My Rare Form of Hearing
By Steve Pettijohn, HLAA-WA Board member

I hear differently than most people. Unlike most people with hearing loss, my ears seem to capture sound normally, but my brain often can’t figure out what my ears are hearing. I have what is called Auditory Processing Disorder (APD). There are several forms of APD, none well-understood by scientists, and all lead to difficulty processing sound, particularly speech. It’s like having hearing ears but a deaf brain.

When I began to talk as an infant, my parents noticed I was talking as if I was hard of hearing. However, tests showed I had normal hearing. So I was given an IQ test, and that too was very good. So I was given lots of speech therapy.

Grade school was difficult. Sometimes I did the wrong homework. Or no homework. Spelling was very difficult. Many letters sounded the same to me, and

A CI, a Hearing Loop and Shakespeare
By Kate Johnston, HLAA Member

Acting in community theater with a new CI sounds like a crazy thing to do. Yet, that’s exactly what I did this year, when I joined the cast of Shakespeare’s “Romeo and Juliet” at the Bellevue Youth Theatre (BYT). Fortunately, the BYT installed a hearing loop while we were in rehearsals for the play, and I was thrilled to find out how much it helped me to understand what everyone was saying!

In December of 2015, I underwent surgery for a cochlear implant (CI), and a week later I went through the process called activation. During activation, the electrodes implanted in the cochlea are turned on for the first time. I heard sounds at activation, but I had to learn to interpret them, a process I’m still going through, many months later.

continued on page 6

Looking for an HLAA Meeting?
See page 4 for locations, dates and times. Information, help and support from other people with hearing loss is just a meeting away!

Cheri Perazzoli Wins HLAA Award
By Warren Weissman, Sound Waves Editor

Cheri Perazzoli, HLAA-WA Director of Advocacy, and founder of the Let’s Loop Seattle initiative, received HLAA’s 2016 Get in the Hearing Loop award on June 26, 2016 at the annual HLAA Convention in Washington, DC.

Cheri earned the award for her role in increasing hearing accessibility in Washington State by encouraging the use of hearing loops and other hearing assistive technologies. She has drawn upon her personal knowledge and advocacy experience to bring hearing accessibility and inclusiveness to the forefront of public attention at area civic and continued on page 11

Cheri Perazzoli (right) accepts the award presented by HLAA Board Secretary Katherine Bouton (center).
In This Issue

Cheri Perazzoli Wins HLAA Award
The annual “Get in the Hearing Loop” award goes given at HLAA Convention 2016.

A CI, a Hearing Loop and Shakespeare
Kate Johnston bravely auditions for a play just after getting a CI, and finds unexpected help through a hearing loop.

My Rare Form of Hearing
Steve Pettijohn on his Auditory Processing Disorder and its similarity with hearing loss.

HLAA Convention 2016: A Great Experience
Don Gischer on his experiences at HLAA Convention 2016 in Washington, D.C., his first HLAA convention.

Seen and Heard
Local news and notes.

Chapter and Support Group News
Find out when and where our chapters meet.

HLAA in the News

HLAA-WA Board of Trustees

HLAA-WA Annual Meeting

HLAA Convention 2016: A Great Experience
By Don Gischer, HLAA-WA Board Secretary

I attended my first HLAA Convention in June. This year’s annual event was held in Washington, D.C., and was also a meeting of the International Federation of Hard of Hearing People.

I had heard from other Washington State HLAA members that annual HLAA conventions are very helpful, educational, and especially oriented to people with hearing loss. I had high expectations, and the convention not only met my expectations but far exceeded them!

There were presentations from nationally-recognized experts on hearing and hearing loss research, and from people with personal stories of coping with hearing loss and succeeding in business and social settings. There were educational work sessions and discussions in small group settings. Two recent U.S. government reports about hearing loss, issued by the President’s Council of Advisors on Science Technology, and the National Academies of Science, Engineering, and Medicine, were among the topics most discussed at the Convention (see page 8 of this issue of Sound Waves).

I had one-on-one conversations with attendees from all over the country and even several foreign countries. The convention opened my eyes (and my ears!) to what can be done to help people with hearing loss to lead productive lives despite their hearing loss, and in many cases because of their hearing loss.

At any time during the four days of the convention, I could choose to attend workshops about Advocacy, Assistive Technology, Hearing Aids & Cochlear Implants, Living Your Life, and State Organization/Chapter Development.

I attended many sessions in the State/Chapter Development track because I am on the Board of Trustees of the Washington State Association of HLAA and also active in the Whatcom County Chapter of HLAA. These workshops were especially helpful for me in learning how the State Association should work and how to avoid overlap between leadership positions and other volunteer work. I also learned many tips and strategies which will help me to contribute to my local chapter.

In addition to the workshops, the convention had an exhibition hall full of booths and representatives from hearing aid and cochlear implant manufacturers. Also in the exhibition hall, hearing accessory suppliers, educational institutions, emerging technology companies and many others provided information and demonstrated their products. I purchased a wristband device that vibrates when my cell phone receives a call, text, or email, because sometimes I don’t hear my cell phone when it is hooked to my belt or when I am in noisy environments. Very innovative and very handy!

All of the convention facilities were looped—the meeting rooms, the main auditorium and banquet hall, even the registrations area for attendees. The convention was billed as the most hearing-friendly convention ever in the USA, and I believe it!

continued on page 3
I got reacquainted with people from other states whom I had met at a leadership conference four years ago. I met several people from Washington State whom I had heard about but not had the pleasure of meeting (I think there were 16 of us), and talked with virtually everyone in the Washington State delegation. And I made many new friends whom I hope to see again at future conventions.

I was able to attend Convention 2016 largely thanks to a scholarship offered by HLAA-WA to partially offset my registration, travel, and lodging costs. I encourage future first-time attendees to inquire about scholarships and to not miss the opportunity to attend at least one HLAA convention. HLAA offers several scholarships, as well.

As you can see, I really enjoyed Convention 2016! I look forward to attending more HLAA conventions—next year’s convention is in Salt Lake City, and I plan on being there.

HLAA-WA Vice President Judi Carr reports that she recently obtained useful communication access after she encouraged fellow residents of Arrowhead Gardens, the senior living community in West Seattle where she lives, to attend a meeting on June 30, 2016, regarding the green space adjacent to their community. The City of Seattle was considering selling the property to a real estate developer.

The community meeting was being held at the Seattle Joint Firemen’s training facility, very conveniently right behind Arrowhead Gardens. The meeting announcement provided information for persons with special needs or language requirements. Judi requested that the event be captioned so she, and others, could understand what was being said.

Meeting planners were not familiar with CART (Communication Access Real-time Translation), so Judi explained the technology and provided names of CART providers who were known to HLAA-WA and might be retained to provide the service.

Judi was joined at the meeting by 14 other Arrowhead Gardens residents. The meeting planners were able to offer CART, and afterwards many people mentioned how nice it was to be able to understand what was being said. Judi reports that attendees also were thrilled that the City ultimately decided not to sell the property, partly because of the comments in this meeting and others like it.

Judi says she is thankful that HLAA has taught her the value of asking for things that help her understand. She encourages all people with hearing loss to ask for captioning, FM receivers, movie caption receivers or other assistive listening devices. She reminds us that asking for help means better understanding what is being said, and that the rest of the audience will quietly thank you for asking!

HLAA-WA Vice President Kimberly Parker was a presenter at the Accessible Tourism and Travel by Design forum on August 15, 2016. The forum, organized by Irene Stewart, Coordinator of the Northwest Universal Design Council, brought together organizations representing people with disabilities, travel and tourism industry representatives, and government officials.

Kimberly’s presentation highlighted what it is like to have hearing loss, in the context of travel and tourism experiences, and how hearing access can dramatically improve the travel and tourism experiences of the rapidly-growing number of people with hearing loss.

HLAA-WA Vice President Judi Carr reports she and fellow HLAA member Laura Ramsey attended the City of Seattle’s July 12, 2016, presentation on Accessible Disaster Communications in this Digital Age.

Judi summarized her take-away from the presentation by saying, “We all benefit from a universally-designed approach to communications! If we assume that there will be multiple barriers, and design our communications to be successfully- accessed by anyone—regardless of ability—it works for everyone.”

The presenters were Deborah Witmer of the Seattle Human Services Department, and Irene Stewart of King County Aging and Disability Services. They alerted all the attendees to the need that everyone be accommodated, no matter what the disability. CART—Computer Assisted Real-time Translation—and ASL interpreters were utilized. The PowerPoint presentation slides were read out loud so that people with low vision or those not sitting in the front row could rely on spoken words. The presenters made sure everyone in the room could understand the presentation through whatever form of communication worked best for them.

continued on page 5
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. Please note that some of the groups do not meet during July and August. We suggest sending an e-mail to be sure the group is meeting when you plan to visit. See www.hearingloss-wa.org for more information.

BELLEVUE—Not meeting at this time.
For more information please email:
info@hearingloss-wa.org

COLUMBIA BASIN—3rd Saturday 9:30am, Sept.—June
Clubhouse—Santiago Sunset Estates
2105 N. Steptoe St., Kennewick
Hearing assistance: To be determined.
Sue: baha2hear@gmail.com

EAST JEFFERSON CO.—No longer meeting.
For more information please email:
info@hearingloss-wa.org

RENTON—2nd Friday 12:30 pm
Renton Senior Activity Center,
211 Burnett Ave. N., Renton
Hearing assistance: amplification, FM system, CART (real-time captioning, most meetings).
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
(Please email to confirm meetings)
Nexus Center, 1206 N. Howard, Spokane
Hearing assistance: amplification, induction loop, CART (real-time captioning).
hlaspokane@gmail.com

TACOMA—2nd Saturday 10:00 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, 10:00 am —(alters with Tacoma Chapter) 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, FM, induction loop and CART (real-time captioning).
Charlene: 360-738-3756 or charmackenzie@comcast.net
Website: www.hearingloss-whatcom.org

Looking for a chapter?
Please contact us if you are interested in attending a meeting 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 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.
The first part of the workshop was on an “Emergency Shelter Communication Toolkit,” a large binder filled with information on how to set up a fully-accessible emergency shelter, with separate sections on what to be aware of for people who are Deaf and Hard of Hearing, people with mobility disabilities and people with visual disabilities.

Included at the back of the binder was information to be used to train others, and all the PowerPoint slides from the first part of the training session were made available on a USB drive so they could be reviewed and passed on to others.

Both Deborah and Irene noted the value of induction (hearing) loops, explained how they work, and mentioned the many City of Seattle facilities that are now looped, though the facility where the presentation was held was not looped.

The second part of the workshop was entitled Accessible Communications in this Digital Age. The information focused on the need for websites to be usable on any device, and for files to be converted to formats which can be opened without the need for a specific program.

Also highlighted was the need to create websites with menus that can be accessed without using a mouse pointer, enabling people who cannot use a mouse to access the menus through a keyboard. Irene also mentioned that she had been scolded a number of times if she sent out a video that was not captioned.

HLAA-WA’s annual family picnic (the 13th such event) was held at Lake Boren Park in Newcastle on July 16. HLAA-WA Board member Glenda Philio, supported by Renton chapter members, once again coordinated the event. Former HLAA-WA Board member Rick Faunt was the event’s master barbecuer, delivering tasty grilled eats to all in attendance. HLAA member Mary Johnson won the $50 gift card at the picnic’s raffle.

Special thanks to Spencer Norby of HearingLoop NW, who graciously donated his services and installed a temporary hearing loop at the picnic. The loop, strung around the roof supports of the picnic area, enabled the words spoken into a hand-held microphone to be heard and understood by all those with telecoils in their hearing aids or cochlear implant processors. The ability to understand the words in the breezy, open-air picnic area added immeasurably to the enjoyment of those present.

Karen reports that the conference following the presentations.

Karen adds, “Together, we can address the challenge of aging and hearing, and we do this at HLAA meetings. Hearing access is available in many places, if we ask for it and use it! If we sit in the back and hide, and don’t ask for help, we don’t understand the presentation and just feel worse.”

HLAA-WA Director of Advocacy Cheri Perazzoli’s article entitled Why the Gap in Hearing Loops and Access Options? was published in the August 2016 issue of The Hearing Journal.

The article discusses why many consumers are unaware of the telecoils in their hearing aids, and of hearing loop technology that is more and more prevalent and can significantly enhance understanding of speech in many settings. The article also comments on reasons why audiologists may fail to apprise consumers of the value of telecoils.

We are thrilled that Sound Waves earned the 2016 HLAA Best State Association Newsletter Award at HLAA Convention 2016 in July. Many thanks to everyone who makes the newsletter possible!
The understanding of speech with CIs isn’t immediate. It can take anything from days to months to years of hard work before the sounds fall into place and make sense. (I still wear a hearing aid in my other ear.)

It certainly wasn’t fast with me. On the day of activation, the sounds from the higher-pitched electrodes were so painful to me that they had to be turned off. My audiologist surmised that this may have been due to my having a life-long hearing loss and never having heard those pitches. Quite frustrating, as hearing but not understanding speech is why I decided to pursue the implant in the first place. But those electrodes are being turned on slowly, and I am sure I will be able to better understand speech with the implant eventually.

Three weeks after surgery, I still couldn’t understand most speech, but I went to auditions for the BYT anyway. The BYT is a community theater that welcomes all participants, no matter their abilities. Everyone who auditions gets a role. I got involved with the BYT five years ago, for the sake of my adult son with autism, and discovered it wasn’t just my son who benefitted from getting out into the community. I did too!

Despite my not being able to hear or understand most anything, the judges at the auditions knew me and what I could do, and my son and I were cast in “Romeo and Juliet.” I was cast as the apothecary, and my son as my assistant. The apothecary, I told (or reminded) everyone who asked, is the one who sells the poison to Romeo.

The way to learn to hear with a new CI is to actually practice hearing, and I figured being in a play would be good practice. I was right! But rehearsals were difficult for me, as they always are. I was doing the best I could, but struggling to understand my cues.

Fortunately, I discovered during rehearsals that the BYT had installed and turned on a hearing loop. One day, the director asked if I had the capacity with my hearing aid and CI to use hearing loops. I turned on my telecoils and it was magical! It wasn’t perfect by any means—I was still a hard-of-hearing actor, but thanks to the hearing loop I missed a lot fewer cues.

Theaters are never quiet, except during performances. Even though actors off stage are asked to be quiet, out of respect to those rehearsing, there’s a lot of noise. The

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VOLUME 24 ISSUE 1   WWW.HEARINGLOSS-WA.ORG   PAGE 6
Directors are conferring on some finer points of the play, actors not in the scene are discussing how to make their parts better, and much more is happening on and off the stage. The microphone for the venue sound system, and therefore for the hearing loop, hangs from the ceiling and picks up everything. Quite maddening for someone with a hearing loss, but it is what it is.

The theater also has loops at the concession stand and the ticket booth, so be sure to turn on your telecoils when you enter! If you don’t have telecoils, the theater has hearing assistive devices with headphones to lend to you for the performance.

Come find out what a pleasure it is to attend the theater when you can hear and understand what is being said! Or, like me, just go for it and audition for a part!

HLAA is honored to offer two types of membership for United States veterans

Please visit:
www.hearingloss.org/sites/default/files/docs/VeteranComplimentaryMembership.pdf

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Each returned newsletter costs us $1.19!
Please help keep our costs down by letting us know when you move or change your mailing address.
NAS Report on Hearing Health Care

The National Academies of Science, Engineering, and Medicine (NAS) issued a report on June 2, 2016, entitled Hearing Health Care for Adults: Priorities for Improving Access and Affordability. The report reviews the importance of hearing for communication and health and the many reasons why people with hearing loss do not seek out or do not receive health care.

The NAS report makes 12 recommendations related to improving access to and affordability of hearing health care. The report concludes, “Hearing loss must be recognized as a public health concern…” It adds, “Improving the accessibility and affordability of hearing health care will require solutions that span society…” The report (including a summary) is available at http://nationalacademies.org/hmd/reports/2016/Hearing-Health-Care-for-Adults.aspx.

HLAA was a sponsor of the report and strongly endorsed its conclusions. The HLAA press release in relation to the report stated, “Implementation of the recommendations will provide people with hearing loss greater access to accurate information, offer more affordable choices and options, and will empower consumers to take steps to address their hearing loss. The current hearing health care model needs to change to be more consumer-focused, and implementing the recommendations...in the report would go a long way toward realizing that change.”

Dan Blazer, M.D., Ph.D., M.P.H., chair of the committee that prepared the report on behalf of the NAS, was a featured speaker at HLAA Convention 2016, held June 23-26 in Washington D.C.

A report covering many of the same topics, and also providing specific recommendations, had been issued in October 2015 by the President’s Council of Advisors on Science and Technology (PCAST). That report (see Sound Waves Winter 2015 edition) also had been enthusiastically endorsed by HLAA. Susan Graham, Ph.D., a member of PCAST, also spoke at HLAA Convention 2016, detailing the report’s conclusions and recommendations related to hearing health care.

continued on page 9
Not surprisingly, the issues raised in the reports were the talk of HLAA Convention 2016. Given the prominence of the issuing bodies, the reports have prompted a national conversation about the public health issues related to hearing loss. U.S. government agencies are likely to have to consider the recommendations in the reports in future rule-making.

**Delaware Approves Telecoil Bill**

Delaware Governor Markell has signed a bill requiring the State’s Board of Speech/Language Pathologists, Audiologists and Hearing Aid Dispensers to establish requirements for informing consumers about the telecoils in hearing aids.

Hearing aid dispensers and audiologists will be required to provide notification and written information on telecoil operation and benefits to potential customers at the initial exam for fitting of a hearing aid.

HLAA’s Wilmington, Delaware Chapter and the Hearing Loss Association of Delaware (HLADE) advocated strongly for this legislation as part of the Let’s Loop Delaware campaign. Delaware is only the second U.S. state to have legislation of this type.

Numerous other HLAA local and state organizations, including HLAA-WA, are seeking to educate lawmakers regarding the importance of telecoils in enhancing the functionality of hearing aids, with the goal of obtaining support for legislation similar to that passed in Delaware.

**Carbon Monoxide Poisoning Incidents**

Incidents where people with hearing loss forget to turn off engines in cars with keyless ignitions, and can’t hear that the engine is still running, have led to more than a dozen deaths from carbon monoxide poisoning.

Telecommunications for the Deaf and Hard of Hearing, Inc. (TDI), a national advocacy organization addressing equal access issues in telecommunications and media, recently issued a Letter of Concern to Toyota Motor Corporation, requesting that vehicle manufacturers incorporate preventive measures into vehicle design.

The National Highway Traffic Safety Administration (NHTSA) has proposed a rule calling for an audible alarm to sound in these situations, but TDI strongly recommended that a visible form of alarm be implemented as well.
Rare Hearing  cont. from page 1

different letter combinations sounded the same. Why is “laugh” spelled l-a-u-g-h and “calf” is c-a-l-f? Let’s not forget “elephant!”

When the music teacher brought in a record player and played some music, she would ask, “Hear the ‘something’ instrument?” I never could. “Is it ‘this’ instrument, or ‘that’ instrument?” They both sounded the same to me. I also could never hear the beat in music—I couldn’t clap to the beat—and now I understand why. My wife says I also often can’t hear harmony in music.

Arithmetic was easy when the numbers were all on paper. But at the blackboard, in class, I would hear the teacher say numbers but couldn’t identify what to do. I would look at the other kids, and they always wrote the correct number the first time. How? For many years I couldn’t understand how. Now as an adult, I did finally develop an understanding that it’s my brain that works differently.

A few years ago, after a bad reaction to medication, I was sent to a specialist who tested my cognitive thinking and determined that I definitely had the characteristics of someone with an auditory processing disorder. I was told that when my brain senses a gap in communication, it tries to fill that information gap with something that makes sense, whether something has been said (and heard by me) or not. Interestingly, that’s the same as what people with hearing loss do when they don’t actually hear a word or a sound. This may explain why I had difficulty doing math problems on the blackboard with the teacher saying the numbers.

Although my ears work well, I benefit greatly from all the technology that has been developed for people that are hard of hearing. Captioning often allows me to overcome the confusion created by APD, and I use assistive listening devices, such as FM systems, that enable me to block out unwanted sounds and adjust the volume to the “center of my head.” I also speech read to use visual cues to understand context and tone.

Many hearing people have no understanding of the difficulty I have processing what is said to me. But I’m also different from most hard of hearing people! Hearing aids and cochlear implants are not a solution for me.

If you are interested in knowing more about me or about my experiences with auditory processing disorder, I write about this in my blog at www.my-thoughts.com/.
entertainment venues, and has guided government officials and venue managers toward successful implementation of hearing accessibility measures.

“For hearing aid users, hearing loops are the equivalent of a curb cut or a wheelchair ramp,” said Perazzoli. She added, “In addition to hearing aids, someone with hearing loss may need assistive technology such as a hearing loop and captions to communicate effectively. Hearing loops can mean the difference between staying home and becoming isolated or engaging once again with work, play, and civic life.”

Recent examples where HLAA-WA advocacy for hearing access has been successful include the City Council Chambers of Bellevue and Seattle, in both of which hearing loops recently were installed. Among the Bellevue civic and entertainment venues recently looped are the Bellevue Library, Bellevue Youth Theatre, Bellevue Arts Museum, and the Meydenbauer Theatre. In Seattle, Town Hall, Seattle Repertory Theatre and Taproot Theatre Company all are now looped.

In accepting the HLAA award, Perazzoli added that she receives tremendous support from HLAA-WA leaders and members, and from Washington State civic and arts leaders, all of whom are working to lessen the impact of hearing loss in their communities.

She also thanked other advocates and supporters with whom she has collaborated, saying “I absolutely share this award with all the people with whom I have worked.”

2016 HLAA-WA Board of Trustees

We are an extension of HLAA. In an effort to make hearing loss an issue of concern within our state, we promote the HLAA philosophy of self-help, while specifically addressing the issues of awareness, education, access and employment among people 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 is 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.

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