HLAA TC May 2023

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.

UPCOMING MEETINGS

May 20, 2023

Group discussion
Strategies for living
with hearing loss
(tech and non-tech)

See President's message (page 2) for registration link



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Officers' emails

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The February Hearing Loss Association of America Twin Cities Chapter meeting (HLAA TC) will be a Zoom meeting on May 20, 2023

To register and receive meeting link, use the registration link on page 2

President's Message HLAA-TC President's Message – May 2023 Robin Coninx

Time sure has flown for the HLAATC Board! The one-year mark brings about the need to call for nominations and votes for following positions within HLAATC Board.

All terms will be for one year.

The following positions are open:

- Vice President –
- Treasurer –
- Director at Large 2 positions need to be filled

The nominations are as follows:

Laura Hagemann for Vice President Christy Myers for Director at Large Ed Benck for Director at Large.

Voting will be at the HLAATC May 2023 Chapter Meeting.

You are invited to a Zoom meeting.

When: May 20, 2023 09:30 AM Central Time (US and Canada)

Register in advance for this meeting:

https://us06web.zoom.us/meeting/register/tZwucOmgpjwoHtVikJRf6VAfNXIGDNgkL0TB

After registering, you will receive a confirmation email containing information about joining the meeting.

Thank-you for your patience as we are trying to streamline some of the process, so it is not so cumbersome for our agency to process chapter meeting attendees

Byrdie

HLAATC's May meeting topic will be a discussion of our various strategies, technological and otherwise, for living with hearing loss. We encourage members to give some thought to what's worked well for them, and also to any ongoing struggles that others may be able to offer ideas about. We'll open with brief presentations by board members, to get the conversation started, and then open it up for supportive discussion. We will also be voting for next year's board of directors.

Unlike the last two meetings, we will not be recording any part of this meeting, so that everyone feels comfortable sharing.

Summary of HLAATC meeting Saturday, May 2023 By Signe Dysken, Vice President

After informal conversation starting around 9:30, Byrdie opened the meeting at 10:00 with an introduction of our speaker Shari Eberts, a nationally known hearing health advocate, author and speaker on hearing loss. She is the founder of LivingWithHearingLoss.com, a blog and online community for people living with hearing loss and tinnitus. She is the author, together with Gael Hannan, of the book <u>Hear and Beyond</u>. The topic of her talk today was *Living Skillfully with Hearing Loss*.

Ms. Eberts began by relating her family history with hearing loss. When she was growing up, her father struggled with shame and embarrassment about his significant hearing loss. His hearing loss was not to be a topic of discussion in the family, and he often isolated himself from groups because he could not hear. Ms. Eberts herself developed genetically caused hearing loss in her 20's and decided that she wanted to approach this problem differently – she wanted to be open about her hearing and communication problems, and she got hearing aids and used them regularly. She wanted to provide a different model of coping for her own children. Her goal became hearing better in order to communicate effectively. She had concluded that there are several influences on how a person copes with hearing loss: life experiences including family attitudes and finances; professional hearing care; and peer resources.

Ms. Eberts pointed out the five stages of coping with hearing loss:

- 1. Debating with yourself, doubt, denial, blame and stigma
- 2. Validating hearing loss by getting an evaluation
- 3. Taking charge --- getting hearing aids and adapting to them
- 4. Living skillfully with hearing loss through strategies and technologies
- 5. Refreshing and restarting, adapting and adjusting as needed

Ms. Eberts introduced the concept of the "Three-Legged Stool" as a way to summarize key ways to learn to cope with hearing loss:

- 1. **An attitude reshift**, where you see yourself as in charge. Optimizing versus seeking perfection. Practicing self-care, good health habits, gratitude, and a sense of humor
- 2. **Technology is my friend**. Hearing aids help, but there is more: using captioning on smartphone Apps and Zoom calls, embracing Bluetooth and telecoils, CART and hearing loops, speech to text apps, and eventually, Auracast (currently in the process of development).
- 3. **Communication game-changers**: self-advocacy, asking people to repeat what they said rather than bluffing, speech reading. Communication involves both speaker and listener, so when necessary, remind the speaker of your difficulty hearing and understanding your communication partner. (Communications Tips include; (1) N-CHATT trainer, (2) Facebook groups: Hearing Tracker (3) You Tube videos on how to use devices; YouTube videos by Cliff Olson, audiologist)

(meeting summary, cont.)

Following the presentation, there was general discussion about problems in daily living such as constantly having to advocate for ourselves, remind others to activate captioning on Zoom calls, frustrations with TV's without captioning, the need for more hearing loops and for knowledge on how to make looping work properly. We discussed the Sunflower program at airports, where you can request a sunflower lanyard from an information desk that should then signal employees at the airport that you have a hidden disability and need special help.

Ms Eberts was thanked for her presentation.

Following a short break, the business part of the meeting began by considering legislative agendas for HLAA-TC: Closed captioning in public spaces, CART at legislative meetings and Hearing aid affordability and insurance coverage.

Byrdie requested nominations and volunteers for the Board.

- 1. Byrdie nominated Laura Hagemann for Vice President.
- 2. Christy Myers accepted a nomination for Director at Large.
- 3. Laura will continue to recruit for Board members on social media and it will also be publicized in the next newsletter. Since we meet on Zoom, Board members could reside in towns outside the metro area. Monique pointed out that being a Board member is something a younger person could put on a resume.
- 4. People were encouraged to talk to family and friends and hearing care professionals about the benefits of attending HLAA-TC meetings. The issue of whether to invite an audiologist to be a member of the board was discussed but set aside because of concerns about conflict of interest. The importance of neutrality in a nonprofit organization like HLAA-TC needs to be guarded. There was consensus that we should be inviting audiologists to attend an occasional meeting so they can tell their clients about the organization and to improve our collaboration with audiologists.
- 5. Discussion about crafting a packet of information to distribute to audiologists, including our mission information, education, support, and advocacy. Christy said she had worked on a brochure some years ago, but this stalled due to lack of focus and action by the Board. However, Christy is willing to try to find her notes from that project and try to update and improve it including communication tips and resources that would really be helpful to a person who is newly diagnosed or new to hearing aids.
- 6. Discussion about how to provide the link to chapter meetings. This is cumbersome at present, and burdensome to the Secretary. However, broadcasting a link to large numbers of people could open us up to scams that could shut down a meeting. Byrdie suggested that the national organization might have tips on how make distributing links work safely and more easily or even automatically.
- 7. Discussion about the newsletter and whether it should still be distributed electronically to the 300-400 members on the list. Vicki favors continuing broad distribution. Susan currently sends about 8 paper copies of the newsletter to people who don't want to or can't read it electronically. Whether this expensive and cumbersome procedure is necessary and whether this could be accomplished in another way is an open question.

The meeting was adjourned after a reminder about the next Board meeting on the second Tuesday in May.

Respectfully Submitted, Signe Dysken, Vice President

Latest Chapter Meeting Links and Video

By Laura Hagemann

On Saturday, April 15th HLAA-TC met on Zoom for our second to last chapter meeting of the 2022-2023 season. We welcomed hearing loss advocate Shari Eberts and she gave a presentation on "How to Live Skillfully with Hearing Loss." We recorded her presentation and the question and answers afterwards and the video is available to view on our YouTube page and our website. For a list of links to pertinent things discussed during the meeting, continue reading this blog post.



https://youtu.be/L1jX0U8QA9E

Sites of Interest from the April Chapter Meeting:

- Living With Hearing Loss is the website and blog of Shari Eberts: https://livingwithhearingloss.com/
- <u>Link to Shari's book on Amazon</u>, but local members be sure to email <u>president@hlaatc.org</u> to purchase a copy from us (HLAA-TC is selling copies to members of Shari's book that we've purchased).
- N-CHATT is the technology program that Shari Mentions in the Q & A: N-CHATT (Network of Consumer Hearing Assistive Technology Trainers): is a volunteer consumer train-the-trainer program. The program's goal is to build a network of consumer trainers with the knowledge and skills necessary to train others impacted by hearing loss. Trainers will assist others in the successful integration of hearing assistive technology to support individual hearing and communication needs at home, work, school, and the community

(meeting links, cont.)

- Various Facebook Groups on Hearing Loss:
 - Living With Hearing Loss (by Shari Eberts) Facebook Group: https://m.facebook.com/groups/livingwithhearingloss/?ref=share&mibextid=1066kq
 - Community for the Deaf and Hard of Hearing Facebook Group: https://m.facebook.com/groups/deafandhoh/?ref=share&mibextid=1066kq
 - Hearing Loss Association of America Official Community & Support Facebook Group: https://m.facebook.com/groups/363776767846053/?ref=share&mibextid=1066kq
 - Cochlear Implants Basics Facebook Group:
 https://www.facebook.com/groups/441587200809972/?ref=share&exp=93fa
 - Hearing Loss The Emotional Side Facebook Group:
 https://www.facebook.com/groups/1636847240030166/?ref=share&exp=93fa
- Doctor Cliff, AuD is a YouTube Channel that Shari mentioned in the Q and A that does a lot of content on hearing loss and product reviews: https://www.youtube.com/@DrCliffAuD/featured
- In the Q&A the Sunflower "hidden disabilities" program is mentioned: https://hiddendisabilitiesstore.com/us/
- Hidden Disabilities Sunflower Program at MSP Airport:
 https://www.mspairport.com/airport/accessibility/hidden-disabilities-sunflower-program
- TSA Passenger Support: https://www.tsa.gov/travel/passenger-support
- Request for TSA Cares Assistance: https://www.tsa.gov/contact-center/form/cares

Hearing Loss Can Be Fun! - a book review (sort of)

By Vicki Martin

There are a lot of books out there about how to live successfully with hearing loss, and many contain much valuable information. But reading is a participatory activity, and all that information won't do you one bit of good if you don't read it. That's where Hear and Beyond comes in.

"Hearing loss can be fun" may be a bit of an exaggeration, but Shari Ebert and Gael Hannan do their best to make it true.

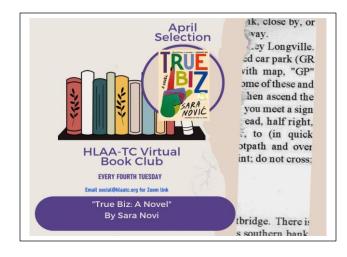
"It didn't seem funny when I accepted a date, only to learn that the man had asked something else entirely", Gael confesses, but the two authors nevertheless do find the humor in hearing loss, and we are the beneficiaries of their willingness to share. (Have fun guessing what that "something else" might have been!)

If you are looking for a book to help you navigate the terrain of your hearing loss journey, this could be the one. There is a lot of serious information here, and you will want to hang on to this book for future reference.

If, like me, you already have several books on your shelf about hearing loss, by all means keep them. Read them again, maybe, and tab the pages you will want to come back to.

Then give yourself a humor break and read Hear and Beyond too. Have a little fun!

Book Club Summary and May Book Announcement By Laura Hagemann



The April book was "True Biz" by Sara Novic:

Amazon link to True Biz book

New York Times Book Review of True Biz

Q and A with author Sara Novic

Video Book Review of True Biz

Meet the author video (Sara Novic)

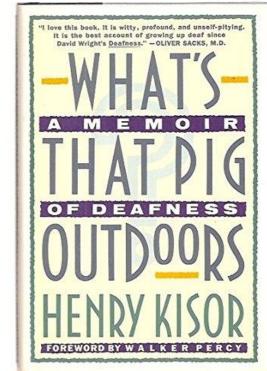
Author video podcast interview (Sara Novic)

Thank you to those who joined us for our April Book Club on April 25th when we discussed the novel "True Biz" by Sara Novic.

Our next book club will be on Tuesday, May 23, 2023 and we are discussing the memoir "What's that pig outdoors: Memoir of Deafness" by Henry Kisor (nonfiction/memoir) BARD/NLS: Yes, Braille: BR 08392; BARD: DB 31492.

"I love this book. It is witty, profound, and unself-pitying. It is the best account of growing up deaf since David Wright's <u>Deafness</u>."

- Oliver Sacks



(Book Club and related material, cont.)

- Alexander Graham Bell and his history with deaf people is mentioned in the novel <u>True Biz</u>. HLAA recently posted about the development of an opera about Bell: "Composer Richard Einhorn—past chair of the HLAA board of directors & vocal Hearing Health advocate—is developing a new opera based on the life of Alexander Graham Bell. 'Bell' explores how the telephone inventor's relationships with his deaf mother & wife influenced his fascination with sound." https://bit.ly/bellopera
- A nonfiction book on Bell: "The Invention of Miracles: Language, Power, and Alexander Graham Bell's Quest to End Deafness" by Katie Bell https://tinyurl.com/5afw8ape
- The HLAA Convention is in New Orleans this summer and the topic is music

General reading on Bell:

- https://www.belllegacy.org/articles/alexander-graham-bell-deaf-community/
- https://en.wikipedia.org/wiki/Alexander_Graham_Bell

Upcoming Captioned Cultural Events By Laura Hagemann

There are several cultural events coming up (some virtual and some in person) that are captioned.

Tuesday, May 16th 5pm - 6:30pm (Central Time): HLAA-NYC is hosting a virtual tour of the Metropolitan Museum of Art (The Met). "The NYC Chapter of the Hearing Loss Association of America is excited to present Museum Educator, Lauren Ebin, who will lead an online tour of The Metropolitan Museum of Art. The tour will feature works by deaf artists, Franciso de Goya and David Hockney and will include Emanuel Leutze's Washington Crossing the Delaware and Jackson Pollock's Autumn Rhythm, among others. We will also explore both grand and hidden spaces in the museum, including the Temple of Dendur and the Astor Chinese Garden Court." Click this link to go their website and find the link to register for the May 16th meeting: https://www.hearinglossnyc.org/meetings-topics

The following are local in-person events that are captioned (this list taken from Minnesota Access Alliance [MNAA] Accessible Arts & Culture Calendar https://calendar.mnaccess.org)

Saturday, May 27, 7:30 PM; Sunday, May 28, 2:00 PM— "The Defeat of Jesse James" at History Theatre, St. Paul— visit link to purchase tickets: https://historytheatre.csstix.com/event-details.php?e=542

Wednesday, May 31, 1:00 PM; Friday, June 2, 7:30 PM; Saturday-Sunday, June 3-4, 1:00 PM; Wednesday, June 7, 1:00 PM — "Murder on the Orient Express" at the Guthrie McGuire Proscenium Stage, Minneapolis — visit link to purchase tickets:

https://www.guthrietheater.org/shows-and-tickets/performance-calendar/

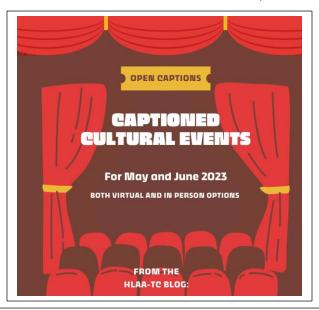
(Cultural events, cont.)

Sunday, June 4, 2:00 PM — "19th Annual 10-Minute Play Festival" at Lakeshore Players, White Bear Lake — visit link to purchase tickets: https://lakeshoreplayerstheatre.my.salesforce-sites.com/ticket#/instances/a0F2I00000V6bxNUAR/sectionGroups/a0b2I00000KZJK5QAP

Friday, June 23, 7:30 PM; Saturday-Sunday, June 24-25, 2:00 PM — "Next to Normal" by Theater Latte Da at the Ritz Theater, Minneapolis — visit link to purchase tickets: https://www.latteda.org/box-office

Saturday, June 24, 2:00 PM — "Relaxed Family Concert - Juneteenth: Celebration of Freedom" by the Minnesota Orchestra at Orchestra Hall, Minneapolis — visit link to purchase tickets: https://www.vividseats.com/minnesota-orchestra-tickets-minneapolis-orchestra-hall-mn-6-24-2023--concerts-classical/production/4377535

If you attend one (or more) of these events be sure to tell us what the experience was like (perhaps even write a review for the newsletter)!



Amazon Prime Video launches a new accessibility feature that makes it easier to hear dialogue in your favorite movies and series

Dialogue Boost is an innovation that lets you self-select dialogue volume levels to suit your needs on any device with Prime Video.

Prime Video is rolling out a new accessibility feature called Dialogue Boost, which has initially launched on select Amazon Originals worldwide. Dialogue Boost lets you increase the volume of dialogue relative to background music and effects, creating a more comfortable and accessible viewing experience that cannot be found on any other global streaming service.

https://www.aboutamazon.com/news/entertainment/prime-video-dialogue-boost

Communicate Better – Your Health May Depend on it!



HLAA's Communication Access Plan (excerpted from hearingloss.org well https://www.hearingloss.org/hearing-help/communities/patients/



Patients must be able to communicate with their doctors, nurses, and other members of their health care team. Providers must communicate clearly with their patients so they can diagnose, care for, and treat them in the best and safest way possible. However, communication between patients and providers is not always effective. To help remedy the situation, it is strongly recommended that patients and providers use the Communication Access Plan (CAP) and include it in the patient's medical record.

A Communication Access Plan (CAP) is a one-page form that will document a patient's hearing status and communication needs. A completed CAP can help ensure that patients and providers communicate effectively using the appropriate aids and services

We want your feedback

Please share your experiences using the CAP with us by emailing HealthcareAccess1@gmail.com.

Hearing Loss Basics video chat

DHHSD video chat for Social workers, Health care workers, nurses and other service providers

One out of five Minnesotans has a hearing loss. If you provide social services, health care or other direct services you are likely to work with someone who has a hearing loss at some point.

Join this webinar to learn how to better serve your clients and patients with hearing loss.

When: Thursday, June 8, 2023, 9 to 11:30 a.m.

Where: Zoom, link will be sent out when you register.

Download a printable flyer.

Register through our <u>online registration form</u>. Registration is free. Register by June 1, 2023.

Email: dhs.dhhsd@state.mn.us
Web: mn.gov/deaf-hard-of-hearing

MIT spinout Frequency Therapeutics' drug candidate Stimulates the growth of hair cells in the inner ear

The biotechnology company Frequency Therapeutics is seeking to reverse hearing loss — not with hearing aids or implants, but with a new kind of regenerative therapy. The company uses small molecules to program progenitor cells, a descendant of stem cells in the inner ear, to create the tiny hair cells that allow us to hear...

In 2012, the research team was able to use small molecules to turn progenitor cells into thousands of hair cells in the lab. Karp says no one had ever produced such a large number of hair cells before. He still remembers looking at the results while visiting his family, including his father, who wears a hearing aid.

"I looked at them and said, 'I think we have a breakthrough," Karp says. "That's the first and only time I've used that phrase."...

Frequency's founders have been thrilled to watch their lab work mature into an impactful drug candidate in clinical trials.

"Some of these people [in the trials] couldn't hear for 30 years, and for the first time they said they could go into a crowded restaurant and hear what their children were saying," Langer says...

"I wouldn't be surprised if in 10 or 15 years, because of the resources being put into this space and the incredible science being done, we can get to the point where [reversing hearing loss] would be similar to Lasik surgery, where you're in and out in an hour or two and you can completely restore your vision," Karp says. "I think we'll see the same thing for hearing loss."

Read the full story here:

https://news.mit.edu/2022/frequency-therapeutics-hearing-regeneration-0329

Note from the treasurer:

After much deliberation, in response to financial pressures, the HLAATC board of directors has voted to increase membership dues. Starting with the fiscal year beginning September 1, 2023, annual dues will be:

Individual membership: \$25 Professional membership: \$50

HLAATC is committed to inclusivity, and to retaining all our members. Contact the treasurer, or acting treasurer, if this increase in dues would be a hardship or a barrier to your continued membership.

HLAA TC PO Box 26021 Minneapolis, MN 55426



Next meeting: May 20 on Zoom

First Class		
HLAA Twin Cities Chapter		
Name	Hearing Loss Association of Americ Twin Cities Chapte Welcomes You!	
Address	President – Robin Coninx president@hlaatc.org	
City	Vice President - Signe Dysken vicepresident@hlaatc.org	
StateZip	Secretary – Susan Arquette secretary@hlaatc.org	
Phone.(area code)	Treasurer – Robin Coninx <u>treasurer@hlaatc.org</u>	
E-Mail		
Newsletter via email included in all memberships	Directors at Large: Laura Hagemann social@hlaatc.org	
Individual \$25	Karla Sand	
Professional \$50	Contact Info info@hlaatc.org	
Supporting \$100	Newsletter Editor: Vicki Martin editor@hlaatc.org	
Newsletter only \$15		
Contact me for newspaper advertising	Photos – Vicki Martin	
Mail to: HLAA Twin Cities Chapter PO Box 26021 Minneapolis, MN 55426	Social Media - Laura Hagemann social@hlaatc.org	

The next meeting of the Hearing Loss Association of America Twin Cities Chapter (HLAA TC) will be held on Zoom May 20, 2023. Open to socialize at 9:30 AM, formal meeting 10 AM.

Register here: https://us06web.zoom.us/meeting/register

After registering, you will receive a confirmation email containing information about joining the meeting. Please visit the chapter's web-site at www.hlaatc.org or visit us on Facebook: groups/HLAA-TC.

Accommodations: All meetings are real time captioned by Lisa Richardson and her staff of Paradigm Captioning (www.paradigmreporting.com).