House Bill 4109
Ordered by the House February 16
Including House Amendments dated February 16
Sponsored by Representative MCLAIN; Representatives ALONSO LEON, GRAYBER, HELM, HUDSON, LEVY, PHAM, POWER, PRUSAK, RUIZ, SCHOUTEN, SMITH DB, WEBER, WILDE, WILLIAMS, Senators FREDERICK, KENNEMER, PROZANSKI (Presession filed.)

SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure.

Directs Newborn Bloodspot Screening Advisory Board to evaluate and make recommendations on adding diseases to Oregon newborn bloodspot screening panel under specific circumstances. Requires board to meet at least four times per calendar year. Subjects board meetings to public meetings law. Requires board to submit annual report to Legislative Assembly. Modifies certain board membership requirements.

A BILL FOR AN ACT
Relating to newborn bloodspot screening; creating new provisions; and amending ORS 433.299.
Be It Enacted by the People of the State of Oregon:
SECTION 1. ORS 433.299 is amended to read:
433.299. (1) The Newborn Bloodspot Screening Advisory Board is established in the Oregon Health Authority.
(2) The board consists of 13 voting members appointed by the Director of the Oregon Health Authority as follows:
(a) 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;
(b) One member who is a licensed physician who by contract provides expert medical advice and consulting services to the Northwest Regional Newborn Bloodspot Screening Program;
(c) One member who is a representative of Medicaid or the insurance industry;
(d) Two members who are representatives of birthing centers or hospitals;
(e) One member who is a representative of [an entity that contracts with] a federally recognized tribe in Oregon that uses the services of the Northwest Regional Newborn Bloodspot Screening Program for newborn bloodspot screening services;
(f) Three members who are representatives of advocacy associations regarding newborns with medical conditions or rare disorders;
(g) One member who is a [representative of a statewide association of nurses] licensed nurse;
(h) One member who is a [representative of a statewide association of midwives] licensed midwife; and
(i) Two members who are [representatives of a statewide association of] licensed pediatricians.
(3) In addition to the requirements provided in subsection (2) of this section, one or more of the following professions must be represented as a voting member of the board:

NOTE: Matter in boldfaced type in an amended section is new; matter [italic and bracketed] is existing law to be omitted. New sections are in boldfaced type.

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(a) Neonatal intensive care specialist;
(b) Licensed physician or nurse practitioner who is board certified in obstetrics, pediatrics or
neonatology;
(c) Obstetrician or gynecologist;
(d) Nurse;
(e) Ethicist;
(f) Geneticist;
(g) Dietician; and
(h) Educator.

(4) To the greatest extent practicable, the director shall appoint members from a diverse range
of socioeconomic, racial and ethnic backgrounds.

(5) In addition to the 13 voting members provided for in subsection (2) of this section, members
of the Legislative Assembly or employees of the Oregon Health Authority may serve as nonvoting
members.

(6) The term of office of each voting member of the board is [four] two years, but a member
serves at the pleasure of the director. Before the expiration of the term of a member, the director
shall appoint a successor whose term begins on July 1 next following. A member is eligible for re-
appointment. If there is a vacancy for any cause, the director shall make an appointment to become
immediately effective for the unexpired term.

(7) A voting member of the board is entitled to compensation and expenses as provided in ORS
292.495.

(8) The board shall select two of its members to jointly serve as chairpersons and another as
vice chairperson, for terms and with duties and powers necessary for the performance of the func-
tions of the offices as the board determines. [One chairperson must be a voting member and the other
chairperson must be the manager of the Northwest Regional Newborn Bloodspot Screening Program
or the manager's designee. The manager or manager's designee must be a nonvoting member.] At least
one chairperson must be a voting member of the board.

(9) A majority of the voting members of the board constitutes a quorum for the transaction of
business.

(10) The board shall meet at least [once every six months] four times per calendar year at a
time and place determined by the board. The board also may meet at other times and places speci-
fied by the call of one or both chairpersons or of a majority of the voting members of the board.

All meetings of the board must be conducted pursuant to ORS 192.610 to 192.690.

(11) The board shall report its findings and recommendations, which may include recommend-
dations for legislative changes, to the committees or interim committees of the Legislative Assembly
related to health in the manner provided under ORS 192.245 no later than September 15 of each
[even-numbered] year. The report required by this subsection must provide a detailed explana-
tion of the information, standards and reasons underlying the board's decision, if any, to add
a disease to the Oregon newborn bloodspot screening panel, to remove a disease from the
Oregon newborn bloodspot screening panel or to take no action on a disease following con-
sideration or evaluation of the disease.

SECTION 2. The Newborn Bloodspot Screening Advisory Board shall evaluate and make
recommendations to the Oregon Health Authority on adding a disease to the Oregon newborn
bloodspot screening panel if:

(1) Ten or more states have already added the disease to the states' respective screening
panels; or

(2) The federal Advisory Committee on Heritable Disorders in Newborns and Children votes to initiate an evidence review of the disease.

SECTION 3. Section 2 (2) of this 2022 Act applies to diseases for which a vote to initiate an evidence review is commenced on or after January 1, 2021.