HB 3192 STAFF MEASURE SUMMARY

House Committee On Behavioral Health and Health Care

Action Date:	04/01/25
Action:	Do pass and be referred to Ways and Means by prior reference
Vote:	9-0-0-0
Yeas:	9 - Diehl, Harbick, Isadore, Javadi, McIntire, Munoz, Nelson, Nosse, Pham H
Fiscal:	Fiscal impact issued
Revenue:	No revenue impact
Prepared By:	Alexandra Kihn-Stang, LPRO Analyst
Meeting Dates:	2/25, 4/1

WHAT THE MEASURE DOES:

The measure appropriates $4 million from the state General Fund to support newborn bloodspot screening for five additional diseases through the Northwest Regional Newborn Bloodspot Screening Program.

Detailed Summary

- Directs funding from the General Fund to be used for the screening of five additional conditions: mucopolysaccharidosis type II (MPS II), guanidinoacetate methyltransferase deficiency (GAMT), Krabbe disease, Duchenne muscular dystrophy (DMD), and congenital cytomegalovirus (CMV).
- Appropriates money from the General Fund for the 2025-2027 biennium.

ISSUES DISCUSSED:

- Importance of early diagnosis to maximize disease treatment options
- Fee-based funding availability limits the ability of the of the Northwest Regional Newborn Bloodspot Screening Program to expand the list of diseases that can be screened for.

EFFECT OF AMENDMENT:

No amendment.

BACKGROUND:

Universal newborn screening is a well-established practice of state public health programs where newborn bloodspot samples are collected for screening prior to hospital discharge. Newborn screening can support the early detection and treatment of potentially serious medical conditions that could result in mortality or lifelong disability even when a newborn appears to be healthy otherwise. The federal Department of Health and Human Services publishes a Recommended Uniform Screening Panel (RUSP) of inheritable disorders that states are recommended to screen for. As of 2023, the RUSP includes 48 core and 26 secondary conditions. States may vary in the conditions that are screened for by their newborn screening program.

Oregon law (ORS 433.285) requires physicians, nurses, and midwives who deliver or care for infants in hospitals, birth centers, or homes to collect a bloodspot sample as part of the Northwest Regional Newborn Bloodspot Screening Program (NBS). Bloodspots are tested by the Oregon State Public Health Laboratory with the intention of identifying infants that should undergo further follow-up testing and medical intervention; as of 2022, Oregon screens for 44 specific medical conditions within the NBS, including a range of metabolic, pulmonary, and endocrine disorders, among others. Collectively, about one in 250 infants born in the U.S. are affected by conditions screened for by Oregon's NBS. House Bill 2563 (2019) created the Northwest Regional Newborn Bloodspot Screening Advisory Board within the Oregon Health Authority which is responsible for recommending additional disorders that should be added to the NBS.

Background on the five diseases:

- Mucopolysaccharidosis type II (MPS II or Hunter's syndrome) is a rare inherited genetic condition that affects the body's ability to process sugars and has been included among the core conditions on the RUSP since 2022. The condition affects predominantly males and is diagnosed in one out of every 100,000-170,000 U.S. children annually. MPS II can lead to long term health outcomes, including physical and developmental symptoms.
- Guanidinoacetate methyltransferase deficiency (GAMT) is a rare inherited genetic condition that impacts an unknown number of newborns in the U.S. annually. GAMT is a metabolic condition that can damage organs and lead to physical and developmental delays. GAMT was added to the RUSP in 2023 as a core condition.
- Krabbe disease is a rare inherited genetic condition that occurs in approximately 40 newborns in the U.S. annually. Krabbe disease is a metabolic condition that can onset at different ages and can result in muscle weakness, seizures, motor milestone regression, and vision loss. Krabbe disease was added to the RUSP in 2024 as a core condition.
- Duchenne muscular dystrophy (DMD) is a neuromuscular disorder that impacts more than 300 newborns in the U.S. annually. DMD is the most common inherited form of muscular dystrophy, it causes progressive muscle weakness and degeneration. DMD was nominated but not added to the RUSP in 2023.
- Cytomegalovirus (CMV) is a common virus of the herpes family that may infect people of all ages. Once infected, CMV remains dormant within a person's body for life where it may be passed to a baby during pregnancy. Congenital CMV occurs in approximately one out of every 200 newborns, of those, one out of every five will experience symptoms that may result in long-term effects, such as hearing and vision loss, seizures, microcephaly, and developmental delays. Congenital CMV was nominated but not added to the RUSP in 2022.

House Bill 3192 allocates an additional $4 million from the state General Fund to support newborn bloodspot screening for five additional diseases through the Northwest Regional Newborn Bloodspot Screening Program.