DRAFT

Oregon Health Authority
Northwest Regional Newborn Bloodspot Screening Advisory Board

Meeting Summary **September 14, 2026**

Location

Videoconference

Quorum

Board attendees constituted a quorum for the meeting.

Board Members Attending

Elizabeth Powers, MD, FAAFP, Board Chair, Representative of birthing center or hospital
Angela Douglas, MD, Vice Chair, Representative of a statewide association of pediatricians
Cheryl Grabham, Representative of advocacy association regarding newborns with medical or rare disorders
Rusha Grinstead, Representative of Medicaid or insurance industry
Marilyn Hartzell, M.Ed. Family Representative
Andrea Keating, LDM, CPM, Representative of a statewide association of midwives
Mort Murry, MD, Representative of advocacy association regarding newborns with medical or rare disorders
Kara Stirling, MD, Representative of a birthing center or hospital
Teryn Suhr, Representative of advocacy association regarding newborns with medical or rare disorders
Amy Yang, MD, Contracted medical consultant

Board Members Absent

Sheevaun Khaki, MD, Representative of a statewide association of pediatricians
Sherly Paul, Representative of a statewide association of nurses

NBS Program Staff

Patrice Held, PhD, OSPHL, Newborn Screening Program Manager
Sarah King, OSPHL, Client Services Coordinator
Megan Sanders, Analyst, OHA Government Relations

Members of the Public

Heather Higgins
Lesa Brackbill

Jensen Strategies Facilitation Team

Amelia Wallace, Board Facilitator
Emily Rehder, Operations Manager

ACTION ITEMS

The Board took the following actions:

- □ Approved meeting summary for the May 27, 2026, meeting
- □ Approved Updated Disorder Review Protocol

MEETING AGENDA ITEMS

1. Welcome / Introductions

Chair Dr. Elizabeth Powers opened the meeting. Dr. Powers asked for the Board members, OHA staff, and facilitators to introduce themselves, specifically noting the new Board member Teryn Suhr.

2. Meeting Overview

Amelia Wallace, Board Facilitator, reviewed the agenda for the meeting. Amelia reminded the Board of the upcoming Board meetings:

2026-27 Advisory Board meeting dates – all are on second Monday of the designated month from 1-4pm:

- December 14, 2026
- March 8, 2027
- June 14, 2027

Amelia reviewed the meeting agenda and recapped the protocol for Board decisions and discussions.

3. Approval of Meeting Summary

Chair Dr. Elizabeth Powers called for the approval of the May 27, 2026, Advisory Board meeting summary and asked for a formal vote.

Decision: The May 27, 2026, NWRNBS Advisory Board meeting summary was approved unanimously with amended language correcting Corrine McKenzie's testimony to reference MLD instead of DMD.

4. Program Updates

Patrice Held, NWRNBS Program Manager, provided updates on the Program.

Newly Released Reports

OHA released two reports: (1) 2025 NWRNBS annual report, available on the website. Emily Rehder will email to the Board after the meeting and is available on the NWRNBS website; and (2) 2026 Advisory Board Report to the Legislature which is pending approval by the OHA Government Relations department prior to distribution to the Board.

Status of Disorders Review and Implementation for Oregon Screening Panel

Patrice provided an update on the status of four RUSP listed conditions recommended for addition or review for the Oregon newborn screening panel. GAMT Deficiency and MPS II were reviewed and recommended for the Oregon panel in 2023. GAMT is scheduled to go live spring 2027. MPS II implementation has not been scheduled yet as

the Program is assessing alternative instrumentation, kits, and reagents methods. MLD is scheduled for Board review at the December 14th meeting. DMD review will likely be in 2027.

HRSA Review of Conditions for RUSP

The Association of Public Health Laboratories (APHL) was awarded funding from the Health Resource & Services Administration (HRSA) to convene a new stakeholder workgroup charged with developing findings and recommendations of disorders for HRSA's review and consideration for inclusion on the RUSP.

BRIDGES Study

Patrice provided an update on the BRIDGES-NBS Study, formerly known as BEACONS, the national feasibility study for whole genome sequencing. Individual participants can enroll their newborn through active recruitment sites at OHSU and PeaceHealth, or through information provided on flyers and social media. Contracts with BRIDGES/APHL have been signed by OHA and PeaceHealth while the OHSU contract is currently under review. The nationwide goal is to enroll 30,000 newborns through the study, including about 4,500 in Oregon in a year and a half. Oregon is the first to go live with active recruitment at Peace Health. The goal to enroll one or two babies to start the study into motion before they scale up. PeaceHealth will implement a soft launch in September (now scheduled for November).

Emails/fliers will be sent to all providers in the state, with targeted communications for PeaceHealth providers for the initial "soft" launch. A state-wide press release is planned for the roll out of this project. PeaceHealth recruiters were trained recently with NBS Laboratory staff trained shortly.

Questions and comments from the Board regarding the BRIDGES study included:

> Comment: There are concerns of parents declining newborn screening due to lack of detailed information about the study such as how long the samples will be kept.
>
> Q: Have the PeaceHealth recruiters been trained to talk about the standard newborn screening process?
>
> A: Patrice doesn't know how they are intending to approach families but will circle back with the study staff to find out.

Unscreened Babies Data Update

As a follow-up to her presentation shared at the last Board meeting regarding 2024 data on unscreened babies, OHA Data Analyst Alyssa Rapp shared the new 2025 data. In 2025 there were 410 unscreened babies in Oregon and of those babies, 123 were due to parent refusals. The number of unscreened babies represented 1.1% of Oregon births, crossing the 1% threshold. Since the collection cards were updated in March 2025 to allow for a "blood not submitted" field it is possible that some or all the other 287 unscreened babies were also refusals.

Questions and comments from the Board included:

Q: Has there been an uptick in the refusal trend because of the improvements to the card or was there an uptick trend already happening?

A: Previously, the unscreened babies were identified by matching the birth record to the newborn screening record. In 2024, there were 357 babies that didn't match, meaning they had a birth certificate but not a newborn screen, but it was not possible to know why screening did not occur. The new cards allowed for the refusal data to be collected.

Q: If a baby is born in Oregon and has an Oregon birth certificate but goes to another state, does this get tracked across states?

A: When matching between birth records and screening, out of state families are excluded.

If a screen is not submitted because the baby was transferred prior to collection, the follow-up care coordinators, reach out to the birth hospital to determine where the baby was transferred and to request a screen from the receiving hospital.

New Laboratory Information Management Systems (LIMS)

Lab Vantage was selected to implement the new LIMS. The project will consolidate four Oregon State Public Health Laboratory (OSPHL) LIMS into one integrated and efficient LIMS with embedded analytical tools. A pilot project for the LIMS was conducted from February 2026 through July 2026. Full implementation of the NBS module is tentatively planned for July 2027.

Screening Card Billing Model

Patrice provided an update on the proposed OSPHL billing model. As a reminder, currently hospitals and midwives pre-order cards, paying $175 for each two-part kit upfront. Presently, screening card orders can be made by the online portal or sending a check with paper forms.

The NWRNBS program is considering a fee for service model where submitting entities would be invoiced upon submission of completed screening kits to OSPHL. Charges would be made on a per baby basis and only for the first screen. One issue to resolve is how the subsidized cards provided to community birth centers for clients who pay out of pocket will be addressed.

The program will be looking further into the pros and cons of this pay for service model over the next few months. A request will be sent out to all screening card submitters asking them to identify people at their organization to consult during the model's development. In addition, outreach will be made to the Oregon Hospital and Midwifery Associations to engage them as well.

Upon completion of the new billing process, implementation will require an update to the Oregon Administrative Rules. The target roll-out for the new process is July 2027.

Questions and comments from the Board included:

Q: If a screening card is transferred, deceased, or refused is there a charge for the card?

A: No, there won't be charge.

5. Newborn Screening Policy Option Packet

Megan Sanders, Analyst, OHA Government Relations, provided an overview of the policy option packet for the 2027 legislative session. OHA and other agencies put forward a suite of legislative concepts, as well as policy option packets, which inform budget requests for the legislative session.

The Newborn Blood Spot Screening Program is primarily funded through fees, and the fees are really the only sustainable source of its funding. The last fee adjustment increased from $80 to $175 per screening card to cover a deficit in operating costs. Based on the program's funding and projected expenses for the 2027-29 biennium, there is an anticipated $2 million deficit. Since the fee adjustment in 2023, operating costs increased approximately 35%. To bring the program to solvency a proposed fee increase would be adjusted from $175 to $210 per screening card.

Comments and questions from the Board included:

Q: As we talk about approving new conditions, the cost of adding those conditions, and the instrumentation needed to add to the repertoire - is there a historical precedent or do other states do it a little differently? Is there a prospective way to say every condition we add will raise the costs?

A: Other states, such as Iowa, can raise their fees without legislative approval, so when new conditions are added, the cost of the cards/screening increase. At this time, Oregon doesn't allow State programs to raise their fees without legislative approval.

Q: During the last price increase, our costs compared to the other states were on the very lowest end and by going up to $175 made us in the very highest end of costs. Are we still at the highest or has that dropped?

A: It is hard to answer that question because other states are funded differently such as New York who is fully funded off their state taxes, the general fund, so they don't charge anything for newborn screening. Other states are higher and Minnesota, which is probably the highest is up to $260-$275 for only one screen. Some states include other factors such as courier costs, so it is hard to compare apples to apples.

Q: Do the projected fee increases include the five conditions under consideration or waiting for implementation?

A: Yes, they are trying to incorporate extra funding for those conditions.

Comment: There is a concern for families who don't have insurance and the increase of fees being a huge barrier for midwives to provide screening at the level that they are right now. Midwives are glad there is different funding model being developed that bills for screens processed rather upfront payment. They are concerned costs are increasing. It is concerning that the rate of unscreened babies is increasing and that the fee continuing to go up rather might further increase the rate of refusals. Alternate ways to supplement funding for the program are needed.

Comment: Knowledge that the reasoning for refusals is based on cost, from a policy standpoint, might change our conversation with the legislature. Information about resource accessibility as a barrier to screening is important for the Board to know and share with Legislature.

Comment: Anything that reduces access the screen or limits timely screening is counter to the goal of adding these conditions.

Q: What was happening in the 10 years when 30 conditions got added?

A: A new technology, tandem mass spectrometry, was introduced as a tool for screening that allowed programs to screen for inborn errors of metabolism by a single punch of the blood spot. Programs were able to add 30 new conditions all at once. At that time there wasn't a review process of those conditions. The majority of them were added because we could test for them. There are people interested in relooking at those conditions and some states have removed some because there wasn't sufficient evidence to screen for them.

Q: If we juxtapose the two graphs (cost of screening and the number of babies screened), will there be a direct cause and effect or correlation in the increase of both at the same time?

A: It is hard to know because there are so many factors as to why families refuse screening. Certainly, the discussion of immunizations and public health, in general, has really brought so much attention and information, accurate or not, to the general public. People are thinking more about public health.

Q: Do you know if other states are seeing increased declines in screened babies? Is it a pattern or just Oregon?

A: There has been an increase in other states. NWRNBS just met with Oklahoma who has also had a sizable increase. The program is working on a proposal to APHL to do a nationwide study on unscreened babies and the rate in which it's increasing and the factors that contribute to that.

Q: Has there been a national study about how other states fund this work aside from fees and general fund? Are there any other revenue sources, potentially from manufacturers or pharmaceuticals or something like that?

A: Sometimes there are federal funds available such as maternal child health block grants used to fund newborn screening, but not aware of any within industry.

Q: What percentage of babies are not being screened and has the percentage been increasing?

A: Yes, it did increase. In 2024, we were just below 1% of unscreened babies, and in 2025 we were at 1.1% unscreened.

Comment: In the last few years there has been a lot of concern about DNA and residual blood spots, so perhaps fear about the government having your DNA is part of the reason for the refusals.

A: The program is starting a project to have a public health nurse create an FAQ of what the program does with the data and the dried blood spots as well as who has

access to that information. The goal is to distribute that FAQ to families so that they feel more informed making a decision about screening and to reduce their fears.

Comment: I appreciate that the FAQ was being created and think that families would want to know about the destruction of their blood since it seems that people have a distrust with data and associated things.

A: COVID changed so much in regard to trusting the public health programs.

Q: Is there any opportunity for people to give feedback on this billing proposal before it goes to the Legislature?

A: Megan said she would be happy to provide the entire slate of policy option plans, and they can share their thoughts with her after the meeting.

6. Discussion: Scheduling Review of MLD and DMD (Agenda Addition)

Amelia Wallace, presented the Board with two scheduling options for review of the Metachromatic Leukodystrophy (MLD) for discussion and asked their preference:

1. Status Quo**:** Conduct scientific review, public input, and Board decision at December 14 meeting.
2. Modified**:** Conduct scientific review and public input in December 14 meeting and make Board decision at March 8 meeting.

After some deliberation, the Board agreed to conduct the scientific review and public input of MLD at the December 14th meeting, and if possible, conduct a special two-hour meeting in January or February for the board to discuss and make a recommendation. If that is not possible the decision on MLD should be made at the March 14th meeting.

Amelia suggested review of DMD begin at the June 2027 meeting. The Board deferred deciding on the DMD review schedule pending how the MLD review process goes and then decide the schedule for reviewing DMD.

7. Discussion: Proposed Disorder Review Protocol

Amelia asked given the information presented earlier regarding the newly funded HRSA committee to review and recommend conditions for the RUSP, does the Board still want to move forward with the revised protocols? Patrice recapped why the Board decided to revise the protocols when the US Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) was dissolved. She asked if the new HRSA committee changed the desire to revise the Oregon process to be independent from the national committee. She also asked if there is still appetite to have conditions coming to the Oregon Advisory Board, that are not on the national panel, and maybe haven't been reviewed or discussed yet.

Board member comments and questions included:

Comment: The new APHL workgroup is currently accepting applications for membership. Oregon legislation does not require RUSP designated conditions be added to the Oregon panel.

Comment: The Board should continue to evaluate the updated disorder review protocol. The RUSP can be a great resource as part of the evaluation, however,

other conditions not on the RUSP should be able to be nominated for inclusion on the NWRNBS screening panel. It is good that a new national committee is being formed, but the Board can still improve the disorder review protocol. It is important to allow additional nominations.

Q: How feasible is it to get the three medical consultants needed for the proposed Step 2? There was some concern it may not be feasible to obtain timely input from professionals.

A: Language modifications were made to the proposed protocol to give more flexibility to this review step.

The Board agreed to move forward in discussing the revised condition review protocol. Amelia Wallace walked the Board through the revised condition review protocol, highlighting the two changes since the Board's last meeting:

- In Step 2, Initial Review Committee, of the three medical consultants on the Review Committee, only two would not provide clinical care for individuals affected with the disorder. The third medical consultant may be someone who treats babies with the disorder.
- In Step 4, TAC Recommendations to the NWRNBS Advisory Board, the following sentence was added after the first sentence: "If three qualified consultants are unavailable due to the rarity of the condition, a TAC with fewer than three consultants is acceptable, provided the reason for the reduced committee size is documented." This change was added to compensate and proactively address capacity issues.

The table below compares the current and the proposed disorder evaluations processes.

Current Procedure	Proposed Procedure
Step 1: Addition to the RUSP	**Step 1: Disorder Nomination**
Step 2: NWRNBS Program Evaluation	**Step 2: Initial Review Committee**
Step 3: Public Input on Disorder Review	**Step 3: NWRNBS Program Evaluation**
Step 4: NWRNBS Advisory Board Evaluation and Recommendation using Input from Steps 1-3	**Step 4: TAC Recommendations to the NWRNBS Advisory Board**
	Step 5: Public Input on Disorder Review
	Step 6: NWRNBS Advisory Board Evaluation and Recommendation

Board members questions and comments included:

Q: Can a member of the initial review committee be allowed on the Technical Advisory Committee? Should they be excluded or can they do both? Are there potential conflicts of interests?

A: That scenario was not addressed; however, it is not prohibited in the current language. There would have to be rationale for excluding an initial review committee member on the TAC. Conflict of interest was discussed which is why the initial committee membership includes two medical consultants that don't treat the disorder and so the majority of the committee would not have a conflict of interest.

Q: Is there a large enough pool of contracted specialists for the TAC if only OHSU contracted entities are used? Why is it necessary that they be associated with OHSU?

A: The OHSU contracts allow added work without adding cost. The NWRNBS program engages OHSU medical consultants for significant program elements, and their opinions are important because adding a condition they do not support would be challenging for ongoing work. Also, as the providers who care for those babies, they are invested.

Chair Dr. Powers called for the approval of the of the protocol review process and asked for a formal vote.

Decision: The revised disorder review protocol was approved unanimously.

8. Discussion: Draft Disorder Nomination Form

Chair Dr. Powers provided a summary of the nomination form draft noting it needs to be rigorous enough to avoid submissions that lack appropriate scientific support. Information requested on the form should provide the initial committee enough to review and decide on whether the disorder should move forward in the evaluation process. Models from other states were reviewed as part of the form's development. The form is intended to be Oregon-specific and culturally appropriate, based on the values of the NWRNBS program. It is designed to identify disorders that cause serious health risks, are unlikely to otherwise be detected, have safe and effective treatments, and has testing available. In addition, ensuring equity and access to effective treatments for all children born in Oregon.

Board member questions and comments included:

Q: For treatments, do you want to know if it is FDA approved? And, if not, should it be?

A: It is not specified on the form. Treatments must be FDA approved for insurance coverage. This criterion should be added to the form.

Comment: A question if it is FDA approved should be included but there are generalized procedures that may not be need FDA approval such as a bone marrow transplant, because it is not a drug.

Comment: In authorization forms, it is asked if it is FDA registered versus FDA approved and usually CMS covers things that are FDA approved and not just registered.

The Board supported having the drafting committee develop language to include the treatment criteria of FDA approval in the next draft for Board discussion.

Q: Should the 60 days for initial review committee to review the condition be discussed?

A: It was a best guess because the initial review committee isn't doing the technical review and aren't supposed to have that knowledge and expertise, and all the necessary information should be in the application.

If any Board members have suggestions, questions, or comments about the nomination form they should email Dr. Powers or Dr. Douglas. A revised draft of the nomination form will be prepared by for Board discussion in the next meeting.

9. Public Comment

No comments were presented.

10. Wrap-up

Dr. Powers said she was looking forward to the meeting on December 14th from 1pm - 4pm and for the Board to look for additional communication about scheduling the additional meeting in January/February. The meeting was adjourned.