

# HEARING HEALTH

Spring 2018 • A Publication of Hearing Health Foundation • hhf.org

## The *Anniversary* Issue

60 Years of Hearing Better

*HHF board member Sophia Boccard  
is mastering Usher syndrome*



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# DEAR READERS & SUPPORTERS,

## FOR OUR 60TH ANNIVERSARY, WE AT HEARING

Health Foundation (HHF) combed through decades of archives to present a history of our organization, which Collette Ramsey Baker launched in 1958 in gratitude after benefiting from a pioneering ear surgery. It is amazing to see the breadth of research HHF has funded.

The very first year's Emerging Research Grants (ERG), in 1959, included improving the evaluation of hearing loss in children, an epidemiological study of types and severity of hearing loss, and the effects of noise and noise-induced hearing loss. These are all topics still being fine-tuned today—demonstrating the immense complexity of the auditory and vestibular system and the ongoing need for education and advocacy.

To ensure all children receive a basic hearing test at birth, we continue to fight for Universal Newborn Hearing Screening legislation, which recently appeared on the federal budget chopping block two years in a row. We also continue to educate the public about the cumulative effects of elevated noise exposure, not least among our military service members.

To this end we welcome to our Board of Directors retired U.S. Army veteran Col. John Dillard, whose tinnitus story appeared in our Fall 2017 issue. Additionally we are thrilled to feature board member Sophia Boccard on this issue's cover. Sophia was diagnosed with Usher syndrome six years ago; her story begins on page 6.

Our article "60 Years Strong," on page 10, summarizes HHF's achievements and timeline, with a map of HHF's reach through our ERG and Hearing Restoration Project (HRP) scientists on page 14. To help celebrate we hosted an educational seminar featuring HRP scientist Ronna Hertzano, M.D., Ph.D., whose work is a perfect example of how our scientists are leveraging technology to advance breakthroughs (see page 36).

HHF would not have come into being without a recognition of the need to fund innovative hearing and balance research, six decades ago.

With HHF's constant aim to serve our community's needs and raise awareness about hearing conditions, we launched a survey last summer whose results appear on page 16. Perhaps not surprisingly, one of the biggest takeaways is that cost and access to hearing treatment rank as top concerns.

Put simply, HHF would not have come into being without Ramsey Baker's recognition of the need to fund innovative hearing and balance research, six decades ago, or—today—with generous donors who are committed to supporting cutting-edge science. While we have come a long way toward understanding hearing, and toward a biological cure for hearing loss and tinnitus, there is still much work to do. Please join us in celebrating and supporting HHF as we work toward our next history-making milestones.




Nadine Dehgan

CEO, Hearing  
Health Foundation  
[nadehgan@hhf.org](mailto:nadehgan@hhf.org)



# HEARING HEALTH

The Anniversary Issue: 60 Years of Hearing Better

Spring 2018, Volume 34, Number 2

Since 1958, Hearing Health Foundation has steadfastly supported groundbreaking hearing and balance research, leading to improved testing, diagnoses, and treatments.



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1. Cochlear Limited. D1190805. CP1000 Processor Size Comparison. 2017, Mar; Data on file.
2. Cochlear Limited. D1182081. CLTD 5620 Clinical Evaluation of Nucleus 7 Cochlear Implant System. 2017, Mar; Data on file.

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# You Are a MASTERPIECE

After receiving a stunning diagnosis, I learned to be in control of my own reality.

*By Sophia Boccard*

**THE DAY BEFORE FOURTH OF JULY, 2012, THE SECOND DIAGNOSIS CAME IN.**

"It's true, you have Usher syndrome," announced the retinal specialist. Baffled and unwilling to accept the corroboration of the first retinal specialist's initial diagnosis, I immediately responded with, "I'd like another opinion—is there anyone you can recommend?" In between both appointments, I had learned that Usher syndrome is the most common genetic cause of combined deafness and blindness.

The hearing loss diagnosis was not a new discovery. It had been detected when I was 4; my parents were told I lost my hearing as a reaction to an antibiotic given to me during an emergency surgery. Since then, having moderate to severe bilateral hearing loss meant wearing hearing aids, attending speech therapy classes, and walking around with an assistive FM listening system in school.

Growing up with a hearing loss gave me a new perspective. I had to learn to defend myself against bullies who would occasionally yank my hearing aids and throw them in the trash. And yet, here I was refusing to accept this "other" condition and learning that I had a combined hearing and vision loss diagnosis. After 26 years of thinking otherwise, it was certainly a rude awakening to learn that the hearing loss was not caused by the antibiotic.

Just a few short weeks before, I had been sitting in my optometrist's office for a routine eye exam to refill my prescription for contact lenses. The optometrist noticed some inconsistencies during my examinations and asked me to stay for more thorough exams. A standard 20-minute visit turned into a two-hour ordeal. After reviewing the results she somberly referred me to the retinal eye specialist who gave me the initial diagnosis.

This retinal eye specialist—who was the first person to utter, "You have Usher syndrome" to me—had the worst bedside manner. I refused to just take his word for it. Immediately after I left his office I cried—a lot—but then regained my composure and made a few calls to see a second retinal eye specialist for a second opinion.

And so on that day in July, even after the second retinal specialist reiterated the first specialist's diagnosis, I insisted on seeing a third specialist who would prove them both wrong.

I went to the National Eye Institute (NEI), part of the National Institutes of Health, in Bethesda, Maryland, for the third opinion. It was there at the NEI when everything came to a screeching halt and the final diagnosis was confirmed with a genetic test.

The test showed I was born with the mutated gene USH2A, a double recessive genetic disorder that requires both parents to have the exact same copy of the gene. Usher syndrome has three types—types 1, 2, and 3—each with many subtypes such as Usher 2A, Usher 3A, Usher 1F, etc. Combined there are approximately 400,000 people worldwide who have been diagnosed with Usher syndrome. But even with 400,000 people around the world with Usher, there still isn't enough information easily accessible for individuals who receive this diagnosis.

That day at the NEI launched the next phase of my life. In the biography of my life, the following four years, 2012 to 2016, could be titled "My Wasted Years." This is when I became a recluse, felt sorry for myself, and cried. Every. Single. Day. I had no way of expressing my sadness or even articulating my feelings, as I didn't even know what it was I was feeling and how to cope with it.

Those were the years I felt as if I went blind overnight (and let me be clear, I did not go blind overnight—nor will I go blind overnight). I felt like there was this black cloud following me everywhere, hovering over my head and bringing constant rain, making me feel like a drowned rat.

Depression became my reality and my identity. I told a few people about the diagnosis but couldn't elaborate on the condition since I felt like my world was ending. My desire to live was negligible. How could I imagine life with no sight? What would the quality of my life be like? What would I do without my independence?



Socrates Figueroa and  
Sophia Boccard in Cape  
Ann, Massachusetts.

These were all questions that ran through my head as the life I imagined living slowly started disappearing from my mind into total darkness. For four long years I asked myself repeatedly, What is the point? What do I have to look forward to?

Then it hit me. Literally. I was walking through Times Square during rush hour, a scenario that can overwhelm most people, when I slammed into someone who screamed into my face, “Watch where you’re going, a\*\*hole!” It was in that instant that an internal shift took over and I shouted back, “Get out of *MY* way, a\*\*hole!”

It was then I accepted I needed to stop looking at myself as a victim of a mutated gene and to start owning it.

I took a step back and recognized that all this time I had erroneously pitied myself. I felt sorry for my own future and what I was going to lose, and I forgot what it meant to just live life. In preparing for a future with vision loss, I was preparing for an apocalypse that would never come—unless I let it. I needed to stop judging myself and learn to respect myself all over again.

Thus 2016 marked the year of learning to be in control of my own reality, a brand new chapter in this biography of my life. I reached out to the NEI to connect me with someone with Usher syndrome who was willing to exchange emails and stories. Soon after, the NEI introduced me to another patient with USH2A who, after initially being pen (well, email) pals, we became “Ushties” (Usher + besties). Later that year I went to an Usher Syndrome Conference, held by the Usher Syndrome Coalition, in Seattle, and continued meeting many incredible, inspirational people who today are still some of my closest friends.

With these newfound connections I began advocating for both hearing loss and vision impairment communities. Through a friend, I was introduced to Hearing Health Foundation (HHF) and joined their Young Professionals Board for two years before being invited to sit on HHF’s Board of Directors. I am thrilled to be a part of such an incredible organization that recognizes Usher syndrome as a condition that benefits from support. HHF has funded many Usher-related research projects and continues to do so.

I also currently sit on the board of the Usher Syndrome Society (Arts for USH), which uses arts and educational events to raise awareness and funding for Usher syndrome, and I am involved with Young Professionals Groups at both the Foundation Fighting Blindness and the Greater New York Chapter of the ALS Association, fighting the progressive neurodegenerative condition known as Lou Gehrig’s disease.

My fiancé and I have also decided to learn American Sign Language as a tool to communicate with new friends from the Usher community. Fundraising and awareness events have started to fill up my calendar. I look at each event as an opportunity to educate those who are unfamiliar with the importance of hearing and vision health and what it means to lose your hearing or your vision, either in part or completely.

For me, it’s the lack of awareness about how the diagnosis of either hearing or vision loss can have an effect on the individual’s own mental health as well as that of their loved ones. There is not enough support for the recently diagnosed. The public isn’t familiar with how to accommodate someone with hearing or vision loss, and since both conditions are not entirely transparent—it’s difficult for people to recognize that they are communicating with an individual with hearing or vision loss—it makes it that much harder to help.

I’m most proud to have the opportunity to teach willing learners that being deaf or blind is not something to pity but rather something to respect. I strive to demonstrate to others that even with our limitations we can still do everything we want, even if we need a little extra help getting there.

Not too long ago someone said to my fiancé, “Sophia is so lucky to have you. You are an incredible person for staying with her even through her diagnosis.” Wait a second, *what?* My first thought was that my fiancé is the lucky one! To be fair, neither one of us is

**It was then  
I accepted  
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stop looking  
at myself as  
a victim of a  
mutated gene  
and to start  
owning it.**



*Sophia Boccard with her brother Christopher in Mexico (top). The siblings with their parents, Chris and Conchita Boccard, and dogs Bruno and Penny in New York City.*

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any more “lucky” than the other. We both equally deserve each other—and despite comments like these, mostly well-intended (or not), no one will succeed at making me feel less of a person.

While we can each feel insignificant about our own lives when there are so many success stories of extraordinary people pulling off impossible accomplishments despite their limitations, let's remember that we are each the star of our own story. We are the masterpieces of our own reality.

My story doesn't have a neat ending or a twist, reassuring the reader with a fairy tale conclusion. I'm just here to remind you, my new friend, that I'm not broken. I'm not half of a person; I'm not someone to “fix.” Usher syndrome is a part of who I am, but it is not my identity. I am a human being, who like any and everyone else, is whole and perfect just as I am.

If you have a health condition, don't let it consume you. Own it. You are the badass who can survive against all odds. People are lucky to have you in their lives. Remind yourself to feel appreciated, get out there, and please, *embrace your newfound celebrity status!*

*HHF board member Sophia Boccard works in digital marketing and lives in New York City. She helped organize an Usher Syndrome Society event, [hhf.org/blogs/illuminating-usher-syndrome](http://hhf.org/blogs/illuminating-usher-syndrome). Learn about Usher research on pages 44 and 50. For references, see [hhf.org/spring2018-references](http://hhf.org/spring2018-references).*

**Share your story:** Tell us about your “aha” moment of owning your hearing condition, at [editor@hearinghealthmag.com](mailto:editor@hearinghealthmag.com).

**Support our research: [hhf.org/donate](http://hhf.org/donate)**

# 60 Years Strong

For six decades, Hearing Health Foundation (HHF) has been making a positive impact in the lives of millions of Americans living with hearing and balance disorders.

**HEARING HEALTH FOUNDATION WAS ESTABLISHED IN 1958 THANKS TO THE VISION,** strength, and determination of a remarkable woman: the late Collette Ramsey Baker. After living with substantial hearing loss for over two decades, Ramsey Baker was able to hear again at age 35, after undergoing a then-pioneering surgery for otosclerosis.

Her daughter, Collette Wynn, remembers, “My mother made a promise that, if the operation worked, she would do something to support research to find the causes of deafness and develop better treatments.” In gratitude, Ramsey Baker sought to support science through a national nonprofit organization funding hearing and balance research—but none existed. As a result, she created the Deafness Research Foundation (now HHF) to fund medical research on treating and preventing hearing loss.

Under Ramsey Baker’s leadership, HHF bestowed grants upon colleges and other research institutions to fund hearing and balance science. For her efforts, she received letters of commendation from U.S. Presidents Herbert Hoover and Dwight D. Eisenhower as well as Helen Keller and Cardinal Francis Spellman. She was also listed in the Who’s Who for Women.

## ***Notable Accomplishments***

### **1958**

HHF is founded as the Deafness Research Foundation. The Emerging Research Grants (ERG) program begins supporting research carried out by hearing and balance scientists.

### **1960**

HHF and the American Academy of Ophthalmology and Otolaryngology launch the National Temporal Bone Banks Program to collect and study the human temporal bone, the parts of the skull that enclose the middle and inner ear, in order to better understand hearing and balance conditions. In 1992 the registry was absorbed by the National Institute on Deafness and Other Communication Disorders (NIDCD).

### **1970s**

HHF supports research contributing to the development of cochlear implant technology. Today, cochlear implants benefit over 300,000 people worldwide with severe to profound hearing loss.

## **EMERGING RESEARCH GRANTS**

## Research Programs

Thanks to Ramsey Baker's vision, HHF has awarded over 2,000 grants totalling nearly \$30,000,000 through our two research programs: the Hearing Restoration Project (HRP) and Emerging Research Grants (ERG), as well as advocating for policies to better the lives of those living with hearing loss. Discoveries made through HHF-funded researchers include contributing to the development of cochlear implants and a surgery for otosclerosis, while ongoing research is investigating a biological cure for hearing loss through hair cell regeneration.

**The Hearing Restoration Project:** In 1987 a remarkable discovery was made by HHF-funded investigators: Birds have the ability to spontaneously regrow inner ear hair cells after damage and restore their hearing. In humans and other mammals, hearing loss is permanent once hair cells are damaged. This discovery led to the founding of the HRP in 2011. An international research consortium, the HRP is focused on uncovering how to regenerate hair cells to develop a biological cure for hearing loss and tinnitus.

The consortium's 15 senior scientists share a core belief: Collaboration will accelerate research. By having almost immediate access to one another's data, HRP scientists are able to perform follow-up experiments more efficiently instead of having to wait years until data is published.

The HRP uses three animal models. Two of these models, the chicken and the zebrafish, show robust hair cell regeneration, restoring their hearing once deafened. If the hair cells of a chicken or a fish are damaged, within a short time—only a day or two for the fish, a couple of weeks for the chicken—new hair cells are formed.

The mouse is the HRP's other experimental model. As with humans, the adult mouse shows no hair cell regeneration once damaged. By learning how to manipulate genes in mice to restore their hair cells, HRP scientists aim to apply this knowledge to regenerate hair cells in humans, resulting in a biological cure for hearing loss and tinnitus.

Each year HHF brings the HRP researchers together for a retreat to discuss progress on the current year's projects as well as to review future

"The question is not *if* we will regenerate hair cells in humans, but *when*," says Peter Barr-Gillespie, Ph.D., the scientific director for HHF's Hearing Restoration Project.

## 1977

HHF-funded research in outer hair cell motility (movement) leads to a new method for measuring the health of a newborn's ear. Hair cells are sensory cells located in the cochlea that help detect sound waves.

## 1985

HHF grants support tinnitus research that leads to the launch of the Tinnitus Registry Database, which pools information about symptoms, diagnoses, subtypes, and management options.

## 1987

A major discovery is made by HHF-funded scientists: Chickens can spontaneously regenerate hair cells, restoring hearing loss after being deafened.



## 1990s

 HHF's advocacy helps lead to Universal Newborn Hearing Screening legislation. Today, 97 percent of newborns are screened for hearing loss, up from 5 percent in 1993.

plans and their alignment with the HRP strategic research plan. In addition, all project plan applications are reviewed by HHF's Scientific Advisory Board (SAB), a group providing oversight and guidance to the HRP consortium, comprising senior researchers in hearing science, regenerative biology, and related fields. The SAB evaluates HRP projects and monitors the performance of projects against the goals of the projects.

**Emerging Research Grants:** ERG provides much-needed resources for cutting-edge approaches to understand, prevent, and treat hearing and balance disorders. Many ERG researchers have gone on to obtain National Institutes of Health (NIH) funding to continue their HHF-funded research. Each dollar HHF awarded to ERG scientists has been matched by NIH investments of over \$90. Within the scientific community, ERG is a prestigious, competitive grant, awarded to the most promising hearing and balance researchers.

Through ERG, HHF funds research focused on hearing loss in children; auditory processing disorders, a condition that affects the way the brain processes auditory information; hyperacusis (loudness intolerance); tinnitus (hearing ringing or buzzing without an external sound source); Ménière's disease, a hearing and balance disorder; the stria vascularis, an important inner ear tissue; and Usher syndrome, the leading cause of combined deafness and blindness. Prior ERG research examined drug ototoxicity, cochlear implant efficacy for patients with single-sided deafness, and the ability to hear speech in noise.

HHF funding is especially important in today's climate, since federal research support has stagnated while research costs have increased. With additional funding, HHF seeks to support science investigating the correlation between hearing loss and conditions such as cancer, diabetes, and kidney and heart disease.

The ERG program is governed by the Council of Scientific Trustees (CST), senior researchers and physicians from universities across the nation who review each application for scientific merit and relevance. The CST is chaired by Anil K. Lalwani, M.D., a member of Columbia University's College of Physicians and Surgeons and one of the leading ear surgeons in the country.

### Awareness and Education Programs

HHF is the publisher of this magazine, Hearing Health, the largest national consumer resource on hearing. Published quarterly and free of charge to subscribers in the U.S., Hearing Health educates individuals about the effects of hearing and balance conditions on overall health and quality of life, and aims to provide real-world solutions based on the latest research and technology. Hearing Health earned this position over the past three decades through quality contributions from the research and clinician

## 2002



HHF acquires Hearing Health magazine, the largest national consumer resource on hearing.

## 2010

HHF's Safe and Sound campaign is launched to educate the general public on preventing noise-induced hearing loss.

## 2011

The foundation's name changes to Hearing Health Foundation. The Hearing Restoration Project (HRP) is formed, a research consortium of leading hearing scientists working collaboratively to restore human hearing through hair cell regeneration.



## 2013

A discovery is made by an HHF-funded researcher: Regeneration of hair cells is possible in young mice, which greatly advances the goal of human hearing regeneration.

“HHF-supported research has laid the foundation for innovative therapies to prevent, arrest, and restore hearing loss,” says Anil K. Lalwani, M.D., who heads HHF’s Council of Scientific Trustees.

community and collaborative support from advertisers.

HHF also disseminates information through digital and social media channels. Hearing Health E-News, the hhf.org website and blog, webinars, and Facebook and Twitter are ways for the professional and consumer community to interact with and stay abreast of HHF’s programs and events.

One such example is HHF’s online resource center specifically for war veterans, hhf.org/veterans. It includes detailed descriptions of hearing conservation efforts in the military as well as human interest stories by and about soldiers who have returned from service.

In 2010, HHF launched Safe and Sound to educate the public about safe listening levels and prevent noise-induced hearing loss. HHF also partnered with the NIDCD on “It’s a Noisy Planet. Protect Their Hearing,” an educational program to help protect children’s hearing.

Twenty percent of American teenagers have permanent hearing loss. With increased institutional and individual support, in 2018 HHF plans to launch a national hearing loss prevention campaign aimed at children and teens,

along with their parents and teachers, to explain how loud noises can cause permanent hearing damage.

HHF has received the highest marks by all charity rating agencies—including BBB Wise Giving, GuideStar, Charity Navigator, and CharityWatch—showing HHF’s commitment to good governance and stewardship.

“Everyone at HHF is grateful we have been able to carry out Collette Ramsey Baker’s dream for 60 years,” CEO Nadine Dehgan says. “We look forward to doing more to prevent, research, and cure hearing loss and other hearing conditions in the next 60.” ■

*This article was prepared by HHF staff members Nadine Dehgan, Laura Friedman, Stephanie Jacovina, Lauren McGrath, and Caroline Oberweger. For references, see hhf.org/spring2018-references.*

*Support our research: hhf.org/donate*

## 2016

HHF-funded research shows that a rare genetic variant makes the middle ear susceptible to bacteria and infection, predicting a higher risk for ear infections (otitis media). Ear infections affect at least three-quarters of children by age 3, half of them repeatedly, and complications can include temporary or permanent hearing loss.

## 2016 & 2017

HHF receives accreditation from BBB Wise Giving Alliance, a Platinum rating from GuideStar, a 4-Star rating from Charity Navigator, and an A rating from CharityWatch for sound financial health and transparency. Consumer Reports cites HHF in its article, “Best Charities for Your Donation,” in two categories, “Blind and Impaired Hearing” and “Health.” HHF is the only organization listed twice, and in December 2017 HHF receives the citation again.



## 2018

HHF advocates for the passage of the Early Hearing Detection & Intervention Act of 2017, reinforcing the ongoing need for legislation supporting the early detection, diagnosis, and treatment of newborns, infants, and young children with hearing loss.

# MAPPING OUR IMPACT

For 60 years since 1958, Hearing Health Foundation (HHF) has funded hearing and balance science at hundreds of institutions in the U.S.

HHF has empowered groundbreaking research around the country at the following institutions, through the Emerging Research Grants (ERG) program and/or the Hearing Restoration Project (HRP).

## **Alabama**

University of Alabama  
at Birmingham  
University of South Alabama

## **Arizona**

Arizona State University  
University of Arizona

## **Arkansas**

University of Arkansas  
University of Central Arkansas

## **California**

Cedars-Sinai Medical Center  
Children's Hospital  
of Los Angeles  
House Research Institute  
Loma Linda University  
Pepperdine University  
Stanford University  
University of California (UC)  
Berkeley  
UC Davis  
UC Irvine  
UCLA  
UC Riverside  
UC San Francisco  
UC San Diego  
UC Santa Cruz  
University of Southern California

## **Colorado**

University of Colorado Boulder  
University of Colorado Denver

## **Connecticut**

University of Connecticut  
Yale University

## **Florida**

Florida Institute of Technology  
University of Florida  
University of Miami  
University of South Florida

## **Georgia**

Emory University  
Georgia State University  
Mercer University  
University of Georgia

## **Hawaii**

University of Hawaii

## **Illinois**

Northwestern University  
Rosalind Franklin University  
Rush University  
Southern Illinois University  
University of Chicago  
University of Illinois  
at Urbana-Champaign

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Indiana University  
Purdue University

## **Kentucky**

University of Kentucky  
University of Louisville

## **Iowa**

University of Iowa

## **Kansas**

University of Kansas

## **Louisiana**

Louisiana State University  
Tulane University

## **Maryland**

Johns Hopkins University  
Loyola University Maryland  
University of Maryland

## **Massachusetts**

Amherst College  
Boston College  
Boston University  
Brigham and Women's Hospital  
Children's Hospital Boston  
Harvard University  
Massachusetts Eye and Ear  
Massachusetts General Hospital  
Tufts University  
University of Massachusetts

## **Minnesota**

Mayo Clinic  
University of Minnesota

## **Michigan**

University of Michigan  
Wayne State University

## **Missouri**

Central Institute for the Deaf  
Stowers Institute for  
Medical Research  
Washington University  
in St. Louis

## **Mississippi**

University of Mississippi

## **Nebraska**

Creighton University  
Lincoln Medical  
Research Foundation  
University of Nebraska-Lincoln

## **Nevada**

University of Nevada, Reno

## **New Hampshire**

Boys Town National  
Research Hospital  
Dartmouth-Hitchcock  
Medical Center  
Dartmouth University

## **New Jersey**

Montclair State University  
Mountainside Hospital  
Princeton University  
Rutgers University  
Seton Hall University

## **New Mexico**

New Mexico State University  
University of New Mexico

## **New York**

Adelphi University  
Albany Medical College  
Albert Einstein College  
of Medicine  
The City College of New York  
Clarkson College of Technology  
Columbia University  
Cornell University  
Good Samaritan University  
and Hospital

## **Manhattan Eye, Ear, and Throat Hospital**

Mary Imogene Bassett Hospital  
Memorial Sloan-Kettering  
Cancer Center

Mount Sinai School of Medicine  
National Cancer Institute  
New York Medical College  
New York State Department  
of Health

New York University  
Rochester General Hospital  
Research Institute

Rochester Institute  
of Technology  
Rockefeller University  
St. Joseph's Hospital

State University of New York  
(SUNY) Buffalo  
SUNY Downstate

Medical Center  
SUNY Plattsburgh  
SUNY Stony Brook  
St. Jude Children's  
Research Hospital  
Syracuse University  
University of Rochester  
Medical Center  
Veterans Administration  
Hospital

## **North Carolina**

Bowman Gray School  
of Medicine  
Children's Hospital  
Research Center

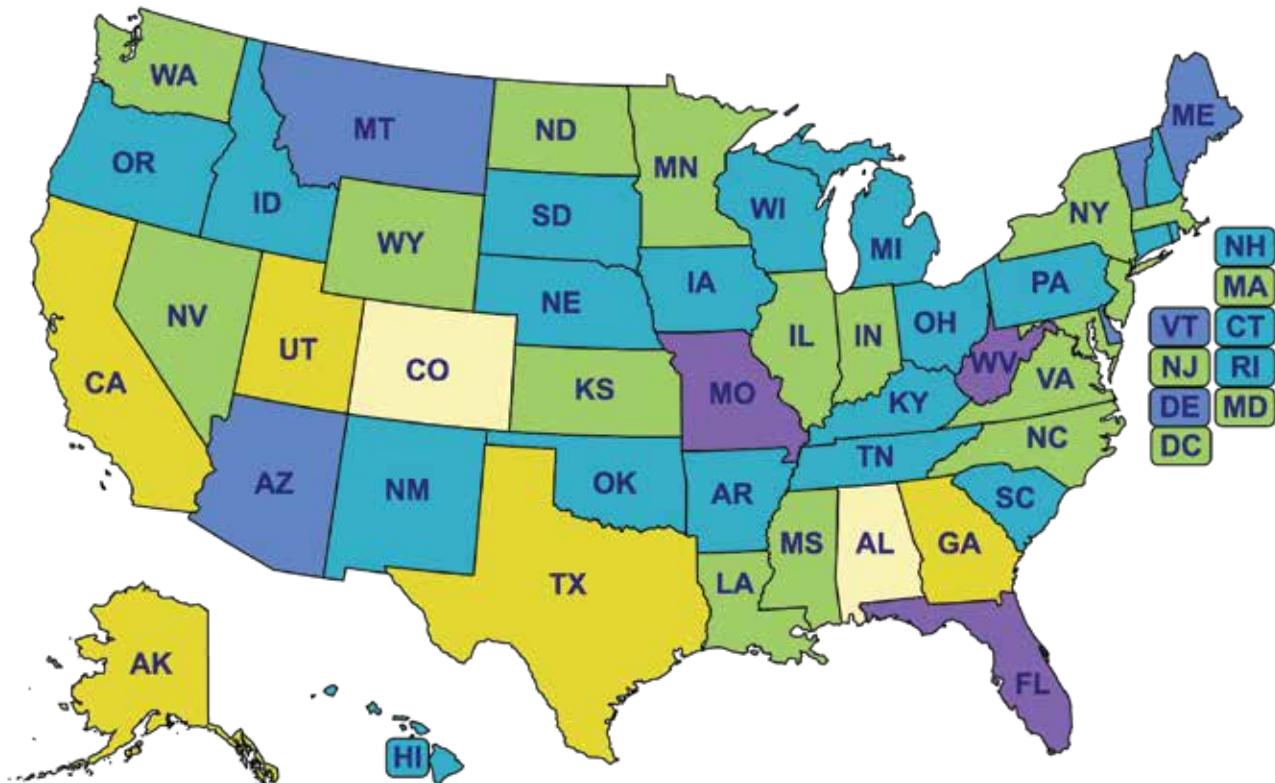
Duke University  
East Carolina University  
University of

North Carolina Wilmington  
University of North Carolina  
at Chapel Hill  
Wake Forest University

## **Ohio**

Bluffton Hospital  
Case Western Reserve University  
Cincinnati Children's Hospital  
Medical Center  
Cleveland Clinic  
James N. Gamble Institute  
of Medical Research  
Northeast Ohio Medical  
University

Using U.S. Census and other published data, the colors below represent the rate of hearing loss in each state's population, with darker colors indicating a greater prevalence.



Oberlin College  
Ohio State University  
University Hospitals  
of Cleveland  
University of Akron  
University of Cincinnati  
University of Toledo  
Wright State University

**Oklahoma**  
University of Oklahoma

**Oregon**  
Oregon Health &  
Science University  
University of Oregon

**Pennsylvania**  
Carnegie Mellon University  
Children's Hospital  
of Philadelphia  
Children's Hospital of Pittsburgh  
Drexel University  
Eye and Ear Foundation  
of Pittsburgh  
Lake Erie College  
of Osteopathic Medicine  
Lehigh University  
Pennsylvania State University

Temple University  
Thomas Jefferson University  
University of Pittsburgh Eye  
and Ear Institute Hospital

**Rhode Island**  
Brown University

**South Carolina**  
Medical University of  
South Carolina

**South Dakota**  
University of South Dakota

**Tennessee**  
East Tennessee State University  
Memphis State University  
University of Tennessee

Health Science Center  
Vanderbilt University  
Medical Center

**Utah**  
University of Utah

**Texas**  
Baylor College of Medicine  
Rice University

Texas A&M University  
Texas Christian University  
University of Texas (UT) Austin  
UT Dallas  
UT Houston  
UT Medical Branch  
UT Southwestern

**Vermont**  
University of Vermont

**Virginia**  
American Academy of  
Otolaryngology-Head  
and Neck Surgery  
University of Virginia  
Virginia Commonwealth  
University

**Washington**  
University of Washington  
Washington State University  
Washington State University  
Vancouver

**Washington, D.C.**  
Georgetown University  
Howard University

**West Virginia**  
West Virginia University  
Research Corporation

**Wisconsin**  
Medical College of Wisconsin  
University of Wisconsin-Milwaukee

For references, see [hhf.org/  
spring2018-references](http://hhf.org/spring2018-references).

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# Hearing Health Foundation 2017 Survey

By Nadine Dehgan, Lauren McGrath, and Rebecca M. Lewis, Au.D., Ph.D.

**HEARING HEALTH FOUNDATION (HHF) AND THE HEARING LOSS ASSOCIATION OF AMERICA (HLAA)** are working together to better serve the needs of our community and to raise awareness of the effects of hearing loss. In a jointly developed survey, we asked wide-ranging questions about the presence and degree of hearing loss, methods of managing it, accessibility to treatments including barriers such as cost, and opinions about over-the-counter hearing devices. The two-page survey appeared in the Summer 2017 issue of Hearing Health, HHF's quarterly print magazine, as well as at hhf.org and in the HLAA's magazine.

**More than 2,300 people responded. Here are the key findings:**

Affordability and accessibility of hearing healthcare is an underlying trend in respondents' concerns. With 40 percent of respondents reporting no coverage for hearing healthcare or hearing aids, it's no surprise that cost is reported as the leading factor that prevents the public from purchasing hearing aids (leading the next top-rated barrier to purchasing hearing aids by 575 percent).

Survey respondents support the government improving accessibility to hearing healthcare, through both support of expanded insurance coverage for audiological services and hearing aids as well as expanding publicly available devices to include over-the-counter (OTC) hearing aids.

The top three listed factors that patients consider when purchasing hearing aids include comfort, settings, and accessories; the fourth-most important factor patients consider is cost. Based on this, respondents seem to want devices that work well for their needs, but cost continues to be a struggle when choosing a set of devices that is best for their lifestyle.

## Characteristics of Most Respondents

- They are between the ages of 55 and 74 years old.
- They are retired, and their annual income is approximately \$50,000 to \$99,000.
- They report experiencing age-related hearing loss.
- Those with hearing loss say they use hearing aids.
- Those with hearing loss say that they have had their hearing loss for more than 10 years.

## Accessibility of Hearing Aids

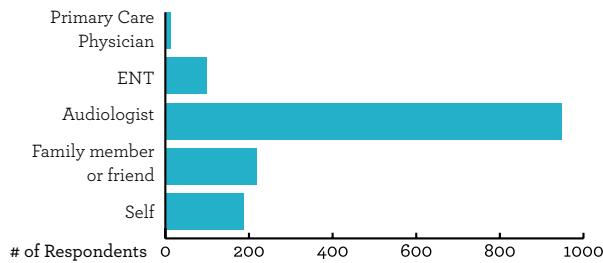
- 80 percent of respondents believe the government should allow safe, regulated, OTC hearing aids to be sold.
- Cost is reported as the leading factor that prevents the public from purchasing hearing aids, leading the next factor by 575 percent.
- At least 40 percent of respondents do not receive any type of hearing aid or audiological coverage through health insurance.
- Only 13 percent of respondents report receiving full coverage for hearing aids and audiology services.
- 27 percent of respondents who say they are veterans also say they have full coverage for audiological care.

## Use of Hearing Devices

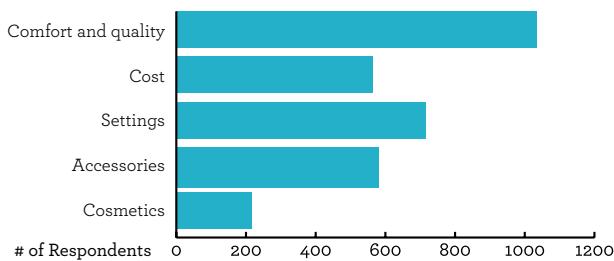
- Respondents report overall satisfaction with their current hearing aids.
- 66 percent of respondents wear hearing aids.
- 64 percent of respondents list their audiologist as the biggest influence on whether they purchased hearing aids.
- 87 percent of respondents state they would be more likely to purchase new hearing aids if there was full or partial insurance coverage for new devices every three years.

# 2017 Survey Results

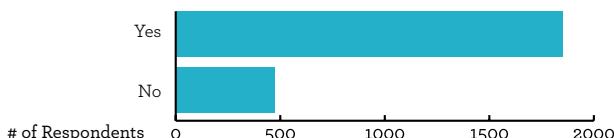
Who has the biggest influence on whether you purchase hearing aids?



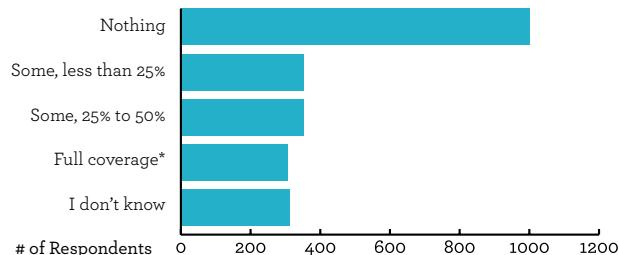
When purchasing hearing aids, please rank the importance of each factor:



Do you think the government should allow safe, regulated, over-the-counter hearing aids to be sold?

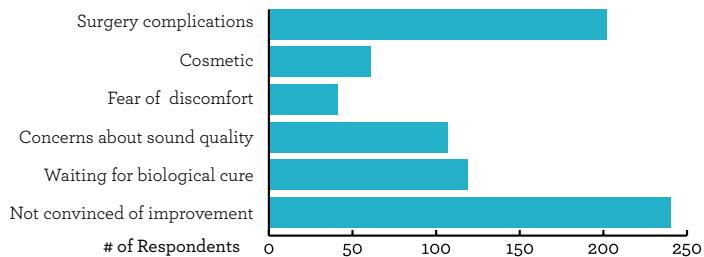


How much hearing aid and/or audiological coverage do you receive through health insurance, Medicare, or Medicaid?



\*27% of respondents who say they are veterans also say they have full coverage for audiological care.

If you qualify for a cochlear implant but do not have one, please indicate the reasons you have not pursued:



**Survey respondents seem to want devices that work well for their needs, but cost continues to be a struggle when choosing devices best for their lifestyle.**



Nadine Dehgan is the CEO of HHF, and Lauren McGrath is HHF's marketing manager. Rebecca M. Lewis, Au.D., Ph.D., is a clinical audiologist and auditory neuroscientist at Massachusetts Eye and Ear in Boston.

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# BETTER HEARING

## *Through the Ages*

Make healthy hearing a priority no matter what stage of life you're in.

*By Rebecca Huzzy, Au.D.*

**CHANCES ARE, YOU VISIT YOUR DOCTOR FOR AN ANNUAL PHYSICAL,** wear a seatbelt, and use sunscreen. These are just a few small efforts we regularly make to stay healthy and injury-free.

Tending to the health of our hearing is another important, simple way we can maintain our overall physical and emotional well-being. Supporting hearing health begins at birth, when we test newborns for hearing loss, and continues into our elder years, when assistive technology can vastly improve overall health and quality of life.

### ***Diagnosing Newborns & Infants***



According to the Centers for Disease Control and Prevention, hearing loss is one of the most common congenital conditions, impacting approximately 12,000 infants per year. About half of these cases are linked to certain genetic syndromes, such as Down syndrome, Treacher Collins, and Usher syndrome.

But with the advent of universal newborn hearing screening programs in the early 1990s, hearing loss can now be identified and treated very early. According to what we call the “1-3-6” EHDI (Early Hearing Detection and Intervention) national goals,

Families should expose their infants to sound frequently and consistently—talking to them, naming objects, narrating actions, singing, and reading books.

infants should be screened by age 1 month; diagnosed by age 3 months; and in an early intervention program by age 6 months.

“The effects of providing acoustic stimulation to the immature neurological system, including the brain, and combining the input with a rich and meaningful environmental experience, allows children to develop sufficient auditory skills to learn spoken language at a very young age,” says Janice C. Gatty, Ed.D., the director of Child & Family Services at Clarke Schools for Hearing and Speech.

This means families should expose their infants to sound frequently and consistently—talking to them, naming objects, narrating actions, singing, and reading books. With access to sound and an early intervention program at this young age, a child with hearing loss can begin learning to listen, babble, and eventually talk.

### **Common Risks for Adolescents & Teens**

Since the prevailing cause of hearing loss in young people with typical hearing is noise exposure, we need to educate kids early, as many begin listening to music on personal devices, playing in bands, and attending concerts at a young age.

According to the American Speech-Language-Hearing Association, exposure to sound that is higher than 85 decibels (the volume of a blender, hair dryer, or siren) for an extended period of time can cause permanent hearing damage. And the maximum output of most MP3 players is a powerful 110 decibels!

Fortunately, there are options for volume-limiting software that can mitigate unhealthy sound levels. Many devices offer parental controls and volume-controlling apps that limit noise levels, and there are various kid-friendly, hearing-healthy headphones available.

Follow the 80/90 rule: Set the maximum headphone volume to be 80 percent (not 100 percent), and listen for up to 90 minutes daily. If you listen for longer, lower the volume even more.

### **How Sound Exposure Catches Up With Us in Middle Age**



“Adult onset hearing loss typically progresses slowly over the course of a number of years,” says audiologist John Mazzeo, Au.D., the audiology supervisor at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware.

Noise-induced hearing loss (NIHL) can have a sneaky, cumulative effect, similar to the impact of years of exposure to the sun. The people at the highest risk for NIHL work in noisy professions and include musicians, farmers, dentists, airport workers, and military service members. For those who spend time in loud environments, wearing hearing protection is the best way to guard against NIHL.

Ototoxic drugs (drugs harmful to hearing) and certain conditions, such as Ménière’s disease, can also contribute to progressive hearing loss over time. Regular screenings, prior to the recommended age of 50, are especially important if hearing loss runs in the family, or if you have symptoms associated with hearing loss, such as tinnitus, dizziness, or a perceived decrease in hearing.

*Hearing loss is not only very common, it's also very treatable, such as through using hearing aids and assistive listening devices.*

A 2012 Johns Hopkins study found that older adults with mild hearing loss were nearly three times more likely to have a history of falling.

### **Caring for Seniors as Hearing Abilities Change**

Hearing loss becomes much more prevalent with age, affecting more than 30 percent of people over age 65, and 80 percent of adults over 80.

Hearing loss in seniors is linked to serious health conditions, including dementia. When communication is difficult, many people will avoid social situations, and research shows that social isolation is linked to cognitive decline, a key symptom of dementia. Additionally, difficulty hearing can impact the effectiveness of our other neural processes.

The risk of falls also becomes more likely with age, due to both decreased spatial awareness and increased cognitive load. A 2012 Johns Hopkins study found that older adults with mild hearing loss were nearly three times more likely to have a history of falling.

### **Staying Fit**

If you're diagnosed with a hearing loss, remember: Hearing loss is not only very common, it's also very treatable! A licensed audiologist or hearing healthcare professional can discuss options with you, including hearing aids and assistive listening devices.

When it's a loved one struggling to hear, or being stubborn about getting help, be patient. Gain their attention before talking, rephrase sentences instead of repeating them, and encourage trying out some kind of amplification.

Think of your hearing health as essential to your body's complete performance. Our bodily systems are all interconnected; neglecting to protect our ears or refusing helpful interventions can have cascading health effects. When you take even small steps to protect your hearing health and that of loved ones, such as through regular hearing screenings and using earplugs in noisy environments, take heart in knowing you have bolstered your overall well-being. ■



*Rebecca Huzzy, Au.D., CCC-A, is an educational audiologist at Clarke Schools for Hearing and Speech at its Philadelphia location and a clinical audiologist at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware. For more, see [clarkeschools.org](http://clarkeschools.org). For references, see [hhf.org/spring2018-references](http://hhf.org/spring2018-references).*

**Share your story:** Tell us how your hearing has changed through the ages at [editor@hearinghealthmag.com](mailto:editor@hearinghealthmag.com).

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ReSound **HearSay**

Be the voice of hearing

# Help others hear.

Did you know that more than 25 million Americans experience untreated hearing loss? Many just don't know how to get started. If you have hearing aids, you can help by sharing your experience and insights. Visit **ReSoundHearSay.com** to share your journey to better hearing.

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ReSound GN

# HOW MODERN HEARING AIDS MAKE HEARING A PLEASANT AND NATURAL EXPERIENCE AGAIN

*By Rebecca Herbig, Au.D.*

**466**  
MILLION

People in the world  
(more than 5 percent of  
the world's population)  
have **disabling**  
hearing loss.

Of these,  
**34 million**  
are children.



People with hearing loss **benefit** from the use of hearing aids, cochlear implants, and other assistive devices; early identification; captioning and sign language; and other forms of educational and social support.

**BEING ABLE TO HEAR AND UNDERSTAND SPEECH AGAIN IS USUALLY THE FIRST** and foremost reason why people buy hearing aids. But since hearing loss typically develops over a long period of time, patients “forget” how to hear certain sounds. As a result, when these sounds are amplified by the hearing aids, they perceive the result as excessively loud or unnatural. Since audibility is the primary goal, patients are often told that learning to hear again takes time, and they will eventually become used to how their hearing aids pick up sound.

Now with the advancement of hearing aid technology, manufacturers are finding ways to improve sound quality without sacrificing audibility. Here are some of the latest hearing aid improvements to help make acoustic environments sound as expected, and as natural, as possible.

## ***Hearings Aids That Recognize the Wearer***

A common problem for first-time hearing aid wearers is how they hear the sound of their own voice through hearing aids. For those who have never tried hearing aids, an approximate analogy would be hearing yourself on voicemail—your voice sounds processed and maybe even a bit jarring. Similarly, new hearing aid wearers often find their voice excessively loud and distracting. A main reason for this is the proximity of your voice to the hearing aids—it is often the loudest sound picked up by the hearing aids and, therefore, is duly amplified just like any other sound in the environment.

In the past, hearing care professionals have had a hard time solving own-voice issues because the hearing aids cannot tell the difference between the wearer’s own voice and any other speaker in the room. If the amplification of the hearing aids is turned down so the patient’s voice no longer sounds too loud, then not enough amplification is applied to all of the important sounds that the wearer needs to hear in the environment.

Recent innovations mean that some of the latest hearing aids can now be trained to recognize their owner’s voice. As a result, a unique and separate sound processing strategy can be applied to optimize the wearer’s voice without affecting amplification for all the other voices and sounds. Everything—the wearer’s own voice and other sounds—can be perceived as more natural and pleasant to the patient.

## ***Cutting Out the Noise***

One of the amazing things about our hearing is that we can “tune out” certain sounds we are not interested in hearing, such as the refrigerator hum or traffic noise outside the window. We notice these noises at first, but over time, we can push them into the background while we concentrate on other, more relevant sounds.

With hearing loss, we gradually stop hearing and come to “forget” these minor but constant noises running in the background. When hearing aids all of a sudden bring these sounds back, they can sound overwhelmingly noisy. This is one of the reasons why new hearing aid wearers sometimes complain that everything sounds too loud.

While it still helps for hearing care professionals to remind patients that we’re supposed to hear these sounds and that our brain can be trained to push these into the background again as necessary, technology helps move along that adaptation process.

Hearing aids today have extraordinarily sophisticated technology for identifying

and categorizing the different kinds of sounds in our environment. Is it speech, music, or noise? If it's noise, is it a constant machinery hum? Or a sharp impulse noise like a clap? Once the noises have been identified, they are cleverly filtered out and minimized without affecting more important sounds, such as speech. The end result is a quieter hearing experience that is a closer approximation of how we hear naturally.

There are even hearing aids that take the wearer's individual "hearing profile" into account. Some patients prefer a cleaner, quieter sound impression, while others can tolerate a more nuanced soundscape. These hearing aids use a specific hearing test plus a questionnaire during initial fitting to tailor sound processing schemes and determine individual preferences to better suit each patient.

### **Maintaining a Sense of Space**

Our eyes perceive distance and allow us to orient ourselves in relation to the world. Your sense of hearing plays a large role in spatial perception as well. With our eyes closed, we can localize where a sound is coming from. Even more amazing, we can walk blindfolded into a room and accurately estimate its size by relying on our sense of hearing alone.

Unfortunately, these abilities also fade away with hearing loss. This is one reason why people with untreated hearing loss have a higher risk of falls. Traditional hearing aid technology sometimes must compromise spatial hearing in favor of better hearing.

For example, standard directional microphone technology can pick up sounds that come from the front instead of from behind the wearer. This helps in noisy situations like restaurants where the patient wants to hear the conversation with the companion sitting in front of them rather than the conversation from the table behind. By the same token, this also means that the wearer is less aware of acoustic cues coming from behind.

In other cases, since our brain relies heavily on loudness cues to detect distance (softer sounds signal that the source is farther away), amplification provided by hearing aids may distort that sense of acoustic space.

With more advanced sound processing strategies, some of the best modern hearing aids no longer have to make that sacrifice. Optimal speech understanding can be achieved while spatial hearing is maintained at the same time, so while you're concentrating on a conversation with a dinner guest, you are still able to hear the waiter behind you. These hearing aids also preserve your sense of distance; sounds that originate from farther away remain in the distance, and sounds nearby are perceived as closer.

Technological sophistication and improved understanding of patient needs have resulted in hearing aids that provide better sound quality and speech understanding. These improvements make hearing aids sound more natural and as expected, while still offering excellent audibility—a win for both first-time and longtime users of hearing aids. —



*Rebecca Herbig, Au.D., is the manager and editor of scientific marketing for hearing aid manufacturer Sivantos USA. Infographic statistics are from the World Health Organization; see [hhf.org/spring2018-references](http://hhf.org/spring2018-references).*

**Share your story:** Tell us which new hearing aid features have made a difference for you, at [editor@hearinghealthmag.com](mailto:editor@hearinghealthmag.com).

**1.1  
BILLION**

Young people (ages 12 to 35) around the world are at risk of hearing loss due to **noise exposure** in recreational settings.

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# What It's Like to BREAK THE SOUND BARRIER (as a Teacher of the Deaf)

**By Jean Irwin Hatfield, as told to Steve Almond**

**WHEN I DECIDED TO BECOME A TEACHER OF THE DEAF,** I enrolled in a program at California State University, Fresno. We started with 80 candidates, but by graduation we were down to 13. That's how intense the program was.

People don't realize the linguistic challenges of deaf students, especially the trouble they have learning to read. Why is that? Because reading is a sound/symbol system. You don't read with your eyes but with your ears. This is why students who are blind, for instance, read at the same level as their sighted peers, while students who are deaf might graduate from high school reading at a fourth-grade level.

When I started out, 38 years ago, teachers dealt with this problem using workarounds, trying to figure out how to get information to students who are deaf in ways that didn't involve reading. Then I heard about a professor in England, David Wood, who was doing groundbreaking work with the deaf.

Professor Wood was studying artificial intelligence, and he fed a computer all the rules of English and programmed it to generate language. But the language that came out was very strange. He passed it around to his colleagues and someone said, "That's deaf language!" And he had this epiphany: A computer is deaf! A computer has no ear for language. So he realized that he would have to study how people who are deaf process language if he wanted to understand how computers process language. That's how he came to form the Learning Sciences Research Institute at the University of Nottingham.

I was at a party talking about all this when a Rotarian overheard me and said, "You know, we have a program that sends teachers overseas to continue their education." I received an Ambassadorial Scholarship worth \$26,000, more than I was earning at the time. The problem was Professor Wood. He told me, "We don't train teachers of the deaf." So the Rotarians sent another Rotarian who



worked in the university's engineering department to talk to him, and he finally allowed me to come over and help with the research.

The technique that Professor Wood focused on, story retelling, had been in the educational toolbox for a long time. It's based on a crucial insight, and one that educators tend to overlook, which is that students develop language intrinsically. How we talk to ourselves in our own heads is really more important than the communication between two people.

We didn't work with grammar books. Instead, we would have students read the same story over and over, then have them retell that story. The kids were confused at first, because they were so used to being with speech therapists and specialists who talked for them.

But Professor Wood was very strict. You said nothing. You let the uncomfortable silence go. Eventually the kids would realize you were going to let them keep talking, and you could see the wheels turning. They would start to correct themselves. It was amazing to watch them have that moment.

Now, education is never quick. It's not like microwaving something. You have to be patient and consistent. But with my students, I started seeing things in writing and reading that I had never before seen from children who are deaf. And once I saw that, there was no going back. I realized that I could choose particular stories that would help with whatever clause structures that student was struggling to master. I also figured out that stories with a lot of repeated dialogue were crucial, because when my students repeated the dialogue, you heard the music come into their voices and out would come these perfect sentences.

After using this method for several years, my graduating students went from reading at a fourth grade level to a 10th grade level, and some of them were exceeding that. Some graduated from college.

We would have students read the same story over and over, then have them retell that story. The kids were confused at first, because they were so used to being with specialists who talked for them. Eventually the kids would realize you were going to let them keep talking, and you could see the wheels turning. They would start to correct themselves. It was amazing to watch them have that moment.

I just went back into teaching after being retired for eight years. Once again the kids have very low reading levels, so I'm starting all over again.

I speak at reading conferences, and I always get letters from teachers who tell me, "What a game changer this method has been!" It's amazing how much the lives of these kids have been changed just by giving one year of education to one teacher of the deaf.

*This originally appeared in the January 2018 issue of The Rotarian, at rotary.org.*

**Share your story:** Has a hearing condition inspired a commitment to community service? Tell us at [editor@hearinghealthmag.com](mailto:editor@hearinghealthmag.com).

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Jordan Conole (left), a representative for California State Senator Joel Anderson, awards Chris and Frank De Francesco a certificate for outstanding community service.

## Missions That Match

By Frank De Francesco

### THE ASSISTANCE LEAGUE OF GREATER

San Diego came to our San Diego Downtown Breakfast Rotary Club looking for help supporting loaner hearing aids. These loaners are for children and young adults up to 21 years old in the San Diego Unified School District whose hearing aids are in for repair and who need a short-term replacement, or whose parents have no other hearing healthcare funding source.

Rotary members all know our daughter has a hearing loss and asked for guidance. Once I heard it was a hearing issue, I got involved, and I was able to double the contribution of our club, of which I am past president.

The missions of the Rotary Club, the Assistance League, and Hearing Health Foundation (HHF), which we support through planned giving, all overlap: All of us want to help people gain the best health outcomes possible.

My wife Chris and I were also fortunate to be honored by California State Senator Joel Anderson at HHF's educational event in San Diego in February. After learning of our longtime dedication to hearing loss research and advocacy, Senator Anderson formally recognized us for "outstanding service and commitment to the health and wellness of our community." It was a complete surprise, and we are truly humbled by this honor.

*Read the De Francescos' Fall 2017 story, "Why We Believe in Hearing Health Foundation," at [hhf.org/magazine](http://hhf.org/magazine). HHF is grateful to the De Francescos for their unwavering support of HHF's mission.*



Hearing Health Foundation  
Prevention | Research | Cure

# CAN A CHICKEN HELP CURE HEARING LOSS AND TINNITUS?

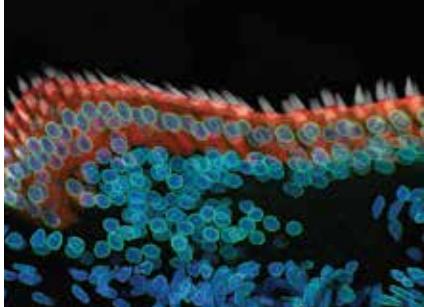


The answer, incredibly, is YES!

If the inner ear hair cells of a chick are damaged, new hair cells spontaneously grow within a couple of weeks, restoring its hearing. Our HRP scientists aim to apply this knowledge to regenerate hair cells in humans—resulting in a biological cure for hearing loss and tinnitus. Learn more at [hhf.org/hrp](http://hhf.org/hrp).

# THE CHOICE YOU MAKE TODAY CAN CHANGE LIVES.

Thank you for trusting Hearing Health magazine as your resource to learn about advancements in hearing and balance science. You can provide even greater support for **a program of your choice** with a gift to Hearing Health Foundation (HHF) today. 100% of every dollar donated to our programs goes directly toward life-changing research and awareness work.



## Emerging Research Grants

You can help tomorrow's innovators by giving to HHF's Emerging Research Grants (ERG) program. ERG-funded investigators are on the cutting edge of treatments and cures for hearing conditions including tinnitus, hyperacusis, and central auditory processing disorder (CAPD). ERG scientists are researching ways to prevent cancer treatments from being ototoxic so survivors do not have hearing loss. ERG recipients are also hard at work studying Usher syndrome, a genetic disorder that is the most common cause of deafblindness, making HHF one of few foundations funding research on this condition.



Research associate Sarah Pickett collects data in the lab of David Raible, Ph.D., a member of HHF's Hearing Restoration Project, an international consortium working to unlock hair cell regeneration in the chick cochlea (top) to translate it to humans.

## Hearing Restoration Project

You can accelerate our quest to cure hearing loss and tinnitus by sending a gift to HHF's Hearing Restoration Project (HRP). This international consortium of scientists studies hair cell regeneration in animals to understand how to replicate the process in the human ear. As a result of this remarkable collaboration, progress has been made, but your support today will bring us closer to the day when human hearing restoration is possible.

## Ménière's Disease Grants

You can choose to give to HHF's newest program, Ménière's Disease Grants (MDG). Established last year, this program funds research focused on the inner ear and balance disorder. Your gift enables researchers to continue to study this chronic condition.

## Education and Awareness Programs

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*P.S. HHF is highly rated by charity-rating agencies, including Consumer Reports, so you can be sure your gift will be well-invested.*

# Try This at Home (or in a Restaurant)

While methods for speaking clearly may come naturally, you may still need to nudge conversational partners. Here's why, and how.

**By Kathi Mestayer**

**JUST BEFORE THE START OF MY CHEMOTHERAPY** for endometrial cancer last fall, I saw my audiologist for an exam. I had read and heard enough about chemotherapy's potential harmfulness to hearing that I wanted to have a baseline, just in case. I have worn hearing aids for over 20 years, to treat my moderate-to-severe bilateral loss.

After a couple of chemo treatments, I went back for a second hearing exam. The good news was that my audiogram hadn't changed measurably. But my word-recognition score had dropped by 25 percent. In addition to wondering whether my hearing would ever come back to pre-chemotherapy levels (the consensus is: not likely), I had a more basic question: What could I do about my decreased word-recognition ability?

Answering this took some detective work—and I'm still considering my options, which include new hearing aids or a cochlear implant—but during the months-long process, I discovered that there were solutions that had never occurred to me.

## The Speech Signal

There's a long list of things that influence speech comprehension. Our brains depend on sound input (accounting for noise); visual data (speech-reading, body language); context and expectations; as well as complex social cues (taking turns to speak). There are so many

inputs that it can be cognitively stressful and exhausting to orchestrate them all.

But in my case, the only thing that had changed was my ability to make sense of auditory input in the form of words—in a soundproof booth, with no visual or other stimuli. It seemed like I was getting the same volume, but speech was somehow fuzzier.

I knew I could keep making use of communication tips I'd been employing for years: asking speakers to face me, to make sure they had my attention, and of course to avoid yelling.

But it turns out I could do more to improve the speech signal itself—coming directly from the person talking. This is because, as Donald Schum, Ph.D., puts it, "The sender is often ignored as a source of variability in speech communication."

Schum, the vice president of audiology and professional relations at hearing aid manufacturer Oticon, conducted a study in 1996 comparing the intelligibility of "natural speech" vs. "clear speech" for people with hearing loss.

First, recordings were taken of a group of test subjects using their natural speaking styles. Then they were given the following instructions: "Imagine that you are speaking to a person that you know has a hearing loss. I want you to speak as clearly and precisely as possible. Try to produce each word as accurately as you can."

And then all of the test subjects were recorded again. Those simple instructions resulted in a 19 percent average increase in intelligibility for the listeners with hearing loss, compared with their ability to understand the baseline “natural speech” recordings. Clear speech is defined as:

- Accurate and fully formed.
- Naturally slower (meaning, this happens automatically when you attempt to be clearer).
- Naturally louder (meaning, your voice raises automatically when you attempt to be clearer).
- Lively, with a full range of voice intonation (tone) and stress on key words.
- Characterized by pauses between all phrases and sentences.

In other words, we already know how to speak clearly. We may just need a reminder from a conversational partner who has a hearing loss.

### **Consonants Are Key**

Sandra Gordon-Salant, Ph.D., a professor of clinical audiology at the University of Maryland, studies how the speech signal changes when we try to speak clearly. In her research, Gordon-Salant has found that consonants play an important role in intelligibility.

“Consonants are briefer, in general, and have less intensity than vowels. When trying to speak more clearly, people naturally increase the duration and intensity of the consonants relative to the vowels,” Gordon-Salant says. “And those changes make speech more intelligible to the people we’ve tested, regardless of age or hearing loss.”

Pauses can play a role, too. For example: “Who ate the last piece of cake?” can sound like “hooate thlasspeesacake?” Pauses that are natural emphasize consonants: “Who aTe... the LasT PeeSe ov... CaKe?”

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“Who ate the last piece of cake?” can sound like “hooate thlasspeesacake?” Pauses that are natural emphasize consonants: “Who aTe... the LasT PeeSe ov... CaKe?”

Says Schum, “The way in which people slow down with clear speech enhances the stress pattern, while it still follows the natural course. Key words get more emphasis, which definitely helps with recognition.”

And while clear speech involves reducing the pace of speaking, slowing down too much, according to Schum, can distort the signal. “It can create an unnatural change in the rhythm and [word] stress patterns of speech,” he says. You may end up sounding even more confusing, rather than less. (Think of Dory imitating whale-speech in the “Finding Nemo” movies.)

Of course, adequate volume and less noise are both critical, especially for people with hearing loss. But according to Gordon-Salant, “Just ramping up the volume doesn’t always improve intelligibility. For example, an increase in overall volume might not be that helpful for someone with a high frequency hearing loss, because it’s mostly the low frequencies that are amplified when we speak too loudly.” Generally speaking, vowels occur at lower frequencies, while consonants, especially fricatives like /f/ and /th/ and plosives like /p/ and /k/, occur at higher frequencies.

While clear speech involves reducing the pace of speaking, slowing down too much can distort the signal, creating an unnatural change in the rhythm and patterns of speech. (Think of Dory imitating whale-speech in the “Finding Nemo” movies.)

### **Clear Speech Tips**

How can we encourage people to make the extra effort in the first place?

**Get in the game.** One of the most effective strategies is to provide feedback, or “back-channeling.” Back-channeling is when the listener gives the speaker verbal and nonverbal cues, like saying “right” or “okay,” nodding, maintaining eye contact, and paying attention.

“It’s a vital aspect of easing communication difficulties,” says Valerie Hazan, Ph.D., a professor of speech sciences in the division of psychology and language sciences at University College London. “Back-channeling encourages the speaker to keep on talking in an effective way, and gives them feedback on how well they’re being understood.”

**Do it yourself.** Another approach to try is “speech accommodation,” a sociolinguistics term for when people mirror each other’s speech behavior automatically. For instance, when one conversational partner slows down, the other person tends to match the pace, slowing down their own speech.

According to Kathleen Pichora-Fuller, Ph.D., a professor of psychology at the University of Toronto, individuals with hearing loss used this tactic when they participated in research she and her colleagues conducted at the University of British Columbia.

“Their approach was self-discovered and self-taught,” Pichora-Fuller says. “It was to talk the way they wanted their conversational partners to talk to them. By simply maintaining the desired behavior, they did not need to keep reminding conversational partners to modify their speech.”

**Take a deep breath.** Finally, a little patience comes in very handy on both sides of communicating with people with hearing loss. It’s tough to relearn how to interact on such a basic level, and when it gets tiring and frustrating, we need to take a break.

### **Try This at Home (or in a Restaurant)**

The benefits of clear speech, and of encouraging people to use it more often, got my attention.

According to Schum, “The harder the listening condition, the greater the benefit.” So I’ve been conducting my own speech accommodation experiments in noisy settings. When I switch to clear speaking mode, I have noticed people following my lead, and becoming easier to understand, often after a brief look of puzzlement.

My observations continue. I plan to attempt, in a natural voice, to stress key words, insert pauses to emphasize breaks, express sounds clearly, and provide positive feedback when my conversational partners do, too. In Hazan’s words, “Successful communication is the greatest reward, really, for all parties involved in the interaction.”



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 references, see [hhf.org/spring2018-references](http://hhf.org/spring2018-references).

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# UGLY Emotions

How I learned to confront and accept feelings such as rage, envy, and hate surrounding my hearing loss. *By Lisa Peten*

**SOME TIME AGO, I WAS TEXTING WITH A FRIEND** who also has bilateral sensorineural hearing loss. When I said I am thankful in many ways for the changes that have occurred from having this condition, she was outraged that I would say such a thing. This prompted her to rant the 1,001 ways in which her hearing loss is essentially ruining her life.

Though my friend is 20 years my senior, we share similar emotions in dealing with our late-deafened and hard-of-hearing experiences, and I imagine my gratitude for having a hearing loss caused her confusion and outrage. As we hashed through our feelings, the discussion included authentic, raw emotion as well as sharing dispassionate experiences in order to persuade the other. In the end, we came to an “agree to disagree” conclusion, marking a crossroads in our friendship, while both being thankful for the honest sharing.

I realized that “ugly” emotions (rage, envy, hate) about being deaf/hard-of-hearing have not been given the time, space, or energy to address them. These feelings

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I realized that “ugly” emotions (rage, envy, hate) about being deaf/hard-of-hearing have not been given the time, space, or energy to address them.

are sometimes buried in the false belief that they are unacceptable, unlike emotions like helplessness, frustration, and sadness, which readily find support.

After years of unsuccessfully trying to bury “ugly” emotions, I found three techniques that help when they arise:

**1. Share immediately.** For a long time I told no one except my family about my hearing challenges. It felt too

vulnerable. Nowadays, sharing this detail immediately has a positive effect on my experiences at restaurants, retail stores, and even medical visits beyond hearing health professionals. Now I know to release the emotions quickly in order to avoid an emotional explosion later.

**2. Disperse energy.** Similarly, when emotions of any kind surface, defuse them—early. In the past, I would practically run from humiliating situations when hearing incorrectly. Now, I can easily own up to the error and explain my hearing loss. While the embarrassment is still present, it releases my ugly emotions and allows the moment to pass without festering.

**3. Forgive with compassion.** I continue to struggle with reactions to my hearing loss. Eleven years after my diagnosis, I still feel sullen when I communicate with people I’ve known before my hearing loss. I find they speak louder and unconsciously use body language to essentially ignore me, especially during group conversations. I know this is ignorance or discomfort on their part, but it still hurts. I have learned to react with compassion in order to ease these emotionally ugly moments.

I tell myself that I will own all the emotions associated with my hearing loss and extend greater compassion and empathy—for all of us—when ugly emotions appear. —



Lisa Peten is the founder of Sound Health and Hearing, a health coaching boutique consultancy, [soundhealthandhealing.com](http://soundhealthandhealing.com). She is also part of HHF's Faces of Hearing Loss campaign, [hhf.org/faces](http://hhf.org/faces).

**Share your story:** How have you handled “ugly emotions”? Tell us at [editor@hearinghealthmag.com](mailto:editor@hearinghealthmag.com).

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# Hearing Enhancement, Inspired by Technological Advances

Three years ago, Alango Technologies, a leading provider of digital sound enhancement technologies since 2002, set out to create a line of multifunctional, high-performance, affordable assistive hearing products, leveraging recent technological and manufacturing advances. The result is its Wear & Hear line.

## Personalized Hearing in the Guise of a Bluetooth Headset

The first product, BeHear® NOW, is a stylish personal hearing product. It looks and functions like a Bluetooth® stereo headset, but also includes ambient hearing amplification. It is fully customizable, using the results of a built-in hearing test that can be performed with the assistance of a hearing professional, or self-administered.

## Top-Quality Components Enhance All-Around Hearing

BeHear NOW uses similar digital signal processing technology found in hearing aids, such as noise reduction, multichannel compression, feedback reduction, and more. It improves the overall hearing experience when conversing in person, watching television, listening to live music, or just going about daily activities.

## Main Features of This Assistive Hearing Headset

**Design & Scope:** BeHear NOW looks, feels, and operates as a fully functioning Bluetooth stereo headset.

**Customization:** Using the BeHear NOW smartphone app, the headset can be fine-tuned easily by the wearer to suit real-time situations.

**Technology:** BeHear NOW leverages the most advanced consumer electronics integrated circuits and Alango's field-proven sound enhancement technologies.

**Sound quality:** The highest quality components designed for high fidelity music allow for the efficient reproduction and amplification of sounds in a much wider acoustic frequency range.



*BeHear NOW pairs with Bluetooth devices, such as phones, to deliver personalized sound directly to your ears.*

**Assistive listening:** Bluetooth connectivity enables audio signals from paired devices—such as a television set, the Wear & Hear HearLink™ TV transmitter, or a remote microphone—to be sent directly to the wearer's ears, improving clarity.

## Converse Freely

BeHear NOW uses multi-microphone technology to feed intelligent algorithms that cancel out unimportant noise. The result: improved intelligibility of spoken language.

On the phone, hearing comprehension tends to decrease when listening to "fast talkers" and foreign languages, complicated by the lack of body language cues. BeHear NOW's EasyListen™ technology works real-time to dynamically slow down incoming speech, whether in a live phone conversation or from a recorded message. This makes speech more understandable while maintaining a natural conversation flow.

## Consistently Comfortable

BeHear NOW's lightweight neck loop design comes with a variety of comfortable earbuds for every ear shape. Plus, the battery is engineered to last throughout your waking hours. Use the neck loop all day and then charge the long-life battery while you sleep. Vibration alerts provide information about phone calls and device states (power off/on, Bluetooth pairing, charging connection).

BeHear NOW heralds a new era of hearing enhancement wherein stylish, affordable, always-on, always-connected wearable audio devices deliver clear, natural, customized audio and voice directly to your ears.



*Wear & Hear is a line of wearable audio devices developed by Alango Technologies, a leading supplier of voice and audio enhancement technologies. Visit [wearandhear.com](http://wearandhear.com).*

# LIFE'S BULLDOZER MOMENTS

Overcoming childhood adversity leads to discovering a life's calling.

**By Donato Tramuto**

**GROWING UP IN THE EARLY 1960S WITH AN ALMOST** total hearing loss, which was caused by an undiagnosed double ear infection, I lived in a world of silence. Many people, including those close to me, believed I was mentally deficient. Few thought I would ever amount to anything. At age 9 I felt like an outsider, even in my own family, and I was a sad, bullied, lonely little kid.

As an adult, I became the cofounder and CEO of innovative healthcare companies that I humbly believe have made healthcare more accessible and safer for millions of patients. I felt driven to succeed by a number of interrelated factors, including wanting to prove to myself and to others that I was worthy and that my life had meaning.

One incident that greatly affected me was the death of my oldest brother's young wife during childbirth, in 1972. The attending physician did not have access to Rosemary's medical records since records back then were in paper form. He prescribed a routine anesthesia that triggered a violent allergic reaction. The frantic hospital staff yanked the baby out of her womb, saving the baby's life.

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I felt driven to succeed by a number of interrelated factors, including wanting to prove to myself and to others that I was worthy and that my life had meaning.

Three months after we buried Rosemary, I underwent an experimental ear surgery from Germany to rebuild my eardrum. My ENT did my left ear first, and after it proved successful, my right ear. I was kept in bed and heavily bandaged for almost two months. When the bandages came off, I began to hear more sounds—at age 17, my life suddenly began anew.

When my hearing began to deteriorate in my 30s, I had surgery at Boston's Beth Israel Hospital to reconstruct my left eardrum from the surgery I underwent in 1972.

After several weeks, when the bandages came off I had a serious ear infection in my left ear. The doctor prescribed oral antibiotics. Two weeks later, I still had the ear infection, the hearing in my left ear was gone, and for nearly two years, the doctor kept prescribing oral antibiotics. I sought a second opinion at the famous House Ear Clinic in Los Angeles.

The House doctor confirmed I'd lost my hearing but that he could stop the infection with a powdered antibiotic, pumped into my ear to reach the site of the infection. He said the oral antibiotic was the wrong delivery method for my type of infection. One dose of the powder killed it.

I was incredulous. How could an experienced doctor at one of Boston's most prestigious teaching hospitals not be aware of best practices at a leading institution in the same country? I began to think about the need for a deeper, more accessible electronic database for physicians.

In this way my medical travails—surgeries to fix my ears, Rosemary's death, and my adult hearing loss, now treated with hearing aids—drove a desire to make healthcare better and safer for everyone. It gave me my purpose in life. These bulldozer moments eventually created an inner strength and moral compass that formed the reason I do what I do, to turn overwhelming challenges into meaningful successes. ■



*Healthcare innovator Donato Tramuto earned the 2014 RFK Ripple of Hope Award, which honors leaders for their commitment to social change. This is excerpted from Tramuto's "Life's Bulldozer Moments," whose proceeds fund The Tramuto Foundation, which provides access to education and healthcare. For more, see [tramutofoundation.com](http://tramutofoundation.com).*

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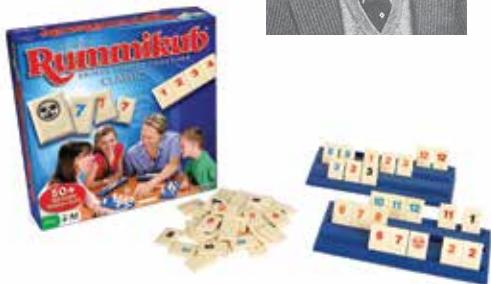
# Game Changer

**HRP** Hearing Restoration Project



Above: Hertzano cycles as part of Team Rummikub in Maryland.

Below: In the 1940s, Ronna Hertzano's grandfather invented the game Rummikub, available now in 26 languages and in more than 50 countries.



A family legacy of entrepreneurship and creative thinking helped lead to an innovative way to present data for this Hearing Restoration Project scientist.

**By Ronna Hertzano, M.D., Ph.D.**

**MY GRANDFATHER, EFRAIM HERTZANO, WAS LIVING IN ROMANIA** in the 1940s when playing with cards was outlawed. He came up with the brilliant idea of substituting tiles for cards and devised new rules for a game, which he called Rummikub, combining elements from rummy, dominoes, mah-jongg, and chess.

After immigrating to Israel, he made sets of the game by hand, and the family sold the sets door to door. His children—my father and aunt—joined the business and turned it into a game played today around the world, available in 26 languages and in more than 50 countries. I have worked at the company since I was a child, and still serve as a referee for the World Rummikub Championships, which takes place every three years.

Would it be a stretch to say this color-coded numbers game affected my choice of career as an otolaryngologist surgeon-scientist? My mother, an audiologist, certainly created an interest in understanding hearing loss. As a child, I used to visit her at a preschool for the deaf and their families on a regular basis. I also saw how she advocated for and implemented universal newborn hearing screening in Israel, which became mandatory in 2010. My

mom's compassion and insight have long inspired me.

From my dad I learned lessons from his leadership and vision. When faced with business challenges, he always finds a way to see them as opportunities and to spring forward with growth. My family's example and that of mentors and colleagues have all shaped my interests as well as how I approach challenges.

### **Wrangling Big Data**

My clinical practice focuses on the diagnosis and treatment of diseases of the ear, with an emphasis on hearing restoration. As such, I see and treat patients of all ages who suffer from hereditary and non-hereditary auditory and vestibular dysfunction (hearing loss and dizziness), including cochlear implantation.

At the same time, 60 percent of my time is dedicated to research, where my goal is to make significant contributions toward improving hearing and balance treatments. As a member of Hearing Health Foundation's Hearing Restoration Project (HRP), I work to unravel the pathways that lead to the proper development of the ear, specifically the inner ear's sensory hair cells.

Several years ago I realized that big data from what are called “-omics” experiments are becoming more prevalent. These experiments look at all of the genes (or proteins) that are expressed (or turned on) in a cell or tissue. The HRP uses a variety of -omics to compare hair cell regeneration in the ears of chicks and fish, which do spontaneously regenerate damaged hair cells, restoring their hearing, with that in mice—which, like humans, do not regenerate hair cells, leading to permanent hearing loss. However, the files are so big and complex that as biologists are creating these giant data sets, they also need computational scientists to access and interpret them.

The ear has a unique and beautiful architecture, consisting of many cell types. I am a runner, and on one of my runs I had an idea of how to turn big data into self-colorizing “cartoons,” where values of gene expression are represented as variations in color intensity—making it much easier to conceptualize than

massive spreadsheet tables or even graphs.

At the University of Maryland we have the Institute for Genome Sciences where I am an affiliate faculty member. Looking for collaborators to work on this idea, I partnered with Joshua Orvis, who is a biologist and bioinformatics software engineer (and a race car driver!). Together, we developed this idea into a portal named the gEAR.

The gEAR stands for gene Expression Analysis Resource. There was no question in my mind that the acronym had to include “ear.” The gEAR grows every month with added tools, features, and data sets. It now includes a variety of data visualization tools and data analysis tools as well as tools, to allow researchers to view their private data in the context of published data and to share it with collaborators and the research community.

We also hold gEAR workshops at the annual Association for Research in Otolaryngology meeting to increase awareness and promote data sharing in the field. With funding from Hearing Health Foundation donors, the HRP supports the gEAR, and the gEAR supports HRP scientists—while also using them as a focus group. This is a perfect relationship, allowing the gEAR to progress much faster than expected.

The neat thing is that all features developed in the gEAR per HRP requests become available to the general research community. Thanks also to support from the National Institute on Deafness and Other Communication Disorders, the gEAR has become a tool that many ear researchers around the world use on a daily basis.

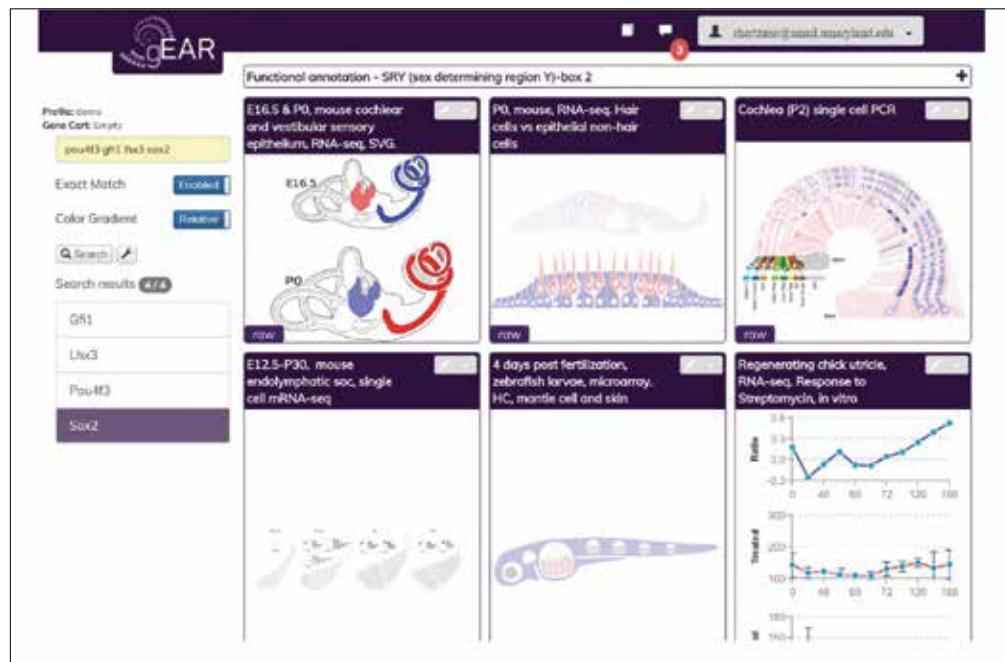
### **Forward Thinking**

I actually did not plan to be a research scientist. In my first summer of medical school I did a research rotation in a cancer laboratory. It felt like the first time I went diving, discovering a new world.

The next year, I looked for a laboratory that focused on genetics, as this was my favorite topic in medical school at Tel Aviv University. Karen Avraham, Ph.D., who studies the molecular basis of hearing loss, offered me a summer research position in her laboratory.

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The ear has a unique and beautiful architecture, consisting of many cell types. I am a runner, and on one of my runs I had an idea of how to turn big data into self-colorizing “cartoons,” where values of gene expression are represented as variations in color intensity—making it much easier to conceptualize than massive spreadsheet tables or even graphs.



This *gEAR* screenshot shows the expression results for the gene *SOX2* in several data sets from different species (mouse, zebrafish, chick).

That summer everything came together. I switched to the M.D.-Ph.D. track and completed a Ph.D. under the guidance of Dr. Avraham and other mentors, focusing on the regulation of gene expression in the ear.

During my residency training at the University of Maryland School of Medicine, I worked on a project—funded by HHF's Emerging Research Grants program in 2009 and 2010—to detect “fingerprints” of regulatory genes in different cells in the ear. This work was a collaboration with a brilliant informatics researcher named Ran Elkon, Ph.D., from Tel Aviv University.

Our top candidate was a match to the binding site of a family of regulators called RFX. These were supposed to be important for the sensory cells' final differentiation (or what the cells ultimately turn into). The day we finally found the correct combination of RFX necessary for hearing was one of the most memorable moments of my career.

Now, my team develops and applies a variety of approaches for cell type-specific genomic analyses of the ear. We couple these results with computational analyses to understand which proteins are important for the differentiation of various cell types in the ear, or the response of the ear to noise or stimuli that can result in hearing loss. This is important for the targeted development of therapeutics.

I will always be grateful to Dr. Avraham, who took me as a medical student with little scientific background and gave me a chance to develop also as a scientist. I therefore always make sure to have at least one undergraduate or medical student as part of the team.

## The Long Jump

The last piece that perhaps explains how I got from there to here is being physically active. Fitness has always played a great role in my life. I used to be a long and triple jumper in the Israeli youth and adult national teams, and then a combat fitness and self-defense instructor for the Israel Defense Forces.

Nowadays I enjoy long distance running, group road biking, and high-intensity interval training. Participating in sports on a regular basis is vitalizing and refreshing; often the best ideas come up during a run, like the one that led to the *gEAR*.

They also spring up from collaboration. The HRP consists of a tremendous group of researchers who are all focused on curing hearing loss. Being able to interact with this diverse group of researchers and exchange ideas on a regular basis have been true highlights of the consortium. I hope the tools I've worked on are beneficial to the group, as I learn something new every time we meet. ■



*HRP* consortium member Ronna Hertzano, M.D., Ph.D., is an associate professor of otorhinolaryngology-head and neck surgery at the University of Maryland School of Medicine. To learn more, see [hhf.org/hrp](http://hhf.org/hrp) and [umgear.org](http://umgear.org).

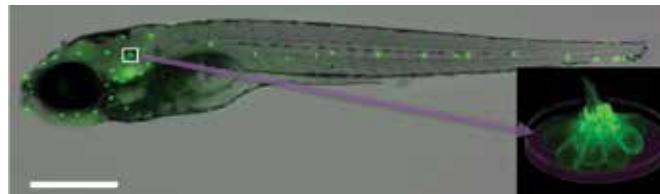
# A CLINICAL TRIAL FOR A NEW DRUG TO PROTECT HEARING

**THE U.S. FOOD AND DRUG ADMINISTRATION (FDA)** has approved a novel drug to protect against ototoxicity (harmfulness to hearing) due to the use of aminoglycoside antibiotics to treat severe infections. The FDA approval paves the way for a Phase I clinical trial to test whether the drug, found to be significantly protective in animals, is safe for humans.

The drug, ORC-13661, was developed by University of Washington professors Edwin Rubel, Ph.D., and David Raible, Ph.D., who are members of Hearing Health Foundation's Scientific Advisory Board and Hearing Restoration Project, respectively, and Fred Hutchinson Cancer Research Center scientist Julian Simon, Ph.D. "While this program was not directly funded by HHF, both David and I have definitely been supported by HHF for a long time," Rubel says. "This is a drug to prevent hearing loss that we've developed over the past 15-plus years."

Rubel points out the drug's two main features: "It is a brand new drug, not one that is used for other medical purposes and being repurposed; and it is the first drug that was developed, from the get-go, to protect hair

Mature lateral line hair cells from larval zebrafish (shown with the neuromast sensory organ enlarged) serve as a platform for studying drugs and genes that modulate hair cell susceptibility to ototoxic agents.



cells from ototoxic injury."

After screening libraries of potential chemicals to see which stopped hair cell death in zebrafish lateral line system, Rubel, Raible, and team identified the best candidate and then boosted its effectiveness by tweaking its chemical structure; results were published in the *Journal of Medicinal Chemistry* in January 2018.

Rubel adds, "Toxicity studies in zebrafish, rats, and dogs required by the FDA show superior safety and nearly 100 percent hearing protection at all frequencies."

If the Phase I trial shows the drug is safe for humans, the next step is to test its efficacy among patients using aminoglycosides. —Yishane Lee

## MOVING TOWARD A FUTURE FREE OF DRUG-INDUCED HEARING LOSS

**A SPECIAL PUBLICATION ORCHESTRATED BY FIVE OF THE NATION'S LEADING HEARING** experts compiles the latest research into hearing loss caused by drugs and solvents—how it occurs, how to treat it, and how to prevent it.

A free e-book comprising 23 scientific articles from 93 authors, "Cellular Mechanisms of Ototoxicity" was published by *Frontiers in Cellular Neuroscience* in March 2018. "We're trying to elevate ways for the human population to avoid losing this important sensation for experiencing and communicating with the world around us," says co-editor Peter Steyger, Ph.D., a professor of otolaryngology-head and neck surgery in the Oregon Health & Science University (OHSU) School of Medicine. A member of HHF's Council of Scientific Trustees, Steyger lost hearing at age 14 months after being treated with antibiotics for meningitis.

"Ototoxicity is a threat to hearing at any age, and hearing loss remains a significant side effect of chemotherapy," says co-editor Jian Zuo, Ph.D., of St. Jude Children's Research Hospital in Memphis, Tennessee. Additional editors included experts from the Department of Defense Hearing Center of Excellence and the National Institute on Deafness and Other Communication Disorders. —Erik Robinson, OHSU News



*HHF Council of Scientific Trustees member  
Peter Steyger, Ph.D.*

*These articles were prepared from press materials by the University of Washington, newsroom.uw.edu, and OHSU, news.ohsu.edu. Learn more about HRP researchers at hhf.org/spotlight, and read more about Steyger's work at "Drug-Induced Deafness" at hhf.org/magazine. For references, see hhf.org/spring2018-references.*

## EMERGING RESEARCH GRANTS



The three Emerging Research Grants recipients on these pages were each generously funded by the General Grand Chapter Royal Arch Masons International.

*For references, see [hhf.org/spring2018-references](http://hhf.org/spring2018-references).*

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

## Recent Research by Hearing Health Foundation Scientists, Explained

### ***Sound Processing in Early Brain Regions***

**STANDARD HEARING TESTS MAY NOT ACCOUNT FOR THE DIFFICULTY** some individuals have understanding speech, especially in noisy environments, even though the sounds are loud enough to hear. To better identify and treat these central auditory processing disorders that appear despite normal ear function, 2016 ERG scientist Richard A. Felix II, Ph.D., and colleagues have been investigating how the brain processes complex sounds such as speech.

In the past, speech processing research has focused on higher-level brain regions like the auditory cortex, but there is strong evidence showing that lower-level subcortical areas may play a significant role in hearing disorders. In their paper “Subcortical Pathways: Toward a Better Understanding of Auditory Disorders,” published online in the journal Hearing Research in January 2018, Felix and team review studies that examine the auditory brainstem and midbrain and their functional effect on hearing ability.

Speech contains various acoustic hallmarks such as pitch, timbre, and gaps between starts and stops of sound energy that the brain uses to create distinct auditory “objects”—for example, listening to one voice among multiple talkers in a noisy room. Our brains extract these acoustic clues by decoding spectral, temporal, and spatial information in order to identify and understand complex sounds.

Studies of mammalian species show that these sound features are extracted at the level of the midbrain by nerve cells in a region called the inferior colliculus, and through the integration of multiple ascending (“bottom-up”) pathways: from inner ear hair cells to the auditory nerve; to the brainstem’s cochlear nucleus and superior olivary complex; to the midbrain’s inferior colliculus; to the forebrain’s thalamus; and to the auditory cortex.

For instance, several key functions of auditory processing previously attributed to the cortex, such as the selectivity of neurons to particular vocalizations, are now demonstrated in subcortical pathways. The cortex builds upon these coding strategies to produce typical hearing and communication abilities in most individuals.

Felix and team go on to detail auditory disorders that may result in large part from subcortical processing failures. Since neurotransmitters are important in the brain, including subcortical regions, an imbalance in these chemicals’ excitatory or inhibitory actions (as typically happens with age) can affect the ability to hear complex sounds.

Disruptions of bottom-up processing may lead to hearing difficulties that are not revealed using standard hearing tests. This includes auditory synaptopathy and auditory neuropathy (terms sometimes used interchangeably), also called “hidden hearing loss.” One concern with hidden hearing loss is that subcortical processing may be affected by noise levels previously thought to be relatively safe (as low as 80 decibels).

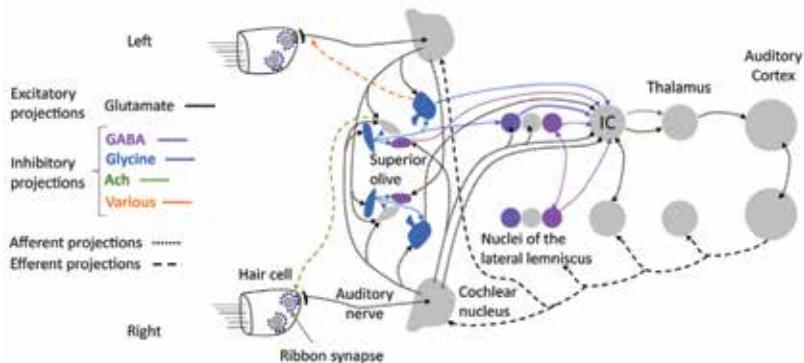
Likewise, central auditory processing disorders may be a result of abnormal top-down processing, leading to problems with selective attention and other hearing-related tasks.

The authors conclude, “Subcortical pathways represent early-stage processing on

which sound perception is built; therefore problems with understanding complex sounds such as speech often have neural correlates of dysfunction in the auditory brainstem, midbrain, and thalamus." The hope is that further study of animal models as well as human subjects will lead to tools to aid in the diagnosis and treatment of hearing disorders caused by problems with subcortical sound processing. —Yishane Lee



*A 2016 ERG recipient, Richard A. Felix II, Ph.D., is a postdoctoral researcher in the Hearing and Communications Lab at Washington State University Vancouver. Read more about Felix in Summer 2017's "Meet the Researcher," at [hhf.org/magazine](http://hhf.org/magazine).*



*This illustration shows the major inhibitory and excitatory, ascending and descending, neurotransmitter connections of subcortical pathways.*

## **Research Aims to Improve Fit and Increase Use of Hearing Aids in the U.S.**

**ALTHOUGH ABOUT 28.8 MILLION AMERICANS** could benefit from wearing hearing aids, not even a third of that population actually uses them, according to the National Institutes of Health. While cost is a contributing factor, experts say many people with hearing loss choose not to wear hearing aids simply because they have difficulty adjusting to them. Researchers with the University of Maryland Department of Hearing and Speech Sciences (HESP) are hoping to improve those figures by developing better procedures for fitting people with hearing aids for the first time.

"Right now when someone is fitted with hearing aids, the focus is on increasing audibility of sounds reaching the ear," says HESP Assistant Professor Samira Anderson, Au.D., Ph.D., a 2014 ERG recipient. "However, in order to actually understand what someone is saying, sound has to travel from the ear up to the brain. We're interested in understanding how wearing a hearing aid affects that process."

Anderson and team outfitted 37 older adults with mild to severe hearing loss with new, in-the-ear hearing aids donated by Widex USA. They placed electrodes on the surface of the patients' skin to measure electrical activity produced in response to sound in the auditory cortex and

midbrain. As reported in the journal *Ear & Hearing* in December 2017, they found that the brain's processing of sounds improves while wearing hearing aids.

"There's a growing body of research showing that hearing loss can lead to accelerated cognitive decline and isolation as people age," Anderson says. "My hope is that we can develop enhanced testing procedures that will allow more people to benefit from hearing aids and enjoy a better quality of life." The team plans to continue evaluating the patients in their study during the first six months of hearing aid use. In future studies, they will investigate the effects of manipulating hearing aid parameters on neural processing. —University of Maryland Department of Hearing and Speech Sciences



*A 2014 ERG recipient, Samira Anderson, Au.D., Ph.D., is an assistant professor in the department of hearing and speech sciences at the University of Maryland, where she is also the director of its Hearing Brain Lab. Anderson wrote about her work in Winter 2014's "A Closer Look," at [hhf.org/magazine](http://hhf.org/magazine).*

## New Data-Driven Analysis Procedure for Diagnostic Hearing Test

### STIMULUS FREQUENCY OTOACOUSTIC EMISSIONS

(SFOAEs) are sounds generated by the inner ear in response to a pure-tone stimulus. Hearing tests that measure SFOAEs are noninvasive and effective for those who are unable to participate, such as infants and young children. They also give valuable insight into cochlear function and can be used to diagnose specific types and causes of hearing loss. Though interpreting SFOAEs is simpler than other types of emissions, it is difficult to extract the SFOAEs from the same-frequency stimulus and from background noise caused by patient movement and microphone slippage in the ear canal.

Srikanta Mishra, Ph.D., a 2014 ERG recipient, and colleagues have addressed SFOAE analysis issues by developing an efficient data-driven analysis procedure. Their new method considers and rejects irrelevant background noise such as breathing, yawning, and subtle movements of the subject and/or microphone cable. The researchers used their new analysis procedure to characterize the standard features of SFOAEs in typical-hearing young adults, publishing their results in *Hearing Research* in February 2018.

Mishra and team chose 50 typical-hearing young adults to participate in their study. Instead of using a discrete-tone procedure that measures SFOAEs one frequency at a time, they used a more efficient method: a single sweep-tone stimulus that seamlessly changes frequencies from 500 to 4,000 hertz (Hz), and vice versa, over 16 and

24 seconds. The sweep tones were interspersed with suppressor tones that reduce the response to the previous tone. The tester manually paused and restarted the sweep recording when they detected background noises from the subject's movements.

The SFOAEs generated were analyzed using a mathematical model called a least square fit (LSF) and a series of algorithms based on statistical analysis of the data. This model objectively minimized the potential error from extraneous noises. Conventional SFOAE features such as level, noise floor, and signal-to-noise ratio (SNR) were described for the typical-hearing subjects.

Overall, the results of this study demonstrate the effectiveness of the automated noise rejection procedure of sweep tone-evoked SFOAEs in adults. The features of SFOAEs characterized in this study from a large group of typical-hearing young adults should be useful for developing tests for cochlear function that can be useful in the clinic and laboratory. —Carol Stoll



A 2014 ERG recipient, Srikanta Mishra, Ph.D., is an assistant professor in the department of special education and communication disorders at New Mexico State University. Read more about Mishra in Summer 2015's "Meet the Researcher," at [hhf.org/magazine](http://hhf.org/magazine).



**EMERGING  
RESEARCH  
GRANTS**

### Cochlear Supports Hearing Health Foundation's Emerging Research Grants

Hearing Health Foundation (HHF) is thrilled to announce that Cochlear Americas is funding a 2018 Emerging Research Grants (ERG) scientist studying noise-induced hearing loss, specifically a mechanism that appears to offer protection. HHF sincerely thanks Cochlear and supports its "MillionEar Challenge" (opposite page) to raise awareness and fund research to benefit ears for years to come. To learn more about ERG research, see [hhf.org/erg](http://hhf.org/erg).

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# PROMISING GENE THERAPY RESULTS FOR USHER SYNDROME

By Kate Telma

## **GWENAËLLE GÉLÉOC, PH.D., REMEMBERS HER**

incredulous response when she tested the first mouse treated with gene therapy. “The [hearing test] recordings we were getting were almost normal. It was so unbelievable that I told my technician, ‘We picked the wrong mouse, there is no way,’” says Géléoc, an investigator at Boston Children’s Hospital’s F.M. Kirby Neurobiology Center and Harvard Medical School.

After double- and triple-checking the auditory brainstem response measurements that quantify the functions of the cochlea and brain pathways, Géléoc confirmed that a single injection of Usher type 1c gene therapy restored hearing in mice with Usher syndrome type 1c. Géléoc’s group and collaborators published results in a pair of papers in *Nature Biotechnology* in March 2017. (Her team includes 2009 and 2011 Emerging Research Grants recipient Michelle Hastings, Ph.D.)

Many different genes contribute to Usher syndrome, the leading cause of combined deafness and blindness, affecting 400,000 worldwide. Scientists have been trying to create representative mouse models to study each specific type. So far, the mouse model for Usher type 1c most successfully reproduces the auditory, vestibular, and visual loss typical of human Usher syndrome.

Usher type 1c is associated with the USH1C gene, which carries instructions for making a protein known as harmonin. Fortunately for gene therapy, USH1C is a short, compact gene, and the easiest of the Usher genes to package into adeno-associated viruses (AAVs), benign viruses repurposed as a gene delivery system. Not all cells accept AAVs the same way, an obstacle to treating Usher syndrome, where different cell types are missing the same crucial gene.

By studying features various AAVs have in common, Géléoc’s collaborators (including her husband, Jeff Holt, Ph.D.) designed an improved AAV that mimics a possible common ancestor of these viruses. The researchers inserted the USH1C gene sequence into this synthetic virus, and injected the virus into the round window membrane at the base of the cochlea in newborn Usher type 1c mice. From there the gene-carrying virus penetrated outer and inner hair cells, giving both types of cells instructions to make the missing harmonin protein.



*Usher syndrome researcher Gwenaëlle Géléoc, Ph.D., and her husband and collaborator, Jeff Holt, Ph.D., in their lab at Boston Children’s Hospital.*

Measuring the auditory brainstem response six weeks after injection demonstrated that the mice could detect 25 to 30 decibel (dB) sounds in the low frequency range, a threshold almost indistinguishable from healthy, untreated mice. The effect was not as strong for higher frequency sounds, but even after six months, the mice

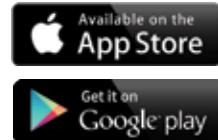
Fortunately for gene therapy, USH1C is a short, compact gene, and the easiest Usher gene to package into a virus-based gene delivery system.

maintained a roughly 45 dB threshold for the spectrum below 22 kilohertz (kHz). The treated mice also performed better in balance function tests.

Perhaps the improvement would be sustainable through a second injection or by regularly applying an AAV gel to the ear, Géléoc says. Critically, mice treated two weeks after birth did not demonstrate any restored function compared with mice treated as newborns.

Géléoc and collaborators are exploring a similar gene delivery approach using monkeys—the next step in creating a gene therapy for humans. ■

*Kate Telma recently completed the MIT Graduate Program in Science Writing. Her thesis on Usher syndrome connected her with HHF board member Sophia Boccard, whose story is on page 6. Gwenaëlle Géléoc, Ph.D., will speak at the 4th International Symposium on Usher Syndrome, July 19–21, at the Johannes Gutenberg University Mainz, Germany. See ush2018.org. HHF is proud to fund Usher syndrome research as part of its Emerging Research Grants program. Read about the 2017 grantee on page 50, and about past ERG recipient Michelle Hastings at hhf.org/blogs/prenatal-intervention-may-be-necessary-for-usher-syndrome-treatment. For references, see hhf.org/spring2018-references.*



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## EMERGING RESEARCH GRANTS

# Meet the Researcher



### Clive Morgan, Ph.D.

Oregon Health & Science University

Morgan received his doctorate in biochemistry from University College London, where he also completed postdoctoral research, and at the U.K.'s University of Manchester. He is a senior research associate at Oregon Health & Science University. His 2017 Emerging Research Grant is supported by donors who designated gifts to Hearing Health Foundation (HHF) to fund Usher syndrome research, and by the board of HHF.

### In His Words

**USHER SYNDROME** is the most common cause of combined blindness and deafness. To further our knowledge about this genetic disorder, our aim is to understand how the ear works at a molecular level. The hair cells of the inner ear detect sound and vibrations using very fine projections. The molecules directly responsible for monitoring movement of the hair bundles are located at the very tips of the projections.

**DURING MY STUDIES** I realized that individual molecules are only as important as the molecules with which they associate. Molecules of the inner ear had been understudied, mostly because of technical limitations. In 2007, Peter Barr-Gillespie, Ph.D. (the scientific director of the Hearing Restoration Project), pioneered a study of the molecular makeup of the hair bundle using mass spectrometry. Now in his lab we use modern mass-spectrometry methods to detect these incredibly scarce molecules.

**BY IDENTIFYING ALL** of the molecules present, and determining how they associate, we should be able to model the fully assembled mechanosensitive apparatus, or how sound is converted to electrical signals. Ultimately we aim to perform structural studies to better understand, at a mechanistic level, why people with Usher syndrome are deaf and why blindness is delayed.

**WE ALSO WANT TO LEARN** how in healthy individuals the ear is able to discern specific sounds in a sea of noise. This is because it could be that some Usher mutations make the hair bundle more sensitive to noise-induced damage. There is evidence in mice that mutations in one particular Usher gene, USH1C, result in hair bundles that are less sensitive to mechanical stimulation.

### Emerging Research Grants (ERG)

As one of the only funding sources available for innovative research, HHF's ERG program is critical. Without our support, scientists would not have the needed resources for cutting-edge approaches toward understanding, preventing, and treating hearing and balance disorders.

**AS A CHILD** I always watched science shows on British TV—"Horizon" and "Tomorrow's World"—and I read New Scientist and Scientific American. The first scientist in the family, I was inspired by my high school chemistry and biology teachers, who introduced me to the British Science Association.

**THROUGH THE GROUP** I was able to visit the University of Oxford to attend the yearly British Science Festival. I saw demonstrations of some of the first high-temperature superconductors, sat on a Cray supercomputer the size of a hippo, and watched detectors being built for the European particle accelerator. All made deep impressions on me on the power of science, research, and technology.

**I VALUE HIGH-QUALITY DATA** and am respectful of hard work and determination and of research that pushes our knowledge forward. I personally try to adhere to these values. I think this is an exciting time for hearing research, and that our understanding is rapidly improving. ▶

Clive Morgan, Ph.D.'s grant was generously supported by donors who designated gifts to Hearing Health Foundation (HHF) to fund Usher syndrome research, and by the board of HHF. We thank these donors for funding research to improve the understanding of Usher syndrome.

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