



Elizabeth Saunders shortly after birth in 1989, with her mother, Lisa, and big sister, Jackie. | Courtesy of Saunders family

Saunders seeks help with CMV ‘silent virus’ prevention bill

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MYSTIC — Lisa Saunders is on a mission to make future mothers aware of the dangers of cytomegalovirus, a “silent virus.”

If you have never heard of the disease, that’s much of the problem because cytomegalovirus, or CMV, is a virus that causes more disabilities than Down syndrome — yet it’s a subject that obstetricians and gynecologists rarely discuss with their patients.

Saunders learned about CMV first-hand when her daughter, Elizabeth, was born in 1989, severely disabled by the disease.

Her daughter never walked or talked. She was cortically blind and suffered from epilepsy, pneumonia, cerebral palsy and seizures. She also lost her hearing as she grew older, the most common symptom of the disease. Throughout it all, Elizabeth held on bravely until 2006, when she died at the age of 16.

It’s possible that Saunders’ loss never had to happen.

“My OB/GYN never mentioned CMV until after my daughter was born,” she said.

It was only then that she was told that women who work in daycare, or women with children in daycare, are at a higher risk for catching the virus because preschoolers are apt to carry it. At the time, Saunders, a Cornell University grad, ran a licensed daycare center.

“None of the doctors of the licensing board said anything about it,” she said. “They call it a silent virus because there aren’t any symptoms.”

According to the national Centers for Disease Control and Prevention, about one in 150 children is born with congenital CMV infection, or about 30,000 in the U.S. each year.

Yet there are simple ways to prevent the spread of the virus such as not sharing food or towels with young children when you’re pregnant, precautions Saunders learned about only when it was too late.

For the last seven years, Saunders has spearheaded a statewide movement to make testing infants for cytomegalovirus immediately after birth a requirement as well as to mandate a public education program to inform pregnant women and women who may become pregnant about the virus.

On her side is state Rep. Elissa Wright (D-41st District), of Noank, who presented bill number 5147 to the Connecticut House of Representatives. Reps. Emmett D. Riley, Michelle L. Cook and Kevin Ryan quickly threw their support behind the proposed legislation.

Two weeks ago the joint Public Health Committee endorsed the bill, clearing the way for the House and Senate to approve the legislation. The committee received over 80 endorsements of the bill and no complaints against it.

Saunders has asked Connecticut residents to call or write to their own local representatives and ask them to support the bill. The State of Utah has already passed a similar bill. “It was the model for our bill,” she said.

A local author and a familiar face in Mystic, Saunders is the national parent representative for the Congenital CMV Foundation and has already testified in Hartford in favor of the bill.

Because of her high profile, she fields many questions from parents across the country whose children suffer from the disease.

“People contact me and it makes me feel sick. I wish I could have done something. These people are so horrified. Some worked in daycare and no one told them anything,” she said.

Her memoir about raising her daughter is the basis for “Anything But a Dog! The Perfect Pet for a Girl With Congenital CMV,” and the topic of CMV is also touched upon in another of her books, “The Mystic Seafarer’s Trail.” For more information about the Congenital CMV Foundation, which raises awareness about maternal testing for infection during pregnancy, newborn testing and the need to develop a vaccine, visit www.congenitalcmv.org.