

The parents of National CMV come from all walks of life and all around the globe. Some of us knew about CMV (cytomegalovirus) very early, and others did not until months or years after our children were born. Our stories are all very different, but there is one commonality between us all: our lives were changed by CMV, for better and for worse. We share our stories, our joys and fears, our struggles and our successes, in hopes that we can help others learn what it's really like to live with this diagnosis.

“The first time I see my daughter, we are baptizing her because she may not live. She is dying. There is no moment where they hand her to me, no moment when I take her face in and know that she is mine. There is, instead, a moment when I look at her and I don't understand what went wrong. Why it is that I expected a healthy baby girl and instead I am looking at a dying neonate? I make myself take pictures of that moment, of us as a family, because I still hope that someday this moment will just be ancient history.” – Lauren Grace’s Story, Iowa

“I remember sitting in the doctor's office at 22 weeks. They told me if I wanted to terminate, they would set me up with a doctor in another state, since it was no longer legal in mine. I was a single 19-year old sitting in a doctor's office in tears. It was the most important decision of my life. I had no one to talk to. I wish I had known about National CMV.” – Logan’s Story, Connecticut

“I received two IV infusions of CMV immunoglobulin and went for another ultrasound at the end of the week. Two perinatologists came in to complete the ultrasound. As they looked at the monitors in silence, I began to cry. The ascites in our baby boy's belly had gotten so much worse. It had also spread to his chest, arms, and legs. His liver was enlarged and damaged. I had barely any amniotic fluid left. I was 23 weeks pregnant. I was induced that night. We understood that our baby would die during the labor and delivery process.” – Milan’s Story, Illinois



“The ultrasounds were never simple. There was always something wrong - usually something minor, but always something. My amniotic fluid was always low, sometimes dangerously low, and the baby had extra fluid around her heart (pericardial effusion)... By the end of my pregnancy, I was going to bi-weekly ultrasounds and wondering if my baby was going to survive. We had no idea what was going on.” –Kaitlyn’s Story, North Carolina

“When I looked at him, I noticed he was covered in red dots... I asked the nurse why he was covered in dots, and she said some babies are born like that... When she came back, she had the pediatrician with her. He told us that Dalen would have to stay in the NICU because he had an enlarged spleen and liver. He didn't know what was wrong with him. My heart sank. I felt like I was in a show on the Discovery Health Channel.” – Dalen’s Story, Mississippi

“He was a very bright boy early on, teaching himself how to read at age two but not learning how to walk until age 2-1/2. At age 5, he was diagnosed with ADHD and takes medication to help him at school. At age 7, Jeb was diagnosed with an autism spectrum disorder, pervasive developmental disorder (PDD-NOS).” – Jeb’s Story, Wisconsin

Read more CMV parent stories from around the United States and the world at www.NationalCMV.org