

My life changed forever on January 31, 2014. My daughter, Madeline Leigh, was born that morning and life seemed absolutely perfect for a short while. An hour later our world caved in. My husband, Patrick, and I were surrounded by doctors and nurses in the delivery room and were being bombarded with information about cytomegalovirus (CMV), which our neonatologist suspected I had contracted while I was pregnant.

Devastating News

We were absolutely shocked because we had never heard of this virus until that moment. The neonatologist informed us that Maddie was born with a rash on her body, called petechiae, and a condition called microcephaly (small head size), which were indications of congenital CMV. We were told that Maddie might be deaf, blind, and suffer developmental disabilities. We were completely devastated. This simply didn't seem possible.

We later learned that toddlers who attend child care often contract CMV from their peers and bring it home to their families. We were shocked to learn that I could have contracted a virus from my 2-year-old that was so devastating to my unborn baby.

Praying for a Miracle

At this point we were hoping and praying for a miracle. Unfortunately, Maddie's blood and urine tests confirmed that she had congenital CMV and the MRI confirmed our worst fears. She had suffered tremendous brain damage and may never have coordinated movement. The thought of our precious baby suffering throughout her life was unbearable.

A few days later, we were hit with more unexpected news. Maddie was terminal. Her liver was shutting down and the neonatologist was not sure if she would live a few more days, weeks, or months. We made the tough decision to bring our daughter home on hospice care. Maddie passed away after two short days at home. She was only 12 days old.

Mom on a Mission

The pain of losing our daughter is indescribable. However, our faith and the loving support of family and friends helped us persevere one day at a time.

A few weeks after Maddie passed away, her purpose on this earth became clear, and her mission was born. Maddie's Mission, a non-profit organization in Katy, was formed to educate families about the harmful effects of CMV during pregnancy. We spent the next 18 months conducting grassroots CMV awareness events throughout the

Houston area, distributing pamphlets to doctor's offices, daycares, and mom's groups, and planning fundraisers to support CMV research and education. We also worked with a team of Texas CMV moms and expert, Dr. Gail Demmler-Harrison, to pass a CMV education law in Texas, which became effective on September 1, 2015.

I am fully committed to increasing awareness of congenital CMV because I do not want other families to suffer the pain that my family has endured. I lost one of the most precious gifts of my lifetime, my sweet baby girl, to this preventable virus. However, I am honored to spend my life fulfilling my daughter's purpose. I am also overjoyed that Maddie's Mission has joined forces with Stop CMV, Utah CMV Council, and the National CMV Foundation as of January 1, 2016 under the umbrella of the National CMV Foundation. I look forward to the opportunity going forward to serve as part of the National CMV Foundation and to make a larger impact nationally in the fight against congenital CMV.

Finding Blessings

My family is very blessed that our story does not end in tragedy. On October 12, 2015 we welcomed a healthy baby boy named William Patrick into our family. God's timing was truly perfect as it gave us time to heal and pursue Maddie's purpose in this world.

Maddie will forever hold a special place in my heart. I think about her constantly and know that she is smiling down on our family from heaven. I will rejoice in seeing her again one day in the future. KM

To learn more about CMV, visit nationalcmv.org.