

**A-Engrossed**  
**Senate Bill 808**

Ordered by the Senate April 24  
Including Senate Amendments dated April 24

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.

Provides that with respect to *[health screen testing for newborns]* **newborn screening**, Oregon Health Authority shall specify that *[health testing service]* **person providing newborn screening** may conduct tests for conditions listed on most recent edition of Recommended Uniform Screening Panel by United States Department of Health and Human Services. **Specifies that person providing newborn screening shall test for certain condition through implementation of laboratory developed test approved by federal Food and Drug Administration, under certain circumstances.**

Establishes Review Committee on *[Health Screen Testing for Newborns]* **Newborn Screening** for purposes of studying, evaluating and making proposals related to *[health screen testing of newborns.]* **newborn screening.**

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. (1) For purposes of this section, “newborn screening” has the meaning given**  
5 **that term by the Oregon Health Authority by rule.**

6 **(2) With respect to newborn screening, in adopting rules pursuant to ORS 433.285, the**  
7 **authority shall specify that a person providing newborn screening may conduct tests for**  
8 **conditions listed on the most recent edition of the Recommended Uniform Screening Panel**  
9 **by the United States Department of Health and Human Services.**

10 **(3) For purposes of complying with subsection (1) of this section, when a condition is**  
11 **added to the Recommended Uniform Screening Panel by the United States Department of**  
12 **Health and Human Services, the authority shall adopt rules specifying the tests that a person**  
13 **providing newborn screening may conduct for that condition as soon as practicable, and no**  
14 **later than two years, after either the date on which the condition was added to the Recom-**  
15 **mended Uniform Screening Panel or the date on which the federal Food and Drug Adminis-**  
16 **tration approves a methodology for a test that a person providing newborn screening may**  
17 **conduct for that condition, whichever is later.**

18 **(4) In the event that a condition was added to the Recommended Uniform Screening**  
19 **Panel by the United States Department of Health and Human Services and the federal Food**  
20 **and Drug Administration has not approved a methodology for a test that a person providing**

**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 newborn screening may conduct for that condition, a person providing newborn screening  
2 shall, to the extent practicable, implement a laboratory developed test approved by the fed-  
3 eral Food and Drug Administration not later than three years after the date on which the  
4 condition was added.

5 **SECTION 2.** (1) For purposes of this section, “newborn screening” has the meaning given  
6 that term by the Oregon Health Authority by rule.

7 (2) The Review Committee on Newborn Screening is established.

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

9 (a) The President of the Senate shall appoint one nonvoting member from among mem-  
10 bers of the Senate.

11 (b) The Speaker of the House of Representatives shall appoint one nonvoting member  
12 from among members of the House of Representatives.

13 (c) The Governor shall appoint:

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

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

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

18 (D) One individual representing health care practitioners who specialize in newborn care;  
19 and

20 (E) Two members of the public.

21 (4) With respect to newborn screening, the committee shall study, evaluate and make  
22 proposals regarding:

23 (a) The availability of tests conducted by newborn screening facilities;

24 (b) Processes used to determine which tests should be conducted by newborn screening  
25 facilities;

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

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

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

31 (f) Reimbursement for, and processes used to update the reimbursement for, tests a  
32 person providing newborn screening conducts;

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

35 (h) The current method of funding the authority’s duties with respect to newborn  
36 screening and alternatives to that method; and

37 (i) Any other matter related to newborn screening.

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

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

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

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

45 (9) The committee shall meet at times and places specified by the call of the chairperson

1 or of a majority of the members of the committee.

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

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

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

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

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

14 SECTION 3. Section 2 of this 2017 Act is repealed on December 31, 2018.

15 SECTION 4. This 2017 Act takes effect on the 91st day after the date on which the 2017  
16 regular session of the Seventy-ninth Legislative Assembly adjourns sine die.

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