

CONGENITAL CMV: SUPPORT AND NEXT STEPS



WHAT IS CYTOMEGALOVIRUS (CMV)?

Cytomegalovirus (CMV) is a common virus that infects people of all ages and is not harmful for most people. CMV spreads from person to person through body fluids, including saliva, urine, and blood. It is prevalent in the saliva of toddlers. Many people catch CMV as toddlers, and about 3 out of 4 adults have had CMV by age 40. Most of us will never even know we have had CMV.

WHAT IS CONGENITAL CMV (cCMV)?

Sometimes a pregnant woman will pass CMV to her baby. When a baby is born with CMV, it is called congenital CMV (cCMV).

- 1 out of every 200 babies are born with cCMV
- About 1 out of 4 babies born with cCMV will have hearing loss at birth or develop hearing loss during the first few years of life
- Some babies born with cCMV will have other challenges besides hearing loss, including vision loss or developmental delays

WHAT HAPPENS AFTER YOUR CHILD RECEIVES A DIAGNOSIS OF cCMV?

If your baby's CMV test is positive, your pediatrician will talk with you about whether your baby needs additional testing or medication. Your baby may need to see other specialists to get the best treatment for cCMV.

IF YOUR BABY IS DIAGNOSED WITH cCMV, WHERE CAN YOU FIND SUPPORT?

The National CMV Foundation may be able to help your family in several ways. The Foundation can help with:

- Learning more about cCMV and the wide range of effects it may have on your child's development
- Connecting you with appropriate state specific CMV support
- Connecting you with other families experiencing a cCMV diagnosis
- Assisting you with finding providers in your state/region familiar with CMV

"A diagnosis changes a lot of things. But don't ever let that define your life, and most importantly, your child's. There is love and life within and after a diagnosis. Fourteen years later, and my daughter Avalee continues to show me this every single day."

Ashley, parent



www.nationalcmv.org



“Having a child diagnosed with cCMV can be scary. There are so many unknowns and every child is affected differently. Having a support system that understands the uncertainty is important.”

Amber, parent

PEDIATRIC SPECIALISTS

Infectious Disease

Ear, Nose and Throat

Ophthalmology

Neurology

PARENT RESOURCES

National CMV Foundation

Local Hearing Loss and Disability Non-profits

Your State’s Hands & Voices Chapter

DEVELOPMENTAL RESOURCES

Your Child’s Pediatrician

Occupational Therapy

Physical Therapy

Your State’s Early Intervention Services

HEARING RESOURCES

Pediatric Audiology

Speech Therapist

Sign Language Instructor

Your State’s EHDI Program

“Receiving our son’s congenital CMV diagnosis was unexpected and heartbreaking. Despite the challenges that Matthew and we as a family face, he inspires us every day, has taught us more than we could have ever imagined, and is the biggest blessing.”

Erin, parent

“It’s OK to be broken and cry, and ask “why us?” But at the end of the day your baby is perfect. Finding support from families similar to mine helped me remember that my child is perfect and that they are mine!”

Jami, parent



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