A-Engrossed House Bill 2741

Ordered by the Senate May 7 Including Senate Amendments dated May 7

Sponsored by Representative NELSON, Senator MANNING JR; Representatives ISADORE, MUNOZ, NERON, OWENS, Senators FREDERICK, JAMA, 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. The statement includes a measure digest written in compliance with applicable readability standards.

Digest: The Act tells the OHA to have a public health laboratory and to run a program for testing newborns. (Flesch Readability Score: 62.8).

Directs the Oregon Health Authority to maintain a state public health laboratory, administer a newborn bloodspot screening program and implement additional programs related to newborn bloodspot screening. 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 the authority. Creates an exemption for parents or guardians who oppose screening of an infant for religious or philosophical reasons.

1	A BILL FOR AN ACT
2	Relating to public health testing; creating new provisions; amending ORS 433.285, 433.290 and
3	433.295; and repealing ORS 431A.750.
4	Be It Enacted by the People of the State of Oregon:
5	SECTION 1. Section 2 of this 2025 Act is added to and made a part of ORS 433.110 to
6	433.770.
7	SECTION 2. (1) The Oregon Health Authority shall maintain a state public health labo-
8	ratory that is capable of:
9	(a) Analyzing biological and environmental samples for public health purposes; and
10	(b) Performing newborn bloodspot screening as specified in ORS 433.285.
11	(2) In accordance with rules adopted by the authority, the state public health laboratory
12	may analyze samples or perform newborn bloodspot screening for any:
13	(a) Country or territory;
14	(b) Federal agency;
15	(c) Agency of another state;
16	(d) Tribal agency; or
17	(e) Health care practitioner licensed in any country, territory or state.
18	(3) The authority shall adopt rules necessary to implement this section and ORS 433.285,
19	433.290 and 433.295, including but not limited to rules establishing laboratory fees for analysis
20	and screening services.
21	(4) All moneys collected under subsection (3) of this section shall be deposited in the
22	Public Health Account established in ORS 431.210 to be used for expenses of the state public
23	health laboratory.
24	SECTION 3. ORS 433.285 is amended to read:

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.

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1 433.285. [(1) It hereby is declared to be a matter of public policy of the State of Oregon that in the 2 interest of public health and the prevention of mental retardation, every infant, shall be given tests 3 approved by the Oregon Health Authority for the detection of the disease of phenylketonuria and other 4 metabolic diseases.]

5 [(2) The authority by rule shall specify the diseases for which infants shall be tested under sub-6 section (1) of this section, the appropriate time following delivery for collecting specimens, the manner 7 in which the specimens are to be submitted, the persons responsible for submitting the specimens, the 8 methods of testing and the manner of payment of the fees.]

9 [(3) The testing required by subsection (1) of this section shall not be required if the infant is being 10 reared as an adherent to a religion the teachings of which are opposed to such testing. The person 11 responsible for submitting specimens under the rules of the authority shall be responsible for submitting 12 a statement signed by the infant's parent that the infant is being so reared. The authority by rule shall 13 prescribe the form of the statement.]

14 [(4) The authority shall adopt by rule a procedure whereby the fees established under subsection 15 (2) of this section shall be waived and no infant refused service because of the parent's inability to pay 16 the fee.]

17 [(5) The authority by rule shall prescribe the procedure to be followed in cases where initial testing 18 for metabolic diseases is administered too early to detect these diseases, where the sample submitted for 19 testing is improperly collected and where a sample shows an abnormal result. The authority, within the 20 limits of funds available from fees collected under this section, shall institute a pilot program for 21 follow-up on abnormal test results.]

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

(b) The Oregon Health Authority shall administer a newborn bloodspot screening pro gram to advance the public health policy described in paragraph (a) of this subsection.

(2) The state public health laboratory, or another laboratory pursuant to an agreement
with the authority, shall conduct the screenings described in subsection (1) of this section.

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

31 (a) The medical conditions for which infants are screened, including higher tier testing;

32 (b) The person responsible for:

33 (A) The collection of specimens for screening;

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

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

36 (D) Following up with the parents or guardians of an infant to discuss the screening re-37 sults;

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

40 (d) The timing and manner for recollection and redelivery, if necessary, of specimens to
 41 the state public health laboratory for screening;

42 (e) Standards for the retention, use and release of residual specimens;

43 (f) Fees for screening in an amount sufficient to cover the costs to administer the new 44 born bloodspot screening program;

45 (g) A process for a parent or guardian to request a fee waiver if the parent or guardian

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1 is indigent or otherwise unable to pay the fee for screening services;

2 (h) The timing and manner for reporting screening results to the medical providers of 3 an infant; and

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

5 (4) The inability of a parent or guardian to pay the fee established under subsection (3) 6 of this section may not be a basis to refuse to provide newborn bloodspot screening services 7 to an infant.

8 (5) A carrier, as that term is defined in ORS 743B.005, and a coordinated care organiza-9 tion, as that term is defined in ORS 414.025, shall cover the costs of newborn bloodspot 10 screening.

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

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

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SECTION 4. ORS 433.290 is amended to read:

19 433.290. [(1) The Legislative Assembly finds that many newborn children are given their first tests for metabolic diseases too early for the detection of these diseases because parents remove these new-20born infants from the hospital before the optimum testing period commences. To assure proper first 2122testing and follow-up testing and increase knowledge about the nature and results of these diseases, the 23Oregon Health Authority shall institute and carry on an intensive educational program among physicians, naturopathic physicians, hospitals, public health nurses, the parents of newborn children and the 24 public concerning the disease of phenylketonuria and other metabolic diseases. This educational pro-25gram shall include information concerning:] 26

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

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

30 [(2) The authority shall make a special effort specifically to inform expectant parents and parents 31 of newborn children of the necessity of newborn infants receiving appropriate tests within the optimum 32 time range after birth to prevent the mental retardation or other serious complications resulting from 33 these diseases.]

(1) To ensure proper testing and follow-up care and increase public awareness of the
 newborn bloodspot screening program described in ORS 433.285, the Oregon Health Authority
 shall, subject to available resources, implement:

(a) An educational program for health care providers, expectant parents, parents or
 guardians of infants and the general public.

(b) A follow-up monitoring program to improve long-term care of individuals with medical
 conditions identified through screening.

41 (2) The educational program must:

42 (a) Provide information on the medical conditions for which infants are screened under
 43 the newborn bloodspot screening program;

(b) Provide information on the importance of newborn bloodspot screening to prevent or
 mitigate the harmful health effects of medical conditions for which infants are screened; and

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(c) If a newborn bloodspot screening detects a medical condition for an infant, provide 1 $\mathbf{2}$ the parents or guardians of the infant information on organizations that serve populations 3 impacted by the medical condition. SECTION 5. ORS 433.295 is amended to read: 4 433.295. [(1) All physicians, public health nurses and the administrators of hospitals shall report 5 the discovery of cases of phenylketonuria to the Oregon Health Authority.] 6 [(2) The authority shall furnish forms that all physicians, public health nurses and hospitals shall 7use to report to the authority the test results for phenylketonuria.] 8 9 Health care providers and health care facilities that provide services to infants in Oregon shall: 10 (1) Ensure that specimens for newborn bloodspot screening are collected and delivered 11 12pursuant to rules adopted by the Oregon Health Authority under ORS 433.285; (2) Ensure that an infant receives medically appropriate care consistent with the results 13of a newborn bloodspot screening; and 14 15(3) Report to the authority for quality control purposes: 16(a) Medical conditions detected by newborn bloodspot screening and subsequently confirmed; and 1718 (b) Medical conditions on the newborn bloodspot screening panel detected by a test other 19 than newborn bloodspot screening. SECTION 6. ORS 431A.750 is repealed. 20

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