

Senate Bill 808

Sponsored by Senators BOQUIST, BEYER, Representatives BUEHLER, PARRISH; Senators DEVLIN, KRUSE, MONNES ANDERSON, OLSEN, ROBLAN, THOMSEN, Representatives BARNHART, HEARD, KENNEMER, KENY-GUYER, LIVELY, MALSTROM, NOSSE, WITT (at the request of Jennifer Knapp, Dean Suhr, National Organization for Rare Disorders)

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**.

Provides that with respect to health screen testing for newborns, Oregon Health Authority shall specify that health testing service may conduct tests for conditions listed on most recent edition of Recommended Uniform Screening Panel by United States Department of Health and Human Services.

Establishes Review Committee on Health Screen Testing for Newborns for purposes of studying, evaluating and making proposals related to health screen testing of newborns.

Sunsets committee on December 31, 2018.

Takes effect on 91st day following adjournment sine die.

A BILL FOR AN ACT

1
2 Relating to screening newborns; and prescribing an effective date.

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

4 **SECTION 1. Section 2 of this 2017 Act is added to and made a part of ORS 438.010 to**
5 **438.510.**

6 **SECTION 2. (1) With respect to health screen testing for newborns, in adopting rules**
7 **pursuant to ORS 438.150 (6)(d), the Oregon Health Authority shall specify that a health**
8 **testing service may conduct tests for conditions listed on the most recent edition of the**
9 **Recommended Uniform Screening Panel by the United States Department of Health and**
10 **Human Services.**

11 **(2) For purposes of complying with subsection (1) of this section, when a condition is**
12 **added to the Recommended Uniform Screening Panel by the United States Department of**
13 **Health and Human Services, the authority shall adopt rules specifying the tests that a health**
14 **testing service may conduct for that condition as soon as practicable, and no later than two**
15 **years, after the date on which the condition was added to the Recommended Uniform**
16 **Screening Panel.**

17 **SECTION 3. (1) For purposes of this section, "health screen testing" has the meaning**
18 **given that term in ORS 438.010.**

19 **(2) The Review Committee on Health Screen Testing for Newborns is established.**

20 **(3) The committee consists of nine members appointed as follows:**

21 **(a) The President of the Senate shall appoint one nonvoting member from among mem-**
22 **bers of the Senate.**

23 **(b) The Speaker of the House of Representatives shall appoint one nonvoting member**
24 **from among members of the House of Representatives.**

25 **(c) The Governor shall appoint:**

26 **(A) Two individuals representing the Northwest Regional Newborn Screening Program;**

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 (B) One individual representing the Public Health Division of the Oregon Health Author-
 2 ity;

3 (C) One individual representing local public health authorities as defined in ORS 431.003;

4 (D) One individual representing health care practitioners who specialize in newborn care;
 5 and

6 (E) Two members of the public.

7 (4) With respect to health screen testing for newborns, the committee shall study, eval-
 8 uate and make proposals regarding:

9 (a) The availability of tests conducted by health screen testing facilities;

10 (b) Processes used to determine which tests should be conducted by health screen testing
 11 facilities;

12 (c) Processes used to monitor, or to follow up on the testing of, newborns with a late
 13 onset condition detected by a test;

14 (d) The feasibility of conducting tests other than tests involving blood screening or tan-
 15 dem mass spectrometry screening;

16 (e) The potential impact of genomic sequencing on tests;

17 (f) Reimbursement for, and processes used to update the reimbursement for, tests a
 18 health testing service conducts;

19 (g) The adequacy of the Northwest Regional Newborn Screening Program's total number
 20 of staff, on-the-job training, equipment and available space;

21 (h) The current method of funding the authority's duties under ORS 438.010 to 438.510
 22 and alternatives to that method; and

23 (i) Any other matter related to health screen testing for newborns.

24 (5) A majority of the voting members of the committee constitutes a quorum for the
 25 transaction of business.

26 (6) Official action by the committee requires the approval of a majority of the voting
 27 members of the committee.

28 (7) The committee shall elect one of its members to serve as chairperson.

29 (8) If there is a vacancy for any cause, the appointing authority shall make an appoint-
 30 ment to become immediately effective.

31 (9) The committee shall meet at times and places specified by the call of the chairperson
 32 or of a majority of the members of the committee.

33 (10) The committee may adopt rules necessary for the operation of the committee.

34 (11) The committee shall submit a report in the manner provided by ORS 192.245, and
 35 may include recommendations for legislation, to an interim committee of the Legislative
 36 Assembly related to health no later than September 15, 2018.

37 (12) The Oregon Health Authority shall provide staff support to the committee.

38 (13) Members of the committee who are not members of the Legislative Assembly are
 39 not entitled to compensation or reimbursement for expenses and serve as volunteers on the
 40 committee.

41 (14) All agencies of state government, as defined in ORS 174.111, are directed to assist
 42 the committee in the performance of the committee's duties and, to the extent permitted
 43 by laws relating to confidentiality, to furnish information and advice the members of the
 44 committee consider necessary to perform their duties.

45 **SECTION 4.** Section 3 of this 2017 Act is repealed on December 31, 2018.

1 **SECTION 5.** This 2017 Act takes effect on the 91st day after the date on which the 2017
2 regular session of the Seventy-ninth Legislative Assembly adjourns sine die.
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