

HearSay

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The Official Newsletter of HLAA-PA

Support and Advocacy since 2001 for Pennsylvanians with Hearing Loss

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HearSay Articles

HLAA-PA welcomes articles of interest to the hearing loss community for publication in HearSay, as well as suggestions for topics. Send e-mail to editor@hlaa-pa.org

DISCLAIMER

Opinions expressed in HearSay are those of the authors. Mention of goods and services in articles and advertisements does not mean HLAA-PA endorsement, nor does absence suggest disapproval.

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Nancy's Message

. By Nancy Kingsley, HLAA-PA State Director

Several research groups have been working on techniques to reverse hearing loss due to hair cells that have been damaged or destroyed by noise, ototoxic medications, and other causes. Frequency Therapeutics, a Massachusetts Institute of Technology (MIT) spinout, is developing a regenerative treatment that involves programming progenitor cells (descendants of stem cells in the inner ear) to make new hair cells. Progenitor cells generate hair cells in the developing embryo but become dormant before birth. In 2012, the research team used small molecules to turn these cells into hair cells in the lab, and more recently, they were able to achieve the same result by injecting the molecules into the inner ear. The treatment improved speech perception in clinical trials with over 200 participants, and results from another trial are expected early next year.

A second approach is being studied by scientists at Northwestern University in Illinois. Two genes, ATOH1 and GF1, are needed to make a cochlear hair cell from a non-hair cell. Most hearing loss results from the death of outer hair cells, which expand and contract in response to sound waves, amplifying the sound for the inner hair cells that transmit the vibrations to the auditory nerve. The researchers discovered a master gene, TBX2, that programs hair cells into either outer or inner ones. When the master gene switch is expressed, the cell becomes an inner hair cell, and when it is blocked, the cell becomes an outer hair cell. The research goal is to reprogram supporting cells latticed among the hair cells into outer or inner hair cells as needed.

State Happenings

by Carolyn Meyer, Outreach Coordinator

STATE HAPPENINGS

Here we go! Time for the Pennsylvania Walk4Hearing, October 16,2022. It is a national fund raising event that promotes advocacy for all of those with hearing loss and benefits local chapters as well. Please go to the website www.walk4hearing.org and find our Pennsylvania walk. Your donation counts. Join as an individual walker or join a team. Details: The Navy Yard 4747 South Broad Street, Philadelphia, PA. Registration at 9 AM and the Walk officially begins at 11AM. There is a raffle table again. Your donation is important. Come on Walk Day and see friends. Bring family if you wish, just join us. The walk is 3.1 miles on flat terrain. Walk for as long as you wish or just come to socialize. See you there!

CHAPTERS IN THE NEWS

MontCo (Montgomery County) chapter met on Tuesday , September 6 from 5:30-7:30 PM at the Jeanes Library, 4051 Joshua Road, Lafayette Hill, PA 19444 for their first in-person indoor meeting of the year. Members were encouraged to discuss the assistive devices they depend on for daily use.

ChesCo (Chester County) chapter planned a BYOL (bring your own lunch) picnic September 10 at the East Goshen Township Park with pavilion, snacks, drinks and dessert provided . Registration requested. A great idea to take advantage of this good weather before winter sets in! The chapter is planning an event in November and a holiday party December 15. All details on their website. hearinglosschesco.com/

Philadelphia Chapter(suburban-northeast) will have its first in-person indoor meeting on Saturday afternoon, September 17, 12;30-2:30 PM at the Huntingdon Valley Library, 625 Red Lion Road, Huntingdon Valley, PA 19006. The format will be a "meet and greet" and all are welcome to attend. Mask optional.

STATE AWARDS

It is never too early to begin to consider candidates for the awards we will be giving in 2023.

The Joe Meyer Memorial Grant Award, The Diana Bender National Convention Award, The Marcia Finisdore Advocacy Award. All applications are on the state website, "description(model)" and approximate price you estimate it is worth used. Send this with the enclosed information to include your name and address to Cochlear Implant Awareness Foundation, ATTN: CIAF Donations, 830 South Grand Avenue West, Springfield, IL 62704. Save your copy of the donation information for your tax records. If you can go to <http://ciafonline.org/> there is a formal donation receipt you can print out. Help others with your donation.

COMING SOON ON ZOOM

PATF (Pennsylvania Assistive Technologies Foundation) Outreach Director, Wendy Davis, will be doing a joint chapter presentation on what PATF has to

offer. This includes low/no interest loans for hearing aids, as well as for other assistive devices. She will discuss Smart Home Technologies and answer many questions we all have describing how PATF can help those with disabilities. Many of their policies have changed so it will be interesting for us to understand what PATF does. Many of us know Wendy from her work on the Walk committee. The date will probably be in November and information will be sent to all greater Philadelphia area chapters that are included in the Zoom presentation.

hlaa-pa.org .

COCHLEAR IMPLANT PROCESSOR DONATIONS

Many of you with cochlear implants have processors and parts that you no longer use. Please take this information and send it in to the following address. The parts and accessories can all be used by those in need. All models from all manufacturers are needed. Do not mail batteries.

The website is ciafonline.org/. If you cannot find that here is what you need to do. Make 2 copies of the information you need to enclose in the package for your processor and parts. List the "item", "quantity"

More than a Hearing Aid

When a patient is initially diagnosed with hearing loss, hearing aids are often the recommended treatment option. Most believe that hearing aids will make sounds louder for them but don't fully understand the way modern devices operate. How exactly does a hearing aid work? And what else can it do in today's world of artificial intelligence, advanced sensors, and connectivity?

The capabilities of digital hearing aids have made significant advancements in recent years, especially when compared to the days when only analog hearing aids were available.

Analog hearing aids had just a few parameters that could be changed, such as volume and amplification strength at higher or lower frequencies. Generally, their primary function was to make sounds louder. The main problem with these hearing aids was that they also increased the volume of sounds that people did not want to hear, such as background noise.

Like an analog device, a digital hearing aid consists of a microphone, amplifier, and speaker. The major difference between digital and analog is that a digital device is programmed in fine detail based on a patient's hearing test and provides a different amount of amplification at individual frequencies. A digital hearing aid can tell the difference between soft, medium, and loud sounds as well as detect different environments. Therefore, a digital hearing aid will adjust automatically, depending on the input it is receiving. These hearing aids are able to differentiate between a quiet environment, speech in noise, speech in the car, echo, music, etc.

The adjustments create a more natural and enjoyable listening experience for the user.

We know that hearing aids assist in communication and in hearing environmental sounds, but now they can do so much more. Many patients are surprised to learn that today’s hearing aid technology has Bluetooth connectivity options that replace the need for earbuds or headphones. Hearing aids are now able to connect to compatible cell phones and other wireless devices to stream phone calls, music, audio books, and podcasts via Bluetooth. Many individuals are using hearing aids to stream virtual meetings and television programs. Users can even adjust their hearing aids via an app on a smart phone.

The newest technological advancement is combining hearing aid technology with artificial intelligence (AI). Artificial intelligence allows hearing aids to learn and make decisions based on the input they receive. Hearing aid manufacturers are offering hearing aids that continuously learn a patient’s listening environments to ease listening effort and help improve speech understanding in background noise. Some hearing aids can send alerts to designated contacts if a patient experiences a fall, and some can track step counts and heart rates and monitor physical activity. One hearing aid manufacturer offers Google translate, which can automatically translate 27 languages in real time.

Hearing aids have come a long way from the days of making everything louder. Users are now able to wear one electronic device that can address a diverse range of needs. Not only are they able to hear and communicate more effectively but they can also find enjoyment in using advanced technology in almost every aspect of life.

*Natalie Watts, Au.D.
Audiologist II
Department of Otorhinolaryngology-Head and Neck Surgery
University of Pennsylvania Health Systems*

Inclusion in the Arts

I have learned a great deal from friends and colleagues in the Hearing Loss Association of America, specifically the Chester County and All Generations chapters. I first connected with this group while working to expand inclusive accommodations for the theater where I had previously been employed. My colleagues and I wanted to expand our welcome and accommodations for the productions on our mainstage. Our first joint effort was promoting the growth of open captioning capacity and then later introducing Smart Caption Glasses for theater goers with hearing loss. See the related story in a 2019 Hearsay article at tinyurl.com/HearSay2019-2

Prior to the introduction of expanded captioning or the Smart Caption Glasses, we embarked on an educational process to produce our first sensory friendly production (which we now refer to as “relaxed”) a number of years ago. These inclusive offerings were then built with the needs and experiences of individuals with disabilities at the center. For the relaxed performance, we engaged individuals with autism and with sensory processing disorder in order to better understand and prioritize their needs in the making of the events. With our very first foray into this effort, we received an

overwhelming response from patrons and community members - those who could attend and others who wished for more offerings - and we were therefore eager to see the work proliferate. We formed a cohort of area theatres and collaborated with celebrated occupational therapy professor Roger Ideishi to bring these inclusive performances to the Philadelphia arts community and tri-state region. Ultimately, we increased relaxed performances by some 600% from 2014-2018, and the work continues.

A relaxed performance essentially involves shifting institutional culture to be intentionally welcoming of patrons in order to enable them to enjoy live theater on their own terms. Patrons are invited to engage as their fullest selves, whether that means vocalizing, moving throughout the venue, and/or utilizing sensory supports or communication devices, as needed. The introduction of relaxed performances opened my eyes to the massive disconnect between (1) the ambition many arts organizations have to welcome all members of their communities and (2) the lived realities of many individuals with disabilities - including those who are neurodiverse or experience hearing loss or D/deafness - that make those arts experiences inaccessible.

Lived experience, preferences, and needs are as individual as each of us. It is therefore important to know that arts inclusion is not a one-size-fits-all situation. Having many (and varied) perspectives is useful. The resulting accommodations should also be adjusted to suit individual needs and preferences.

Since first launching the Smart Caption Glasses, I have started a new journey with Hedgerow Theatre Company, where we have begun to explore further possibilities with open captioning. Nestled in bucolic Rose Valley in Delaware County, Hedgerow owns and operates an intimate historic grist-mill-turned-theater and is embarking on its 100th anniversary season.

We offer a number of inclusive accommodations and will continue to build on those offerings. There is a waiting list for new US sites hoping to employ the Smart Caption Glasses, but when the opportunity arises, Hedgerow will be excited to make that offering a reality for our patrons. In the meantime, we will institute a week of live captioning for each mainstage production and will continue to strategize ways to make our work accessible for the hearing loss and D/deaf communities. Hedgerow will also happily share scripts in advance, offer relaxed performances, and continue to test possibilities for increased access.

Although I am several years into my journey related to this work, it is clear to me that learning and evolution is ongoing, and we arrive at the best solutions together. Individuals who experience hearing loss or are D/deaf should be central in the devising of solutions for their own arts enjoyment.

Marcie Bramucci is a theatre artist and producer, currently serving as executive artistic director of Hedgerow Theatre Company. Marcie seeks out opportunities and resources for increased arts access, engagement, and connection within and across communities. She was recently awarded the Kennedy Center's Leadership Exchange in Arts & Disability "Community Asset" award for her work in arts inclusion.

PA Walk4Hearing

The 2022 PA Walk4Hearing will take place on Sunday October 16, 2022 at the Philadelphia Navy Yard. Registration begins at 9:00 a.m. and the ceremony and Walk at 10:30.

The first PA Walk4Hearing was held in 2006. There were six Walks nationwide that year. In 2022, there were eight in the spring, including a new one held at the HLAA Convention in Tampa in June, and there will be twelve in the fall.

The Walk4Hearing is not just about raising money to support those with hearing loss. It also provides a venue for participants to meet hearing professionals, to learn about assistive technologies and resources for people with hearing loss, and most of all to meet people with hearing loss of all ages and share experiences. The atmosphere is always festive, with music, games for the young people, and free food. There are also raffles online and at the Walk. The online raffle is already active and typically has

items from Philly's sports teams. It can be accessed at
<https://go.rallyup.com/2022pawalk4hearing/Campaign/Details>

So join a team or just come out and walk with us and meet others who also live with hearing loss.

-Mike Miles

Educating Young People About Hearing Loss (3 Tiny Bones)

I was born with hearing loss, and my hearing loss journey has been difficult: I underwent four surgeries in elementary school, which led to missed months of school. I proudly wear a hearing aid, even though it has not always been easy, especially in school.

In 9th grade, I learned about HLAA and volunteered with the Walk4Hearing committee for the 2020 and 2021 Walks. As I was volunteering, I read about the one billion young people worldwide at risk for developing permanent hearing loss due to the abundant noise hazards in our world – headphones, earbuds, loud music, parties, sports, concerts, and more – because of a lack of knowledge about the harmful effects of noise. Seeing the clear need for hearing loss education, I started 3 Tiny Bones, a 501(c)(3) nonprofit organization.

The purpose of 3 Tiny Bones is to destigmatize hearing loss and create a more inclusive society through our “HEAR Principles” mission:

- Help the underprivileged hearing loss community by providing essential equipment and materials
- Educate youth about different types of hearing loss and how to protect their hearing by practicing healthy hearing habits
- Advocate for youth with hearing loss to raise awareness and have safer hearing experiences as a society
- Reach children and teens with hearing loss by creating a community in which they can support each other through their challenges, promoting positivity

Our first campaign was Noise Hazards, a 10-video series and video game educating children about common noise hazards around them and how to protect their hearing. The videos were done in an engaging, fun style to be both attention-catching and informative. They have gotten thousands of views worldwide and been shared by numerous partners, such as the Hearing Health Foundation, Mack's Earplugs, EarGuru, and the Downingtown Area School District.

3 Tiny Bones' current projects are Safe Hearing Zones and the HEAR Better Pledge. Safe Hearing Zones is an initiative to have community centers and related institutions serve as beacons for hearing loss education, support, and de-stigmatization. Last year, we worked to lower the volume at my school's homecoming and prom dances to a safe level. We are now working with numerous schools in Chester County to make the volume safe at school events and provide hearing loss education to children through programs and curriculum changes. I encourage everyone to take the HEAR Better Pledge at www.3tinybones.org/pledge to protect their hearing, and please be sure to share with friends and family.

3 Tiny Bones has been at community events like the Walk4Hearing and Festival of India, where we educate the community through fun activities, raise money, and give out hundreds of earplugs to promote healthy hearing. We have been featured on NBC10, in the TownLively newspaper, and on WWDB-AM's Empowerment Zone radio. So far, our content has been seen over 250,000 times worldwide!

We are also fundraising to help underprivileged children with hearing loss get access to assistive technology. You can donate to help fund our initiatives at 3tinybones.org/donate.

For more information, visit www.3tinybones.org and follow us on Facebook, Twitter, Instagram, and LinkedIn. You will find all our content, resources, videos, as well as our interviews and press coverage there. Happy hearing!

Yaduraj Choudery is a senior at the DOWNTOWN STEM ACADEMY

About HLAA and its State Office, HLAA-PA

The Hearing Loss Association of America (HLAA), founded in 1979, is the nation's foremost membership and advocacy organization for people with hearing loss. HLAA opens the world of communication to people with hearing loss by providing information, education, support and advocacy. The national support network includes the Washington, DC area office, 14 state organizations, and 200 local chapters. HLAA is a 501(c)3 non-profit organization.

Hearing Loss Association of America
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HLAA-PA is the all-volunteer state office of Hearing Loss Association of America. We were established *in 2001 to carry out the mission of HLAA for Pennsylvanians with hearing loss, their families and friends.*

VOLUNTEERS NEEDED!!

Assist the HLAA-PA State Director by serving on the Advisory Council or one of its committees. The Council meets periodically at locations convenient to its membership. But committees conduct most of their business by e-mail and occasionally meet in various parts of the state. If you think you would like to serve on the council or any of its committees, please contact one of the state leaders listed here:

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