



HLAA Fox Valley Chapter News Volume 37 Issue 2

March 2022

## **Chapter Meeting on Zoom**

Monday, March 14, 2022 6:30 PM (CST)

## We Hear You; Now You Hear Us!

Join us to watch the award winning documentary *"We Hear You; Now You Hear Us!"* at our March meeting.

This ground breaking documentary about hearing loss, produced by HLAA members, shines a light on the hearing loss experience as it strives to build awareness, community and a more inclusive world for all.

*"We Hear You"* was named Best Film on Disability in the June 2021 awards of the Cannes World Film Festival. The film was written and produced by HLAA members who live with hearing loss. You can read more at: <u>https://www.hearingloss.org/</u> <u>webinars/we-hear-you-documentary-talkback/</u> Some of you may have seen the film when it was featured in a talk back by HLAA. It was also shown at a chapter meeting of the Madison HLAA Chapter.

We look forward to a lively discussion afterwards. Please register in advance to receive the link to our Zoom meeting. The registration link is below.

You can request the link to this Zoom meeting by e-mail if you prefer. Email us at <u>hlaafoxvalley@gmail.com</u> Advance registration helps your chapter leaders plan for the meeting.

If you had problems signing in to our meeting in February, please let us know that in advance by e-mail so we can walk you through the procedure. We are pleased that online meetings are bringing in people from all over the state! Of course some register and don't show up. We'd like to know why

You are invited to HLAA Fox Valley Chapter's Zoom meeting. When: Mar 14, 2022 06:30 PM Central Time (US and Canada) Register in advance for this meeting:

https://us02web.zoom.us/meeting/register/ tZAkdOqtpj4iE9GMaCZzm4o7SMNgf-nm4TWM

After registering, you will receive a confirmation email containing information about joining the meeting. NOTE: **The room will be open at 6:15 PM. Please come early so we can start at 6:30**.

# We Support the State Steppers Walk Team!



Instead of having a chapter team in the 2022 Milwaukee Walk4Hearing, we will support the 'State Steppers', HLAA Wis-

consin's team. HLAAWI is raising funds to support an annual \$1500 high school scholarship. Please consider joining the team or donating in the name of those who do. To join or donate, go to <a href="http://www.walk4hearing.org">www.walk4hearing.org</a> Choose the Milwaukee Walk and click on the links to either join the team or donate. You will see the names of team members at that link.

# Milwaukee Walk4Hearing

Saturday, May 21, 2022

Location Veterans Park 1010 N. Lincoln Memorial Dr. Milwaukee, WI <u>Map It!</u> (5K/3.1 miles)

Schedule 9 a.m. Registration Starts 10 a.m. Stage Presentation 10:15 a.m. Walk starts



Interested in attending the 2022 HLAA National Convention? We would like to have a chapter delegate, preferably someone who has not attended before, but that can be waived. Your expenses would be covered.

We also have two \$500 stipends available. You must be a national member of HLAA, and show interest in being involved in our chapter. Let us know ASAP. hlaafoxvalley@gmail.com More convention information at: <u>www.hearingloss.org</u>

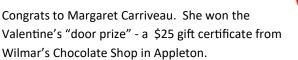
The Research Symposium is on the future of cochlear implants and other technology for hearing loss. The exhibit hall will have some amazing technology to learn about and try. Do think on this. It is a unique and special opportunity.

## Synopsis of our February Chapter Meeting

*"Loving, Living and Laughing with Hearing Loss"* proved to be an informative session for attendees of the chapter's ZOOM meeting held on February 14th. Moderator Julie Olson posed questions to three couples serving on the guest panel. Questions and answers followed.

Topics addressed were far ranging - since hearing loss affects virtually every aspect of our lives. They included dependence on one's hearing partner, coping techniques, auditory fatigue, Assistive Listening Devices, bluffing, telephone communication, education/advocacy, etc. Audience members chimed in on the special challenges posed by the pandemic. Humorous as well as alarming anecdotes were shared describing a miscommunication. We've all been there. Isn't it nice to know we're not alone?

Thank you to Jerry, Andrea, Kevin, Amy, Gary, Karen & Christine for being panelists.



Be sure to check out the HLAA Wisconsin State Newsletter. Lots of good information in the 10 page issue. <u>www.hlaawi.org The</u> link is on the home page. You can subscribe to receive it by e-mail there too.

## HOW TO PARTICIPATE ON ZOOM:

## 1. Register in advance for our meeting at:

https://us02web.zoom.us/meeting/register/ tZAkdOqtpj4iE9GMaCZzm4o7SMNgf-nm4TWM

**2.** If Zoom asks you to update, do so.

3. Sign in by 6:20 so we can start at 6:30. (If you are new to Zoom, you may have to sign up. Follow prompts. This is a one time thing.)

**4.** Registrants will receive a notice of registration, AND a meeting reminder the day of the meeting.

## 5. Join with audio and also with video.

**6.** The host will let you into the meeting room.

**7. ENJOY THE PRESENTATION!** Save questions & comments until after the presentation. Thank you.

8. Time for discussion afterwards.

If you get this newsletter in print, e-mail us at: <u>hlaafoxvalley@gmail.com</u> We will send you the live registration link by e-mail from that address.

## Are YOU Ready to Get Together? WE are!!

Because many of you have said you're itching to get together, we've decided to make that happen, sooner rather than later. We will still have our annual summer party at Appleton Yacht Club, so never fear...that isn't going to change.

Our May meeting, complete with a program on 'Gadgets', will be held in the Joe Bowers Room at the Ground Round Restaurant in Neenah. The chapter leaders are still working out the details, so watch for them in a future newsletter. We thought you should know so you can plan ahead!

This event will involve food. You'll be able to order off the menu. We are not sure yet, whether it will be their full menu or a menu of fewer choices. Everyone will pay for their own food and beverages. We will probably need a headcount in advance. More on that later.

Mark your calendars for Monday, May 9th. We'll have some social time, some good food, and a good program. And, it will be SPRING!!



# Disabilities are Not Binary. Why Do We Treat Them That Way?

Association of American Medical Colleges News — HLAA board member Zina Jawadi states, "Too often, disability is thought of like a light bulb: on or off. A person either has a disability or does not. In reality, most disabilities fall somewhere along a spectrum, and viewing them through a binary lens can have profound consequences.

# Read more

# From: The Wisconsin Department of Health and Human Services

The WisTech Assistive Technology Program has increased funding for hearing aid assistance. The Office for the Promotion of Independent Living (OPIL) announced that the Telecommunications Assistance Program (TAP) is now offering applicants up to \$1500 towards the purchase of new or refurbished hearing aids or cochlear implant processors. Funding is limited and will be distributed on a first-come, first-served basis. To be eligible, applicants must meet the TAP eligibility requirements. For information on eligibility and how to apply go to <u>https://</u> www.dhs.wisconsin.gov/odhh/tap.htm

NOTE: The TAP program is different from the Telephone Equipment Purchase Program (TEPP). There are specific eligibility requirements for TAP, but not for TEPP.



# Can We Hear the Word Cure?

President's Message by Julie Olson

I was 22 years old when my sensorineural hearing loss (SNHL) was diagnosed. It was typical as it was bilateral and progressive. I was told "Your hearing

nerve is dying, and that nothing in your lifetime will ever be available to fix it; medicine or technology. You'll just have to live with it". That was in the 1960s. I am thankful my communication skills had developed naturally because my SNHL wasn't present in childhood. Why I have SNHL remains a mystery, but I suspect it is noise induced as well as genetic, and may have been exacerbated by the bout of measles I had when I was 16.

SNHL has affected my life profoundly. Years passed after diagnosis before I tried hearing aids. They helped a little. What I learned several years later has kept me in the hearing mainstream. I am so thankful.

It wasn't until I learned about the organization "Self Help for Hard of Hearing People, Inc.", known today as HLAA, that doors opened for me. This organization gave me hope through information sharing and peer support. I learned about add on technology that could make my hearing aids work better in noisy settings. I learned I wasn't alone. That gave me confidence to talk about hearing loss. The rest is history long history. Like my involvement in HLAA. It's been over 38 years!

Today, my hearing aid and cochlear implant processor work together remarkably well. I benefit from telecoils, hearing loops, FM systems, BlueTooth microphones, and other gadgets that double the value of my personal technology. That message I received in the 60s was wrong. Cochlear implants are amazing, so are modern hearing aids. Yes, there is help. **Doesn't it make you wonder what will come next?** 

Until recently, the word 'cure' has not been used as it relates to SNHL. The prevailing medical theory, until recently, was that it was simply uncurable, so few research bodies spent the time and money to study it. HLAA has had an impact on change because HLAA has advocated by sharing a positive push to make change happen. Look at all the choices we have today in technology, and take a few moments to thank HLAA for pushing that! Wouldn't a 'cure' be wonderful?!

I'd like to share part of an article that was recently published in *Forbes Magazine* that should give us all hope for what could eventually be a 'cure'. It's good to know that researchers believe it's possible.

Frequency Therapeutics, headquartered in Lexington, MASS., is leading a new category in regenerative medicine that aims to restore function – first in hearing loss and then in multiple sclerosis (MS) – by developing therapeutics that activate a person's innate regenerative potential within the body through the activation of progenitor cells to restore lost function. Frequency's hearing research focuses on cochlear restoration and auditory repair, and its lead asset, FX-322, is a smallmolecule product candidate that is the first to show statistically significant and clinically meaningful hearing improvements in clinical trials for SNHL.

If you are interested in what might come next and are willing to read a rather long article, do take time to do so. The website shares a lot of information for those who wish to learn and hope.

For more information, visit www.frequencytx.com



The 2022 Chapter Sponsor Program Has Begun! Appeal letters to sponsors who have participated in the past were mailed at the end of January. Names will be added as donations are received. Thank you to everyone who supports us this way. This is our only fund raiser. Sponsorships help us cover many costs we incur to reach out to people with hearing loss.

If you wish to support the chapter this way, send your check to: HLAA-Fox Valley Treasurer, P.O. Box 25, Menasha WI 54952. Include instructions on how you wish to be listed.

## **2022** Chapter Sponsors

Platinum Level (\$200 or More)

Audiology & Hearing Center@ ENT Surgical Associates, SC Kristen Borgen AuD, Beth Gabavics AuD Fox Valley Hearing Center Dr. Stephanie Long, Dr. Candy McGinnis, Dr. Brittany Uitenbroek, Dr. Melissa Dintelman Carol Konetzke Memorial Donation from her family Haviland Hearing Aids Peter J Zellmer AuD, Kyle Martell AuD Rural Audiology Services, Waupaca WI Cari J. Kramer Audiologist, Becky L. Franz Audiologist Jim Machalk Tom & Linda O'Connor

Gold Level (\$100 - \$199)

Doug Grant Memorial, from his daughter Elizabeth Lewis Kevin Gossens, Jim Hemmen, Christine Klessig, Barbara Merry, Mike & Susan Landreman, Karen & Tom Schuppe Barb Soderberg, Jan & Diane Veenendaal, Dale Voskuil Juliette Sterkens AuD & LeRoy "Max" Maxfield Grace & Bill Zurovitch

#### Silver Level (\$50 - \$99)

Anonymous, Jim & Rhonda Bartelt, Pat Boldt, Jo Kintopf-Crabb, Michelle Frisbie Charles Hastert, Karen & Gary Kasten, Julie & John Olson, Ione Muehlenbein (In memory of Paul), Patty Reimer, Phyllis & Lyle Sconzert, Kate Wiers, Jerome & Phyllis Van Handel

#### Bronze Level (\$25 - \$49)

Lorna Hamilton, Katie Weber

We are grateful to everyone above and to all who have made smaller donations to our chapter treasury. We are grateful to those who contribute personal resources of time, energy, mileage & more. Your support is what makes our chapter successful.

Our Mission: To share information, educate, advocate and provide support to people with hearing loss who choose to remain in the hearing mainstream with technology.

Meetings are open to the public, and are organized and run by volunteers. Like most small organizations, we need more volunteers!



We are grateful to Carol Konetzke's family for honoring her wishes to remember our chapter with a bequest. Carol joined us in the mid 1980s and was an active member for many years. Thankyou.

HLAA, at all levels, does not recommend or endorse products or providers. We do share our personal experiences with them.

Our newsletter is available by regular mail or e-mail. The e-mail version is in color with live links. Let us know your preference if you wish to change. Disclaimer—HLAA does not endorse products or services. Mention of such is intended to provide readers & those who attend meetings with information on products or services that might be of interest, & is not a recommendation or endorsement.

HLAA-Fox Valley Chapter P.O. Box 25 Menasha WI 54952-0025

## 2022 Chapter Calendar

March 14: Regular Chapter Meeting-Showing of award winning documentary *"Now Hear Us"* plus discussion.
March 22: Cochlear Implant Group at 6 PM
April 11: TEPP Program by HEARWI—Telephone Equipment
Purchase Program for people with hearing loss.
April 19: H.O.P.E. At 1 PM. (Request the link.)
May 9: Share Your Gadgets Night & Dinner OUT!
REQUEST MEETING LINKS AT: hlaafoxvalley@gmail.com

Regular chapter meetings & socials will be on the 2nd Monday of each month. Except in January & August.

Our subgroups; H.O.P.E. and Cochlear Implants, will alternate months for the time being. That may change after we are able to meet in person again, as H.O.P.E. prefers to meet monthly. CI prefers to bi monthly.

## 2022 Chapter Leadership Board

#### Officers:

President & Newsletter Editor: Julie Olson julieo@athenet.net Vice President & HOPE Chair: Dale Voskuil voskuild@gmail.com Treasurer: Michelle Frisbie michellelfrisbie@gmail.com Secretary: Christine Klessig bommaklessig@gmail.com Program Chair & CI Group Chair: Rhonda Clancey rclancey@hotmail.com

Member at Large: Jane Young <u>YBLUEJAY@aol.com</u> Social Committee: Christine Klessig , Grace Zurivitch, Chris Moylan

## Chapter e-mail: <u>hlaafoxvalley@gmail.com</u>

Support Crew: Bob Opsteen, Jerry Van Handel, Colleen Van Rooy, & Paul & Harriet Zuicker

Feel free to contact any of us personally, or use the chapter's e-mail address. We will respond as soon as possible.

\* Designates Members of the Chapter's Board of Trustees.

## Studies Find COVID-19 Vaccines Don't Raise Risk for Sudden Hearing Loss

### By Brian P. Dunleavy

Feb. 24 (UPI) -- People given a COVID-19 vaccine are not at higher-than-normal risk for developing sudden hearing loss, according to a study published Thursday by JAMA Otolaryngology-Head & Neck Surgery.

## **Cochlear Implant Support Group**



The CI Support/Discussion Group will meet on Tuesday, March 22nd at 6:00 PM via Zoom. Our meetings have shared so much information and are quite inspirational. It's the perfect place to share your experiences with CIs, or ask questions

about them if you think they might be worth exploring yourself. Request the link for the CI meeting at: <u>hlaafoxval-</u> <u>ley@gmail.com</u> You may also join our e-mail list by contacting Rhonda Clancey, CI group Moderator at: <u>rclancey@hotmail.com</u>

#### H.O.P.E. Notes: from Dale Voskuil, Moderator

Our February H.O.P.E. meeting was lively and informative. I learn something at every meeting that I attend. And yes, I know that H.O.P.E. is really at its best when we can meet in person because of the opportunity to have one-on-one discussions before and after the meeting, but Zoom also has some advantages. Please

join us. We make every attempt to limit the meeting to about an hour, knowing that you have a busy life. Our next meeting will be on Zoom on April 19th at 1:00 PM. Request link in advance. hlaafoxvalley@gmail.com



# HLAA Plans Legislative Effort Support Needed

An effort to make full disclosure of the options needed to connect to the technology that provides the 'communication access' hard of hearing people are guaranteed through the Americans with Disabilities Act to is once again in the discussion stage.

To follow through on this project, HLAAWI is seeking people in the state who have connections with our state legislators; Assembly and Senate. Please, if you know any of our legislators personally, or have had contact with them, let the members of the state committee know. If you might work with HLAAWI to move this forward know you are needed This is a bipartisan issue that needs support from both sides of the aisle.

Contact Jim Rau, HLWI President at hlaawistate@gmail.com

#### Technology to help you hear:

Some assistive listening **devices are available for loan through Easter Seals.** If you could benefit from having a phone amplifier, a visual alert system, or a Clear Sounds Quattro 4 bluetooth streamer listening system, contact Pattie at 832-0344 or email her at <u>pslempkes@eastersealswisconsin.com</u>