

HERE IS MY LETTER OF TESTIMONY AS A CONGENITAL CMV MOM:

Melvette Ruffin, Congenital CMV Mom

Email Subject: H.B. 5525

Testimony

Public Health Committee

Proposed House Bill # 5525 An Act Concerning Cytomegalovirus

Friday, February 20, 2015

To the Chairs, State Senator Carlo Leone and State Representative Terry B. Adams, US Senator Richard Blumenthal, US Senator Christopher Murphy and US Congressman Jim Himes, and committee members:

I am Melvette Ruffin, a mother and a concerned resident of Connecticut and am in support of H.B. 5525: AN ACT CONCERNING CYTOMEGALOVIRUS.

I am the mother of Jarred Ruffin, born severely disabled by congenital cytomegalovirus (or CMV) in 1989. No one warned me about congenital CMV until after Jarred birth--much too late to protect him from this number one viral cause of birth defects, which causes more disabilities than Down syndrome.

When Jarred was first born, I was devastated at his low birth weight and small head. After spending a couple of weeks in the hospital he had taken ill and was rushed to Norwalk Hospital NICU. Once he was diagnosed with congenital CMV, I was then told that women who work in daycare, or have a young child in daycare, are at a higher risk for catching CMV because toddlers are the majority of carriers. Pregnant women must use caution around a toddler's bodily fluids such as saliva. I was also told that the virus is very similar to the chicken pox family.

In milder cases of congenital CMV, children may lose hearing or struggle with learning. But Jarred's case was not a mild one. During his 25 years, my special young man has never been able to walk (quadriplegic) talk, he is hearing impaired, he wears diapers, and suffers from seizure disorder that is controlled through medication.

According to the Centers for Disease Control and Prevention, congenital CMV causes one child to become disabled every hour in the U.S. (See www.cdc.gov/cmV.) It is the leading non-genetic cause of childhood hearing loss. Of the more than 5,000 babies born disabled by congenital CMV each year in the U.S., 50 are estimated to be born in Connecticut.

Unlike most disabilities, CMV is preventable. With proper education, mothers can reduce the chances of passing it to their unborn children by avoiding kissing toddlers around the mouth or sharing utensils with them. While most expectant mothers know to avoid changing the cat box to prevent toxoplasmosis, which is a less common cause of birth defects than congenital CMV, less than 20% surveyed know how to prevent congenital CMV.

The CMV education proposed in the bill will not only prevent suffering, but it will also save Connecticut money. The cost of caring for one child disabled by congenital CMV is estimated at \$200,000 annually. Many years ago, my daughter's public special education program alone was estimated to cost \$40,000 per year--never mind the cost of major surgeries such as spinal fusion and frequent ambulance rides during prolonged seizures.

Scientists have been working on a vaccine against cytomegalovirus for years. One reason for delay in successful development is there has been insufficient education about the problem. Pharmaceutical companies need to know that a vaccine will be used because people know about the disease.

To help educate the public about congenital CMV, Please pass the bill H.B. 5525.

Sincerely,

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