Submitter: Lauren Green

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure, Appointment or Topic: HB2685

To Whom it May Concern, Id love to add my enthusiastic support for this bill. I am a mother of a deaf child. Till this day we have no known cause for his deafness. It haunted me for years.

What we do know is that Cytomegalovirus (CMV) is one of the number one causes of being born deaf, along with so many other ailments and handicaps it can cause (deafness, blindness, developmental delays, gross motor issues, sensory issues, enlarged spleen, enlarged liver, nervous system issues.. . to name a few). It is the most common infectious cause of birth defects in the United States. For that reason alone you should pass this bill. But another one is: I, along with most other mothers, have never once heard of CMV until after our baby was born (when there was nothing we could do at that point to prevent it). And there are common sense easy steps mothers can take during pregnancy to significantly reduce the risk of getting CMV, IF they are educated in advance during their pregnancy. But of course one cannot take steps in advance if they dont even know there is a risk to begin with. Mothers more than anyone want to do everything they can to protect their babies. Empower them with the education to do so.

Secondly, if once a baby is born, and flagged as having a risk factor (such as my baby who did not pass his newborn hearing screenings in the hospital within 24 hours of his birth) it would make enormous sense to test those babies ASAP for CMV. (Infact it is my opinion that all babies should be tested, regardless of risk factor, in case developmental delays dont appear for a few years down the road). This bill is proposing the very miminum of what should be done which is to test only babies flagged with a risk factor. Baby steps. It would make huge difference compared to what we have now- which is nothing. Oregon should at least do the very minimum!

Also I love that the bill proposes the CMV test within 14 days of birth. My baby tested negative on day 21 and only because we happened to have an appointment that day with an ENT to learn about cochlear implants and he, knowing timing was important, suggested it. (And again, neither my husband nor I ever heard of CMV!) General guidelines for testing recommend testing within the first 2-3 weeks of life, after that testing no longer works. Ive always wondered, since we tested on 21 on the very edge of that guideline would our test have turned out differently had we tested a week earlier? We will never know and we didnt have time to do a second test to double check. On, the other hand, had we had the appointment a week later- we never woudl have been tested at all.

Wouldnt it be amazing to just add this super simple test to the battery of tests that are already done when a baby is born? Its common sense and could make a huge difference for that baby and that family.

Having a new baby in your life is a whirlwind in and of itself. Having a baby born with an unexpected disability or delay can be absolutely crushing and hard to wrap your head around- not to mention time consuming and overwhelming. There are one million things you need to learn in the first few months of your babies life in order to support them (I felt that I could have written 3 textbooks by the time my baby was 6 months old). CMV wasnt something I thought anything about at the time, as there was a million other things to do and to learn. It wasnt until several years later, I learned a lot more about CMV, (after meeting other mama's who's deaf kids were born deaf due to CMV) and began to suspect it could very well be a cause of my son's deafness as well. But again we will never know for sure. And while I think I have finally made my peace with that- Id love to give the gift of knowing to other parents.

Please vote yes in support of this bill to give education to pregnant mothers on how to reduce risk of CMV and to require CMV testing to be done within 14 days of birth for flagged/at risk babies.