

SUMMER 2024

hearing life

THE MAGAZINE FOR BETTER HEARING

Emily Truell with
her daughters,
Audrey and Ivy



Parenting with Hearing Loss

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



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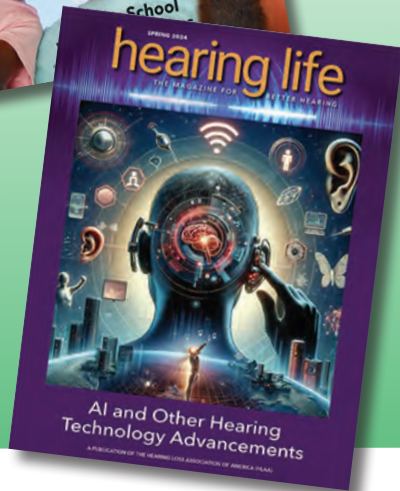
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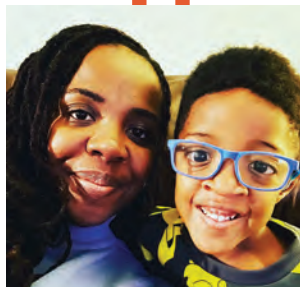


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Feature article writer Emily Truell was inspired while attending her first HLAA Convention in June. Read her story, Parenting with Hearing Loss, on page 7.

On the cover: Emily Truell and her daughters. Photo © Heller Creative

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More than 500 people from around the world converged in Phoenix for the HLAA 2024 Convention, June 26–29. See some of the highlights in photos showing attendees, partners, exhibitors, parents, veterans and more as they connected, learned and enjoyed four days together at a resort on native tribal land.

Fall Walk Season Begins



Following a successful spring season, the 2024 HLAA Walk4Hearing resumes with 13 fall Walks from September through November. Eight Walks in May and June, including the new Twin Cities location on June 2, raised a total of \$325,000 from 200 teams, 1,764 participants and numerous local sponsors and alliance organizations.

Join us this fall to bring hope to millions of people with hearing loss across the U.S.—sign up with an existing team or start your own! It's a great opportunity to connect with local families, HLAA members, industry leaders and health care organizations, while being part of our growing nationwide network of support.



Find a Walk and register at **walk4hearing.org** or scan this QR code.

2024 Fall Walk4Hearing Schedule

Sunday, September 15	New York City
Saturday, September 21	Buffalo
Sunday, September 22	Kentucky
Sunday, September 29	Chicago
Sunday, October 6	Boston
Sunday, October 13	New Jersey
Sunday, October 13	North Carolina
Saturday, October 19	Houston
Sunday, October 20	Pennsylvania
Saturday, October 26	San Diego
Sunday, October 27	Washington, DC
Saturday, November 2	Arizona
Sunday, November 3	Florida

A Mother's Hope

When Michelle Rodriguez's six-year-old daughter, Olivia, was suddenly diagnosed with bilateral hearing loss, the mother of two didn't know where to turn. Ten days later, their family found hope and a community of support at the 2023 Long Beach Walk4Hearing, where they also won a special raffle for hearing aids. By spring 2024, Olivia was thriving with sparkly pink hearing aids and Michelle became a valued volunteer on the Walk organizing committee! Read their story online at **bit.ly/3wAIFly** or scan the code.





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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.

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Parenting with Hearing Loss

BY EMILY TRUELL

An acoustic neuroma survivor and blogger with single-sided deafness shares her experience of raising two young daughters

I was 27 when I realized I couldn't understand phone calls if I used my left ear. I told my primary doctor, who scheduled a battery of tests. After hearing exams, audiology and otolaryngology appointments and an MRI, I was diagnosed with a 3cm acoustic neuroma (or vestibular schwannoma), a non-cancerous brain tumor. At that point, I'd already lost significant hearing in my left ear, and surgery to remove the brain tumor resulted in single-sided deafness.

Throughout all this, I had a two-year-old daughter at home.

As you can imagine, I worried that my brain tumor journey and hearing loss would have a negative impact on my child—and on my ability to be the parent I wanted to be. I imagined my single-sided deafness would mean I'd miss things, leading to frustration and miscommunication. While there have been many struggles and difficult days, I have been amazed at how well my family has accommodated the changes brought by my diagnosis.

Adapting Together

While I struggled with the abrupt transition to a life with hearing loss, my two-year-old daughter was just developing her language and communication skills. She quickly learned the behaviors that we trained her on were necessary to be heard—facing me directly when she wanted to talk, waiting her turn to speak and never covering her mouth. I began to notice people complimenting her diction and clarity of speech, skills that I'm sure she unconsciously acquired to assist in our communication.

At the same time, she was also honing her sense of empathy. Keenly aware of the toll my recovery took, she developed an alertness to my condition, and did what she could to take care of me. Between my daughter and my husband, they managed to keep me from my natural inclination to push too hard and overdo it.

Together, we found strategies that worked for us, and in the end my daughter proved to be the most adaptable one of all. Of course, adaptation never really ends, and soon we were bracing for another big change.

When the Kids Outnumber the Ears

A couple of years after my surgery, we decided to grow our family. I was very concerned about hearing my baby with my single-sided deafness; I'm a side sleeper, and when I'm sleeping on my hearing ear, the world is totally tuned out. (I've even slept through a fire alarm—thankfully a false one!) I had to be sure I wouldn't miss any times when my baby needed me.

We did some research and found a baby monitor that, in addition to transmitting sound, would use light and vibration to notify me when it detected noise. With the receiver under my pillow, I could sleep and still keep tabs on her.

By this time, I had elected to get a bone-anchored hearing aid (BAHA). It really improves communication by capturing missing sounds on my deaf side and sending them to my hearing ear. I also used my smartphone and smartwatch to help me monitor my environment—the Live Transcribe feature on my Android phone passively listens for baby cries, doorbells, fire alarms, etc., and alerts me through watch vibrations. This helps me feel more secure, especially when my husband is away from home.

When it was time to move the baby out of our room, we had both our daughters share a bedroom, so the big sister could come and get me for her little sister when needed. We trained the kids to always use touch to wake me. Although we delayed the move out of our bedroom, we changed from a crib to a toddler bed



“ I imagined my single-sided deafness would mean I'd miss things, leading to frustration and miscommunication. While there have been many struggles and difficult days, I have been amazed at how well my family has accommodated the changes brought by my diagnosis. ”



earlier—I felt much better knowing she could come and get me herself if necessary.

Two kids, it turns out, are exponentially louder than one. I found that the constant auditory input of parenting was a lot more tiring. Hearing fatigue wears me out quickly and makes it harder for me to follow their stories and be present the way I want to be. But in time, I developed strategies for managing. I take listening breaks—even a few minutes of quiet in my room can really help me reset. And I make liberal use of earplugs, especially in the car. (My youngest once told a nurse that Mom was done having children because there is no way she could handle any more noise in the car!) I prefer earplugs that reduce the sound to make it more comfortable, but don't block it out altogether.

Audio Awareness

Over the years, the changes we worked on earlier simply became how we lived.

We keep a quiet home environment to make it easier for me to be able to hear. Our kids know to listen to music in their rooms or on headphones, rather than in the kitchen, when I'm cooking. They realize that there are times and places to be loud, and they work to be respectful of that. This consideration really becomes apparent when we have other children over. While adding more kids is bound to make the din exponentially worse, it's clear that other kids just don't have the same awareness of noise that our children do.

I make sure to stress the importance of good conversation "hygiene" with my kids. I ask them to start by making sure they have my attention, that we are looking at each other and that we are near each other before they launch into a story. Tuning out is a survival skill for me, so they need to make sure to notify me when it's time to listen. They mostly do a great job of this—although I do have to remind them that I can't hear when their heads are stuck in the fridge looking for snacks.

Because they need to get my attention, the conversations we have are more intentional and purposeful. This fosters a value of good communication and provides opportunities to practice communication strategies that will assist them wherever they end up in life. They're also learning to adapt to other's needs and not be too critical of their own bodies, because everyone has parts that don't work quite right.

School Years Bring on New Challenges

In the kids' early years, we crafted a home environment that we could all succeed in. But both are now in school, an acoustic environment that I have no influence over.

“ We keep a quiet home environment to make it easier for me to be able to hear. Our kids know to listen to music in their rooms or on headphones, rather than in the kitchen, when I'm cooking. They realize that there are times and places to be loud, and they work to be respectful of that. ”

The standard script for school parents includes small talk and making connections with other parents during school drop-offs and pick-ups.

With all those kids talking over each other in the hallways, it's impossible for me to pick out the voice of just one person trying to invite my daughter for a sleepover. I find myself avoiding communication in those moments, walking quickly through with a smile and a nod.

Then there are sports activities. Competitions that take place indoors are incredibly loud, so I'm always prepared with earplugs; I want to be vigilant about protecting what hearing I still have. That's not without complication, because this is another space where school parents like to chat. I usually try to place my family on my deaf side. They're trained to let me know if I'm missing someone speaking to me, or to remind the folks next to me that I have hearing loss.

When school events and fundraisers are seeking volunteers, I take a different approach. I make sure to inform the organizer of my hearing loss limitations, that in a full gymnasium (the worst acoustics) I will have a really hard time hearing. I ask to be assigned physical tasks or contribute before or after the event. I find that, when I do a good job of describing my limitations and what I need to be successful, volunteer committees are all too happy to work with me.

But perhaps the most important adaptation I've made is giving myself permission not to attend every child-centric activity. I will drop my daughter off at that birthday party. I steer my kids' party plans toward settings I can enjoy—a pumpkin patch rather than an arcade, for example. Sometimes I drive myself to a field trip I am chaperoning and skip the loud bus ride. A stressed mom doesn't lend itself toward a fun time, and if I'm less overwhelmed, I can fully participate in the event.

In all these settings, the kids see me dealing with overstimulation and modeling strategies to cope. It's improved their own awareness of when they're feeling overstimulated. Through me, they're learning how to make appropriate choices that set them up for success and how to give themselves space when they get overwhelmed.

Just Another Family Culture

Parenting with hearing loss has its challenges, but there are some fun moments, too. During those infant days, I absolutely benefited from sleeping through our baby's wake-ups, as the night shift would at times fall to my husband. I had a lot more staying power when I shifted that crying kid to my deaf side. These days, my younger daughter tells me she enjoys singing in the shower as loud as she wants, knowing I can't listen in. In our house, you can safely giggle during hide and seek, since I can't locate by sound. You can whisper a secret into my deaf ear and know it'll be kept forever.

These days, my kids will help me out in settings where I struggle to hear. My daughters will realize when someone is trying to communicate with me and happily intercede to smooth over any conversation I have missed. We've all learned lessons in grace and the importance of being adaptable and willing to change how we do things. For my kids, Mom having one working ear is normal and nothing to be worried or ashamed about.

And if my hearing fatigue makes me a little more tired at the end of the day—well, I hear parenting isn't typically a well-rested gig anyway. **HL**

A hearing loss advocate with single-sided deafness, Emily Truell shares her experiences and reviews hearing technology in her “Lucky” Brain Tumor blog. She’s an HLAA member who also serves as a peer mentor and young adult support group leader for the Acoustic Neuroma Association. Emily was named a 2023 finalist for Oticon’s Hearing Loss Champion Award. She runs a tourism business and lives with her family in central Wisconsin.

One Mom's Quest to Help Her Son and Other Families

NaTyshca Pickett, M.Ed., and her husband were shocked and overwhelmed when their newborn son was diagnosed with hearing loss. “We weren’t sure how to navigate our new normal, and we had no family nearby to help,” she recalls.

At eight months old, Adrion was fitted with bone-anchored hearing aids, but his parents noticed little progress and questioned their doctor. It wasn’t until Adrion turned three that a new audiologist heard their concerns, retested and fit the boy with traditional hearing aids instead. It was the success they were looking for, and Adrion, who is now nine, has been thriving ever since!

NaTyshca credits crucial educational and support resources, like HLAA, that got her son on the right track. As a member of HLAA and Walk4Hearing volunteer in Arizona, she wants to make sure other parents don’t have the same struggles. NaTyshca spoke on the HLAA 2024 Convention parent-led panel in Phoenix to help provide them with support and guidance, and signed copies of her children’s book, *My Happy Ears*.

Her tips for success for parents of children with hearing loss:

1. You are not alone in your journey! Joining groups like HLAA will build your community, knowledge and support system.
2. You are the best expert for your child. Trust your instincts and advocate for their needs.
3. Extend grace to yourself! Parenting is hard, and having a child with unique needs comes with its own set of challenges.
4. Remember that you’re doing your best, even if things don’t go perfectly!



Wise Words from Parents

Just like every hearing loss is different, hearing loss also affects every family differently. We asked a few parents in our HLAA community to share their advice and encouragement with others. Here's what they had to say...

“As an adult with hearing loss who is also a parent to three kids, my best strategy is advocating for myself and building community within my family. When I was a brand-new mom, I worried that one day my children would learn about my deafness and think that I was not complete or had a weakness. What helped me was becoming comfortable with my hearing loss myself—telling my kids constantly that I cannot hear them, I need them to show me their face/lips or they need to get my attention first by waving or touching me before speaking. We are now learning ASL as a family, which gives my children another way to communicate with me.”

—Michelle Hu, Au.D., pediatric audiologist, Southern California
Speaker at HLAA 2024 Convention parent-led panel



© The Leo Loves



“My daughter Giana is so different. When she got her cochlear implant, I had such high expectations that she would speak by the time she turned four—it did not happen like that. We've learned that what works for our family is to take one day, one week, one month, one year, one season at a time. We look for her strengths and we work on those. Giana is so involved in dance and sports that she sometimes surprises us!”

—Gina Petrus, New Jersey

“I'm a single mom with hearing loss raising two teenage boys. I think it's great that they both have cellphones! I'm able to text with them at a moment's notice because their plans can change in an instant. Also, they are older now and don't 'need' me as much as when they were younger, so the cellphone keeps us a bit more connected.”

—Katie Rojas, Indiana



HLAA is Leading a Hearing Health Movement

*A message from Barbara Kelley, Executive Director
and Michael Meyer, Chair, Board of Directors*

For decades, the growing number of people with hearing loss, their families and friends have turned to HLAA for information, support and connection. During some of their most challenging times, they find resources and hope to live their best lives with hearing loss.

When people discover HLAA's nationwide community of empowerment, they find a sense of purpose—of being part of something that transcends their own circumstances. They're often inspired to help others and create lasting change for the future.

That's how HLAA has built a unique community of support impacting millions. Our advocacy work at the national level, and grassroots efforts across the U.S., have put hearing health and accessible communication on the map.

We connect people in the hearing loss community with industry, regulators, researchers and others, to improve their lives. With a solid reputation as the leading, unconflicted voice for millions of Americans with hearing loss, HLAA is building a hearing health movement at a crucial time when hearing loss is expected to double worldwide by 2050, according to the World Health Organization (WHO).

HLAA's Unique Community of Support

Being part of our community means you're not alone. Members often say they found their hearing loss family in HLAA—like-minded people who share the same challenges and find inspiration and solutions together. It's a community that's reaching more and more people across the U.S. and changing their lives. HLAA is here to empower the 50 million Americans with hearing loss to get the care they need to stay healthy and connected to the world around them.

Strategic Plan in Action

We've spent the last year moving forward the goals of the strategic plan while expanding our engagement with those who need to learn about hearing health, including the media, legislators and policymakers.

Change often happens in our communities first, and HLAA Chapters are key to increasing engagement and building a movement. Led by passionate volunteers, they help provide information, support and advocacy at the local level. This year, we convened a thought-leaders group made up of chapter leaders across the country to discuss where chapters need support and share ideas and success stories. At the HLAA 2023 Convention, chapter leaders met at an all-day session to strengthen leadership skills and learn from their peers.

Reaching People Sooner

We often hear, "I wish I would have known about HLAA sooner." People might say this after retiring early from their jobs in frustration, having relationships break down or struggling and feeling alone with hearing loss.

Thanks to your support, through dollars or time, we are able to positively impact millions of lives. As always, if you know anyone with hearing loss, please tell them about HLAA. They'll thank you for it.

Together with you, we can realize our vision.

Our vision is to create a world where hearing health is a priority for all and every person with hearing loss can thrive.

Our commitment is to grow our community of support to reach, engage and empower more people, across all backgrounds, ages and stages.



Sergio Cuevas and HLAA Board Member Roxana Rotundo at the HLAA 2023 Convention in New Orleans

With HLAA You're Not Alone

"With HLAA, for the first time, I felt like I was not alone in this journey of hearing loss. Since being fitted with hearing aids, I've become more confident in talking to people and advocating for myself. I wish I'd found HLAA sooner."

— Sergio Cuevas, Ph.D.

Read more about Sergio Cuevas' limitations growing up with minimal access to hearing care, and having to figure things out on his own. Sergio's path took him from untreated hearing loss, to higher education, to attending the HLAA 2023 Convention, supported by his employer. Read his story at bit.ly/3yntlJj.



HLAA is Working for You

We work with Congress, federal regulatory agencies, professional organizations, industry, academia, medical communities and the media regularly. The result is not only policy and legislation but changing mindsets about hearing health and communication access.

Here are a few of our Key Accomplishments in 2023:

■ Shaping Media Coverage

HLAA was cited in dozens of national and local media stories in 2023 promoting hearing health, access to treatment and the importance of communication access reaching millions.

■ 100% Hearing Aid Compatibility for Cellphones

Our sustained decades-long advocacy led to a historic proposal by the Federal Communications Commission (FCC) requiring all wireless phones to be 100% compatible with hearing aids and cochlear implants.

■ Videoconferencing Accessibility

HLAA supported the FCC's ruling that makes videoconferencing services fully accessible with improved captioning and sign language interpretation.

■ Accessible Emergency Alerts on Buses and Trains

HLAA is working with the U.S. Department of Transportation (DOT) to provide visual emergency alerts and other new technologies to enhance safety for people with hearing loss.

■ Air Travel Protections

We partnered with DOT and other organizations to include important safety and accessibility provisions in a new bill called the Air Carrier Access Amendments Act of 2023 (ACAAA), which protects the rights of airplane passengers with disabilities.

■ Communications, Video and Technology Accessibility Act (CVTA)

We mobilized support for passage of the CVTA, which has the potential to broaden access to technology like telehealth, online and television programming and videoconferencing, improving the daily lives of millions of people.

Families Find Hope Through HLAA Community

"The feeling of support, joy and hope that my family experienced at Walk4Hearing was overpowering, and my daughter Olivia felt it, too." —Michelle Rodriguez

HLAA is helping so many families navigate the unexpected territory of hearing loss. HLAA is changing lives like those of Olivia and Michelle Rodriguez, who found hope one step at a time through Walk4Hearing. Read their story at bit.ly/3wAlFly.



The Rodriguez Family

HLAA Washington State Association Sparks Change



Washington Governor Jay Inslee signing HB 1222

Local advocates were instrumental in pushing for expanded coverage for hearing aids and services in Washington state. A new law mandates hearing aid coverage and opens the door to change around the country. Read the story at bit.ly/4bkuqFN.

Inspiration at the HLAA 2023 Convention

“Thanks to HLAA and the support of so many others, we’ve found a way to turn our grief into goodness. The future is bright.” — *Maureen Evans*

Maureen Evans says it was the HLAA 2023 Convention that inspired her to be all-in as an advocate for Abby—and for everyone with hearing loss. She says the HLAA community of support changed her daughter’s life. Read their story at bit.ly/4apJosy.



Jack Evans hugs his little sister, Abby, after her cochlear implant surgery.

Impact by the Numbers

- 120 Chapters, Support Groups, State Organizations
- 131+ Virtual Meetings
- 3 New State Conferences (New York, Pennsylvania, Wisconsin)
- 17 Educational Webinars Engaged Thousands of Participants
- 50,000 Social Media Followers
- 10,000 *Hearing Life* e-News Subscribers
- 60,000 HLAA Website Views Per Month



2023 Walk4Hearing Brings Hope to Hearing Loss in 20 Cities

5,435 participants • **555** teams • **\$814,000** in donations

Walk4Hearing is HLAA's community of support in action, breaking down barriers to hearing health and empowering people with hearing loss in their communities. We piloted a new online platform to make it easier, more accessible and fun for Walk participants.

Our Wall of Gratitude

HLAA celebrates our donors who gave \$100 or more in 2023

Our generous donors fuel HLAA's important mission to connect, support and empower people with hearing loss. Go to hearingloss.org/wall for the complete list, or scan this code.



Financial Performance

Statement of Activities—As audited for
Fiscal Year ending August 31, 2023

Support and Revenue

Contributions	\$1,193,327
Walk4Hearing (NET)	\$ 406,334*
Investment income (Loss)	\$ 252,046
Conferences, meetings and seminars	\$ 196,273
Grants and contracts	\$ 167,139
Advertising	\$ 111,590
Membership dues	\$ 97,339

Total Support and Revenue \$ 2,424,048

Expenses

Program	\$ 2,009,619
Fundraising	\$ 376,913
Management and General	\$ 144,156

Total Expenses \$ 2,530,688

Change in Net Assets	\$ (106,640)
Net Assets, Aug 31, 2022	\$ 4,766,697
Net Assets, Aug 31, 2023	\$ 4,660,057

*HLAA gives back **40%** of funds raised through Walk4Hearing to chapters and alliance organizations to fund hearing loss programs and **10%** to local Walk sites to help host walk day events.

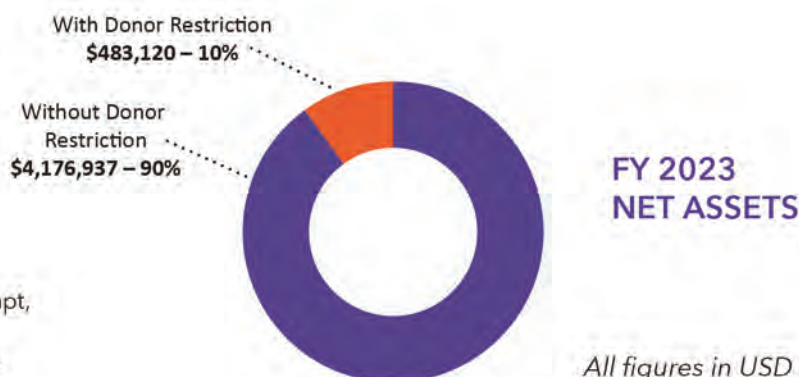
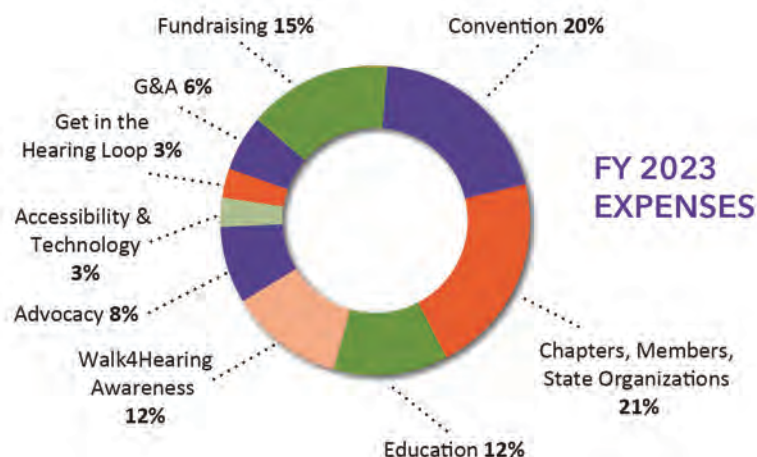
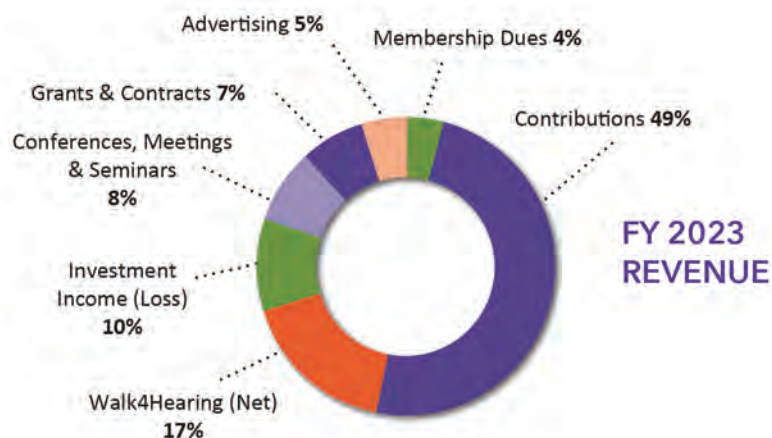


For Every \$ Spent

79 cents to Programs
6 cents to Operations
15 cents to Fundraising



The Hearing Loss Association of America (HLAA) is a tax-exempt, charitable organization under IRS Code 501(c)(3). Complete audited financial statements are available at hearingloss.org.



All figures in USD



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Don't Let Hearing Loss Sideline You This Summer

Tips to protect your hearing technology during warm-weather activities

BY DAVE FABRY

We all look forward to having fun in the sun every summer. However, heat and moisture are two of the biggest enemies of hearing aids and cochlear implant processors, which makes summer activities challenging for people with hearing loss. Despite built-in protections, sweat, water and humidity can still cause problems, such as distorted or weak sound quality, reduced battery life and inconsistent functionality.

Better hearing is better living, and technology should keep you connected, not sidelined. The best advice is to keep up with regular hearing care visits during the summer months, so you're prepared to fully participate in activities with family and friends.



Here are few tips to keep you hearing your best all summer long:

1 Protect hearing aids and processors from water

New waterproof devices, such as the rechargeable Genesis AI hearing aids, are made with gaskets and silicone seals, a protective nano coating inside and out and a fully enclosed battery. Although waterproof up to three feet deep, we don't recommend swimming with them or any other hearing aids. Even waterproof hearing aids could fall out or feel uncomfortable underwater, so remove and safely store your devices before swimming. It's also important to dry your ears and canals before reinserting them.

2 Store hearing devices in a cool, dry place

Whether you're removing your devices to take a dip or to take a nap on the beach, keep them in their case in a cool, shaded place to help prevent damage. Avoid storing hearing aids and processors in a hot car, near dampness or in direct sunlight.

3 Use a dry box or dehumidifier

Even with today's water-resistant technology, you may need a dehumidifier or drying kit if you live in a humid climate, are prone to sweating or do a lot of outdoor activities. Devices that take zinc-air batteries are also more prone to moisture ingress through the battery door. Consult your hearing care professional before choosing products, especially for rechargeable hearing aids which may have heat restrictions.

4 Keep sand, sunscreen and bug repellent away

Sunscreen and insect repellent can clog your microphone and/or receiver, while tiny granules of sand can cause major damage. Apply lotion or spray first, then wash your hands before inserting your hearing aids. At bedtime, wipe off devices and check for any sand before putting them back into their charger or case.

5 Remove hearing devices before rides

Roller coasters and spinning rides are not so amusing if your hearing aids or processors fall out during sudden movements. Be sure to remove and safely stow your hearing aids before any high-speed amusement park rides.

6 Wear the right footwear

What do shoes have to do with hearing? You can improve your balance and minimize the chance of tripping or stumbling when you wear well-fitting, appropriate footwear, especially during hiking and sports—which can help prevent your hearing aids from falling out.

7 Get up to speed on added features

Starkey hearing aids use an app that allows you to perform diagnostic tests, alerts you to needed cleaning and maintenance and sometimes even track your devices if they're misplaced. Whatever brand you use, learn what added features and support are available, so you can stay active and involved.



For more information, visit starkey.com.

Starkey is a leading Hear for Life partner of HLAA, helping to get important hearing health messages to people across the U.S. Starkey employees are often seen at our Walk4Hearing events, which bring hope and awareness to local communities.

Starkey's leadership was recognized with the National Access Award at the HLAA 2024 Convention in Phoenix. See page 24 for a photo.

Dave Fabry, Ph.D., is an audiologist who serves as the chief hearing health officer for Starkey.



Starkey employees at the newly revived Twin Cities Walk4Hearing on June 2. Starkey President and CEO Brandon Sawalich (left-center, next to Barbara Kelley) is a 2024 Walk4Hearing National Honorary Co-Chair.

All in for Water Sports

Seventeen-year-old Katie Byxbee isn't afraid of getting wet. The athletic Connecticut high school senior with hearing loss seeks out every possible opportunity to enjoy water—whether in a kayak, river raft or swimming pool. She even competes on the boys' varsity water polo and swim teams at her high school, as well as on the local YMCA water polo team.

Before entering the water, Katie must leave her hearing aids in the locker room, which can make games and practices challenging. She has learned to adapt while participating in a team sport based on constant communication.



"When I first started water polo, I didn't think my hearing loss would be a problem," says Katie. "Adults told me that going without my hearing aids would be a disadvantage, but I felt that I wouldn't need them to play. I realized that I'd have to pay extra attention to the game around me in order not to miss anything. Of course, there are times when I don't hear a whistle or misunderstand what my teammates say. But having a hearing loss does not weigh me down or make me feel incapable of playing a sport I love. I've learned it is most important to make the most of what you have and grow with what you do not."





Flying with Hearing Loss Could Soon Get Easier

New Air Travel Bill Includes Key Accessibility Improvements

BY NEIL SNYDER

It's one of the most common complaints we get at the Hearing Loss Association of America (HLAA)—trouble hearing and understanding announcements in airports and airplanes—but changes are coming. A new bill mandates wide-ranging improvements to aviation safety and passenger protections, including significant benefits for travelers with hearing loss and other disabilities.

On May 16, the Federal Aviation Administration (FAA) Reauthorization Act of 2024 was signed into law by President Biden with bipartisan support. This vital bill extends the FAA's activities related to airport planning and development, facilities, equipment and operations through September 30, 2028.

HLAA has worked for years with other consumer disability organizations, including the National Disability Rights Network (NDRN), National Association of the Deaf (NAD) and Paralyzed Veterans of America (PVA), to get important accessibility provisions included in the bill.

Here are some of the improvements coming:

• Accessible announcements

Those muffled and hard-to-understand gate and safety announcements could get more accessible. Under the new law, all airport gates, counters, ticketing areas and customer service desks must be disability accessible, including captions for people with hearing loss.

• New wheelchair safety standards

Harrowing scenarios of wheelchair damage and injuries to passengers who are taken in and out of them could diminish as the bill requires the Department of Transportation (DOT) to improve standards for wheelchair transport and stowage.

• In-flight entertainment captioning

DOT is required to issue new regulations requiring in-flight entertainment accessibility, including closed captioning and video descriptions.

• Digital accessibility

Minimum standards to ensure that individuals with disabilities can access websites, software applications and kiosks are also included.

In addition, the FAA Reauthorization Act addresses a variety of general transportation issues, such as the Airport Improvement Program (AIP), aviation workforce development and air traffic controller recruitment, aircraft and pilot certifications, guaranteed family seating policies, the elimination of hidden airline fees and hassle-free refunds to passengers for delayed or canceled flights.

Read the bill at bit.ly/3KTxxZA.

Changes could still be a way off, but this is certainly a big step in the right direction. We know this is a critical safety issue for millions with hearing loss, and ultimately will benefit all travelers in noisy airports and airplanes. A 2023 blog post about protecting yourself while traveling with hearing loss remains one of our top performers, and according to HLAA Executive Director Barbara Kelley, the topic is second only to concerns about the costs of hearing aids and the lack of insurance coverage.

If you have hearing loss and are flying, preparation can be key to your safety and success. **Know Your Rights** before you go and see other important initiatives that HLAA is working on. [HL](#)

Neil Snyder is HLAA's new public policy director, taking over for Lise Hamlin, who retired in February. Neil brings a decade of experience on Capitol Hill and nearly two decades with the American Speech-Language-Hearing Association (ASHA). He hopes to continue moving important accessibility issues forward and inspiring more people to get involved in HLAA. He can be reached at nsnyder@hearingloss.org.



Information

A Spotlight on Chapter Conferences

Two recent regional HLAA events are serving as a model for other HLAA Chapters and State Organizations to emulate: the second **HLAA Southeast Pennsylvania (SE PA) Conference** on April 13 and the **HLAA Wisconsin State Conference**, “Shine New Light on Hearing Loss,” April 26–27. Both spring conferences featured speakers on a range of hearing-related topics, buffet lunch and plenty of socializing time, all for a nominal admission charge—with attendance close to 100 people, including many new to HLAA.

In Pennsylvania, four area chapters pooled their funds from the previous year’s Walk4Hearing and organized the one-day conference jointly. The speakers were educational audiologist Tina Childress, Au.D., and HLAA Executive Director Barbara Kelley. The two-day Wisconsin State Conference was organized by HLAA Fox Valley Chapter with a range of presenters, including Nicholas Reed, Au.D., Tina Childress and Ruth Litovsky, Ph.D., sharing the latest information about research, technology, advocacy and more.

If you’d like to explore a chapter conference in your area, email HLAA Chapter Engagement Manager Melissa Kruse at mkruse@hearingloss.org.



HLAA Executive Director Barbara Kelley with Mike Miles at the HLAA SE PA Conference in April



HLAA SE PA Conference attendees



HLAA Wisconsin State Conference exhibitors



100+ attended the HLAA Wisconsin State Conference



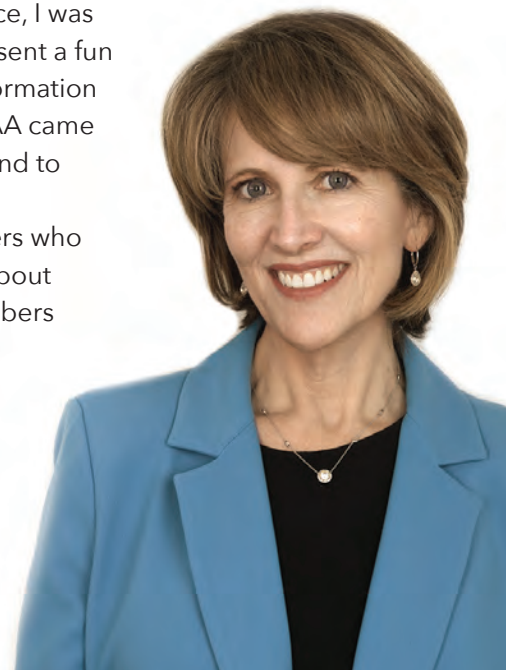
Tina Childress, Au.D., presented at the HLAA SE PA Conference

As a guest speaker at the HLAA Southeast Pennsylvania Conference, I was impressed by how four regional chapters joined together to present a fun and educational event. People new to HLAA attended to get information and some were inspired to start a chapter or join one. Stalwarts of HLAA came with a refreshed outlook of how important their work is in the region and to learn something new.

HLAA Chapters don't just happen, they take dedicated volunteers who realize there are others in the community who just might like to hear about HLAA. Chapters create a community of support where individual members bring hope to people with hearing loss. It's passionate and dedicated volunteers like those in Pennsylvania and Wisconsin who get involved initially to help themselves, then turn around and help others.

We hope more chapters can pull together in a region to hold one or two-day conferences such as those described here. Start simple, start small, see what happens and build on your success!

— Barbara Kelley, HLAA Executive Director



HLAA

CHAPTERS & STATE ORGANIZATIONS

Join a Chapter *Learn that you're not alone in your hearing journey!*

Find an HLAA Chapter near you by visiting hearingloss.org/find-a-chapter. For more information, including how to start a chapter, contact Melissa Kruse, HLAA chapter engagement manager, at chapters@hearingloss.org.



HLAA 2024 Convention in Phoenix



With attendance back to pre-pandemic levels, the HLAA 2024 Convention, June 26-29, was an experience to remember! Soaring temperatures outside didn't slow down more than 500 enthusiastic attendees—longtime members, newcomers, partners, technology experts and hearing health industry leaders—who converged in the Valley of the Sun for four days of learning, growing, networking and fun!



Keynote speaker Shanna Adamic inspired the audience to embrace Audacious Optimism (the title of her new book), sharing how she survived a serious medical diagnosis and learned to thrive with single-sided hearing loss.



The Exhibit Hall, which was free to the public, encouraged attendees to connect with top hearing health companies and discover the newest technology for people with hearing loss.

**Join us next year
in Indianapolis,
June 12-14, 2025!**



HLAA Executive Director Barbara Kelley presented leading Hear for Life partner Starkey with the National Access Award, accepted by Chief Hearing Health Officer Dave Fabry.



HLAA Board Member Cheri Perazzoli (Washington), Ron Tallman (Arizona), Gael Hannan (Canada), Ann Thomas (California) and Brenda Gray (Arizona). Ron led the host committee that provided local support for the HLAA 2024 Convention in Phoenix.



First-timers Ruri and Andrew, pictured here with HLA Board Members Roxana Rotundo and Zina Jawadi, joined us all the way from Tokyo!



HLAA conventions are all about connecting. Emily Truell, first-time attendee and the author of this issue's cover feature, was thrilled to meet fellow acoustic neuroma survivor Shanna Adamic.



Listening raptly is cochlear implant advocate Qais Khan, who traveled to Phoenix from England to attend his first HLAA Convention.



Congratulations to all the 2024 award recipients, honoring HLAA's finest! (Some recipients not in attendance.)



Longtime HLAA member, author and performer Gael Hannan brought home the emotional impact of hearing loss by acting out powerful vignettes from various personas at the Research Symposium.



This year's Research Symposium explored The Emotional Side of Hearing Loss, featuring (L-R) researchers Ivette Cejas, Ph.D., Barbara Weinstein, Ph.D., Kathy Pichora-Fuller, Ph.D., hearing advocate Gael Hannan, and Peter Dixon, M.D. (not shown).



Among the more popular workshops was HLAA's first parenting panel, Parents of Children with Hearing Loss—a discussion with (L-R): pediatric audiologist Michelle Hu, who has a hearing loss, 2024 Keystone Award recipient Steve Wolfert, HLAA Board Member Jennie Antonakis and Hearing Life contributor NaTyshca Pickett.



Young Adrion Pickett is captivated by his mom NaTyshca as she speaks on the parenting panel.



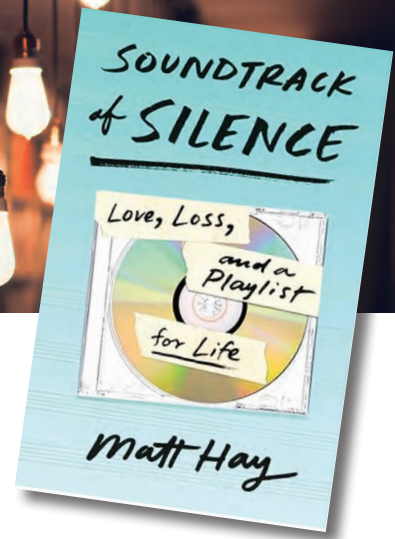
A special luncheon celebrated our Hear for Life partners and their important contribution to HLAA's mission.

BOOK NOOK

REVIEW BY LARRY HERBERT

Soundtrack of Silence: Love, Loss, and a Playlist for Life

A memoir by Matt Hay



This is a hearing loss story. It's also a love story. And it's a story about the power of music to inspire and heal in the face of a life-changing medical diagnosis.

Hearing loss has many causes, but you may never have heard of a rare condition known as neurofibrosis type 2, or NF2—noncancerous tumors on the auditory vestibular nerve of the brain. Author Matt Hay shares his firsthand experience with NF2 in his poignant autobiographical journey, *Soundtrack of Silence: Love, Loss, and a Playlist for Life* (2024, St. Martin Press).

Crushed after failing his physical for West Point because of “substandard auditory acuity,” Matt attended Indiana University instead. While there, he met his future wife, was diagnosed with NF2 and learned that he would eventually lose his hearing. Powerful digital hearing aids slowed the onset of hearing loss and allowed him to successfully work in marketing post-graduation.

But his hearing continued to deteriorate.

When an MRI confirmed the tumor on his auditory nerve, Matt was immediately scheduled for surgery to remove it. As a result, he experienced partial paralysis in his legs and had to recover his ability to walk again. Finally, the day came when he lost the remainder of his hearing. Matt underwent an auditory brainstem implant (ABI)—another procedure fraught with side effects.

His partners in his long recovery were his wife and his unbounding love of music.

Throughout his story, Matt weaves in meaningful lyrics from the songs that he grew up with and feared he might never hear again. He writes that “these weren’t jingles to help move a story along...the songs were all part of my story, my life, as it happened.” He even praises songwriters in his acknowledgments: “You made some tough things more tolerable, you made confusing moments clearer, you made average days more special, and you made great times stick with me forever.”

If you appreciate the power of music and believe in the potential of human resilience to overcome adversity, you will be moved by this courageous, and ultimately inspiring, memoir. **HL**



Larry Herbert is retired and lives in Richmond, Virginia. A member of the HLAA Greater Richmond Chapter, he currently leads efforts to promote hearing loops in the community. His interest in assistive listening technology was initially sparked when he helped his father communicate via text and email. He is a graduate of the University of Virginia and can be reached at lawrence.herbert@gmail.com.



Coming Soon! A completely redesigned HLAA website will soon be available to better serve the increasing number of people turning to us for hearing loss information and support. Stay tuned for this important new tool!

Get the Facts About Over-the-Counter Hearing Aids from HLAA's Webinar Series

Leading experts answered questions about new devices recently made available directly to consumers

Hundreds of viewers tuned in live for the **HLAA HearingU OTC 101: Ask the Experts** webinar series from fall 2023 through spring 2024. Valuable information was shared by leading OTC professionals, including:

- Regulators
- Researchers
- Audiologists
- Manufacturers

All four Q&A events can now be viewed online. Watch the captioned OTC 101 webinar recordings, take our Hearing Health Survey and find more resources at hearingloss.org/otc or scan the QR code at right.



Share Our OTC Resources

Even if you're not a candidate for an OTC hearing aid, all of us in the HLAA community are hearing loss influencers. We can encourage friends and family to pay attention to their hearing health and learn what treatment options are available. Please share these webinars with them!



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