

Parent Story of Cytomegalovirus (CMV)

I found out I was pregnant in April of 2014 and I was excited like any other mother who had been wanting another child would be. I would say my pregnancy was just like any other pregnancy until I hit my 30 weeks. I had the usual morning sickness and tiredness, and I don't remember feeling flu-like symptoms during the first trimester of my pregnancy.

Once I hit 30 weeks, her ultrasounds started to show that she was not growing like she should have been. From there on I had Non –Stress Test (NST) and ultrasounds twice a week. I had a scheduled c-section for November 30, but on November 11 I went in for one of my regular NST visits, and Gabriella's heartbeat wasn't coming back quickly enough after my contractions. We went to Sparrow right from there and at 2:32 I was holding my Gabriella, who was 3 pounds 11 ounces.

She cried like any normal baby at birth. She was in the NICU which was already prepared to take her since she was born early and had already had complications during pregnancy. I remember asking my mom what these red spots were all over her chest; the Dr had told me that it is common for babies born with congenital CMV to have these spots.

I had never even heard of CMV, and why wasn't I tested for this while I was pregnant like I was tested for everything else? I had been in contact with CMV while pregnant in my first trimester and I never knew it. CMV is very common to get and it only affects us like a cold. Gabriella was tested for congenital CMV and a week later we got her results back that she was positive for Cytomegalovirus.

One day I went to go see Gabbie in the NICU and instead I was sent to a conference room where I was greeted by Dr Schein. She informed me on what was possibly going to happen in Gabriella's future - hearing loss, vision loss, mental retardation, low immune system, liver inflammation, cerebral palsy and epilepsy. Gabriella was born with a smaller head than normal, low white blood cell count, cysts and bleeding on her brain, and she had to have two platelet transfusions. We stayed in the NICU for two weeks and I was able to take her home the day before Thanksgiving. We saw multiple doctors for many months while she was also taking a medicine called Valganciclovir to help reduce her health risks.

She passed her hearing screen at birth, but about 6 months old she started failing them. We were referred to Motts Children Hospital to see a specialist, a neurologist, and an audiologist. Gabriella had mild to moderate hearing loss in her right ear and would need a hearing aid. It was to my understanding, and how it was explained to me, that CMV can come back at any

time and become reactive and give her side effects, just like Chicken pox comes back as shingles. So I was aware that her hearing could potentially get worse. And it did, a few months after we received her hearing aid we went in for another hearing test. Results came back that she is profoundly deaf in her right ear and has mild to moderate hearing loss in her left ear. We got a mold for her hearing aid to be switched to her left ear and the doctor suggested a cochlear implant for her right. She also failed a vision screen and we have an appointment coming up for that. My daughter is 17 months and has motor delay, very little speech, she has problems eating and she only weighs 20 pounds. I have decided that I need to start thinking of a second form of communication so I have looked into sign language. I've done my research on implants just like any worried mother would do, and we will go for her sedated MRI soon to have ABR (automated brainstem response) testing and the neurologist will look at her brain. If any women plan on getting pregnant, or are pregnant, I suggest getting tested for CMV and know the precautions to take to help prevent it if you have never been in contact with it.

