I do not know how other people with hearing impairments feel when they visit a doctor or need to be hospitalized, but as for me, I am really afraid of the medical environment. I had to be hospitalized at the age of six because of a high fever, and the doctors could not restore my hearing. Instinctively, I do not like doctors, although they brought me back to life!

Doctors, nurses, and other caregivers often cover their mouths with protective masks.

Once I visited a medical center for an audiogram. I had to wait, and because of my hearing loss, I could only guess when it was my turn to see the doctor. After a while, a nurse wearing a mask appeared at the door and read the name of a patient. There was no reply. Feeling that something was wrong, I went over to her and asked her whose name she called. I immediately realized that I could not hear her voice to find out if it was my turn. “Why don’t you answer me?” the nurse shouted. I felt angry, as I had come to the medical center because of my hearing loss and she was not helpful! This was an area used for patients with hearing loss—the nurse knew it and the patients did too, but she still covered her mouth!

Another time, I went to a hospital to have my ears examined. After listening to my explanation about my hearing loss, my doctor immediately removed his mask and talked to me in a friendly manner. After that visit, my hearing did not improve, but at least I knew how to request assistance for good communication. I think that a person with hearing loss should not visit a medical setting alone; they need a relative or friend to accompany them. Maybe doctors respect people with hearing loss but do not have much time to engage in conversation with them.

I heard that some people from my Deaf Association were given free dental care at a hospital. What surprised me was that many members had some teeth pulled out. Dentists often do not ask questions, just pull out teeth and give treatment without explanations or agreement. This happened to me. “A tooth needs to be pulled out,” a dentist once told me. I answered, “No, I do not want this. It is too painful. Please give me a filling instead!” Another deaf person was told he needed four teeth pulled. He asked me for advice, and I suggested that he ask the dentist to discuss this with his parents. They took him to a private dentist. “Your son’s teeth don’t need to be pulled,” the dentist concluded. Two different decisions, but why?

A 51-year-old member of my organization, who lost his hearing two years ago, told me that doctors would not talk to him; they only spoke with his wife and were not willing to use a notepad for conversation. He felt sad because of this bad situation.

There are two main ways of providing communication access for people with hearing impairments, not only within the health system but in any social context: interpreters and assistive listening devices. How easy or difficult is it to obtain them in Vietnam?

Assistive listening devices are not yet popular in Vietnam. Vietnamese people with hearing impairments are only used to hearing aids. Other assistive listening devices are still
ALDA NEWS

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Note from Nancy

By Nancy Kingsley, ALDA News Editor-in-Chief

In the previous issue, I recounted an experience in a waiting room at my local hospital, where the technician called my name loudly instead of coming over to get me as I had requested. Ironically, the same hospital got it wrong in a different way on an earlier occasion. I had phoned via relay from my computer to make an appointment for a routine mammogram, and when I arrived, the receptionist informed me that my interpreter was waiting for me! Since I hadn’t requested one, it appears that the hospital just assumed I needed an interpreter because I made the appointment via relay and typed my part of the conversation. (When I recently made an appointment with an eye doctor via relay, the receptionist asked me whether I needed an interpreter, which is a much better approach.)

Hospitals and doctors are more aware of Deaf needs because Deaf people have won numerous lawsuits against them for failing to provide interpreters. In contrast, many hard of hearing and late-deafened people put up with poor communication in medical (and other) settings, often because they don’t want to “bother” anyone. Unfortunately, their failure to request appropriate accommodations has resulted in limited awareness of our needs. So if you ever feel hesitant about asking for effective communication, just remember that you’re not doing it only for yourself—you’re a pioneer blazing a path for others!

Nancy Kingsley
To the Editor:

I would like to start a discussion about ALDA’s future. The 20th anniversary celebration last November showed how far the organization has come. It developed from a few dedicated people meeting in their homes to a national organization that serves over 400 people. Many of the original group are still with us.

I never knew ALDA as the small village it once was. As a relative newcomer, I have been a member for seven years and have benefitted from the large national reach of ALDA. I am grateful I gained a family, and now that I am older and more grown up, I want my family to remain relevant.

In recognition of the 20th year anniversary, I’d like to start a dialogue among the members and the Board about the next 20 years. My questions are listed below. Maybe you have a few questions you’d like to write to the ALDA News about.

I’m asking:

- What might be ALDA’s far-reaching objectives for the next 20 years?
- Should ALDA set legislative, outreach, educational, or other goals?
- How do I/you envision ALDA functioning in the next 20 years?
- Who will ALDA serve? Will ALDA serve a wider population?

I’m asking these questions because of something I came to feel at this anniversary conference. The 20th birthday celebration emphasized the history and practices of ALDA that got us to 2008. But now what do we do? Twenty years later is practically a generation. The ALDA “family” culture developed and practiced over 20 years may be in for some changes reflecting the next generation of ALDA members coming up. We’re a huge and diverse family now.

I would like us to have a conversation in the newsletter about ALDA’s vision for the future. Here are some suggestions about opening up a reassessment of ALDA’s vision and practices.

- Writing your ideas about ALDA for the ALDA News.
- Creating and publishing in the ALDA News a survey that the membership could fill out and send to the Board. Follow up by publishing the results of survey to direct further discussion.
- Creating a chat room on the ALDA website where the members could discuss a reassessment of ALDA and new ideas.
- Planning and announcing that there will be a two-hour workshop at the Seattle conference dedicated to ALDA reassessment.

In whatever form the conversation takes, I would like as many ALDA members involved as possible—Board members, first-year members, and everyone in between. It’s our organization and we can only benefit by being involved.

Thanks and sincerely, Margreta von Pein

The editors respond: We are always happy to hear from our readers, and we believe that Margreta has asked important questions about ALDA’s future. Since the ALDA News only comes out four times a year, we believe that the most effective way for members to engage in the kind of dialogue that she is seeking is on the ALDA-ideas email list, and we encourage Margreta to raise these questions on that list. ALDA members who do not already belong can join by sending an email to ALDA-ideas-subscribe@yahoogroups.com. We also welcome articles from readers who would like to share their thoughts about ALDA’s future.
Eileen Here
By Eileen Hollywood, Managing Editor

Hello, everyone!

You may recall that the theme of our previous newsletter was “Dealing with Hearing Loss in a Medical Environment.” Due to the fantastic number of submissions, we were unable to include all the articles in that issue, so we continue the medical theme in this one. Sal Parlato’s engaging poem reminds us of the difficulties we all face in our daily communications.

In “The Vietnamese Medical Environment: Not Easy for People with Hearing Loss,” Duong Phuong Hanh provides an eye-opening account of her personal experiences with the healthcare system in Vietnam. Rebecca Dufek writes candidly about her strategies for overcoming communication difficulties in medical settings in “Navigating the Medical Arena as a Late-Deafened Person.” And we introduce a great new column in this newsletter, “Late Deafened Life: We’re All in It Together” by Michele Bornert, in which she writes about everyday life as a late-deafened adult.

Continuing with our theme, Sharon Milian’s informative article, “Are Communication Needs Falling on Deaf Ears?” speaks about the need for healthcare facilities to comply with the Americans with Disabilities Act (ADA). In “Deafness and My Life,” Harriet Frankel provides a candid and honest account of the effect deafness has had on her life. Brenda Estes vividly recounts her experiences in doctors’ offices and explains how she effectively overcame the communication challenges in “Obtaining Effective Communication in Medical Settings.” And rounding out this issue’s theme is “Helping Physicians Listen,” in which Jack Lewis explains how politeness and assertiveness go hand-in-hand for him in the doctor’s office.

LaRonda Zupp’s personal and moving article, “Parenting from the Heart” describes the joys of being a late-deafened parent. “Our World” connects you to ALDA happenings overseas as the International Committee works diligently to expand ALDA’s presence beyond the United States.

As always, this newsletter would not be possible without the wonderful contributions of our writers. Many thanks to all who have written the articles for this issue. And to all our readers, please consider writing for a future issue. No writing experience is necessary and we would love to hear from you!

ALDAbest,
Eileen

Pierced Ears
By Sal Parlato, Jr.

Pierced are my ears but only deep inside where most of my unhearing hang-ups hide. Hence my laments of yearning to make sense of questions concerning sound-alikes and tense.

What for example had these tongue-waggers said? Elmer’s been deaf for many a year (or dead?) and Eloise is here to prepare a frozen chicken became in my h-ear, to repair a broken kitchen.

So lend, hearer friend, to my damaged twins’ relief by reducing your verbiage to elements more brief. And instead of producing a vocal volume-raise, re-state your words via careful paraphrase. Make lower and slower your high-spoken pace, staying eye-to-eye closer, without an about-face.

Yes, confessing the good that I seek is mainly mine, may I vainly suggest now and then you speak in sign?

Sal’s newest book, Having a Bad Hear Day: Poetry and Verse for the Hearing Repaired, features both the serious and the playful sides of his hearing loss. Married for 40+ years, Sal and his wife Dolores live just outside of Rochester, NY and enjoy other people’s children, cats, baseball, opera, reading, and travel. He also performs readings and signings. For information about purchasing any of his books or scheduling a presentation, contact Sal at MarineBoot@frontiernet.net. His website is www.wordsandthensome.com.
President’s Message

By Kathy Schlueter

By the time you receive this ALDA News, we will have reached the quarter mark in my year serving as your President. Wow! Time has passed quickly. I’d like to share a little bit of what has been happening with your Board’s activities.

We’re like the worker bees, going out to gather our honey, which in reality is information about how we can help ALDA grow. Much to our enjoyment, we received word at the hive of interest in starting a new group in Arizona. We are proud to announce that ALDA-Sonora was chartered as an official ALDA group in January 2009 under the leadership of Cynthia Amerman. We encourage our members from Arizona to contact Cynthia and learn about ALDA-Sonora. Meanwhile, as Chapter Coordinator, I am working on gathering our current chapter/group renewals for 2009. But…we always have room for more, so if you are interested in learning how to start a chapter or group in your area, contact me.

The challenge of keeping our members informed of what is happening and what to expect in the future is being met head on. For example, electronic announcements are distributed to both members and nonmembers in our new eNews. Information about our upcoming annual ALDAcon is in this issue of ALDA News. We are also focusing on getting the word out about open Board positions for our November election.

We are all aware of the economy, and the added stress of making ends meet. The Board has taken this into consideration, as we are going “green” wherever possible, to help save money and our planet. This is why we are taking our official newsletter, ALDA News, to the next level and will have it available via electronic format. You can see the issues in color rather than black and white on the web! We will also be including the information previously contained in the ALDA Biz publication in a separate section of the ALDA News twice a year, to help save on printing and mailing costs. (Rest assured that you may still receive the ALDA News in paper form if that is your preference.) To further save on costs, notification of new or renewal status will be processed electronically if you provide your email address to us.

Our worker bees spare no effort to help ALDA grow, and they enjoy that work immensely! Won’t you consider being part of our colony? Get the buzz on how you can become a leader in your favorite organization; learn how you can serve! More information will be forthcoming.

Kathy
Navigating the Medical Arena as a Late–Deafened Person

By Rebecca Dufek

Since my bad experience without an accommodation when I had to make a life-altering medical decision, I always request CART (realtime captioning). I am completely deaf now and would be unable to understand a word without some form of written communication. When I’m making appointments, it’s apparent I’m deaf because I call via the relay service. However, I have encountered several offices that were completely clueless as to what I need or that just assumed a deaf person needs a sign language interpreter. Not all medical offices have provided accommodations for a late-deafened patient before. I have often been the first, and it has been a long process of trial and error to find the most efficient way to have my accommodation request honored.

Because my disorder is complex, I mostly see specialists who may be at a hospital or a small clinic. As with other public accommodations, the size of the clinic and number of employees determine whether they must meet ADA requirements. For the most part, the doctors I have seen were at a clinic that fell under ADA law. Yet, most optometry and ophthalmology clinics that may be affiliated with a hospital are actually privately run. For eye care, I had great difficulty finding a place willing to accommodate me, as they usually felt they were exempt. [Editor’s note: The overall financial resources of the clinic or private practitioner are the determining factor and are usually sufficient. Even if the cost of the accommodation exceeds what the patient pays for treatment, the ADA requires that the accommodation be provided. However, interpreting or CART does not have to be provided for routine procedures, such as blood pressure readings.]

Before learning all of this, I made an appointment with an optometrist without requesting CART because I urgently needed to be seen. Due to the onset of facial paralysis and a weakened eyelid, I had scratched my cornea and was in pain. There wasn’t sufficient time to wait to reserve a CART provider. I explained my dilemma of being deaf and insisted that someone type to me in the office or at the very least write to me. They agreed to provide an assistant to write notes, but she wasn’t qualified—she only wrote what SHE felt was important to share and easy to jot down. As a result, I only got bits and pieces of sentence fragments I had to decipher from her handwriting. I was disappointed and frustrated, but at least I was able to get my eyes taken care of.

Unfortunately, this set me up for not being accommodated in follow-up appointments. The doctor didn’t feel I needed CART, so my husband came with me. What a mistake! The whole time, the doctor would talk to my husband and not address me. So I had to just go along for the ride and later find out from my husband what was being discussed.

Bigger and more serious eye issues began to occur that required the expertise of an ophthalmologist. At first the ophthalmology office agreed to accommodate me with CART. However, they didn’t realize that they were responsible for paying for it. Once they found out the cost, they called and cancelled. (Many offices think it is the patient’s responsibility to pay for communication access or to bring an interpreter.) To make the situation even worse, this doctor sent me a certified letter saying he wanted to have an appointment with me to first evaluate my ability to understand him without an accommodation. Here I was in danger of losing my sight and this doctor was more concerned about how well I could understand him with no hearing!

My husband was very supportive in advocating for me and finding out the law. He spoke to the Office of Equal Opportunity, which provided us with the procedure for filing a complaint. That clinic had four locations within the Seattle area and did indeed fall under the ADA requirements. They offered to provide me with a free consultation with the doctor who didn’t believe I needed an accommodation, but at that point, I questioned whether this doctor could even provide the care I needed. Therefore, I just decided not to go back there.

After much searching, I found an ophthalmologist who didn’t fall under ADA requirements due to his small private clinic. However, he was a visiting doctor twice a month at the University of Washington Medical Center, where they would provide CART and have routinely done so for other patients. Finally, I was able to find a place to accommodate me for my special eye care visits. I was turned down by several private clinics, though. The hospitals are the way to go! [Editor’s note: as mentioned previously, the income of private clinics and private practitioners is usually sufficient to require them to provide ADA accommodations.]

I made sure to find doc-
I don’t really consider myself unlucky. Sure, I’ve had my share of tough times. Hasn’t everyone? But when I found my hand spewing blood all over my kitchen one day, I considered that my luck might have just run out.

Kenny (my hubby) had finally found a job he could excel in. As an employee for TSA (Transportation Security Administration) at the airport here in Grand Rapids, he found opportunity for advancement and a fulfilling sense of success. However, to begin the job, he would have to travel to Detroit and take a two-week class. This would leave me at home alone with the kids for that time. Although I was sad to see him go and nervous that I was on my own, I reassured him that I would be just fine and sent him on his way. We were new in the neighborhood, but I felt sure things would work out.

My newfound independence was thwarted, though, just a few hours later. As I was cleaning up the mess in the kitchen, I decided to conquer the brownie pan in the sink. Now, if you’ve ever made brownies and then let them sit for a day or two, you know how hard they can be to get out of the pan.

Try as I did to provide Herculean strength for this task, the chocolate treats would not budge. Finally, with a huge sigh and a determined hand, I forced the knife under the brownies to try to free them from the plate. But instead of dislodging the dessert, the knife jumped up and I stabbed my hand. Suddenly blood started shooting out in a pulsating fashion, completely covering the door, the counters, and even the ceiling! I was dumbfounded. I stared at the shooting blood for a few seconds before it occurred to me to get a rag and cover it up. This would definitely need stitches, I thought. But there was one problem. How do I get three small children into a van, drive to the ER and watch them, when I have a scene right out of “Helter Skelter” playing out?

Luckily, I did know one person who lived on the other side of the apartment complex. Carrie was deaf, too, and we’d gotten to know each other a little over the few months I was there. So with my hand wrapped in a towel, I headed over to her house, praying that she would be home. She was and agreed to come to my place and watch the kids while I drove to the hospital.

The emergency room wasn’t busy that day. Thank God for that! But there I was, in need of help, with no one to interpret and an acute inability to lipread even myself in the mirror. I had my pen and paper ready, though, so I felt pretty comfortable with the situation. Unfortunately, it seems that whenever I ask a person to write to me, all of a sudden they have surprisingly little to say. This held true for the workers in the ER as well.

The doctor asked me how I stabbed myself and I explained, with great fanfare, about the brownies, the blood splattered everywhere, and being alone with three kids. Basically, I told him my life story. He mumbled something to me. His assistant laughed. They both looked at me with great expectation. I hadn’t a clue what they were talking about.

“I don’t understand. Can you write?” Again, he mumbled and the assistant chuckled.

“I can’t read lips. What are you talking about?” For the third time they started laughing and talking to one another. I think they saw the frustration in my face, so the assistant picked up my pen and wrote what they had been saying over and over again…. “Did you bring the brownies?”

I learned two things from this experience that I would like to share with you.

1. Always carry pen and paper and make people write whether they want to or not.
2. Sharp knives and hard brownies do not go well together.

Michele J. Bornert was born partially deaf and became fully deaf as an adult. She teaches ASL through her company, Deaf Expressions. Michele lives in Grand Rapids, Michigan with her husband, Kenny, and three kids (Mollie, Jacob, and Natalie). She can be contacted at DeafExpressions05@gmail.com.
ALDA News

Volume 25, Issue 1

ALDAnonymous

By Bill Graham and Robin Titterington, Curators

Has the rapid expansion of online methods of communication—such as email, IM, internet shopping, VRS and VP—affected you in any way socially or psychologically when you are offline?

I have to say yes! I feel completely lost if I am experiencing technological problems! How is it that we tend not to be able to live without it when the older generation didn’t even have any of these things? When I am not near my computer or Blackberry I feel I am disconnect from my friends and family!

I can remember back 15 years ago, when there was only the TTY to use to exchange communication with other TTY users and to occasionally make a business call via relay. In today’s world, use of the PC for text messages, online discussion groups, Internet information, online shopping, responding to surveys, etc., has broadened my world. I’m a profoundly deaf person, and my computer keyboard links me to the world in a way that didn’t exist before. I feel lucky to be living in the 21st century with all its options for deaf persons, including sophisticated hearing aids and cochlear implants, as well as captioned TV and theaters. My social life has been expanded many times through information and contacts through email, and when offline, psychologically I feel far less isolated by my deafness than I did 20 years when none of this existed.

After becoming deaf, I started isolating myself big time. However, because of email and Internet sites like Facebook, I’ve been able to make and keep in touch with friends and family members. We don’t own a landline phone, so if I didn’t have my VP, I would have no way of contacting anyone in an emergency. Online life has served me quite well in many ways.

I think ALL the time of how lucky I am to have access to such technology. If I did not, I think the transition to deafness would have been much more difficult. I still know lots of people who do not use a computer or are just starting to get online! Nuts, eh?

The computer is my link to the world! I get cranky if the Internet is down. The power outage in 2006 was just horrible because we live rurally, and it took weeks for the cable company to reconnect us online. Instant messenger and Facebook have provided me with opportunities to forge and reunite relationships with people of all sorts all over the country and world! Having that strong social connection online has helped me to be confident when out in public settings.

If I did not have access to all this technology for communication, it could be quite lonely. Maybe I would have even been somewhat of a recluse and withdrawn. I would have been pretty lost and my acceptance of becoming deaf would have been a much harder process. Maybe I would never have reached being comfortable with my hearing loss and eventual deafness.

Next ALDAnonymous question: Families! We all have them, whether they are parents, significant others, children, or pets. Well, our next question does not involve pets, but tell us how your family has handled your hearing loss. Have they been supportive and helpful? Shown an interest in new communication modes? Lost all patience? Send your responses to aldanonymous@gmail.com by June 1.
Chapter Happenings

By Anne McLaughlin, Curator

ALDA-Chicago has elected the following officers for 2009: Marsha Kopp - president; John Garvey - vice president; Gary Price—secretary; Kris Worman—treasurer. ALDA-Chicago has a neighborhood group that meets from 10 a.m. to noon on the third Saturday of the month at Immaculate Conception Rectory, Elmhurst. The first hour is used to discuss hearing loss issues and the second hour is a sign language lesson taught by Camille Debevetz. CART realtime captioning is provided. Immaculate Conception is Camille’s parish. The pastor has a deaf brother, so he is very understanding and lets the group use his facilities free. There was a note about the group in the church bulletin recently, and two parishioners have joined. (Submitted by Marlene Thometz.)

ALDA-Suncoast has a good relationship with the local deaf service center (Deaf & Hearing Connection of Tampa Bay), which refers late-deafened people to the group, and the chapter’s website has been another effective outreach source. At the invitation of Communications Access, Inc. (a nonprofit organization promoting access to communication and counseling for Deaf, late-deafened, and hard of hearing people), ALDA-Suncoast’s president, Bill Reese, sat on a panel for veterans with hearing loss to tell them about ALDA. The chapter also joined Advocure (a nonprofit organization searching for a cure for NF2) at a community yard sale, providing outreach opportunities for both organizations. ALDA-Suncoast hopes to have an ALDA team participating in HLAA’s Walkathon in Gainesville. The chapter has a north Pinellas county dinner once a month to reach those a little further north than its monthly meeting place, and a south Pinellas County dinner will be starting soon to reach those a little more south. A few years ago, Lois Maroney helped establish a governor’s council for Deaf, late-deafened, and hard of hearing people in Florida. ALDA-Suncoast hopes to get this council changed to a commission with a mandate next year.

Please, chapter and group leaders, secretaries or scribes, send me information about what your chapter or group is doing by May 15 (my email address is maumsie@sbcglobal.net). We all learn from each other!

Our World—News from the International Committee

Submitted by Lauren for the IC

This column will be the first “Our World” article to summarize some of the topics that the International Committee talks about in its online IC meetings. We use a Yahoo group set up by the IC chair (Lauren Storck) and moderated by her and Kim Mettache. The moderation simply means that Lauren and Kim do the technical work to enter or remove committee members and keep the group moving along. It’s an open discussion, with all IC members encouraged to share news.

One of the topics the IC has been discussing is the potential new ALDA group forming in Asia. Muhammad Akram, who lives in Pakistan, has been working on this and talking with colleagues and friends in other Asian countries (e.g. Vietnam, Bangladesh, and Thailand) to put together the required five ALDA members to start a new group. It’s been enjoyable and educational to work with him on this, and the IC thanks him. When this new group forms, it will communicate via its own online forum.

Among the factors involved in recruiting new members of ALDA from overseas, and having them attend ALDacon, are visa issues and currency regulations in different countries. This is also under discussion among the IC members.

Linda Drattell, an IC member, is the sponsor of an ALDAn in Zambia. He is Mr. Agria Phiri of the Zambia National Association of the Hearing Impaired (ZNAHI), a large organization with three paid staff members. He keeps in touch with the IC annually, giving reports about what it is like to live with deafness in Zambia. We hope to share more with you about his country in the next IC column.

The IC invites all ALDAns to share their international and intercultural experiences, whether in the USA or abroad. Email Lauren Storck at drlestorck@gmail.com or Cynthia Amerman at bigred0822@aol.com.
One of Us

By Dave Litman, Curator

Ken lives in Pennsylvania and has had a hearing loss for most of his life. His hearing got progressively worse as he became older, and he started to learn ASL. Ken’s ASL skills are so good now that he teaches sign language to agencies that employ Deaf people or often have Deaf consumers. When he is not working, Ken enjoys time on the computer connecting with other deaf people on places like LDA Chat and Facebook. He is a strong advocate for deaf people of various backgrounds and we are fortunate to have him as “one of us.”

Name: Ken Mattos

Where were you born? Lubbock, Texas

What is your current residence? Rutledge, Pennsylvania

What is the cause of your deafness? It runs in my family, with a tendency towards becoming deafened in our adult years, usually preceded by a mild hearing loss in our youth. I was diagnosed with Meniere’s in 1985.

Age/year you became deafened? It was a slow process…well, relatively slow. When I was in grade school, my sister and I both had hearing tests, and when I did not respond, the testers invited my mother to help me with the test. Unfortunately, they found that my mother also had a hearing loss! Over the years my hearing slowly got worse, but I became a master of hiding it. However, the most serious threshold for me was around my 31st year.

Marital status? I have been divorced twice and have two children from each marriage. Both of my sons only have minimal hearing loss, while my daughters have shown more fluctuation with their hearing. One daughter is married with two kids; both of whom are hard of hearing.

What is your present job? I am on disability for a few health reasons. I do teach American Sign Language adult and workplace classes on a part-time and contractual basis. I also have experience working with students with disabilities in college.

What is the worst job you ever had? My worst job was as a janitor. It is not that the job was bad but that the boss was difficult and the county had a habit of firing people before they passed their probation period. I did not make it past six months!

Movies you want to see again? Hard to say. I do not tend to watch movies a second time. I like a variety of films.

Books you tell others to read? It has been a long time since I have recommended a book, but I recently read Persepolis. I recommend it, but not for anyone younger than 13.

I stay home to watch: many favorites, including Monk, Psych, Chuck, Heroes, Ghost Whisperer, Numbers, E.R., Kyle XY, Fringe, and Cold Case. I have recently been discovering some police shows.

Favorite pig-out food: Baked potatoes, mashed potatoes.

Hobbies: I am not really into traditional hobbies. My passions are education, politics, and diversity.

If I had more free time, I’d: go to parks. I like natural settings. I presently live in suburbia.

The hardest things about becoming deafened: Not hearing the voices of my children and not hearing music. Not being able to understand dialogue from movies without reading captions. I like stage theatre, but that is pretty much inaccessible now.

I began accepting my deafness: while learning ASL and becoming involved in the communities of interpreters and Deaf people in Seattle.

The worst thing about deafness is: that most people do not understand it.

The best thing about deafness is: all the new connections that have opened for me.

In what ways has deafness enhanced your life? It has given me many new friends and a wider, stronger community. I have positive connections with many in the Deaf community, but our experience of acquired deafness and having grown up in the hearing world is unique.

How did you learn about ALDA? From my dear friend Nick Hutto in Seattle.

What has your involvement with LDA Chat been like for you? A few years ago, Ken Arcia solicited my help with welcoming new members to this group. Over time, my role expanded to the point where I have become a moderator. I have a good deal of patience with people and enjoy the camaraderie of the group. I am also an advocate of the idea that “one size does not fit all” and enjoy the various

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Deafness and My Life

By Harriet Frankel

How has being deaf affected my life? The truth is, not too much, because I now live alone. I have no one to talk to over breakfast, lunch, or dinner. Oh, I have a lovely woman who lives in my terrace apartment, but she has been here for about 13 years and I was very hard of hearing at that time.

Has being deaf made a difference with my friends? Actually I don’t have many friends left, and at this stage in my life I find it pretty hard to make new friends. I don’t go many places on a regular basis to be involved with people, and that is how you meet and make new friends. I have lovely neighbors, all young men. They carry my groceries for me and are very protective towards me. I can always read their lips…”How are you, Harriet? It’s lovely day…” etc., etc. Sometimes we talk about taxes or neighborhood events. As long as I know what the subject is, like my dog messing up on their lawn, I can read their lips. Our relationship hasn’t changed a bit since I became totally deaf.

I have no intention of learning to sign. Who am I going to sign with? Our ALDA-Peach group is lovely, but we only meet once a month, we live miles apart, and with gas at $4 a gallon, I won’t be visiting them often even if they do sign among themselves.

I’m not embarrassed to say that I am deaf—it’s better than having people think I’m stupid. I always carry paper and pen when I go to the grocery store, the bank, the doctor, or the hairdresser. I still want to look as good as possible, deaf or not.

I email my daughter in New York, use my relay phone to talk to my only sister, and use captioning on my TV. If I play bridge, they have bidding boxes, so I don’t have to hear the bids. All in all, after having been hard of hearing for years and years, being totally deaf has only kept me from casual conversations and group dinners in dark places or parties with lots of people.

I haven’t changed my life very much as a deaf person. The biggest change is that I’ve never been this old before, and it takes a lot of getting used to being 91.

Harriet lives in Atlanta, Georgia, belongs to ALDA-Peach, and has had a hearing loss since early childhood. She was a commercial artist and later had her own advertising and marketing agency. When her hearing deteriorated, she received a cochlear implant that was unsuccessful due to previous ear operations. Harriet plans to write her autobiography to help others with hearing loss.
Obtaining Effective Communication in Medical Settings

By Brenda Estes

Several years ago, I had several health crises that could have been averted if only my doctor and his staff had made the effort to utilize effective communication.

In the summer of 2000, I moved back home to my old stomping grounds and had to look for new doctors, dentists, etc. For a late-deafened adult, this is no easy task. Family and friends were eager to recommend their doctors, then became puzzled when I started asking questions like: Is he/she easy to lipread? Does he have any facial hair like a mustache or beard? Does he/she have an accent? Most of their answers were along the lines of “Gee, I never thought about those things before, let me think a second…” I would slowly see their facial expressions change as they recognized why I was asking these questions. Without realizing it over the years, they themselves—not all but some—learned ways of communicating with me.

In October 2006, on the day before leaving for ALDAcon, I went for my annual physical examination, and as the nurse was taking my vitals and asking me routine questions, she mentioned that my lab work from July showed an abnormality and the doctor would discuss it with me. I immediately asked her why the office didn’t contact me by TTY or mail, and her response was, “We did call you once and couldn’t leave a message because you didn’t have an answering machine.” By the time I got into the examining room and the doctor came in, I was pretty upset. I became even more so when my doctor told me that communicating with me was challenging due to my hearing loss. To say I was floored is putting it mildly. I reminded him that in the past six years, when his staff couldn’t reach me at home, they would call me at work or send me a postcard asking me to contact them.

Over the course of the next six weeks, things went downhill pretty rapidly. Referrals to specialists were handled by my doctor’s office staff, which refused to write down the specialist information for me so I could call and set up the appointments myself. The reason they gave me was that they preferred to set everything up themselves. To pacify me, they accepted my offer to show them, again, how to use the relay service. Then they rolled their eyes and didn’t take notes.

The following month, I received a notice in the mail from a local hospital telling me to schedule a breast ultrasound, as my mammogram showed a suspicious mass. I called my doctor’s office to let them know that I had gotten this notice and asked if they knew about it, and they did. The doctor said, “Oh it’s just a little mass,” and he was going to talk to me about it the following week when I came in for an appointment. Needless to say, I called the hospital radiology department to set up the ultrasound myself.

By December, I decide enough was enough—I was taking back control of my health. I contacted my OB-GYN nurse practitioner for a recommendation to another internist. I’ve always been very independent, but I felt the need for moral support and asked my aunt if she would go with me to see the new doctor. So for the next two months, she went with me to all my medical appointments.

For 20 years, when seeing new doctors, I’ve educated them up front about my communication needs and asked them to let me know right then and there whether they are willing to utilize effective communication with me. If not, then I’ll find a doctor who will. For the past two years, communication access with the new doctors and their staff has been absolutely wonderful! Everyone looks at me when talking and utilizes pen/paper if needed, especially when it comes to important information, to make sure there is no miscommunication. Both doctors send me copies of all lab work (something that none of my other doctors have ever done), along with written notes to let me know if my medications need to be changed and/or if there are any further instructions. If they need to contact me, they call me through the relay service, and if I’m out of the office, they have my aunt’s home and cell phone numbers. I travel a lot and my aunt can always reach me by email on my Blackberry.

You are your own best advocate. Arm yourself with information about your ADA rights. Be assertive—don’t settle because you don’t want to create waves. You have the same right as everyone else when it comes to communication access.

Brenda Estes became hard of hearing at age six due to measles. In 1998, at age 33, she had meningitis, which led to bilateral profound hearing loss and Meniere’s disease. Her ENT recommended ALDA and SHHH (now known as HLAA), and she has been active in both ever since. In 2000, she became the deaf and hard of hearing outreach coordinator at the Endependence Center in Norfolk, Virginia. Brenda enjoys traveling and spending time with her two grandchildren. She can be reached at bestes_outreach@yahoo.com.
Navigating the Medical Arena as a Late–Deafened Person (continued)...


tors who were at bigger facilities where providing accommodations is more standard. Some of these hospitals even have their own interpreter services department with a list of CART providers they contract to. The particular clinic only has to give the date and time of the appointment and interpreter services will find someone to fill the appointment slot.

Even if there is such a service available, it’s important for the late-deafened person to clarify the accommodation needed. I have often had to explain the difference between a CART realtime captioning provider and a sign language interpreter. While interpreter services may understand the difference, things can get confused if a receptionist incorrectly reports that an “interpreter” needs to be scheduled. Fortunately, I have never had this mistake happen because I am so adamant about explaining the difference due to a bad experience while job hunting (an interpreter showed up instead of a CART provider when I had only taken two ASL classes!). Just make sure that the receptionist is repeating back to you that you need a CART realtime captioning provider.

Another situation I have encountered is offices that have no idea how to find a CART provider. Luckily, I have a good list of CART providers in the area with whom I worked while in graduate school. I fax their names, contact information, and general availability to the doctor’s office when I need to make an appointment. I also inform the clinic that the CART provider must be scheduled as soon as possible because they often quickly get reserved for other jobs. At least two weeks’ notice is typical, but at times someone has been available with only a week’s notice.

Once the appointment has been made, I send an email to my group of CART providers, letting them know the date. If the doctor’s office tells me that nobody was available, I send an email to the CART providers asking whether they had been contacted. In the past, I had office assistants tell me they couldn’t get anyone when in fact nobody had been contacted. It is a good idea to follow up, as the office could get busy and forget. I ask clinic offices to leave me a relay message or email me to confirm that a CART provider has been scheduled.

In addition to having offices include the list of CART providers in my file, I also have them note that I am a late-deafened patient who must be emailed or contacted through the relay service. In the beginning, people didn’t want to leave me a message via relay, so they called my husband’s cell phone, which is listed as my emergency contact. He was not happy about it and told them it was inappropriate. Thus, I also clarify that communication must come to me through either relay or email, and my husband is to be contacted only in a real emergency. At first some receptionists resisted, but once they learned that email is the best way to get ahold of me, they complied. I have the email addresses of all my doctors and my dentist, who are pretty good about getting back to me, as are their office assistants.

I don’t get CART for all appointments, such as when I’m just going for a test or procedure. When I get an MRI, I am in a tube the entire time, so I normally bring a pad and paper and have the technicians write to me if there is anything I need to know. In the dental office, I am lying back in a chair nearly the entire time, so the staff and I have come up with some simple hand signals to indicate when I should open and close my mouth, and the other times they are great about writing everything to me.

On occasion, I have had a CART provider cancel on short notice or there was a mistake in scheduling. I either was not charged for the appointment or the doctor was good about writing or typing everything out.
considered a luxury. A while ago, a Swedish friend
told me about the loop, FM system, etc., but I neither
understood nor knew what they were until I attended
the World Congress in Canada last July. I was sorry I
could not try them!

In Vietnam, hearing aids are supplied by a few
companies, including Siemens, which is the most fa-
mous. Vietnamese people with hearing impairments
are shy and hesitant to wear hearing aids. Besides, due
to the humid and hot climate in Vietnam, hearing aids
often stop working and must be maintained regularly, so
people with hearing aids do not like to wear them much.

Sign language interpreters in Vietnam are usu-
ally either teachers in schools for the Deaf or hearing
Catholics who help Deaf people in churches. There
are no schools training sign language interpreters in
Vietnam; therefore, many interpreters are not profes-
sionals. They study sign language by themselves or with
Deaf people, and help people with hearing impairments
out of the kindness of their hearts.

Children with hearing loss are trained to speak and
to understand speech by lipreading. If people with hear-
ing impairments and their families can manage alone in
the medical environment, all is well. However, in case of
a serious health concern, the family must find an inter-
preter by themselves, and they usually choose a teacher
with good sign language knowledge who has taught
their children.

There are about 3,550 persons with hearing impair-
ments in Ho Chi Minh City, the biggest city in Vietnam,
but the number of persons who can sign well enough for
interpreting is fewer than 20, which is lower than the
number of hospitals or lawyers’ offices and courts in Ho
Chi Minh City. People with hearing impairments there-
fore find it very difficult to gain sign language inter-
preters’ help. Why don’t more doctors, nurses, and caregiv-
ers study sign language?

Customers are considered “kings” in certain places,
but this is not the case for people with hearing impair-
ments in the Vietnamese medical environment! They are
denied the right to be listened to and to express their
views. How is it in your country?

Duong Phuong Hanh is a social worker and
president of the Ho Chi Minh City Deaf Association
(HDA) in Vietnam.

for me. My internist is as competent a typist as he is a
wonderful doctor! Even when I’ve had to see him in an
emergency, I’ve never had to worry about the communi-
cation.

The terminology that relates to my condition and
care is pretty specific. CART providers maintain a dic-
tionary, so before important medical appointments, I find
out who the CART provider will be and email a list of
the terms that will most likely be used. The provider then
enters the words into his or her dictionary before my ap-
pointment. If I have the same CART provider for another
appointment, I don’t need to submit the words again
because they will still be in the provider’s dictionary.

I have transferred my specialty care to Oregon
Health and Science University in Portland, Oregon. This
is where I had brain surgery a little over a year ago. One
of the reasons I chose this facility and my surgeon is be-
cause of how easy the communication is and how adept
they are with addressing a late-deafened patient. At least
two other patients like me also go there, but one is more
comfortable using an interpreter. It took me several years
to find the right fit, but it was well worth the effort.

Rebecca has been living with progressive hearing
loss for 11 years, but it wasn’t until 1999 that she was
diagnosed with Neurofibromatosis Type 2 (NF2). The
most common symptom is hearing loss due to tumors
that grow on the auditory nerves. Rebecca became com-
pletely deaf at 32. Between her diagnosis and becoming
deaf, she had encounters with at least 12 doctors. In the
4-1/2 years since she became deaf, she has seen or cor-
responded with at least 25 doctors (mostly specialists)
on the West Coast and countless medical professionals
ranging from office staff and nurses to physical thera-
pists. Rebecca resides with her husband and two dogs in
Redmond, Washington, outside of Seattle. To learn more
about how she manages to survive NF2 and deafness,
visit her blog, the “NF2 Odyssey,” at www.diverbeck.
blogspot.com.

NOT A MEMBER?

Join online at www.alda.org

Or

Use the form in this issue of ALDA News
Are Communication Needs Falling on Deaf Ears?

By Sharon Milian

Editor’s note: This article was originally written for Nursing Spectrum to inform nurses about how to communicate with patients with hearing loss; it has been slightly modified.

Mr. Davis* has just been admitted to Nurse Nancy’s unit with a draining foot wound. The doctor has ordered that the patient be taught to perform his own complex dressing changes. There is just one problem: although lucid, Mr. D is very hard of hearing. When Nancy tries to explain the procedure, she realizes he is not singing in the same key.

What next? Call a family member? Try to get an interpreter? Write the instructions down? Whatever she decides, she must find a way to get the instructions across, or she may be setting herself up for a lawsuit. According to the Americans with Disabilities Act, health care workers are obligated to provide communication assistance. Not only that, but a family member is not considered an adequate medical interpreter.

Nearly a third of the population over age 65 has a hearing loss, according to the US demographics fact sheet from Gallaudet University. Given the number of Florida’s elderly, especially on the West Coast, the problem is intensified. The US Census Bureau estimates put the total Florida deaf and hard of hearing population at a whopping one million people.

Since the US Health Care Financing Administration (HCFA) began requesting input from a panel of researchers from Delmarva Foundation for Medical Care in March 2000, many hospitals have begun writing policies to cover themselves when a patient is admitted who needs communication assistance. Others, however, are still out of tune.

An article in the May 2000 American Medical News tells of an elderly man admitted with a cardiac arrhythmia after failing to change his medication dose. The man, it seemed, had misunderstood instructions due to his hearing loss. Further, a nurse told a patient in labor to remove her hearing aids, leaving her unable to understand the masked staff. In another incident, a deaf patient’s family sued a Florida hospital after a woman died from complications of thrombophlebitis. The family stated that the woman was denied communication assistance.

Medical staff may find that it is more difficult, expensive, and time-consuming to hire an interpreter, to speak slowly and distinctly, or to write instructions down. Yet these measures are required by law. Many facilities, however, are not providing them. Members of the Association of Late-Deafened Adults (ALDA) in St. Petersburg know this only too well.

Tess, a late-deafened RN, said that she has often had problems with healthcare workers. “When my daughter (age 11) got sick with Bell’s palsy,” she says, “I took her to the doctor and asked for a nurse while the doctor was in there, so the nurse could write what he had said. I know the doctor won’t write because it will take too much of his time,” she laments. “We saw the doctor twice, and I requested a nurse on both visits, but got nothing. I just kind of asked my daughter what the doctor had said. I was disappointed because I wanted to know what was happening. For those 10 minutes, I had to pay him $60, and I didn’t even get information through any of the staff, only from what my daughter had told me.”

Stories like this one abound. Hard of hearing parents are forced to rely on minor children or elderly spouses to interpret, when they may know little or nothing about medical procedures and may be sick as well. While some ALDA members said that their health care providers are quite patient and do make an attempt to be understood, too many said that they used family members as interpreters, or that they had to demand assistance several times before getting it.

It is the health care staff’s responsibility to know a facility’s policy and be prepared to provide services as soon as the patient is admitted or comes into the doctor’s office. Morton Plant, a major Clearwater-based hospital, has been enforcing such a policy. It states, “Patients who are deaf or hearing impaired shall be provided assistance appropriate to the individual communication techniques.” Admitting nurses must assess the extent of the hearing loss, and whether the patient relies on sign language, writing, speechreading, or family members to communicate. If necessary, a sign language interpreter, closed captioning, written notes, and a TTY phone must be provided. But the majority of late-deafened elderly people do not understand American Sign Language, which is now the third most widely used language in the United States. [Editor’s note: Hospitals are also legally required to provide other forms of effective communication, including CART and assistive listening devices.]

Lora Hall, RN, BSN, Countryside ER manager,
Are Communication Needs Falling on Deaf Ears? (continued)...

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deals with a large Deaf population. “There is an assisted living facility for the Deaf near the hospital, and we provide a lot of services for them,” says Hall. “We have some people who bring in children who are not Deaf, but the parents are. We think it is important that we can communicate with the guardian. Often they are more frightened than the child. In the past, we have based it on the patient’s ability; whether they can read or write, and lip read. We depend on family, but we try to always have an interpreter available when the physician is making an assessment.”

Shands Hospital at the University of Florida in Gainesville also has a written policy about providing communication for its deaf and hard of hearing patients. “It is our practice whenever we get hard of hearing patients that we generally get the service of an interpreter to help with the care,” says Beth Smith, patient representative, coordinator of the department of patient and family resources. “We don’t have an interpreter on staff, but we use an outside agency that provides them. We get one as quickly as we can. There is a policy where it is written.” [Editor’s note: Hard of hearing needs are often confused with Deaf needs; few hard of hearing people know sign language, which is primarily used by culturally Deaf people and some late-deafened people.]

A doctor may be reluctant to pay $30 or more an hour—not reimbursed by insurance companies—to hire an interpreter. Some doctors are scheduling “Deaf Days” so that all of their Deaf patients can be seen while the interpreter is in the office.

A hospital is required by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to provide its clients with communication assistance. “In standard RI 136,” says Walter Diggs, field representative for JCAHO, “it reads, ‘the hospital demonstrates respect for the patient’s needs in communication.’” And at a policy forum on patient safety in fall of 1999, the JCAHO, along with the American Medical Association, held an invitational policy forum on patient safety in Washington, DC. There it was stressed that many patients needed better communication and more adequate education.

As a result of the public outcry from the Deaf community, the HCFA asked a panel of experts from Gallaudet University and Delmarva, a health care watchdog group, to develop standards that would apply across all health care settings. Delmarva documentation stated that there was a “crisis” involving the gap in health care standards for the Deaf. Recommendations were presented to HCFA in 2001. The panel attempted to discover whether Deaf and hard of hearing patients were receiving lower quality care and whether they were more difficult for physicians to treat. Among the panel’s recommendations were requirements that health care staff be awarded CEUs [continuing education units] for coursework in sign language or other work with Deaf people.

Student nurses and physicians can choose sign language as a required foreign language course in most of Florida’s colleges. Those who are already practicing can contact their local deaf service center for available courses. But while some nursing schools may emphasize communication with the Deaf, Marie Taylor, program assistant at University of South Florida’s College of Nursing, office of student affairs, says that in her college’s nursing program, there is not much focus on it. “As far as I know there isn’t anything being taught about communication for the hearing impaired,” says Taylor. “But to fill the foreign language requirements at USF, they can use sign language.” [Editor’s note: The term “hearing impaired” is disliked by many people, and only a small proportion of this population knows sign language.]

Dr. Parks, the nursing program director at St. Petersburg College, says, “We don’t have any foreign language requirements in the program because it is usually part of a baccalaureate in nursing. However, at this institution, sign language is one of the offerings, and any of our students could take it.”

Rose Smitty, RN, Director of Nursing at Crystal Oaks Nursing Home for the Hearing and Visually Impaired in Pinellas Park, knows basic sign. “We have an interpreter who works here five days a week when we need her,” says Smitty, “and have some nurses who know sign. Some of the residents know it and some do not. Some are severely impaired. We don’t have problems with it.”

Facilities that rely on non-professional interpreters, such as a friend or family member, sacrifice confidentiality. One Tampa hospital worker, who asked not to be named, said that she is frequently called upon to leave her post and interpret for hard of hearing patients. “In one instance,” she says, “the lady didn’t know sign at all, so finally the nurse figured out she could read and proceeded to write notes, so I left them.” [Editor’s note: As mentioned previously, facilities are legally required to provide qualified professional interpreters for patients with hearing loss who use sign language and other forms of effective communication for those who don’t.]

As one of the leaders in communication assistance, Jackson Memorial Hospital in Miami has a policy to provide for any kind of interpreter service, whether it is
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foreign language or sign. With its network of interpreters, including a full Deaf program directed by Tammy Martin at the mental health center, they are able to make arrangements at any time of day or night, including holidays. “The agency we contract with is very much in demand for it services,” says Sonia Martinez, assistant administrator of interpreter services, “as it provides not only to Jackson Health System but to all of Dade County. Sometimes there are delays, but the agency does do its best to provide the service as promptly as possible.”

How can nurses be prepared in the event that they are asked to care for a Deaf or hard of hearing patient? First, be familiar with the facility’s policy. Ask the patient or his family if he needs assistance. If he does, find out the best method of communication for him. Assess his ability to read and comprehend as well as his knowledge of sign language, his level of social support, and his ability to speechread. Make sure the patient’s room is well lighted and that he is not distracted by pain or confusion. Note the patient’s comprehension of instructions in the nurse’s notes.

And perhaps most importantly, read the Americans with Disabilities Act, which went into effect in 1992. If your facility is not enforcing it, then it’s time to lend an ear or face the music.

* Name changed

Sharon Milian, RN, C, is a certified gerontological nurse and freelance journalist. She lives in Palm Harbor, Florida and has had a profound hearing loss since the 1990s. She joined ALDA in 2000 and currently works in Tampa, scoring standardized tests.

Green can mean many things.
The grass is greener on the other side.
I am green with envy.
The person has a green thumb.
The entertainer is in the green room.

However, in today’s world the most common use of green is in regard to the environment. One person said, “Going green can mean any number of little steps that you can take to reduce the harm that your living does to the environment.” ALDA supports this idea and needs your help to make it happen. One of the best ways you can help ALDA and the environment “go green” is by switching the way you receive your ALDA News. Did you know that dozens of people are already receiving their ALDA News electronically? This will not only help to save the environment but will also enable ALDA use its resources to better serve our membership. The money ALDA saves by distributing electronically rather than in print will help strengthen our advocacy voice, ensure that our ALDAcon is the best it can be, and support our efforts to broaden ALDA’s outreach. But wait—there is more!

The electronic ALDA News will have an advantage that the paper copy doesn’t have. Are you tired of seeing all the pictures in black and white? The electronic newsletter will bring them to you in living color!

As a one-time special to encourage our members to go green, ALDA is holding a drawing. Every member who signs up to receive the ALDA News electronically by May 15, 2009 will have the opportunity to win a one-year free membership to ALDA (maximum value $25). If you have already chosen the electronic edition, do not worry—your name is automatically registered for the drawing.

To start receiving your newsletter electronically, send an email to our president, Kathy Schlueter, at katherine.schlueter@gmail.com. In the subject heading, please type “Electronic ALDA News.”

Sending the newsletter electronically is a new step for ALDA. We look forward to your feedback and comments about ways we can enhance the ALDA News.

One last thought: if you received this blurb electronically, you would notice that every time the word “green” appeared, it was in the color green!

Sincerely,
The ALDA Board
I lost my hearing at the age of 17 as the result of side effects of ototoxic medications used to treat a rare, life-threatening illness called toxic shock syndrome. In essence, I went into the hospital and 2 1/2 weeks later, I woke up with a permanent and profound hearing loss. I’m glad I survived this ordeal. I got to fall in love, find a career, and become a parent.

My husband and I met in 1982 up at Fresno Dome campground, located in the high Sierras. We’ve been blissfully married for 17-1/2 years. Together, we have one 10-year-old, golden-haired son named Paul. We got a late start in the baby-making business. We were together for almost 14 years before we began to settle and make our family. Because of our late start, we have had to accept that our family would be a small one, kind of like the Three Bears—cozy and loving. We give great thanks for the blessing of our only child, Paul.

At a baby shower before Paul was born, I was given a regular baby monitor that had red lights that lit up when the baby cried. I moved this monitor around the house with me when the Paul was sleeping and looked at it frequently. But this baby monitor would pick up all kinds of sounds in the house and light up all the time. I could be starting the dishwasher and the lights on the monitor would go on because it would pick up that environmental sound. It wasn’t necessarily the baby crying. As a result, I was kept on my toes checking on my sleeping son quite often.

I decided that I needed some input from my deaf colleagues who were also parents to see how they dealt with this issue. After talking with them, I discovered there were assistive devices available that would help, and soon I purchased a plethora of equipment that put our minds at ease. Among the devices was a signal alert component with a flashing light and vibrating monitor that would alert me specifically to our baby’s cries. These devices worked much better and helped me work around my hearing disability as a new mother.

Still, I felt most at ease when the baby was near me. At night, our son slept with us. We shared a family bed for the first few years of his life. As a result, we all became in sync with each other’s sleeping rhythms, and believe it or not, we all slept better. I became ultra-sensitive to movement and would be able to respond more rapidly to our son’s needs this way. Having a husband with normal hearing also reassured me that our baby’s cries would be heard and responded to. However, even though I had my husband’s support and the assistive devices, I pretty much kept the baby near me wherever I was. My eyes became hyper-vigilant and my sense of touch grew more sensitive to vibrations and movement. These senses compensated for the lack of hearing.

I learned how to tell the difference between my son’s cries by watching his face and feeling his chest. I learned to distinguish the needs behind these sounds by looking for clues. My eyes and sense of touch began to differentiate my son’s cries and sounds by watching for the accompanying event, body language, or facial expressions that went along with them. Ironically, because of my hearing loss, I became an extra-attentive and responsive parent—not less aware, but more. I also think every mother or father of a newborn has an instinctual “inner knowing” when their baby is trying to communicate its needs. This goes beyond disability.

When my son began to sleep more in his own bed, my husband took over a lot of the night-time parenting. He, more so than I, would go to our son when he woke in the night or had a nightmare, or when he was up trying to find the bathroom half asleep. I had to learn to let it be okay for my husband to tend to our child, as it sometimes went against my natural instinct. That didn’t make me a bad mom. My husband’s night-time parenting has been wonderful because he and our son have built a trusting and responsive relationship this way as a result. They have become very much in sync with the rhythms of the night, and I sometimes get to sleep in peacefully, which is a nice perk. I do feel when my husband rises from our bed, though, and I usually lie awake until he returns. Occasionally, I get up to see what’s going on, only to discover that my husband has already taken care of things and my son is tucked back into bed. Our family has great trust in one another.

When my son wants me specifically to tend to his night-time needs, rather than calling out for me, he will come to my bed and tap my arm to wake me. He will motion to me to follow him. Then when we get back to his room, I turn on his dim bed lamp that allows me to read his lips without blinding us by bright light. Then, when I’m already there,
he will tell me, “Mama, come to my bed. I’m having a nightmare.” I will help him turn his pillow over to empty out the bad dream and then tuck him safely back in bed with kisses and hugs. This is how it works for us.

I began exposing Paul to sign language when he was a baby. He was using signs before he was talking. I continue to use my voice and sign to him, but Paul still prefers to speak rather than sign. I have not forced him to use sign language, though I do encourage him to use his signs or fingerspelling when I am unable to lipread him. It is my hope that one day he will want to use signs and voice more often with me. To his credit, Paul has become an articulate speaker, which I am most grateful for. He knows he needs to look at me when he speaks so that I can read his lips. He has learned to be patient and repeat things for me when I am unable to follow. We laugh a lot at the funny things I think people are saying. Humor helps us all cope with my hearing loss. Sometimes, Paul will ask my husband to interpret for him, as my husband uses signs and voice with me as well. Eye contact has become an important communication rule in our family. By habit, my husband and son also speak clearly and slowly while looking right at other people when they speak, whether the people are deaf or not. Giving eye contact has just become a natural part of our lives.

Individuals with disabilities have been successfully parenting for ages, and the majority of us have done so without adaptive baby care equipment or professional guidance. Having a disability does not prevent a person from becoming a parent. Nor does it mean that our parenting will be deficient or not up to standards. Parents with disabilities should take heart. We, as well as our spouses and children, learn quickly how to build on our personal and family strengths. We, as well as our spouses and children, learn to adapt.

For example, when my son was in his crawling stage, if my back was turned and I could not hear him, he would stop crying, crawl or scoot over to me until he was in my view, and then, once I could see him, he would begin to emote as he was doing just a moment before. Hearing children with deaf parents learn to adapt.

When my son was about 18 months old, he came toddling into the living room where I was folding some clothes. He tugged on my pants leg and began toddling toward the kitchen. I didn’t think much of it until he came back. He was trying to say something to me, but I couldn’t read his lips yet or understand his gibberish. I picked up on the fact that he wanted me to follow him, so I did. He led me into the kitchen and then pointed his finger up at the sink. I looked up and saw that I had left the water running! He was already alerting me to the environmental sounds around our home that I could not hear! I found that remarkable. Today, Paul will still alert me to the microwave ding, the oven timer, the doorbell, or the phone, regardless of the fact that I have visual alert systems in place for these environmental sounds. He has just taken it upon himself to help keep me connected to my world. It’s pretty wonderful.

Life as a deaf parent is not without its scary moments. One came when my son was just three. We were living in a small cottage isolated on a mountainside in the hills of Fairfax, north of San Francisco. Our cottage was so small that we had to share a bedroom with Paul downstairs. I had just put him down in his own bed for his nap and crawled into my bed nearby to catch a few winks as well. We had done this before. I would close my eyes for about 20 minutes after Paul had fallen asleep. I would always wake before he did, and if by chance he woke first, he would come right to me and wake me up. I practically slept with one eye open during those early years, anyway.

Well, I guess Paul woke up before I did. He might have looked over at my bed, but he didn’t see me. I must have been buried under the covers. So he got up to look for me. Then something woke me up with a start. It happens to all parents. We suddenly know something is not right and we need to check on our children. I popped up in my bed and noticed that Paul’s bed was empty. I shot up the stairs calling out to him. I looked everywhere in our cottage, but Paul wasn’t there! Then I saw the front door open and rushed outside, calling out his name in hopes that he would hear me and come to me. I was frantic with worry!

Then suddenly, I saw the little old lady who lived across the street from us come down her tall driveway on the hill. She seemed to be looking at something in front of our cottage. It was Paul. I could not see him as the fence was too tall, but I knew she must be looking at him. There I found him standing in the middle of the mountain road crying out, “Maaammmaaaa! Maaammmaaaa!” My heart just about stopped! I hurried over to him, reassuring him that I was there. I scooped him up out of the road and rushed him inside, waving to the lady across the street who stood with her arms folded across her apron. Little did she know that she was a guardian angel that day. (I believe I have been given a number of guardian angels.

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as a deaf mom.)

I rarely left Paul out of my sight from then on. Call me overprotective if you will, but my child stayed safe after that! A friend of mine at work helped me deal with my guilt by telling me a story of a time when she put all the baby’s things in her car—the diaper bag, the bottles, the blanket, and the car seat—and drove off to take him to day care, only to discover that she left the baby at home! Eek! She isn’t a parent with a disability. She just goofed. She assured me that we all make mistakes big and small, and that it doesn’t always have to do with disability. In a strange way, her story did console me.

There are inspirational moments as well. I remember one involving my son and his deep awareness of my hearing loss. We were once sitting together as a family watching the Riverdance program on PBS. I loved watching the Irish dancers and could follow the rhythm by looking at their feet. Then a woman played a Celtic melody on a wooden flute while two dancers shuffled lightly about her. My husband made a comment about how beautiful and mesmerizing the flute music was, and how he wished I could hear it. My son, who was about seven then, was sitting next to me. From the corner of my eye, I saw him look up at me a few times and then back to the TV. Then slowly, he raised his hand to his own ears and stuck his fingers in them and looked at the TV. I turned to him and asked him what he was doing. With eyes full of compassion he said, “Mama, if you can’t hear it, I don’t want to hear it either.”

My heart swelled. I told him, “Oh honey, it’s okay. Mama listens to things differently. I see the lady’s fingers on the flute holes. I watch her breath as she puffs out the notes. I can see the rhythm of the dancers’ feet. And more importantly, I see the look on yours and Papa’s faces when the lady plays her flute. That’s how I know it is a beautiful, breathtaking song. I want you to be my ears. I will listen to the music through you and Papa.” Paul’s eyes were full of wonder. He lifted my hair and kissed one of my ears, and then turned back to the TV while I snuggled him up close. I continued to watch the program with tears in my eyes.

The best thing about being a mom is looking into my son’s eyes and discovering God looking right back at me. Heaven on earth is watching my child laugh, cry, play, learn, and grow. In many ways, my son is my church. I learn and relearn and grow from every encounter I have with him. I am reminded daily of what a blessing it is to be a parent, and my heart is full.

As children with deaf parents grow, they begin to distinguish the difference between their parents and those of their friends. They recognize that one parent uses sign language to communicate and another doesn’t. They become aware when one mom responds and another doesn’t. If I had hidden my hearing loss from others, my son might feel embarrassed that his mom was deaf. But I have embraced my deafness, learning everything I could about what it means to be deaf. I have actively taught people what they need to do to communicate successfully with me.

I have helped my son accept my hearing loss by sharing my story with our neighbors, his teachers, his friends, and their parents. I began teaching all the kids in the neighborhood some sign language and made it a cool skill to have. I went into Paul’s classes and taught his classmates how to sign songs and how to communicate with deaf people. One year, I lead Paul and his third grade class in a signed performance for the school’s multicultural festival, with Paul at the microphone introducing his mom’s unique language of signs. Because I embraced my deafness and made it hip to learn how to sign, Paul’s friends were able to accept my hearing loss, rather than tease or make fun of him because his mom could not hear. We have a healthy view of deafness and the use of sign language in our home, in our neighborhood, and at Paul’s school.

My profound hearing loss is not a barrier to my parenting skills. Rather, it has made me a more attentive and responsive parent. I parent with a different-ability, not a disability. It’s all about attitude. Sometimes we need to educate those around us and help them understand that we are much more than just a broken body part. Good parenting comes from a deeper place within. It comes from showing our children unconditional love. I listen and parent with the ear of my heart.

LaRonda Zupp is the program manager for client support services at the Deaf Counseling, Advocacy & Referral Agency (DCARA) in the San Francisco Bay Area. She holds a B.A. in Deaf studies, a master’s in counseling, and certificates in parent education, adult education, and nonprofit management. She focuses on guiding her late-deafened peers along their journey toward creating a greater sense of wholeness by adopting and accepting a new and healthy deaf identity. LaRonda continues to work on her book about her experience of becoming deaf and her journey toward deafhood—a very meaningful endeavor! Her award-winning blog is at www.earofmyheart.com.
As a late-deafened adult, I work to hear what doctors say. However, many physicians who hear just fine seldom listen as attentively to me. Ironically, it’s hearing specialists who often miss what I most want to say to them. But, to be fair, I was spoiled years ago by receiving the ultimate care.

I remember the moment when Dr. William F. House looked me in the eye and asked if I understood that the surgical procedure he was scheduled to perform on me the next morning would result in probable hearing loss. He was the fifth one from his otologic medical group to ask that question in two days. Even though I had signed the waiver that held them harmless, these people were relentless about disclosure.

A world-famous otologist, Dr. House was an inventor of the cochlear implant, and his staff delivered world-class medical care. I had flown to Los Angeles in October 1976 in hope that a new microscopic surgical procedure that he had developed would relieve my symptoms of Meniere’s disease. For the prior nine months, I had suffered debilitating bouts of vertigo and nausea that medication couldn’t touch. I was 30 years old and simply could not “learn to live” with the ceaseless misery. Desperate for relief, I would have signed off on any paperwork to stop the spinning.

Dr. House’s doctors and technicians took time to explain various tests, probe my understanding, and mention probable outcomes. They stressed that this new procedure would not cure my condition but might ease the side effects, and that it was likely that the tinnitus would increase in both ears as my hearing worsened. They were attentive and reassuring as I was prepped for surgery, but without pulling punches. Thus informed, I slept peacefully the night before surgery. Happily, the operation went without a hitch, recovery was easy, and best of all, the dizziness disappeared. I returned home feeling forever grateful, yet also mildly deflated to leave behind such fine professionals. This was a peak experience that formed my expectations of medical care.

Unfortunately, as years passed and my hearing worsened, I didn’t find local ENT physicians or audiologists who listened nearly so well. All were competent professionals but busy and distracted. They tracked my losses and prescribed better assistive devices, but didn’t question my condition. I wanted a collaborative dialogue but resigned myself to be a cog in the wheel of their medical practice. The general expectation was that a good patient sat quietly and followed instructions.

But five years ago, that all changed when my regular ENT ignored and dismissed my concerns. This made me angry at first, and then proactive about getting what I needed. In the spring of 2003, my allergies were in full bloom and my hearing had plummeted. My head was so plugged with phlegm that sound didn’t register. I could not hear when the dishwasher was working. I sat with my ENT, touched my sinuses, and suggested that allergies were causing my sudden hearing loss. He shrugged and jotted a prescription for the latest, most expensive hearing aids, plus some sinus medication. “Just make an appointment today at the hearing center,” he said as he left the room. This was standard advice for him, but his last brush-off for me. Annoyed, I left resolved not to buy new hearing aids, fill his prescription, or schedule a follow-up appointment.

Instead I heard about Bastyr Center for Natural Health in Seattle, Washington, which is well regarded for acupuncture and traditional Chinese medicine. They consider the body as an integral system and symptoms indicate blockage or imbalance. They aim to remedy a core problem rather than treat symptoms. Various specialists assessed my tongue and pulse, listened to my every word, and took copious notes. They concluded that it was poor digestion that had caused my congestion. They prescribed a treatment plan that included daily doses of a nasty herbal tea and regular acupuncture treatments, but within a couple of weeks, the congestion was gone. Then we began testing and eliminating foods that caused my allergies. Within six months my balance was stable and my nasal passages free from pressure. It’s true that I still had a hearing loss, but my ability to hear was no longer complicated by toxic food allergies.

The Bastyr staff modeled an interactive approach to patient care. They listened to me and responded to my questions. I left appointments with a written treatment plan. This was reasonable behavior to them, and I liked how collaborative it felt. Now my challenge was to adopt a similar approach during my appointments with Western-trained physicians.

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Here’s what I do during medical appointments. When I enter a doctor’s office, my first goal is to connect with the person at the front desk. I want to endear myself to the receptionist so that he or she will act as my advocate with other co-workers. I introduce myself and confirm my appointment. Then I state that I’m profoundly deaf, that my ears are really plugged today, and that I don’t know whether I’ll know when my name is called. I flash my most appealing, helpless grin and dial up my boyish charm. Usually the receptionist pegs me as a harmless grandpa or their nice retired neighbor in charge of the block watch. I want the receptionist to endorse me to the next person to call my name so that we begin on the right foot. This may seem manipulative, and I would agree.

When my name is called, I introduce myself to the nurse, audiologist or technician. When we enter the exam room, I say that I’m profoundly deaf and am really nervous during exams because I’m never sure what’s happening. Then I ask them to suggest how I can be a good patient. “Since you work with people like me all the time, what can I do to get the best results from our working together?” I’m trying to break through the mindset they use with patients. I hope they’ll view me as a real person—that nice man—who wants to cooperate. At the same time I’m sending a message that I’m not entirely passive and may get agitated. I want them to pay close attention to me and check their procedures so that everything runs smoothly.

Typically, they pat me on the shoulder, say not to worry, and promise to keep checking back. I ask questions during the tests, compliment them on how well they perform their job, and wonder aloud if these findings are something I should remember to discuss with the doctor. My purpose is to get them to hand me over to the physician with the complete findings, because I’m likely to refer to these test results. Obviously I’m working the situation, and for this I do not apologize.

When the doctor arrives, I expect that she or he will be harried and preoccupied. Some immediately grab the medical chart and read during a mumbled greeting, while others sit at the computer and scroll down the screen rather than look at me. I want to penetrate their concentration, present myself as a capable person, and convey that we have an equal relationship.

I stand, introduce myself, and offer to shake hands. Then I say, “I’m profoundly deaf and sometimes in situations such as this I have trouble understanding exactly what you say. I’m telling you this because I want you to know that I’m not as dumb as I may appear. What would you suggest I do in order to keep up with whatev-
Scholarships for the 2009 ALDAcon
October 14th through October 18th 2009
Seattle, Washington

This year, ALDA's annual ALDAcon will be held in Seattle, Washington. As in years past, ALDA, Inc. will provide a limited number of scholarships to help those in financial need who want to attend. Applicants for a scholarship must be members of ALDA, Inc., and priority will be given to first-time attendees. Deadline for the reception of applications is August 31, 2008.

Requests for applications or questions regarding applying for a scholarship may be sent to Carolyn Piper via her email address at wicwas@wcvt.com or her mailing address at 82 Piper Place, Huntington, VT 05462.

GA to SK
By Anne McLaughlin, Curator

ALDA President Kathy Schlueter has been busy chauffeuring her grandson to physical therapy for injuries he sustained in wrestling (he’s a champion wrestler). In addition to the many other hats she wears, Kathy is a devoted grandmother and daughter who is always there for her family.

Your scribe/curator spent a week in Longboat Key, Florida (near Sarasota) in January. A bunch of girls from my college class met for a wonderful week of laughs, fun, reconnecting, and rehashing of old memories as well as catching up on our lives. St. Joseph College of Emmetsburg, Maryland closed 36 years ago this June, but the spirit and friendships live on. Aside from that, and waiting patiently for “GA to SK” and “Chapter Happenings” material, I do some babysitting and hang out with the girls around here in Diamond Glen.

See you at ALDAcon, but please, send me news of what is happening in your life for the upcoming ALDA News issues (my email address is maumsie@sbcglobal.net). The deadline for the next issue is May 15. Thanks!

SKSK

Our lives begin to end the day we become silent about things that matter.

-Martin Luther King, Jr.
I. King Jordan Award for Distinguished Achievement
Nomination Form

This award will be presented at the discretion of the ALDA Board of Directors, but there will never be more than one recipient in a given year. The award will be presented to a late-deafened person who has (a) had a successful and distinguished career in his/her chosen field of endeavor, (b) made significant contributions to his/her community, profession, and/or nation, (c) served as an outstanding role model for late-deafened adults everywhere, and (d) clearly demonstrated to the hearing community that a person's competence, integrity, and human worth are not necessarily diminished by the fact he/she is deaf. Recipient will be chosen by the ALDA Board of Directors.

Nominations for the 2009 Award should be submitted by August 1, 2009, to:
Kathy Schlueter
I. King Jordan Award
c/o ALDA, Inc.
8038 Macintosh Lane
Rockford, IL 61107
Email: president@alda.org

Nominee

Name of nominee ___________________________________________________
Address___________________________________________________________
City/state/zip/country_________________________________________________
Phone_____________________      Voice __    TTY __   CapTel __   VCO __
Age of onset of deafness ________________
Title/occupation ___________________________________

Is the person you are nominating aware of the nomination?                Yes___ No___
Has person consented to having his/her name placed in nomination? Yes ___No___

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

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

Name of person making this nomination:

Phone: ______________  Voice __   TTY __   CapTel __   VCO __   Email: ____________________
Save with ALDAcon 2009 Early Bird Registration and Prizes

Join us at the beautiful Doubletree Hotel Seattle Airport as we make Sound Connections through workshops, speakers, technology, karaoke, and just plain hanging out at a place and with people where communication is “whatever works, works!”

It pays to be an early bird for ALDAcon 2009. You can save $50 by registering before June 1 for the Full or Lite program. Register online at www.alda.org, by credit card, debit card, or check using PayPal or mail forms available online and in this issue of ALDA News.

Now here’s an even better offer. If you register as an early bird AND reserve your hotel room before June 1, you will be entered in our drawing for one of four great prizes: one full registration* ($215 value), one upgrade from Lite to Full registration* ($65 value), or one of two complimentary nights at the Doubletree Hotel Seattle Airport ($159 or $169). **

The good news gets better: the Doubletree has extended its affordable group rates so that you can visit Seattle three days early or remain three days after ALDAcon 2009 for the same low prices. The hotel is ideally located for you to connect to the beauty of the Pacific Northwest, the waterfront action along the Puget Sound, and the spectacular views of Mt. Rainier and the Cascades and Olympic mountains. Check out the links for area tours and adventures at www.alda.org and make plans for a memorable time with friends and family.

Don’t delay! Register for ALDAcon and reserve your room now to save on registration and enter the drawing for free prizes.

*Registrations must be paid for prior to June 1 to be included in the drawing. Winner of the full registration will have the registration fee refunded.
**To qualify for the drawing for one of two complimentary room nights, registration must be paid AND room reservations made. The hotel will credit the bills of the two winners with the complimentary nights. Roommates need to decide how to use the free night between them.

See you in Seattle!

Christine Seymour (aldachristine@comcast.net)
ALDAcon 2009 Planning Chair
Cathy Hilden (wacathy@comcast.net)
ALDAcon 2009 Co-Chair
**Registration Form**

Please complete ALL three pages of this form and mail to address below, OR register online at [www.alda.org](http://www.alda.org).

Name: _________________________________________________________

Address: ____________________________________________________________________________________________

City/state/zip/country: ___________________________________________________________

Phone: (_____) ______________ Voice __ TTY __ CapTel __ VCO __

Fax: (_____) ______________ Email: __________________________________________________________

___ I DO NOT want my contact information printed in the program book.

**I am:**

___ Late-deafened ___ Hearing ___ Hard of hearing ___ Deaf at birth or before language acquisition

___ I am bringing a hearing/service dog. *(Dogs must remain on leashes in public areas.)*

___ ALDA chapter/group member of _____________________________________________________________

___ Personal care attendant *(Free registration but must purchase meals. Complete a copy of this form.)*

___ Is this your first ALDAcon? *(Please fill out the “Newcomer Form”)*

___ Other (explain) _________________________________________________________________

**Special Needs**

My special dietary needs are: ____________________________________________________________________________

Allergies: ________________________________________________________________________________________

Mobility needs: ____________________________________________________________________________________

Any other needs: ___________________________________________________________________________________

All workshops and events will have sign language interpreters and CART (Communication Access Realtime Translation). If you need any other accommodations, please make specific requests by **October 1, 2009**.

**FM assistive listening systems** will be provided at no cost, but to enable us to have enough receivers available, you MUST reserve yours now. You will be asked to turn in your driver’s license when you obtain the receiver. Your license will be returned when the equipment is turned in.

___ I would like to reserve an FM assistive listening system receiver to use during the convention.

To use the receiver I need: ___ neckloop ___ earbuds ___ headphones ___ other _________________________

**Roommate Match**

___ I need a roommate. Please contact me.

I am: ___ male ___ female
ALDA News

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

Note: Membership in ALDA, Inc. is NOT the same as membership in an ALDA chapter/group. 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)

Full and Lite Registration:

Full registration includes access to workshops, exhibits, and all other events. Limited scholarships are available. Contact Carolyn Piper, Scholarship Chair at wicawas@wcvt.com for more information.

Full registration covers the following events:
* Wednesday Welcome Reception
* Thursday President's Luncheon
* Friday I. King Jordan Award Banquet
* Saturday Award Luncheon
* Friday Buffet Luncheon
* Saturday Karaoke Party
* Sunday Brunch

Lite registration includes access to workshops, exhibits, and some other events. Included in lite registration:
* Wednesday Welcome Reception
* Saturday Karaoke Party
* Sunday Brunch

Additional meals may be purchased. A la carte meals cannot be purchased after September 30.

Will you be attending the Sunday Brunch? Yes______ No_______

Early Bird—before June 1; Standard—before September 22; Tortoise—September 22 and after

<table>
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Single Day Registration (meals not included)

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<tr>
<td>Two Days $90</td>
<td>Amount:</td>
</tr>
<tr>
<td>Three Days $125</td>
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Days Selected: Please indicate which day(s) you will be attending.
Thursday______ Friday_____ Saturday_____

A la Carte Meals (meals must be registered by September 30, 2009)

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<td>Saturday Award Luncheon</td>
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<td>Sunday Brunch</td>
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<td>Friday I. King Jordan Banquet</td>
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</tr>
<tr>
<td>Saturday Karaoke Party</td>
<td>$30</td>
</tr>
</tbody>
</table>

Total meals
Total cost:

Program Book will acknowledge your tax-deductible gift: Donation $__________

Grand total $__________

Page 2 of 3
Method of Payment

Payment made by:

___ Check (Make check payable to ALDAcon 2009)
___ Money order (Make money order payable to ALDAcon 2009)
___ Credit card (Circle one)  MasterCard  Visa

Card holder’s name: ____________________________________
Card number: _________________________________________
Expiration date (month/year): _____________________________
Signature: _____________________________________________

Refund Policy for Registration

Request for refunds (minus $50.00 handling and processing fee) will be honored until September 22, 2009. Substitution of a registration will be allowed ONLY from one member to another. (Contact ALDAcon 2009 Registration at address or email address below for substitution information.)

Register Online at www.alda.org
OR
Mail Registration Form to:

ALDAcon 2009 Registration
c/o Paula Titus
7943 13th Ave SW
Seattle, WA 98106
Email: registrations@alda.org

Reserve Your Hotel Room TODAY!

Doubletree Seattle Airport, 18740 International Boulevard
Located next to the Seatac Airport and 15 minutes from downtown Seattle

Reserve now! The special ALDA room rate ends September 23, 2009.
For reservations, go to Doubletree Seattle Airport

or call 1-206-246-8600 Voice, 1-206-901-5923 Fax
Use Attendee code: ALD

For the latest details on ALDAcon, go to:
http://www.alda.org
**Newcomer Form**

| Name: __________________________________________ |
| Address: ________________________________________ |
| City/state/zip/country: __________________________ |
| Phone: (______) ____________________ __ Voice __ TTY __ CapTel __ VCO |
| Fax: (______) ____________________ Email: __________________________ |

**How did you learn about ALDA:**

| _Friend (name): ______________________________________ |
| _Website: ___________________________________________ |
| _Other (specify): ______________ | |

**I am:**

| _Employed ___ | _Retired ___ | _In transition ___ |
| _In school/training ___ | _Work at home ___ | _Unemployed/looking for work ___ |
| _Unemployed/not looking for work ___ | _Not working due to disability ___ |
| _Other __________________________ |

**Strategies that I use:**

| _Hear in quiet areas ___ | _TTY ___ | _VCO or CapTel phone ___ |
| _Cochlear implant ___ | _Hearing aid(s) ___ |
| _Sign language ___ | _Speechreading/lipreading ___ | _Pencil and paper ___ |
| _Other __________________________ |

**Age:**

| _Under 30 ___ | _30 – 40 ___ | _41 – 55 ___ | _56 – 70 ___ | _Over 70 ___ |

**About me:**

Cause, length, and severity of hearing loss: __________________________________________

Hobbies/special interests: __________________________________________

Please return this form with your paid registration. By completing and signing this form, you are giving us permission to copy and distribute it to other newcomers and officials at this conference.

Signature: __________________________

For more information, please contact Cynthia Amerman via email at cynthiaamerman@gmail.com
Fast Facts About DTV Help Center

The switch to digital TV has stirred up a lot of questions and uncovered unexpected problems. The CSD-DTV Help Center was established with cooperation from the FCC to help the deaf, hard of hearing and deaf-blind community with issues related to the switch and to assist with the increasing problems with captioning people are experiencing.

CSD-DTV Help Center: The CSD-DTV Help Center is tailored to meet the communication needs of 28 million deaf, deaf-blind, hard of hearing and speech disabled consumers seeking information about the DTV transition, assistance with coupon and converter box procurement, installation, and all problems related to captioning.

- Staff communicate with individuals one-on-one to educate them about the DTV change and troubleshoot related issues.
- Deaf and hard of hearing consumers can use the communication mode that matches their needs including voice, videophone, TTY, Instant Messaging, IP Relay, Voice Carry-Over Relay, Captioned Telephone, Video Relay and Spanish Video Relay.
Captioned Telephone’s next generation is here!

No special equipment needed – just a phone and a computer with internet access.

Captions everything spoken to the CapTel user, which is displayed prominently on their computer screen.

Ability to print and save conversations.

* CapTel is an acronym for Captioned Telephone.

For more information:
www.sprintrelay.com/webcaptel.htm
www.sprintcaptel.com
Advocating for:
- Video & CapTel public phones
- Captions on TVs in airports
- Visual public announcements
- 9-1-1 access with pagers
- Captions on all TV programs
- Captioned movies
- And more... 

TDI is working to meet your daily access needs everywhere you go.

Our mission is to provide leadership in achieving equal access to telecommunications, media, and information technologies for deaf and hard of hearing people.

Washington: Where Access Begins

TDI invites all ALDA members to join us for 18th Biennial TDI International Conference July 30 - August 1, 2009

The place where consumers can meet to exchange information and ideas with government and industry.

Renaissance Mayflower Hotel
Washington, D.C.

Contact TDI:
Phone: 301-589-3786; Fax: 301-589-3797; Video (Toll Free): 866-970-6836; TTY (Toll Free): 888-202-1120
VP-200: 71.166.174.51; Ojo: 71.166.174.52; Email: info@tdi-online.org; Web: www.tdi-online.org

TDI - Shaping An Accessible World
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) to be held this year in Chicago from October 29 to November 2, 2008. 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, 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 the ALDA Biz annual report from the Board of Directors, 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, Rockford, IL 61107.

I'd like to: □ Join ALDA □ Give a Gift Membership to: □ General Member, Age 61 or under . . . $25.00
□ Senior Member, Age 62 or over . . . . $20.00
□ Business Membership . . . . . . . . . . . . . $45.00
□ 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 on-line by going to:

www.alda.org/alda_membership_form.htm

For Credit Card Payment by Mail:
□ Master Card □ Visa

Amount _________________________________
Account # _______________________________
Expiration Date ___________________________
Signature ________________________________
(For Credit Authorization)

Newsletter preferred Format (select one):
□ Electronic (Email) □ Paper (Us Mail)

Gender: Male □ Female □

Hearing Loss:
Late-Deafened □ Hard of Hearing □ Deaf □ Hearing □

If paying by check, please mail this member form to:

ALDA, Inc.
8038 Macintosh Lane
Rockford, IL 61107

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, Gloria Popp

glp843@aol.com

or visit [www.alda.org](http://www.alda.org)

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Association of Late-Deafened Adults

ALDA, Inc.
8038 Macintosh Lane
Rockford, IL 61107

Visit us on the web at: [www.alda.org](http://www.alda.org)

Be sure to check your address label. It shows the date your dues will expire. Don’t let your membership lapse!