

# House Bill 4109

Sponsored by Representative MCLAIN; Representatives ALONSO LEON, GRAYBER, HELM, HUDSON, LEVY, PHAM, POWER, PRUSAK, RUIZ, SCHOUTEN, SMITH DB, 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 **as introduced**.

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

1  
2 Relating to newborn bloodspot screening; creating new provisions; and amending ORS 433.299.

3 **Be It Enacted by the People of the State of Oregon:**

4 **SECTION 1.** ORS 433.299 is amended to read:

5 433.299. (1) The Newborn Bloodspot Screening Advisory Board is established in the Oregon  
6 Health Authority.

7 (2) The board consists of 13 voting members appointed by the Director of the Oregon Health  
8 Authority as follows:

9 (a) One member who is a person affected by a disorder included in the newborn screening panel  
10 or a family member of a person affected by a disorder included in the newborn screening panel;

11 (b) One member who is a licensed physician who by contract provides expert medical advice and  
12 consulting services to the Northwest Regional Newborn Bloodspot Screening Program;

13 (c) One member who is a representative of Medicaid or the insurance industry;

14 (d) Two members who are representatives of birthing centers or hospitals;

15 (e) One member who is a representative of [*an entity that contracts with*] **a federally recognized**  
16 **tribe in Oregon that uses the services of** the Northwest Regional Newborn Bloodspot Screening  
17 Program for newborn bloodspot screening services;

18 (f) Three members who are representatives of advocacy associations regarding newborns with  
19 medical conditions or rare disorders;

20 (g) One member who is a [*representative of a statewide association of nurses*] **licensed nurse**;

21 (h) One member who is a [*representative of a statewide association of midwives*] **licensed**  
22 **midwife**; and

23 (i) Two members who are [*representatives of a statewide association of*] **licensed** pediatricians.

24 (3) In addition to the requirements provided in subsection (2) of this section, one or more of the  
25 following professions must be represented as a voting member of the board:

26 (a) Neonatal intensive care specialist;

27 (b) Licensed physician or nurse practitioner who is board certified in obstetrics, pediatrics or  
28 neonatology;

**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.

- 1 (c) Obstetrician or gynecologist;
- 2 (d) Nurse;
- 3 (e) Ethicist;
- 4 (f) Geneticist;
- 5 (g) Dietician; and
- 6 (h) Educator.

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

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

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

17 (7) A voting member of the board is entitled to compensation and expenses as provided in ORS  
18 292.495.

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

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

27 (10) The board shall meet at least [*once every six months*] **four times per calendar year** at a  
28 time and place determined by the board. The board also may meet at other times and places speci-  
29 fied by the call of one or both chairpersons or of a majority of the voting members of the board.  
30 **All meetings of the board must be conducted pursuant to ORS 192.610 to 192.690.**

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

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

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

44 (2) **A nomination for inclusion of the disease on the Recommended Uniform Screening**  
45 **Panel has been submitted to the federal Advisory Committee on Heritable Disorders in**

1 **Newborns and Children.**

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