

Congenital Cytomegalovirus

Information for Families & Caregivers



PREPARED BY

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ACKNOWLEDGEMENT

This page's content was adapted from and developed in partnership with the Minnesota Department of Public Health, the National CMV Foundation, and parents whose children have been identified with congenital cytomegalovirus. The Connecticut Newborn Screening Network would like to thank everyone involved for sharing their experiences and insights.

DISCLOSURE

This handout does not provide medical advice. It provides general information about congenital CMV. Every child and family is different, and some of the information may not apply to your child specifically. Always check with your child's healthcare provider if you have questions or concerns about their condition.

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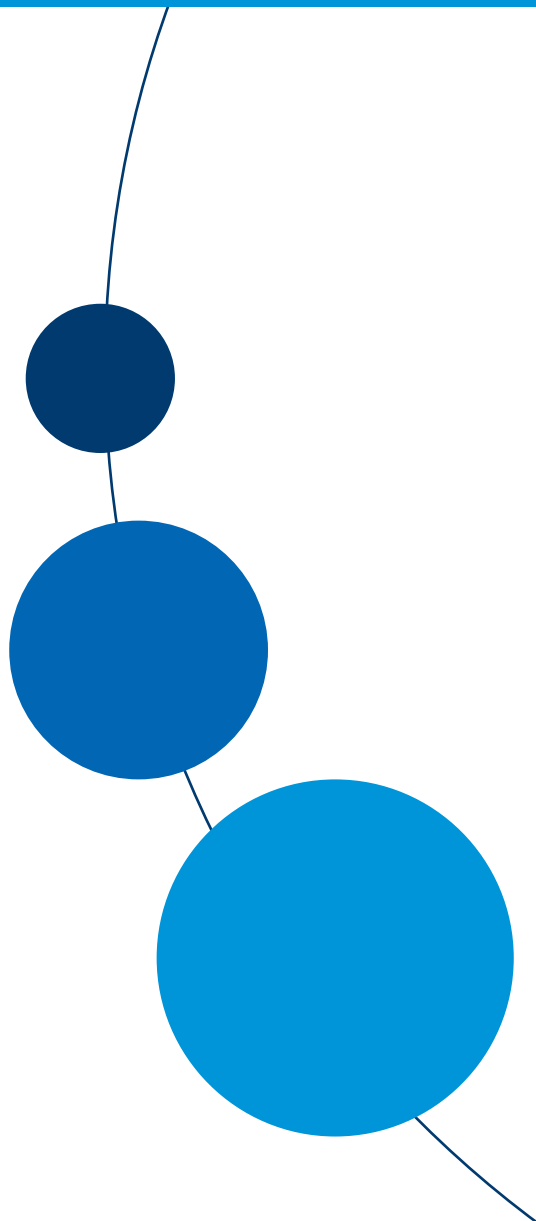
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Section 1

About Cytomegalovirus (CMV)
and Congenital Cytomegalovirus (cCMV)

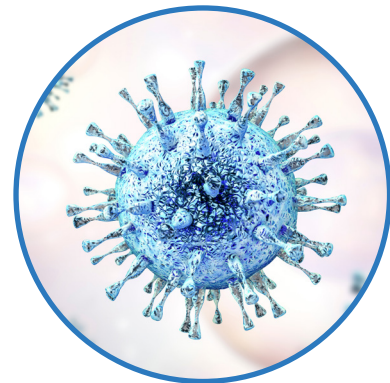


Section 1: About Cytomegalovirus (CMV) and Congenital Cytomegalovirus (cCMV)

What is CMV?

Cytomegalovirus (CMV) is a common virus that can infect people of all ages. One in three children in the United States is infected with cytomegalovirus (site-toe-MEG-a-low-vy-rus) by age 5, according to the Centers for Disease Control and Prevention (CDC). More than half of adults have been infected with CMV by age 40. Once CMV is in a person's body, it stays there for life and can reactivate. A person can also be re-infected with a different strain of the virus.

Most healthy people do not know that they have had a CMV infection, because the virus usually does not cause any symptoms. When people first get infected, they might have mild symptoms such as fever, sore throat, fatigue (being very sleepy), or muscle aches. CMV can cause more serious illness for some people with weakened immune systems.



How do people get CMV?

CMV is passed from person to person through close contact with body fluids like saliva, mucus, urine, feces (stool), blood, semen, vaginal fluids, tears, and breast milk.

CMV is found to pass more easily between people who live in the same house and among young children in childcare settings. High levels of CMV can stay in a child's urine and saliva for months after they become infected. This makes young children a common source of CMV. Children can pass the virus to parents and caregivers, even if they do not seem sick. Contact with the saliva or urine of babies and young children is thought to be an important cause of CMV infection among people who are pregnant.

What is congenital CMV?

A pregnant person can pass CMV to their fetus without knowing it. When a fetus is infected with CMV before birth, it is called congenital CMV, or cCMV. Most babies who are born with congenital CMV never have health problems, but some babies can be sick at birth or develop long-term health problems later.

About 1 in every 200 babies (0.5%) is born with congenital CMV. Based on the birth rate in Connecticut, this means that around 175 babies could be born with congenital CMV in Connecticut each year. Congenital CMV is the most common infectious cause of birth defects in the United States. Congenital CMV is also a common cause of childhood hearing loss.



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How do I know if my baby has CMV?

If your baby's healthcare provider has concerns about possible congenital CMV, they will likely discuss testing your baby. In addition, babies born in Connecticut are tested for CMV as part of the newborn screening program. If a newborn blood screen collected at birth finds CMV, it means that chances are likely that your baby has congenital CMV. More testing is needed to know for sure.

To learn if your baby has congenital CMV infection, a urine test is needed. For the urine test to be accurate, the urine sample must be collected before the baby is 21 days old. After 21 days of age, it is hard to know if a baby was born with CMV or got CMV after birth (known as acquired CMV). Being born with congenital CMV can cause long-term health problems and hearing loss in some children. Getting CMV after birth usually does not cause these things.

What are the signs and symptoms of congenital CMV?

Congenital CMV affects each baby differently. Most babies will not have health problems. This is called asymptomatic, or clinically inapparent. When babies do show signs or symptoms of disease, it is called symptomatic.

Asymptomatic, or Clinically Inapparent, congenital CMV

Most babies with congenital CMV do not show signs or symptoms at birth. Most of these children stay healthy and never have health concerns caused by the infection.

Some children born without symptoms can go on to develop permanent hearing loss. Hearing loss can range from mild to severe and can be in one or both ears. The hearing loss can be present at birth or can happen later in childhood. All children with congenital CMV should have their hearing tested regularly to catch any changes in their hearing.

The chance of having some developmental challenges is a little higher for children with asymptomatic congenital CMV than for children without congenital CMV. Your child's healthcare provider can track their development. Children with asymptomatic congenital CMV qualify to receive early services, such as Birth to Three, to support their growth and development.

Symptomatic congenital CMV

Some babies with congenital CMV have signs or symptoms at birth. Symptoms can range from mild to severe. Some symptoms can be visible, and others may be found only by special tests.

Symptoms include:

- Being born early (preterm)
- Hearing difficulties
- Small size or low birth weight
- Jaundice (yellowing of skin or the whites of the eyes)
- Enlarged liver or spleen
- Small head (microcephaly)
- Feeding problems.

These babies are also at risk for hearing loss, vision impairment, intellectual disability, language delay, poor physical coordination, muscle weakness, and seizures. Even babies without clear symptoms are at risk for congenital hearing loss. Congenital CMV is the most common cause of non-genetic hearing loss at birth. Hearing loss can range from mild to



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severe and can happen in one or both ears. Hearing loss can be present at birth or later in childhood. All children with congenital CMV should have their hearing tested regularly to catch any concerns early.

In addition, children with symptomatic congenital CMV have a higher chance of long-term health concerns and should be followed closely by a healthcare provider. Children with symptomatic congenital CMV qualify to receive early help to support their growth and development. Organizations that offer help can be found in the “Resource” section.

What other tests are possible for my baby if congenital CMV infection is confirmed?

Your healthcare provider will likely discuss follow-up tests after a congenital CMV infection is confirmed:

- Laboratory blood testing – blood draw to test your baby’s liver function and blood cell count.
- Diagnostic audiology (hearing) testing – a detailed hearing test. Even if your infant passed their newborn hearing screen, they remain at risk for new hearing loss. They need this extra testing shortly after birth and regularly throughout childhood to catch any new hearing loss.
- Head ultrasound or MRI (magnetic resonance imaging) scan – tests that produce images to look for changes in your baby’s brain.
- Ophthalmology eye examination – dilated eye exam to look for changes in your baby’s eyes related to congenital CMV infection.

What do follow-up test results mean?

Babies born with CMV can have different outcomes, so it can be hard to predict their specific future health and development. Therefore, your doctor or healthcare provider may use follow-up tests to: look for signs and symptoms of CMV infection; find out the level of your baby’s disease; and help guide your baby’s treatment and monitoring plan, such as deciding whether your baby should start taking antiviral medicine.

Your healthcare provider should go over test results with you. Be sure to ask any questions you have about your child’s test results and about the recommended treatment and monitoring plan.

Long-term health concerns may include:

- Seizures
- Vision impairment
- Motor delay, weakness, or problems with balance
- Intellectual disability

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How is congenital CMV treated?

There's no specific treatment recommended for otherwise healthy kids who get a CMV infection after birth. But for infants who were infected during pregnancy (congenital CMV), there is an antiviral medication that might help. Talk with your child's healthcare provider about the most up-to-date and current treatment options, along with how to monitor your child.

Antiviral medication

Most babies with congenital CMV will not need antiviral medicine to treat the infection. Antiviral medicine might improve the hearing and development of some babies with signs of congenital CMV at birth. Your healthcare provider might send you to a pediatric infectious disease specialist to talk about different treatments. Antiviral medication can have serious side effects, so doctors use it with caution, especially in children. It is important to talk with your healthcare provider about the risks and benefits of antiviral medication.

Other options:

- **Manage and watch for symptoms.** Make sure that your child goes to all appointments recommended by their healthcare provider(s). These visits are important for managing current health issues. Regular visits are also important to help find new concerns as soon as possible, such as hearing loss.
- **Early intervention.** Help Me Grow Connecticut can connect you to resources to help your child develop, learn, and grow. The program can also connect you with your local school district for an evaluation to see if your child can take part in infant and toddler intervention or preschool special education services. Please see "Growth and Development" for information about how to connect with these services.
- **Family support.** Finding out your child has congenital CMV may cause stress or anxiety for some parents. Support from friends, families, therapists, and counselors has been shown to be helpful.



May I breastfeed if my baby has congenital CMV?

Yes, you may breastfeed a baby who has congenital CMV.

A mother with a CMV infection is encouraged to continue breastfeeding her baby. The benefits of breastfeeding are believed to outweigh the risks of passing CMV to the baby, who is unlikely to develop any symptoms if infected. Talk to your baby's healthcare provider if you are worried about breastfeeding your baby.

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Can my baby go to child care if they have CMV?

Yes, infants with CMV can go to child care. CMV infection is very common in babies and young children, and the child care program probably has other children who also have CMV. All children can spread CMV, not just those who have been diagnosed with CMV by a healthcare provider. Children with CMV should not be stopped from going to any child care setting.

All child care settings should practice regular and good handwashing, hygiene, and cleaning habits. These three things can help lower the risk of spreading CMV.

What should I tell people who ask about getting CMV from my baby?

CMV infection is very common in babies and young children. All children can spread CMV, not just those who have been diagnosed with CMV by a healthcare provider. It is usually passed from person to person by contact with body fluids.

One of the most common ways people come into contact with CMV is through contact with young children who have recently had the virus. This is because high levels of CMV can stay in a child's urine and saliva for months after being infected. Friends and family members should wash their hands well after changing diapers or touching the body fluids (like saliva and mucus) of all children. Friends and family members who are pregnant or immunocompromised and are worried about contact with CMV should talk to their healthcare provider.

Can cCMV infection be prevented?

Currently, there's no vaccine to prevent cytomegalovirus infection. Washing hands well and often can help reduce the risk of infection. This is especially important for:

- Pregnant women and those who might become pregnant
- Childcare workers
- Anyone who has close contact with children

If you are pregnant, you can help protect yourself from CMV by:

- **Washing your hands often with soap and water, especially after being in contact with body fluids from babies or children.** Carefully throw away used diapers and tissues. Wash your hands after changing diapers, feeding a child, wiping noses, and picking up toys.
- **Avoid contact with tears or saliva if you kiss a child,** especially if you're pregnant. Kiss babies and children on the cheek or head instead of on the lips.
- **Don't share toothbrushes, food, drinks, cups, straws, forks, or other utensils with your toddler or child.**
- **Don't put a baby's pacifier in your mouth.**
- Clean toys and countertops often.
- If you work in contact with people who have CMV, follow workplace safety rules to protect yourself from infection. Wash your hands often and wear gloves.



Section 1: About Cytomegalovirus (CMV) and Congenital Cytomegalovirus (cCMV)

Where can I learn more about CMV and congenital CMV?

Talk with your healthcare provider about your CMV and congenital CMV questions.

You can also visit:

National CMV Foundation (www.nationalcmv.org)

Cytomegalovirus (CMV) and Congenital CMV Infection (www.cdc.gov/cmv/index.html)

Mother to Baby

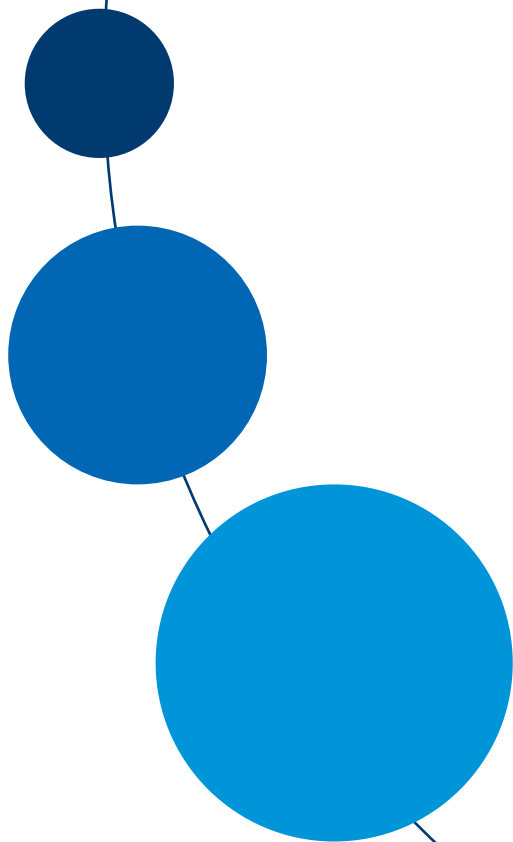
- [CMV: The Most Common Viral Infection Affecting Newborns That You've Never Heard About](#)
- [CMV During Pregnancy and Hearing Loss: A Perspective from the Sound Booth](#)
- [CMV and Birth Defects Awareness Month](#)





Section 2

Hearing and congenital CMV



Section 2: Hearing and congenital CMV

Why test your baby's hearing

Congenital CMV can affect the way your baby's ears work. The virus can affect one or both ears. Congenital CMV can continue to change the way your baby hears over time.

Even if your baby passed their newborn hearing screen, they will still need regular hearing testing. Speech and language start to develop at birth, so it is important to find any hearing changes as soon as possible. Your baby is learning to communicate with you many months before they start using words. If a baby's hearing changes, parents or healthcare providers often do not know it because many babies with hearing loss can still startle to loud sounds and even seem to listen. Regular hearing testing is the only way to find hearing loss early. Knowing of any hearing loss will help you and your baby find the best ways to communicate.



When to test your baby's hearing, and what the results mean

All babies with congenital CMV should see an audiologist (special hearing doctor) as soon as possible, no more than 1 month after learning they have congenital CMV. If the test result is normal or typical, your baby's hearing is normal at that time. However, regular testing is needed throughout childhood, because hearing loss can start later. Testing is performed regularly in the first year, then in longer intervals between visits as the child ages. This may change depending on hearing results. Your audiologist will help you schedule testing for your child.

How hearing is tested

For babies, a small, special earphone is placed in the baby's ear. It plays sounds, and a monitor measures what happens in the ears and brain when the sounds are played. Hearing testing works best when your baby is calm, well-fed, and comfortable. Young babies can be tested while they nap. While it can be difficult to always know your baby's nap schedule, it can be helpful to try to schedule a hearing test visit around the time your baby usually naps. If needed, audiologists can work with a sedation services team to coordinate sedated testing (helping the baby sleep during the test).

As babies get older, hearing testing changes. Your audiologist can measure how your baby turns their head to sound while they sit on your lap. When your child is in preschool, they might be tested while playing a listening game with toys.

If your child's hearing changes

Your audiologist will tell you about ways to help your child communicate with you if testing finds they have hearing changes. If you use spoken language, the doctor might prescribe a hearing device to make sounds and words louder to help your child hear them. Audiologists and their team can also help connect you with early childhood specialists or teachers at your school or clinic to help track your child's language development.

The following audiology centers in Connecticut have the specialized equipment and expertise for infants:

Connecticut Children's	Hartford Farmington Glastonbury	860-545-9642 860-837-6300
Lawrence & Memorial	Waterford	Questions: 860-271-4900 Fax referrals to: 860-271-4801
UConn Speech & Hearing Clinic	Storrs	860-486-2629
Yale-New Haven Children's Hospital	New Haven Trumbull	877-925-3637

Section 2: Hearing and congenital CMV

Preparing for Your Baby's Audiology Appointment

It is always okay to ask the audiology team what to expect before the visit, so that you and your child can feel prepared.

What is an audiologist?

An audiologist is a healthcare professional who is trained to diagnose and manage hearing loss in newborns, children, and adults. Sometimes, they work in medical practices called 'Ear, Nose, and Throat Specialists'.

Someone with hearing loss may be able to hear some sounds, while others may hear nothing at all. There are different types of hearing loss based on the specific problem with one or more parts of the ear(s). A complete assessment of both the type and severity of hearing loss by a pediatric audiologist is important to ensure the most accurate plan for follow-up and management of the hearing loss.

Why is my baby seeing an audiologist?

The hearing testing that your baby received shortly after birth was a screening test. If a baby does not pass the screening test, it tells us that they need to have further testing by an audiologist. If your baby's urine tested positive for congenital CMV, and they passed their hearing test at birth, they still need a full hearing check by an audiologist. A complete evaluation by an audiologist is the only way to know for sure that your baby is hearing all the sounds important for speech and language development.

How long will the appointment take?

Appointments can take 1 to 3 hours. Sometimes it is not always possible to finish a hearing test in 1 appointment. If another appointment is needed, it will be scheduled as soon as possible.

What should I bring with me to my baby's appointment?

- Your insurance card
- A referral if needed
- A current list of medications
- Prior hearing test results and/or evaluations
- Details about any family history of childhood hearing loss
- cCMV testing results, if you have them
- Names/addresses of individuals where you might want the report sent

What do I need to do before the appointment?

The tests are most easily done when your baby is sleeping. To ensure that your baby is asleep during the testing:

- Try not to let your baby nap before the appointment or during the car ride to the clinic.
- Avoid feeding your baby right before the appointment. You will be able to feed your baby at the clinic just before the test.



Section 2: Hearing and congenital CMV

What will happen during the audiology appointment?

The audiologist will collect information about your baby's medical history, the pregnancy, labor, delivery, and family history.

While your baby is sleeping, the audiologist will examine your baby's ears and perform the hearing evaluation. The type of testing performed might include:

- **Auditory Brainstem Response (ABR)**—Sensors will be placed on your baby's forehead and earlobes to measure the brain's response to sounds. Earphones will be placed in each ear to deliver the test sounds. Your baby will not physically respond to the sounds, but the sensors will be able to measure how well your baby is responding to the various sounds. This test helps determine if any hearing loss is present. If hearing loss is present, it can provide information on what type of hearing loss it is.
 - This video shows a baby having an ABR hearing evaluation:
[Mercy: Infant ABR Hearing Screening](#)
- **Otoacoustic Emissions (OAE)**—A soft rubber tip will be placed at each ear to deliver soft sounds and to measure for an echo that occurs when the ear is functioning normally. This test is usually used in combination with other tests to provide the most accurate diagnosis.
- **Tympanometry**—A soft rubber tip will be placed at each ear to measure how well the eardrum moves. This test, when used in combination with other tests, can provide clues about the possible cause of hearing loss.

Will my baby feel any pain?

Your baby will not feel any pain at any point during the hearing testing. Placement of the soft rubber tips and sensors will not harm your baby. Most babies will fuss and wiggle when test equipment is first placed but will calm when held close and swaddled.

Will I get the results of the testing right away?

The audiologist will be able to tell you when the test results will be available and who will be giving you the results. If there are questions about the results, you should contact the audiology clinic.

What if my baby does not sleep through the entire test?

The younger your baby is, the more likely they will sleep through the test, but sometimes an additional appointment is needed. For some older babies, sedation may be recommended by your baby's doctor to help them sleep during the entire time needed for a complete evaluation. To decrease the likelihood of sedation, it is recommended that you make appointments as soon as possible after receiving the congenital CMV diagnosis.

What if something comes up, and I need to reschedule my baby's appointment?

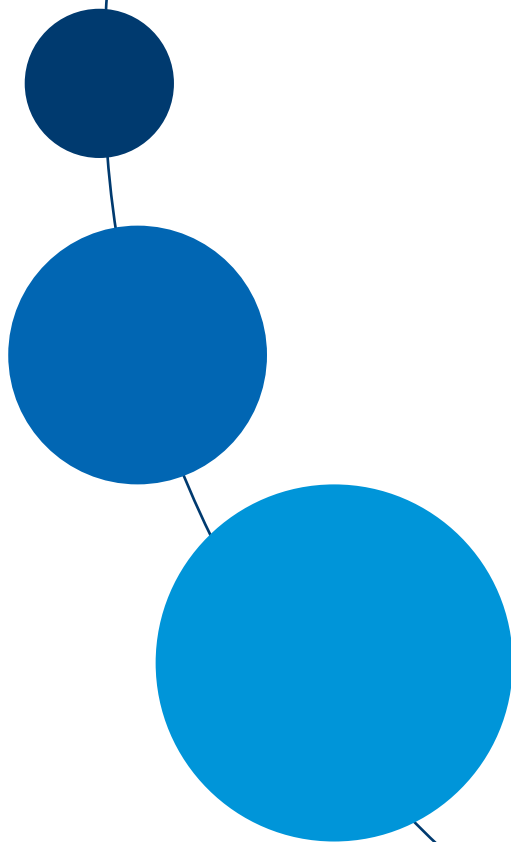
It is very important that your baby sees an audiologist. If you cannot make your scheduled appointment, please reschedule the hearing test right away.





Section 3

Growth and Development



Section 3: Growth and Development

Some babies and young children need extra help to learn and grow. While all young children grow and change at their own rate, some children experience delays in their development. Hearing loss can affect speech and language development. Other health conditions can also affect children's development. Accessing early intervention services as early as possible can help to ensure the best developmental outcomes for these children.

Connecticut has a variety of programs and supports available for all caregivers of young children to help support children's development. For any of these services, call 211 Child Development at 1-800-505-7000 or visit cdi.211ct.org. Your call will be answered Monday to Friday, from 8:00 am to 6:00 pm. All languages can be accommodated.

Help Me Grow

For families with questions about their child's development or behavior

- Care coordinators navigate families to the supports that best meet their needs.
- Families can access free developmental screening – the Ages and Stages Questionnaire – via mail, online, or Sparkler (a mobile app).
- Get connected to community-based supports through local providers.



Birth to Three

For families of infants and toddlers with significant developmental delays or the potential for delays

- Children in CT diagnosed with congenital CMV are eligible for Birth to Three services.
- Developmental evaluation provided at no cost.
- An individualized plan of services and supports.
- Guidance for families to teach age-appropriate skills during daily routines.
- Coordinate support and referrals to community services.



Preschool Special Education

For children who need special education services

- Information on how to make a referral or connect to the local school
- Developmental evaluation provided by the school district staff if there are concerns
- Eligibility based upon an evaluation
- If eligible, special education and related services are identified on an individualized educational program (IEP)

Home Visits

For pregnant women and families of young children who could benefit from in-home support services that promote positive parenting and healthy development

- The CT Home Visiting System welcomes families expecting a baby or having a young child(ren) up to age 5. Home Visiting Programs are available statewide to connect you with a home visitor who will tailor support and services for your unique family, in the home, community, or virtually.

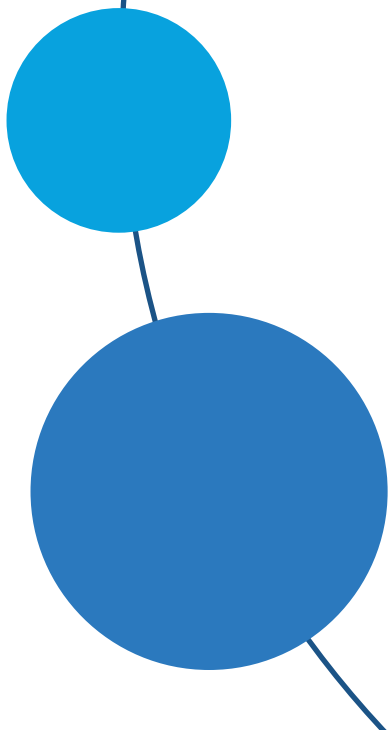


Section 3: Growth and Development

Children and Youth with Special Health Care Needs

For children and youth from birth to age 21 with chronic physical, developmental, behavioral, or emotional conditions who require more health and related services than other children the same age

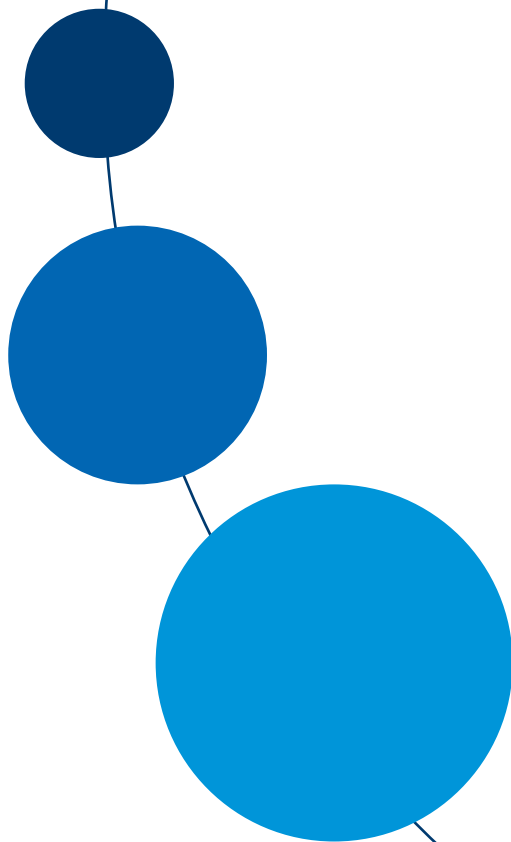
- Service needs assessment
- Family caregiver support
- Respite planning
- Referrals to community-based resources
- Transition Planning





Section 4

Parent and Family Support



Section 4: Parent and Family Support

It is not unusual to feel surprise, confusion, or a range of other emotions if you are told your child has congenital CMV. The following groups may be able to help you find support, resources, and information. When a child is diagnosed with congenital CMV, it can feel overwhelming, but you are not alone.

The videos below were created by the National CMV Foundation and feature families who openly share their experiences having a baby diagnosed with congenital CMV.

[Parent Storytelling Video 2](#)

[Parent Storytelling Video 1](#)

National CMV Foundation

It is the foundation's mission to prevent pregnancy loss, childhood death, and disability due to congenital CMV. Their activities include training local community volunteers, delivering education and outreach, advocating for legislative support, and managing a private CMV family database to connect with others in their region or state. Each year, the group sponsors a national CMV conference, as well as fundraisers and other events. Their website has tips, news items, and other resources for parents and families, childcare providers, and healthcare providers.

Visit National CMV Foundation (www.nationalcmv.org) or email info@nationalcmv.org for more information.

PATH CT

PATH CT offers many programs and services to families of children with special healthcare needs, including parent-to-parent support, a sibling network, help with navigating special education, and general help finding resources that your family may need.

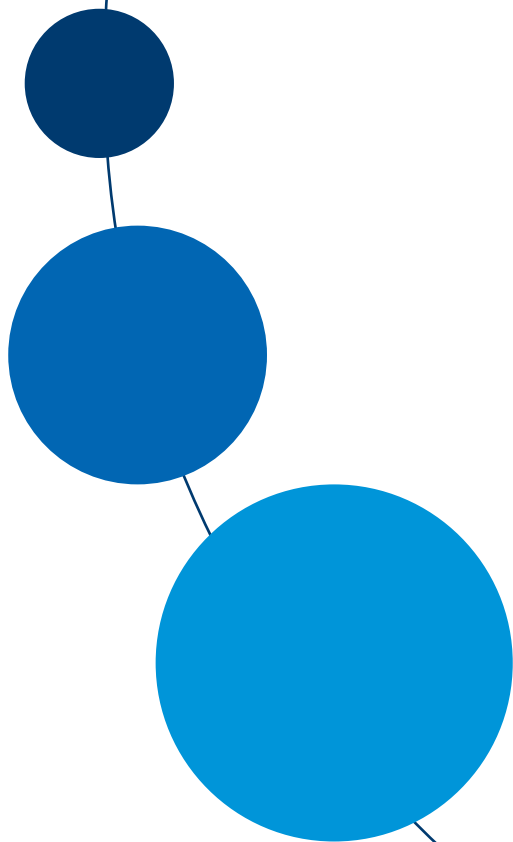
Visit www.pathct.org, call 1-800-399-PATH, or email info@pathct.org for more information.





Section 5

Health Care and
Additional Resources



Section 5: Health Care and Additional Resources

Questions about congenital CMV for your child's primary care provider

Primary care providers are trained to manage many types of health care needs, including regular checkups, ongoing conditions, and illnesses. They may be a doctor, nurse practitioner, or physician assistant, and they are sometimes called a healthcare provider or clinician.

A primary care provider is usually your child's main healthcare provider for day-to-day care. The primary care provider coordinates your child's medical care. They can work in family medicine, pediatrics, or internal medicine.

In addition to getting regular care from a primary care provider, a child with congenital CMV might need to see specialists for more testing and treatment. Specialists are doctors and licensed or certified professionals with extra training in one area of medicine or health. Your child's primary care provider will help decide which specialists your child should see and will make referrals for your child to see them, if needed.

Your primary care provider might recommend that your child see one or more of the following specialists:

Infectious disease (ID) specialist: a doctor who is an expert in diagnosing and treating people with infections. Some infectious disease doctors have specialized training to work with children and are trained as pediatricians before specializing in infectious diseases. They are called pediatric infectious disease specialists.

Audiologist: a licensed professional who tests for and treats hearing loss and balance disorders. Some audiologists have special training to work with children and are called pediatric audiologists.

Ear, nose, and throat specialist (ENT): a doctor who focuses on ear, nose, and throat disorders, including hearing loss.

Neurologist: a doctor who specializes in the brain, spinal cord, and nerves.

Ophthalmologist: a doctor who specializes in eyes and vision care.

Orthopedist: a doctor who specializes in treating issues related to bones, joints, and muscles.

Early intervention provider: a support services person for children from birth to age 3 who have or are at risk for developmental delays.

Occupational therapist (OT): a professional who helps children develop or improve everyday living activities and skills.

Physical therapist (PT): a professional who helps children improve their body's range of motion, strength, flexibility, and movement.

Speech-language pathologist: a professional trained to test and work with children with speech and language challenges.



Section 5: Health Care and Additional Resources

Questions to ask your healthcare providers

Answers to these questions from your child's primary care provider may help you better understand your child's condition and possible care.

Information was adapted from CDC: Questions You May Want to Ask Your Child's Medical Professional (PDF) on the Hearing Loss in Children Resources (www.cdc.gov/hearing-loss-children/communication-resources/index.html) webpage.

- Have you treated other babies and children with congenital CMV?
- Will you need to see my child more often because they have congenital CMV? How often?
- Should my child see specialists for their congenital CMV? What type of specialists?
- How do I get medical referrals to see specialists if my child needs their services? If I have problems with the referrals, or if my insurance company has questions, what should I do?
- Can your office help me coordinate appointments?
- How do we make sure reports from specialists are shared with you? How will I get copies of all reports from specialists?
- How often will screening for development and behavior take place for my child? How will I know the results of the screening?
- Can you tell me about early intervention services in my area? Has a referral for services been completed for my child?



Section 5: Health Care and Additional Resources

Additional Resources

The Connecticut Newborn Screening Network

The Newborn Screening Network can help connect you with doctors and specialists for diagnostic testing, answer questions about your baby's newborn screening results, and help you find resources in your area. The Network helps families with questions and concerns while follow-up testing is done after the initial newborn screen report. If your baby does receive a diagnosis, Network staff will check in at regular intervals after the diagnosis to see how your family is doing and if you could benefit from any additional support. The Network can be reached by phone at 860.837.7870 or by [email](#).

[Learn more about the Connecticut Newborn Screening Network here.](#)

The Connecticut Newborn Screening Program at the Connecticut Department of Public Health (DPH)

The Connecticut Newborn Screening Program (CT NBS) is a public health program that screens all babies born in the state for many serious but treatable metabolic and genetic disorders, including cCMV.

[Learn more about the newborn screening in Connecticut here.](#)

The Connecticut Early Hearing Detection and Intervention (EDHI) Program

EHDl refers to the process of identifying and serving infants with hearing loss. The mission of the Connecticut EHDl program is to ensure that all Connecticut-born infants receive the appropriate hearing screenings, congenital CMV screenings, diagnostic hearing evaluations, and intervention services to maximize developmental outcomes without bias towards communication modes and methods. Learn more about the Connecticut EDHI Program here:

[Home page -Early Hearing Detection and Intervention Program Home Page](#)

Center for Care Coordination

The Connecticut Children's Center for Care Coordination addresses the medical, social, developmental, behavioral, educational, and financial needs of families to achieve healthy development for children. This can include help with insurance, food, diapers, housing, transportation, and other support.

[You can learn more about the Center for Care Coordination here.](#)

Hands and Voices

Hands and Voices is dedicated to supporting families with children who are deaf or hard of hearing without a bias around communication modes or methodology. As a parent-driven organization, they provide families with resources, networks, and information to improve communication, access, and educational outcomes for their children. Their outreach activities, parent-professional collaboration, and advocacy are focused on empowering children who are deaf or hard of hearing to reach their full potential. For more information, [visit www.handsandvoices.org](http://www.handsandvoices.org) or email info@cthandsandvoices.org or mzito@cthandsandvoices.org

Connecticut Family Support Network (CTFSN)

CTFSN offers support to families raising children with intellectual disabilities, developmental disabilities, or special healthcare needs in Connecticut by providing information and resources and helping them connect with services. CTFSN maintains a database of programs and services for individuals who are deaf, hard of hearing, or at risk of hearing loss. You can learn more about CTFSN here:

[Deaf or Hard of Hearing Support - CT Family Support Network](#)

Section 5: Health Care and Additional Resources

National CMV Foundation

The National CMV Foundation's mission is to prevent pregnancy loss, childhood death, and disability due to congenital CMV. Their activities include training local community volunteers, delivering education and outreach, advocating for legislative support, and managing a private CMV family database to help families connect with others in their region or state. The group sponsors a national CMV conference, as well as fundraisers and events, each year. Their website offers tips, news items, and resources for parents, families, childcare providers, and healthcare professionals.

Visit the National CMV Foundation (www.nationalcmv.org) or email info@nationalcmv.org for more information.

Connecticut AG Bell Foundation

The Connecticut Chapter of AG Bell offers local families with children who are deaf or hard of hearing opportunities to connect with other families and professionals through social events and educational workshops across the state. To learn more, visit <https://directory.agbell.org/Connecticut-chapter> or email ctchapter@agbell.org

Perkins School for the Deafblind

The Deafblind School offers comprehensive educational services to students ages 3-22 who are deafblind. The education uses a developmental approach, stressing language and communication development, individualized instruction, and age-appropriate curriculum in a total communication environment.

For more information, visit <https://www.perkins.org/school/deafblind/>