

Thank you so much for the opportunity to speak in support of HB 2685. My name is Sally-Shannon Birkel and I am speaking for myself and my husband T.J. on behalf of our daughter Charlotte.

Charlotte was born in February 2022 after an uncomplicated pregnancy and easy delivery. She came out with a rash called petechiae on her face, which was attributed to the birth process, but was otherwise deemed completely healthy. Before being discharged from the hospital, she failed two hearing screenings. We were told that it was most likely fluid in her ears that would resolve on its own. At two months old, after two follow up audiology appointments, we discovered that Charlotte is profoundly deaf in her right ear. At no point in the hospital, at the pediatrician, or in the multiple audiology appointments, were we told about CMV. We had never heard of it, and it was only after an ENT doctor recommended that she be tested for CMV following confirmation of Charlotte's deafness, that it first came to our attention.

Charlotte's subsequent positive CMV test began what felt like a nightmare for our family. We went from believing we had a healthy baby daughter to being told that her future outlook was uncertain and the only thing we could do was wait and watch her development. The trauma of that time is still visceral, from seeing our two month old baby be carried off by an anesthesiologist to be put under for an MRI of her brain, to suddenly urgently needing to see 5 different specialists at OHSU, which is 3 hours from where we live, for testing and treatment.

One of the most difficult challenges of CMV is that no one can give you an end date. There is always a concern that Charlotte's hearing loss could spread to her other ear, or that other CMV symptoms like vision loss, or developmental issues, could occur.

The strain all of this placed on our family, and my mental health, was immense. It continues to generate a massive feeling of anger that we were not told about this virus during pregnancy, or right after birth, when the antiviral treatment is most effective. It also brings up deep feelings of guilt

that I didn't protect my daughter from this virus because I wasn't educated about it. And feelings of deep fear and powerlessness about her uncertain future. All of these feelings were, and still are, very difficult to process.

Today, Charlotte uses a cochlear implant and so far, other than her hearing loss, is growing and developing normally. We just celebrated her 3rd birthday, and she brings so much joy to our family and those around her. But uncertainty still lurks in the back of my mind, and she continues to be monitored frequently for further CMV related complications.

My husband and I are proud to be part of this effort, and we want to thank Representative Pham for his leadership on this important issue. As a parent, so many things are out of our control as it relates to our children and their health, but what makes CMV unique is that it is preventable. For those of us testifying today, it's too late to protect our children from the effects of CMV, but we can help ensure other families have more tools and knowledge to avoid these outcomes. This is a common sense bill, and you can be part of the solution by voting to approve it. With your support, we can help thousands of Oregon families in the future. Thank you so much.