

# East Bay Chapter: Newsletter

**May 2024** 

Chapter E-mail: <u>info@hearinglosseb.org</u> Chapter Address: PO Box 2266, Alameda, CA

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DON'T FORGET TO RENEW YOUR MEMBERSHIP! Easy way: Go to <a href="www.hearinglosseb.org">www.hearinglosseb.org</a> and click on the "Donate" button to pay through Paypal. OR Mail a check to the address above. Only \$15/person!

<u>WALK FOR HEARING MONTH!</u> Join us on Sunday, May 19<sup>th</sup> at Robert Crown Beach in Alameda for our Bay Area Walk4Hearing! It's going to be fabulous! There will be booths, snacks, t-shirts, entertainment. Bring the whole family for this walk. After some announcements, the walk will begin. You can go 1 mile, 2 miles or 3 miles along the beautiful San Francisco Bay in Alameda. It's a refreshing way to start the day. Register now to jjoin our team (East Bay Chapter Team) and donate. Donations go to support the work of the National organization as well as our chapter. Make sure you check the box to have some money go to our chapter! We will be looking for you and we'd love to walk with you! See the flyer below. Do you need more information? Contact Connie Gee at <a href="mailto:cbgee2014@outlook.com">cbgee2014@outlook.com</a> or Linda Gee at linda.gee4@gmail.com.

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/ Contact us at: info@hearinglosseb.org

<u>Upcoming Meetings:</u> June: Claudia Marseille will talk about her memoir

July & August: Summer break! No meetings.

### 2024 HLAA CONVENTION NEWS- June 26 – 29, 2024

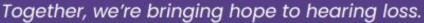
Are you interested in attending the HLAA Convention 2024? Registration is still open but sadly, the Early Bird registration has gone away. This year's Convention will be June 26 - 29 in Phoenix, Arizona at the Sheraton Grand in Wild Horse Pass. Much more convenient for us West Coasters! (The last few Conventions have been in East Coast or Southeast Coast cities.) This is a very nourishing event all about hearing loss. You won't be disappointed that you went!

Some of the events promised at the convention are: Hearing Aids and Cochlear Implants Can Improve Your Quality of Life; Why Is It So Hard to Treat Sensorineural Hearing Loss?; Cybersecurity and Hearing Loss; HLAA's Advocacy ABCs; Growing Up with Hearing Loss and Raising Kids with Hearing Loss; Finding Your Hearing Loss Community on Instagram; and many more... Go <a href="here">here</a> to see more information and to register. Or, hearingloss.org and click on Events and then Convention.

## JOIN US! SUNDAY, MAY 19, WALK4HEARING IS ON! **REGISTER NOW!**

OUR WALK4HEARING MANAGER: CONNIE GEE, cbgee2014@yahoo.com Join our team: HLAA East Bay Chapter Look for us at walk4hearing.org







# **Bay Area Walk4Hearing**

**Sunday May 19, 2024** 



8th Street, Otis Drive Alameda, CA

9:00 am - Registration 10:30 am - Stage presentation

10:45 am - Walk begins



Scan to Register today or visit walk4hearing.org

# MEETING NOTES: Panel Discussion: What's It Like to Have A Cochlear Implant"

At our April 13., 2024, HLAA-EB Chapter meeting, our panel discussion focused on "What's It Like to Have A Cochlear Implant". This meeting topic was a follow-up discussion of our "Cochlear Implants Informational" presentation in February by Audrey Staley, a Cochlear Implant Consumer Specialist for the Northwest Region of Advanced Bionics (AB), one of the three companies authorized to sell Cochlear Implants in the United States. At that time, Audrey gave an excellent presentation that included the basic information about Cochlear Implant candidacy, components of a Cochlear Implant, how the technology of Cochlear Implants works; and various tips and resources for hearing success.

Building on our prior CI Informational meeting a couple of months ago, our panel moderator Peter Townsend proceeded to introduce each of our 5 volunteer panelists and then invited each to give us a short 5–10 minute summary of their own hearing loss journey and experience with hearing loss and Cochlear Implants (CI's). Sticking with a tight timeline for the first half of the meeting allowed enough time for audience members to ask questions and also share their own personal experience with hearing loss and Cochlear Implants during the second half of the meeting.

Introduction of Panelists: Each of our 5 panelists gave a brief overview of their hearing loss and Cochlear Implant journey, as summarized below:

#### ✓ Sally Tannenbawm:

Initially, Sally told us that she has hearing aids (HA's), but not CI's. Nevertheless, she has worked in the hearing loss field, mostly with CI's, for 25 years, first at the House Hearing Institute and currently at Med-EI, one of three corporations approved by the FDA to sell CI's. Sally described how CI's had dramatically improved over the years and noted, in particular, how future CI's will likely include groundbreaking advancements that will transform the auditory technological landscape.

#### ✓ Joan Crighton:

Joan described how she was born with hearing but developed a mild hearing loss as a child. Her hearing continued to worsen so that by age 40, she had profound hearing loss. Then 10 years ago at age 72, she got bilateral Cl's so that she now has 90% hearing. Previously, Joan said that she often remained isolated from social events and relied heavily on family and friends for translation of speech. Since getting bilaterally connected with her Cl's, she has regained her independence and participates regularly in meetings and social events. She also described how she can now detect where sounds are coming from and feels safer and less fatigued in trying to hear what is being said. She noted that Medicare covered most of the costs of her Cl's, and her supplemental insurance covered the remaining costs.

#### ✓ Neil Khan:

Neil explained that he has had a lifelong hearing loss. When he moved to California in 1993, he started seeing an audiologist and an EMT and began wearing one hearing aid. Over time, he was told that his hearing was bad enough that he may qualify for a Cochlear Implant., which he did in 2001. Neil said that he knew other people with Cochlear Implants, so in 2002 he did not hesitate in getting Cochlear Implants in both ears and since then has had 5 different processors put in his Cl's. According to Neil, his experience with his Cochlear Implants over the last 22 years has been "fantastic". Meanwhile, he has

formed a CI support group, as well as continued to talk with others about how his CI's have turned around the quality of his life.

#### ✓ Ann Thomas:

Ann has previously served as a speaker for our EB Chapter, but this time, she was a panel member to talk about her journey to Cl's and how they have impacted her life. She noticed that she was losing her hearing in her late 40's, but when she went to have her hearing tested, she was shocked to discover that she had progressive hearing loss. She got two HA's and some assistive devices, such as an amplified phone, but her hearing continued to fail, so she was evaluated for Cochlear Implants. She was approved for CI's 4 different times before she got motivated enough to get a CI in one ear. She was so happy with the first CI in 2020 that within 5 months, she got a CI in her second ear. Ann confirmed in her own words that she now has "two fabulous CI's" from Advanced Bionics. Ann proceeded to describe some of her early episodes with her Cl's as she learned to adjust to the new sounds she was now hearing, such as "aliens talking" and her car blinker sounding like "an emergency car breakdown". Ann eventually had a talk with herself and decided to engage and welcome new sounds. Ann noted that her Cl's have helped her move from 0% to 30% to 90% speech recognition and acknowledged the "absolutely amazing" impact that CI's have had on her auditory life. In recent years, Ann has taken on many leadership roles in HLAA at the federal, state, and local levels, serving as HLAA-DV Chapter President, as well as speaker/presenter/panel member & support person on behalf of hearing loops, assistive HL devices and captioning.

#### ✓ Joan Adams:

Joan explained how she experienced sudden hearing loss 12 years ago, after which she tested at 0% understanding of words and sentences. She was then diagnosed as having profound hearing loss in the left ear and slight to moderate hearing loss in the right ear. She was implanted at UCSF with her Cochlear Implant in her left ear about 10 months ago, now has 2 processors, and has been learning to adjust to the new sounds she has been hearing since acquiring her CI. She described how initially the new sounds she was hearing "sounded like Mickey Mouse talking". As she learned to adjust to the new sounds, she had to plug her right ear so her brain could relearn sounds in her left ear. She has discovered that streaming new sounds into her left ear with her CI in place has helped her adjust to the new sounds she is hearing. She started with children's audiobooks and now also uses TV streaming and mini mics. After 10 months, she now has about 65% hearing with the expectation of getting to at least 90% hearing. She also feels good that she can now hear and understand other people talking, as well as detect sounds when she is out hiking or driving her car.

# > What We Learned about Hearing Loss (HL) & Cochlear Implants (Cl's) from Our Panel Discussion:

- Each individual's hearing loss journey varies as does their approach to improving their hearing.
- CI's may be a good choice for people experiencing deafness or profound hearing loss.
- ♣ Standards for CI eligibility have changed in recent years, allowing more people to qualify for CI's.
- ♣ Get your hearing tested & re-evaluated periodically as your hearing loss level & CI standards change.
- Consult with your healthcare providers & hearing professionals to determine if CIs are right for you.

- ♣ Do some research to compare different brands of Cls, as well as their expected future advancements.
- Check with Medicare & supplemental insurance plans to see if they will cover the costs of your CI's.
- ♣ Be patient with yourself through training, rehab, & practice as you adjust to your new CI's.
- ♣ Gain support from family, friends, professionals & HL groups in learning to navigate your new Cl's.
- Celebrate your CI successes as you gradually improve in recognizing new sounds, participate in more social events, develop better personal & work relationships, and enjoy your best hearing life.

#### ➤ Wrap-Up:

In wrapping up the panel discussion, our excellent moderator Peter Townsend thanked our 5 panelists, along with participating audience members, for sharing their individual experience and insights into "What's It Like to Have a Cochlear Implant" and providing useful tips for living your best life with Cochlear Implants.

Finally, HLAA-EB leadership team members reminded us that any hearing loss products, equipment, devices or brand names mentioned by speakers, panelists and/or audience members should not be considered promotion or endorsement of those items by the HLAA-EB Chapter. If anyone has questions or needs more information about hearing loss or Cochlear Implants, please contact guest speakers and panelists directly or email our EB Chapter at the contact information below.

For More Information and/or Questions: Email: info@hearinglosseb.org

~ Kathy Fairbanks

### May is Better Hearing Month



It's that time of year again! May is **Better Hearing Month**. We're sharing a range of hearing health content during the month on our dedicated page: <a href="https://hearingloss.org/better-hearing-month-2024">hearingloss.org/better-hearing-month-2024</a>

We're also reprising our **What Does #BetterHearing Mean to You?** social media challenge and would love your support to reach a wider audience.

**To Participate** — Simply follow these four steps, any time during the month of May:

- 1. Post a brief answer to "What does #BetterHearing mean to you?" on your own Facebook or Instagram profile
- 2. Use hashtags: #BetterHearing #BetterHearingMonth #HLAA
- 3. Tag HLAA IG: @hearinglossassociation or FB: @Hearing Loss Association of America (Official Page)
- 4. Include a great photo that shows you living life with better hearing

# 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.
- <u>Google Contacts Assistant</u>: Assist George Chin, Sr. to maintain our Google Contacts based email distribution information. Basic level Excel skills helpful.
- <u>Volunteer Coordinator</u>: Contact people who said they could volunteer and tell them about volunteer needs. Recruit for those positions.
- <u>Outreach Coordinator</u>: 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.
- **Program Team**: Work with Robin Miller to contact potential speakers and arrange for them to speak at one of our meetings.
- Just want to help? All of our committees need helpers! All volunteers are welcome!

### **HLAA SF/East Bay Leaders**

The chapter is run by a Steering Committee, Acting Leader: Len Bridges

Outreach, National Chapter Coordinator/Liaison: Linda Gee, linda.gee4@gmail.com

Treasurer: Len Bridges, <a href="mailto:lenbridges3993-hlaa@outlook.com">lenbridges3993-hlaa@outlook.com</a>

Programs: Robin Miller, robin@robinmillerlaw.com

Technology: George Chin, Sr., <a href="mailto:georgechinsr@gmail.com">georgechinsr@gmail.com</a>

Membership: Connie Gee, cbgee2014@yahoo.com; Marlene Muir, muircmc@comcast.net

Volunteer Coordinator: (need a volunteer)

Newsletter Editors: Nancy Asmundson, nasmundson@comcast.net; Kathy Fairbanks.

mkathyfairbanks@att.net

Publicity: Marlene Muir, muircmc@comcast.net; George Chin, Sr., georgechinsr@gmail.com

Technical/Audio Loop: Peter G. Townsend, peterg.townsend@gmail.com

Website updates: George Chin, Sr., georgechinsr@gmail.com; Peter G. Townsend,

peterg.townsend@gmail.com2

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

<u>hearingloss.org</u> 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.

Go to this URL to donate: Donate Today - Hearing Loss Association of America