

## HB 2741 STAFF MEASURE SUMMARY

### House Committee On Behavioral Health and Health Care

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**Prepared By:** Alexandra Kihn-Stang, LPRO Analyst

**Sub-Referral To:** Joint Committee On Ways and Means

**Meeting Dates:** 2/25, 3/6

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#### WHAT THE MEASURE DOES:

The measure directs the Oregon Health Authority (OHA) to maintain a state public health laboratory that is capable of performing analyses related to public health and the newborn bloodspot screening program (NBS).

#### Detailed Summary

- Directs OHA to adopt rules related to laboratory fees. Directs fees collected for laboratory services to the Public Health Account for use on state public health laboratory expenses.
- Directs OHA to adopt rules to implement NBS, including which conditions are included in the screening panel and protocols for specimen collection, analysis, and follow up. Requires OHA to provide an educational program on NBS to parents, guardians, providers, and the public. Specifies what must be included in the educational program.
- Requires coordinated care organizations and health insurers with plans regulated by the state to cover the costs for NBS.
- Requires the state laboratory to perform newborn bloodspot screening services regardless of a parent or guardian's ability to pay for those services.
- Expands the reasons for which a parent or guardian may decline newborn bloodspot screening to include both religious and philosophical reasons.
- Requires all information related to newborn bloodspot screening be treated as confidential and exempt from public disclosure.
- Requires health care facilities and providers to follow rules related to NBS, including sending specimen for testing and reporting positive tests to OHA.
- Repeals existing statute on the state laboratory.

*Fiscal impact: Has minimal fiscal impact*

*Revenue impact: No revenue impact*

#### ISSUES DISCUSSED:

- Importance of early diagnosis and treatment of rare diseases.
- Importance of providing additional education, support, and community resources to families of children diagnoses with rare diseases.

#### EFFECT OF AMENDMENT:

No amendment.

#### BACKGROUND:

Universal newborn screening is a well-established practice of state public health programs where newborn bloodspot samples are collected for screening prior to hospital discharge. Newborn screening can support the early detection and treatment of potentially serious medical conditions that could result in mortality or lifelong disability even when a newborn appears to be healthy otherwise. The federal Department of Health and Human Services publishes a [Recommended Uniform Screening Panel](#) (RUSP) of inheritable disorders that states are

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recommended to screen for. As of 2023, the RUSP includes 48 core and 26 secondary conditions.

Oregon law (ORS [433.285](#)) requires physicians, nurses, and midwives who deliver or care for infants in hospitals, birth centers, or homes to collect a bloodspot sample as part of the [Northwest Regional Newborn Bloodspot Screening Program](#) (NBS). Bloodspots are tested by the Oregon State Public Health Laboratory ([OSPHL](#)) with the intention of identifying infants that should undergo further follow-up testing and medical intervention; as of [2022](#), Oregon screens for 44 specific medical conditions within the NBS, including a range of metabolic, pulmonary, and endocrine disorders, among others. Collectively, about one in 250 infants born in the U.S. are affected by conditions screened for by Oregon's NBS. House Bill 2563 ([2019](#)) created the Northwest Regional Newborn Bloodspot Screening Advisory Board within the Oregon Health Authority which is responsible for recommending additional disorders that should be added to the NBS.

House Bill 2741 directs the Oregon Health Authority (OHA) to maintain a state public health laboratory that is capable of performing analyses related to public health and the newborn bloodspot screening program (NBS).