




Genetic testing for hearing loss



Genetic hearing loss is when 1 or more changes to the DNA called **genetic variants** cause a person to have hearing loss. Researchers estimate that about 80% of hearing loss that happens before a child develops speech, usually before 2 years of age¹, is genetic hearing loss². **Genetic testing** can be done to learn more about any genetic variants that could cause hearing loss.

How is genetic testing for hearing loss done?

There are 3 main types of genetic testing that can be used to diagnose genetic hearing loss¹. Genetic tests look at **genes**, which are instructions that the body uses to make proteins and other important parts of cells. Genes come from DNA and are passed down from birth parents.

 Individual gene testing	Doctors test for a variant of a single gene that they think might cause hearing loss. This type of testing is no longer recommended because of the large number of genes that are connected to hearing loss.
 Gene panel testing	Doctors test for genetic variants of a set of genes, also called a gene panel , that they think might cause hearing loss. If gene panel testing does not find a gene that causes hearing loss, it does not necessarily mean that there is no genetic hearing loss. It could be because the gene that is causing hearing loss is not included in the gene panel.
 Genomic testing	Doctors look at the entire DNA sequences of a set of genes, or of every gene. Looking at the entire DNA sequence of a gene can tell doctors about all of the variants that a person has. Genomic testing may identify genetic variants that are not related to hearing loss, or that are related to other health conditions.

A doctor or genetic counselor can help you decide which type of genetic testing is best for your child.

Can the results of genetic testing affect how hearing loss is managed?

Multiple studies have looked at the effect that genetic testing can have on the management of hearing loss. Studies show that genetic testing makes parents more likely to get hearing aids or cochlear implants for their children to help with perceiving sound³. However, some families may choose other ways of managing their child’s hearing loss. Research also shows that genetic testing can help doctors predict the type, timing, and degree of hearing loss and can help with deciding on the best way to manage it⁴.



Family experiences with genetic testing

There is excitement and hope in new developments in the genetics of hearing loss⁵. However, many parents are not offered genetic testing for their child's hearing loss, are unable to afford it, or are unaware of it. Genetic counseling can be effective before and after the test results.



About 20%

of parents were not aware of or were never offered genetic testing⁵

Parents were also asked how they felt about new developments in the genetics of hearing loss⁵:



64%

felt "excited"



41%

felt "hopeful"



6%

felt "worry"



4%

felt "confusion"

Genetic counseling is a way for families to learn more about genetic conditions, including how they affect the body and how they are passed on. Over half of the parents whose children had genetic testing did not receive genetic counseling before getting the test results, and about half did not receive genetic counseling after getting the test results.

The questionnaire asked parents about their experiences with genetic counseling⁵:



71%

who received counseling **before**
genetic testing said that it was effective



80%

who received counseling **after**
genetic testing said that it was effective

Where can I learn more?

Ask your doctor to learn more about genetic testing for hearing loss.

For more information, visit
www.aboutgenetichearingloss.com



References

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