

Testimony
Public Health Committee
Proposed House Bill # 5525 An Act Concerning Cytomegalovirus
Friday, February 20, 2015

To the Chairs, Senator Gerratana and Representative Ritter, distinguished vice-chairs, Senator Crisco and Representative Riley, ranking members, Senator Markley and Representative Srinivasan, and committee members:

I am Farah Armstrong, President and Founder of Maddie's Mission in Katy, TX. As an individual who has been personally affected by the devastating effects of congenital CMV, I am in support of **H.B. 5525: AN ACT CONCERNING CYTOMEGALOVIRUS**.

I had never heard of CMV until one hour after my daughter, Madeline Leigh, was born on Jan. 31, 2014. There were no indications of a problem during my pregnancy. I was shocked to learn that I had contracted a PREVENTABLE virus during my pregnancy that was so devastating to my baby. Maddie suffered hearing loss, brain calcifications, liver and spleen damage, and her cerebellum (the portion of the brain that controls coordinated movement) had only formed 10%. Maddie spent ten days in the NICU before we learned the devastating news that she was terminal. My husband and I made the gut-wrenching decision to bring her home on hospice care. This is something no family should ever have to face. Maddie passed away after two days at home. She was only 12 days old. Knowledge about CMV and prevention measures could have prevented this tragedy.

My life is forever changed by this virus, and I do not want it to continue to take the lives of future babies if it can be prevented. Four hundred babies die each year in the U.S. due to complications from congenital CMV and 8,000 per year live a lifetime of suffering with developmental disabilities, hearing loss, vision loss, cerebral palsy, and many other devastating effects.

A few weeks after Maddie passed away, I founded Maddie's Mission, a non-profit organization in Katy, Texas. Our mission is to raise awareness about the harmful effects of CMV during pregnancy and to educate families about prevention measures. Maddie's Mission sponsors CMV awareness events throughout the Houston area, distributes CMV pamphlets to doctors' offices, daycares, and moms' groups, as well as hosts fundraisers to support CMV research and education. Unfortunately, we cannot possibly reach every woman that deserves to be educated about congenital CMV.

Therefore, state policy to mandate education for pregnant women and CMV screening for at risk newborns to minimize the incidence and severity of congenital CMV disease is imperative.

You may not currently have a pregnant wife, daughter, daughter-in-law, niece, granddaughter, neighbor, or friend, but chances are you will at some point in your lifetime. Please do not allow them to be blindsided by this devastating virus.

Thank you for your service to the state of Connecticut. Please support **H.B. 5525: AN ACT CONCERNING CYTOMEGALOVIRUS**. It is a very important health bill to ensure that every mother has a chance to protect her unborn child from cCMV.

Sincerely,

Farah Armstrong
CMV Mother of Madeline Leigh Armstrong
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