

HLAA Membership & Personal Stories of Hearing Loss

I know that some people have trouble if they cannot see captioning or read lips - - I have tried to put everything we are going to say today on slides.

I will TRY to speak slowly, but please raise a hand if I get to going too fast. Please hold questions until the speakers finish and we will stay after the program to answer them, if necessary.

My name is Louise Smith.

I moved to Sun City about 18 mo ago. I have been dealing with hearing problems (first my husband and father-in-law and now my own) for about 50 years.

For maybe 25 of those 50 years I have belonged to a wonderful organization first known as SHHH (Self Help for the Hard of Hearing), but now called Hearing Loss Assn of America or HLAA. I found out about this great organization from another member of my husband's family who is profoundly hard of hearing and was a teacher of the deaf for many years.

In June 2014 HLAA had their National Convention in Austin, and I was lucky enough to attend all 3 days. I learned so many wonderful things that I want to "spread the word" about this opportunity. I have been surprised to learn since the convention how few people with hearing problems seem to know about this organization.

Carolyn Ponder is the Austin HLAA chapter president and we will want to hear from her also. Tom Kisinger is a long-time friend of mine who has Meniere's Disease and suddenly became totally deaf in one ear while losing some hearing in the other.

He also attended the convention and came home with some Assisted Listening Devices (much cheaper than HEARING AIDS!) that he finds more useful than his hearing aids in some situations.

I have gotten to know Emma Hill since the convention and she is a long time HLAA member and has some other experiences to share with you.

I have slides of some of the Workshop Topics that were available at the convention. I will show just a small sample to give you a feel for what was offered, but I have some printed copies of the complete Workshop schedule for those of you who would like to see what topics were covered in more detail. You can also go to the HLAA web site and see the entire Convention Program

<http://www.hearingloss.org/>

**Events / Convention /
Convention Archive**

Thursday

Newcomers Orientation	Learn what technology is in use in workshops and other sessions, and basically how to plan your time so you get the most out of the Convention so you return home with new knowledge and energy.
The Wireless Industry: Finding the Cell Phones or Mobile Devices to Meet Your Need	Provides an overview of the latest developments in wireless devices and services for individuals with a hearing loss who are students, professionals or young at heart.
Perseverance to Triumph	This Session teaches specific strategies to improve personal resilience and address life-changing setbacks and personal crisis.
Jump that Hurdle, Get the Job You Want!	Don't let your hearing loss keep you from getting the job you want. The key is that the job search rules are the same for hearing people and people with hearing loss. Job candidates must convince hiring managers why they are qualified for the position. Learn methods and tools to show you how you can get past the hearing loss hurdle

Thursday

You Don't Have to Shout to Be Heard	For most users hearing aids and/or cochlear implants work well in daily situations yet in order to fully participate in public venues assistive technology is needed. Hearing loops are preferred by most because the access they provide is easy and seamless.
Bilateral Cochlear Implant Users Panel	Seeing and listening to the stories of the panel members in their journey to regain hearing will be an inspiring experience. For those who presently have one cochlear implant and for those who are thinking about getting a cochlear implant, it is important to see, hear, and meet these individuals who are bilateral
Hearing Loss and Memory Decline as We Age	Case studies will illustrate how technology, communication tips and therapeutic intervention play roles in treating the combination of hearing loss and memory issues for all three groups involved: caregivers, professionals and consumers.

Thursday

Communication Strategies for Surviving the Workplace or Job Search	This workshop will cover the following topics: issues facing persons with hearing loss, what the law says about accommodations, tools to help you overcome obstacles, and tips to make your professional life and your job search a little easier.
Cochlear Implants: What Are the Barriers and What Can We Do to Improve Access	This presentation will discuss and explore seven factors that contribute to low utilization of the life-changing cochlear implant technology.
Hearing Aid Manufacturers Panel: Wireless Innovation to Help Connect You with Your World	A panel of experts representing hearing aid manufacturers will discuss how rapid advances in wireless and connectivity technologies are being adapted by hearing aid manufacturers to help people with hearing loss gain connectivity in new ways.

My 2 complaints are that:

- I could not attend ALL 9 or 10 topics, that were offered each day because there were just 3 slots per day and
- I could not absorb everything I did hear in just 3 days!!

I must say that I learned almost as much from talking to the vendors and other people attending the convention, as I did from the Workshops. I found out about the Bellman device that Tom has when I talked to a man who had been in a workshop with me and said he had Meniere's - - so I stopped him afterward asked him what kind of device he was using.

My personal favorite sessions were the Hearing Aid Manufacturer's panel and the 2 sessions on "Searching for Solutions in Amplification" with Doug Beck. He had some really "radical" (to me) ideas - - like telling us that the standard "hearing test" with the tones is only a "medical diagnostic" tool and of no real value in determining your speech understanding! He also talked about the difference between an "audiologist" and a "hearing aid dispenser." And much much more.

Membership

Complimentary HLAA Membership for Veterans

HLAA is honored to offer two types of membership for United States veterans (both include the other [benefits of Individual membership](#)):

- Digital Membership – **this complimentary membership** includes our award-winning *Hearing Loss Magazine* in digital format only; or
- Non-Digital Membership – *Hearing Loss Magazine* will be delivered right to your mail box; **complimentary for one year**, renewal at \$35/year.

<http://www.hearingloss.org/content/join>

NON Veteran Membership

TYPE	USA-ONLY MEMBERSHIP (Annual Dues)	NON-USA MEMBERSHIP (Annual Dues)
Individual	\$35 (1 year) \$95 (3 year) \$140 (5 year)	\$45 - (Non-USA)
Couple/Family	\$45	\$55 - (Non-USA)
Student	\$20	N/A

You can see that cost of membership is very reasonable even if all you got out of it was the bi-monthly magazine.

I personally have learned so much from this Magazine, I cannot recommend highly enough!!

But as you can see on the next slide, there are a lot more benefits than just a magazine to belonging to HLAA.

Member Benefits

- *Hearing Loss Magazine* – the bimonthly magazine.
- Discounted rate to the annual Hearing Loss Association of America **Convention** held in various cities across the country.
- **Discounts** on hearing aids and cell phone data plans (descriptions follow)
- Educational opportunities such as Leadership Training and the Hearing Loss Support Specialist Training
- The support found in our large **chapter network**. Carolyn will speak to this.
- The tangible results of our work with laws and policies that impact people with hearing loss.
- The knowledge that you are an active participant in a highly-respected organization that is a force for change working on behalf of people with hearing loss
- Online activities such as **HLAA Webinars** (captioned), **chat rooms**, groups for young adults, parents, **surveys**, **HLAA e-News**, and more.
- Participation in advocacy campaigns as a member of HLAA.

The American Hearing Benefits program is available to Hearing Loss Association of America members and their immediate families without any charge.

Benefits to HLAA Members Who Participate in AHB

- Free annual hearing screenings for you and your immediate family
- Referrals to AHB's network of recommended local hearing health care professionals
- Advanced hearing solutions with the latest in hearing aid technology
- Up to 60% off suggested retail prices
- Free full two-year extended warranty with every purchase

Text-Only Mobile Phone Plans: Just Show Your HLAA Membership Card

So, the next time you purchase a text-only plan, you don't need an extra visit to a hearing health care provider: you can simply show your **HLAA Membership Card**.

Discounts through cooperating companies

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- **SoundAid Warranties** provides a 10% discount on annual warranty premiums to all HLAA members.
- **Harris Communications** HLAA members get a 20% discount on most items in our store.
- **Avis** gives members \$20 off a weekly car rental in addition to a possible 25% discount.
- **Teltex, Inc.**, provides HLAA members a 20% discount off selected items.
- **ClearSounds Communications** gives a 20% discount at checkout to HLAA members.
- **HITEC** gives a 20% discount for assistive listening devices.
- **HLAA Travel** is a full-featured travel website.

<http://www.hearingloss.org/content/member-benefits>

Thanks to Emma Hill, I have brought a selection of past issues of the HLAA magazine so that you can look at them. And my most current issue which has a lot of Convention Information. Tom also brought his Convention Brochure.

I have also brought brochure's and check lists that you can get from HLAA and catalogs from Harris Communications and HARC with many helpful products including Assisted Listening Devices.

There are not enough for everyone to take one home so please look and share and if you take one home, please bring it back to the next meeting.

Carolyn:

My name is Carolyn Ponder. I am the president of the Austin Chapter of HLAA.

I have had a profound hearing loss since I was 3 years old. I received my first hearing aid in 1st grade. In 2000 I received my Cochlear Implant. All my family is hearing impaired. I have spent my life around those with a hearing loss.

I have been a member of SHHH (Self Help for Hard of Hearing) and HLAA since 1987. I have been a member of both the National Organization and SHHH Austin chapter.

Howard E. "Rocky" Stone a CIA retiree of Bethesda, Maryland founded SHHH Self Help for Hard of Hearing in 1979 as a non-profit educational organization. Rocky's dream was for SHHH to be "The Nations Voice for People with Hearing Loss.

In 2006 the Name SHHH was changed to HLAA Hearing Loss Association of America.

Miss America of 1995, Heather Whitestone, was the first winner with a profound hearing loss. She gave the keynote address at the SHHH National Convention held in Dallas, TX.

My name is Tom Kisinger. I am a retired Naval Aviator and more recently became a retired engineer.

Needless to say, my career was spent in a very noisy environment - jet engines, gun fire, etc. However, I never thought about hearing loss since I always wore hearing protection, and besides, as a flyer I was immortal. After all I had survived over 400 combat missions and over a 1000 carrier landings so nothing bad would ever happen to me.

Several years ago, I was proven wrong. I went from a healthy, happy, aviator to an individual that had totally lost hearing in one ear and had diminished hearing in the other. This happened over a period of just a few hours.

As a result I now wear hearing aids. Unfortunately, these do not work well in all environments – restaurants, theaters, lectures, meetings, etc.

My audiologist and ENT never talked about the HLAA or mentioned that there were other devices that may have helped in these environments. Let's face it, they are in the business of selling hearing aids.

I first heard about the HLAA through Louise. She mentioned that the national convention would be held in Austin this year and since we had just bought a house in the area it would be an opportunity to attend.

I am not much of a joiner but if you get to know Louise you will learn that she is persistent. She convinced my wife and I to attend and I am glad she did. I learned that I was not unique and there was a wealth of information and support available – and had been, but I had not accepted that anything could be done about my hearing situation except what I had been told by my ENT and audiologist.

I attended as many of the programs/presentations as I could. We split up and covered as many as the three of us could and compared notes in the evening.

There was too much to absorb in one convention. It was like trying to drink from a fire hose. We will be going to the 2016 convention just so I can continue to learn.

Anyway, I discovered there were devices that could assist me in my daily activities. I purchased two as an experiment to see if anything helped.

The first was a personal amplifier. It has two settings – directional and omni-directional. It also has a telecoil capability

When I am listening to a speaker I select directional and point it at the him/her. I can usually hear clearly and I do not have to keep asking someone else “What did he say?”

The “omni” setting I use when in meetings around a table. I place the device on the table and can hear everyone clearly.

The telecoil allows me to listen to the speaker without ANY outside noise. Unfortunately this only works if the venue is equipped with a hearing loop as this room is.

The second is a blue tooth device that uses bone conduction and active noise cancellation.

As you can see it is not invisible when it is worn, but I usually use it as a hands free device to connect to my phone while I am driving. I have talked to many people while driving and they all comment on how clear I sound – there is no background noise. The bone conduction makes my reception much clearer. So it is a win-win for me.

It has the capability of connecting to most blue tooth devices and many people use it to listen to their TV – if it has bluetooth – and music. I bought this after we had moved our blue tooth audio/video amp to our new home so I have not been able to see if the amp supports the connection.

AFTERSHOKZ also makes a wired version that is less susceptible to moisture and they recommend it for athletics, i.e. listening to music or phone while jogging.

Louise has at least one catalog that shows my ALD (Bellman) and many other devices. Unfortunately, the SHOKZ2 is not shown. You have to go to their website to get additional info. (WWW.aftershokz.com) We brought a few printouts of the specs.

The long and short of it is that there are devices out there that will help you hear and understand better in many situations, even if you do not have a major hearing deficit.

I wish I had had these devices earlier in my career, even though I had not yet lost my hearing.

In conclusion, I would like to say that a loss of hearing – and understanding – is not something to take lightly.

Most of us do not want to admit that we are – at least in our eyes – less capable than we were when we were younger. But if you lose your hearing you lose a large part of your world.

My hearing loss came suddenly. My hearing had not been deteriorating so it was unexpected. What I found out – too late for me – is that **a sudden hearing loss** is a true **MEDICAL EMERGENCY**. Hearing professionals say that if it is not treated within 24 hours the hearing loss may be permanent and irreversible. This is not currently understood by all of the medical community, but the message is being spread by organizations like the HLAA.

Emma Hill:

My hearing loss began with a severe cold and ear infection when I was 3 years old. After I recovered Mother noticed that I would look at her and Dad intently when they were talking at the supper table. I was teaching myself to lip-read.

The ear infections continued. When I was 5, Doctor's discovered that I had oversize adenoids. Surgery followed but could not reach all the adenoids.

When I was 10 Johns Hopkins Hospital in Baltimore announced a way to remove adenoids by radium treatments. Trips for treatment at Johns Hopkins were by train overnight from Austin to Union Station in Saint Louis, a train change and another overnight to Baltimore. The treatment took about an hour. It was back to the train for Saint Louis and another train to Austin. The 3 treatments about 6 months apart successfully removed the adenoids and prevented further hearing loss.

I was well acquainted with original Union Station in Saint Louis after the trips and I am pleased to know that the HLAA Convention for 2015 will be at that grand old station.

Radium treatments stabilized my hearing loss and I began to wear a huge hearing aid at age 12. Technology has reduced the size and improved performance of hearing aids. With lip-reading and a behind the ear aid, I completed college, worked, married, raised a family, traveled and retired.

It is important to see a qualified doctor that specializes in treating the ear in the early stages of hearing loss to determine the cause of your hearing loss and to choose the most appropriate help for your hearing.

One lady thought she would need a hearing aid but a doctor specializing hearing problems found that the tiny bones in her middle ear had grown together. Surgery was successful and she did not need a hearing aid.

For another person the ear specialist determined that her hearing was damaged by medications. She has to tell all other doctors to not prescribe ototoxic meds.

Usually in the early state of hearing loss a person does not need all the “bells and whistles” of the more expensive hearing aids. At other times one may need an advanced hearing system.

I had a sudden decrease in my remaining hearing after I retired but my husband served as my ears in some situations. After his death I needed more information and blinking light gadgets. I became active in the Fort Worth Chapter of HLAA.

It is in the Chapter meetings that I learned of medicines that damage hearing, helpful products and coping skills.

Carolyn has shared information on the organization and there is more in the handouts.

JUNE 25 – 28, 2015 HLAA Convention in St. Louis MO

The HLAA Convention 2015 will be at the renovated St. Louis Union Station - now a Double Tree by Hilton Hotel. It is on the National Register of Historic Places. You will find helpful information and friendly people.

P.S. It is surrounded by a mall of interesting shops.

[**http://www.hearingloss.org/content/convention**](http://www.hearingloss.org/content/convention)