Provider Fact Sheet

Positive Result:

Blood Spot Screen Result Notification

Cytomegalovirus (CMV) Detected

Next Steps

This week, you should take the following recommended actions:

- **Contact** family to notify them of the newborn screening result and follow-up plan as MDH has **not** notified them.
- **Evaluate** infant (petichiae, jaundice, IUGR, microcephaly, hepatosplenomegaly); call a pediatric infectious disease (ID) specialist if symptomatic. Contact information can be found on the resource list provided.
- **Collect** urine CMV PCR **before the infant is 21 days old**. If collection happens after 21 days of age, call and consult with a pediatric ID specialist for guidance as a later collection may represent an acquired infection.
- **Fax** urine CMV PCR results to MDH program staff at (651) 215-6285.

Most urine CMV PCR results are expected to be abnormal and confirm the screening result, see report for additional evaluations needed.

If urine CMV PCR results are normal, no additional follow-up is required.

If you have questions about the newborn screening result or your next steps, an on-call Newborn Screening Program genetic counselor is available at (651) 201-3548.

Further resources and information can be found on our website at: www.health.state.mn.us/newbornscreening

False Positives

Unlikely. Result could be from contamination.

Differential Diagnosis

The detection of CMV in newborn dried blood spots is primarily associated with:

- Congenital cytomegalovirus (cCMV) — Incidence of 1 in 200 births

Clinical Summary

While a CMV infection is generally mild, a new or re-activated infection during pregnancy can lead to a range of health problems for the baby. Babies born with a congential CMV (cCMV) infection may benefit from monitoring and intervention.

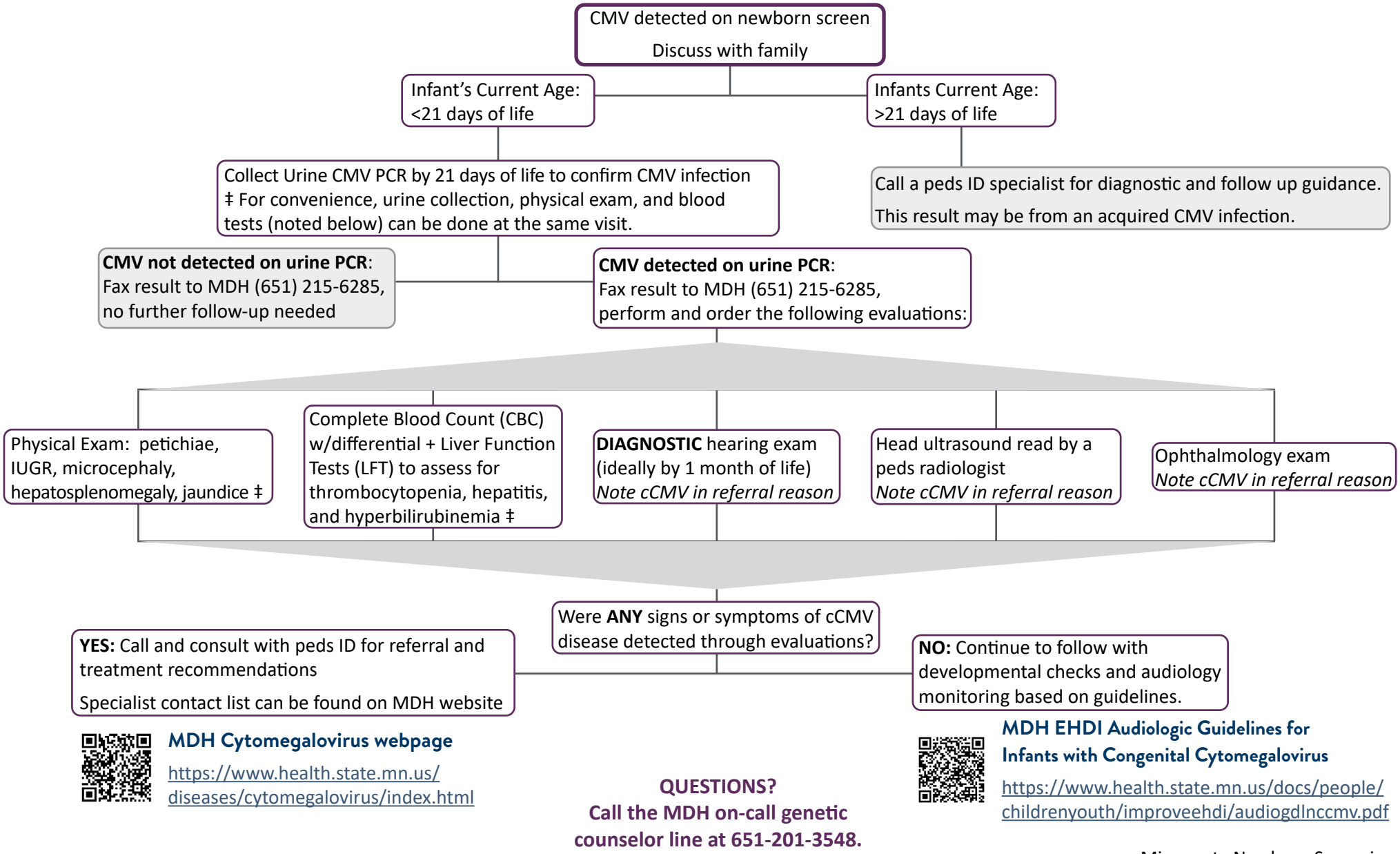
cCMV has variable presentations and there is no way to predict how severe a cCMV infection will be:

- Most infants 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, IUGR, microcephaly, jaundice, hepatosplenomegaly, chorioretinitis, thrombocytopenia, and/or brain imaging abnormalities.

Most infants with cCMV can be managed in a primary care setting. Consultation with a pediatric ID specialist can be helpful if signs or symptoms are found through initial evaluations. Antiviral treatment is available for eligible infants. The risks and benefits of treatment should be discussed with a pediatric ID specialist and the family.

Steps for cCMV Follow-up

Primary care providers of cCMV patients can manage most cCMV follow-up. All infants and children should be offered a referral to early intervention, although those services will likely benefit symptomatic children with cCMV the most.



MDH Cytomegalovirus webpage
https://www.health.state.mn.us/diseases/cytomegalovirus/index.html

QUESTIONS?
Call the MDH on-call genetic counselor line at 651-201-3548.

MDH EHDI Audiologic Guidelines for Infants with Congenital Cytomegalovirus
https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/audiogdlnccmv.pdf

DEPARTMENT OF HEALTH

Minnesota Newborn Screening
601 Robert St. N., St. Paul, MN 55155
Phone: (800) 664-7772* or (651) 201-5466* Fax: (651) 215-6285
*translators available

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Family Fact Sheet

Positive Result:

Blood Spot Screen Result Notification

Cytomegalovirus (CMV) Detected

What was found on the newborn screen?

The blood spots collected from your baby at birth had the presence of a virus called cytomegalovirus (CMV).

What does this mean?

When a baby is born with CMV, it is called congenital CMV (cCMV). Congenital CMV is an infection present when a baby is born. Children with cCMV may have symptoms from birth, develop symptoms through childhood, or never have symptoms from cCMV.

Your child's screening result does not mean your baby has cCMV, but more testing is needed to know for sure.

What happens next?

Your baby's doctor will check to see if the virus is also in your baby's urine. **For accurate results, this test should be done before your baby is 21 days old.**

If CMV is not found in your baby's urine, no more testing is needed.

If CMV is found in your baby's urine, it means your baby has a CMV infection and more testing is recommended to look for health problems caused by cCMV:

- Blood draw
- Hearing testing by a pediatric audiologist
- Eye exam by an ophthalmologist
- Head ultrasound

You may also be asked to meet with a pediatric infectious disease (ID) specialist.

What health problems are associated with cCMV?

Some babies with cCMV will have symptoms at birth, such as:

- Very small head
- Smaller body than expected for age
- Skin rash
- Yellowing of skin and whites of eyes
- Weak muscles

Some babies (up to 20%) with cCMV will have permanent hearing loss. The hearing loss may be present at birth or show up later in childhood. Because of this, it is important to have regular hearing exams, even if no other symptoms are present at birth.

Most babies with cCMV are born without symptoms of disease and are not expected to develop symptoms.

Newborn screening cannot predict if a baby will have symptoms or not, which is why additional testing is important for children with cCMV.

What treatment options are available?

Although cCMV cannot be cured, some of the symptoms can be treated. Possible treatments include:

- Sign language, hearing aids, cochlear implants for children with hearing loss
- Antiviral medication, if recommended by a pediatric ID specialist

Children with cCMV should see their regular doctor and other providers (as needed) based on symptoms present.

Resources

National CMV Foundation
www.nationalcmv.org

Centers for Disease Control and Prevention:
www.cdc.gov/cmv/congenital-infection.html

Baby's First Test:
www.babysfirsttest.org

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Newborn Screening Program, 601 Robert St. N., St. Paul, MN 55155
Phone (800) 664-7772, Fax (651) 215-6285 ***translators available***

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