

Raising CMV Experience through Existing Communities



My Experience With IL Hands & Voices
By: Andrea Stambaugh

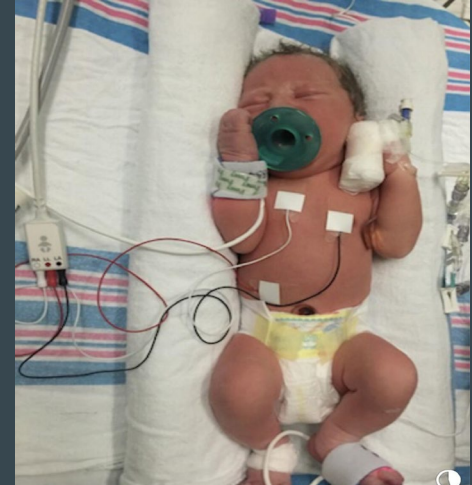
Meet Axel

Axel is the happiest two year old EVER. He is usually remembered for his bubbly personality and his big smile! Axel was born with congenital CMV and has a laundry list of subsequent diagnosis'.

- Spastic quadriplegic cerebral palsy
- Bilateral profound sensorineural hearing loss
- Cochlear implants
- Optic nerve hypoplasia
- Malformation of the brain
- Calcifications on the brain
- PMG
- Global developmental delay
- Motor delay
- G-tube
- GERD
- Hyperekplexia
- Microcephaly.



Our Story: Why Our family Is Dedicated To CMV Awareness

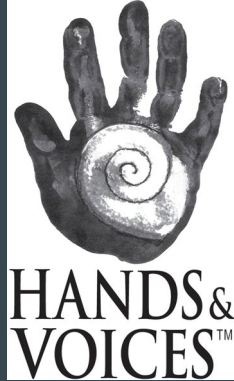






“Hands & Voices”™

Hands & Voices is a nonprofit, parent driven organization dedicated to supporting families of children who are deaf or hard of hearing. We are unbiased about communication methodologies and believe that parents can make the best choices for their child if they have access to good information and support.



“What works for your child is what makes the choice right.”

Hands & Voices supports and represents...

Kids with mild, moderate, severe, profound, unilateral, conductive, auditory neuropathy, deaf plus, congenital, acquired, or age progressive hearing loss or deafness.

Kids who speak, kids who sign, kids who do both, kids who cue, kids who are aided kids who are not and/or kids that have cochlear implants.

The families of these children and all the professionals who work with them in all capacities.

IL Hands & Voices

Shortly after Axel's diagnosis I began to seek out resources for our family. Due to CMV's close relation to hearing loss I came upon H&V. Once finding IL Hands & Voices and becoming an active member I quickly fell in love with the program and wanted to do more. I then became a board member for the organization.

IL Hands & Voices has given me an opportunity to provide awareness and resources to families throughout the state. It also connected me with some amazing people who are supportive of our dedication for CMV awareness.



Hands & Voices Across The World



Awareness Opportunities

- Adam, Axel, and I put together a CMV Awareness Fundraiser in June of 2017 in honor of Axel. We were able to raise and donate \$5,600 to the National CMV Foundation
- Active member on the board of directors for IL Hands & Voices
- We made and entered a CMV Awareness float in our hometown's homecoming parade. Handed out awareness flyers as well as "Meet Axel" flyers
- Submitted Articles to IL Hands & Voices quarterly newspaper and Illinois E.A.R.S about CMV.
- Created a blog on Facebook called "Axel's Journey With CMV"
- Had a CMV Awareness video made
- I became involved on the National CMV Foundation's patient education and outreach committee.
- Currently I am involved in the ParentWise program at Ann & Robert H Lurie Children's Hospital of Chicago where we go in and provide support and resources for newly diagnosed families.
- Parent advocate for Cochlear Americas.
- Working with IL Hands & Voices has given me an opportunity to meet and work alongside other parent professionals which not only helps raise awareness but helps me grow professionally

How can YOU help?

What organization could be a good platform for you to receive support and to raise CMV Awareness?

Local organizations?

Other awareness ideas?

Social media platforms?

#CMVSucks

#StopCMV

#CMVAwareness

#CMVEndsWithMe