



Questions you May Want to Ask Your Child's Genetics Team



Names of Geneticist and Genetic Counselor: _____

Phone/Contact Information: _____

Appointment Date: _____

Next Appointment Date: _____

A "genetics team" is made up of a clinical geneticist, a genetic counselor, and other health care professionals. A clinical geneticist is a doctor who specializes in diagnosing and caring for people with genetic conditions. A genetic counselor is a health care professional who talks with people about the risk for genetic conditions and provides counseling and support. Members of the genetics team work together during a genetics exam.

Deciding whether or not to do genetic testing can be a difficult decision parents of a Deaf or hard of hearing child may face. Each family will have to make their own decision if genetic testing is right for them. The purpose of genetic testing is to learn more about your child's genes and might provide information about what caused your child's hearing difference. Around 60% of hearing differences in babies are linked to changes in genes. Genes are like instructions that guide the body's growth and function, and changes in them can affect hearing. Differences in hearing levels can also be caused by infections, certain medications, or prolonged exposure to loud noises. In many cases, the cause of hearing differences may not be clear, even after genetic testing.

The genetics team will ask you questions about your child and family's history. They may suggest blood tests for both you and your child. They might also recommend seeing another doctor or specialist to learn more. If the team is able to find a genetic cause for your child being Deaf or hard of hearing, they will explain more about the changes in the child's genes. The team may be able to provide information about other developmental differences or health conditions that are also linked to the changes in your child's genes. Sometimes even after a complete genetics evaluation, the cause of your child's hearing difference will remain unclear. The genetics team should provide you with resources and/or refer you to organizations that provide support to parents with Deaf or hard of hearing children.

Questions you may want to ask your genetics team to help you decide whether or not you want to pursue genetic testing:

1. What can genetic testing tell me about my child’s hearing difference? What are some common genetic causes of hearing differences?
2. Is a comprehensive gene panel being used? How many genes are being tested?
3. How can genetic testing help my child?
4. Who will go over the testing process and final results with me?
5. What will the results of genetic testing potentially tell me? Can we prepare ahead of time for what the results might look like?
6. Can the results of genetic testing tell me if my child’s hearing will change over time?
7. What is the process for genetic testing? How is my child’s privacy assured?
8. Why is it important to know my family’s history of hearing differences and what type they had? How is it inherited?
9. If no one in my extended family has a hearing difference, how can it be genetic?
10. Where can I learn more about genetic testing?
11. Where can I connect with other families who have Deaf or Hard of Hearing children to learn about their decisions around genetic testing?
12. Where can I connect with Deaf community members about their decisions and experiences with genetic testing?

Questions you may want to ask your genetics team after testing:

1. How do other partners and families process their emotions after this news?

2. What does this mean for future children or grandchildren?

3. What common concerns do you hear from families about similar results? Could there be additional results in the future?

4. Should I share test results with other members of my family? Could others in my family have children with hearing differences or other conditions? How do you recommend sharing this?

5. This is what I understood you to say... is that correct?

6. How can I meet other families with my child's genetic condition?

7. How can I meet adults with my child's genetic condition?

8. How can these results help with health care and educational decisions for my child, now or in the future?

9. What follow up do you recommend? Where can I learn more about this result?

*Note: Genetic testing can also be ordered by ENTs/Otolaryngologists and audiologists in locations where there may be a long wait for the genetics specialist.

After talking with the genetics team, I/we learned:
