The Long Journey Back

By Anne Marie Killilea

I have been a nurse for over 35 years, working hard to provide the care and nurturing that my patients needed. In June 1998, I took a nurse manager position at a local hospital. The air quality was not good, and I became very sick with respiratory illnesses that necessitated the use of many antibiotics. On January 18, 1999 I took my first dose of Zithromax, and overnight I lost my hearing and my sense of taste and smell. I woke up the next morning puzzled as to what had happened to me and sought medical attention to figure this out. My former physician told me that I had an autoimmune ear disease, but he could not explain why I did not have my sense of taste or smell. After three months, being the nurse that I am, I found out that my laboratory values never indicated that I had an autoimmune disease and the only real reason that I became deaf was having taken the medication. Later I also learned that the 1999 Physician’s Desk Reference (PDR) documents that Zithromax can cause hearing loss.

At first I felt that I still could be a nurse and retain my nurse manager position, but I soon found out that because I had an alteration in my hearing, I was not considered a good role model, and I was forced to leave. During the immediate time after my hearing loss, I was fitted with a large behind-the-ear hearing aid, but it only increased the volume and not the clarity of sound. I was also told by my former otolaryngologist that the nature of my hearing loss made me a poor candidate for a cochlear implant. How wrong this person was! I then secured a position at a large hospital, which required telephone communication. I was frightened. How was I going to manage this situation? I asked for assistance, but my requests were denied. I did finally get a headset to use with the phone, but I could not hear well enough and gradually was written up for poor performance. Within eight months, I left that job heartbroken.

I was able to acquire two more nursing positions, which both ended with failure. I had an amplified stethoscope, which provided a great deal of assistance to others who wanted to hear precise lung sounds. But I gradually became unable to use it because my hearing was deteriorating. No one told me that the hair cells that remain intact after ototoxicity gradually deteriorate over a period of time which produces a greater loss of hearing.

It was not until the fall of 2002, after I obtained a school nurse position at the Learning Center for Deaf Children in Randolph, Massachusetts, that I learned how wrong others were about me. I saw little children implanted with cochlear implants who were speaking, signing, and communicating. They looked happy, they were learning all sorts of things, and they were chatting with each other. I felt that if they could do it, then so could I. I had lost so much since becoming deaf, and we were even in the process of losing our home, that I had to do something. I called up a friend, got the name of a different otolaryngologist, and made an appointment to be evaluated for a cochlear implant. I was very surprised that I was indeed a great candidate.

During the preoperative sessions, each candidate is evaluated as to what the expectations are after the cochlear implant surgery is complete. I said that I had lost so much that all I wanted was the ability to hear, to communicate. Little did I know just how much my life would change! In May 2003, I had

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ALDA NEWS

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“Come here,” my co-worker said to me excitedly. “I’ve got to show you something.” I followed her to her office, where she turned on her iPhone and told me, “Gabe is singing ‘God Bless America’ in sign language.” Having recently talked with her son Gabe, I was eager to see the video that had her so excited. “He was the first in his class to learn the signs to all the words, so he taught the other students,” she said proudly. Thanks to my CI, I could hear his beautiful child’s voice, and thanks to his signing, I could understand the words to this lovely song.

This was a true ALDA moment, reminding me of the value of understanding via both a CI and sign language. Every late-deafened person has his or her own unique experiences, and we are pleased to bring you this issue’s theme of “my journey from discovery of a hearing loss to acceptance/regaining confidence and self-esteem.”

Our cover story, “The Long Journey Back” by Anne Marie Killilea, provides a look at how the author triumphed over hearing loss to re-enter the nursing profession. “Goodbye, Dear Friend” by Tim Kimball is his touching account of grieving a hearing loss. And in “Smoke Rings of Confusion,” Amy Gustavson uses creativity and humor to describe her experiences in the audiology booth.

In “My Daughter’s Birthday Request,” Kristel Scoresby recounts the difficulties of conversing with her daughter about her upcoming birthday. The value of family support and technology is recounted in “My Hearing Loss Journey” by Paula Titus. And veteran ALDA mom Mary Clark shares the importance of helping one another to feel needed in “Pulling Someone Up.”

In “The New Normal,” Maryruth Dilling provides a candid account of adapting to her progressive hearing loss, and Janis Aaron Moore provides her observations on living with hearing loss in her college essay, “Understanding/Hearing.”

“Communication Access for Medical Visits” by Linda Hull explores a topic that is familiar to most ALDAns: communication challenges in a medical setting. Nancy Huffman shares her deep appreciation for captioning in “What the Power of Captioning Means to Me.” Finally, our experienced ALDAcon planner, Terri Singer, offers some excellent tips to help ‘congoers enjoy ALDAcon to the fullest. We also have our regular columns, including “One of Us” and “Chapter Happenings,” and the ALDA Biz is included in this issue as well.

Many thanks to everyone who shared his or her story. If you have comments about the newsletter or ideas for future themes, do not hesitate to contact me.

Eileen

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My hearing loss journey was impeded by a misdiagnosis. When I was five, my kindergarten teacher noticed that I waited to see what the other children were doing before joining in, so she suspected that I might have a hearing loss. My parents took me to Johns Hopkins for an evaluation and were incorrectly told that my problem was psychological, not physical. So throughout my childhood, I was led to believe that some kind of block prevented me from using my hearing properly. I developed excellent speechreading skills, which, combined with what I was able to hear, enabled me to function quite well in one-to-one conversations, but I was lost in groups and couldn’t understand the phone, radio, TV, movies, or presentations in auditoriums. Fortunately, I had a series of best friends, so my social life wasn’t lacking. My most difficult experiences were at summer camp, since I was always in a group, and the evening entertainment included plays and movies that I couldn’t follow.

Finally, when I reached my teens, I asked to have my hearing evaluated again. This time, I was extensively examined at Columbia-Presbyterian and was finally diagnosed with a hearing loss when I was 14, but my parents were incorrectly told that it wouldn’t progress. I was advised to get a hearing aid, but being a teenager, I said no to that yucky idea. Academically, I had no problems because I sat in front in my classes and could understand my teachers. However, that changed when I got to college, because I couldn’t speechread and look down to take notes at the same time. I therefore arranged for students in each of my classes to let me copy their notes during class, but I was unable to participate in any college organizations, and dating was difficult because I couldn’t use the phone.

My self-esteem at this point was extremely low. I didn’t know anyone else with a hearing loss, and I felt defective (it didn’t help to briefly meet one other hard of hearing student at my college who had been put back a year because she had been caught cheating on a test). But in my senior year, I did manage to meet my future husband. And after I graduated, I got my first hearing aids (which, unfortunately, didn’t help much). I had great difficulty finding a job because of my inability to use the phone. Finally, a rehabilitation counselor located a suitable position for me as a technical editor, and I got to know another hard of hearing person for the first time. She was a middle-aged woman who was also a technical editor, and she seemed normal enough to me, which made me realize for the first time that maybe I was too.

But I still had a long way to go toward developing a good self-image. What helped me get started on that journey was the establishment of organizations to serve our population—Self-Help for Hard of Hearing People (now the Hearing Loss Association of America) and, later, ALDA. I devoured the first-person accounts in the early issues of the SHHH magazine, identifying with the struggles of others like myself. I became involved in advocacy, starting a hearing loss support group and then an ALDA group, becoming the ALDA chapter coordinator, serving on my state’s deaf and hard of hearing advisory council and subsequently as its chairperson, etc.

Getting to know others like myself showed me that I really was OK despite having a hearing loss, and my advocacy work made me realize that I was also capable and useful.
Goodbye, Dear Friend

By Tim Kimball

Today I am saying goodbye to a dear friend, a lifelong friend. I cannot begin to tell you all the wonderful things we have shared through the years. Most of these things I have taken for granted, which the majority of us do when it comes to lifelong friends.

Birds singing in the morning. The awesome sound of a thunderstorm. Simple conversation. A whispered answer between two school kids to question # 5 on a math test.

Music. Oh, my beautiful music. I will miss you more than you could ever imagine.

Luckily, my friend didn’t pass away suddenly. I have known this day was coming for years. My friend has been sick for a very long while, becoming weaker as time went by. There was a car accident 22 years ago that didn’t do my friend any favors at all. I can look back now and see that is when things took a turn for the worse. We have tried everything we have known to do to hold onto to my friend, but sadly, he just slipped away. On August 17, 2011, due to brain tumor surgery at the age of 56, I lost my lifelong friend, also known as “my hearing.”

I am writing this to let go of the grief I have been holding onto. It is time to move on, to let go of the anger I feel for my loss.

Thank God for the doctor who told me five years ago, “You need to start learning sign language because in a few years you will become deaf.” In those five years, I learned to communicate through sign language. It’s funny to me how life changes. Because of my hearing loss, I lost some of my hearing friends, but I have made so many friends in the Deaf community.

Yes, it is time to let go of the anger at being forced to accept a change that, no matter how hard I tried to fight it, happened anyway. During these five years, I have met a few angry deaf people who were unable to come to grips with the changes that happen with hearing loss, and took their anger out on the world. I refuse to become one of those people.

I know there are some people in the Deaf community who will say, “You’re not deaf! You still have some hearing in your left ear.”

To this I respond, “Yes, you’re right. With the help of a hearing aid set for a 90-decibel loss, I can make out some sounds, although I’m unable to comprehend any speech. With the aid turned off, I hear…nothing.”

So without splitting hairs, please cut me some slack and agree with me. I am deaf.

In closing, let me say again, goodbye, my dear lifelong friend. As with any loss we experience, there is a period of sadness and grieving. But then the time comes to get up and carry on with our life.

I will miss you the rest of my days, and I will keep my fond memories of you in my heart forever. Goodbye, my dear friend.

Tim is vice president of ALDA-Suncoast (Florida). He was hard of hearing for years due to NF2 brain tumors. Recent surgery to remove the right-side tumor left him totally deaf on that side, and he also has a profound loss on the other side. He wrote this article as part of his grieving process. Tim can be contacted at timjk1954@verizon.net.
Smoke Rings of Confusion
By Amy Gustavson

The day is wrapping heavily around me, humid yet chilly, with gray skies. It’s the type of day that you wish would get the rain out of its system so the sun can shine again.

It’s a perfect day, actually. A day that allows me to feel like hiding under the covers, avoiding faces and places, tasks and chores, and letting tears fall in place of raindrops. It’s a day to permit myself to grieve.

I had my audiological exam yesterday. I have been going virtually every year so I can track “progress” and update my hearing aids. It’s amazing how a few tweaks from a computer mouse can change your world through digital hearing aids. Yet I have been lax—it’s been several years since I stepped into that small office. It’s a cheerful place, with dancing bear paintings on the soft blue walls—a welcome approach to that often dreaded gray steel box filled with wires, speakers, a chair, a red push button, and a window. When one is looking out that window, the world can seem so very far away.

I try to arrive with my sense of humor. I have a wonderful audiologist with excellent credentials and an understanding that many professionals never quite grasp. She smiles easily and sincerely, sharing laughter that tickles my day.

After a brief catch-up on family and events, I am seated in the dreaded booth, and the door is shut. No matter how many times I have sat here, I am still uncomfortable. After all, it is a test. My hands feel clammy as I grasp the “Push Me” button when I hear the tone. For that brief instant before the first “note,” I envision a scene from the magically surreal story of Alice in Wonderland, where Alice has fallen down the rabbit hole and is faced with a “Drink Me” potion. It’s a scene based on trust before stepping into the unknown.

I push the confirmation button to indicate that I have heard the tone. Well, at least I think I heard it. I know that one tone follows another, so it should be happening now, and I push. I add a puzzled look and the words “I think” to confirm that I’m not sure.

When the test is switched to my other ear, I lighten my apprehension with a joke about also needing to switch the hand in which I am holding the button. We both laugh at the silliness and settle in for round two. Same tones, same “I think.”

And then the rabbit hole gets deeper, or the door gets smaller, or the choices of Fear, Fight, or Flight become null. There are neither rescuing potions nor smiling Cheshire cats, although they exist somewhere. They must. Others have come along this same journey.

Having been to my audiologist for many years, I am familiar with her voice and style. I grasp that as a comfort and set off to chase the elusive white rabbit, which is in the form of a white sheet of paper with a list of “repeat after me” words.

As smoke rings floating around a caterpillar’s head, the words come slowly and perfectly formed. Enunciation is placed at proper stress points, carefully repeated if necessary.

And...I reach and grasp. I touch a letter and it dissolves. I try to form my own words in repetition. I guess. I stop and shake my head in confusion and take a deep breath and strive forward. “Road.” I heard “road.” I think it’s “road.” There are no visual cues, and the white paper is blocking any chance of lipreading. The gray booth seems to have wrapped tighter around me, or I have grown taller to face this challenge.

I guess some more. I think. I hope. I struggle through a jumble of letters that no longer form the memorized list of “baseball, cowboy, hotdog, outside, sidewalk.” Simple words. One syllable. Everyday “along the journey” words. And I don’t have a clue.

Numbers and percentages and changes are discussed. Yet numbers can be like boldly displayed hat sizes. In reality, they do not always fit. Being a good guesser fits a small sense of pride on my head. Reality then slips it off.

Somehow in this strange world of galvanized knights and bejeweled monsters, dodos and dancing creatures on the shore, tea parties and silly games and adversity and flowers that chide and sing...one develops a determination and an inner strength. Following a path, standing strong, and placing one foot in front of the other no matter how scary that is,
“Mubba whahean meuab” was my daughter’s answer for the tenth time. “Aleah,” I asked, “I cannot understand what you are saying. What do you want for your birthday?” Aleah sighed. “A toy.”

My heart broke. How I wished I could hear what Aleah wanted for her third birthday. It was not that Aleah spoke like most two-year-olds, unintelligible to anyone outside the family. She spoke clearly, maintained eye contact, and made sure I had her attention. After all, she had been trained to speak to a mother who had a severe hearing loss. But even with all the accommodations we both employed, sometimes I just simply could not understand what was spoken. Such was this occasion. And Aleah, not knowing how else to make me understand what she wanted, simply changed communication tactics. “A toy.” Somewhere in her little brain, the thought came “if mommy can’t hear you ask for what you want, just change what you say you want.”

Running off to play, Aleah did not seem affected by the conversation, at least not externally. But I was greatly affected. Here she was, being patient and working hard, but it wasn’t enough. How was she going to communicate her important needs to me if I could not even understand a birthday request? Would she stop making her wants known because it’s too difficult to have them understood? How much responsibility is she going to feel for me, at the expense of sacrificing her own needs? I wanted her to have compassion and be of service to others, but I also wanted her to be a child and not grow up too quickly. I became determined to never let another year go by in which I could not hear her request for a birthday present.

A few months and several insurance battles later, I was approved to get a cochlear implant. It has been life changing. I have a huge support network of people who were thrilled about my CI, but no one was more excited than my daughter. After every doctor’s appointment, after every mapping, she asked, “Can you hear me better, mommy?” It took time and a great deal of work, but I was eventually able to answer her affirmatively. “Yes, Aleah, I am hearing you better.”

Shortly before Aleah turned four, I asked her what she wanted for her birthday. Right away, she gave me her answer, and it was crystal clear. My mouth dropped open. Not only had I understood her clearly, but now I also had to figure out what to do about what she asked for! It would have made sense if she had said “a doll” or “a scooter” or “a paint set.” Those things would have been easy to get for her! But no, we live in an age when children are more technologically savvy than their parents. Her request for her fourth birthday? An iPad!

Yes, I am hearing better. But do you really think I’m going to get an iPad for my almost-four-year-old daughter? Was I tempted? Yes, for about three seconds. What did she get? A doll, a scooter, and a paint set. After all, I do want her to be a child!

Kristel and her husband Evan have two children, Aleah, 4 and Joshua, 2. Kristel works part time as a therapist, counseling individuals and families and doing some adoption work. She has had genetic progressive hearing loss since the age of 4 and wants to make a difference for those with hearing loss. More about her hearing loss journey on www.journeytosilence.blogspot.com. She can be contacted at kscoresby@gmail.com.

Smoke Rings of Confusion (continued...)

Continued from page 6

no matter how lost one gets, no matter how confusing things are, no matter how the tears might fall, no matter how rocky the road.

“Road.” I’m sure I “heard” road.

Tomorrow will be brighter. Tomorrow will be a few more steps away from the “hit hard” fall. Tomorrow perhaps I will wear a hat that fits, smile boldly, and step into my garden to “hear” the flowers sing.

Amy’s personal fairy tale includes her husband, who refuses to grow up; her dog; and a senior citizen cat. Amy had measles at 21, and shortly afterwards she noticed difficulty hearing various college professors. She finally went to an ENT to have the wax cleaned out of her ears but learned that instead, she had a moderate sensorineural hearing loss. Over the years the loss progressed to severe/profound, requiring a continual readjustment. Amy’s Interests include making pet-related gift baskets, hiking, kayaking, birding for the hearing impaired, flea markets, bingo, wine, beading, cooking, poetry, and her garden in central Massachusetts...where the fairies do live. She can be reached at StarSnow77@aol.com.
My Hearing Loss Journey

By Paula Titus

I lost my hearing when I was four years old. My mother asked me if I wanted a cookie when my back was turned towards her, and her heart sank when I didn’t respond. When she faced me, I told her I wanted the cookie. This started my hearing loss journey. My mother was told that there was nothing that could be done to help her little deaf daughter. Fortunately, she didn’t listen to the professionals, and with the support of my grandparents, I got my first hearing aid. My mother cried when she heard me singing, “I can hear, I can hear!” all the way home. She went back to school and became a speech therapist. She not only gave me speech therapy until I left home to go to college, but she also taught me strategies for making my environment the best it could be, to aid my comprehension.

When my younger sister Ann turned four, she too lost her hearing. It was wonderful to have the support of someone who knew what it was like to be deaf and who understood the struggles this brings. My mother taught both of us how to lipread, so we often had our own private conversations with one another. Our mouths were going a mile a minute, but there was no sound coming out!

I married and moved to Seattle in 1974. My mother was a great support to me long distance, encouraging me as I dealt with five active sons. When I read in the newspaper about the new cochlear implant technology, my mother was excited and encouraged me to check it out, and I was happy to be eligible to be part of the Nucleus 22 processor trials in 1989. I had had a body aid hearing aid as a child and got my first behind-the-ear hearing aid when I was in junior high. With my new cochlear implant, I was back to wearing another body aid, but it changed my life. A few years later, I was delighted to be able to get a behind-the-ear cochlear implant processor.

Once I had a cochlear implant, my sons found that they could not get away with things that they previously could! It was a joyous moment for me to hear a bird for the first time in my life. Now it is a “stop and smell the roses” – “stop and hear the sound” moment whenever I hear a bird singing. I found I had less stress and strain in trying to hear in the hearing world that I lived in. I regained my confidence and went back to school to work towards fulfilling my lifetime dream of getting my bachelor’s degree. I was also able to fulfill church responsibilities and have leadership opportunities I never dreamed I could have as a deaf person. I have been accepted into Gallaudet University’s peer mentoring program and am a team member of CS Deaf and Hard of Hearing Resource Specialists (www.cs-dhhrs.com). What an exciting opportunity this is to learn more, help educate the public about hearing loss, and be a mentor to those with a hearing loss! I am so thankful for the opportunities that I have had, and will have, to grow as a person and a leader. My hearing loss journey continues with bright hope for the future!

Paula Titus has a bachelor of science degree in Information systems. She is an Information systems manager with over 20 years’ experience in information technology and database administration. She has extensive knowledge of designing, implementing, and maintaining databases and is a liaison between her agency and other entities. Her co-workers have her on speed dial for tech support. Paula also works for CS Deaf and Hard of Hearing Resource Specialists as a team member with Kimberly Parker and Christine Seymour, who started the company, and she will enter the Gallaudet University peer mentoring program in the fall of 2012. Paula has been active in ALDA-Puget Sound since she discovered it while learning to become independent after her husband died, and she currently serves as the co-leader. She can be contacted at paulat@centurylink.net.
“You are not going anywhere,” said the doctor. “You are in a-fib,” which I guessed was really bad! My heart had been beating weirdly for a year, and going to a heart specialist to find out why was my first step. They admitted me to Loyola Medical Center immediately.

I knew I was sick. I had lost weight, was short of breath (I could not walk up the stairs to my bedroom), and wanted to sleep a lot on the couch—not to mention experiencing the strange heartbeat. I drove to the medical center on my own, which was a feat in itself. I had always had a weird heart from the moment I was born with an atrial septal defect, and I had chalked up my latest episode as just something related to that.

I was also very depressed, but I thought I was doing a good job despite all my issues. Divorce, my mother’s death, my girls growing up and leaving home, and my just turning 52 were perhaps too much for me? I was supposed to be able to handle anything (work, kids, a house), so there was pressure for me to be strong. Instead, I fell apart!

The psychiatrist by my bedside asked me questions, but I mostly responded “I don’t care.” I was not suicidal by any means, but nothing mattered anymore. “Just let me sleep,” I said. (And don’t let the nurses poke me anymore!)

The psychiatrist completely turned me around, and if I could remember her name, I would send her this article now. She figured me out after two days, and on the third day she asked for my advice regarding a late-deafened girl she knew. I woke up. The conversation was no longer about why I did not eat breakfast or why I did not take my walk around the hall or why I refused to give blood at three in the morning. She was asking for my advice! Someone needed something from me, and it perked me up.

I think that is why I am still in ALDA after all these years. We all need to feel needed in some way, and when we are going through major life transitions—particularly those that are traumatic—we can sometimes disconnect from life, especially when we become deaf and/or important people leave us.

In my case, my coping mechanism was not to care anymore, and then I entered that “nobody needs me anyway” mode. I try to think of that when I see people who are in a “not so good” place. I have learned a lot from my own journey, and that helps me understand others’ journeys.

After eleven days in that hospital and three years of “still working to recover” from both physical and mental trauma, I am getting there. I’ve learned what it is like to be as far down as you can be and then have someone pull you up, so I’m telling everyone to pull up someone else! Call and ask for advice or just say you are thinking of them. To all my ALDA friends...thanks for pulling me up!

Mary has three adult daughters and lives in Oak Park, Illinois. She formerly taught Deaf and hard of hearing students and is now a private consultant for Deaf/deafened issues. She can be contacted at ldmpoppins@aol.com.
One of Us
By Karen Krull, Curator

This issue’s interview is with the very talented Antonia Lindsey, our Facebook maven. I first met her at ALDAcon, where she livened up karaoke with her angelic voice. She’s a late-deafened professional artist/art therapist with Meniere’s disease. It was diagnosed in 2000, and she was profoundly deaf by 2009 after three surgeries to preserve balance and walking. ALDA and ASL gave her back her hope. She consults in mental health, teaching young clinicians, and has over 27 years’ experience in the field of child and family therapy with trauma, addiction, neurological challenges, and communication differences. Her favorite joke is that she used to treat kids with special needs and now she is one. She began studying ASL at Washington School for the Deaf in 2005 because medications and other interventions that sometimes work for Meniere’s failed her. She also lives with Ehlers-Danlos syndrome, a genetic collagen abnormality, so she cannot receive a cochlear implant. Antonia claims she is now the deaf and dizzy stereotype of Meniere’s that others don’t want to become, but she quotes Michael Fox: “I have this disease, but it doesn’t have me.”

Learning ASL allowed Antonia to adapt. She uses an interpreter so she can still work part-time. She’s an online clinical educator who paints and sells her artwork. She and her husband grow their own food, serve three flat-faced Persian guard cats, and raise chickens. Her husband Jeff is hearing, but he has acquired a good bit of receptive sign language skills because his wife is a stubborn deafened German. Read on to learn more about Antonia, and you can reach her by email at Antonia@antoniarathbun.com. You can find her artwork in the NTID/Rochester Institute of Technology’s online gallery of deaf artists at http://idea2.main.ad.rit.edu/padhd/publicDA/main/artists/AntoniaLindsey/index.htm.

Name: Antonia Lindsey Rathbun
Where were you born? Glendale, California
What is your current residence? Damascus (a rural area adjacent to Portland, Oregon)
What is the cause of your deafness? Meniere’s disease
Age/year you became deafened? Age 54 in 2009
Marital status? Married to Jeff Lindsey
What is your present job? Professional artist/art therapist, mental health consultant
What is the worst job you ever had? In college I was hijacked into selling encyclopedias for all of two weeks.

It was terrifying.

Movies you want to see again? Lady in the Water
Books you tell others to read? Be Free Where You Are by Thich Nhat Hanh and Finding Beauty in a Broken World by Terry Tempest Williams
I stay home to watch: NPR’s Masterpiece Theater
Favorite pig-out food: Carrots and peanut butter
Hobbies: Edible gardening, raising chickens
If I had more free time, I’d: “What free time?!”

The hardest thing about becoming deafened is: Missing music and the sounds of foreign languages
I began accepting my deafness: in 2009, when an endolymphatic sac decompression and a shunt surgery on my left side took out all my hearing in that ear, and the residual hearing in my right ear failed four months later, leaving me profoundly deafened.

The worst thing about deafness is: I can’t hear birds, cats, and other favorite voices.

The best thing about deafness is: I learned ASL, so my hands can dance even though Meniere’s took away my balance. I love my Deaf community friends.

How did you learn about ALDA? An interpreter friend told me about it.

In what ways has ALDA enhanced your life? I truly found the “family” sensation in our total acceptance of one another’s communication differences! It is an amazing experience not to have to explain, and to be among those who use “whatever works” to make communication accessible. The spirit here is uplifting and encouraging in ways that go way beyond words! The courage, character, and humor of my friends in ALDA inspire and delight me.

When I am depressed, I: Do service work for animals or other people, tend, mend, pray with my hands, and paint.

My most irrational fear is: Living far from water. I need to be close to streams, rivers, lakes, ponds, oceans…water! (This is rather odd now that I think about it, as I live underwater because of Meniere’s. I guess it’s why I was asked about “irrational” fears, grin.)

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The New Normal

By Maryruth Dilling

The journey down this road started over 25 years ago, when I was a young mother with three children. Occasionally I noticed that I was missing parts of what was being said, and I was starting to say “What?” a bit too often. A friend suggested I get my hearing checked. Since I was working on my degree in Deaf education, this was a simple event to schedule. As a student, I received the service for free. The verdict? Yes, I had a moderate hearing loss.

At that time in my life, I did not pay it any attention. My days were filled with attending classes and taking care of small children, and I was simply trying to survive. I was surrounded by people who signed, and hearing loss was not “abnormal.” I was teaching my children to sign as I learned the language of the hands.

Fast forward a couple of decades. That moderate loss had become severe and was interfering with the way I managed life on a daily basis. Those years of learning sign language had flown by, and I had forgotten many signs because I didn’t sign on a daily basis. My dreams of a career had fallen to the wayside as life made its stringent demands. A set of hearing aids appeared in my life and were great for a while. I was able to hear sounds I had not heard in a long time, and it was amazing how such small things could make a big difference.

Then began the skin allergies to the material the hearing aids were made of. I stopped wearing them as they became less effective, causing more irritation than benefit. My ability to distinguish sounds had worsened. It didn’t matter if I could tell a sound was there, if I could not understand what it was.

Now, the hearing loss is more than just an inconvenience. Talking on the phone is not something to be taken for granted. Listening to a favorite song is no longer a common activity. TV is something to be read instead of listened to.

So how do I adapt? How do I accept this change in my life? A few years ago, I signed up for a class to review some sign language, and I got involved with online groups of like individuals so I can be a part of something. I am no longer hearing, but neither am I Deaf. I am in that special group of individuals who are “late-deafened” adults.

As I finish working on my master’s in counseling, I ask myself why I am working so hard on this degree when my hearing is worsening on a weekly basis. Why? Because I cannot simply give up living. I will not retreat to my world of silence and be content. I am forging a new world for myself. I learn about whatever technology has to offer me to continue living a fulfilling life in giving service to others. I am open to others about my hearing loss. I ask people to face me and slow down when they talk to me. I find a quiet place to communicate if there is a crowd around. I limit background noise as much as possible. I ask, “Can you repeat that, please?” as often as needed. I work to build new relationships with others who understand my world, and I make plans to start a support group for late-deafened adults in my small community.

Hearing loss is not my only challenge in life. Therefore, the lessons I learned in coping with my hearing loss are being applied to my other challenges. I have learned to ask for help when necessary. There is no place for pride when one needs assistance.

Maryruth is a transplanted Texan living in the Pacific Northwest. While working on her master’s degree, she keeps busy with home schooling her son, writing, speaking to groups on mental health issues, communication, and goal setting. She is the president of Kindling Dreams, LLC and can be contacted at maryruthdilling@gmail.com.
Understanding/Hearing

By Janis Aaron Moore

Introduction

As I was about to transfer from a community college to a four-year college to complete my bachelor of arts degree, I was apprehensive about the college I had chosen. The Evergreen State College in Olympia, Washington (“Evergreen”) is outstanding and exceptional. I looked forward to the outstanding part, but was concerned about the exceptions.

I swiftly learned that my progressive sensorineural hearing loss made it very difficult for me to understand discussions in class. In the traditional education mode, the professors faced the students, which made it easy (relatively, at least) for me to understand them because I could read their lips. The problems cropped up when students asked questions or offered their insights. I frequently found myself rubbernecking—scanning the room to see who was speaking, but usually only discovering the speaker as they finished talking. Films shown in class were another problem. I had not gone to movies in years because of my inability to understand them, and I only watched television programs that were captioned. I was usually so focused on speechreading that I could not take the caliber of notes I would have taken in the past. Seeking help, I spoke with the head of the student support services department, who suggested that I ask a student to take notes for me. However, this did not work well because other students did not take the same kind of notes I would have taken for myself. Alarmed at how much class discussion I felt I was missing, I finally learned about CART services. This experience turned my learning life around.

However, among the “exceptional” attributes of Evergreen, most classes are not offered with the traditional classroom layout. Tables and chairs are arranged in a circle or rectangle and the students and professor face each other. This might seem like an arrangement that would make it easier to speechread, but another difference in the teaching mode—what Evergreen calls “seminar” (a verbal free-for-all rather than the professor addressing the class)—was problematic. Even with a CART provider, I still found myself rubbernecking, trying to identify the speaker. And my CART providers often found this style difficult as well.

The seminar classroom setup was only one of many “exceptions” or differences at Evergreen. Before a quarter started, numerous workshops were offered to introduce students to the concepts to help them learn the ropes and succeed in this nontraditional environment. I attended as many as I could. However, I had not yet availed myself of Evergreen’s student support services and had no CART provider to caption these all-important workshops. I remember one particularly frustrating event. Although the professor stood at the head of the class, he frequently spoke while writing on the blackboard. I repeatedly had to ask him to slow down and face me when he spoke, so I could understand him. He never quite was able to change his speech pattern, so I walked away somewhat angry at his seeming lack of willingness to accommodate me, and concerned about what I had missed.

One of my first classes at Evergreen was “Writing for Change.” We were asked to select a theme, and the quarter’s assignments were to be devoted to that theme. Not surprisingly, perhaps, I chose hearing loss. The following essay was written for that class. [Editor’s note: some revisions were made to the original version.]

Understanding/Hearing

Helen Keller was asked if she could have her sight or her hearing, which would she want. She said, “My hearing, because when you lose your sight, you lose things. When you lose your hearing, you lose people.”

Those of us with hearing loss lose many subtleties of human communication. We miss visual nuances because we focus on a speaker’s lips, not their face. We miss audible nuances because a portion of the incoming sound is muted or distorted. When telling a joke, speakers frequently lower their voice at the punch line, leaving people with hearing loss in the dark. Imagine what it feels like (emotionally) to be in a room with people who are all laughing at a joke you can’t hear. Where do you find your own joy in this situation? How can your joy be part of the collective joy when you can’t join in/share it?

The muses often escape us, too. The enjoyment of live theatre and music performances is diminished when we can’t understand the actors or hear certain sounds. I’m sure subliminal tapes fall into the category of “missed connections” as well.

I believe some students shunned me because of my hearing loss. One young chemistry student said she didn’t want to be my lab partner because she mumbled. Perhaps she was one of many students who are terrified about speaking in pub-

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Communication Access for Medical Visits
By Linda L. Hull

My husband Craig became unable to communicate when he had a stroke in 1999. It took some time for a psychologist to convince me that he could hardly understand anything I said. In repeated testing, he understands only 25% of spoken words, under the best of conditions.

A doctor must tell you what is wrong, discuss options, explain medications and treatments, tell you what position to lie in on the exam table, and when to make your next visit. How could your medical provider communicate with you, if you can’t speak any words, are unable to write, and are unable to understand 75% or more of what is being said, like my husband? If you are hard of hearing and need complicated medical procedures, how will you understand your treatment if the doctor or technician only communicates by speaking?

If the doctor/dentist/technician typed or wrote down the words, Craig could read them and understand. The doctor could ask questions to find out the answers, as I do in writing. However, doctors’ offices don’t seem to have the personnel to translate all this talk into writing. IT DOES NOT HAPPEN. Doctors, lawyers, dentists, and other professionals SPEAK and act like they wonder why people with hearing loss don’t understand them. They fail to provide writing or captioning, even when requested many times, both verbally and in writing.

Dentists speak behind a mask, so even if you lipread, you can’t understand them. Clear plastic face-shields are available but most dentists seem unaware of this, and even then, lipreading isn’t enough. But nearly everyone can read. The stories my husband’s dentist tells are enjoyable and informative, but Craig can’t hear and appreciate any of them, so I accompany him into the room and write notes to him, and together we can try to make out what my husband wants us to know.

It seems very difficult for a professional to write what he normally would say. When someone can’t hear and respond, professionals often resort to manual manipulation, such as pulling or pushing a patient into position on the exam table, or shoving someone’s jaw up and down for “Open now please?” and “Close just a little,” which is, at best, UNDIGNIFYING.

A CART provider transcribing the conversation is the only reliable way to enable many individuals with hearing loss who don’t read sign language to understand the information, banter, and engage in the small talk that helps to calm hearing people. Professionals may try to “accommodate” by allowing a friend or family member to transcribe. A family member may be able to do this for some limited transactions, such as bill pay-
What the “Power of Captioning” Means to Me

By Nancy Huffman

By I do not think anyone who hears well could possibly understand what having closed captioning available on television programs, DVDs, You Tube, and at meetings or conferences means to the hearing impaired population. Having been someone who could hear well enough the first 20 years of my life to allow me to have articulate speech, I consider myself fortunate. But I am now age 64, and through the years my hearing loss has progressed from mild to severe/profound, so I have learned the value of closed captioning in its ability to keep me up with the news of the world.

Without captioning, I would never be able to understand the stories, interviews, and special reports as commentated by Brian Williams and other news anchors on television. And during times of crisis when seemingly the entire world is tuned into events, it is totally awesome to be able to be informed because we can read the captioning provided for us, knowing we are receiving accurate information. So not only is closed captioning keeping hearing impaired people informed, it also allows us to feel safe in our homes because we can follow what is happening with accuracy.

As a young person I loved music. I grew up with a Mom who loved the big band era and all the amazing singers of her time. And I loved the rock and roll music of the ’60s during my teenage years! Since I was fortunate to hear with only a mild loss in my young years, I have the lyrics of songs embedded in my heart and soul. Thus, when a song begins to play on a television show now and I begin to see the words, I know the song. I no longer hear the music adequately, but once I see the words I can hum the lyrics, since I know the melody. There are times that this moment has brought me to tears. I’m not sad, but happy—so happy to have captioning that allows me to read the words and remember these songs from days gone by that are stored in my heart.

In my area I do not have theaters that have captioning, but we have Netflix, whose movies can be rented and viewed at home. Before the subtitles were available, there was no reason even to see current movies being shown. But with the subtitles easily being accessed via some Netflix movies, I am able to enjoy movies at home. And, admittedly, there are some movies that we truly need to see on the “big screen” to appreciate all the special effects that have gone into the making of the movie, but without cinema captioning, I am lost in the dialogue.

I know that theaters are beginning to recognize the need for captioning availability, and I realize the expense that it takes to make this a reality; but with all that said, the hearing impaired population is large and worldwide, so we are in hope that we can see a movie again on opening day with captioning in our near future.

Also, I feel that the airlines need to have their televisions closed captioned on the airplanes, and any announcements from the pilot or stewardess/steward captioned. I have no choice when traveling alone but to tell the aircraft staff that I am hearing impaired, so that they will inform me of any directives. And I want to emphasize that I have had only wonderful support from the airline crews in coming to me individually on the plane flight to give me the updates individually, but it still singles me out, making me different when this would be alleviated simply by having captioning on their air flight televisions that are viewed by passengers.

So, in conclusion, it is like…toast without butter? a needle without thread? strawberry without shortcake? hearing impaired without closed captioning?


One of Us (continued)...

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If I could hear again, the first thing I would do is: Sing harmonies with my daughters again.

The thing I like best about myself: Being creative.

Nobody knows: I love reading about neurology and theology.

What I can’t stand is: Fast food. It may be fast, but it is NOT food.

Favorite memory: Being nuzzled by goats in the Austrian Alps.

Favorite saying: “Art is not a thing, it is a Way.”

The bottom line is: Love. Love and only love.
Understanding/Hearing (continued)...
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lic. I couldn’t help but think that she might have benefitted from working with me. Perhaps if we had worked together, she could have helped me in class and I could have helped her improve her speech patterns.

Hearing and understanding are important not only for academic reasons, but for safety reasons as well. This becomes very clear when you’re driving down the highway and see a roadside alert telling you to tune your radio to 1650 to listen to an advisory. Sometimes my car makes noises I don’t hear, and one night I was about to drive away when someone stopped me to tell me it sounded like something was wrong with my engine. I can’t hear smoke alarms at all, even with my hearing aids.

“Understanding/Hearing” is draining. The stress of trying to understand, yet not being able to process them so I can understand speech. What they don’t realize is that understanding/hearing consonants becomes “I come to the store.” Since many consonants are sounded by moving lips, teeth, and tongue, it can be helpful for hard of hearing people to “read lips” or “speechread.” Therefore, it's important for a speaker to make eye contact with the audience, ensure that facial hair doesn’t obscure the lips, and keep the room well lit for visibility.

Sometimes people think we’re hearing selectively because on certain occasions we seem to hear quite well. What they don’t realize is that understanding/hearing depends on many factors. Some vocalized material might have a lot of words that are familiar and easy to speechread, while other material might not. In certain environments I can hear many sounds, but my brain is unable to process them so I can understand speech.

There are a myriad of assistive listening devices. Some have directional microphones that can be worn by the speaker. Others have omnidirectional microphones that amplify all the sounds in the room, including air conditioners, fans and even noises from fluorescent lights.

However, despite these devices, many people with hearing loss still can’t hear perfectly. When I use my assistive listening devices with the omnidirectional microphone, I often leave class exhausted and emotionally distraught. The stress of trying to understand, yet not succeeding, is draining.

I get frustrated. “You’re still talking too fast for me to understand you.” Oh, he’s “one of those”— people who can’t seem to change their speech patterns. “Can you please slow down?” Geez, he’s a faculty member at Evergreen, which is committed to accommodating students with disabilities. Hasn’t anyone coached him? Does he care?

In studying hearing loss and speech, I learned something that has helped me understand why people have difficulty changing their speech patterns to accommodate me. Speech is learned very early in life and, as such, is a very unconscious activity. Even people who understand my situation and attempt to adjust their speech sometimes forget themselves. They get excited about something and move into “motor mouth” mode.

So along with trying to learn what’s being taught and understand what’s being said, I must also try to curb my frustration. Sometimes repeated reminders work... for a while. I need to learn how to approach people so my requests for accommodation don’t become critical or fault finding.

I learned about a variety of things that a speaker can do to help ensure that hard of hearing people in the classroom or audience can both hear and understand. These range from selecting the hearing environment to controlling speech patterns and personal actions. For example, rooms with good acoustics should be chosen. Cement or plaster walls, high ceilings, and wooden or tiled floors make sounds reverberate, creating excessive ambient noise. Windows and doors should be closed if there’s a lot of noise outside the room. Speakers need to have adequate lighting on their face to allow for lipreading. They should get everyone’s attention before they begin speaking; face the audience; and not hide their mouths, chew food or gum, or smoke while talking. They should also speak clearly at a moderate pace, use facial expressions and gestures, give clues when changing the subject, repeat or paraphrase comments from participants, and encourage others to speak clearly and with sufficient volume.

None of these things requires expensive technology or extraordinary effort. It just takes someone who cares. And these simple adjustments and accommodations can make a world of difference to a student who is trying to learn, relate to, and communicate with every person in the room.

Conclusion

My “Writing for Change” professor was impressed with my “Understanding/Hearing” essay and suggested I submit it to the student newspaper for publication. Although I was flattered, I did not take the idea seriously. Then during winter break, I decided to...
my left ear implanted. I was very sick post-operatively. Nurses are never good patients. I hung in there and took my time walking, driving, and doing other things. I was then activated on June 24, my 25th wedding anniversary… and what a gift this was to both me and my husband. He also had been through so much and was at a loss on how to help me. Both of us cried when my eyes lit up after hearing a sound coming from this left-sided implant. It was joyous! It was loud! I had forgotten how loud the world was, and it hurt to hear sounds again. But within a few days, I became acclimated to the noise level and hearing with a cochlear implant.

Within a few months, I was called and asked to teach part-time nursing at Regis College in Weston, Massachusetts. I immediately called them back, using the relay phone, and made an appointment. I told them during the meeting that I was deaf and used a cochlear implant to hear with. I also said that I could use an amplified stethoscope if necessary. They hired me right on the spot. I went back to school to obtain my post-masters certification in nursing education in 2004. I then got a teaching position at MassBay Community College, teaching maternity during the summer. In 2005, I obtained a full-time teaching position at Bunker Hill Community College in Charlestown, Massachusetts, teaching maternity class and clinical practice. I was thrilled! I was awarded tenure in September 2011.

In 2007, I noticed that my hearing had decreased in the right ear. I tried to use several different hearing aids, but the clarity was gone. It was very difficult hearing with one hearing aid and then hearing with a cochlear implant because the sound comes into the ear immediately with a hearing aid, and then it comes into the ear a nanosecond later with a cochlear implant. Hearing the same sound at different times was confusing for me, and I became very tired trying to hear this way. I then decided to go for a second cochlear implant and was implanted on January 2008. I tolerated that operation much better and was activated early in February of that year. I asked for pink “behind the ear” (BTE) models because I wanted to show off my outside technology. I could hear bilaterally!

I went back to begin my courses towards my doctorate in nursing practice at Regis College and am still working on the thesis portion. In the meantime, I have designed seminars in which I teach healthcare workers how to communicate with deaf or hard of hearing patients. I have spoken at several hospitals in the Massachusetts area and received praise for my content. I have also written a seminar that teaches the deaf or hard of hearing patient how to communicate with health-care workers. I presented this at the HLAA convention last year in Washington, DC. As a deaf nurse, I am in a unique position to understand the needs of both sides and to be able to teach both sides how to help each other. I am active in ALDA-Boston and take my nursing students to several meetings to learn how to communicate with deaf and hard of hearing people. This summer, I will present to the PEPnet convention about another topic that is near and dear to me, adapting a nursing curriculum to accommodate a deaf student. The title is: “Leave No Deaf or Hard of Hearing Student Behind! Adapting a Nursing Curriculum to Accommodate a Deaf or Hard of Hearing Student.” I strongly believe that it is time to expand healthcare options as career choices for deaf or hard of hearing students. I will soon need a college to support this endeavor.

There are three things I stress to others who are in the process of losing their hearing or who are deaf or hard of hearing, and that is to develop the 3 F’s: Faith, Family, and Friends.

Faith. I found that it’s important to have some type of faith as you are going through either losing your hearing or learning to use hearing technology. Faith can be the belief in oneself, in a therapy, or in something that supports you. It does not have to be religious. When I was told I was not a good candidate for a cochlear implant, I believed that someday something would happen to help me gain back my hearing. I also did not give up my career simply because some nurse thought I could not do the job. I just had to find my way, and that began with the deep inner belief in myself that I still could be successful. I lost my hearing, not my education. Even though I am religious, and feel that my faith has greatly helped me through such a difficult time, not everyone needs to develop this type of faith. You need to find the strength that has helped you in the past and nurture this to help you get back to where you want to be.

Family. It is important to remember that family members suffer along with the person who is losing their hearing, just on a different level. On the day that I became deaf, no one in my family understood what that meant. I was told that I heard the day before, so I should be able to hear now. I felt so lost, alone, and not understood. What I really needed to do was to learn how to teach my family that I could not hear anymore. I initially could not use the phone, and therefore could not call the physician to tell him that I could not hear. I had to ask for help. Nurses do not like to ask for help, and this was a big part of myself that I had to change. I gave some of my family members A Guide for People Who Become Deaf or Severely Head of Hearing by Karen Rockow, Ph.D. After reading a few pages, they became too depressed to finish the book.

And, they were hearing! My youngest son... Continued on page 17
The Long Journey Back (continued)...

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brought all kinds of ASL materials home for me to learn. My husband brought his good friend who was an ASL teacher in the middle school to help me to learn how to communicate. After a while everyone was trying to help me out. They all realized just how deaf I was and that I could not go through this change all by myself.

Friends. This is a sad topic because many of my nursing friends just did not understand how deaf I was. They did not understand how to make relay calls and just did not call anymore. I felt rejected and alone. But then I realized that these people were really not my friends if they could not help me to communicate with them. One day I opened my front door and realized that this world is bigger than me and my current set of friends. If I was going to make it, I had to choose friends wisely, finding those who would support me and communicate with me in the manner I need. I have since made good friends who know how to contact me and where to sit when we go out to dinner. This took time, and sometimes I got hurt, but having a few good friends was worth more than having many people who didn’t really care about me.

In the end, is it all worth it? Oh gosh, yes! I do get tired, but I am so busy now with my commitments that I do not have the time to remember all the sad things that happened in my past. I keep plugging along, staying positive, and doing the work in my life that I feel I was destined to do. And I continue to work at perfecting my hearing. One day, I had one nursing student try to get my attention in class, and I had to remind her that I am deaf and need certain things to be done to get my attention. She grinned and then said to me, “Professor Killilea, you hear so well that sometimes I forget that you are deaf!”

I smiled and quietly whispered to myself, “I have made it!”

Anne Marie Killilea, RN, BSN, MSN, DNpc, is a professor of nursing education at Bunker Hill Community College in Charlestown, Massachusetts. After graduating from St. Anselm College in New Hampshire in 1977 with a BSN in nursing, she held positions in pediatric nursing, labor and delivery nursing, and in a neonatal intensive care unit. In 1998, she became a nursing manager, and her hearing loss began the following year. She is active in HLAA and has given presentations to several chapters. She is also the secretary of ALDA-Boston and brings her nursing students to meetings. She has been married to her wonderful husband Joe since 1978, raised four amazing sons, and likes to sew, paint and design walls for rooms, do photography, play piano, and walk along the beach and collect shells. She can be contacted at amkillilea@hotmail.com.

Understanding/Hearing (continued)...

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learn the submission guidelines. The paper, Cooper Point Journal, published student articles up to 800 words, and my essay was more than 1,400 words. I emailed a copy, giving them permission to edit the article as they chose to fit their guidelines. I received no response, so I assumed my essay was not deemed newsworthy.

Several weeks later, I received an email from the program assistant of the student support services department, saying my article had been published—in its entirety! Not only that, but her boss had sent an email to all faculty and staff, asking them to read it. What an honor!

Since writing this essay over five years ago, I have attended more than 200 workshops and lectures about hearing loss and presented a few myself. Rereading the essay, I believe I failed to make an important point clear—the difference between “hearing” and “understanding” when it comes to speech. That is why I originally chose to separate “Understanding” and “Hearing” with a slash. Before I became late-deafened, I could usually “hear” someone speak, but this was a far cry from “understanding” what they said. This distinction is important because it can lead to one of our pet peeves. When we say “I cannot ‘hear’ you,” this frequently results in the speaker speaking louder—which can make it even more difficult to understand. So it’s better to say “I did not understand you.”

We may forever be faced with people like the frustrating professor who seemed unable to change his speaking pattern to accommodate me, but it’s important for us to keep on with our efforts to understand and remain connected to the people in our lives.

Janis wears a hearing aid in one ear and a cochlear implant in the other. She gave a presentation on “Empowering Strategies” at the 2008 Canadian Hard of Hearing Association/International Federation of Hard of Hearing People (CHHA/IFHOH) Congress in Vancouver, BC, Canada, and has given presentations on assistive technology and other hearing loss-related topics at both HLAA and ALDA chapter meetings. She uses a web captioning service to facilitate telephone communication. Many of her articles and presentations are available on her website, www.talkshop.info/hoh. She can be contacted at JAMoore@talkshop.info.
Chapter Happenings

By Ann Smith, Curator

Francine Stieglitz reports on ALDA-Boston’s busy schedule. The annual business meeting and election was held in April. Matt Ferrara was re-elected as treasurer (what would we do without him?), Louis Sakin was re-elected as vice president, and Francine Stieglitz was re-elected as president. Anne Marie Killilea was elected secretary and Anthony Cannella was elected member-at-large. Charles Barnes will serve ex-officio for the remainder of his term. Karen Rockow’s and Linda Sakin’s terms were not up, and they will remain on the board.

The guest speaker at the April meeting was Steven Rauch, M.D., professor of otology and laryngology at Harvard Medical School and Massachusetts Eye & Ear Infirmary, who talked about age-related hearing and balance problems.

ALDA-Boston will celebrate Independence Day (and ALDA Boston’s 23rd birthday!) with a barbecue at the home of Linda and Louis Sakin in Framingham. Since July 4th falls on a Wednesday, the celebration will be on Saturday, July 7th, from 4-8 p.m. Members will receive an ALDA-Boston tee shirt, so they won’t have to worry about getting all that delicious food on their clean clothes.

Rachael Morris tells us that the members of ALDA-Carolina Flight have been working hard to make ALDAcon 2012 a success.

Marsha Kopp reports that ALDA-Chicago kicked off the year by participating in their first exhibit shared with ICIC (Illinois Cochlear Implant Chapter) at the Illinois Academy of Audiology Convention. The second event in January was a captioned phone demo workshop by CaptionCall, given by ALDA-Chicago members Ann Anderson-Brooks, CaptionCall outreach manager, and Mimi Killey, CaptionCall trainer. The February social was held at a captioned performance play, “Ameriville,” at Victory Gardens Theater, with a dinner afterward. In March, members enjoyed an Indian culture workshop and learned about Deaf World’s international efforts to help the deaf community. In April, ALDA-Chicago and ALDA, Inc. participated in an exhibit at Village of Niles Health Day. A second event in April was a luncheon celebrating the chapter’s 24th birthday at Carlos Lorenzetti’s in Chicago Heights. In May, ALDA-Chicago co-sponsored (along with three other hearing loss groups in Chicago/central Illinois) a workshop on “Living Well with Hearing Loss: What Works and What Doesn’t” by well-known hard of hearing psychologist Dr. Samuel Trychin.

Diana Fanuel lets us know that ALDA-Garden State in New Jersey recently hosted a spring workshop/birthday celebration for its 17th anniversary. The event was held at Cedar Crest Village, a retirement community in Pompton Plains, and was attended by 38 people. Dana Apruzzese of Sorenson presented on the CaptionCall captioned phone; Cathi Ahrens-Berke of Ahrens Hearing Center presented on telecoils and hearing aids; and Mark Zuckerman of TruHear presented on “mat looping.” The chapter’s new officers are Joanne Sammer, president; Lori Heir-Messing, vice president; and Diana Fanuel, treasurer. ALDA-GS is awarding a $2,000 scholarship to a hard of hearing/deaf high school student enrolling at a higher education institute.

Martha Mattox, group leader, continues to monitor ALDA-Midwest through emails and the online Yahoo group. A dozen walkers from the group represented ALDA, Inc. in the HLAA Walk4Hearing in May at Dayton, Ohio. Monies raised will be given to ALDA, Inc.

Kim Mettache reports that ALDA-Northwest Indiana hosted its first 2012 meeting in March with a captioned movie afternoon at Dyer. In May, 21 members met at the Schererville library, where Tina Childress, a well-known ALDAn educational audiologist, presented her workshop, “Planes, Trains and Automobiles.” She discussed different modes of travel, lodging, and ways to be safe on the road. Terri Singer stated that it was well worth the nine-hour round trip drive she undertook to attend and socialize with fellow ALDAns. Five members who were unable to attend requested a transcript of Tina’s travel tips. The next chapter gathering is its annual dual picnic with ALDA-Chicago in September.

Yael Shaner and Kristin Stansell report on ALDA-Peach’s activities. In March, Julie Kegley, a lawyer from the Georgia Advocacy Office, discussed the legal aspects of the Americans with Disabilities Act (ADA) and resources available to assist individuals with disabilities. Julie, who has a hearing loss herself, also provided several useful handouts. The April gathering featured “Book Reports.” Members discussed interesting or helpful books they had read about hearing loss. The May meeting was a cookout at Redtop Mountain.
Chapter Happening’s (continued)...

Continued from page 18

State Park on Lake Allatoona. Burgers (and veggie burgers) were grilled by Steve Tamas and Jim Stansell. ALDA-Peach’s current officers are Yael Shaner, president; Kristin Stansell, vice-president; Jim Stansell, secretary; Xantha Burghardt, treasurer; and Roxanne Gasaway, member-at-large.

We have a great report on the ALDA-Puget Sound group from Paula Titus. The group, which meets on the first Saturday of the month in Federal Way, Washington, got a good start with a business meeting in January 2012. In February, Rebecca Dufek gave a wonderful presentation about perseverance and her struggles with NF2. She even hiked to the top of Mount Kilimanjaro, Tanzania despite trouble walking and double vision along with her hearing loss!

In March, Penny Allen gave a presentation about CapTel captioned phones and other electronic communication tools. Others agreed that using Face Time on an iPad, iMac, or iPhone was better than using Skype, which has a slight delay. Attendees also learned about a special feature available from some providers that can send a text message from a voice phone message.

In April, Brendan Gramer, the creator of www.captionfish.com, gave a presentation. Attendees were delighted to learn that this website lists all the closed caption movies in one spot and that trailers can also be seen with captions. Members were also informed that http://www.phlixie.com/netflix lists the Netflix captioned shows and movies. In May, Michael Bower gave a presentation on “Misdiagnosis: Hearing Loss or Dementia,” and in June, members attended a Deaf and Hard of Hearing Emergency Preparedness Expo.” Future plans include the annual barbecue in July; a presentation by Laura Gramer of the Seattle Commission on Disabilities in October; a talk by Sara Laufer Batinovich, author of Sound Sense: Living and Learning with Hearing Loss in November, and a holiday party in December.

Two members of ALDA’s Board of Directors, Kathy Evans (Utah) and Cynthia Amerman (Arizona), were recipients of state awards from Hamilton’s Relay in recognition of Better Hearing and Speech Month.

Kathy Cortopassi, a staunch ALDA supporter and member of the ALDA-NW Indiana chapter, was recently surprised when she was awarded the EDGE (Economic Development and Growth through Entrepreneurship) Award from the Northwest Business Development Center at Purdue University-Calumet (Indiana). Kathy is president of Voice to Print, a CART-provider service, which she established in 2010, after working as a subcontractor for 10 years. She developed Voice to Print from a home-based business into a company based in the Purdue Technology Center of Northwest Indiana in Crown Point. Kathy had worked as a court reporter for 25 years before learning that her daughter had experienced hearing loss. At that time, Kathy knew court reporters helping people with hearing loss and decided to expand her technical knowledge to include CART transcription. Today, her company provides realtime closed captioning, CART, court reporting, and audio transcription services with one full-time and one part-time employee besides herself.

Send information about your chapter/group (for “Chapter Happenings”) and about what is happening in your life (for “GA to SK”) to Ann Smith at fabsmith@att.net by August 24.

SKSK

The art of living lies less in eliminating our troubles than in growing with them.

—Bernard Baruch
The ALDA Reader Needs Your Submissions!

Lori Messing and Belinda Miller, co-chairs for ALDAcon’s ALDA Reader, have put out the following call for this year’s issue: Let’s have an article, poem, or artwork from every ALDA chapter. Share your challenges, triumphs, humor, inspirations, and everyday “what it takes” to live in the hearing world. If your chapter has a newsletter, consider sharing with the larger ALDAcon group something of general interest that you’ve already published. Remember, it hasn’t been seen on a national level, and we guarantee that it will appeal to ALDAcon attendees.

Individual contributions are also most welcome. We accept all types of submissions for the Reader—personal essays, fiction, nonfiction, poetry, artwork, jokes, short stories, cartoons, photography, and just about anything as long as it relates to hearing loss. We especially encourage submissions from ALDA members and people with hearing loss, but the writer or artist need not be deaf or deafened. He or she might be a family member or friend of a person with hearing loss. We will consider all submissions for publication, and those whose work is published will receive a copy of the Reader even if they do not attend the ‘con.

The deadline for submission is August 31 – and it’s not that far away, so the sooner you send your contribution, the better! Entries should be emailed to belindamiller@windstream.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!

Contact TDI:
Phone: 301-589-3786; Fax: 301-589-3797; Video: 301-563-9112; TTY: 301-589-3006
info@tdi-online.org; www.tdi-online.org

TDI - Shaping An Accessible World
WHY SHOULD YOU ATTEND ALDAcon 2012?

1. Your self-esteem could use a boost!
2. To meet new friends and re-connect with old ones. You don’t wanna miss an ALDA hug!
3. To learn about hearing loss and technology beneficial to you.
4. You need a vacation and you’ve never visited the Carolinas.
5. To dance like nobody is watching. We all gotta let loose now & then!
6. To sing that BEE-GEE’s hit at the top of your lungs (we can’t hear you). You will be in karaoke heaven!
7. YOU are not alone. Come and re-charge your battery.
8. No matter how severe your hearing loss or what your communication needs are, you will be accepted!
9. Go for the camaraderie. Stay for the friends. Learn from the workshops.
10. CHEERS!…<pass the microphone, please>

“Making your way in the world today takes everything you’ve got.
Taking a break from all your worries sure would help a lot.
Wouldn’t you like to get away?
Sometimes you want to go
Where everybody knows your name,
And they’re always glad you came.
You wanna be where you can see
Our troubles are all the same.
You wanna be where everybody knows your name.
You wanna go where people know
People are all the same,
You wanna go where everybody knows your name.”

ALDAcon 2012 Silent Auction

One of the staples of ALDAcon is the wonderful Silent Auction that helps to support ALDA. Our members, chapters, and groups bring items to the ‘con (or ship them in advance), and the donations are sold to the highest bidder. The items can be useful (like hearing aid batteries), inspirational (like a self-help book), personal (something you made), geographical (something that represents your home area), or anything else you choose to donate. If you are interested in learning how to donate an item for the Silent Auction, contact Nancy Gordon at bonheur19@aol.com. Your donation and support will help ALDA continue to be a leading voice for people who are late-deafened.
Maximizing Your ALDAcon Experience

By Terri Singer

ALDAcon 2011 was a huge success, and I’d like to share comments from the Embassy Suites host hotel. They wanted to adopt us! Brandon, the night manager, told me he wished the hotel could have us as guests every week. Our planners, of course, were delighted by this.

If you’ve ever been involved in planning a ‘con, you know how hard everyone works to ensure a memorable experience. If you haven’t, you can’t imagine all the difficulties the dedicated volunteers face. When the ‘con is over and evaluations are read, the workers are rewarded by positive statements, dismayed by negative ones, and disappointed by the blank ones or those never turned in. Each year the current committee looks at past evaluations in an effort to repeat positive comments and eliminate negative ones.

Here are some considerations that can help you prepare for the ‘con by understanding a bit of what goes on behind the scenes.

First, be aware that the hotel is chosen with various factors in mind, such as room pricing; handicap accessibility, including guest rooms; number and size of workshop rooms; lighting; convenience of elevators; and willingness to work with the planning committees.

Communication is the top priority at a ‘con. If your needs aren’t being met, let someone know. Don’t hesitate to speak with a board member, an interpreter, a CART provider, or one of the planning chairs. Here are two evaluations given last year that reflect opposite communication experiences:

“Everyone lipreads. No real signers. Felt left out.”
“I do not sign and it feels like a handicap in ALDA.”

If these individuals had made their needs known DURING the ‘con, they could have been introduced to others who shared their communication style. In addition, pen and paper are available everywhere, interpreters are always ready to help even when they aren’t “on the clock,” and with CART, no one should miss what’s said by speakers, presenters, or anyone at a microphone.

Keep in mind that there are often last-minute changes that are announced during gatherings of the entire group, so be sure to pay attention.

The planners try to select foods that will appeal to the majority. It’s also important to understand that meals aren’t priced according to what the hotel charges for the food in that particular meal. Instead, meal prices are averaged, which means that the actual cost of the food in some meals is greater than, and in other meals less than, the price charged for it.

You can make your dining experience more of what you want it to be by filling in the diet restriction section of the registration form. I remember an attendee in Seattle complaining about the time it took for the kitchen to prepare a chicken dinner for her because she’d failed to mark her form “no beef.” If you don’t eat beef or pork, if you prefer no dairy, gluten, fish, salt, strawberries, peanuts, or whatever you might be allergic to, you need to add that to your form. (If you’ve already submitted your form and need to list a food or substance, contact the registration chair right away.)

Seating at luncheons and the banquet is sometimes a source of conflict. If everyone understood that at certain meals some people must have reserved seating, there would be less stress. Exhibitors and sponsors are honored at Friday’s Appreciation Luncheon, and giving them reserved seating is one means of doing so. On Saturday, reserved seating is a perk extended to lifetime members as part of their memberships. At least one speaker’s table is needed at each luncheon. Those with low vision are seated up front at every meal. The board prefers reserved seating at some luncheons and not others. Meals provide an excellent opportunity to meet new people, creating bonds that bring you back year after year. If you see an open seat anywhere, don’t hesitate to take it. If the table holds a “reserved” sign, wait to see if it’s filled about five minutes before the meal is to begin and if not, ask if you may sit there. Don’t be shy; you’re among friends.

Everyone heads to an ALDAcon with fun in mind. It’s a great source of information and support. If your reasonable needs aren’t being met, find someone who can change that.
ALDAcon 2012 will feature speakers that have used their passion, knowledge, and leadership to drive positive changes for people with late-deafness. These speakers will re-frame what it means to be "included" and challenge you to think creatively in advancing progress for people with acquired deafness in your community.

ALDA’s first president, Bill Graham, will help us kick off the 2012 conference by looking to lessons from the past and the present as we think through advancing inclusion in the future. Renowned late-deafened motivational speaker Brian Patrick Jensen will challenge us to optimize our thought processes and inspire us to persevere. Past President Christine Seymour will show us how to get involved in emergency preparedness for our community to make sure the needs of persons who deaf/hard of hearing are included. Workshops will also cover disaster planning when radio announcements aren’t accessible and TV warnings aren’t captioned. Our welcoming orientation—a warm embrace to newcomers—will be hosted by immediate Past President Cynthia Amerman. The conference will also offer workshops for women and veterans and about assistive technology, sign language, social media, and movie captioning, to highlight a few. The ‘con will wind down with ALDA's traditional family gathering, our famous, can’t-live-without karaoke party and will conclude with our annual "melancholy baby" farewell—Sunday brunch.

ALDAcon 2012 will be held this year in Columbia, South Carolina from October 17-21. As in years past, ALDA, Inc. will provide a limited number of scholarships to help those in financial need who want to attend. Applicants for a scholarship must be members of ALDA, Inc., and be in actual need of financial assistance in order to attend. Priority in awarding scholarships will be given to first-time attendees. Inquiries regarding scholarship applications should be sent to Carolyn Piper at wicwas@wcvt.com. While email is preferred, you may also contact Carolyn at 82 Piper Place, Huntington, Vermont 05462.

The deadline for application submissions is August 17, 2012.

Donations to the scholarship fund are always appreciated. For information about donating, contact Carolyn at the email or snail mail address above.
I. King Jordan Award for Distinguished Achievement

Nomination Form

This award will be presented at the discretion of the ALDA Board of Directors to a late-deafened person who has (a) had a successful and distinguished career in his or her chosen field of endeavor, (b) made significant contributions to his or her community, profession, and/or nation, (c) served as an outstanding role model for late-deafened adults everywhere, and (d) clearly demonstrated to the hearing community that a person's competence, integrity, and human worth are not diminished by the fact that he or she is deaf. The recipient will be chosen by the ALDA Board of Directors.

Nominations for the 2012 award should be submitted by **August 1, 2012**, to:

Brenda Estes  
I King Jordan Award  
C/O ALDA Inc  
8038 Macintosh Lane, Suite #2  
Rockford, IL 61107  
Email: president@alda.org

Name of nominee __________________________________________

Address __________________________________________________

City/State/Zip: _____________________________________________

Phone_________________________ Voice __ TTY __ CapTel __ VCO __

Age of onset of deafness ______________________________

Title / Occupation _________________________________________

Is the person you are nominating aware of the nomination? Yes___ No___

Has the person consented to having his/her name place in nominations? Yes ___No___

Name of person making this nomination:

____________________________________________________________________

Phone: _______________ Voice __ TTY __ CapTel __ VCO __ Email:

____________________________________________________________________

Please provide the following information in a narrative attached to this form:

1. What are the nominee's significant accomplishments in his/her field of endeavor?
2. What significant contributions has the nominee made to her/his profession, community, and/or nation?
3. In what ways has the nominee been a role model for late-deafened adults?
4. How has the nominee demonstrated to the hearing community that a person's competence, integrity, and human worth are not diminished by the fact that he/she is deaf?
Registration Form

Please complete all pages of this form, print and mail, OR register online at http://www.alda.org

Name: ____________________________________________

Address: _______________________________________________

City/State/Zip: ___________________________________________ Country: ______________

Phone: (____) __________ Voice __ TTY __ CapTel __ VP __

Fax: (____) __________ Email: ________________________________

I am: (Check all that apply)

__ Late-deafened  __ Hearing  __ Hard of hearing  __ Deaf at birth
__ Bringing a hearing/service dog (Dogs must remain on leashes in public areas.)
__ Member of ALDA chapter/group
__ Spouse/companion (Copy and complete this form, select the appropriate rate, and attach with your form.)
__ Newcomer (attending my first ALDacon)
__ Other (explain) ____________________________________________

Special Needs

My special dietary needs are: ____________________________

Allergies: ________________________________________

Mobility or ADA in-room kit needs: ____________________________

Any other needs: _______________________________________

All workshops and con events in the hotel will have sign language interpreters and CART (Communication Access Realtime Translation).

FM assistive listening devices will be provided at no cost. To make sure enough devices are available, you MUST reserve now. You will be asked to turn in your driver’s license when you receive the device. Your license will be returned when the equipment is returned.

__ I need an FM device. Check what you need to use the FM: __ Neck loop  __ Headphones  __ Other  __

ALDA, Inc. Membership: Include payment with your registration.

Note: Membership in ALDA, Inc. is NOT the same as an ALDA chapter/group membership. You must be a member of ALDA, Inc. to obtain the member rate for the convention.

__ New  __ Renewal  __ Already a member; my membership expires on ___________________________

__ Age 62 or older ($25.00)  __ Age 61 or younger ($30.00)  __ Business membership ($50.00)
Registration Fees

**Full registration** includes Thursday Welcome/President’s Luncheon, Friday Buffet Luncheon, Friday I. King Jordan Banquet, Saturday Award Luncheon, Saturday Karaoke Party, Sunday Brunch, Exhibit Hall, and all workshops.

**Spouse/companion registration** (limited to 1) includes all meals, workshops, and Exhibit Hall.

**Veterans /Scholarships:** Early Bird registration fee level applies until Sept. 15th 2012; then the Tortoise level applies. A limited number of scholarships are available. Contact Carolyn Piper, Scholarship Chair, at wicwas@wciv.com for more information.

<table>
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<tr>
<th>FULL REGISTRATION</th>
<th>Early Bird (Registration Mar.1st – July 15th)</th>
<th>Regular (Registration July 16th – Sept. 15th)</th>
<th>Tortoise (Registration Sept. 16th – to onsite)</th>
<th>Amount</th>
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<tbody>
<tr>
<td>ALDA, Inc. Member</td>
<td>$230.00</td>
<td>$270.00</td>
<td>$295.00</td>
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<tr>
<td>Spouse/Companion</td>
<td>$210.00</td>
<td>$250.00</td>
<td>$275.00</td>
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<tr>
<td>Non-Member</td>
<td>$260.00</td>
<td>$300.00</td>
<td>$325.00</td>
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**Day registrations** include access to the Exhibit Hall, workshops, and the luncheon on specified day(s). **Day Rates do not include I King Jordan Banquet.**

<table>
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<tr>
<th>Day(s) selected: indicate which day(s) you will be attending: Thursday_____ Friday_____ Saturday_____</th>
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<tbody>
<tr>
<td>One day $60.00</td>
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<tr>
<td>Two days $110.00</td>
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<tr>
<td>Three days $165.00</td>
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</tbody>
</table>

**A la carte meals:**
- Thursday Welcome/President’s luncheon - $35
- Saturday Award Luncheon - $35
- Friday Appreciation Luncheon $35
- Saturday Karaoke Party $30
- Friday I. King Jordan Banquet $55
- Sunday Brunch $30

**Total due:** Add membership and registration (or partial registration and/or a la carte meals) = $__________

**Method of Payment**

- Credit card (check one): ___ MasterCard ___ Visa ___ Check ___ Money order (payable to ALDAcon 2012)
- Card Holder’s Name: ____________________________
- Card Number: ___________________________________
- Expiration Date (month/year): ____________________
- Signature: ______________________________________

**Mail to:** ALDAcon 2012 Registration
22 Barker Square Dr.
Pembroke, MA 02359

Questions? Email registration@aida.org

To pay through PayPal, go to www.aida.org and register online

I wish to use the ALDA EZPlan and will make periodic monthly payments of $___________. The final payment is due by September 30th, 2012.

**Refund Policy for Registration**

Requests for refunds (minus $50.00 processing fee) will be honored until September 30th, 2012.
Contact ALDAcon 2012 planning chair Dave Litman at litmanalalcon12@hotmail.com for consideration of unique circumstances, such as illness or a death in the family and for registration transfer information.

**Reserve Your Hotel Room TODAY! Use Group Code ALDALDA.**
The ALDAcon room rate of $130.00 ends September 16th.
Reservations may be made online at www.marriottcolumbia.com
Marriott toll-free number is 800-880-1885. The direct number is 803-771-7000.
For more information, go to www.aida.org.
Roommate Information

Complete this section only if you wish to be contacted about a potential roommate for ALDAcon 2012, otherwise skip this section.

I would like the roommate registrar to attempt to locate a potential roommate for me.  
___Yes  ___No

By checking YES, I agree to allow the roommate registrar to share my information via email with any ALDA attendee of the same gender. Also, I agree to coordinate with my potential roommate to determine if we are a match and notify the roommate registrar by email of our decision. (Determining whether to room together and share expenses, and masking room reservations are the responsibility of the agreed-upon roommates.)

Roommate Information

I am ___female / ___male
I am a ___smoker / ___nonsmoker
I will room with a ___smoker / ___nonsmoker (check all that apply)
My pet/assistance animal will attend the convention and share my room with me: ___yes / ___no
I prefer a roommate without a pet/assistance animal ___yes / ___no
Allergies or special conditions my potential roommate needs to know about me:

________________________________________

Complete this section only if you want your name and other contact information included in the ALDAcon Attendees List. This list, including only the information you provide below, will be given to all ALDAcon attendees, who may use it to contact each other after the convention. (Leave blank the communication methods that you do not use.)

Name: __________________________________________

Email: __________________________________________

Text: __________________________________________

Relay: _________________________________________

Voice: _________________________________________

Face book: _____________________________________

Twitter: ________________________________________

Postal Address: __________________________________

________________________________________________________________________________________
WHO? Adults of all ages who have slowly or suddenly lost their hearing from a variety of causes. If you are feeling lonely, isolated, discouraged, confused, or frustrated due to losing your hearing as an adult, then ALDAcon is for you! Are you a spouse, sibling, parent, friend of someone feeling these reactions and want to learn everything you can to support your loved one? If so, ALDAcon is for you! If you want to meet people just like you and feel welcomed and inspired, then ALDAcon is for YOU!

WHAT? ALDAcon 2012. The Association of Late-Deafened Adults (ALDA, Inc.) is an international organization that supports the empowerment of individuals who have lost any amount of hearing after acquiring spoken language. We all come together once a year for this exciting convention. ALDA believes in “whatever works” as our communication strategy. Some use CART (Communication Access Realtime Translation), with words projected onto a large screen. Some have hearing aids or implants, and some just rely on their residual hearing. Some lipread, and some write. No matter how severe your loss or what communication method you prefer, you will be accepted & accommodated at ALDAcon.

WHERE? Down south in Columbia, SC at the Columbia Marriott, located in a vibrant and historical part of downtown and within walking distance to the state capitol building. Columbia’s Museum of Art is just across the street, and you will not want to miss out on the downtown Vista area, full of shopping, dining, and nightlife. Something will surely “tickler your fancy!” You may also be interested in visiting the Riverbanks Zoo or exploring the home of the South Carolina Gamecocks, on the campus of The University of South Carolina. You can take a break to splash in the Columbia Marriott’s indoor pool or head to the gym for a workout. After an exciting day of workshops and activities, you may want to wine and dine and experience southern hospitality with your ALDA buddies in the City Center Grille or Garnets Sports Bar.

WHY? ‘Cause YOU are worth it! YOU need it and darn by golly, YOU deserve this! The con itself will be full of keynote speakers and workshops that will boost your emotional, spiritual, social, and mental well being. You will learn the latest and greatest communication advances. You will find exhibitors showcasing helpful technology and many other services. Of course we cut loose and have fun during group meals, scheduled social events, and our very popular “Saturday Night Karaoke Party.” Put on your dancin’ shoes and leave the hearin’ aids in your room! THIS you won’t wanna miss folks! Ya never know... there may be a Rhett Butler or Scarlet O’Hara sighting somewhere.

I reckon I will stop the naggin’ atcha now and give you a chance to let Carolina settle in your mind. Don’t worry, the slang and twang will come naturally when ya get here and experience all of this goodness! See y’all soon at ALDAcon 2012! Contact Rachael Morris at aldarach2012@hotmail.com for more info 😊
By Brenda Estes

I attended the Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN) meeting in Fairfax, Virginia with ALDA’s Advocacy Chair Cheryl Heppner, who is also DHHCAN’s vice chair. It was truly an empowering and educational experience meeting representatives of other national organizations based in the Washington, DC area. The next time you see an FCC survey in your email box, please respond to it, as the FCC REALLY utilizes that information.

In March, ALDA’s treasurer, Matt Ferrara, and I met with the local ALDAcon 2012 planning committee members in Columbia, South Carolina. The Marriott Columbia Hotel is beautiful. All the meeting rooms are on the same floor and in close proximity. There is a skywalk attached to the parking garage and a Starbucks next door to the hotel. Some other eateries within walking distance are Subway, Cowboy Brazilian Steakhouse, Tony’s Pizza, Atlanta Bread Co., and Café 1201.

We have been working on redesigning/reprogramming the ALDA website, which is taking longer than originally anticipated. Please continue to be patient—we’re working diligently to make the website more user friendly.

ALDA and TDI to Hold Joint Conference in 2013

By Brenda Estes

ALDA’s Board of Directors is pleased to announce that we have a Memorandum of Understanding (MOU) with TDI to co-host a joint conference in 2013. This is the first time two national organizations for individuals who are deaf, late-deafened, and hard of hearing will not only co-host a joint conference but also celebrate their respective 25th and 45th anniversaries together.

Agreeing to a joint conference with TDI in 2013 does NOT mean that we will no longer have our annual traditional ALDAcon. The ALDA Board of Directors wants to assure you there will be an ALDAcon in 2014.

Some general background information on ALDA’s and TDI’s past conventions/conferences:

- ALDA hosts an international convention every year; TDI hosts an international conference every two years.
- ALDA’s first convention was in Chicago (1989); TDI’s first conference was in Chicago (1974).
- ALDA’s conventions usually have 140-250 attendees, who are primarily consumers; TDI conferences usually have 250-400 attendees, who are government policy makers, industry representatives and consumers.
- ALDA’s and TDI’s conventions/conferences usually run from Wednesday through Sunday.

Some advantages of a joint conference:

- Sponsors win by sponsoring one conference instead of two.
- Exhibitors win by only having travel/hotel expenses for one trip and only needing to send their exhibit materials to one hotel.
- Attendees win by getting the benefits of both organizations in one great location.

To ensure that conference attendees feel comfortable at the joint conference, each organization will maintain many of its historically unique features, such as membership business meetings and award presentations. ALDA usually has one plenary session; however, in the proposed joint conference, there will be five. This can lead to greater networking opportunities and foster the “family” feeling.

The newcomer orientation will be for ALL newcomers, but there will be separate tracks of workshops for TDI and ALDA simultaneously; conference attendees will have the option of attending whichever workshops appeal to them. TDI attendees will have the opportunity to experience karaoke-ALDA style and our Sunday morning farewell brunch.

Once the hotel contract has been signed, an announcement will be disseminated via eNews, ALDA Yahoo groups, and on ALDA’s Facebook and Twitter pages. The announcement will include the date, location, name of the conference site hotel, and theme. Members of the Joint Conference Planning Committee are Brenda Estes, Kathy Evans, Cheryl Heppner, Roy Miller, Kathy Schlueter, Carol Sliney, and Claude Stout.

You can learn more about this exciting joint conference by attending ALDAcon’s membership business meeting on October 20.

By Cynthia Amerman

As the ALDA delegate for the International Federation for Hard of Hearing People (IFHOH) World Congress in Bergen Norway, June 25-28 2012, I have made travel preparations to attend this exciting conference with hard of hearing and deafened people from many countries around the world. Several other ALDAns plan to attend, including Hanh Phuong Duong from Vietnam (a member of ALDA’s Asia Pacific group) and Paul Wummer. You will get a report about the IFHOH Biennial General Meeting (BGM) at the World Congress after I

Continued on page 30
Past President’s Report (continued)...

Continued from page 29

return. Go to www.ifhoh.org for information on the World Congress and upcoming meetings.

As past president, I chair the Outreach Committee and oversee its two subcommittees: ALDA’s International (IC) and Social Media Committees. I’m currently working on the Program Committee for ALDAcon 2012 and will head the Nominations Committee. Your suggestions are welcomed at cynthiaaamerman@gmail.com.

President Elect’s Report

By Mary Lou Mistretta

I’ve been busy printing and reading the Board Manual, and as ALDA’s Liaison to NTID/RIT, I have been familiarizing myself with the memo of understanding (MOU) we have with them. I have touched base with Allen Ford to see what the possibilities are. I have also been working with the RDs to set up guidelines for them and future RDs, and I’m serving on the ALDAcon 2012 program committee.

As chapter coordinator, I’ve been working with Brenda Estes in obtaining and processing the chapter and group renewal forms. I plan to hold an online meeting with all chapters and groups so I can become more aware of their needs, help them, and grow more chapters.

Secretary’s Report

By Karen Krull

I continue to update the Board Manual regularly, keep the minutes of Board-related emails, and track motions and tally votes. Following are a few highlights from our year so far. The Board approved the budget for both ALDA, Inc. and ALDAcon and also approved the list of committees for 2012. We voted to name a previously established but unnamed standing committee the “ALDAcon Advisory Committee.” We were represented by Brenda Estes at the Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN) conference in February. We’ve discussed options for ALDAcon 2013, and we sent Brenda Estes and Matt Ferrara to Columbia, South Carolina to meet with the ALDAcon 2012 planning committee. We’ve approved and added incentives and perks to sponsorships for ALDAcon. The Board also created a newcomer mentoring program to assist newcomers at ALDAcon, and we approved renewal of ALDA’s membership in the International Federation of Hard of Hearing People (IFHOH).

Treasurer’s Report

By Matt Ferrara

I want to again thank the ALDAcon 2011 Planning Committee for their excellent job. Although attendance was smaller than usual, it was a very enjoyable event, and it made the largest profit in the past five years—over $13,000.

Below are the balances in the ALDA bank accounts:

- ALDA operating expenses: $15,601
- ALDAcon 2012: $280
- Scholarship fund: $18,318
- Newcomer funds: $6,776

All outstanding bills have been paid and we are on or near budget with our expenses.

ALDA, Inc. is a non-profit organization, and donations are tax-deductible. Also, some employers have matching donation plans. If you have any questions regarding donations, please contact me at treasurer@alda.org.

Region 1 Report

By Paul Wummer, Regional Director 1

I recently started hearing from people interested in joining ALDA and perhaps starting a chapter in the Mount Joy, PA area (between Lancaster and Harrisburg). Prior to that, there was a long, long loll.

Region 2 Report

By Marsha Kopp, Regional Director 2

Happenings in the Midwest included the following:

- Requests for information on starting a new ALDA group
- Inquiry about a chapter in Wisconsin and Michigan
- Requests for information about tinnitus
- Request for information about captioned movies in Missouri
- Concerns about membership renewals online
- Inquiry regarding attorneys related to disabilities

I also received promotions for future conferences.
**REGION 3 REPORT**

_by Rachael Morris, Regional Director 3_

Things are rockin’ here in Region 3, as it will be home to ALDAcon 2012. Our ALDA-Carolina Flighters will be hosting the con in Columbia, South Carolina, and we have been busy bees meeting, emailing, and planning. I do not have a ton of RD “biz” to report. That is probably a good thing, since I am also ALDAcon’s planning co-chair.

I had contact with a woman in Northwest Texas. She is the manager of a retirement home and wanted advice on products to make her facility more hearing-impaired friendly. Some of their biggest problems were with blaring TVs and alarms bothering other residents. I gave her personal advice on tools I use and got her in touch with retailers who could provide information about many other gadgets.

I also had contact with a woman in Raleigh, North Carolina who wanted to know where to go to learn ASL. She has a Baha [bone-anchored hearing aid] but it cannot be worn in the water, and she wants to learn ASL because she is very active in water sports. I passed along information about sources in her city that could help her find a class. I also gave her online resources, books, and DVD ideas. I also mentioned that ALDA Carolina-Flight could be a great support to her.

Another inquiry was from a man in North Carolina whose father had been advised by a doctor to obtain a cochlear implant. They wanted to know whether ALDA considered this device to be a viable aid. I wrote back speaking very highly of CIs and told him we were huge supporters. I also mentioned ALDA-Carolina Flight as North Carolina’s ALDA chapter.

I often get emails asking about ALDA funding for hearing aids. I had a couple this go round and just advised that we do not provide funding but we do provide support. I always tell the inquirers where they can go for help with funding and also advise them to look into an ALDA chapter.

- In trying to meet that need, an agency asked for help finding information to teach classes on lipreading.
- Another agency asked us to help circulate information about a job opening.
- Still another agency wanted to find some independent contractors to provide therapy to elderly and/or disabled clients.
- One family wanted ideas for typing information to their father, who was very hard of hearing and struggling to understand them.
- An interpreter wanted input on making some ALDA-oriented signing videos.
- One person lost all hearing in one ear five years ago and wanted some advice.
- An audiology student was assigned to visit a support group.

I initiated one contact to share some information related to a workshop presented at one of our ALDAcons. The other contacts have been from ALDA members.

- One wanted a reference to participate in a program.
- One had difficulty with the ALDA website.
- Another wanted to receive the printed ALDA News, along with back copies to share.
- One was moving to a new state and wanted to meet other ALDAns.
- One wanted ALDA materials to include in a table display for an emergency preparedness fair.
- And a valiant leader is submitting papers to start a new ALDA chapter!

These people came from California (7), Washington (6), Arizona (3), Utah (3), Oregon (2), Colorado (2), and Mongolia (1).

The job of a regional director is varied, far-reaching and very satisfying. It is interesting to follow up with people I’ve tried to help, and rewarding to learn that they’re doing better. The interaction with other Board members, especially other regional directors, is beneficial—I know they’ll help me when I have questions, and I have opportunities to help them, too. Nearly everything is handled by email, so communication is easy.

**REGION 4 REPORT**

_by Kathy Evans, Regional Director 4_

Twenty-three people in Region 4 (western states, western Canada, and Asia-Pacific area) have contacted me online so far this year.

- Six were looking for chapters.
- Four were looking for research participants.
- One wanted help finding a lipreader to interpret what her father (with a tracheotomy) was trying to say.
**ALDAcon Advisory Committee**

*By Kathy Evans, Chairperson*

The ALDAcon Advisory Committee (AcAC) members and their areas of expertise are:

- Robin Titterington – publicity, Silent Auction
- Matt Ferrara – business, finances, Silent Auction
- Kathy Schlueter – sponsors and exhibitors, planning, program book
- Brenda Estes – hotel selection, ADA accommodations
- Kathy Evans – program, planning, hotel
- Karen Krull – registration, hotel selection

The AcAC was formed as a new standing committee during the board meeting at ALDAcon 2010, to update the ALDAcon guidelines and be available to assist each ALDAcon Planning Committee.

We started with wonderful guidelines that were written about six years ago. We’ve tried to catch the things that have changed (very few), and we are adding samples of forms, PR, program books, etc. so new planning committees don’t have to waste time formatting things that have worked well in the past. New planning committees may have better ways to do some things, and we hope their innovations will be added to the guidelines. There is far more information than a single person will want to read, but sections are useful for individual chairs, and collectively it is a good resource when questions come up. This is part of the effort to implement the strategic planning committee’s goal of better continuity in our organization; we do not want such essential information to reside only in the minds and computers of individuals. When planning committee members need guidance or knowledgeable people to brainstorm with, the AcAC is also available. We have been approached individually and collectively and enjoy being involved in helping with ALDAcon.

One of the projects we’re working on is to create a timeline for all the things that need to be accomplished in planning a ‘con. There are individual documents for each of the committee chairs and a spreadsheet for the planning chair to keep track of all of them. More needs to be done on this, and we are getting input from this year’s planning committee.

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**ALDAcon Scholarship Committee**

*By Carolyn Piper, Chair*

The committee’s member-at-large is Karen Krull, and the Board representative is Cynthia Amerman. The purposes are (1) to ensure the continued availability of ALDAcon scholarships and (2) to oversee the application process and determine the distribution of the scholarships.

Applications are available in the spring of each year, and awards are made approximately six weeks prior to ALDAcon.

ALDAcon will be held this year in Columbia, South Carolina from October 17-21. Applicants for a scholarship must be members of ALDA, Inc., and be in actual need of financial assistance in order to attend ALDAcon. Priority in awarding scholarships will be given to first-time attendees.

Inquiries regarding scholarship applications can be sent to Carolyn Piper at: wicwas@wcvt.com. While email is preferred, mailed inquiries can be sent to Carolyn at 82 Piper Place, Huntington, Vermont 05462.

The deadline for scholarship application submission is August 17, 2012.

Donations to the scholarship fund are always appreciated. For information on making a donation please contact Carolyn at one of the addresses above.

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**ALDA News and ALDA Website Advertisement Report**

*By Paul Wummer*

I revised and updated the ad brochure (with the assistance of several members of the Board).

It’s just about ready to be sent out to the current list of contacts. In the meantime, I received a few inquiries about the possibility of advertising in the ALDA News or on the website, but none have come to fruition.
ALDA Biz

**MEMBERSHIP COMMITTEE REPORT**

**By Karen Krull**

The Membership Committee has been exchanging emails and brainstorming for perks and initiatives for chapters and individuals for an upcoming membership drive. We also decided to send out an exit poll survey to people whose memberships expired in an effort to have them rejoin. Getting a discount rate for ALDAcon is only one reason to be part of ALDA. The success of the Cinemark movie captioning lawsuit, and agreements with other theaters to provide captioning, came about chiefly because of ALDA’s participation. We have also advocated for live theaters to provide captioning for their plays. This is HUGE news, but we can only continue to do it with a healthy membership base. Please check your address labels on your newsletter and make an effort to keep your membership current. [Editor’s note: another perk of membership is the ALDA News!]

**OUTREACH COMMITTEE REPORT**

**By Cynthia Amerman, Chair**

The International Committee, under the leadership of Victor Odandi of Kenya, has prepared a motion for the International Federation of Hard of Hearing People Biennial General Meeting (IFHOH BGM) that deafened people be included in the name of their organization. The Finnish Federation of Hard of Hearing People (with Liisa Sammalpenger, our IC member) also submitted a motion that the Late-Deafened Commission become a more active part of IFHOH again. Both motions were accepted by the IFHOH and will be voted on in June. We hope that these motions, whether or not they pass, will effect greater involvement of ALDA and of other organizations for deafened people in the International Federation.

Our Social Media Committee Chair, Antonia Lindsey, has added to ALDA’s “many mansions” a new perspective on Facebook. Our Facebook page address is http://www.facebook.com/ALDAInc. There you will find information about our organization, our 2012 convention, and how to join ALDA’s eNews list, if you’re not already on it. Contribute to the conversation, ask questions, or make comments.

The Outreach Committee invites you to participate in making a 30-second video for our website. You can make this video on your iPhone, your computer using your webcam, with a Flip camera, etc. Some of us participated in the recent Collaborative for Communication Access via Captioning (CCAC) video-making effort and found it to be fun and educational. For ALDA we are asking that you show your enthusiasm for coming to ALDAcon and the reasons you love to take part in our annual festivities. More information and instructions are coming soon. Please email any questions and comments to cynthiamermer@gmail.com. Members of the Outreach Committee will edit and produce the video. Join the fun and create ALDA history!

**2012 STRATEGIC PLANNING COMMITTEE REPORT**

**By Marta Watson, Chair**

The ALDA Ad Hoc 2012 Strategic Planning Committee has only recently been formed and is in the process of developing an agenda for the next several months. The main focus is to propose recommendations for a business plan for an ALDA national office. That plan would include:

1. Projected costs of hiring an executive director and/or fundraising director
2. Projected cost of a virtual office
3. Projected cost of physical office
4. Projected sources of revenue (grants, fundraising campaigns, and membership dues)
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, 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 connections you with ALDAns throughout the world. Don't miss our informative quarterly newsletter, ALDA News. Check our chapter directory at www.ala.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

I'd like to: [ ] Join ALDA  [ ] Give a Gift Membership to:

Name ____________________________________________________________

Organization: ______________________________________________________

Address ____________________________________________________________

City ___________________________ State: _______ Postal Code: _______ Country: _______

Home Phone: ________________ TTY [ ] Voice [ ] Cap Tel [ ] VP [ ]

Work Phone: ________________ TTY [ ] Voice [ ] Cap Tel [ ] VP [ ]

Fax ____________________________

E-mail ____________________________

URL/Website Address: ____________________________

ALDA Chapter (Name/None): ____________________________

Gender:  [ ] Male  [ ] Female

Hearing Loss:
Late-Deafened [ ]  Hard of Hearing [ ]  Deaf [ ]  Hearing [ ]

Newsletter preferred format (select one):
[ ] Electronic (Email)  [ ] Paper (U.S. Mail)

If paying by check, please mail this form to:

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

[ ] General Member, Age 61 or under......$30.00
[ ] Senior Member, Age 62 or over...........$25.00
[ ] Veterans Membership $25.00..............$25.00
[ ] Business Membership.........................$50.00
[ ] Tax-Deductible Donation..............$ _______
[ ] New  [ ] Renewal

If paying by check or money order, payment must be in U.S. funds and drawn on a U.S. bank. If paying by credit card, complete the section below or Renew online by going to:


For Credit Card Payment by Mail:
[ ] MasterCard  [ ] Visa

Amount ____________________________

Account # ____________________________

Expiration Date _______________________

Signature ____________________________

(For Credit Authorization)

ALDA provides networking opportunities through local chapters and groups as well as at the annual ALDA conference (ALDAcon).
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 Memberships**

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

**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.

Contact ALDA treasurer: treasurer@alda.org

or visit www.alda.org