



TIS THE SEASON TO USE HUMOR WITH HEARING LOSS

Holidays are approaching and you know what that means. It means social functions and social gatherings. My gut reaction is to run and hide in a quiet room. Luckily, I can now use humor to help me cope with my hearing loss in those challenging hearing situations.

Growing up with my hearing loss, I did anything but laugh about my hearing loss. I was embarrassed and ashamed when I had to tell people about my hearing loss. Then one day I made a joke about using my assistive listening device (ALD), which is an Oticon Lexis, at a large meeting for my job. I was not very awake at my early morning meeting and as a result I did not explain the purpose of my ALD. One person asked if it was a tape recorder. Before I could respond, the meeting facilitator explained that this

device helped me with my hearing loss. Then I quickly added with a smile; not only is this device a tape recorder, but it also has a small camera inside too. People began to laugh. After people finished chuckling, I did explain how the ALD works.

After that meeting, I had an "AHA!" moment. Not only did that joke make me feel a little better about having an ALD, but the meeting attendees also felt more relaxed. The humor alleviated the feelings of embarrassment and awkwardness that I felt when I have to explain my hearing loss situation. Now, I think what kind of joke I want to use when I have to explain my hearing loss. But I do want to state that I only use humor in an appropriate manner. Overall, joking not only

(Continued on page 3)

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2007 OTICON FOCUS ON PEOPLE AWARDS HONOR RONNIE ADLER

Ronnie Adler is among nine outstanding individuals with hearing loss honored by the 2007 Oticon Focus on People Awards, a national competition that recognizes individuals who are helping to eliminate negative stereotypes of what it means to have a hearing loss. Ronnie's selection as a first place winner in the Advocacy Category was announced in September at the tenth annual Oticon Focus on People Awards Ceremony in Boston. The Awards ceremony was attended by over 200 leading hearing care professionals from across the country. As part of her award, Ronnie has designated the Hearing Loss Association of America as the recipient of a \$1,000 donation from Oticon, Inc.

Ronnie, diagnosed with a severe hearing loss at birth, is someone who has always looked beyond her own needs to help others. From her early volunteering efforts with the Manhattan, Westchester and New York State Association of SHHH, Ronnie went on to found the Hearing Loss Association of America's GenX Chapter of Delaware Valley, PA in 2001. Ronnie has worked tirelessly, organizing conferences in New York, New Jersey and Pennsylvania and raising funds including national walkathons that enlisted hundreds of people with hearing loss and their families and friends to raise awareness of hearing loss in communities across the country. Perhaps Ronnie's greatest contribution is as a role model for other volunteers. She has been called energetic, empathetic, kind, resourceful, giving and inspirational – all the best qualities of someone who can truly make a difference for people with hearing loss.

The Oticon Focus on People Awards were created in 1997 by Oticon, Inc., one of the world's oldest and most respected hearing instrument manufacturers. By celebrating the accomplishments and contributions of individuals with hearing loss, Oticon, Inc., hopes to call attention to common misconceptions about hearing loss and

motivate people with hearing loss to take advantage of the help that is available to them.

For more information about the Oticon Focus on People Award and hearing health, log on to www.oticonusa.com.



'HOLY GRAIL' OF HEARING: TRUE IDENTITY OF PIVOTAL HEARING STRUCTURE IS REVEALED

In a study published in the September 6 issue of the journal "Nature", researchers have shed new light on the hearing process by identifying two key proteins that join together at the precise location where energy of motion is turned into electrical impulses. The discovery, described by some scientists as one of the holy grails of the field, was made by researchers at the National Institute on Deafness and Other Communication Disorders (NIDCD), one of the National Institutes of Health (NIH), and the Scripps Research Institute in La Jolla, CA.

"This team has helped solve one of the lingering mysteries of the field," says James F. Battey, Jr., M.D., Ph.D., director of the NIDCD. "The better we understand the pivotal point at which a person is able to discern sound, the closer we are to developing more precise therapies for treating people with hearing loss, a condition that affects roughly 32.5 million people in the United States alone."

When a noise occurs, sound vibrations entering the ear, first bounce against the eardrum, causing it to vibrate. This, in turn, causes three bones in the middle ear to vibrate, amplifying the sound. Vibrations from the middle ear set fluid in the inner ear, or cochlea, into motion and a traveling wave to form along a membrane running down its length. Sensory cells (called hair cells) sitting atop the membrane "ride the wave" and in doing so, bump up against an overlying membrane. When this happens, bristly structures protruding from their tops (called stereocilia) deflect, or tilt to one side. The tilting of the stereocilia cause pore-sized channels to open up, ions to rush in, and an electrical signal to be generated that travels to the brain, a process called mechano-electrical transduction.

Most scientists believe that the channel gates are opened and closed by microscopic bridges -- called "tip

links" -- that connect shorter stereocilia to taller ones positioned behind them. If scientists could determine what the tip links are made of, they'd be one step closer to understanding what causes the channel gates to open. This is no easy feat, however, because stereocilia are extremely small, scarce, and difficult to handle.

Using three lines of evidence, the team of scientists have demonstrated that two proteins associated with hearing loss -- cadherin 23 (CDH23) and protocadherin 15 (PCDH15) -- unite and adhere to one another to form the tip link. Mutations in CDH23 are known to cause one form of Usher syndrome as well as a nonsyndromic recessive form of deafness, and mutations in PCDH15 are responsible for another form of Usher syndrome. (A syndrome is a disease or disorder that has more than one feature or symptom, while the term "nonsyndromic" refers to a disease or disorder that is not associated with other inherited characteristics.) Usher syndrome is the most common cause of deaf-blindness in humans.

NIDCD's Kachar, a co-senior investigator on the study, says, "Now that we know how these two proteins interact at the tip link, we can perhaps predict how different types of hearing loss can take place depending on where a mutation is located."

The researchers first created antibodies that would bind to and label short segments on the CDH23 and PCDH15 proteins in the inner ears of rats and guinea pigs. (Both proteins were identified at the tip link, respectively, in earlier studies.) Using green fluorescence and electron microscopy studies, they showed that CDH23 was located on the side of the taller stereocilium and PCDH15 was present on the tip of the shorter one, with their loose ends overlapping in between. The researchers were able to identify both proteins, while earlier studies had not, because they removed an obstacle to the antibody-binding process: calcium. Under normal conditions, CDH23 and PCDH15 are studded with calcium ions, which prevent antibodies from binding to the targeted sites. When calcium was removed through the addition of a chemical known as BAPTA, both labels became visible.

Next, the researchers built a structure resembling a tip link by expressing the CDH23 and PCDH15 proteins in the laboratory and watching how they interacted. When conditions were right, the two proteins wound themselves tightly together from one end to the other in a configuration that mirrored a naturally occurring tip link. The results were surprising, since the scientific consensus had been that these proteins would not interact at all. As with normal tip links, the structure thrived in calcium concentrations that paralleled those found in fluid of the inner ear, while a drastic reduction in calcium disrupted the structure.

Lastly, the scientists found that one mutation of PCDH15 that causes one form of deafness inhibited the interaction of the two proteins, leading them to conclude that the mutation reduces the adhesive properties of the two proteins and prevents the formation of the tip link. In a second mutation of PCDH15, the tip link was not destroyed; the scientists suggested that the deafness is not likely caused by the breakup of the tip link but by interference with its mechanical properties.

Knowing precisely the composition and configuration of the tip link, scientists can now explore how these proteins interact with other components to form the rest of the transduction machinery. In addition, scientists can study how new treatments might be developed to address the breaking up of tip links through environmental factors, such as loud noise.

Now that we understand what the tip link is made of and what conditions are required to assemble it," says Kachar, "we can study what it might take to rejoin tip links as a possible method for restoring hearing in people with some forms of hearing loss that may have resulted from disruption of the tip link."

The complete NIH News Release is available at: <http://www.nih.gov/news/pr/sep2007/nidcd-05.htm>

(Continued from page 1)

lightens the hearing loss situation for me but also for the people who are learning about my hearing loss. So when you are in those challenging hearing situations during the holidays you just may want to use some humor. After all it is the season to be jolly!

Linda Rusinko, rusinko@pa-shhh.org

AOL, GOOGLE, MICROSOFT, YAHOO! UNITE TO ADVANCE ONLINE MEDIA CAPTIONING

In an effort to overcome technology and production barriers, the leading providers of Web-based video have joined with media access pioneer WGBH/Boston to develop solutions that will increase the amount of online video accessible to people who are deaf or hard of hearing.

AOL, Google, Microsoft and Yahoo! have asked WGBH and its Carl and Ruth Shapiro Family National Center for Accessible Media (NCAM) to establish and manage the Internet Captioning Forum (ICF). The ICF will initially address the technical challenges presented by online video repurposed from broadcast or other previously captioned sources, as well as video created specifically for the Web. "More and more people are turning to the Internet to get their news, watch programs and other video," says WGBH's Director of Media Access, Larry Goldberg. "The scarcity of captions online is due to a variety of challenges, including a proliferation of media and text formats and players, editing of programs originally distributed with captions, and lack of clear online caption production and delivery requirements. The founding members of the ICF are all companies long dedicated to making their products and services accessible to people with disabilities. They recognize that working together on this challenge is the best, fastest and most practical way to get more captioned video on the Web. "The collaboration is expected to yield a range of solutions and tools, among them:

- A database for online media distributors, populated by major captioning providers, of previously captioned programs. This tool will facilitate the location and reuse of existing caption files.
- Technical and standards documents, case studies and best practices for accomplishing pervasive online video captioning. Demonstrations of innovative practices to preserve captions while editing and digitizing captioned videos.

In addition to the global audience of people who are deaf or hard of hearing, beneficiaries of the ICF's initiative also include people who rely on

translation engines to convert caption text into other languages, people using online video in noisy situations or at work, and search engines that use caption text to search and retrieve online videos.

Cheryl Heppner, executive director of the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons says, "The formation of the Internet Captioning Forum will become a milestone in the history of access to media. The community of people who are deaf or hard of hearing has worked for decades to achieve the access to television captioning we have now. The partnership of AOL, Google, Microsoft and Yahoo! with WGBH promises to be a major step forward for accessible online video."

For information about NCAM and WGBH visit: access.wgbh.org and www.wgbh.org

MESSAGE FROM DIANA

As the December issue of HearSay goes to press, it has been just over a month since the conclusion of a very successful regional conference in Harrisburg. This was the first time HLAA members from PA, NY, NJ and DE had worked together to provide a conference for our region. More than 250 people attended the **All 4 To Hear Conference** in early October at the Hilton Harrisburg and Towers. Conference attendees learned about emergency preparedness, coping skills, and the latest technology for people with a hearing loss. Stephen Reed, the Mayor of Harrisburg, welcomed us on Friday with wonderful humor and encouraged us to work towards obtaining Medicare coverage for hearing aids. Visitors to the Exhibit Hall found information about hearing aids, cochlear implants, assistive listening devices, telephone and relay services, as well as resources available to people who have a hearing loss. Social events included a river cruise onboard the *Pride of the Susquehanna* paddle-wheeler and the Saturday evening banquet with a sing along. At the Saturday evening banquet, Elaine Mormer of Pittsburgh was recognized for her advocacy

(Continued on page 5)

ELAINE MORMER RECEIVES 2007 MARCIA FINISDORE AWARD FOR ADVOCACY

This year's Marcia Finisdore Award for Advocacy was presented to Elaine Mormer, M.A., Audiology Clinical Coordinator of the Communication Science and Disorders Department at the University of Pittsburgh. The award was presented by Diana Bender, State Director of Hearing Loss Association of Pennsylvania, at the All 4 To Hear Conference awards ceremony honoring outstanding individuals from Pennsylvania, New York, New Jersey and Delaware.

The Marcia Finisdore Award for Advocacy was established by Hearing Loss Association of Pennsylvania in order to recognize an individual who has a positive vision for the hard of hearing community and a continuing commitment to leadership, together with a demonstrated record of advocacy work for the rights and needs of hard of hearing people in the Commonwealth of Pennsylvania.

As persons who are hard of hearing and function in a hearing world, we often feel that there are so few hearing people who "get it". Not only does Elaine "get it", she does her best to get rid of "it". Because, of course, "it" is the cumulative and comprehensive effects and barriers hearing loss imposes on feeling and function every day, all the time.

WANT BETTER HEARING LOSS SERVICES AND ACCESS? YOU CAN HELP TO MAKE IT HAPPEN!

Captioned movies and shows...hospital staffs that know how to accommodate hard of hearing patients...assistive listening systems readily available for spoken presentations...CART realtime captioning provided at major public events. Do you have dreams like these? What else is on your hearing loss wish list?

You can help us to turn dreams into reality! No experience is necessary, just the desire to improve services and access for hard of hearing Pennsylvanians. Our efforts will be coordinated via email. For more information, contact Nancy Kingsley, HLA-PA's Advocacy Chairperson, at kingsley@pa-shhh.org. Together, we can make a difference!

Elaine has a long, active history with SHHH/HLAA. She embraces its members and generously offers her time, talents and resources. In addition to the empowering modality she brings to her professional practice and her teaching philosophy, Elaine lives her advocacy for those with hearing loss like a religion – a reflex response based on unquestioning belief. You see, quite simply Elaine really does believe that we can do everything everyone else can do, but hear. She knows that hearing loss creates logistical and emotional issues, but believes that they are surmountable. She approaches hurdles with creative assistive technology solutions and sound technical knowledge and experience. Elaine makes a positive difference in the lives of those with hearing loss

- by her dauntless and indefatigable advocacy efforts
- by walking mindfully beside us and making sure our right to access all information and services being offered is honored
- by being a life-long learner of hearing assistive technology and promoting communication between manufacturers and users
- by actively monitoring and remediating communication situations that are less than effective or acceptable
- and by never saying no to a plea for support.

Elaine has truly raised the quality of life for legions of people who benefit directly and indirectly from the changes for which she has advocated.

(Continued from page 4)

work, while Nancy Kingsley of Lancaster and a member of the HLA-PA Advisory Council received the NJ state award. Melanie Brand and Julia Sullivan received awards from New York and Delaware, respectively. The conference concluded on Sunday with a research symposium on hair cell research and advances in gene therapies for treatment of hearing loss. Hearing Loss Association of PA thanks all the speakers, exhibitors and volunteers, as well as everyone who attended and made the conference a resounding success.

Diana Bender, HLA-PA State Director

HearSay Subscription

If you would like to receive your own copy of *HearSay*, the official newsletter of HLA-PA, please fill in this form and mail it to the address below. A *HearSay* subscription is free; however, HLA-PA is a not-for-profit organization run exclusively by volunteers and we are grateful for any donations.

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Barb Beard, (Central PA) - 717-534-0820

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VOLUNTEERS NEEDED!!

Assist the HLA-PA State Director by serving on the Advisory Council or one of its committees. The Council meets periodically in Carlisle 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: Diana Bender (bender@pa-shhh.org)
- Membership: Russ Green, Chair (green@pa-shhh.org)
Barb Beard (beard@pa-shhh.org)
Ronnie Adler (adler@pa-shhh-pa.org)
- Communication: Linda Rusinko (rusinko@pa-shhh.org)
- Advocacy: Nancy Kingsley (kingsley@pa-shhh.org)



**Diana Bender, HLA-PA State Director (left)
Awards Marcia Finisdore Award to
Elaine Momer**

**HAPPY HOLIDAYS TO ALL
AND A HAPPY NEW YEAR**