

Twin Cities and Greater Minnesota



The mission of HLAA TC is to open the world of communication to people with hearing loss by providing information, education, support and advocacy.

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HLAA National - Maryland

The February Hearing Loss Association of America Twin Cities Chapter meeting (HLAA TC) will be a hybrid meeting (in person and Zoom) on February 17, 2024 Click "register here" on the HLAATC website to receive link for zoom meeting See page 11 for further details

## President's Message HLAA-TC President's Message – February 2024 Robin Coninx

#### Hearing Loss Conversations in Minnesota

As Hard of Hearing individuals (HOH) we have a responsibility to show up and have our voices heard when it comes to the services we need in our everyday world – tools that afford us the opportunity to lead a full life by keeping us attuned to the larger world. Please don't isolate – join in the discussion!

I bring this forward as Minnesota Commission for the Deaf, Deafblind and Hard of Hearing, HLAATC, and other hearing loss organizations have included the important point of **age-related hearing loss** at the Legislative Task Force on Age Enabling Legislation. Are you interested in this topic and/or have thoughts to share?

Please reach out to Byrdie at 763-447-9672 or president@hlaatc.org

Thank-You to Karla Sand, HLAATC Director at Large, who spoke up on December 12, 2023 at the Minnesota Capitol.

One way you can get involved is to volunteer to testify like Karla, or -- within HLAATC -- to consider joining the board, fundraise or come to the HLAATC monthly chapter meetings and bring your friends.

My time as President is coming to an end. As I stated when I started in September of 2022, I would do my best support the mission statement of HLAATC for the next 2 years. Time has flown by, that is for sure.

We now need to collect nominations, and then vote in May of 2024.

We have the following openings on the HLAATC Board:

- President starting September 2024 supported by past president as mentor for a year
- Secretary Immediate opening
- Treasurer Immediate opening

Email <u>president@hlaatc.org</u> with your nomination. Thank-you for your consideration!

Byrdie, HLAATC President

#### Meeting Summary, HLAATC meeting January 20, 2024 By Laura Hagemann, Vice President

The January hybrid chapter meeting of HLAA-TC (with attendees both at Courage Kenny in Golden Valley, MN and on Zoom) was a presentation by Darlene Zangara, Executive Director of Minnesota Commission of the Deaf, DeafBlind and Hard of Hearing (MNCDHH). This is an annual update that Darlene Zangara gives about the upcoming legislative agenda for MNCDHH for the year.

Darlene explained that the focus of MNCDHH is providing communication access and equal opportunities. She mentioned there are open board positions for MNCDHH, please apply online if interested:

https://commissionsandappointments.sos.state.mn.us/Agency/Details/185

There was a Legislative Agenda Q & A on January 27th and you can view the legislative agenda here: <u>https://mn.gov/deaf-commission/legislation/legislative-agenda/</u> Sign up for the MNCDHH newsletter here (the newsletter sign up is in the middle of the page): <u>https://mn.gov/deaf-commission/</u> Follow MNCDHH on <u>Facebook</u>, <u>Twitter/X</u>, <u>LinkedIn</u>, <u>Instagram</u>, <u>YouTube</u>.

Alicia Lane, MNCDHH Government Relations joined Darlene to discuss the upcoming legislative agenda. They talked about the Legislative Task Force on Aging Meeting (see that website here: <u>https://www.lcc.mn.gov/aging/</u>) and how screening for hearing loss is important for the aging population. They mentioned the Older Americans Act which is happening on a Federal level.

After a break, Ronnie Adler from HLAA joined us on Zoom to talk about the Walk 4 Hearing (Walkathon) that we will be having on June 2, 2024 in Como Park in St. Paul. "Walk4Hearing raises funds to do programs and services for National and local. And, so, HLAA is raising the funds through the walk and other donations to raise awareness about hearing loss", Ronnie said.

More information will be given in the future about the event, and we will likely have more information on our website.

Thank you to Darlene Zangara and members of MNCDHH for all the efforts you are doing and for updating our organization.

Thank you to Ronnie Adler for her update on Walk4Hearing.

Thank you to everyone who attended in person or via Zoom.

# February Speaker



*Phil Burke* Assistant Director, Customer Experience

"Traveling With Disabilities: Accessibility Programs at MSP"

Phil Burke is the Assistant Director of Customer Experience at the Minneapolis-St. Paul International Airport (MSP), the largest of seven airports owned and operated by the Metropolitan Airports Commission.

Phil joined the Metropolitan Airports Commission (MAC) in 2001 in the Commercial Management and Airline Affairs department. Three years later, he was named the Assistant Director of MSP Operations/Facilities.

In 2013 Phil was promoted to the Director of Operations at MSP and in late 2018 transitioned to a new role for MAC to lead the development of a new department – Customer Experience.

Prior to joining the MAC, Phil worked for Mesaba Airlines. He earned a Business Administration degree from the University of North Dakota with a major in Airport Administration. Phil also earned a Master's degree in Organizational Leadership at Bethel University in June 2014.

#### Upcoming Hearing Loss Virtual Events By Laura Hagemann

https://www.hlaatc.org/

February 17th, 9: 30am -12:00pm **Hybrid Meeting of HLAA-TC** (At Courage Kenny, Golden Valley or Zoom). "Traveling with Disabilities (Accessibility Programs at MSP)" Register for Zoom: https://us06web.zoom.us/meeting/register/tZwucOmgpjwoHtVikJRf6VAfNXIGDNgkL0TB

https://www.hearinglossnyc.org/meetings-topics February 20, 6pm-7:30pm (EST) 5pm- 6:30 pm (CST) HLAA- NYC **"What's New in** Hearing Aids" Register for Zoom: https://nyulangone.zoom.us/meeting/register/tJwld-qurzosH9N7J8-nk1Ei1XxATjw 7pE

February 27th, 7pm -8:30pm (CST) HLAA-TC Book Club: **"The Man Who Mistook his Wife for a Hat and Other Clinical Tales"** (Nonfiction) by Oliver Sacks. Register for Zoom: <u>https://us06web.zoom.us/meeting/register/tZEld-</u> <u>yoqzsoE9HgL6RLwaIzAV7HK5s7B1Cs</u>

https://hlaagroups.hearingloss.org/g/HLAALeaders/calendar March 6th, 4pm-5:15pm (PST) 6pm-7:15 pm (CST) HOPE/HLAA Washington **"Monthly** gathering of HOPE (Hearing Other People's Experiences)" Register for Zoom: https://hearingloss-wa.org/what-we-do/hope-hearing-other-peoples-experiences/

https://hlaagroups.hearingloss.org/g/HLAALeaders/viewevent?eventid=2217134&calst art=2024-03-09

March 9th, 1-2:30pm (CST) HLAA- Greater St. Louis, **"Know Your Rights. Ask For What You Need."** Register for Zoom: <u>https://us02web.zoom.us/meeting/register/tZMpd-</u> 2prTsjGtWacrgYnONAV0k3S5pBOgst#/registration

https://www.hearinglossnyc.org/meetings-topics March 19, 6pm-7:30pm (EST) 5pm- 6:30 pm (CST) HLAA- NYC **"Succeeding in the workplace with hearing loss"** Register for Zoom: https://nyulangone.zoom.us/meeting/register/tJEpd-6srzIvH9CvKh4QZSeegqXzS6\_21Jbd

For **in-person accessible Arts events**, The Minnesota Access Alliance (MNAA) provides an **Accessible Arts & Culture Calendar** at https://calendar.mnaccess.org

### **Gene Therapy Treatment for Genetic Hearing Loss**

"In a landmark decision, the Food and Drug Administration Friday [12/8/2023] approved the first gene-editing treatment to alleviate human illness...Decisions are being hailed as milestones for treating sickle cell and for the rapidly advancing field of gene editing, which is stirring excitement for treatment of many diseases". It is being explored in research and clinical trials for a wide variety of diseases, including single-gene disorders such as cystic fibrosis, hemophilia, and sickle cell disease (see medlineplus.gov).

To these we can now add "inherited hearing loss".

The Pioneer Press (January 25, 2024) reports that trials are underway using gene therapy to treat inherited hearing loss in children: "Gene therapy has allowed several children with inherited deafness to hear. A small study published Wednesday (1/1/24) documents significantly restored hearing in five of six kids treated in China. On Tuesday, the Children's Hospital of Philadelphia announced similar improvements in an 11-year-old boy treated there. And earlier this month, Chinese researchers published a study showing much the same in two other children.

"Preliminary results from other research have been just as positive.

"Columbia University's Dr. Lawrence Lustig, who is involved in the Regeneron trial, said although the children in these studies don't wind up with perfect hearing, "even a moderate hearing loss recovery in these kids is pretty astounding."

"Still, he added, many questions remain, such as how long the therapies will last, and whether hearing will continue to improve in the kids."

The condition being treated is fairly rare, however researchers said their work is moving forward. "This is real proof showing that gene therapy is working," Chen said. "It opens up the whole field."







# Book Club February 2024 will meet Tuesday February 27

## About the book for February 2024 Book Club

### By Laura Hagemann

The HLAA-TC Book Club has now selected a nonfiction book for February.

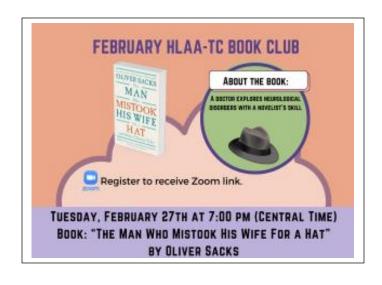
February's nonfiction selection is:

"The man who mistook his wife for a hat and other clinical tales" by Oliver Sacks. BARD: DB 23901; Synopsis: A doctor explores neurological disorders with a novelist's skill and appreciation of his patients as human beings. Sacks suggests that therapy for brain-damaged patients be designed to help restore the personal quality of the individual. Bestseller 1986. Amazon link: http://tinyurl.com/32z33w29

Register for the Zoom meeting: https://us06web.zoom.us/meeting/register/tZEldyoqzsoE9HgL6RLwaIzAV7HK5s7B1Cs

The meeting will be captioned. It will start at 7:00 pm and end around 8:30 pm (central time). (All meetings are free and open to HLAA members or non-members.)

For more information about the book club (a reading schedule for 2024 hasn't been decided on yet), visit the HLAA-TC Book Club Page: https://www.hlaatc.org/book-club/



### Links By Claudia Marseille

### (Editor's note:)

We hard of hearing people may have direct links to those who are closest to us, but we also have indirect links – to nearly everyone else.

Think of the people in your life who have connected you with others. They keep the conversation going when we can't, they share information with us that keeps us from embarrassing blunders, and they give us valuable clues about what is going on when we don't know what to do next.

Claudia Marseille (whose book was reviewed in our January 2024 Newsletter) shares some details of her special relationship with her brother, Elliot.



All my life, I have greatly relied on one important person to help me engage with the hearing world. Over the years, different people filled this role: my younger brother, a best friend, a boyfriend, my first husband, and now my current husband. They helped me connect with other kids in the neighborhood, at school playgrounds, and later on, in classrooms, at social events, and in making important phone calls on my behalf. Often, they weren't aware of what service they were providing me as I took pains not to make my dependency too obvious. But their help was vital in helping me establish social connections, figure out the world, and function productively within it.

I am grateful for the role my brother, Elliot, played in my life when we were little. More than my parents, he was particularly attuned to my hearing loss, always facing me when he spoke to ensure I could read his lips. His clear enunciation allowed me to comprehend him with little effort.

He explained our family dynamics, narrated the plot lines of our favorite TV shows, and guided me through the intricate rules of the games we played with neighborhood kids. We lost ourselves in imaginative games we conjured up, spending hours exploring uncharted territories of our imagination. These shared times were about dependency and our sibling bond that deepened through our connection. I cherish his laughter, love, and contribution to my life. His support and those of others have helped me bridge the gap between silence and sound.

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# splashing mad!

By Vicki Martin

Do you ever get annoyed by people talking noisily, preventing you from hearing anything else? You are not the only one! It can happen any place – as shown by this letter to Dear Abby (Pioneer Press Sunday February 4, 2024):

"I have had it with the talkers in the pool...a handful of ladies disrespect the instructors and the rest of the class...they have been asked to quiet down by the instructors and the other participants. There is even a sign on the door asking for limited talking...

"When these ladies start talking to each other, those nearby get distracted and can't work out..."

Who among us is not pointing a finger at someone else? We have all encountered this sort of thing. But here's the clincher: "Some have hearing loss" (that's us, folks!) "and are oblivious to how loud and disturbing they are".

I guess it cuts both ways, right? So, let's save that conversation for after class



# Hearing the Eclipse



We know how grateful we are for captioning when we just can't hear the message. But suppose the "message" was a silent celestial event, and you lacked the ability to see it? What if we had auditory "captioning" for those with vision loss?

Now we do! Astronomers at Harvard University want to include blind people among the watchers of the solar eclipse due to cross the country in April. The LightSound project uses sonification to translate brightness into sound, increasing the accessibility of astronomy for those who cannot watch these events in the usual way.

"The excitement of astronomical events can inspire the next generation of great thinkers, and we need them all", says Allyson Bieryla, Harvard's Astronomy Lab manager. Read more: https://astrolab.fas.harvard.edu/LightSound.html



# Links from the Commission



## Legislative Agenda

2024 Legislative Agenda - <u>https://mn.gov/deaf-commission/legislation/legislative-agenda/</u>

# **Hearing Aids**

- Your rights while purchasing prescription hearing aids (Commission) <u>https://mn.gov/deaf-commission/advocacy-issues/healthcare/hearing-aids/</u>
- 30 second PSA about over-the-counter hearing aids (Commission) <u>https://youtu.be/Ob6Ev\_HfVOk?si=s1iisXso0kgF33jw</u>
- Getting hearing aids fact sheet (DHHSD) -<u>https://edocs.dhs.state.mn.us/lfserver/Public/DHS-8092-ENG</u>
- Over-the-counter hearing aids fact sheet (DHHSD) -<u>https://edocs.dhs.state.mn.us/lfserver/Public/DHS-8379-ENG</u>
- Hearing aid insurance appeals guide (DHHSD) -<u>https://edocs.dhs.state.mn.us/lfserver/Public/DHS-7915-ENG</u>

# **Hearing Loops**

- Newsletter on hearing loop locator tools <u>https://mn.gov/deaf-commission/news/index.jsp?id=1063-604248</u>
- PSA on telecoils and hearing loops -<u>https://youtu.be/KCQI3aCMNYo?si=omkJOpmiFIM4J-tz</u>

# **Commission newsletter**

 Subscribe today! <u>https://public.govdelivery.com/accounts/MNCDHH/subscriber/new</u> -

Pending – Older Americans Authorization Act (OAA)

### Maya Larson

Administrative and Communications Specialist Minnesota Commission of the Deaf, DeafBlind and Hard of Hearing From the desk of HLAATC President ~ Byrdie



# It is time to create your HLAATC Walk 4 Hearing teams!

Please use this link to register your team/s: <u>Walk4Hearing Supporting Hearing Loss</u> <u>Community</u>

# Walk Date: June 2, 2024 at Como Park

© Remember you can donate to HLAATC to support local Hard of Harding conversation and support.

# **Meeting information**

The next meeting of the Hearing Loss Association of America Twin Cities Chapter (HLAA-TC) will be held at Courage Kenny 3915 Golden Valley Road, Golden Valley MN February 17, 2024, and on ZOOM.

**To register for ZOOM meeting:** Prior to the meeting, click "register here" on the HLAATC website (or click here for direct link to register: <u>ZOOM- REGISTER HERE</u> You will receive a confirmation email containing a link to the meeting.

**To register for the IN PERSON meeting**, email: <a href="mailto:president@hlaatc.org">president@hlaatc.org</a> or call 763-447-9672 and leave a message with how many people are attending in your party. Then, join us at Courage Kenny 3915 Golden Valley Road, Golden Valley MN 55422 on February 17 (the 3<sup>rd</sup> Saturday of the month).

**Meeting time:** Social time in person begins at 9:30 AM (no social time on ZOOM). Formal meeting is at 10:00 AM for both in-person and ZOOM

**Accommodations:** All meetings are realtime captioned by Captioners from Veritext/Paradigm (<u>www.caption-paradigm@veritext.com</u>).

HLAA TC PO Box 26021 Minneapolis, MN 55426



# Next meeting: February 17, 2024 in-person and Zoom

# **First Class**

HLAA Twin Cities Chapter	Welcomes You!
Name	Hearing Loss Association of Americ
Address	President – Robin Coninx president@hlaatc.org
City	Vice President – Laura Hagemann vicepresident@hlaatc.org
StateZip	Secretary – <u>secretary@hlaatc.org</u>
Phone.(area code)	Treasurer – Robin Coninx <u>treasurer@hlaatc.org</u>
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Newsletter via email included in all memberships	Christy Myers Karla Sand
Individual \$25 Professional \$50	Ed Benck Mark Daly
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