

HEARSAY

The Official Newsletter of Hearing Loss Association of PA

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Message from Nancy

This year's HLAA convention was immediately followed by the second international hearing loop convention at the same site, so many of us attended both. Loops (also called "inductive loops") are wires that conduct sound via an electromagnetic field. The other types of wireless assistive listening systems are FM (which conducts sound via radio frequencies) and infrared (which conducts sound via light waves).

The special advantage of the loop is that people with telecoil-equipped hearing aids/cochlear implants don't need to use a receiver--they simply turn on their telecoil, a small wire inside the hearing aid or CI that receives the signal. (Telecoils can also access FM and infrared via a neck loop plugged into

the receiver.) Loops can be installed in a variety of settings, such as ticket booths, taxis, auditoriums, and churches, and portable loops are available for meetings.

In England, hearing aids are provided by the government, which requires them to have telecoils, and (unlike in the U.S.) loops are installed in many locations. In the U.S., many hearing aids lack telecoils (even though the device is inexpensive), and people with telecoil-equipped hearing aids are often unaware of the telecoil or its use with assistive listening equipment. HLAA is working to raise awareness of telecoils and loops so more locations will provide this user-friendly access.

Nancy Kingsley
HLA-PA State Co-Director (director@hla-pa.org)

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**SEPTEMBER 2011 HEARSAY STATE
HAPPENINGS**

An Urgent Request for Chapter Leaders and Members:

In order to make this State Happenings Column in Hearsay more reflective of the entire state, I am asking that you all become "reporters" for your area. Please submit any information relating to your participation in local events, health fairs, or any project with hearing loss as the primary focus. Any article of any length is welcome. We will edit it if needed. We would also like to be informed of any cultural accessibility that is new to your area of the state. The deadlines for each issue of Hearsay are August 1, November 1, March 1, and May 1. You may email the article to Carolyn Meyer at meyer@hla-pa.org.

Outreach:

June 3: Donna Penman, President of Montco chapter, represented HLA-PA at a PaTTAN (PA Training and Technical Assistance Network) training session on Cochlear Implants for parents and service coordinators in King of Prussia, PA. PaTTAN is a project of the Bureau of Special Education in Pennsylvania.

June 8: Marcia Finisdore and Diana Bender presented *Hearing Loss 101* to residents of the Hill at Whitemarsh, a continuing care retirement community in Lafayette Hill, PA.

July 6: Carolyn Meyer and Alice Dungan presented "Here's the Scoop on Hearing Loss" to residents of Wesley Enhanced Living Pennypack Park in Northeast Philadelphia. The program was designed to help attendees cope with hearing loss. We will be returning in the fall for a staff enrichment development presentation.

Reminder: The next Advisory Council meeting is October 15, 2011 from 9:30 am until 4 pm at the Hampton Inn in Manheim, PA. Anyone who wishes to attend as an observer is welcome. This is an opportunity for you to see if you may want to join the Council in the future. There is CART and the room is looped. For more information contact Nancy Kingsley at kingsley@hla-pa.org.

Submitted by Carolyn Meyer

**ASSISTIVE TECHNOLOGY LENDING LIBRARY AND
NEWBORN HEARING SCREENING FUNDS CUT**

Recent budget cuts affecting the Commonwealth's social services have not spared hearing loss--two important programs were seriously impacted. One is the assistive technology lending library (which shares a line item with the Pennsylvania Assistive Technology Foundation--the latter, known as PATF, provides loans for purchasing technology). The lending library gives people the opportunity to try out assistive devices for free in order to be sure that equipment they are considering buying is suitable for them. Funding for the lending library had already been cut almost in half over the past three years, resulting in the elimination of prepaid delivery and pickup even though many people are unable to travel to a regional assistive technology resource center to borrow and return equipment. Outreach efforts such as presentations and exhibits at health fairs also had to be cut, and the program could no longer purchase current devices. All these impediments reduced borrowing by almost 25%. The new budget reduces funding an additional 25%, from \$422,000 to about \$325,000, calling the continued viability of the program into question.

The other affected program is newborn infant hearing screening, for which the \$306,000 in state funding was totally eliminated. The initial screening of babies born in hospitals will still be covered because that funding comes from the federal government, but the

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state funds had supported program administration and training, follow-up of infants who failed the screening, and linkage to early intervention services. In addition, the 4,000 Pennsylvania babies born annually outside of hospitals will get no hearing screening at all, and hospitals with inaccurate testing equipment will not receive the funds needed to upgrade. Lack of follow-up will result in a decrease in early intervention, since parents often do not take action until their child fails to learn to talk on schedule. By then, it is frequently too late to prevent permanent language gaps. Ironically, educating such language-impaired children is far more costly (as well as much less effective) than ensuring that early intervention occurs.

The budget for 2011-2012 has been enacted, but next year is another story. Funding for the assistive technology lending program and newborn infant hearing screening can be restored if enough people let their state representatives know that they want these vital services provided.

Submitted by Nancy Kingsley

WHAT TO REQUEST WHEN PURCHASING A WIRELESS PHONE

There has been much confusion for persons with hearing loss when purchasing wireless phones. At the HLAA convention in June, the FCC representative confirmed our rights when we have a hearing disability. We have 30 days to try the phone outside of the store, with no restocking fee, if the phone does not provide us with adequate hearing. If you are purchasing the phone, you must go to the manager if there is any question, tell them of your rights and of your hearing disability, and write down the manager's name, the date, and store location. If it is documented in their system for you and accepted that they will allow the 30 day trial, then

Walk4Hearing 2011

The annual Pennsylvania Walk4Hearing is happening again! This event brings more and more people every year, which demonstrates that the goal of the walk is succeeding. The goal is to raise awareness of hearing loss across the country. With more walkers and more teams each year we are succeeding in raising awareness in our own state.

Walk4Hearing is a complete and total volunteer event. As Walk Chair the last couple of years, I have been duly impressed by the enthusiasm and energy of all the volunteers who plan for the event and work the day of the walk. Everyone is always ready to have a good time socializing, enjoying all the various family entertainment and cheering each other on. Come on out and join us! If you cannot make it on Sunday September 25th at 9am in Ridley Creek State Park, please check out the Walk4Hearing website and see the new video. Pick a team or walker to donate to and help them reach their goal. Step up for hearing loss! www.walk4hearing.org

Submitted by Beth Ann Rejonis



you are all set. If there is rejection of your request, and refusal to accommodate this, you should inform the person that you are going to file a complaint with the FCC as soon as you leave the store. Here is the complaint information. Include all details mentioned above about your experience. It is important for all of us that you follow through with this complaint.

www.fcc.gov/complaints (an online complaint form)
or call the FCC Consumer Center 1-888-225-5322
or write to
Federal Communications Commission
Consumer and Government Affairs Bureau
Consumer Inquiries and Complaints Division
445 12th Street, S.W.
Washington, DC 20554

Submitted by Carolyn Meyer

My First HLA Convention

Wow! I was really happy when Elizabeth LeBarron asked me to go as a delegate to the HLA Convention in Crystal City, VA. Having never been to an HLA convention and hearing so much about it from other chapter members, I was more than delighted to attend. Donna Penman and I had boarded the MegaBus early that Thursday morning, a scenic bus trip from Philadelphia, Pennsylvania to Washington, D.C. The D.C. Metro then took us to the convention site. Kudos to the convention planners, it was accessible, comfortable, and inviting.

As the vice president of the Montgomery County Chapter of HLA-PA, I was anxious to bring back updated information to share with members of my chapter. Several chapter members who had been to previous conventions assured me that the convention would be informative. So, with excitement, apprehension, and a fresh pack of batteries for my hearing aid, Donna and I were ready to take on our new adventure.

The setting was perfect and there was no doubt that people like me were the target audience. There were kiosks and exhibits of all shapes and sizes, from assistive listening devices, hearing aids, captioned phones, cochlear implants, BAHAs, and jewelry for the tubing part of hearing aids! A brochure here and few questions there, exchanging business cards with vendors, and before I knew it my complimentary Oticon shopping bag was starting to bulge. There was also an evening for socializing and a funny comedian performed magic tricks for us.

I enjoyed the education workshops and the presentations. More specifically, I enjoyed learning about the FCC (Federal Communications Commission) and how the agency advocates for people with hearing loss. They follow through to make sure laws are enforced for us. They also respond to accessibility complaints. There were

other presentations that I attended, and they were just as impressive.

Coming home I felt tired but refreshed, excited, and VERY validated. I had attended my first HLA convention! I got to see some of the superstars of the organization and I heard some dynamic presenters and educators devoted to helping the hard of hearing. I even made a few friends along the way. If I am asked by my chapter members, will you be going to next year's convention? I can only respond by saying, I hope so, and I hope to meet you there too!

Submitted by Pat Cortez

My Cochlear Implant Story

My mother, father and I were all born with a progressive hearing loss. When I was about eight years old, my aunt noticed that while seated in front of the television, my head was turned slightly to the right. I was favoring my left ear without realizing it. My aunt, who was a nurse, advised my mother to take me for a hearing test, but it never happened. My parents also never addressed their own hearing losses, and I grew up thinking it was something that should be hidden.

Of course, those close to me noticed and frequently questioned amongst themselves why I did nothing to address my hearing loss. I was not in denial about its existence, but I was in denial about how well I was managing it without help. About four years ago I couldn't deny it any longer and finally went to an ENT physician. Once he saw my hearing test results, he was literally stunned that I had waited as long as I did, and that I had been managing as well as I had, considering the circumstances. I was fitted for powerful hearing aids which helped to a degree, but not to the degree I had hoped. My hearing continued to worsen and I completely lost the ability to use the telephone. Luckily, I work for a very

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understanding employer who has always accommodated employees with disabilities to whatever degree is necessary. I also received a CART accommodation from Penn State so that I could complete my graduate degree.

Despite my accommodations, however, I struggled emotionally with my loss. I began to spend more and more time at home instead of participating in the things I used to enjoy because even though it was depressing, it just seemed easier and less stressful. I had joined HLAA at the recommendation of my audiologist and found it extremely helpful to meet others who shared the same challenges, but the vast majority of my time was spent with people who have normal hearing. Even when I finally began to speak up for myself and ask those around me to speak so that I could understand them, I still faced a great deal of insensitivity, something Hearsay's readers understand all too well!

Through HLAA I met several people whose hearing had improved considerably with cochlear implants and I decided to discuss it with a surgeon who had come highly recommended to me, Dr. Douglas Bigelow at the University of Pennsylvania Hospital. I was approved for the surgery, which was the first time I was ever happy about failing a hearing test! I had the surgery this past March and was very pleased to understand speech immediately following my activation. Each day I am amazed at what I can hear and how clear it is. I've even noticed that while watching television, I'm looking straight at the screen!

Submitted by Pam Reiher

***Art-Reach Honors HLA of PA at 25th Anniversary
Jazz Brunch
Activities Include First-Ever Assisted-Listening
Tour at Please Touch Museum***

Art-Reach, a nonprofit organization in Philadelphia that connects underserved audiences to the arts, will present Hearing Loss Association

of Pennsylvania with its 2011 Commitment to Cultural Access Award at its 25th Anniversary Jazz Brunch benefit on Sunday, November 6, at the Bellevue Hyatt Hotel in Philadelphia.

The award recognizes the sustained commitment to advocate for and promote open-captioned cultural events that HLA of PA and many of its individual members in the Philadelphia region have demonstrated over the last two years as a community partner on Independence Starts Here, a cultural-access initiative led by Art-Reach and VSA Pennsylvania that helps arts organizations to be more accessible and that develops audiences for accessible cultural events.

"HLA of PA has been one of our most active and engaged community partners," said Art-Reach executive director Michael Norris. "They understood the value and potential impact of Independence Starts Here from the very beginning, and they've been amazing advisors and advocates ever since. Just as important, they've also been active audience members, since one of our main goals is to show arts organizations that there is public demand for accessible events. We are thrilled to recognize these extraordinary efforts by presenting HLA of PA with this year's Commitment to Cultural Access Award at the Art-Reach Jazz Brunch."

Art-Reach's other honoree this year is Laura Foster, president and CEO of the Please Touch Museum, Philadelphia's children's museum, for the commitment they have shown to accommodating visitors of all abilities, especially through this year's "Access/Ability" exhibit promoting disability awareness.

To highlight both of this year's honorees, Art-Reach is coordinating the first-ever assisted-listening tour at the Please Touch Museum on Saturday, October 22, from 9:30-11:30 a.m. The tour will give visitors a behind-the-scenes look at Memorial Hall, the

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museum's National Historic Landmark building in Fairmount Park that was built for the 1876 Centennial Exhibition, as well as the renovated 1908 Dentzel Carousel from Philadelphia's Woodside Park, which the museum acquired in 2005.

HLA of PA members who purchase a ticket to the Art-Reach Jazz Brunch on November 6 will receive a free ticket to the assisted-listening tour of Please Touch Museum on October 22. Tickets for the Jazz Brunch are \$85 each and can be ordered by contacting Nicole Oidick at (215) 568-2115 ext. 5 or noidick@art-reach.org. Tour-only tickets are available for \$15 each.

For more information about Art-Reach, visit www.art-reach.org.

For more information about the Independence Starts Here initiative and to sign up for the monthly email of accessible cultural events go to www.phillyfunguide.com/access.

Submitted by Michael Norris, Exec. Director of Art-Reach

VOLUNTEERS NEEDED!!

Assist the HLA-PA State Director by serving on the Advisory Council or one of its committees. The Council meets periodically in Manheim, PA (1 hour from King of Prussia) 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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