Genetic Counseling and Testing

How do I find out if my child’s hearing loss is genetic?

Talk to a genetic counselor and geneticist if you want to know whether your child’s hearing loss is genetic. Ask your doctor or audiologist to refer you to a genetic counselor or a genetics clinic. Or, search for a genetic counselor on the National Society of Genetic Counselors’ website (http://www.nsgc.org/resourcelink.asp).

What a genetic counselor does
A genetic counselor will explain things to you and offer support. Most genetic counselors have a Master’s degree in genetic counseling. They have to pass a test to get certified. Here’s some things a genetic counselor can do for you:

- Tell you all about genetic reasons for hearing loss
- Answer your questions, and listen to your worries
- Ask you about your child’s hearing loss and other possible problems
- Ask you about your family’s health history (including your sisters, brothers, parents, grandparents and other relatives)
- Help you decide whether you want to have genetic testing
- Help you find other resources you may need
- If you have genetic testing done, explain what the results mean

What a geneticist does
There are two kinds of geneticists:

- Most are medical doctors (M.D.) who has special training in genetics.
- Some aren’t medical doctors, but they have Ph.Ds. They also have special training in genetics.
Many geneticists work with genetic counselors. Here’s some things a geneticist can do for you:

- Review your child’s medical records
- Ask you about your child’s hearing loss and other possible problems
- Examine your child to look for signs of a syndrome
- Read more about this at our section on syndromic types of hearing loss ([http://www.raisingdeafkids.org/hearingloss/genetics/types.jsp#syndromic](http://www.raisingdeafkids.org/hearingloss/genetics/types.jsp#syndromic)).
- Suggest other medical tests ([http://www.raisingdeafkids.org/hearingloss/testing/medtests.jsp](http://www.raisingdeafkids.org/hearingloss/testing/medtests.jsp)). These tests will tell the doctor more about what may have caused your child’s hearing loss.
- Suggest genetic testing if the other tests don’t give an answer.
- If you have genetic testing, the doctor will help explain what the results mean.

**How genetic testing is done**

Genetic testing is done in a laboratory.

1. Your doctor will take a sample of blood from your child and send it to the laboratory.
   - Sometimes the doctor will take a different sample, like a piece of skin for the test.
2. The laboratory will take the DNA out of the cells for testing.
   - The laboratory will run tests to see if there are changes or mutations in the genes that might cause hearing loss.
3. The laboratory will send the results of the tests back to your geneticist.

**What the test results mean**

The results of genetic testing and the doctor’s examination may tell you what caused your child’s hearing loss. But many times, these tests don’t give an answer. Tests can be done for only a few of the most common genetic types of deafness. There might not be a test for the mutation your child has.

From the results of testing, your geneticist and genetic counselor may be able to tell you:

- If there are other problems you should watch for
- If you should go see other specialists
- How likely it is that your child’s hearing loss will get better or worse as he grows
- How likely it is that your next baby will also have a hearing loss. This is called recurrence risk.

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You can find this page online at: [http://www.raisingdeafkids.org/hearingloss/genetics/counseling.jsp](http://www.raisingdeafkids.org/hearingloss/genetics/counseling.jsp)