

Information about congenital CMV infection for healthcare professionals who see newborns

Since the spring of 2018, the Colorado Chapter of the American Academy of Pediatrics and Colorado Hands & Voices have been leading a **Work Group on Congenital Cytomegalovirus Infection (cCMV)**. This Work Group strives to improve the diagnosis and management of cCMV and improve support for families raising a child with cCMV.

cCMV affects 1 in 200 newborns in developed countries, and is the most common congenital viral infection worldwide. 1 in 5 children born with cCMV will have serious problems such as hearing loss, cerebral palsy or developmental delays. cCMV is the most common non-genetic cause of congenital hearing loss, accounting for about 25% of all hearing loss in early childhood. Unfortunately, over 80% of children born with cCMV are never diagnosed. When the diagnosis is missed, these children do not get the care they deserve. Reasons the diagnosis is missed include a lack of awareness of risk factors and missed opportunities for timely testing. Postnatal CMV infection can occur as early as 3 weeks of life, so testing to identify congenital CMV infection needs to be done before day of life 21.

Making the diagnosis changes clinical care in all these ways:

- a. A pediatric infectious disease specialist can explain treatment options. For some infants with cCMV, the anti-viral medication valganciclovir can improve hearing and speech development
- b. Additional testing will be recommended, which might show brain damage, low blood counts, or liver problems
- c. An eye exam will be recommended to look for retinal involvement and plan for ongoing monitoring of vision
- d. Repeated hearing testing will be scheduled, because hearing loss due to cCMV can be fluctuating or progressive.
- e. Frequent monitoring for developmental delay will be provided, and timely referral made for therapy through Early Intervention
- f. If the family knows cCMV is the likely cause of their child's hearing loss, an expensive search for other causes may be avoided
- g. The family will learn about the possible need for hearing aids, cochlear implants, or language development support
- h. Contact with cCMV parent support groups will be provided to the family

The cCMV Work Group encourages **targeted screening for cCMV** in all newborns with risk factors, including all those who have not passed the newborn hearing screen. As of late 2022, more than 40 Colorado hospitals have instituted such targeted screening.

You can access resources for cCMV at aapcolorado.org, including:

- A handout to explain why a newborn is being tested for cCMV ([English](#), [Spanish](#))
- A handout to be provided when an infant tests positive for cCMV ([English](#), [Spanish](#))
- [Flow diagram: How to Screen for Congenital CMV Infection](#)
- [Labs offering testing for CMV in newborns](#)