



Northwest Regional Newborn Screening Advisory Board Charter

Updated: July 2, 2019

Purpose and Scope of Authority

- I. The purpose of the Northwest Regional Newborn Bloodspot Screening (NWRNBS) Advisory Board (The Board) is to provide advocacy, advice, recommendations, and technical information based on members' respective areas of expertise. The Board shall assist NWRNBS Program with strategic planning and the development of policies, priorities, and services related to newborn screening including the addition or removal of tests; while considering the newborn screening system as a whole, to improve health outcomes for all infants and their families.

Sponsor

- I. *Executive Sponsor*: The executive sponsor of The Board shall be the Center Administrator for the Center for Public Health Practice, in the Public Health Division of the Oregon Health Authority.

Membership, Appointment and Service Terms:

I. **Membership:**

a. *Voting Members:*

- i. *Board Representation*: The Board shall be comprised of 13 voting members from the following:
 1. One member who is a person affected by a disorder included in the newborn screening panel or a family member of a person affected by a disorder included in the newborn screening panel;
 2. One member who is a licensed physician who by contract provides expert medical advice and consulting serves to the Northwest regional Newborn Bloodspot Screening Program;
 3. One member who is a representative of Medicaid or the insurance industry;
 4. Two members who are representatives of birthing centers or hospitals;
 5. One member who is a representative of an entity that contracts with the Northwest Regional Newborn Bloodspot Screening Program for newborn bloodspot screening services;
 6. Three members who are representatives of advocacy associations regarding newborns with medical conditions or rare disorders;

7. One member who is a representative of a statewide association of nurses;
8. One member who is a representative of a statewide association of midwives;
and
9. Two members who are representatives of a statewide association of pediatricians.

ii. *Discipline Representation:* One or more of the following professions must be represented as a voting member of The Board:

1. Neonatal intensive care specialist;
2. Licensed physician or nurse practitioner who is board certified in obstetrics, pediatrics or neonatology;
3. Obstetrician or gynecologist;
4. Nurse;
5. Ethicist;
6. Geneticist;
7. Dietician; and
8. Educator.

iii. *Inclusive Representation:*

1. Newborn Screening touches all infants equally and is a system that requires representation from a diverse set of stakeholders to provide the best outcomes for infants and families. As much as possible, Board representation is intended to capture the diversity of the system to bring a balanced and inclusive view to inform the policies and priorities of the NWRNBS.
2. To the greatest extent practicable, the Board shall have representation from a diverse range of socioeconomic, racial and ethnic backgrounds.

b. *Non-voting members:* Members of the Legislature or employees of the Oregon Health Authority may serve as honorary and non-voting members of The Board.

c. *Subject matter experts:* Subject matter or technical experts may be invited as guests to provide pertinent information for board consideration and contribute their expertise to specific topics of discussion. These subject matter experts shall not vote on board items unless they are already a voting member of The Board.

d. *Board Chairs and Vice Chairs:* The Board will have two Board chairs and one vice chair. One chair will be a voting Board member, the other chair will be the NWRNBS Manager or Manager designee and the vice chair will be a voting Board member. The NWRNBS Manager or Manager designee must be a nonvoting member.

II. Appointment and Service Terms:

a. *Appointment:*

- i. *Appointment:* Board members shall be appointed by the Director of the Oregon Health Authority and serve at the pleasure of the director. Before the expiration of the term of a board member, the director shall appoint a successor whose term begins July 1st next following.

- ii. *Vacancies*: If there is a vacancy, the director shall make an appointment to become effective immediately for the unexpired term.
- b. *Service Terms*:
 - i. *Board Membership terms*:
 - 1. *Initial Board terms*:
 - a. Three members shall serve for a term ending July 1st, 2020
 - b. Three members shall serve for a term ending in July 1st, 2021
 - c. Three members shall serve for a term ending in July 1st, 2022
 - d. Four members shall serve for a term ending in July 1st, 2023.
 - 2. *Routine Board membership*: After initial membership, voting members of The Board shall serve four-year terms. Members are eligible for reappointment.
 - ii. *Voting Board chair and vice chair terms*: The initial term for the chair and vice chair will be one year. After the initial term, the chair and vice-chair selected by The Board will serve a two-year term. Term lengths can be reviewed at the will of The Board.
- c. *Resignation*: Board members can resign their membership by notifying the Director of the Oregon Health Authority and the NWRNBS Manager in writing that they wish to resign their position and the date their resignation will be official.
- d. *Absences*: Board members must inform the co-chairs in advance of a Board meeting if they will be unable to attend. A Board member who is absent for two consecutive Board meetings will be considered to have resigned unless there are exceptional circumstances which have been conveyed to the co-chairs prior to their absence from the second meeting.

Sub-committees

- I. *Formation of Sub-committees*: Sub-committees with a defined purpose can be formed as necessary by the co-chairs.
- II. *Appointment*: The NWRNBS Manager shall appoint members and chairs of sub-committees. These appointments shall be reviewed by The Board chairs.
- III. *Operating Procedures*: Sub-committees will follow the same operating procedures as The Board. Sub-committee chairs shall provide feedback to The Board, as well as sub-committee meeting minutes and necessary reports.
- IV. *Dissolution of Sub-committees*: If it is determined that a sub-committee has fulfilled its purpose, it can be dissolved by the NWRNBS Manager upon recommendation of The Board.

Roles and Responsibilities

Board members bring their expertise from many parts of the newborn screening system including, but not limited to, clinical care, patient/family experience, and public health. Together members can provide a more holistic view of the newborn screening system and are expected to share information gained as a member of The Board with their represented organization, stakeholders, and others in their field.

- I. *All Board Members*: Board members shall:
 - a. Bring an open mind and be prepared to work collaboratively with others.

- b. Review and agree to The Board charter and operations.
 - c. Sign a Conflict of Interest Disclosure form yearly.
 - d. Attend Board meetings either in person or by teleconference.
 - e. Inform the NWRNBS Manager of Board meeting absences in advance.
 - f. Review Board meeting materials and participate in Board meetings in representation of their expertise to provide advice and recommendations.
 - g. Participate in Rule Advisory Committees (RACs) for Newborn Screening rule changes.
- II. *Board Chairs and Vice Chair*. Board chairs and vice-chair shall:
- a. Ensure a respectful, professional, and welcoming environment to encourage participation and collaboration
 - b. Assist in the creation of meeting agendas and meeting materials when appropriate.
 - c. Confirm sub-committee members.

Meeting Logistics and Operating Procedures:

I. Meetings

- a. *Frequency*: The Board shall meet at least once every six months. The Board may hold additional meetings by the call of one or both of the chairpersons or of a majority of the voting members of The Board.
- b. *Location*: The Board shall meet at a time and location determined by The Board. One meeting each year shall be an in-person meeting where all Board members shall attend in-person except for exceptional circumstances or as otherwise determined by The Board. All other meetings shall be attended remotely unless otherwise determined by the Board.
- c. *Absences*: Board members must inform the co-chairs in advance of a Board meeting if they will be unable to attend. If a Board member knows they will be absent, they can submit written comments to the NWRNBS Manager in advance of The Board meeting.
- d. *Open to Public*: Board meetings shall be open to the public and adhere to Public Meeting requirements.
- e. *Compensation*: Voting board members are entitled to compensation and expenses as provided in ORS 292.495.

II. Operating Procedures

- a. *Voting on Board items*:
 - i. *Quorum*: A majority of the voting members of the board constitutes a quorum for the transaction of business. Each Board member has one vote and cannot vote in absentia.
 - ii. *Consensus*: The Board will strive for consensus on recommendations provided to the NWRNBS Program and the Legislature.

Consensus is defined as “all group members can live with the recommendation or decision.” Instead of simply voting for an item and having the majority of the group getting their way, a group using consensus is committed to finding solutions that everyone actively supports, or at least can live with.

A consensus tool using a range of 1-5 will be used to signify whether the group has reached agreement *and* the level of agreement on a given proposal which can inform the group, and the Agency, whether more work is needed to refine the proposal toward a stronger agreement.

Given the scale below:

- A **strong** consensus is one in which all or most Board members show 1's and 2's on a given proposal.
- A **weak** consensus is one in which some or several Board members show 3's and 4's.
- If anyone in the group shows a "5", the group **does not have consensus**.
- For weak or no consensus, the Advisory Board will frame up the points of divergence or minority perspectives on a given proposal.

The levels are:

"1" I enthusiastically agree with the proposal/recommendation.

"2" I agree with the proposal/recommendation.

"3" I am on the fence, have questions, or am neutral but can live with the proposal.

"4" I have serious questions or concerns, but am not willing to block the proposal.

"5" I object and will block the proposal.

- Open comment period:* During every Board meeting there shall be a period for open public comments. The length shall be determined by the Board chairs.
- Onboarding of new Board members:* New Board members shall review The Board charter and sign a conflict of interest form.

Reports

I. Reports

- Initial Report:* No later than December 15th, 2019 the Board shall conduct its first meeting and report its findings, which may include recommendations for legislative changes, to the committees or interim committees of the Legislative Assembly related to health.
- Subsequent Reports:* The Board shall report its findings and recommendations for legislative changes to the committees or interim committees of the Legislative Assembly related to health no later than September 15th of each even numbered year.

Values

- Respect – we value all members and welcome the uniqueness and diversity of their experience and viewpoints because it allows us to consider all sides of an issue.
- Inclusivity – we actively search for partners that will help represent diverse communities and viewpoints so that we can work for all infants and their families.
- Candor – honesty and willingness to share information are essential to the communication that will allow us to build a system that works to ensure the health of all infants and their families.
- Collaboration – working collaboratively allows us to leverage each person's strengths and brings balance to our discussions and recommendations.