

Information About Congenital CMV for Pediatric Hospitalists and Other Clinicians who see newborns:

Since the spring of 2018, the Colorado Chapter of the American Academy of Pediatrics (AAP-CO) has been leading a **Work Group on Congenital CMV Infection (cCMV)**. A major focus of the Work Group has been improving the diagnosis of cCMV and improving support for families raising children with cCMV. We would like to share with you several new resources to help you screen newborns at risk for cCMV and manage children with confirmed cCMV.

**Why do we care?** Because cCMV affects 1 in 200 newborns, which means **cCMV is the most common preventable cause of neonatal disability in the United States**, more common than Down syndrome, cystic fibrosis, fetal alcohol syndrome, or spina bifida -- **but fewer than half of all children with disabilities due to cCMV are ever diagnosed**. When cases of cCMV are missed, those children get sub-optimal medical management and suffer worse health outcomes.

cCMV is the most common congenital viral infection worldwide. cCMV is also the most common non-genetic cause of congenital hearing loss, accounting for about 20% of all congenital hearing loss. 25% of those born with cCMV will have hearing loss, either at birth or developing within the first 5 years of life. Reasons why the diagnosis of cCMV 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 should be done before day of life 21**.

**Making the diagnosis of cCMV can change clinical care in these ways:**

- a) A pediatric infectious disease specialist can explain treatment options. In infants with symptomatic cCMV, valganciclovir improves hearing and speech development. Randomized trials of valganciclovir in infants with cCMV and hearing loss alone are underway.
- b) Additional testing might show abnormal CNS imaging, bone marrow dysfunction or hepatitis.
- c) A pediatric ophthalmologist can look for retinitis and plan for ongoing monitoring.
- d) Repeated hearing testing can be scheduled, because hearing loss due to cCMV can be fluctuating or progressive.
- e) Frequent monitoring for developmental delay can be provided, and referral to Early Intervention can be made.
- f) The family can learn whether cCMV is the most likely cause of their child's hearing loss or other health complications, which may reduce the need for genetic testing and/or additional imaging.
- g) The family can learn about the risk that hearing loss will progress and anticipate the possible need for hearing devices (e.g. hearing aids or cochlear implants) or language development support.
- h) Contact with cCMV parent support groups can be provided to the family.

During the past year, our Work Group has been introducing the concept of **targeted screening for cCMV** in all newborns with risk factors, including all those who have not passed the newborn hearing screen prior to discharge from the hospital. As of fall 2020, more than 20 Colorado hospitals are working on developing policies and procedures to institute targeted screening for cCMV. **As a result, we anticipate that you may be screening more children with cCMV, or seeing more children with a positive test for cCMV in your office.**

Here is a simple flow diagram for thinking about screening for cCMV: [Flow diagram for CMV Screening](#).

**These handouts for families have been created by the Colorado cCMV Family Network\*:**

- A handout to explain why a newborn is being tested for cCMV (English [link](#), Spanish [link](#))
- A handout to be provided when an infant has tested positive for cCMV (English [link](#), Spanish [link](#))

**We hope that when you see a child at risk for cCMV, or diagnosed with cCMV, you will share these handouts with the family. You can access these handouts and other resources for cCMV on the AAP-CO website at [aapcolorado.org](http://aapcolorado.org).**

Please share this information with your colleagues. If you want to help start a targeted cCMV screening program in your hospital system, here is a plan: [Targeted screening for CMV](#).

We welcome your feedback on this initiative to improve identification and management of children with congenital CMV infection. Please direct your questions and comments to Ted Maynard at [ted@aapcolorado.org](mailto:ted@aapcolorado.org).

#### **American Academy of Pediatrics, Colorado Chapter**

Edward C. (Ted) Maynard, MD, FAAP, Chapter President

Maureen Cunningham, MD, FAAP, EHDI Champion

Leisha Andersen, MD, MPH, FAAP, Special Projects Manager

Kirsten Nelson, MD, FAAP, CMV Project Manager

#### **Colorado Hands & Voices**

Sara Kennedy, Director

Jami Fries, Guide By Your Side Coordinator

#### **National CMV Foundation**

Megan Nix, MFA, Community Alliance Chair

\*AAP-CO has received grants to support the establishment of the **Colorado cCMV Family Network** from the American Academy of Pediatrics (AAP) and the Colorado Early Hearing Detection and Intervention (EHDI) Alliance. The Network has been developed in collaboration with Colorado Hands & Voices, an organization for families raising children who are deaf or hard of hearing. The Network's mission is to connect families to resources and to each other in order to optimize care of children with cCMV.