

THE HEARING LOSS CALIFORNIAN

A QUARTERLY NEWSLETTER BY THE HEARING LOSS ASSOCIATION OF CALIFORNIA

SUMMER 2012



AMAZING GRACE: A Personal Journey of Growth & Courage

by Grace Waegell Tiessen

Thirty years ago before I found HLAA I was asked this question: "What does it mean to be hard of hearing in the hearing world?"

Hearing loss is a chronic stressor. Trying to hear is exhausting because of the effort and concentration required to understand, to communicate. Sheer fatigue can cause a person to tune out when there is no more energy left to unscramble sounds.

I was depressed all my life. I used to think it was being a woman, or my marriage or the way my family raised me. I began to snap out of it in 1974 when I began Alanon, a 12-step program for friends and family of the alcoholic (but I wouldn't have been able to go to Alanon if I hadn't started to wear two hearing aids in 1970). Alanon did help, but also I could now hear well enough to go back to school, and I now realized that I must sit in the front

row center. It makes me wonder – were my problems caused by my husband's alcoholism or being hard of hearing.

I am often left out and passed over because I cannot communicate as quickly as other people. I feel so close to the hearing community, yet separated by a great chasm. I often laugh at a joke only because everyone else is - but not knowing what was funny, I am crying inside and feel left out.

It is knowing I could be witty and sparkling because I have the personality, the vocabulary and the intelligence for it, but not being able to hear well and quickly enough to respond as I would like. It is being unable to hear your children because their voices are soft and high pitched. It's like being crippled. Conversation is a game of tossing words back and forth. If one is hard of hearing the conversational ball is endlessly dropped and fumbled and thrown back half heartedly because you really can't follow the conversation well. And people get tired of

talking to you. So you withdraw into isolation.

You are careful about whom you talk to. You know whom you can hear and whom you can't. It is living in the same house with your new son-in-law and never speaking to him because his words tumble out far too quickly for you to comprehend and his volume and speech pattern is too breathy and uneven. You avoid anyone who doesn't speak clearly and fairly loudly. It is holding back and not taking the initiative when meeting people. It is being paid a compliment but not really being sure what was said. It is being careful when hugging someone because your ear molds whistle. It is going home after visiting with friends and wondering what was talked about. It is sitting in the patio at a

nice dinner party and knowing that as the sun does down, you will be able to hear less and less easily, and when it gets fairly dark be unable to participate at all.

When I was young I never heard the romantic words my lover was saying. You only make friends with and marry someone who speaks loudly and clearly. I sometimes wonder if my hearing loss kept me from remarrying.

Communication is key in any relationship and hearing loss challenges every part of the communication process. Being hard of hearing is like living in a foreign country where you can never really learn the language

Thirty years later: "Do you feel differently about your hearing loss? What has changed? What has HLAA meant to vou?"

Finding SHHH (Self Help for Hard of Hearing People) in 1984 was the beginning of a whole new life for me. There was a bulletin board in the Audiology Department of my HMO. I took down the names and addresses of all the organizations having to do with

hearing loss and wrote to each. I received a flood of information. I was out of the darkness. I learned about the national support group SHHH now HLAA (Hearing Loss Association of America). I joined and began reading the SHHH Journal. But best of all I found there were SHHH meetings in my area. I went to the very first SHHH meeting in Los Angeles, started by Rocky Stone's sisters. At the meetings I learned about FM and captioned TV. I still remember when someone brought his FM and showed me how to use it. I was no longer alone. HLAA gave me a sense of belonging, friends, causes to advocate for, information, technological support and a hard of hearing family. I had never met another hard of hearing person until I found SHHH in 1984 when I was 65 years old. One of the first hard of hearing people I met was Nanci Linke-Ellis.

Why didn't Audiology tell me about HLAA. Without HLAA I am totally alone, isolated. In the real world, I don't know a

single hard of hearing person (although they are all around me). Nobody ever told me I had a hearing loss and should wear hearing aids. I got annual checkups to get a report on my health. For years I was told my health was excellent when in fact I was in poor psychological health. I was anxious, under stress, withdrawn, isolated. I had trouble with my close relationships. I heard my own children with difficulty. It was impossible for me to go to school or work. My three children, with a mother wearing cochlear implants (CIs) have never had their hearing tested. I don't believe people with hearing loss are in denial - the helping professions are not doing their job.

To this day, in gratitude, I am heavily involved with HLAA,

doing outreach, the Walk4Hearing, advocacy, going to meetings, hosting Christmas parties, editing the state newsletter The Hearing Loss Californian since 2001, anything to help further the aims of HLAA. I was president of the SHHH, San Gabriel Valley Chapter from 1985-1990, and a member of the State Board of Trustees from 1997-2011, serving as President from 2001-2003. I was a member of the California Department of Education Advisory Task Force for the D/Hoh; a member of the Board of Directors of the HEAR Center. a non-profit speech and audiology center in Pasadena from 1996-2007; a member of the City of Pasadena Commission on Accessibility and Disability, from 1990-1995; and winner of HLAA's highest national honor, the Keystone Award, in 2003.

I want to make sure that every person with hearing loss knows about HLAA and the support and information we provide; that everyone becomes aware of how many of us have this invisible disability.

I'm beginning to have fun. Rhianon Gutierrez (CI wearer who lives with me),

a film maker/producer asked me to play *Elegant Lady* in a short student film she was working on. This was a real job. I went to Makeup and Wardrobe, earned \$50 and played one scene (which wasn't cut). I was with Occupy Democracy Pasadena in the Doo Dah parade as *Elegant Lady* (Let them eat cake). National has said several times, "Please don't wear blue jeans to the banquet". Do they mean us in the Wild West? I will dress as an Elegant Lady in Providence to show them that culture is alive and well in California.

I had a big 90th birthday party in 2009, inviting my two Families - my Sacramento family and my hard of hearing family.

I love the arts. I live in an art factory with new works coming out all the time. My house is an art gallery, showing mostly the work of my artist son, Stan Edmondson.

I have always been interested in politics, but because of my hearing loss I never got involved. I just joined Occupy Democracy Pasadena. I made 100 T-shirts with 'We are the



99%' on the front, and a fist and 'Occupy Pasadena' on the back, selling at cost \$8. We meet every two weeks to plan our demonstrations. And here is my hearing problem. It's like trying to hear at Thanksgiving or eating at a noisy restaurant. About ten of us meet at Judy's house. The room echoes, some people don't have great diction and several people speak at once. I haven't told them I am hard of hearing. What to do? Our chapter has a portable loop, but it takes too long to install it every time. I think I will confess I'm hard of hearing, ask that they speak one at a time and ask somebody to be my buddy and fill me in on what is being said. Interesting. These people will never feel like family to me.

In 2010 I got a job as a lab rat for House Research Institute, which paid \$15 an hour and travel expense. I sat in a sound proof booth, listening to musical sounds and recording responses on a computer. The goal was to improve perception through auditory training to make music listening more enjoyable for future cochlear implant users.

My speech comprehension got worse and worse so I finally qualified for a cochlear implant. I am now a bilateral wearer of CochlearAmericas Nucleus 5, one implanted in 2005 and the other in 2010. I am hearing really well with my CIs. With a good loop system, I can hear almost normally without lipreading. I have joined the HLA-LA advocacy committee and I have a goal to loop Pasadena.

My personality has changed. I was always quiet and withdrawn and avoided talking to people. I'm witty and talkative today. I always knew I was but being witty depends on good hearing. My speech pattern has changed. I used to speak in such way that people could just say 'yes' or 'no'. I didn't want people to give long answers that I couldn't understand. I used as few words as possible and never used 'small talk'. Now I can bat the conversational ball back and forth and don't mind if people give me a long answer. I don't avoid people today, or wonder if I will be able to understand them.

Count your blessings. Be grateful. During the recent windstorm in Pasadena, a huge branch broke off a tree and dropped on the porch right outside my bedroom. Didn't bother me at all. Didn't hear a thing. My son said the dog had an anxiety attack.

I have been through three major earthquakes. The plaster is knocked off in the corner of my bedroom from the frame of the house twisting. It must have made an awful racket. But I didn't hear a thing.

Hearing loss has given me a second family - my hard of hearing family.

Come out of the "hearing loss" closet. If you deny your disability, you deny yourself accommodations. Get involved with HLAA.

93 years old, going for 100.

Movie Captioning Glasses



The movie industry's transformation to digital technology has created an opportunity to efficiently deliver closed caption data to movie patrons. This coincides with large demand from people with hearing difficulties to watch movies more easily and enjoyably

Sony is working with American theater chain Regal Entertainment to introduce its new entertainment Access Glasses with Audio, utilizing unique holographic technology that can display closed captions for those with hearing problems.

The new Access Glasses can show text in six different languages, which is then placed directly in the viewer's field of vision so that they don't have to constantly look at the bottom of the screen. The information is streamed wirelessly, and the location of the text can be adjusted to make things more comfortable. The glasses also include features for the blind or visually impaired, as they can be used alongside headphones to provide extra audio detail about just what's happening on screen.

Regal – the largest theater chain in the US - started rolling the Access Glasses out this month, and expects to have them available in practically all of its fully digitized theater locations by early 2013.

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An Audiologist's Perspective Debbie Clark, co-Vice President of HLA-CA



By Debbie Clark

As a board member and co-vice president of the Hearing Loss Association - California, I feel like a bit of an anomaly. First, I am an audiologist. (There are two of us on the board: myself and fellow vice-president Ellen Mastman.) Second, I have normal hearing. What am I doing here? I have to say that I truly felt honored to have this opportunity, and I hope that my professional knowledge is helpful to the board as a whole. So I thought about my experiences as a board member over the past year (as well as my 29 years as a clinical audiologist) and decided to share what I have learned from YOU.

One of my first acts as a board member was to serve on the 2012 California HLAA conference planning committee. I arrived at my first meeting in Oakland knowing only a few of the other people attending. A portable loop was brought in and a microphone was passed around. Communication rules were set. One person speaks at a time. (Wow, I wish our staff meetings at work were like that!) Before you speak, you must stand up and be sure you take the microphone. Speak slowly and clearly. This is something I advise my patients about all the time. In the past, I would counsel them about the importance of these communication strategies. Often I have been met with blank looks or expressions that told me my patient was thinking, "Yeah, sure. Easy for you to say!" So you can imagine how that message was driven home when, at the end of our first

conference planning meeting, I felt exhausted! And I had it "easy" because I have normal hearing! Of course, I know from years of talking with my patients who have hearing impairment how exhausting it can be to work so hard to communicate. But this time, I felt like I actually got a little taste of what my patients have been describing to me all these years. I can only imagine how the committee members with hearing loss felt at the end of each of those meetings.

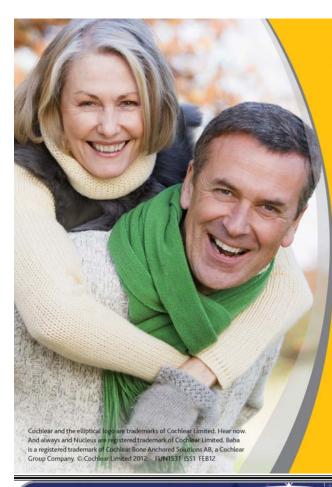
I occasionally attend one of the Peninsula Chapter's Saturday morning meetings. It is fascinating to sit in on conversations about various assistive listening devices...what they like and do not like. Another "wow"! I pride myself on being fairly familiar with assistive devices. We have an ALD display area in both of our offices. But I realize that I do not know all the ins and outs of various devices--why one model might be more convenient to use than another, etc. This is the kind of information only someone actually using the devices on a daily basis could have. And honestly, there are so many gadgets out

I have had an association of some sort with HLAA for many years, if only as an occasional guest speaker at chapter meetings. As an audiologist, I find working with HLAA members to be very rewarding. What a thrill to work with people who actually WANT to hear and are willing to do whatever they can to get better hearing. (This is a stark contrast to patients we often see who are in denial about their hearing loss and are only there because a family member has dragged them to the office.)

I have always felt that the hearing healthcare profession has much to learn from HLAA members. Just as a teacher learns much from his/her student, audiologists, otolaryngologists and hearing aid dispensers have much to learn from their patients. As a person with normal hearing, I can't pretend to know what it's like to have hearing loss. But I can listen. I also know my limits. HLAA has much to offer my patients that I cannot offer. One is camaraderie. Another is first-hand expertise on the nuances of various ALDs. And maybe if I listen enough, I will get better at guiding my own patients through the denial and frustrations of hearing loss. It's about more than the technology.

The way I see it, HLAA and the hearing healthcare profession as a whole is in a symbiotic relationship. We need each other. We all know, despite what hearing aid advertisements might claim, there is no "quick fix" when it comes to hearing loss. It's a process. Human beings are complicated and we can accomplish a lot when we work together!

From the Editor: Audiologists and hearing aid dispensers: There are 100,000 people in California with severe to profound hearing loss. Our California HLAA membership is only 900. Our potential members are in your offices. Suggestion: Give a \$35 membership to HLAA to each hearing aid purchaser and strongly recommend that they attend several HLAA chapter meetings. This will help them become more successful hearing aid users.



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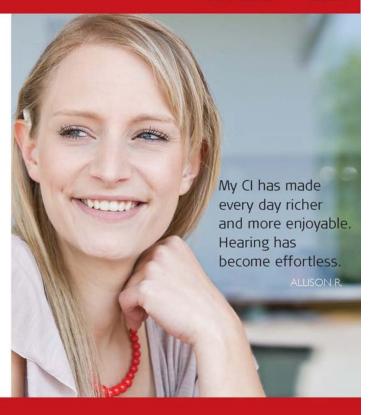
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How to deal with the **Emotional Aspects of Hearing Loss**



By Alison Freeman

Alison Freeman, PhD, is a clinical psychologist who works half time at California State University at Northridge with both hearing and hard of hearing students. She also has a private practice and is particularly excited about doing videotherapy. She has had a severe hearing loss since early childhood, was orally trained and is a long-time member of HLAA. She has developed mental health service programs in several counties and did her post-doctorate fellowship at UCSF Center on Deafness. She recently spoke at the California Psychological Association on "Hearing Loss across the Lifespan: Unique Issues for Therapists Working with People who have Hearing Loss". She is passionate about her work as a psychologist and is honored to be a role model for others, as she wished she had had as a child. www.dralisonfreeman.net

When we talk to someone who is wearing glasses, we don't give any thought to what it is that they need in order to see. Vision is easily measured in finite numbers like 20/100, whereas hearing loss is very complex with a multitude of factors and variations such as frequency, pitch, discrimination and volume.

A person who wears glasses doesn't need to explain their vision impairment, whereas a person who has a hearing loss has an invisible disability that is often vague even when described. Even if we show or wear our hearing aids visibly, this ambiguity is a daily stress that one has to continually adjust to with every person, place or situation throughout the day.

The primary disability of hearing loss is a communication disability rather than just not being able to hear. Struggling to understand conversations, music or professional meetings is a constant stress everyday. An essential part of dealing with hearing loss is recognizing that stress is inevitable. The task is to learn more effective stress management and communication skills which will be much more productive and emotionally satisfying.

There are different emotional challenges between those that have early childhood hearing loss and those that have adventitious loss. Often, the child deals much more with isolation and loneliness, whereas the adult who experiences loss deals with grieving for what they once had. The emotional process and journey leading to acceptance of one's hearing loss is often fraught with denial, anger, grief, frustration, depression, loneliness and finally acceptance. All of these emotions produce stress.

One of the major factors in effective stress management is being able to recognize when we can be in charge and knowing what we can and cannot control. When we educate others about our needs, we take charge and in doing so, we help minimize stress for ourselves as well as others.

I have found two basic assumptions to underlie my **communication philosophy.** Firstly, I assume that most people know little, if anything about hearing loss. Secondly, most of these people are embarrassed about asking me for what I need in order to communicate. They often think that they should know what I need but they really don't and that is embarrassing for them.

I view my role as that of an educator. I believe that the more people know and understand about my hearing loss, the more effective communication will be for everyone involved. When I can provide information to them, I often spare them the embarrassment of having to ask me for what I need. When I do this, I not only lower their stress but mine as well!

When I work as a psychologist at California State University at Northridge or in my private practice, I have a standard spiel whenever I meet a hearing client for the first time. It goes something like this: "Hi. Before we start, I would like to tell you that I have a hearing loss and what that means is that I both hear and lipread. So, if during the course of our conversation, you are not sure I heard you correctly, please don't be shy in telling me so. Likewise, I may ask you to repeat something if I am not sure that I understood you." When I first started doing this, I felt awkward, as if I were taking up their time with my problem because I thought they were there to talk about their problems, not mine! On the rare occasion when I sense that s/he is uncomfortable, I will add, "I will understand that if you are not comfortable with this, I would be happy to give you a referral to see someone else ".

For many people with hearing loss, embarrassment and a sense of shame prevents them from telling others about their hearing loss which often results in giving the wrong impression, i.e. being rude or "stupid". However, if one stops to really think about it, in not addressing your needs, you are really creating your worst fears. So, the question is "which would you rather be seen as, stupid/rude or hard of hearing or deaf?

When people do seem rude, critical or harsh to us, it helps to not take things so personally when we realize that it is probably more a reflection of their own emotional state, i.e. they have someone in their life, a parent, a spouse or a boss who is overly critical of them.

Often, one difficulty in telling others about our hearing loss may lie in making a distinction between the fine line between being assertive and the fear of being aggressive. While being assertive may be easier for people who are extraverted, it helps to remember that when we are not assertive, many erroneous assumptions and / or embarrassing mistakes can be made, and we do end up looking stupid, aloof, rude, etc. Donald Robertson, in his book, *Build Your Resilience*, beautifully explains: "Assertive behavior promotes equality in human relationships, enabling us to act on our own best interests, to stand up for ourselves without undue anxiety, to express feelings honestly and comfortably, and to exercise our personal rights without denying the rights of others."

The journey to acceptance is one where we recognize our sense of control, and over time gradually feel "more and more okay" about not being in control. It doesn't mean I have to like it but it is a fact of life. It helps to keep in mind what I call "the three A's, that we do have choices. In doing so, we can reduce our feelings of powerlessness, victimization or self-pity. The three A's are AVOID, ALTERNATIVE and/or ACCEPT.

For example, when I am invited to go to a restaurant, I recognize that I may not be able to control the acoustics of a room because of

the hardwood floors or the background music, but I can definitely take charge of communicating my needs. I can choose to "beg off" and *avoid* going altogether. I could suggest an *alternative* of going to a quieter restaurant or to go at an earlier time when it is not so noisy. Or I can just *accept* that I will be uncomfortable because it is important for me to be there for a friend or relative's birthday. Likewise, if I am invited to go to a movie, I can *avoid* it, suggest an *alternative* going to a captioned movie (isn't technology wonderful?) or just *accept* that I will not understand everything. I choose to save my energy for when it is very important and have learned not to "sweat the small stuff".

While having a hearing loss is certainly annoying and uncomfortable at times, I have learned that the more I take responsibility for communicating my needs the more comfortable and less problematic my hearing loss becomes. Ultimately, the journey of accepting one's hearing loss is a gradual and continual process.

No-Bluff Pledge

By Gael Hannon

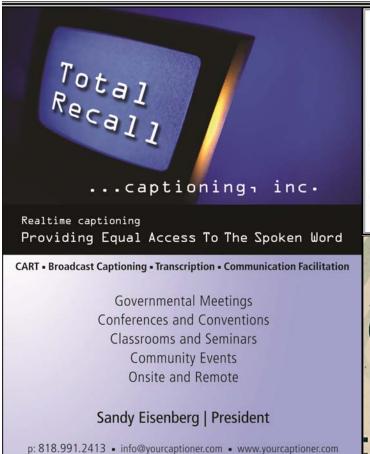
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Current State of Internet Captioning

By John Waldo

In many ways, the internet is a huge blessing for those of us with hearing loss. Email and texting provide us with the opportunity to communicate non-verbally, and the ability to purchase many products and services on line lets us shop at home without worrying about those frustrating telephone conversations.

But the internet hasn't been all up-side. The internet is also an increasingly important vehicle for distributing entertainment like television programming and movies, and information like educational materials. And all too often, the material delivered over the internet is inaccessible to us because it is not captioned.

The basic problem, as I understand it, is not that internet material cannot be captioned, but rather, that captions must be prepared specifically for internet application, even if captions have already been prepared for another application. While a television show may have been captioned when it was originally broadcast, those captions are not automatically captured when the same show is offered on the internet. The same is true of a movie that may have been captioned for theatrical release.

So there is some cost involved. Quality captioning easily costs \$150 per hour or more. If, as I have been told, captioning a movie for the theater costs \$2,000 or more, then captioning the movie for streaming on the internet would cost at least that much again.

Unfortunately, the prospect of increasing the audience by providing accessibility has not been enough to prompt businesses in general to undertake the extra expense of preparing captions specifically for the internet. It was the recognition that market-place forces were not going to provide accessibility for individuals with disabilities that prompted passage of state and federal laws like the Americans with Disabilities Act that require businesses to make their services accessible. But **technology moves much faster than the law**, and with some narrow exceptions, neither federal nor state disability law specifically references the internet.

In some circumstances, an accessibility requirement is clear even in the absence of any specific mention of the internet. **Title II of the ADA**, which applies to government entities, and the federal **Rehabilitation Act**, which applies to federal agencies and to entities that receive federal funds, require affected entities to make all of their "programs, services and activities" accessible to individuals with disabilities. So anything offered on line by a government agency of any sort – a state, a city, a public school or hospital – or by any agency that receives federal funding, must be made accessible through captioning.

It's a different story, though, where **private businesses** are involved. The problem is that **Title III of the ADA**, which applies to most businesses open to the public, requires that those *places* of public accommodation make their goods and services accessible to individuals with disabilities.

That portion of the law requires installation of familiar accommodations like wheelchair ramps to provide physical access to buildings, and in 2010, the Ninth Circuit Court of Appeals declared that the same law requires movie theaters to provide aural accessibility by installing equipment that will enable us to see the captions provided for most movies. But that same Ninth Circuit court, whose jurisdiction includes California and other Western states, has also said that the *places* that must be made accessible

are traditional brick-and-mortar businesses, not websites that have no physical place of business open to the public.

National Federation of the Blind vs Target Corporation. A 2006 decision from a federal district court in San Francisco creates an important exception to that rule. In a case brought by the National Federation of the Blind against Target Corporation, the court agreed that Title III did not apply to purchases made strictly over the internet. But the court said that when people use the website to determine what they want to buy, then go to the store to make their purchase, the lack of access to the website creates a discriminatory barrier to those people's ability to use the brick-and-mortar store. The court said that where such a connection exists – referred to in legal-speak as a *nexus* – then the ADA requirements are applicable even though the discriminatory acts does not actually occur at the physical place of business.

While the legal exception created by that case is fairly narrow, the ultimate outcome was not. By making its website accessible by touch to blind individuals for the purpose of allowing pre-shopping, Target also permitted those individuals to make on-line purchases, even though the ADA would not have required that latter remedy standing alone. Moreover, a number of other on-line retailers did the same.

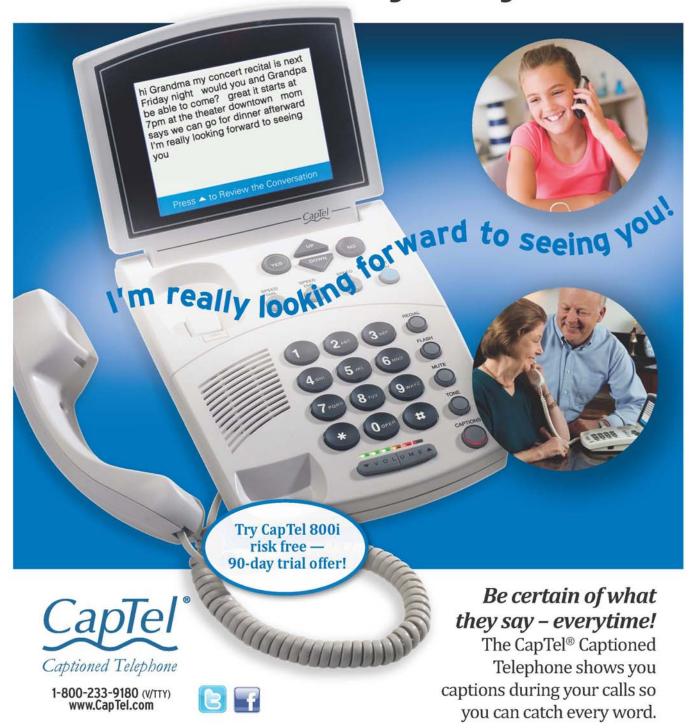
That case does not apply to those of us with hearing loss in the same way as it applies to people with vision loss – we can see department-store advertisements for merchandise. But the principles may well apply to businesses that incorporate verbal descriptions into their on-line advertisements, or to retailers whose products rely on uncaptioned on-line instruction videos rather than printed manuals.

Netflix. The more pressing issue for us is when the online content does not involve any sort of brick-and-mortar **establishment**. One long-standing concern has been the very slow pace at which Netflix has provided captions for its on-line movies. Two lawsuits have been filed against Netflix – one in California and one in Massachusetts. The case in California simply stated that Netflix is a "place of public accommodation" within the meaning of the ADA, ignoring case law to the contrary. After the involvement of highly experienced attorneys from Disability Rights Advocates - the folks I worked with on the Cinemark and AMC movie cases in California – the case against Netflix was re-formulated to make claims based solely on California state law, which may apply broadly enough to include web-only businesses like Netflix. The case in Massachusetts is a bit more hopeful, because the federal court of appeals that covers Massachusetts has said that the absence of a brick-and-mortar store doesn't automatically rule out coverage under ADA.

Those cases are both still ongoing, and from a strictly legal perspective, I'm not sure I would lay odds that either would succeed. However, as occurred with the Target case, Netflix may decide that it makes more sense to provide captioning than to continue to fight legal battles on a number of different fronts.

GLAD vs CNN. Another ongoing case is a class-action case in California brought by the Greater Los Angeles Agency on Deafness (GLAD) against Time-Warner and its CNN subsidiary, again by DRA attorneys. That suit claims that CNN violates California state disability laws by not captioning all of

See Everything That They Say!



HearingLossCA_ad_ff.indd 1 1/16/12 2:14 PM

the news videos that it places on its website. (Recent federal legislation requires broadcasters to caption on-line videos originally shown in broadcast form, which would affect some of CNN's on-line videos, but short excerpts are exempt from the federal law, and the law does not apply to material not first shown on television).

CNN initially tried to invoke the defenses available under the so-called anti-SLAPP statute, an acronym for Strategic Lawsuits against Public Participation. That law provides that when suit is brought against a person or business exercising its free-speech rights under the Constitution, the suit may be dismissed at the outset unless the party bringing the suit can show that it will likely prevail.

The anti-SLAPP statute was intended to deter large corporations from filing defamation lawsuits against citizens who criticized their development plans in public forums. To prevent that kind of bullying of citizens by large corporations, the law provides that when a suit is dismissed under the anti-SLAPP statute, the party exercising its First Amendment free-speech rights is entitled to recover costs and attorney's fees from the "big guys." Here, though, CNN tried to turn the tables, and not only prevail, but recover costs and fees from the citizens and advocacy groups asserting their own rights to be free from disability discrimination.

Fortunately, that strategy didn't work. The court said that CNN is free to report any story it wishes however it wishes, which it has the right to do under the First Amendment. But the court said that captioning of that reporting is nothing more than "a mechanical transcription that does not implicate content and the First Amendment," and that therefore, the provisions of the anti-SLAPP statute do not apply.

This suit still has a long ways to go, and significant hurdles remain. Because it was trying not simply to win but to "punish" the plaintiff through an award of fees and costs, CNN has not yet raised the question of whether the state anti-discrimination laws apply to a business like CNN, which has no physical location open to the public. Nor is it clear whether state law can apply to a situation like this, where the issues are national in scope and arguably are better handled by agencies like the Federal Communication Commission. However, the case is still important and useful in ruling that the decision of whether or not to provide captioning has nothing to do with First Amendment free-speech rights – a defense that some businesses, including movie theaters, have tried to raise in a number of contexts.

The internet is a wonderful tool, but for the moment, it is not universally accessible to people with hearing loss. Technologies that would automatically caption online videos may be possible, but at the present time, provide very uneven captioning quality. Should such technology be perfected, that may solve the access problem. Existing laws do not yet provide a direct and usable mechanism for creating access, and new laws may be necessary.

Ideally, the internet sites themselves would find that captioning makes economic sense, and would voluntarily do so through existing technology, despite the costs. At this point, our collective best bet might be to personally and publicly thank those businesses that do provide captioned content on line, and to persist in requesting captions from those businesses that do not voluntarily provide it.

Pasadena is Hearing INACCESSIBLE Is Your City Hearing Accessible?

What have you done to help make the city in which you live accessible for those with hearing loss?

HLA-LA Chapter just formed an Advocacy Committee, Georgia Fleischer, chair. Pasadena has many commissions, one of which is the Accessibility and Disability Commission. The Pasadena City Council is considering merging several commissions, which would severely weaken this Commission. On March 5 three members of the HLA-LA chapter testified at the Pasadena Council meeting, speaking in favor of keeping the commission at full strength as it is much needed. There was an excellent turnout of speakers - three HLA-LA chapter members, four current commissioners, 3 public members and one former commissioner.

Thelma Johnson, chair of the Accessibility and Disability Commission spoke to the City Council of the importance of the ADA, and the significance of the commission's work to the "quality of life issues" facing residents of Pasadena. She reminded the City Council that all municipalities are required to make city services, programs and events accessible to people of all abilities.

Here is Grace Tiessen's testimony. My name is Grace Tiessen. I am a 60 year resident of Pasadena. I served on the Pasadena Commission on Accessibility and Disability from 1990 to 1995. I am a Board member of the Hearing Loss Association of California. I have a profound hearing loss.

Pasadena is INACCESSIBLE to people with hearing loss. The ADA is over 20 years old. Pasadena prides itself on being an accessible city and won an award for Most Accessible City in 2004. This very meeting, right now, is inaccessible to me.

People with hearing loss are by far the largest disability group. We have an invisible disability and are largely overlooked. The population of Pasadena is 137,000. 15 percent or 20,000 Pasadenans have some hearing loss. Five percent or 6850 Pasadenans have a severe to profound loss. Pasadena is doing fine for people with other disabilities, but is hearing inaccessible to 6850 Pasadenans.

From 2006 to 2010, Pasadena spent \$100,000 for truncated domes, yellow mats, for the blind. From 2005 to 2008 Pasadena spent \$400,000 for curb cuts for wheelchair users. For people with hearing loss, Pasadena spent nothing. It's our turn now. Pasadena needs to have annual budget for hearing accessibility.

Pasadena just built Reese's Retreat, its first universally accessible playground designed with special equipment to delight children of all ages and abilities, at a cost \$1,200,000. KPAS, a Pasadena TV station, made a video of the opening of Reese's Retreat. This major disability PR video was NOT captioned.

Pasadena says it promotes use of universal design elements in all new construction and major rehabilitation projects. This Pasadena City Hall recently had a major upgrade and retrofit. But nothing was done for people with hearing loss. We need meeting rooms looped to be able to hear. To my knowledge there are fewer than 5 loops in the entire city of Pasadena. Where are the hearing accessible looped rooms in this City Hall?

I went to the annual Pasadena Mayor's Prayer Breakfast. The Keynote speaker was Dr. Eric Walsh who spoke about "The Prescription for a Healthy City". Pasadena Mayor Bogaard said, "I am committed to Pasadena's progress as a vital City that offers quality of life to all and compassionate concern for those who are less fortunate." I could not understand a word at this Breakfast. The above information came from the program notes. A city that is inaccessible to the large number of people with hearing loss is neither a healthy city, nor compassionate to those who are less fortunate.

I urge you to continue the Pasadena Commission on Accessibility and Disability at full strength until we people with hearing loss gain accessibility.

This large turnout of the disability community further enlightened the Pasadena City Council about the work of the Accessibility and Disability Commission. Will Pasadena begin to become an accessible city to the largest disability group of all—people with hearing loss?

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California State Conferences To Do or Not to Do, That is the Question

By Don Senger

Don Senger was the first president of the Hearing Loss Association-California state association (then named Self Help for Hard of Hearing) when founded in 1989 and currently serves on the HLA-CA Board of Trustees as Board Member Emeritus and advisor. He has also served on a number of commissions and advisory committees, most notably with the FCC's Emergency Alert System, California State Rehabilitation Council, and co-founder of Californians for Television Access.

Well, another California State Conference is now over and as usual we've had a lot of good comments about it as well as a few not so good.

The "Good" is that the majority of attendees enjoyed themselves, learned new things, and had an opportunity to see and try various products in the Exhibit Hall. Speakers and programs met or exceeded their expectations. While some programs may have been presented before at past conferences or at a local chapter, for many attendees it was all new to them.

With over 30 exhibitors packed within as well as outside of the Exhibit Hall, there was an ample selection of products and services to look over, to try and buy on the spot, whether it was assistive listening devices, web-based captioning services for cellphones or iPads, or joining the line to purchase a new iPad for only \$300. All three cochlear implant corporations were on hand to show and explain the cochlear implant devices they manufacture and offer.

Hotel staff was rated as informed, helpful, and patient with those who had difficulty hearing and understanding. Food was great and with a couple of exceptions, guest rooms were what were expected of a premium hotel like the Hilton.

The "Bad"? The biggest complaint was the sound system. With two systems in operation (FM and audio loop) and representatives from two companies plus a volunteer technician trying to set them up and coordinate their operation, some problems popped up that should not have happened. More attention to this area will be given to future conferences.

Cost was another area of concern to many, particularly those on fixed incomes trying to manage in a difficult economy. It has always been the intent of the HLA-CA state association to provide the lowest registration fee possible. The problems this year were multiple - higher hotel food costs with surcharges as well as lower income from sponsors and exhibitors due to the current economic situation.

Based only on actual registration fees, we lost money on the cost of food. For example, what we charged for the dinner banquet was less than our actual cost for the meal and entertainment. But we realized that many people would not be willing to pay more than \$45 for dinner. So we kept the price as low as we could, knowing we would be losing money on the banquet. There were also a minimum number of meals we had to pay for, but had only half that number of banquet attendees.

Thankfully we had enough money coming from sponsorships and exhibitor fees to cover the registration fee shortfall and allow us a modest profit, part of which we shared with those chapters that served on our conference committee and helped make the conference a success.

I bring up all this information in order to give each of you a little background on the ups and downs of conducting a state conference. The question now is what do we do about the next conference? And should there be another?

In August the HLA-CA Board of Trustees will be making a decision on what direction to go. It would be very helpful to have some input from our members to learn what they want, what they like and what they don't like.

Part of our problem is that we are now required to have an annual Walk4Hearing event. At this writing it is our understanding that the National office has decided that this will be held each year in Long Beach. It needs to be done there annually in order to secure repeat sponsorships, as it is easier to get sponsors to contribute every year to the same event rather than every other year. There is some speculation that they also want the event conducted at the same time in Northern California.

Generally, the people who volunteer to conduct the Walk4Hearing event are the same people who volunteer to help conduct the state conference. Consequently, we can't have both the walk and the conference done by the same people at the same time. Finding new and different people to conduct each event separately is not an easy task.

Then there are the sponsors. The companies that sponsor the walk tend to be the same companies that sponsor the conference. It is not likely the companies will sponsor both events, unless they split their contribution in some way.

So our dilemma -- whether to have a conference, a walk, or both. And if a conference is to be held should it be every two years as is now done or every year? Should we rotate locations in North and South or just hold it in Northern California while Southern California conducts its annual walk? Also, to hold costs down and bring the registration fee down, should we make it a one-day event or continue the two-day format? Should we drop the Saturday breakfast? Is \$75 a more acceptable registration fee to you if we make some cuts somewhere that allow us to make that cost reduction? And what was missing at the conference that you wanted to see or hear about? In short, if you want us to continue having state conferences, what can we do to make it more affordable and attractive to you?

Why have a state conference? One of the stated purposes and goals of the HLA-CA state association is to provide education, information, and resources not available elsewhere to hard of hearing Californians. While some of this can be provided by a local chapter, not all chapters have ready access to the resources that the state association can provide at a state conference. And while it is done at a smaller scale than a national convention, our state conferences are more affordable.

We welcome your comments and thoughts, and want to hear from you. Please send them to me by email at dsenger@hearinglossca.org or mail to Don Senger, 2304 Platt Drive, Martinez, CA 94553. I will share the information with the HLA-CA Board at their August 2012 meeting.

What Is It Like to be Deaf? Or HoH?

By Dianne Switras

What is it like to be deaf? or severely Hoh? People have asked me. Deaf? Oh, hmmmm, how do I explain that? Simply, I can't hear.

Noooo, it is much more than that. It is similar to a goldfish in a bowl. Always observing things going on. People talking all the time. It is being a man on his own island among foreigners.

Isolation is not a stranger to me. Relatives say "Hi" and "Bye". But I sit for five hours among them. Taking great pleasure at amusing babies, Reading books, resting, helping out with food.

Natural curiosity perks up Upon seeing great laughter, crying, people upset. Inquire only to meet with "never mind", "Oh, it is not important". Getting such a summarized statement of a whole story.

Supposed to smile to show the happiness. Little do they know how truly miserable I am. People are in control of language usage. I am at loss and real uncomfortable.

Always feeling like an outsider Among the hearing people Even if it was not their intention. Always assume that I am part of them By my physical presence, not understanding The importance of communication.

Facing the choice between the Deaf & Hoh Camping Weekend and Family Reunion. Facing the choice between the family commitment and Deaf & Hoh friends. I must make the choice constantly, And wonder why I choose Deaf & Hoh friends???

I get such great pleasure at Deaf & Hoh Clubs. Before I realize, it is already 2 am. Whereas I anxiously look at the clock Every few minutes at the family reunion.

With Deaf & Hoh people, I am so normal. Our communication flows back and forth, Catching up with little trivia, our daily life, Our frustration in the bigger world. Seeking the mutual understanding.

Contented smiles, and laughing are musical. So magical to me So attuned to each other's feeling. Truly happiness is so important.

I feel more at home with Deaf & Hoh people Of various colors, religions, short or tall, Than I do among/with my own hearing relatives. And wonder why? We understand each other.

Being at a loss of control Of environment, that is, communication, People panic and retreat to avoidance. Deaf or Hoh people are like the plague.

But Deaf & Hoh people are still human beings With dreams, desires and needs Of belonging, just like everyone else.

RESOURCES FOR HEARING LOSS QUESTIONS OR CONCERNS

Hearing Loss Resource Specialists

Jennifer Stuessy, Greater Los Angeles Agency on Deafness (GLAD), Los Angeles 323-478-8000, istuessy@gladinc.org

Pauline Gaeta, Center on Deafness Inland Empire (CODIE), Riverside 951-275-5000, pgaeta@codie.org

Colette Noble, Sacramento 916-359-1893, cnoble@gmail.com

Sr. Ann Rooney, Burlingame annrooney@sbcglobal.net

Bruce Harris, Berkeley bjharris@ieee.org

Valerie Stern, LCSW, Sunland

Psychotherapist - hearing loss and grief, certified equine assisted psychotherapist 310-936-0939, www.valeriesternlcsw.com

Alison Freeman, PhD, West LA. Sherman Oaks Psychologist - hearing loss, trauma and crisis counseling, stress management and teletherapy, 310-712-1200, www.dralisonfreeman.net

For Parents

Independently Merging Parents Association of California (IMPACT)

Parent group focused on securing the best for children regardless of methodology, www.impactfamilies.org

Hands and Voices

Similar approach as IMPACT but nationwide www.handsandvoices.org

Education Helen Walter hwalter1@dc.rr.com, 951-849-6713

For Youth

Training and Advocacy Group (TAG), LA

A self-advocacy group for deaf/hard of hearing children and teens. www.tagkids.us

HEAR YA NOW. Young Adults Group Social events, online community www.hearyanow.tumblr.com

Cochlear Implants

Cochlear Americas

www.cochlearamericas.com

Med El www.medel.com

Advanced Bionics

www.advancedbionics.com

House Research Institute

213-483-4431, www.hei.org Research on hearing loss and vestibular disorders.

Clinics

The HEAR Center, Pasadena

Hearing/speech therapy, Community out reach, hearing aid dispensing. All ages, www.hearcenter.org, 626-796-2016

House Ear Clinic, Los Angeles 213-483-4431, www.hei.org Cochlear implant services

Stanford University

Cochlear implant services cochlearimplant@stanford.edu, 650-736-4351 www.med.stanford.edu/ohns

Hearing and Speech Center, San Francisco 415-921-7658, info@hearingspeech.org www.hearingspeech.org

Lucile Packard Children's Hospital, Stanford Pediatric hearing loss

650-498-2738, jwinzelberg@lpch.org

John Tracy Clinic

Pediatric hearing loss, free services world wide www.johntracyclinic.org, 213-748-5481

Oberkotter Foundation

Pediatric hearing loss, free materials, oral schools, www.oraldeafed.org

Financial Aid

Audient Alliance

audientalliance.org, 206-838-7194

Let them Hear Foundation, Palo Alto 650-462-3143, http://www.letthemhear.org

Career Counseling/Employment Services HLAA Employment Toolkit

Interview strategies; hearing loss and ADA; communication tips; insurance coverage for hearing aids. www.hearingloss.org/ advocacy/Employment.asp#jobtoolkit

GLAD/EDD

GLAD/Employment Development Dept www.gladinc.org

213-478-8000, info@gladinc.org

Vocational Rehabilitation provides service for clients who meet eligibility requirements. Assistance with hearing aids and devices may be provided to clients who need such devices to secure or retain employment. http://www.dor.ca.gov

Deaf/Disabled Telecomm Access (DDTP)

Administrative Committee (TADDAC)

Colette Noble (Hard of Hearing) 916-340-5493, cnoble@gmail.com

Nancy Hammons, (Late Deafened) hammonsn@aol.com

Chriz Dally, (Deaf) ChrizDally@comcast.net

Equipment Program (EPAC)

Brian Winic (Hard of Hearing), lovetwohear@aol.com

Richard Ray (Deaf),

rlrayada@aol.com

Ken Rothschild (Deaf)

KSRothschild@gmail.com

Vacant (deaf/blind)

Free Telephones (CTAP)

www.ddtp.org/ctap

Lawyers

David Grey, david@greyslaw.com Special education law John Waldo, john@wash-cap.com

Captioning of movies/theatre

Online Videos

HLAA, www.hearingloss.org/learn/ hearingloss vids.asp Listen and Speak, children www.oraldeafed.org/movies/index.html

Captions

Captioned movies search engine Captionfish.com

Captioned Netflix instant library www,phlixie.com

Captioned videos of world's leading thinkers. TED.com

How to get Real Time Captioning

Captioning for workshops, lectures, courts Arlene Patton,

arlepatton@aol.com, 626-337-8331 Captioning at College

Colette Noble

916-359-1893, cnoble@gmail.com

Assistance Dogs for hard of hearing/deaf

Canine Companions for Independence

www.cci.org 800-572-2275 **Sam Simon Foundation**

www.samsimonfoundation.com, 310-457-5898

Other Resources

Lip reading classes

www.hearinglossca.org

Aural Rehab Group for CIs, San Diego Mellisa Essenburg, M.S., CCC-SLP

mellisaslp@yahoo.com, 858-232-5842 www.SanDiegoSpeechPathology.com

Hearing Aids 101

Info about all brands of hearing aids www.hearingaids101.com

Better Hearing Institute

Educates the public and medical profession on hearing loss, its treatment and prevention, 202-449-1100, www.betterhearing.org

Living and Coping with Hearing Loss by Sam Trychin

samtrychin@adelphia.net www.trvchin.com

Hearing Loss Network & Web

www.hearinglossnetwork.org www.hearinglossweb.com larry@hearinglossnetwork.org

Hearing Loss Help E-zine

www.hearinglosshelp.com neil@hearinglosshelp.com

Deafness in Disguise

A fascinating look at the history of hearing devices. beckerexhibits.wustl.edu/did

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805-968-2777

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Ventura County Chapter - Thousand Oaks Ruth Pealer, ruth 6572@sbcglobal.net

805-526-9845
Anni Settingsgard, hlaanni@aol.com
Facebook: Search for Hearing Loss
Association of Ventura County

Is your chapter on Facebook?

Social networking has become the way to do outreach, get your projects known and recruit new members. Danny Tubbs metromann@yahoo.com of the HLA-LA chapter will be glad to help you set it up.

Find a chapter near you:

hearinglossca.org/northern-chapters or hearinglossca.org/southern-chapters

Please join us. Meet others who are facing the challenge of everyday life with a hearing loss. Meetings are free and informal. Bring a friend or family member. Everyone is welcome. Hearing loss is a daily challenge you can overcome. You do not have to face hearing loss alone.

No chapter near you?

Our Chapter Coordinators will help you to set up a local group.

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• Southern CA Chapter Coordinator Nanci Linke-Ellis,

nanci@linkeellis.com 310-922-3884 cell 310-829-3884 phone



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310-922-3884 cell 310-829-3884 phone nlinke-ellis@hearinglossca.org

National Board of Trustees Margaret Wallhagen, ex officio Meg.wallhagen@nursing.ucsf.edu FOUNDER Howard E. "Rocky" Stone, 1925-2004. In 1979, Rocky Stone founded the organization as Self Help for Hard of Hearing People (SHHH). Renamed Hearing Loss Association of America (HLAA) in 2006.

JOIN US! Membership includes national and state memberships, Hearing Loss Magazine and The Hearing Loss Californian newsletter. Rates are \$20 Student, \$35 Individual, \$45 Couple, \$60 Professional. For international and corporate rates, please visit www.hearingloss.org.

Please make check out to HLAA and send it to Hearing Loss Association of America, 7910 Woodmont Avenue, Suite 1200, Bethesda, MD 20814 (include name/mailing address/zip code/ email/phone) OR you can join on line at www.hearingloss.org/membership/renew.asp.

HEAR YA NOW is a network of young adults in California ages 18-40. We aim to unite young adults with hearing loss through social events and an online community where information is exchanged about resources, support, advocacy, and scholarship opportunities. Join our active Facebook discussion group HEAR YA NOW: http://www.facebook.com/groups/hearyanow. In order to join, you must receive an invitation to join or email us at hearyanow@gmail.com with your name, brief hearing loss story, and why you want to join HEAR YA NOW.

Website: www.hearyanow.tumblr.com Twitter: www.twitter.com/hearya now YouTube: www.youtube.com/hearyanow

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ITINERANT TEACHERS OF HOH/D support your graduating seniors in their transition from high school by giving them a FREE trial subscription to *The Hearing Loss Californian*. Please send student name/mailing address/zipcode/email to gtiessen@hearinglossca.org.

FREE trial subscription to *The Hearing Loss Californian*. Please send your name/mailing address/zipcode/email to Grace Tiessen, 714 Prospect Blvd., Pasadena, CA 91103, gracetiessen@gmail.com.

FREE. Hearing Health magazine, a quarterly publication of Deafness Research Foundation. Sign up on line at http://www.drf.org.

HLA-California publishes *The Hearing Loss Californian* quarterly in mid February, May, August and November. The newsletter is available through mail, and on line at www.hearinglossca.org/current-newsletter or www.hearinglossca.org/past-issues.

Demographics. Our database consists of 5300 records--1250 California HLAA members; 1345 California audiologists; 1350 California Hearing Aid Dispensers; Dept of Rehabilitation HoH/D counselors; Itinerant Teachers of the HoH/D; Office of Deaf Access outreach centers; members of the Association of Late Deafened Adults; Kaiser Permanente audiologists; members of AG Bell Assn for the D/HoH; Costco Hearing Aid Centers; HEARx Hearing Aid Centers; Sonus Hearing Aid Centers and others interested in hearing loss issues.

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HEARING LOSS ASSOCIATION OF CALIFORNIA

A Hearing Loss Association of America state association supporting chapters throughout California

Hearing Loss is a Leading Public Health Issue

Who We Are

Hearing Loss Association of California (HLA-CA) is a state association affiliated with Hearing Loss Association of America. Residents of California who join our national organization automatically become members of HLA-CA.

Hearing Loss Association of America (HLAA) is an international, non-sectarian, educational, consumer organization of hard of hearing people, their relatives and friends. It is devoted to the welfare and interests of those who cannot hear well but are committed to participating in the hearing world.

Hearing Loss Association of America 7910 Woodmont Avenue, Suite 1200 Bethesda, MD 20814 (301) 657-2248 Voice (301) 657-2249 TTY (301) 913-9413 Fax info@hearingloss.org

Hearing Loss Association of America

The Nation's voice for people with hearing loss.

Hearing Loss Association of America 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. area office, 14 state organizations, and 200 local chapters.

Our clear, straightforward message has changed the lives of thousands of people.

Hearing loss is a daily challenge you can overcome.

You do not have to hide your hearing loss.

You do not have to face hearing loss alone.

HLAA: www.hearingloss.org HLA-CA: www.hearinglossca.org Facebook: Search for Hearing Loss Association of California

