



**Northwest Regional Newborn Bloodspot Screening
Advisory Board Meeting
Wednesday February 23, 9:00am-11:30am Pacific Standard
Time**

ZOOM MEETING:

<https://pdx.zoom.us/j/83787065768>

Meeting ID: 837 8706 5768

Telephone Commands:

*6 - Toggle mute/unmute

*9 - Raise hand

iPhone one tap mobile

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AGENDA*

*Times are approximate and may be adjusted based on meeting content and time needed for specific agenda items. Agenda items may be taken out of order and the agenda amended.

9:00 Welcome, Introductions, Housekeeping

- Newborn Bloodspot Screening Manager Introduction
- Program Updates
- Board Changes
- Approval of November 1, 2021 Meeting Notes

9:15 Legislative Updates

9:30 Introduction to Upcoming Proposed Fee Changes

The NBS Program is in the beginning phases of planning for a fee increase. The fee increase would provide the resources necessary to sustain the NBS Program and support improvements that will protect the health of infants and ensure equitable services for all Oregonians and align Oregon's fees with other state newborn bloodspot screening programs. Some of the planned program improvements include:

- Addition of new disorders to the NBS screening panel
- Improve timeliness
- Modernization of technology
- Appropriately address complex disorders
- Enhance the equity of screening services

10:15 BREAK



10:30 Rule Changes Related to Adding SMA and X-ALD to the Bloodspot Screening Panel and Update to Practitioner's Manual

The Advisory Board will serve as a Rules Advisory Committee with additional members to review proposed language for rule changes related to two items:

- 1) The proposed rule changes to OAR 333-024-1070 update names of conditions for which the Program tests and updates methods used for testing for housekeeping and to align with current medical and laboratory practice. Further, the Program will add testing for two conditions: X-linked Adrenoleukodystrophy (X-ALD) and spinal muscular atrophy (SMA).
- 2) The Newborn Bloodspot Screening Practitioner's Manual is being updated to version 12 to revise instructions for collecting specimens and to update medical condition summaries, including the addition of sections on X-ALD and SMA. Changes to the manual are considered part of this Rule change. References to the manual are being updated in associated OARs.

11:00 General Public Comment

Time may be limited to 1-3 minutes at the discretion of the Advisory Board Chair(s)



11:15 Wrap Up/ Next Steps

Determine next steps and identify next meeting agenda

- Action items from today
- Identify upcoming Board business:
 - Legislative Report
 - Other
- Next meeting schedule

11:30 Adjourn

The meeting is accessible to persons with disabilities. A request for an interpreter for the hearing impaired or for other accommodations for persons with disabilities should be made at least 48 hours before the meeting to NBS.AdvisoryBoard@dhsosha.state.or.us.