## HB 2685 -3 STAFF MEASURE SUMMARY

## House Committee On Behavioral Health and Health Care

**Prepared By:** Alexandra Kihn-Stang, LPRO Analyst **Sub-Referral To:** Joint Committee On Ways and Means

**Meeting Dates:** 2/25, 4/1

#### WHAT THE MEASURE DOES:

The measure requires the Oregon Health Authority (OHA) to create a targeted screening protocol for and provide information on congenital cytomegalovirus (cCMV) to Oregon hospitals and birth centers.

## **Detailed Summary**

## • Oregon Health Authority (OHA):

- Directs OHA to provide an expanded, targeted screening protocol for to identify newborns that should receive cCMV testing within 14 days of birth and before hospital discharge to all Oregon hospitals and birth centers. Requires OHA to adopt rules related to the targeted protocol.
- Requires OHA to study the feasibility of implementing statewide data collection and analysis for newborn cCMV tests annually.
- Requires OHA to provide a recommended protocol for infant and early childhood testing and care following a positive screening result for cCMV.
- o Directs OHA to expand and disseminate information on cCMV to specific entities and the public.
- Requires OHA to establish the targeted protocol through rule by January 1, 2026.
- o Eliminates requirements if cCMV is added to the newborn bloodspot screening program.

#### • Hospitals and Birth Centers:

- o Requires hospitals and birth centers to comply with the targeted protocol except in certain situations.
- Requires a hospital or birth center to notify the parent or guardian and health care provider when a child screens positive for cCMV.

## • Health Plans:

 Requires state-regulated health plans to cover cCMV testing consistent with the targeted screening protocol.

## **ISSUES DISCUSSED:**

- Importance of preventive education around cCMV
- Limited window for early treatment and the importance of receiving an early diagnosis to prevent long term complications such as hearing loss

Fiscal impact: May have fiscal impact, but no statement yet issued

Revenue impact: No revenue impact

# **EFFECT OF AMENDMENT:**

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- Removes the requirement that OHA study cCMV data collection and analysis.
- Clarifies language around exemptions for hospitals or birth centers in complying with targeted protocol.

Fiscal impact: Fiscal impact issued Revenue impact: No revenue impact

## **BACKGROUND:**

#### HB 2685 -3 STAFF MEASURE SUMMARY

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, this includes 48 core and 26 secondary conditions as of 2023.

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 (OHA) which is responsible for recommending additional disorders that should be added to the NBS.

Cytomegalovirus (CMV) is a common virus of the herpes family that may infect people of all ages. More than half of U.S. adults have been infected with CMV by the age of 40, and nearly one out of three children has been infected by the age of five. Once infected, CMV remains dormant within a person's body for life where it may be passed to a baby during pregnancy. While CMV most often causes either no symptoms or mild illness, those with weakened immune systems, people who are pregnant, and babies born with congenital CMV may have more severe symptoms. 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 vision loss, seizures, microcephaly, developmental delays, and commonly, hearing loss. Congenital CMV was nominated but not added to the RUSP in 2022. There are three approaches to newborn screening for congenital CMV: hearing targeted screening for newborns who fail newborn hearing screening at birth, expanded targeted screening for infants with signs of congenital CMV on a clinical exam or lab testing, and universal/routine bloodspot screening for all newborns at birth.

House Bill 2754 (2017) required OHA to compile and provide educational materials regarding congenital CMV when a child fails a hearing test and to develop a schedule for conducting newborn screening tests and protocol for diagnosing congenital CMV within 21 days of birth. However, HB 2754 did not mandate testing for congenital CMV.

House Bill 2685 requires the Oregon Health Authority to create a targeted screening protocol for and provide information on congenital cytomegalovirus (cCMV) to Oregon hospitals and birth centers.