Hear It Is! Oregon



Winter 2010 Issue 40

Got Spoons?

By Marc Zola LMFT & LPC

A good friend of mine has a chronic physical illness. It is unpredictable in nature and on a daily basis he may feel anywhere from miserable to managing. The illness takes a lot out of him physically; often to the point where it makes it hard for him to communicate with others (just because he is so tired from trying to maintain a reasonable level of engagement).

What surprises most spouses/partners of people with hearingloss is how physically tired they seem. It's a tremendous struggle to attempt to listen closely; particularly when your ears are functioning well below your partner's. In therapy I often see partners who are at first angry and exasperated with the person with hearing loss' seeming lack of physical energy. But when the partners learn about the physical toll that *struggling to hear* takes, they almost always begin to feel guilty and remorseful for their earlier ignorance.

What happens next is partners ask me, "What can I do so that I know how much energy my partner (with hearing loss) has left in his/her daily reserves?" To which I always answer, "Use spoons!"

The friend I mentioned earlier once shared with me that even having a conversation about "how are you doing today" (with regards to the status of his illness) can be exhausting. Instead he asks, "How many spoons do you have today?" It's a metaphor I often use and teach others to use in my practice. The spoons represent the daily amount of energy that you feel you can reasonably exert. It works on a scale of 1 to 20. A 20 spoon day is an excellent day where the person feels as though he has a lot of energy in his reserves. By contrast a 1 or 2 spoon day means the person is at his limit and likely can not handle expending much energy that day.

By asking, "How many spoon do you have today?" the person with hearing loss can provide a one-word answer and immediately, the questioner has a relatively clear idea of what the other person can handle. For instance, a 17-spoon day means the person with hearing loss may entertain going out to a restaurant for dinner with another couple; While a 4-spoon day is more likely to mean the person needs some rest, and the peace and quiet of a meal at home.

This is all completely subjective of course. The spoons are what you make of them, but the idea is that so much angst and distress occurs in families because families lack adequate ways to communicate about stress. The spoons metaphor helps to minimize meta-stress (the stress that occurs when people attempt to talk about stress). How many spoons do YOU have today?

Marc Zola, MEd, LMFT & LPC is a Licensed Marriage & Family Therapist and Licensed Professional Counselor in private practice in Eugene Oregon. Much of Marc's practice is dedicated to helping clients manage the emotional impact of hearing loss. Marc may be reached via email at marc@eugenetherapy.com.

From My Lips to Your Ears

Editorial by Chuck Vlcek

What happens when you lose part or all of one of your senses? Usually you and your brain work together in utilizing your remaining senses to compensate. The most common examples are the sight impaired relying on their hearing and the hearing impaired relying on their sight.

Thus many deaf people use sign language. While most people with residual hearing, especially those who started out with normal hearing, prefer oral communication with various aids, they have one thing in common with the deaf signers: they also rely heavily on the written language.

Thus captioning, both open and closed, has been a godsend to hearing impaired of all stripes who still have decent eyesight. It probably also was a godsend to friends and relatives with normal hearing who no longer had to deal with a blaring TV or explain a plot that the hearing impaired person missed. In the case of TV captions, normal hearing persons needing a quiet or muted TV for any reason (or unfamiliar with English) would also benefit directly.

Captioning has expanded beyond the TV, with real-time captioning being done at public places and on some movies. But there has been resistance in many places, although captioning would help satisfy the requirements of the ADA. To address these concerns, Wash-CAP, and now OR-CAP was born. Read the story on page five.

Board Election Notice

This year there will be three Board positions available with elections in April for those seats on the Board. If there is anyone out there with an interest in serving on the State Board please let us know. We meet formally each quarter (see schedule on page 4). There may also be committee meetings. We are a fun group with lots of work to do. Should you be interested or have questions, please contact Kathy Eckert-Mason, Chair of Nominating Committee for 2010 at k eckertmason@yahoo.com or kathryn.e.eckertmason@state.or.us

Hearing Loss Association of Oregon

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Hear it is! will regularly print your hearing loss-related stories – personal experiences, coping strategies, and evaluations of technology are welcomed. Maximum word count is 500 words. Article contributions should be made to the editor at info@hearinglossOR.org.

For advertising information and rates, contact Karen Swezey at info@hearinglossOR.org.

Deadline for Spring 2010 edition: March 15, 2010.

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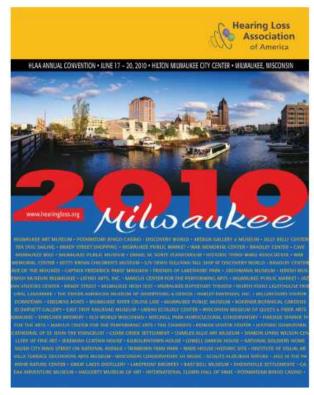
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For questions or comments, contact the OTRS Account Manager: damara.g.paris@sprint.com



Come experience the beauty of Milwaukee during Convention 2010, June 17 – 20 at the Hilton Milwaukee City Center and adjoining Midwest Airlines Center. Located on Lake Michigan, a multitude of attractions await you and your family. From the Milwaukee Brewers team to the many museums, mansions, breweries, and gardens, there is something for every age and interest to experience. Summer is the perfect time to visit Milwaukee – we hope to see you there! The Hearing Loss Association of America is proud to announce the following highlights:

- The Opening Session keynote speaker is Bill Barkeley who is deaf-blind and recently climbed Mt. Kilimanjaro in Africa. Bill is sure to inspire us all;
- The 2010 Research Symposium, Hearing Aid Research and Development: What It Means to the Consumer
- Educational workshops on a variety of topics, all communication accessible;
- Registration discount for first-time attendees. Vets of Iraq and Afghanistan receive a complimentary registration. See www.hearingloss.org for news, updates, and registration details.

HLA-OR Quarterly Meeting Dates

April 17, 2010 July 17, 2010 October 16, 2010 December 18, 2010

To confirm, contact President Bob Russell at bhrussell@verizon.net or call him at (503) 614-9730. Meetings will be held at Albany General Hospital. Guests are invited to attend but should first contact President Bob Russell.

NOTICE TO AUDIOLOGISTS AND HEARING AID SPECIALISTS

Want to keep your clients happy? Want to make them feel special? Want to help them face the world? What better way than to provide a gift membership to the Hearing Loss Association of America? It's easy. Just go to http://www.hearingloss.org/ and select Membership from the menu, then Gift Membership (or Benefits opposite Gift Membership) and follow instructions.

Oregon CAP Is Born

Frustration and isolation: that's what those of us with hearing loss often feel when our impairment prevents us from participating in events where assistive systems are not available. Even if an FM, loop or infrared system is available at a city council meeting, concert, live theatre performance, or movie, those of us with significant hearing loss may find that those systems are inadequate.

With these concerns in mind, Oregon Communication Access Project (OR-CAP) was formed in January modeled after a CAP in Washington State. Wash-CAP acts on behalf of their approximately 150 hearing-impaired members to gain compliance with Washington state and Federal disability law. They do this by working with organizations whose operations fall under Americans with Disabilities Act (ADA) or state regulations, starting with discussion, assistance and advice and negotiation and ending, if necessary, with legal action.

Captioning is the accommodation of choice for CAP. In contrast to infrared, loop or FM systems, captions benefit the full spectrum of hearing ability from mild loss to those who are deaf and even some who have normal hearing. Wash-CAP has had notable successes, for example, getting captioning in live theatre venues and the Washington State Ferries and has a legal case pending that deals with movie theatre captioning.

OR-CAP has developed a priority list of organizations with which to work and which are located in Ashland, Eugene and Portland with other locales to follow. The Advocacy Director and Counsel for Wash-CAP will serve in the same capacity with OR-CAP.

Membership in OR-CAP is open to those with an interest in access issues for hard of hearing individuals. For those who are interested in joining OR-CAP contact Elizabeth Archer (OR.CAP.MEMBERSHIP@gmail.com).

For further information about OR-CAP contact Clark Anderson at or.cap.comm@gmail.com.

A federal appeals court in San Francisco heard oral arguments on Jan. 13 about whether movie theaters must offer services like captioning or audio descriptions so that those of us with sensory losses can enjoy the movies. The arguments of one theater chain that all it needs to do is open the doors and let us in was poorly received. However, predicting the outcome of a case based on the tenor of the court session is uncertain. A decision will probably be rendered 4 to 6 months after the arguments were heard, and will likely impact the mission of OR-CAP and Wash-CAP.

Important Notice about our Website and Electronic Newsletter

Those who have opted to read the electronic version rather than have a printed copy mailed to them will receive an e-mail notifying them that a new issue has been posted on the HLA-OR website, along with a link to the specific web page, http://www.hearinglossor.org/news.htm. Those who have not yet made the change are encouraged to do so by e-mailing your request to info@hearinglossOR.org

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(971) 239-5845 - Videophone

Monday - Friday 8 a.m. to 5 p.m.

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Within Earshot: News You Need to Know

Using Tonal Beeps

Researchers have pioneered a way to program digital hearing aid devices and cochlear or inner ear implants, based on speech sounds such as "aba", "ala", and "asha" instead of tonal beeps. People with hearing loss can now hear spoken words much more clearly and their hearing aid devices can be adjusted much more quickly.

A new company, Audigence Inc. in Melbourne is developing and marketing the software. The arrival of these products on the market will offer economic benefits to audiology clinics as well as improving the lives of their patients. By being able to program hearing aids quicker with better results, audiologists can see greater numbers of patients in a shorter period of time.

The problem with the traditional method for programming hearing aid devices is that it relies on standardized formulas developed for the average patient, while the UF technology customizes the tuning to a patient's individual hearing deficiencies. Hearing loss occurs at different pitches, which vary from one person to the next.

Captioned Hearing Loss Videos

HLAA has made an arrangement with Knowlera Media to produce a series of videos on hearing loss. The videos will be distributed on their consumer-facing website www.monkeysee.com and to several hundred other websites as well as local television stations across the country. The Hearing Loss Association of America will receive its own branded copies of the videos that can be used on its website and its affiliate's websites. All the videos will be captioned. Past board member and VP for policy, Mark Ross Ph.D., has graciously agreed to help to write the scripts for the videos to be filmed in the national office. This is a major opportunity we

could not have taken advantage of without Mark's help. The topics of the videos are:

Video 1: Understanding Hearing Loss/Who is at Risk

Video 2: Hearing Loss Symptoms

Video 3: How is Hearing Loss Diagnosed?

Video 4: Medical Treatments for Hearing Loss

Video 5: Hearing Loss Self Care/Lifestyle Changes

Video 6: Hearing Loss Prevention

Video 7: The Latest Advancements in Hearing Loss

Treatment

Walk4Hearing Update

The HLA-OR boad of directors and the Walk4Hearing committee are continuing work on planning the Walk4Hearing scheduled to take place at the World Trade Center in Portland on September 25, 2010. The initial plans were announced in the Autumn 2009 issue of *Hear It Is*, which can be found at http://www.hearinglossor.org/news.htm.

Information packets will soon be distributed to chapters and other interested parties. HLAA has posted its 2010 Walk4Hearing web page, www.walk4hearing.org. They have developed a Q&A on "What is an Alliance Group" so that other organizations can have a clear idea of how alliance group arrangements work before they sign up. HLAA has proudly announced that Walk4Hearing has raised more than one million dollars nationwide in 2009 from 21 events. This augers well for the walks in 2010.

HLA-OR still needs volunteers to help plan for and execute the walk in Portland. If you or someone you know are interested, please contact Walk4Hearing committee chair Cathy Sanders at catsindallas@q.com or e-mail to info@HearingLossOR.org. Further progress in planning for this event will be reported in future issues of Hear It Is.

Chapter Capers

<u>Lane County chapter:</u> Starting in November, the City of Eugene began offering televised captioning of Eugene City Council meetings as a part of a three year telecommunication fund pilot project. The city had contracted with LNS Captioning in Portland to provide this service. The captioned City Council meetings are published on the city's website after airing on Metro TV, local cable channel 21.

This service has been requested by the Human Rights Commission Accessibility Committee and community members who are deaf or hard of hearing. Captioning provides an opportunity for more people to participate in local government.

What is your chapter doing? Send your story to the editor at cvlcek@centurytel.net.

CI Corner

My New Bilateral Cochlear Implant

By Bob Williams

"You might want to postpone your scheduled surgery," Nancy Cambron told me. "A new processor is coming soon, but must first be approved by the FDA. It is 40% lighter than the old one, it is more water resistant, and it has a remote control to give you much greater flexibility over your listening environment. The problem is that approval might come soon, or it may take a long time."

I elected to wait. The surgery took place November 13, 2009 at Seattle Veterans Affairs Hospital. My surgeon was Dr. Hume. There was something different about this surgery. As I was about to go under the anesthetic he said, "OK team, let's get to work!" Everyone started talking at once then I opened my eyes and it was already early afternoon. This is the first time I had ever heard a surgical team prepare me for surgery. Dr. Hume had left my processor on until after I was asleep.

Nancy Cambron came in during the surgery to ensure that everything was working properly.

My recovery was much better than the first one. There was no nausea although I did have some vertigo the first couple of days.

I was hooked up December 17, 2009. I was able to understand speech immediately, but it was through lots of environmental noise and tinnitus in the newly implanted ear that sounded like a freight train. When I spoke, I heard two distinct voices: one that of a nine-year-old boy whose voice hadn't changed and the other a very deep bass voice.

All voices were bionic in sound quality and speech was much more difficult to understand.

As I write this it is over a month after the hookup. I listen frequently to a program called "Sound and Way Beyond". There are tests to take to follow my progress. This program consists of individual words, sentences, male and female voices, environmental sounds such as water running, police sirens, bells, etc. There are also musical tones to try to identify.

I am doing reasonably well with single words, but the sentences are difficult. I cannot tell the difference in male and female voices and I am not able to identify many of the musical tones. I am doing better on the ambient sounds. Running water, which sounded metallic at first now sounds like running water.

I am also working with musical tones on my piano. I am finding that by striking one key at a time I can differentiate between the tones. When accompanying a single melodic tone, I place a heavy emphasis upon the melody and I can hear it above the accompaniment. I do try to keep the accompaniment fairly simple. If it's too complex I lose everything.

Another thing I do is to use the new processor by itself the first 1 ½ hours each morning. I do a lot of reading aloud during that time. I am noticing that my voice is beginning to sound more like my own.

The greatest benefit so far is when both processors are turned on. I get a stereo effect and a fullness of sound that was not possible with the single cochlear implant. Music and speech has a fuller richer quality and I am able to understand speech better in noisy environments such as restaurants.

The second cochlear implant is a far cry from the first one where I was able to understand speech immediately, but I would do it again in a heartbeat due to the stereo richness of sound. It will continue to improve with time.

Samaritan Health Services Provides Better Accommodations for Hearing Loss

By Bob Williams

In September of 2008, Bob Williams and Lola Linstadt from the Linn-Benton Counties HLA Chapter met with CEO Becky Pape of Lebanon Samaritan Hospital to discuss ways the Samaritan Medical Services could improve their accommodations for persons with hearing loss. They were also concerned about required training components for the new medical school scheduled to open in 2011.

The Hearing Loss Association of Oregon has been working in concert with Samaritan Medical Services to provide better communication and service for patients, families and staff for persons with hearing loss. This hospital and clinic system takes in the communities of Albany, Corvallis, Lebanon, Lincoln City and Newport. Following is a report from Nancy Klinsky, Director of Professional Development for Samaritan Health Service:

"During 2009 Samaritan Health Services (SHS) worked with the Hearing Loss Association of Oregon to learn more about the hearing loss needs in our community. The suggestions and experiences communicated to us throughout the process have been invaluable to SHS. We will put this information to use in the development of improved services and resources for our clinics and hospitals.

"Our hospital nursing leadership reviewed sample information and resource kits. As SHS is moving toward electronic charts, the resource materials are being customized to be available online. Online availability allows staff to readily access information and tips on communication, operating hearing aids and troubleshooting. We are in the process of reviewing resources appropriate to the clinics as well.

"Visual indicators of need will also be provided for patients. A sign will be prominently displayed at the patient's bedside information board, indicating a hearing loss. A card requesting caregivers to "please face me – hard of hearing" will be provided for patients to wear on hospital gowns or attached to a pillow.

"Computer charting at SHS provides a place to document the specific patient needs for communication and assistive devices for hearing loss. The patient's preferred method of communication will be documented here as well. It is available for all caregivers to review. We encourage each patient, family member or friend to communicate their needs for accommodation.

"Part of the training for staff will include increased knowledge of the new resources, as well as reminders of the TTY's and the availability of American Sign Language interpreters, if needed.

"Currently, assistive listening devices are in place and more options are being added."

"The response from Samaritan Hospital Services has been very positive and much has been accomplished this past year," noted Bob Williams, Chairman of the joint committee. I thank Lola Linstadt, Kay Fouts, Duane Davis, Cheryl Davis, Wayne Seely, Karen Swezey and Bonne Bandolas for their assistance in making this a positive experience for all."

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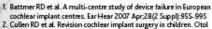
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Neurotol 2008;29(2):214-20

3. Battmer RD et al. A review of device failure in more than 23 years of clinical experience of a cochlear implant program with more th 3,400 implantees. Otal Neurotal 2009 Jun;30(4):455-63



Hear now. And always

"Commitment isn't something that happens to us. It's something that happens because of us, because of a decision we make. When we commit to a person, a task, and to God, we pledge to show up and do our part, no matter what. How will you demonstrate commitment today?" - Rev. Mary Manin Morrissey

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Dr. Mehr has over 27 years experience working with individuals with hearing loss. He has served on the Oregon Speech and Hearing Association and Oregon Academy of Audiology Boards and as chairman of the Oregon Board of Examiners for Speech Pathology and Audiology.

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Chapters in Oregon

Local chapter meetings are open to all. Family, friends, and professionals are encouraged to attend and become involved. Through chapter meetings and newsletters you'll find:

- Insights into effectively living with hearing loss
- Support/Referrals/Information
- Information about the latest technology
- Coping strategies & tips
- An opportunity to make a difference
- Diminished feelings of isolation and aloneness
- Opportunities to share concerns and hear from others



We believe in education - for those who hear well and those who cannot - so that both may understand the causes, challenges and possible remedies for hearing loss. At our meetings, you'll find a comfortable place where hearing loss is accepted and not a problem. Many people report that being a part of a Hearing Loss Assoc. group has made a major difference in their lives. Your participation benefits not only you, but others who attend as well. Following is a list of the current chapters and contact people in Oregon.

Hearing Loss Association of Central Oregon (HLACO meets on the 2nd Wednesday of the month (except August) – 6:00PM at the St. Charles Medical Center, 2500 NE Neff Road, Bend, in Conference Room A (by the front entrance).

Contact: Lois Johnson 64682 Cook Ave. Box 84

Bend, OR 97701

e-mail: HLACO@YKWC.net

(541) 388-6869

Hearing Loss Assoc. of Lane County meets 2nd Thursday each month - 7 PM at the Hilyard Community Center, 2580 Hilyard Street - Eugene.

Contacts: Andrea Cabral OR Jeff Newton e-mail: angora@comcast.net (541)-731-8135

(541) 345-9432 voice

PO Box 22501 OR Clark Anderson Eugene, OR 97402 e-mail:clarkoa@msn.com

Mine to Keep

By Helen Keller

They took away what should have been my eyes (But I remember Milton's Paradise).

They took away what should have been my ears (Beethoven came and wiped away my tears).

They took away what should have been my tongue

(But I had talked with God when I was young).

He would not let them take away my soul Possessing that, I still possess the whole.

Group of of Salem Hearing Loss Assoc. meets the 2nd Wednesday each month (except July and August) - 6:30 PM at the Salem Rehabilitation Hospital – Room 2A (2nd floor) 2561 Center St. NE

Contact: Donald Ladd

e-mail: SHHHSalem@aol.com

(503) 394-3863

38427 Shelburn Dr. Scio, OR 97374

Hearing Loss Assoc. of Portland Clackamas County meets the 3rd Tuesday each month (except July and August) - 7 PM at the Northrup Building in the 1st floor conference room - 2282 NW Northrup Street, **Portland**

Contact: Mark Foster

e-mail: hlaportland@gmail.com (503) 413-7348 - voice or TTY

PO Box 2112 Portland, OR 97208

www.hearinglossor.org/portland/

Hearing Loss Assoc. of Douglas County meets the 2nd Monday each month - 7 PM at the Mercy Hospital Community Education Room - 2459 Stewart Parkway -Roseburg (between Parkway Pharmacy & OfficeMax)

Contact: Chuck Vlcek **OR Barb Stoner** e-mail: cvlcek@centurytel.net (541) 496-0060

(541) 496-4541 P.O. Box 175

Idleyld Park OR 97447

Hearing Loss Assoc. of Linn and Benton Counties meets the 3rd Thursday of each month (except July and August) - 6:30 PM at the Senior Center - 65 "B" Academy Square - Lebanon

Contact: Bob Williams

e-mail: robertiw@comcast.net

541) 258-5818 2020 South 12th #111 Lebanon, OR 97355

> Change will not come if we wait for some other person or some other time. We are the ones we've been waiting for.

> > We are the change that we seek.

Barack Obama

If you are interested in starting a chapter in vour area. contact:

Cathy Sanders

Oregon Chapter Coordinator e-mail: catsindallas@g.com (503) 881-1642 (cell) or (503) 623-4662 (home)

1131 SW Marietta Lane

Dallas, OR 97338

or

Chapter Coordinator

Hearing Loss Assoc. of America

(the National Office)

e-mail: tbarrient@hearingloss.org

(301) 657-2248 - voice (301) 657-2249 - TTY (301) 913-9413 - FAX

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| E-N | Mail | Please send my newsletter via e-mail |
| l le | arn | ed about the newsletter from: |
|] |] | Enclosed is my contribution of \$ to support the Hearing Loss Association outreach programs in Oregon. Contributions will be acknowledged in the next issue. |
|] | 1 | I wish to remain anonymous. |
|] | 1 | I cannot contribute but would like to receive the newsletter. |
|] | 1 | I want to join Hearing Loss Association of America , the National Organization. Please enroll me as a member. I'm including my \$35 membership fee. |
| | | Or you can sign up online at www.hearinglossOR.org (click membership, then click application) |

Hearing Loss Association of Oregon is a 501(c)(3) charity and depends on donations and grants. All personnel are volunteers. Please send your donation to support our efforts to *Hearing Loss Association of Oregon* PO Box Box 22501, Eugene, Oregon 97402.