

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, ranking members, and committee members:

I am Lisa Saunders, parent representative of the Congenital Cytomegalovirus Foundation, and am in support of H.B. 5525: AN ACT CONCERNING CYTOMEGALOVIRUS.

I was the mother of Elizabeth Saunders, born severely disabled by congenital cytomegalovirus (or CMV) in 1989. No one warned me about congenital CMV until *after* Elizabeth's birth--much too late to protect her from this number one viral cause of birth defects.

When Elizabeth was born, I was devastated by the sight of her small, deformed head. Diagnosed shortly thereafter with congenital CMV, it was then that I was told 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. While I was pregnant with Elizabeth, I ran a licensed daycare center. Nowhere in the licensing literature was there a CMV prevention message--and there still isn't in Connecticut.

In milder cases of congenital CMV, children may lose hearing or struggle with learning disabilities. But Elizabeth's case was not a mild one. During her 16 years of life, Elizabeth never held up her head, walked, or fed herself. She wore diapers, was visually and hearing impaired, and suffered from frequent bouts of pneumonia and seizures.

According to the Centers for Disease Control and Prevention, congenital CMV causes one child to become disabled every hour in the U.S. (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, 50 are estimated to be born in Connecticut. The cost of caring for one child disabled by congenital CMV is estimated at \$200,000 annually.

Passing H.B. 5525 will not only prevent suffering, but will also save Connecticut money. In 2014, when the similar proposed bill, H.B. 5147, was passed by the Public Health Committee and House, it was said to cost Connecticut \$40,000 to implement the first year. The cost of implementing a similar passed bill in Utah in 2013, H.B. 81, was \$30,800 per year. Many years ago, my daughter's public special education program alone cost \$40,000 per year--never mind the cost of her extra services and major surgeries, such as spinal fusion.

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, a less common cause of birth defects, less than 20% surveyed know how to prevent CMV.

To help educate the public, I wrote the book, "Anything But a Dog! The perfect pet for a girl with congenital CMV." but I need your help to ensure every mother has a chance to protect her unborn child from suffering as my daughter did until her death during a seizure at 16.

Please pass H.B. 5525.

Sincerely,

Lisa Saunders, Congenital CMV Mom
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Is there a test for CMV?

A blood test can be done to see if a woman already had a CMV infection. More invasive tests, such as amniocentesis, can help find out if your unborn baby is infected. However, these tests are not perfect. Consult your doctor about CMV testing if you are concerned that you became infected with CMV during pregnancy.

Good hygiene by pregnant women is still the best way to protect unborn babies against CMV infection.

What else should you know about CMV?

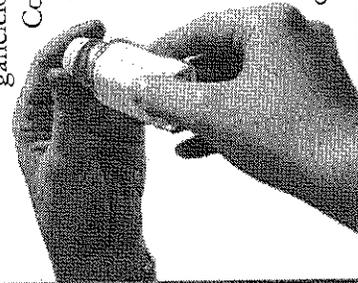
Most children and adults infected with CMV have no symptoms and may not even know that they have been infected. Others may develop a mild illness. Symptoms may include fever, sore throat, fatigue, and swollen glands.

Is there a treatment for CMV?

For pregnant women whose fetus might be infected with CMV there is no treatment. For infants born with severe symptoms the drug ganciclovir is sometimes used.

Consult with your child's doctor about this treatment.

Vaccines for preventing CMV infection are still in the research and development stage.

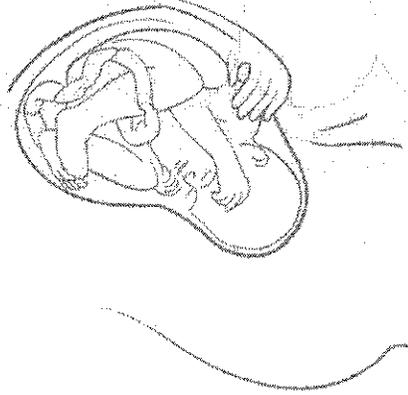


Definitions:

Cytomegalovirus (CMV) – a common virus that can cause disease in infants whose mothers are infected with CMV during pregnancy

Virus – a very small germ that causes a specific disease

Good Hygiene – washing hands, avoiding oral contact with urine and saliva



For more information about CMV, contact:

Division of Viral and Rickettsial Diseases
National Center for Infectious Diseases
Centers for Control and Prevention
1600 Clifton Road NE, MS G18
Atlanta, GA 30333

Visit the CDC website:

<http://www.cdc.gov/cmV>

What Women Should Know About Cytomegalovirus (CMV)

