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convenes the

TWENTY-THIRD MEETING

CAMP LEJEUNE COMMUNITY ASSISTANCE

PANEL (CAP) MEETING

July 26, 2012

The verbatim transcript of the Meeting of the Camp Lejeune Community Assistance Panel held at the ATSDR, Chamblee Building 106, Conference Room B, Atlanta, Georgia, on July 26, 2012.

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

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

(alphabetically)

AKERS, DR. PAUL, CAP MEMBER
BLAKELY, MARY, CAP MEMBER
BOVE, DR. FRANK, ATSDR
BRIDGES, SANDRA, CAP, CLNC (via telephone)
BYRON, JEFF, COMMUNITY MEMBER
CLAPP, RICHARD, SCD, MPH, PROFESSOR
DAVIS, DR. DEVRA, CAP MEMBER (via telephone)
DEARWENT, DR. STEVE, ATSDR
DICK, DR. WENDI, VA, OFFICE OF PUBLIC HEALTH
ENSMINGER, JERRY, COMMUNITY MEMBER (via telephone)
FLOHR, BRAD, DEPARTMENT OF VETERANS AFFAIRS, COMPENSATION SERVICE
MARKWITH, GLENN, NAVY MARINE CORPS PUBLIC HEALTH CENTER
MASLIA, MORRIS, ATSDR
PARTAIN, MIKE, COMMUNITY MEMBER
PORTIER, DR. CHRISTOPHER, DIRECTOR NCEH/ATSDR
RUCKART, PERRI, ATSDR
STALLARD, CHRISTOPHER, CDC

P R O C E E D I N G S

(9:00 a.m.)

WELCOME, INTRODUCTIONS AND ANNOUNCEMENTS

MR. STALLARD: Okay. Are we ready everyone? Let's start. Welcome. We're going to briefly go around the room here with introductions. I'd like to say hello. I missed the last CAP meeting that you had. That was the second one I missed in the five years we've been doing this, roughly. So it's good to be back with you.

I would like -- there are new members here, and there's a new audience perhaps; I see many more people today. So let's recap what are our guiding principles. Okay. For all those in the room, please put your cell phones on off or silent stun so that we do not disrupt proceedings.

The audience is here to observe. There may be members in the audience that the CAP members wish to pose a question to, in which case you might be asked to respond. It's your choice to or not. This is a live public meeting with a video stream. And as you can see it's being court reported.

Respect for the speaker. Speaker -- one speaker at a time. No personal attacks, no profanity. Speak your name when you speak into the microphone before

you speak so that we can attribute your comments appropriately. And use the table mikes to speak. So with that, we'll go around and do introductions.

As I said, I'm Christopher Stallard with the Center for Global Health here at CDC, and I'm your facilitator. And let's just please have an introduction, your name and your role.

MR. BYRON: Good morning, I'm Jeff Byron. I'm with the CAP, from Cincinnati, Ohio. Haven't been able to do much lately 'cause I'm starting a new business, and this'll be my last CAP meeting. So I'm hoping there's a good energetic young Marine that'll take over for me and maybe not raise any profanity but raise a little hell, if they don't do what they're supposed to, like they haven't for seven years. Thank you.

MR. STALLARD: Thank you. Mike.

MR. PARTAIN: This is Mike Partain from Tallahassee, Florida, member of the CAP meeting -- I mean, CAP panel.

MR. STALLARD: Welcome, thank you, Mike.

DR. AKERS: Paul Akers from Columbia, South Carolina, Member of the CAP.

DR. DICK: This is Wendi Dick. I'm with the Office of Public Health at the VA in Washington, D.C.

DR. PORTIER: Chris Portier, I'm the Director of NCEH/ATSDR.

DR. BOVE: Frank Bove, ATSDR.

MS. RUCKART: Perri Ruckart, ATSDR.

DR. DEARWENT: Steve Dearwent, ATSDR.

MR. FLOHR: Brad Flohr, I'm with the Veterans Benefits Administration in Washington, D.C.

MR. MARKWITH: I'm Glenn Markwith. I'm with the Navy Marine Corps Public Health Center in Portsmouth, Virginia. And some of you guys may know Mary Ann Simmons who recently retired. And I've been assigned to take her place on the CAP. And our command provides risk communication support and community involvement planning and community outreach for the Marine Corps and the Navy worldwide, so I think that's why I'm sitting here today. Thank you.

DR. CLAPP: I'm Dick Clapp, member of the CAP.

MR. STALLARD: Welcome. And whom do we have on the phone, please?

MR. ENSMINGER: This is Jerry Ensminger.

MR. STALLARD: Welcome, Jerry, where are you today?

MR. ENSMINGER: Sitting in my dining room.

MR. STALLARD: Is there anyone else on the phone, please? Was Tom able to call in? Was he on the last

meeting?

MS. RUCKART: I think he was.

MR. STALLARD: Okay.

MR. ENSMINGER: Hey, I have a question.

MR. STALLARD: Yeah?

MR. ENSMINGER: What was the name of the guy from the Navy Marine Corps Public Health Center again?

MR. MARKWITH: It's Glenn Markwith, M-a-r-k-w-i-t-h.

MR. ENSMINGER: You must have drawn the short straw after Mary retired.

MR. MARKWITH: I think the world of Mary Ann; I would do anything for her. And she's, in retirement, she asked me if I would take this and I said I'd be glad to do so. I'm glad to be here.

MR. ENSMINGER: Yeah, okay.

RECAP OF PREVIOUS CAP MEETING

MR. STALLARD: All right. Well, then moving right along, Perri, would you like to bring us up through our recap of the previous CAP meeting?

MS. RUCKART: Sure. I handed out to everybody the summary of the last meeting. I'm not going to go over that; you can read about it at your leisure, but I do want to just highlight some of the action items.

So at the last meeting, the CAP asked for

complete access to the unredacted documents for the water modeling. And since then, we have established a standard operating procedure related to the release of information about locations of active public drinking water system supply wells surface water intakes, and we shared this with you at the end of June, and it includes information on how to request the documents.

During the last meeting the CAP also requested that the agency invite the Secretary of the Department of Health and Human Services and the Marine Commandant to the CAP meeting when the results are presented. The Agency's happy to convey your request and will inform the Secretary and the DON of the CAP request ^ a roll-out process for releasing the results. The Agency also recommends that you make requests to the Secretary and the Commandant because we feel it'll have more weight coming from you, so it'll be a joint effort there.

The CAP asked for a written response from the Agency about whether it's possible for ATSDR to take ownership of the USMC registry. The agency would like you to send a written request detailing why you think the Agency should maintain this listing because currently we're able to get access to the list if we need it. We've gotten access to it to send out the

surveys, and as you know, Congress mandated the Marine Corps to have ownership of that.

The CAP requested access to view the "For Official Use Only" water documentation and the BAH index of documents. And everyone should be familiar with that request; it was sent on your behalf and the index was provided to you along with a copy of the request and the response in June.

Mary Blakely provided Frank with copies of files regarding infant deaths, and she wanted his opinion of them. And Frank will discuss that when we get to our health studies updates.

At the last meeting we also had Brad Flohr and Wendi Dick from the VA. They provided their updates. And Brad said he would investigate whether a veteran from Camp Lejeune could get an exam at a VA facility as a precaution. He also said he would look into referencing MSDSs on the training letter for Camp Lejeune. And Wendi said she would look into the reasons why non-veterans can receive care at VA facilities, so you can go into that when it's your turn on the agenda. And that's all we have.

MR. STALLARD: Great, thank you.

MR. ENSMINGER: Hey, I have -- I would like to make a point. When somebody's speaking, if you don't

speak directly into the microphone, the people on the phone can't hear.

MS. RUCKART: Okay, so, Jerry --

MR. ENSMINGER: Perri, you sounded like you were in a cave.

MS. RUCKART: Okay, well, I'll try to talk more directly next time. Sorry.

MR. STALLARD: Thank you for the feedback, Jerry. We will speak directly into the microphone.

MR. ENSMINGER: Anytime, anytime.

CAP UPDATES/COMMUNITY CONCERNS

MR. STALLARD: All right, this, this is our opportunity on the agenda where we invite the CAP members to give us an update of the activities they've been involved in since the last meeting: accomplishments, challenges, concerns. And so...

MR. PARTAIN: This is Mike Partain. Just one quick note about the, with the follow-up that Perri was talking about. Jerry and I had a conference call with Dr. Portier concerning the request to the Marine Corps about access to the documents. Just make a note that, you know, the response that was made back by the Marine Corps was that these documents were available. They didn't directly answer the question whether or not we would be able to view the FOUO redacted

documents. I know we're still trying to get that, and like I said, the note I want to make for the record is that the Marine Corps did not answer the question and still has not answered the question. And we'll follow up on that later.

MR. STALLARD: Thank you, Mike. Steve, do you have something?

DR. DEARWENT: Yes, this is Steve Dearwent. My recollection of that response was that they would deal with it on a case-by-case basis and not grant kind of collective overall access to everything.

MR. PARTAIN: Well, correct me if I'm wrong, but the letter that was sent back to Dr. Portier was basically that the documents are already there; they've been publicly available. They did not address the FOUO other than saying that we could write the FOIA request for them, which would take, you know, an inordinate amount of time, and would not be useful for the purposes of the studies the ATSDR is doing and our function as CAP members. So, now, I understand in the intervening time, Congress has taken a large part of this library and made it publicly available but there are documents that are still redacted in that library, and I think Congress is working on that. So I just want to make a note for the record that that response

was such that the Marine Corps did not directly answer or examine that question.

MR. STALLARD: All right. Thank you. So Jerry, let's start with you on the phone. Would you be so kind to give us an update of the past couple months?

MR. ENSMINGER: Well, I think what's more important is the past couple weeks. The bill that will provide former Camp Lejeune members and their family members healthcare through the Veterans Administration has passed the Senate. It is now sitting over in the House. And those of you who don't understand how Congress works, which is just about 100 percent of us, the House of Representatives does not have a unanimous consent motion, like the Senate does, so when the House wants to bass a bill, like the Senate passed this bill, with a unanimous consent motion, they do meet on Tuesdays in the House of Representatives, and they call it a suspension of the rules.

So next Tuesday, or this coming Tuesday, the 31st, our bill will be presented in the House and voted on. It will not be debated 'cause nobody -- that's why they suspend the rules, it does away with the debate, and they go straight to a vote. And it's expected to pass the House very easily. So that's about it.

I would like to thank everyone on the Senate side who's been involved in this thing and the people that dug their heels in and made this happen. Primarily Senator Burr and members of his staff, Brooks Tucker, David Ward and Maureen O'Neill. They really stuck in there and really helped. And on the Judiciary Committee side, I want to thank Senator Leahy and Senator Grassley and their staffs for the work they're doing on getting these documents released. They are currently looking at all the redacted stuff. And there'll be more to come on that in the near future, so things are moving along.

Now that, you know, we're going to have this bill passed, which is a big accomplishment, I will be able to dedicate more time, more of my time, into, instead of dedicating it toward getting a bill passed and getting these people some help, I can dedicate more of my time into actually getting the truth out of the Department of the Navy and the United States Marine Corps on this issue. And I'm calling officially now for Congress to hold the leadership of the Department of the Navy and the United States Marine Corps accountable for all the misinformation and disinformation that they have distributed relating to this issue over the last -- ever since 1984. And it's

about time we get the truth. That's my update.

MR. STALLARD: Thank you, Jerry. Members in the room.

MR. PARTAIN: I did forget to mention that in the interim we are now at 80 men with breast cancer from Camp Lejeune. So we've got, over the past five years, identified 80 individual men with the single commonality of male breast cancer and exposure to the contaminated water at Camp Lejeune. It seems this number just keeps on going up.

MR. STALLARD: Thank you, Mike.

MR. BYRON: Yeah, this is Jeff Byron. It's like I said earlier, this is going to be my last meeting so I want to thank all the CAP members for your dedication. And, you know, we've come a long way, not near far enough yet. And I am concerned with some of the, you know, how the bill for Congress'll be, you know, figured out how healthcare will cover the other than veterans.

The VA's always been an avenue for veterans to get healthcare but I don't know that it's been one for dependent family members, and I look forward to seeing how that's hashed out with Congress.

But I want to thank the ATSDR people, too, for all the work they've done in this and, you know, to

reach out to 160,000 Marines that were at Camp Lejeune when there was only going to be 12,000 of us notified initially with the in utero study, I think is a pretty big accomplishment for the members of the CAP and for ATSDR.

But like I said, I think, without the CAP and without the community's participation, none of this would have happened. I think the military would have tried to push this under the rug, and the 12,598 families with children in utero, and that would have been the end of it. Thanks to the hard work of Jerry Ensminger; he's been a heck of a mentor to me, and I wish I'd have served under him when I was in the Marine Corps. Didn't have that opportunity but I'd like to thank him personally and Mike Partain for the work you've done over the past few years to bring the timeline to light, and to actually show what happened, you and Jerry, and Major Tom also. He deserves credit for finding documents.

And all the CAP members that put their time in here. It really -- they dedicated theirself to a cause that most people would have thought, when I got involved in this, that you won't have a prayer with the military or the government. And I think we've proven them wrong. I think the people at ATSDR have

fought for us. And I dearly want to thank them for their help. And I hope the studies that come out of this will be used in the future to keep this from happening again.

And in my own life, I've started a business and I've just recently moved the location. The last meeting I mentioned that we thought there was a cancer in my family on the women's side. That was a false positive so we're very glad to hear that; although, both my daughters and grandson are still experiencing medical issues. My daughter's had to have two iron infusions in the past two weeks. And I'm hoping that the government will be able to help pick up some of the tab for the medical care because this girl just doesn't have the money to be forking it out.

I've done it for 30 years now, and I've been in a fortunate position in my life to make enough money that I can be here to help fight. That's one reason why I did it. I knew there were so many families out here that couldn't. And I'll be leaving the CAP and like I said, I hope they find a good young Marine or dependent family member that's interested in carrying this to the finish, and I hope that'll be soon. Okay?

I'd like to see the in utero report come out before the mortality studies in that. It's only gone

on for 12 years. And I hope that Congress sees that, you know, these illnesses go further than just what the NRC found for sicknesses. We're talking about several chemicals. And for this to stop right here and leave half of the people out of getting healthcare would be a tragedy. And I suspect that that could be the case even in my own family because I think that the document requires that you get your doctor to, you know, say that this occurred at Camp Lejeune. Well, if you can get a doctor to say that and to put his name on it, I got some land that I want to sell to you.

But I thank you guys for bearing with me for the past seven years. I been at this 12 years, since I got the letter, and 12 years is enough to dedicate someone's life to try to get justice and now it's about my family and my business. So I hope you guys will excuse me, and I would rather see the job filled out all the way to the end but that's just not going to happen right now because everybody's life changes and you get to a point where you have to make a change for the better. And although this, you know, is kind of a sad time, it's also a joyous time for me. Thank you very much.

MR. STALLARD: Thank you, Jeff. Did someone join

us on the line?

MS. BRIDGES: Yes. This is Sandy. Sandy Bridges.

MR. STALLARD: Hi, Sandy. Welcome.

MS. BRIDGES: Thank you.

MR. STALLARD: We're just going through CAP member updates, activities that you might have been involved in for CAP business over the last -- since the last meeting.

MS. BRIDGES: Right. I was on before. I just -- I'm sorry to hear that Jeff's leaving. I really am. I'm going to miss you, Jeff. Everyone's going to miss you.

MR. BYRON: I don't know about the Marine Corps.

MR. STALLARD: All right. And I'd like to remind those on the phone, if you'd be so kind and if you have a mute function, while you're listening to please engage the mute function.

MS. BRIDGES: Right.

MR. STALLARD: Thank you. Mike, did you have anything else?

MR. PARTAIN: Yeah, just Perri gave me a document that somebody submitted to put as part of the record in the CAP meeting. I just want to acknowledge that it's here and it's from a Mr. Rhodan. It discusses

liability and the Safe Drinking Water Act and so forth. I mean, that is -- and the concerns in the letter really need to be brought up between the EPA, the Department of the Navy, and I don't think the CDC or ATSDR has any jurisdiction on what they say or do. So it's noted that it's in here. Lot of it is reinventing the wheel. I mean, go through and read the timeline that we have and things we've done but, you know, we're not simply here -- it's not part of our function here to discuss what the EPA should or should not have done between the Department of the Navy and the EPA.

So it's here and I guess you guys make it part of the record but it's not really our function to do that.

MR. STALLARD: Thanks, Mike. Paul, anything to offer?

DR. AKERS: Not at this time.

MR. STALLARD: All right. Thank you. Dr. Clapp?

MR. ENSMINGER: Yeah, I have something for Jeff since this is his last meeting. Boy, Jeff, when I heard you sitting there talking about healthcare, you sounded just like a Democrat and it made me proud.

MR. BYRON: I'm never going over to that side, though, so just so you know. I'm pure conservative,

redneck.

MR. STALLARD: All right. Thank you. Let's hear from Dr. Clapp.

DR. CLAPP: Yep, I think the most relevant thing was I was part of a briefing, a Congressional staff briefing, on May 18th, that was organized by Senator Lautenberg. It was mainly about the Safe Chemicals Act, but it was cosponsored by Senator Lautenberg as the sponsor of that bill. But I did talk about Camp Lejeune and I did talk about the health studies for people in the audience, this was Congressional staff.

And then I subsequently went around to meet with two Senate staff, Senator Brown, one of my senators from Massachusetts, and Senator Burr's staff, and Congressional staff in their office. And again talked about both the need for TSCA reform, as they say, and also what the story -- what the current status of the health studies at Camp Lejeune is and what they might tell us. Those are the main things.

MR. STALLARD: Great. Thanks. Yeah, sure, Perri.

MS. RUCKART: I just want to ask that all the audience members sign the sign-in sheet in the back of the room, please.

MR. STALLARD: Loud and clear. Thank you.

Glenn, since you're new to the group, would you just maybe give us a brief, you know, what you bring to the table, your experience and whatnot?

MR. MARKWITH: Yeah. Like I said earlier, one of the primary functions of the Navy and Marine Corps Public Health Center is to provide risk communication support to the Navy and Marine Corps. We're essentially another tool in the toolbox for Camp Lejeune to use for community outreach, community involvement, and that's what the majority of our work is that we do there at our command. And that's basically it.

MR. STALLARD: Okay. Great. Thank you. Very good. Thank you. All right, let's move then -- we're moving ahead, then, very quickly this morning.

Q&A SESSION WITH THE VA

MR. STALLARD: So this is the period in the agenda where we're going to have a Q&A session with our colleagues from the VA.

DR. DICK: I can go first, if you don't mind, Brad, 'cause I think I have a shorter, a shorter answer than you will have for your items.

So at the last meeting people were interested to learn that in some cases family members can get care from the VA or through the VA. This program is called

CHAMPVA, and it stands for Civilian Health and Medical Program of the Department of Veterans Affairs. It's administered out of Denver. And to be eligible as a family member for a CHAMPVA healthcare benefits, well, first of all they can't be eligible for TRICARE. So the coverage would be for a spouse, a widower or children who are, you know, dependent, of a veteran who is permanently and totally disabled through a service-connected disability, and that's probably the most common category. There are a few others for veterans who die in an active duty status, and that could include when their -- when that was during training.

There is some cost sharing if the family members have other health insurance, so they would bill that other health insurance first. And as far as where the CHAMPVA family members get the care, it depends. Some of the care can be provided at VA medical centers but only on a space-available basis after the needs of, you know, veterans have been met. And that list of medical centers changes all the time, so there is a website that you can look up to see if your local VA offers that. And if anyone would like any information on the CHAMPVA program, I have fact sheets and brochures and I'd be happy to just leave them with

anyone who may be interested. Does anyone have any questions?

MR. BYRON: Yes, I do. You say that the veteran himself has to be 100 percent disabled before their children can get care through the VA CHAMP service? That, you know, to me, for me, I'm not experiencing health effects but, say that Congress mandates that CHAMPVA takes care of -- well, number one, I got a daughter who's 27 years old and handicapped. She doesn't work, she lives with me. And, and her son both live with me. I'm not disabled. I haven't claimed any disability. Was I sick during my time in the Marine Corps? Yes, over two issues. Has it affected me to this date? Well, maybe. I don't know, you know but that's what these studies are for. But if I'm not disabled and my daughter has been by what's occurred here, how -- is there an avenue for that or not?

DR. DICK: Is she -- does she have TRICARE benefits?

MR. BYRON: She's on Medicaid, that's it. I don't have insurance. I can't get it. I couldn't afford it if I wanted to with all her medical issues. And my daughter, as I said, my oldest daughter's had to have the iron infusions. And she just had to hand

out $1,200 cash. I mean, how long should the young people that have been, you know, the dependent family members and actually the veterans' families, too. How long are we supposed to just keep putting out money? And I know several families who have been economically bankrupt and had to file bankruptcy because of their illnesses. I don't think that's right. I think it's wrong totally that even my children, you know. One reason why I'm starting a business is so I can vocationally train my daughter and my grandson. 'Cause I know the public school system isn't going to do anything for them.

MR. STALLARD: So the question was, do you have to be a --

MR. ENSMINGER: I have some information about this healthcare thing in this bill, and how this is going to work. Once the bill passes it's going to come down to the VA and different scientific organizations, such as the CDC, to come up with how this healthcare's going to be administered.

Now, I do know this much, that VA, under this current bill, will be the payer of last resort, which means if a person applying for healthcare benefits under this bill for Camp Lejeune, they will be required to -- their healthcare will be billed before

the VA does anything. So my suggestion to anybody who wants healthcare under this provision, to cancel your private insurance. Plain and said and done.

MR. PARTAIN: Well, Jerry --

MR. ENSMINGER: Furthermore, I didn't like that provision. But they really dug their heels in and I had to make a compromise. Gee, Dr. Portier, I do compromise, see?

But anyhow, we have people out there who don't have any kind of insurance, that didn't retire out of the Marine Corps because of pre-existing conditions, because they couldn't afford it, whatever. We had people out there who were having to make the difficult choice of life or death, and losing everything they've ever worked for in their entire lives. And at least I know that this bill, in its present state, will stop that from happening again. And that's what I had to think about. So and I didn't like it. You know, I don't like being put in a position where I have to make decisions like that for an entire community but, you know, somebody had to.

MR. PARTAIN: Hey, Jerry --

MR. ENSMINGER: But how this is going to be administered has not been completely, completely hammered out yet and all the particulars aren't done,

so...

MR. PARTAIN: Hey, Jerry, this is Mike Partain. If I heard Wendi correct, and my knowledge of insurance where I work, when you're talking about the payer of last resort and when she was describing CHAMP there, if there is a primary insurance in effect at the time, like for example my health insurance, that would bill first, and then the CHAMPVA would pick up secondary, including, I would assume, any out-of-pockets or deductibles and things like that. So before anyone would cancel their insurance to go on this, I would recommend they find out what exactly -- what provisions are there.

MR. ENSMINGER: No, not the way it was explained to me. If you have private insurance, they will not compensate you for your out-of-pocket expenses to you that are required through your private insurance either.

MR. PARTAIN: Okay. We'll have to find out.

MR. ENSMINGER: So you would have to totally immerse yourself into whatever the VA is offering before they would take anything.

MS. BRIDGES: Jerry, can I ask you this, what about dental?

MR. ENSMINGER: No, there's no, there's no dental

on this.

MS. BRIDGES: Our children that were in utero, they all have problems with their teeth. And I mean bad problems.

MR. ENSMINGER: You guys can beat the hell out of me later, okay? Once the bill passes.

MS. BRIDGES: We're not beating the hell out of you; we're thankful --

MR. ENSMINGER: I mean, you know, hey, whatever. You know. I've done what I can do.

MR. STALLARD: And Jerry, we appreciate it. Jerry, let's -- Wendi would like to provide some comments here.

DR. DICK: I have a question, Jerry. You probably know this bill better than anyone in the room or on the line. And what I was understanding is that the veterans, they're -- if they have other health insurance, it wouldn't be billed for the conditions related to Camp Lejeune, but for the family members, if they had health insurance, that health insurance would be billed first for conditions associated with Camp Lejeune. Is that --

MR. ENSMINGER: Yeah, I mean, that's for the family members only.

DR. DICK: Right, okay.

MR. ENSMINGER: You're right, Wendi. Once they get taken in under the umbrella of the VA, they're taken care of totally.

DR. DICK: Right.

MR. ENSMINGER: But not the family members. The family members, they just have to have no insurance.

MR. BYRON: Hey, Jerry, it's Jeff. I know you had to make compromises, that's what negotiation is about and getting something accomplished is about. Like I said, I've got some concerns about it. We can talk about it later but as far as, you know, what people --

MR. ENSMINGER: Well, I just wanted to lay that bit of information out now, I mean, because Wendi was talking about CHAMPVA and that spurred me into discussing some of the stuff that I did know about this bill and to be quite frank with you, all the rules and how this is going to be administered, it hasn't even been worked out yet. I mean, that's part of the bill. The bill directs that. And once the President signs it into law, then all the particulars have to sit down and discuss this and how it's going to work. So.

MR. STALLARD: So there's work to be done.

MR. BYRON: This is Jeff again.

MR. ENSMINGER: Yeah. Yeah, yeah, there's still a lot of work to be done on this bill before it becomes a reality.

MR. BYRON: This is Jeff. Just one comment before you leave, and I hope people in Congress are listening. I hope the people in Congress are listening. I think it's tragic that they would throw medical care on insurance companies when they're the perpetrator, the responsible party. And that, you know, if you have insurance and you bill them first, and then if they don't cover it, then the VA picks it up. Though, it's not the VA's fault; it's the Marine Corps and the Department of the Navy; it's actually the United States government. And yeah, I find that tragic that instead of being first to step to the plate and take care of health issues, they want to be last. Thank you.

MR. ENSMINGER: Well, you know, and the same thing goes with the veterans, Jeff. I mean, hell, the VA has been underfunded since after Korea. I mean, when it was first developed after World War II, it was a great program but as years went by, you know, that funding became less and less of a priority, and the VA has been, excuse the phrase, sucking hind tit ever since.

So it's not just this program, it's even for the, for the warriors who served this country and protected it. It's a bad situation. I mean, and our Congress, they have different programs that they want to funnel money to and they all love to go out there and speak about how important all these people our warriors are in protecting this country, but you know as well as I do that that's -- a lot of that's smoke and mirrors and pure rhetoric.

MR. STALLARD: Thank you, Jerry. Thank you for that colorful farm reference.

DR. AKERS: I would like to ask a question.

MR. STALLARD: Sure.

DR. AKERS: I've been told by a former VA administrator that the CHAMPVA program has an age ceiling on the veteran. I've been told it was 65. In other words when the veteran reaches age 65 not only -- well, his family no longer has CHAMPVA coverage. Is that true?

MR. ENSMINGER: Well --

MR. STALLARD: Hold on, Jerry.

DR. DICK: It depends on when the beneficiary turned 65. So when the family member, I think it's the spouse, turns 65.

DR. AKERS: So it's the family member and not the

veteran.

DR. DICK: That's what I understand. It's the family member.

DR. AKERS: 'Cause the way it was explained to me it was the veteran who had -- once he or she reached 65, the coverage ended.

MR. STALLARD: All right, remember, one speaker at a time. Thank you. Is that it -- Wendi, is that it for your...

DR. DICK: Yes.

MR. STALLARD: Okay. Brad?

MR. FLOHR: As long as we're talking about this legislation we -- there's one other caveat for dependent care, and that is the law or legislation links that to appropriations that would be available for that treatment by VA. What that means, I don't know. Congress is going to provide some specific funding for that.

The insurance part only applies to treatment of family members, not to veterans themselves under this bill. They're eligible for care for one of those 14, actually 15 conditions. It's the 14 conditions in the NRC report plus the non-Hodgkin's lymphoma that was added. So any veteran who has one of those 15 conditions, some of those being one infertility, one

miscarriages, it's on that list -- or will be eligible for care through VA.

And it's good news it's going to be passed this week, we hope -- or next week. I know that the Veterans Health Administration is very busy right now. What Congress does quite often, when they pass legislation, they leave a lot of holes in it for the Agency to fill through regulations. For example the bill calls for someone who was at Camp Lejeune for 30 days or more between the period of 1957 to 1987; it doesn't say that that has to be 30 days consecutive or it could be multiple periods reaching 30 days. That's something that the VA will have to work out.

Also in terms of the dependents and age for veterans benefits purposes, a veteran who is service-connected at 30 percent or more gets additional compensation for their spouse, also for dependent children. And that's defined in law and regulations as children between the ages -- or up to the age of 18, 18 to 23 attending school or if they become helpless prior to age 18. That's for benefits purposes. How that's going to be healthcare for, for dependents under this legislation that's something that nobody knows at this point in time, so we're going to have to work it out. As Jerry said, work it

out. Maybe have some conversation with Senator Burr's staff or whoever as we work through this.

But it's going to be interesting anyway. It's as I told Jeff last night, it's a start. It's more than we had. It's a good place to begin.

We've done a lot in the last, as Jerry said, couple weeks. In the last couple months, in December, we have been providing on a regular basis to Senator Burr's staff, to Senator Hagan's staff, to Congressman Brad Miller's staff, data on claims processing that we're doing in Louisville. And in December we provided them an update, and we got a request for additional data that -- and more granular data that we were not capturing in Louisville on their spreadsheet.

So in order to satisfy Senator Burr's request, we had to go down to Louisville. We sent three or four of our physicians from the Veterans Health Administration and three people from my staff went to Louisville, worked over the weekend reviewing every cited claim that Louisville has done since we consolidated claims, and which is about 1,200 to 1,300, something like that. Go over them and capture the data that Senator Burr's staff had asked for.

And we did that. We're going to change the tracking mechanism in Louisville to capture that data

going forward. I can tell you, and you may know because we briefed Senator Burr's staff, Senator Hagan's staff, Congressman Miller's staff just a few weeks ago on the results of our review, give them the data that they wanted. I think it will be interesting to share with you some of that data, if you haven't already seen it. And I think maybe Brooks Tucker might have forwarded it to you. But the categories of breast cancer, bladder cancer, kidney cancer, leukemias, Parkinson's disease, the decisions made on those claims have been over 50 percent favorable. So Jeff I can tell you there are physicians who are willing to put their name on the positive medical opinion. For example, bladder cancer, 71 percent of claims of bladder cancer that have been awarded so far have been granted.

So but what we found, we were looking at the medical opinions provided to determine if they were actually citing to, to relevant information --

MR. ENSMINGER: Hey, Brad, speak into your mike. I'm having a hard time hearing you.

MR. FLOHR: Is that better, Jerry?

MR. ENSMINGER: Yeah.

MR. FLOHR: We looked at the medical opinions to see if they were really good. We know we've had --

Mike has shared some concerns about consistency in some of the decisions so we're looking at a way to improve that.

VHA has identified a list of about 30 subject matter experts in environmental occupational medicine. We have briefed it to our Secretary as going forward that medical opinions will be sent to those particular physicians instead of shot-gunned around to all VA medical centers, to ensure that we get the best -- these are experts who are up to date with all the known information on the contaminants and any associations between them. And that's going to be happening probably in September.

But the first thing that we're going to do is send six or seven of those physicians to Louisville to try to work back the inventory of opinions that they have pending, cases they have pending, to get those down to a manageable level and get decisions out to veterans sooner than what they are now.

Then going forward we'll institute this particular idea. Should be better for everyone. Be better for veterans, better for VA. That's a good thing.

So Perri, you said I would investigate whether a veteran from Camp Lejeune could get an exam at a VA

facility as a precaution. That's really not my area. That's VHA's area. But at this point there are certain categories of veterans who can go in for a one-time examination. By statute, radiation exposed atomic veterans. There's, what else would it be?

DR. DICK: Okay so, Agent Orange registry exam.

MR. FLOHR: Agent Orange registry.

DR. DICK: Also SHAD.

MR. FLOHR: Project SHAD.

DR. DICK: Depleted uranium, Gulf War.

MR. FLOHR: Right now, Camp Lejeune veterans are not in one of those registries. I don't believe you can just walk in and get an exam; although, you might be able to. It depends on where you go.

DR. DICK: SHAD doesn't have a registry but they can have a clinical evaluation to talk about their exposure.

MR. BYRON: This is Jeff Byron, and what I know about the SHAD Project, this is another criminal act that the military perpetrated against veterans. Would you like to explain what that means? Shipboard hazard and detection. They were spraying nerve gas out in a cloud over the ocean and then taking our ship through it to determine whether they could detect it or not. At the same time we were in a war with the Vietnamese.

I suggest if you want to test chemicals, test it on the enemy, not on our own people.

I have some other concerns about the healthcare that's, you know, hopefully coming towards us. My daughter's 27 years old. She was born in 1985. So there's not going to be any children 23, that are in college, and there's not going to be any that are under 25 at this point. So that'll cover none of them, zero.

The most vulnerable group, as I've been told over and over and over, the children that were in utero and children that were recently born and developing. I'm not seeing that type of health, and what I want to know here from ATSDR is when you finish your in utero study, will that list of diseases be broadened or will it just be kept at 14, because I know that's not the end of it, okay?

And speaking to the issue of doctors willing to sign off that your illness came from Camp Lejeune, well, my problem right now is I have two individuals with a chromosome deletion; we've spoken about that. And through all my years in this CAP, it's proven to me, in my mind, that my family's illnesses came from Camp Lejeune. Now, to get a doctor to agree with that, that's a totally 'nother story. They tell me

the chromosome deletion is random.

I finally got them to at least acknowledge that, okay, so if the illness is random, and she was still in utero at the time, don't you think that would have any effect? Oh, yeah, it's a compounder. Well, yeah, okay. Well, how about writing that in the record so that my daughter and my grandson can get some help.

So Congress has got a lot of work to do. And I don't want to really see any of this 23 years old, 18 under, you know, parents care. That doesn't cut it. We're talking about people who cannot provide themselves a living, okay? IQ of fifth grade in every subject matter. What am I supposed to do, as a parent, with that? And her son even worse off, okay?

What, as a Marine veteran, can I tell my family when I go home here, or even if it's six months, a year from now, when the studies are done? And I'd also like to know whether, you know -- first off, when you're going to give the results so that even though I'm not going to be a CAP member, I'll probably come here because I'm the one who asked for the Secretary of Health and Human Services to be here. I believe I'm the one that asked for the Marine Corps Commandant to send the letter.

So, yeah, I'd like to -- I've wanted to see this

to the end but I'm not prepared to sit through more years of more studies that the Marine Corps, Department of the Navy and even more so, the U.S. government can delay healthcare to the victims. And believe me, what they're offering is, if you're talking about a foot, they've offered one inch.

MR. STALLARD: Thank you, Jeff. Let me remind you we're in this question and answer for our VA colleagues right now so let's focus on any questions and answers we might have for them.

And I'd like to welcome Mary Blakely has joined us, for those of you on the phone.

MR. ENSMINGER: Hey, Chris, I got a question for Brad. Hey, Brad, when are you going to be back in your office?

MR. FLOHR: Friday. Tomorrow.

MR. ENSMINGER: Tomorrow?

MR. FLOHR: Yes.

MR. ENSMINGER: I've got a guy that is stage three kidney cancer. He got a response back from Louisville that there's a delay in the processing of the claims and he's going to have to wait. And I mean, come on. Stage three kidney cancer? The guy spent four years at Camp Lejeune during the 70s. That should be cut and dry. And, you know, I want to talk

to you. I'm going to provide you with some of the stuff from his case.

MR. FLOHR: Okay. That'd be good. I'll take a look at it and I'll get with Louisville. I don't know why there would be a delay unless they're waiting for this change-over but they shouldn't be waiting for that.

MR. ENSMINGER: Okay. We'll take that up later.

MR. FLOHR: Okay.

MR. ENSMINGER: This is a specific case.

MR. FLOHR: Okay. That's good. Perri, representing MSDS. Refresh my memory; what is MSDS?

MS. RUCKART: I think this is something that Jeff asked about. It's a material safety data sheet. Someone here asked about a --

DR. AKERS: Actually I asked about it.

MS. RUCKART: Paul. Okay, maybe you want to speak more about your request?

DR. AKERS: Well, --

MR. STALLARD: Into the microphone, please.

DR. AKERS: My question was based on the fact when I read the training letter, MSDSs were not mentioned as the source of information for the evaluating physician. I believe it was they were chemical data sheets but they weren't the MSDSs, and I

canvassed a number of colleagues, some of which are VA employees and others are physicians who actually worked for the VA, and they all felt that the MSDS would have been more informative. That was the reason for the question.

MR. FLOHR: Who generates those data sheets?

DR. AKERS: Individual companies. By federal law, when a new product is introduced into the work place, it requires an MSDS accompany that product. I can give you, actually, a chronological order of the development of the MSDS from a talk that was given a number of years ago. But the MSDS will go through such stages as chemical composition, shipping, handling, safety, combustibility, toxicology and there are other entries in the MSDS, including degradation products, such as TCE breaks down to chlorine phosgene nitrogen chloride gas. And so does TCE.

MR. FLOHR: Trying to think how that would be of use in our training letter. But it sounds like something for people providing medical notes rather than for our adjudicators, which is what the training letter really is for. But we are in the process of revising the training letter based on what's coming, the legislation, the changes we're making in Louisville in terms of getting medical opinions, so

we're working on revising that.

MR. BYRON: Phosgene is the first gas used in World War I, okay, to poison troops. One other thing I did want to mention, I agree with Sandy that these dental issues that these victims have incurred, believe me my family's experienced it and it has cost me tens of thousands of dollars to try and keep up with it, and they still lost their teeth.

And I believe that the Congress, VA should be pressing that matter. And the health survey should definitely discuss that.

And one other issue, I know that somebody handed out a VA report on male breast cancer. And it spoke about increased risks, and I am definitely at an increased risk based on their literature because of having epididymitis. And I'd kind of like to know how many men have that that are, you know, saying that they have male breast cancer or not saying.

The ones that have male breast cancer, do they report these medical conditions that went through diabetes, obesity, epididymitis, Klinefelter's syndrome, and I think one other, were listed as an increased risk. I'd like to kind of know, since we're doing a health survey, how many of these guys reported those conditions prior to, or were seen by the Marine

Corps or VA prior to their diagnosis of male breast cancer.

MR. PARTAIN: Well, speaking of male breast cancer, Brad, you know, when you were talking about the 14 conditions that are being recognized, and I bring this up as kind of a tongue-in-cheek thing, but it is something that probably will happen. The NRC report talks about breast cancer. Is the VA going to recognize male breast cancer as well because, you know, like for me treating, going in, you know, pink rooms, florals. And I've had an insurance company reject coverage on something because they don't have a category for male breast cancer.

MR. FLOHR: Well, Mike, that's what I said. In Louisville, the claims for breast cancer, which are male generally from Camp Lejeune, we've granted 62 percent of those claims.

MR. PARTAIN: I'm just saying that --

MR. FLOHR: So we do recognize it.

MR. PARTAIN: -- point in the procedure. Okay.

MR. BYRON: Well, they're part of the problem. Mike is not a Marine; he's a dependent family member. So I think there's probably some concerns there.

And then the question is is the NRC, is this the same panel that pretty much, you know, just kind of

shuffled us off to the side? I don't know, do any of you CAP members feel that comfortable with what the NRC did while they were here? I don't, from what I saw. And then like I said if this is limited to 14 illnesses, and then VA's my last resort? VA should not be -- I'm not saying the VA should be the one paying for our illnesses. It should be the government through the -- they provided an avenue for the VA to do that for veterans. But 14 illnesses? I doubt that half of these victims here that have been sick are even covered under those 14.

MR. FLOHR: Well, no, Jeff, I think, and Jerry probably can speak to this more than I can, but I believe, you know, there was a lot of resistance in the Senate and the House to any bill on Camp Lejeune, and I think this is a compromise. To get those 14, plus they added non-Hodgkin's lymphoma, so there's 15. It's just, it's all about compromise.

MR. BYRON: Well, I just hope that it's a start, and not an ending. Okay.

MR. ENSMINGER: Well, let me add something there. Something Brad just addressed. This bill, there was a lot of resistance for getting anything for Camp Lejeune.

As a matter of fact the reason that this bill has

an HR on it is because it originated over in the House. And the House Veterans Affairs Committee tried to sneak a bill past. They took it up over in the House, they passed it and it went over to the Senate and luckily Senator Burr and his staff caught it. And Senator Burr dug his heels in and said hell no. If it doesn't include Camp Lejeune, nothing's going through.

So then the compromising started, okay? That's how we ended up with this bill and that's how that HR bill ended up over on the Senate side and got passed in the Senate before it got passed in the House.

So that's just a little bit of the history for you. I mean, you're just getting a glimpse into my life on a day-to-day basis. So anyhow, go ahead.

MR. BYRON: Well, this is Jeff again, and I think it's a hell of a shame when veterans who served their country or patriots have to compromise, and the United States government just signed off $125 million to AIDS research overseas. What the hell? They're handing away my tax dollars and won't take care of us? The people that serve this country? I don't know about you but, you know, I feel the patriots and the veterans deserve it.

MR. ENSMINGER: Well, Jeff, hey, I don't think anybody on this call will disagree with you. And, you

know, that's something we're going to have to take up at a later time. I mean, we're not going to cure it all that here, unfortunately. But, you know, I hear you. You know, we all hear you. And you're right. By the way, Mike, I bought you a pink hat, a pink scarf and pink gloves for this winter, so...

MR. PARTAIN: As long as you made the appropriate donations to Komen so they give you credit for it.

MR. STALLARD: All right, do we have anymore questions for our colleagues at VA?

DR. DICK: I just had a comment. I wanted to step back a minute for something that Brad and I were discussing earlier. If somebody is, let's say, a Camp Lejeune veteran and they don't -- they need treatment for a condition that isn't one of those conditions on the list of 15, VA has something called enrollment priority groups. And so for example the first priority, the top priority, would be for those veterans who are service-connected, with at least a 50-percent disability. The lowest priority group is priority 8, and those are the veterans who make too much money for the VA threshold, and who have no service-connected conditions. Category 6 includes the SHAD veterans, the ionizing radiation, the Gulf War and Vietnam veterans. So if they make too much money

and they're category 8, however they were a Vietnam War veteran, then they move up to category 6. And if someone would like this list, I'm happy to give it out to you. It's online, too.

MR. STALLARD: Yes?

DR. CLAPP: I want to ask Brad, you mentioned the, I think you said 30 environmental medicine experts that you've asked to get engaged, is that a list that's public and could people --

MR. FLOHR: No, that's just being generated.

DR. CLAPP: Okay.

DR. DICK: And Brad, they're already working for the VA, these --

MR. FLOHR: Yes.

MR. BYRON: This is Jeff. Frank, you know, I brought up that, you know, the in utero study, what recommendations -- I mean, you guys have seen the info, you've had it for a long time. I mean, I still can't get an answer, an opinion, from somebody in the scientific community, what's going on? Okay? Why can't anything be released?

Well, I realize the studies aren't finished, but when the study is finished, will there be illnesses that are added to this list for the children, for those that were in utero or what do you think will

happen here? I mean, will you guys be making recommendations to Congress or are we just going to put out a report and that's the end of it?

I don't know. That's why, kind of why I wanted Secretary Sebelius here to tell me what's next, you know. I want to look at 'em right in the face and hear it from 'em.

DR. DICK: VA is very interested in what comes out of the various health study reports from ATSDR, so we're definitely following that closely and we'll look at it very intently.

MR. STALLARD: All right. It seems that we are concluding our question and answer period for --

MS. RUCKART: Mary has a report --

MR. STALLARD: Does she?

MS. BRIDGES: May I say something?

MS. BLAKELY: Well, I'd like to apologize for being late, first, but my two GPSs didn't get me here. It took me to the other CDC. That was interesting. They were nice. They sent me here.

As far as Jeff's question about recommendations, in the first study I actually bought that book, if you want to call it that. And in it they do have recommendations. And I was going to ask if the ATSDR and the scientists would recommend further studies,

especially for the surviving children who have illnesses that aren't listed in that 14 category.

Because one of the reasons that I was late is because I'm late everywhere. I have two GPSs. I have a learning disability. I actually brought my test results. I don't know how my lawyer will feel about this but I'm going to give them to you and let you look at them, because -- I have a good life. I've been blessed but there's a lot of victims out there who are like me, who have learning disability and memory deficit, who don't have the means that I have. And they are suffering. They can't afford to go get tested. They have no idea why they are the way they are. And the knowledge of knowing what has caused me to struggle my whole life, the way I have, has empowered me, has motivated me to stand up and shout for people like me.

And you have a position in our government that you can recommend that these studies be done. And I don't think it's wrong for me to request that of you, from the children, the surviving children who aren't dying of cancer. The children who are struggling and can't make it into colleges. We're all getting older. But you know what? We've passed it on to our children. My daughter's just like me and she gets

lost going around the block. She struggles. She worked hard in school. She has learning disabilities also. And her daughter, she turned six yesterday. She's just like me.

Now there needs to be more studies. We don't need to be shoved under the rug. Neurological effects from those chemicals are spread far and wide. And if you just look at our society as a whole, the children's testing is so screwed up that everybody's on medicine because they either have some sort of social problem or they have a learning disability. Now, what is that from?

This needs to be done and you have the power to do it. And I feel like it's not wrong for me to request that. You put it in writing.

MR. STALLARD: Thank you, Mary. Any other questions for our colleagues from the VA?

MR. PARTAIN: Actually just kind of tag onto what Mary was saying. Jerry -- actually this is going to go to Jerry but it's pertaining to the healthcare. So, but with the bill, Jerry, you know, like for example Gloria out in Arizona where her, I think, grandchild was born with cancer. Her child was born at Camp Lejeune. Does the -- the bill doesn't address, you know, the dependents -- dependent

children, does it? Am I making sense here?

MR. BYRON: In other words Jerry, it doesn't go into the third generation, correct, like my grandson?

MR. ENSMINGER: No, this'll only pertain to people that were directly exposed while they were at Lejeune. Okay? So. You know, like both of your daughters, Jeff. Like Mike, you know, that's who this'll cover.

I mean, yeah, you got to realize something here. We're having a hell of enough time just getting our bureaucracy to help the people that were directly exposed. I mean, hell, the Department of the Navy and United States Marine Corps still sit out there and deny that there were any kind of (indiscernible) due to their neglect of the people that were directly exposed, let alone extending it and going out to children who were born subsequently away from the base.

You know, it's like I said, you can do what you can do, and I'll tell you it's a quagmire up there, and trying to work through -- and then you've got different political parties involved in this thing. I made the statement last week to one of the congressional staffers, I said, you know trying to get this bill passed was like playing a game of volleyball

in a damn mine field. And you -- one of your team members sets you up for a beautiful spike, and you spike the ball, but when it hits on the other side it explodes. I mean, God knows. I mean, it's -- I tell you what, it's a hell of an experience. I've had one hell of an experience in the last 15 years, I'll tell you that.

MR. STALLARD: You should make a movie about that.

MR. PARTAIN: Hey, Brad, I do have a follow-up question. Once the -- provided the bill's passed and we have this legislation in place, the veterans who have been previously denied -- I've had a couple of male breast cancer guys ask me this question and some other people with kidney and bladder cancer and stuff, those veterans who have been previously denied, once the bill is passed, is that system with an appeal or how does the VA look at that? I know you probably haven't really thought that process out but that's something we're starting to get now.

MR. FLOHR: Well, the legislation really only pertains to healthcare and not to benefits. It's healthcare regardless of whether or not somebody's been determined to be disabled due to actually to their military service. So how that's going to impact

claims and certainly someone could, who had been denied could come back to VA, say, you know, I wanted to look at it again possibly but there's no tie between healthcare and disability benefits.

MR. PARTAIN: And I'm not sure -- yeah, I'm not sure how the VA process works since, you know, outside of that, but my understanding is you usually have a year to make an appeal or what have you.

MR. FLOHR: Correct.

MR. PARTAIN: Now, if they're beyond that one year, the bill's passed now, does that open the window back for them to make an appeal again?

MR. FLOHR: No, no.

MR. PARTAIN: They're not.

MR. FLOHR: What -- they can always provide new evidence.

MR. PARTAIN: Okay.

DR. DICK: This is Wendi and I just wanted to -- Jerry was talking about children, and what I understand from the bill is that if there was a child who was not born at Camp Lejeune but the child was conceived or was in utero for at least 30 days while the mother was at Camp Lejeune, stationed or living there, then if that child had -- has any of those 15 conditions, those -- healthcare related to those

conditions would be covered. So 30 days in utero also is in the bill.

MS. BLAKELY: What about if it's the father? My ex-husband was a civil servant in the print shop when I got pregnant with my daughter, and would that include them?

DR. DICK: The civilians -- civilian employees are not included in this bill; only the service members and their family but not the civilian employees.

MR. ENSMINGER: And hey, Wendi, I'm glad you brought that up because there have been newspaper articles ever since the Senate passed this bill and TV spots, and there are a bunch of former civilian employees and their dependents asking about, well, what about us? And you know, I passed this word out on our website, I've passed it over to the other website. It's like talking to a brick wall. But anyhow, beside the point, there is a program in place, it is called the Federal Employees Compensation Act. The acronym is FECA. I won't go into that.

MR. STALLARD: Thank you, Jerry.

MR. ENSMINGER: But anyhow it is administered to the Department of Labor, and I went over and looked at it, and it's basically like the VA for federal

civilian employees. And it looks like a great program.

Now, I don't know, because to be honest with you, in my 15 years' involvement in this situation, I have never had one former civilian employee tell me that they have even applied for that. Now, and let alone somebody coming to tell me, like the veterans do, that I applied but I've been denied. I haven't heard of anybody even applying for that.

So go look it up. It's -- I went and found it on Google. I just did a Google search and boy, right there it was. It took me right to the Department of Labor, and I read up on the program, and it looked like a great program. I mean, it even has widow benefits for a former employee, widow or widower. So I'm glad you brought that up, Wendi, because you reminded me that, you know, that's why civilian employees are not covered in this bill.

DR. DICK: Thanks for that background.

MR. ENSMINGER: (Indiscernible) better programs than what our dependents are getting.

MS. BLAKELY: Yeah, but the civil servants don't know about that program. I spoke with a civil servant in Jacksonville at the showing of *Semper Fi*, and she said that she has learned just for herself about

programs like what you mentioned. But for the norm, civil servants have no idea what kind of benefits that they could possibly have because nobody has shared that with them.

MR. ENSMINGER: Well, the question is -- let me tell you something, Mary. They have a union and their union hall is right out there on Gum Branch Road. And if they have any questions about what they rate, all they have to do is contact their union. I mean, I've been to their union hall probably -- I've been there three times. Some of the documentary was filmed in that union hall.

MR. STALLARD: Hey, Jerry, we need you to talk into the phone, please. Your volume is fluctuating a little bit.

MR. ENSMINGER: Can you hear me now?

MR. STALLARD: Better.

MS. BLAKELY: Well, can we request that somebody from either that union or somebody, you know, in charge of the civil servants be at these meetings? I mean, how many more of these meetings are there going to be?

MR. STALLARD: That is to be determined. I can answer that question for you. We don't have an end date per se, but the CAP will probably at some point

discuss their role into the future.

MR. ENSMINGER: Well, and you know, let's take a look at the statements made by the United States Marine Corps about how important the health, safety and welfare of their former Marines, sailors, their family members and their civilian employees. Why doesn't the Marine Corps notify their civilian employees of the availability of these programs? Well, gee.

MR. STALLARD: So it sounds like that's a whole different issue in terms of what is the procedures that federal employees would have to go through in order to identify work-related, being assigned, you know, like at Camp Lejeune and working there, years later. I'm sure it has its own time-consuming process, so thank you for bringing it up. I think perhaps at some point it would be helpful to know to advise, and who would be the appropriate proponent to do that.

MR. ENSMINGER: That would be their union, Chris. And they have a union hall that's manned out there 24 -- not 24/7, but every day of the week to assist these people with filing claims like that. And furthermore, if there are any civilians listening, the former civilian employees that were affected by this,

our website, The Few The Proud The Forgotten, is not just for veterans. And all that evidence and documentation that we have on that website is readily available and there for them as well, to support their claims.

MR. STALLARD: We heard a beep. Is there someone who's joined us on the phone and hasn't had a chance to announce themself?

DR. DAVIS: Hi, this is Devra Davis, I've been on for a bit.

MR. STALLARD: Welcome, Devra.

DR. DAVIS: Thank you.

MR. STALLARD: Okay. Anymore questions for our VA during this question and answer period, colleagues? We have a choice.

MR. PARTAIN: We were nice to you today, Brad.

MR. FLOHR: It's always appreciated, Mike.

MR. STALLARD: I think you always comport yourselves very well.

MR. BYRON: I do have one thing. Still, like I said, the way that the legislation sounds like it's written to me, no children as dependent family members are going to get help because they're too old. Am I correct or am I wrong?

MR. FLOHR: Jeff, I think it has to be

determined. The same rules that apply to dependency for veterans compensation benefits may not be the same that apply for this particular legislation. It hasn't been determined, I don't think.

DR. DAVIS: This is Devra Davis. I wanted to follow up on that because as you are all aware, there is clear evidence that there are effects on pregnancy but there are also effects on male reproductive health so that men who would be exposed while working there, might have produced children that would have defects associated with their exposures, and that's very important issues that needs to be addressed.

MR. BYRON: So would you consider epididymitis one of those diseases?

DR. DAVIS: Yes, but I don't think you need a -- that's a -- as you know, that's a male reproductive disease. But I'm talking about the fact that there's a phenomenon called male mediated teratogenesis, and that refers to the fact that where fathers work or exposures that they have in the four months prior to producing a conception that results in a child, has an effect on the health of the child they produce and whether or not they can produce any.

And there's a literature on this relating to solvents, relating to pesticides and their effects on

men and the health of the children that those men produce. Male or female children. Epididymitis, of course, is just a male effect.

MR. BYRON: Yes, but my daughter being disabled after me drinking the water is kind of indicative that I had the problem. Yes or no?

DR. DAVIS: That is exactly what I'm talking about, your daughter.

MR. BYRON: And so my request for doing genetics testing, and I was told no way because, you know, first off, the people wouldn't do it, that it wouldn't prove anything so it sounds to me like, like I said through all these meetings, you just verified everything I've thought, and not dispelled any of it. Come on, guys, let's hear something.

MR. STALLARD: We also -- excuse me -- in a minute, Devra, we are going to hear something from the ATSDR. In the afternoon session we're talking about updates, cancer studies and you'll see the agenda, so.

MS. RUCKART: Later this morning.

MR. STALLARD: Later this morning. Okay, later this morning.

MR. BYRON: This is Jeff again. You guys seem mighty quiet today. What's up? Somebody hit you with a stick?

MS. RUCKART: Nobody's trying to dispel your statements that you've made. We just can't really speak about that right now. We're going to give our updates later, and then, you know, we always have a Q&A session, and you can ask us really specific detailed questions at that point.

MR. STALLARD: Yeah. We're -- okay, so next on the agenda is Morris, actually. And we're supposed to take a break at 10:30. Given that this is live streaming and whatnot, are you okay if we take a break now and then bring him back?

MS. RUCKART: Yeah, we're -- we don't have that restriction anymore. They continually stream. They used to stream in three-hour chunks but -- we previously had a restriction that we could only stream in three-hour chunks. If we took the breaks differently it might affect our streaming but I think we continually stream so we can break early.

MR. STALLARD: Okay. Great. So let's please be back. We're going to adjourn for 15 minutes. So please be back and seated and ready to go at 15 minutes from what your watch says.

(Break, 10:22 a.m. until 10:38 a.m.)

MR. STALLARD: All right, well, let's resume. We're going to now -- Jerry, give us just a moment or

two. We have about four people that might be in conference in the hallway.

All right, this is the session that we have set aside time for Morris to provide us with an update on the water modeling. Morris, please speak directly into the microphone. Jerry has asked that we...

WATER MODELING UPDATE

MR. MASLIA: Okay, good morning. It's my pleasure again to bring you up to date on the water modeling activities and associated reports.

The Chapter A report, which is summary and findings and contains eight supplements with supporting information, all analyses have been completed. Division management is reviewing Chapter A and supplements. The next steps are to response -- to response to review comments, submit the report to the Office of Science for peer review. And the Office of Science selects the peer reviewers and submits the reports and supplements for external review.

The Chapter D report, which reports on RCRA site histories and ground water contaminants from above ground and underground storage sites. Their report is in the final stage of agency clearance. The next step is the staff will respond to comments and the staff will submit a final laid out report to the Office of

Communications for release. And that's my report.

MR. STALLARD: Okay. Any questions for Morris?

MR. PARTAIN: Well, Morris, when is the expected date for the water model to be released for the public and the CAP and everybody to hear and see?

MR. MASLIA: I'll have to defer that to someone who makes those decisions.

MR. ENSMINGER: Who's that?

MR. PARTAIN: I think Frank got slipped the fish on that one, so Frank?

MS. FORRESTER: This is Tina Forrester and I'm the Acting Division Director for Community Health and Investigations Proposed. We have a timeline to be complete by November 15th.

MR. PARTAIN: Okay, when you say complete, is that for public release to where it's out?

MS. FORRESTER: Yes.

MR. PARTAIN: Now, is there going to be a time where, as far as the CAP's going to be involved in knowing or having an opportunity to understand the water model before it's concluded as far as, you know, us to have a say-so in it?

MS. FORRESTER: I don't know at this time if a decision has been made on that. I will talk to Dr. Portier.

MR. PARTAIN: All right. Is the water model going to be provided to the Department of the Navy and the Marine Corps for comments and reviews prior to its release as well?

MS. FORRESTER: I'm not sure about that either. I'm not sure.

MR. PARTAIN: Okay, well, I will state for the record if that is the case -- hold on, Jerry. I said I would state for the record that if it is in the intent of the ATSDR to provide this water model for the Marine Corps and the Department of the Navy to review prior to release, that we the community be allowed that same opportunity. And it would be a disgrace if that was to occur.

MS. FORRESTER: I will definitely talk to Dr. Portier about both of your questions.

MR. BYRON: Yeah, this is Jeff --

MR. ENSMINGER: I thought Dr. Portier was there.

MS. FORRESTER: He stepped out of the room momentarily. I'm sure he'll be right back.

MR. ENSMINGER: Oh, gee. Right when the water modeling issue comes up.

MR. STALLARD: Well, I'm sure we have --

MR. ENSMINGER: Wasn't that convenient?

MR. STALLARD: We have more time today, Jerry,

and if you feel the need to circle back to that...

MR. ENSMINGER: All right, when can we expect Chapter D?

MS. FORRESTER: All I can tell you currently is -- what?

MR. MASLIA: I was just going to repeat what I said.

MS. FORRESTER: Okay.

MR. MASLIA: It is -- Chapter D is currently in the final stages of Agency clearance.

MR. ENSMINGER: Yeah, but I mean Agency clearance, Morris, is a damn mystery hole that nobody really understands, except for a small circle of people I understand you're not even included in. So, you know, what is internal clearance? Where in the hell is it?

MR. MASLIA: It is in electronically in the ATSDR, what's referred to as the documentum clearance system.

MR. STALLARD: And Jerry, Dr. Portier is back in the room, if you have a question you wanted to direct to him.

MR. ENSMINGER: Yeah, I mean, where is Chapter D, Dr. Portier? Where is it in your internal clearance process and when can we expect to see that report?

DR. PORTIER: Well, it's within our internal clearance procedure. Every, you know, we have, Jerry, we have the right, but not just the right, we have the responsibility to make sure this document is as accurate and correct as it possibly can be before we let it go out the door. Letting a substandard document out the door would not do you any good nor anyone else. So that document is still in clearance until we're satisfied that it is of high enough quality and meets our standards that we are willing to release it.

MR. ENSMINGER: Well, I mean, you know, we reviewed that chapter. We were given a specific time frame to do the review, and that was researching all the documents and going back through every document that was in that thing, and we met our deadline. And so I just don't understand what's taking so long for people who don't even really understand that issue to do their review. I mean, what are they looking for? To make sure that the spelling's correct or what?

DR. PORTIER: You're absolutely correct, Jerry. You guys met your deadline; you did it extremely well and you did a great job, and we really do appreciate that. Sometimes it is difficult to get documents cleared through a complex organization like CDC, and

it takes time and effort for the people who want to review and make sure that document is correct to get through it. And it's just a matter of sitting and waiting for them to be finished.

DR. DAVIS: This is Devra Davis. In the interest of transparency, it would probably be helpful if you were to name the individuals that are on that internal review committee and tell us what the deadlines are that they're going to be working with, and then I think that would solve some of these concerns that Jerry's raising.

DR. PORTIER: Devra, I can only give you a broad stroke of how review goes on within CDC and ATSDR. For issues that are extremely important to the Agencies, like the Camp Lejeune issue, the review goes from the scientist himself who put together the document, all the way up to the Office of the Director at CDC, so there are a large number of people --

DR. DAVIS: So it's intended to go to the Secretary at HHS?

DR. PORTIER: If the director, if Dr. Frieden's staff feels that it should go to the Secretary's office then it will go to the Secretary's office. So these documents take time and effort for people to read. Chapter D is 400 pages, give or take?

MR. MASLIA: More or less.

DR. PORTIER: Yeah. Different reviewers take more or less time as they review it. That's the best you're going to get out of me.

MR. ENSMINGER: Well, when you use the word, when you have important documents, I think a better choice would be something as controversial as Camp Lejeune is, would be a better choice of words.

And I have another question, has OMB got their fingers in this, too? Are they reviewing these reports?

DR. PORTIER: Up to this point OMB has not reviewed any of our reports. Again, I will point out that sometimes for these reports, it depends on what the Secretary's office might do. We have no indication that this report is going to the Secretary's office or anywhere else other than CDC.

Everybody who is touching this report knows the importance of this report, they know the importance of getting it out in a timely fashion; they are all aware of it. My chief of staff personally calls and checks to make sure where the document is on a routine basis, to keep track on it. So we're trying our hardest to get this thing out as quickly as we can.

DR. DEARWENT: This is Steve Dearwent. One

question that came up while you were out of the room, Dr. Portier, was whether or not we would provide, once all the reviews have been completed within HHS, whether or not we would provide an informational copy to Navy or Marine Corps for their review prior to release or how that process works.

DR. PORTIER: That process is outlined in our memorandum of understanding. There's a specific statement in the memorandum of understanding as to what sort of lead time the Department of Navy gets for any of our documents that are going out of the CDC. I don't know if -- I don't remember the exact time frame.

MR. PARTAIN: Well, Dr. Portier, if the Navy and the Marine Corps are going to be given an opportunity to review the water model prior to release, what have you, is that same opportunity going to be afforded to the community?

DR. PORTIER: If I remember the wording of the memorandum of understanding, they do not get an opportunity to review. They get an opportunity to ^ the document in advance. That's all. They get a head's up.

MR. ENSMINGER: Hell, no. The damn perpetrator gets all the damn benefits.

MR. PARTAIN: Well, then, Dr. Portier, are we going to have an opportunity to see the document, the water model, prior to its release as well? I take the review question out of it.

DR. PORTIER: Mike, I will take that under consideration, I honestly will. I'll talk to my staff about the pros and cons of doing that, and I'll take it under consideration.

MR. PARTAIN: Okay, 'cause, as a CAP member, I'd like to make a formal request that, since they are going to be provided -- they being the Department of the Navy and the Marine Corps, not be review -- I mean, not -- I'm sorry -- to see your work prior to its release, to make sure we're using the correct operational terms here, that the CAP also be provided that same opportunity. And I think it's something that, in the interest of transparency and appearance, I think we should be given that same right, too.

DR. PORTIER: I'll review the memorandum of understanding over lunch, and I will pull my staff in and I'll give you an answer this afternoon.

MR. PARTAIN: Thank you.

DR. DAVIS: This is Devra Davis, just with a scheduling question, because I -- could you just confirm for me what time you're planning to discuss in

more detail the methodology and design for the case control, case, case study?

DR. DEARWENT: Are you referring to the male breast cancer study?

DR. DAVIS: Yes. Yes, sir.

DR. DEARWENT: That would be 1:00 o'clock, right after lunch.

DR. DAVIS: That'll be at 1:00.

DR. DEARWENT: Yes.

DR. DAVIS: All right, I'm going to arrange my schedule so I can be available for that.

DR. DEARWENT: One, Eastern.

MR. STALLARD: Any other questions related to the water modeling? No? Okay, let's move into --

MR. FLOHR: I have one.

MR. STALLARD: Okay.

MR. FLOHR: Morris, this last weekend there was apparently thousands of pages of documents released by DOD on Camp Lejeune. Will that not have any impact on Chapter A, which is in the final stages?

MR. MASLIA: No. We have all the documents from the DON and anyone else, Marine Corps and things like that, and so those documents, to my knowledge, are not anything that we do not have.

MR. FLOHR: Oh, okay.

MR. STALLARD: All right, then, thank you. Let's move on in the agenda.

UPDATES ON HEALTH STUDIES

BIRTH DEFECTS AND CHILDHOOD CANCERS

MR. STALLARD: Perri is our next presenter. Speak clearly into the microphone so Jerry can hear it.

MS. RUCKART: I'll try my best to project my voice very loudly. So anyway, I'm going to be giving you an update on our health studies. A lot of this information just presenting to get everybody up to speed, make sure that everybody understands what we're doing. There are a few new things that I do want to share with you. And I have some slides, just for the benefit of that.

Okay, so everybody knows about our health study on birth defects and childhood cancers. I'm just going to go through this very quickly just to make sure we're all starting from the same point here.

So you know we had that previous survey to identify the population. And we surveyed 12,598 children born to mothers who were at the base 1968 to 1985. From that survey we got 106 reported cases of neural tube defects, oral cleft defects or childhood cancers. As you know we tried to ascertain some

additional diseases. We were not very successful so we moved forward with these.

We were able to confirm 52 of them. The others, they were either confirmed to have something else, they refused to participate in that process, they were ineligible for a variety of reasons, and six of those we couldn't confirm one way or the other, and I will tell you in a little bit what we're going to do with those. So that breaks down to 15 neural tube defects, 24 clefts and 13 cancers. And we interviewed the parents to get more information about potential risk factors in 2005.

Okay. So as you can see this is just a more detailed breakdown of the cases, because neural tube defects encompasses anencephaly, spina bifida and cleft defects are cleft pallet or cleft lip, and the two cancers, so as you can see we're able to interview everybody except one cleft.

MR. ENSMINGER: Hey, Perri?

MS. RUCKART: Yes?

MR. ENSMINGER: How many -- I thought you had 19 confirmed cases of childhood cancers.

MS. RUCKART: No, it's 13. Thirteen confirmed. There were --

MR. ENSMINGER: Damn.

MS. RUCKART: I'm trying to see how many were reported.

Excuse me, I have to go log into the computer again. Somehow the presentation just disappeared. So give me a minute. Frank, can you add up all the cancers?

DR. DAVIS: Maybe you can clarify the numerator and the denominator here.

MS. RUCKART: Of what?

DR. DAVIS: Of these cases, of the 13 or 14 out of -- from what population were they drawn? Was this just self-reporting? I'm a little unclear.

MS. RUCKART: Well, Devra, we had an extensive process to identify all the births on base during that time period as well as births that occurred --

DR. DAVIS: No, that's what I'm asking you just to clarify this. I know the dates of the population that you're looking at. That's what I'm asking. From --

MS. RUCKART: Nineteen --

DR. DAVIS: All children born from as of this time to that time.

MS. RUCKART: Right, 19 --

DR. DAVIS: You actually have the data on all births that took place on the base, and have been able

to follow all those children up to the first 20 years of their lives?

MS. RUCKART: No, that is not really the case. What happened is we have information on the births from 1968 to 1985 for those births on base.

Now, there is really no good source to identify the births off base, and we anecdotally were told there were about three- or 4,000 births that occurred off base. That's because the people at the hospital think that's how many mothers they saw during that time period but didn't deliver there. So we have ascertained -- now, given that that, we only have a rough estimate of those births off base, we have an estimated participation rate of about 80 percent for this survey from which we got the cases.

So there were about 12,493, I think, births on the base during that time period, and an estimated three- to 4,000 off base. That's about 17- to 18,000 total. We ascertain 12,598, and from that we got 106 reports of the cases, and then I described to you how that shapes up. Does that help?

DR. DAVIS: And I appreciate how difficult it is to do that. I'm not trying to give you a hard time but I'm just trying to make clear, and I think everyone understands is, for the record, is this is

not complete ascertainment at all.

MS. RUCKART: Yes, I was just trying to go over this part fairly quickly because most people are familiar with it, but of course stop me if you have questions. Okay, my presentation will be up here momentarily.

DR. DAVIS: Is there any way I can access it remotely since I'm not at the meeting?

MS. RUCKART: Yes, it should be -- well, when it comes back up here, up here in a minute, it should be streamed as well.

DR. DAVIS: All right, thanks.

MR. ENSMINGER: And by the way, while you're waiting on that, Perri, I have the MOU up on my computer screen here.

MS. RUCKART: Wait, we have this back up. Do you want to stop and break for that or do you want me to continue because we do have the presentation back up. And by the way, Devra, there's a slight delay for the streaming, so you should have it streamed momentarily. About one minute I'm told.

MS. BLAKELY: Perri? I'm confused, please forgive me, but are you saying that these numbers are just from the study or are you saying that the Marine Corps provided how many children were born on the

base?

MS. RUCKART: The Marine Corps did provide this. We have birth certificates from Onslow County, where the base is located, and from that there was a study in 1998, the one that we talk about the adverse reproductive outcomes. So from that study there were 12,493 births that were identified from the birth certificate from the county as having been born to parents who lived on the base.

And then the naval hospital anecdotally, and I was not involved back in the early to mid-90s, when this -- when these discussions were taking place, but they estimated that there were about three- to 4,000 births that occurred off base, but that they knew about these pregnancies that had come through and been seen at the hospital there.

So that gives us approximately 17- to 18,000 births during this time frame where any portion of the pregnancy occurred on the base. So from that we were able to survey 12,598 people, that's about 80 percent, that's pretty good. You look like have a further question.

MS. BLAKELY: So you got the number from the other study you're saying? I'm sorry.

MS. RUCKART: Well, that was the basis for the

births that were on base who had birth certificates. So that -- but let me say, out of the 12,598, it wasn't like it was 12,493 of those births are in our study. You know, I think it's 10,500 or so are part of this study on birth defects, and the other 2,500 or so are from the off-base births.

MS. BLAKELY: Is there a way to access how many actual births took place in a county? Like, would the state have a record of that?

MS. RUCKART: You can go to the vital statistics office.

DR. AKERS: Actually it's the Center for Health Statistics in Raleigh. The chairman of that is a Mr. Matt Avery, who's in charge of those records. And regarding the three- or 4,000 births off base, what was happening, at least in the early 60s, is that high-risk pregnancies were transferred to Portsmouth Naval Hospital. And infants that were born that were at high risk, multiple defects, what have you, they were transferred either to Bethesda or to Portsmouth, at least in the early 60s, as far as the location for those individuals.

And according to, again Matt Avery or a Mr. Robert Meyer, birth certificates are a very poor source of information. And the study you mentioned in

the late 90s, was that the one that was done by Wendy Kaye?

MS. RUCKART: No. Okay, first of all, I think there's a lot going on here so there's some confusion. In 1998, the Agency published a study, so it was conducted, you know, in the early to mid-90s about adverse reproductive outcomes in the births that we knew about because of the birth certificates. The parent lived at the base when the child was born.

Doesn't say anything about how long they were there because they could have come in the last month. So that study looked at small for gestational age and preterm birth and low birth weight. And I'll be talking about that in the minute. We're going to be doing some reanalyzing of that study.

Then, as Paul mentioned, the birth certificates are not a good source of identifying birth certificates -- birth defects, I'm sorry. The birth certificates are not a good source of the birth defects. Obviously, you can't get cancer information off of that.

So this is why we did the survey, to ask people: Did you have a child with a birth defect? And then we followed up to get medical records confirmation. So that's what I'm talking about.

So in 1999-2002, Wendy Kaye did lead the effort to do the survey from which we got these 106 reported cases. So 2005 -- so then beginning in 2003, continuing on for several years, we began the very extensive process of trying to get medical records confirmation because these were things that happened a long time ago; it's hard just to get the records. So that's why out of the 106 cases, we confirmed 52.

Now, it's not that the other 54 are unknown. Thirty-two of those were confirmed not to have the condition that for some reason was reported during the survey and some of the people became ineligible. Further checking into them we found out that, a, the pregnancy wasn't really on the base or they lived in Midway Park that's actually off the base, or the pregnancy did not occur between 1968 and 1985.

MR. BYRON: Hold on just a minute. What'd you say about Midway Park? It was off the base?

MS. RUCKART: Part of Midway Park is off base and part is on base, and we've had -- Frank and I did an extensive effort to identify exactly where the mother lived during every month of her pregnancy and the first year of the child's life and a few months before the pregnancy. And in doing that, we found out that part of Midway Park is actually off base and part is

on base, and there's a way it's listed that lets you know which is the case. So anyway, and then, like I said there are six cases --

MR. PARTAIN: Well, hold on, Perri, a second. When you're talking about Midway Park, when you say off base, on base, for purposes of clarification, Midway Park is identified --

MR. ENSMINGER: Hey, let me clarify that because I'm right down here in the area. Midway Park housing area, which is the military housing area, is part of the base. However, there is also a Midway Park civilian -- they have a civilian post office.

(Dog barking.)

MR. STALLARD: Can you translate that for us, Jerry?

MR. ENSMINGER: Midway Park -- whose dog is that, damn it?

MR. STALLARD: I thought it was yours but that's a good reminder.

MR. ENSMINGER: No. Hell no. Somebody needs to mute their phone.

MR. STALLARD: Yes, I would say so.

MR. ENSMINGER: But anyhow, Midway Park has a post office. It is a civilian -- there's a civilian Midway Park is what I'm trying to explain. Okay. Go

ahead, Perri, I'm sorry.

MS. RUCKART: That's okay. So my point is we were able to determine who was in that park and who was actually on base.

And then there were six births defects or childhood cancers that were reported, six conditions where we couldn't get medical records confirmation one way or the other, and those we are including in our sensitivity analyses, I'll explain to you in a minute what that means. So anyway, my point of showing you this is to show you how the 52 cases breaks down, the 52 that the main analyses focused on, and you can see which specific subtype of defect they have, and the other six, you know, where they would fall in there as well.

MS. BLAKELY: Do you have their names?

MS. RUCKART: Well, we have their names but we can't release them. Did you have something, Mike?

MR. STALLARD: Moving on.

MS. RUCKART: So this is some new information that I wanted to share with you. And this gets into what we were talking about before, about how we have information on those who were born on base, we have their birth certificate; and information on those who were born off base. They were identified from a

referral process.

So as you can see more controls were born on base than the cases. And more cases were identified through the word of mouths, the referrals, they were self-selected. So we will use this information to evaluate selection bias in our sensitivity analyses. We'll see if the fact that more cases were identified through word of mouth than the controlled biases the results, meaning change it for -- masking a relationship or changing it.

Okay, this is also some new information I want to share with you. It was collected during the interviews in 2005. This table shows some of the potential risk factors that we will consider in the analyses because these risk factors showed some association with the birth defects or cancer independent of the exposure. And these are maternal age, maternal education, child had a sibling with the birth defect and father smoked around the time of conception.

MR. BYRON: Pardon me, what does education level have to do with exposure to chemical releases?

MS. RUCKART: It has nothing to do with exposure. These are risk factors that are shown to be linked or, you know, have some association with these conditions

independent of the exposure, having nothing to do with the exposure, these are some potential risk factors that may influence the relationship because they appear to have some relationship with these conditions. So we put them in our model, meaning we consider the exposure, and then we say, well, maybe the maternal age is also impacting it. Let's look at both exposure and age and see what we get when we do that, how does it change just when we have -- just the exposure in the outcome.

DR. AKERS: Perri, let me ask you a question. Do you have a group of individuals that are both control and cases, where all those factors are the same except for the exposure?

MS. RUCKART: Well, that's what I'm showing you here. We asked a lot of questions in the survey based on what the literature has shown to, you know, potentially be affiliated with these birth defects. So out of a whole series that we have, this slide and the next slide, which I'll get to in a minute, show the potential risk factors where maybe there is a difference, and that's why we want to investigate it further. If they were the same, then it wouldn't add any information.

DR. AKERS: The additional conditions you've

mentioned are known risk factors to neural tube defects: age, education, exposure to cigarette smoking, what have you. So what I'm asking is: Is there a control group that has those same risk factors as a case group, except for exposure to chemicals?

DR. BOVE: We did not match. What we do is instead we test for it in the models. That's how we test for it, for possible confoundings.

DR. AKERS: Well, that would, seems to me it would be plainer if you could have a control and a case group where everything was the same except for the exposure to the --

DR. BOVE: That's not necessary. You can adjust for it in the models.

DR. AKERS: We'll see.

DR. BOVE: No, no, you can. But the actual -- the issue is this. I mean, there will not be any problem. They could be very different in these risk factors as long as the risk factor isn't related to the exposure itself. If the risk factor is not related to the exposure, it won't affect the outcome at all. But those two things have to happen. There has to be a risk factor first of all, which these are well-known, except for smoking and neural tube defects, it's stronger for clefts actually.

MS. RUCKART: Frank, let me just add these, when I have these up here, these are for all the case groups. I'm not saying that all of these are for each outcome. These are -- I am just showing you some aggregate. All of these cannot be looked at. First of all we have some small numbers that we can get into, but this is just giving you some sense. I am not saying that all of these are going to be considered for each outcome, just to make that point clear.

DR. AKERS: But there are known risk factors with the neural tube defects among other birth defects.

MS. RUCKART: Some of the ones I'm showing you, and as Frank said, some of them are for the cancers and some are for the clefts, and I can move on to the next slide after Dr. Portier interjects.

DR. PORTIER: I just get a feeling Jeff feels he didn't get his question answered.

MR. BYRON: No, no, no.

DR. PORTIER: And I want to make sure Jeff got his question answered and he's happy with the answer. Jeff, what happens in these types of studies is you go and look at the literature, the scientific literature that's out there. You find everything that people have already found that appear to be associated with

this disease. Then when you go and do your analysis, you want to make sure that those things aren't also associated with the people who are exposed versus those who are not, 'cause if it is, then the effect might be due to that thing and not the exposure. So you make sure you correct for all these other things before you look for the effect of the exposure.

In the case of maternal education, it's probably a surrogate for socio-economic status, and that is likely associated because of nutritional differences, because of other things in socio-economic status that play a role.

MR. BYRON: Okay. That clears it up.

MS. RUCKART: Okay, so let me show you the next slide I have, just some additional risk factors. Again, this is for the group, not necessarily for each specific -- or for all of the defects or cancers.

MR. BYRON: Can you go back one? I need to see one thing.

MS. RUCKART: What's that?

MR. BYRON: Child siblings have birth defects. Was that not calculated or did you look at that and it's zero?

MS. RUCKART: I don't know what you mean. I'm showing here --

MR. BYRON: Child siblings have birth defects.

MS. RUCKART: Right, yes or no.

MR. BYRON: I don't see anything in that column.

MS. RUCKART: No, child sibling has birth defect, yes/no.

MR. BYRON: Oh, I'm sorry, I'm sorry.

MS. RUCKART: It's just like a header.

MR. BYRON: Look a little further down, huh.

MS. RUCKART: Okay. But these are just some of the additional things that we're going to be considering for some of these conditions.

First of all, are there any questions before we move on, about the birth defect study? I do want to add that I am fast and furiously analyzing that data. I'm very, very far along, so as Jeff has mentioned, it's taken us a very long time to get to this point but I am very, very close to having a final draft report to start our clearance process, very, very close.

Just doing -- there's a lot of just sensitivity analyses, just things that I'm checking just to make sure I'm not leaving any stone unturned but I would say it's like 99 percent, 95 percent ready to start the clearance process. So any questions about the study before we move on?

MR. ENSMINGER: Yeah, is ATSDR going to make any type of strong conclusions about the findings of this report or are you just going to throw the blanket statistically insignificant on it and move on?

MS. RUCKART: I'm going to submit a report for clearance. And I can't say what'll happen at that point but I will let Steve say. Oh, I'm sorry, you looked like you wanted to say something.

DR. DEARWENT: I was just going to say we will interpret it like we do any other study. I think there's no effort to whitewash or, you know, minimize or maximize it. We will, you know, interpret it as the results indicate. And we're actually working with -- I've got some internal oversight, working with a couple of professors over at Emory, Kyle Steenland and Dana Flanders, who are, you know, kind of looking over Perri and Frank and my collective shoulders to make sure things are being done correctly and interpretation isn't overly strong in one way or another.

MR. STALLARD: Jeff?

DR. PORTIER: Jeff had a whole bunch of questions.

MR. STALLARD: Hold on just a minute, Jerry, we have a speaker.

DR. PORTIER: Jeff had a whole bunch of questions about providing him preliminary findings from the study before we get it through clearance and put it into final say.

Again, we have the responsibility to make sure we say it exactly right when we say it. I'm going to ask Dick to comment on this, being a scientist, to publish his papers. It's quite common for scientists to be very reticent to release anything before the final report is written, for a lot of reasons. But in our case, it's we want to say it exactly right. We want to make sure it's in proper context.

DR. CLAPP: Well, if that was a question for me, you know, it's true that scientists have, sort of, conventions as to how things are stated, and I'm sure that ATSDR and Drs. Steenland and Flanders will apply those conventions.

There's still broad data in tables sometimes that a person looking at the article can say, well, I don't actually agree with the way they wrote this up but I think the data themselves say this. So there will be places where there might be differences in interpretation, but again, I think the scientists that I'm familiar with, some of whom are sitting here in this room and some of whom were just mentioned, are

top quality and will do the job as it's best done, given our scientific conventions.

MR. STALLARD: Thank you. Let's move on.

MR. PARTAIN: And what -- all right, Dr. Portier, what is the anticipated release date for the in utero report out? I know some of this we've already talked about, but for the record.

MR. ENSMINGER: When the water model comes out, Mike.

DR. PORTIER: They should coexist in space pretty closely, in space and time. I've given the program a drop-dead date where they'd better have it to me by a certain date. But again, because clearance for this type of document is going to be -- people are going to scrutinize it very carefully, I can't give you an exact date. I'm hoping well before the end of the year.

DR. DEARWENT: This is Steve. I think in our recent congressional briefing, we indicated the water model out at the end of 2012, and at least the two epi studies of birth defects and mortality at the start of the second quarter in FY '13, so right at the turn of the calendar year.

MS. RUCKART: I want to assure you that I have every intention of meeting that deadline, and I am

very far along, and I've been waking up at five in the in the morning thinking about extra things I want to do to this data. I am leaving no stone unturned. And as Steve said, we've been meeting with Kyle and Dana, and we just met with them Wednesday. They suggested something I have not heard of and ^, you are not familiar with it.

But anyway we are really looking at it. We don't want to -- I mean, my personal feeling is, I mean, it's going to be reviewed, and when you give it to someone to review, people always make comments, but I don't want to feel like a deer in headlights. I want to say, yes, I have looked at that; yes, I have considered that. I mean, I can't even imagine at this point what somebody could say. I mean, I'm sure they will but my point is just to tell you, I am thoroughly looking at this. I am very far along. I am totally expecting to meet deadlines barring any catastrophic occurrence so please, please know we are working just so diligently on this. I don't know what else to say.

DR. DEARWENT: This is Steve. Just to give a little insight into, for you guys, in our last couple meetings that we've had with Drs. Steenland and Flanders, I think one of the biggest points of, not contention, but discussion is which tables to submit

for publication, 'cause at this point Perri's probably created a hundred --

MS. RUCKART: Five hundred. No, no, five hundred.

DR. DEARWENT: And so, you know, she's looked at it many ways but at some point we have to distill it down to what is the most cogent to present both to the lay community and the scientific community.

MR. STALLARD: All right. Thanks.

MS. RUCKART: And I have done that.

MR. STALLARD: With so much discussion about deadlines and drop-dead dates, are we ready to talk about mortalities?

MORTALITY STUDY

MS. RUCKART: What a segue. See, we kind of make the meetings while serious also lighthearted. But seriously anyway.

So as you know we're conducting the mortality study, and again, I just want to remind everybody again, so we're all on the same page, who is included in that study. We had information from the Defense Manpower Data Center, DMDC. This is data that identified people systematically. This is from the military records that started in the second quarter of 1975, unfortunately they didn't have electronic data

before then, and we go through December '85. That is 153,131 Marines or Navy personnel at Camp Lejeune, and we also have the caveat they started active duty on or after April '75 so that we know where they were. You know, that we wouldn't miss somebody being at Lejeune before that 'cause, you know, we wouldn't know.

And then that also includes 4,713 civilian employees. The DMDC had data a little earlier for them, starting a year before. And we also have comparison populations from Camp Pendleton.

So I did report this last time but I just wanted to share this with you again. From 1979 to 2008, recall that we started our follow-up in 1979 because we were using deaths identified from the National Death Index, and that's when they start. And 2008 was the last year of the complete data – by the time when we finished collecting all of our data. And there were 18,818 deaths, that's for both Camp Lejeune and Camp Pendleton, former active duty combined. And as the slide shows, 2,180 deaths were due to cancer as the underlying cause. When you consider underlying or contributing cause, we have 2,317, and there were 16,638 deaths with other conditions listed as their underlying cause.

And for the mortality study we are going to be

looking at cancers specifically, individually and, you know, the certain diseases that we discussed before.

And this basically just shows you the same information for the civilians, 1,413 deaths, that's in both Pendleton and Lejeune, and you can see up there the cancers and the other deaths. Frank, did you want to say more about what you're doing with the mortality study and where you are in that process?

DR. BOVE: Hopefully I won't drop dead but there has been a lot of work that was required for this study that we probably didn't anticipate when we started. The DMDC data was not in as good a shape as we thought it was. The ability to match between the Marine Corps information from the DMDC data, the personnel information, and the family housing records was difficult, more difficult than -- well, we knew it was going to be difficult because we asked the DMDC to do this several years ago and they threw their hands up and said it was impossible.

We had our contractor to make at least three attempts using different kinds of probability matching, because what you -- the way you have to match here is that you have only -- in the family housing records, all you have is full name, which could be misspellings; you have rank and you have the

time period they're in the house and that's it, okay. So you can't match on Social Security Number, which would have been a breeze. You have to match on name pretty much.

And Westat, our contractor, did match on, they tried to incorporate the period of time they were there and to a much lesser extent, used rank, 'cause they had some difficulties using the rank variable from the DMDC data.

So after the third attempt, I thought that it would require, in addition to this kind of probability matching, it would be good to try to match as many people as possible by hand at Tarawa Terrace in particular, because that's, during the time period we're talking about, which is for those people who started active duty in '75, or any time after that up to '85, Tarawa Terrace is the key family housing unit that's being exposed at that point.

So I took it upon myself to do a hand-to-hand match as well, to try to match as many as I could, and I think I was able to match about 90 percent of people at Tarawa Terrace. And the reason I couldn't match some was that, the reason of -- one of the ways we -- this data set was created was the DMDC itself and the Marine Corps, I tried to identify those units that

were stationed at Camp Lejeune and those stationed at Camp Pendleton. Apparently they had to do a historical research to come up with a unit list. They had done it once before, in fact, a couple years ago, made mistakes, and this was the second attempt, from what I understand.

But they still made some mistakes because I found some people at Tarawa Terrace housing, most of them in the Navy, that were not in the DMDC databases that we have at all.

So, and we also found from the survey, which Perri will talk later, that some people have said, we thought that we were stationed there at Camp Lejeune, told us in the survey that they were never at the base. So there are some mistakes, not -- I think that for the most part, this is a good data set. I mean, and it's a large data set, but there are some mistakes. Okay.

So I think it took me at least two months to review some two-, 3,000 records by hand. And that was in addition to about 2,000 that I had done before, earlier on. So it's taken longer to do this study than we thought.

But I'm furiously analyzing the data as we speak, and hope to meet the deadline, which is to try to have

a draft report ready for clearance sometime in September. So that's -- now, I could go into how I'm going to analyze it if you're interested in different approaches; that's up to you. But that's basically what's going on with mortality study. We're looking at it, again, similarly as the case control study for birth defects. We're looking at it in various different ways, taking into account different latency periods for the cancers and the chronic diseases. We're looking at, as Perri said, individual cancers as well as groupings -- like a grouping of what we call hematopoietic cancers, which is leukemia and non-Hodgkin's lymphoma, Hodgkin's disease and multiple myeloma; and also looking at diseases such as cardiovascular disease, ALS; I don't think we can look at Parkinson's because we have so few; and male breast cancer, we have so few. And cervical cancer is another one where we have so few because they're in -- among the Marines, I think are there are about 8,000 women and the number of cervical cancers is not large. But we'll look at it if we can, okay? And as well as female breast cancer. And kidney and liver diseases besides the cancers.

MS. BLAKELY: What about lung cancer?

DR. BOVE: Lung cancer is part of the cancers,

yeah. Oh, yeah. Oh, definitely.

MR. PARTAIN: Frank, how many male breast cancers did you come up with?

DR. BOVE: I'm trying to remember 'cause I -- there are some at Pendleton and -- I think there are less than five during this period for this group. If you take into account all of the cohort, which includes people who started before '75, and include -- and also including Pendleton in that, too, there may be a few more than that. But there really is very few.

Well, we thought -- we knew this going in. I anticipated somewhere between two and three male breast cancers at Lejeune who started in '75 to '85, and that's basically what we're finding, roughly about that much. So I knew the mortality study was not the study to look at male breast cancer.

MR. PARTAIN: Yeah, 'cause typically you don't need breasts to survive.

DR. BOVE: One of the issues about this and is that it is a young cohort. They're all younger or most -- almost all of them are younger than me. And so, you know, and so -- but seriously, you know, the good thing about this study is that there are large numbers of people to study. The bad thing is that

they are young. And so, you know, if it was an older population you'd see more Parkinson's, for example, than we're seeing.

There was some confusion, actually, among our experts that said why are you seeing more ALS than Parkinson's? It should be the other way around. That's true if you're looking at an older cohort but it's not true with this -- with a younger cohort. And so Parkinson's is going to be -- it's pretty much not going to be able to be evaluated in the mortality study because we have one or two or three.

MR. PARTAIN: Well, there's also significance, too, you bring up the younger cohort of age and diagnosis with male breast cancer. It's typically not found in young men. It's typically found in men 70 years of age.

DR. BOVE: That's right. That's why I anticipated two or three in this cohort back then.

MR. PARTAIN: 'Cause it's five out of 153,000. That's --

DR. BOVE: It's very small -- well, that's including Pendleton and all.

MR. PARTAIN: Okay.

MR. STALLARD: Mary has a question.

MS. BLAKELY: Have you looked at how many died of

suicide?

DR. BOVE: I haven't been focusing on trauma or suicide. On the other hand the program that I'm using kicks it out for all causes, so you could look at suicide; you could look at trauma as well.

MS. BLAKELY: Well, the reason I ask is because of the neurological aspect of suicide, you know, could be because of that.

DR. AKERS: Is there any information on individuals who may have been stationed both places during this time period?

DR. BOVE: Yeah, yeah, yeah.

DR. AKERS: Which category are they going to fall under? In other words --

DR. BOVE: Lejeune trumps. Lejeune trumps.

DR. AKERS: Lejeune trumps, so if you were at Lejeune and then were transferred to Pendleton but were diagnosed at Pendleton --

DR. BOVE: Doesn't matter where you're diagnosed. The DMDC data tells me -- well, whether you were at Pendleton or Lejeune or both places, again, based on the unit you're in, and that's how the research was done. There are quite a number of people who were at both bases, they’re trying to say about 20 percent, something around that. And so I take into account

when they're at Lejeune and also when they are at Pendleton in the analysis. It's a complicated process that I can talk to you offline, or if you're really interested, I can go into it.

MS. RUCKART: I didn't add this when we were talking about who was in the mortality study 'cause I was just trying to get to the new stuff, but to be in the comparison population at Camp Pendleton, that means you were only at Camp Pendleton and not at Lejeune, and that's why we started with -- so the people who were there from April '75 to the end of 1985, but they had to start on or after April '75 so they wouldn't have somebody showing up as Pendleton but they started before and they were at Lejeune. So we know if they were at Pendleton in April '75 or later, they were not at Lejeune before that. So that that Camp Pendleton group can be -- we can be sure that they were not at Camp Lejeune, just at Pendleton or elsewhere, but not Lejeune.

DR. AKERS: So they're purer samples then.

MS. RUCKART: Okay. If there's no more questions about the mortality study, we can go on or if you think of them later.

MS. BLAKELY: I have one. So is this study complete then or you're just giving us an update?

DR. BOVE: Yeah, we're just giving you an update. I'm analyzing data right now.

MS. BLAKELY: Well, can I request that you look at suicide?

DR. BOVE: I'll do that.

MS. BLAKELY: Okay.

MS. RUCKART: See, this is why we talk to you when we're in progress.

ADVERSE PREGNANCY OUTCOMES

MS. RUCKART: Okay, so this is the study that I was talking about before the first study in ^ on the adverse pregnancy outcomes, these are the 12,498 or so births that we had birth certificates from, parents lived on base. And this study evaluated potential maternal exposure to the contaminated drinking water in preterm births, small for gestational age and mean birth weight. Now, of course we didn't have our water modeling data at that time so it was just based on you lived in an exposed housing area, you were considered exposed; if you lived in an area that was not exposed you were not exposed.

But since that time we found out that births before 1972 at Holcomb Boulevard were incorrectly classified as unexposed, and this makes a big difference and I'll show you that in a minute. And

we're also going to reanalyze this data because, as I mentioned, this just used the crude, yes/no exposure based on your housing area, but now that we are going to have -- or we have the water modeling data, we're going to be doing a more specific analysis of their levels of contamination. So.

So this shows you how the people changed from the previous analysis in 1998 to the current analysis considering we know what happened at Holcomb Boulevard. So based on this new exposure information, about 1,200 fewer people were categorized as unexposed, so you can see previously there are over 5,700 considered unexposed, and that drops down to 4,530. So where do those people go? They mainly get added to the TCE exposed group. So it goes from 31 to 1,342. There was a couple -- I mentioned 1,200 births moved, roughly, but we have more than 1,200 additional births from TCE because upon further checking, some other people at Tarawa Terrace got moved slightly.

Anyway, the right-hand column shows our numbers and, given that we're going to have so many more births for TCE, that'll give us a lot more power to find something. And so we can evaluate it, you know, a lot more thoroughly at this point. Now, as far as our timeline, as you know, we're very, very focused on

the birth defects study and the mortality study, so we will be analyzing -- they're a high priority and this is our third priority. So once I finish the birth defects study, childhood cancer study, shortly, I will begin analyzing this, and then Frank will start analyzing this as well when he finishes up with the mortality study. Any questions about this one?

DR. CLAPP: I have a question about -- this is a published study that you're going to -- will you submit this to the same journal as the update? Is that the plan?

MS. RUCKART: I'm not sure what journal that was in. Do you know, Frank? Well, we had talked about submitting these three, the birth defects/childhood cancer, mortality study and the adverse reproductive outcomes as a package to Environmental Health Perspectives. I'm not really sure at this point where it will go, but that's our current thinking, it will be good to have a package.

MR. BYRON: Yeah, hi, this is Jeff. The two weeks for the shutdown at Holcomb Boulevard plant, didn't we dispel that by saying that -- didn't we find out that they were watering the base golf courses and that the valves were being open?

DR. BOVE: Actually I was going to say something

but since you're bringing this up. These numbers will change because some of the people who are unexposed during entire pregnancy, nonetheless might have been exposed for a month or two or three during the summer months at Holcomb Boulevard, so -- and since we analyze this data by trimester, I do anyway, I would take that into account. So that 4,530 -- I mean, these numbers will change. The key message of this chart is that there's a substantial shift where we couldn't really not look at trichloroethylene exposure in the previous study because we only had 31 births we thought were exposed to trichloroethylene with any levels to speak of. And so now, that's drastically changed so it's a different study now.

MR. BYRON: I'm going to go back a little bit, okay, 'cause now that I've seen this. So my daughter Andrea had aplastic anemia. Is that one of the hematological diseases? Is that outside of the in utero study? That would be outside of the leukemia end of it?

DR. BOVE: Yeah.

MR. BYRON: So that would have nothing -- then we'll drop that.

DR. BOVE: No, but I am looking at aplastic anemia in the mortality study and we also ask about it

in the survey, yeah. So we are in the larger health survey.

MR. BYRON: Okay. I'll talk to you after.

DR. BOVE: Yeah.

HEALTH SURVEY

MS. RUCKART: Okay, so moving on to the health survey, I want to tell you that in June of this year we mailed out the additional about 58,000 surveys to the registrants who registered with the Marine Corps by June 30th of last year. So far about 11,000 have been returned, that's 18 percent, so that's some good news. Jeff, you know what I'm talking about?

MR. BYRON: I was hoping it would be more.

MS. RUCKART: Okay. I wondered if you had a question. So right now we're beginning the process of confirming the diseases that were reported in the health survey that we're interested in following up on by getting medical records or confirmations from cancer registries.

And so we're trying to confirm 5,777 cancers and 14,315 other diseases. This is a total of 20,092 conditions in 15,058 people, keeping in mind this includes the Camp Lejeune and Camp Pendleton. And I can let, if anyone would like me to, I can let you know specifically which conditions we're following

up on. Anyone? Yeah? All right.

So the cancers include bladder, brain, breast, cervical, colon, esophagus, kidney, leukemia, liver, lung, lymphoma, multiple myeloma, pancreatic, rectal, small intestine and soft tissue. And the other diseases include kidney disease, liver disease, lupus, scleroderma, Parkinson's disease, MS, ALS, aplastic anemia, persistent skin rash with hepatitis, infertility, and endometriosis. We're also going to be looking at miscarriage but we're not going to be seeking medical confirmation for that.

MR. ENSMINGER: Hey, Perri, what about Parkinson's?

MS. RUCKART: I said that. Yes, yes. Yes, we're going to be looking at that. As Frank mentioned, he can't really evaluate that in the mortality study but we will be looking at that in the health survey. We are seeking confirmations, medical confirmations for that. Do you have a question, Mary?

MS. BLAKELY: Yeah, maybe Richard could help me with this one. What other diseases from a neurological aspect would cause somebody to die, that we could ask them to look at?

DR. CLAPP: I think they're all on her list. Yeah, I can't think of any that she just read that

should be included that weren't there.

MR. PARTAIN: Perri, do you have this in paper form to give out to us? I hadn't looked through it.

MS. RUCKART: I didn't give this out but I have to find out from Dr. Portier if this -- you mean the presentation or of the cancer --

MR. PARTAIN: Yeah, the numbers that you read.

MS. RUCKART: Well, is this something I can email out, the numbers of diseases we're following up on?

DR. PORTIER: Just the general demographics that we saw this many of this and this many of that, I don't see why not.

MS. RUCKART: Just the total number of cancers and total number of diseases among both Lejeune and Pendleton?

DR. PORTIER: Sure.

MR. BYRON: I've got one question, too. It just hit me. Has there been any diagnosed cases of toxic shock syndrome as far as the deaths are concerned? Have you looked at that as far as being a cause?

DR. BOVE: No, I don't even know if there's an ICD code for that. No, I can't look at -- we can't look at that. No, I just -- we just don't have -- our -- there's no code for that as far as I know, and our source of information on cause of death would be

death certificate information that is at the National Death Index, and they wouldn't have coded that so we wouldn't have that information.

So if -- but we're able to look at a wide range of diseases here, including -- as we're not just looking at underlying, we're looking at contributory causes. So if someone died of that, there may have been a contributory cause that we would pick up.

DR. CLAPP: Again, I don't think there's a code for that. It might be called septicemia but it wouldn't be specific to toxic shock.

MR. BYRON: But you can clearly die from it, right?

DR. BOVE: Yeah.

DR. CLAPP: Sure.

DR. BOVE: Yeah, yeah. I -- there are 119 disease classifications in this program I use. It's NIOSH's, National Institute of Occupational Safety and Health's program to look at comparing the exposed population, or any population, with the U.S. population, okay? And so you -- so I can look at 119 categories of different causes of death, yeah.

MR. STALLARD: So Perri, would you take us through the last few slides?

MS. RUCKART: Sure. This is all review so we can

go through this quickly. But I just want to remind you that health surveys were mailed to 283,972 study participants or their next of kin. The overall response rate was 27 percent, that's 76,026 surveys. Now we had to have a data collection endpoint so that we can move forward so this is as of the middle of February this year.

Now, the former civilian employees from both bases have higher response rates than the former active duty.

MR. PARTAIN: Hey, Perri, I forgot to ask you, on the diseases and reports you got back, anything about thyroid conditions and thyroid cancers, thyroid problems, anything showing up? 'Cause I know we get -- we hear a lot about it.

MS. RUCKART: You know, with those health survey data, we're just really at the beginning stages. We haven't analyzed that or really looked at that. We're typically focusing on the other studies.

MR. PARTAIN: Okay. I thought that's what you were reporting from?

MS. RUCKART: No, I was -- this is what the contractor told me, the conditions that they're following up on, based on what we've seen -- it was like a collaborated effort. This is what's reported

based on what we had in the survey, you know, because specifically indicate they had. And then we went through that and decided which ones we're going to follow up on. And when we're more likely to see something if there is something.

DR. DAVIS: And to take the example of thyroid, there are many different factors that are suspected of playing a role there. And you're not going to be able to look at all of those as well, so I'm not sure how -- what one can do with it.

DR. BOVE: We had a list of diseases that, for the survey, that we, after a literature review, we thought had some evidence. Didn't have to be strong evidence, some evidence of an association with solvent exposure; it didn't have to be just TCE or PCE; it can be pretty much any solvent. In an occupational setting where most of these studies are done, and also from drinking water studies. And thyroid cancer isn't one of those. I can, of course, look at thyroid cancer in the mortality study. Just, it's one of those 119 conditions, but as far as I know there hasn't been any research linking thyroid cancer to solvent exposure.

DR. DAVIS: That's correct. What I was going to raise, which I know is a methodological nightmare, is

the following. While there is not much evidence on thyroid cancer and solvent exposure, there is some evidence on other common military exposures.

(multiple speakers)

DR. DAVIS: There's no way we're going to be able to deal with that.

DR. BOVE: Right.

MR. PARTAIN: Well, my point in bringing it up is, like I said, we get a lot of reports and we've had numerous families contacting us with thyroid problems, and including thyroid cancer. And, you know, I guess we just need to ask the question, is there something out there? And, you know, if the data's there and it's been reported, you know, are we going to ignore the, you know, the reports and just focus on what you're saying there. I guess my question would be: If there is a presence of an abnormal number of people with thyroid cancers at Camp Lejeune, is that going to prompt ATSDR to ask the question why?

DR. BOVE: Well, again, I mean, I can look at it in the mortality study to the extent that it's worth looking at. I mean, thyroid cancer is another one that doesn't necessarily kill you. But, you know, I can look at it in the mortality study.

As for the survey, we ask for all -- any cancer

the person might have. And we're going to check with the cancer registries to confirm those. Again, we have a list of ones we're primarily concerned with because there, you know, there's some evidence that thyroid cancer is among those candidates, but again, if a person reported it we could send that to the cancer registry as well.

MR. PARTAIN: And I'll just point out real quick, one of our former CAP members, Denita McCall, was a parathyroid cancer survivor, and I don't know if her passing is part of the database that's being collected on the mortality study. She passed in June of 2009.

MS. RUCKART: No. It only goes up to 2008.

MR. STALLARD: Yes, Dr. Portier?

DR. PORTIER: Yeah, so Mike, when you do these types of studies, one of the reasons you search the literature in advance and decide what you're going to look for, specifically, is it gives stronger confidence that you found something real. Because you've laid out the hypothesis before doing the study, you're not fishing for something new. You're actually trying to strengthen evidence that already exists. So that's what they have done to this point.

However, you can also do some fishing as a separate issue of this type of thing. And they will,

and if they see something, then we will try to go after the necessary resources to validate the whatever it is and bring it back into the study. But it will have less strength to it because there will be no other literature supporting it. Okay?

MR. PARTAIN: I just want to make sure that if something's there or seeing that we're asking that question. We don't want to leave the white elephant sitting in the corner of the room there.

DR. DAVIS: And I just want to add a comment to what Dr. Portier just said. It seems that we're -- the study is largely a study of solvents and their effects on health, and not other military exposures. And I just think if that is the case, we need to make that clear because thyroid cancer doesn't usually kill people, and so it would be unlikely to show up in the mortality study; it may show up in the survey. And it has, you know, many different potential causes including x-rays have been associated with it, diagnostic x-rays for example or therapeutic x-rays. So we're not able to evaluate all of these different things, which may have occurred in greater exposures to the military population. And it seems as if the study is increasingly a study of solvent effects and not on other things at all. And that is correct --

I'm asking the question -- is that correct?

DR. DEARWENT: Absolutely. It is only about solvent exposure.

MS. RUCKART: Drinking water, drinking water.

DR. BOVE: These particular drinking water contaminants.

MR. STALLARD: Okay, Perri.

MS. RUCKART: Just, just very briefly, this is not new information so I don't think we can spend a lot of time on it. I presented this last time, the participation rates and the overall of 27 percent. There's another way you could think about this, the cooperation rate. I mean, this number, 27 percent, is just we mailed out this many surveys, we got this many back, we calculate, you know, it was 27 percent.

But then you have to keep in mind that we know that not all the surveys actually got to the intended person even though we tried to find a good address for everybody. Maybe it didn't work out or the person never opens it or there's all kinds of reasons that when you factor in all these reasons, and we do have some information about which ones couldn't be delivered and things like that, the cooperation rate, which it's called, could be as high as 37 percent, and we can discuss that when we get to that point of

writing up the study.

DR. AKERS: I'd like to add something to what Dr. Davis mentioned, the therapeutic and diagnostic x-rays. There was a common practice in medicine years ago that acne was treated with x-ray, especially acne on the chest and face, this sort of thing. So we were in essence exposing our patients to levels of radiation that they didn't need but it was at that time a common medical practice.

MS. RUCKART: And also on the refusals, just want to let you know that we do have some information on people who actively refused. In the second survey mailing, we included a postcard for people to indicate why they didn't want to participate, if they didn't plan to. So those are called active refusals. Many of the people who just never responded at all, we know they're a refusal, but for those that we actually could find out the reasons for not wanting to participate, these are the codes from the first 901 postcards we received. About a third didn't have any health problems; a third didn't want to provide personal information; 21 percent: waste of government money; 10 percent: it would take too much time and effort; and 7 percent: didn't think the survey was important. That just gives you a snapshot of the

reasons for refusal. That's all I wanted to update you on.

MR. STALLARD: All right. We're about ready to eat into your lunch period.

MR. BYRON: Okay, I'm going to ask one question. I hate to keep running back to Midway Park but I got concerns. Because I'd like to know from you guys right now, were any children excluded that were in Midway Park that were in the in utero study because you did not know about the contamination until about a year and a half ago?

MS. RUCKART: No, no.

MR. STALLARD: Okay, then. That concludes our morning session. We're going to go to a lunch break now and we will start at 1:00 o'clock with the male breast cancer update. Please be back and seated, ready to go or be back on the phone for 1:00 o'clock. Thank you.

(Lunch recess, 11:54 a.m. until 1:00 p.m.)

MR. STALLARD: All right, folks, please take your seats; we're about to commence.

Okay, may I remind you of our guiding principles. Thank you so much for your willingness to support those in our endeavors thus far. I remind you to please turn off your cell phones or put them on stun,

if you have used them during the break.

And as promised, at 1:00 o'clock, we're now going to get into our male breast cancer. Yes?

DR. PORTIER: Just very quickly, I wanted to address Mike's question to me. Mike, the answer's yes.

MR. PARTAIN: Okay.

MR. STALLARD: Wait, what was the question?

DR. PORTIER: The question Mike asked was whether or not we would give the CAP a copy of any of our reports at the same time we bring them over to the DON, and the answer is yes.

MR. PARTAIN: Thank you very much.

MR. ENSMINGER: What was that?

MR. STALLARD: The answer was yes. To what question?

MR. ENSMINGER: Yeah.

DR. PORTIER: I'll repeat it, Jerry. Mike had asked if we would be willing to give the CAP copies of any of our reports at the same time we gave them to the DON, and the answer to that is yes, they will be embargoed so you won't be able to share them with anyone else but it will give you time to read them and understand them prior to our final release of those documents. And that way, if there are questions to

you, you'll be prepared to be able to answer them. Seems appropriate to us.

MR. ENSMINGER: Yeah, because I noticed in the MOU that, under the guide or the rules of the MOU, you've got to provide them your draft reports, and they have the opportunity to comment.

DR. PORTIER: Actually what it says in the MOU is when appropriate, we would do that. And in this case I have deemed that providing them a draft copy to comment prior to release of the document would not be appropriate; hence, we will not be doing that, but we will be working with them to provide them --

MR. ENSMINGER: Oh, oh, good.

DR. PORTIER: -- with the document in advance of our release, so they are well aware of what is in the document.

MR. ENSMINGER: Well, okay. Well, I applaud your decision that it's not appropriate. Thank you.

MR. STALLARD: All right. Whom do we have on the line, please? Besides Jerry?

MS. BRIDGES: Sandy Bridges.

MR. STALLARD: Hello, Sandy. Welcome back.

MS. BRIDGES: I'm sorry I couldn't be there.

MR. STALLARD: Well, it's hot and sweltering here so enjoy where you're at. All right, then Steve, if

you're ready --

MS. BRIDGES: I know it's hot. I was surprised to see Jeff's hair. He's as gray...

MR. STALLARD: Yeah, he's as handsome as ever. Thank you for pointing that out. May I remind you please, those on the phones, to put your phones on mute when you're not speaking. Thank you. Steve?

MR. ENSMINGER: Yeah, well, you know it must be hot and sultry down there but I'll bet it's not over at the pool there in the hotel, huh?

MR. STALLARD: No comment.

MR. ENSMINGER: And I have a question. If Partain went in the pool, is there any water left in it?

MR. STALLARD: He did a cannon ball, and they're refilling the pool.

UPDATES ON MALE BREAST CANCER STUDY

DR. DEARWENT: Boy, that's a tough act to follow. Okay. So I'm going to discuss the male breast cancer study today and updates.

Before I do, though, I'd like to introduce myself, since this is -- I'm new to the table, I guess. I observed at the April 2nd meeting and it's my first time to actively be involved in the CAP. I'm Steve Dearwent, I'm Chief of the Environmental

Epidemiology Branch. As many of you know, we have or still are undergoing a reorganization. It's not, you know, finalized yet but as part of that reorganization, the entire portfolio of Lejeune epidemiologic work was transitioned into our branch. So we're now working with Perri and Frank and Eddie, and this is, I guess, my first time to officially participate. So nice to meet you guys.

So first of all, I know we briefly discussed the male breast cancer study at the last meeting and didn't have a lot of substance to update you on. I think we have more substance this time around. So it'll be a little bit lengthier and more in-depth presentation. So for today's discussion, first of all, going to revisit some of the things that Eddie Shanley discussed at the April meeting, and then give you an update on what's occurred in the last three to four months in terms of the NPRC assessment, where Eddie Shanley went to St. Louis for almost a full week in late May to look at a subset of those records, assess if this was going to be a feasible study or not. And then also I'm going to give you an update on our study protocol. And then following those updates, we'll go in and do an overview of the proposed study protocol and then provide you with a list of next

steps.

Just to go back to the last CAP meeting in April, Eddie talked about breast cancer cases that were reported to the VA, to their central cancer registry; that is the source of all cases and controls for this study. Currently the VA cancer registry is indicating they have 61 male breast cancer cases. That's from the start-up of the VA registry, which was in 1995 through the end of calendar year 2010. That is the current number that they've given us but our qualification is that that, for study purposes, is an estimate right now.

First of all, there will be, you know, inclusionary, exclusionary criteria so some of those cases may fall out because they don't meet the inclusionary criteria. There may also be additional cases that are, that are added to this that just haven't, you know, weren't collected in this total number.

The deal with cancer registries is they usually do close-out on a year about 18 months later, so if we're, you know, midway through 2012 the, you know, the final data that they have for any one year will only go up through 2010. And that's -- so we'll probably be, you know, limited to this time frame,

from 1995 through 2010 for inclusion of cases.

So that 61 right now is an estimate. That's what the VA has told us they currently have. As indicated, there could be additional cases that have come in since we've gotten that estimate, and then we'll have to apply the study criteria, and so some of those may fall out. So that's kind of a, you know, a rough estimate right now. It'll fluctuate a little bit.

As you guys know, Eddie Shanley's the lead on this project. Since all the Lejeune work has been transitioned into our branch, I'm working with Eddie, as is Frank and Perri. And we're working through the protocol right now; we'll probably be involved in some of the abstraction of the data, and they've reviewed -- and we have all reviewed the protocol and provided comments. They will help with analysis, what have you, so we're, you know, we're treating this as a team effort, as you've seen with all the studies here.

So in late May, Eddie went to the NPRC in St. Louis. What we did is we started with a subset of records, a total of 21 records. And that subset was defined using different time periods and I believe different ranks also. I know there were a couple criteria that we used to try to get a somewhat random smattering across time frames and ranks and what have

you, to see, you know, how the records, if they were available, if they were sufficient for our needs, what have you.

And after about a week out in St. Louis of abstracting the records, we concluded that they do contain the information necessary for assigning exposure levels. And, you know, the way we were doing that is basically the times you were on base and where you were on base when you were there.

So some of the records in the NPRC or at the NPRC that are relevant here are obviously your records of, you know, your service, training, your dates of separation or date of separation depending on your specific scenario.

And this next slide, I believe, will give you an idea of some of the specific document types that Eddie was looking for. I think the vast majority of them were on microfiche, which is challenging in and of itself. But you can see, you know, he was trying to identify for these 21 individual Marines whether there were documents at NPRC that dealt with separation, that gave some chronology of their service and any indications of deployment or training, and also information on the family or, you know, dependents status. So for the most part, you know, those records

are available, specifically for unit codes and dates of service, which are the big two that we have to have; knowing, you know, when they were there and how long they were there. Those are the, you know, the criteria which we will use to then assign exposure based on the water modeling that Morris has done.

So following the trip to St. Louis back in May, when, you know, we were able to see that this was feasible using those records, Eddie came back to Atlanta, revised the protocol accordingly. Frank, Perri and I reviewed, provided comments. And at this point we are doing some of our required administrative review in tandem to expedite the process. By law, based upon the superfund legislation or enabling legislation, we have to have external peer review done for all health studies for both the protocols as well as the final publications. And so the study protocol has gone out. By law it has to go to, I think, somewhere between three and five disinterested, uninvolved scientists, you know, third-party scientists to provide us peer review and comments back.

We're then required to respond to all of those comments, adjust the protocol accordingly, if we agree, and if we don't agree with the comments, state

why we don't. And that entire package, both the protocol, all the external peer review comments that come in from extramural scientists as well as our responses, that entire package goes up through the center for clearance.

At the same time that we're doing this external peer review and clearance of protocol, we're also putting it through the CDC's IRB, which is required whenever you're dealing with human subjects, so these are kind of two different required administrative reviews, but we're doing them in tandem for, you know, for the sake of timing.

For the external peer review, ironically just this morning I got an email from our Office of Science indicating that it has gone out. We are not allowed to indicate who the three external peer reviewers are. We have to protect their privacy, just so they know whatever the comments they make to us about the protocol, whether it's thumbs up, thumbs down or somewhere in between, that that's kind of confidential information from them. And I think that's a good thing because it basically allows them to say whatever they think without having to worry, you know, if there will be some public review or perception or what have you, so I think it frees them up to really speak to

the science and the, you know, methods and what have you, and give us strong feedback.

MR. ENSMINGER: I have a question on that point.

DR. DEARWENT: Yes, sir.

MR. ENSMINGER: So you say you're not going to reveal the names of your peer reviewers; however, do you reveal their comments to the public?

DR. DEARWENT: On protocols, I don't think that we do. I think we typically, when we release a final document, we do provide to the public the external peer reviewers' comments and our responses to the final, you know, publication. I don't think we do that for protocols, though. But as indicated we do have to, you know, address each one of those comments, and that's part of the package that goes up through clearance and internally. It's kind of a QA/QC process.

Now, I can speak --

MR. ENSMINGER: Well, at least you guys, you know, release your peer reviewers' comments. I mean, the National Academy doesn't do that, I mean, so how the hell you know anybody even peer reviewed it?

DR. DEARWENT: I will say for three external peer reviewers, all three of them are at academic institutions, all three have published on breast

cancer and solvent exposure, and in, I think, at least one case, it was specific to male breast cancer. So they are subject matter experts. And Dr. Portier has a comment.

DR. PORTIER: Yeah, Jerry, just to make it clear, this is on the protocol. We always, for documents that ATSDR releases, when those documents get peer reviewed, those comments are captured and when we release the documents we release the peer review comments, our response to them and who the commenters were.

For protocols it's slightly different but in fact we would be foolish not to pay attention to scientific input on our protocols because if the protocols are wrong, the study in the end will be criticized extremely heavily. So these will be looked at with great scrutiny.

MR. ENSMINGER: Well, you know, I'm glad to hear you guys do release your peer review comments and your peer reviewers; that's great, I mean, that's noteworthy. But, you know, it doesn't seem to hurt the National Academy of Sciences -- well, I mean, nobody makes them have more transparency. I mean, how can anybody even consider them a legitimate scientific body anymore? But, I mean, that's another story. Go

ahead.

MR. STALLARD: Yes, Jerry, that is.

DR. DEARWENT: Another story for another day. One thing that Frank just pointed out to me, it's a really valid point, is if something comes up in the peer review, the protocol, that is, you know, concerning, that, you know, challenging to address, what have you, I think that's open game for us to come to the CAP or at a minimum to talk with Dr. Clapp and Dr. Davis about, you know, their thoughts and get some other perspectives on, you know, how to address whatever those concerns may be.

So in terms of the external peer review, it's gone out, the due date to have comments back from peer reviewers is, I think, August 20th or 21st, so it's, you know, it's a pretty quick turnaround time. I would expect us to have something back from our IRB by the end of August, since that's usually a four to six week review process on their part. So by late August, early September, we should have, you know, all of this stuff back with us, and at that point we'll have to respond to peer review comments and put the full package through internal clearance.

While that's going on and we've gotten the sign-off by CDC's IRB, we'll then go to the VA IRB.

That'll be the next step in the process ‘cause we also have to get their approval.

So, you know, the way things time out here, it will be probably sometime this fall before we’ve got the IRBs from CDC and the VA approvals as well as our external peer review and internal clearance. Once those three things are done, the VA will then be able to provide us -- or actually their cancer registry will be able to provide us all the participant data, and that's both the cases and controls, the cases being the male breast cancer cases in the VA cancer registry, and the controls being another set of cancers as yet to be identified. And we'll get to that. We've got some thoughts on what other cancers that we'll consider.

But once we have all the participant data back, at that point, we'll have to go back to St. Louis, that's probably going to be, you know, about 300 individuals that we're going to have to start doing data abstraction on from the various records in NPRC. So I gather Eddie's going to be spending a lot of time in St. Louis in early 2013.

So I'm just going to quickly go over the current proposed study protocol, talk about the design, the purpose and the methodology.

So in the foundation for the study design, and, you know, I don't mean to speak down to anybody here. A lot of this'll be painfully obvious. I just want to make sure we're all on board and understand exactly what's happening. You know, the study will evaluate the association between male breast cancer and exposure to drinking water contaminated with VOCs, specifically TCE, PCE, vinyl chloride, DCE and benzene. So all five of our VOCs of concern.

So the case control study, generically it enables you to compare one group to the other. Your cases in this case will be male breast cancer cases, and our controls, the comparison group, will be participants with other cancers, but obviously not breast cancer.

In this situation, you know, we'll already know the outcome. Working through the VA cancer registry, we'll identify the cases, the male breast cancers and the controls being, you know, other non-solvent related cancers. So the difficult part is then going back and assigning exposure to those individuals. And, you know, obviously the exposure is from Morris's water modeling combined with the residential location and time of residence that we'll get from the NPRC data.

MR. PARTAIN: Question on the other cancers.

What type of cancers are you looking at to use as your control?

DR. DEARWENT: We've got quite a laundry list, and I know, I think there's even been some emails in the last month between Frank and Dr. Davis on, you know, possible, you know, choosing this one versus that one. I think in the protocol at this point we've provided a list of say eight to ten to 12 possible cancers, and I'm hopeful that some of the input we get back from peer review is, you know, you should look at this one versus that one. And I've got a couple slides that gets into that list of possibilities.

So the study purpose to evaluate the odds of being a case, how that varies between your levels of drinking water contamination, while you lived at Lejeune, that's the primary one. And the other one is to compare the odds of being a case stationed at Lejeune versus not being there, the Pendleton group.

DR. BOVE: Well, just any other base.

DR. DEARWENT: Well, not just -- yeah, not just Pendleton but not -- non-Camp Lejeune Marines.

DR. DAVIS: Just to clarify, so the comparison cases will be non-Camp Lejeune cancer cases?

DR. DEARWENT: Correct. And which cancers those are is yet to be determined. And that's, you know,

and we're about to get to kind of the laundry list that we'll obviously have to select from. And it may not be all inclusive; there may be others that we've yet to identify. So the study population: male Marines; they must have been born between -- or before January 1st of '69, and that is to make sure that someone was, what, 17 or 18 -- they were of age to have been a Marine and served at Lejeune before 1985.

DR. DAVIS: So this will exclude anyone who might have developed breast cancer from prenatal exposures?

MS. RUCKART: Unless their mother --

DR. DEARWENT: Unless their -- no, because they wouldn't be in the VA cancer registry.

MR. PARTAIN: Yeah, technically I would -- if I had joined the Marine Corps I would be one of the ones --

DR. DEARWENT: Yes, if you were born after '69.

MS. RUCKART: Yes.

MR. PARTAIN: I was born in '68, and if I had joined the Marine Corps, I could potentially have been --

DR. DEARWENT: Yes.

MR. PARTAIN: There's a lot of families where -- and, you know, and I don't know if you guys have identified that, but there are families where you have

grandpa was a Marine, dad's a Marine, son's a Marine, you know, generations. So I guess keep an eye out for that.

DR. DEARWENT: Okay.

MR. STALLARD: You have a question?

DR. PORTIER: Steve, let me clarify something. Can you back up one slide, just for a second? Steve, isn't it, evaluate the odds of being exposed?

DR. DEARWENT: Absolutely, yes.

DR. PORTIER: Getting their case and the -- okay.

DR. DEARWENT: Yes, yeah.

DR. PORTIER: I just want to make sure my -- our scientific colleagues were paying attention and don't claim we're kind of a little bit off the mark here.

DR. CLAPP: That's pretty good for a toxicologist to pick up.

DR. DAVIS: He's not an ordinary toxicologist.

DR. DEARWENT: He's special. Yes, you're right. Thank you for that clarification.

So, yes, this bottom line, male Marines, born before January of '69, and the sticking point is you have to be diagnosed or treated for cancer at a VA, after -- between the '95, 2010 time frame.

So, you know, for cases, they must be diagnosed and histologic confirmation of male breast cancer,

which is what you get when you deal with a cancer registry; you'll get that data.

For controls, your controls have to come from the same population; that's why we're, you know, Mike, obviously your list of 80, we will have individuals that you've identified that won't meet these criteria. So the controls have to come from the same population from whence the cases do, which is the theoretically from Marines, but Marines who were seen by the VA, diagnosed and captured within the VA cancer registry.

MR. PARTAIN: Let me ask you, with the list that I have, the -- I know there are Marines who have gone through the VA process, with male breast cancer, that I have on the list. Is there any way we can cross-check those to make sure that everyone was captured through the VA system?

DR. DEARWENT: I think it might be kind of a one-way cross-check.

MR. PARTAIN: Yeah, I know that.

DR. DEARWENT: We can take your list but we can't go back and say, yes, no, yes, no on your list to you. But if you're willing to supply that to us, we'd love to have that.

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

DR. DEARWENT: Okay.

MR. PARTAIN: Yes, and the only thing I would ask is just, I know you can't tell me who or what, but when if there are any additions that are added that weren't captured, I would like to know about that.

DR. DEARWENT: Okay.

MR. BYRON: So this is Jeff. So this is only cases that are captured through the VA from '95 to 2010?

DR. DEARWENT: Correct.

MR. BYRON: Can you explain that?

DR. DEARWENT: Well, the VA cancer registry started in '95. So that's, you know, and actually most state-based registries started in the mid-90s. It was a big effort by CDC to get state-based registries. There are some states, probably Massachusetts being one of them, it might be the best example, that have been around for a long time. What, 30s, 40s, 50s?

DR. CLAPP: That's Connecticut but Massachusetts was '82.

DR. DEARWENT: Oh, okay. I knew there was one of those in the Northeast that's been around forever.

Okay, and you know, for inclusion, those with cancers not known -- for the controls, to be a control, you got to have a cancer not known to be

associated with VOC exposure and never stationed at Lejeune.

At some point we're going to get to a table. There we go. So, you know, the question is: What cancers to use for our control series? These are all cancers not known to be associated with VOC exposure. For those that know the incidence or prevalence for some of these conditions, some of them would not be of much utility; mesothelioma is such a rare cancer. You're not going to have enough controls to really make that, you know, worthwhile. Prostate's probably on the other end of the spectrum where they'll be, you know, there are plenty of prostate cancers but, you know, we probably would not want to focus specifically on a specific cancer or just one cancer to use as a control. And this is one of those areas where, you know, we'll hopefully get some feedback during the external peer review as well as from Drs. Clapp and Davis.

DR. BOVE: Let me say one or two things. One is that we may also include on that list other skin cancers depending on what the VA actually captures in terms of skin cancers. Cancer registries vary on how they capture skin cancers or melanoma.

The other thing is that the cases are all male

breast cancers among Marines, doesn't matter what base they're in. The controls are also all Marines with these other cancers, doesn't matter what base, okay? Then we look and see which cases come from Lejeune and we compare them to -- and which controls come from Lejeune as well, and compare them to cases and controls on other bases. That's roughly how it's done, okay.

But then we're also going to look at different exposure levels. But just keep that in mind. The problem here is that the term control is sometimes used in the context of, like say toxicology studies where it means that the rat that didn't get the dose, okay. But in case control methodology, it's basically a sampling method. Controls are not those who are unexposed; controls are just the comparison population. And you can do it fairly swift. What you're trying to do, and this came up in a discussion, I think, with you, Mike, during the briefing a couple of weeks ago. Trying to get a handle on what the characteristics are of this population that gave rise to these breast cancers, okay?

And by taking a sample of that population -- we don't really know what that population is. We're not sure who the VA covers, and it's a population that

changes, probably constantly. People coming into the VA system, people going out of the VA system, people going other places for healthcare and so on. So it's a changing population.

But we can take a sample of it, even if we didn't -- can't define it very well. We can take a pretty good sample of it by looking at other cancers that aren't related to solvents and using that as the sample, because these people, if they had a cancer, or one of these cancers, would have gone to the VA and would have been captured by the VA cancer registry. So by looking at other cancers that aren't related to solvents, we get a handle on this underlying population, the denominator that we don't have with your population, basically, okay?

So that's the -- so the cases come from all the Marines in the VA cancer registry; the controls come from all the other cancers that aren't related to solvents, and that's how it's done. Is that -- is everyone... okay.

DR. DEARWENT: I think, in a perfect world, every Marine would have always been seen by the VA for life and all of them would be captured in the VA cancer registry, but that's not how it works, unfortunately.

So this is our kind of the list to start from,

then we'll have to narrow it down a little bit at some point.

DR. DAVIS: And I'll be providing you with detailed comments but I can just tell you right now that two cancers that are in the list may well not be in the list, and that is testicular cancer and prostate cancer.

Testicular cancer's been identified in analyses of men who work in the aerospace (phone line interruption) and the solvents to be increasing in men with solvent exposure. And prostate cancer's been identified with studies of people exposed to something called Stoddard solvent has increased as well, so I think that they're not likely to make it onto the final cut, but I appreciate this is an iterative process, and I'm looking forward to working with you constructively on it.

DR. DEARWENT: Great. That's exactly the type of feedback we're looking for. Thank you.

And so the long list of those that have been excluded already, unfortunately there are a lot of cancers associated with VOC exposure, and so, you know, after going through the lit review for PCE, TCE, VC and benzene, you can see that many of the cancers and many of those that are the most incident or

prevalent are going to be excluded.

Another data source that we'll be relying on is the VA's patient treatment files, and the reason for this is there is information that we will need that's not available in the VA cancer registry. We need to look for other conditions that are associated with an increased risk of male breast cancer, and here some examples are Klinefelter's, gynecomastia and obesity.

MR. BYRON: This is Jeff. That's what I was talking about earlier, the VA report that identifies risk factors. But yeah, I'm interested and I hope that, even though I'm leaving the CAP, if I have to pay for the results of the study so I'll be glad to.

DR. DEARWENT: But I think we already have a plan in place, you know, as these things come out, to make sure they're disseminated far and wide and, you know, with you guys as well, so God forbid you have to pay for it. You've already paid for it with your taxes, among other things.

DR. DAVIS: This is typically a very small point but I notice that about .1 percent of your cases are reported as transsexuals, and I suspect you want to exclude them from this analysis because people who are formally identified as transsexuals typically go through massive amounts of hormone treatment in order

to grow breasts, which are in fact known to increase the risk of breast cancer. It's a small number of cases but I just would point that out. You want -- I think you probably want to exclude them from the study.

DR. DEARWENT: Okay, thank you. So for exposure assessment, you know, as indicated we'll, you know, have to assess personnel records, identify, you know, when participants were stationed at Camp Lejeune, and if so, where and for how long.

We then take the estimated monthly VOC drinking water contamination levels, and using that combined with their residential history on the base, we'll be able to assign the monthly exposure to each participant, each case and control. And then you've got a listing there of some of the personnel records and who maintains them, the different data sources we're relying on.

So just to be clear in our exposure assessment, Marines that are not stationed at Camp Lejeune are assumed to be unexposed to VOC contaminated drinking water. And those that are stationed at Lejeune will require additional data abstraction, as I discussed a few times here, for their location of residency, and yeah, that includes barrack locations for enlisted

single Marines, officers' quarters for some single officers and family housing records for married Marines.

So it's going to be -- I guess the sticking point in all this it's going to be trying to link up a lot of disparate data sources, a lot of data abstraction off of microfiche in St. Louis. I shouldn't minimize how challenging that will be, and I think it'll mirror some of the stuff that, you know, that Frank and Perri have dealt with dealing with some of these data sets that, you know, aren't perfect by any means.

MR. ENSMINGER: I got to interject something here. This is Jerry Ensminger. I think you are barking up the wrong tree by doing -- by trying to identify where these people lived. Okay? The reason I'm saying that is because there are -- there is no information in Marine service record books to what barracks or where they lived on base.

All right, number two, what you need to concentrate on is the command that they were assigned to. Because it doesn't make a damn where he -- you lived. You were at work every day, if you were at Hadnot Point, and you were being exposed every day while you were at work. Not only while you were at work, you had to come in three to four times every

week and participate in physical training, PT, for which you didn't get to go home after PT to take a shower and change your clothes. You brought your clothing along and you took the shower in the barracks or at your work place, if showers were there, and then you went to work for the rest of the day.

DR. DAVIS: And let me add, these National Academy of Sciences report on drinking water and health, volume six, had a modeling study in 1986 that showed that 50 percent of your exposure to volatile organic compounds in drinking water comes from cooking, bathing and showering.

DR. DEARWENT: Yeah, this is one area we will lean heavily on Frank and Perri and their experience based on the other studies because I know it's something you guys have had to deal with on a pretty constant basis.

MR. ENSMINGER: Well, I'm just telling you there's no way you're going to find out where these people were barracked, okay; it's not in their service records. You're not going to find that information in any records in St. Louis.

DR. BOVE: Correct. This is Frank. But what we can do is what we're doing in the mortality study, is getting some sense of where people were barracked,

based on the memories of your -- by yourself, for example, and others. And we use that information and see if that affects the analysis. We do a couple of different kinds of analyses here, including just looking at Lejeune versus the other bases, with this in mind, that people get exposed no matter where their residence is, whether it's off base, on base, whether the barracks are at Hadnot Point or somewhere else on base. But we want to use all the information we --

MR. ENSMINGER: That's fine but what I'm trying to avoid, Frank, is people being prejudiced because they didn't actually live on the base. If a guy was married and was living off base, the way it sounds, from what I just heard, that person would not be included in the study.

DR. BOVE: No. No. No, no. No. They're included in the study. The question is: How do -- what to assign as their exposure. So the first cut is to look at Lejeune versus the other bases, okay? So this person, because they're assigned to Lejeune, no matter whether they lived on or off base or where they lived on base, they are considered exposed for that analysis.

And then we try to tease out whether we can use the family housing records and the barrack locations

that we know of, to see if that gives us anymore information, gives us a better sense. And that assumes that the people do get exposures other times of the day but the residential exposure is an additional exposure that maybe the people off base are not getting. That's how that... So --

MR. ENSMINGER: Well, if you really want to look at exposure levels, I can name you one MOS, which was the 3300 field, which were our cooks and bakers. I mean, those people were exposed constantly while they were at work.

DR. BOVE: Yeah, but we're -- actually, now we're talking about the mortality study because the cooks are not in the male breast cancer study. But if we're talking about it, in the mortality study, we're looking at civilians, and I have information on what their occupation was, and that'll be factored in.

(multiple speakers)

DR. AKERS: (Indiscernible) commissary at Lejeune. These butchers were Marines. He was in -- a mess sergeant at Lejeune. These cooks and bakers were Marines.

DR. BOVE: There are civilian cooks, too.

DR. AKERS: Yeah, but that was -- that only recently developed.

DR. BOVE: Okay, okay. Sorry.

DR. AKERS: Back in the 50s and 60s, they were Marines, they had MOSs, butchers and bakers and meat cutters. They were in the Corps, had gone through training.

MR. ENSMINGER: That occupational field was the 3300 field.

MS. RUCKART: But you know, there is one group of people who may have to be excluded. I just wanted to mention this because there were some records -- there were some people who were searched for at NPRC who Eddie could not find records for. So we actually gave him 30 names to search for, and a few people were at Quantico, they had served more recently and the records haven't made it over to NPRC and we can look there, but there were still a few who were unaccounted for so some cases may drop out if we just cannot get any information about where they were located.

DR. AKERS: Let me ask a question, just to make sure I'm perfectly clear. The controls are drawn from people who didn't have the case cancers, per se. They could have been stationed at Lejeune, Pendleton --

DR. DEARWENT: No.

DR. AKERS: El Toro -- well, not El Toro, but Quantico, wherever.

DR. DEARWENT: Correct.

DR. AKERS: You just couldn't have the cancers they were questioning, regardless of where you were stationed.

DR. DEARWENT: Right. And just to be clear, that first table that I showed, that had 61 male breast cancers and it was roughly double that of female cancers, that was for all Marines from '95 to 2010; it wasn't Lejeune-specific.

And then what we just discussed here is a good example of why that 61 is kind of an estimate and won't be the final number once you get into these exclusionary criteria. Some may be eliminated.

DR. AKERS: And again, to make sure I'm perfectly clear, the females that are noted, they are female Marines or dependents or just females in general who had the breast cancer?

DR. DEARWENT: Female Marines. Well, you could catch dependents in the VA cancer registry.

MS. RUCKART: Those were ^ different code. Those numbers are provided for those people who are coded as Marines. There are other breast cancers, but they were not coded as Marines. So that number that he showed you were the numbers of Marines, female and male.

DR. AKERS: How about nurses at the naval hospital? Would they be included under Marines?

MS. RUCKART: Did you search for Navy?

MR. PARTAIN: Corpsmen.

DR. AKERS: Corpsmen?

MR. PARTAIN: There are several Navy corpsmen on my list.

DR. AKERS: So that group of individuals would be lost then?

MR. PARTAIN: There are quite a few Navy corpsmen that went through there, both female and male.

MS. BLAKELY: My father-in-law was a Navy corpsman. He died of the same cancer as my mother, so you're disqualifying people that were in service.

DR. DEARWENT: The question really goes back to: Would those people have been -- if they had been diagnosed with cancer, would they have been captured by the VA cancer registry. That's the kicker.

DR. BOVE: They would be. They would be.

DR. DEARWENT: And if they would be --

DR. BOVE: We were thinking about this as well. The problem as we see it is that the Navy, the percentage of the Navy at Camp Lejeune is tiny compared to the entire Navy personnel. And so we would get a lot of people, and we'd have to do a lot

of work, for one thing, to look at all these cancers, both male and the control series, who would definitely not be exposed because -- on ships or anywhere else. So we thought limiting it to the Marine Corps made sense efficiency-wise 'cause we're going to have to go back and look at hard copy records to do this.

This is also why we decided not at this point to look at female breast cancer, okay, strong case could be made that we should be looking at that as well, because of the work involved in trying to do that, and going through all these records, because it's -- they're not computerized, okay? And unfortunately they're not computerized because if they were that would change things drastically here, but they aren't. And they probably will never be computerized because of the expense that the Marine Corps says it would take and the number of people hours, and so on and so on. So that's why we're not including Navy.

We think we have enough cases -- the key thing here is we think we have enough cases of male breast cancer to do a study and to have sufficient statistical power to see something if there's there. So that's why we're doing it this way.

There are all kinds of other approaches and other populations that we can look at for male breast cancer

but this seemed to be the best thing to do that could be done in a reasonable amount of time, with the kind of work force we have and the limitations of the data that we're faced with. Okay, so we realize we're missing cases but that doesn't mean that the study's invalid at all. It has nothing to do with the validity of this study.

MS. BLAKELY: Yeah, but the study will be valid but will it be full-scale enough to capture the male breast cancer cases and obviously show the evidence that there is a problem?

DR. BOVE: Yes. That's what I'm saying. Because we think that we have enough cases to make -- if it's there, we can make the case that there's an association, a relationship, between this kind of exposure and this disease, yeah. And that's what -- I mean, that's the question we're asked -- that we're trying to answer.

DR. DEARWENT: So, just --

MR. ENSMINGER: Boy, you talk about a break-through study. I mean, if you've got -- if that ever happens, holy Christ.

DR. DEARWENT: So, yeah, earlier in the meeting, we talked about how to -- how we will interpret findings. And just so you guys understand it, and

this really applies across all the epi studies here, that we're looking at multiple aspects in terms of our interpretation, or multiple, you know, considerations. One is the strength of the association, so the magnitude of the odds ratio. Another is an exposure response relationship. Those, you know, are we seeing more cases in those that have higher exposure? And another is the consistency of the findings both within the study and when compared to other studies of this nature.

And that's the timeline that we've laid out, and you'll see that 2012, Q4, that's basically September, end of September, end of our fiscal year, we're indicated, you know, we should be through -- the protocol should be peer reviewed, we'll hopefully have approval from CDC's IRB at that point, we'll have at least initiated the IRB review at the VA.

Once all that's done, which is the, you know, towards the end of the calendar year, we've got all of our approvals and clearances to go, we'll get data back from the VA on the VA cancer registry, actually have the participants' information that we can then go to St. Louis and spend, you know, at a minimum of six months or so doing a lot of this data abstraction, cleaning, what have you.

So we're probably a good year and a half out from having this thing, you know, at least ready to go for clearance. And I think that's it.

MR. STALLARD: Great. Thank you, Steve.

DR. DEARWENT: Yes, sir.

MR. STALLARD: All right. Any questions? Yes?

DR. CLAPP: Frank mentioned power, do you have a slide about power or do you want to say anything about it?

DR. DEARWENT: Funny you ask 'cause I think we have an extra slide set in here just in case it came up. Supplemental slides. Reading their minds there, Dick. So here's your example. So just everyone, statistical power is the ability to find an -- it's the ability to find an association, should it really exist. So bottom line is do you have enough people with enough exposure such that if there was an exposure-disease relationship, you can find it through an analysis like this.

So, you know, what we've done is, you know, we've already identified a 4 to 1 ratio of controls to cases. When you use many more controls than you have cases, that's a way to help increase your statistical power, so we're thinking we're going to have roughly 60 cases and 240 controls, so a total of 300 overall

participants in this study.

And then looking at the assumption of exposure prevalence amongst the controls, bearing that from 10 to 40 percent, you get varying odds ratios that are at least, you know, two, if not three times, you know, what you would expect.

So what we have -- based on having 60 cases and using 240 controls, we have the ability to see something, should it exist. And that's -- and that is really the kicker on this, that Frank was getting to. I mean, obviously there are concerns about narrowing the scope and eliminating the cases, which you never want to do, but as long as we can have very strong criteria that we adhere to for both case and control inclusion, and can stand by that and still have the ability to see something, should it be there, that's, that's our concern.

DR. DAVIS: I think it's important to make clear that the power or probability of finding an effect depends on two different things. One is the expected size of the relative risk that you're looking at. So for example if male breast cancer was five or ten times greater in people exposed to solvents than not, you don't need to look at as many people as if it was for example just 50 percent greater, and that's just

an unknown at this point, isn't it?

DR. DEARWENT: It is. But thank you for that clarification.

MR. STALLARD: Science 101. Any other questions?

MR. PARTAIN: When you guys do get to -- you -- Perri mentioned like you have 30 of the 61 that you're not sure?

DR. DEARWENT: The 30 number was, Eddie took, you know, the subset of folks that he was going to go to St. Louis and try to abstract records on, Frank and Perri were able to give him 30 Marines that spanned across different times of service and different ranks and what have you. And --

DR. BOVE: We just took it straight from the DMDC data. We didn't know anything about their health status at all. Just keep that in mind, okay, it was just 30 people. We just wanted to see if we could find information on a random sample of 30.

MR. PARTAIN: Okay.

MS. RUCKART: And the way it was done was we had the DMDC data from '75 to '85, so I made six three-year, you know, chunks, so ten people from each of those time periods, so they would be more distributed, and then various ranks.

DR. BOVE: Right, in the DMDC data has the date

when you started military service, although sometimes it's pretty flaky, and you get different dates for the same person, which is part of the problem with this data set. But we can base the sampling that Perri just talked about, based on when that date occurred. So if they start at 60s, 70s and 80s, we took people out.

DR. AKERS: So the 30 were not officially had cancer (multiple speakers) showed up on your list, 30 people.

DR. BOVE: Just wanted to see how it worked.

MS. RUCKART: Well, let me add something else, like Frank was saying, we know that the DMDC data is not 100 percent, you know, accurate so another part of this process we wanted to see if the DMDC data shows this person was at Lejeune -- we took 30 random people -- would their personnel records at St. Louis show us that they were at Lejeune? That would make us feel more confident for our other studies 'cause we're basing everything off their unit code from the DMDC.

DR. BOVE: And then that's why -- this is actually -- this was a discussion that occurred between me and the point of our point of contact in the Marine Corps, which was just how good the DMDC data is and whether the St. Louis data would be useful

as a corrective to see how good the DMDC data was. And we thought it was a good idea. Sometimes you get good ideas from all kinds of places. And this idea was instead of relying on the DMDC data for this study, actually to go to St. Louis and get hard copy for all these people, the breast cancer cases and the control cancers as well. And look at that and see, for the people who are in the DMDC data as well, see how the two corresponded. We thought that would be useful as well. So that's why we're going to use the hard copy records as well as the DMDC data and see, and do sort of a quality check.

MR. STALLARD: Thank you, Frank.

MR. PARTAIN: So you think that the 61, granted I know they're not going to all be from Lejeune, but do you think that we're going to be able to get enough to have a statistical relevance for everything?

DR. DEARWENT: Yeah, and that's exactly what that slide addresses.

MR. PARTAIN: Okay.

DR. BOVE: We'd like to get below two but we can't generate more cases out of the VA than are there. But this is reasonable. You always want stronger power, you always want to be able to detect the odds ratios below two, if you can. But increasing

the number of controls here would not really do much more than this. If you take -- have an eight to one ratio you'd still be roughly in the same territory so this is pretty much what you can do with this data.

DR. DEARWENT: And how long ago did we get the estimate on the 61? That's been within the last few months, hasn't it?

MS. RUCKART: Early in the year.

DR. DEARWENT: Yeah, so I would expect more cases have been added since that time.

MS. RUCKART: Well, it depends. I mean, it depends if they're using partial year data or if they want to give -- wait to the full year, so we don't know that yet.

DR. DEARWENT: We'll give you guys the numbers once we get the final, which will be after the VA.

MR. PARTAIN: And just to visit back, I know we were talking about the corpsmen, Navy corpsmen involved, I mean, is there something that can be -- I'm assuming this is computerized and stuff. Is there something the VA can do to produce, maybe Brad, to see how many Navy personnel with male breast cancer have been reported and just to do a quick check to see how many are corpsmen, and look at it. 'Cause the reason I'm bringing it up, there are quite a few corpsmen on

the list that have contacted me.

DR. BOVE: They don't have it broken down that way. It's just simply Navy, Marine Corps -- sort of like the DMDC data. That's all it has is M for Marine, N for Navy, and their unit. If you know what their unit is, then that's fine, but that's the DMDC data. The VA cancer registry will just probably have an indicator variable for -- I mean, that's what we've heard, just simply Marine, Navy, Air Force, so on. That's why.

DR. DEARWENT: And just so I'm clear, so the Navy corpsmen would be swamped by all other Navy's personnel?

DR. BOVE: Yeah.

MR. STALLARD: All right. Well, then I'll get to that. Thank you very much for this presentation. This is an example of the CAP having advanced an idea and its coming into fruition. Frank, you wanted to?

DISCUSSION ON FETAL/INFANT DEATHS

DR. BOVE: Yeah. This is another example of the CAP going way beyond what other CAPs probably do, and collecting data for us, and bringing it to our attention. So Mary Blakely did some work going through death certificates for three years from North Carolina. And so the first year she looked at was

1979. I hand counted it, so it may not be exactly right, but there are 24 death certificates here. Six of them were fetal death certificates. And the thing I was mentioning to Mary before is one of the things I never could understand is when states decide to call it a fetal death and when they decide to call it an infant death. Some of these infant deaths died within an hour of birth but they're given a death certificate, not a fetal death certificate. So there is some movement there that I have a feeling that some states do it differently than others.

But anyway, of the six fetal death certificates, three weren't born while the parent lived on base, according to the death certificate information I saw. But three were born on the base, so half of them were, and two, I know, were in the small for gestational -- were not in the small for gestational age ^ but we got the data for two of those three from the state back in the mid-90s when we found that there weren't enough fetal deaths to really study.

We saw that there were some 80 fetal deaths for Lejeune, and you would expect it something like three times as many, so we knew we weren't getting all the fetal -- even close to getting all the fetal deaths in Camp Lejeune so we didn't go any further with that

information. We also didn't have information for most of them on cause of death.

For these fetal death certificates, some did have a cause of death, including there was one anencephaly, which is in our case control study. So most of the diseases I found on the infant deaths were due to preterm birth, for example immature respiratory system, excessive amniotic fluid because the swallowing mechanism for the fetus hadn't been developed. So these are -- a lot of these diseases are diseases that are related to preterm birth.

And so even though we're not studying these people in particular, we are studying preterm birth in the small for gestational age study, so we'll capture some of this by looking at preterm birth in that reanalysis.

Other conditions included what we called -- what are called pregnancy and delivery complications including cord problems, like being twisted around the neck, ruptured placenta, incompatibility of blood type between the mother and the fetus, and so on. There were a few SIDS cases and one or two septicemia cases. But there were many unknowns, even among the infant deaths and certainly among the fetal deaths. So that was the 1979 package.

There are two other years that Mary Xeroxed death certificates from, in 1960 I counted 101, so you really went to work on in 1960 deaths. Again, most of them were due to the same kinds of diseases I mentioned for the '79 group, related to preterm birth or related to pregnancy and delivery complications.

In this group there were six with heart disease but it wasn't specified as to what kind. There were a couple of ventricular septal defect and one atrial septal defect in this group, which is a hole in either the upper or lower chambers of the heart. There was a patent ductus arteriosus, PDA, which is often called heart murmur, and there it's basically an abnormal blood flow between the aorta and pulmonary arteries, which can be corrected.

All these are corrected by surgery but I guess in cases they do lead to death. There was two hydrocephalies and then there was two mentioned multiple anomalies, it wasn't otherwise specified.

So there were some birth defects within this probably so the other causes of death were either unknown or there's a whole list of all kinds of complications, could be due to birth defects that they just haven't been able to identify. They either didn't do an autopsy or whatever. And there were two

acute lymphocytic leukemias, one age two and one age four. Now these wouldn't be in the study because this happened in 1960.

And then in '58, I counted 97 this time. And there was one what we call conotruncal heart defect, a major heart defect, where the vessels are switched -- aortic and pulmonary vessels are switched, and this is a major heart defect which we were hoping to study in the case control study, and we couldn't because we saw that we were totally underestimating the number. We weren't ascertaining the way we should be. Probably we had about a third of what we expected, so we abandoned looking at that because obviously we weren't capturing them.

There were two NTDs, neural tube defects in this '58 group. Actually there was more than two -- I'm sorry, there were two encephaloceles, which is a very rare neural tube defect. There were four anencephalies, which I saw, another neural tube defect that's forming out of the brain. There were a couple of hydrocephalies, and again a couple with multiple anomalies not otherwise specified. And somehow there was a melanoma, metastatic melanoma, of a 46-year-old.

So anyway no, we really appreciate the work that went into this. This gives us some handle on the

deaths that did occur among those who were not considered fetal deaths. And it strengthens our view that to look at preterm birth a lot more seriously this time around.

In my own research I haven't seen much with preterm birth except one instance where we looked at preterm birth at Hanford and found an association, but in general, I haven't seen much with preterm birth in these kinds of exposures; however, it hasn't been studied that much and, you know, we'll have better data this time around. So maybe we'll see something this time. We did not see it the last time around, with this -- in this small for gestational age preterm birth study.

DR. AKERS: Would you like to have the website for Matt Avery, who's head of the Department of Statistics for the State of North Carolina? I mean, I've got his information here and he can, he can tell you what criteria they use for fetal death versus an infant death and that sort of thing. And the data goes back until somewhere in the 40s. They have data on that going all the way back.

DR. BOVE: Yeah, but as I said for some reason there was a very low number of fetal deaths in this population.

DR. AKERS: I haven't look at the data, I just know it exists and it does go back to the 40s.

DR. BOVE: Yeah, yeah, yeah.

DR. AKERS: Center for Health Statistics in Raleigh has that information.

DR. BOVE: Yeah, thank you.

MS. BLAKELY: This is Mary Blakely. I have been back to the register of deeds, and I have collected up through 1984 and I've got 1990. So I have from '50 to, except four years, which I'm going to go back and get. And I'm more than willing to share all of them with you.

DR. BOVE: Sure. Okay, thank you.

MR. ENSMINGER: I'd like to add that, you know, that Mary's really put a lot of work into this and that it has not gone unnoticed by any of us, so good job, Mary.

WRAP-UP

MR. STALLARD: Thank you. All right, we're at the end of the formal agenda a little bit early this time and it calls for wrap-up. Do we have anything in mind about wrap-up? I mean, do we have a date for the next CAP that will be set up? That's one thing we have to take care of. Do you have anything to add?

DR. DEARWENT: Yeah, I was just going to echo we

might as well talk about the next time that we all get together.

MR. STALLARD: Yeah.

DR. DEARWENT: I get the feeling that you guys would be much happier if when we had the next meeting, we actually had more substance to share. You know, and then based on our timelines, it looks like, you know, at a minimum, I think by end of this calendar year or very early 2013, the water modeling'll be out, at least two of the epi studies will be out. Are you guys willing to -- us kind of play it by ear for a few months and we see how that timeline progresses and then set a date through, you know, communicating via email down the road? Except for Jeff; he's going to excuse himself.

MR. STALLARD: Jerry, any thoughts on that?

MR. ENSMINGER: I didn't pick that up. I couldn't hear.

DR. DEARWENT: So I was saying that I get the impression that that the CAP meeting would be a little more fulfilling if the next one occurred at such a time that we actually had the water modeling out for, you know, for public release as well as, you know, at least a couple of the epi studies. And so I was suggesting maybe we kind of play it by ear for the

next couple months, and as that timeline starts to crystallize a little bit better than it has at this point, we could set a date. And then again --

MR. ENSMINGER: Well, my only problem with that is that historically every time we get a date, it's never a date certain, and the closer we get to the date, then all of a sudden we find out that, well, it's not going to be released. It's not ready yet. So, but --

DR. DEARWENT: Well, based on the recent -- although I wasn't involved, the recent interactions with congressionals, I think we're fairly committed and locked in, at least by the end of this calendar year to have some of these things out. So.

MS. BRIDGES: Did you just mention November?

MR. STALLARD: We didn't. We're talking about that now. Dr. Portier?

DR. PORTIER: I --

MS. BRIDGES: I thought he had mentioned November.

DR. PORTIER: I would bet that the CAP would love to discuss the first study that comes out and not wait for all of them. And what I would suggest we do is, using my best judgment, about a month before I'm pretty sure that report will clear, we start to set up

a time for you to get here. That would be close to the clearance date for the report as best we can tell.

That pushes my staff to clear the report faster, and I will wait to do that until I'm absolutely certain it's cleared my part of the center and is elsewhere in our process of review. Would that work for the CAP? So you might not get more than about a three-week notice that we'd like to have a meeting. But that would give us probably the most accurate chance of getting you a meeting where we're actually going to present results from one or two of these studies.

MR. ENSMINGER: Oh, man, and let's not forget, now, you've got Chapter B that's going to be coming out in between here.

MR. STALLARD: D.

MR. ENSMINGER: Yeah, Chapter D, I'm sorry.

DR. DEARWENT: Yeah, the claim right now is to have the drinking water -- the water modeling out before the epi studies, and that's, you know, that has a lot of substance to it. So we just wouldn't want to set an expectation of say a meeting towards the end of this calendar year where it's all done and at this point looks like maybe just the water modeling or one of the epi studies may be done.

MS. RUCKART: But doesn't it make sense, that, you know, is fine to have a separate meeting dedicated to the water modeling but shouldn't we use that same approach where a few weeks out, when we're very certain when the date is, we have the meeting so people don't come and we're disappointed we can't have approval discussions?

MR. STALLARD: All right. So someone help me to summarize. What did we just decide?

DR. PORTIER: Well, we haven't heard from the CAP.

MR. STALLARD: Well, we heard from Jerry.

MR. PARTAIN: I would like to have a meeting -- you mentioned the water model being done in November. We could spend almost an entire CAP meeting talking about the water model. And I'd like to have -- I would like to have a CAP meeting prior to the release of the water model. You know, you mentioned about getting us a, you know, a copy of the report or whatever before -- at the same time the Marine Corps and the Navy get it. That'd be a good chance for us to get the report, look at it and talk about it before it's released.

MR. ENSMINGER: You know, I agree with that. I mean, and by that time we'll have Chapter D.

DR. PORTIER: That we can't do. What -- this meeting's a public meeting and if we start talking about the results of that document at a public meeting, we have in essence released the document. So --

MR. ENSMINGER: Yeah, yeah.

DR. PORTIER: Yeah, we'll --

MR. PARTAIN: Can we coincide the release?

DR. PORTIER: We can try. We can try to coincide the release with the date that we sit down and talk with you. There's a lot that goes into a release of a document like this with national consequences to the document and national interest in it.

So I'll work with my communications staff to see what we can and cannot do around that. It becomes a bit of a zoo when you have too much going on around the release of a big document. But we'll do what we can. But the bottom line is, we can't talk about the results in this meeting prior to releasing a document.

MR. ENSMINGER: Yeah, that's --

MS. RUCKART: I have an option. Another option, what about a closed CAP meeting, Dr. Portier? Or CAP members? Is that a possibility?

DR. PORTIER: I don't know the rules.

MS. BLAKELY: We could invite the Marine Corps to

that one.

MS. RUCKART: I mean, we have made our CAPs public but just because we are not physically out in the community, but we could have a -- I don't see why we couldn't have a private CAP meeting. It wouldn't be advertised on the website; it would just be a meeting between us and the CAP and the Navy; is there a problem with that?

DR. DEARWENT: Tell you what, for now why don't we say we'll figure out what we can and can't do and kind of talk a provisional time frame of November-ish or early December-ish?

MR. STALLARD: Okay? That sounds good. And by that time we're going to need to have a new CAP member identified to replace Jeff Byron.

And I'd like to take this opportunity to acknowledge and recognize Jeff for his many years of commitment, tenacity and personal sacrifice representing the Camp Lejeune community. And we thank you for your service and wish you and your family the best in all things and in your new endeavors.

(applause)

(multiple speakers)

MR. STALLARD: Hold on, just a minute. Hold on, Jerry. Go ahead, I think we have -- you have our

attention now.

MR. ENSMINGER: I said I hate to tell you this, Jeff, but you will continue to hear from me.

MR. BYRON: Actually I'm glad to hear that, Jerry, and I hope to hear from all of you eventually. But if not, I'll see you in the hereafter.

MR. ENSMINGER: I got a point of interest for everybody. I just got an email from CBS news. They're going to run another story on Camp Lejeune prior to the House vote. So.

MR. STALLARD: All right. Do I have to remind people to submit vouchers and things?

MS. RUCKART: Only if they want to get reimbursed.

MR. STALLARD: Any final notes and comments, Dr. Portier?

DR. PORTIER: I just want to add my thanks to Jeff and all of you for all the efforts you put into helping us to do this the right way. We really do appreciate it. Thank you very much.

MR. BYRON: Thank you.

MR. ENSMINGER: Even me?

MR. STALLARD: Glenn?

MR. MARKWITH: Glenn Markwith from Navy Marine Corps Public Health Center with just a quick

postscript. One of the issues that was discussed earlier in the day was the civilians claim process and getting information out there. And at lunchtime I was looking through the information that is out there, and it's in the FAQs. It's in the FAQs on Lejeune website.

It goes over how to do the VA for the service members and also how to do the claims process for civilians. And even people who don't fall under those categories, if you're not a service member or a civilian, how do you go through the federal torts claim process, and it gives website info numbers. So I just kind of wanted to close with that positive, and that the information is out there.

MR. ENSMINGER: Well, wait a minute. Now, that isn't for health benefits, though. That is only for federal tort claims. That's for SF-95s.

MR. MARKWITH: Well, the stuff --

MR. ENSMINGER: That doesn't have anything to do with the Federal Employees Compensation Act.

MR. MARKWITH: The stuff for the Department of Labor that's on there has to do with workman’s comp claims. If the civilian feels like they --

MR. ENSMINGER: Oh, it does? Okay, okay, good.

MR. MARKWITH: Yes, sir.

MR. ENSMINGER: My apologies.

MR. MARKWITH: There's no worries. And the second thing I wanted to say, I know there was some concern about the registry website not working correctly. And there's going to be a letter forthcoming to the CAP to explain exactly what happened, but the gist of it was that the servers transitioned from the Navy annex to the Pentagon and then down to Lejeune, and during that process some code was messed up and the static monthly report that showed up didn't change from December 2011 until it was finally updated and they caught the error.

The way it was explained to me was the score card kept running, the data kept being recorded but the monthly static report didn't change because it was looking at the old server. And now they've got that corrected and it's been, you know, doing the right thing since the end of March, so another positive note that they've got that corrected. I just wanted to put that out there. Thank you.

MR. STALLARD: Thank you, Glenn.

MR. ENSMINGER: Well, I have a question on that point. And you know, it's something that nobody in the Marine Corps or anybody on Capitol Hill can get the Marine Corps to answer, and that is that migration

that you keep talking -- that's a nice new word, migration, of the computer down to Camp Lejeune. I'd like to know what mode of transportation you guys used to get that down there because it took three damn months.

I mean, that's -- I know you can't answer that but that's just the point I want to make, you know, that the Marine Corps and Department of the Navy's rhetoric is about how concerned they are about our health, safety and welfare, but their actions belie their words, okay?

It has been this way ever since this issue's come up and, you know, for them to -- for the leadership of the Department of the Navy and the United States Marine Corps to put you out here in the front, I think is totally unfair and I'm not aiming this at you in any way. But the conduct and the lies and the misinformation and disinformation that have been put out by the Department of the Navy and the Marine Corps leaders is just, it's -- I can't believe it. I just cannot believe it.

And if you want a prime example, go look at that damn brochure that they posted on 16 March on the website. That thing is full of omissions, full of obfuscations, full of half-truths, full of total lies.

MR. MARKWITH: Well --

MR. ENSMINGER: It's ^.

MR. MARKWITH: In regards to the migration of the servers that we were talking about earlier, I just want to say that the details are going to be in that letter and I'm hopeful that it will answer some of the questions that you have about the time period there.

But I do know in talking with them that there were some errors in the code because it was referencing an old server and the report was not on the old server anymore, and that's the way it was explained to me in terms of why that was in error. But the positive thing I wanted to leave y'all with was that it's now been corrected, and they found out why it was doing that, and it's actually been recording numbers from the registry; it just wasn't showing up on the monthly report card.

MR. STALLARD: All right. Thank you.

MR. ENSMINGER: And then I would like to point your attention to the statement that they put up on their website, which basically blamed all these errors on -- or insinuated that the victims were registering, were multi-registering. The victims were. It wasn't a fault with the Marine Corps or the Department of the Navy's program, it was basically the blame was put on

the victims, like they were some kind of perpetrators, that they were underhanded, and they were registering multiple times. I took that as a damn insult, okay?

MR. MARKWITH: I can --

MR. ENSMINGER: And you can carry that back to your people. You know, I look at that as an insult.

MR. MARKWITH: Yes, sir. I can tell you that certainly was not the intent. The way it was explained to me was that it was an error in coding and it's since been corrected and the details are coming to the CAP in a letter. And hopefully it'll be here very soon.

MR. ENSMINGER: Well, why don't they put that stuff in their statement on their public site? 'Cause that's where everybody sees that thing.

MR. PARTAIN: Yeah, the public site made it very clear that the errors were due to multiple registrations, duplicate registrations so that is, you know, insinuating that the victims are going on there, here, count me; here, count me again.

And if that's true in case it's what you said, what they described, they need to make sure the actions follow up with words and that the public disclaimer that's available for Congress, for media, for people to see, acknowledges that there was an

error on the part of the Marine Corps and the Navy, and that the victims and the families had nothing to do with it. Right now that doesn't read that way.

MR. MARKWITH: Understood. That was certainly not the intent.

MR. ENSMINGER: And the other -- the explanation I got through the congressional offices on this matter was that if people went back into the program they had already registered, but if they went back in to update their information, such as their contact information or they may have moved and may have gone in to put in a new address, the system was counting them again. The program was counting them over again. So I mean, but you get my point. Well, you understand what Mike just said. You know, saying that it was a glitch with the program and, you know, let's stop this finger pointing. I mean, the Department of the Navy and Marine Corps have never accepted any kind of responsibility or blame for this issue, never.

MR. MARKWITH: Well, what I wanted to do was report that they did find the source of the error and they're going to detail that to the CAP in a letter and that it is actually up and running. And that's the positive part I wanted to report to the CAP today.

MR. PARTAIN: One thing, Glenn, if you would,

when they provide us with that letter, I would ask they provide us with a breakdown and count to date as conveyed in the letter, by state and by total count.

MR. STALLARD: All right. I think that wraps it up. And I think I'd like to thank Glenn for being here and joining the CAP as a new member, and we look forward to your participation in the future.

MR. MARKWITH: Thank y'all for letting me be here. Appreciate it.

MR. STALLARD: Absolutely. So safe journey home on the roads today, be careful, and we'll be in touch about the next meeting. Thank you very much. Signing out, Jerry, bye.

(Whereupon, the meeting was adjourned, 2:23 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 July 26, 2012; and it is a true and accurate transcript of the proceedings captioned herein.

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

WITNESS my hand and official seal this the 24th day of August, 2012.

_____

STEVEN RAY GREEN, CCR, CVR-CM, PNSC

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