

Casey Famigletti
232 Jonathan Road
New Canaan, Connecticut 06840
203-966-1025

Testimony of Casey Famigletti

IN SUPPORT OF HB 5147, AN ACT CONCERNING NEWBORN SCREENING FOR GLOBOID CELL
LEUKODYSTROPHY AND CYTOMEGALOVIRUS AND ESTABLISHING A PUBLIC EDUCATION PROGRAM FOR
CYTOMEGALOVIRUS

Before the Public Health Committee

February 28, 2014

As a concerned citizen of Connecticut and a mother of a child born with congenital CMV (cytomegalovirus), I am reaching out to you to request your support for HB 5147, "An act concerning newborn screening for globoid cell leukodystrophy and cytomegalovirus and establishing a public education program for cytomegalovirus".

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 (on Sunday!) and has taught me more about strength and will than I had ever known before she was born.

The effect 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 Yale Children's more numerous times each year. Gracie also has cognitive and 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. 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 if acquiring and passing along such a prevalent and destructive virus?

I strongly request your support for HB 5147 so that pregnant women can be informed of congenital CMV and the behavioral interventions associated with prevention.

Sincerely,

Casey Famigletti