



Educating Early Childhood Providers on the Impact of Congenital CMV (cCMV):

A Learning Module Approach

EHDI March 10, 2025

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With Special Thanks to Members of the MAcCMV Coalition and Our Parent Leaders - Lisa Saunders & Vanessa Colleran

Lisa Saunders is a leading national advocate for Congenital CMV awareness and Screening. She has taught us about the power of hope, perseverance, collaboration, and supporting each other.

Lisa's daughter, Elizabeth, was born with Congenital CMV and was diagnosed with significant multiple disabilities. She passed away at the age of 16 in 2006.





Vanessa Colleran is the Vice President of the MAcCMV Coalition and has been instrumental in the advocacy and legislative efforts in Massachusetts.

Vanessa's son, Logan, was born with cCMV and passed away at the age of 4 months. She is a tireless advocate for cCMV prevention and awareness.





Session Objectives

- Describe the importance of early identification and referral to appropriate agencies and services for babies with cCMV and neurological sequelae.
- Identify the potential neurodevelopmental effects of congenital CMV (cCMV) and risk factors for brain-based visual and hearing conditions.
- Explore the Early Childhood CMV Training Module as a tool to build awareness and support training in cCMV for providers.

NEC Grant Overview



- Funding Source: Federal Technical Assistance and Dissemination project from the Office of Special Education Programs (OSEP).
- Population: Infants through age 21 years, children with combined vision and hearing conditions
- Purpose: To help states improve educational results and functional outcomes for children and youth who are deafblind or at risk (Connecticut, Maine, Massachusetts, New Hampshire, Vermont)
- Including children with congenital CMV (cCMV)
- Services: Consultation, training and information to families and educational teams

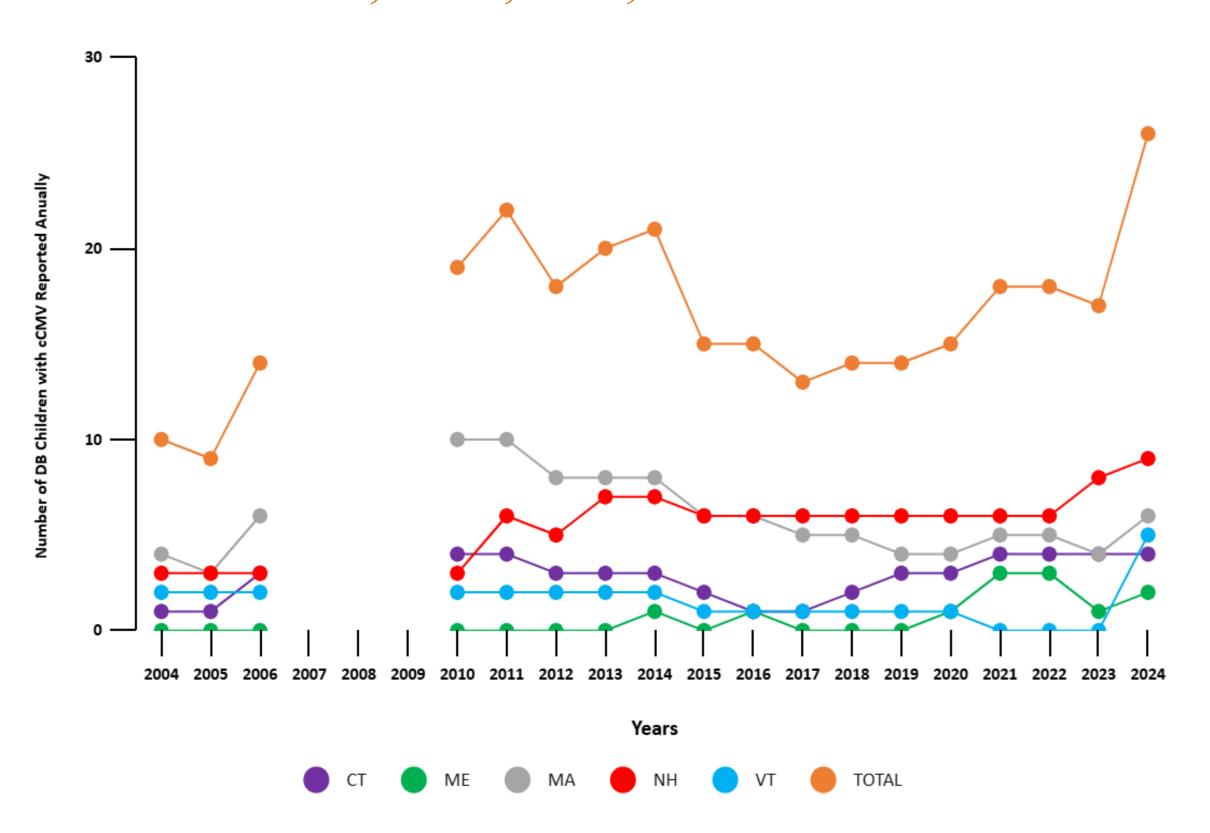
The Range of Sensory Conditions in Deafblind Learners

The Range of Sensory Abilities & Conditions		Classification of Vision					
		Normal 20/12-20/40	Near Normal 20/40-20/60	Low Vision 20/70- 20/160 or field loss <20 degrees	Legally Blind 20/200 or less or field loss <20 degrees	Light Perception or No LP	*Cortical or Cerebral Vision Impairment (CVI)
Classification of Hearing	Normal -10 to 15 dB						
	Slight 16 to 25 dB						
	Mild 26 to 40 dB						*
	Moderate-Severe 41 to 70 dB						*
	Severe 71 to 90 dB						*
	Profound 91 dB or greater						*
	**Auditory Neuropathy		*	*	*	*	*
	***Central Auditory Processing Disorder		*	*	*	*	*

^{*}Condition Impacting the Perception and Understanding of Visual Information
**Condition Impacting the Transmission of Auditory Information to the Brain

^{***}Condition Impacting the Processing of Auditory Information

Children Identified w/cCMV and DB CT, MA, ME, NH & VT



Collaborative Efforts - Our Journey



New England Consortium on Deafblindness

Federally funded grant through OSEP

- Technical assistance and training for providers serving children (B-21) with combined vision and hearing needs (deafblind)
- Increasing knowledge of the educational support needs of Deafblind Learners

Shared Journey
Shared Goals

- Early Identification and Referral for At-Risk Infants
- Education for Early
 Intervention and
 Early Childhood
 Providers to Improve
 Outcomes
- Family Information & Support
- Legislative Efforts for CMV Screening



MA c CMV Coalition

Coalition of Massachusetts Parents, Healthcare Providers, and Educators

- Educate Providers about cCMV
- Prevent cCMV through infection protocols
- Screen all newborns for cCMV in fection
- Care for a ffected children and families with evidence-based practices
- Champions for screening and legislation

Why Early Intervention and Early Childhood Providers Need to Understand cCMV

- 1. Understand Precautions to Minimize CMV Transmission
- 1. Identify Neurodevelopmental Effects of Congenital CMV (cCMV) and Associated Sensory Conditions
- 1. Recognize Risk Factors and Facilitate Appropriate Monitoring and Referrals.
- 1. Encourage Regular Hearing And Vision Screenings
- 1. Deliver Timely, Targeted Services to Support Communication, Mobility, And Learning.
- 1. Collaborate With Audiologist, Ophthalmologists, Early Childhood Educators, And Medical Professionals for Comprehensive Support.



Know your risk when working with infants and toddlers

Most children born with congenital CMV will shed, or pass on, the virus in their body fluids throughout their toddler and preschool years. However, CMV is also a very common childhood virus, affecting 70 percent of healthy children between 1 and 3 years of age.

Daycares, preschools, schools, therapists, churches, and community members should not require a child to be tested for CMV shedding. According to the Centers for Disease Control and Prevention (CDC), screening of children for CMV infection is not recommended, and infected children should not be excluded from school or other settings.

You are four times as likely to come into contact with CMV through a child without a congenital CMV diagnosis.

Children born with congenital CMV pose no threat to their peers and no more of a threat to those at risk for CMV infection (ie. pregnant women) than would any other child.

Know how to serve children with CMV

You likely have served or do serve children with CMV. Each CMV child will have unique needs. CMV causes a wide range of permanent medical conditions and disabilities. CMV can also result in deafness, blindness, cerebral palsy, mental and physical disabilities, seizures, and death.

If a child you work with has hearing loss and does not know the cause, recommend testing for CMV as early as possible. Congenital CMV is diagnosed if the virus is found in an infant's urine, saliva, blood, or other body tissues during the first three weeks of life. After three weeks, blood spot cards can be used for diagnosis but may not be entirely conclusive.

A definitive diagnosis of CMV may provide the family an opportunity for antiviral therapy, early intervention services, and focused surveillance hearing testing since these children are typically at-risk for further hearing loss. A general recommendation for babies diagnosed with congenital CMV is to have a hearing assessment every three months in the first three years of life, and then every six months through six years of age. EI providers can be instrumental in facilitating these appointments.

Learn more at www.NationalCMV.org



The Missing Link:

Need for Early Intervention/Early Childhood Provider Training



The Early Childhood CMV Training Module is a tool for ensuring that all Early Childhood personnel are aware of cCMV and have concise information about identification, assessment, and intervention for cCMV babies.



Increase a wareness of cCMV for Early Intervention & Early Childhood staff, including: Developmental Specialists, Early Childhood Educators, TVI, TOD, SIP, PT, OT

Sim ple & Concise

Effective training materials for personnel that are simple and concise and can be included in existing mandated trainings

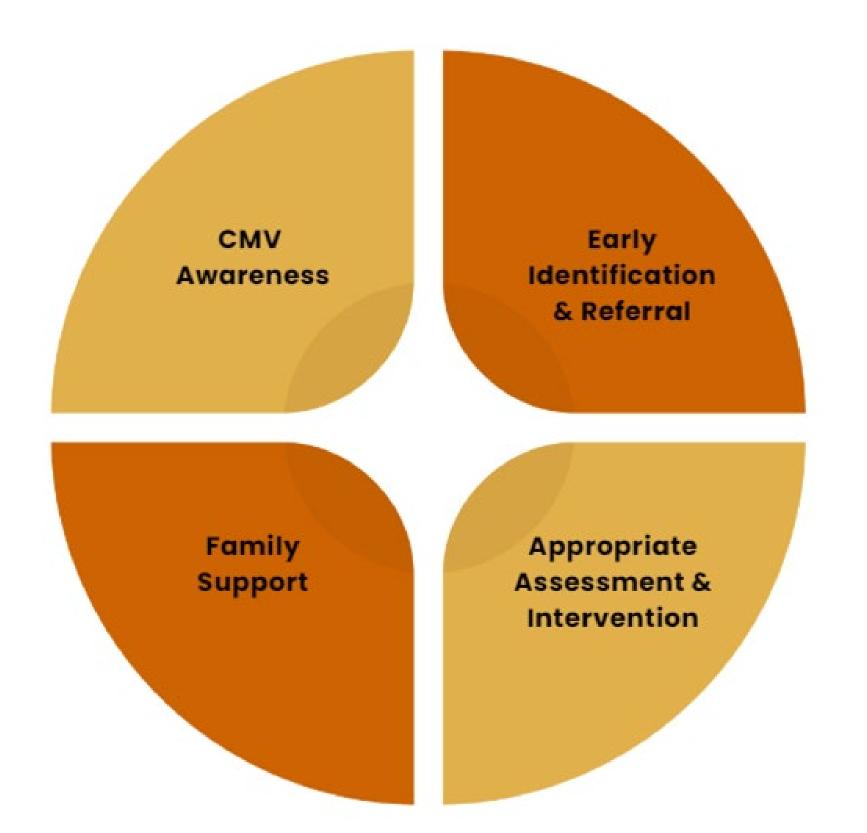
Family Support

Ensure that Early Intervention and Early Childhood Providers have accurate, helpful information for families

Neurodevelopmental Effects

Addresses the potential for neurological sequelae to cause vision loss, hearing loss, or deafblindness in a ffected children.

Module Purpose & Components



Key Components

- ☐ Pre/Post Knowledge Assessment
- ☐ Module PPT
- ☐ Checklist for Providers to Monitor Developmental Domains:
 - Auditory
 - Vision
 - o Communication
- o Ta c tile
- o Cognition
- Gross Motor
- o Fine Motor
- o Social/Emotional
- o Self-Help

Our Targeted Outcomes:

Increased CMV Awareness & Training, Informed Practices, Changes in Policy (Pending MA Legislation)





Referral to Early Intervention & State Deafblind Project



Referralto Additional Programs

Referral of infants with symptomatic cCMV to programs/providers for children who are visually impaired, deaf/hard of hearing or deafblind should be done promptly after diagnosis (with consideration for Communication Access, Followup, and Intervention)



Sensory & Neurodevelopmental Follow Up

Children impacted by cCMV benefit from sensory and neurodevelopmental follow-up, speech and language programs, and educational accommodations to optimize their potential (Demmler-Harrison, 2016)

Deaf/HH: Be aware of the importance of early diagnosis and potential for progressive hearing loss in infants who present with HL and neurological sequelae

Vision: Recognize the frequency and impact of ocular and brain-based visual impairment in infants born with cCMV and the need for ongoing assessment and monitoring of visual development

Dea fb lindness: Monitor both vision and hearing in children born with neurological sequelae and who don't respond consistently to visual and/or auditory input in familiar and unfamiliar settings.



Assessment

Trained and experienced service providers are critical for accurate assessment and intervention for children with cCMV.

Early Childhood
Training Module



Early Childhood CMV Training Module

2025



Acknowledgements - Members of the Massachusetts cCMV Coalition

Dr. La ura Gibson Vanessa Colleran Dr. Cheryl Glovsky Dr. Tracy Evans Luiselli Rebecca Sandvos Shayne Gaffney Dr. Michael Cohen Dr. Barbara Morris Dr. Me re d ith Bra za Dr. Margaret Kenna Evelyn Rankin Peter Colleran Brenda Allair Ta lia Mango Lisa Saunders



Module Purpose

To educate Early Childhood Providers, including Early Interventionists and Early Childhood educators and related providers, about congenital CMV and its impact on development, including vision, hearing, and neurological impacts, as well as strategies for supporting families through the assessment and intervention process.

Module Participant Pre-Test



Early Childhood CMV Training Module Participant Survey



Participant Inf	ormation
Name:	Date: AY MONTH YEAR
Early Intervention or Early Childhood Cente	er
Instructio	one:
Please answer each question on the survey prior to beginning to	MANAGEMENT CONTROL OF THE CONTROL OF
Questions:	Response:
Cytomegalovirus (CMV) is a common member of the herpes virus family that is generally harmless to people with healthy immune systems.	
When a baby is born with a CMV infection, it is called congenital CMV (cCMV).	
Congenital CMV is the leading non-genetic cause of childhood hearing loss.	
Congenital Cytomegalovirus (cCMV) is not PREVENTABLE.	
About I out of every 200 babies is born with congenital CMV infe Of these babies, around I in 5 will have long-term health probler as: hearing loss, vision loss, cerebral palsy, seizures, and other developmental disabilities.	
To prevent the spread of the CMV virus in early intervention and childcare centers, it is important to clean toys, countertops, and surfaces that come in contact with children's urine or saliva.	
Children and an end internationing and only highered	

Childcare workers, early interventionists, and early childhood providers of childbearing age are at increased risk for cCMV.

Washing your hands often with soap and water for 15-20 seconds after changing a diaper or feeding a child will help prevent exposure

All babies with congenital cytomegalovirus are identified at birth.

Babies born with hearing loss due to cCMV and neurological sequelae are at increased risk of visual impairment.

What is CMV?

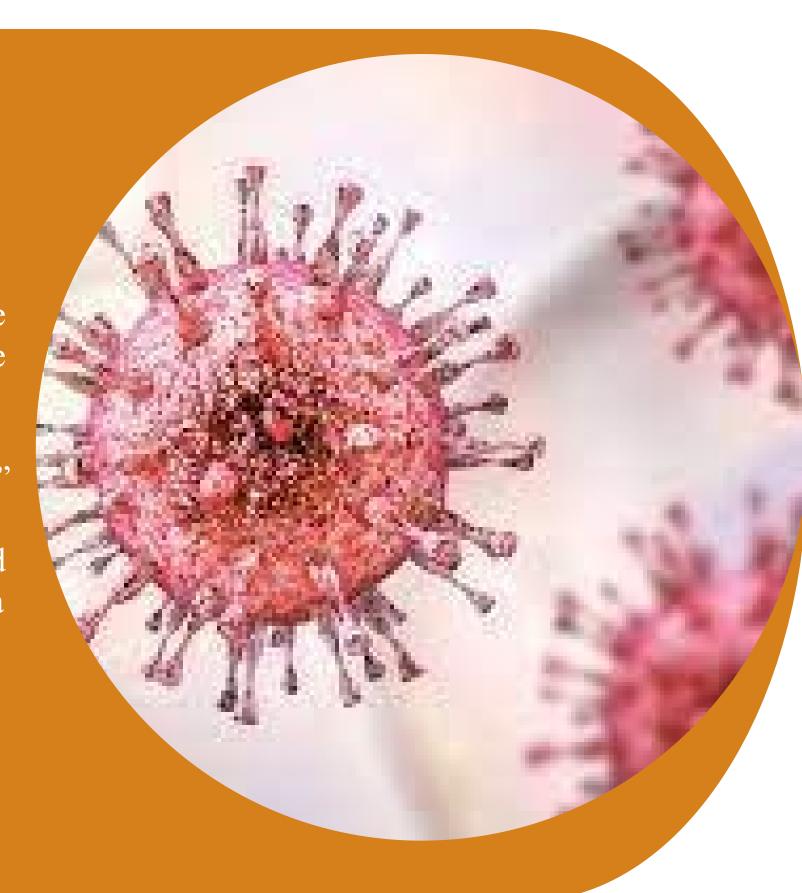
(sytoe MEG a ·low vyrus)

Cyto= cell megalo= big virus= poison

Cytomegalovirus or CMV, is a common member of the herpes virus family that is generally harmless to people with healthy immune systems.

"The most common virus most people have never heard of"

Once CMV is in a person's body, it stays there for life and can reactivate & a person can be re-infected with a different strain of the virus.



What is the Difference between CMV and Congenital CMV (cCMV)?



All Pregnant Individuals are At Risk for CMV



Those with Young Children at Home



Childcare Providers, Early
Interventionists, Early
Childhood & Classroom
Personnel



Healthcare Providers

Is There Screening for cCMV?

Screening protocols are inconsistent across states, and many states do not have a Universal Screening Protocol for cCMV.

Prenatal Screening: Women who are considering pregnancy can be tested for CMV if they request that CMV Ig M and Ig G antibody lab tests be added to their routine labs. These tests are relatively inexpensive and are covered by most insurance plans.

Newborn Screening: The National CMV Foundation maintains a website with current information on states that have adopted or are working towards Newborn Screening for cCMV.

Newborn Screening - National CMV Foundation



Why is Congenital CMV Such a Complex Issue?



A Common Virus, a Complex Problem



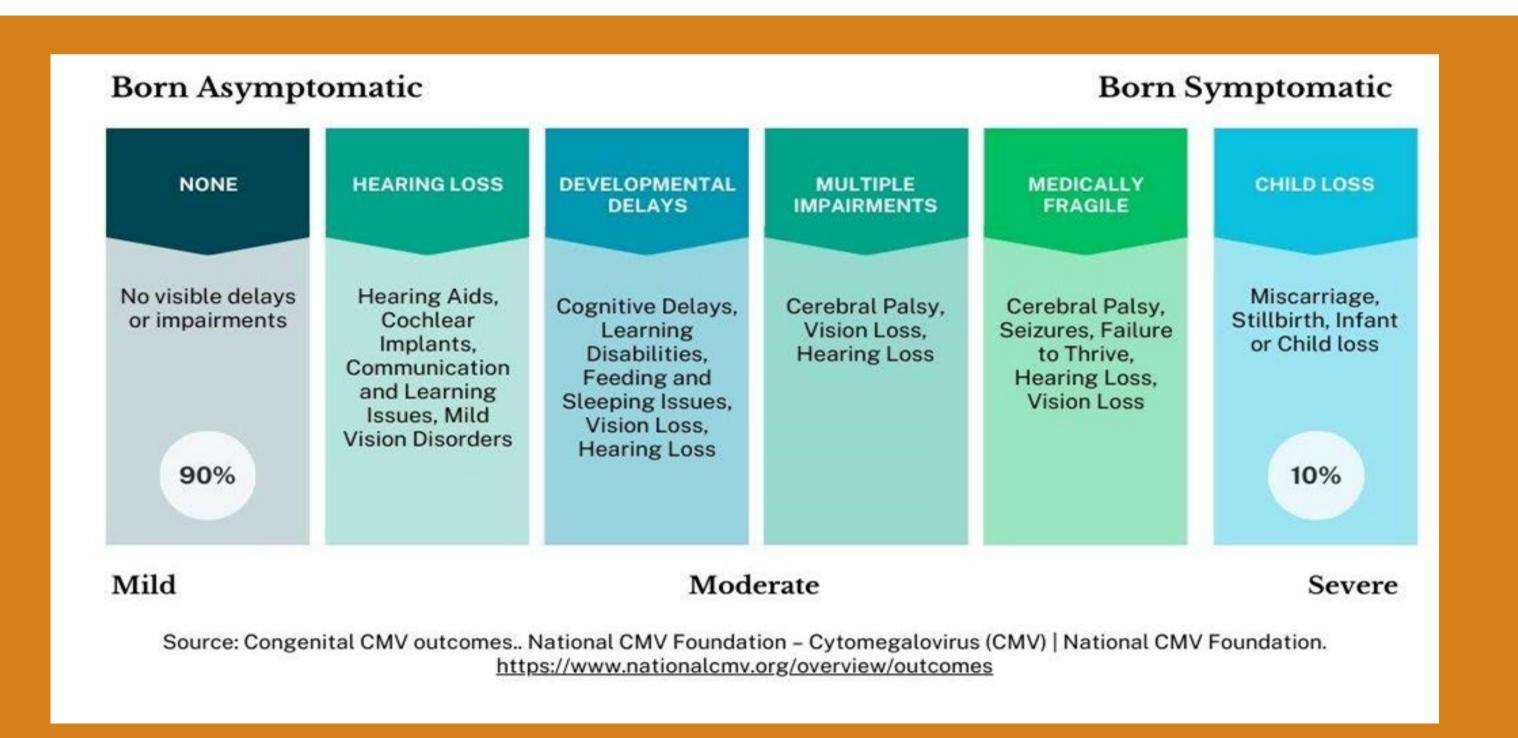




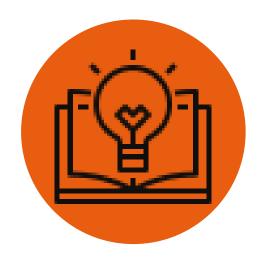
- It is a common virus, especially in young children, and can be easily spread.
- About 1 in 3 pregnant women who become infected with CMV will pass the virus to their baby.
- Most pregnant women are never told about preventative measures for CMV or about the potential risks to their developing babies.
- Many states do not screen for CMV at birth, and even asymptomatic infants may develop serious, long-term problems
- About 1 in 200 infants each year are born with congenital CMV and about 1 in 5 of those will be come disabled.
- (1) child every hour is permanently disabled due to congenital CMV.
- CMV is COMMON, SERIOUS, and PREVENTABLE.
- Lack of state and national prevalence data
- Disagreement about the need for universal screening

cCMV (Congenital CMV) is SERIOUS

20% of babies born with CMV will have disabilities including hearing loss, cerebral palsy, seizures and other developmental disabilities



Early Childhood Providers Can Be Part of the Solution



Educate

- KNOW what CMV is and how it can be spread
- UNDERSTAND who is at risk and what preventative measures are available
- RECOGNIZE the impact of congenital CMV on developing babies, toddlers and young children



Prevent

- Wash hands often with soap and water for 15-20 seconds
- Do not share food, drinks, or eating utensils with young children
- Do not put a child's pacifier in your mouth
- Avoid contact with saliva by kissing a young child on the forehead instead of the lips
- Clean toys, countertops and other surfaces that come in contact with children's urine or saliva



Screen

- Several states have begun implementing universal newborn screening for congenital CMV infection.
- You can learn more about CMV screening at: https://www.nationalcmv.org/overview/newborn-screening



Care

- SUPPORT families to get appropriate medical and developmental follow-ups
- REFER families to specialty services for vision, hearing, or combined sensory loss
- SHARE in form a tion a bout resources and supports with families impacted by cCMV.

Three Simple Precautions to Help Prevent cCMV





- Wash hands after all diaper changes and after wiping runny nose/drool
- Clean changing areas and toys regularly with soap and water



Kiss with Care

 Kiss babies or toddlers on the forehead and not the mouth to avoid saliva



Don't Share

- Do not share any of the following with young children:
 - o food
 - o drink
 - o pacifiers
 - o toothbrushes

Early Indicators for cCMV in Newborns





- Sensorine ura l Hearing Loss
- Optic Nerve Atrophy
- Choriore tinitis
- Macular scarring



System ic Issues

- Intrauterine Growth Restriction
- Jaundice
- Fever
- Rash
- Hepatosplenomegaly



Neurological Findings

- Se izure s
- Microcephaly
- Abnormal Brain Imaging

Dia gnosin g c CMV



- Congenital CMV infection can be diagnosed by testing a newborn baby's saliva, urine or blood.
- Specimens must be collected for testing within two to three weeks after the baby is born in order to confirm a diagnosis of congenital CMV infection.
- Newborn screening protocols are inconsistent across states, and many states do not have a Universal Screening Protocol for cCMV.

Additional Challenges Can Impact Children and Families

Over Time

Some infants born with cCMV may not initially have significant problems, but health and developmental concerns can emerge over time, including:

- Visual Impairment/Blindness
- Hearing Loss/Deafness
- De a fb lindness
- Se izure s
- Developmental and Motor Delays

Families may experience feelings of fear, grief, and frustration as new diagnoses emerge.



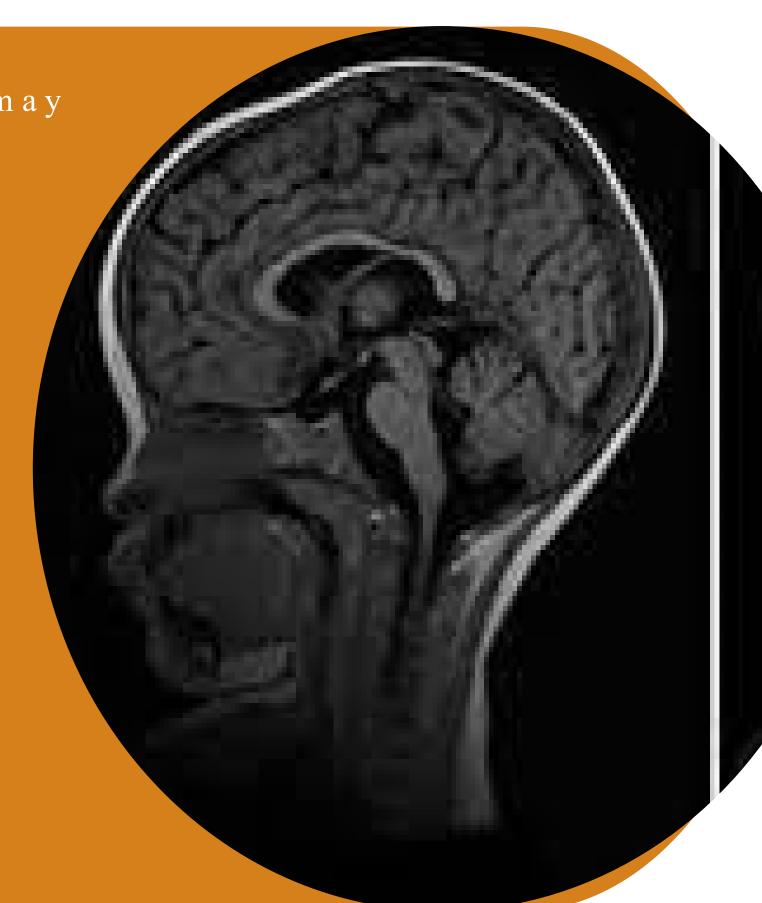
NeurologicalImpactofcCMV

Neurological Sequelae associated with congenital CMV may include:

- Microcephaly
- Se izure s
- Periventricular Calcification
- Cerebral Atrophy
- Malformations of The Brain
- White Matter Signal Changes and Cysts
- Motor Conditions Similar to Cerebral Palsy, Demyelinating Disorders
- Calcified Leukoencephalopathies

These diagnoses are frequently associated with:

- Complex Health Care Needs
- Brain-Based Auditory And Visual Conditions



The Role of Vision and Hearing in Early Development





Com m unication

- Access to spoken or signed language
- Recognizing non-verbal communication



Movement

- Motivation to explore the environment beyond their reach
- Access to visual and auditory cues in the environment for safety/movement



Social Emotional Development

- Access to visual and auditory information about emotions and feelings
- Ability to effectively communicate wants, needs, and interests with others



Cognition

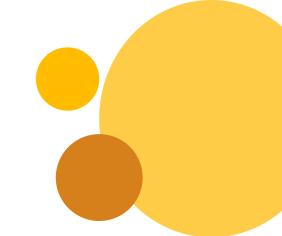
- Developing abstract concepts
- Understanding and building on early learning concepts such as size, shape, color, sound

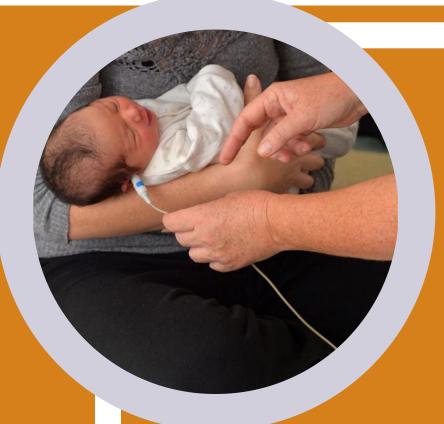


Self-Help and Self-Determination

- Access to visual information about feeding, dressing, toileting
- Understanding relationships between self and others

Hearing Conditions & c CMV





Leading Non-Genetic Cause of Hearing Conditions

- Congenital CMV is the leading non-genetic cause of childhood hearing conditions.
- CMV accounts for approximately 25% of Sensorine ural Hearing Loss (SNHL) diagnosed in children, including an estimated 15-20% of bilateral moderate to profound SNHL diagnoses.

Can Develop Over Time

- 15% of infants diagnosed with cCMV will NOT have symptoms at birth (asymptomatic newborns) but will later develop hearing issues
- The AAP recommends hearing tests at least every 6 months



Hearing Risks for cCMV

The most common disability associated with cCMV is deafness/hard of hearing. It is progressive (worsens over time) for around half of children infected. Children with cCMV are at risk for different types of hearing conditions, including:

Conductive with Middle Ear Effusion

Sensorineural (SNH)

Progressive

Unilateral or Bilateral

Congenital or Later Onset



Hearing Signs & Symptoms in Early Childhood



Infants

- Does not startle at loud noises.
- Does not turn to the source of a sound after 6 months of age.
- Does not say single words, such as "dada" or "mama" by 1 year of age.
- Turns head when he or she sees you but not if you only call out his or her name.
- Seems to hear some sounds but not others.



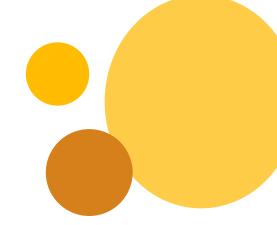
Children

- Speech is delayed.
- Speech is not clear.
- Does not follow directions. This sometimes is mistaken for not paying attention or just ignoring, but could be the result of a partial or complete hearing issue.
- Often says, "Huh?"
- Turns the TV volume up too high

Providers for Children Who Are Deaf/Hard of Hearing



Vision Conditions & c CMV





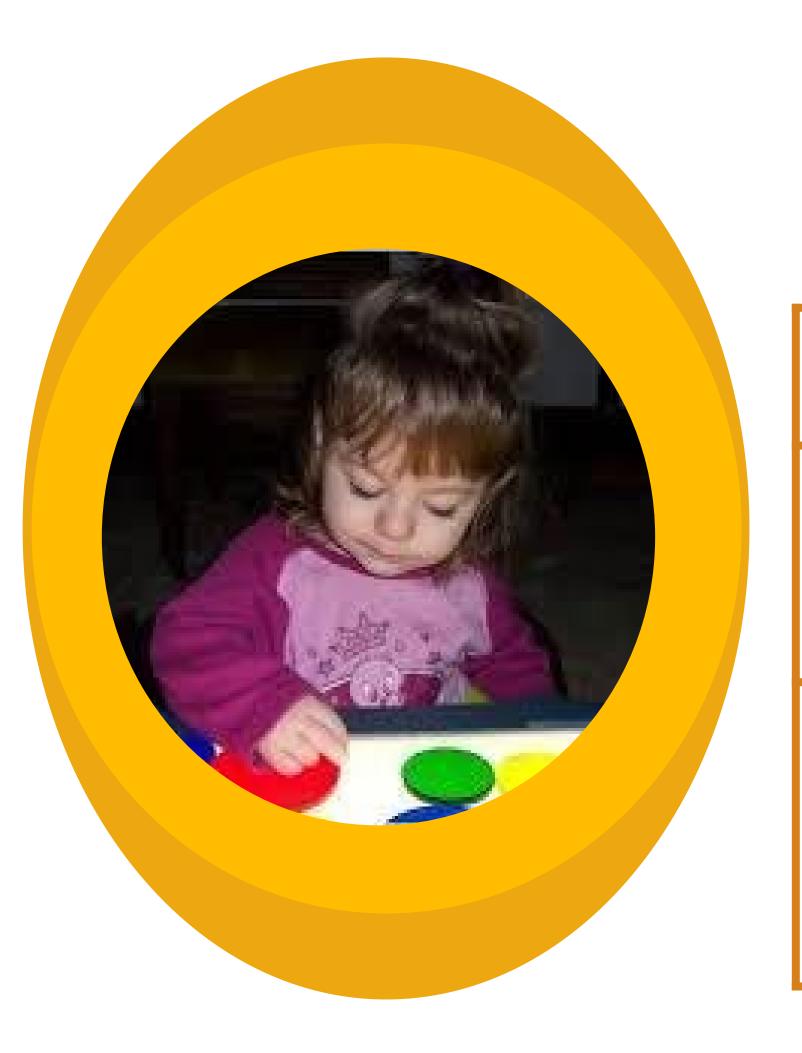
Ocular Visual Conditions

- May or may not be present at birth
- Strabismus
- Nystagmus
- Optic Nerve Atrophy
- Choriore tinitis

Brain-Based Visual Impairment

- Children with neurological sequelae are at increased risk of brain-based visual impairments
- Major risk factors for severe visual impairment in children with cCMV include symptomatic status at birth, optic nerve atrophy, chorioretinitis, cortical/cerebral visual impairment and sensorine ural hearing loss.





Congenital CMV & Brain - Based Visual Impairment

• Children with neurological sequelae due to cCMV are at increased risk of brain-based visual impairment (CVI).

What is CVI?	Com m on Causes	Im pact on Vision
• Cortical/Cerebral Visual Impairment (CVI) is the most common cause of visual impairment in the United States	 Bra in m a lform a tion Hypoxia / ischem ia Prematurity Tra um a Infection Certa in neurological diseases 	 Reduced Visual Attention Difficulty with Visual Localization Poor Visual Tracking Difficulty with Depth Perception
• CVI is characterized by visual impairment due to damage to the central nervous system (CNS) not involving the ocular structures.		 Visual Field Deficits Color and Contrast Sensitivity Visual Habituation Issues Reduced Visual Discrimination Difficulty Recognizing Faces Inconsistent Visual Responses

Vision Conditions & Symptoms in Early Childhood



Infants

- Difficulty visually tracking
- Difficulty viewing people or objects
- Little/no visual regard of faces
- Difficulty with bright lights or increased attention to lights
- Nystagmus (random eye movements)



Toddlers

- Mobility concerns (tripping, falling) that are not accounted for by gross motor delays
- Squinting or covering eyes
- Moving closer to see objects
- Signs of visual fatigue (pushing objects out of view, looking a way frequently, easily overwhelmed by visual stimuli)

Providers for Children who Blind/Visually Impaired



Hearing and Vision in Babies and Toddlers with cCMV



Hearing

The American Academy of Pediatrics general recommendation for all babies with congenital CMV (regardless of their newborn hearing screening results):

- Hearing re-assessment every 3 months in the first three years of life
- Repeat every six months through age six years
- Assessment may need to be more frequent or altered based on antiviral therapy, rehabilitation needs, pediatric audiologist guidance, or parent concerns.
- <u>CMV-associated congenital hearing loss may</u> be progressive in nature

Combined Vision & Hearing Differences (Deafblindness)

- A sensory loss in one
 area (vision or
 hearing) should
 prompt an assessment
 for the other sense
- Neurological sequelae
 are risk factors for
 brain-based vision
 and auditory
 impairments

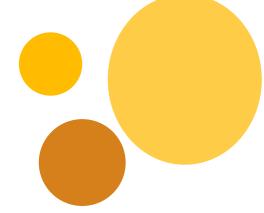


Vision

The American Academy of Pediatrics recommends that all babies with cCMV have an ophthalmology exam within the first year of life.

Babies with neurological sequelae including:

- microcephaly
- seizure disorder
- malformations or calcifications in the brain should also be followed for concerns regarding cortical/cerebral visual impairment



Family Support



Accessible, Clear & Concise Information

- Accurate family-friendly information about the effects of cCMV
- Education about their child's developmental and sensory abilities
- Strategies for supporting their child's learning and growth

Support Along the Way

- Opportunities for connecting to other parents and caregivers
- In form a tion a bout a gencies and organizations that may provide additional education, support, or resources



Family Stories

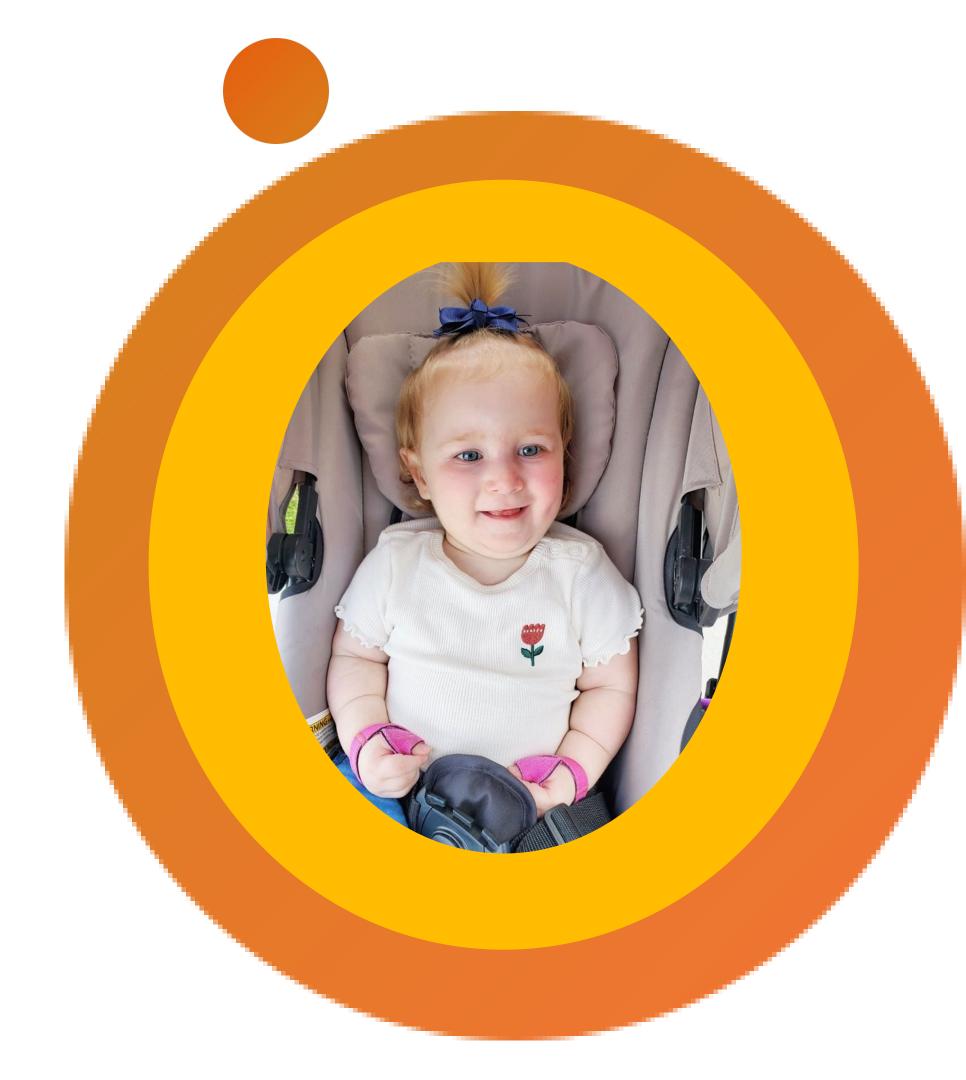
Family stories are important and powerful. They can help Early Childhood Professionals learn more about the impact of cCMV and how to support children and families.

Click the links below to learn more.

Massachusetts CCMV Coalition - Parent Stories

National CMV Foundation - Parent Stories

Instagram Parent Stories



Referrals & Resources

Families of children impacted by congenital CMV (cCMV) need information, resources, and support. Early Intervention and Early Childhood providers can work to ensure that all families have access to appropriate supports and services. While each state may have different agencies or organizations, a list of programs to consider is listed below.









Family Resources

- National CMV Foundation
- PTI (Parent Training and Information Centers)
- Hands and Voices
- National Family
 Association for
 Deafblind (NFADB)

Programs for D/HH

- FHDI
- Early Intervention Programs for Deaf/Hard of Hearing Infants and Toddlers
- ASLPrograms
- Family Support Groups
- State Agencies for D/HH

Programs for Blind/VI

- Early Intervention
 Programs for
 Blind/Visually
 Impaired Infants and
 Toddlers
- Family Support Groups
- State Agencies for Blind/VI

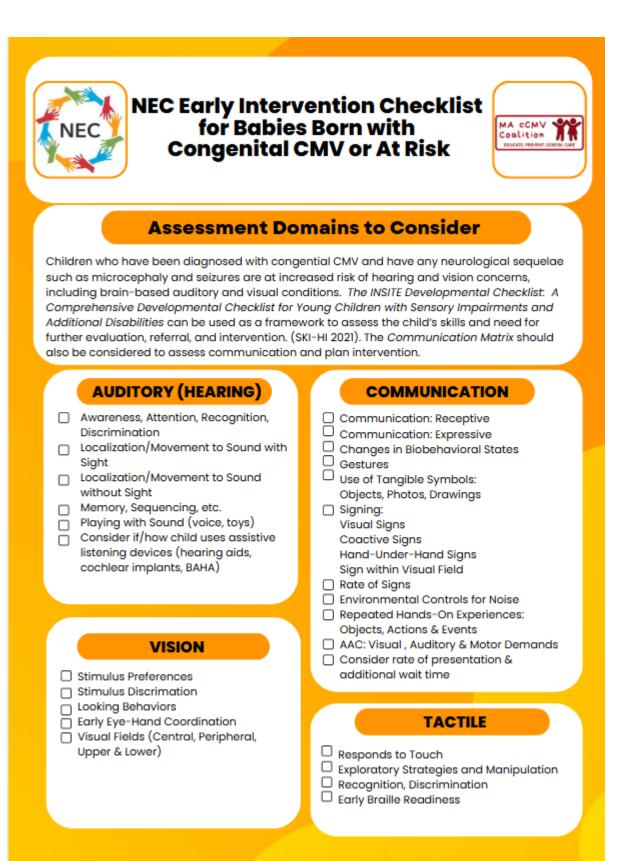
Your State Deafblind Project

- New England
 Consortium on
 Deafblindness (NEC
 (CT, ME, MA, NH, VT)
- <u>List of State Deafblind</u>
 <u>Projects</u> (NCDB)

Congenital Cytomegalovirus (cCMV): Family Guide



NEC Early Intervention Checklist: Important Assessment Information for Babies Born with Congenital CMV



NEC Early Intervention Checklist for Babies Born with Congenital CMV or At Risk		
COGNITION	GROSS MOTOR	
Object Permanence: Memory for Objects, Events, People & Places Object Exploration & Schemes: Play with Toys Means/End: Problem-Solving Causality: Control Spatial Relations: Body to Object, Object to Object Time: Anticipation Classification: Group Match	General Posture: Movement on stomach and back Head Control Rolling Sitting Crawling & Creeping Standing and Walking Climbing Jumping & Hopping Ball Play Orientation & Mobility	
Sort Classify Play Materials and Dramatic Play Patterning & Number Concepts	FINE MOTOR	
SOCIAL & EMOTIONAL Interactions with People Interactions with Environment Social Play Reciprocal Interactions	Reach, Grasp and Release Manipulation and Coordination: Part to Whole Reproducing Designs, Sequences, and Spatial Relationships with Objects Skills for Arts & Crafts Scribbling, Drawing and Printing	
Repetitive Behaviors Sensory Processing Styles Tempermental Styles	SELF-HELP Meal Time Dressing & Undressing Toileting Personal Hygiene Sleep Patterns	
For additional information and support, please contact: New England Consortium on Deafblindness (NEC (CT, ME, MA, NH, VT) or Find your state's Deafblind Project at National Center on Deafblindness List of State Deafblind Projects	Helping Out & Safety	

Module Participant Post-Test



Early Childhood CMV Training Module Participant Survey



	Training Module Parti	cipant Survey
Participant Information		
		Date: MONTH YEAR
	Early Intervention or Early Childhood Center	
	Instructions:	
	Please answer each question on the survey prior to beginning this training	ng module.
	Questions:	Response:
		True False Unsure
	Cytomegalovirus (CMV) is a common member of the herpes virus family that is generally harmless to people with healthy immune systems.	• • •
	When a baby is born with a CMV infection, it is called congenital CMV (cCMV).	• • •
	Congenital CMV is the leading non-genetic cause of childhood hearing loss.	• • •
	Congenital Cytomegalovirus (cCMV) is not PREVENTABLE.	• • •
	About I out of every 200 babies is born with congenital CMV infection. Of these babies, around I in 5 will have long-term health problems such as: hearing loss, vision loss, cerebral palsy, seizures, and other developmental disabilities.	• • •
	To prevent the spread of the CMV virus in early intervention and early childcare centers, it is important to clean toys, countertops, and other surfaces that come in contact with children's urine or saliva.	
	Childcare workers, early interventionists, and early childhood providers of childbearing age are at increased risk for cCMV.	
	Washing your hands often with soap and water for 15-20 seconds after changing a diaper or feeding a child will help prevent exposure to CMV.	• • •
	All babies with congenital cytomegalovirus are identified at birth.	
	Babies born with hearing loss due to cCMV and neurological sequelae are at increased risk of visual impairment.	000

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Thank You

Module End





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