

NBS Advisory Committee Meeting Transcript, November 2024

1

00:00:15.070 --> 00:00:17.949

Jacqueline Isaly: There's all kinds of fun happening this morning.

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00:00:21.230 --> 00:00:23.440

Anna Schmitt (she/her) - Yarrow: Hi, Jacqueline! How are ya.

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00:00:23.928 --> 00:00:24.882

Jacqueline Isaly: How are you?

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00:00:25.200 --> 00:00:26.386

Anna Schmitt (she/her) - Yarrow: I'm good.

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00:00:28.880 --> 00:00:31.030

Abe Elias: Hello, everyone. Morning.

6

00:00:36.820 --> 00:00:42.609

Anna Schmitt (she/her) - Yarrow: Alright, I think we have most of our folks here. Let me just double check one thing.

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00:00:48.780 --> 00:00:55.559

Anna Schmitt (she/her) - Yarrow: Yeah, this is great. I think we can get started. So welcome everyone today to this short 1 hour newborn screening advisory committee meeting. Thank you all for being flexible and allowing us to get this in. So we can keep the process moving.

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00:01:11.630 --> 00:01:26.809

Anna Schmitt (she/her) - Yarrow: As always, we'll do roll call introductions. We actually have some new faces today. So this is exciting. If you can share your name, the organization that you work with your role and your physical description as a reminder, we do this for those who may be visually impaired. I will start, and then I can call on folks as we go through.

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00:01:36.010 --> 00:01:40.480

Anna Schmitt (she/her) - Yarrow: So my name is Anna Schmidt, and I work for Yarrow, which is a small public health consulting company based in Montana.

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00:01:47.245 --> 00:01:52.700

Anna Schmitt (she/her) - Yarrow: Today. My role is facilitator, and my physical description is I'm standing at my desk. I have my dark hair pulled back, and I'm wearing a big chunky sweater.

16

00:02:01.630 --> 00:02:03.429

Anna Schmitt (she/her) - Yarrow: I will pass it to Michaela.

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00:02:06.050 --> 00:02:20.286

Mikaela Miller, Yarrow: Hi, everyone! My name is Michaela. I'm with Yarrow, and my role is co facilitator with Anna. Physical description. I'm Caucasian female with

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00:02:20.960 --> 00:02:26.639

Mikaela Miller, Yarrow: I would say. Brunette long hair. I'm sitting at my desk with a white sweater on.

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00:02:28.400 --> 00:02:30.350

Anna Schmitt (she/her) - Yarrow: Thanks. Michaela, Jacqueline.

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00:02:34.210 --> 00:02:57.701

Jacqueline Isaly: Good morning. I'm Jacqueline Isley, Michaela. I like the role of Co. Host, maybe better than Cole. Facilitator. I am with Montana Department of public health and human services, and I am the family and Community Health Bureau chief here. I have blonde hair that is pulled back. I'm sitting at my desk, and I

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00:02:58.730 --> 00:03:07.819

Jacqueline Isaly: am a white female with a blue sweatshirt on. It is school spirit week. So go bobcats.

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00:03:08.912 --> 00:03:11.199

Anna Schmitt (she/her) - Yarrow: Thanks. Jacqueline Debbie.

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00:03:14.130 --> 00:03:25.599

Debbie Gibson: Hi! I'm Debbie Gibson. I'm also with Dphhs, and I'm the Laboratory Services Bureau. I have long blonde hair, a black shirt with a gray jacket

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00:03:25.840 --> 00:03:27.669

Debbie Gibson: and go grills.

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00:03:28.970 --> 00:03:32.841

Anna Schmitt (she/her) - Yarrow: -Oh, thank you.

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00:03:33.760 --> 00:03:35.330

Anna Schmitt (she/her) - Yarrow: Douglas Harrington.

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00:03:36.420 --> 00:03:43.360

Douglas Harrington: Good morning. I'm Dr. Doug Harrington. I'm the State Medical Officer, and

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00:03:43.860 --> 00:03:51.419

Douglas Harrington: I'm with department public health. I am an old guy with gray hair, glasses, a beard, and a plaid shirt.

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00:03:52.520 --> 00:03:56.310

Abe Elias: Nice to meet you here on this platform, Darren.

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00:03:59.040 --> 00:04:00.240

Anna Schmitt (she/her) - Yarrow: Thank you.

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00:04:02.081 --> 00:04:03.839

Anna Schmitt (she/her) - Yarrow: Let's go ahead with Jeannie.

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00:04:06.940 --> 00:04:26.954

Jeanne Lee: Hi, everyone! I'm Jeannie Lee. I work for the Montana Public Health Laboratory. I'm the newborn screening Supervisor today. I am wearing a gray sweater with this button detail on my shoulders, and I have

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00:04:28.470 --> 00:04:38.470

Jeanne Lee: thin, fine brown hair about collarbone length. So I'm very pleased to have you all here today. Thank you.

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00:04:39.890 --> 00:04:42.080

Anna Schmitt (she/her) - Yarrow: Thanks. Jeannie Shelly.

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00:04:43.950 --> 00:05:00.340

Shelly Eagen: Hi, everybody! I'm Kelly Egan. I'm a pediatric nurse practitioner. I apologize. I'm on a shuttle right now, so you may see some stuff behind me. But I have. I am the chair of the newborn screening Advisory Committee, and I have shoulder length, brown hair.

36

00:05:02.130 --> 00:05:06.439

Anna Schmitt (she/her) - Yarrow: Thank you, Shelly. Thank you for joining while you're in transit, even Jen.

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00:05:20.450 --> 00:05:23.800

Anna Schmitt (she/her) - Yarrow: Maybe she had to step away.

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00:05:24.800 --> 00:05:26.990

Debbie Gibson: Says that she can't unmute. She put a comment.

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00:05:26.990 --> 00:05:33.739

Anna Schmitt (she/her) - Yarrow: Oh, I didn't see that. Okay, Jen, yeah, go ahead and introduce yourself in the chat.

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00:05:43.970 --> 00:05:48.510

Anna Schmitt (she/her) - Yarrow: all right. And then I think we can move on to Abe. Dr. Elias.

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00:05:50.922 --> 00:05:56.810

Abe Elias: Yeah, I'm Abe Elias. I'm the Chief Medical Officer at Shodair Children's Hospital

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00:05:57.130 --> 00:06:03.670

Abe Elias: and I'm a middle aged, dark haired, gray mail.

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00:06:04.900 --> 00:06:10.310

Abe Elias: fresh brewed, freshly brewed cup of coffee and some fall colors. Maybe today.

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00:06:12.490 --> 00:06:14.880

Anna Schmitt (she/her) - Yarrow: Thank you. Dr. Elias, Amanda.

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00:06:24.010 --> 00:06:31.109

Amanda Osborne: Hi! I'm Amanda Osborne, and I am a midwife in Helena, and I run the birth center calling in from the birth center right now, good morning.

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00:06:33.270 --> 00:06:34.780

Anna Schmitt (she/her) - Yarrow: Good morning. Thank you.

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00:06:37.490 --> 00:06:38.440

Anna Schmitt (she/her) - Yarrow: Kotie.

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00:06:42.180 --> 00:06:48.270

kotie: Hi! I'm a high school. Oh, that's the boxes, not me!

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00:06:48.320 --> 00:06:54.649

kotie: High school business teacher blonde hair, black sweater that says, Be kind and good morning.

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00:06:56.630 --> 00:06:59.270

Anna Schmitt (she/her) - Yarrow: Thanks. Cody, Miranda.

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00:07:05.580 --> 00:07:13.740

Miranda McCabe: Hello! I'm Miranda. I'm from Dphhs. I do not have a camera, so I don't have just a blank screen today.

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00:07:16.790 --> 00:07:19.829

Miranda McCabe: and I oversee Epstead. Sorry. I forgot to add that.

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00:07:20.722 --> 00:07:21.627

Anna Schmitt (she/her) - Yarrow: Thank you.

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00:07:22.370 --> 00:07:23.310

Anna Schmitt (she/her) - Yarrow: Sarah.

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00:07:27.310 --> 00:07:41.460

Sarah Sullivan: Hi! I'm Sarah Sullivan, and I am a parent of 2 children with metabolic disorders that were not caught on newborn screening. I have long blonde hair that's half pulled back, and a gray sweater on.

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00:07:45.000 --> 00:07:52.810

Anna Schmitt (she/her) - Yarrow: Thank you, Sarah, and we did just have somebody join. But I'll get them. Give them a second to

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00:07:53.640 --> 00:08:00.719

Anna Schmitt (she/her) - Yarrow: get settled in, and I'm excited to have us introduce our 2 new members.

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00:08:01.060 --> 00:08:03.779

Anna Schmitt (she/her) - Yarrow: So I'll start with Shaunalea.

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00:08:09.680 --> 00:08:12.830

Shawnalea Chief Goes Out, DPHHS: And Chief goes out. I am with Dphhs.

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00:08:13.385 --> 00:08:24.609

Shawnalea Chief Goes Out, DPHHS: My role today is an observer and a future panel member. Physical description is dark brown hair, dark skin, female. Oh, my hair is in a braid.

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00:08:24.770 --> 00:08:28.650

Shawnalea Chief Goes Out, DPHHS: white sweater, black vest, and sitting on my chair.

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00:08:30.240 --> 00:08:33.209

Anna Schmitt (she/her) - Yarrow: Thank you so much. Shannalia and Lynn.

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00:08:34.580 --> 00:08:47.160

Lynne Wood: Hello! I'm Dr. Lynn Wood. I'm a pediatric neurologist. I have dark blonde hair that is long. It's down and I'm in an orange sweater also with fall colors, like Dr. Elias.

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00:08:49.170 --> 00:08:51.430

Anna Schmitt (she/her) - Yarrow: Wonderful. Thank you so much. And Danny.

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00:09:05.220 --> 00:09:08.320

Anna Schmitt (she/her) - Yarrow: all right. Maybe she's still getting settled in.

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00:09:11.330 --> 00:09:15.690

Anna Schmitt (she/her) - Yarrow: I think I got everybody. I apologize. If I didn't.

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00:09:15.710 --> 00:09:21.870

Anna Schmitt (she/her) - Yarrow: I'll give you a second to unmute just a reminder that we only do introductions for

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00:09:22.648 --> 00:09:24.240

Anna Schmitt (she/her) - Yarrow: members of the committee.

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00:09:28.900 --> 00:09:38.470

Anna Schmitt (she/her) - Yarrow: Alright. So this is our agenda today, like I said earlier, we just have this short 1 h meeting, so we'll be doing a little bit of unfinished business.

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00:09:38.670 --> 00:09:58.069

Anna Schmitt (she/her) - Yarrow: and then we'll give you a couple of minutes to have any discussion that you would like to have on. Gosh! We will then vote. We will have our public comment period go over what our next steps are. There will be some voting forms, some Google forms for you to fill out. That will be put in the chat. So please be prepared for that.

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00:09:58.500 --> 00:10:00.940

Anna Schmitt (she/her) - Yarrow: and we'll keep it moving

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00:10:01.380 --> 00:10:06.959

Anna Schmitt (she/her) - Yarrow: just as a reminder. This is how the public comment period works. We give 10 min.

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00:10:07.420 --> 00:10:15.840

Anna Schmitt (she/her) - Yarrow: I will announce when the public comment period starts, you can raise your hand, or if you're calling in, you can Dial Star 9 to raise your hand.

74

00:10:15.870 --> 00:10:18.919

Anna Schmitt (she/her) - Yarrow: I will call your name. You can unmute yourself

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00:10:19.290 --> 00:10:22.880

Anna Schmitt (she/her) - Yarrow: again if you're calling in. That's Dialing Star 6.

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00:10:23.050 --> 00:10:26.469

Anna Schmitt (she/her) - Yarrow: We provide 2 min, Max, per comment.

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00:10:26.540 --> 00:10:40.270

Anna Schmitt (she/her) - Yarrow: and we also allow additional comments up to 1 h after the meeting ends to this email address here, this will be up during the public comment period as well. So you don't have to remember everything, but just as a heads up for everyone.

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00:10:43.810 --> 00:11:00.249

Anna Schmitt (she/her) - Yarrow: And again, we like to go through these ground rules every time that we meet. These are pretty standard, I think, but just sometimes a good reminder, as we're living through day to day. Zooms, please keep yourself on mute if if you can. Please come on, video

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00:11:00.270 --> 00:11:05.330

Anna Schmitt (she/her) - Yarrow: as you can as well. It just helps to know who's engaged and listening in.

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00:11:05.600 --> 00:11:20.290

Anna Schmitt (she/her) - Yarrow: Please ask clarifying questions if necessary, but avoid interrupting. I know we live in a world with a lot of acronyms, but not everybody knows what all of those mean. So please try to say the full. The full phrase.

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00:11:20.360 --> 00:11:26.609

Anna Schmitt (she/her) - Yarrow: use specific examples when you can. And let's remember to focus on the collective interest of this group.



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00:11:26.650 --> 00:11:31.089

Anna Schmitt (she/her) - Yarrow: Remember that additional meetings may be scheduled. This one is.

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00:11:31.170 --> 00:11:34.121

Anna Schmitt (she/her) - Yarrow: in fact, a bit of an additional meeting.

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00:11:35.450 --> 00:11:40.429

Anna Schmitt (she/her) - Yarrow: we will always go through next steps to assure accountability.

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00:11:40.750 --> 00:11:51.909

Anna Schmitt (she/her) - Yarrow: We may call on attendees for input. And we really strive to make this a safe space where people feel like they can share their input and their ideas and their feedback.

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00:11:54.730 --> 00:12:01.150

Anna Schmitt (she/her) - Yarrow: Again as a reminder before we go into the voting section. Only voting members who have submitted their

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00:12:01.802 --> 00:12:17.400

Anna Schmitt (she/her) - Yarrow: conflict of interest statement can vote on gosh! We do have conflict of interest statements from all of our active members right now. So everyone should be able to vote. This meeting is a little bit unique, as we have 2 new members

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00:12:17.480 --> 00:12:25.510

Anna Schmitt (she/her) - Yarrow: like Shannalia said, they are just observing today they will not be voting, since they were not here to hear the Gaucher presentation.

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00:12:26.386 --> 00:12:32.569

Anna Schmitt (she/her) - Yarrow: Another reminder is that we can only vote if we have a quorum. There are 9

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00:12:32.680 --> 00:12:36.740

Anna Schmitt (she/her) - Yarrow: voting members, so we need at least 5 to be able to hold a vote.

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00:12:41.760 --> 00:13:05.259

Anna Schmitt (she/her) - Yarrow: All right, then we'll move into some unfinished business. We have some actually really exciting news to share this time around. Some of you may be aware of this, but Xald screening started on September 3<sup>rd</sup>. So we have added a new condition to the screening panel through the work of this committee. So this committee really is making changes in Montana.

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00:13:05.380 --> 00:13:17.490

Anna Schmitt (she/her) - Yarrow: and since then Pompeii has also been approved by the director upon the recommendation of this committee, and so that will start going through the State addition process to be added to the newborn screening panel.

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00:13:17.500 --> 00:13:19.060

Anna Schmitt (she/her) - Yarrow: That does take

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00:13:19.420 --> 00:13:32.589

Anna Schmitt (she/her) - Yarrow: some months. But the process is, is on the way. And to give an update on membership. We had 4 members that agreed to end their terms early.

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00:13:32.630 --> 00:13:52.848

Anna Schmitt (she/her) - Yarrow: so that we could have a staggered transition, so that not everybody is moving at off at the same time we are because this committee is so new we are still working with the original committee members here. So this is our 1st time going through this transition. So I appreciate everybody's patience and

96

00:13:54.260 --> 00:13:58.233

Anna Schmitt (she/her) - Yarrow: acceptance to work through this process with us.

97

00:13:58.980 --> 00:14:08.519

Anna Schmitt (she/her) - Yarrow: but the positions that we have switching are the Medicaid and insurance position. So that'll be switching from Miranda to Shannelia. Thank you to you both.

98

00:14:09.050 --> 00:14:17.390

Anna Schmitt (she/her) - Yarrow: Also a physician or nurse practitioner who is board certified in obstetrics, pediatrics, family medicine, or neonatology.

99

00:14:17.855 --> 00:14:26.864

Anna Schmitt (she/her) - Yarrow: And that will be Allison switching to Lynn. So thank you so much again, for that. A person or a family member affected

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00:14:28.180 --> 00:14:31.439

Anna Schmitt (she/her) - Yarrow: and that will be Sarah switching to.

101

00:14:31.490 --> 00:14:42.909

Anna Schmitt (she/her) - Yarrow: We have sent out an offer letter to that member, or about about to send out that offer letter, so that position hasn't been confirmed yet, but we do anticipate that that will be filled soon.

102

00:14:42.970 --> 00:14:49.299

Anna Schmitt (she/her) - Yarrow: and so we are still waiting to get applicants for the birthing center representative.

103

00:14:58.964 --> 00:15:05.010

Anna Schmitt (she/her) - Yarrow: And then, Shelly, I know that you're in transit, but I didn't know if you wanted to hop in and say anything.

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00:15:05.500 --> 00:15:06.400

Shelly Eagen: Yeah, I just wanna.

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00:15:06.400 --> 00:15:07.000

Anna Schmitt (she/her) - Yarrow: Thank you.

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00:15:07.500 --> 00:15:16.805

Shelly Eagen: Yeah, I just want to say thank you to Sarah Allison, Miranda, for all that they've done for the committee. Thus far, and we appreciate your

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00:15:17.910 --> 00:15:23.610

Shelly Eagen: commitment to the committee, and for everything that you've done to help us. So thank you.

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00:15:26.570 --> 00:15:28.110

Anna Schmitt (she/her) - Yarrow: Yes, thank you so much.

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00:15:30.153 --> 00:15:31.320

Anna Schmitt (she/her) - Yarrow: Excuse me

110

00:15:31.710 --> 00:15:44.800

Anna Schmitt (she/her) - Yarrow: alright! And then moving on to some feedback that we received after the last meeting, and you know, this has been a little bit of a consistent bit of feedback that we've been getting is that

111

00:15:45.550 --> 00:15:56.959

Anna Schmitt (she/her) - Yarrow: sometimes it feels like there's not as much participation from the members. As would be helpful to facilitate a full and robust discussion about the conditions being presented.

112

00:15:57.090 --> 00:16:23.339

Anna Schmitt (she/her) - Yarrow: And so we have decided that it would be helpful to have an additional time specifically dedicated to discussing member engagement. And you know, with that potentially changing the way that we have laid out the agenda of the meetings or the scheduling of the meetings, just as a way to open up the floor for how we might be able to have more member engagement. And so Michaela will be putting a link in the chat.

113

00:16:24.050 --> 00:16:37.510

Anna Schmitt (she/her) - Yarrow: if you can. Please vote on when you would like to have this discussion. We've given multiple options. This could be an additional 1 h meeting in February. A standalone meeting. It could be

114

00:16:38.521 --> 00:16:46.730

Anna Schmitt (she/her) - Yarrow: before the Asmd. Oh, and now I'm not. I'm breaking the rules acronym.

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00:16:46.980 --> 00:16:50.340

Anna Schmitt (she/her) - Yarrow: and I'm not remembering the the

116

00:16:50.360 --> 00:16:54.203

Anna Schmitt (she/her) - Yarrow: full right out of that condition. I apologize.

117

00:16:55.020 --> 00:16:58.009

Anna Schmitt (she/her) - Yarrow: Anyways, we have our usual spring meeting.

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00:16:58.496 --> 00:17:09.590

Anna Schmitt (she/her) - Yarrow: So either having the discussion before we hear about Asmd or after we hear about Asmd in that usual 3 h to 4 h spring meeting.

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00:17:10.069 --> 00:17:21.929

Anna Schmitt (she/her) - Yarrow: or we could move the Asmd presentation to our usual fall meeting and use the spring meeting to just talk about member participation.

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00:17:22.040 --> 00:17:24.590

Anna Schmitt (she/her) - Yarrow: We've also provided an

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00:17:25.140 --> 00:17:31.720

Anna Schmitt (she/her) - Yarrow: other option, because maybe you have another idea of how we might be able to have this conversation.

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00:17:34.410 --> 00:17:41.620

Anna Schmitt (she/her) - Yarrow: So I'll give a couple of minutes. Now. I do think that it's fine for the new members to

123

00:17:43.990 --> 00:17:49.019

Anna Schmitt (she/her) - Yarrow: fill out the survey. I am seeing in the chat that it says there's not permission. Let me

124

00:17:51.960 --> 00:17:56.199

Anna Schmitt (she/her) - Yarrow: make sure that I I can change the permissions on that form.

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00:18:05.720 --> 00:18:10.570

Jacqueline Isaly: So we at the State are able to use Google forms.

126

00:18:11.140 --> 00:18:13.860

Jacqueline Isaly: or I'm having trouble. I don't know if anyone else is.

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00:18:15.860 --> 00:18:18.649

Anna Schmitt (she/her) - Yarrow: Okay, one second.

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00:18:24.980 --> 00:18:31.980

Anna Schmitt (she/her) - Yarrow: I am just not remembering at this exact point in time how to change the access. Michaela, do you

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00:18:35.050 --> 00:18:36.559

Anna Schmitt (she/her) - Yarrow: know how to do that?

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00:18:41.130 --> 00:18:44.569

Mikaela Miller, Yarrow: Yes, and I'm sure my end that it's not restricted.

131

00:18:44.920 --> 00:18:52.039

Anna Schmitt (she/her) - Yarrow: Okay, I'm showing that it is, but I just changed it. So if folks want to close out and reopen that it should be

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00:18:52.430 --> 00:18:54.420

Anna Schmitt (she/her) - Yarrow: fixed. I apologize.

133

00:18:59.920 --> 00:19:01.990

Anna Schmitt (she/her) - Yarrow: and for the state folks, if

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00:19:02.570 --> 00:19:07.400

Anna Schmitt (she/her) - Yarrow: I can put the answer options in the chat.

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00:19:08.500 --> 00:19:13.170

Anna Schmitt (she/her) - Yarrow: If you want to let us know what works best for you in there.

136

00:19:14.260 --> 00:19:16.690

Sarah Sullivan: Mine is still saying I need permission.

137

00:19:17.460 --> 00:19:19.207

Anna Schmitt (she/her) - Yarrow: Oh, boy, okay.

138

00:19:27.050 --> 00:19:28.689

Anna Schmitt (she/her) - Yarrow: I'm sorry. Guys.

139

00:19:37.930 --> 00:19:40.870

Anna Schmitt (she/her) - Yarrow: Michaela, are you able to just make a

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00:19:46.220 --> 00:19:49.379

Anna Schmitt (she/her) - Yarrow: like a vote in the in zoom?

141

00:19:53.380 --> 00:19:56.899

Mikaela Miller, Yarrow: Yeah, I've never done that before. But let me give it a shot. Oh.

142

00:19:56.900 --> 00:19:58.650

Sarah Sullivan: Her her link, worked.

143

00:19:58.970 --> 00:20:01.130

Anna Schmitt (she/her) - Yarrow: Okay, a new link is working.

144

00:20:05.470 --> 00:20:09.869

Anna Schmitt (she/her) - Yarrow: and I'm still working on putting in the chat the options for the State.

145

00:20:10.180 --> 00:20:11.140

Anna Schmitt (she/her) - Yarrow: Sorry.

146

00:20:11.140 --> 00:20:15.300

Jacqueline Isaly: It now is working for me, too. So I think we might be okay.

147

00:20:15.440 --> 00:20:16.050  
Anna Schmitt (she/her) - Yarrow: Okay.

148  
00:20:16.260 --> 00:20:16.940  
Jacqueline Isaly: Thanks.

149  
00:20:21.610 --> 00:20:25.490  
Jenn Banna: This is Jen. I'm wondering if this is the form you wanted us to fill out, because

150  
00:20:25.590 --> 00:20:28.819  
Jenn Banna: this is, how did the meeting today go. Was it useful?

151  
00:20:29.540 --> 00:20:32.280  
Jenn Banna: Is there anything more you wish we would have talked about.

152  
00:20:32.280 --> 00:20:33.796  
Anna Schmitt (she/her) - Yarrow: Oh, my goodness! I'm sorry.

153  
00:20:34.100 --> 00:20:36.680  
Jenn Banna: That's okay, since we haven't met yet, I'm just not sure if I should.

154  
00:20:36.680 --> 00:20:39.649  
Jenn Banna: Yeah, no, that's not. That's not the one.

155  
00:20:44.460 --> 00:20:47.400  
Mikaela Miller, Yarrow: Okay, we're gonna try this one more time with the new link. I'm about to send.

157  
00:21:42.860 --> 00:21:49.170  
Anna Schmitt (she/her) - Yarrow: And the options are now in the chat as well. I know that's not the best format there.

158  
00:21:50.625 --> 00:21:54.090  
Anna Schmitt (she/her) - Yarrow: I see responses coming through, so it seems like it's working.



159

00:21:57.700 --> 00:21:59.966

Anna Schmitt (she/her) - Yarrow: Thank you for your patience on that.

160

00:22:16.110 --> 00:22:17.450

Anna Schmitt (she/her) - Yarrow: All right.

161

00:22:22.470 --> 00:22:24.930

Anna Schmitt (she/her) - Yarrow: We have almost everyone.

162

00:22:31.060 --> 00:22:33.480

Anna Schmitt (she/her) - Yarrow: And I see, Debbie put in the chat.

163

00:22:34.790 --> 00:22:42.750

Anna Schmitt (she/her) - Yarrow: So it's looking like this will most likely be an additional 1 h meeting in February.

164

00:22:43.246 --> 00:22:52.740

Anna Schmitt (she/her) - Yarrow: But we will reach out after this meeting in the next steps. Portion to confirm that. And and we'll be sending out a doodle poll to schedule that as well.

165

00:22:53.840 --> 00:22:56.199

Anna Schmitt (she/her) - Yarrow: So thank you all for your input on that.

166

00:23:05.140 --> 00:23:09.769

Anna Schmitt (she/her) - Yarrow: I think I just skipped slides. Wow! Having all all the tech problems this morning.

167

00:23:11.140 --> 00:23:14.190

Anna Schmitt (she/her) - Yarrow: No, okay.

168

00:23:14.720 --> 00:23:18.379

Anna Schmitt (she/her) - Yarrow: So now we're moving into our

169

00:23:19.360 --> 00:23:43.620

Anna Schmitt (she/her) - Yarrow: 10 min for any discussion on Gaucher. So I know that Michaela was able to send out the meeting materials from the last meeting where Gaucher was presented. Hopefully, you were able to review those and remind yourself on what happened during that meeting, but we just wanted to provide some space now for any additional discussion or questions that you might have before we vote. On this condition.

170

00:23:53.970 --> 00:23:56.385

Abe Elias: One question I had, so I wasn't

171

00:23:56.770 --> 00:24:00.710

Abe Elias: I wasn't present at the last meeting, but I

172

00:24:00.940 --> 00:24:09.450

Abe Elias: went through our materials and the presentation. By the by, the group, which I must say the the Powerpoint was, was really good. I think it was a very balanced.

173

00:24:09.510 --> 00:24:20.689

Abe Elias: a presentation. So, my it. You know it. It also some of the the factors that were presented. There were some of the issues that have in the past

174

00:24:21.260 --> 00:24:22.450

Abe Elias: led to

175

00:24:23.190 --> 00:24:40.869

Abe Elias: at this point not. This be not inclusion, basically into the national panel. So I was just wondering was that this was the kind of the position and the review that that the Advisory Committee for the National Advisory Committee did not so long ago.

176

00:24:41.866 --> 00:24:47.020

Abe Elias: Was that at all discussed or reviewed, because, if if not, I'd be happy to

177

00:24:47.220 --> 00:24:48.820

Abe Elias: review that briefly.

178

00:24:50.813 --> 00:24:54.960

Anna Schmitt (she/her) - Yarrow: I don't believe so. So if you could provide that review, that would be helpful. Thank you.

179

00:24:56.660 --> 00:24:58.220

Abe Elias: Okay, yeah. So

180

00:24:58.270 --> 00:25:16.879

Abe Elias: you know that. So the National Rasp Committee, which is the Advisory Committee for heritable disorders in newborn and children. They reviewed gaucher disease, and I don't remember now when that when exactly, but it's not so not so long ago, and they so they considered that for inclusion, and the overall review was actually really positive.

181

00:25:18.228 --> 00:25:32.209

Abe Elias: but at the time they decided that there was just not enough evidence to to include it to the newborn screening at that time. And so the the main. I try to kind of

182

00:25:32.410 --> 00:25:53.650

Abe Elias: extract their main arguments. Why? And I think you know the presentation that was given last time seems to follow those actually. So you can have arguments before, you know, for or against, but one is really the especially for gaucher, extremely variable disease spectrum. So gaucher disease is type one which is the milder form.

183

00:25:53.820 --> 00:25:56.729

Abe Elias: It's by far the most common form, and

184

00:25:57.220 --> 00:26:04.370

Abe Elias: you know it can be asymptomatic or very mild, which is the most common course, and so that makes it really difficult to

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00:26:04.380 --> 00:26:05.400

Abe Elias: to

186

00:26:05.880 --> 00:26:20.909

Abe Elias: to to know whom to follow, basically or then there's also so for those that are mild for the type one, it's difficult to often decide who to start early on treatment. This was the other argument.

187

00:26:21.080 --> 00:26:27.980

Abe Elias: and then there was also the concern for a possible overdiagnosis.

188

00:26:28.120 --> 00:26:32.009

Abe Elias: But in in in individuals who have

189

00:26:32.350 --> 00:26:53.879

Abe Elias: variants in the Gba gene, that is, that are so mild that they would otherwise clinically never been or not been diagnosed. And then just the the screening challenges and the follow ups, or the biomarkers that are used for testing, and also the genetic testing. They're not really. And I think that was, it seemed like in the presentation that was actually

190

00:26:53.990 --> 00:26:59.479

Abe Elias: brought up pretty well. They're just not reliable in differentiating between symptomatic and asymptomatic individuals.

191

00:27:00.392 --> 00:27:16.880

Abe Elias: And so you would have to to put on adequate follow-up systems, to to to follow them over time similar to what we discussed in xild. Except for xild, it's much more focused and and well defined.

192

00:27:16.970 --> 00:27:37.180

Abe Elias: so that all then comes down to resource allocation in public health, so given that there's generally a low prevalence of the severe forms of gaucher disease and unclear benefits of the screening for type one. And also, you know, I think the presentation did a really good job in kind of outlining the

193

00:27:37.560 --> 00:27:52.659

Abe Elias: potential treatment options for the severe diseases, however, especially with the newer therapies like gene therapy that is not quite yet available, so that, based on these kind of points. The the National Panel or the

194

00:27:52.690 --> 00:28:01.850

Abe Elias: the National Committee. Decided to, despite a good review, decide to not include it in the RUSP panel. So that's that's kind of the background.

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00:28:05.360 --> 00:28:09.630

Abe Elias: I don't know if that was. If if any of these questions were discussed last time.

196

00:28:14.180 --> 00:28:18.190

Anna Schmitt (she/her) - Yarrow: Thank you, Abe. Does anyone have any follow up questions or response to that.

197

00:28:30.168 --> 00:28:32.739

Douglas Harrington: Hi, this is Dr. Harrington.

198

00:28:34.660 --> 00:28:44.280

Douglas Harrington: it's timely. I'm a senior medical director for change, healthcare and optimum. And I review all of the algorithms for diagnosis and treatment.

199

00:28:44.380 --> 00:28:50.475

Douglas Harrington: And I'm just reviewing all of the Ert therapies and

200

00:28:51.620 --> 00:28:59.399

Douglas Harrington: and what Dr. Elias was talking about is definitely germane to our view of the world, which is that

201

00:28:59.670 --> 00:29:02.889

Douglas Harrington: the variable variability in type one.

202

00:29:03.150 --> 00:29:05.650

Douglas Harrington: the fact that Ert is really

203

00:29:05.720 --> 00:29:15.830

Douglas Harrington: only useful in Type one. And it's only used in Type 3 for amelioration of the non

204

00:29:16.000 --> 00:29:21.043

Douglas Harrington: central nervous system issues and type 2 is not. And there is, you know, the

205

00:29:21.660 --> 00:29:27.219

Douglas Harrington: the possibility of stem cell transplants or gene therapy in the horizon. So

206

00:29:27.922 --> 00:29:33.460

Douglas Harrington: it's a really complex issue. And I can understand why the national organization decided

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00:29:33.580 --> 00:29:38.229

Douglas Harrington: not to go with it because of that. And

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00:29:38.530 --> 00:29:43.749

Douglas Harrington: given the utility in type one which can be diagnosed. Most of the therapies require at least

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00:29:43.880 --> 00:29:49.880

Douglas Harrington: one symptomatic organ group. So I definitely

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00:29:50.140 --> 00:29:54.400

Douglas Harrington: appreciate Dr. Elias's comments, because I think they're germane.

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00:29:57.590 --> 00:30:21.389

Abe Elias: You know, Dr. Harrington, just to kind of put that into context, because the group has previously already kind of voted on the Pompei, which is, you know, also a condition that can be treated with Ert. And so just to highlight a little bit of difference. So both conditions have approved enzyme replacement therapy. So

212

00:30:21.560 --> 00:30:46.510

Abe Elias: the enzyme that is deficient can be replaced. And so with Pompei, disease and Ert is really complex in all conditions, including Pompei. But in Pompeii. The argument here is that early treatment in that infantile form of Pompei disease actually does, indeed. And it does. There's really good evidence for that

213

00:30:47.380 --> 00:30:50.880

Abe Elias: improve significantly

214

00:30:51.210 --> 00:31:15.779

Abe Elias: the cardiac presentation that leads to early heart failure and early death in these patients. What we actually even have seen, even in Pompeii, that the Ert long term does not, you know it does not address all of the issues it does, however, include it does address that most significant issue that really leads to the high morbidity and mortality. Dr. Wood probably could talk about that

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00:31:17.024 --> 00:31:19.492

Abe Elias: to to in and

216

00:31:20.170 --> 00:31:32.360

Abe Elias: And whereas in Goshier we really don't have that, you know the Ert is support in type. One is supposed to address quite a few different different aspects, but even the

217

00:31:32.390 --> 00:31:39.750

Abe Elias: even some of the predominant features like spleen omegaly. For example, hepatomegaly, they're only very gradually are

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00:31:39.900 --> 00:31:50.120

Abe Elias: affected by Ert. And so so that's just to kind of bring that into context with maybe conditions that other that the group already has encountered.

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00:32:12.510 --> 00:32:17.659

Anna Schmitt (she/her) - Yarrow: And I just want to clarify Abe. Do you know, when it was that the Rusp reviewed Gaucher?

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00:32:20.120 --> 00:32:21.930

Anna Schmitt (she/her) - Yarrow: Oh, you're muted sorry.

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00:32:25.270 --> 00:32:29.650

Abe Elias: I I it's been a while I let me look that up. I'll I'll check it.

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00:32:29.770 --> 00:32:30.460

Abe Elias: Well.

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00:33:02.900 --> 00:33:06.179

Abe Elias: oh, so quite recently! So it was in 2,022.

224

00:33:06.750 --> 00:33:08.090

Abe Elias: So not so long ago.

225

00:33:09.908 --> 00:33:15.959

Anna Schmitt (she/her) - Yarrow: I think that I might be missing something here, because I'm not seeing it on the list of reviewed. Is it

226

00:33:16.560 --> 00:33:18.579

Anna Schmitt (she/her) - Yarrow: spoken of with a different name?

227

00:33:23.920 --> 00:33:32.989

Lynne Wood: It might be glucocerebrosidase deficiency. I didn't see it listed on that Rusp page, but also wasn't sure how recently it had been updated.

228

00:33:34.680 --> 00:33:37.431

Anna Schmitt (she/her) - Yarrow: Yeah, it's a little bit strange.

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00:33:44.700 --> 00:33:49.290

Anna Schmitt (she/her) - Yarrow: it says, as of August 2024, so I don't know why it's not listed in here.

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00:33:50.080 --> 00:33:57.929

Jenn Banna: This is Jen. I'm wondering if we might have somebody here who knows more about when that happened, because they have that

231

00:33:58.120 --> 00:34:04.390



Jenn Banna: specific condition, and I know we can ask them a question. This might be a good time to use that technique.

232

00:34:07.480 --> 00:34:14.339

Anna Schmitt (she/her) - Yarrow: Yeah, I guess I'm feeling a little bit unsure of how to do that, because that's a member of the public technically now. And so

233

00:34:14.699 --> 00:34:23.450

Anna Schmitt (she/her) - Yarrow: our public comment period is later. But for the sake of clarification, Aviva, if you can clarify.

234

00:34:24.330 --> 00:34:29.870

Aviva Rosenberg: Thank you. So gaucher disease has never been submitted and has never been reviewed by the Rusp.

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00:34:30.367 --> 00:34:36.770

Aviva Rosenberg: That is something that my organization is currently working on, but it has never been submitted to the rusp.

236

00:34:36.770 --> 00:34:39.929

Jenn Banna: Thank you so much. I figured you would know the answer to that.

237

00:34:40.170 --> 00:34:40.750

Aviva Rosenberg: Okay.

238

00:34:46.090 --> 00:34:47.720

Anna Schmitt (she/her) - Yarrow: Thank you for clarifying Aviva.

239

00:35:04.520 --> 00:35:07.060

Anna Schmitt (she/her) - Yarrow: So, Dr. Elias, maybe you were seeing

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00:35:07.757 --> 00:35:11.450

Anna Schmitt (she/her) - Yarrow: a different review. But you are on mute, just as a reminder.

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00:35:13.310 --> 00:35:16.190

Anna Schmitt (she/her) - Yarrow: You're muted, Dr. Elias, so we can't hear you.

242

00:35:18.120 --> 00:35:22.609

Abe Elias: Yeah, I'm looking at. I had spoken with some colleagues

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00:35:23.000 --> 00:35:33.619

Abe Elias: who are in, who are in the part of the the rest, the national panel, and then had looked at some papers, and so I'm not sure why I must have

244

00:35:34.836 --> 00:35:41.630

Abe Elias: i i i i thought that they that it was reviewed before, and they.

245

00:35:41.630 --> 00:35:43.569

Lynne Wood: Well, you know it's interesting, Abe.

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00:35:43.790 --> 00:35:53.009

Lynne Wood: since I couldn't find it on the Rusp site. I started looking in some other places, and they do have it listed on the health resources and services administration

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00:35:53.140 --> 00:35:57.170

Lynne Wood: site as far as things that can be screened.

248

00:36:00.030 --> 00:36:01.290

Lynne Wood: So.

249

00:36:01.290 --> 00:36:06.480

Abe Elias: Maybe they maybe it was not. Was it nominated then, perhaps, and it was not.

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00:36:06.480 --> 00:36:13.709

Lynne Wood: So I think the page Anna was looking at was the same one I was looking at that lists everything that was nominated. I can share this particular

251

00:36:14.010 --> 00:36:14.840

Lynne Wood: page.

252

00:36:14.840 --> 00:36:16.040

Abe Elias: Yeah, it's.

253

00:36:16.040 --> 00:36:21.360

Lynne Wood: Not on the rust page, but it is on the Hrsa page. Very strange.

254

00:36:24.280 --> 00:36:28.790

Abe Elias: Yeah, I discussed, discussed this with couple of

255

00:36:29.810 --> 00:36:33.220

Abe Elias: people that are on the on the on the panel, and my,

256

00:36:35.300 --> 00:36:41.049

Abe Elias: but I can't see it now on that nomination page, either. I can't see it and see it either.

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00:36:49.180 --> 00:36:54.890

Anna Schmitt (she/her) - Yarrow: Yeah, I would think that the Hrsa website is probably just sharing which conditions can

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00:36:55.440 --> 00:37:00.109

Anna Schmitt (she/her) - Yarrow: be screened for, but not necessarily in connection to the Rusp.

259

00:37:01.855 --> 00:37:02.130

Abe Elias: So

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00:37:02.130 --> 00:37:26.969

Abe Elias: so what I so the summary up kind of what I what I talked about, you know the the difficulty with the variable phenotype and the and the difficulty to really identify those that need early treatment through newborn screening. Those are all aspects that were discussed, you know, in in various papers, basically and certainly by committee members. Of of

261

00:37:26.970 --> 00:37:33.039

Abe Elias: the. But I. So I yeah, I apologize that I can't find it either at all. And.

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00:37:33.900 --> 00:37:41.389

Lynne Wood: I started looking through some of the specific states so specifically, places like Missouri that have robust

263

00:37:41.460 --> 00:37:51.890

Lynne Wood: screening, and it looks like they at least have it listed on theirs. So maybe it's something that the rest hasn't officially reviewed. But I bet it's come up because it looks like it may be covered in a few different States.

264

00:37:51.890 --> 00:37:58.089

Abe Elias: Yeah, yeah, there are not many, I think I don't know. But I I think, yeah. Missouri, Illinois,

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00:38:00.060 --> 00:38:04.380

Abe Elias: Missouri and Illinois, I know, but actually not not many in.

266

00:38:04.860 --> 00:38:09.840

Anna Schmitt (she/her) - Yarrow: 7. Yeah, it's Illinois, Missouri, New Jersey, Tennessee, New York.

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00:38:10.250 --> 00:38:12.459

Anna Schmitt (she/her) - Yarrow: and I guess 2 2 others as well.

268

00:38:12.660 --> 00:38:16.099

Abe Elias: But I think New York only certain hospitals, and is part of a.

269

00:38:16.100 --> 00:38:16.690

Anna Schmitt (she/her) - Yarrow: Yeah.

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00:38:16.690 --> 00:38:22.059

Abe Elias: Out of a kind of ongoing research program. I don't think they all in New York is screening.

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00:38:27.990 --> 00:38:32.059

Lynne Wood: Well, I appreciate you. Bringing up that particular

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00:38:32.920 --> 00:38:38.570

Lynne Wood: argument. I think that helps flesh it out a little bit, and certainly the contrast to Pompeii is very helpful, too.

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00:38:39.080 --> 00:38:47.924

Abe Elias: Yeah, I mean, I mean those those aspects, all have been discussed, you know, in the literature, and and are being discussed between, you know among people who are

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00:38:48.410 --> 00:39:00.509

Abe Elias: who are on the rus, on the national rus, or in in other functions. But yeah, and I think that the presentation. That that was given at the last meeting, I think.

275

00:39:00.520 --> 00:39:05.360

Abe Elias: actually brings out these really well. And you can make an argument for or against. There.

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00:39:08.350 --> 00:39:12.290

Douglas Harrington: I think your comments are still germane to the discussion.

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00:39:12.826 --> 00:39:21.740

Douglas Harrington: So I I don't think it was a wasted conversation, and I'm focused on the treatment side. So I appreciated your comments, Dr. Elias. There.

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00:39:21.750 --> 00:39:24.380

Douglas Harrington: I think they were helpful to the thought process.

279

00:39:25.860 --> 00:39:44.750

Douglas Harrington: I have a tendency to be biased towards screening, because even in mild symptoms, I would like parents to know what they're dealing with. So I'm just going to be honest upfront I always tend towards, if there's an ability to do it with the cost of things being done. Now, I tend to favor that even with the

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00:39:45.010 --> 00:39:47.629

Douglas Harrington: discussion that we had. So thank you.

281

00:39:50.160 --> 00:39:56.419

Anna Schmitt (she/her) - Yarrow: Thank you. And I I think maybe, Jeannie, I might prompt you to just hop in on here on on the lab side of

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00:39:57.448 --> 00:40:00.800

Anna Schmitt (she/her) - Yarrow: the connection between Pompeii and Gaucher, and

283

00:40:01.130 --> 00:40:02.800

Anna Schmitt (she/her) - Yarrow: how that would work for you guys.

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00:40:03.080 --> 00:40:08.049

Jeanne Lee: Yeah, I mean, gosh! Can be multiplexed with

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00:40:08.490 --> 00:40:16.810

Jeanne Lee: Pompei, meaning that you can run. You know the test on the same blood spot that you punch

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00:40:18.300 --> 00:40:30.760

Jeanne Lee: We at the Montana Public Health Lab are not in the position right now that we can start screening for gauche, but Wisconsin would be able to screen it for us. So.

287

00:40:33.170 --> 00:40:35.219

Anna Schmitt (she/her) - Yarrow: That's a helpful reminder. Thank you, Jeannie.

288

00:40:43.990 --> 00:40:49.989

Anna Schmitt (she/her) - Yarrow: Do we have any additional clarification or conversation around this? Or do we want to move into the voting.

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00:40:57.840 --> 00:40:59.960

Anna Schmitt (she/her) - Yarrow: I'll open it to Shelly. Then.

290

00:41:00.940 --> 00:41:05.849

Shelly Eagen: Alright, I think we'll go ahead with the vote. Then, if there's no further comments.

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00:41:06.471 --> 00:41:11.769

Shelly Eagen: So again, for voting members, the options are, you can vote

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00:41:11.810 --> 00:41:27.820

Shelly Eagen: to. Yes, recommend, do not recommend, or you do not have enough information to make a decision at this time. If you decide that way. That would mean that if you are given additional information that would help you to be able to make a final decision to either recommend or not recommend.

293

00:41:53.300 --> 00:42:03.170

Anna Schmitt (she/her) - Yarrow: I do just want to know as I didn't say it specifically earlier. We do have quorum today. So I'll just be giving folks a minute or 2 here to fill out the voting form.

294

00:42:50.880 --> 00:42:57.980

Mikaela Miller, Yarrow: Looks like we have 6 responses, and there's 7 voting members on the call. Oh, 7th response just came in.

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00:42:58.603 --> 00:43:02.989

Anna Schmitt (she/her) - Yarrow: Except for that, that's not a voting member, so we'll have to wait for the other voting member.

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00:43:03.210 --> 00:43:05.599

Anna Schmitt (she/her) - Yarrow: There we go now we have it.

297

00:43:08.610 --> 00:43:12.379

Anna Schmitt (she/her) - Yarrow: Oh, now I'm not able to let me just see.

298

00:43:20.830 --> 00:43:21.234

Anna Schmitt (she/her) - Yarrow: Hmm.

299

00:43:50.150 --> 00:43:54.350

Anna Schmitt (she/her) - Yarrow: alright. So we have decided to. No, not recommend

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00:43:54.520 --> 00:44:00.920

Anna Schmitt (she/her) - Yarrow: this as an addition to the Montana newborn screening panel at this time.

301

00:44:00.950 --> 00:44:05.707

Anna Schmitt (she/her) - Yarrow: Thank you all for your votes today, and we'll send out

302

00:44:06.860 --> 00:44:11.060

Anna Schmitt (she/her) - Yarrow: That official recommendation in the coming days.

303

00:44:21.940 --> 00:44:29.880

Anna Schmitt (she/her) - Yarrow: I think we can now move it into the public comment period. So we're starting this at 9, 45. We have 10 min.

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00:44:30.350 --> 00:44:39.600

Anna Schmitt (she/her) - Yarrow: and I know we only have one member of the comment of the public here, and she has raised her hand, so

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00:44:39.770 --> 00:44:43.500

Anna Schmitt (she/her) - Yarrow: I will let you speak. Aviva.

306

00:44:45.810 --> 00:45:00.950

Aviva Rosenberg: Thanks. I mean, obviously, I'm very disappointed. But I thank you for taking the time. In response to Dr. Harrington's comment. Ert is the standard of care for all types of gaucher disease.

307

00:45:00.950 --> 00:45:24.329

Aviva Rosenberg: And there's an abstract being published at worlds in February that demonstrates that every patient in the United States diagnosed with gaucher disease with type 2 or type 3 is receiving ert as soon as they have the diagnosis, so there is no palliative care anymore. That is not the standard of care for any form of the disease which makes it crucial to have the babies tested.

308



00:45:24.330 --> 00:45:31.530

Aviva Rosenberg: and on treatment as soon as possible, because the suffering of the of the baby, without treatment to their death is

309

00:45:31.540 --> 00:45:50.440

Aviva Rosenberg: unconscionable when there is a medically approved treatment. So you know, I will continue to work through this and continue to try and get babies around the country screened for the disease, so that their families don't have to suffer through unbearable pain and watching their child suffer.

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00:45:50.800 --> 00:46:15.560

Aviva Rosenberg: and the quality of life for a type 3 patient that can be given. You can have a full life. We have type 3 patients that are lawyers and accountants, and they're having their own children, and that's only because they were treated with Ert within weeks of their birth. So you know it saddens me that this is not going to be available in Montana, but I will continue to fight.

311

00:46:18.700 --> 00:46:20.500

Anna Schmitt (she/her) - Yarrow: Thank you for your comment, Aviva.

312

00:46:23.210 --> 00:46:31.929

Anna Schmitt (she/her) - Yarrow: As a reminder. We do take additional comments up to 1 h after the meeting ends, and you can send those comments to this email listed on the screen.

313

00:46:33.190 --> 00:46:38.699

Abe Elias: And can I comment to Avivas? Is that okay? Can I respond to this?

314

00:46:40.110 --> 00:46:42.290

Abe Elias: Or is it just public comments right now?

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00:46:42.290 --> 00:46:45.840

Anna Schmitt (she/her) - Yarrow: Usually we don't respond to public comment as a procedure.

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00:46:45.840 --> 00:46:47.720

Abe Elias: Because I think it's a good. I mean, okay.

317

00:46:48.193 --> 00:46:52.139

Anna Schmitt (she/her) - Yarrow: I know it's a little bit awkward to have it be like this formal, but.

318

00:46:52.140 --> 00:47:09.119

Abe Elias: One thing I want to say, though, is that I mean we I think you know, just because this was not approved. Now I I do think, as I mentioned, there's there's there is, you know, there has previously been good positive reviews, and I think it should be re looked at in the future. So

319

00:47:09.160 --> 00:47:11.922

Abe Elias: it's just my, maybe not a direct response. But.

320

00:47:13.740 --> 00:47:20.419

Anna Schmitt (she/her) - Yarrow: Yes, that that is a good reminder on procedure of how this works is. A condition can be nominated again.

321

00:47:31.110 --> 00:47:46.159

Anna Schmitt (she/her) - Yarrow: All right. I don't believe we have any more public comment, so I will move on to the next steps. So, as usual, we will be sharing meeting materials from this meeting that includes the Powerpoint, the meeting minutes and the recording

322

00:47:46.613 --> 00:47:59.919

Anna Schmitt (she/her) - Yarrow: the public website will be updated with this information, and we will be formalizing the decision to not include Gaucher and sending that to the director for the director's approval.

323

00:48:00.408 --> 00:48:08.879

Anna Schmitt (she/her) - Yarrow: As a reminder, the director does have final say on what is decided on for conditions.

324

00:48:09.800 --> 00:48:25.910

Anna Schmitt (she/her) - Yarrow: We agreed today to have an additional 1 h meeting in February to discuss Member participation. And so we will be sending out a doodle poll for that meeting, and then also for our regular meeting in the spring, where we will be hearing about Asmd.

325

00:48:33.315 --> 00:48:39.699

Anna Schmitt (she/her) - Yarrow: Michaela will be putting another link in the chat right now for our usual meeting. Follow up

326

00:48:39.930 --> 00:48:41.005

Anna Schmitt (she/her) - Yarrow: survey.

327

00:48:42.220 --> 00:48:44.649

Anna Schmitt (she/her) - Yarrow: I hope that you guys know that we do

328

00:48:44.680 --> 00:48:58.939

Anna Schmitt (she/her) - Yarrow: read all of your responses every time and take your feedback seriously. That is one of the reasons why we are having the additional meeting in February. So please do fill out this survey form. It's really helpful for us to get feedback from all of you.

329

00:49:00.170 --> 00:49:07.830

Anna Schmitt (she/her) - Yarrow: and I'll pass it to Shelly if she's still on. I know she's kind of been hopping on and off. It looks like maybe she's not here.

330

00:49:08.000 --> 00:49:09.889

Shelly Eagen: Oh, I'm I think I'm here, am I?

331

00:49:09.890 --> 00:49:11.169

Anna Schmitt (she/her) - Yarrow: You are.

332

00:49:11.810 --> 00:49:29.190

Shelly Eagen: My apologies. It just has been cutting out here. But thank you, everybody for taking time on your day to join this meeting. If there are additional comments. Again, we'll be accepting those for the next hour at the email that's on the screen. And please be sure for the committee to review all of the

333

00:49:29.785 --> 00:49:35.959

Shelly Eagen: Doodle polls and surveys, and be sure that we can get meeting on the books as soon as possible.

334

00:49:37.710 --> 00:49:44.830

Anna Schmitt (she/her) - Yarrow: Thank you, Shelly, and thank you again to our members that this is their last meeting. It's been great getting to know you and having your participation.

335

00:49:44.850 --> 00:49:49.719

Anna Schmitt (she/her) - Yarrow: Thank you so much for all that you've done, and welcome to our new members once again.

336

00:49:55.820 --> 00:49:56.680

Anna Schmitt (she/her) - Yarrow: Okay.

337

00:49:57.070 --> 00:50:01.429

Anna Schmitt (she/her) - Yarrow: that will be the close of our meeting. Thank you, everybody, and have a great rest of our day of your day.

338

00:50:01.970 --> 00:50:02.830

Abe Elias: Hello! Everyone.

339

00:50:13.200 --> 00:50:15.860

Sarah Sullivan: Can I ask you a quick question? This is Sarah Sullivan.

340

00:50:17.150 --> 00:50:19.959

Anna Schmitt (she/her) - Yarrow: Yes, okay. You can pause. Or here let's pause.