U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

CO-OCCURRING CONDITIONS PLANNING GROUP

CONFERENCE CALL

MONDAY, JUNE 9, 2014

The Interagency Autism Coordinating Committee's Co-Occurring Conditions Planning Group convened via conference call at 1:00 p.m., Thomas Insel, M.D., *Chair,* presiding.

PARTICIPANTS:

THOMAS INSEL, M.D., *Chair*, IACC, National Institute of Mental Health (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary,* IACC, Office of Autism Research Coordination (OARC), NIMH

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ALICE KAU, Ph.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), (representing Alan Guttmacher, M.D.)

DONNA KIMBARK, Ph.D., Department of Defense (DoD)

WALTER KOROSHETZ, M.D., National Institute of Neurological Disorders and Stroke (NINDS)

LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds

ALISON SINGER, M.B.A., Autism Science Foundation (ASF)

BUCK WONG, National Institute on Deafness and Other Communications Disorders (NIDCD) (representing Judith Cooper, Ph.D.)

PARTICIPANTS (continued):

HAE YOUNG PARK, M.P.H., Health Resources and Services Administration (HRSA) (representing Laura Kavanagh, M.P.P.)

TABLE OF CONTENTS

PROCEEDINGS:

Dr. Thomas Insel: Okay. Welcome, everybody. Sorry for the delay and a little bit of a technical glitch here, but let's go ahead and get started.

Susan, real quickly?

Dr. Daniels: I'll just go through the folks that are already here. You don't need to say anything. But we have Tom Insel, Lyn Redwood, Sally Burton-Hoyle, Matt Carey, Buck Wong on behalf of Judith Cooper, Geri Dawson, Alice Kau, Donna Kimbark, Walter Koroshetz, Alison Singer, and Hae Young Park for Laura Kavanagh.

Have Idil Abdull or Anshu Batra or Jan Crandy joined?

[No response]

Dr. Daniels: Sounds like they haven't. So we have most of the people in the group here. So we can go ahead and start.

Dr. Insel: Okay. So quickly, this is our second meeting for the Co-Occurring Conditions Planning Group. In the discussion that we had at the previous meeting, we talked about a couple of different ideas for how this workshop could focus, and the decision was to focus on a range of co-

occurring health conditions that are under recognized in service settings and that we would look at how the IACC could recommend a way to support both research and increased awareness of these conditions and ultimately foster the development of guidelines -- so that's not something that the Committee itself would do -- for areas and comorbid areas that are under recognized.

So that's the decision of this group going forward for a meeting. It looks like a date has already been identified for September 23rd for the workshop.

And Susan, where would that take place?

Dr. Daniels: Yes. So the workshop, we have reserved a conference room in the brand-new Porter Neuroscience Center on NIH's main campus. It would be September 23rd from approximately 9:00 a.m. to 5:00 p.m.

And so, once we get more of this going, we will send out announcements and so forth. But that's the time that has been reserved.

Dr. Insel: Purpose of today's call is to focus down a little bit more on who you would like to hear from, how you would like this to run, and

what the workgroup, what the Planning Group really wants to come out of this workshop, what that would look like.

So I'm going to open it up and let's hear your ideas about best way to develop this and who you'd like to see invited.

Dr. Walter Koroshetz: I could start, anyway. This is Walter.

And so, I thought that we would try to identify a couple of areas that are of greatest concern to the parents and affected individuals and their docs that fit into this category, which I wouldn't get too obsessed about the semantics of how to define it. But the areas that seemed to come up are GI problems in people with autism, either because they -- because they have unusual conditions related to autism or because they have common conditions that manifest in behavioral disorders, as opposed to the usual complaints that pediatricians might be expecting related to things like reflux or constipation.

The other one was sleep disorders seems like a big problem, very prominent. Some of these are interrelated. So sometimes a sleep disorder may actually be due to the GI problem. So I think

that's a theme that runs through a whole bunch of these, that they are interrelated.

The other ones are maybe endocrine issues that occur, particularly around the time of menses in adolescent girls; metabolic disorders that might be related to yet-undefined, you know, mitochondrial disorders or some other type of metabolic disorder leading to, you know, trouble with fatigue, poor physical endurance, trouble walking.

And then there are a couple of other things that show up that might be, you know, common problems that occur in individuals on the spectrum like ENT trouble. Big tonsils may be affecting sleeping. Hypertension, obesity occurring potentially with diabetes due to a decrease in physical activity.

So those are the -- those are the things that are on my list of topics. I'd be happy to, you know, have people add, subtract as they feel.

Dr. Insel: One thing that might be useful in introducing the workshop would be to hear from some of the very large studies that have been done in tens of thousands of kids with autism or adults with autism to identify what their health-related

issues are. So the project out of Zak Kohane's I2B2 effort, The Lewin Group's effort. There have been a few others, I think, that have tried to catalogue where are the big issues, where are the big problems.

And the ones you've mentioned, Walter, are there. Also one of the things that emerges is immune issues, and that might be another area to put into the hopper.

Dr. Geraldine Dawson: Yeah, I would mention Lisa Croen has done a recent study looking at a large sample.

Dr. Insel: Right.

Dr. Dawson: And she's a person that could also present in that overview way.

Ms. Lyn Redwood: I also think neurological issues should be included. There's a lot of children that have violent seizures that aren't being picked up on that are subclinical that can benefit from treatment. So that would be another category that I think needs to be included.

Dr. Koroshetz: I'm so glad you said that. I didn't want to say it myself, but the Neurological Institute, we would be happy for that.

Dr. Dawson: Right and that might be nicely

combined with sleep because those are so closely associated often. And certainly there have been a number of studies in autism that have shown their association.

So, in terms of thinking about, you know, combining and making certain parts of the day coherent that would be nice to combine those two.

Dr. Koroshetz: Are there any other things on the list --

Dr. Dawson: You know, one that we might consider that is it may just be that it is so infrequent, I think we really don't know that it's not worth, you know, devoting a lot of time to. But there is some interest in this autoimmune encephalitis perspective and data coming out, at least some case studies of these -- this NMDA receptor encephalitis.

And so, under the category of immune, if we wanted a few speakers there, we could consider including that topic.

Ms. Redwood: And Geri, also there is some research that needs to be replicated and further investigated regarding folate receptor antibodies, and there's been, you know, anecdotal reports of, you know, marked improvement in speech and

language when children are treated for this.

[Pause]

That's very promising, too. And that would fit in again with some of the other autoantibodies that we're seeing in individuals with ASD that could be targets for treatment.

And with the metabolic part, I also think it would be important to look at not only mitochondrial abnormalities, but the whole realm of how oxidative stress may be feeding into sort of a vicious cycle of, you know, immune system impairments as well.

So having a speaker to talk a little bit about oxidative stress would be good. And Jill James is, I think, the person who's done the most research in that area.

Dr. Dawson: One more thing under the area of kind of GI that we may want to consider is something around eating, eating disorders and picky eating and dietary/nutrition issues.

Ms. Redwood: Good point.

Dr. Dawson: I know that clinically this is a huge issue, and it shows up, actually, very early in infancy, even before the onset of the symptoms.

Ms. Redwood: Good point, Geri.

Dr. Insel: Other areas of interest? I noticed in the big Kohane study, the 14,000 people with an ASD diagnosis, that one of the three big areas, they picked up epilepsy, some of the GI stuff, and then schizophrenia as dramatically increased in people with an ASD diagnosis. And my own experience with that is that that's a diagnostic problem, but be curious if other people have a sense of that.

Dr. Matthew Carey: This is Matt. What do you mean by there's a diagnostic problem?

Dr. Insel: Well, there was a time when autism was called early onset or childhood schizophrenia, and 20 years ago, that was a fairly common diagnosis for kids who today would be on the ASD spectrum.

Dr. Dawson: Yeah, my sense is that recently that's -- there's been a question of whether there is increased risk and diathat especially with the, you know, shared genetic networks that have been documented now between schizophrenia and autism, that, you know, there may be a reason for that.

So I do think there's a different perspective emerging.

Dr. Insel: Mm-hmm.

Dr. Carey: Yeah, I -- this is Matt again. I mean, I would, to back up I would very much second bringing in Lisa Croen. And I'm trying to remember what she -- what her work applied to schizophrenia. I know she had some ideas, some aspects of other mental health issues, as did The Lewin Group, right?

But you mentioned -- Tom, I think you mentioned The Lewin Group. If we bring them in, I mean, we've already seen them once. And if they've got new stuff, that would be great. But otherwise, I mean, keeping maybe them a little bit more limited or just recapping what they showed before might make sense, just to reduce our potential for redundancy, if I may put that phrase out there?

[Laughter]

Dr. Insel: I like that. Yeah, so that's a good point. It may not be worth hearing from them a second time, unless there is anything new. And we can check on that.

Dr. Carey: Yeah, but they did have -- I remember the largest thing they found was -- was in sort of other mental health issues. So I mean -- but they didn't break that down, and that might be a very interesting thing to see what the

breakdown of that was.

Dr. Insel: Yeah. So that's actually something we don't talk that much about, but it's an interesting issue when you start to investigate it. It is often the psychiatric comorbidities, especially anxiety, ADHD kinds of symptoms.

Whether you call that a disorder or not and whether it's part of autism or not is sometimes not clear, but those are the things that often drive people into treatment as well.

Dr. Dawson: So in order -- I can tell you --

Dr. Koroshetz: So I think that's a big question of whether we're going to do that.

Dr. Dawson: For Lisa Croen's study, this is the order of prevalence that she found -- so starting from highest to lowest. But she -- suicidal attempts was actually the highest comorbidity noted, followed by depression, anxiety, sleep disorders, obesity, diabetes, hypertension, and then GI disorders, just to give you a sense and perhaps raise some other disorders that we might want to consider.

[Pause]

Ms. Redwood: Yeah, Geri, on the last call, we also talked about the fact that a lot of, the sort

of underlying metabolic and immune issues are not diagnosed. So, in those types of investigations, because under the medical records they're not going to be identified.

So I just don't want to lose, you know, track of those as well being on our radar screen.

Dr. Dawson: Yeah, that's a really good point, Lyn.

Dr. Insel: Yeah, I would second that. I think, you know, it's interesting in the Kohane study there was not an increase in what he called autoimmune disorders, even though they found increases in lots of other things. But you know, one wonders whether that's simply because they don't get picked up or diagnosed in the same way.

They did find an increase in inflammatory bowel disease, which could be related to an autoimmune response. And that was actually, I think, their number three -- I just pulled it up here. Their number one was epilepsy. Number two was schizophrenia, and third was inflammatory bowel disease and other bowel disorders.

Dr. Koroshetz: I think one decision to make is, is it going to be purely the medical things, or should it also include the behavioral, what we

call behavioral issues? You know, depression, suicide, ADHD. Should we attack both those sides of the coin?

Dr. Insel: What's the sense of the group?

Dr. Dawson: I think it would be unusual to have, you know, an overview of medical comorbidities without some discussion of the psychiatric comorbidities because I do think ADHD, anxiety, depression, these are huge, huge issues for families.

Dr. Koroshetz: Right. I mean --

Dr. Sally Burton-Hoyle: I agree.

Ms. Redwood: And you know, it's really hard, in my mind, to separate those because, you know, we really don't know what underlies the cause of a lot of those, you know, suicide, depression, if it could even be metabolic abnormalities in the brain that are driving that.

So I guess I don't always view those as being purely behavioral.

Dr. Koroshetz: Yep. No, it's just going to be a lot to cover, that's all.

Ms. Redwood: Yeah.

Dr. Insel: So one question I have about the list that we have, which is already growing, is

that some of them have been addressed previously. So there are -- I think we talked about this last time. There are guidelines for GI and sleep and epilepsy.

Is it worth re-plowing that field, or are those areas that we have already gotten enough attention to and already have the guidelines that mean that we don't need to go back there?

Dr. Koroshetz: Yeah. Good question. I mean a lot of -- I don't think anybody's satisfied with anything. But I think for time purposes, you know, we did have a workshop on epilepsy and autism. So we could refer back. And similarly for was it a constipation issue that there was a guideline on?

Dr. Insel: Mm-hmm. Right.

Ms. Redwood: Tom, one of the things --

Dr. Koroshetz: But we can't cover something like that for time's sake.

Ms. Redwood: Tom, one of the things that I had proposed I think last week was that this workgroup consider, you know, publishing sort of a position paper that the IACC would adopt that, you know, acknowledges the existence of all of these co-occurring conditions.

And the goal of that would be to increase

awareness of this. And the actual workshop itself would be a little bit more scientific in nature and that we would hope to get like a publication out of that that drilled deeper into these specific comorbidities and ask the participants who are actually -- we're going to invite to this workshop, that one of the products that we would like to see at the end of it would actually be a scientific publication that could help both advance awareness and identify what gaps there are in research.

And you know, whether or not there are existing treatment guidelines, or is this something that we need, you know, the scientific community needs to work on development.

Dr. Insel: If that were the case, though, it sounds like we've got a lot to cover. I'm not sure how deep we can get into any one of these topics. So I'm wondering if -- let me just toss this out there as a proposal, that we focus this on the areas that haven't received as much attention in the past, which I guess would be the more psychiatric/behavioral symptoms and the metabolic/endocrine symptoms or autoimmune, which is the other area.

And I'm not suggesting we do that, but I want to just put that out there for argument's sake to see whether people would feel better about that.

I am concerned that in a one-day workshop, if we want something that would lead to a publication, we'd want to go pretty deep into the issues. And I'm not sure we have enough data or we'd have enough time to do that on some of these.

[Pause]

Dr. Carey: As a practical matter, right, we just -- the meeting we're going to have is 7 days before we sunset, right? I mean, how much -- how much possibility is there to continue the work through to a report or a paper or something else?

Dr. Insel: Well, you can always get people involved in developing it, and then this would go to the next committee, whatever that is. That may take a while.

Last time, it took us a while to get approvals to reconstitute the committee. But I think it actually might be kind of a nice thing to have work continuing during the interregnum between this version of the IACC and the next one. I don't think we did that last time, but we could have and probably should have.

Dr. Carey: I mean, I'm actually very happy to hear that possibility thrown out so we can --

Dr. Daniels: We can only do that if the law is reauthorized. If the Committee is not reauthorized, then we would sunset and not be doing any more IACC work.

Dr. Insel: But it would possible, I suppose, for if we're inviting people, experts to this meeting, we could -- they would have the opportunity, if they wanted to, to write papers on anything that is relevant to their own work and, hopefully, would increase awareness in that respect.

Ms. Redwood: Tom, I was thinking more of like symposium proceedings as a publication versus, you know, like original research. That would just sort of -- you know, it could possibly -- if it couldn't be published scientifically, it could be something that the IACC could publish and put on their Web-site.

Dr. Insel: I guess that's a possibility. I guess I'd really want to look at the quality of what comes forth. I think if it's not really rigorous science and it's not compelling, I'm not sure I'd want it -- I'd want to put the IACC name

on it.

So I wouldn't want to make that decision ahead of time. And I say that because, you know a lot of -- I think a lot of the work in this general area is pretty weak. It's still rather descriptive and anecdotal and probably isn't ready for us to bless. At least that's my read on it.

[Pause]

So let me -- if we can go back to kind of general agenda for this? Do we have agreement that we would start with some overview presentations from people who have done these large population studies to look at a prevalence of comorbid symptoms? So that would be Lisa Croen, Zak Kohane, and then if there's something new from The Lewin Group, from them as well.

Dr. Koroshetz: Yeah, you know, I would also include --

Dr. Insel: I'm not sure that there's anything else of that magnitude out there, but if others know of any large-scale population studies that have looked at health aspects or comorbidities, that would be good to know, in either children or adults.

Dr. Koroshetz: I think that's fine. I think,

you know, I'd be interested also in hearing from somebody who's, you know, seen 10,000 cases over their career give a perspective. Somebody like Margaret Bauman, who's been at this forever.

Dr. Insel: Sort of the clinician's perspective?

Dr. Koroshetz: Yeah. I think we should start off with an overview. And especially if we're going to have a couple of topics that, you know, we have to explain why we're not discussing them in depth and refer to, you know, past guidelines or past workshops.

So the overview would be also an ability to identify and profile those topics that we're not going to go into in-depth discussion.

Dr. Carey: If I could, Tom, I think, yeah, maybe as like a morning part of the session, do that and then in the afternoon, do, you know, more specific people. I don't know if that's what you were thinking?

Because I mean with three people, maybe, you know, that's not a full day. I don't know if that's where you were headed with this, but --

Dr. Insel: Yeah. No, that was just to start it off, and then I think you want to drill deeper on

specific topics, and we can then come to some agreement on what those specific topics are.

Dr. Carey: Yeah. I think that -- to me, that sounds like a good plan.

Dr. Burton-Hoyle: Yeah. Me, too.

Ms. Alison Singer: I'm wondering if it's possible for us to ask the speakers to all present in the same format or actually use the IACC Strategic Plan format of "what do we know, what do we need," and make suggestions for future research.

I mean because, otherwise, I'll be honest. I've seen Lisa Croen present this data now twice, once at the Simons Foundation and then again at IMFAR. So unless she's going to present additional data, it's -- you know, we're not really moving forward.

So if we can ask the speakers to try to instead of just ending saying additional research is necessary, to really outline what is it that's necessary so that it's useful for us as we're formulating the strategic plan.

Dr. Koroshetz: I like that.

Dr. Daniels: We've used that format before in some of our strategic plan workshops, and it's

worked pretty well.

Dr. Koroshetz: Yeah. Also [Inaudible comment]

Dr. Carey: That would be good --

Dr. Koroshetz: And as opposed to people just giving a stock talk.

Dr. Carey: Yeah, and I think, again, as we're reaching toward sunset, to have something to pass on to what I very much hope will be some next version of this or, you know, modified version of IACC like that, gives us something to pass on.

We're not really going to have -- it sounds like we're not going to have like an update to really do for this year. That gives us something to say, hey, here are some -- here are some specific areas to consider and move on.

Dr. Dawson: Yeah, I like that, too. I do think that having people be forward looking and maybe even posing a set of specific questions that everyone addresses, that makes it much more interesting and coherent.

Dr. Insel: The other thing we could do, which I think might help is to limit the presentations and ensure that there's time for lots of interaction and discussion. I think what happens for a lot of these is people come and give their

typical 40-minute symposium talk or 40-minute lecture, and there's really never enough time to -- to discuss what probably is most useful to the IACC.

So I think if we're going to -- in the invitation, besides giving them some challenging questions, we could probably limit their time and set these things up as maybe panels where there'd be three presentations and then conversation with the workshop afterwards, really make it a workshop and not just your typical scientific meeting.

Dr. Koroshetz: Yeah, that'd be great.

Dr. Carey: I agree, Tom. I think that's a good idea.

Dr. Insel: So let's say the first session does include those overviews, and we can maybe cover all that in 90 minutes or something like that with some discussion. And we could add in -- Walter, as you were saying, we could add in the astute clinician's perspective, and there may be lots of opportunities there because I'm sure there are people who would have good ideas that they could share.

What would be the specifics then? For the subsequent two or three panels, where would you

want to drill down deeper?

Ms. Singer: Well, for something like Lisa's data, it's shocking and scary. So I think it has to go beyond her just showing the data again, and we have to be able to talk about what are we going to do about this?

I mean, it's the IACC's responsibility to coordinate the Federal response. So how do we need to do that? And what agencies should be getting involved in trying to remediate some of the issues that Lisa has brought to our attention with her data?

In terms not just of what future research needs to be done, but how do we address it from a services and implementation standpoint?

Dr. Koroshetz: So was the next panel going to be kind of the behavioral disorders associated or suicide, depression, ADHD, aggression?

Dr. Insel: You know, curiously, that is one of the under-recognized areas for which there are no guidelines, and there hasn't been that much attention, which has come out from each of these recent large-scale efforts. So maybe it does make sense to drill down deeper.

And as we're just saying to actually say what

next? What needs to be done here, and how do we fix this?

Dr. Dawson: Yes, in fact, so there are guidelines for ADHD. That was part of that pediatrics special issue on medical guidelines. But I do think perhaps focusing on depression and anxiety, particularly with this new data out of Lisa's study on the high rates of suicide, and I also think there is some -- been some real struggle from a pharmacological point of view of people trying to disentangle autism and anxiety.

And so, there are some important research questions, as well as kind of conceptual and measurement questions, as well as treatment.

Dr. Insel: Geri, who would you recommend for a deeper dive on that topic?

Dr. Dawson: Well, Larry Scahill has been really taking on the anxiety piece, and I know that he's involved in a project now trying to look at anxiety versus autism and how you measure it.

And let me think, who else would be good? I think Evdokia Anagnostou is always good and has done a lot of thinking and work in this area. So she would be another person.

Give me a second, and I'll -- let me just

think about it for a minute. But those two people come immediately to mind.

Dr. Insel: Recommendations from anybody else in this area?

Dr. Carey: Well, I'll point out I wish we had one or more of our autistic adults on this because I mean right now a big opening here would be the autistic adult's perspective on, you know, anxiety, suicidal thoughts, and everything else. I mean, I don't know if there is somebody, you know, who could speak to that, you know, specifically from the community?

Dr. Burton-Hoyle: Oh, great idea.

Dr. Insel: Yeah.

Dr. Dawson: Yeah, I think that would be really, really good, too.

I don't know whether this is getting too far afield right now, but you know there has been a lot recently on cognitive behavioral approaches to anxiety. So Jeff Wood has been studying this, and he's really been working to adapt these treatments to younger and nonverbal individuals or more severely affected individuals with autism because, typically, they'd only been delivered with higher functioning.

So, and he's also done a lot of sort of measurement work on how you separate autism and anxiety, but again, from more of a psychological than a medical point of view.

[Background noise]

Dr. Insel: That might be useful to have someone who's part of the solution and not just describing the problem. That could be helpful.

Is there anybody around looking at depression, anxiety in adulthood that comes to mind?

Dr. Dawson: Let me think. Who would be good?

[Pause]

Dr. Insel: Well, let's think and while you're working on that or people are thinking about that, we can do a little research offline to just fill out that panel. I think we've got a good start.

Dr. Daniels: How many people do you envision per panel?

Dr. Insel: I'd say four.

Dr. Daniels: Four? Because this, right now, is with Larry, Evdokia, Jeff, and a speaker from the community, that's four.

Dr. Insel: Yeah. So that's what we're working is that fourth one.

Dr. Burton-Hoyle: Yeah, that's going to be a

nice panel, actually a very nice complementary perspective.

Dr. Daniels: So that would be a fifth person, right?

Dr. Insel: What's that?

Dr. Daniels: So Larry, Evdokia, Jeff, and then the speaker from the autism community.

Dr. Insel: Be four.

Dr. Daniels: That will be four.

Dr. Dawson: Did you want to include someone --

Dr. Daniels: So we don't need any other?

Dr. Dawson: -- that focuses on depression in that panel?

Dr. Insel: I think we can probably challenge them to do both. Is that feasible?

Dr. Dawson: Absolutely. Yep.

Dr. Insel: So let's move to another area, and the ones I have down are metabolic, endocrine, sleep, GI. And then I think epilepsy has come up in the past. Immune has come up.

[Pause]

Dr. Koroshetz: Do you want to pass on the epilepsy? We had the workshop a year ago or so.

Dr. Insel: Yeah, I thought we did that already, didn't we?

Dr. Koroshetz: Yeah, we had that workshop.

Dr. Insel: So we can refer to that rather than having to go back and replicate that.

Dr. Koroshetz: And sleep? Did -- Geri, did you think sleep has been covered already?

Dr. Dawson: Well, yeah, that's a good question. I don't think we've ever -- have we had a specific seminar or speaker on sleep? I don't recall that we have. How about others on the panel?

Dr. Koroshetz: No, we haven't. But I thought you said that they have some -- that guidelines have been put out or something.

Dr. Daniels: The AIR-P might have done something.

Ms. Redwood: I think also some of the sleep issues may stem from some of the GI abnormalities, too, like pain and reflux.

Dr. Koroshetz: Right.

Dr. Insel: We certainly have the intramural group, Ashura Buckley, who's worked in that area.

Dr. Koroshetz: Beth Malow is quite good.

Dr. Dawson: Yeah, Beth Malow is very -- is very good. And actually, Sue Swedo has been doing some great work in this area.

Dr. Insel: Yeah, that's Ashura's work mostly.

Dr. Dawson: Oh, okay.

Dr. Insel: Yeah, one of the two of them would be good. What about anybody from -- I just met with the Autism Speaks ATN Physical Health Comorbidity Group this past week.

Geri, you know those folks pretty well. Is there somebody there who's really focused on sleep? Because they're very practical. They're --

Dr. Dawson: Well, that's Beth Malow. She's --

Dr. Insel: Okay.

Dr. Dawson: She's very, very good. Yeah, she has two affected children of her own, and she really understands the parent's perspective. And she's done, you know, really nice work on sleep, very practical, both behavioral and melatonin and pharmacological approaches.

She's also a neurologist. So she thinks about, you know the interface between epilepsy and sleep and could even weave that in a bit.

Dr. Insel: Good. Okay.

[Pause]

Ms. Redwood: Tom, for immune, I was thinking Judy Van de Water, who's done a lot of work on the autoantibodies, brain antibodies, would be good --

Dr. Insel: Mm-hmm.

Ms. Redwood: -- to present the immune perspective.

Dr. Insel: Yeah. I would agree, and maybe Paul Patterson can't attend because of health reasons, but maybe Elaine Hsiao would be great. That's an amazing story about maternal immune activation.

Now that's less -- well, I have to say that's really not yet a comorbidity. That's more a mechanism kind of study. And so, Judy Van de Water would probably be better in terms of comorbidity.

Is there anybody else who would be thinking about this from a clinical, on-the-ground kind of perspective?

Dr. Carey: Well, there's Carlos Pardo, right? I mean, they did some work clinically with Sue Swedo just last year, or published just last year. So --

Dr. Insel: Right.

Ms. Redwood: Is Carlos an M.D., though, or a Ph.D.?

Dr. Koroshetz: He's an M.D.

Ms. Redwood: Oh, okay.

Dr. Dawson: So Paul Ashwood is a researcher, but he certainly has done a lot of work in this

area.

Ms. Redwood: Yeah, Paul would be very good, too.

Dr. Koroshetz: Uh-huh.

Dr. Insel: Okay.

Dr. Daniels: There's four names there.

Dr. Insel: Yeah. Did you get those, Susan?

Dr. Daniels: Yes. I've got -- I've got those four names.

Dr. Insel: All right. So we've got depression, anxiety/suicide. We've got immune. We've got sleep, although we didn't get -- did we get four names for sleep?

Dr. Daniels: No. We only have two. Well, we've got Ashura Buckley and Sue Swedo, but along with Beth Malow.

Dr. Insel: We've got two. We can -- so that would give us three areas, in addition to the overview. Are people comfortable with that as a sum total?

Ms. Redwood: What about metabolic, Tom? Because I mean that brings in the mitochondrial problems and also the oxidative stress.

Dr. Insel: Right. I think if we did that, we'd probably have to drop one of the others. I'm not

sure we can -- if we want to have significant time for discussion, I would think four panels would probably be a full day. But we could do -- we could go to metabolic if the group wants to drop something that we've already planned.

Ms. Redwood: Well, if we're doing one on sleep, I do feel like that has received a fair amount of attention already. But you know, more so than metabolic and immune issues.

I mean, if we have to drop a panel that would be --

Dr. Burton-Hoyle: Can you please restate what the four panels are?

Ms. Singer: Yeah, what do you want to drop? I couldn't hear you.

Dr. Daniels: Lyn suggested dropping sleep. We currently have an intro panel, a depression, anxiety, and suicide panel -- this is Susan, by the way -- a sleep panel, and an immune panel.

So if we needed to have a fifth panel that would be too many for one day. So we would need to drop something, and Lyn is suggesting dropping sleep.

Ms. Singer: Well, I wouldn't be in favor of dropping sleep. I mean, I think sleep came up

really high in Lisa's study, and I think it has a huge impact on a really large number of kids and adults.

And I think we need to be thinking about what are the next steps we need to take in terms of doing research in sleep and providing relief for kids who have the sleep disturbances. I would not want to drop sleep.

Dr. Burton-Hoyle: I wouldn't either.

Dr. Daniels: Who was that?

Ms. Singer: This was Alison speaking. Sorry.

Dr. Daniels: Oh, after Alison, though? Sorry, just so that we know for the transcript who was speaking.

Dr. Burton-Hoyle: I concurred with Alison. This was Sally Burton-Hoyle.

Dr. Daniels: Oh, Sally. Okay, thanks.

Ms. Redwood: So then what are the other ones? I just feel like those are such key issues that we've heard from parents over and over again that have come to speak at public comment. And --

Dr. Daniels: Immune was one of the panels, and depression, anxiety, and suicide is the other panel, other than the overview.

Ms. Redwood: I guess I'm referring to the

metabolic, the metabolic issues.

Dr. Daniels: Unless that could be rolled in with immune? Could drop Elaine Hsiao and put in something.

Dr. Insel: Lyn, would that work for you if we --

Ms. Redwood: Yeah.

Dr. Insel: Because Elaine Hsiao is really not appropriate for this particular workshop, but under immune, we could add in something that is more generic around metabolic issues as well.

Ms. Redwood: Yes, I think you know it just is really key when you correct some of the underlying metabolic problems that it affects so many of these other systems as well.

Dr. Koroshetz: We could get Bob Naviaux. Is he kind of a more good general person for that?

Dr. Insel: Who was that, Walter?

Ms. Redwood: Bob is good.

Dr. Koroshetz: Bob Naviaux. You know, the guy at -- from San Diego.

Dr. Dawson: Naviaux, yeah.

Dr. Insel: Yeah, yeah. That'd be great. Okay. So we could add him, too, so that it would be immune/metabolic?

Dr. Koroshetz: Yeah.

Dr. Dawson: Yeah, and again, the folks out of the -- the MIND have also been looking at the interface between those two areas, and so, did we decide, for example, on Paul Ashwood?

Dr. Daniels: Yes. He's on the list. So it would be Judy Van de Water --

Dr. Dawson: Yeah. So I think Paul could, if we asked him to --

Dr. Insel: Could cover both of them.

Dr. Dawson: -- might be able to bring in issues around oxidative stress and things like that.

Ms. Redwood: And Jill James is very good in that area, too, along with methylation and oxidative stress.

Dr. Koroshetz: Jill James. Is that -- where is she?

Ms. Redwood: She's at -- she's at the University of Arkansas. I think it's Arkansas Children's.

Dr. Koroshetz: Yeah, I know that group. Yep, yep, yep.

Ms. Redwood: And she's also part of the ATN, the Autism Treatment Network.

Dr. Dawson: I'm just looking here on PubMed, and you know, Paul has just recently published a paper on the relationship between mitochondrial function and gestational exposure to viral something. Anyway, he does think about the interface between these two areas. And so, I think he would be a nice bridge.

Dr. Koroshetz: U-huh.

Dr. Insel: Yeah. That sounds good. So that would give us, who do we have so far?

Dr. Daniels: That would be four. So we have Judy Van de Water, Carlos Pardo, Paul Ashwood, and then Bob Naviaux?

Dr. Dawson: Naviaux.

Dr. Daniels: Oh, Naviaux. Okay.

Dr. Insel: Right. And then, Lyn, you wanted to add Jill James. But we're at four already.

Ms. Redwood: Well, if Bob could cover some of Jill's work, I think that would be fine.

Dr. Insel: Yeah. I think he could. He's -- we could actually mention that in the -- in the invitation.

Dr. Dawson: You know, Bob is actually coming to visit me next week and going to spend the afternoon here. He just initiated this meeting. So

if you want me to communicate anything, it's an opportunity.

Dr. Insel: Okay. Great. That's great.

Well, it sounds like we've done our work. We've got four panels pretty well mapped out. We've got a sense of what the charge will be to the people we're inviting.

The challenge will be getting them to accept because it's already fairly late to invite for September 23rd, but we'll do our best. We'll try to get some invitations out quickly.

Any other business that we need to take care of before we adjourn?

Dr. Daniels: You've done a great job on this, getting through some speakers here. So we will come back if we get people that turn us down. We'll try to figure out replacements.

Dr. Koroshetz: Or make an offer they can't refuse.

Dr. Insel: Yeah, Walter, only you can do that. That would be good.

Dr. Koroshetz: Oh, Brooklyn upbringing.

[Laughter]

Dr. Insel: All right, anything else?

Dr. Koroshetz: No. Good job.

Dr. Insel: Okay, thanks, everybody.

Dr. Daniels: Thank you.

Dr. Insel: Bye-bye.

(Whereupon, at 1:54 p.m., the Planning Group adjourned.)