I Found a Family at ALDAcon

By Heidi Herzog

I had heard about ALDA and perused the website once or twice but didn’t really know much about the organization or the people who belonged to it. Something that was made for late-deafened people like me did seem appealing, and I just happened to stumble on the information that the 2010 convention would be in Colorado Springs. That is just a hop, skip, and a jump, or a less than a 90-minute drive if you prefer, from my home in Thornton, Colorado. Since I wasn’t sure I wanted to commit to the whole conference without knowing what to expect or if it would even be helpful to me, I registered for just Friday and Saturday. My wonderful and supportive husband, Jason, was interested in seeing what this was about, too, and wanted to come along. Or maybe I begged him to join me, since I wasn’t sure if I would need his assistance, as I often feel like I do in new situations.

After emailing Karen Krull several (OK, several dozen) times, I was able to narrow down my two days of registration to the ones that I felt would have the most impact. I was mostly interested in the workshops, since I was still skeptical that social gatherings and meals would be accessible and fun for me. I wanted to learn as much as possible, since I was not sure I would have an opportunity like this again.

I have neurofibromatosis type 2 (NF2) which caused hearing loss, facial paralysis, and horrid balance, among other things. Usually before a social situation or an event such as a class or informational gathering, I have anxiety ranging from mild to panic. Where can I sit so I can see everything? Will I be able to understand enough? How will I take notes during the class AND pay attention? Will people think I am unfriendly because of my inability to “really” smile? Regarding ALDAcon, in addition to being worried about being perceived as unfriendly, I had new concerns and questions as well. My ASL isn’t great; would I be able to keep up with conversations? What is CART? What about my husband—would he feel left out, as I often do when attending social events with hearing people? Would the workshops and events be interesting to him, or would he be bored out of his mind? Would late-deafened people accept a hearing person at this convention?

I had little to no real-life experience with other late-deafened adults except for people who developed a hearing loss in old age. I did have many friends online, but I hadn’t ever been in a situation like ALDAcon that was MADE for people just like me! My experiences with the Deaf community had ranged…err…from less than pleasant to humiliating and enraging. Most of it was with Deaf instructors at a local college where I started taking ASL courses six months after I lost my hearing. Would late-deafened people have the same attitudes and opinions?

As soon as I set foot in the first workshop, I knew things would be different. I saw some people signing, some writing, and others using voice and lipreading. This was my first experience using CART, and I fell in love with it. Jason assured me that the captioning was in tune with what was being said at that moment. Amazing! For the first time, I felt like I understood all of the information being presented in this type of setting. Seeing so many people with cochlear implants and hearing aids made me feel not at all self-conscious about my own auditory brainstem implant (ABI) wires and coil (I am continued on page 20
ALDA NEWS

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As I write to you, I find myself looking back on my own hearing loss journey. From the onset of total deafness 20 years ago to getting my cochlear implant activated just a few short hours ago, it’s been quite a ride with highs and lows I never could have imagined. And although it’s too early to tell if getting a CI was the right decision for me, one thing is absolutely certain: ALDA has made the bumpy hearing loss journey much smoother and more bearable, and dare I say, at times, enjoyable. Simply finding others who “get it” is half the battle when dealing with hearing loss. For this reason, we are paying tribute to the Association of Late-Deafened Adults by selecting “ALDA” as our theme for this issue. Inside these pages you will find stories about ALDA, ALDAns, and ALDAcon. And, of course, we have articles on other topics as well.

Our cover story, “I Found a Family at ALDAcon” by Heidi Herzog, provides an engaging account of a newcomer’s experience at ALDAcon 2010. If you were unable to attend the ‘con in Colorado Springs, we’ve brought back a piece of it for you (and if you did attend, you’ll find memory joggers of your experiences). You can see photos from ALDAcon and read Jane Schlau’s inspiring I. King Jordan award acceptance speech (congratulations, Jane!) and Pat Graves’ powerful keynote speech, “A Refrigerator Magnet Story.”

We also have some fantastic information about ALDA’s advocacy efforts. In “Association of Late Deafened Adults Files Lawsuit Against Cinemark,” you can read about an exciting development regarding movie captioning. In addition, ALDA’s undisputed advocacy leader, Cheryl Heppner, reports on her recent activities on behalf of ALDA.

In “Text Communication: Finding a Way Past ‘Hunt and Peck,’” Stephen Wallin shares his insights on how this approach has proven to be a valuable tool for those with hearing and vision loss, and Heidi Martin-Coleman’s story, “The Earplug Experience: Two Decades Later” offers an interesting look at her hearing loss journey. Besides these articles and our regular columns, ALDA Biz is included in this issue, chock full of reports from ALDA’s board members and committee chairs. You will also find important information regarding ALDAcon 2011.

ALDAbest,
Eileen
I learned about ALDA during its first ‘con, when I was in the process of organizing a hearing loss support group in New Jersey. I no longer remember how I got the information, but it led to a correspondence with Bill Graham, ALDA’s co-founder, and as a result of his encouragement, I attended the second ALDAcon in 1990.

To appreciate the impact that ALDA had on me at that time, you need to know a little of my history. My hearing loss started in early childhood but was initially misdiagnosed as psychological, so I didn’t get hearing aids. I was able to get through school by sitting in front and combining what I could hear with speechreading. (College was another story that I won’t go into here other than to say that I survived by copying notes from fellow students.)

I got my first hearing aids after college, and they helped with speechreading. But my hearing loss continued to progress, so I realized that I would need to find new coping methods. I enrolled in the ASL and Deaf culture courses at the nearest interpreter training program and began attending culturally Deaf events. However, despite getting high marks in my courses, I had difficulty understanding ASL conversations, and I also discovered that my life experiences were very different from those of people who grew up culturally Deaf. My original plan to join the Deaf community began to crumble, and I didn’t see any other viable alternatives.

ALDAcon 1990 exposed me to an exciting new visual form of access that has come to be known as Communication Access Realtime Translation, or CART. The first time I saw CART, I fell in love with it and wanted to ensure that it would become available where I lived. When I came home, I began organizing an ALDA group, and ALDA-NJ was born in 1991. The easy communication at our social events duplicated what I had experienced at the ‘con.

Another gift that ALDA gave me was an identity. When I attended my first ‘con, I could no longer hear well enough to function as hard of hearing, but I wasn’t culturally Deaf, so who was I? From ALDA, I learned that I was a “late-deafened adult,” and I met many others who shared that experience. I eventually got a cochlear implant (in 1998), which enables me to communicate in small groups, understand a guide when touring a mansion, benefit from assistive listening systems, and the like. So I’m not as deaf as I was when I first joined ALDA, but I’m not at the high end of hard of hearing functioning, either. And there are many others in ALDA who are like that, too.

ALDA’s slogan, “Lost my hearing, found a family” underscores the unique value of our organization. We’re more than just a source of coping information (though we are that, too). We are a community, and I was fortunate to find the perfect fit.

Note from Nancy

By Nancy Kingsley

I learned about ALDA during its first ‘con, when I was in the process of organizing a hearing loss support group in New Jersey. I no longer remember how I got the information, but it led to a correspondence with Bill Graham, ALDA’s co-founder, and as a result of his encouragement, I attended the second ALDAcon in 1990.

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I. King Jordan Award Acceptance Speech

By Jane Schlau

Editor’s note: Kathy Schlueter’s introduction included the following comments about Jane’s background: “She holds a doctorate of education, foundation, leadership, and policy studies; a specialist diploma in school administration and supervision; a certificate in deafness rehabilitation; a master of science in special education; and a bachelor of arts in psychology and education. She is a member of the Surgeon General’s working group to prepare the literature for professionals and parents on children and youth with hearing loss and of the health and human services department working group on closing the gaps in services for children and youth with hearing loss. She has served on several planning committees for our annual conventions in various leading roles. She was elected as our Region 1 director in 2007 and our president in 2005, and she also serves as a member of the advocacy committee.”

This is such an honor. I can’t believe I’m in the same company as some of the people that have already won this award: Ken Arcia, Bill Graham, Cheryl Heppner, Marylyn Howe, Kathy Schlueter, Robin Titterington, Tony Yuppa. I’m honored to be in what I used to think was an elite club, but I’m just me.

It’s been an incredible journey. Back in 1997, at Christmas time, I was sitting at a nickel slot machine in Atlantic City with my husband—we used to go every December—and he told me he was going for a cigarette. I was playing my nickels and turned around and he was gone. I was so mad that I was ready to kill him. I got up and went to the lobby of the hotel and found him, but before I could say one word, he said to me, “We’re not going to fight—we’re going to the doctor.” That is how my hearing loss started. Between that January of 1998 and January of 2000, I became deaf. During those two years, I went through a dozen pair of hearing aids. I kept returning them to my audiologist, and he kept giving me stronger ones. He gave me his samples, because I was going through them so fast. I was very lucky, because he only charged me for about two and a half pair. And then finally, at ALDAcon 2003 in Las Vegas, I just stopped using them. I took them off when I got on the plane and I never put them back. I was working so hard to hear anything that I was exhausted. There was noise, words, noise, words. So I just stopped. At that time, my husband told me I was a different person without them. I was more relaxed, and I think I’ve been fine since.

Even before my hearing loss I could sign. I have a degree in deafness rehab, and because of that degree I met people in my temple who signed. I was the only other person who signed, and we became friends. Every Friday night for about two years, I would go to their home and we would sit and chat so my signing skills could improve. And I was able to keep my job because I could work with an interpreter.

I also had wonderful mentors. Dr. Frank Bowe had been my professor for my deafness rehab degree. At my husband’s suggestion, I contacted Frank, who couldn’t believe that with a degree in deafness rehab, I was becoming deaf. Frank told me to go back to school, which I did, and I ended up earning my doctorate degree. I was an assistant principal at the time, and for five years while I was writing my dissertation, I was studying acquired deafness, which was like five years of therapy.

I was in special ed, so everyone around me understood accommodations. When my hearing loss started, I was just becoming an administrator, and I had to ask my boss for an amplified phone. I’m sure some of you remember the continued on page 17
Pat Graves has been a pioneer in the field of captioning since its inception. She is president of Caption First, established in 1989. She holds every state and national captioning certificate that exists, and she frequently teaches and evaluates those new to the field. She has worked tirelessly to develop standards for CART. In 2000, she was listed in Today’s Chicago Woman as one of the 100 Women Making a Difference. In 2010, she received TDI’s Robert H. Weitbrecht Telecommunications Access Award, which is given for outstanding contributions to improving accessibility. Pat has served ALDA since the beginning and received the ALDA Angel Award and ALDA President’s Award. This is condensed from her keynote speech; two editorial comments are in bracketed italics.

I was asked to talk about myself, my time with ALDA, and my journey of eyesight loss. There are refrigerator magnets that offer wise observations, and the one that I want to discuss is “Life has many twists and turns. You have to take what are given and use it for the best.” I was born in Chicago and have three older brothers, one of whom was born deaf. My “normal” growing up was, from the age of 12 onward, one, two, or three shots of insulin a day, depending on what kind of insulin I was taking, because I had become diabetic. Now I feel a little like a bionic woman because I have an insulin pump. My deaf brother had body-worn hearing aids and went to a deaf and blind school where he learned ASL, but our family was told not to learn sign language, so my brother misses everything at family functions.

I became a court reporter, and my first encounter with ALDA was at Mercy Hospital in Chicago. I was one of the 42 people who attended, because I was interested in the CART and I knew that the president of the National Court Reporters Association would be there. After that, I wanted to write in realtime and work with people who needed these services. So I stalked—I mean, I contacted Bill Graham and begged him to let me donate my services for one of their ALDA Board meetings. I bought the equipment and practiced and practiced, and I walked into that room my very first time with ALDA and met some of my lifelong friends. ALDA has become my own family.

My role as a CART provider is to maintain confidentiality and not get involved, but that doesn’t mean that I don’t observe things. I will, of course, never dis-close any one person’s story, but I want to talk in generalities about what I have observed as I served ALDA members, and to compare that journey to my journey of vision loss. I have made five main observations over the last 20 years, and they fall into these categories: etiology, medical intervention, interactions with people, coping mechanisms, and identity.

The etiology is that people can become deaf overnight or they can have a progressive hearing loss.

The medical interventions occur next. You go to the ENT, and sometimes you get hearing aids, sometimes you have cochlear implants. And then you are sent home because you are “cured.”

Interactions with people change, and their success or failure affects your very soul.

The coping mechanisms are fascinating. Sometimes people withdraw, and sometimes they have a go-for-it attitude. I’ve seen a lot of planning, and then I’ve seen flexibility and adaptation when things don’t go exactly according to plan. And even from behind the steno machine I can see bluffing.

The final category is identity. I asked Sharaine [Rawlinson Roberts], my co-worker, who has a cochlear implant, “Who are you?” She said that she is deaf, but when she puts her cochlear implant in she is hard of hearing. I have heard that from many of you, so you have to find your identity.

Now let me tell you about my journey. Diabetes weakens blood vessels, and my eyes have been affected. At age 25 I had a massive bleed in my right eye and lost my central vision in that eye. Now fast-forward 25 years. I had a bunch of floaters in my left eye, which was technically my good eye. There were so many that the doctors could no longer see my retina, so they decided to do surgery to get rid of them. In layman’s terms, they sucked out the eyeball juice—the formal term is “vitrectomy.” I had a one percent chance of tearing my retina after that and I took full opportunity of that option. Then I had surgery to reattach my retina, and instead of putting in eyeball juice, they put in corn oil and sent me home for 12 weeks with what I call my corn oil glasses, one for reading and one for distance.

The third surgery was supposedly to take the corn oil out, but they found more bleeding, more scar tissue, and also a cataract, so they took my lens out. They put more corn oil in...
Here are four of the activities I’ve been involved in recently on ALDA’s behalf:

1. Functional Equivalency of Telecommunication Relay Services (TRS)

Telecommunications relay services for people with hearing and speech disabilities are mandated in Title IV of the Americans with Disabilities Act (ADA). The ADA says relay services must “provide the ability for an individual with hearing or speech impairment to engage in communication by wire or radio with a hearing individual that is functionally equivalent to the ability of an individual who does not have a hearing impairment or speech impairment to communicate using voice communication services by wire or radio.”

In the 20-plus years since the ADA passed, relay services have gone well beyond the state TTY-to-Voice and Voice-to TTY services. It has been exciting to see the growth of new forms of relay services, yet relay users still do not have services that are equal to those of hearing people.

ALDA has been very engaged in work on a Deaf and Hard of Hearing Coalition Action Network (DHHCAN) committee, which has been meeting for the past few months to help articulate what elements are needed to have relay services that are truly functionally equivalent. Once the work is completed, DHHCAN will submit a document to help the Federal Communications Commission, which has oversight of relay services, to have a clearer picture of consumer expectations.

Some examples of things that are needed for functional equivalency are:
- Calls connected as speedily as calls between two hearing people.
- Ability to buy relay products off the shelf in stores like Walmart, Costco, and Radio Shack by having the necessary features included in mainstream products (as with the decoder chip for TV captions).
- Ability to choose the kind of relay needed for any situation, including relay with multiple features such as video, audio, and captioning.
- Phone features that hearing people have—mute, caller ID, three-way calling, call forwarding, call waiting, etc.
- Interoperability of all equipment, such as equipment that can be used on any video relay service.
- Ability to change provider at any time in the same way as hearing people can change between companies like AT&T, Verizon, T-Mobile, and Sprint.
- Control of the conversation, starting with the choice of how to introduce oneself and ending with the choice of how the call is terminated.

DHHCAN hoped to have the document in the hands of the FCC before the end of 2010.

2. Television Closed Captioning

I have been serving for over a year as an appointee on the FCC Consumer Advisory Committee’s digital TV technical working group established to find solutions to problems with closed captioning and video description. The working group held its last meeting in October 2010, where we received a report from the FCC’s Office of Engineering and Technology and the Consumer and Governmental Affairs Bureau. They studied 107 complaints sent to the FCC between May 2009 and May 2010 and presented a report of their findings, most of which will come as no surprise to ALDAns. Basically, caption failures are happening at various points that captions travel, from creation to showing up on the TV screen. Problems occurred with the caption creation or transmission and during broadcast, due to flaws in the set-top boxes supplied by the cable or satellite companies or the software used in the boxes.

3. Passage of the 21st Century Communication and Video Accessibility Act

ALDA was one of the earliest organizations to join the Coalition of Organizations for Accessible Technology, and the 21st Century Communication and Video Accessibility Act was passed on September 28, 2010. I was thrilled to be invited to the White House on October 8, 2010 to witness President Obama’s signing of this Act. I had a great front-row seat in front of the desk where he signed his name on the document. The legislation set some very ambitious timelines for action on such things as extending hearing aid compatibility to phones used with the Internet, requiring shows that have captions on TV to also have cap-
The 23rd ALDAcon is to be held in Indianapolis, Indiana at the Embassy Suites Downtown from October 26-30, 2011. This may be the most convenient 'con ever. To add to the ease of mobility, all the workshops, luncheons, exhibits, registration, hospitality room, and silent auction will be on the fifth floor. The free breakfast and manager’s reception will be in the atrium area of the lobby.

More enticing news comes in the form of accommodations that feature a room rate of $119 per night. Each suite accommodates up to four people and includes a bedroom with either a king or two queen beds, a TV, a sink vanity, a full bath, and a living room with a sleeper sofa, chairs, coffee table, desk, wet bar, and a TV that also serves as a computer monitor. The suite has a free wireless (Wi-Fi) connection, and each registration also includes a full hot and cold buffet breakfast every morning and a free beer, wine, cocktail and soft drinks manager’s reception with hot and cold snacks each evening. The hotel also features a pool, Jacuzzi, and exercise room.

Have you ever enjoyed an elegant dinner in a medieval castle setting? That’s what you can expect for Friday night. The award banquet will be held in the Indiana Rooftop Ballroom (IRB), which is attached to Embassy Suites and fully handicap accessible. It’s a very glamorous and unique setting with 2.5-story walls and large draped windows on the upper floors, with soft lighting throughout. You’ll feel as if you’re dining on a plaza in Barcelona. There is a separate barroom accessed through a wide doorway. To see photos and read about the IRB, check its website at www.indianaroof.com.

For those who love to shop or want a light supper on Thursday or Saturday evening, the Circle Centre mall is connected to seven downtown hotels, including Embassy Suites. It, too, is handicap accessible and features over 100 shops, restaurants, and entertainment facilities. More information can be found at www.simon.com/mall/?id=163.

A new payment plan is being introduced for ALDAcon 2011 that allows potential attendees to deposit funds toward registration and hotel reservations. See “ALDAcon 500 Club—A Winning Strategy” for details.

In this issue, you’ll find the registration form for the 23rd ALDAcon to be held in Indianapolis from October 26-30. Pay special attention to the 500 Club box, where you can start your account and make deposits as often as you want. There are spaces that allow you to designate a certain amount for your registration and/or for your room reservation. Gloria Popp, our business manager, will credit your account accordingly and when the time comes to make your final payment, all or part of the amount due will be ready and waiting. This plan is designed to alleviate the need to pay the full amount at the registration deadline and to reduce or eliminate the need to pay your hotel bill all at once.

This year, you’ll notice a choice of three registration deadlines. If you commit to the 500 Club before the March 1 Time Trials deadline, you’ll be entered into a drawing for a free night at the Embassy Suites Indianapolis Downtown hotel. Sign up soon for a chance to be a big winner! (Note: To get the discounted rate, the entire balance needs to be paid in full no later than September 30. Otherwise, your initial rate will be increased to the next deadline level. For example, if you sign up for member’s full registration by March 1 but fail to pay the balance by September 30, your balance will be increased by $20 to the Qualifications rate. If you sign up between March 2 and June 1 and don’t pay in full by September 30, your balance will be increased by $25 to the Last Laps rate.)

The planning chair, Kim Mettache, and the program chair, Terri Singer, will be posting new developments every few weeks on the ALDA website, so check it often for lots of surprises that lie ahead.
Do you find it difficult to ask people to write things down for you when you can’t understand what they are saying? If so, why?

No, I don’t find it difficult to ask people to communicate through writing. As long as I provide the paper and pen or pencil, they are willing to do so, though one has to gauge the amount of time it takes for each individual to tire of writing.

I did not mind at all asking people to write their comments to me. In the first year of my deafness, I carried around a notebook and pen and asked anyone whose speech I could not read if they would please write it down for me. I did not hesitate to ask, and only two people refused or ignored me. But, luckily for me, my cochlear implant has made that unnecessary.

I have difficulty asking people to write down what they said so I can understand it because it’s often at a cash register and the clerk is frequently foreign-born with heavy accent. If I ask the clerk to write down something, he/she may have difficulty writing in English, and there may be a long line behind me, impatiently waiting. If there’s a person next to me, I often ask this person to tell me what the clerk said because I am very hard of hearing. Usually, the person is very helpful.

It took me years to feel comfortable asking people to rephrase what they were saying or to write it down. Now it’s second nature, and I also never hesitate to ask them to please spell their names for me when I meet them for the first time.

Most often, when I reach the point where I’ve determined I cannot understand what the person is saying, I respond one of several ways. If it’s face-to-face, I might say something like “Can you please rephrase the question? I cannot understand you.” Or I will ask the person to use a different word if the problem stems from a single word I cannot hear. If it’s over the phone and others are on the line too (like a work phone conference), I might ask someone else, who I know I can better understand, to paraphrase what the first person has said. Or, again over the phone, I will tell the person that I did not catch everything so could he or she please send me an email so that I’m sure not to make any mistakes.

It depends on the situation. If I’m in the doctor’s office and I don’t understand what’s being said, then I have no problem asking people to write. If it’s a question of knowing how much money I owe someone, again, I have no problem asking the person to write the amount down. If it’s a casual conversation and I don’t think it’s really important, then I’ll either bluff or just say “sorry, I can’t hear you” and go on from there.

I’ve never actually used writing for conversation. I lost my hearing during my senior year of high school and was determined to learn to lipread. When that didn’t work out 100 percent, I learned sign language. I guess I just never felt comfortable asking someone to write it out, or I was too impatient.

I have given up on carrying a pen and paper. People refuse to write! They will make ever other effort—pantomime, loud talking, pointing, over-enunciating, etc. It’s almost as if I am asking them to give away a part of themselves to have them write something down. On the rare occasion when someone will write something, I find that it loses the flow and context of communication. That is the main issue. Communication is an exchange, but some people feel that the person-to-paper-to person connection just isn’t worth it—and oh, how I crave the connection.

continued on page 11
The Association of Late-Deafened Adults (ALDA) and two additional plaintiffs, ALDA members Linda Drattell and Rick Rutherford, filed a lawsuit on November 30, 2010 against Cinemark USA, Inc. in California’s Alameda Superior Court for Cinemark’s failure to provide accessibility through captioned movies. The suit alleges violations of the Americans with Disabilities Act (ADA) and California’s Unruh Civil Rights Act and Disabled Persons Act.

ALDA is being represented by Disability Rights Advocates (DRA), a non-profit disability rights firm headquartered in Berkeley, California that specializes in high-impact cases on behalf of people with disabilities.

“This past summer, the nation celebrated the twentieth anniversary of the Americans with Disabilities Act, yet I still can’t see movies at my local Cinemark theater with my family and friends,” said Linda Drattell, ALDA’s 2010 president. “It’s extremely frustrating for me and for others who lost their hearing and depend primarily on visual information.”

“We just want the opportunity to go to the movies with our friends and family like everybody else,” explained Rick Rutherford who lives in El Cerrito. “By failing to screen captioned films, movie theaters like Cinemark are denying me an experience I thoroughly enjoyed before the onset of hearing loss.”

“The theaters’ unwillingness to screen captioned films is short-sighted, particularly as the hearing loss community continues to grow,” noted Kevin Knestrick, an attorney representing the plaintiffs. “The technology is readily available, and financially it is a drop in the bucket for theater chains like Cinemark to provide this service for men, women, and children with hearing loss.”

According to the National Association of Theater Owners, Cinemark USA, Inc. is the nation’s third largest chain in the U.S. and Canada with 3,825 screens at 293 sites as of June 24, 2010. In 2009 movie theaters in the U.S. earned $10.6 billion at the box office.

A ruling this year in the Ninth Circuit stated that closed captioning technology is a valid “auxiliary aid” mandated by the Americans with Disabilities Act, yet Cinemark has not taken steps to provide caption accessibility to its patrons with hearing loss.

Movies in theaters can be made accessible to deaf and hard of hearing individuals through open, closed or individual display captions.

Open captions are ones that cannot be turned off, such as subtitles on foreign films.

Closed captions are those which, as on television, can be turned on or off like the subtitles on television, and are now available through caption projection systems and new digital movies which require no special equipment or cost. More and more movie theaters are making the conversion to digital movie technology.

Individual captions are viewed only by people who have special equipment such as Rear Window Captioning or special glasses.

Do we want closed captioning in a form that requires us to wear, hold, or set up a device to see the captions, as opposed to open captioning which is on the movie itself? Do we want to settle for 50 percent of showings instead of 100 percent of the time like everyone else? ALDA will be collaborating with other national organizations to discuss comments.

Cheryl is the executive director of the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons. She has a BA in journalism, serves on the Gallaudet University Board of Trustees, and is a past president of ALDA. She received the ALDA I. King Jordan Award and the ALDA Brainstorm Award among many other recognitions, and she published her memoir in 1992. Cheryl can be contacted at NVRCheryl@aol.com.
I never ask people to write when I don’t understand something. Instead, I pretend that I understand. I know some people think I’m snobbish when I don’t answer them because I didn’t understand what they said. I have a hard time letting people know that my hearing loss is significant enough to make it necessary for them to write. I can easily tell them that I am hard of hearing, and they see my hearing dog, yet they still act as if I should have no problem understanding what they say. It’s very irritating. I guess I need more acceptance of my hearing loss, and I also need to be more assertive about having people communicate clearly to me.

I don’t carry a pad and pen. I usually inform people that I am deaf and need to see their lips. Most people apologize and proceed to talk to me while facing me. I’ve asked people to spell a key word that I missed, and normally that gets the job done. A few people start talking very loudly, and I explain that volume doesn’t help—just speak slowly and distinctly. A very few start to over-exaggerate their speech, making all sorts of funny faces, and there are also some who continue talking as if I hadn’t mentioned that I was deaf. If a salesperson refuses to communicate so that I can understand, I’ll ask to speak to the manager or someone with authority. That usually gets a much better response. My wife told me that, since I don’t carry a pad and pen, I could use an application on my phone called notepad. It’s great, and I added the app to my shortcuts. I also use my phone for text messaging.

I often have to ask people to write things down when I’m working. Because I work in a library, this isn’t usually a problem, since pen and paper are readily available at my desk. Usually I just tell them I am very, very hard of hearing and am having a difficult time reading their lips, so it would help if they could please write down the author or name of the book or subject or whatever. Occasionally I have to deal with a quiet, shy child whose parent prompts the child to speak up to the “hard of hearing librarian.” The child either doesn’t write well or can’t write. I find these instances the most frustrating and embarrassing for both me and the child. The more demanding the parent becomes, the more uncomfortable the child gets. Sometimes the parent will start scolding or belittling the child. At that point I interrupt with an apology and shove paper and pencil at the parent, hoping to take some of the heat off the child. Other than at work, I don’t find that I need pencil and paper very often. I try to prepare outings so I won’t have to ask too many questions of strangers.

I find that CARRYING a piece of paper and pencil gets people to write more. For example, if I am facing someone and say, “please write,” the person often just repeats what he or she said, ignores me, etc. But if I put paper and pencil in front of him or her, I usually get better cooperation. I am not too patient with salespeople who insist on talking and aren’t willing to write, but with friends, it depends on the person, as I can sometimes see that they are irritated.

I don’t feel comfortable asking people to write, and I have only done this in unique situations. I usually just let it pass and hope that I’ll get some clue as the conversation progresses. In a recent exception, a student asked for help finding books on mattresses, or so I thought. An unusual topic for a college student. After several repeats and finally getting it written it down, I learned that what he wanted was “mathematics.”

Next ALDAnonymous question:

How do you handle situations where you are told “never mind” or “it’s not important” when you ask someone to repeat something?

Send your responses to Bill and Robin at aldanonymous@gmail.com by February 21.
One of Us

By Karen Krull, Curator

I met so many wonderful people at ALDAcon 2010; it was hard to choose just one person to interview. Ellen and I were seated at the same table for one of the lunches, and her wit and good humor elevated her to the top of the list. She was born hearing and is a physician specializing in pediatric rehabilitation medicine. At 27, she contracted encephalomyelitis, which left her paralyzed in her hands and from the upper chest down. Ironically, it happened after she had chosen rehab as her future career. She resumed her training after a year of rehab herself and has been in practice since 1994. In early 2008, she lost her hearing. Shortly afterwards, her audiologist informed her about ALDA, and she attended her first ALDAcon in Chicago about four months after she became deaf. She’s an avid reader and loves movies. Her service dog Travis is her constant companion. I’m sure you’ll agree that Ellen is definitely “one of us.” She can be contacted at doc4kidz@yahoo.com.

Name: Ellen Kaitz, M.D.
Where were you born? Waltham, Massachusetts
What is your current residence? Just outside Columbus, Ohio
What is the cause of your deafness? Autoimmune hearing loss
Age/year you became deafened? 2008 at age 48
Marital status? Happily single
What is your present job? I am a physician in pediatric rehab medicine, an assistant professor at the Ohio State University, and director of the Pediatric Rehab Medicine fellowship, training new doctors to become subspecialists in my field.
What is the worst job you ever had? Washing dishes in the college dining rooms
Movies you want to see again? Oh, sooo many. Let’s see...Letters to Juliet, The African Queen, Casablanca, and Finding Nemo, to name a few. I’m a movie buff with eclectic tastes.
Books you tell others to read? Whatever I just put down
I stay home to watch (TV programs): Project Runway, Dog Whisperer, Antiques Roadshow, and any Ohio State football game.

Favorite pig-out food: fruit, fruit, and more fruit. With a side of Buffalo wings ;)
Hobbies: Scrapbooking, card making, and cruising
If I had more free time, I’d: live on a cruise ship
The hardest thing about becoming deafened is: the social isolation. I hate it when people think I’m rude or ignoring them because I don’t hear them.
I began accepting my deafness: pretty quickly. Since I had already adjusted to becoming a quadriplegic 23 years ago, I knew that life went on after disability. I think that made it easier for me to accept.
The worst thing about deafness is: fear at night—when my dog Travis alerts or barks at night, I fear someone is trying to break in
The best thing about deafness is: the quiet and solitude, especially in beautiful places. And babies on airplanes no longer cause the little hairs on my neck to stand up.
How did you learn about ALDA? My audiologist told me about ALDA shortly after I lost most of my hearing. ALDAcon was in Chicago, a cheap flight away. I flew up with a good friend and met an amazing group of people. When the ’con was in Colorado this year, I wasn’t going to go. Flights were too expensive. But on my last flight before the ’con, the helpers dropped me in the airplane. I wasn’t injured, but they compensated me with a free flight. Colorado Springs, here I come!
In what ways has ALDA enhanced your life? I have this amazing network of friends and “family” who can share my experiences, their successes and failures, and their collective wisdom
When I am depressed, I: eat
My most irrational fear is: most of my fears I believe are quite rational
If I could hear again, the first thing I would do is: This is a hard question. The one sound I miss most is the sound of water. Not the
The computer is a wonderful mode of communication for many late-deafened adults, and its ability to enlarge fonts makes it especially useful to those of us who also have vision problems, but it can be difficult to use if you have trouble learning to type. Fortunately, there is a way around this problem. Let me tell you my story.

As I compose this article, my eye is undergoing treatment for a corneal ulcer that had put the ophthalmologists on edge with extra booking appointments. They sent me from the local eye clinic to a main one in Denver, some 2½ hours away.

I have multiple cranial nerve losses, and I quickly found out that in ALDA, I am not alone. But in my own town of over 100,000 people, I am relatively rare, which makes it difficult for me to find suitable treatment options, especially those that deal with a totally paralyzed facial nerve and cornea, with the paralysis continuing inside my oral cavity and nose. I had tried weights under the eyelid, but they would not stay in for more than a year or two. I attended ALDA in 2000 in Santa Fe for one day and met—for the first time—a few people with NF2. I have also met a variety of people who use eye drops, with eye or cornea degradations. We all share special coping stories, and I appreciate ALDA for the variety.

My journey began with a five-centimeter brainstem tumor while I was a student at the University of Wyoming during the 1980s. It became very symptomatic on a Grand Canyon trip during a spring break. The result was losses in the spine and cerebellum, and cranial nerves like the facial and auditory. My vision and balance were affected along with my hearing. The eye problems included “oscillopsia,” in which objects seem to move back and forth and up and down. I got little advice from ophthalmologists at that point except that the eye was partially sewn shut. I would then hover near a humidifier and grade papers.

I was only a “hunt and peck” typist, and I found this to be a big strain on my eyes. Even handwriting my comments was difficult because my right hand was now slow and error-prone. Some fellow students at the university told me about the development of intercommunication between computers. At that time, mostly mainframe computers existed, using a primitive form of word processing, but I finished a thesis with it. After I graduated, personal computers (PCs) came out. Around 1990, I bought one, but at work, we didn’t use PCs until almost five years later. Our secretarial help had diminished and I needed to type more. I tried to get away from the eyestrain of “hunt and peck” by learning the QWERTY layout, practicing with keys hidden from sight. Over and over, I tried to master this skill, but I could not succeed.

After being motivated by my fast-typing daughter, I explained my difficulty to a community college typing instructor, who suggested that I try the Dvorak layout. I would still use the same standard rectangular keyboard, but all the frequently used characters would be mapped into the central area. This layout avoids long reaches and reduces the error rate. It took me a good half year to learn, but it was nice to get away from always looking for keys.

An NF2 friend with vision problems described how her computer helps her to communicate: “Now that my eyesight is worse, the computer is the best way for me to read and type my answers because I can enlarge the font. Even large-print books (14-font) are hard for me to read because I need the words directly in front of me (like they are on the monitor).” I, too, appreciate text communication and the many other ways in which the computer can open doors for those of us with hearing and vision limitations, and I’m very happy that I’m able to enjoy these benefits because an alternative to QWERTY enabled me to learn to type.

Stephen lives in Pueblo, Colorado. He has some hearing ability on one side, and his worst problem is a clouded dry eye. He helps with local Deaf and hard of hearing community activities and also plays an advisory role at the state level. His work background is in physics, and he once taught the physics of sound to speech/hearing disorders students. He believes that sign language helps to exercise the remaining sensory functions. For queries related to this article, contact him at pubswo-co-lda@yahoo.com. Those interested in communicating via sign language can request VP information.
Over ten years ago, I moved to a different land. I moved from a land where music engulfed me, singing on Broadway was my destiny, and my children’s cries and giggles filled a void within me that often struck hard and without warning.

I didn’t pack any bags. I didn’t hire any movers or inform my friends and family that I would need help with this move. I didn’t do anything to prepare for it ...because I never knew I was moving until I arrived.

The land that I was transported to was quite different, indeed. There was no music. My voice, which once had promise, changed because I could no longer monitor it. There were no more sounds of children’s giggles and cries and “I love you, Mommy’s.” In fact, there was no sound at all. In a matter of weeks, I went from my homeland to a foreign country so far from what I’d been accustomed to that I had no idea what I was supposed to do. I thought my life had ended. And I was right, to a point. The life that I had known had ended. I would never live in that original land again.

But then, as I began to come out of my cocoon and explore this new land, I found hundreds of others who had been drop-shipped to this land as well. Some knew they were coming and tried to prepare, though they admitted they had no idea what to bring or what to expect when they arrived. Many were told they would be going, but weren’t given any more details than that. And most were like me—walking aimlessly in a daze, trying to figure out who they were, where they were, what they were supposed to do now.

As we began to find each other, we discovered similarities that I never had with any other people in my former land. Even though the former land seemed to have more opportunities, with lots of maps and lots of people who could “tell” you how to get from here to there, there wasn’t much cohesiveness. We were all just there. But here, we were together. We felt each other’s struggles and, even when there were no words to describe how we were feeling, the others already knew. You didn’t need words. In fact, most of the time, words were useless.

It’s been ten-plus years now and many things have changed. I have a home here. I call it ALDA. I have friends who live with me in my home and we hug and cry and laugh and share our experiences. New people are dropped off daily and I get the chance to help them see where they are now—as best as I can. The things that were once so very important to me—music, telephones, sound on the television—have become things I’ve adapted to live without. Now I have sign language, Deaf picnics, ALDA conventions, more hugs than I could have ever imagined, and the feeling that I’m not alone.

Yes, I still miss the sound of my children’s voices. I still long to hear the old show tunes I adored. I could sit and think of many things from my past, in the old land, that I miss, and it would make me cry. But instead, I choose to take a closer look at the new home that I’ve found. Find new adventures. Learn new strategies and skills. Grow. I don’t know that I would have grown, had I not been picked up and dropped off without warning. But I do know that I’m growing now. Everyday. And I have ALDA to thank for that.

When I was first deposited in this new land, I didn’t think I could survive. Perhaps some of you reading this feel that way now, and I’m sure many of you have felt that way at some point. The experience reminds me of a quote from Eleanor Roosevelt, which I’d like to pass on to you: “Every time you meet a situation, though you think at the time it is an impossibility and you go through the tortures of the damned, once you have met it and lived through it, you find that forever after you are freer than you were before.”

Ain’t that the truth?
ALDAcon 2010

Able ALDAn Award: Kathy Schlueter, Linda Drattell, Karen Krull (winner), and Marcia Kopp (photo by Ken Arcia)

President’s Special Recognition Award: Nancy Kingsley (winner) and Linda Drattell (photo by Ken Arcia)

ALDA blondes: Kathy Schlueter, Mary Clark, and Cheryl Heppner (photo by Ken Arcia)
Karaoke dancing (photo by Ken Arcia)

Karaoke singing (photo courtesy of Ken Arcia)
first time you needed to ask for an accommodation—it's nerve wracking. I had a lot of support from my family, and my boss said to me: “Jane, we're in special ed. If we can't help you, no one can. Don’t worry.” Ultimately, I went through the amplified phone and CART and ended up working with a full-time interpreter. I had every accommodation that I needed.

My husband Larry has come to seven or eight 'cons, and I have the total support of my family. Larry's grandfather was very, very hard of hearing, and they lived in a two-family house. I’ve known Larry since I was 12, and I was often in his house. We would hear his grandparents fighting all the time, and he swore to me that he would not allow that to happen to us. When I became deaf, Larry called a family meeting, because it was rough on everyone. My son asked how I thought he felt—when he had left for college, I was fine, but when he came home, I was deaf. My daughter seems almost to have never forgiven me for focusing so much on my hearing needs when she was a teenager. It was really hard for her. I think we have both grown up and matured and we’re past some of the rough times.

At some point in the beginning of my hearing loss, about mid 1998, I found other people online like me, including a woman whose screen name was Jazzy. She lived in New Jersey and I was from New York. She started to plan a party and invited me, but I wasn’t intending to go. Then one of the women going to the party emailed me, “Jane, you must come to Jazzy’s party,” so I finally said to Larry, “You don’t want to go to a party in New Jersey with hard of hearing people, do you?” And my husband, who was never very social, said, “Yes, let’s go. You need it.”

My mother thought I was going to an ax murderer’s house. You know the people you meet online—they’re crazy. But needless to say, Jazzy was not an ax murderer. She is a dear friend, and that party changed lives. I met folks from ALDA for the first time, including Tony Yuppa, Lori Messing, and Mark Dessert. Through the folks at Jazzy’s house, I became active in a group called SWC, the Say What Club. And when I was presenting to a small SWC group at a workshop in California, I met Edna Shipley-Conner (may she rest in peace), who said, “Jane, you have to come to ALDA.”

I went to my first ALDAcon that year in New Mexico. At that time in 2000, the economy was better, and I met 400 people like me. Everyone was having fun. Edna would tease me because I cried the whole time. My biggest mistake at that conference was refusing to go to the karaoke party—I won’t miss it now. Ever since then, I’ve been involved in ALDA. I made contacts that have had a lasting impact. One was Dr. Bob Davila, who had interviewed me for a job that I didn’t get. Because he knew me from ALDA and that interview, he recommended me for an appointment to a federal working group. He also gave me wonderful personal advice on job placements.

I met I. King Jordan, who told a story about a mirror. [Editor's note: In his story, King advised newly deafened people to go to their rooms, look in the mirror, and say, “I am a deaf person. I’m deaf today and I will be deaf tomorrow. I will probably be deaf for the rest of my life,” and then recognize that they are not less than they were when they could hear, just different.] I went to my room, looked in the mirror, and cried. Because of that story, I started to accept my deafness, and just this past June, King honored my new school, St. Mary’s School for the Deaf, as our graduation speaker. Without ALDA, I never would have had the honor of meeting him.

I met Cheryl Heppner, who guided me through so many advocacy issues. The one with the most lasting impact is getting my hearing dog, Remick. I just can’t imagine life without him, and I thank Cheryl for her help. I got to know Kathy Schlueter, Lois Maroney, Matt Ferrara, Robin Titterington, and Sally Skyer—and Sally’s son started teaching in my school this fall. Because of ALDA, I’m standing here today, a deaf woman. I’ve earned a doctorate. I’m the principal of a school. I’ve served on government committees. I’ve been president of this organization. I’ve been on the Board as a regional director. King is quoted as saying that “deaf people can do anything but hear,” and we put that quote up on the wall in St. Mary’s.

The sadness of losing our hearing, unbelievably, passes, the grief passes, life goes on, and it can be good. If I weren’t deaf, I can’t imagine winning any award, let alone the I. King Jordan one. I’ve always looked up to the group of people who have won this award, and I can’t believe that one of them is now me! My mentor, Frank Bowe, once told me that he did things for me with the hope that someday I would do the same for others. I hope I have and that I’m not finished yet. My sincere thanks go to the ALDA Board for giving me this honor. I also thank my family—nothing would be possible without them. And I’m grateful to King for telling me to look in the mirror all those years ago and at the same time telling me that I can do anything.

Jane can be reached at JaneS256@aol.com.
my eye, and for six more weeks I had corn oil and no lens, but I had my corn-oil-no-lens reading and distance glasses. The final surgery was to take out the corn oil, and they were also going to put a lens in, but, there was too much scar tissue and damage, so I went home with eyeball juice and no lens. Do I think that I will ever get a lens implant? No. I think it’s pretty dangerous. If technology improves, I will go for it, but right now, no way. So let me go back to these five categories and compare the late-deafened journeys that I have witnessed with my journey.

With etiology, some people lose their hearing quickly and some people lose their eyesight quickly. Some people lose their hearing or eyesight from surgery. There is that similarity.

Regarding medical intervention, I mentioned people getting different hearing aids, cochlear implants, all the things they need to function. For me, it was the same—I had all these glasses.

People go into surgery with a lot of expectations and come out with reality. Now I wear a contact lens. It’s very thick, but it gives me a fairly clear vision—for 15, maybe 20 feet on a good day. My glasses magnify everything about 10 percent, so everyone looks a little larger and closer when they stand next to me. If my husband comes over to hug me, I move back a little because he scares me by being right in my face. [Similarly, late-deafened people tend to startle when approached because they didn’t hear the person coming.]

I lost the ability to drive. Technically, I can drive—I haven’t lost my license, but I’ve chosen to not drive because it’s a little dangerous. I see out of a clear tunnel about 15 or 20 feet wide as a result of all of the lasering. I see nothing on my left side, so if you come up on my left I won’t see you. I’m not ignoring you—I just don’t see you. [Likewise, late-deafened people are often thought to be ignoring someone because they didn’t hear the person speak to them.] So those are some similarities regarding what we are left with.

I was also sent home because I was “cured.” I had a contact lens and five pairs of glasses that I switch depending on what I need to see. Without a lens the eye can’t focus, so my glasses focus for me. It’s kind of like being “cured” with a hearing aid or a cochlear implant.

Let’s talk about interactions with families and others. My family interactions have not been as stressful as what many ALDAns go through. My husband drives me anywhere, as do my children. They will also hold my hand walking when it’s dark, and I’m grateful.

Interactions with others can have problems. Some
and I would be seeing better.

The last category is identity. I’m not really sure who I am because I function fine and bluff well. I don’t drive, but I’m not blind—my vision is “correctable,” and on a good day when the lighting is right and the sun is not in my eyes and everything is perfect, then I can see well enough to drive. I can’t be sighted and have low vision at the same time, but it’s hard to explain. If I’m going to fly, I grip the side of the plane as I enter because I can never tell where the stair is or if there’s a gap. As I climb up I have to feel around a little, and with my very funky glasses people know that something is wrong. And then I whip out my Kindle and read. I guess it’s the same thing as are you hearing or deaf or hard of hearing with your cochlear implant on? Are your hearing aids in or out? It is truly the same kind of search for identity.

I will wrap up with one more similarity. After you lost your hearing, have you been asked, “Your other senses have improved greatly, right?” I hear it for my eyesight, and my answer is, “Yes—my sense of humor has” because I find the world to be absolutely absurd. If I’m talking to you and I look away, I expect you to be in the same place. When my husband Roy comes into the office to talk and I look down and then back up, if he is not standing exactly where he was, I start scanning. I always scan left first because I know I am missing the whole left picture. It’s an absurd way to live.

I had a long talk with my daughter. She was sitting on a dark love seat covered up with a dark blanket in a darkened room. I left, came back into the room, and continued my conversation with her on the love seat except that she had moved to the couch on my left, and I didn’t know it. So Roy and Malia listened until the end of my conversation, and then they both burst out laughing because I, of course, was talking to an empty love seat. Obviously, I didn’t really see her on the love seat, and I didn’t see her on the couch. I think that’s hilarious.

For 20 years you have given me the privilege of being a part of your lives and journeys, and I really appreciate it because you have affected my life and journey. You’ve taught me to recognize that there are some limitations, and they are okay. And sometimes your life will never be the same, but it is a differently wonderful life that you now enter. You’ve taught me that it’s okay to ask for help—you don’t have to apologize. You’ve taught me to plan ahead, and then when the plans fall through, to be flexible enough to get through it. And most importantly, you’ve taught me to recognize the humor.

Pat can be reached at pat.graves@captionfirst.com.
I Found a Family at ALDAcon (continued)...

continued from page 1

often exposed to people staring and asking, “What IS that?!”). My experience within the Deaf community was that my ABI was something I should be ashamed about, and I felt I had to hide the fact that I do need this to help me with lipreading.

From the workshops, I took away a ton of good information regarding technology, specifically cellphone and CapTel technology. The workshops were also empowering on an emotional level. My favorite was “Life After Deaf: Adjusting and Thriving” with Sharaine Roberts. I may not do all the things I had planned before I lost my hearing, or I might still do them, but either way, I can do great things!

My inner kleptomaniac loved the exhibit hall. My husband will tell you that I enjoy taking free samples, and he often chuckles when I leave somewhere and show him my loot. The exhibits were like Halloween for me. Aside from learning about great products and services, I received free items just for stopping by a booth. I think my pen and scratch pad paper supply is stocked until 2020, or at least until next year’s convention.

I am embarrassed to admit that I was not doing such a great job of communicating to the vendors at first. We had stopped by a booth, and when the woman turned to grab something, I just kept on talking. My husband nudged me and said, “She is deaf, too.” I had to remember to use better communication strategies with everyone because, as most of us know too well, hearing loss is not something you can see unless there is a visible hearing aid or implant.

How could I talk about my first ALDAcon and not mention karaoke? When we were registering for the ‘con, I showed the information about this event to my husband. “Doesn’t this sound like so much fun?” I asked. Pause. Apparently not. I registered for it alone anyway, because even though I don’t sing, I was excited to have a way to enjoy music again. Dave Litman tried his best to get me to sing, but it was a failed attempt. “I didn’t sing before and I am NOT going to start now that I am deaf,” I insisted. Even though I knew my new pals couldn’t hear how awful I sounded, I felt bad for the hotel staff. Maybe we should hand out earplugs? Anyway, I loved feeling the boom, boom, boom in my balloon and being able to follow along to the words on the giant screens.

I would never have been able to socialize at such a loud function with hearing people, but because people signed or wrote at the karaoke party, I could carry on a conversation much as if I were in a quiet room. Wow! Often at other social functions, even in a crowd of a hundred, it was easy for me to feel like I was the only one there, since it was hard to communicate with other people. Not at ALDAcon. I was in a room full of people and felt just as included as I would have been in my previous hearing life. I was surprised that the lights were left on; usually events like this are dim. Soon enough, I was dancing to all the great songs with my new pals. My new inspiring friend, Rachael Morris, didn’t let her walker get in her way—she got her groove on anyway. The famous ALDA Blues started to kick in as the event was winding down. I knew this was my last event of the weekend, and I didn’t want it to end!!

Aside from all the great resources and information presented at ALDA and the socializing, I am glad I attended for more personal reasons. Through my online contacts I knew of two or three other NF2ers who would be present, but I ended up with a count of eight that I was able to meet! I had previously only met one other person with this condition, although I have several dozen NF2 friends online. And for the first time at a gathering, I didn’t feel self-conscious about my facial paralysis or worried about being perceived as unfriendly or about people having a hard time understanding my signing. Many attendees seemed at least a little familiar with NF2, since at least two long-time members and presenters of workshops this year also had NF2. There aren’t words to express how comforting it was to meet others like me, share stories, and compare “battle wounds.” Some also had an ABI. It was a great opportunity to connect with others facing the same struggles and gain resources, connections, and treatment options.

The ALDA Blues continued to emerge while I was checking out of the hotel and got worse in the days after the convention. I have to wait a whole YEAR to do this again?? Sniff, sniff. In the meantime, I’m enjoying connecting online with my new friends and reading brochures and information acquired at the ‘con. “Lost my hearing: found a family.” Yep.

Heidi Herzog was diagnosed with neurofibromatosis type 2 (NF2) five years ago and lost her hearing almost four years ago at age 26 after having surgery to remove acoustic neuromas from both hearing nerves. Before her deafness she was an elementary school teacher for several years. While adjusting to hearing loss, she is working as a paraprofessional for students with special needs. Heidi enjoys scrapbooking, baking, and hanging out with family and friends. She lives in Thornton, Colorado with her husband Jason and a three-year-old cocker spaniel named Ellie Mae. Her email address is heidi_benedict@yahoo.com (“Benedict” was her maiden name).
The Earplug Experience; Two Decades Later

By Heidi Martin-Coleman

Ear plugs, blindfolds, enormous welding gloves, football mouth guards, and slings spilled out of a large, battered cardboard box, onto a table in the center of the nursing department’s clinical practice lab. Four wheelchairs and several pairs of crutches leaned against the far wall, in anticipation of my class’ first clinical assignment. Each student in the practical nursing class, made up of 25 men and women ranging in age from 16 to 49 years, was going to choose a prop and experience a “disability for a day,” making a new choice each day for the entire week.

As the youngest and most naïve student in the class, I was given a fair share of gentle ribbing by the older members, some of whom had already experienced the difficulties of short-term mobility problems due to broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities. I was just a baby, never having had a backache in my life! But I wore eyeglasses for driving and had broken bones, as well as chronic illnesses and minor disabilities.

Twenty years later, I can recall some of the highlights of the experience. First, I realized that I knew what the “world” sounded like while wearing earplugs, if you consider the bathroom and a swimming pool “the world”! Wearing earplugs, external sounds are muffled, while internal sounds (chewing, swallowing, speech) are amplified. In class, it was very difficult to maintain my concentration. I had to watch the lecturer at all times, because if I looked away, I missed information. My written notes were very disjointed, because I constantly needed to choose between writing and listening. Chatting with classmates during lunch was impossible, because the sound of my own chewing was extremely distracting. I must admit that I cheated that afternoon; I was a new driver (remember, I was 16), and I was absolutely terrified by the idea of driving home right on top of that. Bye.

Denial carried me through the next two months, but eventually I started noticing some strange, possibly contagious electrical problems around my house. All the television sets and telephones were having volume and reception troubles. The funny thing was, if I turned on the closed captioning and read as I watched, the reception improved. If I looked away, the dialogue changed to Swahili. Hmm, I didn’t notice that happening with the earplugs. Even more distressing than the “foreign language du jour” was the constant polyphonic cacophony. I’d had perfect pitch and synesthesia my entire life, and that went away on its own. Still, she encouraged me to make an appointment with a local ENT. Sure, I’ll get right on top of that. Bye.

The antibiotics did the trick. I survived the pneumonia and eventually returned home to take a long course of the same strong antibiotics that had saved my life. After finishing up the last few doses mid-March, I noticed that I was having some dizzy spells and heard a constant humming, buzzing sound in my head. The visiting nurse showed up for her weekly check-in and asked the question she had asked during every single visit; “Any problems hearing?” No, of course not. If I were having trouble hearing, things would be quiet, like the earplug experience. Here I was experiencing extra sounds. That doesn’t seem like a hearing problem to me. I did mention my dizziness, but I had had a bout of Meniere’s when I was pregnant with my second child, and that went away on its own. Still, she encouraged me to make an appointment with a local ENT. Sure, I’ll get right on top of that. Bye.

Fast-forward to January 2007. I was battling a life-threatening pneumonia. One lung had collapsed and my chest cavity was filled with blood. My underlying genetic illness made me extremely susceptible to the ototoxic effects of aminoglycosides, but the infection that I had was resistant to every other class of antibiotics. I had to choose between risking my life or my hearing, and I would make the same choice again in a heartbeat. “Besides,” the doctor said, “If you do have any damage to your hearing, we can fix it with hearing aids.” Fix it. Just like changing a tire, or gluing a broken mug. After all, hearing aids are just like eyeglasses for the ears, right?

Denial carried me through the next two months, but eventually I started noticing some strange, possibly contagious electrical problems around my house. All the television sets and telephones were having volume and reception troubles. The funny thing was, if I turned on the closed captioning and read as I watched, the reception improved. If I looked away, the dialogue changed to Swahili. Hmm, I didn’t notice that happening with the earplugs. Even more distressing than the “foreign language du jour” was the constant polyphonic cacophony. I’d had perfect pitch and synesthesia my entire life, which made the worsening tinnitus even more maddening. The ringing, buzzing, and blipping had absolutely no respect for the laws of Western tonal harmony. So, grudgingly, I made an...
Everything seemed much louder when the earplugs were
muffled external sounds. This would also explain why
louder because my brain was comparing them to the
conduction. I’m guessing these internal sounds seemed
sounds are transmitted to the inner ear through bone
humming, and chewing) are not affected, since those
inside the head (such as speech but also swallowing,
hums, taps, even sounds resembling the murmur of a
crowded restaurant or a radio tuned between stations. I
no longer hear sounds even when wearing hearing aids,
but I do hear/feel vibrations, which I can sometimes
distinguish (to the left and profound loss on the left). I never would
have believed that there is a difference between “pro-
found with residual hearing” and “profound without
residual hearing,” but there is, and it is significant.

Another surprise: I always thought that being audiologi-
cally deaf meant silence, but it certainly didn’t in my
case. The tinnitus sounded quite loud at times, and it
seemed to exist as an endless variety of rings, buzzes,
resistant sound images. I thought they might be
in the music, but I was beginning to seriously doubt the previous doctor’s claim that hearing
aids would “fix it” anything.

One July morning while I was showering, com-
pletely lost in thought, I suddenly realized that I
couldn’t hear the water hitting the sides of my head. An
audiogram confirmed my fears. My hearing loss had
progressed, and now it was in the severe range. I was
shocked. How could my hearing continue to decline
even though the medicine was discontinued four months
ago? I was able to exchange my two-month-old hearing
aids for a stronger model, but everything continued to
sound distorted. Speech was becoming more difficult to
understand because words seemed to be missing sounds,
or they sounded the same as other words. The most sur-
prising and worrisome change was that my own words
seemed distorted even when I knew I was pronouncing
them correctly, and I was having difficulty speaking at a
volume that was appropriate for a given situation. I was
baffled. When I had worn earplugs that day many years
before, external sounds were muffled and my own voice
seemed louder. Now it was difficult to hear my own
speech sounds, even while wearing hearing aids.

After some thought, I realized that comparing a pro-
gressive hearing loss to the muffling experienced while
wearing earplugs was like comparing apples to oranges.
When a person with normal hearing wears earplugs,
the sound is muffled before it reaches the eardrum.
Any external sounds are muffled, but sounds produced
inside the head (such as speech but also swallowing,
humming, and chewing) are not affected, since those
sounds are transmitted to the inner ear through bone
conduction. I’m guessing these internal sounds seemed
louder because my brain was comparing them to the
muffled external sounds. This would also explain why
everything seemed much louder when the earplugs were
removed; my brain recalled the muffled sounds and un-
consciously compared them to familiar environmental
sounds. Since my progressive hearing loss resulted from
damage to the inner ear and/or auditory nerve, it didn’t
make any difference where sounds originated.

My hearing loss continued to progress. By
September I had a profound bilateral loss, and my last
audiogram in January 2008 showed a complete loss on
the right and profound loss on the left. I never would
have believed that there is a difference between “pro-
found with residual hearing” and “profound without
residual hearing,” but there is, and it is significant.

Another surprise: I always thought that being audiologi-
cally deaf meant silence, but it certainly didn’t in my
case. The tinnitus sounded quite loud at times, and it
seemed to exist as an endless variety of rings, buzzes,
hums, taps, even sounds resembling the murmur of a
crowded restaurant or a radio tuned between stations. I
no longer hear sounds even when wearing hearing aids,
but I do hear/feel vibrations, which I can sometimes
distinguish based on context. I still wear one aid despite
my profound loss. The hearing aid plays an important
role, giving at least one auditory nerve something to do
in order to cut down on tinnitus, which helps keep my
musician’s mind sane.

Simulating a hearing loss by wearing ear plugs, in
my experience, was not terribly accurate, although it
did give me something to think about. At the time, the
assignment was to introduce new nursing students to
barriers that our patients might encounter. But it was
only when hearing loss became a reality for me that my
eyes were truly opened to its actual nature and impact.

Heidi has 20 years of nursing experience as well
as 18 years of experience living with mitochondrial
myopathy, a progressive neuromuscular disease that
resulted in multiple disabilities and severe chronic
health difficulties. Due to her unpredictable health
status, she had to resign from her position as an early
intervention developmental nurse educator and service
coordinator for very young children with disabilities
and their families. In October 2008, Heidi became
an independent disabilities consultant and advocate,
serving local nonprofit organizations and families
to the left.

Hearing aid compatibility, however, is a different story.

After some thought, I realized that comparing a pro-
gressive hearing loss to the muffling experienced while
wearing earplugs was like comparing apples to oranges.
When a person with normal hearing wears earplugs,
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consciously compared them to familiar environmental
sounds. Since my progressive hearing loss resulted from
damage to the inner ear and/or auditory nerve, it didn’t
make any difference where sounds originated.
How many doors does my house have? I counted them: 18. There are plain doors, French doors, glass doors, one swinging door, and seven closet doors. My house is old and was built before architects came up with the current open, free flowing interior design. Why on earth am I counting doors? It's all Biscuit's fault. If I don't close all the doors before I go to bed (Biscuit sleeps with me), I will face who-knows-what in the morning. Biscuit, in case you're wondering, is the name of the one-year-old Jack Russell terrier I got at the Humane Society after I lost my wonderful dog Nader. I'm deaf and live alone, so I need a dog for protection and company and to let me know when my phone or doorbell rings, plus dogspeak is easy to understand. However, getting Biscuit to become more of an asset than a liability turned into a major project.

One Jack Russ breeder calls the dogs Jack Russell terrorists because they're such a bundle of frantic, energy and chew and destroy everything. I had Nader for 14 years and she never chewed anything but dog bones, and she alerted me to phone calls and visitors. Unlike Biscuit, she didn't like to eat my glasses if I left them on my bed, and not just the drugstore reading glasses but prescription ones, too. Biscuit is unpredictable—he will bypass magazines one day, and the next day when I look for what I was reading the night before, I find scraps and pieces of it all over my house. Before I learned to close ALL the doors at night, he chewed chunks out of the legs of my dining room chairs. And nobody told me that Biscuit was an escape artist. I had to put chicken wire over my iron fence to prevent him from squeezing out through the bars and running away, since I'm not good at running after him. Pant, pant, gotcha!

The pet store near me has class lessons in training dogs or private one-on-one consulting priced by the hour. Because I'm deaf, a class is no use to me, so I tried private lessons, but all I got from that was an outline on housebreaking. I've had dogs all my life and never failed to housebreak them without professional help.

What is the outcome of my relationship with Biscuit? I think it's a compromise. We love each other, and Biscuit is almost housebroken. I close all the doors at night so I won't wake up in the morning to find something else chewed up, and I found all his escape routes, so I can leave him in my yard and not watch him 24 hours a day. He is beginning to show signs that he knows I always go to my telephone when the lights flash, and he definitely tells me when someone is at my door.

UPDATE: Biscuit has outgrown all the destruction that he caused at first because he was still a puppy, so I don't have to close all the doors anymore. When he sees me start to turn out the lights after changing into my pajamas, he is waiting in my bed for me and snuggles under the covers with me. He is also aware of the phone when it lights up and runs around the house like crazy when someone is at the door. Biscuit is now my guardian angel and my ears for alerting me to the phone and doorbell!
ALDAcon 2011
RACING AHEAD IN INDY

ALDA News

Registration Form

Please complete BOTH 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:

__ 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: __neckloop   __headphones   __other_________

ROOMMATE MATCH:    __ I need a roommate.  I am ___ male ___ female

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 ($20.00) ___ Age 61 or younger ($25.00) ___Business membership ($45.00)
Registration Fees

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

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

**Veterans:** Time Trials registration fee level applies until August 30, 2011; then the Qualifications level applies.

A limited number of scholarships are available. Contact Carolyn Piper, Scholarship Chair, at wicwas@wctv.com for more information.

**Time Trials**—before March 1; **Qualifications**—before June 1; **Last Laps**— June 2 to October 26

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<th>FULL REGISTRATION</th>
<th>Time Trials</th>
<th>Qualifications</th>
<th>Last Laps</th>
<th>Amount</th>
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*Time Trials and Qualifications registrations must be paid in full by September 30 to keep those rates.*

**Partial registrations** include access to the Exhibit Hall, workshops, and the luncheon on specified day(s).

<table>
<thead>
<tr>
<th>One day</th>
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Day(s) selected: indicate which day(s) you will be attending:  Thursday_____  Friday_____  Saturday_____

**A la carte meals:**

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<td>Friday – I. King Jordan Banquet - $55</td>
<td>Saturday Karaoke Party - $25</td>
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**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 2011)

**Card Holder’s Name:** ____________________________

**Card Number:** ____________________________

**Expiration Date** (month/year): ____________________________

**Signature:** ____________________________

**Mail to:**  ALDacon 2011 Registration

1025 N Canyon Drive

Freeport IL 61032-7222

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

Questions? Email registration@alda.org

If you’re making an initial deposit to your 500 Club account, check here____ and indicate the amount to be credited toward your registration fee __________ and/or to your hotel reservation __________.

To make additional deposits, copy this section, fill in the information, and send to the address above.

Additional deposits also may be made through PayPal.

Refund Policy for Registration

Requests for refunds (minus $50.00 processing fee) will be honored until September 30, 2011.

Contact ALDacon 2011 planning chair Kim Mettache at ALDAkim2011@aol.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  ALD.

The ALDacon suite rate of $119.00 ends October 4.

Reservations may be made online at www.indianopolisdowntown.embassysuites.com

Embassy Suites toll-free number is 800-362-2779. The direct number is 317-236-1800.

For more information, go to www.alfa.org.
Developing Our Storybook

By Muhammad Akram

Documenting knowledge in the form of story may not be new to many of you. Under the Story-based Knowledge Management (SbKM) project, Danishkadah, in cooperation with the Asia Pacific Development Center on Disability (APCD), developed a storybook and DVD to share our knowledge.

First a team from APCD trained us with a workshop on SbKM, where we learned the SbKM philosophy and the initial approach to the project. We were excited and agreed to produce the Danishkadah story. Then we went through different phases of the project from planning to implementation. We decided to develop a cartoon storybook instead of simple video interviews and to hire a deaf artist to draw the cartoons. To make the story accessible for all, we produced a DVD with voice, sign language, and captioning. These phases of the project gave us a great opportunity to learn and develop our organization and empowered our team at the same time.

Our story starts with a person (me) who become deaf at young age and then describes what he faced in society and how he got involved in the disability movement. Showing how the story of an individual turned into the story of an organization can inspire others. People who become disabled and believe that life can’t be same as before they had a disability learn that life can still be wonderful and they can still achieve a lot, and people from mainstream society can learn that it is not an individual’s disability that creates barriers but the inaccessible environment and the attitude (mindset) of people.

Now we are sharing our book with everyone who is interested, and we hope this will make a good impact on society. Anyone interested in reading the story can contact us at danishkadah@gmail.com. We can provide a PDF copy or printed book and a DVD, and the storybook is also on our Facebook photo album. We would love to read your comments about our story. Email them with the subject line “Comments on Danishkadah’s story.”

Muhammad Akram lives in Pakistan, leads ALDA-Asia Pacific, and chairs the ALDA International Committee.
Kim Mettache indicated that in September, ALDA-Northwest Indiana and ALDA-Chicago combined for a picnic at a quiet shelter in Dyer, Indiana. About 40 were in attendance, coming from as far as Grand Rapids, Michigan and Indianapolis. Kitty Berger did a great job of helping and organizing the picnic. Everyone was also invited to come to ALDAcon 2011 in Indianapolis and invited everyone to come. Region 2 Director Marsha Kopp said that in November, ALDA-NWI hosted a presentation by Med-El, a cochlear implant company, with an opportunity to socialize with people who understand the isolation of hearing loss.

Marsha Kopp gave a summary of ALDA–Chicago events, which included participation in a Deaf Awareness Day exhibit; a communication workshop at HiTec (a vendor of assistive technology), with an opportunity to try out text and amplified telephones, signaling devices, hand-held amplifiers, neckloops, etc., followed by a pre-Halloween luncheon at nearby restaurant; and a board meeting (open to members) followed by a pizza party at a nearby restaurant.

Ann Smith said that ALDA-Peach’s September meeting was a “My Summer Vacation” reporting session. Robin Titterington reported on the recent ALDAcon 2010 in Colorado Springs, Marge Tamas told about her family’s “cruise without a ship,” and Belinda Miller shared photographs and stories about caring for her beautiful garden. October’s meeting was a chance to play a new game. Marge Tamas adapted the “Sage or Silly” game for the chapter, and participants had a great time trying to complete proverbs from around the world. ALDA-Peach’s annual business meeting and board election took place in November. Roxanne Gasaway and John Esmay were elected to the two open positions, joining Marge Tamas, Yael Shaner, and Belinda Miller as the board for 2011.

Region 1 Director Matt Ferrara provided an update on ALDA-Boston. Activities for ALDA-Boston members in 2010 included a guided tour of the exhibit “Tomb 10A” at the Museum of Fine Arts, with provision of assistive listening devices; a meeting of the Greater New England chapter of the Advanced Bionics Association for CI users and candidates; a presentation at WGBH about captioning in various media; the ALDA-Boston Birthday Brunch and the July 4 holiday party; a presentation by an audiologist; and a December holiday party.

Diana Fanuel reported on ALDA-NJ and ALDA-Garden State activities. On October 10, Ralph and Susan Marana hosted an ALDA-NJ gathering at their Totowa home for around 20-25 attendees. Gorgeous weather, abundant food and conversation made for a great time. On October 16, ALDA-GS participated in the HLAA-sponsored Garden State Walk4Hearing. Earnings will go to fund the annual ALDA-GS scholarship award.

Diana Fanuel, ALDA-GS treasurer, attended the NJ Division of the Deaf and Hard of Hearing (DDHH) Taste of Technology, which featured the new wireless technology for Sprint products.

Muhammad Akram said that ALDA International Committee member Liisa Sammalpenger reported that the Finnish annual LDA weekend was celebrated on October 23-24, 2010, and the Swedish VIS (late-deafened) fall meeting was held on November 13-14, 2010. ALDA-Asia Pacific will be participating in a regional meeting of hard of hearing and late-deafened organizations to be held in Bangkok, Thailand from November 2-4, 2011.

Send your chapter and personal news to Ann at fabsmith@att.net by February 21.
Book Explores Experiences of a Pioneering Late-Deafened Therapist

[Editor’s note: Holly Elliott, who was 82 when she died in 2002, became deaf during her sophomore year in college. She married, raised three sons, got her MA after her husband’s death, and obtained her first professional position at age 50. She was a member of ALDA and received the third annual I. King Jordan Award. Her book was published posthumously in 2008 by White River Press. The following is condensed from the press release.]

Teach Me to Love Myself reveals a snapshot of a time when deaf culture was first evolving. This transition in the 1970s and ’80s mirrors author Holly Elliott’s own life, which too, was changing because of her adult-onset deafness. Begun as a journal found after her death, this narrative follows Holly as a pioneer of total communication and recounts her struggles.

As she describes in her memoir, she was probably the first professionally trained deaf counselor-therapist in the United States. In her positions as intern and staff member at the University of California Center on Deafness, she became an advocate of total communication—a combination of sign language, lipreading, and oral competency that was a new horizon for rehabilitation therapy for the deaf.

She was one of the first individuals with inner-ear nerve degeneration to receive a prototype cochlear implant and, several years later, one of the first to have an implant upgraded. She made a courageous career shift mid-life. She accepted her deafness and embarked on a retraining that eventually led to a distinguished professional career.

Holly Elliott graduated with a BA in music from UCLA in 1941. She received her MA in rehabilitation counseling in 1970. She was active in the Methodist church, being on the board of directors and President of the United Methodist Congress of the Deaf. She continued her work after retirement by collaborating on a federally funded project dealing with adult-onset hearing loss.

Alone we can do so little; together we can do so much.

—Helen Keller
President’s Report/Farewell

By Linda Drattell

It has been a pleasure serving you all this past year as president of ALDA. The best part was the opportunity to work with many of you as a team, to get to know you not just for your much-needed strengths, but also for your uniqueness of character. Everyone brings so much to this organization. I feel much richer for having gotten to know you, and I want to thank you.

ALDAcon 2010 was a blast. I missed the friends who could not come and tear up the place with us (figuratively speaking!), but I enjoyed being with others who are very dear to us and meeting new people who are now dear to us as well. What I loved most about the ’con, besides the beautiful location, was the spontaneity! I’m sure it drove Jane Schlau and Kathy Schlueter (our co-planning chairs) crazy when people were storming the microphone to speak on Friday night, but that was the way the ’con was—bursting with random acts of warmth, nostalgia, and bonding.

We have accomplished much this year. We worked hard to improve ALDA’s financial position, and we are working feverishly to resolve website issues. We have created a strategic planning committee and an ALDAcon advisory committee, and we are looking into alternative fundraising methods for ALDAcon scholarships. We have also become more involved in addressing global issues affecting deafened adults worldwide. We joined other organizations in advocating for the rights of late-deafened and hard of hearing people. We lobbied Congress, sat on panels with the Federal Communications Commission, fought in California to make the Public Utilities Commission retract the announcement it said was required at the beginning of all captioned phone calls, and we continue to advocate on several fronts for movie captioning.

I look forward to serving ALDA as past president. My duties will include being nominations chair, Board liaison to the website committee, and co-chair of the ALDA Reader. Contact me anytime—my email address for 2011 is pastpresident@alda.org.

President-Elect Report

By Cynthia Amerman

I served on the planning committee and in several capacities at ALDAcon, among which were introducing speakers and presenting the Robert Davila ALDA Angel Award to the National Technical Institute for the Deaf. As newcomer chair, I welcomed the 20 newcomers before and during the convention, and at the ’con I provided the newcomer workshop and spoke at the newcomer breakfast and the farewell brunch. Many newcomers commented on how much they enjoyed the ’con.

I served as Board liaison to the ALDA scholarship committee, both behind the scenes and with the scholarship attendees at the convention. As Board liaison regarding the NTID/RIT Memorandum of Understanding, I revised the ALDA statement’s wording for the NTID/RIT veterans website. I also served along with Kathy Schlueter as chapter coordinator.

On the ALDA International Committee (ALDA-IC), I worked with our chair, Muhammad Akram, to get his video and storybook for the 2010 convention, but unfortunately, the items he mailed did not arrive. However, I brought material from deaf organizations and conferences in Sweden, Finland, Estonia and England to display.

Past President/Nominations Committee Report

By Kathy Schlueter

The 2010 nominations committee included Linda Drattell, Marsha Kopp, Michelle Lewis, Gloria Popp, Carol Postulka; and Bernice Nelson. The committee worked hard trying to have at least two candidates per positions open on the ballot. Announcements were sent out through ALDA News twice and ALDA eNews twice and were made at ALDAcon. We also placed the announcement on the ALDA, Inc. website. Candidate statements and ballots and a bylaws proposals ballot were mailed on November 19, and a membership form was included for those whose memberships had expired. On November 21, electronic voting went to our Regions 3 and 4 members overseas to be sure that their election materials would arrive in time to be returned by the December 10 postmark deadline.

Candidate statements and ballots and a bylaws proposals ballot were mailed on November 19, and a membership form was included for those whose memberships had expired. On November 21, electronic voting went to our Regions 3 and 4 members overseas to be sure that their election materials would arrive in time to be returned by the December 10 postmark deadline.

The Dakota Servant Leadership group was chosen to count the ballots on December 15. Announcement of the new Board of Directors was slated to be placed in eNews and the ALDA, Inc. website by December 31, 2010, with the new Board members taking office
Past President/Nominations (continued)...

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on January 1, 2011.

As nominations chair, I made some recommendations, including: election ballots should only be sent to members in good standing; the cutoff date for candidate statements should be October 15; all election materials and ballots should be mailed by October 25, returned postmarked by November 10, and ballots counted by November 15; there should only be one version of the candidates’ statements that includes all regions and only one ballot that includes all regions, with highlighting in the region the particular ballot should be voted on rather than separate statements and ballots for different regions; and the capability for electronic voting should be added to the website by March 2011, not only for use for the Board election but also for other voting opportunities to be presented to the members for other business activities updated annually and passed on each year.

Motion 2010-36: Motion for the ALDA Board to reaffirm its support for communication policies that are responsive to the diversity in the deaf, hard of hearing, and late-deafened populations that use interpreters and its endorsement of the resolution of 1999 approved by the Registry of Interpreters for the Deaf.

Motion 2010-37: Motion to form an ad hoc committee to look into the issues raised during the discussion of the three-year strategic plan, develop recommendations to deal with these issues, and present the recommendations to the Board.

Motion 2010-39: Motion to hire Donny Jacobs as web developer for ALDA, Inc.

Motion 2010-40: Motion to decrease the business membership rate from $100 to $50.

Motion 2010-41: Motion to print 1000 ALDA, Inc. brochures.

Secretary’s Report

By Brenda Estes

Key 2010 Motions (All Passed)

Motion 2010-24: Motion to establish a standing ALDacon planning committee.

Motion 2010-25: Motion for ALDA to support the movie captioning lawsuit in California with the understanding that ALDA will not be financially responsible for any costs involved.

Motion 2010-26: Motion to move the responsibility of sending membership letters (welcome, membership expiration pending, and membership expired) from the secretary to the database manager effective November 1, 2010. (Any questions regarding membership status should be emailed to Database Manager Gloria Popp at info@alda.org.)

Motion 2010-29: Motion to establish an investment committee consisting of the ALDA, Inc. treasurer, scholarship committee chair, and fundraising chair.

Motion 2010-32: Motion to form an advisory board of former Board members from each Board position so that current officers on the Board will have resources to draw on when they have questions.

Motion 2010-33: Motion to establish the position of web developer.

Motion 2010-35: Motion for the Board to work with the planning committee chairs of the 2010 ’con to prepare ALDacon planning guidelines for the chairs of the next ’con and for these guidelines to be

Treasurer’s Report

By Vaughn H. Shaw

All bills have been paid with one exception and all cash received by me has been deposited through November 30. The bank accounts are reconciled through October 31 and balanced. The lone exception on payments is a bill from the Antlers Hotel (the ALDacon site) that is being questioned.

Below is a brief synopsis of where we stand at November 30th, 2010.

Assets: Cash in the banks $25,796.10, with postal advance of $100.00 and accounts receivable of $150.00, for a total of $26,046.10.

Liabilities/equity: Scholarship Fund $19,272.58, Newcomers Fund $3,676.14, and Net Equity $3,097.39 for a total of $26,046.10.

ALDacon 2010 was profitable and we have many, many people who gave very generously, not only their time but also money or in-kind donations.

More than half of those paying membership dues are new members...welcome to your family at ALDA, Inc.
Regional Director Reports

Region 1

Matt Ferrara

Email inquiries included requests for information about financial assistance for purchasing a hearing aid; support for a hearing aid bill in New York; locating support groups in Maine, Cape Cod, Richmond, Virginia, and New York City; assistance for an agency in setting up a TTY; ALDA materials in other languages (not available at present); inclusion of a review of the memoir of the late pioneering late-deafened therapist and ALDA member Holly Elliott, *Teach Me to Love Myself*, in the *ALDA News*; information on adult-onset deafness; and notifying members of nearby captioned films and plays and of a meeting for motion picture theater access.

Region 2

Marsha Kopp

Inquiries included requests from college students in Iowa and Illinois seeking ALDA information for class presentations and a paper, and one from a Chicago college student seeking a late-deafened individual to interview for a college magazine; I provided an interviewee, but the magazine was being restructured and the interview is temporarily on hold. I also received a request for resources for late-deafened adults in Minneapolis for a family member and another one for CI information from St. Louis. A Michigan member wanted to meet people in her area to give and receive support, and another member needed help in getting a room booked at the ALDAcon hotel. I also received a promotional email from a Missouri Holiday Inn account executive for a future convention and an email from a Medicare representative from Chicago seeking hearing loss information for veterans (I provided the website link of the news story aired on ABC affiliate from the RIT University news department).

Region 3

Dave Litman

Email/phone inquiries included a call from a late-deafened person in the Houston area; requests for information about starting groups in western Tennessee and Oklahoma; a request from a person looking to provide CART services in eastern Tennessee; and an email from the mother of a late-deafened individual in the Atlanta area. ALDA-Carolina Flight face-to-face group meetings are sporadic, but there is an active online discussion group, and members have been discussing trying to host ALDAcon 2012.

Region 4

Michelle Lewis

A person in Australia asked whether there are any local chapters/groups (there aren’t any at this time, but the contact information was saved). Someone in the Phoenix, Arizona area requested an application from the ALDA-Sonora website and visited the ALDA, Inc. website; this individual was invited to join ALDA, Inc. and attend ALDA-Sonora’s next event. Two members in Colorado requested “start-up kits” for a possible group/chapter, and I also followed up with a Colorado audiologist I met at ALDAcon, offering support for starting a group/chapter.

ALDAcon Scholarship Committee Report

By Carolyn Piper

It was gratifying to be able to assist six newcomers to attend the ALDAcon in Colorado Springs this past September. The committee was chaired by Carolyn Piper and included Karen Krull as member-at-large and Cynthia Amerman as Board liaison. A tip of the hat also goes to Vaughn Shawn, the Board treasurer, for steering us through financial questions, as well as to Bill Graham, who shared his executive experience.

The committee is already hard at work for Next year’s ALDAcon. As before, ALDA, Inc. will provide a limited number of scholarships to help those in financial need who want to attend. Scholarship applicants must be members of ALDA, Inc. and need of financial assistance in order to attend ALDAcon. Priority will be given to first-time attendees. Inquiries regarding scholarship applications should be sent to Carolyn Piper at wicwas@wcvt.com between February and the beginning of July.

The Edna Shipley-Conner Newcomer Fund was begun by ALDA’s co-founder Bill Graham in 2008 in honor of the late Edna Shipley-Conner, a past president of ALDA who worked tirelessly to assist newcomers in learning to deal with hearing loss. She was also the presenter of newcomer workshops at every ’con until her death. Those of you who have been to a ’con know how helpful it is for learning to deal with hearing loss through sharing experiences with others, attending workshops, and listening to guest speakers. To make continuing scholarship awards for newcomers possible, donations to this fund are a necessity, and contributions of any size are gladly welcomed. Donations can be made either at www.alda.org (click on the link for donations) or by sending your donation directly to the scholarship chair: Carolyn Piper, 82 Piper Place, Huntington, VT 05462.
ALDA News Advertising Director Report

By Matthew Ferrara

At the request of the ALDA Board, I resumed my ALDA News advertising director position. I contacted former advertisers, including Harris Communications, Ultratec, and Hamilton Relay, and followed up on contacts with Gallaudet, CSDVRS, Satellite Housing, TDI, and Solar Ear. I also sent advertising proposals to Sound Clarity and Dry & Store, which advertise in HLAA's magazine. For the 2010 issues, I obtained ads from Gallaudet, Satellite Housing, Harris Communications, and TDI, and I have commitments from Harris Communications and TDI for future ads in 2011. I am working with HearingImpaired.Net to have them resume advertising, and I plan on continuing to contact advertisers in the HLAA magazine and to follow up with advertisers in the ALDacon program books and with the exhibitors at the 'con.

Bylaws Committee Report

By Nancy Kingsley

Mark Dessert, Roy Miller, and I reviewed the ALDA Bylaws and made a number of proposals for updating them. The Board requested several additional changes, and we prepared the language for those as well. The resulting 14 proposed Bylaws amendments were sent to members for a vote, along with the ballots for Board candidates. Members could vote individually on each proposal or vote to accept all 14.

Among the proposals were changes in the list of ALDA's purposes; categories of membership; terminology used for regional directors; selection of committee members; staggered election of officers; consecutive treasurer terms; elimination of a requirement for special elections; appointments to vacant Board positions; provision for the annual business meeting if no convention is held; allowing ballots to be sent electronically; and permission for chapter to write their own bylaws.

International Committee Report

By Muhammad Akram

You may have read about the International Federation of Hard of Hearing People Biennial General Meeting (IFHOH BGM) attended by two of the IC members, Cynthia Amerman and Liisa Sammalpenger. Cynthia represented ALDA at this meeting, which was held in Stockholm, Sweden this past June. She also had a wonderful time visiting Finnish organizations for Deaf, deafened, and hard of hearing people, thanks to arrangements made by IC member Liisa Sammalpenger, in Liisa's native Helsinki and in Tallinn, Estonia. Cynthia also spoke on behalf of ALDA at the National Association of Deafened People (ALDA's UK counterpart) Annual General Meeting in Liverpool, England, which IC member Geoff Brown also attended.

A group of late-deafened people from different IFHOH countries hopes to revive its Late-Deafened Commission before the next meeting in Bergen, Norway in late June of 2012, where the updated English version of the new German IFHOH constitution is slated to be ratified. As IC chair and group leader of ALDA-Asia Pacific (ALDA-AP), I am promoting this in the Asia Pacific region. Cynthia Amerman reports that an informal Internet group is being established made up of one or two representatives from each of these countries: UK, Finland, Sweden, and the US. Lidia Best of the National Association of Deafened People and the European Federation of Hard of Hearing people and Liisa Sammalpenger of Kuuloliitto in Finland have given input to this group, as has our other UK representative and ALDA-IC member, Geoff Brown, and the group hopes to gather people from more countries who are interested in advocating for the needs of late-deafened people.

One thing that we are demanding is “speech–to-text captioning,” as most of the deafened people need it for access to communication; in this respect, one positive change I observed during the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) second session meeting was the provision of captioning for the first time.

Outreach Committee Report

By Brenda Estes

The committee has identified several areas of concern:

- **Contact person:** Who do members contact if they have questions?
- **Website:** Changes are needed related to member use of the website:
  - Ways to draw members to the website
  - Improvements to the members-only section
    - Way for members to get their log-in information
    - Individual sections for people with NF2 or cochlear implants and for regional directors
Outreach Committee (continued)...
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- Promotional materials: Needed for distribution to medical professionals

Proposed Outreach Plan
1. Develop creative ways to retain/recruit members
2. Network with other organizations
3. Collaborate with the fundraising committee on researching funding for outreach materials
4. Submit an application to Google for a free online ad
5. Utilized the media (e.g., local newspaper, public service announcements)

The outreach committee also worked with several Board members in updating the ALDA, Inc. brochure.

Strategic Planning Committee Report

By Marta Watson

The Strategic Planning Committee (SPC) began by determining five vital areas that we believe ALDA’s board must address: continuity, growth, finances, education, and communication. We began with continuity. Even though bylaws and policies are in place, much of the information in our “organizational memory” resides in the heads of a few people rather than in any set of easily obtainable data, and where data exists it is often difficult to access.

The first recommendation to foster continuity is to provide an “op center” such as a dedicated server where all ALDA data would be stored centrally. This server (whether a hardware or virtual server) would contain the ALDA website with three levels of access (general public, members, and the Board). Key components of the website would include ease and security of access to current information (news, links), archives, chat rooms, and educational resources. The website would be overseen by a qualified webhost, and if deemed necessary, a committee reporting to the Board. A second area critical to continuity is organizational governance (bylaws, policies, and the Board), and recommendations related to amending the bylaws, updating the policies, and reconsidering Board terms of office were offered.

The SPC will continue to focus on the five crucial areas and determine specific recommendations for Board consideration.

Tech Committee Report

By Ken Arcia

The tech committee is changing web hosts for the www.alda.org domain. The cost is only $2.99 per month, which is half what we used to pay at PowWeb. The main reason for this change is that we have been experiencing numerous occurrences of “downtime.” GoDaddy is a nationally recognized, reliable web hosting service, and we should see no “downtime.” We also renewed the www.alda.org domain name for another three years.

We are currently sending out eNews announcements through a paid service. Hopefully, with the help of our new web designer (Donny Jacob), we can discontinue paying for this service and provide eNews on our own this coming year. We also hope to have some added features like a photo gallery and to make it easier to find things on the ALDA website.
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 conference (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.alda.org to find a chapter near you. Our fully accessible annual convention is a must for newcomers and old-timers alike.

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

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

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:

www.alda.org/alda_membership_form.htm

For Credit Card Payment by Mail:
□ MasterCard □ Visa

Amount ________________________________

Account # ______________________________

Expiration Date _________________________

Signature ______________________________
(For Credit Authorization)

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

Education  Advocacy  Role Models  Support

ALDA provides networking opportunities through local chapters and groups as well as at the annual ALDA conference (ALDAcon).
Don’t Just Be a Member, Be 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