

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

Subcommittee on Long-Term Program Funding

Meeting Summary

August 1, 2022

Location

Videoconference

Quorum

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

Board Subcommittee Members Attending

Marilyn Hartzell, M.Ed., (Advisory Board Chair) Person or family member of a person affected by a disorder on the Newborn Screening Panel

Andrea Keating, LDM, CPM, Representative of a statewide association of midwives

Wannasiri (Awe) Lapcharoensap, MD, Representative of a statewide association of pediatricians

Dawn Mautner, MD, MS, Representative of Medicaid or insurance industry

Amy Yang, MD, Contracted medical consultant

Board Subcommittee Members Absent

None

Program Staff

Oregon Health Authority, Oregon State Public Health Laboratory:

- Patrice Held (Program Board Chair), NBS Program Manager
- Sarah Humphrey King, Acting Business Engagement and Policy Analyst

Guests

None

Members of the Public

None

Oregon Consensus Facilitation Team

Robin Harkless, facilitator

ACTION ITEMS

The following action items were identified but not all will be completed prior to the next subcommittee meeting.

- Lab to explore other states' funding models and develop a summary.
- Group to determine what additional parties to engage in the discussion.
 - Advisory Board members to send additional parties to be involved to the advisory board inbox: nbs.advisoryboard@odhsoha.oregon.gov
- Robin to describe a draft scope for this subcommittee.
- Explore other population-based public health program funding models.

MEETING AGENDA ITEMS

1. Welcome and Introductions

Attendees introduced themselves and their representation categories and roles.

Robin Harkless introduced the topic of the advisory board subcommittee, to explore what funding model may work well for Oregon longer-term. She expressed gratitude for the board members sharing their time and expertise for this subcommittee.

2. Subcommittee Scope and Purpose

Patrice Held shared slides to help frame the current situation and frame the long-term planning discussion. (Attachment 1)

Marilyn Hartzell is interested to explore how Oregon's program funding compares and contrasts with other states' programs.

Marilyn Hartzell asked if there is a Federal governing body regarding how states run their screening programs?

- Patrice Held stated that each state manages their own newborn bloodspot screening program. The Federal level recommends what diseases are screened for and has made recommendations for timeliness of newborn bloodspot screening (e.g., results within one week of life). The Federal level has not addressed the topic of programs' funding.
- Robin Harkless shared that the first meeting of the advisory board provided information about the national context, including the federal committee. Members can review minutes from the July 18, 2019 meeting at www.bitly.com/nbs-advisory.

Andrea Keating agrees that finding how other states are approaching their funding and if there is a model from other states that can be a model for our program, both the funding process used and the implementation.

Patrice Held expressed interest in thinking about creative solutions for newborn bloodspot screening, which may mean not directly modeling another state.

Dawn Mautner inquired about whether the Public Health Division is involved in the discussion about NBS funding. They are planning for some population-based models for other programs. Should this level be involved in these discussions?

3. Long-Term Funding for Newborn Bloodspot Screening in Oregon

Robin Harkless set up a discussion for the group around the question, “What key questions or ideas should we investigate related to developing a long-term funding model for Oregon’s Newborn Bloodspot Screening Program?” The group may also include within their responses if there are other organizations or voices that should be a part of the discussion. The group’s post-it exercise brainstorm is included as Attachment 2.

Themes identified:

- Explore different types of available funding (e.g., grants, general fund)
- Criteria – building equity; exploring fee waiver; anticipate increases in costs.
- How are other states funding their programs?

There are some key questions posed to be investigated:

- What other models are available?
- Who needs to be involved?
- Who is ultimately responsible for funding the service?
- What is the scope of focus for the funding? (i.e., the whole service or just the screening?)
- What data is needed to inform decision making?

Dawn Mautner expressed an interest in defining the scope or charter for this subcommittee.

Marilyn Hartzell asked where the NBS Program ends and therefore the scope of the subcommittee and funding may end in the full perspective of the family needs.

Amy Yang expressed an interest in exploring other funding sources to supplement the program instead of raising fees. In addition, looking at equity and supporting self-pay families. Does the committee identify funds for the overall newborn screening program or only support those births that may not be funded by insurance?

- Andrea Keating considered that perhaps investigation and improvements could be tiered by priority at some point in the process.
- Patrice Held suggested the group look at funding the whole program due to the ongoing rate of progress and improvements in newborn bloodspot screening.

Dawn Mautner inquired about the lab potentially framing questions that need to be asked in order to frame the necessary decisions. Where do the questions fit in the context of existing solutions? What is happening currently, and where are the gaps? Where are the solutions?

Andrea Keating posed a key question from the midwifery community, which is around how to move away from fees so the service is funded from other sources.

Amy Yang expressed three primary problems from her perspective:

- Small businesses experiencing a burden. Direct support to this area.
- For technology, may be good to get a grant for the short-term support.
- For long-term sustainability, thinks the group has to ask for state funding.

As a subcommittee member, want to give you ideas to approach financial challenges for both the program and recipients of the program.

4. Public Comment Period

No members of the public present; no public comments.

5. Wrap-Up and Next Steps

Begin evaluation of other potential funding models and report out to the subcommittee for discussion and consideration.

Group agreed to meet in late August to discuss and prepare for the September meeting of the full advisory board.

6. Adjournment

Attachment 1: Slides for Subcommittee Scope and Purpose

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



Subcommittee on long-term
program funding
August 1, 2022







OREGON PUBLIC HEALTH DIVISION
Oregon State Public Health Laboratory (OSPHL)

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How are NBS fees paid? By whom?


- **NBS collection kits are purchased by medical practitioners as single, double or triple kits.**
 - Single kits = \$100.00 (as of 8/1/22)
 - Double / Triple kits = \$175.00 (as of 8/1/22)
- **Practitioners are reimbursed by insurance plans.**
 - Global package payment for inpatient birthing services.
 - Community birth providers are reimbursed for a supply bundle.
- **Some parents self-pay for NBS kits**
 - Fee waiver available for qualifying families

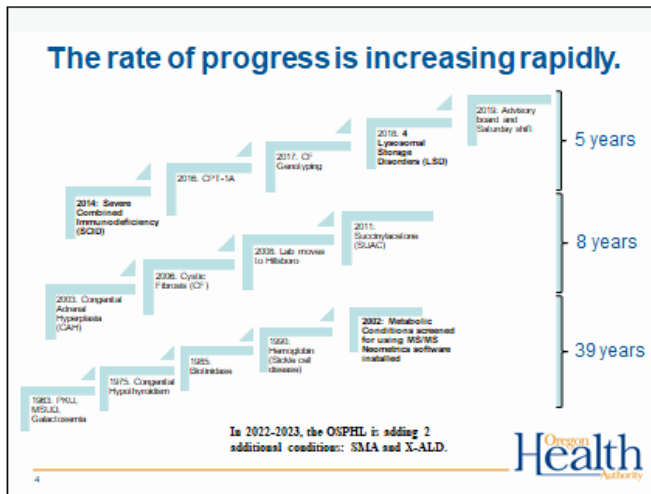
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**2020 Maternal Demographics
Center for Health Statistics**

	% of births (n=40,185)	Medicaid/OHP	Private Insurance	Self-Pay	Other Coverage
Planned hospital births	95.5% (n=38,371)	43.5% (n=16,687)	54.5% (n=20,526)	0.7% (n=277)	1.3% (n=481)
Planned out-of-hospital births (e.g., birth centers, home births)	4.5% (n=1,814)	24.5% (n=444)	43.7% (n=792)	31.2% (n=566)	0.7% (n=12)



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Planning for Future Program Growth

- Additional disorders to be added to Oregon panel
 - Respond to national recommendations
- Expand courier and follow up services
- Develop electronic reporting to comply with the 21st Century
 - CURES Act and align with REAL-D requirements.
- Introduction of new technologies - gene sequencing
- Improved Continuity of Operations Plan (COOP)

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Short-term Support for Fee Increase

- Increase access to fee waiver
 - Review qualifications
 - Accept fee waiver at time NBS kit is requested
- Implement credit card payments for NBS kits
- Medicaid (OHP) Reimbursement for Community Birth Providers
 - Reimburse NBS collection kit separate from supply bundle
 - Match collection kit reimbursement with NBS kit fees

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Long-term Funding Solutions

- **NWRBS Advisory Board**

- Advised that fees are not a sustainable long-term funding model for the program
- Program investigating alternative funding models used by other states
- Program learning about how NBS is paid for in insurance carrier networks
- Program proposing subcommittee of board members to support long-term planning



Attachment 2: Details for Long-Term Funding for Newborn Bloodspot Screening in Oregon

