

What should I know about genetics, genes and hearing loss?

- Genetics is the study of genes. Genes are in nearly every cell of your body.
- Your child inherited, or got, his or her genes from both of his or her natural parents.
- Genes are like recipes. Each gene tells different body parts how to grow and how to work.
- If some genes are changed even a little bit, they may change how parts of your body work.
- Genetic hearing loss in a family can often be a surprise. A person can have a genetic hearing loss even if no one in his or her family has hearing loss. Therefore, it is important to make an appointment with a genetics doctor.
- Scientists have found many different genes that can affect the way ears work. Changes in some of these genes will affect other parts of the body, too.
- Scientists have not found every gene that can cause hearing loss. They are still doing research to learn about other new hearing loss genes.
- An examination by a genetics doctor and genetic testing may not be able to find the exact cause of your child's hearing loss. But it is important to check.

Will insurance pay for genetic testing?

- Medicaid will pay for genetic testing in some states. Many other insurance plans may also pay. You need to check your own plan or state Medicaid, to be sure.
- If you are in a managed care plan (HMO), you will probably need to talk to your child's primary doctor about a genetics referral first.

Local contact information:



National Coordinating Center for the
Regional Genetic and Newborn Screening
Service Collaboratives

www.nccrcg.org

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Hearing loss, genetics and Your Child

A Brochure for Parents of a Child
with Hearing Loss



Now that I know my child has a hearing loss, what should I do next?

- Ask your child's doctor for a referral to a genetics doctor to learn why your child has a hearing loss.
- The genetics doctor is one of many doctors your child may need to see.
- It is also important that your visits to your child's audiologist continue.

Why should I have a genetics doctor see my child?

- Knowing that your child has a hearing loss is different than knowing how the hearing loss happened.
- There is about a 50% chance that your child's hearing loss is due to a genetic cause.
- Learning the cause of your child's hearing loss can help doctors understand the complete picture of your child's health.
- Most children with hearing loss do not have health problems in the rest of their body, but a few do. Genetic testing may help doctors find these problems.
- The genetics doctor might be able to help you make decisions about your child's health care.
- Some children's hearing changes as they grow older. Doctors might be able to figure out if your child's hearing loss will stay the same.
- You could find out the chance that your other children will have a hearing loss.



How can I prepare for the genetics appointment?

You and your child may be seen by a medical genetics team, with a genetics doctor (also called a medical geneticist) and a genetic counselor or nurse. You will get the most out of your visit if you write down your questions and bring them with you. You should also plan to answer questions about the information listed below:

- the health of your child's family members, including brothers and sisters, parents, grandparents, aunts and uncles, and cousins.
- any family members who have problems with balance, heart, diabetes, kidneys, hair, skin, face and eyes. The geneticist will also ask about hearing loss in other family members.
- the pregnancy and birth of your child, including infections and other problems.

Genetics is not just about families. It is also about health.

What happens at the genetics appointment?

- The genetics doctor will review your child's health records with you.
- A genetics doctor will talk to you and examine your child. The doctor will review medical conditions and history of hearing loss in the family.
- The genetics doctor may test your child for previous infection by taking a blood sample.
- The genetics doctor might offer to test for common genes that cause deafness.
- You will have time to ask questions.
- You may need to come back for another visit to discuss the test results with the genetics doctor.
- The genetics doctor will look at all the information and try to figure out if your child's hearing loss is due to a genetic cause.
- This information will help you prepare for your child's future health needs.
- The genetics doctor will send a letter to your child's doctor. Your child's doctor will work with the genetics team to determine if any follow-up is needed.