

# HOUSE CALLS

MAGAZINE

Winter 2020 | Vol. 13, No. 1

FEATURE ARTICLE

## Jessica's Story Decoded: Hearing After 27 Years.



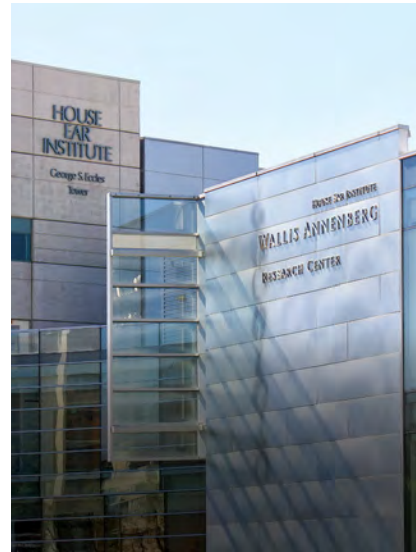
THE HOUSE INSTITUTE  
FOUNDATION

FORMERLY HOUSE EAR INSTITUTE

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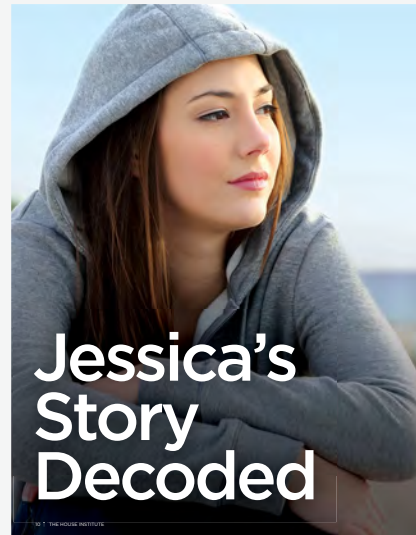


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Dear Reader,

According to the World Health Organization, 466 million people worldwide suffer from disabling hearing loss. Without intervention, this number could swell to 900 million by 2050. Many instances of hearing loss are preventable, and for those already affected, there are benefits from early identification, hearing aids, cochlear implants, and other assistive devices. While life changing, there are many research opportunities to improve sound quality and perception, especially for individuals with more severe forms of hearing loss.

Since 1946, House Ear Institute (HEI) has been at the leading edge of otology research, education, and global hearing health. Major advancements in hearing science have come from the halls of HEI.

Now, seven decades later, we are proud to announce a new name: The House Institute Foundation (HIF). In partnership with the House Institute Neurosurgery and Ear Clinics and the House Institute Hearing Aid Centers, together, we now form the House Institute. Through this collaboration, we are uniquely positioned to continue leading the way in hearing and neurological health.

Two decades ago, after a successful run with a dotcom, I was in search of opportunities with more intrinsic meaning. I rededicated my career to advancing social good and have been honored to be a part of amazing organizations and causes working to address some of the world's most challenging issues including autism, cancer, literacy, poverty, homelessness, mental health, economic and social inequality, and AIDS/HIV.

Hearing loss has a debilitating impact on many areas of life. These include physical challenges like headaches and balance disorders and social challenges such as communication and reduced academic achievement. Hearing loss can cause a myriad of mental and emotional challenges as well, including isolation, loneliness, depression, and an increased impact from dementia in older adults. The economic impact of hearing loss costs an estimated \$750 billion annually, primarily due to unemployment and lack of access to education.

I never imagined myself leading this storied and impactful organization into a new era. I am beyond proud to be associated with this outstanding group of doctors, audiologists, researchers, staff, and volunteers dedicated to improving hearing health, "so all may hear."

Now is your chance to be a part of the next generation of hearing research, education, and global hearing health. We ask not that you "donate" or provide a "gift" to the House Institute Foundation. Rather, we ask that you invest in our work focused on new technology and solutions. Our focus will continue to be policy-based, data-driven programs chosen for their long term sustainability. With your support, we will approach our work with the same seriousness and intentionality that we have for the last 70 years.

In solidarity so that all may hear,

Jeremy Sidell  
Executive Director

The House Institute Foundation



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The House Institute Foundation, formerly House Ear Institute, is a 501-(c)3 private nonprofit foundation with a threefold mission of ear and neuroscience research, education, and global hearing health, "so all may hear." Partnered with the House Institute Ear & Neurosurgery Clinics, the House Institute Foundation has been, and continues to be at the forefront of new discoveries and applications of clinical and translational research in otology (ear medicine) and neuroscience.



# Introducing the New House Institute

*House Clinic and House Ear Institute have officially relaunched as part of the new [House Institute](#), marking a new era for our nationally-recognized organization.*

Those who have been members of the House Institute’s community in the past know the establishment was named for the groundbreaking work accomplished by founder Howard P. House and his brother William F. House over 60 years ago. On this onset of a new era, the House Institute plans to ramp up its fight against a variety of disorders under its new brand name, including Meniere’s disease, acoustic neuromas, skull base tumors, neurofibromatosis, surfer’s ear, balance disorders, allergy-related problems, chronic ear infections, and more.

The House Institute Neurosurgery and Ear Clinics will continue to provide state-of-the-art audiometric evaluations and treatment options to ensure patients receive the best care possible. The world-renowned neurosurgeons and neurotologists are well trained to combat a variety of conditions. Currently, the House Institute Ear

Clinic serves all hearing-related issues, including any allergy and vestibular problems that can affect the inner ear. The highly skilled neurosurgery clinic has a wide breadth of conditions they serve as well, including, but not limited to, brain tumors, skull base tumors, and neuro-oncological diseases.

Meanwhile, the 501-(c)3 private nonprofit House Institute Foundation (HIF), will remain at the forefront of research advancements for hearing loss, ear-related, and neurological issues. This organization has led some of the world’s top breakthroughs under its leadership. We developed and perfected the original cochlear implant and auditory brainstem implant for patients with profound hearing loss. HIF will expand funding and research, provide education, and focus on global hearing health while building partnerships in the community with other organizations around the globe to identify solutions for adults and children who lack the appropriate resources for treating their hearing loss.



# What’s New at House

**1 New Name!** The House Institute Foundation (HIF), as part of the House Institute, will build on our legacy and position ourselves for the next 70 years of hearing health.

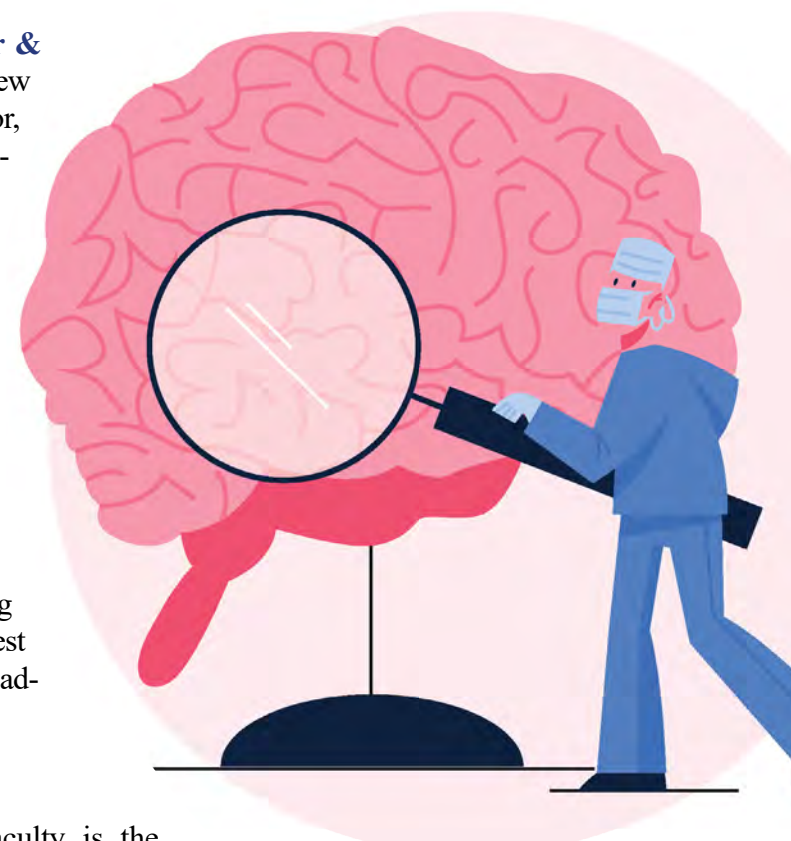
**2 Physician and Principle Investigator Led Research.** HIF has a renewed focus on physician and principle investigator led research. With our world-renowned faculty, HIF will remain at the forefront of advancing hearing health research and medical interventions.

**3 Executive Director & Staff.** With our new Executive Director, Jeremy Sidell, in addition to new staff, HIF has the tools and talent necessary to significantly move the needle on research, education, and global hearing health. With your support, we will continue to grow our team, focusing on bringing the best and brightest talent in the field to advance our mission.

**4 Faculty.** HIF’s Faculty is the engine that feeds our creative, innovative, and focused efforts. Including physicians, audiologists, and scientists, the HIF faculty is poised to provide every dimension to move our mission forward so that all may hear.

**5 Education and Global Hearing Health.** HIF is intently focused on Education and Global Hearing Health. Our educational programs support both medical professionals and consumers. Through social media, professional courses, consumer education, and outreach we support the community in addressing hearing loss. Through our global health initiatives, we provide support, training, and education both domestically and abroad.

**6 Neuroscience Division.** HIF’s new neuroscience division promotes surgeon education on the treatment of acoustic neuromas and supports both basic and clinical research. ‘Bench to Bedside’ research at House includes identifying biomarkers for tumor behavior, using cutting-edge imaging technologies to improve surgical outcomes, and the development of minimally invasive approaches to the internal auditory canal. Our goals: to make facial nerve injury ever rarer and hearing preservation ever more possible.



# Cochlear Clarity



*House researcher John Galvin, Ph.D., details his path to auditory research and his goals to give clarity of sound to cochlear implant users.*

My name is John Galvin, and I am a research scientist at the House Institute Foundation. My path to auditory research has not been typical. Many years ago, I was a comparative literature major at Hampshire College, where I also studied music. While living in Nashville, I became interested in audio recording, which I continued to pursue when we moved to Los Angeles in the mid-1990s. I found myself working as a test subject in Bob Shannon’s lab at the “original” House Institute. I would listen to acoustic simulations of cochlear implants designed to better understand and improve sound perception by cochlear implant users. My time in the lab coincided with a fertile period of research. I was fortunate to be mentored by some of the best researchers in the field, including Fangang Zeng, Monita Chatterjee, and long-time

collaborator Qian-Jie Fu. Over time, my research skills and interests developed. I was able to combine my ongoing interest in music with the challenge of making music sound better for cochlear implant patients. After nearly 20 years of research, I received my Ph.D. with Deniz Baskent (another House alumna) at the University of Groningen in the Netherlands. I was honored that many of my House friends traveled to Europe to see my Ph.D. defense (although I suspect it was to see me wear a tuxedo with tails).

Cochlear implant research requires a multidisciplinary approach. As such, I have focused on many aspects of cochlear implant sound perception, from simple psychophysics (discriminating between sounds), speech perception, music perception, and perhaps most importantly, auditory training. As Bob Shannon once said, the implant provides the sound, but it is the brain that hears. Unfortunately, there are few rehabilitative services for adult cochlear implant patients. Working with Qian-jie Fu, we developed computer-based auditory training that cochlear implant patients could perform at home, at their own pace. This training proved to be quite beneficial, and Dr. Fu has made it freely available to cochlear implant patients.

Given the current state of cochlear implant technology, there are limits to sound perception, especially for challenging listening situations like noisy environments and music perception. One increasingly beneficial approach is to combine residual acoustic hearing with the “coarse” sound representation of electric hearing. For example, this may involve a hearing aid in the same or opposite ear as the implanted

ear. Adding even a small amount of acoustic hearing can significantly improve sound quality for cochlear implant patients. New implant technology and surgical approaches allow for the preservation of as much acoustic hearing as possible in the affected ear. Even patients with normal hearing in one ear and hearing loss in the other ear can now qualify for cochlear implantation, thanks in part to a collaborative effort among the House Institute Foundation, the House Institute Ear Clinic, UCLA, and USC. While combined acoustic and electric hearing may benefit cochlear implant patients, much work remains in figuring out how to best combine these very different modes of hearing. Much of my present research, including

“Given the current state of cochlear implant technology, there are limits to sound perception.”

collaborations with Qian-jie Fu at UCLA, as well as with David Landsberger at NYU and David Bakhos at University of Tours (both House alumni), are focused on improving speech and music. As research progresses, I am confident we will find ways to improve sound perception and quality of life for cochlear implant patients.



# Where Brain Tumors Meet Hearing Loss

*Since 1979, the House Institute has been researching the genetic disorder Neurofibromatosis Type 2 (NF2), finding new ways to advance care for patients.*

NF2 affects roughly one in every 35,000 individuals. Because of abnormal or absent protein production, patients can develop benign tumors of the brain, spine, and peripheral nerves. These include schwannomas, meningiomas, and ependymomas. The hallmark of NF2 is the presence of vestibular schwannomas (also known as acoustic neuromas) in both ears. Given the House Institute Neurosurgery Clinic's (THINC) long-standing expertise with vestibular schwannomas, it is no surprise that we host the largest NF2 clinic on the West Coast.

Because this can happen at an early age, patients with NF2 must receive specialized care. Treatment is challenging as we have to decide not only how to treat a tumor, but when. We must exercise careful screening and judicious treatment when a tumor is growing or causing symptoms, as using surgery or radiation is often not worth the risk. Alternatives can include a medication called bevacizumab, or Avastin, that can help delay hearing loss. For patients with hearing loss, researchers at the House Institute Foundation (HIF) have developed a device called the auditory brainstem implant or ABI. This device channels sound from the outside world directly to electrical impulses on the brain allowing many patients to be able to perceive sounds and words.

Since NF2 is such a challenging disease to treat, researchers at HIF have been studying ways to improve care for the past 40 years. HIF researchers identified that some patients with NF2 benefit from cochlear implantation, which is a less invasive form of hearing restoration. In the 1990s, we led a Department of Defense funded, multi-center study that es-

tablished the growth patterns of vestibular schwannomas. More recently, we conducted a drug trial using the medication Everolimus to treat these tumors. We still need to learn more about NF2 and how best to treat it. Current NF2 research studies at HIF include a natural history study on the growth of tumors and their response to treatments. We are also researching quality of life and the peripheral nerve symptoms that a number of our

“Because NF2 is such a challenging disease to treat, researchers at the House Clinic have been studying ways to improve care for the past 40 years.”

data and help our NF2 patients stay actively engaged. Through their help, we hope to continue to improve the care doctors worldwide provide for NF2.

NF2 patients encounter.

Finally, we have added an NF2 clinical research coordinator Natalie Ziegler, NP. She has become an essential cornerstone of our research studies on NF2. Through our work, we have been able to collect critical research

## My NF2

*House patient Jodi Berlin details her experience with NF2.*



My name is Jodi Berlin, I'm a patient at the House Institute, and I was diagnosed with NF2 in 1981. I didn't have any symptoms at the time, but I was diagnosed because my brother and mother had NF2.

Having NF2 presents several challenges. Losing one's hearing is a big hurdle to cross. When you lose your hearing, you lose a sense of sound and a sense of community. So, when I started to use the ABI, it allowed me to feel part of society. At first, my ABI sounded sort of like synthesizer voices, and it took a while for me to interpret those voices. Some sounds I could hear a lot clearer than others. For example, I have dogs, and I can tell the difference between their barks even if I am not

in the room, which is pretty amazing.

I hear music, but I cannot distinguish what the instruments are. I cannot discriminate between singing and a musical instrument. Fortunately, the clarity of music seems to improve with time. Even though there are many limitations in that regard, I have hope that I will be able to distinguish these sounds with time.

I am so blessed to be a patient at the House Institute. When I think back to when I was losing my hearing, I didn't want to continue on. But the House Institute's doctors and staff were so compassionate and knowledgeable that they restored my hope, and I was able to enjoy life again.

I would advise anyone newly diagnosed with NF2 to go to the House Institute because the doctors are very knowledgeable. And having that knowledge is very powerful when dealing with a debilitating disorder. In other words, I would tell the newly diagnosed that there is hope out there. Have faith, because technology is improving all the time, and when you couple that technology with doctors who care, it makes a huge difference.



# Jessica's Story Decoded

*For our last campaign, we created Jessica, a fictional character who heard the ocean for the first time after 27 years. We caught up with audiologist Alicia Williams, Au.D. to get a sense of how real Jessica's story is.*

## **What are the different options that bring hearing to the profoundly deaf, and under what conditions do patients get each one?**

**Dr. Alicia Williams:** There are two treatment options to restore hearing for individuals with profound hearing loss: cochlear implants and auditory brainstem implants. Cochlear implants can help patients with sensorineural hearing loss caused by cochlear hair cell damage, as long as their auditory nerve is still intact. Auditory brainstem implants can help patients who have a missing or nonfunctioning auditory nerve.

## **How has the technology for the hearing impaired improved over the past 50 years?**

**Williams:** In 1969 we were using analog hearing aids, which amplify sounds but have very little to no noise reduction or filtering capabilities. Now audiologists are fitting digital hearing aids, which come in all shapes and sizes. They can be programmed to an individual's specific hearing loss, and have advanced features to maintain comfort and adapt to different sound environments. Some hearing devices even give patients the ability to control settings on their smartphone and stream phone calls and music directly to their hearing aids. Additionally, there are many assistive listening devices and accessories available that work with hearing aids and implants to help patients in difficult listening situations.

## **Are there deaf adults like 'Jessica' coming into the clinic looking for ways to restore their hearing?**

**Williams:** We get many adults with severe to profound hearing loss who want to restore their hearing. A cochlear implant can

restore hearing for some of these individuals. However, it is not an overnight "cure." There is a significant rehabilitation component that goes along with the surgery, and patients pursuing cochlear implantation should be highly motivated and willing to put the work in to train their brains to hear with the implant.

## **Are there patients who are profoundly deaf that we can't help? If so, for what reasons would we be unable to help them?**

**Williams:** In some situations, some patients are not medically fit for a hearing implant. There are also patients who, although they are medically cleared for surgery and meet audiologic criteria for an implant, will likely get limited benefit due to their medical and hearing history. For example, adults who have a long history of auditory deprivation will have a much harder time adjusting to sounds through a cochlear implant and may never reach the level of benefit that they hope for.

## **What advances are you hoping to see in the world of otology?**

**Williams:** I'm excited to see the range of treatment options expanded so that we can help more and more people with hearing loss. The FDA recently approved cochlear implants as a treatment for single-sided deafness and asymmetric hearing loss, which is huge! Additionally, with advances in surgical techniques, it is becoming more common for patients to retain some of their natural hearing after being implanted as well. These patients can use the residual hearing in combination with the stimulation from the implant to get a better perception of sound quality.

*Join the House Institute as we strive to improve treatments for individuals with disabling hearing loss*

*Visit us online at [www.hei.org/donate](http://www.hei.org/donate)*

## Researchers to Watch in 2020

### M. Jennifer Derebery, M.D.

Dr. Derebery is the principal investigator on a randomized, double-blind placebo-controlled clinical trial using a single injection through the eardrum (intratympanic) of an investigational drug for the treatment of patients suffering from tinnitus. Potential candidates with unilateral (one-sided) tinnitus present for less than six months are encouraged to contact Shanel Hill, [shill@hei.org](mailto:shill@hei.org), for further information.

### Kevin Peng, M.D.

Dr. Peng's current research focuses on cochlear implant performance in patients who are deaf in either one or both ears. He is also interested in analyzing how cochlear implants sound different for patients with different linguistic backgrounds—specifically, English and Mandarin Chinese. In a separate project, he is planning to optimize our view during surgery of vestibular schwannomas, also called acoustic neuromas, using a technology called near-infrared fluorescence.

### Mia E. Miller, M.D.

Dr. Miller is currently investigating hearing preservation after middle fossa craniotomy for vestibular schwannoma tumor removal in patients with Neurofibromatosis Type II (NF2). She is involved in several other studies, including a prospective evaluation with MRV (Magnetic Resonance Venography) and ultrasound to analyze vascular flow after skull base surgery, spearheaded by our senior fellow, Anne Maxwell, M.D.



## New Way to Evaluate Dizziness

*Edward I. Cho, M.D., will be testing a new device to help further his vestibular research on dizziness.*

The video Head Impulse Test or vHIT device incorporates a new technology that uses high speed, lightweight video goggles to measure balance function. Specifically, the vHIT measures the vestibulo-ocular reflex (VOR). The VOR is a reflex that allows the inner ear balance system to stabilize one's vision during activities like walking, driving, or playing sports. Without the VOR, we all would be stumbling and falling constantly. Our world would have a shaky camera effect, similar to movies filmed with handheld cameras. We will be using this device to look at the speed of balance outcomes after surgeries such as acoustic neuroma removal and repair of a condition called superior semicircular canal dehiscence. With data collected by the vHIT device, we hope to find ways to speed up balance recovery after inner ear surgery and improve patient satisfaction.



# Malawi's Neurotological Crisis

*Derald E. Brackmann, M.D., reflects on his time in Malawi and the difference he managed to make there.*

Where in the world is Malawi? Malawi is an independent country in southeast Africa of 15 million inhabitants. It is the third poorest country in the world, with an average family income of US\$250 per year.

Medical care is wanting with only one certified ear, nose, and throat physician in the entire country. Public health is poor. 40% have HIV/AIDS, and there are over one million orphans of AIDS poverty who also have HIV/AIDS. Fortunately, the government now supplies AIDS medication free of charge.

My wife and I traveled to Malawi last year to provide medical care. This was our third trip to Malawi. The first was when I was a third-year medical student. The second was three years ago with a team from Michigan State University, which has established an ENT clinic in Blantyre, Malawi's largest city. The clinic did not have the equipment to do ear surgery, and I raised

about \$100,000 from donors and industry to equip the clinic to perform ear surgery.

Chronic ear disease with eardrum perforations and hearing loss are prevalent. We performed many surgeries to repair the eardrum and improve hearing on this trip. The members of our team who specialize in head and neck surgery were also able to remove many tumors of the head and neck. While severe sensory neural hearing loss is also common, treatment with hearing aids or cochlear implants is not available.

Reflecting on a trip such as this causes one to doubt its worth. One must adopt the philosophy of Oskar Schindler on his preservation of many Jews during the holocaust. He said, "Whoever saves one life, saves the entire world."

The House Institute plans to save as many lives as possible through hearing preservation.



## Malawi

- 3rd poorest country in the world.
- One million orphans of AIDS poverty who also have HIV/Aids.
- Chronic ear disease with eardrum perforations and hearing loss are very common.

# The Solution to the Global Hearing Health Problem

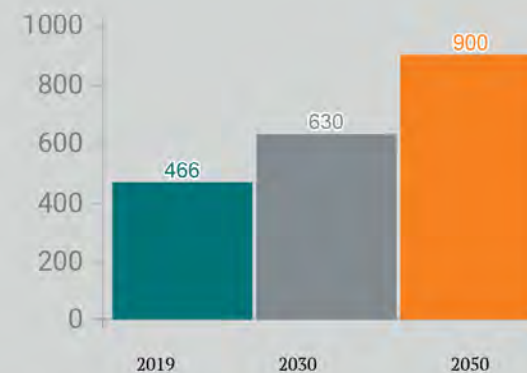
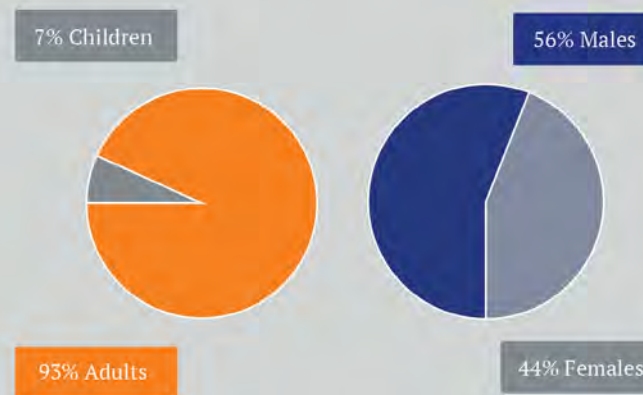
*Global hearing health is an integral part of the House Institute Foundation's (HIF's) mission. There is much to accomplish on this front going forward.*

In 2008, the House Institute began a program that was unique among neurotology fellowship programs. House fellows were encouraged to travel on a humanitarian trip during the second year of their fellowship. Then, fellowship guidelines were updated to include such an experience. These experiences foster attitudes of humanism, cultural proficiency, understanding of efficient delivery of health care in limited-resource environments, and professional conduct and accountability. All of these training attributes fall under the ACGME core competency of professionalism.

HIF included Global Health as part of its new threefold mission. There is much to accomplish. In addition to the humanitarian training component for fellows, the Global Health committee has identified several key initiatives. These include addressing the problem of affordability of hearing aids both globally and in our own "backyard"—underserved populations in the United States. This will require funding and coordination with industry, nonprofit, and governmental partners.

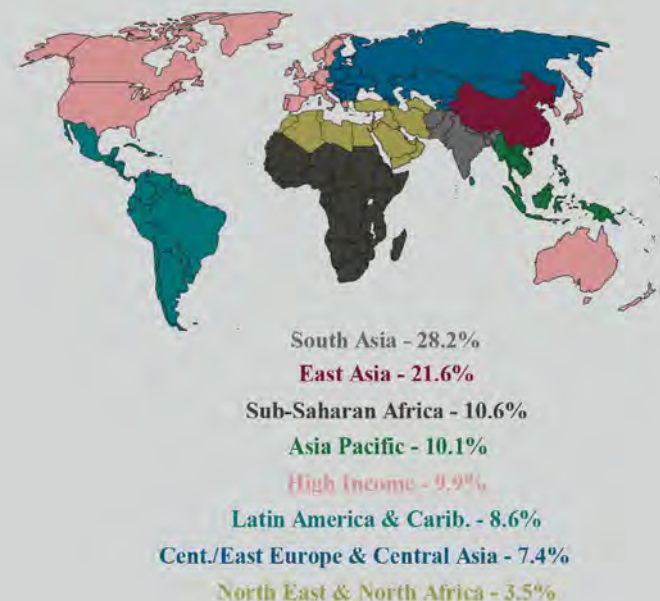
Additionally, the House Institute is uniquely positioned to be a leader in the coordination of otology humanitarian projects on a global scale by helping to establish guidelines for the effective establishment of sustainable programs. Our long-term goal is to have every otologist/neurotologist in the United States cultivate a viable global project during their career. The solution to the global health problem involves breaking down barriers both on institutional and personal levels. We hope that you will partner with us going forward.

466 Million worldwide live with disabling hearing loss



By 2050, the number of people with disabling hearing loss is estimated to grow to over 900 million

Disabling hearing loss is unequally distributed around the world.







# Howard House's Legacy Continued

*How Howard House's vision for sharing neurotology practices and procedures have become a reality.*

When Howard House, the founder of the House Institute, finished his training in Ear, Nose, and Throat in 1937, his father asked him if there was anyone in the world who knew more than he did about his field. Howard, of course, replied, "Yes, there are many." His father loaned him money to travel to various centers, visit these leaders, and spend time with them in their offices, surgeries, and, in some cases, their homes.

Howard spent the next eighteen months taking courses and visiting leaders in otolaryngology. This experience changed his professional life. All the centers welcomed him with open arms. He determined that one day, he would return the hospitality, and thus the Institute's Visiting Physicians Program was initiated in 1946. To date, the Institute has hosted over 30,000 physicians from all 50 states and almost every country in the world. Those visitors are very grateful for their time with us: watching surgeries, observing in the clinic, and attending conferences. This past October and November, we hosted visiting physicians from China, Vietnam, Bangladesh, Croatia, Portugal,

“  
To date the Institute has hosted more than 30,000 physicians.”

Paraguay, and Mexico. Recently, we received a note from one of our visiting physicians from India: "My visit in Feb '19 at House Institute was wonderful. I met all of the surgeons personally, and they all are very, very cordial." He goes on to speak about the "meticulous surgeries like stapedectomies, acoustic neuromas, tympanoplasties, cholesteatoma and pituitary surgeries . . . I am grateful for the opportunity to watch the House legends operating so beautifully."

As Howard House said, "It does not help to develop new procedures unless we share" . . . and we do.



## Moonlight Sonata: Deafness in Three Movements

*Moonlight Sonata: Deafness in Three Movements is a deeply personal documentary about intergenerational deafness. Now available on HBO.*

In "Moonlight Sonata: Deafness in Three Movements," director Irene Taylor Brodsky turns the camera on her own family to tell an intimate story of intergenerationally connected deafness, growing up, and growing old.

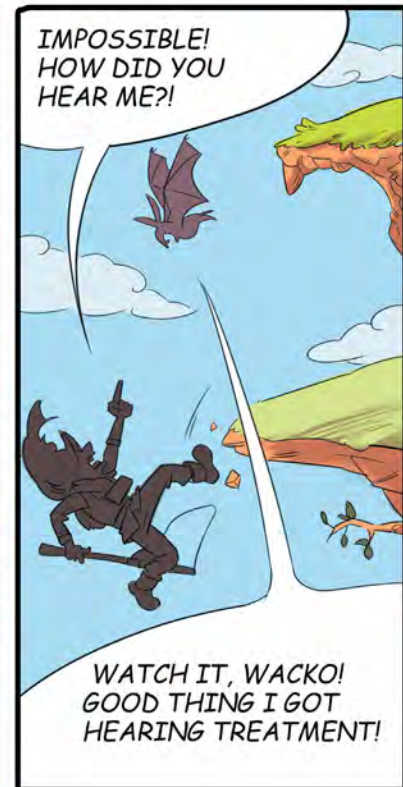
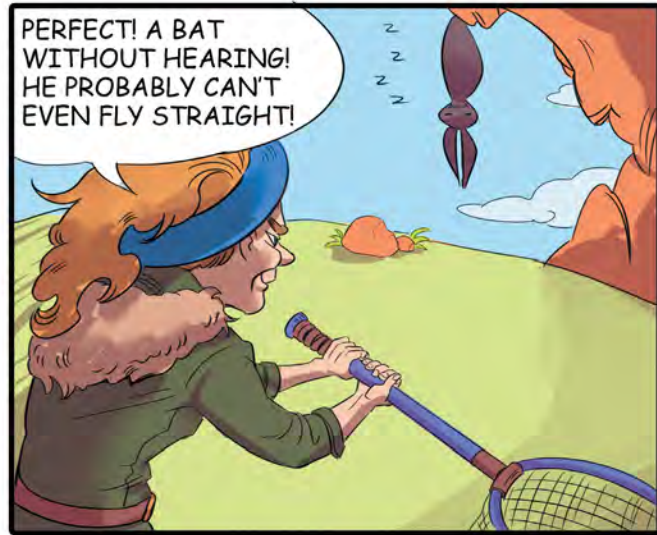
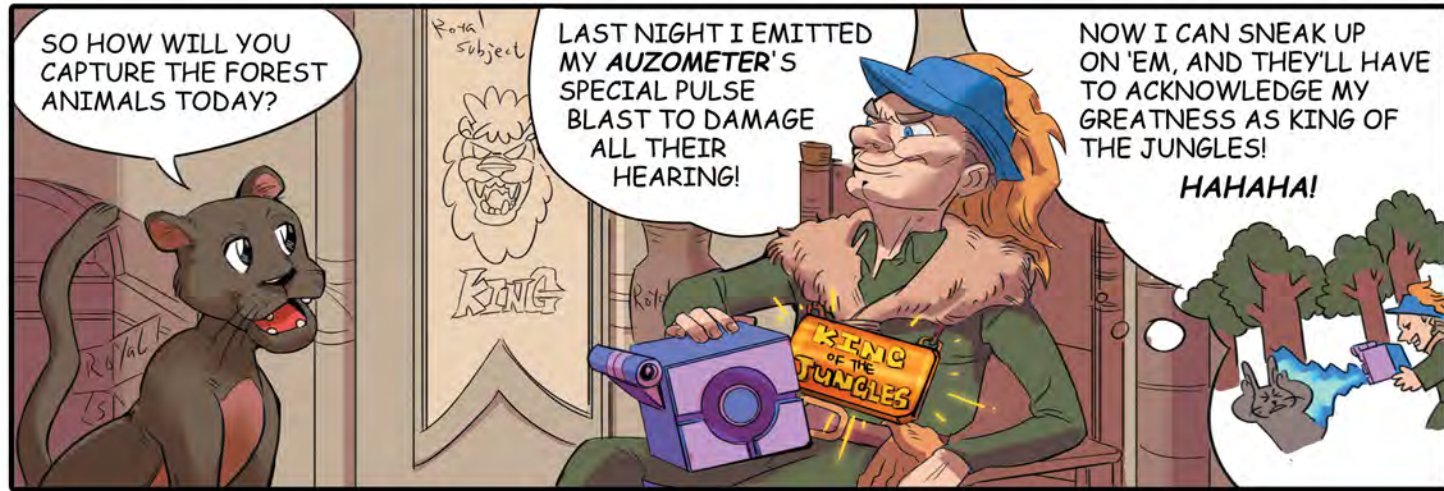
This isn't Brodsky's first time turning the camera on her family. In her 2007 award-winning documentary "Hear and Now," she introduces her parents, Sally and Paul, both of whom grew up deaf but received cochlear implants later in life. While her parents are deaf, Irene and her siblings can hear. Genes may skip a generation or two, but they tend to pop up later in the bloodline. Enter Jonas, Brodsky's first-born child. Jonas is deaf but, with the help of cochlear implants, experiences sound – and music.

At eleven, Jonas begins learning "Moonlight Sonata," the iconic piece Beethoven wrote while dealing with the throes of deafness. Using stylized animation, Brodsky juxtaposes Beethoven's angst and humiliation surrounding his deafness with Jonas' struggle in capturing the soul of the sonata.

As Jonas learns to master the piece, his grandfather's memory starts to fade. The story of Paul's cognitive decline is made more poignant by the fact that, unlike Jonas, his low auditory literacy meant that communication had always been difficult. As Paul experiences this fall in his cognition, he finds peace by looking within himself, a process made more accessible by his ability to turn off his cochlear implant.

Through spending time with his grandfather, Jonas also learns to appreciate the silence. In one memorable scene, when the ambient noise of his family proves to be a distraction from his music, he plays the sonata as Beethoven would have played it, with no implants in, focused more on the movements of his fingers and less on the sound.

This is a profoundly emotional story focused on three lives. With silence and sound integrated throughout, it shows how deafness and hearing coexist, and how this boy, his grandfather, and this composer who lived almost two hundred years ago, learned to use deafness as their superpower.



## 2018-2019 Faculty Publications

Azzadeh, B., Irvine, L. E., Diels, J., Slattery, W. H., Massry, G. G., Larian, B., . . . & Peng, G. L. (2019). Modified Selective Neurectomy for the Treatment of Post-Facial Paralysis Synkinesis. *Plastic and Reconstructive Surgery*, 145, 1483-1496. <https://doi.org/10.1097/PRS.0000000000005590>

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Ding, D., Mehta, G. U., Patibandla, M. R., Lee, C.C., Liscak, R., Kano, H., . . . & Sheehan, J. P. (2019). Stereotactic radiosurgery for acromegaly: An international multicenter retrospective cohort study. *Neurosurgery*, 84, 717-725. <https://doi.org/10.1093/neuros/nyy178>

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
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