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**Phoenix
Children's**

CMV and the Medical Home, in partnership with Midwestern University and Phoenix Children's Hospital

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Kathleen Muldoon, PhD

Kathleen M. Muldoon, Ph.D. is an anthropologist and Professor of Anatomy at Midwestern University, Glendale. She is the course developer and director of Humanity in Medicine and the facilitator training course Medical Improv. Through her experiences with disability, she became interested in science communication, and the effectiveness of professional education on public health knowledge, empathy, and humanity in medicine. She has given more than 100 research seminars and outreach workshops nationally and internationally. Her work has been featured on National Public Radio, USA Today, and several podcasts. Dr. Muldoon has served or led the Arizona College of Osteopathic Medicine Curriculum Taskforce on Diversity, as well as a member of several academic and state committees relating to diversity advocacy and disability services. She is a consultant for Moderna and the University of Arizona College of Medicine, Phoenix, and the Chair of the Scientific Advisory Committee at the National CMV Foundation.



Disclosures

- **Presenter Disclosure: Financial:** Harold Magalnick is employed by the Division of Developmental Disability. He received an honorarium for this course. **Non-financial:** Harold Magalnick has no relevant non-financial relationships to disclose. **Financial:** Kathleen Muldoon is employed by Midwestern University, Glendale. In lieu of accepting an honorarium, a donation has been made to the Ear Foundation of AZ. **Non-financial:** Kathleen Muldoon has no relevant non-financial relationships to disclose.
- **Content Disclosure:** This learning event does not focus exclusively on any specific product or service.
- **Sponsor Disclosure:** This course is presented in partnership with Midwestern University and Phoenix Children's Hospital.



Learning Outcomes

After this course, participants will be able to:

- Describe the incidence, prevalence, and complications that can be present with a CMV diagnosis.
- Name the diagnostic criteria to be Division of Developmental Disability (DDD) eligible and to maintain DDD eligibility.
- Discuss CMV advocacy.

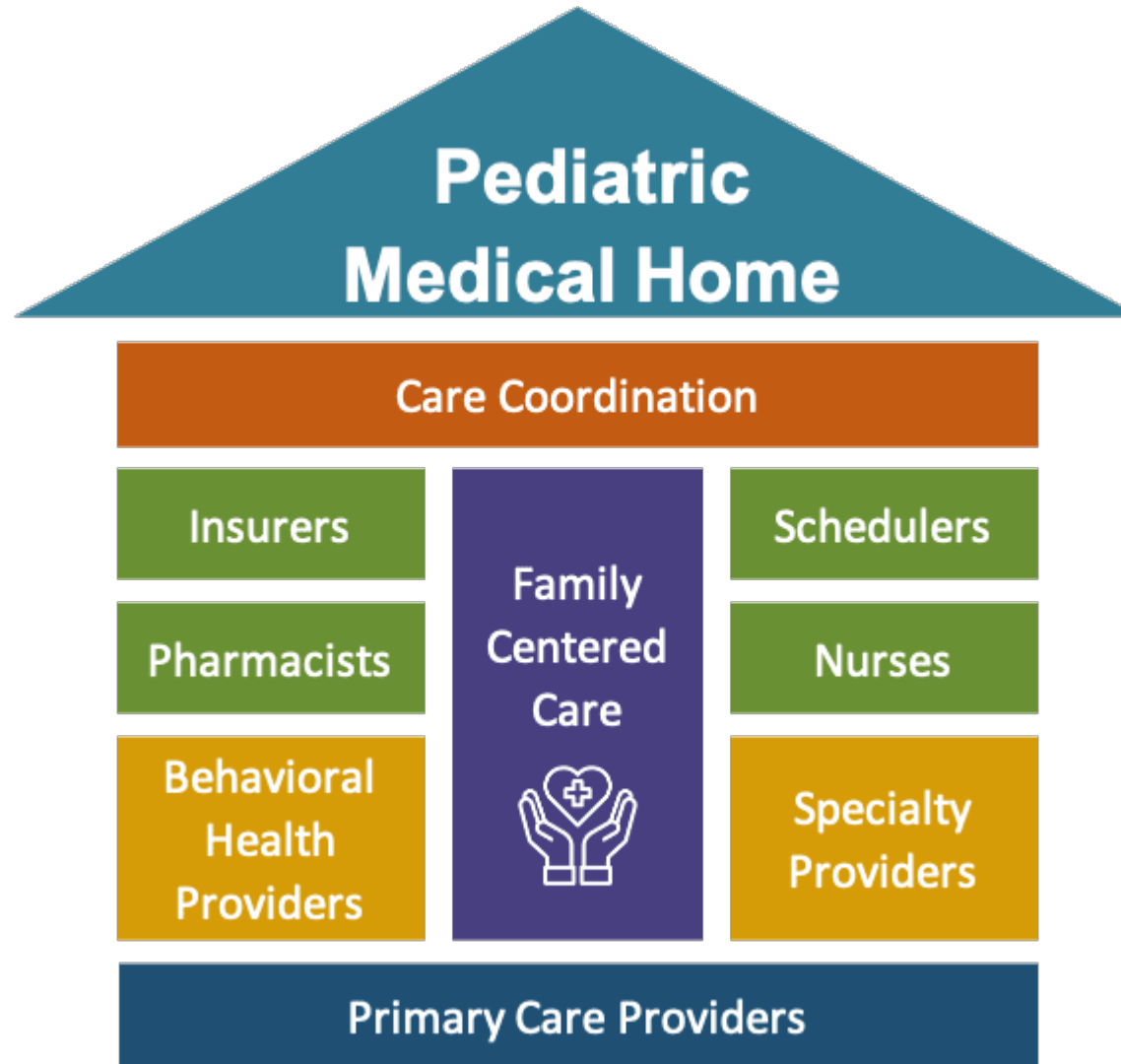
Scope

- In the US, nearly 1 in 3 children are already infected with Cytomegalovirus (CMV) by 5 years of age. Over $\frac{1}{2}$ of adults have been infected with CMV by the age of 40. Once CMV is in a person's body, it stays there for life and can reactivate. A person can also be reinfected with a different strain. Most people with CMV infection have no symptoms and aren't aware that they have been infected.
- About 1 out of every 200 infants is born with congenital CMV infection. Around 1 in 5 babies born with congenital CMV infection will have long-term health problems.

Scope

- A pregnant women can pass CMV to her fetus following primary infection, reinfection with a different CMV strain, or reactivation of a previous infection. Risk of transmission for a primary infection is 30 to 40% in the first and second trimester, and 40-70% in the third trimester. The risk of transmission following non-primary infection is much lower at 3%. The risk of complications to the fetus is greatest if a primary infection occurs during the 1st trimester.
- Babies born with CMV can have brain, liver, spleen, lung, and growth problems. The most common long-term health problem in babies born with congenital CMV infection is hearing loss, which may be detected soon after birth or may develop later in childhood.
- About 10% of infants with congenital CMV infection are symptomatic at birth, which include: Rash, jaundice, microcephaly, low birth weight, IUGR, hepatosplenomegaly, seizures and retinitis. About 40-60% of infants born with signs of congenital CMV disease at birth will have long term health conditions.
- Of the 90% of infants with asymptomatic congenital CMV infection, 10-15% will develop long-term disabilities.

What is the medical home?



Home and community-based services for children with special healthcare needs

- Medicaid is the primary payer for HCBS and plays a significant role in providing children with special health care needs the long-term services and supports (LTSS) they need to live at home with their families.
- Medicaid/CHIP covers almost half of all U.S. children with special health care needs, though the share varies by state.
- The Individuals with Disabilities Education Act (IDEA), Part C, covers early intervention services, which help eligible infants and toddlers (younger than age 3 years) with developmental delays and disabilities and their families to support children's development. Early intervention focuses on helping infants and toddlers learn the skills that children typically develop during the first 3 years of life.
- In some states, CMV is considered an eligible “at risk” diagnosis for referral for early intervention services

Role of the Medical Home in Congenital CMV:

- Identification usually occurs in the newborn nursery and infants come into the office already diagnosed. Acquiring all the medical records especially hearing testing done before infant discharge.
- If the infant is in the need of services, help with coordination of their appointments.
- Make sure that they have enrolled with Arizona Early Intervention Program (AZEIP). Children can continue with AZEIP services until 3 years of age when they must transfer to a developmental preschool for continued services (OT, PT, speech and developmental help).

Role of the Medical Home in Congenital CMV:

- Even if they are enrolled with AZEIP, they can still apply for the Division of Developmental Disability (DDD). In order to qualify for DDD an individual must be diagnosed with 1 of the 5 DDD qualifying diagnosis. They are: Cerebral Palsy, Epilepsy, Autism, Cognitive Intellectual Disability or Downs Syndrome. For children younger than 6 years they can be DDD eligible if they are At Risk for one of the DDD eligible diagnosis.
- Anyone can apply for DDD eligibility, but not all who apply qualify for the full range of DDD services. In order to qualify for the full range of services you must also have substantial functional limitations in 3 of 7 major life activities:
 - Self-care
 - Receptive and Expressive Language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for Independent Living
 - Economic Self-Sufficiency

Role of the Medical Home in Congenital CMV:

- Children under the age of 6 may be eligible for services if there is a strongly demonstrated potential that the child is or will have a developmental disability as determined by the appropriate tests. In the absence of other qualifying circumstances, children with the following conditions are not eligible for services:
 - Congenital Heart Disease
 - Muscular Dystrophy
 - Orthopedic Disorders
 - Speech Delay Involving Only Intelligibility
 - Significant Auditory Impairments
 - Significant Visual Impairments

Role of the Medical Home in Congenital CMV:

- Arizona Long Term Care (ALTCS). Once you have been determined to be eligible for DDD you can apply for ALTCS. Having DDD eligibility but not having ALTCS limits the client to just have coordination of care benefit services from DDD. If the client qualifies for ALTCS that opens many service opportunities beyond what might be available from their primary insurance.
- If the client is not DDD eligible, they might be ALTCS eligible through a different program called Elderly or Physically Disabled (EPD). This gives the client ALTCS eligibility even when they don't have/or are at risk for 1 of the 5 DDD eligibility criteria.

Role of the Medical Home in Congenital CMV:

- After 3 years of age the child transfers from AZEIP to Department of Education (DOE) for many of their service needs. The Medical Home can help with the transition process to make sure that what is educationally required gets paid through DOE dollars and not through their medical dollars. An Individual Educational Program is written every year to show what services the child will be receiving for the year and what can be expected as far as their educational progress. The full evaluation to see that they qualify for Special Educational services must be done every 3 years. These evaluations should be made available to the Medical Home. Coordination of services between the educational community and the medical community should be facilitated through the child's Medical Home.
- At 6 years and at 18 years a child must be re-evaluated to see that they still qualify for DDD services. The child's Medical Home can help to make sure that the child receives the evaluations required so that services do not get interrupted.

cCMV Advocacy (USA)

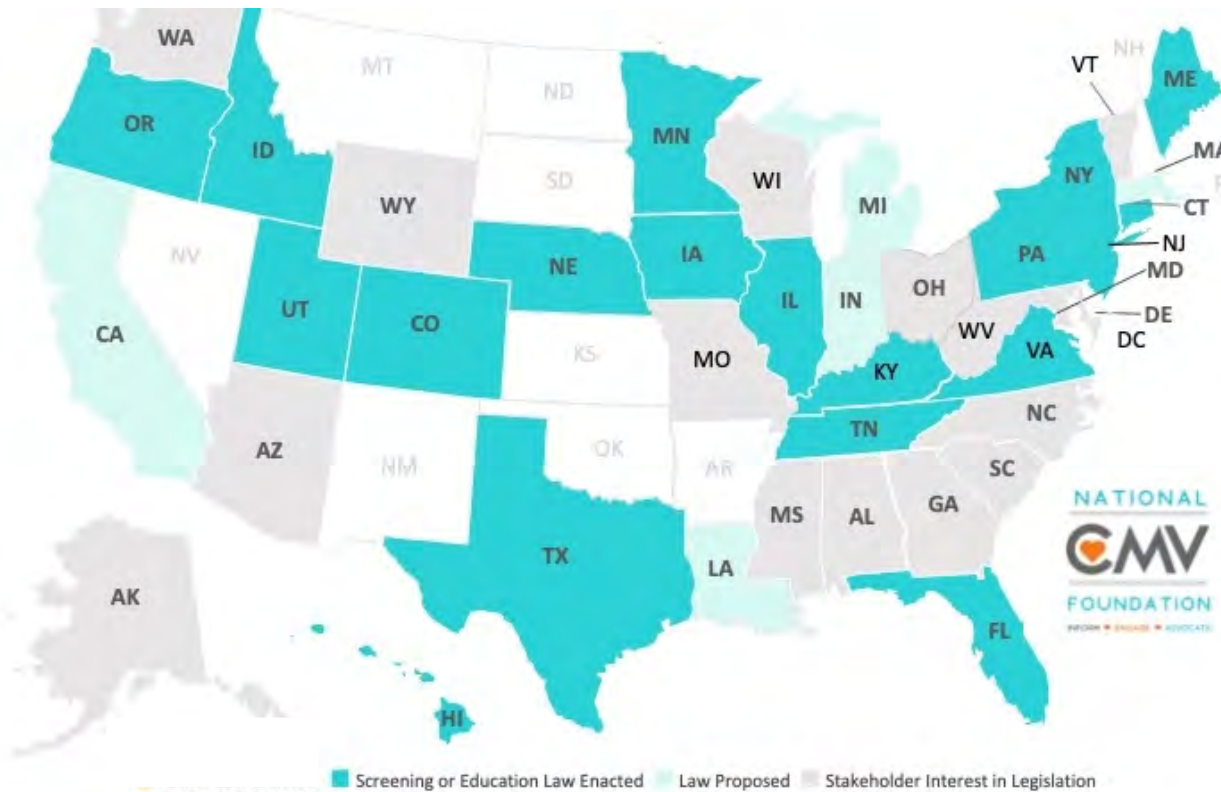
April 2023

2013: Utah passed the first CMV Public Education and Hearing-targeted [HT]-cCMV Testing

2015: NCMVF founded by six mothers and partnering ENTs, audiologists, and infectious disease doctors

2021: Minnesota passed The Vivian Act for CMV Public / HCP education and Universal Testing

2023: CMV legislation has passed in 18 states, with others pending – including states working to establish a health commission to investigate CMV public education and testing



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More children are being diagnosed early...
what are the implications for care management?

Babies born with cCMV may have lifelong disabilities

Born with symptoms of being sick
(10% of babies born infected with cCMV;
of these, ~75% will develop long-term
disability)

Born with NO symptoms of being sick
(90% of babies born infected with cCMV;
of these, 10-15% will develop long-term
disability)

Death	Medically Complex	Multiple disabilities	Developmental Delays	Deaf	None
Miscarriage, Stillbirth, Infant or child loss	Cerebral palsy, Seizures, Failure to thrive, Hearing differences, Vision difference	Cerebral palsy, Hearing differences, Vision differences	Cognitive delays, Learning difficulties, Feeding/sleeping issues, Vision differences, Hearing differences	Hearing differences, Communication and learning differences, Vision differences	No apparent developmental differences or disabilities

Severe

Moderate

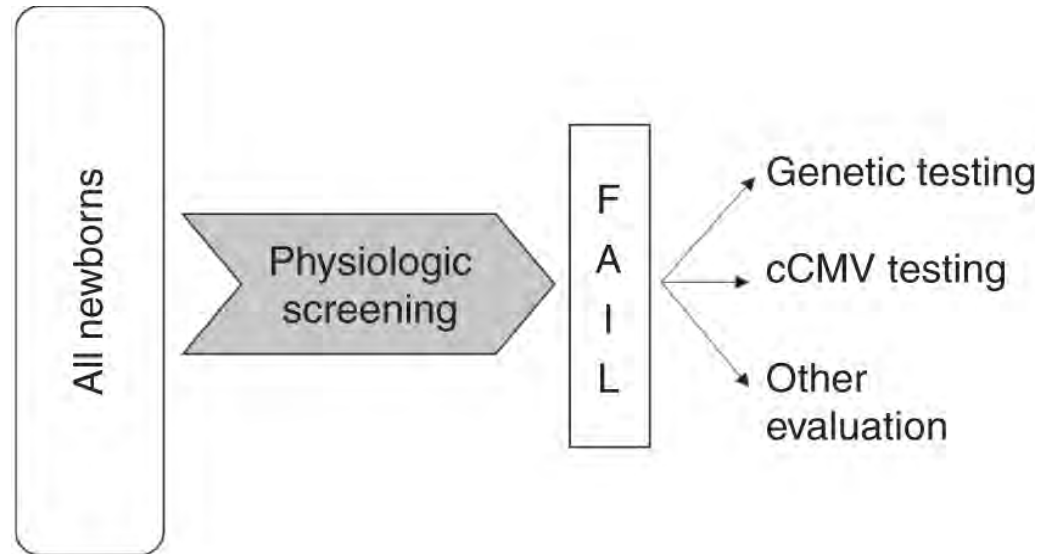
Mild



cCMV and the Universal Newborn Hearing Screen (NBHS)

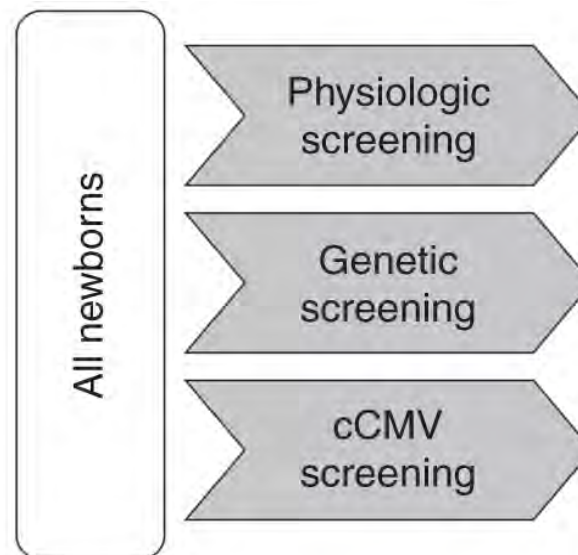
Current NBHS

(Hearing targeted
[HT] for cCMV
added on in some
states)



Proposed comprehensive NBHS

(Universal for
cCMV)



Special considerations for cCMV management & the medical home

cCMV is a leading cause of

deafness

even in babies
born WITHOUT
symptoms.



Hearing differences (deafness) may be present at birth or detected by the NBHS.

Hearing thresholds can change later in childhood.

Hearing thresholds may be asymmetric.

Babies with cCMV may have hearing differences in one ear (unilaterally deaf or hard of hearing [D/HH]) or both ears (bilateral).

Children born with cCMV (with or without a demonstrated hearing difference) benefit from services and monitoring by a **health care team** that centers the patient, pediatrician, and audiologist.



Special considerations for medical management of cCMV-related hearing differences The role of audiologists

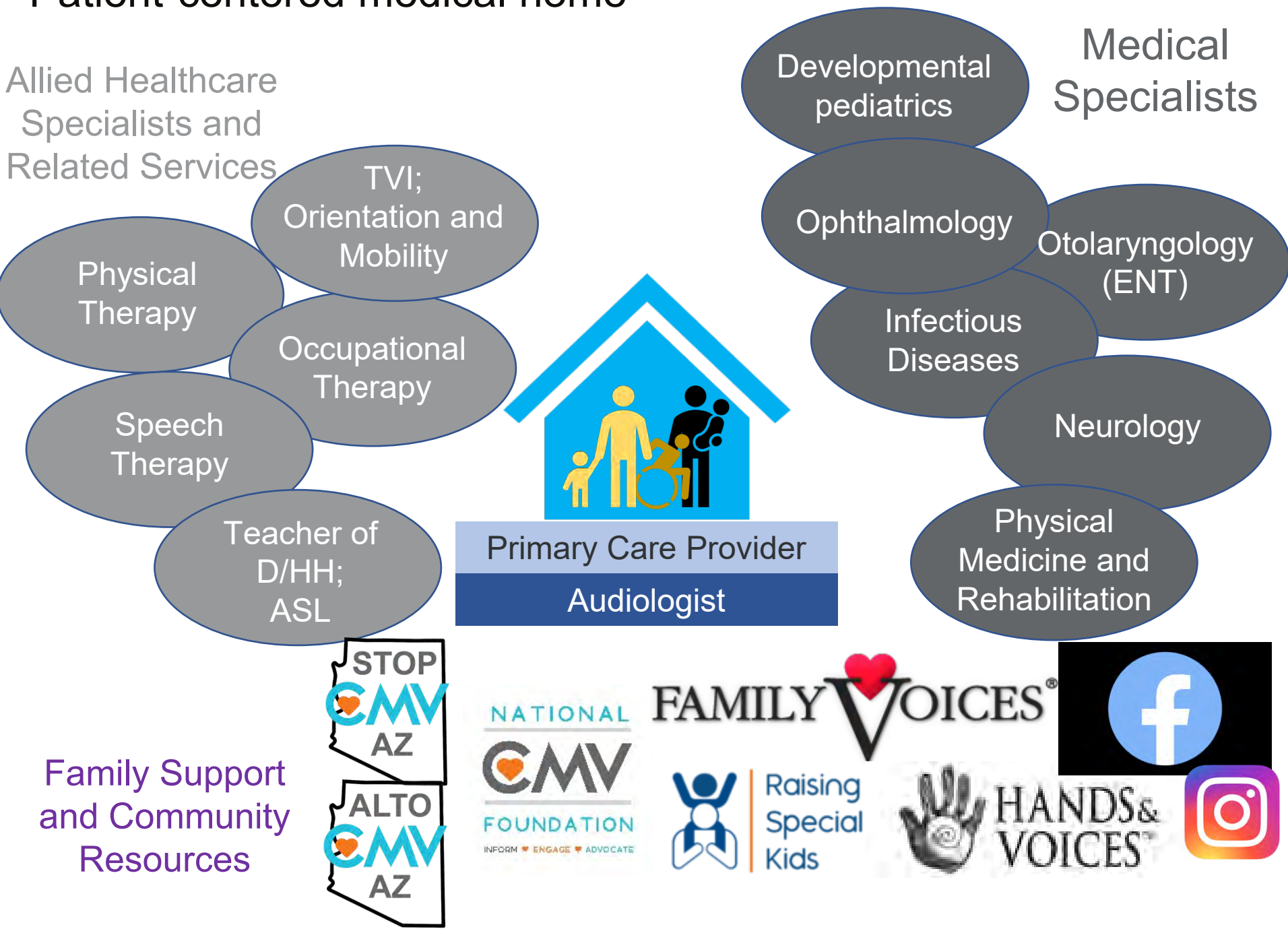
- cCMV **Sensorineural hearing loss (SNHL)** that initially presents as unilateral can progress to bilateral
- Rapid progression of SNHL is likely
- If SNHL is unilateral, the ear with the greatest hearing difference may progress earlier and more quickly than the ear with hearing in typical ranges
- cCMV affects the vestibular system, as well as the auditory system
 - Balance should be monitored
 - Audiologists should include screening for vestibular function
 - (e.g., monitoring movement/physical development milestones) at each follow up visit
 - If concerns identified, children should be referred to vestibular specialists (otolaryngologists, vestibular audiologists, physical therapists)

Patient-centered medical home

- Because cCMV does not have uniform or consistent long-term outcomes, the care team should be individualized to meet each patient and family's unique needs.
- Babies diagnosed with symptomatic cCMV are at a higher risk of developing more severe sequelae as a result of their infection and may need larger care teams due to medical need



Patient-centered medical home





Parent Guide and Care Coordination



NATIONAL ACADEMY
FOR STATE HEALTH POLICY

Committed to improving the health and well-being of all people across every state.

[HOME](#)

REPORT / 10-16-20

National Care Coordination Standards for Children and Youth with Special Health Care Needs

<https://nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/>



Congenital CMV is preventable.

CMV can **survive on objects**,
such as hands, faces, toys, pacifiers, teething rings, food, plates, cups, straws, forks,
spoons, and knives
long enough to be **transmitted between people by touching surfaces**.

Taking these actions while pregnant will protect your baby from ALL germs:



Wash hands often
with soap & water,
especially after changing
diapers, wiping faces,
or touching objects
that have been drooled on.



**Give hugs
& kisses on the
forehead or
top of head to
avoid drool.**



**Clean and disinfect
surfaces
& objects,
such as toys,
often.**



**Eat only your
own
food & drink.**



**Use only your
own
cup, plate,
straws, forks,
spoons & knives.**



**Use only your
own
toothbrush.**



YOU can **prevent cCMV** from affecting someone you love by practicing healthy pregnancy tips to **avoid ALL GERMS**



ARIZONA DEPARTMENT
OF HEALTH SERVICES

ARIZONA BIOMEDICAL RESEARCH COMMISSION



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altocmvaz.org

Strengthening partnerships to promote healthier pregnancies and family empowerment.

Thank you!

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