

I am in support of:

H.B. No. 5147 (RAISED) AN ACT CONCERNING NEWBORN SCREENING FOR GLOBOID CELL LEUKODYSTROPHY AND CYTOMEGALOVIRUS AND ESTABLISHING A PUBLIC EDUCATION PROGRAM FOR CYTOMEGALOVIRUS.
PUBLIC HEALTH COMMITTEE

I am Kendra Matter, of Grafton Wisconsin, a wife, mother to two wonderful boys, and a Registered Nurse. One of my boys just turned 6, a birthday that should have been celebrated with his younger brother Braydon. Braydon passed away August 17, 2012, just 3 days after his third birthday from life long complications of Congenital Cytomegalovirus. I am a nurse, a labor and delivery and newborn care RN, who has been on a rollercoaster of unknowns since Braydon's first ultrasound at about 20 weeks gestation. Why did I know nothing about Congenital CMV? Why did the OB/GYN's that I worked with have minimal knowledge on what it was? Why did the Pediatricians I work with know of it as only something in text books? Why did the Specialists we seek out have no ideas of what care was best for Braydon? Why was there so little insurance coverage? Why were there other families who had traveled this same road and yet we didn't know so many existed?

It took multiple perinatology visits to finally discover that I had been exposed and had an active viral infection of CMV at about 8 weeks gestation, but the complications to our unborn child were not as easily diagnosed. I was monitored frequently, but there was very minimal information provided to us with what CMV involved or the damage that congenital CMV would bring to our son. Braydon was born at 5 pounds 13 ounces, and other than his head size, jaundice, hearing loss, and seemingly minimal initial affects; we were allowed to bring our son home. All of the infectious disease doctors were contacted at our local Children's Hospital, and each one had differing opinions on possible tests and trials that we could attempt. There seemed to be no consistency, or knowledge about what we could do for Braydon, or what the CMV had done to him.

Braydon incurred a life of physician appointments, surgeries, tests, and therapists. We were often told he was a "puzzle", but as parent's, my husband and I searched for answers and help throughout many differing health systems in Wisconsin. We adjusted our family life to accommodate caring from Braydon's needs, while attempting to work and fight for our son. He was a beautiful gift, a brown hair blue eyed little boy who had a huge heart! By the spring of 2012, Braydon had stopped maintaining his weight no matter what attempts we made with his G-tube feedings. He started to not be able to hold himself up, to communicate, and his pain became much more severe. We searched high and low for medical and natural methods to just keep our son comfortable. Only through a therapist's searching did we find out about Dr. Gail Demmler-Harrison in Texas and she was consulted by one of Braydon's doctors. Braydon never made it to Texas to see Dr. Harrison. Braydon's Palliative team did their best to search for dosages and medications that could manage Braydon's symptoms and control his pain, and yet we were led to Hospice care after Braydon's health continued to deteriorate. He eventually needed to be held as his only way of comfort, while we watched and waited, for our son's life to end.

As our family has began to come to terms with losing Braydon to CMV, our fight doesn't end. Where was the support? Why did no one know how to help him? Why could we not find answers to begin putting his "puzzle pieces" together? Throughout Braydon's life, he struggled with developmental delays, brain damage, eosinophilic esophagitis, acute colitis, hearing loss, pancreatic insufficiency, microcephaly,

grade 4 hydronephrosis reflux, growth retardation with complete feeding intolerance, seizures, and so much more.

Our family has been turned upside-down by this virus, and we now know we are not alone in that fact. There are many, many families whose lives have been turned upside-down by CMV. Our hope is to help other families from CMV, and to help educate the people that we rely to care for us and our children. Please do your part to help CMV prevention and education in the state of Connecticut. We are one, of now many families who are hoping to get similar bills in every state and beyond.

Thank you for your consideration.

Sincerely,

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