

Newsletter

Hello from the Boston Chapter of HLAA

Submitted by Sue Schy

Welcome back to a new year (and what feels like a new era) for the Boston Chapter of the Hearing Loss Association of American (HLAA).

As Alexander Graham Bell enforced "oralism", coercing Deaf individuals to learn to speak and not use sign in public, COVID acted the same when it took away coping strategies such as facial views and lip reading with mask mandates, and added physical and emotional losses; giant dismissals such as "never mind" or "forget about it" made one feel not important enough to take part in conversation. It is definitely a breath of fresh air to be able to see full faces and "hear" our way again and perhaps we might dare say we are now post-COVID.

With this we hope for increased in-person participation and greater involvemen, we commit to you new vigor and spirit. We open with an invitation to our first event on September 9th and to fill you in on the recent 2023 HLAA Convention held in New Orleans.

UPCOMING EVENTS

Saturday, September 9th "Talk the Walk" Get-together

12N to 3PM at Cornerstone Cohousing: 175 Harvey Street in Cambridge, building 175 (we will meet behind the building, so turn left at the door)

An in-person social and a pep rally barbecue of sorts to gear us up for the New England Walk4Hearing which will happen on Sunday, October 1st at Artesani Park in Brighton. It'll be a chance to meet in person and spark interest and enthusiasm for the Walk. All food will be provided.

RSVP to <u>hearatboston@gmail.com</u>

October 1st, 9AM- 12N

New England Walk4Hearing

We hope for large participation numbers, whether you walk, volunteer, or raise money. WE NEED YOU!

The Walk is HLAA's biggest and only fundraiser, a 5K route around the Charles River to raise awareness about hearing loss, plus much of the proceeds go to the Boston Chapter, AND more importantly, it is a time to gather and see that you are not alone. Lots of food, vendors, and rallying, in addition to the optional walking. Please sign up to join the Boston Chapter Team at this link:

https://www.walk4hearing.org/site/TR/Teamraiser/NewEnglandWalk?pg=team&fr_id=2827 &team_id=55352

Or drop an email to let us know how you can help: hearatboston@gmail.com

HLAA CONVENTION 2023 RECAP

Despite the heat and humidity, people from all over the United States and Canada gathered for the annual HLAA National Convention in New Orleans, LA (NOLA). Through meetings, keynote, workshops, presentations, and more, information was shared and learned, new and old friendships blossomed. For many, the environment of fully looped venue, captioning, and ASL interpretation made participation relaxed, everything accommodated for without asking and everyone just like you.

Entering her first Convention, Sue shared that she never realized how powerful it was to not feel alone, to be included and attended to without asking. "When I was growing up, hearing loss was just a part of who I was- good, bad, or indifferent, and the only ones I knew with hearing loss were my grandmother and an uncle; the moment I noted '(e)veryone was like me!, there were 500 or so of 'me'!, WOW!"

Highlights from Convention workshops

Keynote

from Sue and Liz

The keynote speaker, Dr. K Renee Horton, shifted from her dream of being an astronaut to engineering and physics after a late diagnosis of hearing loss serving in the U.S. Air Force, yet managed to find her way to NASA as a space launch engineer. She recently performed inflight accessibility experiments as one of 14 Ambassadors in the NASA program, AstroAccess and runs her own program for children with disabilities. That took advocacy and persistence! Her story was featured in the article "Mission Possible" in the Spring 2023 edition of <u>Hearing Life</u>, (check your HLAA membership if you are not getting this magazine as it is a free perk).

<u>Caution urged in interpreting reported "Link" between Alzheimer's and Hearing loss</u> Highlight from Kerry Sullivan

The HLAA featured a timely presentation by Dr. Jan Blustein, M.D., Ph.D., a faculty member of NYU's School of Health Policy and Medicine, where she has taught and conducted research centered on improving health services for older Americans for 25+years. Dr. Blustein described as "misleading" recent media reports alleging a link between hearing loss and Alzheimer's (Washington Post, NPR). She pointed out that the study quoted in the media examined only untreated hearing loss and found it to be one "Risk Factor" among many - not a causal link – to Alzheimer's. Dr. Blustein defined a "risk factor" as indicating the coexistence of an attribute or condition in a patient with Alzheimer's, not a root cause. To underscore her point Dr. Blustein noted that being unmarried and aged was also a risk factor for Alzheimer's but that this "condition" was not the fodder of media headlines. She expressed concern that a lack of understanding regarding the study results could restigmatize the hearing-impaired community as mentally deficient putting it at risk of further discrimination in society and the health insurance /long-term care market. Dr. Blustein stated that the study results are "unsettled science" and that research into Alzheimer's is at such an early stage that almost all things about it are not yet fully understood. Dr. Blustein closed her session at the conference highlighting what IS proven science: that improved hearing can help you think better. She urged all attendees to do whatever possible to fully treat their hearing loss.

Read more about Dr. Bulstein's study and research at this link:

https://www.linkedin.com/search/results/content/?heroEntityKey=urn%3Ali%3Afsd_profile %3AACoAAAa1V-QBmFbM4i7sIeVM_-

ZOKRpzxy6Un9o&keywords=jan%20blustein%2C%20m.d.%2C%20ph.d.&mentionsMember= %5B%22ACoAAAa1V-QBmFbM4i7sIeVM_-ZOKRpzxy6Un9o%22%5D&position=0&sear

Diversity and Inclusion

from Liz

I am happy to report attending two new workshops focusing on the African American community, and the Spanish language and culture respectively. This year, not only were workshops geared for these populations, but led by people representing said populations. Roxana Rotundo and Holly Cohen led the Stigma of Hearing Loss (El Estigma en la Perdida Auditiva) in Spanish and English, and participants were able to share their stories in their native tongue. Culture and language can sometimes compound getting help with hearing loss and it is exciting to hear this and see so many taking action.

Women of color professionals, Dr. Latisha Porter-Vaughn, Valecia Adams, and Dr. Marla Duran, and Dr. Carla Smiley led a workshop to explore the challenges faced by African American women, also referred to as BIPOC, as an often-under-represented group. Cultural values, socioeconomic barriers, and racism largely impact access to hearing loss treatment, and add to stigma.

The topic of stigma was prominent throughout the weekend, including ideas that people with hearing loss are not smart, are rude, or are more likely to suffer cognitive dementia. The positive take away is that we know these are myths and we can find ways to stand up for the truth, advocate for ourselves, and not fear false information.

Loops, Bluetooth and Auracast

From Liz and Carol

Liz attended the Annual Meeting for Get In the Hearing Loop (GITHL) with a panel of professionals including Juliette Sterkins, AuD., Chuck Sabin of Auracast, and other representatives. As the future of technology and communication expands, people with hearing loss are pulled into the advancement of products, changes in systems, and are an integral part of it. This panel and meeting brought up challenges about shifting the use of T-coil, using looped venues, integrating Bluetooth, and in the next few years, a new product, Auracast. Concerns included the compatibility of systems, how to hold on to older systems, and continue to voice for the inclusion and importance of T-coils in all hearing devices, and voicing our concerns when the world wants to shift to newer technology systems.

Carol adds a consumer point of view regarding the existing t-coils and looping. Many audiologists (and some of the panel above) say there is no point in getting a telecoil because few places are looped. They are ignoring the real value of the telecoil. It is true that few venues in New England are looped, but looped rooms are only one way to use telecoils.

Telecoils are not becoming obsolete. Looped places may be hard to find, but assistive listening devices (ALDs) are common. Most venues have ALDs because providing them is the least expensive way to comply with ADA accommodation requirements. And ALDs work best with telecoils.

All you need is a neck loop instead of headphones or earbuds. In case neck loops aren't provided it's easy enough to carry your own. You simply plug one end of the neck loop into the ALD, put the loop around your neck, and turn on your telecoil. The sound goes into your hearing aids instead of into your unaided ears. That's the most comfortable way to use an ALD, and the way to get the best sound.

Don't listen to the "experts" who seem to think room loops are the only reason for telecoils. It's the neck loop that makes the telecoil useful.

There was so much more-

Wonderful researchers and audiologists reaching out to professional musicians, and progress made from not wearing any protection to new advanced and decorated ear plugs (brought on by Michael Santucci, Au.D)! So many people are breaking barriers of hearing loss to pursue careers with music, space, education, and the perseverance and progress shines through.

And of Course, NOLA was great

The weather was hot, but people and music abounded. A taste of culture was given through beignets, Cajun spices and jambalaya flavors appeared in pasta, crab cakes, sausage, Po' Boys and more.



STAY IN TOUCH

Please visit us at the HLAA Boston website to learn more and sign up to join us at upcoming events: www.Hearatboston.org

You can also email the Board members at <u>hearatboston@gmail.org</u> to RSVP to events, ask questions, or be in touch.

SEE YOU SOON.