

I am Lisa Saunders of Mystic, Connecticut, parent representative of the Congenital CMV (cytomegalovirus) Foundation and author of the book, *Anything But a Dog! The perfect pet for a girl with congenital CMV (cytomegalovirus).* *

I am in support of H.B. No. 5147, "AN ACT CONCERNING NEWBORN SCREENING FOR GLOBOID CELL LEUKODYSTROPHY AND CYTOMEGALOVIRUS AND ESTABLISHING A PUBLIC EDUCATION PROGRAM FOR CYTOMEGALOVIRUS."

I am a parent who didn't know how to prevent congenital cytomegalovirus (CMV) until it was too late for our daughter Elizabeth. The moment she was born the week before Christmas of 1989, my immediate thought was, "Her head looks so small—so deformed."

The neonatologist said, "If your daughter lives, she will never roll over, sit up, or feed herself." Elizabeth's birth defects were caused by congenital CMV. I was given literature stating women who work in daycare, or have a young child in daycare, are at a higher risk for catching it as preschoolers are the majority of carriers. Mothers should not kiss their toddlers around the mouth or share food with them.

Why hadn't my OB/GYNs warned me about this before—especially since, according to the CDC, congenital CMV causes more disabilities than Down syndrome? While I was pregnant with Elizabeth I had a toddler plus ran a licensed daycare center in my home. Nowhere in the licensing literature was a CMV prevention message. In milder cases, children may lose hearing or struggle with learning. But Elizabeth's case was not a mild one.

As my husband Jim watched Elizabeth struggle to breathe in ICU, all he could say was, "She needs me"—just like Charlie Brown with his pathetic Christmas tree.

Although my horror over Elizabeth's grim prognosis eventually gave way as my love for her grew, I had to watch her suffer through cerebral palsy; frequent pneumonia; major surgeries, including spinal fusion; and worst of all, seizures.

On Elizabeth's 16th birthday, I felt so proud of her. Weighing only 50 pounds, she looked lovely to us with her long, brown hair, large blue eyes and soul-capturing smile.

Although still in diapers and unable to speak or hold up her head, Elizabeth loved going to school and being surrounded by people.

Less than two months later, I dropped her off at school. Strapping her into her wheelchair, I held her face in my hands, kissed her cheek, and said, "Now be a good girl today." She smiled as she heard her teacher say, "Elizabeth is always a good girl!" That was the last time I saw her alive as she died hours later during a seizure.

While holding Elizabeth's body on his lap, my husband looked down into her partially open, lifeless eyes and cried, "No one is ever going to look at me again the way she did."

After presenting Elizabeth's story at the first international Congenital CMV conference at the CDC in 2008, mothers pushed their children towards me in wheelchairs and asked, "Why didn't my OB/GYN tell me how to prevent this?" One mother even asked, "Learning what you did, why didn't you shout it from the rooftops?"

Last summer, when Utah passed a bill similar to Connecticut's H.B. No. 5147, I finally felt hope that CMV prevention would become as famous as the "don't change the kitty

litter” rule when pregnant. Please do your part to shout CMV prevention from the rooftops by passing this bill.

Until OB/GYNs make CMV prevention a standard practice of care, I'm trying to "shout it from the rooftops" through my memoir, *Anything But a Dog! The perfect pet for a girl with congenital CMV*, and I am the parent representative of the Congenital CMV Foundation, which raises awareness about maternal testing for first infection during pregnancy, newborn testing and the need to develop a vaccine.

You have received testimonies in support of the bill from Yale University’s Dr. Eugene Shapiro, Professor of Pediatrics, Epidemiology and Investigative Medicine, and from Dr. Demmler-Harrison, Director, National Congenital CMV Disease Registry. According to Dr. Demmler-Harrison, “This bill simply supports education that will provide ‘three simple hygienic precautions’ that may save the life and well-being of an unborn child...In addition, it provides for testing newborns for congenital CMV who fail hearing screens...Treatment in randomized clinical trials shown to be beneficial is now easily available...and covered by medical insurance policies.”

The following statistics are from the CDC’s website at: www.cdc.gov/cmV

- CMV is the most common viral infection that infants are born with in the United States.
- About 1 in 150 children is born with congenital (present at birth) CMV infection. This means that in the United States, about 30,000 children are born with congenital CMV infection each year.
- About 1 in 750 children in the United States is born with or develops permanent problems due to congenital CMV infection. In the United States, more than 5,000 children each year suffer permanent problems caused by CMV infection.

Thank you for your consideration.

Sincerely,

Lisa Saunders, Parent Representative, Congenital CMV Foundation &
Author of *Anything But a Dog! The perfect pet for a girl with congenital CMV*
(*cytomegalovirus*)

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***ABOUT THE BOOK, "ANYTHING BUT A DOG! THE PERFECT PET FOR A GIRL WITH CONGENITAL CMV (CYTOMEGALOVIRUS)," WRITTEN BY LISA SAUNDERS AND PUBLISHED BY UNLIMITED PUBLISHING, LLC:**

This is the story of a mother’s humorous and moving search for one pet to suit two very different daughters—one a tomboy, the other mentally and physically disabled from the # 1 birth defects virus, congenital CMV (cytomegalovirus). Lisa Saunders says “no” to her daughter Jackie’s pleas for a dog, fearing it will be too rambunctious around Jackie’s disabled little sister Elizabeth. But she does make her a promise she thinks will never come to pass: “If God brings a dog to our door, then you can have it.” In the meantime, the family wrestles with a series of dysfunctional pets: a flesh-eating hamster, an attack cat, killer ants and a very stinky rabbit. Then one day, the unexpected happens: a shivering, dirty puppy shows up at their door. But is this dog really Heaven-sent?

Plus: The latest news on how to prevent the far-reaching but under-reported effects of congenital CMV, the #1 viral cause of birth defects-more common a cause of disabilities than Down syndrome. It also contains highly useful sections with Resources, Contacts and Support for anyone whose life is touched by CMV.