

HearSay

The Official Newsletter of HLAA-PA

Volume 15 Issue 1 Spring 2016



MESSAGE FROM NANCY

By Nancy Kingsley, State Director



HLAA-PA is an all-volunteer statewide organization. Our Advisory Council meets three times a year on a Saturday in Lancaster, and we invite anyone who is interested to attend and find out what we're all about. Council meetings are communication accessible via a loop assistive listening system and CART realtime captioning, and we welcome your ideas and input.

Are there communication-inaccessible events that you want to be able to attend? Let us know so we can advise you of your rights and how to proceed. Do you like to write? HearSay is looking for

hearing loss related articles. Do you want HLAA-PA to host an event in your area? We'd love to look into doing that, if local folks are willing to help.

Our focus is on education and advocacy, and we are happy to provide guidance and assistance in those areas. The more people become actively involved with HLAA-PA, the more we can accomplish to make life better for everyone with hearing loss in Pennsylvania.

For information about attending one of our Council meetings, writing for HearSay, or any other hearing loss matter that concerns you, just contact me at kingsley@hlaa-pa.org.

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State Happenings and Outreach*By Carolyn Meyer***State Happenings Spring 2016**

News from national: HLAA has hired Valerie Stafford-Mallis to be Director of Chapter Development to replace Ed Ogiba. Valerie hopes to use the skills she learned herself in working in the private and public sector to provide leaders of HLAA chapters with the support necessary to sustain healthy growing chapters. She plans to help those who wish to start new chapters and provide leadership training, online resources, and programs geared to chapter members and the local community's needs. Valerie has struggled with her own hearing loss and feels that joining HLAA "changed her life". With a strong background as business development manager for Alternative Communication Services, she recently served on the HLAA Board of Trustees and is a member of the Sarasota/Manatee Chapter. Chapter leaders please welcome Valerie at vstaffordmallis@hearingloss.org

**MARCIA FINISDORE ADVOCACY—AWARD 2015:**

HLAA-PA announces that Dr. Emilio Cortez is the recipient of the 2015 Marcia Finisdore Advocacy Award.

Emilio was nominated for his advocacy efforts to prevent noise induced hearing loss among both hearing and hard of hearing Pennsylvanians. He founded a committee named "Turn Down the Volume" which he co-chairs with his wife Patty, who has a hearing loss and is an active member of the HLAA MontCo chapter. The mission of the committee is to educate others about the very real dangers of noise induced hearing loss. The committee is active throughout the greater Philadelphia area and continues to educate different groups, including elementary school children, about the steps they can take to prevent this type of hearing loss. During his outreach events, many of which have been to visit local HLAA-PA chapters, Emilio demonstrates several special headphones and ear buds which limit output to levels not harmful to hearing. Emilio will receive this award at the HLAA-PA Lunch and Learn on May 7, 2016 at the Radisson Hotel in King of Prussia, PA.

OUTREACH

January 11: Chestnut Hill

Patricia Cortez, of the MontCo Chapter provided important information and insights related to hearing loss during a presentation at The Center on the Hill in Chestnut Hill. About 17 people were in attendance, including Don Groff and Tom Van Arman. Topics covered during the presentation were: hearing loss, strategies and resources for coping with hearing loss, and preventive strategies to avoid hearing loss.



March 8: Springhouse Estates, Springhouse, PA
Alice Dungan and Carolyn Meyer presented "Coping with Hearing Loss", a seminar using a PowerPoint program to residents of this retirement community. Members of the nearby Ambler YMCA were invited to attend as well. HLAA literature was distributed after the presentation.

**CHAPTER NEWS -
AN INVITATION:**

The HLAA Lancaster County Chapter invites you to their meeting on Tuesday, April 19, 2016 at 10:00 AM. Topic: "How WGAL Captions the News". WGAL, a subsidiary of the Hearst Corporation, is the local TV channel 8 (Comcast channel 3) serving the Susquehanna Valley from Lancaster. HearSay readers living outside this area will find the topic interesting as the process of TV captioning is similar elsewhere. The presenters are John Humphries, President and General Manager and Christine Toldt, Chief Engineer. The meeting will be held at the Village Center Building Fellowship Hall (lower level), Brethren Village Retirement Community, 3001 Lititz Pike, Lancaster. CART and loop provided. Contact Nancy Kingsley for further information kingsnan@aol.com. All welcome.

EFFORTS TO START A NEW CHAPTER:

From Kay Tyberg, past president of the Lycoming County Chapter and member of the HLAA-PA Advisory Council:

Kay has moved to Altoona, PA and describes some of her efforts over the past weeks to try to interest and educate the local residents about HLAA with the hope of starting a new chapter here. Her experience from starting a new chapter in Williamsport has given her a game plan to follow. "What's necessary is publicizing and encouraging people to join me in starting the chapter. I am trying to connect with the local representative and Chamber of Commerce. I am finding out what routine events occur throughout the year here. What are people interested in knowing? I am trying to learn about the geographical culture in the area. No chapter can operate effectively with only 6 or less people. I am using a survey to establish where is the best location, day of the week and time for meetings. Along with talking with community leaders, I am finding area hearing aid dispensers, ENTs, and audiologists and will be making appointments with them to inform them as to what HLAA has to offer them if we established a chapter here. This will be an opportunity to seek Board members. I met with the Carmike Theater managers and complimented them on their services and offered to train their employees on how to interact with deaf and hard of hearing individuals. One final point: be flexible, listen to people, and be compassionate toward others. Sometimes I feel some people are too set in their ways which makes it difficult to grow and inspire young people to join."

Reach Kay tyberg@hlaa-pa.org for some further tips to help you if you wish to start a chapter in your area.

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New Pilot Program to Distribute Free Wireless Devices for Telecommunication

January 2016

Pennsylvania's Telecommunication Device Distribution Program (TDDP), a program of the Institute on Disabilities at Temple University, is piloting a program to distribute wireless devices for telecommunication to eligible Pennsylvanians with disabilities.

Amy Goldman, Co-Executive Director of the Institute on Disabilities at Temple University, College of Education, directs the assistive technology programs at the Institute. Ms. Goldman says that people with disabilities have been asking for these devices to be added to the TDDP program for years. "Wireless technology is no longer a luxury item, but rather an integral part of daily life." Given the proliferation of these devices and the inherent benefit to people with disabilities, manufacturers have developed equipment and applications with accessibility in mind. "Device designers, manufacturers and software developers are mindful of the legal obligation and understand the positive impact from a business perspective of embedding accessibility in their products."

Beginning in January 2016, the TDDP will recruit participants to receive wireless devices through this program. "We are very excited to begin this pilot program knowing that in the past decade, wireless technologies have become the primary method of communication."

Participants must meet disability and income eligibility requirements and will be asked to attend meetings and take part in focus groups throughout the year. "We want to be certain that we match the participant with the right device and that they receive the training needed to get the most out of that device."

If the participant meets all of the requirements of the year-long program, the device will be given to them to keep. "Our goal is to help Pennsylvanians with disabilities communicate effectively at home, at work and in the community."

More information about the TDDP wireless pilot is available on the Institute's website at disabilities.temple.edu/programs/assistive/tddp/wireless.shtml or by email: TDDP@temple.edu; telephone: 215-204-5966 (voice), 215-204-1805 (TTY).

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About PATF - Loans That Change Lives

Adanya and Jesus are excited new parents living in Philadelphia. As they settled into their new roles as parents, one worry kept coming to their minds: they are both deaf and were concerned about missing their baby's cries at night. After doing some research, Adanya and Jesus discovered the perfect baby cry sensor, but with all of the expenses of having a new baby, they needed some financial help to get it. A social worker from the Children's Hospital of Philadelphia referred them to the Pennsylvania Assistive Technology Foundation (PATF), knowing we would be able to help. "Since we are deaf, we need this device for our baby – we can't hear him cry. This is updated technology and the older devices are not as effective," they wrote on their application for a financial loan.

PATF is a nonprofit organization that provides education and financing opportunities for people with disabilities and older Pennsylvanians, helping them to acquire assistive technology (AT) devices and services that improve the quality of their lives. We provide low- and no-interest loans for people with hearing loss to purchase anything from hearing aids to bed shakers to amplified phones. We also provide information and assistance to help people find the best funding options for their AT. We help Pennsylvanians of all ages, all

disabilities, and all income levels.

Adanya and Jesus' situation is a perfect example of what we do—you identify what type of AT you need based on your own lifestyle and interests, and we help you find funding. With the exception of school-age children using hearing aids, and veterans with service-related hearing loss, there often aren't a lot of options in PA for funding assistance for hearing devices other than what's in your own pocket. That's where PATF comes in. This young couple receives SSI, has limited credit and was willing to have their payments electronically withdrawn, so we were able to extend a 0% loan for \$315 to this family with a monthly repayment of \$20.

Learn more about our loan program, financial education, and other funding resources for AT in PA at www.patf.us, or call us toll-free at 888.744.1938.

To receive the PATF newsletter, sign up on the internet at bit.ly/patfsignup.

Susie Daily

Outreach and Social Media Coordinator

Pennsylvania Assistive Technology Foundation

(p) 888.744.1938



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What is a Cochlear Implant and How Do I Know if I'm a Candidate?

As an audiologist specializing in the rehabilitation of hearing loss in adults, I am often met with inquiries regarding what a cochlear implant is and whether it would benefit someone in addition to or in place of a hearing aid. Therefore, I would like to take this opportunity to clarify exactly what a cochlear implant is, who is a candidate for one, as well as some other important factors to keep in mind when pursuing one.

A cochlear implant (CI) is a surgically implanted electronic device that replaces the lost or damaged hair cells in the inner ear, or cochlea. These hair cells, when functioning properly, act to stimulate the hearing nerve which then sends the signal to the auditory processing centers of the brain. However, when these cells are lost or damaged, an impaired signal is sent via the hearing nerve to the brain, making it increasingly difficult for the brain to decode what's being received as the hearing loss becomes more and more severe. Hearing aids merely amplify speech and environmental sounds, relying on this impaired system to convey the message. Cochlear implants replace the source of impairment in order to provide a more accurate signal to the brain.

When a person with a moderately severe to profound hearing loss in both ears doesn't feel that s/he is receiving sufficient benefit from hearing aids, even in a quiet one-on-one setting, candidacy evaluation for a cochlear implant would be appropriate. During this appointment, the audiologist would test your hearing using your own hearing aids or, if necessary, ones programmed for you by the clinic. Specifically, you would be repeating sentences in quiet and possibly in background noise in the right ear only, left ear only, and both ears together to see how you perform with hearing aids. If your scores indicate that you do not receive benefit from amplification according to FDA and Medicare guidelines, when applicable, you would be considered an audiological candidate for a CI. At that point, you would need to meet with an ENT and your PCP to determine medical candidacy which would involve an MRI or CT of the ears as well as medical clearance to undergo anesthesia.

Should you qualify on those studies as well, there are several key points to keep in mind before making the final decision if a CI is right for you, namely expectations and motivation. Reasonable expectations are of the utmost importance when pursuing this process. There are a number of interacting variables that affect performance outcomes with a cochlear implant, such as duration and cause of hearing loss, length of hearing aid use, anatomy and more. There is no way to predict what any individual's level of success would be. Performance outcomes range minimally from improved lip-reading to maximally speaking on the phone without difficulty, with many degrees in between. By seeing any measure of success on this spectrum as positive, you will be pleased with your decision.

Finally, motivation plays a key role as well. Being fit with the external component of the cochlear implant is not the same as having your hearing aids programmed. It requires a time commitment to attend approximately 5 visits in the first 6 weeks of activation in addition to follow-up appointments at 3 months, 6 months, 12 months and annually post activation. Furthermore, recipients who are the most successful are those that engage in auditory training exercises on a daily basis to retrain the brain to hear not only though a different means than it was used to, but also sounds that it has missed for many years.

I like to tell my patients that the ideal candidate is someone who "has nothing to lose and everything to gain." If you feel your hearing loss is isolating you from family and friends, threatening your job security or having an intense emotional impact on you, with the right mindset about performance outcomes and commitment involved, a cochlear implant could be a life changing option for you.

Hannah S. Kaufman, Au.D.

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LUNCH AND LEARN: AUDIOLOGY, HLAA, and WASHINGTON, DC

Saturday, May 7, 2016 - 11a.m. to 3 p.m.

Radisson Hotel Valley Forge, 1160 First Avenue, King of Prussia, PA

Join us for a delicious buffet. Our keynote speaker is Dr. Victor Bray, Dean of the Osbourne College of Audiology of Salus University. Dr. Bray will discuss the relationship of the audiology community and its patients. He will explain possible legislative bills that may serve to redefine the government's control of access to audiology services. Exhibitors will be onsite throughout the event, which is open to the public and will also introduce winners of the Marcia Finisdore Advocacy Award and Diana Bender HLAA Convention Scholarship Award. CART (realtime captioning), ASL interpreters, and a loop will be provided.

For directions, call the hotel at 610-337-2000 or visit its website at <http://www.radisson.com/king-of-prussia-hotel-pa-19406/pavalley/area/map>

Cost: \$28.00 per person Registration deadline: April 23, 2016

Questions? Contact Nancy Kingsley at kingsley@hlaa-pa.org

Please complete this form, make your check payable to HLAA-PA, and mail to Alice Dungan, 6906 Shalkop Street, Philadelphia, PA 19128-3217

Amount enclosed: _____ (\$28 per person)

Name: _____

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Email: _____

Names of additional attendees: _____

Name of HLAA-PA chapter you belong to (if applicable): _____

Get this form online at hlaa-pa.org/docs/LuLe2016.pdf

HLAA-PA at the Farm Show

More than a half million people visited the Pennsylvania Farm Show on its 100th anniversary, and several dozen people affiliated with HLAA-PA chapters were there. It was the 7th time we have had a booth at the Farm Show.

First-time participant Kathy Harral spoke for all of us when she said: "Enjoyed working at the show immensely. Met SO many nice people that stopped by, a lot of them not even HOH. The highlight for me was talking at length to a 10-year-old girl with a CI. She was with her girlfriend and the two dads were wearing chaperone name tags. Her father thanked me profusely for talking with her, saying 'she loves to talk with others with hearing problems.'"

Our new location between the winery exhibit and Punxsutawney Phil increased our visibility greatly. And thanks to a grant from a charitable foundation, HLAA-PA was able to sponsor 15 hours of captioning of some of the major events at the Show on PCN, the Pennsylvania Cable Network. As a local radio announcer used to say at the start of each daily broadcast, "It's a great day in Pennsylvania".

Several volunteers conducted a brief survey about hearing loss with visitors. Among other things, questions revealed that most people were aware of cochlear implants, but not many realized that many movie theaters can provide captioning. Almost everyone knew someone with hearing loss - Her!, Him!, Me!

Thanks to Steve Schultz for once again making it all happen.



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Ask the Expert - THE TRUTH ABOUT COCHLEAR IMPLANTS

Straining to hear each day, even when using powerful hearing aids?

Feeling frustrated and sometimes even exhausted from listening? Whether it happens suddenly or gradually over time, hearing loss can affect you physically and emotionally. Being unable to hear impacts your ability to communicate with your loved ones, hear in noisy environments, talk on the phone, and may force you to become more reliant on your family members to interpret for you.

Cochlear implants work differently than hearing aids. Rather than amplifying sound, they use sophisticated software and state-of-the-art electronic components to provide access to the sounds you've been missing. They are designed to help you hear better and understand speech in all situations, including noisy environments.



David C. Kelsall, M.D.,
Cochlear Medical Advisor

Dr. David C. Kelsall, a cochlear implant surgeon and medical advisor to Cochlear, the world leader in cochlear implants, answers questions about cochlear implants and how they are different from hearing aids.

Q: How are cochlear implants different than hearing aids?

A: Hearing aids help many people by making the sounds they hear louder. Unfortunately, as hearing loss progresses, sounds need to not only be made louder, they need to be made clearer. Cochlear implants can help give you that clarity, especially in noisy environments. If you suffer from high frequency hearing loss but maintain your hearing in the low frequencies, there is a solution called Hybrid™ Hearing that may be able to help as well. Be sure to discuss your options with a Hearing Implant Specialist in your area.

Q: Are cochlear implants covered by Medicare?

A: Yes, by Medicare and most private insurance plans.

Q: How do I know a cochlear implant will work for me?

A: The technology is very reliable. In fact, it has been around for over 30 years and has helped change the lives of over 400,000 people worldwide.

Q: Is it major surgery?

A: No, not at all. In fact, the procedure is often done on an outpatient basis and typically takes just a couple hours.

Q: Am I too old to get a cochlear implant?

A: No, it's never too late to regain access to the sounds you're missing

Call 1 877 804 4000 to find a Hearing Implant Specialist near you.

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DENISE P. - Cochlear Implant user enjoys dining out, talking on the phone, listening to music and meeting new people.

"My hearing was restored with a cochlear implant!"

Struggling with your hearing aids? Cochlear implants can activate your hearing and your life! If you have severe to profound hearing loss, a cochlear implant may be able to help. Unlike a hearing aid that amplifies sound, a cochlear implant is an implantable hearing solution that delivers sound straight into your auditory nerve.

Take the next step in your journey to hearing!

Contact us to:

- Learn about medical treatment for severe to profound hearing loss
- Talk with others who hear with cochlear implants
- Learn how cochlear implants are covered by Medicare, most insurance plans, and may be covered by Medicaid.



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For more information visit www.CochlearAmericas.com or click on the link below to find an informational meeting close to you. <http://www.cochlear.com/wps/wcm/connect/us/home/stories-and-community/events-calendar/cochlear-americas-events>

You should talk to your physician about who is a candidate for implantation with a cochlear implant and the associated risks and benefits of the procedure. ©2012 Cochlear Limited. All rights reserved. Trademarks and registered trademarks are the property of Cochlear Limited or Cochlear Bone Anchored Solutions.

Hear now. And always.



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Convention Highlights:

Keynote Speaker:

Jenny Lay-Flurrie, Chair of the Disability Employee Resource Group and Chief Accessibility Officer for Microsoft

Research Symposium:

Novel Approaches toward Addressing Hearing Loss – Ideas on the Cutting Edge

Moderator: Frank Lin, M.D., Ph.D.

Dr. Lin is an Associate Professor of Otolaryngology-Head and Neck Surgery, Geriatric Medicine, Mental Health, and Epidemiology at Johns Hopkins

Note:

Bender Convention Scholarship deadline is March 30. The application form was in the Winter HearSay. You can also get this form online at hlaa-pa.org/docs/DBSform2016.pdf

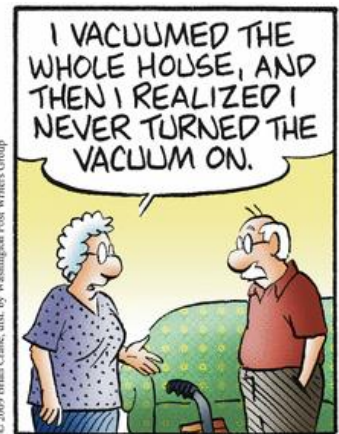


Visit Hearing Loss Association of America on the web! hearingloss.org or scan this QR code .

Visit us on the web! hlaa-pa.org or scan this QR code on your smartphone, for latest news from HLAAP-PA, and a calendar of events.



Pickles



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Headsets and Neckloops

Many entertainment venues offer hearing assistance to meet requirements of the ADA. These systems may be infrared- or FM-based. Infrared systems (IR) usually consist of a headset or stethoscope sort of device (which may not have a jack), while FM systems use a receiver module with earbuds or headphones plugged into the jack. A few offer a neckloop as a plug-in option for people with telecoil (T-coil)-equipped hearing aids or cochlear implants, usually without any knowledge of what a neckloop is or how to use it. I've often been told that very few people use the assistive listening system. It would appear that their main function is to allow the venue to claim ADA compliance.

There are some obvious problems with headsets, headphones, and earbuds:

1. They are hardly discreet. Few patrons wish to be seen wearing a headset at an orchestra performance. Vanity is always a factor to be considered, as hearing aid marketing will confirm.
2. The question of hygiene is one that patrons may consider very important, especially with the devices that work as earbuds.
3. Earbud devices will require taking hearing aids out, satisfactory only for mild hearing loss.
4. The signal delivered to the headphones by the receiver will have minimal delay relative to the acoustic signal, which could be delayed by several hundreds of milliseconds. The hearing aid microphone may also pick up acoustic signal, and the difference between the two creates a degree of reverberation.
5. High power hearing aids can have feedback oscillation (whistle) when an object is close to the ear.
6. If the headphone volume is high, it may be audible to others.

Every one of these objections is answered by the neckloop and T-coil combination, with the possible exception of #4.

#1 The neckloop is virtually invisible.

#2 There is no hygiene issue with a neckloop wire around the neck.

#3 Hearing aids are not removed with the T-coil.

#4 It is possible to have the hearing aid respond only to the T-coil and not the microphone, but this is not always the case.

#5 Feedback is not an issue with the neckloop.

#6 The sound is inaudible to others with the neckloop.

However:

1. Not all hearing aids are equipped with T-coils. I'm told that about 2/3 of those sold today are. But many users don't know about them, or know how to turn them on.

2. Not all hard of hearing patrons have hearing aids. Denial is also a factor to be considered.

Recommendation:

When offered an FM or IR device, ask about neckloops. Don't be surprised by a blank stare. Try to get the staff to at least recognize the word, if not to understand its function.

The ideal is to have the whole theater looped, but looped theaters are few and far between, at least in Pennsylvania. Unlike IR and FM systems, loop systems only require a receiver for users who do not have telecoils.

With some research and expenditure, it is usually possible to use your own neckloop, as well as your own FM or IR receiver with a jack (if the theater's version lacks a jack). I've done this in a number of places. Contact me for details.

-Don Groff

groff@hlaa-pa.org



Get HearSay

To receive HearSay by mail, send this form to the address below. Subscriptions are free; however, HLAA-PA is a not-for-profit organization run exclusively by volunteers, and we are grateful for donations. Donations are tax-deductible.

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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
Bethesda, MD 20814
www.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.

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.

To reach readers of HearSay, contact Director of Marketing Lee Williams (leewilliams@hlaa-pa.org) for information.

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, and 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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