FOR IMMEDIATE RELEASE

Hands & Voices Releases Genetic Testing Resources Centering Informed Choice

April 15, 2026

Hands & Voices announces the completion of a comprehensive, multi-resource project supporting families and professionals in navigating genetic testing in the context of childhood hearing differences.

The project resulted in several key resources offering practical guidance for discussing genetic testing with families in respectful, balanced, and accessible ways. Perspectives from the Deaf/Hard of hearing (D/HH) community, diverse cultures, and families with children who are DHH Plus (with additional disabilities) were included.

Find these resources and more:

- A Parent's Guide to Exploring Genetic Testing
- Keys for Discussing Genetic Testing with Families, A Guide for Professionals (including "Say This, not That" guidance; forewords by Dr. Eliot Shearer and Dr. Dylan K. Chan)
- What Should Parents Know? — family-centered infographic exploring "Why Would You?" and "Why Wouldn't You?" genetic testing considerations
- Questions to Ask Your Genetics Counselor — an updated downloadable document

Each resource was developed with a strong commitment to centering the lived experiences of families, honoring the diversity of Deaf culture and the diverse lived experience of deaf/hard of hearing people, and supporting informed choice for families. Throughout the process, Hands & Voices engaged a diverse range of contributors, including parents, D/HH leaders, and professionals, to ensure the materials reflect real-world questions, concerns, and decision-making factors.

"Families consistently tell us they want clear, unbiased information that respects their values and helps them make the best decisions for their child," said Janet DesGeorges, Executive Director of Hands & Voices. "As genetics and gene therapy move quickly, families are being asked to make complex decisions earlier than ever. Our role is not to steer them—but to make sure they have the balanced information and support to choose with confidence."

This work comes at a time of rapid change in the field of genetics and hearing differences. Current Joint Committee on Infant Hearing (JCIH) guidelines recommend offering genetic testing as part of comprehensive follow-up care. At the same time, Hands & Voices emphasizes the critical role of genetic counseling in helping families understand the process, explore what possible results could mean for their child and family, and even extended family members, and have their questions answered—regardless of whether they ultimately choose to pursue genetic testing.

Gene therapy is emerging as a potential option for some children, including therapies targeting Otoferlin-related hearing loss, with additional studies underway for conditions such as Usher syndrome and Connexin 26 (GJB2)-related hearing differences. As these developments evolve, access to balanced, family-centered information and guidance for professionals will be increasingly critical. These tools are designed to complement clinical care by offering additional context around family and cultural perspectives, helping ensure families have the information they need to make informed decisions.

This project was made possible through funding from Lilly and Sensorion. All content was developed independently, without sponsor oversight or influence.

Looking ahead, Hands & Voices will be expanding this work through new multi-year collaborations that will deepen education and training opportunities in genetic testing, genetic counseling, clinical trials, gene therapy, privacy issues, and effective communication with families. Additional details, such as translation of materials, will be announced in the coming year. These future efforts will build on the same foundation of honoring informed choice, cultural responsiveness, and family-centered support.

These resources are now available to Hands & Voices Chapters, family-based organizations, and professionals across Early Hearing Detection and Intervention (EHDI) systems nationwide and internationally.

Find all genetics education resources here:

https://handsandvoices.org/resources/genetic-testing/

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About Hands & Voices

Hands & Voices is a parent-driven, non-profit organization dedicated to supporting families with children who are deaf or hard of hearing without a bias around communication modes or methodologies. The organization provides resources, networks, and advocacy to ensure that families have access to the information and support they need to make informed decisions.