

**Oregon Health Authority**  
**Northwest Regional Newborn Bloodspot Screening Advisory Board**

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**Meeting Summary**

**September 8, 2022**

**Location**

Videoconference

**Quorum**

Board attendees constituted a quorum for the duration of the meeting.

**Board Members Attending**

Cheryl Hanna, MD, Representative of a statewide association of pediatricians  
Andrea Keating, LDM, CPM, Representative of a statewide association of midwives  
Jill Levy-Fisch, Advocacy association regarding newborns with medical or rare disorders  
Dawn Mautner, MD, MS, Representative of Medicaid or insurance industry  
Elizabeth Powers, MD, FAAFP, Representative of birthing center or hospital  
Joanne Rogovoy, Advocacy association regarding newborns with medical or rare disorders  
Kara Stirling, MD, Representative of a birthing center or hospital  
Amy Yang, MD, Contracted medical consultant

**Board Members Absent**

Marilyn Hartzell, M.Ed., (board chair) Person or family member of a person affected by a disorder on the newborn screening panel  
Wannasiri (Awe) Lapcharoensap, MD, Representative of a statewide association of pediatricians

**Program Staff**

Oregon Health Authority:

- Sheri Hearn
- Patrice Held (board chair)
- Ilana Kurtzig
- Cynthia Munoz Branger
- Sarah Viall
- Leah Wessenberg

**Guests**

Representative Susan McLain

**Members of the Public**

Carolyn Lee  
John Powell  
Pam Shepard

## **Oregon Consensus Facilitation Team**

Robin Harkless, facilitator

Cat McGinnis, project associate

### **ACTION ITEMS**

1. Robin and program will set up a conversation with Rep. McLain in the fall.
2. Long-term funding subcommittee will report to the full group in the fall.
3. Review of MSP-II and GAMT will occur in spring, with a concurrent board re-evaluation of the disorder review criteria.

### **MEETING AGENDA ITEMS**

#### **1. Summary from last meeting—April 27, 2022**

Adopted by the board with no changes.

#### **2. Program updates (also see appendix A)**

- SMA testing is off to a good start. No false positives or missed cases.
- Courier pilot is underway with 16 rural hospitals that have been struggling to get samples to the lab in 2-3 days. Couriers have improved timeliness greatly. The pilot will run for 1 year on public health lab funding and will be continued if funds are available.
- The program is providing USPS overnight shipping envelopes to rural midwives. There has been a dramatic improvement in timeliness and a positive response from midwives.
- Fee increase went into effect on August 1, 2022. It was suggested that the availability of fee waivers be communicated to Coordinated Care Organizations, and that the information be shared at the Oregon Midwifery Council soon. Waivers are available to mothers who qualify for WIC and have no insurance.
- Board membership changes: Dr. Phil Dauterman is no longer on the board. There is a vacancy for a representative of a nursing association.
- RUSP update: Mucopolysaccharidosis type II (MPS-II) was adopted by the RUSP. GAMT deficiency is under review for the RUSP. ACHDC will review Krabbe Disease soon.
  - The program asked: Does the board want to begin an initial process of review for MPS-II and GAMT?
  - A board member felt the board should meet soon to review MPS-II and should be poised to address GAMT and Krabbe, which is also in the review process
  - A board member noted that the legislature funded implementation of SMA testing, but not X-ALD, and this raises concerns about bias. The legislature should fund the program so it can decide what to implement.
  - Does the board want to consider revisiting its protocol and criteria for adding disorders to the screening panel? After some discussion, the board generally agreed that going through another round of reviews of disorders using the current protocol is prudent; and in that process the board could discuss whether updates or revisions are necessary.

- Does the current review process center equity? This would be a topic of consideration of future reviews and in considering revisions to the protocol, per the comment above. Some board members reflected on previously discussed considerations around equity:
  - OR review process needs to determine whether there are particular conditions in particular populations (e.g., indigenous populations).
  - In development of the review process, the board did consider geography, access and available treatments.
  - If there is a beneficial treatment available, a condition should be considered by the board.
  - One board member had an X-ALD case that required the family to go to MN for a bone marrow transplant—is that equitable if some families can't afford it?

### **3. Presentation by Rep. Susan McLain, guest speaker**

- Interested in the program taking advantage of what's happening nationwide. Interested in working in partnership with the board on these issues.
- Looking at the program having what it needs short-term, mid-term, and long-term.
- There are many new people in the legislature, a new governor, new House Speaker. Governor's budget process is not going to be known and budget won't be available until late Jan. or early Feb. This presents an opportunity.
- Plans to introduce a new bill regarding newborn screening, which is built off the bill from last session. In the bill, advisory board would automatically add a condition to the screening panel if it has been added to the RUSP and 10 states have added it to their panel. Rep. McLain suggested that this approach wouldn't require the board to do original research; they could use the research of states that have added the condition. Want to make sure OR is taking advantage of all new treatments, etc. One problem for families is that after RUSP adoption, it has sometimes taken 10 years for a state to add a condition. The bill might change to include a time limit of 18 months for Oregon review.

#### Board questions and comments:

- Does this bill aim to improve the process or assist in adding diseases without too much process?
- If a bill has created the advisory board, is it useful if another bill tells the board how to do its work?
- Will the board have an opportunity to review the bill? Rep. McLain: Yes, we will receive comments back on our draft and hope to bring an updated draft to you for discussion in late November.
- Will you also consider funding for added conditions?
- Concern with the criteria for ten states could reflect a "squeaky wheel effect" and have implications for equity.

#### **4. Re-evaluate condition review process? Review MPS-II and GAMT? (discussion continued)**

- Robin: If the board were to review the two conditions, how much time does the program need to prepare?
  - Program: Could pull a lot from recent national research. Six months for MPS-II and GAMT. Likely will not be ready for board review until spring 2023.
  - Amy Yang said she could present on MPS-II thoroughly. Could give limited info on GAMT (can speak on treatment process).
  - Program: Historically, the program has used FDA-approved tests for screening. None are available for MSP-II and GAMT. Lab can develop tests, but at greater cost. Would also need additional expertise and time. A board member suggested the draft bill should provide funding for development of tests.
- The board agreed it would review its protocol during the process of reviewing MPS-II and GAMT.
- A board member asked what the roles are for Rep. McLain, the program, and the board. The program explained that all serve at the pleasure of the legislature. If the bill passes, the program and board will have to adapt. One role of the program is to explain expenses.

#### **5. Follow-up on proposed bill**

The board would like to have a collaborative discussion with Rep. McLain about the bill, particularly to broaden the conversation about funding in late fall or early winter. Robin and the program will frame up a conversation and arrange a board discussion with Rep. McLain.

A board member suggested there may be an impact on advisory board participation if the bill passes and more conditions need to be reviewed. The program suggested it might be good to limit reviews to 1–2/year and remove the 10-state criterion.

#### **6. Next steps**

- Robin and program will set up a conversation with Rep. McLain in the fall.
- Long-term funding subcommittee will report to the full group in the fall.
- Review of MSP-II and GAMT will occur in spring, with a concurrent board re-evaluation of the disorder review criteria.

**Adjourned**

# NWRNBS Advisory Board Meeting

September 8, 2022

## NWRNBS Program Updates

- **Changes in OSPHL Leadership**

- Dr. Fontana is currently on leave and will officially retire on the 30<sup>th</sup> of September
- Recruitment is underway for a new laboratory director
- Dr. Luedtke will serving as the part time interim director starting in October.

## NWRNBS Program Updates

- **Practitioner's manual was updated June 1, 2022**
- **Testing for Spinal Muscular Atrophy began on June 1, 2022**
  - Three babies with SMA have been identified.
    - Two babies were identified through routine screening.
    - One baby was born prior to screening. The child presented with symptoms of SMA and the screening laboratory was able to test the stored blood spot.
- **Initiate pilot project for courier service for rural hospitals - July 2022**
- **Provide USPS shipping envelopes for midwives/midwifery clinics – July 2022**

## NWRNBS Program Updates

- **Fee for NBS Kits Implemented on August 1<sup>st</sup>.**
  - Website updated to aid parents in finding needed documents/forms
  - Fee exemption can be requested prior to purchase of the NBS kit. Fee reimbursement is also available. Families must meet qualifications for exemption/reimbursement.
  - Credit card payment option *tentatively* scheduled for October 1<sup>st</sup>.



## NWRNBS Program Updates

- **Long-Term Funding Subcommittee Formation**
  - First meeting was on September 1, 2022.
  - Second meeting scheduled for September 21, 2022.
  - Items for the subcommittee to consider are:
    - Explore how other states fund their NBS program
    - Explore different types of funding for public health programs (e.g., grants, general funds)
    - Explore issues of equity in NBS (e.g., criteria for fee waivers, costs for care/treatment incurred by families)

## NWRNBS Program Upcoming Events

- **NWRNBS annual program meeting with OHSU consultants is scheduled for September 16, 2022**
  - NWRNBS board members are invited to attend
  - Guest speakers include OHSU consultants, representatives from Oregon Midwifery Council, and community partners
- **Laboratory implementation of X-linked Adrenal Leukodystrophy screening on or before January 1, 2023**

## 2023 Legislative Session

- **The OSPHL has two legislative concepts for the 2023 legislative session.**
  - Revisions to the statute that authorizes the OSPHL to perform screening and follow-up. The revision also includes updates to align with current practices.
    - The Advisory Board reviewed a draft of the language at the November 2021 meeting.
  - The fee change that occurred between legislative sessions needs to be ratified by the legislature in the next session.