

The newsletter of the Hearing Loss Association of America, Albuquerque Chapter

WIRED FOR SOUND

Advocacy Matters: Be the Change

Melisa Tumblin in the HLAA Magazine summer edition¹

Hearing loss can be a different journey for each one of us. It can be the only thing we have known since birth, or it can show up later, changing our lives forever. Some of us choose to embrace hearing loss, and others continue searching for options to try to restore their hearing. Either way, what matters most is that you find what works best for you. But what happens when you find what works best for you and then cannot get it?

People assume things are just fine unless someone speaks up about it, but if no one speaks up, things will never change. This is why it is so important to advocate for the things you believe in. In fact, advocating not only provides the opportunity for individuals to enjoy a better quality of life but also improves standards of care and life for entire communities.

We Felt So Alone

In 2009, my daughter, Ally, was born without her right ear and also without an ear canal. This condition is known as microtia and aural atresia. In the beginning, our family felt very alone and could not find the answers we were looking for. As a mother, I wondered if I had done something during my pregnancy that may have caused Ally's ear to be missing, even though I had a healthy pregnancy. My family felt lost from being caught up in all of



Melissa Tumblin and Ally



the worries and concerns we had for Ally, and we had no one who could explain to us what we needed to do. There was no community we could join comprised of children and adults just like my daughter, and we didn't have a good understanding of Ally's hearing loss. The medical professionals we consulted at Ally's newborn hearing screening remarked, "She has one good ear and that's good enough."

Our Baha Breakthrough

When Ally was nearly 10 months old, our family realized she wasn't hearing very well. She seemed to be a quiet baby, and one day when I dropped a pan on the floor, she wasn't startled by the loud noise. After wondering if she was struggling to hear, I read about a hearing device online that we should have been told about: a bone conduction implantable hearing device (Baha). Within a couple of weeks, we were able to obtain a loaner Baha from our audiologist. When our audiologist switched the Baha on and whispered Ally's name behind her ear, she whipped her head around, smiling as her face lit up! We both had tears of joy in our eyes, seeing

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¹ https://www.hearingloss.org/wp-content/uploads/HL_2021_3_Tumblin.pdf

WIRED FOR SOUND

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HEARING LOSS ASSOCIATION OF AMERICA
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Providing support and advocacy for
people with hearing loss

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Hearing Loss Association of
 America – Albuquerque
chapter

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16 Oct Meeting 10:00 AM - Noon On **Zoom**

The delta variant surge continues, and so do restrictions. We will continue meeting only on Zoom in October. Our Web Page (HearingLossAbq.org) will have the link to join the Zoom meeting.

Tinnitus: Research and Resources

For the month of October we will be welcoming Dr. Julie Prutsman. Her presentation will focus on ATA updates regarding research and resources for tinnitus management. Tinnitus is the sensation of hearing sound in your ears or head when no external sound is present. If you're experiencing signs of tinnitus, you're not alone.



Dr. Prutsman is the owner and founder of Sound Relief Hearing Center and a third-generation audiology professional. She currently serves on the Board of the American Tinnitus Association, American Academy of Audiology and the Colorado Academy of Audiology.

Upcoming programs:

Scheduling programs and speakers has become more difficult during COVID. Last-minute changes may happen after Wired For Sound is published. Check our Home Page, HearingLossAbq.com, for the latest information.

The HLAA ABQ Chapter is always looking for volunteers. You can man a special project. You can help us out for a few months, or consider a longer-term commitment. "Try us out" for a month or two. We will provide orientation for working on a nonprofit board, share our chapter's mission and goals, and discuss topics we can use your help with. If interested, contact any board member (contact info at left), or use the chapter email hlaabq@gmail.com.

how she responded to sound on that side of her head and seeing her facial expressions. It was truly a seeing-is-believing moment!

Ally's early intervention therapists said it was as if someone flipped on a switch and she had become re-engaged with her environment. When it came time to obtain a Baha for Ally, our insurance provider didn't cover this type of hearing device and denied our claim. We couldn't believe it. We not only knew our daughter was missing her ear and had no ear canal, resulting in a diagnosis of moderate to severe hearing loss, but she also faced a barrier to getting the very device that would help her. Ally's hearing test showed how her hearing loss was brought right back up within normal hearing range when aided with a bone conduction implantable hearing device. I had to ask myself, "Why would I not want my daughter to hear better with this hearing device? And why will our insurance not pay for it?"

Taking Matters Into Our Own Hands

Fast forward a decade later. After founding the Ear Community Organization and watching family after family be denied private insurance coverage for these hearing devices, we began advocating as an organization in 2019. From participating in Advocacy Day on Capitol Hill to meeting with representatives in person, we began advocating for osseointegrated hearing devices, which are surgically implanted in the bone, to be covered by private insurers.

However, when Ally wrote a letter during Better Hearing and Speech Month, that caught the attention of Congressman Joe Neguse of Colorado. As part of a homework assignment, Ally decided to

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Call 1-866-4141 to sign up or re-enroll.
The HLAAbq NPO number for Smith's is 14881.

write to a lawmaker about a cause she cared about. She said, "Mom! We should write about my BAHA!" And, so we did! In her letter to Congressman Neguse, she asked him to help her advocate to hear better, because other kids just like her can be helped by this device but insurance doesn't always cover the expense.

Congressman Neguse wrote to Ally that he would continue to work on ways to help advocate alongside her. In December of 2019, Ally's Act became a reality, ensuring that private insurers would cover osseointegrated hearing devices, including Bahas and cochlear implants, for children and adults from birth to age 64. This January, Ally's Act was the first bill to be reintroduced in Congressman Neguse's office. Ally's Act, H.R. 477 and S. 41, are bicameral, bipartisan, national level bills co-sponsored by Rep. David McKinley and Rep. Mike Thompson, co-chairs of the Congressional Hearing Health Caucus.

You Can Help, Too!

Anyone can write a letter and speak up just like Ally did! If something matters to you, advocate for it. If Ally's Act becomes law, hundreds of thousands of children and adults would have access to life-changing treatment, enabling them to participate in the workplace, school and community of their choice and enjoy a high quality of life. For more information on how you can help support Ally's Act, please visit earcommunity.org.

Amazon Smile You can donate to the Albuquerque Chapter of the Hearing Loss Association of America every time you make a purchase of most of the products from Amazon.

Go to <http://www.hlaabq.com/amazonsmile.html> for more information and detailed instructions on how to designate HLAA-ABQ Chapter as your charity of choice when you make amazon.com purchases.

Once you have set it up, always log into smile.amazon.com to purchase from amazon. 0.5% of the purchase price is automatically donated to HLAA Albuquerque Chapter—at no cost to you.

Will We Ever Meet Live Again?

Bobbi Rodriguez, Treasurer, HLAAAbq

This is a question we all have been asking. In fact, the Board had made plans to resume live meetings with the September meeting. However, with the Delta variant creating a scare, we decided to postpone. We will be continuing a Zoom option no matter what. Zoom allows us a greater choice of speakers, as the past year has shown. It also allows out-of-town members to join the meeting.

Our concerns are your safety and your comfort level. At this point, we could have live meetings, but we feel we would need to require masks. As a hard-of-hearing group that relies somewhat on lip reading, this would be difficult and frustrating.

We did a poll to find out how you felt about the subject and found no definitive answer. If you have an opinion, question or suggestion, please e-mail:

TreasurerHLAAAbq@gmail.com
or EditorHLAAAbq@gmail.com

We, the Board, hope to see you soon in person.

Telecommunication Equipment Distribution Program

Courtney McBride, HLAAAbq

I have a hearing loss and wear hearing aids. This July, I learned about a New Mexico hearing program to help my hearing loss, and the devices offered are free. Yes, free!

You cannot turn that down.

The Telecommunication Equipment Distribution Program (TEDP) is housed in Albuquerque, and the phone numbers are:

V 505-435-9211
TTY 505-383-6541
VP 505-425-9319

So, I called and spoke to Jason Siergey, the program specialist. He said the “showroom” was located at 505 Marquette Ave NW, Suite 1550. I then asked Jason to mail me a catalogue of all the free devices. (They have over 15 devices including iPads, land line phones and hearing accessories.)

I called Jason back and made an appointment. We met in the showroom. It was well lit, quiet, and full of many devices displayed on tables.

We wore our masks, and were able to communicate very well. Jason also has a hearing loss, and knows sign language (if you need it).

I stayed well over half an hour looking at everything and asking questions.

Do you have a personal experience relating to hearing loss that would benefit your fellow HoH readers? It could be something practical or a warning of something to avoid or even something humorous. If you don't mind sharing a short note, send it by email to:

EditorHLAAAbq@gmail.com

Jason explained that if I wanted any of these free items, here is the process. I had the choice to say “thank you, but let me think about it,” or fill out the application. I kept saying “are you sure these are free?” The answer was always “yes.” He told me the State of New Mexico and our land-line phone companies agreed to charge a (small) surcharge to every New Mexican who has a land line. The surcharge pays for the TEDP to help us with hearing loss.

I needed to send Jason 1) certification of my hearing loss from my audiologist, 2) proof of NM residency and 3) a statement that my personal income was less than \$50,000 (not a problem for me). I needed to have a home land-line service or get it at my residence, and WiFi service if I wanted an iPad. They do not offer smart phones, just land lines. That's a good thing for me, because I would be on a smart phone 24/7.

So, I filled out the application and agreed to mail Jason the other required documents, and selected my free items.

Three weeks later, my devices arrived in the mail.

Such a deal! Give Jason a call at 505-383-6530

Amtrak Getting in the Loop

Stephen O. Frazier, Hearing Loss Support Specialist



with customer trip information, a digital seat reservation system, and navigation

In a major upgrade to rail travel, Amtrak has announced that California based Siemens Mobility Inc. will manufacture up to 83 new multi-powered trains consisting of at least five cars each to serve their market. Long term growth plans could add another 130 trains to the fleet. The \$7.3 billion project covers the purchase of equipment and a long term parts and service plus facility modifications and upgrades.

display systems.

Loops to Land at NYC Terminals

The Port Authority of New York and New Jersey has announced a new policy on accessibility for all airplane, bus, train and ferry terminals that it manages in the greater New York City area. Effective March of 2021, any new or significantly upgraded airport terminal in their entire system will be required to install **hearing loops** at all departure gates and information counters. The information counter mandate will also apply to all rail, bus and ferry terminals.



Amtrak said the new trains will offer more comfortable seating, individual power outlets, USB ports and even on-board Wi-Fi.

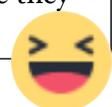
O t h e r amenities will include the fitting of hearing loops, accessible restrooms and vestibules, an accessible food service car and lifts for customers with reduced mobility such as wheelchair users. In response to the Covid 19 pandemic, the latest health and safety standards are being incorporated that include enhanced HVAC, touchless restroom controls and automated steps. The new trains will also offer enhanced lighting and panoramic windows, larger vestibules, and a more contemporary food service experience with self-service options.



In adopting these new requirements, the Authority states that, “ By becoming an early adopter of the groundbreaking space requirements and effectuating other changes based on feedback from people with disabilities that have yet to be addressed in any building code or accessibility standard used in the United States, the Port Authority will be a true pioneer.”

In addition to the new trains, Amtrak reports it plans to make rail travel more digitally accessible

An advertising firm lost an account because they promoted a hearing aid on the radio.



Other Airports

Even before the recent Port Authority rules, their LaGuardia facility in NYC has gotten in the loop by installing induction loop technology at all gates in the new Delta Airlines terminal. At the Delta hub airport in the Twin Cities of Minneapolis/St. Paul, the airport is expanding the presence of hearing loops to new areas in the terminal. The Memphis, TN airport is in the process of looping the gates in the new concourse in their terminal, and LAX will use the technology in a new rental car facility. Completed installations in the Oshkosh, WI and Eugene, OR airports have placed those two facilities on the looped US airports lists. With the Ft. Wayne, IN and Charlotte, NC airports announcing



plans to install loops, that list has grown to 20 airports.

Other Transportation Modes

The city of New York's Metropolitan Transit Authority (MTA) has already looped all of their subway fair/information booths, and now, following the lead of the San Francisco Bay Area Rapid Transit (BART) system, is moving on to subway cars and buses. They issued an RFP for 504 looped subway cars with the option of 445 additional cars, and a second option to buy an additional 415 cars. Meanwhile, NYC Hearing Loss Association of America members were used as volunteers to evaluate the efficacy of hearing loops installed in some test buses by the MTA.

Loop People, Loop Places

Ginevra Ralph

What will they think?

I made a date with a friend who was new to her telecoil to practice using a portable loop. I knew that she had some important meetings coming up with her attorney, and she needed to hear clearly what was being said to her. She also needed practice switching to her t-coil program on her smartphone. I also invited her to go to lunch after our practice in a fairly noisy restaurant, along with my low-voiced husband whom she “can never hear”.

We practiced turning the loop on and off, positioning it near her for signal strength, and moving the additional plug-in mic around to pick up a voice 5-10 feet away. Her biggest challenge was working her cell phone and switching to her telecoil-only or telecoil+mic program. She got it, though!

But then she shyly asked, “How is my lawyer going to feel about me bringing this thing and ask-

ing him to use it?” I told her, “He better feel just fine about it! He wants you to hear what he has to say. Plus, he wants your business! If he gives you any trouble take the loop and your business elsewhere!”

Off we went to lunch, putting the loop on the table, where for the first time I could see that she really was hearing and understanding my husband in conversation. The waiter approached and began mumbling something about the daily specials.

My shy guest suddenly announced, “Just a moment young man!! I need you to speak into this microphone!” And, pointing to the portable loop asked him, “Do you know what this is?” He said, “No, but I expect it lets you hear better. I think I need one!”

So much for being worried about what “they” will think!

I once got an ear infection trying to hear the “snap, crackle, pop” in a bowl of Rice Krispies.



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The Hearing Loss Association of America is a volunteer association of Hard of Hearing people, their relatives and friends. It is a non-profit, non-sectarian educational organization devoted to the welfare and interest of those who cannot hear well. Membership in the national organization is by annual dues, which are separate from the annual Chapter fee paid to your local chapter. National membership includes a subscription to the bi-monthly publication Hearing Life.



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A map of the Los Altos Christian Church area in Albuquerque, NM. The map shows streets like Indian School Rd NE, Haines Ave NE, and Constitution Ave NE. A red pin marks the church location at 11900 Haines Ave NE. Other landmarks include Big 5 Sporting Goods, Arby's, and Chelwood Elementary PFO.

Meeting
HLAA Albuquerque Chapter Meetings are held at Los Altos Christian Church,
11900 Haines Ave NE, on the 3rd Saturday of the month, Sep-Jun.
Socializing starts at 9:30 am; presentation at 10:00.
The public is cordially invited to attend.
on Zoom