UNITED STATES DEPARTMENT OF LABOR

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ADVISORY BOARD ON TOXIC SUBSTANCES AND WORKER HEALTH

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SUBCOMMITTEE ON EVIDENTIARY REQUIREMENTS FOR PART B LUNG CONDITIONS (AREA #3)

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WEDNESDAY, JUNE 29, 2016

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The Subcommittee met telephonically at 10:00 a.m. Eastern Time, Carrie Redlich, Chair, presiding.

MEMBERS

SCIENTIFIC COMMUNITY:

JOHN M. DEMENT

MEDICAL COMMUNITY:

CARRIE A. REDLICH, Chair LAURA S. WELCH

CLAIMANT COMMUNITY:

KIRK D. DOMINA JAMES H. TURNER

OTHER BOARD MEMBERS PRESENT

STEVEN MARKOWITZ, Board Chair FAYE VLIEGER

DESIGNATED FEDERAL OFFICIAL:
CARRIE RHOADS

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

10:09 a.m.

MS. RHOADS: Good morning, everybody.

My name is Carrie Rhoads. I'd like to welcome

you to today's teleconference meeting, the

Department of Labor's Advisory Board on Toxic

Substances and Worker Health. This is a

Subcommittee on Evidentiary Requirements for Part

B Lung Conditions. I'm the Board's Designated

Federal Officer, or DFO, for today's meeting.

First, we appreciate the time and work of our Board members in preparing for this meeting and for their forthcoming deliberations.

Dr. Carrie Redlich is the Chair of the Subcommittee, and the members are Dr. John

Dement, Mr. Kirk Domina, Dr. Laura Welch, and Mr. James Turner. Dr. Markowitz, the Board's Chair, is also on the line, as is Faye Vlieger, who is another Board member. In the room with me are Kevin Bird and Melissa Schroeder from SIDEM, and we're scheduled to meet from 10 to 2 Eastern Time today.

For timing, we're going to plan to take about a 10-minute break at 11:30, depending on where the discussions are, and a 10 to 20 minute break at 1:00, again depending on where the discussions are. Copies of meeting materials and any written public comments are or will be available on the Board's website under the heading Meetings and the listing there for this Subcommittee meeting. The documents will also be up on the WebEx screen, so everyone can follow along with the discussion.

The Board's website is

dol.gov/owcp/energy/regs/compliance/advisoryboar

d.htm or you can just Google "Advisory Board on

Toxic Substances and Worker Health" and it will

probably be the first thing you see. If you

haven't already visited the website, I encourage

you to do so. And after clicking on today's

meeting date, you'll see a page that's entirely

dedicated to today's meeting. We'll publish all

the materials on that page. You can also find

instructions for participating remotely, and

today's agenda will be posted under that.

If you are participating remotely and you're having a problem, please email us energyadvisoryboard@dol.gov.

If you're joining by WebEx, please note that this session is for viewing only and will not be interactive. The phones will also be muted for non-Advisory Board members.

Please note that we do not have a scheduled public comment session today. The call-in information has been posted on the website. You can listen in but not participate in the Board's discussion.

The Advisory Board voted at its April 26th through 28th meeting that the Subcommittee meeting should be open to the public, and so a transcript and minutes will be prepared from today's meeting.

During the Board discussion today, since we're on a teleconference line, please try to speak clearly enough for the transcriber to understand. The transcriber has also called in.

When you begin speaking especially at the start of the meeting, please state your name so we can get an accurate record of the discussion.

Also, for the transcriber, please let us know if you're having an issue hearing or understanding anybody or with the recording.

The minutes are prepared and then certified by the Chair. The minutes of today's meeting will be available on the Board's website no later than 90 days from today, per the FACA regulations. But if they're available sooner, we'll publish them sooner.

Also, even though formal minutes will be prepared, we'll also publish a verbatim transcript, which will be more detailed in nature. We are going to try to have the transcripts posted within 30 days on the Board's website.

I'd also like to remind the Advisory
Board members that there are some materials that
have been provided to you already in your
capacity as special government employees and

members of the Board which are not for public 1 2 disclosure and cannot be shared or discussed 3 publicly, including in this meeting. Please be aware of this as we continue with the meeting 4 5 today. And with that, I convene this meeting 6 7 of the Advisory Board of Toxic Substances and Worker Health Subcommittee on Evidentiary 8 9 Requirements for Part B Lung Conditions, and I 10 turn it over to Dr. Redlich, who's the Chair. 11 Thank you. 12 CHAIR REDLICH: Welcome, everybody. 13 Let me just ask, did anyone else have trouble 14 getting into the WebEx website, or is that just 15 my internet? Yes, I'm having 16 MEMBER MARKOWITZ: 17 trouble, but I have all the attachments that were 18 sent. 19 CHAIR REDLICH: You have the 20 attachments. 21 MEMBER MARKOWITZ: Yes, I have the 22 attachments.

CHAIR REDLICH: Okay. So we put together an outline, and, first of all, as I wanted to say, for anybody who is listening but cannot talk on this conference call, we are interested in your input, thoughts, concerns, so please communicate them afterwards through whichever means you can communicate, and we will receive that input.

We have, I think, a large agenda today, and if anyone has anything to add to the agenda, basically I wanted to give a simplified overview since we've been away from this. I think, Steve, the main thing we were trying to understand was the issues and scope, number three, and then what additional information we needed to accomplish our task and some sort of time line. I was thinking of a time line between now and our next meeting, but there's also a larger time frame, so we could discuss that. Then I just want to make sure everyone has the other documents that were provided.

Does anyone have any big-ticket items

for the agenda that does not fall under one of these categories? Okay.

So I spent the weekend getting back up to speed reading all the various documents that we had received, and I thought, just so we were on the same page, my simplified understanding in about two minutes, and to see if others think that this is our sort of goal, was that we have the EEOICPA Act created by Congress that defined very specific criteria for diagnosing beryllium sensitization, chronic beryllium disease, which is a complex and confusing area even for knowledgeable pulmonologists. And so it seems that this has been a challenging area to review and adjudicate claims.

And then it's sort of complicated by a number of factors. One is that there is a substantial financial implication between having just sensitization versus chronic beryllium disease that can also push agendas and decision-making. And then there's obviously a need for consistency and fairness.

And also, having looked over some of the data and the numbers, appreciation really of the magnitude of the claims process. We're not talking ten claims a year. And also thinking about this, recognizing that there is overlap between our task and that of some of the other committees.

So I think we're going to -- that's sort of the problem is how to make this claims process specifically related to Part B lung conditions, chronic beryllium disease, beryllium sensitization. Silicosis, which is also in with these diseases, seems to be less of an issue.

And so that is my overall sense, as a very simplified view, of the sort of key problems. If anyone has anything to add to that, it would probably be good if anyone just gives their name first before they talk.

Okay. And I will say the other thing that I have done since our last meeting, I went to the American Thoracic Society meeting and spoke at length with my various colleagues at

National Jewish and other places that deal with these claims and patients on a regular basis. I realized over the weekend a lot of the feedback I got from them related to issues about the actual claims process. And so I think we sort of next defined the issues and scope. I personally was sort of feeling that we need to clarify what we're covering to make sure we're not -- the medical evidence group is also obviously dealing with decision-making and processing of claims, I think, overall.

Okay. So does anyone have any other thoughts on the simplified statement of the problem, number two? Okay. So number three, defining the issues and scope of our agenda. And I had thought maybe this will take an hour, maybe it will take longer.

So we have, at the Department of
Labor, that is one of our handouts. We have this
in more than one form. So people aren't
confused, there is the actual document that we
received at the meeting, and then there is -- I

had just sort of taken the questions and claims and organized them just in terms of the categories that they addressed, so it's really the same questions. These aren't additional questions. And they're really quite technical questions in terms of what's the best way to figure out sensitization, and so I think our hope is not to get too bogged down right now in answering any one of these questions but deciding, first of all, if these are the only questions that we need to address or other issues but also then what approach we need to take and what additional information would be useful.

And so we have, for starters, the questions raised by DOL. I put together a couple of things in thinking about this that I also felt we should discuss, potentially areas we wanted to address, and so I wanted everyone's input on this. That's number three under B that we want to, I think, clarify our charge versus the other subcommittees. You know, are we sticking to Part B and not dealing with any of the Part E, sort of

COPD. I think the issue with sarcoid and beryllium disease are closely linked. Add some sarcoid questions. Sarcoid could also be under E. And also if there's any overlap with the other questions.

The other thing that had come up was complications with Part B diseases and how to address them, is that under our scope?

Why don't I stop here and get input from others on the phone?

Dement. As I went through our charge versus the group that's looking at the Site Exposure Matrix, there's a requirement, at least for 1993, and I think the terms are an occupational or environmental history. That's pretty vague. I'm not so sure whether or not that overlaps with the other committee or not or if it's something that we should address directly in this committee, because it relates more to beryllium directly than it does sort of the general Site Exposure Matrix.

CHAIR REDLICH: Okay. There was a weird buzzing noise that seems to be gone. So you're asking whether -- the issue of how we assess exposure related to beryllium?

MEMBER DEMENT: Especially under the pre-1993 criteria. There's a terminology in there that states that what constitutes an occupational or environmental history.

CHAIR REDLICH: Okay. And I think
that this whole issue of pre- and post-disease is
-- one thing that I also sort of, I think
everyone realizes, I just had to also be
reminded, is that we're dealing with the EEOICPA
is a statute from Congress, and that's actually
that one document that has a fancy number, 73841,
as far as definitions. So I think one can
clarify definitions, but we're probably going to
try and have to work within this framework.

And the other document that we had sent out was, I think, a more detailed version of the current way that these two paragraphs are interpreted, so the people actually doing the

claims, and that's something we may want to go
through with more of a fine-toothed comb because
-- okay. So I think let's add, you're right, the
issue of the history, the occupational history.

Carrie, this is Laurie. MEMBER WELCH: Yes, I agree with John, we should probably look at -- well, John was raising the question, but my thought is we should look at exposure assessment for beryllium as it's defined in the statute separately. This committee should look at that. But I think that the other lung disease, like you put in your agenda, Part E, COPD, this committee should not address that, and that will be addressed by probably all the other committees in terms of how COPD is handled from the exposure assessment through the claims process through the consulting, industrial hygiene thing. You know, that's going to come up because it's a big case, but I think this committee should not deal with Part E, other lung disease claims. That would just be way too big.

CHAIR REDLICH: I agree, so I was

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1	hoping others would be as Laura said. Okay. So
2	we can get into the my understanding also was
3	that there was also if you basically spent one
4	day at a beryllium facility, you were considered
5	having had exposure.
6	MEMBER VLIEGER: Dr. Redlich, this is
7	Faye Vlieger. That's correct. The exposure
8	basis for the beryllium is one day of presence.
9	CHAIR REDLICH: Okay. And that's in
LO	the Act.
L1	MEMBER VLIEGER: That's part of the
L2	Act. There's a criteria for 250 days that pops
L3	up a few different places but not for beryllium
L4	disease.
L5	MEMBER DOMINA: This is Kirk. That
L6	one day falls under 10 CFR 850, is where you
L7	apply the one day, which is a beryllium CFR.
L8	MEMBER VLIEGER: That's a DOE CFR, by
L9	the way.
20	MEMBER WELCH: And does that apply to
21	both the pre '93 and the post '93 cases?
22	MEMBER VLIEGER: Yes.

MEMBER WELCH: So this idea of having 1 2 some kind of occupational history seems like it's not really relevant in a way. 3 4 MEMBER VLIEGER: True, but they apply 5 it nonetheless. Oh, so then we need to 6 MEMBER WELCH: 7 understand that at some point. CHAIR REDLICH: 8 Thank you. And 9 please, for those who are more familiar with the 10 details of all of this, don't hesitate to speak 11 up. 12 Okay. And I guess other thoughts --13 thinking through it, part of it, when I spoke to 14 my colleagues, I think how the claims are 15 processed and what things are covered, to me, 16 that belongs through the other subcommittee, and 17 it's not our jurisdiction. 18 MEMBER WELCH: I would agree, too, 19 unless there's something specific, that's 20 beryllium-specific that doesn't apply to all the 21 other claims.

MEMBER VLIEGER:

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There is the issue,

I don't know that it's so much claims processing as it's training, between the CMCs and the CEs, the contract medical consultants and the claims examiners, and the other people who adjudicate the claims is that they're not trained to standard definitions, and they are often -- this comes under ruling medical evidence -- they often discount something they don't understand for that reason.

CHAIR REDLICH: Okay. So we potentially have the situation where beryllium disease is quite complicated in understanding, sensitization disease, the pre, the post, that what you're saying is that pretty much everyone gets the standard training. There isn't sort of a centralized core group that deals with only beryllium or something or --

MEMBER VLIEGER: There may be some sort of training, but it's certainly not standardized.

CHAIR REDLICH: Okay.

MEMBER VLIEGER: And the claims

examiners, there's no group that deals with beryllium claims. And the medical evidence they get when sent to the contract medical consultants, they don't follow the statute because the Department of Labor is not required to remind them of the statute requirements.

Therefore, the doctors use their judgment versus the statute requirements, or they use the beryllium case registry criteria, which is not the statute.

CHAIR REDLICH: Okay.

MEMBER MARKOWITZ: Carrie, this is

Steve Markowitz. I just want to add to this. So

if the general is, should this committee look at

the application of the evidentiary requirements

in the claims process, I think what Faye is

raising is part of a more general issue. It's

not just the CMCs. What comes in from the

medical provider? How does the claims examiner

look at these issues? So I think we have to get,

to some extent, into the claims process to see

how the evidence is constructed, viewed, and

applied.

CHAIR REDLICH: Exactly. I agree.
Okay.

MEMBER WELCH: This is Laurie. One more comment. Your number C, which was complication of Part B, diseases for treatment, I think that DOL had asked for specific help with that: generally, what diseases can be a complication of steroid treatment, for example, which could apply to other lung diseases as well? But I think if we can help define which diseases should be accepted as complications of kind of the central core -- it doesn't mean it would be exclusive, but it would be presumptive -- I think that would probably be helpful.

CHAIR REDLICH: That's right. And I agree. Either fortunately or unfortunately, we treat most pulmonary diseases with only a few drugs, so I think we could cover this. If put under beryllium, it would probably be similar to the COPD group, too, if not exactly the same.

But I think it is something. Or interstitial

lung diseases, which would be under E. So we probably, I mean, we could both give input. I think it would be similar.

Are there any other just sort of defining the issues and the scope of what we're hoping to accomplish? Okay.

So in terms of what we need to accomplish our jobs, I think, Steve, we had put together -- I'll say first we put together a list of data requests, which is one of the other handouts -- I think everyone has seen the forms before -- of the type of information just, I think in part to understand the magnitude and the process. And we got that. I don't think anyone had a chance probably to look at it. There are 20,000, a large number of cases in the database. I think some summary statistics on some of that, of just number of X and percent accepted and the number in the past couple of years.

I think I have played around a little with this over the weekend and sorting by different ways, and what I came back with was my

hope that there was some simple, simple solution that almost there were very few cases that were sensitization only, versus beryllium disease and sensitization, that there would be some very simple fix. I think it's not that simple in terms of just the magnitude. So that piece was helpful to me.

a closer examination of this data. So my thought was one of the key -- I think if one actually looked at the initial request that we had, I think that the Department of Labor was quite good in providing what they had that was, I think, acceptable in their system. Other people will know this better. I think some of the job titles, worker site, gets way more complicated, and so we had a wish list of things, I think. But I think a lot of the basic just of us getting a feel for the claims and what they are and what percentage are accepted.

So what I was going to propose on the data side is that if we all look around at that

Excel spreadsheet sometime over the next couple of weeks and come up with what information, summary sort of information we would like to gain from that, and I am hoping that someone in the Department of Labor could help us. Excel spreadsheets are not my personal forte.

So that piece. And then when we look at it, then I think after looking at that that we might realize, I suspect we will realize that there's additional data, some of which might be on this original list, that we think would be helpful, and we could then come up with an additional list of data pieces that we would find helpful and see what is available.

So that was a general frame of what I was thinking in terms of the data related to beryllium disease, beryllium sensitization, and silicosis. Other thoughts on the data component?

MEMBER DEMENT: Hi, this is John

Dement. Spreadsheets don't lend themselves very

much to really doing much in terms of analyses.

I was able to take that spreadsheet and pull it

1 into SAS. 2 CHAIR REDLICH: Oh, you're ahead of --3 oh, I'm impressed. Okay. I could at least run 4 MEMBER DEMENT: 5 tabulations and summaries on the data. 6 CHAIR REDLICH: Okay. 7 MEMBER DEMENT: I have a question. 8 CHAIR REDLICH: No, that's great. Ι 9 had asked someone to see if they could help me 10 with that, and it was too short time. But that -11 - yes, go ahead. 12 MEMBER DEMENT: What's sort of 13 missing, to me, in the data are, for the denials, 14 the reasons for denial. I mean, we know that 15 they're denied, and we can tabulate the frequency 16 of filing versus accepted versus denied, but is 17 there -- are there other data fields that provide 18 the rationale for denial based on the criteria in 19 the statute? 20 CHAIR REDLICH: Yes, I agree totally. 21 And I think that was sort of, that's exactly one

of the questions I had. I also wasn't, there

were some other more technical questions I had, whether this was like a final denial or an initial. Where in the claims process -- and I also wasn't sure, because someone -- so I had a bunch of questions about the data.

Carrie, in terms of, I wanted to get some clarification, Carrie Rhoads. In terms of - and, John, you're totally right, an Excel spreadsheet, we need to do something with the data. Are we at liberty to do that ourselves and see what additional -- should we request assistance as far as just the process of making sense out of the data?

MS. RHOADS: We can go back to the program and ask them for more explanation of what they already gave you, if you'd like, or additional fields they might have, whatever, we can ask them for some additional help.

CHAIR REDLICH: Okay. John, my guess is that, if we want to, as you said, sort of analyze this, that you're probably as good as anybody at doing this. And I agree. I think we

should come up with a list of additional fields that we would like to see if we can.

MEMBER DEMENT: I know there must be other fields in there that are used for managing claims that I think will be helpful. I think Steve pointed out that if we could get into the claims process, how the statute is actually being applied and look through that, I think this might give us a first glimpse.

I guess, in my view, I think it's going to be very difficult to really get down into the meat of this without having some specific case studies that we look at.

and that's why I put -- and I talked to Carrie
Rhoads before this call saying that I sort of
feel like it's so presumptuous to think that we
either understand it or to make recommendations
without actually sitting down and going through
some claims, seeing what the obstacles are, what
final decisions, and how it works.

So I guess my question is, what would

be the process for us to do this and to get the information in terms of, could we request the paperwork for 30 claims or whatever and --

MEMBER VLIEGER: Dr. Redlich, if I could interject, this is Faye Vlieger. Among the advocates, for many years, we have been collecting a repository of claims paperwork, recommended decisions, final decisions, reconsiderations, remand orders from the claims process, and the repository of the redacted claims has been the EECAP website. And I had sent information out previously about the availability of these redacted files on EECAP, so for expediency, if you wanted to go look at the beryllium sensitization and the beryllium disease files there just for your own leisure while we wait for the Department of Labor to respond, but there is a repository that's available to the public right now.

CHAIR REDLICH: For a given claim -I guess we all have our experience in other
systems, so I had reviewed quite a number of the

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World Trade Center claims, and there was the questionnaires and the forms, and then there was, you could have everything from ten pages to a thousand pages of medical documents. If there were a thousand pages, there were usually ten pages within the thousand pages. So the typical documents you would have on a given claim, what's the magnitude of it? I'm sure it's very variable, but --

MEMBER VLIEGER: The size of the reply, is that what you're looking for? It can range from two pages to ten pages, and many times the denial lies in the Department of Labor's statement of accepted facts. And those facts are the problem, is what they accept, pursuant to the statute, in this particular -- in beryllium disease, what the statute allows and what the doctor that they referred it to decides, and like I said, the further disparity between what the statute allows and what the doctors actually are approving, particularly the contract medical consultants.

Carrie, this is Laurie. MEMBER WELCH: The medical records reside somewhere, and I'm not exactly sure whether the advocacy website has But usually what I end up seeing when I ask for claims, they have a long narrative from usually the adjudication branch that says -- and this is the same kind of information that they send out to the consulting physician if they need a physician opinion on causation. So they'll say, you know, you worked at the Oak Ridge plant from 1952 to 1982, and the SEM says you had these exposures, and we got these medical records, and they'll basically say they've approved, like, say, for a COPD claim, which -- I haven't actually reviewed beryllium claims -- but COPD claims, they'd say, your diagnosis is accepted. So then you don't necessarily, for that claim, need to look at the medical records because they've accepted the diagnosis, and usually the discussion is about the years of employment for construction workers that are accepted facts. may be a smaller subset of what they reported

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they worked there. But then there's always a pretty long narrative about the causation issues, and one can get the consulting medical report, which then is what the claim examiners rely on to accept or deny a claim usually.

So do your files collect the actual medical records, too, or is what you have is the adjudication information?

MEMBER VLIEGER: Are you talking about the EECAP files?

MEMBER WELCH: Yes.

MEMBER VLIEGER: Okay. I'm on their web page right now, and the decisions are listed by year, and it is the document from the Department of Labor. In order to get the medical evidence, you're going to have to have the claimant's permission, or Department of Labor is going to have to do a lot of redacting. And I know that if they do that, it's going to take a lot of time to get your file.

MEMBER WELCH: I actually think, not having looked at files, I think we can make a lot

of progress without the actual medical records because you can see the -- in the rationale, they'll say, well, the pulmonary function test showed obstructive lung disease, something like that.

MEMBER VLIEGER: If they wanted to and it's amenable to the Department of Labor, EECAP would be willing -- I'm speaking for Deb Jerison. She runs that non-profit. She would be willing to compile her files and send it for CBD approval and denial. I'm looking at the website right now, and there are files through 2013 with CBD in them, and she does these by year. She's also done some spreadsheet analysis of CBD and other lung diseases acceptance and denial for the advocates. We've been at this for a number of years, and she's provided the statistics and the website for our data.

So that is something we can reach out to her to do. She did participate or come to the D.C. meetings and publicly speak, so she's out there. She's willing to help.

Steve Markowitz. 1 MEMBER MARKOWITZ: 2 I just want to say something. If we want to understand the DOL process, we have to look at 3 4 data claims that are fully representative of the 5 DOL's process. Otherwise, we can be viewed as looking at a selective population, which is not 6 7 representative and, therefore, doesn't speak to the underlying issue. So I think we need to 8 9 define what we want to know, and if EECAP, in the 10 short term, is helpful in providing some insights, but, ultimately, we want to get our 11 12 data from the DOL database so we have a 13 comprehensive understanding of how they do 14 things. 15 MEMBER VLIEGER: I agree with Dr. This is Faye again. 16 Markowitz. It's just I 17 think there's going to be a sizable delay in 18 getting what we're requesting from DOL. Yes, I 19 agree we need a full spectrum of what's going on. 20 MEMBER MARKOWITZ: Well, the problem 21 is, if we look at our smaller population, we're 22 vulnerable to the criticism that we didn't look

at a fuller population that would have given us a more accurate picture, you know what I mean? In which case, we haven't gotten off step one.

CHAIR REDLICH: Yes. So what I would propose, I think, since -- what is available right now, I think we can look at I think, what would inform potentially what we simply ask or the DOL or at least hone in on, one of the things about beryllium is that there's a lot of -- and the questions that we were asked were very technical questions. What pathology counts and the sensitization. And I suspect that to fully understand this, we are not going to need not only the summary of the rationale for the decision-making but understanding the data that that came from.

Now, the good side about pulmonary disease is that there's a limited number of diagnostic tests. There's PSTs, there's a CT scan, and there's pathology and the beryllium test. So we don't have like 50 different tests.

But I think I'm probably, at some

point, at least to understand this -- is going to need to actually review some claims, what happened, and what information the physician was given and then what decision-making they made based on what was in front of them.

MEMBER WELCH: Yes, I think that makes a lot of sense.

CHAIR REDLICH: Because, I don't know,
I've just been doing IOB, for 25 years and 25
years of IOB conference, and two pathologists
look at a past biopsy, and one sees granulomas,
and the other doesn't. One sees a CT scan that
looks like classic this, and another one says,
no, it's that. Both highly qualified people. So
they're not sort of cut and dry.

I think a key -- I mean, I think we would like -- and, for starters, reading some of the summary reports, for those of us who haven't, would probably be informative. My guess is that the medical records -- I mean, I've never seen anyone receive medical records with the information exactly what we want and all the

extraneous information gone, which becomes one of the problems, let alone the whole redacting names But I also feel that anybody issue. knowledgeable can sort of go through that stack and, for these purposes, select out the critical information because, from experience, when you start to ask for medical records, the person who's putting them together is not the sort of -the person is nervous about not including everything, and then it becomes sort of overbearing because you get 500 pages of documents and findings of five pages. But I do think that's a solvable problem if we sort of clarified what pieces of information from the medical record we were interested in.

So even simple questions, like, okay, in the chronic beryllium disease claims, what percentage of them actually had a biopsy done?

What percentage of -- so I think, you know, some of that -- and even a very basic question, which I have asked a couple of people, and I suspect some people have a better feel, which claims

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currently coming in are the pre and the post 1 2 criteria? MEMBER WELCH: You know, this is a 3 4 little bit getting into the weeds, but I was 5 looking at the spreadsheet that we got, and it tells you the CBD diagnosis dates, but it doesn't 6 7 tell you the claim filing date or the application date or anything like that. So it's hard to know 8 9 10 CHAIR REDLICH: That's right. But you 11 don't know which criteria were being used in 12 those cases, and that was actually one of the 13 questions we were asked is, the onset of disease 14 is important because the pre-1993 is a more 15 inclusive diagnosis. Right. 16 MEMBER WELCH: In the 17 spreadsheet, you can sort of guess at at whether

they had sensitivity, as well as CBD.

CHAIR REDLICH: And some of them, I think from 1950 we know which -- I also think the more recent claims where --

MEMBER WELCH: Yes, but you don't even

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know it's a more recent claim. That's the problem. We know when the diagnosis was. We don't know when that claim was filed. So if a diagnosis is 1980; in theory, the claim could have been filed in 2015. We don't know. So it would be --

CHAIR REDLICH: Yes. So that would be actually one of the additional pieces of data that we would like on the data that we have is --

maybe one thing we could all do is whoever wants to look at the spreadsheet and say, oh, I'd like to know this about the claims, and then we can accumulate a list of additional data fields we'd like to see. Because I know, in the past, when we've asked DOL to give us information, they don't tend to have a data dictionary that will give you all the fields that are available, and we could pick and choose. We have to say, oh, do you have this; do you have this? And for this, maybe there aren't too many fields that we're missing. So if we were all to put our heads

together and say, you give us a date. We could let you know what we see that we want.

CHAIR REDLICH: Yes, I think that's exactly a good suggestion. So we will sort of look through the Excel spreadsheet, at least on that one, come up with additional, in an ideal world, columns that we would like and see what is actually available.

MEMBER WELCH: That would be good.

This is Steven MEMBER MARKOWITZ: Markowitz. Question on process. I'm thinking about the next full meeting in October. So if in the next whatever period of time, a few weeks, whatever it is, we individually communicate with Carrie Redlich about additional data needed, and Carrie could assemble that and submit that to DOL with the idea of getting some output when available but preferably before the October meeting, so that when we come into the October meeting, we will have already understood what's available and even, to some extent, looked at it, with the idea that, in October, we might be able

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to discuss the next level of data we're interested in, which is actually examining claims and a scheme for examining claims. It would be nice to get to that point by the October meeting.

And the question then is, in order to submit the next data request for existing data from DOL in relation to this, do we need a subcommittee meeting in September -- in which case we've got to ask for the Federal Register notice and all that business -- or can we do it through individually sending the ideas to Carrie Redlich, who assembles them and submits them to DOL? So if you could just, for a moment, just focus on that.

about one possibility. John, since you've already put this into SAS, would you be able to, just for basic starters, generate some summary numbers for us to look at? I personally would like to put short time frames on things because I feel like I get my head around everything, and then, if we let it go for a couple of months, it

takes more time total every time we resurrect things.

I would think that we could probably come up with the additional sort of key things, like the reason, if there is a reason, for denial, or Laura's suggestion for clarification, what dates. I mean, I would think in the next week, we could come up with that list of things and get that to the DOL sooner versus later.

MEMBER DEMENT: This is John. The data in the spreadsheet are a little hard to deal with from a summary perspective. For example, many individuals have multiple conditions filed, so there's a lot of parsing out, depending on what kind of summaries you want. But I can send tabulations now. It's just that it will need a little work to pull out each one of these categories for each individual.

CHAIR REDLICH: It's true. I was trying to get the big picture first, because if someone has beryllium, and then they have on the E side additional claims. They could also have

asthma and COPD. I think the various overlaps are important because when someone has beryllium sensitization and some other condition, like asthma or COPD, is that chronic beryllium disease, or is it sensitization plus that? But I was really thinking for just a very initial look to speak to the B side of the spreadsheet because --

MEMBER DEMENT: Yes. I could send some summaries. I need some guidance --

CHAIR REDLICH: I actually, a biostats person who works for us, I had come up with a little list that I had given them to do. But I think it makes more sense for us to do it internally, so I gave them a list, and then I thought let me wait and not have them to do this until we have our call, because I think, and you know what? I could send it to you. Sort of really just percentage of, these claims accepted -- I also wanted to get a sense of, in the past, let's say three years, the numbers of various claims, in terms of the current magnitude of the

volume because part of I feel like the decisionmaking is the magnitude. I think -- yes.

Just a possibility, John, if you're willing, what if we gave you our little wish list and the things that can be done easily, you do, and things that are more complicated -- and then I think, with that, if we came up with the other variables that we were interested in.

MEMBER DEMENT: Yes, that's fine. I need some guidance. Administratively, what is our requirement for sharing this, the summaries, amongst ourselves versus putting it on the website? What is our requirements, for clarification?

MS. RHOADS: This is Carrie Rhoads.

The data set that was sent that you're all talking about, that can't be shared on the website or anything. Discussing it sort of generally like we are now and trends is okay, but the data itself can't be put on the website. You can talk about it and share --

MEMBER DEMENT: Yes, tabulations.

We're not going to put any data out there. 1 Ιt 2 would be simply tabulations. But how do we share that among ourselves, Carrie? 3 4 MS. RHOADS: I can coordinate sharing 5 among the group through the DOL email. CHAIR REDLICH: And the reason I 6 7 actually didn't -- because a person to just help quickly summarize it, I wanted to clarify if it's 8 9 someone I work with regularly as a biostats 10 person, is that okay or not? MS. RHOADS: I think if it's someone 11 that you work with regularly, it's okay. 12 13 me just, I'll check with our attorney. 14 CHAIR REDLICH: John is way more 15 qualified. John, it would be great if you -- I 16 don't think we need more than one person. 17 that would be helpful to know because I just 18 don't want to violate any rules. 19 MS. RHOADS: Right. So the Energy 20 Advisory Board email is usually how we can 21 distribute things amongst the Board members. 22 CHAIR REDLICH: So, John, if we gave

you some ideas that we had on the simple side of 1 2 things, what timing do you think? MEMBER DEMENT: Well, it depends on 3 4 how complicated your questions are. It's fairly 5 easy to write simple code to do tabulations in this data. A week or so. 6 7 CHAIR REDLICH: Okay. So what if we plan, and we'll come up with -- we'll give you 8 9 our suggestions in the next day or two, and then 10 in the next week or two, you would, with the 11 summary that you have --12 MEMBER DEMENT: Yes. 13 CHAIR REDLICH: And I think if we 14 looked at that, while we're doing this, we would 15 come up with a list of the other variables that 16 we would be interested in. 17 MEMBER DEMENT: I think we ought to do 18 it simultaneously actually. CHAIR REDLICH: 19 Yes. Because when 20 you're looking, you realize you want more. 21 MEMBER DEMENT: I think this may 22 stimulate some questions. Tabulations that are

possible on this data are relatively simple.

MEMBER WELCH: You can completely ignore the columns of medical conditions filed and medical conditions approved. The ones that have alphabetical data, like BDDS and stuff like that, because in the end the data is embedded in CBD approved or denied. So I think using the, whether it's a survivor claim, a work site, the diagnosis date, CBD approved, it's probably all we need.

CHAIR REDLICH: Okay, okay. So I think that is a general plan, and I would propose we try and do it just so we can get to the DOL the other variables we want sooner rather than later because that will give them more time to figure out what they can assemble for us.

MEMBER WELCH: This is Laurie. I have a question for Carrie Rhoads. So if we want to send information to John about data runs, should we send those to you or can we send them directly to him?

MS. RHOADS: I would say, for now,

send them to the Energy Advisory Board email. If that proves to be too much of a burden, then we can think about doing something else. But if everything goes through there, it's better.

MEMBER WELCH: Okay, great.

And then you'll CHAIR REDLICH: Okay. pass that on. Okay. So does that seem like a plan as far as the data piece? And I think also -- okay. So I think a little more complicated is, I think, the desire that we all have to better understand the claims process. guess the issue is, what's going to be the best way to do this and also in a way that it might be a more than one-stage process in terms of an initial review of maybe just decision letters that could be done very quickly versus getting medical records that would take more time? So if anyone has thoughts on just the process.

MEMBER WELCH: Well, what I was thinking -- this is Laurie -- what I was thinking about the spreadsheet and additional information.

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If there are things like the date of the initial decision, the date of the file adjudication, you can kind of get a sense which cases went through multiple levels of appeal because there probably are dates for each of those things. Every time they mail a letter to the applicant, there's a And so, hopefully, those are captured in some way. And then we could potentially then be able to see claims that were decided fairly easily without an appeal or ones that went through -- you can end up going back to the adjudication branch many times, and that would probably give us the ability to pick out claims that represented a spectrum of complexity, if they have those dates. We could ask them for that, too. We could say why don't you give us ten claims that were decided in the beginning on these criteria and these criteria and then ten claims that had multiple appeals. But we may be able to figure out how many there if we can get more dates in the spreadsheet. Does that make sense to anybody but me?

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CHAIR REDLICH: I'm wondering whether we should, to get more just of Labor, we could just say, okay, maybe to the past, the 20 claims that were most recently decided, recognizing they may not be representative, but at least rather than them hand -- and then we could sort of ask if we have the 20 most recent, and do they think those were representative. So you may also I think have an idea, and looking over just the decisions in that website -- I don't have strong I think the sooner, if we look over feelings. exactly some of those, I think -- but we'll have to find out then, I mean -- so what do people think? Should we just --

MEMBER VLIEGER: As far as the documents on the website, they are representative of what was submitted voluntarily by workers. So I agree with Dr. Markowitz that we need a full spectrum because we don't want to look like we're slanted. However, I think when we go to the Department of Labor, instead of saying, we want this, do you have it, why don't we have them tell

us what they have, and then we can choose what data we want to see? What are the columns? What are they defined as, and what parameters do they actually track.

What we've found when we've done FOIAs of the system, a Freedom of Information Act request, is many times they'll say, we don't track that, or we don't track that in a way that we can retrieve it. And so instead of a back-and-forth, back-and-forth with DOL, why don't we ask them what they do track, and then we can decide what to get?

MEMBER WELCH: Good idea. We can see what we get in response to that.

CHAIR REDLICH: Others may know better. My sense is that a lot of the tracking has to do more with things like the timeliness of the claims process, rather than like some of the questions we're asking in terms of the reasons for denial or did the person have -- what percentage of these cases that were denied had X tissue diagnosis or something.

MEMBER WELCH: Carrie, this is Laurie. 1 2 I think that that stuff is not in the database. CHAIR REDLICH: I quess we would -- it 3 4 would appear that the paperwork, as far as the 5 summary decision-making and rationale, should be something that we could get sooner rather than 6 7 later. Individual claims, you 8 MEMBER WELCH: 9 mean. 10 CHAIR REDLICH: That's right. 11 MEMBER WELCH: Yes. 12 CHAIR REDLICH: So we could just say, 13 look, we have, for the past 50 claims, the most 14 recent 50, and see what we get. And then we'll 15 take a look through those, and it would give us a 16 flavor, and then we could, I mean, we could even 17 divide it among ourselves. My guess is that it wouldn't take that long to flip through a 18 19 reasonable number. 20 MEMBER WELCH: Yes. I mean, I just 21 counted on the spreadsheet and it's a diagnosis 22 date, well, if the diagnosis date was 2013, for

example, then obviously the claim was after 2013. So there were 35 accepted claims with a diagnosis date of 2013, and there were 20 in 2014 and there were 16 in 2015 with a diagnosis date. Now, I think those are --

CHAIR REDLICH: CBD, correct?

MEMBER WELCH: Well, probably some that were diagnosed in 2015 aren't adjudicated yet, so we might want to, you know, look at the 35 that were adjudicated, that were diagnosed in 2013 that were accepted and then could probably get another set if you want to look at ones that were denied, too.

CHAIR REDLICH: And I think we want to look both at CBD and beryllium sensitization.

Some are both, some are, you know, only sensitization.

MEMBER MARKOWITZ: This is Steven.

But the goal of looking at this limited number is not to draw large conclusions but simply to get a better understanding of the kind of specific information that is compiled and is used by

claims examiners to make decisions?

CHAIR REDLICH: I think so. My
thought was that this initial look could be done
in a week or two to get a feel for what we really
want of the claims process, in terms of the
medical records and the like, rather than
requesting all at once everything and it might
take months to get.

MEMBER WELCH: That makes sense. So everybody gets an idea of what, as Steven just said, what the --

CHAIR REDLICH: That's right. Because I think, Lori, you have been reading these and have an idea. But to me, we could just say, look, could we have just the most recent 50 claims of CBD that have been processed and their decisions, accepted or denied, and the last 50 of sensitization and maybe a smaller number of silicosis. You know, that piece of it -- and we could take a look at that in a short period of time, I think, and then say, okay -- and I personally think it would be helpful to have a

phone call between now and the October meeting because I would rather not, you know, to try and do this, I think it would just be more time efficient that way.

MEMBER WELCH: Yes.

MEMBER MARKOWITZ: So the goal would be -- Steven. The goal would be to develop a provisional understanding for recent claims the claims process has operated to better understand, secondly, to better understand the types of data that enter the system and are used by the various participants in the system, the claims examiner and the like, to draw conclusions.

CHAIR REDLICH: Yes. And I guess I'm partly -- the World Trade Center, there was, you know, a vision of it. And then when you actually looked at, and after looking at about 10 to 15 actual claims, the issues and the problems became much clearer. And some of them seemed to have quite simple solutions and others less simple. And so -- exactly. I think this would, and I think whatever number we got, if we got 50 of

each category, I think it would give us, we 1 2 recognize it's not representative of the whole but at least initially where some of the issues 3 4 lie. 5 MEMBER MARKOWITZ: This is Steven 6 again. Just to --7 CHAIR REDLICH: And I probably would propose like almost a little cheat sheet of 8 9 accepted, you know, we could come up with a 10 little way to go over that and that we sort of 11 not graded it but had a sense of, you know, and 12 what was reason it was denied and does that seem, 13 you know, reasonable or not or what pieces were 14 missing and et cetera. 15 MEMBER MARKOWITZ: This is Steven. 16 But we're not -- this is a question. We're not 17 going to draw conclusions about the quality or 18 the consistency of the decision-making --19 CHAIR REDLICH: No, no, this is just 20 hypothesis, you know, generating, I think, to 21 better hone in on what we do want.

Makes sense.

MEMBER MARKOWITZ:

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CHAIR REDLICH: Does that -- I mean, just as one example, with the World Trade Center, cancer, you think cancer, the diagnosis, the requirement was you need a path report, so that seems pretty straightforward. You know, you get the path report. So there were a bunch of claims that were denied when you looked at it because, you know, there's the fancy oncologist who has all the tumor markers and everything in their notes, but the actual pathology report from the pathologist is not there. Now, the person clearly has a cancer. Any physician looking at that would understand that. So that was like a simple one where -- and there are multiple reasons why the poor patient is unable to get that path report which was done at a different hospital and that hospital has been taken over by this hospital and the records whatever.

So all you needed to say was a path report or an oncologist diagnosis or something, which seems like common sense, but I think when you put these decision-making in a sort of

strict, you know, do this and then that, oh, you don't have that so, you know -- so I think it was at least on feel. I'm not saying that's what's going on here, but I will say that the issues of what was helpful from actually, the reason things were denied. And it looks like, since that's not going to be in the claim data -- and, Steve, you're totally right, we don't want to make preliminary conclusions based on this because we recognize that this is not necessarily representative.

In terms of the initial request, I just put the number 50, but asking the DOL if there are any other suggestions. Let's say 50, you know, decided claims for beryllium disease and 50 for sensitization and, I don't know, 20 for silicosis or something?

MEMBER WELCH: If you want to get a sense of the claims process, I don't think you need to look at a hundred claims. I would hate to have to read a hundred of those.

CHAIR REDLICH: I was thinking maybe

we each did -- okay. We can go to a smaller 1 2 I was thinking why we're asking. number. This is Faye Vlieger. 3 MEMBER VLIEGER: 4 I agree. Once you read ten -- after you read 5 five you'll have an idea. After you read ten, you'll be pretty sure what's going on. 6 7 CHAIR REDLICH: Okay. I say 20. Ι would rather ask for more. 8 9 MEMBER TURNER: I was wondering if it 10 was possible, too, get to my case? My claim? 11 CHAIR REDLICH: Okay. Yes, from 12 talking to a number of people and physicians, I 13 do have some thoughts, but I don't have, but the 14 documentation to -- okay. So I would suggest 15 that we put a request in for, and recognizing 16 there's overlap, but I would like to see some 17 that are sensitization claim only and some that 18 the beryllium disease could be beryllium, 19 obviously, and sensitization. 20 MEMBER VLIEGER: That's fine. 21 CHAIR REDLICH: I think we should look 22 at some of the silicosis, too. So how about 10

of the silicosis, 20 of the beryllium -- so I
think -- Faye and Carrie, you can help us in
terms of what we're actually asking the DOL for.
We're asking for the summary as far as the, you
know, whether it was accepted or not and the
rationale and probably, if it's accepted, there's
less of a rationale.

But a given claim, and then would that come with the history of the claim or is that something we should --

MEMBER VLIEGER: If you're going to be asking for the patient records, that's a different ball of wax then asking for the recommended decision and final decision in the claim. Two different people write those documents, and the recommended decision may differ significantly from the final decision. In each of the final decision and recommended decision, there's something called the statement of accepted facts, and that's what can vary greatly. So that's the procedural process on how they deny the claim.

If you're wanting to see the medical records for each one, that's what's going to take longer. So the initial ask, I would think, would be for a specific claim to see the recommended decision and the final decision, and then you'll see how the process worked.

CHAIR REDLICH: And what about the statement of accepted facts? Do we want to -- is that --

MEMBER VLIEGER: Yes. If there's a referral to a CMC, the statement of accepted facts to the CMC may be significantly different than what's actually memorialized in the recommended decision or the final decision.

Sometimes, they're identical. Sometimes, they're not. And so I would say, if we're going to ask for a medical record for the claim in addition to these, I would think that you would ask for the CMC referral statement and the CMC report, as well. Most of these go to a CMC.

CHAIR REDLICH: So right now I don't think we're asking for the medical records

1 themselves because we want to get something 2 sooner rather than later. So just to be clear, 3 the specific request -- I'm just writing this 4 down -- would be the --MEMBER VLIEGER: Recommended decision 5 6 to deny or accept. 7 CHAIR REDLICH: And then the final decision. 8 9 MEMBER VLIEGER: Right. And that can 10 be to deny or accept or it can be a remand. 11 Those are the three options. And then something 12 that would be, in addition to that later on, you 13 know, we can discuss the contract medical 14 consultant referral and report, but that's going 15 to take more redacting. 16 CHAIR REDLICH: Okay. So the contract 17 -- okay, I understand. And then the statement of 18 accepted facts is what you're saying is really a 19 medical document? 20 No, the statement of MEMBER VLIEGER: accepted facts is recited. 21 It's memorialized in

the recommended decision and the final decision,

so it's in the record.

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included. Okay. So it sounds like then that would be the thing that we should be able to get relatively quickly on each claim. And then when we requested that, if five or ten years ago there had been a previous decision, would that be included? Would we get the history of the claim, or would we only get that one decision-making?

MEMBER VLIEGER: Each person that writes these has a different style, even though there's a formula that they're supposed to follow. And they may just briefly recite that you applied and you were turned down. That may be all they recite. Other times they could recite the entire statement of accepted facts from the previous ones. So if you're looking for the chain on a claim that was attempted multiple times, that's going to be a much more difficult request, rather than saying, you know, for the last 20, you know, you can hand us, it's a different process, and each writer, each claims

examiner, each hearings representative has a different style, even though they follow a certain formula that's put to them in the procedure manual.

CHAIR REDLICH: Okay. So at the least, it would be apparent if it was a totally new claim or one that had a prior decision of denial?

MEMBER VLIEGER: Yes, they recite the dates of claim in the statement of accepted facts, so recite what evidence they received and what evidence they accepted.

CHAIR REDLICH: Okay. Very good. So

I think I would propose, if everyone is in
agreement, that we put in a request for those
items for 20 cases of chronic beryllium disease.
You know, we say the most recent finalized ones.
Twenty of sensitization, or I think we probably
want more of the chronic beryllium disease than
the sensitization, and then also for ten of the
silicosis claims.

MEMBER WELCH: And, Carrie, it might

help to specify some proportion of accepted and 1 2 denied. You know, if we did the last 20 claims and they were all accepted, then we wouldn't have 3 4 seen the -- I mean, it's probably unlikely. 5 maybe you want to say the last --CHAIR REDLICH: Why don't we say at 6 7 least ten that have been denied? 8 MEMBER WELCH: Okay. 9 CHAIR REDLICH: Is everyone okay with 10 that? Yes, this is 11 MEMBER MARKOWITZ: 12 I have a question, and maybe, Laura, you 13 can help here because you've looked at more of 14 these than many of the rest of us. If we're only 15 requesting either compilations or interpretations 16 of the underlying medical information and not at 17 this point requesting either the CMC report or 18 these medical records, how much are we going to 19 In other words -learn? 20 MEMBER WELCH: If a claim was denied, 21 you really don't understand it unless you have

So I think we should ask for the

the CMC report.

CMC report with everything.

CHAIR REDLICH: To redact a CMC report, that's maybe a several page report. We just need to get rid of the name, you know, right? Is that --

MEMBER WELCH: That's correct, yes.

It would probably have the, you know, if they did a report correctly, your name would appear on every page. And then sometimes within the text of it, it will say Mr. Smith did this and Mr.

Smith did that. So someone has to go through it and --

CHAIR REDLICH: Okay. But that's not that --

MEMBER WELCH: The number of times the guy's name is going to be mentioned might be a dozen. Sometimes the report would be long but it's blobbity, blobbity, blah about causation, not about this case.

CHAIR REDLICH: Okay. So I agree. So it seems like the CMC report, assuming it went to a CMC which it sounds like a large number of them

do, would be a critical thing? So what if we add that to our asks?

MEMBER WELCH: I think that's a good idea.

CHAIR REDLICH: Carrie, I guess we probably don't know, but this turnaround time for an ask like this? Because, ideally, what I would like to do is to get these, have us a chance to look at them, probably come up with a summary of our thoughts in terms of, you know, reasons for denial before this October meeting.

MS. RHOADS: Okay. I will ask the program about how long it would take them and tell them, you know, why you need it and when you need it by and see what --

CHAIR REDLICH: I mean, ideally,
because I think it would be very helpful. I
agree I do not think it would take any of us that
long to go through these, and it would, and I
would prefer, even ideally, to have a conference
call after we have done that because I think it
would help us to focus our decision-making, and I

think the critical thing being then also our next request because, having looked at that, how much we felt, you know, we needed more than a CMC report. So that's going to be, I think, in terms of understanding the process --

MS. RHOADS: Right. I'll ask them how quickly they can get this together.

MEMBER WELCH: When I've asked, you know, sometimes our workers ask me to look at their case file, and then I always want to see the CMC report, so the worker actually calls their claims examiner and asks for it, and usually I get it back in a couple of weeks. And that's one individual person, but it's not that long for someone -- so I think when we're keeping our asks down to 50 files, I just don't think it should, it's not that -- it's a copying thing, you know. So I think we should be able to schedule a conference call in September and definitely have time to --

CHAIR REDLICH: Yes. And if there is a piece of the ask that is problematic and the

other pieces are not, that would be helpful to know. Okay. So is that -- I think now we've basically come up with a plan for data in the next really week or two. We've come up with a plan for initially reviewing this information that I think we're talking about over the next, you know, month or two, before September. I would hope that in September we could talk again for the piece in terms of understanding this aspect of the claims.

You know, I think understanding our mission would really be focusing on, you know, the reasons that these are being denied related to really use the criteria and the pre, you know, or post 19 -- you know, versus the issues of what's the, you know, who's the quality or the person doing the review because my understanding is that those aspects of the process would go to the other subcommittees. Is that -- is everyone in agreement?

Okay. So what if we do this? What if we take a ten-minute break and come back? And I

think, looking at our initial agenda, we have gotten up to four. We've addressed A, and we've addressed B, in terms of at least the initial information about that. And we've partially come up with a time line. But I did also want to just raise, you know, potentially other information and also we haven't, information also, you know, our approach to sarcoid question.

So what does everyone think about a ten-minute break? It is, let's call it 11:30.

Or 15 minutes? Any votes here?

MEMBER WELCH: Should we all hang up and call back in? Is that the plan?

MS. RHOADS: We can just have the moderator put the call on hold or mute for ten minutes and then come back on.

CHAIR REDLICH: Okay. So we will be back on at 11:40. And please, everyone, in the meantime, we are actually making very good time, but if there are other items or thoughts, do not be shy. Okay.

(Whereupon, the above-entitled matter

went off the record at 11:29 a.m. and resumed at 1 2 11:43 a.m.) CHAIR REDLICH: I think we are making 3 4 a lot of progress. We are still in the define 5 other data and information needs. MS. RHOADS: Has the moderator added 6 7 back in the public line? OPERATOR: Yes. 8 Everyone can hear you 9 at this point. 10 MS. RHOADS: Okay, great. Thank you. 11 CHAIR REDLICH: I think we have 12 everyone back on. So I had a couple of thoughts, 13 but I wanted other people's thoughts in terms of 14 -- and I think, at this point, we're thinking 15 about additional pieces of data information that 16 will help us. 17 So I will repeat that whoever is 18 listening on the line to not speak. We welcome 19 your comments, suggestions, particularly focused 20 on pieces of information that would be useful in 21 terms of decision-making.

Are there other sort of constituents,

constituencies that we might want to hear from?

And I'm thinking of something, let's say,

physicians who are involved in the decision
making, some of the, you know, people who are

struggling with doing the CMC reports or the

group within the DOL that makes a final decision?

And I was thinking more of really the specific

issues related to beryllium, not the process. So

I wanted other people's thoughts.

MEMBER VLIEGER: The physicians that

I deal with on these claims struggle to write

documents that meet the criteria that the

Department of Labor will accept, and I think

you've already touched on that in the defining of

the criteria. There are physicians who, you

know, from this area, pulmonologists, well
respected pulmonologists that are ignored because

they're not meeting some tick box that the

Department of Labor requires. And I think the

vagueness of those requirements, even though the

statute is quite clear, and then presenting it to

the physicians in a way that they understand what

the requirements are is one of the hurdles for the claimant.

CHAIR REDLICH: Okay. And so I quess do we think that there would be another group that would be helpful, in a more formal way, you know, either canvas which are sort of the particular areas. You know, I assume that there are probably certain pieces that are more challenging than others. I have sort of done this informally with colleagues of mine, and I did find what they told me useful. Some of the things they told me I think related to other parts of the process, but they were also a sort of narrow group of people who know a lot about this and I don't think were representative of the actual clinicians who were --

MEMBER MARKOWITZ: This is Steven.

You know, an interesting idea, I think, Carrie

Rhoads, have we definitely decided to meet in Oak

Ridge next time in October?

MS. RHOADS: Yes, we're looking for places in Oak Ridge.

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	MEMBER MARKOWITZ: So, you know, Oak
2	Ridge has a limited pulmonary community, and we
3	could reach out to them, at least put them on
4	notice that we're meeting them, and they might
5	participate in a public comment process about
6	their experience. And that way, we could get
7	some feedback. The only other organized group
8	would be the CMCs, but we expect to get, you
9	know, some of their issues through looking at
10	claims. I don't really know how else one could
11	look at the practitioner's experience.
12	CHAIR REDLICH: Just so I understand,
13	the total number of CMCs in the system is about
14	how many?
15	MEMBER MARKOWITZ: I think the range
16	is this is Steven. I think the range is 50 to
17	100, but I'm not sure.
18	CHAIR REDLICH: And these are
19	physically scattered in different parts of the
20	country?
21	MEMBER WELCH: Yes.
22	CHAIR REDLICH: Yes.

MEMBER VLIEGER: I mean, in theory, the claims should go to a specialist who's in that area, so you would have an oncologist and you'd have, you know, for the whole range of people, not just for beryllium disease. You'd be sending it to, you know, there could be thousands of consultants.

CHAIR REDLICH: But would it be in certain sort of hotter spots of the country that there might be, I don't know, five to ten CMCs that would be useful to --

MEMBER VLIEGER: The QTC contract vetting process is not understood by anyone, and QTC is the one that collect the doctors -- QTC is the name of the contractor. So the list of vetted doctors in pulmonary occupational medicine specialties is something we probably could request. But I see them from all over the country. They aren't necessarily doctors in the region where the claim is originating.

CHAIR REDLICH: Okay. Because one thought I have thought about, you know, just is

would it make sense, since this is a very complicated area and for consistency and the like, once you have records, you don't have to be geographically for these claims to be sent to a smaller group of people, you know, concentrated in a smaller number, rather than sort of one person has two and another has three all over the place. And I don't know if that's happening now or not, how it's decided. Are there CMCs that only do beryllium disease? Are there others that only do cancer? Because I wasn't totally clear when they say a specialist what they meant by a specialist.

MEMBER WELCH: We'd have to ask the Department of Labor about that.

MEMBER VLIEGER: I was going to say

Laura could speak to that because she's seen more

of the reports probably than I have, but the

vetting process that QTC does, the doctors are

then supposedly reviewed by their application,

but I personally can attest to the fact that QTC

does not always vet the doctors appropriately for

specialty. The doctor may say that they're qualified, but in claims that we review their qualifications at a hearing, we find that the doctor is not qualified to be opining in that specialty.

CHAIR REDLICH: Okay. And I guess some of these issues are ones that, Steve, I assume the other subcommittee is addressing.

Knowing, and I think Laura and I probably are two people from the medical side that know as much about beryllium, as there are really a very small handful of doctors. So just off the bat, and I don't mean to sort of say negative things about my pulmonary colleagues or my occupational medicine colleagues, but, you know, world-renowned interstitial lung disease specialists who deal with sarcoid and all these other diseases are clueless about beryllium.

MEMBER MARKOWITZ: And they're probably not CMCs either.

CHAIR REDLICH: That's true. And the occupational medicine ones, but if someone was

saying were they qualified to be a CMC, they 1 2 would look awesome qualifications on paper, board certified and this and that and the like. 3 4 MEMBER MARKOWITZ: This is Steven. 5 Isn't the underlying problem that, and this is what DOL actually raised in their list of issues 6 and if you look at the statutes, the underlying 7 problem is there's some very vague phrases that 8 9 it's not clear how you apply them. And so 10 whatever group, whether expert or not, until you 11 get in the room to examine records and apply 12 these vague phrases is coming up with 13 inconsistent results. 14 CHAIR REDLICH: For beryllium is 15 pretty specific. Well, not really. 16 MEMBER WELCH: 17 know, you need radiography consistent with the 18 disease. 19 CHAIR REDLICH: But then there is the 20 other more extensive handbook that gives more 21 information. 22 MEMBER MARKOWITZ: You're talking

about the procedures manual?

CHAIR REDLICH: Yes, it's pretty

detailed. I mean, my thought is that it sounds

like what's happening is you've got a list of

pretty specific things you need to meet and you

don't meet them, and that's why it gets denied,

not that it's vague and it would fit under it.

MEMBER MARKOWITZ: Well, you know, but
I have to say, if you look at the issues that DOL
looks, as part of their PowerPoint, one of the
handouts that we received, they want help with
this issue of, you know, "characteristic of CBD."
They want help with a consistent uniform standard
for what is a chronic respiratory disorder. So
whatever details they've elaborated in their
procedures manual, they appear to still be
struggling with this probably for the same
reasons why some claimants are unhappy with how
they apply it, which is that these are, they
haven't been specified enough or some variation
of that.

MEMBER WELCH: Or if the procedural

manual was developed by the claims examiners and one internal physician that's changed or, you know, they asked some external person many years ago, they might want a broader input. You know, maybe, you know, if we look at what they've been using and say that's good, that would be helpful to them because, otherwise, you get people arguing about what the statute says. The procedure manual --

CHAIR REDLICH: So I guess I sort of feel that one of the problems is is that, as you try and define that in more detail exactly what is meant, it then becomes harder to ever accept a claim. And when you go to ILD conference and, literally, a biopsy is read three different ways by three different pathologists, it's almost, and I think it's why people get towards some presumption things because -- so, honestly, if you look at the ATS document on beryllium and the like, yes, you could tweak the manual that they have, but it's pretty detailed.

MEMBER WELCH: Yes, but I think the

question is whether -- so when we look at the denials, we'll get an idea.

CHAIR REDLICH: That's right.

MEMBER WELCH: Because you're coming into it with the idea that there's probably people that have CBD who are having their claims denied because there's evidence required they just can't get, even though they, you know, an expert would say they have CBD, or more likely than not anyway. And I think wait until we see some, and then we'll get a better idea.

CHAIR REDLICH: And I suspect and it sounds like there are also cases, and I think consistency is important, of whether the, you know, person has a positive, you know, sensitization and doesn't have COPD but has some other pulmonary condition, like asthma or COPD and someone sort of decides -- I actually don't think the question is do they definitely have the disease because this is a compensation system, so, I mean, I think that is a question, but then I think it's also what makes sense in the setting

of the current compensation. Because, I mean, with any of these, whether it's Agent Orange in Vietnam or the World Trade Center, it's not, you know, it's sort of defining parameters that you hope in the end that you compensate people that deserve it and the like, recognizing any of these systems, even when we use more probable than not, that means that we're 51-percent sure so half the people maybe it wasn't related.

MEMBER MARKOWITZ: Yes, but WTC and Agent Orange don't give diagnostic criteria, unlike this statute. They don't tell you what criteria you need to meet in order to be recognized as having this disease or that disease.

CHAIR REDLICH: WTC has its criteria, you know, X amount of exposure, you need this to document the diagnosis.

MEMBER MARKOWITZ: But not the level of detail that's in this statute.

CHAIR REDLICH: That's right, that's right. So part of my feeling is the level of

detail, partly the level of detail that we are -because it all does go back to, we go back to the
statute, the statute is pretty specific for, you
know -- that's right. And then there is some
further discussion of what a CT consistent with
beryllium disease.

I think the point is that, everyone is right, that when we review some claims, we'll get some idea of the areas that are being denied and maybe the areas that are being approved, you know. Both ways, we're sort of wondering why.

MEMBER VLIEGER: Well, one of the problems with that adjudication of these claims is the statute is written in a manner that is a little bit of a loop. So pre-CBD claim process is first in the statute, and then, when they transported that with the post-CBD criteria into the procedure manual, instead of saying for pre-1993 diagnoses, this is what's required, under the post-1993, instead of saying in addition to this you need this, they looped it. And to read the procedure manual, it's quite confusing, and

that's why the doctors can't quite understand it.

Many times, I will write a letter and

specifically state out the criteria. And even if

you compare the U.S. Department of Labor's

brochures and pamphlets on the disease, it does

not match the wording that the claims examiners

are held to in the procedure manual.

So I think one of the things that

So I think one of the things that needs to be addressed is the clarity in the procedure manual, and the way it was written is very convoluted.

CHAIR REDLICH: Okay. And that is the document, just so we're all talking about the same thing, I believe that is the document that Carrie sort of sent to everybody this morning in one of the attachments.

MEMBER WELCH: Yes, it is.

CHAIR REDLICH: Okay. It's about a 20-page thing?

MEMBER WELCH: Yes. What you're really looking at is about three paragraphs under CBD, and you'll see that it's very convoluted.

Sorry. The pre-1993 criteria is stated, and then, when you go to the post-1993 criteria, you have to infer from the previous criteria what's in there. And I think that's part of the problem.

And then I CHAIR REDLICH: Okay. think two things related to that, in terms of pieces of data that I think would be helpful, is what percentage of these beryllium claims are under the pre- and post-1993 is one question because, obviously, being pre-1993 gives more wiggle room in terms of not needing to demonstrate the sensitization. And then also how that's being decided because my understanding it seems that that's one of the questions would be onset of disease and how that's being defined in terms of onset of symptoms or documentation that you saw, and I don't know if anyone on the call knows the answer to that. But it sounds like that's an area of confusion.

MEMBER WELCH: Once the worker receives one positive beryllium sensitivity test,

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that qualifies them for a medical benefits card, and then they are eligible to use that card for their ongoing monitoring. That leads into when they would apply for a CBD claim if they meet the criteria, so then we run into the criteria confusion problem.

CHAIR REDLICH: Okay. But does anyone have any sense now of, let's say, claims filed, or reviewed from those when they originally filed, recently, how many of them would be using the pre- or the post-1993 criteria? I mean, when this CMC person, is that part of their decision-making, which criteria am I going to use, or is someone else saying we've determined that this person was pre- or post-1993?

MEMBER WELCH: This is Lori. I'd ask
John to answer about what I said to him in the
meeting. I said it seems like this should be
easier because all your claims should now be post
'93, and he said, no, a lot of claimants are
asking to have the pre '93 criteria applied
because they want to demonstrate that their

symptoms, that their chronic lung condition began before 1993. And so I don't know what proportion it is, but it's something that apparently the DOL is struggling with, whether, you know, what kind of documentation to accept that the chronic lung disease began before '93.

CHAIR REDLICH: That's right. And they asked us that question. Okay. And in the CMC report and the rationale, I would assume that when you read that over, it should be clear what criteria are being used, or is that a potentially wrong assumption?

MEMBER WELCH: No, it's clear.

CHAIR REDLICH: Okay. So that's also something, when we look at the most recent 20 claims or so, we should have a sense of?

MEMBER WELCH: Yes.

CHAIR REDLICH: Okay. I just wanted to make note because I think that is, this is obviously an important area, and it is one of the questions on the list of the specific questions, the pre- and the post-1993, and one could --

okay. And also if we could ask, it's probably not in the database, but we could still ask because then it keeps it as something to remember as a variable that we would be interested in.

MEMBER WELCH: Right, yes. I mean, if we get the --

CHAIR REDLICH: Someone could say,
yes, I saw the doctor now, but my disease started
ten years ago, you know.

MEMBER WELCH: But the date of diagnosis should tell us that. So if there is a case with a date of diagnosis of 1990 and then the case is being adjudicated in 2012, we would be able to see that that's a pattern. But since all we have is a date of diagnosis and not the adjudication date, we don't know if there are many with a long gap, you know, many where there's a 20-year delay between the diagnosis. Those would probably the accepted claims.

Just for everybody's information, I just kind of counted out of that spreadsheet, and there are 24,000 applications for either CBD or

BES, and there were around 2500 approved and 2500 denied for CBD. And I didn't count how many were beryllium sensitization. There's some for which there's no information at all on the claim, whether it was approved or denied, and I don't know what that means, but that was one of our data requests.

Just to give you an idea of what kind of numbers we're talking about, there's been, you know, 2500 accepted ever. In the last three years, it's around 50.

CHAIR REDLICH: That's right. It wasn't a huge number for those. Okay. So I think --

MEMBER MARKOWITZ: Carrie, can I -this is Steven. I'm reading the minutes from the
full Board meeting in April, and John Vance said
that DOL is currently seeing more pre '93 cases
than post '93 cases. So it's a --

CHAIR REDLICH: Okay. We're going to have to deal with that issue. And, again, I think we can clarify what, you know, the wording

on this statute, but I think we're sort of stuck with the statute.

So I guess, potentially, I would be interested, if we -- okay. Maybe this is information we could get. For the past 100 beryllium claims, how many different CMCs were adjudicating? You know, is there any concentration, or it is just --

MEMBER WELCH: There's definitely not concentration. There's no system to send it to a smaller number of people.

CHAIR REDLICH: But at least it would be going, I think what would be helpful would be some idea of, I mean, what have they considered? Because they pick someone, quote, with the relevant specialty, so are these cases -- I think it would be helpful to know -- and the CMC report is, correct me if I'm wrong, that's a critical step in this stage, right? Where things could either --

MEMBER WELCH: Yes, absolutely. I mean, for all these claims.

CHAIR REDLICH: Okay. So I just would like to know for the claims for beryllium, who they send them to. Are they pulmonologists, occ med doctors? We said, okay, these hundred claims were reviewed by these 30 physicians. Who are those 30 people? That's something the DOL should let us know, right?

MEMBER WELCH: Well, when you look at

MEMBER WELCH: Well, when you look at the report, you know, for the claims that we look at, we're going to get the CMC report and it has their, you know, their qualifications, to some degree. I mean, there was a case I looked at recently where he was occupational medicineboarded, but his initial training was in orthopedics.

CHAIR REDLICH: So that's the case with probably the great majority of occupational medicine.

MEMBER WELCH: But that person was considered qualified to opine on an occupational lung disease case.

CHAIR REDLICH: So maybe the, I think

the Department of Labor must have some little
guidance that they use, okay, we have this claim,
we need to decide who to give it to. So we could
ask them what they're using.

MEMBER VLIEGER: They base their

MEMBER VLIEGER: They base their choice of doctors off of who QTC vetted, and the vetting process that QTC uses has not been disclosed.

CHAIR REDLICH: Let's see what we get, right?

MEMBER VLIEGER: No, and we also can't get the CMC training manual, so that might be something you want to ask for, too.

CHAIR REDLICH: We would get the sense of these ten, but the question is -- exactly. I think, frankly, most occupational medicine physicians, you know, I think are people who do, you know, injury management.

MEMBER WELCH: I mean, I think there's two things there. There's trying to find consultant physicians who understand the disease, or they're trying to help with the adjudication

process so it's not so complicated that you need to have everyone being reviewed by, you know, a subset of three doctors in the country.

CHAIR REDLICH: But you know what? The number of total beryllium, those were accepted claims, and that's why I think that recent numbers, but I don't know. Let's say you had 300 claims a year or something will have that information related to beryllium. When you do something regularly and familiar with it and you understand it, it potentially would make sense to concentrate that in a smaller number of people. When we did the World Trade Center, we had, like, five of us who all sort of reviewed them and actually had some conference calls to discuss, you know, so I do think -- why don't we just do this? Say we'd like to know who they consider qualified, you know, which types of physicians. I assume that they have, you know, board certified in occ med or pulmonary, if that's what they're using. But why don't we just find out? So you said the thing that you

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haven't been able to get is the training, the criteria used?

MEMBER VLIEGER: We don't know the vetting criteria, and we also don't have the CMC training manual.

CHAIR REDLICH: Okay. So there's probably a vetting criteria for just, in general, being on their panel. And then once you're on the panel, depending on what your disease is, would you go to like a neurologist or a -- you know what I mean? Do we know?

MEMBER VLIEGER: Like Dr. Welch said, it's they don't look any further than the certifications. They also don't look if they meet the criteria where they're supposed to be actually practicing still, where they're supposed to not get more than 25 percent of their income from doing CMC work, you know. That's the type of thing that nobody ever seems to want to answer --

CHAIR REDLICH: But I'm just asking is there a separate criteria depending on what the

condition is?

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MEMBER VLIEGER: Well --

CHAIR REDLICH: Criteria for any case.

MEMBER VLIEGER: Well, criteria for using a particular CMC, the claims examiners and their supervisors are supposed to choose who is well qualified.

CHAIR REDLICH: Okay. So I think, personally, it would be helpful to know, and I don't want to overlap with the clinical subcommittee, but just simply for cases that have to do with Part B, are there specific criteria that they use to decide which CMCs they use? could they let us know for the past, you know, I don't know, 20 or 30 CMCs. Maybe it will become apparent from the reports, but I think that this is an issue it can't hurt to ask. We would like to know for the last, I don't know, 30 cases reviewed that were under Part B who the, you know, what the credentials were: how many were board certified in what -- or even it seems to me there's a pool of people that then review any of

I just don't understand quite the process, 1 them? 2 unless someone else --3 MEMBER MARKOWITZ: You know, who the 4 CMC is ought to be in the database. 5 CHAIR REDLICH: That's what I'm They should have --6 saying. 7 MEMBER MARKOWITZ: And we want a larger, I don't know, number per year I can't 8 9 remember, but we want a larger representative 10 So if we ask for the last couple years --11 CHAIR REDLICH: And I think the other 12 committee may be looking at this across the whole 13 system, and maybe it is the same across the 14 But I think specifically related to system. 15 beryllium where they, you know, having different, 16 you know, who they're picking. So could we put 17 that in as a request? Carrie, do you understand 18 what we're asking? 19 Yes, I'll write it down MS. RHOADS: 20 and send it to you after just to make sure. 21 CHAIR REDLICH: So we're trying to 22 understand who is actually writing these reports,

and we'll get some idea from the claims that we're looking at. We would just like a little bigger look at that question. And then we also would like, if we can see the criteria that are used to pick people, if they have criteria, in addition to who actually got picked. And we also are interested whatever information about the training that these people get. Have we covered those pieces?

And then just also related, you have the CMC report, and then how critical is the next stage in terms of the person in, like, the Department of Labor, the person who makes the final decision?

MEMBER WELCH: Well, if the CMC report come back and say it's not CBD and the claims examiner recommends a denial and it goes to the adjudication branch and they look through the whole file and make sure it was handled properly and then they send the letter denying the claim.

CHAIR REDLICH: Okay. So the claims person pretty much goes along with the CMC

report; is that what you're telling me?

MEMBER WELCH: Yes, they send it to the CMC because they need a causation opinion to adjudicate the claim.

CHAIR REDLICH: Okay. So that carries a lot of weight.

MEMBER WELCH: There might be some cases that where the claims examiner can award it based totally on the evidence in the record. But probably most are going to a consulting physician to get a causation opinion, like this is CBD opinion.

CHAIR REDLICH: Okay. So I think, in terms of that's something that we should be able to get relatively quickly and have some idea of who's reviewing the CMCs, what their qualifications, at least on paper, are. We recognize that that may not reflect reality, but it's a start. And whatever information we can get as far as their training specific to this, and we'll also get a feel for some of this by the claims that we review. Does that seem like --

And then I think, from there, we could 1 2 decide whether we thought that any more physician-level input would be useful. 3 4 So, now, Carrie, the list of questions 5 that the DOL came up with, you know, which are all very specific, good questions about what to 6 7 do about -- they have felt that, after years of looking over these claims -- so I'm just curious 8 9 who in the Department of Labor came up with those 10 questions. 11 I think it was probably MS. RHOADS: 12 the policy branch, but I can ask who they had 13 working on it, if you want to know specifically. 14 CHAIR REDLICH: I just think that 15 we're trying to sort of -- yes, I think that 16 would just be helpful. People directly involved 17 with the claims --18 MS. RHOADS: Okay. I can ask them how 19 they put that list together. 20 CHAIR REDLICH: And I don't know, in

terms of the claims person, again, that reviews

beryllium, is it decided on a geographic basis or

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the beryllium are funneled to their beryllium 1 2 specialist claim people? How does that work? MS. RHOADS: 3 Okay. 4 CHAIR REDLICH: Because this is just 5 a small number of all the claims. So it seems to me it might make sense to have your beryllium 6 7 specialist who are very familiar with those issues, but I don't know. How many different 8 9 claims people are reviewing these CMC reports 10 just for beryllium? 11 MS. RHOADS: Okay. CHAIR REDLICH: If we're thinking 12 13 that, at some point, there needs to be further 14 education of people involved in the process, I'm 15 just trying to get a sense of the number of who 16 we're talking about. 17 MS. RHOADS: You mean the number of 18 different claims examiners? 19 CHAIR REDLICH: Well, that are dealing 20 with beryllium. 21 MS. RHOADS: Okay. 22 CHAIR REDLICH: Because I think if

we're trying to fix something then it sort of figuring out just the stages that it might need some fixing at. Okay. So are there data and pieces of information that we would like? I also felt what we needed to talk about was sarcoid.

MEMBER WELCH: I was actually just looking at how many beryllium sensitivity cases there were, but I can tell you how many sarcoid cases there are in the database. That might help. Let me just do that.

There were not nearly, there weren't, they're more on the east side. And I guess for anybody who's not directly familiar, sarcoid looks like beryllium disease, and so I do know from seeing some of the data from Hanford and talking to some of the physicians involved that the feeling is -- and, actually, I pulled off the internet some of the data they had from Hanford, and the feeling was there was an excess number of sarcoid cases. So rather than getting in the details of one side of things, you know, there are, it can be

1	confusing. If someone has sarcoid and worked
2	with beryllium and, for whatever reason, didn't
3	have a BeLPT done or it was done and was
4	negative, assuming that they had exposure and how
5	common would that be, you could argue for some
6	sort of presumptions in certain circumstances.
7	So I do think that is something that we should
8	consider, and then, right now, the issue would be
9	what other data would be useful to help in that
LO	decision-making?
L1	MEMBER WELCH: The other thing that
L2	can also happen with those cases is that they
L3	could go to, become a Part E.
L4	CHAIR REDLICH: And the database, most
L5	of them are on the E side.
L6	MEMBER WELCH: Right. But there's a
L7	lot of denials on the E side, too.
L8	CHAIR REDLICH: Exactly. So I think
L9	I was sort of thinking that okay. So to
20	address that
21	MEMBER WELCH: I guess the question is
22	if there's some data you want at this point, when

we go back to our data request, that would help you. Do you want to look at some of those cases specifically?

CHAIR REDLICH: Yes. So that's what I was thinking, that the sarcoid cases would be helpful to look at.

MEMBER WELCH: Why don't you ask for ten that were approved and ten that were denied?

CHAIR REDLICH: Sounds good. So that is going off into the E category, but that's the one pulmonary disease in the E category, unless other people objected, that I thought we should take a look at.

MEMBER WELCH: Well, how about cases that were denied -- I mean, there were some that were approved under B, and it would be interesting to know about those. But, I mean, we could ask John to give us a list of, an idea, like, of all the people who were approved for sarcoid under B also were beryllium sensitive, for example. That would make it like that's not a question. But it might be interesting to look

1	at ones that were specifically denied under B and
2	then approved under E to see what additional
3	information was, you know, because E allows a
4	much more open interpretation of the medical
5	results.
6	MEMBER VLIEGER: The other disease
7	that they tend to get shunted to is
8	pneumoconiosis, and that's also an E disease.
9	And just a point of clarification, beryllium
10	sensitivity is an E coverage, Part E like echo.
11	MEMBER WELCH: Oh, because it's
12	medical card only.
13	MEMBER VLIEGER: Right.
14	MEMBER WELCH: Okay.
15	CHAIR REDLICH: I thought beryllium
16	sensitization was B and E. Am I wrong about
17	that?
18	MEMBER VLIEGER: There are not Part B
19	benefits under beryllium sensitization.
20	CHAIR REDLICH: So you don't get
21	benefits, but you file under both; is that it?
22	MEMBER VLIEGER: Yes, that's right.

1 CHAIR REDLICH: Okay. So you could 2 be, in other words, what you're saying is -- is it possible that, let's say, beryllium 3 4 sensitization, it could be denied, could it be 5 denied in B and accepted in E, or once it's accepted it's accepted in both, but then the 6 7 benefits you get would potentially be in E and not in B; is that it? 8 9 MEMBER VLIEGER: Right. The E would 10 follow with one beryllium sensitization, and you would not get Part B, like boy, unless you were 11 12 approved for CBD, sarcoidosis, or for silicosis. 13 CHAIR REDLICH: Okay. So if you are, 14 if you're approved for being sensitized, then it 15 should be in both B and E; is that correct? 16 MEMBER VLIEGER: Right. Now, you 17 would only get the Part B if you were first 18 approved for beryllium sensitivity or pre-1993 19 CBD. 20 CHAIR REDLICH: Okay. I think I 21 understand. So you raise a good point, though.

I think when we are looking at this -- it is true

that you could have interstitial lung disease, pneumoconiosis, one of those diagnoses, and -yes, we're getting into the potential category.

And that category with sensitization, a category for even without it, but, basically, because a lot of people with interstitial lung disease do not end up getting a tissue diagnosis, but they have a diagnosis of pneumoconiosis or ILD.

I eyeballed the data, and it didn't look like there was huge, huge numbers, but I think it would be helpful, John, in terms of we'll add this to the list of the basic data things, at least I think it would be helpful to get a sense of just the numbers. So in addition to sarcoid, at least to get some idea of what's in the pneumoconiosis/ILD category?

MEMBER DEMENT: Yes, a lot of the workers list multiple conditions. And if you look across the table, you can see the ones that are approved and not approved. Most of the sarcoid under B, and there are relatively few, have other conditions, as well. Most of the

sarcoid looks like it's under E.

CHAIR REDLICH: That's right. The sarcoid -- that's exactly -- yes. Sarcoid is under E, that's right, and they tend to be multiple things. So I think it would, because there is the potential that the diagnosis of CBD was called something else, and the things that would most likely be called, if that were the case, would be sarcoid or this pneumoconiosis/ILD.

MEMBER MARKOWITZ: This is Steven. B doesn't recognize sarcoidosis as compensable, so sarcoidosis couldn't appear under B.

CHAIR REDLICH: That's right, yes.

All I'm saying is if we're addressing the problem related to CBD, we're sort of not doing justice if we -- the question is, are there some CBD claims that are in the E category that really belong in B because the person was -- I guess they should be -- ideally, if someone thought that that's what they had, they would file under B, get denied, and maybe they would be accepted

under E. I think, Laura, that's what you were getting at.

MEMBER WELCH: Yes, and you don't have to worry about cases being under E that weren't reviewed under B. B is worth more to everybody, and the claims examiners look at that. And I don't think that gets overlooked.

CHAIR REDLICH: Okay. So I'll tell you what. As a data point that I think would just help to see how big this pool is, would be - I would propose, as far as the data side, that we look at the overlap of people that have filed a B -- I mean, my guess is if you file for silicosis it's under E, but it's conceivable you also filed under B.

But I would simply say for how many total silicosis claims and then how many of those were, as Laura suggested, filed under both B and E.

MEMBER WELCH: Well, do you remember that under B you had to work at a lot of test sites for silicosis? I thought you said another

site.

CHAIR REDLICH: I'm sorry. Excuse me.

I meant sarcoid. I apologize.

MEMBER WELCH: Oh, okay.

CHAIR REDLICH: I apologize. So, for sarcoid. For sarcoid, just because that is so sort of specific in the beryllium issues, let's just look at sarcoid. It does look like -- my look at this, it looks like a lot of the sarcoids were an E. And to me, it seems like that same person would have -- what we're talking about, would have filed under B because there would be more benefit there and might have been denied but awarded under E.

But whichever way it is, if we simply got a sense of diagnosis sarcoid, how many are filed under B, how many under E, how many under both, how many are denied, we'll have a feel for what this sarcoid tie is.

MEMBER WELCH: Well, the thing is when you look at the spreadsheet a little more, you'll see that there are people who are just -- it

seems that sarcoid is not compensable under D.

They have to get CBD. But they could have a sarcoid diagnosis and be accepted as CBD, and you'd see that in the -- you'd see, for some reason, they're listed denial for sarcoid under B. And they should all be denied, and there's some that for which there's a yes.

CHAIR REDLICH: I know, I know. I spent many hours looking and sorting this data set over the weekend.

MEMBER WELCH: If you look at the CBD column alongside, the ones that were accepted for sarcoid were also accepted for CBD and some that were turned down were accepted for CBD.

under B is going to be extremely confusing because, as Steve said, there's not supposed to be any. They're all supposed to be nos. It's really only there -- the way it would help us is not the yes or no on those but the fact that they came in with a diagnosis of sarcoid and were applying for CBD under B, so --

1	CHAIR REDLICH: Yes, and we may not
2	from this initial look, because if we don't have
3	the chronology, in terms of just looking at what
4	the piles look like, we could just and then if
5	we see what the numbers look like, what if we
6	simply said what number of sarcoid cases are
7	there under, you know, E, and what percentage
8	have been accepted, and what number are under B,
9	and which are under both, something like that,
LO	and just see what they, recognizing
L1	MEMBER WELCH: Yes, maybe. And I
L2	CHAIR REDLICH: And there should be
L3	if sarcoid has been accepted under B, there
L4	should also be a diagnosis of beryllium disease.
L4 L5	should also be a diagnosis of beryllium disease. MEMBER WELCH: Yes, that's right.
L5	
L5	MEMBER WELCH: Yes, that's right.
L5 L6	MEMBER WELCH: Yes, that's right.
L5 L6 L7	MEMBER WELCH: Yes, that's right. I'll CHAIR REDLICH: So I think if we just
L5 L6 L7 L8	MEMBER WELCH: Yes, that's right. I'll CHAIR REDLICH: So I think if we just see what these piles look like, and I think then
L5 L6 L7 L8	MEMBER WELCH: Yes, that's right. I'll CHAIR REDLICH: So I think if we just see what these piles look like, and I think then we could, you know, we'll look at it and we'll

1	then, you know the other one is if they have
2	sarcoid and they are sensitized to beryllium, to
3	me, that should be chronic beryllium disease. So
4	
5	MEMBER DEMENT: There are no 135 is
6	sarcoid, right?
7	CHAIR REDLICH: Yes. Or I'd have to
8	check.
9	MEMBER DEMENT: There are no medical
10	conditions approved under B that have sarcoid in
11	any way. I mean, even in a multiple diagnosis.
12	MEMBER WELCH: Yes, so that makes
13	sense.
	sense. CHAIR REDLICH: Okay so then they are
13	
13 14	CHAIR REDLICH: Okay so then they are
13 14 15	CHAIR REDLICH: Okay so then they are all under E, so that's okay. So that's where
13 14 15 16	CHAIR REDLICH: Okay so then they are all under E, so that's okay. So that's where I thought they were mostly.
13 14 15 16	CHAIR REDLICH: Okay so then they are all under E, so that's okay. So that's where I thought they were mostly. Okay. So let's just look at sarcoid.
13 14 15 16 17	CHAIR REDLICH: Okay so then they are all under E, so that's okay. So that's where I thought they were mostly. Okay. So let's just look at sarcoid. They could have been denied under B. Is that
13 14 15 16 17 18	CHAIR REDLICH: Okay so then they are all under E, so that's okay. So that's where I thought they were mostly. Okay. So let's just look at sarcoid. They could have been denied under B. Is that right? But they shouldn't even

propose this? Let's look at whatever sarcoid is 1 2 under B, and it appears whatever number that is should have -- are all been denied. But let's 3 4 just see what number are in that B category. 5 MEMBER DEMENT: In the B category, there are four that are purely sarcoid, and there 6 7 are four that are sarcoid plus something else: one beryllium disease, one sensitivity, and one 8 9 just a lung disease. 10 CHAIR REDLICH: Okav. 11 MEMBER WELCH: Yes. Can I just add 12 something? I think the data actually has the 13 date of approval and denial. 14 MEMBER DEMENT: In that calendar year. 15 MEMBER WELCH: Yes. 16 MEMBER DEMENT: We have your approval or denial, so we can look at that. 17 18 MEMBER WELCH: Right. I just don't 19 know what the initials underneath it stand -- you 20 know, ICY and CY. I couldn't figure that out. 21 So you actually can see what a lot of 22 claims that have a diagnosis date in the '70s and

1	'80s were adjudicated in the 2000s. How
2	interesting.
3	CHAIR REDLICH: Yes, I know. It's a
4	huge lag between the diagnosis on some of them.
5	MEMBER WELCH: Well, that's because
6	people are trying to get before that '93 date, I
7	think.
8	CHAIR REDLICH: So you don't know when
9	it was filed. Okay. So let's do this then.
10	For under there's only a handful,
11	so you already could have answered that under the
12	B. So let's now just go to sarcoid under E, and
13	if we could just look at, from the data, the
14	total number of sarcoid cases, how many are
15	accepted, how many are denied, and I guess among
16	those, under E, I think it would be helpful to
17	know if there's sarcoid with beryllium
18	sensitization. If there's sarcoid with beryllium
19	disease, it should be over in B.
20	MEMBER DEMENT: Well, possibly. It
21	could have been filed but denied in B.
22	CHAIR REDLICH: Maybe yes. I think

1	you're right. I think we know what we're talking
2	about. We just want to see what's in this
3	sarcoid category that is maybe, you know, been
4	accepted, denied, and what's going on there. And
5	I would propose also then, could we, in the
6	request, when we ask for some CMC reports, if we
7	could request the last ten sarcoid claims? Is
8	that okay with everybody?
9	MEMBER MARKOWITZ: Do you want to
LO	differentiate between approved and denied or
L1	CHAIR REDLICH: Why don't we say of
L2	the last
L3	MEMBER DEMENT: Well, most of them are
L4	denied.
L5	CHAIR REDLICH: A bunch of them are
L6	denied. That's right. So we need why don't
L7	we just take the last 15 sarcoid claims and at
L8	least ten of them denied.
L9	MEMBER DEMENT: Most of the claims are
20	denied, unless they also have beryllium disease.
21	The rest of them are pretty much
22	CHAIR REDLICH: Yes and what I didn't

look is I think the issue is, to me, if they have 1 2 sarcoid and beryllium sensitization, that's sort of the key thing that -- but also I think -- so 3 let's do the both from the data and requests from 4 5 review of claims with sarcoid. MEMBER WELCH: I don't think you need 6 7 to bother. I just looked at it, and under Part E it says if they have a sarcoid approved, they 8 9 have a CBD approved. All of them, every single 10 one. 11 MEMBER DEMENT: They do. They're --12 pretty much. 13 MEMBER WELCH: There's a couple that 14 are blank. 15 MEMBER DEMENT: Yes, there are a couple 16 blanks in there but most of the sarcoid have 17 something else. 18 CHAIR REDLICH: So I still would like 19 to look at, I don't know, five or ten denied 20 sarcoid claims. MEMBER DEMENT: Actually, Laura, there 21 22 are six approved that just are sarcoid.

1	MEMBER WELCH: They don't have
2	anything under CBD one way or another.
3	MEMBER DEMENT: No, they have nothing.
4	If you look at the medical conditions
5	MEMBER WELCH: You look at the medical
6	conditions, too, over there.
7	MEMBMER DEMENT: The medical conditions
8	that are approved over there
9	MEMBER WELCH: Yes, you're right.
LO	That's 135, you're right.
L1	CHAIR REDLICH: I think, you know,
L2	sarcoid is something that is pretty specific when
L3	someone has sarcoid.
L 4	MEMBER WELCH: Right. But if they're
L5	denied yes, you can look at them, but it's
L6	like
L7	CHAIR REDLICH: Because it's a whole
L8	literature on machining and, you know, there are
L9	all kinds of other exposures, but the type of
20	work, and there is an excess of sarcoid in
21	Hanford from this study. I had pulled one I
22	found on the internet including a PowerPoint of

data presentation on Hanford.

MEMBER MARKOWITZ: This is Steven. So the goal in looking at the denied sarcoid is to look at the level of evidence, whether or not they have any beryllium sensitivity or disease, and then also to look at what affirmative evidence exists that they actually had sarcoid. Is that right?

CHAIR REDLICH: Yes, I think the question is if it's true sarcoid and they worked in a place with beryllium, because some people would argue just in terms of probabilities that on a more probable than not basis, that is more likely beryllium disease than sarcoid.

MEMBER MARKOWITZ: But the point of looking at the claims is actually to examine what the claim record shows in terms of beryllium exposure and what it shows in terms of --

CHAIR REDLICH: Right, exactly. So the question is, is it really truly sarcoid, and if it is sarcoid, is it beryllium disease that's being miscalled sarcoid?

And I think, by a look at -- we would have a feel for that because I feel like, after the end of the day, we don't want to then feel like, gosh, we actually missed a group of people that -- and concern has been raised.

My understanding is that Hanford also, if you have sarcoid, and I can check because I was reading this last night, and in the Navy, I - - we have the Groton Sub Base here, that they consider sarcoid an occupational disease, in the sub. So I just -- I think we should see what the sarcoid is. They're not a huge number. And then, is it truly sarcoid, and do they have beryllium exposure, as you said.

MEMBER WELCH: So there were -- so you kind of figure -- well, there's two categories with sarcoid. There's sarcoid that is beryllium disease accept it as that under the Part E, for whatever reason. And then there's sarcoid that they decided wasn't CBD and of those, there were 130 cases in the database, people who applied with a diagnosis of sarcoid primarily and were

denied. 1 2 CHAIR REDLICH: Okay. So what if we took a look at -- requested 15 of those? 3 4 MEMBER WELCH: That's fine. 5 MEMBER MARKOWITZ: It's Steven. Again, the 15 is just going to get -- it's fine. 6 7 It's going to give us some hints about what's going on. Knowing that to actually get a more 8 9 thorough look at possible misdiagnosis or 10 misrepresentation of the validity of the claim 11 that we would need a considerably larger number, 12 right? 13 CHAIR REDLICH: Yes. I was thinking 14 just in this very short run to even get a feel 15 for what other questions we might want about that 16 group and what's in it. 17 MEMBER MARKOWITZ: Because if we look 18 at a limited number and don't find a problem, 19 we're not necessarily going to conclude that 20 there's not a problem, right? 21 CHAIR REDLICH: That's true. But we

will also, by looking at the data, we'll at least

have some idea of the total number of sarcoid 1 2 claims in there, which is not huge huge. that is correct. I guess I would call it 3 4 exploratory, and maybe we should look at a little 5 bit larger number. They wouldn't take very long to look at, I don't think. 6 7 MEMBER MARKOWITZ: Well, I mean, for exploratory purposes, you know, we only need a 8 9 limited number. To get a real handle on it, 10 we're going to need a significantly larger 11 number. So that's fine. I just wanted clarity 12 about --13 CHAIR REDLICH: That's right, I would 14 consider this -- that's right. It's exploratory. 15 MEMBER MARKOWITZ: Okay. 16 CHAIR REDLICH: That is correct. And 17 I was thinking also if then we do want more 18 information at least it would give us some idea 19 of what information to request. 20 MEMBER MARKOWITZ: Right, right. 21 CHAIR REDLICH: That's what I was 22 thinking.

3 4

And then, not to prolong this until whenever, but I think once we are looking at sarcoid and because of the point that was made, I feel like we should do the same with the ILD/pneumoconiosis. And you know what, I don't have the data set open now because I didn't want to start cooking on columns and sorting, but I think it would be helpful to know the number of ILD/pneumoconiosis claims, again, accepted and denied, you know, similar questions to that that we're asking about sarcoid.

And if -- because if you had a pneumoconiosis and you had a sensitization, a lot of people would say that sounds like chronic beryllium disease. Laura is probably looking at that right now, but I am refraining myself and I am not opening the data. So if we could just add that to the data piece.

MEMBER WELCH: I mean, the thing is if you have -- you'll be looking at the interstitial lung disease under Part E includes a lot asbestosis but you don't -- I mean it's a very

1	non-specific diagnosis. Maybe we should leave
2	that for later because there are well let's
3	see, there are
4	CHAIR REDLICH: It didn't seem like
5	that large a number, but I
6	MEMBER WELCH: Two hundred approved
7	under interstitial lung disease and a lot more
8	denied, like
9	CHAIR REDLICH: Okay. Since I don't
10	have it open, the other aisle, is pneumoconiosis
11	separate from ILD or is it in the same
12	MEMBER WELCH: In this spreadsheet,
13	all we got was ILD. So there's, you know, 900
14	altogether, 200 approved and 700 denied.
15	CHAIR REDLICH: Okay. But that's over
16	all these years.
17	MEMBER WELCH: Yes.
18	CHAIR REDLICH: Out of 20,000 claims.
19	MEMBER WELCH: So asbestosis is
20	clearly a different category because there are
21	thousands and thousands of those.
22	CHAIR REDLICH: Okay. So I would

1	propose that we, in the same exploratory way, I
2	think we would want to first look if there are
3	any with pneumoconiosis, or ILD, excuse me, and
4	beryllium sensitization from the data piece.
5	That's really the piece that could be a
6	potentially an inappropriately denied claim.
7	Does that make sense?
8	MEMBER WELCH: Yes, there are some.
9	CHAIR REDLICH: So I would propose
10	that we also request I'll look at the overlap
11	with sensitization. I would think, you know, if
12	they have CBD also then they're in the B
13	category, so we're talking about the people that
14	don't have CBD but have pneumoconiosis,
15	sensitization, and are denied.
16	MEMBER WELCH: There are, you know, a
17	very small handful. There's like six that are
18	sensitized and have a diagnosis date under ILD.
19	CHAIR REDLICH: Okay. So I think
20	MEMBER WELCH: And they were all
21	adjudicated more than a decade ago.
22	CHAIR REDLICH: Okay. So

MEMBER WELCH: And I don't know that that -- I'm not so sure we'll get much out of that.

CHAIR REDLICH: Okay. So should we -then the other pneumoconioses are -- do not have
sensitization?

MEMBER WELCH: Right.

CHAIR REDLICH: Okay. So since that is a grab bag, I would still personally just like to -- because a lot of things get thrown into that grab bag, as just an exploratory thing, I don't -- if we could maybe look at ten of those claims to see what's going into that category?

MEMBER WELCH: There's a handful that have -- that were approved that had both beryllium sensitization and ILD, and they're under Part E, and there's a handful that have beryllium sensitivity and were denied for ILD. So you could look at, you know, you could look at five of each of those that are beryllium sensitive and approved and beryllium sensitive and denied.

CHAIR REDLICH: Okay.

MEMBER WELCH: You won't get more than that many for each one because there's only about that many. There's a few more that were beryllium sensitive approved and ILD, and John is quicker than I to look at the diagnoses. They had multiple lung disease diagnoses.

CHAIR REDLICH: Okay.

MEMBER WELCH: Accepted as beryllium disease and beryllium sensitivity, and then they have this ILD diagnosis, too, so they may --

CHAIR REDLICH: So I guess -- you know what? I think the issue that comes up is and another way to look at it is -- and from talking to some of the physicians involved, it seems like there's many more people have beryllium sensitization than have beryllium disease. When you have beryllium sensitization with another pulmonary condition, that starts to get confusing in terms of, do you have two separate entities or do those two combined and now you have chronic beryllium disease?

Since that seems to be an intersection that generates a lot of issues, it might just be good to have a sense of how big that tie is, which really would say, if people have beryllium sensitization, how many of them have some other pulmonary diagnosis?

MEMBER WELCH: So in some ways the other thing that comes up with that is that beryllium sensitization, and they have some chronic lung disease that is an interstitial disease, not just COPD, why wasn't their claim already accepted as CBD?

CHAIR REDLICH: That's what I'm saying.

MEMBER WELCH: Well you won't find -well, you might find those by looking at these
ILD diagnosis dates. But I think the problem is
then piecing that out of the spreadsheets could
be hard.

CHAIR REDLICH: Yes. So I would just say why don't we, at least to have an idea of the numbers because basically, a lot of people, once

they have a chronic pulmonary condition and they ever smoked one cigarette in their life, that condition is COPD. So I've had lots of patients that are called COPD and they're not COPD. They got ILD and, you know --

MEMBER WELCH: Right. Well take a look at whatever number you want, and then we'll go from there because otherwise we're kind of, I think, spinning a little bit.

CHAIR REDLICH: Yes. So let's just say why don't we just look at -- because this is an initial look and we'll have some idea of positive BeLPT with another diagnosis in the pulmonary realm and what those are, and then we'll have an idea. You know, because the main pulmonary diagnoses are COPD, asthma, and then this, you know, ILD thing.

MEMBER WELCH: Okay.

CHAIR REDLICH: And the question is was their diagnoses that they gave us, were those all the pulmonary -- you know, we basically want to see that overlap because that's just a

potential pile of things that could be getting 1 2 denied, then re-evaluated, and -- so just to summarize then, the other categories we wanted to 3 look at was the sarcoid, if we are -- people are 4 5 getting misdiagnosed as sarcoid, and also if they are sensitized and have a pulmonary condition 6 7 that's getting not called CBD, what is that? 8 MEMBER WELCH: Okay. 9 CHAIR REDLICH: And then we would have 10 some idea of at least as an exploratory --11 MEMBER WELCH: Can you make a request 12 that DOL be able to understand, like, you know, 13 it's called this and that, you know, like ones 14 that have a positive, whether B has approved and 15 interstitial lung disease approved, those are the 16 ones you want to look at, that weren't accepted 17 for CBD, is that the group? 18 CHAIR REDLICH: Well, I mean I guess 19 to do this, the first thing we need to make sure 20 is that in the Excel spreadsheet we were given, 21 that that captures the pulmonary conditions.

MEMBER WELCH: Well, I guess the ones

we asked for. It captures COPD, asthma, and 1 2 interstitial lung disease. CHAIR REDLICH: 3 Okay. 4 MEMBER WELCH: But it's not everybody 5 with a COPD diagnosis. It's people that have something related to beryllium in some way. 6 CHAIR REDLICH: Well, what we 7 requested was -- no because there are people 8 9 under there that are in Part E that are not in B. 10 MEMBER WELCH: Right because we didn't 11 get every single COPD E case. We got ones where 12 they had filed for something related to 13 beryllium. CHAIR REDLICH: I think we'll have to 14 15 clarify that. 16 MEMBER WELCH: You don't want all the 17 COPD cases. There are 10,000 of those. 18 CHAIR REDLICH: I know, but --MEMBER WELCH: We definitely don't 19 20 want them. I mean we only want the ones where 21 people were asking to be adjudicated for 22 beryllium disease in some way or another, not a

1 COPD case. 2 CHAIR REDLICH: I'm just saying the initial request didn't clarify that, so I think 3 4 we should check. MEMBER WELCH: And I think what you 5 can see, and this is a visual thing, but you can 6 7 see what conditions people filed for. CHAIR REDLICH: Yes and I don't have 8 9 it open now, but when I looked it looked like 10 there were people, you know, if you sorted under 11 COPD, that filed only under E. 12 MEMBER WELCH: I don't know. 13 CHAIR REDLICH: Okay. Well, we'll 14 have to check that in terms of what data we have. 15 MEMBER WELCH: Yes, because I think 16 these are all people who had a Part B claim to 17 start with. I mean, everybody's got something 18 over on the Part B side. So they originally had 19 applied in some way or another for a beryllium --20 CHAIR REDLICH: Okay, so that's what 21 we want.

MEMBER WELCH: Yes, and then they end

up on the E side with other diagnoses. 1 2 CHAIR REDLICH: Okay, that's right. And what we're trying to get a feel for is really 3 4 do we have people that are on the E side that may 5 be misdiagnosed or denied chronic beryllium disease who have it? 6 7 MEMBER WELCH: All right. So if you look at people with an ILD diagnosis who are 8 9 beryllium sensitive and those who are not, just a 10 handful of those, to get some sense of what's 11 going on. 12 Exactly. CHAIR REDLICH: That's 13 right. 14 Okay, and so we're going to look at 15 that on just the numbers data that are not a huge 16 number, and we're just going to do that to get a 17 feel for the overlap with other pulmonary 18 conditions, recognizing that things like COPD and 19 ILD can get misdiagnosed. 20 MEMBER DEMENT: Yes, this is John. 21 It's not clear to me what data we really have.

There are people, and a lot of them in this

database, in fact most of them, who have nothing in terms of medical conditions filed under Part B but under Part E.

MEMBER WELCH: Oh, really? Okay.

CHAIR REDLICH: And that's -- I didn't want to open it now on the call, but when I looked at it over the weekend that was my take.

MEMBER DEMENT: Yes, and actually the majority of them --

CHAIR REDLICH: And the request was, not knowing what the numbers were like, the request was COPD, too. But we can, it's clear, if someone hasn't filed under B, then we would just not look at those for the question we're asking now, right?

Because really the question we're asking now is if someone got beryllium sensitized, they think they have a beryllium condition, and it's being called sensitized, but there's possible CBD because those are also the people, a number of the questions that we were asked relate to that cohort, and then what is

being done then to evaluate if they have CBD and how frequently and all these other things. So I think at least getting a sense of what that group is.

So I think we at least have the request in terms of the data piece, and then, in terms of the CMC reports that we want to review related to all of this, I think, basically, we're interested in people that have, there aren't that many, you know, with pneumoconiosis and a BeLPT that have been accepted or denied. And I think also, at this point, we're not interested in ancient history. So another way to look at this, since there's not a ton of those claims is, you know, the last ten pneumoconiosis claims and making sure that we include the few that have a positive BeLPT. Is that -- in terms of the actual claims that we're looking at. And I think, in terms of looking at further, it would just be helpful to see what the numbers are with this overlap, you know, how many overlap with COPD and things like that. Is that okay with

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1 everybody? 2 MEMBER WELCH: Are you talking about 3 that latter part of the spreadsheet analysis 4 request or something from DOL? 5 CHAIR REDLICH: I think the piece from DOL, I would like to see the grab bag of the 6 7 pneumoconioses diagnoses. 8 MEMBER WELCH: Okay. 9 CHAIR REDLICH: And I think the other 10 stuff, let's just wait and see how big this pie 11 is. 12 MEMBER WELCH: Okay. 13 CHAIR REDLICH: I think it is an 14 important pie, a piece of it, because those are 15 people that, you know, have a lung condition, are 16 sensitized, and then are being, you know, re-17 evaluated and the like. 18 MEMBER DEMENT: Are you talking about 19 the silicosis? 20 CHAIR REDLICH: No, all I was simply 21 saying was the people that are sensitized that

have some other pulmonary condition.

MEMBER DEMENT: Okay.

CHAIR REDLICH: Okay. And then I
think we decided that -- so for silicosis, I
think we would just want the same number of
claims. I think silicosis is not as complicated,
the number of claims, the number denied and
number accepted, and I think we decided we wanted
to review, we picked a number of silicosis cases.

MEMBER DEMENT: Just on a quick look under Part B, it looks like about half the silicosis cases or slightly less than half were approved.

CHAIR REDLICH: Yes, okay. I think, in terms of other data, and we've expanded the data section, we've expanded a little bit some cases we want to review, and with that expansion has included some sarcoid and some pneumoconiosis. And we have talked about also other information related to who is the people reviewing the beryllium claims that we would like.

We can get input from whoever is on

this call, but is there other pieces of data we think or information that we, at this point -- obviously, I think, once we look at things, we will decide we want more, but, at this point, do we have any other asks? Going once, going twice. Any other people we want to talk to? Oh, and I guess, Carrie, we also asked just who came up with the list of questions for us.

MS. RHOADS: Right.

CHAIR REDLICH: And where they got their -- I mean, I think it's a good list of questions, I just, in terms of their sources because those are issues. Okay. So I think that's a very pretty thorough and good list of data information needs.

So in terms of the timeline for this data. So, John, you had volunteered the sort of basic stuff in a week or two?

MEMBER DEMENT: Yes, if you can get me the questions, I can, first of all, evaluate the data here to respond to it and get back, and I should be able to turn it around in about a week.

CHAIR REDLICH: Okay. And my guess is, when we look at that, we will have other -and I think also what we were going to do in that time and while we're doing that is any other variables that we are hoping we can get for the data piece, correct? And then, in the meantime, we are hoping in the next, like, month or so, that the Department of Labor, just speaking in terms of timeline, would come up with the examples of the recommended, you know, the decisions, the final decision, the statement of facts, and the CMC reports. And, Carrie, you're going to find out what's feasible there.

Yes, I'll ask the MS. RHOADS: program.

CHAIR REDLICH: Okay. And, ideally, we'd love to get those sooner, rather than later, because we'd like to review them before our next in-person meeting. And I would propose that we pick a time for a call, you know, after we have at least had a chance to look at the basic data, and, hopefully, depending on how long it takes to get the reports --

MEMBER WELCH: Well, we have to do the Federal Register notice, so I think we have to pick, we have to give six weeks. So we don't have to pick a date now and then see where we get that in because we have what? Let's see. July, August, September. We have three months, July, August, and September, before we're getting close to our meeting.

MEMBER MARKOWITZ: If we pick a date, you know, mid-September, that's probably the best we can do.

MEMBER WELCH: Yes, that's what I was thinking, too.

CHAIR REDLICH: Okay. So, and actually, six weeks would be in the beginning of August.

MEMBER WELCH: Right. So we could wait a little bit and then pick a date, or we could just -- I mean, I suggest why don't we start working on a date in September, and then we'll deal with what we have by then.

1 CHAIR REDLICH: I agree. So Labor Day 2 this year is on September 5th. It's a little bit How about if we pick the week after that? 3 4 MEMBER WELCH: Do you want to do it 5 over the phone or -- I guess we could. So why don't we 6 CHAIR REDLICH: Yes. 7 do this? Carrie, can we have someone send out like either a, you know, invites or, you know, 8 9 one of those calendar things, whatever, and we'll 10 find a time for a call the week of -- or do people want to do it that week of Labor Day? 11 12 Right now, does anyone have a strong preference? 13 MEMBER WELCH: I mean, doing it the 14 week of the 12th just gives us that much more 15 time to get --16 CHAIR REDLICH: Yes, exactly. I think 17 that is better. And Labor Day week is always a 18 dangerous week. 19 MEMBER MARKOWITZ: Why don't you poll 20 people for the week of the 12th and the week of 21 the 19th just to be safe? 22 CHAIR REDLICH: Okay. That sounds

So our goal is to set up our next call the 1 2 week of either the 12th or the 19th and, at that point, we will hopefully have reviewed data, have 3 4 some idea. I mean, in the meantime, we can request -- we don't need to wait until then. 5 think very shortly we could request additional 6 7 variables that we would like and go ahead and we'll, you know, however people want to do that, 8 9 either feed it to me and I feed it to Carrie or 10 if someone else wants to be the person. And then 11 we will, hopefully, by the October call, have reviewed data, even if there's any additional 12 13 data, and, ideally, some of the reports.

So my thought, if we get, in an ideal world, if we get the reports in time to review, I was thinking it would be helpful to make up a little criteria for rejection or whatever thing so that we could then come up with some summary of the reports, and I think it would probably become apparent, once we reviewed some of them, what we would want. So, ideally, we'd be able to sort of say we've reviewed the 50 reports and I

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think, at that point, have a better feel for some 1 2 of the issues. And then I guess also, Carrie, by that 3 4 call, whatever information the additional things 5 that we had requested, in terms of just information about the physicians doing the CMC 6 7 reports because I think that's probably something either -- they should be able to give that to us. 8 9 And I think someone had also mentioned also 10 whatever that people that had trouble getting before but at least what criteria there are from 11 12 the selection and training. 13 MS. RHOADS: Okay. I will pass those 14 on to the program. 15 CHAIR REDLICH: And I guess, you know, 16 if it's something that we can get and it will 17 take extra time or if, for some reason, we can't, 18 then that's probably, you'll probably get an 19 answer relatively quickly. 20 MS. RHOADS: Probably. 21 CHAIR REDLICH: Okay. Are there any other items? 22

MEMBER MARKOWITZ: This is Steven.

There are a couple of issues. One is the silicosis is within the domain of the committee.

It's a lot more straightforward for a number of reasons.

And then, secondly, on the attachments that Carrie sent around, which was from our April meeting where the DOL lists issues that they want help on, there are a number of scientific issues related to CBD that we haven't discussed -- and sensitivity -- that we haven't discussed, and we probably don't need to discuss them here now.

But we should develop a plan for it.

For instance, they've asked for our input into, quote, consistency of testing results among different diagnostic facilities. We're probably not going to get that from the claims.

That's probably --

CHAIR REDLICH: You know what? Thank you because that was another question I had.

And, actually, Laura knows a lot about the literature on consistency. But my understanding

now is that there are two facilities doing the testing. Is that correct, or it is more than two currently?

MEMBER WELCH: I don't know what happens if you're, you know, if you call up Quest and they tell you what that was. I don't know where it goes. You know, then we send them out, from our program, we send them out to National Jewish or ORISE.

CHAIR REDLICH: Yes. So I guess the first question I had related to, those are the only two that I am familiar with. So an important question is are there any other labs that are doing the testing? And that's something that whoever is getting these records would know from reviewing them.

MEMBER WELCH: For the Department of Labor's question, are they questioning a particular lab?

MEMBER MARKOWITZ: My guess is -- it's Steven. My guess is they see discrepant results between the two labs.

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Thoracic Society came out about a year or two ago with one of their official documents that sort of reviewed this. My understanding is that I think there is much more consistency, and you can correct me, Laura, that I think this is more of a history issue, but I think there is --

MEMBER WELCH: Yes. I mean, I think that there's a -- DOL did a cross-comparison of labs, but it was probably ten years ago, between what was done in the three reference labs because Specialty in California was doing it. think there's been so much cross-reference between the two, but, you know, you can get, if you take the same guy and test him every year for ten years, you will not come up with the same results. I mean, the data from Wellman or whatever their new name, shows that in their surveillance program. And sometimes it's people who have a very low sensitivity index, and then the next time it's negative, the next time it's borderline, then it's positive. So they're not

really, it's not a lab variation as much as it's the biological variation of the test.

CHAIR REDLICH: That's right. And -
MEMBER WELCH: I'm happy to take a

look at what's new on that and just kind of put
together a summary.

CHAIR REDLICH: I have recently done this, and, honestly, there wasn't, as far as I was aware, of anything really new on this since the ATS document. And I sort of, you know, the newer, more relevant science on diagnostic tools, I just don't think there is a newer or better tool out there now. But it is true that we need to address, I guess, at this point, the question is a plan for how to address this.

MEMBER WELCH: You know, if what they're getting, is they're getting reports from physicians that are saying, well, we don't have an LPT, but we've done this something or other and it shows sensitivity. Then they may need help knowing whether to accept that or not. So I think maybe some more clarification, and then we

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can do that at the next meeting on what the -you know, we don't see there's an issue on moot
or variability, but can they be more specific?

CHAIR REDLICH: Okay. And maybe, in terms of an approach, I don't really want to propose a whole evidence-based review. I mean, I think there's a recent official document that -but, you know, there are, and I think it's beyond our scope, there's issues of, you know, one test, two tests, and the like, but that's sort of been decided, and that one positive is positive. I do think there was one or two other questions that I actually wasn't totally clear what the question was, and I would propose, if anyone has -- like, one of them I think I put a question mark on it. I just have to find it. But I think if we have questions that we're not quite sure they're asking, we could go ahead before the meeting and, since Carrie is going to get back to who actually came up with these questions, we could ask for clarification, as far as that goes.

And then I think -- but, Steve, you do

raise a question. I have an opinion on some of these, and I think it's reasonable, but, like, something like input of false negative and false positive and contribute to that. What I would not like to propose is that we do some evidence-based review on the subject. That's over and beyond. But I think that there are -- and I think we could cite, you know, recent, like ATS document, address a number of these questions.

MEMBER MARKOWITZ: This is Steven.

Look, I don't think we have the resources or

ability, nor are they asking for any sort of

systematic review.

CHAIR REDLICH: Yes, but I think guidance and I --

MEMBER MARKOWITZ: They're trying to take advantage of the fact that, you know, their expertise in the past has not been necessarily all that great, so they're trying to take advantage of the fact that they have some people that will do some work. And I think if a subset of people put together their own consensus

opinions that are reference that that would suffice.

CHAIR REDLICH: I agree. And I think, at this point, that many of us would be able to do that. Now, I mean, don't you agree, Laura, that I think -- and John -- you know, just in terms of if you've been seeing these people that I guess, you know, I was feeling a -- okay. little bit -- but, like, looking at some of the actual claims reports might add some clarification to some of the questions, and so that's why I didn't want to get too bogged down. And a couple of them are, like, you know, one was on critically ill patients. Yes, you don't do that. And that's one of the reasons why you might not have a tissue diagnosis.

MEMBER MARKOWITZ: So maybe in the September call, we can revisit these questions when we know more and kind of identify what our product is and also what our time table is.

CHAIR REDLICH: That sounds good. And I think what we could also do by then is, you

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know, sort of maybe identify those that require a little more time than others. Okay.

And then the other issue that you mentioned was silicosis. So I think we had included that in the data requests and also the review of charts request. I occasionally mince my words between silicosis and sarcoid, so we were going to look at the number of cases in the data accepted and then also look at, given a number of silicosis cases and at least, you know, the number that have been denied.

Okay. So I think that is the silicosis piece. Do we have other items or issues?

MEMBER VLIEGER: I'd like to point out that, along with the review of records that we're requesting, please review the procedure manual for these conditions, particularly CBD and sarcoidosis, as the procedure manual is very convoluted for both the claims examiner and the claimants. And if we could, you know, look at that and maybe clean that up a bit with the way

that we look at the wording of it. A lot of why 1 2 these claims go to a CMC with a really circuitous list of evidence is based on the way the 3 4 procedure manual has the claims examiner do the 5 work. 6 CHAIR REDLICH: Okay. So now just so we're clear, are you talking about the document 7 that got emailed? 8 9 MEMBER VLIEGER: No, there's 10 additional evidence. You only sent part of the 11 procedure manual. It's actually a few paragraphs 12 below CBD is where sarcoidosis is. So you need 13 to look at the procedure manual starting under --14 MEMBER MARKOWITZ: 12C. 12 is 15 sarcoidosis. Yes, but there's more 16 MEMBER VLIEGER: 17 to the procedure manual than what you were sent. 18 It's actually quite lengthy. 19 MEMBER WELCH: At one point, we got 20 sent, in response to a question, a link to the 21 procedure manual, and I can send that or Carrie

can.

CHAIR REDLICH: Yes. What I had done 1 2 is I thought I had taken the relevant chapter from it, but what you are saying is that there 3 are other relevant chapters in there that I 4 5 missed. Is that --6 MEMBER MARKOWITZ: Actually, it's in 7 the same chapter, but, regardless, you know, the procedure manual is available on the EEOICP 8 9 It's available through the Advisory website. 10 Board, our first meeting with the references. 11 CHAIR REDLICH: Okay. And I had just 12 So I agree. And that's something I resent it. 13 think -- you had mentioned that it conflicts with 14 some other either pamphlets or information. 15 think if there is any other sort of documents 16 where there are some conflicts, that would be 17 really helpful to get them. 18 MEMBER VLIEGER: Those are DOL 19 publications. 20 CHAIR REDLICH: Okay. Was there a lot 21 of -- Carrie, is there someone who could take a 22 look and see what other relevant information

there is? 1 2 MS. RHOADS: Well, which ones are people thinking conflict with each other? 3 4 Because I can look up whichever ones you think 5 conflict. I think, Carrie, if 6 MEMBER VLIEGER: 7 you provide the current pamphlets on CBD and Part B lung conditions, they show a simplified method 8 9 for what's really required, but then, when you 10 provide that information, it doesn't meet the 11 criteria in the procedure manual. 12 MS. RHOADS: Are you talking about, 13 like, brochures or something? 14 MEMBER VLIEGER: Yes, the pamphlets 15 and the handouts, the one-pagers that are at the 16 resource center and then the handouts that DOL 17 gives out at town hall meetings. There's like 18 five pamphlets. 19 Those should be on the MS. RHOADS: 20 website, as well. I'll take a look and see 21 what's on there.

Yes.

There's

MEMBER VLIEGER:

different versions of them, too, and I'm not sure which versions are still active. So it will be important to see if there's more than one version of those.

MS. RHOADS: Okay.

So this is just a CHAIR REDLICH: general question, and I suspect it will come up under the medical advice subcommittee, but, as institutions have switched to electronic medical records, any medical history has sort of disappeared from some institutions and it's become sometimes even more challenging to get records, at least at our institution. And I don't know if that is a more general problem or In this case, I guess we will find when we review some cases because there can be an issue of lack of documentation and then there can be an issue of lack of actually having the record that would have the documentation. And the World Trade Center, that was only, you know, 10 or 15 years old, that was a big issue where just not really even being able to get the medical

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So I think we will get some insights 1 records. 2 into that when we review things. I don't know if anyone has a thought or opinion on that. Laura 3 4 or --5 I mean, I think we MEMBER WELCH: No. should, maybe partly because I'm running out of 6 7 steam a little bit, I feel like we have a lot of stuff that's going to be coming in and we have 8 9 another call and I can process it all better the 10 next time around. 11 CHAIR REDLICH: Maybe just because --12 I think let's leave that for now. Okay. I think 13 we have gotten a ton done today. Any other 14 thoughts? Steve, anything else that you think we 15 should be covering? 16 MEMBER MARKOWITZ: No, no, that's it. 17 CHAIR REDLICH: You know what? I do 18 think the overlap between the others, you know, 19 maybe when we have our call in September, it 20 might be good to get a little feedback on the 21 other two.

Right, yes.

MEMBER MARKOWITZ:

wouldn't worry, you know, I wouldn't worry about 1 2 overlap at this point. Well, thank you 3 CHAIR REDLICH: Okay. 4 all very much. I appreciate everybody's time. 5 Carrie, do you have anything else? MS. RHOADS: No, nothing else. 6 thanks, everybody, for your time. 7 8 CHAIR REDLICH: Okay. And --9 MS. RHOADS: And all the work that 10 you're going to do. 11 CHAIR REDLICH: I guess you'll 12 circulate maybe the current understanding of our 13 endless requests, and then we will review it and 14 see if we have it on paper correctly. 15 I can send you a list of MS. RHOADS: 16 what we think the action items are, and also I'll 17 send something around about picking a date for 18 the next call. 19 CHAIR REDLICH: Right. And then we'll 20 also get with John in terms of the data requests. 21 Very good. Okay. I think we are ready to 22 adjourn.

1	And then, in terms of getting feedback
2	from anybody who is on the phone, how does that
3	work?
4	MS. RHOADS: Well, anybody who has a
5	comment, in the Federal Register the comments
6	were to be sent to the Energy Advisory Board
7	email. That can be used for anything, as well,
8	after the meeting.
9	CHAIR REDLICH: Okay. So someone
10	would submit comments or suggestions to that, and
11	then you would pass them on to us?
12	MS. RHOADS: I would, yes.
13	CHAIR REDLICH: Okay, very good.
14	Thank you all. Happy July 4th.
15	(Whereupon, the above-referred to
16	matter went off the record at 1:24 p.m.)
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<u>C E R T I F I C A T E</u>

This is to certify that the foregoing transcript

In the matter of: Subcommittee on Evidentiary Reqs.

for Part B Lung Conditions (Area 3)

Before: Toxic Substances and Worker Health Adv. Bd.

Date: 06-29-16

Place: teleconference

was duly recorded and accurately transcribed under my direction; further, that said transcript is a true and accurate record of the proceedings.

Court Reporter

near Nous &