



# Congenital Cytomegalovirus (cCMV): The Most Common Cause of Non-genetic Hearing Loss

**Ruth S. Marin PhD, CCC-A**

Carolyn Horton AuD, CCC-A

Carolyn Jenks, MD

National EHDI Conference

Denver, Colorado

March 2024

# What is Congenital Cytomegalovirus (cCMV)?

- A very common virus, member of the herpes family
- Most of worldwide population has been exposed by early adulthood
- No serious complications for healthy people if acquired after birth
- Can have serious effects on the immunocompromised inc. transplant pts
- Potential for very serious complications for fetus if a pregnant woman is infected
- **MOST COMMON** intrauterine infection
  - Birth prevalence is approx. 0.7% (est. 20,000/year) or **about 1 in 200**
  - Approx. 15-20% of those who are cCMV+ will be symptomatic at birth (up to ~4000/year)
- **The most common cause** of non-genetic deafness and birth defects

# CMV Transmission

- Through bodily fluid: saliva, tears, breast milk, urine, semen, vaginal
- Pregnant women who get CMV have a 1 in 3 chance of passing to fetus
- Women who work/live with the birth-5 population are at greatest risk of passing CMV to developing fetus
- Most women of childbearing age have been exposed (~80%)
- Latent CMV virus can be reactivated and transmitted to the fetus; reactivation causes more cases, therefore education alone can't reduce the risk

[www.nationalcmv.org](http://www.nationalcmv.org) & <https://www.marchofdimes.org/>

# cCMV Statistics/Info

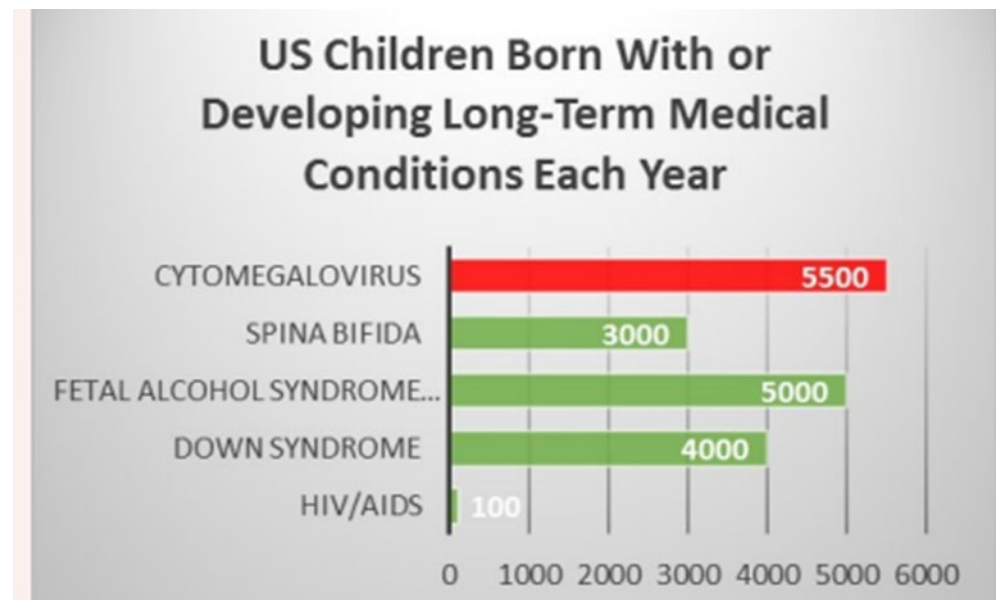
- cCMV is more common than the 29 combined metabolic and endocrine disorders on the RUSP
- 1/200 babies in US will be born with cCMV
  - Only ~10% are symptomatic at birth
  - Up to 90% will have no clinical manifestations\* at birth (with or without hearing differences)
  - Additional 15% will not have symptoms at birth but will develop a delayed-onset and/or progressive change in hearing status and would be missed by NBHS
  - Total 20% will have long-term health complications
- Affects those from lower SES and people of color more
  - Leading to more health disparities
- [www.nationalcmv.org](http://www.nationalcmv.org)

# Potential cCMV complications

- **Sensorineural Hearing Loss (SNHL)** from birth and/or late onset or progressive decline in hearing status
- Vision loss/retinitis
- Petechiae
- Microcephaly
- Seizures
- Kidneys, lungs, liver damage
- Small for Gestational Age (SGA)
- Cognitive and motor skills disabilities
- Intrauterine growth retardation (IUGR)
- Jaundice (hyperbilirubinemia)
- Blood disorders: thrombocytopenia, anemia leukopenia
- Cerebral palsy
- Fetal demise
- Miscarriage
- And more.....

# Comparison of congenital disorders

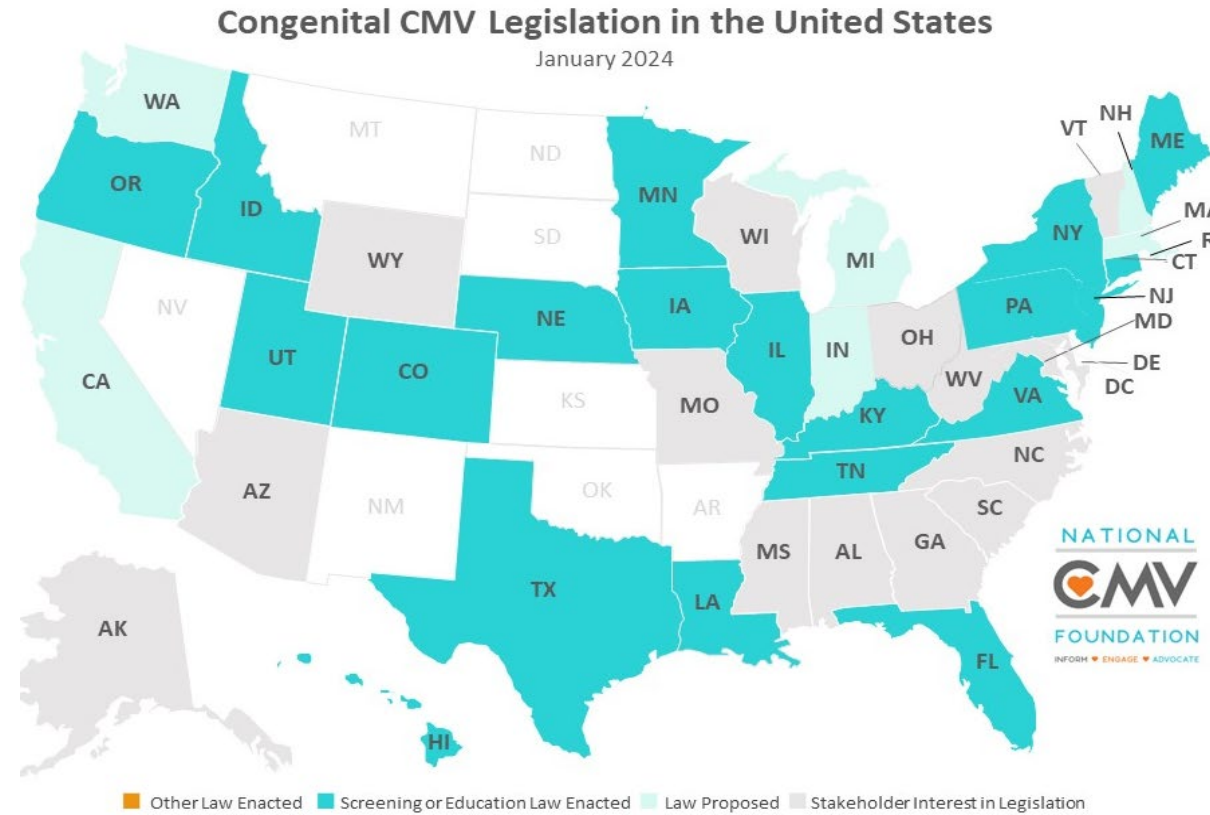
- More children will have disabilities due to congenital CMV than other well-known disorders, including Down Syndrome, Fetal Alcohol Syndrome, Spina Bifida, and Pediatric HIV/AIDS.



# Screening Methods: Targeted vs. Universal

- (Hearing) Targeted Screening
  - Screening based on a failed newborn hearing screening
  - Not effective since most affected babies won't have symptoms at birth
  - Will only identify **7%** of all children born with cCMV
- Expanded Targeted Screening
  - Screening when other birth conditions are present e.g., microcephaly, IUGR, neurological involvement, jaundice
- **Universal Screening**
  - Screen ALL newborns to improve detection, intervention and outcomes
    - Senator Blumenthal (CT) just introduced federal legislation to provide funding for screening programs, research and education (similar to the EHDI program)

# Current cCMV screening in the United States\*



© National CMV Foundation, <http://www.nationalcmv.org/>

\* Constantly changing (current as of 2/27/24)  
<https://www.nationalcmv.org/about-us/advocacy>



# Why hearing targeted screening is inadequate

- Most infants with symptomatic cCMV are missed (>90% missed in one study) because we rarely test even when there are symptoms
- All patients without clinical manifestations of cCMV who do not fail the newborn hearing screen are missed
- Delayed identification of hearing status and neurodevelopmental issues impact treatment, access to language, intervention, education, outcomes

# Value of Universal Screening

- Universal screening identifies children with "asymptomatic" cCMV at risk for changes in hearing as well as children with symptomatic cCMV who are at risk for neurodevelopmental issues, visual impairment, and other comorbidities in addition to changes in hearing status
- Universal screening would:
  - Enable prompt referrals and evaluations for all
  - Allow for hearing and neurodevelopmental monitoring
  - Facilitate services and treatment (antivirals, early intervention, access to language, hearing aids, cochlear implants)

# The financial benefit

- In addition to health outcomes and quality of life benefit, a cost-analysis study concluded that universal screening for cCMV would be cost-effective and result in net healthcare savings (Gant et, al, 2016)
- Other studies demonstrating cost benefit conducted in Japan, China, Australia
- There is clear data supporting the financial benefit of early identification and intervention for sensory disorders, in general, in terms of reduced educational costs, and increased earning potential

# cCMV Screening Methods

- Current “gold standard” tests: Urine viral culture, Saliva and Urine PCR
  - Saliva PCR average \$15
  - Covered by most public and private insurance
- Dried blood spots are collected for all infants and would be easier to use for universal screening
  - CMV dried blood spot testing has improved greatly in recent years (up to 86% sensitivity in a recent study)
  - MN using DBS testing

# Hearing Status and cCMV

- Up 25% of all sensorineural hearing differences may be due to cCMV
- Can occur with or without other ‘clinical manifestations’ (aka symptomatic/asymptomatic)
- Differences in hearing status can be **congenital, bilateral, unilateral, early-onset, delayed-onset, progressive**
  - Up to 50% with cCMV may experience fluctuations and/or progression in hearing levels
    - May progress throughout adolescence, but greatest changes occur by age 5-6 (peak language learning time)
    - Progression can occur after years of stability
- $\geq 50\%$  can't be detected on a NBHS
- Frequent audiological monitoring needed throughout childhood to ensure access to language and to improve outcomes

# Hearing Status in Symptomatic vs Asymptomatic cCMV

- Higher proportion of hearing loss in symptomatic vs asymptomatic
- However, asymptomatic accounts for the greatest number of SNHL cases
- ~5% of asymptomatic cases have severe HL in at least one ear by 12 months, and half meet CI criteria by 5 years
- Microcephaly and abnormal head CT scan associated with increased risk of SNHL in symptomatic babies

# Hearing Status Research study #1

- Rohren, et al., 2023 (MN data)
  - Retrospective study of cCMV+ babies (n=44 /445) (~10%)
  - 75% (n=33) had SNHL
    - Mean age of detection was 13 months
    - Hearing decreased in  $\geq 50\%$
    - Hearing fluctuated in  $\geq 23\%$
    - Those who were symptomatic at birth had poorer hearing levels
  - 39% (n=17) passed NBHS bilaterally
    - 35% (6/17) developed SNHL by 20 months
    - 65% (11/17) had stable hearing levels though 18 months
  - 39% (n=17) failed NBHS bilaterally
    - 100% had severe to profound, bilateral SNHL
    - 94% (16/17) diagnosed by 2 months
  - 23% (n=10) failed in one ear
    - 52% with unilateral SNHL later developed bilateral SNHL
  - 55% (18/33) received antiviral meds
    - less decrease in thresholds than those who didn't get treatment, seemed to help stabilize

# Hearing Status Research study #2

- Lanzieri et al., 2017 (n=92)
  - 65% had progressive decrease
  - 25% that passed NBHS developed a change in status
  - Most unilateral SNHL progressed to bilateral SNHL
  - Those with unilateral had more changes and decrease than those with typical hearing at birth
  - The hearing change risk for cCMV+ children from birth through age 18 was 4x greater than for control group
- “We estimate that 5% of children with asymptomatic cCMV infection, about **900 annually**, will have SNHL 70dB or greater in at least 1 ear by age 12 months” and
- “An estimated 2% (~400 per year) of children with asymptomatic congenital CMV infection develop severe enough SNHL to meet cochlear implant candidacy, but their risk of developing hearing loss after age 5 years is not significantly increased compared to uninfected children”



# Hearing Status Research study #3

- Lanzieri et al., 2018 (n=168)
  - Longitudinal study, compared cCMV<sup>+</sup> babies symptomatic at birth vs non-symptomatic at birth
  - 74% of symptomatic group and 22% of the asymptomatic group had SNHL
    - The majority of SNHL was present at birth in the symptomatic group
    - The majority of SNHL was later onset in the asymptomatic group
  - ALL that were identified with SNHL after NBHS experienced a decrease in hearing levels
    - Those diagnosed soon after birth had poorer thresholds than those with delayed-onset
  - In the asymptomatic group, a majority that had UNHD progressed to bilateral by 18 years old
  - Steepest progression in status by 5-6 years old, but could continue beyond even after years of stability
  - **Approximately 50% with cCMV hearing differences were not detected by NBHS**
  - Microcephaly & other brain abnormalities were associated with increased risk of a change in hearing
    - 20% of asymptomatic infants had brain abnormalities in this study
  - Estimated about 900 per year will have severe to profound SNHS by 1 year old with half meeting criteria for CI by 5 years old

## Unilateral hearing loss in CMV

- One of the most common causes of ‘single-sided deafness’
- In multiple studies, infants with unilateral hearing loss later developed hearing loss in the opposite ear
- Unilateral SNHL more common in asymptomatic cCMV than symptomatic
- In most cases the poorer hearing ear worsens earlier and more precipitously than the better-hearing ear

# Recommended Hearing Monitoring Timeline(s)

- American Academy of Audiology Position Statement (2023)\*
  - Diagnostic ABR every 3-6 months for the first year after initial test
  - Every 6 months until age 3 years
  - Annually until age 6 years
- Minnesota guidelines:
  - Diagnostic ABR by 1 month
  - Repeat ABR by 5 months
  - Every 3 months through age 2 years
  - Every 6 months from 3-6 years
  - Every year after through age 10
- International cCMV Recommendations Group (2015)
  - 6-month intervals through age 3
  - Annually from 4-19 years
- National Deaf Children's Society
  - Every 3-6 months from birth – 3 years
  - Annually 3-6 years

# Antiviral Therapy

- Antivirals may improve hearing and neurodevelopmental outcomes if started in the first month of life
  - Some research suggests that there may be some benefit even beyond the first month
- Current 'standard of care' is to offer antivirals for babies with moderate to severe symptoms
  - Ongoing research for babies with more mild symptoms or only hearing differences, but this is not 'standard of care'
- Antivirals may have serious side effects, so must weigh risk/benefit

# cCMV Vaccine

- Research and trials in process – showing promise
- NIH recently (2023) had a hybrid conference
  - Discussed vaccine protocol options for who to vaccinate
  - Informal consensus seems to be that vaccinating the toddlers rather than the women, so they can't pass it to the pregnant women, would be the most effective in reducing primary infection
    - This won't solve the issue of re-infection
    - For women who work with toddlers, all children would have to be vaccinated

# Professional Position Statement Support for CMV screening

- American Academy of Audiology (AAA)
  - Recommends early identification but does not specifically recommend universal screening
    - <https://www.audiology.org/practice-guideline/american-academy-of-audiology-position-statement-on-early-identification-of-cytomegalovirus-in-newborns/>
- American Academy of Otolaryngology – Head and Neck Surgery (AAO-HNS)
  - “It is estimated that 1 in every 200 US newborns have congenital cytomegalovirus (cCMV). Delayed identification of cCMV in newborns precludes timely intervention to mitigate sequelae of the infection such as hearing loss and other neurological complications. Newborn testing for cCMV enables appropriate diagnosis and intervention by multidisciplinary teams to properly manage the immediate consequences of cCMV, avoid unnecessary additional testing that can result from delayed diagnosis, and monitor for future complications. It is the position of the American Academy of Otolaryngology – Head and Neck Surgery that universal newborn cCMV screening is necessary to best accomplish these goals.”
    - [www.entnet.org/resource/universal-newborn-congenital-cytomegalovirus-ccmv-screening/](http://www.entnet.org/resource/universal-newborn-congenital-cytomegalovirus-ccmv-screening/)
    - February 19, 2024

# Conclusions

- cCMV is a leading cause of childhood hearing loss
  - Hearing thresholds in cCMV must be monitored for years
- Screening for cCMV is important and timely
- The cost of screening and early intervention is less than delayed identification and intervention
- More and more states have screening and/or education requirements
- Federal legislation has recently been introduced
- Professional organizations starting to get on board with support
- Vaccine trials are in progress but may be a long process
- We hope that you will support our mission to bring universal cCMV screening to all babies in your (and all) states

# New National CMV Foundation flyer

**AUDIOLOGY SURVEILLANCE IN INFANTS AND CHILDREN WITH CONGENITAL CMV**

**NATIONAL CMV FOUNDATION**

- DIAGNOSTIC AUDIOLOGY EVALUATION BY 3 MONTHS**  
Initial diagnostic audiology evaluation should take by 3 months of life, even if the infant passes the newborn hearing screening
- SURVEILLANCE THROUGH AGE 6 YEARS**  
Diagnostic evaluations every 3-6 months for the first year, then every 6 months until age 3, then annually until 6 years old
- AMPLIFICATION**  
Amplification should be discussed with families of infants with documented sensorineural hearing loss, and accordingly devices should be fitted expediently
- SURVEILLANCE THROUGH AGE 6 YEARS**  
Unilateral SNHL can progress to bilateral; rapid progression is likely. The poorer-hearing ear may worsen earlier and more precipitously than the better hearing ear
- DISCUSS VARIETY OF COMMUNICATION OPTIONS**  
Visual acuity and fine motor coordination may be impacted by cCMV. Consider communication approaches that will best meet the needs of the individual
- MONITOR FOR VESTIBULAR INVOLVEMENT**  
Balance should be monitored and referrals for vestibular evaluation made as needed.
- MULTIDISCIPLINARY TEAM**  
A multidisciplinary team may be needed to support the unique needs of each child with cCMV due to heightened risk of neurodevelopmental disabilities.

Based on:  
Kettler, M., Shoup, A., Moats, S., Steuerwald, W., Jones, S., Stiell, S.C. and Chappetto, J., 2023. American Academy of Audiology Position Statement on Early Identification of Cytomegalovirus in Newborns. *Journal of the American Academy of Audiology*.



# cCMV – Support and Next Steps

## CONGENITAL CMV: SUPPORT AND NEXT STEPS



### WHAT IS CYTOMEGALOVIRUS (CMV)?

Cytomegalovirus (CMV) is a common virus that infects people of all ages and is not harmful for most people. CMV spreads from person to person through body fluids, including saliva, urine, and blood. It is prevalent in the saliva of toddlers. Many people catch CMV as toddlers, and about 3 out of 4 adults have had CMV by age 40. Most of us will never even know we have had CMV.

### WHAT IS CONGENITAL CMV (cCMV)?

Sometimes a pregnant woman will pass CMV to her baby. When a baby is born with CMV, it is called congenital CMV (cCMV).

- 1 out of every 200 babies are born with cCMV
- About 1 out of 4 babies born with cCMV will have hearing loss at birth or develop hearing loss during the first few years of life
- Some babies born with cCMV will have other challenges besides hearing loss, including vision loss or developmental delays

### WHAT HAPPENS AFTER YOUR CHILD RECEIVES A DIAGNOSIS OF cCMV?

If your baby's CMV test is positive, your pediatrician will talk with you about whether your baby needs additional testing or medication. Your baby may need to see other specialists to get the best treatment for cCMV.

### IF YOUR BABY IS DIAGNOSED WITH cCMV, WHERE CAN YOU FIND SUPPORT?

The National CMV Foundation may be able to help your family in several ways. The Foundation can help with:

- Learning more about cCMV and the wide range of effects it may have on your child's development
- Connecting you with appropriate state specific CMV support
- Connecting you with other families experiencing a cCMV diagnosis
- Assisting you with finding providers in your state/region familiar with CMV

**"A diagnosis changes a lot of things. But don't ever let that define your life, and most importantly, your child's. There is love and life within and after a diagnosis. Fourteen years later, and my daughter Avalee continues to show me this every single day."**

*Ashley, parent*



www.nationalcmv.org



**"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 EHDI 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."**

*Erin, 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*

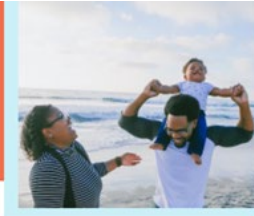
Text from this educational resource is credited to The Colorado cCMV Family Network at Colorado Hands & Voices, in collaboration with the CO Chapter of the American Academy of Pediatrics (AAP), with grant support from the AAP and The Colorado Early Hearing Detection and Intervention (EHDI) Alliance.

@nationalcmv National CMV Foundation info@nationalcmv.org



# Support and Next Steps – Spanish

## CMV CONGÉNITO: APOYO Y SIGUIENTES PASOS



### ¿QUÉ ES EL CITOMEGALOVIRUS (CMV)?

El citomegalovirus (CMV) es un virus común que infecta a las personas de todas las edades y no es perjudicial para la mayoría de ellas. El CMV se propaga de persona a persona a través de los fluidos corporales, incluyendo la saliva, la orina y la sangre. Prevalce en la saliva de los bebés. Muchas personas contraen el CMV cuando son bebés, y aproximadamente 3 de cada 4 adultos lo han tenido a la edad de 40 años. La mayoría de nosotros nunca incluso sabremos que nos infectamos con CMV.

### ¿QUÉ ES EL CMV CONGÉNITO (cCMV)?

Algunas veces, una mujer embarazada le transmitirá el CMV a su bebé. Cuando un bebé nace con CMV, se denomina CMV congénito (cCMV, por sus siglas en inglés).

- 1 de cada 200 bebés nace con cCMV
- Aproximadamente 1 de cada 4 bebés que nace con cCMV experimentará pérdida auditiva al nacer o la desarrollará durante los primeros años de vida
- Algunos bebés que nacen con cCMV enfrentarán otros desafíos aparte de la pérdida auditiva, incluyendo pérdida de la vista o retrasos en el desarrollo

### ¿QUÉ SUCEDE DESPUÉS DE QUE SU HIJO(A) RECIBE UN DIAGNÓSTICO DE cCMV?

Si su bebé da positivo en la prueba para CMV, su pediatra hablará con usted acerca de si su bebé necesita pruebas adicionales o medicamentos. Es posible que su bebé necesite ver a otros especialistas para recibir el mejor tratamiento para cCMV.

### SI SU BEBÉ ES DIAGNOSTICADO CON cCMV, ¿EN DÓNDE PUEDE RECIBIR AYUDA?

La Fundación Nacional de CMV puede ayudar a su familia de muchas maneras. La Fundación puede ayudar con:

- Brindarle más información sobre el cCMV y la amplia variedad de efectos que este puede tener en el desarrollo de su hijo(a)
- Enlazarlo con el apoyo estatal adecuado y específico para el CMV
- Conectarlo con otras familias que experimentan un diagnóstico de cCMV
- Ayudarlo a encontrar a los proveedores en su estado/región que se familiaricen con el CMV



"Un diagnóstico cambia mucho las cosas. Sin embargo, nunca deje que defina su vida y, lo más importante, la de sus hijos. Hay amor y vida durante y después de un diagnóstico. Han pasado catorce años y mi hija Avalee me lo sigue demostrando todos los días".

Ashley, madre



"Tener un hijo con un diagnóstico de cCMV puede ser atemorizante. Hay mucho desconocimiento del tema y cada niño es afectado de una manera diferente. Es importante tener un sistema de apoyo que comprenda la incertidumbre".

Amber, madre

## ESPECIALISTAS PEDIÁTRICOS

Enfermedades infecciosas  
Oídos, nariz y garganta  
Oftalmología  
Neurología

## RECURSOS PARA PADRES

Fundación Nacional del CMV  
Organizaciones sin fines de lucro para pérdida auditiva y discapacidad  
El Capítulo de Hands & Voices de su estado

## RECURSOS DEL DESARROLLO

El pediatra de su hijo  
Terapia ocupacional  
Terapia física  
Los servicios de intervención temprana de su estado

## RECURSOS PARA LA AUDICIÓN

Audiología pediátrica  
Terapeuta del habla  
Instructor de lengua de señas  
El Programa EHDH de su estado

"Recibir el diagnóstico de CMV de nuestro hijo fue inesperado y desgarrador. A pesar de los desafíos que Matthew y nosotros como familia experimentamos, él nos inspira todos los días, nos ha enseñado más de lo que pudimos imaginar y es la mayor bendición".

Erin, madre

"Está bien derrumbarse y llorar y preguntar '¿por qué a nosotros?' Pero al final del día su bebé es perfecto. ¡Encontrar el





# Roadmap for cCMV Work-Up English



## 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

#### BLOOD WORK

##### FOR CLINICIANS:

- Assess for hepatitis, conjugated hyperbilirubinemia, hematologic abnormalities (e.g. thrombocytopenia)
- Order a CBC with Differential, AST, ALT, total bilirubin and fractionated bilirubin

##### FOR CAREGIVERS:

- These labs must be drawn from a vein, and may not be accurate if collected by "heel poke"
- Can be collected at a local lab



#### DIAGNOSTIC HEARING EVALUATION

##### FOR CLINICIANS:

- Diagnostic audiologic testing performed by a pediatric audiologist when possible
- Due to the unpredictable nature of CMV-related hearing loss (rapid onset, delayed onset, fluctuating) close monitoring is recommended

##### FOR CAREGIVERS:

- Even if an infant passes the newborn hearing screen, they remain at risk of hearing loss
- CMV-related hearing loss can be present at birth or develop in infancy and childhood
- Close hearing monitoring by an audiologist is important to catch any developing hearing loss early

#### DILATED EYE EXAM BY A PEDIATRIC OPHTHALMOLOGIST

##### FOR CLINICIANS AND CAREGIVERS:

- A baseline dilated eye exam by a pediatric ophthalmologist (not an optometrist) to evaluate for chorioretinal involvement is recommended

## LEARN MORE



• National CMV Foundation: [www.nationalcmv.org](http://www.nationalcmv.org)

• Centers for Disease Control and Prevention: [www.cdc.gov/cmvi/](http://www.cdc.gov/cmvi/)

• Luck, S. E., Wieringa, J. W., Blázquez-Gamero, D., Henneke, P., Schuster, K., Butler, K., ... & Vossen, A. C. (2017). Congenital cytomegalovirus: A European expert consensus statement on diagnosis and management. *The Pediatric Infectious Disease Journal*, 36(12), 1205-1213.

• Rawlinson, W. D., Boppana, S. B., Fowler, K. B., Kimberlin, D. W., Lazzarotto, T., Alain, S., ... & van Zuylen, W. J. (2017). Congenital cytomegalovirus infection in pregnancy and the neonate: Consensus recommendations for prevention, diagnosis, and therapy. *The Lancet Infectious Diseases*, 17(6), e177-e188.

# Roadmap for cCMV Work-Up Spanish



## GUÍA PARA EL EXAMEN DE CMV CONGÉNITO PARA UN RECIÉN NACIDO

Todos los bebés que son diagnosticados con citomegalovirus congénito (cCMV) necesitan una evaluación adicional para determinar la gravedad de la enfermedad y definir qué tratamientos son los correctos para ellos. Incluso los bebés sin signos visibles de infección requieren las siguientes evaluaciones para garantizar que no tengan ningún efecto desapercibido derivado del virus.



### REMISIÓN A UN ESPECIALISTA PEDIÁTRICO EN ENFERMEDADES INFECCIOSAS

#### PARA LOS CLÍNICOS:

- Haga una remisión urgente para paciente externo
- Iniciar con la siguiente evaluación antes de la cita puede proporcionarle información importante al especialista en enfermedades infecciosas para determinar el tratamiento
- La gravedad de la enfermedad se basa parcialmente en la siguiente evaluación
- Para los bebés que califiquen, se debe iniciar con los medicamentos antivirales antes de 1 mes de edad

#### PARA LOS CUIDADORES:

- El especialista podrá discutir los siguientes pasos
- Haga preguntas sobre los posibles beneficios y riesgos de los medicamentos antivirales

### ULTRASONIDO DE LA CABEZA

#### PARA LOS CLÍNICOS:

- Las imágenes de ultrasonidos cerebrales son necesarias para descartar o confirmar una patología intracraneal
- Si se encuentran anomalías en el cerebro, considere realizar una IRM

#### PARA LOS CUIDADORES:

- El ultrasonido se realiza sobre la parte blanda o fontanela del bebé
- Los ultrasonidos no producen dolor y no implican radiación
- Los niños que muestran signos de CMV en las imágenes cerebrales pueden ser elegibles para medicamentos antivirales

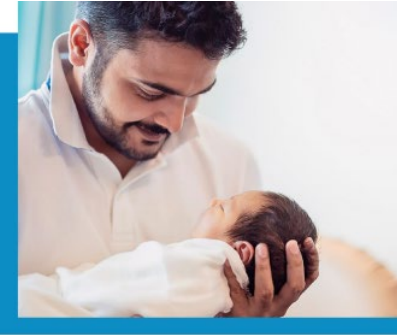
### PRUEBAS DE SANGRE

#### PARA LOS CLÍNICOS:

- Evalúe si hay hepatitis, hiperbilirubinemia conjugada, anomalías hematológicas (por ejemplo, trombocitopenia)
- Ordene un CSC con diferencial, AST, ALT, bilirubina total y fraccionada

#### PARA LOS CUIDADORES:

- Estas pruebas de laboratorio se pueden extraer de una vena y es posible que no sean precisas si se recolectan de una "punción en el talón"
- Se pueden recolectar en un laboratorio local



### EVALUACIÓN AUDITIVA DIAGNÓSTICA

#### PARA LOS CLÍNICOS:

- Las evaluaciones audiológicas de diagnóstico son realizadas por un audiólogo pediátrico cuando sea posible
- Debido a la naturaleza impredecible de la pérdida auditiva relacionada con el CMV (inicio rápido, inicio retrasado, fluctuación), se recomienda el monitoreo cercano

#### PARA LOS CUIDADORES:

- Incluso si un bebé aprueba la evaluación auditiva para recién nacidos, sigue teniendo riesgo de pérdida auditiva
- La pérdida auditiva relacionada con el CMV puede estar presente al nacer o desarrollarse en la infancia y niñez
- El monitoreo auditivo cercano por parte de un audiólogo es importante para detectar oportunamente cualquier pérdida auditiva en desarrollo

### EXAMEN DE OJOS DILATADOS POR PARTE DE UN OFTALMÓLOGO PEDIÁTRICO

#### PARA LOS CLÍNICOS Y CUIDADORES:

- Se recomienda que un oftalmólogo pediátrico (no un optometrista) realice un examen inicial de ojos dilatados para evaluar el compromiso coriorretiniano

## MÁS INFORMACIÓN



• National CMV Foundation: [www.nationalcmv.org](http://www.nationalcmv.org)

• Centers for Disease Control and Prevention: [www.cdc.gov/cmvi/](http://www.cdc.gov/cmvi/)

• Luck, S. E., Wieringa, J. W., Blázquez-Gamero, D., Henneke, P., Schuster, K., Butler, K., ... & Vossen, A. C. (2017). Congenital cytomegalovirus: A European expert consensus Statement on diagnosis and management. *The Pediatric Infectious Disease Journal*, 36(12), 1205-1213.

• Rawlinson, W. D., Boppana, S. B., Fowler, K. B., Kimberlin, D. W., Lazzarotto, T., Alain, S., ... & van Zuylen, W. J. (2017). Congenital cytomegalovirus infection in Pregnancy and the neonate: Consensus recommendations for prevention, diagnosis, and therapy. *The Lancet Infectious Diseases*, 17(6), e177-e188.

# CMV Education/Advocacy

- <https://www.nationalcmv.org/about-us/advocacy> (National CMV Foundation)
  - Founded in 2014 by parents of children with cCMV
  - Established a clearinghouse for information, research, parent support and education, prevention, etc.
- [www.Acialliance.org](http://www.Acialliance.org) (American Cochlear Implant Alliance – ACIA)
  - Many children with cCMV receive cochlear implants
- American Academy of Pediatrics (AAP)
- American Academy of Audiology (AAA)
  - Position paper 2023
- Individual state and local groups (parents and/or professionals)
- American Speech, Language & Hearing Association (ASHA) has added it to their agenda for 2024
- American Academy of Otolaryngology – Head Neck Surgery



# CMV Resources

- National CMV Foundation – [www.nationalcmv.org](http://www.nationalcmv.org)
- The CDC - <https://www.cdc.gov/cmvi/index.html>
- American Cochlear Implant Alliance [www.acialliance.org](http://www.acialliance.org)
- American Academy of Audiology position paper – <https://www.audiology.org/practice-guideline/american-academy-of-audiology-position-statement-on-early-identification-of-cytomegalovirus-in-newborns/>
- [www.marchofdimes.org](http://www.marchofdimes.org)
- American Academy of Pediatrics – [www.aap.org](http://www.aap.org)

# Link to Reference List and Thank you!

- Please scan QR code for reference list or email [rmarin@adventisthealthcare.com](mailto:rmarin@adventisthealthcare.com)

THANK YOU

