

The Official Newsletter of HLA A-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 HLA A-PA endorsement, nor does absence suggest disapproval. To reach readers of HearSay, contact Dale Long (long@hlaa-pa.org)

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Nancy's Message

. By Nancy Kingsley, HLA A-PA State Director
. Social settings can be especially challenging for those of us with a hearing loss. Here are a few coping tips from an article by AARP (formerly called the American Association of Retired Persons), along with some additional suggestions.

Contact the host before a lunch or dinner gathering. Ask to be seated in the middle of the table, where you will be closer to more people. TV sound and music should preferably be turned off.

Ask for what you need. Explain that you have a hearing loss and need the speaker to face you, speak slower, etc. (And remind people if they forget—they concentrate on what they're saying, not on how they're saying it.)

Find a quiet spot for a one-to-one conversation during the gathering. This can be in another room, away from the crowd.

Take breaks. Listening for long periods is tiring. Go to the restroom or another suitable location to get refreshed.

Bring an assistive listening device. A small wireless microphone can improve the signal-to-noise ratio, enabling you to hear better over the noise.

Use your smartphone as an amplifier. There are apps that enable your smartphone to function as a remote microphone, sending the sound to earbuds or to hearing aids that can be paired with your phone. These include the iOS app Live Listen and the Android apps Headset Remote and Sound Amplifier. Another app, Chatable, works with both iOS and Android devices. Turn on the app and give your phone to the person you are speaking to, or point the phone's microphone at the speaker.

Use a speech-to-text captioning app on your smartphone. Live Caption, eyeHear and TextHear are available for iOS devices, Speechnotes for Android devices, and Ava for both iOS and Android.

Visit restaurants during off-peak hours. Fewer people present means less noise. In daytime, avoid seats facing a window, so the faces of your companions won't be in a shadow.

State Happenings Spring 2022
by Carolyn Meyer, Outreach Coordinator

Things are truly “happening” as we all begin to emerge from the pandemic restrictions of the past two years. Chapters are now planning in-person meetings in the coming months. The requirements for facial coverings, which impede communication due to our hearing loss, are beginning to ease. So what is going on in HLAA-PA?

CHAPTERS IN THE NEWS

The Chester County chapter hosts a spring “Meet and Greet , Saturday April 2 at McKenzie Brew House 11am-! pm, Malvern, PA. Chapter leaders say they missed seeing everyone for the December Social so this should be a great time to get together for food, drinks, and good conversation. There are tentative plans for a May 10 meeting. June 14 is the Annual Mortimer Bauer Scholarship Award and Ice Cream Social. For more information about these events contact hlaachesco@gmail.com

The Montgomery County chapter has had Zooms through the past year and now looks forward to an in-person meeting in May, with the date to be announced. A Zoom meeting on Tuesday, March 1 from 6-7 pm provided chapter updates as well as an opportunity to share, connect, and support one another.

The PITTSBURGH CHAPTER has a new president and we await news from them. Many of us get their excellent newsletter online.

PLEASE SEND YOUR CHAPTER EVENTS TO MEYER@HLAA-PA.ORG SO WE CAN INCLUDE YOUR NEWS IN THIS COLUMN.

REMINDER: HLAA NATIOL CONVENTION

The HLAA 2022 Convention is June 23-25 in Tampa, Florida! HLAA is very excited to be hosting an in-person Convention again. This year the exhibit hall, workshops, demo presentations, plenary sessions, social events and Research Symposium will all be held under one roof at the brand new JW Marriott Tampa Water Street. When you aren’t learning and networking at the most communication accessible convention for people with hearing loss, you can explore Tampa’s new Sparkman Wharf area or cruise down the local Riverwalk. Start booking your trip now! A great way to spend a summer vacation.

Note: HLAA will require all attendees to be fully vaccinated against COVID-19. For more information visit HLAA’s Vaccination Requirement page. Learn more about the HLAA Convention Health and Safety Protocols. Please note that safety protocols may change as we move into spring and summer so check the website for the national convention for updates.

AWARDS 2022

The committees have decided to extend the deadlines to April 1, 2022. Please check the information requirements for these awards as many of you could be eligible

recipients. Questions? Contact meyer@hlaa-pa.org. All the awards have financial benefits.

- The Marcia Finisdore Advocacy Award;
- The Diana Bender HLAA National Convention Award;
- The Joe Meyer Memorial Grant Award.

2022 LUNCH AND LEARN

This has been postponed until 2023 due to Covid restrictions.

THE 2022 FARM SHOW

After much discussion, HLAA-PA declined to participate with a booth. The event did take place but our members did not feel it advisable this year. Let us all look ahead to returning to our normal lives in the days ahead. Stay healthy and safe!

Hearing Loss and Genetics

With 15% of Americans over age 18 (37.5 million people) experiencing some trouble hearing, hearing loss is an exceedingly prevalent ailment that becomes more likely with age. Over recent decades, it has becoming increasingly understood that genetics play a major role in many cases of hearing loss, both age-related and not.

Our knowledge of human genetics has grown substantially in the last two decades, thanks to advances like the Human Genome Project that have allowed mapping of the entire human genetic code (genome). Many large scale “biobanks” – huge repositories of genetic information from many patients, in the form of biologic samples (blood and tissue) – have been developed, including the UK Biobank and our own Penn Medicine BioBank. These research initiatives have allowed the collection and categorization of genetic samples from individuals with a wide array of disorders, in order to facilitate research efforts into the genetic causes of and contributions to diseases.

In hearing loss, the role of genetics can be variable. For children born with hearing loss, genetic causes can be identified a large proportion of the time. On the other hand, hearing loss from some causes – like loud noise exposure – seem to be clearly the result of environmental factors. Yet even so, in the latter case, an individual’s genetics may play a greater role in determining susceptibility to hearing loss as a result of noise exposure than we may have previously thought. In middle-aged and older adults, individual genetics likely underpin susceptibility to hearing loss and interact with a variety of environmental factors to determine the development of hearing loss, including its type and severity.

Identifying the role of genetics in hearing loss – including specific causative genes and how they interact with environmental factors (such as medications and noise exposure) to cause hearing loss – is an important pursuit for several reasons. First, in families with multiple members with hearing loss, identifying a gene in one individual may enable prediction of the development of hearing loss in others who possess the same gene variant. Second, we may

come to recognize that specific genes portend different hearing loss prognoses, such as whether the loss will be mild or severe, stable or progressive. This could result in more personalized management for individuals with hearing loss. For those who receive cochlear implants, we could even use genetics to predict who is more likely to get a good outcome with the implant.

Identification of the multitude of genes that can cause or contribute to hearing loss can help to pave the way for the development of individualized gene therapy for hearing loss – a goal that seems futuristic but may be achievable in our lifetimes. Gene therapy would involve the delivery of a functional copy of the nonfunctional gene in order to restore hearing. Several studies have been underway for years, testing gene therapy for hearing loss both in cells and in animals. While results are promising, there is work to do yet. Still, genetics research is a vital part of the development of gene therapy that could help members of our or future generations with hearing loss.

For more information about the Genetics of Hearing Loss program at Penn Medicine, follow the link below.

<https://www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/ear-nose-and-throat/general-audiology/genetic-analysis-for-adul-onset-hearing-loss>

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Fellow, Neurotology

Department of Otorhinolaryngology - Head & Neck Surgery



Meet Our Sponsors

HLAA recently instituted a sponsorship program with platinum, gold, and silver levels. Sponsors are listed in HearSay and the HLAA-PA website for one calendar year, and we would love to include your organization. Information about becoming a sponsor is available from our sponsor coordinator, Dale Long, at long@hlaa-pa.org.

We are pleased to recognize the following new HLAA-PA sponsors:

Platinum Level



Jefferson Balance & Hearing Center: Physicians and doctors of audiology offer comprehensive evaluation, treatment, and rehabilitation, including hearing aids, cochlear implants, implantable devices, and custom ear pieces. A musician services program provides evaluation and custom musician devices. Financing for hearing aids is available through Care Credit and the Pennsylvania Assistive Technology Foundation. Appointments can be scheduled by calling 215-955-6760.

Platinum Level



Penn Audiology – We are “hear” for you!



Penn Medicine is ranked as one of the top in the Nation and **NUMBER ONE** in the region



Penn Audiology within the Department of Otorhinolaryngology – Head & Neck Surgery at Penn Medicine provides comprehensive assessment, diagnosis, and treatment for people with all types of hearing loss and balance problems.

All of our audiologists hold a clinical doctorate in audiology and have extensive experience in treating hearing loss. Our surgeons are world leaders in otology and neurotology, specializing in the medical and surgical treatment of the ear.

Cochlear Implant Program

- Highest number of cochlear implants procedures performed in the region
- Only center to offer all three manufacturers of cochlear implants & hybrid devices
- Innovative Implantable Hearing Device research program

Hearing Aid Program

- Offer hearing aids from a wide variety of manufacturers at varying levels of technology and price ranges
- Extensive selection of assistive listening devices
- Ongoing support by our trained professionals for the life of your hearing aid

Four convenient locations:

Penn Medicine Perelman Center for Advanced Medicine
3400 Civic Center Boulevard, South Pavilion, 3rd Floor
Philadelphia, PA 19104

Penn Medicine Washington Square
800 Walnut Street
Philadelphia, PA 19107

Penn Medicine Radnor
145 King of Prussia Road
Radnor, PA 19087

Penn Medicine University City
3737 Market Street
Philadelphia, PA 19104



Set up your appointment today:

215-662-2784

audiology@uphs.upenn.edu

Platinum Level

olelo

Captioned Calls

Olelo Captioned Calls: This easy-to-use 100% private app was developed by MachineGenius, a telecommunications company founded in Holliston, Massachusetts in 2017 to help people with hearing loss have a seamless calling experience via advanced speech recognition technology. The app is free for those with hearing loss and is supported by the Federal TRS / IP CTS fund. Website: www.olelophone.com.

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
7910 Woodmont Avenue, Suite 1200
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hearingloss.org

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:

- State Director: Nancy Kingsley (kingsley@hlaa-pa.org)
- Editor: HearSay and HLAA-PA Website Don Groff (groff@hlaa-pa.org)
- Advocacy: Nancy Kingsley, Chair (kingsley@hlaa-pa.org)
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Link to online version: tiny.cc/HearSay20221

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