



Hearing Loss Association of America–New York State is an educational and advocacy organization of people working together across the State to promote issues of importance to New Yorkers who have a hearing loss.

WHAT IS THE STATE ASSOCIATION DOING?

The Board of Directors meets three times a year in Albany, and all members who are residents in New York state are welcome to attend these weekend meetings. Officers and committee chairs report on their progress during the prior months, and plans are made for the upcoming year. At the fall Annual Meeting, a slate of officers and Board members is presented for election. A report on the recent elections is on page 5. Presentations are often made on subjects of interest. Information on the upcoming presentations is on page 8.

Since New York is a large state, we are aware that attendance may not be feasible for many members. Therefore, the Board has asked me, as Secretary, to write a summary of committee reports from the last meeting in *Reporter*, which is sent to all our national NYS members.

At the board meeting of November 1-2, 2008, the following reports were submitted:

Treasurer

Assets currently total over \$23,000, which are mostly invested in CDs.

Since we do not plan a state conference in 2009, another source of fundraising besides advertising must be found.

Finance

The proposed budget was presented and accepted, with some amendments, by the Board. In the current economic climate, we need to be fiscally conservative, find ways to raise funds, and to raise our association's visibility and credibility in the state.

Walk4Hearing

In 2008, the three New York walks contributed 30 percent towards the almost \$760,000 which was received by the HLAA national organization from the proceeds of walks nationwide. The inaugural Manhattan Chapter fall walk (see page 5 for story) was a great success, as were the spring walks held by the Westchester/Mid-Hudson and Rochester Chapters. Planning meetings are already taking place for next year's walks.

Corresponding Secretary

Letters of thanks were sent to individuals who made donations. Members are welcome to make tax-deductible donations at any time.

Universal Newborn Hearing Screening

At the August, 2008 meeting, the Board heard a presentation by the producers of the Manhattan Chapter's very impressive brochure, which informs new parents of the availability for hearing screening and follow-up, and the urgent need for early intervention and advocacy. The State Association supports this project, and a committee was formed to address it. Research is being made into existing publications in the state and possible sources of funding for publication and distribution.

Chapter Development

The newest New York chapter in Syracuse is up and running. Our Upstate District Coordinator and our newly elected Vice President are attending and addressing various chapter meetings, to offer assistance and support.

To encourage chapters to benefit from the HLAA national convention in Nashville, TN, a discount is being offered for one chapter delegate to attend. Our NYS Chapter Coordinator will send a color brochure, containing registration information and application form, to all chapters for distribution to their members. General information on convention registration is at hearingloss.org/convention/index.asp.

Chapter leaders should be keeping their members informed of the continuing efforts being made on their behalf at the national and the state level. These advocacy efforts have resulted, for example, in increased accessibility at airports and other public places, TV captioning and cell phone use.

Please see page 3 for an account of HLAA national activities by our past National President, who is also a NYS Board member. We are fortunate that some current and former members of our NYS Board are also HLAA national board members and serve on important national committees. One example is the newly formed Chapter/National Partnership committee, chaired by an NYS board member and including our NYS Chapter Coordinator. NYS is very well represented at the national level.

Hearing Loss Magazine, one of the benefits of HLAA national membership, is an excellent source of information on many issues, so do take the time to read it when it arrives in your mail.

continued next page

WHAT IS THE STATE ASSOCIATION DOING? (continued)

Captioning

When cable TV providers apply for license renewal, our HLAA captioning Chairperson testifies on members' behalf, to ensure that closed captioning will not be lost with the advent of digital TV. Consumer complaints should be made to the provider in writing; if no response is received within 45 days, complaint should be forwarded to the FCC, using the link on the HLAA-NYS website hearingloss.org/advocacy/telecomm.asp.

FCC regulations require closed captioning but do not regulate quality. COAT (Coalition of Organizations for Accessible Technology), of which HLAA is a participating member, is insisting, on our behalf, that poor, unsynchronized captioning is equivalent to no captioning. See coataccess.org.

Court reporting is another area where HLAA-NYS is advocating on behalf of our members. Technology used by court reporters is the same as that used by the CART (Communication Access Realtime Translation) reporter at HLAA meetings. Therefore, the transcript could easily be projected simultaneously on a screen, as it is at our meetings.

The NYS Attorney General's office is requesting input on this and other difficulties experienced in NYS courts (city, state or local) by people with hearing loss. See below:

I am an assistant attorney general in the civil rights bureau of the New York State Attorney General's Office. I received your contact information from Christina Curry of the Harlem Independent Living Center. I wanted to follow up with each of you regarding whether you, or someone you know, has ever been denied the opportunity to serve on a jury or grand jury because of a disability - specifically, because you are deaf or hard of hearing and required assistive listening devices or interpreter services. If this has happened to you or someone you know, could you please reply to this email and include detailed information about the incident - including the time frame and courthouse where it occurred.

Thank you for your assistance.

*Beth Frank, Assistant Attorney General,
Civil Rights Bureau
NYS Attorney General's Office
120 Broadway, New York, New York 10271
tel: 212-416-8974, fax: 212-416-8074
Beth.Frank@oag.state.ny.us*

Assistive Listening Devices

CART and audio loop are available at every HLAA-NYS meeting, so that everyone present is able to participate fully in the discussion.

Newsletter

Members are encouraged to make suggestions for material they would like to see published in the newsletter. Anyone who prefers to receive the newsletter by email see page 11 for information. This would save postage and also help your newsletter to "Go Green"!

Database

Our state database now numbers over 700 newsletter recipients. The newsletter and website are the major sources

of information on HLAA-NYS matters, for our members and for the general public. All chapter members who are not national members are encouraged to join the national organization. Those who are national members are automatically members of the New York State association and receive the *Reporter*.

Website

Updates and additions are continuously being made to the website, and suggestions from members will be welcomed.

A list of bills pending in the NY Legislature, plus information and form letters for contacting your senators and assemblypersons, is provided by our Legislative Chairperson and posted on the HLAA-NYS website under "Legislative Advocacy Update." Check out all the useful links on our website at hlaa-nys.org, and then click on [Related Links](#).

The Board is looking for a volunteer to assist our excellent webmaster. Please contact the association's president; see p. 11.

Leadership

Strengths and weaknesses of the state association were discussed. Overall goals, objectives and action steps are being set by the committee for the future of the state association.

State goals must, of course, reflect and support the goals of the national organization, which have been very clearly articulated by Executive Director Brenda Battat. Major goals which were agreed upon for HLAA-NYS were:

- Increase membership of younger adults with hearing loss aged 18-25 through education and advocacy. Objectives for this goal are to educate leaders of institutes of higher education, and students entering postsecondary education, regarding their rights under the ADA related to hearing, and to encourage students with hearing loss to form social networks.
- Strong legislative advocacy on behalf of all our members.
- Increased collaboration between the state organization and the chapters. Chapter leaders will be invited to attend state association meetings and share some of the wonderful projects their chapters have undertaken, as well as sharing local concerns which may be addressed at the state level.
- Increased communication to members on how we can live better with hearing loss, through the use of current technology.
- Increased visibility of the association through our print publications, website and by establishing a presence at health fairs and other related events, to make us better known to the general public.

These goals and objectives will be tabulated and the committee will report on progress at the next meeting.

The board meeting concluded on a high note of enthusiasm and optimism. The State Association is alive and well, and working on behalf of all New York state residents with hearing loss, our families and those with whom we interact.

The next meeting of the Board of Directors is set for the weekend of February 28-March 1, 2009 (see mailing page).

Vivien Maisey
Secretary, HLAA-NYS

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HLAA NATIONAL OFFICE UPDATE

Here are some highlights of the national office activities:

Programs

- The walk has made close to \$760,000 – a remarkable amount of money for a program only three years old. We should be enormously proud that our New York walks have raised an amazing 30 percent of the total. Thanks are due to our national sponsors, Advanced Bionics, Aetna, Phonak, Sorenson and T-Mobile.
- For younger people, a social networking website called HearingLossNation was started by Patrick Holkins, who was featured on the September/October 2008 issue of *Hearing Loss Magazine* cover. Patrick is a student at Harvard and has twice been an intern in the national office.
- Developed live web chat program with experts – Marcia Dugan was the first, followed by Michael Seidman on tinnitus and Sam Trychin on surviving the holidays.

Education

CART providers, social workers and rehabilitation counselors can now receive continuing education credits from our online Academy program.

Community

Executive Director Brenda Battat has been getting HLAA out into the community – meeting with the attorney who runs the US Business Leadership Network, a group interested in best practices and diversity in the workplace; presenting at the NJ Taste of Technology put on by Sprint and the Deaf and Hard of Hearing Services of NJ; providing a booth at the AARP conference. Brenda has also been visiting chapters, regional conferences, and walks across the country.

Advocacy

- HLAA has submitted comments to the FCC on the misuse by large companies of exemptions for small companies having to do with hearing aid compatible cell phones, sent comments to Medicare to ensure adequate reimbursement to hospitals for CIs and what are called osseointegrated devices – Baha® is the only one at this time.
- The FCC process for complaints about captioned TV has been streamlined; complaints must now be resolved within 30 days, instead of taking up to 100 days.
- Brenda had a follow-up meeting with the Dept. of Transportation to express dissatisfaction with the new Air Access rule requiring self-identification for two reasons – many HoH people don't self-identify, and staff is too busy to remember you to give you information at gates and in flight. DOT reported that there were virtually no complaints coming in about airlines and said that decisions are based on number of complaints. HLAA has put information on the complaint process directly on the website and provided a downloadable form that can be sent either directly to DOT or via HLAA.

- HLAA also submitted comments on the Social Security Administration criteria for eligibility of people with hearing loss for disability. Issues are testing protocols, who does the testing, what the tests are called, how long someone post-implantation can be considered eligible for disability, and most importantly, if someone is denied disability, providing them with information and resources on how to stay on the job with communication accommodations.
- Signed on to an FCC filing in opposition to a request for a waiver to 10-digit numbering for video relay services customers. Sorenson has asked for approval from FCC to use proxy numbers for their VRS customers. HLAA supports the rollout of 10-digit numbers, not proxy numbers, as soon as possible.
- Joined a friend of the court brief in opposition to the Arizona court ruling on movie access. The AZ court found that the ADA does not apply to movies – we *cannot* let that pass.

There were, of course, all the usual activities as well – putting out the magazine, updating and improving the website to make the huge amount of information more easily accessible, providing support for chapters, answering information requests from non-HLAA members, running the Academy, renewing the grant for HAT training, managing the walks across the country, researching future convention sites, and planning and organizing the Nashville convention. The convention will be an exciting 30th birthday celebration for HLAA. Highlights include the research seminar sponsored by the Deafness Research Foundation, to update us on the latest research in hair cell regeneration, and a talk about technology and hearing loss by Vint Cerf, Ph.D., known as one of the “Fathers of the Internet.” In addition to tracks on healthy living and working, relationships and communication, hearing technology, advocacy and access, there will be a new track for young adults. The Rocky Stone Scholarship is available to help defray convention costs. People with hearing loss, family members, and professionals in the field are warmly encouraged to attend the 2009 HLAA national convention in Nashville, TN.

Anne Pope
Immediate Past President HLAA
HLAA-NYS Board Member (ex-officio)

* * *



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NIDCD LAUNCHES CAMPAIGN TO PROTECT THE HEARING OF TWEENS

New Web Site Offers Parents Resources to Help Tweens Avoid Hearing Loss from Noise

A new campaign to help parents of 8- to 12-year-olds teach their children how to avoid hearing loss from overexposure to loud noise was launched today by the National Institute on Deafness and Other Communication Disorders (NIDCD), part of the National Institutes of Health. The new campaign, called *It's a Noisy Planet, Protect Their Hearing*, features a new Web site that offers advice to parents on the causes and prevention of noise-induced hearing loss, how to recognize when a child's hearing is at risk, and ways to reduce noise exposure. The site contains games, posters, and interactive information about noise and hearing loss tailored specifically for tweens.

"Noise is everywhere, and children and adults alike are at risk for hearing loss from overexposure," said James F. Battey, Jr., M.D., Ph.D., director of the NIDCD. "Our goal through this campaign is to increase awareness among parents and children so that it will become second nature to use protective hearing techniques when they're exposed to loud noise, just like it's become second nature for many people to wear sunscreen when they're at the beach or to snap on a helmet when they go biking."

Children often are exposed to noises that can reach harmful levels and durations. Doing yard work, such as using a power mower, playing a musical instrument, whether it's a violin or electric guitar, or attending a sports event in a large stadium can be the source of too much noise.

Noise-induced hearing loss occurs when too much noise damages small sensory cells in the inner ear, called hair cells. Once damaged, these hair cells cannot be repaired. Hair cells can be injured instantly by an intense blast of noise, such as the bang of a firecracker, or gradually from repeated exposure to excessive noise. Overexposure to noise also may cause tinnitus, a ringing, roaring, or clicking sound in the ear. Research also suggests that genetics may play a role in increasing a person's vulnerability to noise-induced hearing loss.

The campaign targets tweens because they are at an age when they are no longer little children, and they are beginning to develop a sense of who they are and what they like to do. Reaching them at this age, while they're forming attitudes and habits related to their health, will help them understand that healthy hearing habits will benefit them for a lifetime.

The Noisy Planet campaign advocates three ways to prevent NIHL:

- Block the noise by wearing earplugs or protective earmuffs, like those used by airport or lawn service workers.
- Avoid the noise by walking away or limiting time spent in noisy environments.
- Turn down the sound on the growing number of tools, toys, and gadgets that add to the increasing noise level of daily life.

Information on NIDCD's Noisy Planet campaign is available at www.noisyplanet.nidcd.nih.gov.

NIDCD, which celebrated its 20th anniversary in 2008, supports and conducts research and research training on the normal and disordered processes of hearing, balance, smell, taste, voice, speech and language and provides health information, based upon scientific discovery, to the public. For more information about NIDCD programs, see the Web site at www.nidcd.nih.gov.

The National Institutes of Health—*The Nation's Medical Research Agency*— includes 27 institutes and centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

National Institute on Deafness and
Other Communication Disorders
National Institutes of Health
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Bethesda MD USA 20892-2320
E-mail: nidcdinfo@nidcd.nih.gov

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An advertisement for WebCapTel by Sprint. The background is dark with a woman in a blue shirt talking on a mobile phone. In the foreground, a laptop screen displays a website. Text on the ad includes: "WebCapTel®", "Sprint", "www.sprintcaptel.com", "Click. Listen. Read. Talk.", "It's that simple!", "Start today and enjoy telephone communication over the web with ease!", and a small note at the bottom right: "WebCapTel is a registered trademark of Ultratec, Inc."

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PRESIDENT'S MESSAGE

Happy New Year! I hope everyone had a wonderful holiday spending time with their families and friends and giving to one another.

Let me introduce myself in case you don't know me. I have had a progressive sensorineural hearing loss for over 50 years. Currently, I wear a hearing aid and a cochlear implant. These wonderful technologies have allowed me to continue to function in this hearing world and work full time as a Registered Nurse.

As our country moves into a transition period with a change in government and the onset of difficult economic times, we must change too. Our main focus is to streamline our energies to make the best use of the resources that we have available. One of our goals is to see increased focus on high school age and young adults with hearing loss who need support during their transition to college and/or workforce. Another is to improve awareness of hearing loss issues. I see the *Walk4Hearing* as a great way to increase our visibility and hope that each of you contributes in some way or another.

As you see, there's a full plate to meet these challenges. I hope that each of you participates in some fashion to help us achieve our goals.

Pam Foody

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HLAA-NYS ELECTION RESULTS

At the board meeting on Saturday, November 1, 2008, the following new officers were elected for a one-year term from January 1, 2009 to December 31, 2009:

President	Pam Foody
Vice President	JoAnne Spoto-Decker
Secretary	Vivien Maisey
Treasurer	Sue Miller

On Sunday, November 2 at the annual meeting, the following members were elected to the board for the classes as indicated:

Class of 2009	Mary Fredericks
Class of 2010	Anne Pope
Class of 2011	Florence Butler Suzanne Jeffery Vivien Maisey

The new nominating committee is as follows:

Karen Ratner (Chair)	Melanie Brand
Florence Butler	Dan Farfaglia
	Pat Mirza

There are vacancies on the board for 2010 and 2011. Requirements to be a board member are: one must live in New York State, have email, and be a member of the HLAA national organization. The board meets three times a year in winter, summer and fall, in Albany.

Anyone interested in joining the board, should please email Karen Ratner at kkratner@aol.com.

**Melanie Brand, Chair
2008 Nominating Committee**

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INAUGURAL NEW YORK CITY WALK4HEARING

It was a chilly, crisp but sunny morning on Sunday, October 19, when 450 walkers huddled together around the microphone and CART provider, Lauren Schechter, (whose fingers were freezing). Anne Pope, HLAA's Immediate Past President, introduced the festivities, Brenda Battat, HLAA's Executive Director, thanked all our national Walk sponsors, then I thanked our 54 teams for their stupendous fundraising, bringing the total funds raised to just over \$124,000. "Mr. G," weather forecaster for WCBS-FM radio and WPIX-11 TV station, called in a TV crew to cover our Walk. Our fall-colored balloon arch swayed in the wind, and we wore the wonderful golden *Walk4Hearing* baseball caps donated by our chapter member, Lenny Kleiman. A sea of yellow-gold then walked 3.1 miles through lovely Riverside Park on the Upper West Side of Manhattan.

The inaugural NYC *Walk4Hearing* was indeed a momentous occasion. A small volunteer group from the HLAA Manhattan Chapter began this venture and with creative outreach, we found many corporations, hearing-related nonprofit organizations, foundations, college and hospital audiology departments as well as schools for the deaf and hard of hearing, all of whom joined us in raising money for our cause and walking with us. We made new friends who are committed to help raise awareness of hearing loss.

I know we will continue to do well with our future Walks but the first one is always the most memorable, and we thank all those who made it possible.

**Ellen Semel
2008 NYC Walk Coordinator**

See photos next page

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New York City Walk4Hearing Riverside Park, Manhattan | October 19, 2008

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- Top Row, L-R Start of Walk at the colorful balloons
Mr. G of WPIX TV and WCBS Radio with Anne Pope and Brenda Battat, HLA Executive Director
- Middle Row, L-R Registration table at entrance of park
Walkers enjoying the brisk day!
- Bottom Row, L-R Ellen Semel, with Lenny Kleiman, who donated the hats for the volunteers and walkers
Lauren Schecter, *Total Caption*, who provided captioning for the talks
Left to right: Michael Pope, videographer; Suzanne Ressa and Susan Shapiro

CART v. CAPTIONING - WHAT'S THE DIFFERENCE?

The terms CART and captioning are often used interchangeably. However, there are differences, which I hope to explain in this article, so that you will know exactly which service you need to request.

The acronym CART stands for Communication Access Realtime Translation. CART is when the spoken words are typed by a CART provider/stenographer on a stenotype machine which instantly, or in real time, translates into English words through a software program designed for translating the stenotype into English. Then the verbatim text is projected onto a laptop screen or large screen, if more than one person is viewing.

CART is used in the classroom environment on a one-on-one basis with students who are unable to hear the day's lessons. The CART provider sits with the student during class and produces a verbatim account of the words spoken, allowing the student to read along during class. The student is then given a text version of the day's lessons for storage on their own computer for review later. The benefit of a CART provider for the classroom/college setting is the student receives every spoken word in a text format which they can print and use later when preparing homework assignments or studying for exams.

CART is also used in the workplace, public meetings, courtrooms, the arts, theater, places of worship, or wherever access to the spoken word is required. CART in the theater is provided with a large LED panel projecting two or three lines at a time, which are lit with red lights for easy reading in the dark.

There is also a service called remote CART. This is the same as on-site CART, except that the CART provider and recipient are at different locations. The CART provider calls in to the client, establishing the audio connection. Those attending speak into microphones. Their speech is transmitted back to the CART provider, who types what is said and sends it over the Internet to a text-streaming host, who then sends the text to the client at their location via computer connections! There are still some glitches being worked out with interfacing computers and website connections, etc., but the technology is there to be used!

Captioning is different only in the venues where it is used. Television and broadcasting companies use a captioner to provide captions for TV programs, similar to subtitling in a movie. Captioning is provided the same way, with a stenographer typing the spoken words, except the software delivers the words through an encoder which then sends the signal to a decoder in the television which in turn, scrolls the English text line-by-line under the speaker on the television screen. Closed captions can be turned on or off at the desire of the user. Open captions, however, are permanently "burned" into the picture, and cannot be removed from the screen. Many movie theaters are now offering open-captioned movies.

Whatever your need, CART or captioning, now you know what to ask for when requesting accommodations. Many companies, courts, schools, etc., are not aware of what CART is and need to be educated by you, the consumer, when requesting the service. The National Court Reporters

Association (NCRA) has a directory of CART providers throughout the United States. Those providers must be members of the association and adhere to strict guidelines promulgated by the NCRA, including rigorous testing to achieve certification. You can find more information on their site, ncraonline.org, and look for the "Communities" tab and then the "CART" or "Captioning" links.

For more information about my services, I can be reached at CARTandCaptioning@gmail.com or 800.787.3376.

Renee D. Leguire, CSR, RPR, CRR
Certified Realtime Reporter

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DONATIONS

We are most appreciative of donations received during 2008. Thank you to the following donors for their contribution:

Lois Beadle | HLAA-Huntington Chapter | Mary Mazeau
Adrienne Mennis | Sal Parlato | Cynthia Reich
Mr. & Mrs. David Siegel | Mr. & Mrs. Vern Thayer

Donations allow HLAA-NYS to further its programs in providing education, support and advocacy to people with hearing loss in and around New York State. *Your dollars are at work for all who cannot hear well.*

See page 11 for information to send in your support.
Thank you!

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DID YOU KNOW?

The Consumer Product Safety Commission Modernization Act was signed August 14, 2008 — but does not take effect until February 2009. The Keenan's Kids Foundation estimates roughly 20 percent of toys currently on retail shelves will not pass the new safety standards. Toys that are still considered “safe” will soon be considered inadequate under federal safety standards.

Parents know their children best and always need to be looking out for their child's safety.

Item #7. Loud Sounds: High School Musical Rockerz

Item Description: The sound effects and riffs from original High School Musical soundtracks allow children to play along with the songs. Price \$14.99. Made by Disney. Age: 5+. Where you can find it: Target, Wal-Mart, Toys'R'Us.

HAZARD

- Sound toys over 85 decibels can be harmful to a child's ear development and hearing.

FACTS

- High School Musical Rockerz registered 90+ decibels and are an example of toys that can be harmful if a child is exposed to the noise for a prolonged time.
- More than 5 million children ages 6-19 have some degree of noise-induced hearing loss in at least one ear. (Source: National Center for Health Statistics, 2006)
- At 85 decibels, a child's hearing can be damaged when exposed for 8 hours; at 90 decibels it only takes 2 hours; and in mere minutes, hearing loss can happen with toys that register 97 decibels or higher.
- Noise specification standards were created in 2003, recommended at 90 decibels or lower, but they are not mandatory. Parents should screen a sound toy first, if it seems too loud and doesn't provide volume control, then it could be potentially dangerous.

Source: via Google Alert, *The 10 Most Dangerous Toys for 2008 - Greater Fort Wayne Family*, www.fwfamil.com, January 1, 2009. For more of this story, fwdailynews.com/articles/2009/01/01/family/front/hid114436sect_e161d9ca39b0e54534.txt

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TALKS TO BE PRESENTED AT FEBRUARY MEETING

(scheduled at press time, subject to change.)

Saturday afternoon, February 28

Ways to Improve Relationships between Professional Audiologists and HLAA

Presenter: Harriet B. Jacobster, AuD

This will be an interactive discussion allowing for audience input. Some of the issues planned to be covered are:

- What can we do to facilitate audiologists' understanding of the needs of the hard of hearing client beyond the sale of hearing aids?
- As a state organization, what can we do to help young adults learn to cope with hearing loss and advocate for themselves?
- How can we help the audiologist dispel the general notion that hearing loss treatment ends with the hearing aid?
- How can we - the professional and the hard of hearing person - work together to achieve our mutual goals?

If you have an issue that you would like addressed during this discussion, email Dr. Jacobster at hjacobster@aol.com.

Sunday morning, March 1

Postsecondary Education Programs Network - Northeast

***Presenter: Desiree Duda-Blumenthal
Outreach Specialist for New York***

PEPNet is a federally funded program with a regional office based at the Rochester Institute of Technology. Its mission is to improve transition services and educational access for students who are deaf or hard of hearing, including those with co-occurring disabilities, thus enhancing educational opportunities.

A major goal of HLAA-NYS coincides exactly with this mission, and we hope to form a valuable partnership with PEPNet.

Desiree will present valuable information on what services and resources are available, as well as best practices and strategies for HLAA to reach out to educators and to students. She will demonstrate an online database of colleges and universities which currently provide services, and a new online resource for instructors on how best to accommodate students with hearing loss; she will show extracts from the “Achieving Goals” DVDs, depicting individuals with hearing loss working in various occupations, and give us tips on encouraging students with hearing loss to form social networks and join support groups. These are exactly in line with some of the objectives identified at our Fall 2008 meeting, and PEPNet can be a useful source of shared information and ideas for addressing our joint concerns.

***Florence Butler
Chair, Leadership Committee***

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SUDDEN SENSORINEURAL HEARING LOSS - AN OTOLOGICAL EMERGENCY

Sudden Sensorineural Hearing Loss (SSNHL) has been recognized as an emergency since 1944 because it is potentially treatable, if therapy is started within a narrow window of a few days following the onset of the hearing loss. The patient may first notice a hearing loss, usually unilateral, appearing suddenly or gradually within a three-day period. Its presentation can be variable, with an acute hearing loss observed in about 50% of the cases seen. Sometimes the hearing loss is first noted upon arising or with attempts to use the telephone with the affected ear. The hearing loss may present intermittently over 72 hours. A sense of fullness or pressure may accompany the hearing loss, or may precede the hearing changes. Tinnitus (ear noises) may or may not occur with the onset of these symptoms. Dizziness, off balance, or vertigo may be seen with some patients with SSNHL.

These symptoms can overlap with those associated with non emergent problems, such as ear fullness associated with an upper respiratory infection (URI, common cold), ear wax, eustachian tube dysfunction/congestion after altitude changes seen with flying, middle ear fluid from allergies, middle ear infection (acute otitis media), temporomandibular joint problems, which can lead to delay in proper diagnosis of SSNHL. The patient may be screened over the telephone by a nurse, seen by a primary care physician, seen in the emergency room, all of whom may initiate treatment for these common non-urgent causes of ear fullness and hearing loss. If the patient has not benefited by the initial treatment(s), he may be then referred to a primary care physician, who might try treating a different non-SSHL diagnosis, which may further delay appropriate diagnosis of SSNHL another few weeks to months, before finally referring the patient to an otolaryngologist/otologist for a definitive evaluation along with audiogram.

We have found that SSNHL occurs in about 5 to 20 cases per 100,000 population per year. This translates to about 400-1,600 cases per year in the NY metropolitan region. It occurs equally in men and women, highest in the 43 to 53 year age range. The prognosis for recovery is less in the pediatric, geriatric populations and those with dizziness or vertigo. The spontaneous recovery for complete to partial hearing recovery ranges from 30 to 60%. There is poorer recovery of hearing with the more severe hearing loss, particularly with 90dB or more hearing loss.

Unilateral hearing loss makes it difficult to understand speech in background noise and impairs sound localization. Bilateral (stereo) hearing is needed to distinguish and understand speech in the midst of background noise and to locate from where a sound is coming. Psychological adjustment to the emotional trauma of this acute loss can take up to a year, even if the hearing does not return. Amplification with hearing aid or bone anchored hearing device (BAHA®) has been helpful for certain patients.

The cause of SSNHL is IDIOPATHIC (unknown), but most investigators feel that a virus causes it. In about 10 to 15% of cases presenting with sudden hearing loss, an alternative diagnosis is identified such as Meniere's disease, trauma, autoimmune disease, syphilis, Lyme disease, and inner ear membrane fistula (perilymphatic fistula). In 1% of the cases, the cause of the hearing loss may be acoustic Neuroma (brain

tumor), multiple sclerosis and stroke. If the cause of the sudden hearing loss is not identified, it is called idiopathic (unknown) sudden sensorineural hearing loss or, more commonly, sudden sensorineural hearing loss (SSNHL). As mentioned earlier, SSNHL is an otological emergency because it is treatable with varied degrees of success. The most common medication is a corticosteroid, usually prednisone, which is taken orally over ten days, best started within the first week after the onset of the hearing loss.

Data suggest that steroids improve the recovery rate for 68% compared to 30% of subjects if untreated. More recently, some studies suggest that direct injection of corticosteroids directly into the middle ear may be equally or more effective treatment without the potential systemic side effects of oral steroids. It is felt that injected steroids achieve a higher concentration of medication in the inner ear, where the affected auditory nerve endings (hair cells) are located. To evaluate this treatment for SSNHL, an NIH funded multicenter clinical trial throughout the country has been established to follow 254 subjects with either of these treatments: oral prednisone (corticosteroid) or middle ear injection of corticosteroid. The website for this study for more information is at www.suddendeafness.org.

Please see the entry criteria below:

SUDDEN SENSORINEURAL HEARING LOSS (SSNHL)

1. Adult men or women (18 years and older) with a history of normal hearing in both ears prior to symptoms.
2. Sudden hearing loss in one ear (muffled or absent hearing that occurred within a 1 to 3 day period).
3. Symptoms of hearing loss must be within the past 1-14 days - patients that have had hearing loss for longer than two weeks are not eligible.
4. Audiogram - thresholds of 50dB PTA or worse on the affected ear. The other ear should have normal to near-normal hearing.
5. No more than 10 days of treatment with oral steroids - ideally, we need patients who have received no therapy for this study.

We encourage referring physicians to not begin any treatment on patients who are sent to one of the study centers.

Any patients who do not fulfill our study criteria will be started on appropriate therapy and returned to the referring specialist.

By recruiting patients who have received no treatment prior to enrollment in our study, we can ensure that we collect the most accurate data about how patients respond to each of the randomized treatment arms.

If there are any questions, please contact Dorline Jean, RN at 212.263.7488 or at D.Jean@med.nyu.edu or Paul E. Hammerschlag, MD at 212.889.2600 or at PaulHammerschlag@nyumc.org

For other centers in other parts of the country, please go to www.suddendeafness.org.

Paul E. Hammerschlag, MD, FACS
Associate Clinical Professor
Dept. of Otolaryngology, NYU School of Medicine

* * *

HEARING LOSS ASSOCIATION OF AMERICA WILL CELEBRATE 30 YEARS IN 2009!

C'mon down to Nashville, the Capital of Country Music. Don't forget to register for this year's exciting event to be held June 18-21, 2009! The Gaylord Opryland Resort & Convention Center is the site for the largest and most accessible convention.

For details, schedules and to register, go to hearingloss.org/convention/. You will find all you need to know.

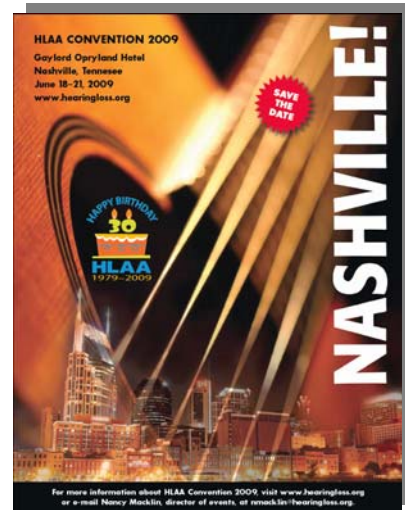
Highlights of the convention:

- **Research Symposium** – *An Update on the Latest on Hair Cell Regeneration Research*, sponsored by the Deafness Research Foundation
- **Opening Session Keynote Speaker** – Vint Cerf, Ph.D., one of the "Fathers of the Internet"
- **Exhibit Hall** – Myriad of vendors and the latest in hearing loss related assistive devices
- **Workshops** – many for young adults

Don't forget to register for Saturday at the Grand Ole Opry for an accessible performance (\$ ticket required.) If you plan to stay on after the convention, there are four additional tours (\$) scheduled on Sunday.

If you know a young adult who has never before attended an HLAA Convention, and has demonstrated interest in and is currently involved with hearing loss issues, why not nominate that person (you may also self-nominate) to be one of three persons to receive and share a Rocky Stone Scholarship to attend? Visit: www.hearingloss.org/convention/RSScholars.asp for the application and nomination forms.

Check it out. Go to the website and learn more about this exciting convention!



JOE GORDON RETIRES AS STATE CHAPTER COORDINATOR

After more than 12 years serving as New York State Chapter Coordinator, Joe Gordon has retired from this position effective February 1, 2009.

Joe has tirelessly dedicated his time to the development of the network of affiliates in the state of New York.

His services on chapter development will surely be missed by HLAA, but he will continue to be an active member.

Thank you Joe!

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PROFESSIONAL ADVISORS TO HLAA-NYS

Professional Advisors serve as consultants to the HLAA-NYS board of directors and its committees. They are individuals residing in New York State with expertise in their particular fields who can relate to concerns of people with hearing loss. Terms are for two years, with a maximum of three terms. Of a total of eight advisors, four are asked to serve each year, with terms being staggered in order to provide continuity.

Recommendations for new Professional Advisors may be made to the chair of the Professional Advisory Committee, Sue Miller at susanleemiller39@cs.com. The committee proposes a slate to the HLAA-NYS board for approval. The candidates are announced at the HLAA-NYS annual meeting held in the fall. Service officially begins the following January.

Many thanks to Mary Beth Barber-Mothersell, LMSW; William H. Shapiro, M.A. CCC-A; Cathy M. Thornton, Prof.; and Robert F. Zogas, Esq., who served during 2007-2008.

Below is the current roster for 2008-2009:

James J. DeCaro, Ph.D.

Director, PEN-International
National Technical Institute for the Deaf, RIT

Marcia B. Dugan

Past President of HLAA National Board of Trustees
Former Director of public affairs at NTID/RIT in Rochester
Author of *Living with Hearing Loss*
Gallaudet University Press, 2003

Paul E. Hammerschlag, MD, FACS

Associate Clinical Professor, Dept. of Otolaryngology
New York University School of Medicine

Joseph J. Montano, Ed.D.

ASHA Fellow
Assistant Professor/Director of Hearing and Speech
Weill-Cornell Medical College/NY Presbyterian Hospital

Sue Miller
Chair, Professional Advisors Committee

* * *

Hearing Loss Association of America 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 through information, education, support and advocacy.

7910 Woodmont Avenue - Suite 1200 • Bethesda MD 20814
301.657.2248 V • 301.657.2249 T • Fax: 301.913.9413

website: www.hearingloss.org / **email:** info@hearingloss.org
travel site: www.HLAATravel.org

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Winter 2009

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website: www.hlaa-nys.org

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UPCOMING EVENTS

Feb.28-Mar. 1, 2009

HLAA-NYS Board Meeting

Hotel Indigo
254 Wolf Road
Albany NY
518.869.9100

~ WALK4HEARING ~

May 2, 2009

Westchester/Mid-Hudson | FDR Park, Yorktown Heights

May 3, 2009

Rochester | Perinton Park

Fall 2009

New York City | Riverside Park

June 18-21, 2009

HLAA Convention

Gaylord Opryland Hotel
2800 Opryland Drive
Nashville, TN 37214

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