

What is congenital CMV and why it is important?

What is Cytomegalovirus?

Cytomegalovirus (CMV)

- Common and widespread virus
- Can cause mild cold like symptoms
- Most US adults have been exposed
- Generally harmless in healthy people



Congenital Cytomegalovirus (cCMV)

- People who are pregnant and develop an active CMV infection can unknowingly pass the virus to their growing fetus.
- When the baby is born with a CMV infection, it is called cCMV.



How is Cytomegalovirus Transmitted?

Cytomegalovirus (CMV)

- CMV is transmitted by direct contact of mucous membranes or open skin with body fluids (such as saliva, urine, nasal mucus, tears, blood, semen, vaginal fluids, stool, breastmilk) from someone with an active CMV infection.



Congenital Cytomegalovirus (cCMV)

- Congenital CMV is when a person who is pregnant develops an active CMV infection and unknowingly passes the virus to their growing fetus.
- When the baby is born with a CMV infection, it is called congenital CMV.



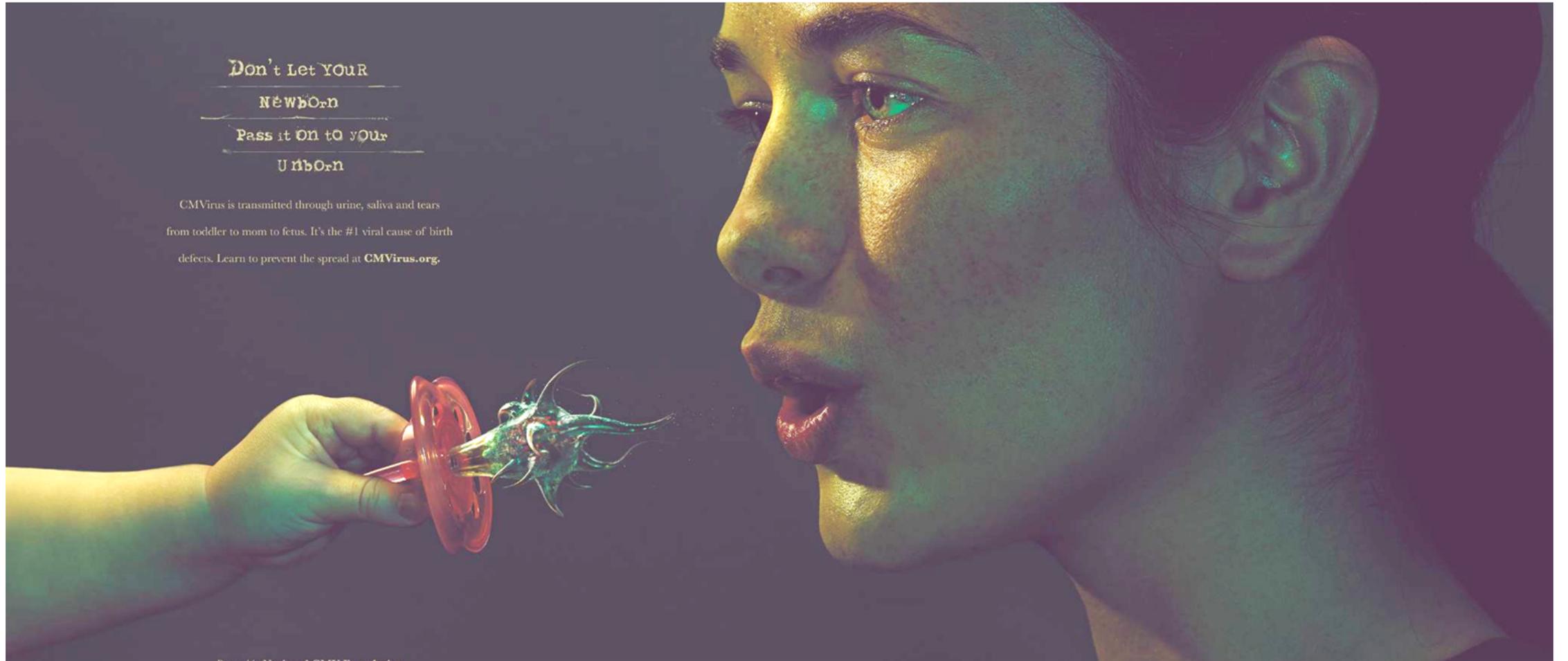
Don't Let YOUR

NEwBOrn

Pass it ON to YOUR

UnbOrn

CMVirus is transmitted through urine, saliva and tears from toddler to mom to fetus. It's the #1 viral cause of birth defects. Learn to prevent the spread at CMVirus.org.



Minnesota Congenital CMV Screening

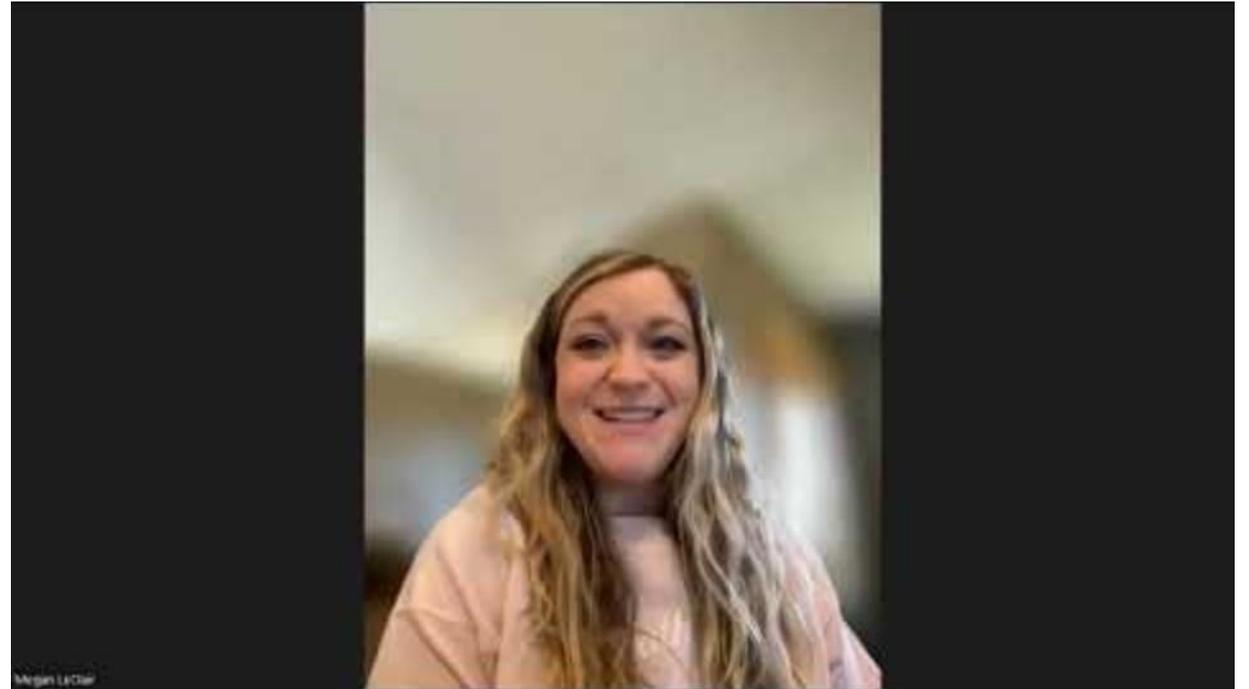
Minnesota is the first state to screen every newborn for congenital CMV! (February 2023)

Purpose	MN Screening	Follow-Up
<p>Identify infection and any health or developmental concerns as early as possible.</p> <p>Offer interventions that can help minimize the impact of the virus.</p>	<p>Newborn CMV screening through the Minnesota newborn screening panel (blood spot)</p> <p>If CMV is detected, the baby's health care provider is notified, and a urine test is collected before the baby is 21 days old to check for the virus.</p>	<p>Initial medical evaluation and treatment</p> <p>Letter and information booklet from MDH sent to families</p> <p>MDH connects families with a Local Public Health nurse</p> <p>Ongoing hearing monitoring</p> <p>Public health longitudinal surveillance</p>

Parent Stories: Diagnosis

Video (0:44 sec):

<https://youtu.be/cJmeUpaoWuY>

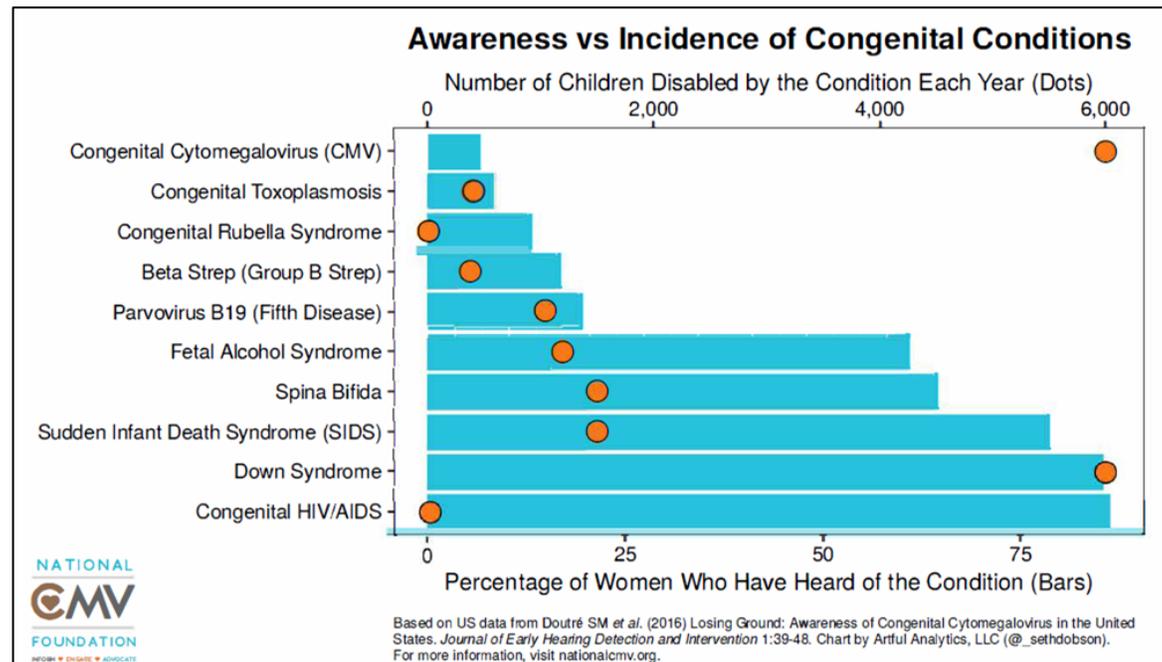


CMV Prevalence

According to the Centers for Disease Control and Prevention (CDC), congenital CMV is the most common viral cause of birth defects and developmental disabilities in the U.S.

- 1 in 200 children are born with congenital CMV
- Congenital CMV is arguably the most common preventable cause of neonatal disability in the U.S.
- More children will have disabilities due to congenital CMV than other well-known infections and syndromes
- It is more common for families who have a toddler at home, to have a baby born with congenital CMV.

CMV Prevalence chart



Congenital CMV Possible Impacts

Born Symptomatic				Born Asymptomatic	
Death Miscarriage Stillbirth Infant or Child Loss	Medically Fragile Cerebral palsy Seizures Failure to Thrive Hearing Loss Vision Loss	Multiple Impairments Cerebral palsy Vision Loss Hearing Loss	Developmental Delays Cognitive delays Learning issues Feeding and sleeping issues Vision Loss Hearing Loss	Hearing Loss Hearing Aids Cochlear Implants Communication and Learning Issues Mild vision disorders	None No visible delays or impairments
Severe		Moderate		Mild	

Adapted from the National CMV Foundation.

Note: This table is not meant to be all-inclusive, each patient and case is distinctive

Monitoring Importance

Long-term Outcomes in Asymptomatic congenital CMV:

~20%

Hearing Loss by 18
years

~45%

Vestibular & Gaze
Stability Dysfunctions

~30%

Balance Difficulties

?

Autism Risk

?

Learning Disabilities

?

Developmental Delays

Inclusion

Children with a congenital CMV infection should not be excluded from school or other settings.

Children born with congenital CMV pose no threat to their peers and no more of a threat to those at risk for CMV infection (ie. pregnant women) than would any other child.

Inclusion Q&A

Question: I am pregnant (or attempting to become pregnant) and one of the young children in my program was diagnosed with congenital CMV. Should I avoid being around this child to protect myself from a CMV infection?

Answer (from MN Department of Health): No, you do not need to avoid being around a child with congenital CMV. Asymptomatic excretion of CMV is common in people of all ages; a child with a congenital CMV infection should not be treated differently from other children. It's important to protect yourself from a CMV infection by using standard precautions with ALL children.

AAP Red Book: Report of the Committee on Infectious Diseases (2024)

Tips to reduce your risk of getting CMV

1. Wash your hands with soap and water often, especially after wiping a child's nose or mouth and changing diapers.
2. Try to avoid contact with saliva by kissing a child on the forehead instead of the lips.
3. Try to avoid sharing food, drinks, straws or eating utensils with young children. Wash your hands after handling these items.
4. Avoid putting things in your mouth that have been a child's mouth, such as a pacifier or toothbrush.
5. Properly clean/disinfect objects and surfaces that may have a child's urine or saliva on them.

CMV Prevention Infographic

5 Simple Tips to Help Prevent CMV



Avoid contact with saliva when kissing a child



Do not put a pacifier in your mouth



Do not share food, utensils, drinks or straws



Do not share a toothbrush



Wash your hands after changing a diaper

Video: Preventing Congenital CMV

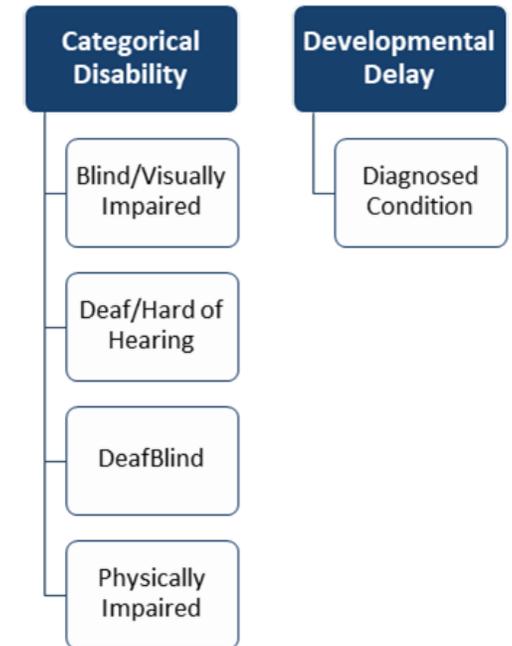
Video (4:16 mins, sec):
<https://youtu.be/1XgQcnYwisU?feature=shared>



Eligibility for MN Special Education Services

Potential Eligibility under Part C IDEA with Congenital CMV Diagnosis.

- Cytomegalovirus is a known condition to hinder development listed on the Early Intervention Colorado List. ([Established Conditions Database](#))
- A congenital CMV diagnosis should have continued monitoring for progressive sensory loss.



Continued Monitoring: Hearing

Hearing loss related to CMV can be fluctuating and/or progressive, so it is important that all children have continued and close monitoring with an audiologist to detect changes.

MDH Early Hearing Detection and Intervention Audiology Guidelines for Infants with Congenital Cytomegalovirus

Continued Monitoring: Vestibular

It is recommended that all children with congenital CMV have vestibular screening because they are at an increased risk for vestibular dysfunction that can disrupt their balance and visual gaze. It is recommended that audiologists include screening for vestibular dysfunction at each follow up visit.

MDH Early Hearing Detection and Intervention Audiology Guidelines for Infants with Congenital Cytomegalovirus

cCMV Public Health and Policy Conference Series: Pediatric Vestibular Dysfunction

Continued Monitoring: Overall Development

The child's overall growth and development should be monitored closely.

Recent research has shown that children with congenital CMV are more likely to be diagnosed with autism spectrum disorder (ASD) than their peers. It is recommended that parents and professionals be proactive in monitoring for early signs and doing formal assessments for ASD at appropriate ages. Families of children with congenital CMV may seek specialized assessments or care from a Developmental Behavioral Pediatrician.

Parent Stories: Reality and Awareness

Video (0:39 sec):

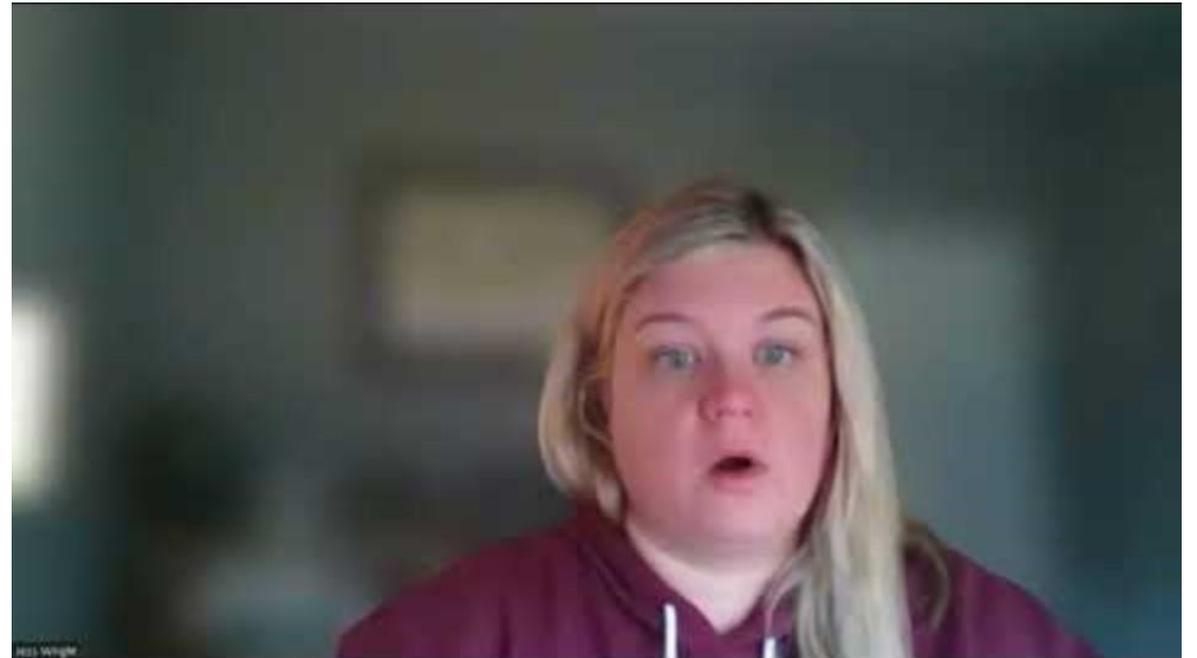
https://youtu.be/WQvaPrB_ff8



Parent Stories: Early Intervention

Video (1:06 min, sec):

<https://youtu.be/gkBgi1Tp-JU>



IFSP or IEP Considerations: Document

It is important to document the congenital CMV diagnosis in every IFSP or IEP and update with symptoms:

- This ensures the child's diagnosis is not 'lost' from report to report and/or case manager to case manager.
- Provides necessary information for the child's team to ensure proper development monitoring, health care follow-up and supports.

IFSP or IEP Considerations: Impact Statement

Importance for all service providers to be aware of congenital CMV possible impacts:

- Awareness of how cCMV might affect a child
- Awareness of how cCMV might manifest over time
- Awareness of how a cCMV diagnosis could be impacting the child's caregivers
- Importance of quality monitoring of all areas of development to quickly address any areas of need if they arise.
- Practitioners share relevant information in a timely manner with caregivers and connect to resources and other families

IFSP or IEP Considerations: Impact Statement Example

[Name] was born with congenital cytomegalovirus (cCMV), which is a viral infection [he/she] caught in utero. Children with congenital CMV are at higher risk of developmental delays and differences due to the virus impacting their in-utero development. Some of the effects of congenital CMV on a child's development can be apparent early in infancy, whereas other impacts may appear later on in childhood. In **[name]** case, they have the following apparent impacts of congenital CMV: **[list known impacts]**. Children with congenital CMV are also at greater risk of developing new onset or progressive hearing loss, autism spectrum disorder, and learning difficulties that may not be apparent early in life. Of note, children with congenital CMV have lower rates of 'success' with using Listening and Spoken Language strategies only, therefore multimodal language learning strategies are paramount.

IFSP or IEP Considerations: Impact Statement possible known impacts

- Hearing loss
- Vision loss
- Seizures
- Cerebral Palsy
- Low Tone
- Delayed Gross Motor milestones
- Speech/Language/Communication delay
- Behavioral difficulties
- Global Developmental Delay
- Other

IFSP or IEP Considerations: Impact Statement Additions (based on areas of need)

Examples:

- **[Name's]** speech and language delays impact their ability to communicate and express themselves effectively.
- **[Name's]** hearing difference impacts their ability to understand and follow verbal instructions in the classroom.
- **[Name's]** hearing difference impacts their ability to naturally acquire language through implicit learning of what is happening around them.
- **[Name's]** vision loss impacts their ability to navigate within spaces.

Parent Stories: Language Access

Video (0:39 sec):

<https://youtu.be/-ZxDq2W03jY>

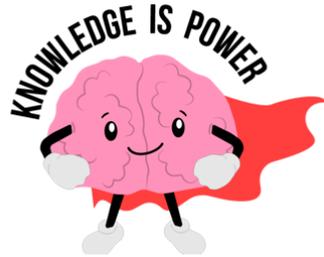


Parent Stories: Words Matter

Video (1:21 min, sec):

<https://youtu.be/rRs-4csLCy0>





Thank you for Learning more about congenital CMV

The MN Low Incidence Projects and this initiative are made possible with a grant from the MN Department of Education, federal award Special Education-Programs to States, CDFR 84.027A. Unless otherwise specified, this activity is not reflective of official policies or recommendations of the MN Low Incidence Projects, Brightworks, the MN Department of Education, or local education agencies.

Survey

After learning from this overview presentation on congenital CMV, please complete the following survey, so we can track the presentation's use for our federal grant goals.

LINK:

<https://www.surveymonkey.com/r/cCMV101Packet>



Resources: Parent Stories All Videos:

Megan

- ★ [cCMV Screening](#)
- ★ [Initial Referral Process](#)
- ★ [Unknown Frustrating and Scary](#)
- ★ [Early Intervention and Daycare](#)

Cadie

- ★ [Exhaustion](#)
- ★ [Teacher DHH Answers Questions](#)
- ★ [Outpouring of Support](#)
- ★ [Having a Point Person](#)
- ★ [Telling In-Laws](#)

Resources: Parent Stories All Videos, cont.:

Jess

- ★ [Early Intervention and Asymptomatic Child](#)
- ★ [Connect with Other Moms](#)
- ★ [Importance of Educating Expectant Mothers](#)

Julie

- ★ [Uncertainty of Prognosis](#)
- ★ [Words Matter ENT](#)
- ★ [Many Doctor Appts](#)
- ★ [Dr Visits/Hospital Stays in First Year](#)
- ★ [Language Deprivation](#)
- ★ [Deaf Community Access](#)
- ★ [Additional Thoughts](#)

Resources: Congenital Cytomegalovirus

- [National CMV Foundation](#)
- [National CMV Foundational Educational Downloads \(referenced in slideshow\)](#)
 - What Everyone Needs to Know About Congenital Cytomegalovirus Booklet
 - Awareness vs Incidence of Congenital Conditions
 - CMV Shedding
 - CMV Prevention Infographic
- [MN Department of Health Cytomegalovirus and Congenital Cytomegalovirus](#)
- [Preventing Congenital CMV YouTube Video](#)

Resources: Minnesota cCMV Screening

- [MN Department of Health The Vivian Act Legislation](#)
- [Minnesota Legislature Statute 144.064 The Vivian Act](#)
- [WCCO News Minnesota First US State to Screen All Newborns for Congenital Cytomegalovirus MN](#)
- [Department of Health EHDI Audiology Guidelines for Infants with Congenital Cytomegalovirus](#)

Resources: Minnesota Early Intervention

- [MN Department of Education Part C and Part B Resources](#)
- [MN Help Me Grow](#)
- [Early Intervention Colorado List of Established Conditions Database](#)

Resources: cCMV Research Articles

Topic: Mother's at risk for cCMV

- Source: Pass RF, Little A, Stagno S, Britt WJ, Alford CA. Young children as a probable source of maternal and congenital cytomegalovirus infection. *New England journal of medicine*. 1987 May 28;316(22):1366-70.
- Source: Leruez-Ville M, Magny J-F, Couderc S, et al. Risk factors for congenital cytomegalovirus infection following primary and nonprimary maternal infection: a prospective neonatal screening study using polymerase chain reaction in saliva. *Clin Infect Dis*. 2017;65(3):398–404

Resources: cCMV Research Articles, cont.

Topic: Listening and Spoken Language (LSL) for Children with Congenital Cytomegalovirus

- Source: Kraaijenga, V. J. C., et al. "Cochlear implant performance in children deafened by congenital cytomegalovirus—A systematic review." *Clinical Otolaryngology* 43.5 (2018): 1283-1295.
- Source: Yoshida H, Takahashi H, Kanda Y, Kitaoka K, Hara M. Long-term outcomes of cochlear implantation in children with congenital cytomegalovirus infection. *Otology & Neurotology*. 2017 Aug 1;38(7):e190-4.