



VOICES of Experience

Parents' Insights on Congenital

presenter team



Megan Becker, Ed.D.

Megan became an advocate for Cytomegalovirus (CMV) education when her son was born affected by the virus in 2022. Megan volunteers as a Community Alliance Chair with the National CMV Foundation for Virginia as well as a volunteer Family Navigator with VCU's Center for Family Involvement. Megan and her family live in Richmond, VA.

Lisa Eickel, MS CGSCLP

Lisa is the Co-Chair of the Virginia EHDI Advisory Committee. She is a volunteer Community Alliance Chair with the National CMV Foundation and works as the DHH Project Director and Family Engagement Coordinator for the Center for Family Involvement, Virginia's EHDI supported Family Based Organization. She is a parent to a child born with congenital CMV in 2017. Lisa lives in Loudoun, VA with her three boys.

objectives

1.

Participants will gain a deeper knowledge of congenital CMV, including its prevalence, symptoms and long-term impacts on families

2.

Participants will identify current shortcomings in the healthcare system related to congenital CMV diagnosis and treatment, motivating them to advocate for better practices

3.

Participants will leave with specific strategies to implement in their clinical practice, enhancing the overall care for families affected by congenital CMV

IMPACT



Impact of CMV

1 out of 3



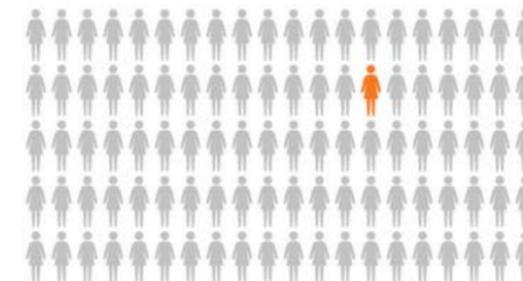
pregnant women who become infected with CMV will pass the virus to their unborn child

1 Child



is permanently disabled by congenital CMV every hour

1 in 200



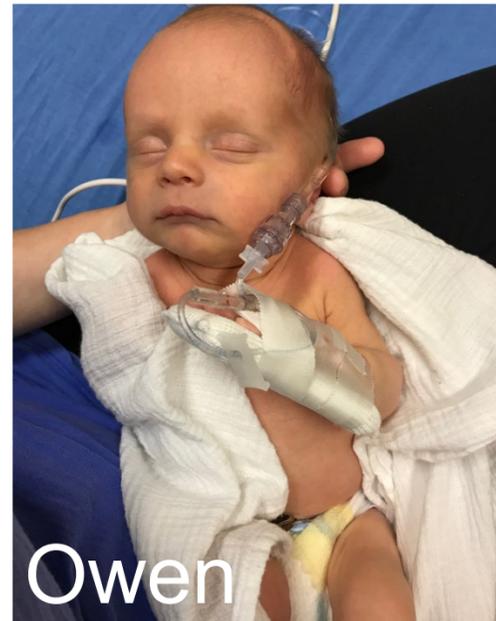
children are born with congenital CMV each year

symptoms



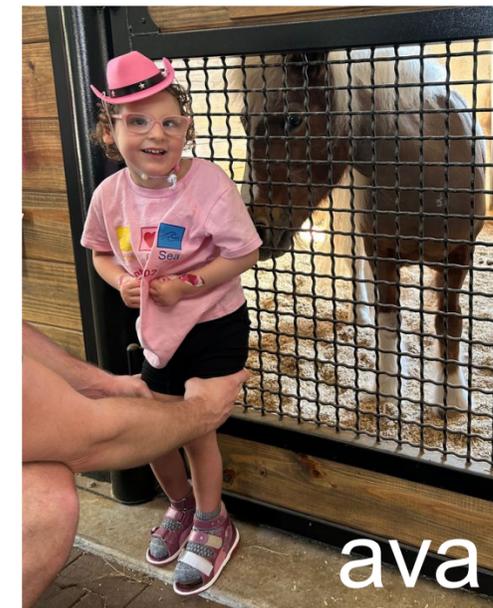
MOTHERS

Asymptomatic
Mild cold-like symptoms
Often unrecognizable to the mother as significant



INFANTS

Hearing Loss
Vision Impairment
Seizures
Microcephaly
Petichaea rash
Preterm delivery
Low birth weight
Failure to Thrive



CHILDHOOD

Vestibular disorder
Feeding disorder
Autism
Intellectual Disabilities
Learning Disabilities
Progressive hearing loss
Late onset hearing loss

Our why



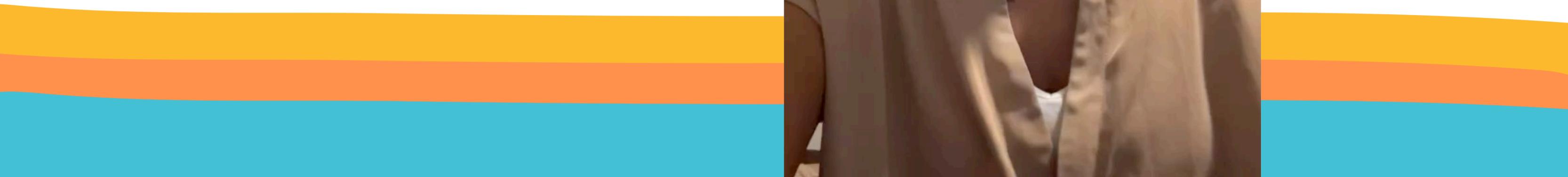
Our why

NATIONAL
CMV
FOUNDATION
INFORM ♥ ENGAGE ♥ ADVOCATE



Unexpected

Impacts



Unexpected

Impacts

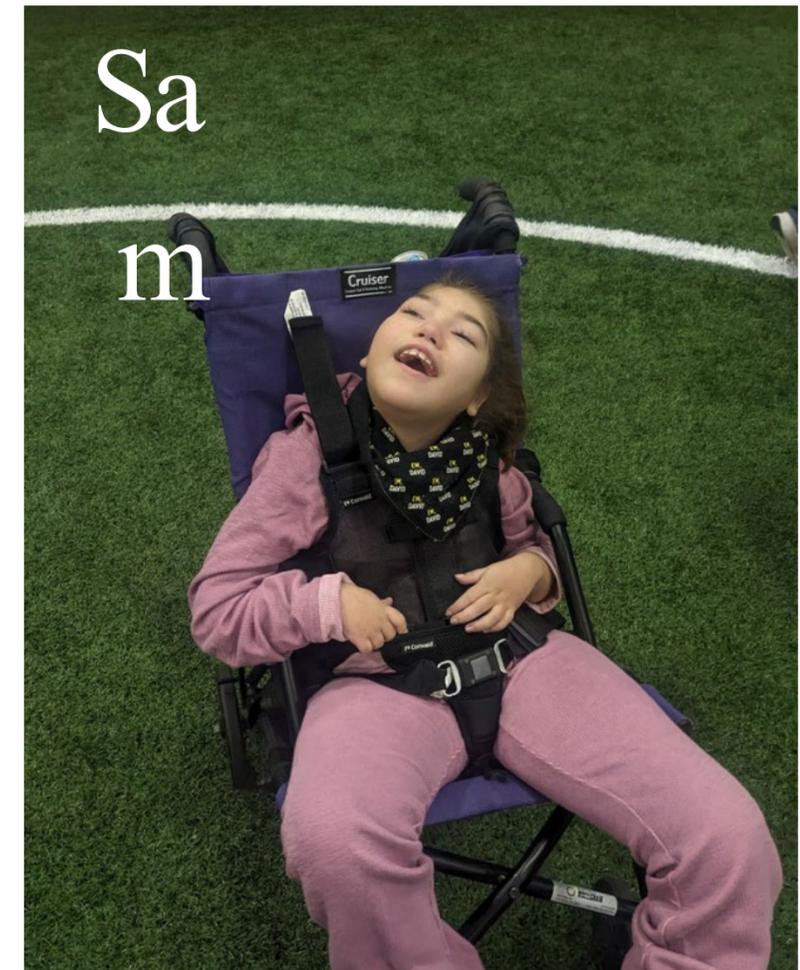
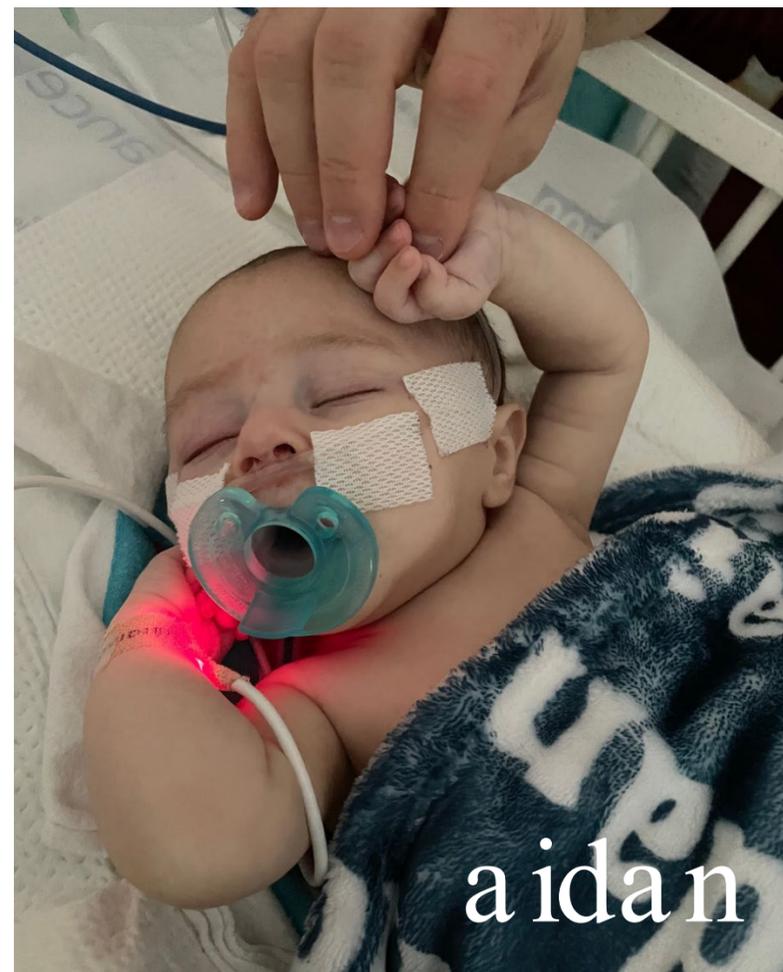
SHORTCOMINGS

System shortcomings families face

- Inadequate prenatal educational programming
- Lack of knowledge among providers
- Difficulty in obtaining a diagnosis
- Limited timeline for availability of treatment
- Poor understanding of potential outcomes
- Inadequate access to mentors/ families with experience
- Negative impacts on maternal/ infant bond
- lack of community knowledge/ resources
- prejudice
- Financial strain



The hard stuff and strong kids



What veteran parents want new parents to know

- Take it one day at a time!
- Comparison is the thief of joy. Don't let the resentment build and prevent you from bonding with your baby.
- Do your research and ASK QUESTIONS!
- Don't be afraid to seek different providers or second opinions.
- Connect with Early Intervention, early!
- Find your support network, community, family, or friends.
- Tap into each and every resource you can find!
- Do your research, prepare for all possibilities
- No two patients'/ families' stories are the same, but find someone who's walked this road too!
- Take the time to mourn what didn't go the way you thought, then advocate and fight!



Caroline

Faces of CMV



ENHANCING

SUPPORT

prevention

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

Remember

Even if your state does not have universal or targeted screening, testing can be at the parent or physician's request if the symptoms match or there's a reason to believe the mother acquired CMV during pregnancy.

Resources For Providers

National CMV Foundation

Connect families with local CMV families
for mentoring/ support

Prenatal Congenital CMV Signs

- Placental thickening
- Organomegaly – abnormal enlargement of organs
- Hepatomegaly – abnormal enlargement of the liver
- Splenomegaly – abnormal enlargement of the spleen
- Pyelectasis – dilation of the renal pelvis, the funnel-like dilated proximal part of the ureter (muscular tubes that propel urine from the kidneys to the urinary bladder) in the kidney (also a marker for Down Syndrome)
- Megaloureter – abnormal dilation of the ureter
- Ascites - gastroenterological term for an accumulation of fluid in the peritoneal cavity (is a potential space between the parietal peritoneum and visceral peritoneum; that is, the two membranes that separate the organs in the abdominal cavity from the abdominal wall)
- Fetal hydrops - accumulation of fluid in the fetal compartments
- Abnormality of amniotic fluid
- Microcephaly – small head circumference, more than two standard deviations smaller than average
- Cerebral ventriculomegaly – dilation of the lateral ventricles of the brain
- Intracranial calcifications – the build-up of calcium salts in the soft tissue of the brain
- Hyperdense image in thalamic arteries
- Periventricular echodensities
- Hepatic echodensities
- Intestinal echodensities
- Cystic structures in the germinal zone

A newborn presenting with any of the following signs or symptoms may have congenital CMV.

Neonatal Congenital CMV Signs

- Thrombocytopenia – low blood platelet levels
- Petechiae (purpura) – red or purple spots on the body caused by broken blood vessels
- Jaundice – yellow skin and eyes caused by increased bilirubin levels in the blood
- Microcephaly – small head size
 - Small for gestational age (SGA)
 - Intrauterine growth restriction (UGR)

Downloads

- CMV Blood Spot Testing**
Download
- CMV Testing After Birth**
Download
- Congenital CMV Audiology Surveillance**
Download
- Congenital CMV Booklet**
Download
- General CMV Awareness**
Download
- General CMV Awareness**
Download

How to read CMV IgG and IgM lab results:

IgG negative + IgM negative = Not previously CMV infected, at risk for primary infection – Recommend CMV prevention precautions to your patient to help minimize their risk of contracting CMV during pregnancy. No further CMV antibody testing should be necessary unless the patient begins showing signs of a CMV infection or if the baby shows sign of a possible CMV infection during a routine ultrasound.

IgG positive + IgM positive = Recent CMV infection – Recommended that your patient delay conception until her CMV IgM antibody levels decline to an undetectable level and her CMV IgG avidity index climbs to a high favorable percentage. These results would show that her primary CMV infection has resolved itself and that there is minimal risk of CMV transmission to a new baby. It can take anywhere from 6 to 12 months for these CMV antibody and avidity tests to be favorable so that a woman can be safely ready to conceive without fear of passing her CMV infection to her baby. If your patient is already pregnant, consider extra ultrasounds to track the baby's development in utero and to confirm that there are no prenatal signs of CMV infection. If the baby does show signs of CMV infection in ultrasound, an amniocentesis may be necessary to determine whether the baby has a CMV infection.

IgG positive + IgM negative = Past CMV infection that is not recent – Recommend that your patient practice CMV prevention recommendations during pregnancy. It is still possible that a recurrent CMV infection or an infection with a different strain of CMV can occur.

Signs/Symptoms of CMV in Utero

If your patient is believed to have contracted CMV during their pregnancy, regular ultrasounds and/or amniocentesis are the preferred methods to determine if CMV has been passed to the baby in utero. The CDC includes information about diagnosis, treatment and ongoing monitoring in their PDF download, ["Diagnose, treat, and monitor children with Congenital Cytomegalovirus \(CMV\) to help improve their health outcomes"](#).

Signs of CMV infection in utero include the following:

What Everyone Needs to Know About

Congenital Cytomegalovirus



PATIENT EDUCATION HANDBOOK





ENHANCED BY Google

- About
- How Do I
- A-Z Index
- Locations
- Data
- Clinicians
- Newsroom
- Contact

Virginia Department of Health > Early Hearing Detection > Resources for Professionals

- Early Hearing Detection and Intervention
- ASL COVID-19 Resources
- Preparing for Birth
- Early Hearing Screening
- Congenital Cytomegalovirus (cCMV)
- Children with Hearing Loss
- Resources for Professionals
- Events and Information
- 2024 Virginia EHDI Conference
- MyEHDI
- Links
- Contact Us

Email this page

Resources for Professionals

Primary Care Providers - Shared Plan of Care for Children with Hearing Loss



Newborn Hearing Screening Risk Factors for Recommended Follow up Testing



- Prenatal Providers +
- Congenital Cytomegalovirus (cCMV) Providers -
 - Hearing Targeted congenital Cytomegalovirus Screening Protocols
 - What Do You Know About CMV?
 - Protect Your Baby From CMV
 - Infectious Disease Regional Contacts for cCMV Screening
 - Virginia's Targeted Congenital Cytomegalovirus Screening Frequently Asked Questions (FAQs)
 - cCMV VISITS Guide
 - Assessment and Management of congenital Cytomegalovirus Fact Sheet
 - When to Screen for cCMV
 - Otolaryngology Regional Contacts for cCMV Screening
 - cCMV Sample Collection Checklist
- Audiologists +
- Early Interventionist +
- Primary Care Providers +

Congenital Cytomegalovirus (cCMV) Training Video Series

All information displayed in this video is for training purposes only and none of the information represents real child data.

CYTOMEGALOVIRUS (CMV)

[CMV Home](#)

[About CMV and Congenital CMV](#)

[CMV Prevention](#)

[For Families and Caregivers](#)

[For Health Professionals](#)

[For Childcare and Education Professionals](#)

RELATED PROGRAMS

[Newborn Screening](#)

[Children and Youth with Special Health Needs](#)

[Early Hearing Detection and Intervention \(EHDI\)](#)

CONTACT INFO

Children and Youth with Special Health Needs
651-201-3650
800-728-5420 (toll-free)
health.cyshn@state.mn.us

Information for Health Professionals

In February 2023, the Minnesota Department of Health (MDH) Newborn Screening Program became the first in the nation to screen all newborns for congenital CMV. These resources provide information about congenital CMV and may help health professionals as they provide care to affected children and their families.

For information to share with families after a child is diagnosed with congenital CMV, visit [CMV Information for Families](#).

Webinar for doulas and birth workers

Mechanisms of Fetal Injury

From a US state public health authority

- Placental Injury**
 - End organ damage
 - IUGR/SGA
- Viral Replication in Fetal Cells**
 - Disrupted development
 - Excessively attracted to cells in the brain and inner ear
- Maternal Immune Response**
 - Inflammatory environment

Watch on YouTube | WJ, Jonjic S, Brizic I. Cytomegalovirus Infection and Inflammation in Developing Brain. Viruses. 2021 June; 13(6): 1078. 13

Care to Talk

NATIONAL CMV FOUNDATION

Join Us For Our
CARE TO TALK SERIES

Thursday, March 21st at 8 PM EST

This is a CMV family support group hosted by volunteers. No matter what your CMV journey looks like you are welcome to join!

MODERATORS



Samantha Nikirk
CMV Mom and NCMVF
CCA Co-Chair
Michigan



Lisa Eickel
CMV Mom and
NCMVF Chair
Virginia

Pre-registration required. Use QR code to register.



NATIONAL CMV FOUNDATION

Join Us For Our
CARE TO TALK SERIES

Thursday, June 20th at 8 PM EST

This is a virtual CMV family support group hosted by volunteers. No matter what your CMV journey looks like you are welcome to join!

MODERATORS



Kelsi Gagne
CMV Mom and NCMVF
CCA Chair
Maine



Amanda Devereaux
CMV Mom and
NCMVF Program
Director

Pre-registration is required. Use the QR code to register.



NATIONAL CMV FOUNDATION

Join Us For Our
CARE TO TALK SERIES

Thursday, September 19th at 8 PM

This is a virtual CMV family support group hosted by volunteers. No matter what your CMV journey looks like you are welcome to join!

MODERATORS



Patty Cutshall-Bailey
CMV Mom and NCMVF
CCA Chair
Montana



Megan Becker, EdD.
CMV Mom and
NCMVF CCA Chair
Virginia

Pre-registration is required. Use the QR code to register.



NATIONAL CMV FOUNDATION

Join Us For Our
CARE TO TALK SERIES

Thursday, December 19th at 8 PM EST

This is a virtual CMV family support group hosted by volunteers. No matter what your CMV journey looks like you are welcome to join!

Special Segment: "Fostering Joy"

MODERATOR



Beth Jones
Executive Director,
Nevada Hands &
Voices

Pre-registration is required. Use the QR code to register.



CMv CCA Map



What parents want YOU to know

- Prenatal Education!
- Do you research/ learn more
- Refer to specialists if you aren't experienced
- Recognize our grief
- Be gentle with us
- Don't underestimate our kids
- Find compassion and empathy
- Our children are not CMV, they have CMV
- Tell us what to watch for/ later complications
- Don't share "best case only" scenarios
- Be kind when delivering the news
- Treat us like you would want your loved ones treated
- Trust our gut instincts



Faces of CMV





Aidan

Q&A



NationalcmvVA@gmail.com



References

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National CMV Foundation. Signs and Symptoms of CMV Infection (<https://www.natcmv.org/symptoms>). Accessed 02/16/2025.

Schleiss MR. Congenital Cytomegalovirus Screening Moves Ahead. *JAMA Pediatr*. 2025 Jan 26;179(1):e240001. doi: 10.1001/jama.2024.39836395. PMID: 39836395. Accessed 02/16/2025.

U.S. Centers for Disease Control and Prevention. Babies Born with Congenital Cytomegalovirus (CMV) Infection (<https://www.cdc.gov/nczod/dzdx/congenital-cmv-infection/index.html>). Accessed 02/16/2025.

Walsh H, Zuwala J, Hunter J, Oh Y. Congenital Cytomegalovirus and Human Immunodeficiency Virus Effects on Development and Clinical Outcomes in Children. *Front Pediatr*. 2021 Dec 16;9:771192. doi: 10.3389/fped.2021.771192. PMID: 34976192. Accessed 02/16/2025.