HB 2563 A STAFF MEASURE SUMMARY

Carrier: Rep. McLain

House Committee On Health Care

Action Date:	03/19/19
Action:	Do pass with amendments. (Printed A-Eng.)
Vote:	10-0-1-0
Yeas:	10 - Alonso Leon, Drazan, Greenlick, Hayden, Keny-Guyer, Mitchell, Noble, Nosse, Prusak, Salinas
Exc:	1 - Boles
Fiscal:	Fiscal impact issued
Revenue:	No revenue impact
Prepared By:	Oliver Droppers, LPRO Analyst
Meeting Dates:	3/12, 3/19

WHAT THE MEASURE DOES:

Establishes a 13-member Newborn Bloodspot Screening Advisory Board (Board) in the Oregon Health Authority (OHA). Specifies members are appointed by the Director of OHA for four-year terms and may be reappointed. Entitles voting members to compensation for expenses. Specifies that the Board must meet at least every six months and may meet at the call of one or both chairpersons, or a majority of the voting members. Requires the Board to report findings and recommendations to the Legislative Assembly by September 15 of each even-numbered year. Declares emergency, effective on passage.

ISSUES DISCUSSED:

- Early newborn screening for genetic diseases, particularly Krabbe; 1:150 adults are carriers
- Newborn screening processes in Oregon and other states
- Diseases recently added to Oregon screening program
- Costs of screening; costs of treatment for diseases detected later in child’s life
- 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; need for immediate intervention and treatment for infants diagnosed with a genetic disorder upon a positive screening test
- Ability of the Oregon Health Authority to determine the types of 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:

Replaces measure.

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., 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.