

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 writing in support of HB 2685. (This serves to supplement the testimony I previously submitted).

My daughter Lilah was born with multiple impacts from cCMV. 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. She has been slow to meet most milestones, but she is making her own way through the world, and she is enjoying the journey. With CMV we live in limbo, as further impacts could surface down the road. My kid who loves using sign language, could lose her ability to see.

Lilah is an amazing, strong, resilient, joyful kid. We will cross future bridges as we come to them. We have had much good fortune on this journey so far. I want to share three reasons we feel lucky, which are not true for many Oregon kids with CMV, which are why I feel so passionate about screening and prevention.

1. Lilah gets to see every specialist possible to help her development. As a kid with multiple impacts from CMV, Lilah has often had 4-5 appointments each week. It feels like we've met most of Kaiser's pediatric specialists! Scheduling, organizing and advocating for these appointments is a huge workload. We consider ourselves lucky to be able to dedicate the time for these opportunities, and the insurance coverage to pay for them. The CMV hustle is an issue of equity. We need to prevent CMV as much as we can, to decrease this additional cause of inequity.
2. Lilah was tested for CMV at birth, and so has gotten to see these specialists from the time she was born. She also got to take the antiviral valganciclovir, which may have prevented more severe impacts. We need to screen all symptomatic babies.
3. Lilah is here. The moment Lilah was born, I was terrified. She was full term, but she was shockingly tiny. And she was so still. A second later when she started to cry, relief and gratitude coursed through me. I learned later that what caused her to be tiny CMV (something I had never heard of before), could have caused her instead to be stillborn, and another wave of gratitude crashed over me. We need better awareness and education around CMV and its prevention, to prevent these dire impacts. Oregon families deserve better.

There is no guarantee of preventing cCMV, but there are steps we can take to lower the risks of transmission. I was devastated to learn about these steps only after it was too late.

When I was 20 weeks pregnant with Lilah, she measured small on her anatomy scan. My OBGYN said that I should eat more avocados and referred me to a nutritionist. She did not mention CMV, despite my higher risks having a 1.5 year old toddler in daycare and being a teacher. We want OBGYNs to talk with patients about CMV. Our bill does not legislate the specifics of how to do this. We simply ask that OBGYNs share basic information with patients.

One way could be with a simple pamphlet. OHA has already prepared one, with clear, helpful information about cCMV and its prevention. Our family received it, but 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 timing. I am thankful for the chance to do so during our hearing with the committee. You can make this change.

Let's get this information to families during pregnancy, while it can make an impact. We can do this with HB 2685.

Thank you to Representative Pham for your leadership and believing in our endeavor. Thank you Representative Levy for your support as well. Thank you to Anna, Sara and everyone who has championed for us. Thank you to all of the families in the Oregon CMV Project team - you are a group of extraordinary parents.

Committee, thank you for your time and consideration.

Kathryn Dillon
Parent of an amazing daughter
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