



East Bay Chapter:Newsletter September 2025

Here comes the sun!

Chapter E-mail: Info@HearingLossEB.org

Chapter Address: PO Box 2266,
Alameda, CA 94501

- **SEPTEMBER MEETING: September 13: Dr. Gabriel Liboiron-Cohen** from the Berkeley Hearing Center will be presenting in person about **Hearing Loss and Music**.
 - Dr. Liboiron-Cohen holds a Doctor of Audiology degree from the University of the Pacific and a master's degree in Operatic Studies from the San Francisco Conservatory of Music (2014). Combining his background in music and expertise in Audiology, he is dedicated to helping his patients enhance their quality of life and enjoyment in all things.

Saturday, September 13, 2025

- **9:30 a.m.: Social and Refreshments**
- **10:00 a.m.: Presentation (Zoomers can join at 10 am)**
- **11:30 a.m.: Complimentary Pizza**

**Location: Kaiser Permanente, Fabiola Building,
3801 Howe St, Basement Room G-26,
Oakland, CA.**

FREE PARKING is available across the street at the Kaiser parking structure.

Please come to the in-person meeting to meet the speaker, meet others who have hearing loss and enjoy complementary refreshments.

The meeting is available both In-Person and Virtual (Zoom).

Please register at: www.HearingLossEB.org by 5 PM, Friday, Sept. 12, 2025

Questions? Info@HearingLossEB.org

HLAA-EB posts our newsletters to the California State Association webpage and a link on our website. **VOLUNTEER! Contact us to let us know you are available!** Check out our website at: [http://www.HearingLossEB.org/](http://www.HearingLossEB.org) Contact us at: Info@HearingLossEB.org

Coming Soon:

- October – Tom Pritskey from Captify.com re: Captioning glasses.
- November: Courtney Austin @ UCSF, Emotional effects of hearing loss and coping with hearing loss in adults.
- December: Dr. Susanah Storm, Blue Sky Hearing – What’s new with hearing loss
- January, 2025: Brooke Barry, @ UCSF, Spotify research group — Sound and music perception

NOTE: If you have old hearing aids you no longer use, you may donate them. Drop them off at a meeting and we will make sure your hearing aids get new life for someone else. Also, bring any hearing assistive technology items you no longer use that you may have (such as a Roger Pen or??) to a meeting to see if anyone at the meeting can use them.

This month we are sharing a report from Jane Neilson who attended the June HLAA Convention in Indianapolis, Indiana on June 11-14, 2025.

REPORT ON: *Stigma and Its Impact, A Research Focus at the 2025 Hearing Loss Association of America Convention*

by Jane Neilson

Thanks to sponsorship from the East Bay Chapter, I attended my first HLAA national convention June 11-14 in Indianapolis. The research symposium, entitled “**Stigma: Making the Invisible Actionable,**” was my favorite session. The 5 panelists* addressed a quandary. Many people with hearing loss wait 7 years or longer to seek treatment or never get treated it all. The researchers wanted to understand why. What role does stigma play in this dynamic and is the public’s perception of hearing loss improving over time?

The presenters were hearing loss experts from public health, medical school faculties and impacted community. One specialist previously headed stigma research in HIV. I am sharing what I learned because stigma can play a big role in determining health outcomes. I summarize content but include an abundance of quotes from patient studies because they colorfully illustrate the issue’s importance.

What is hearing loss stigma? Hearing loss stigma is the negative or unfair beliefs about hearing loss (or hearing devices) that make people view it as abnormal and undesirable.



Why focus on hearing loss stigma in health care? Stigma is a barrier across the hearing care pathway. It can affect whether or not a person perceives the need for care, desires care, actively searches for services, has access to appropriate and thorough health assessments, is included in healthcare decision-making and experiences inappropriate assumptions about their cognitive status.

How does someone with hearing loss experience stigma? A person with hearing loss may experience a sense of stigma in different degrees or stages:

- **Anticipated:** You may have a fear of stigma, whether it is actually experienced. E.g., You are afraid of being viewed as older than you are or weak when you wear your hearing device.
- **Internalized:** The stigma may be self-directed. E.g., You feel a burden to others. You feel embarrassed or ashamed. You feel helpless, insecure, an outsider.
- **Perceived:** You may witness stigmatizing attitudes in the community or among groups (e.g. health care providers). If you see someone else with hearing loss being viewed as less intelligent, less capable, unfriendly or rude, you may fear being judged yourself or treated with impatience.
- **Experience:** You may have had real-life events of stigmatizing behavior. E.g., how often were you shown less respect, excluded from activities, teased or made fun of? How often does someone become frustrated with you? How often are others unwilling to communicate with you?

How does Stigma Impact the work of Healthcare Practitioners who are serving patients with hearing loss? Communication difficulties affect practitioners as well as patients. See examples below.

- **Compromised Symptom Assessment:** Practitioners noted that their symptom assessment often ended up being limited or not completed. E.g.,
 - “It’s difficult to assess symptoms accurately when the patient has a hearing loss.”
 - “I tend to not do a full symptom assessment when confronted with problems in communication.”
- **Misinterpretation of Cognitive Status:**
 - “A patient can be assumed disoriented if not answering questions correctly. It can be very difficult to assess a patient who cannot hear what you are asking them.”
 - “Prior to the erasable communication board, everyone on the team thought he was demented. He wasn’t.”
 - “An elderly man whom people assumed had dementia; he did not and felt very belittled.”
- **Left Out of Goals of Care Discussions:** Self-determination in decision-making can be compromised.
 - “Self-determination in decision-making can be more difficult. They may defer to their family as they can’t hear the options presented.”
 - “The patient could not hear well, and the caregiver spoke on his behalf despite attempts to communicate directly with the patient.”
 - “The patient was not able to participate in decision making . . . they thought he was confused and noncompliant.”

Examples of Patient Experiences Comments from patients highlight the need for integrating a concise screening and educational protocol on hearing loss into primary care settings.

- **Never Asked** {re. hearing} “Not that I recall...Because I never came in for any issues with my hearing and I didn’t get my hearing aid from {health system}. I’m thinking of my current person. Probably way back when, 10 years ago before I got a hearing aid, I’m sure we discussed it, because obviously somebody at the {X} Clinic referred me to the hearing department. But that, actually because I initiated it because I could tell I needed an aid for work so I have to say no...[and] I’m not bashful about saying could you please repeat that.”
- **No Accommodation** M: “I also, unfortunately, have ended up in ER a few times, because I have some coronary artery issues. I have a couple of stents. And I’ll tell them, you know, I’m deaf in the right ear and there’s not a whole lot of attention to it.”
 - “Even in ER?”
 - M: “yeah, even in ER, yeah”
- **Missing Information Without Knowing.** . . .”Do you routinely tell them you have difficulty hearing?”
 - M: “I do more now, because I need to hear what they say. I need to know what points they are trying to make, so yeah, it is past the point where, you know, just tolerating it, or letting it slip by, yeah, yeah.”
- **Barriers To Advocacy** –“So you always ask for clarification?”
 - P: “Yes. If I couldn’t hear, I did, yeah. I felt funny about it though. You know, you hate to say what did you say? But I did, because I needed to know.”
 - “Why did you feel sorry about saying that you needed to have them clarify what they were saying”
 - P: “Because, I guess, I didn’t want people to think I couldn’t hear. . . . It’s like there’s something the matter with you. What’s wrong with you? You can’t hear?”

How does self-advocacy affect outcome? Research reveals that patients with hearing loss realize the need for self-advocacy but also experience exhaustion because of it.

- “The constant self-advocacy can lead to burnout. I can begin to feel anxious again about telling people I am deaf or asking someone to communicate with me in a different way. I end up forgetting parts of my usual script, leading to further mop-up conversations in the future.”
- “Hearing people do need to be reminded. They start out well but soon forget that I need to see their lips. They speak clearly for the first few sentences, then taper off into a mumble. It is a perpetual internal battle between ‘am I making too big a deal of this?’ and ‘I deserve access. ‘ ”

What Needs to Happen Next? The mission of this session was to expose the impact of hearing loss stigma on healthcare. It was seen by the panel as a necessary first step to developing remedies. Among conclusions and necessary next steps noted were these:

- Stigma measurement is necessary to catalyze action and track change.
- Hearing assessment needs to be integrated into routine healthcare.
- Integration as a routine matter will advance understanding of the impact of hearing loss and help mitigate stigma.
- Settings with age-friendly initiatives provide a natural place to start making improvements.

- People with hearing loss still need to self-advocate in the healthcare environment but should not bear the full burden of having their needs met. Effort is needed by both the health care practitioners and the people with hearing loss to improve the experience.

Personal Action Steps Wrapping up the session with an invitation to transform stigma into strength was an inspiring nonmedical community leader. His journey has included feeling ashamed of needing hearing aids even when they help; withdrawing socially to avoid the struggle; fear of being seen as less capable or broken, and hiding hearing loss at work, school--even around family. Now he is a leadership and resilience coach, keynote speaker and advocate. He advocated:

- **5 Steps to Overcome Stigma**

- **It Starts with You** Accept your hearing loss as part of who you are. Recognize that seeking help shows strength, not weakness.
- **Talk to Someone You Trust** Share your experiences. Practice explaining your needs in a comfortable setting.
- **Connect With A Community** Join hearing loss support groups such as HLAA. Learn from others who face similar challenges.
- **Advocate for Yourself & Your Own Story** Share your story to help others understand. Ask for what you need without feeling embarrassed.
- **Rise with Strength and Purpose** Use Your Experience to Help Others. Support others with hearing loss. Educate people about hearing loss when opportunities arise. Work toward positive change

He urged that stigma can be challenged and conquered and quoted Nelson Mandela who said, “It always seems impossible until it’s done.”

*The panel included Laura Nyblade, Ph.D., Margaret Wallhagen, Ph.D., Jessica West, Ph.D., and hearing advocate Ibrahim Dabo, moderated by Carrie Nieman, M.D. The symposium was supported in part by a grant from the National Institute on Deafness and Other Communication Disorders of the National Institutes of Health.

What did you do this summer? Trips? Beach? Visits with family? BBQs? Think about some things and you can share with your fellow HLAA-EBC members at the September 13 meeting while enjoying coffee, snacks or pizza. Looking forward to seeing you there!



WOULD YOU LIKE TO PARTICIPATE IN THIS RESEARCH STUDY?

Vocal Boost in Music Study

Music perception can be challenging for cochlear implant (CI) users, but what if we could make it better? Researchers in the Jiam Lab at the UCSF Department of Otolaryngology are passionate about improving this experience and invite you to participate in a new online study.

Our work explores a promising idea: that specific vocal enhancements in music could significantly enrich sound quality. By getting direct feedback from CI users, we hope to pinpoint what makes the biggest difference and help guide the development of the next generation of sound processing strategies for music. Your contribution is incredibly valuable to the future of this work!

We are seeking participants with the following details:

- ***Who: Adult cochlear implant users (18 years or older).***
- ***What: A 1-hour online study that involves listening to short music clips and providing feedback through a survey.***
- ***Where: From the comfort of your own home, using your own device.***

If you are interested in participating in this exciting research, please click the link below to begin. Your participation is voluntary and all of your responses will be kept confidential.

Link to survey: https://ucsf.co1.qualtrics.com/jfe/form/SV_6Shzoqlbjl3DvIY

For any questions, please contact Stephanie Younan at stephanie.younan@ucsf.edu or (818) 626 -6271

Stephanie Younan

M.D. Candidate UCSF | 2026

M.P.H. Columbia University | 2022

B.S. UCLA | 2020

We need your help! Can you volunteer? Contact us at: info@hearinglosseb.org

Here is a list of volunteer positions we are seeking to fill:

- **Zoom Assistant** - Assist George Chin, Sr. to run Zoom, cameras, and PA/Audio Loop during in person/hybrid meetings.
- **Camera Operator** - Use a remote control to operate our 2 cameras for in-person Zoom meetings.
- **Volunteer Coordinator**: Contact people who said they could volunteer and tell them about volunteer needs. Recruit for those positions.
- **Outreach Coordinator**: Organize a table for our chapter at various street fairs and other venues. Set up the table. Recruit volunteers to help with the events. Reach out to people who participate in our meetings. Let people know about our chapter.
- **Just want to help?** All of our committees need helpers! All volunteers are welcome! Contact us and we'll help you figure out what would be a good fit for you.

HLAA SF/East Bay Leaders

NEW! The Steering Committee has become the Board of Directors:

Contact us at: info@hearinglosseb.org

President: Len Bridges

Vice President: Peter Townsend

Secretary: Linda Gee

Treasurer: Len Bridges

Director of Technology: George Chin, Sr.

Director of Membership: Connie Gee

Co-Director of Programs: Robin Miller

Co-Director of Programs: Verna Dow

Co-Director of Newsletters: Nancy Asmundson

Co-Director of Newsletters: Kathy Fairbanks

Director of Publicity: Marlene Muir

Director at Large: Jay Mumford

Consulting Legal Counsel: Gerald Niesar

Communication Access Realtime Translation (CART) services: Audrey Spinka,

JOIN HEARING LOSS ASSOCIATION OF AMERICA (HLAA) – THEY ADVOCATE FOR YOU!

hearingloss.org Membership is now open to all of our valued supporters who help fuel our mission and change the lives of people with hearing loss. **Everyone who gives is now an HLAA member, helping to amplify our HLAA voice, and fulfill our important mission— together!**

COST OF MEMBERSHIP: The HLAA national office had consolidated the donation and membership processes. Presently, anyone who donates as little as \$1 would become a member of the national HLAA. Additionally, with a donation of \$45 annually, individuals have the option to receive a hard copy of the Hearing Life magazine from the national office.