



Collaboration between Public Health, Education Professionals, and a Family-Based Organization to Support Families Identified through Universal Screening for Congenital Cytomegalovirus (cCMV)

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Objectives

- Discuss one way to promote awareness, understanding, and compassion for children with cCMV and/or other conditions with a high probability of resulting in a developmental delay.
- List 2 methods to reach professionals working in educational settings with information about congenital CMV.
- Describe a model for parent-to-parent support of a child with congenital CMV.

The Vivian Act (2021)

Education/Public Awareness

- Make information available and establish an outreach program to reach women who may become pregnant, expectant parents, and parents of infants.
- Raise awareness for CMV among health care providers.

Screening

- Advisory Committee on Heritable and Congenital Disorders to review cCMV for possible inclusion on Minnesota's newborn screening panel.
 - Recommended for addition by the Committee and approved by Commissioner of Health (early 2022)
 - Universal newborn screening for cCMV started (February 2023)



Photo credit: Michelle Wiley/MPR News

Minnesota cCMV Cases (born 2/6/23 – 1/31/24)

- Approximately **60,000** newborns screened
- **185** Minnesota infants identified with a cCMV infection and in longitudinal follow-up
- In the group of infants with completed and available initial follow-up information:
 - **27%** had signs at birth that may be associated with cCMV
 - Many signs at birth were considered non-specific or transient
 - **11** infants identified with cCMV and sensorineural hearing loss



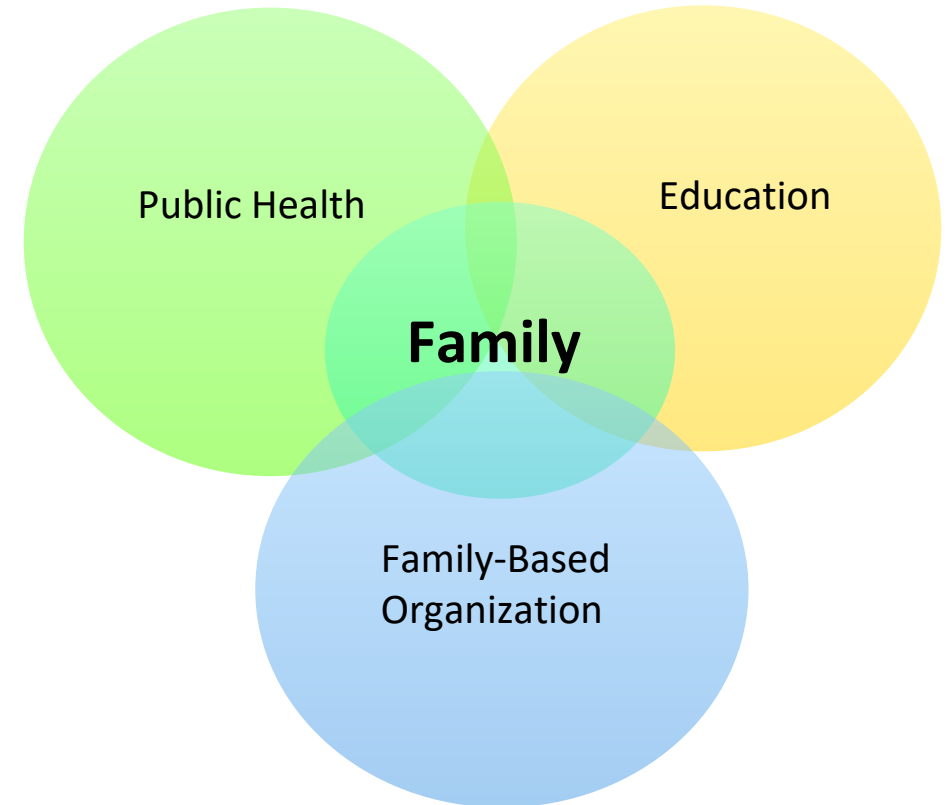
Universal Newborn Screening for cCMV

Purpose

- Identify the infection and any concerns as early as possible and offer interventions that can help minimize impacts

Considerations

- What will be the experience of impacted families?
- What systems will they interact with?
- What supports will be needed?
- How can those supports be facilitated?



Reaching Education Professionals



Jess Moen

General cCMV Information Sharing with Educator Groups

The MDH EHDI/cCMV Program and MN Low Incidence Projects staff shared about cCMV with multiple Minnesota educator groups:

- Early Hearing Detection & Intervention Statewide Representatives
- Teachers deaf/hard of hearing
- Educational Audiologists
- Early Childhood Special Education Leaders
- DeafBlind Community of Practice
- Regional Low Incidence Facilitators



Sharing about cCMV with Educators

Targeted practitioners working with and supporting children and their families in educational settings, such as:

- Early childhood special education and family education staff/administrators
- Teachers of students that are blind/visually impaired, deaf/hard of hearing, or have physical/health disabilities
- Childcare providers
- School nurses
- Audiologists (Educational and Clinical)



Remedies for Sorrow Book Study

[MN Low Incidence Projects: Congenital Cytomegalovirus \(cCMV\) resource webpage](https://mnlowincidenceprojects.org/cCMV/index.html)
<https://mnlowincidenceprojects.org/cCMV/index.html>

Initial book study created for and conducted with Early Hearing Detection & Intervention statewide representatives

- Educational Audiologists
- Early Childhood Special Education Teacher
- Speech Language Pathologists
- Teacher deaf/hard of hearing

Considerations for broader audiences



Remedies for Sorrow Book Study: Participant Feedback

45

Participants

97%

of participants report positive
effectiveness of the book study

Participant reported next steps:

- Share information about cCMV with families and colleagues
- Be mindful of potential emotional impact of cCMV diagnosis for families
- Learn more about cCMV and potential educational impacts

Minnesota cCMV Webinar Series

[MN Low Incidence Projects: Congenital Cytomegalovirus \(cCMV\) resource webpage](#)

- 1. Webinar #1: All Hands on Deck! Supporting the Development of Children with Congenital CMV**, presented by Dr. Megan Pesch, University of Michigan
- 2. Webinar #2: All Aboard! Impacts of Congenital CMV in Early Childhood Special Education in Minnesota**, presented by the Minnesota Department of Health and Minnesota Low Incidence Projects Statewide Specialists



Minnesota cCMV Webinar Series

Pre Webinars

Developed by a multidisciplinary team

Promoted to various groups:

- Early Childhood Leaders
- Low Incidence providers
- Related service providers
- Local Public Health Nurses
- School Nurses
- Audiologists

Webinars

Webinar #1

270 participants

Webinar #2

230 participants

Post Webinars

- Recorded webinars and presentation slides posted on the MN Low Incidence Projects website
- Linked from MDH CMV web page

Webinar Series Participant Evaluations

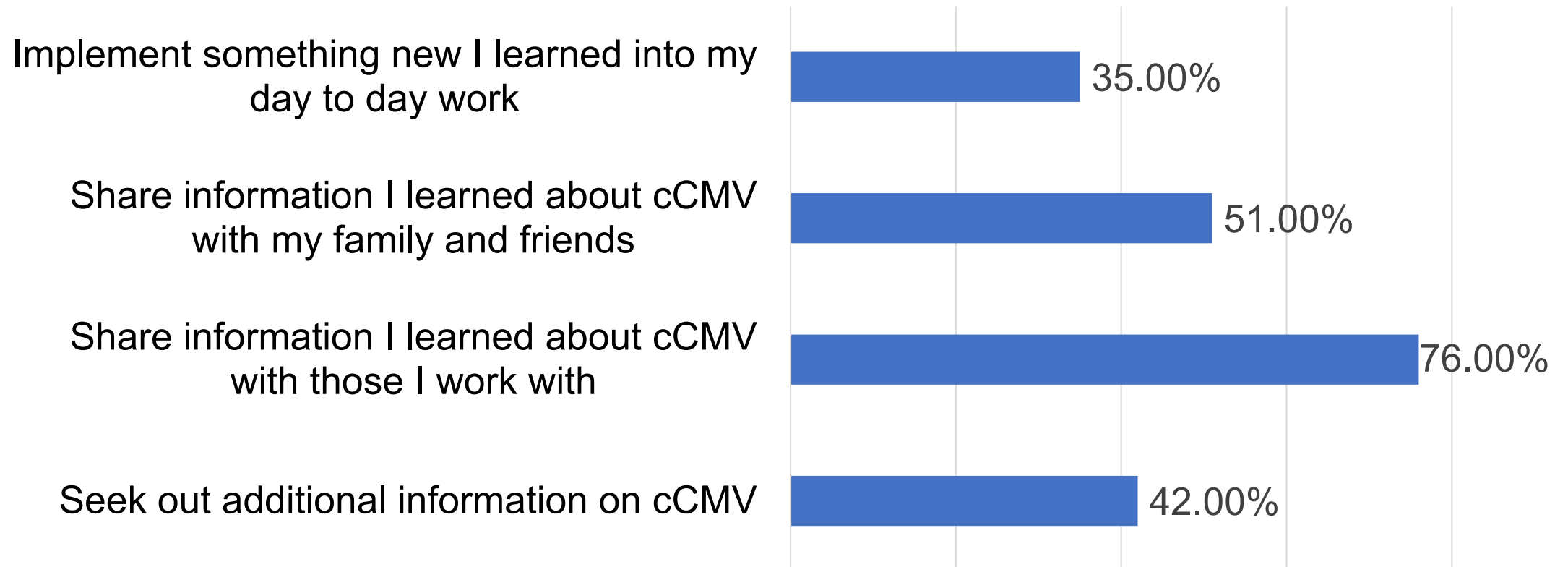
My understanding of cCMV has improved after attending this webinar.

94% of participants agreed or strongly agreed

The information provided in the webinar is relevant to the work that I do.

92% of participants agreed or strongly agreed

Select any steps that you are planning to complete after attending this webinar:



cCMV Parent Outreach & Support



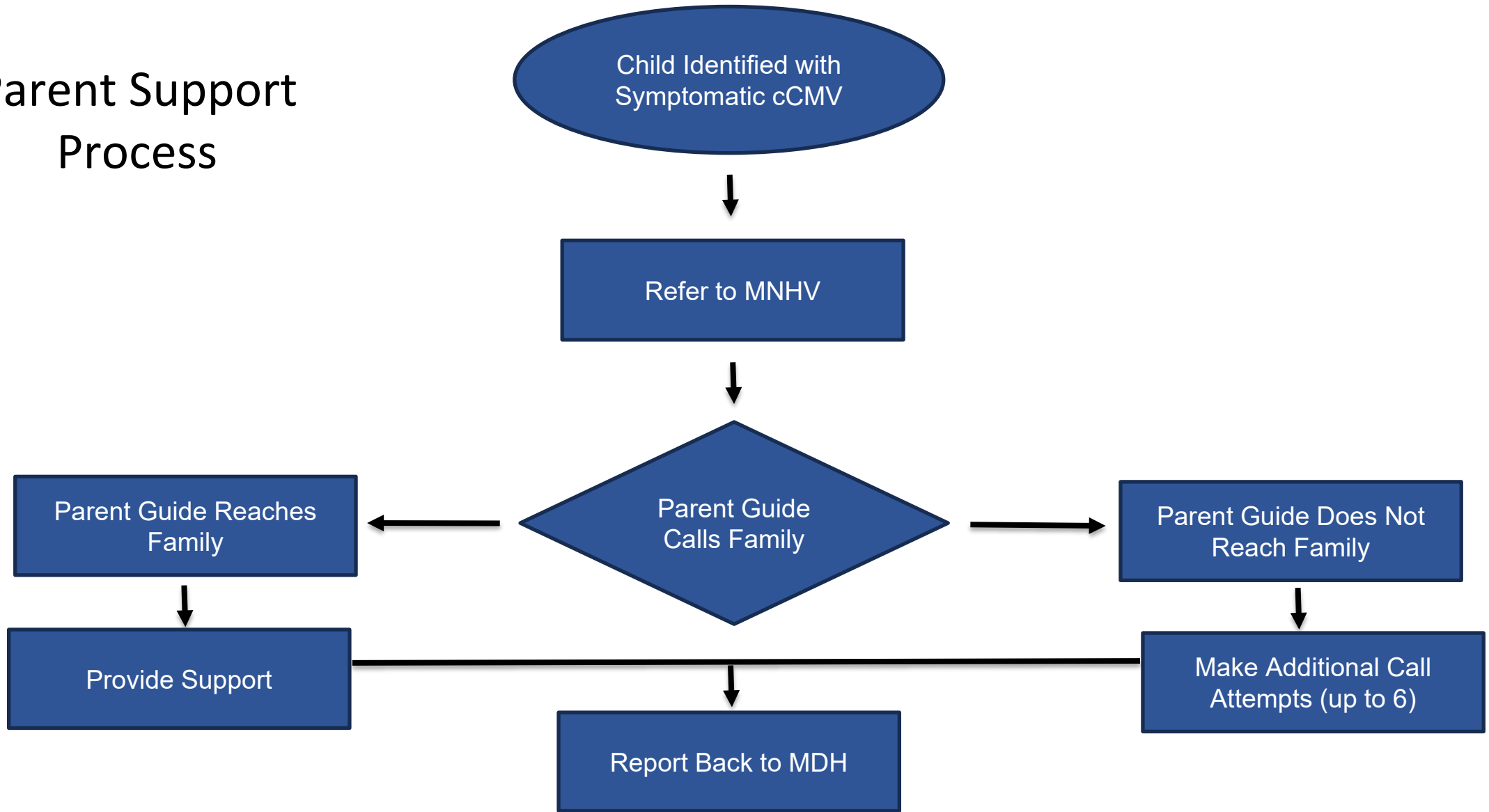
Brenda Hommerding

Callie Holmes

- Parent of a child born with cCMV
- Minnesota Hands & Voices Parent Guide
Providing Statewide cCMV Parent
Outreach



Parent Support Process



When Parents are Reached, the Parent Guide...

- Discusses the child's wellbeing and development
- Discusses the parent's support network and emotional health
- Shares opportunities for parent-to-parent connection; including connection to another Minnesota family via our database as well as cCMV Specific Parent Support Groups on Facebook
- Asks families if they have received the cCMV parent booklet from MDH, and offers to go over it with them and/or answer any questions they may have about it
- Makes sure families know where to find reliable, consistent, and factual information through the MDH cCMV Webpage and the National CMV Foundation Webpage
- Connects families to Early Intervention if not already connected

Parents want to discuss...

- Their pregnancy, the child's birth, and what lead up to the child's diagnosis
- Antiviral treatments
- Previous and upcoming testing and the results such as ultrasounds, MRI's, hearing screenings and vision screenings
- What the future may look like for their child
- Concerns about childcare, breastfeeding, and future pregnancies
- Their emotional health and how they are handling the diagnosis, treatment, and the unknowns and uncertainties surrounding cCMV
- How to obtain mental health support while caring for a newborn (virtual, in-person with the baby, etc.)
- The support or lack of support from family and friends

February 2023 - February 2024

- 38 referrals to MNHV for a child with “symptomatic” cCMV
 - 27 referrals were for cCMV only
 - 11 referrals were for cCMV + sensorineural hearing loss
- 1 child was identified with hearing loss after initial referral for cCMV
- 27 families were reached by the Parent Guide
- 34 total connected calls to families (out of 129 total call attempts)
- 2 families had more than one connected call and 1 family had an in-person visit

Parent Quotes

- "I've been feeling so alone and isolated. My family doesn't even understand. I didn't realize how bad I needed to talk to someone who gets it."
- "It was really scary in the beginning, but it wasn't all for nothing. Now I know about CMV and I have told everyone I know about it."
- "I have spent so much time blaming myself, thank you for reassuring me that it's not my fault. I can't believe that people don't know about this."

Questions



Thank you!

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