Submitter: Andrew Sloan

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure, Appointment or Topic: HB2685

I am writing in support of HB2685.

My daughter Lilah was born with congenital CMV in October 2022. My wife and I never heard of CMV prior to Lilah's diagnosis.

We were diligent about prenatal education for both Lilah and our older son, Ryder. We took classes through both hospital and birthing center settings. We learned all about the risks of my wife eating sushi, gardening without gloves, and unpasteurized cheese.

Never once were we told that my wife may be at increased risk of passing CMV to our baby girl in utero. We were living with three big risks and didn't know it. Ryder was in daycare, my wife was around kids all day as an elementary school teacher, and my wife never had CMV before. When a birthing parent has never had CMV, contracting it while pregnant increases the risk of severe impact to the baby. With a kid in daycare and my wife working everyday with young children, the chance of CMV exposure was much greater.

Our son didn't need to be in daycare, my wife didn't need that part time job. We could have made different decisions had we known we were at higher risk than most families of passing cCMV to our baby. Every family should have the information to make their own decisions. It could be big decisions like job or daycare changes, or small decisions like washing hands more regularly, wearing a mask in certain settings. If we take seriously educating pregnant parents about risk factors like eating sushi and unpasteurized cheese, or gardening without gloves, then there's no reason cCMV shouldn't be discussed.

In other ways, we were lucky. Lilah was born small for gestational age (SGA) and didn't pass her newborn hearing test. Two indicators. Our hospital pediatrician thought to perform a CMV test. The results came back positive within a few days. We were able to give Lilah the antiviral medication course when it was most impactful in her first 6 months of life and potentially reduce the risk of further impacts developing later on. She will live with CMV her entire life. She is profoundly deaf and will navigate the world with cochlear implants and ASL. We, as her family, support her every step of the way for exactly who she is.

The State of Oregon clearly wants to do the right thing. ORS 433.298 and 433.321

aimed at solving for this, but they don't go far enough. We, and many other families, are proof of this.

HB2685 will ensure expecting parents learn about CMV from their prenatal care providers so they can be informed, assess their own risks, and make their own decisions about CMV - as they do with so many other factors of pregnancy.

HB2685 will ensure parents know if their newborn has CMV, and be given the opportunity to administer antiviral medications during the most critical period for effectiveness.

I want to thank Representatives Pham and Levy and their staff for their leadership and sponsorship of this important bill.

Andrew Sloan
Parent of an amazing girl with cCMV
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