

Submitter: Katherine Fox  
On Behalf Of:  
Committee: House Committee On Behavioral Health and Health Care  
Measure, Appointment or Topic: HB2685

My name is Katherine Fox and I am supporting HB2685 on behalf of my son and my family.

My two-year-old son Parker wears a cochlear implant and communicates in English and ASL, because he was born with permanent hearing loss caused by congenital CMV.

I am testifying in support of this bill to ensure other Oregon families don't have to endure the nightmare our family experienced.

It would have been bad enough that my OB never mentioned the risks of CMV to me, despite having a toddler at home.

But even after Parker was born with hearing loss, we were lied to and misled about CMV.

By an audiologist who told us "CMV can cause hearing loss, but he would have other symptoms so it isn't that."

By an ENT who told us "it's OK, we can test to see if his hearing loss was caused by CMV later."

On the car ride home from that ENT appointment, my husband Googled CMV.

And we learned that this virus, which our medical providers had so casually dismissed, could affect the rest of our child's life.

That CMV could continue to make his hearing worse. That it could cause long-term developmental delays. That it could harm his ability to run and jump and play with his big sister. That his vision could be permanently affected. That he was now at risk for cerebral palsy, seizures, and sensory issues.

Even once we knew about CMV, we were on our own. We had to educate our providers, figure out how to get testing done ourselves, and push for the specialist referrals Parker needed.

We were fighting the medical establishment every step of the way.

We found a physician who was willing to offer us treatment, but who said it probably wouldn't matter for Parker because it was too late in his life.

So we moved on.

Parker has grown into a happy, healthy toddler who happens to be deaf in his left ear.

We got incredibly lucky.

But more than luck, my family has almost every privilege an Oregon family can enjoy. We had the time, expertise, and resources to undertake a new full-time job - learning about cCMV and fighting for the medical care and attention Parker needed.

And we were still too late to do anything to help our son fight this virus.

If HB 2685 had been in place, we would have had Parker's diagnosis in the hospital, a day after he was born.

We could have worked with specialists THEN to consider treatment, to start early intervention for his hearing loss, and to learn about CMV when we could do something about it.

And if my OB had ever mentioned the risks of CMV to me, and told me about the easy strategies I could use to reduce the risk of catching this virus from my toddler, I might not be standing in front of you today.

Don't ask other Oregon families to go through what we went through.

Support HB 2685 and advocate for this bill to go further by including a mandate for prenatal providers to educate pregnant people in Oregon about the risks of cCMV and the ways to reduce transmission.