

*Highlighted words would be hyperlinked to the definition (which also is highlighted in this document)
See other FAQs on Region 4 – Family Support Resources web page for examples.*

Genetics and Hearing Loss – Frequently Asked Questions

What is congenital hearing loss?

Congenital means that a person was born with the hearing loss.

How is congenital hearing loss identified?

Babies born with a hearing loss can be identified through a newborn hearing screening test. The test is generally done before the baby leaves the hospital. All infants who do not pass the newborn hearing screening are referred for medical testing to rule out or confirm hearing loss.

What causes hearing loss?

About 1 in 500 infants is born with hearing loss or develops hearing loss in early childhood. Hearing loss can be caused by changes in genes, illness, infections, injury and noise.

What is a gene?

Genes are a packet of information that tell our bodies to do the things they are supposed to do, such as for an ear to hear.

How is hearing loss genetic?

Genetic hearing loss occurs when genes which cause hearing loss are passed through the family. There are about 20,000-25,000 genes in our bodies. Genes come in pairs. One member of each pair is inherited from a child's mother, and one from a child's father. Most of the time, both genes within a pair are nearly identical. At least 100 genes play a role in hearing. Sometimes, a small change occurs within a gene which may be harmful. A change in one of the many genes controlling the functioning of the ear may lead to hearing loss.

Is my child's hearing loss genetic?

At least half (50%) of all children with inner ear (sensorineural or "nerve-based") hearing loss have a genetic cause for their hearing loss. Sensorineural / Nerve-based hearing loss is likely to be genetic if:

- Hearing loss is present at birth or in early childhood
- Hearing loss is related with other health problems the child has
- Hearing loss affects both ears
- Hearing loss is severe to profound
- There is a family history of hearing loss

How can my child's hearing loss be genetic if no one else in the family has hearing loss?

Your child's hearing loss may be genetic, even if no other people in your family have hearing loss. A small change in even one of the many genes which control the functioning of the ear may lead to

hearing loss. Ninety percent of babies with hearing loss are born to parents who can hear. This can happen when:

- Both parents are **silent carriers** of a hearing loss gene
- Your child's hearing loss is the result of a new gene mutation or change that is not present in either parent
- For some genetic conditions hearing loss may be only one of many symptoms. You may discover that some family members have other features of the diagnosed condition, but no hearing loss.

What does "carrier" or "silent carrier" of hearing loss mean?

A carrier of a genetic condition is someone who has a change in one of his or her genes but does not show symptoms of the condition. People who are a carrier of a genetic condition can pass the condition on to their children. So, it is possible to have a child with genetic hearing loss, even when parents are hearing and have no history of hearing loss.

How do I find out if my child has a genetic hearing loss?

Make an appointment to have your child seen at a genetics clinic. Your child's doctor, audiologist or an early intervention service provider can help you make the appointment and collect the medical information needed. You also can click [hear](#) to locate a genetics clinic in your Region 4 state.

What is genetic testing?

Genetic testing is the process by which the more common genes related to hearing loss are analyzed in a laboratory. A small sample of blood or other tissue (skin or cheek cells) is needed for analysis.

What is it important to find out if my child's hearing loss is genetic?

Genetic testing can determine the exact cause of your child's hearing loss. In some cases, knowing the cause of your child's hearing loss may:

- Help you and your child's doctor determine the best treatment and long-term medical management for your child
- Provide you with information about your child's future hearing
- Alert you to other problems you should look for
- Tell you if other family members might develop hearing loss
- Provide family members with information about the chances that they may have a child with the same condition

What happens during a visit with a geneticist and genetic counselor?

As parents, you will be asked many questions about your child's medical history, hearing loss and family history. In addition, the counselor will review your child's medical records.

Next, the geneticist will examine your child for physical features related to **syndromic** forms of hearing loss. Sometimes, this initial evaluation will provide enough information to establish a diagnosis. More

often, however, the geneticist will recommend additional tests or evaluations – such as an eye exam or lab work for genetic testing – to get more information.

Once these evaluations are completed, the geneticist and genetic counselor will schedule another meeting with you to discuss the test results and any possible diagnoses. If a specific diagnosis is established, the geneticist and genetic counselor will explain the details, including specific causes, the kind of genetic testing that is available, the prognosis (what you can expect for your child's future) and recurrence risks (chances of it occurring in future pregnancies).

What is syndromic hearing loss?

Syndromic means that the hearing loss is just one part of a condition that may have many other features. These other features can be:

- things that make a child look different, like eyes that are different colors
- things that you can't see, like kidney or heart problems

What happens if the genetic specialists can't determine the exact cause of my child's hearing loss?

Sometimes, a genetic evaluation and other studies can't immediately determine the exact cause of your child's hearing loss. If this is the case, doctors will continue to monitor your child and treat her for any medical issues she may develop, such as vision problems or hypothyroidism. In addition, scientists continue to develop new genetic tests for hearing loss, so it's important to maintain contact with your geneticist and genetic counselor.

If a diagnosis is established for my child's hearing loss, how can I contact other parents whose children have the same diagnosis?

Your geneticist and genetic counselor can give you information about local and national parent support groups associated with your child's diagnosis. You also can find additional information on this website under Family Support Resources.

Where can I get medical consultation and genetic counseling services?

Link to location on R4 website