Congenital Cytomegalovirus (cCMV) Diagnostic Testing and Care Protocol

Guidance for primary care providers caring for children diagnosed with congenital cytomegalovirus (cCMV)

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Purpose

To provide diagnostic testing and care recommendations for primary care providers caring for newborns diagnosed with congenital cytomegalovirus (cCMV) in Oregon.

Congenital Cytomegalovirus (cCMV) Overview

Cytomegalovirus (CMV) is a common infection in newborns with an estimated 1 in 200 babies infected at birth. CMV spreads easily, especially in settings with children such as childcare, and often has no symptoms. Babies born with CMV and diagnosed within 21 days of age are considered to have congenital cytomegalovirus (cCMV) which can cause long-term health impacts. Of newborns infected with cCMV, around 10% are symptomatic at birth while around 90% are asymptomatic. While most babies with cCMV will grow and develop typically, some may experience serious and permanent health issues, including problems with their brain, eyes, and inner ears that can be present at birth or develop later in childhood. In rare cases, cCMV may cause death.

Hearing loss is among the most frequent long-term impacts of cCMV. It is the most common non-hereditary cause of sensorineural hearing loss in children, accounting for 20% of diagnoses at birth and 25% by age four. Hearing loss from cCMV can be progressive or late-onset, making ongoing monitoring by a child's primary care provider and audiologist essential to support communication, language acquisition, and developmental outcomes.

Screening newborns for cCMV risk factors and clinical signs within 21 days of age helps with early detection, access to care, and enrollment in early intervention services to support long-term health outcomes for these infants. This timing helps determine whether the infection was acquired congenitally (present at birth) or postnatally (acquired after birth). Postnatal infections are generally not associated with serious health concerns, whereas congenital infections can impact long-term development.

Following a positive test result from cCMV screening, newborns should complete additional diagnostic lab-based testing and imaging as well as further evaluation by various health care professionals for possible treatment and ongoing monitoring.

Oregon Congenital Cytomegalovirus (cCMV) Screening Rules

Oregon licensed hospitals and birthing centers must screen newborns for cCMV pursuant to Oregon Administrative Rules 333-020-0125 through 333-020-0187. The hospital or birthing center must conduct cCMV screening based on the Congenital Cytomegalovirus (cCMV) Screening Protocol developed by the Oregon Health Authority (OHA), which includes:

- assessing each newborn for known risk factors and clinical signs of cCMV, and
- as necessary, based on the presence of one or more of the risk factors or clinical signs, conduct CMV testing.

The screening must be completed prior to discharge or within 14 days of age, whichever occurs earlier, unless parents or guardians refuse in writing. If the hospital or birthing center is part of a licensed Health Maintenance Organization facility, screening shall occur within 14 days of age.

Below are the list of risk factors and clinical signs associated with cCMV that all newborns must be assessed for:

- Birth parent diagnosed with primary CMV infection during pregnancy
- Did not pass the newborn hearing screening (one or both ears)
- Symmetric small for gestational age: birth weight <10th percentile
- Microcephaly: head circumference <3rd percentile based on gestational age, recommend remeasuring 24 hours after delivery
- Unexplained petechial rash or blueberry muffin rash
- Unexplained abnormal red reflex, retinitis, or cataracts
- Unexplained fetal hydrops or ascites, abdominal calcifications, or thickened bowel on prenatal ultrasound
- Unexplained or persistent hepatomegaly, splenomegaly, or elevated liver function tests (AST or ALT >100 U/L or direct bilirubin >1.0 mg/dL)
- Unexplained abnormal brain imaging including ventriculomegaly, intracerebral calcifications, white matter changes, periventricular echogenicity, cortical or cerebellar malformations, or migration abnormalities
- Unexplained thrombocytopenia (platelets <100,000/mm3)

Following a positive test result, hospital and birthing center staff must inform the newborn's parent or guardian and primary care provider or their designated staff through direct personal communication. Document all interactions in the newborn's medical record.

Congenital Cytomegalovirus (cCMV) Diagnostic Testing and Care Recommendations

Around 10% of infants diagnosed with cCMV are symptomatic at birth and early access to treatment and care may improve their long-term health outcomes. Asymptomatic infants with cCMV may develop symptoms later. All children diagnosed with cCMV should be closely monitored for ongoing development and care.

Diagnostic Testing, Imaging, Exams, and Referrals

Following receipt of positive urine CMV PCR results, primary care providers caring for a newly diagnosed infant are encouraged to complete additional diagnostic lab-based testing, imaging, and referrals. If a saliva sample was used, cCMV diagnosis should be confirmed by a positive urine PCR test within 21 days of age.

Following a positive urine PCR test result, the following are recommended to evaluate for further evidence and extent of cCMV disease:

- Complete Blood Count (CBC) with differential
- Complete Metabolic Panel (CMP)
- Head Ultrasound (HUS)
- Physical exam with height, weight, and head circumference measurements
- Referral to audiology for diagnostic audiology evaluation
- Referral to Early Intervention services

The following referrals are recommended to support ongoing continuity of care and evaluation:

- Pediatric Infectious Disease
    - When possible, it is preferred that results from CBC with differential, CMP, HUS (or other brain imaging), physical exam, and diagnostic audiology

evaluation be available prior to being seen by Pediatric Infectious Disease specialist for clinical management.

- Pediatric Otolaryngology (ENT) if hearing loss is identified by audiology
- Pediatric Neurology if abnormal imaging, microcephaly, hearing loss, or abnormal neurological exam
- Pediatric Ophthalmology or Pediatric Optometry
    - When possible, indicate any abnormal eye findings, hearing loss, or abnormal neurological exam on referral.

Types of Referrals

Pediatric Infectious Disease (ID)

A pediatric infectious disease specialist can assess appropriate treatment and guide families through available options. For some infants, antiviral medication may improve hearing and speech development. If eligible, treatment is most effective when started early and should be considered before 13 weeks of age.

Pediatric Audiology

An audiologist measures hearing ability in infants. Newborns should be referred to an audiologist as soon as possible to complete diagnostic audiology evaluations, regardless of newborn hearing screening results. Results from audiology evaluation should be obtained no later than 12 weeks of age to allow for consideration of treatment options by Pediatric Infectious Disease specialist. Children with cCMV are at high risk for progressive or late-onset sensorineural hearing loss so ongoing audiologic monitoring is essential.

Few audiologists throughout the state have the skills and equipment to test infants under 6 months of age. Please refer to the OHA EHDI website (healthoregon.org/ehdi) for a list of available providers. Referring to audiologists not on this list may result in incomplete or inaccurate testing.

Recommended follow-up schedule for children with a cCMV diagnosis:

- Every 3 months until 1 year of age
- Every 6 months from 1 to 3 years of age

- Annually until 6 years of age

More frequent evaluations may be needed based on audiologist recommendation.

Pediatric Otolaryngology (ENT)

A pediatric otolaryngologist can assess ear conditions and works closely with audiologists to monitor a hearing loss. If hearing loss is identified by an audiologist, newborns should be referred to a pediatric otolaryngologist for additional evaluation and monitoring. Families may choose to learn more about the availability of hearing technology and a pediatric otolaryngologist can discuss available options.

Pediatric Neurology

A pediatric neurologist can assess for neurological disorders. Infants with cCMV may develop neurological conditions that require ongoing monitoring. If a newborn has abnormal brain imaging, microcephaly, hearing loss, or an abnormal neurological exam, they should be referred to a pediatric neurologist for additional evaluation.

Pediatric Ophthalmology or Pediatric Optometry

A pediatric ophthalmologist or pediatric optometrist can assess for eye conditions and discuss need for assistive technology such as glasses. Children with cCMV are at risk for progressive or late-onset vision loss so ongoing vision monitoring is essential. Newborns should be referred to a pediatric ophthalmologist or pediatric optometrist and should indicate if abnormal eye findings, hearing loss, or abnormal neurological exam were identified.

More frequent evaluations may be needed based on provider recommendation.

Early Intervention Services

Children diagnosed with cCMV are eligible for Early Intervention services through the Oregon Department of Education to monitor and support ongoing development. Early Intervention services provide free, timely, and individualized services that enhance learning and development through everyday opportunities for all infants, toddlers, and young children with disabilities. All children with cCMV should be referred to Early Intervention Services as soon as possible following a confirmed diagnosis.

More information on the Oregon Department of Education Early Intervention and Early Childhood Special Education (EI/ECSE) can be found on this webpage: https://www.oregon.gov/ode/students-and-family/specialeducation/earlyintervention/Pages/default.aspx

Ongoing Monitoring

PCPs should consider frequent monitoring of child's growth and development due to progressive symptoms. Children with cCMV may have difficulties with hearing, vision, communication, growth, cognition, learning, and motor coordination.

All children with cCMV are recommended to be monitored by an audiologist, even if they pass the newborn hearing screening, because they are at risk of progressive hearing loss. For children with cCMV, families should plan for audiology visits every 3 months until 1 year of age, then every 6 months until 3 years of age, then yearly until 6 years of age. More frequent evaluations may be needed based on audiologist recommendation.

Congenital Cytomegalovirus (cCMV) Diagnostic Testing and Care Process Map

To view the Congenital Cytomegalovirus (cCMV) Diagnostic Testing and Care Process Map, please refer to the attachment at the end of this document or visit Oregon.gov/CMV.

Reporting Requirements

cCMV is not a reportable condition in Oregon.

Additional Resources

To find more information and resources about Cytomegalovirus (CMV) prevention, testing, and care in Oregon, visit Oregon.gov/CMV.

American Academy of Audiology on Congenital Cytomegalovirus: https://www.audiology.org/consumers-and-patients/hearing-and-balance/congenital-cytomegalovirus-cmv-infection/

American Academy of Pediatrics on Cytomegalovirus: https://www.aap.org/en/patient-care/congenital-cytomegalovirus-ccmv

American College of Obstetricians and Gynecologists on Cytomegalovirus in Pregnancy: https://www.acog.org/clinical-information/physician-faqs/cytomegalovirus-in-pregnancy

Center for Disease Control (CDC) on CMV in Newborns: https://www.cdc.gov/cytomegalovirus/congenital-infection/index.html

National CMV Foundation: https://www.nationalcmv.org/

Acknowledgements and Contributors

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Congenital Cytomegalovirus (cCMV) Diagnostic Testing and Care Process Map

Primary Care Provider Recommendations

OREGON HEALTH AUTHORITY

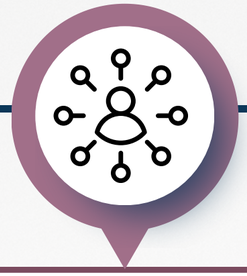
Oregon.gov/CMV

Review and Order

Following receipt of positive urine CMV test results within 21 days of age, the newborn's primary care provider is encouraged to complete the following to evaluate for further evidence and extent of cCMV disease as soon as possible:

- Complete Blood Count (CBC) with differential
- Complete Metabolic Panel (CMP)
- Head Ultrasound (HUS)
- Physical exam with height, weight, and head circumference measurements
- Referral to audiology for diagnostic audiology evaluation
- Referral to Early Intervention services

Step 1



Refer

The primary care provider may consider the following referrals:

- Pediatric Infectious Disease
  - When possible, it is preferred that results from CBC with differential, CMP, HUS (or other brain imaging), physical exam, and diagnostic audiology evaluation be available prior to being seen by Pediatric Infectious Disease specialist for clinical management.
- Pediatric Otolaryngology (ENT) if hearing loss is identified by audiology
- Pediatric Neurology if abnormal imaging, microcephaly, hearing loss, or abnormal neurological exam
- Pediatric Ophthalmology or Pediatric Optometry
  - When possible, indicate any abnormal eye findings, hearing loss, or abnormal neurological exam on referral.

Step 2

Monitor

Primary care providers are encouraged to consider frequent monitoring of a child's growth and development due to progressive symptoms. Children with cCMV may have difficulties with hearing, vision, and cognition leading to possible developmental delays.

All children with cCMV are recommended to be monitored by an audiologist, even if they pass the newborn hearing screening, because they are at risk of progressive hearing loss. For children with cCMV, the American Academy of Audiology recommends audiology visits every 3 months until 1 year of age, then every 6 months until 3 years of age, then yearly until 6 years of age. More frequent evaluations may be needed based on audiologist recommendation.

Step 3