

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

To the committee, thank you for your review of our written testimony. I am the parent of a child affected by cCMV and I am in support of HB 2685. My daughter Lilah was born with cCMV and it caused her to be small for gestational age, to have developmental delays with walking and eating, and to be Deaf, in a hearing family and hearing-centered world.

The moment after Lilah was born, I was terrified. She was so tiny, and so still. A second later when she started to cry, relief and gratitude coursed through me. I learned later that CMV, something I had heard of before, could have caused her instead to be stillborn, and another wave of gratitude crashed over me. I feel passionate about CMV awareness with the hope of preventing these more dire impacts for Oregon families.

I also feel passionate because living with CMV is a challenging experience for children and their families. And it is more challenging for families who do not have thorough insurance coverage, extra financial resources or other privileges we have. In Lilah's first two years, we have seen a long list of doctors and specialists, often 4-5 appointments per week. (It feels like we've met most of Kaiser's pediatric specialists!) Maintaining this workload of appointments, including critical early intervention sessions, are crucial for a child with CMV's best case of development. We consider ourselves lucky to be able to dedicate the time to give Lilah all these opportunities, and we know this isn't possible for many Oregon families.

We can do better. We can help prevent CMV.

One way is with a simple pamphlet. Our family received an excellent OHA pamphlet with helpful information about cCMV prevention, but after Lilah was already born and diagnosed and forever impacted. This timing felt like a failure of our public health system.

But I am a teacher and believe in our public systems.

I kept the pamphlet, because I hoped that someday I could show it to people who could change this. I am thankful for the chance to do so during our hearing with the committee. You can make this change.

Let's get this pamphlet to families during pregnancy, while it can make an impact. We

can do this with HB 2685. Thank you for your consideration.

Thank you to Representative Pham for your leadership and believing in our endeavor. Thank you to everyone who has championed for us. Thank you to the whole Oregon CMV Project team, we are lucky to know you.

Kathryn Dillon
Parent of an amazing daughter
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