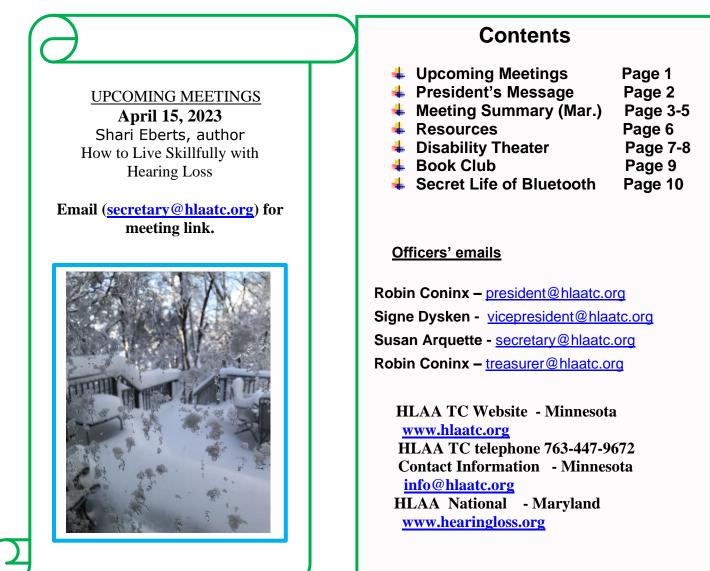




The mission of HLAA TC is to open the world of communication to people with hearing loss by providing information, education, support and advocacy.



The February Hearing Loss Association of America Twin Cities Chapter meeting (HLAA TC) will be a Zoom meeting on March 18, 2023 Email the secretary (secretary@hlaatc.org) for meeting information and link. President's Message HLAA-TC President's Message – April 2023 Robin Coninx



April has arrived with gusto, all that snow that fell between late Friday night and Saturday morning, while predicted, still caught me off guard.

As I write this, I wonder how all in our Hard of Hearing Community are doing, hopefully spring arriving has given you the opportunity to get outside more...vitamin D from the sun is a very important part to daily life.

I would like to call attention to another wonderful speaker, who is the author of '**Hear & Beyond'** Live Skillfully with Hearing Loss' <u>Shari Eberts and Gael Hannan</u>. On April 15, 2023, Shari will be the Guest Speaker for HLAATC Chapter meeting, social time begins at 9:30 a.m. with Shari beginning her presentation at 10 a.m.

We would also like to offer you her book. HLAATC has a limited supply of 'Hear & Beyond'. Please reach out to me at: <u>president@hlaatc.org</u> for your copy. Purchase price is \$18.00 a copy plus delivery charge that will be figured out if it is hand delivered or mailed. Please support Shari today with a purchase of her book. (HLAATC does not receive any financial benefit from the sale of these books.)

On another front, the HLAATC board continues to work with the Minnesota Commission of Deaf, DeafBlind and Hard of Hearing Minnesotans, communicating the needs of HOH individuals that use listening and spoken language as a means of communication. Please let your HLAATC Board know your thoughts and concerns, the goal is so that you can live a full and productive life while having hearing loss and access to all information and communication, whether it be in your personal or public life.

Best to you all!!

Byrdie Coninx – President of HLAATC

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

Signe introduced the speaker, Dr. Jon Taylor, who gave his presentation from New York City. Jon has been very active in the NYC chapter of HLAA for many years and served as President for two years. He is on the Board of Directors of the NY State Association of HLAA.

Jon's educational accomplishments include advanced degrees in developmental psychology. His career for many years, however, was as a musician. As a professional trombonist, he performed and recorded with the Brooklyn Philharmonic, Paul Taylor Dance Company, NY Philharmonic, Orpheus Chamber Ensemble, and Empire Brass Quintet. His career also included performances with more than twenty Broadway shows and numerous ballet and opera companies.

Jon began by saying that many people ask him if his hearing loss is due to his profession as a trombonist. He believes the cause is both the loud music he was exposed to during his career as well as an inherited vulnerability to loud music. He got his first hearing aids in 1991 when his hearing loss was mild. He wore his hearing aids in private so as not to risk losing work if it became known that he had a hearing loss. By 1996, it was becoming difficult to play in ensembles, as he wasn't clear about whether he was in tune with the orchestra. He lost confidence in his ability to play on pitch and increasingly found playing in ensembles to be stressful. He did not want to compromise the quality of professional performances, nor tarnish his career by poor performances in important venues such as Carnegie Hall. In 1997, he decided to retire from his performing career and publicly acknowledge his hearing loss. Retiring from his career in music meant a loss of income as well as a loss of identity as a professional musician. He was able to pursue other occupations, including orchestra management, but after 2008, he rarely picked up his instrument. In 2019, his hearing loss was considered severe to profound, and his audiologist recommended cochlear implants. After consulting with others, he decided to have an implant, which was done in March, 2021. His hearing improved gradually but impressively over subsequent months.

Three months after activation of his CI, he received an announcement for band camp at the Interlochen Michigan Arts Center. He had previously attended the "National Music Camp" at Interlochen for four summers during high school. The allure of going back motivated him to sign up and practice his instrument daily for the three weeks before camp. He knew that band camp would involve four hours of daily practice, but his strenuous preparation had improved his stamina sufficiently. He chose to bring his euphonium, his favorite brass instrument, because keys on the euphonium make playing on pitch easier than it is with a trombone, which is a "slide instrument." At band camp, he did not hide his hearing loss. During practices, he did not know idea if he was playing in tune, and had trouble hearing the conductor, but was pleased to find that he did not feel competitive with the other musicians. He enjoyed the visceral sensation of producing beautiful sounds once again and he enjoyed the band's camaraderie. The following year at band camp, it was announced that the conductor would be using a microphone when addressing the band, and the loud applause that erupted from band members told him that he was not the only one with hearing loss.

(meeting summary, cont.)

Jon's hearing today has improved from a baseline measure of sentence repetition before implant surgery at 62% to an astonishing 97% when last tested. He also has found over time that his ability to enjoy music has improved steadily. His brain seems to have relearned to distinguish the harmonics of the sound patterns of birds, oboes, trumpets etc. He recommended the book "Of Sound Mind" by the neuroscientist Nina Kraus, which provides explains how the brain processes hearing. His experiences lead him to believe that the limits on pitch perception with a CI are not as rigid as he had previously thought. He now can separate out different instruments in an orchestra performance and is able to enjoy live performances. He thinks that various factors have contributed to these improvements – including exposure to speech and sounds, auditory training and practice including *Angel Sound*, listening to podcasts, practicing his instrument, and playing in an ensemble. The advice of professional musician friends and his own experiences and learning have been helpful in resetting his expectations and not giving up on his ability to play music. Jon provided a video of his playing Auld Lang Syne on his euphonium.

Jon then talked about the New York City HLAA chapter. In 2016, he joined HLAA at the suggestion of his audiologist. He found that HLAA guickly became an important part of his life. He appreciated going to meetings where everyone faced the same challenges and where there was captioning and a loop system. He was asked to be vice president, and in 2020 he succeeded Katherine Bouton as president. During the pandemic, meetings became virtual – a mixed blessing but also an advantage in that through Zoom, the chapter has been able to draw upon speakers from a much larger pool. In addition, since meetings are taped and placed on YouTube, there is a wider audience of listeners, including those from around the country and on occasion from around the globe. There have been 80 to 90 people at their meetings with a high of 125. One of the reasons for this large attendance is extensive publicizing of meetings – including stories in an online New York magazine, emails to ENT's and audiologists, and an eblast to a mailing list of about 800 people prior to meetings. All meetings are captioned and recorded for subsequent viewings on YouTube. Links to these meetings can be found on the chapter website <u>hearinglossnyc.org</u>. The chapter hopes to soon move to hybrid meetings.

Jon emphasized the importance of self-advocacy as well as public advocacy by those who are able. The NYC chapter successfully lobbied for Lincoln Center administrators to install a hearing loop during its major music hall renovation. The chapter and many individual board members also have contributed to open captioning of a Broadway show. The chapter also was part of a lobbying effort that successfully got the city council to pass legislation requiring movie theaters to open caption 25% of their screenings of most films every week. An initiative to require NYC to get auditory screening into schools is underway.

Despite the above successes, challenges remain. A lot of money is raised by participation in the Walk4Hearing, but the bulk of contributions come from board members and their friends and relatives. Furthermore, almost all the work of the chapter is done by the board – there is a need to involve the membership in chapter projects. In addition, the chapter needs to improve diversity on the board and in the membership, both with respect to ethnicity and age. Younger members are needed to succeed current board members and to facilitate use of social media.

(meeting summary, cont.)

Questions and Comments:

- 1. A participant asked about the likelihood that he might be able to regain the ability to play the trombone and to sing. Jon replied that a euphonium is a good substitute for the trombone because it is a keyed instrument. Singing is difficult but not necessarily impossible. He referred to the December 2022 presentation that featured a singer with implants.
- 2. A participant commented on the exhaustion of trying to hear all day, and how an implant had reduced her stress and improved energy.
- 3. A participant recommended the App Meludia for rehab.
- 4. A participant commented on her background of singing and perfect pitch and subsequent loss of confidence in being able to sing. She now feels encouraged to try singing again.
- 5. A participant asked about Beethoven's ability to compose fantastic music despite ever-worsening hearing loss. Jon's comment was that Beethoven was one of a kind, with his unique ability to hear complex music in his head. A NYC chapter speaker in December, 2021 (Gabriella Lena Frank, a composer) spoke about Beethoven's composing despite his hearing loss.
- 6. A participant asked how to get back into hearing music despite hearing loss. Jon recommended listening to simpler music for example a quartet, or a folk singer with a guitar.

Jon provided his email address: <u>jontaylor5819@gmail.com</u> to answer further questions, and he thanked HLAA-TC for inviting him to speak.

Business meeting:

- 1. Discussion of where to focus energies in the coming year or two. One possibility is to plan an October convention for 2024, a tradition prior to the pandemic. Other possibilities include focusing on increasing the membership and working on setting up hybrid meetings.
- Monique discussed good progress in working toward more looping. Five more sites will be installing loop systems. The airport is making progress in installing loops in Terminal 1, where loops are now available on the main floor and in the baggage area. Terminal 2 might install loops under its new carpeting. See the website <u>loopminnesota.org</u>.

3. Some speakers for next year's meetings have already been lined up, but suggestions are welcome.

Following further discussion of possible plans for next year, the meeting was adjourned at noon.

Links from the Chat will be listed by Laura in the article below, and on the HLAA-TC website.

Laura noted that the speaker's presentation is recorded, but not the questions and answers. The speaker's presentation is available on YouTube (see link on page 6 of this newsletter) and through the HLAA-TC website.

Resources and links shared at March 18th Meeting By Laura Hagemann

Thank you to those who joined us for another virtual/Zoom meeting on Saturday, March 18th and thank you to our speaker. Jonathan Taylor spoke to us about music and hearing loss. Jonathan performed as a trombonist but after his hearing loss progressed Jonathan retired as a musician and has been active in <u>his</u> local HLAA- New York City Chapter (where he now serves as Vice President).

We decided to record Jonathan's presentation and offer it as our first chapter meeting presentation on our HLAA-TC YouTube channel. You can watch the video here: <u>https://youtu.be/_Am0hbh8c1o</u> The video will also be on our website.

During and after the presentation there was a lot of information being shared in the chat. For a comprehensive list of those resources, see below:

Links Shared During Presentation:

- <u>http://angelsound.tigerspeech.com/</u>
- Wendy Cheng's Association of Adult Musicians on Facebook: <u>https://www.facebook.com/aamhl</u>
- A live theater captioning app mentioned by Jon, Gala Pro: <u>https://www.galapro.com/</u>
- The President of Jon's HLAA-NYC chapter is Katherine Bouton, you can view her blog, here: <u>http://katherinebouton.com/about/</u>
- Katherine Bouton is also an author and has written several books about her experience with hearing loss (and appeared at our book club). Her books can be found here: <u>on her Amazon page</u>
- <u>https://www.hearinglossnyc.org/</u>
- HLAA-NYC Upcoming Meetings: <u>https://www.hearinglossnyc.org/meetings-topics</u>

Links Shared After Presentation:

- Loop Minnesota is the organization Ross and Monique Hammond run: https://www.loopminnesota.org/
- Zoom TroublesShooting and saving Zoom Chats How-to: <u>https://support.zoom.us/hc/en-us/articles/115004792763-Saving-In-Meeting-Chat#h_7c38bc86-66ca-483f-8fee-2d508da8418e</u>
- University of Minnesota, Speech, Language and Hearing Sciences Labs: <u>https://cla.umn.edu/slhs/research/centers-labs</u>
 University of Minnesota, Listen Labs as run by Dr. Matthew Winn (a previous HLAA-TC speaker): <u>http://www.mattwinn.com/Research.html</u>
- "Listening Effort" as researched by Dr. Matthew Winn: <u>Research.html#effort</u>
- Hidden Disabilities Sunflower Program at MSP Airport: <u>airport/accessibility/hidden-disabilities-</u>
- TSA Passenger Support: <u>https://www.tsa.gov/travel/passenger-support</u>
- Request for TSA Cares Assistance: <u>https://www.tsa.gov/contact-center/form/cares</u>
- Tip for iPhone Users: Did you know that if you have an iPhone 11 or newer that you can update your Operating System to iOS 16 and enjoy the incredible feature of Live Captions? It also works on iPads too. Not only can you caption online videos but you can also caption FaceTime calls and in-person conversations. (Or other videos that go to your phone such as video doorbell feeds, etc.). This article has a good overview of the features and how to use them in different settings: <u>how-to-use-live-captions-audio-video</u>

Disability in Theatre: A Performance By Laura Hagemann



On Saturday, April 1st, <u>Mixed Blood Theatre Company</u> of Minneapolis put on the first performance in their series called " 12×12 ." This series is 12 artists collaborating with 12 different neighborhoods throughout the Minneapolis/St. Paul Metro to create performances that represent the neighborhoods and its people.

The "12x12" series culminates with a celebration where all 12 groups get together to perform at Mixed Blood Theatre in August. Starting with the performance on April 1st there will be a new 12x12 performance every two weeks until August.

The performance on April 1st took place at Powderhorn Recreation Center and featured performers with disabilities talking about their experiences living with disabilities. Why focus one of the twelve neighborhoods on disability? From the 12x12 website: "[this performance is] A collaboration with and about folks with varying disabilities from across the Metro Area, it is estimated that at least 12% of the state's population experience disability. 32 years after the passage of the Americans with Disabilities Act, this community immerses itself in the values of the Disability Rights and Disability Justice movements—embracing the rallying cry of, "Nothing About Us Without Us."

(Disability theater, cont.)

Our own HLAA-TC Director-At-Large and Social Media Specialist, Laura Hagemann, participated as one of the performers.

Laura's experience:

"I am not an actor or performer by any stretch of the imagination. So why did I participate in this? I wanted the experience of telling my story about disability so I get better at being an engaging storyteller. I want to be an engaging storyteller because I am actively writing my memoir. I would have never done something like this before my severe Traumatic Brain Injury because I was shy, nervous and anxious. After the TBI I am none of those things. It's an amazing change that I am taking full advantage of by participating in things pre-TBI Laura never would have done. The other performers were like me and not actors. Over the course of several weeks we met primarily via Zoom to create this 15-20 minute performance. The group was led by Alison Bergblom Johnson who is an artist and is also disabled. She recruited members of the disability community online (primarily) and helped us create this piece that answered the question: What is our NOW? We ended up structuring it like a day and the performers worked in pairs standing on either side of a mirror. We mimed daily activities (brushing teeth, talking to pets) while talking outloud to ourselves in the mirror talking about our experiences with disability. Each person had a different disability (although there was another woman with a brain injury as well). I spoke specifically about my Traumatic Brain Injury and how it has resulted in hearing loss. I hope that by sharing my story that I drew attention to the issues of brain injury and hearing loss."-Laura Hagemann

To learn more about the 12x12 series and reserve tickets for upcoming shows (you can attend either in person or virtually), visit this website: <u>https://mixedblood.com/12-x-12/</u>

12 x 12 Performance Schedule:

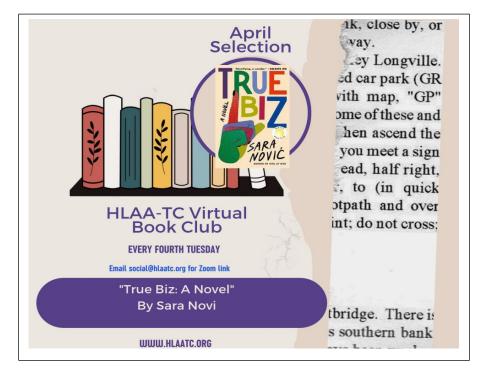
- April 1st Disability x Alison Bergblom Johnson) in Powderhorn
- April 15th Subversive Sirens (Synchronized Swimmers) in Phillips
- April 29th Rachel Noon x Maplewood Maplewood Mall
- May 6th Ernest Briggs x Westside
- May 20th Reinaldo Moya x Northeast
- June 11th Yia Vang x Brooklyn Center
- TBD Hawona Sullivan Janzen x Rondo
- June 24th Trans/non-binary (performed in Loring Park x Bryce Burton
- July 1st Katie Ka Vang x Little Mekong
- July 29th Joe Davis x North Minneapolis
- August 5th Cedar-Riverside x Ifrah Mansour
- August 18th Brownbody x Woodbury
- August 19th and 20th All 12 Groups at Mixed Blood

Note: The Disability performance was recorded and we are waiting to learn if and how people will be able to access it to view on-demand.

April Book Club

By Laura Hagemann

After meeting in March to discuss the memoir <u>"Chasing Space: an astronaut's story of grit, grace and second chances</u>" by Leland Melvin, the HLAA-TC Book Club will be reading a novel for April: <u>"True Biz" by Sara Novic.</u>



A brief description of the novel from <u>Amazon</u>: "True biz (adj./exclamation; American Sign Language): really, seriously, definitely, real-talk

True biz? The students at the River Valley School for the Deaf just want to hook up, pass their history finals, and have politicians, doctors, and their parents stop telling them what to do with their bodies. This revelatory novel plunges readers into the halls of a residential school for the deaf, where they'll meet Charlie, a rebellious transfer student who's never met another deaf person before; Austin, the school's golden boy, whose world is rocked when his baby sister is born hearing; and February, the hearing headmistress, a CODA (child of deaf adult(s)) who is fighting to keep her school open and her marriage intact, but might not be able to do both. As a series of crises both personal and political threaten to unravel each of them, Charlie, Austin, and February find their lives inextricable from one another—and changed forever.

This is a story of sign language and lip-reading, disability and civil rights, isolation and injustice, first love and loss, and, above all, great persistence, daring, and joy. Absorbing and assured, idiosyncratic and relatable, this is an unforgettable journey into the Deaf community and a universal celebration of human connection."

April Book Club will meet on Zoom to discuss this book on Tuesday, April 25th at 7:00 pm (Central Time). All book clubs are FREE and open to anyone and captioned (using computer/AI captions). To request a Zoom meeting link, email <u>social@hlaatc.org</u>



A whole community of bluetooth devices surrounds me. They talk conspiratorially to each other behind my back. I know they do this, but I'm not sure they know I know. The main players in this deceit are:

PClip (Phone Clip) IPhon (i-phone) Landy (Landline phone) Sony (smart TV) Minnie (Mini-mic)

The Phone clip started it, but the others were all too willing to go along. They're all in on it. I go from one to another looking for consistent behavior, but I can't find it. In the middle of the night when I awaken and can't go back to sleep, their plotting can be heard on the edge of consciousness:

PClip: C'mon, guys, let's get Vicki totally confounded!

I-Phon: She already is. Did you hear all the questions she was asking about Minnie Mic? PClip: I did - but she got the answers. Minnie was just a pushover once Vicki got working instructions. No fun at all! Sony, do you have any idea how we can make these evenings more exciting?

Sony: No, not with Minnie here. She comes in every night at 10 sharp and sits right there in front of me like Vicki's obedient puppet.

Landy: Party Pooper!

I-Phon: Yeah, we can do better.

Landy: I've got an idea – let's play hide and seek! PClip, you can hide and I'll seek. I'll look for you high and low, everywhere. Then I'll find Sony - but I won't find you!

PClip: Good one! She won't know what to do next.

I-Phon: Haha. She'll think she's going nuts:

Landy: She will be, before we're done with her. I-Phon, why don't you pretend you are looking for her processor – but don't actually find it.

I-Phon: Cool! - I can just twiddle my thumbs when she searches for BT connections. And I'll pretend I can't see her processor until she completely shuts her phone down a couple of times.

PClip: I like that. And I can pretend to be my evil twin who died two months ago – now he's back but unknowable, like the ghost in the machine. I-Phon, why don't you interrupt a few calls too, just to put her on the wrong track.

IPhon: Oh I don't know, PClip. That's getting pretty mean.

PClip: Oh, come on. Just a couple.

IPhon: Well, OK. I see her computer is working again, so she could always do email. Landy: Hey, she's doing that right now, reporting on us to Cochlear!

PClip: Uh-oh, I hope she doesn't send me back. IPhon: Don't worry, PClip, she loves you. PClip: I know, but I may have overdone the pranks this time. Oh, here she comes. Oh, no! No, no please! I'll be good, I promise. Sony: Poor PClip. She's putting him back in the box. Landy: Oh, dear. Do you think maybe she'll give him another chance...?

Afterword:

PC is indeed in his box, awaiting deportation. I still hold out a tiny ray of hope for him, but that is fading fast. I implore users, professionals, and qualified amateurs - if you know anyone capable of managing this rebellious little guy and his friends, please contact me. I'd love to have him stay – his potential is great – but I have to think of myself too. My frayed nerves are crying out for relief.

Vicki

Prevention What invisible disabilities are — and why they matter

LIZZ SCHUMER Updated March 23, 2023, 11:47 AM

"The CDC estimates that approximately <u>26 percent of the population lives with a</u> disability, including non-apparent and invisible ones. That's one in four people. And that prevalence matters, because the larger a group of people, the louder their voices and the more power they hold in society."

You can read the article here: https://www.prevention.com/health/a41248327/what-is-an-invisible-disability/

'Hear & Beyond' by Shari Ebert and Gael Hannan

is being offered for \$18 per copy through HLAA-TC. For your copy, contact president@hlaatc.org

You will be supporting today's speaker Shari Ebert (HLAATC does not receive any financial benefit from the sale of these books.)

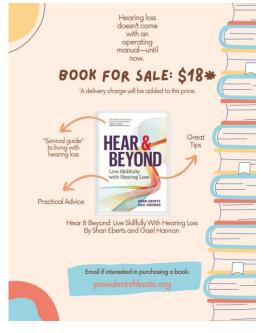
Reviewed on Goodreads:

"Hearing-health advocates, consultants, and speakers Shari Eberts and Gael Hannan offer a new skills-based approach to hearing loss that is centered not on hearing better, but on communicating better.

With honesty and humor, they share their own hearing loss journeys, and outline invaluable insights"

Read the whole review:

https://www.goodreads.com/book/show/61024453-hear-beyond



HLAA TC

PO Box 26021 Minneapolis, MN 55426



Next meeting: April 15 on Zoom

First Class

HLAA Twin Cities Chapter	HLAA
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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 <u>social@hlaatc.org</u> Karla Sand
Individual \$15 Professional \$50 Supporting \$100	Contact Info info@hlaatc.org Newsletter Editor: Vicki Martin editor@hlaatc.org
Newsletter only \$15 Contact me for newspaper advertising	Photos – Vicki Martin Social Media - Laura Hagemann <u>social@hlaatc.org</u>
Mail to: HLAA Twin Cities Chapter PO Box 26021 Minneapolis, MN 55426	

The next meeting of the Hearing Loss Association of America Twin Cities Chapter (HLAA TC) will be held on Zoom April 15, 2023. Open to socialize at 9:30 AM, formal meeting 10 AM. Email the secretary (secretary@hlaatc.org) for meeting information and link.

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).