

Genetic hearing loss: when genes cause hearing loss



Most of the information in this document can be found in the article “Genetic Hearing Loss Overview” by A. Eliot Shearer and others¹.

What is genetic hearing loss?

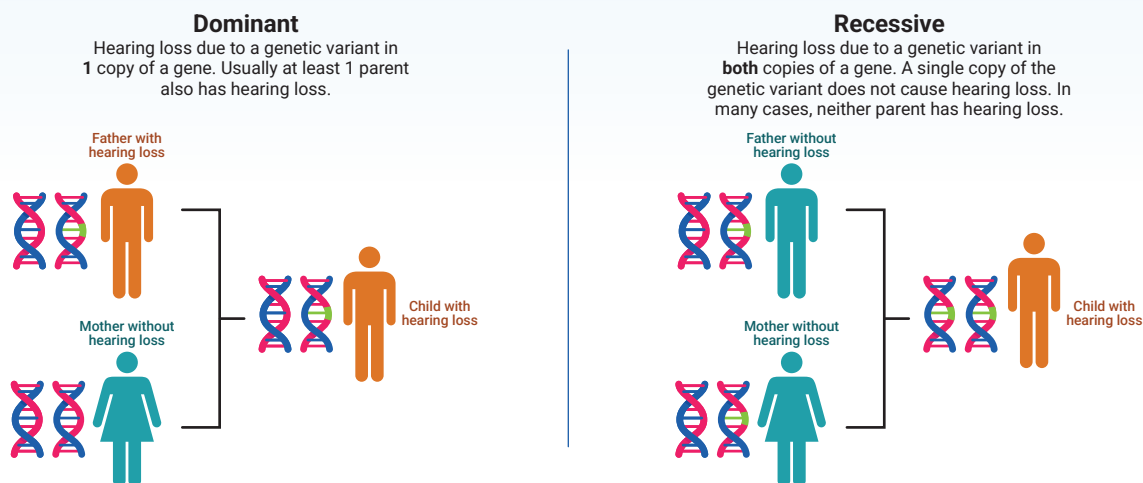
Hearing loss is a common condition that children are born with.

Genetic hearing loss is hearing loss caused by variants of certain genes that affect hearing. Genes in the body are made of DNA. **Genetic variants** are changes in the DNA that can affect the function of genes. Researchers estimate that about 80% of hearing loss that happens before a child develops speech, usually before 2 years of age², is genetic hearing loss. Understanding the genetic causes of one’s hearing loss can help inform the decision-making process to determine the best path forward.



How do genetic variants cause genetic hearing loss?

The genetic variants that cause genetic hearing loss are usually known as either **dominant** or **recessive**.



Syndromic and non-syndromic hearing loss

There are 2 main types of genetic hearing loss.

Syndromic hearing loss

Hearing loss that is related to conditions in the ear or with other organs.

About 30% of genetic hearing loss before the development of speech is syndromic.

Non-syndromic hearing loss

Hearing loss that is **possibly** related to conditions in the ear but **not** with other organs.

About 70% of genetic hearing loss before the development of speech is non-syndromic.

Most genetic hearing loss is non-syndromic and recessive. In these cases, a child can have genetic hearing loss even though both of their parents do not.

Genetic testing can be done to learn more about any genetic variants that could cause a child's hearing loss, and to help families plan for the care their child may need.

How is genetic hearing loss managed?

Hearing loss is usually managed with hearing aids or, for more severe cases, **cochlear implants**. Both hearing aids and cochlear implants help with processing sound and words. Also, people can choose other ways to communicate, including sign language, captioning, and interpreting services.

Cochlear implant: a device that is surgically placed in the ear that turns sounds into signals that the brain can understand



Genetic hearing loss is managed similarly to other types of hearing loss. Genetic hearing loss may cause severe hearing loss at birth, or it may cause sudden or gradual hearing loss later in life. Some types of genetic hearing loss may cause hearing ability to decrease faster than others, and some types can lead to conditions with other organs in the body. For this reason, it is important for people with genetic hearing loss to have regular checkups with their doctor.

Where can I learn more?

Genetic counseling can help children with hearing loss and their families learn more about genetic conditions, including how they affect the body and how they are passed on. The goal of genetic counseling is to help individuals and families make informed decisions regarding if and how to address their children's potential genetic hearing loss. The child's doctor can provide more information about genetic counseling.

For more information about genetic hearing loss, visit www.aboutgenetichearingloss.com



References

1. Shearer AE, Hildebrand MS, Odell AM, et al. Genetic Hearing Loss Overview. 1999 Feb 14 [Updated 2025 Apr 3]. In: Adam MP, Feldman J, Mirzaa GM, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2025. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK1434/>
2. National Research Council (US) Committee on Disability Determination for Individuals with Hearing Impairments. Hearing Loss: Determining Eligibility for Social Security Benefits. (National Academies Press (US), Washington (DC), 2004). Available from: <https://www.ncbi.nlm.nih.gov/books/NBK207838/>

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