

Family Health

The Tragic Kiss

Suffern mom works to spread the word about CMV

By Lisa Saunders

Did you know that when a pregnant woman kisses a young child on the cheek, she is risking mental retardation and hearing loss for her unborn child? That daycare workers are also putting their unborn children at risk? Most women don't, and when I was pregnant with my daughter Elizabeth, I didn't know either.

The moment Elizabeth was born, I knew there was something very wrong. My immediate thought was: "Her head looks so small — so deformed."

The neonatologist confirmed my fears. "Your daughter has profound microcephaly," he said. "Her brain is very small, with calcium deposits throughout. If she lives, she will never roll over, sit up, or feed herself." He concluded that Elizabeth's birth defects were caused by congenital cytomegalovirus (CMV).

CMV, known as a "silent virus", causes either flu-like symptoms or no symptoms at all in the mother. The infection in healthy children and adults does little harm, but it is devastating to the unborn.

My obstetrician had never warned me about CMV, but I soon learned that women who have young children at home or who work in daycare centers are at a higher risk for catching it because preschoolers are the majority of carriers, shedding it through their saliva and urine. Women get the child's saliva or urine on their hands and then touch their nose or eat something without washing their hands first, allowing the virus to enter.

While I was pregnant with Elizabeth, I not only had a toddler of my own, but also ran a licensed daycare center in my home and cared for infants in Sunday school. I felt sick at what my lack of knowledge had done to my little girl. In milder cases, children with congenital CMV may lose hearing or struggle with learning disabilities later in life. But Elizabeth's case was not a mild one.

so proud on Elizabeth's 16th birthday. She had fought hard to stay with us, surviving several bouts of pneumonia, seizures, and the crippling effects of cerebral palsy. Weighing only 50 pounds, she looked funny to strangers, with her small head and big adult teeth, but she was lovely to us. Although Elizabeth was still in diapers, and could not speak or hold up her head, she was a happy young lady, with a love of adventure — long car rides being one of her favorites. She especially enjoyed going to her special-ed school and being surrounded by people, paying no mind to the stares of children who approached her in public.

Less than two months later, I dropped Elizabeth 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 what she said every time, "Elizabeth is always a good girl!"

At the end of the day, I got the call I had always feared. "Elizabeth had a seizure and she's not breathing. We've called 911."

The EMT workers and doctors did

all they could, but Elizabeth was gone. While holding her on his lap in the hospital, my husband, Jim, looked down into Elizabeth's partially open, lifeless eyes and cried, "No one is ever going to look at me again the way Elizabeth did." I knew he was right. No one adored us as Elizabeth did.

It has been more than a year since we lost our little girl. At times I miss her so much I can barely breathe. Yet at other times, I feel happy for her —

never again will I see that look of terror in her eyes as a seizure begins and she can't catch her breath. Never again will she be cold or sick. She is finally free. For the remainder of my days, Elizabeth will be forever "Sweet Sixteen".

Today, my sorrow is gradually being replaced by a passion to prevent others from going through what Elizabeth experienced. According to the Centers for Disease Control and Prevention (CDC), about 40,000 children a year are born with congenital CMV infection, and approximately 1 in 750 children is born with or develops permanent disabilities due to CMV. It is a more common cause of disabilities than Down syndrome, and is the leading viral cause of mental retardation and hearing loss.

I contacted Dr. Scott Schmid, leader of the herpesvirus team at the CDC, to learn more about the prevalence of disabilities caused by congenital CMV infection. He wrote to me: "It is difficult to arrive at precise estimates for the disease burden of congenital CMV disease, primarily because the overwhelming majority of cases are not evident at the time of birth, and it is not usually possible to establish a definitive causal association with CMV more than a few weeks following birth. In many instances, the development of symptoms, such as neurosensory hearing loss and mental retardation, may not manifest for a year or longer. However, using available CMV studies and other available data, we estimate that between 4,000 and 11,000 new cases of congenital CMV disease occur every year in the US. This represents a range of between 1/360 to 1/1,000 births (0.1 to 0.3 percent)."

If there are ways to prevent congenital CMV, then why aren't women of childbearing age routinely being told about it? According to the 2005 article, "Washing Our Hands of the Congenital Cytomegalovirus Disease Epidemic", published in *BioMed Central Public Health*, Dr. Cannon and Davis write: "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." Drs. Cannon and Davis conclude: "Given the present state of knowledge, women deserve to be informed about how they can reduce their risk of CMV infection during pregnancy."

What can you do to avoid contracting CMV?

According to the CDC, no actions can eliminate all risks of becoming infected with CMV, but there are measures that can reduce the spread of the disease:

—Wash hands often with soap and water, especially after changing diapers. Wash well for 15 to 20 seconds.

—Do not kiss young children under the age of 5 or 6 on the mouth or cheek. Instead, kiss them on the head or give them a big hug.

—Do not share food, drinks, or utensils (spoons or forks) with young children.

—If you are pregnant and work in a daycare center, reduce your risk of getting CMV by working with children who are older than 2 1/2 years of age, especially if you are CMV seronegative (have never been infected with CMV) or are unsure if you are seronegative.

Learn more about CMV

—Visit the Centers for Disease Control and Prevention at www.cdc.gov/cmrv

—Visit the National Congenital CMV Disease Registry at www.bcm.edu/pedi/infect/cmrv

LISA SAUNDERS lives in Suffern with her husband, Jim. A staff writer for SUNY Rockland Community College, she has authored a book of Civil War love letters, "EVER TRUE: A Union Private and His Wife" (Heritage Books), a children's novel, "Ride a Horse, Not an Elevator," and "Forever Sweet Sixteen", an inspirational look into life with her daughter. For more information, visit www.authorlisaanders.com.



Sixteen years later, I awoke feeling