

February 19, 2015

RE: HB 5525 – An Act Concerning Cytomegalovirus

POSITION: Support

Dear Honorable Committee Chair Representative Gerratana, Chair Representative Ritter, and the distinguished members of the Public Health Committee,

I encourage you to support HB 5525 because I believe in the importance of cytomegalovirus (CMV) education to women and the early identification of children with disabilities.

I found out my daughter Gracie was infected with CMV while she was still in utero during our 18 week anatomy scan. This information was confirmed 6 weeks later through amniocentesis while I was spending the remainder of my pregnancy in the Maternal Special Care unit at Yale New Haven Children's Hospital due to her poor health. Gracie was born 2 ½ months early weighing just 2 pounds. We are

blessed she made it through her time in the Newborn Intensive Care Unit. Currently, Gracie is 5 years old (she will be 6 in two weeks!) and has taught me more about strength and will than I had ever known before she was born.

The effects of being born with Congenital CMV have left Gracie with profound bilateral deafness (she wears cochlear implants), severe lung disease for which we have oxygen at home for when she gets ill and her lung disease gets us admitted to the hospital numerous times each year. Gracie also has motor delays (she began walking when she was four) and severe feeding issues which has left her reliant on a feeding tube to get enough nutrition to sustain life as she will not orally eat. Finally and most recently Gracie was diagnosed with autism.

Had I been informed of CMV during my pregnancy and about preventative measures I could have taken during my pregnancy, I could have possibly saved my child from these lifelong disabilities.

Through my work with Stop CMV, I have learned about the simple steps I could have taken to prevent Gracie from being born with this virus. What has been most frustrating to me is the fact that I was informed about not eating soft cheeses and deli meat (to prevent listeria), to not clean kitty litter boxes (to prevent toxoplasmosis), to avoid alcohol (to prevent fetal alcohol syndrome) and to take an

adequate amount of folic acid (to prevent spinal bifida). If, according to the CDC, 1 in 150 children is born with congenital CMV, making it more prevalent than everything else I was informed of, why was I not informed on the simple step to reduce my risk of acquiring and passing along such a prevalent, preventable and destructive virus?

I strongly request your support for HB 5525 so that pregnant women can be informed of congenital CMV and the behavioral interventions associated with prevention.

Sincerely,

Casey Famigletti