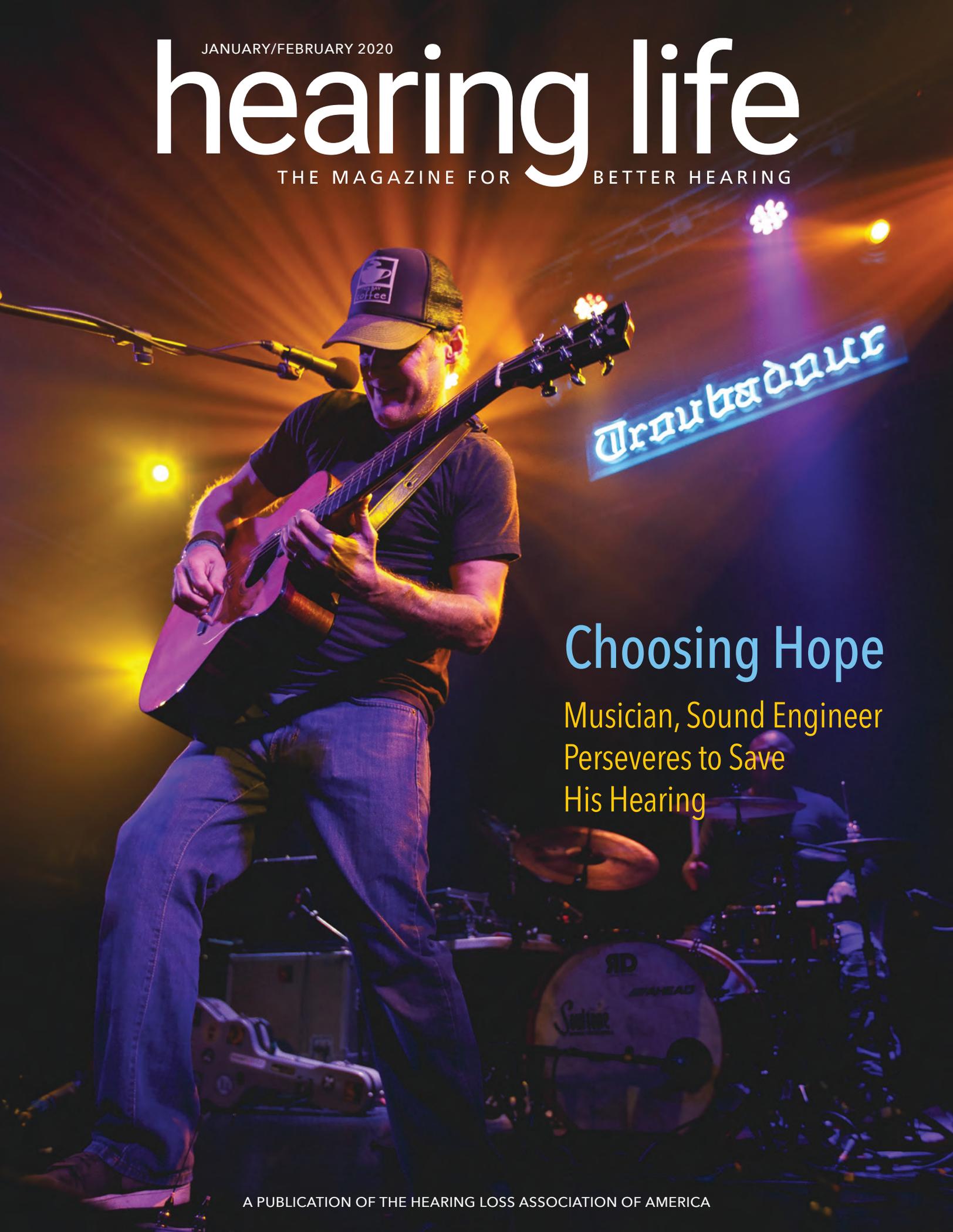


JANUARY/FEBRUARY 2020

hearing life

THE MAGAZINE FOR BETTER HEARING



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Musician, Sound Engineer
Perseveres to Save
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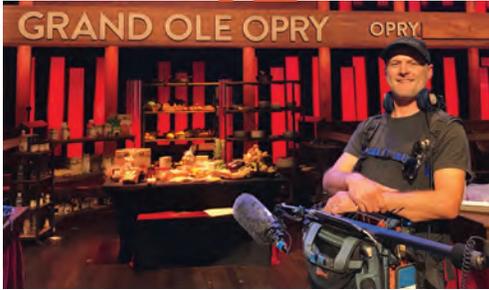
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The Arts

This issue of *Hearing Life* focuses on the role that the arts play in our lives. For people with hearing loss, the arts can offer a path for greater self-discovery and expression. But they're also an eloquent means for advancing awareness, understanding and empathy. Beautifully stated by French author André Maurois, "Art is an effort to create, beside the real world, a more humane world." We hope the pages of this issue provide a welcome glimpse of the transformative power that the arts can play in our own lives, in enhancing the vitality of our communities, and in our greater understanding of the world and each other.

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Cover photo by Reid Murphy.

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Executive Director
- Fabia D’Arienzo
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- Lise Hamlin
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David Gayle, Hollace Goodman

Hearing Loss Association of America

7910 Woodmont Ave., Suite 1200
Bethesda, MD 20814
301.657.2248 Voice
301.913.9413 Fax

Graphic Design by Cindy Dyer
cindydyerdesign.com

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Barbara at the 2019 HLAA Wisconsin State Association Conference, sporting a scarf to celebrate her favorite team for the "get acquainted tailgate party."

The HLAA mission is to open the world of communication to people with hearing loss through information, education, support and advocacy.

The HLAA Mission Is Fully Alive!

BY BARBARA KELLEY

“Welcome to the frozen tundra!” were the words I heard when I landed in Appleton, Wisconsin, last November. I was greeted by Julie Olson, longtime member, former chair of the HLAA Board, and current co-chair—along with Christine Klessig—of the HLAA Fox Valley Chapter. Wisconsin might be known for its cheese, the Green Bay Packers and bitterly cold climes, but it’s also the land of warm hospitality from HLAA members working in their state and communities to shine the light on hearing loss.

I had the honor of speaking at the 2019 HLAA Wisconsin State Association Conference on Nov. 16 with the theme “Shining New Light on Hearing Loss!” This conference gave Wisconsin people the opportunity to attend an event with a rich educational program, including updates on Wisconsin state legislation affecting people with hearing loss; learn from exhibits by companies and service providers; have some fun; and be in a communication accessible place where it’s OK not to hear well. Events like this are especially important because not everyone has the means or time to attend HLAA National Conventions. Thank you, Wisconsin members, for work well done.

The “Wisconsin effect” is coast to coast in all of our HLAA Chapters and State Organizations. My trip to Wisconsin, and any time I meet our chapters on their turf, brings home to me how the HLAA mission is fully alive anywhere HLAA is part of the local fiber. HLAA Chapter members welcome people in their local communities who want to learn, give support, and advocate for the basic human right of access to life’s offerings.

HLAA Chapters come in many flavors and sizes. But all are volunteer-led, and all carry out the HLAA mission. Thank you to the volunteers who lead, pitch in, take on major endeavors, help with the Walk4Hearing, and hold true as the unconflicted voice for people with hearing loss. Don’t ever underestimate your contribution to *your* organization. We have a lot of people to reach to let them know they’re not alone in their hearing loss. And we can’t do it without the help of chapters.

Don’t ever underestimate your contribution to your organization. We have a lot of people to reach to let them know they’re not alone in their hearing loss. And we can’t do it without the help of chapters.

A Look at 2020

Here are some issues we'll be keeping our eyes on in the new year:

- **Medicare:** Medicare coverage for hearing aids is still on the table on Capitol Hill. HLAA has visited several Congressional offices and met with colleagues who also are working on this issue. If there comes a time when we need you to write letters, we'll call on you. Our constituents who speak up are powerful. Medicare coverage is important for all the good reasons we know, but it also sets precedent for other insurance plans to follow.
- **Over-the-counter hearing aids:** The Food and Drug Administration must meet its deadline early this year for putting out proposed rules for over-the-counter hearing aids. HLAA will comment on those rules to ensure safety, efficacy, proper labeling and connectivity.
- **Captioning:** You answered our survey on realtime captioning on local news, and that has carried a lot of weight with the Federal Communications Commission (FCC). We've filed a petition on live captioning with the FCC and will be working to ensure quality captioning in local news markets. Captioned telephone service also is on the radar of the FCC, HLAA, and Internet Protocol Captioned Telephone Service (IP CTS) providers. We'll work to ensure quality standards of this service and access to those who need it.
- **Hearing loops:** The HLAA Get in the Hearing Loop Program volunteers will continue advocating for hearing loops in public places and other establishments such as places of worship. There's legislation in several states addressing hearing loops and telecoils. We'll support those chapters and state organizations however we can.
- **Cellphones:** HLAA is representing people with hearing loss on the hearing aid compatible (HAC) cellphone task force that was directed by FCC in 2016. Together with the wireless industry, hearing aid companies and others, we're working toward the goal of achieving 100% HAC wireless phones. The goal is to deliver recommendations to the FCC by Dec. 31, 2022.

- **Technology partnerships:** We continue our long-time relationship with the Deaf/Hard of Hearing Technology Rehabilitation Engineering Research Center at Gallaudet University, with HLAA as a subcontractor for a new grant-funded, five-year technology project.

This year's HLAA events—such as the Walk4Hearing in 20 cities in the spring and fall, and the HLAA2020 Convention in New Orleans in June—will bring thousands of people together, all behind the mission of information, education, support and advocacy. And I should add, these also are fun, motivating events.

We'll keep you updated in the pages of *Hearing Life*, on hearingloss.org, and in the free, online *Hearing Life e-News*. You can sign up for the free e-news online and find an HLAA Chapter on hearingloss.org.

Spread the word and stay close to us as we welcome 2020. **HL**

Barbara Kelley is executive director of HLAA. Reach her at bkelly@hearingloss.org. Follow her on Twitter @Bkelley_HLAA.

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The Near Future

BY RICHARD EINHORN

Imagine that you're out for dinner in a noisy restaurant. With a few taps on your smartphone, the mics on your friends' phones get wirelessly connected to your hearing aids or cochlear implants. As a result, a great deal of the background noise

immediately disappears, and you can more easily follow the conversation than if you were simply listening normally over your hearing instruments.

After dinner, you go to see the latest movie. As you enter the theater, your phone alerts you that a wireless listening system is available and asks if you'd like to connect. You tap "Yes," and your hearing instruments are instantly

connected directly to the film's soundtrack. All the distracting ambience in the theater disappears.

After the movie, you go to a sports bar to watch a ballgame. Once again, you connect your friends' phones so you can better hear them. Another friend with hearing loss but with a different brand of hearing aids joins you at the bar. With another tap on your phone's app, she joins your network of friends. Then, you tap one more time, and your hearing aids get connected to the sound of the bar's TV. You can hear your friends, the commentaries on the game—and very little background noise.

For those of us who love going out but get frustrated because our hearing loss often makes it nearly impossible to hear anything clearly, this scenario sounds close to sheer fantasy. But because of a just-released update to Bluetooth—which defines the way that consumer headphones, car audio systems, and other sound-enabled devices wirelessly connect to each other—this dream will start to become a reality within the next few years. And because Bluetooth is open and not proprietary, assistive listening devices—like remote mics or TV streamers—will be universal, not tied to a single manufacturer.

One of our primary goals at HLAA is for the stigma associated with hearing loss to wither away. The new Bluetooth specification will help do exactly that.

I recently spoke to Nick Hunn, chair of the Bluetooth Hearing Aid Workgroup within the Bluetooth Special Interest Group—a member-only industry association that oversees the development of Bluetooth standards and the licensing of the Bluetooth technologies and trademarks to device manufacturers.

Nick told me that it was the need for better connectivity to hearing devices that informed the new Bluetooth specifications. Although Bluetooth was originally developed for consumer devices, people without hearing loss also have wanted Bluetooth features that are quite similar to those we need for assistive listening. And with the new Bluetooth specification, manufacturers now can build consumer devices with the advanced features that we all want.

In other words, the new Bluetooth embodies the basic principle of "universal design." Curb cuts on sidewalks—which are critical for people in wheelchairs—also are extremely useful for people making deliveries, not to mention parents navigating baby strollers. Similarly, what we think of as assistive listening technology will now be fully integrated into the lifestyle of the general public and will find many consumer uses. Consumers will use the new "Bluetooth Broadcast Audio"—as of this writing, the name wasn't yet finalized—to share music with friends over their earbuds or listen to movies in the language of their choice. And yes, people without hearing loss are likely to use their consumer earbuds to better hear their friends in restaurants—just like we will.

One of our primary goals at HLAA is for the stigma associated with hearing loss to wither away. The new Bluetooth will help do exactly that. By enabling low-cost installation of wireless technology similar to Wi-Fi but specialized for audio, consumers will have cool new capabilities to play with once the new Bluetooth appears in devices. And in many more places, we—people with hearing loss—will have the advanced assistive listening technology we need. **HL**

Richard Einhorn is chair of the HLAA Board of Directors and lives in New York City. Reach him at chairperson@hearingloss.org.



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 or email GITHLinfo@hearingloss.org.

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BY FABIA D'ARIENZO

Choosing Hope

Musician, Sound Engineer Perseveres to Save His Hearing

For Bruce Beacom and his young son, those chimes built into the start-up program of Bruce's hearing aids have become part of a daily ritual. When Bruce's 5-year-old son wakes up each morning, he enters his father's room afloat with excitement and asks his daddy to put his hearing aids in. Bruce then puts in his hearing aids and turns them on.

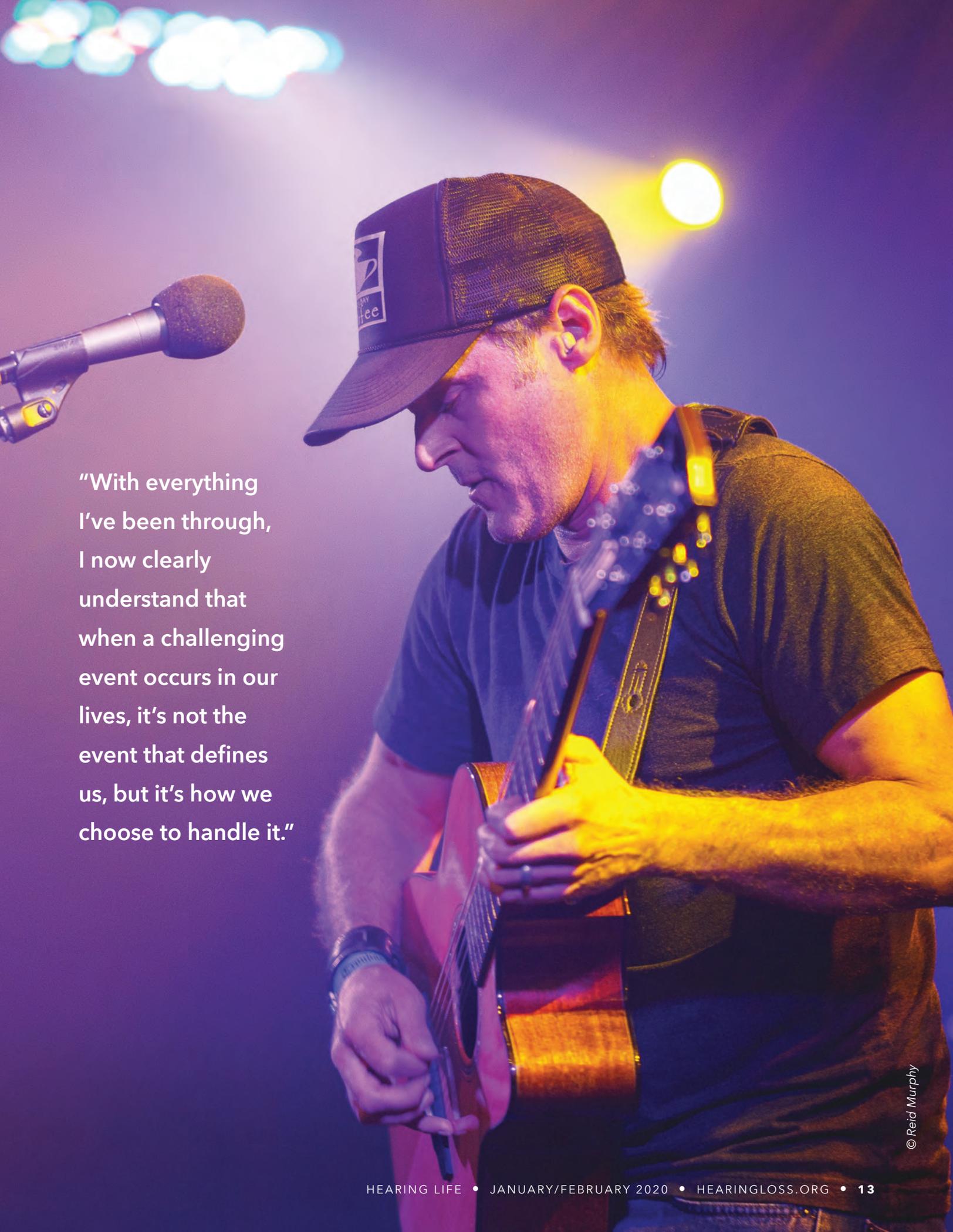
Together, father and son patiently count down with fingers in the air—five, four, three, two, one—as the chimes sound off in Bruce's ears and his hearing aids kick into gear. The instant they reach zero, Bruce's son showers his dad in a symphony of words, conveying each and every pressing thought he wants to share.

It's almost ironic how such treasured moments as these can come from some of life's most trying twists. For Bruce, these are moments he'll never take for granted—because at one time, they seemed unimaginable.

Bruce is a singer, songwriter and guitarist. He and his band have performed at such iconic venues as the Troubadour, the House of Blues in Los Angeles, the Viper Room, and The Roxy Theatre. He's also a professional sound engineer who's been awarded honorary certificates three times from the Academy of Television Arts & Sciences for his contributions as a sound mixer to *The Amazing Race*—CBS's Emmy Award-winning reality competition program. He's worked on other notable shows as a sound engineer, including Bravo's *Top Chef*, ABC's *American Idol*, *The Bachelor* and *Bachelor in Paradise*, and HBO's *Project Greenlight*, season 4—produced by Matt Damon and Ben Affleck—for which Bruce was nominated for an Emmy for sound mixing. He also works the Red Carpet at the Oscars.

Bruce manages all this with the help of hearing aids, which bring his hearing up to 80%. One of the four programmed channels of Bruce's hearing aids is specifically tailored for sound mixing and making music.

Bruce Beacom live at the legendary Troubadour in West Hollywood, Saturday, Apr. 1, 2017.



“With everything I’ve been through, I now clearly understand that when a challenging event occurs in our lives, it’s not the event that defines us, but it’s how we choose to handle it.”

© Reid Murphy

It's an impressive list of accomplishments. But for Bruce, getting to this point was a hard-fought, often frightening—and at times, seemingly bleak—battle.

A Sharp Turn in the Road

When he was in his late 20s, Bruce began to experience “a horrible and deafening” ringing in his ears that steadily worsened. It was “like an internal siren that was so loud, it was incapacitating.”

By the time he was 33, he had 95% hearing loss—and he didn't know why. Desperately trying to save his hearing, Bruce went to numerous medical appointments and was tested for one thing after another.

Still, he was never given a clear explanation as to why his hearing was disintegrating. From doctors simply saying it was severe tinnitus, to significant misdiagnoses of the underlying cause, the entire experience was discouraging.

For an aspiring musician earning his living as a sound engineer, the loss of hearing was devastating enough. But just shy of the time that his hearing began to take a turn, Bruce had proposed to his now wife, actress Holly Reiser—and the uncertainty of his situation made it even more stressful for both of them.

The Window of Hope

It took Bruce more than three years of searching for answers. But with Holly's constant support, he finally

found them—starting with one life-changing visit to audiologist Sol Marghzar, whom Holly serendipitously found through an online search in 2003.

The couple went to the appointment with the intention of getting new hearing aids for Bruce—as the pair he'd been using for the past 18 months were no longer adequate for his still-declining hearing. In fact, Bruce was struggling to such an extent that throughout the audiology appointment, Holly had to repeat everything that was said directly into Bruce's ear—just so he could follow the conversation.

When Dr. Marghzar said he wasn't willing to sell Bruce any hearing aids until he had surgery, Bruce and Holly were more than a bit stunned.

Dr. Marghzar urged Bruce to go to the House Clinic in Los Angeles to be assessed for a special surgery. He strongly suspected that otosclerosis was the cause of Bruce's hearing loss. He wanted Bruce to undergo some blood tests and CT scans to confirm the diagnosis.

It was the first time that any medical professional had mentioned the word otosclerosis to Bruce. In fact, it was the first time Bruce had ever heard of it. He had no knowledge of any family history of the inherited disease.

Bruce recalls the exchange vividly: “That was the exact moment when Holly and I felt like there was finally hope. It was the first time that I didn't feel so lost.”

An abnormal overgrowth of bone in the middle ear is associated with otosclerosis, and it's what causes the



© Ezequiel Casares

Bruce working on Spotify's streaming content *Music Happens Here*.



© Kirk Donovan

Bruce working at the 89th Oscars Red Carpet ceremony, February 2017.

mechanical problems that lead to loss of hearing in people with the condition. More specifically, the build-up of extra bone stops one of the three tiny bones in the middle ear from vibrating like it should, limiting the transmission of sound from the middle to the inner ear, from which signals are sent along the auditory nerve to the brain where they're interpreted for meaning. The stapes is the bone in the middle ear that's affected by otosclerosis.

Recognizing the urgency of Bruce's situation—and empathetic to Bruce and Holly's exhaustion, given all the confounding information that they'd already been given in their search for an accurate diagnosis—Dr. Marghzar personally put Bruce in touch with surgeon William H. Slattery, III, and was able to get him scheduled for an expedited appointment.

Although he wouldn't sell Bruce any hearing aids that day, Dr. Marghzar gladly loaned him a high-quality pair that would allow Bruce to continue to work and communicate in his daily life.

Rebuilding: 2004–2008

Over the course of the next several years—and under the attentive care of Dr. Slattery at the House Clinic in Los Angeles—Bruce underwent four special surgeries called stapedectomies to restore as much of his hearing as possible. By removing the diseased bone in the middle ear that causes the conductive hearing loss associated with otosclerosis—and by replacing it with prosthetic bone—the specialized procedure provides a new mechanism for transmitting sound waves to the inner ear.



© Austin Sipes

Bruce working on *Top Chef*, season 16, at the Grand Ole Opry in Nashville, TN.

While most cases of otosclerosis require just one surgery for each ear, Bruce needed four, two for each ear.

In total, the surgeries spanned the course of roughly four years. With each surgery, Bruce and Holly put their wedding on hold.

Today, Bruce has titanium prosthetic bones in both his ears. As a result, 60% of his hearing was restored. With hearing aids fitted by Dr. Marghzar, he's been able to gain an additional 20% of his hearing ability—for about 80% in both ears.

Making the Diagnosis

Bruce is emphatic that finding the right hearing care professional made all the difference in his ability to appropriately address his hearing loss. It took him more than three years to get an accurate diagnosis.

“Dr. Marghzar cared more than anyone else I'd seen previously,” Bruce says. “He dug deeper and identified the otosclerosis behind my hearing loss. That turned my ‘losing battle’ into an ‘uphill battle’—and eventually, into ‘a battle to be won.’”

When *Hearing Life* asked Dr. Marghzar what made him suspect that Bruce had otosclerosis, he explained it like this:

Otosclerosis causes a conductive hearing loss—which means there's a physical problem that stops sound from moving through the middle ear. Patients with conductive hearing loss can hear better through the vibrations of their skull—which are transferred to the inner ear directly—than they do by the normal propagation of sound through the ear. Bruce could hear the sounds when I placed the bone conductor on his mastoid bone much louder than when I put it next to his ear. Therefore, I was looking for a conductive hearing loss. In patients with otosclerosis, the hallmark in audiologic diagnosis is the presence of a notch in bone conduction thresholds at 2 kHz. This is called the Carhart notch.



Hanging On

In the early years of his hearing loss, Bruce was able to keep working as a sound engineer: “I’d raise my headphone volume to feel the vibration and pay close attention to the visual readings on the sound VU meters—which showed me if I had good sound levels.”

When it comes to his music, Bruce says, “I’ve adapted by playing my acoustic guitar as an electric. I can feel the acoustic vibrate, which puts me more in tune with the instrument.”

Embracing the Future

At last, in 2008, Bruce and Holly had a beautiful wedding among supportive family and friends. Their son was born in 2014.

Now, the simple act of communicating is a blessing that Bruce thankfully counts each day.

Yet, he also acknowledges that he'll always have to remain vigilant in his efforts to preserve his hearing. From the very start, Bruce made a personal pledge to choose hope—and to never let his hearing loss stop him from living his life as fully as he can, or to allow it to deter him from pursuing his dreams.

Over the years, Bruce has had to learn to be an advocate for himself. In sharing his story, he hopes to be an advocate for others.

He wants people of all ages to understand the value of hearing. But he also wants people of all hearing abilities to understand the value of people. Undoubtedly, losing your hearing is a difficult and trying experience. But having hearing loss doesn't define an individual.

Above all, Bruce hopes that his story will help others find the courage and determination they'll need when faced with their own challenges.

And if, by chance, you ever ask Bruce what single word has the sweetest sound, his answer will be quick: "Daddy." **HL**

© David Cook



From the jungles of the South Pacific to train stations in India, Bruce has traveled the world mixing and recording audio for reality-TV programs like *The Amazing Race* and *Top Chef*. Today, he continues to carve out a name for himself in an industry that relies heavily on sound.

"I'm amazed at how Bruce maintains his career in sound and continues to play his music in spite of his daily struggles to hear. It's a testament to his perseverance and positive outlook. I hope his story is an inspiration to others." – Holly Beacom

Platinum Pennies

In late 2002, Bruce started recording his second album, *Platinum Pennies*. A year later, he was almost completely deaf. But Bruce persevered—and he prevailed. In 2009, the record was released.

*"Platinum Pennies is a testament of what it simply means to hear. During the early stages of its recording, I was diagnosed with a genetic hearing disorder known as otosclerosis. Over the next few years, I underwent four ear surgeries on separate occasions to try to save my hearing. There were many times when it appeared as if I'd never hear again. So I prayed, went under the blade, continued to write, continued to play, then yet again, went under the blade—three more times. To this very day, I pray. I've got prosthetic bones in both ears and have to wear hearing aids. But I can still hear because of it, and I'm forever thankful. *Platinum Pennies* is an oxymoron and a metaphor for life. Platinum is the most precious metal and pennies are the least valued monetary unit. Never overlook the smallest things in life—often they become the most valuable. Turn those pennies into platinum, y'all!" —Bruce Beacom*

When you listen to Bruce's music, you can hear an eclectic mix of rock, blues, punk, funk and jazz—all influenced by his growing up in the Washington, D.C., area, and having developed his style as a musician in both New York City and Los Angeles. Bruce is now working on a third record.



Live at the Viper Room, Sunday, June 30, 2019.

© Darren Bunkley

"I'm beyond thankful that God gave me the strength to persevere and not become a victim of the circumstances that had befallen me—but to overcome them."



The Beacom Family

The Curtains Go Up: Live Theaters Become Accessible

BY JOHN WALDO

Live theater captioning has been around for almost 20 years. But while available, not all theaters provide it. Even when provided, it's typically been available only on a limited basis during the run of a show. A court case filed by advocates in St. Louis, represented by attorney John Waldo, has the potential to radically change the way theaters present—and how people with hearing loss experience live theater captioning. In this guest column, John explains the significance of the case. —*Lise Hamlin*

A recent federal court decision is going to permit those of us with hearing loss to enjoy live theater at our convenience. In the first case dealing with live theater captioning, the court declared that the theater must offer captioning for any performance whenever an advance request is made, and may not limit captioning only to specific prescheduled performances. While that ruling imposes a significant new burden on live theaters, developing technologies are making this much more affordable.

The Fabulous Fox Theatre (Fox) in St. Louis, one of the largest live theaters in the country, offers a menu of touring Broadway productions. In 2015, Tina Childress—known to many HLAA members through her frequent convention presentations—requested captioning for the musical *Rent*, which was scheduled a year later. Live theater captioning, like movie captioning, puts the dialogue and lyrics into writing and displays them in sync with the performance.

Fox said it didn't offer captioning and had no plans to do so but would provide an American Sign Language (ASL) interpreter. Childress replied that although she is fluent in ASL, she wanted to enjoy the performance in English, her native language.

In an effort to break that impasse, I wrote Fox and explained their obligations under the Americans with Disabilities Act (ADA). When Fox ignored that letter, we filed a lawsuit in federal court. The HLAA Greater St. Louis Chapter and its former president, Mary Stodden, along with the Association of Late-Deafened Adults (ALDA), joined as plaintiffs. I represented them.



© Matthew Sluka

In the first case dealing with live theater captioning, the court declared that the theater must offer captioning for any performance whenever an advance request is made, and may not limit captioning only to specific prescheduled performances.

After some initial negotiation, Fox agreed to offer captioning—but only for one performance of each production when a request is made. It scheduled captioning for the matinee performance on the second Saturday of each production. Fox wirelessly transmits the captions to tablets, which it furnishes, so the captions are available from every seat.

The one-performance policy was problematic. Not everyone can adjust their schedule to attend on the day when captioning is scheduled. In fact, the Saturday matinee conflicted with the HLAA Chapter meeting time. So we asked Fox why it couldn't offer captioning whenever requested.

We based our argument on the provision of the ADA that prohibits offering people with disabilities a benefit that isn't equal to that provided to other individuals. We noted that fully hearing patrons are able to attend any performance, making it much easier to enjoy theater visits with friends and family, and we argued that people who need captions should have that same flexibility.

The U.S. District Court for the Eastern District of Missouri agreed with us. It ruled that limiting

ability to attend theaters when it works for us.

The Court of Appeals majority agreed with us. In a decision handed down in August, the Court of Appeals affirmed the trial court's ruling on every point. It directed Fox to provide captioning whenever a request is made, but did say that if Fox ever believes that the number of requests does impose an undue burden, it can ask the U.S. District Court for relief. It also directed Fox to pay my fees and reimburse me for the costs incurred, a provision of the ADA that enables attorneys to take these cases at no cost to the client. The decision is available at bit.ly/3537g4f.

We were concerned, of course, about Fox's decision to transmit the captions to tablets, because holding a tablet for the duration of a performance can be uncomfortable for anyone and impossible for some. When we asked Fox to provide some form of support device, the response was that the fire code would prohibit anything of that nature, which might impede evacuation.

Fox did offer to provide a stand that could be used in the wheelchair seats. We questioned whether that would be legally permissible, because there is some case

Because this case was the first live theater case to be decided at the Court of Appeals level, it's essentially the law of the land.

accessibility to specific prescheduled performances did indeed constitute an unequal benefit, and that Fox would need to offer captioning on request unless it could show that doing so would impose an "undue burden"—meaning essentially that the cost would be prohibitive. Because Fox declined to provide any information about its financial resources, we argued that it had waived any "undue burden" argument. Again, the District Court agreed.

Fox appealed to the U.S. Court of Appeals for the 8th Circuit, the level right below the U.S. Supreme Court. Fox argued that the ADA doesn't guarantee people with disabilities an equal outcome, which it contended we were seeking. We stipulated that unless medical science finds a way to completely cure hearing loss, the outcome will never be precisely equal. But we said that the ADA does require that we be given an equal opportunity, which in this context means the

law declaring that wheelchair users can evict nonusers from those seats even if there is nowhere else to sit in the theater. The U.S. District Court disagreed with us on that issue and declared that anyone with a disability should be able to use those seats on an equal basis.

This ruling, which wasn't an issue in the appeal, may end up being fairly important. The regulations implementing the ADA have some detailed requirements about "accessible seating," including, for example, the requirement that those seats remain available until the facility is sold out, the requirement that the user can bring three companions, and favorable rules about ticket pricing. Those regulations have defined "accessible seating" as meaning wheelchair seats, but this ruling from the judge raises at least the possibility that when accommodating a disability requires specific seats, those regulations also should apply.

During the appellate court argument, one of the judges asked why, if Childress is fluent in ASL, Fox didn't satisfy its obligations through its offer of an ASL-interpreted performance. We argued that ASL and English are separate and distinct languages, an argument usually made by ASL users trying to argue that captioning doesn't provide "effective communication" for them. The Court of Appeals picked up on that argument in the appellate opinion, which also can be useful in other contexts.

Because this case was the first live theater case to be decided at the Court of Appeals level, it's essentially the law of the land. On its face, it imposes an onerous burden on all live theaters. At the same time, that burden creates a market for affordable solutions.

This dynamic of judicial action driving innovation is already underway. Even prior to the Fox case, the Broadway theaters, led by the Shubert Organization, were working on a smartphone app called GalaPro that provides captions for every seat and every performance.

As Kyle Wright of Shubert explained at a recent HLAA Convention, the captions are prepared in advance, and the app uses a combination of lighting cues and voice-recognition software not to create the captions, but to display them in sync with the performance. Once a theater installs the necessary equipment, captions can then be offered for any performance of a production. And no advance request is necessary.

The hope is that the Fox decision will incentivize more theaters to invest in technology like this. Not surprisingly, Fox has done so. And GalaPro already is available in theaters around the country presenting productions beyond Broadway shows. But the

expanded use of these technologies needs to continue. We look forward to a time when we can walk into any live theater with no advance notice and know that the performance will be accessible to us through captioning.

It's worth noting that although our particular case dealt only with captioning, the legal requirement for equal benefits and an equal array of choices applies as well to ASL performances and audio-described performances. Similarly, the case dealt with captioning for Broadway-type productions. But the legal principles apply to all types of performances. It's my hope that theaters of all sizes begin to take their legal obligations more seriously without the need for further court action, and that they plan to make all their offerings accessible to everyone with sensory disabilities. **HL**

John Waldo is an attorney whose practice focuses exclusively on systematic advocacy to make public life more accessible for people with hearing loss. He tries to resolve problems through persuasion and education. Through these methods, he's instituted captioning at live theaters in Washington, Oregon and California, and scoreboard captioning at a number of sports stadiums. When persuasion fails, he looks to the courts to implement the benefits and protections of state and federal disability laws. In that connection, he's represented the plaintiffs in a number of cases that ultimately resulted in a federal mandate for closed-captioning at all movie theaters. He lives in Houston and works throughout the country, always at no charge to the client. He welcomes questions and comments at johnfwaldo@hotmail.com.



HLAA Mission Circle

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

hearingloss.org/make-an-impact/donate/



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DO YOU HAVE TROUBLE TELLING WHERE SOUNDS ARE COMING FROM?
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“

Even though I had one good ear, all of the music that I loved and listened to every day was like it was in another room. And I was locked out of that room. Now I can enjoy the feeling of being immersed in music once again.

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Recipient and music lover

About three months after getting my implant, my wife said, You're back to your normal self. I felt that freedom again. It was as much a life-changing, positive experience as losing my hearing was a devastating one. **IT IS A REMARKABLE GIFT.**

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”

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¹ Dillon MT, et al. Effect of Cochlear Implantation on Quality of Life in Adults with Unilateral Hearing Loss. *Audiol Neurotol* 2017;22:259-71.

For information on potential risks and contraindications relating to implantation, please visit www.medel.com/us/isi

HLAA2020
convention

New Orleans Is Calling Your Name

Are you ready—as the locals say—to “pass a good time” in the Big Easy?

BY AMANDA WATSON

Join us for the year’s most communication-accessible gathering for people with hearing loss—our HLAA2020 Convention.

It’s sure to draw you in, keep you engaged, and leave you informed. With the Exhibit Hall, workshops, demo presentations, plenary sessions, social events and Research Symposium all held under one roof at the New Orleans Marriott, your days will be chockful of learning and networking. Then, when it’s time to explore, all you’ll have to do is grab a friend and step outside the hotel for a quick walk to the nearby French Quarter and other fascinating NOLA sights.

Here’s what we have in store for you at the convention—but until then, keep adding to your New Orleans bucket list for a not-to-be-missed adventure!



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Research Symposium: The Latest on Tinnitus Research

Friday, June 19 • 8:30–11 a.m.

HLAA's mission is to open the world of communication to people with hearing loss by providing information, education, support and advocacy. Since 1994, each HLAA Convention has featured a morning-long Research Symposium that covers cutting-edge scientific topics relevant to adults with hearing loss. The sessions are special because they're geared toward educating the hearing loss public about research. "The Latest on Tinnitus Research" is this year's topic. The Symposium will feature talks by top scientists and clinicians who'll tell us what tinnitus is, what causes it, what treatments are available and how to manage it, and what researchers are thinking about in terms of prevention and treatment in the future. The Research Symposium is funded by a grant from the National Institute on Deafness and Other Communication Disorders (NIDCD).

Get Acquainted Party: A Night Out on the Town!

Friday, June 19 • 5:30 p.m.

Sponsored by
CaptionCall



This year's Get Acquainted Party will be held on the Friday night of the convention as we head out to experience New Orleans! The off-site event will be a guaranteed good time with NOLA-style food, drink and entertainment. More information to come.

UPCOMING DEADLINES

Early Bird Registration Deadline

Closes March 2

Haven't registered for the convention yet? The time is now! Register today using the form on page 25, or register online at hearingloss.org to get the early bird rates.

Rocky and Ahme Stone Endowment Scholarship Deadline

Closes February 10

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

SCHEDULE OF EVENTS

Exhibit Hall Grand Opening

Thursday, June 18 • 11 a.m.

Opening Session

Thursday, June 18 • 5–6:30 p.m.

Research Symposium: The Latest on Tinnitus Research

Friday, June 19 • 8:30–11 a.m.

Get Acquainted Party: A Night Out on the Town!

Friday, June 19 • 5:30 p.m.

HLAA2020 Convention Walk4Hearing

Saturday, June 20 • 8–9:30 a.m.

Awards Ceremony and Reception

Saturday, June 20 • 5 p.m.

Stay Up to Date

Stay up to date on HLAA2020 Convention news:

- Subscribe to the HLAA biweekly *Hearing Life e-News*
- Check the Convention page regularly at hearingloss.org/programs-events/convention/
- Like HLAA on Facebook at facebook.com/HearingLossAssociation
- Follow @HLAA on Twitter and use #HLAA2020
- Follow @hearinglossassociation on Instagram



Amanda Watson is the HLAA meeting planner. Reach her at awatson@hearingloss.org.



Attendee Name(s) _____

EARLY BIRD REGISTRATION DEADLINE: **March 2, 2020**

What does a General Package include?

- ✓ Exhibit Hall Grand Opening, Thursday morning, June 18
- ✓ Opening Session, Thursday evening, June 18
- ✓ Research Symposium, *The Latest on Tinnitus Research*, Friday morning, June 19
- ✓ Get Acquainted Party (GAP) – Off-site Event, Friday evening, June 19
- ✓ HLAA2020 Convention Walk4Hearing, Saturday morning, June 20
- ✓ Awards Ceremony and Reception, Saturday evening, June 20
- ✓ Unlimited entry to Exhibit Hall and Socials
- ✓ All workshops, demo presentations and featured speakers

Select your registration package below:

General Package			
<i>FIRST-TIMER must be an HLAA member who has never attended an HLAA Convention in the past. *</i>			
	By 3.2.20	By 5.22.20	On-site
Member Individual	<input type="checkbox"/> \$299	<input type="checkbox"/> \$359	<input type="checkbox"/> \$419
Member Couple	<input type="checkbox"/> \$469	<input type="checkbox"/> \$529	<input type="checkbox"/> \$589
*Member First-Timer	<input type="checkbox"/> \$285	<input type="checkbox"/> \$345	<input type="checkbox"/> \$405
*Member First-Timer Couple	<input type="checkbox"/> \$449	<input type="checkbox"/> \$509	<input type="checkbox"/> \$569
Member Student	<input type="checkbox"/> \$140	<input type="checkbox"/> \$200	<input type="checkbox"/> \$260
Non-Member Student	<input type="checkbox"/> \$175	<input type="checkbox"/> \$235	<input type="checkbox"/> \$295
Non-Member	<input type="checkbox"/> \$345	<input type="checkbox"/> \$405	<input type="checkbox"/> \$465

Daily Packages			
	By 3.2.20	By 5.22.20	On-site
Thursday	<input type="checkbox"/> \$125	<input type="checkbox"/> \$150	<input type="checkbox"/> \$200
Friday (Includes GAP and Off-site Event)	<input type="checkbox"/> \$125	<input type="checkbox"/> \$150	<input type="checkbox"/> \$200
Saturday (Includes Awards Ceremony)	<input type="checkbox"/> \$125	<input type="checkbox"/> \$150	<input type="checkbox"/> \$200

Registration Total: \$ _____

Please RSVP for events included in General Package:

Get Acquainted Party (GAP) / Off-site Event
An Evening in the Big Easy!
Friday, June 19

Free!

Yes # of Tickets: _____
 No

Awards Ceremony and Reception
Saturday, June 20

Free!

Yes # of Tickets: _____
 No

Those who are **not registered** for the convention and wish to attend the above special events:
Additional tickets:

Get Acquainted Party: #tickets _____ @ \$30/per person = \$ _____

Awards Ceremony and Reception: # tickets _____ @ \$30/per person = \$ _____

Tickets Total: \$ _____

Dietary Needs

Primary Attendee: Vegetarian Low Sodium Diabetic Gluten Free
Second Attendee: Vegetarian Low Sodium Diabetic Gluten Free

Are you a young adult (ages 18-30)?

Yes No

Are you a Veteran?

Yes No

Membership for NEW Veteran Members

COMPLIMENTARY one-year Regular and Lifetime Digital Membership

Communication Access at HLAA2020

HLAA will continue to employ realtime captioning during every plenary session and workshop in addition to hearing loops in all rooms. Sign language interpretation is available during plenary sessions and **by request** for workshops. All requests must be sent to convention@hearingloss.org by **May 22, 2020**. Please see the Convention page for more information.

Annual Membership Options

New Renewal

Individual \$45 Couple/Family \$55 Professional \$80 Nonprofit \$80

Individual \$35 (digital only) Student \$25 (digital only/enclose copy of student I.D.)

Would you like to make a contribution?

Contributions help support the information, education, support, and advocacy efforts of HLAA throughout the year. Donors who contribute to the Convention will be listed in the *Convention Program & Exhibit Guide* if received by April 15, 2020.

Membership total	\$
Registration total	\$
Tickets total	\$
Contribution	\$
PAYMENT TOTAL	\$

Registration Information (please type or print clearly)

Primary Registrant (Name as it will appear on badge)		Secondary Registrant (Name as it will appear on badge)		
Address		City	State	Zip
Email		Phone / Cell Number		

Payment Information

Check: make payable to *Hearing Loss Association of America*

Credit Card: American Express Discover Master Card Visa

Card Number		Expiration Date MM/YY	Security Code	
Cardholder's Name		Cardholder's Signature		
Address		City	State	Zip

Billing Address (must be associated with credit card used)

Mail form and payment to:

Hearing Loss Association of America
7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814

Or fax form to:

301.913.9413

Questions? Call or email us at:

convention@hearingloss.org

Phone 301.657.2248

CANCELLATION POLICY

The following policy applies to refunds of registration fees:

- Cancellation on/or before **March 2, 2020**: Refund = full amount of registration fees and event tickets less a \$50 cancellation fee.
- Cancellation between **March 3 and April 30, 2020**: Refund = 75% of registration fees and event tickets.
- Cancellation between **May 1 and May 22, 2020**: Refund = 50% of registration fees and event tickets.
- **No refunds will be honored after May 22, 2020.**
- **Cancellation must be received in writing.**
- Cancellation date will be determined by USPS postmark or email receipt date.

Hollywood and Hearing Loss: What Four Contemporary Films Say About Us

BY NAN E. JOHNSON

Films that feature characters who are either deaf or have hearing loss shape perceptions and influence culture. It's therefore critically important that the stories about people with hearing loss—real or fictional—be true to life.

A quick look at four contemporary films provides a snapshot of where we are today in how people with hearing loss are depicted in the entertainment industry.

***Wonderstruck*, a 2017 drama and mystery film**

In *Wonderstruck*, we meet Rose—played by Millicent Simmonds—in 1927. She's 12 years old, deaf from birth, doesn't speak orally, and doesn't know American Sign Language (ASL).

Rose's mother—played by Julianne Moore—is silent movie actress Lillian Mayhew and is divorced from Rose's father. Lillian's career requires her to be away often and for long periods of time. Both of Rose's parents are guilty of child neglect, which intensifies Rose's sense of isolation.

Rose decides to run away from her father's mansion in Hoboken, New Jersey, by taking the ferry to New York City. She wants to see her mother perform in a play there. But when Rose shows up at a rehearsal, her mother scuttles her off into a locked dressing room. Rose escapes through the transom and finds her way to the American Museum of Natural History where her much older brother, Walter—played by Cory Michael Smith—works.

Walter takes Rose into his permanent custody and enrolls her in a school for the deaf in Manhattan where she learns ASL instead of speechreading and oral English—both of which her father had insisted upon.

Fifty years later, we meet 12-year-old Ben—played by Oakes Fegley—who lives with his single mother in rural Gunflint, Minnesota. Ben begs his mother for information about his father. But she replies that she'll talk about it at the right time. When Ben's mother dies in a car wreck, he knows he's on his own to learn who his father is.

Ben finds a copy of a book titled *Wonderstruck* in his mother's belongings. Inside is a bookmark with a handwritten message from Danny, who pledges to wait for her. The bookmark is from Kincaid Books, with the store's phone number and New York City address. Thinking that Danny may be his father, Ben dials the phone number during a thunderstorm. Lightning strikes through the phone line and deafens Ben in both ears.

Undeterred, Ben catches a bus for New York City. Having just lost his hearing and being a stranger to the big city make him vulnerable. He's robbed of all his money shortly after arriving. But Jamie, a hearing boy of similar age, is kind and helps Ben, who ultimately finds his way to Kincaid Books. There, he meets a deaf woman named Rose and a hearing man named Walter. Rose can't speak orally, and Ben doesn't know ASL. She writes him a note asking if his name is Ben. He asks how Rose knows his name, and Walter translates the question into ASL for her. As the movie progresses, Rose reveals that she's Ben's grandmother. At last, Ben has a family.

In real life, it's implausible that Ben would lose his hearing yet still survive the lightning strike as he did. The audience is asked to believe that the electrical current traveled through the phone line and across his brain from his telephone ear to the other ear without killing or leaving him with brain damage.

***A Quiet Place*, a 2018 horror and science fiction film**

Millicent Simmonds appears again in this 2018 horror film as Regan, a cochlear implant recipient, which Millicent is in real life. She's a lead character in this film about monsters destroying the earth. The monsters can't see, but they have extremely keen hearing. Regan's family must help her, and everyone else, refrain from making any noises that would attract the monsters.

Regan suffers feedback from her cochlear implant processor. They believe that the shrill noise endangers her entire family. But Regan saves herself and others by discovering that the noise irritates and weakens the attacking monsters so much that her mother can fatally shoot them with a rifle. Horror films

about deaf characters rarely show deaf females as heroines—but instead, as victims. I applaud this film for defining Regan as a successful defender of her family.

Nevertheless, in real life, Regan’s processor could never have produced the shrill feedback that repels the monsters. Feedback occurs with hearing aids when the earmold doesn’t lock snugly into the ear canal. As a result, amplified sound escapes the ear, is reamplified by the hearing aid, and can be heard by others. A cochlear implant processor isn’t a hearing aid and isn’t worn with an earmold. This technical inaccuracy could’ve been avoided if Regan had been depicted as using a hearing aid instead of having a cochlear implant.

***A Star Is Born*, a 2018 drama and musical film**

This 2018 film differs from *Wonderstruck* and *A Quiet Place* in that it features a man with hearing loss. As a preadolescent, Jackson “Jack” Maine—played by Bradley Cooper—developed tinnitus by frequently putting his head inside the large speaker of an old Victrola record player. The tinnitus set in at the same time that Jack became an adolescent alcoholic, drinking with his father who emotionally rejected him. Jack views the combination of tinnitus, alcoholism and parental rejection as the cause of his chronic depression.

When Jack performs, he refuses to wear the ear plugs that can filter out the extraneous, high-frequency deafening noises from the audience. He meets Ally, a budding songwriter and singer—played by Lady Gaga—whom he mentors, romances and marries.

From early in the relationship, Ally learns that Jack has a hearing loss and is an alcoholic. I credit the screenwriters for the realism of hearing loss. Jack asks Ally to repeat several of her comments to him when they’re having a conversation in a bar. Ally is so starstruck by Jack and grateful for his career help that she discounts his hearing loss and chemical dependency as reasons to avoid their courtship and marriage.

Jack views Ally’s success as a stadium-filling singer and Grammy Award winner as what he could’ve been without his disabilities. He publicly embarrasses her when she wins a major trophy. He’s on the stage when she accepts it, staggers about, and then urinates on himself in front of the TV cameras.

Rather than glory in Ally’s success—that he fostered—Jack sees himself as a liability to her. To save Ally’s career, Jack commits suicide.

***Creed II*, a 2018 sports drama film**

The sequel to the 2015 movie *Creed*, this film updates the story of young World Heavyweight Boxer (WHB) Adonis Creed—played by Michael B. Jordan. Adonis—or Donnie—is the only son of Apollo Creed, another world-famous boxer who died in the boxing ring. Donnie now is challenged by Viktor Drago—played by Florian Munteanu—to defend his WHB title. Viktor is the Russian boxer whose father fatally injured Apollo Creed. Coach Rocky Balboa—played by Sylvester Stallone—urges Donnie to ignore the challenge. But Donnie wants to avenge his father’s death. Clearly, much of the drama is about Donnie trying to do just that.

Another part of the plot involves the people in Donnie’s life: Bianca—played by Tessa Thompson, his stepmother—played by Phylicia Rashad, and Rocky Balboa. Bianca and Donnie have an egalitarian relationship. And she’s anchored by her own career as a singer and composer, and by her loving relationship with Donnie. She wants them to move from Philadelphia, where Donnie has trained with Rocky, to Los Angeles, where he can develop a boxing career with his father’s first coach—and where she can be closer to record labels that could help her sell her songs. Importantly, it will put them within a short drive of Donnie’s stepmother, who can provide them both with moral support.

Bianca has a genetic bilateral hearing loss that’s progressive, and she wears hearing aids. When Bianca proposes that they move to Los Angeles, she reminds Donnie that she doesn’t have much time left to pursue her music career.

The movie realistically portrays Bianca’s hearing loss. When Donnie comes home with a diamond engagement ring and kneels for the proposal, she can’t hear him proposing marriage. Bianca’s in the master bathroom, where she’s just washed her hair. She isn’t wearing her hearing aids—and her back is turned when he kneels and starts proposing through the open bathroom door. When she turns around and sees him kneeling, she realizes something has just happened and asks what it was. The awkward scene illustrates how hearing loss can complicate tender moments in a relationship, when one lover hears normally and the other doesn’t.

When Donnie and Bianca discover that she’s pregnant, she asks him what they’ll do if the child inherits her genetic hearing loss. He replies, “Everything is going to be fine!” I think the message to the audience is that Donnie can accept his wife’s hearing loss and therefore can accept his child’s.

When their baby girl is born, the hospital's audiologist hooks her up to a testing machine. Donnie asks what will prove that the baby can hear. The answer is spikes. But none appear on the computer screen. A tear trickles down Donnie's cheek. But in the final scene, Donnie, Bianca and their infant daughter approach the gravestone of Apollo Creed. Donnie introduces his wife and daughter to Apollo's spirit. Symbolically, the athletic hero accepts the hearing loss of both his wife and child.

Analysis

If movies promote cultural beliefs about people with hearing loss, then what do these four movies invite us to believe?

They say that people with hearing loss are girls and boys, women and men, white and black, and live in both rural and urban settings. The films show that hearing loss can arise from genetic inheritance—Rose, Regan, and Bianca and her daughter; from injury—Ben; or environmental noise—Jack. When genetics cause the hearing loss, the onset of profound deafness can be immediate—Rose, Regan and Bianca's daughter; or gradual—Bianca.

People with hearing loss might prefer to communicate with hearing people exclusively through ASL—like Rose and Regan, or through oral English—like Ben, Jack and Bianca. People with hearing loss can get jobs that support them—like Rose, Jack and Bianca—and can use methods that make the hearing world accessible to them.

The pluralistic images of people with hearing loss in different theatrical settings promote a positive message about people with hearing loss—who are both capable and everywhere.

Making Film Characters True to Life

In the future, filmmakers can pave wider paths toward a new theater that shows characters who are deaf or have a hearing loss in ways that don't stereotype, embarrass, or misrepresent the consequences of hearing loss. There are at least three ways.

1) Cast characters with hearing loss with performers with hearing loss. Filmmakers should always employ actors and actresses with hearing loss to portray characters with hearing loss. Casting people in this way will increase the likelihood that the situations are portrayed realistically and empathetically. It should be easy to find performers with hearing loss by contacting the Department of Art, Communication and Theatre at

Gallaudet University, the National Theatre of the Deaf, and the Deaf West Theatre.

2) Avoid gender stereotypes. Filmmakers should avoid gender stereotypes. Every female character in the four films described has an inherited hearing loss. The male characters, however, experience hearing loss after birth. This gender contrast feeds a long-standing stereotype that genetic conditions are OK for females but make males seem weak and vulnerable. In the future, I want to see more movies with boys and men born with genetic hearing loss—and these movies shouldn't all be about Beethoven.

3) Stop portraying all families affected by hearing loss as dysfunctional. Filmmakers should stop promoting inaccurate stereotypes of families whose members have hearing loss as dysfunctional. In *Wonderstruck*, Rose grows up in a home where her mother is physically absent and her father is emotionally absent. In *A Quiet Place*, Regan feels rejected by her father as a result of her younger brother being killed by one of the monsters, and suffers from guilt. In *A Star Is Born*, Jack grows up in a motherless home and is rejected by his alcoholic father. Only in *Creed II* do we see a functional family in which the sports hero father accepts the hearing loss of both his wife and child.

I look forward to seeing future films that realistically reflect the experiences of people with hearing loss and portray the full extent of their capabilities and lives. I urge filmmakers to show people with hearing loss in mutually supportive relationships with their parents, siblings, spouses and children—because in the real world, those relationships exist. **HL**

Nan E. Johnson, Ph.D., is a professor emerita of sociology at Michigan State University. A bilateral cochlear implant recipient, she served as the first chair of the Status Committee on Persons with Disabilities in Sociology for the American Sociological Association. She recently published Images of an Invisible Disability: Framing Hearing Limitation in Film and Television, which is available on Amazon.com. Contact her at peeledeyespress@gmail.com.



BOOK NOOK

BY RICHARD EINHORN

The Two B's: A Review of *Hearing Beethoven*

Ludwig van Beethoven was one of the world's greatest composers and perhaps the most famous musician to cope openly with a severe hearing loss. In October 2018, Beethoven scholar Robin Wallace published *Hearing Beethoven*, an exploration of Beethoven's efforts to compose as his hearing loss worsened. By skillfully weaving Beethoven's story with that of his own wife, Barbara—who developed a profound hearing loss in both ears—Wallace tells a moving dual story of endurance and adaptation.

Wallace discusses a wide range of coping techniques used by both Beethoven and Barbara, from handwritten “conversation notebooks” to speechreading and aural rehabilitation therapies. He also describes hearing technologies that run the gamut from early 19th century ear trumpets to 21st century cochlear implants and assistive listening devices. Wallace writes eloquently about Barbara's life—she passed away in 2011 due to complications from cancer—and clearly feels her loss deeply. But by closely observing how she responded to her own hearing loss, Wallace also gained unique insight into how Beethoven managed his declining hearing. And large sections of the book describe in fascinating detail how he adapted.

Beethoven

Beethoven was born in 1770 and, at a very early age, gained fame as a talented pianist, improviser and composer. But by 1796, if not earlier, Beethoven was struggling to hear conversations and music. Sounds—especially high-pitched sounds—were distressingly quiet. And loud sounds—including those made by a full orchestra—had become an unbearable experience.

Like many others, Beethoven initially tried to hide his hearing loss. By 1802, when Beethoven was 32 and his hearing loss had become quite severe, he fell into a deep depression. In a letter he wrote to his brothers but never sent, Beethoven poured out his despair and frustration:

Oh, how harshly was I repulsed by the doubly sad experience of my bad hearing, and yet it was impossible for me to say

to men, 'Speak louder, shout, for I am deaf!' Ah, how could I possibly admit such an infirmity in the one sense which should have been more perfect in me than in others, a sense which I once possessed in highest perfection, a perfection such as few surely in my profession enjoy or have enjoyed?

While Beethoven couldn't admit to his hearing loss, his friends noticed, of course, but few said anything. It was an open secret: One of the finest musicians who ever lived could barely hear his own music anymore.

Nevertheless, he persisted. In fact, a surprising amount of Beethoven's greatest music—including the *Fifth Symphony*, the “Moonlight Sonata” and the *Ninth Symphony*—were written after Beethoven's hearing loss became quite severe. His resourcefulness was remarkable.

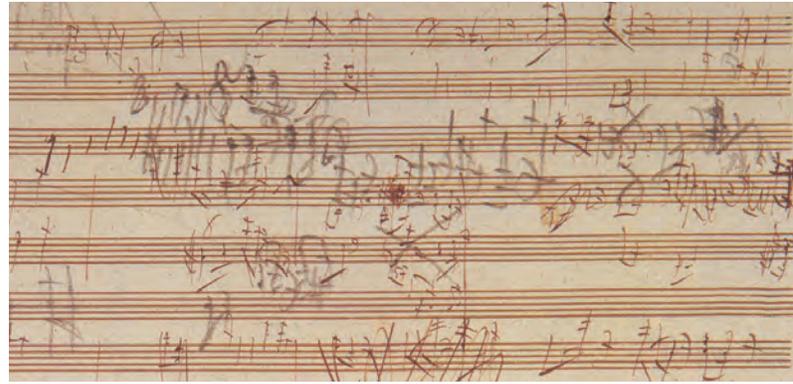
To stay connected with others, Beethoven's visitors would write down what they wanted to say in conversation notebooks to which Beethoven would orally respond. Beethoven also used custom-made ear trumpets to hear speech. As part of his efforts to continue to compose, Beethoven acquired a newer, louder piano. An inventor attached a funnel-shaped resonator that fit over the piano's strings to further focus and amplify the sound.

Wallace debunks the popular myth that Beethoven imagined fully detailed symphonies and concertos in his head while taking long walks in sylvan fields. Although he always carried pen and paper with him to jot down musical ideas, Beethoven was a very hardworking composer, and most of that work was done at home by or near his keyboard.

Beethoven was a great improviser. Like many composers and songwriters today, he'd use his improvisations as starting points. Even up to the end of his life, when he had next to no usable hearing, he continued to play piano, feeling its vibrations more than actually hearing any sound—all the while rapidly scribbling down the ideas he liked in a nearby sketchbook.

But as it got harder to hear, he changed how he composed music, relying increasingly on the way the music looked on the page to organize and inspire more musical ideas. He'd jot down short visual patterns, change

A page from one of Beethoven's sketchbooks. Beneath the apparent chaos lies the first draft of a section from one of his greatest piano sonatas, *Opus 109*.



them, change them again, and change them some more. These short musical fragments—think of the “dit dit dit-daaah” of the *Fifth Symphony*—came to characterize more of his music as he adapted to writing with hearing loss. In order to organize entire movements, Beethoven “created long, complex musical structures visually,” Wallace writes, “with the fragments serving as bricks and mortar to fill in the frame.”

Many otologists believe it was likely that Beethoven's hearing loss was caused by otosclerosis, a middle ear condition.

Once you get used to them, Beethoven's sketches—which at first glance can seem completely illegible, even to musicians—are an endlessly fascinating and even logical record of intense creativity captured literally as it happened. His great excitement is reflected in the sprawling calligraphy and endless corrections, cuts, changes, revisions and reimaginings. When composing, Wallace notes, Beethoven threw, with ferociously focused energy, his body, eyes, great imagination and ears—to the extent that he could still hear—into his music.

Barbara

Many of Wallace's insights into how Beethoven worked and lived were deepened as he watched his wife, Barbara—a nurse and mother—struggle with her own hearing issues. In her early 20s, after the discovery of a malignant brain tumor, she had radiation therapy that gradually affected her hearing. By her late 30s, she was wearing hearing aids. Then, in 2000, when she was 44, she experienced sudden sensorineural hearing loss and lost all the hearing in her right ear.



Musicologist and author Robin Wallace with his wife, Barbara.

Then, in 2003, Wallace recalls: “I heard a sudden desperate cry. ‘I can't hear anything!’ Barbara exclaimed.” The hearing in her remaining ear was suddenly gone. “Searching for something to say, I realized that nothing I could say would make any difference. Spoken words were futile” because Barbara could no longer hear them as she had only “3 percent” of her hearing remaining, and that was in only one ear.

Barbara acquired a Pocketalker. But with almost no hearing left, it was useful only in the most limited circumstances. “Facing a sudden loss of hearing was the most challenging experience of her life, far more challenging than her cancer,” Wallace writes.

Wallace movingly describes how he and Barbara, like Beethoven and his companions more than 100 years earlier, used writing pads and gestures to talk to one another. During the last years of her life, after receiving a cochlear implant, Barbara did regain some ability to understand speech—and even in some instances, music. But it wasn't easy. Barbara struggled with depression and despair. But using all the resources available to her, she still stayed connected to her life.

Wallace observes that while Barbara's life was very different than Beethoven's, her experience with hearing loss was in many ways similar. The technology may have changed since the early 19th century, but hearing loss still remains a considerable human challenge. Barbara, like Beethoven, used whatever resources she could find to hear better. Both B's grew internally in response to their hearing loss.

Beethoven, like Barbara, found the kind of health “that belongs not to a perfectly functioning body but to a vital and unified spirit.” Wallace's book movingly tells that tale with skill and eloquence. **HL**

Richard Einhorn is chair of the HLAA Board of Directors and is a composer whose music is regularly performed around the world.





Improving Your TV Time Enjoyment With Technology

BY BRAD INGRAO

The winter months are a great time to hunker down to watch some good movies and TV shows. But what happens when understanding what's being said is a strain? Audiologist Brad Ingrao explains why TV listening is so often problematic—and offers some practical suggestions.

Hearing aids and cochlear implants are really great at making speech loud enough to hear. In professional audiology circles, we call this audibility. It's the foundation of any hearing technology solution because it tells us if the hearing aid or cochlear implant actually works well for the individual.

The American Academy of Audiology and the American Speech-Language-Hearing Association have specific guidelines to help hearing care professionals ensure that audibility is achieved when a hearing aid is fitted. It's called real ear measurement (REM)—with a more specific type of testing called speech mapping. It allows hearing care professionals to verify that your hearing aids produce the correct amount of sound at the most important frequencies to allow you the best opportunity to understand speech. It's a powerful data set for assessing the benefit of the hearing aid to the individual—but it's also very limited when it comes to TV listening.

Here's why: These tests are performed at a distance of about 3 feet, or 1 meter, in a very quiet room with very little reverberation. That is, there's no echo. That's a very different setting than where most people listen to the TV—which means that the assumption of audibility made by the hearing care professional—based on the tests—isn't valid for all TV listening situations.

Distance, reverberation and background noise are the hearing hazards that pose the greatest challenges for audibility. And distance and reverberation inherently plague TV listening.

TV Watching in the Real World

I used to work in a hearing aid practice with two offices. The average client in office A was retired and living on Social Security benefits, had a modest individual retirement account income, and was living either in a mobile home or a small house of less than 1,000 square feet. The rooms where they watched TV were typically about 8 feet by 10 feet with carpet and an 8-foot ceiling. These clients generally bought entry- or mid-level hearing aids and actually did quite well hearing and understanding the TV.

Clients in office B had average incomes in excess of \$1 million, lived in upscale condos, and typically had large rooms with 13-foot ceilings, and lots of marble or wood. These clients most often bought the premium or highest-tech hearing aids. But ironically, TV listening almost always was a significant problem for them.

There's more technology available today than ever before to make your TV time more relaxing. I encourage you to work with your hearing care professional to ensure that you find the solution that works best for you.

Why would people with better hearing aids hear worse than those with more basic technology? The answer is room acoustics. The office A clients listened to TV under nearly ideal conditions. All three of the greatest hearing hazards were well controlled. By contrast, the more affluent clients in office B were trying to hear speech in the worst possible settings.

The CCC Approach to TV Listening

So how do you address the hearing hazards associated with TV listening? The answer lies in a basic CCC approach: capture, carry, couple. Here's how it works.

1) Capture

If you intercept the TV dialogue before the sound carries into the room, you can overcome all three hearing hazards. The best way to do this is by connecting cables to the TV's audio output. Nowadays, a TV's audio output typically requires either the RCA brand—a pair of round plugs color-coded red and white; or TOSLINK, a standardized optical fiber connector system commonly referred to as an optical cable or an optical audio cable—a plug shaped like a small house.

2) Carry

Once you capture the signal coming from your TV with the RCA or optical cables, you can transfer it across the room to your hearing technology of choice. You can do this using one of these connective technologies:

- **Bluetooth:** This wireless technology connects devices within a range of about 30 feet. For hearing assistance, it often requires a small gateway or intermediary device worn around the neck that captures the signal and sends it to your hearing aid or cochlear implant.
- **2.4 GHz wireless technology:** Built into many modern hearing aids and cochlear implant processors, this wireless technology provides a more robust, longer-range signal of about 60 feet. Made-for-

iPhone functionality for wireless streaming and Bluetooth Low Energy (BLE)—which works like Bluetooth but for applications that don't need large data exchanges—are subsets of 2.4 GHz wireless technology.

- **Infrared wireless:** This technology sends an invisible beam of light from the TV to a receiver that's often worn around the neck. It requires what's called line of sight. That is, there must be an unobstructed straight line of sight between the source—the transmitter—and the receiver. Infrared wireless technologies generally are universal and will work with any hearing device—and even if you don't wear hearing aids at all.
- **Magnetic inductance:** Commonly called hearing loops, this technology sends the TV audio signal through a loop of wire that's placed either around the room or in a small pad under the viewer's seat cushion. To use this option, you'll need an activated telecoil in your hearing aid or cochlear implant processor. (For more information, see "Hearing Loops at Home" in the November/December 2019 issue of *Hearing Life*.)

3) Couple

Now that the signal has been carried, you'll need to get it into your hearing technology of choice, which could be any of the following:

- **Near Field Magnetic Induction (NFMI):** NFMI is a short-range wireless signal that mobile payments like Apple Pay and Google Pay use to let you tap your smartphone at your favorite coffee shop and pay for your pumpkin spice latte. It also lets hearing aids talk to each other to control volume or programs. In some hearing aids, NFMI allows connection to Bluetooth cellphones or TV adapters through an intermediary device. Examples of this are Phonak ComPilot and TV Link, Siemens miniTek and transmitter, Oticon Streamer Pro and ConnectLine TV adapter, and Widex TV-Dex.
- **2.4 GHz:** This is a radio broadcast frequency at which many wireless devices of all kinds operate. Hearing aids with 2.4 GHz technology—such as ReSound LiNX2, 3D and Quattro, Oticon Opn S, Signia Nx, and Phonak Marvel, and Cochlear Americas Nucleus 5 and 6—eliminate the need for a gateway or intermediary device, allowing for direct wireless transmission to TV streamers.

Distance, reverberation and background noise are the hearing hazards that pose the greatest challenges for audibility. And distance and reverberation inherently plague TV listening.

- **Infrared wireless:** Most of these assistive listening systems use earbuds or a headset—like TV Ears or the Sennheiser Set 830-TV assisted listening system. For people whose hearing aid or cochlear implant has an activated telecoil, there are neckloops.
- **Telecoil:** To use the telecoil in a hearing aid or cochlear implant, it must be activated as a separate manual program. But auto-telecoils don't generally work well with hearing loops or neckloops. Auto-telecoils—available in some hearing aids—are for telephone use, and they switch on automatically when you bring the telephone handset near the hearing aid. If your hearing aid has an auto-telecoil, ask your hearing care professional to set up the telecoil program for "public" or "loop" orientation. These are identical in function but are labeled one or the other in the hearing aid programming software. Also ask your hearing care professional to set the program for M+T—for microphone and telecoil. This will enable you to hear people in the room as well as the signal coming from the TV.

There's more technology available today than ever before to make your TV time more relaxing. I encourage you to work with your hearing care professional to ensure that you find the solution that works best for you. Enjoy! **HL**



Brad Ingrao, Au.D., is the audiology team leader at the Watson Clinic in Lakeland, Florida. He's been in clinical practice since 1992 in a variety of settings, including academia, private practice, educational audiology, the Department of Veterans Affairs and the hearing aid industry. He specializes in severe-to-profound hearing loss, including cochlear implants, musicians with hearing loss, and hearing assistive technologies. He's presented at professional and consumer conferences in 48 states and six countries, in both English and American Sign Language. Reach him at brad.ingrao@gmail.com.

VA Provides HLAA With Helpful Information for Veterans

BY LUCILLE B. BECK

Hearing Life recently reached out to the Department of Veterans Affairs (VA) with questions so our readers could better understand the hearing health services it offers and how to access them. VA responded with some very helpful information. Here's what they told us.

What can you tell us about Veterans and hearing loss?

Hearing loss is one of the top three service-connected disabilities among Veterans. It impacts approximately 45% of adults older than 65 in the general population. The most common type of hearing loss among Veterans is high-frequency sensorineural hearing loss, which varies in severity from mild to profound. This type of hearing loss is generally caused by noise exposure, age or both, and it causes difficulty distinguishing sounds or understanding speech. The most common treatment for this hearing loss is hearing aids and/or cochlear implants. Audiologists work with Veterans and their families to improve communication by using advanced technologies and extensive counseling. See bit.ly/2XuxaLt.

How do Veterans know if they're entitled to hearing health care benefits and what those benefits are?

Contact your local VA to determine your eligibility and enroll for VA health care.

All Veterans enrolled in the VA health care system are eligible for comprehensive audiology diagnostic evaluations. And VA offers comprehensive care services to Veterans with hearing loss, tinnitus and balance disorders. Employing more than 1,300 audiologists, VA is the largest employer of audiologists in the U.S.

VA audiologists provide a range of clinic services to our nation's Veterans and service members, including hearing screenings, diagnostic hearing evaluations, hearing aid fittings, aural rehabilitation, vestibular (balance) assessment and rehabilitation, tinnitus assessment and rehabilitation, and ototoxic (drug) monitoring.

To receive hearing services through VA, Veterans must first register at the Health Administration/Enrollment Section of the VA medical center of their choice.

The following documents are usually needed at the time of registration:

- A copy of the Veteran's DD214
- Driver's license
- Health insurance, if available

There are several ways to enroll:

- In person at any VA medical center or clinic
- Online by filling out Form 10-10EZ
- By mailing completed Form 10-10EZ to the VA medical center of choice—be sure to sign the application or it can't be processed for enrollment

Once registered, Veterans may schedule an appointment at the Audiology and Speech Pathology Clinic for an evaluation of their hearing. The audiologist will make a clinical determination on the need for hearing aids and/or other hearing assistive devices. If hearing aids are recommended and fitted, the hearing aids, repairs and future batteries will all be at no charge to the Veteran, as long as they maintain VA eligibility for care. See bit.ly/32XJsgv.

Where should Veterans go for hearing testing?

Contact your local VA facility to set up a consultation with an audiologist who can determine your hearing needs and assist you with obtaining the care you need. Many VA facilities offer teleaudiology for those who live far from a VA medical center. To locate the VA audiology clinic closest to you, see www.accesstopwt.va.gov.

Is there an advocate or person who can help Veterans navigate the system?

Veterans who need help getting care or getting problems resolved can talk to the patient advocate at their VA medical center. VA wants to provide world-class Veteran customer service, and this is just one important way in which we do that!

The Patient Advocacy Program is for all Veterans and their families who receive care at Veterans Health Administration (VHA) facilities and clinics. We want to be sure Veterans have someone to go to with concerns in a timely manner and to help them receive care.

Will Veterans need to prove that their hearing problems are service-connected?

Veterans who believe their hearing loss and/or tinnitus resulted from military service should visit their local VA regional office to apply for disability, or visit va.gov/disability/ to see how to apply online.

Are Veterans entitled to hearing health care benefits even if their hearing problems aren't service-connected?

Veterans who qualify for VA health care can receive hearing care. Veterans who think they have a hearing loss should contact their VA audiology clinic directly for an appointment. VA offers comprehensive care services to Veterans with hearing loss, tinnitus and balance disorders.

If a Veteran's hearing problem is service-connected, is the Veteran entitled to a cochlear implant?

Veterans who think they may benefit from a cochlear implant should contact their local VA audiology department. A VA audiologist will perform a comprehensive audiologic evaluation and, if indicated, recommend a referral to a cochlear implant center to determine cochlear implant candidacy. The Veteran will need to have completed a trial with the best possible hearing aids prior to scheduling the referral. The cochlear implant candidacy evaluation will include tests to determine understanding of speech with hearing aids that have been set to obtain optimal performance.

If test results indicate that the Veteran has poor speech understanding while wearing hearing aids, the audiologist will discuss the benefits and risks of a cochlear implant procedure with the Veteran and the family. If the Veteran decides to proceed, an appointment will be scheduled with an ear surgeon who will check for ear and hearing nerve disorders, and determine whether the Veteran is healthy enough to have surgery.

Are hearing problems of spouses or other dependents covered by VA?

As the spouse or dependent child of a Veteran or service member, that spouse or dependent child may qualify for certain benefits such as health care, life insurance, or money to help pay for school or training. As the survivor of a Veteran or service member, you may qualify for added benefits, including help with burial costs and survivor compensation. If you're caring for a Veteran with disabilities, you may also qualify for support to help you better care for the Veteran—and for yourself. See bit.ly/359rQ2E.

VA provides a Caregiver Support Program called CHAMPVA, which provides health care benefits for the

primary family caregiver. Only the designated primary family caregiver who is without health insurance coverage is eligible for CHAMPVA benefits. Some of the health plans that would make a primary family caregiver ineligible for CHAMPVA benefits include TRICARE, Medicare, Medicaid, commercial health plans through employment, and individual plans. Family members also aren't covered. Only the approved primary family caregiver can be eligible for CHAMPVA health care benefits. Not all services are covered under CHAMPVA. Routine hearing exams and hearing aids aren't covered. See bit.ly/34gtYpp.

Are there VA-sponsored support groups for Veterans with hearing problems?

Local VA facilities may offer support groups. HLAA has established the Veterans Across America Virtual Chapter where members communicate via an online platform called Basecamp and hold monthly meetings complete with captions, using Zoom. See hearingloss.org/Veterans or email chapters@hearingloss.org.

Where can Veterans get additional information?

Veterans can call 844.698.2311. If a TTY is used, dial 711 and then the number shown. Or the Veteran can send specific questions through the webpage iris.custhelp.va.gov/app/ask.

Additional information can be found at VA.gov. A directory of where people can find VA on social media is at va.gov/opa/socialmedia.asp.

For VA Rehabilitation and Prosthetic Services, see bit.ly/2qqUH3N.

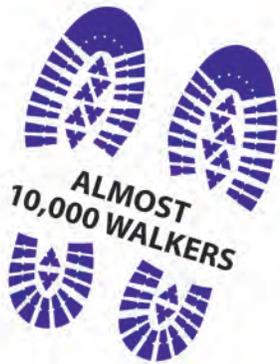
For information on how to apply for VA health care, see va.gov/health-care/how-to-apply/. **HL**

Dr. Lucille B. Beck serves as the Deputy Under Secretary for Health for Policy and Services at the Department of Veterans Affairs (VA), Veterans Health Administration, where she provides leadership and oversight on health care policy and clinical programs, strategic objectives, Department of Defense/VA interagency efforts, and requirements for legislatively mandated health care delivery programs. She's a recipient of the Presidential Rank Award for Meritorious Executive Service, and the Presidential Rank Award for Distinguished Executive Service. In 2008, she received the Deafness Research Foundation Research and Public Education Award, and in 2016, the HLAA Howard E. "Rocky" Stone Humanitarian Award. She's a founding member and past president of the American Academy of Audiology, and a recipient of its Distinguished Service Award. She's held faculty appointments at Gallaudet University, George Washington University, and the University of Maryland.



2019 Walk4Hearing Rallied for Hearing Health!

BY NATIONAL WALK4HEARING STAFF



No one needs to be alone on their hearing journey.

That was made clear by the 20 amazing Walks across the country that were part of the 2019 Walk4Hearing. All 20 Walks went far in promoting awareness for hearing loss and hearing health. And some participants realized they can do something about their hearing health by participating in our free hearing screenings.

Thank you to our walkers, volunteers, donors, and local and national sponsors for helping make each Walk a meaningful day that our walkers will remember for years to come!

Our thousands of walkers were the real stars. They came out and celebrated their achievements through self-advocacy, felt the support of family and friends, educated others about hearing loss, and promoted communication access. Walk day is the perfect opportunity for those in the community to come together and bond over shared experiences. And the Walk4Hearing is a great vehicle for promoting HLAA's mission of information, education, support and advocacy.

Spring

We kicked off the spring Walk season in early May in Milwaukee. There, we celebrated the event's 10th anniversary with cupcakes and pizza. Then, after getting damp weather for Walk day over the last few years, Westchester/Rockland, New York, finally got a gorgeous day to walk proudly in the bright sunshine that matched their spirits!

Two cities welcomed the Walk4Hearing: Nashville and Salt Lake City. And in Salt Lake City, CaptionCall took top honors as the highest corporate fundraising team across all Walks, raising more than \$20,000 through generous gifts and companywide events.

Fall

As cool temperatures rolled in with the coming of autumn, leaves began to change and pumpkin spice took over. Our fall Walks were in full swing!

Speaking of leaves turning colors, a stilt walker at the New York City Walk4Hearing transformed into a butterfly, creating a picture-perfect memory—especially for the kids. In contrast, New Jersey went stealth with their Ninja Warrior course, where walkers tested their athletic skills. And both New Jersey and North Carolina held cookouts after their Walks, with North Carolina delighting the senses with their annual southern-style barbecue. Up in Buffalo, New York, they brought in carnival-themed popcorn and cotton candy machines for a sugar rush before their Walk.

Four Walks had raffle prizes. And Arizona and Chicago had lots of local support with in-kind donations. While it's no competition—as both Walks had dozens of prizes to win—Arizona piled up 25 prizes, and Chicago came out on top, raffling off 42 items and raising more than \$1,000!

Washington, D.C., was among the Walks with the greatest increase in walker participation. Taking place at the National Harbor, it also may have had the most scenic views. In the meantime, just up I-95, Pennsylvania had something to celebrate as it continued its winning streak as Walk4Hearing's top Walk. But it was New England who won the award for most-spirited. Our walkers there didn't let the wind and rain deter them from celebrating awareness!

We topped off the season with a sparkling visit from Miss Kentucky and Louisville's minor league baseball mascot, Buddy the Bat—while the temperatures called for puffy coats!

How was all this fun made possible for our thousands of walkers? Without the many hours poured into the Walks by our hardworking volunteers and Walk committees, the 2019 Walk4Hearing season wouldn't have been possible. The Walk4Hearing really is a team effort—and we're so grateful to have all of you on our team. Your commitment to HLAA's mission is second to none. Hats off to you—and thank you!

Interested in joining a Walk committee in your city? Contact walk4hearing@hearingloss.org. **HL**



Congratulations to the 2019 Walk4Hearing Top Walkers and Teams!

We thank each and every one of you who supported the Walk4Hearing in 2019.

COMPANY TEAMS

CaptionCall	Salt Lake City	\$	22,745
Decibel Therapeutics	New England	\$	12,990
Team CapTel	Milwaukee	\$	11,805
Hear at Columbia	New York City	\$	6,670
CARTAttack	Long Beach, CA	\$	4,795
U.S. Captioning	Milwaukee	\$	3,936
Frequency Therapeutics	New England	\$	3,545
Listening Partners	Westchester/ Rockland, NY	\$	2,885
CRM Audiology	Westchester/ Rockland, NY	\$	2,875
Team Sonus Hearing	San Diego	\$	2,340

ALLIANCE TEAMS

Summit Speech School	New Jersey	\$	8,475
Sound Start Babies	New Jersey	\$	7,701
Team ECHO Center	Long Beach, CA	\$	6,302
Buffalo Hearing & Speech Center	Buffalo, NY	\$	6,085
Soundbridge Supersonics	Connecticut	\$	5,523
The Center for Hearing & Speech	Houston	\$	5,110
Cleary School for the Deaf	New York City	\$	5,055
Cutie PIES	Long Beach, CA	\$	4,408
HES	New York City	\$	3,956
WCU NSSLHA	Pennsylvania	\$	3,678

Thank You to Our 2019 Walk4Hearing Supporters!

A huge thank you to our 2019 Walk4Hearing national sponsors! Your partnership and presence at each Walk were vital to our mission of promoting hearing health and sharing the tools that help us get there. We couldn't have achieved this year's success without you!

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FAMILY TEAMS

Team Kiki	Pennsylvania	\$	25,374
LAudible	Washington, DC	\$	8,702
Merrick MouseketEARS	New York City	\$	8,063
Groovy Girls!	New York City	\$	6,598
Team Leatherman	Washington, DC	\$	6,010
Team RICH	New England	\$	4,880
Team Jessica	Westchester/ Rockland, NY	\$	4,716
Team Layla	Chicago	\$	4,546
Team Avery	Long Beach, CA	\$	4,520
Phackler's Phanatics	Buffalo, NY	\$	4,450

CHAPTER TEAMS

Walk New York!	New York City	\$	29,318
The X-Factors	Pennsylvania	\$	11,621
LA Stars	Long Beach, CA	\$	10,377
Chesco Striders	Pennsylvania	\$	8,100
Royal Oak Rowdies	Michigan	\$	7,694
Montco Marchers	Pennsylvania	\$	5,700
Listless	Connecticut	\$	5,391
Sound Off for Hearing	Chicago	\$	5,037
Mighty Macombers	Michigan	\$	4,020
HLLA Kentuckiana Chapter	Kentucky	\$	3,690

LARGEST TEAMS

Cutie PIES	Long Beach, CA	115
Team Cochlear - Colorado	Colorado	103
Summit Speech School	New Jersey	85
Team Cash	Pennsylvania	74
Salus University - SAA	Pennsylvania	67
Team AB	Long Beach, CA	66
Gilbert Public Schools	Mesa, AZ	64
Credit Suisse - Team Nicco	North Carolina	61
WCU NSSLHA	Pennsylvania	61
MED-EL Corp	North Carolina	60



Hearing Music Through Deeper Senses

BY ABIGEL SZILAGYI

Fall 2003

My ears perked up and tuned into the strange noises all around me. Daddy was slowly driving us home, down the back roads north of Pittsburgh. It was a sunny fall morning, and I'd just gotten my first pair of hearing aids. They felt very foreign to me. They were something that I knew my body needed, but they'd yet to own their place in my ears.

What—what was that? That noise—no, wait. It's a sound, a beautiful singing sound. It's like a trill, and it's so lovely to hear.

"Daddy, what is that?" I asked. I desperately wanted to know. I'd always been a curious girl. "Those are the birds chirping," Daddy replied, smiling up at me through the rearview mirror. I think I saw tears in his eyes. I didn't look long enough though, because I quickly tried to search for the source of those chirps.

My eyes were peering through the window next to me, looking closely at the trees for any sign of the birds. There were so many yellow leaves hanging on the branches and lying all over the ground. Maybe that's what that crunching noise was under the tires.

There! There they are! They fly around, they perch on branches, and they huddle around closely, fluttering their wings as they sing their morning songs. It feels like they sing for me. It's as if they're celebrating my first time hearing everything so clearly. What vibrant sounds they make! It feels so comforting to my ears. I wonder what else I'll hear with my new hearing aids.

Looking Back, More Than a Decade Later

When I was 4 years old, doctors discovered that I was born with a 50% sensorineural hearing loss in both ears. A couple of months later, I got my first set of hearing aids. My family was living in Pittsburgh at the time, which is where I was born. We later moved to Germany, where I started studying the violin at the age of 8.

Looking back at my early years of music making, I never once considered my hearing loss to be an obstacle in my life. The possibility of hardship didn't cross my mind when I told my mom I wanted to learn to play the

violin after coming home from school in third grade. As a preteen, I had no hearing aids for two years for financial reasons, and I still never considered that my hearing loss negatively affected my violin career. Yes, socializing was a challenge, and understanding what was going on around me was incredibly frustrating. Regardless, I believe that those were the years when I really learned to tap into my other senses more, to make up for what was lacking. Without even realizing it at first, I was implementing this skill in my violin studies as well.

It was a sunny fall morning, and I'd just gotten my first pair of hearing aids. They felt very foreign to me. They were something that I knew my body needed, but they'd yet to own their place in my ears.

Throughout the early stages of my career, I was fortunate to study at the Colburn School, which is known as the "Julliard School of the West," and is located in downtown Los Angeles. I've received several scholarships and have attended summer music programs all over the U.S. for many years. I've also participated and received awards in national and international competitions, including the VSA International Young Soloist Award, through which I had the stunning experience of performing at the Millennium Stage at the John F. Kennedy Center for the Performing Arts. I've been actively involved in my community in the music program at the Lake Avenue Church in Pasadena, California, where I've performed solo, chamber and orchestra music at the Sunday services, which are attended by thousands of people.

Being a child of immigrant Hungarian parents and a sister to four siblings, I've been blessed to be able to take advantage of all that Los Angeles has to give in order to pursue my dream as a musician. It's how I found my current private music teacher, Danielle Belen, who's a professor at the University of Michigan School of Music, Theatre & Dance, where I'm pursuing my Bachelor of

Every day I have a choice to make—the chance to decide to take that extra mile to go out there, to embrace my hearing loss, and to allow it to be a tool that can propel me to do more.



© Didier Heslon

Music in violin performance. Ms. Belen has played an essential role in my development as a musician, a student and a person. She's someone who believes in my potential and understands that my hearing loss is as much a part of me as being a musician is—because I've always been passionate about connecting those two parts of myself.

As a violinist with hearing loss, I've learned over the years how to adapt. But the challenges of my life didn't stop there. They increased. During my freshman year of college, I had ear infections for six months, and developed chronic ear pain and migraines. I was in and out of the emergency room due to complications from infections, and severe side effects from antibiotics and other medications. I've been working with doctors in Ann Arbor, Michigan, and in Los Angeles, and they're still searching for a solution for my pain. As my condition exacerbated, I couldn't wear hearing aids for a year. They were outdated, worn out, and made the chronic pain and infections worse. I wasn't able to purchase new aids, which cost \$9,000, until the summer of 2018, through a fundraising event at my church, where I performed a selection of pieces and gave a speech.

Since my health has declined, I've had to make a lot of changes in how I create music on my violin. I trained myself to learn how to practice and perform with ear plugs, as I'm no longer able to use my hearing aids when making music due to the sensitivity and pain in my ears. It's hard to face that kind of vulnerability and expose myself like that, especially on stage during a live performance, where there already are so many emotions and variables. I can't rely on my ears as much as I want to, so I'm learning how to use my other senses more—muscle memory, sight, instinct, vibrations, passion and audiation, which is essentially internal hearing that takes place in the absence of physical sound. I'm also learning to practice with a tuner, a device that helps me play with precisely the correct pitch.

Developing these skills as a violinist is certainly a different and perhaps unconventional way of playing in

the music world. But that doesn't mean it's not possible. The whole concept of using my other senses while making music relies on mental strength. It takes a conscious effort and a certain frame of mind to accomplish this. I have to expand my awareness of my surroundings and work twice as hard to be more observant of every detail in every moment.

Though my life as a musician and human being has changed because of these difficulties, my desire to pursue my dreams remains the same. If anything, my determination is even stronger than before. As with every challenge that comes in life, one learns to be patient, open-minded, resourceful, hardworking, compassionate, passionate and resilient. I know in my heart that it's always worth it to try rather than to give up and wonder. In times of despair and sadness, I think about all those people out there who suffer terrible illnesses, loss and other adversities—and still, they make the choice to be happy, to live selflessly, and to be grateful for the big and little things, because they're reminded of how fragile and precious life is.

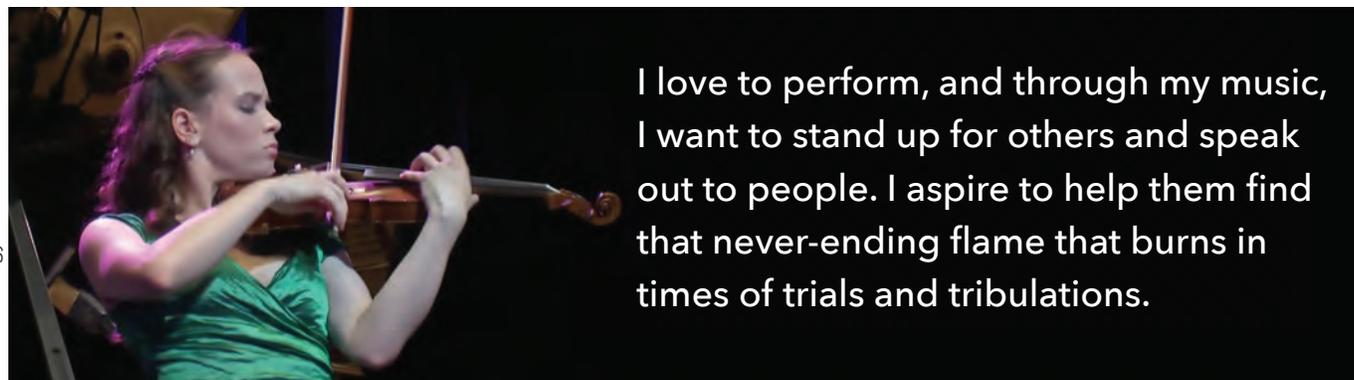
Every day I have a choice to make—the chance to decide to take that extra mile to go out there, to embrace my hearing loss, and to allow it to be a tool that can propel me to do more.

I love to perform, and through my music, I want to stand up for others and speak out to people. I aspire to help them find that never-ending flame that burns in times of trials and tribulations. As a Christian believer, I want to glorify God through my music. I dream that people find a sense of comfort, peace and inspiration when hearing my music—just as the song of the morning birds have been a source of solace, tranquility and joy for me. **HL**

Abigel Szilagyi attends the University of Michigan in Ann Arbor and is working toward her Bachelor of Music in violin performance. She was born with a 50% sensorineural hearing loss in both ears.



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Teen's School Project Helps Local HLAA Chapter

BY JERRY LAPIDAKIS

What can a daughter do to support her mother with longtime hearing loss, satisfy a high school class requirement, and raise awareness of hearing loss in children—all at once? Emma Schaefer found a way.

Emma, daughter of HLAA Member Leona Schaefer, is a sophomore at Wisconsin Heights High School in Mazomanie, Wisconsin. For her humanities English class, she needed to choose a research topic and devise an action plan to implement it. She wanted to do something that made a difference. The topic she chose, and the only one she considered seriously, was youth hearing loss.

Emma completed her school assignment by writing a paper on the effects of hearing loss in children. But now she needed the action portion. After considering several ideas, she realized that her topic was close to home. She'd focus on her mother's hearing loss story, research hearing loss in children, and come up with a plan to raise awareness of the topic.

Her Mother's Story

Emma's mother, Leona, was diagnosed with severe hearing loss in both ears when she was 3 years old. She was fitted with bilateral, behind-the-ear hearing aids and participated in speech therapy as a young child. She received no other services throughout grade school or high school. She met some deaf students and learned about sign language in high school. She continued to do well using hearing aids and speechreading in high school and college.

Over the years, Leona's hearing loss gradually worsened, and her family struggled to communicate with her. When Leona's children were 6 and 8 years old, her husband encouraged her to explore cochlear implantation. She now has bilateral cochlear implants that have greatly improved her life.



Emma Schaefer (left) with her mother, Leona Schaefer, who's a member of the HLAA Madison Chapter.

From Term Paper to Action

Emma wanted an action project that would both complement her school project and honor her mother. She thought designing and selling a T-shirt that brought attention to hearing loss was a way to do both. Emma decided on the theme "Listen Up" for her T-shirt sale.

"In past years, students have sold various items to raise money for an organization," Emma said. "I thought it'd be a great way not only to raise money, but also to spread even more awareness—by people walking around with my cause on their T-shirt." The sale of 59 T-shirts raised \$249, which Emma donated to the HLAA Madison Chapter.

Project Within the Project

But Emma didn't stop there. Emma—along with two friends also in the humanities English class—decided to hold a bake sale to raise additional funds for their three independent projects.

"We thought it'd be a great way to raise some extra money for our organizations because the three of us all love baking," Emma said. "We sold homemade donuts, brownies, cookies and cupcakes before and after school for three days. We ended up making it a lot more of a project than we'd planned. After the first night, we all went home and made extra batches because we sold out of what we'd originally brought.



Emma Schaefer with Jack Spear showing off T-shirts.

“Emma’s donation was a complete surprise. As a chapter, we struggle with our own fundraising. Emma went out and showed us how it’s done. But she also showed acceptance, understanding, honor and love for her mother, who demonstrates that having a hearing loss doesn’t prevent living life fully.”

—HLAA Madison Chapter President Jack Spear

In the end, we raised \$162 from the food items, which we thought was pretty good for our small school.”

Emma donated her \$54 share of the project to the HLAA Madison Chapter. All in all, Emma learned about youth hearing loss, donated a total of \$303 to the HLAA Madison Chapter, and best of all, honored her mother. **HL**



Jerry Lapidakis is a member of the HLAA Madison Chapter and serves on its board. He also is immediate past president of the HLAA Wisconsin State Association and is an active member of the state board. He’s retired from the Wisconsin

Department of Natural Resources, where he was a forester for 35 years. Jerry’s hearing loss has been progressive over the past 19 years. He recently received a cochlear implant on his right side and continues to wear a hearing aid on the left. He credits the education and support received from HLAA and its members for opening the world of better hearing to him.

Listen Up!

BY EMMA SCHAEFER

Hearing loss is a much more common condition than we let on. In fact, it’s the third most common physical condition in the U.S., behind arthritis and heart disease. With this shocking statistic, the importance of maintaining good auditory health is clear, especially in youth.

According to the Centers for Disease Control and Prevention (CDC), 14.9% of America’s youth, ages 6-19, have some degree of hearing loss, which translates to more than seven million children. Early detection is important when it comes to youth hearing loss, as it can affect a child’s social interactions and quality of life.

Signs of potential hearing loss in children include delayed speech or language, asking for repeated instructions, turning up the volume on the TV, and repeatedly asking, “Huh?” or “What?” If you notice any of these signs in your child, have your child’s hearing screened.

Nursing2019 recommends getting your child’s hearing screened regularly. Not all schools perform basic screenings though. Janice Sampson, DNP, R.N., CNE, says that children should have their hearing checked at 4, 5, 6, 8 and 10 years of age. Sampson recommends that if a screening is failed, to have a full evaluation by an audiologist. Also keep in mind that babies should have their hearing checked at 1 month and then have a full evaluation at 3 months. Stay safe and get your child’s hearing checked! **HL**



Join a Chapter

Learn that you're not alone in your hearing journey!

Find an HLA Chapter near you by visiting hearingloss.org/chapters-state-orgs/find-a-chapter/.

For more information, including how to start a chapter, contact Carla Beyer-Smolín, HLA national chapter and membership coordinator, at cbeyer-smolin@hearingloss.org.

Sign Up for the Free Chapter Blogs for All the News From National

Go to hearingloss.org.

Scroll down on any page (other than the homepage), and look on the right for the box that says, "Subscribe to receive HLA News via email." When news is published, it goes right to your email—no need to log in.

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Are you a Veteran living with hearing loss, tinnitus or other auditory issue?



HLAA stands ready to help our nation's Veterans live successfully with hearing loss and related issues. In addition to a complimentary Online Membership and first-time convention registration, you can participate in the HLA Veterans Across America Virtual Chapter.

The mission of the HLA Veterans Across America Virtual Chapter is to provide education, be an advocate for Veterans with hearing loss, and to provide a support system to help them return to civilian life.

For more information, go to hearingloss.org/Veterans or email chapters@hearingloss.org.



Want to know more about hearing assistive technology?



HLAA is here to help.

These three short videos provide easy-to-understand information to help you maximize the benefits of hearing assistive technology (HAT):

- *Technology in the Workplace*
- *Technology for Patients*
- *Technology for Leisure Time*

Find these videos, made possible through a grant from the Consumer Technology Association Foundation, at hearingloss.org/hearing-help/technology.

Have a specific question?

HLAA also offers HAT HELP. Just email your HAT-related question to hat_help@hearingloss.org. Supervised volunteers—doctor of audiology graduate students from the University of Washington and Gallaudet University—will answer your question with an email reply.

“...and then, I have nature and
art and poetry, and if that is not
enough, what is enough?”

—*Vincent Van Gogh*



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