

Oregon Health Authority

Northwest Regional Newborn Bloodspot Screening Advisory Board

Meeting Summary

July 12, 2021

Location: Videoconference

Attendees

Board attendees constituted a quorum.

Board Members

Silke Akerson, CPM, LDM Representative of a statewide association of midwives
Anna Dennis, MS, CGC, Advocacy association regarding newborns with medical or rare disorders
Marilyn Hartzell, M.Ed., 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
Joanne Rogovoy, Advocacy association regarding newborns with medical or rare disorders
Cate Wilcox, MPH, Honorary Representative
Amy Yang, MD, Contracted medical consultant
Collette Young, PhD, Honorary Representative
Jill Levy-Fisch, representative of an advocacy association regarding newborns with medical or rare disorders
Cheryl Hanna, MD, Representative of a statewide association of pediatricians

Absent

Dana Hargunani, MD, MPH, Medicaid or insurance industry
Kara Stirling, MD, representative of a birthing center or hospital
Philip Dauterman, MD, FCAP, Entity that contracts with NWRNBS for newborn bloodspot screening

Members of the public

Carissa Bishop
Shelby Hahn
Carolyn Lee
John Powell
Sarah Viall
Leah Bjornskov Wessenberg
Maynard Friesz

Staff

Nicole Galloway, PhD, NBS Program Co-chair

Oregon Consensus Facilitation Team

Robin Harkless, Facilitator
Jennah Stillman, Note-taker

ACTION ITEMS

- Nicole Galloway will reach out to the DOJ and OHA government relations team to seek clarity on the advisory board's ability to functionally weigh-in on legislation as a collective body, public meeting requirements, general guidelines for communications in between meetings, and board membership abilities or restrictions. Potential presentation/orientation for next meeting.
- The program will track data on Gaucher disease and Fabry disease throughout the next year. In 2022 the board will review and discuss the available information at that time and make a decision about whether or not to conduct another review on whether to remove them from the screening panel.
- The program will provide updates on the potential legislative funding for the program to implement SMA testing when information is available.
- Robin will develop a visual/reference 1-pager out of today's discussion on equity goals for future planning.
- Jill Levy-Fisch will share a video resource used in educational materials for health providers and parents who want to opt-out of screenings with those who are interested.
- At the next meeting the board will address screening accessibility of out of hospital births and Silke will share information regarding how the midwifery system currently functions.
- The board will review the statute to address the core equity principles identified by the group and outline the board's role in providing support.
- Board members can reach out to Nicole to review their board term appointment.
- Robin will send a poll to schedule the next meeting for mid fall-early winter.
- The board will send feedback and suggestions to Robin Harkless if they have any thoughts about the desired meeting cadence moving forward.

1. NWRNBS program updates

Screening panel changes. At this time, the program will not remove Gaucher disease and Fabry disease from the screening panel. There was general agreement to provide more time for data collection and national scale consideration of these disorders. The board will review this additional information and make a decision in one year.

Oregon State Public Health Lab staffing. A new follow-up coordinator was hired and will start in October. A Program Manager position is posted and open for recruitment. It was noted that Chris Briggs may potentially return in some capacity.

Process improvements. Changes are being made so that report comments and results will be delivered to providers in a more streamlined way to make information more accessible and centrally located. Lysosomal storage disorder testing is being moved to a new platform and will be fully transitioned in August. Updates are being made to the practitioners' manual and educational materials in targeting improved satisfactory rates and providing more support and resources. The first cohort of innovations for newborn screening with partners in Maternal and Child Health will start at the end of this summer and engage on the national level to create a roadmap for more electronic test orders and reporting, aimed to advance interoperability with providers. Consultants are currently being onboarded to help support the process.

Communications. An email listserv was developed for delivering program information. A client survey was sent out and responses are currently being reviewed. There was a meeting between regional partners and OHSU medical consultant partners this past spring.

Accreditation. The bi-annual accrediting inspection for the laboratory is coming up this summer.

Changes to the Newborn Screening partners: Idaho is officially no longer part of the Regional Program. MPSI and Pompei were added to the screening panel for New Mexico.

2. Notes from last meeting

Nicole requested more time to review the notes; as such they will be finalized at a later date.

3. 2021 Legislative Session Report

Neither HB 2987 nor HB 3107 moved forward during the legislative session, both of which would have had outcomes relevant to the board and program's work with the newborn screening program, including the potential addition of varying disorders to the screening panel. Despite this, there may be potential funding for the program to implement SMA testing. More updates will be shared regarding this development. In addition, the House Committee on Health Care heard updates from the Program and Newborn Screening Advisory Board members Marilyn Hartzell and Cheryl Hanna about the program and role and work of the Advisory Board. Overall, everyone conveyed it was a positive learning exchange and prompted some thinking about how to stay connected with legislators in this process outside of legislative sessions.

Discussion: Recognizing that this was the first time the board went through a full legislative session, the group had questions about the relationship between the board, program and legislature. Given that OHA and other State agencies cannot weigh in on bills that do not come from the Executive Office, there are challenges and uncertainty around the board providing input or supporting information on legislation. There was interest in exploring pathways to provide information to decision makers about legislation that would impact the program, but uncertainty around how that could be done, either individually or collectively.

Action: Nicole will coordinate information and a presentation from the Government Relations team and Department of Justice (DOJ) to assist the Board and Program in gaining clarity on some key questions: How to communicate and collaborate as a board and a program around legislative issues within compliance of public meeting requirements? Can the board collectively look at issues that will have impacts on the program and work that is done, and offer themselves as a resource? Can the board weigh-in on legislation as a collective body?

In addition, it was acknowledged the need to be more proactive and thorough in providing future legislative information with the board, so that individuals can determine how they would like to engage and highlight that the board is available as a resource.

4. Newborn Screening Advisory Board Governance and Communication

Governance. The group reviewed and discussed the role of the advisory board in advising the program. It was clarified that the board can advise and make recommendations to the program and that based on input from the group, decisions will ultimately be made by the program. There was no opposition to this process as it currently stands and all present were in favor. There was desire for additional clarity around what rules exist and what the needs there may be for the co-chair representation and board representation, for matters that are not within the board's forum.

Communication. The requirement and current scheduling are for the board to meet every 6 months. For agenda items, board members can email and provide input to the chairs, Nicole and the facilitator

directly. The group discussed opportunities for the Program to orient with the board in a way that provides flexibility for broader communications and more timely organization in between meetings. It was acknowledged that additional information is needed for potential process improvements to be considered. This will be added to a future meeting agenda following engagement with the DOJ. There were no issues raised regarding the public engagement protocol, which provides opportunity for a fifteen-minute public comment period on all agendas.

Action: Nicole will also gather information and a presenter to help the group clarify communication sideboards and open space within public meeting laws.

5. Public comment period

There were no written or spoken comments.

6. Strategic Planning

Following an initial strategic visioning exercise from the last meeting, with more context now available for delving into strategic planning, it was acknowledged that there may be adjustments and adaptation to consider how to best support the changing needs of the system for the future 5–10-year horizon of newborn screening. For today, Robin asked the group to consider what the purpose of newborn screening is, whether the current OHA Program is aligned with that purpose and finally, what priorities and principles are needed to help guide the Program moving forward? The group also discussed strategic challenges the Program is currently facing that the board will need to help work through, as well as external factors that could impact the Program.

Discussion: The group acknowledged that the overarching strategic planning priority was to focus on improving equity. The identified elements and considerations of equity, but were not limited to:

- *Accessibility.* Making core screenings and treatment more accessible and maintaining cost effectiveness.
 - Desire for more universal agreement around newborn screenings and access to screening services around the state and country, regardless of where a newborn is born.
 - For babies born at home or in birth centers (which account for 5%), there are currently reimbursement challenges for midwives and therefore many will opt out of the screening because of this cost. For a future meeting the board will address screening accessibility of out of hospital births, recognizing that midwives are being excluded from a type of billing.
- *Family centered care.* Providing more effective family-centered care through social and emotional support, education, and assistance navigating the system. Also ensuring that providers have the resources needed.
 - More established overall communication, outreach and follow-up for families around testing; particularly about the process if a positive result is received, so people have more awareness from the beginning.
 - Communication often ends at a positive result and the responsibility for seeking follow-up tests often falls on the family. What are the available resources outside of the Program and screening that could support this?
 - Currently, families and patients are not equally educated and there is a lack of alternative language translation in education materials.
 - How can the Program improve education effectively with the resources at hand?

- *Timeliness.* Delivering timely services and results by keeping pace with the available technology and improving electronic transmission of test orders, reports and information.
 - There may be a time in the future when the pace of treatments and ability to detect them outpaces the process or available funding. To that end, it will be essential to remain nimble.
 - Ensure that GAO standards are being met.

External Forces. The Board acknowledged financial limitations and the subsequent cost increases of potential expansions. It was acknowledged that finding supplementary funding may be needed, but that to create meaningful change and expansion, funding should be sustainable, which is more challenging. As a next step the board will work to identify what is within the scope of the Program and set priorities accordingly, then identify funding pathways and potentially advocate for additional funding if gaps arise through that learning. Opportunity for more collaboration with community-based partners around education, outreach, or connecting to care through resources was noted as a key role for the Program in closing any gaps in the system around education, communication and other family support. Another external force acknowledged was the rapid development of technology which can be a support and a challenge to the Program. Nicole also noted that interoperability and transfer of information is a critical strategic challenge and opportunity for the Program and system.

Statutory Review. The board discussed the process around a statutory review of the Program and how to ensure the strategic priority considerations for equity can be addressed in the statute language and benefit for the Program throughout the next 5-10 years. Over the next year, the board will review the statute and address the core equity principles identified by the group. Nicole and Robin will work to identify the timeline for the statutory review process and at the next meeting Nicole will report-out. In addition, Robin will develop a reference/check list tool of the equity principles developed today to assist with bridging these goals into updated statute language. The equity goals can also inform the Program's strategic priorities and lead to development of a funding plan for supporting these goals.

7. Next steps

At the next meeting, the board will revisit strategic planning and equity standards and goals that the board has articulated. The first space for this discussion will be in the statute review and update process and in a specific area of need that has surfaced in this process, midwifery reimbursement. Silke will share information regarding how the midwifery system currently functions. Board members are encouraged to send any additional agenda items suggestions to Robin or Nicole.

Adjourned