have served. When I go to Lowe's, and they say, thank you for your service, I go, I was a bookkeeper.

So I think I could talk about my personal story, but I think I have a couple questions, maybe, for the VA, and I could probably do a web search on some of

this stuff, but being that I have the experts, I had an opportunity to speak with some of them earlier at break, but what does the VA estimate the number of individuals that have been exposed to industrial contaminants at Camp Lejeune, either in the water or through other sources? How many individuals?

MR. FLOHR: VA doesn't have its own estimate; we have no way to do that. But what the Navy has estimated as many as 720,000 Marines during the period of water contamination.

MR. SHUMARD: Okay. And is that based on a particular study or is that based on the number of people that have served at Camp Lejeune?

DR. BOVE: It's based on whatever data is available, from personnel records that are held in California, also from estimates from that same database about how many workers were on base, and then estimates about how many people attended schools and so on. It's very soft. They have a figure of 728,000, but it could be anywhere between 500,000 and a million, and could be more. We really don't know exactly. They don't have the records; although they have scanned, now, what's called muster rolls, so they could at least know how many Marines stepped foot on that base from the day it started. So they do have

that, and that will be available for researchers and for the Marines and probably the VA at some point in the near future.

MR. SHUMARD: And currently how many of those are registered or known exposures, individuals that have already been registered through the Marine Corps or through the Agency?

DR. BOVE: I don't know how many were registered. There were... I don’t remember.

MS. RUCKART: That was 250,000, but that was out of the 20 --

DR. BOVE: Yeah, yeah. So we don't know how many -- and also some of the people registered were not necessarily there. It was a mailing list mostly, a way the Marines could notify people about information, so it wasn't a strict registry of sorts.

MR. SHUMARD: So out of those, say, quarter million that might be registered, how many veterans have sought VA care or have gotten care based on exposure to...

MR. WHITE: I can answer that. Give me just one second.

MS. RUCKART: I just want to clarify, all the people that have registered with the Marine Corps are not just Marines. It could be dependents, spouses and

civilian workers.

MR. ENSMINGER: And Navy.

MR. SHUMARD: And that number reflects that civilian base as well?

MR. ENSMINGER: Yeah. And naval personnel.

MR. WHITE: Yeah, we have, as of September 30th, VA's provided healthcare to 16,466 Camp Lejeune veterans.

MR. SHUMARD: Out of nearly a quarter million people that are registered? Is that -- did I get the numbers close there? 16,000 are currently being delivered medical care.

MR. WHITE: Correct.

MR. SHUMARD: And now, is there a particular reason why the others are not? Because they just...

MR. ENSMINGER: Everybody that's on that registry, so-called registry, the Marine Corps's got, is -- it's like Dr. Bove just tried to explain, that is family members. I mean, that registry's open to everybody and anybody. So they weren't -- all the people on that registry were not necessarily exposed, okay?

MR. WHITE: But we reached out to everybody on that registry, letting them know about, you know, the benefit that is potentially available to them.

MR. SHUMARD: Okay. And just a couple more questions. On the projected cost of the VA, does the -- what, what does the VA have budgeted to service the group of veterans, their families and civilians that were stationed there? There's some presumed additional veterans that you might be serving? I'm hearing that we don't exactly know where this is going to go. Is there a budgeted...

MR. WHITE: I don't have the specific numbers for the amount of money that we provided for healthcare for veterans, but I do know that we've covered the cost, whatever that was. I don't have the specific numbers right now.

MR. SHUMARD: And my question that's been related to denial of benefits. If an individual comes to the VA, and there is a presumption that one of these 15 diseases is linked to exposure, if that veteran seeks evaluation, study, tests to determine whether indeed that disease is present, and that request is denied, is that what you're terming as denial of service? What is denial of benefits, I think, is my question here, is if you seek treatment for one of the 15 diseases, and you're denied treatment, would that be denial of benefits?

MR. FLOHR: Are you talking about disability

compensation, monthly compensation benefits?

MR. SHUMARD: No, just the treatment.

MR. FLOHR: Just treatment.

MR. SHUMARD: You walk into a clinic, and you go, hey, I was exposed, and --

MR. WHITE: Yeah, again, for -- the process is supposed to be very simple as far as for a veteran to be eligible to receive healthcare benefits. All they need to do is -- there's a box that they can check saying that they were at Camp Lejeune during the covered time frame. And they are, then, supposed to be able to receive healthcare in the VA medical center system. They're prioritized as a category 6, priority 6 veteran, and their healthcare for those 15 conditions, then, is not supposed to be any cost to that care for those 15 conditions.

MR. SHUMARD: Would -- then that would also include any prescription drugs that that --

MR. WHITE: Yes, sir, absolutely.

MR. SHUMARD: Okay. So, and -- well, on a personal note, I had made several requests based on neural behavioral effects, and those requests were denied. Am I to understand that I should indeed be delivered services to determine any neural behavioral effects from exposure to industrial waste in the

drinking water?

MR. WHITE: I'm not sure what the question is.

DR. ERICKSON: In the 2012 healthcare law, the word neurobehavioral effect was used but it was never defined. And so that -- it's true, okay. It just wasn't defined in the law. And we had sought additional guidance from the Institute of Medicine to help us define that. And that is something that's being worked through this revision of our clinical guidelines, which, as I told you before, I can't show you just right now. It is very soon to be coming out.

So there may be some resolution on that shortly. It really depends on your -- the specifics of your situation, which we probably don't want to talk about in public. But the neural behavioral term was a problem, just because it was put into the law but it wasn't defined, and then it was -- it was one of these things that simply wasn't clear to VA as how to initially deal with it.

DR. BREYSSE: Thank you, sir.

MR. SHUMARD: Thank you very much for your time.

DR. BREYSSE: Okay, now we're over to the right. We have time for, at the rate we're going, two or three more questions. So if you're going to be here tomorrow you'll have another shot, so just keep that

in mind.

UNIDENTIFIED SPEAKER: My wife told me when I stood up to keep it short, and I will. But I just -- the first thing, I do want to appreciate your -- Jerry and Mike's opinion, you know, when it comes to the news media. I've, you know, been in the -- in jobs -- and exposed to the media, and one thing about it is, if you don't want your picture taken, then maybe you better look at where you are. If it embarrasses you, maybe you're in the wrong place. And if they stick a microphone in your face, all you have to do is refuse to talk or refuse to answer. I mean, all of us know -- have got to look at the right to free speech. And amen, yes, we need the media, whether we agree with them all or not.

But my main question is for the lady that was doing the research for the dead babies. Unfortunately that's a bad research, not one that would be very happy. And you mentioned several times about the Marines. You also want to remember that -- I was a hospital corpsman in the Navy. And there were several corpsmen assigned to each company on Camp Lejeune as well as two or three medical battalions and the staff of the US naval hospital. So as you're out there, you know, looking at those grave sites you might also

remember those in the Navy.

MS. FRESHWATER: Yeah, we're aware of that. We're mainly talking about the graves that are marked Army, and some of the Navy graves have Marine Corps rank, and say Navy. So it's contradictory. So we're -- but we are aware of that, thank you. In fact his father was in the medical field, so.

DR. BREYSSE: Okay. And in the back?

UNIDENTIFIED SPEAKER: Yes, I was curious how many people in the panel are from the VA?

DR. BREYSSE: Raise your hand if you're with the VA.

UNIDENTIFIED SPEAKER: Okay, thank you. Well, in 20 years it won't be a problem anymore. Thank you.

MS. FRESHWATER: I'm not sure what that meant, but I think Dr. Breysse asked us at the beginning of the meeting to keep this civil.

DR. BREYSSE: So we're moving on.

UNIDENTIFIED SPEAKER: I got handed a mic so Sheila and everyone else is going to have to suffer.

So one of the issues that was brought up briefly was anonymity of the SME people, which, while I appreciate the need for it, I also was here for -- too high? Too low? What? Oh, no one can hear, okay.

It is the reality that these people anonymously

screw our veterans. An occupational therapist who can overrule an oncologist or your regular treating doctor, or say that all the tests you've had done for the past ten years are irrelevant because me, living somewhere anonymously, as a private contractor for the VA, has decided that I will send something to -- what do you say, Louisville? We send it to Louisville, right? And some piece of paper that one person looked at a file for 15 minutes, with really no oversight, in, say, Chicago, sent it to the VA, the VA sends it to Louisville.

Veterans expect better than a private contractor telling them that they and their doctor don't -- didn't do their work, didn't do their job, and aren't eligible for treatment.

I, thankfully, am a healthy Marine. I know friends who are not healthy. I've got a buddy who's been texting me all night long who's watching this live, Mark Davis. Don’t know how it's been on Facebook. Mark Davis says that court reporter -- or that reporter is a douche bag and does that to people. We do deserve respect from the media. And we need -- we do need sensitivity to it.

I also know, as a Marine, no one in America had any problem showing my face on TV when I was in

uniform committing violent acts in other nations. But they have absolutely put a blind eye to what we've all been suffering. So I appreciate the fact that the media is here. How they did it, I know, is an issue for some people. But I'm glad they're here.

So wrapping it up, my main thing is how we get any accountability for these people doing the SMEs? And that's for you guys.

DR. BREYSSE: So I think we spend a lot of time talking about that, and I think one of the things we hope to do, as we've said earlier, in the next meeting, is maybe to review the function of the SME process, and the transparency of the SME process, and maybe that'll -- we'll work on that and we'll get to that. Is that fair?

MS. FRESHWATER: Dr. Breysse, can I ask Brad something real quick? He helped me a great deal at a prior meeting, and I can't remember his answer. I just need to ask because people keep asking me, and I can't remember the answer. You know how it says on the denials that they -- their symptoms were not showing up when they were on base, and clearly someone doesn't get cancer immediately when they're exposed, and I asked you about that? And you gave me an answer that made sense, and I can't remember it. And now

people are still asking me, how was I supposed to see symptoms of cancer?

MR. FLOHR: Well, that doesn't make sense to me because, and we'll talk about this some tomorrow. The claims process is based on statute that Congress passed.

There are three requirements for service connection: One, that you had an injury or disease resulting in disability while you were on active duty, which is -- also includes an exposure, not just an injury or disease while on active duty, but an exposure to something that may later develop into a disability; and that you have current evidence of a disability; and that you have a medical nexus, or a link, between what you have now and what happened in service. So what you say you saw there, that doesn't make sense because you didn't have symptoms in service.

MS. FRESHWATER: I know but it's on a lot of the denials. And I asked you about it, and you told me something that made sense.

MR. ENSMINGER: Well, is that language boilerplate in your decisions?

MS. FRESHWATER: Yeah, it was something like you had to put it in there for something --

MR. ENSMINGER: It says your records are -- your, your --

MR. FLOHR: Oh, you know what? Yeah, yeah, yeah, yeah.

MR. ENSMINGER: -- your military records or health records are silent.

MR. FLOHR: Yeah. Thanks for reminding me, jog my memory. Okay, we look at --

MR. ENSMINGER: I mean, it's, it's crazy.

MR. FLOHR: Jerry, let me answer.

DR. BREYSSE: I want to make sure we get back to the audience, which is the purpose of this time, but go ahead, we'll let you finish your thought.

MR. FLOHR: When we decide claims we not only decide claims based on something that occurred in service and now has caused a disability, but also whether or not that particular disability was actually incurred while the individual was on active duty. So we use the language, there were no signs or symptoms while you were on active duty, so you won't get service connection on that basis, but then you still may get service connection based on an exposure which subsequently results in a disease.

MS. FRESHWATER: Well, maybe that might be just something you could look at as being more consistent,

'cause some people get that listed and some people don't, and it's usually for a cancer that would not show up.

MR. FLOHR: Yeah. I can understand how that might be -- yeah.

MS. FRESHWATER: It makes them think it means more than it does.

MR. FLOHR: I can understand why it might be confusing, yeah.

MS. FRESHWATER: And I appreciated you answering it before, and I felt terrible I couldn't remember it.

UNIDENTIFIED SPEAKER: Why is it, when they discharge, a medical discharge, and give you severance and say you're discharged because of a hearing loss, because of infection and stuff, but they don't tell them to go to the VA and get their disability or anything? They just throw them out there and just say, well. And then we go and get a job and use your, your insurance from your job, when it's -- when my husband was there, he was on Camp Lejeune, got a severe ear infection, and they did squat for over I don't know how many years, 50 years, and now he's just now realizing he was able to apply for all these years, and they discharged him and said, bye, here's $1,200 severance.

MR. ENSMINGER: Well, I can answer that. And that was a failure of his own leadership. That's not the VA's fault.

UNIDENTIFIED SPEAKER: But he didn't -- nobody told him that he could --

MR. ENSMINGER: That's what I'm saying. That was a failure of his own leaders.

MS. TRELLEM: All right, so hi. My name's Marie Trellem(ph), and I was stationed at Camp Lejeune. I was there for about eight months. I had a cancer diagnosis not even two years ago. I've had six surgeries, a double-mastectomy, and a year of chemo which I finished back in February.

I was denied service connection, and it's from the SME, and they said because women are a hundred times more likely to develop breast cancer than men, that was one of the reasons, the first reason given for my denial.

Of course this person went to a wonderful, of course, scientific site, the Cancer Society, and it's not a peer-reviewed study at all. And my, my thing is is these chemicals are endocrine disruptors, which means they mimic estrogen. By default women have more estrogen receptors than men. My cancer was estrogen positive, along with progesterone and the other one,

and so I am more likely to get it.

So if I am exposed to an endocrine disruptor, and I have a better chance of getting it than a man because I have more estrogen receptors, my question is why isn't -- that should be more of a reason to make it service-connected than to deny it.

In addition they wanted to cite -- oh, my computer went to sleep -- they wanted to cite my age, and quote, the risk -- this is his quote, my SME's quote, the risk increases with age with about 12 percent of invasive breast cancers being diagnosed below the age of 45, and 66 being diagnosed in women over the age of 55. I was 46 at the time of diagnosis. I was actually 46 by two months, which means I'm way closer in the 12 percent than the 60 percent -- 66 percent at over age 55. That's a bogus reason also.

No first-degree relatives; that's in my favor. Here's another one. Caucasian women have a slightly higher risk of developing breast cancer than do African-American women, Asian, Hispanic, Native American women. That's the end of his quote. But if you go to the same website, again, not a peer-reviewed study, that says, and this is because African-Americans, Hispanics and so forth are less

likely to be diagnosed. They don't go for screenings. So -- and again, then, if I am Caucasian, and they're saying -- he didn't use the reason it's because those groups of people don't get screening; he's just saying because I'm white.

Well, if the VA truly believes that, because I'm white, I should be more likely to get it, again, because you've exposed me to a carcinogen, you should be more likely to cause me to be service-connected than not.

He also went on to say that, women -- quote -- here's a quote, women who have not had children have an increased risk of developing breast cancer. Ms. ^ has not had any children. So if I go back to his website, he conveniently left out the word slightly, because if you read the real quote from the real website, again, not a peer-reviewed study, it simply says, not having children or having them later in life, women who have not had children or had their first child after age 30 have a slightly higher risk of breast cancer. Again, he left out the word, slightly, cherry-picking.

He also went on to go on to say, number 8, quote, women who are using birth control pills have a somewhat higher risk of developing breast cancer than

women who have never used them. Ms. ^ was using OCP at least in 2003, 2004 and 2005, and had a tubal ligation in 2008. But if you go and you do look at the peer-reviewed studies, you'll find that overwhelmingly the studies show that oral contraceptives do not increase the risk of breast cancer, only the ones back when they were first being developed.

And then he went on for risk factor number 9, drinking alcohol. His quote, those who have two to five drinks daily have about a one and a half times the risk of women who don't drink alcohol. Well, I might drink maybe two to three drinks a year. So he pigeon-toed [sic] me into somebody who drinks alcohol. He also denied me, saying tobacco smoke. I have never smoked a cigarette. And then also quoted obesity. So two days before my double-mastectomy I ran eight miles at a nine-minute pace.

DR. BREYSSE: Thank you, so --

MS. TRELLEM: And I have not been obese ever. I just want you to know, VA people, this is what your SME people are doing. I have my papers in, what do you call it, like I filed my NOD. I have a nexus letter. I've also been threatened to be removed from the VA healthcare system completely, and I have a

bunch of copays.

MR. UNTERBERG: Brad, just, when I hear those letters, it seems like the problem is that the explanation for why they're getting denied, basically eliminates entire categories of people. So I mean, if you're saying to someone is a female or they're white, that's not a specific -- you're applying such a specific nexus from our side, and then you're just saying that whole categories of populations can never overcome the nexus -- the anti-nexus presumption. So to me that means that it looks like you're looking for ways to deny, and you have then in your pocket a way to deny entire classes and groups of people.

DR. BREYSSE: All right, so we literally only have five more minutes, and there's a couple people who are desperate to be heard, including up here.

MS. ZAMBITO: I'm Judy Zambito. This is my husband, Danny Zambito. He was in the Marine Corps and at Camp Lejeune as well. He's lost both kidneys and his bladder have been removed, from cancer. He's on dialysis now. That's the only way he can live.

And I just wanted to just let you know what we get. He was given -- granted at zero percent. He was given -- service connection for bladder cancer is granted with an evaluation of zero percent, effective

August 7, 2012.

Service connection for kidney cancer with renal disease is denied. It goes on to tell you he was assigned zero percent because his cancer is inactive. A no-brainer, if the kid -- if the organ is removed, it's inactive. But we're not talking about an organ that you can -- you need it to live. It said a higher evaluation of 100 percent is not warranted unless there is active malignancy; surgery, which he had; x-rays, which he had; chemotherapy, which he had; other therapeutic procedure, he had BCG treatments at Moffitt Cancer Center.

It goes on to tell you he'd get an extra ten percent if he had issues in voiding. And it goes on to, to wearing Depends, all of this. In other words, give him an extra ten percent.

Should we have told his surgeons, leave the bladder, leave the cancer in me, because I'll get a hundred percent disability? No, he needed it removed because he would die if he left it in his body.

He's been having surgeries on his urinary tract for, how many years, 15? And the last kidney was removed three years ago, four years ago, I believe.

But this is the kind of thing that, if you go back and you say, we're going to cover you for the

kidney cancer. Are we going to fall under the same category? It's not active anymore; he has no kidneys. He's not going to need any more chemotherapy because he had it. It didn't work. They had to be removed.

I just want you guys to know what we deal with. That's the only reason I'm speaking right now. I'm already going to talk to him about that because I've been paying for his $50 copay to go to the VA to have his kidneys checked, which he doesn't have. He has to go to a nephrologist for that. And all of his medications. I told them I wasn't supposed to be paying the copays. Whoever I talked to in your billing told me they would gladly charge me interest, which they did, for not making the payments. So now I'm making the payments. They just -- they told me to keep track of them because, if and when, one day, they cover his kidney cancer, these drugs would be covered, and the visits to the VA. So right now we're out over a thousand dollars in just copays for these things.

DR. BREYSSE: Thank you for your story. We have time for one more, and there's somebody's waiting over there. And so we have to be out of the room is the problem. We only reserved it 'til 8:30.

ELIZABETH: Hi, I'm Elizabeth. And my husband isn't here today because he got too sick to come. But

I decided I better talk today 'cause I plan on having him here tomorrow, and my problem-Marine probably won't let me talk tomorrow.

So anyway, we have been fighting with the VA of course. And I can remember not too long ago I walked into an attorney's office, because I may be the layperson but trying to get through your system is like Greek. And I'm no dummy. I have been in that hospital so many times with my husband, fighting for his life. We've coded four times over the last four and a half years. And I have worked with doctors at other facilities, not at the VA, to understand what's happening with him.

I recently, a year ago, was diagnosed with Parkinson's. I did not think -- I mean, my first thought was not about me. My thought was, I promised him I would take care of him and that he would not see -- he would not see a nursing home.

It shouldn't be this difficult for these families to get through your system. I have worked with so many different agencies, and the right words haven't been stated. My last hope was to go to an attorney. I don't know where we're going to get with this. And I don't know what's going happen to me. But I know that these guys should not be put through this burden

of fighting your system. And as the layperson, God help them, because you count on us giving up. And if you don't, I know that's not you personally, but it's as if the system counts on us to give up.

And I can remember my husband's first denial, the first denial, and as a proud Marine, he said, I was denied, and I have to accept it. And I said, hell, no. But when we went to see that attorney the attorney asked him, why have you not done anything yet? I had to put the attorney in time-out, and say, sir, do you not understand, we have done nothing but fight to live. That's all we've done. I don't have time to learn the VA's codes, their language. I don't have that kind of time, and he doesn't have the energy.

And that's what I'm hearing here from all these people, is they are fighting for their loved ones to have the quality of life and not to have to fight your bureaucracy. (applause)

WRAP UP/ADJOURN

DR. BREYSSE: Once again, thank you very much for your story. I'm afraid we're going to have to call it a night. And tomorrow we're going to set up from 9:00 to 10:00? Sheila, help me out.

MS. STEVENS: Yeah, so tomorrow, in this room, we will have -- before you get in this room we will have some desks outside. And it will be subject matter experts and folks that can -- you can come and talk to, and the people here that did studies. And then at 10:00, we start the public meeting, which is in here. And there'll be chairs all facing this direction and a stage up there.

DR. BREYSSE: So I want to thank you all for coming and have a good night.

(Whereupon the meeting was adjourned.)

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 December 4, 2015; 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 28th day of December, 2015.

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

CERTIFIED MERIT MASTER COURT REPORTER

CERTIFICATE NUMBER: A-2102