

## CHAPTER CALENDAR

Chapter and Board meetings held at:  
Weingart Center, 5220 Oliva Ave, Lakewood 90712

**September 10** - Chapter meeting: Dr. Fred DiTirro,  
“Qualifying for a Cochlear Implant”

Refreshments provided by Betty Rainey, Eleanor Palmer,  
Marion Camilleri, Marie O'Brien. *Thank you!*

**September 2** - **Wednesday Lip Reading class**,  
9:30– 11:30am.; Weingart Center

**September 14** - **Monday Lip Reading class**, 10am - noon  
Weingart Center

**September 14** - **HAT Committee Meeting**, 12:30pm.,  
Mimi's Café, Lakewood

**September 18** - **HAT Demo**, 10am - noon, Weingart Center

**September 23** – **Board meeting**, 12:30 Weingart Center

**October 14** – **Boeing UAW #148 Health Fair**, 9-11am

## **AUGUST MEETING SUMMARY**

Sandy Wedgeworth, Coordinator of Public Health Management for the City of Long Beach, spoke to us about the City's disaster plan. Most disaster planning agencies are just coming to terms in how to assist those with hearing loss. Los Angeles County recently lost a lawsuit because emergency services and public health were not in compliance with the ADA.

The first thing they are doing is dispelling misconceptions among first responders about those with hearing loss. Another thing they are working on is appropriate communication/notification for those with hearing loss.

She suggested, if possible, using your smartphone to access information. The city uses Facebook and Twitter to send out emergency information. There are also “apps” that can be used to receive emergency alerts. If that's not a possibility, you can sign up for “e-notify” with the City to get notices through email.

The best thing we can do is be prepared: let a trusted neighbor know you will need help keeping up with information, have an out-of-state contact, keep a few days' supply of food, water, medicines and hearing aid batteries handy and have an emergency kit in your car, including comfortable shoes.

## **HEARING LOSS ASSOCIATION OF AMERICA OUTRAGED BY CDC STUDY IGNORING PEOPLE WITH HEARING LOSS**

**Bethesda, MD:** According to a new study published by the Centers for Disease Control and Prevention (CDC), one out of every five adults has a disability. The study, *Prevalence of Disability and Disability Type Among Adults, US, 2013*, examined vision loss, cognition, mobility, self-care and independent living, but failed to study hearing loss. The CDC ignored 48 million Americans with hearing loss. HLAA is taking action with the White House and the CDC to see that swift and meaningful steps are taken to correct this gross error.

In the CDC's own words, “Understanding the prevalence of disability is important for public health programs to be able to address the needs of persons with disabilities.” Excluding people with hearing loss is not giving serious consideration to hearing loss as a disability that has an impact on a person's quality of life, ability to work, and to fully participate in society.

### **Hearing Loss is a Major Public Health Issue, Third Most Common Behind Arthritis and Heart Disease**

- Hearing loss has been shown to be linked to an increased risk of falls, dementia, depression and other conditions that lead to a poor health status, according to Frank Lin, M.D., Ph.D. of Johns Hopkins University School of Medicine and Bloomberg School of Public Health.
- 20 percent of people in the United States, 48 million, report some degree of hearing loss.
- U.S. Department of Health and Human Services specifically includes people with hearing loss in their guidance on standards of data collection for people with disabilities, which CDC chose to ignore.
- In 1988, Congress authorized the formation of the National Institute on Deafness and other Communication Disorders, National Institutes of Health (Public Law 100-553), to conduct research and training on hearing and communication disorders.
- Under the Americans with Disabilities Act of 1990 (ADA), hearing loss is recognized as a disability that substantially limits a major life activity, and provides guidelines for communication access such as Telecommunications Relay Services, established under Title IV of the ADA.
- The CDC itself devotes an entire section of their website to children with hearing loss and includes research papers on adults with hearing loss.

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“People with hearing loss have been denied communication access in hospitals and doctors’ offices, and by public programs such as Medicare which does not currently cover the cost of hearing aids,” said Anna Gilmore Hall, executive director of HLAA. “The release of the report comes on the heels of celebrations surrounding the 25th anniversary of the Americans with Disabilities Act, and we are stunned they failed to understand the impact of excluding hearing loss as a disability that needs to be addressed.”

**Link:** Read HLAA’s Letter to the White House.

**Editor’s note:** The studies and websites referred to in HLAA’s press release were removed for the purposes of this newsletter. If you wish to view the original press release and the embedded links on the HLAA website, please go to <http://tinyurl.com/pfazhm6>.

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## CHANGE.ORG PETITION ON THE CDC STUDY

There is a petition on Change.org addressed to the White House Office of Public Engagement that the study, *Prevalence of Disability and Disability Type Among Adults – United States 2013*, be amended to include hearing loss as a disability.

This is from the Hearing Health Foundation: When asked about the exclusion, the CDC had the following response: ***“We would have loved to include data on people with hearing loss. The report is based on the BRFSS, which is a telephone survey that doesn’t reach people with hearing loss.”*** Whatever their reason may be, this oversight demands immediate attention and correction. On behalf of the 48 million Americans with hearing loss, we request that the CDC rethink their methodology of data collection and re-conduct the survey in a more accommodating manner.

HHF is outraged by this gross oversight and finds the exclusion of people living with hearing loss from the report to be a troubling concern. Failure to include hearing loss diminishes the fact that it warrants attention and treatment, as well as neglects to recognize its impact on a person’s quality of life, interactions in school, and ability to work. It also undervalues the effects it can have on one’s health, including but not limited to the increased risk of falls, dementia, and depression. **But worst of all, this omission gives the public the excuse to discount hearing loss as a disability; to believe there is no need to protect hearing; and to lack empathy for and fail to accommodate those with hearing loss.**

Nearly 7500 signatures have been added to the petition at the time of this newsletter’s publication. If you wish to add your name, go to <http://tinyurl.com/nfx5v9u> or [change.org](http://change.org) and search for “hearing loss”

## UPDATE ON HAT COMMITTEE

By Dr. Bill Busch for Herb Balkind

### HAT IS BACK!

Summer vacation is over for the HAT Committee. We ended our vacation by supporting Congresswoman Linda Sanchez’s Senior Fair on August 14<sup>th</sup>. More than 1500 people attended the fair and a large number visited our table where we displayed several of our hearing assistive technology devices and our chapter literature. Our ability to pull this off was made possible with the outstanding help from our wonderful HAT Committee members, who volunteered to work the entire morning. A huge THANK YOU to Helen Bologna and Gordon Langsam for organizing our effort and setting up the equipment early in the morning. Thanks also to Bonnie Strutin, Katie Wright, Ron and Elfriede MacIver, and Ram Kakkar who all helped explain to countless seniors with hearing loss about technology that can help them to hear better.

Next event is our HAT Committee Meeting at Mimi’s Restaurant on Candlewood in Lakewood at 12:30 on September 14<sup>th</sup> where we will begin planning our activities for the rest of the year.

We will restart our monthly Rocky Stone Hearing Device Exhibits also referred to as our HAT Demonstrations on September 18 from 10 AM to noon in the Weingart Center’s Craft Room. Invite your friends and relatives with hearing loss to come and try out a large variety of devices that can improve their ability to hear better in difficult situations. These devices can be very beneficial to people with or without hearing aids and are a lot less expensive.

A representative from CaptionCall will be on hand to offer information on phones with captioning. Sam Moghadam, Hearing Instrument Specialist from Ascent Hearing Center will also be present to assist with hearing aids. HAT does not sell hearing aids or Hearing Assistive Devices, but provides information on where to purchase items demonstrated. For further information, please call 562-630-6141 or visit our website: [www.hlalongbeachlakewood.org/](http://www.hlalongbeachlakewood.org/).



Gordon Langsam, Bonnie Strutin, Helen Bologna, Elfriede MacIver, Sabrina Junkin, Katie Wright (not pictured: Ram Kakkar, Ron MacIver)

# STUDENTS ADVOCATE FOR HEARING LOOP

By Jennifer Maas on August 25, 2015  
Reprinted from the Santa Monica Daily Press

Santa Monica High School students John Butchko, Isaac Horwitz-Hirsch and Xander Lee decided to advocate for additional access for those with hearing loss in the City as part of their 10th grade community service project for English class.

They made public comments in front of the Santa Monica Disabilities Commission, the Planning Commission and City Council. And on July 22, as a result of their efforts, City Hall installed an induction hearing loop system.

“When my English teacher assigned the community service project, I had already been trying to get looping in some of the new projects that were proposed to be built in Santa Monica and realized that it was going to be a difficult task,” Butchko, 16, said. “I thought it would be a good community service project and was excited to have two friends help me try to change the laws to require additional accommodations for those with hearing loss.”

The boys approached Otojoy, a Santa Barbara-based company that has installed over 100 hearing loop systems, about implementing the system in City Hall.

Mayor Kevin McKeown was involved in the project as well, as the team approached him to learn about the civic process; but he gives full credit for its success to the students.

McKeown advised the team on how to take their idea and make it heard and get it advanced through the Disabilities Commission and the Planning Commission, before bringing it in front of the City Council for funding.

During the process of advocating for the hearing loop system, Butchko (who is deaf) and his friends learned how difficult it was to get their idea through all of the proper channels and achieve the outcome they wanted.

“It’s been surprisingly hard to change local law regarding new public venues and commercial facilities to require accommodations for those with hearing loss, but I will keep pushing the City leaders to try to find a solution and I think that we are making progress,” Butchko said. “My next project will be to try to get looping in the new movie theaters that are proposed to be built in Santa Monica.”

Butchko plans to speak in public comment at the City Council meeting on Aug. 25 at 5:30 p.m., to thank the Council.

# WHAT IS A HEARING LOOP?

Otojoy president, Thomas Kaufmann, explains a hearing loop: A hearing loop is an assistive listening system that transfers the sound from a venue’s public address system directly to the user’s hearing aid or cochlear implant.

It allows the user to simply walk into a room, sit down, and press a button on their hearing device to directly tap into the sound system. It turns their hearing aids into wireless earphones that broadcast sound customized for the individual’s level and pattern of hearing loss.

Much like eyeglasses, hearing aids are always personalized and calibrated for someone’s individual hearing loss. With the hearing loop system, we’re utilizing that calibration, which results in the user not only hearing sounds louder, but much clearer.

What also contributes to the clarity is the direct connection to the sound system. The user does not perceive distracting noises in the room or echo and reverberation that make it more difficult to understand the spoken word. To them, it sounds like the person speaking into the microphone speaks to them from three feet away.

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## SEPTEMBER PROGRAM

### “Qualifying for a Cochlear Implant From the Surgeon’s Point of View”

Dr. Frederick R. DiTirro, Head and Neck Surgeon, Board of Otolaryngology of Kaiser Permanente, will be guest speaker at the next Chapter meeting. Dr. DiTirro will relate his knowledge about hearing loss, cochlear implant surgery and what it takes to qualify for such surgery along with recovery time and its success. He will share a surgeon’s viewpoint not only on implants but on hearing in general. Dr. DiTirro has been with Kaiser Permanente for 33 years and primarily sees patients for ear surgery and with ear problems. He has done the majority of the cochlear implants for Southern California Kaiser in the past 20 years and performed about 1600 cochlear implants.

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## SCOREBOARD

	MEMBERS	GUESTS	TOTAL
August ‘15	28	2	30
July ‘15	27	1	28
June ‘15	21	2	23
May ‘15	22	6	28

## KEEP OUT OF MY WAY! (HASHTAGS FOR NEW HEARING AIDS)

By Gael Hannan On August 24

It's that time of life again. I'm breaking in new hearing aids before the old ones break down. Although *I* may be the first one to break down, and I know my family is on edge. If you use hearing aids or cochlear implants, you know what I'm going through.

I've lost count of how many sets I've had since my first beige behind-the-ear model in 1975, but I'm guessing at least 10 iterations of hearing technology made by a Who's Who of the hearing industry: Phillips, Unitron, Beltone, Starkey, Widex, and Oticon. (If your company isn't on the list, I'm open to donations.)

Regardless of who makes them, with every new set of aids, there's always a breaking-in process that works on the principle of *no pain, no gain*. Sometimes, when the aids are replaced with the same style, the process is not so bad. But this time, I'm trying out a different model that looks different, feels different, and sure as heck SOUNDS DIFFERENT! All the little knobs and switches are in different places and I'm constantly pawing at the side of my head looking for the program change or the volume control or the battery door.

But I love getting new hearing aids, it's *exciting!* They are amazingly cool; they boost our hearing and connect us to other devices and people in ways we once would never have dreamed. But it's not as easy as getting a new car where you pay for it, put gas in it, buckle up and then step on the gas to a beautiful future together. No, it's more like taking dance lessons for the first time. You and your hearing aid(s) have to get used to each other; there will be a lot of smashing into each other, painful foot-crunches, and wanting to go in opposite directions. It takes more than a few lessons before the old bump and grind becomes a smooth tango. The hearing healthcare professional usually must perform a series of tweaks on the fit, the venting, the volume, the programs, the highs, the lows and so forth. Then, when you first insert these new ear-babies, the brain just about loses its mind with the *shock* of the new information pouring in, before it settles down to the business of adapting to it (on no set timeline).

So, pity the poor *user* while the professional and the brain are tinkering at their jobs. Everything sounds ridiculously loud and different. We can't imagine it will *ever* get better or be as comfortable as the old aids. It takes time, patience and sometimes a fist through the wall before you and your hearing aids start tango-ing.

And then there are the unique frustrations of family and friends: it's not easy living with a loved one who's undergoing a brain transformation.

In an attempt to help anyone who may be going through this (again), I'm offering a few guidelines. And to emphasize the emotions behind them, I've added the popular hashtag used in today's social media, which is the # sign, followed by the sentiment. For example, when I tell my family we're about to once again climb on the *hearing aid merry-go-round*, the hashtag might be **#carouselfromhell**. If this were a social media page, clicking on **#carouselfromhell** would take you to a site which lists all comments relating to the stressful merry-go-round.

Here we go. During those weeks of 'getting used' to new hearing aids:

Don't breathe loudly. Especially through your mouth and that includes loud yawns. And if you're breathing through your nose, clear the passage. **#whistlingnosesarenoisy**

At dinner, the crashing sound of cutlery jars my nerves. **#eatwithyourfingers**

Before speaking, get my attention first. Then try saying two words to me, and if it's not too loud, you may continue. **#don'tbeahumanfoghorn #ignoreatyourownperil**

Have patience with me, because I will have none with you. **#truerwordswereeversaid #i'mnotkidding**

But don't blame *everything* about my current bad mood on my hearing aids. I may snap at you for many reasons. **#justbecauseyouexist**

Don't ask me if perhaps my old hearing aids were *better?* I'm not putting us through this torture for the sheer pleasure of it. **#theydon'tlastforever**

If you see me *not* wearing my aids, remind me to put them in, otherwise I won't get used to them. **#thengetoutofmyway**

Keep me away from sharp knives and instruments. **#becauseiwillstabtheaids**

I don't care that you can't hear the TV. *I* say it's too loud! **#readthecaptions**

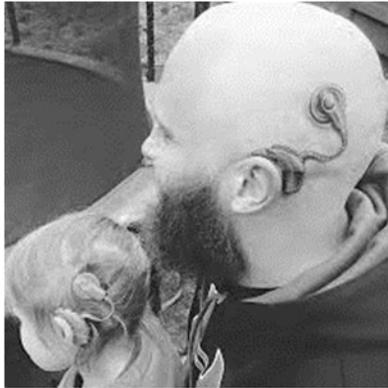
Just remember, I'm getting new hearing aids so I can hear what you are saying. **#becauseiloveyou**

I think that about sums it up. I'll report on my progress in a month or two.

**#crossyourfingers.  
#itwillbefine  
#iwanttohear**

## AMAZING TATTOO, AMAZING DAD

Reprinted from *lipreadingmom*



Alistair and Anita Campbell wanted to do something to help their young daughter, Charlotte, adjust to having two cochlear implants. So, Alistair received a matching cochlear implant tattoo placed above and behind his left ear.

Charlotte was implanted in her right ear the first week of August. That prompted Alistair to get his matching tattoo. They wanted to "celebrate Charlotte's journey and to show her how special her ears are," say the Campbells. "Charlotte and her brothers loved the tattoo. We could never have imagined how much attention this would draw."

Since posting the photo on social media, the Campbells, who live in New Zealand, found almost instant celebrity. On August 4, the photo went viral and went on to achieve more than 80,000 views and 15,000 shares on the Facebook page **Life of Dad**.



It's time again to renew your participation in the Ralphs Community Contribution Program. The new year begins on September 1. Ralphs will contribute a small percentage of your dollars to the Long Beach/Lakewood Chapter of the Hearing Loss Association of America if you enroll in the program and designate us as your charity.

You can register online at [www.ralphs.com](http://www.ralphs.com) or you can get a scan bar letter from Stephen Fisher, Ways & Means Chairman, at our Chapter meeting. You can also arrange to have a letter mailed to you; contact Bill Busch at 310-540-6322 to do so. If you still have your scan bar letter from last year, it can be used again.

Take the letter and your Rewards card with you the next time you shop.

Ask your friends and family to sign up also!

## HEARING LOSS ASSOCIATION OF AMERICA LONG BEACH / LAKEWOOD CHAPTER

### Officers

President - Bill Busch  
Vice - President - Gail Morrison  
Treasurer - Walt Lowrie  
Recording Secretary - Craig Bowlby  
Corresponding Secretary - Ken Saw

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Information - Vacant  
Lip Reading - Linda DeGuire  
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Membership - Flo McDavid / Katie Wright  
Newsletter - Katie Wright  
Programs/Publicity - Gail Morrison  
Refreshments - Marie O'Brien and Marion Camilleri  
Ways and Means - Stephen Fisher

### Support

Newsletter Layout - Lisa Rettino  
Professional Adviser - Dr. David DeKriek, Au.D.

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Gail Morrison, 562-438-0597, [gail7go@gmail.com](mailto:gail7go@gmail.com).

## HLAA

Join HLAA now to receive *Hearing Loss Magazine* and become part of the one organization that represents the interests of 48 million people with hearing loss in the United States. Send \$35 / \$45 for individual/family membership to:  
Hearing Loss Association of America  
7910 Woodman Avenue, Suite 1200,  
Bethesda, MD 20814.

Phone: (301) 657-2248 Voice; (301) 657-2249 TTY

To join online, go to <http://hearingloss.org/>

Membership brochures are available at our chapter meetings.

### CTAP

California Telephone Access Program  
Information, Repair & Exchange  
**English** Voice 1-800-806-1191  
**Spanish** Voice 1-800-949-5650

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Long Beach/Lakewood Chapter

Hearing Loss Association of America -  
Long Beach/Lakewood Chapter  
c/o Katie Wright  
7802 Kingbee Street  
Downey, CA 90242

**First Class**

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## FUTURE PROGRAMS

**October 8** - Dennis Merkley, Marriage and Family Therapist, "Improving Listening Skills"

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HLAA Long Beach/Lakewood Chapter Meetings are on the second Thursday of each month at 6:30 pm.  
We meet at the **Weingart Center, 5220 Oliva Ave, Lakewood 90712**

All meetings are Captioned with CART (Communication Access Realtime Translation), the hearing Induction loop and Williams Sound System. Light refreshments are served.  
For more information, please call **562-438-0597** or visit [www.hlalongbeachlakewood.org](http://www.hlalongbeachlakewood.org).



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**The Hearing Loss Association of America (HLAA)** opens the world of communication to people with hearing loss through information, education, support and advocacy. The national support network includes the Washington, D.C., national office, state organizations and local HLAA Chapters. **Join HLAA now** to receive *Hearing Loss Magazine* and become part of the one organization that represents the interests of 48 million people with hearing loss in the United States.

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