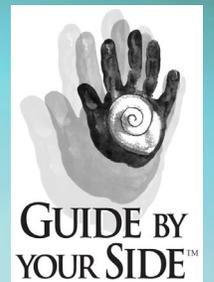


A Guide for Parents: understanding best practice recommendations for children with unilateral hearing loss

**Janet DesGeorges, Hands & Voices Headquarters
Shelli Janning, Nebraska Hands & Voices**

2021 EHDI Conference



Presenters:

Janet DesGeorges

Parent of a young Deaf Adult

Co-founder and Executive Director
Hands & Voices

www.handsandvoices.org

Member: Phonak Pediatric Research Advisory Board
– Parent Representative



Shelli Janning

Parent of a 14-year-old who has UHL.

Program Coordinator for
Nebraska Hands & Voices
Guide by Your Side

Shelli is passionate about self advocacy and the power of parent-to-parent connections



Please quote me....

“If half the people would use half the resources that are available half the time, our kids would be doing twice as well...”

–Janet DesGeorges

Phonak Parent guide

Guide for understanding best practice recommendations for children with unilateral hearing loss

By Janet DesGeorges, Executive Director of Hands & Voices, a parent-support organization for families who have children who are deaf/hard of hearing. Thank you to the families worldwide who have children with UHL who reviewed and recommended content for this guide.

February, 2020: Janet DesGeorges

Created from the *Consensus practice parameter: audiological assessment and management of unilateral hearing Loss in children*.

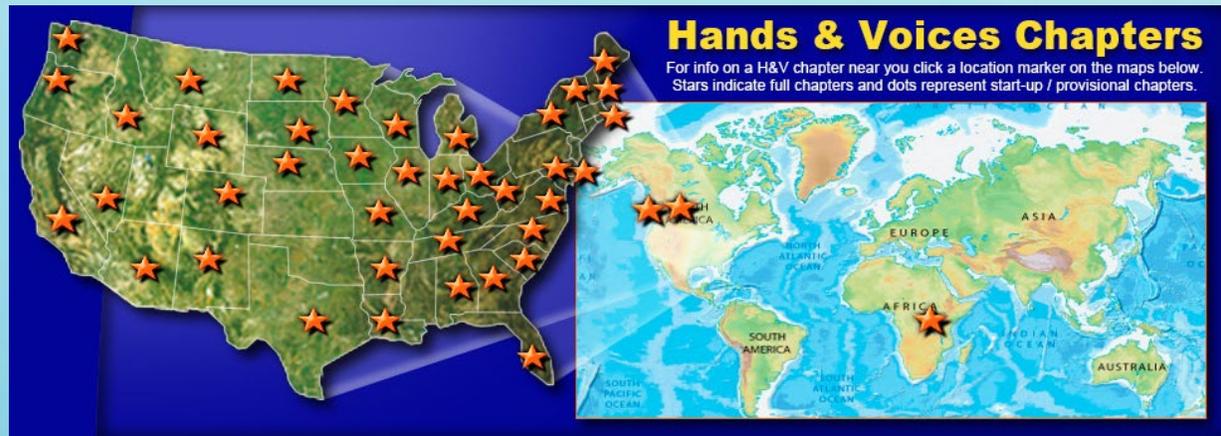
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A taste of Hands & Voices...



- 1 Chapter – 1997
- 46 Chapters – 2021 (US/Canada)
- 25 Guide By Your Side programs
- 12 ASTra Programs (education)

Serving over 27,000 families a year



www.handsandvoices.org

H&V at a Glance
"What works for your child is what makes the choice right."

Programs of Success:

- Professional Guidance
- Guidance of Learning (G/L) relation
- What's a New and Communication
- How to do Learning

Measures of Success:

- Improved quality of life for children who are 50/50 and their families
- Improved academic outcomes for children who are 50/50 through dual language learning
- Improved educational outcomes through parent involvement learning
- Reduced mental health and social and behavioral problems for children with autism
- Improved communication skills for all 50/50 children and their families

Ways & Voices Chapters:

- 46 of 46 chapters nationwide

Innovative Programs:

- Guide By Your Side (G/S):**
 - Developed and tested by a team of experts
 - Used by parents and professionals
 - Helps parents understand their child's needs
 - Provides a clear path forward
- Family Support & Learning (F/S):**
 - Provides a safe space for parents to share their experiences
 - Offers a supportive community
 - Helps parents learn from each other
 - Provides a clear path forward
- Learning & Language (L/L):**
 - Provides a safe space for children to learn
 - Offers a supportive community
 - Helps children learn from each other
 - Provides a clear path forward

Impact & Reach:

- Change Agents:**
 - Helping Leadership
 - Helping Leadership
 - Helping Leadership
- Resource Share:**
 - Join the Site
 - Join the Site
 - Join the Site
- Individual Support:**
 - Coaching the Site
 - Coaching the Site
 - Coaching the Site

FL "Where love, learning, and language thrive."

50/50 Involvement:

- 50/50 Involvement
- 50/50 Involvement
- 50/50 Involvement

Parents and Collaborators:

- Parents and Collaborators
- Parents and Collaborators
- Parents and Collaborators

Language & Literacy Research and Resources:

- Language & Literacy Research and Resources
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Family to Family Support:

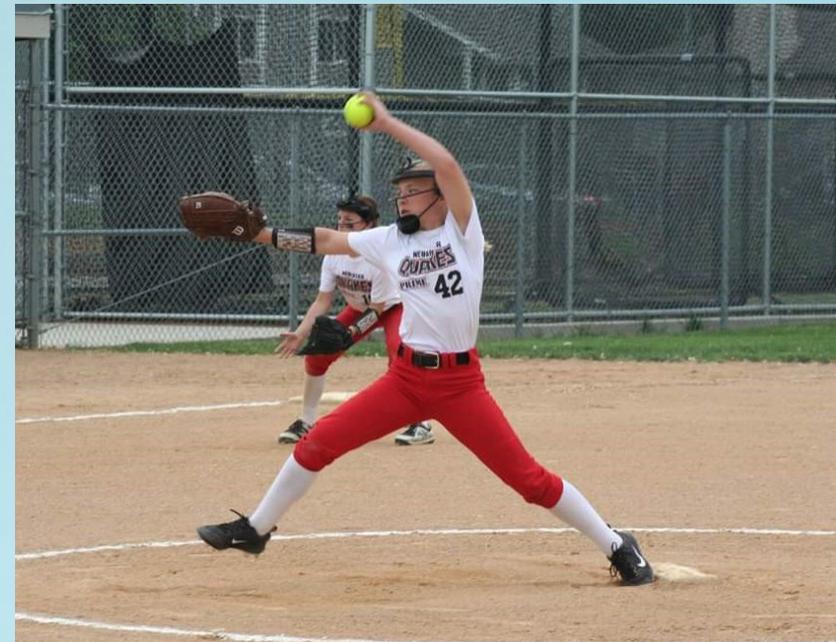
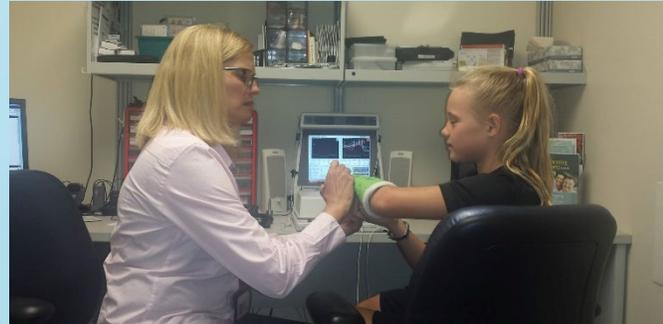
- Family to Family Support
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Parent Leadership:

- Parent Leadership
- Parent Leadership
- Parent Leadership

Join the movement. parents@handsandvoices.org www.handsandvoices.org

<https://handsandvoices.org/pdf/hv-at-a-glance.pdf>



- Receiving the diagnosis was devastating to me.
- Mixed messages were challenging.
- Where do we fit in? Is my child deaf enough?
- Workshops and networking were key.
- Kids and parents are so resilient.
- Able to give back to new parents.



“How do we know if our child with unilateral hearing loss (UHL) is receiving the right services/audiological management based on our child’s individualized needs?”

Questions Families Ask:

- We just got the news that my child has hearing loss! What should we do?
- When I was told that my baby had a UHL I was shocked. How do other parents react?
- When I go online, I often find families who have gotten different messages from their hearing health care professionals than I have received from mine. Why is that?
- What should I say when people/professionals say to me, “He/she still has one ‘good ear’”?
- Do all audiologists have expertise working with infants and children?
- Should I still seek out parent-to-parent support groups? I’m not sure I will fit in, since my child ‘only’ has UHL?
- Will my child’s hearing level get worse? Will it progress to both ears?
- I’m frustrated because everyone says, “Let’s just ‘wait and see’ if any delays occur.” Isn’t there something I can be doing now?

(Can be found in the FAQ of the document)

The source of information for this parent guide

- An international panel of experts on the screening, assessment, management, and monitoring of children with unilateral hearing loss convened on October 24, 2017, following a day and a half of presentations on the same.
- Evidence reviewed was gathered through literature searches using web search engines specifically designed for academic and health care resources and two recent systematic reviews of the literature were considered (Appachi et al., 2017; Anne, Lieu, & Cohen, 2017).
- The expert panel created and published guidelines in the Consensus Practice Parameter.

Consensus practice parameter: audiological assessment and management of unilateral hearing Loss in children. Bagatto, M., DesGeorges, J., King, A., Kitterick, P., Lurnagaray, D., Lewis, D., Roush, P., Sladen, D.P. & Tharpe, A.M. (2019): Consensus practice parameter: audiological assessment and management of unilateral hearing loss in children, International Journal of Audiology, DOI: 10.1080/14992027.2019.1654620 to link to this article:

<https://www.tandfonline.com/doi/full/10.1080/14992027.2019.1654620>

Idea for the parent guide came as the group was working for the recommendations for professional clinicians.

UHL Guidelines for Families

- **This Guide can:**
- Help families understand recommended practices for children with UHL.
- Help families assess services based on the principles recommended by an expert consensus group.
- Empower families to advocate for appropriate services.
- Improve partnerships with hearing healthcare professionals.
- Help families process decisions and recommendations regarding UHL.

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Includes: Introduction, definition of terms, principles, and FAQs

Each Principle Organized into 4 sections:

- **Principle:** Components of the principle as it appears in the Consensus document:
 - Identification and assessment
 - Management and monitoring
 - Technology management
 - Information to be conveyed to families
 - Further research needs (not included in the parent guide)
- **What this means to me:** Brief description of what the principle means to your family
- **Things to think about:** Ideas about what your family may want to consider
- **Additional resources**

Example Principle 3 – Principles of Technology Management

- **Things to think about**

- I have a right to expect:
- Technology options and evidence (or lack thereof) will be discussed based on my child's individual needs.
- Our audiologist will have experience working with children with UHL and the technology considerations for this population.
- If the UHL is known to be associated with progressive hearing loss, our audiologist will consider how the various technology options perform as hearing changes.
- For some children, detection of sound – not just speech perception – might be a desirable outcome of an aided ear for safety purposes.
- Our audiologist will consider our child's future needs as well as current concerns, so quality decisions can be made towards the best value of investment (both time and money).

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