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.

The purpose of a genetic testing or exam is to find out if the cause of your child’s hearing loss is genetic. About sixty percent of all hearing loss in babies is caused by changes in genes. Genes contain the instructions that tell a person’s cells how to grow and support the body. Some changes in a gene can cause hearing loss. Hearing loss can also be caused by infections, certain medication, and risks such as prolonged loud noise in the environment. For many children, the cause of hearing loss may not be known.

The genetics team will ask you questions about your child and family. They will do a complete physical exam and may recommend that your child and you have a blood test. They may suggest your child see another doctor or specialist to help them better understand the cause of your child’s hearing loss. Knowing the cause may help you and all the professionals who work with your child better plan for his/her future needs. They may also be able to inform you and your family of the chance of having another child with hearing loss.

Sometimes the cause of a child’s hearing loss cannot be found even after a complete evaluation. The genetics team will work with you:

The genetics team will work together to offer the best advice and care for you and your child.

For more information about children’s hearing visit www.cdc.gov/ncbddd/hearingloss
Questions you may want to ask your child’s genetics team:

1. Will a genetic exam or test tell me the cause of my child’s hearing loss? What are some common genetic causes of hearing loss?

2. Why should I try to find out the cause of my child’s hearing loss? How can this information help my child?

3. What will the results of genetic testing tell me? Does a negative test result mean that my child’s hearing loss is not genetic?

4. Can the results of genetic testing tell me if my child’s hearing loss will get better or worse?

5. How will genetic tests be done? What other kinds of tests are needed in order to find out the cause of my child’s hearing loss?

6. Will my child need to come back to your office after testing? If so, why?

7. Why is it important to know if members of my family have hearing loss, what type of hearing loss, and when they started developing the hearing loss?

8. How is hearing loss inherited?

9. If no one in my family has hearing loss, how can my child’s hearing loss be genetic?

10. Should my other children have genetic testing, too? Why?

11. If I have another child, what is the chance that he or she will have hearing loss?

12. Should I share test results with other members of my family? Could other people in my family also have children with hearing loss?

13. Where can I learn more about genetic testing for hearing loss?

14. Where do I meet other families whose children have the same type of genetic condition as my child?

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