# Hear It Is! Oregon



Spring 2014 Issue 57

# Stanford Initiative to Cure Hearing Loss

Notes from webinar held by Sacramento chapter, March 8, 2014

Kate Morris is the mother of a four year old child who wears hearing aids after being diagnosed with genetic hearing loss. Age-related hearing loss also runs in the family. Kate's current position is to raise awareness of Stanford's initiative to cure hearing loss. The primary goals of the initiative are to study regeneration of inner ear hair cells, imaging to help understand processing, and learn the effects of various drugs on hearing.

The research staff includes engineers, cell biologists, and geneticists. There were 6 in 2005 and now there are 80 people working on the goal. They still need to raise awareness among researchers. One researcher is Prof. Stefan Heller who was born in Germany in 1982 and joined Stanford 8 years ago in the Dept. of Otolaryngology where he works in the Molecular Biology Lab. He has a mild noise-induced hearing loss and discovered that inner ear stem cells can be regenerated to create new ones. He is now working on regeneration of hair cells in animals.

They have known that birds can regenerate hair cells. Birds that become deaf due to loss of hair cells for any reason will regain hearing in about 2 or three weeks. Sensory hair cells are frequency specific and fragile. They can be pushed over and die easily, and are irreplaceable in humans. There are also supporting cells that have no hair bundles and are thought to separate the hair cells. When hair cells die in a bird, the supporting cells will respond. Some will convert into a hair cell, thus leaving a gap. Other supporting cells fill the gap by dividing, thus creating new support cells. The researchers also found signs of stem cells in the vestibular system in all mice but only newborn mice have stem cells in the cochlea. These cells can be activated in the neonatal ear. There is hope that as drugs are found to trigger the mouse stem cells, research and testing of drugs for use in humans will follow, but that will be at least 5-10 years away and will not work for everyone. It will take a few additional years to collect sufficient data to determine which drugs are safe and effective, particularly for age-related hearing loss.

The webinar also covered other causes of hearing loss, current and possible future treatment, and ongoing clinical trials. The research can be supported by informing others of the project via Blog, Facebook, Pinterest, and/or Twitter accounts. For additional information, see <a href="https://www.Hearinglosscure.stanford.edu">www.Hearinglosscure.stanford.edu</a>.

# From My Lips to Your Ears

Editorial by Chuck Vlcek

We are back to 16 pages. The reason we went to 20 pages was to make room for an ad being placed in exchange for the reception of audio loop equipment. The time for that ad has expired and it is not being renewed, at least not immediately. We need additional ads to continue supporting 20 pages. The newspaper can only be expanded in fourpage increments and ideally two pages of ads will support two pages of content. So if you want to place an ad (or sponsor some space) or know someone who does, please let us know.

There is still content worth reading. The front page article offers a hopeful look at future developments. There was more to the webinar than was presented but the remaining information was rather fragmented. You are encouraged to participate in these webinars or at least view an online transcript if one is provided.

There is yet another call for help with the Survivors Manual (page 6). In a nutshell we need suggestions for updating it and help with distribution. By doing this work we are helping others and also helping ourselves in the process.

The article on page 7 reminds us that we should keep track of technological advances when providing and/or using assistive listening devices (ALD) for the public. In some cases the technology (or upgrade) is not that new but has only recently been made available to the public at reasonable cost. It also brings in another factor to consider when providing ALDs for the first time at a given location or facility: how easy would it be to upgrade and how much would it cost.

### **HLAA**, Oregon State Association

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Hear it is! #57, Spring 2014. 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 <a href="mailto:info@hearinglossOR.org">info@hearinglossOR.org</a>.

For advertising information and rates, contact Karen Swezey at <a href="mailto:info@hearinglossOR.org">info@hearinglossOR.org</a>.

Deadline for Summer 2014 edition: June 30, 2014.

### Oregon Deaf and Hard of Hearing Advisory Committee

The Oregon Deaf and Hard of Hearing Advisory Committee (ODHHAC) was officially restarted on March 14, 2014 at DHS. The purpose of ODHHAC is to represent the interests of deaf and hard of hearing Oregonians and to provide feedback and recommendations and to ensure that state agencies make programs available and accessible to individuals who are deaf or hard of hearing. Members of the advisory committee are appointed by DHS Director Erinn Kelley-Siel. All Committee members have experience and/or knowledge about deaf and hard of hearing services, including four people who are deaf, four people who are hard of hearing and four who are hearing.

The new Committee is off to a strong start, and they encourage the public to attend their future meetings with comments and/or concerns. At their first meeting, the Committee discussed and identified future strategies for bringing their work to the public and how to best involve the community. At their second meeting on April 18th, members selected two Co-Chairs, Chad A. Ludwig, who is Deaf, Carol Mauser, who is late stage hard of hearing, and a Secretary, Sara Weiner-Collier, who is deaf.

Chad A. Ludwig said serving on this committee is important to him because, "I've lived in five different states before coming to Oregon. This is the state where I see the most significant disparity in having resources and services for the Deaf, deaf, deaf plus, Deaf Blind, Hard of Hearing and late deafness community. I want to see a significant change in that."

Carol Mauser said "One of the things that has been really important to me is educating the community about resources and services that are out there and available for everyone to use."

After the last ODHHAC meeting on April 18th, members voted to support a statewide community-based needs assessment to identify the needs for services or programs to better support Deaf, deaf, deaf plus, Deaf Blind, Hard of Hearing and late deafness individuals. The areas of assessment will include, but are not limited to education, employment, early intervention strategies, mental health, housing, alcohol and substance abuse. Currently, there is a significant lack of direct services available in Oregon in which this population can acquire the knowledge and skills to self-advocate or obtain equal access to program and services offered by non-profit, business and government agencies.

Theresa Powell, an Operations and Policy Analyst on the committee, encourages people to attend their future meetings and get involved. "We have a full commitment to our members but welcome and encourage the community to attend our meeting to receive information, provide personal stories and public comments."

The next meeting is scheduled for June 20th 10:00a.m-12:00p.m at HSB room 160, 500 Summer St. NE, in Salem.

For more information about ODHHSP, please contact Theresa Powell at: <a href="mailto:theresa.a.powell@state.or.us">theresa.a.powell@state.or.us</a>.



# http://www.hearingloss.org/content/convention

The link shown above will provide you with the latest information and convention plans, and provide additional links to the fine details as well as the registration page. The keynote speaker for Convention 2014 is music composer Richard Einhorn. He will speak at the opening session scheduled for Thursday, June 26, 5 p.m. -6 p.m.

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 <a href="https://www.hearingloss.org">www.hearingloss.org</a>.

PLEASE JOIN TODAY!

### **HLAA Names New Director of Chapter Development**

HLAA has appointed Edward F. Ogiba of Sarasota, Florida, to be its new director of chapter development with the primary charge of helping current chapters to grow and building new ones through strategic development, best practices and leadership training. The post entails providing HLAA's state organizations and chapters around the country with the direction and support they need to deliver the organization's acclaimed education, support and advocacy services to open the world of communication for those with hearing loss.





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# Within Earshot: News You Need to Know

### **Survivors Manual Update**

Have you ever watched a dog chase its tail? It really wants to get a hold of that tail but just can't figure out how! Do you remember when you started going in circles looking for something (anything) to help you deal with your hearing loss and you just couldn't get a hold of it? What a gift it would have been to have a book like the Survivors Manual (Facing the Challenge) to help you in your time of need. You can always continue to use the Survivors Manual as a resource. It is available online at www.hearinglossOR.org.

HLAA-OR has a committee working to update and reissue the 4th edition of our Survivor's Manual. It's a lot of work getting it organized, off to the printers, and into the hands of the people who NEED to have it. We have printed and distributed 62,000 copies over the years and now we're ready to do another 20,000. We are getting sponsors and financing in place.

The biggest challenge is distributing those 20,000 books. *This is where your help is needed!* They need to be delivered to audiologists, dispensers, pharmacies, doctors, churches, schools, and organizations (Lions, Rotary, Kiwanis, etc.).

To volunteer to help with distribution, contact Leone Miller at <a href="mailto:vngleone@comcast.net">vngleone@comcast.net</a> and she will provide you with information about resources, and encouragement about places and ways to distribute the manuals. When you distribute the books, you should provide her with a periodic progress report and also share any creative new ideas about making those distributions. Each chapter is strongly encouraged to have a contact person.

You are also strongly encouraged to make suggestions for any changes to the manual.

## **OHSU Research Study**

Subjects are invited to participate in a research study in Lina Reiss's Cochlear Implant and Hearing Aid Research Laboratory in the Department of Otolaryngology at the Oregon Health & Science University (OHSU).

This National Institutes of Health funded research project is aimed to improve our knowledge of how to improve listening with cochlear implants and hearing aids.

In this particular study, we will be studying how sound input from two ears combine in a listener with hearing loss and how this might explain some of the variability observed in cochlear implant and hearing aid users.

The research subjects must be adults (18 years or older) with moderate to profound (40-90 dB) hearing loss in both ears. Candidacy for this study will be determined by reviewing an audiogram completed within one year or through a hearing test completed at the research study visit.

Participants will be asked to listen to sounds and words, and respond by pressing the appropriate button on a computer touch screen. The time needed to complete the study varies from two to three sessions (2-3 hours/session). In addition, participants will receive \$15/hour for their time.

If you would like to participate in this study or for more information, please contact Lina A.J. Reiss, Ph.D., Principal investigator, Assistant Professor of Otolaryngology at <a href="mailto:reiss@ohsu.edu">reiss@ohsu.edu</a> or by phone at (503) 494-2917.

# **Tech Topics**

# **Local Church Provides Modern FM System**

### By Chuck VIcek

Juanita, a woman in her mid-nineties, was able to understand the sermon for the first time in years. She was overjoyed. The reason? She had just been fitted with an FM receiver with a headphone carefully fitted over her tiny hearing aids. The North Umpqua Bible Fellowship (NUBF) near Glide had just purchased and installed a new FM system after a hiatus of several years. The church used to have an FM system but the receivers were hard to maintain. They kept drifting off frequency and suffered other problems. The church finally gave up on it.

During the intervening years the rest of the sound equipment was upgraded, especially the mixer. But a decision still had to be made on how to serve the hearing-impaired community. Looping was considered but apparently impractical in this case. There is a dearth of qualified loop technicians in Oregon, and mating it to the rest of the sound equipment added another layer of complexity. So the church went back to the FM system.

So what was special about this one? Larry, the pastor's brother who was in charge of the sound system explained that the new FM operated on UHF frequencies and was supposed to be quite stable. The specifications indicate that the system uses 16 selectable frequencies between 518 and 928 MHz via Phase Locked Loop (PLL) circuitry which helps to select a frequency that is free of interference. Frequency stability is listed as plus or minus 0.005%. The signal to noise ratio in the receiver was listed at more than 94 dB.

There are currently six receivers available, and more can be purchased if needed. At least four of them are being used during the service. I was intrigued. Obviously I had to try it out for myself. I had been frustrated by the static that I always seemed to be getting out of the old receivers and I do not recall being able to use it at all after getting my second cochlear implant. The implants worked pretty well – I could follow the sermons without too much strain or difficulty if I sat near the front. But the receiver offered an even more relaxing way to listen, and I would not even need to sit up front.

I brought out my powered neckloop that I had not used in quite a while and plugged it into the receiver jack. Now I had three ways of adjusting the sound level: in the receiver, in the neckloop, and/or my Cls. I had to do some experimenting to get the best results, especially since the "T-switch" mode on the Cls still included some sound through the microphone. During the worship I could get clear sound from the instruments and singers on the stage but also wanted to include some sound (via Cl microphone) of the singers in the congregation and get a good balance between the two. For the sermon, I only needed to keep the Cl microphone sensitivity low and take advantage of the clear voice coming through the FM system.

The system worked very well. During the worship the leader would offer quiet prayers from time to time and it was easy for me to hear those, even when I was still in the back where I had picked up the receiver. Once I had made the proper adjustments I didn't have any problems with echo or unbalanced sound, and there was no static. My only quibble is that the new receiver is bulkier than the old one and the jack is on the side, making it harder to slip it into a pocket with the neckloop plugged in. It has a clip but tends to slip off.

And Juanita? She needed some help in getting the proper fit and that required communication with the person helping her. She also needs a better (and necessarily larger) hearing aid, one equipped with a t-coil. She noted that even with the technology, you can't change the way people talk. "They talk too fast." Sound familiar?

### **Chapter Capers**

**Douglas County Chapter:** Since the regular May meeting would have fallen on Memorial Day (observed) when the meeting place would be closed, the date and place was changed. Instead, members Frank and Dolores Elias graciously hosted a potluck picnic at their home near Riddle on May 17. HLAA-OR President Clark (a former Douglas Anderson County chapter member) and HLAA-OR treasurer Cathy Sanders were guests at the meeting. Cathy used her laptop and expertise to obtain the proper form for instituting the required name change for the chapter. Thanks, Cathy!

Portland Chapter: Dr. Tina Penman was the speaker at the chapter's April 21 meeting on the topic of noise exposure and hearing loss. She is a member of their chapter and an audiologist at the National Center for Rehabilitative Auditory Research (NCRAR) at the Portland VA Medical Center. Her research interests include the effects of military, recreational, and occupational noise exposure on the auditory system, including skydiving noise exposure.

Her long-term goal as an audiologist is to better serve the active military and veteran populations through the application of research findings to clinical practices, the real world, and combat-related settings.

What is your chapter doing? Send your story to the editor at <a href="mailto:cvlcek@centurytel.net">cvlcek@centurytel.net</a> See pages 14-15 for contact information for these chapters and events.

### **CI Corner**

Are you thinking about investing in new hearing aids? Ask your audiologist about Bluetooth options that are now available. Bluetooth is a wireless communication system that is incorporated into many devices that we all use every day. The way that Bluetooth technology is incorporated through hearing aids is with the use of a streaming device, which is usually worn around the neck. The Bluetooth is activated in a device, such as a cellular phone, and the signal is wirelessly transmitted to the streaming device, and from the streaming device to the hearing aids.

In addition to cellular phones, this technology can be used with any device that has Bluetooth capabilities. This may include mp3 players, such as iPods, as well as computers. There are also additional accessories that can be purchased to allow a Bluetooth signal to be streamed from your television and landline telephone. Many manufacturers also have developed a miniature microphone, which functions similar to an FM system. The person with the hearing aids wears their streaming device and they can ask another person to wear the miniature microphone. When used, the microphone allows the talkers voice to be wirelessly streamed to the hearing aids. allowing for better speech understanding in noisy environments.

Other amplification options are beginning to incorporate this type of technology as well. Advanced Bionics is the first cochlear implant manufacturer to incorporate Bluetooth technology into their processor, and it is compatible with the Phonak ComPilot system. Other manufacturers can utilize a Bluetooth neckloop through the sound processor's telecoil. Furthermore, Cochlear's BAHA4 bone-anchored hearing aid device has Bluetooth capabilities. If interested in this new technology, consider asking your audiologist about available options, and whether your currently technology is Bluetooth compatible.

We hope you have found this information helpful. Please send any questions you may have regarding cochlear implants to <a href="mailto:cochlear@ohsu.edu">cochlear@ohsu.edu</a>.

- OHSU Cochlear Implant Team (see ad on page 10)



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Today they can hear because one man chose not to listen. Read their stories at Cochlear.com/US/Hear or to connect with a Cochlear Concierge call 800-483-3123 or email Concierge@Cochlear.com

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Amy L. Johnson, AuD, CCC/A Jennifer J. Lane, AuD, CCC/A Devon M. Paldi, MA, CCC/A

V/TDD <u>Cochlear@ohsu.edu</u> www.ohsu.edu/ent

### **HLA-OR Quarterly Meeting Dates**

The next meeting will be held on June 21, 2014 at Albany General Hospital (Room 1AB, 3<sup>rd</sup> floor). Dates of other meetings in 2014 will be announced later.

To confirm, contact President Clark Anderson at <a href="mailto:clark-anderson">clarkoa@msn.com</a> or leave a message at (541) 736-4804. Guests are invited to attend but should first contact President Clark Anderson.

### **Board Election Results**

A brief annual meeting was conducted in conjunction regular board meeting on March 15, for the purpose of electing board members. Candidates Clark Anderson, Vincent Portulano, Karen Brockett, and Cathy Sanders were all elected to the board. Cathy is an incumbent elected to a new term. She was subsequently elected to serve as treasurer, replacing Wayne Seely. Karen Brockett returned to the board after a one-year "sabbatical" while traveling. Clark Anderson had also served on the board, but not as recently. He was subsequently elected to serve as president. Vincent Portulano is the only truly new member of the board.

The incoming board members then elected the officers. As previously noted, Clark Anderson was elected president and Cathy Sanders was elected treasurer. Vicki March was re-elected as V.P. and Chuck Vlcek was re-elected as secretary. The Chapter Coordinator position is vacant. To volunteer for this position or inquire about chapter matters, send an e-mail to <a href="mailto:info@hearinglossOR.org">info@hearinglossOR.org</a>.

No action was taken in forming a new Nominating Committee, as required by the bylaws. At least three persons are required to serve on this committee, and up to seven members are permitted. Not all of them need to be current or former board members. The duties of the committee are to recruit and vet candidates for the board of directors. They have nothing to do with the election of officers, and current officers are not permitted to serve on this committee. If you are willing and able to serve on the Nominating Committee, please contact President Clark Anderson at clarkoa@msn.com.

### Dr. Allan S. Mehr

**Board Certified Audiologist** 

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# Michael W. Kelber, MD, FAAFP Salem Family Physician

Dr. Mehr has over 32 years experience working with individuals with hearing loss. He started his career as a teacher of deaf children. He taught at schools for the deaf in Oregon, Maine and New York.

After obtaining his doctorate degree in Audiology from Adelphi University, he worked at the New York League for the Hard of Hearing in Manhattan. He was then hired by the Oregon School for the Deaf to supervise their Evaluation Center. He then established Pacific Audiology Center.

He has served on the board of the Oregon Speech and Hearing Association and the Oregon Academy of Audiology. He was appointed by Governor Kitzhaber to serve on the Oregon Board of Examiners for Speech Pathology and Audiology. He became chairman of that board.

120 Ramsgate Square SE www.pacificaudiology.com

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# 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:

Celia Roberts Burford Roach Dolores Elias William Ennis

Lucy Lindley Anne McLaughlin Josephine Bateman Christina Leippe

Joan Siegienski Jo D'Antonio Eugene Holcomb John Warner



# 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 2<sup>nd</sup> 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

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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 4<sup>th</sup> 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) 7 PM in the Wistar-Morris Conference Room, at the Good Samaritan Main Hospital Building, 1015 NW 22<sup>nd</sup> 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 4<sup>th</sup> Monday of each month at 6:30 pm. Location is Mercy Hospital Community Education Room (2<sup>nd</sup> floor), 2459 Stewart Parkway, Roseburg (adjacent to Office Max).

Contacts: Vincent Portulano, President:

email: vportulano@hotmail.com

Robin Illers, Secretary (541) 580-7180

HLAA of Linn and Benton Counties meets the 3<sup>rd</sup> 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

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If you are interested in starting a chapter in your area, contact:

Cathy Sanders

Oregon Chapter Coordinator e-mail: catsindallas@q.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: <a href="mailto:chapters@hearingloss.org">chapters@hearingloss.org</a>

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### ADDRESS SERVICE REQUESTED

### Here It Is! Oregon Spring 2014 Newsletter

#### I would like to receive (or continue to receive) this newsletter.

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Ph	one	
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E-ľ	Mail	Please send my newsletter via e-mail
l le	arn	ed about the newsletter from:
[	]	Enclosed is my contribution of \$ to support the <b>Hearing Loss Association</b> 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 <b>Hearing Loss Association of America</b> , the National Organization. Please enroll m as a member. I'm including my membership fee (see bottom of page 5 for fee schedule).

\*Hearing Loss Association of America, Oregon State Association, Inc.\* 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 \*HLAA, Oregon State Association\* PO Box Box 22501, Eugene, Oregon 97402.

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