

MAY/JUNE 2020

hearing life

THE MAGAZINE FOR BETTER HEARING



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2020 Doll of the Year
Joss Kendrick Joins
the Walk4Hearing

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“Affirming words from moms and dads are like light switches. Speak a word of affirmation at the right moment in a child’s life and it’s like lighting up a whole roomful of possibilities.”

— Gary Smalley, family therapist

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ABOUT HLAA—Founded in 1979 by Howard E. “Rocky” Stone (1925–2004), the Hearing Loss Association of America (HLAA) is the nation’s leading organization representing consumers with hearing loss. HLAA opens the world of communication to people with hearing loss through information, education, support and advocacy.

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Hearing Life (ISSN 1090-6215) is published bimonthly by the Hearing Loss Association of America®, 7910 Woodmont Ave., Suite 1200, Bethesda, MD 20814. HLAA members receive the magazine bimonthly via postal mail. For membership rates, go to hearingloss.org and click on “Become a Member” to join.

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Barbara and the 2020 American Girl Doll of the Year—Joss Kendrick—who is a competitive athlete and wears a hearing aid. HLAA and American Girl have partnered to create awareness about hearing loss. Find out more about how Joss is involved in the 2020 Walk4Hearing. See page 12.

In our social distancing, let's find ways to stay connected. It was always in our future but in the last month or two the future came banging at our door. Let's look at all these things as opportunities.

Ready or Not... The Future is Now

BY BARBARA KELLEY

As I write this column, most of the country is under stay-at-home orders due to the Coronavirus. By now, many of us know someone with COVID-19. Hearing loss is isolating enough, now another layer of isolation is added by having to distance ourselves from others due to the pandemic. Hope flourishes in community, not isolation. Turning inward and being caught up in self-pity, anger and, in some cases, despair, can diminish us as human beings.

Bringing people together who share something in common—hearing loss—was why HLAA was founded by Rocky Stone in 1979. People's desire for a community where it's okay not to hear well has not changed. We crave interaction and information and when we learn how to live well with hearing loss, we naturally want to help others do the same.

Because of the pandemic we had to alter how we bring people together. Little did we know that when we set out to celebrate the 15th anniversary of the HLAA Walk4Hearing that our spring walks would prohibit us from gathering on Walk Day in cities across the country. A quick pivot and an outpouring of support has inspired us to hold our Walk Day celebrations online.

The HLAA2020 Convention in New Orleans is cancelled in order to keep people safe. This is very disappointing to many of us. Our conventions are where we come together, almost like a family, to learn, see the latest technology, and to see old friends and meet new ones. This is where we share our hearing journey.

The Exhibit Hall provides hands-on experience with technology all in one big gathering place. We are planning some type of online experience in late June, open to everyone. It will include a broadcast with captions of the HLAA Research Symposium on the "Latest in Tinnitus Research." We don't have all the details now because we have to adjust fire (using an old military term here!) and see what we are capable of and find funding to bring you information online.

HLAA Chapters, who provide peer-to-peer support, advocate at the local level and provide people with information, have canceled meetings. This leaves a big hole in communities across the country for people to feel supported and give support. Some of our chapters have moved to online meetings, something that many were thinking about for sometime in the future, but now they are forced to adapt in a time of crisis. The need is great for people to not be isolated and chapters who are capable of holding online meetings are stepping in.

Telehealth is something being talked about for hearing health care. The U.S. Department of Veterans Affairs is adept at providing telehealth for all medical conditions even hearing health. But, for most of us, it is something for the future. But, the future is now. With many audiology practices closed, people want to know what to do. If their hearing aid breaks, what if they need programming on cochlear implant processors? Some hearing care providers are offering curbside service or telehealth. But, people have concerns about being able to understand on a telehealth call. How will this work? My orthopedic doctor announced that she would be doing her visits by telehealth. Even I'm a little wary of how this would

work. I mean, can she diagnose my sore bicep without touching it, moving it and doing an x-ray? Are we ready for this?

There's already talk about using artificial intelligence and robots to fit hearing aids. I don't have the timeline on this, but this technology would certainly come in handy right now.

How Do We Function in this New World?

The pandemic has caused us to take a huge leap into the future. What we planned for to happen down the road—telecommuting, online classes, online meetings, telehealth, bringing people together virtually is happening now, ready or not. This will become the new normal. There are so many unanswered questions as we take this giant leap into the future. How can we keep relationships that are so important; how do hearing health professionals keep patient-centered care at the fore when they are physically distant from their patients via telehealth, and, even more extreme, how can patient-centered care be delivered to you by a robot?

Please stay connected with HLAA. There's a section

on hearingloss.org for resources during the COVID crisis; for example, what to do if you are hospitalized, a guide for medical professionals, access for telework and online courses, and more.

Sign up for the free, online *Hearing Life e-News*; go to: hearingloss.org/news-media/e-news/. This is the way we bring you the latest news on a timely basis. Whether we like it or not, this virus has taught us to be agile as we adapt to a new way of life. In our social distancing, let's find ways to stay connected. It was always in our future but in the last month or two the future came banging at our door. Let's look at all these things as opportunities. We are going as fast as we can, learning along the way, to find ways to keep the HLAA community connected.

I hope to see you all soon, it will most likely be online. Until we can meet in person, stay well. **HL**

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



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It's Time to Walk4Hearing with Joss!

BY WALK4HEARING STAFF

American Girl's 2020 Doll of the Year, Joss Kendrick, is a fierce athlete born with hearing loss and a passion for surfing and competitive cheer. Joss wears a hearing aid and is the newest doll in American Girl's collection of inspirational characters who impart lessons to help kids grow with confidence. To celebrate her arrival, American Girl teamed up with Caroline Marks, a 17-year-old surfing prodigy and member of the first U.S. Women's Olympic surfing team. "This is a chance for me to show girls that it's possible to achieve your goals," says Caroline, "no matter how high they may be, if you are passionate and willing to work hard." Caroline and Joss show us that kids can do anything!

Celebrate Walk4Hearing Days Online

Walk4Hearing begins its 15th anniversary online. With the support of sponsors, alliances, and local walk committees, plans were altered to conduct a new type of Walk Day that allows us to remain connected in the midst of the pandemic.

Beginning May 2 at Westchester/Rockland, walkers are giving their shoes a rest and signing on with their computers and smartphones for Walk Day. During a 30-minute online program, we will share stories, learn more about HLAA's important work, be entertained, hear from a special guest or two, and have fun like we always do.

Keep the Spirit of the Walk4Hearing Going

While the spring Walk Days have had to shift to virtual events, the spirit and commitment to hearing health and helping people with hearing loss is stronger than ever. The Walk4Hearing is proud to partner with HLAA Chapters, 16 national alliances, and numerous local nonprofits, whose programs count on receiving 40% of the funds they raise.

Keeping our community together through the Walk4Hearing is not only important to stay focused on our mission, but also to provide comfort to each other and support those with hearing loss who are struggling with the added isolation and challenges created.



2020 Walk Days

On the day of each spring walk, there will be an online celebration.

Visit walk4hearing.org for details.



SPRING

Westchester/Rockland, NY – May 2

Milwaukee, WI – May 9

Milford, MI – May 16

Nashville, TN – May 16

Salt Lake City, UT – May 16

Alameda, CA – May 30

Long Beach, CA – May 31

Hartford, CT – June 13

All Spring Walks are Virtual Events.

FALL

Louisville, KY – September 19

New York City – September 20

Buffalo, NY – September 26

Chicago, IL – September 26

San Diego, CA – October 10

Cary, North CA – October 11

West Windsor, NJ – October 11

Washington, DC – October 17

Philadelphia, PA – October 18

Brighton, MA – October 25

Mesa, AZ – November 7

Houston, TX – TBD

HLAA on Good Morning America

On New Year's Eve, American Girl revealed its 2020 Doll of the Year, Joss Kendrick, on *Good Morning America* (GMA). Three young girls from the Walk4Hearing family were among the lucky kids who welcomed Joss on national television. In sharing their experiences with hearing loss, it is clear that Joss has a profound impact on these girls. Joss is a role model that inspires them to work hard and pursue their dreams.

2020 EDUCATIONAL PARTNER



"Something I've learned from my daughter Nikki is that people who get challenged in life are the ones who can overcome those challenges. When people see Nikki and hear her speak on TV, hopefully they see the sky is the limit for anyone born with hearing loss. Nikki sees Joss as a girl exactly like her trying and achieving anything she wants in life, and this will continue to reinforce the fact that she has no limitations."

– Dave, father of Nikki Kramer

"Mila likes Joss because "she can do what people with hearing loss can do, whatever they want." Mila truly feels that being deaf is just another thing in life, and it will not affect what she can do in her future. Mila is going to bring Joss with her everywhere she goes this year!"

– Sarah, mother of Mila Durlacher



"It was and is Lily's most cherished memory. Hearing Lily describe Joss as athletic, strong and competitive, just like her, was even more exciting. As we left the studio, Lily was recognized as one of the girls who was just on *Good Morning America*, and that made the day even more special. When she returned to school, her teacher played the video for the class and the principal announced over the school's loudspeaker about Lily's experience. Thank you for this wonderful experience."

– Randi, mother of Lily Lieberman



Walk with Joss Kids Contest

Children, ages 5-12, who register for the Walk4Hearing, can enter the contest for a chance to win a Joss Kendrick doll and accessory package. One child from each Walk4Hearing location will win! Visit walk4hearing.org to enter.

Joss Kendrick Launch Parties

HLAA local chapter members participated in launch parties that presented Joss Kendrick to the public at American Girl stores across the country. It was clear by the joy expressed on the faces of kids and adults alike that meeting Joss was more than just seeing a new doll. Joss has a hearing loss and wears a hearing aid. Thank you to these members for visiting the stores on behalf of HLAA!

"It was an amazing experience! You would think seeing Joss with the hearing aid would be the best part, but the best part of the experience was seeing the kids with hearing aids and cochlear implants getting Joss! Even though I am 40 years old, I had to get Joss. She looks just like me and reminds me to never forget that I can do anything!"
– Deirdre Keane, Chicago Walk4Hearing



"Growing up, I always wanted an American Girl doll. The highlight of that day was meeting the store's manager, Glenn. I learned that his father has a severe hearing loss. I jumped on the opportunity to educate Glenn about HLAA, its mission, programs and services, and how HLAA changed my life. Because of this experience, I joined the Bay Area Walk4Hearing as a Walk Chair. I am excited to share HLAA with others to help make a positive impact on their lives."
– Sally Edwards, Bay Area Walk4Hearing



"Kalia was born hearing, then became profoundly deaf by age three and has cochlear implants. Sendie, Kalia's mom, has slowly lost her hearing as well.

It was wonderful to see a doll who has hearing loss just like us, something I certainly never had growing up. Girls can do and be anything they want to be, even with a hearing loss. Thank you, American Girl!"
– Debbie Mohny, president, HLAA Boulder Chapter



Even if you aren't in a Walk4Hearing city, you can join the spring Walk Day celebrations online from anywhere!

Questions? Contact our national Walk4Hearing managers:

Ronnie Adler	radler@hearingloss.org
Alissa Peruzzini	aperuzzini@hearingloss.org
Ann Rancourt	arancourt@hearingloss.org

Celebrating 15 years of Walk4Hearing!

In 2006, when the first six Walk4Hearing events were held, HLAA envisioned an event where people in local communities could gather to share their experiences living with hearing loss and to see that they were not alone on their journey. Fast forward 15 years—with 20 walks this year, the Walk4Hearing has continued to expand across the country with the support of more than 105,000 walkers and 9,200 dedicated teams! It is evident that raising awareness about hearing loss is very important to a lot of people. Through the efforts of our walkers and teams over the years, the Walk4Hearing has raised nearly \$16 million to help support local services for people with hearing loss, as well as national resources and advocacy work.

We've chosen a few team stories to share which help convey how meaningful the Walk4Hearing is and what it means to those who continue to return year after year.

For more information, or to find a Walk4Hearing in your area, please visit walk4hearing.org.



WALK4 HEARING
Hearing Loss Association of America
15 YEARS 2006 - 2020

2006	Walk4Hearing begins in six cities
2007	National sponsors provide support
2008	Alliance program started
2009	Hit \$1 million fundraising goal
2010	Record year with four business team chairs
2011	Both New York City and Chicago Walks welcome more than 1,000 walkers each
2012	Christopher J. Artinian, president and CEO of Morton's The Steakhouse, named HLAA national spokesperson and heads a team in Chicago
2013	More than 10,000 walkers across the nation
2014	Just eight years old, Katherine Pawlowski is named first Walk4Hearing Ambassador
2015	HLAA celebrates 10 years of Walk4Hearing
2016	First call to action introduced: #CommAccess
2017	First Convention Walk4Hearing held in Minneapolis
2018	New call to action: #screenURhearing
2019	217 national and local alliances participated; Nashville and Salt Lake City added
2020	15th anniversary; Bay Area Walk added; American Girl joins as first educational partner

WHY WE WALK

"I started team Cutie PIES because, as an educator for the deaf and people with hearing loss, I wanted the children and families I work with to feel a sense of community and know that they are not the only ones walking this journey. It's a wonderful opportunity to raise awareness for hearing loss and bring people together. What I enjoy most about Walk Day is reconnecting with those families and students who have left my program.

Walking alongside adults and children with various types of hearing loss means community, camaraderie, and intertwining of lives and experiences. Not only am I an educator, but I am now a mom with an adorable six-year-old boy with hearing loss. The Walk became extra special last year as he joined our team. We proudly walk in support of Ear Community, a national alliance of the Walk4Hearing."

– Elizabeth Desloge, Team Cutie PIES, Long Beach Walk4Hearing



"Gilbert Public Schools has been a proud participant and alliance with the HLAA Walk in Arizona for the past few years. We are thrilled to come together to show our district's support for individuals—especially students—who are deaf or have hearing loss.

We adore being a part of this important event to show that communication is not about modality, but about access, language, and connection. Together we are creating a stronger, more aware community that allows for greater universal design for everyone—those with and without hearing loss."

– Dana Leonardo, Team Gilbert Public Schools, Arizona Walk4Hearing

"We first discovered the New Jersey Walk4Hearing in 2016 after our daughter, Nadia, was diagnosed at birth with bilateral sensorineural loss. I rallied our friends and family together, created a team name, developed a logo, purchased t-shirts, and we were ready to walk! I never imagined what that first walk would mean to me and the lifelong relationships that would be created that day.

The Walk4Hearing is beautifully and emotionally overwhelming. This will be our fourth year participating and watching all the families arrive in support of one another is always so humbling.

We walk because we want Nadia to be happy, confident, independent and to love the life she was given. She is not different. She is not a stereotype. She will make waves and she will fight for her rights. She will overcome and we will be right there with her." – Valerie Cruz, Team Nadia's Cruzers, New Jersey Walk4Hearing



WHY WE WALK

"For Keegan's Super"hear"os, the Walk4Hearing means we are supporting my son Keegan, who is single-sided deaf and has a cochlear implant. The world is more challenging for him and participating in the Walk shows we support him and believe in him.

The Walk opened Keegan's eyes to the fact that there are other people in the world just like him. We live in a small community where there are only two other children in the school district with hearing loss, so he often feels like he's the only one. It has opened some of my family members' eyes to see that those with hearing loss are capable of doing the same things that people with normal hearing can do."

– Jennifer Violette, Team Keegan's Super"hear"os, Connecticut Walk4Hearing



"The Los Angeles Chapter of HLAA has been an active participant in the Long Beach Walk4Hearing for over a decade. One of our captains, Katherine Burns, named our team the LA Stars. We enjoy the beautiful beach location, socializing, getting some exercise, raising awareness about hearing loss, and raising funds for HLAA and the Chapter.

The LA Stars have consistently been the top fundraisers for the Long Beach Walk. I am so happy and proud to say that the LA Stars raised more than \$10,000 and that the Long Beach Walk4Hearing raised about \$50,000."

– Wendi Washington, Team LA Stars, Long Beach Walk4Hearing

Thank You to Our 2020 National Walk4Hearing Sponsors!

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EDUCATIONAL PARTNER



Hearing Loss in the Time of Coronavirus

BY LISE HAMLIN

Your rights under the Americans with Disabilities Act don't disappear in a time of emergency. Here's important information for people who now are required to work from home or attend classes online.

The coronavirus pandemic is upending everyone's daily life. Schools have been closed, people are working from home, Broadway and local theaters have shut down, and movie theaters, bars and gyms are closing one by one, state by state. Many people are staying at home, self-isolating or in some cases in quarantine.

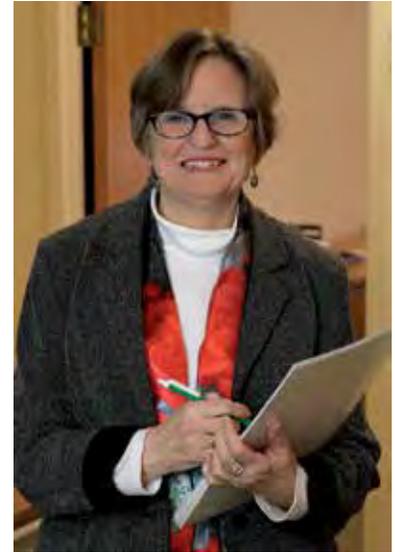
If you are working from home or attending school remotely via online coursework, emergency or no emergency, you still have a right to meetings and online coursework that is accessible. But it's not simply a matter of exercising your civil rights, it is important to do the best work you can. To do that, you must be able to communicate effectively with your team, whether at work or school.

In April 2015, the U.S. Department of Justice (DOJ) reached a settlement with edX Inc., a provider of Massive Open Online Courses (MOOC), to make its website, online platform and mobile applications accessible under the Americans with Disabilities Act (ADA). In their press release announcing this settlement, DOJ said, in part:

“Critical portions of education are moving online, in tandem with the rest of our social experience,” said U.S. Attorney Ortiz. “This new, educational online world readily can, and should be, built from the outset in a way that does not discriminate against those with disabilities.”

Title III of the ADA prohibits discrimination on the basis of disability by public accommodations in the full and equal enjoyment of the goods, services, facilities, privileges, advantages and accommodations of places of public accommodations. Title III of the ADA also requires public accommodations to take necessary steps to ensure individuals with disabilities are not excluded, denied services, segregated or otherwise treated differently because of the absence of auxiliary aids and services, such as accurate captioning of audible materials and labeling of visual materials. The DOJ has long considered Title III and its implementing regulation to apply to the online services and communications of public accommodations.

The ADA is intended to level the playing field for all people with disabilities at work, in public places, for telecommunications access, and when interacting with state or local governments. Just as Title III prohibits disability discrimination online



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Your rights under the ADA do not disappear during an emergency. But the Hearing Loss Association of America advises, whether you are at work or school, to reach out first to make sure your access needs are known.

or in person, so does Title I, which covers employment provisions under the ADA.

The U.S. Equal Employment Opportunity Commission (EEOC) enforces workplace anti-discrimination laws including the ADA and the Rehabilitation Act, including the requirement for reasonable accommodation and rules about medical examinations and inquiries. In a technical assistance document issued March 18, 2020, “Pandemic Preparedness in the Workplace and the Americans with Disabilities Act,” the EEOC notes:

The ADA and Rehabilitation Act rules continue to apply, but they do not interfere with or prevent employers from following the guidelines and suggestions made by the CDC or state/local public health authorities about steps employers should take regarding COVID-19. Employers should remember that guidance from public health authorities is likely to change as the COVID-19 pandemic evolves. Therefore, employers should continue to follow the most current information on maintaining workplace safety.

For more information, see [eeoc.gov/facts/pandemic_flu.html](https://www.eeoc.gov/facts/pandemic_flu.html).

In short, your rights under the ADA do not disappear during an emergency. But the Hearing Loss Association of America advises, whether you are at work or school, to reach out first to make sure your access needs are known. Talk to your college disability coordinator or your supervisor at work to ensure access as soon as you can. They cannot know what you need unless you tell them.

There are many resources to help you navigate our upended world in this time of coronavirus. And now we are seeing more information specifically for people with hearing loss. One particularly helpful resource is the Hearing Tracker. They have posted information about how to get captioning online, as well as how to communicate via video conferencing even if you don’t need captioning, but do need to make the most of the audio connection. See their news here: hearingtracker.com/news. **HL**

Lise Hamlin is director of public policy at HLAA. Reach her at lhamlin@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 Americans with Disabilities Act (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.

A NEW SOLUTION FOR SINGLE-SIDED DEAFNESS

DO YOU STRUGGLE TO FOLLOW CONVERSATIONS AROUND A NOISY DINNER TABLE?
DO YOU HAVE TROUBLE TELLING WHERE SOUNDS ARE COMING FROM?
IS YOUR COMMUNICATION WITH YOUR LOVED ONES SUFFERING?

LIVING WITH SINGLE-SIDED DEAFNESS IS NOT EASY.

If you answered “yes” to those questions, you may benefit from a new solution that could change your life.

The SYNCHRONY Cochlear Implant from MED-EL is the world’s first and only cochlear implant FDA-approved for single-sided deafness. Studies show¹ that SYNCHRONY can help listeners hear speech in noisy environments and tell where sound is coming from.

“

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.

SIMON M.

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.**

RICHARD S.

Recipient and avid cyclist

”

FIND OUT IF SYNCHRONY IS THE RIGHT SOLUTION FOR YOU.

Contact a MED-EL expert today. **Visit go.medel.com/ssd-us**

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

COVID-19 and Hearing Loss

BY RICHARD EINHORN

Make the extra effort to stay in touch during this global health crisis.



The worldwide COVID-19 pandemic has disrupted the lives of everyone around the world. In addition to observing the guidelines and protocols established by our local governments, those of us with hearing loss need to be aware of and address the special challenges we face at this time.

I'd like to share some tips and resources with you. Be sure to check the HLAA website (hearingloss.org) for additional information.

Staying in Touch

Numerous studies have demonstrated how important it is for the emotional health of people with hearing loss to make an extra effort to stay connected.

Shari Eberts, vice chair of the HLAA Board of Directors, has a wonderful blog called Living with Hearing Loss (livingwithhearingloss.com). She writes, "While meeting in person is not an option, commit to speak to at least one person each day. Contact that long lost friend you are always meaning to see, but never have time. You are more likely to catch them at home in the next few weeks."

Be aware of and be patient of potential technical glitches with your communications technology. For example, the FCC recently relaxed some of the rules for the use of Internet Protocol Captioned Telephone Service (IP CTS also known as captioned telephone) or Video Relay Services (VRS). HLAA's website notes, "If you use an IP CTS phone, you are probably accustomed to picking up the phone and having an immediate connection. During this emergency, there may be times that prompt connection time takes a little longer. Providers

are doing their best to fully staff their call centers to ensure that the phones are answered as quickly as possible. But understand if there are a lot of people calling at the same time, it may take a bit longer to get connected."

As an alternative to IP CTS or VRS, Katherine Bouton, a former HLAA Board member and president of the HLAA New York City Chapter suggests on her excellent blog (katherinebouton.com) that another way to connect with others while at home is through a video-calling or videoconferencing app like Skype or Zoom. These apps, which work with any modern computer, smartphone, or tablet, are pretty easy to set up and use. The advantage of video-calling is that you can see the lips and expressions of the people speaking to you. In addition, the sound quality is often clearer than a standard phone call and several of these services have built-in captioning (which can often be quite good).

Speaking of sound quality, it is possible on some smartphones to go into the sound settings to enhance the sound. Also, the SonicCloud app, the brainchild of Larry Guterman, another HLAA Board member (soniccloud.com) enables you to personalize the sound of phone calls, video calls, podcasts, audiobooks, etc., for specific hearing profiles.

Your Hearing Devices

If your hearing aids use replaceable batteries, now is the time to stockpile several months' worth of extra batteries. If your devices use rechargeable battery technology, consider purchasing a spare recharger—and keep all of them charged. Check hearingloss.org under Become a Member and learn about hearOclub, a battery subscription service for new HLAA members.

If you think you need a tweak to your device's settings, contact your hearing health care provider (via email or phone/video) and see if it's possible to do so remotely. Several newer model hearing devices allow your audiologist to make adjustments over the cloud. I've used this service myself and it works quite well with my hearing aids.

If you have an older model hearing aid, you can use it as a spare if your current device stops working for some reason. Be aware that your older hearing aid may

take a different size battery than your newer device so be sure you have the right batteries.

If you don't have an older hearing aid around and your hearing loss is in the mild to moderate range, you might consider purchasing an over-the-counter personal sound amplification product (PSAP) as a backup device. Bose, Nuheara, Sound World Solutions, and Etymotic all make high-quality devices that might work for you as a spare.

Another solution—if you're in a pinch and can't get your hearing aid repaired—is to use a free smartphone amplification app like Petralex, EarMachine from Bose, or Jacoti's ListenApp for iOS (disclosure: I consult for Jacoti). These and similar apps allow you to use your smartphone and a pair of earphones as a hearing device for live situations. As with PSAPs, hearing apps are likely most useful for people with mild to moderate hearing loss.

Visiting Your Health Care Facility

If, for any reason, you need medical attention, Shari advises that you contact your health care providers first before showing up. If you do need to go, be sure to take along everything you need in order to hear and understand what is being said by your health care providers. Make sure your hearing devices' batteries are charged (and that you have spares). Bring along any assistive listening devices like the Roger Pen—that you might need. Also bring along a pencil and paper so that nurses, aides, and doctors can quickly write notes for you in case you can't understand them. You might also want to download a speech-to-text app like Otter or Google Live Transcribe to provide captions in case CART isn't available. Just be sure to learn how the app works before you go. That way, you can concentrate fully on what your physician is saying, not on troubleshooting.

Katherine adds that if your health care providers are wearing masks, you could ask them whether transparent masks are available. While not in widespread use, they might have some and that will enable you to read their lips.

Stay Active and Engaged

Since, as of this writing, we are confined to our homes, it is essential that we take care of both our physical and our mental health. If you haven't already, get into a regular exercise routine. Hearing loss can be exhausting and it helps to be in shape. You can easily find online exercise videos with a simple Google search.

Shari points out that it's a perfect time to learn something new, perhaps through a class that meets regularly over the internet. In fact, I'm signed up for two online courses right now and they're a blast. Many of these courses have captions available as well as online forums where you can leave messages and comments for your fellow students. It's an enjoyable way to make new friends from all around the country. What should you learn? It's up to you!

If you're a veteran, HLAA has a wonderful virtual chapter for vets run by Board member (and proud Marine) Don Doherty. Just go to hearingloss.org and do a search for "veterans" and you'll find more information.

HLAA is also in the early stages of setting up another virtual chapter for younger people with hearing loss. If you're interested, feel free to write me at the email below and I will put you in touch with the people setting it up.

In General

Get your COVID-19 information only from highly reputable sources, for example, the World Health Organization (WHO) or major public health institutions like Johns Hopkins, Stanford Medical School, the Center for Disease Control, local and state health authorities and so on. Stay informed and concerned, but don't panic. Likewise, don't minimize the seriousness of the situation.

Be sure to wash your hands regularly with soap and water, but before using any cleaners or sanitizers, carefully read their labels. Some can be very unhealthy if misused, for example, on food products.

While we are all, quite understandably, worried about our own health, it's important to remember that our personal safety directly depends upon keeping others safe, too. If ever there was a moment for altruism, loving-kindness, and giving, this is it.

May all of you, your loved ones, your friends, your co-workers, and your communities stay healthy during this unprecedented time. **HL**

Richard Einhorn is chair of the HLAA Board of Directors and lives in New York City. He can be reached at chair@hearingloss.org.

Disclaimer: Mention of products or services in this article does not mean HLAA approval or endorsement, nor does exclusion of a product or service mean disapproval.

Asking for Accommodations in the Workplace

BY LEONA SCHAEFER

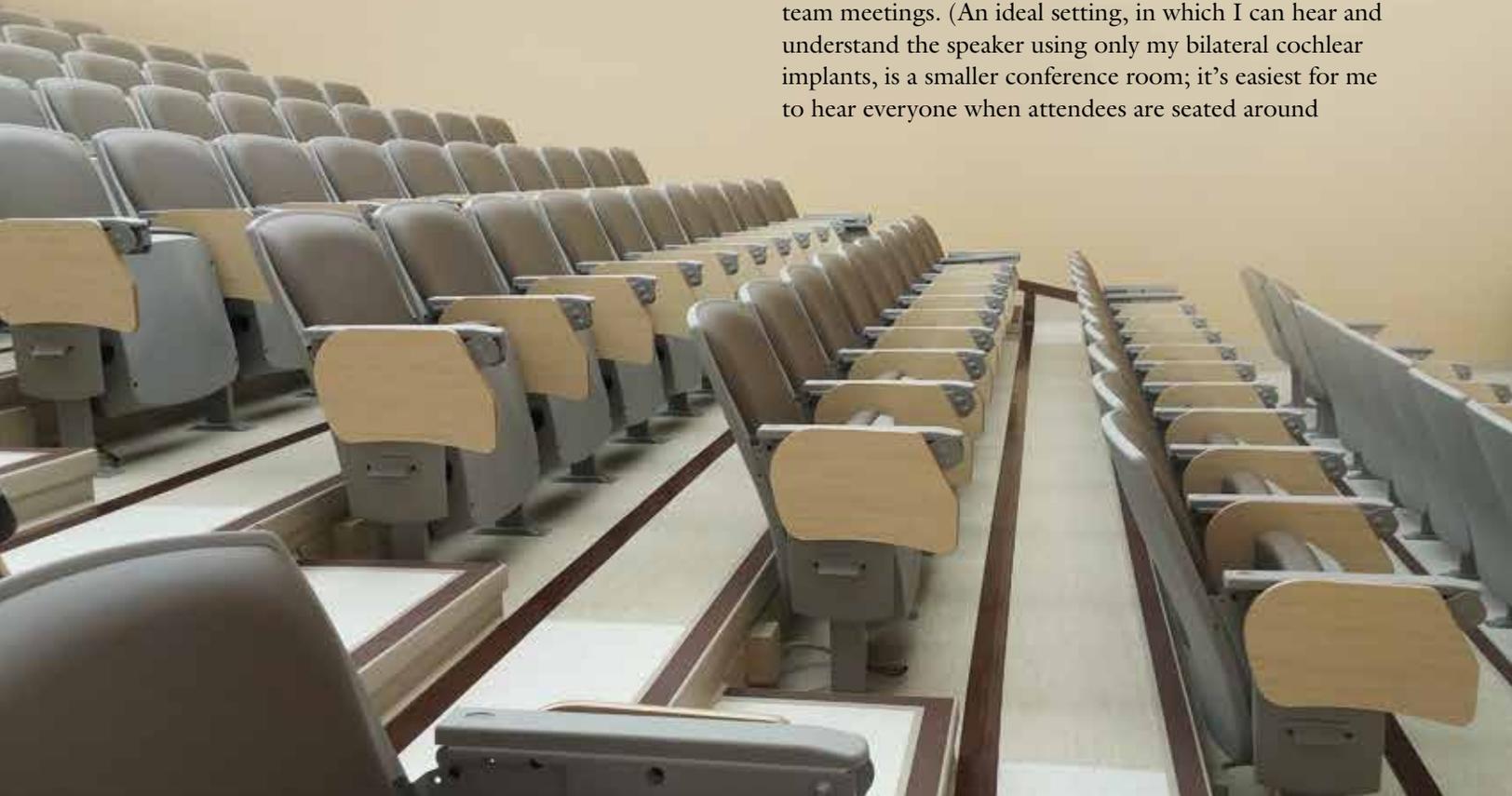
Hearing loss disability can often be overcome with the right accommodations at home and in the workplace. These accommodations may be as simple as positioning oneself in direct sight of a speaker or as complicated as installing updated technology or equipment in a large meeting space. It is important to become as informed as possible about which form of accommodation is best, and then you must have an action plan for putting it in place.

The Change Begins with You

I have worked as a physical therapist assistant since 1997. In my earlier years at my job, I used bilateral hearing aids to hear, and required face-to-face contact with my co-workers and patients in order to understand their speech. I also needed a captioned telephone for any telephone communication, and my employer honored my request for it, which enabled me to make outgoing calls. However, answering incoming calls was still a problem. I avoided answering the office telephone because I knew I would not be able to understand callers or direct them to a colleague who could meet their needs. I was dependent upon my co-workers to answer it, and when I was alone in the office, I simply let voice-mail take a message.

In 2012, I decided it was time for a better solution, especially because new technology was available. I chose to undergo bilateral cochlear implant surgery, and I now no longer need a captioned telephone. I can use cellular, desk or wireless telephones to communicate with the nurses, doctors and other clinical staff members while performing my job. I can also answer and direct incoming calls on the office telephone, as well as take messages for my co-workers.

Soon I moved to the Madison, Wisconsin, area, where I found employment as a physical therapist assistant with a much larger hospital system. In the past, I was able to hear well in a small group setting, such as team meetings. (An ideal setting, in which I can hear and understand the speaker using only my bilateral cochlear implants, is a smaller conference room; it's easiest for me to hear everyone when attendees are seated around



a large table and the speaker is no more than 30 feet from me.) However, department meetings at my new Madison workplace are often held in a larger conference room or a pit-style lecture room with a microphone system or room acoustics that make hearing very difficult. The conditions are made worse because the speaker is farther away from the audience due to the layout of the larger room. I knew that a hearing loop—a special type of wireless sound system—would help me hear the speaker in these larger conference rooms, but it was unavailable in my workplace. I decided to begin the process of requesting an accommodation that would enable me to hear in these large rooms.

Stand Up for Yourself—One Step at a Time

I discovered that I needed to be assertive, patient and persistent in my efforts to help others understand the hearing loss community's universal need for various accommodations in the workplace—and to move these efforts past the talking stage. In general, my experience has taught me that there are three steps involved in successfully implementing this type of positive change:

Step One: Go through proper channels to ask for what you need. The first step I took was to inform my manager of my difficulty in hearing in large meeting rooms and suggested installation of a hearing loop as the best accommodation for my needs. I was told to contact the audiovisual staff members at the hospital to find out what kind of equipment was already present in the rooms. After meeting with an audiovisual representative in one of the large meeting rooms, I determined that my workplace's current hearing assistive technology—earbuds with an assistive listening device—was not compatible with my cochlear implants. My manager provided the documents necessary to request the hearing loop, which I completed to the best of my ability. The documents required a statement from my medical provider acknowledging that I had a hearing disability and detailing how it affects my ability to perform my job, which my audiologist agreed to provide.

Looped lecture room: The hearing loop installation is complete in one of the lecture rooms at the hospital. Submitted by Lisa Zovar of [Hear Here! Hearing Loops](#)

Step Two: Identify the solution and enlist the aid of others for its implementation. The second step was to meet with my manager and a representative from Human Resources (HR). The HR representative was my helper behind the scenes: she completed the research necessary to implement my accommodation request, while my manager and I continued to complete the daily tasks associated with our jobs. Some of the HR representative's research included contacting the audiovisual and construction managers to inquire about costs and the installation process, securing funds for the project and choosing the most beneficial process for everyone involved. For a time, it appeared that funds might not be available to complete the entire project. Fortunately, I had learned about local hearing loop installation providers at chapter meetings and told my HR representative about them. I also encouraged her to obtain additional quotes for the hearing loop installation. The team selected the most satisfactory bid, and a date was set for installation in not one, but three locations: the original room that I had requested and two other rooms that my department occasionally uses.

I discovered that I needed to be assertive, patient and persistent in my efforts to help others understand the hearing loss community's universal need for various accommodations in the workplace—and to move these efforts past the talking stage.

Step Three. Be patient and persistent as you actively monitor progress. The third step in this process was to wait. And wait. It took four long months from the day I originally approached my manager with my accommodation request until the request was approved, and another four months elapsed before the date of installation finally arrived. I then waited for five additional months until I had the opportunity to use the hearing loop for the first time at an actual team meeting. The entire journey took more than a year, but I am happy to say that I have now used the hearing loop three times, and the results have been excellent: I am able to hear and understand speakers in the large, lecture pit-style meeting room without difficulty. Universal hearing loop signs are posted at the front of the room to alert others

Asking for an accommodation at work for a disability is not easy. Doing your homework and sharing your knowledge—kindly and honestly—will make the process easier.

that this technology is available, so the benefits of this accommodation are not limited to me. Numerous other employees with hearing loss in my workplace can use our new technology, too, as will others in the future.

Clearing the Path to Accommodation

I am fortunate to have a kind, compassionate manager and HR representative, as well as an employer with funds available to accommodate my request, but I recognize that individual situations will vary widely. It's important to know what you need and educate yourself about how your chosen technology works. You may also need to patiently educate your employer about your disability and clearly explain the specific ways the appropriate accommodation could help you improve your job performance. (It helps to imagine that you are a teacher who is helping others learn about something with which they are unfamiliar.)

Be prepared for pushback: Have your research ready, as well as strategies to counter opposition. For example, suggest a “field trip,” so your employer can see how the proposed accommodation operates at another workplace. If cost seems prohibitive, suggest possible fundraising strategies at your workplace that will also help raise awareness about how the accommodation will help numerous people, rather than just one.

Be sure to follow up by sending a polite email to your manager or HR representative to check in about



Leona is ready to start her day as a physical therapist assistant at the hospital.

the status of your accommodation request, and ask for a progress update if one is available.

Asking for an accommodation at work for a disability is not easy. Doing your homework and sharing your knowledge—kindly and honestly—will make the process easier. Completing the steps I've outlined here takes time, but it will be time well spent, because it is patience, professionalism and a collaborative spirit that ultimately get the job done. **HL**

Leona Schaefer, an HCAA member, is a licensed physical therapist assistant with 22 years of experience at hospitals and a skilled nursing facility in Wisconsin. Her bilateral cochlear implants enhance her enjoyment of gardening, birdwatching and listening to her children's musical performances.

What do you hope to have taught your children about life through how you've managed your hearing loss?

Through managing my hearing loss I know I have taught my children to show kindness to those they meet every day, for they have no idea what that person went through to get there that day. We have an opportunity to bring joy and comfort to every person's day, and something as simple as a smile may be exactly what that person needs to turn their day from a bad one to a great one. My hearing loss is a “hidden disability” and my daughters have shown kindness to others who may be in a similar situation, not knowing how they are struggling, but choosing to offer kindness to bring light to their day.

—Leona Schaefer

Listen Up!

BY EMMA SCHAEFER

While I was growing up, not facing my mother was not an option. It was disrespectful and rude, and neither of my parents would stand for us talking behind her back. I mean this not metaphorically, but physically: I always had to face my mother while speaking. Facing my mom was not just a required sign of respect, either; in my household, my sister, father and I faced my mother so she could understand us. If her eyes could not see our lips, the words coming out of our mouths were easily lost. You see, my mom, Leona, has hearing loss. It is not the result of anything she did in her youth, nor of medical complications from an infection or other mishap. This is simply the way it is. When my mother was two, my grandparents began to notice her turning up the television to excessively loud volume. She also could not hear things that were said or responded with the question, “What?”

By speaking up about hearing loss and listening up when others do, we can change lives.

My grandparents took her to see several audiologists and they determined that my mom was losing her hearing, but they couldn’t figure out why. To this day, my mother has no idea what the cause was and has just had to accept that this is the way her life is. Because the hearing loss began at a very young age, she also developed a slight accent. “What country is she from?” and “Where did she grow up?” are questions I am often asked. I respond with, “This one,” or “Here,” and people look at me with confusion. They don’t believe that she could be from the Midwest, since she doesn’t sound exactly like other Midwesterners—and definitely not like stereotypical Wisconsinites. When I explain that my mom has hearing loss, the people shut up. They apologize to me, or to my mom if they are talking to her, as if they should be ashamed for merely making an observation, and then they instantly drop the subject.

But if I had my way, that wouldn’t happen. People shouldn’t shut up; they should listen up!

Hearing loss is something that many Americans are ashamed to have, but they shouldn’t be. Hearing

impairment is a problem that should be talked about. According to Hearing Loss Association of America, only one-fifth of the people who need hearing aids actually use them, and it takes the average person with hearing loss seven years to seek help. Imagine going seven years without being able to hear everything that you used to be able to hear, but refusing to get help. The stigma about hearing loss needs to change. People who have hearing loss deserve to hear birds chirping in the morning or leaves rustling in the wind just as a person with perfect hearing does. By speaking up about hearing loss and listening up when others do, we can change lives.

I watched my mom’s life change when others spoke up in this way. She began attending HLAA Chapter meetings, where she was able to meet people who’ve had similar experiences and struggles. At these meetings, others with hearing loss talked about how they have been affected, challenges they have overcome and more. They also shared hearing solutions that they heard of or used—from hearing loops and t-coils to captioned phones and cochlear implants. My mom knew what some of these were. She had hearing aids and was accustomed to using hearing loops in buildings that had them, and we had a few captioned phones in our home when I was



Leona and daughter Emma holding their awards from the HLAA WI State Conference in November 2019.

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



Visit hearingloss.org/Veterans or email chapters@hearingloss.org.

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 HLAA Veterans Across America Virtual Chapter.

The mission of the HLAA 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.



growing up, so she could read the captions on a phone call to understand what was being said on the other end. But cochlear implants? That was new information. What were they? My mom learned a little bit more about them, and so did the rest of my family. Her audiologist explained to us how they worked, and we found out that they are worn similarly to a hearing aid but work even better. They are also partly internal, so in order for my mom to try them, she would have to undergo surgery. The opportunity for her to hear better outweighed the risks, though, and soon enough, she had scheduled appointments to begin her cochlear implant journey.

I was young. I don't remember exactly how old I was, but I couldn't have been more than ten. I remember being a little scared because my mom was going to have surgery, but she was so excited about the potential results that the fear didn't bother me that much. I don't remember much from the day that she had the surgery, but what I do remember is that there was a lot of training afterward. My mom basically had to relearn how to hear, so she would spend hours at the computer, doing speech therapy and relearning what words sounded like. I remember that we had to be completely quiet while she was doing that. I also found it kind of funny when she would say that certain words sounded a lot weirder in reality than she thought they would, because until then, she had heard them so differently. The way she heard following her cochlear implant surgery was so different from the way she had been hearing her whole life, but she loved it. She could understand people without having to face them, too, for the first time in her life.

My mother went through the entire process a second time when she received a cochlear implant in her other ear. I still think she was so brave for going through

another surgery, as well as the therapy and other work all over again, but when she talks about hearing things she's never heard before, I know that it was worth it. I vividly remember eating breakfast around the table one morning when she asked, "What's that sound?" and then mimicked the sound that she was hearing. The way her face lit up when we told her it was birds chirping still warms my heart. "I've never been able to hear that before," she said. Little moments like that are what make me want to spread awareness so much.

When I see how much my mom benefits and how much her life has completely changed with her cochlear implants, it proves to me just how important speaking up is for those who have something to say—and how important listening up is for those who could benefit from hearing it. I am so thankful to those who spoke up and helped give my mother new opportunities, and I am eternally grateful to anyone who will listen up to hear her story. **HL**

Works Cited

Hearing Loss Facts and Statistics, Hearing Loss Association of America, 2019. This source provided data information on hearing loss from HLAA. (In-text cited as HLAA)



Emma is a junior at Wisconsin Heights High School in Mazomanie, Wisconsin. She excels in school and in her free time enjoys acting, music, being outdoors and spending time with her friends. She also loves spending time with her family, who inspired her to do this project: her mom Leona, dad Kyle, and sister Cora.



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HLAA Mission Circle

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

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

Starting a New HLAA Chapter

BY HLAA STAFF

We got together with the founding members of the HLAA Essex County Chapter (New Jersey), to learn more about what drove their decision to launch a local HLAA Chapter—now celebrating its fifth year—as well as understand how the organization serves the Essex County hearing loss community.

A fundamental human need inspired the idea to create the HLAA Essex County Chapter. Shelly Simpson, Gina Thomas and Lisa Webb shared a common goal: to build a community that would support their children, who were challenged by varying levels of hearing loss. The women joined forces with Latisha Porter-Vaughn, an adult who lives with sensorineural hearing loss and who is a member of the same community, to form a local HLAA Chapter. The group found that creating a local chapter also began a new chapter in each of their own lives: it empowered all of them with a deeper understanding of hearing loss and put beneficial resources and networks, as well as social activities, within their reach, as well as the reach of others in the community.

Shelly, Gina, Lisa and Latisha each had her own reasons for wanting to start a new HLAA Chapter and

help shape its future. Shelly understood how important it was for her 16-year-old son, Rashaun, who has a hearing loss, to have a role model who was successfully navigating the challenges of hearing loss to attain goals and manifest dreams. Gina’s daughter, Giana, was born profoundly deaf, and Gina felt alone because she did not realize that there were so many other parents with deaf children who might be able to offer helpful suggestions. Lisa had already become a strong advocate for her 17-year-old son, Naim, who has hearing loss, looking beyond Naim’s disability and instead focusing on developing his abilities. And finally, Latisha, an adult with hearing loss, had come to the realization that she needed to take better control of her life by engaging with the wider hearing loss community.

What were some of your considerations as you decided to start a local chapter?

Gina: I am a finance manager, and I sometimes felt guilty, wondering whether I should abandon my career to become a stay-at-home mom after my daughter, Giana had her first surgery. My son is just a few years older than Giana, and I knew giving up my salary would cause a hardship for my family. So I took charge and decided to take part in supporting deaf and hard of hearing people.



From left: Latisha Porter-Vaughn, Shelly Simpson, Lisa Webb, and Gina Petrus Thomas.



The HLAA-Essex County 5th Annual Chapter Meeting Celebration was held March 7, 2020, at the Nutley Public Library in Nutley, NJ.

That is when I told Latisha I was not available to be the vice president of the chapter since my family needed me, but I was willing to assist as treasurer.

Latisha: When I finished my master's degree in 2014, I believed doors would open and provide me with more opportunities in my career. Unfortunately, little advancement came. At that time, my enhanced self-confidence and belief in my abilities sparked my interest in increasing awareness of hearing loss—especially in the workplace. I realized I didn't know many people with hearing loss, and I decided it was time to become part of a broader community that looked like me and had experienced my perspective. I felt that this would increase my self-awareness, support me with encouragement and enable me to be of use in helping others—and it has.

I want to be a mentor and role model; hence, I'm now only months away from finishing my doctorate program concentrating on the experiences of deaf and hard of hearing college students. In addition, a writer has just completed a biography of my life, in which the story of my persistence in overcoming hearing loss is told.

In what ways has the Essex County Chapter succeeded in helping others?

Latisha: Our goals have always been to provide advocacy, education and emotional support to people with hearing loss, especially those who reside in Essex County. At our meetings, we educate the public about the implications of hearing loss, which empowers many and enables them to improve the quality of their lives.

We strive to make a difference in the lives of children with hearing loss, so each year, we manage a toy drive for schools that serve deaf and hard of hearing students. We also collect donated dresses, suits, jewelry and shoes for deserving teenagers who want to attend their proms. In addition, we use social media to communicate with teens who have hearing loss. For example, we launched a Facebook young adult VIP page to bridge the communication gap between deaf and hard of hearing youth and their peers who hear. Our efforts earned this chapter the HLAA Social Media Award in 2019! We also like to give back to the families, volunteers and members who make a difference, so we celebrate them by sponsoring family events. Perhaps most important, though,



From left: Rashaun Boyd, member; Sasha Black, member; Shelly Simpson, president; Gina Petrus Thomas, treasurer; Elizabeth Hill, director of NJ Division of the Deaf and Hard of Hearing; Latisha Porter-Vaughn, co-founder and former president; Arlene Romoff, HLAA NJ State Association; and Lisa Webb, vice president.

is the fact that when we open our doors, we provide an opportunity for people to share their personal feelings and experiences in a safe environment where deaf and hard of hearing people can connect comfortably with others.

Please share some of the ways your personal experiences inspired you to play an active role in creating the Essex County Chapter.

Shelly: I suspected that my son, Rashaun, had hearing loss when he was just two-and-a-half or three years of age. He was unable to form sentences, and he could not enjoy television programs except at loud volume. I noticed that he stared at my mouth when I spoke, and if I spoke to him while his back was turned, he couldn't hear me. Experts confirmed that Rashaun had hearing loss following three failed hearing tests and a sleep study test. When he was four, he began wearing hearing aids and started speech therapy.

I was overwhelmed at first, but I did my research and found some resources, which at the time were limited. There were few schools in New Jersey for the deaf and hard of hearing. Rashaun excelled over the years academically, and he became fluent in American Sign Language. At about that time, I discovered the absence of social networks for deaf and hard of hearing children, teens and young adults in my demographic area. That is when I was introduced to HLAA, and I met Latisha after reading an article in an HLAA State Organization



From left: Lisa Webb, Gina and Gianna Thomas, Frank Barnes III, Latisha Porter-Vaughn, Elizabeth Hill, Rachel Lieberman (back), Arlene Romoff, Shelly Simpson, and Rashaun Boyd.

newsletter. We connected and discussed starting a local chapter. Our goals include bringing deaf and hard of hearing people together to reduce their feelings of isolation, improve their coping skills and facilitate a social support network with educational outings, meetings and events.

I wanted Rashaun to see that he can accomplish anything in life and live well with hearing loss. I knew the impact of mentors and role models, and I could see that starting a chapter would provide him with support, guidance and opportunities. I could also see the value of increasing social interactions among him and his peers, as well as his peers who do hear. My involvement in the launch of our local HLAA Chapter was fueled by my son's needs, as well as my own recognition of the value of chapter resources in facilitating social capital and engagement with the community, as well as managing life with hearing loss.

Latisha: Growing up, I didn't know I had hearing loss, and it wasn't detected until I moved from Ohio to New Jersey to live with my oldest sister at the age of 19. At that time, the only people I had seen who wore hearing aids were my grandmother, dad and aunt. I have sensorineural hearing loss and wear two behind-the-ear hearing aids, but I have never allowed my hearing loss to stop me from believing in my dreams.

Gina: Giana was born profoundly deaf and failed the universal newborn hearing screening test. By the time she was three months old, she had endured many tests and

doctors' visits that confirmed her deafness. This was devastating for my family, and I passed through a season of anger, fear and denial. Once I got beyond feeling sorry for myself, I rose to the occasion and decided to become the best advocate possible for my daughter. I visited with our audiologist team and reached out to the New Jersey early intervention program. I became proactive, as well as a problem-solver. Giana was implanted with a cochlear implant at the age of 16 months, thanks to Advanced Bionics, and later I enrolled her at Summit Speech School for early intervention. She then transferred to the Hackensack

School. After her cochlear implant surgery, we had high hopes and could not wait for Giana to start developing her speech and language skills; however, her communication was still delayed. We took action and enrolled her in a total communication school, which includes signs, gestures, fingerspelling, body language, listening, lipreading and speech. Today she is fluent in American Sign Language.

A fundamental human need inspired the idea to create the HLAA Essex County Chapter. Shelly Simpson, Gina Thomas, and Lisa Webb shared a common goal: to build a community that would support their children, who were challenged by varying levels of hearing loss.

Lisa: Shortly after my son, Naim, received his hearing aids, I felt insecure about taking him into the "mainstream" world. Naim is the only person with hearing loss in our family and neighborhood, and I felt that might saddle him with a sense of isolation and the feeling of being different. I was still in the early stages of dealing with his deafness, and I was not sure how to talk to people about it or answer their questions. I felt like I needed to reach out to the Deaf community so my family and I could learn more. I found a few internet websites and through doctors, school services and support groups, I learned about auditory verbal therapy, American Sign Language and total communication. I discovered that some people were very passionate about their chosen

therapy and spoke of it with great conviction. I enrolled my son in school and camp programs that would reduce his sense of isolation by providing an environment for him to learn with others like him.

Gina: One thing I have learned from this experience is that your perspective determines whether you will focus on the problem or find a solution. I chose to find the solution for my girl. Giana is involved in dancing and swimming, and I want her to understand that she is not limited because of her hearing loss.

Lisa: Both my membership in HLAA and my service as vice president of the Essex County Chapter have given me the opportunity to learn and share my experience with others. I've discovered how valuable good mentors and friends are to me, as well as how important a sense of belonging is for our families. Being a part of HLAA has taught me ways to encourage Naim to have fun and develop his potential in a nurturing environment. It has also helped me guide him in making a contribution to society at large by participating in community service projects. That positive experience has helped me see that my son has a special gift: he is able to live in two worlds—the hearing and the deaf—and he is comfortable in both. And so am I.

The group found that creating a local chapter also began a new chapter in each of their own lives: it empowered all of them with a deeper understanding of hearing loss and put beneficial resources and networks, as well as social activities, within their reach, as well as the reach of others in the community.

Latisha: While I was initially interested in starting our chapter because of my own hearing loss, I can relate to each of my team's/friend's stories. I've faced many challenges while learning about my hearing loss, and I'm grateful for the role launching the Essex County Chapter has played in helping me overcome them. The entire experience has helped me open many new doors, develop great relationships, expand my social networks, hone my leadership skills and publicize the impact our chapter has made in the lives of many people. **HL**



HLAA

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Microtia and Atresia Navigating a World of Difference

BY CAMILLA N. GILBERT

I was born different. At birth, I had a very rare deformity with both of my ears called microtia and atresia. Here is the story of my journey.

Labeled Before I Had a Name

I was born in Cincinnati, Ohio, and lived in the West End community. I was the firstborn and the first grandchild in my entire family—as well as the first baby born with two non-developed ears. My journey with bilateral microtia and atresia began in December 1982, when I entered this world and was immediately labeled “abnormal and defective with special needs” before I was even given my name: Camilla N. Gilbert. My parents felt shocked and anxious, but they were never ashamed of me; they encouraged, supported and loved me for who I was. They were also not too focused on the many recommendations from various professionals, audiologists and surgeons, who wanted me to have surgery and ear reconstruction in the late 1980s. My parents declined their suggestions about fixing my ears, preferring to allow me to make my own decision when I was ready.

School of Hard Knocks

My school system seemed to focus on my “disability,” rather than on my capabilities. I recall feeling different at the age of three, when I entered preschool, and according to my Individualized Education Program (IEP), I was different. I was grouped with other students who were different, too. The students in my classes did not look, act or learn the same way the rest of the student body did, nor were we treated the same way. At first, I thought that riding a short, yellow bus to and from school was fun, but I quickly realized that this mode of transportation labeled me as a student with a learning disability, even though I was actually intelligent. For example, I had to leave class ten minutes early just to get on this special bus, and I recall feeling embarrassed because my classmates made fun of me. I often asked myself, “Why do I have to live like this? Why am I so different? Why don’t I have ears like everyone else?”

My physical appearance did not help my self-confidence. I had ears that resembled pizza slices and walked around wearing an uncomfortable, metal hearing aid device. Enduring stares and teasing became norms for me as a child, and I hated it. I used to look down while walking in public to try to avoid the humiliating moments when others would stop, stare, point and laugh at me. I became known as the smart student with no ears, and I was bullied until the seventh grade. I suffered many physical, emotional and verbal attacks simply because I looked different.

My parents may have told me about my condition, but I refused to accept the diagnosis. I just wanted to be normal. To me, being normal was having the ability to plug my ears with my index fingers like other kids, but I did not have ear canals. I longed to play the telephone game with my classmates and hear what they might whisper in my closed ear, but I could not.

As it turned out, though, my experiences of riding the short, yellow bus, learning in a segregated, special education classroom and being bullied by other kids were excellent preparation for the many obstacles I was to face in living with microtia and atresia.

Hiding Behind a Headband

In seventh grade, I discovered cloth headbands, which I used to cover my ugly hearing aid and unusual ears. My cloth headbands became my safety net when I left my house and ventured out into the community. I wore a headband every day, no matter the location—school, friend’s or family’s homes or sporting events—and no matter the occasion—weddings, funerals or parties. I was ashamed to display my uniqueness, so I covered my ears and hearing aid for more than 13 years. In my isolation, I developed low self-esteem, confusion and depression, which continued into my early adulthood.

Embracing Motherhood—and My True Self

I graduated from Central State University in 2005, and I began to be curious about myself. I wondered why I did not have fully developed ears. I began researching

bilateral microtia and atresia. In 2007, I found out I was expecting a baby girl, and I felt ready to take on the role of motherhood. When Jada, my daughter, was born, I had her ears checked and requested a hearing test. Everything was normal! At that time, I was still covering my ears and hearing aid with cloth headbands, but I knew I had to stop hiding from the world. Becoming a mother changed my mindset; I began to accept myself as a woman who happens to have microtia and atresia. By 2009, I had stopped wearing the cloth headbands and began focusing on being my true self and becoming a role model for Jada.



Camilla in the first grade

Connecting With the Hearing Loss Community

I began seeking ways to connect with people who understood my experiences living with a hearing loss. In 2012, I discovered HLAA and attended my first Walk4Hearing event, where I met others in the hearing loss community who were not only knowledgeable but also proud of their achievements. This was the first time I had experienced a community of others who understood my invisible “disability.” HLAA empowered me to make a contribution to my new community by sharing my story and experiences. I participated in the third annual HLAA Ohio Chapter Leaders Conference in Newark, Ohio, in August 2012; the HLAA Fall 2012 Leadership Training Conference in Bethesda, Maryland, in October 2012; and the HLAA Convention in Portland, Oregon in June 2013. Attending these events enabled me to connect with a caring network and gave me an understanding of leadership roles in the hearing loss community.



Camilla with her daughter, Jada

Soon I discovered the organization known as Ear Community, which is an online resource designed to help children and adults with microtia and atresia. I was able to meet others with microtia and atresia and attended Ear Community’s Microtia and Atresia Picnic in 2013. I recall feeling excited, overwhelmed and emotional in the company of others who understood the obstacles and challenges that I faced. Parents of children with microtia and atresia and adults with the same condition wanted to hear my perspective, experiences and advice. This experience led me to a new passion: educating others about hearing loss and microtia and atresia, as well as motivating them with emotional support.

Before I knew it, I had become an advocate—before I even knew what advocacy was—for a condition that used to bring me shame. Throughout my life, even with the odds against me, I had always prevailed and overcome any obstacle. As I stepped into an advocate’s role, I felt empowered to offer encouragement to others



The future Dr. Camilla Gilbert

I have overcome the obstacles of living with microtia and atresia with perseverance, ambition and community support. My challenging experiences provided the foundation for the life I've built today because as difficult as they were, they sparked empathy for individuals with disabilities and hearing loss.

who have my condition or any form of hearing loss. My creator did not design me to be isolated in my skin but to empower and inspire others to conquer obstacles in their hearing loss journey.

Finally, after a lifetime of wearing analog bone conduction hearing devices, I decided it was time to upgrade and try something new. I chose not to have ear reconstruction surgery. Instead, I consulted medical professionals, hearing loss community members, HLAA and Ear Community associates and decided that the bone-anchored hearing system was the best choice for me, and I had my implant procedure with Oticon Medical in 2014.

Coming Out of My Shell

Society's correlation of the term "deaf" with the concept of "dumb" had stigmatized me in my youth, so I had long been dismissive of my own culture. I also had a negative association with sign language, since it fell outside of our cultural norm. However, my ideas were beginning to change, and my changing mindset led me to enroll in Cincinnati State Technical and Community College with the goal of becoming an American Sign Language interpreter. In the process, I ended up learning more about myself as a person with a hearing loss. My instructors there were deaf, and they taught me about their language, culture and experiences. I learned that they did not feel abnormal in our society, and that deaf people just want to be themselves. They are not interested in conforming to the standards of the hearing community.

This was my "aha" moment, and I began to re-evaluate myself as a person who was born deaf. I realized that I had been misinformed for most of my life about the hearing loss and deaf community. Suddenly, I was on a mission: I wanted to educate and motivate others living with differences to be themselves and resist forced assimilation into a cultural standard that excludes them. This realization forged a new path for me, and I decided to switch my field of study from social work to education.

Achieving My Full Potential: Advocate and Educator

I am now enrolled in the Doctor of Education in Educational Leadership program at Northern Kentucky

University. My purpose is to be an effective educator who offers empathy and motivation to people in the microtia and atresia, hearing loss and deaf communities. I also want to raise awareness of the needs and perspectives of people in these communities. My hope is to challenge those in the hearing community to re-evaluate, restart, regroup and reinvent their preconceptions when interacting with individuals who have hearing loss. I want to reinvent the mindset of people who pity those who were born different. I grew up being stared at and pitied—mostly by people who judged me even when that was not their intention. I hope to educate others through my experiences as a person stigmatized at birth with the "disability" label. I want to inspire those with hearing loss to defeat all odds and become knowledgeable, and I intend to accomplish this through education, advocacy and mentorship.

I have overcome the obstacles of living with microtia and atresia with perseverance, ambition and community support. My challenging experiences provided the foundation for the life I've built today because as difficult as they were, they sparked empathy for individuals with disabilities and hearing loss. They also ignited a genuine passion to encourage and inspire others who have endured the stigma of being different from "normal" society.

Becoming an inspiration for those who look like me has motivated me to be a leader and advocate. After connecting with the hearing loss community, I developed the confidence to speak up and educate others. My passionate advocacy for individuals with differences will only continue to grow, and I am proud to be a leader in helping others who feel they do not have a voice. **HL**



Camilla N. Gilbert has been an advocate for people with hearing loss for more than 30 years. She is the recipient of the 2015 Oticon Focus on People Award for Advocacy, has served as a board member for the non-profit organization Ear Community, and is a past president of Southwest Ohio Chapter of the Hearing Loss Association of America (HLAA). She is attending Northern Kentucky University for a Doctor of Education Degree in Educational Leadership. She has a Master's in Social Work from the University of Cincinnati, a Bachelor of Science in Computer Science and Mathematics from Central State University, and a Certificate in Deaf Studies from Cincinnati State Technical and Community College. She can be reached at microtialife@gmail.com. Follow her on Facebook and Instagram @microtialife.



Experience HLAA Virtually!

We plan to deliver some of the featured content, such as the Research Symposium, from HLAA2020 online in June. We are looking into technology solutions and talking with our sponsors about how best to do this. So stay tuned for our Virtual Events!



HLAA is very disappointed that HLAA2020 Convention in New Orleans was canceled due to the global pandemic, COVID-19.

We hope to see you in beautiful San Diego in 2021!



June 24-26, 2021 / Town and Country / 500 Hotel Circle North / San Diego

Women with Hearing Loss Experience Higher Rates of Complications in Pregnancy and Birth

BY DR. MICHAEL MCKEE AND DR. MONIKA MITRA



You see the results of a positive pregnancy test and a range of emotions hits you. You are pregnant! For many women, it can be an exciting time and for some, even a scary time. For women who are deaf or hard of hearing, this also becomes an important time to think about ways to have a healthy pregnancy.

A 2016 article in the *American Journal of Preventive Medicine* raised concerns that women who are deaf or hard of hearing were more likely to experience low birth weight and preterm births. Amid the current increasing focus on addressing maternal and infant health gaps among disadvantaged populations, this was the first time that pregnancy and birth health concerns were identified among women who are deaf or hard of hearing. Additionally, there has been recent research using the Massachusetts Pregnancy to Early Life Longitudinal data system that links birth certificates, fetal death reports and delivery—and non-delivery-related hospital discharge records for all infants and their mothers.

This rich dataset, which includes women who gave birth in Massachusetts between January 1998 and December 2013, allowed researchers to deeply probe pregnancy and birth health outcomes for women who are deaf or hard of hearing. When findings were published in 2020, they demonstrated that women who are deaf or hard of hearing were not only at higher risk for adverse birth outcomes, but were also at elevated risk for a variety of health conditions that could impact their pregnancies.

Several health conditions, including diabetes, hypertension, gestational diabetes and preeclampsia or eclampsia, were more common in women who were deaf or hard of hearing than in hearing individuals. Women who were deaf or hard of hearing were also more likely to have cesarean sections and to encounter longer hospital stays after giving birth. This contributes to the growing list of publications demonstrating that individuals who are deaf or hard of hearing struggle with a variety of health disparities, including mental, cognitive and cardiovascular health.

To help us understand why women who are deaf or hard of hearing are more likely to encounter health concerns during pregnancy, the Eunice Kennedy Shriver National Institute of Child Health and Human Development at the National Institutes of Health awarded a 5-year grant to Monika Mitra, Ph.D., of The Lurie Institute for Disability Policy at Brandeis University's Heller School for Social Policy and Management and Michael M.

McKee, M.D., MPH., associate professor and Lead Director of MDisability at the Department of Family Medicine at the University of Michigan, along with their colleagues, to help study the problem.

The results continued to demonstrate that deaf and hard of hearing women were at increased risk of developing chronic diseases and having pregnancy complications, premature delivery and a baby with very low birth weight. It was time to identify what may be driving these health disparities and find ways to intervene. —American Journal of Preventive Medicine

Drs. McKee and Mitra and their research teams set about exploring these drivers by interviewing 67 mothers across the United States who are deaf or hard of hearing with the aim of understanding what may be driving the women's increased risk for adverse birth outcomes. Many of the mothers described challenges with finding relevant, accessible pregnancy information, as well as significant communication breakdowns in health care settings. "With my [medical] chart being passed around so many times...I don't know if they knew I had hearing loss or not," stated one of the participants. Another described being taken for an emergency cesarean section, saying "I didn't have a clear idea of what was going on. The doctor was not my doctor, and everybody had face masks on, and I...need face masks removed so I can read their lips." Participants often highlighted the need for health care providers to both identify and understand how to care for women who are deaf or hard of hearing.

Findings from these interviews helped the research team develop a series of questions for the first national survey solely designed for women who are deaf or hard of hearing. Their responses helped the team learn more about the women's personal and health care system-related pregnancy experiences, unmet needs and barriers and/or facilitators to a healthy pregnancy. **HL**

Dr. McKee is a family physician with clinical and research expertise in disability health. As a physician with hearing loss, he is an advocate for the rights of patients to obtain equitable health care, including accessible communication. His research focus includes health disparities for individuals with various disabilities, health information accessibility, health literacy and telemedicine applications. Dr. McKee is on the board of the Association of Medical Professionals with Hearing Losses (AMPHL). He is an appointed member of the Roundtable on Health Literacy of the National Academy of Sciences, Engineering, and Medicine. He is also a member of the AcademyHealth Disabilities Research Interest Group (IG) Advisory Committee.



Dr. Monika Mitra is the Nancy Lurie Marks Associate Professor of Disability Policy and Director of the Lurie Institute for Disability Policy at Brandeis University. Her research examines the health care experiences and health outcomes of people with disabilities, with a particular focus on sexual and reproductive health of women with disabilities.

RESOURCES

According to Dr. Mitra, "The findings from this research will help develop evidence-based policies and practices to guide and improve health care providers who provide perinatal care for women who are deaf or hard of hearing." Drs. Mitra, McKee and their colleagues intend to develop perinatal care recommendations to provide clinicians with practical tools that address the unique needs of women who are deaf or hard of hearing.

Survey Now Available: If you are a deaf or hard of hearing woman who has given birth in the past ten years, please read more about participating in the survey at: <http://sardiprogram.com/DeafPregnancyOutcomes>. The survey is both accessible and available in American Sign Language, English and Spanish. Participants who complete the survey will also be entered into a drawing for Amazon gift cards. The survey will go live in May.

Survey Results: Press release for the *American Journal of Preventive Medicine* (AJPM): medicine.umich.edu/dept/family-medicine/news/archive/202001/new-study-finds-deaf-hard-hearing-women-more-likely-have-pregnancy-complications

Article Citation Link: Mitra M, McKee MM, Akobirshoev I, et al. Pregnancy, Birth, and Infant Outcomes Among Women Who Are Deaf or Hard of Hearing. *American Journal of Preventive Medicine*. 2020. doi:10.1016/j.amepre.2019.10.012.

Publication that Prompted the Grant: [ajpmonline.org/article/S0749-3797\(19\)30477-5/fulltext](http://ajpmonline.org/article/S0749-3797(19)30477-5/fulltext)

Wireless Works for Employees with Hearing Loss

PROVIDED BY CTIA

Wireless makes it easier than ever to connect with the world around us. That's particularly true in the workplace. Employees with hearing loss can tap into the power of their wireless devices to hear and more easily engage during meetings, presentations, conference calls, and in conversations with co-workers. Thanks to the wireless industry's collaborative relationship with the accessibility community, built-in features and apps have been designed with accessibility in mind to "work" for people with hearing loss.

Built-in speech-to-text features available on most smartphones and tablets are a great starting point to customize your personal wireless experience. Mobile apps that provide

live captioning are also great examples of tools in your wireless communications toolbox that can expand the capabilities of your device.

CTIA's accesswireless.org is a helpful website for finding information about the latest accessible devices and apps that fit your specific needs. From the homepage, you can find a searchable database—called GARI—that provides details about more than 300 wireless accessibility features, as well as consumer resources specifically designed for people with hearing loss.

CTIA is proud to work closely with HLAA to continue to advance the way we all communicate through wireless. If you're interested in learning more about how wireless is working for people with hearing loss, visit accesswireless.org. **HL**

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You can contact CTIA by email at CTIAExtStateAff@ctia.org or by phone at 202.736.3200 with any questions.

IN MEMORIAM

Grace Waegell Tiessen, "Our Miss Grace"

BY Nanci Linke-Ellis



Grace Waegell Tiessen, affectionately known as “Our Miss Grace,” passed away on March 23, 12 days shy of her 101st birthday. She passed away calmly and quietly in Pasadena, her home for 74 years. Grace Tiessen was a legendary pioneer of hearing loss causes, and had been a champion of SHHH, HLAA, and HLAA-CA for more than 30 years.

Grace was the editor of the HLAA-CA State Association newsletter, *The Hearing Loss Californian*, from 2001 to 2019. Grace was president of the HLAA (called SHHH at the time), San Gabriel Valley Chapter from 1985 to 1990. Furthermore, Grace was a member of the HLAA-CA State Board of Trustees from 1997 to 2011, where she also served as corresponding secretary (1997–1998), vice president (1999–2000), and president (2001–2002).

For decades, Grace had been deeply involved with HLAA, doing outreach, participating in Walk4Hearing, performing advocacy, attending meetings, hosting Christmas parties, and anything to help further the aims of HLAA. Grace recruited and mentored scores of young adults for HLAA. She was a role model to many.

Grace was a member of the California Department of Education Advisory Task Force for the deaf and hard of hearing; a member of the Board of Directors of the HEAR Center, a nonprofit speech and audiology center in Pasadena, from 1996 to 2007; and a member of the City of Pasadena Commission on Accessibility and Disability from 1990 to 1995. Grace was the recipient of HLAA’s 2003 Keystone Award.

Grace was born in 1919 in Sacramento, California, just one year before women were able to vote. Grace attended UC Berkeley, graduating in 1940 with a bachelor’s degree in English. Later, Grace obtained a second B.A. in Psychology from California State University of Los Angeles, then a third B.A. in Math and Computer Science. Grace worked as a software engineer for Jet Propulsion Laboratories (JPL) from age 62 to 73.

At UC Berkeley, she met and married, Leonard Edmondson, who was an artist and art professor. They had three children: a son, a daughter, and then a second son. In the 1970’s Grace took her mother’s name, Tiessen.

Grace grew up with hearing loss, started wearing two hearing aids in 1970, and later was the recipient of bilateral cochlear implants. **HL**

Nanci Linke-Ellis was appointed HLAA Southern California Chapter Coordinator in 2010 until she retired in June 2016. She was an elected HLAA-CA trustee 2007–2009. She is a hearing loss and disability consultant to movie studios, theatres, and the film industry. She is an experienced captioning advocate and a partner of Captionfish, an entertainment deaf and hard-of-hearing source. She holds a BFA in theatre from Ohio University, Athens, Ohio. Nanci has hearing loss, uses cochlear implants, and lives in Santa Monica, California.



My Friend *Amazing Grace*

BY ZINA JAWADI

On June 30, 2012, a beautiful warm day, I drove to Pasadena in southern California to attend my first Los Angeles Chapter meeting of the Hearing Loss Association of America (HLAA), the nation's largest nonprofit organization serving people with hearing loss. At the time, I was 17 years old and would often sit by myself during lunch at school, because it was less isolating for me to eat alone than to sit in the noisy cafeteria where I could not hear anything because of my hearing loss. Five minutes after I arrived, I introduced myself to Grace, better known as Amazing Grace, a then 94-year-old woman wearing a green shirt, yoga pants, and Coach brand sneakers. Unsure how to converse with a lady more than five times my age, I complimented her on her shoes. We then started chatting about my internship at the former House Research Institute (now House Ear Institute) in Los Angeles, my volunteer experiences, and my academic pursuits. Other HLAA-Los Angeles Chapter members interrupted our conversation to either excitedly introduce themselves to me or to admire Grace's efforts as former president of the HLAA California State Association.

Two weeks later, I drove north to attend my second chapter gathering. Although my father was driving above the speed limit on the way to Simi Valley, a large car passed us on the right on the freeway. Arriving, I noticed that same large vehicle was parked—it was Grace's. She had driven more than an hour by herself to attend the event. Halfway through the meeting, Grace suddenly asked me, "Would you like to run for the HLAA-CA state board?" My jaw dropped, unsure how to respond. I thanked her for her faith in me and scheduled a time to connect with her. On the way back, Grace passed us again on the freeway, speeding back to Pasadena where she lived.

A week later, I met with Grace at her house to continue the discussion. She gave me examples of resumes of prior board applicants. My hands began to sweat when I noticed the resumes of members with 30 years of work experience, and people who had been

members of HLAA before I was even born. At the time, I could not understand why such a highly-respected woman would nominate a 17-year-old high school student for a state board. She insisted that HLAA needed younger voices like mine, but I remained incredulous. I took Grace's advice and submitted my application. To my delight I was accepted, becoming the youngest board member of any HLAA board nationwide ever. I am and will always be so humbled and grateful to have received this honor. It is ultimately because of Grace that I was able to begin my advocacy dreams that started in eighth grade—becoming active with HLAA. Eight years later, in 2020, I am serving on the HLAA Board of Directors.

I met Amazing Grace again at the 2013 HLAA Convention in Portland. This time, I spent hours with her, discovering that she is not only a dedicated advocate for a great cause, but also a brilliant, classy, and sharp woman. Grace grew up with hearing loss, which was not diagnosed until she was 50 years old. She would be one of the few female undergraduate students, let alone one with disability, at UC Berkeley, decades before the Americans with Disabilities Act was enacted.

Her class was seated alphabetically, and with her last name beginning with W, Grace was regularly placed in the back of very large classrooms. She still managed to graduate, which is extraordinarily impressive. At the age of 65, wishing to be challenged more, Grace decided to study computer science, obtaining her third B.A. (this time in math and computer science), and then working as a software engineer.

Grace discovered HLAA more than 35 years ago, shortly after retiring from her engineering job, and remained very active. Grace is highly respected across HLAA locally, statewide, and nationally. After all, she attended almost every convention, served as chapter president and as HLAA-CA president, and was an active participant and team leader in the annual local Walk4Hearing, raising thousands of dollars annually. She would spend hours in Los Angeles traffic to attend HLAA-CA's full-day board meetings, even after her

board term finished. For 18 years starting in 2000, Grace served as editor of the HLAA-CA newsletter, *The Hearing Californian*, which was mailed to thousands of individuals across California every three months. She edited the newsletter, expanded membership, fundraised, and solicited and signed up advertisers. Grace was extremely passionate about hearing accessibility. In the words of Grace, “I live in Pasadena, and they say that we have a very accessible city. But it’s not true. It’s totally inaccessible to people with hearing loss.”

Although I do not live in southern California, over the years, I seized any opportunity to see Grace in Los Angeles, HLAA-CA board meetings, and HLAA conventions. We had a reputation of being, at the time, the oldest and youngest HLAA members in California, and possibly across the nation. Amazing Grace may have been the oldest member, but her energy was exhilaratingly youthful. Grace managed to find time to go to the gym several times a week. A highly intellectual lady, Amazing Grace constantly had a facial expression of curiosity, advocated for underrepresented groups, and demonstrated for social causes.

I most admire Grace’s dauntlessness, wit, dedication, and faith in others. She changed the lives of so many people, including mine. She believed in my potential as a young person with hearing loss, and tirelessly served as my mentor for years. She had also greatly contributed to the hearing loss community. Grace is one of my greatest friends, and I love and care for her deeply.

Amazing Grace was determined to turn 100, and she did. In fact, the first time she gave me an invitation to her 100th birthday party (April 4, 2019) was seven years earlier in the summer of 2012. Although I could not attend Grace’s party, I did visit her on August 22, 2019 during a short trip to LA. She met me at her front door and led me to her office, which had photos of her family’s farm in Sacramento, collections of meaningful items such as petitions and socially progressive books, and several large computer monitors. Grace’s office was more technologically advanced than mine.

I asked how she was since fully retiring from doing the HLAA-CA newsletter in 2018. For the first time in her life, Grace was truly retired. She continued to go to the gym, although not as frequently as before. Grace, her son Stan, and I discussed what Grace’s next milestone should be—perhaps turn 105—but she was content enjoying life day-to-day.

I was sharing with her my major life updates, including finishing my master’s degree at Stanford and beginning my first full-time job. I also started ranting about some negative experiences that happened a couple



Amazing Grace, you are a legend. You are what I want to be—a Grace to a young child with hearing loss. I am extraordinarily grateful to you for changing my life, for seeing potential in me when I was so young, and for making the earth a better place to live. You served as an inspiration to people across the nation. You helped give me the strength to stop sitting by myself during lunch. I have since gained a phenomenal set of friends, including you, and I am also a member of the beautiful HLAA family. For that, I am forever indebted to you. You are my hero. Thank you for being a Grace to humanity. Your spirit and legacy will carry on forever. You have left an indelible imprint on my life, and I will never forget you.

For links on Amazing Grace, please see these links:

<https://youtu.be/F0fVbZWDaIE>

<https://youtu.be/phPIXSiInz4>

<http://www.hearinglossca.org/the-amazing-grace-tiessen-a-personal-journey-of-growth-and-courage>

<http://www.hearinglossca.org/grace-tiessen>

<https://hamiltonrelay.com/news/grace-tiessen-selected-for-hamilton-relay-2015-better-hearing-and-speech-month-recognition-award-for-the-state-of-california-477.html>

<http://www.hearinglossca.org/recognizing-grace-tiessen>

of months earlier. All of a sudden Grace started laughing. I asked her, “Grace, why are you laughing?” She replied, “Life is too short to let that frustrate you.” For the first time in months, I started laughing about something that had been bothering me for months. She brought some life perspective I needed. Before heading to my hotel, I gave Grace a huge hug and said goodbye. Each time I saw Grace, I made sure she knew how much I appreciated her.

I was hoping to see Grace in early April this year, but due to the COVID-19 outbreak, my trip to Los Angeles was cancelled. Earlier last month, I contacted Stan to FaceTime with Grace.

Sadly, August 22, 2019, would be the last time I would see Grace in person. In the middle of the afternoon on Monday, March 23, while working on a cold rainy day in northern California, I found out from Stan that Grace had passed away the previous morning. Fortunately, though, Grace died the way she wanted—of natural causes, with her family, and with little pain. In a way, it is beautiful that her destiny was to pass away at 100, the age she had been so determined to reach. Although I miss Grace so much, I am so glad I spent time with her, and that she watched me grow from a high school student to a working woman. I also know that Grace would not want us to be sad. After all, she embodied what it means to have a meaningful, fulfilled life. **HL**



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2019, both from Stanford University. Zina has been serving on the Hearing Loss Association of America Board of Directors since 2019. Previously, she served as trustee (2013–2019), secretary (2013–2014), vice president (2014–2015), and president (2015–2019) of the Hearing Loss Association of America, California State Association.

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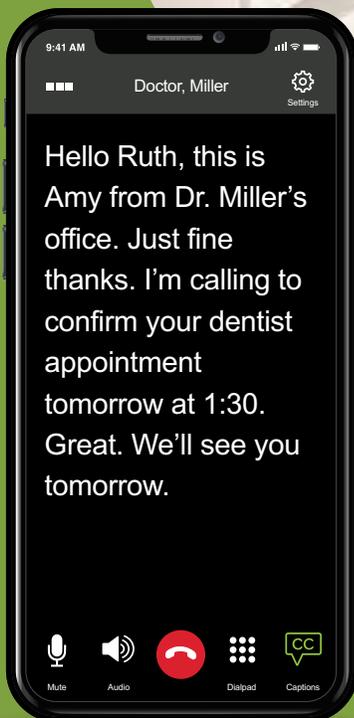
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