

Health, Human Services and Medicaid Committee
Chair Sen. Burke, Vice Chair Sen. Beagle, and Ranking member Sen. Tavares
Proponent Testimony

HB 165

Mr. Chairman and members of the the Health, Human Services and Medicaid Committee, my name is Amanda Fontana and I have a daughter Lilli, who is 16 years old and was born with Congenital Cytomegalovirus ("CMV").

When I was pregnant with my first child, I started having complications and was put on bed rest until my fifth month of pregnancy. During my last trimester my doctors noticed that my daughter was not growing so my labor was induced at 38 weeks' gestation. My daughter was born with a small head circumference, she was small for gestational age and she had to be kept under a lamp for hours because of jaundice.

I had no idea that anything might be wrong, 2 weeks after her birth I received a phone call indicating that my labs were sent to pathology. Apparently, the hospital ran some tests including a test for CMV which came back positive. They informed me that Lilli then had to be tested and this was the first time I had ever heard of something called Cytomegalovirus. At 6 weeks old my daughter was then diagnosed with congenital CMV. Despite all my complications, tests, ultrasounds, and countless doctors' visits the word cytomegalovirus was never mentioned until those two phone calls! So after coming home with what I believed was a typical, healthy baby I now have a baby with a CMV diagnosis. Little did I know that this one diagnosis would lead to many, many more issues.

Over the years, Lilli's disabilities came to light leaving her with a diagnosis of severe intellectual disabilities, global developmental disabilities, malnutrition, silent aspiration, anxiety disorders, profound deafness, low muscle tone, epilepsy, as well as currently being tested to see if she is on the autism spectrum. Lilli is unable to feed herself or use the toilet. She is unable to do routine living skills, including showering, dressing, or brushing her teeth. Lilli must have a caretaker perform these tasks for her. Our days are filled with doctor appointments, physical therapy, occupational therapy, and speech therapies. She has attended schools in our district for children with special needs and when her needs were not being met there she went to the Ohio School for the Deaf which is 2 hours away from our home.. Again, because of her complex needs it was not a good fit and now she goes to another school for kids with developmental disabilities out of our district. Even still, her needs are not being met. Even with me fighting as hard as I do, my daughter is still falling through the cracks. Her needs are so great that she requires 24-hour care and with this and the fact that in our area there are no day care facilities that take special needs kids it renders me not being able to work so we have to rely on the social security system and the welfare system for help financially.

I often think about had I only known about CMV could I have changed the outcome for my daughter and the answer to that is YES. Had my doctors and professionals provided me with education about CMV and what I needed to do to protect my unborn daughter than at 16 Lilli would be preparing to take a test to get her driver's license instead of having to be spoon fed by her mother. Please help us increase awareness and education of CMV to reduce the risk of this debilitating virus affecting more children and families in our state. I would ask you to support, H.B. 165 to ensure that more families are not impacted by the complications caused by CMV.