

HB 5525

Krystyn Aquinaldo

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 Krystyn Aquinaldo-lokia, mother of a daughter severely affected by cCMV and 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. Congenital CMV is the leading non-genetic cause of childhood hearing loss. 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.)

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."

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 approximately \$200,000 per child. The annual cost of caring for children disabled by congenital CMV in Connecticut can be calculated: 36,359 births X .0013 disabled by congenital CMV = 47 children X \$200,000 mean that it costs over \$9 million annually to care for Connecticut'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.

In 2014, Connecticut's Public Health Committee and House of Representatives unanimously passed H.B. 5147, a bill similar to this year's H.B. 5525, but the Senate did not vote on it before the end of the

session. The cost of passing H.B. 5147 was estimated at \$40,000 the first year, \$26,000 subsequent years.

Connecticut can reduce the suffering caused by congenital CMV by passing H.B. 5525, similar to Utah's H.B. 81 (2013), which requires 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.

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

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.

I was never told about CMV at any prenatal OB/GYN appointments. I was never given any prevention measures, something as simple as washing your hands after changing diapers or while around small children. According to the CDC, CMV causes more disabilities than down syndrome. Oddly, not important enough to warn and educate pregnant mothers about this debilitating virus. When education, a simple pamphlet could reduce, even eliminate transmission of cmv to unborn babies. For my daughter Kulia Although failing 4 hearing tests (a distinctive sign of CMV) she went undiagnosed for months and failed to get proper treatment. Proper treatment with antiviral drugs which have been shown to help hearing, brain growth, increase head size and increase reaching developmental milestones. Currently Kulia is 18 months old and she has not reached any developmental milestones, she suffers from cerebral palsy, epilepsy, severe brain damage, intellectual disability and will be permanently disabled for the rest of her life. Kulia requires 24 hour care and supervision. Please help us educate women who are pregnant or who plan to become pregnant about the cytomegalovirus. Please help us raise awareness because CMV is the #1 cause of viral birth defects. This is reason enough. Thank you for your time and consideration on this extremely important bill. Please feel free to contact me at anytime.

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