

Thank you for taking the time to read my written testimony about CMV and why early detection/education is crucial.

You heard my spoken testimony that our son James tested positive for cCMV at three months old. He failed his newborn hearing screening and at six weeks we first saw a pediatric audiologist. Those six weeks of waiting were full of anxiety and uncertainty. How did James have hearing loss? We are a blended family and this was mine and my husband's first child together, but our other children don't have hearing loss and we don't have it in our family. It was at that six week appointment we learned James had severe/profound hearing loss in his right ear, and moderate hearing loss in his left. Our audiologist told us transparently to anticipate his hearing to continue to decline.

We began to process hearing loss as a family and recognized the need to learn ASL. James got hearing aids around 10 weeks old. At this point, we were coming to terms with James' hearing loss and how it would affect his life.

We decided to do genetic testing to try to find the cause of his hearing loss. Was this something that's genetic and would affect future generations in our family, or was this isolated to James? Our genetic doctor met with us to tell us that the hearing loss wasn't genetic and that conversation was the first time I had ever heard of CMV. She advised James be tested, and we quickly received the diagnosis.

We had just begun to feel we were in a decent place with processing his hearing loss and hearing aids, but then we needed to learn about CMV. We received a diagnosis, and I was provided absolutely nothing with regards to information on CMV. No plans on how to address it, no one to answer my questions, and no information on what was next for us. So I began to do my own research. I found groups online and panicked as I watched other mom's on a Facebook group lose their kids to CMV. I felt lost and discouraged, and betrayed by mine and my child's medical team.

I received a call from a non profit called Hands & Voices and was connected to Stephanie, who you heard testify today. It was with her that I had one of the first real conversations about CMV—with another mom who understood and had walked the road I was beginning. She provided me guidance and connected me to other moms, and it's us who are here today. Through other parents I learned what I needed to advocate for, something I expected to hear from my child's medical team.

When James' pediatrician learned of his diagnosis, he shared he didn't know much about CMV and wasn't sure what things would look like for James. I had so many questions and did not have a medical provider to go to.

When James' hearing declined further and we were given the option of a cochlear implant, I was told he'd need an MRI of his ear. I used this as an opportunity to advocate for a full brain MRI after research showed me the damage CMV can cause to a brain. I received pushback that they were only concerned about the formation of his ear at this point and wanted to make sure he could get a cochlear implant and was told there's no reason to sedate him for longer when we have no reason to believe there's damage to the brain.

I asked for a referral to an infectious disease doctor, I received pushback that that wasn't necessary. I fought until it happened. In meeting with Dr. Baker, she advocated for a full brain MRI, vision testing, and early intervention. She felt like a miracle for us.

James wasn't meeting his milestones, he couldn't keep his head up, couldn't roll over, couldn't sit up, etc. I watched children his age reaching their milestones and felt alone wondering how long I'd have to wait to have people understand his diagnosis and need for services. I advocated for the referral to early intervention and physical therapy and received pushback. I was told all kids develop at differing paces and to "give it time."

But that is the problem. These kids and families affected by CMV don't have "time" to just wait and see. Parents receiving prenatal care need to have the information provided to them about CMV so they can take precautions during their pregnancy. Parents aren't able to make an informed decision without the proper information. When a child fails a newborn hearing screening, a discussion and testing for CMV should be the natural next steps. Given that James didn't receive his diagnosis until three months old, we missed the window of opportunity for any medication for him. We weren't able to make informed decisions on behalf of our child, because we didn't have the information.

I am privileged that we are the point that James has a phenomenal team. He's got the best audiologist who will always advocate for him, a physical therapist who challenges him and fights on his behalf with insurance, early intervention who helps us navigate his varying needs and development, a speech therapist who believes in him, and an ophthalmologist who looks forward to seeing him every six months, and shares with transparency that because of CMV, glasses are on the horizon for him. But this team didn't just "show up," it took a lot of advocacy. I believe every parent should have the information about CMV during their prenatal care. Yes, we are fortunate that we learned of James' diagnosis at three months, but we should have known sooner. It's crucial for parents to know in advance so these children can get the services that they need.

Thank you for your time and willingness to read this testimony and consider this bill.