Submitter: Stephanie Lucas

On Behalf Of: HB2685

Committee: House Committee On Behavioral Health and Health Care

Measure, Appointment or Topic: HB2685

Hello and thank you for taking the time to review this written testimony. My name is Stephanie Lucas, I am a licensed marriage and family therapist in Oregon and mother to a child who was born with congenital CMV. In my verbal testimony I shared the story of our diagnosis. How we were caught only because our ENT electively recommended screening, and that our window for antiviral treatment had closed. How abandoned our family felt by the medical community, and the monumental climb we faced alone to seek appropriate care for our child.

In my written testimony, I would like to go into more detail of my observations as a professional, and the ongoing experience that having a deaf child has taught me about why early education, screening and prevention are essential to successful outcomes.

Our family sought a second opinion at OHSU, and we were able to enroll in a research study for the option of trialing valganciclovir (the CMV antiviral treatment) outside of the FDA approved window to determine its efficacy on slightly older babies. To participate, we were required to travel from Bend to Portland weekly, completing painful blood draws each time. This included overnight stays, days off of work and all told cost our family thousands of dollars for the chance to prevent progressive hearing loss. Riley’s hearing loss progressed from single sided deaf on her left side, to include mild-moderate sloping loss on her right side around her first birthday.

As time went on I used my knowledge as a mental health professional to build intentional community with the Deaf community and other parents of children with hearing loss. I joined an organization called Hands and Voices and provided peer support for parents in my region as well as CMV parents across the state. In this role I had the repeated experience of being one of the “first calls” for parents with a new cCMV diagnosis. I processed their grief with them, helped to educate them and empowered them to seek resources and support for their children. In this role I was also witness to parents of children with complex disabilities. I have witnessed young children with severe language delays and behavioral disorders due to their parents lack of access to education, resources and support.

I have fought tirelessly at the IEP table and recreational offerings for my daughter to have access to ASL in her childcare and educational settings. We have paid for private tutoring, arranged playgroups and researched issues on language access and hearing loss. Now that she is in kindergarten, we are holding the school district responsible for providing full language access with a full time ASL educational interpreter.

Finally, I used my expertise to teach about trauma informed care and family support in the realm of childhood hearing loss and early intervention. Through this I have met cCMV parents who have lost their children, families with medical trauma, catastrophic medical debt and marriages that were crumbling under the weight of it all. I have met early education providers who feel overwhelmed by the dearth of challenges their clients face. My heart and mind remain burdened with the catastrophic toll that a simple, “cold-like” virus can take on our families, health care system and community wellbeing.

All of these responsive resources to support our daughter are a huge cost on the health and social welfare systems in Oregon, and they are needs that are PREVENTABLE. Through simple requirements early in pregnancy and postnatal care. Through early education, screening and basic infection prevention. There may be those who argue that the requests we have submitted to you today are a tax on the system and to medical providers. They are not wrong, but I ask you to consider - which tax has greater consequences? Which response creates a greater opportunity for all Oregon families to thrive? Thank you for voting to pass this important bill.