Newborn Screening and Congenital Cytomegalovrius

Clinical Summary of Congenital Cytomegalovirus

Cytomegalovirus (CMV) is part of the herpes virus family. A person infected with CMV (acquired CMV), typically experiences cold-like symptoms. When a pregnant person has a CMV infection, the virus can pass through the placenta to the fetus and cause long-term health problems.

Congenital CMV has a variable presentation:

- Majority are asymptomatic at birth and are never expected to develop sequelae.
- Up to 20% will have permanent hearing loss that may be present at birth or manifest later in childhood.
- Some newborns will have signs/symptoms at birth such as petechiae, microcephaly, jaundice, hepatosplenomegaly, chorioretinitis, and/or brain imaging abnormalities.

Not all infants with cCMV need to be referred to a peds ID specialist. However, if an infant has ANY signs or symptoms of cCMV disease, then a referral may be helpful in determining eligibility for treatment with antivirals. The decision to treat involves weighing the risks and benefits. Initiation of antivirals should involve a peds ID specialist and the family.

Newborn Screening

- Since 1964, the Minnesota Department of Health (MDH) has screened Minnesota newborns soon after birth to see if they are at risk for rare, hidden disorders. If left untreated, these disorders can lead to illness, physical disability, developmental delay, or death.
- By identifying these disorders early, however, interventions, medications, or changes in diet can help prevent most health problems caused by the disorders on the newborn screening panel.
- Shortly after a baby is born, nurses prick the heel of the baby and place several drops of blood on a specimen card that is sent to MDH's Public Health Laboratory for analysis.
- If a condition is detected, MDH genetic counselors alert the child's health care provider, who then initiates a conversation about appropriate follow-up with the parents.
- In addition to the blood spot screen, newborn screening also includes point-of-care screens: testing the baby's hearing in the range where speech is heard and using pulse oximetry to catch any critical congenital heart defects that may have been missed on prenatal ultrasounds. If either of these screens discover something, providers will examine the baby and work with the family to identify the next steps for treatment or intervention.
- In 2020, almost 66,000 newborn screening specimen cards were received and almost 928,000 tests were performed.
    - 122 newborns were identified with a health condition through blood spot screening and received timely follow-up and intervention.
    - Pulse oximetry screening was able to detect 2 newborns with critical heart defects that were missed by prenatal ultrasound and physical exam at birth, so a doctor could examine them before they experience a crisis.
    - 269 newborns were identified with hearing loss and connected with early intervention, such as ASL, cued speech, hearing aids, cochlear implants, and family support.

Newborn Screening for Congenital Cytomegalovirus

- Newborn screening will use real-time polymerase chain reaction (RT-PCR) to test for the presence of CMV DNA in dried blood spots.
- We expect about 300 infants will be born with congenital cytomegalovirus each year in Minnesota.

- We expect that the vast majority of identified children will not have symptoms of congenital CMV, but some will be at risk for permanent hearing loss or other serious health problems.
- Screening for congenital CMV will help identify infants at risk for developing hearing loss and who may benefit from follow-up monitoring and early access to interventions and treatment.
- Screening cannot predict which babies will have symptoms, or whether a baby with congenital CMV will ever develop symptoms. Additional evaluations and monitoring will be important in making that determination.
- Clinical testing cannot tell the difference between congenital CMV and acquired CMV, therefore, we rely on timing. Testing after the baby is 21 days old cannot distinguish the difference between infections that happened before or after birth. Detecting congenital CMV can find the virus at birth and can help find potential complications from the infection.
- Some newborns infected with CMV before birth will not have enough virus in their blood to be detected on screening. As a result, some cases of congenital CMV (cCMV) will be missed. Clinicians are advised to maintain a high index of suspicion for patients whose clinical presentation suggests cCMV but CMV was not detected on screening.
  - MDH is working with the CDC on a surveillance program to evaluate CMV screening.
  - Surveillance will help MDH identify cases that were missed by screening and determine if newborn screening has improved outcomes for those babies that were identified.
  - As with all screening conditions, MDH recommends pursuing diagnostic testing if a child is showing symptoms of a disease despite their newborn screening result being normal.
- For babies who have CMV found on newborn screening, MDH will work with their healthcare provider to obtain confirmation testing and provide them with education and resources about congenital CMV and connect families to information, resources, and supports.

How are families of children identified with congenital CMV connected to information and resources?

- MDH mails each family a packet of information and resources after their child is confirmed to have a congenital CMV infection. The materials were developed in collaboration with the National CMV Foundation.
- Families are connected to a local Public Health Nurse (PHN). After speaking with the family, the PHN shares information and resources of interest. Topics and resources that may be discussed include, but are not limited to, financial assistance, medical insurance, transportation, housing, food and nutrition, and childcare.
- Minnesota Hands & Voices provides parent-to-parent support for families of children recently identified with congenital CMV and experiencing signs or symptoms of infection, regardless of hearing status. A parent guide will reach out directly to the family.
- Longitudinal Follow-up activities are offered at no cost to families. Families may choose to decline participation at any time.

Newborn Screening Nationally

- A federal advisory committee recommends a panel of disorders every state should be screening for called the recommended uniform screening panel or RUSP.
  - cCMV was nominated in April 2019. In August 2022, the ACHDNC Nomination and Prioritization Workgroup conluded that there was insufficient information to move the nomination forward in the process.
- A number of states are doing targeted screening—only babies who do not pass their hearing screen; known that they'll miss affected kids
  - CT, FL, IA, KY, NY, UT, VA (required) and IL (optional)
- Select hospitals across the U.S. offering either targeted or universal screening, including M Health Fairview system and Mayo Rochester here in Minnnesota
- Ontario, Canada is doing universal cCMV screening as a risk factor for hearing loss.