

# ***Hear It Is!***

Oregon



Winter 2017

Issue 68

## **Alert a Police Officer That You Have a Hearing Loss**

Being stopped by law enforcement when you're in your car may quickly become complicated if you do not understand what the officer is telling you. Not following an officer's direct orders in this situation can be interpreted by the officer as a threat. You can't blame the police for being careful. Theirs is a difficult, sometimes dangerous job, especially at night.

It is critical to establish at the beginning of this encounter that your communication needs are different from a person with normal hearing. Neal Bauman, Ph.D, is the director of the Hearing Loss Help Center. He offers a visor card to state that the "Driver is Hard of Hearing". The back side of the card gives clear instructions to the officer about how to communicate most effectively so the driver will understand all directions. There is also a visor card that reads: "Driver is Deaf". One may choose whichever is appropriate for use in a car.

You may purchase a visor card, a wallet size card with same information and a brochure that explains how best to use the visor card. It is offered at a reasonable price. This visor card is also available as a "free" download. You may make your own copy. See this website address to obtain a visor card:

<http://hearinglosshelp.com/wp-content/uploads/2011/12/visorcardbrochure2016.pdf>

The website suggests that a person may want to have two visor cards, one for each front visor. Sometimes, an officer will choose to stand outside of the passenger side of the car, especially if the driver's side is adjacent to highway lanes with heavy traffic. In the event of two officers stopping a driver, they will likely approach both sides of the car. With a visor card in place, attached to the visor, the driver will pull open the visor so that the card is facing the window. If it's night time, turn on the dome light. Police want to see the driver's hands. Place them on the steering wheel and do not remove them until the police officer has read the visor card.

In the event of being stopped by a law enforcement officer, be prepared to inform the officer immediately about your hearing loss.

*This article was prepared by Eileen Marma, V.P. of the HLAA-OR board of directors.*

## From My Lips to Your Ears

Editorial by Chuck Vlcek

Snowflakes fall silently, but they can silence a meeting. The Portland Chapter was one victim of a January storm, and the president and secretary of HLAA-OR were unable to attend a board meeting in Albany due to the same storm. As the secretary, I could have made it if I had been home since it didn't snow there, but I was visiting a sister near Seattle. It didn't snow there either, but I had to go through Portland to get to Albany.

My sister took me to a theatre to watch a movie, and I decided to try one of those new-fangled captioning devices. I do not watch movies much, partly because I live in the boonies. However, I do watch TV with the captions on. So I was curious to see how well it would work. I got one of those goose-neck devices with a ball mount that was supposed to fit into a cup in the armrest. The ball did not seat well – very tight fit – and the gooseneck was very stiff. That made it difficult to position the caption display bar properly and keep it steady. In the process I may have accidentally changed the settings. Bottom line was some previews were captioned but the main feature was not.

When I returned the device, I mentioned these problems and was given a voucher to attend another movie free of charge, which I gave to my sister. The two staff members were very friendly and helpful. The device does appear to have potential and I am willing to give it a chance, but apparently there is just a bit of a learning curve to use it properly and effectively.

### 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](mailto:info@hearinglossOR.org).

For advertising information and rates, contact Eileen Marma at [info@hearinglossOR.org](mailto:info@hearinglossOR.org).

Deadline for Spring 2017 edition: Mar. 31, 2017.

## Board Election Notice

Elections will be held on April 8, 2017 at HLAA-OR's Annual Meeting for Board members and officers. Since there are no contested positions for board members, recent changes to the bylaws permit the candidates (three board members seeking another term) to be confirmed by the outgoing board rather than by vote by all of the members of HLAA-OR. The incoming Board of Directors shall then elect officers. A brief bios of each candidate seeking re-election to the board is listed below.

Clark Anderson is currently president of the HLAA-OR board, former president of the Douglas County Chapter, current Board Member of HLAA Lane County, and current president of OR-CAP. He had a progressive bilateral hearing loss due to genetic predisposition and first wore hearing aids in 1994, then graduated to bilateral cochlear implants. He conducted research and teaching in sociobiology, followed by an MBA and work in hospital administration. He retired in 2006.

Vincent Portulano is a current board member and one of two Chapter Coordinators. He is the president of the Douglas County chapter. He was born prematurely with ears not fully developed, resulting in a moderate to severe bilateral hearing loss. He learned to lip read and utilize what hearing he had left while growing up and took some ASL courses during college. He obtained a BA in Political Science concentrating in Public Administration at Washington State University in 1991, followed by a Masters in Public Administration at Portland State University in 1995. He has had several jobs that involved working with children.

Cathy Sanders is the current Treasurer and former President of the HLAA-OR board, and has also served as Chapter Coordinator. She became involved with SHHH (now HLAA) in 2000 and with the board in 2001. She started a chapter in Bend, OR and left that chapter to lead the Salem chapter when she moved to Dallas, OR in 2007. She currently works as an Occupational Therapist in home health, and enjoys traveling, card crafting, and reading.

## HLAA-OR Quarterly Meeting Dates

**The next meeting will be held Apr. 8, 2017 at Albany General Hospital (Reimer Building). Other meetings will be on July 8 and Oct. 14, 2017.**

To confirm, contact President Clark Anderson at [clarkkoa@msn.com](mailto:clarkkoa@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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## ***Within Earshot: News You Need to Know***

### **P.S.A.P. Update**

The Summer 2016 issue of this newsletter had an article titled “An Inexpensive Alternative to Hearing Aids?” on page 11. It described a new category called Personal Sound Amplification Products. These are not quite hearing aids but do offer assistance to those with mild to moderate hearing loss at a reasonable price.

In the January/February 2017 issue of the Hearing Loss Magazine (page 8), Barbara Kelley, executive director of HLAA, updated the status of these products. Here they are called over-the-counter (OTC) hearing aids and may not include every product described as P.S.A.P.

On December 1, 2016, Senate Bill S.9 was introduced by Elizabeth Warren (D-Mass.) and Chuck Grassly (R.-Iowa) to provide for the regulation of OTC hearing aids. The “Over-the-Counter Hearing Aid Act of 2016” would make certain types of hearing aids available over the counter and remove many of the barriers for consumers who could benefit from hearing aids.

HLAA is a supporter of this bill along with several other groups such as AARP. It is expected to be reintroduced in the new 2017 Congress with broad bipartisan support.

While the Warren-Grassley bill uses the term “hearing aids”, the final name and definition of what qualifies as an OTC device is determined by the Food and Drug Administration (FDA). HLAA will work with the FDA and industry to ensure that these products are safe and effective, are clearly labeled with information important to consumers, have clear return policies, and ensure that the devices are compatible with other technologies and hearing assistance technology. It should also outline any red flags that point to a need to see a physician before purchasing one of these devices.

### **ABLE Accounts for the Disabled**

A new federal law, the Achieving a Better Life Experience (ABLE) Act was passed in December 2014. It permits those who acquire significant disability, including hearing loss, before the age of 26 to invest a substantial amount of money tax-free without jeopardizing their eligibility to receive federal benefits such as SSI and Medicaid. Prior to the passage of this law, a disabled person’s account could not exceed \$2,000 without losing these benefits. Now they can invest up to \$14,000 per year and have an account grow up to \$100,000 before other benefits may be suspended or terminated.

ABLE programs are administered by the individual states and not all states have them. But if your state does not have one, you may obtain an account in a state that does have one, under the laws of that state, without needing to live there. Additional information can be obtained at [www.ablernc.org](http://www.ablernc.org) and [www.realeconomicimpact.org/publicpolicy/able-act](http://www.realeconomicimpact.org/publicpolicy/able-act). The ABLE National Resource Center (ANRC) website provides information on which states are offering plans and a webinar that describes how to open and use an ABLE account.

*This information was summarized from an article by Marilyn L. Weber, “Saving Tax-Free With an ABLE Account”, Jan/Feb 2017 issue of Hearing Loss Magazine.*

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## ALDA's Advocacy Corner: Movie and Live Theater Captioning

*By John Waldo, Curator*

Just when we were beginning to think the drama would never end, it did. The Department of Justice (DOJ) has now issued the long-awaited movie-captioning regulations. And in a welcome footnote, the Department specifically acknowledges the role ALDA (Association for Late Deafened Adults, Inc.) played in making captioning available throughout the country. In a nutshell, **the regulations will require all indoor movie theaters that either have or will install digital projection systems to provide caption-viewing equipment in every auditorium.** Unfortunately, the theaters will have 18 months to comply. But by mid-July of 2018, this regulation will mean that no matter where one lives, one should be able to attend almost all movies and be able to read the dialogue as the movie happens.

Theaters are required only to provide individual caption-viewing devices, so-called closed captioning. The devices are either glasses that display the captions or cell-phone-like devices attached to a flexible support that fits in the cup-holder. While many deaf and hard of hearing individuals prefer open captioning, in which the captions are displayed on the screen and visible to everyone, this is not required. However, if a theater wants to avoid the expense of providing closed captioning, it may instead offer open captioning either for all showings or upon request prior to the start of the movie. The regulations also stop short of what many of us wanted with respect to how many viewing devices a theater must have. The regulations initially proposed in 2014 would have required many more devices than are generally used, and the theaters balked at the expense. Recognizing that an insufficient number of devices was seldom a problem (as opposed to inoperable devices), the advocacy groups agreed to support a much reduced device count coupled with a mechanism to increase the number if demand warranted. However, we only got the bad half of that bargain—the reduced device count—since DOJ did not agree to our half of the trade—the mechanism for an increase if demand warrants.

We were also disappointed with the 18-month compliance deadline, a change from the initial proposal of six months. DOJ's justification is that there might be such a crush of demand that the device-makers could not fill all the orders. That strikes me as unlikely—something like 70% of the movie auditoriums are presently equipped to show captions, so most of the demand has already been met. The regulations also don't help with increasing the amount of captioned content. *Editor's note: Because the Americans with Disabilities Act doesn't cover products, captioning of the films themselves (as well as of DVDs) is done on a voluntary basis.* The captions are done by the studios as part of the production, and they are furnished at no charge to the theaters. While most movies are captioned, a few are not, and relatively few previews are captioned. On the plus side, though, we did during this process establish a reasonably cordial working relationship with the theater owners' lobbying group, the National Association of Theatre Owners (NATO). We agreed to work together to encourage more captioned content, particularly captioned previews, and I recently got in touch with John Fithian, NATO's executive director, to ask that we begin.

While the movie regulations have been published, they are not yet cast in concrete. The Trump administration has vowed to rescind a lot of regulations. To repeal a regulation, an agency has to undertake the same sort of lengthy process required to adopt it. But for a considerable period after a regulation is adopted, Congress can rescind it by a simple voice vote. If Congress wants to rescind as many regulations as possible without any great concern for content, the movie regulations could get caught in that net. If that were to happen, though, we could still demand and almost surely obtain captioning in court.

DOJ did not buy the argument from the theaters that they always intended to provide captioning voluntarily. The Department said that in its view, the accessibility achieved to date has been because of litigation brought by states and private organizations, and the Department specifically referenced the cases ALDA and Linda Drattell brought in California against Cinemark and AMC, two of the nation's three largest theater chains (Regal is the third). We played a major role in making this access happen.

With the movie problem apparently resolved, a lot of ALDA's advocacy efforts over the last year have focused on live theaters. As I reported in my previous column, the ALDA Board has approved what I labeled the Broadway Project, which is aimed at using the financial and technical resources of the Broadway theater community to develop and test new ways of providing captioning at live theaters. Live theater captioning is a considerably more difficult problem. As with movies, the captions are prepared in advance. But unlike movies, where the content is exactly the same whenever and wherever a movie is shown, each live theater performance is unique—the timing varies from performance to performance, and sometimes the script changes in planned or unplanned ways. So the captions must be displayed by a live operator in sync with the pace of that individual performance. *[ continued on page 11 ]*





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## Chapter Capers

**Douglas County Chapter:** This chapter held its first meeting (on Jan. 23) at its new location at the Westside Christian Church in Roseburg. The meeting room is quite small and cozy but adequate for the eight people who attended. A larger room may be available if the chapter gains new members. It no longer has an audio loop available, since that was a permanent fixture at the old meeting place. Purchase of a portable loop was discussed but the consensus was to defer until a later time. At the Christmas party held in December, a brief business meeting was held to re-elect all four officers. President Vince Portulano and former president Chuck Vlcek plan to attend the Chapter Building workshop in Vancouver on March 4.

**Portland Chapter:** Their January meeting was canceled due to snow and ice on the streets and sidewalks. Their scheduled speaker, Evonne Serpa, Au.D., audiologist at the Hearing Resource Center in the Hollywood District, will attend a future meeting bringing a selection of assistive Listening Devices (ALDs). On February 20 Carol Studenmund from LNS Captioning will talk about progress in captioning on television, at live events, and elsewhere. On March 20 Nicole Brent from Cochlear will talk about cochlear implants. No speaker or topic has been scheduled for later meetings but the chapter's board election will be held on May 15. No meetings will be held during the summer.

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

## CI Corner

Cochlear implants have been around for over thirty years and has brought hearing to over 60,000 Americans whose hearing loss was beyond the reach of hearing aids. Yet this number is only five percent of those who could benefit from this technology. Why is that?

Cost is certainly one factor, although much of it is now covered by insurance, including Medicare. There are other issues, some of which were covered in this column, but the most significant one is lack of awareness of the technology and/or resources to pursue it.

Vint Cerf, "father of the internet", has written an article addressing this problem. "Cochlear Implants: A Hidden Technology?" appears on page 34 of the January/February 2017 issue of the Hearing Loss Magazine. Although he wears hearing aids, his wife Ingrid grew up with hearing loss and eventually obtained CIs in 1996 and 2006.

Vint noted that in addition to the general lack of awareness about CI technology, potential candidates who do know about it tend to underestimate the huge improvement it brings to their ability to hear. The ability to understand speech with a CI does depend on the candidate's age and history, but for the "ideal" candidate the difference is like night and day.

Vint and Sigrid recently became aware of a non-profit organization formed in 2012 to address these concerns: the American Cochlear Implant (ACI) Alliance. It is described in more detail in another article by Donna Sorkin on page 38. Details can also be found on its website: [www.acialliance.org](http://www.acialliance.org).

ACI Alliance is currently involved in a multi-center study to evaluate expansion of Medicare candidacy criteria for adults as a first step to change Medicare criteria to more closely match the FDA criteria. If successfully implemented, this change would allow more candidates to qualify for Medicare coverage.

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



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## Movie and Theater Captioning (*continued from page 7*)

This means that unlike a movie theater, a live theater bears an additional cost for each performance unless a staff person takes on the caption display responsibility, which may not be permitted by some union contracts. Nor is there any established and universally acceptable way to display the captions in a live theater. What is most often done is to have specific captioned performances, at which the captions are displayed on a portable reader-board placed in front of and towards one edge of the stage. Patrons requesting captions are then seated where they can see the captions and stage in the same line of sight. But this requires setting aside a block of premium seats.

What is needed is some means by which a live theater can provide captioning for every performance. And because we would like to be able to buy tickets at the last minute, just like everyone else, the captions need to be visible from any seat. The Broadway Project was conceived when I learned that such systems are, in fact, available. I was particularly impressed to learn about the efforts of a small theater in Baltimore, Maryland. That theater, the Everyman, uses a system that stores the prepared captions in the cloud (whatever that is), then uses a staff person to sync them to individual viewing devices, either cell phones or tablets, which can be provided by the user or the theater. The Everyman can offer captioning for every performance, and the director told me that there are usually half a dozen requests for the viewing devices. Our initial working group was ALDA and two theater buffs, Tina Childress (a frequent Broadway visitor and ALDA stalwart) and Jerry Bergman (a New York resident). Our plan was to ask the three large Broadway theater owners to begin testing systems of that nature with the goal of every-show, every-seat captioning. Once the testing period was completed, we intended to ask theaters elsewhere to install similar systems. But we got a huge surprise.

A week before we were going to send out our initial demand letters, we learned that the Shubert Organization, by far the largest of the Broadway theater owners, planned to test a similar system and was seeking deaf and hard of hearing theater-goers in New York City to participate in those tests. The system Shubert is testing is called GalaPro, made by an Israeli company, and is basically a smartphone app. The captions are prepared in advance in several languages, and patrons can access them from their own smart phones or tablets. The syncing is done through the lighting cues rather than by a live operator. Jerry Bergman attended the first test run and a subsequent group debriefing. Generally, the system was deemed promising, although it was still a work in progress. Syncing the captions to the lighting cues, which had been tried in the past with other systems, is problematic, because there isn't necessarily a close correlation between dialogue and lighting. Holding a viewing device for the entire performance isn't desirable, either, and battery capacity is also a problem. But those difficulties may be fixable. Actors' microphones are usually turned on or off as the actor speaks, so it would make more sense to sync captions to the mic cues rather than to the lighting cues. The Baltimore theater fixed the problem of holding the viewing device by buying flexible clamps from Amazon. One end holds the device and the other attaches to the seat's arm rest, allowing the user to position the device so that the captions and stage can be seen in the same line of sight.

Our understanding is that Shubert intended to display the system for its board of directors in December 2016, and then to roll out some form of every-seat, every-performance captioning throughout its system of 17 of the 41 Broadway theaters. Should that happen, we will then ask the other Broadway theaters to adopt something similar. Our hope is that if systems like this prove feasible, competitors will enter the market (there are already a number of similar systems and approaches), causing costs to decline, and—as has occurred with movie captioning—it will become financially feasible for smaller live theaters across the country to provide captioning.

It is worth noting that while systems of this nature provide access for people with hearing loss, the economic benefit to the theaters may come more from the ability to offer captions in multiple languages. Since almost 20% of Broadway theater-goers come from abroad, there could be a significant market for this access. (I continue to be baffled that the movie studios do not seem to be interested in doing something similar, considering the number of foreign language speakers here).

We have been blessed in the past eight years with an extremely active, able, and sympathetic Department of Justice. The Disability Rights Section of DOJ's Civil Rights Division has done wonderful work on our behalf. The incoming administration may have other enforcement priorities, especially immigration. In that case, private enforcement will become even more important, so the role of individual advocates and organizations like ALDA will increase.

John can be contacted at [johnfwaldo@hotmail.com](mailto:johnfwaldo@hotmail.com). This article originally appeared in the ALDA News Winter Edition 2017 and is reprinted with permission.



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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.

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**We are grateful to the families and friends of Everett Swezey and Janet Langdon, who have asked that their memorial donations be made in support of HLA Oregon in memory of their loved ones.**





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# Chapters in Oregon

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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 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](mailto:hlasalem@live.com)  
(503) 409-5491  
3253 Dallas Hwy NW Salem, OR 97304-4222

**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](mailto:angora@comcast.net)  
(541) 345-9432 voice  
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Eugene, OR 97402

Clark Anderson  
e-mail: [clarkoa@msn.com](mailto:clarkoa@msn.com)

## Take the Next Step to Better Hearing

If you or a loved one are struggling to hear, even with your hearing aids, it's time to consider the many benefits of solutions beyond hearing aids, including cochlear implant technology.

Join us for an informational meeting in Portland, OR to discuss the latest advances in hearing technology.

### Please Join Us!

Call **661.476.7915** or email  
[Sarah.Benner@AdvancedBionics.com](mailto:Sarah.Benner@AdvancedBionics.com)  
for meeting details.

Come learn about the benefits of cochlear implant technology. Family members and friends are welcome!

Want to learn about cochlear implants from the comfort of your own home?

Join the conversation at [HearingJourney.com](http://HearingJourney.com), the premier place to chat, laugh, learn, and share stories about cochlear implants and hearing loss. Chat live on Thursday nights from 4 pm - 8 pm PST.



Meet recipients and professionals who use and work with these amazing technology solutions!

For a **free** informational packet on cochlear implants, contact  
[Sarah.Benner@AdvancedBionics.com](mailto:Sarah.Benner@AdvancedBionics.com)

Your audiologist can perform tests to determine whether you are a cochlear implant candidate. For more information on the benefits of cochlear implant technology, visit [AdvancedBionics.com](http://AdvancedBionics.com)



Advanced Bionics

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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](mailto:hlaportland@gmail.com)  
PO Box 2112  
Portland, OR 97208-2112  
[www.hearinglossor.org/portland/](http://www.hearinglossor.org/portland/)

HLAA of Douglas County meets the 4th Monday of each month at 6:30 p.m. at Westside Christian Church, 2712 West Harvard Avenue, Roseburg, Oregon.

Contacts: Vincent Portulano, President:  
email: [HLAADC@outlook.com](mailto:HLAADC@outlook.com)

Ann Havens, Secretary (541) 673-3119

HLAA of Linn and Benton Counties meets the 3rd Thursday of each month (except July, Aug., and Dec.) – 6:30 PM at the Senior Center, 65 "B" Academy Square in Lebanon.

Contact: John Hood-Fysh  
e-mail: [jhood-fysh@wwmore.com](mailto:jhood-fysh@wwmore.com)  
(541) 791-3725 (H) (541)-220-8541 (cell)  
818 Broadalbin St. SW  
Albany, OR 97321

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**Eugene, OR 97402**

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E-Mail \_\_\_\_\_ ☐ Please send my newsletter via e-mail

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☐ 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.

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Or you can sign up online at [www.hearinglossOR.org](http://www.hearinglossOR.org) (click membership, then click application)

**\*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 22501, Eugene, Oregon 97402.