

Hearing MAGAZINE Loss

July/August 2008

En pointe with
Alexa Vasiliadis

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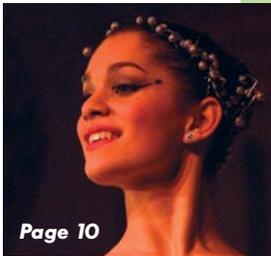


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July/August 2008



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COVER: High school student and dancer Alexa Vasiliadis. Photograph by Cindy Dyer.



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In 1979, Rocky Stone founded the organization as Self Help for Hard of Hearing People (SHHH).

The thinking behind the self-help philosophy for SHHH was to enhance each of us as human beings. Hearing loss was an important but secondary consideration. Once we accept responsibility for ourselves, we have to learn to love ourselves, and then, each other. —Rocky Stone

CONTRIBUTORS

Brenda Battat is executive director, Hearing Loss Association of America.

Andy Bopp is director of regulatory affairs, Hearing Industries Association.

Barbara Liss Chertok is a member and writer from Sarasota, Florida.

Barbara Kelley is deputy executive director and editor-in-chief, Hearing Loss Association of America.

Kathleen Galvan is a member from Dallas.

Lise Hamlin is a director of public policy and state development, Hearing Loss Association of America.

Robert Labadie, M.D., Ph.D., is associate professor of otolaryngology-head and neck surgery at Vanderbilt University.

Anne T. Pope is president of the board of trustees, Hearing Loss Association of America.

Mark Ross, Ph.D., is an audiologist and associate at the Rehabilitation Engineering Research Center (RERC) at Gallaudet University, Washington, D.C.

Eddie Sierra is a person with hearing loss from Miami.

Alexa Vasiliadis is a high school student from Great Falls, Virginia.

Lynne Vasiliadis is the mother of a teen with hearing loss.



7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814
301/657-2248 Voice
301/657-2249 TTY
301/913-9413 Fax
www.hearingloss.org
info@hearingloss.org

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Katie Barnett Colleen Reeping
Cheryl McKenzie Rachel Trask
Barbara Miller

Academy Curriculum Consultant

Scott J. Bally, Ph.D.

Hearing Loss Association of America Washington, D.C., Area Office Volunteers

Billie Ahrens Jeannette Kanter
Bob Benson Joan Kleinrock
Christie Berner Linda Katz
Manell Brice Willie Kleppinger
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Graphic design by Cindy Dyer/Dyer Design

For advertising information, contact Christopher Sutton at csutton@hearingloss.org.

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By Brenda Battat

Going to College with a Hearing Loss



From the Executive Director's Desk

The college application process can be stressful for anyone but even more so for students with disabilities. Students with disabilities, whether seniors in high school or older students returning to school, often select mainstream colleges for their education. This is the result of more appropriate hearing aids, a plethora of assistive devices, the rising popularity of implantable devices, and disability rights laws. Further, the first generation of children implanted with cochlear implants as toddlers are now in their college years and they are just the beginning of a rapidly growing wave.

The transition from the school environment where the Individuals with Disabilities Education Act (IDEA) guarantees an education as a right, to one in which nothing is guaranteed in college, can be extremely challenging for students. In a mainstream college, the only law is one that requires that individuals put up their hands, identify themselves and request the communication support they need. There is no such thing as postsecondary "special education."

Too often, young adults do not request needed accommodations or even disclose their hearing loss. Parents often take the lead in advocating for their children's educational rights in primary and secondary schools. As a result the young adult may lack the self-advocacy skills, assertiveness, and knowledge about technology that can benefit them in the classroom. Older returning students may not be familiar with the technology that is available to help them. I went back to school in my mid-forties (pre-ADA) and used an FM system in all my classes. Without this assistive listening device, I would not have gotten my master's degree.

Consequently, the transition to college may turn out to be an unnecessarily difficult one with the worst-case scenarios of semesters missed due to lack of communication supports, to scenarios of the stress of working double time to keep up with their peers who do not have hearing loss. Further, in a mainstream setting, students with hearing loss lack interaction with other young or older adults with hearing loss to share and exchange information and ideas. It can be a lonely experience.

HAAA and other organizations have helpful resources to cope with entering college—how and where to research a college and the accessibility provided; what questions to ask; self advocacy skills; assistive technology for use in the classroom, on campus and off; legal rights; working with the disability services office; guidance for parents on letting go; interview practice and role playing; seeking a mentor; and building relationships with faculty, among other things.

Our cover story this issue features Alexa Vasiliadis, a lovely, talented, confident high school junior who wears a hearing aid. Alexa is not timid about telling people about her hearing loss and asking others to repeat or advising teachers how to communicate with her. She is just starting her research to choose a college. We will try to keep up with her and see what she decides and what her experiences are when she gets there. Meanwhile, enjoy the story and photos. 

Brenda Battat is executive director of Hearing Loss Association of America. She can be reached at Battat@hearingloss.org.

For More Information

How to Get the Most Out of College
www.hearingloss.org/docs/Get_the_Most.pdf

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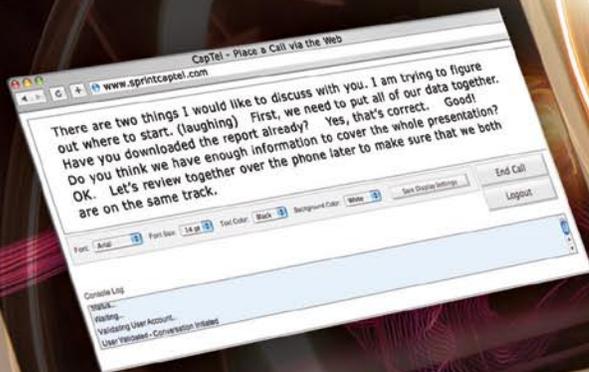
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By Anne T. Pope



President's Message

Anne Pope hands over the presidential gavel.

This is my last president's column. Every two years, once the convention has ended, a new president of the Board of Trustees takes office. As each of us who has been elected knows, holding this office is not only an honor and a privilege, but in many ways rewarding. So in this last column I want to say thank you to all for your part in helping the Hearing Loss Association thrive.

First, thank you to all of our members. During the past two years, I have met and heard from thousands of you. I am impressed, each time (whether we agree or not!), with your dedication, your loyalty, and your determination to forge a better world for people with hearing loss. I have seen and learned about myriad things chapters and state organizations are doing. Not only are there regularly scheduled monthly education and support programs, there are also special efforts; educational outreach within the larger community, advocacy campaigns, workshops, conferences, scholarship programs for college bound students, special grants, educational literature, library subscriptions to the magazine, and the list goes on and on.

Members working harder than they ever dreamed possible have expanded the *Walk4Hearing* from a small experimental pilot program to a major event that carries our message to hundreds of thousands of people. You do extraordinary work.

Next, I would like to thank the staff. As I'm sure anyone reading this column knows by now, we have only a tiny staff in the Bethesda headquarters office. Even so, they do great things. Under the leadership of Executive Director Brenda Battat, this small but excellent staff is bringing new meaning to the phrase "doing a lot with a little." Brenda, of course, has known the organization for many years. Yet, she is looking at it with fresh eyes, examining every program, moving energetically to create partnerships and alliances, and thinking of new and creative ways to accomplish our mission. The whole staff is moving forward with energy and enthusiasm. I am so very grateful that Brenda agreed to take on our challenge. What she and the whole staff are doing is amazing.

I would also like to thank the Board of Trustees for their hard work and dedication. Board members volunteer substantial amounts of time and, because of the organization's limited funds, we pay our own expenses. Myths swirl around the workings of the board although there isn't anything very mysterious about us. We work hard at carrying out our responsibility to ensure the future of the organization. Anyone is welcome to come to any board meeting either in Bethesda or at the convention—and I hope you do. You will find us a highly committed group.

This June, I am delighted to be turning over the gavel to Michael Stone, Esq. Michael has long been a part of our wonderful organization. A son of our founder, Rocky Stone, Michael was an office volunteer early on and also served on the first board when our organization was called Self Help for Hard of Hearing People. He has the strong Stone family love for, and commitment to, the organization. In addition, Michael brings to the president's position broad experience that will serve the Hearing Loss Association well. He has worked in various capacities in both the public and private sectors and brings an understanding of the needs of business as well as the workings of government. As we all know, a non-profit, in today's world, has to combine the best traits of both sectors in order to survive. Michael is an excellent person to lead the Hearing Loss Association into its next phase.

At the end of my term, I am filled with optimism for the Hearing Loss Association and its future. And for that, I thank each and every one of you again. Nowhere is there a group of people with more determination. Nowhere is there an organization with members more passionate about its mission. Nowhere is there any other group doing what we are doing. ■■■■

Anne T. Pope was president of the Board from 2006 to 2008. A slate of new officers will be published in the September/October Hearing Loss Magazine.



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*Intelligence, beauty,
talent, confidence,
and a hearing loss...
all in one graceful
package.*

By Barbara Kelley

Alexa Vasiliadis

Alexa Vasiliadis is 17 and a junior at Langley High School in McLean, Virginia, where she is in advanced placement classes. She is a member of both the National Honor Society and the Spanish Honor Society. She enjoys art—especially painting—and her subjects tend to be dance-related or portraits of family members.

Outside of school, she studies dance at the Classical Ballet Academy of Northern Virginia and participates in approximately 25 hours of dance per week (including both classes and rehearsals Monday through Sunday). She takes classes in ballet, pointe, partnering, character (Russian folk dancing), modern, and jazz.

Alexa has one younger brother, Austin, who is an eighth grader at Cooper Middle School in Northern Virginia. She says she is very fortunate to live near both sets of grandparents, two aunts and uncles, and nine cousins!

We first heard of Alexa last December when she was dancing in a performance of the Nutcracker Ballet by Tchaikovsky. Our photographer, Cindy Dyer, got a back stage and front-row view through her camera lens and captured Alexa on these pages for you.

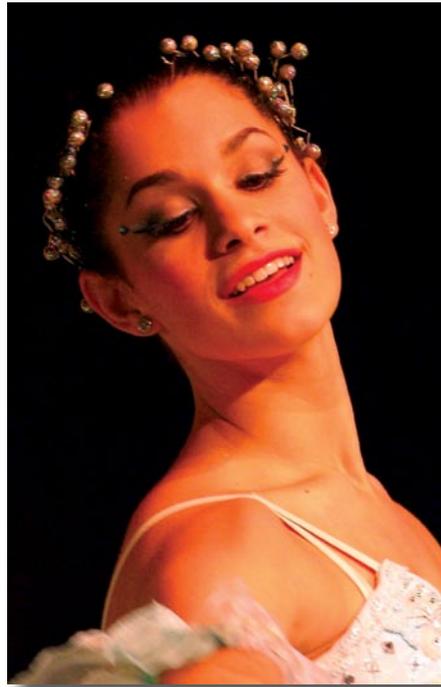
Alexa and her mother, Lynne, were generous to share their time with us. This young woman carries no light schedule with her studies and dance, in addition to a bustling family life.

We hope you enjoy Alexa as much as we enjoyed meeting and photographing her. And, we hope to check in with Alexa as she transitions from high school to college.

Talking with Lynne (Alexa's mother)

Hearing Loss Magazine (HLM): Lynne, how did you first learn that Alexa had a hearing loss?

Lynne: Alexa was born in 1991, which was before hospitals began routine and sometimes mandatory audiological screening for newborns. We first discovered Alexa's hearing loss when she was three-and-a-half or four years old. Her father called from work to say hello and when Alexa answered



My hearing loss is something I am accustomed to, as it is all I have ever known. I am not self-conscious about it and do not feel negatively toward it at all.

the phone, she was unable to hear his voice. I happened to have another receiver close by and was able to hear him clearly, so I suggested that she switch the phone to her other ear. She could then hear what he was saying and it was at that moment that I knew there was a problem.

Looking back, we had always had considerable difficulty communicating in the car with her. I later realized this was because she was sitting behind me in her car seat and was unable to read my lips when I spoke. As she was my first child, I assumed our difficulty communicating in the car was normal toddler behavior, and because her speech had developed normally, it never occurred to me that it could be anything else.

HLM: What did you do next?

Lynne: After the phone incident, my husband who is a physician recommended that I take her to see

Dr. Ted Fetter, an otolaryngologist in Vienna, Virginia. After an examination, he referred Alexa to his audiologist, Cheryl Rice.

Alexa was diagnosed with bilateral hearing loss—a mild loss in her right ear and moderate loss in her left. The audiologist explained that the type of loss which Alexa presented could be a genetic defect, something that developed in utero, or the result of a prior ear infection.

We scheduled her for ear drum tubes and made an appointment for her to be fitted with a hearing aid. I remember her preschool teacher at the Nysmith School being very surprised at the news of her hearing loss. Even at a young age, Alexa was a very good student and had apparently learned to adapt to her environment, relying heavily on lip-reading.

In first grade, she went to Great Falls Elementary, and in third grade, she was accepted into Fairfax County's Gifted and Talented Program. On a number of occasions, I inquired about arranging for services for Alexa, but because she was a successful student, I was told she was ineligible.

HLM: How did you feel when you heard the diagnosis?

Lynne: I remember the day the audiologist broke the news regarding Alexa's hearing loss. Every parent wants his or her child to be healthy and happy and to have every possible advantage in life. Hearing loss was unfamiliar territory for me; the news brought with it a multitude of feelings...surprise, sadness, uncertainty, disbelief and worry.

After coming to terms with the diagnosis, I was determined to help Alexa view her hearing loss as matter-of-factly as possible. I hoped that over time she would equate wearing a hearing aid to someone wearing glasses for poor eyesight or braces for crooked teeth and not something to be embarrassed about or uncomfortable with. (Although hearing aids don't "correct" hearing, it was the most useful analogy I could come up with.)

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"I love any opportunity to perform, so any role—no matter how big or how small—is a role I look forward to dancing."



© Cindy Dyer

En Pointe *continued from page 11*

HLM: How did your toddler react to getting a hearing aid?

Lynne: Most young children are curious and uninhibited by nature; so Alexa had to learn early on how to explain, 'that thing' in her ear and what its purpose was. It was important that she be confident enough to handle this type of attention on her own. Discovering Alexa's hearing loss at such an early age was a blessing because it is all she knows; and wearing her hearing aid is just part of her daily routine.

Talking to Alexa

HLM: When did you become interested in ballet?

Alexa: I started taking dance classes in kindergarten, but by the time I reached third grade I decided to focus on piano and soccer. Soon after, I realized how much I missed dancing, and decided to start it up again. However, this time I took mostly jazz and modern with a little ballet.

It was not until my first year of high school that I really became serious about my ballet training. Since then I have been taking ballet classes Monday through Friday for at least two hours each day (sometimes three), and supplementing this training with modern, jazz, character (Russian folk dance), conditioning, partnering, and Pilates; each once a week. Rehearsals are on Saturdays and Sundays and we have two productions a year in addition to multiple community service events.

HLM: Do you wear hearing aids?

Alexa: I wear one hearing aid in my right ear. I also have hearing loss in my left ear but it is mild enough that I feel a hearing aid is unnecessary.

HLM: Does having a hearing loss come into play with your dancing?

Alexa: Hearing loss does not have a significant effect on my dancing. However, it does force me to be much more aware of my surroundings and

the people dancing near me. Hearing the music is rarely an issue, because it is usually fairly loud. However, I do have difficulty hearing my teachers' voices and understanding if they are speaking over the music.

During rehearsals when there are multiple instructors in the studio it can be very difficult to differentiate who is speaking to whom when corrections are being given simultaneously. This is especially true when the music is playing and I am dancing since I prefer to look at the person speaking to me.

Occasionally I will have to ask the teacher to repeat a correction or comment. Like in school, if I have a new teacher. For example, when I go away for summer programs, I must inform them of my hearing loss. However, this does not present too great of a problem overall.

HLM: What has been your favorite role you've danced? Is there any role you hope to dance in the future?

Alexa: I've danced many roles that I've enjoyed, but one of my favorites was dancing the role of Snow Queen in the *Nutcracker*. I love any opportunity to perform, so any role—no matter how big or how small—is a role I look forward to dancing.

HLM: Do you know other people your age with hearing loss?

Alexa: One of my friends from dance does have hearing loss, but she does not wear a hearing aid.

HLM: Please tell us about your hearing loss.

Alexa: My hearing loss is something I am accustomed to, as it is all I have ever known. I am not self-conscious about it and do not feel negatively toward it at all. Sometimes, if I am meeting a person for the first time, they won't notice I have a hearing loss. If I find myself repeatedly asking them to speak up, I will then explain to them the reason. My hearing loss does force me to pay very close attention to what people are saying to me. I sometimes get frustrated when

I cannot hear someone in a noisy or crowded situation, or if they are speaking softly in my 'bad' ear.

The cafeteria at school can be very noisy and a difficult place to communicate which is frustrating because for most people, lunch time is a great opportunity to socialize with friends. However, I am used to my condition and my friends, family members, and peers know that if I cannot hear them they will have to "switch sides" or I will turn my head so they can speak on my left side.

One more scenario that is difficult for me is in the car, especially if I am driving or sitting in the back of the car and there is loud music playing or it is windy. This is because in addition to the added noise, I cannot see who is talking, and I often subconsciously rely on reading lips.

I am used to the difficulties that come with hearing loss, and often forget I even have hearing loss. I feel that it is a part of who I am, but it does not define me.

HLM: Do you use any assistive devices in the classroom? Do you have to educate teachers about how to communicate with you? Do you have an IEP (Individualized Education Plan)? Have you had to advocate for yourself to get the type of communication help you need?

Alexa: In school, I do not use any assistive devices or have an IEP. At the beginning of the school year, I always make sure to inform my teachers of my hearing loss and what it entails. I often will not have any trouble

Sometimes, if I am meeting a person for the first time, they won't notice I have a hearing loss. If I find myself repeatedly asking them to speak up I will then explain to them the reason. My hearing loss does force me to pay very close attention to what people are saying to me. I do sometimes get frustrated when I cannot hear someone in a noisy or crowded situation, or if they are speaking softly in my 'bad' ear.

hearing a teacher, especially if I am in a small classroom and his or her voice carries well. However, in the event that a teacher is very soft-spoken, mumbles, or there is lots of excess noise, I may have to sit in the front of the classroom.

Acoustics—air conditioning vents, computer buzz, and open doors—sometimes present a problem but I am never hesitant to ask a teacher to repeat something if I missed what was said. However, with hearing loss, if you miss something, sometimes you don't always realize it. Overall, I think that communicating with me is just like communicating with any other student.

HLM: Do you know about Vocational Rehabilitation?

Alexa: No, I'm not familiar with it.

HLM: What are you most looking forward to in the next year?

Alexa: Being a senior!

HLM: Have you thought about your choice of a college yet?

Alexa: Since I am a junior, I have really just begun the whole process. I have visited a number of Virginia schools as well as a few out-of-state schools. I am currently in the process of researching schools to try to figure out where I want to apply.

HLM: How do you research colleges?

Alexa: I have been researching colleges via websites such as Princeton Review, College Board, and Family Connection (a college database provided by my school). I have also done some college visits and attended the informational meetings and campus tours. It has also been helpful to talk to my friends who are seniors and learn from their experiences.

HLM: In your research, have you looked into communication access on the campus? In classrooms, dorms, fire alarms, phones? Have you checked out colleges with disability services departments?

Alexa: No, I haven't.

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Alexa's favorite role was that of the Snow Queen in the Nutcracker.

En Pointe *continued from page 13*

HLM: What do you plan on studying in college?

Alexa: As of now, I am undecided. However, I am considering nutrition, exercise science, physical therapy, and psychology. I also really enjoy art, languages, and working with people (especially kids), which may lead me to another area of study.

HLM: Any other hobbies? Favorite movie? TV shows?

Alexa: I like to paint in acrylic—most portraits. I have painted my family. I like to go to the movies. *A Walk to Remember* is one of my favorites. We use TIVO Because I never have time to watch shows when they're on. My favorites are *So You Think You Can Dance*, *American Idol*, and *Gray's Anatomy*.

HLM: What are your plans for this summer?

Alexa: I will be attending a six-week summer intensive program at the Houston Ballet's Ben Stevenson Academy.

HLM: Will you continue to dance?

Alexa: Yes, as long as my body allows. It's what I love! 🎭

Barbara Kelley is editor-in-chief of Hearing Loss Magazine and deputy executive director of HLAA. She can be reached at bkelly@hearingloss.org.

*Hearing Loss Magazine would like to thank the Classical Ballet Academy in Northern Virginia for allowing us to photograph *The Nutcracker* performance in December, as well as use of the studio for additional photographs. Visit CBA's website at www.cbanva.com.*



Alexa with her mother, Lynne

HLAA Initiates Meeting with Surgeon General on Issue of Hearing Loss

May 12, 2008, Washington, D.C.:

Brenda Battat, executive director of Hearing Loss Association of America, and members of six other organizations met with Acting Surgeon General Steven K. Galson to talk about the need for more public education about hearing loss. The group stressed the need to start a public dialogue about the causes, impact on physical and psychosocial well being of untreated hearing loss, treatment options available, and the need to protect hearing from noise. There are 31 million Americans with hearing loss with 10 million resulting from noise exposure that could have been prevented but cannot be reversed.



From left, back to front: Karen Sealander (International Hearing Society), Barbara Raimondo (National Association of the Deaf), Alex Graham (A.G. Bell Association), Rear Admiral Steven K. Galson, acting surgeon general, Andy Bopp (Hearing Industries Association), Brenda Battat (HLAA), Pam Mason (ASHA), Phil Bongiorno (American Academy of Audiology), Joy Trimmer (American Academy of Otolaryngology-HNS), and Rear Admiral Robert C. Williams, acting deputy surgeon general.

FULL PAGE

HAMILTON CAPTEL

Can You Find Your Way Around a Website?

By Kathleen Galvan

Access

It is HLAA's goal to make www.hearingloss.org completely accessible to people with all disabilities. Currently, the home page is accessible. Kathleen Galvan knows the issues and shares them with us to create awareness and to help people who are currently constructing websites.

In the past decade, the web has rapidly changed our way of life and has become our primary way of obtaining information. Many of us now wonder how we ever lived without it. Instead of going to the library and spending a whole afternoon researching a topic, I now sit down in front of my computer in the comfort of my home and Google.

I have the information at my fingertips. If I need to share the information with someone, I open my e-mail and a few clicks later, my mission has been accomplished. And instead of going shopping, I type in a web address and do my shopping online.

Unfortunately, much of this information and the ability to conduct business online is not available to those with hearing loss, vision and mobility disabilities, seizures, learning and cognitive disorders, as well as other disabilities. As a result, the ability for disabled people to obtain the needed information and conduct business online is limited.

People with Hearing Loss

For example, people with hearing loss find many news sites frustrating, as many of the videos are not captioned. My former colleague, who is color blind, has a rough time navigating web sites when colors are used alone to convey information. Another friend of mine who is blind and losing her hearing runs



for People with Disabilities

into problems when no keyboard alternatives to the mouse are available and when pictures are not labeled.

Yet another colleague who cannot use his hands cannot navigate many websites, as they are not designed to take voice commands. Another older friend of mine finds it hard to read websites that do not have the option of easily enlarging the text.

I've never known someone with photo epileptic seizure disorder, but I do know that they cannot visit any site with flashing objects, visual strobes, and in many cases, animation, as these sites can cause them to have a seizure.

Universal Appeal

An accessible website not only helps people with disabilities, but also those who have no disability, such as those who have dial-up or other slow Internet connections. Web accessibility makes a site more usable for those with a temporary disability, such as a broken wrist or recent shoulder surgery.

A usable website can help our parents and grandparents who cannot use a mouse due to arthritis or because the eyes and hand will not cooperate with each other.

Tips

The following is a list of a few important "tips" from the World Wide Web Consortium web site (www.W3C.com). This list is not all-inclusive, as it would take several pages to list all the criteria and explain why those criteria exist.

For more information and details, please go to their checklist at <http://www.w3.org/TR/WCAG10/full-checklist.html>.

1. Ensure that there is a "skip to content" link in the header (you can create the link with a



small font in the same color as the header), which skips to the main content. This way the blind person does not need to read the header each time he goes to your page.

2. All pictures and image maps should have alternative text (alt-text). I create a separate section on the page or another page for image maps.
3. Provide descriptions of video for visually impaired people and captioning of transcripts of audio for people with hearing loss.
4. For hyperlinks, avoid using "click here" or other descriptions that cannot be understood outside of the context.
5. Do not use tables for layout. They confuse readers for the blind. Use Cascading Style Sheets (CSS) instead. CSS not only makes a site more accessible, but it also makes it easier for the designer.
(If you have any questions about how to use CSS, please feel free to contact me.)
6. Use relatively sized fonts (small, medium, large, percent) instead of absolute font sizes. This will enable people with vision loss to use the control key and the up arrow key to enlarge the font.
7. Summarize graphs and charts on the web page or use the

longdesc attribute to describe it for blind people.

8. Ensure that all applets, plug-ins, and scripts will work if they are turned off or not supported. If they will not work, provide a separate page with content only.
9. Label frames and use the noframes element.
10. Ensure that your content is written in plain and simple language and is broken up into manageable chunks with appropriate lists, headings, and sub-headings.

Tools

There are many accessibility tools on the market, but the one I like best for small websites is *Bobby*. (For a complete list of these tools, see <http://www.w3.org/WAI/ER/tools/complete>).

However, there is no accessibility tool that can be used without human judgment. All of the tools will catch some things, but they cannot check to ensure how the content is presented. For example; they may catch the lack of a summary for a table, but they can't provide the summary itself.

The Hearing Loss Association of America is committed to making its national website accessible to all. It is my ardent wish that some day all websites will be accessible to everyone. ♣♣♣

Kathleen Galvan is a management information specialist and an HLA member from Dallas. She can be reached at Kathleen.Galvan@att.net.



In 1979, retired CIA agent Howard “Rocky” Stone founded SHHH—Self Help for Hard of Hearing People—because he believed people with hearing loss should have the chance to live independently despite their “invisible condition,” as he liked to call it.

Twenty-nine years later with its thousands of volunteers, 200 chapters and 14 state organizations, HLAA is perfectly positioned to reach the estimated 31 million people with hearing loss in the United States.

Brenda Battat was born and raised in England where she received a degree in physical therapy. She lived and worked in England, Canada, China and the United States, receiving a master’s degree in counseling from Indiana University.

Four generations of paternal hearing loss are responsible for Brenda’s own progressive sensorineural hearing loss. Brenda has worked in the National office of HLAA for 20 years in a variety of positions including acting executive director three times and advocacy director. She lives in Bethesda, Maryland, with her husband, Joe. They have a son and a daughter.

Barbara Chertok (BC): You have been offered the position of executive director in the past and refused. What prompted you to accept this time?

Brenda: HLAA needed someone who could hit the ground running and not take a year to learn the ropes. Some personal reasons are: I was ready; I never wanted to stop my advocacy work before; and I decided it was the right time to be the executive director.

BC: If Rocky Stone were alive today, how would he counsel you as you take over the reins of the organization he founded?

Brenda: I can hear him saying: “It’s the people that matter.”

BC: You have proven yourself to be a dedicated and skillful advocate.

From my perspective, stigma is related to how hearing loss is perceived: an inconvenience of old age. That is far from the truth. Hearing loss can happen at any age and it is showing up earlier and earlier. It is a health condition that needs attention, management, and also prevention.

—Brenda Battat

Were these traits you inherited from a parent, or ones that you developed?

Brenda: My mother in her heyday was a good communicator and not afraid to speak up. She is still not afraid to speak her mind at 91! My father was diplomatic. Advocacy is really about communication, education, and persistence with a strong dose of reasonableness. Perhaps I got something from both my parents.

BC: Your collaborative approach to advocacy has been successful for you. Which of your accomplishments are you most proud of?

Brenda: Working for over ten years with the wireless phone manufacturers, service providers and the FCC to ensure that people with hearing aids and cochlear implants can use these products and services. We negotiated for hours but have ultimately come up with a joint agreement that lays a solid groundwork for future advocacy work in this area.

I have been impressed with the industry’s willingness to put resources and time into making their handsets and services hearing aid compatible and the FCC’s commitment of ensuring that people with hearing loss have access to today’s and the future nationwide communication system.

BC: How closely will you work with the other organizations that focus on hearing loss?

Brenda: I will continue to work very closely with all the major hearing loss and disability organizations. Each organization has their own market niche and yet we all have overlapping issues and ultimately are working for the same cause.

BC: What do you feel is the most important piece of legislation currently awaiting approval by our government?

Brenda: There are three, for three very different reasons.

1. The ADA Restoration Act is to restore civil rights under the ADA for individuals being judged in the courts for not having enough disability to qualify for civil rights.

2. The 21st Century Communications and Video Programming Accessibility Act of 2007, which is a comprehensive legislative agenda to make sure that the next generation of communications services and products, including those provided over the Internet, do not leave people with disabilities behind. There is a report by Lise Hamlin in the National Update column in this issue.

3. The other is the Hearing Aid Tax Credit. This bill is a small step in the right direction. Even though it does not cover the full cost of hearing aids and does not include everyone, if passed, it would make a strong statement that Congress understands and takes seriously hearing loss and the needs of hearing aid users for some financial relief.

BC: How would you advise members of HLAA who would like to work more closely with their state and local government offices on issues facing people with hearing loss?

Brenda: Get to know your state legislators before an issue arises. Let them know hearing loss is an issue that you care about and want them to pay

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Our Own
Brenda Battat

Answers the
Call to Serve
as Executive
Director
of HLAA

*Brenda Battat talks about
the vision of the organization
and reveals a little of herself
in the process.*

By Barbara Liss Chertok



Brenda Battat *from page 19*

attention to. Form coalitions to get legislation passed.

BC: *Hearing Loss Magazine* Editor Barbara Kelley has taken over your former job of deputy executive director of HLAA? How will the responsibilities be divided?

Brenda: We are going to work it so that Barbara supervises program staff on a day-to-day basis and I am focused on fundraising, strategic alliances and direction. Barbara will also be here to support the staff while I am out traveling. But we are flexible, and I can see Barbara also being involved in strategy and fundraising—as I hope all staff will be in some way or another. I am delighted that Barbara agreed to come back into the office after eight years of telecommuting. Here since April 1988, she brings 20 years of valuable experience with HLAA and is as determined as I am about having clear-cut expectations and policies and procedures for staff. She is as committed to HLAA as I am.

Hearing loss is a health issue just like heart disease or diabetes. We should be checking our hearing regularly as part of good health care just as we check other parts of our bodies.

—Brenda Battat

BC: What do you feel are the greatest challenges facing people with hearing loss today?

Brenda: Negative stereotypes about hearing loss, stigma related to using hearing aids, and lack of access to technology because of cost and/or lack of coverage by insurance. This impacts every aspect of a person's life including social and economic.

BC: What do you feel is the most important issue we can educate the public about?



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HLAA announced the agreement with the wireless industry in June 2007. Back row, from left: Shelley Blakely, T-Mobile; Linda Kozma-Spytek, RERC Gallaudet; Scott Kelly, Motorola; Mary Brooner, Motorola; Jim Turner, ATIS; Tom Goode, ATIS. Front row, from left: Martha Ciske, ATIS; Karen Peltz Strauss, RERC Gallaudet/Trace Center; Harold Salters, T-Mobile; Brenda Battat, Hearing Loss Association of America; and Susan Mazrui, AT&T.

Brenda: Hearing loss is a health issue just like heart disease or diabetes. We should be checking our hearing regularly as part of good health care just as we check other parts of our bodies.

BC: The HLAA membership base appears to be comprised of older hard of hearing people who use hearing aids and/or cochlear implants. HLAA has begun to target professionals. What about parents, or will you leave that to the Alexander Graham Bell Association for the Deaf and Hard of Hearing?

Brenda: Actually, our critical mass of membership according to our 2005 member survey is ages 47 to 64. Not at all old by today's standards.

But we do have the reputation of being an older person's organization and it's hard to break. We do welcome more professionals to join us and hope they are inclined to refer their clients to HLAA.

I am also personally passionate about the transition stage for young people age 16 and up—going from high school to college. It's a time that can be confusing especially now that mainstreaming is so popular.

For now, I will leave children younger than that up to A.G. Bell because language development and education are very specific areas of expertise. But we do have the expertise to work with teens and young adults

and their parents at the stage leading up to college and beyond.

BC: What's the difference between ALDA (Association of Late-Deafened Adults) and HLAA? Is there a need for both organizations?

Brenda: ALDA seems to me to be a fit for those people who lose significant amounts of hearing later in life. Individuals who may not have developed coping strategies gradually over many years and who prefer to try their hand at using sign language as well as assistive listening devices. If ALDA attracts members, then, clearly, they are offering something that other organizations are not. I know they like to socialize.

BC: What is your vision for HLAA? Are there any big changes ahead?

Brenda: I have a two-year plan and a big vision for HLAA. We have not even begun to tap our potential. I want to work on eradicating the stigma of using hearing aids, have hearing loss be recognized as a health issue, and hearing aids not a luxury, but a medical necessity. I hope to bring my collaborative advocacy style to work with hearing aid insurance companies and open up dialogue with them.

We went to break into new sectors for sponsors of our programs. Aetna, the health insurance company,

has already become a national sponsor of our 2008 *Walk4Hearing*. Have a more open dialogue directly with our chapter members. Change the way we communicate on our website—have a more interactive system and customize how we deliver information to our supporters who use our website. Boost the information we provide about technology via our message boards, website, seminars, webinars—especially technology to use in the workplace.

I have a two-year plan and a big vision for HLAA. We have not even begun to tap our potential. I want to work on eradicating the stigma of using hearing aids, having hearing loss be recognized as a health issue and hearing aids not a luxury, but a medical necessity.

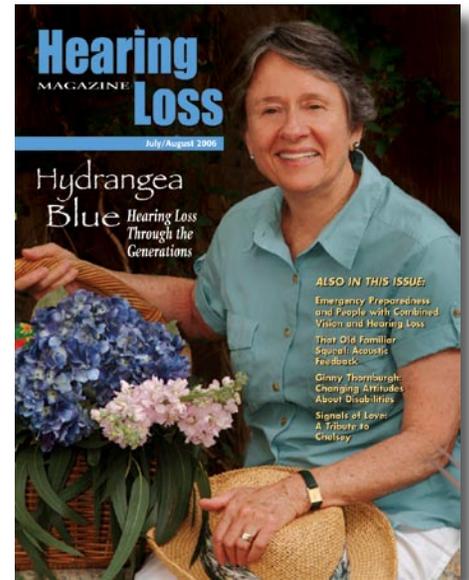
—Brenda Battat

BC: You have said you wish to develop sufficient financial resources to support the HLAA mission and program activities. HLAA raised its dues, yet they rank lower than most other organizations of its kind. Why?

Brenda: Membership dues are not going to support the revenue needs of this organization. The increase was voted on before I took over as executive director. I sense there was great hesitation about making the dues too expensive and excluding people who might not be able to afford more. But the fact is it was the first increase in over a decade and does not begin to cover the increase in cost of operating today. I am determined to get more supporters and members.

BC: What is HLAA doing to help eradicate the stigma attached to wearing hearing devices? People walk around with Bluetooth gizmos in their ears, while advertisements say, “With Brand X, wearing hearing aids will be your little secret.”

Brenda: The *Walk4Hearing* is going to impact the public’s perception of hearing loss and help to eradicate the stigma of using devices. There are 17 HLAA *Walk4Hearing* programs this year in 17 cities. We are committed to the walk for the long haul until it is known as a national *Walk4Hearing*—really known! That is why we are aggressively going after sponsors to have the resources to support our chapters who put on the walks—all volunteers—



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Brenda wrote about her sensorineural hearing loss in the July/August 2006 issue of *Hearing Loss Magazine*.

and get the word out about the walk and make it known nationally.

Walk4Hearing was the brainchild of our president, Anne Pope, and it will be her legacy after she completes her term of office this summer. We owe Anne a lot for persisting that we should start a walk and for the effort and resources she has devoted to make it a success.

I don’t think stigma is related necessarily to the size of the device. If you can wear a small device and if the device is suitable to your hearing loss configuration and can include all the features you need to function according to your lifestyle and listening needs, then why not get a small device? Get the hearing aid to best suit your needs.

From my perspective, stigma is related to how hearing loss is perceived: an inconvenience of old age. That is far from the truth. Hearing loss can happen at any age and it is showing up earlier and earlier. It is a health condition that needs attention, management, and also prevention. Noise-related hearing loss is preventable and ten million people today have hearing loss as a result of noise exposure. We have to get people comfortable with the idea of

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Left to right: Barbara Kelley (deputy executive director, HLAA and editor-in-chief, *Hearing Loss Magazine*), Ray Thorn (legislative assistant to Rep. Chris Van Hollen, MD, and co-sponsor of *The Hearing Aid Tax Credit*), and Brenda Battat (executive director, HLAA). Ray was profiled in the March/April 2008 issue of *Hearing Loss Magazine*.

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Brenda Battat

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checking their hearing in the same way that other health conditions are approached—mammograms, blood pressure, diabetes, etc.

BC: Culturally Deaf organizations such as the National Association of the Deaf has added “and Hard of Hearing” to its name. It often refers to “the deaf and hard of hearing who use sign language” when soliciting funds for its programs. What are your thoughts on this?

Brenda: HLAA, when it was SHHH, actually pushed to have the terminology divided up into ‘deaf’ and ‘hard of hearing,’ to bring attention to the different populations and their needs. This brought more awareness to the different needs but we still have a long way to go. The litmus test is *who* joins an organization. If you meet a certain constituent’s needs—no matter what you have in your title—they will join or support your organization.

HLAA does and has challenged organizations and companies when they give the impression that people who are hard of hearing use sign language. A small number learn it to have one more communication skill in their arsenal, but they are a very small minority and we have to represent the millions of people with hearing loss who don’t and probably never will use sign language.

I never thought I would enjoy the act of listening, but since my implant I do, and without straining with every cell in my body to hear. I can actually relax as I listen and so I feel as if I am not scrunching up my face as much in effort.

That has to keep the lines from forming, right?

—Brenda Battat



Left. Board of Trustees member, Dave Crocker, listens as Brenda Battat explains her vision for HLAA during a “meet and greet” function in Virginia.

BC: In your frequent interactions with legislators, have you met anyone with or without hearing loss with name recognition, whom you could solicit as a spokesperson or a board member for HLAA?

Brenda: Any connection to a spokesperson will be welcome! I am forming a Business Advisory Council (BAC) to be made up of business/industry leaders both inside and outside the hearing related fields to give me support and advice to help grow and strengthen HLAA, find new corporate supporters, increase networking opportunities and bring fresh perspectives and best business practices to HLAA. Donna Sorkin, vice president of consumer affairs, Cochlear Americas Corporation, has graciously agreed to chair the BAC.

BC: You were born in England. What brought you to America?

Brenda: I left England to travel for six months, starting out in Canada—the ‘Commonwealth’ for a Brit! I ended up working and staying for several years. After marrying, I spent time in China and then came to the U.S. (job related for my husband).

BC: Your son—but not your daughter—has inherited the family progressive hearing loss. Your hearing loss was not discovered until you were 19. Why so late, and did you get hearing aids at that time?

Brenda: My parents never got my hearing tested and at school I used to bluff hearing the watch ticking, which is the test they used. I always convinced myself that I would have heard it if they had just held it by my ear a bit longer.

I had a moderate loss by the time I was 19, and it was not recommended that I get hearing aids. I was told not to worry by a male ear-nose-throat doctor because I would still be able to hear men’s voices OK! I did not get hearing aids until well into my thirties.

BC: You returned to college for a master’s degree using a personal FM system in class to understand the lecturer and other students. Why do so few people with hearing loss today fail to make use of assistive listening devices?

Brenda: They don’t know about them.

BC: It took you five years to decide on a cochlear implant. After you were implanted, an article quoted you saying: "No one told me that implant surgery comes with a face-lift thrown in but that is how I feel." Tell us more.

Brenda: I never thought I would enjoy the act of listening, but since my implant I do, and without straining with every cell in my body to hear. I can actually relax as I listen and so I feel as if I am not scrunching up my face as much in the effort. That has to keep the lines from forming—right?

BC: Bilateral implants are becoming very popular. Have you given any thought to having your other ear implanted?

Brenda: Right now, I like using a hearing aid in the other ear. If I reached a point where I could no longer use a hearing aid, I might consider another implant.

BC: To date, three executive directors of HLAA have been cochlear implant (CI) recipients: Rocky Stone, Donna Sorkin, and you. To qualify as a candidate for an implant, a person's hearing loss must be severe-to-profound in both ears. Do you envision a time when our membership will be comprised of more cochlear implant users than hearing aid users?

Brenda: Everyone needs information when they first learn they have a hearing loss, no matter the degree of their hearing loss. But ongoing support, peer mentoring, in-depth information and strategies, legal rights—the kind of ongoing support that HLAA offers—is more likely to be attractive and needed by someone with more than just an early hearing loss.

Therefore, we have many members who come, get the information they need and leave to move on with their lives. That is success as far as I am concerned. But you also hope that you can provide ongoing help as

their hearing loss progresses or that they will want to stay involved in an organization that has given them help. Usually, it is individuals with more severe hearing loss that stick around, whether they use hearing aids or cochlear implants.

BC: Rocky Stone's legacy was 'self help for hard of hearing people.' Under your leadership, will HLAA following that same path?

Brenda: Self advocacy is very important to anyone with a challenge such as hearing loss. I believe strongly in personal responsibility and not just asking others to make things accessible without considering how we can help ourselves in different situations.

We have many members who come, get the information they need and leave to move on with their lives. That is success as far as I'm concerned. But you also hope that you can provide ongoing help as their hearing loss progresses or that they will want to stay involved in the organization that has given them help.

—Brenda Battat

BC: An estimated 58,000 military personnel will be returning from the war with hearing loss. Plus, there are thousands of musicians and baby boomers who have acquired hearing loss. Will their visibility lead to hearing loss becoming more accepted in our society?

Brenda: Possibly, although in all of these groups, there is not much motivation to publicize hearing loss. With returning military personnel there are other very pressing issues they will be dealing with. For example, more severe injuries such as loss of limbs and post traumatic stress disorder, so that hearing loss is likely to take a back seat at least for a while.

BC: Will there be a need for an organization like HLAA 25 or 50 years from now? If so, what would it be like then?

Brenda: As long as the technology still does not 'correct' hearing loss, there will be a need for an organization that provides information on self advocacy, strategies, available technology, etc. I hope by the time that voice recognition will have arrived at such a point where it will be instantaneous, that will have a tremendous impact for people with hearing loss. Also, noise cancellation has great promise. I also expect that the research that is going on with genetics and hair cell regeneration will have reached the next stage and offer solutions.

BC: Hearing loss can be painful at times, but it can be humorous as well. Can you share a humorous anecdote with our readers?

Brenda: While walking to work one day, my hearing went dead and I thought I had lost my implant processor only to find it dangling from my umbrella where the magnet in the head piece had attached itself to the metal frame. As I placed the processor back on my ear, I gave a sigh of relief and continued on my walk. 🎧🎧

Barbara Liss Chertok was suddenly deafened in 1957 at age 21 due to an autoimmune disease, and received a cochlear implant 41 years later. She is a former lip-reading/speechreading teacher. A freelance writer, her articles appear regularly in hearing loss journals. She serves on the board of the American Hearing Research Foundation. She joined HLAA in 1979 and is active in Hearing Loss Association of Sarasota, Florida. Barbara can be reached at barbchert@aol.com.





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National Update

The Hearing Loss Association of America works at the national level to impact public policy that benefits our members and all people with hearing loss.

Equal Access to Technology for People with Hearing and Vision Loss

COAT Hearing on Capitol Hill
May 1, 2008, Washington, D.C.
The U.S. House of Representatives Committee on Energy and Commerce, Subcommittee on Telecommunications and the Internet held a hearing on "draft legislation enhancing access to broadband technology and services for persons with disabilities." The draft legislation is titled, "21st Century Communications and Video Programming Accessibility Act."

Hearing Loss Association of America and many HLAA chapters are founding members of the Coalition of Organizations for Accessible Technology (COAT). COAT has been a champion of the draft legislation since its release in December. The nearly 200 members of COAT agree that legislation that ensures equal access to technology for people who are hard of hearing, deaf, blind and who have low vision is long overdue.

The Congressional hearing room was packed with disability advocates, industry representatives and interested parties. Spotted in the audience were many members of the COAT coalition, including representatives and members of Hearing Loss Association, Communication Services for the Deaf, the National Association of the Deaf, American Association of People with Disabilities, American Association of Deaf-Blind, Alexander Graham Bell Association for the Deaf and Hard of Hearing, American Council of the Blind, American Foundation of the Blind, VITAC, and Snap! VRS. Also attending was I. King Jordan, past president of Gallaudet University, who was recognized and welcomed by the chair of the subcommittee, Representative Edward Markey, and by Ranking Member Cliff Sterns.

Chairman Markey set the tone, opening the hearing with comments that the regulations as they stand now are antiquated in the face of rapid advances in technology. He noted

that technology is only good if we can access it, and as the population ages there will be more of us who need to find ways to access new technology.

Chairman Markey also mentioned that the resistance coming from the communications industry was "eerily similar" to opposition he faced when battling to enact the original closed-captioning law in 1990, with the help, he noted, of I. King Jordan and other disability advocates.

The chairman recalled, "We were told that mandating closed captioning would add \$20 to the price of a TV set and that it was overly burdensome, would crush the industry, it would take a lifetime and a fortune to caption all the movies and television programs out there... today, not only is it indispensable to millions of individuals who are deaf or hard of hearing, but closed captioning is used by immigrant families to help them learn the language and seen in sports bars across the country...and it didn't cost remotely \$20, it cost about \$1 per TV."

Members of the subcommittee who spoke indicated the draft legislation provided a way that new technology could include people, and ensure that when it comes time to access new technology, no one is left behind.

Witnesses

Witnesses at the hearing speaking for COAT were: Russell Harvard, deaf actor who played in the movie *There Will Be Blood*, Jamaal Anderson, professional football player for the Atlanta Falcons and son of Glenn Anderson, Ph.D., past chair of Gallaudet University Board of Trustees. Sergeant Major Jesse R. Acosta, U.S. Army, veteran of the war in Iraq who was blinded while on active duty testified on behalf of the American Council of the Blind.

The COAT witnesses testified with passion and a good dose of humor. They spoke of the burdens

faced when accessing new technology.

Russell Harvard recounted the problems in the early days of captioning when the close-captioned decoder boxes his family purchased often overheated, making captions unreadable for their favorite programs. That didn't change until Congress required all televisions over 13 inches include a decoder chip. In the same way, the new legislation would bring Internet access by ensuring captioning on the Internet and devices smaller than 13 inches being able to decode the captions. For Russell Harvard, access to movies and television is not simply an issue of enjoying the same entertainment as everyone else; it's a matter of being able to have access to the tools of his profession.

Jamaal Anderson spoke poignantly of his recent draft to the NFL team. Video clips of the draft selection were posted on the web, but without captions, forcing his father to find someone to act as an interpreter to watch his own son. Jamaal urged support for equal access to mainstream Internet products included in the draft legislation as well as inclusion of broadband services for Lifeline and Link-Up services, and hearing-aid-compatible telephones that connect to the Internet.

Sergeant Major Jesse Acosta was amazed that his 30-year old Chrysler LeBaron included technology that would voice when the systems needed maintenance, but that he could not get voice access to products like DVRs and cable boxes. This, he said was "beyond me." He felt that the legislation would be a big step forward by allowing more devices to be accessible to people who are blind or have low vision with video description, with the possibility of creating way for onscreen emergency information presented in text to be voiced, and to allow audio output for on-screen menus.

Other witnesses were: Larry Goldberg, director, Media Access, WGBH Boston; K. Dane Snowden, VP, External and State Affairs, CTIA, The Wireless Association; and Ken Nakata, Director of Disability Initia-

tives & Government Compliance for BayFirst Solutions LLC.

Larry Goldberg from WGBH provided videos that demonstrated captioning on the web and video description. He noted that the courts had overruled the FCC's video description requirement, arguing that Congress hadn't clearly stated its intention to require description. The new legislation would clarify Congress' intent.

He also noted that "many hurdles remain to make captioning of web-based media as pervasive as it is on television." In his testimony and the questions from the members following his testimony, it was clear that market pressures often don't help the community of people with disabilities achieve equal access.

Dane Snowden emphasized the work the wireless industry has already done to provide access to people with disabilities. He argued against the use of the "readily achievable" as the standard in any new legislation; that the legislation should not be enforced by "private right of action" litigation (i.e., the right of individuals to bring a case to court), and that the legislation should not impose new reporting requirements on either service providers or manufacturers. He said, "As currently drafted, the proposed legislation would unnecessarily burden the industry with little countervailing benefit to the disability community."

Ken Nakata indicated he supported the goals of the legislation but argued against including a private right of action and he argued against holding industry to a high standard, the "undue burden" standard, to ensure that equipment and services are usable by people with disabilities.

Chairman Markey's questions after the panel spoke focused much attention on the wireless lobby, asking carriers and device manufacturers to help him set a deadline under which to work out new standards governing communication access for people with disabilities.

"It's amazing how much can get done under a deadline," Markey

said. Snowden, representing the wireless industry, indicated their willingness to work with the subcommittee.

At the end of day, it was clear that the subcommittee and even witnesses were aware that it was not a matter of whether this kind of legislation would move forward, but when.

What is COAT?

During the spring of 2007, a new coalition, the Coalition of Organizations for Accessible Technology (COAT), was established. Founding organizations include Hearing Loss Association of America (HLAA), Communication Services for the Deaf (CSD), the National Association of the Deaf (NAD), the American Association of People with Disabilities (AAPD), and the American Foundation for the Blind (AFB). As of May, 2008, almost 200 national, regional, state or local organizations are members of the COAT.

COAT's primary goal is to ensure that legislative and regulatory safeguards are in place so people with disabilities have access to evolving high speed broadband, wireless, and other Internet-based technologies.

COAT has identified two main areas for advocacy: Communication Access and Video Programming Access.

What is the 21st Century Communications and Video Accessibility Act for People with Disabilities?

On December 21, 2007, the U.S. House of Representatives released a draft bill, the long-awaited "Twenty-First Century Communications and Video Accessibility Act." This proposal is a dramatic and comprehensive step forward for consumers with disabilities. It proposes to amend the Communications Act—the main statute that impacts the telephone and video programming industries—to add new consumer protections that will ensure people with disabilities do not get left out or left behind as telephones and

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National Update

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television programming increasingly rely on digital and Internet Protocol (IP) technologies.

See a summary of the bill at www.hearingloss.org/magazine.

ADA Restoration Act

The Americans with Disabilities Act of 1990 (ADA) was passed with overwhelming bipartisan support and signed by President George H.W. Bush in order to give people with disabilities a chance to be judged fairly.

Just as other civil rights laws prohibit employers from basing decisions on characteristics like race or sex, Congress wanted the ADA to stop employers from making decisions based on disability.

The ADA Restoration Act (H.R. 3195/S. 1881) ensures the right to be judged based on performance. It restores the original intent of Congress, harmonizing the ADA with other civil rights laws and requiring

the courts to interpret the law fairly. Hearing Loss Association of America supports the H.R. 3195/S. 1881. We have been working with the Consortium for People with Disabilities to ensure that language is included that considers the needs of people with hearing loss.

For more information about the ADA Restoration Act, visit the blogspot hosted by The American Association of People with Disabilities: <http://adarestoration.blogspot.com/>.

Lise Hamlin is the director of public policy and state development. She joined the HLAA staff in April this year after being a long-time member and serving on the HLAA (then SHHH) board of trustees as well as working at the League for the Hard of Hearing in New York City. She lives in Rockville, Maryland, and her most recent position was with the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons. She has a long record of volunteer grassroots advocacy. Lise can be reached at lhamlin@hearingloss.org.

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Listening to Music through a Cochlear Implant

Part one of this series on how to pick up musical cues with a cochlear implant appeared in the May/June 2008 issue of *Hearing Loss Magazine*.

For the last few months, I've been giving myself a "musical auditory training program" by listening to various kinds of music for 30 to 40 minutes a day. My musical selections have ranged from the classics to operatic arias, Chassidic music, country and folk, pop, Broadway musicals, etc. It's been an enlightening, frustrating, disappointing, but occasionally rewarding experience.

It's important to note at the outset that my conclusions apply only to me. If there is one generalization that can be made regarding the outcome with a cochlear implant (CI), whether for speech or music, it is that individual variations are the rule and not the exception. Still, I hope that some of my personal experiences and insights may be applicable to other implant users.

Brain Training: Using a Patch Cord or Using One Ear

At first, I directly connected the implant to a CD player using the supplied patch cord. While this worked very well, it did mean listening only with the implant and not utilizing the residual hearing in my contralateral ear. Although I have about a 95 dB hearing loss in that ear, it is still

functional and it made no sense for me to ignore it. Indeed, the bimodal condition (CI plus HA) is being supported by more and more objective evidence as generally superior to the implant alone (at least in terms of speech perception).

Through Speakers or Using Both Ears

So now, I listen to music using both ears in two ways. One method is to use my computer, which comes with excellent speakers that I position some 18 inches from me. This stimulates both ears naturally. I have found several sites which provide me with a wide sample of musical genres and selections from which to choose. I listen in my home office, away from the noise and distractions in the house.

Inductive Coupling

Using the other method, I switch the hearing aid and the implant to the telecoil position, plug a neckloop into the output of the CD player, and listen with both ears using inductive coupling. Initially, I found that I had to situate the neckloop on top of my ears rather than around my neck, in order to increase the strength of the inductive connection. More recently, I have switched to using a pair of silhouette inductors which I place behind my ears. These are more convenient to use and provide both the HA and the CI with excellent inductive coupling to the CD player.

When listening, I explicitly focus my attention on the auditory sensations I am experiencing. Attention is a way of increasing the readiness of the central nervous system to receive and benefit from the auditory stimuli it is receiving. My goal is to recapture

at least some of the pleasure I used to experience in listening to music. This requires that I focus on the signal that I'm listening to, trying to separate the various acoustical elements as well as to identify and experience the melodic themes. Every once in a while, however, I do stop myself when I'm listening to a piece that I can still enjoy, and shift my mind from a training mode and back to the simple pleasure of listening to music. This, really, is the whole point of this exercise.

The Role of Auditory Memory

I have found that my auditory memory plays a crucial role in my training program. There have been a number of reports that have noted the contribution of memory to melody recognition and enjoyment; however, I do not think that this aspect has been sufficiently stressed. As I listen to the music, I find that I constantly engage my auditory memory in the listening process. I keep trying to discern a familiar pattern, one that I can then relate to my vivid memory of the same melody. In other words, the acoustic sensations, how they vary and change in time, are constantly being compared to my recollections of how they sounded in my pre-implant days.

Without these stored memories, I would not be hearing a melody at all, only a cacophony of unrelated sound sequences. It seems that the stored memories of some musical selections serve as a kind of template to which the incoming sounds are compared. My ability to enjoy music depends, then, not only on what comes through the implant, but also on what my memory contributes to the listening experience.

Selective Listening

After many hours of listening, I feel comfortable with some general conclusions. One of the primary ones is that any piece that I didn't know or recognize before I got the implant, I find that I still don't recognize or enjoy. I can easily follow the beat and rhythm of the selection; I feel that I can distinguish the unique timbre of many of the various instruments; I often understand most of the lyrics, perhaps even more than I did pre-implant; I can hear distinct pitches and pitch changes (the prerequisite for melody recognition); but even so, for an unfamiliar selection, I am unable to create a melodic experience out of all these auditory sensations.

I've tried and tried, but any selection I didn't already know—and this includes all the musical genres that I've listened to—still sounds rather flat and basically atonal. At this point, therefore, I do not think further efforts with this category to be a good use of my listening time, though I may continue to sample such selections (even if inadvertently, at social events, etc.).

Then there are a number of selections that I did know in the past, but didn't particularly like. In listening to these, I usually find that I still don't like them even though I can recognize the melody. So that leads to my second conclusion:

If I didn't like a selection pre-implant, it is unlikely that I'll like it now. This shouldn't be surprising. My musical tastes haven't changed just because I now use a cochlear implant, and there is no reason to think that they will. My reactions reflect the fact that I'm an adult with a mature neurological system and formed listening preferences (unlike a child whose system is more readily modified by new sensations and experiences). So spending time listening to these selections also does not seem to be a good use of my listening time.

While omitting unfamiliar musical selections and those I disliked from my training activity would appear to be quite a limiting condition, I haven't found it so. I find that I still have a large repertoire of music fixed

in my auditory memory that I can draw on, music that I liked in the past that I can now listen to and enjoy. This includes original recordings made in the 1920s and 1930s ("rag-time" piano included), operatic arias, many classical pieces, country and western music, and many pop singers from the 1930s through the 1960s. In terms of modern tastes, however, I am probably a musical Neanderthal in that even when I was able to hear and enjoy music via my hearing aids, I rarely listened to any music composed after the 1970s; it simply never "spoke" to me. So my musical auditory memory encompasses a much earlier period than a younger implant user would have (or, perhaps, some older person more tolerant of modern "sounds" than I am!).

Music for Pleasure

Still, whatever a person's musical background and preferences, the task is the same: The implant user must determine if listening to music, in any genre selected, is or can be made pleasurable. For example, the fact that an implant user can usually still perceive beat and rhythm fairly normally will make rap music more accessible than another genre that depends more on the melodic component, particularly since the lyrics may now be more easily understood. People who have enjoyed and can relate to this musical genre before receiving an implant should still be able to find pleasure in listening to it. And this is exactly the way it should be since, as has already been pointed out, music appreciation entails very personal preferences.

Testing Melody Perception

Because I wasn't able to discern a melody in any unfamiliar musical piece, I wondered if I possessed the necessary prerequisites for melody perception (the sensory capacity to discern pitch changes moving up and down a musical scale). So with the assistance of my very patient implant audiologist, we tested my ability to discriminate between various notes on a piano. I could reliably discriminate one note differences of all the piano keys at the

midpoint on the keyboard, but did much poorer at the very low and very high pitches.

Additionally, I was able to perceive a pitch sensation when each of my 22 electrodes was stimulated. Still, while I think I did quite well on these measures, it evidently was not good enough for me to hear or appreciate an unfamiliar melody. Something else, some other sensory capacity, must still be lacking. We also tried changing the stimulation rate of the processor and using a number of slightly different maps. None of these proved to be any better than the one I was already using.

Observations and Conclusions

After four months, what kind of observations and conclusions can I make regarding my "musical auditory training" program? In brief, I would say the results have been mixed. I have found that listening to many of the songs (but only the ones I already knew and liked) seems more pleasurable. It is also clear that I am adopting a lower standard of normalcy.

I find myself overlooking some atonal passages, something I would not have tolerated years ago. I haven't noticed any clear preference for any of the genres that I've listened to. In all of them, there are pieces that sound "not bad," some that actually sound "pretty good," and many that seem to be simply tolerable. For some pop music, I find that if I sing along, it sounds much better. It is as if I'm blending what I hear and what I produce.

However, I'm rarely sure than I'm on key with my own singing—I don't really trust my self-monitoring - but my wife assures me that I usually am.

Clear Differentiation

What seems to come through best in any of the genres is when there is a clear differentiation between some desired signal (vocals, a few instruments, etc.) and the background sounds or accompaniment (a positive signal-to-noise ratio). It is when there is too much sound,

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Cochlear Implant

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like a full orchestra, with or without vocals, that everything sounds dense and the sound elements tend to blend together. This applies to choral music as well; it is the soloists that I most enjoy.

Apparently, besides auditory memory, much depends upon the interaction of the acoustics of the input sound and the processor. For example, I've noticed that my appreciation of the same song sung by two different vocalists can vary significantly; I may enjoy one but not the other. The role of auditory memory still seems dominant, however: even if I usually like a singer, if he or she is singing an unfamiliar song, I still don't get it.

My Music Finale

It seems to me that I've come close to what kind of music appreciation can be realized with a cochlear implant, at least for me. Even at its best, when

I can recognize and enjoy listening to some piece, it is clear that some "flavor" of the music is missing. It is hard to define, but music simply does not move me the way it did before. A musical piece is a complex acoustic event, different from speech, and the current generation of implants is not designed to transmit a full-bodied musical signal.

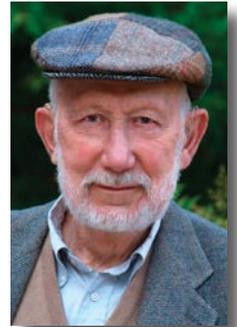
CI Music Research

I understand that music appreciation is now a research priority for manufacturers and basic researchers. Among the abstracts of papers delivered at a recent CI convention, there were a number that dealt with enhancing music appreciation.

What's clear to me is that we need changes in processing strategies, some that are explicitly devoted to music perception. The challenge, of course, is to determine exactly what these changes should be. I do believe that we will be seeing progress on this front in the not-too-distant future—

hopefully soon enough so that I personally can take advantage of them. ■■■■

Mark Ross, Ph.D., is an audiologist and associate at the Rehabilitation Engineering Research Center (RERC) at Gallaudet University. He and his wife, Helen, live in Storrs, Connecticut. To find more



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Dr. Ross articles on technology for consumers, go to: www.pa-shhh-org and www.hearingresearch.org

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You Asked for It: Live from New York City!

In the last issue we reported on the Manhattan Chapter's new brochure on Infant Hearing Screening produced from the proceeds of their *Walk4Hearing*. Here's what the brochure looks like.



Infant Hearing Screening brochure from the Manhattan Chapter

Wisconsin State Conference

The Hearing Loss Association of Wisconsin State Conference is scheduled for October 2-3, 2008. The Western Wisconsin HLA Chapter of Menomonie will host the biannual event. The keynote speaker will be David Myers, Ph.D., from Holland, Michigan, who founded the "Loop America" project now taking hold throughout the United States. Information will be posted on the Wisconsin website at: <http://hlaawi.org>.

Rochester Chapter Holds Day and Evening Meetings

Early in May HLA Executive Director Brenda Battat was the speaker for the Rochester Chapter's Day and Evening meetings. She spoke about HLA's current projects and telephone accessibility respectively.

Scholarships

May is the annual awards presentation month for the Shasta County (CA) Chapter. For many years, this chapter has been presenting scholarships ranging from \$100 to \$1,000 each to deserving young children with hearing loss. Each June the Rochester (NY) Chapter awards \$1,000 scholarships to college-bound hard of hearing students. Other chapters have developed or are planning to initiate scholarship awards supported by money raised through local *Walk4Hearing* events.

San Antonio in May

San Antonio (TX) Chapter Members Barbara Hunter, Sylvia Laurel, Rita Cage, Jeanne Jansen and Betty Berg participated in the San Antonio College Interpreters Training Open House May 2 at the Nail Technical Center on the San Antonio College campus. They dispensed hearing loss

information and literature and answered questions to create awareness of the Hearing Loss Association of America. They also promoted May's Better Hearing and Speech Month.



Dr. Norman Dawson and Virginia Carr hold the legacy plaque.

Albuquerque Chapter Honors Long-Time Leader

Over 20 years ago, a group of 12 hard of hearing Albuquerque, New Mexico, residents got together and formed the Albuquerque Chapter of Self Help for Hard of Hearing People (SHHH) which, a few years ago, became the Hearing Loss Association of Albuquerque (HLAAbq). In the years following its formation, many leaders came and went but one person's devotion to SHHH and to the needs of people with hearing loss never waned. That person is Virginia Carr.

Virginia served in various leadership roles in the chapter and eventually became the New Mexico State coordinator. In that role, she oversaw the formation of a number of other SHHH chapters in the state and

applied her energy to learning all she could about dealing with hearing loss and sharing that knowledge with others. The members know that without her care and guidance the chapter wouldn't enjoy the enormous success and recognition in the community as it does today.

In recognition of her great contribution in New Mexico, the HLAAbq Board of Directors created The Virginia Carr Award. The inscription on a legacy plaque that will record the names of those who receive the award says: "The Hearing Loss Association of Albuquerque presents the Virginia Carr Award to the following in recognition and thanks for outstanding and selfless service to the hard of hearing community. They honor the example of leadership and devotion set by Virginia during her many years of service to those with hearing loss."

The Board will consider nominations each year for an individual to be recognized for his or her contribution to the hearing loss community but may not make an award every year if, in their judgment, there is not a suitable candidate to be recognized that year. A luncheon is planned for July 19 to honor Virginia and she has been asked to select the first person to receive the award. That individual will be announced at the luncheon. All members of HLAAbq and friends of Virginia are invited to attend.

HLAA Permian Basin Chapter Awarded \$5,000 Grant from the Odessa Junior League

The Odessa, Texas, Junior League invited the HLAA Permian Basin (TX) Chapter to submit a request for a grant. Chapter Secretary Linda Belk spent many hours researching and writing the grant. The chapter has been awarded the \$5,000 and it will be used to furnish the Ector County Library with books, videos, DVDs, and more, on hearing loss.

A Nascent Chapter in Southwest Ohio

Southwest Ohio Chapter President Linda Fowler reports that they have

just completed their second year and are now getting a good turnout at meetings. She says, "Besides sending out flyers, we have found the best way to communicate our existence and recruit members is to get published in the local newspapers."

A Mature Chapter in Wisconsin

The Waukesha (WI) Chapter reports 19 years of creating awareness about hearing loss in their community. Congratulations to Waukesha!

News from Home

Yearning for news from Western Pennsylvania? Go to www.pa-shhh.org/chapters/Pittsburgh.html to read their latest newsletter and more.

And, how about some Pacific Northwest news? The summer issue of *Sound Waves* is available on the Hearing Loss Association of Washington state web site: <http://www.hearingloss-wa.org/Summer%2008.pdf>.

Rochester Walks4Hearing

Don't these snaps make you want to get involved? Learn about upcoming walks at www.hearingloss.org.



Got Germs?

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The Future is Headed Our Way

A Less-Invasive Approach Eases Cochlear Implant Surgery

By Robert Labadie

Can you imagine a cochlear implant surgery performed with minimal invasiveness, in an outpatient setting and allowing activation of the device on the same day?

Met James, a 34 year old male, who started losing his hearing as a child. Now, as an adult, he cannot hear on the telephone and hasn't used his hearing aids for the last year. This evening he is recovering at home after earlier in the day undergoing percutaneous cochlear implantation surgery. He can even hear this evening for the first time in many years. Is this possible?

No, not today; however, new possibilities are on the horizon. Imagine, though, a cochlear implant surgery performed with minimal invasiveness, in an outpatient setting and allowing activation of the device on the same day.

Currently, Robert Labadie, M.D., Ph.D, associate professor of Otolaryngology and Biomedical Engineering, and his colleagues at Vanderbilt University Medical Center in Nashville, along with three other medical centers in the United States (University of Texas Southwestern in Dallas, Texas, Case Western Reserve in Cleveland, Ohio and University of North Carolina at Chapel Hill) are collaborating to develop a new and improved approach to cochlear implantation.

Presently, cochlear implantation involves approximately two hours of surgery performed under general anesthesia. Drilling away a large section of the skull behind the ear is necessary to prevent damage to specific structures, such as the facial nerve, which is mainly responsible for the movement of the muscles used to exhibit facial expressions.

A surgeon must rely upon electronic sensors and meticulous visual observation in the identification of certain landmarks to avoid contact with small and important parts of our anatomy. Once the surgery is completed, recovery time before activation of the device can be as long as three weeks as swelling resolves and incisions heal. This is a time of great anticipation as patients wait to learn if they will be able to hear.

Dr. Labadie and his colleagues at Vanderbilt University Medical Center are working under a four-year, \$3 million grant from the National Institute on Deafness and Other Communications Disorders, National Institutes of Health,

to test an image-guided, minimally-invasive approach to cochlear implant surgery they believe will make cochlear implant surgery faster, less invasive and more precise. They have termed this process percutaneous cochlear implantation."

The group feels that this new technique will result in less time in the operating room potentially even eliminating the need for general anesthesia. In addition, they predict that recovery time may be completely eliminated allowing activation of the device at the time of implantation. This may even allow custom placement of cochlear implant electrodes—"James, can you hear better with the electrode here (position 1) or here (position 2)?"

Percutaneous cochlear implantation involves the patient having three "anchor screws" inserted into the skull surrounding the ear following which a CT scan is performed. The CT scan is currently necessary prior to cochlear implant surgery to ensure normal ear anatomy; however, it is an essential part of the "new" procedure as this is the basis of how the image guided path is created. The CT scan shows exactly where the anchor screws have been placed in relationship to the other ear anatomy including the cochlea and the facial nerve.

Next, using proprietary software, a path to the cochlea avoiding the facial nerve is projected onto the scan and a surgeon verifies that it is correct. This information is sent electronically to a rapid prototyping facility to build a customized drill guide or frame. At the time of the percutaneous cochlear implant surgery, the frame is fixed to the anchor screws and the drill is constrained to follow the planned pathway safely getting to the cochlea.

The electrodes for the cochlear implant device are "threaded" down the drill path to a designated area within the cochlea. The body of the implant is secured under the skin in a pocket behind the ear similar to the current conventional cochlear implant procedure. Once the cochlear implant is in place, the anchor screws are

removed. Essentially, with the expertise of computer software created by humans, the surgeon will be able to find his designated target with minimal cutting and completion of the whole procedure is about 45 minutes.

Who is This Procedure For?

The majority of current cochlear implant candidates could undergo the procedure, the exceptions being those with unusual anatomy such as bone-filled cochleas sometimes seen after meningitis.

The percutaneous cochlear implantation project is a collaboration of multiple disciplines. J. Michael Fitzpatrick, Ph.D., of Vanderbilt's Department of Electrical Engineering and Computer Science has written software that automatically identifies the anchor positions. His graduate student, Ramya Balachandran Ph.D., is now working full time on the project.

Dr. Labadie and Dr. Fitzpatrick were the initial driving force for this project. Beniot Dawant, Ph.D., and Rui Li have developed planning software that automatically identifies the purposed surgical path bypassing the facial nerve. Jack Noble, a former Vanderbilt undergrad now pursuing his Ph.D., has further automated the

planning software. Jason Mitchell, M.S., a machinist in the Vanderbilt Department of Mechanical Engineering, designs and builds customized surgical tools for the project. Wendy Lipscomb, RN, BSN is the research nurse coordinator.

During the first two years of the grant, the team is validating the accuracy of drill guidance on patients who are undergoing the traditional wide-field cochlear implant surgery. Presently, with six patients validated in the operating room, they are ahead of schedule. The researchers anticipate performing the first percutaneous cochlear implant surgery in April 2009.

Could this new procedure be to ears as the "LASIK" procedure is to eyes? Only time will tell, but this group certainly believes—and is showing—that it is possible. ■■■

Robert Labadie, M.D., Ph.D., received both degrees from the University of Pittsburgh. He did his residency in otolaryngology at the University of North Carolina at Chapel Hill, and has been on staff at Vanderbilt University Medical Center since 2001 where he is currently associate professor of Otolaryngology and Bioengineering. As is apparent from this article, both his clinical and research interests focus on cochlear implants.



Robert Labadie, MD, Ph.D. adjusts a drill guide/platform on patient Rodney Poling.

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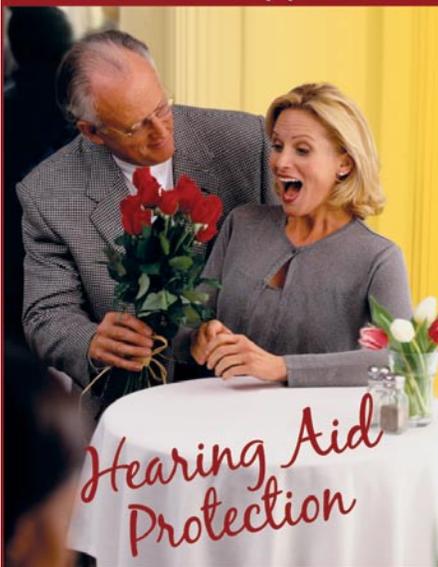
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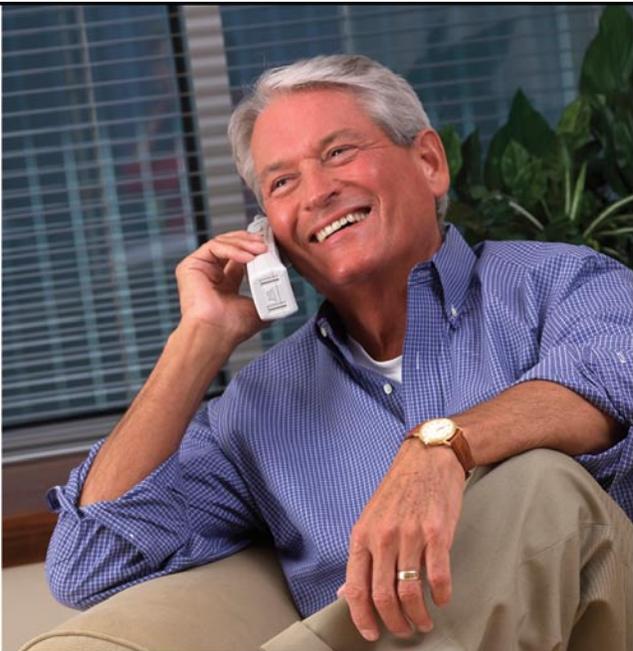
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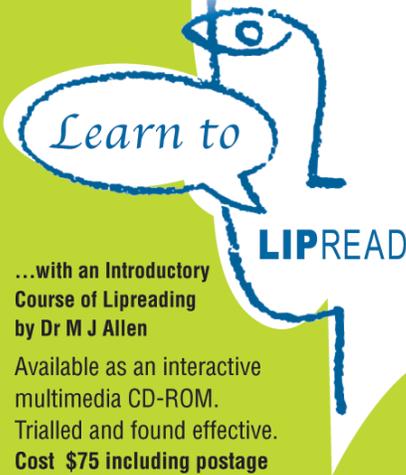
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**CONVENTION 2008
RENO WRAP-UP
COMING NEXT ISSUE!**

By Andy Bopp



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The Eddie Sierra Story

Andy Bopp (pictured above) loves telling the story about Eddie—a student with hearing loss who was an intern for the Hearing Industries Association (HIA).

Internships provide an outstanding opportunity for college students to gain practical experience and to make contacts that will help find a job after graduation. Almost all House and Senate offices provide internship opportunities, as do many associations and other organizations. Such internships often enable a student to work for a cause of personal interest while gaining experience at the same time.

Some organizations such as HLAA and allied hearing health organizations offer internships that enable the student to make great contributions to an effort such as the Hearing Aid Tax Credit (H.R. 2329).

Eddie Sierra, a Miami native who graduated from Florida International University, had such an internship when he worked for the Hearing Industries Association in fall 2005. His focus was on arranging and attending meetings with congressional staff to discuss the Hearing Aid Tax Credit as well as assisting with other research projects.

Eddie has a severe-to-profound hearing loss, and he used the telecommunications relay system to place calls to congressional offices to set up meetings. (Such calls are placed through a relay operator—communications assistant—who types the text of the conversation so Eddie can read it. A person with hearing loss can use his own voice to speak to the person at the other end or type it and the communication assistant voices it to the hearing caller.)

An Unexpected Result for Eddie and Our Staff

Eddie also attended the meetings with HIA staff to convince legislators to support H.R. 2329. Far from being an obstacle, Eddie's use of the relay system was tremendously helpful. While congressional staff members are extremely busy, and callers are usually routed to voice mail; Eddie's calls using the relay service were almost *always answered by a staff member*.

As a result, Eddie was able to schedule a record number of meetings with House and Senate staff which helped HIA, Hearing Loss Association of America, and others to greatly increase co-sponsorship of the hearing aid tax credit. Eddie's hearing aids and other technical assistance devices such as the relay system enabled him to achieve great things as HIA's intern.

Eddie is an advocate for using available technology and an example for all people with hearing loss to pursue their goals and not to let anything stand in their way. ■■■

Andy Bopp is director of regulatory affairs at Hearing Industries Association. For information about HIA's and other internship programs, contact Andy Bopp at abopp@clarionmanagement.com.

The Hearing Industries Association is located in Washington, D.C., and can be found at www.hearing.org.



Eddie Sierra, left, and a congressional staffer



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