

What should parents know?

Genetic testing for childhood hearing differences:

- Can play a role in planning for your child's future.
- 40-50% (and rising) have a genetic cause as we learn more.
- Helps to know if your child's hearing difference is
 - Nonsyndromic (no other issues)
 - Syndromic (hearing + other differences, e.g. vision, kidneys)

Why would we pursue genetic testing?

- The "why" has helped other families move on to "how"; even if questions are not answered.
- Possible results can inform future decisions for health and education.
- Answer my questions/my child's questions now or in the future.
- Free testing is often available; cost barrier removed.
- Contribute to research for future families.
- Providers recommended.

Why wouldn't we?

- Might give no new information if CMV, antibiotics, prematurity or other cause involved.
- Results may be difficult to process. Learning unexpected news is stressful.
- Tension or strong emotions may occur in extended family.
- Conflict with faith or belief system may occur.
- Belief that testing won't change anything for our child.
- Cost can be expensive and insurance doesn't always cover it.

Family & Child Genetic Testing Considerations

Genetic Counselors

- Provide non-judgmental information about testing and inheritance patterns.
- Explore what potential results might mean for your family ahead of time.
- Help families navigate emotions and the process.

Parent to Parent Support

- Share perspectives from families who did/did not pursue testing
- Share what other families have learned about the process.
 - Share the latest information about genetic testing.
 - Help families find more information on any aspect of genetic testing.

DHH Community/ Culture

- Highlight value of Deaf community
- Testing itself may impact views of Deaf culture
- Being D/HH is not a problem to be fixed; it is a natural part of human experience and diversity.