

A-Engrossed
House Bill 2617

Ordered by the House March 13
Including House Amendments dated March 13

Sponsored by Representative MCLAIN; Representatives GAMBA, HARTMAN, NOSSE, Senators PATTERSON, WOODS (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 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.]* **Waives newborn bloodspot screening fees for parents or guardians who pay out of pocket birthing fees as defined by rule by authority or who are indigent or otherwise unable to pay newborn bloodspot screening fees.**

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;]*

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

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

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

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

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

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

12 (a) Neonatal intensive care specialist;

13 (b) Licensed physician or nurse practitioner who is board certified in obstetrics[, *pediatrics*] or
14 neonatology;

15 (c) Obstetrician or gynecologist;

16 [*(d) Nurse;*]

17 [*(e)*] **(d)** Ethicist;

18 [*(f)*] **(e)** Geneticist;

19 [*(g)*] **(f)** Dietician; and

20 [*(h)*] **(g)** Educator.

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

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

26 (6) The term of office of each voting member of the board is [*four*] **two** years, but a member
27 serves at the pleasure of the director. Before the expiration of the term of a member, the director
28 shall appoint a successor whose term begins on July 1 next following. A member is eligible for re-
29 appointment. **If a person serves two consecutive full terms, a period of at least four years**
30 **must elapse before the person is again eligible for appointment to serve on the board.** If there
31 is a vacancy for any cause, the director shall make an appointment to become immediately effective
32 for the unexpired term.

33 (7) A voting member of the board is entitled to compensation and expenses as provided in ORS
34 292.495.

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

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

43 **(b) Opinions expressed by a member of the board in carrying out the duties of the board**
44 **are the member's opinions and do not represent the opinions of any entity with which the**
45 **member works or volunteers.**

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

5 (11) The board shall report its findings and recommendations, **which may include recommen-**
6 **dations** for legislative changes, to the committees or interim committees of the Legislative Assembly
7 related to health in the manner provided under ORS 192.245 no later than September 15 of each
8 [*even-numbered*] **odd-numbered** year. **The report required by this subsection must provide a**
9 **detailed explanation of the information, standards and reasons underlying the board's rec-**
10 **ommendation, if any, to add a disease to the newborn bloodspot screening panel, to remove**
11 **a disease from the newborn bloodspot screening panel or to take no action on a disease fol-**
12 **lowing evaluation of the disease.**

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

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

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

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

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

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

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

31 (4) The authority shall consider, and to the greatest extent practicable shall implement,
32 screening for a new disease under ORS 433.285 no later than 18 months after the date on
33 which the federal Advisory Committee on Heritable Disorders in Newborns and Children re-
34 commends adding the disease to the federal Recommended Uniform Screening Panel by
35 sending a letter to the United States Secretary of Health and Human Services.

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

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

44 (a) A description of the standards, criteria and processes used to determine whether
45 Krabbe disease, Mucopolysaccharidosis type II (MPS II) or Guanidinoacetate

1 **methyltransferase deficiency (GAMT) should be added to the newborn bloodspot screening**
2 **panel and any recommendations to improve those standards, criteria and processes;**

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

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

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

8 **(b) The authority shall submit the final report no later than September 15, 2025, as part**
9 **of the report required under ORS 433.299 (11).**

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

11 433.285. (1) It hereby is declared to be a matter of public policy of the State of Oregon that in
12 the interest of public health and the prevention of mental [retardation] **disorder**, every infant, shall
13 be given tests approved by the Oregon Health Authority for the detection of the disease of
14 phenylketonuria and other metabolic diseases.

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

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

24 (4) The authority shall adopt by rule a procedure whereby the **newborn bloodspot screening**
25 **fees established under subsection (2) of this section shall be waived for:**

26 **(a) Parents or guardians of an infant who pay out of pocket the birthing fees of the infant**
27 **as defined by rule; and**

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

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

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

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

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

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

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

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

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

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

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

8 **SECTION 8.** This 2023 Act being necessary for the immediate preservation of the public
9 peace, health and safety, an emergency is declared to exist, and this 2023 Act takes effect
10 on its passage.

11
