Enjoy it Live: Access via Captions
By Dean Olson, President of Wash-CAP and Charlene Mackenzie, Wash-CAP Board Member

More and more entertainment and sports venues are offering accommodations for people with hearing loss. But where there is background music or crowd noise, when dialogue moves quickly or performers vary their tone and volume, or when a venue’s microphone system is limited, it is the written word that enables hard of hearing people to understand what is being said.

Captioning is the form of hearing access that works for every degree of hearing loss, enabling us to increase our participation in events and our enjoyment in being there.

The Washington State Communication Access Project (Wash-CAP), a non-profit founded by noted disability

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Reflecting on HLAA at 35
By Karen Utter, President of HLAA-WA

HLAA is celebrating its 35th anniversary in 2015 as the premier U.S. organization dedicated to supporting and advocating for those of us who have hearing loss. All year long, we’ll be reflecting on what HLAA means for people with hearing loss, whether they attend HLAA chapter meetings or not.

In today’s world, hearing loss increasingly affects not just “older people.” Nearly every one of us will be affected by hearing loss, whether our own or that of a relative, friend, co-worker or associate. Studies indicate that one in five teens already has some damage to their hearing, and that 60 percent of people who have hearing loss are of working age, 21-65. It’s estimated that 48 million Americans have some degree of

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hearing loss. It’s past the time where we can ignore this often invisible disability, and past the time when we have to do more and do better to help those with hearing loss!

The unfortunate reality is that even if hearing loss is recognized, most people don’t know what to do, where to go for help or even what questions they should be asking. Information about hearing loss is readily available in our connected world, and the sheer number of people with hearing loss is leading to greater awareness of the problem. But people still don’t talk to one another about hearing loss nearly enough.

People complain about a seemingly irritating spouse who “won’t pay attention,” or share a horror story about “uncle so ‘n so” who has expensive hearing aids in a drawer, or share frustration that a loved one has hearing aids yet continues to struggle with understanding. But meaningful conversations about the invisibility of hearing loss, about the nuances of understanding in one situation and then not in the next, and about the emotional impact of hearing loss, are few and far between.

HLAA is dedicated to creating meaningful conversations about hearing loss. I greatly appreciate the information that HLAA provides, and the advocacy work that improves our lives, but I most value the many significant conversations about hearing loss that I have had through HLAA. I have talked extensively with healthcare professionals and other experts during HLAA activities, with fellow HLAA leaders, and with so many of those who attend HLAA chapter meetings and national conventions.

HLAA meetings and conventions are the best places to get answers from people who love to share their own experiences about hearing loss. Communication with HLAA members is easy, because we’ve already learned that using good communication strategies really does make a difference. People who nearly gave up because of their hearing challenges learn new ways to manage their lives. Many have started using hearing aids or received a cochlear implant, because they were impressed with how well somebody else was doing.

Whether you attend local HLAA meetings or not, joining HLAA can often be a life-changing decision. The HLAA website (www.hearingloss.org) contains a wealth of information and links to many resources, while our Washington state website (www.hearingloss-wa.org) provides information and resources specific to our state. HLAA’s Hearing Loss Magazine, available to all members, always surprises me. Despite my long involvement with HLAA and with hearing loss outreach and advocacy, the magazine always contains much food for thought—personal stories, technology updates, and information on the rights of people with hearing loss. Our local newsletter provides resources specific to Washington State, as well as names of places and events where all people with hearing loss are welcomed and provided communication access.

Please join HLAA online at http://www.hearingloss.org/content/join and see all the additional benefits that are included with your membership. Like so many people I have met over my 26 years as a member of HLAA, you’ll wonder why you didn’t join sooner.
**REGULATORY UPDATES: HLAA IN THE NEWS**

**Hearing Aid Compatible Cell Phones**

HLAA, together with several other consumer groups, responded to the Federal Communication Commission (FCC) request for comments to its Public Notice related to the compatibility of hearing aids and cochlear implants with cell phones. The consumer groups urged the FCC to require that all wireless mobile phones be hearing aid and cochlear implant compatible. When consumers are abandoning landline phones at record rates, HLAA believes it simply makes sense that the FCC acts to ensure consumers with hearing loss do not have to struggle to find a phone that works well with their hearing devices.

**Hearing Aid Tax Credit Reintroduced**

Senators Dean Heller (R-NV) and Amy Klobuchar (D-MN) reintroduced the Hearing Aid Tax Credit (Senate Bill 315) on January 29, 2015. If enacted, S. 315 would provide a $500 tax credit per hearing aid for people of all ages. The tax credit would provide critical assistance to consumers, as 61 percent of all hearing aid purchases involve no third-party payment. Medicare expressly excludes coverage of hearing aids, as do most private insurance policies. As a result, cost is cited as a prohibitive factor by two-thirds of the people who do not treat their hearing loss.

In the news release sent out by Senator Heller, Anna Gilmore Hall, executive director of HLAA, said, “Hearing aids are essential to enable millions of people with hearing loss to fully engage with family, friends and colleagues. And we are thrilled that Senator Heller is continuing to be a champion of efforts to provide a tax credit to help people purchase hearing aids.”

**Hearing Aid Coverage under the Affordable Care Act**

HLAA and other organizations joined Hearing Access & Innovations in comments filed with the Centers for Medicare and Medicaid Services (CMS). In the comments, the CMS were urged to include devices (in addition to services) in the “essential health benefits” provisions of health plans offered through the exchanges established by the Affordable Care Act. The CMS were also urged to establish minimum coverage levels for hearing devices and to oppose age-related limitations on coverage.

For more information on these issues, and on many other regulatory and legislative developments affecting hard of hearing people, please see [http://hearingloss.org/advocacy/news](http://hearingloss.org/advocacy/news).
Local HLAA Chapters and Support Groups
Information, Education, Advocacy, and Support

Meeting times may change. Visitors, friends, family members and healthcare professionals are always welcome at any of our meetings. We suggest sending an email to be sure the group is meeting when you plan to visit. See www.hearingloss-wa.org for more information.

BELLEVUE—2nd Saturday 1:00 pm
Lake Sammamish Foursquare Church,
Rm. 104, 14434 NE 8th St., Bellevue
Hearing assistance: amplification, FM system, induction loop, CART (real-time captioning).
info@hearingloss-wa.org or Karen: 206-817-3213

EAST JEFFERSON CO.—4th Monday 1:00 pm
Port Townsend Community Center,
620 Tyler St., Port Townsend
Hearing assistance: amplification, FM system.
Emily: 360-531-2247, mandelbaum@olympus.net.
Meetings are held Sept—Oct and Jan—May

RENTON—2nd Friday 12:30 pm
Renton Senior Activity Center,
211 Burnett Ave. N., Renton
Hearing assistance: amplification, FM system.
Glenda: philiofam@gmail.com or 253-631-2345 (evenings).

SEATTLE—2nd Tuesday 6:45 pm
Aljoya Conference Room
450 NE 100th St., Seattle
Hearing assistance: amplification, induction loop, CART (real-time captioning).
Karen: 206-817-3213 or SeattleHLA@gmail.com.

SPOKANE—2nd Saturday 9:30 am
Spokane Nexus Center
1206 N. Howard, Spokane
Hearing assistance: amplification, induction loop, captioning.
Margaret 509-893-1472 or halspokane@gmail.com.

TACOMA—2nd Saturday 9:30 am
(alternates with CI Support Group)
HLAA CHAPTER meets in Sept, Nov, Dec, Feb, Apr and Jun.
TACID, 6315 S. 19th St., Tacoma
Hearing assistance: amplification, FM system, CART (real-time captioning).
Jerry: 253-686-1816 or Penny: pennyallen@q.com

SOUTH SOUND COCHLEAR IMPLANT SUPPORT GROUP—
2nd Saturday, 9:30 am — Meets Oct, Jan, Mar, May, Jul.
TACID, 6315 S. 19th St. Tacoma
Hearing assistance: amplification, FM system, CART (real-time captioning).
Christine: Christine@cs-dhhrs.com or 253-256-4690.

WHATCOM CO.—3rd Saturday 9:30 am
Christ the Servant Lutheran Church,
2600 Lakeway Dr., Bellingham
Hearing assistance: amplification, induction loop and CART (real-time captioning).
Charlene: 360-738-3756 or charmackenzie@comcast.net

Looking for a chapter?
Please contact us directly if you are interested in attending or if you’d like to start a chapter in your area. Karen, SeattleHLA@gmail.com or info@hearingloss-wa.org

Online Resources to Keep Informed
Bookmark the HLAA-WA website at hearingloss-wa.org for resources and information.

Like our HLAA-WA Facebook page at www.facebook.com/HLAofWA

Like the HLAA Facebook page at www.facebook.com/HearingLossAssociation

Find out which venues are looped for your entertainment at www.loopseattle.org

Hearing Loss Magazine is available online at www.hearingloss.org/membership/hearing-loss-magazine/current-issue

Sign up for the HLAA monthly eNewsletter at www.hearingloss.org/content/e-news-sign
Seventy-five induction loops? That’s a lot of loops. That is what you will find at Washington State Community Services Offices (CSOs) and Division of Vocational Rehabilitation (DVR) offices across the state. Oh, and two of those loops are in their mobile vans!

Inspired by the Let’s Loop Seattle and Let’s Loop America campaigns, the Office of the Deaf and Hard of Hearing (ODHH) began its own Let’s Loop DSHS (the Washington State Department of Social and Health Services, of which CSOs, DVR and ODHH are a part) campaign. The loops were funded with State General Fund dollars, and more funding has been added for repairs and replacements.

“For DSHS to be proactive and have loops available, should any client with hearing loss walk into one of our state offices, is excellent customer service. This is preferable to being reactive and unprepared, without the proper equipment. Hence, we committed the resources to accommodate clients’ communication needs,” said Eric Raff, ODHH Director

You will find loops at many DSHS offices. To see if the DSHS office near you is looped, visit www.loopseattle.org for a downloadable list of available loops. The mobile CSOs are an especially handy resource in rural areas. The vans can help with cash, food or childcare assistance, eligibility reviews, Electronic Benefits Transfer cards, and some Medicare and Medicaid questions. Check the mobile CSOs’ schedule to find out when a looped van will be near you.

Director Eric Raff and the ODHH staff welcome feedback so they can track who’s using the loops and how well they work. When you visit, look for the blue ear symbol (see page 2 of this newsletter), turn your hearing aid to telecoil mode, and make sure the loop is on. (It’s OK to ask!). If the loop doesn’t work, politely let them know, and refer them to HLAA if they need assistance.


Let us know by writing to loopseattle@gmail.com if you’ve used these loops and how they worked for you. Please thank ODHH staff for this valuable service and share the news with people with hearing loss.
sometimes it hit too close to home for comfort. The specifics in the show were autobiographical, and we know that each person’s experience of hearing loss is unique. But the emotions portrayed on stage were universal, and very familiar to all of us with hearing loss. I identified with everything Kimberly described: denial, confusion, embarrassment, procrastination as to treatment, isolation and depression, frustration with family members, and the lure of alcohol or other substances to ease the pain.

Many scenes in the show triggered memories of mortifying moments that hearing loss has caused in my own life, as well as the raw and excruciating emotions I felt at the time. Kimberly’s courageous, honest on-stage confrontation of her own journey caused me to face how unrelentingly hearing loss has impacted my own life and how it has adversely affected my relationships and interactions. It was surprising, even scary, to realize how close to the surface some of those events and emotions still are.

But the show also brought to mind my own hilarious predicaments over the years, and the genuine kindness and compassion of many people who have been understanding and accepting of my hearing loss. Also very familiar was the empowerment stemming from dealing with hearing loss directly, and the joy and relief of joining with others who have hearing loss and understand what you are going through. I loved Kimberly’s portrayal of discovering HLAA and how it improved her life.

I have spoken with several other audience members who were moved to share their reactions: One man admired Kimberly’s guts in putting on a one-woman show, and felt the interplay of the various characters gave the audience a greater sense for the many emotions felt by people with hearing loss. He found it hard to sit through the performance because it hit home so directly. It was “painful therapy.”

A woman in the audience found Kimberly’s story close to her own, and it brought forth painful memories of her own family experiences. She recalled attending her children’s school and sporting events and sitting in the middle of crowds, yet feeling alone. And she described family dinners she had spent days cooking, where she sat in isolation trying to figure out what was being said or even who was talking. She talked of sometimes sharing her feelings with family members, only to be given a blank
Lost in Sound  cont. from page 6

look or a promise of support that never materialized.

Another man found a lighter similarity. Kimberly mentioned during the performance that she long thought Dorothy’s dog in “The Wizard of Oz” was named Coco, instead of Toto. He recalled initially thinking that TV’s “The Brady Bunch” was called “The Brady Bugs.”

Another woman, with normal hearing, found the play to be a “teaching moment” for friends, loved ones and even more, those who set policy in government, schools, business and churches. She planned to talk with her pastor.

A doctor of audiology student felt the play gave her insight into a hard of hearing person’s daily life and emotional experiences, something that she often won’t see in a typical audiology appointment. The play helped her understand the emotional impact of hearing loss, which will help her empathize with patients and understand their point of view.

The honesty and integrity on stage were inspiring and humbling. I think all of us were deeply moved by Kimberly’s show. For me, it was encouraging to finally see her story—my story, your story, our shared story—told publicly.

If you get a chance to see this show, go! It will be an evening you are likely to remember for a long time.
rights attorney John Waldo, has successfully advocated captioning as the best means for hearing access since 2008. Good news—2014 was a landmark year! More venues made their entertainment accessible to those with hearing loss—we can go out, fit in, and have more fun!

Movie theaters have made great progress, as digital films make captioning easier and less costly. The large chains, such as AMC, Regal and Century (Cinemark), were the first to make captioning available in many of their theaters across the country. During 2014 more independent theaters began to offer captioning as well:

- The Rose Theater in Port Townsend shows open captioned films (visible to all) one day a week.
- The Grand Cinema Theater in Tacoma has open-captioned movies on Wednesdays.
- Bellingham has captioned films at the Regal theater complex. Through the determined efforts of HLAA Whatcom chapter and Wash-CAP advocates, the independent Pickford and Limelight Theaters have very recently begun showing open-captioned movies on Tuesdays, with closed captions very soon to come during the rest of the week.
- In Anacortes, open-captioned movies are shown on Wednesdays at the Anacortes Cinemas.
- The Edmonds Theater now shows open-captioned films upon request.
- AMC theaters in Spokane have recently begun to offer captioning through the persistent efforts of Margaret Mortz, (Wash-CAP board member from Spokane) and Mary Jo Harvey (Spokane HLAA chapter member).

This is our good news! The persistence of Wash-CAP and others in educating theaters, large and small, has borne fruit. Enjoying a night or day out at the movies is more and more an option for people with hearing loss.

In live theater, Wash-CAP had significant success from 2008 to 2012 in influencing theaters to begin offering captions at selected performances of each production. In Seattle, the ACT, 5th Avenue, Paramount and Seattle Repertory theaters all offer at least one captioned performance of each production. Still, people with hearing loss are being offered limited choice, so there is more work to be done. We understand that it is more difficult and more
expensive to caption live performances than digital movies—human effort is required to manage the timing of captioning at each live performance—but we believe that people with hearing loss should have choices equivalent to those of all audience members.

Sports fans can now enjoy captions at many Washington sports venues. Wash-CAP has had a significant role in bringing this about. Seattle Mariners baseball at Safeco Field and Washington Huskies football at Husky Stadium both started captioning game activity and general announcements in 2014. This accomplishment followed the implementation of captions at Century Link Field for Seattle Seahawks football and Seattle Sounders soccer in 2013.

Captioning works for the majority of us. Theaters and sports venues continue to seek the best method to provide that captioning. Technical solutions keep changing, improving accessibility and increasing customer satisfaction. Captioning eye glasses, which keep the captions in our field of vision even as we move our heads, are getting the latest rave notices. Do check it all out and plan to be impressed. It’s time to venture out from the comfort and limitations of our living rooms!

The critical next step is for us to regularly attend the theaters and sports venues that offer captioning. Thank them and let them know how valuable their efforts are to us. Offer suggestions! And where access is not available, let the venue know it’s needed, possible, and happening elsewhere. Hearing loss is an often invisible disability; hard of hearing entertainment goers are also invisible—unless we make ourselves known...and heard!

Looking ahead, where should Wash-CAP target its advocacy efforts? Should the Carmike theater chain implement captioning in more places, such as the Tri-Cities? Would you like to see Washington State and Gonzaga universities implement captioning at their games? How about captioning at live concerts?

Hearing loss is highly variable among individuals and among situations. Searching for workable solutions to accessibility is a huge challenge. But we have achieved great successes at Wash-CAP and have increased the enjoyment that people with hearing loss can have at public entertainment venues. Let us hear from you on all this at www.wash-cap.com. We need you!

**Need Assistance Processing Phone Calls?**

The **Washington Relay Service** can help you make a convenient connection. Washington Relay is a free service provided by the Washington State Office of the Deaf and Hard of Hearing (ODHH) ensuring equal communication access to the telephone service for people who are deaf, deaf-blind, hard-of-hearing and speech-disabled.

For more information:
Call 800-422-7930 (Voice/TTY)
Visit www.washingtonrelay.com
Hospital Communication Kits Revisited

Are you going to be a prepared patient when you go into the hospital? Will they know you have a hearing loss if you can’t tell them? Will they take proper care of your hearing devices?

What can happen if hospital personnel don’t know you have a hearing loss is frightening! In 2006, HLAA-WA began creating hospital kits for you to use during a hospital stay. The kits include signage of several types and sizes to let hospital personnel know about your hearing loss—cards with tips for hospital staff on communicating with you, communication aids and several other handy items.

When we started making the kits, we sent them to each chapter in Washington State, and chapters were encouraged to distribute kits to people and hospitals in their areas. Since then, we have made over 800 kits and distributed them all over the world. Once the word got out, we received requests for kits not only from U.S. hospitals but from hospitals in England, Australia, Hong Kong, New Zealand and other places.

An important result of our hospital kit project has been to encourage hospitals to create their own kits for patients with hearing loss. We are aware of significant progress in this regard. But it has been equally important to raise the awareness of people as to the importance of politely advocating for themselves when faced with a hospital stay.

When I was in the hospital, I wore my “Face Me” button and put up the sign that said “I AM HARD OF HEARING, PLEASE FACE ME, AND SPEAK CLEARLY.” A friend used her sign that said she had two cochlear implants and was deaf if she wasn’t wearing them and had them turned on. The nurses were so pleased and impressed. They copied the signs so they could share them and use them again.

There are two convenient web sites where you can now print out the parts of the hospital kit that will alert the hospital personnel to your needs. The Lane County chapter in Oregon has a printable hospital kit at http://hearinglosslane.org/how-to-make-your-own-hospital-kit/. Swedish Hospital in Seattle worked closely with HLAA-WA and has made available on-line a number of accessibility aids. They can be accessed at www.Swedish.org/Patient-Visitor-info/Accessibility. (Look on the left side of the page for “Printable Communication Aids.”)

If you would prefer to receive a kit in the mail, they are available for $10 each, postpaid. Send an email with your mailing address to judi.carr@comcast.net, putting “hospital kit order” in the subject line.

It’s important to be a prepared patient. Make sure the hospital personnel know you have a hearing loss. Use your hospital kit to let them know how to take care of you!
Study to Evaluate Expansion of CMS Criteria for CIs

The American Cochlear Implant Alliance (ACI Alliance) is conducting a Centers for Medicare and Medicaid Services (CMS)-approved study to evaluate expansion of cochlear implant (CI) candidacy to include adults with pre-operative speech recognition skills better than currently permitted by the CMS. If expanded, the CMS’s criteria would be brought more in line with those of the Food and Drug Administration and private health insurers.

Ten CI centers across the country, including the University of Washington (UW) in Seattle, are taking part in this study. Dr. Jay Rubinstein, who spoke recently at the Bellevue HLAA chapter, is the principal UW investigator for the study.

Study participants must be 65 or older and CMS-eligible for their primary health insurance coverage. Participants in the study must have the CI surgery and specific follow-up appointments at one of the ten study sites, but some follow-up may occur at centers closer to the study participant’s home. If you are using hearing aids, and still having difficulty hearing, or if you have been evaluated and told that you have too much hearing for a cochlear implant under Medicare’s more stringent criteria, please see https://clinicaltrials.gov/ct2/show/NCT02075229 to learn more about the study.

For additional information and to check on your eligibility to receive a cochlear implant as part of the study, please contact ACI Alliance Executive Director Donna Sorkin, at dsorkin@acialliance.org.

Additionally, note that Donna Sorkin and Dr. Teresa Zwolan, Director of the University of Michigan’s CI program and the principal investigator for the overall study, will conduct a workshop at the 2015 HLAA convention in St. Louis (see http://www.hearingloss.org/content/convention for full information on the convention).

2015 HLAA-WA Board of Trustees

We serve as an extension of HLAA in an effort to make hearing loss an issue of concern within our state by promoting the HLAA philosophy of self-help while specifically addressing the issues of awareness, education, access and employment among our citizens who are hard of hearing.

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We welcome articles, letters, and notices of coming events. We may abbreviate submissions due to space constraints. Any content may be reprinted or disseminated, as long as the author or this publication are credited. We encourage health and service professionals to make copies available to their clients. Submission deadlines are April 1, July 1, October 1 and February 1.

Opinions expressed in this newsletter are not necessarily those of HLAA-WA or HLAA. Mention of goods or services does not mean endorsement; nor does exclusion suggest disapproval.

Please contact us about advertising rates. Questions about this newsletter may be addressed to editor@hearingloss-wa.org.
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Spring 2015

A quarterly publication of the
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Mission Statement:
To open the world of communication to people with hearing loss by providing information, education, support and advocacy.

CELEBRATE THE SOUNDS OF YOUR LIFE
MAY IS BETTER HEARING MONTH

REGISTER NOW FOR HLAA CONVENTION 2015

HLAA’s Convention 2015 registration is OPEN! Attend the 2015 Convention and help us celebrate HLAA’s 35th anniversary. Sign up for one of several convention packages, and learn about hearing loss, meet new friends and share experiences.

June 25-28 at the St. Louis Union Station Hotel

Be sure to reserve your room SOON at the historic convention hotel. Union Station in St. Louis, Missouri, built in 1894, was once the largest and busiest train station in the country, combining the train services of 22 railroads. Your stay at the St. Louis Union Station, a Doubletree by Hilton hotel, will allow you to fully enjoy this beautifully-restored architectural marvel. See details and book online at http://www.hearingloss.org/events/convention/hotel-and-travel.

A convention schedule and all other details about Convention 2015 are available at http://www.hearingloss.org/content/convention.

We look forward to seeing YOU in St. Louis!