THE GENESIS OF RESOURCE DEVELOPMENT AND PARTNERSHIPS: GENETIC TESTING EDUCATION FOR FAMILIES

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Janet DesGeorges

Executive Director, Hands & Voices Headquarters

Always start with joy…

Janet DesGeorges

Parent of a D/HH Adult (still on the journey)

Co-founder and Executive Director

Hands & Voices

www.handsandvoices.org

Principal Investigator

Family Leadership in Language and Learning

Co-founder and Committee Member

Global Parents of DHH Children

(GPODHH)

http://www.gpodhh.org/

TODAY LET'S… (IN 25 MINUTES!)

- Understand the Ethical and Emotional Considerations of Genetic Testing in Deaf and Hard of Hearing Children.

- Analyze the Impact of Early Genetic Identification on Family Decision-Making and Support Systems.

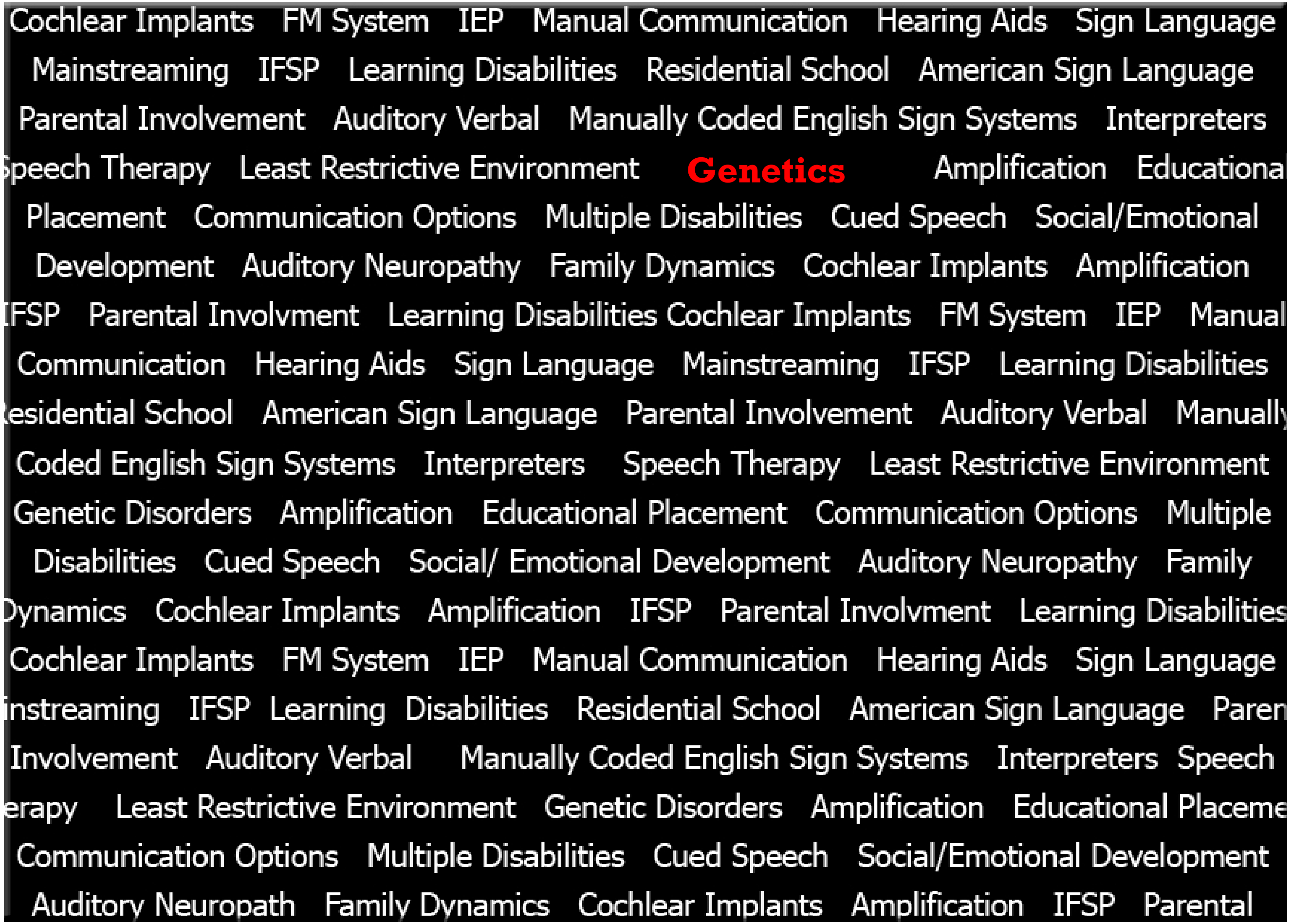
- **Apply Best Practices for Parent Advocacy Organizations in Navigating Relationships with Pharmaceutical Companies.**
  - You can apply this to other relationships!

HANDS & VOICES ORGANIZATIONAL LENS

- Framing our conversation today:
  - Family-Centered
  - Parent Choice - Informed decision making and consent
  - Individualized (*"What works for your child is what makes the choice right."*)
  - Current Resources/Projects

WHO IS IN THE ROOM?

- Parents
- DHH Leaders
- Professionals
- Students
- State Agencies
- Medical Agencies/Companies
- Other



Cochlear Implants FM System IEP Manual Communication Hearing Aids Sign Language
Mainstreaming IFSP Learning Disabilities Residential School American Sign Language
Parental Involvement Auditory Verbal Manually Coded English Sign Systems Interpreters
peech Therapy Least Restrictive Environment **Genetics** Amplification Educationa
Placement Communication Options Multiple Disabilities Cued Speech Social/Emotional
Development Auditory Neuropathy Family Dynamics Cochlear Implants Amplification
FSP Parental Involvment Learning Disabilities Cochlear Implants FM System IEP Manual
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Auditory Neuropath Family Dynamics Cochlear Implants Amplification IFSP Parental

DEVELOPING RESOURCES FOR FAMILIES

CONSIDERATIONS FOR PARENTS THAT GUIDE OUR GENETIC TESTING RESOURCE DEVELOPMENT:

- Why would we?
- Why wouldn't we?
- The Role of Family
- The Who, What, Where, When, Why
- Deafness is 'Different'
- Cultural considerations
- Questions Parents want Answers to
- What about families who have kids who are D/HH+?

WHY IS THIS IMPORTANT FOR FAMILIES?

Not just a ‘next step’ in the process

- The decision to obtain genetic testing is dependent on informed family choice in conjunction with standard confidentiality guidelines (Chu et al., 2015).

- Genetic testing. Although an individual family may choose not to participate in genetic testing for a variety of reasons, the American College of Medical Genetics recommends offering genetic counseling and genetic testing for all infants who are deaf or hard of hearing and their families (Alford et al., 2014).

APPLYING BEST PRACTICES IN OUR RELATIONSHIPS

OUR PROJECT PARTNERSHIPS

Insights from our community

Akouos/Lilly

- Developing resources for families about genetic testing considerations.
- Serves as sponsor for our H&V Conference.

Sensorion

- Developing resources for professionals about how to talk to families about genetic testing considerations.

Regeneron

- Serves as sponsor for our H&V Conference.

GUIDING PRINCIPLES

Principles for interactions with biopharmaceutical companies: the development of guidelines for patient advocacy organization in the field of rare diseases. *(*Stein, *et al. Orphanet Journal of Rare Diseases* (2018) 13:18 DOI 10.1186/s13023-018-0761-02) These Guidelines recommend best practices and standards for interactions between patient advocacy organizations and industry.

FOUR AREAS OF ENGAGEMENT BETWEEN PATIENT ADVOCACY ORG. AND BIOPHARMACEUTICAL COMPANIES

- Identification and Engagement between Companies and patient/parent advocacy organizations
- Patient Engagement and Patient Privacy
- Financial Contributions
- Clinical Trial Communication and Support

IDENTIFICATION AND ENGAGEMENT BETWEEN COMPANIES AND ADVOCACY ORGS (TRANSPARENCY)

- Mutually beneficial dialogue and information exchange.
- Community-wide insight and perspective as needed and appropriate to inform the development efforts and strategic decisions of the company.
- Strives to collaborate with multiple biopharmaceutical companies to ensure the sustainability of its initiatives and to allow for a diversity of views and therapeutic approaches.

PATIENT ENGAGEMENT AND PATIENT PRIVACY

Engagement:

- Diverse approaches to engaging with companies – from actively facilitating dialogues to passively providing training and education for patient community members on best practices.
- Encourages biopharmaceutical companies to obtain insights from group discussion rather than from one-on-one conversation with single individuals.

PATIENT ENGAGEMENT AND PATIENT PRIVACY

Privacy:

- Assists individual patients in thinking through their decisions about providing information or consent.
- Helps patients convey their expectations about privacy.
- Ensures that biopharmaceutical companies, and other organizations, have in place at least basic guidelines or a policy for ensuring patient privacy prior to any data collection, including surveys, photographs, video and audio recordings, slide decks, and consent forms.

FINANCIAL CONTRIBUTIONS

- A robust advocacy organization is a vital partner to biopharmaceutical companies in the development of potential therapies. Financial resources are a key need for the growth and maintenance of the patient advocacy organization.

- The patient advocacy organization accepts financial contributions that support its stated mission and allow the organization **to maintain its autonomy**. The patient advocacy organization assesses the alignment of mission between the two organizations as part of the funding discussions.

CLINICAL TRIAL COMMUNICATION AND SUPPORT

- The patient advocacy organization acts as a conduit for information about clinical trials by providing education and resources to the patient community
- The choice to participate in any particular trial is an individual one; the patient advocacy organization does not seek to influence that choice, but rather, assists patients and families in making informed decisions through education and awareness.

IN CONCLUSION

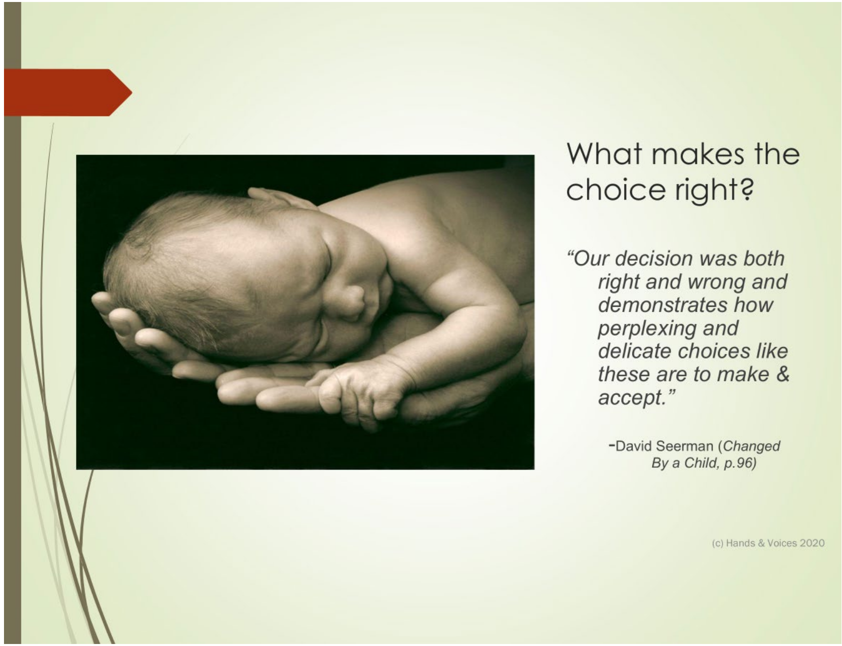
- Parent organizations play a crucial role in empowering families with children who are deaf/hard of hearing/dhh+ by providing vital information, resources, and emotional support.
- We bridge the gap between families, educators, for profit companies, and professionals, ensuring that every child has access to the tools they need to thrive.
- By fostering a sense of community and advocating for inclusive opportunities, we help parents become confident advocates for their children.
- Together, we can create a more informed, connected, and supportive environment for children who are deaf and their families.

YOUR TURN

COMMUNICATION GROUND RULES

- Identify your role before sharing (parent of DHH child, DHH Leader, professional, etc)
- One person at a time
- Use “I” statements
- Keep it to about 60 seconds

THANK YOU!



What makes the choice right?

"Our decision was both right and wrong and demonstrates how perplexing and delicate choices like these are to make & accept."

-David Seerman (*Changed By a Child, p.96)*

- Share more with us at janet@handsandvoices.org