HB 2563 STAFF MEASURE SUMMARY

House Committee On Health Care

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Meeting Dates: 3/12

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.

REVENUE: May have revenue impact, but no statement yet issued.
FISCAL: May have fiscal impact, but no statement yet issued.

ISSUES DISCUSSED:

EFFECT OF AMENDMENT:

No amendment.

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.

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.