Kassandra’s CMV Story: A Parent Leads Advocacy to Advance Awareness

When did you find out your child had CMV?

I found out that my daughter Nova was born with congenital CMV when she was about 3 years old. Unfortunately, our local hospital did not screen for CMV at birth when she failed her newborn hearing screen. By the time I learned of CMV as a possible cause of her hearing loss, I also learned that she was outside of the critical testing window, which is within the first 21 days of life. Without blood or urine from those first 21 days, it was next to impossible to confirm if she had CMV in utero. Then the impossible happened. One afternoon, I was going through a box of baby memorabilia and I found the clamp to her umbilical cord that I had saved when it fell off at 7 days old. To my surprise, it had the tiniest spec of dried blood on it. With the help of one amazing medical team, we were able to test the dried blood spot and confirm she had past CMV infection.

When was CI presented as an option and how was the process for you? Denials? Hard? Easy?

Our goal from the very beginning was to give Nova as much access to sound as we possibly could. Her hearing loss was progressive (like many CMV related cases of hearing loss in young children) and it seemed at each audiology appointment she would continue to lose more and more of her hearing. Although we talked about CIs in the early stages as a future option, she wasn’t a candidate until her hearing levels began to shift into the severe to profound range. At that point, without hesitation, we started the process to CIs. It was an incredibly easy decision for me because I saw her beginning to struggle to keep up with just her hearing aids and knew it was going to continue to get worse. I always stayed true to our goal for her and knew in my heart it was the right decision.

How old is your child now and how are she doing?

Nova is 4 years old and is doing absolutely amazing. With her CIs, her hearing is in normal hearing range and developmentally, she is above average when compared to her hearing peers. She is wise beyond her years, clever, creative, full of energy and just so sweet. Her CIs have truly been life changing for both her and our family.

A bill for CMV screening was recently introduced in Pennsylvania. How long have you been working on this issue and what got you started?
I began my involvement with legislative efforts in Pennsylvania in June of 2020. Within the first few months after I found out that Nova had been infected with CMV, I started connecting with other families affected by CMV and the stories always seemed to have one common denominator—no one had known about CMV until it was too late, and their child was affected by it. The fact that the awareness of CMV was so low, yet the incidence was high compared with other childhood diseases was the motivating factor for me to find ways to help in closing that gap.

I started by sharing our story with family, friends, and more broadly through my social media platforms. The responses I received validated that the awareness gap was very real, and I knew we needed real change for the future babies of Pennsylvania. Over the last year, I have been collaborating and leading legislation efforts in Pennsylvania to establish the CMV Education and Newborn Testing Act which will advance public awareness of CMV and screening for newborns, specifically those who fail their newborn hearing screen.

**How did you get involved with the ACI Alliance?**

I got involved with the ACI Alliance quite simply because our goals aligned perfectly. One specific goal of the organization is to help support CMV related issues. As a hearing loss advocate and mom of a child born with hearing loss due to CMV, my passion lies in improving protocols and policies surrounding CMV and CMV-related hearing loss. I knew that together in collaboration with the ACI Alliance, we could work efficiently and effectively to bring real change forward.

**How can ACI Alliance members help?**

ACI members can help to support our PA bill by getting in touch with me via email at kassandrakordish@gmail.com.

Additionally, I would encourage all members to take any and every opportunity to educate on CMV in efforts to help close the public awareness gap. Two specific ways to do this is:

1. Ask any parent of a child with hearing loss, especially infants, if they were tested for CMV and recommend they do so

2. Share information on CMV with any pregnant woman or woman trying to conceive so they are aware of the preventative measures they can take to protect themselves and their babies from the effects of congenital CMV