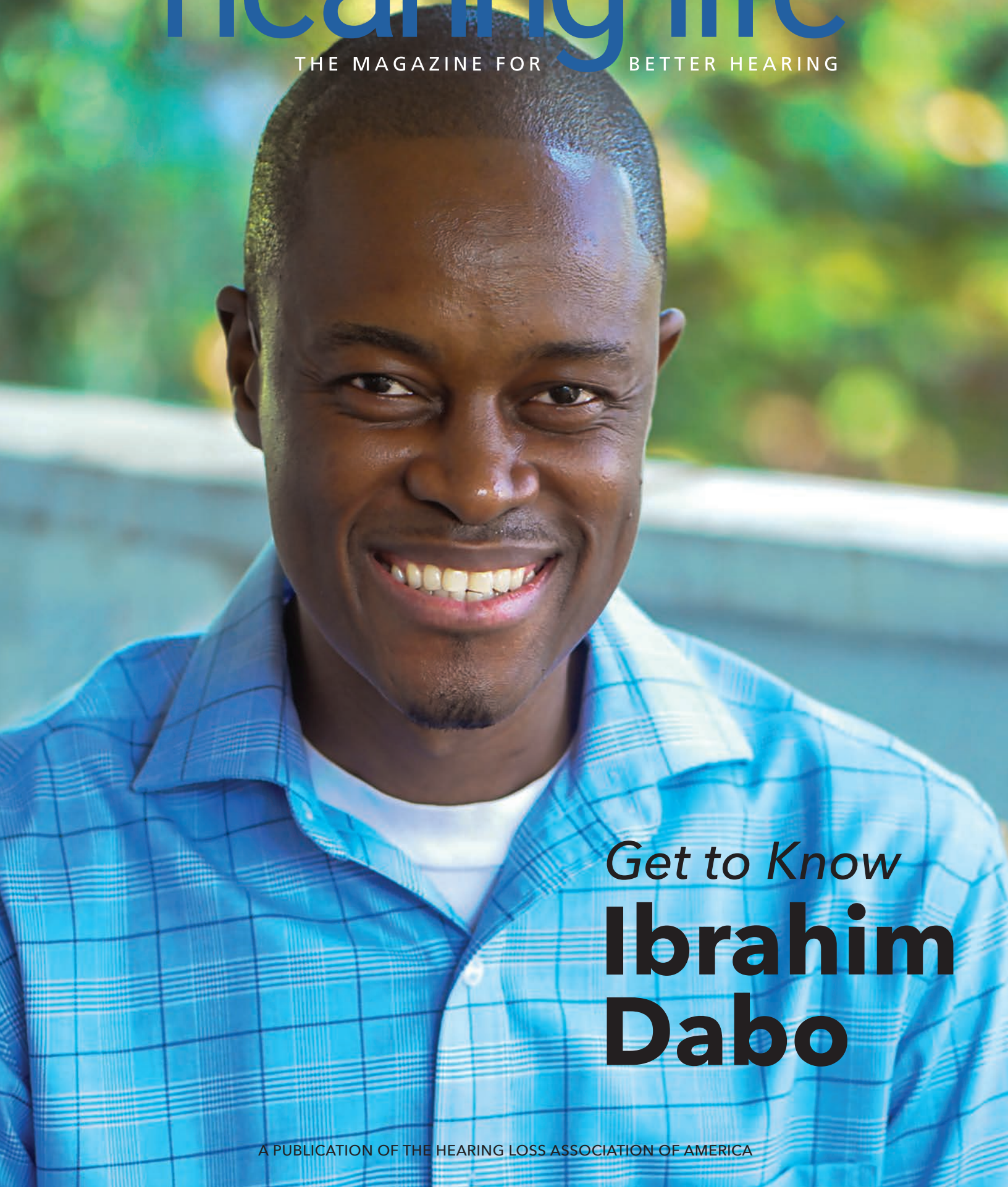


WINTER 2022

# hearing life

THE MAGAZINE FOR BETTER HEARING



*Get to Know*  
**Ibrahim  
Dabo**

A PUBLICATION OF THE HEARING LOSS ASSOCIATION OF AMERICA



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# Cochlear Foundation Launches Global Partnership with Malala Fund to Raise Awareness of Hearing Loss and Remove it as a Barrier to Education

BY CARRIE JOHNSON

Malala Fund and hearing health nonprofit Cochlear Foundation have partnered to raise awareness about the barriers keeping millions of children and young people with hearing loss from accessing a quality education.

According to the World Health Organization, 34 million children around the world live with disabling hearing loss.<sup>1</sup> Without equal access to a quality education and early access to hearing health care and support, these children may not realize their full potential.

Malala Fund and Cochlear Foundation are inviting children and young people with hearing loss to share their stories of personal achievement as part of the *'Achieve anything program.'* This new program will highlight and publicly recognize the real-world experiences of children and young people with hearing loss and promote their equal rights to an education and early access to hearing health care and support.

"My hope is that all girls can have equal opportunities and that we ensure a world where every girl has access to free, safe and quality education," said Malala Yousafzai, co-founder of Malala Fund. "Hearing loss doesn't need to be an obstacle to education."

Cochlear Foundation Chairperson Professor Anne Simmons said hearing loss was a global issue that requires greater awareness and a global solution.

"Malala Fund and Cochlear Foundation's missions are connected by a desire for children around the world—including those with hearing loss—to access education and embrace all of life's opportunities."

Visit [www.cochlearfoundation.org/achieve-anything-program](http://www.cochlearfoundation.org/achieve-anything-program) to learn more about the partnership and how to submit stories to the *'Achieve anything program.'*

Oklahoma City teen Lily Hernandez was born with progressive hearing loss. But thanks to a hearing health nonprofit, Hearts for Hearing, Lily was able to receive a cochlear implant at three years old, giving her full access to the hearing world. Now, nearly 12 years



later, Lily is a 4.0 student and the team captain of her cross-country team.

Lily is sharing her story in partnership with Malala Fund and Cochlear Foundation's *'Achieve anything program.'*

I spent a lot of time during those early years worrying about things that never came to be. I worried that she would struggle, that she would be left behind, that she would feel isolated...but the staff at Hearts for Hearing never lowered the bar for Lily. Their expectations were high, and she surpassed them all. —Lily's mom

I finished my first year at Harding Charter Prep High School with a 4.0 and am working on repeating that this year—mostly so I can remind my brother that he only did it once, which makes me the superior child. I'm joking. Mostly. —Lily

Carrie Johnson is senior communications manager at HLAA. Reach out to her at [cjohnson@hearingloss.org](mailto:cjohnson@hearingloss.org).



<sup>1</sup> World Health Organization. Factsheet: deafness and hearing loss. Available here: <https://www.who.int/news-room/factsheets/detail/deafness-and-hearing-loss>



© Cindy Dyer

There's no such thing as a small hearing loss. Help yourself and others not to reach the pain point, but rather, begin today to treat hearing health as part of your overall wellness plan.

# The Pain Point

BY BARBARA KELLEY

It was Thanksgiving dinner with the family chatting, laughing, and eating, silverware and glasses clanging. Abruptly, in the middle of the festivities, Mark's dad got up and left the table and headed to his bedroom to be alone. You can guess why. It happens when the stress and frustration of trying to hear is just too much to manage. The self-perceived embarrassment of not being able to hear, of giving the wrong response to a comment, is too humiliating. Withdrawal seems like the only solution at the time.

Hearing loss can be insidious, chipping away at the hearing you have, zapping energy and eroding confidence and the will to stay engaged, especially with those we love. People are meant to live in community—relationships thrive with conversation, and when that breaks down, so do we.

Mark said the hearing loss not only affected his dad, but also his mom. They were once a social and active couple. They didn't realize it, but they withdrew together because of hearing loss. The pain of the Thanksgiving dinner was the crescendo of many small events of not paying attention to hearing and how it was affecting life. Unless it's a sudden hearing loss, hearing loss "creeps in this petty pace from day to day" (a nod to Shakespeare's *Macbeth*).

Sounds like a bleak picture, doesn't it? This true story has a happy conclusion. Mark's dad got hearing aids, worked through the adjustment of wearing them and got back to his old self. But as Mark will tell you, one of the people who benefited just as much was his mom. She got her life back, too. She started working out to get into shape for their planned trip to Machu Picchu. This couple was again excited—ready to take on life in their older years. Together they came so close to slipping away and aging ahead of their time.

## Addressing Hearing Health

A lot has changed for the better over the last few decades. Technology—hearing aids, cochlear implants, captioning, speech-to-text apps, smartphones—has improved and works well for people with hearing loss. Lately, there's been more attention paid to hearing health as part of overall wellness and why it's important to protect your hearing, get your hearing tested and take action.

One thing that hasn't changed much is the emotional toll hearing loss takes and what happens when you don't do anything about it. The old advice that hearing loss is part of aging and you should just learn to live with it, is just that, old advice. Don't believe it if anyone or any health care provider tells you there's nothing you can do.

Most people reading this have taken care of their hearing health. You know the consequences of not trying to do something. There are so many people who have yet to take action.

People often hesitate to take care of their hearing and, if they know it's a hearing loss, wait far too long to get hearing aids. Share this story with those you care about—you might have influence.

## Amplifying the Message

Here at HLAA we've been working to shine a light on hearing health and drive people to hearing care. We're looking for new ways to communicate, whether it's

in new printed publications or messages across digital platforms and our website. We want to meet people where they are, and not wait for them to find HLAA. We want to provide solid information and support to anyone who needs it along their hearing journey. HLAA offers chances for engagement with a community where it's okay not to hear well—HLAA Chapters, Walk4Hearing, the HLAA Convention this June in Tampa and virtual meetings and webinars.

With our partners in the hearing health care industry and professional organizations, we're building on the successful "*Hear Well. Stay Vital.*" media campaign. We are working with the Hearing Health Collaborative here in the U.S., the World Hearing

Forum, the Ida Institute in Denmark and the Cochlear Implant International Community of Action. We cherish our partners, supporters and donors, our volunteers at the grassroots level, and you who have chosen to associate yourself with HLAA in some way.

There's no such thing as a small hearing loss. Help yourself and others not to reach the pain point, but rather, begin today to treat hearing health as part of your overall wellness plan. **HL**

*Barbara Kelley is executive director of the Hearing Loss Association of America. Follow her on Twitter @Bkelley\_HLAA.*

# Sound Advice...

*from the HLAA Facebook community*

Login to Facebook.com. The "Search Facebook" field is at the top left corner of the page. Type "Hearing Loss Association of America—Official Community & Support" to get to the group page, and request to join the private Facebook group.



"In a world of rapidly changing ways to get new hearing aids, there are online hearing tests, coupons in the mail and flyers for "free" hearing tests, online hearing aids to buy, and soon—Over The Counter (OTC) hearing aids...plus the ones you can already buy through Walgreens, WalMart and other local franchises...plus all the latest changes in health insurance coverage, which are not always what they seem. The one piece of advice I always give is to make sure you have a thorough, professional and complete (not just a graph, but a full test in the booth) hearing test before venturing into the world of "Direct to Consumer" (DTC) purchasing. You wouldn't buy a pair of glasses other than "readers" without an eye exam, and with hearing loss having more complexity, why not invest in getting a determination of your hearing loss from an audiologist first? Then you can choose which direction is right for you."  
— Mary Clark

- 1) First—always get your ears checked by an ENT. Then, get a referral from the ENT for a good audiologist.
- 2) Then go to the audiologist for a good audiogram (hearing test).
- 3) If the audiologist has a hearing aid dispensary and is reasonable, get a quote for the aids, and
- 4) shop around.
- 5) If you need ear molds made, they will do it at the first appointment with the dispensary that you choose.
- 6) When you are fitted with the aids, ask lots of questions about the aids and what's the best way to get the best success with them!
- 7) It will take several adjustments to the aids on different appointments.

— Liz Fletcher





A key job of the board is renewing itself. HLAA board members serve three-year terms, and up to three consecutive terms. All board members are constantly on the prowl for new prospects who may wish to donate their time, treasure and talent to the organization to help it fulfill its mission.

## Serving on the HLAA Board of Directors

BY KEVIN H. FRANCK

I've served on the Hearing Loss Association of America's (HLAA) Board of Directors since 2015. I'm confident that HLAA has benefited from my service, but I have benefited, too. I've been able to have a front row seat to some of the most fundamental changes in the hearing health care field. I joined HLAA as it was sponsoring the National Academies of Sciences, Engineering, and Medicine study on Hearing Health Care for Adults—Priorities for Improving Access and Affordability. The study came out with 12 recommendations regarding how to improve access to hearing health care for adults. Then, HLAA was the trusted advisor to legislators, serving as the voice of the consumer as they drafted the bill to address **Recommendation 7: Implement a New Food and Drug Administration Device Category for Over-The-Counter Wearable Hearing Devices**. HLAA stayed active and is now commenting on the U.S. Food and Drug Administration's proposed definition of OTC hearing aids. Also, Medicare is now considering hearing aid service and device coverage, asking HLAA what its constituents want. I would not have had this view if not for my HLAA board position.

I've learned about board governance. I aspire to be a member of for-profit boards, and the nonprofit context has been a great place to gain direct experience.

My fellow board members are a fascinating group comprised of e-commerce executives, professors of health policy and hearing science, higher education executives, state advocacy champions, U.S. Marines, global ministry directors, writers, Hollywood creators, future and current physicians, lawyers, film distributors and real estate developers. I learn from every one of them every time I interact with them.

During my tenure, we've navigated the Black Lives Matter societal shift. I've learned the impact embracing diversity can have on our group dynamics and am beginning to see how this can help us reach people we wouldn't have been able to reach before. Our commitment to diversity wasn't as deliberately integrated as it is now. This required conversations I'd never had, and I feel better equipped now to improve how I see the world and embrace differences.

We've adapted to the COVID-19 global pandemic, and I've learned how to remain effective behind a computer screen—perhaps even more effective.

### Serve on HLAA's Board of Directors

But enough about me. This column is a call for interest of others to serve on HLAA's Board of Directors.

To be a nonprofit in the United States, an organization needs to have a board. The board and individual board members are fiduciaries, ensuring the organization's well-being. The board works with management to oversee major functional duties such as budgeting and other committee work, and to set the overall strategic direction of the organization. Finally, the board chips in—leveraging everyone's unique set of skills and perspectives to provide input to the organization as volunteers. The board also chips in literally to fundraising efforts, donating money and helping others to do the same.

A key job of the board is renewing itself. HLAA board members serve three-year terms, and up to three consecutive terms. All board members are constantly on the prowl for new prospects who may wish to donate their time, treasure and talent to the organization to help it fulfill its mission. We look for new board members who are seasoned in their board experiences, but also people who bring new perspectives. We look for members who are familiar with hearing loss, but also those who could translate a related experience. We seek diversity in many forms, as the lived experiences of hearing loss are as unique as each of the qualities that define us. From this diversity, we seek to build the tools, policies and community to support this relevant quality of each of us.

Board member prospects come from nominations of HLAA's existing board and staff, but anyone can also nominate or even self-nominate for board service. To do so, follow this link to see relevant instructions: [www.hearingloss.org/about-hlaa/our-team/board-of-directors/](http://www.hearingloss.org/about-hlaa/our-team/board-of-directors/). Selfishly, I can't wait to work with you as we work together and with the talented leadership of HLAA. **HL**

*Kevin H. Franck, Ph.D., is chair of the HLAA Board of Directors and lives in Concord, Massachusetts. He can be reached at [chair@hearingloss.org](mailto:chair@hearingloss.org).*

## Back Together! HLAA 2022 Convention



**The Hearing Loss Association of America invites you to attend our Convention in Tampa! Don't miss the largest communication-accessible event in the country for people with hearing loss. Join us for an exhibit hall/tradeshow, an extensive educational program, social events, and so much more!**

**See you June 23-25, 2022 in Tampa, Florida!**

**Find out more at [hearingloss.org/programs-events/convention/](http://hearingloss.org/programs-events/convention/).**

# Get to Know

# Ibrahim Dabo

BY CARRIE JOHNSON

**This month's *Hearing Life* feature provides an introduction to Ibrahim Dabo, a new member of the HLAA Board of Directors. I interviewed Ib virtually on Zoom. I hope you enjoy getting to know Ib as much as I have!**

## About Ib

Ibrahim Dabo's friends call him Ib (pronounced Eeb) or I-B. He was born in Sierra Leone, a country in West Africa, where he lived until he was a teenager. Ib was not born with hearing loss, but developed it as a young adult. He came to find HLAA through an online search. Ib is the newest member of the HLAA Board of Directors. Like most, he experienced a grieving period when he was diagnosed with hearing loss. Ib has a fascinating story to share, and his encouragement and positivity are infectious.

Ib Dabo grew up in a very loving family and community. He loved learning and going to school, which was encouraged by his family of educators and his extended family. Ib grew up wanting to learn as much as he could from older people, whom he naturally gravitated toward. "In my family, I did all I could to excel because I had all the support that I needed to excel," said Ib.

At the age of eight or nine, Ib discovered that he loved the news. "From a young age, I was particularly disturbed about the West Africa news I heard on the radio, or read in magazines. I learned about the war in Liberia, and how people were becoming refugees. I wanted to help," said Ib. It bothered Ib a lot that he was not in a position to help the refugees. Little did he know that at age 14, war would drive him out of his country. "I was a teenager when I learned teenagers had been abducted. Some of them were put on drugs and given guns to fight alongside the rebels. And so, when the rebels came to the capital city Freetown, where I was living, I was terrified. I wanted to grow up and be successful, so I can help people in need. Maybe the news I was hearing contributed to my desire to want to help people," said Ib.

"I was fearful for my life, my dreams and my future," said Ib. So, he and his older brother (and 600 others) boarded a boat for a journey across the Atlantic Ocean. "So, we were heading for Guinea, but that seven-hour journey turned into a five-day journey to The Gambia, after we were informed the Guinean authorities did not allow us to enter their borders. A lot happened on that boat that was so terrifying and at one point in time, I felt like this was it, this was the end." One of the boat's two engines stopped working. The communication system on the boat broke. The passengers ran out of water and food.

Thankfully, Ib did get off the boat. He lived the next seven years as a refugee in The Gambia, a country in West Africa. It was from there that Ib made his way to the United States.

“I was fearful for my life, my dreams and my future....So, we were heading for Guinea, but that seven hour journey turned into a five day journey. A lot happened on that boat that was so terrifying and at one point in time, I felt like this was it, this was the end.”

## From West Africa to the United States

Ib settled in Maryland, where he met his wife in 2004 at Baltimore City Community College. He holds an associate degree in business administration from Baltimore City Community College, a bachelor's degree in management information systems from the University of Baltimore and a master's degree in applied information technology from Towson University. It was in 2013, while in graduate school in his 30s, that Ib was diagnosed with bilateral sensorineural hearing

*Right: Ib Dabo, photo by Kara Hudson. Inset photo, left: Ib as a young man in Sierra Leone. Inset photo, right: Ib with his wife, daughter and son*

“Hearing aids changed my life. To hear so many new and beautiful sounds, like on a beautiful sunny morning hearing the birds. It was amazing all the sounds I heard and it made a big difference.”





© Kara Hudson

loss through a hearing screening on campus. “I got to understand why I isolated myself from some people. Why I stayed away from a lot of social interaction. I got to understand why I was stressed out a lot, especially when I was in school. I remember some classes in undergrad, for example, I could not understand anything my professor was saying. I would only go in to take notes if there’s any notes on the board, and figure out what the homework is and I remember specifically turning to my friends and saying, ‘I don’t know why the Professor speaks like this,’” said Ib.

### Hearing Loss Diagnosis

Ib was devastated when he received his hearing loss diagnosis. He went through a grieving period (2013-2020) after he was diagnosed and received his hearing aids. Not knowing many young people, or many in the Black community, with hearing loss, Ib felt a bit hopeless, and was searching for support.

“Hearing aids changed my life,” said Ib. “To hear so many new and beautiful sounds, like on a beautiful sunny morning hearing the birds. It was amazing all the sounds I heard and it made a big difference,” said Ib.

Ib is now a leader and advocate who works to support and guide others. His focus is on building relationships, especially with young people and those in marginalized communities, so they will know that they are not alone in their hearing loss journey. Ib’s advice to those first diagnosed with hearing loss is—“Get support and be easy on yourself.”

### Finding HLAA

Ib found the HLAA community through a Google search. He immediately joined the HLAA Facebook Official Community and Support Group ([www.facebook.com/groups/363776767846053/](https://www.facebook.com/groups/363776767846053/)), and became a member of HLAA. He learned as much as he could about HLAA and attended the Virtual Convention in 2021.

Ib, his wife and their three children (including one brand new baby boy!) now live in Atlanta, Georgia, where Dabo is currently the director of enterprise business systems for the General Board of Global Ministries, the global mission agency of the United Methodist Church, which operates in at least 100 countries.

Through his work, Ib is finding ways to use technology to solve problems. “So, in my daily work when I’m dealing with systems, our organization has projects around the world. Our projects include global health,

*Left: Ib in his home office. Right: Ib and his family*

“ In 2021, when I made that decision that I’m going to get involved with the HLAA Board of Directors—that’s when I made the decision my goal was that I’m finally going to step out and stop hiding my hearing loss. ”

agriculture and education. I focus on implementing the systems and thinking about the beneficiaries, people who are in need. So, how can we use the systems and technology in general to drive the work that we do to ultimately benefit the people who desperately need help?” said Ib.

### Passion for Journalism

Ib also has a passion for journalism. Ib started writing professionally when he was a refugee in The Gambia, West Africa, at the age of 17. Even though he did not have any experience in journalism or training at the time, he just believed he could do it. The leading international soccer website at the time that appointed him Africa Lead Correspondent was SoccerAge. It was four years later that he started working as Africa Editor for Goal.com, which then became the leading global soccer website.

“As a teenager in The Gambia as a refugee, I wanted to share stories. My story is one of war and survival. I had family members who were killed brutally during the war. I wanted to raise awareness and the need for peace and love. But I also wanted to share stories of how soccer united refugees,” said Ib.

Mr. Dabo has written for several international publications and interviewed people from all walks of life. Ib loves writing and sharing stories, which he does through his blog. His writing since he came to the U.S. mainly covers nonprofit organizations.

“In 2021, when I made that decision that I’m going to get involved with the HLAA Board of Directors—that’s when I made the decision my goal was that I’m finally going to step out and stop hiding my hearing loss,” said Ib.

Ib says, “With faith, determination and hard work, you can do anything.” **HL**

*Ib Dabo serves on the HLAA Board of Directors. To connect with Ib, email [ibrahimdabo@gmail.com](mailto:ibrahimdabo@gmail.com), or you can connect with him on social media, [www.facebook.com/IbTalkOnline](https://www.facebook.com/IbTalkOnline).*





**Atlanta, Georgia**  
**Born in Sierra Leone,**  
**West Africa**

# Ibrahim Dabo

**My hearing loss** has allowed me to pursue my God-given purpose of inspiring people with my story through public speaking and advocacy.

**My sage advice for someone newly-diagnosed with hearing loss is to** find a support network that understands what you are going through and will support you so that you can thrive. The HLAA Facebook Official Community and Support Group ([www.facebook.com/groups/363776767846053/](http://www.facebook.com/groups/363776767846053/)) is a great space to connect and get such support.

**When I grew up, I wanted to** become a philanthropist.

**The hardest thing I've ever done was** public speaking.

**My little-known talent is** that I'm a self-trained artist.

**Hobbies?** I love listening to Christian praise and worship music and am very competitive at playing Scrabble.

**Kids?** I have two beautiful toddlers who are teaching me how to be patient and have fun at the same time. We are also blessed to have a bouncing baby boy who joined us in December, just in time for Christmas."

**Pets?** I had a rooster as a pet in Sierra Leone. How we bonded surprised everyone.

**I definitely am not** a morning person.

**Working nine to five (current and past jobs):** At age 17, I worked as a journalist for the leading global soccer website at the time—SoccerAge—and four years later as Africa Editor for Goal.com, a leading global soccer website. Other companies I have worked for as an information technology leader include PRIME Research (a global public relations consulting company; now Cision Insights) and the General Board of Global Ministries (the global mission agency of the United Methodist Church).

**Happiness is** awesome when it comes from within regardless of our situation. If we solely search for happiness externally, we're likely to be disappointed.

**My favorite season** is the summer. It's a reason I was happy to move from Michigan to Georgia.

**I am** a Christian, husband and father.

**I have a weakness for** Cadbury Dairy Milk and Almond Joy Coconut Chocolates.

**I have the uncanny ability to** fix things.

**I simply cannot live without** my family.

**My three favorite possessions are** my cellphone, laptop and wallet.

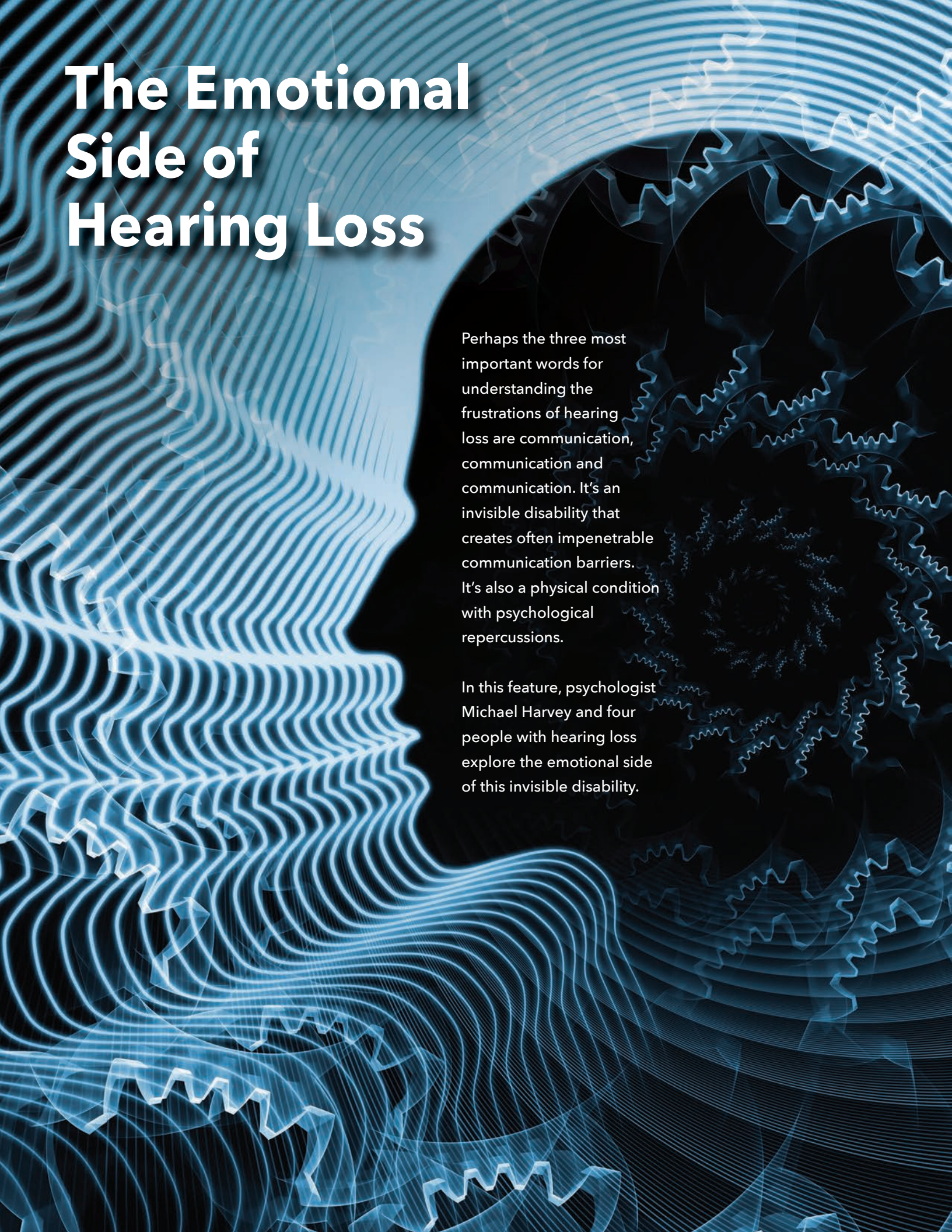
**If I ruled the world** I would make it a happy place for children by supporting their education and basic needs so they can thrive and live a fulfilling life.

**My long-term goal is** to start a nonprofit organization.

**My greatest accomplishment is** becoming a journalist at age 17 when I was appointed Africa Correspondent for a large Internet media company without experience in journalism.

**I want to be remembered** as someone who inspired people globally to believe they can accomplish any goals they set for themselves by faith, hard work, perseverance and determination and fulfill their God-given purpose.

# The Emotional Side of Hearing Loss



Perhaps the three most important words for understanding the frustrations of hearing loss are communication, communication and communication. It's an invisible disability that creates often impenetrable communication barriers. It's also a physical condition with psychological repercussions.

In this feature, psychologist Michael Harvey and four people with hearing loss explore the emotional side of this invisible disability.



# The Emotional Side of Hearing Loss

BY MICHAEL A. HARVEY

“What do you know about hearing loss?” Jill scowled. Her accusatory question was valid. I didn’t have a hearing loss and had only recently completed my clinical training (which didn’t include requisite coursework). She requested therapy from me for “hearing loss issues” because I directed a program predominantly for culturally Deaf persons. She mistakenly assumed that I therefore knew about persons with moderate hearing loss.

Jill typically began our meetings with, “Can’t you understand what I’m going through?” and we would struggle for the remaining time. Given her age of 17, I privately asked myself what adolescent doesn’t feel misunderstood? But thankfully, something finally clicked for me. I asked her to stand with both her arms outstretched and imagine that she was being pulled on one side from the hearing world and on the other side from the Deaf world. As she enacted this scenario, back and forth, back and forth, she began to cry and exclaimed, “Now you get it! I feel pulled toward the hearing world and pulled toward the Deaf world; but I’m in neither one.”

## Hearing Loss Through a Psychological Lens

For the previous 40 or so years, I’ve had the privilege of bearing witness to many stories told by persons with hearing loss and of examining their stories through a psychological lens. Jill’s between two worlds experience is quite common. Consider a quotation by Holly Elliott:

*Hearing people often think I am hearing because my speech is good; deaf people often think I am hearing because my signs are bad...we are caught between incomprehensible speech on the one hand and incomprehensible signs on the other. If only those hearies would talk more clearly! If only those deafies would sign more slowly!*

Perhaps the three most important words for understanding the frustrations of hearing loss are communication, communication and communication. It’s an invisible disability—not like a broken leg—that creates often impenetrable communication barriers. As one man with hearing loss lamented, “Why does my wife always wait

until I'm in the opposite end of the house before asking me to Merm frner mernferr brernfr?" His sentiment is echoed on a posting on the Hearing Loss Association of America—Official Community & Support Facebook group: "Why do people immediately assume that I can hear? I hate it."

As another example, Sue, a middle-aged woman with congenital hearing loss, was asked to write a letter to her mother that she may never send. The following is an excerpt of her letter:

*If only you had known how much I had tried to please you and daddy by not going to my bedroom every Thanksgiving and Christmas and escape all those people, and by eating at the dinner table, nodding my head or smiling at strategic points in the conversation in order to pretend that I could follow it.*

*Please don't blame all this on my ears, cuz it's not that simple. If I had no legs, you wouldn't force me to jump! If I was blind, you wouldn't force me to drive a car. So why did you force me to hear when I couldn't? And by the way, why did you have the TV on during most every meal, anyway?*

The potent antidote to being stuck in limbo between the Deaf and hearing worlds are groups like Hearing Loss Association of America (HLAA). Psychologically, we humans need to spend a chunk of our time with our peers, people like us, for what is termed emotional refueling. I'm reminded of when my wife and I were chatting with our same-aged peers (70 y/o) and I heard one of my daughters whisper to the other, "It's good that they're with their own kind."

Many people with hearing loss find that being with their "own kind" is a profound healing experience. As one woman put it, "It helps me recover from the insensitivity of hearing people." She was referring to what I have come to call ordinary evil. I define it as an event that feels "evil"—dirty—but isn't evil enough to make the headlines because it occurs too often. Consider the following post on the Hearing Loss Association of America—Official Community & Support Facebook group:

*We had a team meeting at work today with seven people I couldn't hear. They all know that I'm partially deaf but somehow, I ended up being the butt of a joke and because I couldn't hear them, they thought it was even funnier. So embarrassed and hating my life right now.*

*A response: I had this all my adult life. Hearing loss seems to be the one disability where taking the mic is deemed acceptable. One of my old bosses referred to me as*

*'ol trumpet ears' and she was the disability awareness officer. You couldn't make it up.*

## Psychological Armor

It's essential to develop psychological armor to protect one's self esteem from ordinary evil. So-called anticipatory coping is predicting that you will at some point be subjected to ordinary evil and figuring out how you'll internally deal with it. This is where positive self-talk becomes important. For example, "Because he said it wasn't important to make communication accessible to me doesn't mean that I'm not important." "My boss's insensitivity toward me doesn't mean that I'm unworthy of respect." It's more adaptive to feel anger toward the insensitive other than toward oneself.

Psychologist Beatrice Wright coined the term spread to describe how much a person views one's disability as determining, not some aspects but all aspects of his/her identity. Maximum spread is shame, a self-attribution that, as one person put it, "I'm a big blob of worthless, deaf and dumb human flesh, inferior to everyone." He would recall countless times his mother would admonish him not to show that he wears hearing aids—to hide them as best he could. Although he acknowledged his mother's good intentions, her actions caused him shame. In contrast, limited spread is exemplified by a quotation from Al Pimental, the previous director of National Association of the Deaf: "The only thing a deaf person cannot do is hear."

## Forming a Solid Identity

Forming a solid identity is easier said than done. What exactly does a solid identity mean? George, a man with hearing loss, shared his personal answer to that question: "My identity is 33% hearing loss, 20% chef, 30% writer (poetry) and the remaining percentage is 'To Be Announced'." His response illustrates how one may have multiple identities and suggests that the number of "identity categories" may be related to psychological resilience. For example, those who put all their identity into one's career run the risk of becoming depressed upon retirement. I asked George to explain his percentage criteria:

*A good chunk (33%) of my identity is as a person living with hearing loss. I've joined HLAA, keep up with the hearing aid technology and cochlear implant technology, and advocate at City Hall for them to install a looping system. But I need to be careful how much percentage I put in that box. Yes, my ears don't work right, but I'm much more than that.*

## Impact of Acquired Hearing Loss

The psychological impact of acquired hearing loss later in life is different from when it is congenital or longstanding. Please bear with me for what may seem like a bizarre non-sequitur. There is a Buddhist story about how to catch monkeys. You take a coconut and make a hole in it, just large enough that a monkey can squeeze its hand in. Next, you tie the coconut down and put a piece of candy inside. The monkey smells the candy, puts its hand into the coconut, grabs the candy and finds that the hole is too small for its fist to get out. The last thing a monkey would consider is to let go of the candy. Often, they only let go because of exhaustion. Ultimately the monkey's unwillingness to let go of its attachment to the candy is the cause of its suffering.

Do you see where this is going? Letting go of the candy (hearing identity) in order to embrace being a person with hearing loss or deaf identity—aka the grieving process—is much easier said than done. Jack Ashley, a member of British Parliament who became deaf, described this journey as “tortured months,” “shattering beyond belief,” and “plummeting of my happiness, aspirations and hopes for the future.” That journey doesn't end at a blissful state of perpetual acceptance. Just when someone feels like they're “over it,” anything, such as a song, a date on the calendar, or significant events, can trigger renewed painful emotions that one assumed have been long since buried. Thankfully, these lapses don't last as long and aren't as intense.

## It's Not All Negative

Let's kick this up a notch, as it's not all negative. Often, we simultaneously accept and lament a loss. Indeed, psychiatrist George Valliant in his longitudinal study of adult psychological development, stated, “Wisdom is the ability to hold a paradox.” As one man with hearing loss said, “I am both grateful for my hearing loss for the opportunities it has given me, yet if there were a medical cure, I'd accept it in a heartbeat.”

Indeed, many people have emphasized that there are opportunities inherent in hearing loss. Many persons noted existential benefits:

- My hearing loss has given me greater purpose in life
- Has made me appreciate what I have more
- Gives more contrast and texture to my life

Others noted spiritual benefits:

- My hearing loss has begun a spiritual quest for me
- Expanded my experience of humanness

- Teaches me that humility is okay, that there's a higher power
- I appreciate group church less; I pray more individually

One not only notices acts of ordinary evil, but also relishes acts of kindness. Consider the following Facebook posting:

*Today I had to go to my ENT appt. The tech there was so nice. I told her I had to take my hearing aids out for the x-ray, so when she spoke to me, she tapped my shoulder, spoke louder and asked if I heard her. I wanted to cry; it was so nice!*

\* \* \*

I met with Jill for a year as she transcended the tug of war between the Deaf and hearing worlds. She told me that she had begun dating a “cute boy” with hearing loss, but she and her parents are arguing about curfew.

On our last visit, I thanked her. “For what?” she asked, appearing surprised.

“For getting me to finally understand you, your world, how being a person with hearing loss affects you, all of that!”

“I knew you would get it eventually,” she said with a smile. “Hey, maybe you can write an article about me?”

“Maybe I will.” **HL**

*Michael A. Harvey, Ph.D., ABPP, is a psychologist in private practice in Framingham, Massachusetts. He provides training and consultation on mental health issues having to do with hearing loss, including consultation and training for audiologists regarding motivational interviewing and the psychological aspects of patient care. As a clinical psychologist, he was on the faculty at Salus University, where he taught online courses relating to the psychosocial aspects of hearing loss. He has published more than 50 articles in the field and his latest books are Listen With the Heart: Relationships and Hearing Loss and The Odyssey of Hearing Loss: Tales of Triumph.*



“But I need to be  
each percent  
box.”

# An Emotional Ride with Hearing Loss

BY DARLEEN WILSON

I am a life-long musician. As a sound engineer and record producer, I relied on my ears to make a living. You might suspect where this is going. Some years after I had (fortunately) shifted into developing multimedia and Web content, there was a moment when I was listening to an Aretha Franklin record, and it sounded altogether different to me than I remembered.

Aretha’s voice, being more powerful than the technology that recorded her, produced high-end distortion that is embedded in the recording. Suddenly I was aware that I was not hearing that. And I reconsidered the number of times I had strained to listen to conversation or perceived that people were mumbling. What was going on? I had my ears checked. Emotionally daunted at the idea of hearing loss, I was momentarily relieved to verify the cause of my perceptions: at least I wasn’t crazy.

“Yet, beyond the frustration and the ache of loss, other feelings arise: Gratitude for the kindness of people willing to accommodate me when I explain I have hearing loss—those who somehow become more open to share their own vulnerabilities, and instead of distance we share a sense of closeness.”

Then the emotional rollercoaster. One moment I was hopeful that there was something I could do to be able to hear better. The next moment I was distraught by the quality of sound delivered by my hearing aids—it was as if richness of color was drained, leaving everything in harsh black and white and hard-to-interpret shades of gray. Still, I was relieved to be able to follow some conversations more easily. Then again, I could be overwhelmed by noise, and plunged into despair.

I heavily mourned my hearing loss for at least a decade and a half, anticipated gatherings with trepidation, knowing I’d have to steel myself against each ripple of laughter as I missed the joke, and dreading the sense of cluelessness I felt when I could not decode the details of

some inside story. Most painful of all perhaps, the loss of music was completely disorienting. I felt like an outsider who could never come back in, forever abandoned to stark, leaden days. Music, which had always been my solace, no longer felt available to me, and as disheartening as the disconnection with people is, the broken connection with music felt like proverbial insult to injury. And of course, it was all exhausting. It still is.

Yet, beyond the frustration and the ache of loss, other feelings arise: Gratitude for the kindness of people willing to accommodate me when I explain I have hearing loss—those who somehow become more open to share their own vulnerabilities, and instead of distance, we share a sense of closeness.

Lately I have found it exhilarating to be able to hear at all. I have been fortunate to spend extended time in a sparsely populated tropical area, living in a screened-in cottage, close to nature. I wake up pre-dawn and all is dark and silent. Then the sun heralds the day, I put in my hearing aids and the world goes from silent to alive. I hear birds! The ocean! Sweet murmurs of my husband’s voice... and my healing heart rebounds with joy.

One of these days I may even reach for my guitar. **HL**

*Darleen Wilson is a former record producer and engineer. She served as director of WGBH Online in Boston, and holds a master’s degree in Human Factors in Information Design. When she is not weeding or writing essays, she spends her time researching services and technologies to support better hearing. She and her husband split their time between Pahoehoe, Hawaii and Lowell, Massachusetts.*





# Hearing Challenges in the Time of COVID-19

BY ENA BROWN

I thought COVID-19 mask shopping would be like shoe shopping, finding something comfy and attractive. But when you live in a hot climate, a comfy face covering is unrealistic. I just had to get used to wearing it. Then I realized I had a bigger problem. I couldn't understand people when they wore their masks. How could I get used to that?

I already knew that I couldn't just say I had hearing loss and expect people to know what to do. Pre-COVID-19, I might reluctantly ask: "Please look at me when you speak. Talk louder but don't yell. Speak more slowly please. Repeat, rephrase."

“ Like all of us, I want this pandemic to end, but this horrible virus has forced me to be upfront about my hearing loss so I can hear better. My mask doesn't support a sports team, corporation or cause. I just want to be able to understand what people are saying. ”

When decorative masks became popular, they were emblazoned with sports teams, company logos and causes. My friend, with her die-cutting machine, made me a mask: "Hard of Hearing. Please Speak Up." But my custom mask wasn't always the answer. Sometimes people didn't read it, so I had to explain my hearing loss and point to the mask to reinforce my needs. A Target cashier laughed at my mask, telling me it was hysterical. I explained it wasn't funny and that I really had hearing loss. She felt terrible when I told her. We were all learning.

In addition to making good use of my custom mask, I turned to my assistive listening device. This gadget brings speech directly to my hearing-aided ears, even filtering out some background noise. Pre-COVID-19, my

device stayed connected to my TV, streaming the volume to my ears. Now I put my device on the masked cashier's counter. I ask my doctor to clip it to her lab coat. My Pilates instructor wears it so her masked voice clearly streams directly to my hearing aids.

When I explain the purpose of my device, many are fascinated and want more information. Some take pictures of it or make a note so they can tell friends or family who have hearing challenges. There are many of us with hearing loss—48 million Americans—who need hearing support. (In sharing my device information, I always suggest checking possible insurance coverage and the state's vocational rehabilitation assistance.)

Like all of us, I want this pandemic to end, but this horrible virus has forced me to be upfront about my hearing loss so I can hear better. My mask doesn't support a sports team, corporation or cause. I just want to be able to understand what people are saying. **HL**

*Ena Brown has a glomus jugulare tumor that left her deaf in one ear. She also lost some hearing in her other ear due to age, or as she calls it—genetics. She was in public and alumni relations, then worked in education when she moved to Arizona. Now retired, she's a volunteer tutor for not-for-profits and enjoys the visual and performing arts. Until this essay, she says her most noted publication was her letter that David Letterman read on his Viewer Mail segment of "Late Night" in 1984.*



# Becoming an Ambassador for Hearing Loss

BY GAIL WEISS

Several years ago, I was the subject of an intervention. No, I'm not a substance abuser. I have hearing loss and the co-workers who brought me into a conference room and sat me down opposite them wanted me to know that my failure to modulate my voice during telephone conversations and lower the ringer on my phone was making it hard for them to focus on their jobs. The experience was both jarring and eye-opening—jarring because it was so unexpected; eye-opening because although I knew that my hearing loss had long been a source of emotional distress, until the intervention I hadn't realized the extent of that distress.

When I was 6 years old, a bout of measles robbed me of about 40% of my hearing. My parents responded by taking me from doctor to doctor in a desperate search for a remedy. In addition to radiation treatments, I had three tonsillectomies and a series of painful procedures that involved sticking long needles into my ears. Finally, when I was 12, a doctor convinced my parents that sensorineural hearing losses such as mine weren't fixable, so they did what they had resisted for six years and bought me hearing aids.

What we didn't do was talk about the hearing loss. Indeed, because having a child with a disability embarrassed my parents (and, by extension, me), it was a verboten subject. After I got hearing aids, I always made sure my hair was long enough to cover my ears, so the aids remained out of sight. Faking it—pretending I could hear a statement—sometimes helped me dodge the dreaded but all-too-frequent, "It wasn't that important," or, worse, "Oh, never mind." Still, because my comments were sometimes off-topic, I was subjected to considerable teasing. Occasionally, people who I misheard reacted with humor, such as the fellow who suggested I write a book called "Things I Thought I Heard." More often, however, the responses were ego-deflating and hurtful. In group settings, people looking at each other and laughing is one example. Being tacitly excluded from conversations is another.

After working my way up in the publishing world, I became a writer for a trade magazine. My hearing loss remained a veiled issue. Then the intervention happened,

and I fled from the room, but not before unleashing a barrage of tears that left the participants mortified and apologetic. I'm not sure what my co-workers learned from that showdown, or from my flummoxed response to it, but I definitely learned something: My hearing loss was more of an emotional burden than I cared to admit, and it was time to recognize and address that. I began using the words "I have a hearing loss" more often, especially to enlighten people who assumed my non-germane comments or difficulty tempering my voice stemmed from inanity or thoughtlessness.

Do more folks in my orbit "get it"? Not to the extent I'd prefer. The invisibility of hearing loss makes it easy for people to assume it's nonexistent, or a minor problem. Still, my journey from denial to acceptance continues, aided by the realization that I wasn't doing myself, or anyone else with compromised hearing, any favors by intimating that hearing loss is a source of shame best dealt with by adopting a "Who, me?" attitude. Having hearing loss presents many challenges. Overcoming these challenges, while at the same time being—in the words of HLAA activists—an "ambassador for hearing loss," makes personal and professional successes especially gratifying. **HL**

*Gail Weiss graduated from The City College of New York (CCNY) and earned a master's degree in social work from Fordham University.*

*Professionally, she worked in the publishing industry for many years.*

*During her tenure as a writer for Medical Economics, a magazine for physicians, she won three Neal Awards, which are presented annually to business media journalists. From 2009 until 2021, she put her MSW to use as a New York State Adult Protective Services worker. Currently, she is a freelance editor. Although she is a Nassau County resident, Gail is an HLAA-NYC board member and co-editor of the chapter's newsletter.*



# Finding Peace and Acceptance with Hearing Loss

BY MARY BRISTOW

Quiet, a sense of calm...I remove my hearing aids for the evening. The only sounds I hear are muted in the distance. It is peaceful. I've begun to accept this over time. It was not like that before—I would feel the anxiety growing into a sheer panic attack, not being able to hear the sounds more completely around me. I remember the spring of 2012. I would go for a walk and could not hear the birds singing. I was missing dates of events. In groups all voices were saying the same thing: blah, blah, blah. I would come home and tell my husband that no one seems to speak up, or the sound in the room was very bad. I thought my husband had developed a mumbling problem! It was so annoying. One night we went to a lecture and I was not able to understand the speaker. My husband mumbled something about calling a hearing doctor the next day.

I'll never forget that day at the ENT's office. There I was tested in a little booth, where I used the clicker to mark the sounds of words and sentences. When I left the booth, the audiologist was mumbling to me. (Everybody was mumbling.) She said, "You have sensorineural hearing loss." Then came her explanation and her recommendation that I needed hearing aids. I was in my 50s at the time. Up to that point I thought I had excellent hearing, so it was hard to grasp.

They gave me a pair of hearing aids to try. The next day I went outside and could hear the birds and wind in the trees. It was magical! I began to adjust to my new way of life, but as time went on my hearing took a drastic turn. I wanted to join the community theatre, get a part-time job, but words went into my ears and not to my brain. My husband was very supportive. I was annoying to family and friends. No one wanted to keep repeating things to me. I became very anxious at events, in groups and with friends. It was too exhausting trying to hear. I made mistakes on sentences, dates—everything. The more anxious I became, the more I could not hear. I was too exhausted, embarrassed, and yes, ashamed.

And then it all became too much to handle and I spiraled into a deep depression. I would not go out.

My aids were programmed to work with my phone, but I would not talk. Texting seemed exhausting. In fact, everything was. I would stay in my night clothes and stare at a TV with no sound. When I was alone, no one knew the horrible things that went through my mind. My sweet dog was my only friend, and I couldn't even walk him in case someone saw me and wanted to talk.

The anxiety and depression sent me into almost total agoraphobia. I felt worthless and withdrew from society. Of course, it only made my situation worse. I went to a therapist and began to work on a new life—one in which I could start liking myself for who I am and not be ashamed when someone walks away when I say, "Pardon me, I have hearing loss."

I'm accepting it now after so many years. I spend my time with my husband and dogs. That's where I feel comfortable now—and I like myself. I have many projects and each day I broaden my horizons a little farther. I've attended a couple gatherings and did not have a fear of being rejected. I love the quiet now and am becoming more at peace with myself. **HL**

*Mary Bristow was born and raised in Michigan. After college she pursued a career in hotel sales and marketing. She moved to Florida and continued working in hotel sales in Tampa, Sarasota and Naples. While in Naples, she met her husband. They eventually followed his career to northwest Arkansas.*

*It was after that move to Arkansas that she discovered she had hearing loss. She and her husband are now "pet parents" to two terriers (one of which also has hearing loss). Mary enjoys a variety of crafts and working with her local animal shelter.*



# Power of Community



BY ANN RANCOURT

Throughout another year of uncertainty, the dedication of this community kept the Walk4Hearing strong. The commitment of our volunteers, walkers, teams, supporters and partners paved the way for exciting Walk Days—celebrating virtually in the spring and reuniting in person this fall.

With the support of 4,700 walkers, 550 team captains, 200 alliances, 60 HLAA Chapters and State Organizations and 250 volunteers, Walk4Hearing raised awareness for hearing health in 19 cities across the country. Whether they were online or in-person, participants showed up to celebrate with creative team t-shirts and colorful signs ready to display their Walk spirit. Our community came through, raising more than \$1 million dollars to provide people the tools and resources to live well with hearing loss.



23andHear teammates walked after the Bay Area celebration at their headquarters where they hosted a 5K Walk for their employees.

## Walk4Hearing Weekend

Our spring Walks joined forces for a star-studded Walk4Hearing Weekend on June 12-13. Over two days, we gathered online then walked with friends and teammates in our own neighborhoods. Special guests included comedian D.J. Demers and inspirational singer Mandy Harvey, both of whom are hearing loss advocates. We were also joined by kids from No Limits for Deaf Children for a special national anthem performance.

After their celebration in the Bay Area, company team 23andHear organized a 5K walk at their headquarters and raised an impressive \$2,588! To encourage safety and to educate employees about communication access, the team wore clear masks to bring more awareness to lipreading.

In the country music capital of the world, team Amelia Aid Charms raised \$1,070 and gathered 35 of her teammates at a park in Nashville, Tennessee. Team Captain Amelia and her friends created signs to hold while they walked around town raising awareness for hearing health. Afterward, they enjoyed delicious cookies!



Team Amelia Aid Charms created signs to display proudly while walking in their neighborhood to raise awareness.





## Reuniting the Community

As fall rolled around, Walk4Hearing eagerly reunited for in-person events. Seeing old friends and connecting in person brought a renewed sense of excitement! Throughout the fall season, several people were acknowledged for their contributions to the community and for advancing HLAA's mission.

NYC Walk4Hearing kicked off the fall season with 400 people in attendance at Riverside Park. During the opening ceremony, a long-time participant, Nikki Kramer was named NYC Walk4Hearing Ambassador. Since 2013, Nikki and her team generated more than \$34,000 in support of HLAA.

In the City of Brotherly Love, Kierstyn "Kiki" Kuehnle, an incredible hearing health advocate, was recognized for raising \$170,000 since 2015. Her success comes from her strong community outreach, speaking engagements and bake sales. Team Kiki raises funds for HLAA and Ocean City ASL Club which welcomed Nyle DiMarco, deaf activist and model, to speak at her school. Kiki has also supported Ocean City Tabernacle to provide closed captioning for church services and events.

At New Jersey Walk4Hearing, HLAA New Jersey State Association was presented with a proclamation for spearheading the effort to require induction loop assistive listening systems in public spaces to address the need for communication access. At Washington DC Walk,



*Kierstyn "Kiki" Kuehnle, seen here with Walk4Hearing Senior Manager Ronnie Adler, was recognized at the Pennsylvania Walk.*

HLAA-DC President Judy Alden was honored for her unwavering dedication to the creation of the Office of Deaf, Deafblind and Hard of Hearing in the District of Columbia.

2022 Walk4Hearing is just around the corner and HLAA is excited to welcome back our spring participants in person! Learn more and register at [walk4hearing.org](https://walk4hearing.org). **HL**

*Ann Rancourt is the Walk4Hearing manager. She can be reached at [arancourt@hearingloss.org](mailto:arancourt@hearingloss.org).*

# 2022 HLA Hear for Life Partners

## Leaders



Hear better. Live better.

## Champions



## Advocates



We want to recognize all our inaugural Hear for Life partners including CTIA, Sensorion and Otonomy.

# 2022 Walk4Hearing Spring Schedule

May 15 Westchester/Rockland

May 21 Michigan  
Milwaukee

June 4 Bay Area  
Nashville

June 5 Long Beach

June 11 Connecticut

June 25 Florida **\*NEW**

Visit [walk4hearing.org](http://walk4hearing.org) for Walk4Hearing's fall schedule.



Take the first step, today! Contact Walk4Hearing Senior Manager Ronnie Adler, [radler@hearingloss.org](mailto:radler@hearingloss.org), or Walk4Hearing Manager Ann Rancourt, [arancourt@hearingloss.org](mailto:arancourt@hearingloss.org).

Arizona Walk4Hearing





HLAA is all about empowering people with hearing loss to find their way out of their own isolation. We are happy to work with TSA to make that a reality in the airport for all.

# Flying Again With TSA

BY LISE HAMLIN

The Transportation Security Administration (TSA) was born right after 9/11 and continues to this day. Their mission is simple: Protect the nation's transportation systems to ensure freedom of movement for people and commerce.

Interestingly, when polled, many people report that TSA has been doing a good job. After all, there have been no major hijackings or major airline incidents since 9/11. People really do see the importance of keeping us all safer.

However, for people with hearing loss in particular, air travel remains stressful. No matter what we do, being in a long line when you cannot hear what the security officer is shouting means you might not get important information. Then the COVID-19 pandemic hit. Masks shut down the possibility of speechreading and created muffled voices, and the stress level of people with hearing loss only increased—big time.

So, it's good to know that in the face of all our worries, TSA has been proactive, working to make those lines less stressful for all. They are working on creating better technology to make the security lines run more quickly and smoothly, without sacrificing security. At the same time, they have reached out to the disability community to see what they can do better.

Recently, HLAA received an award from TSA in recognition of our collaboration with TSA to ensure that people with hearing loss have a smooth and less stressful trip through the security line. HLAA tries our best to ensure TSA has the best information we can provide to break down communication barriers in the airport. But we don't always know when we succeed.

We recently received an email from one of HLAA's supporters reporting that the work TSA has been doing has in fact improved the experience of traveling through these lines. Our supporter wrote:

*"I am very hesitant to travel by myself. But this spring [2021] I had to make a trip to Dallas from Minneapolis. Before the trip, I checked with the TSA website and saw they have a badge that can be shown to alert anyone at the airport of my disability, and it reads, "profoundly hearing impaired." I printed the badge and attached it to a lanyard.*

*I must tell you that I have never experienced such quick awareness of my disability than I saw immediately from everyone at TSA.*

*How, you ask? (lol) The first person, as he directed the traffic pattern of people down the lines, saw me and immediately took note. When I came close to the agent, he went with me. Oh yes, he didn't leave me to do that by myself—the area wasn't jammed with people, but it wasn't empty either. He told the agent that I was hearing impaired. That person took down his mask and motioned to put my ID out. He then told me to take my mask down so he could see if it matched my ID.*

*Then he showed me I needed to put my ticket on the scanner, and he told the next agent with the luggage rack that I was hearing impaired. That person double-checked my bag and took out the laptop.*

*The X-ray person showed me how to put my hands and was very kind. And of course, I walked off without my laptop—they came and put their hand on my shoulder and motioned to come back and get it.*

*At the gate, the same thing occurred with American Airlines staff. They told me they would come get me, and sure enough, they did.*

*On the plane, there were two different attendants and one told the other. For the entire flight, they took down their masks quickly to ask me something. They were calming and asked if I needed any help when I got off the plane.*

*I can't tell you how reassuring this entire experience was for me. With COVID-19 and some of the things we've seen on airlines, I thought I would for sure be the one who got removed from the plane for doing something incorrectly. It turned out to be eye-opening and made me believe I could do more on my own. What a wonderful feeling. I've been reluctant to go out, but even more so to tell people I'm hearing impaired.*

*COVID-19 and masks have been the worst, shutting me out of life and interaction with other people. No one*

*would take time to write anything down for me, so I stayed home.*

*But I'm braver now and happier to know that there are people who don't think of me as a hindrance. TSA was amazing. Lucky me to find it out through that experience."*

HLAA is all about empowering people with hearing loss to find their way out of their own isolation. We are happy to work with TSA to make that a reality in the airport for all.

Visit the TSA Disabilities and Medical Conditions web pages for more info at [www.tsa.gov/travel/special-procedures](http://www.tsa.gov/travel/special-procedures). **HL**

*Lise Hamlin is director of public policy at HLAA. Reach out to her at [lhamlin@hearingloss.org](mailto:lhamlin@hearingloss.org).*

**See The Workplace, COVID-19 and Hearing Loss, on pages 30-31.**



**GET IN THE HEARING LOOP**

**It's Time to Get in the Hearing Loop**

Many people aren't yet aware of hearing loops or other technologies that can improve communication access and public engagement, or how they can enrich the lives of people with hearing loss, their families, friends, colleagues and even communities. The Get in the Hearing Loop Program is changing that—one loop, one advocate, one ADA request at a time.

Get in the Hearing Loop, a communication access program of HLAA, is dedicated to providing and promoting community education, advocacy on behalf of people with hearing loss, and consultation services to help venues of all kinds successfully implement hearing loop technology.

We dream of a world where people with hearing loss can thrive each day with communication access, full inclusion and equal participation in all aspects of life, everywhere they go.

For more information about hearing loops and the Get in the Hearing Loop Program, visit [hearingloss.org/GITHL](http://hearingloss.org/GITHL) or email [GITHLinfo@hearingloss.org](mailto:GITHLinfo@hearingloss.org).

**Hearing Life e-News** is delivered to your inbox twice per month. **Hearing Life e-News** keeps readers up to date on the latest news and information on hearing loss. Each issue features high-interest content such as recent legislation and advocacy efforts, technology, new products for hearing loss, human interest stories, webinars, updates on the Walk4Hearing, Convention and information on HLAA Chapter happenings.

**Sign up today at [hearingloss.org/news-media/e-news/](http://hearingloss.org/news-media/e-news/).**



# The Workplace, COVID-19 and Hearing Loss

BY LISE HAMLIN

*Reprinted with permission from The Hearing Journal's patient handout series.*

**Y**our rights under the Americans with Disabilities Act (ADA) of 1990 don't disappear during a pandemic. Here is important information for workers and employers as offices reopen or provide hybrid (both remote and on site) employment opportunities.

The COVID-19 pandemic, which started impacting the workplace in March 2020, continues to force employers and employees to rethink how to get the job done safely. While early summer 2021 held out the promise of us all going back to the office for an in-person workday, the Delta variant soon emerged and it became clear we are still very much in the midst of a pandemic. That requires us all to think safety first, whether working remotely or on site.

## What does that mean for people with hearing loss?

- If you have a hearing loss, be sure to understand what you need on the job to be the best employee you can be while at the same time understanding your rights under the law.

## Are there any laws that help me get accommodation or prevent discrimination in the workplace based on disability?

- Yes. The ADA is a federal law that seeks to level the playing field for all people with disabilities at work, in public places, for telecommunications access, and when interacting with state or local governments.
- Title I of the ADA prohibits employers from discriminating against employees or applicants with disabilities in all aspects of employment, including hiring, pay, promotion, and firing.
- If you have a hearing loss, you have a right to accommodations under the ADA. That's not just a matter of exercising your civil rights; accommodations allow you to communicate effectively with your team and clients to get the job done.

## Does working under the COVID-19 change my rights under the ADA?

- No. The U.S. Equal Employment Opportunity Commission (EEOC) enforces workplace anti-discrimination laws, including the ADA. In a technical assistance document issued March 18, 2020, "Pandemic Preparedness in the Workplace and the Americans with Disabilities Act," the EEOC says:
  - The ADA, which protects applicants and employees from disability discrimination, is relevant to pandemic preparation in at least three major ways.
  - ADA regulates employers' disability-related inquiries and medical examinations for all applicants and employees.
  - The ADA prohibits covered employers from excluding individuals with disabilities from the workplace for health or safety reasons unless they pose a "direct threat" (a significant risk of substantial harm even with reasonable accommodation).
  - The ADA requires reasonable accommodations for individuals with disabilities (absent undue hardship) during a pandemic.

## What is a reasonable accommodation?

A "reasonable accommodation" is a change in the work environment that allows an individual with a disability to have an equal opportunity to apply for a job, perform a job's essential functions, or enjoy equal benefits and privileges of employment. Examples of reasonable accommodations that may be requested by people with hearing loss include:

- Captioning on video conferencing platforms
- CART (Communication Assistance Realtime Captioning) for on-site meetings
- Assistive listening devices for on-site meetings

- Written agendas before the meeting and written notes and action items after the meeting
- Captioning on videos
- Speech-to-text apps and/or assistive listening devices for one-to-one meetings
- Captioned telephones or video relay phones
- Sign language interpreters

**For more information, refer to the following resources:**

- Employees—Hearing Loss Association of America
- Accessible Remote Work Meetings for Deaf and Hard of Hearing Employees-Hearing Loss Association of America
- Pandemic Preparedness in the Workplace and the Americans with Disabilities Act
- What You Should Know About COVID-19 and the ADA, the Rehabilitation Act, and Other EEO Laws—U.S. Equal Employment Opportunity Commission (eoc.gov)
- The ADA: Your Employment Rights as an Individual With a Disability-U.S. Equal Employment Opportunity Commission (eoc.gov)
- JAN—Job Accommodation Network (askjan.org)

**Optimize Hearing Assistive Technology at Work**

Whether it's a meeting, remote work, or hearing on the phone, hearing assistive technology can help. Some examples of hearing assistive technology include:

- Personal hearing devices such as hearing aids, cochlear implants, or bone-anchored devices
- Assistive listening devices for one-to-one meetings
- Assistive listening systems for large meetings and events using hearing loop systems, FM systems, or Infrared systems
- Captioning and CART, including speech-to-text apps
- Captioned phones and apps; videophones
- Video conferencing platforms with captions
- Visual and tactile alerting for emergency alerts, phones, clocks and doors

Additional information can be found at Technology—Hearing Loss Association of America.

**What can I do if people around me must use face masks?**

As long as COVID-19 is around, it looks like face masks in the workspace will be needed. Cloth and surgical masks pose a particular problem for people with hearing loss: They both muffle speech and hide the face and lips. For people with hearing loss, that means hearing and understanding what is being said becomes much more difficult and speech reading (lipreading) others becomes impossible.

The problem of masking is not easily solved. The workaround you choose will depend on your degree of hearing loss and whether you depend on speech reading. Some possible workarounds include:

- Speech-to-text apps such as AVA, Live Transcribe, Microsoft Translate and Otter.ai
- Assistive listening devices
- Clear window face masks
- White board or pen and paper

**For more information, visit the following:**

- COVID-19: Considerations for Wearing Masks—CDC
- Proposed Settlement Reached in ADA Face Mask Lawsuit-Hearing Loss Association of America
- Face masks make it harder to hear, but amplification can help—Innovation in Augmented Listening Technology—University of Illinois at Urbana-Champaign

*Lise Hamlin is director of public policy at HLAA. Reach out to her at lhamlin@hearingloss.org.*

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BY AMANDA WATSON

**H**HLAA is very excited to once again host an in-person Convention in beautiful Tampa, Florida! You are sure to be busy at the HLA A 2022 Convention with all the exhibitors to see in the exhibit hall, a riveting opening session, more than 30 workshops to attend, demo presentations, social events, a symposium presented by top researchers in the field—and more!

When you aren't inside enjoying the Convention, head outside to explore and experience Tampa. Step outside the JW Marriott's doors and walk along the Tampa Riverwalk. From there you can explore the restaurants at the new Sparkman Wharf area or go a little further and see the marine life at the Florida Aquarium. Head over to Ybor City and experience the authentic Cuban cuisine that Tampa is famous for. Enjoy these attractions and so many more museums, restaurants and sights when you come for the HLA A 2022 Convention.

### JW Marriott Tampa Water Street

510 Water Street  
Tampa, FL, 33602  
813-221-4950

Don't forget to reserve a room at the JW Marriott Tampa Water Street. All workshops, plenary sessions and the exhibit hall will be located in the hotel. Don't forget to mention the HLA A room block when you call to make a reservation or book online at <https://book.passkey.com/go/2022HearingLossConvention>.



**Register now!** *Early bird rate available until March 4.* HLA A 2022 Convention registration is OPEN and we have made it quicker and easier than ever using the Cvent platform! To register online just go to <https://www.hearingloss.org/programs-events/convention/hlaa-2022-convention-registration/>.

If you are a state organization or chapter leader, veteran, or speaker please register offline by downloading your corresponding form and filling it out. You can find the forms with further instructions on how to submit them on the registration page of the HLA A website.

### Vaccination Requirement for HLA A 2022

All participants at the in-person HLA A 2022 Convention at the JW Marriott Tampa Water Street, whether a presenter, attendee, exhibitor, staff, guest, or vendor, will be required to be fully vaccinated. Participants must provide proof of vaccination to register for the in-person event. For information on providing your proof of vaccination information visit the Convention web page.

### Opening Session

We are excited to welcome our keynote speaker for the HLA A 2022 Convention, Achin Bhowmik, Ph.D. Dr. Bhowmik is the chief technology officer and executive vice president of engineering at Starkey. He is responsible for the organization's technology strategy, global research, product development and engineering departments.



# HLAA 2022 Convention is Back In-Person!



# SCHEDULE OF EVENTS

## Exhibit Hall Grand Opening

Thursday, June 23  
11 a.m. - 1 p.m. ET

## Opening Session

Thursday, June 23  
4:30 - 6 p.m. ET

## Welcome Back Bash

Thursday, June 23  
7 - 9 p.m. ET

## Research Symposium— Cochlear Implants:

### *What's new? What's next?*

Friday, June 24  
8:30 - 11 a.m. ET

## HLAA Awards Ceremony & Reception

Friday, June 24  
5:30 - 7:30 p.m. ET

## Florida Walk4Hearing

Saturday, June 25  
8 - 10:30 a.m. ET

## An Evening with the Filmmakers— “We Hear You | Now Hear Us”

Saturday, June 25  
4:30 - 6 p.m.

Prior to joining Starkey, Dr. Bhowmik served as vice president and general manager of the Perceptual Computing Group at Intel Corporation. There, he was responsible for the R&D, engineering, operations and businesses in the areas of 3D sensing and interactive computing, computer vision and artificial intelligence, autonomous robots and drones and immersive virtual and merged reality devices.

We are sure that Dr. Bhowmik's expertise on emerging technologies will benefit the hearing loss community.

## 2022 HLAA Research Symposium

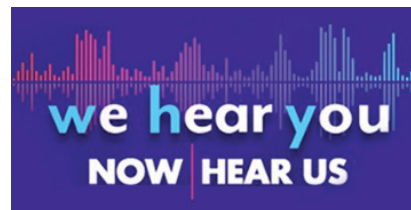
### *Cochlear Implants: What's new? What's next?*

The first cochlear implants (CIs) were introduced in the 1970s, but the technology remains relatively poorly understood and underused in the hearing loss community. This year's Research Symposium will address the knowledge gap around CIs, explore who is a potential candidate for implantation, what's involved in treatment and how CI technology has changed and will change further in the future. A mix of clinical information and science, this session is a “must attend” for anyone with hearing loss.

The 2022 Research Symposium is supported, in part, by a grant from the National Institute on Deafness and Other Communication Disorders, National Institutes of Health (Award Number R13DC017913).

## An Evening with the Filmmakers— “We Hear You | Now Hear Us”

“We Hear You” is an award-winning documentary about hearing loss, the invisible disability that impacts 430 million people worldwide, including 48 million in the United States alone. By shining a light on the hearing loss experience, it strives to build awareness, community and a more inclusive world for all.



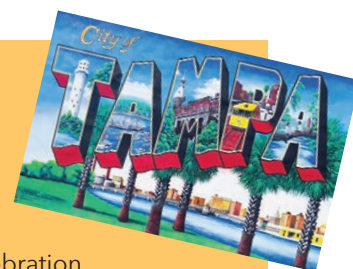
This session will be the first of its kind for HLAA, bringing the typical film festival experience directly to the HLAA community. We will screen the 45-minute film and then open the floor to the community for an additional 45 minutes of questions for the filmmakers. Together we can help raise awareness, create change and improve lives for people with hearing loss.

## Rocky & Ahme Stone Endowment Scholarship Deadline – February 25

If you are an HLAA member and have never been to an HLAA Convention before then you are eligible to apply for a scholarship (you may also nominate another HLAA member). See more details and the application/nomination form on the Convention web page.

## Fun Facts About Tampa

- Since 1904, pirates sail their ship into Tampa every year during Gasparilla. The whole city dresses in costume and attends the celebration.
- The Cuban sandwich was invented in Tampa.
- The famous restaurant, the Columbia, is the oldest restaurant in Florida and the biggest Spanish restaurant in the world.
- Tampa has the longest continuous sidewalk that is 4.5 miles long and called the Bayshore Boulevard. This path runs entirely along the water.
- Tampa's temperature has never exceeded 99 degrees. It has felt hotter with the heat index but has never gone over 100 degrees.



For more than 20 years I enjoyed a career as a professional musician in New York City, playing trombone and euphonium in many orchestras, including, among others, the Brooklyn Philharmonic, Orpheus Chamber Orchestra and on two occasions, the New York Philharmonic. I also played in more than 20 Broadway shows and with numerous ballet and dance companies. I got my first hearing aids in 1991 when my hearing loss was relatively mild, with thresholds around 30dB. At that time, I only wore my hearing aids in private because of the not-unreasonable fear that I would lose work if people knew I had a hearing loss, although my loss was not yet affecting my ability to perform.

By 1997, with my hearing loss progressing, it had become more important to me to hear people speaking than to continue a career which had provided a great deal of satisfaction for decades. I made the difficult decision to retire from my performing career and to reveal my hearing loss. Although my skills on my instruments remained intact, I was no longer confident in my ability to play in an ensemble. I didn't know if I was in tune with the other musicians and had trouble understanding the conductor when he spoke to the orchestra. Playing trombone in an orchestra can be stressful when everything is working, but when my hearing was failing, it exacerbated the stress, and my nerves told me it was time to quit.

I did not want to compromise the quality of the ensembles in which I played, nor did I want my career

to be tarnished by poor performances on important concerts in major venues such as Carnegie Hall or the Brooklyn Academy of Music. I did play a few low-pressure jobs in the following few years—park concerts and children's concerts—and played with some frequency until 2006. After 2008, I almost never picked up an instrument. Inspired by Betty Hauck's presentation at the 2019 HLAA Convention in Rochester, I tried to practice a few times, but the results were not good, and I didn't continue. When you have done something at a high level for a long time, it is not fun to do it badly.

My hearing continued to deteriorate, with my thresholds increasing by about 1.5 dB per year. Because that annual change is imperceptible, I had grown accustomed to the gradual increase in hearing loss. But over a period of 30 years, the change was huge. When two audiologists told me that I had reached the limits of the benefits that hearing aids could provide, I decided to get a cochlear implant (CI) in one ear but postponed the actual surgery until March 2021 when I was fully vaccinated against COVID-19. I am happy to report that testing shows that my sentence comprehension has enormously improved with the CI, a finding that matches the improvement in communication my family has noticed.

This past July, an email arrived announcing a week-long adult band camp at the Interlochen Center for the Arts in Michigan. In high school, I spent four wonderful summers in Interlochen, at what was then called the National Music Camp. Those summers gave me the

# Music Camp with a Hearing Aid and a Cochlear Implant

BY JON TAYLOR

experience to become a professional musician without attending a conservatory, or even taking a music course. For decades I have wanted to visit the camp, but never got around to it. The email about band camp motivated me to practice euphonium a little. I was also curious about how playing would sound through my recent cochlear implant.

The first day I tried to play was a disaster. I could barely make a note come out. It was a little better the next day and improved for a couple of days. However, my lip started to hurt and swell. Putting ice on my lip after practicing helped, but I probably would have given up if I didn't have camp as motivation. Gradually, I got into good enough shape to play in an amateur band and found that my endurance was sufficient to make it through four hours of daily rehearsal at camp.

So, on August 9, after about 13 years of rarely picking up an instrument, followed by three weeks of practicing, I boarded a plane to Traverse City, the airport closest to Interlochen, to attend the camp. The seat next to me was occupied by my euphonium, an instrument which is essentially a tenor tuba. As a seat mate, a euphonium is ideal. It didn't talk much, didn't have bad breath and didn't climb over me to go to the bathroom.

Although it is occasionally called for in symphony orchestras, the euphonium is primarily a band instrument. Outside of the military bands, it is impossible to earn a living playing the euphonium exclusively. As a result, I mostly played trombone throughout my professional career, though some of my best engagements, such as a concert with the New York Philharmonic and a recording with the Empire Brass Quintet, were on euphonium. I started on the euphonium when I was eight years old because my arms were too short to play trombone. At age 10, I took up the trombone which became my primary instrument, but euphonium remains my first love because of its rich, dark sound. If you are going to play in a concert band, as I did at camp, the euphonium parts are better than the trombone parts. And if you can't hear pitches and intonation well, valves are better than a slide. The other reason I started practicing euphonium rather than trombone is that it was on a lower shelf in the closet.

The music program my audiologist installed on my new CI warmed up the sound, but didn't improve

**In a way, when I was at band camp,  
I was like those college kids  
out on the field, trying to play  
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I was not hoping to be noticed  
and make it to the big leagues.  
Like the other band members,  
I was satisfied with simply  
enjoying the moment.**

my ability to hear pitch, which was already poor before I got my implant. With respect to pitch perception, the 22 electrodes in the CI cannot equal the approximately 12,000 outer hair cells in the cochlea, each tuned to individual frequencies. The truth is that I have no idea if I was playing in tune, but my neighbors in the band didn't complain. I did have a difficult time hearing the conductor who was possibly 30-35 feet away in a large auditorium. As a result, when he would say, for example, start at letter B, I had no idea what he had said and tried to

figure out, not always successfully, where they were when they started to play. I was not hiding my hearing loss. When I applied for the band, I informed them about my hearing loss. I always wore my devices, and sometimes turned to one of the players next to me to ask what the conductor had said. In retrospect, I should have advocated for myself by asking him to speak more loudly, but part of me was still reticent about calling attention to my hearing difficulties. Maybe next year.

I was pleased to discover that at this point in my life, my competitive juices were not flowing. At camp, I did not meet anyone else who had had a professional career as a musician, and I didn't care where I sat in the section or who played the solos. I had nothing to prove. Although I certainly wanted to play well, the stakes were lower than when I played professionally, and I was no longer striving for perfection.

I was curious about who the other campers would be. It turned out the median age was probably mid-60s, with a few younger people age 20 to 40. At 71, I was by no means the oldest, with several in their 80s. Almost 40% of the 70 band members live in Michigan, with the remainder spread over 17 other states. It was an interesting group of people, with very little in common except for their love of playing. The first person I met was a percussionist from South Carolina who had been a camper in 1947. In his youth, he had been an Air Force pilot who flew over Vietnam in the 1960s. Several other band members had also attended the camp decades earlier, including a still-terrific trumpet player who went to law school and has retired after being a judge in Michigan, and a trombonist, about 80 years old, who does research on lupus at USC. The other euphonium players were a retired post office worker who had played in a Navy



Me and the Pit Spitter (I am the one on the left.)

Below: My euphonium



band; a carpenter who works in residential construction, who also has taught high school physics, calculus and statistics; and a high school band director with a master's degree from Michigan State University.

All in all, I had a great time at camp. Because I had a career as a musician, I have been accused of being creative. The truth is that I was never creative but was good at my craft. And part of what I enjoyed about playing was the visceral sensation of producing beautiful sounds. Even with impaired hearing, it felt good to be doing that again, and to be part of an ensemble.

To cap off the terrific week, after the concert I went to a Northwoods League semi-pro baseball game,

in part because I was intrigued by the name of the local semipro team, the Traverse City Pit Spitters, who defeated the Kokomo Jack Rabbits 9-2. As someone who spent considerable time playing in Broadway and ballet pits in NYC, surrounded by brass players' spit, the name meant something different to me than to the residents of Traverse City, which calls itself the Cherry Capital of the world.

In a way, when I was at band camp, I was like those college kids out on the field, trying to play as well as I could, but with an important exception. I was not hoping to be noticed and make it to the major leagues. Like the other band members, I was satisfied with simply enjoying the moment. **HL**

*During his career, Jon Taylor performed with the Brooklyn Philharmonic, NY Philharmonic, Orpheus Chamber Ensemble, Empire Brass Quintet and many Broadway shows and dance companies.*

*He has a bachelor's degree from Harvard College, a master's degree from Yale University and a Ph.D. in developmental psychology from The Graduate Center, The City University of New York (CUNY). His analysis of the admissions test to NYC's elite public high schools was published in the Journal of Women and Minorities in Science and Engineering and discussed in the NY Times and the Wall Street Journal.*

*He is president of the HLAA New York City chapter and on the board of the NYS Association. He can be reached at jontaylor5819@gmail.com.*



## HLAA Mission Circle

A monthly online giving program offering convenience while supporting work for people with hearing loss.

[hearingloss.org/make-an-impact](https://hearingloss.org/make-an-impact)

# Joan Kleinrock Leaves a Legacy of Support in HLAA Chapters

BY CARLA BEYER-SMOLIN

I have to dedicate this chapter column to the memory of Joan Kleinrock, who passed away in November. Joan was one of the original volunteers who helped Founder Rocky Stone develop and grow Self Help for Hard of Hearing People, Inc. (SHHH), known today as the Hearing Loss Association of America (HLAA). Joan became the first chapter development coordinator for SHHH and helped build the chapter network that we know today. When Joan retired after 17 years, Rocky Stone said, “Her place in HLAA history is unrivaled.”

I had the pleasure of working with Joan after I graduated from college. I interviewed with Rocky Stone and was hired to be Joan’s assistant chapter coordinator. It was such a learning experience and a very exciting time. Joan had worked hard to grow the chapter network and I remember at one point in time, SHHH had over 250 chapters and groups. She loved meeting new people and making local connections that would nurture the development of chapters that would eventually help people with hearing loss in their communities. Joan was a great listener, teacher and coach. She encouraged personal growth to all, passing on the support and care that she received when she joined HLAA.

Joan enthusiastically believed in the support that HLAA could provide people with hearing loss, and truly cared about the HLAA Chapter network. After retiring, she was ever curious and thirsty for news from HLAA, and always asked, “How are chapters doing?” “How is Barbara and the staff?”

*Joan was a lovely, generous lady, a second mother to me and a caring and sage advisor for chapter development. She will be missed very much. I pray we can carry on her passion and enthusiasm for HLAA and see soaring heights to HLAA’s efforts.* —Carla Beyer-Smolín, HLAA Chapter and Membership Coordinator

These were her words in her final column when she retired and they bear repeating again:

*“Thank you for the privilege you gave to me. I shall miss you, but am confident that you will continue to do your part as individuals and as HLAA Chapter organizations to make the world a better place for people with hearing loss.”* —Joan Kleinrock

**J**oan Carlucci Kleinrock, 86, passed away peacefully at Suburban Hospital in Bethesda, Maryland, on November 9, 2021, after being admitted for pneumonia. Joan, along with Rocky Stone, built the HLAA Chapter network we know today. She started as a volunteer with Founder Rocky Stone after seeing a newspaper notice about a new organization called Self Help for Hard of Hearing People, known today as the Hearing Loss Association of America. She literally knocked on the door of the Stone family home and, like so many people, she needed information and support, which up until 1979 nothing was available.

Joan wrote in a memoir about Rocky Stone:

*I was searching for meaningful work that could make a difference. Out of the blue, I saw a newspaper notice of an initial meeting of a chapter for an organization for people with hearing loss. I’d never had anyone to share my hearing loss with. The founder Howard Stone would be there. I could barely wait for that day to come.*

*The greatness of HLAA today and the differences we now enjoy as people with hearing loss is largely because SHHH/HLAA, founded and influenced by Rocky, continues to grow through empowered people. Today, Rocky would remind us that we did this together, and together we will move on. Personally, I am still in awe of the privileged opportunity I had to be a small part of making a difference.*

Joan began as a volunteer in 1980 in the Stone family home in Bethesda. In 1982, she completed the first “chapter manual” to assist 25 chapters. SHHH held its convention in Chicago and a large number of attendees returned home committed to starting chapters, so by November, SHHH had 122 chapters. In 1983, Joan became one of the early board members, and later became one of the first paid staff until her retirement in 1998. Joan continued as the HLAA professional adviser for chapter development until her death.

Joan traveled the country finding people who wanted to start chapters, people hungry for information and to meet others with hearing loss. She wrote



thousands of letters, later emails, and influenced the peer-to-peer support network we know today. She kept a map of the United States in her office and when a new group or chapter formed, she excitedly put another pin on the map. We can say Joan put SHHH/HLAA Chapters on the map! Her contribution to our organization was formidable.

In 1992 she received the Rocky Stone Humanitarian Award given to a former board member. This prestigious award, established in 1990 by the Board of Trustees (now known as Board of Directors), honors an outgoing or past trustee for his or her extraordinary contributions toward the furtherance of the objectives and personal exemplification of the philosophy envisioned by Howard E. Stone, founder.

Joan formed personal connections wherever she went. She probably knew more members than any other staff with the exception of Rocky. Long-time member and former board member, Wayne Roorda, from Voorhees, New Jersey shared this:

*When I saw a blurb in the NAD Broadcaster paper about a new organization for hard of hearing people and that the dues was \$7, I immediately sent in a check and wrote on the note, "Where have you been?" Joan was working in Rocky Stone's family room "office" and wrote back to me, "Where have you been?" That started my introduction to Joan and her family. So many memories and stories.*

Joan is survived by two sons and two grandsons. If you would like to send a card, please address it to her eldest son, Jeffrey Kleinrock and Family, 9708 Parkwood Drive Bethesda, MD 20814.

Contributions can be made to HLAA in Joan's memory to the Hearing Loss Association of America. **HL**



Full time volunteers who helped SHHH start from 1981 to 1985—left to right: Pat Clickener, Joan Kleinrock, Rocky Stone and Carol Lingley

## Tributes to Joan Kleinrock

*I'm so saddened to hear about Joan. When we first started our chapter, she was my source of motivation, inspiration, education and excitement. I can still remember opening the mailbox at the end of our driveway and being excited beyond words to see a handwritten letter from Joan Kleinrock....I can feel that thrill as if it were yesterday.*

*I remember her hosting informal board gatherings at her home after an all-day board meeting at the national office on Battery Lane. We would sit around on her living room floor and talk for hours.*

*I would always search for her at Conventions and what fun we would have, reminiscing about those early days of SHHH. I have held her in my daily prayers since hearing of her son passing on.... I can imagine they've had a wonderful reunion today. Thanks so much for writing this beautiful tribute to her...I will miss her, indeed. – Sue Miller, NY*

*Please accept my donation in memory of Joan Kleinrock, a great friend. – Molly Corum, FL*

*She was precious! Gave so much of her time to help build this amazing organization. She will be missed! – Kim Brownen, TX*

*She was my first connection to SHHH back in the day. Lovely lady. – Teri Gerson Wathen, TX*

*A lot of memories now. Joan was a dedicated believer in helping everyone with hearing loss. My condolences to her family. When I think of my own journey through my communication issues Joan will be there, never forgotten. – Joan Black, NC*

*So sad to get this news. Joan was such a good person and a great asset to HLAA causes and its members. – Paul Silverman, MD*

*So sorry for her loss and my condolences to her family. I will miss her. Rest in peace. – David Sherman, PA*

*Thanks for letting me know. Meg and I are so saddened that another hero of ours is gone. She will live in our memories forever along with Rocky. – Joe Duarte, VA (after receiving an email notice from HLAA)*

*Joan and I worked together on the first one-day New Jersey State Conference on December 7, 1991, where 125 people attended. I was lucky to have her help, knowledge and support. – Sandy Spekman, NJ/MA*

*Joan was a wonderful lady. I corresponded with her for many years and met her at my first convention in Bethesda [1989]. Enclosed is a chapter donation (Charlotte Chapter, NC) in her memory and my personal check is in her memory. Thanks for all you do. – Myra White, NC*

*On behalf of the New York City Chapter, I am enclosing a check in memory of our beloved Joan. She was a great help to me when I was named secretary more than 30 years ago! She was never too busy to answer my questions about organizing and keeping things orderly in our then-infant SHHH Chapter. SHHH/HLAA truly owed her our sincerest gratitude. May she rest in peace.*

– New York City Chapter via Mary Fredericks

# BOOK NOOK

REVIEW BY LARRY HERBERT

## Padapillo

by Valerie James Abbott  
(KWE Publishing, LLC, May 2021)



Valerie James Abbott

A perceptive preschool teacher sensed something was amiss in nearly 3-year-old Bridget Abbott's language and speech development, and suggested further investigation by the county's early intervention office. They recommended a hearing screening. It was a pivotal moment for her and her family, as the test revealed that Bridget had late onset hearing loss. It was all the more surprising because she had passed her newborn screening for hearing loss, and there was no history of hearing loss in her family.

The family began to notice things about Bridget's behavior—her non-responsiveness to the doorbell and telephone, as well as her frequent requests for mom, dad and sister to repeat themselves. Bridget began wearing hearing aids while the family learned to support her cognitive, emotional and social development.

Bridget's experience inspired her mother, Valerie James Abbott, to write *Padapillo*, a children's book incorporating her daughter's journey through the eyes

of her older sister, Mary Clare. Abbott is "a parent-advocate, a champion for early hearing detection and intervention programs and an active promoter of parent-to-parent support organizations. She is a graduate of Hollins College and has served on boards and state councils that are dedicated to serving families of children who are deaf or have hearing loss."

The story begins when Bridget points out a green caterpillar to her sister, calling it a "padapillo." Mary Clare is mystified by her sister's verbal description, but attributes it to her "weirdness," in a typical older sibling put-down. After Bridget's preschool teacher's intervention, Mary Clare accompanies her to the ENT office, but skeptically views the audiologist's exam and conclusions. But when she conducts her own hearing tests at home with Bridget, it turns out the "weird" sister does have hearing loss.

Abbott is taken aback with the diagnosis—both thankful for the evaluation and concerned for Bridget's

## Late Onset Hearing Loss Awareness Week

BY LARRY HERBERT

The Olive Osmond Hearing Fund was founded in 2010 by Justin Osmond, son of recording artist and producer Merrill Osmond. The organization is devoted to improving and providing access to educational and musical opportunities and hearing technology to children who are deaf or have hearing loss, and their generosity has touched the lives of families across the U.S, the U.K. and more.

In May 2021, Justin and the Olive Osmond Hearing Fund partnered with parent-advocate and author Valerie James Abbott to establish Late Onset Hearing Loss Awareness Week, shining a spotlight on a population of young children who often go unnoticed and undiagnosed because they passed the newborn hearing screen, but developed hearing loss later on. The campaign's main goal of improving the lives of children with postnatal hearing loss through earlier identification aligns with their foundation's mission of helping children who are deaf and have hearing loss become all they can be through effective identification, services, support and resources.

For more information about the Olive Osmond Hearing Fund, visit [www.hearingfund.org](http://www.hearingfund.org) and <https://www.facebook.com/HearingFund>.



future. Panic ensues, as well as guilt about missing Bridget's developmental delay clues. She begins researching and reaching out to other parents of children with late onset hearing loss, and to support groups and organizations.

Parents and pediatric audiologists will want to share this empathetic story with their late deafened children and patients. Abbott describes Bridget taking a hearing test while sitting on her lap, being fitted for ear molds with "gook" squirted in her ears, and the inevitable anxiety and fear as Bridget hears sounds she has not experienced before—causing her to remove her instruments and retreat to the audiologist's office. She also includes Bridget's acceptance by her classmates as she returns to school with her pink hearing aids.

Abbott's quest for support and information was far ranging, and *Padapillo* includes a list of 16 organizations or agencies which offer help to parents of late deafened children. When I interviewed her, she highlighted two in particular: "the Olive Osmond Hearing Fund (see sidebar on page 39) and the National Center for Hearing Assessment and Management (NCHAM). It's headquartered at Utah State University and is funded by the Health Resources and Services Administration at the U.S. Department of Health and Human Services."

Abbott and Justin Osmond of the Olive Osmond Hearing Fund have established a Late Onset Hearing Loss Awareness Week held May 4-10 annually, in the hopes of bringing further interest on this issue to the attention of parents, audiologists and the greater hearing loss community.

The story of *Padapillo* ends with Bridget pointing out a butterfly to her sister—a symbolic observation that shows Bridget's growth and emergence as a young girl coming to terms with her hearing loss. Today Bridget is the typical teenager, immersed in high school life, occasionally rolling her eyes at her mother and definitely engaging in selective hearing with her—according to her mother. **HL**



*Larry Herbert is retired and lives in Richmond, VA. A member of the Greater Richmond Chapter of the Hearing Loss Association of America, he currently leads efforts to promote hearing loops in the community. He is a graduate of the University of Virginia and can be reached at [lawrence.herbert@gmail.com](mailto:lawrence.herbert@gmail.com).*



# 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/chapters-state-orgs/find-a-chapter/](http://hearingloss.org/chapters-state-orgs/find-a-chapter/). For more information, including how to start a chapter, contact Carla Beyer-Smolin, HLAA chapter and membership coordinator, at [cbeyer-smolin@hearingloss.org](mailto:cbeyer-smolin@hearingloss.org).

#### *Sign Up for the Free Chapter Blogs for All the News from National*

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# An Interventional Audiology Program: Improving Access, Raising Awareness

BY CATHERINE V. PALMER

Interventional Audiology includes identifying and treating hearing loss when hearing loss is not the primary concern of the patient or health care provider, but is expected to negatively impact health outcomes. Interventional Audiology happens outside of the audiology clinic and within busy outpatient and inpatient settings.

Undetected and untreated hearing loss have negative consequences for patients, families, health care providers and health care systems, resulting in excess medical spending due to adverse events, hospitalization and readmission due to misunderstood communication. Seniors with untreated hearing loss are less satisfied with their health care experience. Over 60% of older adults have hearing loss, yet only about 18% use personal amplification, resulting in the majority of aging individuals being faced with effortful or inaccurate communication during health care visits which present high stress, complex listening environments.

A number of national guidelines for inpatient and outpatient settings include recommendations for hearing screening and attention to adequate communication for older adults. We developed our Interventional Audiology program to address the problem of untreated hearing loss negatively impacting health care interactions in inpatient, outpatient, home health and senior living environments. Currently, we use three models to achieve the goal of identifying and treating hearing loss during health care interactions: 1) embedding an audiology clinic within another setting, 2) assistants providing hearing screening and non-custom amplifiers in interprofessional clinics, and 3) providing and supporting the use of non-custom amplifiers in diverse health care settings.

## Embedded Audiology Clinics

*EAR* (Embedded Audiology Resources, 2016-present). We have embedded audiology services into two Geriatric Outpatient Clinics. In this way, individuals can be seen for their audiological needs in the same clinic where they see their geriatrician. There are non-custom amplifiers in each treatment room to be used during health care interactions. Individuals can then have a full hearing evaluation and treatment recommendations in the same clinic if

warranted. Interestingly, a number of individuals purchase the simple amplifier for their hearing needs once they have experienced it in the clinic.

*HearCARE* (Hearing Communication Assistance for Resident Engagement, 2015-present). We provide audiology services once per month in the 33 University of Pittsburgh Medical Center (UPMC) Senior Living communities (Independent, Assisted Living/Personal Care, and Skilled Nursing). In addition, we have introduced the services of a Communication Facilitator in several locations. This is an individual who supports communication throughout the community by providing supportive services (e.g., managing hearing aids, providing non-custom amplifiers, supporting group communication and managing phone and television use).

## Assistants Screening Hearing and Providing Amplifiers

Our audiology assistants are part of the interprofessional teams in the UPMC outpatient Trauma, Survivorship and Perioperative clinics. All of these clinics allow patients to interact with multiple providers to coordinate care. In these clinics, the audiology assistant is first in the room to screen hearing and provide amplifiers when needed to support communication through the day. As part of the perioperative clinic (pre-surgery rehab), it is noted in the patient record that an amplifier was used, allowing for an amplifier to be provided through pre-op and post-op care.

## Supporting the Use of Non-Custom Amplifiers

*UHEAR* (UPMC Hearing Education and Amplification for Recovery, 1988-present). In our inpatient program we provide non-custom amplifiers to any patient identified as having untreated hearing loss. The inpatient takes the amplifier home or on to rehab upon discharge.

*IHEAR* (Interprofessional Help Encouraging Auditory Rehabilitation). We train and support other professionals in hearing screening and/or non-custom amplification provision. An example of this type of program includes our work with 167 home health rehabilitation specialists who provide amplifiers during home health

# Teaming Up with Audiology

BY JONET VACSULKA

interactions (2018-present). Observations in the home make these providers very aware of hearing ability.

We track the relationship between the answer to “Do you think you have hearing loss?” with the results of the hearing screenings and find consistently that fewer than 50% of individuals correctly self-identify that they have impactful hearing loss as defined by the World Health Organization; (this is more than a mild hearing loss.) In addition, untreated hearing loss may be mis-identified as cognitive decline. Although individuals with more severe hearing loss will be identified, individuals with mild to moderate hearing loss will often go unidentified without a screening program in place.

Our interventional audiology models are designed to be overseen by audiologists who specialize in hearing and communication and are largely implemented with extenders (audiology assistants) who are supervised by audiologists. There certainly is room for other models, but we feel strongly that the involvement of audiology supports appropriate screening protocols and recommendations, as well as identifying efficacious amplifiers for use in these situations. **HL**

*Catherine Palmer, Ph.D., is professor in the department of communication science and disorders at the University of Pittsburgh and serves as the director of audiology for the University of Pittsburgh Medical Center (UPMC) Integrated Health System. Dr. Palmer conducts research in the areas of auditory learning post hearing aid fitting, the relationship between hearing, cognitive health and health outcomes and matching technology to individual needs. Dr. Palmer serves as editor-in-chief of seminars in hearing and served as the president of the American Academy of Audiology in 2019-2020.*



Patients with brain tumors come to our clinic for radiation treatment. This type of treatment can last from a few hours to the majority of the day, and includes important communication throughout the treatment. These patients experience conscious sedation, meaning that they are awake and are being provided with instructions, and may have questions throughout the process. We identify individuals who may not be hearing easily through family and patient report and our own observation. If hearing is creating a barrier for communication, we provide a non-custom amplifier. Even individuals who use hearing aids have to remove them during some of the procedures, so using the non-custom amplifiers helps these individuals as well. The amplifiers allow us to obtain consent, provide directions and answer questions without having to raise our voices to communicate with patients.

We introduce amplification use by saying, “You’ll be getting a lot of information today and I think using an amplifier will make this easier for you.” The amplifier makes communication easier for everyone.

Teaming up with audiology has enhanced our ability to provide patient-centered care. One man comes to mind who had a very difficult diagnosis and was barely participating as he started his day with us. We provided him with an amplifier and his eyes lit up, he was amazed that he could hear. We sent him home with the amplifier so he could spend the time he had communicating on his own terms, hearing and answering questions himself.

*Jonet Vacsulka, RN, BSN is a clinician in the UPMC Gamma Knife Center and in this role coordinates activities as well as provides direct clinical care. Jonet has a history of hearing loss and uses personal amplification. This gives her insight into the needs and concerns of patients with hearing loss and has made her very supportive of the work in Interventional Audiology. She is acutely aware of the need to provide patients with a device to assist with hearing and communication in the medical setting.*



## News and Notes

### HLAA Communication Access in Health Care Program Projects:

Participation in sessions at American Speech-Language-Hearing Association Annual Convention, November 2021

- Research Symposium: Engaging Diverse Stakeholders in Achieving Equitable Healthcare for Persons With Communication Disabilities (coordinated by Disability Equity Collaborative)
- Advocating for Medical Communication Access for Adults With Hearing Loss (panel presentation)

Meeting with Association of American Medical Colleges (AAMC) telehealth equity competencies team, October 2021

Creation of Constituent Call to Action:

- Call for communication access stories related to telehealth experiences. (Please share your anecdotes about telehealth experiences by emailing the Communication Access in Health Care program at [healthcareaccess@hearingloss.org](mailto:healthcareaccess@hearingloss.org).)



Left to right: Peggy Ellertsen; Nicholas Reed, Ph.D.; Joseph Montano, Au.D.; Toni Iacolucci

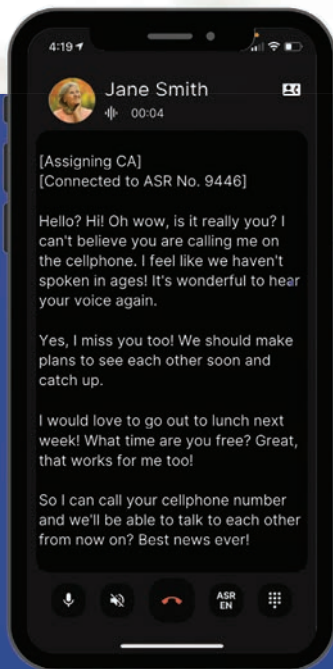


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