

Amanda Dawson

I support

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

I am the mother of a 6 month-old little boy born with congenital CMV (cytomegalovirus). It appears I caught the virus in the first month or so of the pregnancy and I assume it was passed from my 2.5 year-old daughter who attends daycare. I had never heard of the CMV virus before it was introduced to us as a problem after my 20-week ultrasound. I consider our family to be one of the “lucky ones” because we had early detection that resulted in receiving treatment during the pregnancy and my son receiving treatment as soon as he was born.

During these pregnancies we work so hard to protect our unborn children. We avoid medicines and foods that could lead to complications, we avoid sleeping on our back, we take prenatal vitamins to give them the needed nutrition...and these are just to name a few. We do these things because they are guidelines we receive in our doctor’s office and in medical books/web searches. After going through our experience with CMV and the lasting effects it has on our son, the lack of education and screening of this common virus is extremely frustrating. I wish someone had warned me about this virus. I wish someone had told me to take extra caution around my 2.5 year-old daughter while pregnant...to avoid kissing her on the lips, to never share food or drinks and to be extremely vigilant in my hand-washing. Maybe this knowledge would have protected my son from this virus.

Again I do consider us “lucky” because of the early treatment our son received. So far his only CMV-related complication is profound hearing loss in his left ear. We’ve had a ‘wait-and-see’ mentality for his entire life and unfortunately that will continue as he continues to be monitored for hearing and developmental delays.

CMV education and newborn screening is essential for every pregnant woman and I support all efforts to bring these bills forward in every state. I hope one day I am sending this same letter to my own state of Texas.

*Sincerely,
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