

Hear It Is!

Oregon



Winter 2018

Issue 72

Scholastic Challenges with Hearing Loss

By Tashiko Weinstein-Poulson

I have been attending post-secondary schools since I was 19. I am now 28. For the last 9 years, I have either been a full time student or a part time student. During the last 3 years I have been a part time student attending until just recently Chemeketa Community College located in Salem, Oregon. Now why have I been in school for so long? Hearing Loss! My hearing loss has made it very difficult for me to get an education. I was born with Hearing Loss, but nobody discovered it until I was 9. I didn't get diagnosed and given hearing aids until I was 12 years old. So from K-6 grade I went to school without hearing aids and received no accommodations or help from the public schools even though I was on an IEP (Individual Education Plan). It wasn't until I graduated from high school that I got the accommodations I needed and should've gotten in K-12. Because of this, I spent three years at Lane taking low level classes playing catch up as well as taking required classes. I still got a letter saying I used up all of my financial aid money for Community College credits so I had no choice but to transfer to Portland State University. I spent 2 years there and learned that I have more disabilities than Hearing Loss (I never graduated and took out loans to live there).

If any of you ever decide to go back to school then there are a few things you should consider: 1) Not all classes will transfer. 2) Teachers can be hard to work with, the classes may not be accommodating, and lastly don't expect the school to have your back. These are all things I have learned in the last couple years and they have made it difficult to get my education. The last 3 years I have had to take classes at Chemeketa Community College as a part timer but I started out as a full timer which is 12 credits, then had to drop classes due to accommodation issue or lack of help. On top of that if I fight for my rights then I can get penalized by the school so even if I wanted to I couldn't. Now, I am forced to go to Oregon City because the school won't let me attend until I pay them 1100 dollars for a stolen FM system. They have no insurance, and the school has a huge theft problem and I am still forced to pay \$1100 for a device I depend on into order to hear my classes. This problem is not just at Chemeketa, it is all over the state. I am being penalized for being Hard of Hearing and if I fight for my rights then I get retaliated against. It has gotten to the point that I don't even use the Disability Resource center anymore because they won't help me. Since this fiasco, I am now behind again. I would like to graduate but it is difficult. Most people say get a job but no one will hire me and I don't drive. Most people say get a scholarship, but there are very few scholarships out there for people with disabilities and many of them are for recent graduates, not people who are currently in college. So what is my take back on all this? Being a college student with hearing loss is very hard and you are alone most of the time, but if I get my degree it will all be worth it.

From My Lips to Your Ears

Editorial by Chuck Vlcek

Tashiko Weinstein-Poulson continues to write riveting articles. On the front page she describes her struggles in obtaining an education, especially post-secondary. It shows that even though there is more assistance for students with hearing problems than there was several decades ago, challenges still remain. The theft of the FM receiver that was lent to her is particularly troublesome, given the consequences.

Her scenario and tips article on mental health on page 7 is even more compelling. It took her a lot of courage to write that article, especially on short notice while recovering from an episode. The relationship between hearing loss and mental health issues is a bit of a tango. The root causes of each can be entirely separate but even when they are, the presence of one can compound the problems caused by the other. Of particular note is the self-isolation that often occurs with people who suffer hearing loss, which can cause depression and/or exacerbate its effects. Hearing loss can also interfere with the communication necessary to address and overcome mental health issues.

Research continues on making it all go away. Articles on page 11 describe gene therapy that has the potential to prevent hearing loss and/or restore hearing, and 3-D printing techniques that also have the potential to restore hearing in some cases. The possibilities for future prevention/restoration techniques are endless, even with just the present technology.

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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.

For advertising information and rates, contact Eileen Marma at info@hearinglossOR.org.

Deadline for Spring 2018 edition: Mar. 31, 2018.

The next HLAA-OR board meeting and annual meeting of all HLAA-OR members will be held April 7, 2018 at Albany General Hospital (Reimar Building).

Other 2018 meeting dates will be July 7 and October 20.

Guests and persons wishing to confirm should contact President Clark Anderson at clarkoa@msn.com or leave a message at (541) 736-4804.

Board Election Update

Elections will be held in April 2018 for up to 12 positions on the HLAA-OR Board of Directors (3-year term). The terms of six current board members are expiring and all have agreed to run again. However, there are no new candidates. Since the number of candidates does not exceed the number of board positions available, all candidates will be confirmed by a simple majority of current board members at the annual meeting of all HLAA-OR members on April 7, 2018, in conjunction with the quarterly board meeting on that date. The president may appoint someone to fill a vacancy at any time, subject to confirmation by a majority vote of the board of directors. Appointees shall complete an unfinished term or serve until the next election.

Mark Knecht was appointed by President Clark and is now seeking a full term. Mark is a veteran with hearing loss who works at Chemeketa Community College. He is on the advisory board for the committee for the Salem Housing Authority. He does other advocacy work for veterans and people with disabilities, and helps with the incarcerated veterans program in the Oregon state penitentiary.

David Baldrige was also appointed by President Clark and is seeking a full term. He had progressive hearing loss since third grade and now has bilateral cochlear implants. He has a Ph.D. in Management from the University of Connecticut. His research included examination of the workplace experiences of people who are deaf or hard-of-hearing.

Richard Little is a chapter coordinator who is seeking a new board term. He was born with hearing loss and wore hearing aids since age 5 until he received CIs in 2014 and 2016.

Kathy Eckert-Mason is seeking a new term after serving for 9 years. She has over 30 years of experience working in the field of disabilities in a variety of capacities, including work within the Deaf and Hard of Hearing Community, Autism, Developmental Disabilities, etc.

Eileen Marma is currently Vice President of the board and is seeking another term. She is also the business editor for the newsletter "Hear It Is". She developed hearing loss about 25 years ago and wears two hearing aids and also utilizes assistive listening devices.

John Hood-Fysh is seeking another term on the board. He currently operates HLAA-OR's website. He was born in Canada and became a U.S. citizen in August 2008. He has suffered hearing loss since the late 1980s and has used hearing assistive devices since the early 1990s.



Next HLAA Convention: Join us in Minneapolis, Minnesota June 21 - 24, 2018, home of the 2018 Super Bowl LII! With its urban edginess and cultural authenticity, the city of lakes guarantees visitors a fabulous time. Stay tuned for more details to be posted soon: <http://www.hearingloss.org/content/convention>

HLAA Membership

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

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Within Earshot: News You Need to Know

More Flying Tips

A conversation that appeared on Facebook on February 2, 2018 discussed the availability of closed captions on in-flight movies. It turns out that at least a few airlines do provide this service. Air Canada and Westjet will provide captions based on your assigned seat number if you ask the flight attendant. Cathay Pacific and Delta were also mentioned to have captions. Bottom line: it never hurts to ask.

Deaf Digest suggests that when you are booking a flight, you should mention your hearing loss. This may open the door to some accommodations. *Ed. Note:* I did that once while booking online a flight from Eugene to Honolulu with a change at San Francisco. Snowfall at Eugene delayed takeoff, resulting in a very tight connection at San Francisco where the arrival and departure gates were far apart. When I deplaned, a flight attendant brought me over to a ground transport with some other passengers and whisked me to the departure gate just as the Honolulu flight was boarding. I was put on priority boarding so I didn't have to wait in line.

Underutilized CART

Deaf Digest also noted that many attorneys who have hearing loss but do not use ASL would benefit from CART, but have never heard of it. Apparently CART service must be requested from the court before it will be provided. If a person is unaware of its existence or benefits, that request will not be forthcoming.

“FM Loops” are not Hearing Loops

Juliette Sterkens, leader of Loop Wisconsin and Loop America reports that some venues are providing neckloops with FM receivers and calling them “FM loops”, which is misleading. The neckloops are plugged into the headphone jack on the FM receiver, and the user puts his hearing aid or cochlear implant processor into T-coil mode. This arrangement does work but not as well as using an FM headset or room loop. The primary reason is that neckloops are not yet required to meet any standards such as the IEC 60118-4 international standard for room-sized loops. Hearing loops installed to meet this IEC standard, ensure that the magnetic signal is loud enough, operate over a broad frequency response (100-5000 Hz), and free of electro-magnetic interference. However, work is being done to develop this kind of standard for neckloops.

Inferior neckloops may not provide sufficient power or clarity for the user to hear well when used in conjunction with another device. Since the supplied equipment at churches, movies, and other venues may also have other problems Juliette prefers room-sized loops for its simplicity and quality assurance. *Ed. Note:* I have used a personal powered neckloop with FM and infrared receivers with mixed results. Obviously the condition of the receivers and batteries can be an issue, and the earphone jack may not be compatible with the neckloop's plug. If a headset is supplied, try using that with the processor's T-coil setting – some do work.

Hearing Loss Scenario: Mental Health

By Tashiko Weinstein-Poulson

I originally was planning to write on a different topic, but after suffering a mental health crisis I decided that for this tip and scenario I would advise on how to deal with a mental health crisis. Disclaimer: what I am about to share with you is very personal and I am doing so because I believe this will help others living with hearing loss. I have reached out to a Mental Health Care provider and I am doing all that I can to get to where I need to be with the help of close friends and families, so do not worry, I am ok.

On Friday February 17th 2018, I suffered a mental health crisis. The experience was traumatic for me and I was freaking out about it. I had a sudden urge to do something very dangerous that would no doubt end my life. It was as if something had come over me, and I felt like I had no self-control. Fortunately I was able to jump back into reality and regain my self-control, but the thought of it was scary and it caused me to have a mental break down. So, I hope this will help others going through something similar. Here is what I did during my crisis and I hope it helps you.

1. **Seek out help.** When you are going through a crisis the first thing you need to do is seek out help whether that is calling 911, a hotline, or calling close friends and family. The important thing is that you get help during your times of need.
2. **Talk to someone.** It is very important that you talk to someone during your “time of need”. You are going through a traumatic experience and knowing that you are not alone can be life-saving, so make sure to talk to someone right away. My advice is to keep it among trained professionals, close friends, or family.
3. **Do not be alone.** It is very important that you be around people that you are close to during this event and while you are in “recovery” because being around them makes you feel better and you know that people care about you.
4. **You are not a burden.** During your time of need it is important to know that you are not a burden and that having people come over to help you is not a bad thing. You are not imposing on them; you need them because you are going through something that you can’t help and you can’t do it alone. Don’t feel like you are being a burden to others because you are not. They are there because they care and that is all that matters.
5. **This is not your fault.** When going through a crisis, especially in mental health, people often blame themselves for what is happening, and the fact is that you shouldn’t. This is out of your control and you can’t help what is going on. Your body is simply saying that there is something wrong and is reacting to it and that again is something you can’t always control.
6. **Take it day by day.** After you go through this experience give yourself much needed relaxation time and don’t be in a hurry to get back to work, because chances are you’ll be right back where you started. Take a break, go on vacation if you can, or treat yourself. You earned it and you should reward yourself.
7. **Take this experience as a valuable moment** and value and cherish the people that came to your aid in times of great need and think about the people you have in your in life.

All of these things helped me through my crisis and I hope they help you. Here is a hotline if you feel like you need to talk to someone: **1-800-273-TALK (8255)**

Do you have an experience, plausible scenario, and/or tips you would like to share? If so, please e-mail info@hearinglossOR.org with “Hearing Loss Scenario” in the subject line, or write to HAAA-OR, P.O. Box 22501, Eugene, OR 97402.

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Chapter Capers

Douglas County Chapter: The four current officers were re-elected during the Christmas potluck. Two new members came to the January meeting. The chapter now has 16, double the number it had a few months ago.

Portland Chapter: At the Feb. 19 meeting Andrea Maurer, Au.D. and Dan Cain HASP of Costco discussed current and anticipated advances in mechanical hearing assistance devices including hearing aids. On March 19 the topic will be “Communicating with the People Important in Your Life” – bring somebody important with you. The April 16 meeting will be held in room 302 instead of the usual location. Carol Studenmund of LNS Captioning in Portland will discuss captioning of public events. The annual election for board members will be held on May 21.

Linn-Benton County Chapter: See page 15 for general meeting information (time and location). Meetings have a T-coil loop, and real-time captioning courtesy of Archer Captioning. Refreshments are provided. You can check the chapter’s web site for current meeting topics: <http://www.hlaa-or.org/linn-benton-chapter.html> Facebook, Twitter, and Instagram sites are on: <https://www.facebook.com/linnbenton.hlaa> <https://twitter.com/LinnBentonHlaa> <https://www.instagram.com/linnbenton.hlaa/>

What is your chapter doing? Please submit your story to the editor at cvlcek@centurytel.net See pages 14-15 for contact information for these chapters and events.

CI Corner

There is a closed message group on Facebook for CI users. Some interesting items have been posted on it recently.

Oticon has introduced its Neuro 2 processor. Information gleaned from discussion reveals that Oticon bought out Neurelec several years ago and has entered the CI market. AB had joined Phonak, one of Oticon’s competitors, in 2009. Slick advertising from Oticon suggests that their Neuro 2 is comparable to the most recent generation of processors provided by the other cochlear implant companies. Oticon does not have FDA approval to market in the U.S., and so far only the Neuro 1 is available in Canada. In addition to Oticon, there are other small local CI manufacturers. The increased competition should ensure more advances in future generations of CI processors and more peripheral products. The current round of bells and whistles revolve around improved programming options (especially for noise reduction), increased resistance to water, and wireless connectivity to other peripherals and assistive listening devices. There are also button-type off-the-ear processors.

A very useful side-by-side comparison chart of the 3 major global manufacturers of cochlear implants (AB, Cochlear, and Med-EI) is available for downloading. A link to it can be found on <https://cochlearimplanthelp.com> .

There is another useful tool that consumers will not see because it is for professionals but will greatly benefit folks getting new implants. Med-EI has developed software called OTOPLAN that works on a tablet-based platform. What it does is gather patient information, including CT and MRI images and generate patient-specific 3-D reconstructions. The resulting displays help the implant surgeon tailor the electrodes, etc. to fit and get the optimum insertion into the cochlea. It is likely that other CI manufacturers will develop similar products.



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CRISPR Gene Therapy to Prevent Hearing Loss?

A genetic editing tool called CRISPR-Cas9 has been used in mice to prevent hearing loss caused by a genetic mutation. A paper published in *Nature* on Dec. 20, 2017 described the research and its results. Kate Sheridan subsequently wrote an article on this topic for *Newsweek*, which is summarized below.

First, it should be noted that while the same technique should work on humans, no human trials have been conducted. Even if future research is successful, it will be at least a decade before this therapy becomes operational. The experiments were all done on mice made to have a particular genetic mutation that is also found in humans. A common type of mutation, it results in just one DNA base pair in a copy of a gene called TMC1 being “off”. In this case it rendered one of the channels necessary for cochlear hair cells unable to function, causing the cells to die off. Since the hair cells are responsible for transmitting sound signals from the ear to the brain, their demise results in hearing loss and ultimately deafness. In humans, this mutation is called the Beethoven mutation, although there is no concrete evidence that it was the cause of Beethoven's deafness. Children with this mutation typically begin to suffer progressive hearing loss before age 20.

A team of researchers from the Broad Institute, the Howard Hughes Medical Institute, and Harvard led by David Liu went to work on the mutated mice. CRISPR-Cas9 works by making a cut in the cell's DNA sequence, forcing it to make repairs. The cut disrupts the mutated TMC1 gene, rendering it harmless. They ran a number of experiments to determine how well CRISPR did work. Typically one of the mouse's ears was treated and the other one left alone, then the mouse's ability to hear with each ear was tested. The mouse's ear cells were examined to see how many were actually edited. It turns out that only 10%-25% of the hair cells were edited, by rough estimate, but that still significantly improved the ability of treated ears to hear.

The next step in research may be to use human stem cells and larger animals like pigs to further test the therapy. That step may begin during the next few weeks or months.

Scientists Test 3-D Printing of Middle Ear Bones

Work being done by researchers at Baltimore's University of Maryland School of Medicine takes a novel approach to restoring lost hearing. Rather than creating an external hearing aid or an in-ear implant, they are using 3-D printing to fabricate the tiny bones (ossicles) in the middle ear to help restore hearing in instances when these bones have become damaged by trauma, disease, or infection. Damage to these 3 small linked bones is a common cause of conductive hearing loss. The middle bone (incus) is the most frequently affected.

A well-established procedure called ossiculoplasty or ossicular reconstruction uses a prefabricated prosthesis that is felt to have suboptimal success rates. The research work involves fabrication of a custom-designed prosthesis that would be a snap-fit replacement to restore the missing middle link of the chain. A better fit should improve the success rate of surgery to restore conductive hearing loss.

Current methods can restore hearing levels of less than 20 decibels in just half to three-quarters of cases. Several things might account for this less-than-perfect success rate, but the hope is that using 3-D printing to create submillimeter-accurate custom prosthesis could greatly help. Early tests have shown that this degree of printing accuracy can be accomplished, but they still need to find a biocompatible material that is good at conducting sound. Research continues, and it may be awhile before this procedure becomes operational.

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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*



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 4th Tuesday each month (except July and August) - 6:00 PM at the Salem Hospital Community Health and Education (Building D), Creekside Overflow Room, 939 Oak Street SE, Salem, OR.

Contact: Mary Fagan
e-mail: hlasalem@live.com
(503) 409-5491
3253 Dallas Hwy NW Salem, OR 97304-4222

HLAA of Lane County meets quarterly: 2nd Thursday in March, June, Sept., and Dec., at 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
Eugene, OR 97402

Clark Anderson
e-mail: clarkoa@msn.com

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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
PO Box 2112
Portland, OR 97208-2112
www.hearinglossor.org/portland/

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

Contacts: Vincent Portulano, President:
email: HLAADC@outlook.com

Ann Havens, Secretary (541) 673-3119

HLAA of Linn and Benton Counties meets the last Wednesday of each month (except July and Dec.) – 6:30 PM at the Reimar Building, next to Albany General Hospital, 1085 6th Ave. SW, Albany, OR 97321.

Contact: John Hood-Fysh
e-mail: jhood-fysh@wwmore.com
(541)-220-8541 (cell – call or text)
818 Broadalbin St. SW
Albany, OR 97321

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Chapter coordinator contacts:

Oregon: Richard Little
e-mail: Richard16@comcast.net
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