

# Cytomegalovirus (CMV) A Parent's Perspective

Understanding It, Coping With It, and Reducing the Risks



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# What is CMV?

50-80% of adults have had CMV by the time they reach 40 years old.

Nearly 1/3 children have had it by the age of 5.

CMV Presents itself as a cold in most cases.

When you are pregnant or planning to become pregnant it can be very dangerous. 1/3 of women who catch CMV while pregnant will pass it on to the baby.

CMV is the most common virus transmitted from a pregnant woman to her baby.



91% of women haven't  
heard of it

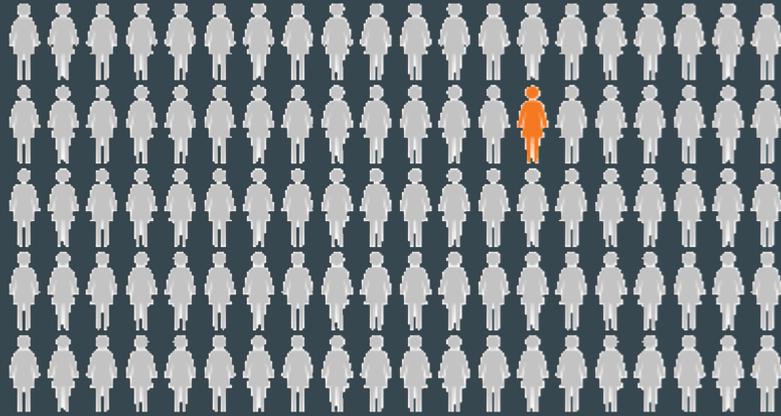


# CMV is Serious

- Congenital CMV can cause multiple birth defects and developmental disabilities such as:
  - Hearing loss
  - Vision loss
  - Developmental/ intellectual disabilities
  - Microcephaly (small head or brain)
  - Intracranial calcifications
  - Lack of coordination
  - Cerebral Palsy
  - Feeding issues / Failure to Thrive (FTT)
  - Sleeping, behavior, sensory issues
  - Seizures
  - Death (in rare cases)

**CMV is the leading non-genetic cause of hearing loss in children.**





1 in 200 babies

or

approximately 30,000 babies are born in the USA every year with cCMV.

# Asymptomatic CMV

- 90% of babies every year are born asymptomatic
- 4-5% will have a hearing loss at birth
- 10-15% will eventually have a hearing loss
- The loss can be progressive into young adulthood and it can fluctuate.

# Symptomatic CMV

- 10% of babies are born with symptomatic cCMV.
- Small head size, jaundice, petechiae/pupura (blueberry muffin rash), and/or enlarged liver or spleen.
- Approximately 75% will develop a hearing loss later on.

It was previously thought that Risk of transmission for primary infection is 30 to 40% in the first and second trimesters, and 40 to 70% in the third trimester. The risk of transmission following non-primary infection is much lower (3%).

However, “in a recent population-based prediction model, it was estimated that non-primary infections account for the majority of CMV-related hearing losses”.

\*de Vries JJ, Zwet EW, Dekker FW, Kroes AC, Verkerk PH, Vossen AC. The apparent paradox of maternal seropositivity as a risk factor for congenital cytomegalovirus infection: a population-based prediction model. *Rev Med Virol.* 2013;**23**:241–249. doi: 10.1002/rmv.1744.

# What Does This Mean For The Family?

Lots of appointments, hospital stays, surgeries, medical equipment, insurance battles, and a lot of assumptions with unanswered questions.

It also means an unfair “label” of being contagious.

# American Academy of Otolaryngology-Head and Neck Surgery CMV Position Statement

- CMV is not an occupational health and safety risk, even for pregnant women, **if routine practices are followed.**
- 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.



# Nathan's Journey





*Water broke at 30 weeks. Spent 4 weeks on hospital bed rest, 1.5 hours away from Liam.*

*Nathan was born at 34 weeks, weighing 6lbs 7oz.*





*We spent a little over  
1.5 months in the NICU.  
On day 3 Nathan was  
diagnosed with cCMV.*



*We were given no information while in the hospital  
or at discharge about CMV or antivirals.*

*Follow up with the Urologist and Audiologist at 6  
months.*



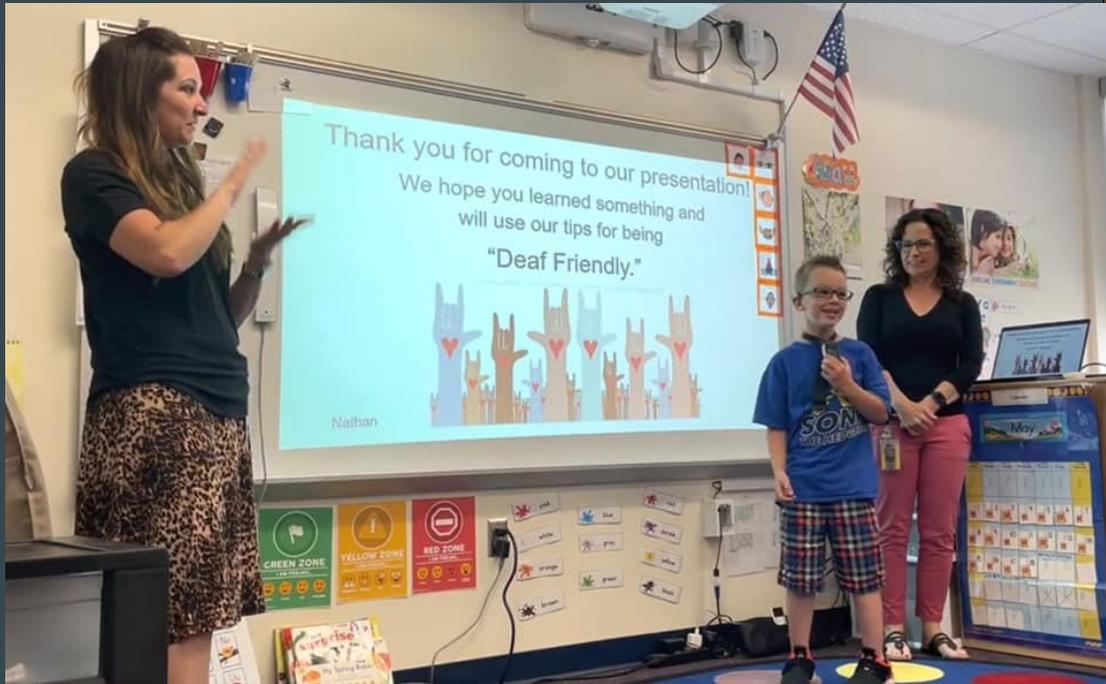
*Did not pass his sound booth test at 6 months old and we scheduled an ABR.*



# *Cochlear Implants at 12 months old*



*Years 1-5: Weekly Auditory Verbal Therapy (AVT), Speech Therapy (SLP), and ASL Classes.  
At School (3 years old - now):  
Speech Therapy, Physical Therapy,  
Occupational Therapy, and a  
Total Communication Classroom*



*Today we continue to stimulate and push him to be adventurous and to advocate for himself. In doing so, we continue to grow in new environments.*



# Meet Axel



Pregnancy, birth story,  
and CMV discovery



# First Year





# *Parents of newly diagnosed kids*

*It is going to be okay. Your child is still the same child. Your love for them won't ever change.*

*There will be days that are hard. Heartbreaking even. It's okay to not be okay. Just don't get stuck there. Your child needs you to be strong.*

*When you think you have it hard, remember, it's harder for your child.*

*Find your tribe. Find those who support you and understand the path you're walking.*

*Channel your emotions towards the fight. The fight for services, quality education, and quality of life.*

*Never give up.*

*ALWAYS have hope. Your child is going to teach you SO MUCH!*

- Research: Learning about the diagnosis, treatment, and outcomes. Truly understanding the language being used by the medical community.
- Be comfortable with your healthcare team. You want to make sure you feel comfortable asking questions and that they are knowledgeable about your child's diagnosis
- Expect to remember only some of what you're told.
- Have someone else with you to take notes for you or remind you later .



# *Prevention*

Women who are pregnant or are planning to become pregnant, including mothers, daycare workers, preschool teachers, therapists and health care workers should use caution around all children because:

**CMV is found in bodily fluids,  
including urine, saliva,  
blood, mucus, and tears.**



Saliva may remain on food, cups or cutlery and could transfer a CMV infection to you and your unborn baby. Although it may be easier to feed your child from your own plate or you do not want to waste remaining food from your child's plate, it is best not to share food or cutlery.



How many of us are guilty of wanting to clean our child's pacifier by putting it in our mouth? Or, your hands are full and you put the pacifier in your mouth just to hold it for a moment? Saliva on your child's pacifier may transfer CMV to you and your unborn baby. Try to get in the habit of putting a pacifier on your pinky, not in your mouth.

Try not to kiss a child under six years of age on the lips or cheek to avoid contact with saliva. Instead, kiss them on the forehead or top of the head and give them a big, long hug.



Toddlers love to imitate everything Mommy does, including pretending to brush their teeth with Mommy's toothbrush. Store your toothbrush in an area that your child cannot reach.



# Wash Your Hands

Wash your hands often with soap and water for 15-20 seconds, especially after the following activities:

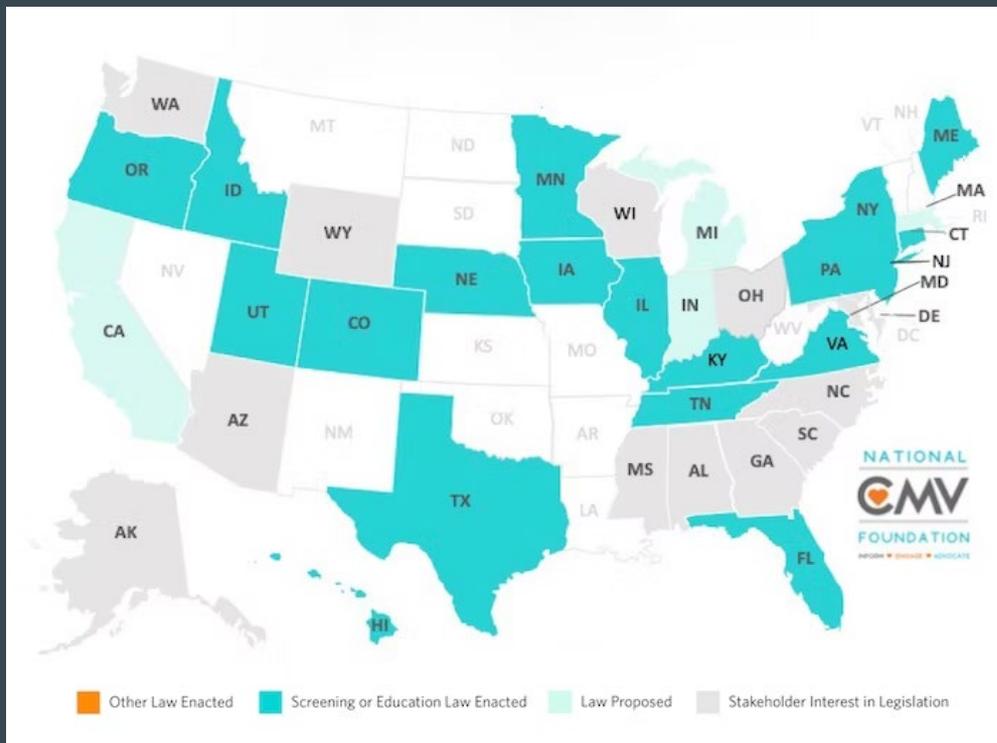
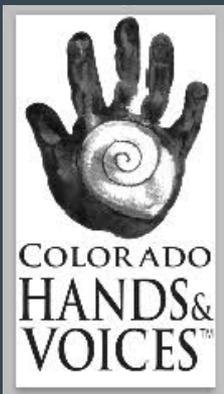
Wiping a young child's nose or drool

Changing diapers

Feeding a young child

Handling children's toys





## Contact Information

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