

Hear It Is!

Oregon



Summer 2016

Issue 66

Eileen Marma Goes to Washington

Representing the Oregon State Association, Vice President Eileen Marma attended the HLAA convention in Washington, D.C. on June 23-25. She reported primarily on the Leadership Workshops that were held the afternoon prior to the start of the main convention.

The first topic was clarification of the roles of state organizations, state organization leaders, and chapter coordinators. The state organization is responsible for providing information, education, and advocacy for those with hearing loss across the state. It can work with the state legislature to ensure that proposed laws are friendly to people who have hearing loss. It should also support HLAA's public policy agenda by proposing state and local laws that ensure that HLAA's mission and vision are being implemented. A state organization leader's job is to ensure that the state organization is running smoothly with input from as many people with hearing loss as possible across the state. The state chapter coordinator's role is to support existing chapters and help create new chapters. Valerie Stafford-Mallis is HLAA's leader for chapter development work and oversees the state chapter coordinators. Lisa Hamlin is HLAA's leader for state organization work. There are monthly webinars for leaders that are captioned, convenient, computer-based training sessions to help a person lead the state organization or chapter(s) with greater knowledge and confidence. Specific topics may be requested. Contact Lisa at LHamlin@hearingloss.org

The second major topic was fund-raising. Walk4Hearing is a major source of funds and the proceeds are divided between the state and/or sponsoring chapters and the HLAA national office. The money first goes to HLAA which keeps 40%, and the balance is remitted to the sponsoring organization(s). Since hearing loss organizations in Oregon do not currently have the manpower to run a Walk4Hearing, Eileen focused more on other means of fund-raising. There are foundations that are already prepared to support worthy causes. They can be located by searching their websites for sections called Social Responsibility or Community Investment. Their Annual Reports may also be a source of information. They can be approached for help with a specific project like looping a meeting room. At the workshop, Lions Club and Sertoma were most frequently mentioned. Examples given was Sertoma's help in starting up a Walk4Hearing and upgrading a website for a local chapter.

The third (and last) major topic was a new concept called Unified Membership. Persons joining HLAA have been paying them \$35 per year for membership, but then were on their own on finding and joining a local chapter. Recently two chapters, Sarasota/Manatee and New York City, completed a successful pilot project to test Unified Membership. Persons joining HLAA (or renewing) still paid \$35 per year, but \$10 was then rebated to the chapter, and the new/renewing HLAA member automatically became a chapter member. Unified Membership is now being offered nationwide. The person joining or renewing with HLAA automatically becomes a member of the nearest available chapter, based on the person's zip code and the zip code of the chapter's meeting place, and \$10 is remitted to that chapter. The chapter can then contact that person. The chapter can also request a list from HLAA's database of all HLAA members living within the chapter's area, but may not use that list to advertise or solicit donations.

From My Lips to Your Ears

Editorial by Chuck Vlcek

At a recent meeting of the Douglas County chapter, members Frank and Dolores Elias described a conversation they had with a man who had a severe hearing loss. The man complained that he had paid \$6000 for a hearing aid that did not help him at all. When asked if he considered a cochlear implant, he said he never heard of such a thing. It so happens that Dolores wears a cochlear implant, and when she told him she was totally deaf without it, he didn't believe her.

Cochlear implants have been around long enough (and the technology sufficiently mature) that this lack of awareness is no longer excusable. Fortunately, help is on the way: software to help audiologists and cochlear implant staff to share information about clients with hearing loss and build a database that will ultimately help clients obtain better service. This is the topic of an article in CI Corner on page 9.

I had an interesting but less dramatic encounter with a woman while I was taking

an exercise walk near my sister's place north of Seattle. Her father also had a severe hearing loss and she was asking me about cochlear implants. I mentioned HLAA, and she tried typing the web address into her smart phone, without much success. She finally spoke into it: "Hearing Loss Association of America". Bingo! Technology is wonderful!

HLAA, Oregon State Association

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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 Eileen Marma at info@hearinglossOR.org.

Deadline for Autumn 2016 edition: Sept. 30, 2016.

KINDLY SPEAK UP, SPEAK KINDLY

The light has come, I have no fear
The sounds are fading from my ears
Each sound fading, year after year

First the crickets, and then the frogs
I still hear whistles, rivers, and dogs
I feel vibrations and the voice of God

I have in the past been able to hear
I remember the sounds of my yesteryear
I mostly miss voices and kind words from friends
I know that this silence will never end

The things I don't miss are the cruel words
That came from some people I wish I'd never heard
Didn't they know my loss couldn't be cured?

The comments were hurtful and I was surprised
When I listened so carefully to only find
Harsh words of judgment, now stuck in my mind
They didn't know how hard I tried
With hearing aids and gadgets that amplified

Your voice is too loud
You embarrass me
You talk too long
You are boring to me

I never understood why
Those that can hear
Would say cruel words
When I worked so hard to hear

They'd yell and scream
And laugh and sneer
Put in your hearing aid
So you can hear

It didn't work anymore
My silence was here
And I wondered why
They used words to smear
Their beautiful voices
That I held so dear?

They could hear the owls
That I couldn't hear
I hadn't heard them
For thirty years

Yet they kept asking
Are you sure you
Can't hear?
Their faces revealing
Their thoughts with a sneer.

My wish is that someday they will know
How much cruel words hurt me so.

You can hear and I have thought
You would be kind because my ears forgot
How to hear crickets, birds, and fish
That they learn to speak kindness
Is my dearest wish

Linda Diaz -- 5/31/16

HLAA-OR Quarterly Meeting Dates

**The next meeting will be held Oct. 1, 2016 at Albany General Hospital
(Room 1AB, 3rd floor). See next (fall) issue for 2017 meeting dates.**

To confirm, contact President Clark Anderson at clarkoa@msn.com or leave a message at (541) 736-4804. Guests are invited to attend but should first contact President Clark Anderson.

HLAA Convention News

Check out the main convention page on <http://www.hearingloss.org/content/convention>

The next convention will be held at Salt Lake City June 22 – 25, 2017

Salt Palace Convention Center and Little America Hotel

Details will be forthcoming in the next issue. *Check the convention page listed above.*

Convention 2016 Workshops and topics: Summaries and/or transcripts of the workshops and topics covered during the 2016 convention in Washington, D.C. are not yet available. They will appear in the Archives section when they do come online. The titles of these workshops and topics can still be found in the Schedule section of the 2016 convention page. There were 10 sessions in each of five categories: Advocacy, Assistive Technology and Large Area Systems, Hearing Aids and Cochlear Implants, Living Your Life, and State/Chapter Development. Eileen Marma reported on some of the State/Chapter Development sessions (see front page) and David Viers made a presentation on TV Captioning under Advocacy (see page 7).

HLAA Membership

Individual Membership in HLAA is \$35 for 1 year, \$95 for 3 years, or \$140 for 5 years.

One-year membership in HLAA is \$20 for student, \$45 for couple/family, \$50 for professional.

Membership includes the award-winning bi-monthly magazine, *Hearing Loss*.

Write to HLAA, 7910 Woodmont Ave., Ste. 1200, Bethesda, MD 20814

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Within Earshot: News You Need to Know

Community Needs Survey

The Oregon **Community Needs Assessment survey** is now available! The Regional Resource Center on Deafness wants to hear from you! The Oregonian Department of Human Services wants to collect information from Oregonians who are Deaf, Hard of Hearing, or anyone with a hearing loss. We will report the survey results to the Oregon Legislature, identifying barriers and gaps in public services for Oregonians who have a hearing loss. *The results will affect future Oregon legislation and programs for people with hearing loss.* Please take a moment to fill out this survey. **The deadline is Wednesday, August 31.**

The survey is available in three different languages: English, Spanish, and American Sign Language. Just copy and paste: <http://www.wou.edu/rccd/home/cna/> It will take you to the Regional Resource Center on Deafness' webpage where you can choose the language survey version that works for you.

Lions Roar Update

The Lions Roar program provides low cost hearing aids to persons with mild to moderate hearing loss who have a financial need. It is administered by the Oregon Lions Sight and Hearing Foundation (OLS&HF) in partnership with local Lions clubs. Audiological services, such as testing and fitting, are included.

Qualified recipients pay a small amount themselves, depending on the actual arrangement between OLS&HF and the local club. Recently OLS&HF has reduced the

amount of costs it will cover, requiring that the recipient pay more (currently \$150 per hearing aid, up front) unless the local club elects to cover that cost. It is still a good deal for the recipient, but terms and conditions may continue to vary. Anyone wishing to apply for this program should contact his local Lions club.

The OLS&HF needs more donations and/or grants to cover its own costs of administering this program. To donate online, go to its home page www.olshf.org and click on "donate" at the top right corner of the page. For more information on the Lions Roar program, go to the lower left corner of that home page and click on "ROAR Hearing Assistance".

Drug to Relieve Noise-Induced Hearing Loss

The July-August 2016 issue of HLAA's Hearing Loss Magazine has reprinted an article by Patricia Kline for the *Military Times*, which describes testing of a compound that promises to reduce damage to hearing caused by noise. Very loud sounds overstimulate cochlear hair cells, causing them to release free radicals which can then injure or kill the cells. The compound being tested, D-methionine, is an antioxidant that neutralizes the free radicals, and stimulates the body to release an antioxidant of its own called glutathione. It is found in cheeses and yogurt. It is being tested on persons exposed to loud sounds and also on persons taking chemotherapy drugs known to damage hearing (see Ototoxic Drugs, page 11).

A couple of other substances are also being tested, N-acetylcysteine (NAC) and ebselen, which boosts the body's own antioxidants. An additional benefit is the possible prevention of tinnitus. All of these tests show promise, but they are still ongoing and the substances are not yet prescribed on a regular basis. In any case they are meant to supplement rather than replace the use of noise protection devices.

TV Caption Workshop at HLAA Convention

I was asked to do a write-up on a workshop that was recently given at the 2016 HLAA Convention. Originally, three people were going to be involved in this presentation but, due to work conflicts, it came down to just myself doing the actual presentation.

The workshop was about the ordinance passed in 2015 requiring Portland businesses that have TVs for public viewing to have the Captioning feature activated when the TVs are on during business hours. A PowerPoint slide presentation was given discussing the ordinance and the various steps that were taken to accomplish passage of this landmark legislation.

Some of the issues covered were the importance of collaboration amongst individuals and reaching out to organizations representing stakeholders (e.g. both the Portland chapter and the Oregon state association of Hearing Loss Association of America, the Oregon Association of the Deaf, the Portland Commission on Disability, and others). In addition to this, connecting with the actual legislators (i.e. the Portland Commissioners) that would be casting the votes (Yea or Nay) on this legislation was covered - as well, as the Media (both TV and newspaper).

Having a game plan in the form of Talking Points (and specifically what these were) was covered. A number of related matters were also discussed. Much of this information can be accessed at: www.hls-nw.org/captions-on-now.html

The presentation attracted a fairly good-sized audience from people from diverse locations (probably the person traveling the longest distance was from New Zealand). There seemed to be quite a lively interest in this subject and I continued to meet and discuss it with people after the conclusion of the actual workshop.

Advocacy efforts of a similar type are being conducted in other parts of the country. For example, one of the main advocates in Portland has moved to the Seattle area and is continuing to push for this kind of legislation in his new locale. Kansas and New York states are seeing advocacy efforts, as well. People from other areas have also made contact in this regard.

I believe this is advocacy whose time has come and we will see continued interest in the future. Perhaps one of you reading this will elect to push for similar legislation in your own area - or even at the state level. If so, best wishes!!

David S. Viers (former HLAA-OR Board member)

Chapter Building Workshop Update: Chapters in Oregon and Washington are still in the early stages of planning a joint workshop to be held on **March 4, 2017**. Keep this date open and stay tuned.



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Chapter Capers

Douglas County Chapter: Chuck Vlcek and Tasha Havens manned a booth at a health fair put on by the Wolf Creek Job Corps near Glide. They distributed about 130 Survivors Manuals. Robin Illers also manned a booth but it was for those with impaired vision. Robin had to resign as secretary due to a change in her job situation that required her to move to Eugene. Tasha's mother Ann Havens will join and take over the secretarial duties. The August picnic at the Havens' residence had to be postponed until Sept. 10 due to unexpected scheduling conflicts that would impact attendance. There will be no regular meeting in August. Member Doris Clark will be celebrating her 95th birthday on August 27.

Portland Chapter: The chapter is enjoying its summer siesta and will meet again on September 19. It did e-mail a newsletter on July 18. Anne McLaughlin continues to serve as secretary, newsletter editor, and contact person for the chapter. They have three new at-large board members: Tad Boxell, Judy Cirillo and Jocelyn Cox. They now have seven board members. Mark Foster and Vicki March have completed their terms as officers.

Linn-Benton County Chapter: The chapter has changed its meeting location to the third floor of Albany General Hospital, Conference Room A.

Central Oregon Chapter: This chapter has become inactive and is no longer holding meetings.

What is your chapter doing? Send your story to the editor at cvlcek@centurytel.net See pages 14-15 for contact information for these chapters and events.

CI Corner

CI Data Sharing Software Shows Promise

A nonprofit organization founded in Wichita Falls, TX, Auditory Implant Initiative (Aii), is changing the way cochlear implant hearing device data is being shared, according to an article by Danielle Malagarie for KAUZ News published on June 17.

Aii is using software known as HERMES (HIPAA-Secure Encrypted Research Management Evaluation Solution) across the nation. HERMES was developed in 2014 by Midwestern State University computer science students. These students are still used for help and design. The effort was led by Jed Grisel, a Wichita Falls cochlear implant doctor and the co-founder of Aii.

Institutions may use HERMES for free in exchange for data, and it can connect with another software called Noah, the largest product to track hearing aid patients since the 90s. This increases the amount of information in HERMES's database, changing the way physicians share patient information and helping candidates for the implant to get access to this procedure.

1.2 million people in the U.S. are candidates for cochlear implants, but only about 5% are actually implanted, compared to 50% of candidates who are implanted in Europe. Access is limited due to lack of enough information, and any one center does not have enough volume to be able to make a big difference. The software helps to collect data together from different centers. Aii's mission is to provide more cochlear implants to people who need them. HERMES's technology accomplishes this goal via patient tracking, provider communication, and collecting research data.

Cochlear implant procedures are team based, so this software is allowing all doctors to get a complete picture of patient's needs and situations. This results in patients getting better and more detailed care. Aii is approaching its goal of becoming the largest collection of cochlear implant outcomes data in the world.

From California to New York, 12 centers throughout the country use HERMES. Groups from Great Britain, Australia, India, China, and elsewhere around the world also want to adopt the software.

- OHSU Cochlear Implant Team (see ad on page 12)

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An Inexpensive Alternative to Hearing Aids?

It is well known that most adults over age 65 have a hearing loss, but only a few of those who would benefit from hearing aids actually have one. Cost and the lack of insurance coverage for hearing aids are the major reasons, although there are other factors as well. In an article written for the New York Times on July 15, Paula Span explored an alternative: personal sound amplification products, or P.S.A.P.s.

P.S.A.P.s are not hearing aids, they do not require an audiologist, and they are not regulated by the FDA though they cannot be labelled or advertised as being intended to help with hearing loss. They can be purchased at drugstores, ordered from magazine ads, or ordered online. They cost much less than hearing aids, but how good are they?

It should be stated upfront that only those with mild or possibly moderate hearing loss will get any benefit under any circumstance. Those with a more severe hearing loss can simply forget it. Aside from that is the adage “you get what you pay for”. Prices range from less than \$100 to around \$700 (a mid-priced hearing aid costs \$2500). At least one of those selling for less than \$100 was tested and found to be worse than useless.

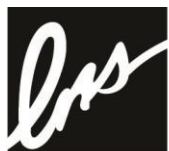
Paula reported that several P.S.A.P. devices marketed online were tested by Nicholas Reed, a John Hopkins audiologist. Dr. Reed ran electroacoustical tests to measure their output or gain (volume), frequency ranges, and clarity, and also tested them with users with mild to moderate hearing loss. Three devices costing from \$350 to \$400 came fairly close to the “mid-priced” hearing aid in performance, but one of them operates with a smartphone. Also, Dr. Reed cautioned that just 29 participants were tested, and real-world results could vary.

There is a movement afoot to have regulators establish a new product category for them, and have the F.D.A. set specifications that ensure safety and effectiveness, and to require that these devices meet certain manufacturing standards.

Beware of Ototoxic Drugs

AARP has published an article written by Katherine Bouton (Feb. 12, 2016) which lists drugs that can damage or destroy your hearing. The best known ones are in a class called aminoglycoside antibiotics, which have the suffix -mycin, used effectively to treat serious infections. The decision to use one of these is a tough one to make, but a drug is being developed to mitigate the deleterious side effects and preserve hearing.

Other harmful drugs are antibiotics Cipro and Levaquin, antidepressants Prozac, Elavil, Paxil, Zoloft, and Celexa, some loop diuretics prescribed for heart or kidney problems, chemotherapy drugs Cisplatin and Carboplatin, and Quinine. Surprisingly, even some over-the-counter drugs like aspirin, ibuprofen (Advil), acetaminophen (Tylenol), and Naproxen (Aleve) can increase the risk of hearing loss when frequently taken in high doses.



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If you benefited from reading this edition, got a pearl of wisdom, or found a new resource for yourself or family member, please make a donation to support this newsletter.

If you have not contributed in the last 12 months and are able to do so, please use the form on the back of the newsletter, and mail your tax-deductible gift to:

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We thank the donors who have contributed since the last issue:

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Chapters in Oregon

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- *Insights into effectively living with hearing loss*
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- *Coping strategies & tips*
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- *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.

HLAA of Central Oregon (HLAACO) is currently inactive until further notice.

Contact: Cliff Tepper
1664 NE Redrose Court
Bend, OR 97701
(541) 390-2174

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

Contacts: Andrea Cabral
e-mail: angora@comcast.net
(541) 345-9432 voice
PO Box 22501
Eugene, OR 97402

Clark Anderson
e-mail: clarkoa@msn.com

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Applications are generally due mid-March each year.

HLAA of Salem meets the 4th Tuesday each month (except July and August) - 6:00 PM at the Salem Hospital Community Health and Education (Building D), Creekside Overflow Room, 939 Oak Street SE, Salem, OR.

Contact: Mary Fagan
e-mail: hasalem@live.com
(503) 409-5491
3253 Dallas Hwy NW Salem, OR 97304-4222

HLAA of Portland meets the 3rd Monday each month (except June, July and August) 6:30 PM in "Building 2", 2nd floor, on the Legacy Good Samaritan Campus, 1040 NW 22nd Ave. (at Marshall), Portland 97210

Contact Anne McLaughlin
e-mail: hlaportland@gmail.com
PO Box 2112
Portland, OR 97208-2112
www.hearinglossor.org/portland/

HLAA of Douglas County meets the 4th Monday of each month at 6:30 pm. Location is Mercy Hospital Community Education Room (2nd floor), 2459 Stewart Parkway, Roseburg.

Contacts: Vincent Portulano, President:
email: HLAADC@outlook.com

Ann Havens, Secretary (541) 673-3119

HLAA of Linn and Benton Counties meets the 3rd Thursday of each month (except July and August) – 6:30 PM at Albany General Hospital, Conference Room A (third floor).

Contact: John Hood-Fysh
e-mail: jhood-fysh@wwmore.com
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Chapter coordinator contacts:

Oregon: Richard Little
e-mail: Richard16@comcast.net
(541) 223-8810 (cell text only) or
(541) 818-0003 (home)
PO Box 215, Sweet Home, OR 97386

Oregon: Vincent Portulano
e-mail: vportulano@hotmail.com
15491 Highway 99, Oakland, OR 97462

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E-Mail _____ ☐ Please send my newsletter via e-mail _____

I learned 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.
- ☐ I wish to remain anonymous.
- ☐ I cannot contribute but would like to receive the newsletter.
- ☐ I want to join **Hearing Loss Association of America**, the National Organization. Please enroll me as a member. I'm including my membership fee (see bottom of page4 for fee schedule).

Or you can sign up online at www.hearinglossOR.org (click membership, then click application)

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