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Expert Panel Meeting Feb. 17 – 18, 2005 Meeting Transcript Day Two

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Transcript of the
Camp Lejeune Expert Panel
Convened on February 17-18, 2005

DAY TWO – February 18, 2005

Mr. Stallard: Good day ladies and gentlemen, please take your seats. Welcome back. I hope everyone is well rested and well fed. Hello. I have a few announcements to make. There will be verbatim transcripts made available to you both hard copy and it will be posted to the Website as well. However, on the Website, just for your information, the attribution will not be there about so and so from the public said x, y or z. But the comments will be there. Okay?

Now, here we go with a little bit of flexibility. We realize that we have two speakers who were not here yesterday, who had not the opportunity to make their public comments. We had intended for this morning to be solely focused on the panel deliberations. However, for those two people who had not the opportunity to speak we're going to have them present this morning that the panel may consider their thoughts in their deliberation. Is that okay? All right. Also, Ms. Harris has asked for additional time and I have agreed to do that given that she had not the opportunity yesterday to speak. Those of you here have had several opportunities. Is that okay? All right.

So, ladies and gentlemen. . . Ms. Ellen Harris will now present her public comments to the panel.

Ms. Ellen Harris: I am finally happy that we have gotten a board of toxic experts, not fly-by-nights, but men and women of distinction in their field. I have been a lab rat for so long, I don't know what it feels like to take and finally meet those that [know] what we'll be talking about. As we know, America was founded on God, liberty, trust and truthfulness. Ashamed to say that Marine Corps and the Department of the Navy, that is supposed to be so outstanding, allowed the American holocaust to happen at Camp Lejeune, North Carolina and did nothing about it. We were stationed there in 1971 to 1972 when Jim returned from Vietnam his second term in country. After a short time off base, we moved into Berkley Manor. My husband was nuclear, biological, chemical. He, for fifteen years eleven months of his twenty years in the Marine Corps, he was, what he said he was, a trained killer.

Stationed at Camp Geiger, our first tour, there was an accident that happened and I was called to pick him up and he was in his underwear and a blanket was around him, he was sopping wet and his Commanding Officer said, "Take him home and put him to bed. He'll be all right." I said, "What in the hell has happened to him? Why isn't he at the hospital?" "Ms. Harris, he'll be all right. We've had to give him two shots of atropine." I took Jim home the next morning he told me, he says, "Ellen, for what had happened yesterday, we have cost the lives of many." I did not know through so many years of marriage what was taking place would form history by being the largest water toxic spill in United States history aboard a military installation. Hell hole, Camp Lejeune. We, as wives and mothers, we are the backbone behind the husband. The husband's able to go to deploy at any given time. We pay bills. We take care of the children. We do the thrift shop. We do whatever needs to be done, to keep the family floating, to keep it going. To take and have our lives changed because of rank climbing military and civilians and those within government. The ATSDR is involved and I should see Dr. Wendy Kaye, which I begged and pleaded many a time from the first and Marie Socha from when the study started in 2000.

My physicians could not find out what was wrong with me. 1971, '72 I was pregnant and the bottom started falling out. When I say the bottom starts falling out, my children sick, I'm pregnant. Six months pregnant, they're telling me, I'm going through the change of life. I'm having hot flashes. I'm broke out with sores. We're dizzy. We're vomiting. It wasn't like the other two pregnancies. This was totally different. This was a nightmare. This was passing pus in our urine. The women that was going into the ob/gyn clinic was so numerous that we spent more time with our legs up in the stirrups than we did resting in bed. Every time we went in we were being checked-the urine, the blood, miscarriages, gall bladders, women being spaded in their early twenties, total hysterectomies. Those who had been on base quite some time, the outpouring of compassion from one wife to another for these younger women that would never know motherhood. For the mothers that lost their children. For the fathers that lost their children. They still live this nightmare today.

'71, '72 was so bad. In '72 approximately February of '72 . . . Excuse me. . . '72, Dr. Bobo, pediatric physician, the hospital was full with children, adults, troops. Onslow Memorial Hospital was full.

Portsmouth, Virginia was full. Cherry Point was full. All the surrounding areas was full with people sick. Dr. Bobo and other pediatricians was coming to the quarters and seeing children. Twice a day-in the morning and in the evening time. He was coming to see his children. We had five or six vaporizers and I believe it was Albuterol or something we put in them. The respiratory infections were so bad, no sooner was those children well, what we thought was well, they were sick again. Continual antibiotics. I was also sick, back and forth, back and forth. I'd already delivered, back and forth to the clinics, the different clinics, high fevers for no apparent reason, the children would run 103 to 105 fever. Usually when it would go to 104.4 or 6 we would see seizure activity. That was very common. That was par for the course on living in housing. We didn't know what was going on at this time.

Being from a military family and my dad, career Marine, thirty-one years, in charge of MPs at Pearl when it was bombed, very outspoken. I kept on questioning, "what in the hell is goin' on?" Children were being seen also in Portsmouth. They were flyin' in the neurologists. The drug of choice was Phenobarb. So I raised much dickens in the clinic and with the Captain and with the Commanding General. We got a set of orders to Kanehoe Bay, Hawaii. 1973. Dr. Bankhead, navy officer asks, "Ellen, what the hell have you people gotten into at Camp Lejeune? Every damn one of you is sick and you're sick with the same damn thing." Those were his exact words. He issued a letter to the commanding officer which was the General to go ahead and put us in base housing. My children were so sick. Day and night my children were sick. So, about 1974 we left and went from that side of the island because I kept on pushing the issue after Dr. Bankhead left. "What is going on with my children?" God is my witness, ... my kids were sick and I left the hospital with twenty four bottles of medicine, six medications a piece for each of us. I got so good about the different medications. They'd say, "What do you need this time?" You know it's kind of hard for a mom, but there was a group of us. You only see a few here, but let me tell you. Each one of us here represents thousands that's not here. We also represent those that's gone ahead in heaven to be with the Lord, Jesus Christ.

When we got a set of orders for Pearl City, and we were able to use Tripler. Tripler didn't have the answers either. I threw a blood clot in '74. They almost had to amputate my left arm. Then in '75 we got a set of orders to back to Lejeune. So, we lived off base for a brief time, then we moved into TT2. My hair starts to fall out. Look like I've been through chemotherapy. No one can figure out why my hair is falling out. There's a large group of women. We're bald. No eye lashes. No pubic hair. We didn't have to shave our legs. We were thankful for that. Under our arms, but all of our hair was gone. I wore a wig for two and a half years. I was on 80 milligrams of valium. God knows how much Elavil. I was told that the reason for the headaches was . . . what was . . . they had several different excuses-change of life, being upset regarding my husband being a Marine, the other one, we just don't know. It's just migraines. No it wasn't migraines. We've now found that to be the thing. When Watkins Village was completed, we moved in to Watkins Village, which was a new townhouses. After probably about a year or so, Elizabeth my oldest daughter lost the use of her arms, neck and legs, spiked a high fever. They were continuously sick now. This whole time everybody's sick. I never knew what it was to have a birthday party for the children, to have an anniversary

or my birthday. Somebody was always at the hospital. I was always at sick call. They knew me well, but my children's was always sick. It was always a bona fide emergency, never abuse of the hospital.

The children, my children, as other children, spent many hours in the clinic, pediatric. I spent in ob/gyn, internal medicine, dermatology, ENT, all over-we spent it. Visits for one thing or another-rashes, such horrifying rashes, such bad ear troubles, such throat. You don't have little girls that's born and six and seven years old that spot blood. I was told that it was normal. We know now it wasn't normal. The hormone tendency really escalated within all of us.

So after Elizabeth was in the hospital, they came and they told me, they didn't know what was wrong with her and that she might die. Prior to me being taken to her room in the emergency room, they were taking their time. I want to share with this. Two weeks before she'd gotten baptized at church. Elizabeth couldn't say that much. She was scared. You could tell by her eyes. There could only be a whisper and she looked at me and she says, "Mama, Jesus is coming to get me." I want you to know that I cleaned that emergency room out in the loud voice I have. Doctors and lab techs started moving. She spent several weeks in the hospital, never with a diagnosis, at no given time. She had to eat liver every other day. I was told that there was a young woman Marine and a young male Marine that had the same thing. They didn't know what it was.

Short time later, after she comes home, they were home schooling her or they were coming to school over there at the house. The birds started falling from the sky. It was just like you were watching a cartoon and you see a bird flying and he'd go around hit the ground, flop and die. I called the housing officer and he told me they had trouble with mosquito spray. I was smart enough to know that when the raccoons were coming out of the woods, and the possums and the foxes, because I trapped with my husband, this was something I'd never seen before.

I called the CDC three different times, begged for help. I had a litter of pups, show English Bull Dogs, they muscle spasmed out, hemorrhaged from the mouth and rectum at the same time, within seconds death came quickly. It was a violent surge. So all this was within a certain period of time. I had called the Base Health Officer. I had called the Commanding General. I was raisin' hell like no one had ever seen with the hospital. I begged the CDC to do something about this. The Base Vet is the one that sent a Marine in a staff car to my home and picked up that puppy in a mason jar that I wrapped in the paper towel and was told to refrigerate until they picked it up. They flew it out of New River to Atlanta. Not only are the records gone from our hospital, the satellite clinics, the ob/gyn, pediatrics, the logs from the pharmacy, everything is gone to cover hindquarters, because the logs would have had the Social Security numbers of the sponsors, the medication was being used to treat the patients. Prior to Jim retiring in June . . . excuse me . . . In October 31st of 1980, June of 1980 I went in with cancer, to remove my uterus, because I had cancer. It's kind of strange that the next day, they removed my husband's testicle, left testicle because they said he had cancer.

Same household experts, my children today still are sick. My youngest one has lost thirteen babies. My middle daughter carried around a dead baby for two weeks before it could be taken. My middle daughter cannot conceive. Our husbands, brothers, aunts, uncles, served this country with pride, to defend 7/24, 365 days a year. There's no overtime, for us to be Americans. You saw it yesterday. The pictures of Paula's mother laying and dying. I've got the spots. I've done some TV stuff. I have the spots, I get covered and I'm not going to get graphic. Ladies and gentlemen, this is what happens to our bodies. My blood vessels bust, bleed out, crystallize, and form tumors. Little bit funky isn't it. Even with antibiotics, this will not clear up. There are times I have three or four hundred sores on me at a time. ... We had to take and go and scrape them. The surgeon scraped 'em and cauterized them twice. This is violent gunk that the Marine Corps and the Department of the Navy and ATSDR has put on us. ATSDR is supposed to be an independent affiliation of our government, but it's not. This is the biggest cover up in our nation's history. Our lives have been meaningless. The JAG office refers to us as alleged victims. We're not alleged, we are the victims. I've said many times, "God, why am I alive?" My husband committed suicide seventeen months ago, like I said. The word radiation has never came up. My husband also carried a rads meter. There's radiation. He told me the week before he died that if the people in North Carolina, that they were dumping in the ditches aboard the base at Camp Lejeune and that if the people in North Carolina, knew what was really on that base, they'd be raisin' hell so bad to shut it down. And he better shut his mouth for what he had just told me would cost him the rest of his life in Leavenworth. Now we have a man that was career Marine that loved his family. I've got a little boy back at the hotel, which is our grand son, that we adopted and he loved him, with so much love and compassion. For him to go off and take 300 pills, they quit counting, that he took of his prescriptions medicine.

I've never smoked. I've never done drugs. I was never promiscuous. Thirty-five and a half years faithful to my husband because I loved him, good, bad, indifferent, whatever went on. If it didn't have four legs and white tail, we hunted, we fished. We had a commercial fishing license. The water we took and swam in, got the shell fish. It was all contaminated.

The ATSDR/CDC at no time ever warned the American public that our blood is tainted! Whoever received my blood that I donated to the Red Cross got a death sentence ladies and gentlemen! This was something I could not understand. Why wasn't the public notified! Dr. David Williamson at the ATSDR/CDC admitted to me that my blood cannot be used! My organs cannot be used! I've got so much wrong with me, five trips to Mayo, Emory, which also there was a board member at Emory, a doctor that didn't even take and put his hands on me wrote a letter that any first year medical student could have wrote! When we say government and toxic poison, nobody wants to get involved! Our lives are meaningless! We are transients! You know, we move around a lot! Okay, fine! We move around, but I tell you what, when it's called to take and do security on this country, my husband, Mr. Ensminger, Jeff Byron was willing to put their lives on the line, and my dad, for me and you. To keep us safe from harm! Hell hole Lejeune is going to keep on killing us without a fight! As long as we can take our last breath, we will fight it all the way! We want those held accountable that made rank and position in this horrifying hell that has taken so many lives! All I got to say

is God bless our men and women in uniform, because if you don't help us, you won't help them! You as parents and as grandparents, you're looking at a disaster from the manufacturing industry to dump whatever they want and you drink it and you eat it. God bless each one of you and you're in my prayers because I really prayed a lot for you. Thank you.

Mr. Stallard: Thank you Ms. Harris.

Ms. Harris: Life isn't easy. It's not easy.

Mr. Stallard: Thank you, ma'am. Robert Thomas? Ms. Sandra Bridges? Let me just clarify please that neither Robert Thomas or Sandra Bridges is present. Okay. Thank you. Yes ma'am.

[voices too low]

Female Voice: [off-mike] Sandra is here.

Mr. Stallard: Is she?

Female Voice: [off-mike] But her elderly father is with her and he's ____ So there could be something going on. So she will be here. Do you want us to . . . ?

Mr. Stallard: She will have her opportunity to be heard. I just want . . . if she were here right now, this would be the appropriate time for her to speak. But when she does arrive, we'll make time for that. Is that all right? Very good. Okay. At this point in time, then, we are . . . since the other members are of the public have spoken before the panel yesterday we will stick with the schedule that we have for this afternoon for you to make additional comments at that time. Okay? This turns it over to the panel.

Dr. Cantor: Okay. Thank you. Our charge, we're going to go back to our charge which is to recommend specific types of studies that might be considered by ATSDR with some kind of a . . . I think it would be good to recommend . . . give a priority recommendation for different types of studies that might be considered. And, in thinking about how we could structure our discussion, I thought of two possible ways. They form kind of a matrix of information. One we went over briefly yesterday, through a list of the types of diseases or conditions that might be related to the exposures that we've been discussing. And so, that would form one part of the matrix. So we had . . . we can go over those in just a moment.

The other thing that we discussed was the various populations that have been exposed to at least some exposure. One of them at least is being studied by the current ATSDR study, but there are several others that came up. So the ones that are being studied, these are people . . . these are in utero exposures that took place. And the ones that we have not discussed, and have not been brought up for study, would be children who were living on the base. And I'd like any of the panel members to jump in if I miss one of these categories of . . .

So it would be children who'd be living on the base with their families; it would be civilians living there for longer periods of time, who might in fact be more affected because they had longer term exposures; civilians who lived off base, but who worked on base, and through their activities on base would be drinking the water being exposed in that way.

Now, did I omit any of the groups that we discussed? So we can think of the conditions and we can go down those in a minute as the rows and the populations as the columns. Conditions can be very very broad. Do you have the list Christopher that we put together yesterday? Does somebody have that? I might have that in my notes. Okay. Great. Yeah. Okay. So, uh. . . I'll just read down the list. I'll ask the panel to see if there's anything that is missing that we want to add at this point to this list. Neurological effects. As I go down this I'm not commenting whether this is feasible, whether it's doable. Some of these, as we get into our discussions, we may decide that would not be feasible to look at for any one of a number of reasons, but let's just go down the list.

So, neurological effects, spontaneous abortion, immune system effects, and this would . . . that's a broad range in itself, could be autoimmune disease or decrements in immune function. A broader range of heart defects than is currently in the study. This would be included under birth defects, I would assume. I mentioned autoimmune diseases. Umm. . . Then there was this very broad category of adult cancer.

Dr. Drane: What about the failure of any sub-systems such as the liver, kidney, spleen and so forth, all the vital organs.

Dr. Cantor: Failure or low functioning . . .

Dr. Drane: Dysfunction of.

Dr. Cantor: Right. Dysfunction. Okay. We'll make it very general, vital organs.

Dr. Ozonoff: Long as we're making sort of a . . . this is sort of a wish list. . .

Dr. Cantor: Yes.

Dr. Ozonoff: All right. Right. I'd add adult heart disease. So sudden death particularly, because these solvents are related to electrical disturbances.

Dr. Lynch: Along the same lines, if we're not going to discuss possible feasibility right now, I'd like to add to the wish list reproductive outcomes of children born at Camp Lejeune.

Dr. Cantor: Both male and female?

Dr. Lynch: Male and female. So, their children that they would have ...

Dr. Drane: You're talking second generation.

Dr. Lynch: Yes, I'm talking second generation. Particularly concerned about exposure of . . . at the time ovaries are developed and so forth.

Dr. Drane: Speaking also of children. Developmental disorders.

Dr. Selmin: Birth defects in general for children.

Dr. Cantor: Birth defects in general. So this would be broader than . . .

[voices overlapping]

Dr. Selmin: Broader.

Dr. Cantor: What is now being. . .

Dr. Selmin: But including neural tube defects and all. Because right now I guess we only have heart defects.

[Voices murmur, overlap]

Dr. Lynch: Also would consider adding issues such as anxiety disorders and depression.

Dr. Ozonoff: Skin disorders, rashes, ulcerations.

Dr. Visintainer: You know, I'm also thinking that cancer as an outcome would cover any cancer. What about liver function, kidney function, anything. I don't know if the records would be available but . . .

[voices overlap]

Dr. Drane: that's why I said the major organs.

Dr. Visintainer: Oh, okay.

[Dr. Visintainer and Dr. Ozonoff inaudible conversation]

Dr. Ozonoff: One thing that I've heard a lot about from community groups is urinary tract infections.

Dr. Cantor: Okay, so we have a vast list, I would say, that includes most things that can happen to us. So the question is how can these be addressed in a scientific and an epidemiologic way, in which they could be truly evaluated in terms of the exposures that took place. Are there, first of all, are there any that maybe we should at this early stage in our discussion, not consider any further, because it's highly unlikely that the effects would be seen, the exposure stopped almost twenty years ago. Are there any that we should not consider further because of that, because we wouldn't expect or there's a very low expectation that we could see them? Umm. . . for example, well, I don't know what . . .

Mr. Stallard: Ms. Harris would like to speak.

Dr. Cantor: Yes.

Ms. Harris: [off-mike] I didn't hear you say anything about muscle, nerves and bones. This has been one of [inaudible]. Muscle, nerve and bone disorders.

Dr. Cantor: We do have neurological effects in there, but we could include muscle and bones.

Ms. Harris: Muscle, nerves and bones. Also with the eyes, sir. A lot of the children, they are color blind. They have a lot of lost vision. Thank you.

Dr. Visintainer: An obvious one to add is just mortality studies.

Dr. Cantor: Mortality.

Dr. Visintainer: Adult mortality studies.

Dr. Cantor: Right.

Dr. Visintainer: And child.

Mr. Byron: [off-mike] Can I ask one thing? What about dental history? Both my daughters have issues with dental. I've heard other family members where the adults have lost their teeth all of a sudden. I don't know if anybody knows what that's about. Extensive dental history.

Ms. Harris: Can I have two minutes?

Mr. Stallard: No. No. Not two minutes, this is a time for the panel to deliberate. So I ask that the guidelines we agreed to yesterday that we adhere to them. Although the chair may ask . . .

Dr. Cantor: If there are one or two particular conditions you think we have not covered in a word or two, if you have a suggestion, I'd be happy to add this to the list.

Ms. Harris: [off-mike, inaudible]

Mr. Stallard: Okay, but Mr. Ensminger had something to say.

Ms. Murray: He has to be on the microphone or it won't be in the transcript.

Mr. Stallard: That's true.

Ms. Murray: Thank you.

Mr. Ensminger: I have talked to a lot of people that have been involved in this over the years. There is a

high incidence of female problems, with the children and women in general, that were exposed to this stuff. Mr. Rick Raines, who worked at Camp Lejeune's Environmental Management Department, he was on some of those emails that I provided you yesterday, grew up on the base. He was the dependent son of a Marine Colonel. His mother died of female cancer, both of his sisters had full blown hysterectomies in their twenties. My daughter was seven months old when we moved into base housing. She has extreme female problems. It's pretty general. It's quite frequent that hear about this from other people.

Mr. Stallard: Thank you.

Dr. Visintainer: Picking up on Mr. Ensminger's comments, can we do incidence or prevalence of hysterectomies, infertility of men or women . . . inability, I mean, as a way of measuring infertility. Spontaneous abortion presumes that a woman can get pregnant. So, if there's known infertility, and I think maybe that coupled with the cancers, and the surgical histories.

Dr. Cantor: Amenorrhea, perhaps?

Ms. Harris: Reproductive; a lot of men could not father children.

Dr. Visintainer: Cancer.

Ms. Harris: [off-mike] Reproductive. A lot of the younger girls . . . [inaudible]

Dr. Cantor: I think after yesterday's discussion the people here who aren't epidemiologists are getting perhaps an appreciation that the tools we have to look at these in any critical quantitative way are very very limited. So, we'll now turn to looking at the different groups of people and just discuss them briefly. My perception is . . . and people can amplify this, on the panel. . . That there's a certain . . . certain feasibility studies would have to be done to see if in fact some of these groups can be studied. The issues are first of all identifying who is in the group. It sounds very simple, but it's not simple at all. Once having done that, seeing if there are adequate personal identifiers available to researchers, and what the resources are for follow up of these individuals, both in terms of health events and their life and in terms of what record systems exist. I'll leave it that broadly.

So, what are the four or five groups? One of the groups we talked about was the children who were living at . . . on the base, for any length of time, be it rather transient or being children of civilian people. The question is can we identify this group of people? Let's say a child is up to high school graduation, up to 16 or 17, 17 years old. Things that first come to my mind are school records. I have no idea whether these exist; whether they could be available. This is the kind of feasibility study that would have to be done; there would be a need, to find out more than the person's name. That is . . . So that is one group. Does the panel have any comment about this?

Dr. Ozonoff: Well, I think it's evident to everybody that we're thinking this through along with you, and trying to figure what to do here. So, here is one idea of what to do. Let's take any of these groups. Let's

take the children, for example. If you had a list of the children who were exposed to Camp Lejeune water, drank it, swam in it, ate food that was prepared in it, and so on, and you were able to find out, for example, how many of them were learning disabled or had dental problems or gynecological problems, you could then ask the a question; is it more common amongst children who drank Camp Lejeune water than you would expect to see just in the average group of children? I think that's a sensible question and it gets at; are they sicker than other kids? – is sort of the bottom line here.

So how would you do that? First of all, you would need to find, to get as a good a group of children that were exposed and unexposed kids to compare them with, and then find out something about that. So here is a suggestion, for this group and for all the other groups that we're talking about-the adults and whoever. Finding a group like that of sufficient size, so you would be able to do some studies on it, takes a little bit of ingenuity, knowledge and hard work. I don't think that ATSDR can do that by itself. So, my suggestion would be that it do it in partnership with you. You know better probably than they do, in some areas, how to find people. Where they are, and all those kinds of issues, and you have the motivation and the persistence and the ingenuity to think of things that they don't have the ability, 'cause they're doing other things as well. Let's assume that you did that for each one of these groups-the adults, the children, the people on base, off base, and so forth. Once you had a list like that assembled then there are ways to find people. Given enough money you can find people in this country. I don't know if that's good or bad, but it's true.

[off-mike inaudible comment-laughter]

Yeah. They . . . right . . . and they can keep after you until they get what they want, so you can keep after people 'til you get what you want. That means that you don't have to decide all this all at once because there's one task that has to be done first, which is to get this group of people, and then some way to find them afterwards.

Mr. Ensminger: The issue of finding these people. . and that's something that really bothered me for a long time. Everything in the military, as Chris knows, hinges around the sponsor, the service member. My record book when I got assigned to base housing, there was an assignment, entered in my record book because they had to pull my basic allowance for quarters. If I lived off base they paid me that money. When I moved into base they took that money. There was an entry in my service record book. There was an entry in my pay record. When you cleared housing there was an entry made, when you left housing, when you cleared housing, so that you started to draw on that money again. These people in DOD cannot tell me that they cannot find these people that were in that housing area. That's a lie. They can do a computer program and find every individual that was assigned to what housing, what street number.

Dr. Lynch: Mr. Ensminger, I would be interested in your thoughts on an issue I was thinking about, since I think the panel really should be all inclusive of all those individuals who were potentially exposed. One issue that might be a concern, I'm particularly concerned that this particularly linked to the service person.

So, in instances where there might have been a divorce or separation, you might lose the other half of that family. Do you have any thoughts on how people might be able to, say, find a child, mother and child, or a father and child that might have been separated from the service person. Do you think that could be done?

Mr. Ensminger: There's another thing, all right, whenever you have a dependent that's the sponsor. There's a dependency form filled out and it's entered in your service record.

Dr. Lynch: Okay.

Mr. Ensminger: That's the only way you can have a bona fide, certified dependent. . And you've got to enter that in your record. My wife has an ID card. She's in my record.

Dr. Lynch: All right. Good to know.

Mr. Ensminger: All those children had IDs. Before they could live with you in housing they had to be in your record book. They had to be a bona fide dependent.

Dr. Lynch: Do you happen to know if they collected information about Social Security numbers of those children on those dependent forms?

Ms. Harris: [off-mike] Yes.

Mr. Ensminger: If the child had one at that time. See back then, they didn't require it.

Dr. Lynch: Right.

Mr. Ensminger: That wasn't 'til

Dr. Lynch: Eighties or nineties.

Mr. Ensminger: Yeah.

Dr. Lynch: Okay.

Ms. Dyer: [off-mike] Can I give some good news about the [inaudible].

Dr. Lynch: Please. Name

Ms. Dyer: Terry Dyer. Just to let you know. I'm going to address a couple of things. You were asking about divorcees, that sort of thing. Just to let you know, our Website, the water survivors. When they contact us, I talked about to just about every single one of them. Karen [Strand] and I try to either e-mail them or call them.

[Tape change]

Okay, and that's 650 people, from that we talk to their families. I get calls all day long. This is like a job. They're sending calls to me from all over the country, their children. One thing that I have made an issue with them is that there is a lot of divorce. Okay. So, I have asked, I specifically say are you still married to the Marine that you lived with at Camp Lejeune? And a lot of them aren't, and I have said, "Will you please contact them and then let them know about Lejeune?" I've actually had a few of them say, "I don't talk to the SOB anymore, but I have his telephone number and I will give it to you." I've called them. I've told them, "This is so important. If you don't want to speak to him that's fine, but let me call him and I'll tell him."

The next thing, I've been hearing a lot about . . . I just want to address this, everything he says, that they're transient, they're all over the place. I mean it sounds like, you know, they're a bunch of carnival people or something. I'm sorry, but that's what it sounds like. I just want you to know, we weren't military. We were civilians. I lived out there and everybody else was moving around, but this is the tightest knit group of people you will ever come across. They stay in touch with each other. These relationships that were formed on that base, and probably most bases around the country, it's a time of war, you've got fathers that are leaving, these people bind together. They're a family and we were a part of that family. I belong to Lejeune alumni. I didn't get to graduate at Lejeune because my dad died, but I was invited back to give an honorary diploma to. I go to all of the reunions. We have a reunion every five years. That's pretty good for people that are transient, isn't it. They come from all over the country. This July they're going to have another one. There were thousands of people there the last five years . . . five years ago. We have . . . they have a Website that I'm a part of. . that I give updates to people. I have been asked to speak at this year's reunion on the water contamination. So, yeah . . . we get people together from the fifties until last year graduating. Okay? So, there is that group of people. So, I think that that's good news. That's a lot of people.

Dr. Cantor: About how large is the graduating class?

Ms. Dyer: Our graduating classes? I can't remember. They weren't that large. I mean Lejeune is a small school, it's not, you know, huge, but I would say probably several hundred and we all get together. So, this is . . . It's really amazing. You can go onto Lejeunealumni.com and they have a memorial board on there. You can also look at the years that these students died. I can't tell you how many of my friends that I was in school with are already dead. Okay? Thank you.

Mr. Stallard: Thank you very much.

Dr. Ozonoff: It seems to me that's sort of a good example of the kinds of things that are known by you, but might not necessarily be known by ATSDR or a university or something. So, I think that the ground rules under which this panel is operating, as far as I understand it, are that we're not going to give a consensus thing, but each of us are going to speak for ourselves. So, I'm speaking for myself now.

If there's going to be a partnership, first of all, it's got to be a real partnership, but secondly, people . . . ATSDR's not going to work for nothing. If there's going to be a real effort on the part of Lejeune residents and people who've lived there and have a stake in this, they can help to work on this and help assemble a cohort, there ought to be funds available for that, staff funds. It's a job to find all these people and do it. So you should be compensated for it. That . . . to build in an infrastructure in the non-ATSDR part of this, seems to me a reasonable thing to ask for-help maintain the Website, to pay your hours for calling on the telephone, and the telephone bills, and all the kinds of things that have to be done. To staff it up, in other words. It's a real operation, as a part of assembling a cohort that could be studied at some point for almost . . . for whichever of these things turn out to be feasible. It's not always possible to get information on all of these things, but I would think that a genuine partnership is about the only way it's going to be done in a reasonable time fashion and . . . whether it's feasible or not.

Mr. Stallard: Yes.

Mr. Byron: I would think that the Marine Corps publications would be about the most effective, similar to the Leatherneck magazine, the Marine Corps Association, . . . Oh, I'm forgetting, see I'm not married [laughter]. I think they've been reluctant to put anything in their publication concerning Camp Lejeune toxic water. Obviously that's not the issues that they cover. They cover the Marine in the field which we all appreciate, but I think if the DOD and the Marine Corps and the Department of Navy would ask in the proper manner, the Marine Corps Association I'm sure would put it in. But it's going to have to come from the Marine Corps and the DOD, not Jeff Byron, the veteran. They don't listen to Jeff Byron, the veteran. They listen to the DOD. They listen to the Marine Corps. If the Commandant was to write a letter and ask them to publish that for the next three months, you'd see people come out of the woodwork.

Then they could tell their friends and even if they were divorced they'd go to their wives and their children and say, "You've been contaminated when you were at base. You should see your physician or you should call ATSDR." But this hasn't happened, when the Marine Corps and the DOD has come out and publicized this, it's all in small print. Just like when you sign a contract and you want to dupe somebody, you put the fine writing at the bottom. Well, that's basically what they've done. We can show examples of that. So what they really need to do is open their hearts and be compassionate to these victims, and really put out a public statement and make it meaningful and not just a token effort. And, really . . . I challenge them to do that once again. Thank you.

Mr. Stallard: Thank you.

Mr. Ensminger: [off-mike] Plus they have . . . they have the tools.

Mr. Byron: [off-mike] That's what I mean.

Mr. Ensminger: [off-mike] They've got the records.

Mr. Byron: They use Lexus Nexis to find us. I've lived in the same city my whole life? They said they couldn't find me for twenty years. Come on guys. Use Lexus Nexis to find the rest of us.

Mr. Stallard: I want to see if the panel has any comments at this point.

Dr. Cantor: A brief comment?

Mr. Stallard: I'd like to remind the public that if your comments are germane to your ability to help organize and find information resources on how to get to the people, that's . . . try to confine your comments to those topics.

Ms. Harris: The ATSDR already has . . . my name is Ellen Harris. The ATSDR already has the original surveys that was done back in 2000. There are a large number of people that, when we were called regarding the child that we had aboard the base, we were asked regarding our other children and our health. At the time, in April of 2000, they asked regarding my other two children. They wanted to know immediately if my daughter was dead or if she had cancer. They wanted to know my background healthwise. We should go forth with those information, and we will get a big start on those right there. They've already got that, if those haven't been shredded, but we've got to remember the Marine Corps and Navy is not willing to give one bit of the logs and information to any of the panels.

Mr. Stallard: Thank you. Thank you.

Ms. Harris: Medical records are missing. A lot of records are not found.

Dr. Cantor: Yesterday we requested a copy of the questionnaire from ATSDR. Do we have that? Good.

Dr. Lynch: Actually I just want to make sure that this doesn't get missed. I just want to go on record, as has Ms. Harris, they have already started the study. I actually think that study needs to be expanded to all children who were conceived at Camp Lejeune. I understand that children move and so forth, but we can find these people. I have a little bit of concern that sick people might have moved, and might have had reason to deliver elsewhere. So I just want to kind of go on record that I think there should be . . . Someone should assess the feasibility of trying to locate children conceived . . . all of the children conceived at Camp Lejeune.

Dr. Cantor: So which children are missing from . . .

Dr. Lynch: My understanding is that initial survey only included children who delivered in the county . . . conceived at Camp Lejeune, delivered in the county. I would actually like to see them assess the feasibility of finding all children. For instance, if a woman received prenatal care and then they have it on record that she moved before she delivered. Make some effort to contact all of those people.

Dr. Cantor: Is there an ATSDR person who can respond to that. I guess not. Frank. Frank Bove just walked

in. Could you repeat . . .

Dr. Lynch: I was just making a comment that we were talking about the different populations, potential cohorts that might be interesting to assemble. Obviously you have this cohort right now of children conceived at Camp Lejeune who delivered in the county. I was making a comment that I thought it would be good to assess the feasibility of potentially finding all the children who were conceived at Camp Lejeune. For instance those who might have received prenatal care and might have moved. I'm particularly concerned there might have been some reason for people to move, if they were more sick. Maybe they moved home to live with their mother.

[Overlapping voices]

Dr. Bove: Or just plain transferred. People moved in and out of that base, especially during the Vietnam War period, but even after that. So no, that's not the reason, but we did try to find those people. We used all kinds of approaches. We don't know what the denominator is. We're basing that 3,000 to 4,000 on conjecture, basically, from the Naval hospital, because there's no other way of knowing.

Dr. Lynch: So those people who . . .

Dr. Bove: At least, no other way of knowing that we had access to. Now if there are broader databases that the Defense Department has, and that's what I was doing outside there, just discussing with someone from the military exactly what . . . the woman who actually was in the military . . . she works for ATSDR now . . . what data is available and what she thought, if there is some larger database Defense Department has, we haven't had, we weren't permitted to have access to it. And I'm not sure how the database would be linked and what's in it. This is something that could be looked at. One of the reasons why we didn't, of course, was, remember, the Public Health Assessment said that adult cancers were not a problem. That sort of tied our hands to some extent working with the Navy.

These are things now that we might look at, with your suggestions, but that's the question. I think that's the key question. What databases are available in the Defense Department? What are the identifiers there? How can you adjudicate common names? That's the question. That will probably be important for all the sub-groups you're talking about, because I think that there probably is information on dependents in that database, as well as link to the military sponsor... But whether we could get access to that for privacy reasons; what the data looks like; what's available and how far back is it computerized. Because the housing records at Camp Lejeune are in boxes in a spare office in my building. They are not computerized. Now whether they're computerized somewhere else, we don't know, but they weren't computerized and we had to hand search them.

Dr. Lynch: Right.

Dr. Cantor: David, you have a comment.

Dr. Ozonoff: Yeah. Dr. Lynch made a really interesting suggestion this morning before the meeting started, about revisiting the Public Health Assessment. I'm trying to think of any incidences where ATSDR has done another Public Health Assessment. Let's face it, there's been additional information generated since 1997.

Dr. Bove: [off-mike] That's true.

Dr. Ozonoff: Without going into opinions, you know, of that 1997 assessment, what if you did another Public Health Assessment?

Dr. Bove: There's been, now that I think about it, in fact, one that comes to mind immediately is Tinker Air Force Base, where, because of something else going on at the base, we went back and did additional work. So, that's not . . . there's some precedent, I guess.

Dr. Visintainer: Especially, since it's not just new information, but identification that there was misclassification. There was an error, not just a difference of opinion, but there are errors in that report.

Dr. Bove: There are errors in the report, but I don't think . . . Distinguish the study from the report, because there are errors in the study. The report itself is based on a risk assessment of sorts, although we're not supposed to do risk assessments. That is a matter of dispute. Okay? The battle going on among researchers/agencies around TCE and PCE, around risk assessment, you should be aware of that. So I think that that . . . my agency hasn't had the chance to sit down and hash that out.

Dr. Ozonoff: I'll just speak to you as an individual in your agency for the moment. The 1997 judgment about adult cancers, not being . . . not likely to be a problem, from my point of view as somebody who's pretty familiar with the TCE/PCE literature, is a faulty judgment and needs to be revised. It's just plain wrong and needs to be revised. If a good way to do that is to have another Public Health Assessment, which will then have another opportunity to take into account additional information that's been generated since 1997; if doing another Public Health Assessment has the benefits of correcting that earlier judgment, on the one hand, in also providing a rationale that will allow ATSDR to do some things that it's found difficult to do vis a vis the Marine Corps, because of that Public Health Assessment, that's another good reason to do it.

Dr. Bove: Well, I think it's a good reason to do it also, because after the water modeling is done, we'll be able to characterize the exposure situation a whole lot better than we did in the past. So I think you can make that recommendation. I think, though, that we'll probably want to see what EPA does with its TCE risk assessment.

Dr. Ozonoff: I don't know how old I'll be. . .

[laughter]

Dr. Bove: I don't know how old I'll be either. I don't know how that . . . my agency will resolve these issues

that are internal to the agency, disputes around the toxicity.

Dr. Lynch: I think the inherent problem with that is that, with the concerns with some of the information about the Public Health Assessment, that although there is sort of an institutional memory, people recognize that some errors were made, and so forth. Until that's documented, until that's acknowledged in writing, that's maybe not sort of the whole story. I think it may be difficult to have future studies then. So, I think it's very important to have that in some way acknowledged in writing. If a whole Public Health Assessment can't be done, an addendum or whatever may be the appropriate way, I think it's important that that be documented.

Dr. Cantor: Yeah. In the absence of a recommendation such as that from us, for us to say that we think that adult cancers should be a legitimate end point or a high priority would, however we would say it, would sound ridiculous.

Dr. Lynch: Right.

Dr. Cantor: So. We have someone who would like to comment from ATSDR? CDC? Please introduce yourself.

Dr. Daphne Moffett: Good Morning, my name is Daphne Moffett. I'm with ATSDR. The only point of clarification that I wanted to make is that when ATSDR evaluates a site and actually writes a Public Health Assessment or health consultation, it is with the understanding that the agency will go back and take a look at new data that becomes available and reevaluate it, if need be. As I understand it, the Public Health Assessment that was released for Camp Lejeune is in that process right now. So, I just wanted to clarify. Yes, it is a different Division. That's not my Division, but because I've been on this work group, I'm looking at TCE. I have spoken with the author, so I do know that they are taking a look at it.

Dr. Ozonoff: So there's another Public Health Assessment being done on Camp Lejeune? Is that what you're saying?

Dr. Moffett: Usually they don't go . . . what is normally the case is they will go back and re-evaluate with the new data, whatever the public health action was recommended in the past, or whatever the public health call was in the past, to see if there is something that needs to be addressed. So it may be that we did not have access to all the data prior, or that there are new issues.

Dr. Visintainer: I would like to know, I was going to say I assume, but maybe . . . why don't you tell me, there is coordination then among these offices? They're not just working parallel and independent? You would use the water modeling. You would use the reanalysis.

Dr. Moffett: Yes.

Dr. Visintainer: In the Public Health Assessment?

Dr. Moffett: Most definitely.

Dr. Visintainer: You will coordinate and wait for this information to come out, and then be informed by ATSDR's findings.

Dr. Moffett: Yes. What I can say is that the Division of Health Studies, which is where Frank is located, the Division of Toxicology, which is where I am located, the Division of Health Assessment/Consultation which is where Carole Hossom is located, who is one of the primary authors for the Health Assessment, have all spoken about some of the issues for TCE. Some of it's been in coordination with our Washington office. So, yes, yes, Morris Maslia is conducting the. . .

Dr. Visintainer: What about timing? How long does this process take?

Dr. Moffett: That I can't Since I'm not the one with primary responsibility I'm afraid I can't comment on that.

Ms. Harris: [off-mike]: 30 years.

Dr. Bove: I do want to say this; there is a new table that was put on the Website, our Website that updated, and sort of an update of the Health Assessment. And it's not much that much different from the old table, I have to admit. So I don't know . . . I just don't know what stage they're in . . . that's a different process. Keep them separate. The water modeling is part of the study. We asked the other Division to do that, 'cause that's their specialty, this group, and that's part of our study. So we're very closely connected there. But the health assessment process is a different process. That's done in the Division of Health Assessment and Consultation. We may not know what stage they're in, my Division, because that's something that they do, but I am not aware of any changes to the Health Assessment going on now. But, there may be some, but I think it wouldn't hurt to make any recommendations in this area.

[Inaudible comments]

I don't know if we can answer that.

Dr. Moffett: It would probably be best, if that Division would state where they are, because it is their . . . it's an agency product, but they are the lead on this, but I would also like to make . . . perhaps you are all aware that NAS is not finished with their deliberations for TCE also. So, there will be . . . that will be forthcoming. So . . . great . . .

[Inaudible comments]

Ms. Sandy Isaacs: Hi, I'm Sandy Isaacs. I work in the Division of Health Assessment and Consultation. As far as the issue of what we will do with the Health Assessment right now? We look... you know, we do the pathway exposure, and very the dose is very important. There was a lot of uncertainty, when we did the

Health Assessment about the dose, and so what Morris Maslia is doing will certainly elucidate some questions we had; when pumps were used and things like this. So, we're not currently working on the Health Assessment. We do . . . we'll wait and see what those doses come out to be. Certainly, as Frank stated, after we've done the Health Assessment, we are open, if some more information comes out that may affect the exposed population, the doses received, or really the state of the knowledge of the time. It's been mentioned, there are a lot of issues about TCE, but if information comes and goes, "Okay it's been updated since then," we're always open to redoing that. There is not, let me reiterate, there is not currently activity to redo that Health Assessment right now. We're very dependent on the completion of Morris Maslia's work to determine the doses. We made some assumptions in our Health Assessment. He should be able to fine tune that.

Dr. Lynch: So when these things are revisited typically what form does a reassessment take? Is it a new report, because my concern is even though you might make an updated table available on your Website, unless it's published in an official form, I fear that might not be acknowledged by sort of the appropriate entities.

Ms. Isaacs: We have some options on how to do that. We have . . . it could be a new amended Health Assessment.

Dr. Lynch: Okay.

Ms. Isaacs: Or, we have a document we also use, as a Health Consultation that if there's a specific focused issue that needs to be revisited, we may just do a shorter document, easier to get out, that will address what is updated, what we have learned, how it impacts our conclusions, and previous conclusions.

Dr. Cantor: Do you have an external advisory committee for the Public Health Assessment?

Ms. Isaacs: The Agency has a Board of Scientific Counselors . . .

Dr. Cantor: Do they review each one? Or do they make recommendations for changes or revisions or future areas in which Public Health Assessment should be made?

Ms. Isaacs: They look at broad areas. We do have the Board of Scientific Counselors, which looks at our approach, but does not look at individual documents. However, in the Agency, we have a mechanism that we can send our documents to independent peer reviewers for comment.

Dr. Ozonoff: Hi, Sandy, it's been quite a few years. Here's what I worry about, from what I'm hearing. It sounds sort of like the town in the Midwest that has a law that says that when two cars to the same intersection on different streets with stop signs, each one has to stop and wait for the other one to proceed. You know, the Health Assessment is effecting the studies, because, you know, from what I understand, the Marine Corps is saying, "Well the Health Assessment said adult cancer is not a problem, so

you're not going to do adult cancers." On the other hand, now the Health Assessment is saying, "Well we're waiting for the study to find out and the water modeling, what's going on." It sounds like it's gridlock. Or am I misinterpreting this?

Dr. Bove: Well, there's a third party here. The Navy. So, you know we have to justify why we're doing the study, and you know how difficult that can be at times, especially on a controversial substance like TCE and PCE. So it's not just gridlock, if you will, within the Agency, but we also have to make a case with the Navy, because they're funding the studies for one thing, or we're going to be using their data.

Ms. Isaacs: Certainly as far as the doses . . . as far as we know we have the information that was available, but the dose reconstruction is going to be very important to that, to give a better idea. As far as the science now. . . That is not something that has to wait on a Health Assessment. If we need to look at that and go, "Did we consider everything? Or is there new information that should be considered?" So, I believe there are other avenues, other than a Health Assessment that we may be able to look at. But as far as . . . a Health Assessment now, we would look at the pathways, the susceptible populations, whether there's a completed pathway, which we know there is, but then we look at the science. So, if we can't fine tune the doses, then the other thing we can look at to see if we need to reconsider something, is where is the state of knowledge on TCE and its impacts. That part is not having to wait for the dose reconstructions first.

Dr. Ozonoff: Well, TCE is something that I actually know a reasonable amount about. The thought that there is, like, an algorithm or computer program that'll tell you what the state of the science is, is not exactly it. There's a lot of disagreement out there and if you have, you know. . . there are people who for one reason or another don't think that TCE is bad. Then, there is probably most of us who know the science, who think there's quite a lot of information about it, about TCE and PCE. It's hard for me to understand . . . I don't understand the judgment that was made in the '97 Public Health Assessment, Sandy. I'll be quite frank with you, that adult cancers were dismissed didn't make any sense to me then, and the science now has only made the case stronger. So, at the same time, that judgment is really affecting what can be done now, it sounds like. When I hear about where the science is and where the science is going to be . . . I see what happened. The reason that NRC is looking at this is because it was a hot potato, and EPA didn't want to touch it. Whenever that happens, they kick it over to the NRC, and that buys them another year or something like that. I'm just speaking as an individual. I'm concerned about this whole thing. The wheels are spinning here.

Ms. Isaacs: I don't believe the Health Assessment is the stopper right now to going further. I think the discussion about TCE and what's known is very key to that. The reason I say that is we look . . . we do, we put out, we call it a final Public Health Assessment with acknowledgment that if something changes we look at it. I'll give you an example. We certainly . . . lead exposure, at one time 50 were considered safe, and we might have made a call at that time. However, the increase . . . as knowledge increased about it, health impacts about lead, the weight of evidence shows that what was once considered protective is not. We had information that we could go back and look at those sites. It didn't require a Health Assessment to

perhaps say, revisit. One of the purposes of a Public Health Assessment is to determine actions that stop exposure. Well, that doesn't help in the past. If you've got a current or future potential exposure, a Health Assessment makes recommendations to mitigate that. However, in the past, it also points out areas where more information may be needed for ATSDR to make a call on whether, on a public . . . looking at public, not health, not individual health, if more information may be needed. That's why we work with toxicologists. We actually, at Camp Lejeune, it was an example where we worked very closely with DHS in discussions of exposures we were seeing. The first study was actually done during the process of a Public Health Assessment, which is quite unusual. We saw an exposed population, and they started a study, which is the way it should work and not have to wait until a Health Assessment is finished.

So, I believe there's ways we can consider what needs to be done without a new Health Assessment. Again, we'll be going on our conservative assumptions about the dose. A better assessment of that might be what the actual dose . . . as far as the doses, would be to wait for the dose reconstruction is finished, because we don't have any more information that might change the dose. However, perhaps to look at the science, based on what we know now, should more be done?

Dr. Ozonoff: Well, let me just make a general comment about the agency, and not about the Federal Facilities Branch or anything that you folks have done. Having worked with you a number of years ago, I'm really aware of the difficult problem that you have. You face a daunting task, but my general observation is that when considering the science, the criterion the agency has used is, hit me over the head with a two-by-four. I mean, I don't know what it takes to convince ATSDR about the science of some of these things. You have to have a nuclear device set off underneath you in order for you to, "Oh gee, I guess maybe those things are bad." It's a problem. I can't believe that people are arguing about TCE. I really can't believe it.

[Off-mike comments] Inaudible.]

I know they are because I run across those people all the time. But, give me a break. And I left out a word before break.

[laughter]

Dr. Maas: Maybe just to reiterate, what some of the things that Dave has said that I think most of us on the panel are agreed with; is that, in terms of the Health Assessment, what we heard first hand yesterday was some new information that there were areas on the base that in fact were supplied by contaminated water, which you at ATSDR now realize that it was true. So, where we stand right now is that you know that this Health Assessment is incorrect in some major ways. I think what we're all concerned about and trying to get at here; is there some way to not sit around for a long time until this new hydraulic modeling and the exposure assessment is finished? To acknowledge that there are some problems here that we already know are problems, in terms of areas of the base that were served by contaminated water. Probably now in 2005, you might take another look at the kind of out of hand dismissal of adult cancers. So there might

be some reason to, least in the interim, put some kind of addendum or something that acknowledges that there's new evidence that's come out here and there are some problems.

Dr. Bove: There is some new evidence, but even the old evidence . . . Okay, remember there were . . . the evidence hasn't changed until Morris does his modeling for the PCE exposure at Tarawa Terrace, that hasn't changed. What also hasn't changed is the exposure at Hospital Point, all those years. The thirty-something births in Nancy's study. So that hasn't changed either. So the doses haven't changed for them, unless Morris's work does change them. So, so, what? So just keep that in mind, that we're talking about numbers changing, not doses changing. More people than we thought were exposed but the doses haven't changed for them. I mean the doses changed for those people, but there were people there . . . the assessment was based on those people who lived at Hospital Point, the TCE people who were exposed long term; that's part of that Public Health Assessment.

So, I do think that the problem lies in disagreements around the toxicity of TCE and PCE and I think that my agency is also watching developments with EPA with NRC. Correct me? That's maybe how, with the nuclear device that we need, to feel justified to go ahead. Now, whether that's right or wrong is up to you to decide, but, of course . . . we can make our own decisions, but that I think is part of the problem. There is just this debate within the agency, as well as across the agencies, on the effects of TCE and PCE.

Dr. Cantor: So, we can certainly in our report make comments on the Public Health Assessment and where that would take us in terms of our recommendations. Many of us will. We're going to act as individuals on this. It's a little after 10:30. We will take a break now for

Mr. Stallard: 15 minutes.

Dr. Cantor: 15 minutes. We'll see you back here five of the hour.

[Whereupon, those assembled adjourned for a break, and then reconvened.]

Mr. Stallard: Okay, ladies and gentlemen, please take your seats. We will resume. We have two members of the community who have arrived who have not presented before the panel who we will ask at this point to make their presentation. Limit to ten minutes each. Is Miss Sandra Bridges here please? Please come forward. This is a good crowd. We're looking forward to hearing from you. So just have a seat right here.

Sandra Bridges: Okay, I've never done this before, and I wasn't here yesterday, so I don't know what went on, how other people explained themselves. I know I've been done wrong and I'm asking you to help us. I had a son that was born, was conceived there at Camp Lejeune, was born at Camp Lejeune and is very sick. He's a grown man right now. He's thirty-three. He has two children, but his problems, I believe at least to his speech, maybe hearing has been passed onto his children and the curvature of the spine, both of those things have been passed on. We moved to TT. My daughter was three. Excuse me. Yeah, three, when we moved to TT. At that time Ken was a staff . . . rather a sergeant. We really were entitled to better

housing, the four bedroom, two bath, but because we were on a waiting list we took TT. He came back from overseas, Cambodia and then 'Nam. We didn't move, we stayed there. Don't ask me why, I couldn't get him motivated to move, and I was an obedient Marine Corps wife. I stuck with him. So we lived a lot in the same place, with a lot of various people came and went, corporals and lance corporals. So we were probably the oldest ones there. So I'm probably the oldest one here from them. John, when he was born, he was sick. He just stayed sick. They were going to put tubes in his ears, but he couldn't get over a cold. He would cough.

[Tape change]

It never got to that point where they could put tubes in his ears, which was the thing to do at that time. At four months old, I went through a week of hell with wild temperatures, I mean 103, 104. I'd take him to the children's hospital there on base. It was nothing they could do. They didn't see anything wrong with him. They didn't know why. They'd give medicine. Tell me to put him in a cold tub of water. Finally, I made an appointment with a woman pediatric doctor in town, but before I did that I went out to the base early one Saturday morning, took him out there again. I wanted to be that dutiful Marine Corps wife. They say, "It is spinal meningitis." Well, no one else had spinal meningitis. No one else on the base, but he had spinal meningitis, after doing a spinal tap. They'd made what had supposed to have been a ten- to twelve-day stay ended up being twenty-one days. Why? Because he couldn't stop throwing up, they'd feed him and he'd throw up. When I fed him, he didn't throw up. Thought, what is this, you know? Why is it when I feed him? It never dawned on me. Did it dawn on them? I don't know. They were giving him formula diluted, Similac diluted with the water, and he was throwing up, but when I was feeding him they gave me the regular bottle. It wasn't diluted. It was straight formula. He wasn't throwing up.

I brought my son home. He was my little blond haired, blue eyed baby that had been sick. I had my tubes tied after my son was born. So, I knew I wouldn't have any other children. That child, John, got straight formula, there was nothing . . . I got the best I could for him. He never did . . . I never did dilute his formula. Sure he had the water, which was boiled. I would boil the water before I gave it to him. It was right after that that we moved from the base. We move to Charlotte, but I know in my heart it's the water. It was the water. Not only did I subject him to that, but I subjected him not only the water that we had at the apartment, but to the water in the swimming pool.

At that time, it wasn't open. It was closed. You walked in, I remember it burning your eyes. You walked in, it just burned your eyes, just walking in the fumes from it. It was all closed in. My daughter was six months old, and I had her swimming in that pool. She was born at the base, but at that time we didn't live on base. We lived in New River when she was born, the oldest one, my daughter. Two children. She was six months old. That was in '68 and she was swimming under the water and opened up her eyes, you know. We always were at the pool, especially when we lived at the TT. It was every other day I had the kids there. It was something to do, and I've always enjoyed the water and Nita would dive off the diving board. But anyway, that was another contamination point.

Those apartments, I mean, they were just put together . . . and water underneath the building, in the backyard. It would just . . . when it would rain it would . . . the porch, the little screen porches like . . . it would cover the cement and just lay there in the back. We'd have mold in the bottom of the closets. You put your shoes in there and three or four, well not three or four, maybe a week, you'd see this mold. You'd have to wipe your shoes off. It would just cover it. Mildew, not mold, mildew, cover the shoes.

As a result of, John, he has a speech impediment. He grew up with that. He's overcome it, not overcome it, he's learned to compensate for it. When he's tired, he slurs his words a lot. But normally, he's pretty good in that respect. He had therapy and we worked with him. A learning disorder, we channeled him in the right direction. He got into something that he was able to do. He went to school for it. He went to college for it and he's got himself in a little business. The hearing, nothing you can do about that. Now, those things may not have been a result, a result of the water, it might have been of the medication that they gave him. I know that his head, a number of times I'd go in, and his head would be all swelled up. You couldn't even see his eyes. The needle was so little at four months old, the needle would go in and they weren't able to keep it in there. So, they sewed it finally into his legs and into his ankles. He still has the thread, brown thread, or black thread in his ankles, you can see it. His disabilities, maybe they didn't come from the water, maybe they came from the medication they gave him afterwards in the hospital.

I don't know, but I know the water made him sick. My kids have never been really sick since we left the base, when they were little. If anyone, John would be a prime example to study, because the only times I ever took him to the doctor, I was so turned against doctors and the military, but . . . especially the military . . . but not . . . but the doctors. I didn't feel that they had really done what they needed to do for my son. He never . . . laughed, until he was five months old. Do you know what it's like to have a child that doesn't laugh, a baby, that doesn't laugh with you. You play with him and . . . he doesn't laugh. He doesn't hardly smile. My son didn't. He's different today, he has a wonderful personality.

My daughter had a heart murmur, they said at the hospital. I hadn't heard anything in the last fifteen years about a heart murmur, but she used to play in the dirt right out front. We lived at 2816, I believe, Boganville. It was right behind the little shopping center. There was a daycare, which we got free day care, which I took advantage of. Not with John. I never left John. He always stayed with me, but prior to John getting sick I took advantage of the childcare, because Ken was on Tarawa Terrace Community Center. They had bingo in this great big huge room that used to be, I guess, a skating rink and the commissary, but they played bingo in there on . . . two nights a week. Ken was on the committee. He used to buy the gifts, or the prizes, so we got free child care. There it [inaudible] . . . in the truck; and they had a dry cleaners right next to it. Right next to it, there was a real small dry cleaners. I don't know exactly what they did there. I know you'd get clean pieces of utilities [uniforms] done for \$2.50, but me, you know, being a Marine Corps wife I did them by hand, the starch and all.

But, uh . . . Nita's. . other than the heart murmur, she's okay, but John's not. I don't think it's fair. I think he

should . . . the Marines or the government, whoever, I'd like to help him. He was born with a small empty place at the bottom of his spine. His two children have the same thing-that little empty place at the bottom of their spine. The little girl more so. Hers is more than John's was. But John's spine curves. He's in constant pain. He's in construction and he aches all over, especially his shoulders and his arms. This is how he makes a living for his family. He'll never know what he could have been. We'll never know what he could have been.

Really all I have to say, but there's probably a lot more. We even had a dog, a litter of puppies. The dog . . . whether this had anything to do, I don't . . . probably not, but I've never seen it, I've never heard of it happening, but the dog was blind and he walked on an angle. This dog, 'stead of walking straight, this dog was at an angle, he would walk at an angle. His whole body was at an angle. It was weird. Kept him alive until he was six months old, and then one of the vets, we gave him to one of the vets. And he did autopsies and whatever they did, you know, we couldn't keep him anymore.

Mr. Stallard: Thank you, Ms. Bridges.

Ms. Bridges: You're welcome. Thank you.

Mr. Stallard: Ms. Monique White, please.

Ms. Monique White: My name is Monique White. I'm a dependent. My father was a career Marine. We moved to TT when I was one and a half. It was 1968 and we lived there for two years. I just found out about this on Sunday. My parents still live in Jacksonville, North Carolina. They've lived there forever and they saw an article in the paper about this. So I don't have a whole lot of information. If I had more time, I would have gotten more information about myself and my two sisters, as we were sick growing up. But the main thing is, for me is, I was diagnosed with breast cancer in 2002. I was only thirty-five years old.

I've gone through a lot. I've had a double mastectomy, chemo, radiation. You fear for your life. The biggest question for me was, "How did I get this?" It doesn't run in my family. Nobody on my dad's side or my mom's side has this. It has since spread. I have a tumor on my right femur that I have to get an infusion once a month for the rest of my life. There's nothing they can do about it. This kind of puts a face on my cancer. I'll never really know how I got it, why I got it, but this kind of makes me wonder if this is why I have cancer. My two little girls may lose their mother. I have two older sisters. All three of us have had miscarriages. My middle sister, she's had four miscarriages all together. In 1990, I was . . . had problems with my thyroid. For five years I took Synthroid. They finally removed the left side of my thyroid. I had severe nose bleeds for about a year. They would never stop. They could never figure out what they were. My dad, he had a heart attack when he was forty-seven. He's sixty-three now and he's had just chronic problems. He's got Chronic Fatigue Syndrome. He's had bad bad sinus problems. He's had operations. He's on so many medications, it just fills up his dresser. I mean, it's ridiculous.

My biggest concern is obviously for my life. I'm young; I have a long life to live. But for my kids, I want to

know if this is going to affect them at all. That's why I'm here...[inaudible]

Female Voice: [inaudible]

Ms. White: I told them. I was one and a half years old when I originally moved there. We lived there for two years.

Mr. Stallard: Thank you, Ms. White.

Ms. White: Sure.

Dr. Cantor: Thank both of you for appearing today. It's hard to get back to work after that. So, I think we have started, at least, a process of discussing what the target populations would be for what I think we would look at as cohort studies. In other words, groups of people who would be followed up in some way, through either medical records or mortality records or other records, or the kind of study that ATSDR is doing right now-interview information from individuals. We have, I think, four groups identified, and we will in our report elucidate those. I think the recommendation will be something from most of us . . . I can't speak for everybody. We will be making our individual recommendations, but I think the ideal would be that further work would have to be done to address the feasibility of identifying these groups, as groups of people for further follow up to be done. Any comment or discussion on that point right now?

Dr. Ozonoff: [Taking to the audience.] The only thing that I can say is that I think the feasibility of this depends on to some extent on the amount of help that ATSDR can get from you folks, because it seems to me you know a lot of stuff that they don't, that they need to know. So, I personally would recommend that they work closely with you on this.

Dr. Visintainer: I think that also a concern that there seems . . . has to be . . . the critical information is coming from sources that appear to be beyond the reach of ATSDR. That's a real concern.

Dr. Cantor: Are you thinking of the Marines. . .

Dr. Visintainer: I think there certainly has to be substantial buy in further up. I think that's absolutely necessary. We've heard a number of examples where information has come in . . . just this last example, here it is 2005, and ma'am, did you say you just heard about this?

Ms. White: [off-mike] Yes.

Dr. Visintainer: And your folks are in Jacksonville around . . . is that around the Marine Base?

Ms. White: [off-mike] Yes. Suburb. It's right outside Camp Lejeune. We've lived there, since I was five years old.

Ms. White: Jacksonville, North Carolina.

Dr. Visintainer: To me, it's absolutely unbelievable the amount of time that has gone by and people still don't know about this. I think that's a travesty. But buy-in from the community is, obviously, it's essential. [Speaking to the audience] You can see that you're playing a very critical role here. To move things forward that's going . . . you know, you're going to be a team member.

Dr. Cantor: Was there a comment from some of you. Your name please.

Ms. Orellana: I just had a question. I was never contacted by the ATSDR, in any of this. My mother was, okay. I was conceived and born at Camp Lejeune. You say about, us helping ATSDR. I'm willing to do what I can, but if they don't contact me I don't know who I'm supposed to contact. They never contacted me. They contacted my mother, and that's where my question came in yesterday. What if the parent passed away? Does that leave me out?

Dr. Lynch: I can make a brief comment about that. There is a little bit of a problem with contacting you directly, not only because it was easier for them to find your mom, but there's actually now a problem with privacy concerns. For instance we did a study looking at people who were in utero, their mothers had X-rays, while they were in utero, and we wanted to follow them up and see how they did as they grew and developed. There's actually, we ran into a problem with them. The Ethics Review Committee, they wouldn't let us specifically go to the children, because they were the ones . . . they did not have the X-rays and so forth. So . . .

Ms. Orellana: Yeah.

Dr. Lynch: There'd be issues like that that would need to be worked around. Maybe, if they find that both parents have passed away, there would be a way that they could try to contact you directly, but there is a little bit of an issue with that. But I can understand why that's frustrating.

Ms. Orellana: Okay. Well, since I'm here and I'm not really . . . I give ATSDR full permission to contact me.

[laughter]

No legalities, no law suits, nothing. Contact me.

Ms. Harris: [off-mike] Paula, tell them how much your medicine bill is for one month for your three boys and your disability.

Dr. Cantor: We did cover that yesterday. There was another comment.

Mr. David Paulin: [off-mike] I know a girl that was born at Camp Lejeune. She's right around twenty years old.

Ms. Murray: It's not going to be on the transcript, if you're not on the microphone.

Dr. Cantor: Excuse me. No, David, please, please. We haven't heard from you much.

Mr. Paulin: I know a girl that's twenty years old that lives in Birmingham, Alabama that was born at Camp Lejeune, and she wouldn't come forward, because she doesn't have any health problems.

Dr. Cantor: But presumably, if she were born within the period that was of interest, her parents were contacted. She was born in 1984/1985. So that's within that period.

Dr. Ozonoff: Can I say something about the issue of helping ATSDR. What I'm suggesting is that there be a formal kind of set up and a relationship, which doesn't require anybody's permission. But it's like a staff, made up of people who have been exposed or who are worried about it, or want to help out with that, and that they work in partnership with ATSDR in figuring out ways to do this; because I don't see any other way it can be done to everybody's satisfaction, including the scientists' satisfaction, because you can't get to adequate scientific data without your help. Paul's point about buy-in is important. I would actually say the buy-in is a two way street; that ATSDR has to have a buy-in to your concerns too. I don't get it, that they don't get it.

[background voices, a little clapping]

Mr. Stallard: Excuse me, just a minute. I'm going to . . . Mr. Byron has asked for a moment, and then we'll resume with the panel discussions.

Mr. Byron: My name's Jeff. Byron. My concern is where is the Navy Medical Department in all of this? Where are the medical records, the ob/gyn records? Where are our health records? What's going on here? Why hasn't the Surgeon General of the Navy, previous Surgeon General, Rear Admiral Cowen, who spent half his career at Camp Lejeune, where is the notification from him? Where is the birth defect records at Camp Lejeune, if they kept those at that time? Why didn't they see that there were issues then? I know the March of Dimes has been in existence for a very long time and tracks that in a civilian community. Where is that in the military community? Why hasn't the Navy Department stepped up to the plate, come forth with these records? Because they're there. Let's face it, when the Nazis committed atrocities in World War II, what sank the ship for them in Nuremberg, was that they were so efficient at record keeping. I know the Marine Corps, and every branch of the military, is just as efficient.

Male Voice: I'm curious, if there's anybody from ATSDR that would have a comment about that.

Dr. Sinks: [off-mike] I'll be happy to comment . . . I can't comment . . . is it on? [on-mike] Okay, I'm Tom Sinks. I can't comment about what we actually have ongoing with the community, individual; oh, here's Frank, he can do that. I'll put that question to Frank. Let me comment about your comment about what the military may or may not have on birth defects. I am familiar with birth defects surveillance. In general birth defects surveillance is pretty limited, with the exception that CDC does put money out to state health departments for birth defects surveillance, beginning maybe '93, '94. Right now it is a reasonable thing, but

I don't think before that there's been any systematic surveillance of birth defects by either the military or civilians. March of Dimes doesn't do birth defects surveillance. It does work with our birth defects group in partnership, but their role isn't really surveillance. Frank, there's a question to you about . . . Or I'll put this question to you as "What are we actively doing in terms of communicating with the community and having ability for them to communicate with us?"

[Voices overlapping]

Dr. Maas: That wasn't quite the question.

Dr. Bove: What was the community?

Dr. Maas: Right. No, this was more . . . Jeff was asking about why the military hasn't been forthcoming in giving you all the records of births . . . birth defects and what not. Jeff, you should just take a second and restate that.

Mr. Byron: Yes, my concern is that the Naval Regional Hospital had to be dealing with all these cases. My child was up there fifty-seven times in two years for high fevers, the same things that Ms. Bridges has. My second daughter also had these birth defects that her son's experienced. I just can't believe that the medical community didn't see this, in this scale. I mean it's across the board, and I'd like to know how many cancers are reported at Camp Lejeune through that time period, if that's elevated compared to the national average. I've never heard ATSDR once come out and say that, "These averages for anencephaly or neural tube defects are this percentage higher than the national average." They've never come out to say that. Why not? Because, the records are right there on their own Website. The averages are there. We've looked them up. I calculated them a couple of times. I don't remember what it's been since their report came out, but it's there, and why don't you say it?

Dr. Bove: We don't say it because we want to verify those cases first. The records you're talking about in the hospitals, they don't keep those records for very long. So, we're able to find some records, but for most of the cases we've had to ask the families themselves to send us some verification/medical record. In some cases, we're asking people with spina bifida to see a physician, if they don't have a medical record, so we can confirm it. For oral clefts, we're asking people to see a dentist, so they can see some evidence, because they don't have medical records. So we're trying all kinds of ways to verify these conditions, and when we verify them, we could do what you're suggesting. We could have . . .

We had this discussion about whether to say whether the number of reported ones were twice or three times higher than the national average. We felt . . . we had this discussion. We felt we ought to do it after we'd verified the cases, not before. Maybe that was the wrong decision, but that's what we decided to do. We also wanted to do the study because now, not all the people at the base were exposed. There are unexposed people, and who knows where the excess birth defects are coming from. I mean, you know. Sure, common sense would say it would come from the exposed group, but if you don't do the study, you

don't really know. So that was another reason why we wanted to not do that, but. . . But it did tell us that we were ascertaining, maybe not completely, but a high percentage, we felt. Because we could see that they were higher than what you expect from a pretty good birth defects registry. As for birth defect registries in the country . . . I don't know if that was a question but . . .

Dr. Cantor: It hasn't . . . well; Tom Sinks just sort of started to discuss that. It hasn't come up generally until now. Thank you. I think Dr. Ozonoff has a comment.

Dr. Ozonoff: Yeah. A general observation here is that, one of the things we're . . . I'm seeing, is the unbelievable corrosive destructive effects of distrust. It colors everything. Frank's explanation of a lot of this is right. Medical records get lost all the time, not just at Lejeune. My son's medical records have been lost. There's just a lot of sloppy stuff that goes on. There's incompetence everywhere. Also, institutional policies. We have to find some way to re-establish some kind of bonds of trust here, or we're not going to get anywhere, because nobody's ever going to be able to figure out what's right and what's wrong when it's looked at through that kind of lens.

So, it's not only trust on your side but it's sort of defensiveness on the part of the agency, sort of circling the wagons around and a reliance on sources that maybe they shouldn't rely on as much and also, basically not getting it . . . Not getting it that if they don't work with you, then nothing's going to work.

So that's one comment and I have one other observation to make and that's . . . you know, we hear about a lot of people who don't seem to care, you know high up in the military. Since I've been doing this a long time, I run across a lot of people who don't care-in asbestos companies, in chemical companies, in state government, and federal government, in universities where I work. There's an awful lot of people who don't care. Sometimes, the not caring is so cruel on the human basis, you wonder how it can be possible. I think the answer when you come right down to it is, usually fairly simple. People don't care because nobody makes them care. So you have to make them care. You're engaged in that operation, in a way, because you're organized. That's how you make people care. So I would encourage you to keep doing it, because that's the only thing that's going to work.

Ms. Dyer: Can I say something?

Mr. Stallard: We're trying to be extremely flexible and to hear your voices. This is the only time that this panel is going to be together and they need, in my view, and you can correct me if I'm wrong, they need to have the time to actually deliberate amongst themselves in order that their recommendations can be put forth on what the next steps are. Yet, we need to walk this fine line about being sure they have the relevant information that you have to offer, to inform them of their deliberation. So my question to you is, what you have to say can it wait 'til your open period this afternoon, or must it be spoken now?

Ms. Dyer: [off-mike] it's kind of going along with this [inaudible]

[Voices overlapping]

Dr. Drane: She just wanted to add the one thought to Frank.

Ms. Dyer: What I was going to say is you know we've been talking a lot about miscommunication, and about bad information being given, and about mistrust. That is from both sides. I think it's mostly from our side, because of trying to gather information and it not being given to us. When we were in Washington on our first trip to Capital Hill, there was a Congressional hearing going on, on the SHAD project. I sat in on it for a while. That is one thing that I just want to ask you all, because I know that you have a relationship with members of Congress on Capital Hill. After you have heard what has been said here today and yesterday, and the miscommunication and the things that have happened, and the possible cover ups and things like that, that you might put it forth to them that a congressional hearing, aside from everything we're talking about today, might be in order, to get to the lack of . . . the miscommunication, and the outright lies and things we believe took place. So that's all that I was going to say, is that that might be a possibility.

Dr. Cantor: Thank you for your comment. I think you may be assigning to us a little more power and influence than we actually have. Dr. Drane had a comment on . . .

Dr. Drane: Want to make just a short comment regarding what Frank had said, when he said "we have the cases reported, but we haven't assigned cause, such as the water or something else." You don't need the inside of the table, if you know that the margins are out of range of what's expected, i.e., the people are at Lejeune, and if you have many more cases than expected, you don't need to say much more than that than . . . because the data already say the problem is at Lejeune. It doesn't say why it's greater on one side of Lejeune than the other one, but it does say the problem is at Lejeune. You can say that much. [makes click sound] That was a period.

[laughter]

Mr. Stallard: You have something relative to this?

Dr. Cantor: This kind of goes back to some of the discussion we had yesterday, in terms of the early reports that are coming from the ongoing study and our question to the researchers, "are these the expected values are?" When we say "expected values," these mean taking national rates, and do you see it above or below? So that was what that discussion was all about. It's not clear to me right now whether there are, there were excesses of these conditions. I think that remains to be seen, and especially the comparison among those births that occurred among people who did have exposure relative to those who didn't, who were in Lejeune. So I think that's what we're waiting for. The jury is out on that until the study is completed. Were there some other comments?

Dr. Lynch: I just wanted to add something to what Dr. Ozonoff said about cooperation being very

important and making people care. I'm not quite sure how to make the Marine Corps and the Navy care. The only thing I can suggest to maybe more formalize what you suggest this partnership is. Maybe a good first step would be to convene a meeting between ATSDR representatives as well as concerned parties. It's pretty clear, for instance, a number of Freedom of Information requests have gone forward and clearly they have some data that ATSDR might not be privy to, that they might then be able to turn around take it to the Navy/Marines and say, "Hey look, we noticed there's information here, could you please provide us with this information." Perhaps if asked direct questions, they might get some more information that would help sort of move this process along. It also seems that, although everyone is quite organized, there are groups that might have other information. If everyone can maybe bring, maybe all the information that they've personally gathered through documents, Freedom of Information Act requests and so forth, that might be a good place to start and kind of see what do we have and where can we go from there.

Dr. Ozonoff: I think those are good suggestions and let me just amplify what I said, making people care, maybe, if you don't know me . . . you wouldn't understand what I meant. I didn't mean convince them. I meant make them care. Asbestos companies now care because they got sued.

[un-miked voices]

Right, right. That didn't convince them that the people they killed, you know . . . [trailed off]

Mr. Stallard: Mr. Ensminger has requested a comment relative to this discussion.

Mr. Ensminger: This cooperation we're talking about, got ATSDR here. You have the Department of Defense over here. ATSDR needs information. DOD has the information. They have the knowledge of their own records, how they can gather this stuff, where the information is. They have a vested interest in ATSDR not getting that information. ATSDR, on the other hand, doesn't know the workings of DOD. I'm right now volunteering to be that person in the middle. Just during this meeting, I have given Frank Bove several different ideas on how to research certain information. Because of my career, I know the inner workings of the military. The thing about the two places, in each service member's records, to seek out dependency and housing records. Also, the information about the plant accounts, which are on those emails. They had no idea about that. Plant account records are the historical records of the water systems, when each well was constructed, when it went online, when it went offline, when it was closed, when each water plant was constructed, when it was taken off line, demolished. It's there. They had no idea about that. So this tells me that ATSDR's here, DOD's here, ATSDR wants this information, they don't know how to ask the question. I do, and I am volunteering right now to be that middle person. If they have any questions on how to find information, I'm willing to answer. If I don't know, I'll find out.

Dr. Drane: Stay there.

[laughter]

When I was in the service many years ago, and I moved from one location to another, they gave me a manila folder and almost dared me to lose it. It was a . . . I still have it today, but I did turn it in and then it was turned back to me when they added a DD214.

Mr. Ensminger: Yes, sir.

Dr. Drane: My records obviously did not completely evaporate, because I qualified for the VA bill. .

Mr. Ensminger: Yes, sir.

Dr. Drane: To help buy houses and things. Does an electronic version of that manila envelope exist for you and all the other Marines?

Mr. Ensminger: To my knowledge, yes, sir. First they were downloaded to microfiche. Now, I understand that they've all been loaded into a database, which is located at the retirement records facilities that are in this country.

Dr. Drane: If we have a need to know, the signature high enough in the echelon, we could download or upload those, whatever.

Mr. Ensminger: Yes, sir.

Dr. Drane: Onto CDs or, I call them sticks, memory sticks. Then we could look into your manila folder and find where you went into base housing, left base housing, filed your next baby as a dependent, and all of this information.

Mr. Ensminger: I can guarantee you that every scrap of paper that was ever generated on me throughout my career, I'll bet you by a ten . . . a million dollars, they've got every piece of it on me right now.

Dr. Drane: Be sure to bet more than you can deliver [inaudible].

[laughter]

Thank you.

Mr. Stallard: Let me please at this point; excuse me; I need to do something here. I need to summarize where I think we are, so that we can move forward and allow additional deliberation of the panel. Although this is not a consensus set up, there appears to be some unanimity of opinion that a very strong recommendation from this panel will be that a new model of ATSDR community engagement and partnership with funding be formalized, built on genuine trust. Does that seem to capture the essence of . . .?

Dr. Ozonoff: It captures my view.

Mr. Stallard: Does that . . . I see heads nodding.

Dr. Cantor: I doubt you'll find any disagreement at all.

Mr. Stallard: So there you have one very strong recommendation that this panel is willing to make.

Ms. Harris: [off-mike] Christopher, real quick. Mine's only thirty seconds. In 1971 to '72, and back in '75 to '80, whenever a woman miscarried, that fetus was put in a cup and sent to the lab. [on-mike] Ellen Harris. In '71-'72, I worked as a stand-by whenever I was in the clinics, and that's how I know in the different clinics what was going on. The caps, the little cups, that had the red gel in it, whenever a woman miscarried she was to bring the tissue that she had, or when she was in the hospital, the tissue was sent to the laboratory. What they did with it, I don't know, but there was a Ronald Naus, with the Navy, that was a laboratory tech, and he said that he'd never seen so much stuff in all of his life. The logs had that information on infections, tissue samples and so forth. That's why they don't want to give it up.

Mr. Stallard: Yes, sir, did you have a comment?

Captain Chris Rennix: I'm Captain Chris Rennix from the Naval Environmental Health Center. I think I can provide some information about record retrieval from the personnel side and the medical side, since I did a major research project on this.

Mr. Stallard: Please come to the table to do so, and thank you.

[whispered voices back and forth]

Captain Rennix: Good morning. My primary research project for my Ph.D. was looking at breast cancer in young women in the Army, which required me to go and retrieve not only personnel records, but health records from the system. The study was conducted from 1980 to 1986, but we had to go back and retrieve records all the way back into the late 60's. During that research time, I found the gaps in the recordkeeping and was able to explore them quite closely. 1980 is the first year that computerized inpatient records were kept consistently across the services; before that it was not a consistent practice. Each hospital may have had its own system. There was no attempt at the tri-service level to try to bring it to a single system. Some records were kept and were available, but not . . . There was no systematic re-collection of that and archiving of those records. So, you basically started from scratch around 1980. That's only inpatient.

Outpatient records were not systematically collected and retrieved in computer until the '90's. Paper records were not ever computerized. They were collected in boxes for inpatient visits, like surgical records, that sort of thing, were collected and archived in boxes. They are in the respective archive for the National Archive Center. So, each hospital would have an archive center that they would send their records to. An inventory of the records in the box would be kept by something called an accession number. So, if you had the accession number for the case, you could then request that box and they would send you the box and

you could pull out the record and do a manual extraction of the data.

Personnel records for active duty go back to the sixties, but in the sixties they are basically kept as text files. That record is just a pay record, not the personnel records, the pay record; the person was on active duty, where they served and what their job was. The actual service record is not computerized. There is a database of Social Security numbers that will tell me where the file was located in the National Archives. I then need to send a list of those socials to National Archives with \$3.65 for each record, and they will go and pull the record off the shelf, put them in a room for you, and then you manually abstract. Either you can read the record on its paper, or if it's been microfiched, you can read the record on microfiche. You're not able to make copies at the National Archive level, unless it's your own personal record.

Now, the problem is as alluded to by one of the panel members, if you get a V.A. loan your record is removed from the National Archives and sent to the regional V.A. office, so they can process your request for a V.A. loan or V.A. educational benefits. The record does not go back to the National Archives. It stays at that local level for five years, after its last use. So if you apply for a house loan and you don't do anything else, that record sits there for five years and then it goes back to the V.A. archives in St. Louis. So now we have two different locations for service records, actually three-the local V.A. office, the V.A. national archives and then the National Personnel Record Center in St. Louis. Again these are just . . . It's a record, but it's not; you can't computer abstract it. You have to manually read each microfiche and pull out what information you want.

Dr. Visintainer: When these records are shipped from one location to another is there tracking. . .

Captain Rennix: I hope there is now. There wasn't when I did my study. When I was looking for individual women, I had to contact the National V.A. Archive Center, and then they would send an email to all the Regional V.A. offices with socials of the women I was trying to contact. Then they would check their files locally. Now from the availability of the actual medical record . . . in the folder, each service member folder has their pay record, their personnel record and their medical record, if they retired it. About only thirty percent of medical records are available records, because they were never turned in when they retired; they were retained by the service member. Or, just the exit physical is in there, and that's it. That's been published several times by other people going through this process that the record of success in retrieving is about 30 percent.

Dr. Lynch: My understanding, related to the difficulty with health records, is that they seem to be stored by, as you are indicating, by facility and date, rather than the person per se.

Captain Rennix: That's correct. That's the inpatient record. The health record itself is tied by social.

Dr. Cantor: And so there's no cross-referencing of these.

Captain Rennix: No. No. The volume is too high. That's only the inpatient care records. So, the ambulatory

clinics, where probably most of these people were seen, that's a paper record that's destroyed after so many years of retention on station. There's no requirement to keep those kinds of records. Now, that's all changed. It's all computerized, it's retained forever. But, if it's gone . . . it's not going to help you much here.

Dr. Visintainer: What about microfiche? What determined whether these paper records you said might, may have been microfiched?

[Tape change, tapes did not overlap, there is a gap]

Captain Rennix: There was an effort by the National Archives. They had a fire back in 1966, or something like that. They lost the entire top floor of the National Archives and they had to reconstruct a lot of the records. So they made a huge effort there. So, there are some records, when you pull the file, you'll get a paper record; because they may have been out at the V.A., when they did the microfiche and then it comes back.

Dr. Ozonoff: Everything you say really accords with my experience, when we were doing Gulf War stuff. My colleagues said, "Oh you're so lucky, because you're doing epidemiology on the military and everybody knows the military keeps paper forever and it's . . . they've got paper on everybody." In fact, it turned out the military was just like every other institution I've ever dealt with; which is they had some stuff, they lost stuff, there's stuff in paper cartons in warehouses somewhere, and nobody knows where it is. In fact, actually it sounded even better in your rendition of it than in some experiences we had. I only say this to, just as a caution to everybody, that what everybody thinks is true, sometimes isn't true.

I went into . . . I was an experienced epidemiologist, when I started this. I thought I was really set up because it was going to be easy. It turned out not to be. Having said that . . . One feature of . . . I suppose people everywhere, but experts are particularly prone to this, is, whenever you suggest something to them, they'll tell you a hundred reasons why you can't do it, and why it won't work; but the fact is that some of these problems are really difficult. They seem like they're impossible to deal with, but they . . . if you put effort into them you can actually get a lot of material. You can figure some of this stuff out. With the expertise that you guys have, and you have, and ATSDR has, and NIOSH has, you know, people who do this kind of stuff, you can probably reconstruct a lot of stuff that looks like, when you first think about it, It is impossible; but it just takes a lot of effort, and unless ATSDR enlists your aid, they're not going to be able to do it.

Dr. Cantor: Thank you very much. Very helpful.

[Voice responding off-mike] Thank you.

Mr. Stallard: We're coming close to our lunch break. Do we have any comments around the table about what has transpired this morning about this latest presentation? Further comment on this?

Dr. Drane: I'd like to put a piece of optimism in here. I think that this is a study that can be done, but taking Dr. Ozonoff's essay on caution, it's going to take a lot of work, but yes, it can be done.

Female Voice: Thank you.

[applause]

Mr. Stallard: Given that it's five minutes until noon time, our planned lunch break, I'm suggesting that we conclude this mornings' activities and resume our discussions . . . our dialogue at, actually, resume the panel deliberation this afternoon, when we return at 1:30pm. There will be then, just so you know, the expectation this afternoon; there are a few of you who have signed up to have additional public comments, which will happen after the panel deliberation. Okay? So, I need to ask Athena, is there a bus, a shuttle bus, Athena?

Ms. Gemella: [responds off-mike.]

Mr. Stallard: Okay. Thank you. The shuttle bus will be here for your convenience, if you wish to go to the Marriott again for their delightful brunch, lunch, whatever. Thank you. Buffet, that's the word I was looking for.

[Whereupon, those assembled adjourned for a lunch break, after which they reconvened.]

Mr. Stallard: We have just this afternoon . . . excuse me . . .

[Multiple voices overlapping off-mike]

All right, welcome back. I'd like to ask you to take your seats, those of you who have not done so. I need to make an absolute plea with you. You are not really members of the general public, you are a community, and you seem to be speaking with nearly one voice. I'm asking that, during this next couple of hours, that you hold that voice until your opportunity to speak later this afternoon, lest we not accomplish what we are here to do. That is to get the recommendations of an expert panel that will determine what the next steps are in this process, and beyond that I might never be working in this town again, if we do not achieve those objectives. Okay? Thank you.

Dr. Cantor: So we are going to go right to our charge now, which is to focus in on our recommendations for our specific studies, specific study designs, end points and so on. This morning we took a few minutes and made a list of the possible end points that might be of interest in such studies. Now, I would like to first of all turn to Dr. Ozonoff who has a suggestion for how we can proceed, and what our primary recommendations might be. David?

Dr. Ozonoff: One thing that seemed to have emerged from these conversations is that there are quite a few different populations. . . . do it this way . . . populations at the base, which so far haven't been looked

at. I think Dr. Cantor made a list of some of those populations.

One thing that could be done is to assemble what we call a cohort, which is a bunch of people who share a common experience. One cohort would be people who are exposed to contaminated water and then a comparison group that's not exposed, and make some comparisons between those two groups for various kinds of health outcomes. The difficulty is in assembling this cohort, finding the lists of people. It seemed to me that's where you had special expertise to help ATSDR.

So, the first suggestion is that a collaborative arrangement be set up. In my experience that works best, if it's a formal collaborative arrangement with paid staff, meaning that the time that you folks spend on it be compensated time. The task is to work together in partnership with ATSDR to assemble this cohort of exposed and unexposed people. That means finding them and finding all the data sources; where you find that, and maybe even data sources about exposure at some point and that for each of these population subgroups, when they are assembled, to look at certain kinds of outcomes where you don't actually have to find them. One of them would be mortality, because there you can use the National Death Index. Cancer might be another one, where you might be able to use cancer registries without having to go and find the people and interview them and take samples, or whatever it is. So, that would be one thing that could be done right away, without the problems of a finding everybody; but then there are a lot of these health outcomes that you would want to find people for, because you know, there aren't any records that would allow you to do it, or the records are in ten different places.

So, at that point, everybody needs to sit down together and figure out which of those things are possible to do. They're not all going to be possible, because the records don't exist or the disease is so rare that, although some people may suffer from them, they may suffer from them as a result of exposure, there's really no hope from the epidemiology point of view of being able to demonstrate that, although there is some hope of being able to locate people and notifying them.

So, this is sort of a three-stage process as it is now, the most important part of it that could be started relatively soon, a partnership between the community. The Camp Lejeune community and those groups that represent them, and ATSDR, to assemble these cohorts, and then the next steps could be taken as far as looking at outcomes like mortality and cancer. Then a reevaluation as to which of the other things are possible. Those things could actually be done together, the second two parts of this.

So that's an initial suggestion. As we talk here, we might be able to refine that and get some more ideas. Where I come from we call that shark bait-stuff that you throw out and people then can proceed to tear it apart, but at least we need to have some place to start from. That's what I'm suggesting to begin with.

Dr. Cantor: Other panel members have some comment. I have . . . just to elaborate on this idea. What we mean . . . I think, correct me, if I'm mistaken here, but what I . . . I'll tell you what I mean when I talk about assembling a cohort. It means a number of things, first of all defining who was in and who was out of the cohort.

So, one of the cohorts we talked about was children who lived in the housing. Well, you might not want to include children who lived there for less than two months, or a month, or something of that sort. You want to have adequate time for them to have received, if they were exposed, adequate exposure, so if there was an effect, if there weren't an effect, you'd eventually see it. So, that might be one of the criteria that are used. You'd have to define "children"; do we need everybody through sixteen years old, through eighteen years old, whatever that is?

The other aspect of defining a cohort, to the extent possible for follow up purposes, if we use these automated available, in some cases national or state databases, you need personal identifiers. So, I understand, I don't know the exact year that Social Security numbers were required at birth; it was maybe in the mid-eighties. For anybody born after that date, it would certainly be Social Security numbers. If Social Security numbers were available in some other way, it would include Social Security numbers, because that's a very basic way of matching the people with the existing database. Certainly, date of birth, age, I'm sorry, sex, and full name. So that's one aspect of assembling the cohort.

The other, I think, has to do with the . . . and this need not be done at the very outset, but at some point you have to define the exposures to these people. Some of the people will have very low exposures. Some of the people will have exposures. That has to be defined. The timing of the exposure; if they were, for example, if it were civilians . . . if one of the cohorts is civilians who were working on base, but living off base, an estimate of the amount of time they spent on base; if they're doing physical work, well, maybe you would increase the estimate of their water intake, because physical activity entails generally higher water intake. So, there'd be as full personal identifiers as possible, a definition of who is in and who is out of that particular cohort, and some estimate of exposure, and this would certainly tie with the modeling work that is being done here for the other study. Other elaborations on . . .

Dr. Visintainer: I have to say that in establishing the cohort . . . and we can talk about the different kinds of cohorts . . . I would cast the net far and wide. You know, we don't have to think about exposure initially in defining the cohorts. The cohorts are going to be defined by passing through Camp Lejeune, if you're military personnel during some specific dates. If you're a child who was born, while a resident on the base, could establish during the exposure period. If you're a resident of the communities around the base, we've identified this other cohort. Again, I guess I would worry about . . . I can't get over the notification, that people still don't know that this is a problem. So I, at this point, would just cast a wide net. I would get notification out there anyway. And then we can set our . . . you can set your inclusion/exclusion criteria. One thing to note is that, as these cohorts are established, people may pass through different cohorts depending upon cohort definition. The child who is in utero on the base is born and is . . . gets a two-year exposure as a young child, is now thirty years old and has children of her own, can pass through four different cohorts, as we have talked about them. So at this point, I would just try to identify everybody that we can.

Dr. Lynch: I was just going to say . . . just agree with that. And that I actually think it would be more efficient to sort of identify the family, say the adult that resided there, and then to say, "Tell us about all of the children that lived with you, while you were . . . actually, tell us about all of your children. Then, tell us which of your children resided with you at Camp Lejeune at that time." Then, you know, we can figure that out in . . . certainly for studies, we're going to have to decide who's exposed versus unexposed. We're going to have to have a definition of exposure, but I think initially, in just sort of defining who might have been exposed, going with a family approach in that sense. I think just even two separate cohorts . . . I see one cohort as the people who resided at Camp Lejeune and the other cohort as the people who worked at Camp Lejeune, and then their associated family members at least for those who resided there.

Dr. Cantor: A brief comment. Umm, I think I did jump the gun talking about exposure that certainly doesn't define the cohort in any means, but it'll be an aspect of . . .

Male Voice: A very important aspect

Dr. Cantor: Just to that clarification. Thank you.

Dr. Drane: What I'd like to add to that is that I would like to get the cases first, without defining a cohort, and then attempt to get the controls simply by matching on the cases. So instead of pointing out we're going after cancer, we're going after something else, let's look at who are the cases and then go after the matching.

Dr. Visintainer: I think, if I'm reading your mind, that we respectfully disagree. The cohort . . . and this is something that's . . . again maybe this is the first non-consensus item that we have, is that we won't know who the cases are until we identify people . . . just get people notified. Get them to come forward, get them to give us our dates of residence in the community. For instance, the residents on the base, where we know whether they can be included in establishing the cohort or excluded, the child . . . we identify, as Dr. Lynch had said about the family members. There may be some children there that were born after residence on the Camp Lejeune, so they wouldn't be included, but we don't know that 'til we contact the families and we get histories and we get, you know, all this kind of information. So, I think . . . The other advantage of establishing the cohort is that it lays the groundwork for many studies, as opposed to talking about a specific study. That's what I think is the advantage here. It provides a foundation for looking at many different things. As information . . . as we identify information that is either available, those studies can be conceived, if it's . . . if the information is not there, they can be dropped . . . or defined as not feasible, but we won't know that until we know who we have available to us.

Dr. Lynch: Now, was there a specific outcome, like for instance, had there been a Naval Cancer Registry; I could see how that would be a very efficient first approach to take, but was there a specific outcome you were thinking of that might . . . you would prefer to do that before assembling the cohort?

Dr. Drane: What I was thinking of is follow your procedure. Record the illnesses reported. All right? Once

the illnesses are reported, decide then who you're going to match with these people. I'm thinking about a case control. All right? I think of cohorts as starting the same year and without regard to whether they have already have the disease, but you might have an exposure control. I want to stay away from that. I want to find some cases, whatever they report. Right? I'll sift through those and pick out the one that you think that could have any remote relationship with water. Then form your controls on the basis of that.

Dr. Visintainer: Actually, I think we are coming at this in the same way. Like I said, if as we establish the cohort this could be the foundation of many different kinds of studies, primarily they're going to be . . . case control studies with . . . case control studies within the cohort.

Dr. Drane: I looked at what you said about calling families, identifying families, these are details of procedure.

Dr. Visintainer: Right. Right.

Dr. Drane: I haven't approached that yet at all.

Dr. Cantor: One of the . . . one of the . . . if I can speak to the cohort idea side of things. One of the advantages here is that may be some conditions, diseases, whatever, that we really don't expect to be happening, to be related to this exposure. If the cohorts are formed and follow up is done appropriately, this would come out during the follow up. We haven't talked about thyroid conditions. There was some mention of one of the people here's parathyroid problems, but . . . So, some of those that we haven't really focused on very highly, that aren't a priori expectations, might be, in fact, evident when that was done.

Dr. Ozonoff: Let me start by agreeing with everybody, including the people who disagreed with me. I actually think that all the comments that were made are good, because they fleshed out a primitive idea which I sort of got off to a wrong start maybe by using the word cohort loosely. I was using it as a sort of original sense of people who shared a common experience. I probably shouldn't have talked about the unexposed group, because the real task here is to assemble the cohort of potentially exposed people, which is, I think, what both of you have suggested.

The advantage of a cohort study . . . the disadvantage of cohort studies over case control studies, is that cohort studies you're pretty much limited to one or very few exposures, but you get to study a lot of outcomes. It's just the reverse for case control studies, where you've got one outcome, but you can study lots of exposures. I think that we are probably in a situation here where we know what the exposure we want is, and so we're better off with the group of people who share a common experience, which in this case is potential exposure to the water at Camp Lejeune, but who as yet don't have any kind of health outcome. That means going back to find them before they got sick, before they even moved, maybe not before they moved, but when they moved to Camp Lejeune. Then using various means to follow them forward, to figure out what the health outcomes have been.

This kind of design allows lots of different health outcomes including things that we haven't thought about before, like thyroid and so on, if you can get the information. This design is not well suited to certain kinds of outcomes. It's not well suited to very rare outcomes, because you need huge populations for very rare outcomes, but that's something that can be decided after the cohort is assembled, and . . . which is another advantage of this. If you had, in the ideal situation, if you have the complete cohort, then you could do the case control studies and that's the case control study after follow up.

I suppose a bit of warning, which is that when you try to assemble cohorts like this, you can't always do it. Right. Your ability to do it will depend upon ingenuity and persistence and raw brain power and a whole lot of other things. If after application of all that and the best everybody can do, you can't do it, then that's the way the world is, but mostly you can, if you work hard at it. But, my personal opinion is ATSDR does not have a hope of doing this without your substantial help, and maybe the majority of this will be done by you rather than the other way around.

Dr. Cantor: Richard, do you have a comment?

Dr. Maas: Yeah. Well from hearing and deliberating everything we've heard the last two days, I have five specific recommendations for ATSDR regarding this. Some of these have been voiced by others. So, I will give them to . . . give my reinforcement of that.

First of all, as we've just been discussing, I'm in absolute agreement that one of the most important things that's got to be done is that ATSDR, with the help of local citizens, as David has pointed out, needs to put more effort into expanding the cohort in this study. In particular, I think that they need to go back and look at people that were born before 1968. I know it was convenient to start with 1968, because that's when those records were computerized, but let's face it, with some additional effort you can go back and find people that were born before 1968. I was born way before 1968 and you would have no trouble finding my birth records with even a modicum of effort.

Second, I think that this issue of improved notification is very important. And it's important for two reasons. It's important for establishing that larger cohort, but it's also important from a community awareness aspect. I think all of us were really moved the last couple of days, when we saw that there were people that had family near the base that still hadn't heard about this until just recently. So, I think that there are red flags all over the place that a strong legitimate effort for notification has not been done. That needs to be done one way or the another.

Male Voice: Now, is that an ATSDR responsibility or Marine Corps responsibility?

Dr. Maas: Well, I think it's probably a joint responsibility. I certainly think it's a Marine Corps responsibility. Certainly, as David has pointed out, it will work better with the help of the people that are actively involved here, but as far as ATSDR, if they're the ones in charge of doing this epidemiological study, that's the first

step of doing an epidemiological study, . . . So, certainly some of that responsibility falls to them, as well. Certainly, they did a lot of this work up until now. They just chose for time efficiency reasons to start with 1968. I don't disagree with that as a first cut, but at this point I think we're seeing . . . from what we've seen here, that we need to expand this cohort to people born before then as has been pointed out by others.

My third recommendation is that ATSDR should make every effort to move up the finish date of the current study that they're doing, that's scheduled for 2007. I teach ground water modeling courses at UNC Asheville. I'm familiar with those techniques. When I saw the timeline in their presentation yesterday, they're going to have a groundwater panel here next month. Then they're going to spend the entire rest of 2005 collecting hydraulic data. Then they're asking for all of 2006 to analyze this data, so that the study doesn't come out 'til 2007. That just doesn't stack up with me, either scientifically or from a time wise thing. I have some specific suggestions for how they could do that.

They certainly could be collecting . . . doing the groundwater modeling at the same time that they're doing the hydraulic modeling. Again, what I'm seeing is that they're looking at way, way, too much detail in the hydraulic modeling. It would be very nice to have that data, but since you're going to be doing an epidemiological study that combines that with other factors that are only accurate within a factor of two, it doesn't make much sense to be a bottleneck and hold back this study for an additional year, to take one very small aspect of this and try and make it even a little more accurate. Especially, when you consider that, when you get all done and you've got . . . and you figure out exactly how many gallons of water were used at each house and how each water was mixed and . . . so that you get a, what I would say, a theoretical calculation of the concentration of TCE and PCE at each home. That would make sense, if you had a tremendous amount of data concerning the TCE and PCE levels back then, but when you get all done doing that modeling exercise, you've only got a handful of grab sample data points that even tell you what the, you know, . . . that even tell you what the concentrations ever were. So, once you meld that, then you're going to lose all that accuracy anyway. So, I think there's a real opportunity to speed that up.

Related to that, I certainly want to recommend that ATSDR not wait until this other study is finished before starting the studies that we're recommending, particularly because the main work in the studies that we're recommending is going to be to start establishing a larger cohort. That's going to be the main work, and that can happen simultaneously with doing the groundwater modeling, the hydraulic monitoring. So there's absolutely no scientific reason to hold back and wait for any results from the current study before you start expanding this cohort.

Then finally, as others have mentioned, in establishing this cohort. I think that the purpose would be to look at different exposure groups and different outcomes. In particular, I think I would recommend, and I think most of you agree with me, that the cohort be expanded to include children that were living on the base, children that were in utero on base, but were actually born off the base, and adults that were not living on base, but were working on base. In terms of outcomes, I would like to recommend that they be increased to adult cancers, other types . . . and other types of birth defects. Thanks.

Dr. Cantor: Thank you. Dr. Selmin.

Dr. Selmin: I have to agree with both Paul [Dr. Visintainer] and Courtney [Dr. Lynch] and with all the rest of you that we need a much larger cohort, just to get the big picture, . . . everybody who was possibly exposed should be in the study, and then follow from there.

Dr. Cantor: Okay, thank you. Further comments on this general issue.

Dr. Maas: One thing that I would like to recommend . . . as I heard come out of the committee . . . out of the testimony . . . that there needs to be an estimate of the magnitude of the disease burden in this community. That can be done in establishing. . . at the time establishing the cohort. It can be done by survey. It can be done by phone call. We just need to know. They need to know. It's a prevalence study. There are many examples of this in the literature. That is something that can be done . . .

Dr. Cantor: My question to you . . . you're talking about current disease burden or cross-sectional back in 1980?...

Dr. Maas: I guess it would be part of a current and medical history survey. I'm not talking about medical monitoring. This is something that can be completed with pencil and paper, or interview or mail-in questionnaire with a phone call follow up. We just . . . and they need to know what the magnitude of the burden is.

Dr. Cantor: As an epidemiologist I will ask you . . . that could certainly be done descriptively.

Dr. Maas: Yes. Yes. I'm talking . . .

Dr. Cantor: No doubt...Would you want to see this compared with other populations? Or could you suggest other populations for a comparison?

Dr. Maas: From the perspective of a study, it would need comparison, but from the perspective of policy, I think it's a starting point to let people . . . to have this information available to them, so they can pursue other avenues that are open to them, other than the scientific avenue. They need to know this information.

Dr. Ozonoff: Well, expert panel members are allowed to disagree with each other. So, let me say this in a way that makes it sound like I'm not disagreeing with Dr. Maas, although I really am. I would be really careful about pushing ATSDR on the exposure end of things. As an environmental epidemiologist, the exposure part is just critical, absolutely critical. It could be used not just for the study that they're doing it for, but for every other thing that they're talking about as well.

I don't know the fineness of detail with which they're doing this exposure reconstruction, but I'm pretty sure they know what they're doing. It sounds like they're doing the right thing. We do these same kinds of studies on our. . . these same kinds of modeling things with our studies. They take a fair amount of effort

and it sounds like they're really doing it the right way. So, I wouldn't push them too hard on that. That's my personal opinion about it. I feel a little peculiar about this. I've sort of made a career, a long career out of criticizing government agencies, state level, local and so on. I almost got my wife fired once for what I said about her boss, the Commissioner of Public Health, on the front page of the Boston Globe. She was union, however.

[laughter]

So, . . . but I, . . . people at ATSDR, you know, they're like every agency. There are all kinds of people in it, but they're public servants that are really doing a very difficult job, a really tough job under very difficult circumstances I really want to acknowledge that. I mean, what they're doing is hard to do. There's all sorts of forces pulling and pushing at them from different directions. One reason why I like to do panels like this and help in advisory bodies is with a hope that we can actually make their difficult job easier. So part of my plea to you would be to think about it in that sense, which is, by pushing them on something. . . the reason I criticize these agencies is because there are people, wonderful people, inside these agencies who are helped tremendously, when people push from the outside. Right. Whenever I push from the outside, I try to make it in a way that's going to help people inside these agencies do good . . . just remember that, these are . . . there are great people inside these things that want to do the right . . . but they're pushed and pulled in all sorts of different directions. So, my wife being a public servant, too, we really owe people who are public servants, including people in the military, a tremendous debt of gratitude. One reason why I'm an outside critic is I know I couldn't do it. I'd never last two seconds inside a government agency. I'd be gone in, you know, a nanosecond, so. . .

Dr. Cantor: Okay, do we have anymore comments on what has been said so far?

Dr. Lynch: I just have one thing to add. I know it was mentioned yesterday by the ATSDR folks, that it was not really our need to worry about their funding, but I really do feel the need to comment on that. I have serious concerns with this money being sort of . . money for the studies being overseen by DOD. I mean, I think it's possible to ask DOD to give the money for these studies, but I think oversight for the expenditure of those funds should be given to ATSDR, or whatever other agency works on the studies, because I really think it's a conflict of interest. So, I know it's not our problem to worry about it, but I think it has scientific bearing on the outcome of the studies.

Dr. Cantor: That independent oversight is set up for this. Yeah. This is an idea that I came into this panel with, in fact, and it's a model from the National Cancer Institute. From our epidemiologic group we do studies that are highly visible and highly controversial. For example, there was a major study on formaldehyde industries that we did. There was . . . there's an ongoing cohort study called the Agricultural Health Study, which is following 80 to 90,000 people who applied pesticides in the states of Iowa and North Carolina. There is a Diesel Exposure Study that is going on. In each of these cases, because . . . in our case, because they are such controversial issues, and there are tremendous pressures from industry on

one side, from the environmental groups on the other, and other forces, that in fact, we found it very very useful to have independent outside panels be set up, in some cases of only scientific panels and in some cases they include members of the affected public. The agricultural health study, for example, there's a, . . . I forget whether it's twelve or sixteen member panel, but there are two farmers on this panel. They have been very, very helpful in advising us on how to, . . . and criticizing us . . . in our conduct of that study and likewise with these other studies. That certainly is going to be one of my recommendations, and if the other panelists would join in that recommendation that, not us, but an external continuing panel, review panel that might include, one or two members of the affected public, as well, who could then serve as liaison. . help input for this one study or this set of studies that are continuing.

Dr. Ozonoff: Let me join in that recommendation. I think it's very pertinent and also add something that I forgot when I went off on my . . . you know, my rant, that's the medical monitoring part. This is the Agency for Toxic Substances and Disease Registry. They have a TCE registry. [To audience] I don't know if you guys are on it. Are you?

Male Voice: [off-mike] No

Dr. Ozonoff: Well, I don't . . . well, there supposed to be enrolling TCE exposed people in it.

Mr. Ensminger: [off-mike] As far as we know that thing is dead. It was under review for validity. They were talking about doing away with it is the last thing I heard.

Dr. Ozonoff: Oh.

[overlapping voices]

Male Voice: Maybe we need to look into . . .

Dr. Ozonoff: Yeah, eh. . . Tom? What's the story?

Dr. Sinks: [off-mike] I can't tell you the specifics about that, but, um, we did [on-mike] . . . Tom Sinks. I can't be specific, because frankly, I don't know the specifics. In the past couple of years, CDC has come up with some guidelines about peer reviewing our scientific programs across the agencies. The first one that has been done at NCEH or ATSDR is, actually, the registry program of the original registries that were built, which were substance specific registries including, I think, the TCE registry. There have been a couple of rounds of reviews for those. We did get a lot of critical comments on them, and the future of those registries will depend on our . . . will come back onto those comments. It was also done by an external review panel.

There are a lot of deficiencies in those old registries that probably aren't in the current registries. The two more current ones are the Libby, Montana, registry and the registry on the World Trade Center. So, basically I can't tell you, if it would be a good idea or a bad idea to think about lumping this group of

people into that . . . into that pre-existing registry, which was built fifteen years ago or so.

Dr. Ozonoff: Well, I guess that when we're talking about assembling this cohort of potentially exposed people, we're really talking about a Camp Lejeune registry, in essence.

Dr. Sinks: Well, there is kind of a cohort now. I presume we have a cohort now, of people who meet a certain definition, for we followed and found them and tracked them. The issue becomes, do you expand that into another group? Whether you call that a registry or not, it's a cohort from an epidemiologic perspective. Obviously, you would want a range of exposures among those people to do scientific work. Right.

Dr. Visintainer: You established the registry based on passing through Camp Lejeune within a specific period of time. You don't base it on the exposure, within that you will get your range of exposures. Now part of that is individuals that may be excluded from that [definition of the cohort] are those that are not residing on the base, but work on the base. So that would be a very important additional cohort to identify.

Dr. Ozonoff: Or just establish a registry of people potentially exposed to Camp Lejeune water. That includes people who didn't live there, but worked off the site, of people who were in utero and delivered elsewhere. I mean, that includes everybody. It'll have a range of exposures. I probably shouldn't have brought up the registry issue. It was related to the question of medical monitoring which is . . . the registries really weren't comparisons that much, they were groups of people who shared a common exposure to look for patterns. So I thought, "Maybe that's an opportunity under that," I guess ATSDR is going to be "ATSD," at this rate.

[laughter]

Dr. Visintainer: I think the idea of a registry, though, is what we're talking about here. I think that would formalize, that would absolutely formalize beyond the idea of any specific scientific study, this more formal process of routinely and consistently collecting information and identifying individuals.

Dr. Lynch: I'd actually like to add that, I think, if we're recommending or maybe thinking about a registry as well . . . I like the idea of a registry, because it acknowledges that individuals were exposed to something. I think that's important.

Dr. Drane: It's also open-ended.

Dr. Visintainer: Yes. Yes.

Dr. Maas: Or, if you're making that in the form of a recommendation, I certainly would add my support to that.

Dr. Visintainer: That's a recommendation.

Dr. Maas: While we're at it, Dr. Cantor, I'd like to add my formal support to your last recommendation of an independent oversight committee for this work.

Dr. Cantor: Okay, so let me see, if I understand the distinction between a cohort and a registry. I'd like you to just expound on that a bit.

Dr. Visintainer: Cohort would be a scientific endeavor; a registry would be something funded by Congress.

[laughter]

But it does get back to, if you have a registry and it's identified, I imagine you have a Website and you have mechanisms for identifying people; and you have mechanisms for gathering information; and it resides; and there's a staff that manages this; and cleans it and makes sure . . . It's formalized.

Dr. Drane: But wouldn't you also say that to become a member of the registry you would have a minimal set, such as you ever worked or served in the Marines at Camp Lejeune?

Dr. Visintainer: Well, the registry, should be defined as . . . in my mind the registry should be defined around Camp Lejeune, between the dates. . . and I have to say, you know, from everything that I've read here, I would assume that the exposure probably took place in the 1950's, and it should cover people moving through that period of time. It should cover the towns around it for that period of time. You would collect this information. You would actually . . . I imagine you would have individuals demonstrate that they are part of the cohort.

[Tape change]

So you have criteria that are mentioned, none of it defined around our exposure, but rather around this common shared characteristic, which is within a certain geographic area, Camp Lejeune, including Camp Lejeune over a certain period of time.

Dr. Cantor: From within that you could choose end cohorts.

Dr. Visintainer: Yes.

Dr. Selmin: I agree.

Dr. Cantor: So this would be an umbrella, a large umbrella, from which cohorts could be defined.

Dr. Visintainer: Then it has a name, and it becomes known, and it becomes owned.

Dr. Ozonoff: As the Camp Lejeune Registry.

Dr. Visintainer: Yes.

Dr. Cantor: I don't know if we've exhausted this topic. I would like to turn briefly. . I'm struggling with this issue of what health end points are not the ones that everyone should look at, but the ones of greatest concern, the ones of greatest interest, the ones of greatest biologic rationale, in terms of laboratory work that's been done, but also the limited amount of epidemiologic data that are available that speak to populations that have been exposed to TCE.

We went through a long laundry list before. I would like to think now about, not eliminating things from that list, but at least where we would like ATSDR to place some emphasis. One of my thoughts, of course, is if a cohort study is done and they go to the National Death Index, they will get everything. They will get everything-everything that leads to death anyway with any probability. So, that's kind of easy in terms of defining end points that it will come out of that kind of study. The study will produce a list of end points.

But I was wondering if there are other things that aren't fatal, usually, that are . . . that might be feasible. We have certainly the current study, the way it's being done, the way the data are being collected. There was some mention here that there are a large number . . . I don't know if it's a plurality of people that have been in the Marine Corps, but a large number of people do stay in North Carolina. So, if they could be enumerated at some historical point and then followed through the North Carolina Cancer registry...which is a good, which is a good complete cancer registry. For the information of people watching, every state in the country now has a cancer registry of one type or another, but some are much more...much better than others, in terms of being complete, in terms of having the diagnosis and the other information you would need to conduct a study. Many states do not have the quality of data that would be required for this. So, if the numbers were large enough for North Carolina that would be one possibility. Other suggestions/comments on this?

Dr. Ozonoff: You mean other than cancer and mortality and so on, because I have a list of cancers that I think are probably related . . .

Dr. Cantor: They would come out of whatever study that . . .

Dr. Ozonoff: Well . . . autoimmune diseases, like Lupus, Scleroderma, mixed connected tissue diseases, hard to study, not exactly clear how it might be done, but I plausibly relate them to this kind of exposure. There are a lot of things that are like autoimmune diseases. It's a big spectrum of stuff and they shade into each other and probably should be looked at. A second area is skin rashes, which I hear a lot about around hazardous waste sites. The third is urinary tract infections and cystitis and things like that. I just . . . it's a common report that you hear about those kinds of things. We've heard here in the last two days a lot about gynecologic problems, especially in young women. That's not something I've heard about before, but I've certainly heard about it plenty here, sounds like it is of concern. It's actually hard to imagine how it would have come up other places. So, it could very well have just gone unnoticed.

Lastly, ATSDR did have a TCE Registry, Ginger Gist and others, and it collected a lot of information. There was actually a lot of stuff mentioned in that registry. I think urinary tract infections, cystitis, might have been among them, and skin rashes, and I can't remember what else, was on there. They produced a couple of reports. It's worthwhile checking that out, especially to look at the things that have been mentioned here and the things that are mentioned in that registry, if you don't want to use the whole thing as sort of a guide to this.

Dr. Visintainer: You know, we heard this morning, there might be inpatient records. The other place we might see this . . . you do a survey and you look at medical history. People . . . assuming included in that, hopefully, is there is any kind of inpatient or surgical history that could also be verified with medical records, particularly around some of the female conditions, like hysterectomies that we heard.

Dr. Cantor: So this would be naval medical records?

Dr. Visintainer: Yeah. I assume they're probably in hard copy form in some box somewhere. They would be in patients, so they would be available.

Dr. Drane: For the older people that might be in our registry, who are not retirees, who might want to go to UB82s, or whatever they're called nowadays, hospital discharge that are available through HCFA that deal with Medicare/Medicaid. Some states have a . . . well, in South Carolina; we simply call it the Statistical Research Department. They are responsible for amassing all of these data, making them available to the people who need them. I would think that North Carolina would have something like that also.

Dr. Cantor: It would be available for research purposes?

Dr. Drane: Yes. We make use of them all the time there at the university.

Dr. Visintainer: You know that's actually a good point. Another reason to push the registry is that it opens it . . . makes it accessible to researchers in different places, just like the TCE registry was available, so, not all the research on the registry has to come through ATSDR. You get a bunch of people working on this thing, if the information is there. Plus, I guess it's that it comes from a variety of funding sources.

Dr. Lynch: Being a reproductive epidemiologist on the panel, I'd just like to . . . I actually concur with the list of items Dr. Ozonoff came up with, but I would actually argue in identifying cohorts . . . I do like this idea of a registry now, but if you at some point need to find out the children of the people, say, who had registered, the adults who had registered, you would want a reproductive history anyway. We conduct that type of . . . those types of things all the time, where you know we ask about reproductive history, miscarriages, gynecologic disorders, because we want to know about those things. That would be something that could easily be collected when assembling the cohort of children, exposed children and so forth.

Dr. Ozonoff: One thing I forget and it reminds me of it. . . Around hazardous waste sites, the things I hear

about all the time are frequent illnesses in children, babies and toddlers and young kids. I just hear it over and over again. I heard it over and over again here the last two days. Children are also interesting for another reason, which is, of all populations, they're the ones that almost always go to the doctor when they're sick. Adults don't go to the doctor, but they take their kids to the doctor. So, there's a source of information there that may not be available for frequent infections in adults.

Dr. Cantor: If we have no more comments now we can move. How are we on schedule here?

Mr. Stallard: We're doing, we're doing fine. We can take a break here shortly if you would like and have Ms. Thompson speak before we do that.

Dr. Cantor: Why don't we do that?

Mr. Stallard: Okay. For the record and for your information, Ms. Alison Thompson, representing Senator Dole's office, has asked for an opportunity to speak just prior to our break.

Ms. Alison Thompson: I'll stand over here so everyone can see everyone. I have to leave to catch a plane, so I just wanted to make a couple of comments before I left. I am from Senator Dole's office. I'm also an active duty Marine. So, I'm kind of in a unique position, being on a fellowship on Senator Dole's staff, but I'm absolutely here representing the Senator and I didn't bring my armor, so don't hold it against me that I'm a Marine.

Couple of things I just wanted to note though was that going forward, obviously, it has been pointed out that it's going to need funding for whatever study takes place. Ultimately, as pointed out too, it's a conflict of interest; I think everyone would agree, for the Navy to be funding this. So, it's going to require a Congressional mandate of some sort. So, just a few thoughts I had on that was, although it's outside of the charge of your group to get into these types of things, and obviously you all are scientists and focusing on that between your panel's recommendations, we have GAO, which I'm very happy about sitting here as well, that's what's going to give kind of fodder to Congress to request this stuff and kind of get support and get it passed for funding, because with the budget coming out that is a huge issue. So, if you know, if outside of your scientific recommendations, if you can just throw out recommendations for funding, for oversight, those types of things are going to be very useful. I think that was about all I had to say on that.

One other comment was the hearing versus something else. You know, we talked about a congressional hearing. I was talking with some of you all at lunch, and this is certainly just my opinion, I've been on the Hill all of a month and a half, I'm a helicopter pilot by trade, but my very brief exposure to all this is that hearings are kind of three ring circuses; make everyone jump very high and are defensive in nature. I don't know that they are necessarily what would be best. I think that they would best be used as a kind of a fallback. As Paula, I think, very succinctly said yesterday, what are the ultimate outcomes that everyone is looking for from you all? Constituents, and members of the base and I think those were what I have written down here: first, that everyone be notified; that the Marine Corps make some kind of public apology; and

that compensation be given to those who need it. I think that was fairly succinct.

Unfortunately in this world, public apology and compensation, that's kind of an all or nothing type thing. I lost my point on that. I'll think about . . . Oh, back to the hearings and some other mandates. So, I don't know necessarily that to reach those objectives, if that is what the objective is, and that's kind of for you all, more or less the victims, to decide. A hearing will take a lot longer, I think, to achieve that, and possibly some sort of Congressional mandate for the parties of the Navy, DOD, you all, experts, to sit down in a forum much like this. Maybe we can get Chris back to be our facilitator? [laughter] Might be useful. So, I just caution you as far as what you ask for, make sure that's what you want.

To the board, certainly, thank you all for coming. It's probably a Pandora's Box that you didn't realize you were going to open and . . . yes?

Dr. Drane: It would not be out of order, would it, for Senator Dole to ask information from us, not having a panel in Washington?

Ms. Thompson: Right. Yeah. That's a very good point. I will certainly be briefing the Senator on this. That was something else I wanted to bring up, as a Marine Corps, was chain of command. There are no representatives here, so I will be briefing the Marine Corps on what took place, and some of the things to look for coming out of it. I don't necessarily know what they'll do, but I think it's important. I'm going to brief the Office of Legislative Affairs and to I&L, [Installations and Facilities], which is where Kelly Drier is, as Mr. Ensminger mentioned, I know she was planning on being here, I don't know what happened; so that information will get back. Like I said, yes, Senator Dole can certainly make inquiries and mandate some stuff, but for any type of mandate or legislation, we're going to need fodder, which is what all your recommendations and GAO's will provide, as well as constituent interest. Certainly, we appreciate you all being here, because I know it takes obviously time of your lives, money. It's painful to relive all this stuff, but it's your activism that has caused Senator Dole in the past to act and certainly brought everyone here together, so we appreciate that. So, that was all I had. Yes?

Dr. Ozonoff: Just a clarification, asking the panel to possibly weigh in on funding issues. Are you talking about level of funding or source of funding?

Ms. Thompson: No. Umm, you know, . . . like I say, I don't really know, but I'm just thinking, if you make your scientific recommendations and then kind of as an aside, you know, "Hey, this is outside of the purview of our scope, we just, as one of the few bodies I would say to date that has had the most" ... I think you all have the most objective and greatest amount of information pooled together. I mean there has been the Commandant's study, and then the other ATSDR study, but I really think you all have been privy to the most objective and full base of information. Say, "Based on that fact, as a group of knowledgeable experts we would recommend that oversight . . . We would recommend Congressional funding for additional studies." Because it's certainly going to take empowerment and manpower and tools and money to make those happen. Does that answer your question? I'm not sure how to go about that. I'm just

thinking, you've got your study, your recommendations and then say, "Aside, we recommend . . .or whatever the case may be."

Dr. Ozonoff: I just was unclear on whether you thought it would be helpful to have a number, a dollar number or just a comment about where the funding would come from or the mechanism or . . . I wasn't sure what you meant . . .

[Overlapping]

Ms. Thompson: I would just say . . . I certainly don't know the dollar. You guys probably know better what it would take to fund these studies, but just "that they be funded" would be sufficient.

Dr. Ozonoff: Oh. Right.

Ms. Thompson: That there's a requirement fund, and that they should be funded from Congress and not necessarily from the Navy, type of conflict of interest, or a line item from the Navy, something like that. Any other questions?

Dr. Cantor: Thank you very much.

Mr. Stallard: Have a safe flight. Forgot what I'm doing here. Okay, it's 2:35. We'll take a fifteen minute recess break and then resume. Fifteen minutes sharp.

[Whereupon, those assembled adjourned for a break and then reconvened]

Mr. Stallard: Please take your seat and we will resume.

[General voices conversing]

Dr. Cantor: Okay, well we are in our final. . Did you want to say something?

Mr. Stallard: No. . . . Well, let me just say, they are in their final deliberation and we still have time for the public comment period.

Dr. Cantor: When will that start Christopher?

Mr. Stallard: When you're done.

[laughter]

Dr. Lynch: All right.

Dr. Cantor: When we're done. Okay, first of all, I want to make something clear in terms of the health end points that we're talking about, the health conditions that we're talking about.

In the case of particular recommendations that aren't included in the mortality study, I think that many of us are thinking about, these are questions of feasibility. We don't really know whether given the groups that have been put together, once cohorts have been identified, whether or not it would be possible to study, for example, immune deficiency conditions, such as Lupus, to study dermatologic problems. These depend a lot on the existence that we really don't know about, of certain medical records, on the access to medical records, on the existence of medical records 20,30,40 years ago, and the ability to match the names and personal identifiers of the people in the cohorts that we're referring to with those medical records.

So, whatever outcome other than mortality and I think we mentioned the National Death Index, which is a national aggregation of all deaths that occur in the United States. They are assembled in one place and any death that has occurred since 1979, '78 are in this record system, and you can query, if you're a legitimate researcher, you can query that record system with a name and either a date of birth or Social Security number and come up with. In the case of the Social Security number, an exact match or, if you have the date of birth, the most probably matches from that resource. Then using other methods you can decide, whether it's the person that is on your list.

So, for these other health effects, feasibility work must be done. So, while we can recommend that these are possible outcomes, outcomes of interest, in terms of the exposure that we're concerned about, and certainly many of you have brought these forward in the last two days; we . . . from a scientific point of view, the point of view of the existence of the medical records and our ability to get to them. We really don't know, if it's feasible. This is something that the research team would have to look into with your collaboration. So, I just wanted to make that clear; that we're not opening up a Pandora's Box, "do this, do that, do everything else." We can't possibly do that without the feasibility being evaluated fully first.

Now, I think we have some area of discussion between registries and cohort. It might be a lack of my understanding what is meant by a registry, because I think registry means different things under different circumstance, or maybe I understand very well and I don't agree with the concept. So, I'd like Dr. Visintainer to address that issue briefly and then we can maybe have back and forth on the question.

Dr. Visintainer: When we talk about, or when I talk about cohorts, I'm talking, thinking about a very specific study design. I'm talking about epidemiologic studies. In my head it has a very specific context. It has an expected study design. It has expected classification schemes. It has expected . . . I anticipate having some concept of time frame. I have some idea of what the data analysis will show. I'll have some idea of what kind of measures we'll be able to estimate. So, "cohort" to me is something very specific. In fact, as we were talking about it, I think initially this morning we were talking about maybe about three or four or five different cohorts were going to be defined. I see a registry as something much larger. It's a way of identifying and managing this information. It can certainly be defined along certain guidelines or criteria similar to cohorts, but I think that the registry would contain many different cohorts that would then be

defined for study purposes. At the core of this it would be consistently collected information at entrance, with some assumption that there would be follow up over time.

Dr. Cantor: That would be for all members of the registry or just for selected members of the registry?

Dr. Visintainer: No, for all members, not that . . . by that follow up it could be the death index, it could be a cancer registry. They may drop out from contact over time, but at least you would have baseline information on them. Then you'd be able to do future studies. I guess I would say, for instance as an example, I would see something like the Kaiser Permanente, their medical database as a registry. People enter the health coverage. They fill out a comprehensive medical history at entrance and then within that depending on the question being investigated at studies they either be . . . look forward or backward or however, but it's a registry. It is actively maintained. At entrance information is comprehensive and it is systematically collected. So, I see the registry as a way of encompassing, rather than talking about four different cohorts, we would talk about a registry that would contain these four different cohorts.

Dr. Lynch: Now, when you say registry are you indicating a registry of persons or registry of affected families or exposed families.

Dr. Visintainer: Well, I know that a lot of registries are constructed around exposures. If this is going to support research it can't be constructed just around exposures. It has to be constructed around potential for opportunity. To me that would mean individuals that were within Camp Lejeune during the affected time, regardless of their exposure, and their family members.

Dr. Cantor: So, the starting point for putting this registry together would be to go back to the residential histories, I suppose, and the civilian and other occupations who were at Camp Lejeune who may have lived off base. Is that correct?

Dr. Visintainer: Right. I imagine that, you know . . . this would, this would probably be far more detail, but you know, years can be added as . . . you don't have to bite off everything at one time, but in order for this to work you'd have to have it to be consistent and valid, and active searching for individuals who were actually . . . say we defined one year base . . . residing in base housing '72 to '73. If the DOD can tell us the number of individuals were there and we can get 90 percent of them, and identify them and survey them at base line, then step back one more year, and keep adding a year, as long as it is consistently and systematically collected. It can't be volunteer to work, to support epidemiologic research, it can't be volunteer. We can't . . . it can't be passive let's say. Obviously . . .

Dr. Cantor: Thank you for that clarification, because in many cases registries are comprised of people who elect to be in the registry, who . . . the word goes out and people somehow hear about it and then they call in and then they're in the registry. You're talking about a much more comprehensive...

Dr. Visintainer: An active searching.

Dr. Cantor: This is a cohort.

[laughter]

Dr. Visintainer: The TCE originally was a volunteer, I think . . .

Dr. Ozonoff: It was. I'm the guilty partner in inserting the word registry into this. It occurred to me, "Oh, well, we're suggesting something like this." But really a [inaudible] a registry and a cohort are the same thing. They're a group of people who have a common experience, which is the textbook definition of a cohort. Here the common experience is exposure or potential exposure to contaminated water at Lejeune. So, potentially, I suppose, it's anybody who's worked or lived on the Camp from 1954 on. However, it may . . . in recommending that ATSDR, in collaboration with others, establish something like this, it may turn out that quickly becomes apparent that some of the groups here, it's hopeless. All right? Well, okay, then you pare it down a little bit, but keep pushing on the other stuff, so you can get something done. It may be that nothing is hopeless – that you can actually get the complete list. I don't think that we'll know this until you really try it, until it's really been tried. What I like about doing it this way is it doesn't require making a choice ahead of time, before you don't know what's feasible or not. That you're just going to do children, or you're just going to do adults, or you're just going to do people who are in military service. Although, it may wind up that you have a smaller set than you originally envisioned, you don't have to make that choice ahead of time. I wouldn't advise doing it.

Dr. Drane: I have a single sentence with a colon here. Members qualify by having spent time at Lejeune: civilians, Marines, spouses, and children.

Male Voice: Time frame.

Dr. Drane: Time frame, 1955-2005.

Female Voice: 1950.

Dr. Drane: Since you asked me [laughter] . . .

Male Voice: Or are you basically defining a Marine?

[laughter]

Dr. Ozonoff: Why would you . . .

[overlapping]

Dr. Drane: Or, take it back to '50, but you wouldn't expect to get too much on that end of the . . .

Dr. Ozonoff: Is there a date when people say there wouldn't be anymore TCE exposure?

(Voices from the back): 1985.

Dr. Ozonoff: So somebody who got there in '93 for example, you wouldn't necessarily . . .

Ms. Dyer: [off-mike] we do get calls from people that are sick that were stationed there after '85. I have told them that if they feel like they were poisoned at Lejeune by the water, whether they were civilians, whether they worked on base and then lived off base, whether they visited, that if they feel like they're a victim, they can go on to our registry. Then, what we have in the back end of the registry is the name, their addresses, the dates that they lived at Lejeune and where. [on-mike] And then, the 55 pages that you all have is the registry that we have right now and that's from people all over the country. You don't have their last names, but we do. We have their addresses and telephone numbers now. So that registry that you're looking at is up to date. Every day, another one is added.

Dr. Drane: Do you ask questions like do you fish or hunt on the property of Camp Lejeune?

Ms. Dyer: No, but we can because we have had people that have told us that they actually, that's what they did. You know, they fished in the waters and ate the sea food around there.

Dr. Drane: This would be especially true with fishing, if the stuff had been dumped in the waters.

Ms. Dyer: Right. That's right.

Dr. Drane: Or hidden in the woods, but especially with the fishing.

Ms. Dyer: But we have not denied anyone that has contacted us, because I have had people that said. "You know, I worked on base, but I lived out in town, but I drank that water." I've also had a couple of people that visited family members every summer, while they were stationed there and are very sick. So, our thing has been, if you went through there and you drank the water and you feel like you were a victim, then you can register on our Website. So, it's started for you.

Dr. Cantor: Thank you. Well, thank you for that clarification, because I think we're having a semantic rather than a conceptual problem here. I would, in terms of making a time frame and interest . . . these particular contaminants I would narrow it down somewhat. I would take it to maybe a year or two after the wells were capped and in fact, I don't know if it's possible to modify the ongoing study any more to include that. One of the really interesting findings in Woburn was that childhood leukemia, which was the effect of major concern there, had a temporal relationship with the stopping of the exposure. So, it would be interesting. . .

[Inaudible off-mike voices]

Dr. Maas: Well, depending upon the type of study design we ultimately decide is feasible and go ahead with, it might be useful to have those post 1985 people as a comparison group, for a few years certainly.

Dr. Cantor: I agree, I agree. Going back to the earliest time period, I think Paul's suggestion, maybe of selecting a few years and then adding on. The system could get overwhelmed rather rapidly, if one is too ambitious at the outset.

Dr. Visintainer: If this is going to underwrite or serve for scientific base, it has to be comprehensive and complete, as complete as possible. So, I would do small bites.

Dr. Cantor: But I think that one of the issues that comes up is statistical power, which from a scientific point of view is the major issue, from a public health point of view may not be the major issue. So perhaps the starting in the mid-'70s and going to '87 or '88 for starters and then, if that works then to expand it, to earlier time periods. Might be . . . Is there any comment on that or thought on that?

Dr. Lynch: I would just agree with that, because you don't want to start as too small of a chunk and you spend all of this time getting three years of data and you find you really can't do anything with three years worth of data. You need to get more people. So I think you need to have an adequate chunk to be able to say something initially and then continue.

Dr. Drane: I was about to say something like, carry it far enough to have the sample sizes you need for detecting the difference.

Dr. Lynch: Right. Absolutely.

Dr. Visintainer: Although, if we think about people being contacted actively, aggressively, they're going to come in from all sorts of years. Now, the studies can be determined based on the feasibility and completeness of the data and of the cohort by year, but I certainly wouldn't turn anybody away.

[general voices overlapping comments]

Dr. Cantor: Someone who was there in 1965, 75, presents data, you gather the data.

Dr. Visintainer: Some outcome study you may not use him, but he's in the registry should future studies be undertaken.

Dr. Cantor: We've talked . . . one of the . . . I would like to narrow things down just a little bit, or maybe help to put some emphasis on it, and priority, on some of the things that we've talked about. I always count three or four different cohorts. Maybe . . . Christopher, do you have a list of them, or Marie, do you have a list of the . . . somewhere. . . well, we could generate it pretty easily.

Dr. Drane: Here's a list right here. Start here and go to there.

Dr. Cantor: I'm talking about the cohorts not the outcomes.

Dr. Lynch: Yeah. I think we have it. It's children in utero at the time, children residing on base, adults residing on base, and those who did not reside on the base, but worked on the base. At least that is the four cohorts that I can recall we discussed.

Dr. Cantor: Okay, and the adults on base, there're two subcategories, but I don't think we need . . . that's the military and the civilians. I don't think we need to worry about adults working on base. So, in terms of a cancer follow up study, one that would take each of these as a separate cohort and link them to the National Death Index to see what the cancer mortality was among these groups. I'm just going to go around the table and see who . . . how you would rank them. David? How would you rank those four?

Dr. Ozonoff: You mean which cancers?

Dr. Cantor: No. Which cohort would you want to look at first? If you were doing this study, children in utero, children on base, adults on base, adults working on base, but living off base?

Dr. Ozonoff: I'm not sure which of those groups is the largest. That's the one I would choose.

Dr. Cantor: Okay.

Dr. Ozonoff: My preference would be for adults, rather than children, but that's because I do adult stuff.

Dr. Lynch: I would agree.

Dr. Drane: I would agree with that and you could start with all adults. One thing, cancer, many cancers I look at as an adult disease. You're going to have plenty of cancer with those not exposed as well as with those exposed, but the numbers will be high enough to tell the difference.

Dr. Visintainer: One other thing to think about . . . adult cancers, if the sample size is large, then imagine it will be person time follow up. So were generating a lot of person time. The thing about childhood cancers is that they are limited to a certain age. If they don't get a cancer by . . . I don't know . . . 18, is it? Then they're not going to be classified as a childhood cancer. If we look at 1985 and we say 18 years as the last child who could have been exposed . . .

Dr. Cantor: Two years ago or three years ago.

Dr. Visintainer: Would have been three years ago, so all possible outcomes would have occurred already.

Mr. Byron: [off-mike] My daughter is 19, and she was born in 1985.

Dr. Visintainer: Okay, one year ago.

Mr. Byron: [off-mike] ___ I had the wrong . . .

[laughter]

She was born in '85, April of '85. She's 19 now.

Dr. Visintainer: So, I would argue, if we take, let's use the dates 1960, well let's take 1968. There's no reason for picking '68, because that's a birth, but we're not doing the in utero, but if have 15 years of childhood exposures and we can follow them completely to 2004, 2003, that might generate a substantial number of cases and person time, if we can identify them.

Dr. Cantor: Do you have an estimate of what the child, children, population of children are?...

Dr. Visintainer: Right, right, right. I don't know.

Dr. Cantor: Don't know.

Dr. Visintainer: Or whether it's easier to identify the adults versus the children now, at this time.

Dr. Cantor: To go back and just, a question for Frank. How many childhood leukemias do you, more or less, do you have? That's out of . . .

Dr. Bove: [inaudible]

Dr. Cantor: Fifteen or fifty. Fifty. And that's . . .

Dr. Visintainer: But, that's from the in utero group right?

Dr. Cantor: Right.

Dr. Visintainer: So this would be expanded to all children and adolescents. I mean, I think that's appropriate.

Dr. Lynch: That's in utero were born in the county. So that's a very narrow group.

Dr. Bove: [off-mike] Those are our diagnosed before age 19. [on-mike] They're diagnosed before age 19, but you're right, they are in utero. If you're talking about exposures . . . if you're talking about children who were at the base after birth and were exposed for the first time after birth, they're not in the study. So, that's the population you're really talking about, but keep in mind, when the . . . unless you think it's a promoter, when do you think the initiating events would have occurred. I think that's something to think about.

[Odd ambient noise-laughter]

Dr. Drane: Don't adjust you pace makers.

Dr. Ozonoff: The advantage of adults is you have a lot more cancers to choose from and much higher cancer risks with age. So there's an advantage. Like everything else, there are trade offs here. I just don't think we're going to know this until we start collecting some of the information.

Dr. Maas: I think that's a really important point, because while you're trying to guide us into prioritizing in this, and that's okay, I think we should make it real clear that, if we're going to cast this wide net, that we've all agreed on in principle of expanding the cohort, I wouldn't want a prioritization recommendation to be misinterpreted to say that any of these aren't extremely important. I certainly want it to be at a point that all four of these groups are extremely important, but if you're forcing us to give a priority, we'll do that, but we're not seeing a whole lot of difference in priority and certainly all of them are very important.

Dr. Cantor: I wonder if we could focus in on a recommendation that would go something like this. One of the issues that I think we're struggling with is even the feasibility of establishing this registry. So, the idea would be to select a fairly narrow time range—two years, three years. 1972, '73, '74, in which an attempt would be made to establish such a registry that would consist of the cohorts that we mentioned, plus any other that . . . there's probably some people that we've forgot about that are there; and then, if successful, and if . . . I don't know if we can supply the criteria for what a successful; what is successful and what is not, but there are general standards that would apply to this. That you would have more than 85 percent, more than 80 percent of the people who you know lived there, for example, then the registry be broadened into full, into maybe the next time range, which would be from that starting time, from that earliest time to 1987 or '88. Then, if that's successful, you could go back in time. I'd like to have some discussion on that proposal. I think we have to give them something to start with, to start working with.

Dr. Lynch: It seems to me that the most reasonable chunk of time to start with would be the time at which we have the water sample data, that the modeling will be based off of, because, you know . . .

Dr. Cantor: So basically between 1980 . . .

Dr. Lynch: and '85.

Mr. Byron: [off-mike] There are also other reasons. You have Agent Orange exposure, which goes back to Vietnam. So how do you differentiate?

Dr. Drane: Well, that would confound only with the Marines.

Dr. Lynch: Right.

Dr. Drane: That would not confound . . .

Mr. Byron: That would confound with the Marines, but there's also, I believe, like 75 different sites on Camp Lejeune that were contaminated with more than just TCE and PCE, talking about DCE. How do you get a cohort . . . I mean that's from their own Public Health Assessment, if I'm not mistaken, is that right? Wasn't

there DCE on the base from contamination from that and many others . . . There's 75 different areas of the base. So how do you . . . right now we're talking about TCE and PCE, because I think the majority of the people here that have been affected were in base housing, and that's been the major identifier. I'm not trying to throw a monkey wrench into the works but, you know you're looking for these illnesses, how are you going to distinguish whether it was from the TCE and PCE or children being at the child care center where they stored DDT?

Dr. Ozonoff: That's why I think using an entire sort of Camp Lejeune cohort, registry, whatever you want to call it, is helpful, because there'll be a range of exposures there. In that case, the design that you would use is what we call internal exposure comparison. So it will be people at Camp Lejeune based on the modeling who had very little exposure versus people who had medium to much more exposure. What you expect in those three groups is all those other things will be roughly the same. Unless it could be shown that, you know, only people who drank TCE contaminated water were exposed to DDT, which seems unlikely, then an internal exposure comparison works.

Dr. Maas: There's lots of ways we have to deal with confounders, if we know what they are. We can quantify them and we can adjust for them. All it does is make your study a little less sensitive, so there has to be a bigger effect for it to stand out from the background noise.

Dr. Ozonoff: Of course, being able to quantify them is the issue right here. How do I know that somebody was exposed to DDT. I don't, usually.

Dr. Drane: You're not going to.

Dr. Ozonoff: Yeah.

Dr. Lynch: Yeah.

[Tape change]

Dr. Lynch: Dr. Bove, for what years do you have the water quality information that you're using for your modeling? Is that '80 to '85?

Dr. Bove: The sample data started in 1982 for the trihalomethane analyses. And so, we don't have specific data on TCE and PCE until '82 when they actually analyzed for that. What we have before that is interference with trihalomethane analysis.

Dr. Lynch: Okay.

Dr. Bove: One other thing that I want to say was, if you do look at children who were exposed after birth, you have to keep in mind what we've seen in other studies. I mean, the Woburn study, the Tom's River study, the cluster studies, all seem to point to in utero exposure. That's why we were thinking of it in the

same way. I'm not aware of much literature about exposures after that we've seen with these kinds of exposures, but just keep that in mind.

Dr. Cantor: I don't think we're dismissing that, although, yeah, that is one of our cohorts. So maybe the suggestion can be modified to, say, start out with the most recent time period, or a more recent time period, let's say 1983, '84, '85 and if successful then . . . go back. So the registry would be any person, and I don't know if you want to say more than a week, more than a month, I think you have. . .

[voices overlap]

Dr. Visintainer: Well, that I think would have to be informed . . . Right.

Dr. Cantor: Right. It's not someone who's just driving through or making an inspection or something of that sort.

Dr. Ozonoff: Frank, what's the ability of the model to estimate exposures previous to 1982?

Dr. Bove: I think the modeling will be able to go back pretty well to close to '68. I mean, Morris [Mr. Maslia] throws out the date '74 for some reason or other, I'm not sure exactly why. I don't think, well, I mean, I'm not supposed to direct you any direction, I guess, but it would seem to me that it would be much better to focus on a particular cohort you thought might be the best one to follow, and go back in time and capture them; rather than looking at a whole bunch of cohorts of different kinds of exposures, and different kinds of situations and following them for, and only having a short period of time. So, that would be my suggestion to you. Even though the sample data only is from '82 really to '85, we can go back in time with simulations. That's why we're doing all this work.

Dr. Ozonoff: Now, what's your reason for saying we should restrict ourselves to one cohort.

Dr. Bove: I think that . . . well, I hear you saying a whole lot of cohorts, several different cohorts, and a short period of time and, I, it . . .

Dr. Cantor: No, no, let me correct that. That's . . . Maybe I didn't say it quite right. I think, what I'm suggesting is that a restricted period of time be selected to establish the feasibility of establishing what we're calling a registry, which would be a number of cohorts within a larger umbrella. Once having established the feasibility of doing that, then to broaden the time period. Now, you might find that it is not possible to enumerate all the children who were living. That's the one group that seems to be maybe the most . . . or one of the more difficult groups. Maybe not, maybe it's some other, but it might be difficult, so then you'd say, "Well, we will stick to . . . we'll not include them because we just cannot do it with any certainty that we're getting most of the people, but we'll expand the rest of the group to cover a much broader time period, let's say, from 1968 through '85." So, I'm proposing this as almost a necessary feasibility exercise. Then, once having been successful it would be broadened out, not that that is the cohort.

Dr. Ozonoff: The other thing I would say Frank is that I take what you say pretty seriously. You have a lot of experience with this and I trust you, but the way I see this working is that you would be a voice which would count for quite a lot I would think, but Jeff [Byron] and Jerry [Ensminger], and Terry [Dyer], and everybody else also would have a voice and opinion about this. Right? It may be that, after hearing them, that it's easier than you thought, or it's do-able, and maybe after hearing you they'll say, "Yeah, you're right. Maybe we shouldn't do it that way." What I think is hard to do is to sit here now without really digging into this thing and deciding what to do, that we just don't know at this point.

Dr. Cantor: More comments on this basic approach.

Dr. Visintainer: I would just say that I think whether it's a child cohort or adult cohort, for the scientific study, it looks like cancer would be the outcome of choice, because it's a hard end point. Hopefully it will be systematically collected.

Dr. Cantor: There are registries...

Dr. Visintainer: Right.

Dr. Ozonoff: The only thing I'd add to that is that if you establish that. . . for everything that has been mentioned in the last two days, if you . . . in the ideal case, if you establish the entire registry that allows you to do everything that you wanted to do, right. Maybe the first thing you'd want to do is cancer, because you don't have to go back to people to do it, but if you can't do this, then some of those other questions have to be attacked in a much different way, maybe more difficult to do, but not impossible to. This would seem to be the key that could unlock a lot of things, if you could get it done. If you can't get it done, then we have to go back and think of a different way to do it.

Dr. Drane: Let me put as a second priority, the developmental problems of children and the dysfunctional organs of the children. These two jumped out at me as being measures of what they bring into the world. I think this ought to have a pretty high priority.

Dr. Lynch: The only thing I worry about. . . I agree, I think developmental . . . looking at child development is very important, because it's sort of a subtle marker of some sort of insult, but it's a little difficult. You know, we've tried to do some cohort study follow up on development of children and short of being able to get medical records, it's very very difficult to do standardized evaluations, you know that you can do much with. If you have suggestions, I think that would be great if we could put those in our recommendations. I just know that those are tough sort of studies to do.

Dr. Drane: Well, maybe we can think . . . maybe we can be inventive and, in coming up with something.

Dr. Ozonoff: We're actually doing studies like that now and ...

[Voices overlapping]

Dr. Lynch: Are you?

Dr. Ozonoff: On PCE and TCE exposed cohort, but I don't know whether it worked out. So, I mean, they're in the field now, it may be a bust.

Dr. Lynch: What sort of evaluations are you doing?

Dr. Ozonoff: I was afraid you were going to ask me that question, [laughter] because as I sit here right now, I can't remember. Ann is doing it, but I think they're using like psychophysical testing, yeah.

Dr. Cantor: One thing that would be more possible, perhaps, would be the offspring of the children who were exposed in utero now, who are being born now. If that group could be identified, then developmental issues could be addressed among them. That's again something that would be uncovered. I think the existence of those people and those records would be uncovered in the original survey.

Dr. Drane: It would certainly unfold the mutagenic properties of the insult.

Dr. Visintainer: What about mortality studies? Again, once either an adult or child cohort can be established, let's say and I think, you say the Social Security number came into being assigned in 1980 at birth?

Dr. Cantor: 1980, did someone say '85?

Male Voice: Inaudible.

Dr. Visintainer: So, it wouldn't help us there, but you know, again I . . . mortality would be the same kind of thing, and it'd be using the National Death Index.

Dr. Cantor: Given the existence of that data source that would be . . . could be readily done, once the cohort is established. Then all causes of death would be examined under that circumstance, right, cancer and everything else? Right? Okay, I think before Christopher [Stallard] made a list of some other items that we had discussed previously that, I'd like to revisit. I think that we have maybe not complete consensus but there's general agreement on the first point, which we've just been discussing.

Mr. Stallard: Let me read it for those who can't. It . . . This is . . . I've consolidated basically what you offered earlier in terms of bullet recommendations as there was some similarity to theme and topic. An active registry for Camp Lejeune established . . . be established and funded covering the periods as you've said, the fifties to the 1985 including surrounding townships. Now that we have distinguished the meaning of cohorts perhaps this still follows . . . that cohorts follow from the registry as do future studies. That encapsulates much of the dialogue on that thing. Media strategy communication and improved notification strategy, again supports how you get the people to participate in the registry, I believe. Then, a

new model formalized, partnership between community and agencies, ATSDR and DOD, funded with top-level buy in and ongoing external panel representing all stakeholders, which under that is subsumed, if there's top level buy-in and representation, there would also be access to data. That more or less encapsulates what you've discussed.

Dr. Cantor: So there are many things in each one of those.

Mr. Stallard: There are.

Dr. Lynch: The one thing I think is missing from the first bullet point is that that registry should be developed soon, not waiting for the current study to be completed, that that work can start in parallel with the current study.

[Dr. Drane and Dr. Cantor overlapping]

Dr. Drane: It could be institutionalized, it's already been started.

Dr. Lynch: Exactly.

Dr. Drane: When was the big accident? It was 1972 wasn't it? When they had a great spill?

Dr. Cantor: And the very first part of that would be feasibility for a limited . . .

Dr. Drane: 1971, '72.

Dr. Cantor: For a limited recent period within that time period that you're citing.

Dr. Drane: Spike somewhere down the line

Mr. Byron: [off-mike] I think it was '81 or '82. They didn't do any sampling until the '80s.

Dr. Lynch: Oh right.

Dr. Drane: I was listening to what Ellen Harris had to say.

Mr. Byron: . . . '81, '82.

Mr. Stallard: So how do you want that reflected here? That a feasibility for a limited recent time period include what?

Dr. Lynch: Early '80s. I don't know.

Male Voice: '83 to '85.

Dr. Drane: Include the periods around whenever that accident was; I can't remember it right now. There

was a big spill of . . .

Mrs. Byron: The Holcomb Boulevard spill?

Dr. Drane: Yes

Mrs. Byron: That was in '82.

Dr. Drane: Okay, then that is essentially where we would start going both ways.

Mr. Byron: Sampling started in '82 anyway.

Mr. Stallard: Okay, I have that '82 to '85, place holder.

Dr. Maas: I have a little bit of problem with that, because they've already identified all the people that they could from that time that had . . . you know, that were in utero and births. What we're trying to do is get them to expand it to include all the children and what not. So, I don't think those years are a good test, because you're taking one that they've already done half of and seeing if they can do the other half. Scientifically, it would make sense to go, since ultimately we want them to look at everything from the fifties and eighties, I think we'd want to pilot this thing in a fresh time zone, not one that they've already beaten the track down. Take a fresh couple of years and see how we do with that starting from scratch.

Dr. Cantor: There are people that I think that we're interested in, that aren't included in the current study. That would include children of the families living there that would include people living off base working on base. Did I miss any groups that?

Male Voice: And adults.

Dr. Cantor: Well, adults

Male Voice: That was living . . .

Dr. Maas: Well, that's all true, but I'm still saying, it's not as good a test for what we're ultimately going to do, because we've already gotten a lot of data from the children that were born on base during that time. So it's not a good test of what we're ultimately trying to do. The better test would be to go and see what they can do with an earlier cohort; where they are starting at square one.

Dr. Lynch: I actually think it would be an okay task and let me tell you why, because that sample that they found was identified through birth records, that's one method, but it seems to me here we would want to go to housing records. Start with housing records and identify people. So, I think that's a different task. So, even though we're looking at the same time period, I don't think we're looking at the same method of identification. Now, of course you would have the problem that, if you want to call someone who was called in 2000 about the other study, and they'll say; first thing they'll say is, "Well, you already talked to

me.” I mean, you’re going to have that problem, but I think the searching is not . . . wouldn’t really be duplicative effort.

Dr. Maas: Again, we already know what percentage of the people in that time zone that they can, that they can identify. What we need to know for this registry is what percentage of people from other earlier time zones can you identify? The way this is put up right now, you won’t get any additional information on that.

Dr. Lynch: Well, I actually think right now what we know is how easy is it to find people who have births. I don’t think you know, for instance, how easy is it to find the single male living at Camp Lejeune in early 1980’s, which may be much more difficult. Or actually, probably the single female would be the most difficult because she could have potentially married and changed her name, but. .

Dr. Maas: Well, I agree with a lot of what you’re saying. I’m just saying that I think that you would agree too that a better task would be, since ultimately we want to look at all this period from 1950 to..., you know, that we didn’t look at before, a better test of whether that’s going to work is try some of that period and see how it goes.

Dr. Drane: It only strengthens your study to increase the distance and time.

Dr. Visintainer: I’m just approaching it more from a practical perspective. You know, I’m just saying, there’s going to be an awful lot of data and the systems have to be established. It’s much easier to do that where you don’t have to worry about everything. You only have to worry about 90 percent of it, you know. If you take a small piece, if you take a chunk and you establish, you get to your protocols in and you get your questionnaires together, you’re not delaying things by taking too big of a piece.

Dr. Cantor: We’ve asked Dr. Bove to comment.

Dr. Bove: Let me say a few things, because I can’t sit still. [laughter] First thing is, if you do restrict the period to around the 1980, it’s a PCE study, not a TCE study. You need to include . . . you have to go back in time to get the TCE exposures. The TCE exposures happened up until ’72, for the most part. Then you have one housing area beyond that’s getting TCE. So you need to go back in time. The Hadnot Point system, which is where the TCE is, served a large housing area from ’68 to ’72, that was later Holcomb Boulevard, and also served other areas before that. That’s where the TCE exposure cohort would come from. After ’72, correct me if I’m wrong, you have one housing area, Hospital Point, that’s getting exposed to TCE. That’s why there are only thirty-one births, because we thought that was it. We didn’t know that there was exposures before ’72. So by limiting . . . that’s why. . .

Another reason why I didn’t want you to limit the time to the period you were talking about, if you could look at several cohorts at once and go back in time, fine. The reason I mentioned focusing on maybe one or two is just to see, if we could we do it for the ones we think have the most likelihood to be enumerated, but that is something that needs to be negotiated with the community. The pros and cons of which group

to focus on first needs to be discussed, at least in my opinion anyway, in that kind of discussion, but anyway, if you want to include TCE in any meaningful way you have to go back in time.

Dr. Cantor: At least to 1972.

Dr. Bove: I would say you want to go back in time further, '68. Because we . . . but '68 is a funny date. I mean, '68 has to do with birth certificates, just forget about it being . . if you're looking at adults, there's no reason . . . we may have a different date, given what's available computerized at the Defense Department.

Dr. Ozonoff: But the dry cleaner opened when?

Male Voice: '54

Dr. Bove: '54. So we're talking . . .

Dr. Ozonoff: But that's PCE right?

Dr. Bove: Right. I said you'd have a PCE study. If you want a TCE study, you need to get the people who received Hadnot Point water, and most of those people were before '73.

Dr. Ozonoff: I thought you said the other way around.

Dr. Bove: No. I also said that it's in utero that we know we think that the cancers – that leukemias – are initiated in, children, not after births, but. . .

[voices overlapping]

Dr. Ozonoff: But you know . . .

Dr. Bove: But we can debate that.

Dr. Ozonoff: Yeah, but those childhood cancer studies are studies of childhood cancer. So a child ...

Dr. Bove: That's what I was just talking about.

Dr. Ozonoff: Yeah, but a child exposed when they're three to five years old, for example, may get cancer when they're thirty-five. Then they're not part of those other studies.

Dr. Bove: They're not a childhood cancer either.

Dr. Ozonoff: They're not a childhood cancer, but they are an exposed child, an exposed child who gets cancer.

Dr. Bove: Right. No, I thought . . . we were talking about childhood cancers, I thought. Maybe I

misunderstood; maybe I'm falling asleep back there. That's what I thought we were talking about. Okay.

Mr. Byron: [off-mike] The only thing I have to add is that the well was dug in Tarawa Terrace for PCE in 1958. The dry cleaners started their establishment in 1954, from my understanding of the way that they dumped . . . [on-mike] from my understanding of the way that they dumped their solvents into the ground was through the septic system, and they started that immediately in 1954. The Corps dug the well in 1958, so for PCE at Tarawa Terrace, if everyone would be in agreement, 1958 to 1985.

Dr. Maas: Well, that sounds to me like a pretty strong argument for maybe looking at '68 to '72. 1968 is good because it's easier for them to get computerized birth certificates, and it's back far enough that we should still have pretty widespread TCE exposure.

Dr. Visintainer: Or let's not define the time, and let's let them [ATSDR] define the time frame, as the information guides them.

Dr. Cantor: I think the basic principle is to restrict the first look to a relatively narrow range of years, just to limit the years.

Dr. Visintainer: To make it manageable.

Dr. Cantor: Yeah, make it manageable and once having shown you can do that, and then you expand it in any and every way that you can to include all of the cohorts that we mentioned. Yes?

Mr. Stallard: Just a point of process. We have about an hour left together as a group to conclude this two day session. Within that time, I know of three individuals who have public comments, which will be thirty minutes, if they all take their ten minutes. So, the question I pose to the panel, can you in fifteen to twenty minutes conclude your deliberations relative to, I think, what we're trying to do is narrow down for the writer/editor to encapsulate what your recommendations are?

Male Voice: We'll do what we have to do.

Dr. Maas: Ken [Cantor], I have one thing that I think we'll all agree is very important, and hopefully we'll unanimously agree on as part of the overall number three recommendation here. Basically, we came in here yesterday morning assuming that, as in the past, that DOD would fund this next level of studies. So, we kind of worked on that assumption kind of implicitly. We brought it up over and over again that we need to make sure that money goes into some kind of line item where it's moved, so that we have some kind of ongoing independent board to deal with it, so that there's not a conflict of interest and undue influence on that. Then we heard this afternoon from Ms. Thompson from Senator Dole's office. What she left us with was the idea that Senator Dole's office certainly felt like this should be even more independent than that, that there should be Congressional funding. Her final words that she left us with was a very strong admonition to make sure that we had a recommendation explicitly, while she said this is out of our purview, it's really not because it has to do with making sure that solid independent science is done. So, I

would like to have us unanimously agree as part number three that our recommendation is that the funding for this be from a source other than DOD, if possible. Then that we would have an ongoing and independent board involved with that.

Dr. Cantor: Okay. Thank you. Just as a matter of clarification, we are making these recommendations as individuals. This is a bureaucratic matter, more than anything else, but I think if we all make that recommendation it'll be well understood.

Dr. Maas: My understanding is we all have lots of individual recommendations, but my understanding is that Chris [Stallard] took these three and said, "Well, here's three that I've heard that there is a unanimous opinion on." I'm suggesting that we add this portion to number three as one of those three recommendations.

Dr. Cantor: So that there be independent funding, or be as independent as possible, and that there be an external independent review panel. That right.

Several Voices: Yes.

Dr. Ozonoff: Let me make . . . speak in favor of not restricting it to a group of years for feasibility purposes, because I'm just talking off the top of my head so, maybe this is wrong. It seems to me that, if you start to do this and you discover that it's really tough to get information on '71 through '74, but '75 through '82 is real easy, you would miss that, if you decide that you would pick the '71 through '75 period.

Dr. Lynch: I was thinking that as well. I was hoping we wouldn't pick the wrong time period. So, it'd be difficult and they'd [ATSDR] say forget it, we're not going to do it. It's a concern.

Dr. Maas: I thought that I was the only one thinking of that. I didn't want to throw it out again and . . . It makes me nervous, because you know, if, for instance, if ATSDR goes out, and let's assume that in good faith they put out a strong legitimate effort, but for one reason or another it's not adequate, then the whole thing... they've got a basis for saying, "Oh, well that didn't work." I think it might make more sense to go back to what Paul [Visintainer] said from the beginning, let's practice casting a wide net and see what we get. So, I would really be more comfortable with that. I understand the practical considerations, Ken [Cantor], that you're bringing up for narrowing it, but I think that those other considerations might outweigh that.

Dr. Cantor: I hear what you're saying, and it is an excellent point. So, what I was trying to do, and maybe there's another way of doing it, is restricting the universe in some way, while not excluding any of the particular cohorts to make the first efforts a manageable effort in that way to make it feasible. So, I don't quite know how the housing records are kept, but if there is a universe of housing records, then maybe you can randomly select every tenth housing record of the whole base, and accomplish this in the same way. If something like that would be possible for another period . . .

[overlapping voices]

Male Voice: I like that idea a lot better.

Male Voice: Or again, let's just, can we say, leave it to the investigators to determine what a feasible and relevant time period is?

Dr. Maas: Yeah, I think I'm okay with that. I mean, the idea is that we're giving them some general guidance that probably they will need to pilot this thing, and use their own judgment on how to pilot and how to interpret those results, to be able to move forward.

Dr. Drane: Assuming, first of all, this will be an advertised study to be done and there will be competitive bidding, the competitive bidding and their designs and plans would be peer reviewed. At that time in particular, their designs could be evaluated which are the best and which are the non-competitors.

Dr. Cantor: Presumably, if they follow our advice and elect to have an outside panel, this panel would provide oversight for that process.

Dr. Maas: Right, that's a bit of an unknown. The other logistical thing that strikes me is that, if you ...if the way you pilot, let me call it a pilot study, if you will, instead of a feasibility study, because we're just kind of trying to see how this development of this larger cohort will work. If you throw out a lot of improved information, advertising, and notification, you're going to get people interested from all those years. It would be an incredible waste and inefficiency of effort to say, "Oh, well you weren't here in '68 and '72, so we'll keep a record on you, maybe we'll get back to you." It seems to me that, once you've done that, you better get the information from those that come forward and then make your judgment about what works based on that database.

Dr. Barrett: I just wanted to comment that there is a requirement for all research protocols that are done by ATSDR staff to be externally peer reviewed. Our office sets that up.

Dr. Cantor: That includes feasibility studies as . . . pilot studies as well as full studies?

Dr. Barrett: It includes anything that involves research.

Dr. Cantor: Thank you.

Dr. Ozonoff: I think probably, if this is like everything else, the result will be that 80 percent of the effort will be in the last 20 percent of the ascertainment, but who knows. It's a question of 80 percent of what? Right?

Dr. Cantor: Any further comment on the kind of three items that are on the board right now? Well, Christopher [Stallard], I will hand it over to you for additional public comment, then.

Mr. Stallard: Thank you. Okay, I have on my list Ms. Karen Strand to speak. Is Robert Thomas here? No. Is Sandra Bridges here? She spoke this morning. Thank you. That would leave Mr. Jerome Ensminger. So the three of you. Correct? Okay.

Mr. Stallard: We will hear from Ms. Karen Strand.

Ms. Karen Strand: Okay. As I was reminded we are limited on time and I do appreciate that and I will very briefly read my statement that I'm submitting. I do wish to thank our distinguished panel and the Agency for Toxic Substances and Disease Registry for making possible this opportunity for us to express our concerns and share our statements.

It has been a long, hard, and sometimes discouraging journey to get to this point. Long, twenty years long, from 1985 to 2005, too long. Hard, it started as individuals, numerous efforts and then became a united voice of survivors so that we could become a voice loud enough to be heard. This led to trips to Washington, phone calls, emails, and letters to our representatives. Discouraging, because of all of the above. Even after twenty years we are still forced to slowly crawl and claw our way at getting what we need-to getting medical care, the studies, notification and even the dignity of having those responsible-intentional or not-to stand up and accept that responsibility.

On a personal note, in 1958 my dad took the job as Principal of Tarawa Terrace II Elementary School. I was six years old and we lived in Tarawa Terrace from 1958 to 1973, fifteen years, in which time we went through our developing stages. Daddy was thrilled to have his three little girls grow on a military base. He was especially happy that we would have an excellent school system. He dearly loved his country and was proud to be working for a school system that served the military. He died at age forty-five and did not live long enough to learn about the contamination to his family.

At age nineteen, while still living in the Terrace, I spent five days in intensive care and a total of seventeen days in the hospital, where I almost bled to death with a peptic bleeding ulcer. A year after that, I developed a goiter from Graves disease and had surgery to remove that. It returned ten years later too, and I was given radioactive iodine treatment, so I no longer have a thyroid. During hospitalization for a hysterectomy for fibroid tumors, they also discovered and removed a cyst on my abdominal wall. In addition to that I have allergies, asthma, a vaginal vestibulitis, and IBS. I've also been treated for migraines, fibromyalgia and depression. Three years ago, I was also hospitalized again with a bleeding ulcer. In that same year, I had surgery to remove a tumor from my parathyroid gland. Recently, I was diagnosed and I am still being treated for gastric antral vascular ectasia, and if I mispronounced that I'm sorry, short is GAVE. It causes pain and bleeding from the stomach. I also have left plural effusion on my lungs.

I'm not alone, because of our Website

[www.watersurvivors.com]

, my sister and I have had the privilege and sometimes the pain of hearing and reading the stories of the many victims whose statements you have received some in the mail. I'm sure, the contamination has had a far reaching effect. The ones I think it's hardest on are those who are of course the parents, who have had to suffer through by watching their children suffer. Almost all are discouraged and hurt, because they feel that the country that they fought for has turned their back on them. The financial burden has been more than almost they can bear, especially hard for those that we've heard from who have more than one family member ill. Some haven't been able to receive life insurance or health insurance.

The emotional burden, which some of us seem to forget, or tend to forget about, sometimes can become unbearable, but it's the hope of finding truth and justice that we seek that makes it worthwhile. Knowing that there are those out there who don't know yet, but are depending on us, makes it not only worthwhile, but necessary. Those same people are depending on this panel and the decision that you make. We are hoping that further studies such as those of the children and adults, and the modeling side that's being studied, will lead to notification, official notification, as well as answering all of the unanswered questions that we've had to live with for much too long. Thank you.

Mr. Stallard: Ms. Terry Dyer.

Ms. Dyer: Can you give this to them, if you would, Chris [Stallard]? I wanted them to see this, while I was talking because that way they can put a face on this, besides the one's that they've seen.

Distinguished panel members and fellow victims, my name is Terry Dyer, and from the bottom of my heart, I really would like to thank you for being willing to give up time out of your busy schedules and lives to give this group of survivors hope for a better tomorrow. The pictures that you're looking at right now are my dad. Isn't he . . . he was handsome wasn't he? He was forty-five when he died. The other picture that you're looking at is three little girls. My sister Karen, she just spoke and is standing in the back. Then you'll see my little sister, Johnsie, with her blonde hair. Then you'll see Terry, the Terror of Tarawa Terrace, that's what I was called, and I guess I'm living up to it now.

My family, as Karen said, lived at Camp Lejeune for fifteen years. As children we were always sick. We were known as the little sick Bristo girls. We were in the doctor's offices all the time. I gave each one of you a memo. These are our medical problems. I thought you would be able to take it. They are of Karen's, mine. It starts with Karen and then her children and then myself and my children, and then Johnsie, my younger sister, her children, my father, who is deceased now, and my mother. Our immune systems were extremely low. As a side note, our grandmother lived with us from 1958 'til when she died. She lived with us for almost seven years, in Tarawa Terrace. She died at the age of seventy with cancer. The reason why I mention this, because I know seventy is a . . . a lot of people look at that and say, she could . . she lived a good life, but all of her siblings lived to be in their nineties and died in their sleep. She died. She had breast cancer that then went into other areas.

My dad died at forty-five of a cardiac infarction. He had daily nose bleeds, severe migraines, terrible allergies and sinus problems. He was hospitalized with hepatitis, that they could not understand how he had contracted it. I just wanted . . . before I go on, I just want to tell you about my dad, because I think you need to know, I was sixteen when he died. He was so neat. He was so neat. To be able to say that I had a dad like that, a lot of people can't say that. You know, today we just, we hear all this about dysfunctional families and things like, and I didn't have one. I was blessed with parents that loved us and gave us good self esteem. He used to show up at the teen club early to pick me up, so he could come in and dance with me. He'd come to the high school and get me out of class just to see me around lunch time. We walked through the halls holding hands. I wasn't ashamed of it. He wasn't a Marine. He was an educator. He educated the children of Marines. At Christmas he would dress us up and he would dress himself up as Santa Claus and we would go around to children's houses, whose dads were off on leave. My dad did that just because he was a good man. I miss him. He didn't get to see my children. He didn't get to see me graduate or get married. I kept him alive, because I talk about him. I just want you to know that he was really special. I believe with all my heart that they took him away.

There were other principals that were there in the fifties and sixties that died of heart attacks also. There was a principal and an administrator who died of leukemia, and his grandchild has since died of leukemia. They lived in Tarawa Terrace.

My younger sister Johnsie, the little blonde you see, was two months old, when we moved to Lejeune. I was one and a half and Karen was almost six. Johnsie, my youngest sister, was developing normally and could even read upside down. She stopped talking suddenly for several years, and when she started back she had a severe speech impediment and learning disabilities. She and I were in the same speech classes as children. We used to have ear infections, eye infections. I can remember my mother and my grandmother having to take warm rags, wet rags, when we woke up in the morning, when we were living at 3500 Chosen Circle in Tarawa Terrace, the first house. We lived in four houses at Lejeune. The reason why they kept moving us is because they thought my dad was having allergies and sinus problems because of the heating system and he used to sneeze when he took a shower. I thought that was ironic because we used to say, "Daddy, are you allergic to the water?" But we had this goop in our eyes, when we would wake up and it would just crust over and this went on for months and months and months. Mom and daddy would have to wipe our eyes out, before we could even open them.

My sister Johnsie has never been able to hold down a job. She has debilitating migraines, as do Karen and I. She suffers stomach problems, like we do, and extreme depression, and low, low self esteem, now. She had a twenty-five pound tumor the size of a basketball removed in a hysterectomy before the age of forty. Both of her children suffer from numerous illnesses too. My sister Johnsie has never had a life. They took it away from her. My sister Karen shared her story with you.

I suffer from migraines, fibromyalgia, stomach problems. I had a golf ball size cyst on my ankle, and one coming up on the other ankle, when this one on my right ankle has been removed. I have cysts on the

undersides of my arms; I have fibrocystic breast disease. I've had four aspirated in the last six months. I have to go back in three to six months to get mammograms and sonograms all the time. I went two weeks ago, and just got the report that I'm just full of them in my breasts. They come up and sometimes they'll come up over night and they'll be like the size of a golf ball. They're very, very painful. I am in constant pain. I have knots running through all my muscles. They know that I have a connective tissue disease, and they're testing me to find which one. They don't know if it's the start of lupus or what, but they are trying to find out. I've had miscarriages. I've had fibroid tumors on my ovaries and a grapefruit size tumor on my uterus with fibroids attached to it and endometriosis all over my female organs. I had a radical hysterectomy also at forty. All three of us girls have had to have hysterectomies and yet our mother and all of our female aunts on both sides have all their female organs in tact. Most of them died with them. We were at Lejeune during our developmental stages. What did this do to us? I suffer from anxiety attacks. I'm on medication for that. Depression, asthma, different parts of my body swell, I might wake up and my eyes will be swollen or my lip or the glands here in my neck will get real big.

Both of my children have been affected by these chemicals. My daughter has a double kidney on one side, a split uterus, endometriosis, kidney stones starting at fourteen, ovarian cysts that burst, migraines, asthma, and she has several different skin diseases. She just went to the doctor yesterday and they have found another one. She breaks out in these rashes. This is my daughter. She didn't live on base. They look like bruises that come up on her periodically. Allergies and depression. My son suffers from allergies, skin disease, chronic sinus infections. We can read the EPA's blue books on each one of these chemicals, but we want to . . . and we, you know, and what they do to the rats as well as groups that are tested, you know, humans that have been tested, but I mentioned this before about putting the chemicals together and what they've done to us, the drinking and showering and playing water, developing children.

[Tape change]

I speak daily to families that live all across the country who are sick, whose children and grand children are sick, sick with serious and chronic illnesses; illnesses that sometimes appear overnight and take their lives in just a matter of months. Doctors across the country have asked us, "What have you been exposed to?" I know our victims registry is not scientific, but the one strong thread that moves through this list is the victims have all lived at Camp Lejeune, born or worked there. There are too many of us with illnesses, to disregard that they are similar illnesses. We've suffered for too long with no answers and I do beg you to look into this national disaster. I thank you from the bottom of my heart for the comments that you have made and the discussion that we've heard here.

We want help to find the answers. We are willing to do anything we need to do to help ATSDR and you. This has been a full-time job. It's not going to stop being one, because we're not going to stop. No one will ever know the years that we've suffered in silence, thinking that we were crazy. Nobody can feel like this and be sane, is what people say. No one can understand the fear that we feel each time another doctor's appointment is scheduled. We don't know what our future holds. We deserve better than this. We

did thirty years ago and we do today. I thank you for what you're doing.

One question I did want to direct to Frank [Bove] was, when Vietnam was going on, there were a lot more uniforms being cleaned, there were a lot more machinery being worked on, the degreaser being used and things like that. Will the modeling show that, will we be able to go back into the Vietnam conflict at that time and see, would that have made the chemicals stronger at that time? Would there have been a more . . . would they have been concentrated larger at that time? I just wanted to know that and then I wanted to ask the panel, if there was anything you wanted to ask me.

Okay. Thank you.

Mr. Stallard: Thank you, Ms. Dyer.

Dr. Cantor: Thank you very much.

Mr. Stallard: Mr. Jerome Ensminger.

Mr. Ensminger: We've covered a lot of ground here the last few days. One of the main issues that I want to discuss right now is. . . we talked about getting the major players involved in this, make them part of this effort, but, boy, I'll tell you we're asking an awful lot out of DOD. While we're asking DOD to become part of this and give notification and funding and information, at the same time, they are seeking immunity from environmental regulations, the very agencies that have oversight over them, primarily on perchlorates, TNT, RDX, HMX. I think we're . . . we have a lot of expectations, if we think we're going to get cooperation from DOD in this matter. They're going to have to be forced. The last three years in a row, they have sought immunities. They are coming back again this year.

DOD was instrumental in getting the 2002 TCE maximum contaminant level shut down. EPA was going to recommend one part per billion, Air Force/DOD report came out and said it would cost us \$10 billion more to clean up, if you lower it from five to one. Henceforth, the Bush administration, shot down EPA's recommendation, sent it to the National Academy for Sciences, or NRC, and that's where we are today. Dr. Ozonoff was right, he doesn't know how old he'll be, when we finally get that report back, I'm afraid.

Another one is the Office of Management and Budget. ATSDR had a heck of a time with the involvement of these people in previous studies on Camp Lejeune. There are people in there whose tentacles reach very far. So, I appreciate your time your expertise. I don't mean to paint a dark picture, but we've got to change the mindset of a lot of people in this country. Each case such as this, people not allowing it to die, is another chink in their armor. As long as I have a breath in me, I'm going to fight this. I thank you.

Multiple voices: Thank you.

Dr. Cantor: Thank you very much.

Mr. Stallard: Is there anyone else from the public who has not had an opportunity to speak that would like to make a statement to the panel? That's fine. We're here to hear your voice.

Lita Hyland: Is any way that we can get notified by the Navy, the ones who are taking care of our children? You are talking about 1985. They are nineteen years old kids out there, somewhere that . . . with problems, just like my children. Very soon they will lose their ID cards. They allow us until they are twenty-one and then they have to go to school. I have to drive my daughter, when she got sick before everything started, two years prior to [when] she became twenty-three, to a school, to go to school, and had to almost one time get on my knees and ask the, you know, I don't remember, I'm sorry, the person in charge of the school, to please allow her to go to school because she would lose her military privilege. One of my privilege was to let my kids bring myself to this country to be born in here and be respected. A little ID card for the kids is not too much money for this country. That's number one.

Number two, is that I think that the General Surgeon of the Navy has to be [brought] to this. He is the leader of the doctors. He [has] to let the doctors know that cases, the special cases like our kids have to been taken care, because is a moral duty for the military to do it. They have to do it. I'm fighting every three months to have a military ID for my daughter. I am sure like everybody here, I will do this until I die. I am hoping that my daughter will never die because I don't know what I am going to do. I am already having disappointment. We need everybody at ATSDR to be with us. We want to be American, the leader of the world; we are the people who guard all the freedoms, human rights, to be respectable to our children. There's guys here used to be the children's dad. We have to protect them, but they have to start with this people, you know, that run everything. Don't disappoint us anymore, because we don't need it.

Thank you very much for everything to all of you. You are the real true Americans that I always hear [about] all my life. The ones that they are going to fight for [these] rights today. Let's start a new thing, let's run before our kids die. We need it. Thank you for everything.

Mr. Stallard: Thank you.

Dr. Cantor: Thank you. Okay. I would like to first of all, reiterate a statement that I made before in terms of our recommendations. I think we have a number of rather firm recommendations in terms of cohort, in terms of setting up . . . I'll speak for myself . . . we're not speaking as a panel. In terms of setting up future oversight for studies, in terms of recommending funding, in terms of media outreach and communication, and a recommendation for notification. And also, in terms of specific outcomes, we have tremendous difficulties in being very firm in our recommendations.

I think the two things that we have said is that we feel that given the record keeping systems that are available, a study of mortality once a cohort is established would be quite feasible. Secondly, it may be feasible to look at cancer incidents in this population. As for the other recommendations which might require getting into medical records, doing medical examinations and so on, and so forth, we have to be much more cautious about those. This will depend on feasibility in each particular case, feasibility would

have to be done by the researchers involved. So, just want to make that. . . just want to make that clear. Are there any other comments on this particular issue by other panel members? I'd like to open up to the panel other comments they may have during our closing few minutes here.

Dr. Ozonoff: Let me just comment on the three presentations we just heard. They remind us of something that is both very important and sometimes easy to forget, which is, we're all in this together. We really are. We're not from Camp Lejeune, but we are from other communities that have problems. There are problems all over this country. ATSDR is in this with us. Sometimes, they feel like the enemy, I know. The Marine Corps sometimes feels like the enemy, but there are people in the Marine Corps and there people at ATSDR, the state government and the federal government, that have the same interests that we all do. They have kids. They have families. Sometimes hard to remember that, but it really is. I think we'll get farther, if we make common cause with our friends and allies in all of these agencies, and fight like hell the people who aren't our friends and allies, because they're in all of these agencies too. They are. It will be a long struggle and it has been, but as you pointed out, you don't have any choice, but to keep up.

Dr. Cantor: Other comments?

Dr. Maas: Yes, I think that we've spent the last two days as a panel trying to be the best scientists we can, trying to use our creativity to come up with some practical suggestions. I just feel that it's time to make a personal statement before I leave here. I think I probably speak for everybody telling you how moved I am by your stories, you survivors. How absolutely admiring and respectful I am of your persistence, your creativity and your hard work to do something about this. Your patience and letting your good sides flow. As Dr. Ozonoff said, that really will accomplish more. You have to be nice to your friends and tough on your enemies. One of the hardest wisdoms is to know, is to recognize the difference, and know that enemies can become friends.

I would also like to put out a kind of a special, personal call to the folks at ATSDR, because I really empathize with how tough their job is. They have thousands and thousands of Superfund sites that they have to study and deal with, but I would also say to all of you, that very few Superfund sites that I've been aware of in the last twenty years have affected this many people for so long. We probably have had a half a million to a million people come through this base and . . . during the time that this water was contaminated. I'm very aware, for each one of you and your stories here, that there are hundreds more people with similar stories that were probably also caused by this contamination. So, I guess my appeal would be at a personal level to the folks at ATSDR to give this project the highest priority they can, recognizing that few systems have probably effected so many, so profoundly and so long. It's probably really would be something you could take a lot of pride in to put extra effort in here to move this along, and in each day with your intent, give your very, very best efforts to trying to see what we can do about this and what we can find out, so that a fair and timely resolution to this can finally happen. Again, I wish that as a panel that we had more power, but certainly I'm personally committed to doing everything that I can for all of you in my position on this panel. Thanks.

Dr. Cantor: Anybody else wish to?

Dr. Drane: I'll just add a ditto to what they said.

Dr. Lynch: The only other thing I wanted to add was, I think that those survivors that may be victims/survivors who have not yet been notified, or could not come here today, are very lucky to have such a well spoken group of people speak on their behalf. I've been personally very impressed by the organization of your presentations, because I know that this is a very emotional issue for all of you, but you've really given us a lot of information that's helped us in developing our recommendations, and I really appreciate it. I think that your colleagues appreciate your speaking on their behalf, and I encourage you to hang in there. This isn't going to be an easy process, but persistence will get you somewhere, I think. So. . .

Dr. Cantor: I understand that Dr. Sinks who has rejoined us would like to say a few words, before we close.

Dr. Sinks: As long as I don't have to sit in the hot seat and face all of you and be stared down at. Yeah. I just wanted to express at least my thanks and the Agency's thanks for Chris [Stallard], for Marie [Murray], for our sound man, and I don't know the sound man's name. For all of you, for taking two days out of your lives, or however many other days have gone into attending this workshop. I know many of you have put many, many days and perhaps many years into this. I want to thank all of you for that time.

I want to commend all of the people who got up in front that microphone and were in the hot seat. I know it's a very nerve wracking experience, even though it's a fairly small group of people you're in front of, to put your life on the line and tell hard stories that make you sad and make you upset, and we can't give you answers for. I think it's very brave of you to get up and tell us those stories and I can tell you having sat on many of these panels that it is extremely important to put a face and a story onto something that is as boring as we deal with every day, which is data and computers and sitting at our desks. Being removed from the place where you live. It's very important that we hear from you, that we have those connections and . . . So, thank you very much.

I also want to thank the panel for taking two or more days out of your lives for listening, for being open-minded. I want to reassure you that the reason we created this panel is we want to be open minded. We don't want to be just rigid and say "this is what we're doing; this isn't the only thing we're going to do." I'm looking forward to the panel giving us advice. I'm also hoping you will give us priorities. There's . . . if we just get laundry lists, quite frankly, I'm concerned that laundry lists are never ending, and it puts you in a position of saying what do I do first? What's the most important thing? So I will hint to you, I would rather see priorities of what you think are the most important, then to just simply see "do everything." I know you want us to do everything, but the reality is that doing everything is tough. When you do everything, I find that it becomes almost impossible to get anything done quickly. What else?

I want to thank Drue Barrett. Drue? Stand up. Drue is going to come up and she's going to tell you about the process that we're going to take, but, just my personal thanks to all of you. I apologize that I have been in and out. I can tell you that every minute in here was rewarding for me and I learned something more about this project and this group of folks. Thanks everybody, I think you all did a great job. I hope that you all feel that this has been worth your time and that we will do a good job with the information. Drue?

Dr. Barrett: I want to thank the public, especially for all your help, during the planning of the meeting and your input during the meeting. Thanks also to the panel and our great facilitator here and our writer/editor.

[applause]

I also especially want to . . . I think we all want to thank Athena Gemella, if you'll stand up.

[applause]

Athena did a great job, couldn't have done it without her and I think we all appreciated her input. In terms of the process, we will be getting verbatim transcripts. It's going to take at least three weeks to even get the first draft. Then we're going to need to read through it and make sure that there are no incorrect words. Our plan is to mail the verbatim transcripts to whoever was registered for the meeting. We have all your addresses. On the copy that we mail for the public comments, your names will be listed with your comments, unless I hear from people that you don't want that, but my preference is what we put on the Internet and that we do not necessarily list your name. We'll just put 'public comment' 'commenter' [Audience indicates they want their names listed.] Then we'll have your name. We need to have unanimous agreement, because it's on the Internet, it's available to the whole world, if people are comfortable with that. So, maybe we'll leave it with, if anybody's uncomfortable with that, they can let me know. I can take their name off.

Dr. Sinks: [off-mike] Just be aware that it's a privacy issue. There are a lot of people out there who use information they see on the Internet, the names, we don't want anybody taking advantage of you, because your name appears on this site. So think about it.

Ms. Dyer: [off-mike] We know.

Dr. Sinks: [off-mike] As a matter of record, your name will be on this. It's just a question of what's on the Internet.

Dr. Barrett: So, unless I hear from anybody that you do not want your name on the transcript that goes on the Internet, we will include all the names. Okay? We will be working with the chair and the panel to make sure there's a report that comes out of this meeting. That will be distributed to everyone as well as posted on the Internet.

Ms. Dyer: [off-mike] Can this panel stay together?

Dr. Barrett: This panel was put together for the purpose of coming up with this report. The report, as we've said many times, is a compilation of all of their individual opinions. Once the report is finalized the panel will have input into the final report. Once it is finalized, then the panel will be disbanded.

Ms. Dyer: [off-mike] They can't oversee what we've done today and what they've done?

Dr. Cantor: One of the, well, . . . one of the recommendations or the recommendations of many of us will be that an oversight group be set up to do exactly, I think, what you have in mind. Whether that recommendation is accepted or not accepted is a matter of ATSDR to decide, but presumably...

Dr. Sinks: Let me comment a little bit about this. One of the things we have to deal with is the Federal Advisory Committee rule. This panel here is a panel of individual experts who are frankly, giving us individual advice. They are not empowered to give us advice as a Federal Advisory Panel under the FACA rules. If Ken [Cantor], if you folks come back to us and say, you know there should be some kind of panel. The question then becomes, if it's a Federal Advisory Panel under the FACA rules or something other than that, I will tell you, we do not have the ability to tell the federal government they will have a Federal Advisory Panel. So, we could consider it. We could take steps to try to do that, but that is a different . . . We can't promise, even, if we wanted to create a federal committee on this, we don't have that leverage. That's a higher level than us. So that's something you might want to consider in this. If you're asking for some kind of group or panel, you might want to think about whether this should be a FACA committee, should it be something other than that? Are you talking about a community advisory panel that may not be FACA? But very different rules and believe me you don't want . . . it's a different issue. So, we need to walk that one carefully. We just can't say, yes, we'll have a Federal Advisory Panel. That actually I think has to be approved at the Secretary's level.

Dr. Barrett: But there could be an advisory group that is . . . essentially provides their individual input. So, there's a distinction there.

Dr. Cantor: Okay, well I would like to personally thank everyone who came, who made an appearance here. I know how difficult it is, how much courage it takes, and how much hard work you've been doing for a long period of time to come to this point. I hope we have facilitated the movement of this whole effort further and faster than it would otherwise would be. I'd also like to thank my fellow panel members. It's been a pleasure to work with all of you. It's been very easy. And especially to Christopher [Stallard], who I think has been absolutely masterful in smoothing the process for us [applause] and for you and for everybody else. Also, thank you very much to ATSDR for giving us this opportunity to participate and to share our ideas with you. With that I will close the meeting. Thank you.

[With no further comment, the meeting adjourned at 4:55pm]

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