



## **All Aboard!**

# **Potential Impacts of Congenital Cytomegalovirus (cCMV) in Early Childhood Special Education in Minnesota**

**Presented by Statewide Specialists**

Minnesota Low Incidence Projects, Minnesota Department of  
Health and Minnesota DeafBlind Project

**February 1, 2024. We will begin at 12:00 pm**

# Webinar Logistics

- Please turn off your camera
- Please ensure your microphone is muted
- Captioning is available by turning on captions within Zoom or by clicking the link in the chat provided by the captioner.
- This webinar will be recorded, and the link will be emailed to everyone who is registered.
- Certificates of Attendance will be available to those who registered, viewed the webinar, and completed the evaluation survey. (Survey link will be emailed)

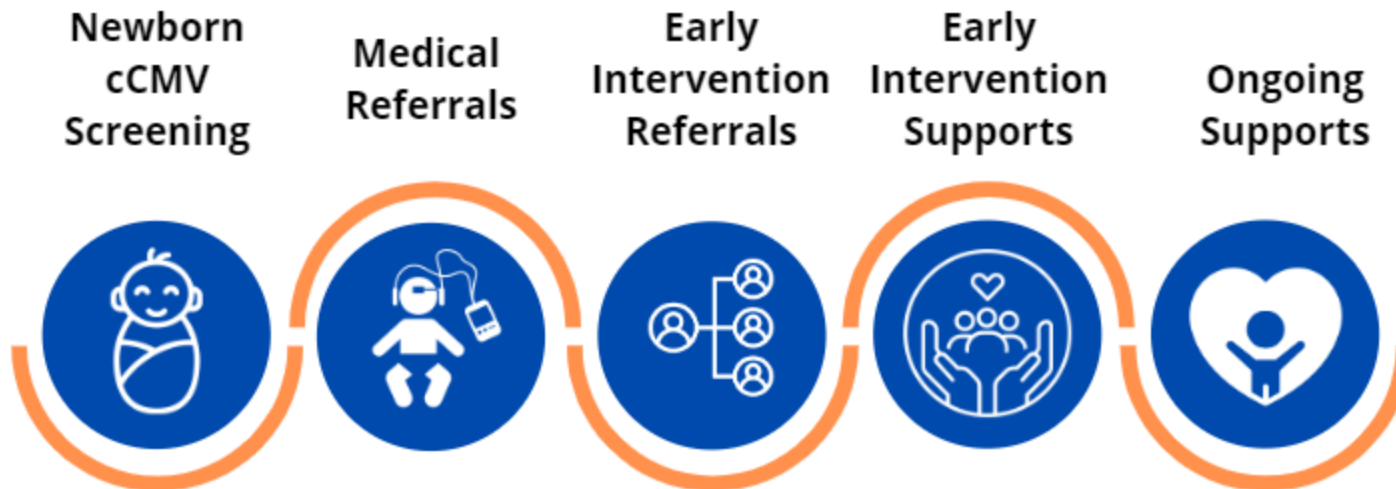
# Questions & Answers (Q & A)

- Please place questions in the Q & A in Zoom.
- Questions will be compiled and answered in a Q & A document and made available for viewing at a later date.

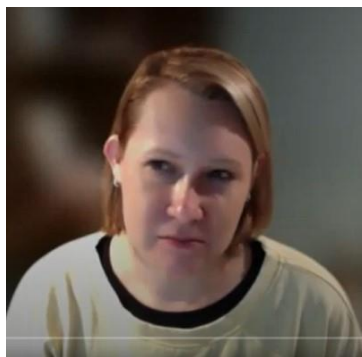
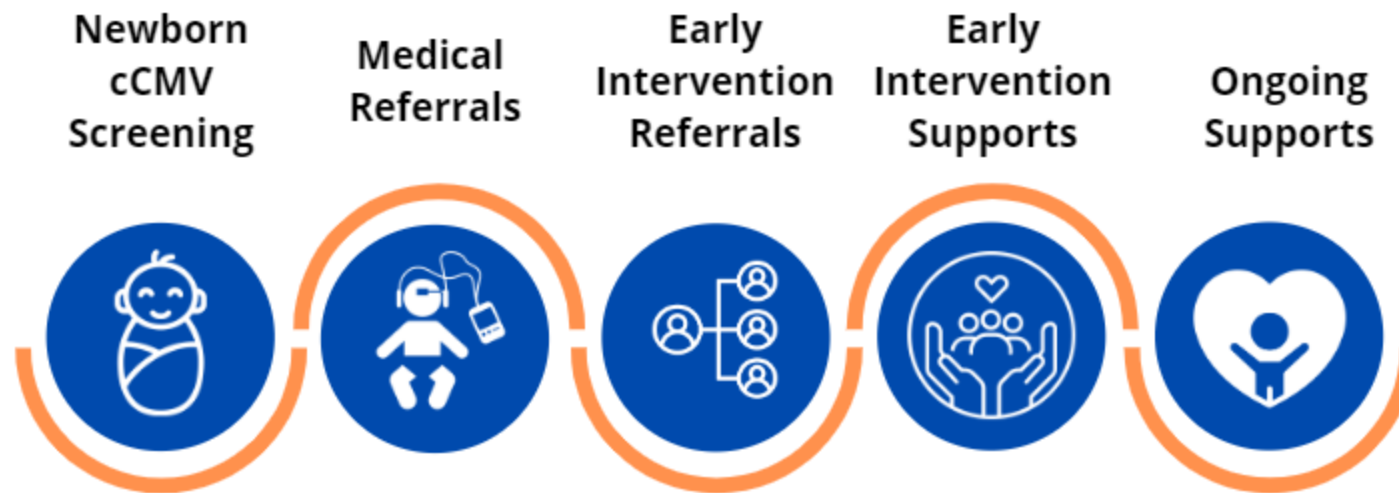


# Webinar Objectives

- Review of Minnesota (MN) cCMV screening, referral process, and current data
- Resources to support early educators working with children who have cCMV and their families
- Strategies to promote early intervention recommended practices



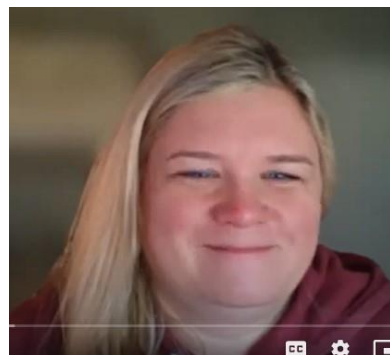
# Parent Stories



**Cadie**



**Callie**



**Jess**



**Julie**

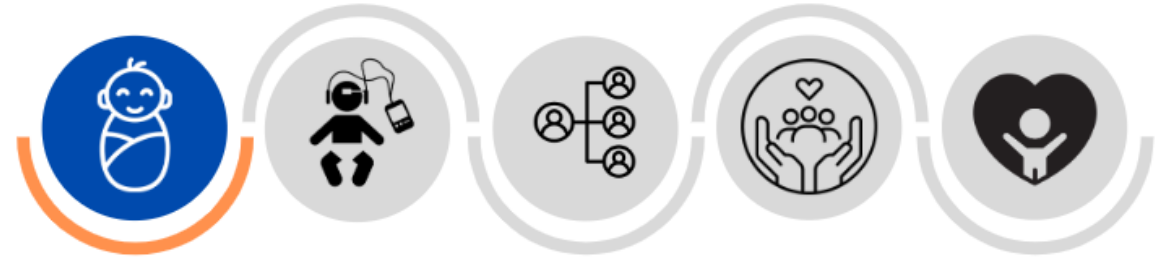


**Melissa**



**Megan**

# MN CMV Legislation – The Vivian Act (2021)



## Education

- Make information about CMV available to health care providers, women who may become pregnant, expectant parents, and parents of infants.
- Establish a CMV outreach program to educate women who may become pregnant, expectant parents, and parents of infants.
- Raise awareness for CMV among health care providers.

## Newborn Screening

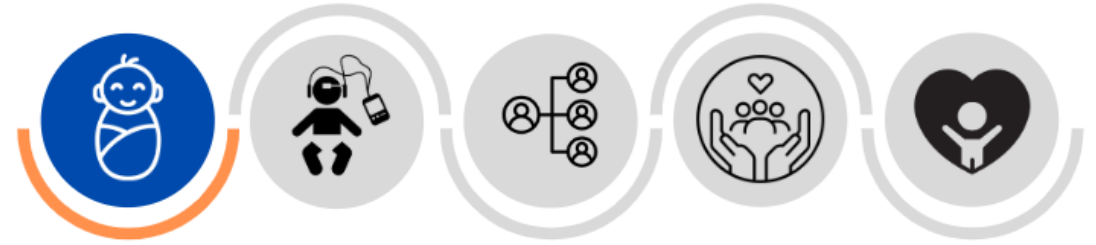
- Advisory Committee on Heritable and Congenital Disorders to review CMV for possible inclusion on Minnesota's newborn screening panel.
- Recommend for addition by the Committee and approved by Commissioner of Health.
- Minnesota became the first state to screen every newborn for CMV.



Photo credit: Michelle  
Wiley/MPR News



# Universal Newborn Screening for CMV



## Purpose

- Identify the infection and any health or developmental concerns as early as possible
- Offer interventions that can help minimize the impact of the disease

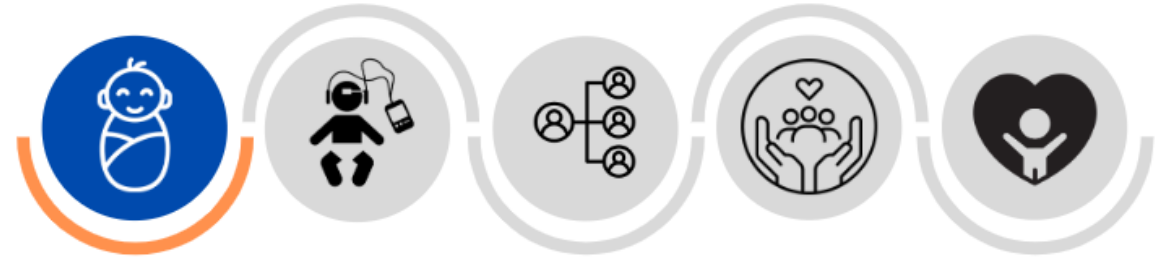
## Recommended Initial Evaluation

- Collect urine sample for confirmation of infection
- To determine severity of disease and recommended treatment
  - Laboratory blood testing
  - Physical exam
  - Head imaging
  - Dilated eye exam
  - Diagnostic audiology exam
- Usually coordinated by the Primary Care Provider



# Parent Stories:

Callie, Randy and Dixie



Callie and Dixie

"Universal screening of all newborns is such an amazing advancement in Minnesota. I feel it will help families access Early Intervention services quickly, giving their children the most support from the start."

Callie & Randy, parents of Dixie

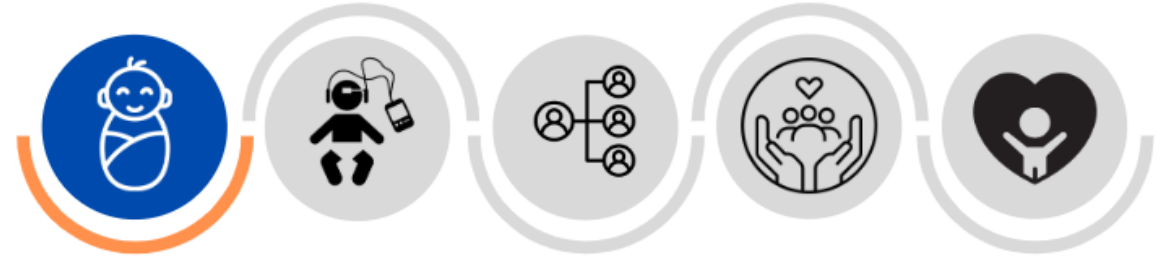


Randy and Dixie



# Parent Stories:

Megan

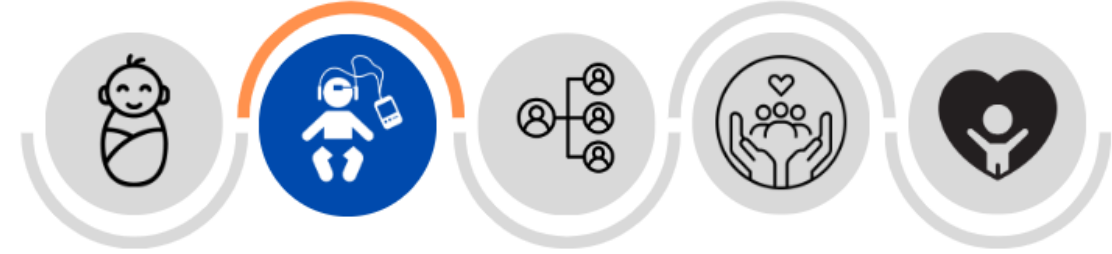


Share about your first experiences with screening your child for cCMV.



<https://youtu.be/cJmeUpaoWuY>

# MDH Follow-up and Surveillance



**Mail parent/guardian letter and information booklet**  
(available online)

## Hearing Monitoring

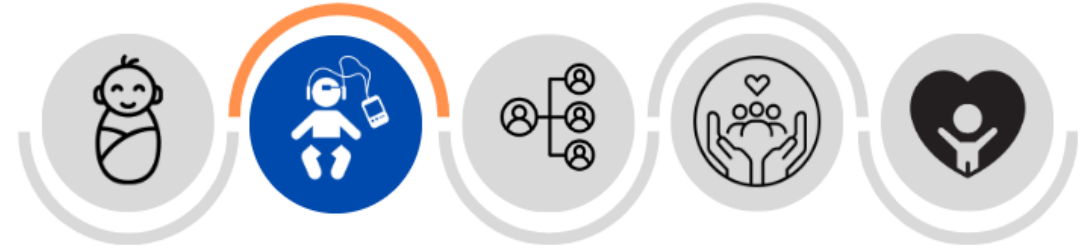
[Audiology Guidelines for Infants with cCMV](https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/audiogdlnccmv.pdf)

(<https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/audiogdlnccmv.pdf>)

## Longitudinal Surveillance



# Connections to Resources



## Local Public Health Referral

- Contact family and complete a nursing assessment
- Goal: Identify child and family needs and to ensure connection with appropriate community resources and services

## Parent Support and Networking

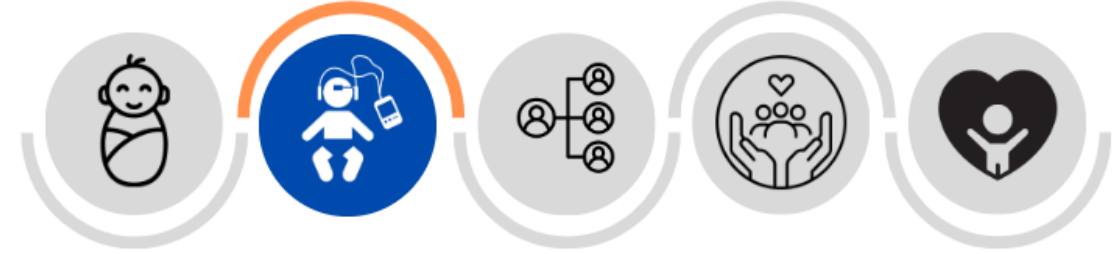
- Pilot program in collaboration with Minnesota Hands and Voices for 1:1 support for parents of “symptomatic” children
- National CMV Foundation

## Growth and Development

- Help Me Grow referrals by providers
- Promote the Follow Along Program

# PARENT STORIES:

Melissa and Remi



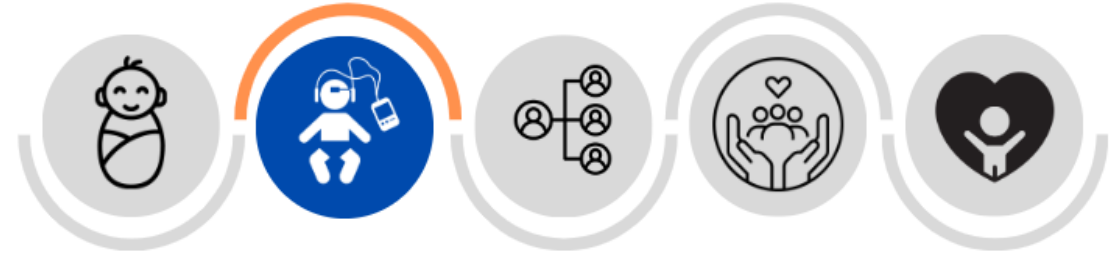
Remi

"I think having a specialist for CMV at that hospital was very helpful but when it came to follow up after we had to drive all the way to the cities to talk to the same person, which was a long drive for us."

Melissa, parent of Remi

# PARENT STORIES:

Jess and Julie



Share about your initial experiences navigating life with a child who has a cCMV diagnosis.



<https://youtu.be/mtXFo8J2Hc0>



<https://youtu.be/aud3K6UYk-s>

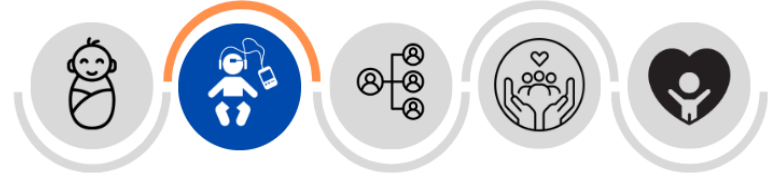


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# Confirmed MN Congenital CMV Cases

## 02/06/2023-11/30/2023



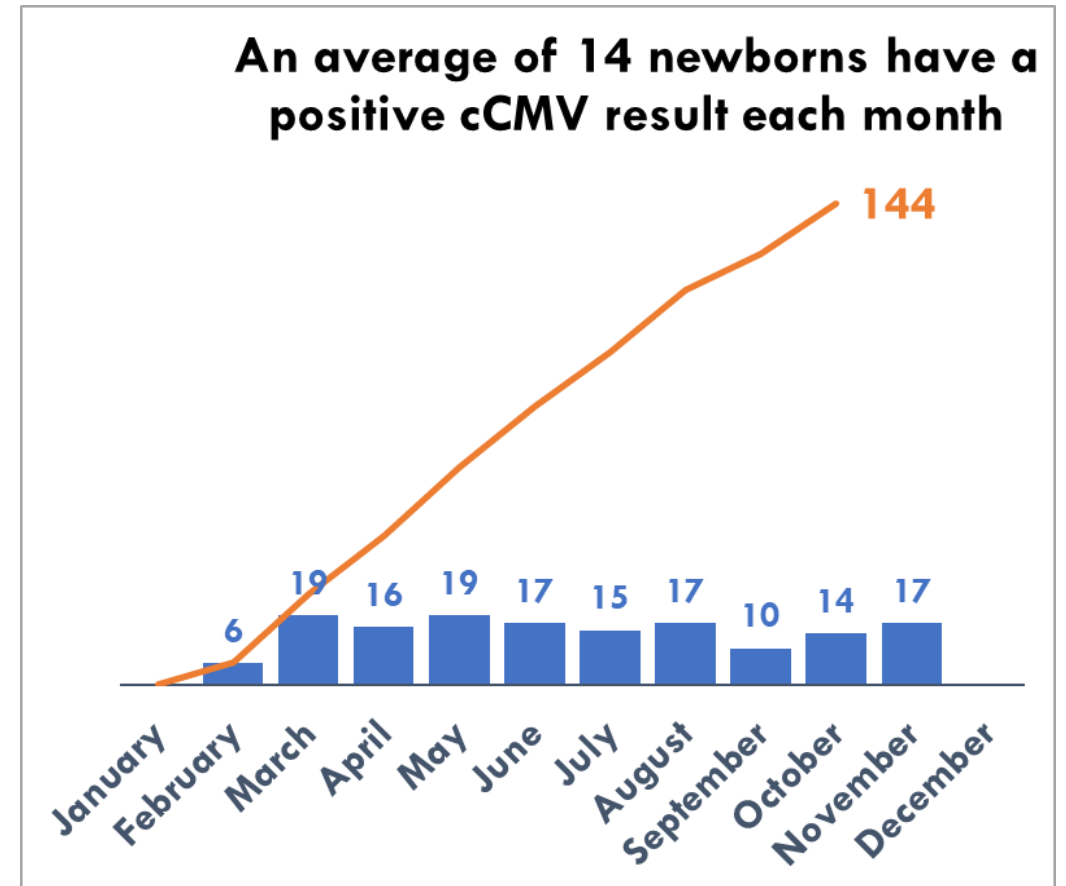
**49,823** newborns screened

**144** newborns confirmed to have a cCMV infection

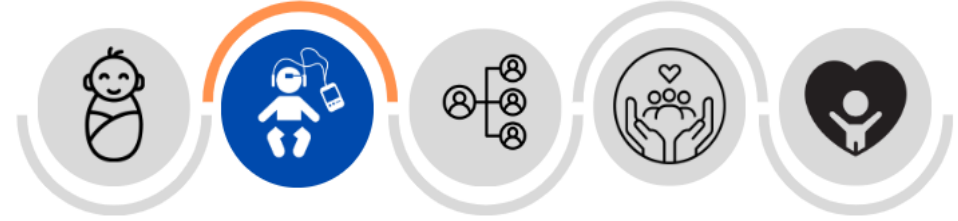
cCMV prevalence = **1:345** newborns

Wide geographic distribution

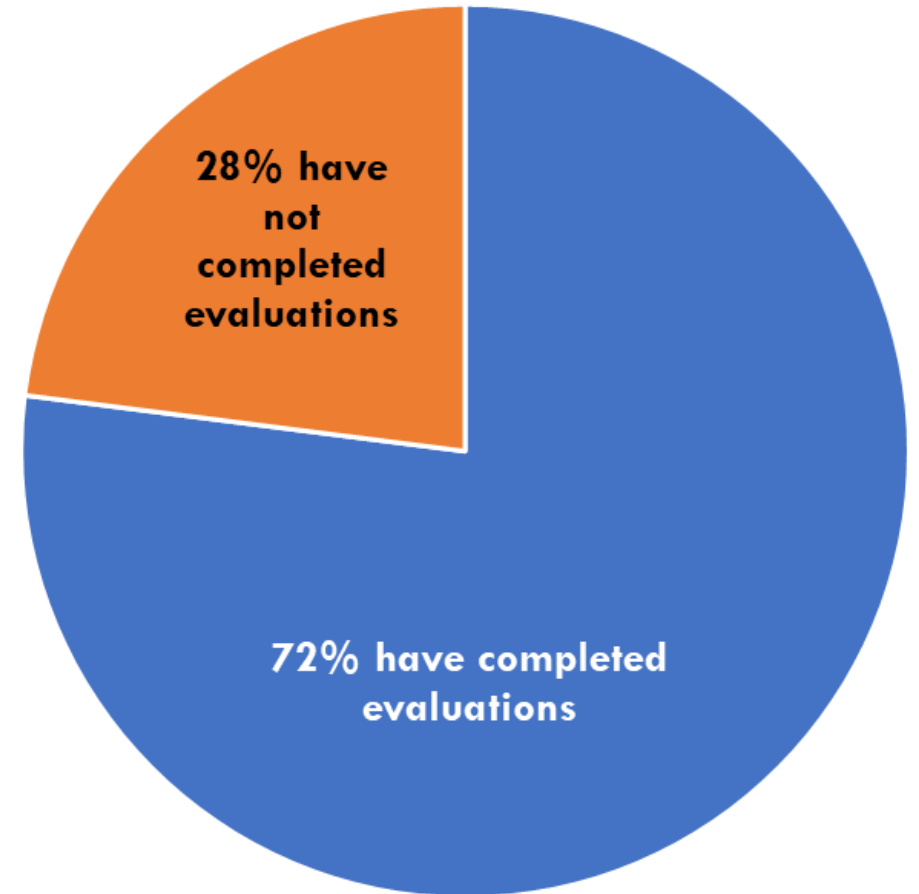
- **62%** of newborns live in 7-county metro
- **38%** of newborns live in greater MN
- **37** MN counties have at least one newborn identified with cCMV since screening began



# Recommended Initial Evaluations



- Charts have been reviewed for XXX cases to determine if initial evaluations have been completed
  - **23%** infants have a clinical finding that may be related to cCMV
  - **11** infants with cCMV identified with sensorineural hearing loss
- Chart reviews for longitudinal surveillance will begin at one year of age



## Early Intervention Referrals



1. [Help Me Grow](#) referral to local school district

[Diagnosed conditions affecting development](#)

2. Part C screening and/or evaluation

[Minnesota Department of Education Part C and Part B Resources](#)

3. Part C eligibility and services for children with cCMV and their families

Potential Eligibility under Part C IDEA

With Congenital Cytomegalovirus (cCMV) Diagnosis.

*A cCMV diagnosis should have continued monitoring for progressive sensory loss.*

**Categorical Disability**

Blind/Visually Impaired

Deaf/Hard of Hearing

DeafBlind

Physically Impaired

**Developmental Delay**

Diagnosed Condition

# Early Intervention Referral Resources



## Children and their Families

- Learn about their local program early intervention process
- Learn information for additional support
  - Local Public Health
  - MN Hands & Voices
  - Deaf Mentor Family Program
  - MN DeafBlind Project
  - CMV Foundation
  - Social Media Groups

## Educators

- Gather medical information
  - Review [MDH Audiology Guidelines for Infants with cCMV](#) and consider how to utilize information already being collected.
  - Document comprehensive developmental history
- Review MDH [Tips to reduce your risk of getting CMV](#)
- Review National CMV Foundation's [Early Interventionist Flyer](#)

# Early Intervention Referral Resources

## PARENT STORIES



Share about your experience being referred for early intervention services.



Dixie



Dixie with her brothers Ben & Brantley

"We had a lot of support from Early Intervention. The whole team was amazing, and as a huge bonus, they were able to connect us with another local family who had a child with cCMV."

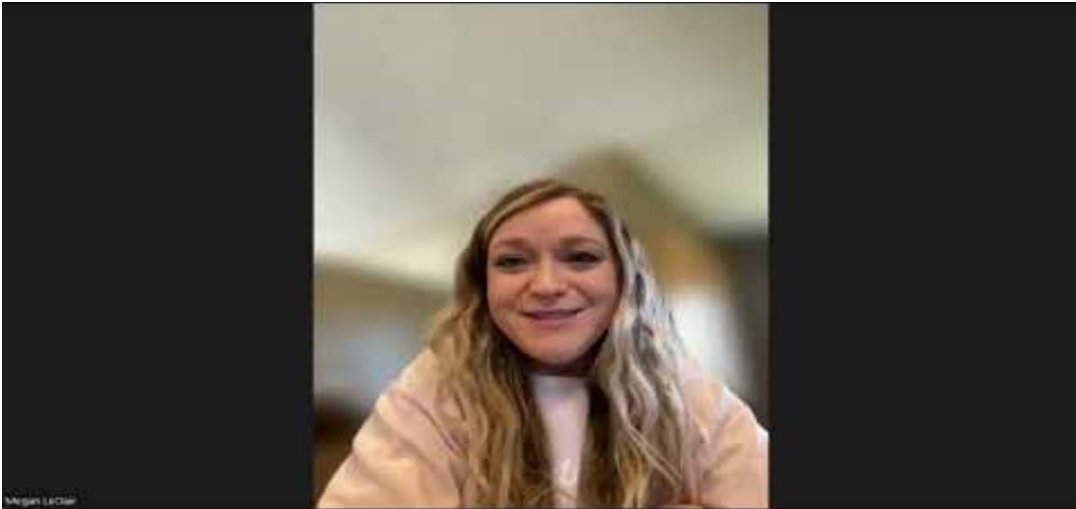
Callie, parent of Dixie



# Early Intervention Referral Resources: PARENT STORIES



Share about your experience being referred for early intervention services.

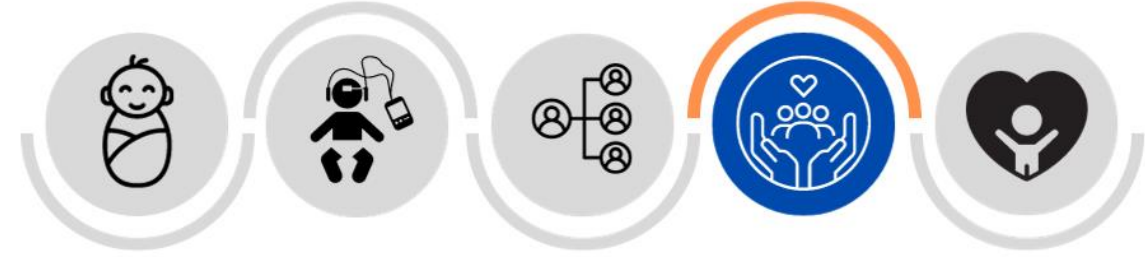


<https://youtu.be/u4jScsyHCNg>



<https://youtu.be/vqKr-mHid3Q>

# Early Intervention Supports



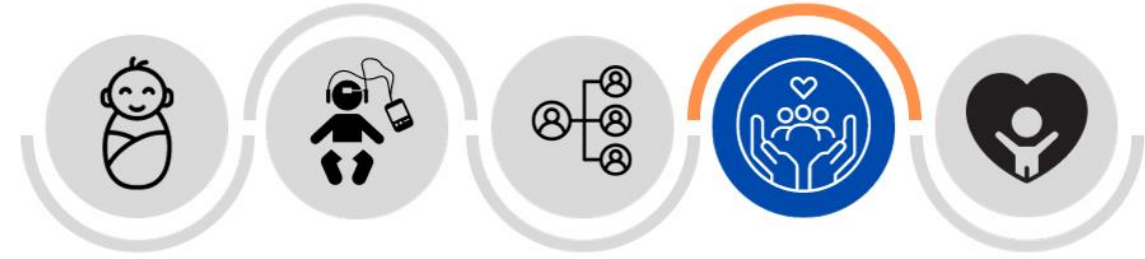
## For Children and their Families

- Increase confidence and competence to support their child
- Coordinate child supports
- Infuse language all day long to support robust language acquisition
- Learn about the importance of etiology and awareness of changes that could occur due to cCMV

## For Educators

- Utilize recommended Part C collaborative practices with low incidence specialists and related service providers
  - [Part C Intervention Services for Infants and Toddlers with Sensory Loss: Recommended Collaborative Practices](#)
- Service Coordination
- Share with parents/caregivers the importance of language acquisition and impact of language deprivation
- Document cCMV on each IFSP or IEP
- Recognize the complexity of coordinated supports and the strains this can place on families

# Early Intervention Supports PARENT STORIES



Share about your Early Intervention experiences related to cCMV and your hopes for early interventionists working with children with cCMV and their families.



Callie, Dixie and their family

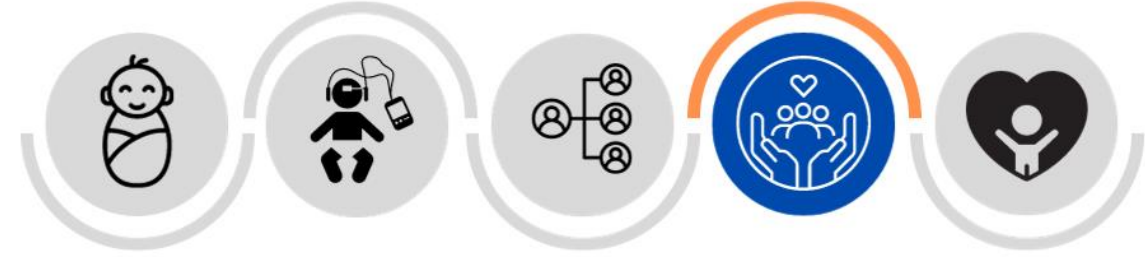
"Our Early Intervention team felt like family after being in our home multiple times a week for 3 years. They were understanding, gentle, and caring. They watched our family grow, they watched us move to a new home, they sympathized with the struggles and celebrated the joys right alongside us. They were one of our greatest sources of support in those first three years."

Callie, parent of Dixie

# Early Intervention Supports

## PARENT STORIES

Remi and Melissa



Share about your Early Intervention experiences related to cCMV and your hopes for early interventionists working with children with cCMV and their families.



Remi

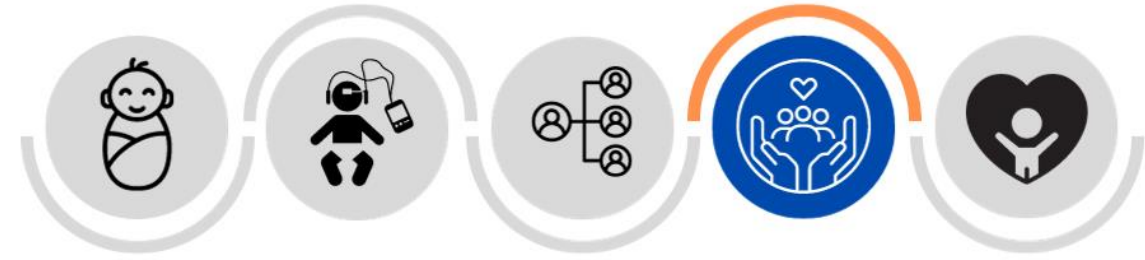
"I really loved the early intervention services that came to our home and were flexible with our schedule and supported us in any way they could have. Only 2 of the teachers were aware of cCMV because of working with kids in the past, but a few of the teachers had no idea what cCMV was and were scared that they would get sick not knowing what all the virus entailed."

Melissa, parent of Remi



# Early Intervention Supports PARENT STORIES

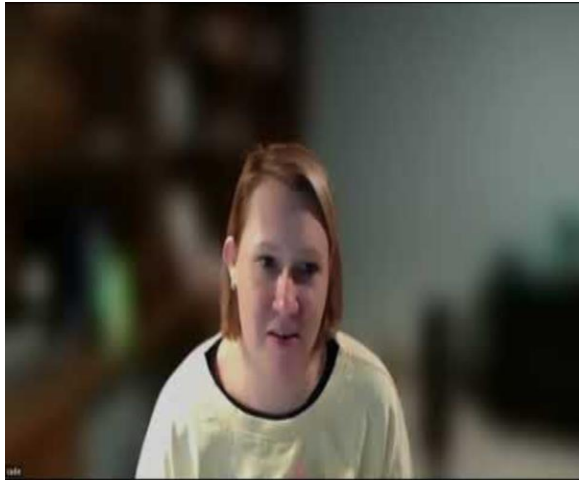
Cadie, Jess and Megan



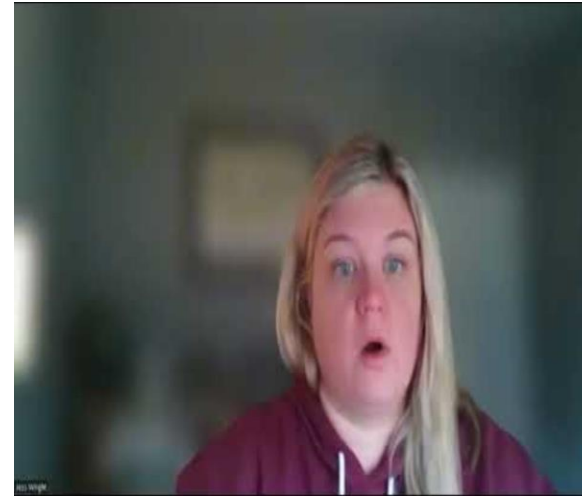
Share about your Early Intervention experiences related to cCMV and your hopes for early interventionists working with children with cCMV and their families.



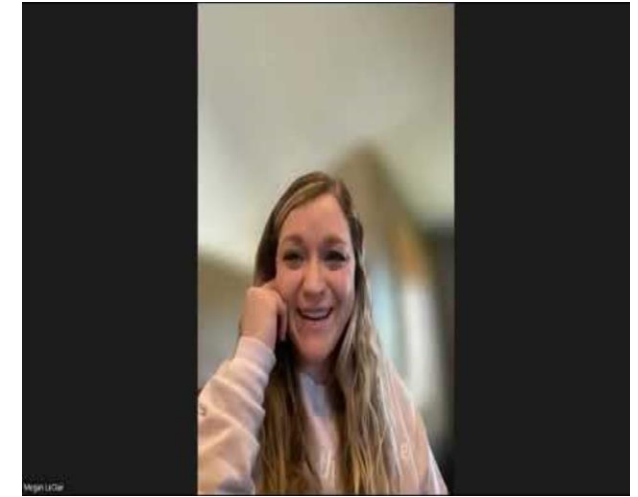
<https://youtu.be/rkilUjHmckQ>



[https://youtu.be/WQvaPrB\\_ff8](https://youtu.be/WQvaPrB_ff8)



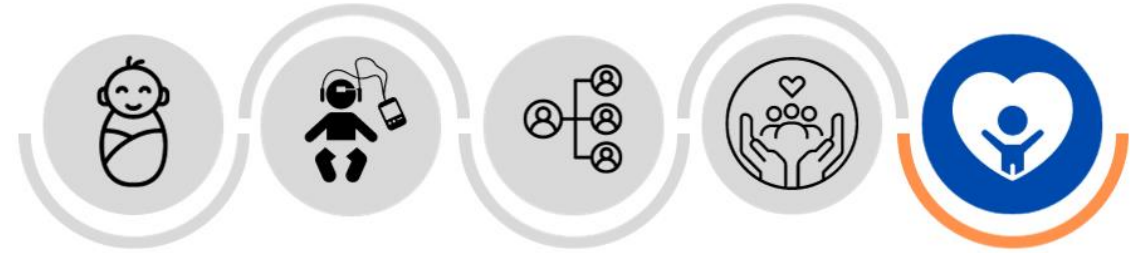
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<https://youtu.be/cYj7AwamYZk>



# Ongoing Supports



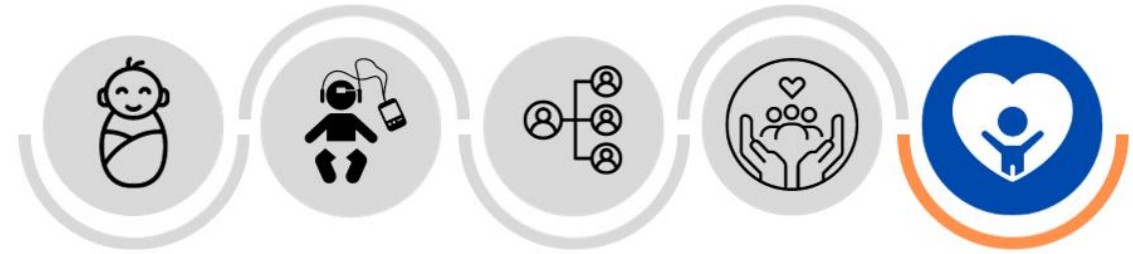
## For Children and their Families

- Continue to increase confidence and competence in supporting their child
- Access community resources and supports
- Connect with other children and families with cCMV
- Continue to follow up and track their child's medical needs and developmental progress

## For Educators

- Support parents/caregivers in continual learning about their child's development and encourage their competence and confidence in supporting their child's growth
- Document the child's developmental milestones, including language acquisition on a frequent basis
- Continue to document cCMV on IFSP and IEP

# Early Intervention Supports PARENT STORIES



Share about your experiences, related to cCMV, and the support you received from family and community.



Dixie with her dad, Randy



Dixie

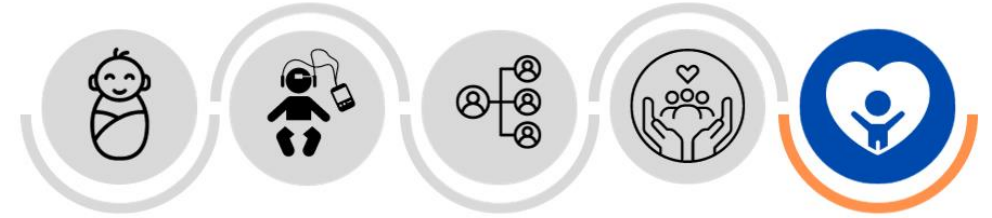
"Connecting with another family was probably the most significant part of our journey. Having another parent who had lived through the same thing we were was a blessing I didn't know I needed."

Callie Holmes, parent of Dixie

# Early Intervention Supports

## PARENT STORIES

Callie and Dixie



"I think it is important to share that a huge source of our support came from our local Public Health. We were assigned a Public Health Nurse after birth due to my age as well as the medical complexities of our daughter, and we developed a very meaningful relationship. I relied heavily on the support of our Public Health Nurse, who also helped to get us set up with a social worker. The two of them helped arrange transportation to and from medical appointments, one of our greatest barriers. They also assisted me in obtaining my drivers license, a necessary step in the process of being able to care for my daughter with all of her additional needs. They helped us to access government assistance which allowed me to stay in school and graduate with my class, and connected me to the workforce center which helped me to develop a plan for what would come after high school. They also helped us connect to resources such as PCA services. I am grateful for the tools they gave me, they are absolutely the reason why my daughter and I made it out on top, even when I felt like we were drowning."

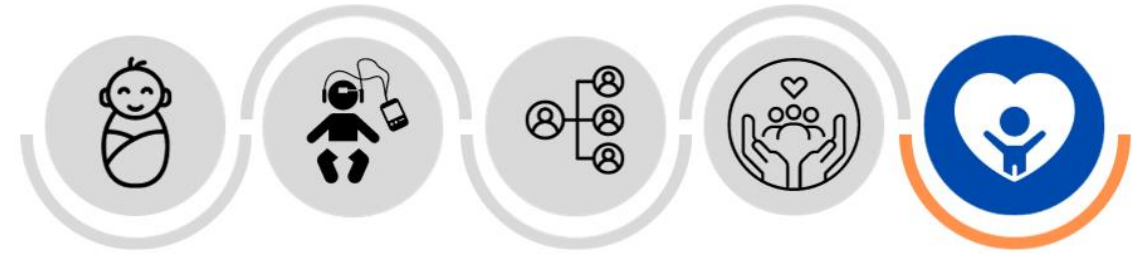
Callie Holmes, parent of Dixie



Callie holding Dixie

# Early Intervention Supports PARENT STORIES

Cadie, Megan and Julie



Share about your experiences, related to cCMV, and the support you received from family and community.



[https://youtu.be/l\\_L3YDpGpXk](https://youtu.be/l_L3YDpGpXk)



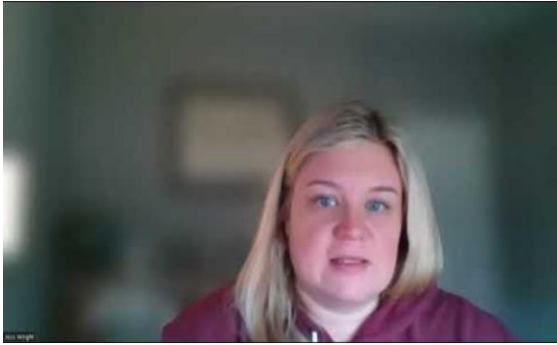
<https://youtu.be/CGzmZKXaH5A>



<https://youtu.be/JFy09JtpBCw>



# FINAL THOUGHTS FROM PARENTS



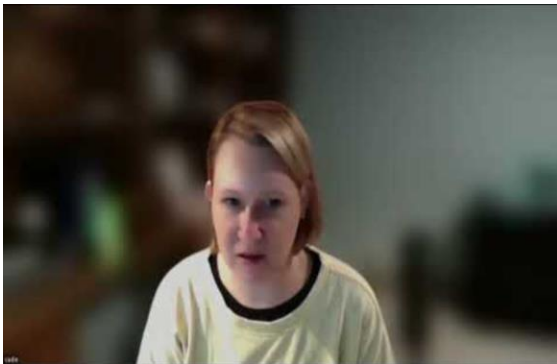
<https://www.youtube.com/watch?v=rwnvZ5QCvx4&t=7s>



[https://www.youtube.com/watch?v=x0suhXc\\_taw](https://www.youtube.com/watch?v=x0suhXc_taw)



[https://www.youtube.com/watch?v=wT\\_O9g94e7o&t=3s](https://www.youtube.com/watch?v=wT_O9g94e7o&t=3s)



<https://youtu.be/73bbvbbmIXs>



<https://youtu.be/QwJov0a8sMQ>



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



# Credits & Resources

## Minnesota Education-based:

- [Minnesota Low Incidence Projects](https://mnlowincidenceprojects.org/) (https://mnlowincidenceprojects.org/)
- [Exploring Communication Opportunities](https://mnlowincidenceprojects.org/Projects/ehdi/ehdiCommunicationOpp.html)  
(https://mnlowincidenceprojects.org/Projects/ehdi/ehdiCommunicationOpp.html)
- [Minnesota DeafBlind Project](https://www.dbproject.mn.org/index.html) (https://www.dbproject.mn.org/index.html)
- [Minnesota Department of Education \(MDE\) Part C and Part B Resources](https://education.mn.gov/MDE/dse/early/ecse/bc/)  
(https://education.mn.gov/MDE/dse/early/ecse/bc/)
- [Part C Intervention Services for Infants and Toddlers \(Birth to Age 3\) with Sensory Loss: Recommended Collaboration Practices](https://education.mn.gov/mdeprod/groups/educ/documents/hiddencontent/cm9k/mdm0/~edisp/pod034482.pdf)  
(https://education.mn.gov/mdeprod/groups/educ/documents/hiddencontent/cm9k/mdm0/~edisp/pod034482.pdf)

# Credits & Resources

## Minnesota Department of Health (MDH):

- [MDH Cytomegalovirus and Congenital Cytomegalovirus](https://www.health.state.mn.us/diseases/cytomegalovirus/index.html)  
(<https://www.health.state.mn.us/diseases/cytomegalovirus/index.html>)
  - [MDH Vivian Act](https://www.health.state.mn.us/diseases/cytomegalovirus/vivianact.html) (<https://www.health.state.mn.us/diseases/cytomegalovirus/vivianact.html>)
  - [MDH EHDI Audiology Guidelines for Infants with Congenital Cytomegalovirus](https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/audiogdlnccmv.pdf)  
(<https://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/audiogdlnccmv.pdf>)
  - [MDH Tips to reduce your risk of getting CMV](https://www.health.state.mn.us/diseases/cytomegalovirus/childcareeduc.html)  
(<https://www.health.state.mn.us/diseases/cytomegalovirus/childcareeduc.html>)
- [MDH Early Hearing Detection and Intervention \(EHDI\)](https://www.health.state.mn.us/improveehdi) (<https://www.health.state.mn.us/improveehdi>)  
[MDH Resources for Families](https://www.health.state.mn.us/people/childrenyouth/improveehdi/resources.html)  
(<https://www.health.state.mn.us/people/childrenyouth/improveehdi/resources.html>)
- [MDH Follow Along Program](https://www.health.state.mn.us/people/childrenyouth/fap/index.html) (<https://www.health.state.mn.us/people/childrenyouth/fap/index.html>)

# Credits & Resources

## Minnesota (other)

- [Minnesota Deaf Mentor Family Services](https://www.lssmn.org/services/families/deaf-hard-of-hearing/mentor-services)  
(<https://www.lssmn.org/services/families/deaf-hard-of-hearing/mentor-services>)
- [Minnesota Hands & Voices](https://www.lssmn.org/mnhandsandvoices) (<https://www.lssmn.org/mnhandsandvoices>)

### National

[National CMV Foundation](https://www.nationalcmv.org/) (<https://www.nationalcmv.org/>)



**Thank you!**

**Jess Moen**

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