

HB 2563 -1 STAFF MEASURE SUMMARY

House Committee On Health Care

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Meeting Dates: 3/12, 3/19

WHAT THE MEASURE DOES:

Requires the Oregon Health Authority (OHA) to adopt rules to ensure infants are tested for approximately 50 different newborn screening tests. Allows OHA to adopt rules for collection and submission of specimens, and testing methods. Authorizes OHA to establish a pilot program for abnormal test results. Removes OHA's authority to determine by rulemaking the types of newborn screening for phenylketonuria and other metabolic diseases.

ISSUES DISCUSSED:

- Early newborn screening for generic diseases, particularly Krabbe; 1:150 adults are carriers of Krabbe
- Newborn screening process in Oregon
- Recent medical advances, treatment, and cure for Krabbe and symptom onset (i.e., late infantile onset)
- Severity and progression of Krabbe among infants and toddlers diagnosed with the medical condition; need for immediate intervention and treatment for infants diagnosed with a generic disorder upon a positive screening test
- Ability of the Oregon Health Authority to determine the types screening tests required for newborns
- Need to establish transparency and a public process to review, select, and recommend genetic diseases for the state's newborn screening list
- Prior state legislation to address newborn screening for rare diseases

EFFECT OF AMENDMENT:

-1 Replaces measure. Establishes a 13-members Newborn Bloodspot Screening Advisory Board in the Oregon Health Authority (OHA). Specifies membership. Each member is appointed by the Director of OHA for a four-year term and may be reappointed. Entitles voting members to be compensated for expenses. Specifies that the Board must meet at least every six months and may meet by the call of one or both chairpersons, or majority of the voting members of the Board. Requires the Board to report its findings and recommendations to the Legislative Assembly no later than September 15 of each even year. Declares emergency, effective on passage.

FISCAL: Fiscal impact issued.

REVENUE: Revenue impact issued.

BACKGROUND:

A well-established practice of state public health programs is universal screening of newborns before leaving the hospital. Screening helps to detect serious medical conditions that can result in early death or lifelong disability even when a newborn appears healthy. Early detection and intervention can prevent mortality and improve the quality of life for newborns with metabolic disorders. Advances in screening technologies have enabled health care providers to detect an increased number of metabolic disorders.

The federal Department of Health and Human Services (DHHS) publishes a recommended set of disorders for newborn screening programs (i.e. Recommended Uniform Screening Panel). The most recent recommendations include 32 core disorders and 26 secondary disorders (2016). Based on the federal recommendations, each year, approximately four million babies in the U.S. are screened for disorders. As a result, the Centers for Disease Control and Prevention (CDC) reports, nationally, that newborn screening detects 3,000 new cases of metabolic disorders each year.

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Oregon law requires hospitals and midwives to collect a blood sample from every baby born as part of the newborn screening program (ORS 432.285). Newborns are often screened twice, once at the hospital and then again at the child's first medical appointment. As of 2014, the Northwest Regional Newborn Screening Program screens newborns for more than 40 metabolic disorders approved by the Oregon Health Authority (OAR 333-024-0210). On October 1, 2018, the Oregon State Public Health Laboratory added lysosomal storage disorders (LSD) to the newborn screening panel for infants. According to OHA, LSDs are a group of over 40 genetic disorders that result in enzyme deficiencies within the lysosomes of the body's cells, causing irreversible damage to the muscles, nerves, and organs in the body over time. The Oregon State Public Health Laboratory (OSPHL) tests blood samples from newborns and shares the results with health care providers. The testing results help health care professionals know when a newborn needs immediate medical attention.

House Bill 2563 expands the list of diseases for which newborns are tested in Oregon.