

Submitter: Shelby Atwill

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure, Appointment or Topic: HB2685

Good afternoon, Chair Nosse, Vice Chairs Javadi and Nelson, and members of the Committee.

For the record I am Dr. Shelby Atwill. I am here today in support of HB 2685. While I am a contracted audiologist for OHA's Early Hearing Detection & Intervention Program, today I am speaking with you not from my role with the Program, but as a private audiologist. I am a pediatric audiologist who cares for over 400 deaf/hard of hearing children in the Portland area and southern Oregon.

The goal of HB 2685 is to implement education and expanded targeted screening in newborns for congenital cytomegalovirus, or cCMV. How apt that we are discussing this bill during Rare Diseases Week and International Cochlear Implant Day!

HB 2685 has been a labor of love for the parents in this room. While I have expertise in pediatric hearing loss and its causes, these parents have accumulated years of lived experience I could never get. The theme throughout their stories will be, "We wish we had known about CMV sooner."

My role today is to share key information about cCMV, a leading cause of birth anomalies and developmental disabilities. cCMV's spectrum of impacts includes stillbirth, organ failure, hearing loss, vision loss, cerebral palsy and cognitive disabilities. It is a progressive disease, so symptoms can develop and worsen over time.

According to the CDC, most people in the United States have had a CMV infection by the time they are 40 years old. Most people experience CMV as a bad cold. CMV is dangerous when passed to an unborn baby during pregnancy, especially if the pregnant person has never had CMV before. Some babies can show symptoms at birth, and in others, cCMV is invisible.

A baby not passing their newborn hearing screening is often a first sign of a congenital CMV infection. Hearing loss is also invisible, which is why Oregon pioneered universal newborn hearing screening 25 years ago.

Expanded targeted screening for CMV will find virtually all of the children at risk for life-long effects from this virus. It will allow them to start antiviral treatment, and potentially reduce many of the serious symptoms. CMV screening is already

occurring in Oregon's largest birth hospitals. This bill requires the remaining birth hospitals to start similar programs which are already proven cost- and outcome-effective. If passed, Oregon will join 20 other states that have CMV screening programs.

An expanded targeted CMV screening program will make identifying and treating this condition more equitable. Marginalized communities have less access to medical resources, screenings and therapies and are inherently disadvantaged with complex and rare conditions such as CMV. Significant racial and ethnic differences exist in the prevalence of CMV, even after adjusting for SES.

I care for many children impacted by cCMV, because hearing loss is a common outcome. I have seen how progressive hearing loss, without appropriate monitoring and intervention, leads to language deprivation, behavior disorders and cognitive delays that are very challenging to overcome. The additional state resources needed to treat preventable CMV outcomes far outweighs the small, upfront cost of the screening. Early education and detection is an effective way to reduce a burden on our social system and improve outcomes across our state.

While there is no guarantee of preventing cCMV transmission, there are steps that pregnant people can take to reduce their risk. This bill's educational component aims to raise awareness about CMV to help prevent it from affecting so many Oregon families.

Let's build on our tradition of screening newborns for what may be invisibly impacting them. Thank you for your time and support of HB 2685.