

# **Oregon Health Authority**

## **Northwest Regional Newborn Bloodspot Screening Advisory Board**

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### **Meeting Summary**

**November 16, 2020**

**Location:** Videoconference

#### **Quorum**

Board attendees constituted a quorum.

#### **Board members present**

Silke Akerson, CPM, LDM Representative of a statewide association of midwives

Chris Biggs, MS, NWRNBS Program Manager (co-chair)

Anna Dennis, MS, CGC, Advocacy association regarding newborns with medical or rare disorders

Cheryl Hanna, MD, Representative of a statewide association of pediatricians

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

Jill Levy-Fisch, Representative of an advocacy association regarding newborns with medical or rare disorders

Joanne Rogovoy, Advocacy association regarding newborns with medical or rare disorders

Kara Stirling, MD, Representative of a birthing center or hospital

Cate Wilcox, MPH, Honorary Representative

Collette Young, PhD, Honorary Representative

#### **Absent**

Philip Dauterman, MD, FCAP, Entity that contracts with NWRNBS for newborn bloodspot screening

Dana Hargunani, MD, MPH, Medicaid or insurance industry

Amy Yang, MD, Contracted medical consultant

#### **Members of the public**

Rick Frees

#### **Staff**

Chris Biggs, MS

Nicole Galloway, PhD

John Fontana, PhD, HCLD (ABB)

#### **Oregon Consensus Facilitation Team**

Robin Harkless, Facilitator

Cat McGinnis, Note-taker

## **ACTION ITEMS**

- NWRNBS program will include an interim email update between board meetings to provide more continuity and help tee-up substance for better preparation by the board.
- The board asked the program for the following additional information regarding expedited shipping:
  - Breakdown of weekday shipments vs. weekend—average transit time based on day of the week that birth occurs.
  - Information from other states that are doing well with specimen transit.
  - Deeper dive into specific provider sites that are having trouble with transit timeliness.
  - Data on whether midwives are batching specimens for shipment.
- Nicole is keeping a list of current board tasks/agenda items and will share this out with the board for feedback on how to prioritize the items. She will work with the facilitation team and new co-chair to develop a proposed work plan, and this will be shared with the board by the end of this year.
- The program is looking for an additional board member from a small rural hospital. The board also has a vacant position for a representative from a nurses' association. The board was asked to share suggestions with the program.

### **1. Review of meeting summary**

Summary from the June 29, 2020, meeting was unanimously approved without changes.

### **2. Board chair and vice-chair**

Terms for the current board chair and vice-chair have expired. The new chair will be Marilyn Hartzell and vice-chair will be Jill Levy-Fisch. Each will start the term on January 1, 2021, and will serve a two-year term. Nicole Galloway will take over as the NWRNBS program co-chair on January 1, 2021. She will become acting newborn screening laboratory manager upon Chris Biggs's retirement at the end of the year.

### **3. Check-in on meeting effectiveness**

The program asked for board input on how meetings are going so far and whether there are topics they would like to see covered at upcoming meetings or other changes. Input included the following:

- It would be good if a workaround could be found that would allow board members to communicate directly with the program outside of meetings.
- Meetings are excellent. Time between meetings may be too long. It's hard to get back up to speed. Is there a better way to tee up meetings? The program offered to provide interim updates.

### **4. NWRNBS program updates**

*Board report.* The last report to the legislature was submitted on time. There was no response from the legislature, but the board may hear more as the legislative session approaches.

*Disorder removal.* The program asked how the board would like to accomplish the work of reviewing disorders for removal from the screening panel. Independent reports on the disorders are underway and Cheryl Hanna is reconciling them with the criteria the board established for disorder removal. A question arose whether there should be more frequent meetings to address disorder removal. Some felt it would not be feasible to commit to additional meetings. The group settled on reviewing materials between meetings to expedite work on review of disorders for removal.

*Midwife costs for newborn screening.* Silke Akerson provided the program with some information and the program added it to the information the program has, but they discovered gaps that still need to be filled and are trying to get that information. One possible issue may be that midwives are not getting reimbursed for screening or not getting reimbursed what it costs.

*OHA policy option package.* While OHA finds the board's recommendation to add spinal muscular atrophy (SMA) and X-linked adrenoleukodystrophy (X-ALD) to the newborn screening panel important, other funding requests took priority in the agency's policy option package for the 2021. While legislative session funding to allow addition of the disorders was not included in the agency requests, OHA is exploring whether funds can be identified to support adding SMA and X-ALD to the screening panel. The board asked whether other steps could be taken towards adding the disorders in the absence of funding. While the program has evaluated its ability to add the test, additional steps are not possible without funding.

## **5. Public comment period**

There was no public comment.

## **6. Specimen transport**

Chris Biggs presented the following information on transport of first specimens from January-October 2020:

- Specimens (first specimens) transported to the lab (via courier, USPS, UPS, or FedEx): 33,252
- Sent from 95 zip codes
- Average transit times from birth to report of results: hospitals—5.6 days; midwives—7.7 days; overall—5.7 days
- Geographic distance does not necessarily correlate with longer transit times—facilities in the same area may have quite different transit times.
- Midwives appear to face additional challenges for timely collection and transport.
- It does not appear that COVID-19 is affecting transit times for first specimens.
- The program is working on a cost estimate and time savings analysis for FedEx-express overnight shipping. There are areas of the state where FedEx does not pick up, so drop-off would be required. Pickup times may affect transit times, particularly in areas where specimen drop-off is the only option—the effect of this will be difficult to determine.

Board discussion:

- Are midwives mailing specimens from their own home or from the client's home? It varies a lot. Most ship by USPS and in the case of weekend births, specimens won't go out until Monday.
- Why are hospitals in areas close to each other experiencing different transit times? The program agreed to look further into this and suggested they have nurse educators who could assist hospitals to examine their workflow processes to potentially improve transit time.
- Oregon doesn't pay for shipping of specimens. Midwives and hospitals pay shipping costs.
- Program asked regarding expedited shipping—where is it needed and what would it cost? Should the program provide for targeted facilities or all?
- The board requested the following additional information regarding expedited shipping to inform a next step discussion and deliberation to advise the program:
  - Breakdown of weekday shipments vs. weekend—average transit time based on day of the week that birth occurs. (Would it make sense to focus transit support on births that occur close to or on weekends?)

- Information from other states that are doing well with specimen transit. The program will gather this information.
- Dive down into provider sites that are having trouble with transit timeliness. Would it make sense to seek funding to help those that are having problems with timeliness?
- Data on whether midwives are batching specimens for shipment. The program can pull data to look at this.
- How can we make transit more equitable for hospitals and midwives? Would expedited shipping help midwives? Probably, but perhaps focus groups would tell us more. Note that midwives attend at only 4% of Oregon births. Maybe it would be more cost-effective to focus on hospitals, which do many more tests at once.

## 7. Preliminary discussion of strategic planning

The program shared their goals for strategic planning:

- Decrease risk for newborns.
- Help the program modernize its statute.
- Planning should occur through an equity lens.
- Planning should be holistic and address not just the program but the whole newborn screening system, e.g., hospitals, midwives.

The advisory board walked through a high level visioning exercise, brainstorming responses to the question: *If everything were working perfectly, what would the program look like in 10 years?* This will serve as a foundation for the board's work with the program to build out a Strategic Plan in 2021.

- The program is sustainably well-funded.
- No matter where or when a baby is born, the baby gets timely screening and gets linked to any needed care.
- Communication for all impacted providers is seamless.
- Families are centered not only in communications, but also in services.
- Even if results are negative, there's a discussion about disorders at the first well-baby visit with a doctor.
- Families are educated about newborn screening so they know the importance of it.
- There are no financial barriers for low income families.
- There is a strong linkage to a system of care—no delays between diagnosis and care.
- Lab is interoperable, which ensures results are accessible in the right places.
- Education is provided in a culturally-competent way.
- "Timeliness" is standardized—birth to report-out to linking with clinical providers.
- Disorders and roll out testing are done in a timely way so families benefit.
- Providers have education and resources they need to address timeliness and quality.
- There is robust case coordination for abnormal test results and follow-up.
- Program does long-term follow-up, especially for new disorders.
- There is a robust system that keeps track of children over time to watch for information that would help other families.
- The newborn screening system can easily transition to new technologies.
- There are collaborations and synergies with other newborn screening labs and programs for mutual support.
- The program engages community support for families where they live and work.
- All results are available in every hospital medical record system.
- Reimbursement for screening is adequate.

- If a condition is recommended for the panel, diagnosis and treatment of the condition are covered by insurance.
- Consultation with an expert is offered to all families in a timely manner.
- There is access to telemedicine and other forms of timely human connection for affected families.
- Program has genetic counselors and nurses within the program.
- Social workers/system navigators are added to the support team.
- There is wrap around with behavioral/mental health support.

Robin offered some thoughts on how the strategic planning effort could look, with a commitment to follow up with the new chairs and program staff to build the process out further:

- It's a blank palette—not updating an existing plan so a good opportunity for partnership between the program and board on how best to modernize the program.
- A follow up step to today's visioning exercise would be to conduct a gap analysis, comparing the items in the vision with the current state to know where there are gaps and needs/opportunities. This can then lead the group to identifying program goals and strategies.
- Strategic planning will happen in 2021. Timing will depend on the board's other priorities—disorder removals, midwifery coverage, status updates, etc. Nicole is keeping a list of current board tasks/agenda items and will work with Marilyn and Robin offline to prioritize these items into a work plan. To inform this, Nicole will share the list of current board topics and request feedback from the board over email about which of the items stand out as priorities.
- It was noted that some agenda items may be best informed by strategic planning and will be sequenced as such.
- Robin will share a proposed 2021 work plan with the board by the end of the year.

### **8. Other business**

The program is looking for an additional board member from a small rural hospital. The board also has a vacant position for a representative from a nurses' association. The board was asked to share suggestions with the program.

### **Adjourned**