Submitter: David Stein

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure, Appointment or Topic: HB2685

My name is David Stein and I am supporting HB2685 on behalf of my son and my family.

My son was born with permanent hearing loss caused by congenital CMV. His hearing loss was detected the day after he was born, thanks to the newborn hearing screen conducted at the hospital, but it would take months for us to receive a diagnosis of CMV.

It should have taken a day.

Like most people, I had never heard of CMV before my son was diagnosed. Even though CMV is the most common infectious cause of birth anomalies and developmental disabilities in children, Oregon has no standard protocol for newborn CMV screening. Many newborns are not tested, even when they have CMV symptoms at birth, like my son did.

The first time I heard about CMV was when a provider told us he probably didn’t have it. I Googled CMV and learned how serious it could be. I learned how testing for it must be done within the first 21 days of life and that treatment is most effective if started within the first 30 days – windows we had already missed.

The system failed us. And I felt like I had failed my son.

Since the medical system failed us, we had to do it ourselves. We learned from a CMV awareness group that we could request his newborn blood spot card from the state storage facility. If there was enough of a sample remaining, we could send it for CMV testing ourselves.

By the time we got a positive CMV diagnosis, Parker was already 4 months old.

With this diagnosis, we found a physician who was willing to offer treatment, but we were well passed the window when treatment is most effective.

Even though we missed the treatment window, having a diagnosis was still vital. It allowed his early intervention services to be tailored to his CMV diagnosis. It meant our audiologist could adjust his follow-up hearing tests to monitor for progressive hearing loss since that is a possibility with CMV.

Today, our son is a happy, healthy 2-year-old. He wears a Cochlear Implant, and we are learning ASL as a family.

Other Oregon families should not have to go through what we went through.

If HB 2685 had been in place, we would have had our son's diagnosis in the hospital, a day after he was born. We could have worked with specialists to consider treatment, to start early intervention immediately, and to learn about CMV when we could do something about it.

Support HB 2685:
- Allow Oregon to join other states who have established clear guidelines for those babies who are born with CMV
- Reduce the number of babies born with CMV by improving prenatal education on simple CMV reduction techniques