Hearing Loss
MAGAZINE

March/April 2007

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Disclosure is a Personal Choice

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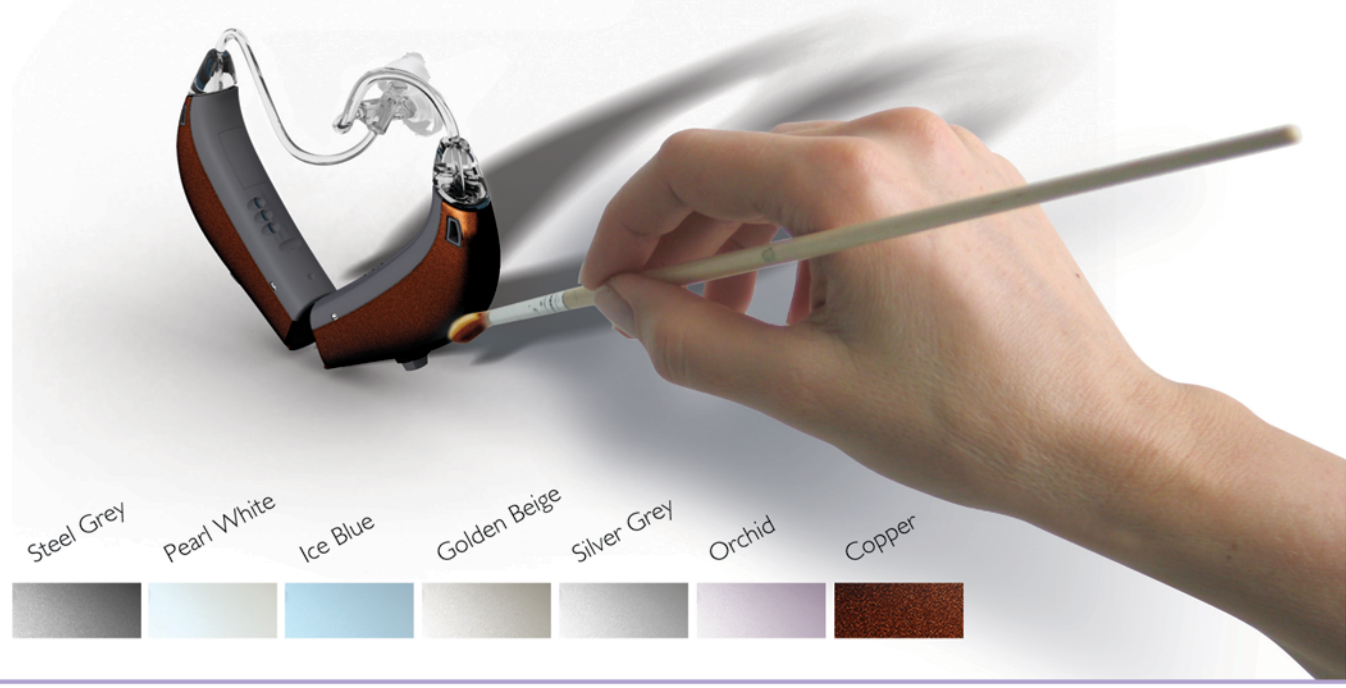
Speechreading Suggestions

Tea With Marie
Moving Beyond Hearing Loss

Meet Attorney
Karen Peltz Strauss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Hearing Loss
MAGAZINE

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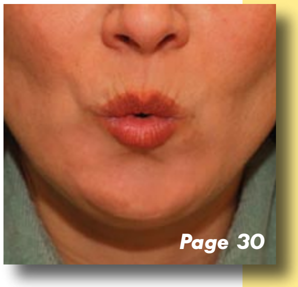

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The Hearing Loss Association of America is the nation's foremost membership and advocacy organization for people with hearing loss. Hearing Loss Association of America opens the world of communication to people with hearing loss through information, education, support and advocacy. The national support network includes the Washington, D.C., area office, 13 state organizations, and 250 local chapters. Our clear, straightforward message has changed the lives of thousands of people: *Hearing loss is a daily challenge you can overcome. You do not have to hide your hearing loss. You do not have to face hearing loss alone.*

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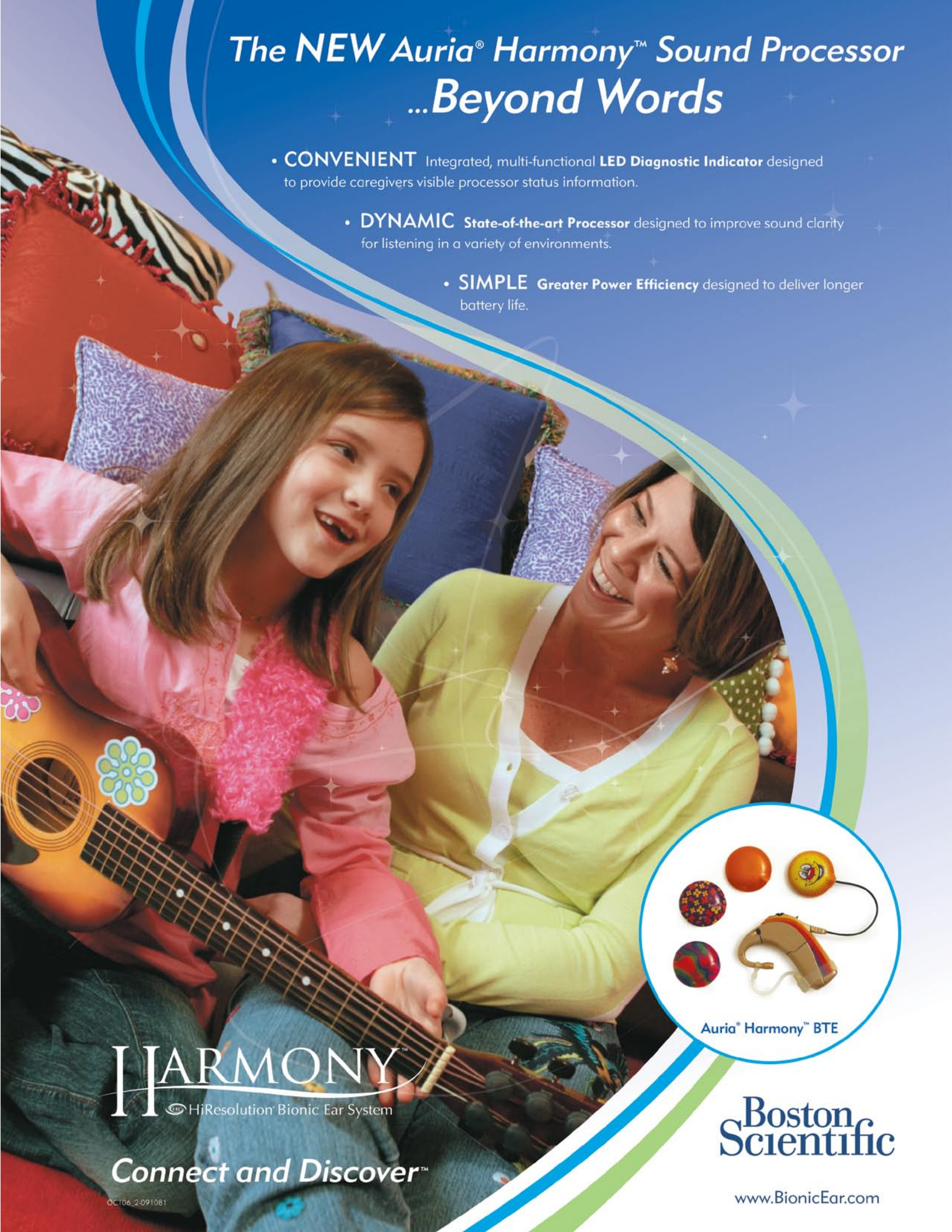

Auria® Harmony™ BTE

By Terry D. Portis

A Reason *Not* to Hate Your Telephone

> "Using technology to maximize and complement residual hearing is critical for the vast majority of people with hearing loss. It is the key to more effective communication and a greater quality of life."

Often, the first signs of hearing loss are difficulties with the telephone. Many people with hearing loss find the telephone to be a frustrating experience. Making or receiving a telephone call can be very upsetting. People have shared with me that they "hate the telephone." A person may hear just enough of a telephone conversation to be frustrated. Nevertheless, the telephone still remains an important communication tool in our society.

The challenge is finding a solution that is seamless, transparent, inexpensive, and functionally equivalent to what people have been used to for most of their lives. Relay services and TTYs have frequently proven difficult to use, especially for people who lose their hearing late in life. People are accustomed to picking up the telephone and simply making a call.

Suddenly, people find themselves hesitant to do something they have done their whole lives. TTY technology is limited to friends, families and businesses that also have a TTY. Relay services are not seamless, and people may find using "GA" and other terms aggravating.

In 2005 the Hearing Loss Association of America petitioned the Federal Communications Commission to approve funding for an Internet-based captioned telephone service. Thirty other organizations signed on in support of this petition.

In December 2006 the FCC approved funding for this exciting new telephone service. The service is widely known as IP Captioned Telephone and will be increasingly available across the country in 2007. You may already have all the equipment you need in your home. A computer with an Internet connection (broadband will work best), and a regular telephone are all that are required.

In one demonstration I have seen, the person desiring to make a call went to a website and typed in the number he was calling from and then the number he was calling to. Within a few seconds an operator called him, then connected him with the other party. Almost instantly the words of the other party began appearing on the screen. Unlike relay, the operator was not involved as a participant in the call.

Behind the scenes at the call center for IP captioned telephone, an operator is repeating what the other party is saying into a computer. The operator is using voice recognition software that has been specially trained for his voice. This method is usually much faster than typing, and often more accurate. Thus the lag between when the person you are talking to says something and when the words appear on your screen will be shorter.

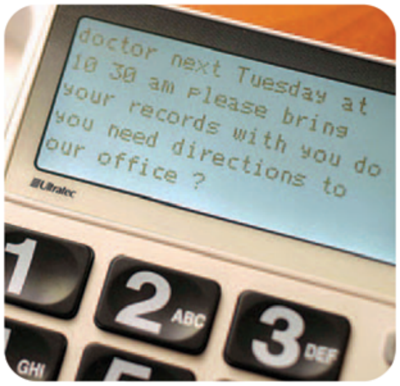
Advantages

IP captioned telephone has several other advantages. First, as I have already mentioned, there is no need for special equipment. With the severe rationing of captioned telephones in many states, this is extremely important.

People in the workplace are going to be exceptionally happy about this service, because it can go through a regular switchboard and does not require a dedicated line. People will simply use the telephone and computer on their desks. The service is also transparent; the other party does not know who is using the service and who is not. We know there will be a lot of questions about this new service; so we will work with service providers to share information.

Using technology to maximize and complement residual hearing is critical for the vast majority of people with hearing loss. It is the key to more effective communication and a greater quality of life. IP captioned telephone is yet one more step toward making this country more accessible for people with hearing loss, and we applaud the FCC for the approval of funding for this new service. HLM

Terry D. Portis, Ed.D., is executive director of the Hearing Loss Association of America. He can be reached at **tportis@hearingloss.org**. *You can read the executive director's blog at www.lightkeepersjournal.org.*



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By Anne T. Pope

President's Message

> "My hearing aids go on first thing in the morning and stay on until I am ready to turn out the light at night. They are my lifeline."

I have a wonderful audiologist—so wonderful that she has been my audiologist for over 20 years. She keeps up to date on the latest hearing aid technology. She is careful to match my hearing needs to the particular features of the hearing aids. She makes hearing aid molds that are comfortably snug and never whistle.

She has another critically important asset; she *really listens.* She is never in too much of a hurry to discuss the quality of the sound, the situations in which I am having difficulty, and how what I do in my life impacts what I need in hearing aids. She knows that how I perceive the sound is a critical factor, that the key to a successful hearing aid fitting is not only good technology, but also good communication.

Many of us have that same wonderful relationship with our hearing health professionals. All of us who have experience wearing hearing aids know that getting the best instruments for us depends on that good partnership. We know that our hearing aids are the most important technology in our lives. Mine go on first thing in the morning and stay on until I am ready to turn out the light at night. They are my lifeline.

Yet until the elusive perfect hearing aid is manufactured, for many of us—particularly those of us with a moderate or greater hearing loss—even the best hearing aids aren't enough. As everyone in the hearing health field will remind you, hearing aids are only an aid, not a correction or a cure.

The hearing aids certainly didn't return the hearing I had before my sudden loss. I was completely lost at sea in the beginning. My life seemed to have spun out of control. I needed something more. To be sure, I had no idea what that more was, and I fumbled through some rather dark years.

What I wanted (don't we all?) was to have my hearing restored. Since that was not to be, what I needed was a much better understanding of the communication strategies necessary to stay tuned in to the world around me and some much needed support while I learned them. I took speechreading classes at the League for the Hard of Hearing in New York and that was a big help. I not only learned how to supplement what I heard, but my classmates also became an informal support group as we all struggled to learn. But it wasn't until I found Self Help for Hard of Hearing People (now the Hearing Loss Association of America) that I really began to put my life back together.

What did I find? I found people who were warm and welcoming. I found people of all ages—some many years younger and others many years older. I found people who were completely comfortable acknowledging their hearing loss. I found a place where I could hear almost everything and, when I missed something, felt no embarrassment about asking for a repeat.

I learned that there were innumerable strategies that I could use to understand what was going on—that there were ways of clarifying information, of explaining what I needed, and of putting others at ease with my communication needs. I learned that hearing aids weren't the only technology available to help me hear.

I also found a wonderful group of people who enjoyed one another. I found smart, confident people who knew how to manage their hearing loss and were terrific role models for anyone embarking on that journey. Most of us have had this same experience. Many of us come, learn and move on. But there are always thousands who stay on to welcome, support, and instruct those who follow.

These thousands—in chapters all over the United States—are the heart of the Hearing Loss Association of America. They provide the missing ingredient that technology cannot supply. They are the core of our organization. The thousands are us!

Anne T. Pope is president of the Hearing Loss Association of America Board of Trustees. She lives in New York City and can be reached at **president@hearingloss.org**.

Meet New Board of Trustees and Vote for Regional Representative. See the insert in this issue along with 2007 Convention Registration.

Hearing Loss Association of America

The Premier Club is a special group of contributors to the Hearing Loss Association of America. Premier Club members sustain our mission of information, education and advocacy by authorizing 12 monthly payments of $15 or more on a major credit card. Because we receive these credit card donations every month, Premier Club members play a vital role in our financial health by allowing us to plan and manage our finances effectively, sustain general ooperations, and maintain a healthy cash flow. These are standards every successful nonprofit should meet.

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Latisha can be reached at 301/657-2248 or by e-mail at lsteele@hearingloss.org.

Are You a Member of the Club?

Convention 2007

Oklahoma City, OK

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See **page 19** for information and registration

Telecommunications

Karen Peltz Strauss is a leading advocate and attorney who is recognized nationally for her work over the past several decades to expand telecommunications access for people with hearing loss.

During the early 1990s, the work that SHHH did together with Karen Peltz Strauss centered on the initial implementation of the Americans with Disabilities Act. Back then, much of our concern focused on making sure that the Federal Communications Commission (FCC) rules governing the nation's telecommunications relay services achieved telephone equality and provided voice carryover, a technology that allows individuals with residual hearing to speak directly to the receiving party during a telephone conversation, while receiving responses in text.

In the mid-1990s, our attention turned to securing federal requirements to caption television programs, as well as convincing the FCC to require wireless manufacturers and service providers to make their telephones and services hearing aid compatible (The latter struggle continues to this day.)

More recently, we have been working with Karen to convince the FCC to expand mandates for captioned telephone relay services. In addition, we are now returning to Congress to secure new federal laws to bring telecommunications access into the 21st century—that is to make sure that the protections that we secured for plain old telephone services are now extended to Internet-based technologies.

I had a chance to interview Karen for *Hearing Loss Magazine* so readers can hear about what is behind the telecommunication laws that have made a difference in the lives of people with hearing loss.

Karen commented: "Throughout these many years, it has been a joy for me to work with tireless advocates on the SHHH/HLAA staff whose expertise and passion for equality know no bounds. Over the years, I have been both fortunate and privileged to work extensively with you on efforts to expand telecommunications access. "

— Brenda Battat

Hearing Loss Magazine (HLM): You are synonymous with telecommunications policy for people with hearing loss. How did you decide to get into this field?

Karen: It was circumstantial. My undergraduate degree was in psychology and I had wanted to go into mental health law. After I graduated from law school in 1981, I took a two-year fellowship at the Georgetown Law Center Institute for Public Representation where I got tremendous experience in public interest law and received my L.L.M. (master's degree in law). While there, among other issues, I worked on a law to improve access to federal polling places called the Voting Rights for the Elderly and Handicapped Act and organized a coalition that included the National Association of the Deaf and the National Center for Law and the Deaf (NCLD) of Gallaudet University.

Following that, as there were no jobs in mental health law, I took a job in the federal government at the U. S. Department of Health and Human Services. I did not enjoy the bureaucratic nature of the work, and after a year or so, in 1984, decided to find something else.

Even though I had little background in deaf issues, I went back to my acquaintances at NCLD as soon as I learned of a job opening in their offices. The Law Center hired me and immediately assigned me the telecommunications access issues. I smile when I think about how lucky I was. At that time, telecommunications was not the hot issue that it is today and so the attorneys already working there gave it to the new lawyer, which was me!

Over the next five years, I also provided general consumer legal services on such topics as immigration, wills, and social security. In the late 1980s and early 1990s, however, my work began to focus almost exclusively on telecommunications access, as relay services, hearing aid compatibility and other telephone-related issues began to take on greater importance.

HLM: When did you learn sign language?

Karen: When I first came to NCLD, Gallaudet provided me with a tutor; later on I took sign language classes at the university.

HLM: What are the changes you have seen since you started working on telecommunications policy?

Karen: Advances in technology have revolutionized telecommunications access. We could never have foreseen the types of products and services that now exist when we first started working in this area—closed captioning, speech synthesis, paging devices, hearing aid compatibility of wireless devices, and different types of relay services, including captioned telephone and Internet relay access. These have completely changed the way people with hearing loss communicate.

HLM: How would you say technology has impacted people with hearing loss and which changes do you see as most critical to access for this population?

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Equality

Meet Attorney Karen Peltz Strauss

By Brenda Battat

Telecommunications Equality

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Karen: People with hearing loss no longer have to rely on others to make phone calls for them. They can communicate from wherever they are to whomever they wish via text devices, hearing aid compatible coupling, telephones with volume control, and relay services. This promotes independence and privacy, as well as greater productivity. People are able to better perform their jobs and are far less isolated than they would be without telephone access.

Similarly, television captions, which are required on nearly all new television programming since January 2006, allow people with hearing loss to be fully informed about community, national, and international events, and to enjoy a plethora of entertaining shows.

HLM: Of your many accomplishments which one are you most proud of?

Karen: I am most proud of two accomplishments. First, helping to draft and convince Congress to enact the relay section of the Americans with Disabilities Act (ADA)—Title IV—that mandated nationwide 24/7 telecommunications relay services. Second, writing and working to push through the closed-captioning mandates of the Telecommunications Act of 1996.

Of course, I did neither of these alone; I worked with many disability organizations and incredible advocates, including several from SHHH (Hearing Loss Association of America's predecessor), to make both these laws and their implementing regulations a reality. It is wonderful for me to know the tremendous impact that they have had on people's lives.

HLM: How hard was it to get those two pieces of legislation through?

Karen: Comparatively easy, believe it or not. Title IV of the ADA flew through the Senate and then the House. This was because for the most part, the phone industry was supportive of providing this new service. The challenge was coming up with the mechanics of how to implement the service and make it work.

For example those of us representing consumers had wanted the costs of relay to be embedded in the rate base—so that these costs would be treated the same as the costs of providing other telephone services. But in the end, we had to compromise on a system that added surcharges to telephone bills.

Similarly, although cable companies expressed some opposition to the closed-captioning law, television broadcasters were generally supportive because they were already providing most of their national programming with captions when the law was under consideration. We negotiated with the cable industry to give them some captioning exemptions, but were successful in keeping "undue burden" as the standard for enforcement. This is a very high standard because it requires each programming provider to include captions unless it can demonstrate that doing so would impose an undue burden on its business.

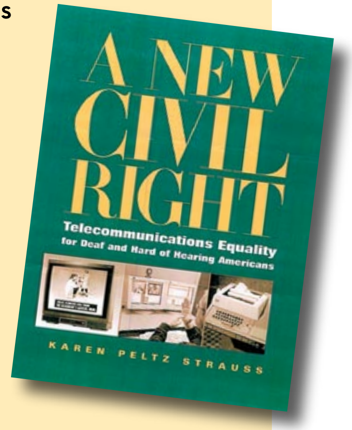
> "The biggest challenge facing people with hearing loss today is keeping up with new technology. Technology is changing so rapidly and unless it is designed from the start to be accessible, people with hearing loss will eternally be playing catch-up. We also need strong advocates to be up front and center as new policies are formulated. We need more trained, committed future leaders to maintain a stake in policy debates."

HLM: Many of our readers are hearing aid and cochlear implant wearers that have telecoils, but we still don't have full access to wireless and cordless phones. Where do you see that going in the future?

Karen: Amazingly, this is the longest running battle in the field of telecommunications access, and I am afraid that it may continue to present a struggle for the foreseeable future. It all started with David Saks advocating through the Organization for the Use of the Telephone, a group he and his wife, Reba, started in the Baltimore area in 1973. For over a decade, Saks was a virtual "one-man band," relentlessly advocating on his own for universal hearing aid compatibility (HAC) throughout the halls of Congress, to ensure that hearing aid wearers would be able to use the phone like everyone else.

"Karen Peltz Strauss reveals the behind-the-scenes struggles and perseverance of the dedicated advocates who worked to bring about a number of federal telecommunication access laws."
– I. King Jordan, Ph.D., president emeritus, Gallaudet University

"The lessons revealed in the pages of this book offer a compelling roadmap to those who are willing to take up this challenge in the decades to come."
– William E. Kennard, FCC Chairman, 1997-2001



Order online at www.hearingloss.org. Click on Bookstore.

Saks was finally partially successful when in 1982, the Telecommunications for the Disabled Act was passed. Although this law only required certain "essential phones" to be HAC (how can one truly figure out which phones are "essential" and which are not?), it proved to be landmark legislation because it was the first time that Congress ever recognized that competitive market forces would not bring about access, and that regulation would be needed to remedy this market deficiency.

It was also the first time that Congress ever established accessibility as a national priority in our nation's telecommunications policies.

After the 1982 Act was passed, Saks went back to Congress to again demand universal hearing aid compatibility for all phones, everywhere. He finally got his way in the Hearing Aid Compatibility Act (HAC) of 1988. Some might say this is a model law, because it has teeth and explicitly mandates all landline and some wireless phones to be hearing aid compatible without subjecting these mandates to lenient defenses.

What I mean is, the requirements of this law are absolute—they are not like the captioning mandates, which as I mentioned, are subject to an "undue burden" defense, or like the telecommunications accessibility provisions of Section 255 of the Communications Act, which only require access to telecommunications products and services when it is "readily achievable" to do so.

Despite the potential strength of the 1988 HAC Act, however, the hearing aid compatibility issue is one that is still not completely resolved. Fortunately, SHHH advocates picked up where Saks left off. To this day, Hearing Loss Association staff and advocates continue the struggle to achieve equal access to telephone products and services for people with hearing loss.

HLM: What do you see as the biggest challenge facing people with hearing loss today?

Karen: Keeping up with new technology. Technology is changing so rapidly and unless it is designed from the start to be accessible, people with hearing loss will eternally be playing catch-up. We also need strong advocates to be up front and center as new policies are formulated. We need more trained, committed future leaders to maintain a stake in policy debates.

HLM: You have a new book, *A New Civil Right: Telecommunications Equality for Deaf and Hard of Hearing Americans*, covering the history of telecommunications access by people with hearing loss. What inspired you to write this book?

Karen: I felt strongly that it is vital for the history of telecommunications policy to be documented. Policymakers in the Administration and in Congress are constantly changing. I wanted to ensure that as new people continue to fill these positions, they are able to learn from the successes and failures of the past.

I also wanted to ensure that these government officials understood the intent behind these laws so that they could effectively implement their provisions. Finally, I wanted to make sure that advocates benefit from the experiences of advocates who have preceded them.

HLM: How long did it take to write and will there be a second edition?

Karen: It took three and a half years to write, including editing. A second edition? Ha! I am just recovering from having written the first edition! My twelve-year-old son promises me that he will take on the second edition when he turns 20.

HLM: You have worked for different organizations. Now you have your own company. Can you tell us a bit about the consulting you do?

continued on page 14

Laws That Impact Telecommunications Access for People with Hearing Loss

■ Rehabilitation Act of 1973, as amended —discrimination on the basis of hearing loss prohibited in:
- Section 501: Federal employment
- Section 504: Programs and activities that receive federal financial assistance
- Section 508: Electronic and information technology (access required when this technology is used or provided by the federal government)

■ Telecommunications for the Disabled Act of 1982—hearing aid compatible phones required in essential locations, includes all workplace, hotels, and nursing homes

■ Hearing Aid Compatibility Act (HAC) of 1988—hearing aid compatibility required on all wireline and cordless telephones; partial exemption for wireless phones

■ Telecommunications Accessibility Enhancement Act of 1988—federal relay services required for federal employees and retirees

■ Television Decoder Circuitry Act of 1990—closed captioning decoder circuitry required on all televisions with screens over 13 inches

■ Americans with Disabilities Act (ADA) of 1990—discrimination on the basis of hearing loss prohibited in:
- Title I: Private employment (employers with 15 or more employees)
- Title II: State and local governments (courts, libraries, public schools, public transportation facilities, etc.)
- Title III: Places of public accommodation (retail businesses, private schools, professional offices, health care facilities, etc.)
- Title IV: Telecommunications relay services (required nationwide)

■ Telecommunications Act of 1996
- Section 255: Access mandated in telecommunications products and services
- Section 713: Closed captioning required on TV programming (FCC-enforced schedule of mandates)

Karen: My company, KPS Consulting, represents non-profits, consumer organizations, relay providers such as Ultratec and Communication Service for the Deaf, and the Rehabilitation and Engineering Research Center on Telecommunications Access of Gallaudet University, and the Trace Center at the University of Wisconsin.

I also consult for government agencies, such as the National Council on Disability and the Institute of Medicine. It's a great position to be in. I love being able to work with so many different people and I especially enjoy the variety of issues.

HLM: What was your favorite job?

Karen: No question—it was working at the FCC as deputy chief of the Consumer and Government Affairs Bureau (previously named the Consumer Information Bureau) from 1999-2001 when William Kennard was the chairman. During his tenure and because of his leadership, more regulations expanding telecommunications access for people with disabilities were released than ever before.

Right up until the moment he left, he was putting a stamp on a new committee he approved—then called the Consumer and Disability Telecommunications Advisory Committee. The Committee is still functioning although with a new title that no longer has disability in its name.

HLM: I have always thought you might return to the FCC. Is this in the cards?

Karen: I have considered it, but not for a few more years until my children are all out of the nest.

HLM: What laws/regulations would you like to see in place in the future?

Karen: We need laws drafted to take care of future innovations. In the 1996 Telecommunications Act, the Internet was not covered. Back then, no one could have predicted the impact that this technology would have on our society. Unfortunately, this means that the access provisions passed in that Act do not apply to Internet-based technologies.

For example, consider Internet products that substitute for telephones, such as those used for VoIP or Voice-Over Internet Protocol. Although Section 255 of the 1996 Act requires telecommunications products to be accessible, it says nothing about these kinds of devices. The FCC has already extended mandates for emergency services and surveillance by law enforcement officials to Internet-based products and services. Although it also has the authority to extend mandates for disability access, it has not done so. We must push aggressively for that as well.

Also, consider television shows and other videos that are shown over the Internet. We are already working with Congress to make sure that these are accessible through captions. We also need to make sure that all of the newer types of devices that can carry video programming—such as portable MP3 players (for example, iPods) and cell phones—can transmit and display closed captions to the same extent that televisions can.

In a perfect world, these and other new technologies would be accessible at the same time that they are made available to the general public. Now in many situations, software changes make this very feasible.

Finally, we need to greatly beef up enforcement of existing laws and regulations—there are a lot of good laws that already exist, but are not getting the attention they need from the FCC and other enforcing federal agencies. For example, one law that used to get very little attention was a mandate for television stations to make their emergency information accessible to people with hearing loss. Fortunately, in recent years, the FCC has begun taking steps to focus more attention on this requirement.

For example, just recently, the Commission entered into a consent decree with FOX television stations requiring them to dramatically improve their policies to ensure visual access to their televised emergency programming. I applaud this action and hope that more like it will follow.

HLM: What would be your advice to consumers with hearing loss to ensure implementation of policies, regulations and laws?

Karen: Consumers need to be informed about the laws and regulations that give them communication access. They need to read and understand them. They need to keep abreast of the latest developments. And they must be active and file complaints when policies and regulations are not followed. When the FCC and other government agencies don't hear from consumers, they assume everything is fine.

HLM: Would you be willing to comment on the clash between students and the administration of Gallaudet University that went on for several months this past fall?

Karen: Rather than comment on the recent protest, I would like to remind readers of the 1988 Deaf President Now movement that brought in I. King Jordan as the first deaf leader of the school. That event was indeed a watershed event and truly a declaration of empowerment for deaf people. It paved the way for numerous laws expanding the civil rights of people with hearing loss, including the Americans with Disabilities Act, the Television Decoder Circuitry Act (requiring all televisions with screens 13 inches and greater to be capable of receiving and displaying closed captions) and the 1988 HAC Act.

HLM: Where did you grow up and go to school?

Karen: I grew up in Brooklyn, New York, and went to Boston University,

> **"Consumers need to be informed about the laws and regulations that give them communication access. They need to read and understand them. They need to keep abreast of the latest developments. And they must be active and file complaints when policies and regulations are not followed. When the FCC and other government agencies don't hear from consumers, they assume everything is fine."**

where I majored in psychology with a minor in Hispanic Languages and Literature. I got my J.D. from the University of Pennsylvania Law School.

HLM: Have you used your Spanish language training at all?

Karen: Yes. Initially I used it to communicate with deaf Latino Americans while providing basic legal services at NCLD. Over the past decade, this part of my schooling influenced my work on telecommunications access. For example, I worked to ensure that Spanish language TV programming contained closed captions and that relay services are available in Spanish.

HLM: Would you be willing to share with our readers information about your family?

Karen: I have three sons—two are in college (University of Michigan and Tufts University) and one is a seventh grader. My husband is a lawyer specializing in the consumer side of energy regulation.

HLM: Are any of your children following in your footsteps?

Karen: During his high school years, my oldest son was an actor in the Deaf Access Company of the Maryland-based Bethesda Academy for the Performing Arts and learned American Sign Language. All my children are socially conscious, care about civil rights and the environment, and are politically active.

HLM: Describe your dream for people with hearing loss.

Karen: That the struggle for equal access to telecommunications will no longer be necessary. Access will just automatically be there as products and services are made available to everyone else.

My dream is also that the barriers of attitudinal discrimination will be torn down, so that children with hearing loss no longer face ridicule by their peers and adults with hearing loss are treated with the same respect and integrity that are provided for people without hearing loss.

HLM: What do you enjoy most about your work?

Karen: Knowing that what I do makes a difference in people's lives. It's an incredible feeling.

HLM: When you are not working on issues relating to people with hearing loss what do you like to do?

Karen: My family is the most important thing in my life and I tend to always be busy with one family activity or another. I love hiking, going to movies, and visiting museums, when time allows. I also truly enjoy traveling—up until now, mostly with my family throughout the United States, Canada and Mexico. At home, I have taken an interest in gourmet cooking and am taking a few cooking classes. I regularly invite friends over to be my guinea pigs while I experiment in the kitchen—maybe you'll be next on my list!

Brenda Battat is associate executive director and director of public policy and state issues at Hearing Loss Association of America. She has worked with Karen Peltz Strauss since 1989 on SHHH/HLAA public policy issues.

By Brenda Battat

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.

KEEP INFORMED

New issues and updates change frequently. Read the bi-weekly Hearing Loss Association of America *Advocacy and Legislative Update E-Newsletter* to stay well-informed of national updates. It is now delivered as part of the *Hearing Loss Association of America e-news.*

To subscribe, visit www.hearingloss.org/membership/Sen.asp

The Hearing Loss Association of America Applauds the FCC for its Decision to Approve Internet Captioned Telephone for People with Hearing Loss

In October 2005, the Hearing Loss Association of America petitioned the Federal Communications Commission (FCC) to include Internet-enabled captioned telephone for reimbursement from the telecommunications relay fund. This petition was supported by more than 30 other organizations that support full telecommunications access for people with hearing loss. In December 2006, the petition was approved, bringing captioned telephone into the broadband world.

In 2006, the Hearing Loss Association of America together with other advocates and industry professionals held many meetings with FCC Commissioners, Chairman Kevin J. Martin, and FCC staff to demonstrate and discuss the benefits of captioned telephone for a significant group of Americans with hearing loss who up to now have been underserved by existing relay services.

Brenda Battat, associate executive director of the Hearing Loss Association of America commented, "We are delighted that the FCC listened and took a great leap forward by approving Internet Protocol captioned telephone. IP telephone captioning gives the most transparent, flexible and portable telecommunications service for those people with hearing loss who use their residual hearing and use spoken language. This is indeed a great way to finish up the year and gives us hope for other work that needs to be done in 2007."

Statement from the FCC

The Commission adopted a Declaratory Ruling finding that Internet Protocol captioned telephone service (IP CTS) is a type of telecommunications relay service (TRS) eligible for compensation from the Interstate TRS Fund.

Chairman Kevin J. Martin stated on December 20, 2006: "Today we take another step to help improve the quality of life for individuals with disabilities. By finding that Internet Protocol captioned telephone relay service is eligible for reimbursement from the Interstate Telecommunications Relay Services Fund, we make progress in fulfilling our statutory goal of ensuring that every person has equal access to this nation's communications services."

For more information go to **www.fcc.gov** or e-mail media contact Rosemary Kimball at r**osemary.Kimball@fcc.gov**.

Read Executive Director Terry Portis' comments about this decision on page 6 of this issue. HLM

Brenda Battat, M.S., is associate executive director and director of public policy and state development the Hearing Loss Association of America. She can be reached at **battat@hearingloss.org**.

Hearing Aid Tax Credit: Change of Control in House and Senate Alters Landscape for Hearing Aid Tax Credit

By Andy Bopp

On Election Day in November, control of the both the U.S. House of Representatives and Senate shifted to the Democrats for the first time since 1994. This change will have major repercussions for a wide variety of legislative issues including tax and healthcare policy. Hearing aid tax credit legislation and related proposals addressing the lack of financial assistance for most hearing aid purchases are also likely to be viewed from a different perspective by the new Senate and House leadership including influential members of the critical Senate Finance and House Ways and Means Committees.

We believe that prospects for hearing aid tax credit legislation have not been harmed by the Democratic Party takeover of Congress. The legislation has always been bi-partisan in nature, with more Democrats co-sponsoring the hearing aid tax credit bill in the

continued on page 18

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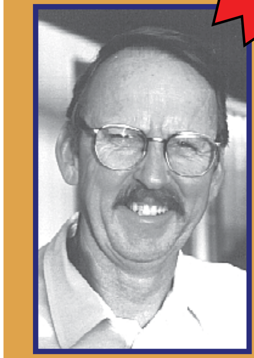

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National Update

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House(H.R. 414) than Republicans (59 Democrats, 52 Republicans).

In addition, targeted tax credit legislation has generally been considered more favorably by Democrats than Republicans who often focus on broad tax relief. Democrats have also traditionally focused attention on older Americans and children who are the two primary beneficiaries of the tax credit bill as drafted.

The close cooperation between the Hearing Loss Association of America and the Hearing Industries Association (HIA) in addition to other hearing health coalition partners has been fruitful over the past three years in generating broad support for the hearing aid tax credit.

In the 108th Congress (2003-2004), the group worked to galvanize coalition support and to supplement the efforts of Rep. Jim Ryun (R-KS) who introduced tax credit legislation in the House and Senate. Norm Coleman (R-MN) introduced a Senate companion bill. The House bill (H.R. 3103) attracted 68 co-sponsors while the Senate bill (S. 2055) was co-sponsored by two Senators.

In the 109th Congress (2005-2006), a direct focus by the coalition on increasing support helped to increase co-sponsorship of the House bill (H.R. 414) to 111 and 17 for the companion Senate bill (S. 1060). Rep. Jim Ryun (R-KS) and Senator Norm Coleman (R-MN) continued as the lead sponsors in each chamber. Of great significance, efforts to support the tax credit have worked to unify the hearing health community to work together for an issue of critical importance. In addition to HIA, which represents hearing aid manufacturers, the Hearing Loss Association of America has worked with groups that represent parents of children with hearing loss and several hearing aid dispenser groups.

The level of cooperation reached a new height on October 30, 2006, when the Pennsylvania state organization and the Pittsburgh Chapter of the Hearing Loss Association of America hosted a tremendously successful event to demonstrate to Rep. Melissa Hart (R-PA, Ways and Means Committee member) the importance of H.R. 414 to her constituents.

In addition, the A.G. Bell Association for the Deaf and Hard of Hearing and the DePaul School for Hearing and Speech in Pittsburgh co-hosted a program sponsored by HIA. Such targeted constituent activities will also be critical in the future to demonstrate genuine local interest to representatives and senators.

Outlook for 110th Congress

Not only did both legislative chambers change hands, but also several key hearing aid tax credit supporters were defeated in their reelection bids. The original sponsors of tax credit legislation in the House, Rep. Jim Ryun (R-KS) and Rep. Melissa Hart (R-PA), a leading Ways and Means supporter, were both denied reelection by voters. In addition, eleven other House co-sponsors either did not seek reelection or were defeated, although two House co-sponsors, Bernie Sanders (I-VT) and Sherrod Brown (D-OH), were elected to the Senate where they could have greater impact on passage of the bill. Also, several S.1060 co-sponsors will enjoy greater influence in the 110th Congress including Sen. Hillary Clinton (D-NY), Sen. Herb Kohl (D-WI), who is the new chairman of the Senate Aging Committee, and Sen. Tom Harkin (D-IA) who is a longtime supporter of hearing health initiatives.

Our original Senate sponsor, Sen. Norm Coleman (R-MN), will continue as a champion of the hearing aid tax credit in the 110th Congress, which is critical given the importance of bi-partisan Senate support.

Although the chances for a major tax overhaul package are slim in the upcoming Congress, targeted tax credit proposals are likely to be considered favorably. Nancy Pelosi, the new Speaker of the House, has indicated that she supports increases in specific tax credit programs, which generally bodes well for a bipartisan proposal such as the hearing aid tax credit.

In addition, our coalition has already met with a representative of the Bush Administration, and we believe that the hearing aid tax credit represents the type of bi-partisan legislation that can attract support from a Democratic Congress and Republican Administration.

In the final analysis, congressional changes could create more opportunities for passage of a hearing aid tax credit bill in the 110th Congress. The actions of the hearing health coalition over the past three years to generate broad bi-partisan support should enable the group to work with the new Congress as well as the Bush administration to advance the bill. HLM

Andy Bopp is director of Regulatory Affairs, Hearing Industries Association. He can be contacted at **abopp@clarionmanagement.com**.

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All sessions, workshops, and major events at the convention are real-time captioned. Assistive Listening Devices (ALDs) are provided free of charge by request at the Hearing Loss Association of America Registration Desk. Sign language interpreting services are provided at all major events. If you have assistive listening devices that you can use during the convention, please bring them with you.

Special Events

Harn Homestead and Museum Offsite Event

Put on your casual duds and head out to an 1889 old west Victorian homestead for dinner, entertainment, games, and more. This ticketed event is included in the **Full Activity Package**. Tickets can be purchased separately in advance for $35. Have a peek at **www.harnhomestead.com**.

Association Banquet

Please join us for the annual Association Banquet the evening of Saturday, June 23. Ticket availability is limited so please register in advance. Banquet tickets are included in the cost of the **Full Activity Package**. If you are purchasing your tickets separately, the cost is $65 in advance or $70 at the convention.

Research Symposium

Psychological and Social Issues Related to Hearing Loss

Co-Chaired by Terry D. Portis, Ed.D., and Carren J. Stika, Ph.D.

Hearing loss can have a dramatic impact on a person's quality of life. Issues such as self-esteem, relationships, emotional well being, and interpersonal communication will be discussed during this three-hour session. The Research Symposium is included in the **Full Activity Package** and the **Education Package**. For Symposium only, the **Sunday Package** is $25.

Hotel Accommodations

Group room blocks have been secured at two locations which are conveniently connected to Cox Business Services Convention Center, the site of Convention 2007. Please make your reservations by June 1, 2007, to secure your $125 Single/Double rate.

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Online reservations:

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(Remember to mention **Group Code HLAHLAA** when making your reservation with The Renaissance via phone or enter the Group Code in the provided space when making your reservation online.)

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One N. Broadway, Oklahoma City, OK 73102
405.235.2780 phone • 405.272.0369 fax

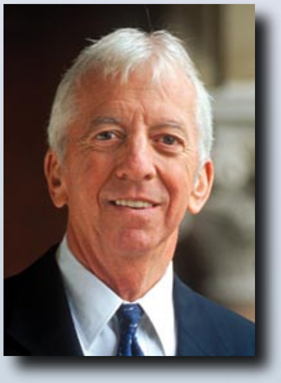
Online reservations:

www.starwoodmeeting.com/Book/HLAA

I. King Jordan to Deliver Keynote Address at Opening Session, June 21, 6:30 p.m.

I. King Jordan, Ph.D., made history in 1988 when he became the first deaf president of Gallaudet University in Washington, D.C., the world's only university with all programs and services designed specifically for students who are deaf and hard of hearing. That year Gallaudet students, with support from many alumni, faculty, staff and friends of the University, protested the Board of Trustees' appointment of a hearing person to the presidency.

Called Deaf President Now (DPN), the week-long protest was a watershed event in the lives of deaf and hard of hearing people all over the world. At its conclusion, the Board reversed its decision and named I. King Jordan, one of three finalists for the position, the eighth president of Gallaudet and the first deaf president since the institution was established in 1864.



Since DPN, Dr. Jordan's leadership has heightened public awareness of the important educational contributions Gallaudet makes to the nation and the world. He serves as an international spokesperson for deaf and hard of hearing people, as well as an advocate for all persons with disabilities.

Dr. Jordan is a native of Glen Riddle, Pennsylvania, a small town near Philadelphia. After graduating from high school, he enlisted in the U.S. Navy and served four years. An automobile accident left him profoundly deaf at age 21. Dr. Jordan earned a bachelor's degree in psychology from Gallaudet in 1970. The following year he earned a master's degree, and in 1973 a doctorate, both in psychology and both from the University of Tennessee. As professor, department chair, dean, and president, Dr. Jordan has made numerous scholarly contributions to his field. In addition, he has been a research fellow at Donaldson's School for the Deaf in Edinburgh, Scotland, an exchange scholar at Jagiellonian University in Krakow, Poland, and a visiting scholar and lecturer at schools in Paris, Toulouse, and Marseille, France.

In 1990 President George Bush appointed Dr. Jordan Vice Chair of the President's Committee on Employment of People with Disabilities (PCEPD). In 1993, President Clinton reappointed Dr. Jordan Vice Chair of PCEPD.

He Jordan retired as president of Gallaudet University on December 31, 2006. Shortly after his appointment as president, Dr. Jordan spoke at the 1988 SHHH Convention in Rochester.

CONVENTION 2007 PROGRAM HIGHLIGHTS

Dates and times are subject to change. You will receive the most current schedule at the convention when you receive your Convention 2007 Program book. Check www.hearingloss.org for the most up-to-date schedule.

THURSDAY, JUNE 21

8:30 a.m. **Open Board of Trustees Meeting**
Meet the Hearing Loss Association Board of Trustee members.

10 a.m. **Registration Opens**
Attendees pick up their badges, special events tickets, Convention 2007 Program book, tote bag, and sponsor giveaways at the Hearing Loss Association Registration Desk.

11 a.m. **Exhibit Hall Opens**

1:30 p.m. **Newcomers Meeting**
All first-time attendees are invited to attend this informative overview program. Hear about what's at the convention this year, and how to find everything you'll need for an amazing learning experience.

4 p.m. **Exhibit Hall Grand Opening & Reception**
Welcome to the Exhibit Hall where attendees can learn about the latest hearing assistive technology and services, participate in product testing, and meet absolutely everyone while enjoying hors d'oeuvres.

NEW THIS YEAR!

6:30 p.m. **Opening Session**
Keynote Address given by Dr. I. King Jordan, president ermeritus of Gallaudet University

8 p.m. **Get-Aquainted Party**
Get reacquainted with colleagues and meet new ones at this always-popular bash arranged by the Oklahoma Host Committee. Come for the food, libations, entertainment, and camaraderie!

FRIDAY, JUNE 22

8:30 a.m. **Awards Ceremony and Breakfast**
Join us as we recognize the outstanding achievements of our dedicated members and volunteers.

10:30 a.m. **Workshops Begin**

7 p.m. **Harn Homestead & Museum Offsite Event**

SATURDAY, JUNE 23

9 a.m. **All-Day Workshops Begin**

3:30 p.m. **Ice Cream Social**

6 p.m. **Banquet Reception**

7 p.m. **Association Banquet**

SUNDAY, JUNE 24

8 a.m. **Worship Service**

9 a.m. **Research Symposium**
Psychological and Social Issues Related to Hearing Loss — *Co-Chaired by Terry Portis, Ed.D., and Carren J. Stika, Ph.D.*

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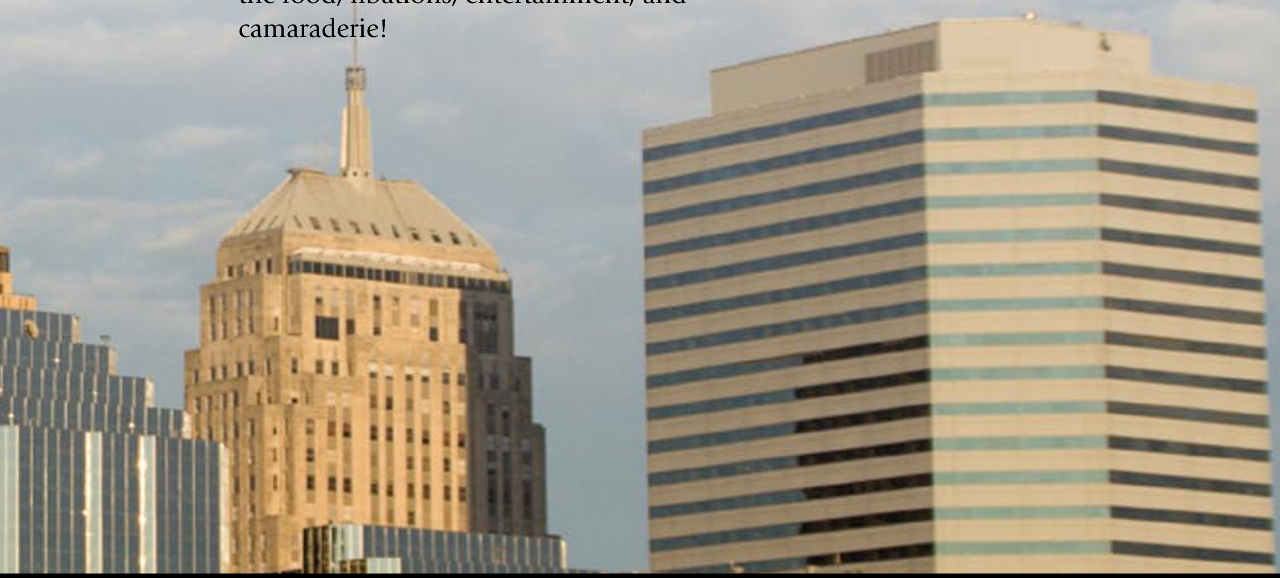

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"To Be, or Not to Be"
Disclosure is a Personal Choice

By Scott J. Bally

Deciding to reveal one's hearing loss is a difficult personal decision and requires some soul searching. Individuals must decide for themselves when and to whom they will reveal their hearing loss.

There are several reasons which people use to justify not telling others about their hearing loss. I'd like to express my thoughts on each of these "reasons" for your consideration.

These may include:

No one knows, so why should I tell them?

People will think I am less competent.

People will make fun of me.

I can hear well enough; when I need to, I just try harder.

Hearing aids are too expensive.

People may think I am getting old.

It's no one's business but my own.

I'm just not ready.

No One Knows

Big news! They already know! Reports from hundreds of adults with hearing loss reveal that, in most cases, when individuals do decide to reveal that they have a hearing loss, they report that the people they tell first...family and close friends...say they already knew.

Further, the friends say that they didn't bring it up because they didn't want to embarrass you or feel uncomfortable. In some cases they may have guessed that hearing loss was a problem before you did.

> "When you are not successfully communicating, it becomes the business of others. How you respond to the questions and comments of others may have a strong influence on their lives. Mis-communications can cause hurt feelings, missed appointments, and misunderstood directions."

People Will Think I'm Less Competent

Consider that the misunderstandings and mistakes you make because of hearing loss may be interpreted in a variety of ways. When you don't understand people and say "Huh?" they may assume you are: 1. not too bright; 2. not too articulate; or, 3. not too interested.

From my perspective, having them know you have a hearing loss is the better alternative. At least they will know I am competent enough to address the issue and do something about it!

People Will Make Fun of Me

It's more likely that people will make fun of you when you don't address the effects of hearing loss. Wrong or inappropriate answers to questions will leave people with puzzled looks or shaking their heads. If the pattern continues, you could become the object of ridicule. Frankly, I'd rather let people know I have a hearing loss and openly try to address its effects than to have others have an opinion of me based on my misunderstandings.

People May Think I'm Getting Old

It's hard to argue with this. Hearing loss is a natural and normal part of the aging process. However, we all want to grow older gracefully. Careful use of discreet technology such as an in-the-canal hearing aid (when appropriate) and effective use of communication strategies may allow us to have successful communication. When a person is less able to compensate and communication problems do occur, there may be good reason to disclose the hearing loss.

I Can Hear Well Enough When I Need To; If I Have Problems, I Can Just Try Harder

This mind set suggests that hearing loss is only a problem in limited contexts or when you are aware that there is a problem. It also suggests that making some minor adjustments allows you to compensate for the loss.

Think how much easier it would be if you could address the problem by making some small, but ongoing adjustments to your life style such as using less noticeable forms of amplification or employing communication strategies to prevent the problems from occurring in the first place. Disclosure may give you the opportunity to ask others to help in small ways such as speaking a bit louder or more slowly.

Hearing Aids Are Too Expensive

No doubt about it, hearing aids are pricey. Hearing aid dispensers explain that manufacturer's research costs and store overhead are factored into hearing aid costs. Also, each customer must have separate testing, fitting and adjustments, which are also part of the cost. They also emphasize that hearing aids are not sold in vast quantities like televisions. However, dealers still need to make enough profit to earn a living. So, it would appear, buyers pay more to compensate.

When you consider the cost of amplification you should consider the frustration of difficult communication as well as the time wasted when communication fails. Your self-image and the perspectives of others with whom you communicate cannot be ignored. It would be difficult to put a cost on the psychological and social impact of hearing loss on communication, but it should be considered when thinking about such an investment.

Costs may be contained somewhat if you are a good comparison shopper. Within one community, a $500 difference in the price of a specific hearing aid was documented by a consumer magazine. In addition, if you are in serious financial need, many community clinics and universities that have audiology training programs have sliding fee scales for those in need.

It's No One's Business But My Own

When you are not successfully communicating, it becomes the business of others. How you respond to the questions and comments of others may have a strong influence on their lives. Mis-communications can cause hurt feelings, missed appointments, and misunderstood directions.

I'm Just Not Ready

Indeed, that may be true. Ultimately each person needs to make his or her own decision about disclosure. For some, disclosure may be very painful; however, the pain may be relative and consideration should be given to the perception others have of you as well as the difficulties which are caused by communicating in a less than optimal way.

You may opt to disclose on a need-to-know basis. Trying it with a trusted friend or family member may be easiest. Explain the situation and be prepared to give suggestions for how the person you tell can be supportive of your needs. Don't forget to tell them the things you are doing to help yourself.

> "Readiness is an important factor in disclosure. Only you know when the time is right and you are truly ready to to take that important step. It may take a measure of courage to do so."

Readiness is an important factor in disclosure. Only you know when the time is right and you are truly ready to take that important step. It may take a measure of courage to do so. If you are not ready at this time, try to keep disclosure as a personal objective, knowing that when you are ready and able you will.

Knowing that revealing your hearing loss may help you and others better adapt to your hearing loss is an important first step in coping with it. HLM

Scott J. Bally, Ph.D., CCC-SLP sits on the faculty of both the speech-language pathology and audiology programs in the Department of Hearing, Speech and Language Sciences at Gallaudet University and teaches in both master's and Au.D. programs. He holds a bachelor's degree in education with a major is speech & hearing science from Truman State University. He has a master's degree in communication disorders with a specialization in aural rehabilitation from Colorado State University, and a master's of social work with a focus on aging and hearing loss from Gallaudet University. He earned his interdisciplinary doctorate in gerontological aural rehabilitation from The Union Institute. Dr. Bally also is curriculum consultant for HLAA's American Academy of Hearing Loss Support Specialists.

REFLECTIONS

...On My Cochlear Implant

We've valued his insight for years on hearing aids and assistive technology. Now, world-renowned audiologist and regular contributor, Mark Ross gets a cochlear implant.

By Mark Ross

At the time this article was written in late December 2006, Mark Ross was scheduled to receive a cochlear implant. We are pleased to report he had the implant with success. In this article he talks about his personal experiences leading to his decision to get an implant.

Not only is Dr. Ross an audiologist, but he is also a consumer, which makes his articles unique. He has always married these two perspectives for our readers on various topics. He will continue to write about research, hearing aids, and assistive technology, but we will also be treated to articles about his observations, adjustments and the rehabilitation process from having a cochlear implant.

Making the Decision

I am sure that my experiences leading to the decision to get an implant were no different than those confronted by thousands of other current implant users. Like them, I experienced declining auditory abilities, to the point where many verbal interactions became very difficult and often impossible.

Superficially, I appeared to be doing acceptably well, particularly on a one-to-one basis or when I was controlling the conversation. This can be attributed, I believe, to my ability to compensate by using visual and non-verbal clues, to predictable situations, the innate redundancy of the English language, and some creative guessing on my part. But it was (and is) tough going. Only I (and my wife) really know how much effort I put into these discussions and what I was actually missing.

Having an easy conversational exchange, where I could comprehend both the speech directed to me and toward others in the group, just doesn't happen anymore. In some ways, the most frustrating experience of being severely hard of hearing occurs when I am sitting at a table with three or four people and unable to participate fully in the exchanges, simply because I can't comprehend what they say to each other. And it happens even among members of my own family whose love and respect for me cannot be doubted. For me, an improved (not perfect!) ability to participate in such group conversations will serve as my major criterion for a successful implantation.

During this period of declining auditory abilities, I often upgraded my hearing aids to compensate for the progression in the hearing loss. I was determined to squeeze out every dB of audible speech possible in every situation. Since I kept up with new developments in hearing aids, I knew what was available; and, fortunately, I am usually able to try promising new hearing aids, which has often helped.

At that time, however, some power digital aids were introduced that included effective feedback management systems. This meant that I could obtain about 10 dB more effective amplification without feedback, and this made all the difference for about a year. But my hearing loss, particularly in my right ear, continued to worsen, and soon the additional amplification possible with these new aids had less and less practical significance (though some aided audibility was still possible). My hearing thresholds now average about 110 dB in the right ear (95 dB or so in the left). The fact that I could do as well as I did for as long as I did is testimony to the marvelous advances in hearing aids.

I finally reached a point, about a year ago, where I was ready to get an implant. I could no longer understand on the telephone using just my right ear (I now routinely use both my ears on a telephone with a neckloop). However, given that I believe I had reached the maximum hearing aid benefit possible, coupling that with the impressive progress made by cochlear implants in the last few years; it seemed past time to make the implant decision for myself.

Auditory Limits

It is important to note that the potential benefits of any hearing aid are ultimately fixed by the limits imposed by a damaged auditory system. No hearing aid can exceed these limitations. If the hair cells in some portion of the cochlea are dead, then they cannot trigger neural impulses no matter how much amplified sound is delivered. Additionally, even when they are not completely dead or are absent, scattered dead and damaged hair cells will produce fundamental psychoacoustic abnormalities that will likewise limit the basic speech perception capacities of that particular ear.

Audiologists try to fit hearing aids with the kinds of "prescriptions" and features that will enable them to get as close to these physiological limits as possible. Also, much can be accomplished with current technology that is not being fully exploited (e.g., personal FM systems).

Eventually, however, the speech analytic capacities of the ear will have been reached, no matter how much "better" (or more expensive) the hearing aids are. When these limits fall significantly below the average results now obtainable with a cochlear implant, then the time has come to consider an implant.

But, it wasn't easy for me to make this decision for myself. In the last 15 or 20 years, I have suggested the possibility of a cochlear implant to many people (referring them to cochlear implant centers). Although it was a move I encouraged, it was never a recommendation that I made lightly.

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Cochlear Implant

continued from page 25

But, it was one I was glad to make; I well remember the difficult situations that existed in the years before implants were developed, the options that did not exist for late-deafened adults and deaf children.

Now that I myself was the patient, the decision seemed to take on a whole different order of difficulty and conflict; it was a lot easier to suggest that someone else consider an implant than to get one myself. I still wonder if I'm doing the right thing (even now, as I'm writing this section three days before my surgery).

The Next Steps

My next step was to refer myself to a cochlear implant center and go through its routine procedures. As a veteran with a service-connected hearing loss, I elected to obtain my implants through the Veterans Administration (V.A.) As it happens, in New York the well-reputed NYU Cochlear Implant Center manages this responsibility for the V.A, with many of the professional personnel holding joint appointments. All my pre-op testing was conducted at the NYU Center, as will most of the programming procedures to be conducted after the implant is activated.

Testing

The results I obtained on the speech tests presented me with a quandary. If one judges implant candidacy primarily upon sentence recognition scores, then I was not a candidate since I obtained scores in excess of the usual criteria (50 percent or less in the ear to be implanted and no more than 60 percent bilaterally).

But I achieved my relatively high scores with a great deal of effort, using my knowledge of the language to make linguistic predictions, but I was rarely completely sure that my choices (or guesses) were correct. As long as I could hear part of the sentence, however, I could often figure out the rest.

Many people with long-standing hearing losses possess similar capabilities. Current audiological tests administered to any person with a hearing loss—implant candidate or not—do not measure the *effort* required to comprehend speech, the time it takes to make a decision, or the *confidence* with which a decision is made.

But these factors define the reality situation confronting a person with hearing loss who is attempting to understand speech. It often takes me longer to figure out what someone has said and I expend much more energy doing this than someone with normal hearing. Moreover, I am never quite sure that I'm completely correct.

My basic acoustic potential was much more accurately reflected in my scores in a test in which linguistic competency was basically irrelevant (a monosyllabic word recognition test). In this test, I obtained an 18 percent score in my right ear. It was this score that validated my decision to get a cochlear implant. And, any objective evidence regarding the efficacy of the implant will have to be demonstrated primarily by significant improvements in this score.

Realistic Expectations

As an audiologist, I've counseled many people regarding what realistically can and cannot be expected from a hearing aid. We know that hearing aids usually do "aid" hearing, but also that they cannot completely replace natural hearing. This is a message that ethical hearing aid dispensers consistently convey to their clients. The need to do this is even truer for potential cochlear implant candidates.

Audiologists will emphasize, over and over again, that the cochlear implant, while a truly marvelous technical creation, is not going to replace a normal cochlea. People cannot enter the implant process expecting to exit with normal hearing. So "realistic expectations" is always an important component of the pre-implant counseling process.

I know all this, and I am aware that I must be realistic in my expectations, and I believe I am. But at the same time, unbidden and lurking not far beneath the surface, are my unrealistically high hopes. Not that I will wind up with normal or close-to-normal hearing—I can't imagine that result even in my wildest daydreaming—but that I will, for example, be able to function fairly normally in challenging group conversational situations. Rationally, I know this is unrealistic, but irrational hope cannot easily be contained.

It is currently impossible to predict precisely just how a specific person will function when using a cochlear implant. The group results to date have been impressive. There is no doubt but that the overwhelming majority of new implant users hear better with the implant than they did before, with hearing aids.

Still, one puts one's residual hearing in the implanted ear at risk when the internal electrode is inserted into the cochlea. So if a person has something to lose then the decision to be implanted means balancing the probability of losing one's natural hearing with the strong possibility that the overall results will be favorable.

Of course, the worse one's natural hearing is, the better the chances are for net gains in speech perception. In my case, the odds seem to be in my favor and so I am going ahead with it. Nonetheless, it would not be honest for me to suggest that I do not feel any apprehension that I will lose this particular bet. Of course I do. So, I suppose like most people embarked on this course, I am balancing "realistic" expectations, my highest hopes, and my underlying apprehensions.

> **"Of course, the worse one's natural hearing is, the better the chances are for net gains in speech perception…the odds seem to be in my favor and so I am going ahead with it…it would not be honest for me to suggest that I do not feel any apprehension that I will lose this particular bet. Of course I do…I am balancing realistic expectations, my highest hopes, and my underlying apprehensions."**

Choices

Then the time came for me to make a decision regarding which one of the three current cochlear implants to request. From everything I have been able to determine, from the research and from anecdotal reports, people do well with all brands of cochlear implants. No one of them stands out as clearly superior. All companies have introduced new models that seem to be "state of the art" systems (at the present time only!). I would have been as comfortable with my decision with any—and as apprehensive.

I spent quite a bit of time reviewing these companies' websites, communicating with their representatives, and discussing the pros and cons of each with various colleagues. Each time I looked at the technical specifications and marketing claims of the implants, or each time I listened to an advocate, I was convinced that that was the one for me. The companies made convincing cases and the devices appeared to be designed to maximize the amount of speech information available to a listener.

While each has unique features, these differences (such as they are) do not seem to result in speech recognition scores clearly superior to the other. What it seems to come down to, at least to my way of thinking, is the immense contributions made by the human brain in the speech recognition process. Evidently, the acoustic raw material (transformed into electrical impulses) that either implant provides to the central auditory system permits fairly equal auditory learning to take place.

The Map

As I considered the pros and cons of either implant, it was also apparent that one crucial consideration, applicable to all implants, is how the device is programmed (the "map"). Unlike hearing aids, this is not a pre-programmed response pattern that depends primarily upon variations in audiometric results. With hearing aids, all that is necessary is to plug the audiometric results into the fitting computer and a "prescribed hearing aid response" (or several) emerges—to be "fine-tuned" later as required.

The people receiving implants, on the other hand, begin at ground zero; all are considered to have a non-functioning cochlea. Therefore, an audiogram is irrelevant for the mapping process. Because of the likelihood of individual differences in the survival of various auditory fibers in the auditory nerve, and because of variables associated with the insertion of the internal electrode, it is impossible to create a standard program for each individual. There are default measures, to be sure, gained from research and from generalizing the results taken from thousands of people who have already been fit, but some actual programming measures still have to be taken.

Only a few at first, for the youngest children, since they are unable to make the necessary voluntary responses; these are supplemented by interpolations and general estimates in setting some of the dimensions. These settings are refined later as the child gets older and can participate in the test. Adults, on the other hand, have to go through the entire mapping sequence, a process that will take a number of hours. Even now, before I am actually implanted, the NYU Cochlear Center has scheduled me for four follow-up appointments subsequent to the device's activation.

The Process of Mapping

The process of mapping actually begins in the operating room. My audiologist will be there during surgery to measure the viability of each electrode electronically (impedance and neural response telemetry). Then an X-ray will be taken and if the scan looks good, the surgeon will close the incision. Once the incision has healed and the implant's external component placed in position, the implant will be activated. At this time, the audiologist will commence her/his critical role in programming.

The more I have gotten into this, the greater is my appreciation of this whole new world of professional challenges facing audiologists. Mapping (or programming) the implant is a complex process, depending, it seems, equally on the client's responses and the competency of the audiologist. Clearly, it is not a "cookbook" procedure. From everything I've been able to gather, the "art" of working with human beings, plus the ability to interpret a client's overt or involuntary responses, is a key ingredient to a successful map. An overriding goal is to "map" as much of the acoustic input as possible into the electronic dynamic range determined during the mapping process.

The audiologist determines the amount of electrical current necessary to produce an audible sound in each electrode (the "T" level), and then the current level which produces a loud, but comfortable audible sensation (the "C" point). The difference between these two points is the electrical dynamic range. The audiologist also has to make a number of other programming decisions, such as the rate of stimulation, the bandwidth of

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Cochlear Implant

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each electrical pulse and the acoustic frequencies to assign to each electrode. Other controls (such as microphone sensitivity and volume) are under the control of the user, but it is important to realize that variations in one setting may impact upon others. This is evidently where the "art" of mapping comes in, where the audiologist will make changes depending upon the experiences of the user.

Also, maps may change over time, though I'm not yet sure why. Possibly a certain amount of neural adaptations occur at certain frequency and contact positions, to the extent that it is necessary to reset some of the initially mapped parameters. This is an area that I expect to learn much more about as I proceed with my own mapping. I'm afraid the audiologist who will be working with me (who has been gracious and forthcoming) is going to be faced with a patient with lots of inquisitive questions.

In a future article, I'll comment on what I will have learned about mapping as I went through the process myself as a patient.

Hearing Aid Fittings vs. Cochlear Implant Follow-Up

The organized and careful follow-up testing that is done for people receiving cochlear implants does raise a question about the relative absence of such care for people wearing hearing aids. People listening through hearing aids want to, and need to, hear as much as they are able to with their device. After all, what is heard through a hearing aid is no less significant than what is heard via an implant.

Yes, I know that implants were designed for people with more severe hearing losses than hearing aid users usually have. And I know that implants require a time-consuming activation process that necessitates special training and skill on the part of the audiologist. But that does not mean that the selection and fitting of hearing aids is a trivial and superficial process in comparison.

On the contrary, to do it right and to be assured that a person is obtaining the most hearing benefit that can reasonably be expected takes skill, special knowledge, and time. I have no quarrel with the care with which implants are fit and followed up; my concern is that this same degree of commitment is also required when it comes to hearing aids, something that is more often lacking than present.

For example, the American Academy of Audiology-recommended guidelines in fitting hearing aids includes the necessity of measuring the output of a hearing aid in the real-ear. What this measure requires is the insertion of a very fine tube into the ear canal, alongside a hearing aid and extending slightly beyond it. This tube leads to a microphone that measures the amplified sound in the ear canal between the tip of the ear mold and the eardrum.

It is the best direct measure of hearing aid performance available. By plotting the amplified sound on the same chart as a person's hearing thresholds and loudness tolerance levels, a single graphic displays the degree of aided audibility across frequency. No other audiological measure can do that, not traditional coupler measures nor the programming computer used in fitting hearing aids. Real-ear measures permit a visual display of what a particular person actually hears with the hearing aid in his or her ear.

Real Ear Measurement

Only a few audiologists (about 20 percent) routinely do real-ear measures in their hearing aid fittings. And there are other tests and measures which can be used to evaluate and to modify the performance of hearing aids, such as speech-in-noise measures, which only a minority of hearing aid dispensers routinely administer.

Unlike hearing aids, when it comes to implants, audiologists generally do not short-change the evaluation or follow-up process; it's all considered necessary.

My hope is that the same degree of care and concern shown with implants also be provided to people wearing hearing aids. In my case, I can almost hear my left (hearing aid aided) ear complaining about the extensive services, its sibling (my right, soon-to-be implanted ear) has and will be receiving compared to what it receives.

The Implant is in Place

The surgery date has come and gone and I'm now one week into the recovery process. I was advised that the surgery itself is a "minor" procedure, and I always thought it was. However, when one is the recipient, no such procedure can be considered "minor." In anticipation, I worried about the general anesthetic, about pain, and about the success of the operation.

Fortunately, my worries were groundless. I had a first-class group of professionals taking care of me, which was comforting. During surgery, the audiologist determined that all the electrodes were fully functional; i.e., that I will be starting this particular game with a "full deck."

Now all I have to do is wait until the next challenge: the first activation date. Initially, realistically, I expect to hear sound-gibberish through the implant, sounds that—with time and training—will organize itself into intelligible speech. But still, unrealistic as it may be, I hope for more immediately. When next I write on this topic, we'll see what the reality is. HLM

*Mark Ross, Ph.D., is an audiologist and associate at the Rehabilitation Engineering Research Center (RERC) at Gallaudet University. To find more Dr. Ross articles on technology for consumers, go to: **www.pa-shhh.org** and **www.hearingresearch.org***

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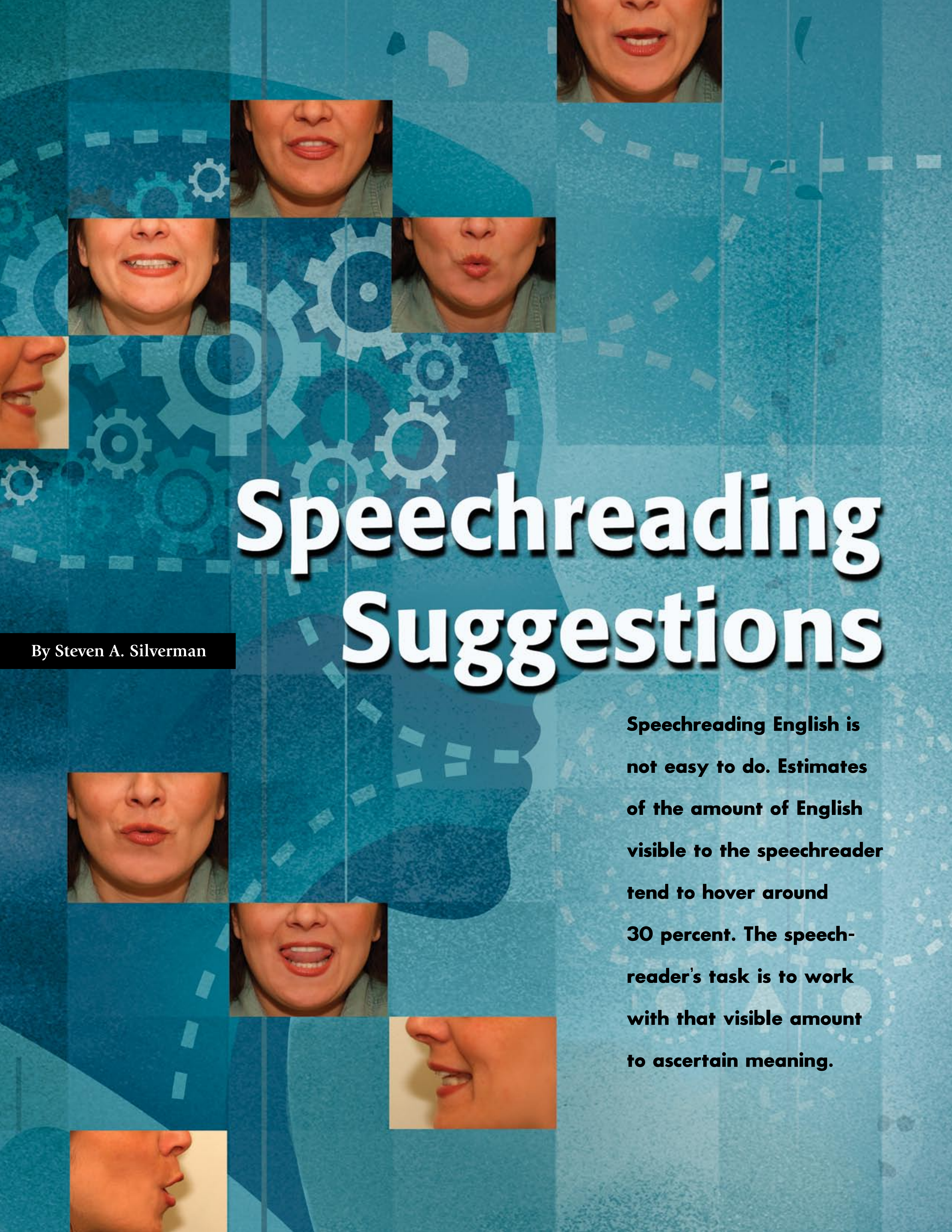

Speechreading Suggestions

By Steven A. Silverman

Speechreading English is not easy to do. Estimates of the amount of English visible to the speechreader tend to hover around 30 percent. The speechreader's task is to work with that visible amount to ascertain meaning.

The suggestions in this article for speechreader and speaker are mostly from personal experience and unattributed materials acquired over 20 years of hearing loss. — Author

The camera pans to a young woman sitting alone in a convertible as her traveling companions leave her at the pump while they run into the mini-mart. A man, one she has presumably never seen before, goes into a phone booth, picks up the receiver, and engages in a prolonged conversation. While his profile or less is all she can see, the young woman watches intently, and becomes increasingly agitated, only to fairly pour out sign language when her companions return. She had read the lips of that stranger, and had seen him discussing the most heinous plans, which she delineates in animated, accurate detail, having understood every nuance. TV reality.

Real life: speechreading a stranger 50 feet away and not even facing you? No way. In his *HOH-LD-News*, Volume 14, Issue 5, Larry Sivertson reports that a Scottish woman lipreader, "Can lip read what is being said even when her subject is not facing her, is speaking in an accent, and has a beard.

"Her skill has caught two IRA bomb plotters and snared a gang behind a £2.9 million heist at Heathrow Airport in London. She has watched people talking about how to chop up corpses before."

That statement immediately follows Sivertson's assertion, "The media often portrays people with hearing loss who can understand a complete conversation from across the room. But speechreading (lipreading) experts assure us that those depictions are very unrealistic."

It *is* unrealistic. No qualifiers. Can that woman do it? An everyday maxim says, "Don't let those who say it cannot be done get in the way of those doing it." I have seen entirely too many validations of that expression to discount it entirely. At its very best, however, those kinds of speechreading skills have to be no more than extraordinarily rare, noteworthy for their vast distance from mainstream lipreading abilities. The simple facts are that lipreading strangers, mustachioed men, people with accents, fast talkers, three-year olds, and mumblers ranks perilously near impossible.

> "The media often portrays people with hearing loss who can understand a complete conversation from across the room. But hearing loss experts assure us that those depictions are very unrealistic."

In terms of physical realities, speechreading at all should be impossible. The human eye simply cannot process visual information at the speed of normal speech. Nevertheless, I do it, and have seen others do it as well or better than I.

The suggestions below for speechreader and speaker are mostly from personal experience and unattributed materials acquired over 20 years of hearing loss.

Much of the available information on speechreading focuses only on language reception. This information overlooks both the speechreader as a party to communication and his or her expressive obligations in the conversation. These omissions mean communicative flow is not discussed as fully or helpfully as it could be, so I will include those aspects as well as language reception.

I will use the words "speechreading" and "lipreading" interchangeably. Forgive me, please, if some of these observations are insultingly obvious.

Speechreading Suggestions for the Speechreader

Educate. You know more about lipreading and your needs than the other person, so you are actually doing him or her a favor and educating by making communication more accessible.

Maximize your residual hearing. Do this by manipulating the circumstances to minimize or eliminate competing sound, making sure the better hearing ear is oriented toward the speaker, and by using assistive devices (audio loop systems, FM and infrared systems, or others). Combining your residual hearing, amplification, and lipreading in efficient ways provides the greatest amount of information.

Assert your needs. You want to understand as much as the speaker wants you to, so show that. Request what you need politely, such as, "Will you please take your hand off your chin?" or "Please face me," or "Please throw out your chewing gum because it will make it easier to understand you," or ask the restaurant manager to lower the sound of the music, raise the lights, or place you at a well-lit table.

Ask for the topic so you know what it is. "What are you (we) talking about here?" works a whole lot better than taking time to figure it out.

Choose where you sit or stand in anticipation of your communication needs. For example, face where the waiter will be, where there is little movement or light behind the speaker you will talking to most, and position yourself where you can use your residual hearing best. Sometimes it's necessary to prioritize these things (if I must choose, I prefer to face the person I wish to hear most and not where the waiter will stand).

Find the best listening position. Ask if a small change will help your visual access, "Please move a little to the right." Make sure your back is to the light so that it falls on the speaker's face ("Can you please move a little to the right so I can see you

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better?") and that the speaker is at the same relative height as you ("Won't you please take a seat, too?") Move to make sure you are between three and six feet from the speaker if possible.

Assume that you have a right to understand. If people are saying it, obviously, they think it's important for you to know it. A personal pet peeve: being told, "It's not important," or "Never mind." Anything important enough to say to me once is important enough to repeat or rephrase.

Do not bluff. Bluffing is exposed sooner or later, sometimes with very embarrassing results, such as finding you've "uh-huh"-ed yourself into a commitment when you were just trying to appear understanding; or saying something totally inappropriate, such as, "That's nice," immediately after someone passed along very distressing information. (Been there, done that.) That's why I try to never bluff, although honesty directs me to admit that I do have some rare moments of it.

Ask for repetitions when you need them. When asking for a repetition, also ask for clarification or to rephrase the sentence. Instead of "Huh?" or "What?" or "I didn't understand that," ask the speaker to fill in the blanks by letting them know what you do understand "I know you're talking about a family member, but don't know if you're saying Gary or Karen." (Yes, non-lipreaders, those look identical.)

Let the speaker know you're lipreading. Say, "Please face me so I can read your lips." If your request begins, "I'm sorry, I'm hard of hearing (or deaf)," implicit is that you're sorry for yourself. You have no reason to be, so there's no need to begin that way.

The opposite side of that is how you handle when a person responds to that opening by saying, "I'm sorry." I tend to smile and reply, "I'm not," which normally gets a smile in return and seems to calm a lot of tension during communication.

Make conversations one-on-one to the greatest extend possible. In big groups the topic is hard to follow, the speaker harder still, especially if people talk at the same time.

Use reflective listening techniques to show understanding. "Ah, you're going to the big party next weekend, too," so the speaker knows you're understanding. A bluff "Uh-huh" doesn't help you or the person who wants you to understand.

Author Steven Silverman is speechreading his wife Lisa. © Steven A. Silverman

Anticipate context. At the bank, they'll ask about whether you want to make a deposit or withdrawal. At a restaurant, the waiter will want to know what kind of salad dressing you want or what you want to drink; and your mother…(I think I will leave that one to you…)

Remember, you don't have to get every word, just the meaning of the whole. It's not worth the aggravation trying to get every article or preposition.

Suggestions for Communication Help

Read the book or play first if you're going to be attending a movie or play without communication access beyond sound.

Be aware of hearing people's reactions to the environment. Did someone just come into the room? The hearing person usually looks toward the door when someone enters.

Be prepared that the conversation's topics will change. Ask for clarification of the topic by telling what you know "We were just talking about Debbie's wedding, but now we're not. What are we talking about now?"

Keep abreast of the news and world events. These will help when people are talking by providing you with more and better context.

Relax! Straining to lipread is counterproductive. Lipreading is harder if you TRY. Relaxing helps lipreading more than getting anxious does. Too much deliberate concentration tends to interfere with understanding, not help it.

Speechreading takes *much* more energy than listening with ears. Take what I think of as "eyeball breaks" (in a group setting, that sometimes means a false bathroom run for me). Turn to another activity or rest when your eyes let you know they need a break. It's fair and reasonable to say, "I'm going to tune out for a couple of minutes. Who will fill me in on what I miss?" Realize that lipreading is more difficult if your eyes are stressed or you're tired. Being sick or tired makes lipreading harder because it makes any kind of concentration harder.

Familiarity with the speaker tends to make lipreading easier. Even if initial contact proves frustrating and only minimally successful, time will normally make the new person's speech patterns more familiar and easier to read.

That's not to say that even the very best speechreaders will be able to understand everybody and everything. They won't. The attitude that works best for me is that all I can do is all I can do. If that comes up short, I am more than willing to explore other ways to get the speaker's message, including asking them to verbally spell the word I missed or to write it down.

Speechreading Suggestions for the Speaker

Speak slowly, but not too slowly to keep meaning, since all languages have comparable rates of processing.

Separate your words when you speak. In English, people naturally get a bit lazy. "Some monkeys" looks like "somonkeys" most of the time. Separating greatly eases the lipreading challenge of knowing when one word ends and the next begins.

Beware of that childhood bit of nonsense in which one child asks another, "Is that water coming out of your nose?" To which the other child answers, "No, itsnot." A lipreading teacher disagrees with this and says, "Speech must be natural for a lipreader to be able to follow what is being said. By separating the words, it becomes unnatural."

In my experience, it doesn't affect natural communication and the person I know who does this best, my wife, is widely considered an extraordinarily easy person to lipread. Within language's pace, there is sufficient flexibility to maintain integrity while enunciating better.

Speak with normal, not exaggerated, mouth movement.

If the listener uses residual hearing, make your voice a little bit louder, but not a lot. That little bit louder helps compensate for figure/ground discrimination challenges in people with hearing losses, challenges that a hearing aid normally cannot compensate for well.

Face the listener, with nothing obstructing your face or mouth.

Use natural, again, not exaggerated, facial expression or gestures, but do use them. They convey important information and are somewhat subdued by normal hearing folks' convention.

Keep your face well lit and three to six feet from the listener.

Make sure that the listener knows you're talking! Tap, wave, flash the lights, stomp, or whatever, but make sure the listener is looking at you.

If you know which ear hears better, stand toward that side. If not, ask.

When the listener doesn't understand something, rephrase it. "Begin" is easier to lipread than "Start." And be very careful of look-alike words. Provide context; summarize the topic at hand, "We're talking about…"

Know that the lipreader will do best one-on-one; the more people in the speaking group, the harder the lipreading task is. By the time a lipreader figures out who's talking next, he or she is a half sentence or more behind, a hole that's very difficult to get out of.

If you hear something you must respond to, remember the person with a hearing loss may not have heard. Be sure to let him or her know what is happening.

Learn and teach the suggestions for the listener above.

Look-alike words are particularly challenging in English. I mentioned a few above, but to get the idea across to someone who doesn't understand the difficulty and complexity of speechreading, I often provide the list below. Note they are all easy to understand, common English words, and ask the person (usually a hearing one) to mouth the words to someone else and ask them to identify which of this closed set of words is being said:

pat
man
bad
pan
ban
mat
pal
bat
mad
pad

After the person is frustrated, I explain that these words are an example of what makes lipreading so very hard. All ten look exactly the same. With no context, they are virtually indistinguishable. Having context, as lipreaders normally have, eliminates much of the ambiguity and makes overcoming look-alikes easier.

In closing, I repeat. Speechreading English is not easy to do. I hope these suggestions on lipreading help you in a conversation as they help me in my daily interactions.

Steven A. Silverman, M.A., has a master's degree in Communicative Disorders-Education of the Deaf, and has taught for 25 years. He currently team-teaches a full inclusion fifth grade class of deaf, hard of hearing, and hearing children in Southern California, where he lives with his wife, family, and hearing dog Bailey. Steve is deaf and has no residual hearing fromNF2. For letters pertaining to this article, he can be contacted at **steveweeb@yahoo.com**.

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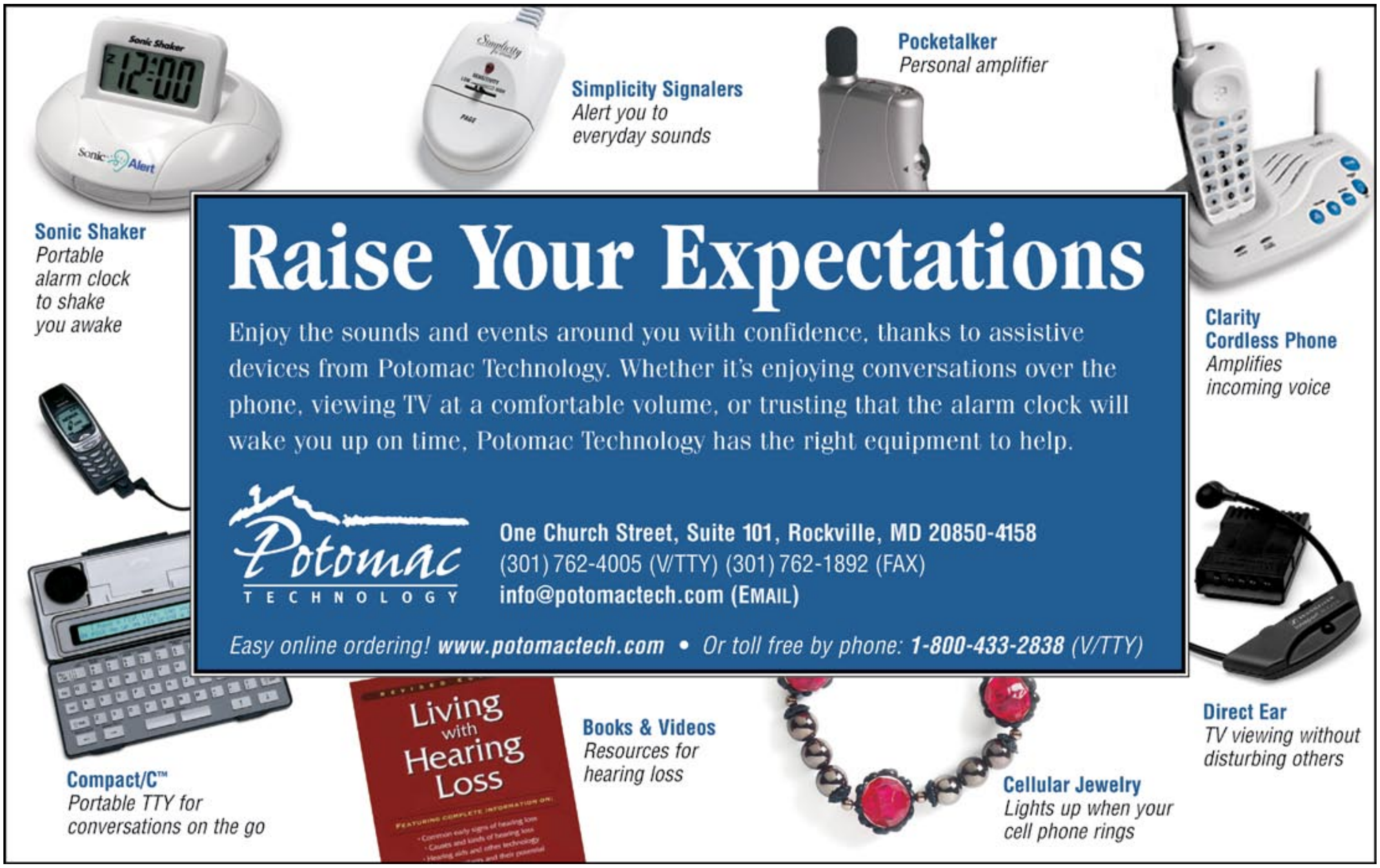

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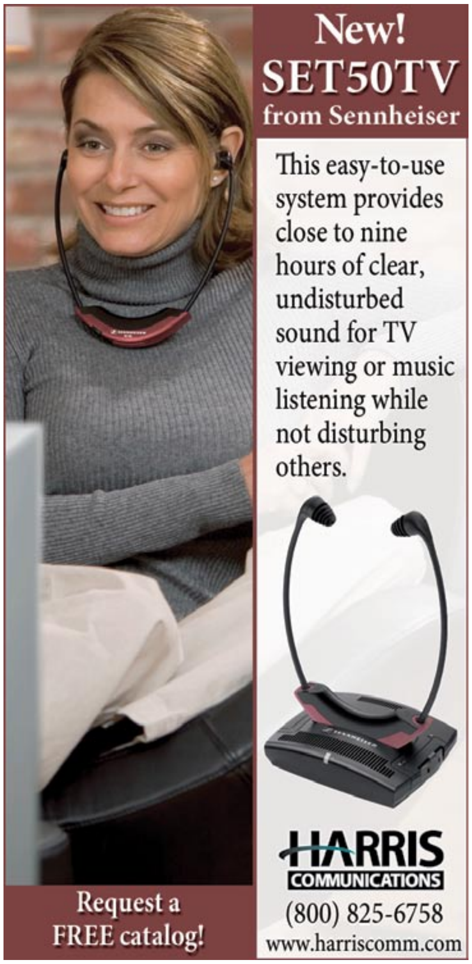

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Tea With Marie

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Mainly, during the show, I wear my hearing aids, face the guests and read their lips. Guests are prepped beforehand on how to communicate with me. I am not afraid to remind them on the air about what I need to communicate. It is a comfortable show and we all have a good time.

We've had some shows dealing with hearing loss such as a young man with a cochlear implant going to medical school, a new book on hearing loss by a hard of hearing woman (who, oddly, just received a cochlear implant herself at the age of 70 something).

I might mention my hearing loss in regards to various things so my audience knows I have one. But, the focus of our show is on slowing down and putting more beauty in your life as I mention at the end of every show. Last year we won our first PEG (Public, Educational, and Government Access) award in the industry and this year we have six nominations as finalists. I relish the moment when I accept the award and say:

"Thank you very much for honoring my creative expression, hearing loss or no hearing loss."

Talk about positive thoughts!

Marie Younkin-Waldman is a member from Narragansett, Rhode Island. Among her many volunteer commitments she served as president of Hearing Loss Association Sargent Chapter in Rhode Island. She also advocated for a new Commission for the Deaf and Hard of Hearing in Rhode Island, chaired the RI Assistive Technology Council, and was the disabilities representative for the Rhode Island Cable Commission. She has worked with Easter Seals, the Governor's Commission on Disabilities, Tech ACCESS of Rhode Island, and for Sprint and AT&T Telecommunications Relay Service. Marie can be reached at **teawithmarie@cox.net**.

Join Marie for Tea—Visit www.teawithmarie.com for Tea With Marie shows with streaming video.

Betty Bonvillian and Marjorie Boone

In the next issue...

You'll meet two sisters with hearing loss who share a special synergy.

and

Bone-Anchored Hearing Aids: Who are they for and how do they work? Charles Limb, M.D., from Johns Hopkins Hospital covers the topic.

By Marie Younkin-Waldman

Tea With Marie

Moving Beyond Hearing Loss

In a book I am reading now by Alan Seale, *Intuitive Living*, the author speaks about our thoughts actually being a form of energy. This energy is constantly vibrating, as does everything in the Universe according to the ancient Principle of Vibration proven by quantum physics. In this vibration, our thoughts move out to create our lives.

Interesting concept—especially as it applies to those with hearing loss. I had an opportunity to discuss this more with the author on my show "Tea with Marie" last October. Seale writes that we must monitor our thoughts if we want to create the world and life we truly desire.

How do we monitor our thoughts? Do we let the limitations of our hearing loss take over or do we focus on the essence of who we are as unique individuals and let our thoughts emerge to create the world we want for ourselves?

I mention this principle because I believe this type of thinking happened to me five years ago when I was starting to fulfill a new dream. For the 15 years before that time, I had been fully immersed in the area of work for people with disabilities. I was born with a bilateral sensorineural progressive hearing loss that has worsened with age and is now profound. I wear hearing aids and rely primarily on speechreading. I had been a teacher for many years but after I could not continue in the classroom, I acquired a master's degree and worked in fields related to disabilities or hearing loss. I found that a fulfilling mission and I derived much satisfaction from a long list of volunteer positions, including heavy involvement in Hearing Loss Assoication of America (then called SHHH).

A New Horizon

One day about five years ago, I decided that I wanted a change that would reflect who I was and not what my disability was. I had been a volunteer host for the "Able-TOO" television program produced by the Rhode Island Commission on Disabilities for eight years and had gained much experience there. *That was it.* I would host and produce my own television program.

The idea of my own show came partly because I loved the afternoon teas my grandmother had every day. I also detested the ugly and upsetting material that was becoming more and more prevalent on television. I would have a show called "Tea with Marie" where we would focus on the concepts of beauty, gentility and tranquility and I would pour tea for my guests as I engaged them in conversation about their interesting lives.

This was my new dream in the middle of my fifties!

After grabbing some videos of "Able-Too" shows and a scrapbook with my credentials, I went for an interview with the Cox cable program director and voila, "Tea with Marie" was born. I was so happy now that I could express my talents and be recognized for the things I could do and not the things I couldn't do.

I loved doing the program and I blossomed as it progressed—challenging myself to produce more stimulating shows with substance. Soon I was executive producer of a crew of ten women all about my age, mostly retired teachers. We each had our jobs: host, producer, director, editor, set design, assistant producer etc. We all learned new skills. I relied on Joan Vessella, my production assistant and scheduler.

It was a mini business with a wonderful crew of women bonding together and learning together on a mission to spread positive messages to our audiences. Last winter we all went down to Florida for a vacation at the director, Judy Begin's, house and had a blast! The local NBC affiliate did a spot on how I produced this show with a hearing loss.

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