

D R A F T

SUMMARY

Directs Oregon Health Authority to maintain state public health laboratory, administer newborn bloodspot screening program and implement educational program for newborn bloodspot screening program. Requires health care providers and health care facilities to ensure collection and delivery of specimens for newborn bloodspot screening and report certain test results to authority. Creates exemption for parents or guardians who oppose screening of infant for religious or philosophical reasons.

A BILL FOR AN ACT

Relating to public health testing; creating new provisions; amending ORS 433.285, 433.290 and 433.295; and repealing ORS 431A.750.

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

SECTION 1. Sections 2 and 5 of this 2023 Act are added to and made a part of ORS 433.110 to 433.770.

SECTION 2. (1) The Oregon Health Authority shall maintain a state public health laboratory that is capable of:

(a) Analyzing biological and environmental samples for public health purposes; and

(b) Performing newborn bloodspot screening as specified in ORS 433.285.

(2) In accordance with rules adopted by the authority, the state public health laboratory may analyze samples or perform newborn bloodspot screening for any:

(a) Country or territory;

(b) Federal agency;

1 (c) Agency of another state;

2 (d) Tribal agency; or

3 (e) Health care practitioner licensed in any country, territory or
4 state.

5 (3) The authority shall adopt rules necessary to implement ORS
6 433.285, 433.290 and 433.295 and this section, including but not limited
7 to rules establishing laboratory fees for analysis and screening ser-
8 vices.

9 (4) All moneys collected under subsection (3) of this section shall
10 be deposited in the Public Health Account established in ORS 431.210
11 to be used for expenses of the state public health laboratory.

12 **SECTION 3.** ORS 433.285 is amended to read:

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

18 *[(2) The authority by rule shall specify the diseases for which infants shall
19 be tested under subsection (1) of this section, the appropriate time following
20 delivery for collecting specimens, the manner in which the specimens are to be
21 submitted, the persons responsible for submitting the specimens, the methods
22 of testing and the manner of payment of the fees.]*

23 *[(3) The testing required by subsection (1) of this section shall not be re-
24 quired if the infant is being reared as an adherent to a religion the teachings
25 of which are opposed to such testing. The person responsible for submitting
26 specimens under the rules of the authority shall be responsible for submitting
27 a statement signed by the infant's parent that the infant is being so reared.
28 The authority by rule shall prescribe the form of the statement.]*

29 *[(4) The authority shall adopt by rule a procedure whereby the fees estab-
30 lished under subsection (2) of this section shall be waived and no infant re-
31 fused service because of the parent's inability to pay the fee.]*

1 *[(5) The authority by rule shall prescribe the procedure to be followed in*
2 *cases where initial testing for metabolic diseases is administered too early to*
3 *detect these diseases, where the sample submitted for testing is improperly*
4 *collected and where a sample shows an abnormal result. The authority, within*
5 *the limits of funds available from fees collected under this section, shall in-*
6 *stitute a pilot program for follow-up on abnormal test results.]*

7 **(1)(a) It is the public health policy of the State of Oregon that each**
8 **infant in Oregon undergo newborn bloodspot screening for medical**
9 **conditions that if detected early can be mitigated or treated to prevent**
10 **harmful health effects.**

11 **(b) The Oregon Health Authority shall administer a newborn**
12 **bloodspot screening program to advance the public health policy de-**
13 **scribed in paragraph (a) of this subsection.**

14 **(2) The state public health laboratory, or another laboratory pur-**
15 **suant to an agreement with the authority, shall conduct the**
16 **screenings described in subsection (1) of this section.**

17 **(3) The authority shall adopt rules necessary to implement the**
18 **newborn bloodspot screening program, including but not limited to**
19 **rules establishing:**

20 **(a) The medical conditions for which infants are screened, including**
21 **second tier testing;**

22 **(b) The person responsible for:**

23 **(A) The collection of specimens for screening;**

24 **(B) The delivery of specimens to the state public health laboratory**
25 **for screening;**

26 **(C) The delivery of signed exemption forms to the state public**
27 **health laboratory; and**

28 **(D) Following up with the parents or guardians of an infant to dis-**
29 **cuss the screening results;**

30 **(c) The timing and manner for collection and delivery of specimens**
31 **to the state public health laboratory for screening;**

1 (d) The timing and manner for recollection and redelivery, if nec-
2 essary, of specimens to the state public health laboratory for screen-
3 ing;

4 (e) Standards for the retention, use and release of residual speci-
5 mens;

6 (f) Fees for screening in an amount sufficient to cover the costs to
7 administer the newborn bloodspot screening program;

8 (g) A process for a parent or guardian to request a fee waiver if the
9 parent or guardian is indigent or otherwise unable to pay the fee for
10 screening services;

11 (h) The timing and manner for reporting screening results to the
12 medical providers of an infant; and

13 (i) The exemption form described in subsection (6) of this section.

14 (4) The inability of a parent or guardian to pay the fee established
15 under subsection (3) of this section may not be a basis to refuse to
16 provide newborn bloodspot screening services to an infant.

17 (5) A carrier, as that term is defined in ORS 743B.005, and a coor-
18 dinated care organization, as that term is defined in ORS 414.025, shall
19 cover the costs of newborn bloodspot screening.

20 (6) A parent or guardian of an infant may decline to screen the in-
21 fant under the newborn bloodspot screening program if the parent or
22 guardian opposes screening for religious or philosophical reasons and
23 signs an exemption form prescribed by the authority by rule.

24 (7) All information and documentation related to the newborn
25 bloodspot screening program that identifies an infant, a parent or
26 guardian of an infant or a health care provider involved in the care
27 of an infant is confidential and exempt from public disclosure under
28 ORS 192.311 to 192.478.

29 **SECTION 4.** ORS 433.290 is amended to read:

30 433.290. *[(1) The Legislative Assembly finds that many newborn children*
31 *are given their first tests for metabolic diseases too early for the detection of*

1 *these diseases because parents remove these newborn infants from the hospital*
2 *before the optimum testing period commences. To assure proper first testing*
3 *and follow-up testing and increase knowledge about the nature and results of*
4 *these diseases, the Oregon Health Authority shall institute and carry on an*
5 *intensive educational program among physicians, naturopathic physicians,*
6 *hospitals, public health nurses, the parents of newborn children and the public*
7 *concerning the disease of phenylketonuria and other metabolic diseases. This*
8 *educational program shall include information concerning:]*

9 *[(a) The nature of these diseases; and]*

10 *[(b) Examinations for the detection of these diseases in infancy in order that*
11 *measures may be taken to prevent the mental retardation resulting from these*
12 *diseases.]*

13 *[(2) The authority shall make a special effort specifically to inform*
14 *expectant parents and parents of newborn children of the necessity of newborn*
15 *infants receiving appropriate tests within the optimum time range after birth*
16 *to prevent the mental retardation or other serious complications resulting from*
17 *these diseases.]*

18 **(1) To ensure proper testing and follow-up care and increase public**
19 **awareness of the newborn bloodspot screening program described in**
20 **ORS 433.285, the Oregon Health Authority shall implement an educa-**
21 **tional program for health care providers, expectant parents, parents**
22 **of infants and the general public.**

23 **(2) The educational program must include information on:**

24 **(a) The medical conditions for which infants are screened under the**
25 **newborn bloodspot screening program; and**

26 **(b) The importance of newborn bloodspot screening to prevent or**
27 **mitigate the harmful health effects of medical conditions for which**
28 **infants are screened.**

29 **SECTION 5. A person may not bring an action against the Oregon**
30 **Health Authority, or any employee of the authority, for performing**
31 **or omitting to perform any duty or function or exercising or omitting**

1 to exercise any power of the authority set forth in ORS 433.285 or
2 433.290 or section 2 of this 2023 Act or in any other law of this state
3 requiring the authority to perform a duty or function or exercise a
4 power related to testing or screening.

5 **SECTION 6.** ORS 433.295 is amended to read:

6 433.295. *[(1) All physicians, public health nurses and the administrators of
7 hospitals shall report the discovery of cases of phenylketonuria to the Oregon
8 Health Authority.]*

9 *[(2) The authority shall furnish forms that all physicians, public health
10 nurses and hospitals shall use to report to the authority the test results for
11 phenylketonuria.]*

12 **Health care providers and health care facilities that provide services
13 to infants in Oregon shall:**

14 **(1) Ensure that specimens for newborn bloodspot screening are
15 collected and delivered pursuant to rules adopted by the Oregon Health
16 Authority under ORS 433.285;**

17 **(2) Ensure that an infant receives medically appropriate care con-
18 sistent with the results of a newborn bloodspot screening; and**

19 **(3) Report to the authority for quality control purposes:**

20 **(a) Medical conditions detected by newborn bloodspot screening and
21 subsequently confirmed; and**

22 **(b) Medical conditions on the newborn bloodspot screening panel
23 detected by a test other than newborn bloodspot screening.**

24 **SECTION 7.** ORS 431A.750 is repealed.

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