HB 4109 A STAFF MEASURE SUMMARY

House Committee On Health Care

Action Date:	02/14/22
Action:	Do pass with amendments and be referred to Ways and Means. (Printed A-Eng.)
Vote:	9-1-0-0
Yeas:	9 - Alonso Leon, Campos, Hayden, Moore-Green, Noble, Prusak, Salinas, Schouten, Weber
Nays:	1 - Dexter
Fiscal:	Fiscal impact issued
Revenue:	No revenue impact
Prepared By:	Brian Nieubuurt, LPRO Analyst
Meeting Dates:	2/4, 2/14

WHAT THE MEASURE DOES:

Directs Newborn Bloodspot Screening Advisory Board (Board) to evaluate and make recommendations to the Oregon Health Authority on adding diseases to Oregon newborn bloodspot screening panel under specified criteria. Applies criteria to diseases for which a vote to initiate an evidence review is commenced by Board on or after January 1, 2021. Updates elements and frequency of required report by the Board to Legislative Assembly. Modifies Board meeting standards, membership requirements, and meeting frequency.

ISSUES DISCUSSED:

- Federal Recommended Uniform Screening Panel (RUSP) and use by states
- Process for adding diseases to state screening panel
- Krabbe disease and screening by other states
- Changes to Board membership

EFFECT OF AMENDMENT:

Clarifies criteria requiring Board evaluation of diseases to add to newborn bloodspot screening panel. Applies criteria to diseases for which a vote to initiate an evidence review is commenced by Board on or after January 1, 2021.

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 433.285). Newborns are often screened twice, once at the hospital and then again at the child's first medical appointment. The Northwest Regional Newborn Bloodspot Screening Advisory

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Program screens newborns for endocrine, hemoglobin, cystic fibrosis, and metabolic conditions. 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. In 2019, House Bill 2563 passed creating the Northwest Regional Newborn Bloodspot Screening Advisory Board (Board) in the Oregon Health Authority. The Board is responsible for recommending the addition of disorders to the state's newborn bloodspot screening panel.

House Bill 4109 A directs the Newborn Bloodspot Screening Advisory Board to evaluate and make recommendations to the Oregon Health Authority on adding diseases to Oregon newborn bloodspot screening panel under specific circumstances.