

# SENATE BILL REPORT

## SB 5829

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As of January 12, 2024

**Title:** An act relating to screening newborn infants for congenital cytomegalovirus.

**Brief Description:** Screening newborn infants for congenital cytomegalovirus.

**Sponsors:** Senators Frame, Rivers, Shewmake, Trudeau, Lovelett, Dhingra, Hasegawa, Kuderer, Lias, Nobles, Valdez and Wilson, C..

**Brief History:**

**Committee Activity:** Health & Long Term Care: 1/12/24.

**Brief Summary of Bill**

- Creates an opt-in screening for Congenital Cytomegalovirus if Department of Health has obtained informed consent from the newborn infant's parents or guardians for the optional screening.

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### SENATE COMMITTEE ON HEALTH & LONG TERM CARE

**Staff:** Julie Tran (786-7283)

**Background:** Congenital Cytomegalovirus. Congenital Cytomegalovirus (cCMV) is a common congenital infection and is present in approximately 1 in 200 babies. cCMV occurs when a pregnant individual is infected with cytomegalovirus and subsequently passes the infection to their unborn child. It can result in hearing loss and is the leading cause of nonhereditary, sensorineural hearing loss.

Washington State's Newborn Screenings. Department of Health (DOH) must require screening tests of all newborn infants born in any setting. No tests shall be given to any newborn infant whose parents or guardian object on the grounds of religious tenets and practices.

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*This analysis was prepared by non-partisan legislative staff for the use of legislative members in their deliberations. This analysis is not part of the legislation nor does it constitute a statement of legislative intent.*

Each hospital or health care provider attending a birth outside of a hospital must collect and submit a sample blood specimens for all newborn infants within 48 hours following the birth. The initial screen or signed refusal must be delivered to the state laboratory within 72 hours of collection, excluding Sundays and Thanksgiving Day. Laboratories, attending physicians, hospital administrators or other persons are required to report all positive test results to DOH.

Annually, DOH performs nearly 12 million tests on more than 172,000 specimens from about 85,000 newborn infants. DOH also provides information and training to parents and health care providers about newborn screenings (NBS).

Newborn Screening Panel. Washington State adds tests to the newborn screening panel only after a consideration of the following criteria set by the State Board of Health (Board): available technology, diagnostic testing, and treatment available; prevention potential and medical rationale; public health rationale; cost-benefit and cost-effectiveness.

In October 2021, the Board convened a technical advisory committee to consider adding cCMV to the list of mandated NBS conditions. In October 2022, the Board determined cCMV should not be considered for addition to the newborn screening panel at this time and moves to reevaluate the condition in three years as a candidate for mandatory newborn screening in Washington State.

In Washington, there are no state requirements for cCMV education, screening, or reporting. Cytomegalovirus testing is up to a provider's discretion and results are not reported to DOH.

**Summary of Bill:** DOH may conduct screening tests for cCMV as a part of the existing newborn screening panel tests if DOH has obtained informed consent from the newborn infant's parents or guardians for this optional testing. This testing may only occur after all the DOH-required tests are complete.

DOH must design, prepare, and make available written material to inform health care providers and the newborn infant's parents or guardians about the nature and consequences of cCMV.

**Appropriation:** None.

**Fiscal Note:** Requested on December 28, 2023.

**Creates Committee/Commission/Task Force that includes Legislative members:** No.

**Effective Date:** Ninety days after adjournment of session in which bill is passed.

**Staff Summary of Public Testimony:** PRO: CMV is the leading viral cause of birth

defects and developmental delays in children as well as other condition such as seizures, hearing loss, cerebral palsy, brain abnormalities, autism, and sadly, death. CMV is easily preventable and most babies with cCMV never show any signs of health problems. The bill does two things: education upfront so parents understand and take the necessary precautions and an opt-in newborn screening for the condition. This bill includes DOH guidance to have an opt-in screening using the existing blood sample that DOH already has and prioritizes the use of existing tests, so that CMV was the last test in case the blood sample did not go as far. This condition causes more birth defects than other well-known disorders and syndrome, more than any other disorder currently tested for in the Washington State newborn screening panel. Early treatment and intervention is paramount. There are antiviral medication that can improve outcomes but newborn infants must be screened in the first 2-3 weeks of birth to receive the medication. The antiviral medication can minimize outcomes and improve many children's lives. This bill allows Washington to have a formal screening protocol and allows families an opportunity to have their infant screened for CCMV. The state should advocate for newborns and families by giving them the option to take a quick and education action at birth.

CON: cCMV is a serious condition and a public health problem of great consequence. The board and the department recently reviewed cCMV for inclusion in the state's NBS panel and found that screening babies through a bloodspot specimen is not the most effective way to prevent death and disability from the condition. Early identification and treatment through NBS will not prevent severe death and disability from cCMV. Current antiviral therapy has not been shown to prevent death for babies with symptomatic CMV infection. The current test on dried blood specimens is only 75 percent sensitive and there are concerns about offering a test that will miss 25 percent of the babies with CMV. Screening using other tests such as saliva testing has a higher sensitivity but the Board and DOH do not have the authority or capacity to conduct these tests. There also may not be sufficient audiologists to handle the increased follow-up diagnostic testing for babies identified with this condition. Implementing the necessary screening and follow-up will require significant funding, and it was not included in the Governor's budget. The board has committed to reevaluating the condition next year in 2025 and ask for the ability to follow their process for considering candidate conditions. The way to save lives is to prevent transmission of CMV from pregnant individuals, which is through education instead of optional screening.

**Persons Testifying:** PRO: Senator Noel Frame, Prime Sponsor; Mallory Baker, Washington CMV Project; Cathleen Ackley; Lisa Aamot; Kelsey Gellner, WSNA.

CON: John Thompson, Washington State Department of Health; Molly Dinardo, Washington State Board of Health.

**Persons Signed In To Testify But Not Testifying:** No one.