

East Bay Chapter Newsletter May 2023

On May 13 our topic will be: World Institute on Disability's Accessibility and Universal Design Work

Kat Zigmont will give an overview of the history and current initiatives at the World Institute on Disability, also known as WID. WID, headquartered in Berkeley, California, was established in 1983 as one of the first global disability rights organizational think tanks, founded and continually led by people with disabilities. WID's current work falls under the following three areas: Time to Renew your membership in our local chapter for only \$15 a year! If you already renewed, Thank you! Ways to renew: pay at our website on the "Donate" button in the upper right-hand corner; mail your renewal with your name, address, phone number, and e-mail to: East Bay Chapter, HLAA, P.O. Box 12484, Oakland, CA 94604-2484. See the back page to sign up and support National HLAA.

- Disaster Risk Reduction, Humanitarian Action, and Climate Justice for Resilience and Sustainability;
- Policies, Systems, and Tools for Global Community Inclusion;
- Accessibility and Universal Design Solutions (AUDS)

Kat Zigmont is the Deputy Director, Senior Director of Operations, and leads the Accessibility and Universal Design Solutions (AUDS) division at WID.

In this presentation, we will focus on the work of the AUDS division, which centers on the lived experiences of people with disabilities and their use of Assistive Technologies in our research studies, including hearing-related technologies. **Presented Via Zoom, Greetings 9:30 a.m.**; **presentation 10:00 a.m.**

Register for this FREE event <u>HERE</u>. Or use this link if you are getting a hard copy of the newsletter: <u>https://www.hearinglosseb.org/monthly-meetings-1</u>. After you register, you'll be sent the link to join the meeting. Consider staying after the meeting for AfterWords – a chance to ask more in-depth questions, as well as discuss anything you want with fellow members!

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/



CONVENTION New Orleans, LA June 29 - July 1, 2023 HLAA2023 Convention will be in New Orleans, Louisiana!!! Meet other members from around the country and hear the latest info! Get all the information and register below.

Check out this flyer that describes the various events at the Convention:

HLAA 2023 Convention (hearingloss.org) Use Ctrl Left click to access.

MEETING NOTES: All about Cochlear Implants

At our April. 8, 2023 meeting, our guest speaker was advocate and author Richard Pocker, founder and producer of *Cochlear Implants Basics*. Unlike our previous speakers who have typically been licensed audiology professionals, Richard made no claims of expertise regarding the technical aspects of cochlear implants (CI's). Rather, he spoke from a personal CI recipient's point of view, emphasizing the emotional side of getting cochlear implants.



Richard Pocker's Personal Story: Richard told his story of hearing loss (HL) and what changed when he got Cl's.

At the very young age of 5, Richard got scarlet fever. From age 7 to age 30, he experienced progressive hearing loss for which he wore hearing aids (HA's). Then, suddenly at age 30, Richard lost all hearing and became deaf, so he relied on sign language for the next 35 years. In 2016 at age 65, Richard received bilateral cochlear implants, helping him to move from zero speech recognition to 85% after rehabilitation with his new CI's.

Richard's Mission: Since receiving bilateral cochlear implants seven years ago, Richard has made it his mission to tell his own story and that of other CI recipients and professionals in order to spread information about CI's in the hope that education will help others who can possibly benefit from CI's. He is attempting to accomplish his goal of getting hard-of-hearing and deaf individuals out of isolation by sharing information about how CI's work and how to access personal services, support and resources on CI's, through his website, Facebook site, and book that he has written on the basics of cochlear implants. Please see below for more details on these resources.

Cochlear Implant Components: Initially, Richard reminded us of how the major components of each CI work.

- An externally worn sound processor with a transmitting coil sends out coded electrical signals across the skin.
- The Internally Implanted electrode array in the cochlea picks up the signals by the inner ear's nerve fibers & are transmitted to the brain, where they are interpreted & heard as sound by the individual.

Podcast Interviews: Richard conducted 25 interviews with CI recipients and professionals, summarizing the results on his website and in his book. Here are a few examples of the podcast interview testimonials that Richard shared with us:

- ✓ Elena LaQuatra -- TV newscaster: "You don't look deaf. You don't sound deaf. You don't seem like you are deaf. I get that all the time."
- ✓ Mike Dailey Deaf fireman with bilateral cochlear implants: "The only advice I could give anyone that would really help is don't give up. You can do it. The longer you put things off, the more you're going to miss out."
- Nanette Florian Former lead singer of the New Christy Ministrels: "I started playing the piano and singing when I was five and there was this picture of Beethoven . . . oh, the poor guy lost his hearing, never realizing that the same thing was going to happen to me."

- ✓ Mike Michenfieder Member of the Facebook Group Bilateral Cochlear Implant Warriors: "Just can't get over the pleasure of streaming Sheryl Crow at 38,000 feet. Bilateral N7s for three years now. Such a gift. They are, best decision I've ever made."
- ✓ Jack Barnes Cochlear implant recipient who lost his hearing at age 11 after getting spinal meningitis and didn't regain his hearing until he had his cochlear implantation in 1988. "One thing that not everyone knows about cochlear implantation is that once you've lost your hearing entirely, as I like to say, there's no downside. If it completely fails, I'm going to be exactly as I was before I got the implant."
- Cynthia Robinson -- Educator of the deaf & hard of hearing: "If a family's goal is for their child to have listening and spoken language, you cannot wait because neuroplasticity will disappear. You must make a decision for the child. You cannot wait for the child to be old enough to make the decision, or you've missed the opportunity."
- Lou Ferrigno Professional musclebound bodybuilder & TV screen actor in *The Incredible Hulk* (1977), who had a series of ear infections and lost 75-80% of his hearing by age 5, causing him to be bullied during much of his childhood. Although he wore hearing aids throughout much of his life, it was in April 2021 when he got cochlear implants that much of his hearing was restored. "I think that if I wasn't hard of hearing, I wouldn't be where I am now. Early on, as a youngster, hearing was difficult, but I'm not ashamed to talk about it because many people have misconceptions about hearing loss and those who have hearing loss and what it's like not to hear, so I do talk about it. I think my hearing loss helped create a determination to be all that I can be and give me a certain strength of character, too."

Tips for Hearing Better with Cochlear Implants: Richard offered ideas from his own experience with Cl's.

- Don't hesitate or be afraid to look into CI's if you are deaf or have poor hearing even with HA's.
- Talk to other people with hearing loss and ask about their own experience with Cl's.
- Ask your audiologist for a hearing test or retesting as the eligibility standard for CI candidacy has been raised from 40% to 60% speech discrimination, increasing CI access for more individuals with hearing loss.
- See your doctor prior to getting CI's so you can discuss with your doctor any medical concerns that might interfere with successful CI surgery.
- Follow your doctor's CI post-operation instructions or restrictions to the letter.
- Be patient as you learn how to activate, rehabilitate and fully use your new Cl's. as your hearing improves over time.
- Research the accessories compatible with CI's that may help you hear better in the car, on the TV, on the computer, and on the phone.
- Regain the ability to more clearly hear speech and environmental sounds, even after a long period of deafness.
- Enjoy the full pleasure of playing and listening to music and using the telephone without fear.

Wrap-Up: After wrapping up his very enthusiastic presentation, Richard took questions from audience members about cochlear implants and other related hearing loss issues. While never claiming audiology expertise but having experienced his own decades-long hearing loss, he noted with compassion that he does understand how devastating the loss of some or all of one's hearing can be.

Nevertheless, Richard passionately urged those of us who are dealing everyday with deafness or any level of hearing loss that "We must never give up." He has, therefore, now made it his 24/7 mission in life to get deaf and hard-of-hearing (HOH) people out of isolation and living life fully by educating others about the basics of cochlear implants and how they can change one's life for the better. He is seeking to accomplish this goal by setting up a website and a Facebook page, as well as authoring his book *Cochlear Implant Basics: What a Candidate for a Cochlear Implant Needs to Know* (Available from Amazon in print or on Kindle). He designed his book to assist CI candidates to navigate the CI process and to negate some of the misconceptions about cochlear implants.

Richard assured us that making money from all of these efforts has never been his objective. Rather, he simply wishes to disseminate beneficial information about the difficult emotional side of hearing loss and what we can do about it. Finally, Richard encouraged anyone who needs more information or has questions about any of the topics discussed to see his website and/or contact him directly via his email stated below.

For More Information: www.cochlearimplantbasics.com Email: richardpocker@gmail.com

~ Kathy Fairbanks

****Help us decide about In-Person/Hybrid meetings by taking this survey** <u>HERE</u>. For those of you who only receive a hard copy, go to <u>www.surveymonkey.com/r/VYNPYDC</u> to take this survey.**

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:

- **Volunteer Coordinator**: Contact people who said they could volunteer and tell them about volunteer needs. Recruit for those positions.
- **National Chapter Coordinator/Liaison**: Coordinate with the national organization (HLAA). Go to online meetings.
- **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.
- There may be more possibilities.

Walk4Hearing is coming up!

HLAA <u>Walk4Hearing</u> is a nationwide campaign which brings hope to people with hearing loss in 20 cities, meeting them in their communities to raise awareness and show support. Teams of family and friends join with local HLAA Chapters and nonprofit and business partners to raise funds for local programs and promote hearing health. Walk4Hearing is HLAA's community of support in action, breaking down barriers to hearing health and empowering people with hearing loss across the U.S.

Last year's Bay Area Walk4Hearing was a lot of fun! Our chapter had a table so we got to meet and greet a lot of people. The Alameda High School cheer leaders were there with rousing cheers and demos for all. Giant's mascot, Lou Seal, was there also!

The Bay Area Walk4Hearing is scheduled for June 3, 2023! To be held at Robert W. Crown State Beach, 8th & Otis Drive, Alameda, CA Registrations are OPEN Register here to join our East Bay Chapter team: <u>2023 Bay Area Walk4Hearing - Hearing Loss Association of America</u> OR register to be a team captain and bring your own team (your family or friends)! E-mail Connie Gee to volunteer to help at our table at the event. <u>Cbgee2014@outlook.com</u>





HLAA-East Bay booth at the 2022 Walk4Hearing

Lou Seal, S.F. Giant's Mascot

Alameda High School Cheer Leaders

Come see who shows up this year! YOU and ???

JOKE CORNER



East Bay Leadership Team

The chapter is run by a Steering Committee, Leader Dale Davis, <u>ddavis94605@gmail.com</u> Outreach, National Chapter Coordinator/Liaison: (need a volunteer) Treasurer: Len Bridges, <u>lenbridges3993-hlaa@outlook.com</u> Programs: Robin Miller, <u>robin@robinmillerlaw.com</u> Technology and AfterWords Small Group: George Chin, Sr., <u>georgechinsr@gmail.com</u> Membership: Connie Gee, <u>cbgee2014@yahoo.com</u>; Marlene Muir, <u>muircmc@comcast.net</u> Volunteer Coordinator: (need a volunteer) Newsletter Editors: Nancy Asmundson, <u>nasmundson@comcast.net</u>; Kathy Fairbanks, <u>mkathyfairbanks@att.net</u> Publicity: Andrea Doehrman, <u>andreadoehrman@gmail.com</u>; George Chin, Sr., <u>georgechinsr@gmail.com</u> Technical/Audio Loop: Peter G. Townsend, <u>peterg.townsend@gmail.com</u>

JOIN HEARING LOSS ASSOCIATION OF AMERICA (HLAA) – THEY ADVOCATE FOR YOU! Go to this URL to join: <u>https://www.hearingloss.org/make-an-impact/become-a-memberrenew/</u> OR, if you prefer to pay by check or card thru the mail, Nancy Asmundson has membership forms to send to you, or contact HLAA at 301-657-2248 or e-mail <u>membership@hearingloss.org</u>. Your membership form & payment go to HLAA, 6116 Executive Blvd., Suite 320, Rockville, MD 20852. **COSTS:** Regular Membership/year (will receive *Hearing Life* magazine in print and digital format): Individual - \$45; Couple/Family - \$55; Professional - \$80; Nonprofit - \$80; Veteran Membership: Complimentary 1-Year Regular Membership & Lifetime Online Membership.