

"Elizabeth: A Christmas Blessing Always"

Expecting our second child, due to arrive Christmas Eve of 1989, had been a delightful experience. What a Christmas present! But the moment Elizabeth was born, I felt a stab of fear. I knew there was something very wrong. My immediate thought was, "Her head looks so small--so deformed." Before she was twelve hours old, I found out why.

When the neonatologist entered my room the following morning, he said, "Your daughter has profound microcephaly--her brain is extremely damaged 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) — a virus that may have no symptoms for the mother, known as a "silent virus," or it may present itself with mild to severe cold-like symptoms.

The Centers for Disease Control and Prevention states that approximately 8,000 babies a year are born with or develop permanent disabilities because of congenital CMV. It is more common a cause of disabilities than Down syndrome.

How and why did I catch this virus that I had barely heard of? I read the CMV literature. It stated that women who care for young children are at a higher risk for catching it because it is frequently being shed in the saliva and urine of toddlers.

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. 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.

"My life is over," I thought. I asked God to heal her instantly, but since He didn't, I begged him to strike me dead. I just couldn't handle raising such an afflicted child, period. Although children are supposed to be a blessing, I felt far from blessed--I felt stricken.

Thankfully my husband Jim's love for Elizabeth far outweighed his grief. He said, "She needs me. I want to protect her from this cruel world she has been born into." He was just like Charlie Brown with that pathetic Christmas tree.

"Oh God," I prayed, "please help me love Elizabeth too."

We took Elizabeth home Friday morning, December 22. Although Elizabeth was no longer at death's door, my horror over her prognosis had not left. But I had to fight through it; Christmas preparations needed to be made. Christmas had not turned out as hoped.

Initially, whenever I looked upon Elizabeth, my heart broke afresh--all I could see was her prognosis. It was as if the prognosis was more of a person than she was. This "prognosis" was like a living creature relentlessly torturing me. I couldn't seem to get past it and see Elizabeth for the sweet little girl she was.

In those early months of Elizabeth's life, it seemed all I could do was rock Elizabeth and read the book of Psalms. Many of the psalmists wrote things I wouldn't dare say to God. They questioned His love and power, thus helping me to honestly express my grief to God. I could relate to the writers' pain and feelings of abandonment as they waited on God's deliverance. Knowing I wasn't the only one despairing of life made me feel less alone in my anguish.

Elizabeth loved to be held--something my first-born daughter Jackie never enjoyed. Seeing Elizabeth rest contentedly in my arms brought me pleasure. One day, she looked directly into my eyes and smiled. We had finally connected! I eventually stopped asking God to kill me. Like George Bailey standing on the bridge at the end of the movie, "It's a Wonderful Life," I too began to cry, "I want to live again!"

Years later, I awoke feeling so proud on Elizabeth's 16th birthday, one week before her 17th Christmas. Listening to nostalgic songs like, "I'll be home for Christmas," I thought about how hard Elizabeth fought to stay with us each Christmas--overcoming several battles with pneumonia, recovering from major surgeries and most recently, seizures. Weighing only 50 pounds, she looked funny to strangers as a result of her small head and big adult teeth, but she was lovely to us with her long, thick brown hair, large blue eyes and soul-capturing smile. Although Elizabeth was still in diapers, and could not speak or hold up her head, she was a very happy young lady with a love of adventure — long car rides being one of her favorites. She especially enjoyed going to school and being surrounded by people, paying no mind to the stares of other children who approached her in

public. Unlike Rudolph the Red-Nosed Reindeer, she had no desire to live on the Island of Misfit Toys.

Less than two months after she turned 16, 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!" With that, I left.

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

The medical team did all they could, but she was gone. While holding Elizabeth 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 Elizabeth did." I knew he was right. No one adored us as Elizabeth did. Although I was happy that she was free from her body, I knew it might be a very long time before we crossed the great divide to join her.

Today, my sorrow is gradually being replaced by a passion to prevent others from going through what Elizabeth did. Although congenital CMV is the #1 viral cause of birth defects, OB/GYNs still do not routinely warn pregnant women how they can avoid it, so for now, it is up to parents like me and CMV experts to warn the public. The CDC recommends that pregnant women:

#Do not kiss young children under the age of five or six on the mouth. Instead, kiss them on the head or give them a big hug.

Do not share food, drinks or utensils with young children.

#Wash hands often with soap and water, especially after changing diapers.

As I prepare to celebrate what would have been Elizabeth's 20th Christmas had she lived, it is with some heartache that I lift the holiday decorations from their boxes. Elizabeth used to love to sit on the couch with her formerly homeless, old dog Riley, and watch me decorate. But now our family has a new Christmas tradition: I open Elizabeth's drawer and pull out the black and red checked shirt she wore on her last day with us and drape it over an empty chair placed beside the fireplace. I still feel she is my Christmas blessing, my "Tiny Tim," saying, "God bless, everyone!"

I wrote my latest book, "Anything But a Dog! The perfect pet for a girl with congenital CMV," which is about my search for a suitable pet for Elizabeth and her big sister, Jackie, to raise awareness and

funds for congenital CMV research. The last chapter includes CMV prevention and treatment tips; ways the general public can raise awareness and encourage OB/GYNs to warn their patients; and organizations that help families affected by congenital CMV. Available through the National Congenital Disease Registry, "Anything But a Dog!" raises funds for congenital CMV awareness/research and parent support if purchased through:
<http://www.unlimitedpublishing.com/cm/>

Copies of "Anything But a Dog!" are available to members of the working press by contacting 800-218-8877 or news@unlimitedpublishing.com. For permission to publish an excerpt, contact: ops@unlimitedpublishing.com

Thanks for reading my story!

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