NATIONAL CMV FOUNDATION
INFORM ❤ ENGAGE ❤ ADVOCATE

VOICES OF EXPERIENCE

Parents' Insights on Congenital CMV

PRESENTER TEAM

NATIONAL CMV FOUNDATION
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MEGAN BECKER, ED.D.

LISA EICKEL, MS CCC-SLP

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.

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 for the Center for Family Involvement, Virginia's EHDI- supported Family Based Organization. She is a parent to a child born with congenital CMV.

OUR WHY

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OBJECTIVES

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

2. Participants will identify current shortcomings in the healthcare system related to cCMV 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 cCMV.

CMV OVERVIEW

A viral infection that can live dormant in one's body and reactivate later (similar to Chicken Pox, Herpes, Mononeucleosous).

Widespread throughout the general population:
1 in 3 children have had it by the time they're 5 years old.

Higher risk for severe infection occurs in individuals with weakened immune systems:
(organ transplants, chemotherapy, and pregnancy)

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

CONGENITAL CMV

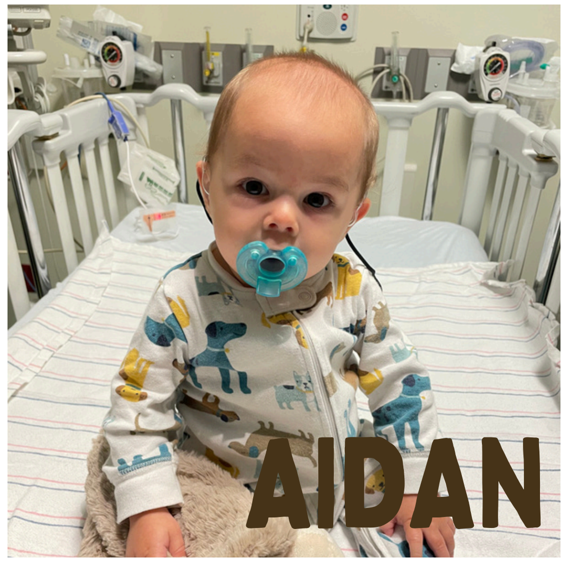
CMV is a viral infection that occurs when an unborn baby is infected by CMV during the prenatal period.

Transmission happens when the virus passes from an infected mother to her baby.
The virus is picked up through bodily fluids from another infected individual (saliva, mucous, urine, blood)- often from our own family members.

CMV can lead to birth defects, hearing loss, developmental disabilities, vision impairment, permanent disabilities, miscarriage, stillbirth, and even death.

FACES OF CMV

OWEN


AIDAN


TRENTON

EDISON


KADEN


GIADA


DREXEL


ALYSSA


LYLA


MILO


ADALINE


PIPPA

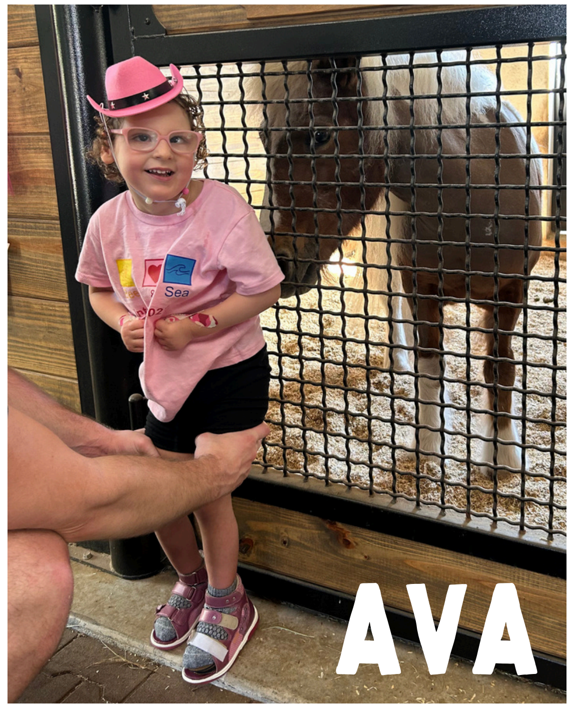
SYMPTOMS

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

DIAGNOSIS

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1. TESTING

CMV can be screened for through a saliva swab, but it is diagnosed through blood test or urine test (best specificity and sensitivity)

2.

EARLY DETECTION

Early diagnosis can lead to better management and treatment options. Diagnosis within the first 21-30 days of life opens the possibility to antiviral drug treatment and a diagnosis or “answer” to a child’s symptoms

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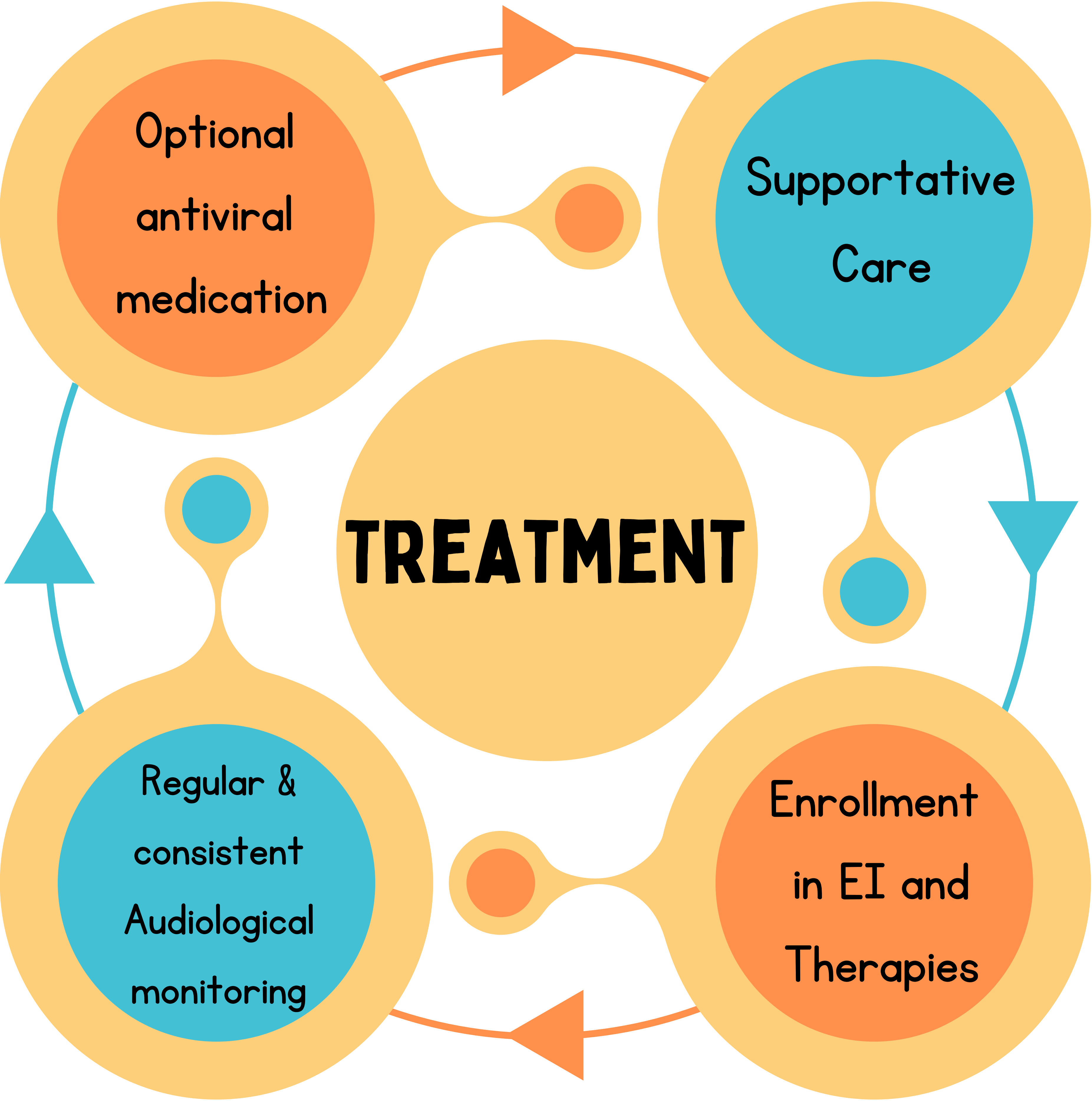
3. ADVOCACY

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.

TREATMENT



TREATMENT

Optional antiviral medication

Supportive Care

Enrollment in EI and Therapies

Regular & consistent Audiological monitoring

PREVENTION

PREVENTION

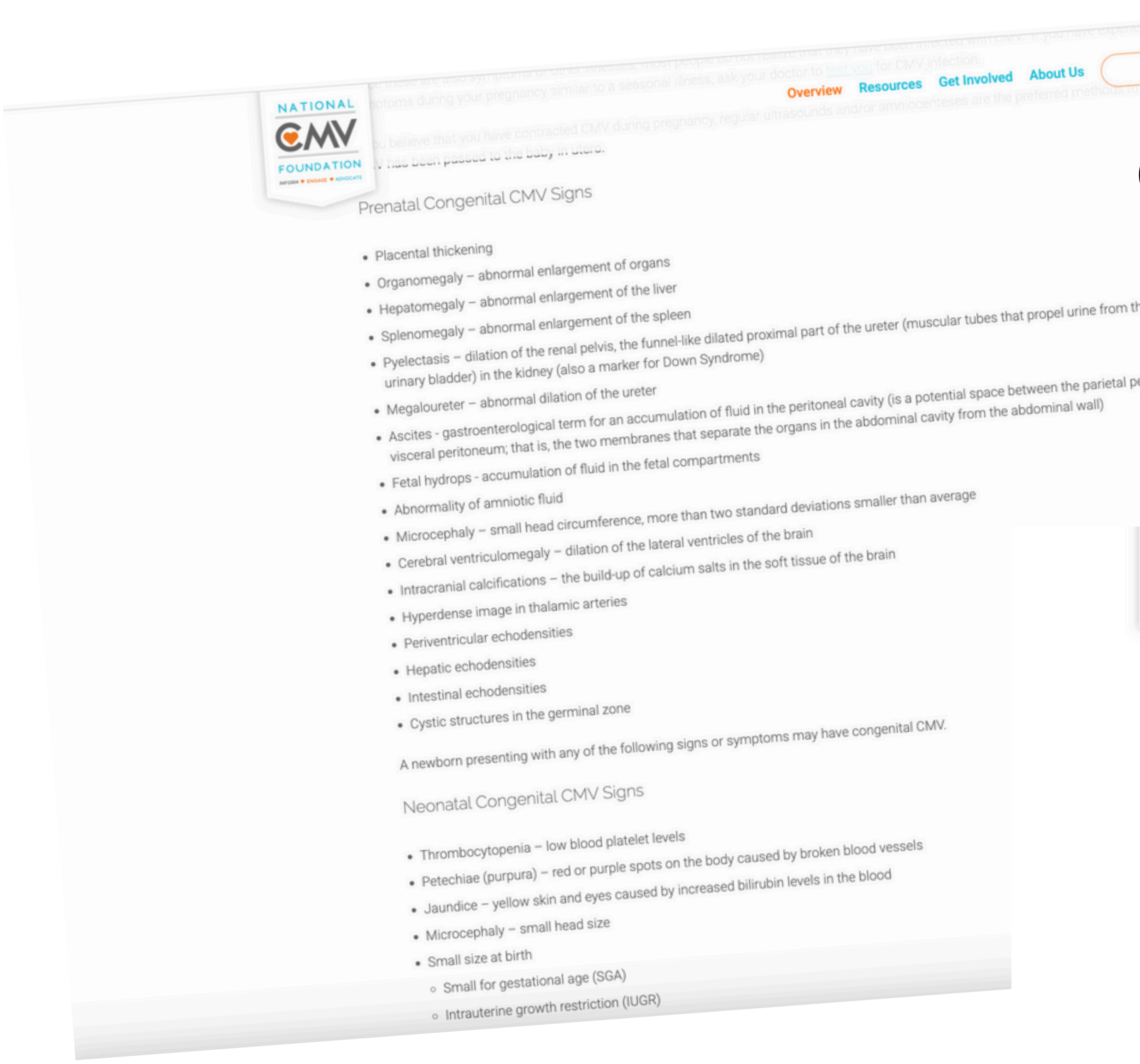
5 Simple Tips to Help Prevent CMV

- 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

RESOURCES FOR PROVIDERS

National CMV Foundation

Connect families with local CMV families for mentoring/ support



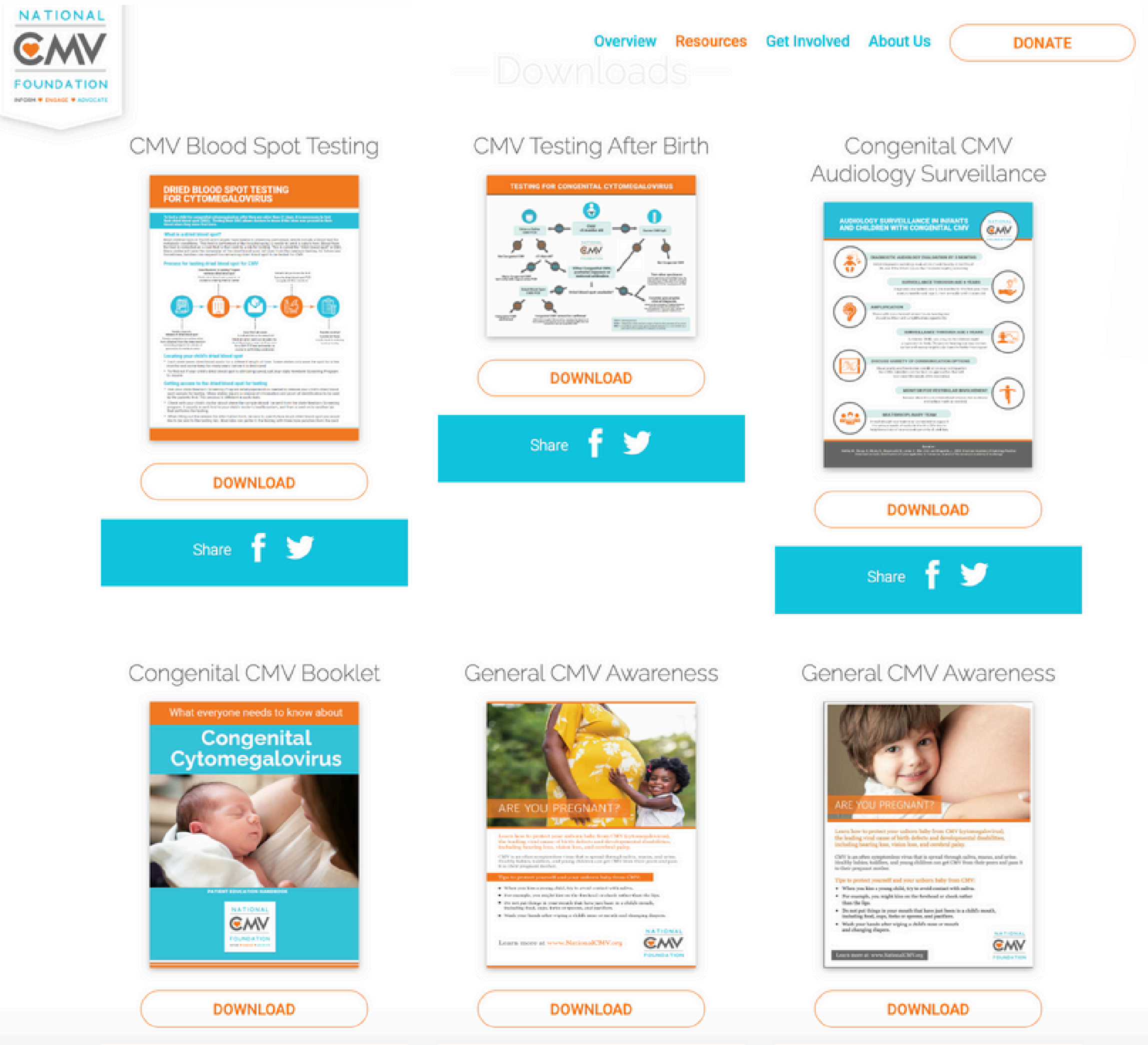
Prenatal Congenital CMV Signs

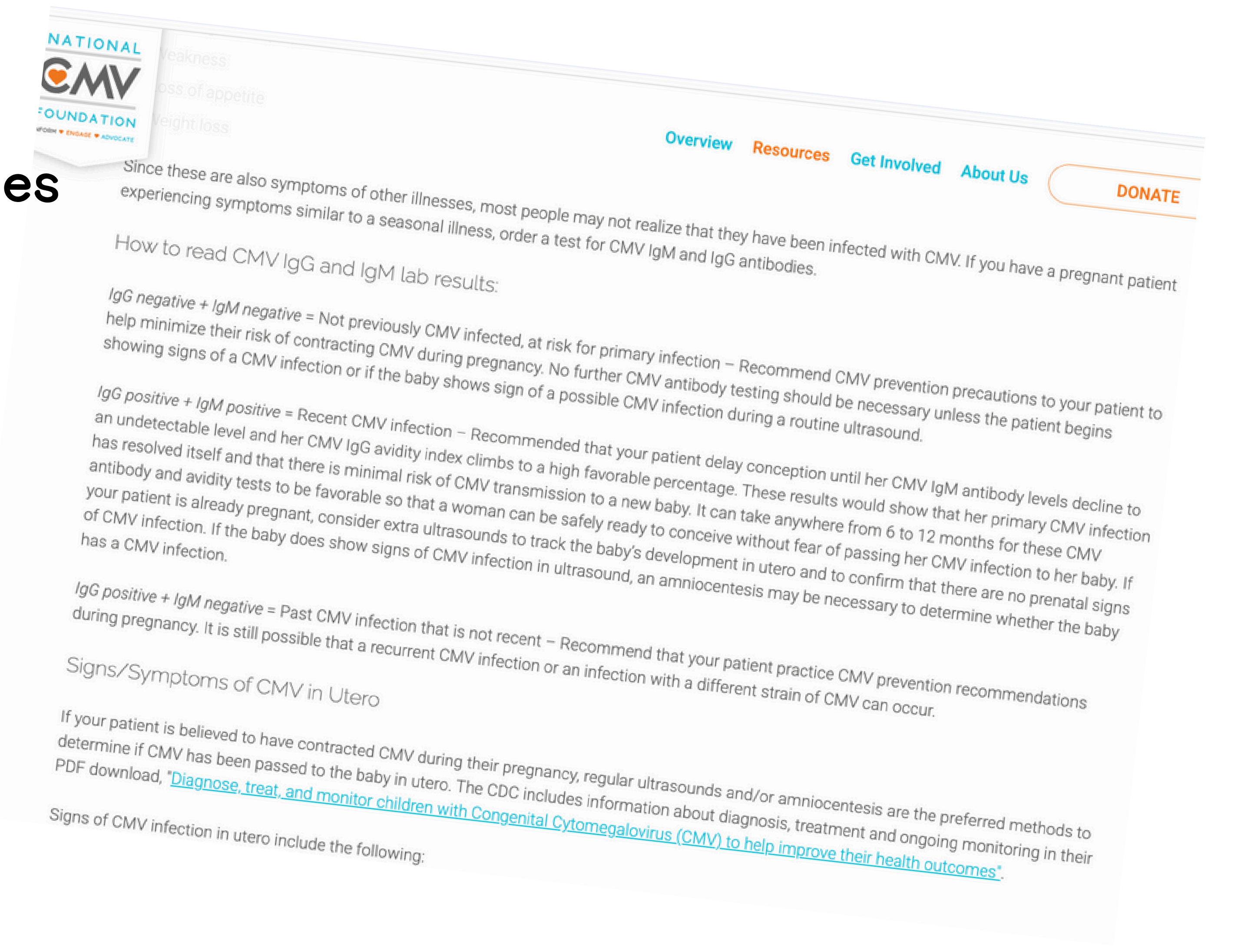
- Placental thickening
- Organomegaly – abnormal enlargement of organs
- Hepatomegaly – abnormal enlargement of the liver
- Splenomegaly – abnormal enlargement of the spleen
- Pyelectasis – dilation of the renal pelvis, the funnel-like dilated proximal part of the ureter (muscular tubes that propel urine 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 size at birth
  - Small for gestational age (SGA)
  - Intrauterine growth restriction (IUGR)





Since these are also symptoms of other illnesses, most people may not realize that they have been infected with CMV. If you have a pregnant patient experiencing symptoms similar to a seasonal illness, order a test for CMV IgM and IgG antibodies.

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:

CARE TO TALK

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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

Lisa Eickel
CMV Mom and
NCMVF Chair
Virginia

Samantha Nikirk
CMV Mom and NCMVF
CCA Co-Chair
Michigan

Pre-registratio
required. Use
QR code to re

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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

Amanda Devereaux
CMV Mom and
NCMVF Program
Director

Kelsi Gagne
CMV Mom and NCMVF
CCA Chair
Maine

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

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

Patty Cutshall-Bailey
CMV Mom and NCMVF
CCA Chair
Montana

Pre-registration i
required. Use th
QR code to regi

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.

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

IMPACT

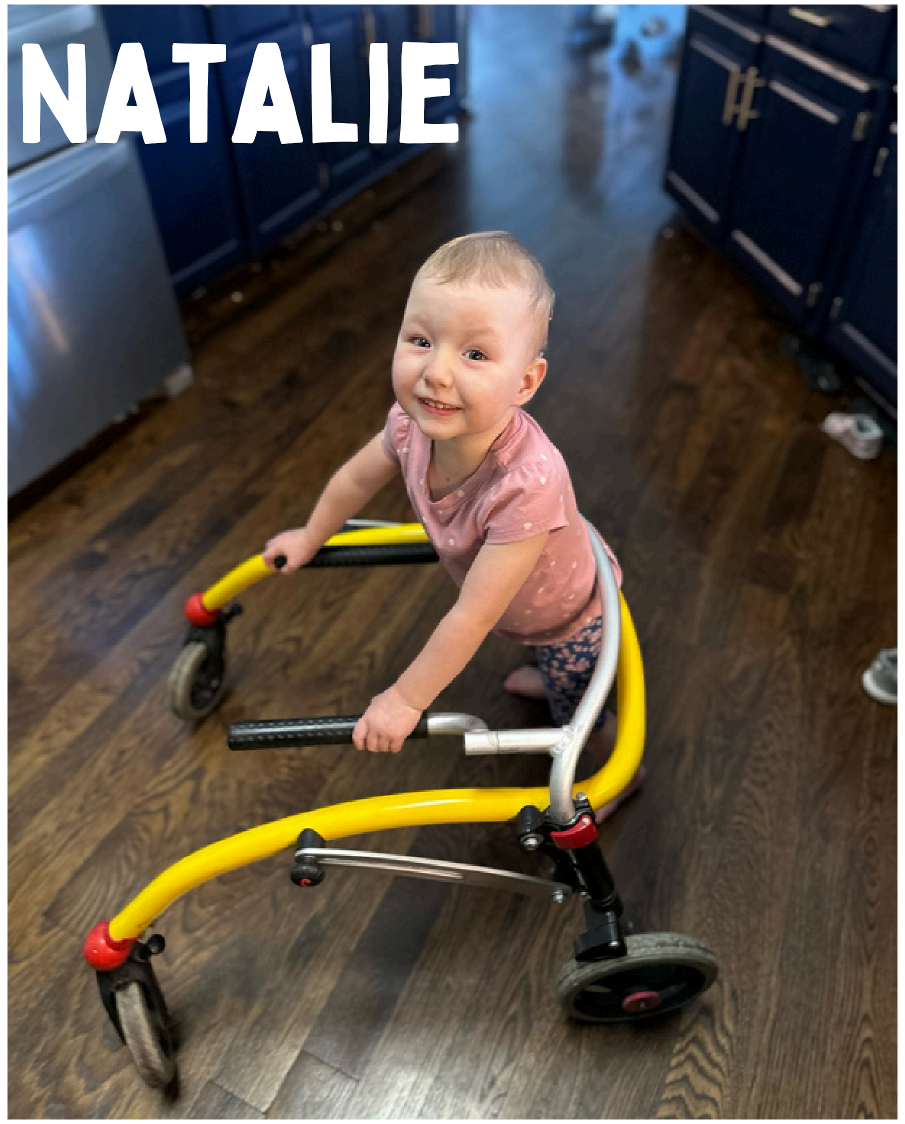
SYSTEM SHORTCOMINGS FAMILIES FACE

- 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


AIDAN


OWEN


NATALIE


SAM

PARENT EXPERIENCES

worried
disbelief
bewildered
clueless
stressful
angry
sad
isolated
anxiety
alone
sadness
cheated
struggling
loss
unknown
scared
panicked
surprised
uninformed
shocked
optimistic
helpless
shock
capsized
unsupported
anger
mourning
uncomfortable
fear
devastated
clarity
confused
unfamiliar
pining
ppd
hopeful
asymptomatic
fearful
despair

WHAT VETERAN PARENTS WANT NEW PARENTS TO KNOW

- Take it one day at a time!
- Comparisson 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!

FACES OF CMV


BEN


MARGOT


KACE


KYNLEE


CHARLIE


JUNE


BAILEY


RILEY


NATALIE


MAVERICK


ODESSA


COLT

VIRGINIA'S STRIDES 4 CMV 5K

SAVE THE DATE

STRIDES 4 CMV 5K WALK

RICHMOND, VA

JUNE 21, 2025

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Q&A

✉ NationalcmvVA@gmail.com

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