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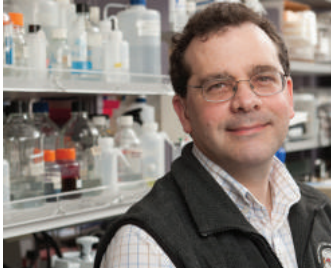
HEARING HEALTH

The “Living *Well* With Hearing Loss” Issue

Spring 2016, Volume 32, Number 2

Having a hearing condition doesn't have to stop anyone from living a full, happy life, as the stories in this issue vividly demonstrate.

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HEARING LOSS & HEARING AIDS



Hearing Loss Stats

1 in 5 Americans ages 12 and over has a hearing loss, while 1 in 8 has a hearing loss in both ears.

1/2

Nearly **half** of people older than age 75 and approximately one-third of those ages 65 to 74 have a hearing loss. It is the third most prevalent chronic health condition facing seniors.

90
PERCENT

More than **90 percent** of children who are born with hearing loss are born to typical-hearing parents.



An estimated 12.5 percent of U.S. children ages 6 to 19 show evidence of noise-induced hearing loss.

#1

Hearing issues, including hearing loss and tinnitus, are consistently the top reported health conditions for military service members and veterans.

Hearing Aid Facts

- » Hearing aids have been shown to provide a **significant benefit** to individuals with hearing loss.
- » About **80 percent** of hearing losses can be treated with hearing aids, but only 1 in 4 individuals who could benefit from using hearing aids, including those with mild hearing loss, currently owns them.
- » The risk of dementia may be up to **five times greater** and the risk of falling **three times greater** among people with untreated hearing loss.
- » Hearing aids have been shown to **reverse** negative changes (psychological and emotional) and may **offset** cognitive decline from untreated hearing loss.
- » Older adults who use hearing aids show **reduced** depression symptoms and **improved** quality of life.

For references, see hhf.org/spring2016_references.

HEARING HEALTH

The "Living Well With Hearing Loss" Issue
Spring 2016
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Hear now. And always



DEAR READERS & SUPPORTERS,

AS CHAIR OF THE BOARD OF DIRECTORS,

I am pleased to announce Nadine Dehgan as the new Chief Executive Officer of Hearing Health Foundation (HHF), effective this January. Dehgan brings considerable nonprofit foundation experience to HHF, including consultation work for us over the past 18 months. She has worked with dozens of charities around the world through the management consultant company she founded in 2004.

Dehgan has a very personal connection to both hearing loss and tinnitus. Her father has adult-onset tinnitus, and her younger brother, Caleb, has had a detectable hearing loss since childhood. Because school was challenging without the full ability to hear, her brother threw himself into sports, one area where learning emphasized visual cues. While he now uses hearing aids, he has found that his experience with visual learning has helped him become a better leader at his sports-related nonprofit. (Read Caleb's account about his experiences at hhf.org/blog?blogid=123.)

Despite seeing her brother's childhood frustrations firsthand, Dehgan admits it still didn't occur to her that her youngest daughter's developmental delays as a baby could be hearing-related, since her child had passed the newborn hearing screening. Her daughter had painful, recurring ear infections that affected her ability to hear. Ear tubes helped immensely, and while she has experienced some scarring and permanent hearing loss, her daughter is thriving—today she is a funny, social, and confident 5-year-old.

"I am excited to be joining an organization whose programs directly benefit and enhance the lives of my loved ones, as well as millions of individuals living with hearing loss and tinnitus," Dehgan says.

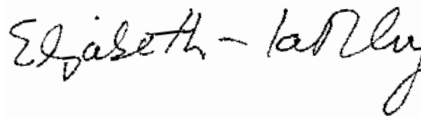
Dehgan has previously held executive positions with Brandon University and The Humane Society, both in Canada. She holds a B.A. from the University of Winnipeg and received an MBA from New York University's Stern School of Business.

"I am excited to be joining an organization whose programs directly benefit and enhance the lives of my loved ones, as well as millions of individuals living with hearing loss and tinnitus," Dehgan says.

We would like to thank our outgoing CEO, Claire Schultz, for her work at HHF over the past two years. We wish her well in her future endeavors.

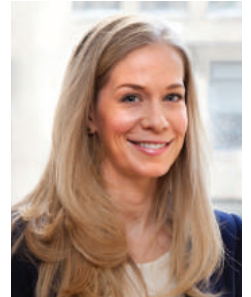
"I am often reminded of how much HHF has done and will continue to do for hearing research and for those living with hearing loss," Dehgan says. "To those who have financially supported HHF—you have my sincere thanks and my commitment to work with our team to make the best of every dollar given. Thank you for your trust and confidence that together we will continue to do great things."

Sincerely,




Elizabeth Keithley, Ph.D.

Chair of the
Board of Directors,
Hearing Health Foundation



Nadine Dehgan
CEO,
Hearing Health
Foundation



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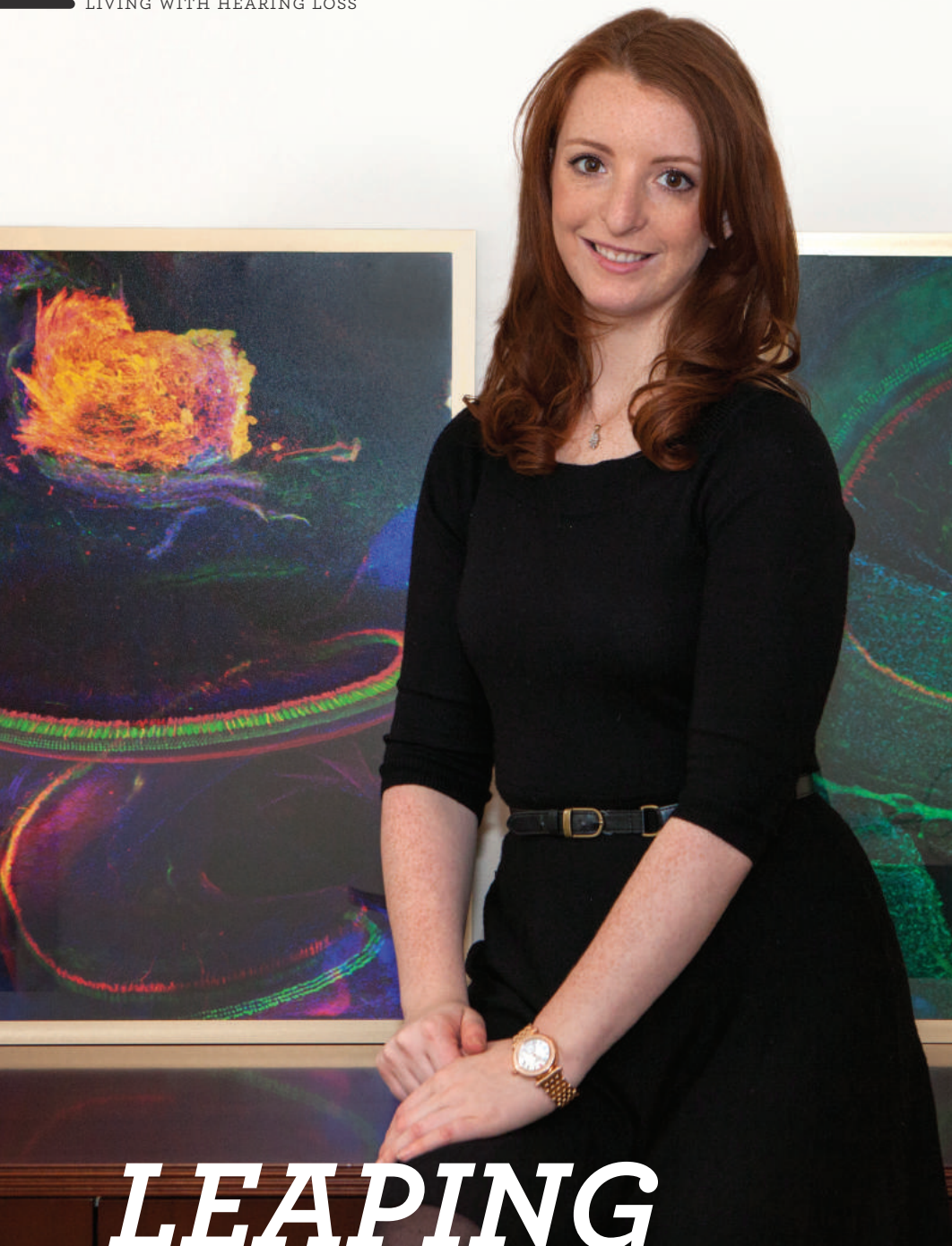
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Clockwise from left:
Friedman at HHF's offices,
in front of hair cell images
by Edwin W. Rubel, Ph.D.;
with her nephew; and
holding her hearing aids.



LEAPING Over HURDLES

Overcoming adversity is something I personally experienced and a message I passionately promote at Hearing Health Foundation.

By Laura Friedman

ATTENTION DEFICIT. DEVELOPMENTAL DELAYS. PROCESSING DISORDER.

These were the words my parents heard about me from a half dozen doctors, audiologists, and speech-language pathologists. But both my parents (and my grandmother) work in the medical field, and these diagnoses just didn't fit what they saw: When my attention was grabbed, I had no issues sitting still or focusing. Simply put, I was not speaking or responding to sounds.

After 18 months of being tested and retested, with one misdiagnosis after the next, someone advised my mother to take me to the school district for testing. This was after a year's worth of constant speech and language therapy. Fearing I would be labeled, my mother initially objected, but eventually she relented, and within minutes of my being tested, the school district informed her I had hearing loss. I was 3 ½ at the time, and this was only the beginning of a long road ahead.

The diagnosis finally made sense. The doctors started talking about hearing aids, schools for the deaf, and sign language, telling my parents I would never be able to function in the hearing world. My parents were devastated—their world was flipped upside down.

Like 90 percent of other deaf or hard of hearing children, I was born to parents with typical hearing (their eyesight, that's another story). I thank my grandfather for giving my mother this advice: "If you don't try teaching her language now, you'll never know if she's capable or not." From that day on, my parents were determined to have me learn to listen and talk. If I failed, I would have failed trying.

Around this time, I started preschool. My first year, I was in a predominantly deaf and signing class, and I was one of three students with hearing loss. I was not learning spoken language or socializing with children who were oral.

For my second year of preschool, my parents enrolled me in a language-delayed class with verbal students for half the day and, for the other half, in a typical, mainstreamed preschool. The school district was not supportive—mainly because they would lose funding if I was not in a deaf class. They even threatened legal action, but my family did not care and was prepared to fight. Luckily it didn't come to that. I attended the language-delayed class for half of the day, and the other half I attended mainstream preschool classes. I was just fine and remember loving school.

When I started kindergarten—with new kids at a new school—things were less seamless. Socializing with my peers didn't come as naturally as it did in preschool. The first few days were tough and I went home and cried; I felt scared and lonely. I also remember feeling different because people were asking about my hearing aids, and for the first time, I had to answer these questions alone. Fortunately, my older brother came to the rescue. He taught me how to introduce myself to people and make conversation. I remember we sat in my room practicing for hours after school, until my skills were perfected. This was the beginning of learning to accept my hearing loss.

One of the more difficult questions I had to answer was what "those things in my ears" were. I was frustrated that it seemed that people of all ages and backgrounds

didn't understand why I needed hearing aids and asked repetitive or invasive questions in order to point out what was different about me. Now that I'm older, I realize that many were asking about "those things in my ears" not to belittle me. They simply were uninformed and trying to understand what I endure on an everyday basis. (Of course some were just bullies.)

For a large part of my youth, it felt like the world was staring at my ears. Self-conscious, I kept my hair long to cover my hearing aids. I was also tall for my age (still am at 27) and the only one in my class with red hair. I always loved my hair color, but sometimes felt I stuck out too much. Over time I began to slowly comprehend that being different was not always a bad thing.

Sometimes I would wonder, Why me? But then in young adulthood I started to realize how lucky I am; having to overcome so many obstacles helped me develop a better understanding and appreciation of life and the struggles that come with it. Gradually I became more and more comfortable with my differences.

I learned to take ownership of my disability, and encouraged others to do the same. I want to dedicate my life to contributing to the hearing loss community on a daily basis, rather than only through a few independent experiences.

My hearing loss is part of my life, but it does not control my life. I learned to take ownership of my disability, and encouraged others to do the same. In high school I started a website, Hears Help, to provide a means for children and young adults with hearing loss to get advice about social and academic issues via an anonymous and confidential email exchange. After a few inquiries from parents, I expanded this service to caregivers, who emailed my mother a range of questions about audiologists and educational services. Hears Help was the support network that both my mother and I wished we'd had when I was young.

When I was a sophomore at Barnard College of Columbia University, my audiologist, Jane R. Madell, Ph.D., fitted me with Phonak Naída hearing aids, and

All my life was about ensuring I didn't miss a beat in class, that my 3 ½ years without spoken language didn't impact my understanding of the world around me. I always had a set goal of getting from A to B, with the help of my family and language training. After college, I was free to pursue a life and path of my choosing in an unaccommodating, unforgiving world. I was unprepared for that moment.

the company asked me to be filmed in videos tracing my adjustment. These videos, which focused on my life and struggles as an adult with hearing loss, influenced thousands of other adults and healthcare professionals, as well as the general public. The videos went beyond YouTube (with more than 50,000 views) and are used at medical conferences and doctors' offices around the country. (A family friend once saw my picture in a Phonak brochure at an audiologist's office in my hometown. Over seven years later, I'm still hearing about it!)

In 2014 Dr. Madell asked me to appear in her documentary on hearing loss. I had the opportunity to share an even greater part of my story, including some of my struggles entering a down-market workforce with the added pressure of having a disability. Dr. Madell has nearly five decades of experience treating pediatric hearing loss, and I attribute a large part of my success to her.

When I taped my story for the documentary, Dr. Madell instantly knew something was not right; as someone who watched me grow up, she knows me, my tone of voice, and my demeanor almost too well. I once thought of becoming a lawyer—a direct result of my parents' early advocacy efforts. Through talking with her about my job, life, and career aspirations, we both came to the conclusion I needed to make changes to feel fulfilled and happy.

All my life was about ensuring I didn't miss a beat in class, that my 3 ½ years without spoken language didn't impact my understanding of the world around me. I always had a set goal of getting from A to B, with the help of my family and constant language training. Suddenly I was free to pursue a life and path of my choosing in an unaccommodating, unforgiving world. I was unprepared for that moment.

There was one common denominator that Dr. Madell and I uncovered: I am happiest when helping others. I realized I wanted to dedicate my life to contributing to the hearing loss community on a daily basis, rather than only through a few independent experiences.

I had spent a large part of my academic career studying

disability as it pertains to labor, employment, and reasonable accommodations in a variety of situations. One of the most disconcerting things I learned was that the very policies that are supposed to help individuals with disabilities gain equal access have instead continued to put them at a disadvantage. I want to change that.

After Dr. Madell helped me define my life goals, I reached out to various hearing loss associations with a presence in New York City, where I live. As a member of Hearing Health Foundation's National Junior Board (now New York Council), it was natural that HHF was one of the first organizations I contacted. I never imagined that the timing would be serendipitous; with my background in corporate marketing and public relations, I landed the communications and programs position. I have been in my role a little over a year, and I am privileged to work with an amazing and dedicated staff and volunteers, both at HHF and other organizations, who are working to make all of our lives better.

On those occasions when I'm sick and tired of having a hearing loss, I sing myself the refrain from a song by Chumbawamba: "I get knocked down/But I get up again/You're never going to keep me down." Because it's simply the truth. —

Laura Friedman is HHF's communications and programs manager and serves on the NYC Mayor's Office for People With Disabilities (MOPD)'s Disability Youth Council.

Share your story: What challenges have you overcome as a person with hearing loss or other hearing issue? What have you learned about yourself? Tell us at editor@hearinghealthmag.com.

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Common Myths About Hearing Loss— Dispelled

Myth:

Hearing loss affects only older adults.

Fact: There are an estimated 48 million people with hearing loss in at least one ear in the U.S., and about two-thirds of this number are under 65 years old, according to the Better Hearing Institute. A 2010 Journal of the American Medical Association study examining a comprehensive data set of the U.S. population found that 1 in 5 children ages 12 to 19 showed some sign of hearing loss in one or both ears.

The World Health Organization has warned that 1.1 billion teenagers and young adults are at risk of hearing loss “due to the unsafe use of personal audio devices, including smartphones, and exposure to damaging levels of sound at noisy entertainment venues such as nightclubs, bars, and sporting events.”

Myth:

Hearing loss doesn't affect the rest of my health.

Fact: Frank Lin, M.D., Ph.D., of the Johns Hopkins School of Medicine, has published a number of oft-cited epidemiological studies tracing the relationship of hearing loss to other health conditions.

Hearing loss has been associated with cognitive decline, dementia, falls, social isolation, and depression.

It's theorized that the “cognitive load” on the brain (as it tries to make sense of speech in the presence of background noise, for example) may take away resources the brain uses for other functions—such as short-term memory. Lin is now studying whether treating the hearing loss, such as with hearing aids, can reverse or even prevent some of these conditions. A 2015 French study examining population-based data spanning 25 years found that hearing aid use “attenuated” (reduced) hearing loss-associated cognitive decline.

Myth:
Hearing aids
are like
glasses.

Fact: When you put on a pair of glasses, your vision instantly can be corrected to 20/20. This is not true of hearing, as your brain needs time to adjust to the sound coming through the hearing aid. Because of each person's unique audiogram, with differences in abilities to hear various frequencies, the hearing aid needs to be programmed to the patient's hearing ability, and the fine-tuning may take repeated trips to the audiologist or hearing healthcare provider. Even the most advanced hearing aids will not restore hearing 100 percent, according to the American Speech-Language-Hearing Association, and you may need auditory training to help your brain process the sounds you now hear.

There is no
vision training
to wear glasses.

On the other hand, hearing aids today are like sophisticated, wireless, mini-computers sitting on or in your ears, helping you not only better discern speech in the presence of noise but also fully navigate all the sounds that populate your world.

Myth:
Hearing loss
is inevitable,
especially with
age, and can't
be prevented

Fact: Hearing loss has many causes, including genetics, certain medications, and exposure to loud noises. Smoking and diabetes can also lead to hearing impairment. Damage to inner ear hair cells, which convert sounds into electrical impulses for the brain to interpret, is permanent. Despite its prevalence among seniors, there is some debate as to whether hearing loss is an inevitable outcome of aging. "Auditory acuity appears to be preserved in quiet, primitive societies," says Daniel Fink, M.D., who cites studies of the Mabaan population in the Sudan, published in 1962, and one

of Easter Island in 1983. Like skin damage from sun exposure, the cumulative effect of today's loud societies has led, he says, to a greater incidence of hearing loss that becomes increasingly apparent over a lifetime—that is, in older adults. That said, noise exposure is the most preventable cause of hearing loss.

And while hearing loss and/or cognitive decline are common among the elderly, it does not mean they are unavoidable, according to a 2014 report in the journal Biomedical Research International.

Myth:
I don't need
hearing aids
since my
hearing is
mostly fine.

Fact: "When you have a hearing loss in some frequencies and not others, it is easier to dismiss it as unimportant," says Hearing Health staff writer Barbara Jenkins, Au.D., BCABA.

But even a mild hearing loss can adversely affect your work, home, and social life.

Fortunately, the brain's neuroplasticity means that treating hearing loss allows the brain to relearn how to hear. Research also shows that satisfaction with hearing aid use correlates with improved outlook, mood, mobility, independence, communication, and social interaction. —

By Yishane Lee, editor; reviewed by Barbara Jenkins, Au.D., BCABA, and Joscelyn Martin, Au.D. For references, see hhf.org/spring2016_references.

Share your story: What are other hearing loss myths to dispel? Tell us at editor@hearinghealthmag.com.

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Dial, Look, & Listen



Even in the age of email and texting, voice phone calls remain a prime mode of communication among people with hearing loss.

Captioning helps make it happen.

By Kathi Mestayer

WHEN MY FATHER AND I TALK ON THE PHONE, WE listen to each other and read the captions on our phones, simultaneously. Sounds like sensory overload, right? But it's really our only alternative to email, snail mail, or smoke signals. He wears a cochlear implant and I wear hearing aids.

Our captioning phones stream data to our eyes and ears, while our brains put it all together. We use email, too, but it's nice to hear each other's voice once in awhile, if only for the occasional chuckling.

These days, people are much more familiar with television and movie captioning than with phone captioning, which is very different.

There are two kinds of captioning that work with landline phones. Both display captions on the readable screen of a specially designed phone. Analog service transmits the call and the captions over a traditional

landline telephone network. Digital service sends the captions over the internet, and the voice over the landline network. Since it's a little faster, digital is gradually replacing analog.

There are other ways to access phone captions that don't require any traditional telephone connection. Internet-based devices, like smartphones, tablets, and computers, send both voice and captions over the internet.

According to Clayton Bowen, the manager for Virginia's Relay and Technology Programs, IP (internet protocol) access is growing in Virginia, while traditional phone service has been declining slowly over the past few years. "Since we began offering that type of access in 2012, the number of calls IP per year has more than tripled," he says.

Compared with landlines, smartphones generally provide reduced sound clarity, due to factors like signal compression and distance from cell towers. So as people

start to use more wireless means of communication, captions may become more necessary for a greater number of people, with and without hearing loss.

Who's Footing the Bill?

The federal government, state governments, and, sometimes caption users pay for captioning services. The federal government, through the Federal Communications Commission (FCC), covers the cost of captioning for digital, IP, and interstate calls, by reimbursing state programs for those costs. States pick up the bill for analog captioning, intrastate calls, and equipment, and manage captioning through their relay (captioning) programs.

Since there is no federal support for equipment, it is up to the states to decide what they will provide, and what to charge for it. For example, some might provide analog and/or captioning phones, smartphones, or tablets, while others don't offer equipment. Captioning equipment and services are also available through independent, private companies. (See "Where Do I Start?" on page 16 for information on how to find captioning in each state, and equipment resources.)

For caption users, the captions themselves are free. In states that offer equipment, qualifying users often get subsidies, and even free equipment, if their criteria (such as financial need and degree of hearing loss) are met.

Outreach and Tech Support

To alert potential users of these services, states use newsletters, presentations, networking, and advertising. In 2007, Arizona passed legislation that requires state-licensed audiologists and hearing-aid dispensers to inform consumers about the services and equipment that the Arizona Telecommunications Equipment Distribution Program (AzTEDP) offers. "In essence, anytime a hearing aid is sold, the bill of sale needs to include information about the AzTEDP and the telecoil," says Vicki Thompson, AzTEDP's program planner.

Many state programs have outreach staff who deliver captioning devices to the user, help them with setup, and run through the basic operations. In those states they also walk users through setting up smartphone, tablet, and laptop access.

Software developers are working hard to improve speech-recognition capability, but for now, a human brain is hard to beat.



The author reads real-time captions for her phone conversation.

"Maryland's approach is what we call triage, working one-on-one with people who need help using the phone," says Sabrina Fields, the contract administrator for Maryland's Telecommunications Access Program. "In some cases, an amplifying phone will do the trick, but some people need captioning, and some have hearing and vision issues."

In addition to touch-screen operation, captioning phones now offer text size and font adjustment, background color adjustment (good for users with low vision), and the ability to save the captions to review them after hanging up.

How Do You Make a Captioned Call?

Either party engaging in a phone call might have captioning service and a captioning device. When a call is made or received, each user with a captioning device will activate captioning on their end (in most cases, by pressing a button). Once the communication assistant (or CA, the FCC's term for captioner) joins the call, the CA starts generating captions for everything said by the called party, for the caller to read. When both callers are caption users, each has their own CA.

A party who does not have captioning service will not know that captions are in use, unless the caption user tells them.



Where Do I Start?

Since states generally manage captioning and equipment through a single program, either site below should get you to the right contact. And they can provide information on the availability of equipment and services outside the state's programs.

Telecommunications Equipment Distribution Program Association
tedpa.org/stateprogram.aspx

National Association for State Relay Administration
nasratrs.org/staterelayprograms.aspx

If your state does not provide equipment, try online retailers such as ClearSounds and Harris Communications. It's possible Flexible Spending Accounts can be used for their purchase; check with your employer.

Where Do Phone Captions Come From?

The captioning is done by the CA, working with computerized speech-recognition software that has become habituated to the captioner's voice. The FCC website describes it this way: "The CA repeats or re-voices what the called party says. Speech-recognition technology automatically transcribes the CA's voice into text, which is then transmitted directly to the user's captioned telephone text display."

So, it's humans and software. According to Bowen, the final step by the CA is to correct any mistakes made by the software, as time allows, and occasionally insert comments like "indistinguishable conversation," so the caption user knows that the CA can't hear the called party clearly.

"We heard from consumers that the sounds of people's voices, laughter, and tone were as important to them as the word content."

The central role of the CA means that phone captions are more accurate than the software-only captions provided by many online videos. Software developers are working hard to improve speech-recognition capability, but for now, a human brain is hard to beat for speech comprehension.

There's a little time delay between hearing the speaker's voice and seeing the captions on your screen. And even seasoned CAs make mistakes, such as when people talk really fast, with accents, with a gravelly voice (like my father), or in background noise, just like the rest of us.

With texting and email so widely available, why have captioning phone calls at all? Bowen says when Virginia began providing captioning, in 2002, "We heard from consumers that the sounds of people's voices, laughter, and tone were as important to them as the word content." Hearing the sound of someone's voice makes all the difference. —

Staff writer Kathi Mestayer serves on advisory boards for the Virginia Department for the Deaf and Hard of Hearing and the Greater Richmond, Virginia, chapter of the Hearing Loss Association of America. For more, see beaconreader.com/kathi-mestayer.

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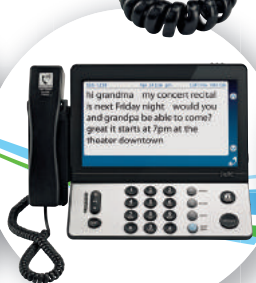
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WHAT



STIGMA?

Despite never feeling a stigma against my hearing loss and hearing aids, I still had to come to terms with both.

by Terry Golson

FORTY YEARS AGO, IN MY TEENS, I told my parents that I wasn't as spacey as people thought. I was sent to an audiologist who informed me that I had a mild hearing loss and added, "You might need these in college," showing me bulky, ugly hearing aids. I said no thanks.

Five years later I had a sore throat. I asked the doctor if that might be affecting my hearing. Once again I was given a hearing test. This time I was told that the loss was serious and would likely worsen over time. I got a hearing aid. It was a hard plastic shell that filled the ear and stuck out a tad. It was uncomfortable and whistled from feedback, but still, with it I could hear. I wore it.

I did not like these ugly hearing aids. I kept my hair long. I didn't want to have to talk about my disability unless I brought it up first.

Over time, my hearing worsened so that even with aids I struggled. I wasn't shy about telling people that I was having difficulty hearing them, but it was awkward to interrupt conversations to ask people to speak up. When I did they would talk louder for a word or two and then revert back to their normal speaking voice.

I started to fake it when I couldn't hear. Early on with my hearing loss I heard well enough to fill in the blanks. But as my hearing declined, I couldn't catch up. I'd miss half a sentence and nod in agreement, or I'd think that I understood something, only to find out later that I had misheard.

And like many people with hearing loss, I found it was easier to talk rather than to listen. I would dominate a conversation, or come across as rude because I missed the verbal clues signaling when to enter and end an interaction. Fortunately, I was self-aware enough to recognize that this was happening. I no longer cared if people saw my hearing aids—in fact, I hoped that if they did they would help me out. As my hearing loss continued to worsen I switched to powerful behind-the-ear devices. I cut my hair short.

My ability to engage in conversation and be part of groups declined. I felt socially inept. I often misheard others and talked off-topic. I came across as rude, or scatterbrained. But I discovered that the more open that I was about my hearing loss, the less my behavior was misunderstood.

In my experience, there is no stigma associated with wearing hearing aids. Rather it was the glitches in communication that cause people to judge. In the years since I started wearing aid, much has changed. Look around—these days half the people walking down the street have some sort of electronics in their ears.

I now have cochlear implants (CIs), and my hearing is almost fully restored. Conversations are now easy, and I still wear my hair short with my CIs visible to all. I've never had anyone think less of me because of these devices; in fact they are viewed with wonder and enthusiasm.

The people who have a hard time believing that there is no stigma seem to be the ones with hearing loss. A friend of mine has always hidden her disability because she worried that being open about it would impact on how people perceive her at her job. She's a high-level manager at a world-renowned research lab.

Recently a woman joined her team. At the first meeting this new hire announced that she wore hearing

I discovered that the more open that I was about my hearing loss, the less my behavior was misunderstood.

aids and there were times during communication that she would need help. No one blinked. These are people used to working with technology. They were interested and helpful. It took my friend aback. All of those years of struggling with her loss alone had been unnecessarily difficult.

I understand not wanting to show off one's aids. I don't want my hearing loss to be the first thing someone notices about me. Also, I'm vain enough to care that my CIs are not beautiful. They're the color of office furniture. But, there is hope. Another friend, Karen, recently upgraded her hearing aids to devices that are sleek and stylish. She got the piece that sits behind the ear in a brilliant blue to match her eyes.

Karen is 83 years old. Her hearing loss and her hearing aids have no stigma—not in her mind, and not to anyone around her. She's a noted scientist and, because her devices enable her to stay in the hearing world, she continues to speak at conferences and is a mentor to many.

I've learned that it's life without hearing devices that brings limitations. —

Terry Golson lives in Massachusetts. To learn more about her life and work, see hencam.com.

Share your story: Have you tried to hide your hearing aids or your hearing loss? Tell us at editor@hearinghealthmag.com.

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The Pros and Cons

The “Pro” Side

PSAPs are relatively low in cost, ranging from about \$100 to \$600 each, versus \$1,000 to \$5,000 for a hearing aid. PSAPs can act as effective “gateway” instruments to actual hearing aids. Sophisticated newer models have Bluetooth connectivity, smartphone app integration, and noise reduction. Ready to wear, PSAPs provide an immediate solution in difficult hearing situations.

HHF encourages everyone who suspects a hearing loss to first see a medical professional such as an audiologist or an ear, nose, and throat doctor (ENT). All groups agree this is a critical initial step for addressing hearing loss.

The “Con” Side

Since they are essentially sold over the counter, the instruments cannot be fine-tuned to an individual’s specific needs. As a result, consumers who try PSAPs may expect too much, ending up disappointed that an inexpensive PSAP does not perform like a premium hearing aid. They may give up and fail to address any hearing difficulties. Without individualized professional care, consumers may also damage their hearing.

The debate over personal sound amplification products (PSAPs) includes issues of cost, safety, efficacy, and regulation. Where does that leave the consumer? **By Elizabeth Stump**

of PSAPs

SIMILAR TO HEARING AIDS, PERSONAL SOUND

amplification products (PSAPs) are worn in or behind the ear, picking up sounds around you, filtering out background noise, and amplifying speech. But unlike hearing aids, they are not regulated by the Food and Drug Administration (FDA) as they are not considered to be medical devices.

According to the FDA, “a hearing aid is a wearable sound-amplifying device that is *intended to compensate for impaired hearing*.” A PSAP, on the other hand, “is *intended for non-hearing impaired consumers to amplify sounds*.” (Italics added in each.) However, some people with hearing issues wear PSAPs.

In an October 2015 report, the President’s Council of Advisers on Science and Technology (PCAST)

recommended that rules guiding the usage of PSAPs be relaxed to lower cost and encourage innovation in the hearing aid market, especially given the additional health risks associated with untreated hearing loss. It recommended the creation of a new class of over-the-counter, “basic” hearing aids.

The PCAST report sparked much debate and helped prompt the reopening of comments, in January, on the FDA’s 2013 Draft Guidance Report on Regulatory Requirements for Hearing Aid Devices and Personal Sound Amplification Products. The FDA is also holding a public workshop to discuss alternative models of regulation of hearing aids and PSAPs in April.

Public Voices

Anil K. Lalwani, M.D.

Director of the Columbia Cochlear Implant Program, Columbia University, Head of HHF’s Council of Scientific Trustees

“I used to be against off-the-shelf hearing aids. But, given that hearing loss is associated with significant negative consequences (reduced quality of life, falls, cognitive decline); the majority of hearing impaired individuals do not have access to hearing aids; that the average cost of a hearing aid is roughly \$2,400; and that there is a lack of innovation to reduce cost, my opinion has changed over time. These are all factors cited in the PCAST report, which also identifies untreated hearing loss as a ‘substantial national problem.’ While measures should be taken to assure consumer safety, making PSAPs available to all who need it is an important first step in meeting the needs of the hearing impaired.”

Lise Hamlin

Director of Public Policy, Hearing Loss Association of America (HLAA)

“The number one call we receive at HLAA is requesting help purchasing hearing aids, because these callers cannot afford what is on the market now. PSAPs are one possibility to help those consumers. HLAA sees the potential of well-made, clearly labeled hearing devices as offering an alternative to the high-cost hearing aids that act now to shut many people out of the market.... PSAPs generally are best for people who have a mild to moderate hearing loss. Many of our members have a significant hearing loss that would preclude the use of PSAPs.... For many people a hearing aid will still be the best choice.”

Barbara Jenkins, Au.D., BCABA

Hearing Health staff writer

“I equate PSAPs to reading glasses. Real handy and useful at times, but never as good as a well-fit prescription.”

Andy Bopp

Executive Director, Hearing Industries Association (HIA) and Better Hearing Institute

“HIA believes that hearing aid satisfaction and patient success depends highly on the involvement of a hearing health professional in the diagnosis, evaluation, fitting, and follow-up treatment for people with hearing loss. Hearing aid technology and manufacturing processes are at the cutting edge of the wireless/digital/device revolution, but top technology without adequate professional assistance will fail to meet patient needs. PSAP sales by definition eliminate professional involvement, as these products are sold at retail stores and through the mail/internet.”

John V. Brigande, Ph.D.

Oregon Hearing & Science University Hearing Restoration Project scientist

“Many patients become frustrated with the technology [of assistive

devices like PSAPs] not working for them, and stop using it. But if there is appropriate fitting and follow-up, the patient enters a new auditory world.”

Richard Einhorn

New York City musician and composer who experienced sudden severe hearing loss in one ear in 2010, and who uses hearing aids, PSAPs, and other assistive listening tools

“There are so many reasons why people with hearing issues should begin to use hearing technology as soon as they need help and not wait until they are desperate to hear better and have a medically dire condition. Making hearing assistance ubiquitous will lower stigma, lower the cost, and improve their effectiveness.”

Lori Foss

Marketing Director, Harris Communications, which began selling a selection of PSAPs in 2014

“For many years we avoided selling PSAPs in our catalog and website due to the quality of the products available and the risk of offending some customers. But the decision to sell some PSAPs was based on their improved quality and presence in the marketplace, and the increased acknowledgment and discussion in the audiology community.... Harris understands that PSAPs cannot replace hearing aids. We market them as ‘in-ear personal amplifiers’ so people understand they are not standard hearing aids.”

Brian Taylor, Au.D.

Editor, Hearing Health & Technology Matters

“I support the idea of having low-cost, carefully vetted products available direct to consumers as a way of addressing the unmet need of individuals coping with age-related hearing loss and its complications. It’s up to hearing care professionals to find innovative ways to incorporate them into their practices, thus I am

in favor of re-regulation. Further, I believe PCAST and IOM [the Institute of Medicine] overstate cost as the main barrier to hearing aid use. Numerous recent studies suggest many other reasons... preventing their uptake, such as passive acceptance [of] hearing loss, stigma, and negative attitudes about hearing aids.”

Published Accounts

Frank Lin, M.D., Ph.D.

Associate Professor, Johns Hopkins School of Medicine; convened January 2014 Institute of Medicine (IOM) and National Research Council of the National Academies workshop on “Hearing Loss and Healthy Aging.”

From “Dr. Frank Lin Details Consequences of Age-Related Hearing Loss and Future Avenues at Academy of Doctors of Audiology Convention Keynote,” Hearing Review, November 11, 2014:

“The air became a bit chillier as Dr. Lin detailed the use of personal sound amplification products (PSAPs)—which, by FDA definition, are devices not intended for hearing loss—as good low-cost solutions for the hearing-impaired population.... Lin proposed a range of possible dispensing solutions, from least expensive/effective to most expensive/effective that included PSAPs without any supervision, PSAPs provided by [community healthcare workers], hearing aids dispensed by hearing instrument specialists, and hearing aids dispensed by audiologists (which he referred to as the ‘gold standard’).”

Judith L. Page, Ph.D.

President, American Speech-Language-Hearing Association

From written comments to PCAST, November 2015:

“We are... disappointed that the Council [PCAST] was tasked to evaluate only one aspect of hearing health care services—an amplification device. By focusing solely on a device, the Council has made an error in

assuming that hearing is analogous to vision and has inadvertently dismissed the importance of an individualized treatment plan developed by an audiologist as best practices in hearing healthcare.”

The Short List

Katherine Bouton’s 2015 book “Living Better With Hearing Loss” provides a brief overview of PSAPs to choose from, based on her research:

- Able Planet Personal Sound In-Ear Amplifier
- Etymotic BEAN Quiet Sound Amplifier
- NeutronicEar
- Soundhawk
- Sound World Solutions Personal Sound Amplifier

The Bottom Line

First see an audiologist or ENT if you suspect you have a hearing loss. Then do your research, and ask questions. —

For references, please see hhf.org/spring2016_references.

Share Your Story: What’s your take on PSAPs? Tell us at editor@hearinghealthmag.com.

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Hearing Aids

“Keep old hearing aids in case your current ones get damaged. When I kayak I use a hand-me-down aid from my dad (who now has a cochlear implant) programmed for me so I don’t have to worry about getting my ‘good’ set wet.”

—Staff writer Kathi Mestayer

“In my state I was stunned to discover Medicaid now covers hearing aids—for children as well as adults, which is amazing. Since coverage changes year to year, check with your insurance every time you get a new pair of hearing aids.”

—Ann Conway, Ph.D., who manages the Facebook page *Hearing Loss Toolkit*

“If you are visiting New York City, take advantage of the many hearing loops installed at various tourist attractions, such as the Metropolitan Museum of Art, Lincoln Center, Madison Square Garden, all 482 subway station information booths—even taxis!”

—Janice Schacter Lintz, the founder of *Hearing Access & Innovations*, which has established or enhanced hearing access programs at more than 100 companies and organizations around the world

“A snack-size baggie for storing hearing aids will work in a pinch, such as when caught in a rainstorm.”

—Tish Hamilton, via email

“Always have a hearing aid container on you. I never put the hearing aid anywhere else but in the container, and the container never leaves my pocket except to go into my sock drawer.”

—via HHF survey

“My perfect hearing aid would include auto-charging batteries. We are close—ZPower makes batteries that can be recharged without having to remove them from the hearing aids. You plug in your hearing aids into a dock just like you would a smartphone, and the batteries get replaced once a year by your audiologist. So far it’s available for just a few brands/models of hearing aids, but I am hopeful that this is the wave of the future!”

—via HHF survey

“Once you take the tab off the battery, expose it to air for about five minutes before inserting it into the hearing aid; it lasts longer. I prep my aids and batteries and then brush and floss my teeth. By the time I am done, the batteries are ready.”

—Eloise Schwarz, co-leader, *Metro Milwaukee Chapter of the Hearing Loss Association of America*, via email

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Tinnitus

"This is advice I give my musician patients: If you've used hearing protection but still experience post-show tinnitus, take a capsaicin supplement. Capsaicin, the compound that makes chile peppers hot, is a vasodilator—so it allows for easier and quicker flow of blood to the sense organ, which reduces the sensation of tinnitus."

—Melissa Heche, Au.D., HHF editorial committee member

"My ReSound hearing aid has a tinnitus masking program which is superb. It also has a tinnitus app on the iPhone I use. This allows me to pick and choose whatever tune I want to listen to."

—Eloise Schwarz, via email

Workplace

"Get a copy of the Job Accommodation Network's booklet for employers and employees on how to deal with hearing loss. This is an incredible tool that will allow the employee to learn the right 'language' to use with an employer so you can get what you need to work at full potential. Employers should also get this to understand how easy it is to make the workplace accessible for all employees with disabilities."

—Leslie Carol Berg Weiss, via Facebook

Hearing Better

"Many times people will start talking to me without letting me know that I'm part of the conversation. Use my name to get my attention before you start talking to me."

—Mitch Ziegler, via Facebook

"On a recent trip to Disney World, I brought noise-canceling headphones, since I had them anyway for the plane ride down to Florida. The headphones worked wonders—I was able to enjoy many attractions that would otherwise have been way too loud, and it helped keep my hearing loss exhaustion at bay."

—Shari Eberts, HHF board member, from her blog *livingwithhearingloss.com*

"I advise students with hearing impairment to research and try an assistive listening system of some kind, learn its proper use, and see if it works for them. Putting the challenge to the student to understand a technology is all about taking ownership of their hearing loss and promoting self-advocacy."

—John V. Brigande, Ph.D., Hearing Restoration Project researcher (see page 36)

"In a noisy bar I will watch the lips of the person I am talking with. Of course, I let them know what I am doing so they don't think I have a weird fetish!"

—via HHF survey

"My biggest regret is that all my life I concealed my hearing loss from colleagues, acquaintances, and even friends because I was embarrassed. Now at 68 years old... I have finally faced my disability with honesty, letting my friends and family know the hearing saga of my life."

—Nancy Donna Huffman, via email

The Silver Lining

"Occasionally my hearing loss is a blessing. We had a squeaky motor on our fridge that drove my family crazy, and I couldn't hear a thing!" —via HHF survey

Share Your Story: Tell us your best tips and tricks for living well with hearing loss or tinnitus! Email editor@hearinghealthmag.com.

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AMPLIFICATION FOR INFANTS & TODDLERS WITH HEARING LOSS

By Kathryn Girardin, Au.D.

This is the **third of eight columns** from Clarke about children with hearing loss, their families, and the professionals who serve them.

TWO TO THREE OF EVERY 1,000 CHILDREN IN THIS country are born with hearing loss in one or both ears. Ninety percent are born to parents with typical hearing. The majority are choosing a Listening and Spoken Language approach (LSL) for their child's primary mode of communication. A central focus for hearing professionals working with LSL families is ensuring that children receive access to sound and to early intervention therapies at the youngest age possible.

As a pediatric audiologist, I follow the recommendations issued by the Joint Commission on Infant Hearing: screening hearing by 1 month old; diagnosing hearing by 3 months old; and ensuring the child is enrolled in an early intervention program by 6 months old. Infants don't talk, but they do listen and learn. The earlier, more consistent use of properly fit amplification, coupled with high-level speech modeling by caregivers, has been shown to have a direct impact on these infants' and toddlers' ability to develop spoken and receptive language at a rate similar to their peers with typical hearing.

For families who want their child to learn to listen and talk, the infant is typically fit with a behind-the-ear

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hearing aid—an electronic device using a microphone, amplifier, and receiver to bring sound to a specially fitted ear mold. I make sure the child has the maximum available access to sound based on their hearing aid prescription and that the family understands the importance of consistent use. Keeping a hearing aid on an infant is no small feat, so we share tips, such as where to find specially designed bonnets that will keep the devices in place.

For a small percentage of children, hearing aids are not effective enough. These families may elect for their children to receive cochlear implants, surgically implanted devices coupled with an external microphone and processor that bypasses the hearing organ, sending sounds to the brain.

Hearing aids and cochlear implants provide access to sound, but what and how the child is hearing makes a big difference in language development. Learning to listen and talk requires a team of professionals, including speech-language pathologists and teachers of the deaf, who are trained to work with families to help them develop good communication and language modeling for their infants.

It takes time and training to develop spoken and receptive language. In preschool programs like Clarke's, teachers of the deaf work with children using hearing aids, cochlear implants, and other devices, in state-of-the-art classrooms designed specifically for children with hearing loss.

We hear with our ears, but we listen with our brains. Regardless of the devices used to access sound, children with hearing loss can best make *meaning* of that sound with intervention from a team of listening and spoken language professionals and mentored parents. —

Next: Early Intervention. Read previous Clarke Corner columns at hearinghealthmag.com.

Kathryn Girardin, Au.D., is the director of the Clarke Hearing Center. See clarkeschools.org.



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PEDIATRICS



Take It From Me

A high school senior with auditory processing disorder shares her classroom coping techniques, useful for all students.

By Eliza Uberuaga

MY LEGS GROW TENSE AS A CLASSMATE'S whispers flood my ears. My breath becomes short as another taps his foot against the desk. My stomach lurches as I watch two students turn in their tests.

Why can't I block out the noise? Why can't I answer the questions faster? Why am I the only one struggling? I must run while they walk, work while they sleep, and prepare while they rest.

When I was diagnosed with a learning disability, my parents brought me to the most respected doctors in New York and enrolled me at one of the most prestigious schools in the country. However, that did not cure, fix, or help me. Why? Because no doctor, teacher, parent, or friend can change the world that tells me I have a problem. I am labeled with auditory processing disorder (APD), characterized as slow, and viewed with pity.

Having APD is like listening to a voicemail message on a busy street while everyone else is listening to it in a quiet space.

I am not asking for sorrowful looks, sympathy hugs, or uplifting pep talks. I am asking you to understand that the student in your classroom who needs extra time wasn't daydreaming during the test. The girl who needs directions to be repeated *is* listening. The boy who is last to raise his hand knows the answer to the question you asked.

These kids likely have APD, a learning disability that slows the comprehension of information. (It is also known as central auditory processing disorder, or CAPD.) It is not their hearing that is impaired, but their auditory pathways. Information that is spoken can be difficult to process if said too quickly, in a loud place, or in large chunks of speech.

Having APD is like listening to a voicemail message on a busy street while everyone else is listening to it in a quiet space. While most people can block out the background noise, people with APD hear that noise as if it is the message itself. When given directions, most brains organize the information, like putting it into filing cabinets. Those with APD take longer to find the filing cabinets, which slows the pace at which they comprehend.

APD affects students in a variety of ways, but students with APD (and most other students) could benefit if we looked at our classrooms the way we look at our world: valuing everyone's uniqueness—in this case, the unique ways in which they learn. Here are some techniques that helped me.

1. Stimulate the Senses

In an art history class, we learned about the making of a blind arch. Rather than looking at a diagram, my teacher had four kids (including me) make an arch with our arms. Putting pressure on our formation and watching it collapse taught us how to make the most effective structure. I learned about arches by listening, watching, and feeling, as opposed to simply listening and writing.

2. Teach With Variety

In a science class, my teacher gave us an outline of the notes, wrote them on the board, and lectured us on them—supporting auditory, visual, and kinesthetic learners. He allowed each student to retain the information in whatever ways worked for them. In this class, no kid was left behind because every kid was supported.

3. Create a Quiet Learning Place

In order for all students to be able to focus, especially ones with APD, it is best to minimize all noise when students are working or trying to concentrate. Although it may seem helpful to speak in a quieter voice, for a student with APD, hearing whispers while working can actually be worse than hearing words spoken at normal levels. So while it may seem helpful to speak in a quieter voice, it is best to not talk at all.

I hope that, by writing to teachers and sharing my story, I can help the 10-year-old girl who cries when she gets home from school and tells herself she will never be smart. Although she may not feel intelligent when she goes to the library to finish a test, she must understand that she does not have a problem. She only feels like she has a problem because the world around her is unable to understand her intelligence. The day will come when she feels the way she learns is truly all right, but maybe that day will come sooner for her than it came for me. —

Eliza Uberuaga is a high school senior in New York. This was originally published in Teaching Tolerance magazine and is reprinted by permission of the author. With our Emerging Research Grants program, HHF is committed to funding research in the area of CAPD. CAPD research is generously sponsored by the General Grand Chapter Royal Arch Masons International. To learn more about supporting hearing research, see hhf.org/name-a-grant.

Support our research: hhf.org/donate



Spurred by her tinnitus and experience doing community outreach, a young woman maps out a way to make a difference. **By Kailey McGarvey**

FIVE YEARS AGO, IN 2011, AFTER A HEAD COLD, I developed tinnitus in my right ear. Since the ringing in my ear was so faint I could only hear it in complete silence, it was merely an annoyance, and I didn't take it too seriously.

I had some ENT and neurological tests done just to be sure the tinnitus wasn't a symptom of something bigger. It wasn't. So it was never more than a mild concern—until I woke up one morning in 2013 with an even higher pitch ringing in my left ear.

This was solid proof that *something* was happening and that it had the potential to worsen. I went through a second round of ENT and neurological testing to check for new developments. The ringing had become louder and took more effort to ignore. Again, the tests showed nothing abnormal. This was good, but I was told nothing could be done about the distracting sounds in my ears.

It was then that my tinnitus began to consume a greater amount of my focus, energy, and thoughts. My anxiety skyrocketed with thoughts of how it could progress and what it would mean for me in the future.

During the summer of 2015, my tinnitus worsened, again. Listening to music is one of my favorite pastimes, but now I hear sounds of high-pitched feedback during certain chords in songs. This is particularly devastating—my tinnitus has distorted how I hear music. But since

throwing my energy into finding answers was not proving productive, what would be a better outlet?

I have always been involved in community outreach, and have been working as a finance assistant for a congressman. I decided I would fundraise for tinnitus research. It would be an opportunity to manage my own fundraiser, while raising funds for a cause very important to me. Living on Long Island in New York, I have access to a beautiful boardwalk, and I decided the fundraiser would start in my backyard with snacks and drinks, and once everyone arrived we would walk the boardwalk.

Hearing conditions are often seen as “problems for old people”—but this simply isn't true. Hearing loss and tinnitus can begin at a young age, and when the cause is excessive noise, it is entirely preventable.



How to Host a Fundraiser

Host a fundraiser to help HHF find better therapies for treating and preventing hearing loss and tinnitus!

Set up your fundraiser in three easy steps:

- 1) **Register.**
- 2) **Create** your Giving Page.
- 3) **Share** with family and friends and ask for their support.

Get started at hhf.org/fundraise, where you can also see examples of past events and get ideas for creating your own—such as golf outings, bake sales, birthdays, weddings, marathons, and triathlons. Let your talents and interests guide your ideas; no event is too large or small.

Questions? We're here to help! Email fundraise@hhf.org.

Above left:

The author (long hair, standing, in a black dress) with friends and family at her Dollars for Decibels event in October 2015.

I chose Hearing Health Foundation as the beneficiary of my fundraising because its focus is on research. Research is how we will find answers about hearing loss and tinnitus; research is what will move things along. Funding will help accelerate the pace toward a cure for hearing loss and tinnitus.

The day of the fundraiser, which I called Dollars for Decibels, was a beautiful, warm Saturday in October. I had set a goal of \$1,000 and asked for \$35 per person. Those who couldn't make the fundraiser were asked to donate online.

I ended up with 23 people in attendance and \$1,120 in contributions. Not only was it a fun social gathering of family and friends, but the fundraiser was a success! I raised money for an organization I believe in, and the experience reinforced the extraordinary support system I am grateful to have around me.

In addition to fundraising, I can also use my time to educate others and help the tinnitus community as a whole, rather than just trying to find answers for myself. It is important to educate the younger generation about the harmfulness of noise.

Hearing conditions and hearing loss are often seen as “problems for old people”—but this simply isn't true. Hearing loss and tinnitus can begin at a young age, and when the cause is excessive noise, *it is entirely preventable*. I was just 20 when my hearing became noticeably affected.

The outreach and education among my friends is working. Just recently, one friend decided that we shouldn't go to a certain bar because it is always way too loud. —

Kailey McGarvey lives in New York.

Support our research: hhf.org/donate

9 **DO'S** & **DON'TS** When Talking to a Person with Hearing Loss

Hearing loss is invisible. When people aren't aware of your hearing loss, they may make assumptions and be less willing to make accommodations. But I have found that even when someone is aware of my hearing loss, we can still become impatient and frustrated trying to communicate. Over time, I've compiled these tips to help. I hope you find them useful.

By **John Cech**



DO Face me and make eye contact.

Reading your lips helps me fill in missing pieces of conversations.

DON'T Mumble or talk softly, especially in a noisy environment. I can hear you talking, but the background noise makes deciphering what you are saying very difficult.



DO Position yourself next to the person I am talking to in order to help restate what they are saying.

Stand so that I can see your face so I can speech-read if needed.

DON'T Avoid me or talk behind my back to people, telling them I don't hear. I do hear. I just don't understand clearly, and I am aware of being dismissed.



DO Schedule meetings with fewer people in smaller, quieter quarters.

DON'T Put me in a position that will make hearing difficult, like conference calls or group meetings in large rooms with people spread out.



DO Help re-explain what was asked of me if I answer incorrectly.

DON'T Apologize for me to others. I can do that myself.



DO Drop me a text message or email for important information. Take advantage of voice recognition to dictate the message if typing it is too time-consuming.

DON'T Expect me to hear you clearly on a cell phone. The microphones pick up too much ambient sound.



DO Speak slowly but naturally. No need to shout.

DON'T Look away with a frustrated or disgusted look. My disability is difficult enough for me. I don't need it to be reinforced by people's negative reaction to it.



DO Try a different word if I still don't understand what you are referring to. Or repeat the whole sentence.

DON'T Repeat only the word I say I didn't catch.



DO Smile. Look at me with understanding, not pity.

DON'T Talk to me in short, single-syllable words, like to a child. Thank you. —



DO Ask me what I didn't understand, and try saying it another way.

DON'T Say "never mind" or "it isn't important." If it was important enough to try to talk to me about something, don't give up in frustration.

John Cech lives in New Jersey.

Share your story: Tell us your useful communication tips at editor@hearinghealthmag.com.

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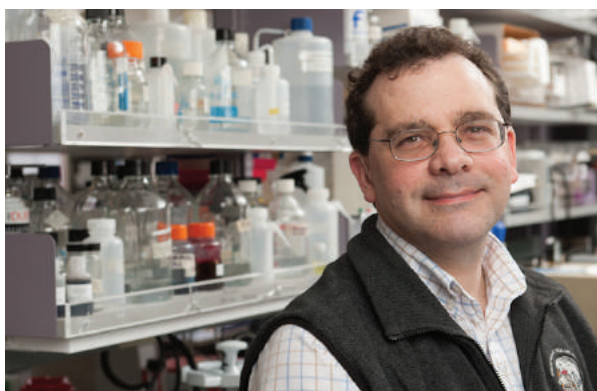
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Hearing Loss vs. Dizziness: If I Could Choose!

by John V. Brigande, Ph.D.



I WAS ABOUT 9 WHEN HEARING LOSS IN MY LEFT EAR WAS FIRST DETECTED.

The audiologist explained to me that as a result, I may not be able to hear birds singing as easily, and that I may need to concentrate more to understand words starting with “sh,” “k,” or “t.” Sensing my alarm, she tried to reassure me by saying it was unlikely that the hearing loss would affect both ears, and if it did, it would likely not be to the same extent. I compensated in school by simply tilting my right ear toward sound sources.

Over time my hearing loss became bilateral and progressive, and its cause remains unknown. In graduate school I began using hearing aids and later received a cochlear implant in my left ear. I continue to use a hearing aid in my right ear, and thankfully for the past eight years, my hearing has remained stable, if stably poor.

While I do not consider my hearing loss to be a profound limitation personally or professionally, it has certainly sculpted my career path. After receiving my undergraduate, master’s, and doctoral degrees, all in the biological sciences, I settled on a career in auditory neuroscience to better understand hearing loss. I also reasoned that auditory

research conferences would likely have assistive listening technology to allow me to participate more fully.

As I entered my 40s, I experienced vertigo for the first time. The clinical data do not fit with a diagnosis of Ménière's disease, and the link between my vertigo and hearing loss is unclear.

When I have an acute attack of dizziness, my visual field scrolls from right to left very quickly so that I must close my eyes to avoid profound motion sickness and vomiting. I must lie down until the dizziness subsides, which is usually 12 to 16 hours. I honestly cannot do anything—I can only hope to fall asleep quickly.

Vertigo is a profound limitation for me. With no disrespect or insensitivity intended toward the hearing impaired community—of which I am a passionate member—I would take hearing loss over vertigo in a heartbeat. Dizziness incapacitates me, and I cannot be an effective researcher, educator, husband, or father. Some people perceive an aura before their dizziness occurs, but I do not get any advance warning. Unlike hearing loss, I cannot manage my dizziness—it takes hold and lets go when it wants to.

I recall one episode especially vividly. I was invited to give a seminar at the National Institute on Deafness and Other Disorders and experienced a severe attack just hours before my flight. Vertigo forced me to reschedule my visit, which was tremendously frustrating. That night, I slept in the bathroom (my best solution when vertigo hits). Vestibular (balance) dysfunction is quite simply a game changer.

A satisfying part of my research involves trying to define treatments for hearing loss and dizziness. Usher syndrome is a condition combining hearing, balance, and vision disorders. In Usher syndrome type 1, infants are born deaf and have severe vestibular problems; vision abnormalities appear by around age 10. In working with a group of dedicated colleagues at various institutions, we have evidence that fetal administration of a drug in mice with Usher syndrome type 1 can prevent balance abnormalities.

As part of HHF's Hearing Restoration Project (HRP) consortium, I have been

working on testing gene candidates in mice for their ability to trigger hair cell regeneration. This research is exciting as it is leading the HRP into phase 2 of its strategic plan, with phase 3 involving further testing for drug therapies. The probability is that manipulating a single gene will not provide lasting hearing restoration, and that we will need to figure out how to manipulate multiple genes in concert to achieve the best therapeutic outcomes.

It is an exciting time to be a neuroscientist interested in trying to find ways to help patients with hearing loss and balance issues. I am hopeful that we will make progress in defining new ways to treat and even prevent vertigo in the near future as well as determine effective therapies tailored to address the unique causes of hearing loss and tinnitus. —

Hearing Restoration Project consortium member John V. Brigande, Ph.D., is a developmental neurobiologist at the Oregon Hearing Research Center. He also teaches in the Neuroscience Graduate Program and in the Program in Molecular and Cellular Biology at the Oregon Health & Science University.

Your financial support will help ensure that HHF can continue funding this vital research in order to find better therapies to treat hearing loss and tinnitus in our lifetime. Your donation will fund the top scientific minds working collaboratively toward a common goal. For more information or to make a gift, email us at development@hhf.org.

Your help provides hope.

Share your story: Do you experience dizziness? How do you manage it? Tell us at editor@hearinghealthmag.com.

Unlike hearing loss, I cannot manage my dizziness—it takes hold and lets go when it wants to.

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Recent Work by Hearing Health Foundation Scientists, Explained

The Hearing Restoration Project (HRP)

The goal of the HRP is to determine how to regenerate inner ear sensory cells in humans to eventually restore hearing for millions of people worldwide. These sensory cells, called hair cells, in the cochlea detect and turn sound waves into electrical impulses that are sent to the brain. Once hair cells are damaged or die, hearing is impaired, but in most species, hair cells spontaneously regrow and hearing is restored. The HRP is aiming to enable this ability in humans.

Unraveling Genes Critical for Inner Ear Development

From HRP researchers Alain Dabdoub, Ph.D., and Albert Edge, Ph.D.

All cells develop through a chain of events triggered by chemical signals (proteins) from outside the cell. The signals kick off responses inside the cell that can change the cell's ability to proliferate (grow and divide) and differentiate (take on specialized functions).

The Wnt signaling pathway, a sequence of events triggered by the Wnt protein, helps guide inner ear cell development, including the proliferation of cells that differentiate into the hair cells and supporting cells necessary for hearing and balance. But in mice and other mammals, inner ear cell proliferation does not continue past newborn stages.

Underscoring their importance in evolutionary terms, Wnt signals occur across species, from fruit flies to humans—the “W” in Wnt refers to “wingless”—and Wnt signaling is guided by dozens of genes. Alain Dabdoub, Ph.D., Albert Edge, Ph.D., and colleagues performed a comprehensive screen of 84 Wnt signaling-related genes and identified 72 that are expressed (turned on) during mouse inner ear development and maturation. Their results appeared in the journal *PLoS One* this February.

The Wnt signaling network has three primary pathways. Two are known to be integral to the formation

of the mammalian inner ear, including the determination of a cell's “fate,” or what type of cell it ultimately turns into. This is particularly significant because the inner ear's sensory epithelium tissue is a highly organized structure with specific numbers and types of cells in an exact order. The precise arrangement and number of hair cells and supporting cells is essential for optimal hearing.

The relationship between the Wnt-related genes, the timing of their expression, and the various signaling pathways that act on inner ear cells is extremely complex. For instance, the composition of components inside a cell in addition to the cell's context (which tissue the cell is in, and the tissue's stage of development) will influence which pathway Wnt signaling will take. It is known that inhibiting the action of Wnt signaling causes hair cells to fail to differentiate.

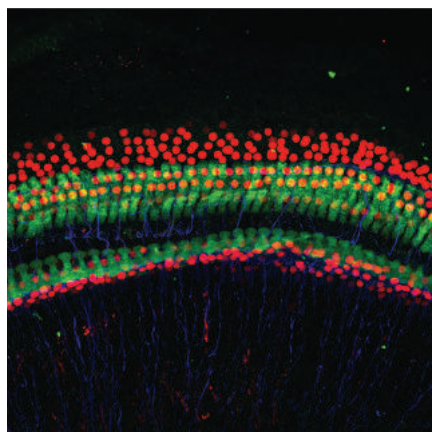
The new research complements previous chicken inner ear studies of Wnt-related genes as well as a recent single-cell analysis of the newborn sensory epithelium in mice (conducted by HRP scientist Stefan Heller, Ph.D., and colleagues). Comprehensively detailing these 72 Wnt-related genes in the mouse cochlea across four developmental and postnatal time periods provides a deeper understanding of a critical component of hair cell development, bringing the HRP closer to identifying genes for their potential in hair cell regeneration.



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Emerging Research Grants (ERGs)

Recent accomplishments by ERG recipients underscore the importance of supporting early-career scientists who bring fresh approaches to hearing and balance studies.



Green indicates outer and inner hair cells in the mouse cochlea.

A New, Scalable Cell Line for the Study of Hair Cell Regeneration

From 2013 ERG scientist Brandon J. Walters, Ph.D., and 2012 ERG scientist Bradley J. Walters, Ph.D. (no relation)

Mammals, unlike birds and fish, cannot spontaneously regenerate their inner ear hair cells to restore hearing. Also mammals have two types of hair cells: inner hair cells, which more closely resemble the hair cells in other species, and outer hair cells, which are unique in mammals.

Studying the mechanisms by which hair cells are formed and regulated has been restricted not only by the relatively sparse number of these cells in a mammal's cochlea, but also by the fact that cell lines that are grown in vitro (in a petri dish) are not able to effectively mimic the unique outer hair cell in mammals. The lack of hair cell lines that appropriately mirror various types of hair cells limits large-scale research on hair cells and makes the study of complete hair cell development—where the hair cell reaches full maturation—more difficult to observe.

To overcome these challenges, Brandon J. Walters, Ph.D., and Bradley J. Walters, Ph.D., and colleagues set out to create a hair cell line whose maturation could be studied. In a December 2015 *Scientific Reports* study, they describe using a procedure called “conditional reprogramming” of progenitor (original) cells. This procedure was originally developed in studies of breast and prostate

progenitor cells, and allowed for the unlimited generation of these progenitor cells.

The researchers predicted that because the breast, prostate, and cochlea contain epithelial tissue, this procedure could allow for limitless proliferation of cochlear progenitor cells that are able to develop into both inner and outer hair cells.

The procedure worked: The cochlear progenitor cells grew unrestrictedly (they usually stop growing within a short time after isolation) and without compromising their ability to develop into mature hair cells. The real surprise was that these cells retained their ability to form mature outer hair cells—a first for an in vitro hair cell line.

They were then able to demonstrate that these “pseudo-immortal” cells grew fully functional. They determined that the cells expressed the motor protein prestin, a key protein only found in outer hair cells and important for outer hair cells to respond to and amplify sounds. Additionally, prestin is known as a terminal hair cell gene, as its activation appears at the end of hair cell development.

This amounts to the creation of a new, easy-to-generate, scalable hair cell line that can help researchers study the actions of the many genes leading to the development and regulation of inner ear hair cells, including the unique outer hair cells. It is a powerful new tool to investigate the potential regeneration of mammalian hair cells.

When Cochlear Development Goes Awry

From 2013 ERG scientist Junhuang Zou, Ph.D.

Usher syndrome is the leading genetic cause of combined hearing and vision loss. With no known cure, it occurs in about 4 of every 100,000 births. Usher syndrome has three types; Usher type 2 (USH2) is the most common.

As a fetus develops, hair cell stereocilia (the parts that extend out like hairs) grow to various lengths, thicknesses, and rigidities. They also form into precisely arranged rows of bundled hair cells. Fibrous links that link hair cells at their base appear to be necessary for these processes to occur. Previous studies have found that genes associated with Usher syndrome encode protein components of some of these fibrous links.

Junhuang Zou, Ph.D., and colleagues have uncovered clues about how the fibrous link known as the ankle link complex develops, and whose disruption contributes to USH2. Building on his prior work identifying four proteins and how their interactions contribute to USH2, and using high-resolution immunofluorescence on USH2 mutant mice, Zou and his team systematically examined these proteins and detailed their actions. As reported in the journal *Human Molecular Genetics*, they discovered that the proteins each play distinct roles in the creation of the ankle link complex, with a protein called the “G protein-coupled receptor 98” being the most important.

This research contributes to the greater understanding of USH2,

pointing the way toward better diagnosis, prognosis, and treatment, as well as providing additional critical information about the complexities underlying hair cell development.

Evaluating a Mouse Model for Regeneration

From 2012 ERG scientist Bradley J. Walters, Ph.D.

One of the challenges of testing hair cell regeneration therapies in mice is making sure that the cells present after a treatment were, in fact, newly generated. Indeed, in many studies in which induced regeneration has been attempted in mammals, the numbers of hair cells are often less than that of an undamaged cochlea, and any functional benefit often falls dramatically short of normal hearing.

Investigators have since figured out a way to insert a marker into all types of supporting cells, with the marker remaining after the supporting cells have regenerated and turned into hair cells, using a mouse line called Sox2-CreER. Bradley J. Walters, Ph.D., and colleagues have further refined this ability to track regeneration by examining the presence of the marker at various stages of the mouse’s development. In a study in *Scientific Reports*, they conclude that this mouse line is useful for testing if regeneration is induced in young adult mice, but not in neonatal mice.

Since this mouse model is currently in use by several scientists studying hair cell regeneration, the finding that current protocols are effective for tracking regenerated supporting cells at mature but not neonatal ages is both significant and timely.

Improving the Diagnostic Process for Ménière's

From 2015 ERG scientist Wafaa Kaf, Ph.D. (funded by The Estate of Howard F. Schum)

Vertigo, dizziness, a sense of ear fullness, and ringing in the ears are all symptoms for a variety of illnesses, including migraines. A patient with these symptoms may not think they are serious, according to Wafaa Kaf, Ph.D. However, these symptoms can also be signs of Ménière’s disease, which has no definite cause or cure, but if left untreated can lead to deafness.

Kaf wants to improve the diagnostic process to boost earlier detection and distinguish it from other inner ear or nerve lesions. A current test places one electrode behind the ear and another in the ear canal. Clicking sounds are presented to the patient’s ear via earphone, and responses from the inner ear and the auditory nerve are recorded. The diagnosis is based on whether there is an abnormally large response from the inner ear compared with the hearing nerve response.

Kaf says if the click sounds are presented at much faster rates, the increased speed acts as a stressor to the inner ear and auditory nerve, much like using a treadmill during an echocardiogram (EKG) allows doctors to detect early heart dysfunctions.

Early detection of Ménière’s will help researchers better understand the origin of the disease and its long-term effects.

Council of Scientific Trustees (CST)

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Engineering Music to Sound Better With Cochlear Implants

From Anil K. Lalwani, M.D., the head of the CST

When hearing loss becomes so severe that hearing aids no longer help, a cochlear implant (CI) not only amplifies sounds but also lets people hear speech clearly.

Music is a different story. CIs are designed to process speech, which is a much simpler auditory signal compared with music. People with severe hearing loss also have lost auditory neurons that transmit signals to the brain.

It's not possible to tweak the settings of the implant to compensate for the loss of auditory neurons, says Anil Lalwani, M.D., the director of the Columbia Cochlear Implant Program. "It's unrealistic to expect people with that kind of nerve loss to process the complexity of a symphony, even with an implant."

Instead, as they report in the journal *Behavioural Neurology*,

Lalwani and his team are trying to reengineer and simplify music to be more enjoyable for listeners with CIs. "You don't necessarily need the entire piece to enjoy the music," Lalwani says. "Even though a song may have very complex layers, you can sometimes just enjoy the vocals, or you can just enjoy the instruments."

The group is testing different arrangements of musical compositions to learn which parts of the music are most important for listener enjoyment. Down the road, Lalwani thinks software will be able to take an original piece of music and reconfigure it for listeners or give the listener the ability to engineer their own music.

Watch Lalwani describing the method: youtu.be/Jik7T4i5r0s. —

Kaf's and Lalwani's stories are reprinted with permission from Missouri State University and Columbia University Medical Center, respectively. For references for all of the research stories in this section (pp. 38-41), see hhf.org/spring2016_references.

HHF hosted a webinar with Peter Barr-Gillespie, Ph.D., the scientific director of the HRP, in March. Check hhf.org/blog for a captioned video and transcript.



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HEARING AIDS ARE MY LIFEBLOOD

By Courtney Campbell, Au.D.



Courtney Campbell,
Au.D.

MY FIRST SOLID RECOLLECTION OF my hearing loss goes back to 10th grade English class. We were going around the room, student by student, offering a comment about the book we had just read. The only instruction from the teacher was that we were not to repeat another person's comment.

I remember straining so hard to understand what was being said and worrying about saying the wrong thing. My turn came and, of course, my comment had already been discussed. People started giggling, and the teacher scolded me for not paying attention.

This type of interaction was becoming more and more frequent. I spent most of my class time worrying, not learning. I was 16 years old and had no idea hearing loss could be the reason why.

My first official hearing test was the same year. I was diagnosed with a mild conductive hearing loss. My family knew this was a possibility due to a genetic condition I have called osteogenesis imperfecta (brittle bone disease), but my hearing loss was starting at a much earlier age than was typical.

I underwent surgery (a stapedectomy) for my hearing loss two days after graduating from high school, but it was unsuccessful. I went away to college that fall and was fit with my first set of hearing aids that winter.

Hearing aids are my lifeblood. I need them to function, and when they fail me, my day can be ruined. One Christmas about six years ago both hearing aid batteries died, and I was unprepared—without any backups—on a holiday when all stores are closed. I spent the entire time completely isolated from my family. It was one of the worst holidays I've ever had. To

me the most telling quote about hearing loss is from Helen Keller: "Blindness separates you from things; deafness separates you from people." I really felt it that Christmas.

I spent most of my class time worrying, not learning. I was 16 years old and had no idea hearing loss could be the reason why.

But hearing aids are also an imperfect science, and despite being lucky enough to have access to the newest and best hearing aid technology, there are still days, at a party or family gathering, where I'll find myself nodding and smiling because the ambient noise is making it difficult to fully catch everything.

If there is a silver lining to my hearing loss, it is that it led me to my passion: audiology. My own experiences with hearing loss and hearing aids pointed me toward a career helping other people with hearing loss to live full, happy, hearing lives—like the one I now lead. —

Staff writer Courtney Campbell, Au.D., is an audiologist at A&A Hearing Group in Chevy Chase, Maryland, and has been wearing hearing aids for over a decade.

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KELLY RADZIWON, Ph.D.

University at Buffalo, the State University of New York

Radziwon received her Ph.D. in cognitive psychology at the University at Buffalo, the State University of New York, where she is conducting postdoctoral work at its Center for Hearing and Deafness. Radziwon's 2015 Emerging Research Grant is funded by Hyperacusis Research Ltd.

In Her Words

HYPERACUSIS IS A CONDITION in which sounds of moderate intensity are perceived as intolerably loud or painful. Despite the apparent link between pain and hyperacusis in humans, little research has been conducted that directly compares the presence of inflammation (a possible cause of pain) along the auditory pathway with the occurrence of hyperacusis.

ONE PROBLEM HAS BEEN the lack of a reliable animal behavioral model that demonstrates hyperacusis—till now. In my lab, I have successfully assessed laboratory rats for drug- and noise-induced hyperacusis.

WE KNOW FROM A NUMBER of previous human studies that the more intense a sound, the more quickly someone will respond to it. So if a listener is asked to press a button when they hear a sound, their reaction time is faster the louder it is. Using lab rats and sounds varying by volume, pitch, and frequency, I can check whether an animal responds to sounds faster than normal following a drug or noise exposure. If it does, then the animal may be experiencing one aspect of hyperacusis—an increased sensitivity to sounds.

USING THIS LOUDNESS MODEL, my current research is to determine the relationship between pain-associated proteins in the auditory pathway and hyperacusis. I hope we can determine the underlying mechanisms of hyperacusis and then assess the effectiveness of drugs or other therapies on alleviating sound intolerance.

I WAS ALWAYS INTERESTED IN SCIENCE but never thought I would have a career in it. My plan entering college was to eventually go to law school, but I fell in love with a psychology course on “sensation and perception.” The class focused on how human brains convert the physical

things in our environment into all of the sights, sounds, and smells that we experience. This sensory input shapes our perception of reality and memories.

WHILE I DO NOT HAVE direct experience with hyperacusis or other hearing issues, the older members of my family have some age-related hearing loss, and my uncle sought treatment for tinnitus that he likely developed by working at a machine shop most of his adult life. Ultimately, I hope that my work can contribute to finding a cure for hyperacusis, and until then there is no real end for this project for me. —



Kelly Radziwon, Ph.D.'s project is funded by **Hyperacusis Research Ltd.** We thank Hyperacusis Research Ltd. for its support of studies examining hyperacusis and other severe forms of loudness intolerance.

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