

## Daisy's Story



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Daisy Emma was born on March 9, 2011. The c-section was routine, Daisy looked beautiful and she nursed right away. During our five-day hospital stay, Daisy had a newborn hearing screening - she actually had several because she just wasn't passing them. I was assured that it was simply amniotic fluid in her ears and there was nothing to worry about. While we were there, because she had a large fontanel, she also had a head ultrasound and an MRI that revealed some possible cysts or calcifications in her brain. The pediatricians told me that it was likely I had gotten sick during my pregnancy and that it may have caused a hiccup in her development, but that there was nothing to worry about. When Daisy was two weeks old, we had a follow up hearing screening. Daisy didn't pass the screening and so the audiologist performed an ABR. The results of the ABR did show some mild loss, but the audiologist said that it may have been because she woke up during the ABR and that we didn't need to worry about it, just to follow up when she was one year old for sound booth tests. We discussed the results with our pediatrician and he agreed. I asked about any possible connection to the MRI results and was told there was none. Daisy developed typically for the first year. We had Daisy's hearing tested again at one year in the booth and the audiologist had no concerns. That spring and summer, Daisy had several ear infections. We were referred to an ENT for follow up at 16 months. At our first appointment, booth testing showed some hearing loss. The ENT quickly moved to put tubes in to see if they would help and to test for CMV. Immediately after reading her chart and seeing the MRI report, he suspected congenital cytomegalovirus (CMV). Daisy got tubes in August 2012 and the same week, we found out she had the antibodies for CMV. Researching CMV was shocking, over and over again. I was a special education teacher. My parents both have PhDs in special education. I was a well-informed mom

and had red tens of books on pregnancy. Why had I never heard of CMV? In September 2012, Daisy had a sedated ABR that showed mild to moderate hearing loss in her left ear and severe-profound hearing loss in her right ear. By November, she had a profound loss in both ears. We were blessed to immediately be surrounded by great support. We were referred to an ENT at the University of Utah who is familiar with CMV. He was able to obtain her dry blood spot and test it for CMV. It showed evidence of CMV at birth, so he was able to diagnose her with congenital CMV. She immediately began to receive early intervention services. Daisy had bilateral cochlear implant surgery on December 7, 2012 and was activated two weeks later. She did well for a while but then her maps became less stable and she didn't seem to be hearing as well. She had revision surgeries in December 2014 and February 2015 and it made a world of difference. Daisy just finished mainstream kindergarten and is doing excellent. In Fall 2017 she will start a dual language immersion program at our local elementary school where she will attend half day in Portuguese and half day in English. She is excited! The journey to implants that work and to getting the services she needs on her IFSP and IEP has not been an easy one. We have had to go to mediation with the school district and the school for the deaf and the blind multiple times to ensure she gets what she needs. I anticipate that struggle isn't over and we'll have to keep fighting to get her the accommodations and help she might need in the future.