Parent + Professional on cCMV

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Holly Frigerio, MA

Teacher of the Deaf Wife Adoptive Mom to Owen



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Teacher of the Deaf



Adoptive Mbm to Owen



Teacher of the Deaf

The Professional



What is CMV?

Cytomegalovirus is a common virus that that infects people of all ages. ACMV infection causes cold-like symptoms, such as sore throat, fever, fatigue and swollen glands. These mild Cytomegalovirus symptoms last for only a few short weeks and is rarely a cause for concern for healthy kids or adults. The symptoms are sometimes so mild, resembling a common cold, that most people do not even know they have it. Once the CMV virus is in the person's body, it stays there for life.



CMV Facts:

- CMV is a member of the herpes virus family. By 40 years of age, up to 80% of all adults have been infected with CMV.
- There is always a small risk for recurrence or reinfection.
- 1 per every 200 children is born with congenital CMV he United States, making it the most common congenital viral infection affecting newborns
- CMV is very common among healthy children one to five years of age (one in three five-year-olds are already infected)
- CMV can be serious in individuals with a weakened immune system or if they are pregnant
- Serious CMV disease can be treated with antiviral medications
- No CMV vaccine is available
- There is screening and testing available (ask your doctor prior to pregnancy about the antibody blood tests: CMV IgG and CMV IgM

-National CMV Foundation (2020)



The Impact



Congenital MV (cCMV) is the leading cause of non-genetic sensorineural hearing loss (SNHL) inchildren in the U.S.

Hearing loss following cCMV infection may be present at birth or occur later in the early years of life.

Children with SNHL due to cCMV infection may have further hearing deterioration.

-National CMV Foundation (2020)



- Hearingoss
- Vision loss
- Mental disability
- Intrauterine growth restriction
- Hepatosplenomegaly (enlarged liver and spleen)
- Microcephaly (small head or brain)
- Intracranial calcifications
- Lack of coordination
- Cerebral palsy
- Feeding issues / Failure to Thrive
- Sleeping, behavior, sensory issues
- Seizures
- Retinitis (damaged eye retina)
- Death in some cases



The Spectrum

| Born symptomatic | | | | Born asymptomatic | |
|---|--|--|--|--|---|
| Death Miscarriage, stillbirth, infant or child loss | Medically fragile Cerebral palsy, Seizures, Failure to Thrive, Hearing loss, Vision loss | Multiple impairments Cerebral palsy, Vision loss, Hearing loss | Developmental delays Cognitive delays, Learning issues, Feeding and sleeping issues, Vision loss, Hearing loss | Hearing loss Hearing aids, Cochlear implants, Communication and learning issues, Mild vision disorders | None No visible delays or impairments |
| Severe | Moderate | | | | Mild |



Please don't be afraid to interact with children with cCMV, but use these precautions:

Wash your hands, wear gloves during diaper changes, don't share food or drinks, sanitize toys and don't kiss young children on or around the mouth.



Adoptive Mbm to Owen

The Parent



Owen

GraysonStevenWalsh was born on April 3, 2019. His birth mother had chosen a family to adopt him early on in pregnancy,after the suspicion of cCMV during an ultrasound towards the end of her pregnancy,the family withdrew from the adoption. At birth, the doctors prepared his birth mother for his death.





The Diagnosis



Symptomatic at Birth

Owen was in the 10% of babies born symptomatic with cCMV at birth. He presented with

- Low birth weight
- Microcephaly
- Enlarged liver and spleen
- Jaundice
- "Blueberry muffin rash"





Today

Owen presents with:

- Microcephaly
- Hearing loss
- Suspected Cortical Vision Impairment (CVI)
- Epilepsy
- Suspected Cerebral Palsy
- Pure happiness





Specialists + Therapusts frequents:

- Neurologist
- Pulmonologist
- ENT
- Audiologist
- CP Clinic
- Infectious Disease
- Pediatrician
- Occupational Therapist
- Physical Therapist
- Nutritionist
- Hearing Itinerant



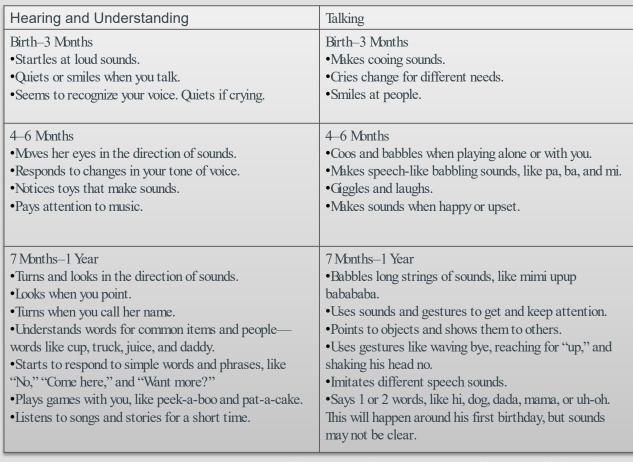




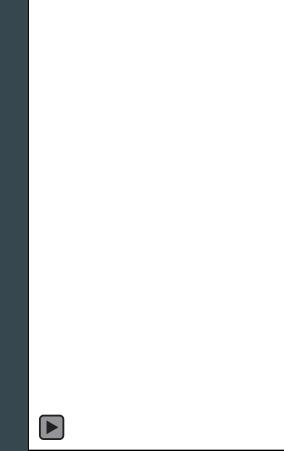




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Owen's Chronological Age: 8.5 Months (Developmental Stage: 6 Months (sits supported)



BREAKOUT

Advocacy as the Professional

Empower the Parent Audiological Needs Collaborate between Professionals Speak up



BREAKOUT CONTINU

Advocacy as the Parent



















Mess-Free Touch-Lights



cCMV Parent Support:

Online:

- CMV Mommies Group on Facebook
- CMV Family Support Group on Facebook
- Parents of Children with Epilepsy Group on Facebook
- Instagram Accounts:
 - o lynzypma1
 - brandihurtubise
 - hearwithdess
 - o hollyfrigerio
- Instagram search: #cCMV
- National CMV Foundation
 - o Blog
 - Podcasts
 - Parent stories
 - Educational Downloads





Thank you!

Contact Information:

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Please don't hesitate to reach out if you have any questions as a parent or professional!





Sources

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