

# 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.

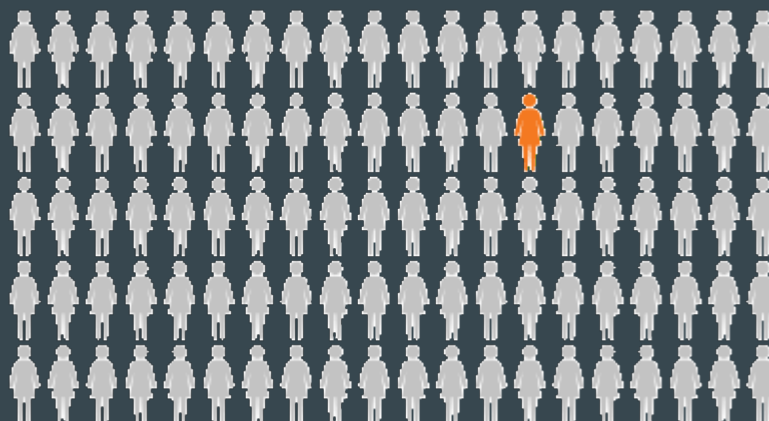
CMV Presents itself as a cold in most cases.



1/3 of women who  
catch CMV while  
pregnant will pass it  
on to their baby.

CMV is...

- #1 virus transmitted from mom to baby
- #1 reason for non-genetic hearing loss in children
- #1 reason for stillbirths and miscarriage from a virus
- #1 reason for Cerebral Palsy in children



1 in 200 babies

or

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

One in every five children born with cCMV will develop  
permanent health complications (roughly 6,000 children).

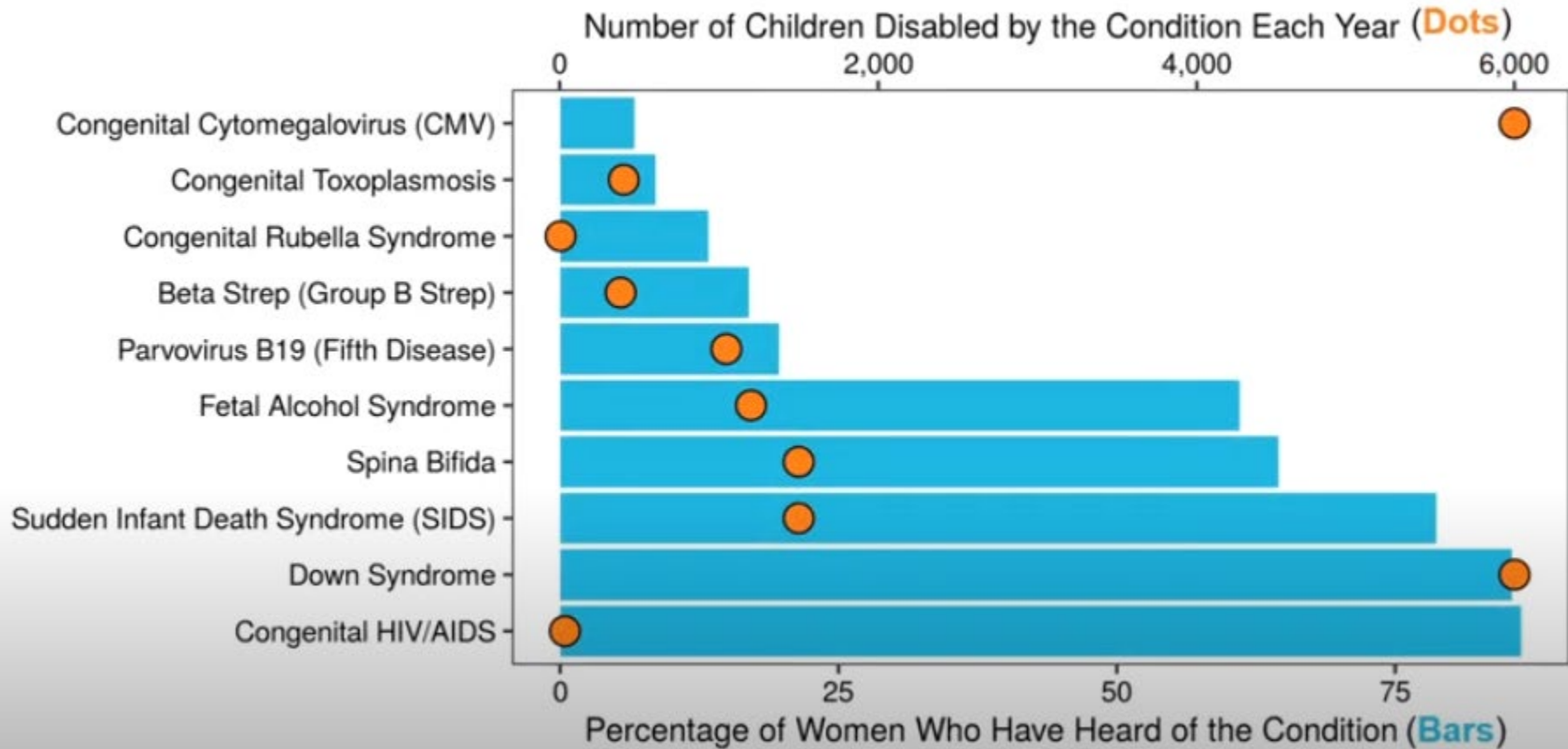
And as many as 400 infant deaths annually.

# Cost of cCMV vs Cost of Education and Testing

- Figures are based off information UT used during their legislative campaign for education and screening laws (Prior to 2020).
- By age 4 ~~amoderately~~affected cCMV child had cost UT Medicaid \$280,000. (Approximately \$70,000 per year, for one child).
- At age 10 ~~æ~~severelyaffected cCMV child had cost UT Medicaid over \$1,000,000. (Approximately \$100,000 per year, for one child).
- UT estimated that education and screening would cost \$40,000 initially and \$26,000 annually after the first year.
- This is less than the cost per year for ONE moderately affected cCMV child.

# Only 9% of women have heard its name

## Awareness vs Incidence of Congenital Conditions



Every woman who is pregnant or trying to become pregnant has the right to know their risks, and the right to protect themselves and their unborn child.





# 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)





# 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 hearing 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 (blueberry muffin rash), and/or enlarged liver or spleen.
- Approximately 75% will develop a hearing loss later on.



# 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.



- 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.





# Meet Nathan





*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 54  
days in the  
NICU.  
At Day 3  
Nathan was  
diagnosed with  
cCMV.*



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

*Follow up with urologist and audiologist at 6 months.*



*Did not pass his sound booth test at 6 months old and we scheduled an ABR for 4 weeks later.*





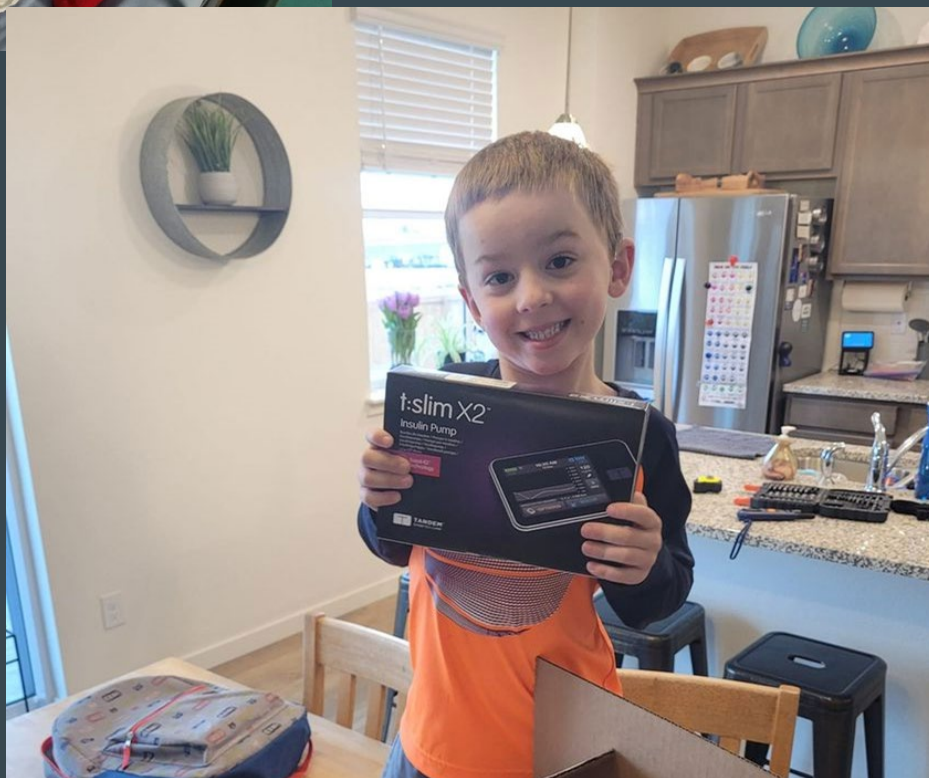
# *Cochlear Implants at 12 months old*





*A lot of testing including EEG's for suspected seizures, and vestibular evaluations.*

*At 3 years old we found cysts on his brain.  
At 4 years old he was diagnosed with Type 1 Diabetes.*

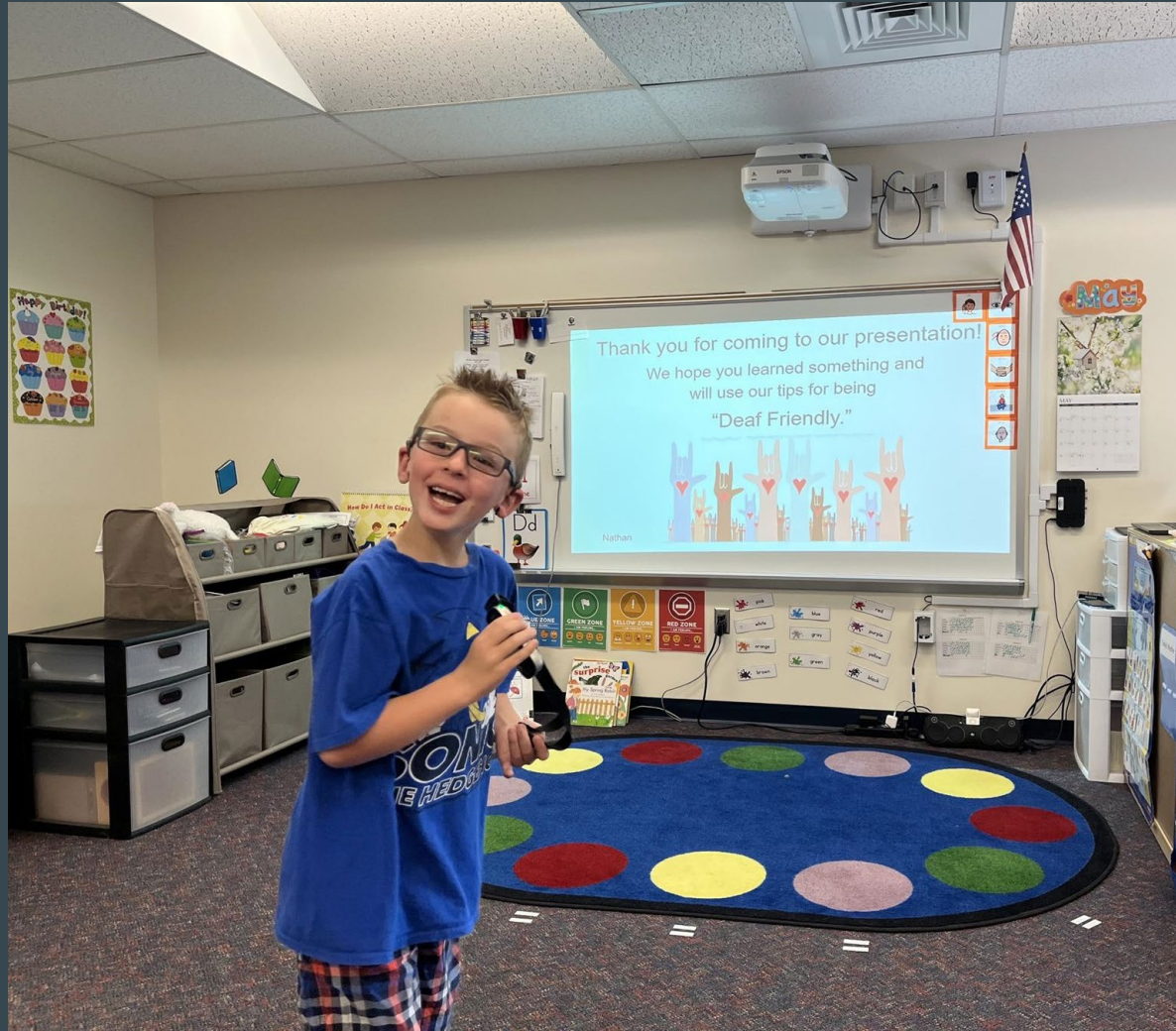




*Auditory Verbal Therapy (AVT), Speech Therapy, Physical Therapy, Occupational Therapy, and ongoing sign language education.*



*Today Nathan attends a Total Communication School.*





# Meet Axel







NICU Admission  
immediately after birth



Sleep Study and  
hyperekplexia and sleep  
apnea diagnosis



First cochlear implant  
surgery



G-tube surgery



One of many hospital  
admissions



Weekly blood  
draw Tuesday



Second cochlear  
implant surgery



Feeding therapy through  
early intervention





“Challenges are what make life interesting and overcoming them is what makes life meaningful.”



# *Cytomegalovirus (CMV)*

## *Public Education and Testing*

- *On July 1, 2013, Utah became the first state in the nation to mandate a cytomegalovirus public health initiative to inform pregnant women and women who may become pregnant about CMV .*
- *This law included a mandate for testing all babies who fail two newborn hearing screenings for congenital cytomegalovirus prior to 21 days of age.*
- *On February 2, 2022 Minnesota became the first state in the US to require universal screening at birth for CMV.*

*How can we help families?*

*Deep breaths... and education!*





# *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 that are pregnant or planning to become pregnant including mothers, daycare workers, preschool teachers, therapists and health care workers should use caution when in contact with:*

*Tears*

*Urine*

*Mucus*

*Blood*

*Saliva*





*Saliva may remain on food, cups or silverware 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 to snack on the remaining food from your child's plate, please make your own.*

*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 their parents do, including pretending to brush their teeth with their 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:*

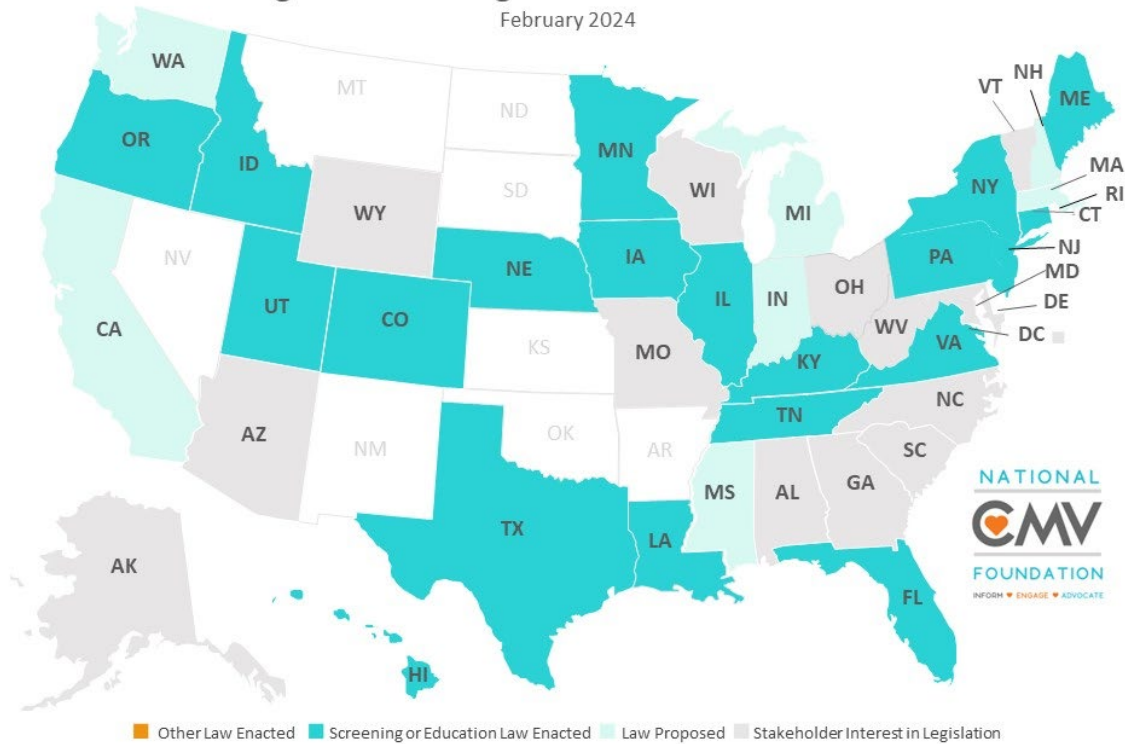
- *Wiping a young child's nose or drool*
- *Changing diapers*
- *Feeding a young child*
- *Handling children's toys*





# Congenital CMV Legislation in the United States

February 2024



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