

Hello, my name is Andrea Stambaugh, I am happy that you are joining me today to learn more about Cytomegalovirus or CMV for short. I'm a mom of two, my oldest son Axel was born with congenital CMV and unfortunately, he is severely affected by the virus. I had a very normal pregnancy in the beginning, and I was never informed about what CMV was, how common or how preventable this virus could be. Whether you are a mom who's pregnant or trying to become pregnant, a professional or someone who has a child born with congenital CMV I am glad you are here to learn what CMV is, how it is prevented and how CMV can affect our kids and the kids you work with.

From the national CMV Foundation, Congenital Cytomegalovirus is the most common viral infection and the leading non-genetic cause of hearing loss that infants are born with in the United States. Every pregnant woman is at risk of acquiring CMV and yet only 9% of woman know about it. Did you know that between 50% and 80% of adults have contracted CMV by the time they have reached 40. And nearly 1/3 have had the virus by the age of 5? In most of these cases CMV presents itself as a cold. 1 in 200 babies will be born with congenital CMV. CMV is serious and can cause multiple disabilities and birth defects.

There is a broad spectrum of ways in which children can be affected by CMV. Some kids may have no subsequent diagnosis and others may have many. Some of the possible issues children can experience when born with congenital CMV can include hearing loss, vision loss, intellectual disabilities, microcephaly, brain calcifications, lack of coordination, Cerebral Palsy, feeding issues, seizures and sometimes death.

When a child is born with congenital CMV they will typically fall between the 2 categories of asymptomatic or symptomatic. 90% of babies born with CMV every year are considered asymptomatic, these are the babies that have no side effects of contracting CMV or may only have hearing loss at birth. 4-5% of these babies will have a hearing loss at birth but 10-15 of these kids will eventually have a hearing loss. The loss can be progressive and into young adulthood and this is why it is so important that all CMV kids regularly see an audiologist and understand their risk of hearing loss even if it did not present with a hearing loss at birth.

The other category is symptomatic CMV, this is where my son falls. 10% of babies born with CMV each year will be symptomatic at birth from CMV. These babies will present with complications of the virus, for example microcephaly, jaundice, enlarged liver, or hearing loss. 75% of these kids will develop a hearing loss and this is why it is so important for all CMV kids to regularly see an audiologist and understand the risk of hearing loss, even if they did not present with a hearing loss at birth. For families this means a lot of hospital stays, surgeries, medical equipment, assumptions, and unanswered questions.

In my experience I've have family friends and professionals refuse to see my son due to his congenital CMV diagnosis. A few years ago the American Academy of Otolaryngology, head and neck surgery put out a statement on CMV that stated that CMV is not an occupational health and safety risk even for pregnant woman if routine practices are followed. Since not all children undergo CMV testing and most of CMV show no symptoms of infection workers and staff must follow precautions for all children including handwashing, and avoiding contact with saliva, mucus, blood, or tears.

Women who are pregnant or planning to become pregnant should use caution when coming into contact with the tears, mucus, blood, urine and saliva of any child. For example, you should not share toothbrushes, silverware, or put pacifiers in your mouth. Good handwashing is key and you should wash your hands often with soap and water for 15-20 seconds. Handwashing after feeding your child, handling toys diaper changes, etc. is key to CMV prevention. Simple precautions can prevent this serious virus from affecting our babies. If you are the parent of a newly diagnosed child, we know that this is not the journey you planned for, take a deep breath, and follow these tips. Do your research, learn about the diagnosis, treatment, terminology, and outcomes. Be comfortable with your healthcare team, be sure you are comfortable asking questions. Only expect to remember some of what you are told and always try to have someone with you to take notes. For support, resources or more information, be sure to connect with IL Hands & Voices and IL Guide By Your Side, the national CMV foundation or the IL Department of Public Health.