THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

AGENCY FOR TOXIC SUBSTANCES AND DISEASE REGISTRY

convenes the

FOURTEENTH MEETING

CAMP LEJEUNE COMMUNITY ASSISTANCE PANEL (CAP) MEETING

OCTOBER 14, 2009

The verbatim transcript of the

Meeting of the Camp Lejeune Community Assistance

Panel held at the ATSDR, Chamblee Building 106,

Conference Room A, Atlanta, Georgia, on Oct. 14,

2009.

STEVEN RAY GREEN AND ASSOCIATES NATIONALLY CERTIFIED COURT REPORTING 404/733-6070

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TRANSCRIPT LEGEND

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- -- "*" denotes a spelling based on phonetics, without reference available.
- -- "^" represents inaudible or unintelligible speech or speaker failure, usually failure to use a microphone or multiple speakers speaking simultaneously; also telephonic failure.

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(alphabetically)

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PROCEEDINGS

(9:00 a.m.)

WELCOME, INTRODUCTIONS AND ANNOUNCEMENTS

MR. STALLARD: Welcome everyone. I'm told by Ray this is our 17th --

COURT REPORTER: Fourteenth.

MR. STALLARD: Fourteenth, I stand corrected.

Fourteenth CAP meeting. And so what I would like to do is start things off a little different this time. Whenever we start I sort of go over the operating and guiding principles and whatnot and then introductions. But today we're going to start a little differently in many ways.

We're going to start with a moment of silence for our fallen comrade and CAP member, Denita

McCall, who expired during our last meeting, July

8th. Many of you remember her. She was ardent and passionate about this CAP. And so if we would, please just take a moment. Here's her own handwriting of her name card up there, and let's just reflect on what she brought to us and her life. (Whereupon, a moment of silence in honor of Denita

1 McCall ensued.) 2 MR. STALLARD: Okay. So in the past to sort of lay 3 out --Ray knows you well enough to capture your name 4 5 while you're doing this, but I would like for you to 6 tell me what are our guiding principles rather than 7 me telling you. We've been doing this 14 times now, 8 so I think it's, I'd like to hear from you. How do 9 we operate here? What are the guiding principles 10 that govern our interactions? 11 MR. ENSMINGER: No personal attacks. 12 MR. STALLARD: Okay, thank you, no personal attacks. 13 What else? 14 MR. ENSMINGER: Try to stay on the issue at hand. 15 MR. STALLARD: Stay on the issue at hand. 16 What else? 17 DR. CLAPP: No talking over one another. 18 MR. STALLARD: Thank you. 19 MR. BYRON: Say your name before you speak, Jeff 20 Byron. 21 MR. STALLARD: Thank you very much. Say your name 22 before you speak.

MR. ENSMINGER: That was for him over there. He knows all of us now, so.

MR. STALLARD: Yes, he does. Anything else?

MR. STALLARD: Respect, from Sandy. Thank you.

MS. BRIDGES (by telephone): Respect.

Just a few things that we might not have covered. When you speak, push the microphone down to engage it, and you'll see the red light. When you're finished, please turn it off. The audience is here to listen and observe. They may be asked by the CAP panel, by the members, to respond if there's someone that you know in the audience who has the expertise or the wherewithal and desire and choice to respond to any questions that you might have for them.

CAP UPDATES

So, likewise, I would like to do something a little bit different this time in terms of introductions. In the past it's been pretty curt, you know, my name, CAP member. I'd like to hear a little bit more. Who you are, why are you a member of this CAP, and what has transpired since the last

meeting. What are some of the things that you have done and that the CAP is doing since our last meeting to get a sense of between meetings what's going on with the CAP activities. So, we'll start in no particular order.

MR. BYRON: Hi, this is Jeff Byron from Cincinnati,
Ohio. I guess one of the major reasons I'm a CAP
member is because I believe that if you're going to
ask someone for help, you have to be willing to help
yourself and that who can guide your destiny better
than you.

And a lot of the reasons that I got involved is that I could see from the very get-go that they only wanted to contact the people who had children in utero, and I wanted to change that. I wanted to make sure that all Marines who were exposed had the opportunity to be told and make the decisions for their family members, you know, in an educated manner.

So they started with Jerry Ensminger and the website, The Few, the Proud, the Forgotten. And I believe we have over 1,360 members now, and I

believe now the government has contacted over

140,000 Marine Corps veterans. So I think we've

been very successful there. Since the last CAP

meeting, I went to Washington to attend a meeting on

veterans affairs concerning Camp Lejeune and other

exposures that occurred in the military. It wasn't

just on Camp Lejeune.

I spoke to my senator, Brown from Ohio, and I told him that we had a lack of VA participation in the CAP meeting, and I made a motion to bring a VA representative on the CAP so that when we're researching the future studies for mortality and cancer incidence, that we wouldn't have to wait as long for databases that the VA holds. And as you know, now we have someone here from the VA to give a presentation so I think that's one accomplishment we've been able to do and is important for the future of what we're doing here.

MR. STALLARD: Thank you, Jeff.

MR. PARTAIN: Go ahead, Tom.

MR. STALLARD: Yeah, go ahead.

MR. TOWNSEND (by Telephone): I've been a CAP member

since its inception along with Jerry. I've been working on finding the documentation since 1990, since 1999, when I first found out about the survey of the 17,000 women at Camp Lejeune. I've lost my wife. I've lost my child.

I've been recently working on directing my activity towards the Veterans Administration. I have been in contact with the Under Secretary for Benefits and have been telling him directly what's going on, that there's, the Veterans Administration is a very closed society.

I'm a disabled veteran myself and can get good service from the medical facilities, but the 'when dealing with a 'like this is very difficult. And I think the fact that the VA has been pushed on by several 'members is productive. I think there's a great number of veterans out there that have been injured are still unknowing of the cause of their injury so I'm pleased that this is going forward.

MR. STALLARD: Thank you, Tom.

Sandy, do you want to go next, please?

MS. BRIDGES (by Telephone): Sure. I've been a

1 member for almost ten years now. And what I've 2 tried to do is to help everyone involved here on our 3 CAP as well as to inform and get lists and data and try to help people, dependents, that are in a 4 5 similar situation that we are. My children have 6 been affected and a lot of my close friends. 7 MR. STALLARD: Thank you, Sandy. 8 MS. BRIDGES (by Telephone): Thank you. 9 MS. RUCKART: Allen. 10 MR. STALLARD: Allen, yes, take care of the phone 11 call-ins, please, so would you share? 12 MR. MENARD (by Telephone): Sure. I've been a CAP 13 member since last year, and what I've been doing 14 since the last CAP meeting is I've been talking with 15 people around Wisconsin and the neighboring states. 16 And I've been helping them with their VA claims and 17 stuff like that. 18 And I've been contacting, I've been on Senator 19 Feingold and finally he co-sponsored. I've been 20 trying to get Senator Kohl to co-sponsor the Camp 21 Lejeune, Caring for Camp Lejeune Act. And I've also

been trying to get the neighboring state senators

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1 around here to do that and been getting a lot of 2 phone calls from vets wanting information and help. 3 And basically, that's what I've been doing. 4 MR. STALLARD: How has that been for you working with the VA in Wisconsin? 5 6 MR. MENARD (by Telephone): It's been actually 7 pretty good, and to me I found out that the VA 8 office, they don't know hardly anything as far as 9 this Camp Lejeune thing is concerned. They might be 10 finding out more now, but their knowledge of 11 everything that's going on in regards to Camp 12 Lejeune has been nothing. 13 In fact, what I tell them is all news to them. 14 And I think the VA needs to do a lot better job in 15 informing their field officers, however they say 16 that, to what's going on here and the sensitivity to 17 the, you know, to the issue at hand. 18 MR. STALLARD: Thank you, Allen. 19 Mike. 20 MR. PARTAIN: This is Mike Partain. I joined the 21 CAP in December 2007, after I was diagnosed with 22 male breast cancer. I'm one of the in utero

children who was born at the base back in 1968.

Pretty much we're working to, as everyone said, get the word out. I found out by chance seeing a news report shortly after I was diagnosed.

One of the big things we're working on right now is trying to get support for S.B. 1518, which is the Caring for Camp Lejeune Veterans Act, which was introduced by Senator Burr. And I understand there's a companion bill in the House.

Do you know the number over there, Jerry?

MR. ENSMINGER: No.

MR. PARTAIN: A companion bill in the House for this, so this is the way we get VA assistance for the people that were affected at Camp Lejeune. And, of course, recently we had a major news media event concerning the other known breast cancer cases we've been finding over the past two years starting with me and now we're up to 49 men. The last man I was contacted last night was diagnosed yesterday with male breast cancer and e-mailed us to let us know that he was at Camp Lejeune and now has male breast cancer.

As usual with anything, the more attention we get on it, the more involved in it, the more people become aware and the more we can talk about this issue and get a resolution.

MR. STALLARD: Let me just clarify. Before Mike joined this CAP, were we looking at male breast cancer at all?

DR. BOVE: We were looking at all cancers, including trying to look at breast cancer. We were looking at every cancer in the health survey study and the mortality study that we were proposing. But trying to look at male breast cancer in a mortality study would be extremely difficult.

It's not a very fatal cancer and the population we will be studying is relatively young, so it's likely we'd find very few deaths from breast cancer among men so that the mortality study is not the best vehicle, at this point anyway, to evaluate breast cancer. The health survey is a better vehicle. We can talk more about other options later today.

MR. STALLARD: Thank you.

1 2 You had, I think 25 or so? 3 MR. PARTAIN: Well, when we started the CNN --4 5 6 7 8 week and a half. 9 10 11 12 13 14 15 and approaching tripling the number. 16 17 Friday? 18 19 20 21

22

So what happened since your CNN presentation?

actually, going into June of this year I had found roughly about ten men. And then there was an article in the St. Pete Times down in Florida. article produced ten additional cases within like a

And then shortly after that article, CNN contacted us expressing interest in the male breast cancer issue that we've identified. And when CNN went to air their program, we had 20 cases, and now we're up to 49. So in the space of what, two and a half weeks, three weeks, we've doubled the number

DR. BOVE: It was also in "NBC Nightly News," was it

MR. PARTAIN: Yeah, Thursday night, NBC, and my understanding CNN ran it over the weekend, and I think there was a small blurb about the hearing last week on ABC. We also had a hearing where we were able to discuss the Camp Lejeune issue in the Senate

Veterans Affairs Committee from bringing the issue up to the Senate.

MR. STALLARD: Perhaps during today we'll get some feedback on how that went. Thank you.

Jerry.

MR. ENSMINGER: I'm Jerry Ensminger. I'm a retired Marine. I lost my daughter Janie, who was the only one of my four children that was conceived or had anything to do with her birth at Camp Lejeune. She was the only one. When she was six, she was diagnosed with acute lymphocytic leukemia, and she died at the age of nine.

I've been involved in this situation from the beginning. I realized, you know, Tom Townsend and I worked very close at hand at digging up information. And the more that I looked, the more dismayed I became as I saw internal e-mails from Camp Lejeune and Norfolk and Headquarters Marine Corps. The misconduct that was taking place in regards to the military and even some of our other federal agencies was, to say the least, disheartening.

And my goal has been on this CAP is to be, I

don't know, the mouthpiece for the community as a conduit to assist ATSDR. And, you know, ATSDR has their problems. Everybody realizes that. But the Department of Defense, especially Department of the Navy and the Marine Corps, have been less than forthcoming with ATSDR, and they've had a lot of problems dealing with these folks.

I mean from the lack of providing data to incorrect data they were being provided for their work. Like I said that's not to say that some people at ATSDR didn't screw up either, but, you know, there's enough blame to go around to everybody in this situation. And I became very politically active, and I'm working my butt off on Capitol Hill to get political support and backing for this issue.

When you boil this thing down to the facts, it is quite clear. We had Camp Lejeune, which is a known superfund site, documented. It's an NPL site; one of the worst contamination sites in the country. Number two, we know we had human exposures at Camp Lejeune. It's documented. So where the hell's the question at here?

We know that the Marine Corps and the

Department of the Navy had regulations that would

have avoided this. They didn't follow them. And

now nobody wants to talk about those. They talk

around them. Well, the day is coming, the day's

coming. We're going to have to address these

regulations that you all had in place, and we're not

going to talk around them. We're going to talk

right at them, like the BUMED and the base orders.

I mean, I saw a motion to dismiss presented by the attorneys representing the Department of the Navy in a court case. It is absolutely ludicrous. They talked around everything they didn't want to confront in those regulations, but they didn't confront the meat of the regulations as far as the standard of care and the duty that was created by those documents.

And, you know, right now we've got an issue going with the Department of the Navy about funding. Where's the money? Like the old commercial, where's the beef; where's the money? ATSDR is statutorily required to do these investigations at NPL sites.

1	And the people responsible for the contamination are
2	responsible for funding their activities. Title 42
3	requires it. Now, October 1 st was awhile ago. We
4	need to find out today where the money is.
5	MR. STALLARD: Thank you, Jerry.
6	You, too, Perri.
7	MS. RUCKART: Perri Ruckart, ATSDR.
8	CAPTIONER (by Telephone): What is ATSDR?
9	MS. RUCKART: Is that the closed captioner?
10	CAPTIONER (by Telephone): Yes. What is ATSDR and
11	what does Cap mean? I'm sorry for the ignorance.
12	MS. RUCKART: Who's that? Is that the closed
13	captioner? Who is that who is asking the question?
14	CAPTIONER (by Telephone): Yes, I am the closed
15	captioner.
16	MS. RUCKART: ATSDR, Agency for Toxic Substances and
17	Disease Registry; we're the meeting host. And the
18	CAP is the Camp Lejeune Community Assistance Panel.
19	MR. STALLARD: And there was a question of the NPL
20	site or
21	CAPTIONER (by Telephone): (Indiscernible)
22	MS. RUCKART: Community Assistance Panel.

1 CAPTIONER (by Telephone): Thank you very much, 2 ma'am, and I apologize. 3 MS. RUCKART: Okay, no problem. Perri Ruckart, ATSDR. I've been working on the 4 5 Camp Lejeune project since 2003. Do you want me to 6 talk about what I've been doing? 7 MR. STALLARD: I want you to say what we were 8 talking about -- well, you're here because you're part of ATSDR, number one, so that's 9 (indiscernible). What has happened since the last 10 11 meeting that you contributed to the CAP, or do you 12 want to defer that to your update? 13 MS. RUCKART: Well, yeah, because I'll be having a 14 whole section on that. 15 MR. STALLARD: Frank. 16 DR. BOVE: My name is Frank Bove. I'm a senior 17 epidemiologist, Division of Health Studies, ATSDR. 18 I don't know how long I've been involved in this 19 issue. Peripherally involved with this small for gestational age study, so I guess it goes way back. 20 21 And I will update you. 22 MR. STALLARD: Okay, thank you.

1 DR. SINKS: I'm Tom Sinks. I'm the Deputy Director 2 of the National Center for Environmental Health and 3 ATSDR, and you folks seem to welcome me enough that 4 you let me sit at the table. I'm not a member of 5 the CAP, but I always enjoy the interactions and 6 want to keep the communications as open as possible 7 between everybody who's interested in Camp Lejeune. 8 MR. STALLARD: Thank you. 9 MS. SIMMONS: I'm Mary Ann Simmons, Navy-Marine 10 Corps Public Health Center. I've been attending the 11 CAP since it started and became a member I'm not 12 sure when, awhile back, at the request of the CAP 13 members that they wanted a DOD representative. And 14 my duties here as I see them is to be a good liaison 15 between the CAP and DOD. 16 MR. STALLARD: Okay, thank you. 17 MR. BYRON: One minute. What have you done since the last meeting? Sorry. 18 19 MS. SIMMONS: That's okay. I forgot. Working on 20 many different issues, trying, I've actually tried 21 to watch the hearing the other day, but I couldn't 22 get it to stream on my video at work, and just

trying to keep up with the news because there's always lots going on with this project.

MR. STALLARD: So just to satisfy my curiosity I suppose, as the liaison to DOD, do you communicate and provide information to the CAP members?

MS. SIMMONS: When there's something that they requested. What I've usually done is provide it to Perri and ask her to send it out to the rest of the CAP members.

DR. CLAPP: My name is Dick Clapp. I guess my involvement in the CAP goes back actually to college where a good friend and, not roommate but I lived next door to him, went into the Marines and died in Viet Nam, and this was in 1968, but he went through Camp Lejeune.

And then subsequent to that I studied the Agent Orange health effects and ^ on vets as in the early '80s and got involved deeply with ^ on vets at that point, testified in front of two committees of Congress and then went to the VA and presented some results of some work that we had done in Massachusetts, and, you know, actually to this day

continue to stay involved in the Agent Orange issues, dioxin especially.

And then more recently got involved with a program that would be useful in public health that we call the Boston Environmental Hazard Center, which was a VA-sponsored and VA-housed research project on health effects of exposures in the Persian Gulf War on veterans. And we did a study of cancer in Massachusetts Persian Gulf War veterans.

And then Frank called me, I think in probably the winter of 2003 or thereabouts, and Frank's an old friend of mine, and he said we're setting up this CAP. We need an epidemiologist among others, so I said sure. And I got involved I think February in 2006 was my first, I probably got involved in the winter of 2006 and then February was the first meeting.

And it's been an amazing process, an amazing experience for me personally and professionally.

The reason I'm here I think is because of the people sitting around this table and on the phone and one departed member. And so I'll continue. I'm

planning to retire next June from my job at the BU School of Public Health, but I don't think I can retire from this.

I guess the other question was what's happened since the last meeting. I've been interviewed on CNN, an interview for about 20 minutes, and I think they used about three seconds, but that's how it goes. I talked to, briefly, to three members on the NRC Committee, the National Research Council Committee, Dr. Jay Nuckols, Dr. David Savitz, and Dr. Bruce Lanphear, two of them in person and one on the phone.

And it was really in passing. It was because they were, either I was at a meeting that they were at or one of them, David Savitz, came to a meeting at BU that I happened to, I wasn't part of the meeting, but I knew he was coming so had further conversations with them about what they were doing and what they thought they were doing. And I think what I said at the last meeting here about the naiveté I would still hold to.

I've also gotten phone calls from a number of $% \left\{ 1\right\} =\left\{ 1$

vets, phone calls and e-mails from a number of vets, some asking for clinical advice. How do I get diagnosed for this or who can treat this. I'd have to say I guess that's because my name has been attached to this. I'm not a clinician. I don't really have any way of answering those questions. I tend to refer them to their local medical facility or the local teaching hospital if they have one.

And I also got a call or an e-mail rather from a Senate staff member before the hearings last week. I think those are the things. Oh, and I teach about this stuff. I have to say that this story, this unfolding research effort as well as the human part of this story, students are fascinated by this, and students really want to know what's going on. And so from the point of view of academic this is rich material so I talk about it in my class.

MR. STALLARD: Dick as well can use your input in the next dialogue we're going to have about what is a CAP, you know, what's it supposed to do. I have you until ten to go through this process of introductions, welcome and then talk about how we're

structured and whatnot.

But Dr. Clapp, I'd like to ask about the NRC. Didn't you put together a, I don't know if you call it a rebuttal, but you had other colleagues who saw things differently and to that report. What has transpired since then?

DR. CLAPP: Well, with the five of us, which we did at the request of CAP members, five of us, only one of us was a member of the CAP but my four colleagues drafted and redrafted and finally signed a statement that was I guess you'd say it was a rebuttal or at least we took issue with the, especially the epidemiologic part of the NRC report, how they reviewed the scientific information about trichloroethylene and perchloroethylene, for example. And there's been nothing new on that.

Dr. Nuckols asked me why don't we have a debate. Why don't the people on the NRC who are interested and the five of us that signed that statement have a public debate somewhere at some conference or somehow. And that's still on the table, I guess. And I think I'm pretty sure at

least two or three of the people who signed that rebuttal would do it, you know, would appear at some event.

I talked with Dr. Savitz about us having a point-counterpoint exchange in a journal like something called Environmental Health Perspectives, which is, you know, like it sounds, an environmental health journal that's published by a federal agency, and we may do that. Dr. Savitz is personally not interested, but he said he would talk to some other members of the NRC, that maybe they would agree to do that. And in that case I think we might carry the conversation forward.

This is sort of in the point of what's the purpose of scientific studies after all, and when is uncertainty a cause for no action as opposed to some action, and what are those kinds of actions. I guess that's basically the summary of that conversation. Watch out. I'm a professor. I'll go on for an hour if you let me. The issue about science and how it's used is at the root of this I think, and/or misused is at the root of this. So

1 there's a lot here to talk about. 2 MR. STALLARD: Thank you. 3 MR. PARTAIN: Dr. Clapp, as a member of the CAP, I 4 mean, you mentioned that Dr. Nuckols expressed an 5 interest maybe in doing a debate. I would like to 6 see that and what better form to do it here at a CAP 7 meeting or at ATSDR since they are the statutory 8 agency required to do the health assessments and to 9 NPL sites such as Camp Lejeune. 10 MR. STALLARD: Well, we can talk about that. 11 Tom, did you have something? 12 DR. SINKS: Yeah, I just wanted to add that since 13 the last CAP meeting we had said that we would 14 provide a written set of plans for our work on Camp 15 Lejeune following the NRC report. 16 Jerry, you tried to hold me to a pretty tight deadline. I think we were two weeks ahead in terms 17 18 of getting that report out. So we did get that 19 report out. We did take, we asked the CAP to get us 20 written comments, which the CAP did. 21 We also had the comments from Dick Clapp, and

we received some from the NRDC, National Research

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and Defense Council. We used all of that in our decision process as well as the comments from our staff and put that out. And I think you all have that.

MR. STALLARD: Right, thank you.

Any my name is Christopher Stallard, and I've been with the CAP since the inception based on the meeting that I facilitated with the expert panel that essentially said that future studies were warranted and then therefore this CAP was established.

Before we move on to talk about the CAP having been established and how it's structured, I would like to point out to those of you on the phone who might not be able to see, that we have this candle lit and flowers that CAP members brought in for Denita, just so you're aware visually of what we have in the room.

CAP CHARTER AND MEMBERSHIP

So we had an expert panel that said future studies are warranted and said, okay, we need to establish a CAP to do that, and shazam, lo and

behold, we all came together and here we are. That was going on three years ago I believe.

We never really, I think, CAPs are different all over the world where they exist. They can be highly structured, or they can be organic in nature. And so what I'd like to do is have a dialogue about this CAP: what's working well, what's not working well. Is it structured to do what you think it needs to be accomplished, and if it's not, how would we structure it to be more effective to accomplish its goals.

So I would like for this to be a dialogue of sorts, and I'll capture your ideas about it. Now, Frank, I think, has a lot of experience in working with CAPs. To me, the A in CAP is assistance. So the reason we're together is to provide assistance to whom is the question I have. To whom?

MR. ENSMINGER: First word, community.

MR. STALLARD: The community, right. And so we all, by being members of it, have a responsibility because we choose to be here to provide that assistance. And so are we structured in the right

1 way to do that? 2 CAPTIONER (by Telephone): This is Tom Mitchell. Му 3 name is Tom Mitchell. I am one of six kids that 4 lived at CL and all of us are sick. I have been 5 dealing with Channel Four in my area for a CP 6 broadcast and interview. I hope I get more than 7 three. My mother was pregnant with me at Camp 8 Lejeune when I was born. 9 One moment, please. 10 MR. STALLARD: Thank you for sharing. 11 MR. PARTAIN: And closed captioner, if you'd go 12 ahead and send me an e-mail, I'd appreciate it. 13 I'll talk to you after the meeting. CAPTIONER (by Telephone): I'm sorry. I'm not sure 14 15 I understand. I've been speaking for Tom Mitchell, 16 and I'm so confused here. He is typing as they are speaking. I'm not sure if I should break in and 17 18 interrupt. 19 MR. PARTAIN: I misunderstood you. 20 MR. ENSMINGER: Ask her if this thing is closed 21 captioned. MR. STALLARD: First of all, thank you for being on 22

1 the phone. We need to kind of clarify, who is Tom 2 Mitchell that's calling in, and are you getting 3 closed captioning on the broadcast that's being sent 4 to you? 5 CAPTIONER (by Telephone): I'm not sure who Tom 6 Mitchell is. I work for a company ^ Colorado. 7 (Indiscernible) 8 MR. STALLARD: Excellent, thank you. I think now we 9 have a better understanding. 10 CAPTIONER (by Telephone): I'm sorry, and I'm a 11 little confused, too, because I have like over ^. 12 MR. STALLARD: No, no, no, it's all about 13 understanding and communication. I think your role 14 for the purposes of this meeting would be most 15 effective if you would capture the questions that 16 come in to you, and then hold them and share them at 17 the end electronically with the people that you're 18 working with, the CAP members. And then we will 19 address those questions and you can respond to them. Hold on just a minute, and I'll have Perri provide 20 21 some additional information. But this is not the 22 forum for us to provide responses to the general

1 public who might be listening in, real-time. 2 MS. RUCKART: So, closed captioner, you can just e-3 mail those questions to me. I'm the person who sent 4 you the e-mail requesting the service that you 5 provide. So if you still have that e-mail 6 requesting that, you can send all your questions at 7 the end back to me, Perri Ruckart. 8 **CAPTIONER** (by Telephone): Okay, (inaudible). 9 MS. RUCKART: Whatever questions you're getting in 10 from the public, you can just send them to me at the 11 end, and then we can address them. But you can ask 12 the people to provide you with some contact 13 information. That would be helpful. 14 CAPTIONER (by Telephone): It would be helpful for 15 me, too, ^ contact information and they can send it 16 to you directly at ^. That's not actually our role ^ . 17 18 MS. RUCKART: Yes, they can submit it if they go to 19 our ATSDR Camp Lejeune website which is where they 20 should be right now to see the closed captioning 21 link. We have contact information on there.

can submit their questions directly to us, and we

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can answer them.

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the forum for that, so if anyone is watching this, either streaming on the internet or looking at the closed captioning, please, if you have questions just send them to the ATSDR Camp Lejeune mailbox or CDC info. You'll find that information on our ATSDR Camp Lejeune web page, which is the website you're on right now to view and learn about this meeting. MR. PARTAIN: And unfortunately, we don't have the time to address individual questions here, but as a member of the CAP, if anyone out there has a question to us, they can also go to our website, The Few, the Proud, the Forgotten, and send an e-mail to either, Jeff, myself or Jerry, and we'll be happy to answer that question for you. CAPTIONER (by Telephone): ^ Or would you like me to

As Christopher was saying, this is not really

hold off ^.

MS. RUCKART: I think we'll just have them send the questions directly to us at ATSDR CDC Info or they can contact the community members at that website, The Few, the Proud, the Forgotten. So if anyone is

1 watching this, listening to this, reading it through 2 closed captioning, we're happy to answer questions, 3 but please do it through the ATSDR e-mail, CDC Info 4 or if you have questions for the community directly 5 to The Few, the Proud, the Forgotten website. 6 you. 7 CAPTIONER (by Telephone): Thank you very much. 8 appreciate it. 9 MR. STALLARD: Thank you. MR. PARTAIN: Actually, it's a good thing. People 10 11 want to interact and --12 MR. STALLARD: Yes, that's great. If you have any 13 more questions, please don't hesitate to ask. It's 14 all right. 15 So let's get now to structure. Is this an 16 issue for this group? Is it something we need to discuss? 17 18 MR. ENSMINGER: I don't have a problem with it. 19 Jerry Ensminger. Somebody got their hackles raised 20 about wanting to replace people that had left the 21 CAP. I mean, we've got people that are sick, that 22 can't participate. We've got people that have other

family members that get sick, and they can't really dedicate a lot of time to this. We started this CAP with seven community members and two experts, Dr. Clapp and Dr. Fisher.

DR. CLAPP: And Rennix.

MR. ENSMINGER: Well, he was part of the DOD. The DOD when we offered them to, after the first meeting we realized that we were having to go out to the audience to get responses, and I asked that the CAP would allow two members from the Department of Defense on.

But it's still a messenger service. They
haven't put anybody on here from Headquarters Marine
Corps after we got rid of the lawyer off of the CAP.
We still don't have anybody representing
Headquarters Marine Corps at the table, but that's
their call. So be it.

But as far as us keeping our original numbers filled, who is it that has the problem with this? I mean, every time we go to submit a new name, we get push back. Where's it coming from? Let's get it out. Come on.

MR. STALLARD: We missed something on our operating guidelines. That would be openness and transparency.

MR. ENSMINGER: Transparency.

MR. STALLARD: And let's just put in I like to operate under that, honesty. So the question is who has a problem with it and --

MS. SIMMONS: This is Mary Ann Simmons from DOD and the Navy. I'm not sure what problem that you've seen. What I would suggest, I haven't been on a CAP before, been familiar with those, but I have been involved with restoration advisory boards which, Jerry, you're on Camp Lejeune, and they're much more structured.

And I'm not saying this is what we need, but that's what we're used to, at least in DOD, where there's a process for putting new people on, how long people stay, what the purpose of the group is, et cetera, et cetera. So the only, I think that would be personally, that would be a good thing for this group. Again, that's what DOD's used to.

The only other thing I know about the push back

1 is when I believe somebody nominated Mr. Menard to 2 be on. And I just simply asked who, where he was 3 from because the name wasn't familiar to me, and 4 that was it. I mean, I don't think that was a push 5 back. That was just a question. And perhaps if we 6 had a structure for nominating new people that that 7 wouldn't have been perceived as a push back. 8 MR. STALLARD: Thank you, Mary Ann. 9 MR. ENSMINGER: What kind of structure are you 10 talking about? 11 MS. SIMMONS: You know, I'm not sure. Again, we 12 could, my familiarity is with the Restoration 13 Advisory Board. Perhaps Frank, Scott or Perri has 14 some other information about other CAPs. 15 sure how these are typically structured or chartered 16 or whatever the right word is, so maybe Frank. 17 DR. BOVE: That was mentioned to me before about the 18 Restoration. What is it called? 19 MS. SIMMONS: Advisory Board. 20 DR. BOVE: Maybe it would be interesting to find out 21 because I've been asked that, too, why isn't the CAP 22 run like the Restoration Advisory Board? And I said

1 it's because it's a different entity altogether. 2 But I would be interested just for my own education 3 how that is structured. How is that structured, and then I'll tell you more what I think about the CAP. 4 5 MS. SIMMONS: Okay. I can provide you -- or you 6 probably could, too -- charters from different ones. 7 And basically they put out the purpose of, the 8 Restoration Advisory Board in this case, who is 9 eligible to be members. What the process is to get 10 new members, et cetera, et cetera. The purpose of 11 the meetings. How do you know you're through, those 12 sorts of things. 13 DR. BOVE: That's a FACA? It's under the FACA law? 14 You said it's advisory committee so it must be. 15 MS. SIMMONS: And I just know that's part of our 16 clean-up process. It's just part of the DOD's 17 clean-up process, and everybody in DOD who sites on 18 a superfund site is supposed to have a RAB. 19 MR. STALLARD: That's an interesting question. 20 do you know when you're done? 21 MR. TOWNSEND (by Telephone): This is Tom Townsend. 22 I've got an inquiry here.

MR. STALLARD: Well, go ahead, Tom, ask it.

MR. TOWNSEND (by Telephone): I think our CAP works exceedingly well. It's comprised of victims. We know, I think we know where we're going. I think we know who has the information. I think we know who has to make the decision, who has to make some recompense.

I don't think that I'm particularly interested in a -- we can certainly write down how we do our business, but we seem to do our business as a group of individuals that have a personal role in this situation. Jerry and I and all the rest, Mike and other folks all have contributed in their own way to moving this issue forward.

Some of us, I don't show up because it's difficult for me to walk, and I don't want to hoof around the Atlanta airport and CDC so I participate this way. But I'm continuing to participate in my own fashion as a family member that has lost two of his folks and myself.

And I'm still looking for material, like the 36 FOIA requests I got. So I'm still involved in doing

what I do, and I don't think if you want me, if any
of us can tell, can state on a piece of paper how we
operate and all that kind of junk. But I don't
think we have to be a structured, definitively
structured group. I think we're doing very well as
we are.

MR. ENSMINGER: Hey, Tom?

MR. STALLARD: Thank you, Tom.

MR. ENSMINGER: This is Jerry. Another thing is with this CAP, yeah, we have agenda items that the CAP and ATSDR work together putting together for these meetings. But, you know, let's face it, every time we come to one of these meetings there's some kind of damn crisis going on.

It's like playing wack-a-mole, you know. It's either the Department of the Navy's withholding the funding, or we find out that there's some database out there that hasn't been provided to Morris and his group. There's always some crisis at every meeting. It never fails. How many times has it been now on the funding? What's this, the third time that the Department of the Navy's threatened

withholding the funding?

So we need some cooperation from the other side, and they're creating these crises. And it's nothing but a delaying factor that's built into their system. Keep pushing this thing and kicking this can down the road a little further.

MR. STALLARD: Thank you, Jerry.

Frank, did you have something?

DR. BOVE: Well, I would like to mention some of the issues that I've heard, and again, I'm going to be the messenger here. I'm not going to let you know right away where I stand on this, but just give you an idea of what kinds of things I've heard internally and externally - some of the issues that have been raised.

One is the issue of how representative the CAP is. There is another group, for example, that is not being represented on the CAP. So that's been raised. It's been raised internally and externally.

Some CAPs are representative in the sense that they try to actually get a good cross-section of the particular community. That's sometimes easier when

the site is in a community and the community's not dispersed all over the place but instead the people affected live in that community. So they try to get the librarian and someone from church groups and so on and so forth, all the major players in town politics, and someone would represent city hall. Some CAPs have been organized that way, and sometimes they work, and sometimes they don't.

Other CAPs have instead, been more like this CAP, consisting of members who are, what I would call, key informants or people who have been actively involved, and they make up the CAP. And sometimes they work, and sometimes they don't work as well. This kind of CAP involves the people who do the research and the people who are extremely interested in the issues.

So there's no blueprint to what works. We're not a FACA. That's why we call ourselves an assistance panel to avoid all the FACA regulations because they get in the way. We want, and what we hope to get is more on the model of what's been called community-based participatory research or

participatory action research.

Community-based Participatory Research
basically means that the community, the affected
community is involved at the ground floor in the
decision making, or at least provides input into the
decision making if not making the decisions
themselves in what happens in that community and
then takes the ball after agencies like us disappear
and carry it through.

So that's sort of the model, I think, that was in the minds of some people at ATSDR when the CAP was first introduced. But there are differences of opinion within my agency. So that's one issue. Is it representative or should it be representative or should it just involve what we call the key people in that community who are affected and do the research and do the work.

So that's one issue. The other issue is what does the CAP deal with? Now, we've all agreed from day one that the main issue was to inform us on how to do our work in terms of future studies, both the water modeling effort and the mortality study, the

health survey, the cancer incidence study, even our current studies, any input into how we carry those studies out. That was the charge that comes out of that science panel in 2005, and I think the CAP has addressed those issues very well.

Part of doing the future studies, in particular the health survey, but in general it's also to help us communicate about these studies and about the water modeling research to the general public and to the affected population. So that was part of the charge, if you will. We didn't have an official charge. That was our, but I think that that was, actually, we did call it a charge back then so I think we did have an official charge.

I think some people internally don't think we have an official charge, but I remember that that was pretty clearly stated. So I think we do have an official charge. The question is, is that the right charge or -- and the other issue is have we stayed on the charge or have we strayed into other issues which I've heard people say.

For example, BUMEDs, I mean, that's not

necessarily connected to future studies, for example.

MR. BYRON: But it has to do with the last --

DR. BOVE: I'm just saying --

MR. BYRON: -- item, honesty.

DR. BOVE: Right, I'm not pushing this position. I am just bringing up these issues so we can discuss them so at least they've been brought up. The people who raised these issues with me are not here to raise them. They chose not to bring them up, so instead I will raise them.

So the other issue is, well, for example, the VA denial of benefits. The VA providing data for us in our future studies is one thing. VA denial of benefits is another issue. Is that an appropriate issue for the CAP to deal with? Some people would raise that. So these are the kinds of things that have been raised.

My feeling, for what it's worth, is I think the CAP is working very well, that the word has gotten out, and I think that you've helped us a great deal on the water modeling effort finding documents.

You've critiqued the NRC reports and that I think was helpful. There are various things that the CAP has done.

I do think it would be great if we could get someone from the other website to be a part of this because I think that because they're not, it's been difficult sometimes to get them to understand what we're doing, but I understand the issues there. And so if it can't happen, it can't happen.

In an ideal world all the groups would be working together spreading the message and working together in one coalition, but that doesn't always happen and hasn't happened here. And so that may be a drawback, but I think it's been working pretty well. That's my opinion.

MR. BYRON: Well, this is Jeff, and I'd like to speak to the matter of representation as you were talking about. First off, there were two CAP members from the other group that were here and present, and they declined to attend any longer because they're interested more in compensation versus healthcare studies. Now, I think all the

members that are here today are interested in the future studies.

I believe we're wasting our time talking about structure because really what we're doing is we're addressing those few individuals who believe that they're not represented here today. And they think that the veterans are only representing veterans. That could be the furthest thing from the truth because I'm here representing my family and the two individuals who are sick in my family are dependent daughters, both of them. One has a bone marrow disease, the other has multiple issues, and that's why she's in the in utero study.

So I have never brought up my medical issues here as a veteran, although I support bringing the VA in. I'm the one who made the motion to bring them here. As a matter of fact I wish they were sitting at the table because they have been asked to be a CAP member. There was a motion made. It was seconded, and everybody asked them to be, and we'll wait for that presentation.

But to this matter of who's being represented

1 and who isn't being represented, all the victims are 2 represented, military, civilian, dependent family 3 members, male, female, children, adults. And I 4 resent the fact that anyone would imply that our 5 group does not represent everyone. 6 MR. STALLARD: Just as a, before we continue on, I'm 7 going to carry this through to our break at 10:15. 8 MR. BYRON: And real quick, I'd like to say that I'd 9 like to get on to where we're at in the mortality 10 and cancer incidence instead of rehashing how people 11 outside of the group are unhappy because I would 12 have liked them to be here, too. But they are the 13 ones who declined to be here. They weren't asked to 14 leave. 15 DR. BOVE: The issue of structure, the issue of who 16 should be represented on the CAP, is not necessarily 17 coming from the group you're talking about. 18 keep that in mind. It's coming from other places as 19 well, including within ATSDR. 20 MR. PARTAIN: Well, but the structure, I mean, look 21 at the, we have three members who are veterans. 22 have two members who are dependents, and we

represent pretty much the cross-section of the community. We don't have a member who was employed on the base. That's the only group that's really not represented on the CAP. So spectrally we are representing everybody who's in the affected community. And, I mean, functionality, we do function. We police and monitor ourselves, you know, the people that we nominate and vote on as a member of the community are functional and are working. So why fix something that's not broken?

And on the subject of straying off, like you mentioned the BUMEDs and the history and everything, you know, my degree's in history. I'm not an epidemiologist or a scientist, but I am degreed in history, and you cannot know where you're going in the future if you don't know where you've been in the past.

And I think you can agree with me the research that we have been doing uncovering the documents has led to a lot of revelations, for example, the interconnections between Hadnot Point and Holcomb Boulevard which affects a great number of people who

otherwise didn't know they were exposed. So, yeah, we're going to go on some tangents, but they're all interconnected. It all has merit and all has purpose. MR. ENSMINGER: With that being said -- this is Jerry Ensminger -- with that being said I'm going to nominate Terri Huntley to the CAP right now. the dependent wife of Phil Huntley, a former Marine, that was stationed on Main Side. They lived in Tarawa Terrace. And Phil has central nervous system vasculitis.

And Phil has central nervous system vasculitis. He suffers just multiple strokes. He cannot live at home anymore. He is in the Iowa Veterans Home. He needs constant, round-the-clock care. And Terri has become very active in this situation. She's sought out her senators and both of them have come onboard with the situation and co-signed, co-sponsored bills. And she's gotten some media coverage out in Iowa, believe it or not.

MR. STALLARD: Will she be taking Denita's vacant spot?

MR. ENSMINGER: Yes.

1	MR. STALLARD: So do we need to take a vote?
2	MR. ENSMINGER: Yes.
3	MR. BYRON: I'll second the motion.
4	MR. PARTAIN: I'll third it.
5	MR. STALLARD: All in favor?
6	(Whereupon members voted in favor.)
7	MR. STALLARD: Any opposed?
8	MR. PARTAIN: We didn't hear from the people on the
9	phone.
10	MS. BRIDGES (by Telephone): Sandy Bridges, I'm in
11	favor.
12	MR. STALLARD: Thank you, Sandy.
13	Allen? Tom?
14	MR. TOWNSEND (by Telephone): I'm in favor.
15	MR. MENARD (by Telephone): Yes, I'm in favor.
16	MR. STALLARD: Okay, very good. Thank you.
17	There's a couple things before we move on. I'd
18	like to hear from Dr. Clapp. He had something to
19	say about the CAPs, and I think that from what we've
20	heard from the community side is about the
21	representation.
22	We also have government representatives on this

1 CAP, and the question I have to ask is are they the 2 appropriate people and the appropriate 3 representatives of their agencies? We still would 4 like to have somebody from the Veterans 5 Administration. I think that's outstanding to be 6 addressed, and hopefully this afternoon maybe we'll 7 get some clarity on that. And so I'm just throwing 8 that out there. It's not just the community. We're 9 all part of this panel. Okay. 10 DR. CLAPP: Just going back to the structure again 11 and a question came up about I guess you'd say 12 professional epidemiologists or trained 13 epidemiologists on the CAP. And I'm the only one 14 right now. I think I'd describe myself as the last 15 epidemiologist standing in this effort. And it reminded me --16 17 MR. PARTAIN: Dr. Davis is. 18 DR. CLAPP: Dr. Davis, right. 19 MR. PARTAIN: She's ill. 20 DR. CLAPP: I stand corrected. Dr. Devra Davis, who 21 is an epidemiologist, is going to join or has 22 joined. The previous experience that I had on this

-- this is really a narrow point, but it's about the structure. It was with the Otis Air Force Base-Camp Edwards study. This is the upper Cape Cod study around another military base.

It's a superfund site in which the study was actually done, the initial study was done by colleagues at BU School of Public Health, David Ozonoff and Ann Aschengrau were the co-principal investigators of this in the early 1990s. And there was a community advisory committee that was chaired by actually a professor of mathematics at the local community college on Cape Cod.

It had several other members who were actually on the advisory committee to the study because they had been part of a base transition team as it was being transferred from the federal military to the state air national guard and the state army. I guess national guard. And that led them to want to know what were the impacts of the pollution from that site, and it had a lot of similar characteristics to this committee.

But there was a separate professional advisory

committee which I was on and Dr. Steve Lagakos and Dr. Richard Monson, the three of us were the professional advisory committee. We sometimes met together, but often we met separately. And the veterans, well, not the veterans, the community members were pushing the researchers to do more study of the type of exposure that people got from the base and how it was modeled and so forth, very sophisticated input actually, the math professor in particular.

And the researchers, Dr. Ozonoff and
Aschengrau, came to us, the professionals, to say
what about this. And I remember saying or I
remember Dr. Monson saying -- this is really a small
point -- but the way that the math professor had
proposed modeling it was probably inappropriate for
the type of exposure it was, but the researchers
went ahead and did it anyway.

And it actually didn't wind up saying anything different than the way they had originally planned to monitor it, but it was an example where the professionals actually disagreed, or at least one of

the professionals actually disagreed, with the community advisory board.

And the upshot was the researchers did what the community recommended anyway. And I guess the point of saying all that is that you can either have the professionals separate or as part of the CAP, and I recommend as part of the CAP. I think that the process is better that way. And the outcome might be better or it might not make a difference, but at least there's more communication.

MR. STALLARD: Thank you.

Frank, do you want to wind up?

DR. BOVE: That CAP had some difficulties and there was a lot of animosity between the community members and the state and the military and even with ATSDR. It was a situation where things had broken down so much that the state was trying to get out of doing anything more. We were trying to get out from doing anything more. Some of the researchers high-tailed it out because of the clashes. And I got involved at that point because I wanted the state to stay in. I wanted us to stay in. I wanted the state to stay

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MR. ENSMINGER: ^ in all of them.

DR. BOVE: I wanted us to stay in, and I wanted to find some solution, and it was very difficult. But what we did is, and later -- I don't know the chronology --

DR. CLAPP: But this was later. What you're talking about was later than what I was talking about.

DR. BOVE: Yeah, was to ask the three CAP members, because at that point there were only three CAP members, a very closely knit group of people who'd been active on this issue going back to issues on the Cape in the '60s and '70s, '70s at least.

And we said to them, okay, we need to have this CAP continue. We want this research to continue. Let's all of us agree on some researchers that we can all agree on and have them develop a plan. And that actually worked, happened, and a plan was developed and some more studies were done with that.

So I think that Dick's right. That it's good to have the professionals in with the community people and hash it out. I think that that works

better than separate. But I've seen it done both
ways. I think in the Mattel-Tyco situation a group
of scientists had conference calls with the state,
and then there was a community thing, not a CAP,
separate.

So each site in each situation they developed a different mechanism and some worked. Sometimes it's just meetings with the affected families. At Brick Township, NJ [i.e., the ATSDR/CDC autism cluster investigation], for example, meeting with family in their home with a few other families and hashing out with their expert what to do. That worked pretty well.

So sometimes these things don't work. At Fallon with the childhood leukemia cluster there, things didn't gel as well I think, but it really depends. And again, whether it's representative or whether it's made up of key people, there's no guarantee of success either way. It really depends on the situation and what seems to work.

And what we want, what the Agency wants I think
-- sometimes I'm not sure what the Agency wants --

well, actually, what the Agency should want is input that can help us direct our work. It's my firm belief that community input improves the science.

I've seen it done at Woburn. I've seen it at Brick Township, not so much at Fallon.

But I've seen the science improve when the community is involved at the ground floor and helps the researchers see things that they wouldn't see otherwise because they do not live in that community and do not know all the details of what's going on.

And it's certainly the case with Camp Lejeune. We've learned a hell of a lot from the community people, and we're still learning today. So I think that that's the purpose of the CAP is to actually educate us as professionals in the Agency as to what the hell's going on at the base, what has happened and give us some direction.

MR. STALLARD: Thank you.

MR. ENSMINGER: Chris had a good point. This is

Jerry Ensminger. Chris brought up a good point

about the DOD representatives. Why isn't there

somebody on this CAP from Headquarters Marine Corps'

Installations and Logistics Management? I mean, they're supposed to be the experts in this, the controlling force. They handle environmental issues for the Marine Corps at all Marine Corps bases, and they don't have a representative on here.

Now, I mean, we don't need a messenger.

Somebody who's going to sit here and say I don't know. I'll get back to you and take notes and run back to their Headquarters and then have all their attorneys go over all this with questions and then their responses and before we get anything out of them. I mean, if you just can't sit here and answer the questions honestly, what the hell are they here for?

MR. BYRON: This is Jeff Byron. And just as an example, I mean, and I haven't heard this presentation yet, but we have a handout here. It's DOD Birth and Infant Health Registry. Well, how long has this been going on? How many years has that been in effect? Nobody's told the Camp Lejeune victims that there's a Birth and Infant Health Registry? We've only been here for four years.

1 MS. SIMMONS: Since '98. 2 MR. STALLARD: Nineteen ninety-eight. 3 MR. BYRON: Since 1998. Now, we need to get back to 4 honesty, transparency and back to really the business at hand instead of discussing our 5 6 structure. I thought our structure was fine 7 personally. It appeared to me that we were moving 8 along. 9 MR. ENSMINGER: Is this grandfathered? 10 MR. BYRON: Hang on. 11 It appeared to me that we were moving along 12 with mortality and cancer incidence studies, but 13 these roadblocks keep popping up. One is funding. 14 We're not getting any from DOD. How is the water 15 modeling going at Camp Lejeune on Main Side? 16 what I really want to hear about. 17 When will the in utero study be done? 18 don't want to hear, you know, this year that it's

going to be 2013 now. How about we have
transparency and get the information that we need.

And when we ask for a member onto the CAP, that it's
not just shuffled off to the side because the VA

representation, this is the third meeting since we asked them to be involved. And I've asked them to be involved since 2002, by the way.

So transparency, honesty, handing over the rest of the documentation of COWs, which how many of those is the DOD still holding based on national security interests? That's what I'd like to know.

Because there's not one single document that should be held back from the victims at this point unless you can show my senator the documents, and he can tell me personally that there are national security interests involved here.

Because he's about the only person I'm going to believe that looks at those documents unless I get them myself. And then I think I can determine, but that's the real question here.

MR. STALLARD: Thank you, Jeff.

So it would appear that as a CAP unless we can, unless someone steps forward to present what is not working with this group that needs to be addressed and fixed and implemented, my sense is that this is a pretty good model of an effective CAP from the

1 members who have spoken thus far. 2 MR. BYRON: This is Jeff. 3 Frank, is this an effective CAP or is it not? DR. BOVE: I said so. 4 5 MR. BYRON: We follow parliamentary procedure, and 6 we make the nominations or some member makes a 7 nomination to bring on a new CAP member. 8 seconded. It's voted on plain and simple. you're not in the CAP you can't make a nomination 9 10 unless you want to present it to a CAP member for 11 someone to be presented at a meeting. 12 MR. STALLARD: I can imagine that based on the media 13 coverage there's going to be a lot more interest and 14 focus. And I know that Jerry probably has more 15 people who want to participate, who want to be here. 16 And so there needs to be some structure and process to that, but it seems like --17 18 DR. BOVE: Well, one of the things again that I 19 forgot to mention that's been raised is when we 20 nominate a new CAP member, when someone nominates a 21 new CAP member, I think what would be useful is to

find out exactly what that CAP member can provide or

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what kind of work the CAP member wants to do that would complement what's being done already.

So I think that that is one thing I've heard over and over again. And I don't think that's a bad idea actually. It's one of the few ones I've heard that I didn't think was bad. So if we can do that, that might be helpful. We'll nominate this person. This person has acted, can do this, that and the other that we think is important for the CAP's work and for ATSDR's work.

MR. BYRON: And I agree with that. This is Jeff.

And I think we also need to get a verbal commitment that they will try to be at the meeting. I know we have some individuals that can't make it, like Tom because he's older and has some issues walking, but we need to try to be here face to face and interacting eye to eye. And I think that's very critical.

So whoever we nominate in the future needs to make that commitment that they are going to be here just about no matter what. I've not missed a single one. Jerry's not missed a single one. It'd almost

have to be a death in the family to do that.

MS. RUCKART: Well, I have a question. So you have a request to nominate this new person and everybody accepted that. But you said something like she's filling Denita's seat. So seven, are we right now saying that we feel that seven is our maximum?

Because there's this discussion, Frank said if you want to add somebody what strengths do they bring to the table that's not already present here.

And I think that make sense because you all are supposed to be representing the groups. And we talked about how you're doing that except for maybe there's someone not representing civilian employees, but otherwise we feel that we're covered with all the different groups that were on base.

So I was just curious. Are we saying that we think seven's a good number, and we'll nominate as needed to replace or are we saying we think nominations should be open regardless of the number?

MR. ENSMINGER: No. We started with seven. Seven is, in my opinion, the working number that we will work with and the two experts. I mean, we're not

asking for any increases. And Terri Huntley represents a dependent wife of a Marine who had a good job, had good health insurance, because of his strokes lost his job, lost his health insurance.

He's in a veterans' home now, but he does not have veterans' benefits. They're having to pay and scrape and scrimp, and it's had a heck of an impact on these people's lives. And from that aspect and that point of view she would be very useful on this CAP for the struggles that these people are going through that she could represent them and voice that at these meetings and that is important.

MR. STALLARD: Thank you.

Let's wrap this up real quick.

MR. PARTAIN: Yeah, one thing, with Terri she's also a mother of a child who was born at Camp Lejeune and a child who was several months old when they arrived at Tarawa Terrace. So she represents the entire spectrum in the community as well.

Now, one thing, too, as a member of the CAP we also represent the community. We do need to hear from the community and not just wild speculation or

things but constructive, documented input. So things that the community can bring to us that we can bring to the table, going back to the example of the interconnection between Hadnot Point and Holcomb Boulevard.

There are people out there that have documentation or expertise that can be brought up to us so we can bring things up like that. The CAP is not here asking for compensation or, you know, that's not our purpose. But the community can get involved through us by helping us bring the history bringing out the exposures and everything, and we ask that and communicate that to us.

DR. BOVE: And one of the things you could also do is give us a sense of what kinds of things you're getting from your website. What kinds of concerns, what kinds of issues are they raising. If you could bring that up each CAP meeting, I think that that's another thing that I've heard people ask why don't the CAP members tell us what's going on with their website, what kind of concerns people have, and I think that's a good idea, too.

So if we can do that from now on, I'd really appreciate it, and in between, too, if there are issues that are being raised. You hear stuff. For example, about male breast cancer increase from the ones you've identified 20 now to 49. That's interesting to know. We didn't know how many, or I didn't, we don't trust CNN as our source necessarily. We'd like to hear from what you have to say.

Now, there have been a couple of recommendations or suggestions. One is to have someone from Headquarters Marines on the CAP.

Another is to have a VA rep on the CAP. I think that we should discuss this at some point during this meeting further or come to a consensus on whether we want to ask, we want ATSDR to ask or who asks these people to be on the CAP.

MR. STALLARD: Mary Ann, you had something?

MS. SIMMONS: Yeah, I just had a quick, I'm just trying to get this clear in my own mind. So would everybody agree that a mission statement could be for the CAP, for the purpose is how ATSDR should do

future studies and help communicate about future studies?

MS. RUCKART: As well as the ongoing studies?

DR. BOVE: Well, also to be the eyes and ears of the community, to let us know what kinds of concerns are coming in. For example, is the CDC info providing proper responses to people. We've heard problems in the past. That's been very helpful trying to correct them. Other issues that might arise that you find out that you could let us know then that would be important.

MR. ENSMINGER: Eyes, ears and voice.

MR. STALLARD: Let me interject here because we could take absolutely all day trying to come up with a mission statement. But I appreciate that Mary Ann's taking a stab at it. And what I would suggest is for the next meeting we perhaps have a draft mission statement that would be a step toward structure, if you will, that we can publish and say this is what we're all about that's all encompassing of what we've talked about here today. Is that fair to say? Let's set some time aside to do that at the

1 next meeting? 2 MR. ENSMINGER: I notice on our agenda there's 3 nothing on here about the funding for FY2010. 4 MS. RUCKART: Yes, it's there. 5 MR. ENSMINGER: Where? 6 MS. RUCKART: Future studies. 7 MR. STALLARD: Right. And what I'd like to do is 8 before we convene, finish for today, I would like to 9 talk about the representation. We're going to have 10 a presentation from the VA. It might be useful, 11 depending upon how that goes and the position of the 12 presenter in the organization, how best to go about 13 doing that. 14 MR. ENSMINGER: Is the VA going to be a permanent 15 member of this CAP? 16 MR. STALLARD: I'm not in a position to answer that. 17 We can ask that during the presentation or shortly 18 thereafter who to talk to. 19 Did you have something you wanted to say? 20 DR. CLAPP: Yeah, it was really about, one more 21 thing about a successful CAP is to have a good 22 facilitator. And in my experience we've got an

1 outstanding facilitator standing here in front of 2 us, and I just want to commend you for that. 3 MR. STALLARD: Thank you. 4 Well, with that we're a half hour behind time. 5 MS. RUCKART: And we just want to give you kudos. 6 MR. PARTAIN: I want to just add before we go. This 7 discussion of mission statements and purpose and 8 things like that, I just want to make sure that this 9 isn't a discussion to put limitations, constraints 10 on the CAP. 11 I mean, if we see an issue that needs to be 12 addressed, and if there's some type of mission 13 statement that's put out, and it's outside that, we 14 do not need to be constrained by that if it's a 15 valid and legitimate issue. And I just want to 16 express that concern and that thing that's been 17 bouncing around in my head. 18 MR. ENSMINGER: No, we're going to do a draft so 19 that we can address all this stuff. 20 MR. STALLARD: We're going to take a break and it's 21 going to be ten minutes. So please be back in ten 22 minutes.

(Whereupon, a break was taken from 10:30 a.m. until
10:45 a.m.)

MR. STALLARD: I have a little administrivia for you. If you haven't signed in, please do so. Who's got the sign-in list? It's going to make it's way around the table and the audience. We'd like, we don't just like to, we do keep track of who is here through the sign-in sheets.

I met with Tom Kniffen --

Did I pronounce that right?

MR. KNIFFEN: Yes, you did.

MR. STALLARD: -- who is here from the Veterans

Administration and the Under Secretary's Office.

He'll give you the whole organizational role that he plays there. But after lunch I'm going to invite

Tom to come sit here and his presentation I think based on his experience this morning, he wants to tailor a little bit and have an open sort of more informal dialogue with you all. So we're going to work with him and invite him to the table shortly after lunch.

WATER MODELING UPDATE

Welcome back for another exciting installment of Morris Maslia's presentation on the water modeling.

MR. MASLIA: We're ready to begin. I'm going to give you an update on some databases and modeling activities that we've done and not a very long presentation then open it up to specific questions.

I have placed three posters around and I'll explain what they are in just a minute. They are in draft form, and if those are not located strategically, please feel free to move it. I do have it up on the screen, but the resolution on the screen up here is not the resolution of a poster.

Before I get to the posters, we had at the end of September, actually the end of August, the expert panel report with the verbatim transcript. We had the report and transcript reviewed internally, and then sent the documents to all stakeholders and members of the expert panel, and courtesy copies were sent as well to some of the Agency's external contacts. The purpose was to verify and check the verbatim transcripts because there were a lot of

technical jargon that needed to be looked at as well as to see if we interpreted or misinterpreted any salient points.

We have gotten back responses from a number of experts on the panel, which is really what I was concerned with for the expert panel report. Again, the expert panel report is not necessarily an interpretive report but just an attempt to capture what went on in the meeting and what the recommendations were for the benefit of the stakeholders, the CAP, Department of Navy, Marine Corps and so on.

At the same time, or nearly at the same time which was a challenge, we also sent out for what we were calling data verification and review, what we're referring to as the Chapter C report of the Hadnot Point-Holcomb Boulevard data. This is the data report on strictly the IRP sites.

As you know last March we were provided with additional information or data which we are referring to as the underground storage/above ground storage tank, ASD-USD sites. And because of the

number of reports, I don't know at this time, but the number of reports, we decided to separate out the data into Installation Restoration Program sites and underground storage. That's why there'll be two separate data-type reports.

We're still going through the UST-type reports as I speak, but the Chapter C report, again, we sent out for people to look at, the data, if there are any questions that arise. I will tell you that is not an interpretive report. There is no simulation involved in it. I think the last couple pages in the summary we made some interpretation as far as the quality of data, where it came from, why some of it's better than other data. But in terms of where the groundwater flows and things like the water contaminants originated from, we don't do that in that report. That's not the purpose of the report.

The purpose primarily is because there was orders of magnitude more data at Hadnot Point than at Tarawa Terrace. Rather than repeating all the data and all the modeling reports subsequent to that or piece-mealing the data, we felt it would be

better to put all these documents from the disparate sources that we obtained into one report so everyone would sort of be on the same page.

So if one was referring to a certain well and certain concentration, they could refer to that report and we would all be there. So the plan is to get comments back, revise the reports accordingly, and hopefully, before the end of this calendar year have them published and on our website. That's the plan.

We were provided about 10,000 records of water distribution system operations data from the Marine Corps from the water utilities on site from like '98 to 2008. They scanned those in, and we did have temporary workers, and we provided them with input templates, and all of that has been entered, not necessarily quality checked, but it has been entered. And so that's where that activity is at...

We will, as we did with the IRP site data I'm going to show you in a minute, the UST site data we will also need to input that data and have workers as well enter that information.

That brings us to what I wanted to show you some of the effort that this chart here basically is a consequence of about 18-to-24 months worth of effort. And what it shows really we have I think for the first time captured all supply wells that we know about and been provided information in some logical and chronological order.

And what this shows -- and I'll point it out
here -- for example, here's HP-601, the open circle
says when it began operations. The solid line is
when it's operating. The solid blue line is when it
finished operating or taken offline, and the red
ones -- if you're color blind, I'm sorry, but it's
got some letters -- that is documented
contamination. The chart is not a modeling chart.
This is strictly data information that we retrieved
by going through the documents, either CLW
documents, CERCLA files and so on.

The reason we need this information, number one, is, for example, when modeling a particular well's operation. For example, modeling well HP-605. I think that's HP-605; I'll move my mouse here. HP-

605. And you say, well, gee, it stopped. It's not even getting into hardly the period of the study, but that's not true because you've got another well in its identical location picking up from there. So now we know we have pumping all the way through here, but it's just changed the well out.

This is the first step in how you're going to organize the data on well operation for modeling - you need to recognize the chronology of the well operations. And we have separated this out by service area. This would be the Hadnot Point area, and again, the lighter green below is the Holcomb Boulevard area.

Now, what we've done, this is nice and helpful for us, but the more powerful aspect of this is, for example, if you wanted to look at Well-601, we can link it. And now this pulls up all the information and the chronology that we have retrieved from documents provided from various sources, the capacities where we have them, and the data source. In other words whether it's a driller source, a capacity draw-down test. Down here the documents

where the referencing material where we obtained it from. And if we go right here we also note, for example, that Well-601 was replaced by Well-660.

So all this is behind that, and if we go one further step we can do the same thing. And, for example, right here if we click on Well-653, we now pull up -- and I don't know why that one's not coming up, but we'll, there you go. We now see behind that we can see the concentrations PCE, TCE and so on. Or if we go to one that's with an example of benzene, recorded benzene, you can see t.hat..

So the natural extension of this would be then at some point this can be provided as an information source for the public by just putting something like this up on your website, and you can click on the different wells and see the background material, when it operated, what the contamination levels were. Again, this is from the documents. There's no modeling involved on here. It's just strictly from the documents that we have been provided by the Navy and Marine Corps.

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And so that is what we have. The entire staff basically has been spending the last 18 months going through the various documents trying to resolve any conflicts, reviewing the conversations we've had with the water utility guys at Camp Lejeune trying to figure out when certain wells were operating, because all this is important information to assemble before we ever start the first modeling activity.

So is there any question on this aspect?

Actually, let me finish because I've just got a little more to go.

So that brings us to the actual modeling issue or historical reconstructing of concentrations. And in our expert panel as well as the NRC report the recommendation was made to use -- I'm putting it in quotations -- simpler modeling. And that's a nice term and unfortunately it really does us a disservice because it doesn't tell us what simpler means.

And our concern is that what we may think is simpler may not be considered simpler by our

critics, not that we shouldn't get critiqued, but our critics may say that that's not the direction we wanted you to go in, that it is too complex or too simple. As an example, we were criticized because some people thought we made a too-simplified assumption at Tarawa Terrace.

So what we are in the process of doing, I've actually got a draft and hopefully it'll go through internal review within the next few weeks, is coming up with an ATSDR position paper on what, and I'm calling it Cost and Time Effective Methods for Modeling Hadnot Point and Holcomb Boulevard.

I'm trying to get away from the use of the word simpler because what's simple to one person may be too simple or too complex to another person. And I think it clouds the issue. It's trying to get, as someone said here, you know, not spending another five years doing something if we can get 60 percent assurance with some simpler approach in two years, why spend five years and only get 70 percent assurances. I mean, there's going to be uncertainties in whatever we do. So that's really

what we need to do.

And I think learning from Tarawa Terrace we need to have this position up front. So I brought an example. For example, one of the activities in this approach is to concentrate much more on data analyses. That was one of the recommendations of our expert panel. So for example, even though we may have limited observation data in terms of mass and time, we can still make some simplifying assumptions and come out with some trend lines here and even some spatial analyses — this is conceptual — whereby then we can determine if these simplifying assumptions can be used to model. That's part of this position paper, using some parametric and non-parametric techniques.

Another thing that I want to point out is as part of this -- and you can't see this -- but there's really three, I would call them categories that we need to look at in order to come to terms with limiting the time and the cost associated with completing the model.

And the first one is the source

characterization, of course, because at Hadnot Point unlike at Tarawa Terrace we do have D-NAPL, a Dense Non-Aqueous Phase Liquid. So the question, the comment is, yes, there are D-NAPL models out there, but can we make some simplifying assumptions and assume it's dissolved.

Or can we assume if we're doing a D-NAPL that it's stationary and the heavy, dense stuff is not moving along in time. These are some of the things that will be in the position paper. And the reason that's important is because there's uncertainty associated with all of this.

Obviously, the most rigorous approach would be to assume a mobile D-NAPL source where we throw some high-end, numerical code at it that would minimize your uncertainty relatively speaking, but it would increase your cost substantially both in time and in money.

Another thing is, how are you going to classify the aquifer? Should we model all 14 layers or can we reduce it down to two or three, the pumping zone, the source zone above and the source zone below and

get the likely concentrations that we need.

And in terms of simulation, you know, again, do we go with a multi-phase, stationary D-NAPL source or do we go with, which was shown at the expert panel, a control theory where we don't care about the individual movement of the individual contaminant or water droplet in the aquifer itself, but what we're more concerned about is what is the resulting concentration in the supply well every month.

So that's what we have written in the draft position paper - a broad, general scheme. Frank will be reviewing it and it will be reviewed internally. And then once the Agency approves of it, what we intend to do is as our expert panel suggested bring two or three experts together and let them say yes or no or you missed this or you didn't miss that. And hopefully within the next couple months that will take place, and then we will post that as our approach to doing the modeling.

The bottom line is simpler modeling can go all the way from taking that whatever it is, 18,000

parts per billion of TCE and assume everyone was exposed to that supply well at one end. That's a simple model approach. All the way to the mobile, non-stationary D-NAPL source at the other end. And obviously what we want to do is try to minimize our uncertainty and at the same time we want to minimize our cost and time.

In terms of time we are targeting right now to be completely finished by September of 2011. We should have some preliminary results for the epi people sometime in the latter part of 2010. That really is -- oh, one last thing and then I'll open up for questions.

Next week, also I think it's one of the recommendations of our expert panel, we are bringing in Dr. John Doherty, who's a world renowned expert in data analysis and parameter estimation.

Specifically, he is providing us some input and interpretations with respect to the Hadnot Point area, hopefully will guide us with his input as to how we should approach data analyses. And he'll be here for three days. He'll be presenting a lecture

1 over at Georgia Tech, lecture here not just for our 2 water modeling group but some other interested 3 people. And I believe that will be very useful and 4 helpful to us. 5 So with that I'll open it up for questions. 6 Jerry. 7 MR. ENSMINGER: What's the status of the expert 8 panel report? 9 MR. MASLIA: The status is we have gotten returned 10 reports. I asked for people to either mark on the 11 hard copies or send us an attachment with any 12 changes both in terms of the verbatim transcripts as 13 well as any other thoughts they may have. We got 14 them back from all I think but two of the expert 15 panel members. 16 I know you told me you would be providing it 17 this week or today. 18 And we still need to get comments back if they 19 have any or even if they don't have any I've asked 20 people to send a report back and write on it you 21 don't have any comments. All this is FOIA-able from

the Department of Navy/U.S. Marine Corps. We got

comments back from ^ EPA as well as the CAP member as well ^ other stakeholders. So we're waiting for a couple more returned reports.

Our contractor, Liz Burleson, with ERG is I'm pleased to say is back from family leave, and in fact, I'm meeting with her tomorrow to start resolving some of those comments. Most of the comments we've received are editorial-type. We can slide a week or two, but I really do not want to go past October of not getting responses back. Then we will have to make a decision to go with what we have.

MR. TOWNSEND (by Telephone): Morris?

MR. MASLIA: Yes.

MR. TOWNSEND (by Telephone): This is Tom. You explained that there's a spectrum of difficulties or complexities ranging from increasing, incredibly complex to progressively very simplified. I just hope that any inference by the Defense Department of their desire not to pay is not influencing the downgrading of your studies to an acceptable level.

MR. MORRIS: No, actually, we submitted back in the

end of August I think, Frank, it was, our budget for FY10 and projected for FY11. And it really, in the Hadnot Point area I would say if you want to call it difficulty or what takes up the time and money is the data analysis. That's really where the crunch is unlike at Tarawa Terrace where we had only 12 wells, really only, at one time, three or four operating. So trial and error to get the model to run was sufficient.

Here, as you see by the chart, there, even just during the epi period from '68 through '85, you've got about 30-some-odd wells. And as I said, just to get that chart took us about 18 months to put together to get some logical and rational approach that we can all refer to a common base to put in there.

So that's really, if you go to a simpler model, it runs faster, but you may have to make more analyses because you have some limitations you need to test out. That's one of the reasons we're bringing in somebody like John Doherty, who's an expert in some of these techniques that we can use.

So the answer is no. We submitted a budget sufficient for us to be able to provide monthly concentrations at Hadnot Point for the epi study. That's really the driving force behind our budget considerations.

MR. ENSMINGER: Morris, what about Chapter C, the data report?

MR. MASLIA: Chapter C, we asked for it to be back October 16th, which is, I think, the end of next week, the end of this week. My phone message still says it's September, so... And it is, again, we sent it out to what I'm referring the stakeholders, Navy and Marine Corps. We also sent it out to the North Carolina DNR. They wrote back that they just want to be kept in the loop, but they had no comments.

We also sent it out to the North Carolina Water Science Center from USGS because they're doing onbase studies as well. They reviewed it and said, again, just keep us in the loop, but we have no critique of the report, which is fine. Those who are more keenly interested or more familiar with the

information, we would hope that they would go through at least some of the tables.

I can assure you our staff has been using both temp work, temporary workers, as well as, as I said, going through all of the tables and all of the references. And as you know with any report of that magnitude no matter how many times you go through it, accuracy is our goal. And again, my aim is to get that published before the end of the calendar year.

And one of the things I might add, that we learned from the expert panel was having as much of the data in printed form. Because in the expert panel, if you'll recall, we provided some printed sample tables and then we put the rest of it on a CD for them to look at. The feedback we got was that the panel members could not find this table or that table, and that convinced us that we should not just provide a few printed sample tables and then refer them to a CD.

So as a consequence, we're planning to print out all 80 tables in the report and all 30-some-odd

1 figures and stuff like that. We'll still provide 2 the CD for look-up and stuff like that, but our 3 conclusion was that if a room full of experts had 4 trouble doing that, that would not be a good way to 5 present the information to the public, just have 6 them referred to a CD, so it will be printed out. 7 So that's our goal. Our goal is to get both 8 the expert panel report and the Chapter C report, 9 the IRP site data report online and printed by the 10 end of the calendar year. And I'll just say on the 11 Chapter C it will be vitally important to get some 12 feedback from those people that we have sent the 13 report to. 14 Any other questions? 15 CAPTIONER (by Telephone): I have a question from a 16 ^. 17 MR. MASLIA: Somebody's got a question but I can't 18 hear it. 19 MS. RUCKART: Is that the closed captioner? 20 **CAPTIONER** (by Telephone): Yes, ma'am. 21 MS. RUCKART: We're not taking any questions. 22 Please tell that person to submit the question

1 through ATSDR's Camp Lejeune e-mail, CDCinfo, or to, 2 well, I guess it's a question for us on water 3 modeling? Yeah, so they wouldn't go to the community. Just have them send it to us. 4 5 **CAPTIONER** (by Telephone): Okay. 6 MR. STALLARD: Did we have a change in the closed 7 captioner? Okay. 8 MR. PARTAIN: Morris, you've got on this chart here 9 Holcomb Boulevard Well-706. 10 MR. MASLIA: Right. 11 MR. PARTAIN: It's showing contamination with 12 benzene. What's the story behind that? I'm not 13 aware of this well. 14 MR. MASLIA: Well-706? 15 MR. PARTAIN: Yeah. It's on the bottom of the 16 chart. 17 MR. MASLIA: Hold on. First of all, let's see when 18 it operated. That came in in 1986, and that's in 19 2001 it was noted as contaminated. And then in 20 2001, and let me tell you what the levels in that 21 were --22 MR. PARTAIN: Do we know what the levels were?

MR. MASLIA: Yes, yes, let me get that right now, 1 2 0.6 micrograms per liter, and then in '98 it had 3 6.1. That's probably, you know, a spill from one of 4 the above ground or underground storage tank areas 5 where it had a local impact. 6 MR. PARTAIN: Yeah, it looks like it's across the 7 street from the Piney Green Shopping Center. 8 looks like there's a gas station not too far from 9 there. 10 MR. STALLARD: Anything else for Morris? 11 MR. MASLIA: We'll also have like we did with the 12 capacity, the referencing information on these 13 sheets. We just didn't get a chance to put them on 14 for this presentation, but that will be on here. 15 Any other questions? 16 MS. SIMMONS: Is this information available on your website? 17 MR. MASLIA: This is in draft. It says draft on it. 18 19 This is the type of information that I feel that 20 once it's approved, when Chapter C is approved, this 21 will be on our website because all the data tables 22 behind this chart are in Chapter C. So this

1 information is nothing different than is presented 2 in Chapter C. It's just presented in a compact 3 form. 4 And this is a web application, for example, 5 that I could see putting on our website that 6 involves no simulation, no interpretation. 7 rather than going through all the CLW files and 8 stuff like that, someone could just look at that, 9 click on the well and get that. 10 MS. SIMMONS: I think this is really useful. 11 MR. MASLIA: Thank you. Thank you. 12 MR. STALLARD: And this is like a simplified 13 reduction of everything? MR. MASLIA: Yes, that is, and that's sort of unique 14 15 in that it puts everything, all the documents and 16 the different types of documents and all of that, it 17 still provides you with a source that came from a 18 CLW file. That was already, the CLW files, are up 19 on a CD or on the website. 20 Somebody can go and read through them. We had 21 to go through them to decipher sometimes what

numbers to use and stuff like that. But, yeah, this

1	presents the entire chronology and listing of wells
2	from 1941 through 2008 for the Hadnot Point-Holcomb
3	Boulevard area.
4	MR. STALLARD: Maybe I missed it, so when might that
5	be available?
6	MR. MASLIA: Once Chapter C is approved, and when I
7	say approved, comes back from the external review
8	and cleared by ATSDR, then we would get with our web
9	people and
10	DR. BOVE: Next year?
11	MR. MASLIA: I'd say probably beginning of next
12	calendar year to do that.
13	MR. STALLARD: Thank you, Morris.
14	Any other questions?
15	(no response)
16	MR. STALLARD: Thank you very much.
17	RECAP OF LAST MEETING
18	Okay, we're going to move on now and have Perri
19	give us a brief update from what transpired since
20	the last meeting of July 8^{th} .
21	MS. RUCKART: Well, I've passed out this handout.
22	It's just a summary of our last meeting. At our

last meeting we had a presentation from Christian

Scheel on the new ATSDR Camp Lejeune website. And
he mentioned that we would be requesting the CAP and
the community's assistance to further improve the
website.

And I sent you an e-mail on September 10th asking for volunteers to participate in what is called a card sorting study. We had a few people volunteer for that. I think the deadline is right around now, so I'm not sure if it's passed or it's coming up. But anyway, that's coming to an end. So I guess there will be some more refinements to the website after he looks at the feedback.

At the last meeting there was a request for ATSDR to provide a copy of the letter sent to the VA in which we requested a representative for that July CAP meeting. And we e-mailed that to you right after the meeting that same day, July 8th.

We had a lot of discussion at the last meeting about the need to engage the VA to be present at the meeting. You can see some actions that we took, but the end result is we do have somebody here today

1 who'll be giving a presentation in the afternoon. 2

> look into how the PHA came up with 3 parts per billion vinyl chloride.

At the last meeting Bill Cibulus said he would

You were going to say something about that? DR. BOVE: That's an estimate from the lab. vinyl chloride level was below the detection limit, and so that's just an estimate that the lab makes. You know, we don't make an estimate.

DR. BOVE: The method itself has a detection limit, and I would say the vinyl chloride -- well, I don't know. I'd have to look up the detection limit. could be as high as 100 parts per billion.

MR. ENSMINGER: Who sets the detection limit?

know what the detection limit is.

MS. RUCKART: Also discussed at the last meeting, a request for ATSDR to submit a list of questions to EPA as to whether or not the LOAEL was properly used in the NRC report, and I guess, the Agency did not do that.

DR. BOVE: Well, I mean, to be transparent we had internal discussions about this issue, but nothing

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formal was done. So why? I don't know why. Not because of interest on our part. I think that the decision -- I'm not sure how the decision was made and who made the decision. But the decision was made to focus on the epi and the water modeling aspects of the NRC report and not to deal with the tox issues.

We went back and forth because earlier drafts had some statements about how we felt about the use of the LOAEL in the NRC report, and the NRC report's conclusions on TCE in comparison to previous NRC reports on TCE, for example. But then that material disappeared from the final draft, and I don't know how that happened. I was not part of that discussion. So we did not do that.

There've been informal discussions, conversations between EPA and us, some of it around, of course, the TCE risk assessment that's in draft as well. So those conversations have been ongoing but nothing formal between the two agencies has been written down.

What I said at the last meeting was what I

thought which was that the LOAEL was used inappropriately, and I reiterate that today. But that's not an official ATSDR position.

MS. RUCKART: At the last meeting we discussed if the CAP would send ATSDR their written response on the NRC report, and earlier we talked about how that happened. We got the response on July 24th. Tom talked about this, too. He was talking about our updates, what we as an Agency have been doing since our last meeting.

And as he mentioned we issued a final plan for Camp Lejeune, and we did brief the CAP August 12th about that. That's our response to the NRC report. And Tom discussed that he received comments from various agencies, NRDC and others, and we formulated a plan that's also been posted on our website.

We can get into that a little bit later coming up when we talk about some of the items under future studies, and we can talk about specific items in our plan.

DR. BOVE: Actually, we never did brief the CAP on the actual response, did we? Because the CAP

1 meeting was in July. This came out in August. 2 MS. RUCKART: No, we had that conference call on 3 August 12th. DR. BOVE: Oh, that's right. 4 5 MS. RUCKART: But we can get into some more specifics on what's been going on since August 12th a 6 7 little bit later this morning. 8 So at the last meeting there was a request for 9 Mary Ann to find out if the military has a birth 10 defects and cancer registry currently, and a 11 mortality database for children born to active-duty 12 Marines and when they started. I have passed out 13 something that Mary Ann sent to me on the DOD Birth 14 and Infant Health Registry. 15 Did you want to say something about that? 16 MS. SIMMONS: No, just that it started in 1998, and 17 I think, Jerry, you asked if it was grandfathered. 18 I assumed you mean retroactive, and it's not. 19 just started in '98. There is a cancer registry 20 within the Navy or at least I know about the Navy. 21 However, what I was told that there's issues

with pediatric cases because if a child is

diagnosed, they usually send him to a specialist right away. So that information may not always be captured by the cancer registry.

MS. RUCKART: There was some discussion at the last meeting for Scott's e-mail to ATSDR, the file he distributed at the meeting on notification and registration first by the USMC. And Scott told me he noticed the CAP was able to scan the handout with just the color contrast the number showed up, and he said he provided something additional since then.

And then Christopher passed out during the break some notification updates. You can see here their efforts at notifying people, the numbers they've reached and some information by state.

That's all we have for the summary.

MR. STALLARD: Any points of clarification?

MR. ENSMINGER: The thing about the pediatric oncology or cancer cases, when Janie was diagnosed, her diagnosis was suspected at Camp Lejeune. And I had to take her to Norfolk to Portsmouth Naval Hospital to confirm her diagnosis, which was another military hospital. So I mean, aren't all the

pediatric cancer cases diagnosed by the military, a confirmed diagnosis?

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MS. SIMMONS: What I was told is not necessarily. Like I work at Portsmouth, and what the person who was explaining this to me said if they would get a child in who they suspected might have leukemia, that they would send the child to King's Daughters, which is a private hospital in Norfolk. So my understanding is they're sending more pediatric cases to outside the military health system to be treated because they have the better specialties. MR. ENSMINGER: Oh, yeah, but I understand that. But back when Janie was diagnosed, it was almost like she had to be diagnosed by the military facility back at that time. I mean that's half dozen or the other. I mean, you know, these children when their diagnoses are confirmed whether it's King's Daughters or Duke University.

I mean, the parents are going to have to come back and let the military know because that child's healthcare is being provided through the military system. So for them not to capture that is a bunch

1 of crap. I mean, somebody's blowing smoke here. 2 MR. STALLARD: So you want clarity? Is that 3 correct? You want clarity on whether or not if they're referred out --4 5 MR. ENSMINGER: Yeah, I mean, there should be no 6 child escaping the military's cancer registries 7 because the military's ending up having to foot the bill for that child's treatment no matter where it 8 9 is. 10 MR. STALLARD: So ^ how is it entered into this 11 registry, for instance, and captured. 12 MR. ENSMINGER: Well, that's up to them. 13 MR. TOWNSEND (by Telephone): Chris? 14 MR. STALLARD: Yeah, go ahead, Tom. 15 MR. TOWNSEND (by Telephone): I have a comment on 16 that although my child was not a cancer patient, but 17 when I reported a problem with my child in '67 at 18 Camp Lejeune I was referred for pediatric advice to 19 take the child to Bethesda. So at that time 20 referrals for these exotic types of things went from 21 ^ like Camp Lejeune, they went to Bethesda. 22 was a long time period that they did not go outside

1 the military chain.

MR. STALLARD: Thank you.

DR. BOVE: We looked into what's called ACTUR.

MS. SIMMONS: ACTUR?

DR. BOVE: A-C-T-U-R, the DOD's automated cancer tumor registry, and I'm trying to remember. From what I gathered when I did the feasibility assessment, when I did that work I looked at ACTUR. It is a so-called passive surveillance system. The completeness of reporting from DOD treatment facilities is unknown. It was established in mid-'86. I can go back and see if there's more recent information about the registry in any scientific reports and get a handle on it.

We have, Perri and I have contacted ACTUR

awhile ago now and asked for their help as well in

verifying, confirming cases that come to us through

the health survey. They're willing to participate.

I have a feeling that I don't know how useful that

database is. That's why we want to use states to

help us as well and the VA and so on. So we never

want to rely on this database. Apparently, it's not

1 clear how useful it is for research.

MS. RUCKART: Well, I'll just add to that in addition to VA databases and the state cancer registries, we also have the support of the DOD cancer registry. So all of the possible places -- DR. BOVE: The one I just talked about, ACTUR, is the DOD one.

MS. RUCKART: Okay, and then we also have the VA. So any possible place that these cancers could be reported has pledged to cooperate with us. So we have, you know, the best chance of actually confirming any reported cancers.

MR. STALLARD: Okay, thanks.

FUTURE STUDIES

So we're going to move in now to your future studies update.

MR. BYRON: This is Jeff. I wanted to see if I could get a copy of the introductory e-mail to the new registrants. I'd like a copy of that if that's possible. I don't remember getting that. This is on the notification update. It's on the last page right before keeping contact information current.

MS. RUCKART: Yeah, Christopher Gamache indicated
that he can provide that.
MR. BYRON: Will you get that today?
MR. GAMACHE: Not today but probably either by the
end of this week.
MR. BYRON: No way I could get that today?
MR. GAMACHE: No.
MR. BYRON: You e-mailed it to people, can't you e-
mail it to us?
MR. GAMACHE: I don't have my contractor's phone
number right now so it'll be by the end of the week.
MR. BYRON: That don't help me today. Okay, thanks.
DMDC DATA
DR. BOVE: We received a shipment of the DMDC data
last week. I had a chance to just upload one file
to see what shape it's in. These are the active
duty and civilian databases for Camp Pendleton and
Camp Lejeune. It's some 50 files. It's done
quarterly from '75, except for '75 there were only
two quarters.
It started in June '75. That's when the data

starts. So it's quarterly after that to '87. And

there are some issues about lining up the variables
that a contractor can certainly deal with quicker
than I can. So we have the data so far.

We may get another shipment of the data because they may have left one important variable - the MCC, the Military Command Code - off by mistake although they have, in the data I saw they have a space for it. And MCC was not coded in the database until much later than '75. I can't remember exactly when, but at least in the late '70s, early '80s before MCCs were in the database.

MR. ENSMINGER: What kind of identifiers were in there earlier?

DR. BOVE: The RUC. They call it the UIC, but it's the RUC.

We got the civilian data a couple weeks ago, and I actually loaded that in. That's easier to load in and did some frequencies on that, but I don't have them with me right this minute, but that data's ready, too. So I'd like to look at it a little bit more, but I think we have what we wanted from DMDC.

MS. RUCKART: Yeah, I want to add that it includes
Camp Lejeune and Camp Pendleton. So we're covered
as far as our data needs to begin our studies when
we're able to do so.

FUNDING

I guess one part of being able to do so, I guess, is the funding. And as Morris mentioned earlier, we submitted our funding request late August. You know we work on a fiscal year so October 1st starts our fiscal year.

Carolyn Harris in a minute will come up to the table and give some more specifics on the funding, but we did get funding for this CAP meeting. We've not yet gotten the full funding, but we were pleased to get funding to at least travel everyone in and hold this meeting. We have funding for our salaries.

Would you like to come up now and give some more details about funding?

MR. ENSMINGER: What salaries?

MS. RUCKART: Well, Frank, myself, our internal salaries so that we can keep working on Camp Lejeune

1 projects. 2 MR. ENSMINGER: What about these temporary workers 3 that Morris talks about that he's got working? mean, is he going to be able to continue --4 5 DR. BOVE: That's being worked out. That's being 6 worked out. From my last understanding -- there's 7 been a flurry of e-mails back and forth. 8 MS. HARRIS: Am I on? 9 MR. STALLARD: You're on. 10 MS. HARRIS: My name is Carolyn Harris. I work with 11 Perri and Frank. And I'm a public health analyst so 12 I handle all the contracts and the funding for Camp 13 Lejeune and have for the last 15 years. 14 He's right. So far we don't have approval yet from the military to fund Morris' staff, but we're 15 16 hopeful that will come through soon. 17 MR. ENSMINGER: What are we talking here? I mean --18 DR. BOVE: Well, for the temporary workers I think 19 it was \$50,000, and as I said, there was some back 20 and forth within Morris' division about this so I 21 don't have the latest on this. Maybe Morris can

tell us later, trying to resolve that particular

1 issue. But as for the water modeling itself, Fiscal 2 Year '10 and any future studies, we have not 3 received funding yet. MR. PARTAIN: Now, is this lack of funding 4 5 disrupting, delaying, causing problems as far as 6 y'all being unable to execute your job? 7 MS. RUCKART: Well, let's let Carolyn give an update 8 on where we are with funding and when we might 9 expect some funding and then we can get into that. 10 MS. HARRIS: We have the mortality study ready to go as soon as we get the funding from the military. 11 12 All the contractors have extended their quotes to 13 January so that if we don't get it in the first 14 quarter, hopefully in January we can get some 15 funding on the mortality study. 16 We have the health survey pilot and the health 17 survey in the pipeline. We expect that it might be 18 funded about the same time period in January. 19 MS. RUCKART: Can you tell us about that bill? 20 MS. HARRIS: Well, the Defense Reauthorization Bill, 21 which has the appropriations, which leads to the 22 funding is soon to be voted on in Congress. So, you

know, this happens every year with the funding cycle so usually when it's approved, it doesn't filter down to us until sometime between January and April so that we can actually get the contracts out the door.

MS. RUCKART: Now your questions about when we can actually start the studies, is it a funding issue or some other issues. Well, I'll say that for the mortality study, it's been approved by our IRB, Institutional Review Board, and it's also received Agency and peer review approval.

Those are the only approvals we need for the mortality study. We don't need to go to OMB because we're not contacting anyone. The mortality study just links databases. So once we receive word that the funding has been received, and we select the contractor, we can begin meeting with them and actually start that study because now we have the DMDC data so we can hit the ground running.

As far as the health survey --

DR. BOVE: Hold on a second.

If, on the other hand, there's -- and correct

me if I'm wrong -- if we don't get funding soon, we
may have to start the whole process over again to
re-bid it and everything else.

MS. RUCKART: By January.

DR. BOVE: By the end of January we actually need to have a commitment.

MS. RUCKART: Yeah, but the Navy is aware of that fact.

So as far as the health survey this was mentioned in our final plans, and we can get into some more specific details in a few minutes how we're going to be now moving in a slightly different direction and starting off with a pilot health survey. As far as that even if we were to get the funding tomorrow, let's say, there's still some extra hurdles.

We need to get OMB approval and recently, last month or I guess August now, a few weeks ago, we've had some interactions with OMB. And because we're moving in this slightly new direction of including a pilot health survey, they had asked us to withdraw our submission for the full health survey, which we

1	did.
2	MR. ENSMINGER: Who did?
3	MS. RUCKART: OMB asked us to formally withdraw our
4	submission, our package, for the full health survey
5	and re-submit to include the details of the pilot.
6	So we submitted here at CDC, I'm not sure if it's
7	left CDC and gone to OMB to be officially seen as
8	our request for the Do you know, Anne?
9	MS. SOWELL: I do not know the status.
10	MS. RUCKART: So we here in the Agency have
11	submitted that to our CDC OMB office, and we're not
12	sure if it left CDC. But anyway that's inevitable.
13	So we are re-submitting a new OMB package, which
14	includes the health survey pilot, internally here to
15	our CDC OMB, and then it will leave and go to
16	Washington OMB.
17	This is Anne Sowell. She can maybe answer more
18	specific questions you have about the process.
19	But anyway, so the package has been revised
20	just to include the pilot details.
21	Do you want me to talk about what's going to
22	happen as far as

MR. ENSMINGER: Stop. Stop. Why did OMB come back and ask you to withdraw your initial proposal?

MS. SOWELL: They apparently have timelines they have to work on it because they delayed this review because they were waiting for the NRC report. They are way past their timeline. They have assured us that they will do an expedited review.

And, in fact, we have received assurances that when we re-submit it to OMB, we don't have to do the 60-day notice and the 30-day notice. So that's shortened the review process significantly.

And they, OMB Washington will have reviewed the package by the time it gets there so it should be a very simple thing. We don't think this is going to add more than a couple of weeks to the timeline if we had submitted an amendment. But it works out better for them, and because we want to keep them working with us on this, we will sacrifice those couple of weeks for that.

MR. ENSMINGER: My question is how did the initial health survey morph into a pilot?

MS. RUCKART: Well, we were considering the comments

made in the NRC report. We are trying to -- just
because of all the comments we received, you know,
we have NRC comments. We have comments from expert
panels, both the water modeling, and we have one,
last March I believe it was, to get some direction

and guidance for our future studies.

So I guess the Agency wants to be responsive and yet also, we don't like some of comments and recommendations in the NRC report. There's certain recommendations that we don't agree with and are not comfortable with, so we are not going to be following them. But when there are things that we are comfortable doing, we don't want to just totally ignore the report. So --

MR. ENSMINGER: Why not?

MS. RUCKART: The Agency management feels that -MS. SOWELL: The pilot gives us an opportunity to
fine tune things in the health survey study like the
recruitment procedures, to make sure that what we
have planned for obtaining medical records is going
to work out. It gives us a chance to smooth out any
rough edges before we actually start the full study

data collection process. 1 2 MR. ENSMINGER: But my point is that this health 3 survey is not something that can be batted around 4 between the NRC nor anybody in ATSDR. 5 law. It's signed by the President of the United 6 States, and it says this thing will take place. 7 MS. RUCKART: That --8 MR. ENSMINGER: Now wait a minute, wait a minute. 9 Damn it. This thing keeps getting dragged out 10 longer and longer. Every time we turn around 11 somebody's throwing something into the mix that's 12 extending this thing for the answers that we're 13 looking for from the community. Now, this is 14 another year at least. 15 MS. RUCKART: You're right. What you're saying is 16 true. We did discuss this I thought in the August 17 conference call that we had with you because it is 18 in our final plan --19 MR. ENSMINGER: I mean, that conference call, that 20 conference call, you know, we get slapped with this

stuff on a phone call, and we didn't even have the

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report.

1 MS. RUCKART: Right, so we --2 MR. ENSMINGER: We didn't have your response until 3 the minute that phone call took place. MS. RUCKART: Right, so that's why we --4 5 MR. ENSMINGER: I mean, that was, that was unfair to 6 begin with. I mean, why wait until the minute 7 you're going to make the conference call to give us 8 the materials that you're going to cover in the 9 conference call? 10 MS. RUCKART: So we had a follow-up call I believe 11 it was a week or so later. 12 MR. ENSMINGER: Well, I was too busy to do that 13 again. But, you know, I'm airing my problems right 14 This is crap. 15 MS. RUCKART: Well, all I can say is this is our new 16 position. We have to move forward with it. And I 17 want to address your question about this being 18 congressionally mandated, so why are we going to be 19 testing procedures and things like that. So that's 20 true. It is congressionally mandated so we're going 21 to go down the path, as Anne was saying, to just

test out certain procedures, make sure that, as Anne

said, any fine tuning that can happen will happen.

PILOT HEALTH SURVEY

So I guess we can start talking about the pilot health survey now. We may have to finish discussing it after lunch. But actually, the pilot health survey is going to employ basically the same procedures as the full health survey but be done on a smaller scale. So we estimate there's approximately 300,000 participants for the full health survey.

So we would be testing the methods on a ten percent sample, approximately 30,000, and those will be selected to represent the different water systems. So we don't want to just say, oh, we're going to just take any old ten percent, 30,000 people. We want to make sure that we're getting a representative of people who were on different water systems and civilians and dependents so it's a good mix of the full population.

We'll be employing basically the same procedures that we talked about all along in terms of our introduction letter to the survey and the

intervals we'll contact them if we don't hear back to try to increase their participation. We'll try to confirm the cancer cases and other reported conditions as we've discussed before.

I would say the one change is we're not going to send surveys to the known decedents as part of the pilot. They'll be flagged, and they can be contacted later on when we do the full health survey. So that is one slight change.

Also, during the pilot when we have our phone contact, if somebody ultimately does not participate after these reminder postcards and reminder letters and we get to the point where we're going to contact them by phone as one last attempt to gain their participation, we would ask them if they would share with us their reason for not participating and then this could help inform us to maybe make some tweaks for the full health survey.

So, we're going to collect all this information in the pilot, what are we going to do with it? How are we going to make a decision to say what fine tuning needs to be done? Was it successful or not?

We're going to convene an expert panel. We're going to invite external epidemiologists to help us come up with how best to evaluate this.

We can do that while the pilot health survey is underway. We're not going to wait for the data because we're going to have criteria established ahead of time so that when we get the data we'll be able to say whether the pilot was successful in terms of how many people participated, in terms of whether there was significant selection bias.

Some questions that the pilot can answer are:

Did more people participate from Camp Lejeune than

Camp Pendleton? How successful were we in verifying

self-reported cancers? Is it likely that people with

diseases participated more than those without

diseases, and if so, what would be the impact on the

results?

And then if, using whatever criteria are established, it is determined that it is not advisable to move forward with a full health survey, then, because as you mentioned this was congressionally mandated, we will still mail out

surveys to the rest of the population however, it

won't be done as a study, and there will not be

these intensive efforts to get them to participate

or to confirm their cases.

MR. ENSMINGER: This is something that we touched on with our initial thing about the CAP, and, you know, the community members versus the experts. And the one thing that, the one dividing line here between the community members and the researchers -- and I didn't mean to feel like I was attacking you -- my frustration is that as a community member, and a very active one, and Jeff and Mike and Tom and Sandy and Allen, you know, we talk real world with the people that have been affected by this.

We're not dealing with numbers and facts and figures every day. And we're not secluded or sequestered into an office where we're just dealing with these numbers. We're talking to these people every day. I mean, and there's a world of difference when you're talking to these folks, and you try to make sense of, well, why are they doing this this way? Why is this going to take another

1 year or a year and a half before we get answers? 2 There's people out there dying. That girl 3 right there is one of them. These people want 4 answers. And every time we turn around there's some 5 other lengthy thing that's been thrown into the mix. 6 I mean, that's my frustration with this pilot thing 7 is this wasn't part of the proposal initially, and 8 all of a sudden this pops up. 9 I mean, it just seems like somebody's trying to 10 build in delays into this thing every time we turn 11 around. And for lack of a better term, it's B.S. 12 I'll clean it up. 13 MR. STALLARD: You said crap. I was thinking we 14 could do an acronym. It's creditable, reputable, 15 applicable and prudent. 16 DR. BOVE: Let me try to bring transparency to this 17 issue, too. I may get in trouble, but that's tough. 18 I'm opposed to doing a pilot. I think it's 19 unnecessary. 20 When we submitted the health survey study 21 package to OMB, it had already been peer reviewed -22 the health survey study protocol had been peer

reviewed and it was approved by the CDC IRB. This approved study protocol and OMB package had no pilot as part of it. So before the NRC report came out we had a package at OMB with no pilot.

The reason we didn't have a pilot is because we were going to be using the standard technique that's used in these kinds of mailed surveys which is called the Dillman Method or modified Dillman Method. There is no better approach to doing a mail survey study that's out there than this approach.

When we received the contractors bid to conduct the survey study, some of them recommended a few variations on the Dillman Method that they, you know, each contractor said that what they do is slightly tweak it a little bit this way, a little bit that way. But essentially the approach was going to be the Dillman Method that they felt comfortable with, their version of it, because each one of these contractors have a lot of experience doing survey research. That's why they bid on it. And they all use some variation on the Dillman Method.

So why a pilot? When we had the March 2008 meeting of epidemiologists, and Dick was there so he can correct me if my memory fails me, the notion of doing a pilot was mentioned at that meeting. And there's differing interpretations of what reason it was raised and what the purpose of that pilot was.

And my interpretation was that at that point we weren't sure, there was no mandate at that point to do the survey yet, right?

MS. RUCKART: That came out in January.

DR. BOVE: That came out in January. And there was some concern as to what method might bring out the best participation, e.g., monetary incentives or a letter from the Marine Commandant. So there was some talk of trying to pilot that to see what would increase participation.

So that was mentioned at the meeting. I think that was the main thing, there was some concern about medical record confirmation, but I don't think there was a discussion about piloting that. I think the main -- if you remember --

DR. CLAPP: That's right. That's how I remember it.

I mean, we want a high participation rate. We were asked when we were challenged internally to come up with criteria for what is a successful survey, what was a participation rate that means it's a success.

And so I searched high and low, and I found a published study that had 25 percent participation rate in the exposed group and 12 percent participation in the unexposed group.

And that was published in a reputable journal, or somewhat reputable, The Journal of Occupational and Environmental Medicine. It is a peer review journal. So that gets published. There appear to be no hard and fast standards for participation rates. In the early '80s, 65 percent, maybe 70 percent, was considered a minimum participation rate, but as time went on it kept dropping.

And now, for example, the Millenium Cohort

Study, which is a military cohort study, the initial participation rate was around 40 percent or so or even less. And the participation rates for the Gulf War studies varied. Some had high participation

rates in the 60s and some had in the 40s, but it looks like what mailed surveys are getting these days is somewhere in the 40 percent range, 40 to 50 percent, although there are published studies that have participation rates much lower.

So I guess you could make a case that it's important to do a pilot to see if we can improve participation. For example, a pilot could determine if a letter from the Commandant was sufficient to get a high participation rate or whether we'd have to move to a monetary incentive. So there's one argument for a pilot.

Again, we didn't propose a pilot before the NRC report. The NRC report never asked for a pilot.

The NRC report basically said that none of these studies were really that feasible, even the mortality study they said was feasible, then they said we wouldn't have statistical power. They were incorrect in that, but they were criticizing both studies not just the survey.

Keep in mind that the real issue is not participation rate. The real issue is, is there a

bias. You could have a low participation rate and very minimal bias and a high participation rate and a lot of bias. Whether or not there is selection bias depends on whether people who are both exposed and have the diseases that you're interested in are more likely (or less likely) to participate than people who are not exposed and do not have these diseases. So what you hope is you have a high enough participation rate so that this bias is less likely. With a low participation rate you have to make a strong case for why this bias is not likely to have occurred.

MR. ENSMINGER: Well, if they keep delaying this stuff, you'd probably do away with the survey and just do the mortality study because I think what they're doing is trying to delay this thing so that everybody dies.

DR. BOVE: With the delay -- to hurry up here, the other issue for the pilot was can we confirm cases, and that's another reason why we're doing the pilot apparently. What the pilot will do will delay one year the completion of this full survey. So if we

1 did the survey instead of the pilot, we'd be done a 2 year earlier instead of if we do the pilot and the 3 full survey. So that's the implication. But in between we have to deal with OMB still 4 5 and funding. 6 MS. RUCKART: And then also getting the cancer 7 registries on board, just beginning the process of 8 formalizing that so they will be able to confirm 9 what's reported. 10 MR. ENSMINGER: So now we're looking at the 11 mortality study and this pilot survey are going to 12 be delayed, what, four-to-six months now because of 13 funding, say six months. Then the pilot survey is 14 going to add another year to a year and a half, 15 well, maybe even more. So there's two years. 16 Where's this heading? 17 DR. BOVE: What we think if we get funding in a 18 timely basis in the next few months, the mortality 19 study takes a little less than two years to 20 complete. That's how long it takes; that's the 21 normal rate. And then the survey will take three 22 years, the first year for the pilot, then two years to finish the full survey, if the full survey is conducted.

And remember what Perri said is true. We're going to set up a panel of expert survey researchers, and they are supposed to come up with criteria before we even look at the data, criteria for what would be a successful survey. Based on my own research into this there are no criteria. They're going to have to come up with them in some kind of Delphi process, I guess, or some kind of consensus. But as far as I know there are none, but that's what we've offered to do.

We also have said we would do certain analyses to tease out from the data all the information we can about whether there's bias, how much the bias would be to obliterate any findings that were positive, just to get a handle on whether it's plausible that bias could explain any positive results we find.

So that kind of analysis is not done that often but has been done, for example looking at the effects of smoking where you're looking at lung

cancer and occupational exposure and try to see how much confounding there'd have to be to explain a finding.

Usually there isn't that much confounding. And we would do something similar, an approach to see how much selection bias there would be, have to be so that a positive finding would be explained by that bias.

MR. ENSMINGER: Well, the military can't say much about smoking any how. They used to provide cigarettes with our meals so for god's sake, you know.

MS. RUCKART: I just want to say one thing. Frank
was giving like in general it takes this long or it
takes that long. I wanted to kind of ground that
into calendar years for you. So if we're able to
start the mortality study very soon, the next few
months, this year, we're projecting a completion
date of like summer 2012 for that. Fiscal Year...

DR. BOVE: Before you do that let me. This is the
timeline, the most recent timeline. We're talking
by July of 2011. A lot of things, this is -- before

1 I even say that --

MR. ENSMINGER: Read that thing quick, Frank. It keeps moving.

DR. BOVE: Yeah, well, part of the problem with it keeping moving, part of the problem is the complexity of modeling Hadnot Point. That's part of the issue here. A lot of things depend on us getting preliminary data from Morris. A couple months ago it appeared that we would get preliminary results from the Hadnot Point modeling in October of next year. Now it's moving to November, December.

So it's creeping, and I have a feeling it's going to creep a little more. As that creeps, it pushes the timeline, that in itself pushes the timeline, just the complexity and difficulty of Hadnot Point. There's nothing we can do about that.

It's a very complex situation where we are doing cutting-edge stuff, we have experience at Tarawa Terrace, but this is different from Tarawa Terrace. And it's different from any other situation I'm aware of in terms of water modeling and exposure assessment. We're in the frontier so

you have to expect that there probably will be some slippage of the timeline just because of that.

But if Morris provides data to us let's say by December of next year or January of 2011, several things can be finished before the end of 2011 and that would be the mortality study and the reanalysis of the small for gestational study and the analysis of the case-control study of specific birth defects and childhood cancers. The re-analysis of the small for gestational age study and the analysis of the case-control study are totally dependent on getting that Hadnot Point monthly contamination estimates and modeling that interconnection between Hadnot Point and Holcomb Boulevard. Once we have these data, these studies can be finished quickly.

The NRC report said that we should not wait for the Hadnot Point modeling results, but instead, finish these two studies now. If we did that, we would make the same mistake again as we did with the original small for gestational age study. So we don't want to do that. We want Morris to finish, at least providing preliminary data we feel comfortable

with, and then we can run with it. So that's the idea.

The mortality study also will be affected by that water modeling delay, too. But it's also the funding issue and when we get that funding. So there's two things going on with the mortality study. Is that being clear?

(no response)

DR. BOVE: The health survey is this way. It's unclear to me whether we would have gotten OMB approval for the full survey or not. It was unclear. And right after the NRC report we weren't sure, and though we had a good conversation with OMB, they didn't say definitely positively. We came back with a pilot that changes things. That's why we had to pull the survey and re-apply with the pilot. So that's how that works.

MR. ENSMINGER: Well, the foundation for everything that's going to happen at Camp Lejeune and has happened at Camp Lejeune like the in utero study and all the studies that will go forward from here on out, the foundation for everything is the water

1 model and without it there's nothing. 2 MR. STALLARD: So we need the funding for that. 3 I'm going to use this as an opportunity to discontinue the conversation because we have lost 4 5 our feed during lunch. So let's take a break and 6 come back. I'd like to invite Dr. Clapp to comment 7 on his perspective on the pilot, and then we'll 8 finish with Frank's presentation. One hour. 9 (Whereupon, a lunch break was taken from 12:02 p.m. 10 until 1:00 p.m.) 11 MR. STALLARD: We're going to continue to talk about the future studies but what I would like to do is to 12 13 invite Mr. Thomas Kniffen, who is from the VA. I 14 have been remiss. I think I should have invited him 15 to sit with us earlier because it has long been our 16 intention to have a representative of the VA. 17 this man has come here to be that for today. 18 And so if you would, join us at the table. 19 And then he'll have his presentation, and we'll 20 make his introductions at that time. 21 And so welcome and thank you for being here and

we'll go to formal introductions shortly with the

presentation.

So we left off with a dialogue about the pilot study. I asked that when we came back there were two things I'd like to know, get more information on. I would like to hear from Dr. Clapp about it and maybe a little bit more information about the role of OMB. They're a big player in this and why working with them is important to everyone.

DR. CLAPP: I said before the break that I've done studies of veterans where we looked at both deaths and cancer incidence. And we've never done a pilot study before you embarked on it, but both those were funded at the state level. They were state Office of Veterans Services level and not federal funds. So there was no OMB involved. So I can't really comment on the difficulties that are put in place by having to go through an OMB review or an OMB process before starting a study.

All I can say is that in my experience you make a decision on what it is you want to study and what the population is that is of concern. And then based on an approval of that, you go ahead and do

1 the study, and it isn't necessary to in all cases do 2 a pilot study. 3 I think that the train has left the station 4 though as far as this particular OMB request. going to be first for a pilot study and then 5 6 revisited later on. So I don't know what to say 7 about how, what we can do at this point in the state 8 of things. It seems like it's a done deal. 9 MR. STALLARD: All right, well, we have here Frank, 10 Perri, Dr. Clapp and we still have to talk about 11 funding, congressional briefing, cancer incidence, 12 male breast cancer. MS. RUCKART: We talked about that. 13 14 MR. STALLARD: All of them? 15 MS. RUCKART: We talked about the funding. 16 CONGRESSIONAL BRIEFING 17 MR. STALLARD: Let's talk about the congressional 18 briefing. 19 MS. SIMMONS: Could I just ask a question about the 20 pilot study? Didn't you all do one of those before 21 for I think the current study that's going on?

MR. ENSMINGER: The in utero.

1 MS. SIMMONS: That's what I was thinking. Right?
2 MS. RUCKART: Well, that wasn't really a pilot.

MS. RUCKART: Well, that wasn't really a pilot.

DR. BOVE: I think there was something done prior to the survey itself. Is that what you mean?

That was, well, we had to ascertain the cases so --

MS. SIMMONS: That's what I was --

DR. BOVE: Yeah, and I think the issue there was whether we could find people. For example, you do a pilot when you're not sure whether you can locate the people you want to sample. For example, if you were doing a study of people who lived in FEMA trailers after Hurricanes Katrina and Rita, they scatter around. You may not be able to enumerate them all to get a sampling frame.

So a pilot can be conducted to determine whether we even have an idea of who was there and whether we can locate them. So for Camp Lejeune we have the birth certificates, but we wanted to expand it to those who were pregnant on base but who left the base before giving birth. Well, if the parents gave birth outside North Carolina, the birth certificate data for NC would not have this birth

and we would not know about it. And so I think that that was part of the reason for the pilot - to see how you would find these births that occurred off-base in another state. And the other issue was could we actually locate and contact the parents of children born on or off-base. We have birth certificate information. Now we're contacting them a long time afterwards, you know, can we contact them?

For the health survey, for the people who are in the DMDC database we have social security number and data of birth. So locator firms are much better now than they were even back then. So with that information it's pretty clear that you could identify and try to contact them.

So the question -- and another issue with a pilot could be -- and we haven't talked about this -- but there are people who are in the 1999-2002

ATSDR survey who we want to send a health survey to where we don't have social security numbers. It's not a large group but there are a couple thousand or so I would say. I'm not exactly sure, but five, ten

thousand maybe, somewhere in that range. So that could be piloted. Can we identify the current mailing addresses? And then for the people who register with the USMC, I'm not sure what information is being collected, so that could be another thing to pilot. But what we decided to pilot instead was to pilot not necessarily could we find these people and send

them something, but how many would participate in the survey, because that appeared to be the chief concern - NRC's concern, others' concern. Who would participate and who wouldn't participate?

MS. RUCKART: Frank, we're including the way to find them in the pilot.

DR. BOVE: Well, okay.

MR. STALLARD: Sandy, would you mute your phone, please?

DR. BOVE: Tom Sinks and I and Tom Frieden, who's head of CDC, met with Senator Burr and Senator Hagan and their staffs about three weeks ago, for about 40, 45 minutes and were asked a number of questions about funding, about what our statutory authority

1 was and some questions about the survey. So we did 2 that. 3 And we had a call with them yesterday to follow 4 up on some of the issues around funding. Funding is 5 the key issue. So that happened. Any questions on 6 that? 7 MR. STALLARD: Yeah, what was the atmosphere like? 8 I mean, how did it go? 9 DR. BOVE: Well, the atmosphere was that the two 10 senators and their staffs support our studies. They 11 support our getting funding for the future studies. 12 They support the water modeling effort. They think 13 it's important that those who were at the base, 14 either the Marines or their dependents or civilian 15 workers, have a right to know what happened, and 16 they want answers and so on. So they feel that our 17 water modeling and our studies will help provide 18 this answer. So that is their... 19 MR. BYRON: Are you getting any -- this is Jeff. 20 Are you getting any other congressional inquiries 21 into this or...

DR. BOVE: That's all I know about is these two

1 briefings we've had with Hagan and Burr's staff. 2 Hagan and Burr are North Carolina senators. 3 Republican, Burr, and the other Democrat, Hagan. CANCER INCIDENCE STUDY 4 MALE BREAST CANCER 5 So we've talked about everything but the cancer 6 incidence study and male breast cancer situation, 7 and I think that they're kind of linked to some 8 extent. 9 Did you want to say something about it at this 10 point, Mike? 11 MR. PARTAIN: Well, we continue to find out about 12 more male breast cancer cases. Actually we're up to 13 Mrs. -- I don't know if she had to leave or 14 not. 15 MS. RUCKART: She'll be back. 16 MR. PARTAIN: She'll be back? And I apologize if I 17 mispronounce her name, Appalooto (ph)? Her husband 18 was at the base, and she's here today in the 19 audience. And he was diagnosed with male breast 20 cancer in his early 60s and passed away in 2006.

So I know with the attention we've been getting

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through the media, we've been finding quite a few cases. I mean as early as June this year we started out, we had nine or ten that I had found, and then once we got the media involved we've jumped to 51.

And one of the things we want to look into, I mean, you know, one of the things we want to look into is this, you know, occurrence rate to try to get an idea of how many cases we could expect to see. And one of the reasons I bring that up is right after the hearing last week, and the NBC story in particular, I received a phone call from a news agency informing me that Headquarters Marine Corps, a major had called in and quoted a occurrence rate for male breast cancer at one in 1000 in the general population, and therefore there should be 400 cases of male breast cancer present at Camp Lejeune, and there's really no cancer cluster or any type of abnormality in the fact that we have so many men with male breast cancer. And I find that disturbing. I didn't know that the Marine Corps was in the business of epidemiological studies and such.

MR. ENSMINGER: Not according to their general

staff.

MR. PARTAIN: And unfortunately one of the news agencies actually published this statement by the USMC that 400 cases would be expected based on the 1 in 1000 figure. It's my understanding -- and I'm not an epidemiologist myself -- but my understanding in talking to you and Dr. Clapp and some of the other people out there including Dr. Davis, you know, they quote the SEER rates, statistical rates for male breast cancer is like 1 or 1.06 in 100,000 people, which is a pretty small number.

So is there something that ATSDR can do maybe working with some of the other agencies to help identify just what would be expected or what kind of rates we're looking at to see if this is something that is abnormal.

DR. BOVE: Well, it's very hard to know how many expected when we don't know how many were exposed, how many were at risk. The 400,000 figure, my guess is that when we first got data from DMDC -- well, we didn't get it -- when the Marine Corps first got data from DMDC for the '75 and '85 years, there were

about 200,000 people in it. And they figured, well,
okay, that's 200,000 in that ten year period and
200,000 in the ten year period before, so from '65

to '85, let's say 400,000.

Of course, that leaves out dependents and so on. But it also includes people who may have been at other parts of the base where exposures didn't occur or whatever. So we don't know. That's the first question - how many people are in the exposed population that we're concerned about? We cannot determine the number of male breast cancer cases expected if we don't know the size of the exposed population.

The second issue is, and Dick and I were just talking about it, is the incidence rate of one per 100,000 person-years for male breast cancer. This incidence rate is averaged over all age groupings.

Now, you know, an average is a good summary measure, but it hides things, too. Any average does.

In the early age groups, the incidence rates are much lower than 1 per 100,000 person-years. And as you get older it's higher than that, and the

1 average is averaging all together, right? So you 2 would like to know since this population -- well, at 3 least from '75 to '85 are younger than me -- for 4 example, what the age specific rates for male breast 5 cancer are. So that would be something that we could 6 probably get from SEER if they're willing to part 7 with the data. I think part of the issue might be -8 9 MR. ENSMINGER: It's already there. 10 DR. BOVE: Well, by age-specific for male? 11 MR. ENSMINGER: Yes. 12 DR. BOVE: Okay, because I haven't seen it. 13 DR. CLAPP: It's not published, but they have it. 14 DR. BOVE: But they have it, yeah. They don't 15 publish it because probably it's based on small 16 numbers. 17 MR. ENSMINGER: It's less than two for any age 18 group. 19 DR. BOVE: Less than two what? 20 MR. ENSMINGER: Per 100,000. 21 DR. BOVE: Well, it's one per 100,000 average over 22 all the ages. I should think for ages 35 to 55

1 it's considerably less than one per 100,000. 2 MR. PARTAIN: It's my understanding the younger the 3 diagnosis, the more rare it is. 4 DR. BOVE: Absolutely. 5 I mean, that's something that ATSDR MR. PARTAIN: 6 can contact SEER and even I know the EPA is working 7 on PCE and TCE risk assessments, so they probably have some data that you guys can get from them. 8 9 DR. BOVE: Again, we could play around with numbers. 10 We don't know, and there's no data on how many 11 people were at the base between '65 and '75, and 12 then there's no data on how many dependents were on 13 the base from '75 to '85 or before 1975. 14 You can get a sense maybe from the high school data in microfiche, which are falling apart and 15 16 disintegrating, so you can't really utilize that data. And so it's difficult in other words to 17 18 figure out how many, how large the exposed 19 population is. That's the first issue. 20 Then --21 MR. PARTAIN: Do a quick look. I mean, there's got 22 to be some type of --

1 DR. BOVE: Yeah, we can come up with some scenarios. 2 I did one over the phone with you, and I'll share it 3 with everyone for what it's worth. You have 400,000 people from '65 to '85, probably based on the DMDC 4 5 data that indicates about 200,000 Marines and Navy 6 personnel were at Lejeune anytime between 1975 and 7 1985. So, just let me play this out because that's 8 where the 400,000 came from I think. 9 MR. PARTAIN: We don't know where it came from. Ι 10 don't know where Marine Corps pulled that out. 11 DR. BOVE: Well, let's assume that's where it came 12 from. So 400,000 people, you're following them. 13 Take the middle of that period so it's 1975. You're following them 'til now, which is 34 years. 14 15 you factor in a 20-year latency period. And so if 16 you do all that, you end up with probably you'd expect about 60 cases. Now, there's all kinds of 17 18 problems with what I just said. 19 MS. SIMMONS: Four hundred thousand? 20 DR. BOVE: Yeah, what we should do, it's person-21 years, one case per 100,000 person years. You 22 follow 400,000 people up to now, let's say, and some of them are in the '65 to '75 period. Some of them are in the '75 to '85 period, figure they're evenly distributed.

Take the middle year, '75, -- I'm playing around. 'Seventy-five 'til now is 34 years, right? Lop off about 20 years to take into account a latency period for the cancer, and you get something like 15 person-years times 400, which is six million person-years, which gives you 60 cases. So we can play that game. But, again, keep in mind all the assumptions I just made. In any case, it's not 400, okay? It's not 400.

MR. PARTAIN: Or even 60. I mean, 60 sounds high.

DR. BOVE: If we could get some good data on the size of the exposed population -- and the other issue here is we haven't ascertained all the cases. That's the other side of the coin, right? I mean, you're getting people contacting CNN, but there's a lot of people who didn't watch that show.

I wouldn't have watched it, for example, if someone didn't tell me it was on. I don't watch Campbell Brown or even NBC Nightly News for that

Ιt

1 matter. I would have missed it. I could have 2 missed this all kinds of ways. We haven't 3 ascertained all the male breast cancer cases from 4 Camp Lejeune, I'm sure. So that's the other side. 5 MS. RUCKART: But when you're talking about your 6 rough estimate of 60 cases, that's just --7 DR. BOVE: I don't want to get quoted on that. 8 was just a hypothetical scenario. 9 MS. RUCKART: Okay, but you're not talking about 10 necessarily factoring in their exposure. 11 just what you would expect for 400,000 people. 12 DR. BOVE: Well, I'm assuming in this scenario that 13 there were 400,000 people exposed to Hadnot Point 14 water or Tarawa Terrace water. If they were just 15 like the general population, how many breast cancers 16 would we expect in these 400,000 people? That's 17 what I was trying to do, but there are a lot of 18 problems with making this estimate. If we can get 19 better data on -- well, first of all, we need to 20 find out how far back in time the Hadnot Point water 21 system was contaminated, how high the levels were 22 how far back in time. So that we need to wait for.

I know Scott Williams has been trying to figure out how many people were on base over the years.

There was a lot of consternation when I said to the press a couple of years ago that it could be up to a million, 750,000, a million. I was playing this numbers game that I just played with you now. When you actually start trying to find data on this, you find that there isn't much to go on. And when you come up with different scenarios, actually you turn out that what I said wasn't that far off or off at all.

But the problem is the data's not there. So you're going to have to use all kinds of different assumptions as to how many people went through the base and which water system we're talking about. If we're talking about Tarawa Terrace it's considerably small.

MR. PARTAIN: Let me ask that. Can we go ahead and try to nail down some type of population figure just to kind of give us a rough estimate to give meaning to what we're looking at with this.

DR. BOVE: Four hundred thousand sounds as good as

any number out of thin air. We can just come up
with a number, but it will not be based on a whole
lot of information.

MR. STALLARD: Tom, go ahead.

MR. TOWNSEND (by Telephone): I disagree with Frank on finding the population figures. I have the document that shows the quarters I lived in for a period of 20 years. It was a printout that came from the Base Housing Office.

Now, if we know from the unit diaries how many troops were living in those, in the barracks, and I damn well know that every set of quarters on that base -- it included Tarawa Terrace after a certain point in time -- every house had a number and the Marine Corps knew the people who were in it. And the only time that the population dropped the dependents was during Viet Nam when they may have dropped but they tried to keep people in them.

And the Marine Corps certainly knows what units they called up at Camp Lejeune for Viet Nam. I mean, there was a drop during Viet Nam of the active duty people, but I don't think the houses were

1 empty. I think people were allowed to stay in them. 2 Like I said, I just don't buy it. I figured 3 about a million or a million and a half people have lived in that place over that period of time. 4 5 DR. BOVE: What we were missing, Tom, is not the 6 housing, family housing information. We have the 7 family housing information and can make some 8 estimates based on that. What we don't have is the 9 barracks information. 10 MR. TOWNSEND (by Telephone): What happened to the unit diaries? 11 12 DR. BOVE: If you have this data, then you ought to 13 give it to us because we don't have it. 14 MR. TOWNSEND (by Telephone): I don't have the bloody unit diaries. The Marine Corps should have 15 16 them. 17 DR. BOVE: I thought it was, I would like to see any 18 estimates that the Marine Corps has. That would be 19 fine. What I've heard informally is that you have 20 to make a whole lot of guesses because the data's 21 not there. Now, that's what I've heard. I don't have access to this data either, Tom. 22

1 You're right about family housing. If we want 2 to know how many people were in Tarawa Terrace, we 3 could make some educated guesses based on how many 4 housing units there are and how many people were 5 there in each unit and how often the turnover was. 6 That can be done pretty easily. 7 MR. ENSMINGER: Well, and Tom, hey, Tom? 8 MR. TOWNSEND (by Telephone): Yeah, I'm still here. 9 MR. ENSMINGER: This is Jerry. You know, in reality 10 we wouldn't even need the unit diaries. All we 11 would need is the Command Chronologies, and I know 12 damn well they exist. 13 MR. TOWNSEND (by Telephone): I know they do. 14 MR. ENSMINGER: I mean, the Command Chronology shows 15 what the unit rates, what their actual strength was, 16 shows new joins, drops. It shows everything in the Command Chronologies. And as much as the Marine 17 18 Corps loves its history, I know damn well those 19 Command Chronologies are available. 20 DR. BOVE: I think that we can come up with a couple 21 of scenarios and play around with these numbers, but 22 the other question is this. What would be useful in trying to get an understanding of this group of men.

What kinds of questions could be asked of these

people that would help us understand what kinds of

activities they had on the base that would inform

not only their situation but could also inform the

future studies in general.

It's always useful to hear from people who were at the base just what they did on base because there have been activities such as how long, you know, how often they did calisthenics or what they used to clean their rifle or what jobs they did and what kinds of experiences they had on those jobs and so on. So there's information that would really be helpful, not only to get an understanding of them, but as I said, would be useful in general for our studies.

So I would suggest that some of us work

together to come up with some kind of instrument to

-- whoever wants to do it. Devra Davis is doing it

or whoever wants to interview these cases that we'd

ask the same questions, try to elicit this

information: when they were on base, where they

1	lived, how long they lived on base, what kinds of
2	activities on base; really get a handle on what
3	their life was like on a daily basis at the base.
4	MR. STALLARD: Would that be
5	MR. TOWNSEND (by Telephone): What population are
6	you asking these questions though, Frank?
7	DR. BOVE: Sorry, Tom?
8	MR. TOWNSEND (by Telephone): What populations are
9	you asking these questions of?
10	DR. BOVE: Well, first I would want to just do the
11	cases that have been self-reported or
12	MR. ENSMINGER: He's just talking about the male
13	breast cancers right now, Tom.
14	MS. RUCKART: Wouldn't this come out as part of the
15	health survey if these people
16	DR. BOVE: Well, this is a little bit more
17	information, I think, than we're asking for in the
18	health survey. So we are asking people where they
19	lived and where they worked on base. So that's part
20	of the health survey. So, yes, we would get some of
21	this information.
22	But I was thinking it would be interesting to

1 2 3 4 5 6 MR. STALLARD: Part of what's going on is that we 7 8 9 10 11 12 13 14 what I'm hearing? 15 DR. BOVE: Dick, did you want to weigh in here? 16 17 18 19 20 21 22

get even more information on their activities if we could because they're interested. They selfidentified themselves. I think it would be useful if they were willing to do that.

MR. PARTAIN: Yeah, most of them are.

have a bunch of people who are stepping forward now. And there's going to be some expectation of something I would imagine. And so what you're suggesting is that there may be an opportunity to engage these people in a more meaningful way to find out what their activities were so that they're not just identified and waiting for something. Is that

DR. CLAPP: Yeah, I'd actually like to ask Mike, what kind of information are you collecting, or is Devra checking the diagnosis and more or what? MR. PARTAIN: And Devra on the original group, she did check on diagnostic ^ reports. Of course, when she wrote the initial report, we only had nine or so and then it's blossomed up to 51 now. But when I

contact the families of those that are deceased and the current, the ones that are currently living, I try to find out where they lived when they were on the base, what they did in the Marine Corps.

And I'm asking these people, I'm not asking for it right now because I don't feel that it's really my position to get a copy of their D-214 and their diagnosis. I ask them to see if they can find it so when they do the studies, the scientists are looking to verify these things, can get that documentation. That's what I'm doing with just that group there.

One thing I want to jump back on with the male breast cancer issue, I mean, by no means this is not the only rare cancer that we're getting reports of on our website. Non-Hodgkins lymphoma, which if you go back to the NRC report, shouldn't be happening. We're getting a lot: non-Hodgkins lymphomas, leukemias, bladder cancers, kidney cancers, liver cancer, thyroid cancers.

So the reason why this male breast cancer issue has kind of stepped out and taken a different form here is because it is extremely unusual. It's a

rare disease, and ^, you've got men who are supposed to be in the tip-top physical part of their lives, you know, the Marines, the roughest, toughest bunch in the world, coming down with a rare disease that's normally associated with women.

And by the way, we have tons of women, female breast cancer coming that step forward, too. So and one of the things I, and the point I want this cluster that has shown up is that to me it's indicative that something happened on the base.

There is an adverse health effect that has shown up.

You've got a cancer occurrence that shouldn't be happening, and one of the questions that's been fed back to me and asked is just how rare it is.

And that's what I'm trying to get at here is how rare is this cancer. Should we be seeing 51 men?

And the other big thing, too, that I'm understanding is that most of these men, I want to say about 22 to 23 of the 51, were diagnosed under the age of 56, which is another oddity.

We've got two children who were born in the same year, off base. Came on base and were exposed

on base. One was diagnosed at 18 with two separate breast tumors, had a double mastectomy. A second child came on base after he was born at the naval hospital, lived on base for two or three years. He was diagnosed at the age of 18 -- I'm sorry -- 20, with an actual breast cancer tumor.

And for a 20-year-old male and an 18-year-old male to develop this disease is almost statistically unheard of. And even my case, you know, I'm 39 when I was diagnosed. That is extremely rare, and to have these men in their 30s and 40s being diagnosed, my understanding talking to people such as yourself, Dr. Clapp, and Dr. Bove, that is indicative, it would skew the numbers to have these younger diagnoses to make it even more unusual and more, stand out even more.

DR. CLAPP: While I have the chance, I did have to talk to Mike to look up the SEER Program. And their statistics for age-specific incidents or even age-specific probability of diagnosing cancer, for breast cancer it's only published for females. But they do give --

MR. PARTAIN: And why is it published for only females?

DR. CLAPP: Because it's so rare in males. Then they do give this other table that is an estimate of the U.S. prevalence for the year 2006. This is from their Prevalence Report. And actually, this would be cases alive and living with breast cancer in the year 2006 whenever they were diagnosed.

through 19, there would be no cases in the U.S. And for those age 20 to 29, this is in the entire U.S., they estimate there would be 23 male breast cancer cases, and then it goes up. And they estimate a total of -- and this is again one year, live, living with breast cancer -- 13,132 male breast cancer cases of which more than half are age 70 and above, and then a smaller number between 60 and 69 and then much smaller numbers as you go back down.

So this is their estimate that is published, and it's based on --

MR. PARTAIN: It's based on the population of the entire United States. So from zero to 19, you said?

1 DR. CLAPP: Zero is what they had. 2 MR. PARTAIN: I mean age one to 19, zero cases. 3 DR. CLAPP: Right. 4 MR. PARTAIN: So, and we know where to get two, and two if you count 20, and then from -- what about 55 5 6 and below? 7 DR. CLAPP: They just have 50 to 59, a total of 8 2,078 cases; 40 to 49, 542 cases in the whole U.S.; 9 30 to 39, 75 cases; and 20 to 29, I said 23. 10 far the bulk of the male cases would be over age 70 11 and even counting over 60, that's almost 80 percent. 12 MR. PARTAIN: And coincidentally most of the male 13 breast cancer cases that we have at Camp Lejeune are 14 well under the 70-age frame. 15 DR. BOVE: Well, this is why I wouldn't want to use 16 the one per 100,000 because as I said it's an 17 average. You'd really want to know what the age-18 specific rates are because they're much lower than 19 one per 100,000 in those younger age groups. 20 have to be. But we can pursue this. We need to 21 move on, but I can think of a couple proposals.

One is to get this information from SEER, and

we'll try also our CDC people as well because they have other cancer registries, and they get data from a wider, larger group of registries than SEER does, and see what the age-specific rates are for male breast cancer. Like I said, that's one thing we can

do.

The second thing is I was proposing that some of us get together and come up with an instrument or talk to Devra Lee Davis first of all and find out what she's doing and coordinate with what she's doing to try to get more information about what experiences these men have had at Camp Lejeune. Is that something the rest of the CAP, does that sound like something...

MR. PARTAIN: Yeah, well, is there something maybe we can get in writing to like start the inquiry as far as, and that's what my understanding that Dr. Davis was doing was basically a case history saying there are X number of men with male breast cancer that we have identified from Camp Lejeune, and throw it out into the scientific community so people can start looking.

DR. BOVE: Yeah, this is what I was thinking of case reports. If we have case reports of 51 male
breast cancer cases with an extensive exposure
assessment, I think that would be interesting as
well as all the other information that Dr. Davis was
collecting, i.e., whether they were positive for the
breast cancer gene, for example, and so on, all the
other risk factors that she was trying to collect
information for those few cases that they did look
at.

Because I saw the preliminary stuff that she wrote up and there is some, you know, she was trying to capture that information as well. We could try to capture that for all 51. So we would want to try to come up with some kind of instrument that would ask them these questions, dove-tailed with what Dr. Davis is doing so we're not, you know...

MR. PARTAIN: And we'd also like to get --

DR. BOVE: And that's what I'm suggesting, is that something that the rest of you feel is a good idea?

MR. PARTAIN: And one thing we need to include, too, is I guess a formal request to the Department of the

Navy and the Marine Corps to produce some type of population census for the base I would say from the 1950s up to 1985, maybe provide it on a decade basis or something like that.

DR. BOVE: I'd like to see some numbers, but I would actually like to see what's behind the numbers.

There is some information about how many units were, how many services per water system, there's some data that I know Scott was working with because he shared it with me a couple years ago. There's some information and maybe we can see what, if you make certain assumptions, maybe we can clean up this so we have a better sense of how many there were.

We still would have a lot of uncertainty, but maybe we can justify a 400,000 figure because we're making these assumptions, but it's based on this information. So we could work together maybe with the Marine Corps on that if that's something we can do. I'd like to do that.

MR. STALLARD: I've captured those three things about the SEER age-specific incidents of male breast cancer, working with Dr. Davis for an instrument for

1 a case history case report, something to get 2 additional information, and a request for some type 3 of population census for the years 1950 through '85, 4 some data that we can see what this 400K is all 5 about. 6 Anything else in terms of updates? 7 DR. BOVE: We have to move on. I think maybe let's 8 hold the cancer incidence study to a later CAP 9 meeting because it has been back-burnered for now 10 because our focus has been on the health survey and mortality study. There are some issues with cancer 11 12 registries, some saying they can't do a data linkage 13 without getting consent. Other cancer registries 14 have been able to do that as they do it for the Gulf 15 Wars study. So I think at a future date we may want 16 to have a fuller discussion of this. 17 MR. STALLARD: Is that all right with everyone? 18 (no response) 19 MR. STALLARD: Is that all right, the cancer 20 incidence? We're going to talk about it at the next 21 CAP meeting?

MS. BRIDGES (by Telephone): Sandy. It's fine with

1 me. 2 MR. STALLARD: Thank you, Sandy. 3 And at some point during this discussion I'd 4 like us to address there was some question about 5 timelines that we heard. I don't know, alternate 6 timelines? 7 MR. PARTAIN: What timelines? 8 MR. STALLARD: I'm trying to understand the way, 9 when things were going on at the base and things 10 were known. What your research has said versus what 11 the Navy chronology timeline --12 MR. PARTAIN: What was the question, plus why are 13 you asking the question? What came up or what 14 concern came up? That's probably better. 15 something asked to you? 16 DR. BOVE: One of the things, yeah. At a future CAP 17 meeting it would be good for you to go over your 18 chronology. I know you've developed one, and none 19 of us have actually, you haven't presented it, and I 20 think that would be something and another 21 contribution --

MR. PARTAIN: We'd need an entire CAP meeting to

present things.

it, not just you but I know Jerry was involved in that, Jeff and so on, your take on the chronology.

MR. ENSMINGER: It's not our take. This is made from very specific documents. So there's no speculation. There's no editorializing in it. I had to beat the hell out of him to keep him from editorializing.

DR. BOVE: It may be interesting for your take on

DR. BOVE: Fine, whatever, but you've done a body of work, and at a future CAP meeting, I think that's what we were talking about.

MR. STALLARD: It is what we're talking about.

MR. PARTAIN: I mean the timeline, basically the research that went into the timeline was based on the Marine Corps and Navy's documents and in the laying it out and making sense of everything. And, of course, we've gotten several versions of the Marine Corps' timeline throughout this ordeal that morphs and changes depending on what document or what fact has been culled out.

But, yeah, I would be more than happy to do

that. Now, one thing I'll note is the timeline is actually two parts. The first part is from the 1940s up to 1989. The second part is still, I'm still working on that --

DR. BOVE: When you're ready. People have asked us, well, what does the CAP do, and this is one thing you have done among other things, and so it would be good to hear.

MR. PARTAIN: And one thing, you know, for those who are interested, the timeline is posted on our website and updated as we find new documents and new information pretty much on a regular basis. I think the last update was October 3rd, and you can download it. It's a PDF document. And just whatever you want me to do I'll be more than happy to talk about next time.

MR. STALLARD: Yeah, let's talk about because I think that visually it gives us all a frame of reference. What is it we know. Instead of talking about it in the abstract. And then if we have an ah-ha moment in these meetings, like, oh, look, here's a new document, we can place it in the

chronology of why is that important.

PRESENTATION AND DISCUSSION ON DISABILITY BENEFITS FOR VETERANS WHO FILE CLAIMS RELATED TO CAMP LEJEUNE

So we're going to move on now and introduce

Tom. So if you'll give us a little background, why

you're here. How is it you are able to join us

today?

MR. KNIFFEN: My name is Tom Kniffen, and I work for the Department of Veterans Affairs. And I'm very happy to be here today. I'll give you a little background on my job, what I do, who I work for. I work in the Veterans Benefits Administration.

And the VA, if you don't know, except for the cemetery part is divided into two huge business units. The first is the healthcare side, the VHA part, and then there's the Veterans Benefits

Administration, which is where I work. Even though I don't work directly with the healthcare side, I do on occasion work with them on various projects.

My boss is the Under Secretary for Benefits,

Admiral Patrick Dunne, who reports directly to the

Secretary of Veterans Affairs. My day-to-day work

1 is that I'm in charge of the department that writes 2 all the regulations for the benefits side of VA, 3 whether it be on the adjudication side or the rating side. 4 5 MR. MENARD (by Telephone): I can't hear him. 6 on the phone. 7 MR. TOWNSEND (by Telephone): I can't hear him 8 either. 9 MR. KNIFFEN: I have a staff of four medical doctors 10 and four attorneys and three or four policy 11 analysts, and we, as I said, write the regulations for the benefits side of VA. 12 13 I want to indicate to you how happy Secretary 14 Dunne is that we were invited today, that I'm here 15 on his behalf to answer your questions the best I 16 can. If you ask a question I don't have the answer 17 to, I'll try and get the answer for you. 18 MR. TOWNSEND (by Telephone): We can't hear him. 19 MR. STALLARD: Just put that a little bit closer. 20 I'm sorry. 21 MR. KNIFFEN: If you have any questions that I 22 cannot answer, I will try to get the answers for

1 you, and I'll try to answer your questions today.

First I wanted to talk about the slides that I brought today. When we were preparing these slides, we really didn't know who the audience would be, what the composition of the audience is, so I think if I had known what I learned in the morning session and after talking to a group of people, some of you, we would have written these slides in a different manner, so I apologize for that.

Basically, I'd recommend that we move to page six because I think everything in between you already know. It'd simply be restating information that you already have.

I wanted to touch on a couple things that I took notes as I was listening this morning. First was a report that was issued by the Veterans

Disability Benefits Commission, and I know there's some disagreement in the room as to what that report said.

The Veterans Disability Benefits Commission, similar to the Dole-Shalala Commission, similar to the Advisory Committee on Disability Benefits,

similar to the ACVAR* Study of the 1970s. committees or commissions were created by Congress or by Secretary of Veterans Affairs at the direction of Congress to study what we do and to take testimony from the public, from experts, statisticians and then develop recommendations and write a report.

> Although we may provide testimony, and we may provide written inputs to their deliberations, we do not have any control over what they write. We may implement some of their recommendations. implement parts. We may implement none of a particular recommendation.

> But my point is their report, which is about an inch and a half thick, is the report they wrote. They had a full-time staff I think for almost 18 So we're not insensitive to your possible months. disagreement to what they said in their report, but we really had no, we had no control over their recommendations.

Now, on page six, page six of our slides where we start to talk about the NRC recommendations from

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June of this year, I'd like to give you a little background as to how the Department of Veterans

Affairs works with the national academies and the IOM reports that we receive.

Typically, what we receive are IOM reports from the national academies. We receive those reports because of a couple of statutes involving Agent Orange and the Gulf War. And I'll give you, the most current example would be on Monday this week, the Secretary issued a press release indicating that he had decided to accept certain recommendations for Agent Orange presumptive service connection.

But that process started months ago when the national academies conducted a research project, a detailed report was written. When I say a report, it was probably an inch and a half thick.

What happens then that report is given to the

Department of Veterans Affairs, and then we have

representatives within VA from the healthcare

disability side, the Office of General Counsel and

the Office of Policy meet, study the report, and

then make recommendations to the Secretary. The end

product is what occurred Monday in the case of Agent Orange. The point of what I'm trying to explain is that we rely upon the report from IOM. We study it internally, and then we make recommendations.

Now typically, at least since I worked at the VA, I haven't seen the report from NRC and the national academies, but I'm equating it essentially to an IOM report as far as how we evaluate scientific data and outside reports. And the structuring of the 14 -- on page seven, the list of 14 conditions as limited or suggestive evidence -- I think that's, I have a copy of the NRC report over in my chair, but I think it's the first one down.

There's five different levels of recommendations. This is the second one. We deal with their five levels all the time. Third, I'm sorry. So we evaluate based upon their ranking of different disorders just as the NRC did although we do it in the IOM reports. So in this case as you may know, we have convened a work group at VA to study these recommendations.

And the work group is composed of

representatives of Secretary Dunne, who I work for, is Under Secretary for Health, General Counsel's Office and Assistant Secretary for Policy. That group will meet. I don't know when they will complete their deliberations. It's hard to say, six months, 12 months. They will make recommendations to the Secretary as to what to do or how to react to the recommendations from the NRC.

Now, this leads me to the method by which the Department of Veterans Affairs adjudicates claims for disability. We follow statutory requirements. There are federal statutes that tell us exactly how to address and adjudicate claims for disability. There's two ways.

One method is a factually specific, veteran specific claim for disability benefits where the veteran has to show a current disease or diagnosis, and incident of service and then usually medical evidence linking the two together, the current diagnosis and the incident of service. If the veteran's able to do that with or without representation, then typically the veteran's awarded

what's called service connection.

Once that happens we move into the next level of analysis which is whether it's, to what degree it's compensable, whether the degree to which the veteran is impaired. That's one way to approach a claim for service connection.

The other way is what I refer to occurred on Monday or Tuesday of this week is something called presumptive service connection, and Agent Orange is probably the best example. Where going through the process I described to you with research that we receive from the national academies, we receive a report. We study it internally. We make a recommendation to the Secretary of Veterans Affairs ultimately makes the final decision.

We have a list of diseases or conditions which, for which an individual may receive presumptive service connection. You don't have to go through this factually specific process of showing an inservice event, diagnosis and a linking of the two. It's presumed to have occurred and service connection is established.

1 And the best example again is Agent Orange, and 2 we are expanding our list of presumptive conditions 3 based upon a decision Secretary Shinseki made, I 4 think he probably made it last week, but it was made 5 public on Monday. We're not at that point yet. 6 We're not at the point where we would even make 7 recommendations to the Secretary based upon the 8 report that came out in June. I would call it the 9 first step. 10 Regardless of what you think of the report, I 11 know there was talk this morning of questioning it 12 or debating it. I'm talking more now about the 13 process, the route that we follow. The route that 14 I'm describing to you is set by statute, and we 15 implement it through our regulations. 16 Any questions? 17 MR. TOWNSEND (by Telephone): I've got some 18 questions for the gentleman. 19 MR. STALLARD: Go ahead, Tom. 20 MR. TOWNSEND (by Telephone): I couldn't hear him 21 very well, but your name is Mr. Nixon?

MR. KNIFFEN: Kniffen, K-N-I-F-F-E-N.

here.

MR. TOWNSEND (by Telephone): I have been in contact with headquarters of the VA since 25 March of this year, and the first contact was not mine. It was Tom Sinks as Director of ATSDR sent a letter to Admiral Dunne and asked him if he would cooperate.

I sent material to Admiral Dunne on 15 May. Senator Feingold sent the information to General Shinseki on 6 July. I've been in contact with Admiral Dunne on 23 September and 30 September, and they've been dragging their feet like bloody god damn anchors.

Now, am I going to the wrong place?

MR. KNIFFEN: Sir, I'm here to answer your questions, and I'm going to take your message back to the Secretary. I can assure you that our goal

And I appreciate your efforts making contact with Secretary Dunne, or the two letters Secretary Dunne received, and that's why I'm here today. And I'm trying to answer the questions that were raised in the, I think the March letter to Secretary Dunne.

today is to participate in an open dialogue with the

Department of Veterans Affairs, and that's why I'm

1 And I will take your questions and your concerns 2 back to Washington with me. 3 MR. TOWNSEND (by Telephone): I'll give you some 4 quick background. I'm a 50 percent disabled 80/50 5 right now, okay? 6 MR. KNIFFEN: I'm sorry. I couldn't hear the last 7 part, sir. 8 MR. TOWNSEND (by Telephone): I'm a disabled veteran 9 already. I'm a confirmed VA patient. I'm 50/80/50 10 diagnosis, okay? You got that? 11 MR. KNIFFEN: Yes. 12 MR. TOWNSEND (by Telephone): I went 18 months ago 13 for a C and B exam at the Spokane Veterans Medical 14 Center for neuropathy that my neurologist says was 15 caused by exposure to VOCs. I have lost my wife and 16 my son to what I think is VOC contamination. 17 in Boise, Boise, Idaho, said don't examine Townsend 18 for neuropathy. Try to make some bloody connection 19 between radiculopathy and an injury I suffered in Viet Nam. 20 21 So today I'm going finally for my exam I asked 22 for 18 months ago. I'm 78 years old. This is going

1 on and on and on. And I really have very little 2 faith, I like my providers at the VA MC and it's in 3 Idaho, but I don't like the bureaucracy in Washington, D.C. that has a closed mind. 4 5 MR. KNIFFEN: Could I make a suggestion to you, sir? 6 I want to answer your question in two parts. 7 first part is I'm trying to focus my comments today 8 on the NRC report and the work that the CAP is 9 trying to do. However, if you want me to address 10 your specific --11 MR. TOWNSEND (by Telephone): No, you said you 12 weren't trying to talk about what we're talking 13 about. 14 MR. KNIFFEN: I don't think I follow your last 15 point, sir. 16 MR. TOWNSEND (by Telephone): You gave more crap about the NRC. That's down the drain now. 17 18 MR. STALLARD: Okay, Tom, this is Christopher. I 19 think that what we have here is an opportunity with 20 Mr. Kniffen's presence, and I appreciate the fact 21 that you have shared the difficult challenges that 22 you personally had to go through to get something

1 resulting ultimately today in Mr. Kniffen's presence 2 here. 3 And part of what we're trying to accomplish as well is a commitment to move forward in partnership 4 with the VA as the CAP has asked for a VA member to 5 6 be part of the CAP. So I hear it in your voice, and 7 you've had a long row to hoe here. And we're 8 appreciative as well that Mr. Kniffen is here. 9 we're going to continue on and address what we can -10 11 MR. TOWNSEND (by Telephone): Hey Chris, I'd like to 12 have his phone number, his phone number and his fax 13 number. 14 MR. STALLARD: All righty, we can do that. 15 Is that all right with you? 16 MR. TOWNSEND (by Telephone): Okay? Move on. 17 MR. KNIFFEN: I would like to finish what I was in 18 the middle of saying. I feel even more interested 19 in finishing my comment based upon your request for 20 my phone number. I prefer to give you me e-mail 21 address.

MR. TOWNSEND (by Telephone): I want your VA fax

1 number, Mister. 2 MR. KNIFFEN: I'll give you my e-mail address, and 3 I'd like you to e-mail to me a summary of the problems you're having --4 5 MR. TOWNSEND (by Telephone): Not a god damn e-mail, 6 Mr. Bureaucrat. You have a fax number and a number 7 That's what I want. at work. MS. BRIDGES (by Telephone): Chris, I think Tom is 8 9 just very flustrated (sic) right now. He cannot 10 hear very clearly. I can't hear very clearly 11 myself. I think Tom is just so flustrated, he's 12 just overwhelmed. That's the problem. 13 DR. SINKS: Tom, this is Tom Sinks. 14 MS. BRIDGES (by Telephone): Is that right, Tom? 15 MR. TOWNSEND (by Telephone): No, the problem is 16 this guy that doesn't want to do business is a VA 17 bureaucrat. Tom, Tom, this is --18 DR. SINKS: 19 MS. BRIDGES (by Telephone): But you can't hear very 20 well, can you? 21 MR. TOWNSEND (by Telephone): No, I can't hear very 22 well.

MS. BRIDGES (by Telephone): Okay, I'm going to get off the phone and let y'all talk.

DR. SINKS: Colonel, this is Tom Sinks. Let me make a suggestion if I can. First of all just in general, I think a measure of success for the CAP has been to get Tom here. There was no obligation for the VA to show up or to be here. And, in fact, because of Tom Townsend and other people around this table putting some pressure on us and our writing letters and a bunch of interest, graciously the VA has come.

And, Tom, I would ask you to treat them graciously, not to intermingle your personal frustration with our representative here of the VA. I think, Tom, it makes a lot of sense if you would go ahead and send, if you, anything that you would fax to Tom instead if you would fax it to Perri. Perri can make a PDF of it, and we can send it by email to the VA for you. We're happy to do that.

And I know you know how to use a fax because I get them all the time.

MR. TOWNSEND (by Telephone): Why the hell can't I

1 talk directly to the VA? 2 DR. SINKS: Tom, the CAP is not a vehicle to talk 3 specifically to the VA, but --4 MR. TOWNSEND (by Telephone): I'm a VA recipient. 5 DR. SINKS: Okay, but --6 MR. TOWNSEND (by Telephone): I'm a disabled 7 Who the hell else would I go to? veteran. 8 DR. SINKS: Tom, let's separate the issue of you as 9 a member from the CAP from you as dealing with the 10 VA. I can't speak for the VA. I certainly can't 11 speak for how the VA wants to interact with 12 individual veterans. And I'm certain that plenty of 13 them like yourself have frustrations. 14 But I think we want to keep, you know, if I 15 remember this morning the session had to do with how 16 does the CAP operate. And the first thing that I 17 heard I think it was Jerry say is we don't attack 18 the people who are here. And I think it's 19 inappropriate to personally attack somebody who 20 volunteers to show up. 21 MR. TOWNSEND (by Telephone): He volunteered to show 22 up, but he won't take --

DR. SINKS: Tom --

MR. TOWNSEND (by Telephone): -- he won't provide any information about how to contact him at a later date.

DR. SINKS: Tom, I think the main point is that the VA would, I'm hoping would like to become more of our process and more of a mechanism of communication to help us in the bigger issue in terms of Camp Lejeune and perhaps be able to help you as an individual. What I heard from Tom was he was very willing to get your information. And for him it's more efficient if he gets it by e-mail.

MR. TOWNSEND (by Telephone): Tom, look, the VA has known about this since 25 March. Here it is October, and one guy shows up finally. Oh, bloody god damn good deal. I should be grateful?

DR. SINKS: Tom, he isn't here to specifically

respond to the issue you've brought up with the VA back in your personal health issues. He's here in terms of the CAP and Camp Lejeune. And I'd really like us to cut off the personal attack. So I've offered a mechanism for you to be in contact with

1 him. And I think if you can't do it yourself on e-2 mail, we will facilitate it for you because --3 MR. TOWNSEND (by Telephone): ^ e-mail, Tom Sinks? 4 DR. SINKS: Tom, you can fax me. You know my fax 5 number. We will translate anything you fax to us 6 into a PDF and have it sent by e-mail to the VA for 7 you. 8 MR. TOWNSEND (by Telephone): That's very nice, but 9 I don't appreciate you being a conduit. DR. SINKS: Well, okay, but I want to move on 10 11 because I think I want to ask Tom a specific 12 question because he mentioned a word I had not heard 13 before which was presumptive service claim. And I 14 think what the major issue here is how do we move 15 from a situation from where people like Tom Townsend 16 are trying to get an individualized service-related 17 connection to --18 MR. TOWNSEND (by Telephone): ^ to have a god damned 19 ^. ^ Agent Orange. ^ with Agent Orange and purple 20 and green. DR. SINKS: Tom, let me finish. I think the major 21 22 issue here for us is, is the VA thinking about a

process by which they look at Camp Lejeune and what are the steps that are needed to move from where you are into a presumptive service connection where people from Camp Lejeune would qualify. And what is the thinking there and is there a role, how can the CAP remain informed about it or become involved.

MR. TOWNSEND (by Telephone): Well, let the messenger roll out the words then.

MR. ENSMINGER: Tom, I have a question.

MR. KNIFFEN: Can I answer his question? The question is, I brought up the concept of the idea of presumptive method to obtain service connection.

And as I first explained there's two approaches, and each one is statutory.

The first is the individual claim for service connection. The individual, could be me. I'm a veteran. I could say, I file a claim and say that I was injured or I became ill during my active duty, or in active duty for training and that today, three years after I left active duty or the reserves, I had a symptom or a diagnosis.

At that point on a factually, individually

process claim, I would have to go and get a CNP exam or a private exam hopefully showing that there's a connection between my current diagnosis and what happened in the service. And it takes some time to do for a lot of reasons. The Veterans Claims

Assistance Act. There's a huge volume of claims now. Our claims, the numbers have gone up. I know it's not an excuse, but I'm just explaining it takes a while.

The other method, it's called Method B, presumptive service connection. All you really have to do is show you were in a certain place at a certain time, and you have a diagnosis. The whole nexus connecting part you don't have to deal with. Agent Orange is a perfect example.

Now, not every disease someone may allege or currently have from service in Viet Nam is listed in our categories for presumptive service connection.

But as I said Tuesday I believe, Tuesday was the day that the press, I know it's the day I saw it in the "New York Times". I think the press release was issued Monday.

The Secretary, based upon this process that I described with the national academies, decided to add I think three, four new diseases to our list.

If you go to the VA website, the press release from Monday is the lead press release and it lays out the details.

That's what I mean by presumptive service connection. It's faster. It's easier, and it takes not nearly as much time to process.

DR. SINKS: But in this category B, and right now you have I think two areas. You have Agent Orange and Gulf War.

MR. KNIFFEN: Correct.

DR. SINKS: And the question to me is if there is, what is the possibility of moving the Camp Lejeune volatile organic compound issue into a potential third element of this presumptive service connection? What's the process to getting it on the, even considering it?

MR. KNIFFEN: I understand your question, and we have other presumptive areas other than Agent Orange and Gulf War. I cannot represent what the chances

are. I have no idea. I cannot officially even present a guess as to what the chances are that this CAP or any other group could ultimately find a result whereby anything related at Camp Lejeune becomes presumptively service connected. I'm not authorized to do that. But even if I was, I have no idea at this time.

However, I can discuss the method, the route that is taken, and the route goes to the national academies. Because by statute we review the IOM reports that are issued by the national academies. Then we set up internal study groups made up of VHA, VBA, Office of General Counsel and our Office of Policy.

They read the report issued by the IOM. They may not recommend any additional disease or they may recommend one. They may recommend three. They may recommend three and the Secretary decides to go with four. It's ultimately up to the Secretary. It's a fairly lengthy process.

And so that is the road map, but the road map doesn't always end in a disease being added as a

1 presumptive disease. Many times it doesn't happen. 2 We receive the Gulf War reports every year and study 3 them carefully. So, did that answer your question? 4 5 DR. SINKS: Yeah, I think so. I think what you were 6 saying is by the mere fact that an NRC report or an 7 Academy of Sciences report has been done on Camp 8 Lejeune, it opens up the potential for 9 consideration, that you don't need an act of 10 Congress to consider it, that because this report 11 has been written it provides you the opportunity to 12 consider it. I'm not sure if that's correct. 13 MR. KNIFFEN: Yes, that's exactly what I said. 14 DR. SINKS: Okay. 15 MR. KNIFFEN: Because speaking of this report in 16 particular, the report only recommended 14 17 conditions and only categorized them as limited or 18 suggestive evidence of association. Typically, 19 those do not promote or develop into a 20 recommendation to the Secretary. They're not high 21 enough on the list of five that I discussed earlier. 22 MR. BYRON: Mr. Kniffen --

1 MR. KNIFFEN: If I could just finish. 2 So even if they did, the internal VA working 3 group, which I describe on page eight of our slides, 4 would review that report from the national academies 5 and make a recommendation. They may recommend no 6 presumptives. They may recommend one. 7 ultimately it's still by statute up to the 8 Secretary. 9 So I don't want to even suggest there's any 10 remote possibility that the NRC report could result 11 in presumptive service connection. 12 I'm sorry, sir. I cut you off in mid-sentence. 13 I apologize. MR. BYRON: You're fine. Is it doctor? 14 15 MR. KNIFFEN: Tom. No, I'm an attorney. 16 MR. BYRON: First off, we need to clarify a couple 17 things. You're here because who told you to come 18 here? 19 MR. KNIFFEN: I'm here because --20 MR. BYRON: Because of the NRC report? 21 MR. KNIFFEN: No, I'm here because Under Secretary 22 Dunne, the Under Secretary for Benefits, told me to

1 come to the meeting. 2 MR. BYRON: Okay, and then, because I've been in 3 contact as I told you with Dr. Brown, Dr. Brown with 4 the VA since 2002. And I was always told that the 5 VA, Veterans Affairs Committee and Armed Services 6 Committees are the ones who need to direct the VA to 7 be involved. Is that correct? Because that doesn't 8 sound correct. 9 MR. KNIFFEN: That sounds -- I couldn't comment on 10 that statement. 11 MR. BYRON: So now that you're here, this 12 presumption of disability, what we really need to do 13 is get on with the final studies, don't we, to have 14 more of a chance to --15 MR. KNIFFEN: I can't comment as to what you need to 16 do to increase your chances. All I can do is 17 describe the process. We follow, when we adjudicate 18 claims, whether it's claim specific or on a 19 presumptive basis. That's all I can explain to you 20 today. 21 MR. ENSMINGER: Is the VA aware that these lists of

conditions that were covered by the NRC report are

only for perchloroethylene and trichloroethylene?

That the two known human carcinogens that were involved in the mixture at Camp Lejeune were omitted from their assessment of health effects, benzene and vinyl chloride, which were both present in the wells?

Now, it's not our fault that the Marine Corps and the Department of the Navy never tested for those constituents in the final tap water while those wells were online. They were tested for those constituents after the contaminated wells were taken offline.

We know that these were present in the wells. The water modeling will show that, I'm quite sure. But the assessment by the national academy did not take those two known human carcinogens into consideration. That came out in the hearing the other day.

Furthermore, these folks did a literature review to come up with these lists and their findings, and I'm quite sure that there are studies out there, quite a few of them, that show non-

1 Hodgkins lymphoma as a cause from exposure to VOCs. 2 They left it off. 3 I also have some inside information that the 4 new risk assessment, draft risk assessment for TCE 5 is now going to declare TCE as a known human 6 carcinogen, which is going to be released for public 7 review the end of this month. What's that going to 8 do to this report? 9 And one more question. Why does the VA use the 10 National Academy of Sciences, which is a dot org? 11 It's an organization. It's not a governmental body. 12 Why do you constantly go to them? Why don't you use 13 the EPA? Why don't you use the National Institutes 14 of Health, which are federal agencies? You're a 15 federal agency yourself. Why do you go to the 16 National Academy? 17 MR. STALLARD: Are your questions done? 18 MR. ENSMINGER: Yes. 19 MR. KNIFFEN: We're required by statute to use the 20 national academies. 21 MR. ENSMINGER: Which statute?

MR. KNIFFEN: It's a federal statute. We have no

choice in the matter. And as far as this report is concerned, we are bound to study this report and present recommendations to the Secretary of Veterans Affairs, to set up an internal committee to do this. We're bound by statute to do that as I indicated.

The internal study group is composed of members selected by the Deputy Under Secretary for Health, for Benefits, Office of General Counsel, and the Office of Policy. They have not commenced their review. That report just came out a few weeks ago, month ago. We are following the statutory guidelines we follow on every single issue related to Agent Orange or the Gulf War or any other potentially presumptive condition.

MR. ENSMINGER: I'm not blaming you guys for this report by any means. But I just want you to know and be aware that there were some serious omissions and flaws in this report. And basically, the charge for this thing is written by the Department of the Navy. And you're working with a flawed piece of junk right here, right now.

MR. STALLARD: So the question I have then is if

you're bound by statute to do it in this way and
look at this report, are you able to look at any
other information in that process or is it strictly
that report?

MR. BYRON: And as an example, Tom, my daughter has aplastic anemia. If you look in a medical dictionary under aplastic anemia, it says 40-to-70 percent of all cases are caused by exposure to benzene. So this is, I think, why Jerry's asking. Is this the only thing you'll look at when assessing Camp Lejeune or will there be, I guess, you know, since there were omissions as far as documentation before they wrote their report, will that be a chance to be brought up and, I guess, discussed in your committee meetings? Thank you.

MR. KNIFFEN: We're statutorily required to follow the report -- not follow the report, but make it our primary source of consideration. However, internal study is conducted by a committee that's made up of epidemiologists such as some of the gentlemen sitting here. They bring their expertise to the table.

I've sat in on some of the meetings on other subjects to talk about other studies. But I have to emphasize that when we follow the National Academy's work product, whether it's the NRC or the IOM, we're doing what the statute requires us to do.

MR. ENSMINGER: Where did your statute come from that requires you to use the NAS?

MR. KNIFFEN: It's a federal statute, federal law.

MR. ENSMINGER: Federal law. It's congressional?

DR. SINKS: First off, let me answer part of Jerry's question which I think actually applies to all of our federal agencies, Jerry, which is that many of us, because we are federal agencies and there's often a question about transparency within federal agencies, go to the National Academies of Sciences for advice.

And it's very common for all of us as federal agencies to use that resource to give us independent advice, not advice bound by us as federal agencies.

So that's typical. We may not like what this report is, but I'll also describe that the relationship between the VA and the IOM on the Agent Orange issue

Let me ask Tom a question which is, is there a fundamental difference here between this NRC report which was charged by the Department of Defense, for the Department of Defense charged the NRC to provide that information versus the relationship that you have with the IOM for Agent Orange? Is that a process where you had a standing committee that actually the VA has charged to provide information versus this non-standing committee which gave a one-time report to the Department of Defense?

MR. KNIFFEN: I'm not sure about the Department of Defense part, but I know that there's a statute unique to Gulf War and Agent Orange to follow regarding the national academies.

DR. SINKS: But it's your, your charge, you fund -MR. KNIFFEN: Correct.

DR. SINKS: -- you fund the committee, and you charge the committee.

MR. KNIFFEN: Well, we don't charge the committee.
We follow the statute, which requires us to go to

1 the national academies. 2 MR. PARTAIN: But who tells the national academies 3 what to do? 4 The standing committee has a charge DR. SINKS: 5 which actually you work with, VA works with the IOM 6 to create whatever that charge is. The charge on 7 the NRC was a, the NRC report, which was a, not a 8 standing committee but a one-time report, was a 9 charge that was developed because of the statute by Congress asking DOD to do it, but was specific to 10 11 the Department of Defense's needs. 12 It was different fundamentally than the 13 relationship you have with the IOM and that 14 committee. 15 MR. KNIFFEN: I think the answer's probably yes, but 16 when you use the word charge, I'm not sure I exactly 17 follow what you mean. But we have an ongoing 18 statute that we follow with regard to the Gulf War 19 and Agent Orange. 20 DR. BOVE: Right, but you don't have one for Camp 21 Lejeune.

Correct.

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MR. KNIFFEN:

DR. BOVE: And the IOM charge is in the law itself using that term charge. It's in the law itself.

So the charge given to the NRC was not to come up
with a list of, or not to come up with a list of
compensatory, presumptive -- what's the word,
presumptive. What is that term? I had it written
down, presumptive service connection; that's it.

But to answer questions that the Department of Defense had concerning Camp Lejeune and what to do in the future. So it's a very different situation actually. Now, that's one thing --

MR. KNIFFEN: I don't know that -- first of all, I have to say that when you use the word charge, I'm going to have to back off that because I'm just not prepared or knowledgeable what exactly you mean.

DR. BOVE: If there's no legislation --

MR. KNIFFEN: Please let me finish. And I cannot say that the IOM is charged to make recommendations on what should be presumptive and what shouldn't be. What they do is provide a ranking, the one-through-five listing, which I made reference to before, which is set out in this report. That's as far as

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they go. Do you follow what I'm saying?

So I don't want, please don't read too much

into what I've said about presumptives. Don't over-

evaluate those comments I made.

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DR. BOVE: I'm making a distinction because at Camp

Lejeune the legislation that asked for the NRC

report did not ask for a one-to-five listing.

That's something NRC took on itself. Whereas, the

Agent Orange and Gulf War probably did ask for such

an exercise. That's one difference.

But I have another question. So there are five The first level is sufficient evidence for causality. So any disease there probably make it to the -- if we were talking about Agent Orange now -any in that box probably ended up with going on your presumptive service connection list. The second level is sufficient evidence for an association, a statistical association. That's the second one.

The third level is limited or suggestive evidence of a statistical association, and the fourth level is insufficient evidence to determine whether a statistical association exists. The fifth level is limited evidence against an association, I guess. I can't remember what the fifth one was. So that's how it's layered.

Now, and Jerry was pointing this out, some of those listed by the NRC report as having limited or suggestive evidence for an association should be bumped up at least one level to be consistent with previous NRC reports. And for TCE and kidney cancer, if the EPA draft risk assessment stands, there is sufficient evidence of causality. So that would be bumped up two levels.

So this is a fluid situation. I think with Agent Orange you had to base a lot of your work on studies of veterans. There was some information about agricultural use of these herbicides and had some information from them as well. But most of the information probably came from -- correct me, Dick, if I'm wrong here -- on studies of Viet Nam vets itself.

At Camp Lejeune we're very far away yet from coming up with any definitive, any results from our studies. I shouldn't say the word definitive. And

this chart is really based on occupational data for the most part. They did look at the drinking water studies. They didn't like any of them. I disagree with their assessment, but that's, -- none of the drinking water studies really entered into this.

This is pretty much occupational data, a very different kind of exposure scenario or at least somewhat different than the scenario at Camp Lejeune.

So this is going to change as more occupational studies get done. It may change based on our studies, and then there are other drinking water studies that may happen in the future. So do you revisit this? I mean, how does it get revisited? I guess that's the long --

MR. KNIFFEN: I need to, I cannot even comment on what you just said because you're crossing over the area of policy into medical science and the studies. And I think I know where you're going, but I'm just not qualified to respond. And I'm not trying to avoid answering your question, but you're moving into an area that I don't, I'm just not qualified.

1 DR. BOVE: How does the VA update its information? 2 MR. KNIFFEN: We receive reports every year on the 3 Gulf War and Agent Orange every single year, and they're available for free on the website. 4 5 MR. PARTAIN: Like with the IOM, would the VA be 6 capable of going to the NAS and asking for an IOM 7 review of VOC exposures? Granted that this NRC 8 report which seems from what I'm hearing is taking 9 greater weight on everything --10 MR. KNIFFEN: I don't know the answer to your 11 question. I don't know. 12 MR. PARTAIN: If we're identifying that there's a 13 problem, obviously, there are people coming to the 14 VA asking for assistance. 15 MR. KNIFFEN: Well, they're asking for assistance, 16 again, I recommend you not over-focus on my comments 17 regarding presumptive service condition. 18 asking for assistance on filing claims for 19 disability benefits, individual claims primarily. 20 MR. PARTAIN: Yeah, there are people coming to the 21 VA saying I was exposed at Camp Lejeune. I have XYZ 22 disease, whatever, and I'm asking for assistance

1	through the VA for the medical coverage and
2	disability or what have you. Would the VA not then
3	go to IOM and ask for a review on VOC exposures? It
4	seems to me that there's just a blanket well, you
5	weren't harmed because this is what the NRC report
6	said that was commissioned, that was released this
7	year.
8	MR. KNIFFEN: I don't know the answer to your
9	question. It hasn't come up. I don't know the
10	answer.
11	MR. PARTAIN: So I mean, what would trigger the VA
12	to start
13	MR. KNIFFEN: I can't answer that question. That's
14	a policy matter that I'm not prepared to answer
15	today.
16	MR. PARTAIN: Okay.
17	DR. SINKS: I'm going to try my hands at
18	interpretation. Let me know if you think I'm, any
19	of you let me know if you think I'm off base. The
20	good news that I'm hearing because I want to put
21	this into good news and maybe some other news as

well.

The good news that I'm hearing is that there is attention in the VA office on Camp Lejeune, and they've started a process by which to evaluate this on a broader scope than just individuals. The not-so-good news is they have a report right now that perhaps many of us aren't as comfortable with to use. That doesn't mean it's the only report they will ever use, but that's what they've got.

So I'm hearing kind of a balanced presentation, if you will, which is that there is attention at the highest levels of the VA that Camp Lejeune is an issue that is appropriate to be looking at because you've formed some type of review group to look at this. That they have what they have, and you can't comment on what they have, which is this NRC report. And that in some ways this will likely be a fluid situation that may change over time.

MR. KNIFFEN: I would respond this way. As I said at the bottom of page eight of my chart, page eight, that we have a work group being convened at the highest level, policy level, to review the report. So that should indicate the level of interest.

MR. BYRON: Mr. Kniffen, one thing when you go back that you might want to express is that through all these reports that have been done, documentation has been kept from those people who were writing these reports. So we now have a public health assessment that's been torn down because documentation was kept from that report. There was an EPA criminal investigation that I'm sure they're not aware of the benzene exposure.

Do you think, Jerry?

MR. ENSMINGER: Oh, I know it.

MR. BYRON: Then there was the Commandant's supposed independent panel report which had an Assistant Commandant of the Marine Corps on it. Can you see our concerns? And then we had this NRC report that comes out that the Marine Corps continually states that they were aware of the benzene exposure, which is totally untrue, totally untrue.

And this is why I think there's so much hostility in the room sometimes, and even those individuals that are on the phone. And I don't, it might have been personally directed toward you, I

don't think that that's really what he wanted to do.

I think he is frustrated, and hopefully, you won't

go back and also be frustrated and say that these

people are crazy and, you know, don't send another

representative to the CAP.

Because what we really need to do is show the VA that over here is one individual who is getting compensation for his injuries at Camp Lejeune. We already know this. We know there's individuals out there that have received compensation. And then there's other individuals that are receiving no compensation. We're trying to figure out how this determination was made over here and then this one's denied over here.

We're not understanding that because number one, we didn't think anybody was being looked at from Camp Lejeune with the VA. You're the first person who's showed up. I'm still trying to figure out exactly who's directed, I mean, I know the Secretary directed you. And I'm sure that it was spawned by Senate --

MR. ENSMINGER: The hearing.

MR. BYRON: -- and hearings and CNN reports to get someone here today. But what I really need to know is will there be continued VA involvement here at the CAP, if you know that?

MR. KNIFFEN: I will certainly recommend it. I don't make that decision. I was told to come here today, and I will report that I had a totally positive experience here. I'm serious.

MR. ENSMINGER: And that would be a lie.

MR. KNIFFEN: I didn't say that. He did.

And that the give and take of information is what we're looking for because it ultimately helps veterans, and I'm going to make that recommendation.

MR. PARTAIN: Tom, one thing I want to point out and kind of piggyback on what Jeff was saying. Last week at the hearing during the question-and-answer session, Dr. Nuckols, apparently Dr. Savitz didn't want to have anything to do with hearing in truth, not to show up, but Dr. Nuckols was there on behalf of the NRC report.

And when Senator Burr was questioning him as he sat next to me concerning how and whether or not

they evaluated benzene and vinyl chloride in their final product, he started to go into and stated that they were relying on what ATSDR had done, and that ATSDR's concern was PCE and TCE. And then stopped himself mainly because of the public health assessment.

The benzene/vinyl chloride issue was not addressed in the 1997 ATSDR public health assessment and that document was withdrawn. The NRC report was commissioned while that document was available. The direction they took was based on that document, by Dr. Nuckols' own admission. And then the report was issued two months after the public health assessment was withdrawn.

So the report was structurally based on a flawed piece of science that had to be withdrawn, and therefore, there's some grave concerns with the validity of the report. So that's one of the things that we're trying to articulate to you and to the VA.

Because like I said, from what I heard earlier
-- and I'm not a veteran so this doesn't directly

affect me -- but for all these people out there, if
the VA's relying on this NRC for guidance, you're
following a roadmap that is flawed. And to put this
in a real-time perspective, there are people out
there -- and this is why I'm sitting here -- that

have been affected by this, that need VA help.

Phil Huntley, I'll put a name out there, in

Iowa whose family's being ruined. He has a terminal
condition called central nervous system vasculitis.

Basically, his blood vessels in his brain are coming
apart. He's had 43 strokes in two years before the
age of 49. He's been denied VA benefits. He's lost
his job, lost his medicals. He's in a nursing home
now in Iowa, an Iowa veterans nursing home Jerry
mentioned earlier.

Those are the things we're dealing with. Those are the real people we're dealing with. One of the male breast cancer cluster gentlemen, he's stage IV, metastatic cancer to his bones. And hopefully, he will beat the odds, but they're not in his favor. He has no medical coverage, and he's on disability. Those are things, those are the real-time things

1 that people are needing help from the VA. 2 And that's why I wanted to articulate my 3 concerns about this NRC report being the catch-all right now which it seems to me that's what 4 5 everyone's leading to. 6 MR. BYRON: You actually did a better job than me. 7 MR. PARTAIN: And I'd just ask you to go back and 8 review the hearing part during the question-and-9 answer session where Senator Burr is questioning Dr. 10 Nuckols, and then I follow up, jump in there after 11 he had stopped and so kind of finished it for him. 12 MR. STALLARD: We're coming toward the end of the 13 day. I would like to thank Mr. Kniffen for being 14 here. We had some, I guess what we will need to 15 know for the next meeting is will you provide us 16 feedback once you return about a VA representative 17 to join the CAP? 18 MR. KNIFFEN: I'll find out very quickly for you. 19 MR. STALLARD: I appreciate it. Thank you. 20 And that will be communicated how? 21 MS. RUCKART: I can receive e-mails from him so you

can e-mail me and I can share the news.

1 MR. STALLARD: Okay, very good. 2 MR. PARTAIN: And thank you, Tom, for coming. MR. BYRON: I did want to ask one last question. 3 There is proposed legislation as you 4 I'm sorry. 5 know for veterans of Camp Lejeune and also dependent 6 family members. And I know you may or may not be 7 able to answer this question, but what would be the 8 mechanism if there was to be help from the VA for 9 families, for veterans and dependent family members? 10 What is the avenue or is there an avenue with the VA 11 for dependent family members just so the people that 12 are listening might know? 13 MR. KNIFFEN: I can't comment on pending or proposed 14 legislation for which we've not issued official 15 views through OMB. That's just a standard, hard-16 and-fast rule. I expected you were going to ask 17 about pending legislation today, but that's the 18 answer I have to give you. 19 MR. BYRON: May I ask you this? Is there any --20 I'll hold that for another meeting. Thank you. 21 MR. PARTAIN: My understanding is when Congress 22 passes legislation saying there is a presumption of

1 service connection, then the VA is bound to follow 2 that because it would be law. And then they would 3 go, from what I read here, then they would go to IOM 4 and try to get the medical diagnosis that would be 5 connected to that service connection. 6 MR. BYRON: I understand that, but what I was 7 getting at is in the past I've been told that 8 there's no avenue for dependent healthcare through 9 the VA. I don't know if that's correct or not. 10 I'll hold that until another time. 11 MR. STALLARD: So I guess we're at the point where 12 we need to talk about the next meeting. Is that 13 correct? 14 MS. RUCKART: Just a general wrap up as well. 15 MR. BYRON: I did have one other issue to bring up 16 as far as notification to the veterans that are 17 being notified by the Marine Corps and so forth. 18 You know, we asked for the Commandant's cooperation 19 for a second letter concerning the water survey, 20 health survey. 21 I noticed I could only get an answer of the 22 highest office possible, but as soon as the NRC

report came out, they sent out some propaganda in my opinion, but they sent out what was basically the summary of the report which was telling people, you know in my estimation, don't worry. You're not going to get sick. And right at the top of the letter is the Commandant's Office.

So I don't understand why we can't get commitment from the Commandant's Office to send out the follow-up letter to participate in the health survey for Camp Lejeune. And I'd like to have that answer by the next meeting in writing by the Commandant if that's possible.

MS. SIMMONS: I'll bring it forward.

MR. BYRON: Okay, thank you.

And then the other question on that issue is when individuals are registering with the Marine Corps website, the Public Affairs Officer there is telling them that they've got nothing to worry about. I don't believe that's true, and we have several examples. I'll provide the e-mails to you on that, and I'm going to start asking those people whose names those people are --

1 MS. SIMMONS: They should not be saying that. 2 MR. BYRON: -- because if they are saying that, 3 somebody should be bringing ^ minimum against them. 4 They got no business putting in their bias. We're 5 talking about bias in reports and so forth, and for 6 somebody to come up and say to a veteran or his 7 family member that you don't have anything to worry 8 about what happened at Camp Lejeune, first off, they 9 don't know that because I don't know that. And I've 10 been following this for ten years, and we're still 11 waiting to see that through these studies. So I 12 want that corrected. 13 MR. STALLARD: Yes? 14 UNIDENTIFIED SPEAKER IN AUDIENCE: This at Camp 15 Lejeune? 16 MR. BYRON: Yes. 17 **UNIDENTIFIED SPEAKER:** Do you have an e-mail? 18 MR. BYRON: I'll get the e-mails for you. Can I get 19 a card? 20 (Whereupon, multiple speakers spoke.) 21 MR. MENARD (by Telephone): Chris, could I bring up 22 a suggestion?

1 MR. STALLARD: Yes, Tom. 2 MS. RUCKART: Allen. 3 MR. STALLARD: Allen or Tom? 4 MR. MENARD (by Telephone): Yes, yes. Has the 5 Marine Corps used the avenue of the VA Department to 6 go into all these local veterans offices for them to 7 use their lists of people that were stationed at 8 Camp Lejeune to get a hold of them as far as being, 9 you know, exposed to the toxic water? 10 MR. STALLARD: I'm not sure I understand the 11 question so what we'd like to know is has the VA 12 used the local offices to reach out to the veterans 13 they serve? 14 MR. MENARD (by Telephone): Has the Marine Corps 15 used the VA to get a hold of these people because I'm sure all the local offices can go through their 16 17 list of all the Marines that were, that are actually 18 registered in that county or that state or whatever 19 how they use it. Have they used that avenue? 20 MR. STALLARD: Mary Ann? 21 MS. SIMMONS: We've worked with a lot of different 22 veterans' organizations at affairs, different

1 places, so in terms of getting a specific list of 2 names, no. But we're doing wide publicity. We just 3 provided another update of ways we're trying to get 4 the word out. Do you guys post this on your 5 website? 6 MR. PARTAIN: We've been posting the breakdown by 7 state and for that particular document right there, 8 it doesn't have any letterhead on it, so we haven't 9 posted it, no. You talking about the... 10 MS. SIMMONS: It's just the notification update, and 11 this is the summary of the Camp Lejeune outreach as 12 of 7 October '09, just different things that's going 13 on. 14 MR. BYRON: We can. 15 MR. PARTAIN: Yeah, we can put that on. 16 MS. SIMMONS: It might be a good idea. 17 MR. BYRON: Yeah, we'll put that on. 18 I did have one more question for Tom. 19 hearing that was last week, the VA representative, I 20 think incorrectly, thought that they had the list of 21 the registrants for Camp Lejeune, 144,000 I believe

it is. Is that correct?

1 MR. KNIFFEN: One hundred and forty-six thousand. 2 MS. SIMMONS: Yeah, 146,000. 3 MR. BYRON: And I think he indicated that they did 4 have the list because they were asked if there was a 5 cross-reference to that list and individuals coming 6 into the VA. And I believe he said they had the 7 list, but the Marine Corps even there indicated 8 that, no, they don't have the list. 9 So I'd like if that's possible for the Marine 10 Corps or DOD to provide that list of the 146,000 to 11 the VA, and if possible, present this to the 12 Secretary as can they do a cross-reference to see 13 how many of these veterans are actually. 14 MR. KNIFFEN: I just don't know the answer to your 15 question, but I can take it with me. 16 MR. BYRON: That'd be great. 17 MR. KNIFFEN: Sure. 18 MS. SIMMONS: I don't know. I would think there 19 might be privacy issues. I don't know. I can ask 20 the question. 21 MR. PARTAIN: During the hearing Senator Burr asked 22 them to do that, and I think they're working on

1 getting that done. 2 MR. GAMACHE: Yeah, it has to be approved. 3 are some federal statutes that there's some 4 notification requirements ^ federal agency. But it 5 can be done. MR. BYRON: (Inaudible) 6 7 MR. GAMACHE: No, I'm unsure of the process so I 8 can't really comment on how long it would take. 9 MR. STALLARD: Is there some way that someone will 10 have their finger on the pulse for that so that by 11 the next meeting we have some sort of update there 12 was progress or no progress or action, no action? 13 Who could be that person? 14 MR. GAMACHE: (Inaudible) 15 MS. SIMMONS: We can note to the next meeting. 16 MR. TOWNSEND (by Telephone): They know how to ask 17 questions of the VA. 18 WRAP-UP 19 MR. STALLARD: We're about ready to wrap up here. 20 We need to think about our next meeting which is 21 where we'd either have to be right after the new 22 year I'm guessing at this point or right before.

1 MS. RUCKART: Don't look at me. I'm not going to be 2 here. 3 MR. STALLARD: I know. We won't have the services of --4 5 MS. RUCKART: If you wait for me to get back, you'll 6 be planning on meeting in April. 7 MR. STALLARD: So what time frame are we looking at? 8 MR. PARTAIN: January. 9 DR. BOVE: Well, that would be the earliest. 10 the issue would be to meet to find out what happened 11 with the funding. By January we'd know something. 12 We really do know something then that would make 13 sense. We probably would also, there's something, 14 the mortality study should be, hopefully, would be 15 started. 16 MR. STALLARD: Morris would have his stuff finished. 17 DR. BOVE: Yes, Morris would have, hopefully, have -18 - I'll speak for Morris. 19 MR. MASLIA: I'll speak for Morris. 20 DR. BOVE: I'll speak for Morris. No, go ahead, 21 Morris. 22 MR. MASLIA: By January we will definitely have,

much sooner than January, an ATSDR position on what 2 modeling approach or approaches we will be taking. 3 Again, that will be determined by exposition paper that we're writing, reviewed through the hierarchy 4 5 through ATSDR and then presented to a small group, 6 three or four, experts, not the huge expert panel, 7 but experts to comment or give us feedback on. 8 so by January we will have done that.

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We will also have hopefully by January the Chapter C, the data reports of the installation restoration program sites published and online. hopefully, the underground storage tank sourcing data in a draft form of a report for people to be reviewing.

MR. STALLARD: So Morris is definitely on the agenda for the next meeting with a lot going on in his arena.

MS. RUCKART: I know what's going to happen. when the next meeting is going to be. It's going to be my second day back in the office just like it was last time I came back from maternity leave. So I'll predict you're going to have it mid-to-end February

1 so I can hit the ground running as soon as I get 2 back. 3 MR. MASLIA: Perhaps we should have an alternate 4 location like Hawaii or some warm place. 5 MR. STALLARD: That question has come up. We could 6 be closer to our VA colleagues if we go to 7 Washington, D.C. MR. MASLIA: It's sort of cold in D.C. 8 9 MR. STALLARD: Okay, so clearly we're not going to 10 decide then right here, right now. What we're going 11 to look at is toward mid-to-late January, early 12 February. Is that all right? 13 MR. PARTAIN: I think we probably should stay in 14 January now. 15 MR. STALLARD: Okay, January, I hear a bid for 16 January. Certainly, when the funding is verified, 17 before then I'm sure you'll all know. The e-mail 18 will go out. 19 MS. HARRIS: The CAP funding that we have would cover this meeting and one more already. 20 21 MR. STALLARD: Okay, good. 22 DR. BOVE: In Washington, D.C. maybe.

1 MS. RUCKART: Yeah. That's very difficult to ^. 2 DR. BOVE: Well, actually we do have a D.C. office. 3 MR. STALLARD: We do. 4 MS. RUCKART: But there's more funds involved, 5 there's more funds involved because there's more 6 travel involved for more people. 7 MR. STALLARD: We could have a CAP meeting at Camp 8 Lejeune, you know. 9 DR. BOVE: No, we've already nixed that idea. 10 MS. RUCKART: ^ and the airport. 11 DR. BOVE: Well, play around with --12 MR. ENSMINGER: ^ the airplanes. 13 MS. RUCKART: I have a request from Jeanette. She 14 asked me to let you know that when you submit your 15 vouchers, please use the travel expense form that's 16 in the envelope, the postage-paid envelope. I just 17 wanted to pass that on. MR. STALLARD: We did things a little different this 18 19 time. Thank you for coming up with your own 20 operating guidelines and principles and adhering to 21 them for the most part. Be prepared next time. 22 want to make this a little bit more informational

1 sharing as we did this time, but you're going to 2 tell us what have you done personally to contribute 3 to the CAP, what activities are going on. What's 4 going on in your world relative to the CAP. 5 And, again, we're very thankful, if not 6 grateful, that you were here with us today 7 representing the VA. Thank you for taking the 8 barrage of emotion that came with that being the 9 very first representative. 10 MR. KNIFFEN: I was happy to be here. 11 MR. STALLARD: It gets better. 12 So unless there's anything else, that adjourns 13 our meeting for today, and I thank you all for 14 coming and wish you a safe journey home. 15 (Whereupon, the meeting was adjourned at 3:00 p.m.)

CERTIFICATE OF COURT REPORTER

STATE OF GEORGIA COUNTY OF FULTON

I, Steven Ray Green, Certified Merit Court Reporter, do hereby certify that I reported the above and foregoing on the day of Oct. 14, 2009; and it is a true and accurate transcript of the testimony captioned herein.

I further certify that I am neither kin 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 19th day of November, 2009.

STEVEN RAY GREEN, CCR, CVR-CM, PNSC
CERTIFIED MERIT COURT REPORTER
CERTIFICATE NUMBER: A-2102