



PRESS RELEASE

Mother Asks Residents of Connecticut To Support Public Education Bill to Prevent #1 Birth Defects Virus H.B. 5147 includes Cytomegalovirus (CMV) Public Education Program

Mystic, Conn.— Lisa Saunders of Mystic didn't know how to prevent contracting CMV (cytomegalovirus), which causes more disabilities than Down syndrome, until it was too late for her daughter Elizabeth born severely disabled by the disease. Women of child-bearing age in Connecticut are not being routinely advised on CMV's prevalence and how to avoid it just before or during pregnancy.

Saunders said, "My OB/GYNs didn't tell me how to prevent congenital CMV until *after* my daughter was born. Then I received literature stating women who work in daycare, or have a young child in daycare, are at higher risk for catching it as preschoolers are the majority of carriers. While I was pregnant with Elizabeth, I had a toddler plus ran a licensed daycare center. Nowhere in the licensing literature was there a CMV prevention message. In milder cases, children may lose hearing or struggle with learning. But Elizabeth's case was not a mild one.

At the time of Elizabeth's death at 16 during a seizure, Elizabeth had never walked, talked or held up her head. Cortically blind, Elizabeth was still in diapers and was beginning to lose her hearing. Pneumonia, epilepsy and surgeries had been a content source of suffering throughout Elizabeth's life.

Saunders, the parent representative for Congenital CMV (cytomegalovirus) Foundation, testified in Hartford on February 28 to the Public Health Committee in favor of H.B. 5147, which includes a mandate to education the public about Cytomegalovirus (CMV). Several medical doctors, including one from Yale University, posted letters in support: Click for Public Hearing Testimony.

According to one study, "fewer than half (44%) of OB/GYNs surveyed reported counseling their patients about preventing CMV infection" despite the following statistics from the Centers for Disease Control and Prevention (CDC):

- About 1 in 150 children is born with congenital CMV infection (approximately 30,000 children are born with congenital CMV infection in the U.S. each year).
- Congenital CMV causes one child to become disabled every hour.

## Click for the CDC's prevention tips.

Saunders is now asking the public to call or write to their <u>local representatives</u> and members of the <u>Public Health Committee</u> and ask them to support H.B. 5147. The <u>State of Utah</u> has already passed a similar bill. According to an article co-authored by Dr. Cannon of the CDC, "<u>The direct annual</u> <u>economic costs of caring for these children are estimated at \$1-2 billion</u>...by missing prevention opportunities, we in the medical and public health communities are washing our hands of the congenital CMV disease epidemic."

Saunders, who has written the happier side of Elizabeth's life in her memoir, <u>Anything But a Dog!</u> <u>The perfect pet for a girl with congenital CMV (cytomegalovirus)</u>, has provided a sample letter for Connecticut residents to use in support of <u>H.B. 5147</u> in her blog at: <u>http://congenitalcmv.blogspot.com</u> For more information about the Congenital CMV Foundation, which raises awareness about maternal testing for first infection during pregnancy, newborn testing and the need to develop a vaccine, contact Lenore Pereira, Ph.D., Congenital CMV Foundation founder and Professor, Microbiology and Virology, Cell and Tissue Biology Department, University of California San Francisco, at <u>lenore.pereira@ucsf.edu</u>, or visit <u>www.congenitalcmv.org</u>.

For more information about Lisa Saunders, see her short CMV interview in the <u>USA 9 News clip</u> or visit her at <u>www.authorlisasaunders.com</u>