## A-Engrossed House Bill 2563

Ordered by the House March 25 Including House Amendments dated March 25

Sponsored by Representatives MCLAIN, SOLLMAN, SCHOUTEN, HAYDEN; Representatives ALONSO LEON, KENY-GUYER, NOBLE, NOSSE, PRUSAK, SALINAS, SMITH WARNER, WILLIAMS, WITT (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 to adopt rules requiring infants to be screened to detect certain diseases.]

[Takes effect on 91st day following adjournment sine die.] Establishes Newborn Bloodspot Screening Advisory Board in Oregon Health Authority. Declares emergency, effective on passage.

A BILL FOR AN ACT

2 Relating to screening newborns for diseases; and declaring an emergency.

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

4 <u>SECTION 1.</u> (1) The Newborn Bloodspot Screening Advisory Board is established in the

5 **Oregon Health Authority.** 

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

8 (a) One member who is a person affected by a disorder included in the newborn screening

9 panel or a family member of a person affected by a disorder included in the newborn 10 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;

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

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

16 (e) One member who is a representative of an entity that contracts with the Northwest

17 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;

20 (g) One member who is a representative of a statewide association of nurses;

21 (h) One member who is a representative of a statewide association of midwives; and

22 (i) Two members who are representatives of a statewide association of pediatricians.

23 (3) In addition the requirements provided in subsection (2) of this section, one or more

24 of the following professions must be represented as a voting member of the board:

- 25 (a) Neonatal intensive care specialist;
- 26 (b) Licensed physician or nurse practitioner who is board certified in obstetrics,

1 pediatrics or neonatology;

2 (c) Obstetrician or gynecologist;

3 (d) Nurse;

4 (e) Ethicist;

5 (f) Geneticist;

6 (g) Dietician; and

(h) Educator.

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8 (4) To the greatest extent practicable, the director shall appoint members from a diverse 9 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 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 reappointment. 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 functions 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.

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

(10) The board shall meet at least once every six months at a time and place determined
by the board. The board also may meet at other times and places specified by the call of one
or both chairpersons or of a majority of the voting members of the board.

(11) The board shall report its findings and recommendations 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.
 <u>SECTION 2.</u> Notwithstanding the term of office specified by section 1 of this 2019 Act,

35 of the members first appointed to the Newborn Bloodspot Screening Advisory Board:

36 (1) Three shall serve for a term ending July 1, 2020.

37 (2) Three shall serve for a term ending July 1, 2021.

38 (3) Three shall serve for a term ending July 1, 2022.

39 (4) Four shall serve for a term ending July 1, 2023.

40 <u>SECTION 3.</u> No later than December 15, 2019, the Newborn Bloodspot Screening Advisory 41 Board shall conduct its first meeting and report its findings, which may include recommen-42 dations for legislative changes, to the committees or interim committees of the Legislative 43 Assembly related to health.

44 <u>SECTION 4.</u> This 2019 Act being necessary for the immediate preservation of the public 45 peace, health and safety, an emergency is declared to exist, and this 2019 Act takes effect A-Eng. HB 2563

- 1 on its passage.
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