HearSay

The Official Newsletter of HLAA-PA

Volume 16 Issue 2

Summer 2017



Pennsylvania State Office

MESSAGE FROM NANCY

By Nancy Kingsley, State Director

On February 21, Frequency
Therapeutics announced that a team



led by its scientific co-founders published research about a new approach to regenerate inner ear hair cells, which could lead to the development of a treatment for noise-induced hearing loss. The team included researchers from Harvard Medical School, the Massachusetts Eye and Ear Infirmary, Massachusetts Institute of Technology (MIT) and Brigham and Women's Hospital.

Hair cells in the cochlea, which are responsible for transmitting sound, can be damaged by noise and cannot regenerate. According to the World Health Organization (WHO), 360 million people have moderate or worse hearing loss, with an additional 1.1 billion people at risk for noise-induced hearing loss.

Previously, it wasn't possible to obtain sufficient numbers of mammalian cochlear hair cells for developing treatments for hearing loss. By targeting cells that were discovered to be the source of sensory hair cells in the cochlea during development, investigators succeeded in growing cochlear progenitor cells into large colonies that were able to develop into hair cells, even in tissue that had been depleted of hair cells by exposure to an ototoxic antibiotic.

Researchers are working with Frequency Therapeutics to develop an injection that targets drugs to the inner ear, and human clinical trials are expected to begin within the next 18 months. More information is at www.bit.ly/FTXHS20172. A hat tip to Emilio Cortez for providing this link!

INSIDE

- 2. State Happenings
- 3. Penn Audiology
- 4. Disequilibrium
- 5. Jacob's Ride
- 6. NIHL@YMCA
- 8. Lunch and Learn
- 9. Cochlear America
- 10. Pickles, Convention
- 11. Walk4Hearing
- 12. About HLAA-PA, Donors

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Resting Loss Association of America Pennsylvania State Office AS6 Cedarcroft Road Kennett Square, PA 19348

STATE HAPPENINGS AND OUTREACH

By Carolyn Meyer

.The Advisory Council and all of us at HLAA-PA mourn the loss of our beloved member, Steve Schultz. Many of you got to know him well when you volunteered at the Farm Show. He organized our state booth for eight years. Steve's attention to detail and careful organizational skills were to be commended. As past president of the HLAA Capital Region Chapter, he worked hard to help the chapter fulfill its goals. As Chairperson of the Pennsylvania Telecommunications Relay Service Advisory Board, he devoted his energy to fulfilling the demands of

that important position. In 2013, he worked

diligently as Chair of the HLAA-PA Employment

Conference in Harrisburg, PA, attended by persons



with hearing loss who were seeking employment as well as professionals and employers working with people with hearing loss. We all knew that when Steve was involved, things would work as smoothly as possible. His devotion

to advocating for those with hearing loss will never be forgotten. Our condolences go to his family at this sad time. We shall keep him in our hearts. We will miss him.

AWARDS, AWARDS:

We applaud all our recipients of the following awards:

HLAA national awards go to:

- Don Groff: as our HLAA-PA Webmaster as well as the Editor of HearSay
- HLAA-PA: The Chapter and State Organization Award

The above national HLAA awards will be presented at the HLAA national convention in Salt Lake City in June.

HLAA-PA state awards go to:

- Kay Tyberg: The Marcia Finisdore Advocacy Award
- Sue Farrell: The 2017 Diana Bender HLAA National Convention Scholarship Award
- Nan Herson: The Tony Finamore HLAA National Convention Scholarship Award (a one- time award in memory of Tony Finamore, a MontCo chapter member)

THE ANNUAL HLAA-PA LUNCH AND LEARN 2017

What a great attendance we had! Details and photos on p.8.

CHAPTER NEWS

Alan Kutner is attempting to revitalize the Delaware County chapter of HLAA by relocating it to the campus of the retirement community of Maris Grove located in Glen Mills, PA, in Delaware County. Anyone can join the chapter or become active once again since meetings will be held in Delaware County on the Maris Grove campus. So far, Alan has said that the response has been excellent and after only two meetings, there is a membership of 53 people. Alan remarks: "It is difficult to say whether that number will increase as more people learn about the chapter (we have more than 1600 residents) or if it will decrease once people get used to it. I don't know. I just know I'm going to try to make it as interesting as possible. Only time will tell." Alan was the speaker at the first meeting, suggesting ways to cope with hearing loss in daily life. Don Groff was the next speaker and he described difficult hearing situations and the electronics used to enable people to hear better. The final topic before the chapter recesses for the summer will be captioned telephones. Alan notes: "It is all very exciting and new to me. I have a fair amount of knowledge, but I have never run a chapter so the dynamics will be a challenge for a while." Alan is a resident of Maris Grove.

Nancy Kingsley, and Dale Long staffed the HLAA-PA table at the Berks Vision & Hearing Expo at the Crowne Plaza in Reading on May 17. Nancy also spoke briefly about HLAA-PA for the local radio station and gave a presentation about hearing loss and HLAA. Five people signed up with interest in forming a Reading chapter of HLAA

If any of our readers are interested in being part of a Berks County chapter, please contact Dale Long, Central PA Chapter Coordinator long@hlaapa.org.



Advertisement





We are top 10 in the nation and #1 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.

All of our audiologists hold a clinical doctorate in audiology and have extensive experience in treating hearing loss. In 2015-2016, *U.S. News & World Report* ranked our program the highest in the Philadelphia region and top 10 in the nation for Ear, Nose & Throat.

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 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

250 King of Prussia Road Radnor, PA 19087

Penn Medicine University City

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(215)662-2777

http://www.pennmedicine.org/otorhinolaryngology/patientcare/clinical-programs/audiology/

DISEQUILIBRIUM

Understanding Our Balance Function and How to Prevent Falls

Getting out of bed and walking about is routine for most of us, but for those who experience a loss of balance, such basic tasks may require planning and assistance. Disequilibrium can include difficulty walking straight, widened stance, a tendency to rely on walls and furniture for stability, inability to stand unassisted, frequent tripping, or even falling.

In some cases, unsteadiness is temporary and associated only with periods of dizziness. At other times, imbalance can be specific to situations such as walking in the dark or open spaces, walking on a ramp, or climbing steps and curbs. Depending on the severity, chronic disequilibrium can significantly impact a person's quality of life.

Our equilibrium is a complex system requiring reliable senses of vision, proprioception (touch), and vestibular function (inner ear), as well as coordination from our central nervous system. A common misconception is that a certain degree of imbalance occurs naturally with advanced age. However, it is not the process of aging that creates unsteadiness; the cause is degradation in the quality of sensory input and our ability to process this information.

Vision allows us to see where things are in relation to where we are. For example, a jogger on a wooded path may trip on a tree branch because the object was simply unseen. Cataracts, glaucoma, macular degeneration, and other conditions that affect visual acuity can influence our confidence or ability to move with ease. Blurred or double vision, loss of peripheral vision, poor night vision, or blind spots may also increase the risk of falls.

Proprioception provides a sense of our body's positioning in the world. In overly simplified terms, it is the sense of touch from our limbs, trunk, and spine. Most people know from experience that

walking on a flat pavement takes less effort than walking on an uneven hiking trail. Without reliable proprioception, we would be unable to adjust for the increased difficulty when stepping from a stable boardwalk onto a soft, sandy beach. Conditions such as peripheral neuropathy, poor circulation, and arthritis may result in a gradual loss of proprioception. Assistive walking devices such as canes or walkers can provide an additional sense of touch during the recovery period after orthopedic injuries, thereby reducing the risk of falling.

Our inner ear balance mechanism, also known as the vestibular system, acts as an internal gyroscope to provide us with a sense of movement and spatial orientation. With any movement of the head, this system detects motion and gravity. This information is crucial for enabling us to maintain a sense of stability as we move through our daily activities. An abrupt disruption of the vestibular system may lead to the sudden onset of vertigo or room-spinning dizziness. Gradual loss of inner ear function can cause a general sense of unsteadiness or blurred vision with head movements.

Once the sensory information is delivered to the brain, it is the role of our central nervous system (CNS) to process it and react appropriately. Patients with neurologic conditions such as multiple sclerosis (MS) or movement disorders such as Parkinson's disease have progressive balance impairment due to ongoing degeneration of the CNS. In addition, a sudden event such as a stroke or concussion may interfere with the brain's ability to process sensory input.

Since a deficit in any of these systems may result in disequilibrium, assessment and management may require consultations with various medical specialists, including audiologists, otorhinolaryngologists (ear, nose, and throat doctors), neurologists, ophthalmologists, orthopedists,

HearSay

(Continued from page 4)

physical therapists, and/or occupational therapists. Many patients experience multifactorial disequilibrium attributed to more than one cause. Therefore, a medical facility that offers advanced diagnostic procedures and an interdisciplinary team approach to management is often recommended.

Preventive action may involve regular monitoring of progressive vision disorders. Management of certain chronic conditions such as diabetes may prevent gradual loss of vision and proprioception associated with retinopathy and peripheral neuropathy. Low-impact exercises like tai chi and water aerobics have been shown to improve balance by easing pain from arthritis, promoting bone health, and strengthening core muscles. A review of medications with a physician may be useful in reducing side effects that lead to dizziness and imbalance.

Finally, modification of the home environment may lessen certain situational fall risks. Examples include installation of grab bars and non-slip mats in the shower, removal of throw rugs, installation of railings along stairs, and use of night lights in rooms and hallways. To reduce the risk of tripping, avoid ill-fitted clothing and select appropriate footwear that provides sufficient support and traction. With awareness of your surroundings, general caution, and an active lifestyle to prevent weakness, most falls can be prevented.

Y .J. Mary Kim, Au.D. Clinical Audiologist

Penn Medicine



Jacob's Ride Around the Altoona Curve

The newly formed Blair County HLAA Chapter arranged a visit by Jacob's Ride at the game on May 20, to see the Curve defeat the Erie SeaWolves 4 - 1. The event included a Meet and Greet at Peoples Natural Gas Field, and the chapter sold more than 150 tickets.

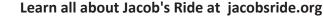
Cochlear implant recipient Jacob Landis has ridden his bike over 20,000 miles, and the resulting donations have financed over a dozen cochlear implants!

Attendees were presented with information about kinds of hearing loss, and supportive technology from many manufacturers. Local audiologists Lemme Audiology, ENT Associates, and Professional Hearing Aid Center, as well as representatives from Cochlear and Starkey were present to provide information and do hearing screening.

Attendees were also treated to a Home Run Derby with baseball legend Jose Canseco and great night of baseball with the Altoona Curve. Two of our youngest members, Hannah Davis, 2 and Toby Weaver, 7, who have bilateral severe to profound hearing loss, accompanied Jacob to throw out ceremonial first pitches. The night was capped off with fireworks.

















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

5

YOUR LOCAL YMCA: FRIEND OR FOE OF NOISE-INDUCED HEARING LOSS?

Exposure to very loud noise or music for even a short period of time can cause permanent hearing loss. Noise-induced hearing loss (NIHL) is the result of permanent damage to hair-like receptors (stereocilia) in the inner ear (cochlea). Damaged human stereocilia do not grow back, unlike those in birds and fish. Stereocilia are damaged when battered by the force of excessively loud noise or music. The more that are damaged, the more hearing is affected. NIHL is gradual and insidious, but fortunately, it's preventable in many cases by using earplugs and avoiding venues with excessively loud noise and music.

- With 91 decibels of loudness, hearing loss can occur within 2 hours.
- With 100 decibels of loudness, hearing loss can occur within 15 minutes.
- With 120 decibels of loudness, hearing loss can occur within 7 seconds.
- With 140 decibels of loudness, hearing loss can occur immediately.

Be Decibel-Wise: Under 85 Keeps Hearing Alive

It is important to remember that exposure to noise or loud music is cumulative. Consider this: if you drive to work for an hour while listening to music at 91 decibels and then you do the same on the drive home, the cumulative effect is equal to listening to music at 91 decibels for two straight hours without any interruption, which can cause hearing loss.

Your Local YMCA

The YMCA fosters good health by offering a variety of healthy activities, including exercise classes led by enthusiastic instructors who play motivational music. It has addressed the issue of loud music and noise in an informative document from the YMCA's Medical Advisory Committee (Google "Noise and Music Levels in YMCAs and YMCA Programs"). While the YMCA document lists a maximum of 90 decibels, the updated Occupational

Health and Safety Administration (OSHA) guideline is now 85 decibels; it was formerly 90 decibels. Here are the recommendations of the YMCA Medical Advisory Committee:

- Evaluate the noise and music levels of the facilities and programs. This can be done by placing a decibel meter [available as a free app on your smartphone] on a stand near the front or middle of the exercise room. Some music systems have built-in sound meters for this purpose. YMCA site directors may consider contacting their local health departments or industrial hygienists for a professional noise level assessment of the entire facility.
- 2. Set and enforce a standard that music volume levels should measure no more than 85 decibels in any area of the facility or any program.
- 3. Educate members regarding the safe levels of music used in personal headsets during exercise.
- 4. Educate employees about the use of ear protection, especially exercise instructors (who may be exposed to high-intensity music on a regular basis) and maintenance staff (who find that certain tasks and/or areas of the facility have high noise levels, such as boiler rooms, pool pumps, and construction work sites). In addition, employees should be encouraged to have periodic hearing tests for their own health and safety.
- 5. Become familiar with OSHA compliance and penalties for noncompliance regarding noise levels in their facilities and programs.
- Discourage practices in YMCA programs and activities that unnecessarily raise sound levels that can prove damaging, such as encouraging noise and screaming in camp programs and dining halls.

The Problem

As a YMCA member who visited 14 YMCA sites in Pennsylvania, I found that 80% of the classes I attended featured excessively loud music played at dangerous decibel levels above the OSHA guideline of 85 decibels. What totally surprised me was the

indifference and hostility of some of the instructors and management when I expressed my concern about the loud music. One site manager, who was particularly condescending, told me that his YMCA was like a franchise that could either accept or reject the recommendations of the YMCA Medical Advisory Committee. Not one instructor I met had any concern, knowledge, or understanding about dangerous decibel levels and noise-induced hearing loss.

My letters of complaint were ignored, and on one occasion, I was ejected from a Zumba class just because I had a decibel meter—despite showing the site manager the YMCA Medical Advisory Committee document that encourages taking decibel readings. Another time, a YMCA site supervisor walked into a Zumba class and turned down the music because the main desk personnel had complained that it was so loud that they couldn't hear the phones ring. As soon as the supervisor left, a class member turned up the volume with the approval of the instructor and the majority of class members, who applauded.

Protecting Your Hearing at Your Local YMCA

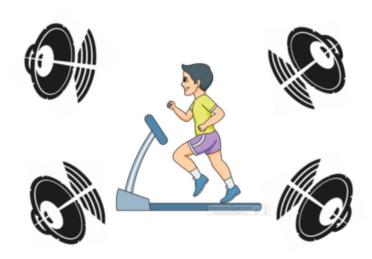
- 1. To determine whether you are listening to dangerously loud music that may cause hearing loss, you can use free apps for your iPhone, iPad, or Android. IPhone users can go to the app store and download a "decibel meter," and decibel meter apps are available for Android users at the Play Store. After downloading a decibel meter, check it for accuracy; normal speech loudness should register 65-75 decibels. For more precise readings, purchase a decibel meter at an electronics store.
- Take a decibel reading using your iPhone or Android to see if the music volume consistently exceeds 85 decibels.
- 3. If the music is habitually too loud, ask your instructor to set the volume to 85 decibels or less, in keeping with current OSHA guidelines.
- 4. Share the YMCA Medical Advisory Committee's information with YMCA instructors, staff, and

- members.
- 5. Be prepared to protect your hearing with foam earplugs if the instructor doesn't sufficiently lower the music volume, and share extra earplugs with other class members. Use earplugs, available at local pharmacies, that have a minimum NRR (noise reduction rate) of 32 decibels. If you have normal hearing, you will find the music loud enough to enjoy as you exercise even while wearing earplugs.
- 6. Earplugs need to be inserted properly, which may take a little practice. Use the fingertips of both hands to roll an earplug to the width of a toothpick. Roll gently at first to avoid creases and gradually increase the force. Then put your left hand over your head, lift the right outer ear up and back, insert the earplug, and hold it in your ear for 15 seconds as it expands. Roll another earplug for insertion into the left ear. You can also refer to the YouTube video, "Fitting Foam Earplugs."

Normal hearing is too precious to squander. The YMCA is a wonderful organization, but it's up to you to find out whether your local YMCA is a friend or foe of NIHL. For more information, refer to www.dangerousdecibels.org and www.noisehelp.com.

Emilio Cortez, Ed.D.

Dr. Cortez is co-chair of HLAA-PA's "Turn Down the Volume" Committee and can be contacted at cortez@hlaa-pa.org.



THE ANNUAL HLAA-PA LUNCH AND LEARN 2017

What a great attendance we had! Our speaker, Dr. Steven Eliades, an associate professor of Otorhinolaryngology: Head and Neck Surgery at the University of



Pennsylvania School of Medicine captured the attention of the audience as he explored his topic "Cochlear Implants: Where Are We, How Did We



Get Here, Where Are We Going?" With detailed illustrations in his presentation, we could all follow the technical terms of the subject. His willingness to answer

questions after his presentation was most appreciated by those who stayed even after the program was

completed. We had some happy winners of the raffle prizes, and Alice Dungan contributed her big prize after winning the 50/50 as a donation to HLAA-PA.



A delicious buffet lunch was enjoyed by all. Exhibitors were Advanced Bionics, The Association of Adult Musicians with Hearing Loss, Caption Call,



Cochlear Americas, The HLAA-PA Assistive Device Coordinator Bill Best, HLAA-PA Walk 4 Hearing, PA Captioned Telephone Relay Service, TDDP. Participating chapters

in the audience included: Blair County, Bucks County, Capital Region, Center City Philadelphia, Chester County, Central Delco(Delaware County),



All Generations,
Lancaster County,
Lebanon County,
Montgomery County,
Philadelphia 1
(Suburban/Northeast).
Our raffle prize donors

were: ADCO (https://adcohearing.com) and

GOLDKOW Global Litigation Services (www.golkow.com)

CART was provided by Archive Reporting Services and interpreters from The Deaf-Hearing



Communication Centre(DHCC). Don Groff set up the HLAA-PA hearing loop as well.





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Ask the Expert

COCHLEAR IMPLANTS - LIFE BEYOND HEARING AIDS

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.



Thomas Roland, M.D., Cochlear Medical Advisor

Dr. Roland, 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 but clearer. Cochlear implants can help give you that clarity, especially in noisy environments. Hearing aids are typically worn before a cochlear implant solution is considered.

Q: Are cochlear implants covered by Medicare?

A: Yes, Medicare and most private insurance plans routinely cover cochlear implants.

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 450,000 people worldwide. For many people, cochlear implants are better than hearing aids in noisy environments.¹

Q: What does a cochlear implant system look like?

A: There are two primary components of the Cochlear™ Nucleus® System, the implant that is surgically placed underneath the skin and the external sound processor. Cochlear offers two wearing options for the sound processor, one that's worn behind the ear – similar to a hearing aid – and the new Kanso™ Sound Processor which is a discreet, off-the-ear hearing solution that's easy to use. The Cochlear Nucleus System advanced technology is designed to help you hear better and understand conversations.



Call 1800 354 1731 to find a Hearing Implant Specialist near you.

Visit Cochlear.com/US/HLAA for a free guide.

The Nucleus Freedom Cochlear Implant System: Adult Post Market Surveillance Trial Results. 2008 June.
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Location:

Salt Palace Convention Center 100 South West Temple Salt Lake City, Utah 84101

Highlights:

Research Symposium

Hearing Aids and Cochlear Implants:

Merging Technologies,

Expanding Benefits

Dinner Theater

Huh? Life with a Cranky Cochlea

Author Gael Hannan
Opening Session Keynote Speaker
Staff Sgt. (RET.) Shilo Harris,
Iraq Veteran and Author.



Visit HLAA on the web! Visit hearingloss.org or scan this QR code on your smartphone.

Pickles





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10



PENNSYLVANIA WALK4HEARING!

Put it on your calendar!

The Kick Off: Sunday August 27, 2017 from 12 noon until 2 PM

American Helicopter Museum 1220 American Blvd West Chester, PA 19380

The Kick Off event is free to all guests and includes food, games for children, and team information folders and posters and everything you need to be successful in your fundraising.

The Big Day: : PA Walk 4 Hearing: Date: Sunday October 22, 2017

The Navy Yard 4747 South Broad Street Philadelphia, PA

10am - Registration/Check-in 11am - Walk begins Distance: 5K (3.1 miles)

Any questions? contact Walk Chair:

Ronnie Adler radler@hearingloss.org



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

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.