Congenital Cytomegalovirus:

A Parents Guide for Navigating Hearing Loss

University of Iowa
Department of Communication Sciences and Disorders

Last Updated **May 28, 2025**

Dear Parents,

Your child’s diagnosis may be the first time you have heard of **congenital cytomegalovirus (cCMV) —** and that’s completely okay. It’s natural to have many questions, concerns, and emotions. Although not widely known, cCMV affects approximately **1 in 200 children,** and every family’s experience is different. Please know: **you are not alone on this journey**.

As Doctor of Audiology students at the University of Iowa, we’ve had the privilege of learning from and supporting families like yours. Their insights inspired us to create this booklet, which focuses on **hearing-related information** that may be relevant to your child’s care.

While this booklet is not exhaustive, it’s meant to serve as a helpful guide through the **screening, diagnosis, and hearing management process.** Inside, you’ll find answers to common questions and a collection of **local and national resources** to support your family every step of the way.

With care and support,
The University of Iowa Audiology Team

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What is CMV?

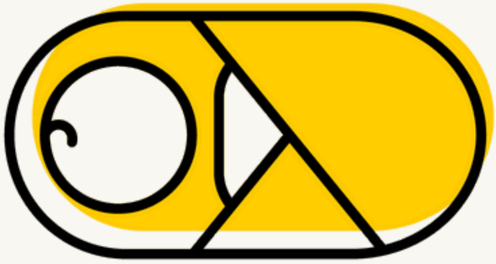
What is CMV?

Cytomegalovirus (CMV) is a common virus that most people will encounter at some point in their lives. A member of the herpes virus family, CMV infection typically presents as mild cold-like symptoms in the general population. Most people with CMV infection will have no symptoms at all, while others may experience a sore throat, fever, and fatigue. Many healthy children and adults will not know they have contracted CMV, but the virus may become more serious in those who are immunocompromised or are pregnant.

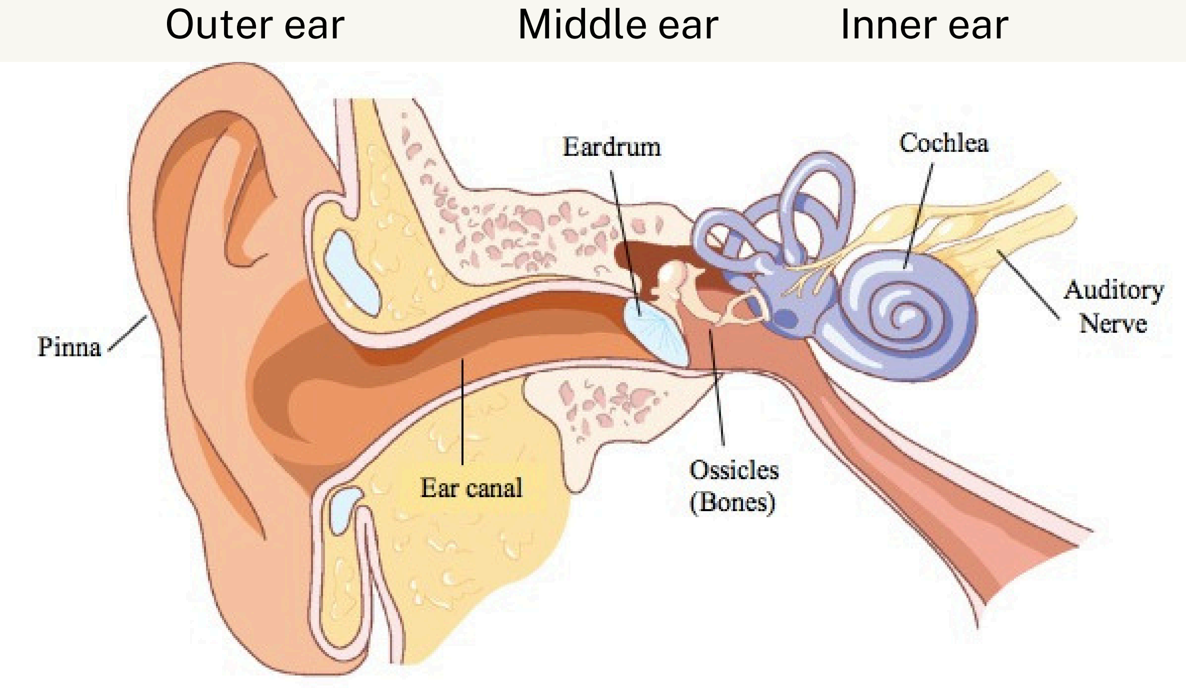
CMV infection is primarily transmitted through bodily fluids, such as blood, urine, saliva, tears, and breast milk. After a person contracts CMV, the virus remains inactive in their body for life. Expectant mothers should take special precautions during pregnancy, as contracting an active CMV infection may cause symptoms and complications in the infant following birth. If an infant contracts the virus in utero, this is referred to as congenital cytomegalovirus (cCMV). cCMV can lead to complications in infants, such as hearing loss, vision problems, intellectual delays, seizures, or growth problems.

02

Newborn Hearing Screening



How We Hear



Our ears consist of three different parts: outer ear, middle ear, and inner ear.

The outer ear consists of the pinna and the ear canal. The pinna and ear canal are responsible for funneling sound into the rest of the ear.

The middle ear consists of the eardrum and a chain of three tiny bones. When sound waves travel into the ear canal, it causes the eardrum and chain of bones to vibrate. These vibrations push the sound further into the inner ear.

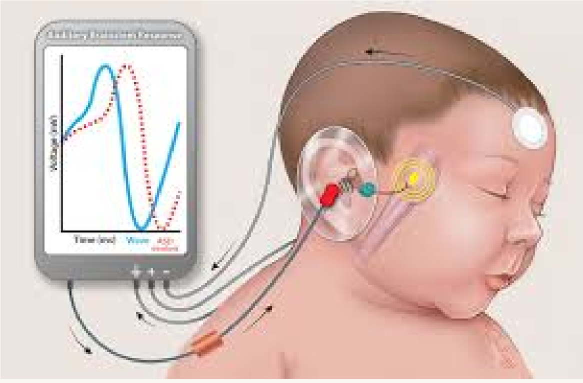
The inner ear consists of a snail-shell-shaped organ called the cochlea. The cochlea is filled with fluid. When the middle ear bones vibrate, the fluid in the cochlea moves. The fluid movement excites thousands of tiny hair cells in the cochlea. These hair cells send electrical signals to the brain via the auditory nerve. The brain is able to interpret these signals as sound.

Hearing loss can be caused when one or more parts of our ear does not work properly.

Otoacoustic Emission Testing

Otoacoustic emission (OAE) testing is an objective hearing test that is often used in hearing screenings of newborns and young children. The test involves placing a foam earphone in the ear canal that plays various tones. These sounds travel through the child’s ear canal all the way to their cochlea. There are tiny hairs in the cochlea, and if they are functioning properly, the tiny hairs will generate faint sounds or emissions. The emissions travel back through the ear and are picked up by the foam headphone.

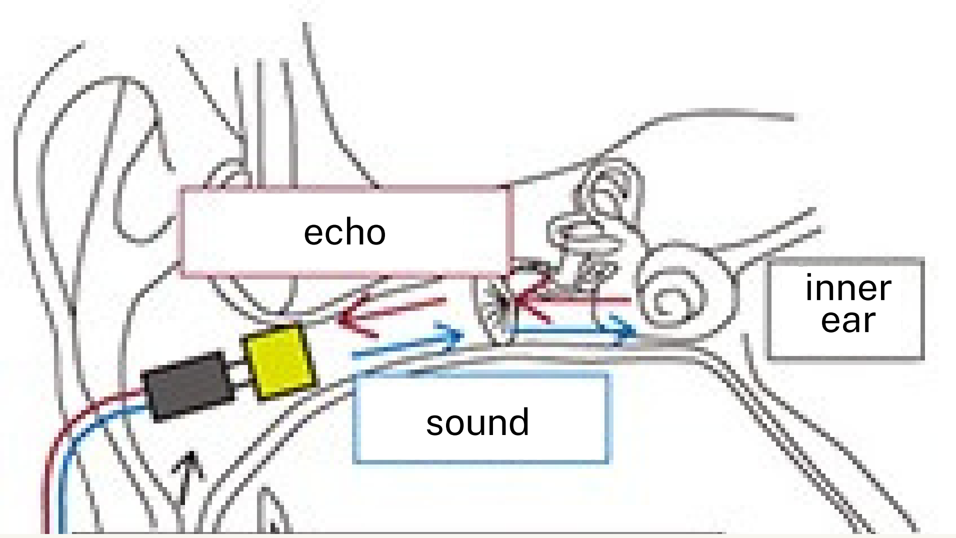
When a child has otoacoustic emissions, screeners will say they “passed” the screening. If these emissions are not detected by the foam tip, screeners will say the child “referred” because they cannot rule out hearing loss. The next step they may recommend is a test called an auditory brainstem response (ABR).



Otoacoustic Emissions

Otoacoustic emissions (OAEs) test the function of a type of hair cell in the cochlea. A small rubber earphone is placed in the ear, and different sounds are played.

Our hair cells, if working correctly, will send an "echo" of the sound back out of the ear. The earphone placed in the ear measures these "echoes."



Absent OAEs can indicate a problem in the middle or inner ear. OAEs are typically used to screen hearing of newborns and infants. They can also be used when behavioral testing is not possible yet.

Auditory Brainstem Response Testing

Auditory brainstem response (ABR) test is another objective way of assessing a child's hearing status. The ABR tests the function of the auditory system from the outer ear to the brain. During the test, a earphone in the child's ear will play sounds or clicks that travel through the hearing system. Electrodes placed on their head will measure brain activity while they listen to those sounds. The test doesn't require any movement or active response from the child, making it the perfect assessment of hearing.

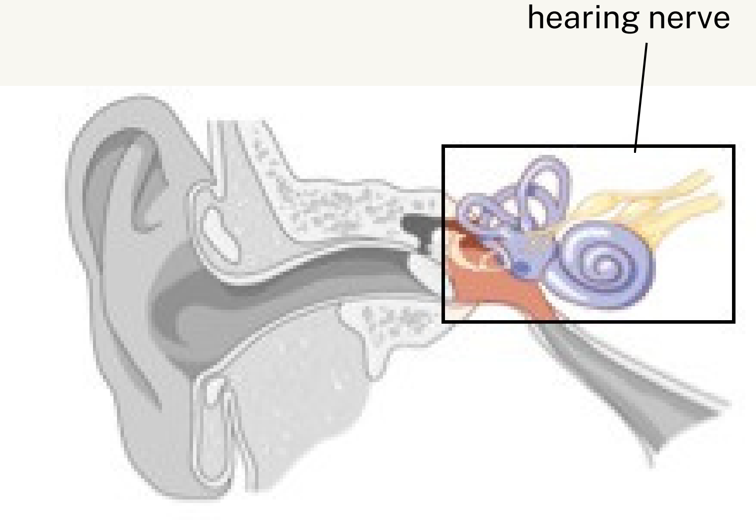
Often times, a screener version of this test called automated auditory brainstem responses (AABR) will be completed. Like OAEs, the result will either be "pass" or "refer." If the child passes, no further testing is needed; however, if the child refers, a diagnostic ABR will be scheduled.

The diagnostic ABR will confirm if the child has hearing loss or not, as well as determine the severity of the hearing loss. From here, the audiologist will work with the family to determine next steps.

Auditory Brainstem Response

Auditory brainstem response (ABR) testing measures how the hearing nerve responds to sounds. A shortened version of an ABR can be used to screen a newborn's hearing. Foam-tipped earphones are placed in your baby's ears and sensors are placed on their head.

Different sounds are played into the earphones. The sensors measure responses from the hearing nerve. With this test, the audiologist can find the softest sound that the hearing nerve will respond to. In a complete ABR, these responses give a pitch-specific estimation of your child's hearing in each ear.



Your child must be asleep in order to record these responses. For infants age birth to 6 months, ABR testing can be done during natural sleep. For infants older than 6 months, then the ABR testing might be done under sedation in order to get the best results.

Summary

Otoacoustic Emissions (OAEs) and Auditory Brainstem Response (ABR) testing are the most commonly used and reliable objective tools to estimate a child's hearing status — especially when behavioral responses are not yet possible, such as in newborns and infants. These tests are non-invasive and can help identify potential hearing concerns early in life.

While they do not measure hearing in the same way as behavioral tests, they provide valuable information about how well parts of the auditory system are functioning.
If a child does not pass these screenings, follow-up diagnostic testing is recommended to confirm hearing ability and guide the next steps in care and management.

03

Testing for cCMV

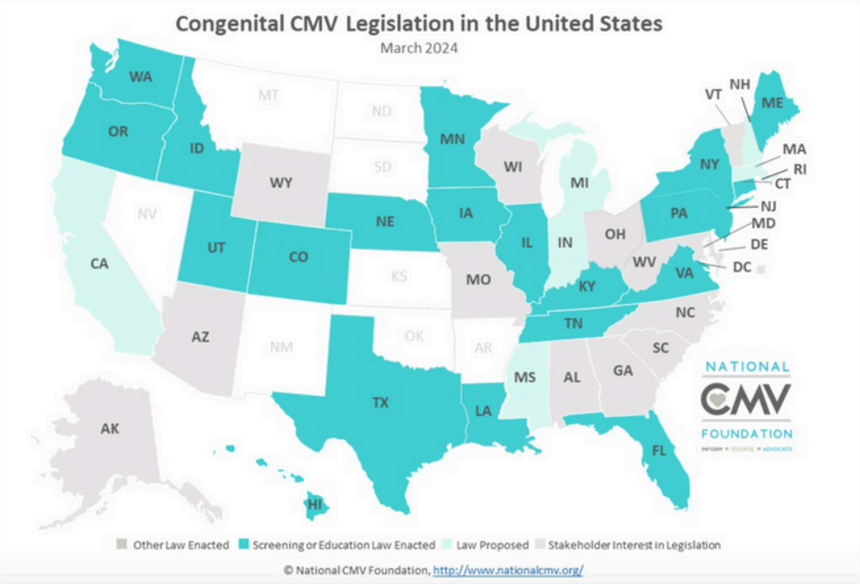
Screening for CMV

Currently, there are no universal or standardized protocols for screening all newborns for congenital cytomegalovirus (cCMV) at birth. However, a growing number of U.S. states now require targeted cCMV testing for babies who refer on their newborn hearing screening or present with physical signs suggestive of a viral infection.

If a baby is referred or symptomatic, cCMV testing can be performed using saliva, urine, or blood samples. To confirm that the infection is congenital (present at birth), testing should be conducted within the first 21 days of life. In some cases, a provider may also request testing of the baby’s leftover dried blood spot (used for standard newborn screening) to assess for cCMV, especially if symptoms are present.

Screening for CMV

As of March 2024, 21 states have enacted CMV-related legislation. In 2017, Iowa became the 9th state to pass such legislation (Senate File 51), which mandates public education about cCMV and targeted testing for newborns who do not pass their hearing screening.



Congenital CMV Legislation in the United States

March 2024

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In Iowa, congenital CMV (cCMV) is automatically recognized as a qualifying condition for early intervention services, ensuring that eligible children can access support as early as possible. For more information, visit the National CMV Foundation.

04

Hearing Loss and cCMV

Hearing Loss and cCMV

The development of hearing loss is a major concern for infants diagnosed with **congenital cytomegalovirus (cCMV)** at birth. In the United States, cCMV is recognized as the **leading cause of non-genetic sensorineural hearing loss** in children.

While hearing loss is common among children with cCMV, its presentation can vary widely. It may affect **one or both ears, worsen over time, or even fluctuate**. Hearing loss may be **present at birth** or may have a **delayed onset**, developing months or even years later. This variability highlights the critical need for **ongoing audiological monitoring** in children diagnosed with cCMV — even if they pass their initial newborn hearing screening.

What to Watch For:
Early Signs of Hearing Loss

Since hearing loss related to cCMV can be present at birth, develop later, or change over time, it's important for parents to stay alert — **even if their child passed the newborn hearing screening**. Being aware of the early signs of hearing loss can make a big difference in getting timely support and care.

According to the Centers for Disease Control and Prevention (CDC, 2024), here are some common signs of hearing loss in infants and young children:

- Doesn't startle at loud noises
- Doesn't turn toward sounds or their name
- Isn't saying simple words like "mama" or "dada" by age 1
- Has delayed or unclear speech
- Struggles to follow directions
- Often turns up the volume on the TV or other devices

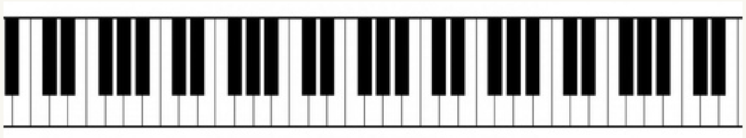
If you notice any of these signs, don't hesitate to talk to your child's pediatrician or audiologist. Early identification helps ensure your child receives the support they need to thrive in their communication and development. For more information, visit U.S. Center for Disease Control CMV

Understanding Your Child's Audiogram

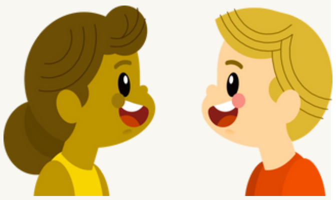
The results from your child's behavioral testing is plotted on an audiogram. Audiograms show the results from listening to different sounding beeps. The lines of the graph are your child's "thresholds." Thresholds are the softest sound that your child can hear.

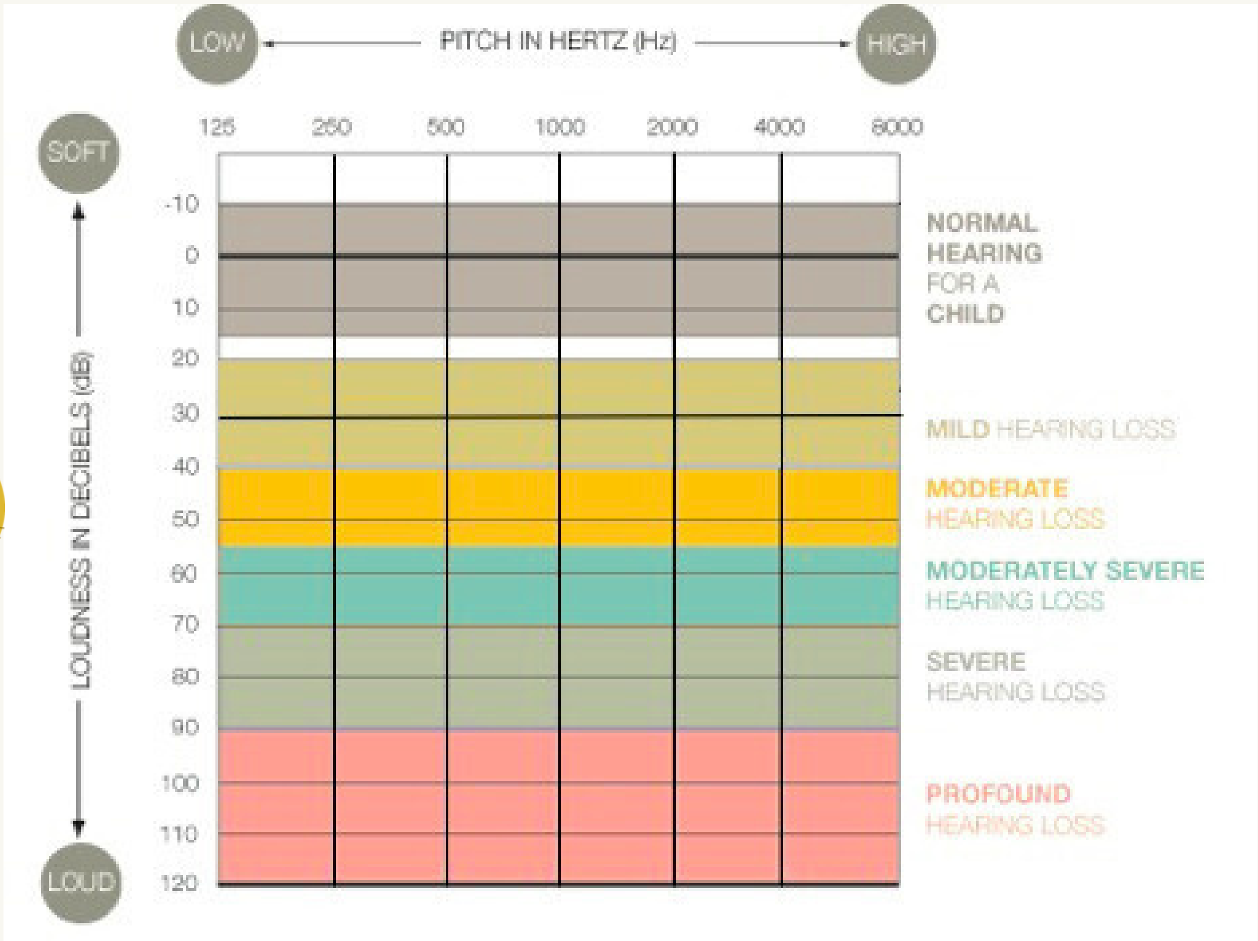
Moving from left to right are the different pitches, or frequencies. Low pitches, or deep sounds, are on the left and high pitches, or squeaky sounds, are on the right. This is the same as how a piano is organized.

Moving from the top to the bottom are the different volume levels of the sounds. Soft sounds are at the top, and loud sounds are towards the bottom.



X = left ear
O = right ear





05

Beyond Hearing: Other Developmental Impacts of cCMV

Beyond Hearing: Other Developmental Impacts of cCMV

While this booklet focuses on hearing loss caused by **congenital cytomegalovirus (cCMV)**, it's also important to understand that cCMV can affect a child's development in other ways. I**n addition to hearing differences**, some children may experience:

- **Vision loss**
- **Behavioral or sensory differences**
- **Cognitive differences**
- **Seizures**

cCMV can also lead to certain birth defects, such as:

- **Cerebral palsy**
- **Microcephaly** (a smaller head size)
- **Decreased motor function**
- In rare cases, **fetal death**

One of the best predictors of how cCMV may affect a child is whether or not they show symptoms at birth. According to the **National CMV Foundation**, about **90% of babies born with cCMV are asymptomatic at birth** and are likely to experience **typical development**. However, because symptoms can develop later, **ongoing monitoring** by parents and physicians is essential.

Research shows that babies who **do** show symptoms at birth are more likely to experience the developmental challenges listed above — and often with greater severity.

06

Family Stories

Hearing Their Stories: Life After cCMV Diagnosis

The following stories represent just a few of the many experiences families have had after receiving a congenital CMV (cCMV) diagnosis. While they don't reflect every possible outcome, these real-life examples offer a glimpse into the diverse journeys children and their families may face. Each story highlights different aspects of the process, including newborn hearing screening results, cCMV testing, the child’s hearing and amplification journey, and developmental outcomes. The cases also show the wide range of how hearing loss can present in children with cCMV — from normal hearing, to referral at birth, to fluctuating or progressive hearing loss.

These stories also explore various paths families take with hearing devices and amplification, showing how care plans are tailored to each child’s unique needs.

6.1 Typical Hearing Outcomes with cCMV

While cCMV is a leading cause of non-genetic hearing loss in children, not every child diagnosed with cCMV will experience hearing differences. The following stories feature children who were diagnosed with cCMV but have maintained **typical hearing and language development** to date.

These cases illustrate the importance of:

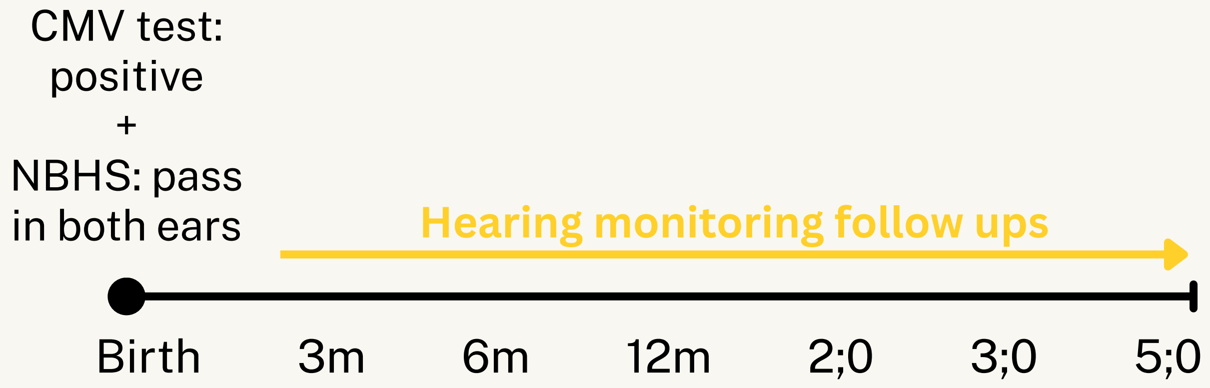
- **Ongoing hearing monitoring**, even when newborn screening is passed
- The **varied ways cCMV can be diagnosed** — before or after birth
- The **emotional and clinical experiences** that families navigate after a diagnosis

Bella, Tommy, and Sarah each show a different path within the cCMV journey — but all highlight the value of continued follow-up and awareness.

Bella’s Story: Typical Hearing

At 21 weeks gestation, baby Bella was diagnosed with Intrauterine Growth Restriction. After completing a panel of tests, her pediatrician determined she had elevated CMV antibodies. Just 13 weeks later, she was born at 34 weeks and 6 days. Through the CMV cheek swab, doctors confirmed she had CMV. Her overall health was monitored for the next year, and routine hearing tests indicated she had no significant hearing loss or language delays.

Bella’s mom is a healthcare worker, so she had heard of CMV previously; however, she was disappointed she never received education on how to prevent CMV. Her experience highlights a gap in prenatal education — even among healthcare professionals. Bella’s story is a reminder that cCMV awareness and prevention should be part of routine prenatal care for all parents.


CMV test:
positive
+
NBHS: pass
in both ears

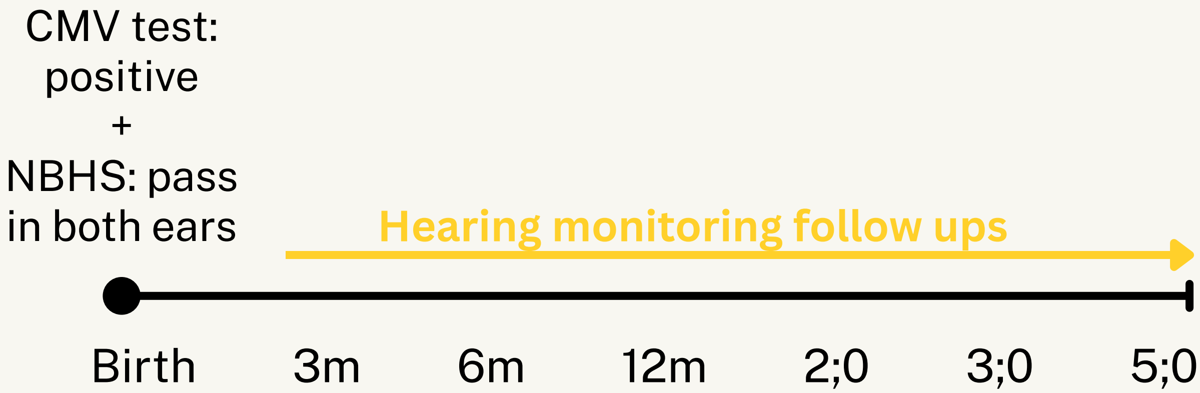
Hearing monitoring follow ups

Birth 3m 6m 12m 2;0 3;0 5;0

Tommy’s Story: Typical Hearing

Tommy’s mom was diagnosed with CMV when she was in her first trimester of pregnancy. She felt like she had an intense cold that she likely got from her toddler, who goes to daycare.

After the diagnosis, Tommy’s mom received antiviral infusions monthly until she gave birth. When Tommy was born, he passed his newborn hearing screening, but his mom still had concerns about her CMV diagnosis and the impact it might have on Tommy. The nurses completed a CMV swab on Tommy, and the results came back positive for cCMV. As a result, he receives regular hearing tests to monitor his hearing changes and has remained asymptomatic to date.



CMV test:
positive
+
NBHS: pass
in both ears

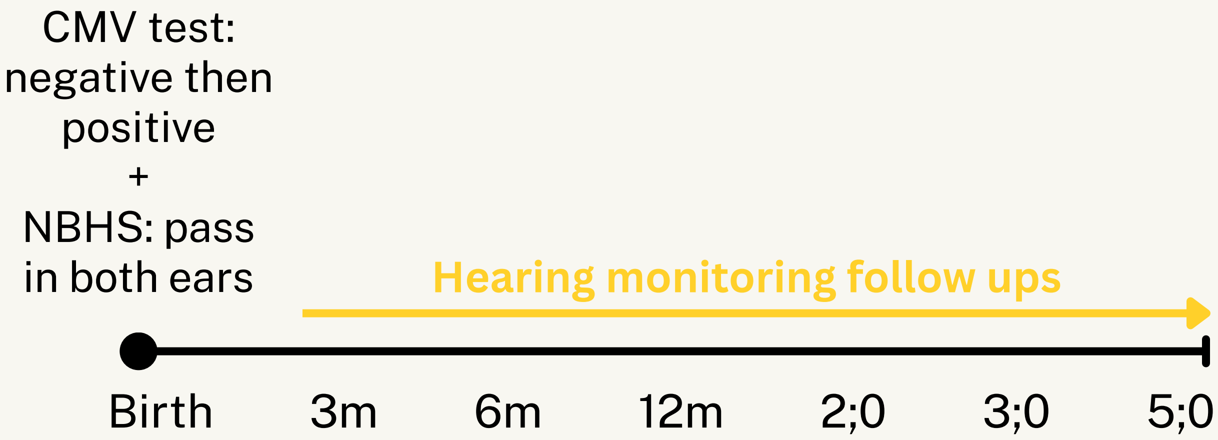
Hearing monitoring follow ups

Birth
3m
6m
12m
2;0
3;0
5;0

Sarah's Story: Typical Hearing

Sarah's mom contracted the CMV infection when she was 27 weeks pregnant and gave birth to Sarah when she was 39 weeks pregnant. Sarah's first CMV swab showed she was negative for cCMV infection. At a well baby check two weeks later, Sarah was tested again for CMV. This time, she tested positive.

After the positive diagnosis, Sarah's parents were advised to schedule hearing and vision screenings every 3-6 months in case any changes should occur. Sarah is now 3 years old and remains asymptomatic.



CMV test:
negative then
positive
+
NBHS: pass
in both ears

Hearing monitoring follow ups

Birth
3m
6m
12m
2;0
3;0
5;0

6.2. Early Significant Hearing Loss and cCMV: Three Case Examples

The hearing journeys of Brady, Ciera, and Ellie highlight the diverse and often complex experiences families face when a child is identified with hearing loss, particularly when (cCMV) is involved. All three children did not pass their newborn hearing screening, which led to diagnostic ABR testing confirming bilateral hearing loss, with degrees ranging from residual to profound. Each family was referred to early intervention services, with parents playing a critical advocacy role in pursuing further evaluations and seeking out communication supports, including sign language and hearing technology.

These stories emphasize the importance of:

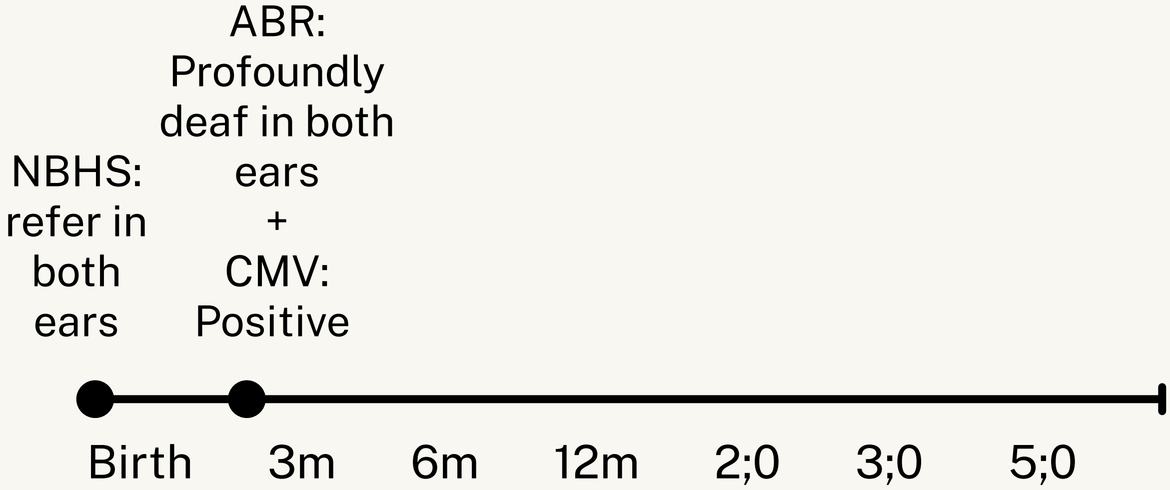
- **Early detection through newborn hearing screening**, even when no outward symptoms are present
- **Timely and accurate diagnosis**, including CMV testing following a failed hearing screen
- **Strong family advocacy and individualized care**, from hearing technology to communication and educational planning

While each child's path is unique, their experiences reinforce the value of ongoing follow-up, early support, and collaborative care to ensure the best possible outcomes for children with hearing loss linked to cCMV.

Brady’s Story: Early Significant Hearing Loss

When Brady was born, he did not pass his newborn hearing screening. After not passing the screening, he was referred for a diagnostic ABR at 6 weeks to determine if Brady had any hearing loss. The audiologist determined that he was profoundly deaf in both ears.

Brady’s mom was surprised by this news and asked Brady’s pediatrician for further testing to determine the cause of his hearing loss. At first, his pediatrician did not want to test for CMV because Brady was not exhibiting typical CMV symptoms. However, Brady’s mom continued to advocate for him to receive this test. Brady’s tests concluded that Brady did have cCMV.

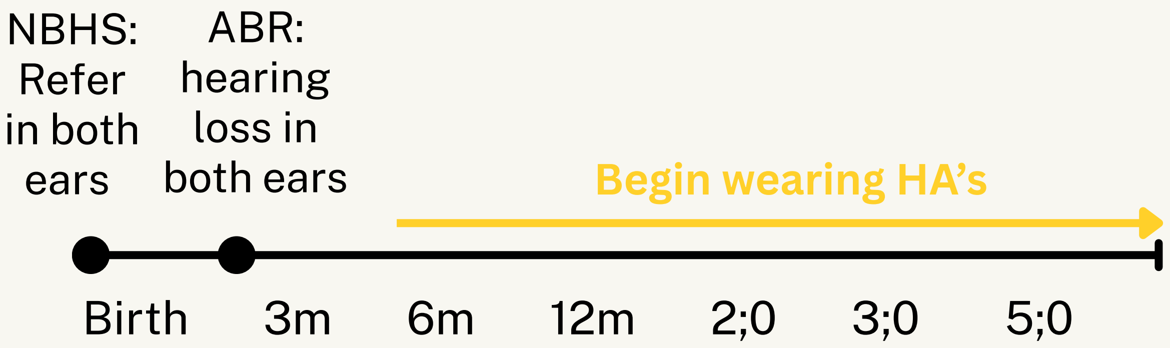


Ciera’s Story: Early Significant Hearing Loss

Ciera’s mom was at a doctor’s appointment for a 35-week prenatal appointment when the doctor shared that the baby had low weight and the baby’s bones were not growing properly.

After careful monitoring, the doctor made the decision to induce Ciera’s mom early at 37 weeks because Ciera was not getting adequate blood flow from her mom.

Shortly after she was born, Ciera received her newborn hearing screening, which she did not pass. Hearing loss was confirmed after receiving a diagnostic ABR test several weeks later. It was determined Ciera had residual hearing, and she was fit with hearing aids bilaterally.

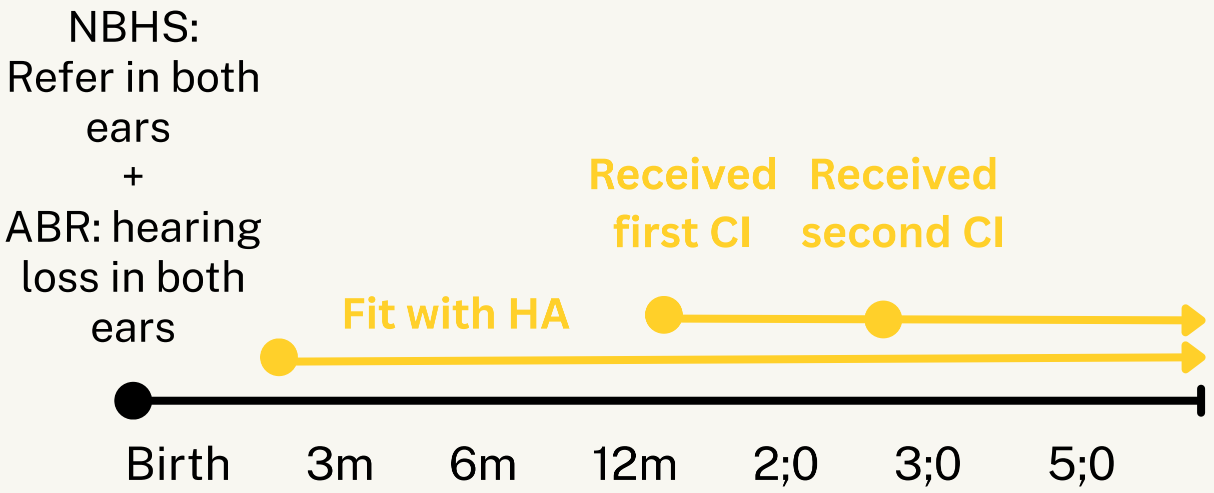


Ellie’s Story: Early Significant Hearing Loss

At 24 weeks pregnant, Ellie’s mom found out she had CMV. 11 weeks later, Ellie was born at 35 weeks gestation.

She did not pass her newborn hearing screening in either ear and was fit with her first hearing aid at 6 weeks of age. Routine hearing tests showed Ellie’s hearing loss progressed quickly. At 12 months of age, she received her first cochlear implant. At 23 months of age, she received her second cochlear implant. Upon diagnosis, Ellie enrolled into Early Intervention, and her parents began learning and using sign language to communicate with her.

At 3 years old, Ellie began attending a deaf/hard of hearing preschool where total communication was used. Now in kindergarten, she attends an auditory-oral school.



6.3 Fluctuating Hearing Loss and cCMV

While cCMV is most often associated with permanent sensorineural hearing loss, in some cases, hearing loss may fluctuate — changing in severity over time, sometimes improving temporarily or worsening unexpectedly.

Although fluctuating hearing loss is less common, it presents unique challenges for families and providers, including:

- Inconsistent responses to sound in daily life
- Difficulty in determining the best timing and type of amplification or intervention
- The need for frequent hearing evaluations to track changes

This pattern highlights the importance of:

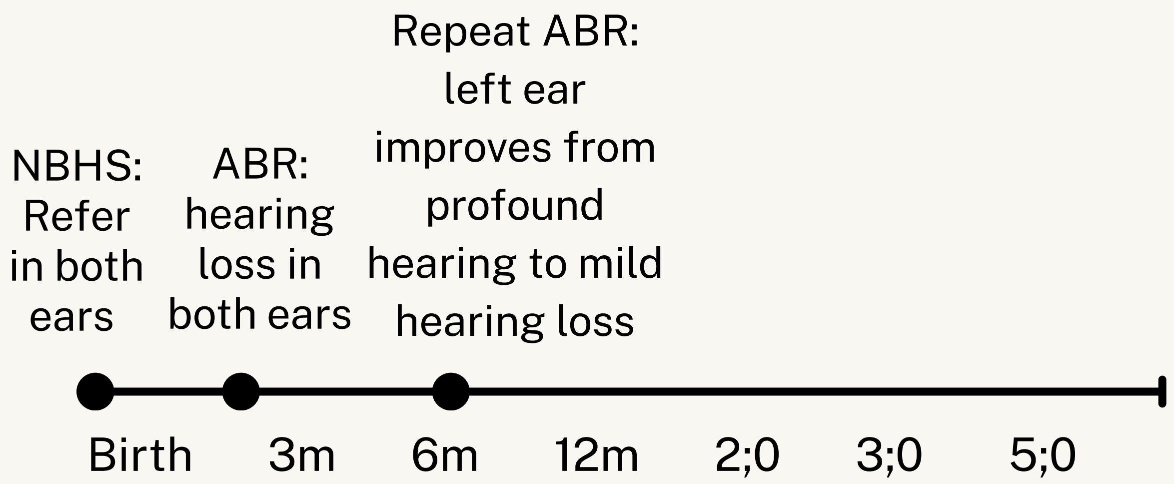
- **Ongoing hearing monitoring**, even after initial diagnosis
- **Clear communication with families** about the possibility of change in hearing levels
- **Flexible intervention** planning that adapts as the child's hearing status evolves

These cases remind us that cCMV-related hearing loss can be unpredictable — not only in onset and severity, but also in stability — and underscore the value of a personalized, responsive care approach for each child.

Haedyn’s Story: Fluctuating Hearing Loss

Immediately after Haedyn was born, doctors discovered she had an enlarged liver and spleen, low platelets, jaundice, and no brain calcifications. Her vision appeared normal, but she did not pass her newborn hearing screening. Two months later, a diagnostic ABR showed Haedyn had profound hearing loss in the right ear and severe hearing loss in the left ear. The most recent ABR results indicated Haeydn still has a profound loss in her right ear, but her left ear now indicates a mild hearing loss.

This change in hearing is known as a fluctuating hearing loss, which refers to hearing thresholds that get better or worse over time. While fluctuating hearing losses are less common than progressive hearing losses, they are important to identify so clinicians can provide appropriate ranges of amplification for the child.



6.4 Progressive Hearing Loss with cCMV

In some children with cCMV, hearing loss may not be present at birth but instead develops or worsens over time. This type of progression can delay diagnosis and intervention if routine hearing monitoring is not in place. The stories of Sloan, Lindsey, and Jackson highlight how cCMV-related hearing loss can emerge gradually, even after a newborn passes initial hearing screenings.

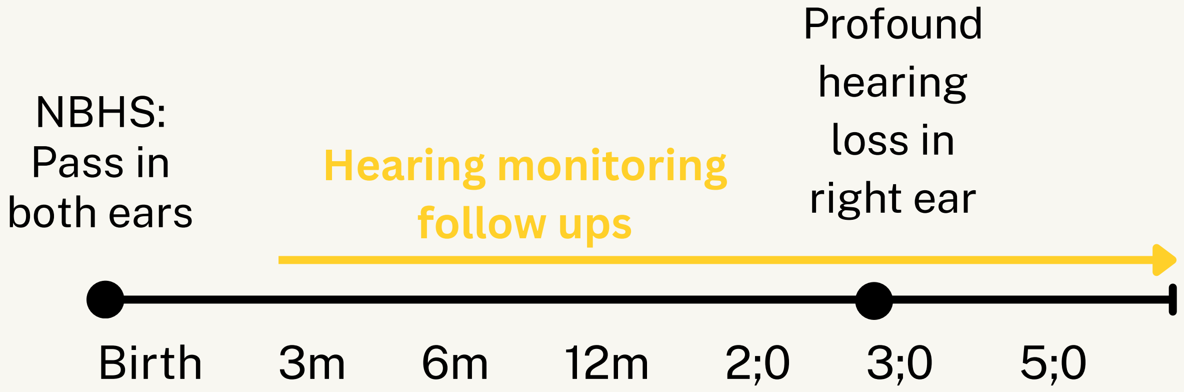
These cases illustrate the importance of:

- **Ongoing hearing monitoring**, even when a baby passes the newborn hearing screen
- **Awareness of progressive patterns**, which are common in children with cCMV
- **Early diagnostic testing and timely intervention**, including cochlear implants and hearing aids
- **Parental involvement and communication planning**, especially when sign language is used as a primary mode of communication

Sloan, Lindsey, and Jackson were each diagnosed months or years after birth, with hearing loss ranging from unilateral to bilateral and mild to profound. Despite the delay in onset, all three children were entered in early intervention services and communication supports — demonstrating how routine follow-up and parental awareness are essential to ensuring children with cCMV receive the care they need to thrive.

Sloan's Story: Progressive Hearing Loss

When Sloan's mom was in the first trimester of her pregnancy, she had a long-standing cold, which caused doctors to do several tests, including the CMV swab. The CMV swab came back positive. As a result, Sloan contracted cCMV in utero. Sloan was born asymptomatic, but at a hearing test when she was two years old, she was diagnosed with a profound hearing loss in her right ear.



NBHS:
Pass in
both ears

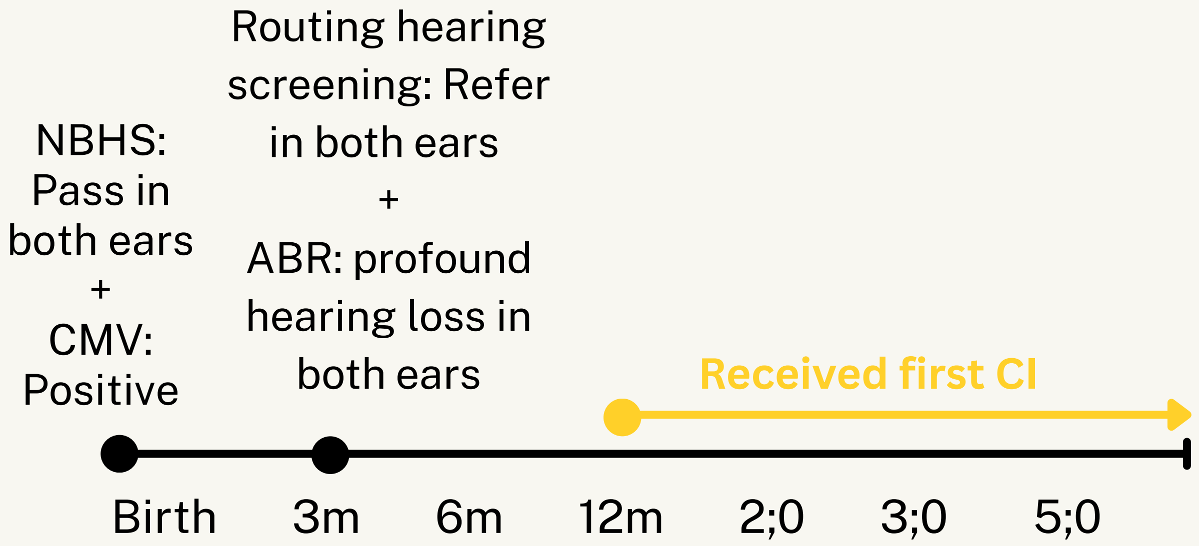
Hearing monitoring
follow ups

Profound
hearing
loss in
right ear

Birth 3m 6m 12m 2;0 3;0 5;0

Lindsey's Story: Progressive Hearing Loss

When Lindsey was born, she was transferred to the NICU to receive care for breathing difficulties, an unexplained rash, and an enlarged liver/spleen. In the NICU, Lindsey was tested for CMV, which came back positive. While she passed her initial newborn hearing screening, at a routine 3 month screening, she did not pass. This warranted a diagnostic ABR. The test found she had a profound hearing loss in both ears. After learning the news, Lindsey's parents decided to move forward with left and right cochlear implants, and she was implanted before her first birthday.



NBHS:
Pass in
both ears
+
CMV:
Positive

Routing hearing
screening: Refer
in both ears
+
ABR: profound
hearing loss in
both ears

Received first CI

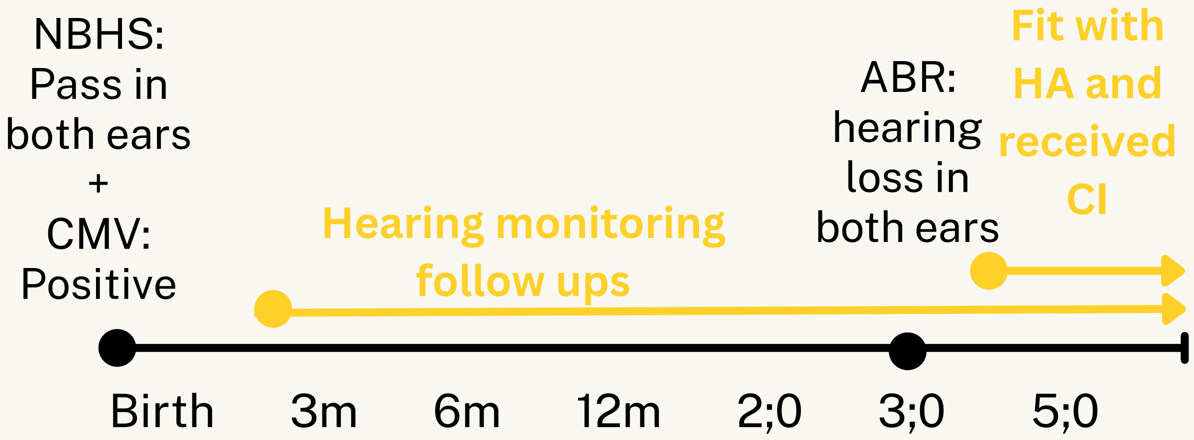
Birth 3m 6m 12m 2;0 3;0 5;0

Jackson’s Story: Progressive Hearing Loss

Shortly after Jackson was born, he was rushed to the NICU because his breathing, liver functioning, and white blood cell counts were concerning to the doctors. One of the many tests Jackson had in those first few days was the CMV swab, which was positive.

When his hearing was screened in the NICU, Jackson passed the screening, so no further testing was completed. However, since progressive hearing loss is very common in children who have CMV, he had routine hearing tests. When Jackson was two years old, a diagnostic ABR found he had a profound hearing loss in his left ear and a moderate hearing loss in his right ear. A few months later, he received a left cochlear implant and a right hearing aid.

Jackson’s primary means of communication is sign language, which he is excelling at!



NBHS: Pass in both ears + CMV: Positive

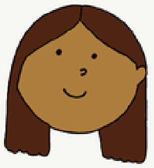
Hearing monitoring follow ups

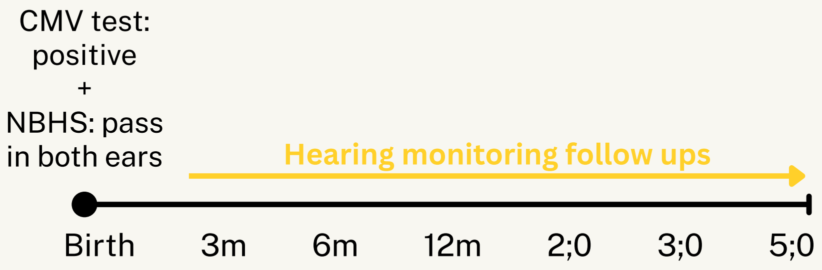
ABR: hearing loss in both ears

Fit with HA and received CI

Birth 3m 6m 12m 2;0 3;0 5;0

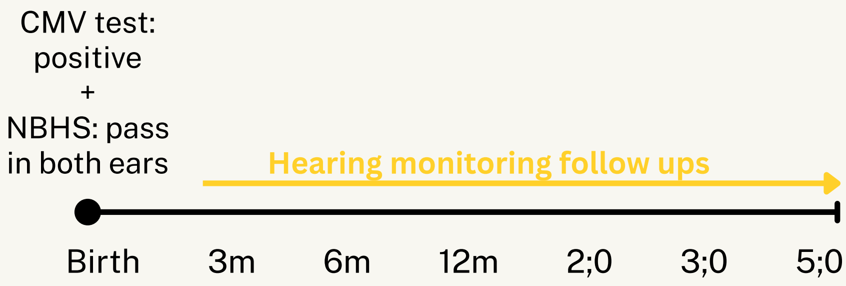
Bella





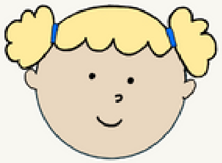
CMV test: positive + NBHS: pass in both ears

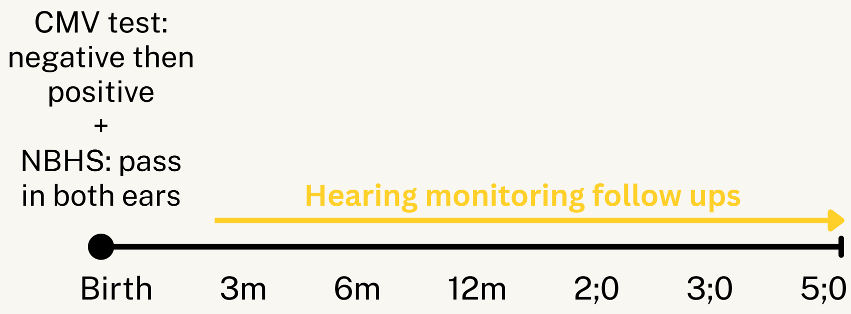
Tommy



CMV test: positive + NBHS: pass in both ears

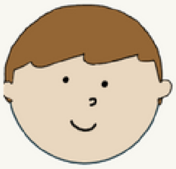
Sarah

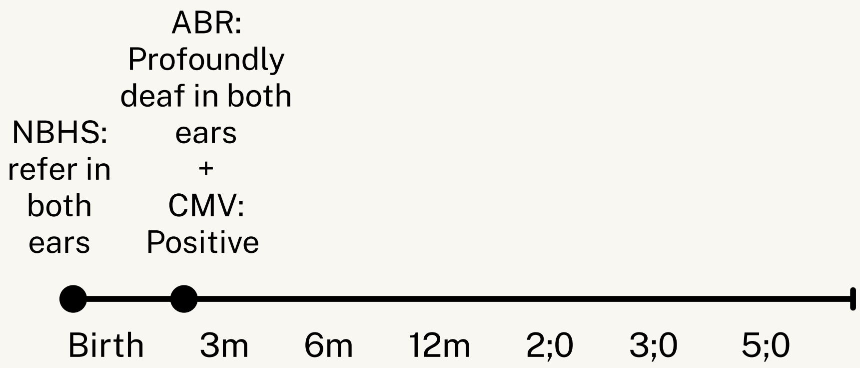




CMV test: negative then positive + NBHS: pass in both ears

Brady

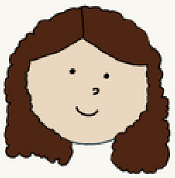


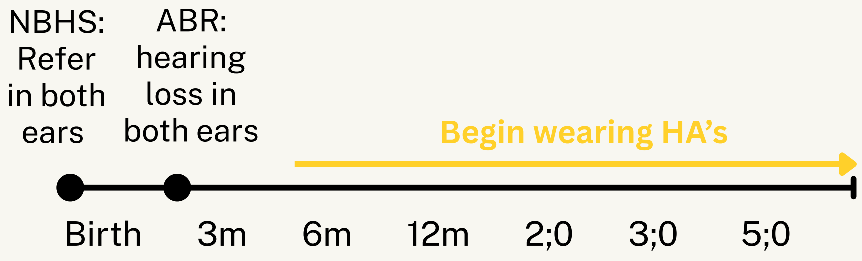


NBHS: refer in both ears

ABR: Profoundly deaf in both ears + CMV: Positive

Ciera

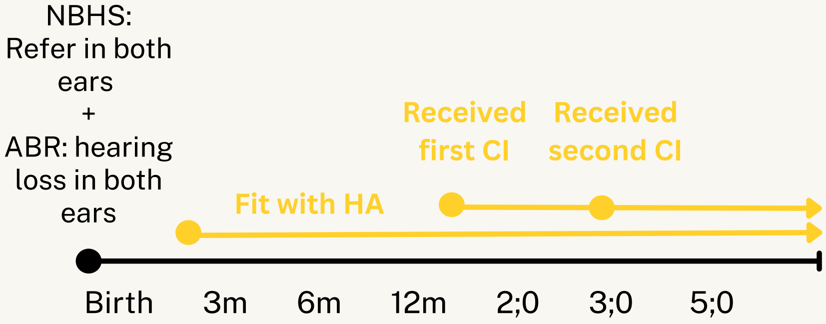




NBHS: Refer in both ears

ABR: hearing loss in both ears

Ellie



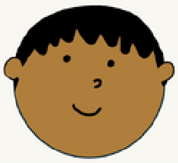
NBHS:
Refer in both ears
+
ABR: hearing loss in both ears

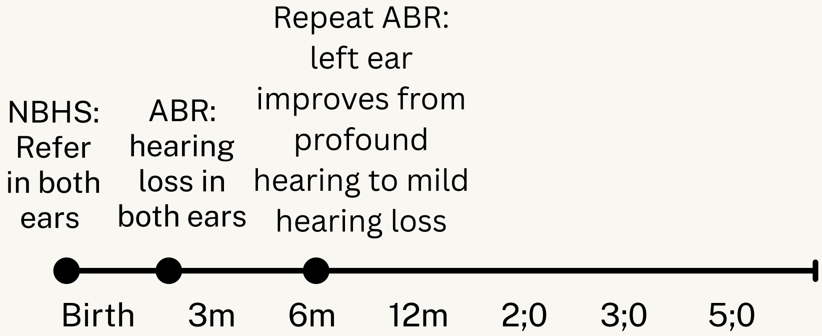
Fit with HA

Received first CI

Received second CI

Haedyn



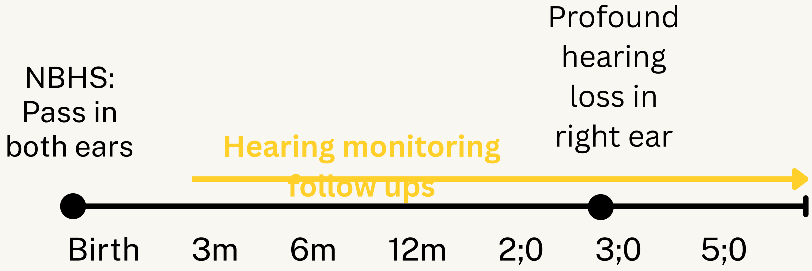


NBHS:
Refer in both ears

ABR:
hearing loss in both ears

Repeat ABR:
left ear improves from profound hearing to mild hearing loss

Sloan

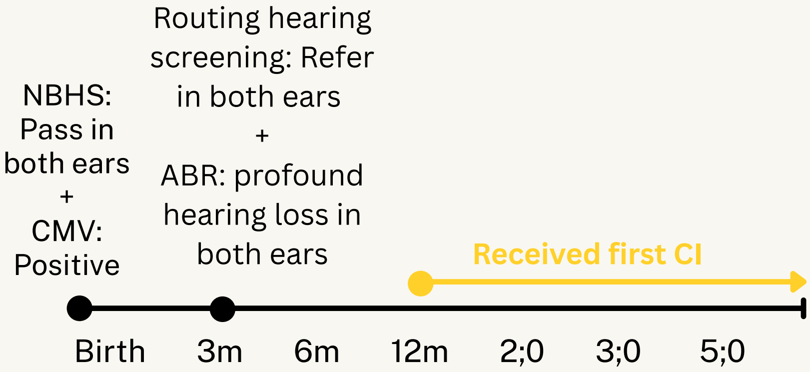


NBHS:
Pass in both ears

Hearing monitoring follow ups

Profound hearing loss in right ear

Lindsey

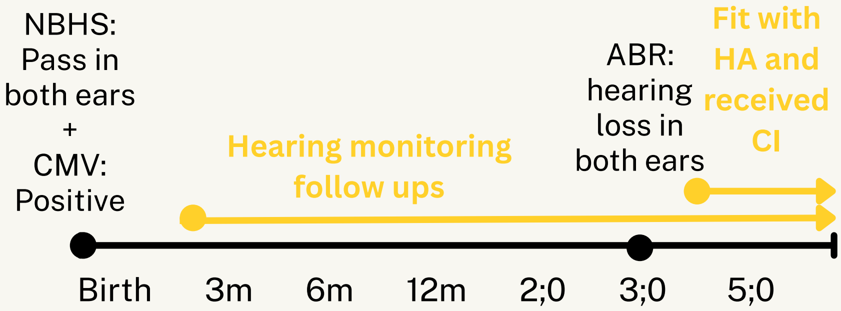


NBHS:
Pass in both ears
+
CMV:
Positive

Routing hearing screening: Refer in both ears
+
ABR: profound hearing loss in both ears

Received first CI

Jackson



NBHS:
Pass in both ears
+
CMV:
Positive

Hearing monitoring follow ups

ABR:
hearing loss in both ears

Fit with HA and received CI

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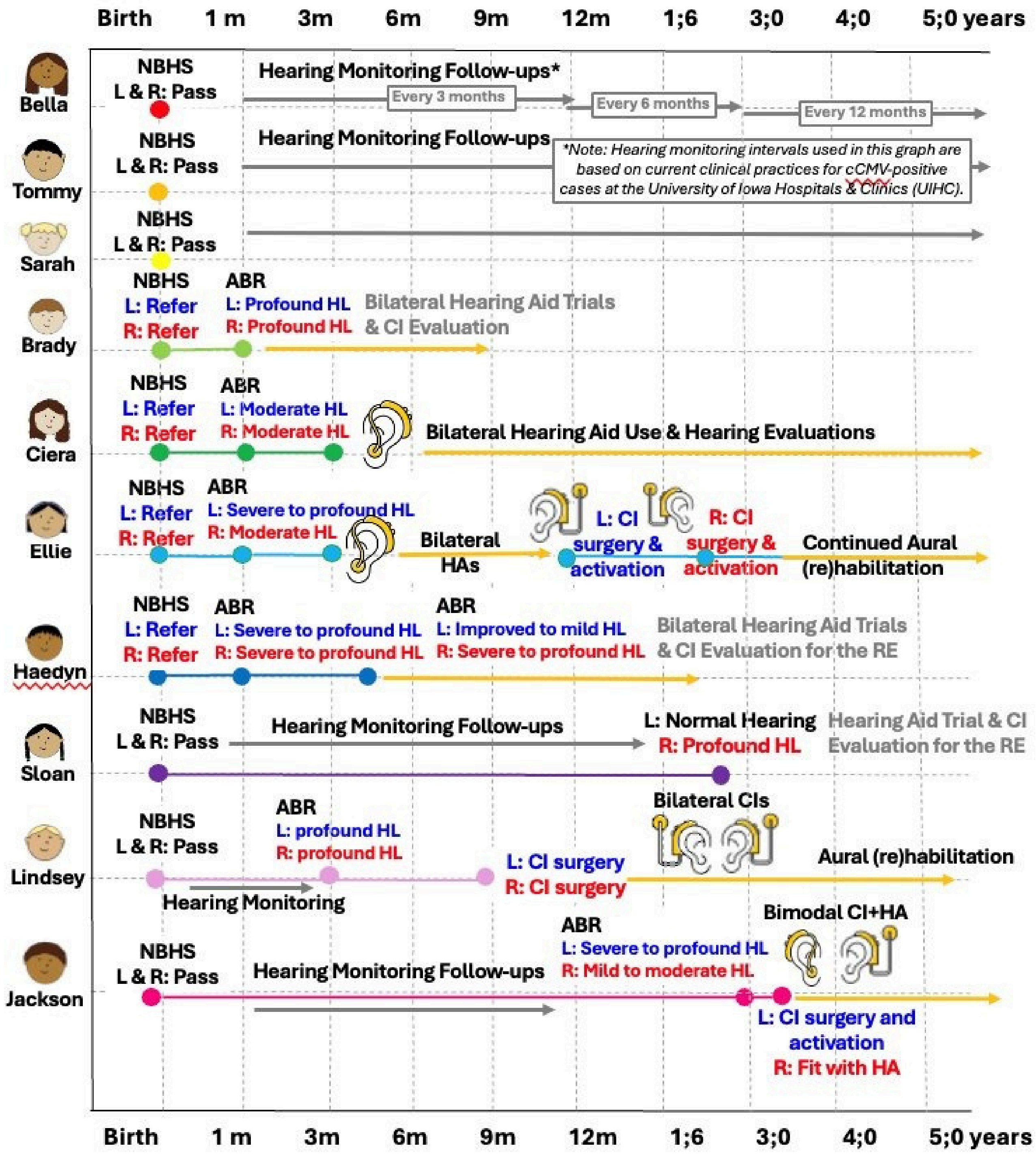
Family Stories Summary



Family Stories Summary

As you have seen, every family's journey is different, and there is no uniform presentation of hearing loss in children with cCMV. Some children remain asymptomatic with typical hearing throughout their lives, while others progress to profoundly deaf.

By highlighting this variability, we hope to support and empower you to make informed decisions about your child's hearing care. These decisions may include pursuing routine hearing tests to monitor changes throughout your child's life. Additionally, you have seen a variety of communication modalities chosen by families of children positive for cCMV. Whether it be amplification through hearing aids or cochlear implants, or manual modes of communication like American Sign Language, we support the choice that fits each family's needs. What is best for the family is best for the child.

07

Interventions

Expectations

As hearing loss with cCMV can present itself as progressive, fluctuating, or absent at birth, it is important that a child with cCMV be monitored by an audiologist. Pediatric surveillance should include evaluations by an audiologist through 6 years of age with consistent follow-ups through their teens.

Infants and children with sensorineural hearing loss due to cCMV may be candidates for hearing aids or cochlear implants based on their degree of hearing loss. A slight or mild hearing loss may progress in degree of loss and limit auditory access necessary for the development of speech and language cues.

If your child has been diagnosed with cCMV, it is important to see other healthcare professionals to rule out other conditions and establish a baseline should symptoms appear later.

Antiviral Treatment

One treatment option for cCMV is the use of antiviral medications. Ongoing research is exploring the use of antiviral medications — **Ganciclovir** and **Valganciclovir** — for newborns diagnosed with symptomatic congenital CMV (cCMV). These medications are intended to reduce the risk or severity of hearing loss and are generally considered for infants who show moderate to severe symptoms at birth.

Treatment typically lasts between **6 weeks and 6 months** and may be given **orally, through an IV,** or via a Peripherally Inserted Central Catheter (PICC) line. In contrast to an IV, a PICC line can stay in place for weeks or months to deliver medications to veins near the heart. However, these medications can carry **serious side effects,** so careful monitoring is essential throughout the treatment process.

Please consult with your child's healthcare team to discuss whether antiviral therapy is appropriate and to understand the potential risks and benefits for your child.

Hearing Aids

Hearing aids are a common option for children with hearing loss, including those with cCMV. These small electronic devices typically sit behind the ear and connect to a soft plastic piece that fits inside the ear canal.

Each hearing aid has four main parts:

- **Microphone –** picks up sound from the environment
- **Amplifier –** makes the sound louder
- **Receiver –** sends the amplified sound into the ear
- **Battery –** powers the device

The goal of the use of a hearing aid is to make sounds clearer and louder, helping your child hear and respond to the world around them. Many children with cCMV benefit from hearing aids, especially when fit early and monitored regularly.

Because hearing loss with cCMV diagnosis can change over time — either improving, worsening, or fluctuating — ongoing hearing screenings are important to ensure the hearing aids remain a good fit for your child's current hearing needs.

Cochlear Implants

Cochlear implants may be considered when a child's hearing loss is severe to profound and hearing aids are no longer able to provide enough benefit.

A cochlear implant is a surgically implanted device that helps provide sound to a child who cannot hear well enough with traditional amplification. It works by directly stimulating the auditory nerve using electrical signals.

The implant has two main parts:

- **External components** include a microphone (to pick up sound), a speech processor (to convert sound into digital signals), and a transmitter (to send signals to the internal device).
- **Internal components** include a receiver (implanted under the skin) and an electrode array (placed inside the cochlea to stimulate the hearing nerve).

Research shows that children who receive auditory stimulation early have the best outcomes in terms of listening, speech, and language development.

Hearing Assistive Technology (HAT)

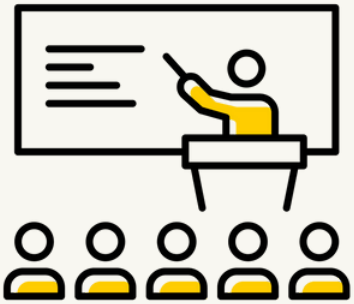
Hearing assistive technology (HAT) systems can be used along with hearing aids or cochlear implants to help children hear better in loud or noisy environments.

One common type of HAT is the **remote microphone system,** often used in classrooms or busy settings. This system includes:

- A **microphone** worn by the speaker (such as a teacher or parent)
- A **receiver** that delivers the speaker's voice directly to the child's ears

By sending the voice straight to the child's hearing device, remote microphone systems reduce background noise and make it easier for the child to understand speech.

Your child's audiologist can help select and fit a system that best supports your child's hearing needs and daily environments.



Communication Options for Children Who Are Deaf or Hard of Hearing

There are several communication options for children who are deaf or hard of hearing. The approach you choose may depend on your family’s preferences, the availability of communication services, and your child’s developmental needs. Common communication approaches include:

- **American Sign Language (ASL):** A complete and distinct language that uses hand shapes, movements, facial expressions, and body language. ASL is not based on English grammar or structure.
- **Auditory-Oral:** Focuses on listening and spoken language development. Children use hearing devices to access sound and may use speechreading (lip reading) to supplement understanding.
- **Auditory-Verbal:** Similar to auditory-oral, but with an emphasis on developing spoken language through listening alone, using minimal to no visual cues like speechreading or gestures.
- **Total Communication:** Encourages the use of all available modes of communication — including speech, sign, gestures, and visual aids — to support language development.

Most importantly, hearing management plans can evolve over time as your child’s hearing changes. Ongoing evaluations and close collaboration with your child’s care team are essential to ensure they receive the appropriate support at every stage.

Referenced source: Iowa HHS EHDI: Communication Options

Summary of Treatments and Intervention Options

There are several treatment and intervention options available, depending on the **type and severity of your child's hearing loss.**

- **Antiviral medication** may be considered for infants with moderate to severe symptoms of cCMV at birth, with the goal of reducing the risk or severity of hearing loss.
- **Hearing aids** are non-surgical devices worn behind the ear that help amplify sound and are often a first step for children with mild to moderate hearing loss.
- **Cochlear implants** are a surgically implanted device that are an option if the hearing loss is severe or profound and the hearing aids no longer provide enough benefit.
- **Hearing assistive technology (HAT)** systems, such as remote microphones, can be used with hearing aids or cochlear implants to improve listening in noisy settings like classrooms.
- **American Sign Language (ASL)** or other manual communication provides access to communication and language to supplement or replace amplification.

Most importantly, hearing management plans can change over time as your child's hearing changes. Ongoing evaluations and collaboration with your child's care team are essential to ensure they are receiving the right support at every stage.

08

Milestones

Considering Important Communication Milestones

While some babies initially pass their hearing screenings, the progressive nature of cCMV can lead to hearing loss later in life.

Hearing differences can sometimes delay development of speech and language. Because of this, it can be important to know speech and language milestones, so that you know what to expect with your own baby. The following pages contain a checklist of what early speech and language skills infants achieve within a certain range of ages. If you are ever worried about your child's development, talk with your doctor and/or audiologist.

Communication Milestones

Below are milestones a child with normal hearing should meet.

Birth to 3 months

- Startles to loud sounds
- Quiets or smiles when spoken to
- Begins to squeal, coo, gurgle
- Makes vowel sounds like ooh or ahh
- Makes different sounds depending on different moods or needs

3 to 6 months

- Looks for sounds with eyes
- Reacts to toys that make sounds
- Giggles and laughs
- Responds to facial expressions
- Vocalizes different vowel sounds combined with a consonant
- Blows “raspberries”

6 to 9 months

- Uses non-crying sounds to get someone’s attention
- Understands things like “bye-bye”
- Recognizes the names of some people and objects
- Imitates sounds they hear

9 to 12 months

- Respond to their name being called
- Points, waves, and shows or gives objects
- Tries to copy sounds that you make
- Enjoys dancing
- Responds to simple words and phrases
- Correctly says one or two words

12 to 18 months

- Understands simple yes-no questions
- Can identify one or more body parts
- Begin to say consonants such as m, n, p, b, d, w, and h
- Follows one step directions
- Learns new words each week and can understand many words
- Vocabulary between 10-20 words

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Communication Milestones

18 to 24 months
- Understands simple commands and understands simple questions
- Puts two or more words together
- Follows two-step directions
- Vocabulary more than 20 words
- Enjoys simple stories, songs, and rhymes
- Acquires new words regularly

2 to 3 years
- Begins using word combinations
- Says their name when asked
- Uses some plural words
- Uses –ing verbs and adds –ed to when talking about the past
- Asks why and how
- Speaks in a way that is understandable to familiar listeners who know the child

3 to 4 years
- Compares things
- Tells you a story from a book or a video
- Understands and uses more location words
- Pretends to read alone or with others
- Pretends to write or spell and can write some letters
- Speaks smoothly saying all the syllables without repeating sounds or words

4 to 5 years
- Produces most consonants and grammar correctly, and speech is understandable in conversation
- Follows simple directions and rules to play games
- Recognizes and names 10 or more letters and can usually write their own name
- Imitates reading and writing from left to right
- Identifies some rhyming words

The majority of babies with cCMV are asymptomatic at birth. That being said, cCMV is progressive in nature and babies should be followed by an audiologist until around 5 years of life.

09

Commonly Asked Questions

How common is cCMV?

- CMV is the most common congenital infection passed from mom to unborn baby.
- Most babies are unaffected, but about 10% have one or more abnormalities.

Can I prevent contracting CMV?

- CMV infections are common in toddlers and preschool age children, and the virus is frequently transmitted in family or group day-care settings.
- The "Universal Precautions" practiced by health professionals and others who come in contact with body fluids are sufficient to prevent transmission of CMV.
- Wash hands thoroughly, avoid sharing food or drinks with children, avoid kissing young kids on the mouth or cheek, etc.

What are signs and symptoms of CMV?

- May experience mild cold or flu symptoms.
- May have no signs or symptoms.

If I have one baby with cCMV am I at risk for having another?

- Having one child with cCMV does not make you more susceptible to having another child with cCMV.
- Should you become pregnant before the CMV infection has resolved, the risk of transmission to your baby will be increased.

Is there a vaccine for CMV?

- There is currently no vaccine available to prevent cCMV.
- There is potential for a vaccine to be created in the future, mainly targeting women of childbearing age.

10

References and Referrals

Resources & Referrals

Nationwide

- **American Academy of Pediatrics (AAP) —** https://www.aap.org/en/pages/contact-us/

- **Early Hearing Detection & Intervention (EHDI) –** https://www.infanthearing.org/

- **Hearing First –** https://www.hearingfirst.org/

- **Iowa Hands & Voices —** http://www.iowahandsandvoices.org/

- **Iowa Deafblind Project —** https://iowadeafandblind.org/

- **Joint Committee on Infant Hearing (JCIH) —** https://www.jcih.org/contactus.htm

- **National CMV Foundation —** https://www.nationalcmv.org/default.aspx

State of Iowa

- **Iowa Early Hearing Detection & Intervention (EHDI) —** https://hhs.iowa.gov/programs/programs-and-services/ehdi

- **University of Iowa - Department of Otolaryngology**
  - Telephone: 319-356-2201

- **Wendell Johnson Speech and Hearing Clinic -**
  - Telephone: 319-335-8736
  - Email: CSD-WenjoClinic@uiowa.edu

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