



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

February 4, 2020, 8:30am-4:30pm Pacific Time  
Oregon State Public Health Laboratory (OSPHL)  
7202 NE Evergreen Pkwy., Suite 100, Hillsboro, OR 97124  
Call-in: West Coast: (720) 707 2699 East Coast: (646) 558 8656  
Meeting ID: 753 960 1319

**NOTE: Please check-in at the front desk and bring a photo ID**

**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.*

8:30 Welcome and Introductions

8:45 Recap and Review of work

- Legislative Report
- Rules
- Action items and follow up from last meetings

9:00 Disorder Review Introduction

- Process and Criteria for Recommending Addition to the Panel
- Introduction of ethicist
- Overview of materials compiled by research consultant

9:30 Break

- 9:45 Spinal Muscular Atrophy Review and Discussion
- Disorder review
  - Public Comment (10 minutes) - *time may be limited to 1-3 minutes at the discretion of the Advisory Board Chair(s)*
  - Category 2 Review
  - Advisory Group Category 3 criteria review and deliberation
  - Recap of discussion and Consensus check

11:45 Break for Lunch

- 12:15 X-Linked Adrenoleukodystrophy Review and Discussion
- Disorder review
  - Public comment (10 minutes) – *time may be limited to 1-3 minutes at the discretion of the Advisory Board Chair(s)*
  - Category 2 Review
  - Advisory Group Category 3 criteria review and deliberation
  - Recap of discussion and consensus check

2:30 Break

- 2:45 Review DRAFT protocol and criteria for removal of disorders
- Review, refine as needed, and perform consensus check

- 4:00 Wrap up and Next Steps
- Next meeting – scheduling and anticipated content
  - Review Advisory Board Work Plan
  - Next Report to Legislature: review process

4:30 Adjourn

The meeting location 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](mailto:NBS.AdvisoryBoard@dhsosha.state.or.us).