

NATIONAL  
**CMV**  
FOUNDATION  
INFORM ♥ ENGAGE ♥ ADVOCATE



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# Our Mission:

Prevent pregnancy loss, childhood death, and disability due to congenital CMV (cCMV)

Achieved by Supporting Science-based Interventions Including:

CMV vaccine development

Risk-reduction precautions

Newborn CMV screening

Investigational treatments during pregnancy

Treatment, early intervention, and monitoring of infants with cCMV

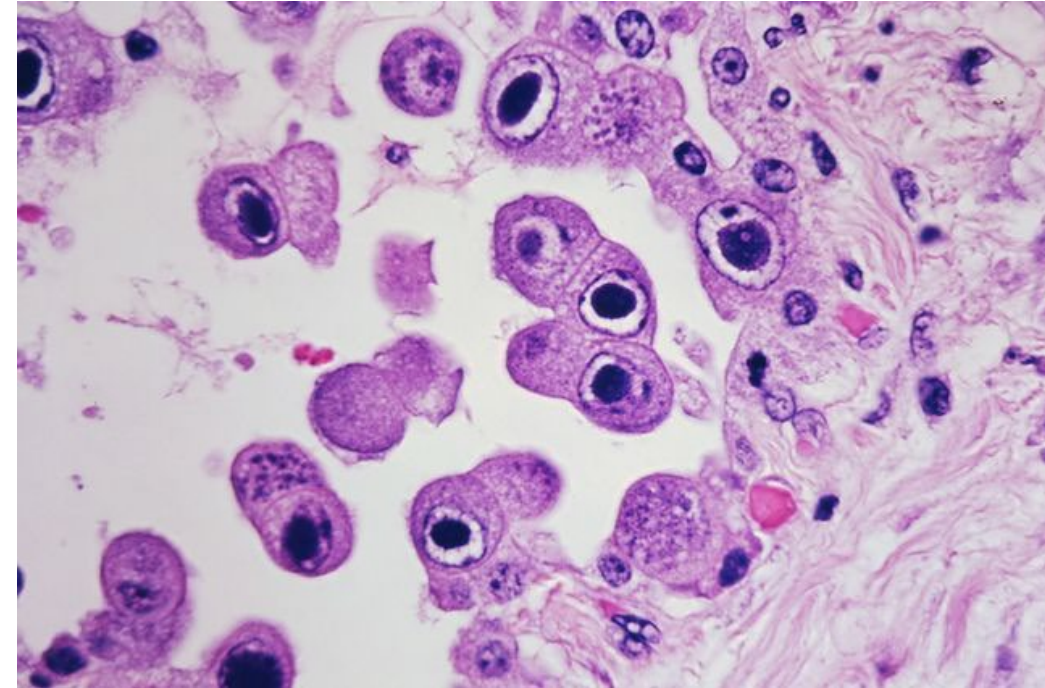


# Pippa's Story

- Planned 2nd pregnancy, toddler in daycare
- Diagnosed with cCMV at 21 weeks pregnant, by amniocentesis
- Received “experimental” treatment at U of Minnesota during pregnancy
- Pippa was born with CMV in blood, urine, saliva
- Symptoms at birth included thrombocytopenia, intracranial calcifications
- Treatment: Valcyte twice daily for 180 days
- Follow ups included: hearing, vision, early intervention, developmental clinic, infectious disease, PT, OT, SLP, feeding therapy
- Current diagnoses (age 7): polymicrogyria, developmental delay, intellectual disability, epilepsy, non-verbal, feeding disorder, bilateral hearing loss

# Cytomegalovirus (CMV)

- Double-stranded DNA virus
- Herpes family
- Most infections are “silent”
- Common
  - Most adults (50%-80%) have been exposed by age 40
  - Up to 80% of healthy children are shedding the virus at any given time



# Congenital Cytomegalovirus (cCMV)

- When an expectant mother catches CMV, the virus can cross the placenta and infect the developing baby
- When a baby is infected with CMV before birth it is called congenital CMV (cCMV)
- 1 in 200 infants is born with cCMV
- 1 in 5 of these infants will have a birth defect or permanent health condition
- CMV is the most common infectious cause of birth defects and the most common non-genetic cause of pediatric hearing loss (25%)



# Transmission

- Risk of transmission through casual contact is small
- Virus is mainly transmitted through urine and saliva (toddlers are “hot zones” for CMV), or other body fluids
- Virus can be transmitted from mother to baby during pregnancy. Most common cause is from child < 3 yrs
  - 1 out of 3 women who are infected during pregnancy will pass the virus to their developing baby



# Impact

- 1 in 200 babies is born with cCMV- approx. 30,000+ babies/year in the US
- 90% are asymptomatic at birth
  - >90% of infants with symptomatic cCMV are not identified
- 1 out of every 5 babies born with the virus will have a permanent health condition (may show up months or years later)
  - 6,000 birth defects or permanent health conditions per year
- Recent research indicates nearly half of children with asymptomatic cCMV have vestibular, gaze, or balance disorders
- Black and multi-racial infants are at increased risk for cCMV
- In a study of 20,000 infants, second-born infants had a higher risk of cCMV

# Spectrum of Symptoms

Born symptomatic

Born asymptomatic

<p><b>Death</b> Miscarriage, stillbirth, infant or child loss</p>	<p><b>Medically fragile</b> Cerebral palsy, Seizures, Failure to Thrive, Hearing loss, Vision loss</p>	<p><b>Multiple impairments</b> Cerebral palsy, Vision loss, Hearing loss</p>	<p><b>Developmental delays</b> Cognitive delays, Learning issues, Feeding and sleeping issues, Vision loss, Hearing loss</p>	<p><b>Hearing loss</b> Hearing aids, Cochlear implants, Communication and learning issues, Mild vision disorders</p>	<p><b>None</b> No visible delays or impairments</p>
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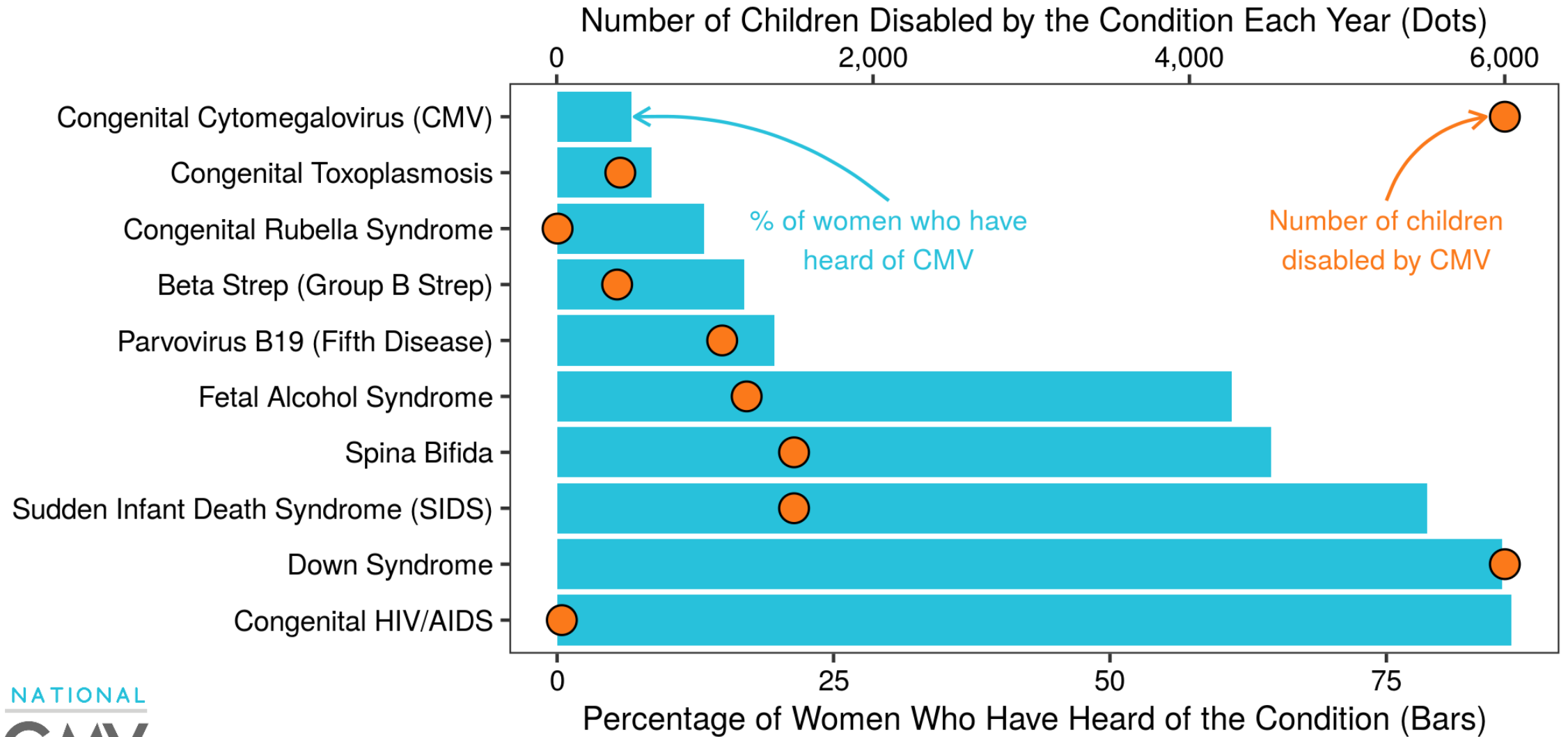
Severe

Moderate

Mild



# Awareness vs Incidence of Congenital Conditions



# “Silent Global Burden”

- Why is attention to CMV low?
  - Maternal and newborn infections are usually asymptomatic
  - Sequelae are usually delayed, and once visible testing for cCMV may not be possible
  - False belief that congenitally infected children who are born to women with preexisting antibodies have typical outcomes
    - 2/3 of infants with congenital CMV are born to mothers who were seropositive before conception and these infants can have consequences of the virus

# Vaccine Development

- Immunity reduces incidence of transmission to fetus, and severity of the disease if transmission occurs
- Vaccines have been in development for over 30 years
- Institute of Medicine gave development of a vaccine “highest priority” rating
- Most cost-effective vaccine in development (pre-COVID)
- Many vaccine studies underway, including phase 3 trial

## 5 Simple Tips to Reduce Your Risk



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

# Should I Avoid Children with a cCMV Diagnosis?

- 95% of children born with CMV are not diagnosed. Additionally, 1 in 3 children will be infected by age 5.
- "Since not all children undergo CMV testing and most with CMV show no signs of this infection, workers and staff must follow these precautions for **all** children. These precautions should also apply to daycare workers or staff who work in schools and who are in contact with young children."
- "Adults are at a much higher risk of acquiring CMV from children living in the same household than from an occupational exposure."

-AAO-HNS Position Statement



- The CDC and AAP do not recommend treating children with cCMV any differently than other children. Asymptomatic shedding is common in people of all ages. Standard precautions should be used.

# Treatment

- Pregnancy (not standard)
  - Experimental treatment with immunoglobulin
  - Oral Valaciclovir to prevent transmission to fetus
- After birth (note: babies will miss out on treatment if they are not diagnosed)
  - Infants need regular follow up: hearing, vision, development, etc.
    - Automatic qualifier for early intervention in many states
  - Infants who received antiviral therapy had improved outcomes
    - 6-month oral therapy regimen
    - Need to be monitored by infectious disease specialist
    - Need frequent blood work
    - Need to start in first month of life

# Interventions/Support for Children with cCMV

- Infectious Disease Specialist
- Head Ultrasound
- Diagnostic Hearing Evaluation
- Dilated Exam by Pediatric Ophthalmologist
- Parent Resources
- Follow up:
  - Developmental Screening
  - Therapists (SLP, feeding, OT, PT, etc.)
  - Neurology
  - ENT
  - Hearing Screening (next slide)

**NATIONAL CMV FOUNDATION**

## ROADMAP FOR A NEWBORN CONGENITAL CMV WORK-UP

All infants diagnosed with congenital cytomegalovirus (cCMV) require additional evaluation to determine the severity of disease and what treatments are right for them. Even infants with no visible signs of infection require the following evaluations to make sure they do not have any unseen effects from the virus.

**REFERRAL TO A PEDIATRIC INFECTIOUS DISEASE SPECIALIST**

**FOR CLINICIANS:**

- Place urgent outpatient referral
- Beginning the work-up below prior to the appointment can provide the Infectious Disease Specialist with critical information that will inform treatment
- Disease severity is based partly on the work-up below
- For infants who qualify, anti-viral medication must be started before 1 month of age

**FOR CAREGIVERS:**

- This specialist will be able to discuss next steps
- Ask questions about the possible benefits and risks of anti-viral medication

**HEAD ULTRASOUND**

**FOR CLINICIANS:**

- Ultrasound brain images are necessary to rule in/out intracranial pathology
- If brain abnormalities are found, consider MRI

**FOR CAREGIVERS:**

- Ultrasound is done over the infant's soft-spot or fontanelle
- Ultrasounds are painless and do not involve radiation
- Infants with signs of CMV seen on brain imaging may be eligible for anti-viral medication

**National CMV Foundation:** [www.nationalcmv.org](http://www.nationalcmv.org)  
**Centers for Disease Control and Prevention:** [www.cdc.gov/cmV/](http://www.cdc.gov/cmV/)

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## CONGENITAL CMV: SUPPORT AND NEXT STEPS

"Having a child diagnosed with cCMV can be scary. There are so many unknowns and every child is affected differently. Having a support system that understands the uncertainty is important."  
Amber, parent

**PEDIATRIC SPECIALISTS**

- Infectious Disease
- Ear, Nose and Throat
- Ophthalmology
- Neurology

**PARENT RESOURCES**

- National CMV Foundation
- Local Hearing Loss and Disability Non-profits
- Your State's Hands & Voices Chapter

**DEVELOPMENTAL RESOURCES**

- Your Child's Pediatrician
- Occupational Therapy
- Physical Therapy
- Your State's Early Intervention Services

**HEARING RESOURCES**

- Pediatric Audiology
- Speech Therapist
- Sign Language Instructor
- Your State's EHD! Program

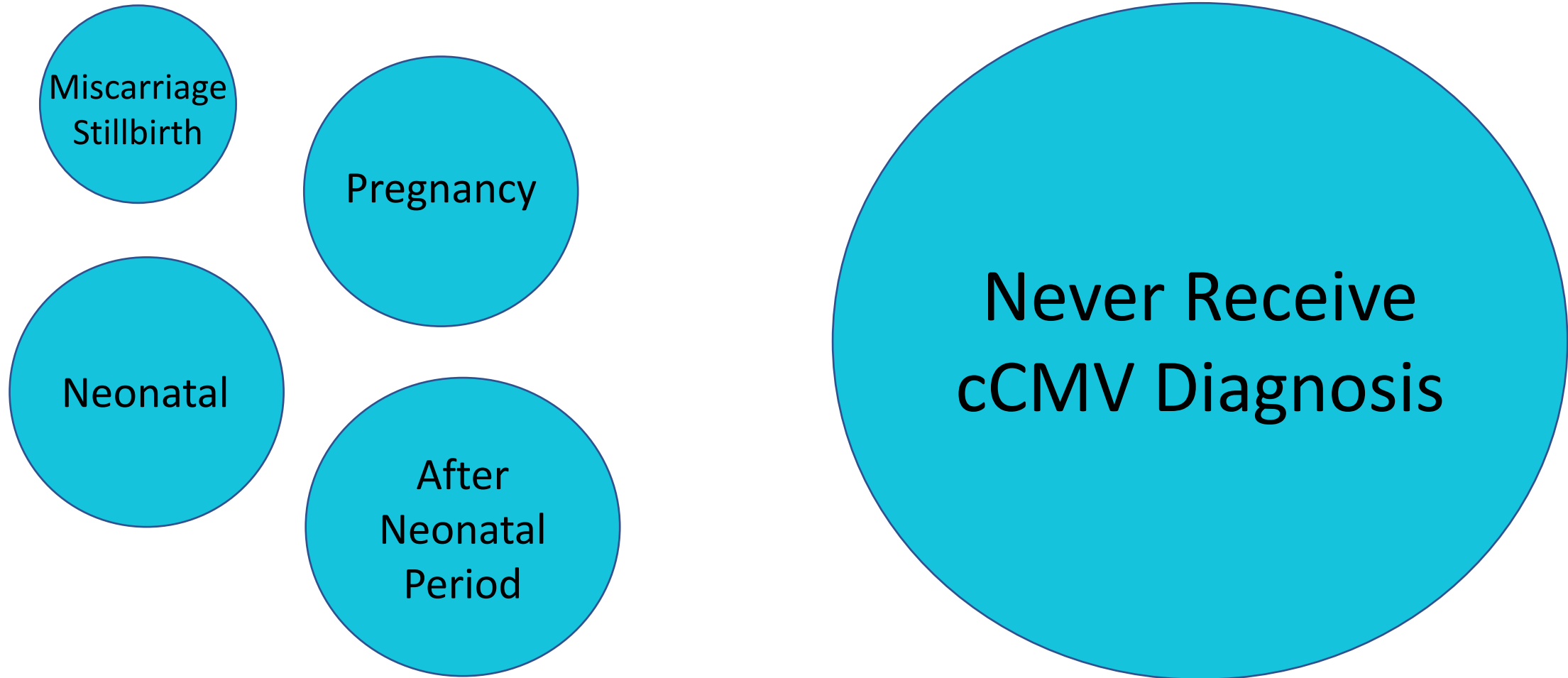
"Receiving our son's congenital CMV diagnosis was unexpected and heartbreaking. Despite the challenges that Matthew and we as a family face, he inspires us every day, has taught us more than we could have ever imagined, and is the biggest blessing."  
Eric, parent

"It's OK to be broken and cry, and ask "why us?" But at the end of the day your baby is perfect. Finding support from families similar to mine helped me remember that my child is perfect and that they are mine!"  
Jami, parent

Text from this educational resource is credited to the Colorado CMV Family Network at Colorado Hands & Voices in collaboration with the CO Chapter of the American Academy of Pediatrics (AAP), with grant support from the AAP and the Colorado Early Hearing Detection and Intervention (EHDI) Alliance.

[@nationalcmv](https://www.facebook.com/nationalcmv) National CMV Foundation [info@nationalcmv.org](mailto:info@nationalcmv.org)

# Typical Family Experience-Diagnosis





# Typical Family Experience

Diagnostic  
Odyssey

Loss of a  
dream

Frustrated by lack of  
awareness and  
knowledge in the  
medical community

Angry/resentful  
about missed  
opportunities for  
CMV prevention and  
early  
diagnosis/treatment

Uncertain  
future

Dismissal of  
concerns by  
medical  
community

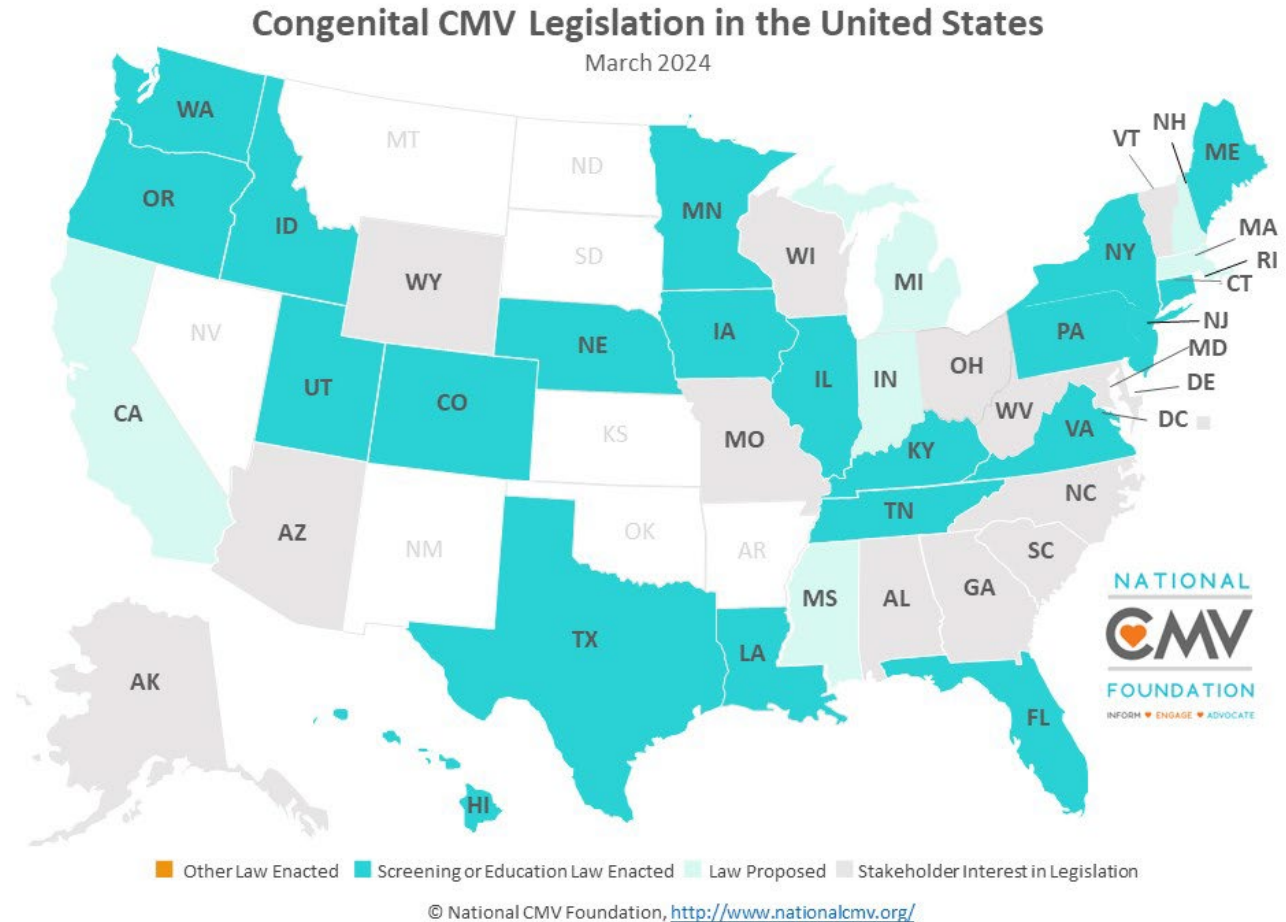
Let  
down

“Why didn’t  
anyone tell me  
about this?”

Guilt

# cCMV Newborn Screening

- Early identification allows for evaluation, treatment, and monitoring
- Most infants (>95%) with cCMV are not identified
- Several states have mandated “targeted screening” where infants are screened for CMV if they fail newborn hearing test
- Minnesota is the first state to screen all babies at birth
- RUSP (Recommended Uniform Screening Panel) nomination
- More common than the 29 combined metabolic and endocrine disorders on the RUSP
- Research has indicated parents are supportive of CMV screening
- AAA and AAO-HNS are supportive of screening.



## CONGENITAL CMV Testing Modalities

URINE



SALIVA



DRIED BLOOD  
 SPOT



SENSITIVITY

99%

99%

75%

EASE OF  
 COLLECTION

Difficult

Easy

Easy

TIMING

<21 days

<21 days

Anytime

OTHER

Send out lab

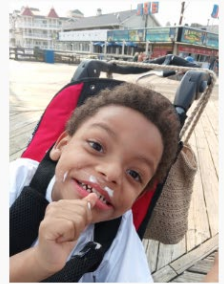
Breastmilk false  
 positives

Not stored by all  
 states

# Federal CMV Legislation

- The bipartisan Stop CMV Act has been introduced by Senators Richard Blumenthal (D-CT), Chris Murphy (D-CT) and Roger Marshall (R-KS), and Representatives Mike Lawler (R-NY) and Greg Landsman (D-OH).
- Funding for states and hospitals to administer congenital CMV tests
- Encourage state healthcare agencies to prescribe standards and procedures for the administration of CMV testing
- Creates grant programs to provide funds to administer CMV tests, improve CMV data collection systems, and assist in CMV education and training
- Advances National Institutes of Health and CDC funding for research, screening techniques, diagnostics, prevention, vaccines, and treatments.

## Support the Stop CMV Act



**Contact your legislators to ask them to Co-Sponsor The Stop CMV Act.**

Visit our advocacy page on our website for more details and a template to use to send to your legislators!

**Make a donation to support our advocacy efforts.**

This work is only possible through your generous donations. Visit our website and donate today!



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# CONTACT NCMVF

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**FOR MORE INFORMATION, VISIT:**

<https://www.nationalcmv.org>

**OR VISIT US ON SOCIAL MEDIA**



NationalCMV

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- [www.nationalcmv.org](http://www.nationalcmv.org)
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