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# Advisory Committee on Health-Related Effects of Herbicides

## Transcript of Proceedings

### Twenty-Sixth Meeting
### October 21, 1986

April 1987 Washington DC 20420

1 VETERANS ADMINISTRATION

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6 ADVISORY COMMITTEE ON

7 HEALTH-RELATED EFFECTS OF HERBICIDES

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15 Tuesday,

16 October 21, 1986

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18 Room 119
Veterans Administration
810 Vermont Avenue, N.W.

19 Washington, D.C. 20420

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

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1 P R O C E E D I N G S

2 (8:40 a.m.)

3 CHAIRMAN SHEPARD: I'd like to call the 26th Meeting
4 of the VA Advisory Committee on Health-Related Effects of
5 Herbicides to order. We are very pleased to have you all with
6 us. I have a number of announcements to make. A lot has hap-
7 pened since we last got together.

8 Just a few housekeeping notes for those of you who have
9 not been attending our meetings. Would you all please sign in?
10 There is a registry in the back of the room. We like to keep
11 track of the attendance at these meetings, and we prefer that
12 you not smoke in this room. There is coffee available in the
13 foyer. Restrooms are adjacent to the conference room off the
14 hallway, and there is a cafeteria on the floor below us.

15 Today we have scheduled a slightly longer than usual
16 meeting. We will have a lunch break, and then reconvene after
17 lunch. We have a lot of issues to cover, and so I think we
18 have a need to stay here for more than just the usual morning
19 session.

20 Once, again, the VA telephone system has undergone
21 some changes, and for those of you who may not be aware of that,
22 in this building, the old 389 number, FTS 389 exchange number,

1 has been changed to 233. So those of you who are trying to reach
2 offices in the main building from outside the VA dial 233, and
3 then the previous four digit extension number.
4 Our office, that is the Agent Orange Project Office,
5 which is located not in this building but in the Cafritz Building
6 just on the other side of 16th Street, has a new number, and
7 that is 653-5043, 5047 or 5049. That's also an FTS number.
8 653-5043, 47, or 49.
9 Congratulations are in order to Dr. Hugh Walkup who
10 just received his Ph.D. in social sciences and social and
11 educational psychology. Congratulations.
12 DR. WALKUP: Thank you.
13 CHAIRMAN SHEPARD: We are delighted to hear that.
14 That is very good news. I know Hugh has been working on that
15 for some time, and it is very satisfying, I'm sure.
16 I'm very happy to announce the awarding of two very
17 important contracts. First of all, the ongoing effort of the
18 literature review underwent competitive bid process. A number
19 of good proposals were received, and it was a close call.
20 However, Clement Associates, who have had the contract, were
21 once again awarded the contract, and that was awarded on Septem-
22 ber 22.

1 So we have already had some additional meetings with
2 them, and they are getting underway to start the next review
3 which will be covering all the literature in 1985 and then 1986.
4 In that regard, we will very soon be issuing Volume 7
5 and 8 and a synopsis of Volume 7 and 8. Those have been submit-
6 ted and are about to go to the printer so we will be seeing those
7 very soon.
8 Another important contract was the award of the con-
9 tract for the design of the women's study. As you know, Public
10 Law 99-272 mandated that the VA conduct an epidemiological study
11 to look into the health effects of women veterans who served in
12 Vietnam.
13 And the contract was awarded on September 17 to New
14 England Research Institute. Again, a number of very good pro-
15 posals were submitted, and we're very happy to have that contract
16 awarded. I just emphasize that that is a contract, and the
17 details of this are fairly carefully spelled out in the language
18 of the legislation, the mandated legislation.
19 This contract is for the design of the study, the
20 development of the protocol. Another contract will be awarded
21 for the actual conduct of the study. And we have monies identi-
22 fied in the FY 88 budget for the conduct of the study. We hope

1 that the study protocol will be approved well in advance of
2 that date so we will have time to have the contracting process
3 so that we are ready to roll at the very beginning of FY 88
4 which will be about a year from now.
5 Members of the committee have received copies of a
6 recent study carried out, an intramural study, carried out by
7 the National Cancer Institute under the leadership of Dr.
8 Sheila Hoar. That article appeared in the September 5 edition
9 of the Journal of American Medical Association, the study on
10 risks of developing various cancers, specifically soft tissue
11 sarcoma and other cancers as they occur in farm workers in the
12 State of Kansas.
13 This study, a milestone study, I believe, will be
14 reviewed by the VA Advisory Committee on Environmental Hazards
15 at their next meeting which is scheduled for the third week in
16 November.
17 You may have heard about a similar study, an extra-
18 mural study, being done under contract to Battelle Institute.
19 Dr. James Woods is the principal investigator of that study,
20 a similar study looking at the risk of developing certain
21 cancers among farm workers and forestry workers in the State
22 of Washington.

1 I've been in touch with Dr. Woods. His abstract
2 appeared in the program at the Japan meeting. He unfortunately
3 was not able to be there to discuss his work. Actually his
4 work has not quite been completed. The report has not been
5 published. It is very close to being published, and I under-
6 stand he has tentative approval for publication of that article,
7 and I believe it is to appear in the Journal of the National
8 Cancer Institute, JNCI. That's one we'll certainly be in-
9 terested in looking at.
10 Since our last meeting, we have a new Deputy Administra-
11 tor, Mr. Tom Harvey. Those of you who have been following
12 the work of the VA and work on the Hill will know Tom. There
13 is a biographical sketch of him in the recent issue of Vanguard.
14 Mr. Harvey is a Vietnam veteran and has had a
15 distinguished career of public service, having served as senior
16 staffer to the Senate Veterans Affairs Committee. He was
17 confirmed by the U.S. Senate last month, excuse me, in August.
18 We had asked him if he would be willing to address the
19 committee, and he said he would like to. However, he had a
20 conflict and was not able to be with us today, but I am hopeful
21 that we can persuade him to be present at our next meeting.
22 I would like to thank and applaud the work of the

1 committee, a subcommittee of this committee, chaired by General
2 Wells who put together a report to the Administrator, and I'm
3 happy to report that the report has been forwarded to the
4 Administrator, and should be on his desk, if not now, very
5 shortly.
6 And members of the committee have been provided, I
7 think it was a draft of this report was circulated for comment
8 prior to it being sent out by my office through the Chief
9 Medical Director to the Administrator.
10 It's a two-page report that summarizes the work of
11 this committee, and I think it's a very good piece of work.
12 GENERAL WELLS: Dr. FitzGerald and Keith Snyder were
13 on that committee with me.
14 CHAIRMAN SHEPARD: Dr. FitzGerald and Keith Snyder
15 were also members of that committee. Thank you.
16 I'm sure that many of you are aware that some of us
17 were privileged to attend the Sixth International Symposium
18 on Dioxins and Related Compounds, held in Fukuoka, Japan, in
19 September 16-19. Dr. Kahn was there, I know, and Dr. Han
20 Kang, and myself.
21 It was a very well attended meeting. A number of
22 very interesting reports were presented. Dr. Kahn, later on

1 in the program, will present the results of a study, that he is
2 undertaking which we are very interested in, which he presented
3 at the Japan meeting and has attracted some attention from the
4 press since then.
5 So we look forward to Dr. Kahn's presentation.
6 DR. KAHN: I don't answer my phone anymore.
7 (Laughter.)
8 CHAIRMAN SHEPARD: We had the privilege of presenting
9 two papers and two posters on some of the work that we have been
10 involved in. I presented our work on the suicide study, and Dr.
11 Kahn presented the work on the soft tissue sarcoma efforts.
12 As I say, the meeting was very well attended. I
13 think there were probably in excess of 250 people registered at
14 the meeting. Of interest was the fact that there were a number
15 of Vietnamese scientists there who presented several papers,
16 and it was very interesting to meet them and hear the results of
17 their efforts.
18 My deputy, Dr. Lawrence Hobson, is no longer in the
19 Agent Orange Projects Office. He has recently been made the
20 director of the Office of Emergency Management and Resource
21 Sharing Service. We wish Dr. Hobson success in his new
22 responsibility.

1 The Agent Orange Working Group
2 Science Panel and the parent body meet the last week of
3 September primarily to consider the proposal of CDC for a
4 validation effort of military records in order to proceed with
5 the Agent Orange cohort study.
6 I'm sure many of you have been following the progress
7 of that with interest, and we are very pleased that we will have
8 a report from CDC later on on the agenda. But I just wanted to
9 share with you the fact that the Science Panel reviewed the protocol
10 submitted by CDC to conduct a study to look at the correlating
11 levels of serum lipid dioxin levels with military records in
12 order to validate military
13 records which suggest high levels, high opportunity for exposure
14 among certain ground troops in Vietnam, and similarly troops
15 with little or no opportunity for exposure.
16 The current proposal is to study approximately 250
17 individuals in whom the military records suggest high levels
18 of exposure or high opportunity for exposure, and 150 veterans
19 with little or no opportunity for exposure, to see if there is
20 a good correlation between the serum levels of dioxins and
21 that fact of exposure.
22 DR. KAHN: Barclay, I would like to put it out on

1 the table that I think this committee should have a careful look
2 at that as well. I don't think that study should proceed until
3 we've had a good careful opportunity to see the plans and comment
4 on them. That's what we are here for.
5 And if anybody has "dibs" on thinking about that kind
6 of a procedure, I do.
7 CHAIRMAN SHEPARD: I see no problem with that.
8 Whether or not the committee considers itself -- I'll stop there.
9 There are a number of reviews going on, as you probably know.
10 By law, the Office of Technology Assessment is required to
11 review the study, and that is scheduled for later on this month,
12 I believe, on the 27th of this month.
13 They are scheduled to meet to look at that protocol.
14 Yes, I see no problem with that protocol being reviewed by this
15 committee, as well. As a matter of fact, it's on the agenda,
16 we have a letter from -- we, the Administrator, Mr. Turnage --
17 received a letter from Senator Murkowski asking this committee
18 to review the validity of using blood dioxin levels for validating
19 exposure. And it is on the agenda to address that. So I will
20 bring it up in a little bit.
21 The Science Panel the following day reported to the
22 parent body of the Agent Orange Working Group which approved

1 the protocol to be reviewed by the Office of Technology Assess-
2 ment, and directed CDC to proceed with the next step of identify-
3 ing the criteria for selecting the individuals to be tested and
4 details relating to that.
5 Another announcement deals with an upcoming airing by
6 NBC of the made-for-TV movie entitled "Unnatural Causes." You
7 may have seen the announcement. We have information that this
8 is being scheduled for airing on the evening of November 10
9 at 9 p.m. on NBC.
10 Some of the lead cast include Patti LaBelle, John
11 Ritter and Alfre Woodard.
12 DR. HODDER: Are you in it, Barclay?
13 CHAIRMAN SHEPARD: Not to my knowledge. One never
14 knows.
15 (Laughter.)
16 DR. KAHN: What is this film on? What is the NBC
17 film on?
18 CHAIRMAN SHEPARD: I think it's the story of Maude
19 DeVictor and the genesis of the Agent Orange issue. It's
20 called "Unnatural Causes." I haven't seen it so I can't tell
21 whether I'm in it or not.
22 I think we will now move into our agenda. You should

1 all have copies of that in front of you. Unless there are any
2 questions on the announcements I've made, any questions or
3 comments from the committee?
4 (No response.)
MASSACHUSETTS HEALTH SURVEY OF VIETNAM VETERANS
5 CHAIRMAN SHEPARD: At our last meeting, there was a
6 discussion of the Massachusetts Survey of Vietnam Veterans,
7 and we agreed to include it on the agenda today. A number of
8 you asked for that to happen.
9 Some of you provided comments to us about the study,
10 but I would like to open up the discussion now on the study
11 for any further comments that you may have. As you recall, this
12 is a study, a survey -- this is not to be confused with the
13 mortality study by Massachusetts. That's a different issue.
14 This is a survey of Vietnam veterans in the State of
15 Massachusetts which was provided to us, I think, at our last
16 meeting. Any comments, questions?
17 Question on the agenda is "Of what value is this survey
18 to the Veterans Administration in the resolution of the herbicide
19 controversy?"
20 So in your capacity as advisors to the VA, we would
21 like to have some kind of comment in that area.
22 GENERAL WELLS: I have some concerns about that study.

1 I saw it for the first time after this meeting, and I think it
2 is important for the VA to know how those people in Massachusetts
3 feel. And it is very important for the State of Massachusetts
4 to know how the veterans feel.
5 But I'm a little bit concerned that there were -- and
6 this may be old hat to you people -- that there was no control
7 group, and in reading that I thought that was maybe a kind of
8 biased group of people that they studied, and so I would throw
9 that out on the table for discussion.
10 CHAIRMAN SHEPARD: Thank you. Any other comments?
11 DR. WALKUP: I think that is something we see a lot
12 of times, especially in this kind of survey. I think as you
13 said initially, though, the perception of a lot of veterans
14 still is consistent with what shows up here and shows up time
15 after time.
16 And I think that is something that the VA has not been
17 effective in dealing with. And we've talked about that a number
18 of times and voiced a lot of concern about it, but how we go
19 about identifying better with the studies that are underway,
20 what the real health problems are after all this time, or how
21 we go about communicating with veterans that they don't need
22 to be as anxious as they are seems to be something that is beyond

1 the Veterans Administration and the rest of us. I think the
2 study again points out, whatever the validity of the study,
3 whatever its methodological problems, vets are still worried.
4 And that is something that we need to deal with.
5 CHAIRMAN SHEPARD: If I may just step in for a moment.
6 I think that's a very important point, Hugh, and I would really
7 urge and solicit this committee to take on the issue of how
8 do we communicate better to veterans in terms of either
9 raising concerns or allaying concerns or just giving the facts
10 because I personally feel that this is an area where we need to
11 strengthen our position. And I would strongly solicit this com-
12 mittee to address that issue in whatever ways you feel appro-
13 priate because I think you've touched on really the heart of
14 the matter that veterans who are not perhaps scientifically
15 sophisticated or medically sophisticated are bombarded with
16 tremendous amount of information. It's very difficult, I think,
17 for them to sort out all of it and try and make some sense of
18 it.
19 That isn't to say that that same bombardment doesn't
20 go on with everybody everyday. I mean I don't want to single
21 out the veterans, Vietnam veterans, as being in that sense very
22 different than many other people. But I think it's of particular

1 concern because, for example, and I'm inclined to make this
2 announcement, there is another series of concerns that have
3 been raised, largely as a result of the Zumwalt story. As you
4 know, Admiral Zumwalt and his son have written a book called
5 My Father, My Son. It had a long -- I think it got a 15 minute
6 airing on "20/20," and in the "New York Times" and "The Washing-
7 ton Post." It today appeared in "Navy Times," yesterday a full
8 page article.
9 So that is a situation which is ongoing, and albeit
10 a single case, it is nevertheless a fairly powerful case in view
11 of the position that Admiral Zumwalt held in his last years
12 serving in the Navy.
13 Anyway, that is another example of the information
14 explosion on this issue, and I personally -- and I'm just speak-
15 ing for myself now -- feel that there is room for considerable
16 effort in terms of communicating to veterans. And I, again, sin-
17 cerely hope that this committee can address that issue.
18 DR. WALKUP: I think an underlying thing that is
19 happening there is that the media, at least, and a lot of
20 veterans, I think, have switched positions with the VA. That
21 they are asserting presumptive cause which is a traditional
22 test for disabilities in the Veterans Administration.

1 On the Agent Orange issue, there is no presumptive
2 cause, but it's proof. But what we're trying to prove is the
3 null hypothesis that there is some specific link between
4 dioxins and the problems that veterans are alleging. I think
5 that underlies a lot of the communication problems and a lot
6 of the perception of veterans that makes it difficult to trust
7 some of the information that says that Agent Orange doesn't do
8 all the things that we say it does. Because the people who
9 are saying that are the people who have been saying that for
10 a long time without a lot of information.
11 And I think somehow if the Veterans Administration
12 credibility or the Administration's credibility is going to be
13 improved with Vietnam veterans, it's going to be necessary to be mor
14 open to some of the possible health effects of herbicides than
15 has been displayed in the past.
16 Specifically, when the first interim procedures were
17 put out, there were several possible health problems associated
18 with Agent Orange that were listed. A short while later
19 chloracne was the only one on the list still. Given the
20 scientific evidence that is available, I don't think we can
21 say with certainty that chloracne is the only one that is out
22 there still. Yet that has become the Veterans Administration

1 position. As long as that continues, the communication problem
2 is going to be there, I believe.
3 CHAIRMAN SHEPARD: Okay. Thank you. Any other
4 comments?
5 DR. KAHN: I'll offer one. One of the things that
6 has bothered me about the issue since its inception is the
7 fact that the federal government appears to be hiding behind
8 science on an issue which contains at least as much of a moral
9 and political component as it does a scientific.
10 If you look at the collection of symptoms that veterans
11 in the aggregate seem to display, while there is great variation
12 from man to man, there certainly is consistency with the kinds of
13 stuff we see in person who have been exposed in factory accidents
14 but, of course, on a lower scale.
15 One can advance a plausible argument, even if it's
16 not ironclad, that many of the problems the vets do have might
17 well be related to Agent Orange exposure. They might not be,
18 but they might well be. You then face a choice of which kind
19 of error you're willing to risk.
20 One kind of error that we're willing to risk which is
21 the one we're taking now is that we'll do not very much for
22 these men until such time that science can prove beyond

1 reasonable doubt, in the sense of a murder conviction, that the
2 medical problems are attributable to exposure to Agent Orange
3 in Vietnam.
4 And if that takes 20 years, well, then those men will
5 go 20 years without necessary help, help that they need now.
6 Well, it may turn out --
7 CHAIRMAN SHEPARD: Excuse me for interrupting. Could
8 you be a little more specific when you say help? I think that
9 needs to be defined because I think there is help there, but
10 maybe --
11 DR. KAHN: There is some help there. There is some
12 degree of medical help for them. There's not a whole --
13 CHAIRMAN SHEPARD: I'm not sure that I understand
14 what you say when you say "help." If you would be a little bit
15 more specific, that would be very helpful, I think, to all of us.
16 DR. KAHN: In part it's medical help, but I know they
17 get some of that. In part, it's disability for those who are
18 incapable of working. In part, it's some sort of insurance in
19 the event they kick off prematurely.
20 I don't know all the kinds of help that the VA is
21 empowered to make available. In other cases, of a man being
22 shot, for example, the perception is out there is that the

1 government has basically turned its back on these men, and we
2 take a risk by going on for 20 years, and finding out that sure
3 enough, there was a connection 20 years later.
4 The reverse possibility would be to offer generous
5 help, perhaps beyond what is offered to veterans of Korea, offer
6 generous help for a period of time, and let the science proceed
7 in the organized leisurely way that science has to proceed if
8 it's to get any kind of credible results at all.
9 That way the pressure if off the likes of me. I don't
10 have to do my work in a goldfish bowl. I don't like having to
11 deal with this all the time. Well, if we say we're going to
12 offer generous aid, perhaps beyond what the VA now offers to
13 disabled veterans, to Vietnam veterans, whatever their problems,
14 we will be taking a reverse risk.
15 And the nature of that reverse risk is we may be
16 helping me whose problems do not arise from military service.
17 And if in ten years or 20 years, or whatever period of time it
18 takes, we can prove that, well, then you stop the help. Okay.
19 Well, it seems to me the choice of which of those you
20 take, whatever the current state of the legislation on this
21 subject, is primarily a moral issue and to some extent a political
22 one. It is not a scientific issue.

1 And I think the quality of the country, the moral
2 quality of the country, is shown in the choice that we have
3 taken, and I don't like that choice. I particularly don't like
4 a consequence of that choice is it makes science and scientists
5 the public scapegoat for inability at present to prove beyond
6 reasonable doubt, as opposed to preponderance of evidence
7 perhaps, that Agent Orange, dioxin, whatever, is guilty.
8 I can't do that yet. I may never be able to do that.
9 Because there may not be a connection, and if there is we may not
10 have the tools to prove it. And in the meantime because of the
11 weaknesses of science, these fellows are left twisting in the
12 wind.
13 Now, the VA's current legislation which governs what
14 you may and may not do may not allow you to go out and pay men
15 money, provide extended GI bill, extended counseling, whatever
16 is needed, and whatever is not now being provided under current
17 law.
18 But the VA has the power to go to the Congress and make
19 this case and say this is a moral issue; this is what we think
20 ought to be done; and if you did this, you would come up smelling
21 like roses, and the credibility of the government would be im-
22 measurably raised, not just in the eyes of the Vietnam veteran,

1 but in the eyes of all people. And yet the VA and the rest of
2 the government -- I won't blame the VA entirely -- seems to go
3 along in its same old way without a clue as to the erosion of
4 the consent of the government going on underneath it.
5 You can change that. In one day you can change that
6 by going to the Congress and saying you think these men should be
7 helped against the possibility that what seems a little plausible
8 now may prove true in ten years time.
9 And we think this would be the generous and decent and
10 humane way to deal with the Vietnam vet. If you do that, all
11 credibility problems with disappear. The science can proceed
12 in a leisurely way with the eager help of everybody around.
13 True, you may spend money on men whose problems are not Agent
14 Orange related.
15 True, there are going to be some guys out there who
16 are going to want to skin Uncle Sam for every dime they can get.
17 But you make a deliberate choice of putting up with that in order
18 to benefit the greater number over that period of time.
19 CHAIRMAN SHEPARD: Okay. I'm wondering if we can get
20 back to the Massachusetts survey and sort of close the loop on
21 that unless that's already been accomplished.
22 DR. KAHN: Well, I was on that subject and picking up

1 on Hugh's point.

2 CHAIRMAN SHEPARD: Okay.

3 DR. KAHN: Okay.

4 CHAIRMAN SHEPARD: Then can we get back to the question
5 of whether or not the survey as conducted and reported will be
6 helpful in the process of adjudicating -- well, I shouldn't
7 say necessarily adjudicating claims, but resolving the herbicide
8 controversy?

9 DR. WALKUP: Let me summarize maybe how I think the
10 conversation responded to that. As the General said, although
11 there may be methodological problems with the study, it definite-
12 ly indicates attitudes and perceptions among veterans regarding
13 the Agent Orange controversy; and specifically in response to
14 your question about how the VA could respond to that sort of
15 perceptual set, I think Dr. Kahn was offering some suggestions
16 about a more pro-active stance the Veterans Administration could
17 take to overcome the attitudes that the veterans have as they
18 are represented in the Massachusetts study and any other survey
19 that you take of Vietnam veterans.

20 CHAIRMAN SHEPARD: Okay. Are there any other comments
21 on the Massachusetts survey? I appreciate your comments, I
22 really do, and I think that, as I said earlier, I think that

1 this can be certainly one of the data bases for information
2 which could be helpful in not telling us whether there is an
3 association between Agent Orange exposure and health problems,
4 but the broader question of what kind of health problems are
5 Vietnam veterans experiencing?
6 Am I correct in that assumption? Dr. Hodder?
7 DR. HODDER: At the risk of getting off the track, to
8 follow up on what Peter and you have said, following along
9 the logic of what we've been working on, the concept of science
10 trying to resolve the problem and guide congressional response, I often
11 have used the example that science has presented an extremely strong case
12 against tobacco to Congress since 1952. Yet the magnitude of response has
13 been limited to a change in the advertising label on the cigarette pack
14 and a ban in the advertising on TV.
15
16 Otherwise, basically that's been very little responded
17 to. I think it's interesting that we're now
18 getting closer to the heart
19 of the issue: getting the message correctly carried to Congress.
20 I think some of the frustration you have, and I know
21 Peter is stressing also for the scientists, is that the rhetoric
22 the veterans' advocates have had to use to bring the issue before

1 the media and before Congress may be harmful to the in-
2 dividual veteran out there who really has a very poor capability
3 perhaps of dealing with scientific information. We are after all
4 pulling together some pretty sophisticated scientific groups, e.g. the
5 Science Panel, to evaluate the information and there is considerable
6 difficulty coming to agreement even among those scientists.
7 What I find interesting is that I don't
8 think this same discussion could have been held two years ago
9 though. I don't think Congress was structuring the question
10 the way that it could be responded to, and I don't think the
11 veterans were, at that point,
12 willing to raise the question of whether dioxin
13 could perhaps be a false trail.
14 I welcome the idea of addressing the
15 basic questions of "were the surviving veterans from Vietnam ex-
16 posed to other problems that they brought back with them and
17 which gives them a disease burden beyond the general public's
18 expectation?" And "can we pose the question in a constructive way to our
19 lawmakers and our executive branches to respond in
20 such a way that we can get harmful rhetoric out of the system
21 and perhaps look for some reasonable solution.
22 I would just make one other point. Science has got to

1 be maintained as a tool. It can't do what I think a lot of the
2 media thinks it's going to do. None of these studies
3 are going to give anymore than a statement of some form of
4 probability with varying sophistication of the possible link of an
5 exposure with a disease.
6 Science will not give an exact answer regardless.
7 CHAIRMAN SHEPARD: Thank you, Dr. Hodder. Any other
8 comments?
9 Next, I would like to move on to the question of --
10 again, this is as request of our deliberations last time --
11 an update on the status of veterans disability compensation
12 claims. And I have asked Mr. Herb Mars and Mr. Gary Hickman
13 if they would address the committee on those issues. I see
14 Gary is here. Gary, would you like to come up here.
15 Members of the committee have been provided, I
16 believe you have been provided a statement or a memorandum
17 concerning this issue, and Gary is prepared now to elaborate
18 on that. Gary.
19 VA DISABILITY CLAIMS
MR. HICKMAN: Thank you, Dr. Shepard. It's a pleasure
20 for me to be here. I'm substituting for Mr. Mars. I'm the
21 Assistant Director for Policy in the Compensation and Pension
22 Service.

1 As of 9/23/86, our system of records indicates that
2 29,191 veterans have filed claims alleging Agent Orange exposure.
3 We have evolved into a system of records from a handcounting
4 system and our handcounting system begins with someone claiming
5 Agent Orange on their application. We counted that as a case in
6 our system of records today.
7 We are modifying our system
8 to allow us in the future to identify the specific disability
9 or disabilities alleged to have been caused by Agent Orange
10 exposure.
11 It will be some time, however, before all of the 29,000
12 records are updated to reflect this. Of those 29,000 plus
13 veterans, a total of 39,237 service-connected disabilities have
14 been granted, of which 9,249 or 23 percent of the service-con-
15 nected conditions are skin disorders.
16 We also have 90,763 non-service connected disabilities
17 of which 25,000 are skin disorders. Another issue which I think
18 you are interested in is the statutory authority for interim
19 benefits under Public Law 98-542 expired on September 30 of this
20 year.
21 We received 41 claims during this two year period:
22 12 for chloracne, 28 for PCT, and one for death benefits. None

1 were allowed. The major reasons for disallowance were non-
2 existence of the qualifying condition, or manifestation of a
3 condition more than one year after leaving Vietnam
4 The Veterans Advisory Committee on Environmental
5 Hazards will meet November 17 and 18th, and we've been following
6 and working with that committee in order to determine whether
7 changes in our existing regulations based upon 98-542 would be
8 responsive.
9 I think that is basically the issues where we are
10 today. I'll be happy to answer any questions.
11 CHAIRMAN SHEPARD: Thank you, Gary. Yes?
12 MR. SNYDER: On the 41 cases for the interim benefits,
13 do you have all those cases here at the central office. Were
14 copies of any decisional documents called up and medical records
15 to confirm the diagnosis here?
16 MR. HICKMAN: We do have the records, the rating
17 decision sheets are here in the central office.
18 MR. SNYDER: I notice your reference here in the
19 report -- and thank you very much for providing that -- in-
20 dicated that the main reasons for denial were non-existence of
21 the claimed condition. Of those 41, where there were 12 for
22 chloracne, were any of those chloracne cases actually diagnosed

1 as chloracne, or was that simply the claim that then was un-
2 substantiated by the medical records?
3 MR. HICKMAN: I'll have to go back and check the
4 records. I cannot give you a definitive answer at this time,
5 but we can check and give you something later.
6 MR. SNYDER: What about the PCT? Is that the same?
7 MR. HICKMAN: Same thing. I would have to go back
8 and review the records.
9 MR. SNYDER: Could you please, or would it be possible
10 to have copies of the rating decision simply with names and
11 identifiers expunged. That would tell us, I presume, there was
12 a confirmed diagnosis of a specific condition.
13 MR. HICKMAN: That would be available, yes.
14 MR. SNYDER: I would appreciate it if we could --
15 I would be very interested in seeing those claims.
16 I'm also wondering -- do you know because part of the regulations
17 provide for benefits -- if those conditions appeared within a
18 specific time period.
19 The regulations and the manual provisions that imple-
20 ment those regulations are a little difficult to read, and I
21 sympathize with those people that would have to apply them.
22 For example, if the chloracne, under the regulations it has

1 to develop within three months, but under the interim benefits
2 within 12 months. Of the 12 chloracne cases, do we know
3 whether, for example, the chloracne manifested itself within
4 13 months or 12 months, just outside the 12 month period?
5 Do we have any idea, any sense of when the chloracne
6 was showing up?
7 MR. HICKMAN: If it did show up, then it would have
8 been within that time frame. I'm sorry. For the most part, it
9 did not show up. There was a claim for it, and it did not show
10 up. But we'll have to review those records to give you an
11 answer. We'll provide that for you.
12 MR. SNYDER: Okay. Because I would be very interested
13 in seeing for those cases in which chloracne or PCT was actually
14 confirmed, what then was the time factor of its appearance.
15 I had one other concern, too, about the method of
16 adjudicating both the regular service connected claims as well
17 as these interim benefits claims because the manual that the
18 adjudicators rely upon, and I believe in part, the materials
19 that you or Mr. Mars had provided with us in advance, there was
20 an excerpt from that manual, the M21-1 manual.
21 It indicated very plainly there that -- well, actually
22 what it indicated was no reference whatsoever to the interim

28

1 benefits being available in the manual provision. The manual,
2 as I understand it, simply implemented the regulations, and the
3 regulations say chloracne within three months.
4 The regulations, the 3.800 part, that talk about the
5 interim benefits were not implemented in the manual, and that
6 raises a concern with me that are you confident that your
7 adjudication staff, new people in particular that would come
8 on, that would have this manual, and it would say chloracne has
9 to appear within three months, and there was no reference on
10 this page or in this paragraph, no cross-reference to any other
11 explanation of interim benefits. I would be a little concerned
12 if I saw this, or if I were an adjudicator I would not know that
13 there was anything else available to people.
14 Are you confident that in the training program that
15 you've got for your adjudicators that they know that other
16 literature is out there guiding them on how to do the interim
17 benefits claims?
18 MR. HICKMAN: I am confident for several reasons.
19 We're not talking about new people who are actually working
20 these cases. We are talking about experienced people on the
21 rating boards who are actually doing the adjudication of the
22 cases, for one thing.

1 We did issue interim instructions at the very begin-
2 ning when the public law was passed informing these people, and
3 we have had rating training classes subsequent to the law
4 explaining this issue to the rating board personnel.
5 We also went through our system of records at that time
6 and went back to find out all claims in which chloracne or PCT
7 were mentioned, and I think it was approximately 25 initially,
8 and we sent those back to the field stations and ask them to
9 rerate the cases.
10 MR. SNYDER: Looking specifically to see if interim
11 benefits would be appropriate?
12 MR. HICKMAN: Yes, interim benefits, yes.
13 MR. SNYDER: And but the result of that was not?
14 MR. HICKMAN: The results were none were shown to be
15 service-related.
16 MR. SNYDER: I guess one followup I have on the dis-
17 ability claims and the process the VA is engaging in here, you
18 have -- the other committee that is kind of our sister or
19 brother committee, in a sense, the Environmental Hazards Commit-
20 tee, had to review various studies as part of its mandate from
21 Congress, I believe, to decide on what specific conditions
22 should be allowed for service connection.

1 But as I've understood from review of the minutes of
2 those meetings that there were only about maybe seven studies
3 that had been reviewed prior to issuance of final regulations.
4 You've gotten some more scheduled to be reviewed in the November
5 meeting, I believe.
6 But the reference, Dr. Shepard, that you had made
7 earlier for us to the numbers of scientific studies that have
8 been digested and the contracts awarded to was it Clement
9 Associates for additional review of the literature, it was
10 suggested -- I think there are many more than seven or 17 or
11 30 studies out there, but in fact, maybe hundreds of studies.
12 How is decided which studies should be presented and
13 reviewed prior to selecting a condition which would then be
14 service connected? Do you have any awareness of what that
15 process was, and how we might as a committee affect what
16 studies should be presented to the other committee for its re-
17 view, or to the VA?
18 MR. HICKMAN: I'll have to defer to you, Dr. Shepard.
19 Maybe you can provide an answer to that. I cannot provide you
20 an answer as to exactly what studies that are out there, and
21 which ones they should review from this point on, and why they
22 selected those in which they did.

1 All I can say is it is a short time frame in which the
2 initial regulations were developed. We asked the committee to
3 review them. They did and provided comments. I know that they
4 will be reviewing further studies, and if necessary, we will
5 modify our regulations when such evidence is presented.
6 MR. SNYDER: Because the regulations are, I think, one
7 of the central issues to this committee, and how the service
8 connected compensation, those claims are adjudicated. I would
9 be very interested in having an opportunity for that person
10 or people who make those preliminary decisions on what scientif-
11 ic studies to present, having an opportunity to have them speak
12 to us and explain how the studies were selected.
13 It just seems that if there are, in fact, a thousand
14 or more studies out there, certainly in the annotated bibliogra-
15 phies that the VA has caused to be published, there are many
16 hundreds of studies.
17 It's of interest to me how it was that only seven or
18 only a couple dozen have been considered then by the committee in
19 making a decision then on what condition is to be service
20 connected. So I would appreciate it -- you don't know now if
21 someone could be -- we could be told who we could ask and perhaps
22 the committee could specifically invite for our next session

1 someone to tell us how that process went. That is of interest
2 to me.
3 CHAIRMAN SHEPARD: Okay. I'm sure that we can --
4 I say I'm sure -- I will be happy to ask Mr. Conway who is the
5 Executive Secretary for that committee to provide us with some
6 statement as to how the studies to be reviewed by the committee
7 are determined.
8 Just as a matter of announcement, we are now in the
9 process of putting together a statement for the Federal Regis-
10 ter that will summarize the studies that have been reviewed and
11 the conclusions that have been drawn. So there will be something
12 coming out within a relatively short period of time.
13 I would also encourage any of you who are interested,
14 there is the Advisory Committee on Environmental Hazards. It,
15 like this committee, is an open committee, and I would urge
16 any members of this committee who can do so to attend the next
17 committee meeting. I believe it's on the 17th of November,
18 17th and 18th, two-day meeting. That will be held in the Omar
19 Bradley Conference Room on the 10th floor of this building.
20 And I think it might be possible to address that
21 question to the chairman of the committee at that time. My
22 personal observation is that most of the studies that have

1 reviewed are ones that are con-
2 sidered scientifically valid studies in that they have appeared
3 either as reports by state organizations or have appeared in the
4 peer review literature and relate directly to health effects of
5 herbicides.
6 Obviously, it would be an impossible task for the
7 committee to review all of the literature, animal studies and
8 so forth. It's a large volume of literature, and if you get
9 into the chemical analysis and all the technology that is
10 burgeoning in that area, I think it would be an unreasonable
11 task for that committee to review all of the literature on
12 the subject.
13 I think that the committee has a rather specific
14 charter, that is, to look at evidence for adjudicating,
15 that would affect VA's policy for adjudicating claims. And
16 so they are, I think, understandably concerned about scientific
17 literature or scientific studies that relate to that particular
18 question.
19 But I can see it's a good question, Keith, and I think
20 it is one that needs to be answered, if there is a process. I'm
21 not even sure that there is an organized process --
22 MR. SNYDER: I should hope there is some organized

1 process. May I --

2 CHAIRMAN SHEPARD: Mr. Conway, would you like to

3 answer the question or address the question? Mr. Conway is

4 here.

5 MR. CONWAY: I can answer the question.

6 CHAIRMAN SHEPARD: Good. Mr. Fred Conway from the

7 General Counsel's Office who is the Executive Secretary of

8 the Advisory Committee on Environmental Hazards.

9 MR. CONWAY: The process is really a very simple one.

10 I have asked the Agent Orange Projects Office and the Director

11 of Radiology Service to keep me advised of current literature

12 that would include studies that would be of relevance to the

13 subject matter, namely health effects of exposure to dioxin.

14 I have also asked the committee members if they become

15 aware of studies and they want to have them brought to the

16 committee's attention, to let me know, and I'll put them on

17 the agenda.

18 I have also asked individual organizations when from

19 time to time they ask about data for the committee, what they're

20 doing, I in my letters back to them will invariably ask them if

21 they are aware of any studies or any issues they want to have

22 the committee address, please bring them to my attention.

1 I asked the Vietnam Veterans of American that question
2 also. Some individuals and organizations do respond with
3 suggestions. Others provide me unsolicited copies of studies,
4 some of which are not very, in my judgment, very good, but I
5 don't make that decision. I report them right to the committee
6 chairman, Dr. Kurland, who is the Scientific Council chairman,
7 and let him make the final decision as to whether he feels that
8 the study is of such merit as to deserve the attention of the
9 committee or whether it is so on its face not worthy of dis-
10 cussion that it won't go any further than that.
11 But the decision as to which studies are being con-
12 sidered by the committee is ultimately determined at the Scienti-
13 fic Council.
14 MR. SNYDER: Had there been a decision made that no
15 animal studies regardless of their significance were appropriate
16 for consideration?
17 MR. CONWAY: No, there has been no decision setting
18 forth the parameters of the studies that will be considered.
19 If there is someone out there, either a member of the committee
20 or a member of Dr. Shepard's office, or service organization, or
21 any scientific entity, who believes a study is of some significance
22 to the issue and wants it to be considered by the committee, I

1 would be glad to present it to Dr. Kurland and let him make
2 the decision. And I must say up to this point I'm not aware
3 of any study that Dr. Kurland has rejected that I have brought
4 to his attention.
5 MR. SNYDER: Thank you.
6 DR. WALKUP: Back before that committee was formed
7 when we were talking about its formation and its impact on this
8 committee, I think you were with us, and one of the things we
9 talked about quite a bit was as the two committees went their
10 different ways, it was important to maintain communication.
11 And as you said, Dr. Shepard, they are public meetings and anyone
12 can attend.
13 For those of us from the Pacific Northwest, that's a
14 little difficult, and I would really encourage you again, as I
15 did then and as we talked, to schedule at least one meeting of
16 that committee and this committee in conjunction with each
17 other, and maybe schedule some time for dialogue between the
18 two committees so that we can share some information.
19 I recognize they're also dealing with radiation,
20 but I think the issue on dioxin is important. I guess this is
21 my annual "let's talk with those folks plea." I would really
22 appreciate that, and would appreciate any sort of recommendation

1 you would have about what actions this committee could take to
2 either communicate directly with that committee, with the
3 Administrator, something to be able to effectuate that sort of
4 conjunction of meetings.
5 MR. CONWAY: Our meetings are not held with the fre-
6 quency that this committee has its meetings. We have been
7 holding them on a semi-annual basis up to this point. My guess
8 is the next meeting after the November meeting will be sometime
9 in March or April. That may give us enough leeway and planning
10 time so maybe we can work something out to have a joint meeting.
11 I think it would be a worthwhile venture so that you
12 can all get to know each other and know who the players are
13 on the respective committees. I would be willing to try to work
14 that out. As I say, because of the kind of individuals we have
15 on our committee, their schedules are usally set far in advance. I have
16 difficulty in March finding a time for a meeting in November when
17 everybody or a vast majority of the members could be present
18 because of their busy work schedules and travel schedules and
19 so forth.
20 So that's why I plan much further in advance than I
21 would like to. Maybe we could work something out for March or
22 April if that is agreeable to the members of this committee.

1 I will certainly mention it at our advisory committee
2 in November. If the committee members are agreeable to it, I
3 will try to my best to work with Dr. Shepard.
4 MR. SNYDER: I think perhaps, Dr. Shepard, our report
5 of this meeting should reflect our desire that there be such a
6 coordination. And that that either be in the form of a formal
7 resolution, or simply as one of the recommendations in that
8 report. I think that unless there is disagreement that that
9 would be a useful thing to try to do.
10 MR. CONWAY: I honestly don't recall -- has this
11 committee been given copies of the summary minutes of the
12 Advisory Committee on Environmental Hazards?
13 MR. SNYDER: I don't believe so. These are summary
14 minutes, not a transcript?
15 MR. CONWAY: Summary minutes. We do not keep a tran-
16 script. We keep only summary minutes. There is a tape recording
17 of the meeting available if you want to listen to the 16 hours
18 of tapes, but we do not have a verbatim transcript.
19 MR. SNYDER: But there is a summary of --
20 MR. CONWAY: There are summary minutes available, and
21 I can distribute them to make as part of the regular process .
22 My mailing list is getting longer and longer. I don't mind

1 adding a few more names, if you want. If you feel it would be
2 helpful, I'd be glad to do it.
3 CHAIRMAN SHEPARD: Yes. I think we discussed that, and
4 if we haven't done it, I apologize, but we will certainly take
5 care of that, and even if we have it, we'll mail them out again.
6 But I gather we did not send out copies of the minutes. Okay.
7 MR. CONWAY: Do you want all the previous minutes or
8 just from now forward, or --
9 MR. SNYDER: I would enjoy -- we're only talking about
10 two or three other previous sessions?
11 MR. CONWAY: Yes. Three sessions.
12 MR. CARRA : I would like the previous minutes.
13 MR. CONWAY: No problem.
14 MR. SNYDER: Maybe, Dr. Shepard, while Mr. Conway is
15 here since you're with the General Counsel's office, I had kind
16 of a related question that is semi-legal perhaps. The interim
17 benefits program did, as we all know, expire last month, and I
18 am wondering whether the consensus perhaps of the committee
19 would be that we ask the Administrator to consider one of
20 two things, either administratively extending that period within
21 which people can apply for interim benefits, or going to Congress
22 and saying that given the legislative history of the bill that

1 led to these interim benefits, and that legislative history
2 briefly, I think, and strongly suggests that interim benefits
3 were desired by Congress for a two year period because there
4 was a feeling that for sure there would be -- the epidemiological
5 study results would be out, and there would be some sense of
6 where to go well within that period of time.
7 And as we know, that hasn't happened. But the interim
8 benefits period has expired, and I should think that that might
9 be something which, again, the Administration either could do
10 administratively, simply by extending it through a proposed
11 rulemaking or some sort of a notice fashion.
12 Of if you feel that that's not appropriate, there has
13 to be new legislation, can you report to us whether there is
14 any movement afoot to initiate that in the legislation?
15 MR. CONWAY: I would defer to the Department of
16 Veterans Benefits on that. I'm not aware of any initiative on
17 the part of the agency to either administratively or legislative-
18 ly seek an extension of the benefits.
19 MR. HICKMAN: We have not made any move at this time.
20 I think that would be something in which the Administration,
21 the Administrator and the Administration, would have to con-
22 sider. That's something to be considered, and we cannot make

1 a statement here as to what we will or will not do at the
2 time.
3 MR. SNYDER: Dr. Shepard, if I might then follow that
4 up. If there is no movement by the Agency currently to ask for
5 such an extension, I think it would be appropriate for our
6 committee to either strongly recommend and so report in our
7 report of this meeting, or have a formal resolution that the
8 Administration, in fact, consider an extension of the interim
9 benefits period.
10 Is there any reason perhaps the other service organiza-
11 tion representatives might not want to ask the VA for such an
12 extension, or can we include in our report that we recommend
13 to you, to the Administrator, that he, in fact, pursue such an
14 extension, whether it be administratively or through new legisla-
15 tion.
16 I think in terms of the cost to the VA if the 41 claims
17 so far have not been allowed, there shouldn't be much reluctance
18 to open the period a little bit longer, and I think it does
19 signal a message certainly to the veterans community that the VA
20 is interested in soliciting those specific claims even those are
21 fairly narrow conditions for which it would grant interim
22 benefits.

1 I think it would be a useful endeavor for the VA to
2 be on record as, at least this committee on record, as to calling
3 for the VA to extend the interim benefits period.
4 DR. KAHN: Make it a formal motion. Make it it formal
5 advice.
6 MR. SNYDER: Last time I did that I had to end up
7 typing it several times, but we certainly can try that.
8 DR. KAHN: This is short enough that you can hand-
9 write it in 30 seconds.
10 MR. SNYDER: And read my handwriting. Why don't I
11 do that and then pass that out to people at the lunch break.
12 We're going to be here through this afternoon, and then I'll
13 take it quickly after lunch.
14 DR. KAHN: If we're going to give advice, let's give
15 advice.
16 MR. SNYDER: Okay.
17 CHAIRMAN SHEPARD: I would agree certainly.
18 MR. SNYDER: And the sense of that advice would be to
19 recommend to the Administrator either to pursue simply an order
20 or a notice, some administrative procedure by which the
21 Administrator simply says the interim benefit period is
22 extended, or if on advice of general counsel or somebody else

1 says that we can't just order it done, then go to Congress and
2 say let's get new legislation to extend the interim benefits
3 period.
4 DR. WALKUP: I think I concur with you, but I would
5 really like to clarify some of what you were saying now. What
6 I interpret what I heard from you is that this isn't really
7 going to do veterans a whole lot of good anyhow, but it will
8 give the impression or convey the Veterans Administration's
9 concern about veterans who may have some concerns about this.
10 I mean 41 vets have applied. They haven't gotten any-
11 thing. We may have three -- you know, if it's extended, and
12 they won't get anything either, but at least by extending it,
13 it may give some sort of impression of concern on behalf of
14 the Veterans Administration. Is that what you're saying?
15 MR. SNYDER: Well, there is always the hope, too, that
16 in fact somebody is going to have their claim allowed. And the
17 interim benefits period for when chloracne and PCT manifest is
18 one year versus the three months for the regulations so that it
19 is more liberal.
20 And I think there is -- I certainly believe there are
21 people out there who need the benefits for at least those two
22 conditions certainly. So more than simply a message that the

1 VA is sending may not bear fruit may well, in fact, give people
2 an opportunity to get benefits that they need.
3 DR. WALKUP: A related question to that is out of 41
4 cases did anyone have claims allowed under other provisions, or
5 were they denied totally?
6 MR. HICKMAN: We'll have to check that. A lot of these
7 claimants have had claims allowed because there is evidence ofthe
8 disability occurring in service. That was one of those statements I
9 made earlier. The fact that of the 29,000 we've rated there are
10 39,000 service connected conditions. These mav
11 or may not be related to Agent Orange. It makes no difference to
12 us just as long as there is an occurrence or aggravation
13 while on active duty.
14 DR. WALKUP: Could you --
15 MR. HICKMAN: We will be checking the 41 for Mr. Snyder
16 and we can do the same thing related to your question.
17 DR. WALKUP: Thank you.
18 CHAIRMAN SHEPARD: Any other questions for Mr. Hickman?
19 Or for Mr. Conway?
20 (No response.)
21 CHAIRMAN SHEPARD: Thank you very much, gentlemen.
22 Next on our agenda is a discussion of the New Jersey dioxin

1 study. This is a study, as you know, that has been underway for
2 some time now. We have been following its progress with great
3 interest, and I can assure all of you that the VA is very in-
4 terested and applauds the efforts of the State of New Jersey,
5 and I would like very much to hear about the results of your
6 study. Peter Kahn.

NEW JERSEY STUDY OF DIOXIN LEVELS IN VITENAM VETERANS

7 DR. KAHN: I'll need that transparency machine.
8 The study that I'm going to present to you was undertaken as a
9 direct result of a meeting held in Ottawa, Canada in May of 1981.
10 At that meeting, Christoffer Rappe of Sweden, whom I had not at
11 that time met, presented the results of the analyses of blood
12 serum of survivors of the Japanese, Yusho disaster. The Yusho
13 disaster, for those who are not familiar with it, is an accident
14 that occurred in 1968 in western Japan.
15 In that accident rice oil that was being processed
16 from rice in a factory became contaminated by a PCB mixture that
17 leaked from the heat exchange oil that was used to heat the oil
18 during the processing.
19 The PCBs, in turn, were contaminated by dibenzofurans
20 which are chemically and toxicologically as close to the dioxins
21 as you can get. About 1600 people fell ill in western Japan.
22 Most of the initial illness would have been due to the PCBs

1 which are pretty noxious in and of themselves. But a considerable
2 number of those individuals remain ill to this day even though it
3 was 1968.
4 It is now pretty much accepted, not universally but
5 mostly, that the lingering illness is not so much PCB-related
6 as dibenzofuran related. Eleven years after the end of that
7 exposure, blood samples, blood serum samples, were analyzed by
8 Christoffer Rappe in Sweden and found to contain parts per tril-
9 lion levels of the dibenzofuran that had been present in the rice
10 oil.
11 I was astonished to hear that it was possible to detect
12 it at those levels that many years later, and immediately realiz-
13 ed that it might just be possible to do the same kind of thing
14 on Vietnam veterans who were heavily exposed to herbicides during
15 the war. At least it became rational to try.
16 I then approached Dr. Rappe who invited me to his room
17 where we polished off a bottle of Seagrams and discussed the
18 possibilities of a research collaboration. In October of 1981,
19 we met again at the International Symposium on Dioxins and Re-
20 lated Compounds that took place in Arlington, Virginia, and we
21 at that time agreed to a collaboration, and planning began as
22 of that date.

1 From October of '81 till December of '84 we were in
2 the planning stages. In December of '84 we froze the analytical
3 protocol. I'll make some comments about that later, and we
4 then began to study Vietnam veterans.
5 The project is called the Pointman Project. It's an
6 idea that came up in a brainstorming session. We wanted to call
7 it something. The formal title is rather a mouthful and nobody
8 can remember it. We called it the Pointman Project because of
9 the possibility that there may actually be a connection between
10 Agent Orange exposure and later medical problems.
11 And in view of the increasing contamination from the
12 civilian environment by a whole host of chloronated aromatic
13 compounds, if we do demonstrate a connection in the case of
14 Vietnam veterans and that extends, then, to the general public,
15 it may turn out that the Vietnam veterans is playing pointman
16 for the rest of society.
17 My co-authors in the work are Michael Gochfeld who
18 is an M.D. and a Ph.D. in toxicology and a Vietnam veteran and
19 is a Professor in the Department of Environmental and Community
20 Medicine; Christoffer Rappe and his group; Martin Nygren who
21 was completing his Ph.D. and did the blood work; and Maryanne
22 Hansson who did most of the fat work in Chris' laboratory;

1 Henry Velez, an M.D. and Terry Ghent-Guenther, an occupational
2 health nurse with advanced training, were in charge of our
3 hospital admissions and examinations that were made in the
4 hospital which I'll just describe shortly; and Wayne Wilson
5 who is sitting in the back here somewhere. Wayne -- he left
6 the room. He would.
7 Wayne Wilson is Executive Director of the New Jersey
8 Agent Orange Commission and appears as a co-author because he
9 was in charge of the actual recruitment of the participants in
10 the study, of organizing the administration of an extensive
11 questionnaire to each potential participant, and in matching
12 our exposed men with the unexposed, and handling all of the
13 logistics of taking care of the men, getting them to the
14 hospital, getting them home again, taking care of their families,
15 and so forth.
16 He has learned in the space of five years an enormous
17 amount of science. He now thinks like a scientist so he de-
18 serves to be on here. What we have selected for
19 study were ten heavily exposed Vietnam veterans, and by that
20 I mean men who handled spray on a regular basis.
21 We did not include ground troops or any men who simply
22 spent time in a defoliated area. We felt that the likelihood of

1 finding dioxin in these men was no better than 50/50, if that,
2 at the beginning of the study, and we wanted to load it in
3 the direction of being able to find it. We selected two groups
4 of controls. One group that we called the Vietnam controls.
5 That's the first line. These are Vietnam veterans whose exposure
6 we rank as minimal or zero. We can never be sure of the zero
7 so we call it minimal. We were able to recruit ten such men.
8 We had wanted to recruit ten veterans who did not
9 serve in Southeast Asia, and these we called the era controls,
10 but for reasons of time and availability of the men and the
11 matching criteria that I'll show you in a moment, we could only
12 get seven of them on stream at the time we wanted to conclude
13 the study.
14 Our subjects were individually matched in that each
15 exposed man was matched to one Vietnam control and in seven
16 cases a Vietnam era control for age at the time of hospital
17 entry, dates of service in the military, race, ethnicity in the
18 sense of black, white and hispanic, and rank in the sense of
19 officer versus enlisted status. Of course, everything was
20 matched for sex as well, and for obvious reasons.
21 The research subjects that we obtained were all
22 volunteers. We sought these through a variety of means. Some

1 were obtained through the mass media, veterans service organiza-
2 tions, community church groups, et cetera. Once a man came to
3 our attention as a potential research subject, we evaluated his
4 exposure status ourselves initially be a detailed questionnaire
5 that covered both military and non-military occupational
6 histories.
7 There was a small amount of medical history in that
8 questionnaire as well, simply to ensure that we would know
9 whether a man was sufficiently healthy to withstand the rigors
10 of the hospital regimen to which we were later subjected, and
11 a considerable number of heavily exposed men were rejected from
12 the study on the grounds of being unable to withstand biopsy
13 or 24 hours of starvation which I'll discuss shortly.
14 We were fortunate in having the assistance of the
15 Dick Christian, whom I see sitting over there, in that we pulled
16 the records from the St. Louis Records Center and asked Dick
17 Christian's office to evaluate them, and our men were either
18 "1's" in the sense of minimal exposure or "5's" in the sense of
19 exposure highly likely.
20 And we are exceedingly grateful for Dick's coopera-
21 tion. We have learned that you need to put together a large
22 amount of information to really assess an exposure accurately.

1 Each man was admitted to the hospital. We admitted
2 them in groups of three to six men at a time in North Jersey,
3 and they underwent a substantial medical examination including
4 most of the routine stuff you would expect in any physical examin-
5 ation. As well as we did an exceedingly thorough immunological
6 screen.
7 That work was done in the laboratory of Ronald Kerman
8 at the University of Texas, and we did an extensive psychological
9 and psychiatric profiling of the men. That all was done locally.
10 None of that data has been collated as yet. That will be done
11 soon.
12 While in the hospital, we took adipose tissue by
13 liposuction biopsy. We took ten to 20 grams of it from the
14 buttock, by an incision made at the crease line between the
15 buttock and the upper leg.
16 We fasted our subjects for 24 hours before we drew
17 blood. The reason for this is that dioxin deposits in the
18 adipose tissue. Most of the circulating blood fat is derived
19 from the last two or three meals, and we wanted to increase
20 the likelihood of finding it in the blood. And felt that if
21 we forced the body to consume circulated blood fats from the
22 last two meals, stored reserves would be going down, and this

1 being done, some of the dioxin present in those stored reserves
2 would accompany them into the blood.
3 We then took three to 400 ml of blood into heparin
4 anticoagulant, and by the way we took extreme pains to avoid
5 possible contamination of the sample by plasticizers using the
6 blood drawing apparatus. The bags all contained anticoagulant.
7 We used the first 10 or 15 ml of blood as a rinse.
8 We rinsed the bags. We emptied them by means of a syringe
9 fork present in every bag.
10 We then injected our own hand-prepared heparin solution
11 into those bags. The blood was then drawn and immediately packed
12 on ice, and within a few minutes after all men in the group were
13 taken, we removed it to the hospital laboratory where the bags
14 were opened, and the samples were placed into carefully solvent
15 washed glass containers for transport to my laboratory in New
16 Brunswick which was an hour's drive from the hospital.
17 In my laboratory I centrifuged out the red cells and
18 froze the plasma. We also froze the adipose tissue. All con-
19 tainers were carefully solvent washed and one sample was
20 frozen. They were maintained in that state.
21 After the samples were frozen, they were taken to an
22 independent referee team of two people. Neither individual was

1 associated with Rutgers University or with the University of
2 Umea, where the analyses were done. I did not know either in-
3 dividual in advance of their agreeing to take part in this
4 study.
5 We would simply bring them the samples. They would
6 put their code numbers on specially prepared labels, and they
7 would remove my labels on the samples, with the result that I
8 would get back samples that I now no longer knew which came
9 from an exposed man and which came from an unexposed man.
10 In this state, the samples were packed in dry ice
11 and shipped to the University of Umea. At the end of the study,
12 Chris Rappe came from Sweden with the results in hand to make
13 sure that everything was to our satisfaction on them, and the
14 results were handed over to the referees before the referees
15 gave us the code.
16 Of course, once we got our hot hands on the code, we
17 sat at the referees desks in there for a couple of hours getting
18 a quick look at the data, and then took ourselves out for a good
19 lunch.
20 In the laboratory -- here I don't have a slide -- we
21 had methods validation that we had to undertake for both the
22 fat samples and the blood. In the case of the fat samples,

1 Rappe's laboratory had participated a year or so ago in an inte
2 laboratory study done by Philip Albro et al. and published in
3 "Analytical Chemistry" in 1985. Eight laboratories participated
4 Each was given aliquots of standard samples that had
5 been spiked by Albro's laboratory. And so they were all spiked
6 identically. A single material was spiked, and divided into
7 samples, sent to the eight laboratories, and the results were
8 then collated to see which laboratory's methods gave accurate
9 results and which did not, and Rappe's lab was found to have a
10 high degree of quantitative and qualitative reliability.
11 The also took a number of fish samples and fortified
12 these at three different levels with C-13 containing dioxins,
13 and analyzed and showed that they got those numbers back.
14 They analyzed cow milk fortified at four different levels,
15 getting fat tissue of fat material in there, and they analyzed
16 human milk fortified at four different levels with dioxins to
17 ensure that they got correct results.
18 So the validation of that has been extensive and has
19 gone on for many years. Until recently when the CDC came on
20 stream with their laboratory, Rappe's lab was the only lab with
21 the procedure for doing blood serum. The CDC now have a procedur
22 that is very similar to Rappe's.

1 They undertook a validation study in which they took
2 from the blood bank at Umea a pool of homogenized plasma sample
3 of considerable volume which contained an unknown level of
4 ordinary dioxins and furans. PCDD means dioxin. PCDF means
5 furans. I put "natural" in quotes because they are not natural
6 compounds. But these what they were looking at is the background
7 that seems to be present in all individuals by virtue of residenc
8 in an advanced industrial company.
9 The idea was that if you divide this into 12 aliquots,
10 which is what they did -- I didn't write 12 aliquots on there.
11 I should have -- and you spiked these aliquots with carbon 13
12 dioxins and dibenzofurans, you used the recovery of those carbon
13 13 samples as a way to quantitate the amount of natural isomers
14 present and if you do this on 12 samples, you should get the
15 same answer for all 12 samples.
16 They spiked at four levels, ranging from .018 part
17 per trillion up to .58 part per trillion with the series of
18 seven compounds shown here: tetradioxin, tetrafuran, pentadioxin,
19 a hexadioxin, a hexafuran, heptadioxin, and octadioxin. These
20 are all C-13 as opposed to C-12 isomers.
21 Three of the 12 samples were spiked at each level,
22 and the recoveries were then used to calculate the amount of

1 the natural isomer present those samples.

2 DR. KLAVITER: What is the percent of recovery?

3 DR. KAHN: 100 plus or minus 30.

4 DR. KLAVITER: 100 plus or minus 30?

5 DR. KAHN: Well, occasionally you get a high one.

6 Occasionally you get a low one.

7 DR. KLAVITER: I don't understand the range. Is that

8 range for each of the compounds?

9 DR. KAHN: Yes. Okay. The cleanup of these samples

10 for blood is extraction by a modification of a classical method

11 of Bligh & Dwyer for removing fat from tissue samples which is

12 a chloroform methanol water extraction. This is just a brief

13 outline of it.

14 There is then a silica column which takes out most of

15 the fat, the dilution of the compounds that we're interested

16 in, on to normal hexane, and then there is a carbo-packed C-

17 column which takes out the dibenzofurans and the dioxins. The

18 validation of the carbon-packed column is by Markland, et al.

19 from the ACS Miami symposium a year or so ago.

20 The analysis is by high resolution GC mass spec, using

21 Supelco 2330 and 2331 columns on the GC, and a BG-7250 mass

22 spec instrument at a resolution of 5000 to 8000.

1 The spikes in this case for the unknown samples were
2 Carbon 13 TCDD and Carbon 13 octadioxin. Bear in mind that the
3 analytical method was frozen in December of 1984, and since
4 then there has been considerable developments. These were
5 the C-13 isomers that were readily available for use at that
6 time.
7 If we were to do this now, we would be using a differ-
8 ent set of isomers, a considerably more extensive one. And
9 I'll point to a problem with one of the isomers a little later
10 that we got into because of the spiking protocol. The ion curves
11 that you get typically from the mass spectrometer for adipose
12 tissue in the top right -- it's a little blurry -- you can see
13 here that you get nice clean peaks from TCDD at the top, in the
14 penta and hexafuran and dioxin respectively in the middle, and
15 the pentadioxin at the bottom. The noise level is really
16 quite good.
17 There is, of course, correlation of these with re-
18 tention times of the known standards. Every third sample that
19 is analyzed when the unknowns were in progress was a laboratory
20 blank. And here are typical ion curves that you would get in
21 blood showing the same, most of the same set of compounds as
22 dioxin on the top, pentafuran in the middle, and a pentadioxin

1 at the bottom. We did a nice clean spectra.

2 The validation study on the blood gave the following

3 results. The top line is a little faint, but you can see

4 that the agreement across the board on these is generally very

5 good. These are the 12 samples from the same aliquot of

6 pooled plasma, and this is from Rappe's talk that was given the

7 day before my talk in Japan.

8 So the validation here worked out quite well. We're

9 reasonably pleased with this. The CDE put out a similar valida-

10 tion with virtually the same results in their study.

11 So what have we for results? In the case of adipose

12 tissue, for TCDD, we have 11 parts per trillion. The left bar

13 where there is a 30 -- for example, here -- the left bar is

14 the exposed man. The middle bar is the Vietnam control, and

15 the right hand bar, rather small in this case, is the Vietnam

16 era control.

17 We were missing the Vietnam era control for trios

18 one, seven and ten. Here we have a Vietnam control which is

19 exceedingly low. But there was a control there, and there was

20 a number. It just doesn't appear very well on this graph.

21 The upshot of this is that in nine of the ten cases

22 -- this being the only exception -- the Vietnam exposed man

1 exceeds the controls. And because of the matching, individually
2 based matching, even though the excess here is very small and
3 if this pair of individuals were to be repeated, if there is
4 a reasonable likelihood they would come out the other way around,
5 over the entire group of ten men, the likelihood that nine of
6 the ten would come out in excess of their controls by chance
7 is very, very small.
8 One of the things that we have begun to look at, but
9 have not yet fully analyzed, is the isomer ratios, the ratio
10 of dioxin to various other isomers in the group that we have
11 found in these materials, and if you look at the isomer ratios,
12 we do find, for example, that this one is high, and this control
13 is low. The same thing is true here. The same thing is true here
14 But I'm a little uncomfortable with the isomer ratios yet because
15 in the case of the dibenzofuran, 2,3,7,8 of furan as an isomer
16 ratio, the furan itself -- the level of that is exceedingly
17 low. And laboratory error begins to be rather a large factor
18 in furan level and the ratio becomes unreliable.
19 Nevertheless this is really quite striking. The
20 same thing in blood looks like this. We had one failure of
21 a blood sample on an exposed man. In number five, the exposed
22 sample we just had all kinds of laboratory problems with that,

1 and there was basically no data to be had from that sample.
2 So that we only have the Vietnam control and the Vietnam era
3 control here. So we only have nine pairs that we could compare,
4 and in six of those nine pairs, the exposed man exceeds the
5 controls, and the probability is not quite as good as in the
6 case of adipose, but it's certainly very good, indeed.
7 It's also of interest that the men who were high in
8 the adipose are also high here. And I'll show you that correla-
9 tion separately later.
10 These are the averages for TCDD alone. Other isomers,
11 we haven't gotten to yet. In the case of adipose, with an "n"
12 of 10, on our exposed have a value of 41.7, and the Vietnam
13 controls with 5.1, 3.2 and if the controls are pooled, these
14 10 plus these 7, the average is 4.3 with a standard error of
15 measurement shown here.
16 In the case of blood, we get virtually the same number
17 here, and by the way the New York Times got this wrong. They
18 put 48. The number isn't 48. Here is our full controls at 5.7.
19 The ratio here here is on the order of ten to one, not quite
20 in this case, but about ten to one in that case.
21 If we now look at the other isomers, we've found a
22 total of 13 isomers in these men, TCDD being one of them.

1 CHAIRMAN SHEPARD: Excuse me. But those fat analyses
2 are lipid weight?
3 DR. KAHN: No, that's per gram tissue weight.
4 CHAIRMAN SHEPARD: Of the blood ones?
5 DR. KAHN: The blood one is for gram fat.
6 CHAIRMAN SHEPARD: On a lipid basis then. I understand
7 DR. KAHN: Yes. The blood is on a lipid basis. The
8 fat tissue is on a per gram tissue weight. Okay. I think we
9 would have been better off in the fat case if we had done it
10 per gram tissue lipid, but it turned out the CDC examined that
11 question, and they got their best correlations if they did it
12 per gram tissue as opposed to per gram tissue of fat. That's
13 for adipose only.
14 For blood, they did the same thing we did. They
15 measured the amount of fat. Okay. Here we have all the other
16 isomers that we have found in the samples. We'll look at the
17 octa and the other over there in a moment. They all don't fit
18 on the screen at the same time. Okay.
19 TCDD is here, where "X" represents the exposed man;
20 "V" represents the Vietnam controls; and "E" represents the
21 era controls plus or minus standard errors of the mean. Clearly
22 this is far outside the bounds of these.

1 If you look at the others, here are the furans, all
2 about the same. Here is another isomer of pentafuran, all
3 about the same, and the same thing is true across the board.
4 We certainly don't have large excesses in the exposed members
5 of the controls in any of these cases. Likewise here in the
6 case of others on a different scale.
7 This is consistent with the notion that these compounds
8 are present in everyone regardless of service in Vietnam, regard-
9 less of the nature of that service in Vietnam. Whereas this
10 one -- although present in the background, as expected. It is
11 now no longer controversial -- it is present in excess in our
12 exposed people.
13 Here I'm afraid I don't have quite as clean a slide
14 for you. This is the same thing in blood. This was handmade
15 from a graph. A good one has been made, but I haven't got it
16 made into a transparency yet. Here you see in the same order
17 the same compounds across as in the previous one. There is
18 TCDD. Here are the controls.
19 And for the most part, you can see there is no excess
20 in the case of the exposed men versus the unexposed with one
21 or two exceptions. One exception here in the octa where the
22 exposed appeared to be higher. We had a recovery problem in

1 the case of octadioxin on some of these blood samples, and that
2 may be responsible for this. This is something that will probab-
3 ly have to be looked at in further detail.
4 We're not quite sure what this is due to. We think
5 it's a recovery problem. Here's one in which the exposed
6 exceeds the Vietnam era controls, but does not exceed the Vietnam
7 control. We think this also might be a recovery problem, but
8 we're not quite sure. We didn't quite know what to make of
9 that one. It certainly is nothing on the scale of this.
10 Okay. Now, the correlation of blood with fat. You
11 can see a hint of us this already in the two bar graphs that I
12 showed before in which the same men were high in both. I'm
13 going to present this to you in two ways, the first of which
14 is the direct correlation in which we plot versus fat levels
15 in parts per trillion, and this is the gram blood fat, and this
16 is per gram tissue.
17 Okay. An open circle is an exposed man. A dot, a
18 black dot is a control. There were nine exposed that we could
19 use in this comparison because of the failure of the analysis
20 in one of the bloods.
21 And what is seen here is that if you draw a box at
22 15 parts per trillion on both axis that box contains all 17 of

1 the controls and three of the exposed. Outside the box, we have
2 six additional points for the other exposed men. There are no
3 controls outside that box.
4 Now, I'm going to come back to this in a moment. So
5 I'm just going to set it aside where I can get it because I will
6 have one more comment about it. These data are not normally
7 distributed, and so to put a least square's line through that,
8 and this is the line that I had there, is really not legitimate.
9 So what we did is we did the log/log transform of this and plott-
10 ed that in these squares with my trusty Apple computer, and this
11 is the least square line that fits all of these data after the
12 log transformation.
13 These are the 95 percent confidence limits on these.
14 Now, there were 26 data points that we could use in this analysis,
15 nine of exposed and 17 of controls. If you include all of the
16 data points, the correlation coefficient in the log/log plot,
17 it's .72. And for this sort of work, I'm told by people who
18 do it that is itself very good.
19 However, that includes a number of data points,
20 specifically four, in which the values are between zero and
21 one part per trillion. That is the range of the data in which
22 the errors are likely to be largest. That is also the range of

1 the data in which small changes are are going to have a rather
2 large effect upon the logarithmic value. So if those four data
3 points are dropped out, and CDC did the same thing for their
4 data, we're now down to 22 data points, and the correlation
5 coefficient goes from .72 to .89. And that is what is shown
6 here.
7 These are the 95 percent confidence limits at .89.
8 You can see we have a really nice correlation here. Now, I'd
9 like to go back to the previous one for a moment, if I may,
10 and point out something that I want to raise in the conclusions.
11 Clearly, whether you take this at 15 parts per tril-
12 lion or 20 parts per trillion, I don't care. It doesn't really
13 matter. Anywhere outside the box, wherever you choose to put
14 it, would classify a man as heavily exposed by any definition.
15 However, it would not be correct to say that a man
16 who is inside the box can be classified solely on the basis
17 of dioxin measurements as unexposed because the exposure on
18 these men was high.
19 Why they are inside the box is an unknown question.
20 It could be that the particular Agent Orange they were exposed
21 to was relatively clean. There were after all a dozen or so
22 manufacturers, and even within manufacturer, it varied batch to

1 to batch. Also possible is the likelihood that people differ
2 in their excretion rates. And you could have someone who is
3 a high excreter. In that case, the isomer ratio of dioxin to
4 one of the isomers might be useful when you had begun to explore
5 pattern recognition analyses for that purpose.
6 So that one has to be very careful later on down the
7 road, particularly, as people begin to use these measurements
8 for extablishing epidemiological cohorts that you don't use a
9 low measurement as a sole basis for classifying person to the
10 unexposed cohort.
11 Conclusions. Clearly Vietnam veterans who were
12 exposed exceed the matched controls in dioxin level even though
13 it's 15 to 20 years since the end of that exposure. I think
14 there is no arguing with that conclusion, and that is consistent
15 with what the CDC reported on people from Missouri although the
16 time period there was in many cases somewhat less.
17 It seems likely that from these results -- in fact,
18 highly likely. I can't think of any other way to explain it --
19 that the high levels in the exposed men is due to their war
20 time exposure to Agent Orange. Otherwise, the other isomers
21 would also show the same kind of variation and they don't.
22 There is an excellent correlation between adipose

1 tissue and blood levels which makes it almost certain, virtually
2 certain that within a short time blood sampling will replace fat
3 sampling. I don't think we're quite there. I don't think we're
4 quite at the stage where blood sampling replaces fat sampling.
5 We've a few "i's" to dot and "t's" to cross.
6 And the results support the statement that highly
7 exposed men can be distinguished from all others both by blood
8 and by adipose tissue testing, and I think within a short time,
9 six months to a year, we'll be able to use these methods as a
10 way of establishing cohorts for epidemiological studies. That
11 ends my presentation.
12 CHAIRMAN SHEPARD: Thank you, Peter. Any questions?
13 Mr. Carra?
14 Mr. CARRA: If I remember correctly, the charts that
15 you showed had plus or minus one standard deviation; is that
16 correct?
17 DR. KAHN: Standard error of the measurement.
18 Mr. CARRA: Standard error. Did you do any statistical
19 testing on this to show significance --
20 DR. KAHN: Yes, we did.
21 Mr. CARRA: And on the TCDD?
22 DR. KAHN: Yes. Every one of the numbers have

1 been tested by various statistical analyses. In the case of
2 simple binomial distribution for greater than or less than,
3 it comes out highly significant.
4 Mr. CARRA: In terms of the nine, the number of --
5 now, what about the levels, though? It would appear that they
6 might not come out to be statistically significant.
7 DR. KAHN: They do come out to be statistically
8 significant. I don't have the numbers in front of me. They
9 will be in the manuscript.
10 Mr. CARRA: And that's after transformation?
11 DR. KAHN: Yes.
12 Mr. CARRA: Okay. Because you showed the graph without
13 transformation.
14 DR. KAHN: Yes, I did.
15 Mr. CARRA: Okay. All right.
16 DR. WALKUP: Has this been accepted for publication,
17 or is going to be appear soon?
18 DR. KAHN: It's being submitted for publication
19 in the very near future. What I've done -- see we presented
20 this at the International Symposium in Fukuoka as a preface
21 to writing a manuscript, and I made careful notes of some of
22 the comments people made, and I incorporated that into the

1 manuscript which will be submitted very shortly.

2 DR. WALKUP: Do you have copies of the paper you

3 presented there?

4 DR. KAHN: There are no written copies. See the way

5 you do this sort of thing is you present a verbal talk or a

6 poster on the wall, and we did both of those because we were

7 required to present a poster. And then based on that you write

8 the manuscript and send it in, and that is what is happening

9 right now.

10 So what will happen next -- I don't give out any-

11 thing in writing until we have been through peer review at a

12 journal. And as soon as that has happened, preprints will be

13 made available if the journal permits and if anyone wants them.

14 DR. WALKUP: What would be your guess about what it's

15 going to take for other members of the scientific community to

16 accept your conclusions as gospel? What holes do you see in

17 what you've gotten, what should be replicated?

18 DR. KAHN: Well, the CDC have already replicated

19 basically the same results that we have. They looked at 50

20 heavily exposed people from Missouri and 50 controls. Their

21 heavily exposed were drawn from residents of Times Beach,

22 people who were involved in the horse arenas where waste was

1 always sprayed, and workers from the factory in Verona where the
2 material was made that ended up at Times Beach and horse arenas.
3 And they presented it in the same program we did in
4 the morning. I was in the afternoon, and they have exactly the
5 same kinds of results we do, exactly the same numbers. Some of
6 their heavily exposed people are higher than ours, but the
7 exposures are more recent, and also more massive in some cases.
8 DR. WALKUP: It either that study or yours, was there
9 any --
10 DR. KAHN: Excuse me. Their correlation coefficient
11 on a log/log basis was .97 which is actually staggering. And
12 they didn't use 24 hours of starvation. They only used 12.
13 That's one of the things we're going to investigate, the
14 necessity of starvation.
15 If you don't have to starve people for 24 hours
16 it's a whole lot easier. I'm sorry. I didn't mean to interrupt
17 your question.
18 DR. WALKUP: Did you or they look at possible rela-
19 tionships between the health problems of the people in the
20 study from the different groups?
21 DR. KAHN: We have all of that data. For example,
22 the next thing that will be correlated once this manuscript is

1 in the mail, we turn our attention to the immunological data
2 which we have quite a lot to see if any of that correlates
3 with either exposure status or dioxin level. We do these
4 analyses separately.
5 Following that, and that will be published regardless
6 of what the result is, positive or negative -- following that,
7 we'll take the rather large amount of psychological and psychia-
8 tric data that we have which is easily amenable to analysis,
9 and that will be done next. And then right after that, we'll
10 have a look at the health effects data of which we have a great
11 deal on these men.
12 I don't think we're going to see anything in the
13 health effects data for two reasons. One reason is the number
14 of men is rather small to find any health effects. Secondly,
15 we biased the sample against the ability to detect health
16 effects by excluding heavily exposed men who were severely
17 ill for ethical reasons. I wasn't going to a surgical biopsy
18 and starve a seriously ill man for 24 hours.
19 DR. WALKUP: Congratulations. I've been wondering
20 what you've been doing all these years.
21 (Laughter.)
22 DR. KAHN: Sometimes I wonder also. Yes, a question?

1 DR. KLAVITER: The correlation between the adipose
2 and the blood tissue samples is very nice.
3 DR. KAHN: I hadn't expected any of this.
4 DR. KLAVITER: Yes. I guess it would be safest to assume
5 that you would see some variation. After all, they're different tissues.
6
7 DR. KAHN: Sure.
8
9
10
11
12
13 CHAIRMAN SHEPARD: Please identify yourself. We are
14 departing a little bit from tradition, and I think under the
15 circumstances that is okay. If I'm not mistaken, you're one of
16 the chemists from CDC?
17 DR. KLAVITER: Well, I have to say that you are mis-
18 taken, Mr. Chairman and members of the committee. I very much
19 appreciate being able to attend and take a moment or two of your
20 time.
21 DR. KAHN: Tell us your name.
22 DR. KLAVITER: I'm Roy Klaviter from the Michigan

1 Department of Public Health. I'm a member of the Center for
2 Environmental Health Sciences there. And as you can tell, a
3 person that fusses with laboratory data and tries to understand
4 it like yourself.
5 The percent recovery that seems to be the most impor-
6 tant to me here is that which you got specifically for 2,3,7,8
7 TCDD because that is what you're following through the tissues
8 and so forth. It would be reassuring to those of us who are
9 also laboratorians to see that specific number.
10 DR. KAHN: We'll have that in the manuscript.
11 DR. KLAVITER: That specific number.
12 DR. KAHN: Chris Rappe has most of that stuff and
13 we'll be putting it in the manuscript when we publish it.
14 But in a 15 minute talk, I couldn't do all that.
15 DR. KLAVITER: But the limits -- you're telling me
16 that those recoveries which you got were within acceptable
17 limits.
18 DR. KAHN: Yes.
19
20 DR. KAHN: Certainly within what's normal for the
21 field.
22 DR. KLAVITER:

1

2

3 Did you try a saline solution that was stored in those

4 containers treated in the same way as the samples to check for

5 plasticizers and plastics?

6 DR. KAHN: Only did it once. I didn't try to reproduce

7 it. Nothing there.

8 DR. KLAVITER: But you can say you did it.

9 DR. KAHN: Yes. Good point. And we also ran a

10 laboratory blank, method blank every third sample. Yes?

11 Mr. CARRA: In an EPA study that we've heard about

12 on adipose tissue that one day might get done that we're con-

13 sidering doing some matching, have you looked at the efficiency

14 of the matching, the things you matched the samples on?

15 You selected certainly factors to match on, and I'm

16 wondering whether any analysis was done as to whether those were

17 good selections because we would be doing -- the protocol that

18 we proposed awhile ago on the adipose tissue analysis lists

19 the archive adipose as similar to yours.

20 But I think what you match on might be different, and

21 I'm just wondering --

22 DR. KAHN: Well, one of the factors that seems to be

1 especially important is age. One of the papers that was pre-
2 sented at the Japan meeting is that there is a steady increase
3 with age and the background that are found in the normal popula-
4 tion. In actual value, there is so many PPT per decade of life
5 that are in there. So I think age is an important factor.
6 Mr. CARRA: There is also a service date or something
7 like that in your matching, is that right?
8 DR. KAHN: Yes, we did match on that. The reason we
9 matched on that is we wanted to ensure that time since exposure
10 was roughly comparable and with reasonable limits. I think the
11 half life is going to turn out to be in the human body is going
12 turn out to be on the order of five to eight years, five to
13 ten years for human beings. So that if you're within a couple
14 of years, you're all right.
15 We initially started out matching on branch of
16 service and discovered that it was not possible to match the
17 Vietnam era controls for that. We just couldn't get the men
18 to do that. And matching, let me tell you, is a pain. That
19 was the most painful part of this procedure. And that is
20 responsible for taking so long. Our first group was December
21 '84. Our last group was July '86. Wayne Wilson bore the brunt
22 of every bit of this matching. He did it.

1 Now, the results of the matching were subject to re-
2 view by a committee on which Wayne and I and three others sit,
3 and all the decisions of the committee had to be unanimous.
4 If anyone vetoed a person, the person was out. Nevertheless,
5 Wayne deserves enormous credit for the burden of work done
6 matching.
7 We have two to 3,000 men in our files in order to get
8 27 people.
9 CHAIRMAN SHEPARD: Did you draw blood on the people
10 prior to fasting? I think it would be very interesting to
11 have some data that would tell us what the effect of fasting
12 was. I know it's expensive.
13 DR. KAHN: That's next. You see we couldn't do it
14 in the context of the study as of the time we froze the protocol
15 because we needed three to 400 ml of blood, and you can't do
16 that twice on a guy in 24 hours. You starve him in the middle.
17 CHAIRMAN SHEPARD: I understand.
18 DR. KAHN: That's a bit much. But what's happened in
19 the interim is methods development has gone on, and we now need
20 about half of that.
21 CHAIRMAN SHEPARD: That's why I asked the question,
22 whether you did the analysis. Did you draw some blood so that

1 you can go back now and do it?

2 DR. KAHN: Well, what we're going to do is, you see,

3 you have to do them both at once. So we are bringing the men

4 back, the heavily exposed men back.

5 CHAIRMAN SHEPARD: No, I mean did you draw any blood

6 prior to fasting the individuals and store it?

7 DR. KAHN: No, we did not. See we only had them in

8 the hospital for three and a half days. There was no way I

9 could two and a half units of blood from a guy in that amount

10 of time under any circumstances.

11 CHAIRMAN SHEPARD: I'm not suggesting that you take

12 that much blood. Techniques are being refined now to the point

13 that you can do it on much smaller samples.

14 DR. KAHN: Yes, all we're going to do now is the

15 equivalent experiment. We're bringing the men back. We're

16 going to bleed them first, fast them, and bleed them again.

17 But we're bleeding half this amount, maybe even a little less.

18 So we'll get the answer to that question. That's one of the

19 things we want to do right away.

20 One of the other things we want to do right away,

21 well, soon, is we want to start looking at a couple of other

22 targeted groups. One in particular we want to look obviously

1 at ground soldiers since these were spray handlers. We would
2 like to recruit, and we are going to hopefully negotiate this
3 with Dick Christian, who is hearing it now for the first time,
4 we would like to look, for example, at the ten most exposed
5 ground soldiers we can get our hands on carefully matched
6 against controls using the same kinds of procedures we've al-
7 ready worked out.
8 The second group that we're very eager to look at is
9 women. We would very much like to recruit ten women who are
10 the most heavily exposed women we can lay our hands on, possibly
11 using Dick Christian to help us find them, and match them
12 against controls in the same way that we have done for our men,
13 and see what we find there.
14 These are small targeted studies that we want to have
15 a go at. We think we have the ability to organize those studies.
16 I'm sorry. Is there a question?
17 MR. CONROY: Peter, the study took place obviously over
18 a couple of fiscal years.
19 DR. KAHN: Yes.
20 MR. CARRA: Do you have any ballpark ideas as to what
21 the entire study cost?
22 DR. KAHN: Yes, I do. Our entire research budget since

1 the inception of this project has been $377,000. That's over
2 five years. I'm not salaried on the project. I'm paid as a
3 faculty member and so is Chris Rappe. So my salary doesn't
4 come out. I do this as a volunteer.
5 I would be pleased to see anyone who has further
6 questions afterwards.
7 CHAIRMAN SHEPARD: Thank you very much, Peter. Again,
8 I congratulate you on this very interesting piece of work, you
9 and all your colleagues. For those who are not aware of it, I
10 think this is the first time where this matching has been
11 completed. As you know, CDC is doing the same thing, but I
12 think that to New Jersey's credit, they're the first to report
13 on their efforts.
14 I think we'll take about a 12 minute break now. If
15 you will all reconvene at quarter of 11, we'll be happy to hear
16 from Dr. DeStefano from CDC.
17 (Whereupon, a short recess was taken.)
18 CDC AGENT ORANGE STUDY
CHAIRMAN SHEPARD: We're very pleased to have with
19 us on the program today Dr. Frank DeStefano who is known to many
20 of you. He's been very much involved in the CDC epidemiological
21 efforts related to Agent Orange, the Vietnam experience, and he
22 has very kindly consented to give us an update on the status of

1 things at CDC. Frank.

2 DR. DeSTEFANO: In the next half hour or so, I'll

3 try to update you on the epidemiological studies that CDC is

4 conducting relating to Vietnam veterans. As you may know,

5 currently we have ongoing what we call the Vietnam Experience Study.

6 This study compares the health status of a group of Army

7 veterans who served in Vietnam with a similar group of

8 veterans who served during the Vietnam era, but not in Vietnam.

9 They would be veterans who served either in the continent-

10 al United States, Germany or Korea.

11 The purpose of this study is to address a question

12 that was raised earlier about possibilities that other exposures

13 in Vietnam, not just Agent Orange, may have had some impact on

14 health. So this study looks at more or less the whole Vietnam

15 service experience for Army veterans who were below the officer

16 ranks.

17 The study began with a random selection of participants.

18 The sample was drawn from accession numbers at

19 the National Personnel Records Center. Over 18,000 veterans

20 were identified as eligible for this study, and these broke

21 out almost evenly between Vietnam and non-Vietnam veterans.

22 A lot of the abstracting of service characteristics

1 eligibility criteria was performed by the Environmental Support
2 Group of the Army. This is the agency which does most of the
3 record reviews and has the expertise in military records handling
4 and review. As you heard from
5 Dr. Kahn, they did some of the exposure assessment in their
6 study.
7 So for the 18,000 eligible participants several government agency
8 files were searched that may have information on veterans that
9 have died: Social Security Administration, the National Death
10 Index, Internal Revenue Service, and the Veterans Administration
11 BIRLS files. These were all searched, and veterans who
12 had died were identified, or for those that were not known to
13 have been dead, current locating information was obtained.
14 Those who have died form part of the mortality
15 study component that compares rates of mortality
16 as well as specific causes of death. That study has been
17 completed, and the report should be issued in November.
18 Those veterans who were not determined to have died, we
19 had their names forwarded to the interview contractor, Research Traingle
20 Institute in North Carolina which does the locating and contacting
21 of the veterans for participation in a rather extensive health
22 interview.

1 Over 15,000 veterans have thus been contacted and
2 participated in the interviews. A subsample of interview
3 participants were then selected to undergo an extensive two-
4 day medical and psychological examination. All the examinations
5 are being done at Lovelace Medical Foundation in Albuquerque,
6 New Mexico.
7 Examinations were completed in September, so both the
8 interview and examining process, at least the data collection phase,
9 has been completed, and we're now in the process of data
10 analysis. We have a target date of issuing the reports in
11 late summer of fall of next year.
12 Basically the Vietnam Experience study, the process
13 itself went well. It went on schedule. I think our participa-
14 tion rates exceeded expectations, and we should have those
15 results reported within the next year.
16 The other large study is the Agent Orange study. It
17 is the one that focuses more specifically on health effects of
18 exposure to Agent Orange while in Vietnam, and as you probably
19 know, this study has been on hold since about last December.
20 When the epidemiological studies first started,
21 a lot of the initial
22 work went into how to assess exposure to Agent Orange among

1 ground troops. The initial design was always to use available
2 records to somehow establish exposure on the basis of frequency
3 of number of times a veteran was within close proximity to
4 known Agent Orange applications.
5 The CDC submitted to the Office of Technology
6 Assessment of the Congress, which has oversight responsibility
7 for our study, two reports in the spring and fall of '85. There
8 were problems identified in determining exposure and Congress
9 did not feel as of last December that sufficient progress had
10 yet been made in coming up with a reliable way to assess exposure
11 using the military records to proceed with a full-scale Agent
12 Orange exposure study at that time.
13 So the study was placed on hold. In the interim, in
14 the past year, a lot of activity has gone on, much of it directed
15 or carried on by the executive branch's Agent Orange Working
16 Group. There have also been several new findings and
17 developments which impact on the conduct of this study.
18 Probably the most important is one which you have
19 just heard about by Dr. Kahn: the ability to
20 measure dioxin levels in blood in minute quantities. And
21 the development of that technology, I think, has really altered
22 the whole picture on how we might approach an Agent Orange

1 exposure study. I'll give you the bottom line of where CDC stands
2 now, and then some of the background of what has happened this
3 past year, and give you an historically flavor anyway of how
4 rapidly information was coming out, and the sort of environment
5 we were operating in in formulating our plans.
6 Since dioxin can be measured in blood quite reliably
7 now, we have proposed doing a vali-
8 dation study on several hundred veterans to measure dioxin
9 levels in their serum and see how well that correlates with
10 military records assessments of exposure and also compare Vietnam
11 veteran levels with a group of non-Vietnam veterans who served
12 during the same time.
13 I'll just go into some of the background of what has
14 happened and some of the findings.
15 Once the study
16 was placed on hold, the Agent Orange Working
17 Group formed a sub-panel of its Science Panel to review issues
18 related to Agent Orange exposure, methods for determining ex-
19 posure using available records, et cetera.
20 As part of that evaluation, the Environmental Support Group
21 was asked to conduct a pilot study of selected battalions
22 to determine location information and how many men might have

1 been frequently in close proximity to Agent Orange applications.
2 Prior to this pilot study, one of the problems had been
3 that for a substantial number of days a location was not avail-
4 able at a company level to be able to place companies on that
5 day with a specific location in Vietnam relative to where
6 herbicide applications had occurred.
7 As part of the pilot study, ESG was able to develop
8 methods to fill in the missing days, for most of the
9 missing days for nearly all companies in the seven battalions.
10 Once the locations were filled in, they compared the
11 company locations with herbicide application records to determine
12 a frequency distribution, of number of men
13 who were within so many kilometers within so many days of
14 herbicide applications during their tours in Vietnam.
15 That pilot study was completed in April, and involved
16 seven battalions. The subpanel of the Agent Orange Working
17 Group Science Panel reviewed those findings as well as other
18 information pertinent to exposure assessment.
19 They had several meetings and deliberations with mili-
20 tary experts and others, and their final recommendation was that
21 " . . . any study of grounds troops which is dependent upon military
22 records for the assessment of exposure to herbicides not be

1 conducted without an additional method to verify exposure.
2 The reasons for this were mainly two problems. One, troop
3 dispersion, and two, incompletely documented sprays.
4 The review determined that all available records were
5 being used and being used appropriately, and that locations at
6 the company level could be determined on almost a daily level.
7 Still once you had all that information, it was evident
8 that the company level was the smallest unit at which you could
9 place a veteran, and that frequently you would have several loca-
10 tion points reported for the same day, either because companies
11 moved around, or because sub-units of a company were in different
12 locations.
13 So it was not uncommon to find troop dispersion at
14 a company level for up to 20 kilometers. The other problem with
15 available records had to do with the availability of spray
16 records, particularly those from either helicopter or ground
17 application.
18 The subpanel felt that documentation of sprays
19 from fixed-wing aircraft, so-called Ranch Hand sprays, is
20 complete and adequate. But expert opinion was that the
21 sprays from around perimeter bases, helicopter sprays, and
22 ground applications are probably substantially under-documented

1 although all the documents have been obtained that are available.
2 It is felt that these sprays were not fully reported. And in-
3 terestingly enough, as part of the pilot study that was done,
4 it appears that most of the times the veterans were in close
5 proximity to spray applications occurred near these helicopter
6 and ground applications. So it looks like a major part of
7 potential exposures may not have been recorded.
8 That left the dilemma of exactly what to do with these
9 sprays. I mean there was some nagging concern that, well, maybe
10 they're not complete but no one knew how incomplete they may
11 be. The records could still be useful for epidemiologic purposes.
12 Fortunately this summer, as we have heard, the serum measure-
13 ment was developed, and it allows for the independent verification
14 that was called for by the subpanel.
15 So that's where we were with the records and the need
16 for verification. Also, there has been a lot of new research
17 that just came out towards the end of '85 and in '86 which lead
18 us to believe that dioxin levels can still be elevated in
19 persons who may have been exposed 15 or 20 years ago in Vietnam.
20 When the protocols for the epidemiologic studies were
21 first put together in 1983, the issue of measuring had come up is
22 tissue dioxin as a biological marker of exposure had been considered.

1 At that time I think most
2 experts and reviewers who evaluated the protocol felt that
3 probably the half-life was about one year. That came mainly, or
4 almost exclusively, from extrapolation of animal studies. I
5 don't think anyone at that time was as prescient as Dr. Kahn,
6 who in '81 had the notion that maybe dioxin would still be
7 present in the body 15 to 20 years later based on the furan work.
8 But people who were reviewing the protocols and developing
9 at that time in '83 thought that the best guess was a one
10 year half-life for dioxin in human tissue. If that was the case,
11 15 to 20 years later, only a negligible amount should be avail-
12 able. Based on this belief a tissue measurement strategy
13 was not pursued.
14 There have been a couple of studies in this past
15 year--
16 DR. KAHN: You know the results had been published
17 by '83.
18 DR. DeSTEFANO: Pardon me?
19 DR. KAHN: The initial results had been published in
20 '83.
21 DR. DeSTEFANO: Yes, I realize that. And also PCB's
22 half-life information was available at that time. At the time experts

1 and reviewers, taking all available information into consideration,
2 felt their best estimate was about one year.
3 I'm sure there were arguments about that. If you look at the
4 furans, they are very similar to dioxins. If you look at the
5 PCBs, they're very similar, and their half-lives are on the
6 order of years.
7 This past year at least some studies have come out
8 that suggested the half-life is five years or more. And
9 also prior to the New Jersey results, there were a couple
10 of other studies that suggested that dioxin levels would still
11 be elevated in Vietnam residents or veterans 15 to 20 years after
12 exposure.
13 In 1985, Gross and his colleagues published a small
14 study in which they obtained adipose tissue samples from about
15 23 self-selected Vietnam veterans who believed they had been
16 exposed to Agent Orange and were suffering adverse health
17 effects as well as from ten veterans who had not been exposed to
18 Agent Orange. The classification was done on likelihood of
19 exposure, and interestingly enough, three men who were in the
20 highest exposure category had the highest levels of dioxin.
21 In two of them the levels were 35 and 99 parts per trillion. In one
22 the level was controversial because in one sample there

1 was poor detection of the internal standard, but a sample from
2 the same veteran run by another lab detected a level of 20
3 parts per trillion.
4 For the other levels of exposure, the dioxin levels
5 were not different from the controls. They were in the 5 to 6
6 parts per trillion range which is the level that is basically
7 the background level in an industrial society.
8 There was a hint there that dioxin still persists in
9 Vietnam veterans. The veterans in the study all had exposure
10 eight years or more prior to the time their samples were taken. So
11 eight years or more, in 15 to 20 years, there still might be
12 detectably elevated dioxin levels.
13 Also, in '85, Schecter and colleagues reported a
14 study of Vietnam residents. They were able to obtain some
15 samples from North and South Vietnam. These were surgery
16 patients and autopsy cases, and they obtained 15 specimens from
17 the south. They reported that these people lived mainly in
18 outlying provinces away from Saigon, and they detected dioxin
19 in 12 of the 15, the average was 28 parts per trillion.
20 They also obtained nine specimens from the North
21 Vietnam. These were people who had never been in the south and
22 had no known herbicide exposures. No dioxin was detected in

1 any of these nine people. The detection limit was about two or three
2 parts per trillion, and it may be the case in a non-industrial-
3 ized society that you would not detect dioxin.
4 Then just this past September, the New Jersey findings were re-
5 leased, and these provide, I think, dramatic evidence for both
6 the half-life and persistence of dioxin as well as the high
7 likelihood that some veterans were exposed to high enough
8 levels of dioxin that they still have considerably elevated levels
9 in their bodies at this time.
10 Given all that information last spring, we still had
11 the problem that almost exclusively dioxin
12 measurements relied on measurements in adipose tissue which
13 does require a surgical procedure to obtain, with attendant
14 risks of surgery and incision, et cetera. Certainly,
15 ethically and practically it would not have been easy to obtain adipose
16 samples in any kind of large study.
17 This past summer, the Environmental Health Laboratory
18 at CDC completed work on development of their method
19 to measure dioxin in blood, or the serum fraction of blood.
20 They worked, or had been in contact with and collaborated
21 with Dr. Rappe in Sweden. As Dr. Kahn said, their methodology
22 is very similar. As you have heard, they conducted a study,

1 a validation study of their serum measures using some samples
2 that they got from Missouri persons exposed at Times Beach
3 or in occupational exposures, et cetera. They got 50 paired
4 samples, fat and serum, and quite frankly their correlations
5 were astounding. There was almost a straight line correlation
6 between the fat levels and the serum levels. On a lipid
7 weight basis, the correlation coefficient was .98 which
8 means that whether the fat is in adipose
9 tissue or whether it's in serum, there is virtually a
10 one-to-one correspondence of the dioxin concentration.
11 They've also worked on refining their methodology
12 to the point where now they're fairly confident of being able to
13 detect 2,3,7,8 TCDD at the one part per trillion level in
14 about 75 milliliters of serum, which would require about 150
15 milliliters of blood.
16 So with this available, it will at least open the
17 possibility of using the serum measurement of dioxin as a
18 validation of exposure assessment methodologies for an Agent
19 Orange study. We have developed a protocol to do just
20 that. We are proposing studying about 400 Army veterans who
21 served in III Corps area of Vietnam in 1967 and 1968.
22 We would study two groups based on military records estimates

of possible exposure. A high group would be veterans who on several occasions were within a couple of kilometers of a known herbicide application within one week of the spray, and a low group who have no such documented exposures.

We plan to use similar procedures as were used in the Vietnam Experience Study in terms of tracing, locating, contacting veterans, and inviting them to participate. We propose obtaining the blood specimens at the Lovelace Medical Foundation in Albuquerque for several reasons. The mechanisms are set up. We would be able to provide the veterans a service which we feel is important, to provide them with a medical examination, and it also is an incentive quite frankly for them to participate.

The ultimate goal of this study would be to compare the serum dioxin levels with the exposure estimates derived from the troop location and spray data, see how well they correlate, and, depending on those results, make a decision on how to proceed with a full-scale study.

The protocol, before it can be implemented, needs the approval of two main groups. The Agent Orange Working Group reviewed the protocol at the end of September and gave unanimous approval. In addition, they recommended that we add a group of non-Vietnam veterans and obtain blood samples from non-Vietnam

1 veterans so we get a good idea of what the distribution of
2 dioxin levels would be in a similar group of men who almost
3 certainly were not exposed to Agent Orange while in the Army,
4 with the concern being that even with our high and low groups,
5 if we find no difference between the two groups, could that have
6 been due to such extreme misclassification that both groups
7 could have been high levels that the levels are similar in
8 the two.
9 So the non-Vietnam group was added to address that
10 question. The other group that needs to review and approve this
11 protocol before we can begin is the Office of Technology
12 Assessment. Their advisory committee is due to meet on the
13 protocol next Tuesday, October 27. Once approval is obtained
14 we are set to begin the validation study almost immediately.
15 If we get approval within the next couple of weeks, we think
16 we could have sample collection completed by April of '87, and
17 an analysis and write-up of the results by June for review
18 and consideration of how to proceed with a fullscale study.
19 Now, I would like to make some points before I close.
20 First of all, I would like to stress that we are measuring
21 dioxin levels as a marker of Agent Orange exposure in this
22 validation study.

1 The validation study is not designed to
2 detect "biologically meaningful differences in dioxin levels."
3 First of all, we don't think we can define
4 "biologically meaningful" at this point because dioxin concentra-
5 tions at which adverse health effects occur in humans are not
6 known presently.
7 Second of all, our exposures would have occurred
8 20 years ago, and the half-life is not known precisely enough
9 to be able to extrapolate dioxin levels now to
10 what they might have been 20 years ago at the time of exposure.
11 I think at least theoretically you have to leave open
12 the possibility that some adverse health effects from Agent
13 Orange could have been due to some of the other components,
14 particularly the active ingredients 2,4 D and/or 2,4,5-T.
15 In this case although all of the Agent Orange mixtures
16 were contaminated to some extent with dioxin, you cannot be
17 certain that it was dioxin that could have caused all of the
18 health effects.
19 So for those reasons, it's difficult for us to say
20 what is a biologically meaningful difference at this point.
21 We are doing a study to detect a difference as a marker
22 of possible Agent Orange exposure.

1 There is another key question in this whole issue
2 and that has to do with the half-life of dioxin. I think the
3 evidence is mounting that it's five years or more. How much
4 more who knows, but it's also not known if it could be three
5 years. Who knows? It's based on scanty evidence thus far, most
6 of it indirect, and there has only been one person who has
7 ever had serial measurements -- and this investigator actually did ingest a
8 dose of radioactive dioxin and did serial measurements over the ensuing
9 months, and the half-life extrapolated out to be five years.
10 But as one of our reviewers on the Agent Orange
11 Working Group Science Panel stated, he is not very comfortable with a
12 sample size of one. But I think that fortunately there is an exciting opportuni
13 ty still present to be able to get a precise estimate of the
14 half-life in collaboration with Ranch Hand. The Air Force knows
15 about our methodology and are interested in measuring dioxin
16 levels on some of their participants, the Ranch Hand study
17 being the Air Force study of Air Force veterans who flew the
18 fixed-wing aircraft or loaded the aircraft, or cleaned them
19 out, the aircraft that sprayed dioxin.
20 They have 20 cc's of frozen serum on a number of
21 their study participants which were collected five years ago.
22 So if they can obtain some specimens now, they will have two

1 points in time separated by five years which should be --

2 DR. KAHN: We're going to be doing the same kind of

3 follow-up.

4 DR. DeSTEFANO: Pardon?

5 DR. KAHN: We are going to be doing the same kind of

6 follow-up.

7 DR. DeSTEFANO: That's good. When would your follow-

8 up? How long has it been since --

9 DR. KAHN: Well, our first men were December '84.

10 But our last men were July '86 .

11 DR. DeSTEFANO: So for the ones from '84, if you did

12 them now, you would have almost two or three years on them.

13 That's crucial information to get right now to be able to try

14 to precisely estimate what the half-life might be.

15 I just would like to conclude that this has been

16 certainly an exciting year with a lot of new developments in

17 the area of dioxin research in general, and for the CDC Agent

18 Orange projects, in particular. There have been several im-

19 portant developments which have opened the possibility of ob-

20 taining scientifically acceptable answers to the Agent Orange

21 exposure controversy.

22 And I will conclude with that and take questions.

1 CHAIRMAN SHEPARD: Thank you very much, Dr. DeStafano.
2 Are there any questions from members of the committee?
3 DR. WALKUP: Are you able to talk about the mortality
4 study at all yet? Do we have to wait --
5 DR. DeSTEFANO: No. Policy is --
6 DR. WALKUP: Could you make sure that we receive
7 copies as soon as that is available for the committee?
8 DR. DeSTEFANO: Yes.
9 DR. WALKUP: I'm sure that can be arranged. The
10 Agent Orange study started off -- when was it? '79?
11 CHAIRMAN SHEPARD: Legislation was passed in December
12 of 1979.
13 DR. WALKUP: Yes. So an act of Congress back then,
14 and we're still working on it. And maybe we'll see a pilot
15 come out in June of '87. Could you tell me how much money has
16 been spent on this project since 1979?
17 DR. DeSTEFANO: I don't really know. I know budgeted
18 for our epidemiological studies was about on the order of 70
19 million, I think. And we have spent maybe a third of that so
20 far, a rough guess.
21 DR. WALKUP: Since CDC took it over?
22 DR. DeSTEFANO: Right.

1 DR. WALKUP: Barclay, do you know how much the VA had
2 spent on it before it went over?
3 CHAIRMAN SHEPARD: No, I don't have that figure off
4 the top of my head. Most of the money went into the contract
5 with UCLA to design the study. $200,000 maybe. I'm not sure.
6 DR. WALKUP: We spent a lot of time and a lot of
7 money to get to where we're at.
8 DR. DeSTEFANO: Well, in my own personal view, I
9 think the delay that occurred last December was perhaps fortui-
10 tous given what has developed in this past year. I think if we
11 had plowed ahead a year ago, based on the information we had
12 then in doing some rather crude exposure assessments, I don't
13 know. Maybe we would have come out with some un-
14 satisfactory result. Now, we have the ability to move forward
15 on some firmer ground.
16 DR. WALKUP: I --
17 CHAIRMAN SHEPARD: Excuse me, if I may insert.
18 In fact, a lot of that
19 money has gone toward the Vietnam Experience study and the mortality
20 study, special cancer study. So it isn't as though all of that
21 money was in one basket.
22 DR. WALKUP: Is there a way to segregate that out and

1 identify how much is going to --

2 DR. DeSTEFANO: I think almost all of it because last

3 December for the Agent Orange study, we were ordered by Congress

4 not to spend anymore funds on the Agent Orange study, and we

5 hadn't begun other than protocol development. That's about

6 all that has been spent so far.

7 DR. WALKUP: I would just like to offer an observation,

8 not personally directed to any one agency. But it seems like

9 given the presentation by Dr. Kahn and the repeated presentations

10 about the status of this study from the Veterans Administration

11 and CDC that science has been taking a bum rap around a lot of

12 the things that have been going on and environmental studies

13 and especially in Agent Orange that the source of the problem

14 appears to be science by committee, or science by government.

15 I know the CDC has done a lot of good things, and

16 there is a lot of neat, socially useful work going on there.

17 But in observing the attempt to consensus formation around

18 the Agent Orange study for the past six or seven years, it

19 appears that the kind of insight, creativity, willingness to

20 take risks, ask ridiculous questions and see where they take

21 you, are something that are not within the purview of the

22 academic structures we have.

1 And that for $277,000 --

2 DR. KAHN: $377,000.

3 DR. WALKUP: $377,000. We have considerably more

4 information than we have from an act of Congress and somewhere

5 between $200,000 and $20 million.

6 CHAIRMAN SHEPARD: Yes, Dr. Kahn.

7 DR. KAHN: I would like very much to review that proto-

8 col, along with my colleagues in New Jersey. I think if anybody

9 is in a position to understand how these measurements can be

10 organized we are. We've done it. And I don't want to be left

11 out of that, and I don't want to find out that the procedure

12 has been engraved in stone by the time I get a copy of the thing

13 to review.

14 And I don't want to get the copy and have 48 hours in

15 which to review it and turn it around. I would like very much

16 to have a good careful going over with it and to ask my -- at

17 least my senior investigators in New Jersey to go over it with

18 me because we do have some expertise here.

19 And I think it would be stupid on the part of the

20 federal government to toss that expertise aside.

21 DR. DeSTEFANO: We can discuss this later in follow up.

22 DR. KAHN: As you wish.

1 CHAIRMAN SHEPARD: Dr. Hodder?

2 DR. HODDER: I hate to go against the unanimous deci-
3 sion of the AOWG, but I still need to be convinced that we are
4 on the right track. The technology is very easy to be seduced
5 by. But there are several big problems I have with what you're
6 talking about doing. First of all, the question is what
7 question are we looking at?

8 I think the main study, the 18,000, is looking at the
9 question "given you went to Vietnam, and survived, and came
10 back, have you now developed higher disease
11 burden." That's obviously an important question. The question
12 of the dioxin study still eludes me.

13 I think the concept is very good to say that you can
14 look at people who were highly exposed to dioxin and look at
15 those who were not and decide whether dioxin is a danger.
16 Okay. We're doing that in the Ranch Hand, and it's been done
17 in industrial studies. I'm not sure that looking at 400 in-
18 dividuals who were in Vietnam is worth doing that for several
19 reasons. Obviously 400 is considerably less powerful than the
20 Ranch Hand study is going to be.

21 But you're carrying -- to me you're carrying a lot of
22 difficulties with this. First of all, the technology

1 although it's very effective, still leaves a lot of questions
2 like what happens to people with middle exposures. If the half
3 life is sufficiently short, then you may only be able to use this
4 to document the extremes. That is only reduplicating at a
5 tremendous cost what you're doing in Ranch Hand and what Peter
6 has already done.
7 I think that's a necessary step to take
8 first because if you can't look at the middle exposed groups,
9 you're adding nothing new at a tremendous cost.
10 I think that model needs to be worked out.
11 The second part of it is even if you do show in this study
12 that people being exposed in Vietnam seem
13 to have a disease burden, have you thought about how you're
14 going to carry that forward to Congress, or to whoever is going
15 to make the decision, in some kind of a mechanism that they can
16 work with it or act on it. That's the other part that
17 I'm very concerned about.
18 If you do go back with a relative risk of double,
19 what are they going to do with that? I think you have
20 to look at how the policy decision is going to be made. There
21 are two reasons I bring that up. One is the assumption almost
22 universally been made that we're going to come up with a big

1 difference on a very uncommon disease, and that would, of course,
2 be very easy for Congress to deal with. Suppose this doubling
3 of relative risk or one-and-a-half relative risk over very
4 common disease like atherosclerosis? There requires a whole different
5 policy you know taking scientific information and converting it
6 into useful data to guide decision requires some kind of a
7 format that the science is going to present to them.
8 Has that been approached?
9 MR. SNYDER: May I interrupt briefly? What you are
10 suggesting needs to be done to present it to Congress is what
11 Congress said a couple of years ago the VA was to put in place
12 as a structure for evaluating what the science comes up with.
13 Regulations were to be in place to have standards in
14 them that were specific so that when the science came down and
15 said whatever, then it would be clear under existing regulations
16 and not some fluid standard that maybe could be changed or
17 fudged with, but there had to be regulations in place that
18 said you get scientific results, whatever they are, and then
19 the VA is to respond to them pursuant to the regulations that
20 are already developed. It wouldn't go back to Congress.
21 It at least shouldn't unless service organizations
22 or others had a problem with how the VA were implementing what

1 the science came up with. But the process should be that the
2 science comes with a result and says there is some significant,
3 or potentially significant development here or condition that
4 shows up, and then that the VA should apply "xyz" regulation
5 and say, well, that means we now will agree that something is
6 service connected and allow disability claims.
7 Now, we as an organization, Vietnam Veterans of
8 America, have had a problem with the existing VA regulations
9 that set up that structure because we don't, I don't think we're
10 confident that the existing standards of those regulations
11 are firm enough so that we would know what happens with these
12 results. And that's been a continuing source of aggravation
13 that what you see is you're asking the CDC person to come up
14 with is what's the structure for Congress to apply is what
15 we have been complaining about for a couple of years. What's
16 the structure the VA is going to comply with?
17 DR. HODDER: I don't think you're getting quite my
18 point. If you are designing a research project, one of the
19 things that is part of the ethics of it -- and I'm sure you're
20 well aware the NIH and FDA have talked about this --
21 you do the minimal amount, particularly if you're exposing
22 people to potential injury. You have to use the smallest "n"

1 in terms of both risk to people and also in terms of utiliza-
2 tion of resources. So it is, in fact, the power that you set
3 up the experiment very much depends on what the strength of
4 the associations and data you need to respond to.
5 I'm saying that I don't think that exists. I don't
6 think that that really does exist in terms of models. I don't
7 know that we won't come up with a lot of studies that won't
8 guide us.
9 DR. DeSTEFANO: I could try to address some of your
10 questions. First of all, basically I think I understand what
11 is the goal of the Agent Orange study. And basically the Agent
12 Orange study is designed to evalute the health effects that may
13 have been related to the Agent Orange exposures that occurred in
14 Vietnam amongst the ground troops, or the more heavily exposed
15 ground troops.
16 And we've had the Ranch Hand study to look at Ranch
17 Hand fliers, but I think there is always some nagging concern
18 about the ground troops were different. I mean they were down
19 there. They were living in the stuff. They were breathing it.
20 And they were eating it. They weren't going home and showering
21 everyday. I think it's basically to get at that question
22 that the ground troops had a different exposure than the Ranch

1 Hand crews.

2 DR. HODDER: But is your instrument sensitive enough --

3 are you only going to pick up the extremes? Again, are you

4 going to still not be able to address the question

5 of the rest of the ground troops?

6 DR. DeSTEFANO: Well, we'll find out. The validation

7 study, the 400, is designed to get at that question. It's not

8 designed to look at health effects. I mean we realize 400,

9 200 in a group is too small to look at the types of health

10 effects that have been postulated to be associated with dioxin.

11 It's there to see what the levels are, and who still

12 has elevated levels. Is it only ones that were at the highest

13 end of exposure. That's the whole question of the validation

14 study is to address that very issue there. As far as interpreta-

15 tion of results, both the Vietnam Experience study and the Agent

16 Orange study, we as a scientific organization do a thorough

17 and careful valid analysis and try to present it as carefully

18 and as lucidly as possible.

19 The policy decisions from that will be made. I'm not

20 sure exactly who will make policy decisions on what we find.

21 DR. HODDER: Let me perhaps funnel the question a

22 little differently. To look at these 200 people -- as I mentione

1 the technology when it's new has to be characterized and per-
2 fected. There are things such as sex, geographic area, urban/
3 rural differences, occupational differences -- how will you in-
4 terpret those 200 versus 200 with that kind of baseline data?
5 DR. DeSTEFANO: Well, 200 for these kinds of measures
6 given what is known about expected levels and what the variance
7 of the measures are is a very powerful study. And I think it
8 will allow us to take into account adjustments if they need to
9 be made for age, race. We're administering an extensive
10 questionnaire on exposures to dioxin, either through occupations
11 or residentially, et cetera, to account for those in the
12 analysis as well.
13 MR. SNYDER: I understood the timetable -- getting
14 back to that -- basically we've had a year to year different
15 time tables, but time table for this pilot study would have you
16 come up with results that you would be able to publish or release
17 to us maybe in June of next year?
18 DR. DeSTEFANO: Yes.
19 MR. SNYDER: There then is a timetable for someone
20 to decide whether those results warrant going forward with a
21 study.
22 DR. DeSTEFANO: Exactly.

1 MR. SNYDER: And then there is a timetable if that
2 decision is made to go forward for having results. Have you or
3 anyone in your shop given any thought as to what those respective
4 timetables would be if, for example, in June you come up with
5 results that are --
6 DR. DeSTEFANO: I think if all the review processes
7 went very smoothly and quickly, we'd be talking about implement-
8 ing a fullscale study, if it is determined, in fact, that that
9 was appropriate and feasible, you would be talking
10 about implementing a fullscale study probably a year from
11 now at the earliest.
12 MR. SNYDER: So this is October. So we're talking
13 June for a pilot to be done, and then fullscale maybe in
14 October, and the completion of the collection of data goes from
15 then to --
16 DR. DeSTEFANO: Well, you know, it's hard to say.
17 I'm sure this pilot study we'll learn a lot from the pilot
18 study and the timetables may not bear that close a resem-
19 blance to what was put forward originally for the Agent Orange
20 study which was an 18 month period.
21 MR. SNYDER: But the original -- the pilot study, as
22 I understand it, the pilot study would tell us whether the

1 records are sufficient, and you're not going to have to draw
2 blood from 18,000 people?
3 DR. DeSTEFANO: That's right.
4 MR. SNYDER: If the records are sufficient, then you
5 are going back to the same analysis that was done pre-serum
6 availability of that, and then the timetable there was 18 months
7 So begin in October of '87, year and a half after that -- what
8 is that-- April of '89?
9 CHAIRMAN SHEPARD: That's just for the data collection
10 phase.
11 DR. DeSTEFANO: Data collection phase.
12 MR. SNYDER: And then what happens?
13 CHAIRMAN SHEPARD: Another year for data analysis,
14 and report preparation.
15 MR. SNYDER: And then a review prior to release?
16 CHAIRMAN SHEPARD: I would think that would include
17 that review.
18 MR. SNYDER: '89, '90 -- so we are talking April of '90
19 rather. 1990.
20 DR. KAHN: The best of all possible worlds.
21 MR. SNYDER: That's, I think, always astonishing
22 the length -- science takes time to have good science, and I

1 think we can all appreciate that. I think our committee, this
2 means even more importantly to us, that you do something in the
3 meantime. You just don't wait for the scientific results to
4 finally be all there. That, I think, gives us a greater
5 responsibility to figure what needs are unmet and try to push,
6 at this stage, perhaps for compensation, for certain conditions.
7 And if, as we noted earlier, it turns out that
8 science doesn't bear out some conditions that we think should
9 be allowed, better that there be thousands, hundreds of thousands
10 even potentially millions of dollars put out in compensation, I
11 think. Better that now in the interim than let people's lives
12 who have performed valuable services just be -- when you've
13 got people, I think, whose lives are being, don't have a very
14 good quality of life now, from many diseases, when you see the
15 statistics that we had earlier on the people who have applied
16 for compensation and been uniformly denied, you've got almost
17 a thousand cancers in that section, that selection of data.
18 You get an increase in four months time of about 200
19 cancers that people are coming in asking for compensation for
20 that are being denied. And I think that that there are a lot
21 of people out there suffering that somehow we as a committee
22 should try to nudge somewhat more forcefully the Administrator

1
2 to act now. If it requires legislation, then encourage the
3 Administrator to go for legislation, but to wait now for another
4 potentially two or three years for maybe some final conclusions,
5 my earlier point to you, Dr. Hodder, was that VA regulations
6 currently in place do not give me any assurance that regardless
7 of what CDC finds that we will know what the VA will do with that
8 science.
9 The regulations are not that specific, and I think
10 that still is a big problem, and that is a source of concern for
11 us.
12 MR. CARRA: Along those lines, would the Veterans
13 Administration have to go through a formal rulemaking suppose
14 the results were positive and there was an indication that
15 the Agency decided that something should be done to address
16 that it was some cause and effect relationship, for example?
17 Would there have to be some formal rulemaking then
18 undertaken by the Veterans Administration? And how long would
19 that take?
20 CHAIRMAN SHEPARD: If you are asking me the question,
21 I'm not a lawyer and I'm not an expert on rulemaking. Is Mr.
22 Conway here? The question is would the VA have to undertake

1 additional rulemaking for the purpose of adjudicating claims
2 in a system different than now exists? I think I'm boiling
3 your question down.
4 MR. CARRA: Right.
5 MR. HICKMAN: We would have to go through a rulemaking
6 process that is through the Federal Register. How long
7 that is going to take --
8 MR. CARRA: What does it usually take?
9 MR. HICKMAN: Normally it takes -- when we have the
10 item prepared, usually we give 30 days, sometimes 60 days,
11 public notice for comment. After that, it would take another
12 60 days for implementation. We're talking probably a minimum of
13 four to six months.
14 DR. KAHN: Keith, I think you make your motion on the
15 interim compensation.
16 MR. SNYDER: As a matter of fact, I wrote something
17 up. Do we want to put that off a second?
18 CHAIRMAN SHEPARD: I want to take questions. Yes,
19 Dr. Hodder? Let's restrict our comments and questions to the
20 CDC efforts because I think that is the issue on the table.
21 DR. HODDER: Actually Mr. Snyder's point actually
22 reminded me the last question with the new technology, the other

1 issue is rather than go ahead as a prospective study, particularly
2 to answer the questions that the VA wants to know, i.e., does
3 the fact that an individual having been exposed to an herbicide
4 have a higher risk of say developing soft tissue sarcoma, that
5 technology to me seems to be much better and much less expensively
6 applied to case control studies.
7 DR. DeSTEFANO: I think you may be right. We may
8 have to consider that. That's why I say at this point --
9 DR. HODDER: I guess I'm saying not only do you have
10 to consider it. The question is isn't that maybe what ought to
11 be done. Is there enough justification to do prospective study
12 at tremendous cost when the models haven't been worked out and
13 that's I guess what I'm getting at in the long run?
14 CHAIRMAN SHEPARD: As you know, Dick, there are four
15 case control studies underway at CDC dealing with specific
16 cancers which have been alleged to have some association with
17 herbicide.
18 DR. WALKUP: One of the things that has been coming
19 up more and more frequently is the base line levels of dioxin
20 and some other compounds that we have been concerned about in the
21 general population and the difficulty that presents in being
22 able to assess health effects on Vietnam veterans.

1 It seems like there are two issues that are very im-
2 portant for social policy in this area, and I wanted to find out
3 what CDC had underway to look at those. One is how do you --
4 with the difficulty that you're having assessing half-life and
5 minimum exposure impact on health effects, and with the -- in
6 addition to the baseline exposure of the population, the exposure
7 of workers in a number of industries, not just producing this kind
8 of stuff but producing a lot of other things, and with the
9 problems of waste sites and accidental spills and all that, we're
10 not just worried about Vietnam vets.
11 What studies does CDC have underway to look at those,
12 and when might we know something about that, and a subset of
13 that, within those kind of studies, are you looking at inter-
14 action of Vietnam service and possible exposure in industrial
15 settings?
16 DR. DeSTEFANO: You're right. Dioxin is a concern in
17 several settings besides for the Vietnam veterans. The two
18 studies that I know that are going on in CDC or soon to begin to
19 address those issues are: (1) a continuation of the Missouri
20 study in Times Beach. These were people who were exposed
21 when waste oil which had been contaminated with dioxin was
22 sprayed on dirt roads in certain areas of Missouri for dust

1 control. There has been an initial evaluation of a few hundred
2 residents of the Quail Run Trailer Park, and those results were
3 published this past summer. Exposure assessment there was
4 basically done on number of years of residence at the trailer
5 park compared with a control group of residents in another
6 similar trailer park where the oil had not been sprayed.
7 And you know with a small study, they had some interest-
8 ing results. Last winter I think there was some
9 sentiment brewing that all these studies had been done on
10 dioxin and none of them were finding anything in humans. The question was
11 raised whether it was worth pursuing doing any studies. And this summer we have
12 the Missouri results which found
13 some pre-clinical or laboratory abnormalities.
14 But they did find a markedly decreased cell mediated
15 immunity in the exposed individuals,
16 as well as a definite dose response relationship with
17 liver function abnormalities, microsomal enzyme abnormalities,
18 in the exposed group.
19 Fat and blood samples were obtained on
20 these peoples and measured for dioxin levels. The
21 health effects will be correlated with the dioxin levels. I
22 don't know when that manuscript will be completed and published.

1 I would imagine soon, probably not to exceed a year.

2 The other study has to do with occupational exposures.

3 NIOSH, the National Institute of Occupational Safety and Health

4 which is a part of CDC,has a protocol approved, and the last I

5 knew was ready to initiate this study, contingent on approval

6 of Superfund money, appropriation of Superfund for the next five

7 years.

8 They propose to study a group of workers who worked

9 at a plant in New Jersey. I don't know specifically what com-

10 pounds they were manufacturing, but there was dioxin.

11 DR. KAHN: I do. There was 2,4,5 trichlorophenol,

12 hexachlorophenol. They made hexachlorophene. They made 2,4,5 T.

13 They made 2,4 D, and they received 2,4,5 T. And they formulated

14 Agent Orange for shipment to Vietnam.

15 DR. DeSTEFANO: Okay. So they have a study about to

16 get underway, a study about the health status of these people.

17 MR. SNYDER: Wasn't that the study that Dr. Young had

18 some input on through OMB? Is that actually ongoing or is that?

19 DR. DeSTEFANO: OMB did have some input on it. I

20 don't know.

21 MR. SYNDER: There was some press that a NIOSH study

22 of dioxin had been put on hold or sidetracked in some

1 characterization through the efforts of Elton Young?

2 DR. DeSTEFANO: I think a similar tact was

3 taken there. It has been scaled back to do an initial

4 pilot study which is going to be, I guess, about a hundred or

5 so people, and pending the results of the pilot a determination

6 will be made about whether or not to proceed. They are also planning to

7 do blood dioxin measurements in that study.

8 Those are the two main studies I know of that CDC

9 is involved with.

10 DR. KAHN: Are you going to do the blood dioxin work

11 for the Newark dioxin people?

12 DR. DeSTEFANO: Excuse me?

13 DR. KAHN: The Newark dioxin workers?

14 DR. DeSTEFANO: Yes.

15 DR. KAHN: You guys are going to do that?

16 DR. DeSTEFANO: Yes.

17 DR. WALKUP: Were Vietnam veterans or veteran status

18 generally identified as one of the -- is that part of the

19 protocol in the study?

20 DR. DeSTEFANO: I have not seen their questionnaire.

21 We will check with the investigators and see that that is

22 added. But as far as the Missouri -- actually, I have seen the

1 Missouri questionnaire, but I don't recall if service status
2 was on there.
3 DR. WALKUP: Would it be possible for members of the
4 committee to have the report that was published this summer on
5 Times Beach?
6 DR. DeSTAFANO: That was in JAMA.
7 CHAIRMAN SHEPARD: You mean the Green study?
8 DR. DeSTEFANO: Yes.
9 CHAIRMAN SHEPARD: It's been published in the JNCI.
10 DR. DeSTEFANO: JAMA.
11 CHAIRMAN SHEPARD: JAMA; right. I thought we circu-
12 lated that. No. Okay. I think we did, but if not, we will.
13 DR. DeSTEFANO: Probably another study you ought to
14 know about is the National Cancer Institute in September publish-
15 ed a study of Kansas farmers.
16 DR. KAHN: We got that.
17 DR. DeSTEFANO: Okay. That was another -- that was
18 JAMA as well.
19 CHAIRMAN SHEPARD: We have that here; right. JNCI
20 study would be a different -- we have circulated the --
21 DR. WALKUP: I'm sorry. That isn't quite it. Are
22 there any mechanisms underway to deal with the same issues that

1 Dr. Hodder was talking about for veterans to impose controls on
2 introduction of this stuff into the environment or to have OSHA
3 standards for worker exposure to this stuff? Everybody has got
4 it. How are we going to stop it?
5 DR. DeSTEFANO: I do not believe there are any
6 standards yet. Do we have anyone here from the EPA?
7 MR. CARRA: EPA. No, I don't think there are any
8 standards yet.
9 DR. WALKUP: That might be something for our
10 committee to discuss also.
11 CHAIRMAN SHEPARD: I think we'll take our lunch break
12 now and reconvene at 1:00 o'clock.
13 (Whereupon, at 11:50 a.m., the meeting recessed, to
14 reconvene at 1:00 p.m., this same day.)
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22

1 A F T E R N O O N S E S S I O N

2 (1:10 p.m.)

3 CHAIRMAN SHEPARD: I think we better get started.

4 I recognize that some of the members of the committe aren't back

5 from lunch yet, but we still have a number of issues to deal

6 with so I think we better push on.

7 Prior to the break, Mr. Snyder asked me to introduce

8 Mr. Christian and asked him if he would be available for some

9 questions. I thought he was going to be able to come back this

10 afternoon, but I just saw him a few minutes ago, and he has a

11 meeting at Forest Glen that he has to attend. But he said if

12 anybody had any questions to please transmit them to him, and he

13 would be more than happy to handle them.

14 So if in the course of the discussions, questions

15 occur to you, things that you would like to ask Dick Christian,

16 I'm sure that he would be more than happy to oblige. Dick is

17 well known to many of you, I know, and his work certainly has

18 been immensely important to all of us.

GAO REPORT - JANUARY 1986

19 The question of the GAO report is next on the agenda,

20 and you have a number of questions that have been raised by

21 members of the committee. What has been the VA's response to

22 the GAO recommendations? What suggestions were implemented?

1 Which ones were rejected and so forth? Each of you should have
2 a copy of the GAO report which contains the agency's response
3 to the recommendations of the GAO. Some were rejected. Some
4 were accepted. And some of the recommendations are being
5 implemented.
6 So why don't we just open up a discussion on the GAO
7 report, and those of you who have concerns about it, please
8 raise them at this time.
9 Take a few minutes to look over some of those
10 questions.
11 MR. SNYDER: Well, a number of my questions with the
12 GAO report had to do in particular with the medical care that
13 was available through Public Law 97-72, and I would like to
14 focus if I could on that.
15 CHAIRMAN SHEPARD: Okay. Could you refer us to --
16 as appropriate, refer us to the page or whatever?
17 MR. SNYDER: Page 50 of the GAO report is Chapter 6
18 entitled "VA Needs To Clarify How Public Law 97-72 Should Be
19 Interpreted and Its Impact Measured."
20 There were a number of issues, I think, raised by
21 that report. One of which is that it was not clear to VA medical
22 centers -- at least there seemed to be some divergence in what

1 they understood the guidance from the Central Office was, and
2 I think there was some question, some differences between people
3 that GAO had interviewed at Central Office as to what Central
4 Office guidance was on one issue in particular, I guess. Under
5 Public Law 97-72, just to refresh our memory, and I think I've
6 got this clear, people who allege exposure to Agent Orange
7 can be provided medical treatment.
8 And if what they're seeking treatment for is something
9 which is possible to relate to Agent Orange
10 exposure then they are to be treated, and there is some guidance
11 on what is obviously not related to Agent Orange exposure: a
12 hernia, a heart attack. There is a list of three or four things.
13 CHAIRMAN SHEPARD: Five.
14 MR. SNYDER: Otherwise people could be treated.
15 That's 97-72 for medical treatment. You had, though, layered
16 into that in chronological and time order before that public
17 law, the VA was offering an Agent Orange examination, and there
18 appears to have been, and still is, some confusion in the
19 medical centers as to what the relation is between that
20 medical examination and getting treatment under 97-72, and
21 whether people had to come in who are looking for treatment
22 and had to be examined and formally examined and entered into

1 Agent Orange registry first before getting treatment. In the
2 past three weeks, I guess I had one veteran from Ohio who had
3 called -- he has a kidney cancer, and he for the first time just
4 a few weeks ago had been asked for his Agent Orange registry
5 number before he would be treated.
6 And he argued with whoever he was talking to and they
7 conceded that he didn't have to come up with some number. I
8 had called your office and talked to Mr. Rosenblum in your
9 absence, and we really couldn't clarify what this Agent Orange
10 registry number might have been that was being requested.
11 But as I understand the Agent Orange registry examina-
12 tion program, there is no real number that is assigned to any-
13 body. The only numbers that Don and I could think of were in
14 the Agent Orange law suit. When people filed a preliminary
15 claim form, there is an Agent Orange claim number that might
16 have had some confusing element in that process.
17 But this individual at the medical center -- it's in
18 Iowa City -- said that he had been asked to fill out on a
19 clipboard. He was given two clipboards when he went in for
20 his exam. One clipboard asked if he was there, what his income
21 was, some other questions, and if his income was "x" level, he
22 would be given the second clipboard. And one of those somehow

1 he was being asked to produce an Agent Orange registry number.
2 That is one of the questions that -- and I think it exemplifies
3 perhaps some of the confusion in medical centers as to the
4 relationship between the screening program and the treatment
5 that is available.
6 And the concern for us as an organization, of course,
7 is that if you can -- when you want treatment -- when you're
8 sick enough to go to a VA facility and seek treatment, you don't
9 want the additional hassle of being told, well, before we're
10 going to treat you you have to down the hall and have "xyz"
11 examination, and it may have nothing to do with what you're
12 really looking for treatment for specifically that day.
13 So anything that can be done to reduce the potential
14 for that kind of confusion when somebody seeks treatment, I think,
15 is very useful. And that was part of what GAO was suggesting
16 wasn't there. There was a differing interpretation of whether
17 the Agent Orange examination had to be conducted prior to
18 obtaining treatment.
19 And I'm not sure that that is addressed finally in
20 the VA comments on the report.
21 CHAIRMAN SHEPARD: Okay. Can you refer us to the
22 specific statement in the GAO report that show that there is a

1 confusion between --

2 MR. SNYDER: Well, page 51, we're talking about claim-

3 ing exposure, and whether they had to claim exposure to be

4 treated. I may be confused as to which --

5 CHAIRMAN SHEPARD: Yes. Public Law 97-72, just

6 to refresh your memory was -- first of all, it has nothing to

7 do with the Agent Orange registry per se. Agent Orange

8 registry was set up long before Public Law 97-72 was passed.

9 There is no requirement that I'm aware of --

10 certainly from this office or from this headquarters that a

11 veteran must have an Agent Orange registry examination prior to

12 becoming eligible for treatment under Public Law 97-72.

13 The purpose of the Public Law 97-72 was to provide

14 medical care to veterans who thought they had a health problem

15 related to Agent Orange. I guess tacit in that is the fact

16 that for that to apply a veteran has to claim --

17 MR. SNYDER: Claim the exposure.

18 CHAIRMAN SHEPARD: Right. But I don't think there was

19 ever any requirement that he establish exposure in order to be

20 eligible for that. I think the only requirement was for him to

21 state that he believed he had a problem related to exposure.

22 MR. SNYDER: But did have to say exposure, or did

1 have to at least indicate affirmatively that "I was exposed."
2 On page 52, they were talking about the difference in establish-
3 ing priorities for treatment.
4 CHAIRMAN SHEPARD: Page what? I'm sorry.
5 MR. SNYDER: Page 52.
6 CHAIRMAN SHEPARD: Yes.
7 MR. SNYDER: In the bulleted section, they were
8 talking about given priority care whether they have an Agent
9 Orange examination or not. Three centers they give priority
10 for the examination regardless of when exposure is identified.
11 CHAIRMAN SHEPARD: Okay. Is that a problem?
12 MR. SNYDER: Well, the last paragraph of page 52
13 talks about the priority, what the 97-72 gives us is a priority that
14 getting care. And although GAO concluded generally that there
15 was no problem in those priorities because there was not
16 an excess demand, it anticipated that there would be a problem
17 in the future, and I think on page 52 we see that there was a
18 problem with two of the nine places they visited.
19 They said that they could not schedule people in
20 clinics unless they had a service-connected disability. And
21 people who would come under 97-72 would not be coming saying
22 they have a service-connected condition.

1 So people going to those facilities would not get the
2 treatment, if I read that correctly.
3 CHAIRMAN SHEPARD: Yes. Okay. Let me try this on,
4 and see if it answers your question. If you'll look carefully
5 at the language of Public Law 97-72, it provides priority
6 eligibility within the non-service connected community. That is,
7 it does not place a Vietnam veteran who does not have a service-
8 connected disability ahead of anybody who has a service-connected
9 disability.
10 So in hospitals where priorities are given for treat-
11 ment to people with varying degrees of service-connected dis-
12 abilities even Public Law 97-72 does not place an individual
13 ahead of that process.
14 So a non-service connected veteran under Public Law
15 97-72 is not placed into higher priority than a service-connected
16 veteran.
17 MR. WILSON: I want to say something here. And this
18 guy -- I think there is a comp and pension guy behind me. If
19 I'm not mistaken, the majority of care provided at VA
20 facilities is of a non-service connected basis; is that right
21 or not? Well, if he doesn't know, I'm telling you that most
22 of the care in VA facilities is non-service connected, and a

1 very large percentage of it. The law says that these Vietnam
2 veterans will have priority care equal to that given former
3 prisoners of war which have the highest category of non-service
4 connected treatment.
5 So let's just say for the sake of argument -- you can
6 check it upstairs if you want, 80 percent of all the services
7 conducted at a VA facility are non-service connected, and 20
8 percent are service connected.
9 That means that these Vietnam veterans along with
10 former prisoners of war should be at the 79th percentile and not
11 below it. And so you can argue all you want, the thing is they
12 should have a substantial -- you can say non-service connected,
13 or you can call it anything you want -- they should still have
14 a substantial priority in a VA health care system.
15 CHAIRMAN SHEPARD: Okay. I'm not -- I don't doubt --
16 MR. WILSON: Check it out.
17 CHAIRMAN SHEPARD: Wait a minute. I don't disagree
18 with that you said. It also doesn't contradict what I just
19 got through saying. Okay.
20 MR. SNYDER: Let me try -- just to make sure I under-
21 stand what would happen for people under 97-72. If, for example,
22 you had a woman veteran, Vietnam veteran, who alleged exposure

1 and was concerned about breast cancer, had an outpatient clinic
2 near her. What's going to happen if she goes and alleges ex-
3 posure and needs a biopsy? First, will she get it, and if she
4 gets that, and it's malignant, then what happens within the VA
5 system for someone under 97-72, for her under 97-72?
6 I'm not sure what happens in that situation. That's a
7 case I've been asked -- I've been contacted about.
8 DR. FITZGERALD: I think that's a further distinction.
9 Are you asking for hospital treament or outpatient treatment?
10 MR. SNYDER: The biopsy would be outpatient presumably?
11 DR. FITZGERALD: No, that could be inhouse that she
12 would be eligible for.
13 CHAIRMAN SHEPARD: It depends on the nature of the
14 biopsy, too.
15 DR. FITZGERALD: The potential for other than service
16 connected patients in today's economic strata of getting outpat-
17 ient treatment is very small.
18 MR. WILSON: 97-72 doesn't distinguish between
19 inpatient and outpatient. It just says priority care and
20 treatment. It does not distinguish between outpatient/inpatient.
21 MR. CONWAY: It does. Public Law 97-72 extends health
22 care eligibility for inpatient care only or outpatient care

1 to obviate the need for hospital care or to follow-up on hospital
2 care.
3 MR. WILSON: That's what I just said.
4 DR. FITZGERALD: No, that isn't what you said.
5 CHAIRMAN SHEPARD: No, you didn't.
6 MR. CONWAY: It's an entirely different thing from
7 whether a person gets outpatient care only.
8 MR. SNYDER: Well, in my hypothetical, it depends on
9 the nature of the biopsy that she might have to have whether
10 that's an outpatient or hospital service?
11 GENERAL WELLS: All right. Well, let's say she had
12 to have a mammogram. Would she be able to have a mammogram?
13 CHAIRMAN SHEPARD: I can't answer that.
14 DR. FITZGERALD: I would think she probably would in
15 order to obviate the need for hospitalization.
16 CHAIRMAN SHEPARD: Right.
17 DR. FITZGERALD: That would be a presumption. But
18 what I'm not clear about is the VA staff has the capability of
19 determining whether it is reasonable for a diagnosis to be
20 associated. That would be the point that I think might come
21 in contention more frequently than anything else.
22 MR. SNYDER: So that the five conditions that clearly

1 are not related, there is in addition the guidance or the
2 discretion to decide that something else is clearly not related?
3 CHAIRMAN SHEPARD: No.
4 DR. FITZGERALD: Right. And I think that is put into
5 the hands of the chief medical director, as I recall.
6 CHAIRMAN SHEPARD: Well, I think it's the other way
7 around. I think if at any -- even given the five exclusionary
8 conditions, or cases, if in the judgment of the chief of staff
9 or chief of medicine or whatever -- I forget the exact wording
10 -- but that there are extenuating circumstances, then he's not
11 bound by those.
12 In other words, that is general guidance, the
13 provision of that guidance is stipulated in the law that the
14 chief medical director shall provide this guidance, and that is
15 why those five areas are there.
16 But there is also a clause that states in that same
17 guidance that if there are extentuating circumstances, then
18 the chief of the staff of the hospital has the authority to
19 provide the care anyway.
20 MR. SNYDER: So a mammogram may or may not -- first,
21 we don't know whether they are generally available at VA
22 facilities in the first place, but if available, there is the

1 discretion to say yes or no under 97-72?

2 CHAIRMAN SHEPARD: Yes. My hunch is that in a majority

3 of instances, if there is a real threat of something as serious

4 as cancer, and breast cancer certainly is one of the more serious

5 forms of cancer, that in the majority of instances that would be

6 pursued.

7 I mean I think it's unlikely that there would be many

8 cases in which somebody would get turned away if they have

9 evidence that they might have --

10 MR. SNYDER: But would the advice to us as service

11 organizations be to get that person as near as possible not into

12 a clinic setting, but to go to a hospital and ask for

13 hospital care, couch it in terms of that?

14 DR. FITZGERALD: I think it would be even more com-

15 pounded in view of recent legislation, as to the financial

16 responsibility of the individual. That would make it even more

17 difficult.

18 MR. SNYDER: Although people if they allege Agent

19 Orange and seek treatment under 97-72 are regardless of ability

20 to pay --

21 DR. FITZGERALD: They're not required to show the

22 income. But then if the determination is made that the particular

1 diagnosis for which they are seeking treatment is not related
2 to Agent Orange by the chief of staff, then they would come
3 under the financial responsibility.
4 MR. LATTANZI: We had an incident in New York that
5 was pertinent to what Keith was saying that a female era veteran
6 had presented to VA with an ob-gyn emergency and was told that
7 she could not be treated, and subsequently went to a public
8 hospital in New York, was treated, and then tried to obtain
9 reimbursement from VA, and ultimately was denied reimbursement.
10 CHAIRMAN SHEPARD: I don't doubt what you're saying.
11 I don't know how that applies. If you're talking about a non-
12 Vietnam veteran -- are you suggesting --
13 MR. LATTANZI: No, no. Vietnam era.
14 CHAIRMAN SHEPARD: But did she go in-country veteran?
15 MR. LATTANZI: No.
16 CHAIRMAN SHEPARD: Not alleging Agent Orange?
17 MR. LATTANZI: No.
18 CHAIRMAN SHEPARD: Then I don't think that is germane
19 to the conversation as far as Public Law 97-72 is concerned. It
20 is another issue of concern. I'm not suggesting that it's not an
21 issue of concern. But I don't think it pertains to our discus-
22 sion.

1 And the other thing I would just like to say, and
2 here again this is my own thought on the subject is that it's
3 very difficult to generalize what might happen in one hospital,
4 and may not necessarily happen in another hospital because
5 there is a variety of factors at work. In other words, an
6 outpatient clinic may not have -- may not be staffed to take
7 care of a particular problem for some reason or other.
8 And it may be that another hospital or clinic would
9 be. So it may be that an individual cannot be seen at a particu-
10 lar clinic for one of a number of reasons. And maybe referred
11 to a VA hospital which might alter the circumstances in terms
12 of the kind of care he or she gets.
13 But in general, these guidelines are fairly broad,
14 and fairly inclusive, I think. That was their intent. I think
15 that was the intent of the legislation, and when you're, as
16 I've said before, dealing with a system as large as ours, it's
17 difficult (a) to monitor every case; and (b) to assure that
18 the process if applied uniformly throughout in a very ununiform
19 system.
20 But let me also say that if you hear of cases where
21 you feel that any of your constituents or people that you are
22 concerned about are not getting care under Public Law 97-72

1 that you think they're entitled to, please let us know and we'll
2 be happy to look into it.
3 MR. SNYDER: Do you have in terms of statistics of
4 incidence of treatment being provided, is there a breakdown by
5 facility -- and I know you provided us with national statistics
6 year by year or so -- is there a breakdown that indicates that
7 some facilities provide much greater percent of their inpatient
8 hospitalizations perhaps are attributable to 97-72? Is there a
9 a wide variation in that percent that might suggest in itself
10 some differences in understanding of what the law is to apply
11 to?
12 CHAIRMAN SHEPARD: Not really. For a variety of
13 reasons, it's very difficult sometimes to know exactly what
14 constitutes a 97-72 eligible individual and characterize them
15 as such. I mean an individual comes in and says, "By, God" --
16 doesn't usually come in and say "By God, I'm here because of
17 97-72, and I demand treatment based on 97-72," and that
18 suddenly sets into motion a whole system that is different,
19 and that can therefore be counted.
20 So it's not that easy. And oftentimes people come
21 in with maybe more than one complaint, and one complaint may
22 be related to Agent Orange. Another one is not related to

1 Agent Orange. Are they then counted as a 97-72 case? These are
2 just a couple of things that come to mind. And on top of that,
3 I'm not sure what utility they would -- is it worth expending
4 a lot of effort, setting up a whole new record system to monitor
5 97-72 eligible individuals?
6 And we've thought about that, and we've done, I think,
7 as much as can be reasonably expected in terms of monitoring
8 the overall impact of the law. But to do it on a hospital by
9 hospital basis, I believe I'm correct, and this is a little
10 out of my area of responsibility, but I think that the VA puts
11 out a report that deals on a hospital by hospital basis as to
12 the workload of service-connected and non-service connected
13 veterans.
14 I think that is available, if that would
15 be useful to you.
16 MR. SNYDER: On the question of what people are being
17 treated for when they go -- this is separate from the Agent
18 Orange registry and trying to record what people are presenting
19 with, what kinds of complaints they are raising for the
20 general examination, but when people get treated, do I under-
21 stand that there is some confusion as to how and what your
22 record-keeping requires in terms of what people end up being

1 diagnosed as having and being treated for? The code sheets
2 that record someone coming in and claiming Agent Orange ex-
3 posure, and you get a credit for 97-72, does any of that record-
4 ing process include the diagnosis that is confirmed by the
5 doctor as someone getting treatment for, or are you simply
6 counting episodes of treatment?
7 CHAIRMAN SHEPARD: Okay. As far as I know, there is
8 no code sheet for people coming in claiming eligibility under
9 97-72. There is a code sheet for --
10 MR. SNYDER: For the examination?
11 CHAIRMAN SHEPARD: Well, there is a code sheet. And
12 what I mean is I mean computerized code sheet, or a code sheet
13 to be used for computerization for the Agent Orange registry.
14 But I'm not aware of any code sheet that is used specifically
15 for 97-72 eligibility.
16 MR. SNYDER: Would it be for statistics purposes or
17 for a better view of what is happening in terms of people's
18 medical complaints and problems, would it be more useful to have
19 the diagnosis of people who are coming for treatment saying
20 they were exposed to Agent Orange? Would that be more useful
21 than what you're collecting in the Agent Orange registry?
22 Is it or is it not more important to know what people

1 are actually coming for treatment for? Because I know that
2 in the registry, the quality of the data in the registry,
3 I think it's pointed out here, is you're missing a lot of
4 information.
5 And your latest circular suggests you have to have a
6 bunch of disclaimers whenever you're talking -- whenever VA
7 central office people are talking about the Agent Orange
8 registry and its results and what it's finding, make sure you
9 have all these disclaimers in your speech because you're missing
10 a lot of data. And it would cost a lot of money to pick up all
11 that data and maybe have a limited value.
12 But maybe a more important source of data that would
13 tell us what kinds of health problems people are having would
14 be when they go for treatment for something, what are they gettin
15 treatment for as opposed to you want a general physical examina-
16 tion, and you do or do not find specific problems.
17 Has there been any thought given to -- I mean part of
18 your question here is maybe dropping the Agent Orange registry
19 examination program and all the record keeping that goes with
20 that. And I think what I'm close to suggesting is maybe drop
21 that. Maybe don't have these elaborate code sheets for
22 people having general physical examinations. Continue to offer

1 an examination program, a physical examination, a general
2 examination. If something shows up, continue the guidance you
3 have that says tell people treatment is available. But more
4 importantly to record the statistics relating to the type of
5 treatment that people are having.
6 I'm not sure -- what are the other thoughts of what
7 would be more useful in terms of statistics and reports?
8 CHAIRMAN SHEPARD: Of course, we have the patient
9 treatment file which does track people who receive inpatient
10 care. Now, it's not broken out in terms of whether they're
11 getting care under the provisions of 97-72 for the reasons that
12 I stated earlier. Sometimes the reason an individual is there
13 is not all that clear. I mean it's hard to separate out that
14 that is a principal reason. People go to hospitals because
15 they're sick. They don't go to hospitals because Public Law
16 97-72 tells them to go to hospitals.
17 So it would be difficult, and I'm not sure how useful,
18 except perhaps in a health survey kind of way, to determine
19 what kinds of problems veterans are receiving treatment under
20 this provision. It would be a curiosity, I think. I mean I
21 would think it would be a legitimate question.
22 It would be difficult to derive the answer to that

1 question, I think, without expending a lot of additional
2 administrative time and effort.
3 MR. SNYDER: You don't now breakdown -- you have an
4 age, but you don't have an era, period of service recorded.
5 CHAIRMAN SHEPARD: Yes, we do. Yes.
6 MR. SNYDER: Is that?
7 CHAIRMAN SHEPARD: It's coded.
8 MR. SNYDER: You don't distinguish between in-country
9 and not.
10 CHAIRMAN SHEPARD: We tried that at one time, and that
11 became an administrative headache, and we finally abandoned that
12 effort. We tried to have a distinction between whether or not
13 people served in-country and whether they did not. And
14 theoretically that is still supposed to be in place. Veterans
15 are supposed to have a "V" after their "7" if they actually
16 served in-country, but that also became someone onerous to get
17 that information and get it cranked in so we have not been
18 pushing that.
19 Theoretically, it's there, but how accurate it is,
20 I would not attest to.
21 MR. SNYDER: Well, you asked here the question of
22 whether the registry should be continued or not. And I know that

1 at least one state has dropped its -- no longer advices members,
2 veterans in its state to obtain that examination. And there
3 was, I think, a survey that the New Jersey Agent Orange Commis-
4 sion had conducted of why they made that recommendation, and I
5 think it might be useful if we maybe heard briefly summarizing
6 what that summary showed. And I would ask Wayne to do that.
7 CHAIRMAN SHEPARD: Sure. Do you have that information,
8 Wayne?
9 MR. WILSON: Yes, I do. Actually, it's the second
10 survey that we've done. The first one I did for Congressman
11 Chris Smith several years ago. Interestingly enough, the
12 results unfortunately correlate very close with the results
13 of our first survey.
14 The survey is small. It's an ongoing survey. At this
15 point, we had a total of 43 respondents. But what was interest-
16 ing about the survey, I think we asked them 22 questions. This
17 is not scientific, and I'm not Dr. Peter Kahn. Okay.
18 I'm interested in what consumers -- in this case,
19 Vietnam veterans, both men and women -- have to say. And
20 clearly it reinforces what I've said and the position our
21 commission has taken, and as Keith mentioned, our state
22 commission, an official agency of the State of New Jersey, no

1 longer recommends that Vietnam veterans avail themselves of the
2 Veterans Administration Agent Orange screen exam. We found that
3 the examination in many cases was of poor quality. Veterans
4 often left the facility angry, and as the survey indicates --
5 and I won't go through all 23 questions, but just to give you
6 some idea of where the responses came in from, they came in from
7 San Juan, Puerto Rico; Castle Point, New York; Lakeside; Chicago,
8 Illinois; North Chicago; East Orange; Baltimore; St. Louis;
9 Philadelphia; Manhattan; Lyons; Elsmere, Delaware; East North
10 Port; Fort Hamilton, New York; Iowa City; Hines Coatesville,
11 Asheville North Carolina; Brecksville, Ohio; Milwaukee, Wiscon-
12 sin; Marion, Illinois; Omaha, Nebraska; Togus, Maine; Columbia
13 Missouri.
14 On the first question we asked: "Do you as a Vietnam
15 veteran believe you were exposed to Agent Orange," there were
16 43 responses to the question, and I'll just give you percentages
17 of the question. Generally, we had anywhere from 38 to 43
18 responses on the 23 questions. 88 percent said yes. Zero
19 percent said no, and 12 percent said not sure.
20 Some of the interesting statistics in terms of what
21 Vietnam veterans thought about -- question number eight: "What
22 was the attitude of the person who examined you at the VA

1 facility?" Let me just see what question number eight said.
2 There were 40 responses to the question. 13 percent answered
3 helpful; 87 percent of these 43 Vietnam veterans from across
4 the country -- 87 answered that the VA person didn't seem to
5 care.
6 Number ten: "Would you describe the exam as thorough?"
7 43 responses, 19 percent answered yes; 81 percent answered no.
8 Let's see. "Were you asked to provide a medical
9 history?" Question number 14. Let's see what Vietnam veterans
10 said about that. 39 responses to this question. 31 percent
11 said yes. 69 percent said that they were not asked to provide
12 a medical history.
13 And some of the real interesting questions. Let's go
14 to -- did you receive -- 16. "Were the illnesses or disabilities
15 you described in question number five evaluated?" These are
16 the illnesses, disease, diseases, whatever that veterans reported
17 to the VA.
18 Question number 16. The responses are yes, no, and
19 some. Let's see what they said. There were 38 responses to
20 this question. 13 percent said those illnesses or diseases were
21 evaluated. 53 percent said they were not evaluated, and 34
22 percent said they were partially evaluated.

1 "Did you receive exam results?" Ten percent, ten
2 percent said they received exam results. 65 percent said they
3 did not receive exam results. 25 percent said they received a
4 form letter response that they did not understand.
5 Question 18: "Did anyone discuss exam results with
6 you?" 13 percent, yes; 87 percent, no. That correlates more or
7 less with the question prior.
8 Here we go as a finish-up. "Has the VA followed up on
9 the illnesses or disabilities noted in question-- I gave you that
10 one.
11 Question 20: "Were you satisfied with the exam?"
12 You know companies spend a lot of money to find out whether
13 people are interested in buying their product. Let's see what
14 people think of this product. "Were you satisfied with the
15 examination?" Simple yes or no. Eight percent said they were
16 satisfied. 92 percent said they were not satisfied.
17 Question No. 21: "Are you satisfied with follow up
18 care or treatment as provided by the Veterans Administration?"
19 Again, we asked Vietnam veterans a simple yes or no. Would any-
20 body want to guess what they said? There were 39 responses to
21 this question. Eight percent said they were satisfied. 92
22 percent said they were not satisfied.

1 As I said, this correlates very closely with the
2 survey we did three years ago. I sent Mr. Snyder a letter when
3 I sent these results to him. And in effect, I said that I would
4 bet a year's pay, or as I always do here, my life, that if we
5 surveyed a hundred or a thousand that the results would generally
6 hold, and I believe that the Veterans Administration works for
7 Vietnam veterans. And I think that we can talk about it all we
8 want here, and if you recall, I've been talking about this for
9 six or seven years; right, Chuck? Generally -- maybe not in
10 West Virginia, but clearly in some parts of the country, maybe
11 most of the parts of the country, we've got a major problem in
12 terms of this, Agent Orange registry, the Agent Orange exam pro-
13 cess. It's a mess.
14 And this is what veterans are saying. And some of the
15 comments. I didn't even share the comments. Did you read some
16 of those comments? Let me tell you -- you know -- don't go to
17 some of these parts of the country, Barclay. There are some
18 angry people out there. Okay. And most of the comments were
19 not complimentary to the Veterans Administration system.
20 And the comments, I think, more than anything else got
21 to me. So there is what we found. And if you want, I'll repeat
22 this next month with 43 different respondents. They're already

1 starting to come in, and I guarantee you if I just add to these
2 figures it will be even worse.
3 GENERAL WELLS: How many did you send out?
4 MR. WILSON: About 500. We usually get a very good
5 response back. They were distributed primarily through the
6 American Legion and the Veterans of Foreign Wars who we work
7 closely, and I would say that most of these responses came from
8 veterans in those organizations.
9 In fact, we patterned this very much after the
10 American Legion questionnaire, and we had sampled a couple hun-
11 dred veterans using the American Legion questionnaire a number
12 of years ago, and found generally the same thing.
13 So I think when I did the one for Congressman Smith,
14 I think we sampled one hundred veterans for him, and I think we
15 got 56 responses back, which was just outstanding. And it show-
16 ed there was a problem in 1980 and '82' and I think that's a
17 matter of record. I saw it printed in a subcommittee hearing
18 transcript.
19 CHAIRMAN SHEPARD: Thank you, Wayne.
20 MR. SNYDER: What use do you make of the registry
21 in terms of whatever statistics you can generate out of that?
22 Do you feel personally that there is some value in maintaining

1 the reporting requirements separate from continuing to offer an
2 examination? But of what use can you make of whatever statistics
3 you can generate out of that examination? You can't make
4 scientifically valid statements about, extrapolate from who
5 comes in for an exam what they've got to anybody else in the
6 population.
7 So that would seem to be a significant limit on the
8 value of reporting and keeping those statistics in as detailed
9 as you currently do. And I would think there would be some
10 interest in the field for perhaps not having to generate one
11 report if it's not able to be used as was originally intended
12 perhaps.
13 CHAIRMAN SHEPARD: That's a good question, and one that
14 has always been difficult to answer. When we set up the process,
15 first of all we felt it important to develop some kind of data
16 gathering system. In the early stages, we felt that was not
17 being adequately implemented. So we went through a major revis-
18 ion.
19 We recognize that we haven't got all the bugs out of
20 it, but we think it's better than it was when it was first
21 started. It's always been my hope that at some time we could
22 analyze, at least in the more recent years, and we still have

1 that hope, the data that, say, has developed in the last three
2 or four years, maybe two years even in the registry.
3 That is a fairly substantial undertaking, and at the
4 moment we are involved in a lot of other research efforts which
5 take up most of our staff time. So we don't really have the
6 resources now to do a detailed analysis of that data. Now that
7 isn't to say that we won't be able to do it at some point in
8 time. I think it's still an interesting question.
9 We didn't know how many people would respond to the
10 Agent Orange registry for process when we first started the
11 process. We've learned a lot, and I think we still have the
12 potential for doing some analysis of that.
13 I think one of the basic purposes of the registry,
14 however, still pertains that as this research develops that we
15 will have a mechanism for getting back to individuals if we
16 want to do any follow-up examination.
17 GENERAL WELLS: Yes, that was a question I had.
18 It was also to be a form to contact the veteran. And one of
19 the problems that seems to come up around the table is trying
20 to get back to the veteran with information. And if you phase
21 out the registry, do you have something then that gives you
22 name and addresses to send information to people?

1 MR. SNYDER: But the names and addresses you have now,
2 what percent are likely to be current?
3 CHAIRMAN SHEPARD: I can't answer that.
4 MR. SNYDER: Was that looked at in this or not?
5 GENERAL WELLS: There were duplicates.
6 MR. SNYDER: Because I thought -- not only duplicates,
7 but you have not really been able to afford to go back to
8 people and mail houses would go back and forth and confirm
9 addresses and make sure that people are still there.
10 CHAIRMAN SHEPARD: The instructions, I believe, state
11 that the hospitals should make an effort, or should impress on
12 veterans the importance of staying in touch with the hospitals.
13 If there is a change of address, please make that fact known.
14 MR. WILSON: Well, I'm here as living proof. I never
15 get your Agent Orange review. Togus, Maine has never caught up
16 with me from 1980, and if the VA don't know me by now, Barclay.
17 I notify you folks. You call me in for reevaluations all the
18 time to make sure my PTSD has been squared away, and yet you
19 can't keep track of me on the Agent Orange.
20 How many other people are like that? And you turn my
21 name over to the courts without my permission. Just thought I
22 would throw that in, Keith. Wayne Wilson. Put that on the

1 record.

2 MR. SNYDER: I think maybe that suggests that we look

3 again at what the value of the registry is in light of a lot of

4 the missing data, in light of the fact that -- I mean you're not

5 able now to be sure that what's going into it is being entered

6 properly and so that down the road you would be able to do the

7 data analysis you would like.

8 CHAIRMAN SHEPARD: Wait a minute. I have to -- I'm

9 sorry. I think you are making a very broad generalization

10 based on limited data. I don't think you can say validly that

11 what is going into the registry is not accurate.

12 There may be instances, and any review, any meticulous

13 review is going to turn up flaws in a system. But to say

14 that that applies across the board and that a majority of the

15 data in the registry is faulty, which is what I think you're try-

16 ing to imply, I don't think that's a legitimate statement.

17 Now, we can talk about it afterwards, but I --

18 MR. SNYDER: But that is what GAO has said here at

19 page 41, that the 86,000 veterans before the improvements were

20 made, you've got problems that remain. 86,000 out of the 200 --

21 what's your total now -- 220 -- is a significant percent of who

22 you have in the registry.

1 CHAIRMAN SHEPARD: Okay. That's why I made the state-
2 ment earlier that the system, I believe, has been improved. And
3 that if we were to make a statistical analysis we would want to
4 probably focus on the individuals who have come into the regis-
5 try more recently than earlier. I accept that. I think I stated
6 that earlier.
7 Are there any other questions on the GAO report,
8 comments? I would urge the committee to address the question
9 as to whether or not you believe the registry should continue or
10 should not continue in its present form, or changing the issue,
11 I think that's a legitimate question, and one on which some
12 advice perhaps should be provided to the VA.
13 I have my personal views on the subject, but that's
14 beside the point at the moment.
15 DR. KAHN: I have a problem with the way in which the
16 registry has been used in the past. Maybe I should turn this
17 thing on, and I don't know the extent to which that is going to
18 continue in the future. But I remember an American Chemical
19 Society meeting here in Washington some years ago in which some
20 data from the registry was presented. This was mostly on the
21 86,000, I believe, at that time. And the attempt was made to
22 persuade the chemists there assembled to believe that the

1 distribution of problems faced by those Vietnam veterans who had
2 reported themselves in the registry was about what you would
3 expect in men of that age. Okay. That may or may not be true.
4 MR. WILSON: Shouldn't have said it anyway.
5 DR. KAHN: It came across as an attempt to say that
6 the Vietnam veteran really doesn't have much of a health problem.
7 That's how it came across, and whatever the intention may be,
8 and then you went out and had a press conference, which I didn't
9 realize until I saw it in the newspapers a few days later,
10 because I stayed in the meeting room. None of the criticisms
11 of the GAO which were available, the first GAO report, were
12 out by that time, were voiced at the meeting except by me who
13 stood up and said them from the floor. And I got a shocked
14 reaction from the assembled chemists who, of course, have no
15 idea what's going on in all of this.
16 And, you know, that wasn't good work. That was shoddy
17 work. There are legitimate reasons for maintaining a registry.
18 But doing epidemiology with it is not one of them, and as the
19 VA frequently said, and yet in front of the assembled chemists
20 of the ACS, it came across as an epidemiological study of a
21 sort.
22 CHAIRMAN SHEPARD: Well, I don't have a transcript of

1 that meeting, but I think that any time I've said anything about
2 the registry, I've been very careful.
3 DR. KAHN: You didn't say anything about it. It was
4 Al Young who did it.
5 MR. WILSON: Al Young. He reported it. That's the
6 way the press reported it. Wilson, put that in. Because I
7 was upstairs with the Administrator with some other veterans
8 complaining about the use of the registry, and Dr. Young's
9 comments, and I quite frankly, we asked for his removal from
10 this agency. I'm telling you right here and now -- you can put
11 this on the record -- you guys use that Agent Orange registry
12 for what you want to use it for, i.e., that business that Dr.
13 Kahn is referring to, and then you use it for what you want to
14 and then you defend it when you want to.
15 So why can't we see how many illnesses are in there,
16 how many cancers, how many veterans? Why can't you tell us that?
17 How many guys are reporting headaches? Are 180,000 reporting
18 headaches? Or gastrointestinal? It doesn't have to be an
19 epidemiological study. Why can't you give us a printout of
20 what the data shows in there? Why are 180,000 veterans reporting
21 headaches or stomach disorders or skin disorders?
22 You tell us selectively what you want us to have.

1 That's not right. What good is that registry? Why can't we
2 know what's in there.
3 CHAIRMAN SHEPARD: Excuse me. I have to return to the
4 committee and ask them if they have any specific recommendations
5 or advice for the VA in terms of ways in which the registry can
6 be used, and I certainly think that that is important informa-
7 tion to have on the record.
8 DR. KAHN: Epidemiology is one way I wouldn't use it.
9 CHAIRMAN SHEPARD: I agree.
10 DR. HODDER: As I recall, that question really was
11 discussed two or three years ago. It was started with a multi-
12 tude of ideas, and at the time I think the group who were
13 recommending it I don't think had an epidemiologist on
14 it. Did you at the time?
15 CHAIRMAN SHEPARD: No.
16 DR. HODDER: But I remember, at least when I joined
17 the committee, it was clearly stated it would not be used at
18 least as an epidemiologic case/control study. It would, like
19 any other registry, register people who had specific concerns and
20 complaints. It might be a resource given the right question
21 could be asked to go back to and identify case/controls. But I don't
22 think anybody has come up with that question yet to go back

1 to look at. So it really would be a waste of time.

2 The other part of it, though, was the question of

3 getting physicans for the veterans and having them

4 contact the VA. And how that has worked out at different

5 facilities is a different question.

6 GENERAL WELLS: I'm not sure that we have answered

7 if the VA has gone far enough in implementing the recommenda-

8 tions, and I can only say to the people in the service organiza-

9 tions that I read it. And it appeared satisfactory to me.

10 But I don't know what the feelings of the people are that have

11 a much greater knowledge of the Agent Orange registry.

12 DR. KAHN: It's a long time since I've looked at it.

13 I mean at the GAO report. I've been to Japan and back since,

14 and some things like that get foggy in my head. But I wonder

15 whether the problems of simply maintaining the addresses of the

16 men in the files has been corrected, the ones that the GAO

17 pointed out the first time around. Are we maintaining a clean

18 address file so that if something does come up and you want to

19 contact all 200 and some odd thousand men, you can do it?

20 CHAIRMAN SHEPARD: I'm saying that that is certainly

21 the attempt. I don't think how effective that is has been

22 tested. In other words, I don't think we have mailed out --

1 DR. KAHN: I understand.

2 CHAIRMAN SHEPARD: -- mail back cards, but that is

3 something that certainly should be considered to find out how

4 good is our address file currently. I don't think that that has

5 been done. At least it has not been done by the VA. I don't

6 know if the service organizations or state organizations have

7 done that.

8 MR. SNYDER: With your list?

9 CHAIRMAN SHEPARD: Excuse me?

10 MR. SNYDER: With your list?

11 CHAIRMAN SHEPARD: Yes.

12 MR. SNYDER: It's available to us?

13 CHAIRMAN SHEPARD: No. Well, I don't know if it's

14 ever been asked for.

15 MR. WILSON: You gave it to the court.

16 CHAIRMAN SHEPARD: We gave it to the court?

17 MR. WILSON: Who gave it to the court?

18 CHAIRMAN SHEPARD: I don't know. I didn't give it to

19 the court.

20 MR. WILSON: The court has those names.

21 MR. SNYDER: Yes. Well, maybe the committee should

22 consider recommending to you that, in fact, you look to see if

1 the addresses are good, and send maybe a sampling of either
2 mailhouse people know how you sample -- what the appropriate
3 sample size might be -- but send out 10,000 pre-addressed, pre-
4 stamped, return notices or the envelope is stamped, so you
5 can determine whether the addresses are good.
6 And if you find that most of the addresses from that
7 sample are no good, then I think that suggests that you've lost
8 one of he principal purposes of the registry, and perhaps it
9 should be simply reduced to offering people an examination
10 with a greater emphasis on steering them to treatment when it's
11 needed, and explaining that 97-92 provides you with a priority
12 for treatment. And not simply the letters that you've got now
13 that suggest treatment could be had.
14 CHAIRMAN SHEPARD: I guess I would be of the opinion
15 that a 65 percent adequate or accurate mailout list is better
16 than no mail out list at all. In other words, if we can reach
17 at least 65 percent of the veterans who we want to to give them
18 information, that's better than not having that capability at
19 all. I don't know. I guess we could debate that issue, but
20 that is just my personal, unsolicited opinion.
21 DR. FITZGERALD: I'm a little confused as to why we
22 want the addresses, the current addresses of Vietnam veterans

1 over say any of the other veterans. My understanding of the
2 Agent Orange registry was originally it was to give an evalua-
3 tion as to whether they had a treatable disease that should be
4 treated. And that the other secondary purpose of it was to
5 establish a record of complaints of illnesses so that if in
6 later years it was determined that indeed there was a relation-
7 ship between Agent Orange and the complaints that they had
8 that it would be invaluable to them as an establishment of a
9 claim for compensation.
10 I do not think it was intended to keep a current
11 registry of the present addresses of all veterans anymore than
12 any other veteran who comes to the Veterans Administration.
13 From an administrative standpoint, I think it would be a night-
14 mare.
15 MR. SNYDER: But it also cannot be used, according to
16 general counsel interpretations, for establishing an early or
17 effective date for a claim because for those people who may have
18 examined two or three years ago but never filed officially a
19 compensation claim, having had an examination that indicated
20 "xyz" symptoms would not mean that you would get an effective
21 date for your service claim back to the date of that examination.
22 So that purpose of that, if that was thought to be

1 part of it --

2 DR. FITZGERALD: That's not completely true. No.

3 It would not give a date for retroactivity of a claim, but it

4 would be another piece of medical evidence, such as all the

5 pieces of medical evidence that come before the board --

6 MR. SNYDER: To potentially establish service-connec-

7 tion at all.

8 DR. FITZGERALD: -- to potentially establish it at

9 a later date, and granted it would be valid at the time that

10 it was later established.

11 CHAIRMAN SHEPARD: Well, I would certainly entertain

12 a recommendation from the committee dealing with several issues,

13 first of all, whether or not to test the validity of the

14 address list. I think we have a handle on some of that by

15 virtue of the fact that some time ago veterans on the registry

16 were asked whether or not they wanted to receive ongoing in-

17 formation such as Agent Orange Review, and I forget now what the

18 result of that survey was. It was some time ago.

19 But maybe it's time to do that again.

20 MR. SNYDER: I would suggest as much so that perhaps

21 in the next meeting, or the meeting after, we'll have some

22 result, and we can revisit the issue as it were, and see if we

1 should make a stronger recommendation that perhaps the effort
2 to keep track of people is not useful and doesn't render the
3 system useful.
4 DR. KAHN: Another possibility might be to a more
5 rigorous consumer survey than the one we were able to do.
6 CHAIRMAN SHEPARD: I was going to ask Dr. FitzGerald
7 if the Legion has kept up its effort in terms of that satisfac-
8 tion survey that you all did with the registry?
9 DR. FITZGERALD: I don't think it has. I'm not
10 completely knowledgeable, but I don't think it has.
11 CHAIRMAN SHEPARD: Has not been kept up?
12 DR. FITZGERALD: Has not been kept up, yes.
13 CHAIRMAN SHEPARD: Maybe if you wouldn't mind asking
14 some folks in the Legion to see if there was ever a wrap-up
15 report because I don't remember seeing a final report of that.
16 MR. WILSON: Mr. Lee did come here from Chicago or
17 Indianapolis American Legion and did give us a report.
18 CHAIRMAN SHEPARD: I'm aware of that, Wayne. I'm
19 saying a final wrap-up. In other words, if it has come to a
20 close, if they have, in fact, prepared a final report, or if
21 it's an ongoing process, if we can get another interim report.
22 MR. SNYDER: So far there was just the one published

1 report of that. I thought was literally phase one.

2 CHAIRMAN SHEPARD: No, that was the --

3 DR. FITZGERALD: I think we are confusing two issues

4 here. There was a study that was done by the Veterans -- by

5 the American Legion of Vietnam veterans in distinction to an

6 inquiry out to the veterans as to what their reaction was to the

7 Agent Orange examination.

8 MR. SNYDER: The American Legion had sponsored both

9 of those.

10 CHAIRMAN SHEPARD: Way back. Yes. Satisfaction sur-

11 vey.

12 DR. KAHN: Should we have a look at a survey?

13 We could make that a recommendation that somehow a survey be

14 conducted. I'm not sure what the best form would be, but that's

15 not my place to say.

16 CHAIRMAN SHEPARD: Okay.

17 DR. KAHN: And if it turns out that you get a black

18 eye, then you've really got to think about what you're doing.

19 CHAIRMAN SHEPARD: Well, it was such a survey that was

20 conducted by the VA. I think the first survey, in fact, was

21 conducted by the VA which led us to -- even before the first

22 GAO report came out -- to implement the process of mailing out

1 follow-up letters which had not been done previously.

2 DR. FITZGERALD: I think that has been the biggest

3 complaint. Two big complaints. One, dissatisfaction on in-

4 dividuals as far as what they were examined for. And two,

5 more importantly and more widely, dissatisfaction because the

6 results of the examination were not explained to them. We

7 followed up on that, and there was correction as far as that

8 was concerned, although not complete eradication.

9 Again, time has passed, and I don't know what the

10 satisfaction is at the present time.

11 CHAIRMAN SHEPARD: Okay. Do I sense, then, that the

12 committee is in agreement that some steps should be taken to

13 do a follow-up with the registry participants?

14 Any other comments on the GAO report?

15 DR. WALKUP: I'm sorry. I was late and missed what

16 was probably the presentation on it, but I had noticed in the

17 Administrator's response to the GAO report that in a number of

18 instances reference was made that small budget and staff

19 available for responding to some of the recommendations that

20 GAO had made specifically about -- most of them related to

21 monitoring complaints at the local level.

22 Could you elaborate on that to some extent and maybe

1 let us know what some of the constraints you're working with
2 are and the level of compliance monitoring that you feel is able
3 to be done around the issues that were identified here?
4 CHAIRMAN SHEPARD: They are basically three methodolo-
5 gies, I guess. One is the so-called systematic internal review
6 system in which each hospital is required to do an evaluation of
7 its own operations and procedures.
8 There is a systematic external review program, so-calle
9 SERP program, in which evaluation teams go out to various
10 hospitals and review their procedures, and then from time to
11 VA, our office, has on a much less wide scale basis, but fair
12 amount have gone out to various hospitals in which we sensed
13 there may be a problem.
14 Either hospitals may ask for somebody to come, or we
15 sense there may be a problem.
16 MR. CONROY: Are your visits always announced, Dr.
17 Shepard, in advance?
18 CHAIRMAN SHEPARD: Announced to the hospital?
19 MR. CONROY: Announced to the hospital.
20 CHAIRMAN SHEPARD: I think for the most part, yes.
21 I don't know that we've done any surprise visits, certainly
22 not systematically we haven't done any surprise visits. I have

1 dropped in on hospitals from time to time unannounced, but not
2 intentionally with the purpose of doing it.
3 So there I would say those three general areas in
4 which the program is looked at.
5 DR. WALKUP: What were the resource or staff constaints
6 that occurred in those areas that led to the Administrator's
7 comment?
8 CHAIRMAN SHEPARD: I'm sorry. I missed that.
9 DR. WALKUP: What were the budget or staff limitations
10 in those areas that led to the Administrator's comment that
11 there weren't necessarily sufficient people to do that?
12 CHAIRMAN SHEPARD: I guess I'm not clear on what --
13 either I don't understand the question or I don't know the
14 answer maybe.
15 DR. WALKUP: Well, in response to --
16 CHAIRMAN SHEPARD: Can you refer me to a page?
17 DR. WALKUP: Okay. I think it's basically pages 61
18 through 65.
19 MR. CONROY: I think what he's trying to get at, Dr.
20 Shepard, has your budget been cut recently? Has your staff been
21 cut recently?
22 CHAIRMAN SHEPARD: Yes. We've lost one staff person.

1 MR. CONROY: One.

2 CHAIRMAN SHEPARD: Right. Dr. Hobson has been assign-

3 ed to another office.

4 GENERAL WELLS: I understood your question to be the

5 people at the local level that manage the Agent Orange registry,

6 not the people that came in from central office?

7 DR. WALKUP: Probably. I was trying to find out, and

8 I'm still looking for my reference here. But, yes, thank you.

9 CHAIRMAN SHEPARD: As far as I know, there haven't

10 been any cuts in the field specifically aimed at reducing the

11 capability of implementing the Agent Orange registry, if that is

12 your question.

13 GENERAL WELLS: But there were never any additional

14 staff put in the field to implement Agent Orange, as I under-

15 stand it.

16 CHAIRMAN SHEPARD: Oh, that is correct. That is

17 correct. There were never --

18 DR. FITZGERALD: The individual hospital directives

19 have the capability of assigning their resources to where they

20 think the priorities are. Conceivably at a given hospital,

21 Agent Orange registry might get a lower priority, but I don't

22 think any of them would eliminate the Agent Orange examinations.

1 MR. WILSON: They ought to.

2 DR. FITZGERALD: They might decrease the number of
3 people, and the length of time before an examination would be
4 completed might increase. They are going to be under pressure
5 with the reduction in monies and people which we have in the
6 system.

7 DR. WALKUP: I'm still not finding my reference and
8 I'll get it to you later. But what I guess I'm hearing from you
9 is you don't have a perception with lack of staff support to
10 ensure that concerns raised by the GAO won't reoccur?

11 CHAIRMAN SHEPARD: I don't think it's a question of
12 staff support. This is my sort of off the top of my head im-
13 pression. I think it's more a question of implementing a fairly
14 -- on top of everything else, implementing a program for which
15 additional resources have not been provided.

16 I think we have made a reasonable effort to incorporate
17 those recommendations provided by the GAO that we think would
18 have some likelihood of success given the staffing and so forth.
19 Obviously, up to a point if we could have somebody at each
20 hospital whose sole duty was to do the administrative aspects
21 of the Agent Orange registry program, and a physician whose sole
22 duty it was to do all the examinations, then probably the system

1 would perhaps run a little more smoothly, or we could do more
2 examinations in a given time, but we've never been provided
3 those resources.
4 DR. WALKUP: Essentially that's the core of the point
5 that with the examinations or with follow-up letters, or those
6 sorts of things, of the resources aren't there, or the people
7 who have to deliver those services are having to deliver them
8 in addition to the baseline responsibilities they've already
9 got, we have had and we'll probably continue to have delivery
10 problems at the local level.
11 CHAIRMAN SHEPARD: I think it's a base -- I'm going
12 to ask Layne in a minute to talk. But I think you have to keep
13 bearing in mind that the Agent Orange program is in addition to
14 the basic, many other basic, fundamental roles and responsibili-
15 ties that the VA health care delivery system has. And clearly
16 the number one priority is to deliver health care for patients
17 who are ill in hospitals. That includes all veterans, whether
18 they be Vietnam veterans or a number of other veterans.
19 So I think one has to keep bearing in mind that what
20 we do for any given group of individuals has to be bounced up
21 against the total scope and responsibility of a hospital's
22 charter. Layne, did you have something to say?

1 MR. DRASH: I just want to make the observation that
2 one of the concerns of the General Accounting Office when they
3 were meeting with us
4 was about the ability of our particular office
5 to undertake quality assurance reviews of Agent Orange
6 Registry and Public Law 97-72 activities. They were cogni-
7 zant of the level of our staffing at the time of the review
8 which at that time was 16 people on board.
9 Last year, the Agent Orange Projects Office underwent a
10 reduction during which we lost Dr. Kang's office, that is the Research
11 Section, which relocated to the Armed Forces Institute of Pathology, a
12 detail from the Washington VA Medical Center.
13 Part of our problem has been the fact that on our
14 staff, a very small staff, we have lost Dr.
15 Hobson, the Deputy Director. Also we have only a
16 very small number of professional staff who can undertake a
17 review, an ongoing review, of the Agent Orange Registry. We
18 have multiple duties within our program. As for example, we have one
19 person who is designated as the Agent Orange Registry coordinator who
20 handles this function in addition to other assignments. The quality
21 assurance function for the Agent Orange registry is only one part of that
22 individual's

1 job.

2 Be that as it may, since the GAO review, and even prior to

3 that, we have been planning and working on the development of

4 some type of quality assurance program so that we can conduct

5 ongoing on site reviews of the registry.

6 The amount of dollar resources that we have are

7 extremely limited as regards travel opportunities. We just don't have

8 a great amount of travel dollars. We have requested such resources on

9 numerous occasions, but again, as was pointed out earlier, the realities are

10 that resources, in general, are being cut, and quite truthfully, we're

11 taking our fair share of that cut.

12 So we have sought alternative means. I believe

13 you have a supplemental circular which points out part of our

14 plans for a quality assurance review of the registry. It's going to be an

15 ongoing review. We're going to look at it to see if it's working. We'll wait

16 for comments back from the field, and if they're negative, then

17 we'll adjust it or, we'll terminate or revise a particular type of

18 quality review.

19 Going back to the original

20 aspect of the concerns about GAO, I think that was their primary

21 concerns in terms of budgetary staffing requirements during

22 their review of the registry program.

1 Be that as it may, we are still continuing to implement innovative programs to
2 conduct quality assurance reviews, in concert with other ongoing reviews,
3 that is, the Systematic External Review Program,
4 Systematic Internal Reviews, et cetera.
5 In conclusion, we're doing, the best we can with the re-
6 sources that we have.
7 CHAIRMAN SHEPARD: Thank you, Layne. Any other
8 comments?
9 DR. KAHN: Well, whatever the small, incremental
10 changes that you're able to make and are inclined to make, the
11 perception out in the boondocks is that the program is a
12 charade. I go out and talk to veterans groups and veterans
13 call me; we have commission meetings with public comment which
14 veterans attend and speak, I've been all over the state, and
15 the perception is that the program is a sham, a fraud.
16 CHAIRMAN SHEPARD: Well, to say it's a fraud I think
17 is a little bit strong. I don't think --
18 DR. KAHN: That's the perception.
19 MR. WILSON: How about sham?
20 DR. KAHN: That's the perception, Barclay. Okay?
21 CHAIRMAN SHEPARD: Okay.
22 DR. KAHN: Whatever --

1 CHAIRMAN SHEPARD: If you have some suggestions, then,
2 I would like very much to have your input.
3 MR. WILSON: We've made suggestions over the years.
4 And you never take any. We told you, Barclay. It's a matter of
5 record.
6 CHAIRMAN SHEPARD: Wayne, I wasn't addressing my
7 question to you. Peter, would you care to respond to my
8 suggestions, or request for suggestions? If you can think of
9 specific areas in which we can improve the Agent Orange registry
10 program, I would really like to -- and it may be that you should
11 give that some more thought and write them down and send them
12 to me.
13 DR. KAHN: I'll write you something down. Most of
14 my criticisms the GAO and others have already voiced. That when
15 the veterans are taken care of inside a VA facility that they
16 be treated decently. They aren't, with a few exceptions. There
17 are a few hospitals that do.
18 Secondly, that they get proper follow-up, and that
19 the follow up be explained to them in layman's language. Those
20 are the two principal complaints that we get. There are other
21 minor ones that occur occasionally. Fixing those two things
22 would go a long way toward giving the veterans some confidence

1 in the system.

2

3

4 MR. WILSON: Barclay, you can get pissed off all you want. I

5 care about the veterans, not what you think. I can tell you

6 that. Put that on the record. You ought to start caring about

7 the veterans.

8 DR. HODDER: The question I guess I would raise is

9 is this a specific thing of VA hospitals, or is this -- well

10 care in almost any hospital is a serious problem.

11 DR. KAHN: That I don't know.

12 DR. HODDER: That's another issue here that is a

13 little difficult. Part of it is also the expectation -- (let's

14 not put it that way). I wonder how the veteran is approached

15 when he is asked for the opinion. If he is approached in a biased

16 way by whoever is asking you'll get a negative response

17 if you're going to go to him and say aren't those things lousy,

18 et cetera. That's one thing.

19 DR. KAHN: Well, we don't do that. The complaints

20 that come to us come unsolicited.

21 DR. HODDER: But the other one I would tell you is

22 that if you ask people about how their medical care is you

1 usually get a fairly positive response. If you ask people how
2 their well care, i.e., their health screening and physicals and
3 things like that, you usually get a fairly benign or negative
4 response.
5 I don't know that I have a frame of reference to tell
6 you how good or bad that is, but --
7 CHAIRMAN SHEPARD: Yes. I also think it's probably
8 fair to say that the GAO report was done without benefit of very
9 much medical input. I personally have talked to the individuals
10 and there are times when I was appalled at some of the judgments
11 they made because they clearly were medical judgments for which
12 individuals require a fair amount of medical training.
13 And we did point out some of those points to them,
14 and I think finally they did agree that yes, they -- for example,
15 some of the reviewers were going through and making judgments
16 as to whether diagnoses were accurately made in the reports
17 based -- and these are things that require medical knowledge,
18 and very in-depth medical knowledge.
19 Some of these things, the differences are fairly
20 subtle, and I don't think that any non-trained individual, and
21 non-medically trained individual really has the capability of
22 making many of these value judgments and quality of care

1 judgments. Now, whether or not a veteran is happy with the care
2 he gets does not necessarily correlate with the quality of the
3 care. It may, but I say it does not necessarily.
4 Many people are very unhappy because they are sick.
5 And many people who don't get better are unhappy and tend to
6 blame the care they're getting as a reason for their not getting
7 better. Some diseases don't get better.
8 GENERAL WELLS: One of the questions that I had was
9 I had a problem with your regulations. All right. But I have
10 here something that you sent us that was dated September 25,
11 1986. Now, is this what was the result of the GAO report to
12 implement those changes?
13 CHAIRMAN SHEPARD: Yes.
14 GENERAL WELLS: Well, I think it's rather difficult
15 to evaluate changes that just went to the field the 25th of
16 September.
17 CHAIRMAN SHEPARD: Thank you. That's true.
18 GENERAL WELLS: And I think we ought to say, okay,
19 they are trying to implement the recommendations, but I think
20 it's too early to say whether we have.
21 DR. FITZGERALD: I think that what we're bringing up
22 here is the fact that there are valid complaints out in the

1 field as you would anticipate. That there has to be a constant
2 upgrading of the instructions given to the people out there to
3 be sure that they are accomplishing what is originally intended.
4 When you have an overworked staff and one doctor has
5 to do Agent Orange examinations, and he doesn't want to do Agent
6 Orange examinations, you're going to have a disgruntled individu-
7 al, who is not going to satisfy that veteran.
8 It is that individual who has to be constantly moni-
9 tored, and the other valid complaint that we've repeatedly said
10 is the briefing of the veteran subsequent to the examination
11 as to what they found. In some hospitals this is done very
12 well. In a significant number, it is not.
13 DR. KAHN: You might consider taking a few of the
14 hospitals in which it's done well, and I believe Wilmington is
15 one of them. They used to have a marvelous nurse. I think
16 she's still there. I don't remember. She's wonderful. We get
17 nothing but praise about that lady. And she just makes the whole
18 examination system work smoothly for the people down there.
19 Why not take a couple of hospitals where you have good
20 programs that work and clone them elsewhere?
21 CHAIRMAN SHEPARD: Well, we have made some attempt
22 along those lines. Boston VA has a very good system, and we

1 have solicited comments and suggestions. So I think there are
2 some shining stars in the field, and we have attempted to
3 identify them and have solicited comments from them and have
4 tried to see what works in one place to, as you say, clone to
5 another place.
6 DR. KAHN: That girl in Wilmington is worth her weight
7 in gold to you folks.
8 DR. WALKUP: I think an underlying part of that
9 discussion that is important to remember -- I know sometimes I
10 forget and I'm sure everybody else does -- is that the percep-
11 tion of a sham that I hear, too, and yes, it's from people who
12 have some other problems often, and maybe get set up -- but I
13 think there are just some structural things that are within the
14 system that make it possible for people to have that perception.
15 Their understanding of what an Agent Orange examination
16 should be is something that tells you whether you've got Agent
17 Orange or not, or whether you have something wrong with you
18 and what it is and how come.
19 There is no way anybody can deliver on that. So
20 structurally, they're going to be disappointed. The delivery
21 system for that, as you pointed out, is not a separate delivery
22 system. has a lower priority than ongoing services, and is an

1 additional workload added on to people. A volunteer pops up
2 within the organization now and then who will make it work but
3 it's not because of the organization or the structure of the
4 program. It's in spite of it.
5 And I think that we should expect people to be very
6 satisfied with the Agent Orange program, or to sell it as often
7 as it's been sold as the Veterans Administration or the nation's
8 response to the needs of Vietnam veterans sets them up to have a
9 very negative perception of their experience there. And some
10 clarification of well, this is the best we can do with the
11 staff that we've already got, and they're being cut back, and
12 we've got additional demands, and we can't tell you anything
13 anyway might be somewhat in order as a leavening to the
14 expectations that people have got there already.
15 CHAIRMAN SHEPARD: Okay. Thank you. I think we need
16 to move on. We have a couple of other things that we need to
17 cover. We've asked Mr. Conroy from West Virginia to give us
18 an update on the various state activities. Chuck, can you
19 fill us in.
STATE ACTIVITIES
20 MR. CONROY: Thank you, Dr. Shepard. Knowing we
21 are running behind schedule, I'll try to keep this as brief
22 as possible. I distributed, I think, to all the committee

1 members, and I've left back at the table a couple of handouts.
2 One is a map indicating states that have programs, commissions
3 or studies; states without those studies; discontinued programs;
4 and the blank states are states that didn't respond to my
5 inquiry.
6 I would appreciate it if you would look at this very
7 much as a preliminary or a working draft because I have already
8 been advised by a representative from Minnesota that I have
9 prematurely terminated that state's program.
10 Let me explain methodologically how I conducted this
11 survey. Those states that we were pretty much aware of the
12 fact had ongoing programs, I corresponded with that contact
13 person directly, simply because I knew them from coming and
14 attending these meetings.
15 Those states in which I was unsure of whether they
16 had an ongoing program or activity, I corresponded with two
17 sources. One, the Department of Health, and the second being
18 the Department of Veterans Affairs. What I found is that most
19 states that have a program, organizationally tend to house that
20 program within either one of these two agencies, Health or
21 Veterans Affairs.
22 So as you can see, there are 13 states that I have not

1 received a response yet from. And I'm at the point now of
2 actually phoning those states and trying to solicit some more
3 input from them.
4 There are a number of states that I have indicated
5 on this map that I know at one point in time had ongoing pro-
6 grams, but I've not heard from yet. For example, Maine, Ohio
7 and Wisconsin. Wisconsin was for funded awhile. Then they were
8 de-funded. Now, I understand they're back in business again.
9 So I would sincerely like to fill out all the blanks
10 on this state map. But nevertheless, I think there are some
11 interesting trends that I would just like to highlight here.
12 The first being those states that are terminated, and again,
13 I think I mentioned Minnesota. There was a representative that
14 was faithfully attending our meetings Jerry Bender -- I
15 understand he is no longer with the program.
16 And that organizationally the Claims Office of the Department
17 of Veterans Affairs will be responsible for the Agent Orange Program in
18 Minnesota. There was a Mr. Olson here who, I believe, had to depart early
19 for a plane, but I will be getting in touch with Mr. Olson again. He tells
20 me that they are going to continue the program.
21
22 The other states that have terminated their programs

1 did so primarily because they were defunded by their particular
2 state legislatures. And most -- in fact, all of them to this
3 point in time have issued a final report and have sent that
4 report to me.
5 So any of you that are interested in receiving a final
6 report from those states that have terminated their activities,
7 I have copies of all those individual state reports.
8 Some of the states did some rather innovative things,
9 I think, before the programs were terminated. For example, the
10 State of Tennessee, prior to their termination, got involved
11 in the Agent Orange litigation and the law suit
12 and actually got in touch with all -- they have some 94 counties
13 in Tennessee.
14 They got in touch with county sheriffs and got in-
15 volved in that claims process before they terminated that
16 program. So some of those states, as I say, did some innovative
17 things. I would like to just highlight what some of the states
18 with ongoing programs are doing for you.
19 Initially, the state of California has, I think, got
20 an excellent idea going if they can solicit the cooperation of
21 the Defense Department. I am advised that what California
22 is trying to do is get a listing from the Department of Defense

1 as to all the Vietnam veterans who served in country which they
2 would like to bump against that state's tumor registry.
3 They tell me they're having some difficulty in terms of
4 the confidentiality of those records in securing them, but it's
5 one that I think is well worth their pursuing.
6 The State of Connecticut has put out a number of self-
7 help guides, a little pamphlet on testicular cancer and just a
8 number of educational pamphlets and brochures.
9 Illinois is a state, again, that was active, and went in-
10 active for awhile. It is now getting back on the bandwagon.
11 Back in 1983, the State of Illinois sponsored a symposium on
12 Agent Orange and was fairly well attended. They lost their
13 source of funding, and now I understand are coming back on line,
14 and within the next six months there is to be appointments made
15 to that state's Agent Orange commission.
16 The State of Louisiana is a new state that has very
17 much just come on line, and is organizationally just feeling its
18 way around, as is the state of Maryland. By the way, I have
19 extended invitations to a couple of these states to appear at
20 these meetings. I talked to a Mr. Linden from Maryland. Or a
21 representative?
22 MR. WHITE: We have Mr. White.

1 MR. CONROY: Mr. White. Okay. And I did inform him
2 of this meeting, and he said he would have try to have a repre-
3 sentative here. I would like at the end of my presentation
4 perhaps to yield some time to Maryland and Michigan who have
5 respresentatives here today to let them explain about some new efforts they've
6 got in those states.
7 Massachusetts, most of the committee members are
8 aware of the mortality study we heard last time, and the
9 health survey. The State of Michigan, we have a representative,
10 Mr. Roy Klayiter, that I will yield some time at the end of my
11 presentation.
12 New Jersey, I think, was eloquently represented here
13 by Dr. Kahn and Wayne and everyone is aware of the fine work
14 they have been doing.
15 New York, most of you who were in this survey early
16 on, realize that the State of New York had a temporary commission
17 on dioxin exposure, but went out of business. It was supplanted
18 by a dioxin outreach program. To date, they have issued two
19 newsletters, have established a very extensive bibliography on
20 dioxin and intend, I understand, to continue publishing that
21 newsletter.
22 So they are back up and geared up and working again.

1 The State of Oklahoma has conducted a rather limited
2 health survey, about 1500 veterans, but is still conducting
3 that survey.
4 Pennsylvania, most of you are aware of the physicians
5 educational program which was launched, the cassettes by Pennsyl-
6 vania. They are also now in a process of developing their own
7 questionnaire and health survey. South Carolina is a new state
8 that just came on board. Legislation was enacted at the end of
9 the fiscal year, and so they will be gearing up.
10 South Dakota is in the process of conducting a survey.
11 Again, some of these states by virtue of the size of the state,
12 the surveys are very limited. South Dakota, I guess, has dis-
13 tributed about 1500 questionnaires or health surveys thus far.
14 The State of Washington has developed a very fine
15 self-help guide based a lot on the information that New Jersey
16 had prepared earlier. And West Virginia, of course, is still
17 involved in medically testing Vietnam veterans and to date we
18 have tested close to 500 of those veterans.
19 As I said, I would like to make this a draft because
20 what I would like to do, and what we are going to do, is to put
21 the information in the form of a pamphlet, and we're going to
22 list the contact person with an address, and then a brief

1 description, similar to the oral presentation I've given, in-
2 dicating what type of activities are being conducted, and we'll
3 make that available to anyone that would like this when those
4 are available.
5 CHAIRMAN SHEPARD: Thank you very much, Chuck. That's
6 very helpful. Yes, I would certainly encourage that because I
7 think we need that kind of an inventory, and I think in pamphlet
8 form I think it would be very helpful.
9 MR. CONROY: Yes. One thing I just might mention,
10 you know, the feelings in terms of Agent Orange certainly still
11 do run strong. In my correspondence with these different
12 agencies, I told them the purpose I was soliciting this
13 information for and offered all of them a final copy of the report.
14 I was told by a couple of southern states that they
15 had no Agent Orange programs going, were not interested in
16 getting into the Agent Orange business, and were not interested in
17 receiving any information on Agent Orange.
18 And I also thought it was interesting from the State of
19 Mississippi I got a response that indicated that they thought
20 there was more herbicide used in that particular state, Arkansas
21 and Louisiana than was ever sprayed in Southeast Asia.
22 So the feelings run --

1 MR. SNYDER: Probably true on the rice.

2 MR. CONROY: At this point I would like to defer to

3 my colleagues, first from Maryland, Mr. White.

4 MR. WHITE: We've only had one meeting, and it was

5 Saturday. I'm surprised you found out about us so fast.

6 CHAIRMAN SHEPARD: You want to come up here, Mr.

7 White, and Dr. Klaviter, why don't you come up here and be

8 up here where we can all hear you.

9 MR. WHITE: The Governor for the State of Maryland,

10 Harry Hughes, he signed the bill the 5th of September. We had

11 our first meeting this past Saturday. We are about to elect

12 an executive director. We have to also appoint one more person

13 for our board because we had a female veteran who got a new

14 position, and suddenly moved to Texas.

15 So we'll be keeping in touch. As you know, I've been

16 attending this (committee's meetings) for quite some time, and I plan

17 on continuing to attend until this thing is finalized. I am definitely

18 looking forward to working with everyone here because this problem has

19 to be resolved, especially with me myself being a Vietnam

20 veteran and I have my problems with Agent Orange.

21 And hopefully things can be resolved.

22 CHAIRMAN SHEPARD: Thank you very much. Would it

1 be possible for you to share with Chuck and our office also
2 the implementing legislation. Is there a governor's order,
3 executive order? I'm not quite sure what the process was for
4 establishing the commission.
5 MR. WHITE: What it was --
6 CHAIRMAN SHEPARD: Just for our file so we have some
7 idea.
8 MR. WHITE: Yes. After working with the New Jersey
9 Agent Orange Commission and getting some ideas we went home and
10 put together a bill and took it to a delegate, and they were
11 looking for some votes this year because it was election time
12 this year, and we got it through. And that's basically it.
13 The House passed it. The Senate passed it. And the governor,
14 he wanted to be senator, and he signed it.
15 (Laughter.)
16 MR. SNYDER: And it survives him.
17 MR. WHITE: It survives him because he didn't make it.
18 CHAIRMAN SHEPARD: Mr. White has provided to us a
19 nice letter announcing this and also a list of the members of
20 the commission.
21 DR. KAHN: Did they give you guys some decent money
22 to work with?

1 MR. WHITE: Well, I'll find out when I get back, but
2 the last I heard we're going to start with -- the bottom price
3 is 150,000 We have a lot of lottery games in Maryland so
4 this should be getting on all right.
5 CHAIRMAN SHEPARD: Okay. Anything else? Any questions
6 for Mr. White?
7 DR. KAHN: I guess you don't really know what you're
8 going to do yet since you've only had your first meeting?
9 MR. WHITE: We're leaning on you a lot. Quite a bit.
10 DR. KAHN: All right.
11 MR. WHITE: I have a vague idea where I would like to
12 see it go. I have yet to hear anything about a chromosome
13 study.
14 DR. KAHN: Oh, that's a can of worms. That's a real
15 can of worms. Talk to me later.
16 MR. WHITE: Okay.
17 CHAIRMAN SHEPARD: We'd be happy to -- if you have any
18 thoughts, or we can set up other meetings just while you're
19 getting off the ground. I've tried to make myself available to
20 any commissions that are beginning to start up, if I can be of
21 any help in talking to the commission or making suggestions.
22 MR. WHITE: Oh, we're going to be getting -- that's

1 in the letter. We're going to be getting in touch with you,
2 bring you to charm city.
3 CHAIRMAN SHEPARD: Very good. I just wanted to --
4 MR. WHITE: Put you up and feed you and everything.
5 CHAIRMAN SHEPARD: Seriously, I would be more than
6 happy to do that. And would welcome an invitation to do that.
7 MR. WHITE: Right. And please everybody keep in
8 touch. That is how this thing is going to work, everybody
9 networking.
10 CHAIRMAN SHEPARD: Congratulations. Good luck.
11 MR. WHITE: Thank you.
12 CHAIRMAN SHEPARD: Dr. Klaviter.
13 DR. KLAVITER: I appreciate being able to attend and
14 take a few minutes of your time. I have two purposes in attend-
15 ing your meeting. First is to learn from those who have worked
16 in this field and have been trying for some time to be of
17 assistance to the Vietnam era veteran.
18 The second purpose is to ask for input
19 and help on the efforts in Michigan. We serve at the pleasure
20 of the governor and the legislature in Michigan. The legisla-
21 ture for a number of years considered bills that would enable
22 us to do health studies for

1 Vietnam era veterans, and this last year, passed a budget re-
2 solution setting aside a small amount of funds, $ 150,000, really
3 for a pilot program, and for planning purposes.
4 So that amount of money is available to the Michigan
5 Department of Public Health and specifically to the Center for
6 Environmental Health Sciences which is an internal consultant
7 group within the Department of Public Health that serves health
8 and other state agencies.
9 Our planning group includes myself, and a medical
10 consultant, a person in the epi studies area, and a person who is literate
11 in terms of computer technology.
12
13 We've been actively soliciting input from veterans groups
14 in Michigan. We have asked for their ideas on what would be of value to the
15 Vietnam veterans and specifically related to Agent Orange
16 exposure and those attendant concerns.
17 We've gotten some good input
18 from veterans groups, and our first thoughts on what we would
19 do are as follows:
20
21
22 First, to establish a registry in

1 Michigan so that we can find these people and be in touch with
2 them. We have used the Michigan Vietnam Bonus list, this was
3 a bonus that was given by the State to people who served during
4 the period or the Vietnam war. We
5 would very much like to have the names and addresses of the
6 Michigan residents from the Agent Orange Registry.
7
8 We would also like to have the
9 the Michigan residents from the Disabled Veterans registry. Our
10 purpose in getting both registries is to set up a d-base three
11 merge file with a current address.
12
13
14 see it now.
15 Second, we want to be able to give information that
16 will be helpful and informative. I think what's required here
17 is bullets of information written in common
18 parlance that are clear and that are useful to the Vietnam era
19 veterans. And I invite your help in obtaining those pieces
20 of information.
21
22 I see here in the advisory committee and the friends,

1 the supporters and interested parties, a group of medical
2 scientific and technical people that collectively have all the information
3 that's available. We need the current information written in common parlance
4 language, that is clear and understandable to the veteran.
5
6
7 And, we have to distribute it.
8 It has to get to the veterans or it's worthless.
9 We have an initial agreement, and statement of support
10 from the Michigan Association of County Veterans Counselors to
11 establish a network of Agent Orange information centers through-
12 out the State of Michigan, using, or through the Country Veterans
13 Counselors offices. The County Veteran Counselors talk to veterans
14
15 everyday.
16 They have agreed to work with us in terms of distributing
17 information.
18 As we go along, there will be some thought given to
19 the possibility of a health survey. I don't know if I want to
20 say anymore about that, or how we would do it, because
21 we're just approaching the first step. With more
22 funding support, a health survey could be done in the second year.

1

2 Thank you very much for your time.

3 I might just say in a personal vein that I'm a

4 veteran with Vietnam service as a member of the Navy seal teams. I have a

5 Ph.D. from the University of Minnesota, and several years of experience in

6 environmental health.

7

8

9

10 CHAIRMAN SHEPARD: Well, thank you very much.

11 DR. KLAVITER: Yes, sir. Thank you.

12 DR. KAHN: We might be able to help you with the

13 question of maintaining, shall we say, continuity of state re-

14 sources.

15 DR. KLAVITER: I would be very happy to talk with you

16 about that.

17 DR. KAHN: It wouldn't take long.

18 CHAIRMAN SHEPARD: I would also say that I congratulate

19 you for establishing the commission and I wish you great success

20 in the future. I also would like to make myself available to

21 you and your commission in any way that I can.

22 Do you have -- let's see. You were established again

1 legislative act. Obviously, you have an appropriation. Do
2 you have a list of members of the commission? Is it a commission?
3 Do you call yourselves a commission?
4 DR. KLAVITER: No, we don't as a matter of fact.
5 The legislation was a line item in the appropriations
6 budget to the Department of Health and the Center for Environ-
7 mental Health Sciences to set up the program. I can give you a
8 copy of that. But we don't, as a matter of fact, have a formal
9 commission.
10 CHAIRMAN SHEPARD: But you are tasked to work through
11 the county health veterans counselors?
12 DR. KLAVITER: Well, we've chosen to do that.
13
14 CHAIRMAN SHEPARD: Right. I think that's a very smart
15 move.
16 DR. KLAVITER: Well, yes. We've got to ask them what
17 would be helpful to the Vietnam veterans.
18
19
20
21
22

1 We'll see.

2 CHAIRMAN SHEPARD: So you're still in somewhat of a

3 formative process?

4 DR. KLAVITER: Yes, we are in a formative process.

5 CHAIRMAN SHEPARD: Well, if we can be of any help to

6 you, please call on us.

7 DR. KLAVITER: Right. Thank you.

8 MR. CONROY: Dr. Shepard, I would like to yield the

9 final portion of my time to New Jersey here.

10 MR. FALK: Just very briefly, Barclay, in light of

11 the presentation, New Jersey has some new legislation that I

12 wanted to bring forth. I'm Allen Falk. I'm chairman of the

13 New Jersey Commission, and since the results of the Pointman

14 Project came in, we've had two bills introduced in the state

15 legislature, in the Senate specifically.

16 Right now, the first bill is Senate 2591 appropriates

17 the sum of a million dollars to the commission to continue on

18 to the final stages of the Pointman Project. We think that's

19 a very substantial commitment by the legislature and governor.

20 Of course, we have to now go through hearings and

21 give the details which Peter will be working on as far as where

22 exactly the money will be going, but also even more interestingly

1 is a companion bill that has been introduced to establish a
2 consortium, a scientific consortium on dioxin research in
3 general in the State of New Jersey involving the medical schools
4 and universities. And there is approximately two million dollars
5 that will be devoted to that project under the bill, including
6 hopefully obtaining of the machinery that currently Christoffer
7 Rappe is using and the CDC is using so that that will also be
8 available in the future for dioxin research directly in New
9 Jersey.
10 I would like to welcome the new Agent Orange programs.
11 We were the first state commission in the country. We were
12 enacted in '79. You can see the lead time that it takes to come
13 up with a meaningful program. It's a long hard process, and I
14 think, as you also all saw today, the frustration level of the
15 Vietnam veteran is no less today than it was in 1979. And Wayne
16 is sort of the conscience of the veterans, and you guys have to
17 put up with him a couple of times a year. We have him everyday,
18 and he keeps after us, and he reminds us what we're there for.
19 And I sort of feel sorry for the new people because
20 that lead time is so long. You've got to get right into it,
21 and get to work, but we wish you the best.
22 CHAIRMAN SHEPARD: Thank you very much, Allen. We

1 appreciate your appearance.

2 MR. CONROY: That's it, Dr. Shepard, and I hope, as I

3 said, to have a brochure available for distri-

4 bution to the entire committee and interested members of the

5 audience in the not too distant future.

6 CHAIRMAN SHEPARD: Thank you very much. Any other

7 questions for Chuck?

8 (No response.)

VETERANS SERVICE ORGANIZATIONS REPORTS

9 CHAIRMAN SHEPARD: Very good. Okay. Let's move on to

10 our next agenda item which deals with the veterans service or-

11 ganization reports. We've asked Dr. FitzGerald, Hugh and

12 Keith Snyder to tell us a little bit about their various re-

13 spective organizations activities related to Agent Orange.

14 Dr. FitzGerald?

15 DR. FITZGERALD: I think we have covered this pretty

16 well in our criticism of the complaints concerning Agent Orange

17 which are intended to be constructive, and I don't think I have

18 anything else to say.

19 CHAIRMAN SHEPARD: Okay. Hugh?

20 DR. WALKUP: I'll keep it brief, too. I've shared

21 again the constructive criticisms which also I hope were taken

22 that way that are shared by a number of people. One observation

1 I would like to pass along on what's happening in the field is
2 that with continued funding cutbacks, we are seeing community-
3 based organizations that used to provide supplemental service,
4 especially targeted to Vietnam veterans and people who had limit-
5 ed access to the system falling away.
6 To some extent, those were supplemented for a time
7 by Vietnam Veterans Leadership Projects or volunteer organiza-
8 tions. The lack of funding VVLP, that's falling away, and we're
9 continuing to see an erosion of those kind of community-based
10 services available to veterans.
11 And I think that puts increased responsibility on the
12 Veterans Administration which is also having funding cutbacks,
13 on the traditional service organizations which are not able to
14 be all things to all people, or to necessarily stay on top of
15 that.
16 And particularly, I think, for the Vietnam veterans
17 one of the major impacts that we're going to be seeing in that
18 kind of a resource situation is with the cutback in the vet
19 center program that really for a lot of veterans, I think, has
20 been the major source of information and support about Agent
21 Orange that has been relative to the needs of most veterans.
22 That program is already in a phase-out mode, and I understand to

1 be gone next year. It's going to be a major hole in services to
2 Vietnam veterans. Now, I'll be proposing a resolution for us
3 later that the committee encourage the Veterans Administration to
4 take another look at the status of the vet centers because of
5 their impact on Agent Orange as well as other Vietnam veterans
6 issues.
7 CHAIRMAN SHEPARD: Thank you, Hugh. Keith, do you
8 have something to share with us?
9 MR. SNYDER: Just briefly a reminder about that NBC
10 movie on November 10. It actually is a very dramatic and very
11 powerful movie that I think will lead to a lot of people, a lot
12 of veterans and family members coming to us. So our organiza-
13 tion is looking for answers, looking for help. And we should
14 anticipate that kind of a increased number of responses. If you
15 Chuck, are able to get back to the state people you've been in
16 touch with and remind them, oh, by the way, November 10th.
17 People could also capitalize, I think, quite success-
18 fully on the publicity that NBC is putting into it that should
19 be more obvious very soon. But many times, I think state agen-
20 cies, those commissions would be able to go the local NBC
21 affiliates --
22 MR. CONROY: We've already been contacted and asked if

1 we would prepare something for the presentation of that movie.

2 MR. SNYDER: But the whole focus of the movie leaves

3 you in the last few minutes to feeling like you just have to

4 act. You can't just sit there and flip channels. You have to

5 do something, and I think what is to be done then is something

6 that we can help shape. So I would remind people to tune into

7 that.

8 The only thing else I would comment on is that I have

9 at lunchtime passed out the two drafts of resolutions that we

10 had referred to earlier this morning. I think each of you has

11 -- it's a three page item. The first one is on interim benefits

12 and that joint meeting we wanted to have with the other committee

13 Is that something that now would be appropriate to deal with?

14 CHAIRMAN SHEPARD: Yes. Did I get a copy?

15 MR. SNYDER: Since I went back to my office and had

16 the word processor available, then I could plug in these

17 "whereas's" and "therefore, be it resolved's" and I apologize

18 for that. It's some of the legal training that I was inculcated

19 with.

20 But I think what is here is not anything different

21 than what we had discussed this morning, or if it is then I need

22 to be reminded of that. Delete things, or add things. Let me

1 know. The purpose of this interim benefits resolution was to
2 encourage Dr. Shepard to encourage the Administrator to either
3 administratively or if they view it requires new legislation,
4 to then seek new legislation to extend until such time as the
5 Agent Orange epidemiological study is out there and giving the
6 VA some other guidance, reopen that window of interim temporary
7 benefits, and that's what the purpose of that first resolution
8 is.
9 Does anybody have any problem with the wording of that?
10 DR. KAHN: I think this is fine.
11 MR. SNYDER: Do you as the chair want to call for
12 something?
13 CHAIRMAN SHEPARD: Call for discussion. Are there
14 any comments? First of all, see if there are any questions or
15 comments on it?
16 DR. KAHN: I think we discussed this to death earlier
17 today.
18 CHAIRMAN SHEPARD: Yes. I just wanted to make sure
19 that everybody had a chance to read it, and I had the sense
20 that there was a general agreement instructing me to forward
21 this to the Administrator?
22 MR. SNYDER: And we would include this in our report.

1 CHAIRMAN SHEPARD: Yes.

2 MR. SNYDER: The second item is also what we discussed
3 this morning, I think at length, was to try to coordinate with
4 the Environmental Hazards Committee possibly at the very next
5 meeting -- I'm not sure if on that short notice it's possible
6 to coordinate and get us invited.

7 CHAIRMAN SHEPARD: It's an open meeting. You don't
8 require an invitation. I pointed out it's the 17th of November.
9 It will be upstairs in the tenth floor in the Omar Bradley
10 Conference Room. I encourage your attendance at that.

11 MR. SNYDER: Is it an open forum in the sense of
12 anybody could ask questions at virtually any point, or is it
13 kind of like this that you wait until the end and you submit
14 written questions or what --

15 CHAIRMAN SHEPARD: I think it's a little more struc-
16 tured. I think that in order to get on with the business of
17 reviewing scientific information that it's more helpful to
18 have a time on the agenda.

19 Fred, is the agenda finalized? Is there -- okay.
20 So is it fair to ask if there could be a time slot on the
21 agenda to --

22 MR. CONWAY: It's fair to ask.

1 CHAIRMAN SHEPARD: Somewhat different. Fred is the
2 executive secretary for that committee. He is not the chairman.
3 The chairmanship of that committee resides outside the VA, and
4 that is another question that is on the agenda for this after-
5 noon.
6 DR. KAHN: Before we conclude with these two, do we
7 want to actually vote for these things so that we have a clear
8 expression from the committee?
9 CHAIRMAN SHEPARD: I am assuming that the first re-
10 ceived a unanimous vote, not hearing anything to the contrary.
11 I would be happy to go through the formal process.
12 DR. KAHN: No, no. If it's agreed that it's unanimous
13 that's fine. What about the second?
14 CHAIRMAN SHEPARD: We're in the middle of discussion
15 there.
16 MR. SNYDER: The only extra point, I think, of having
17 a joint session is more than just being -- knowing that we can
18 come, if we want, as members of the public, let alone as members
19 of the committee, was to I wanted to ensure that we as members
20 of this committee could, in fact, have maybe some special
21 status and be able to ask questions more freely perhaps of the
22 other committee than ordinary members of the public perhaps.

1 Is that something that is unrealistic to ask for?

2 CHAIRMAN SHEPARD: It's certainly not unrealistic to

3 ask for. No. My only point in bringing it up for the next

4 meeting, I thought you were going to say a comment about having

5 a joint meeting. I don't think that would be possible for this

6 next meeting, but to lay the ground work for a joint meeting at

7 the subsequent meeting. Am I understanding you correctly or not?

8 MR. SNYDER: What's the sense of anybody else? Our

9 next quarterly session we try to run together a larger room

10 with all of us at a big table, and this next one simply be avail-

11 able to go and participate as anyone else can.

12 MR. WALKUP: It sounded before -- well, it depends

13 on our schedule. But it sounded before as if that committee

14 has got a tentative schedule for April or --

15 MR. SNYDER: What's the next one after this?

16 MR. CONWAY: It probably would be tentatively set for

17 March or April of '87.

18 MR. SNYDER: And ours next would be ordinarily January.

19 CHAIRMAN SHEPARD: Or February.

20

21 Since our reorganization there has not

22 been a set time, a scheduled time on which we meet. So that

1 at least gives us a little flexibility. And I would suggest that
2 at the next meeting of the Environmental Hazards Committee
3 ask that the possibility be raised about having, if not a joint
4 meeting -- I don't think a joint meeting is necessarily, in my
5 opinion, necessarily a good idea -- but to have it at a time when
6 the two committees could get together for discussion.
7 In other words, they've got a specific set of goals
8 What I would propose, just for discussion, is
9 that we schedule them so that the meetings are on contiguous
10 days. So that people who had to travel from out of town could
11 avail themselves of the opportunity of sitting in on that
12 committee's deliberations.
13 And then we would have a meeting on the following
14 day or whatever. We could discuss that. I mean there are a
15 number of options. I think it would be, well, difficult to
16 run all sessions together concurrently because they have, as I
17 say, an agenda that is a little different from ours.
18 MR. SNYDER: Then the 17th, then, you would be avail-
19 able to ask and coordinate, try to coordinate that with them?
20 CHAIRMAN SHEPARD: Yes. But I would also encourage
21 any of you who can be there for that meeting.
22 But I plan to be there.

1 MR. SNYDER: Well, I think there is some value to be
2 had in seeing how they operate and being able to add what we
3 can, and if that's as easily done by being there and commenting
4 at appropriate intervals, then that would be fine. And if you
5 could try to set the next meetings of both committees, or to
6 see how well you can coordinate that so that either one begins
7 in the afternoon, the other in the morning, or somehow over-
8 lapping but back to back, somehow maybe that would be good.
9 CHAIRMAN SHEPARD: Yes. I will take it upon myself to
10 discuss the matter with Mr. Conway and see if we can set up a
11 time on their agenda for the upcoming meeting where members of
12 this committee, myself included, can address these concerns
13 to that committee.
14 MR. SNYDER: Okay.
15 MR. WALKUP: A couple of parts to that I would like
16 to stress are, one, it may not necessarily be suitable for us
17 to postpone our next meeting until that meeting happens, depending
18 on what other issues are up for us. It sounds as if there
19 could be a number of things that we maybe should deal with
20 sometime before nine months from now which would be next April
21 or May.
22 I won't go into them. We've been talking about them.

1 Especially if there is a conference planned next fall, or if
2 some of these things, the studies that are coming out come up,
3 there may be some things we want to deal with before waiting for
4 their meeting.
5 So maybe our meeting after next would be a place to
6 look at it, which is my second point that despite open invita-
7 tions, I really appreciate the wording of your resolution that
8 encourages us to have a joint meeting. That at least part of
9 our meeting be set up that way. And we've been talking about
10 doing that since before that committee was formed. I think that
11 would be very useful.
12 CHAIRMAN SHEPARD: Any other comments or questions on
13 the resolution?
14 (No response.)
15 CHAIRMAN SHEPARD: I will then assume that this is
16 a unanimously accepted resolution, and I will pass it along to
17 the Administrator.
18 MR. SNYDER: The third piece of paper, there was a list
19 of things that we had talked about this morning that we were
20 looking to get copies of. And either you, Dr. Shepard, or
21 Mr. Conway, I think commented that minutes of the Environmental
22 Hazards' meetings would be made available, the summary minutes.

1 And Mr. Hickman had commented that the rating decisions
2 for the interim benefits cases, he would make those available.
3 I just made a list of those things here. I would add, I think,
4 a number four item. There was a reference in the GAO report to
5 a videotape on the Agent Orange program that I believe that you
6 had been instrumental in preparing that described the various
7 aspects of the VA's Agent Orange program.
8 I think it would be useful to us as a committee if
9 we want to describe to our members what's out there and what's
10 available through the VA, maybe this videotape would be a way
11 to do that. Would you try to arrange perhaps for the next
12 session for us to see it? I don't know what that would involve,
13 but that might be something, 23 minutes, that would both educate
14 us and tell us what's there that we could pass along to our
15 respective organizations.
16 So I would request that you try to make arrange-
17 ments for that to be available to us.
18 CHAIRMAN SHEPARD: Okay. Now, we have in addition to
19 the videotape "Agent Orange Update," there is prepared a shorter
20 videotape which was aimed to instruct VA, primarily medical
21 administration service personnel dealing with veterans on a
22 face to face basis.

1 MR. SNYDER: So that is a separate tape?

2 CHAIRMAN SHEPARD: Yes, it's a separate tape so we

3 have two tapes now I think

4 this committee did look at an earlier version of the "Agent

5 Orange Update" which has not been released.

6 MR. SNYDER: And the other -- the "Agent Orange

7 Update" is --

8 CHAIRMAN SHEPARD: The other one has been approved for

9 release, and I think is now in the process of being copied and

10 ready for release?

11 PARTICIPANT: Within the immediate future, the next

12 few weeks.

13 CHAIRMAN SHEPARD: Okay.

14 MR. SNYDER: It's the "Agent Orange Update" one that

15 still in the works somehow?

16 CHAIRMAN SHEPARD: Somehow.

17 MR. SNYDER: What's that called? "Agent Orange Update"?

18 CHAIRMAN SHEPARD: "Agent Orange Update." That's the

19 follow on to "Agent Orange: A Search for Answers."

20 MR. SNYDER: Do you think you might be able to arrange

21 for both of those in the last final editions?

22 CHAIRMAN SHEPARD: I certainly will attempt to, yes.

1 MR. SNYDER: Thank you.

2 CHAIRMAN SHEPARD: Are there any other materials that

3 might be requested that fall under this same sort of general

4 category?

5 MR. WALKUP: There were a couple of studies we talked

6 about this morning, but you had made notes of them at the time,

7 with the presenters.

8 MR. SNYDER: Times Beach was one we weren't sure

9 that it had or had not been distributed.

10 CHAIRMAN SHEPARD: Times Beach has been published. We'll

11 get copies for you. Okay. Actually, I think it's the Quail

12 Run. Have you all seen -- I think we sent copies of the NCI

13 study, Sheila Hoar study?

14 MR. SNYDER: Yes.

15 CHAIRMAN SHEPARD: Everybody received that.

16 MR. SNYDER: I'd like to take a minute. I appreciate

17 over the past several weeks that you've gotten a number of items

18 to us, and that has been very helpful, and I thank you for that,

19 for arranging for all that.

20 CHAIRMAN SHEPARD: Hugh?

21 MR. WALKUP: Yes, I would like to add to that. That

22 I think since our last meeting I have really appreciated your

1 office's responsiveness and the amount of information and mater-
2 ials that we have received. I thank General Wells, Dr.
3 FitzGerald and Mr. Snyder for their help in helping us get or-
4 ganized and communicating our suggestions and helping implement
5 them. I think that has helped this meeting immeasurably.
6 I know it's helped me be better prepared for the
7 meeting and I feel as if we're making more of a contribution
8 than in the past. Thank you.
9 CHAIRMAN SHEPARD: Thank you. Okay.
10 MR. WALKUP: Would this be an appropriate time for that
11 resolution I was talking about, or when would be a good time for
12 me to bring that up?
13 CHAIRMAN SHEPARD: Any time. Go ahead.
14 MR. WALKUP: Lacking my word processor, but getting
15 into "whereas's" let me read it to you. "Whereas the veterans
16 outreach program vet centers have provided invaluable outreach
17 and information and support to Vietnam veterans on Agent Orange
18 as well as other issues, and whereas federal and community
19 resources for Vietnam veterans issues continue to decline while
20 demand increases, the committee encourages the Administrator to
21 identify means to continue existing vet centers and community
22 outreach locations.

1 MR. SNYDER: Second.

2 CHAIRMAN SHEPARD: That's fine. Any discussion?

3 DR. KAHN: The outreach centers are something that

4 works.

5 CHAIRMAN SHEPARD: I think that's fine, and I will

6 be happy to transmit that to the Administrator. There is

7 another advisory committee that deals

8 more closely, historically,

9 with the vet center program. So it might be a good idea if

10 you have somebody

11 on that committee

12 to introduce it.

13

14 You're smiling. You're sounding like it's already

15 been done.

16 DR. WALKUP: They're way ahead of us.

17 CHAIRMAN SHEPARD: They've done it. Okay. So what

18 you're doing is adding --

19 MR. SNYDER: Adding the number and the noise, yes.

20 CHAIRMAN SHEPARD: All right. Okay. Fine. Very good.

21 I was not aware that it had been introduced in that because I

22 haven't attended that last meeting.

1 Can we have a copy of that, and we'll type it up and
2 add to this?
3 DR. WALKUP: Oh, of course.
4 CHAIRMAN SHEPARD: I've given it to Don Rosenblum.
5 Appreciate it. Okay. Any other questions concerning service
6 organization concerns? Unfortunately Mr. Estry is not here and
7 Mr. Gorman had to leave. By the way, did someone pick up Mr.
8 Gorman's folder? Okay.
9 AGENT ORANGE WORKSHOP
Next on the agenda is the discussion of the Agent
10 Orange workshop idea. Should a consensus Agent Orange workshop
11 be held next year to review available information regarding Agent
12 Orange effects? Who should sponsor it? How should it be
13 structured? What should the VA's role be? We circulated
14 these questions to the committee, and we have had some responses.
15 I think in general, if I'm correct in summarizing
16 this, there seems to be a general consensus that it would be
17 helpful to have such a workshop. I'm not sure the level of
18 enthusiasm for it. Let me just share with you an idea I've
19 just developed in my mind in the last couple of days.
20 Next year there is to be an Agent Orange, a dioxin
21 workshop in Las Vegas, similar, I guess, in some respects to
22 the workshop -- excuse me -- the symposium that was recently

1 held in Japan. I think at a previous meeting, Hugh Walkup
2 suggested that maybe it would be a good idea to have this workshop
3 outside the Washington area in a more central location. And I
4 think he even volunteered maybe to have it closer to the State
5 of Washington.
6 DR. WALKUP: Another central location.
7 CHAIRMAN SHEPARD: Right. Another central location.
8 Maybe Las Vegas is something a happy medium.
9 DR. WALKUP: How about Hawaii?
10 CHAIRMAN SHEPARD: I think -- at least it's worthy
11 of consideration perhaps to think about organizing, if it's
12 the feeling of the committee that such a workshop would be
13 helpful, perhaps to organize it in conjunction with the Las
14 Vegas meeting. The timing is about right, about a year from
15 now. A lot of studies will have been completed between now
16 and then. Hopefully, the program will be of interest to --
17 at least in large measure to the work of this committee and
18 also the Environmental Hazards Committee.
19 I have volunteered, and it's my understanding that my
20 volunteering has been accepted, to serve as a member of the
21 committee for that symposium. So I just throw that out as a
22 thought, the possibility of running an Agent Orange workshop

1 in conjunction, or back to back with this symposium.

2 MR. SNYDER: Would it be realistic to think that both

3 these commitee and the Environmental Hazards Committee could

4 happen to have their meetings the day after or before or during?

5 CHAIRMAN SHEPARD: That's, in essence, what I'm pro-

6 posing and run a workshop, a consensus workshop, in conjunction

7 with that.

8 DR. FITZGERALD: I'm not sure what you mean by a

9 "workshop"?

10 CHAIRMAN SHEPARD: Okay. It seems to me that what

11 is needed at this juncture, or more accurately maybe a year from

12 now when much of the research that we've all been anxiously

13 awaiting for will, in fact, be completed and published. Research

14 that deals directly with the Vietnam veteran. A lot of research

15 has gone on, and much of it has been presented at these various

16 symposiums. Relatively little of it, and Dr. Kahn's study, of

17 course, is a notable exception, relatively little of it has

18 dealt directly with the Vietnam veteran and the Agent Orange

19 issue although tangentially they are related in many ways.

20 So a consensus workshop, as I would envision it, would

21 be an attempt to bring together the research that pertains

22 directly to the Vietnam veteran and Agent Orange exposure for

1 the benefit of people in leadership positions who deal with
2 concerns of veterans in an attempt to come to some kind of, at
3 least beginning a process for developing a consensus as to where
4 we stand, what the evidence is so that we can all be sharing
5 that. And hopefully be speaking with one voice, not that we'll
6 ever get total agreement on all of these issues, but at least
7 begin to build a sense of consensus as to the relevance of
8 this research and begin to sort out for veterans what has
9 developed and what may still lie ahead unresolved.
10 For example, the question of birth defects --
11 DR. FIZGERALD: Question of what?
12 CHAIRMAN SHEPARD: Birth defects. Two large studies
13 have been done. I don't know that I'm speaking for veterans,
14 but I have a sense that birth defects question is, at least in
15 part, resolved in the minds of many veterans. I'm sure there are
16 people who will not accept that, but I just cite that as an
17 example. Whether it's a good example or not, I don't know.
18 But to begin to look at the evidence and see if we
19 as people who are familiar with the research, have been monitor-
20 ing the research, are comfortable saying words of assurance, if
21 that is appropriate, or words of concern, if that's appropriate,
22 to veterans who continue to be concerned. In other words, to

1 have a network of informed people to relate questions on an
2 informed basis to veterans. That's a longwinded answer. Did
3 I answer your question?
4 DR. FITZGERALD: Not really.
5 CHAIRMAN SHEPARD: Maybe that's as close as I come to
6 answering your question.
7 DR. FITZGERALD: I think really what I'm after are
8 the nuts and bolts, what format it would be in, what we're talk-
9 ing about because when you're talking about a workshop among
10 different organizations, they're all going to have to clear that
11 answers with the individual organizations.
12 CHAIRMAN SHEPARD: Maybe the first one of these work-
13 shops will be more exploratory than definitive. But it seems to
14 me that this time a year from now we're going to have a lot more
15 answers, or a lot more evidence, a lot more results of studies
16 that we can deal with than we have now.
17 DR. FITZGERALD: I can't think of a better place than
18 Las Vegas.
19 CHAIRMAN SHEPARD: Put all the studies in the hopper
20 and spin the wheel.
21 GENERAL WELLS: I have a problem.Who is going to attend
22 this workshop?

1 CHAIRMAN SHEPARD: I'm sorry?

2 GENERAL WELLS: Who's going to attend this workshop?

3 Just committees or state committees, or veterans or --

4 CHAIRMAN SHEPARD: All of the above. I don't know.

5 GENERAL WELLS: Oh, I see. Okay.

6 CHAIRMAN SHEPARD: Yes. That's obviously a very

7 legitimate question and one that would have to be worked out by

8 a planning and organizing committee. I guess I would like to

9 hear some expression from other members of committee as to

10 whether or not they would think such a process would be

11 useful. Obvioulsy, it's going to take a lot of work, and probab-

12 ly some degree of money.

13 My sense is that the VA should not be the prime

14 sponsoring organization. I would like to have somebody outside

15 the VA take a leadership role. I mean not to say that the VA

16 won't cooperate and co-sponsor, whatever, but I think it would

17 add to the credibility of the process if it were at least

18 co-sponsored by other than the VA. A consortium of service

19 organizations, for example. A consortium of state organizations,

20 for example.

21 MR. CONROY: Do you envision the results of this

22 workshop being published, Dr. Shepard?

1 CHAIRMAN SHEPARD: I would certainly hope so. If it
2 were well put together, I think it would be a great shame if the
3 results were not published. It would be fact-finding and then
4 consensus building, and then a publication that the various
5 sponsoring groups would endorse.
6 In a sense, and in somewhat a different way, in a
7 sense, not too dissimilar to what the American Medical Associa-
8 tion is attempting to do, to gather the facts and come up with
9 conclusions, aimed at a different audience.
10 MR. SNYDER: I think for our organization that we are
11 generally in support of opportunities to get information.
12 Whether this would be the shape or the forum to do that, I'm
13 not sure yet until we know more of whether we're guessing that
14 this would be something potentially co-sponsored by -- perhaps
15 a workshop added to the symposium, and would have some reserva-
16 tions, I think, about VVA appearing as a co-sponsor along with
17 the American Chemical Society. It wouldn't exactly be like
18 cosponsoring something with Dow, but close to that.
19 CHAIRMAN SHEPARD: I wouldn't say so.
20 DR. KAHN: That should not be an objection. I'd say
21 the power of Dow Chemical in the American Chemical Society is
22 minor, at best. You would not get any hanky-panky, as it were,

1 occurring in a meeting with ACS sponsorship. And if there were
2 there would be bloody well loud scream from within the ACS about
3 any such attempt. One would have to be somewhat careful in
4 organizing a conference to be sure that all views are represented
5 but that would not be something that the ACS itself would take
6 part in. The conference organizers would do that.
7 Where you would get help from the ACS would be in
8 logistics, how to set up a conference. There may be reasons not
9 to do this, but that's not one of them.
10 MR. SNYDER: Good. Thanks for clarifying that.
11 CHAIRMAN SHEPARD: ACS is a professional society.
12 DR. KAHN: I'm a member of ACS.
13 MR. SNYDER: Okay.
14 CHAIRMAN SHEPARD: Any other comments? Do you think
15 it's a good idea? Am I whistling in the wind? I view it as a
16 service to concerned veterans. In other words, if they
17 can't look to this committee as coming up with some kind of
18 information, and it very much touches on what you were saying
19 earlier, Hugh, and I'm in full sympathy with.
20 DR. KAHN: The problem would be this, Barclay, I see
21 two kinds of problems. One is somewhat philosophical. One is
22 practical. Okay. I don't think either are insurmountable, but

1 the practical one is organizing a conference, and I've done it
2 before, is one hell of a job. I can't take it on. I don't know
3 about the other people here. I'm already drowning. I have a
4 fulltime teaching load, two fulltime research activities, and
5 I have a sabbatical coming up in a year, and I'm not going to
6 miss it.
7 So the practical aspects of getting such a thing off
8 the ground done in a craftsmanlike manner are not trivial.
9 CHAIRMAN SHEPARD: No. I know. I've done it too.
10 DR. KAHN: The second is somewhat more philosophical.
11 And that is that the notion of consensus meetings in science is
12 a slightly sticky one in that consensus is not something that
13 you can force, nor is it something that you're likely to arrive
14 at by extended discussion if the data themselves still leave
15 room for doubts on either side.
16 And the data will leave doubts in this case on both
17 sides. To try to impose a consensus in that kind of a situation
18 is going to be badly perceived from the hinterlands, and could
19 cause more trouble -- could. So one would have to be extremely
20 careful in writing up the results of such an event to ensure
21 that where there is disagreement, the nature of the disagreement
22 is fully aired so that people understand where it is one side

1 says yea and the other side says nay.

2 And why? If you don't do that, then you've done more

3 harm than good, and you're just going to add fuel to the fire.

4 And that in itself because of the philosophical problem of

5 dealing with the notion of consensus in science when it may be

6 premature that's a sticky wicket.

7 CHAIRMAN SHEPARD: I couldn't agree more. I agree

8 with everything you have said wholeheartedly. And I

9 didn't want to imply that this would wrap up the whole issue,

10 and we could all walk away from Agent Orange and wash our hands

11 of it. Not at all.

12 When I say a consensus workshop, I didn't mean that

13 this would put the lid on it or make it -- I think at some point

14 the process needs to be started, and this would be an attempt

15 to see what it takes to start building consensus. Obviously,

16 one cannot force consensus, and it's highly unlikely that there

17 would be consensus on every point.

18 But to begin to look at the issue of where science

19 can help and where it can't, what studies seem persuasive,

20 what studies have scientific acceptance, peer acceptance,

21 that sort of thing. In other words, we could start, it seems

22 to me an effort could be made to start looking at how we can

1 agree on certain things.

2 MR. CONROY: And I think, Dr. Shepard, Congress and
3 veterans, too, have been coming to us saying, well, now the
4 federal government has invested well over $100 million in-
5 to Agent Orange related research. Where does the preponderance
6 of the evidence comes down, and I think that would be a starting
7 point for establishing that.

8 CHAIRMAN SHEPARD: I think we owe it to the taxpayers
9 to begin to start this process. As you say, a lot of money has
10 been expended, but my first concern is really for the well-being
11 of veterans, and I think that they are looking to groups such
12 as ours to give them the answers.

13 DR. WALKUP: I think there are two points I would like
14 to make. One, as I understand it, we would not necessarily be
15 a group of scientists having a quasi-formal consensus of thing.
16 That in addition to the problems that Dr. Kahn identified that
17 there would be a number of non-scientific members and a number
18 of interested parties who had some other issues.

19 Consequently, I think that the number of the issues
20 that would need to be discussed would be issues that aren't
21 doable by science, or aren't relevant to scientific studies,
22 but are to some extent political, moral, philosophical sorts of

1 issues that I think often are of a concern to the veterans we
2 have been talking about.
3 Second, I would like to point out that I have the im-
4 pression that initially this idea got underway when Dr. Young
5 was here about a year ago, and referred to getting closer to the
6 point where we could identify Agent Orange as a myth. And there
7 may be expectations in some circles that we may be moving towards
8 the place where there would be a consensus as we saw to some
9 extent from the AMA, or the Scientific American article, are
10 those kind of things that says, okay, we haven't found anything
11 real relevant. We've spent a lot of money. Let's get off of
12 this dime. If that is the expectation of a workshop organized
13 in a way you're talking about, I think they would be better off
14 investing their money someplace else.
15 I think that what would happen, as you said, a con-
16 tinuing dialogue that may resolve or clarify some issues for
17 some veterans, but would hopefully expand the involvement of
18 people in the sorts of issues that we deal with frequently.
19 CHAIRMAN SHEPARD: Okay. One of the things that I
20 would envision is that the science would be presented at the
21 symposium. The detailed technical scientific papers and evidence
22 would be presented at the symposium. People who are interested -

1 DR. KAHN: Well, those are going to be current papers,
2 Barclay.
3 CHAIRMAN SHEPARD: What?
4 DR. KAHN: At the symposium, the Dioxin '87, those
5 are going to be current papers.
6 CHAIRMAN SHEPARD: Yes. That's what I'm saying.
7 DR. KAHN: All right. So it wouldn't be the whole --
8 CHAIRMAN SHEPARD: The new science would be presented
9 at that.
10 DR. KAHN: But some of the background stuff has been
11 out there awhile, including stuff that is now already published,
12 won't appear.
13 CHAIRMAN SHEPARD: That's true. That's true. But --
14 DR. KAHN: If that is going to get reviewed as part
15 of our general discussion --
16 CHAIRMAN SHEPARD: If I may finish?
17 DR. KAHN: Sorry. Go ahead.
18 CHAIRMAN SHEPARD: Okay. The new science will be pre-
19 sented at the symposium so we don't have to spend at the work-
20 shop which will be possibly a follow-on to the symposium, but
21 scientists would be attending the symposium in order to absorb
22 the new science, and then could follow on with an interpretation

1 in somewhat less scientific terms. You know we've been grappling
2 with trying to make science understandable, or translated to
3 people who are not scientifically trained necessarily.
4 But that would be one of the benefits of having them
5 run back to back and that the scientists attending the symposium
6 chances are would have attended symposia and would be familiar
7 with the science in its larger context, and then could be
8 available for commenting on the completed research, either
9 old research or a new research.
10 But I agree. I'm not of a mind, or I'm not persuaded,
11 or not naive enough, to think that one such workshop is going
12 to solve the issue. But I think a start needs to be made. That
13 is my personal opinion. I just wanted to get feelings from the
14 rest of you as to whether or not you think that would be the
15 worth the effort.
16 DR. KAHN: It depends on whose effort.
17 CHAIRMAN SHEPARD: Sure. But aside from whose effort,
18 if the concept is a good one, is worth pursuing at least,
19 through exploratory, then I guess who would be willing to be
20 part of the process? I think it ought to be a broadbase group.
21 And the VA, although playing a supportive role,
22 should not necessarily be playing the lead role. So I'm even

1 hesitant to leap into this very far without fairly broad
2 support.
3 DR. FITZGERALD: I think I disagree with you, and the
4 reason for that is that I think the summation of Agent Orange
5 has got to come from the VA per se. But this group as well as
6 the scientific group acts as an advisory, not as a prime body.
7 I don't think you'll ever get complete consensus, as we've
8 already expressed. We'll get a lot of agreement, and I think
9 it might be quite appropriate because of the time that has
10 passed and the multiple meetings that we have had to spend a
11 meeting to come up with a summation of what at this time we
12 agree on.
13 And what we don't agree on that has to be pursued
14 further, rather than have just a workshop. I think your question
15 is very valid. The time has come now to come and say where are
16 we, what have we done, what do we agree on, where we should be
17 going, rather than just listening to a lot of individual pre-
18 sentations.
19 CHAIRMAN SHEPARD: As part of the process, the next
20 meeting, for example, of this committee could be started along
21 those lines.
22 DR. FITZGERALD: The entire meeting.

1 CHAIRMAN SHEPARD: Yes, the entire meeting. How would
2 you all feel about that? Or if not the next -- well, the next
3 meeting, if it were done in conjunction with the Environmental
4 Hazards, and at least we would have a fairly broad-based process
5 there that would involve a lot of individual scientists and two
6 committees. Does that make sense?

COMMITTEE EFFECTIVENESS

7 All right. Thank you very much. We have another agenda
8 item -- committee effectiveness. I don't know if you want to
9 start discussing that. It's a rather knotty problem at this
10 late hour, but --
11 DR. KAHN: There is one thing that I would like to
12 raise here that came to mind, and I don't think we should spend
13 much time on this. The CDC has just done a study of 50
14 exposed people in Missouri, as we mentioned, and 50 unexposed,
15 and they presented it in Japan, as I described, and as Mr.
16 DeStefano described.
17 They did an excellent job of it. No question about it.
18 And the first time the existence of that study became known
19 to the members of the committee is when they presented it in
20 Japan. We didn't know that they were studying dioxin levels
21 in Missouri people until that study came out.
22 And yet the planning for that study must have taken

1 some time. I know for a fact that they began serious measurement
2 sometime after March of this year. And that they have been
3 working on the laboratory getting it up to scratch until then,
4 and getting their methods worked out and so forth.
5 Why weren't we told? That is certainly relevant to
6 the questions we consider? Why didn't we know about that study
7 in the planning stages?
8 CHAIRMAN SHEPARD: Well, a couple of things come to
9 mind. First of all --
10 DR. KAHN: We are here for that purpose.
11 DR. HODDER: They did make it known that they were
12 going to be doing serum levels. If that was a pilot study, I
13 doubt if it even had a very significant write-up. It was probab-
14 ly done fairly much -- for two years now they have been talking
15 about -- Vernon Houk has been talking about trying to do
16 blood levels in lieu --
17 DR. KAHN: Talking about is one thing. Coming out
18 with a formal protocol for a study which they followed quite
19 well. They actually did a very nice job of it. No quibble.
20 CHAIRMAN SHEPARD: They never sent us the protocol.
21 If you are suggesting that we had prior information, it was
22 -- first of all, it was not a study of veterans. As far as I

1 know, there was no veterans.

2 DR. KAHN: I realize that, but certainly it bears on

3 the question over which this committee has purview, and while

4 they may never have sent you the protocol, I find it hard to

5 believe that somebody in the VA didn't know it was going on.

6 You may not have had the documents, fair enough, but in any

7 case, since the VA does have some liaison role with the CDC

8 to know what's going on in the field, I find it -- I just don't

9 find it believable that the VA didn't know that this was going

10 on.

11 CHAIRMAN SHEPARD: The VA knew that the CDC was doing

12 an analysis of blood and fat levels in people exposed,

13 occupationally exposed and residentially exposed. They were

14 also doing --are you talking about the blood and fat analysis?

15 DR. KAHN: Yes. Yes, the blood and fat analysis.

16 CHAIRMAN SHEPARD: Analysis.

17 DR. KAHN: You must have known about that.

18 CHAIRMAN SHEPARD: Yes, and so did the Congress and

19 so did the congressional --

20 DR. KAHN: We didn't know about it at all. We had no

21 clue.

22 CHAIRMAN SHEPARD: Okay. I apologize if that is the

1 case. I had the impression, as Dr. Hodder did, that it's been
2 talked about in this committee for some time as a proposal that
3 CDC has been entertaining.
4 DR. KAHN: Yes. We knew that there had been a proposal
5 entertained, but you know, proposals rise and proposals fall.
6 They come and they go. And you never know when you hear that
7 whether it's real.
8 CHAIRMAN SHEPARD: I guess if you're concerned
9 about it, then one way to deal with that is ask. We were aware
10 of it. It didn't bear on this committee directly. I'm sure
11 it bore much more directly on you. I was under the impression,
12 as a matter of fact, that you -- as a matter of fact, I was told
13 at the Beyreuth Conference that you had talked with the people.
14 DR. KAHN: I have indeed. I knew they were planning
15 -- but the point is, see, even there they were cagey with me.
16 I talked with Jim Pirkle and several other folks down there,
17 but mostly with Pirkle. And they were pumping me for informa-
18 tion which I was freely willing to give about what we were
19 doing. Okay. I couldn't get a squeak out of them as to what
20 they were doing.
21 CHAIRMAN SHEPARD: We didn't either, Peter. We had
22 no inside information. I mean you were privileged to as much

1 information as we --

2 DR. KAHN: Mind you I didn't try very hard at that

3 time. But it seems to me that if there is something that goes

4 on in the area of health related effects of herbicides that

5 that certainly is related. We should have known about it. Some-

6 body dropped the ball.

7 DR. HODDER: I hate to go on record of saying some-

8 thing like this, but having worked with the CDC before, informa-

9 tion transfer often is one way.

10 DR. KAHN: Yes. Right.

11 MR. SNYDER: Is that one of the studies -- as I under-

12 stood the process -- things presented at the symposium have not

13 been published.

14 DR. KAHN: That's correct. They have not been publish-

15 ed.

16 MR. SNYDER: They take comments and then he writes

17 something.

18 DR. KAHN: Right.

19 MR. SNYDER: And there is not even any preliminary

20 stuff in writing to pass on for example to the other like the

21 Environmental Hazards Committee?

22 DR. KAHN: No, but for example, I got up here -- but

1 see, Keith, what's happened is I've gotten up here at this
2 committee meeting a number of times, two or three times, I guess
3 over the last few years, and I've explained what we're doing,
4 how we're doing it, why we're doing it, and what our progress
5 is without giving results. Okay. Why didn't the CDC do that?
6 Certainly if they're going to use the measurements
7 they made on Missouri people as justification for doing a pilot
8 study of Vietnam veterans in order to rescue the big epidemiologi-
9 cal study on Vietnam veterans, we damn well should have been
10 in there at the groundwork, and we weren't, and I want to know
11 why the hell we weren't.
12 You know, information sharing has got to be a two-
13 way street. To put it crudely, if it doesn't come my way, it
14 isn't going to go the other way.
15 CHAIRMAN SHEPARD: You're looking at me as though I
16 have the responsibility of sharing all scientific --
17 DR. KAHN: No, no, I don't mean that. The point is,
18 Barclay, I think you've been had here. Barclay, I think you've
19 been had here. I don't rank you as holding information back
20 from us on this particular case. I agree you probably had no
21 more information than I did in this.
22 And what I had was damn little. And I don't think

1 that is the right way to go. Well, you have some oversight
2 capacity over what the CDC is doing.
3 CHAIRMAN SHEPARD: Not in that regard.
4 DR. KAHN: No?
5 CHAIRMAN SHEPARD: None of that money, or any of that
6 money was provided for the Agent Orange work. No, that is
7 not true. The only hesitancy I have is, in part, you're right
8 because they did propose that at one of the Agent Orange Working
9 Group science panel meetings this summer. And it was also dis-
10 cussed during one of the House -- well, I think the House hearing
11 was it not? Dr. Mason, Dr. Houk.
12 DR. KAHN: It was the House committee meeting that
13 occurred sometime before I went to Japan.
14 CHAIRMAN SHEPARD: Last summer, yes.
15 DR. KAHN: It was summertime. That's the first I heard
16 of it.
17 CHAIRMAN SHEPARD: Well, you heard about it very soon
18 after I first heard about it because they came up with the
19 proposal at the same time.
20 DR. KAHN: They had been working on it. That was in
21 the summertime, late July, early August, something like that
22 before Congress broke up. They had been working like dogs on

1 that thing since March doing the samples.

2 CHAIRMAN SHEPARD: They had been talking about since

3 the Beyreuth meeting.

4 DR. KAHN: Yes. And the methods work must have been

5 going on for the previous year. If all that is in the works,

6 why the hell didn't we know about it? That's our job to know.

7 CHAIRMAN SHEPARD: I guess it's our job to find out,

8 too, Peter. I think that you as a member of this committee have

9 an equal responsibility if you think something is going on to

10 pursue it or to ask me. If you can't pursue it, then ask me to

11 pursue it in your behalf.

12 DR. KAHN: It only occurred to me in Japan. The

13 problem only occurred to me when I was in Japan of why the hell

14 didn't I know about this in advance.

15 CHAIRMAN SHEPARD: 20/20 hindsight is good stuff.

16 DR. KAHN: Yes, right. Okay. But the point is --

17 I don't blame you for this. You're not responsible for what

18 happened. Okay. You've been had like the rest of us.

19 CHAIRMAN SHEPARD: Well, I don't --

20 DR. KAHN: I'm a little bit annoyed over that.

21 DR. WALKUP: Okay. What we do around here when we

22 get annoyed about things is we pass resolutions, Peter, which

1 really solves all the ills of the world.

2 DR. KAHN: A resolution, whereas, et cetera --

3 I would like to see some way of finding out -- I don't quite

4 know how to frame this -- that the CDC could be admonished in

5 some way to share with us what their plans are before those

6 plans are engraved in stone.

7 CHAIRMAN SHEPARD: Well, they had -- it was kept

8 fairly --

9 DR. SNYDER: Well, for the final study for this thing,

10 the gentleman, Dr. DeStefano said he would talk to you after-

11 wards about the protocol for the pilot study on the serum,

12 the cross-reference to records and what not.

13 DR. KAHN: Yes, I talked to him afterwards. He gave

14 me his name.

15 DR. SNYDER: But he didn't volunteer to give us the

16 protocol. And we didn't have that ahead of time. Are we

17 going to get it?

18 DR. KAHN: He told me he didn't have the authority to

19 have me review it in advance of the 27th, but that if I would

20 call him at his office within the next day or two, he would see

21 about arranging that. Mind you I have to write a major bio-

22 chemistry exam for the 28th. I have all sorts of other things

1 to do, and it's now the 22nd, 21st. I forget. How am I going to
2 do all that?
3 MR. SNYDER: Do you have access to that? I mean if
4 you had access to it, I guess is one question. But are you free,
5 then, to pass it along is, I guess, always a separate question.
6 CHAIRMAN SHEPARD: Well, this has all happened very
7 recently. It was passed to the Agent Orange Working Group
8 science panel.
9 DR. KAHN: What's going to happen is they're going to
10 review this thing on the 27th, okay. They're going to approve
11 it; right. And after that any sort of comments --
12 CHAIRMAN SHEPARD: I would not be so confident that
13 that was the case.
14 DR. KAHN: Well, I think that's going to happen.
15 Any further comments from us are going to be irrelevant at that
16 point. What sort of way is that to run a railroad?
17 MR. SNYDER: Well, wait a minute. If in fact --
18 CHAIRMAN SHEPARD: It's a question of who's running
19 the railroad.
20 MR. SNYDER: What do you think our committee should
21 do, for example, if there was not approval to go forward with
22 the pilot? I mean if you don't have approval to go through with

1 the pilot study, then you don't have approval to go with the
2 epidemiological study.
3 CHAIRMAN SHEPARD: Let me point out something. This
4 committee is not in the approval chain for protocols to be done
5 by another agency. Okay. I have to tell you that.
6 DR. KAHN: I realize that. But we are--
7 CHAIRMAN SHEPARD: I'm not in the approval chain.
8 DR. KAHN: Okay. But we are advisory.
9 CHAIRMAN SHEPARD: The VA really isn't in the approval
10 chain. The only role the VA plays is a member of the Agent
11 Orange Working Group, and I do sit in as a member of the Science
12 Panel of the Agent Orange Working Group.
13 DR. KAHN: Yes. But the point is, Barclay, what you
14 said is part of the truth, not the whole truth. Okay. We are
15 advisory to the VA, and the VA has a role in that approval
16 even though you don't dominate it.
17 CHAIRMAN SHEPARD: Okay. I think the VA also has
18 the prerogative of asking what kind of advice they want. Not
19 necessarily that. Let me withdraw that. Back up.
20 MR. SNYDER: Well, no, that's an interesting state-
21 ment, since this is a transcription of that. You can't exactly
22 withdraw that.

1 DR. WALKUP: That's a very true statement. I think --

2 CHAIRMAN SHEPARD: That isn't to say that you cannot

3 advise the VA on any subject you wish, but if the VA wants your

4 advice, if the VA wants and solicits your advice, then I think

5 the VA initiates that. If you feel that VA needs your advice,

6 then it's your opportunity and responsibility to initiate that

7 advice.

8 If we don't know that you want to give us advice on

9 something, then for you to turn around and say why weren't we

10 consulted on this, I think is a little bit out of the prerogatives

11 Now, you may feel that way, and I can't fault you for your

12 feelings, but I think an advisory committee -- my understanding

13 of it is to be available when advice is sought on a particular

14 issue.

15 DR. WALKUP: Okay. I think maybe it would --

16 CHAIRMAN SHEPARD: It's a two-way street, though. I

17 agree.

18 MR. SNYDER: That's a big difference I think than my

19 view of what advisory committees should be doing in any capacity,

20 whether it's us advising a federal agency or us, a subcommittee

21 of an organization, advising the organization. Certainly you

22 are given a charge, and you are asked to do things. And maybe

1 your advice is specifically solicited on some items, but you're
2 always out there and you're supposed to be awake and being con-
3 scious of issues that are developing and bring them to the
4 agency.
5 And I wouldn't want to think that we're not asked to
6 comment on things because our comments aren't wanted on certain
7 things. I'm not sure that's the message that you were partly
8 suggesting or not.
9 GENERAL WELLS: I don't think that's what you meant to
10 say.
11 MR. SNYDER: You said that the VA is free to solicit
12 from whom it wants advice.
13 CHAIRMAN SHEPARD: Yes.
14 GENERAL WELLS: Sure, and it is.
15 MR. SNYDER: And it's free to not solicit it from us.
16 And I think what I'm saying is that we as a committee or I as a
17 member of this committee want to feel a little more like I'm in
18 a position to advise whether my advice is sought or not.
19 GENERAL WELLS: That's right. We can advise. Whether
20 they take it or not -- and the other thing is I think we can
21 request information, but I don't think we can demand it.
22 DR. KAHN: Fair enough. Fair enough. But here is the

1 case, though, where something that was directly relevant to
2 what we are here for -- okay -- you can't get much more relevant
3 than the chain of logic linking the current CDC results on fat
4 and blood measurements to the ultimate epidemiological study.
5 So it was directly relevant, and the CDC did not trouble to
6 share what they were doing with anyone.
7 I don't blame you for this, Barclay. Let me say it
8 again. You didn't create that situation.
9 CHAIRMAN SHEPARD: My shoulders are broad. You can
10 blame me if you want to. No, I --
11 GENERAL WELLS: I don't see anything wrong where we
12 could make a comment that there was question in the committee as
13 to why. But for us to say they will, I think, is --
14 DR. KAHN: No. I'm just raising the question, Barclay,
15 for you to pass on to wherever it might do the most good as to
16 why we were not told about this at a more advance stage.
17 CHAIRMAN SHEPARD: I guess I, in part, feel that you
18 as an interested scientist has an obligation to this committee
19 to find out, or if you're having trouble finding out that you
20 then maybe turn to me and say can you help me. I'm an interested
21 scientist, a member of your advisory committee.
22 DR. WALKUP: I would suggest that the advice of this

1 committee to the Veterans Administration be that the Veterans
2 Administration through the Science Panel or whatever is the
3 appropriate means attempt to make veterans concerns and issues
4 relevant to any study touching on health effects of herbi-
5 cides, whatever the agency -- I think that's the advice Dr.
6 Kahn has been giving you.
7 MR. SNYDER: Yes, and raise --
8 DR. WALKUP: That it's as an advocacy -- within the
9 federal government, the Veterans Administration role -- my
10 advice to the Veterans Administration would be that you take
11 on the role of advocate for the veteran vis-a-vis other agen-
12 cies where their activities touch on the health and well-
13 being of veterans. I think this is a prime case of when that
14 was there. And hopefully somebody in the Veterans Administra-
15 tion on the Science Panel did talk about some of those issues.
16 And as advisors we would like to help you do that
17 better.
18 CHAIRMAN SHEPARD: In response to that -- you almost
19 volunteered, and I will pick that up -- I would like very
20 much to consider the appointment of a small subcommittee of
21 this committee to look at the issue which you brought up earl-
22 ier, Hugh, of setting up a mechanism for communicating points

1 of value to the veteran community who remain concerned about
2 this issue. And I would like very much, Hugh, for you --
3 you don't have to give me an answer now -- to consider chair-
4 ing such a subcommittee to look at how information can be
5 organized effectively to be shared with the veterans.
6 As I said, you don't have to give me an answer now,
7 but please think about it and we can get together by phone
8 or by letter or whatever. I think it's a very important issue,
9 and I think it may turn out that that is the most important
10 function of this advisory committee to advise the VA on how
11 to share and to help in the process on how to share informa-
12 tion with concerned veterans. Because we keep getting criti-
13 cized for -- I get the sense that the VA keeps getting
14 criticized because there are still concerned veterans out
15 there.
16 We cannot, I don't think, turn off that concern.
17 I think that concern is going to be with us for quite awhile.
18 But I think we do have an obligation as an agency, and I'm
19 speaking for the VA now, we do have an obligation to share
20 information in an as effective a way as possible with veterans
21 which will be helpful to them.
22 DR. FITZGERALD: I'm not sure that that's an appropriate

1 task for this committee, but rather for the Information
2 Service of the Veterans Administration. We can pass on to
3 them information that should be publicized. In fact, that is
4 how the pamphlets got started. That's how your tapes got
5 started. We can say to you this isn't sufficient. The
6 Information Service is not doing an appropriate job at the
7 present time.
8 CHAIRMAN SHEPARD: I'd like to go off the record for
9 a minute and share some things.
10 (Whereupon, a discussion was held off the record.)
11 CHAIRMAN SHEPARD: Yes. I certainly will make an
12 attempt to have the tape shown to the committee.
13 GENERAL WELLS: I don't see any reason why the
14 committee couldn't say that one of the major issues within
15 this committee is the lack of credibility or the lack of
16 capability to get information out to the concerned veteran.
17 DR. WALKUP: I want to make sure. We kind of
18 switched there. I want to reiterate my point before. I agree
19 that information out to the veterans is important, but I think
20 the other issue about the role of this committee, and the role
21 of the Veterans Administration vis-a-vis other federal entities
22 is important, not to be lost. And I just want to make sure

1 that we don't get the two things crossed.

2 CHAIRMAN SHEPARD: And I think we've done that,

3 Hugh. The Agent Orange review talks about research being

4 done outside the agency as much as it does about --

5 DR. WALKUP: Right. Right. And specifically one

6 of the things that I don't think we've talked about a lot,

7 but something that seems to me like it's going to -- that we

8 need to look at some more is how do we look at the sub-popula-

9 tion of Vietnam veterans within the epidemiological studies

10 or studies of other populations where at times we've got

11 people living in the trailers who are Vietnam veterans.

12 Now, what's the impact of the double exposure that

13 they are experiencing? Is there any possibility of that? Or

14 people who work in the forest or the farm? Some of those sorts

15 of things I think are relevant to the work of our -- relevant

16 to the interest of the veterans and the Veterans Administra-

17 tion. And I think a real legitimate role for the Veterans

18 Administration, and consequently this committee to be giving

19 some unsolicited advice to the other agencies who are involved

20 in those kinds of issues.

21 MR. SNYDER: Well, it's also partly what was men-

22 tioned earlier in terms of considering standards, how to

1 limit exposure perhaps, looking at ways and issues relating
2 to avoiding exposure, avoiding the problems in the future.
3 We should be advising that those questions be looked at and
4 examined.
5 CHAIRMAN SHEPARD: You're suggesting something
6 along the lines, if you are exposed to Agent Orange don't use
7 Weed-B-Gone in your backyard?
8 MR. SNYDER: Perhaps.
9 CHAIRMAN SHEPARD: Yes. I mean that's an example.
10 MR. SNYDER: Folks need to be educated that those
11 substances aren't terribly healthy to spray around your cats,
12 let alone your kids. And a broader than simply narrow
13 veterans -- maybe the Veterans Administration takes the lead
14 and points out that there is more than just Vietnam veterans
15 involved here. That we as an agency have been looking at
16 Vietnam veterans concerns, and those concerns have other
17 ramifications in the environmental movement as a whole.
18 DR. KAHN: One of the things that is happening in
19 New Jersey is as a result of our findings there is now going
20 to be a much more serious effort at looking at the implica-
21 tions of exposure to dioxins in dioxin-like compounds in the
22 general population.

1 I think this is just a minor aside scientifically.
2 Dioxin is an interesting compound, not just in its own right
3 but for what it signifies by way of toxic exposures to a host
4 of compounds that have similar effects and similar long life
5 in the environment.
6 So the Agent Orange question has catalyzed that work
7 in Jersey now. There is now going to be a consortium with
8 two or two-and-half million dollars of research money to go
9 at it hammer and tongs. And they are talking about consider-
10 ably more than that in the medium future. They are talking
11 about bricks and mortar and research buildings and stuff like
12 that.
13 CHAIRMAN SHEPARD: Any other comments? We haven't
14 had our open forum yet.
15 DR. KAHN: Our forum has left.
16 (Laughter.)
17 CHAIRMAN SHEPARD: We've talked them down.
18 GENERAL WELLS: I must say that I really learned
19 a lot this meeting, and I think it's been a very productive
20 meeting.
21 CHAIRMAN SHEPARD: Thank you for participation.
22 DR. KAHN: Let's bag it.

1 MR. SNYDER: Thank you, sir.

2 CHAIRMAN SHEPARD: Okay. Any other comment? Thank

3 you. Thank you very much.

4 (Whereupon, at 3:55 p.m., Tuesday, October 21,

5 1986, the meeting was adjourned.)

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