

A Parent's Guide to Congenital Cytomegalovirus (cCMV)



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 mucous, 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)?

A pregnant woman with active CMV infection can pass it to her baby in utero.

- 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

WHEN WILL MY CHILD BE SCREENED FOR cCMV?

Any child who fails their final hearing screen at birth in Virginia and is 21 days of age or younger will receive a cCMV screen before hospital discharge. Visit our [website](#) or email us at va_ehdi@vdh.virginia.gov for information on your child's cCMV screening.

WHAT HAPPENS AFTER YOUR CHILD RECEIVES A DIAGNOSIS OF cCMV?

If your baby's CMV test is positive, your Primary Care Provider (PCP) 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. Talk to your child's PCP today to discuss next steps.

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

Virginia EHDI program can help your family in several ways. They can:

- Refer you to resources which can help you learn more about cCMV and the wide range of effects it may have on your child's development.
- Connect you with other families experiencing a cCMV diagnosis.
- Discuss next steps after diagnosis and help with finding providers who are familiar with CMV.

Contact us at
va_ehdi@vdh.virginia.gov
for more information.

“ 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



“ 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](#)
- [Virginia Early Hearing Detection and Intervention](#)

DEVELOPMENTAL RESOURCES

- Your child’s Primary Care Provider
- Occupational Therapy
- Physical Therapy
- [Infant and Toddler Connection Virginia](#)



HEARING RESOURCES

- Pediatric Audiology
- [Speech Therapist](#)
- Sign Language Instructor

“ 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



VDH.virginia.gov/hearing

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