



**NBS Advisory Committee Meeting
MINUTES**

Wednesday, February 26, 2025
12:00pm - 1:00pm

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Attendees

Voting Advisory Committee Members Present (Name - Position)

- **Shelly Eagen**, Chair - Nurse Practitioner, Pediatric Pulmonary, Billings Clinic
- **Jennifer Banna**, Vice Chair - Center Coordinator, Family to Family, Parent of child with rare metabolic disorder, Representative of an advocacy association regarding newborns with medical conditions or rare disorders
- **Steve Shapero** - Family member of persons affected by a rare genetic disorder
- **Amanda Osborne** - Licensed, Certified Professional Midwife, Helena Birth Studio
- **Shawnalea Chief Goes Out** - Representative of the Medicaid insurance industry, Perinatal Health Program Officer at the Health Resources Division, DPHHS
- **E Lynne Wood** - Pediatric Neurologist, Billings Clinic
- **Abdallah “Abe” Elias** - Director of Medical Genetics and Clinical Geneticist, Shodair Children’s Hospital

Voting Advisory Committee Members Absent (Name - Position)

- **Kotie Dunmire** - High School Business and Special Education Teacher, Butte High School and Parent of child with Cystic Fibrosis and PKU
- **Marion Rudek** - Nurse Practitioner, Blackfeet Community Hospital, Representative of a tribal health care system

Non-Voting Advisory Committee Members (Name - Position)

- **Amber Bell** - Newborn Screening Coordinator, Children’s Special Health Services, DPHHS
- **Debbie Gibson** - Lab Services Bureau Chief, Montana Public Health Laboratory, DPHHS
- **Jeanne Lee** - Newborn Screening and Serology Supervisor, DPHHS
- **Jacqueline Isaly** - Family and Community Health Bureau Chief, DPHHS
- **Douglas Harrington** - Acting State Medical Officer, DPHHS

- **Nikki Goosen** - Newborn Screening Clinical Laboratory Science Lead, DPHHS
- **Chelsea Pugh** - Nurse Consultant, Newborn Screening, DPHHS
- **Dani Lindeman** [absent] - Laboratory System Improvement Manager, DPHHS
- **Miranda Reddig** [absent] - Program Specialist, Newborn Screening, DPHHS

Facilitators (Name - Position)

- **Stephanie Burkholder** - Public Health Specialist, Yarrow
- **Mikaela Miller** - Public Health Specialist, Yarrow

Guests (Name - Position)

- **None**

Public (Name - Position)

- **None**

Welcome & Roll Call

- Mikaela Miller welcomed the group and conducted roll call while leading introductions so each person could introduce themselves by providing their organizations, roles, and a description of themselves.
 - Note: physical description is requested during introductions for those that might be seeing impaired.

Background/Purpose of Meeting

- Mikaela provided an overview of the Agenda, Ground Rules, and the Public Comment Period.
 - Purpose of the meeting: After receiving feedback from committee members, it was determined to hold an additional meeting to discuss committee member engagement. Specifically would like to discuss:
 - Committee engagement
 - Meeting procedures

Acknowledgment

- Mikaela introduced the rationale for reading this acknowledgement slide at the beginning of each meeting. The internal committee recognizes the general nature of the meetings and often difficult decisions that voting committee members must make, so this acknowledgement is a way to honor that.
- Co-Chair Jenn Banna read the acknowledgement slide.
 - *"We would like to thank the families and caregivers who bravely share their stories, the committee members who bring their expertise and lived experience, and the advocates and members of the public who are committed to the important work of informing the Montana Newborn Screening Program. We recognize that every condition that is recommended for review by this committee represents children and families in Montana who have been or may be affected by the condition in the future. Holding space for the experience, emotions, and vulnerability shared by families, presentations of subject matter experts, and the discussion on logistics, finances, etc - all at the same time is a difficult balance to find. We recognize that this process of reviewing conditions to potentially be recommended to be added to the Newborn Screening Panel requires in depth consideration and potentially uncomfortable discussion. It is our priority to ensure a process that is public and accessible."*
- Jacqueline Isaly asked for a check-in on the acknowledgement piece and wondered about members' thoughts/feedback on it.
 - Amanda Osborne commented that if long meetings are a reason committee members can't attend, then it might be better to just simply show the slide instead of reading it.
 - Abe Elias echos Amanda. But likes the acknowledgement, as this is the basis we're operating on. But maybe not go into it every time.
 - Jenn Banna wonders if we can shorten it but agrees it is important to keep and that there really is a harder piece to this work, helps to hear it as a parent and have it said.
 - Jacqueline: We can think about how to consolidate it a bit. Thinking about accessibility, it is a lot of words and wonders if it is just up on the screen and those with visual challenges then they wouldn't get as much out of it as others. Might continue to read it for accessibility and inclusivity.

Committee self-assessment and brainstorm improvements for engagement

- Mikaela introduced the discussion period and reviewed the three discussion prompts offered up for potential discussion.
 - What do you see as barriers that prevent you from participating in discussion during a meeting where a condition is being reviewed?
 - In times where there was good discussion about the particular condition being voted on, what helped you to participate or be engaged?
 - Meeting procedure: How far in advance does it take to plan a meeting, schedule 8 or 12 weeks in advance, do we want to shorten to 3 hours?

- Discussion:
 - Shelly Eagen: a lot of disorders we may be unfamiliar with and sometimes all we hear is what's presented at the meeting. It is hard to retain that information and then make the best decision we can. Sometimes I have to do additional digging on my own and come up with questions, which takes more time.
 - Jenn Banna: At times of good discussions there have been people on the committee or in the room who are able to explain complicated things and ask clarifying questions
 - Abe Elias: Is the way we do it the optimal format? It takes some time, especially with conditions that are not mainstream. Especially difficult with those as there isn't as much information. Concerns about people rushing to get to a decision.
 - Getting information ahead of time: National RUSP page is there but not the most user friendly. Can Yarrow facilitate getting that information, extracting the important information, and sending it to members long ahead of time so they can review it beforehand?
 - The NBS committee is not an expert committee. Sometimes the most basic questions are the most important to ask. Some of the best discussions we've had are when people ask very basic questions.
 - Amanda Osborn: Also admits to not typically having an in-depth understanding of these conditions. Appreciate the technical presentations but those might be less relevant to the decisions they need to make. Look at what we are here to do and what is the information we've been given? How much will this cost? Is it treatable? Can we even test for it? How soon do we have to detect it? Need to bring it back to the charter and what the committee's purpose is. Use those criteria to lead the discussion and THEN use the SME to get into the weeds. Not to drive the meeting but to help bring it back to what we are supposed to be doing at these meetings, do it from that standpoint in light of all the emotions that are involved.
 - Jenn Banna: take it a step further and let them know that those are the questions we're trying to answer. It's hard to stay focused on what they're talking about. Like both cases: use questions to guide our discussion but also know which questions we need to answer by the family and the expert.
 - Abe Elias: Could we give these questions to the SMEs ahead of time to review and then ask additional f/u questions?
 - Jenn Banna: How was submitting a condition and going through the process for you, Steve?
 - Steve Shapero: thought the process was good, experts were there, committee was then well-informed on the issue and what's available for treatments, what's available in Montana. He felt it was easy to follow along and watch the process go through. Easy to engage with everybody, got the answers he needed and it went quickly. Can't think of too many things to do to make it better but to ensure we make sure the experts are

available and know what the questions are to be asked and why we're asking them.

- Amanda Osborne: Where can we find our charter? Needing a 40,000 foot view of what we're doing. Maybe needing to refamiliarize with the criteria and trying to be unbiased as possible.
- Abe Elias: Maybe we need a general statement displayed and read at the beginning of the meeting to briefly list out our criteria
- Lynne Wood: Agree, it would be helpful to have a refresher on the rubric before we're hearing all the information.
- Douglas Harrington: In his work he reviews algorithms for treatment protocols, etc. It's helpful to have an introductory session/format of things that are helpful - what is the incidence? Clinical consequences? Natural history? Existing treatments/costs of treatments? The part that seems to be most helpful is where they explain acronyms and terms in very plain language for lay people. So have some structure to it but let the experts know so they can come prepared. Might even be valuable to have an introductory presentation.
- Jacqueline Isaly: Can't see each piece of the application (since it is automated) but we can work on putting together those components that we're reviewing for. Reminder we have modeled this off other states and the process for review by RUSP. We can certainly provide that to the committee and presenters and build into the process for review each time.
- Jenn Banna: The public isn't seeing those questions, just the person who turned in that request. Might help to share all those things up front to explain how we make these decisions.
- Lynne Wood: This lends to transparency, too, so the public understands why we are making these decisions. Goes back to the acknowledgement too.
- Amanda Osborne: All of this will help us stay on point. Keep objectives in mind and keep our speakers in the loop on our objectives. May lead to a more productive meeting and shorter meeting.
- Jacqueline: To recap, build into the discussion after presentation:
 - Prompting through the pieces we need to be considering that were part of the nomination process, to help guide the committee back to those points
 - We don't want to be directive to the committee in any way. Reminder that this is an advisory committee to the state, so we need to keep that process/discussion left to the committee. If this is what the committee wants to do in terms of facilitation then we can do that.
- Discussion of meeting scheduling/length of meetings:
 - Shelly Banna: If we're able to get more time to plan committee meetings, it helps those with clinic days to schedule around. Okay to shorten to 3 hours if we're able to get through all of the agenda
 - Lynne Wood seconds this
 - Abe Elias: One difficulty is that 8 weeks is often not enough for SMEs

Public Comment Period

- Mikaela acknowledged we did hold space today for a public comment period. No one from the public joined the meeting today.
 - Due to no public in attendance, any additional thoughts on the previous discussion to share during this time?
 - Steve Shapero: Where would I go or who should I ping to get a status update on a particular test that I'm interested in? Not hearing any feedback on how things are moving along. Seeing that things are "pending" and how long will it be pending?
 - Jacqueline Isaly: lab could probably answer that
 - Debbie agrees, reach out to the lab
 - Nikki Goosen: good clarification point on what they are and are not allowed to answer re: state lab
 - Jeanne Lee: yes, we can answer that question. Spreadsheet is available on the website
 - Jenn reiterated we don't know, clarified that the silence is we don't have the answer to those questions

Thanks and Next Steps

- Follow up email will be sent soon and will include:
 - Meeting minutes
 - Recording
 - Presentation slides
 - Feedback survey link (was also put into the chat)
- A doodle poll will be sent out to Committee members to schedule the next meeting.
 - Abe Elias: important to get internal committee dates as soon as possible, acknowledges it sometimes gets lost. Suggests regularly sending follow-ups with (weekly?) follow-ups to fill it out
 - Mikaela will continue to do regular follow-up, including phone calls (and will limit to only those who haven't filled it out yet)
- At the next meeting, will discuss Niemann-Pick disease (NPD), which is a lysosomal storage disease caused by acid sphingomyelinase deficiency (ASMD)
- Please email if you have questions, comments, or need anything.

This meeting was concluded by Mikaela Miller at 12:57 pm on February 26, 2025.