

# The Colorado cCMV Work Group: An Advocacy Journey

Ted Maynard MD FAAP  
[ted@aapcolorado.org](mailto:ted@aapcolorado.org)

- A collaboration between the Colorado Chapter, American Academy of Pediatrics (AAP-CO) and Colorado Hands & Voices
- Pediatricians, neonatologists, pediatric ID and ENT, audiologists, health department and EHDI staff, and parents of children with cCMV
- Virtual meetings 2-3 times a year



# Why do we have a cCMV Work Group?

- cCMV is a major cause of congenital hearing loss
- Most cases of cCMV are missed and many children are not getting the care they deserve
- We can improve the identification and management of children with cCMV
- We can educate families on how to reduce the risk of CMV infection during pregnancy

All the children pictured on these slides are living with cCMV in Colorado; their parents have given permission to include their photos here.

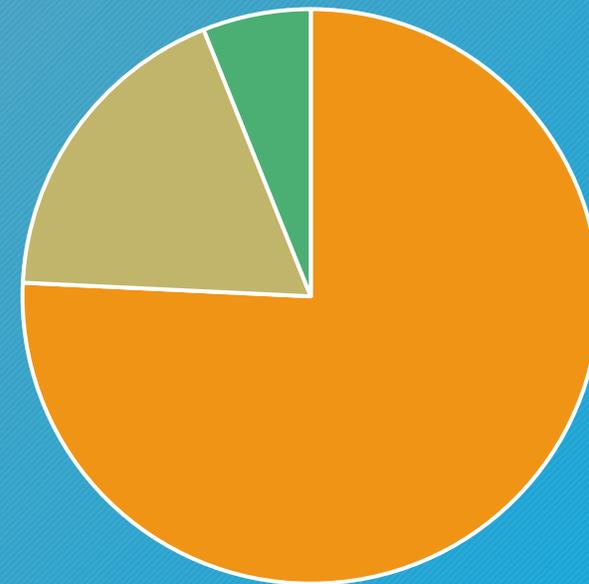


# Most cases were being missed in Colorado

$65,000 \times 0.5\% = 325$  births/year

20-25% with hearing loss, other problems: 65-80 children

Fewer than 20 were being diagnosed each year



- 250 missed, unaffected
- 60 missed, affected
- 20 identified

# It Matters Because Timely Diagnosis Leads To...

1. Ordering of additional testing
2. Consultation with an ID specialist to discuss antiviral treatment
3. Repeated hearing testing
4. Monitoring for developmental delay

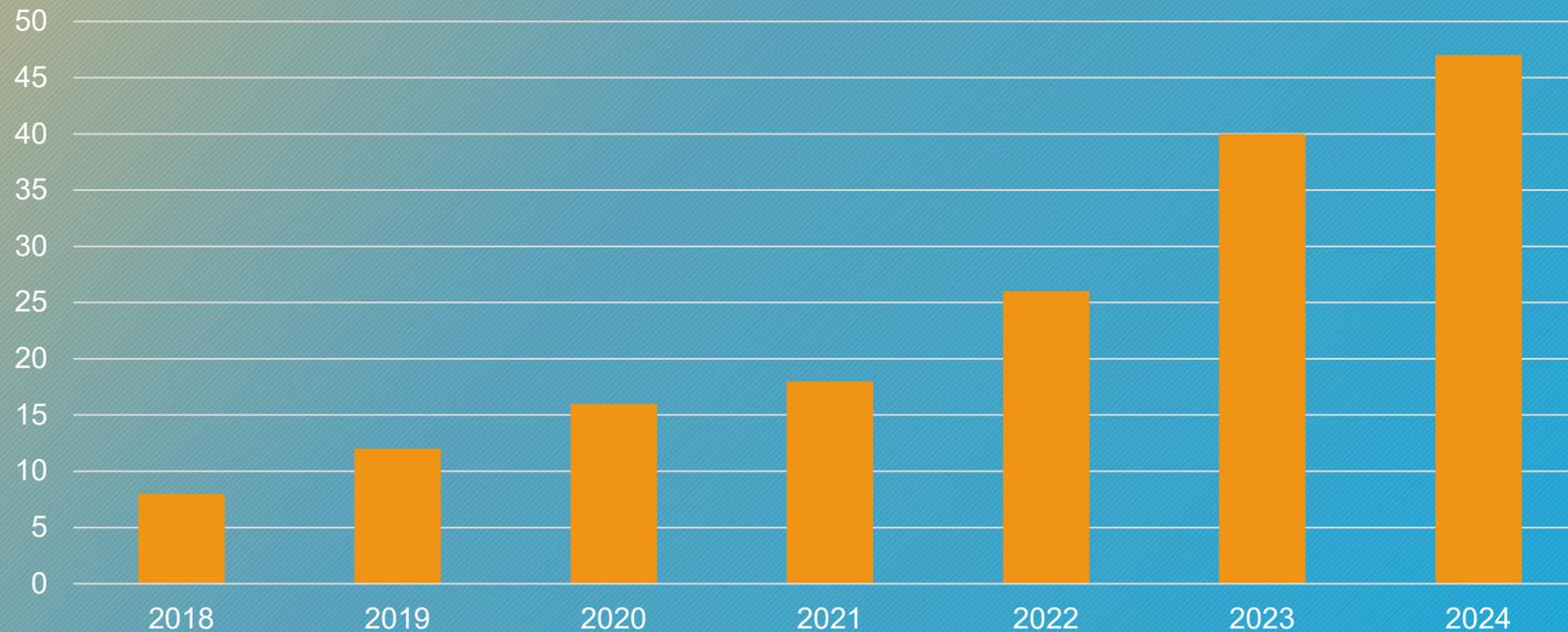


# It Matters Because Timely Diagnosis Leads To...

5. Referral to pediatric ophthalmology
6. Family awareness of potential progression
7. Family connection with support groups
8. Sparing the search for other causes of hearing loss



# Now more children are being identified



New patients with cCMV seen at the Children's Hospital ID Clinic

# Now we can track the children who are identified

- Colorado became a SET-NET site for cCMV in 2024, to improve surveillance and track every child to age 3
- cCMV was made a reportable condition in January 2025
- 35 infants have had urine test positive for CMV in the first 6 months of 2025

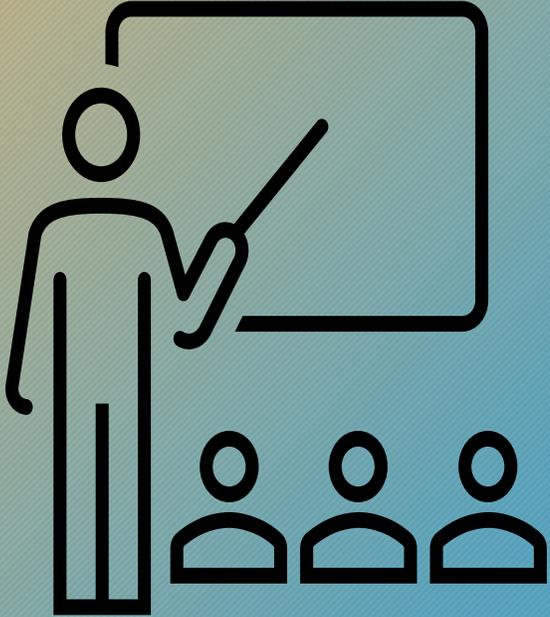


# The Colorado cCMV Work Group: Areas of Focus

- Creating a cCMV family support group
- Educating healthcare professionals who see newborns
- Promoting targeted screening
- Creating and sharing resources through webinars, conferences, website, social media
- Helping develop policies for healthcare systems



# The Colorado cCMV Work Group: Areas of Focus



- Creating a video on prevention of cCMV
- Educating child care workers
- Testing the newborn dried blood spot for CMV
- Making cCMV a reportable condition
- Improving the EHDI system:  
Early Hearing Detection and Intervention

# The Colorado cCMV Work Group: Timeline

2018: Newborn screening bill, family network

2019: Inviting participants, educating ourselves

2020: Improving information provided by the  
Colorado Department of Public Health & Environment (CDPHE)

2021: AAP-CO website: family handouts, lab list, flow chart

# The Colorado cCMV Work Group: Timeline

- 2022: Practice alerts in the electronic health record (EHR), detailed rationale for blood spot testing
- 2023: Prevention video, request cCMV be reportable
- 2024: Blood spot testing approved, SET-NET project, educating childcare workers and school nurses
- 2025: Social media for CMV Awareness month, clinical worksheet for primary care providers (PCPs)

# Educating Ourselves

- Literature searches
- Outreach to experts- Alabama, Baylor, Utah, Seattle, Minneapolis, CDC
- Public Health & Policy Conferences
- National CMV Foundation



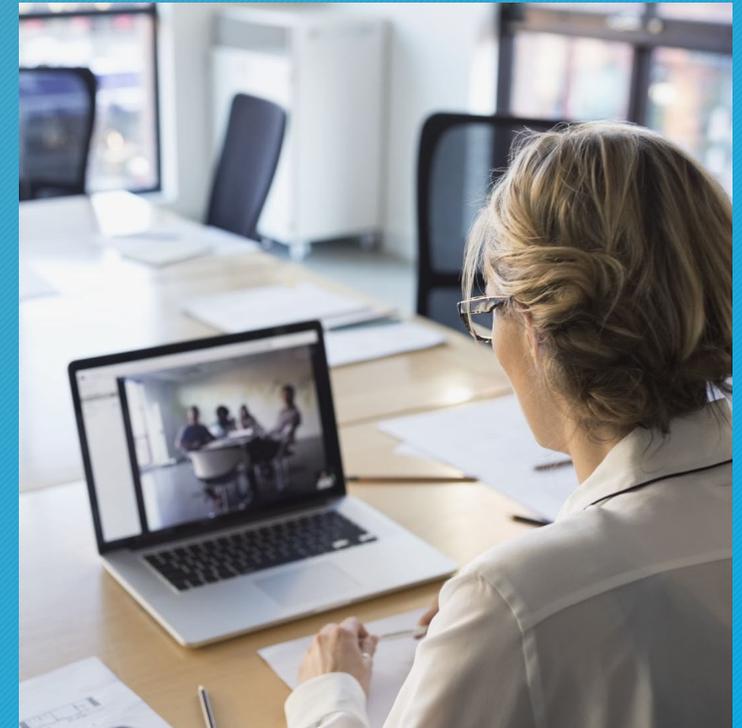
# cCMV Family Support Group



- Hosted by Colorado Hands & Voices
- Education, peer support, social events
- Family handouts, social media
- Building a better referral system so every family has parent-to-parent support

# Educating Healthcare Professionals

- Webinars at every birth location in Colorado
- Newsletter articles- AAP, family medicine, audiology, perinatal collaborative
- Emails - ENT, ID, neonatologists, hospitalists



# Educating Healthcare Professionals

- Conferences- AAP-CO CME, Children's Hospital, Colorado Academy of Audiology, EHDI
- Classes for pediatric and family medicine residents, audiology graduate students
- Training for hearing screeners
- Webinars for midwives, early intervention staff

## Colorado Chapter

American Academy of Pediatrics

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Children's Hospital Colorado

# A Family Story To Begin Each Meeting



## One mother's story: Anna's Journey

- No mention of CMV during pregnancy
- Microcephalic on 36 week ultrasound: “Wait and see”
- Born SGA (5 pounds at 40 weeks): No mention of CMV
- Failed three in-hospital hearing tests: No mention of CMV
- Failed ABR test at audiology clinic: No test for CMV

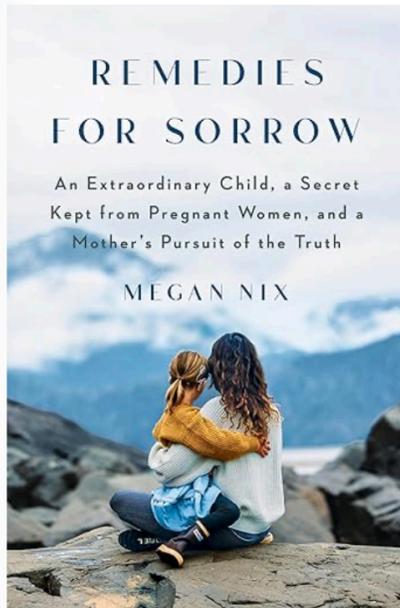
# A Family Story To Begin Each Meeting



## Diagnosis

- Pediatrician tested urine at 10 days old
- Positive result at 14 days old
- Started Valgancyclovir at 21 days
- Cochlear implants, mainstream in school

# A Family Story To Begin Each Meeting



Read sample

▶ Preview

## Remedies for Sorrow: An Extraordinary Child, a Secret Kept from Pregnant Women, and a Mother's Pursuit of the Truth

Hardcover – April 18, 2023

by [Megan Nix](#) (Author)

4.7 ★★★★★ (83) 4.4 on Goodreads 430 ratings

**Editors' pick** Best Biographies & Memoirs

[See all formats and editions](#)

**This "compulsively readable memoir...brings to light an issue that has been too long ignored...An immensely important book" (Emily Oster, *New York Times* bestselling author of *Expecting Better* and *Cribsheet*).**

**A story of a mother's fierce love for her exceptional child and her courageous journey to break the silence about a hidden risk to pregnant women: "both a beautiful family story and an urgent call to action... [A] moving, potentially life-altering book" (Robert Kolker, author of #1 *New York Times* bestseller *Hidden Valley Road*).**

After a seemingly uneventful pregnancy, Megan Nix's second daughter, Anna, was born very small and profoundly deaf. Megan and her husband, Luke, learned that Anna could have lifelong delays due to an infection from a virus they had never heard of: cytomegalovirus, or CMV, which Megan had unwittingly contracted from her toddler during pregnancy.

# Creating and sharing resources

## Why is my baby being tested for congenital CMV infection?



Your baby's doctor has recommended your baby be tested for a virus, or germ, called CMV. This stands for "cytomegalovirus." CMV is a common virus which is usually harmless, but CMV sometimes causes medical complications for newborns and young children. If a baby catches this virus before being born, it is called **congenital CMV**.

There are several reasons why a baby should be tested for CMV. The most common reasons are that: (1) the baby is small, or (2) the baby might have hearing loss.

This is the reason **your baby** is being tested:

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The test for CMV should be done within the first 3 weeks of life. The test is easy and painless, using either saliva or urine. Saliva is collected with a swab from the mouth and urine is collected in a plastic bag. The test result comes back in 3-7 days. The result is sent to the doctor who ordered the test in the hospital and the doctor who will be seeing your baby after you go home from the hospital.

Your baby's doctor is: \_\_\_\_\_

That doctor's phone number is: \_\_\_\_\_

If you have not been told the result of this test by the time your baby is 10 days old, call your baby's doctor to ask about the result. If the test shows your baby has congenital CMV infection, your baby's doctor will order more tests and talk to an expert about what to do next.

To learn more about CMV in newborns, you can look at these websites:

Center for Disease Control: [cdc.gov/cmV/resources](https://www.cdc.gov/cmV/resources)

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

If you want to talk with a family that has a child with congenital CMV, send an email to the Colorado cCMV Family Network at [cCMV@co-hv.org](mailto:cCMV@co-hv.org)



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# Creating and sharing resources

¿Por qué mi bebé se está haciendo la prueba para la **infección congénita por CMV**?



El médico de su bebé ha recomendado que se haga la prueba de un virus, o germen, llamado CMV. Esto significa "citomegalovirus". El CMV es un virus común que generalmente es inofensivo, pero el CMV a veces causa complicaciones médicas para los recién nacidos y los niños pequeños. Si un bebé contrae este virus antes de nacer, se llama **CMV congénito**.

Hay varias razones por las que un bebé debe hacerse la prueba de CMV. Las razones más comunes son que: (1) el bebé es pequeño, o (2) el bebé puede tener pérdida auditiva (sordera).

Esta es la razón por la que **su bebé** está siendo examinado:

\_\_\_\_\_

La prueba para el CMV debe realizarse dentro de las primeras 3 semanas de vida. La prueba es fácil y sin dolor, porque se toma de la saliva o la orina. La saliva se recoge con un hisopo de la boca y la orina se recoge en una bolsa de plástico. El resultado de la prueba regresa en 3-7 días. El resultado se envía al médico que ordenó la prueba en el hospital y al médico que verá a su bebé después de que usted se vaya a casa del hospital.

El médico de su bebé es: \_\_\_\_\_

El número de teléfono de ese médico es: \_\_\_\_\_

Si no le han informado el resultado de esta prueba para cuando su bebé tenga 10 días de edad, llame al médico de su bebé para preguntar sobre el resultado. Si la prueba muestra que su bebé tiene una infección congénita por CMV, el médico de su bebé ordenará más pruebas y hablará con un experto sobre qué hacer a continuación.

Para obtener más información sobre el CMV en los recién nacidos, puede consultar estos sitios de internet confiables:

Centro para el Control de Enfermedades: [cdc.gov/cmvr/resources](https://www.cdc.gov/cmvr/resources)

Fundación Nacional CMV: [nationalcmv.org](https://www.nationalcmv.org)

Si desea hablar con una familia que tiene un hijo con CMV congénito, envíe un correo electrónico a la Red familiar de cCMV de Colorado en [cCMV@co-hv.org](mailto:cCMV@co-hv.org)



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# We invite you and your child with congenital CMV to join the Colorado cCMV Family Network



## 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. Many of us catch CMV as young children and the virus is prevalent in the saliva of toddlers. 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 infection, it is called congenital CMV (cCMV).

- 1 out of 200 babies is born with cCMV infection
- 3 out of 4 babies born with cCMV will never have any health issues
- 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 issues with seeing or development

## 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 (*see graphic on second side*).

## If your baby is diagnosed with cCMV, where can you find support?

The Colorado cCMV Family Network can benefit your family in several ways. By joining, you can:

1. Connect with other families who have children with cCMV
2. Choose to meet with a Parent Guide who can share their CMV experience and resources
3. Join a private Facebook group for Colorado families with cCMV
4. Visit the [National CMV Foundation](#), [CDC](#), and [AAP Colorado](#) websites to learn more
5. Learn more about cCMV so you can advocate for the best medical care for your child
6. Participate in building a unique community here in Colorado for children with cCMV

To join the Colorado cCMV Family Network, visit  
<http://tiny.cc/COcCMVFamilyNetwork>,  
email [cCMV@COHandsandVoices.org](mailto:cCMV@COHandsandVoices.org), or call 720-598-COHV (720-598-2648)



Grants to support the establishment of the Colorado cCMV Family Network have been provided by the American Academy of Pediatrics (AAP) and the Colorado Early Hearing Detection and Intervention (EHDI) Alliance. The Colorado cCMV Family Network is a collaboration with Colorado Hands & Voices, an organization for families raising children who are deaf or hard of hearing. The Colorado cCMV Family Network includes families who have kids with typical hearing.

*"If we don't connect families to each other and to cCMV information, they can't connect the dots about their children's health. They need to find their tribe."*—Luke and Megan, parents

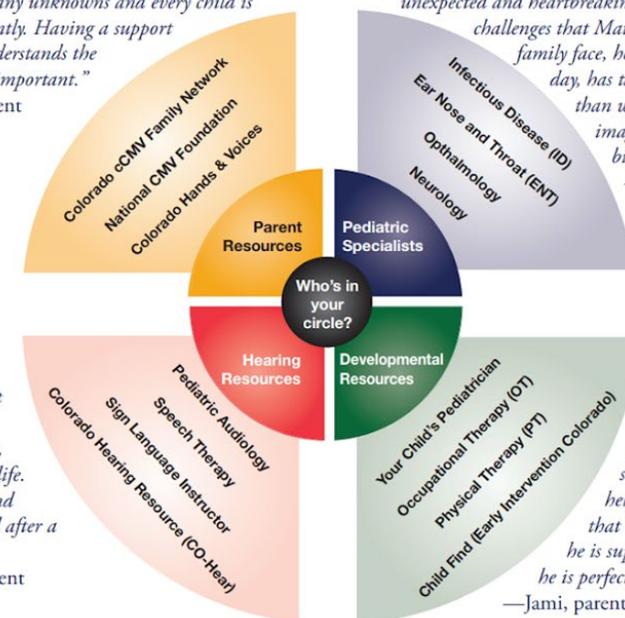


*"Having a child diagnosed with cCMV can be scary. There are so many unknowns and every child is affected differently. Having a support system that understands the uncertainty is important."*  
—Amber, parent

*"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 more every day, has taught us more than we could have ever imagined, and is the biggest blessing."*  
—Erin, parent

*"A diagnosis changes a lot of things. Don't ever let that define your life, or your child's life. There is love and life within and after a diagnosis."*  
—Ashley, parent

*"It's ok to be broken and cry, and ask 'why us?' Finding support from families similar to mine helped me remember that my child is who he is supposed to be and he is perfect!"*  
—Jami, parent



## To join the Colorado cCMV Family Network:

- Visit <http://tiny.cc/COcCMVFamilyNetwork>
- Email [cCMV@COHandsandVoices.org](mailto:cCMV@COHandsandVoices.org)
- Call 720-598-COHV (720-598-2648)
- OR scan the QR code to the right





Who's in your circle?

Graphic included in a handout given to a family if a baby tests positive for cCMV

# Promoting Targeted Screening

- A quick reference for all those caring for newborns
- Accessible on [aapcolorado.org](http://aapcolorado.org) with links to parent handouts



## How to Screen for Congenital CMV

A clinical guideline from the Colorado Chapter, American Academy of Pediatrics

### ASSESS for Risk Factors:

1. Mother diagnosed with CMV infection during pregnancy
2. Small for gestational age: birth weight <10th percentile
3. Microcephaly: head circumference <10th percentile
4. Low birth weight or preterm: birth weight <2000 grams
5. Did not pass the newborn hearing screen (one or both ears)
6. Fetal hydrops or ascites, abdominal calcifications, or thickened bowel on prenatal ultrasound
7. Hepatomegaly, splenomegaly, or elevated liver function tests (AST or ALT >100 U/L or direct bilirubin >1.0 mg/dL)
8. Abnormal brain imaging
9. Persistent thrombocytopenia (platelets <100,000/mm<sup>3</sup>)
10. Petechial or "blueberry muffin" rash
11. Retinitis or other eye finding



### SCREEN if any risk factors are identified:

1. Order Qualitative CMV PCR on urine or saliva, with a diagnosis code indicating the risk factor
2. If saliva CMV PCR is positive, order urine CMV PCR to confirm
3. Give the family the handout: *Why Is My Baby Being Tested for CMV?* (English [link](#), Spanish [link](#)).
4. Add the diagnosis **Screening for CMV** to the Problem List



### If urine CMV PCR is POSITIVE:

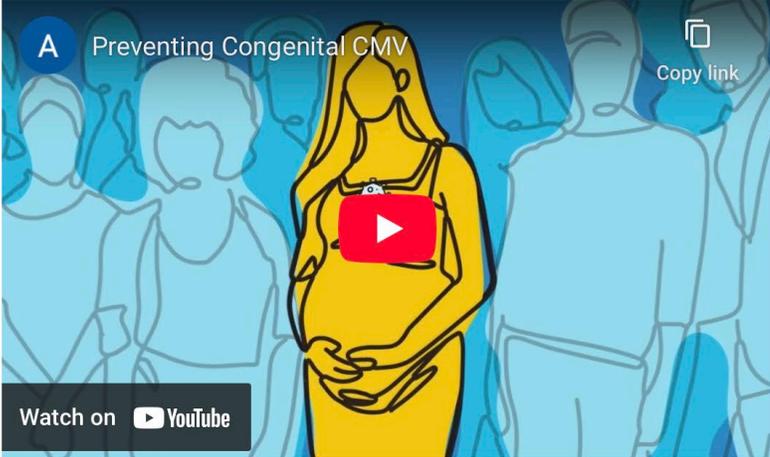
1. Add the diagnosis **Congenital CMV Infection** to the Problem List
2. Give the family the handout *We invite you and your child with cCMV to join the Colorado cCMV Family Network* (English [link](#), Spanish [link](#))
3. Discuss the case with a Pediatric Infectious Disease specialist
4. Order a CBC with differential and liver function tests
5. Order brain imaging, either head ultrasound or brain MRI
6. Refer to a pediatric ophthalmologist, to look for CMV retinitis
7. Refer to Early Intervention, to monitor for developmental delays
8. Refer to Pediatric Audiology and Pediatric ENT
9. For more information, go to [aapcolorado.org](http://aapcolorado.org)

# cCMV Resources: the AAP-CO website

About Membership Events Secure Their Future Resources Donate

HOME / RESOURCES / CMV

## Special Topic: Congenital CMV Infection



Watch on YouTube

**NEW RESOURCES!**

- [CMV Clinical Care Worksheet](#)
- [Family ACTION Sheet](#)
- [CMV is now a reportable condition \(flyer 1 and flyer 2\)](#)

# cCMV Resources: the AAP-CO website

## Information about Congenital CMV and Hearing

- [What is CMV?](#) (National CMV Foundation)
- [CMV and Congenital CMV Infections](#) (CDC)
- [Early Hearing Detection and Intervention Resources for Families, Professionals, and the Community](#) (Colorado EHDI Alliance)
- [Family Resources](#) (Colorado Hands & Voices)
- [Colorado Newborn Hearing Screening Program](#) (CDPHE)
- [Medical Evaluation for Newborns with Hearing Loss](#) (Colorado Newborn Hearing Screening Program)

## Handouts

- [Why is My Baby Being Tested for congenital CMV infection?](#)
- [¿Por qué mi bebé se está haciendo la prueba para la infección congénita por CMV?](#)
- [For The Family When A Child in Colorado Has Been Diagnosed With Congenital CMV](#)
- [Te invitamos para unirse a la Red Familiar de cCMV de Colorado](#)
- [Babies born with Congenital CMV infection](#) (CDC)
- [Congenital CMV and Hearing Loss](#) (CDC)
- [Family handout on Unilateral Hearing Loss, English](#)
- [Family handout on Unilateral Hearing Loss, Spanish](#)

## Targeted screening

- [Information About Congenital CMV for Healthcare Professionals Who Care for Newborns](#)
- [Flow Diagram: How to Screen for Congenital CMV](#)
- [Targeted Screening for Congenital CMV](#)
- [Labs Offering Testing for CMV in Newborns](#)
- [Procedure for ordering a CMV test on the newborn dried blood spot](#)

## Videos

- [AAP-CO & Project Firstline: Preventing CMV Infection during Pregnancy](#)
- [Congenital CMV: A Webinar for Early Intervention Providers](#)
- [Congenital CMV: A Webinar for Midwives in Colorado](#) (Access Passcode: UG#\$4N\*O)
- [Alto CMV Arizona: Manos y Voces Arizona](#) (Spanish)
- [Information about cCMV in American Sign Language](#)
- [Medscape: Perspectives on cCMV](#)

## Research

- [Baylor College of Medicine CMV Research Group](#)
- [University of Alabama Birmingham](#)
- [The University of Minnesota, Schleiss Laboratory](#)
- [Sallie Permar, M.D., Ph.D.](#)

Let's break for a video

# Educating childcare workers and school nurses



- Monthly meetings with childcare educational specialists at CDPHE
- Updated infectious disease guideline
- Added CMV to required annual training
- Annual webinar for childcare workers and school nurses

## 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

# Promoting development of policies in healthcare systems

- Contact the right people- department leaders, quality improvement staff, nurse managers, lab
- Order sets, standing orders
- Best Practice Advisory in the EHR
- Designated person responsible for positive tests



# Advocating for testing the newborn dried blood spot for CMV

- Joined the newborn screening stakeholder group
- Educated the group on testing the dried blood spot for CMV
- Organized testimony for the Board of Health: pediatricians, experts, parents



# Testing the newborn dried blood spot for CMV in Colorado



- Targeted CMV testing approved March 2024
- Estimated 20% of newborns:
  - those who do not pass the hearing screen
  - have no screen reported by day 10 of life
  - have a birth weight below the 10%ile
- Testing will begin fall 2025

# Testing the newborn dried blood spot for CMV in Colorado

- Developing messaging for PCPs
- Contracted support to guide PCPs
- Emphasizing continued targeted screening
- Created a clinical care worksheet for providers







# Social Media Campaign for CMV Awareness Month

- AAP grant for Chapter coordination with the SET-NET project
- Targeted pediatric providers and families with children
- Interactions in 1 month:
  - Impressions: 41,332
  - Link clicks: 1,100
  - Reach: 26,901
  - Reactions: 75
  - Comments: 2
  - Shares: 5



**The Colorado Newborn Screening Program is adding a new condition in 2025 — Congenital CMV**

This is a common virus that can cause hearing loss and other health problems and affects 1 in 200 babies.

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**COLORADO**  
Department of Public Health & Environment



**Congenital CMV is now a reportable condition in Colorado**

Positive CMV testing in a child younger than 1 year of age (all specimen types) must be reported to CDPHE within four days; labs must also report all urine CMV results (positive or negative).\*

\*Only labs who report electronically are required to report negative urine results to CDPHE

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# Policy change versus legislation

- Legislation in 2018 mandated that CDPHE educate providers on cCMV
- Many states have mandated CMV testing for those who do not pass the newborn hearing screen
- Educating providers and changing behavior is hard
- Colorado has favored working with state agencies to improve policy, rather than new legislation



# Grant support

- AAP Family Engagement
- Colorado Commission for the Deaf, Hard of Hearing and DeafBlind
- Colorado EHDI Alliance
- AAP/CDC Project Firstline
- AAP SET-NET Coordination



# Colorado cCMV Work Group: Participants

## Leaders

Ted Maynard, Crested Butte  
Kirsten Nelson, Colorado Springs  
Jami Fries, CO H&V Director

## Pediatricians

Leisha Andersen, Denver  
Maureen Cunningham, Aurora  
Christine Gold, Aurora  
Katie Joy, Grand Junction  
Kelly Miller, Durango  
Patrice Whistler, Grand Junction

## Neonatologists

Patricia Hagan, Denver  
Madoka Hayashi, Denver  
Lilliam Samour PA, Denver  
Dan Satterwhite, Fort Collins  
Rebecca Shay, Aurora  
Erica Wymore, Aurora  
Rachel Wright, Denver



# Colorado cCMV Work Group: Participants

## Pediatric ENT

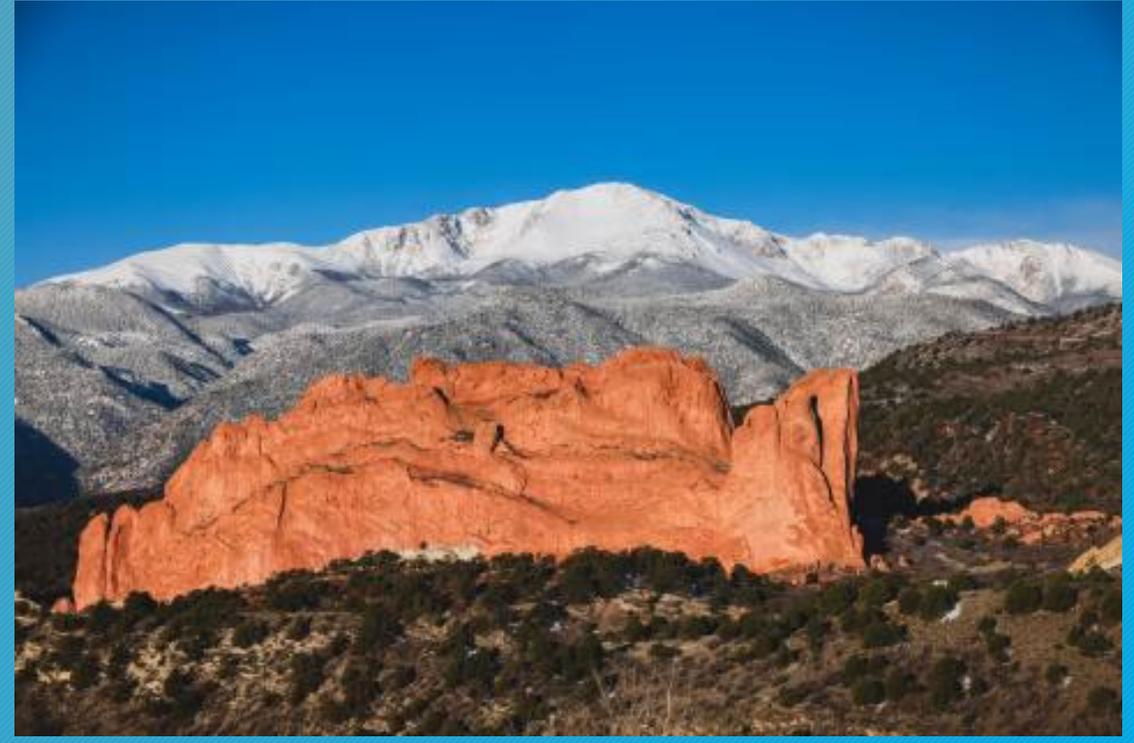
Alison Dobbie, Colorado Springs  
Brian Hermann, Aurora  
David Kelsall, Denver  
Ryan Mitchell, Denver  
Tammy Wang, Denver  
Patricia Yoon, Aurora

## Pediatric ID

Mark Abzug, Aurora  
Shannon Hughes PA, Aurora

## Audiologists

Becky Awad, Aurora  
Kate Geisen, Denver  
Karen Hendrick, Aurora  
Elissa Jodon, Aurora  
Dawn O'Brien Taylor, Colorado Springs  
Lauren Pontis, Boulder  
Stacy Stiell, Aurora



# Colorado cCMV Work Group: Participants

- Parents Elaine Angelo  
Ashley Mains Espinosa  
Sara Kennedy  
Amber Mustain  
Megan Nix Weidel  
Erin Swetnam
- CDPHE Greg Bonn, Lab  
Alexis Burakoff, SET-NET  
Kendra Croak, Lab  
Jacqueline Denning, SET-NET  
Kristen Dynes, Project Firstline  
Leanne Glenn, Newborn Hearing Screening  
Therese Pilonetti, Educational Specialist  
Briana Sprague, SET-NET
- EHDI Arlene Stredler-Brown



# Colorado cCMV Work Group: Participants

D/HH support staff, Colorado School for the Deaf and Blind

Jill Cimino  
Kelly Doolittle  
Kirsten Gardzelewski  
Robin Getz  
Annette Landes  
Elaine Kim McCarty  
Sarah Mullervy  
Ashley Renslow  
Lynn Wismann  
Dee Woodard

Nurse Managers at many birth locations

Wyoming EHDI staff

Bradley Bakken  
Meg Callahan  
Sarah Fitzgerald  
Carleigh Soule

