

HB 5525  
Terry Bedard

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

My name is Terry Bedard, and I am a parent of a child with hearing loss and an attorney/advocate for legislation supporting those with hearing loss and their families. I am in support of H.B. 5525: AN ACT CONCERNING CYTOMEGALOVIRUS.

Congenital Cytomegalovirus, or cCMV, is the #1 viral cause of birth defects, causing more disabilities than Down syndrome. It causes mental retardation, liver disease, cerebral palsy and deafness as a result of infection in pregnant women. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. According to the Centers for Disease Control and Prevention, in the U.S.:

Every hour, cCMV causes one child to become disabled.

Approximately 1 in 150 children is born with cCMV infection (30,000 each year).

More than 5,000 babies born each year are permanently disabled by cCMV.

(See [www.cdc.gov/cmV](http://www.cdc.gov/cmV));

Congenital CMV 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 causes fewer birth defects than congenital CMV, less than 20% surveyed know how to prevent congenital CMV.

Doctors don't often warn their patients about congenital CMV prevention because they don't realize how prevalent it is. Fewer than half (44%) of OB/GYNs surveyed reported counseling their patients about preventing CMV infection. "The virtual absence of a prevention message has been due, in part, to the low profile of congenital CMV. Infection is usually asymptomatic in both mother and infant, and when symptoms do occur, they are non-specific, so most CMV infections go undiagnosed," according to the article, "Washing our hands of the congenital cytomegalovirus disease epidemic."

Certain women are more at risk for contracting CMV than others. According to Stuart Adler, M.D., "75% of women with a primary infection during pregnancy acquire CMV from their own child under two years of age." Data from a variety of day care center studies indicate that between 44 to 100% of two year olds at a single given time were shedding cytomegalovirus. Day-care workers are at greater risk than people who don't work in such a setting.

According to studies in the U.S. and France, congenital CMV is reduced when women are educated about prevention.

The CDC suggests the following steps to reduce chances of contracting CMV (See CDC: CMV Prevention tips at: <http://www.cdc.gov/cmV/index.html>);

Wash hands often with soap and water for 15-20 seconds, especially after wiping runny noses, changing diapers, picking up toys, etc. If soap and water are not available, use alcohol-based hand gel.

Use soap and water or a disinfectant to clean hard surfaces that have been contaminated by secretions.

Don't share food, drinks, or eating utensils with young children.

Don't kiss young children on the lips—give them a big hug and a kiss on top of the head.

If you work in a day care center, limit close contact with children younger than 2½ years of age, especially if you've never been infected with CMV or don't know if you've been infected.

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.

According to researchers and the Institute of Medicine, the annual cost of cCMV is \$1 - 4 billion. Using a conservative \$1 billion per year, the annual cost per disabled child is  $\$1,000,000,000/5139$  (children born disabled by cCMV) = \$194,590/year/child or approximately \$200,000 per child annually. The annual cost of caring for children disabled by congenital CMV in CT can be calculated: 36,359 births X .0013 cCMV disabled = 47 children X \$194,590/year/child= \$9,145,730, or over \$9 million annually to care for CT's children disabled by congenital CMV. "This figure is almost certainly an underestimate, especially now with enhanced mobility aids, surgical interventions, cochlear implants, antiviral therapies, occupational and physical therapies, etc., which were not likely included in the older cost estimates," says Dr. Demmler-Harrison, Director, Congenital CMV Disease Registry and Research Program.

Connecticut can reduce the suffering caused by cCMV by educating the public by passing H.B. 5525, which is similar to Utah's H.B 81 (2013) requiring its Health Department (Children's Hearing and Speech Services) to provide cCMV prevention brochures for doctors, parents, and daycare providers and test newborns for cCMV if they fail two hearing screen tests so their families can be educated about early intervention services and treatment options.

To see a list of sources for the above information, click on: Congenital Cytomegalovirus (cCMV) Fact Sheet\*

Sincerely,

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