

House Bill 2617

Sponsored by Representative MCLAIN; Representatives GAMBA, HARTMAN, NOSSE, Senators PATTERSON, WOODS (Pre-session 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 Oregon Health Authority, in consultation with Newborn Bloodspot Screening Advisory Board, to adopt rules for board to evaluate and recommend adding disease to or removing disease from newborn bloodspot screening panel or taking no action on disease. Requires board to evaluate and make recommendations pursuant to rules, including rules for public request process. Requires board to meet at least four times per calendar year and to submit biennial report to Legislative Assembly. Shortens term of office of board member to two years. Limits reappointment. Modifies board membership and requirements. Subjects board meetings to public meetings law. Waives fees for parents or guardians who pay out of pocket for newborn bloodspot screening services.

Requires authority to consider, and to greatest extent practicable implement, screening for disease no later than 18 months after federal committee recommends adding disease to federal Recommended Uniform Screening Panel. Directs authority to complete pilot study to demonstrate standards, criteria and processes for determining whether to add disease to newborn bloodspot screening panel and to report to Legislative Assembly on findings and recommendations for improvements.

Declares emergency, effective on passage.

A BILL FOR AN ACT

1
2 Relating to newborn bloodspot screening; creating new provisions; amending ORS 433.285 and
3 433.299; and declaring an emergency.

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

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

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

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

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

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

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

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

17 *[(e) One member who is a representative of an entity that contracts with the Northwest Regional*
18 *Newborn Bloodspot Screening Program for newborn bloodspot screening services;]*

19 **(e) One member who is a representative of a federally recognized Indian tribe in Oregon**
20 **that uses the newborn bloodspot screening services of the Northwest Regional Newborn**
21 **Bloodspot Screening Program;**

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

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 (g) One member who is a [*representative of a statewide association of nurses*] **licensed nurse**;
- 2 (h) One member who is a [*representative of a statewide association of midwives*] **licensed**
- 3 **midwife**; and
- 4 (i) Two members who are [*representatives of a statewide association of*] **licensed** pediatricians.
- 5 (3) In addition to the requirements provided in subsection (2) of this section, one or more of the
- 6 following professions must be represented as a voting member of the board:
- 7 (a) Neonatal intensive care specialist;
- 8 (b) Licensed physician or nurse practitioner who is board certified in obstetrics[, *pediatrics*] or
- 9 neonatology;
- 10 (c) Obstetrician or gynecologist;
- 11 [*(d) Nurse*];
- 12 [*(e)*] **(d)** Ethicist;
- 13 [*(f)*] **(e)** Geneticist;
- 14 [*(g)*] **(f)** Dietician; and
- 15 [*(h)*] **(g)** Educator.
- 16 (4) To the greatest extent practicable, the director shall appoint members from a diverse range
- 17 of socioeconomic, racial and ethnic backgrounds.
- 18 (5) In addition to the 13 voting members provided for in subsection (2) of this section, members
- 19 of the Legislative Assembly or employees of the Oregon Health Authority may serve as nonvoting
- 20 members.
- 21 (6) The term of office of each voting member of the board is [*four*] **two** years, but a member
- 22 serves at the pleasure of the director. Before the expiration of the term of a member, the director
- 23 shall appoint a successor whose term begins on July 1 next following. A member is eligible for re-
- 24 appointment **one time only**. If there is a vacancy for any cause, the director shall make an ap-
- 25 pointment to become immediately effective for the unexpired term.
- 26 (7) A voting member of the board is entitled to compensation and expenses as provided in ORS
- 27 292.495.
- 28 (8) The board shall select two of its members to jointly serve as chairpersons and another as
- 29 vice chairperson, for terms and with duties and powers necessary for the performance of the func-
- 30 tions of the offices as the board determines. [*One chairperson must be a voting member and the other*
- 31 *chairperson must be the manager of the Northwest Regional Newborn Bloodspot Screening Program*
- 32 *or the manager's designee. The manager or manager's designee must be a nonvoting member.*] **At least**
- 33 **one chairperson must be a voting member of the board.**
- 34 (9)(a) A majority of the voting members of the board constitutes a quorum for the transaction
- 35 of business.
- 36 **(b) Opinions expressed by a member of the board in carrying out the duties of the board**
- 37 **are the member's opinions and do not represent the opinions of any entity with which the**
- 38 **member works or volunteers.**
- 39 (10) The board shall meet at least [*once every six months*] **four times per calendar year** at a
- 40 time and place determined by the board. The board also may meet at other times and places speci-
- 41 fied by the call of one or both chairpersons or of a majority of the voting members of the board.
- 42 **All meetings of the board must be conducted pursuant to ORS 192.610 to 192.690.**
- 43 (11) The board shall report its findings and recommendations, **which may include recommen-**
- 44 **dations** for legislative changes, to the committees or interim committees of the Legislative Assembly
- 45 related to health in the manner provided under ORS 192.245 no later than September 15 of each

1 *[even-numbered]* odd-numbered year. The report required by this subsection must provide a
 2 detailed explanation of the information, standards and reasons underlying the board's rec-
 3 ommendation, if any, to add a disease to the newborn bloodspot screening panel, to remove
 4 a disease from the newborn bloodspot screening panel or to take no action on a disease fol-
 5 lowing evaluation of the disease.

6 **SECTION 2.** (1) To advance the public health policy described in ORS 433.285, the Oregon
 7 Health Authority, in consultation with the Newborn Bloodspot Screening Advisory Board,
 8 shall by rule establish standards, criteria and processes for:

9 (a) The board to evaluate and recommend to the authority whether to add a disease to
 10 the newborn bloodspot screening panel, to remove a disease from the newborn bloodspot
 11 screening panel or to take no action on a disease following evaluation of the disease.

12 (b) Members of the public to request that the board subject a disease to the evaluation
 13 and recommendation process established by rule under paragraph (a) of this subsection.

14 (c) The board to determine whether to subject a disease, as requested by a member of
 15 the public under paragraph (b) of this subsection, to the evaluation and recommendation
 16 process established by rule under paragraph (a) of this subsection.

17 (2) The authority may exercise discretion to decide whether to adopt by rule a recom-
 18 mendation received from the board under subsection (3) of this section.

19 (3)(a) Except as provided in paragraph (b) of this subsection, the board shall evaluate a
 20 disease and make recommendations to the authority in accordance with rules adopted by the
 21 authority under subsection (1) of this section.

22 (b) The board may not subject more than three diseases at any given time to the evalu-
 23 ation and recommendation process established by rule under subsection (1) of this section.

24 (4) The authority shall consider, and to the greatest extent practicable shall implement,
 25 screening for a new disease under the newborn bloodspot screening program no later than
 26 18 months after the date on which the federal Advisory Committee on Heritable Disorders
 27 in Newborns and Children recommends adding the disease to the federal Recommended Uni-
 28 form Screening Panel by sending a letter to the United States Secretary of Health and Hu-
 29 man Services.

30 **SECTION 3.** (1) As a pilot study to demonstrate the standards, criteria and processes the
 31 Oregon Health Authority uses to determine whether a disease should be added to the new-
 32 born bloodspot screening panel, the authority shall evaluate and decide whether Krabbe dis-
 33 ease, Mucopolysaccharidosis type II (MPS II) and Guanidinoacetate methyltransferase
 34 deficiency (GAMT) should be added to the newborn bloodspot screening panel.

35 (2) The authority shall submit a preliminary report and a final report, in the manner
 36 provided in ORS 192.245, to the interim committees of the Legislative Assembly related to
 37 health, that contain:

38 (a) A description of the standards, criteria and processes used to determine whether
 39 Krabbe disease, Mucopolysaccharidosis type II (MPS II) or Guanidinoacetate
 40 methyltransferase deficiency (GAMT) should be added to the newborn bloodspot screening
 41 panel and any recommendations to improve those standards, criteria and processes;

42 (b) Recommendations, if any, on adding Krabbe disease, Mucopolysaccharidosis type II
 43 (MPS II) or Guanidinoacetate methyltransferase deficiency (GAMT) to the newborn bloodspot
 44 screening panel; and

45 (c) Proposed policies to carry out section 2 (1) of this 2023 Act.

1 **(3)(a) The authority shall submit the preliminary report no later than September 15, 2024.**

2 **(b) The authority shall submit the final report no later than September 15, 2025, as part**
 3 **of the report required under ORS 433.299 (1).**

4 **SECTION 4.** ORS 433.285 is amended to read:

5 433.285. (1) It hereby is declared to be a matter of public policy of the State of Oregon that in
 6 the interest of public health and the prevention of mental [*retardation*] **disorder**, every infant, shall
 7 be given tests approved by the Oregon Health Authority for the detection of the disease of
 8 phenylketonuria and other metabolic diseases.

9 (2) The authority by rule shall specify the diseases for which infants shall be tested under sub-
 10 section (1) of this section, the appropriate time following delivery for collecting specimens, the
 11 manner in which the specimens are to be submitted, the persons responsible for submitting the
 12 specimens, the methods of testing and the manner of payment of the fees.

13 (3) The testing required by subsection (1) of this section shall not be required if the infant is
 14 being reared as an adherent to a religion the teachings of which are opposed to such testing. The
 15 person responsible for submitting specimens under the rules of the authority shall be responsible for
 16 submitting a statement signed by the infant's parent that the infant is being so reared. The au-
 17 thority by rule shall prescribe the form of the statement.

18 (4) The authority shall adopt by rule a procedure whereby the fees established under subsection
 19 (2) of this section shall be waived **for:**

20 **(a) Parents or guardians of an infant who pay the fees out of pocket; and**

21 **(b) Parents or guardians of an infant who are indigent or otherwise unable to pay the**
 22 **fees.** [*and no infant refused service because of the parent's inability to pay the fee.*]

23 (5) The authority by rule shall prescribe the procedure to be followed in cases where initial
 24 testing for metabolic diseases is administered too early to detect these diseases, where the sample
 25 submitted for testing is improperly collected and where a sample shows an abnormal result. The
 26 authority, within the limits of funds available from fees collected under this section, shall institute
 27 a pilot program for follow-up on abnormal test results.

28 **SECTION 5. (1) The amendments to ORS 433.299 by section 1 of this 2023 Act become**
 29 **operative July 1, 2024.**

30 **(2) On June 30, 2024, the term of office for existing members of the Newborn Bloodspot**
 31 **Screening Advisory Board shall cease.**

32 **(3) A member whose term of office has ceased under subsection (2) of this section is el-**
 33 **igible for reappointment to the board.**

34 **(4) The Director of the Oregon Health Authority shall appoint 13 new members to the**
 35 **board on July 1, 2024.**

36 **(5) Notwithstanding the term of office specified in ORS 433.299, of the members appointed**
 37 **to the board under subsection (4) of this section:**

38 **(a) Seven shall serve for a term ending June 30, 2025; and**

39 **(b) Six shall serve for a term ending June 30, 2026.**

40 **SECTION 6.** Section 5 of this 2023 Act is repealed on January 2, 2027.

41 **SECTION 7.** Section 2 (4) of this 2023 Act applies to diseases for which the federal Advi-
 42 sory Committee on Heritable Disorders in Newborns and Children sends a recommendation
 43 letter to the United States Secretary of Health and Human Services on or after January 1,
 44 2022.

45 **SECTION 8.** This 2023 Act being necessary for the immediate preservation of the public

1 **peace, health and safety, an emergency is declared to exist, and this 2023 Act takes effect**
2 **on its passage.**

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