

HEARSAY

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The Official Newsletter of Hearing Loss Association of PA

Message from Diana

Thank you to the many HearSay readers who responded to my December request for contributions to help defray the costs of producing and mailing our quarterly newsletter. HLA-PA really appreciates the generosity of so many of our readers.

I am currently making plans to celebrate HLAA's 30th birthday at the HLAA National Convention in Nashville, TN. The convention will be held from June 18 – 21, 2009 and I hope to see many HearSay readers there. Conventions present a wonderful opportunity

to learn about the latest technological advances which can improve our ability to understand speech. Conventions are also a time to interact with others who have a hearing loss and who know how having difficulty hearing can affect all aspects of life. For the first time this year, HLAA is presenting a series of workshops especially for young adults. Whether you are young, old, or some place in between, you are sure to enjoy the HLAA convention. You can find out more about all the convention events and how to register at <http://www.hearingloss.org/convention/index.asp>.

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Coping with Multiple Disabilities

In the Fall 2008 NIH Medline Plus magazine, there was a wonderful interview printed about how the Woodruff family has been coping with multiple disabilities in their family. Bob Woodruff, the ABC news correspondent who suffered traumatic brain injury (TBI) while in Iraq, has recovered miraculously well. His wife Lee, states "there is no medical explanation for his recovery..." She goes on to say that he still has his challenges, such as speech problems with aphasia. These are much more noticeable when fatigue sets in.

I bring this up, because Bob and Lee have 4 children, Mack and Cathryn, and the youngest are twins, Claire and Nora. Nora was born hearing impaired, yet she was not diagnosed until she was 9 months old. All of the other children have normal hearing.

In the interview with Lee, she describes how learning that a family member has any kind of disability or illness changes life in an instant, and that it can often bring out the best and sometimes the worst in people. "It ripples out to the entire family. So you have to look at anything like that holistically in terms of the whole family."

Learning of Nora's disability was devastating in the beginning also..."because we all have a vision of our children as perfect and normal, right?"

Nora, now 8 years old, wears hearing aids and is mainstreamed in school with the help of ALD's. Lee states that it is not often apparent that there is an issue when you first meet Nora, although "she may not speak as crisply as everyone else, so it is hard to know how that will define her and what the challenges may be as she matures."

Interestingly, the parents have not discussed these potential challenges with Nora yet, preferring to approach it in a matter-of-fact way. "Like another child might wear glasses, Nora wears hearing aids.... But the rubber's going to meet the road in the next few years when the academics become more rigorous."

The interesting connection that was made in this article was that when Nora was diagnosed, the entire family had to be re-educated in how to communicate. This seemed to serve them well when Bob suffered the TBI in Iraq.

One final note: the interviewer asked Lee what kind of advice she might have for other families with multiple disabilities and she responded, "It's really about acceptance of the human heart and mind. Accept that you cannot rewind the tape, and pledge to do the best they can."

For the full article you can access www.nlm.nih.gov/medlineplus/magazine.html

Hearing Loss Harms Marriages

There have been quite a few studies done in recent years about how hearing loss can be detrimental to relationships. The studies focused on marriages of people between the ages of 44 through 70. Some of them knew they were getting into a relationship with a hard of hearing person, some of them were cases of a spouse losing hearing due to aging and how the hearing spouse may (or may not!) deal with it.

The Journals of Gerontology (2004) state "most health care providers pay minimal attention to hearing deficits because they are not immediately life threatening. Further, when problems are addressed interventions are generally aimed at the affected person with less attention paid to family members. Prior data demonstrated the impact of hearing loss on the well-being of older adults; data from the

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current study demonstrates that hearing loss has broader implications, affecting not only the person with hearing loss but also increasing the likelihood of subsequent poorer physical, psychological, and social well-being in partners or spouses. This emphasizes the importance of treating hearing loss to promote the health and well-being of both affected individuals and their partners.”

They go on further to give a very common example, “activities carried out as a couple are potentially constricted; for example, if the hearing-impaired spouse no longer wants to go to concerts or plays.”

The Energizer All Ears Survey (May 2008) polled both men and women and found some interesting facts:

- 47.8% of respondents feel their marriages have suffered because of a spouse’s hearing loss. Seven out of 10 respondents feel annoyed when a spouse can’t hear them speak.
- 16.4% feel ignored and 8.1% claim they feel sadness or are hurt by the lack of the spouses’ response.

More than half of survey takers report talking louder so the spouse can hear, while eight out of 10 spouses reveal that by talking louder, they can better communicate with husband or wife. That’s a whole lot of loud talking going on!

A few more fast facts: 56.8% feel their spouse is reluctant to have a hearing test. 46.4% believe their spouses are in denial about hearing loss. One-third of spouses are certain their partners have not had a hearing screen in the past three years and almost one-quarter report that spouses have never had their hearing tested by a professional.

An August 2008 Cochlear Americas survey reveals what most of us already know. Hearing loss hurts relationships—personal, professional

all relationships. Spouses describe feeling neglected, feelings are hurt, perceptions of being ignored erode even the best friendships, marriages and business or work-related contacts.

The Cochlear Americas survey reveals some (more) interesting data:

- 50% of survey respondents said that significant hearing loss causes less intimate relationships between those with hearing loss and their family and friends. A significant quality of life issue.
- 60% of those living with someone with severe hearing loss want that individual to get treatment a hearing device to improve communications.
- 44% of survey takers believe there is no remedy for their hearing loss. Very surprising.
- 47% of those who sought hearing treatment did so at the urging of the family.
- In summary, hearing loss has a significant effect not only on the person with the disability, but also on their spouses.

The Cochlear Americas survey found that two-thirds of the individuals who had sought treatment reported being satisfied with the treatment they received and were able to once again enjoy the sounds of life they had been missing.

However, we all know that even with treatment issues still arise. Sometimes we accuse our spouses of having “selective hearing” – especially after getting treatment, thinking maybe the aids or implants “fixed” all the problems. This is not the case. Selective hearing has nothing to do with hearing loss. It would be wonderful if we could get some responses to this article and the surveys written about from readers of HearSay who are in a relationship. What are some examples where you and your partner have had to change communication styles; what is

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VOLUNTEERS NEEDED!!

Assist the HLA-PA State Director by serving on the Advisory Council or one of its committees. The Council meets periodically in Carlisle but committees conduct most of their business by e-mail and occasionally meet in various parts of the state. If you think you would like to serve on the council or any of its committees, please contact one of the state leaders listed here:

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HAAA MEMBERS TAKE GUIDED TOUR OF JAMES CASTLE EXHIBIT AT PHILADLEPHIA MUSEUM OF ART

On January 3, 2009, 16 members of HAAA took a tour of the James Castle exhibit at the Phila. Museum of Art. Our tour guide was Ginny Shoff, who is a member of HAAA – Bucks County Chapter, and works as a volunteer guide at the museum. We had wonderful accommodations for the tour -- FM listening systems with headphones and neckloops and also an interpreter, for those who used American Sign Language.

James Castle (1899 – 1977) was a self-taught deaf artist from rural Idaho who could not read or write and, despite undergoing no formal or conventional training, produced amazing drawn images using soot, spit and a stick! He would use whatever paper was available for his drawings, such as the inside

of matchstick boxes, detergent boxes, etc. His work is known for its unique homemade quality, graphic skill, and visual and conceptual range. The exhibition consisted of some 300 drawings, color wash pieces, handmade books, assemblages, and text works selected from museums and private collections, including many from the holdings in Castle's estate.

HLA-PA will be sponsoring an Asian tour at the Philadelphia Museum Art on April 25, 2009. We receive the special disabled group discount rate of \$6 per person. Space is limited, so if you are interested in joining us, please contact Marianne Lock at MCL0312@comcast.net with subject line: Asian Tour.

If you would like to arrange your own private guided accessible group tour at the Philadelphia Museum of Art (minimum 15 people), you can contact:

Marissa A. Clark, Program Coordinator,
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Submitted By: Marianne Lock, HAAA Bucks County Chapter President

Magnetic Imaging Machines May Damage Cochlear Implants, BUT there is hope!

When medical issues come up and an MRI machine is involved, patients with cochlear implants will need to consider the effect on the implant. The 3T MRI machines can demagnetize the patient's implant according to new research published in the December 2008 issue of *Otolaryngology- Head and Neck Surgery*.

A cochlear implant is an electronic device that restores partial hearing to the deaf. It is surgi-

HLAA CONVENTION 2009

**GAYLORD OPRYLAND RESORT AND CONVENTION CENTER, NASHVILLE
JUNE 18-21, 2009**

Vint Cerf, Ph.D., vice president and chief Internet evangelist for Google and widely known as one of the “Fathers of the Internet,” will be the keynote speaker at the Opening Session. This year, the Research Symposium will inform us with “An Update on the Latest Hair Cell Regeneration Research.” Workshops will be presented in the following categories: Healthy Living and Working, Relationships and Communication; Hearing Technology; Advocacy and Access and Young Adult Issues.

cally implanted in the inner ear and activated by a device worn outside the ear. The cochlear implant bypasses damaged parts of the auditory system and directly stimulates the nerve of hearing, allowing individuals who are profoundly hearing impaired to receive sound. It is estimated that more than 100,000 people have cochlear implants.

As discovered via a study conducted by a team of German researchers from the International Neuroscience Institute, Hanover, and the Medical University of Hanover, and American researchers from Vanderbilt University, Nashville, TN, the MRI machines adversely and permanently affects the non removable magnets within the cochlear implants. The demagnetization reached via the 3T MRI scanning exposes the patients to undesirable magnetic forces.

3T MRI scanners are the next generation of MRI scanners and are significantly more powerful than 1.5T MRI scanners. When getting the necessary MRI scan, per the suggestions of the researchers, get the 1.5T MRI if possible, before choosing the 3T MRI machine. The 3T MRI scanners are a lot more powerful, and more damaging to the cochlear implant. Only use the 3T MRI scanner if the 1.5T MRI is not available, and if the scan far outweighs the risk of demagnetizing the cochlear implant.

As discovered in another article, there are some cochlear implants companies that have removable magnets. It involves a simple outpatient surgery under local anesthetic and the magnet is taken out temporarily so the patient could undergo the MRI scan. The magnet can then be replaced immediately. When considering cochlear implants, this is another factor to consider. Find out if the cochlear implant you are considering can be removed with a small incision temporarily to get the MRI. With the advances of technology, it is to be hoped that with all the newer technology coming out that all the cochlear implant companies offer this option of a small surgery before having an MRI.

Works Cited:

Medical News Today. Accessed 2/9/09.
<http://www.medicalnewstoday.com/articles/131308.php>
Audiology Online. Accessed 2/9/09
http://www.audiologyonline.com/askexpert/display_question.asp?question_id=147
Other Source: www.healthyhearing.com
Alice Pakhtigian

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it about the disability that frustrates you. We would love to hear from both partners because sometimes the experience is very different. Please email your responses to baf@fast.net with subject: “HearSay Marriage Response”. Your responses will remain anonymous.

Sources:

May and August 2008 [Healthyhearing.com](http://www.healthyhearing.com)
The Journals of Gerontology: Series B 2004

HearSay Subscription

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

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Enclosed is my contribution of \$_____ to support HearSay.

Donations are tax deductible.

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About HLAA

Hearing Loss Association of America (HLAA), formerly Self Help for Hard of Hearing People, Inc., which was founded in 1979, is a non-profit consumer self-help organization. HLAA opens the world of communication to people with hearing loss by providing information, education, support and advocacy.

The primary purpose of all HLAA members is to educate ourselves, our families, friends, co-workers, teachers, hearing health care providers, industry, government, and others about hearing loss.

HLAA has members and chapters in all 50 states. To find the chapter closest to you and to learn about membership benefits, contact the HLAA National Office:

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