Hear It Is!

Oregon



Summer 2015 Issue 62

Finally! Chapter Coordinators for Oregon

The long search is over. We now have not one but *two* new Chapter Coordinators for the state of Oregon. Richard Little of Sweet Home and Vincent Portulano of Oakland will share the duties. Richard has outlined their view of their tasks below.

Our main focus will to help ensure the overall growth and well-being of the HLAA Chapters in Oregon by providing a crucial link to the Hearing Loss Association of America's (HLAA) headquarters and its resources. We will foster chapter-building initiatives among existing chapters to help them attract new members and grow. We will forge strong ties with chapter leaders and mentor them on how the HLAA national organization and the HLA-Oregon can support and benefit their organization. We will be seeking prospective leaders interested in starting new HLAA Chapters and will providing them with the support they need.

Our other priorities are to: 1) Help chapter leaders position their individual chapter as the local resource for programs that support the HLAA mission. 2) Counsel the chapter leaders on how to ensure their education and support programs are consistent with HLAA's mission, and addresses the major needs of their members, visitors, and the local community of people with hearing loss. 3) Help the chapter leaders to nurture, develop, and support other chapter leaders, and to identify prospective leaders. 4) Guide the chapter leaders on how to attract more active volunteerism. 5) Encourage the chapter to build HLAA memberships on both the state and local chapter level. 6) Counsel the chapter leaders on how to support HLAA advocacy efforts on a local level. 7) Help to identify and support prospective leaders interested in starting new chapters. 8) Encourage chapters to seek the sources of funding (membership fees, donations, sponsorships, grants, etc.) necessary to help underwrite the meaningful delivery of the above programs. 9) Provide the HLAA Director of Chapter Development with an annual State-of-the-State report that assesses each chapter's overall health, major opportunities, and needs as well as to provide a summary of the plan to deliver the above objections in the coming year. 10) Reach out to the HLAA Director of Chapter Development for guidance and support when facing a major issue in achieving the above goals, or if a chapter is dealing with either a major growth opportunity or a serious issue affecting the chapter's health.

If you have any questions be sure to contact either Richard or Vince (see page 15 for contact information). We will be looking forward to seeing you at one of your chapter meetings.

From My Lips to Your Ears

Editorial by Chuck Vlcek

The big front page news is that after much searching, we actually have two chapter coordinators. We welcome aboard Vince Portulano and Richard Little and wish them well in their endeavors. Once they get up to speed, their work should help revitalize the chapters in Oregon and strengthen ties between them, as well as with HLAA.

Equally important is the upcoming workshop on chapter development scheduled for October 24 (see page 6). While this is geared for present and future leaders of various chapters in Oregon and Washington, others who are not yet members of any chapter may be eligible. All that is really needed is a can-do attitude. One example is one of our new chapter coordinators, Richard Little. One year ago he had not even heard of this organization. Yet he was able to run for a position on HLAA-OR's board of directors, then fill one of the coordinator positions. His leadership role at work as an entomologist honed his organizational skills which will be very useful in his present role as a chapter coordinator. The point is that there IS room at the top. So if you are not just a joiner but a mover and shaker, this workshop is for you. Don't be bashful about registering!

You may also want to consider a position on HLAA-OR's board of directors. The official call for candidates is made in the next (Autumn) issue of the newsletter, but now is the time to be thinking about it. Ideally, submission of an application and personal bio to the Nominating Committee should be made by December 31, even if the published deadline is later. The 3-year term of a board member begins at the conclusion of the Annual Meeting in March.

HLAA, Oregon State Association Officers and Board Members

President Clark Anderson Vice President Karen Brockett Secretary Chuck Vlcek Treasurer Cathy Sanders

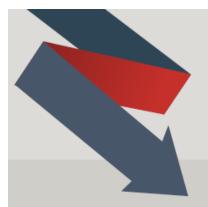
Board members: Vincent Portulano, Richard Little, Kathryn Eckert-Mason, Duane Davis, Eileen Marma, and John Hood-Fysh.

Hear it is! #62, Summer 2015. Published quarterly by the HLAA, Oregon State Association, Inc., PO Box 22501, Eugene, OR 97402. Chuck Vlcek, Editor; and Karen Swezey, Business Editor.

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 Autumn 2015 edition: September 30, 2015.



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HLA-OR Quarterly Meeting Dates

The next meeting will be held Sept. 12, 2015 at Albany General Hospital

(Room 1AB, 3rd floor). The last meeting in 2015 will be held Dec. 5.

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.

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

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1919 Connecticut Avenue, N.W.
Washington, D.C. 20009

Convention 2016 Registration will be Open: In keeping with tradition, early-bird registration will open no later than October and will provide discounted registration rates through January 31, 2016. Increased rates will begin February 1 and continue through May 31 when pre-convention registration closes. On-site registration will be available.

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; 301-657-2248 (Voice); 301-657-224 (TTY); 301-913-9413 (Fax) or www.hearingloss.org.

PLEASE JOIN TODAY!

General Coping Skills

Reprinted from Facing the Challenge of Hearing Loss, page 45

Those of us with hearing loss sometimes forget how difficult it is for others to understand our hearing loss or remember how best to communicate with us. But it's self-defeating to think others don't care. Even our family and our best friends will forget from time to time – sometimes because they're so excited and interested in the conversation that they don't think about how it's coming across to us. We think they're mumbling; they think we're not paying attention. We think they're talking too fast; they think we're really slow on the uptake. We notice they are walking away before finishing their statement; they think we can still hear them talking.

We must try to remember that the hearing world really does not know that, unlike glasses, hearing aids and cochlear implants do not correct, they merely AID, they do NOT restore normal auditory function. We must keep in mind that others may not comprehend the importance of, for example, maintaining visual contact with the speaker because we depend so much on lip or speech-reading.

As another example, even those with whom we live may not understand that our ability to hear can depend on the time of day, how we are feeling, or our surroundings. People may mistake our lack of instant response for indifference or even consider us a bit dull, not knowing that it takes time for our brain to sort and process the somewhat muddled sound we receive.

All this means that we must educate our friends, family, and coworkers – and enlist their help – sometimes repeatedly, but in a manner that does not alienate them. That calls for considerable finesse, a good sense of humor, and patience, patience, patience!!

Hot Off the Press!!

Do you have your own copy of the newly updated booklet "Facing the Challenge of Hearing Loss - A Survivor's Manual"? It's full of good information. Buy them in quantity as gifts for birthdays, Holidays, and other times. Send your check for \$4 for each copy or \$35 for 20 booklets to Hearing Loss Association of Oregon (PO Box 22501, Eugene, OR 97402)

Within Earshot: News You Need to Know

SB449A Update

Senate Bill 449A would have established the Office for Deaf, Deaf-Blind, and Hard of Hearing Services. It was submitted to the Ways and Means Committee but died there. The legislators felt that more research needs to be done to fully understand what is really needed to set up services for the community. To accomplish this, a new budget line item will be added to DSHS SB 5026. This item will ensure \$200,000 for the next two years, 2015 – 2017, budgeted as \$100,000 for each year.

The money will go towards research such conducting community а assessments and gathering much information as possible related to Deaf, Deaf-Blind, Deaf Plus, and Hard of Hearing populations. The goal is to get involvement from as many people as possible in our community with a wide range of people with various backgrounds experience. They want a robust snapshot of our community and to understand what people's needs are, what they are looking for, and what services need to be in place.

This update was provided by Chad Ludwig, President, Oregon Association for the Deaf. Additional information will be provided when it becomes available.

Problems with Stadium Captioning

More stadiums and arenas have captions on their scoreboards, but many deaf people are not happy with the quality of these captions. A captioner said that students are trained in these fields: court reporting, attorney deposition reporting, closed captioning, news captioning and classroom CART. Stadium captions? Not taught at many stenotyping schools. Many captioners are bothered by stadium noises. Possibly in due time, stadium captioning quality will improve. – Reprinted from Deaf Digest.

Chapter Building Workshop

The Oregon and Washington state associations of HLAA are co-hosting a workshop on Chapter Building for current and prospective chapter leaders on October 24. The meeting will be held in the Cascade Room at LaQuinta Inns and Suites Portland Airport. Registration is from 8:30 to 9:15 a.m. and the workshop begins at 9:30 a.m. and ends at 3:30 p.m.

Pre-registration is recommended as seating is limited. The cost is \$15 which covers beverages, lunch, and materials. However, lunch will not be available if the registration is received after Friday, October 16. To register, provide your name, address, phone number, and e-mail address (if you have one), plus your check or money order for \$15, and send to the Hearing Loss Association of Oregon, P.O. Box 22501, Eugene, OR 97402.

If you wish to lodge at LaQuinta, you may make reservations under the Hearing Loss Association rate of \$99.00 per night by October 9. Call them at 503-382-3828 or email them at cpollack@pacificinns.com or link to www.laquintaportlandairport.com.

Study Shows Relief for Tinnitus

By Lynne Terry, The Oregonian, July 17, 2015

Imagine dealing with the stresses of everyday life, juggling the demands of a family and deadlines at work, with a constant ringing in your ears.

That's what millions of Americans who suffer from tinnitus face.

Hope could be on the way. New research by the Portland Veterans Affairs Medical Center and Oregon Health & Science University found that a noninvasive technique involving stimulation of the scalp can help.

The study involved 70 patients suffering from tinnitus, a condition that affects up to 15 percent of adults in the U.S. Patients hear sounds that have no apparent source. It can be a buzz, hum or whistle that they hear in one ear, both ears or in their head.

Some of the study participants received a placebo treatment and the others underwent a repetitive transcranial magnetic stimulation, or rTMS, which involves delivering electromagnetic pulses through a coil to the scalp. Researchers have proposed low-frequency rTMS, which reduces brain activity in the stimulated regions as a treatment for the medical conditions associated with increased cortical activity, including tinnitus.

The participants who received the treatment were zapped with 2,000 pulses per session on 10 consecutive workdays. Others got a placebo treatment. No one withdrew from the study because of adverse effects.

Assessments were done at successive intervals. At 26 weeks, those who had received the treatment reported about a one-third reduction in the ringing. The placebo group reported a 7 percent reduction.

Robert Folmer, the lead investigator, said researchers hope to conduct a larger, multisite clinical trial. If effective, the stimulation should be adopted as treatment for chronic tinnitus, the authors said. The study was published in the journal of IAMA Otolaryngology -- Head and Neck Surgery.

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Here It Is! Oregon Summer 2015 Newsletter





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Now CaptionCall offers two revolutionary, no-cost solutions to help you use the phone with confidence ... the CaptionCall phone and our brand-new CaptionCall mobile app for iPad.

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Professional certification of hearing loss required to participate in this program. A standard phone line and Internet connection are also required. The free phone offer includes free delivery, installation and in-home training by a friendly CaptionCall Trainer.

Chapter Capers

<u>Douglas County Chapter:</u> No meeting was held in July due to several members being out of town. A potluck picnic was held near Sutherlin on August 22, attended by nearly all of the chapter members. Richard Little, who is our new chapter co-coordinator along with chapter president Vince Portulano, was a guest at the picnic. A lively discussion ensued as we got to know each other. There was still time to munch and play card games afterwards.

Portland Chapter: The chapter did not meet during the summer. The September meeting location may be changed, with two weeks advance notice, so visitors should check with the contact person before attending (see page 15). Their electronic newsletter is now more readily accessible to mobile devices. Their August newsletter provided updated information on Open Captioning performances in Portland and at the Shakespearean Festival in Ashland.

<u>Oregon State Association:</u> The next board meeting will be held at Albany General Hospital on September 12. A workshop on chapter development has been planned to be held in Portland on Saturday, Oct. 24. Leaders from each chapter in Oregon and Washington are invited (and encouraged) to attend. See page 6 of this issue and page 10 of the Spring 2015 issue of this newsletter for details.

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 Equipment Troubleshooting Tips

Greetings from the OHSU Cochlear Implant Team! We wanted to take this opportunity to provide implant users with helpful tips and reminders for troubleshooting external equipment.

Do you ever find that your cochlear implant processor doesn't sound as clear and crisp as it has previously? Does your processor ever function intermittently? Try these suggestions before contacting the cochlear implant manufacturer:

- Change the battery to ensure you're utilizing a fully charged/new battery source
- Replace the microphone cover/s
- Change headpiece/coil with back-up coil
- Change coil cable with back-up coil cable
- Change processor with back-up processor
- Change battery controller/battery pack with back-up battery controller/battery pack

If you have attempted all of these suggestions and are still experiencing equipment malfunction, please contact your cochlear implant manufacturer for further troubleshooting tips. Remember that your cochlear implant manufacturer is committed to providing you with excellent customer service and is there to assist you in with any equipment problems. Do not hesitate to contact them with any and every equipment question.

Advanced Bionics (866) 431-4977 support@advancedbionics.com

Cochlear Americas (800) 483-3123 customer@cochlear.com

Med-El (888) 633-3524 audiologyus@medel.com

We hope you have found this information helpful. Please send any questions you may have regarding cochlear implants to cochlear@ohsu.edu.

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

Advocacy Updates – CDC Gets an Earful!

On August 7, 2015, Hearing Loss Association of America (HLAA) issued an action alert regarding a recent study, <u>Prevalence of Disability and Disability Types Among Adults</u> conducted by the Centers for Disease Control and Prevention (CDC). That study excluded people with hearing loss.

The response was overwhelming! Consumers and professionals alike were aghast at the exclusion of people with hearing loss in a study administered by CDC. The responses were compelling, heartfelt stories of what it really is like living with a hearing loss:

An advocate in New York wrote, "We need to take hearing loss in the United States from the realm of invisible, often ignored and still too often regarded as a shameful or embarrassing personal affliction to the forefront of major public health concerns."

"We can't fix that which we fail to see," wrote one teacher.

A consumer in Virginia said, "Given how this report will be used by federal, state, and local governments, as well as by other organizations to help them make decisions about funding and other issues to support the disability community, I really think you need to meet with the people at the Hearing Loss Association of America and listen to what they have to say."

CDC itself notes in this study, "Understanding the prevalence of disability is important for public health programs to be able to address the needs of persons with disabilities."

The study is part of a collaborative project among all the states in the country and CDC, and is administered and supported by CDC and conducted via phone. The objective is to collect uniform, state-specific data on preventive health practices and risk behaviors that are linked to chronic disease, injuries and preventable infectious diseases that affect the adult population.

HLAA made it clear to CDC that it had received a strong response from our community. It is vital that public health programs have access to data that includes people with hearing loss. CDC heard our message.

A dialogue has now been opened up between HLAA and CDC and they will continue to work together. We know that data regarding the health needs of people with hearing loss is sorely needed. This is just the first step to ensure that people with hearing loss are counted and there are voices heard.

When Should I Consider a Cochlear Implant?

There are an estimated one and a quarter million persons in the US who could benefit from a Cochlear Implant (CI), but only about one hundred thousand have one. So why do less than 10% of those who are qualified for a CI have one? Some of the reasons are:

- Most people still do not know about Cls.
- The person's primary care physician and/or hearing aid audiologist does not know the current candidacy criteria and/or understand how much benefit some people could achieve.
- There are still controversy and misunderstanding from some within the Deaf Culture.
- The expenses and/or coverage issues for a CI procedure.

The FDA has a specific set of guidelines concerning CIs. Most private insurers typically follow FDA guidelines. Medicaid varies by state but tends to follow FDA. Medicare has been more restrictive.

If you are recently diagnosed with severe/profound hearing loss and were thinking of 'looking' into CIs but had questions or concerns or perhaps you have decided to postpone getting a CI, do not delay this critical and important decision. Read on to see why it is so important to give yourself this life altering procedure now and not years from now.

The average delay between onset of severe/profound hearing loss and receipt of a CI is 10 years. Duration of deafness is consistently cited as one of the most significant predictors of post-operative hearing outcomes with a CI. Simply put, the shorter the duration of deafness before being implanted, the better the outcome will be with a CI.

Adults who do well with CIs typically maintain good speech recognition skills for a very long time. Waiting to receive a CI could result in poorer speech recognition initially, and speech recognition may never reach the potential that could have been obtained if the CI was received sooner.

Here are some more reasons to start the process for evaluating your candidacy for a CI:

- Adults with hearing loss demonstrate a 30% 40% accelerated rate of cognitive decline and a 24% increased risk for cognitive impairment than adults with normal hearing.
- Adults who receive CIs tend to show improved global cognitive function.
- Adults who receive CIs tend to demonstrate less depression post-implant (59% versus 76% 12 months post-implant).

Age is not a factor. Cls have been placed into patients over 90 years old. Several investigators report that cochlear implants are safe and effective for people over the age of 65; elderly patients do not experience more complications from surgery and do not experience more device failures than younger patients.

If you have been refused a CI under Medicare rules the ACI Alliance might have some options for you to pursue to see if you qualify for their study. They are working on getting Medicare to change their rules to at least mirror FDA guidelines for determining CI candidacy.

Thanks to the American Cochlear Implant Alliance for much of this information. Check them out at www.acialliance.org





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Marco Jurado, AuD, FAAA

Cochlear@ohsu.edu www.ohsu.edu/ent

We ask for Your Support!

Please, if you can, support HLAA, Oregon State Association and this newsletter through your donations. With your help, we can continue to reach out and educate Oregonians about hearing loss and the many ways to cope with it. *Knowledge is power.* We love sharing helpful information.

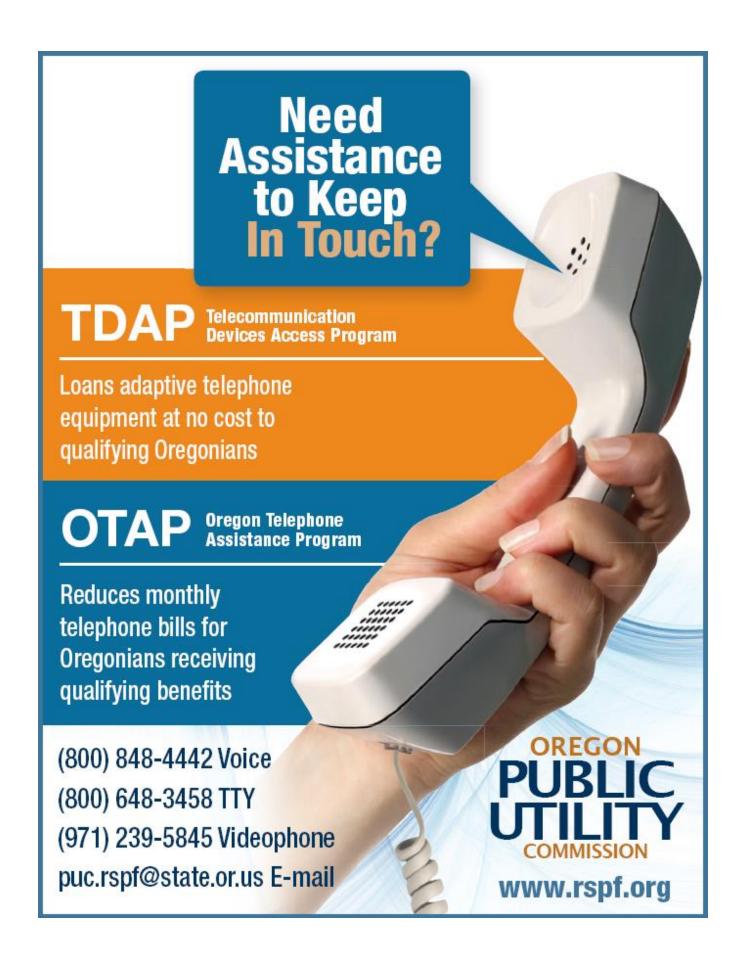
If you have not contributed in the last 12 months and are able to do so, please use the form on the back of the newsletter, and mail your tax-deductible gift to:

HLAA, Oregon State Association, PO Box 22501, Eugene, OR 97402

We thank the following folks who have sent donations since the last issue:

Milton Anderson Vance Taylor Amy Beller

Jo D'Antonio Katherine MacQueen William Thomson



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



Oregon State Association

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) meets on the 2nd Wednesday of the month from 6 to 8 PM at the St. Charles Medical Center, 2500 NE Neff Road, Bend, in Conference Room A (by the front entrance).

Contact: Cliff Tepper 1664 NE Redrose Court

Bend, OR 97701 (541) 390-2174

WESTERN OREGON UNIVERSITY

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The Regional Resource Center on Deafness offers degree programs to prepare professionals to meet the unique communication, rehabilitation, and education needs of individuals who are hard of hearing, deaf, late-deafened, and deaf blind.

Please visit our Web site: www.wou.edu/rrcd or contact us at 503-838-8444 or e-mail: RRCD@wou.edu.

Applications are generally due mid-March each year.

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 OR Clark Anderson Eugene, OR 97402 e-mail:clarkoa@msn.com 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: hlasalem@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 the Wilcox Building, Room ACR 102, on the Legacy Good Samaritan Campus, 1015 NW 22nd Ave., Portland 97210

Contact Anne McLaughlin (president) 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 (adjacent to Office Max).

Contacts: Vincent Portulano, President:

email: <u>HLAADC@outlook.com</u>

Robin Illers, Secretary (541) 580-7180

HLAA 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: John Hood-Fysh

e-mail: jhood-fysh@wwmore.com

(541) 791-3725 (H) (541)-220-8541 (cell)

818 Broadalbin St. SW Albany, OR 97321

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http://www.hearinglossor.org/news.htm

To subscribe, e-mail info@hearinglossOR.org and we will notify you with the above link when a new issue is available.

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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

HLAA:

e-mail: chapters@hearingloss.org

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

7910 Woodmont Avenue Suite 1200

Bethesda, MD 20814

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