SUMMER 2025

# hearing life

THE MAGAZINE FOR BETTER HEARING

## Community Collaboration Creates Dynamic Hearing Loss Exhibit in Boston

A PUBLICATION OF THE HEARING LOSS ASSOCIATION OF AMERICA (HLAA)

ADVERTISEMENT

Cochlear®

As the global leader in implantable hearing solutions,

Cochlear is dedicated to helping people with moderate to profound hearing loss experience a life full of hearing. We have provided more than 750,000 implantable devices, helping people of all ages to hear and connect with life's opportunities.

We aim to give people the best lifelong hearing experience and access to innovative future technologies. We collaborate with leading clinical, research and support networks.

That's why more people choose Cochlear than any other hearing implant company.

©Cochlear Limited 2021. All rights reserved. Hear now. And always and other trademarks and registered trademarks are the property of Cochlear Limited or Cochlear Bone Anchored Solutions AB. The names of actual companies and products mentioned herein may be the trademarks of their respective owners. Please seek advice from your health professional about treatments for hearing loss. Outcomes may vary, and your health professional will advise you about the factors which could affect your outcome. Always read the instructions for use. Not all products are available in all countries. Please contact your local Cochlear representative for product information.

www.cochlear.com/us

Follow us on

CAM-MK-PR-581 ISS1 NOV21

# Changing Lives for 45 Years

HLAA

CHANGING LIVES FOR 45 YEARS

HLAA 2024 ANNUAL REPORT

| FACT: | THEN: | NOW: |
|---|---|---|
| 50 million Americans have hearing loss. | 45 years ago, people with hearing loss had no voice, nowhere to turn. | HLAA fights for change, empowers millions and promotes hearing health. |

**As HLAA celebrates this milestone, see the impact we made together last year, including:**

- Ushering in new hearing aid compatible cell phone requirements
- Improving the safety and accessibility of air travel for people with hearing loss
- Empowering thousands through 21 Walk4Hearing events throughout the U.S.
- Educating tens of thousands with reliable hearing loss information and resources

**Read our 2024 Annual Report for more about our work and how you can help.**

# Get the Latest News from HLAA

SPRING 2025

hearing life

THE MAGAZINE FOR BETTER HEARING

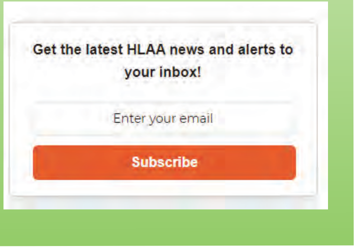
Hearing Loss Affects More Than Your Ears

HLAA welcomes story ideas for our seasonal magazine at **magazine@hearingloss.org**

All issues of *Hearing Life* magazine are online at **hearingloss.org/hearinglife**

Sign up for monthly *Hearing Life* e-News at **hearingloss.org/e-news**

Sign up for the latest HLAA updates as they happen at **hearingloss.org/news-alerts**



**Get the latest HLAA news and alerts to your inbox!**

Enter your email

Subscribe

hearing life
THE MAGAZINE FOR BETTER HEARING

SUMMER 2025 | ISSUE 2 | VOLUME 46

10

18

22

26

## departments

© Nic Czarnecki

***On the cover:*** HLAA Boston Chapter Members and Museum of Science (MOS) staff at the MOS Hearing Loss exhibit. Photos by Nic Czarnecki, except where noted.

## features

ADVERTISEMENT

are you coming to the parade on Sunday? great we'll meet you in our usual spot looking forward to it

# Special Moments, Everyday Events.

Be a part of it all with a CapTel® Captioned Telephone. CapTel connects you with the important people in your life, showing accurate, real-time captions of what they say over the phone. Enjoy every moment, confident you'll catch the whole conversation.

CapTel phones are available at no cost to people with hearing loss.

Call or visit online to learn more.

1-800-233-9130
www.captel.com

CapTel®
Captioned Telephone

MADE IN AMERICA
From Worldwide Components

REQUIREMENTS: Hearing Loss, High Speed Internet. No-Cost phone option is subject to change without notice. Terms and conditions may apply. FEDERAL LAW PROHIBITS ANYONE BUT REGISTERED USERS WITH HEARING LOSS FROM USING INTERNET PROTOCOL (IP) CAPTIONED TELEPHONES WITH THE CAPTIONS TURNED ON. Automatic speech recognition software generates captions of what the other party to the call says, and, in certain circumstances, a live communications assistant may be included on the call to make needed corrections and/or add call details. The captions are then sent to the phone. There is a cost for each minute of captions generated, paid from a federally administered fund. No cost is passed on to the CapTel user for using the service. CapTel captioning service is intended exclusively for individuals with hearing loss. CapTel® is a registered trademark of Ultratec, Inc. (v1.9 01-25)

**ABOUT HLAA**—We are the leading organization representing the growing number of people with, and at risk of, hearing loss in the U.S. HLAA helps millions thrive with hearing loss through information, education, advocacy and a nationwide network of support.

## BOARD OF DIRECTORS

Ira Rubenstein, VA
*Chair*

Zina Jawadi, CA
*Vice Chair*

Peter C. Fackler, NY
*Secretary*

Elaine McCaffrey, IL
*Treasurer*

Barbara Kelley, MD
*Executive Director*

David Baldridge, Ph.D., OR
Frank Bryant, CA
Liz Frank Cathcart, VA
Henry Fader, PA
Michael J. Frank, MD
Larry Guterman, CA
Andrea Kaneb, NH
Michael Meyer, IL
Carrie Nieman, M.D., MD
Cheri Perazzoli, WA
Roxana Rotundo, FL

## PROFESSIONAL ADVISERS

**Audiology**
Larry Medwetsky, Ph.D.
*Gallaudet University*

**Captioning (CART)**
Lisa B. Johnston, RMR, CRR, CRC

**Hearing Loop Technology**
Juliëtte Sterkens, Au.D.

**Medical**
Frank Lin, M.D., Ph.D.
*Johns Hopkins University School of Medicine*

**Behavioral Health**
Samuel Trychin, Ph.D.

**Health Care Access**
Megan Morris, Ph.D., MPH, CCC-SLP
*University of Colorado School of Medicine*

Nicholas Reed, Au.D., CCA-A
*Johns Hopkins Bloomberg School of Public Health*

**Technology**
Linda Kozma-Spytek, M.A., CCC-A
*Project Lead*
ICAAT: Industry-Consumer Alliance for Accessible Technology
*Deaf/Hard of Hearing Technology RERC – Gallaudet University*

Recycle this issue of *Hearing Life* by passing it along to a friend, or leave it in a waiting room where hearing health care is provided.

*Hearing Life* (ISSN 1090-6215) is published seasonally by the Hearing Loss Association of America, 6116 Executive Blvd., Suite 320, Rockville, MD 20852. Some HLAA members receive the magazine via postal mail. For membership information, visit **hearingloss.org/membership**

Opinions expressed in articles appearing in *Hearing Life* are those of the author. Mention of goods or services in advertisements does not mean Hearing Loss Association of America endorsement, nor should exclusion suggest disapproval. The Hearing Loss Association of America cannot be held responsible for loss or damage of unsolicited materials.

Readers may enjoy *Hearing Life* online at **hearingloss.org/hearing-life-magazine**.

For advertising information in *Hearing Life* magazine and other HLAA publications, contact **advertising@hearingloss.org**.

We welcome *Hearing Life* article queries from hearing health care professionals, subject matter experts and people living with hearing loss. Find guidelines at **hearingloss.org/submit-an-article**. Send submissions to **magazine@hearingloss.org**.

HLAA
Hearing Loss Association of America

## HEADQUARTERS

Barbara Kelley
*Executive Director*

Stacy Clift
*Director of Donor Relations and Strategic Partnerships*

Meredith Resnick
*Director of Strategic Communications*

Neil Snyder
*Director of Public Policy*

Rini Indrawati
*Director of Finance and Operations*

Melissa Kruse
*Chapter Engagement Manager*

Ann Rancourt
*Development and Engagement Manager*

Tim Browning
*Digital Communications and Web Specialist*

Teri Breier
*Communications Specialist*

Robin Gardiner
*Events and Chapter Engagement Assistant Manager*

**Hearing Loss Association of America**
6116 Executive Blvd., Suite 320
Rockville, MD 20852
301.657.2248

Cindy Dyer, Dyer Design
*Graphic Designer*

@HearingLossAssociation
@hlaa
@hearinglossassociation
hearingloss.org
inquiries@hearingloss.org

# New "Beyond Your Ears" Resources Reach Thousands

Have you seen the Hearing Loss Association of America's (HLAA) new content about the wide-reaching impact hearing loss can have in your life, affecting work, school, relationships, confidence and more?

We launched our **Beyond Your Ears** campaign in May.

This campaign has helped to raise awareness and share new resources with members, chapters and thousands of new people who visited the web page, attended our webinar or engaged in social media posts.

## Beyond Your Ears

Exploring the wider emotional and social effects of hearing loss.

**Learn more at**
**HearingLoss.org/BeyondYourEars**

HLAA
Hearing Loss Association of America

a note from our executive director

We hear stories about how people, just like you, took a small step to find HLAA and how much it mattered. You tell us how HLAA has changed your life for the better. It has changed mine. We do big things at HLAA, but we also help people every day, one person at a time.

# From Little Acorns, Mighty Oaks Grow

BY BARBARA KELLEY

Life is full of surprises. You wake up and never know what the day will bring. A few months ago, I was driving home from work and my neighbor called in a panic.

The wind had picked up a mighty oak in my yard and felled it, shaking the earth, terrifying the neighbors who stood by helplessly watching it hit our house.

The impact went beyond a mess to clean up. There were emotions ranging from fear to relief that no one was hurt. The teenage neighbor girl came by and simply said, “That was the tree with the swing.” Our son called after seeing the photo of the tree on our family text and asked, “Was that the tree with the swing?” A two-year-old still looks at the hole in the ground and asks, “Swing?”

One innocuous mighty tree we watched grow over the years, logging hours of memorable rope swinging, left a significant impact when it tumbled in the wind.

Continuing my drive home after this shocking news, another call came from an unknown number. I picked it up and the man said, “Barbara? This is Brian. I wrote to you several months ago and you gave me your cell phone number.”

Still recovering from the tree news, I collected myself and said I was happy he called. Brian has two sons, one with hearing loss, one without hearing loss. The one with hearing loss, Eric, passed away a few years ago at the young age of 26.

Brian said he was working on his will and estate plan, his living son would be executing the estate, and he wanted to be sure everything was buttoned up tight so his son could easily carry out his wishes. Brian shared openly his plans: he is giving one-third of his estate to a charity he cares about; one-third will go to his surviving son; one-third will go to the Hearing Loss Association of America (HLAA) in memory of his son with hearing loss who passed away.

He continued telling me about the life of his son, Eric, now deceased, who was born with a hearing loss. The social workers and medical professionals had told Brian and his wife that their son would probably not graduate from high school. The boy proved them wrong. Eric went on to college and earned a degree in deaf studies from Towson University in Maryland.

I had to ask, “What inspired you to plan for a legacy gift to HLAA?” He said he wants to make a gift in his son’s name to an organization with hearing loss in its mission that makes an impact on people’s lives.

He continued, “I researched, and HLAA came up. I looked at what you do, looked at your financials on your website and saw your high charity ratings and contacted you.”

It was simple as that. Brian and his wife didn’t know about HLAA, but they wished they had. They could have used a community like HLAA when Eric was growing up. They were grateful for his life and accomplishments beyond the odds they were given, and they wanted to pay it forward. He is planning a gift in Eric’s honor, and he wants to let Eric’s friends know about it now while they still remember the good times with their buddy.

Another story of impact.

Every day HLAA makes an impact, whether it’s on a big scale, like advocating for legislation that affects every American with hearing loss or welcoming someone into a local HLAA Chapter who is searching for help, and everywhere in between. We count the number of times people come to our website, land on a resource page and get the help they need.

In 1979, we started small—gathering people in a handful of community chapters to offer them hope—and inspired a cadre of professionals who care about hearing loss to help us out. We grew into the HLAA you know today. Our work is never done; it has just changed. There are new challenges, current issues to tackle, innovative technology and more and more people every day discovering they have a hearing loss—the numbers don’t lie.

We hear stories about how people, just like you, took a small step to find HLAA and how much it mattered. You tell us how HLAA has changed your life for the better. It has changed mine. We do big things at HLAA, but we also help people every day, one person at a time. Tell someone you know about HLAA; they will be glad you did. **HL**

*Barbara Kelley is executive director of HLAA. She can be reached at* bkelley@hearingloss.org.

# A Unique Community Collaboration Brings Hearing Loss to a Popular Museum

## *HLAA Chapter Helps Create Dynamic Boston Hearing Loss Exhibit*

BY TERI BREIER

More than a million annual visitors to the Museum of Science (MOS) in Boston can now learn all about hearing loss. The newest installation in the 195-year-old museum's permanent Hall of Human Life exhibit, "Hearing Loss," explores aspects from ear anatomy to assistive technology with a variety of interactive components.

This one-of-a-kind exhibit represents a unique collaboration between MOS staff and the local Hearing Loss Association of America (HLAA) Boston Chapter community. As the leading voice of the growing number of Americans with, and at risk of, hearing loss, HLAA empowers millions to thrive through education, advocacy and a nationwide network of support. Our 126 local chapters and groups around the U.S. are an integral part of that mission.

The "Hearing Loss" exhibit was conceived and sponsored by MOS trustee and longtime HLAA Boston member Andrea Kaneb, who has genetic progressive hearing loss. Through her involvement in HLAA, Andrea advocates for herself and others with hearing loss, while advising people about hearing assistive technology. She approached the MOS exhibits team in 2023 with her vision—an interactive exhibit to educate, inform and break down hearing loss stigma (read more from Andrea on page 15).

### A Match Made in Heaven

"The Hall of Human Life has been a favorite at the museum since 2012, exploring different facets of bodies and what they can do," says Kate Marciniec, MOS director of exhibit planning and operations. "A primary goal is to make this information directly relevant to middle and high school students, while matching their curriculum. We've found that there is great value in telling more diverse stories from different perspectives that touch

### MOS "Hearing Loss" Exhibit Elements

**Ear Puzzle** — Visitors learn the importance of each piece of the hearing system functions.

**Hearing Safety** — A quiz tests knowledge of noise levels of everyday activities, risks for noise-induced hearing loss and gives protection tips.

**Communication** — A silent looping video showing visual communication cues simulates the experience of someone with hearing loss.

**Technology** — Visitors explore six types of assistive technology that can support communication, accessibility and independence.

**Human Body Theater** — Four animated personal impact stories told by people with hearing loss, sharing everyday challenges and solutions that empowered them. Two of these stories are from members of the HLAA Boston Chapter community.

*HLAA Boston Chapter Members Andrea Kaneb and Jonathan Ozek (at left) stand in front of the Museum of Science (MOS) "Hearing Loss" exhibit with key project staff members (left to right): Kate Marciniec, director, exhibit planning and operations; Benjamin Chong, senior exhibit designer; Caroline Cocossa, digital project manager; and Sylvie Rosenkalt, accessibility coordinator.*


Museum of Science
dcr
Massachusetts

on various aspects of being human. So, when Andrea proposed the hearing loss installation, it was a match made in heaven! Over one year, we developed it in collaboration with Andrea, who was a true partner from the start."

The project evolved from an early sound booth concept into a larger vision through a 40-person brainstorming session and a dedicated five-person core team. As the primary sponsor, Andrea wanted to be closely involved every step of the way. She helped guide the exhibit's development from start to finish in monthly meetings over 18 months and received weekly updates.

The four phases of this process were:

**1. Concept development** — Brainstorming, goals and objectives, initial research online and via conversations with subject matter experts and people with lived experience of hearing loss. What is most important to communicate with visitors, and how to best engage them?

**2. Experience design** — A prototype was created to test concepts and components with a wide range of visitors, all ages and backgrounds, plus a special focus group of local high school students with hearing loss. How does this align with your stories and experiences?

**3. Fabrication and production** — Building the physical elements and recording/animating the video stories—four at the museum and six on the museum's website.

**4. Installation and testing** —Placing the elements and making sure everything works properly before opening to the public.

According to Kate, this exhibit took longer than usual to allow for the human element, beyond their typical scientific approach. "We moved carefully to ensure that we were creating an authentic experience that reflects the perspectives of many individuals with hearing loss. As a result, we created something that our partners are proud of and our visitors enjoy."

## Highlighting Diverse Experiences

During Phase Two, Sylvie Rosenkalt, accessibility coordinator for MOS, reached out to the HLAA Boston Chapter's president, Kerry Sullivan, as part of the museum's search for diverse candidates with hearing loss to share their stories for the exhibit. Among the dozen community members Kerry referred were Jonathan Ozek, 40, and Saaim Khan, 22, a recent Harvard graduate, both of whom were selected after reviewing numerous submissions.

Kerry shares, "MOS is such a respected institution in the Boston area, so we were very excited to learn about their planned exhibit on hearing loss. It was an opportunity to raise awareness and understanding of hearing loss in our community at a scale beyond what the chapter can do. Imagine our pride when two of our HLAA Chapter members' stories were featured in the exhibit!"

*The communication component of the "Hearing Loss" exhibit, showing visual communication cues with captions on a silent video.*

*Visitors walk past the entrance of the Museum of Science Hall of Human Life (above); HLAA member Jonathan Ozek poses next to his illustrated portrait at the animated video story booth (right).*

Jonathan jumped at the opportunity to participate. Since joining HLAA in 2018, his personal mission has been to reduce stigma and spread awareness about this increasingly common disability. Born with nerve damage, he is deaf in the right ear and has severe hearing loss in the left. Jonathan was discriminated against in school, which his video illustrates with an example from sixth grade.

"My goal is to help the community of people with hearing loss from my own personal experience," he says. "I don't want anyone to go through the same situation that I went through."

Saaim, the son of immigrants from Pakistan, was born in Detroit and raised in Ontario, Canada, before attending Harvard University in Cambridge, Massachusetts. Diagnosed with sensorineural hearing loss at age four, he wears one hearing aid in his right ear. Like Jonathan, Saaim experienced discrimination and was sometimes bullied in his mainstream schools. After attending medical school, his goal is to become an otolaryngologist or other related specialist.

He says, "I first got interested in science in middle school. Later, in high school, I was mentored by a Wayne State professor, researching proteins related to hearing loss and existing drugs on the market. I just earned my undergraduate degree in human developmental and regenerative biology and will start Harvard Medical School in the fall [of 2025]. Eventually, I want to develop gene therapy trials to provide alternative treatment options for children with hearing loss."

The four animated stories in the exhibit are told by:

- Jonathan, on being left out at school and finding true friendship
- Saaim, on trying to hear in the car with friends
- Charlene, who experienced hearing loss late in life, on finding connection through a familiar song
- Katie McCarthy, outreach coordinator for the Boston Children's Hospital Deaf and Hard of Hearing Program, on sharing a meal while using ASL

The associated digital component on the MOS website, Hearing Well, was curated by Caroline Cocossa, MOS digital project manager. It features three individuals, each appearing in two videos: Saaim, Andre "Dre"

Robinson, a DJ who uses American Sign Language (ASL) and a mother, Beth Leipholtz, with her toddler son, Coop, who is Deaf. This series bridges the worlds of assistive technology and Deaf culture, showing how they coexist and enrich one another.

## Spotlight on Accessibility

Soon after the "Hearing Loss" exhibit opened in June 2024, it was featured at a special disability rights event in July, where the HLAA Boston Chapter staffed an information table with five of its leaders. July is Disability Pride Month, celebrating people with disabilities and commemorating the passage of the Americans with Disabilities Act (ADA) in 1990—in fact, July 26, 2025, marked the 35th anniversary of this milestone civil rights legislation that mandates public accommodations. HLAA was among the advocacy organizations that supported its passage and advised on the bill's accessible communication provisions.

MOS features inclusive, universal design of the facility and exhibits that welcome and accommodate visitors of all abilities. Their accommodations for people with hearing loss include:

- Assistive listening (amplified audio) systems
- Scripts and captioning for some shows
- All videos captioned in English and Spanish
- ASL interpretation and Computer Aided Realtime Transcription (CART) with two weeks advance notice
- ASL interpretation for select shows on the second Sunday of each month
- All exhibits go through an accessibility advisory committee testing to assess and give feedback

*HLAA Boston Chapter Member Saaim Khan contributed two online videos on the MOS website, in addition to his animated story for the exhibit itself. Photo credit: Museum of Science*

The museum is currently exploring other assistive technology, such as Auracast Broadcast Audio and Xander Captioning Glasses.

## The Power of Community Collaboration

Hearing loss is a growing public health crisis that affects people of all ages. More than 50 million Americans (one in seven) have some degree of hearing loss, and many more are at risk. The World Health Organiza-tion (WHO) expects as many as 2.5 billion people world-wide to experience hearing loss by 2050, and one billion young adults are at risk due to unsafe listening practices.

Despite the alarming numbers, many of us still don't pay attention to our hearing as an important part of overall health and well-being. Hearing should be tested, protected and treated—crucial messages that HLAA is spreading at the national level. The organization also fights hearing loss stigma through education, a mission that Andrea took on locally in Boston.

"Through my involvement with HLAA and volunteering as a hearing assistive technology adviser, I began to see the many roadblocks that keep people from seeking help for hearing loss, which audiologists don't have time or knowledge to address," says Andrea. "I realized that information about its causes, related stigma, technology and other issues needed to reach more people in welcoming public spaces. That inspired me to reach out to the Museum of Science."

Personal stories like Jonathan's and Saiim's have the power to connect more deeply and emotionally with museum visitors, generating compassion in a way that written facts don't. Through sharing his story, Jonathan hopes "…to make the world a better place for people with hearing loss, where others understand where we're coming from and provide reasonable accessibility accommodations at school and work."

This unique collaboration with MOS reaches well beyond the museum exhibit—it's a powerful community partnership inspired by a local HLAA Chapter to change mindsets about hearing loss. The more we work together to weave hearing loss information into the mainstream, the more we can reduce stigma and other barriers, together. **HL**

**More information:**
mos.org/visit/exhibits/hall-human-life

**Online component:**
mos.org/hearing-well

*Teri Breier is the communications specialist for the Hearing Loss Association of America (HLAA). She can be reached at* tbreier@hearingloss.org.

# The Ripple Effect

*By Andrea Kaneb*

*Andrea Kaneb and Jonathan Ozek view a component of the "Hearing Loss" exhibit with Sylvie Rosenkalt.*

It's been powerful to watch the stories ripple outward from the new Museum of Science (MOS) exhibit on hearing loss—something I never imagined back in sixth grade while building a science fair project with my dad. I inherited my lifelong, progressive hearing loss from him, along with his love of problem-solving and storytelling. He lived through the Hurricane of 1938 as a boy on Cape Cod, and together we recreated that storm for my project—white swirls across a poster board. The next year, we built a model water treatment system using cardboard houses and snipped copper pipes. I didn't realize it then, but our work together sparked my love of storytelling and the idea that a simple, hands-on model could help people understand something important.

Over the past 10 years, HLAA has opened my eyes to just how much people need to know, and often don't understand, about living well with hearing loss. HLAA introduced me to the personal "toolbox" I need to stay connected with my world, like wireless audio that brings surprising clarity. And when I sought a return to work, HLAA's Network of Consumer Hearing Assistive Technology Trainers (N-CHATT) program training set me on a purposeful path to help others understand hearing assistive technology (HAT).

After creating a website and giving public presentations, I saw how stigma and lack of awareness kept people from understanding the tools that could help them stay connected. I began imagining something more visible and immersive, set in a public space. That's when the idea of a museum exhibit started to take shape. Encouragement from Harvard Medical School scientist Dr. David Corey, who researches inner ear hair cells, gave me the push I needed, and a chance meeting with the president of the Boston Children's Museum connected me to the team at MOS. Within weeks, I was sharing my ideas.

From an initial brainstorming session with about 40 MOS staff to 18 months of collaboration with a dedicated core team, the exhibit evolved into a hands-on area, story booth and social media campaign. In some ways, it was the grown-up version of that first science fair—still fueled by storytelling, still aiming to make something complex more understandable.

I'm deeply grateful to the Museum of Science for embracing this vision and working closely with me to shape an exhibit that teaches about HAT and word clarity, how sound travels to the brain, the importance of safe listening, why facial expressions and speechreading matter and the emotional realities of hearing loss. Together with many wonderful storytellers, we created something both educational and empathetic, honoring the wide spectrum of experiences from people who rely on technology to those who find identity and community in Deaf culture and American Sign Language (ASL).

It's been especially meaningful to see stories like Jonathan Ozek's, which builds empathy and awareness, and Saaim Khan's, highlighting his journey into genetic research to better understand the causes of hearing loss in children. Their contributions reflect powerful, vital ways of deepening public understanding—and I believe my dad would have admired them both.

What began as a personal vision has grown into something much larger. It moves me to see how one story can spark another, and how, together, they ripple outward—connecting people in ways I never could have imagined. HL

*Andrea Kaneb is a frequent presenter, adviser and hearing technology advocate through her website,* gatheringsound.com. *She is a newly elected HLAA Board Member and also serves on the board of the Museum of Science and as a trustee for Massachusetts Eye and Ear, both in Boston. Andrea was honored with the Keystone Award at the HLAA 2025 Convention in Indianapolis.*

**This article appeared on our website in May. Read the original blog post and sign up for alerts like this at hearingloss.org/hear-this-blog.**

# Critical Infant Hearing Screening at Risk from Budget Cuts

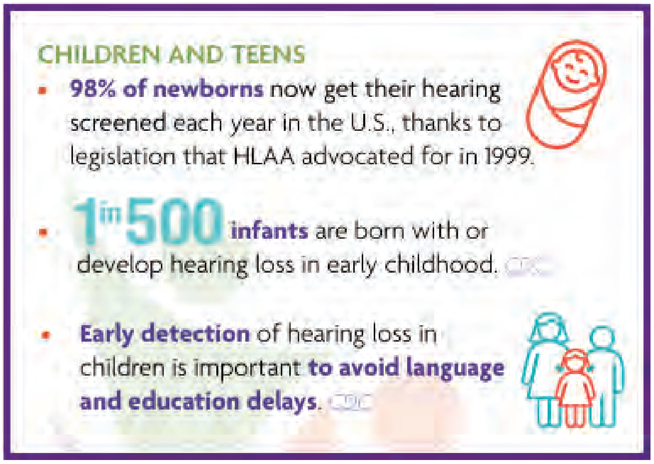
BY NEIL SNYDER

Before 1993, fewer than one in 10 newborns in the United States were screened for hearing loss. By 2025, thanks to decades of advocacy and public health efforts, an estimated 98% of all newborns receive this critical screening. Today, this hard-fought success is in jeopardy from proposed dramatic federal budget cuts, putting our nation's infants again at risk.

## Advocating for Newborn Screening

This public health success story began in the 1990s, when the **Hearing Loss Association of America (HLAA)** and other advocacy organizations championed the passage of the Early Hearing Detection and Intervention (EHDI) Act, which became law under the Children's Health Act of 2000. Since then, the EHDI Act has been updated several times, most recently in 2022, when Congress reauthorized annual funding for both **Centers for Disease Control and Prevention** (CDC – $10.7 million) and **Health Resources and Services Administration** (HRSA – $17.8 million) through 2027.

"Passing the EHDI law was a huge success for HLAA and its advocacy partners," said Barbara Kelley, executive director of HLAA, the leading voice for the growing number of Americans with hearing loss. "It means that parents know before they leave the hospital whether their newborn's hearing is functioning properly, and if not, take immediate action to provide early intervention for their child."



CHILDREN AND TEENS

- **98% of newborns** now get their hearing screened each year in the U.S., thanks to legislation that HLAA advocated for in 1999.
- **1 in 500 infants** are born with or develop hearing loss in early childhood. CDC
- **Early detection** of hearing loss in children is important **to avoid language and education delays.** CDC

## Why This Matters

**One in 500 babies are born with hearing loss** or develop it in early childhood, which ranks among the most common congenital conditions. With hearing loss numbers rising, early detection and intervention is critical to ensuring that children meet speech, language, social and emotional development milestones.

The EHDI story is held in high regard by many HLAA members from the organization's nationwide network of support. Many are now in their 50s and 60s—born before that legislation passed—and did not get diagnosed with hearing loss until later in childhood or even as young adults. Pre-EHDI anecdotes abound about delayed intervention. Most say the lack of early diagnosis caused lifelong issues, including delayed speech, academic challenges and trouble making friends. Had their families been alerted earlier of their hearing loss, timely treatment and accessibility might have given them more confidence, equipment and support services, potentially changing their lives' trajectories.

For instance, one person on our national staff was diagnosed with genetic bilateral hearing loss at age seven, yet didn't receive hearing aids until her sophomore year of college, after struggling to hear in class and connect with peers all through her schooling. With the benefit of EHDI, her family likely would have learned about her hearing loss and treatment options much sooner.

Since its passage, EHDI has helped states dramatically improve newborn hearing screening rates—from just 46.5% of infants before the program to nearly 98% today. Between 2018 and 2022 alone, more than 320,000 children received diagnostic services after failing initial screenings, and more than 19,000 children were enrolled in early intervention.

## EHDI Supports State Programs and Research

The EHDI program accomplishes three key objectives:

**1. Supports state data systems:** Directs the CDC to fund and assist states in developing and maintaining data systems to evaluate progress, inform research and policy, and identify gaps in follow-up services.

**2. Provides state grants:** Funds the HRSA to award grants that help states implement and improve EHDI services through technical assistance.

**3. Encourages research:** Promotes hearing research at the National Institutes of Health (NIH) through projects supported by the **National Institute on Deafness and Other Communication Disorders (NIDCD)**.This progress—decades in the making—is now in jeopardy.

## State Programs Will Suffer Without Funds

Recent federal budget proposals would eliminate all HRSA grant funding that supports newborn hearing screening programs. Without this funding, many states may be forced to scale back or discontinue their screening services entirely. Our country would be returning to a patchwork of protection for infant screenings, depending on where they are born and potentially burdening families with additional costs.

In addition, a recent reorganization within the Department of Health and Human Services (HHS) has eliminated CDC's role in data collection and program assessment—functions that are essential to the success of early hearing detection and intervention efforts at the state level. HL

Make your voice heard
on this and other legislation at
hearingloss.org/action-alerts

*For more information or questions, contact: Neil Snyder, HLAA's director of public policy, at* nsnyder@hearingloss.org

ADVERTISEMENT

# Back to School with Confidence:

## *Helping Kids with Hearing Loss Start Strong*

BY MICHELLE HU

Back-to-school season often brings images of fresh, new pencils, color-coded folders and first-day outfits to mind. But for families of children with hearing loss, it also brings a unique mix of emotions—hope, nervousness and often a hefty load of behind-the-scenes preparation. I'm Dr. Michelle Hu, a pediatric audiologist, bilateral cochlear implant user, and creator of the *My Child Has Hearing Loss, Now What?* parent program and guidebook. Long before I became a professional, I was that child with hearing loss navigating noisy classrooms, struggling with listening fatigue and trying to fit in.

Each fall, I watch families juggle more than just school supply lists. Parents of children with hearing loss are managing individualized education program (IEP) meetings, connecting with mentors and constantly checking on hearing technology. From both personal and professional experience, here's what I want every parent and provider to know: Your child's success doesn't just come from using the right devices—it comes from strategic, ongoing support.

### The Emotional Load

Parents of children with hearing loss carry a kind of invisible labor—packing spare batteries, planning around audiology appointments, adjusting therapy schedules and pushing through quiet fears like:
*What if they didn't hear me? Am I doing enough?*

My mom still remembers a day from my toddler years. She had tucked herself into a quiet corner of the house, crying. I found her and asked what was wrong. Through tears, she said, "I wish I could take your hearing loss for you."

With the honesty only a toddler can offer, I told her, "But Mama, what if this is the way I'm meant to be?"

That seemingly ordinary moment changed everything for my family. It was a turning point—from grief to growth, from fear to hope. That was the day my parents shifted their focus on what I couldn't do with hearing loss, to what I *could* do.

Parenting any child is demanding but parenting a child with hearing loss can feel especially isolating. My parents were Chinese immigrants, far from extended family and navigating an unfamiliar culture. They had no roadmap, no peers to share their journey with, no internet or social media to connect with others or search for answers. For a long time, they felt alone.

Now, as a parent myself, I reflect on those early days with deep appreciation. When I was pregnant with my first child, I wasn't scared of becoming a parent—I was scared of the day she'd realize I wasn't a superhero, that I couldn't hear everything she said. But over time, I learned to share my identity with her. I explained my hearing loss, my devices and what I needed to communicate well. I advocated for myself in front of her. That transparency built trust—and reminded me that who I am is something to be shared, not hidden.

## Paddling Furiously to Keep Up

One of the biggest myths I encounter is the belief that hearing aids or cochlear implants "fix" hearing loss and level the playing field. This simply is not true. Hearing devices are powerful tools—but they do not restore natural hearing. They provide access to sound, but that access takes effort to interpret, especially in noisy classrooms, bustling cafeterias or when teachers turn away mid-sentence. Unlike glasses, which often correct vision to near-perfect, hearing technology cannot close the gap entirely between students with hearing loss and their peers.

This misconception can lead to skipped accommodations, missed instructions and unnecessary pressure on kids to just "keep up."

As a child, I often came home from school *exhausted*. And not just from learning—exhausted from *listening*. Trying to follow every instruction, every joke, every announcement was like paddling furiously under water while appearing calm on the surface. I call it the "duck on a pond" metaphor. To an observer, a duck may appear calm, cool and collected while swimming across the water—but underneath, they are paddling furiously and working incredibly hard.

I worked tirelessly in the classroom, exhausted myself in group projects and I even had to concentrate at lunchtime—a break that is usually relaxing for other students. I was always paying attention—hyper-aware of faces, lips and cues. I became a pro at smiling and nodding, even when I wasn't sure what had been said. And while "I didn't even realize you had a hearing loss" sounded like a compliment, it often meant simply that I was really good at hiding how hard I worked just to keep up.

**Invisible Handicap:**

"If you can imagine, I was like a duck on a pond, appearing calm, collected and cool, but paddling furiously underneath the water."

### Tip 1: Help your child prepare for different sound environments. Practice classroom scenarios at home. Role-play what to do if they can't hear the teacher or how to ask for clarification. Let them explore the language of self-advocacy in a safe space—before they need to use it in real life.

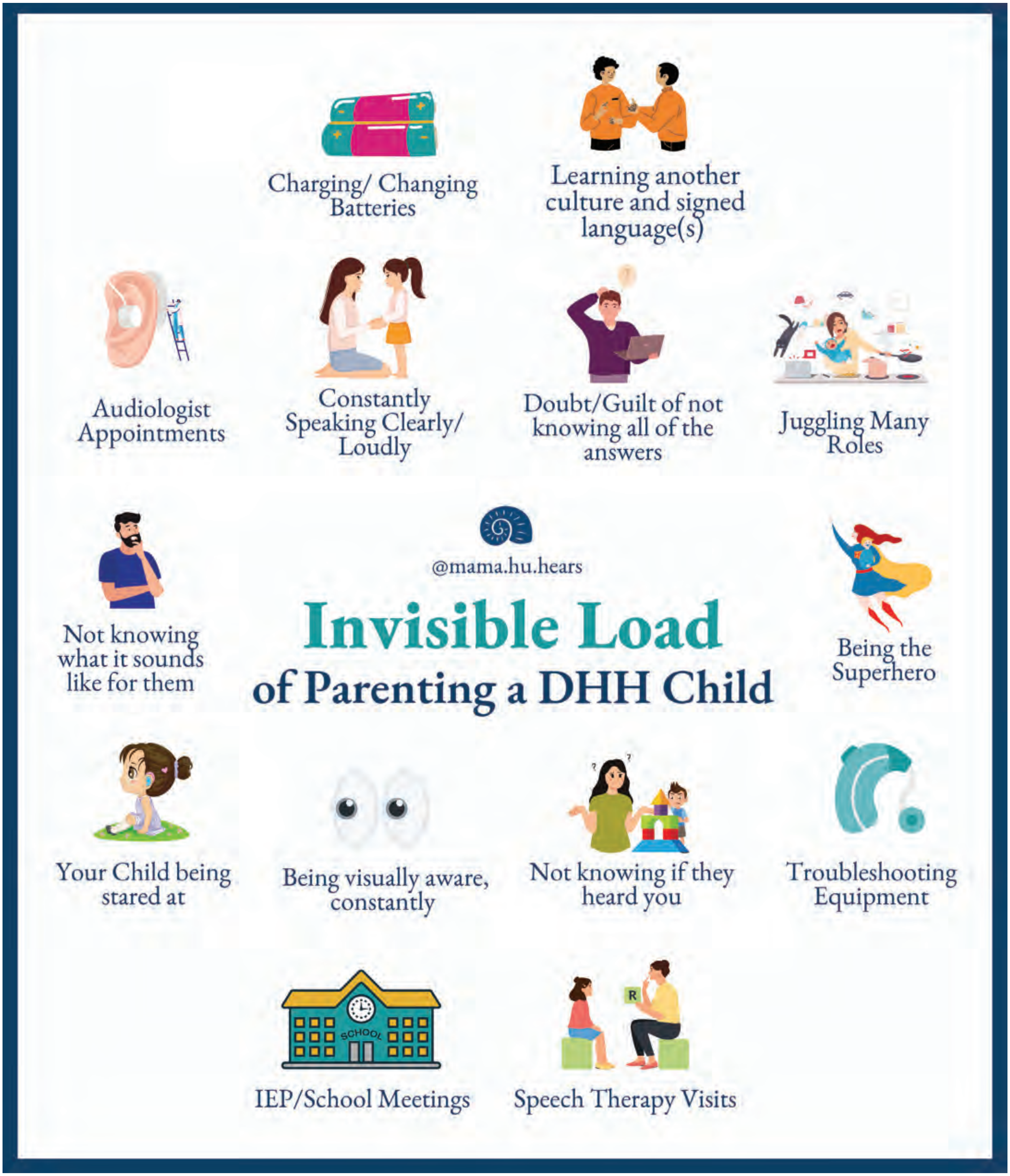
## Tools & Accommodations

Hearing technology is just one part of a much bigger picture. Schools can—and should—offer essential accommodations that make a world of difference:

- Remote microphones
- Preferential or strategic seating
- Written instructions
- Buddy systems for clarification
- Visual schedules

These supports don't signal weakness—they open the door to full participation.

Looking back, I remember the accommodations that *didn't* help me just as vividly as those that did.



@mama.hu.hears

# Invisible Load of Parenting a DHH Child

- Charging/ Changing Batteries
- Learning another culture and signed language(s)
- Audiologist Appointments
- Constantly Speaking Clearly/ Loudly
- Doubt/Guilt of not knowing all of the answers
- Juggling Many Roles
- Not knowing what it sounds like for them
- Being the Superhero
- Your Child being stared at
- Being visually aware, constantly
- Not knowing if they heard you
- Troubleshooting Equipment
- IEP/School Meetings
- Speech Therapy Visits

When a teacher forgot to turn on the remote microphone system, or I was placed at the back of a noisy classroom, it was easy to feel invisible. That's why today, I'm so passionate about making sure families know their rights and options.

**Tip 2: Meet with your child's educational audiologist or teacher before or early in the school year. Learn the correct terminology so you can confidently ask for what your child needs. Knowing how to name devices, programs and support tools gives you power in meetings and conversations.**

## Advocacy Starts Early

Self-advocacy is one of the most important skills a child with hearing loss can develop—and it starts at home. From a young age, give your child words to talk about their hearing and needs. Try phrases like:

- "Can you say that again, please?"
- "I use a cochlear implant to help me hear."
- "Could you face me when you speak?"

In my program, we dedicate an entire module to helping families foster advocacy at home. We walk through real-life scripts, school scenarios and even a bonus interview with an educational audiologist.

I like to break advocacy into **four foundational keys**:

1. **Language:** Teach children the right words to describe their devices and hearing. When they can explain what they use and why, they're more confident asking for help.

2. **Respect and Confidence:** Let them take ownership of their differences. They're not broken—they have hearing loss, and that requires navigating the hearing world with a different lens.

3. **Empowerment:** Show them that when they speak up, people listen. Let them help during audiology appointments or lead conversations at school meetings.

4. **Community:** Surround your child with peers, mentors and adults who reflect their experience. Community reduces shame and builds identity.

## Rest and Recovery

Listening fatigue is real.

It doesn't always look like a yawn or droopy eyes—it often shows up as hyperactivity, zoning out, irritability or sudden mood swings. Kids may seem "fine" all day at school, only to melt down the moment they walk through the door at home.

As a child, I often pushed myself to appear "normal." But by the end of the day, I was spent. That duck on the pond metaphor? It doesn't clock out at 3 p.m. Please build in time for rest. Quiet time after school isn't laziness—it's recovery. Trust your child's cues. And yes, these signs of fatigue aren't just for kids. As an adult, I still experience them. Be gentle with your child—and with yourself.

## Conclusion: You Are Not Alone

Back-to-school season isn't just about academics—it's about access, identity and belonging. Your child has infinite potential. And you? You're doing the brave, beautiful work of making sure they start strong. You are not alone in this. Reach out for support. **HL**

*Michelle Hu, Au.D., is a pediatric audiologist, bilateral cochlear implant user, founder of Mama Hu Hears and creator of the* My Child Has Hearing Loss, Now What? *program. For resources, visit* mamahuhears.com.

Hundreds of experts and people with hearing loss from across the U.S. connected at the HLAA 2025 Convention

Mark your calendars for the HLAA 2026 Convention June 10-12 in Louisville, Kentucky.

# Inspiration in Indianapolis

**Indianapolis was the backdrop of this year's Hearing Loss Association of America (HLAA) annual convention, with more than 30 workshops, a Research Symposium* exploring the stigma of hearing loss, motivation from a former NBA player with hearing loss, social events, HLAA awards, a hearing health and technology expo and more. Here are a few highlights from the week:**

*Four HLAA 2025 National Award winners were honored at the General Session by HLAA Executive Director Barbara Kelley and members of the Board of Directors—incoming Vice Chair Zina Jawadi, incoming Chair Ira Rubenstein and outgoing Chair Michael Meyer: Andrea Kaneb, NH, Keystone Award (second from left); Peggy Ellertsen, MA, Rocky Stone Humanitarian Award (second from right); Shannon Tyree, AZ, with Riley the hearing dog, Community Service Award (right); and Katie Byxbee, CT (appeared by video), Outstanding Young Adult.*

*Our inspiring keynote was delivered by motivational speaker, author and TEDx star Lance Allred, who shared his experiences and lessons as the first National Basketball Association (NBA) player in history with hearing loss.*

*Our Indianapolis Walk4Hearing led hundreds of participants through beautiful White River State Park, just across the street from the JW Marriott Hotel.*

*Left: The 2025 Research Symposium–Stigma: Making the Invisible Actionable–featured presenters Laura Nyblade, Ph.D., Margaret Wallhagen, Ph.D., Jessica S. West, Ph.D., and hearing advocate Ibrahim Dabo, moderated by Carrie Nieman, M.D.*

*Below: The audience is mesmerized by keynote speaker Lance Allred.*

*HLAA Chapter and State Organization Leaders from across the U.S. gathered for a daylong training.*

*The HLAA 2025 Chapter Awards were presented at a special reception. Congratulations to all the winners!*

*The Exhibit Hall showcased leading hearing health companies and the latest accessible technology, such as captioning glasses.*

*HLAA recognized Hear for Life partners and key donors at a special reception. Left to right: Rehan Ehsan, senior manager, public policy, Samsung Electronics; Angela Dais, director, federal regulatory, AT&T; Shellie Blakeney, government affairs, T-Mobile; Joshua Nogle, accessibility relationship manager, T-Mobile Accessibility.*

*More than 30 educational workshops were presented on a wide range of hearing health topics, from advocacy to technology to parenting and more.*

**The HLAA Research Symposium is supported by the National Institute on Deafness and Other Communication Disorders of the National Institutes of Health under Award Number R13DC017913. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.*

# Walk4Hearing Celebrates 20 Years of Inspiration

> **"Whether you're just starting to explore treatment options or have been navigating hearing loss for years, Walk4Hearing is a space where you'll feel welcomed and understood and get important resources."**
> *Katherine Lu, Westchester/Rockland Walk4Hearing*

## HLAA's Nationwide Empowerment Tour

As the number of Americans with, and at risk of, hearing loss continues to grow, education and support are critical. One of the best ways The Hearing Loss Association of America (HLAA) supports people and families impacted by this growing public health crisis is through our annual Walk4Hearing awareness and fundraising events in 20 cities across the U.S. The first Walk4Hearing was held in 2006, making this its 20th year.

Two decades later, the HLAA Walk4Hearing continues to meet people where they live, work and go to school. Walks bring hope to hometowns across the country, inspiring people of all ages to thrive with hearing loss. These events educate thousands each year about the importance of hearing health, bring communities together and empower families facing hearing loss.

The Walk4Hearing is often the first place people with hearing loss report feeling accepted and part of a community of others facing the same challenges. Many participants become inspired to seek treatment and help others.

## Walk4Hearing Inspired Stories

College freshman **Katherine Lu** says she felt an "amazing sense of unity and hope in the air" at the Walk4Hearing. After her grandmother was diagnosed with hearing loss two years ago, the Walk gave her a way to work towards change and help others. Katherine has served as a team captain and on the planning committee for the Westchester/Rockland Walk in New York since the diagnosis, and she co-founded the Deaf Culture and Awareness Club at her school.

*Team Katherine Lu*

*Griffin Polaske*

**Chelsea Polaske** is excited to lead a team for one of the newest walks in Madison, Wisconsin. Her son, Griffin, has Usher Syndrome Type 2A—after reading Mackenzie's similar story on HLAA's website, she wanted to connect and raise awareness about this rare condition. Now over a year old, Griffin was diagnosed with mild-to-moderate bilateral sensorineural hearing loss at six weeks of age. Chelsea and her family are focused on creating a future where Griffin feels empowered and part of a caring community at every stage. She says Walk4Hearing is a great step toward building that future for Griffin.

*Brenda Lopez, bilingual engagement manager, Cochlear, and David Espiritu at the 2024 San Diego Walk4Hearing.*

**David Espiritu**, a production coordinator for the University of California, San Diego music department, experienced sudden hearing loss and became a recent bilateral cochlear implant recipient before attending the San Diego Walk4Hearing in 2024. "As soon as I heard about the event, I was excited to go," he says. "It was surprising to see how many people and teams showed up, and it inspired me to continue connecting with and supporting others with hearing loss. I want to be a resource to those who have lost their hearing like me, by sharing my experience and helping them through a very difficult, life-changing time."

## Be Part of Walk4Hearing

Join us and celebrate, inspire and empower your local community! Register or donate to a Walk4Hearing event today. HL

## FALL WALKS

| | |
|---|---|
| Kentucky | Sunday, September 14 |
| New York City | Sunday, September 21 |
| Chicago | Sunday, September 28 |
| Boston | Sunday, October 5 |
| North Carolina | Sunday, October 12 |
| New Jersey | Sunday, October 12 |
| Washington, DC | Sunday, October 19 |
| Pennsylvania | Sunday, October 19 |
| Arizona | Saturday, November 1 |
| Houston | Saturday, November 1 |
| Nashville | Saturday, November 8 |

Scan the QR code to find a Walk near you!

Walk4Hearing.org/find-a-walk

*(Above) A team at the Long Beach Walk4Hearing on May 31, 2025. (Left) The Walk4Hearing in Houston began in 2006 and is now the oldest continuous Walk event. This team is the Wathen Walkers from 2009.*

# It's Never Too Late for Better Hearing

## *A Past, Present and Future Hearing Loss Success Story*

Brenda Battat worked in the field of hearing loss for 30 years, including several in leadership positions with the Hearing Loss Association of America (HLAA). She's lived with bilateral, genetic hearing loss since she was 19 years old. Brenda received her first cochlear implant (CI) 20 years ago in 2004, which opened her world to new sounds and experiences.

She was able to function well with one hearing aid in the other ear, until recently when she noticed deterioration and distortion in that ear, too. Testing showed that her speech discrimination was only four percent with the hearing aid. Her doctor suggested another CI, but Brenda was concerned about the effects of general anesthesia at the age of 82.

In May of 2024, Brenda received her second CI under sedation and local anesthesia, and now she's sharing her experience to inspire others.

### In Brenda's Words:

It was fascinating to be awake for 75% of the surgery and to be able to let the surgeon know when I felt dizzy, and when I heard the sounds as the electrode array was inserted and activated.

A year later, I am glad that I made this decision. I hear better in noise, I definitely locate sounds much better, and apart from some disequilibrium for a week post-op, my balance is about the same as before the surgery. My recovery was much easier than the first time.

Hearing loss is a journey and along the way, you need to respond to changes as they occur. Now I want to spread the word about the new surgical approaches that were available to me when considering a second CI surgery two decades after my first. There are many new advances, including robotic assisted surgeries and local anesthesia options, to consider. Perhaps it will encourage more people to take the plunge to get their first or second implant—even in the eighth or ninth decade of life.

**“There are many new advances, including robotic assisted surgeries and local anesthesia options, to consider. Perhaps it will encourage more people to take the plunge to get their first or second implant—even in the eighth or ninth decade of life.”**

*Brenda Battat retired as executive director of HLAA in 2013. She has served on many advisory boards including the National Academies of Sciences, Engineering and Medicine (NASEM) Consensus Committee on Affordable and Accessible Health Care. She can be reached at* bebattat@gmail.com.

# HLAA's Legacy of Self-Help Expands Nationwide

BY MELISSA KRUSE

When the Hearing Loss Association of America (HLAA) was founded in 1979, it was grounded in the principle of self-help. Members offered one another emotional and practical support, sharing strategies, experiences and encouragement in ways that professionals alone could not provide. At the heart of this model were HLAA Chapters—local groups that embodied our mission of education, advocacy and community.

More than 45 years later, this principle remains central to HLAA's work, and we are thrilled to see a wave of new and revitalized chapters forming across the country. In the past year alone, HLAA Chapters and support groups have launched or reemerged in California, Washington, Arizona, Nebraska, Texas, Florida, New York and Virginia.

HLAA
Hearing Loss Association of America
Virginia Peninsula Chapter

One inspiring success story comes from Virginia's Peninsula region. This chapter began thanks to a generous bequest from Ms. Jean Cline, who directed funds to HLAA after her mother Jean Hibbard's passing, with the hope of reinstating the former Williamsburg Chapter. With guidance and support from the HLAA Virginia Beach Chapter and Access Virginia, volunteers came together to form an exploratory group. Recognizing the need to serve a broader area, the group adopted the name HLAA Virginia Peninsula Chapter. Just over a year later, the group officially became an HLAA Chapter.

Following discussions with the new chapter's leadership and Ms. Cline, the remaining funds from her bequest will now be used to support the formation of more HLAA chapters across Virginia. Using the successful Virginia Peninsula model, HLAA Virginia Beach and Access Virginia are now considering new chapter development in regions such as the Eastern Shore, Charlottesville and Roanoke.

## Interested in Starting a Chapter?

Starting an HLAA chapter or support group in your area is easy:

1. Join HLAA
2. Read about our Mission and Impact
3. Fill out the Chapter Interest Form
4. Connect with at least three unrelated HLAA members in your community
5. Set a meeting schedule and begin gathering

We can help new groups by identifying potential members in your area. Together, we can expand our reach and continue to build a stronger, more connected community for people with hearing loss across the country. **HL**

For more information, visit hearingloss.org/start-a-chapter or email Melissa Kruse, chapter engagement manager at **mkruse@hearingloss.org**

*Above: Lois Boyle, executive director of Access Virginia, speaks at the HLAA Virginia Peninsula Chapter launch on June 21, 2025.*

*HLAA Virginia Peninsula Chapter co-founders Bobby Graves and Thomas Blackman.*

Scan QR Code to get the Toolkit

# New HLAA Tools for Hearing Loss

**Introducing our new Get the Basics Toolkit, with shareable resources that take the guesswork out of understanding and living well with hearing loss.**

- Discover key facts & stats
- Find helpful tips & tools
- Learn success strategies

Now, millions of Americans can get trusted information all in one place.

**Visit hearingloss.org/toolkit**

---

# Join HLAA and Be Empowered with Hearing Loss

**When you join HLAA—the nation's leading organization for people with hearing loss—you get:**

- **Support & Connection**
- **Education & Resources**
- **Advocacy & Empowerment**
- **Social Engagement & Activities**

A donation of any amount makes you an annual member.

**hearingloss.org/donate**

> **"I am expanding my understanding of hearing loss, thanks to HLAA. I became a member and swiftly joined the advocacy efforts. I am now serving as the vice president of my chapter."**
>
> *—Valecia Adams, Los Angeles, CA*