



Genetic Testing

Resources:



[Genetic Hearing Loss FAQ](#)



[Genetics of Hearing Loss Video](#)



[CDC Parent's Guide to Genetics and Hearing Loss](#)



[Akouos Resonate Program](#)

- Congenital hearing loss means a baby is born with hearing loss. It happens when the ear can't turn sound vibrations into nerve signals. It can be conductive, sensorineural, or a mix of both.
- There are 3 causes of hearing loss: **genetic, environmental and pregnancy complications**.
- **Genetic** origin is found in approximately 50-60% of congenital hearing loss cases. Genetic hearing loss can occur either as an inherited condition or as a sporadic event. It may also present as part of a genetic syndrome (syndromic) or as an isolated finding (non-syndromic).
 - Syndromic (30%): associated with other congenital anomalies or medical findings involving other organs or organ systems.
 - Nonsyndromic (70%): hearing loss is seen in isolation, although not all syndromic effects may be apparent at birth.
- **Environmental** factors such as ototoxic medications can cause hearing loss in a fetus if taken during pregnancy, as well as in the NICU. This is because the ear continues to develop from the 4th to the 30th week of pregnancy.
- **Pregnancy Complications** such as preeclampsia, premature birth (born before 37 weeks), low birth weight, congenital cytomegalovirus, and birth injuries may also effect the baby's hearing.
- Genetic counseling can guide you through the process and help you find out if conditions like hearing loss run in your family. A genetic counselor reviews your health and family history to see if testing might help.
- Genetic testing for hearing loss can help find the cause, show if other family members might have it, guide treatment, and tell if it could happen again.
- Different places may test for different genes. The genes tested can depend on things like whether the hearing loss is part of a syndrome, when it started, family history, and other health signs.
- A test that comes back negative doesn't always mean there is no genetic reason for hearing loss. Some genes may not be known yet, and sometimes the test doesn't give a clear answer.
- Genetic testing can be done through a cheek swab, saliva, or blood draw.
- Genetic testing results can typically take 3-4 weeks.
- The cost of genetic testing depends on your insurance and whether you meet certain guidelines. Most insurance plans, including Medicaid, help pay for the test. However, you still have to pay any copays or deductibles. To make sure insurance will cover the test, genetic counselors will request approval before the testing is done.
- The best time for genetic testing is usually when symptoms first appear. This helps find a diagnosis early and plan the best care. However, the timing can vary based on the symptoms, how serious they are, family history, and what works best for each family.