HB 2563 A STAFF MEASURE SUMMARY

Senate Committee On Health Care

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Meeting Dates: 4/17, 4/22

WHAT THE MEASURE DOES:

Establishes the Newborn Bloodspot Screening Advisory Board (Board) in the Oregon Health Authority. Specifies Board membership and meeting requirements. Requires Board to report finding and recommendations for legislative changes to the Legislative Assembly no later than September 15 of each even numbered year. Requires Board to conduct its first meeting an report its findings no later than December 15, 2019. Declares emergency, effective on passage.

REVENUE: No revenue impact
FISCAL: Fiscal impact issued

ISSUES DISCUSSED:

- Funding through fees
- Gaps in screening from Recommended Uniform Screening Panel
- Effects of delayed diagnosis of diseases like Krabbe

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. Advanc es 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., the Recommended Uniform Screening Panel). The most recent recommendations from 2016 include 32 core disorders and 26 secondary disorders. 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. 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. 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 muscles, nerves, and organs over time. The Oregon State Public Health Laboratory (OSPHL) tests blood samples from newborns and shares the results with health care providers. Test results help alert health care professionals when a newborn needs

immediate medical attention.

House Bill 2563-A creates the Newborn Bloodspot Screening Advisory Board in the Oregon Health Authority.

HHC Vote: 10-0

House Floor Vote: 58-0