ALDA News Discontinues Print Edition

In November, the ALDA Board voted to discontinue paper copies of the ALDA News. This decision was made due to the cost of publishing the print edition and the need to reduce costs for the organization overall. Many members have already been receiving the electronic version, which is in full color. Former print subscribers will be added to the list for the electronic version. Members who do not have email addresses will receive a paper version of the web issue through the mail.

Loving Someone with a Hearing Loss

By Eve Leonard

The first time I met John Waldo, he had come to the singles book group I was leading at The King’s English, a small bookshop in Salt Lake City, Utah. He arrived early and took a seat directly across from me. He was charming and bright and well-spoken, but what impressed me the most was that he seemed to hang on my every word. When I or anyone else in our circle spoke, we had his complete attention. At the break, as we helped ourselves to wine and conviviality, he sought me out for a focused, one-on-one chat. He eventually won not just my notice but my heart, and we’ve been a couple ever since.

What I didn’t realize at the time was that John was using his best coping skills so that he could participate in our discussion and fully communicate. Probably most of you know John, or know of him. Hard of hearing likely since he was a small boy, he was wearing two hearing aids when I met him. The next month, when he made the bold move of sitting next to me in the book group circle, he sacrificed easy speechreading for cozy proximity. It’s a trade-off we have been navigating ever since. I’m the wife of someone who doesn’t hear well, and that’s both a challenge and an amazing blessing.

When my three teenagers first met John, they were thrilled. They thought, “Here’s a man who won’t hear all the shenanigans we’re up to!” And John had a plan for coping with their ruckus. When the volume and chaos was too much, he simply unplugged.

For most of our married life, John lived and worked exclusively in the hearing world. His hearing aids were state-of-the-art, and he had developed excellent speechreading skills. Even so, it wasn’t always easy. On our first date, we went to a British movie I wanted to see, not realizing how impossible it would be for him; I learned years later that he wasn’t able to follow any of it. When our whole family watched The Simpsons, John missed all the dialogue and fun. TV wasn’t his thing.

My kids and I always made annual treks to the Cedar City Shakespeare Festival, but when John joined us, he wasn’t able to understand any of the performances. Dinner parties around our long rectangular table left him unable to follow the quick and wonderful banter. Playing music in our home made conversation difficult. Gradually, many of things I dearly loved

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Note from Nancy

By Nancy Kingsley, Editor-in-Chief

This is a combined Fall 2015—Winter 2016 issue of the ALDA News. The reason we didn’t publish a separate fall issue is because we didn’t receive enough submissions to do so. Fortunately, our new managing editor, Marta Watson, was able to obtain enough additional articles for us to produce the issue you are now reading. But we are always in need of submissions (at least 600 words long), since we publish four issues each year.

We are looking for anything related to hearing loss—we only ask that articles not tell others what they “should” do. You don’t need to be a polished author to write for us, as we edit submissions for grammar, etc. We particularly want to know about your experiences, feelings, and concerns about having a hearing loss or being connected to someone with one. Submissions from professionals in the field are also welcome. If you would like to submit an article or want more information, just contact Marta at aldamartacitaw@gmail.com.

Marta’s Meanderings

By Marta Watson, Managing Editor

It’s been such a pleasure working with all of our contributors to this issue. We have a very eclectic lineup, including personal stories and advocacy updates, but the primary focus is ALDAcon 2015, which took place in September in Scottsdale, Arizona. Hopefully, whether or not you were able to attend, you will experience the thrill of those Desert Vibes! You’ll read articles by this year’s I. King Jordan award recipient, Dr. Neil Bauman, and our Able ALDA award winner, Terri Singer as well as two reflections on hearing loss through the eyes of hearing spouses, and much more. There’s a lot of enjoyable winter reading here!
Dealing with My Spouse’s Hearing Loss

By Amanda Mchenry

When I met my husband and we started dating, I never considered that his hearing loss would be a challenge in our marriage, but it became evident after we were married. Part of my husband’s profound hearing loss is due to osteoblastoma (a bone tumor). When it was removed from his head, the surgeon had to cut through the auditory nerve. At the time, he was told that he was the only person to have had an osteoblastoma in the head.

This has been a real learning curve for me about my husband’s hearing loss. I believe I have more compassion for all people with partial and total hearing loss because of this experience. I have even tried to learn a little bit of sign language.

I am definitely protective of my husband when we are in public. If I know he doesn’t hear someone or understand what someone is saying, I step in to help. However, it wasn’t until I visited the audiologist with him that I gained a greater understanding of the details. I then realized that I could be more sensitive at home concerning his hearing loss and the challenges it presented.

I couldn’t understand why I had to repeat things so often and I couldn’t comprehend how he could hear me so wrong. The visit to the audiologist was a real revelation for me. It helped me to realize how he puts some words together based on context and if the subject is quickly changed, he may not catch up right away. I know I am one to change subjects often.

Ever since that visit, I have tried to be more sensitive. I am a Hebrew teacher and he would often ask me how to pronounce something in Hebrew, but he said he hated to ask because of my impatience with him. It certainly struck me hard to hear that from him. One thing I find ironic is that my husband is quite impatient with me if I ask him to repeat something. I would think he would understand, but he doesn’t seem to grasp that sometimes I need things repeated too.

Pronunciation can be challenging for my husband because many times he is attempting to say something based only on how it looks in writing. Of course, our English language is not so simple and that doesn’t always work. I worry that people think that he is not very learned because of that. Sometimes the mispronunciation can be somewhat funny and we can get a good laugh out of it.

One of the challenges at home is that my husband doesn’t wear his hearing aids. He doesn’t realize how loud he is and that is hard on me because I am sensitive to loud noise. Clanging dishes are like fingernails on a chalkboard to me, and I haven’t been able to get him to understand this. So many little things he does are hard on my sensitive ears.

I find it interesting to observe some of the things he cannot hear, such as high-pitched noises. He usually cannot hear the purr of our cat even when her motor is quite loud to my ears. He is good at fixing cars, but he often has to rely on my ears to try to figure some things out. It is hard sometimes for me to describe certain noises that I need him to be aware of when it comes to our vehicles or other things around the house.

We always use the closed captioning on the television, and sometimes that is a pain because the captioning gets in the way of what is on the screen. I can talk while watching television, but he needs to focus on the closed captioning. My mom was thrown off when we were at her house and put the closed captioning on her television. She didn’t understand why we were using it.

I continue to struggle with the need to be looking right at my husband when I talk to him. Another frustrating thing is that he can call out to me anywhere in the house if he needs me, but I can’t do the same for him. If I am in the shower and need something, I am on my own. I doubt that he would hear me if I ever had to scream about something.

Sharing life with a person with a hearing loss has its challenges, but it is certainly not anything that we cannot overcome together. I think, as with all things in marriage, it is important to work to understand each other and to communicate. I know I don’t want to be insensitive to the things that he is dealing with and I hope he feels the same way about me. I still have to be reminded about the things he doesn’t hear at home because it is easy to take for granted that I have my hearing.

My husband wears hearing aids to help him hear better and I wear earplugs to help me hear less. I think we are quite a pair.

Amanda is a freelance writer and blogger who likes to share about her adventures on the homestead with her husband, cat, and chickens. She is also a Hebrew professor and Bible study teacher. She can be contacted at chickmamasan-writes@yahoo.com.


ALDAcon 2015 Award Winners

By Steve Larew

Dr. I. King Jordan Award winner: Dr. Neil Bauman

As I was going through my education, I came across writings by Dr. Bauman several times. As a social worker, I was excited to see how much he addressed coping with hearing loss and the emotional impact hearing loss has on our lives and everyday communication. But until last year, I had never met the man behind the writing.

The first time I met Dr. Bauman was through a third person, who informed me that he was frustrated by the lack of clear lighting during the luncheon at ALDAcon and wanted to know if we could do anything about it. AND HOW HAPPY I WAS THAT HE SAID SOMETHING! Through my work, I talk with people every day about being assertive about their hearing loss. If you say nothing about what you need, you get exactly that back—NOTHING. This incident showed me that not only does Dr. Bauman talk the talk in his writings, but also walks the walk in his everyday life.

ABLE ALDAAn Award Winner: Terri Singer

We all bring with us to ALDA differences, not only in how we lost our hearing but also our personalities. As much as we talk about making sure everyone is included and part of ALDA regardless of hearing loss and mode of communication, I have also learned how important it is to value those differences in regards to personality and what people bring to the ALDA table…and let me tell you that over the last several years, Terri has brought A LOT to ALDA.

Terri has worked on different capacities for several ALDAs, been responsible for writing, collecting and editing the ALDA Reader, written for and been a part of the ALDA News. Since this is a short summary I am not trying to document every way she has helped and I know will continue to help and support ALDA. In fact maybe you will see her in a different role with ALDA starting in 2016! What I do know is that ALDA is a better and richer organization with having her on our team!

ALDA Angel Award Winner: Carol Postulka

The Angel Award is presented to an individual, group, organization, or business that serves as an unsung hero through dedication and support to the growth of our organization. Throughout the years, Carol has worked in that capacity for us behind the scenes. No task has been too small or too big for her to complete.

Carol first became involved with an ALDA group in Freeport, Illinois and began serving ALDA at ALDAcon 1995 as her group took on the task of hosting ALDAcon. She continues to support and encourage new people by sharing the goals of ALDA—education, advocacy, role modeling, and support. She has served as a committee member at the convention and as board member and social chair in her chapter, to name a few of her contributions. Without the assistance of unsung heroes like Carol who volunteer their time and service to our organization, ALDA would not exist.

President’s Appreciation Award Winner: Cheryl Heppner

In addition to being a previous president of ALDA, Cheryl served as the ALDA representative to the Deaf and Hard of Hearing Consumer Action Network (DHHCAN) for the past 23 years. During this time she has been an officer of that organization, most recently as vice chair. She has taken a leading role as an advocate for improved captioning and video relay services.

While in this role, Cheryl has also been the chair of the ALDA Advocacy Committee, and she continues to serve on the Editorial Review Board for the ALDA News. She was not in attendance for ALDAcon 2015, so the personal hug of appreciation has been placed on hold.

Steve Larew
This Is My Life—From Being Hard of Hearing to Running the Center for Hearing Loss Help

By Neil Bauman, Ph.D.

I was born with an extremely rare kind of hereditary hearing loss—one that let me hear high-frequency sounds so faint that a person with perfect hearing needed the sound pressure level amplified 1,000 times before he could just faintly hear them, and yet at the same time, at the frequencies our voices are pitched—around 1,000 Hz—I needed the sound pressure level amplified 100,000,000 times before I could just hear these sounds.

Having this extreme reverse-slope hearing loss meant I could hear whispers from across a room, but couldn’t hear a person talking to me from just three feet away without speechreading. Furthermore, in the late autumn I could hear a single dry leaf skittering along the gutter from half a block away but couldn’t hear thunder unless it was directly overhead—and even then it wasn’t very loud. That’s one strange hearing loss!

Even so, I went to a regular school. My only accommodation was to be able to sit at the front of the classroom. I didn’t get a hearing aid until I was in grade 10. Fortunately, I did well at school in spite of my hearing loss. This was due to four things. First, I am a good speechreader—I had to be in order to “hear” anything. Second, I was an avid reader and made up for my lack of hearing by learning through reading. Third, God had given me a good brain to learn things. And finally, I had the drive to achieve in spite of my lack of hearing.

I lived a more or less normal life—went to college and accumulated a handful of degrees in various fields, worked in several jobs, got married, and had two daughters—one of whom has my rare kind of hearing loss. For 40 some odd years I didn’t have much to do with people in the hard of hearing world—I was just involved in living my life in the hearing world.

However, when I was 42 or so, something happened that totally changed the course of my life, although I didn’t know it at the time. Out of the blue, I received a letter asking me if I would be interested in becoming a speechreading and hearing loss coping skills instructor. I thought about it and, because I was between jobs at the time, I said yes. Thus began my contact with other hard of hearing people and hearing loss organizations. Somehow the coordinator for the new “Coping with Hearing Loss Independence Program” (CHIP) sponsored by the Canadian Hard of Hearing Association (CHHA) had heard about me and asked if I would be a part of this new program.

CHIP was a three-year program for people in Alberta, Canada. About 30 of us met for one week of classroom work to learn Level I of the program. Then we went home and taught it to hard of hearing people in our towns and surrounding areas. The following year we met again for a week to learn Level II and then went home and taught it to the people who had taken the Level I course the previous year. Ditto for the Level III program.

At the time, I lived in central Alberta on the cold Canadian prairies where the temperature at times fell to -40 degrees F in the winter. Since we typically taught our classes in the fall and spring—and since winter came early and left late—most of our classes were conducted when snow was on the ground, not to mention blizzards blowing at times. The result was that attendance was sporadic for some students, particularly the elderly ones. Travel was just too difficult for them under these conditions. This got me to thinking about how I could make this program available to everyone, no matter where they lived.

I decided to distill all the information I had learned while in CHIP training, plus all the coping strategies I had learned through living a lifetime as a hard of hearing person, and put them into one book that anyone could read. I chose the grandiose title of Everything You Wanted to Know about Your Hearing Loss But Were Afraid to Ask (Because You Knew You Wouldn’t Hear the Answers Anyway). This title was somewhat autobiographical because I remembered lots of times when I wouldn’t ask people questions because I knew I’d never understand what they replied.
Believe it or not, receiving the 2015 Able ALDAn award was not the highlight of ALDAcon 2015 for me. While I admit it was one of them, nothing could surpass just being with my ALDA friends. I was particularly eager to see Georgia van der Gen, our friend from Holland, and to meet Marta Watson, who had been a constant support throughout planning the program for the ‘con last year.

I inherited a sensorineural hearing loss that became noticeable at age 37. I was fitted with bilateral hearing aids and used those until I lost all hearing in my right ear in the late 1990s. In 2005, I received my first cochlear implant at Riley Hospital in Indianapolis, and I lost all hearing in my left ear a few months later. Having regained most of my hearing in the right ear, I was able to wait five years before receiving an implant in the left ear at Vanderbilt University Hospital in Nashville.

I joined ALDA after years of urging by my cousin, Dennis Gonterman, who had been a member for many years. I resisted his invitations until the convention was to be held in St. Louis, less than three hours from my home in Evansville, Indiana. I attended ALDAcon 2006 and haven’t missed one since. For me, the five days of ALDAcon are the best of the whole year. Nowhere else do I feel so normal and included, and I’m never told, “never mind.” ALDAns are the best communicators—we truly focus and listen and work to be certain our conversations are understood.

In 2009, following ALDAcon in Seattle, Kim Mettache contacted me to suggest that our Northwest Indiana chapter submit a bid to host ALDAcon 2011 in Indianapolis. I agreed to chair the program committee and immediately contacted Jane Schlau for assistance in putting a bid together. Jane was an enormous help—we’d never have won without her guidance and the support of Linda Drattell (ALDA’s president at that time). Kim had a gazillion ideas, and I implemented as many as possible. We’re most proud of arranging the free captioned movie and live play and our Friday night banquet in the Indiana Rooftop Ballroom.

Serving as program chair requires ultimate organization and dedicated communication with presenters, speakers, the ALDA Board, and ALDAcon committee members. I developed spreadsheets for tracking every task. There never really was a moment of panic. The willingness of the Embassy Suites sales and catering agents to bend over backwards to please us made the job a delightful experience. The night manager came for the final minutes of our karaoke party and was thrilled to see our enthusiastic and joyful spirit. He even joined hands as we sang “You Are the Wind Beneath My Wings.”

I had previously served on the program committee for ALDAcon 2012, with chair Marylyn Howe. With the planning changes implemented the year before, Marylyn and I were able to put together an outstanding program that everyone enjoyed. In 2013, I worked with Marylyn to locate representatives from an Indian tribe to provide a dance routine as entertainment following the Friday night banquet.

While preparing for ALDAcon 2014 in Norfolk, Virginia, the planning committee experienced a last-minute cancellation of Thursday’s boat excursion and were at a loss for a replacement outing. Since I had established rapport with Regal Cinemas in 2011, I offered to contact the company to arrange for a captioned movie to replace the cruise. Regal had been generous in 2011, and they came through with a huge discount in 2014. The planning committee was very pleased and the then ALDA president, Dave Litman, recognized my effort at the Friday night banquet.

Because of all the experiences mentioned above, when Dave asked me to chair the program committee for ALDAcon 2015, I felt well prepared to handle the responsibilities. I expanded my organizational spreadsheet and immediately began updating forms and letters with the Scottsdale ‘con logo. My past experience helped everything to run smoothly until May. At that time, the Hilton sales agent advised me that one room would not be available to ALDA for any of the five days. This meant cutting the exhibit hall to one salon, as two others were needed for dining and plenary sessions. Then, in June, the sales agent notified me that yet another room had been given to a different group. Panic almost set in as I looked for ways to rearrange the meeting rooms. Because of the inconvenience, I was able to negotiate with the hotel to give us a hospitality suite at no charge, but the program schedule had to be revised once again.

The only fly in the ointment for me at ALDAcon 2015 was the overcrowded workshop rooms. There was no way to anticipate such a large turnout, especially with 55 newcomers, mainly from the Phoenix area. While I am grateful to the Arizona Commission for the Deaf and Hard of Hearing and Cynthia Amerman’s Adult Loss of Hearing Association (ALOHA), I wish people had...
Editor’s note: John Waldo has graciously agreed to write this column for each issue of the ALDA News to keep us informed about relevant advocacy issues, progress, and needs.

At ALDAcon 2015 in Scottsdale, President Steve Larew announced that our long-time advocacy chair Cheryl Heppner had retired. I asked to be considered as a replacement, and I’m pleased that the ALDA Board agreed.

Cheryl was an active member of the Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN), a consortium of advocacy organizations that represents our interests before federal regulatory agencies on matters like television caption quality. Because DHHCAN meets monthly at Gallaudet University in Washington, D.C., I could not take her place on this group. Fortunately, our dear friend Bernie Palmer (who, like Cheryl, is a former ALDA president) stepped into that role.

Better laws and regulations, while necessary, are not sufficient. Those measures need to be implemented in the real world. That is what I have been trying to make happen for the last eight years in Washington State and Oregon. This is an area where ALDA can make a significant contribution—indeed, it has already done so. I want to use this opportunity to let our members know how I envision ALDA working in a meaningful way to improve all of our lives.

When enacted 25 years ago, the Americans with Disabilities Act (ADA) stated that it was to be a “clear and comprehensive national mandate for the elimination of discrimination against people with disabilities.” For those of us with hearing loss, the ADA rightly declared that to eliminate discrimination, we must be provided with “effective” communication, including means other than sound.

The ADA requires government entities and “places of public accommodation”—private businesses open to the public—to provide that effective communication at their expense. They must furnish “auxiliary aids and services,” defined by example as interpreters or “other effective methods of delivering aural material to individuals with hearing impairments,” unless the business can demonstrate that doing so would impose an “undue burden.”

Some businesses have complied. Most of the major movie-theater chains now provide individual devices that enable us to read captioned dialogue without changing the movie-going experience for others. Some live theaters provide some captioned performances, and some provide induction loops that work together with our hearing aids and cochlear implants. So life is better for us today than it was before the ADA was enacted.

That said, I don’t think any of us believes that public life is completely open to us in the same way those events are open to people with complete hearing, even after 25 years.

When what is supposed to happen doesn’t happen, the logical conclusion is that somebody is not doing their job. And that is certainly the case here. So the next logical question is, who is it that is not doing their job?

The answer is…it’s us. You and me. Every one of us who copes with hearing loss by isolating ourselves and withdrawing from the life that many of us used to live frustrates the ADA’s promise of letting us live that life again. And this is where ALDA advocacy can make a difference.

The underlying reality is that there is no effective ADA “police force.” While the federal Department of Justice has done admirable work in enforcing ADA requirements in response to complaints, it does not have the personnel necessary to monitor the millions of agencies and businesses that are subject to the “effective communication” requirements.

Obtaining implementation of the ADA’s promises is our job—yours and mine. The ADA states that anyone “subjected to discrimination in violation of this chapter” can go to court and get an order requiring the business to provide the services to which the law says we are entitled.

Eight years ago, I began devoting my legal practice exclusively to implementing the ADA and some state disability laws for those of us with hearing loss. Using a model developed primarily by environmental advocacy groups, I worked with oth-

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ers in Washington State to form the Washington State Communication Access Project, or Wash-CAP. This is a nonprofit corporation whose stated purpose is to enrich the lives of people with hearing loss by making public businesses accessible to us.

Wash-CAP’s overriding objective was to become seen as an organization that is knowledgeable, reasonable, and formidable. Through our collective experience and those of our members, we have developed a body of knowledge about the technologies that will provide us with effective communication and the providers of those services. We eagerly share that knowledge with businesses willing to work with us.

We try to be reasonable. We contact the businesses with a friendly letter explaining who we are, what we need, and why. We encourage continuing discussion to develop solutions that work for both sides. As part of that effort, we recognize that no accessibility solution is going to be 100% perfect 100% of the time for 100% of people with hearing loss. But we also firmly take the position that the inability to do everything cannot become an excuse for doing nothing.

We also need to be formidable. While we try for cooperative outcomes, when businesses either refuse our requests outright or cut off communication, we need to demonstrate that we will indeed go to court to vindicate our rights, and that we will be successful.

As a new organization, Wash-CAP believed it would be important to establish credibility with both the hearing-loss population and the businesses that we were approaching. And we believed that the best way to establish credibility was to develop an essentially unbroken record of success.

We began with live theaters in Seattle. After some correspondence and discussion, Seattle’s largest theater, the Paramount, began offering one captioned performance of each of its productions—the first theater in the Northwest to do so. Seattle’s second-largest live theater, 5th Avenue, took the position that it couldn’t afford captioning, so we had to go to court. But once we did that—essentially calling their bluff—they instituted captioning, we dismissed the lawsuit, and that theater has been delightful to work with.

Another live theater, Seattle Rep, added captioning voluntarily. A fourth, the Intiman, pleaded poverty and subsequently proved the point by shutting down. We are presently in discussions with the ACT Theatre about captioning, but we don’t yet have a resolution.

Although it seemed risky at the time, the Wash-CAP board of directors believed we needed to address the problem of movie captioning. I was concerned, because suits seeking to compel movie captioning had previously been unsuccessful, including a case from Arizona that was then on appeal.

So Wash-CAP did two things. First, we filed a friend-of-the-court brief in the Arizona case, asking the Ninth Circuit Court of Appeals to reverse the trial court and rule that the ADA does require movie theaters to provide caption-viewing devices. Then we sued the corporate theater chains that operated in Seattle under a Washington State law that we believed was better than the ADA in many respects.

I traveled to San Francisco to watch the oral argument in the Arizona case, and while having a cup of coffee in the snack bar prior to the argument, I had the great good fortune to meet Linda Drattell, who was then immediate past president of ALDA. We talked a little about what our group was doing in Washington State, saw some possibilities in California, and agreed to keep in touch.

The parallel movie cases were both smashing successes. The federal appeals court in the Arizona case ruled that movie theaters must provide individual viewing devices unless they can show that doing so would be an “undue burden,” a term that is not defined with any precision in the law itself, the implementing regulations, or case law. At just about the same time, we got a very similar ruling from the Washington State court.

Shortly afterwards, I got a call from Sid Wolinsky of Disability Rights Advocates in Berkeley, who wanted to discuss bringing a case in California against the movie theaters there. I got in touch with Linda Drattell and subsequently with another ALDAn, Rick Rutherford. We agreed that Rick and Linda would be the individual plaintiffs and ALDA would be the organizational plaintiff. We decided for a number of reasons that the Cinemark chain was the appropriate target defendant, and after Cinemark failed to respond to a request letter, we filed a class-action lawsuit.

After some preliminary skirmishing, we went to mediation, during which Cinemark agreed to equip all of its California theaters with

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became something that divided us or isolated John. I gave up lots of things and became a bit isolated, too.

On October 19, 2000, John’s hearing grew significantly worse when he lost all the hearing in his “good” ear overnight. The doctors checked for causes and sent us home to cope on our own. For a year or two we waited anxiously to see if he would lose all his remaining hearing in another sudden attack. Fortunately that didn’t happen, but over the next several years, John’s hearing grew worse. By 2010, we could only communicate in a quiet, well-lighted room, face-to-face. Off-hand comments and casual humor went out the window. The ease and charm of our lives together faded, and I found myself living in a world sometimes almost as silent as his.

Fortunately for both of us, during these years John became involved with ALDA and found a community of wonderful folks. Some of you encouraged him to pursue testing for a cochlear implant. By then we had our first grandchildren, and John wanted to be able to talk to them and hear their sweet little voices. Five years ago he had a unilateral implant, and that turned our lives around. Other areas improved as well. We had already begun to watch all our TV shows with captions. And through John’s and others’ work, we can now go to the movies whenever we choose. The ease and charm of our lives together faded, and I found myself living in a world sometimes almost as silent as his.

Other areas improved as well. We had already begun to watch all our TV shows with captions. And through John’s and others’ work, we can now go to the movies whenever we choose. John “hears” them more clearly than I do through the closed captioning devices available at all the showings. (After watching British movies, my friends and I ask John to explain the bits we missed!) We’ve been known to text each other in bed after John “unplugs.” Many of the sports venues we attend have open captions, and we’ve enjoyed live theater with open captions prepared in advance, especially the Oregon Shakespeare Festival in Ashland.

There is nothing unique about our story. Through the hard of hearing, late-deafened, and Deaf friends John has made and who have welcomed me as well, I’ve learned so much about how others cope and thrive. I’ll never forget one evening at ALDAcon in Indianapolis, when John Kinstler was telling a huge group of us gathered in the bar a joke about the dangers of weight lifting while wearing CIs. I watched in awe as he repeated the joke over and over with the same good humor and patience until every person there had heard the punch line and was sharing in the laughter. I learned a lot about what I could do better that evening. I’ve seen first-hand how important this community of friends is to the members, and how joy-filled ALDA gatherings are.

After this year’s ALDAcon in Arizona, John told me that several attendees said that if they were offered a chance to hear perfectly, on the condition that they would have to give up all the connections and life lessons and friends they had made through not hearing, they would choose to remain as they were. I get that, I truly do. I wouldn’t want to change John’s hearing either, because the work he does is so much of what I admire about him, as well as the strength he shows every day in spite of difficulties I can only imagine. I like to think I’m a better and more compassionate person because I have been blessed to walk this life with him.

I’ve met a handful of other hearing spouses of hard of hearing and late-deafened folks, and we compare notes every few years. I find that incredibly helpful. Unfortunately, I haven’t found a community of spouses that is equal to the community that John enjoys. My guess is that most of us are home coping on our own with the challenges of living with someone for whom understanding speech is difficult. There are probably millions of us hearing spouses or partners in this country. Aside from an occasional seminar, I don’t know of any support available for hearing/non-hearing relationships. As much as I celebrate and appreciate the blessings of community that John enjoys, I wish more were available to hearing spouses who may be sharing some isolation and frustration and, indeed, anxiety about our relationships and what the future might hold.

John and I have struck a deal with each other. On my honor I will do my best to minimize distractions, to invite him to choose the best seat for himself at the table, to speak clearly where he can see me, and to be patient (not my best quality) when he can’t understand me. What I have asked of him is to acquire and make use of the best equipment and technology available, to not “fake” understanding, and to be patient with me. He also tries to respond when I say something, because if he doesn’t, I’m likely to assume he didn’t hear and repeat myself, which can sound like nagging. John gave me permission to say that responding is not his strong suit, a trait that may be tied to his Y chromosome, but I’m no expert on that.

We’ve entered a realm now where my hearing is not as sharp as it once was, and sometimes we do a whole “Who’s on First” routine, where I say something he doesn’t hear, then I don’t hear...
his response, then he doesn’t understand what I’m saying, and we go around and around in our “Whats?” This will probably only get worse with time. Fortunately, the dogs seem to understand whatever we say, our grown kids don’t much listen to us, and our grandkids love us no matter what, so life is good.

I’ve never felt as at home and comfortable as I did at ALDA. The first day was rough, as I couldn’t bring myself to communicate, but the next morning I was invited by another ALDAcon couple to join them at breakfast. After that, I found such camaraderie among everyone at the conference that participating was much easier than usual for me. I learned a lot about myself and better ways to cope. Sad to say, upon my return home, I was still unable to locate anyone else with my hearing loss experience, so I’m back to where I started.

However, I do know that ALDA is there, as well as the many wonderful people who helped me not to feel that I belong in the “Land of Misfits.” I hope to be attending ALDAcon next year. Thank you to all who helped me through tough times.

Colette lives in Colorado with her husband and two teenage children. They are very active and love to bike, bike and river raft. She is an avid dog lover and just retired her service dog, Blanca, who helped Colette with her hearing loss for the past 11 years. Bianca is now a pet and enjoys the company of Colette’s two other dogs, Smudge & Shebe. For several years, Colette has run her own businesses, mobile dog grooming and now also pet sitting and training. She recently started working at the Rolf Institute and was very happy to be accepted despite her hearing loss. Her hobbies are cooking (everything made from scratch—old school), sewing, and drawing.

Loving Someone with a Hearing Loss (continued)...

Continued from page 10

By Colette Cole

I found out about ALDAcon while I was chatting with Robin Taber on the Cochlear Experience Facebook site. I received a cochlear implant in February 2015, but unfortunately, my brain has not yet accepted the sounds. I have a hearing aid in my other ear, which I limp along with. Robin told me that I should check out ALDA and come to the conference. I decided to attend, since it was in my husband’s hometown. I was very nervous, as I’m somewhat shy and have never been very social. I’ve rarely met anyone who shares the same hearing issues, so this was a completely different experience.

Since I’ve been given a soapbox for a brief moment, I’m going to step up onto it and say what I would change if I could. I would provide everyone diagnosed with a significant hearing loss—AND their significant others and loved ones—with support and training and even therapy to learn how to cope. Blind folks don’t get handed a cane and a bunch of Braille books and sent home to cope on their own. But that’s essentially what happened to us when John lost most of his hearing overnight. I’ve heard lots of stories of other couples who faced similar situations alone. Also, with a wave of a magic wand, I would see to it that every hard of hearing and late-deafened person had access to and information about the wonderful group support available to them, and I’d wish for more support for the spouses and loved ones. Next, I’d banish all denial of hearing loss, because it’s so damaging to the deniers and so unfair to the people in their relationships. And I’d wish for more public recognition of hearing loss, a silent and invisible condition that is kind of the Rodney Dangerfield in the disability world. [Editor’s note: The late Rodney Dangerfield was a comedian known for the catch phrase “I don’t get no respect.”]

My guess is that in the next few years much of this will be achieved, and we spouses need to step up to help make it happen. I can’t say enough about how much I admire the people I’ve met who work so hard to make communication and life as a whole better for hard of hearing and late-deafened people, my sweet husband John Waldo included.

Eve Leonard works as the creative director of her own life, which currently includes painting and sketching, writing, travel, knitting for the grandkids, and collecting every culinary tool available. She’s been a carhop, a cherry picker (real cherries, before Amazon hired people to pull merchandise), and an English and debate teacher. She has also worked in advertising, public relations, fund-raising, and real estate and was briefly an author escort, which is more respectable than it sounds. Her life has been more of a crazy quilt than a road map. Contact Eve at eveleonardhome@gmail.com.
New Credential Combines CART and Broadcast Captioners

By Gayl Hardeman

The National Court Reporters Association (NCRA) has created a new credential to combine both CART providers and broadcast captioners into one certification called the certified realtime captioner.

So yet another acronym! CCP, CBC, and now CRC, which also stands for certified rehabilitation counselor, but I guess they didn’t think of that. Anyway, it seems as though there are not enough of us nationally to have two different tests, so they are combining the written knowledge tests into one CRC test. It’s no “biggie” except that you will need to find out from the CRC whether they actually do onsite CART, as all broadcast captioners were grandfathered in, and unless they also hold a CCP (certified CART provider) at the time of the grandfathering, which is January 2016, the chances are that they may not know about (1) setting up a projector for a group CART event, (2) the different needs of people who are Deaf, late-deafened, and hard of hearing, or (3) any platforms for remote CART other than dialing into a TV station encoder. Conversely, a CRC may not have experience in TV broadcast captioning.

So just be aware that we are being combined (without being consulted), and each camp will have to make its specialty known in marketing to the public or else learn the other camp’s specialty as well. NCRA’s stated goal in doing this is to create more broadcast captioners because of FCC mandates and the exploding need for such captioners. Simultaneously, demands for onsite and remote CART are growing, and many broadcast captioners, weary of ever-lowering rates because of contracting, are jumping to remote CART and need training in all the platforms like StreamText, Adobe Connect Pro, GoToMeeting, etc. There are some new ones, like the Blue Jeans Network, that even I hadn’t heard of although I’ve been providing remote CART for years! And I’m sure there’s a lot I’ll have to review, as I haven’t done broadcast captioning since 2002. I did attend the first NCRA-sponsored CRC workshop in NYC on July 29-31 and took the first CRC written knowledge test—100 questions on CART, broadcast captioning, and (I was happy to see) the people we serve.

So if you have any questions or comments about the CRC credential, I’d love to hear them. Also, if you live in Florida and have questions or comments for the Florida Coordinating Council for the Deaf and Hard of Hearing (FCCDHH), I’ve succeeded Chris Littlewood (quite dauntedly) as chair and would be happy to take your concerns to this Council as well. So fire away!

Gayl is a CART provider who owns Hardeman Realtime, Inc. in Pinellas Park, Florida. Her company website is www.hricart.com and she can be contacted at gayl.hardeman@gmail.com.
I was born in 1968 in Myagdi, one of the remote Himalayan districts of Nepal, and became deaf at the age of five from typhoid fever. My parents made lots of efforts in performing religious and other local rituals according to the Buddhism in which they trusted instead of taking me to the hospital for medical treatment. They took me to several dhamis and jhankris, wizards who chant some kind of Tantric mantra to bring wicked spirits under their control. But their efforts were in vain; I could not hear anymore.

Though I had already started speaking, due to developing my hearing loss at such an early age, I can speak very few words now. I was sent to school in the village at the age of six but could not learn to read and write since I could not hear the teachers and they did not know any sign language. Moreover, standard Nepali Sign Language had not developed at that time.

My parents found the only Deaf school in Nepal in Bhairahawa, so at age 11, I went to this school, which taught in sign language. The school was founded by my uncle, Saryu Prasad Sherchan, who was Deaf himself and educated in a Deaf school in India. I received formal education up to eighth grade and then learned tailoring and started working in a tailoring shop that was also run by the same Deaf uncle.

As I grew older, I gradually became involved in the various local and national Deaf organizations. I also took training in photography and videography, and at 35 I got married to a Deaf girl. Now we have two sons who go to school, my wife has a job in a garment factory, and I run a photo shop in partnership with a Deaf friend. In addition, I am a committee member of the National Cricket Association of the Deaf-Nepal (NCAD-Nepal), the Asia Deaf Cricket Council (ADCC), and the Deaf International Cricket Council (DICC).

ALDAcon 2015 was the third international convention on deafness in which I took part. My first was the World Federation of the Deaf gathering in Japan in July 1991 and my second was the World Deaf Magic Festival in Chicago in October 2014. ALDAcon was different from the other two because it was not the convention of the deaf people who cannot both hear and speak, but of the deaf people who can speak. I was amazed to see all the deaf people speaking like hearing people; hence, in the beginning I could not believe them that they were deaf. Later on I came to know that they were people who have a hearing loss and some of them could hear with the support of hearing aids. [Editor’s note: the difference in language usage is due to the fact that most ALDAns became deaf after mastering spoken language, while most Deaf ASL users were born deaf or became deaf prelingually.]

Since I do not know much ASL, I could not chat easily with friends at ALDAcon. I wished I had an interpreter. However, during the various workshops and presentation sessions, I understood the discussions by reading the CART captions, which were in English. Hence, somehow I absorbed the main theme of the convention and learned a lot about the attendees’ way of life. The presentations were on subjects like employment discrimination, coping effectively with hearing loss, sign language for beginners, audiology appointments, the courts and legal agencies for the support of hearing loss rights, etc. There were some entertaining performances as well.

I brought gifts, two bronze sculptures of Buddha and Arya Tara, for ALDA President Steve Larew, who had sent me the invitation letter to attend ALDAcon, and for Cynthia Amerman, who corresponded with my friend Prem Bahadur Gurung in Nepal and made my visit to the US possible and easy. I explained that Buddha was born in Nepal and Arya Tara was Buddha’s wife. I am sorry that I could not carry more gifts for other friends due to luggage limitations by the airlines. I enjoyed visiting some places in Scottsdale, Arizona with some of my American friends. The stay in the hotel was pleasurable and the meals were delicious. I shared a room with David Litman, so we could say that Nepali Hitman and American Litman stayed together!

The knowledge I gained from the convention will increase my self-confidence and help me in my skill development. I am happy that I have made lots of new friends, and I miss the convention very much.

Hitman can be contacted at hitsarl@hotmail.com.
I'm not much on socializing, so I wasn't sure if I wanted to go to a conference of strangers. But being profoundly deaf for almost two years, I decided to check out ALDA. I applied for a scholarship and received one, so how could I refuse? Surprise, surprise, I had a great time! Meeting others with similar histories (waking up one morning totally deaf), as well as people with more interesting stories, was a very pleasant experience. There were folks from Hawaii, Illinois, Oklahoma, Utah, Massachusetts, etc., but surprisingly no others from neighboring Nevada. Hmmm, maybe I need to start a chapter?

We newcomers were treated with special activities and goodies. I had taken extra treats for the hotel room but didn’t eat a bite of what I had brought. The meals were scrumptious, and there were lots of goodies in the hospitality room!

“Whatever works” is a good motto, as there were folks talking, lipreading, signing, writing, and using interpreters, with a few hearing dogs added to the mix. There were knowledgeable, informative speakers and inspiring stories. It was a great pleasure meeting Kelly DeHart, the Rachael Morris Ray of Sunshine scholarship recipient.

Every day was busy with activities or workshops. The trolley car ride to downtown Scottsdale and eating dinner there was fun. There was even a foot reflexology workshop by Ilse Jobse from the Netherlands.

I’m not into music and had never done karaoke. No way! Needless to say, I surprised myself again and actually enjoyed the camaraderie there with my new friends. And they didn’t even care that I couldn’t carry a tune (or maybe they couldn’t hear me!)

ALDAcon was a fun time. An exploring time. An empowering time. A learning time. I’m thankful for the scholarship, and I’m saving my money for the Milwaukee ‘con!

Lin lives in Las Vegas. Her school district (the fifth largest in the nation) has a critical shortage of teachers, so she’s back in the classroom (having retired three years ago) teaching a primary special education class. Her spare time is spent visiting her seven grandchildren (two of whom are deaf). Her email address is linadams7@gmail.com.

**Dr. Jane K Fernandes to be Keynote Presenter for ALDAcon 2016**

ALDA is pleased to announce that Dr. Jane K. Fernandes has accepted our invitation to be the opening keynote speaker at ALDAcon 2016. Dr. Fernandes, who is the first deaf woman to lead an American college or university, will speak on Thursday morning, September 15, about the challenge of being a deaf person working in the hearing world.

Dr. Fernandes is the ninth president of Guilford College in Greensboro, North Carolina. She began her work at Guilford on July 1, 2014, having served as provost and vice chancellor for academic affairs at the University of North Carolina at Asheville since 2008. At Guilford, she holds the faculty rank of professor of English.

A native of Worcester, Mass., Dr. Fernandes is a graduate of Trinity College in Connecticut, where she earned a B.A. in French and comparative literature, and of the University of Iowa, where she earned an M.A. and a Ph.D. in comparative literature. Born deaf to a deaf mother and hearing father, she learned American Sign Language (ASL) as a graduate student.

Dr. Fernandes’ career took her first to Boston as acting director of American Sign Language programs at Northeastern University and then to Washington, D.C., as chair of the sign communication department at Gallaudet University. Moving to Hawaii, she became the founding coordinator of the University of Hawaii’s sign language/English interpreter training program and later, director of the Hawaii Center for the Deaf and Blind.

She returned to Gallaudet as vice president of the Laurent Clerc National Deaf Education Center in 1995 and served as provost of the university from 2000 to 2006. After her leadership roles at Gallaudet, she became a senior fellow at the Johnnetta B. Cole Global Diversity & Inclusion Institute at Bennett College in Greensboro, a post she held from 2007 to 2011.

The ALDAcon 2016 theme is *Grand Slam with ALDA*. The conference will be held September 14-18, 2016 at the Sheraton Milwaukee Brookfield Hotel. Registration and hotel reservation information will soon be available at www.alda.org.
This is My Life (continued)...

Continued from page 6

As I began writing this book, I separated the topics by chapter. One chapter was on drugs that could damage our ears—known today as ototoxic drugs. Up to the time I took Level III of CHIP, where we spent less than an hour learning about ototoxic drugs, it had never crossed my mind that drugs could damage our ears. Since this topic intrigued me, I decided to write a chapter on it. I took the two short handouts we received in class, did some research, and came up with about 13 pages on ototoxic drugs. I finished that chapter, I thought, and went on to write other chapters.

Some months later, I decided to review that chapter and see if maybe, just maybe, I had overlooked an ototoxic drug or two. So I began researching in earnest. Five years later, after wading through thousands upon thousands of pages of fine print, my little 13-page chapter had grown considerably—so much so that it was now much too large to be a chapter in my book. In fact, it became a 600-page book called Ototoxic Drugs Exposed. (Note: the 4th edition, when it comes out, will be close to 1,000 pages!)

About the same time as I was doing research on ototoxic drugs, I joined the Internet age in November 1996. The very first day I got my computer hooked up, I set out to discover what the Internet was good for. Since I was now interested in hearing loss and related matters, I typed the words “hearing loss” into the rudimentary search engine of the time. To my surprise, I discovered that there were two online hard of hearing groups. I joined them that day, and my life has never been the same since. I'm still a member of both—the SayWhatClub and Beyond Hearing—but I also belong to numerous other online groups, some of which I started and own. Since that day, I have been in constant contact with thousands of hard of hearing people from all over the world.

I began sharing online some of the things I had learned, and people started asking me questions and sharing their experiences. The more I learned, the more I wrote about all sorts of things pertaining to our ears and incorporated them into my “Everything” book. It didn’t take me long to realize that even without the drug chapter, this book was going to be enormous, so I began spinning off the various chapter topics into smaller books.

My “big book,” as I call it, will never be finished. Instead it has become the title for the set of my books that now number 11. I have four more half-written that will be coming out whenever I have the time to finish them. On the copyright page of each of my books is the inscription, “Another book in the series: 'Everything You Wanted to Know about Your Hearing Loss But Were Afraid to Ask (Because You Knew You Wouldn’t Hear the Answers Anyway)’.” Maybe I should just shorten it to “The Encyclopedia of Hearing Loss,” but the long title makes people chuckle when they read it.

I began receiving so many emails (several hundred a day) that I got tired of answering the same questions over and over, so I began making my responses into articles. I created a website at http://hearinglosshelp.com and published my articles there. In addition, I have written articles for publications all over the world. This was the beginning of the Center for Hearing Loss Help.

I have continued to publish articles and today, if you check out the Center’s website, you’ll find 878 articles that I have written on all aspects of hearing loss. (Bet you didn’t know there were that many topics related to hearing loss to write about, did you?) Below these articles you’ll find thousands of comments and my replies.

Without my really realizing it, my outreach has continued to expand as I help more and more people deal with their hearing losses. I never dreamed that one day not just hundreds or thousands, but millions of people would be coming to the HearingLossHelp.com website each year for help.

In addition to my “formal” writing and putting out an ezine that goes to 10,000 people—including many audiologists in addition to hard of hearing people—I answer hundreds of phone calls and thousands of emails each year. And I speak all over Canada and the U.S.

What do I do with my spare time? Well, back in 2006 I got hooked on collecting hearing aids. It’s hard to believe, but I now own the second largest collection of hearing aids in the world as far as I can tell—certainly the largest online collection. You can view the Hearing Aid Museum at http://hearingaidmuseum.com. People from all over the world ask me to identify and appraise their old hearing aids.

This is a very abbreviated outline of my life—I’ve left lots out. My old life, before I got into helping hard of hearing people, is now just a memory. This is now my life! Helping people is the ministry that God has given me—and I plan to continue until the Lord takes me home.
**Tanka Road Trip**

*By Sam Turner*

Association
Of Late Deafened Adults an ALDA Conference.
International meeting organization with an

“anything” will work unique communication method: Signing – yes including writing reading lips – and facial expressions

On nine—seventeen we rode Ollie the Trolley for Old Town dinner
The FNB restaurant Served another outstanding Dinner for enjoyment

“No Ear Left Behind” one of the best attended “Emergency Preparedness” “Afternoon with Hearing Loss” Don’t forget Karaoke!

Holding balloons next to dancing into the evening We lasted ‘most to the end. your ear improves the sound!
(I didn’t know that!) A hundred-fifty adults Dancing and singing loudly

Loud music not heard only the vibrations felt creating laughter dancing into the evening We lasted ‘most to the end.

Reprinted with permission from Tanka Road Trip by Sam Turner. Sam graduated from Pepperdine College and received his master’s in education from the University of Arizona. Raised on the south rim of the Grand Canyon, he contributed many of his memoirs to Arizona Highways. He also published articles in the Aviation and Business Journal, and he teaches memoir writing in Tucson, Arizona. As members of the Compassionate Friends, he and his wife Phyllis published volumes one and two of This Might Help, offering guidance and hope to parents who have suf-

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**I. King Jordan Award Acceptance Speech**

*By Neil Bauman, Ph.D.*

It is indeed an honor to receive the prestigious I King Jordan award. I’ll always treasure it. I never dreamed I’d ever receive an award like this. You see, I typically work behind the scenes helping the hard of hearing people that come to me via phone, email, and website. I’m not a big name that is in the limelight all the time.

In spite of its name, the Center for Hearing Loss Help is actually a tiny organization. (It consists of just me and my wife Diane.) When I started the Center 15 years ago, I never envisioned that it would have the outreach and impact it now has. From our home office and website, we help hard of hearing people, not only here in America, but in more than 180 different countries every month. The last time I checked, a mind boggling 2.3 million people visit the Center’s website each year looking for information and help, which they get from the many hundreds of articles I’ve written.

I typically spend hours every day fielding phone calls, answering emails, and replying to comments and questions posted on the website. In between doing that, I’m busy researching and writing new articles for the Center’s website and for our free ezine that goes to many thousands of people. And, as time permits, I continue to update the 11 books I have already written on hearing loss, as well as working on several new books that are half written at this point.

I once calculated that I’d need to clone myself eight times in order to get all my work done properly. Thus, it was a welcome change to get out of the office and spend some time interacting with the good folks at ALDAcon 2015. So, once again, thank you for bestowing this honor on me this year.
**Previous ALDA presidents.** Front: Linda Drattell, Kathy Schlueuter. Back: Cynthia Amerman, Marylyn Howe, Bill Graham, Lois Maroney, Steve Larew, Dave Litman, Bernie Palmer, Ken Arcia, Roy Miller

**2015 ALDA Board of Directors.** (L to R): Chris Littlewood, Dave Litman, Brian Patrick Jensen, Karen Krull, Matt Ferrara, Kathy Schlueter, Sharaine Rawlinson Roberts, Eleanor Shafer, Steve Larew
Photo Album from ALDAcon 2015 (continued...)

Kathy Schlueter, Carol Postulka (winner, Robert Davila Angel award), and Steve Larew

Kelly DeHart (first recipient of the Rachael Morris scholarship) and Dave Litman
Biggest newcomer group ever!

ALDA-Chicago members
Kicking it up on the karaoke dance floor!

Lisa Harbour, Tina Childress, and Stormy Iverson belt it out on stage

Kicking it up on the karaoke dance floor!

Photo Album from ALDAcon 2015 (continued...)

ALDA News
Why I Created the Bay Epicenter of Advocacy for the Deaf and Hard of Hearing (BEADHH)  

By Linda Drattell

I realized years ago, after the successful negotiations with Cinemark and AMC Theatres for movie captioning in California, that there was no central place to publicize the fact that captioned movies were now a reality in California—not just Rear Window captioning, if it was offered, or open captioning at odd hours of the day, but captioning of all new releases using the latest technology. Movie captioning became our right. Yet a couple of years later, I was approached through my work at DCARA (Deaf Counseling, Advocacy and Referral Agency) by people who did not realize that this fight had been fought and won.

I chose to create the Bay Epicenter of Advocacy for the Deaf and Hard of Hearing (BEADHH) to meet the informational needs of deaf and hard of hearing people in the San Francisco Bay Area. BEADHH’s mission is to facilitate and promote dialogue and sharing of experiences among local deaf and hard of hearing individuals and organizations to maximize the effectiveness of advocacy efforts. Getting “all the wood behind one arrow” can ensure that the needs of deaf and hard of hearing people are addressed.

BEADHH does not compete with existing organizations; rather, it is designed to support each local organization by meeting its advocacy information needs in one central place and referring others to the organization based on their advocacy needs. To that end, BEADHH is developing an advocacy network in which the impact of local advocacy efforts can benefit from the synergies of being aligned and united.

On the national level, there are organizations such as Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN), and Coalition of Organizations for Accessible Technology (COAT), each of which works with the broad spectrum of deaf and hard of hearing organizations and their communities to align advocacy efforts, but local advocacy efforts are not similarly aligned. There is a need for coordination of advocacy efforts among organizations and learning from each other the best methods for achieving advocacy goals. BEADHH will work toward filling that void wherever possible.

How did I choose the BEADHH name? I started with the acronym, actually. Each individual advocacy effort is like a bead, and like well-designed jewelry or artwork, when the beads are strung together, the aligned advocacy efforts make a powerful impact.

BEADHH will focus on the following nine goals:

1. Facilitate the search for role models for deaf and hard of hearing advocates, partnering seasoned advocates with individuals wishing to advocate.
2. Facilitate partnerships with other advocates working on similar projects.
3. Work with advocacy leaders to create a tutorial based on past advocacy experiences.
4. Provide information about new areas of advocacy and the status of existing advocacy issues, including a newsletter (BEADHH Report) that highlights current efforts and publishes interviews with advocates on successful strategies to solve local issues.
5. Launch an annual or biennial advocacy conference with three primary objectives:
   • Invite leaders of the deaf and hard of hearing organizations to present and share their organizations’ efforts and advocacy experiences.
   • Support the coordination of deaf and hard of hearing advocacy efforts.
   • Empower a new generation of deaf and hard of hearing advocates with tools to assist in their success.
6. Create an “A List” of local advocates (individuals and organizations) in different advocacy categories (education, employment, transportation, entertainment, sports, courts, prisons, lifetime award, etc.).
7. Recognize the accomplishment of local advocates.
8. Create a BEADHH Facebook page and Twitter account to post and share advocates’ efforts and inform the community of advocacy issues.
9. Establish a BEADHH website that will provide a one-stop place to announce local events, advocacy efforts, and advocacy contact information.

Continued on page 23
caption-viewing equipment. (Cinemark had previously made a similar commitment in Washington State, but since it only operated one theater there at the time, it didn’t necessarily follow that Cinemark would do the same thing in California, where it has a major presence.)

On behalf of ALDA, we also sent a demand letter to AMC, the nation’s second-largest movie chain, which was also a defendant in our Washington State case. In Washington, AMC argued that providing full captioning capability would constitute an undue burden, but after looking at the financial data we provided, the Washington court soundly rejected that argument. Rather than undertake an exercise in futility in California, AMC announced—before ALDA filed suit in California—that it would also equip its California theaters to show captions. Rather than continue to fight battles they would almost surely lose, the major theater chains committed to equipping all of their theaters nationwide to show captioning.

My vision for ALDA advocacy is to take some of the approaches and lessons that we learned in Washington State (and in our subsequent sister organization in Oregon) and apply them on a nationwide basis, wherever ALDA has members. That approach involves three steps.

First, we need to hear from you, our members, about where you are encountering inaccessible businesses or business types, like live theaters, movie theaters, or professional sports venues. This is absolutely essential, and oddly, the major impediment to getting more done is the scarcity of people who say, “I want to go” to that theater or concert or stadium. ALDA can act as an organization on behalf of any of its members, but that member must in fact want to access whatever the aural content may be at that business.

Second, we contact the business in writing, explain who we are, what we need, and why we need it, and invite a dialogue that we hope will lead to our desired outcome. The initial letter would only allude in passing to the existence of laws—there would be no overt threat of litigation. If people balk—and oftentimes, the initial response is “we can’t afford it”—then we explain their legal obligations in more detail and ask for more information. Showing them that they would likely lose if the matter went to court frequently does the trick.

Finally, if the business refuses or ceases to communicate, then our response in the past has been to file a lawsuit. We have not had to do that often in Washington State, but word gets around, and when people understand that we will go to court if we need to, and that we will win, they get wonderfully reasonable. I staunchly believe that the litigation possibility is an arrow that we cannot remove from our quiver, even though we seldom shoot it.

We currently have several projects underway on behalf of ALDA and its members. We are trying to initiate or reinstate captioning at several live theaters in the Bay Area, Las Vegas, and Utah. The Berkeley Repertory Theatre almost immediately started offering captioned performances; we haven’t received a final commitment yet from theaters in San Jose and Mountain View, California, but they have assured us that they will work with us. The theaters in Las Vegas and Utah aren’t willing to do exactly what we are asking, but what they are willing to do may be sufficient, and we’ll likely try that before going further.

A major project at the moment is working in partnership with the National Association of the Deaf to make accessibility the rule in professional and major-college sports venues. We worked with the NAD to develop what we believe are “best practices” at athletic facilities, specifically including captioning of all public-address announcements and other aural information like song lyrics on one or more scoreboards visible from every seat.

On behalf of ALDA and the NAD, I sent a letter to the 29 U.S.-based Major League Baseball teams asking them which of those best practices they have implemented and which they are willing to implement. The initial response was very encouraging. I received an email from an official with the St. Louis Cardinals stating that he is on the board of the Stadium Management Association, a professional trade group, and suggesting that we meet with them in an effort to agree on a set of “best practices” that they could recommend to their members.

This seemed like a great idea, because while there might be disagreements, we thought it made a lot of sense to have the discussions once rather than with every team individually. Unfortunately, though, that cooperative effort faltered—the stadium managers recently informed us that accessibility

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decisions are made individually, and that each team has its own attorneys and ADA consultants. That same day, ironically, Linda Drattell contacted me and said she was at a professional basketball game with a large group of deaf folks, that there were no captions, and that we need to do something. So ALDA will indeed do something, although the NAD’s attorneys and I are trying to work out exactly what.

We are also interested in working with the Live Nation/Ticketmaster group, which owns and manages many music venues. We have learned that they can do a pretty decent job of providing captioning at concerts, but there is no indication anywhere that captioning is available, or any way of requesting captions without persistent and creative telephone queries. We’d like a transparent website that clearly advertises the availability of captioning or other accommodations for people with hearing loss and that permits us to buy accessible tickets with a few mouse clicks.

Advocacy to implement the benefits and protections of disability law is something that can improve our lives and the lives of many, many other people with hearing loss. But we can’t do this without help from you, our members. We need more people like Linda Drattell in the Bay Area, and Dean Olson in Seattle, who are not content to sit at home and give up on public life. We need every one of you to consider how accessibility can be improved in your area.

Please think about access issues in your community, and let me know about them. If it is something we can reasonably address, I’ll run it by the ALDA Board, and with their approval, we’ll get rolling. Contact me at johnfwaldo@hotmail.com. If we work together, ALDA can make a real difference in access for all of us.

John Waldo is an attorney whose practice is limited to working on behalf of people with hearing loss to improve their access to public life. He founded and represents the Washington State Communication Access Project and also represents a sister organization, the Oregon Communication Access Project. He has represented ALDA in the past, and he is delighted to do so on a more structured basis as ALDA’s advocacy committee chair. John was the I. King Jordan award winner in 2011. He has been hard of hearing most of his life and currently has one CI and one hearing aid. He and his wife Eve Leonard live in Houston, Texas.

Bay Epicenter (continued)...

There are many local issues facing deaf/late-deafened/hard of hearing/deaf-blind people. For example, the BART train system relies on a text telephone (TTY) to provide us with communication access, a technology that is obsolete. The San Francisco Giants, Warriors, and San Francisco 49ers are just a few of the local sports teams that do not provide captioning at their events. There is no training in American Sign Language for staff working with culturally Deaf adults who have various disabilities (Deaf Plus). Many local hospitals and court systems rely on video remote interpreting (VRI) for full communication with a Deaf person rather than using this technology until a live interpreter can arrive, which can result in misinterpretation of key information.

We need to work on these areas of advocacy together. We need to coordinate, document, and publish advocacy efforts of the various deaf and hard of hearing organizations in the San Francisco Bay Area. Many deaf and hard of hearing would-be advocates are unaware of advocacy efforts already taking place, whom to contact for support of their advocacy project, and how to most effectively manage their advocacy issue. It is my hope and vision that BEADHH will effectively meet each of these needs, providing a central place to find resources, receive information, and improve the odds of each individual’s or organization’s local advocacy objectives.

For more information, contact Linda Drattell, founder and president of BEADHH:
925-271-7415 VP
925-398-8689 captioned phone
linda@beadhh.org
website: www.beadhh.org
Facebook: Bay Epicenter of Advocacy for the Deaf and Hard of Hearing

Linda is a former president of ALDA and worked as community relations director and hard of hearing support specialist for DCARA. She served as an advocate in obtaining communication access in BART trains and stations and in her successful settlement with Cinemark Theatres and AMC Theatres for movie captioning. Linda received ALDA’s I. King Jordan Award, the Hearing Loss Association of California’s Outstanding Service Award, and DCARA’s Employee of the Year Award.
The Wonders of ALDAcon

By Chelle Wyatt

I heard of the famous ALDAcon karaoke night years ago and always wanted to go but couldn’t find the time or money. This year, ALDAcon was held in Scottsdale, Arizona, and since I have family in Arizona, that made it much easier for me to attend. Two other wonderful ladies from Utah also came, so Utah had a nice showing!

At the welcome party, I found more people I know from other hearing loss organizations. It was terrific visiting with old friends and making new ones as well. I came with a black feather boa that shed everywhere, so I could see exactly where I’d been, Chelle was here, Chelle was there and Chelle had a good time!

There was a good variety of workshops, and my favorites were the ”ADA/Advocacy Update,” “Advocacy Arizona Style,” and “Lipreading: To Make a Good Thing Better.” I learned something at each workshop I attended and left inspired.

The “Afternoon with Hearing Loss” was out of this world! The Arizona Commission for the Deaf and Hard of Hearing had fit local hearing people involved in professional sports with earplug molds to give them a 40% hearing loss and followed four of them around with a camera. At the ‘con, we watched the resulting video. Afterwards, another four hearing people sat on a panel to talk about their experiences with hearing loss and answer our questions. I think everyone learned how much even a mild hearing loss can impact lives. Some of the comments were priceless:

• “I’m more cautious, not as motivated.”
• “Was she talking to me?” one man turned around to ask the camera crew because he didn’t know.
• “It was unsettling.”
• “Everything sounded like it was underwater, it made me feel claustrophobic.”
• “I felt panicky in traffic.”
• “I couldn’t multitask.”
• “I missed a lot of phone calls.”
• “The phone was pushed so close to my ear it hurt.”
• “Being on the phone was the most difficult part of the day.”
• “I couldn’t hear my co-workers.”
• “Some people made jokes about hearing loss and it wasn’t funny.”

• “I would have to change my personality to be more assertive. I’m not like that. It was eye opening.”
• I don’t wish hearing loss on anyone, but I would love for some hearing people to experience life my way with these ear plugs, especially the people who have refused to cooperate with my communication needs. Simulating a hearing loss made this panel the most interesting presentation I’ve ever been to. Michele Michaels, the hard of hearing specialist in Arizona, did a great job leading this panel.

There are so many wonderful folks in the hard of hearing and late-deafened world, and that was my other favorite part of the convention. I loved the personal contacts I made. They were always willing to help, wanted people to feel included, and showed so much patience in communication. It was fun trading ideas and learning new ways to cope with hearing loss.

At the end, there was the karaoke party, and it was everything it was said to be. The music was loud (earplugs were offered to hearing people) and lights were dimmed so disco lights could flash, but there was enough light to make speechreading possible. Balloons drifted around the room. If people were shy at first about getting up on stage, they weren’t by the end.

“Who cares if you can’t sing well, it falls on deaf ears anyway.” Everyone had such a good time. I particularly enjoyed watching two people pick up a balloon to feel the music vibrations for the first time.

Well done, ALDA. You have an awesome convention, and I was so glad to be able to participate this year. I’ve got my sights on Wisconsin in 2016.

Chelle lives in Salt Lake City with her husband and works part time for the Utah Division of Services to the Deaf and Hard of Hearing as a hard of hearing assistant. She raised three kids with her hearing loss and now has two grandsons. Her hobbies are traveling, reading, crocheting, and keeping a blog at https://hearinglosspages.wordpress.com. Contact Chelle at livinglife.fullest@gmail.com.
Simulating a Hearing Loss

By Paul Wummer

ALDAcon 2015 this past September was held in sunny Scottsdale, Arizona. For someone who likes to walk a lot, the relentless sun was a bit much. However, the brightest spot (pun intended) was the last workshop, “An Afternoon with Hearing Loss.” A number of hearing Arizonans had volunteered to have their ears plugged for part of their typical day. On the panel were four of the volunteers, including a reporter, a firefighter, and a coordinator for the Arizona Commission for the Deaf and Hard of Hearing (ACDHH). A few others relayed their experiences via video. Listening to the panel discussion and having the opportunity to interact with the panelists individually afterwards was an enlightening experience. The afternoon totally brightened my day!

Echoing the folks in the video, all the panelists shared the experience of learning how difficult it was to navigate the hearing world with a hearing loss. A few mentioned having to state (sometimes several times), “No, I’m not ignoring you.” Each panelist had differing observations, reactions, and takeaways from the experience.

The firefighter was unlike the others in that she had experienced very little emotion. She explained that the stress involved in fire fighting prepared her for the experience of not hearing. Her job involves wearing a heavy claustrophobic face mask and having to enter dark, smoky, burning buildings. Since I was dealing with a lot of stress at the time, it was beneficial for me to talk to her afterwards and learn some new coping techniques.

The second panelist was a journalist who writes for the Arizona Republic. She mentioned developing anxiety and discovering how hard it was to work in the newsroom and answer the phone. When the earplugs were removed, she appreciated sound more, even welcoming the humming of the air conditioner. I talked to her afterwards about my inability to discuss my hearing loss with my brothers. Even though all four now experience hearing loss, the topic is still “off-limits.” The reporter’s experience led to an article titled “I thought I knew what would happen when I lost my hearing. I was wrong,” available at www.azcentral.com/story/news/local/inspire/2015/11/14/hearing-loss-deaf-education-empathy/73874852/.

The third panelist started her day wearing the earplugs. Driving to work, she needed to drop her young son off at school along the way. While pulling into traffic, she feared that she was endangering her child and immediately removed the earplugs. In my humble opinion, she failed the experience/"test." It was a bit disconcerting, since she also works as a coordinator for ACDHH.

The fourth member of the panel was the only male. His takeaway from the experience was that it brought him and his brother closer to his dad (who has a hearing loss).

It was an awesome final ALDAcon workshop.

Paul lives in Portland, Oregon and has had a hearing loss since birth, but it wasn’t diagnosed until he was six. Since then, he’s worn many types of hearing aids in his left ear over the past 51 years. A member of ALDA for 16 years, he’s attended every ALDAcon beginning with the one in Santa Fe (November 2000). He enjoys being outdoors in the beautiful Pacific Northwest, and his passions include watching classic movies and reading nonfiction and historical-fiction books. Paul can be contacted at pwummer@gmail.com.
I first met Cassandra when she was a newcomer last year’s ALDAcon. She has a bubbly personality and is easy to get along with. This year, she volunteered to help with the newcomers, welcoming them to ALDAcon and being available to answer their questions. Enjoy her interview. She’s definitely one of us.

**Name:** Cassandra R. Horton

**Where were you born?** In Huntsville Alabama, one of the South’s leading technology hubs. It’s the home of the US Space and Rocket Center and the location of the Redstone Arsenal, a military base of the US Army. On that base is NASA’s Marshall Space Flight center, where the nation’s journey to space began.

**What is your current residence?** Nanuet, New York., which is in easy commuting distance from the tristate area of New York City, Northern New Jersey, and Connecticut.

**What is the cause of your deafness?** In 2000, I was hospitalized after contracting meningitis. I didn’t feel too bad that day, but I called my mother and asked her to pick me up to take me to the hospital. On the way, I opened the car door once to vomit, and within 30 minutes of reaching the hospital, I was in a coma and remained in it for three days. Unbeknown to me, the doctors were trying to move me into the psychiatric ward because they thought I was crazy or had taken some type of drug! The high fever had me acting like a raging bull, and I was saying anything and everything, insulting all people who came in contact with me. They were actually afraid of me and had to put me in a straitjacket. However, my mother said, “my daughter is not crazy—she needs medical attention.” When the doctors asked whether my Mom was a nurse, she said no, she was a psychiatric social worker. It was not until that moment that the doctors and nurses began to work on me to determine the cause of my condition. After drawing fluid from my spine, they found I had meningitis and had to apologize to my mother. Had it not been for her, I would not be telling my story, as I certainly would have died. Fortunately, I am alive, and everything works well except my ears.

**Marital status?** I am single and loving it, although I

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**What is your job history?** I work for the County of Rockland as a special projects assistant in the staff development unit. I started out in the employment unit, where I was promoted to supervisor. I celebrated my 17th anniversary with the county in July. Before my current position, I had several jobs, including working for IBM in several capacities for 17 years. I liked all my jobs and was happy to be gainfully employed after graduating from North Carolina Central University, in Durham, in 1977, where I majored in sociology. Later I attended Fairleigh Dickinson University in Rutherford, New Jersey, where, through IBM, I was part of an EMBA (executive master’s in business administration) program. As part of that program, I was fortunate enough to travel to Europe for an international business course. I had a great time in London and Paris and actually stayed in an old castle in Wroxton, England.

**Movies you want to see again?** *Imitation of Life*, *Back Street* with Susan Haywood, and *West Side Story*. Each time I see them I shed more tears!

**Books you tell others to read?** I have never liked to read because I am a slow reader. When I was in elementary school, the teacher would tell us to read pages or paragraphs to ourselves and then the class would discuss them. I was never done reading before the discussion began! Now that I’m deaf, I must now read everything, but I do not enjoy it. I read motivational books that deal with personal growth. I read for information only, not for enjoyment.

**I stay home to watch:** I don’t stay at home to watch anything on TV, but if I am home, I like to watch *Jeopardy*, *Wheel of Fortune*, *Who Wants to be a Millionaire*, and *Deal or No Deal*. I like the game shows that allow contestants win money, and I would love to be a contestant on one of them. Do you think they might be able to accommodate a deaf person? Perhaps that is something we can work on together! I also enjoy many of the movies on the Lifetime channel.

**Favorite pig-out food:** I love food, PERIOD, and as you can see, it shows! I especially love Italian food and soul food. I can pig out on lasagna or spaghetti with meatballs and a tangy marinara sauce. I love chopped barbecue, spare ribs, collard greens, and baked macaroni and cheese with some extra
sharp cheddar.

If I had more free time, I'd: travel and socialize with my family and friends; doing fun things that make us laugh or going to places I have never been to before.

The hardest thing about becoming deafened is: that I cannot hear a thing. I am still profoundly deaf after receiving a cochlear implant. Can you imagine the disappointment I experienced after being lead to believe that I would be able to hear again with it? I was in a coma for three days, and when I woke up, I could hear for a day or two. Then my mother and sister were at my hospital bed talking and I said, “Why are you whispering? There is no one in this room but us.” My sister answered, “We are not whispering.” I have had total silence ever since.

I began accepting my deafness: I readily accepted my deafness. It is what it is, and I was shocked to find out about all the denial stories and the shame that some people felt. I always tell folks I am deaf. There is no faking it.

The worst thing about deafness is: people thinking being deaf means you are also dumb. People exclude you from conversations because they have no patience to make sure you understand. Another thing that I do not like is people who try to speak for you in restaurants or when you start talking to someone else. I realize that people think they are being helpful, but I ask them not to speak for me. I often travel alone and manage better when others do not try to help. Occasionally I need help, but at those times I ask for it. People also only tell you the part they think you need or want to know and exclude things they don’t want you to know.

How did you learn about ALDA? I attended my first HLAA convention in Austin, Texas in 2014, and Angie (Fuoco) Fuoco was in one of my workshops. I spoke about there being some differences between culturally Deaf, late-deafened, and hard of hearing people but we should all be working together, trying to understand our differences, and respecting the different choices that people with hearing loss make. After that workshop, Angie stopped me to say she agreed and told me about ALDA. She gave me Cynthia Amerman’s name and said I should look for her because Cynthia was the chairperson of the ALDAcon newcomers committee. That evening, there was a Texas BBQ event with line and square dancing, and Cynthia located me, briefed me about ALDA, and told me how to apply for an ALDAcon scholarship. I was ecstatic to find out about a group of people who might understand and relate to me better as someone who could not hear at all.

In what ways has ALDA enhanced your life? I am so glad I attended ALDAcon in 2014. I met inspiring, friendly, down-to-earth people who cared about others and made me feel just like family. “I lost my hearing but found a family” is so appropriate for ALDA. I actually fell in love with some ALDAns.

If I had more free time, I’d: have already researched what it takes to form an ALDA group in my area. I hope to work on it, but it might have to be two years from now, when I plan to retire. I am going to call it ALDA-Rock because I live in Rockland County.

When I am depressed, I: I don’t often get depressed, but when I do, I sit and think about why I am feeling that way and often conclude that it is nothing to be depressed about. All the trouble in the world today, and I am depressed...for what? It does no good. It helps nothing.

If I could hear again, the first thing I would do is: go out and get some of the latest music CDs and possibly the latest CD player, and sit back and enjoy some music, which is what I miss most! I use to put on some of my favorite tunes and vacuum, dust, and clean my house from top to bottom as I moved and grooved to the beat. Now my house is a mess because I cannot hear the music to clean it by!

My most irrational fear is: crossing over a bridge, like the Tappan Zee, George Washington, or Brooklyn Bridge in New York—any bridge that extends a great distance over a body of deep water. That is because it is the only time I feel helpless. If something were to happen, like the bridge collapsing or a major accident occurring, I would have no control at all! I feel the same way when traveling through the Lincoln Tunnel, which is underwater.

What I can’t stand are: liars and thieves. I cannot understand the need for someone to be either.

Favorite memory: One of my favorite memories is when I went to Rome and Sicily and flew there business elite! It was the first time I was not in a hurry to get off the plane. From before we got off the ground until we landed, the service, food, drinks, private area with TV, computer, games to play, seat that could turn in to a comfortable bed, EVERYTHING...
Hearing Loss Grand Slam

By Angie (Fugo) Fuoco

HLAA's 2015 convention in the stunning St. Louis Union Station Doubletree was, by far, the best I'd attended and the first at which I presented. Yet I intentionally split that four-day weekend to include some other amazing opportunities for connecting with and serving friends with hearing loss. And though I missed several exciting professional baseball games in two cities, I consider my weekend a kind of “grand slam” for hearing loss. [Editor’s note for non-baseball fans: a “grand slam” in baseball is a home run hit with all the bases loaded, thus scoring four runs, the most possible.]

1st Base: Day 1 (Thursday, June 25)

I flew in for the convention’s opening session that evening, delighted to be a part of the crowd honoring renowned disabilities champion Senator Tom Harkin of Iowa (retired). HLAA gave him a special award for his advocacy in securing rights and accommodations for people with all kinds of disabilities, including hearing loss. Senator Harkin’s late brother Frank was Deaf, so he has a special heart for people who can’t hear or can’t hear well, like us! I felt privileged to thank him for his work.

I also had a personal reason to thank Senator Harkin: I work in a building on the Centers for Disease Control (CDC) campus in Atlanta that bears his name; he told me that he was involved in ensuring that this building got appropriate hearing accommodations. I told him that I was a direct beneficiary of his life’s work, using the system he insisted on in meetings and training. I also told him how I’ve been able to continue his work by reminding the CDC that we needed signage in visible areas so staff and visitors would know that hearing assistance was available and where to find it. We took a picture, both of us signing “I love you” in American Sign Language (ASL), and it now adorns my Facebook wall.

2nd Base: Day 2 (Friday, June 26)

This was my presentation day. I spent the morning chatting with exhibitors in both English and ASL in a light-filled hall, then glanced over my notes in a quiet spot of the hotel’s Station Grille. Meghan, my server, noticed my cochlear implant and asked about it, sharing with me that her mom had just received two new hearing aids and was having difficulty adjusting. On cue, I sprang into action, giving Meghan information about HLAA and ALDA, my favorite hearing loss groups that are uniquely equipped to support her mom’s venture.

My presentation, “Harness Your Hearing Loss Superpowers: Amaze with Your Gifts,” was well attended for a Friday afternoon spot opposite Gael Hannan and attendee preparation for official Midwest convention fun, a Cards vs. Cubs challenge. Afterward, several of us used our “hearing loss superpowers” in the grand lobby over drinks and bites. (Don’t know what those superpowers are? I am presenting again in Scottsdale at ALDAcon!) Then some HLAA/ALDA friends and I battled a long line and the hottest wings my mouth ever met at the infamous Sweetie Pie’s. Fortunately, our Sweetie Pie’s trio knew some ASL, so we could keep communicating during the hour-long wait and impossible speech-in-noise levels. We even met a former teacher of the Deaf who joined us in signing!

3rd Base: Day 3 (Saturday, June 27)

Still reeling from 1½ days of wonderful hellos, goodbyes, and new information, I took an early-bird flight to my hometown of Pittsburgh for the Pittsburgh Symphony Orchestra’s (PSO) first sensory-friendly concert. PSO, Pirates’ Charities, and other sponsors provided multimodal accommodations: CART, ASL interpreters, and a large projection screen over the orchestra. I borrowed an assistive listening device and found a group of six friends from Hear Fayette, a hearing loss ministry of St. Vincent de Paul in Fayette County, Pennsylvania. Many of the ladies, most of whom I had met in March, hadn’t heard music so well in a long time.

Heinz Hall was filled with folks of all ages and abilities, some in wheelchairs or sitting near interpreters. Conductor Loh engaged a rapt audience, talking to us frequently and teaching us to “conduct” for him. Songs were familiar sing-alongs, some accompanied by tap dancing, a song leader, or cartoon artistry projected on-screen. Also included were a slideshow tribute to Fred Rogers and orchestra accompaniment by guitarist Joe Negri of Mr. Rogers’ Neighborhood. (I’ll bet you didn’t know that both men were Pittsburghers and the show was filmed there.) The performance brought joy and laughter to all—it was a sensory success that I would be glad to support and enjoy again. Fittingly, a Pirates/Braves game was in full swing.

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Hearing Loss Grand Slam (continued)...

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a few blocks away, so toward the concert’s end, every-
one who could, stood up and sang Take Me Out to the Ballgame as our own “seventh-inning stretch.”

The Grand Slam: Day 4 (Sunday, June 28)

I eagerly attend my hometown church whenever I visit my dad, but this time was special, as it marked the first time I attended since donating an assistive listening system to the church. I’m proud of my dad, who brought it to the priest, showed parishioners how to use it, and raved about how it helped him hear. I was thrilled that the receivers were charged and located in a special place where any congregant could pick one up. My childhood friend Philomena (“Phil”) also sat with us and got a receiver, telling me how she heard so much better with it but could only use it in one ear because she was recently issued only one of the two hearing aids that she needed.

Hearing this led me to work on the weekend’s final mission: introducing Phil to Cathy Zimmerman, Hear Fayette leader and self-appointed liaison for Deaf/hard of hearing networking in southwestern Pennsylvania. Cathy had attended the concert on Saturday, and we’d agreed to meet Sunday afternoon at a local restaurant to begin planning a hearing loss conference for emergency personnel. So after church, I coaxed Phil to come and meet Cathy. And while we only touched on the conference planning, Cathy bonded with Phil and immediately connected her to agencies that could get her a low-cost or free second hearing aid.

This, I felt, was a hit out of the ballpark and a game win! Linking someone I’ve known all my life to a source of help for her struggle made it a real grand slam weekend. The other days were amazing... seeing a noble leader honored, giving others ideas about their own gifts that they might not realize they had, and connecting grateful ladies with sounds they hadn’t heard in a long time.

So I encourage everyone to get off the bench and batter up!

Angie (Fugo) Fuoco works at the Centers for Disease Control and Prevention (CDC) in Atlanta. She is a member of the Hearing Loss Association of America (HLAA) and is president of ALDA-Peach. She is currently enrolled in a multifaceted program of ASL study, disabilities studies, and hearing loss help training through her work at CDC. Contact Angie at angiefugo@yahoo.com.

One of Us (continued)...

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was spectacular and unforgettable!

Nobody knows: I am basically a shy person.

The thing I like best about myself: is that I have a lot of faith. I believe in miracles, and I believe that I will hear again. I attended the Cochlear Celebration in Orlando in 2014. I really didn’t have anything to celebrate, since I am not a cochlear implant success story, so I went there looking for help. I had a great time, met new people, and participated in a research group. I met Jim Patrick, a Cochlear scientist, who arranged for Cochlear technical representatives to come to New York to have my audiologist try additional things with me. I currently hear some more clings and clangs but still have no speech recognition. I am not giving up! I am keeping the faith! I believe!

Favorite saying: When I get ready to leave a place where family and friends have gathered, I usually say, “Plant you now, dig you later!” I also often say, “It is better to wear out than to rust out. Let’s keep it moving,”

The bottom line is: you cannot hide from yourself; everywhere you go, there you are.
Chapter Happenings and GA to SK

By Ann Smith, Curator

Francine Stieglitz reports that ALDA-Boston has been busy. In April, the chapter had a variation on a high tea with scones and savories. The guest speaker, Megan Ford, discussed dealing with insurance for hearing aids and CIs as well as how to buy hearing aids. The annual business meeting and election of officers took place after Megan's talk. This year, ballots were sent via email, which made matters much easier. April was also Deaf and Hard of Hearing Constituents Day at the State House, and CART reporter Nancy Eaton was a recipient of the Outstanding Service Provider award. The weather was perfect for the annual 4th of July picnic and barbecue on July 5. Admission was by donation to one of the area food banks, and the chapter was able to donate quite a lot.

In October, the long-postponed panel discussion was held in the looped room of the Lexington library. Five ALDA members, each with different combinations of cochlear implants and hearing aids, shared their stories, explaining how they realized they had a hearing loss and what they did about it. Original ALDA-Boston members Gerry Lyons and Lee Salvucci attended, and Lee subsequently made an appointment with her audiologist. The ALDA-Boston members at the October Walk4Hearing had a fabulous time in spite of the threatening weather. ALDA-Boston's ALD tours at the Museum of Fine Arts have been well attended. MFA tour guide Karen Moss even did a back-to-back ALD tour because so many ALDAns wanted to see the exhibit on Dutch Painting in the Age of Rembrandt and Vermeer. The year concluded with the popular holiday party on December 12.

ALDA-Peach had a planning meeting in June. Programs for the remainder of 2015 were planned, and a general discussion of the “state of the chapter” was held. In July, members and guests met at President Angie Fuoco's home for an indoor picnic. Members brought side dishes, and chefs Steve Tamas and Jim Stansell braved the hot weather to man the grills. The August meeting featured an excellent presentation by Timothy Cheek. Tim and his wife Angela are travel consultants with Signs of Travel and specialize in arranging trips for people with hearing loss. Tim gave a lot of useful information and advice. A report of his presentation is available on Peach’s website, www.aldapeach.org. The Cheeks’ website is www.signsoftravel.com. In September, the ALDA-Peach Literary Society shared book reviews. Members giving reviews of favorite books included Robin Titterington, Marge Tamas, Steve Tamas, and Mary Platt. ALDAcon 2015 was the main topic of discussion at the November meeting. Ann Smith gave a brief report and answered questions from other Peach members. Peach’s 16th annual holiday luncheon was held on December 12.

Roxanne Gasaway, one of Peach’s founding members, has moved into a nursing home and says she is “okay enough.” She recently discovered the Reader’s Digest large print condensed books and is enjoying them immensely.

In Memoriam

ALDA-Boston is sad to report that Charlie Barnes passed away on June 2. Charlie was also a past ALDA-Boston Board member. He and his wife Connie hosted the annual 4th of July barbecue for some years at their beautiful home in Medfield. Chapter members will miss his warm sense of humor and gentle ways.

Submit your chapter and personal news for the next issue to Ann by February 22 at fabsmith@att.net.
Your support is essential to help TDI maintain its advocacy work in our nation’s capital, Washington, D.C. Here are some of our goals!

♦ Current Bills in Congress on Internet Access (HR #3101 & S #3304)
♦ Mandate for Captioned Telephone Relay Service
♦ Relay for Deaf-Blind Users
♦ Universal TV Captioning at All Hours
♦ Captioning at Movies, Live Events and Online
♦ National Broadband Plan
♦ Modernized NG-911 Services
♦ And much more... 

Join TDI as a member and help us fulfill our mission for accessible telecommunications, media, and information technologies!

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SKSK

We must let go of the life we have planned, so as to accept the one that is waiting for us.
—Joseph Campbell
As this is written, I am nearing the end of the first year of my two-year term as president. The Board is meeting monthly online to discuss various concerns. The two-hour meeting allows us to do business in a more timely fashion than would be possible via email or phone calls. If you have issues or concerns you would like the ALDA Board to address, feel free to contact me personally at SLarew@aol.com.

I want to thank Cynthia Amerman, Dave Litman, and Terri Singer for their work as ALDAcon 2015 co-chairs and program chair. We had approximately 55 newcomers, which was exciting, since the first ALDAcon can be an especially memorable experience.

2015 Awards

One of the privileges of being president of ALDA is presenting the annual awards. I would like to again congratulate the 2015 winners. The I. King Jordan Award was presented to Dr. Neil Bauman, the Able ALDAn Award to Terri Singer, the ALDA Angel Award to Carol Postulka and the President’s Appreciation Award to Cheryl Heppner. Thank you to all four for your contributions to ALDA!

ALDAcon 2016

I will be serving as co-planning chair for ALDAcon 2016 along with Jane Schlau. Since I am mostly retired now, I decided to use my experience in planning conferences to assist in planning the next ALDAcon. Kathy Evans has agreed to be program chair. I hope to see many of you in Milwaukee next September.

I am pleased to announce that Dr. Jane Fernandes, the first deaf female president of an American college, has agreed to be the ALDAcon 2016 opening keynote presenter. I had the privilege of working under Dr. Fernandes while I was employed at the Gallaudet University Regional Center at Flagler College in St. Augustine, Florida. Dr. Fernandes was born deaf but did not learn American Sign Language until college, so some of her experiences are similar to those of ALDA members, and I am sure you will enjoy her presentation.

Past President’s Report

By Dave Litman

As past president, my role is primarily to support the president and set up the election for the next year. I also took on the role of ALDAcon 2015 co-planning chair with Cynthia Amerman.

After ALDAcon, my primary focus was on recruiting people to run for secretary, treasurer, and regional director 1 and 2. My goal had been to get at least two people to run for each position, but I was not successful. However, I am grateful for the people who agreed to run, and I am confident that they will be an asset to ALDA and the Board.

For the second year, the election was conducted electronically (for those with email address). As of the writing of this report, we have received about a 50% return rate on the election, and feedback has been quite positive about the simplicity of doing the election electronically.

These past three years on the Board have been quite rewarding for me personally and professionally. ALDA is such a unique organization and I feel so lucky and loved to be part of the ALDA family.
Secretary’s Report
By Karen Krull

This is the last ALDA Biz report I need to make, before turning over the reins to a new secretary. My five years as the ALDA, Inc. Secretary have gone by fast, and I will always treasure the time I served on the Board.

I’d like to share some of the Board highlights from this past year. We endorsed the Live Nation project initiated by John Waldo. The Board approved the creation of the Ray of Sunshine Scholarship Fund in honor of the late Rachael Morris. We focused on budget, membership growth, and website structure, and we considered award recipients prior to ALDAcon 2015. We discussed and chose the hotel for 2016 ALDAcon and started a search for a 2017 hotel. We sent out a request for proposal to fix website issues and we also concentrated on membership growth. We passed a motion “to establish a three-member task force on ASL interpreting and signed and oral transliteration; to develop a position paper for approval by the Board reflecting the cultural and linguistic interests of late-deafened adults; and that would include a general reference to all the different ways we might choose to communicate; to be an ongoing resource for the Board and membership on such matters; to ensure that late-deafened consumers are informed self-advocates for appropriate services when needed.” The task force has since been established. We made it mandatory for scholarship recipients to write about their ALDAcon experience for the ALDA News. The Board once again decided on utilizing an electronic election, and saved on the mailing cost by doing so. We approved the planning and program chairs for ALDAcon 2016.

I’m sending you all a fond farewell, and best wishes to the new Board for 2016.

Treasurer’s Report
By Matt Ferrara

This report completes my present term as treasurer. Between the two terms and my takeover year, I spent five consecutive years in this position. This has been my fourth round altogether as treasurer. It has been a pleasure for me to serve and I thank you for your continuing support.

ALDAcon 2015 was not a great financial success, but we did make a small profit.

As of November 19, 2015, total cash in the ALDA bank accounts was $58,018. The balance Sheet for the accounts is as follows:

- ALDA operating expenses: $23,727*
- ALDAcon 2015 account: $919**
- ALDA-Carolina Flight chapter: $750***
- Scholarship funds: $32,622

All federal and state (Illinois) forms that were required for 2015, to date, have been filed. All outstanding bills have been paid. We are about on budget.

*This includes the $20,000 bequest from the Mary Clark Estate.

** This is the profit as of now. There may still be minor changes subject to final audit.

***ALDA-Carolina Flight has donated most of the ALDAcon 2012 profits to ALDA, Inc.

Finance Committee Report
By Matt Ferrara

The committee is investigating the best ways to use the Mary Clark bequest money and is also looking into different fund-raising campaigns.

As a reminder, ALDA, Inc. is a nonprofit corporation and donations may be tax-deductible. Also, some employers have matching donations plans. If you have any questions regarding donations, please contact treasurer@alda.org.

I will be the business manager for ALDAcon 2016 in Milwaukee and hope to see you then.
The mission of the Association of Late-Deafened Adults (ALDA) is to support the empowerment of late-deafened people.

Late-deafened adults are people who have lost their hearing in any degree after having acquired spoken language. ALDA members may or may not use hearing aids, may or may not use assistive listening devices, may or may not use cochlear implants, may or may not use speechreading/lipreading, and may or may not use sign language. What ALDA members DO is “whatever works.” This is the philosophy that keeps the doors to ALDA wide open to anyone who is interested.

ALDA is committed to providing a support network and a sense of belonging to late-deafened people, sharing our unique experiences, challenges, and coping strategies; helping one another find practical solutions and psychological relief; and working together with other organizations and service providers for our common good.

ALDA provides networking through local chapters and groups as well as our annual convention (ALDAcon). We offer social activities, advocacy, peer support, up-to-date information on new technology, and guidance for late-deafened adults, their families, and their friends on ways to deal effectively with the difficulties arising from losing our hearing. ALDA is inclusive, never exclusive. Members find themselves part of a family, with emotional and social support, and, above all, acceptance.

Membership in ALDA provides support for outreach: newsletters, brochures, mass mailings, public presentations, and participation in local and national events to spread the word about ALDA to the more than 31 million Americans, and other late-deafened people worldwide, who would benefit from our organization. ALDA also assists chapter leaders and regional directors to expand ALDA through more chapters and groups and increased membership.

You can join ALDA via the form in this issue, or go to www.alda.org or contact ALDA, Inc. at 8038 MacIntosh Lane, Suite 2, Rockford, IL 61107, 815-332-1515 V/TTY. Membership entitles you to receive the quarterly ALDA News, which spotlights personal experiences of late-deafened people, and to attend ALDAcon at the lower member rate.

If you are interested in learning about ALDA in your area or seeing ALDA become active there, please contact your regional director (contact information is at “Contact Us” on the ALDA website).
JOIN THE FAMILY.....JOIN ALDA!

Your membership in the Association of Late-Deafened Adults connects you with ALDAns throughout the world. Don’t miss our informative quarterly newsletter, ALDA News. Check our chapter directory at www.alda.org to find a chapter near you. Our fully accessible annual convention is a must for newcomers and old-timers alike.

To join or renew using credit cards on our secure site, go to www.alda.org. To mail your membership, please complete this form and send with check payable to:

ALDA, Inc., 8038 MacIntosh Lane, Suite 2, Rockford, IL 61107-5336

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ALDA’s Mission Statement:
To Support the Empowerment of Deafened People.

Education
Advocacy
Role Models
Support

ALDA provides networking opportunities through local chapters and groups as well as at the annual ALDA conference (ALDAcon).
Be sure to check your address label. It shows the date your dues will expire. Don’t let your membership lapse!

Visit us on the web at: www.alda.org

Make a Difference! Become a Lifetime Member!

**Why a Lifetime Member?**

A. ALDA and the work it does to support the empowerment of deafened people means a lot to me; I want to support ALDA financially

B. I don’t have to worry about forgetting to renew my dues

C. I plan to live to be at least 130 years old; think what a bargain Lifetime Membership will be!

   *Ann Smith, Lifetime Member*

**Lifetime Membership Tier**

- **Bronze** $500 - $1,499: receive a personal letter from the President, bronze plaque
- **Silver** $1,500 - $2,999: receive a personal letter from the President, silver plaque and priority seating at future ALDAcons
- **Gold** $3,000+: receive a personal letter from the President, gold plaque, priority seating at future ALDAcons and complimentary registration to a future ALDAcon.

**Lifetime Memberships** may be tax deductible and can be paid in three annual installments by check or credit card.

Contact ALDA treasurer: treasurer@alda.org or visit www.alda.org