After nearly a decade with a serious medical condition and the latter four years of that being completely deafened, I don’t think this topic could be more relevant to my life. In the beginning, my hearing loss was mild. For the first year, I didn’t even wear a hearing aid, so in subsequent years, not having any accommodations for medical appointments seemed normal.

My hearing loss is actually the most common symptom of my condition (NF2). Interestingly, however, informing me of the strategies I needed to learn in order to adapt to and cope with that loss was not seen as part of the medical community’s job description in treating me holistically. In fact, it was not until I realized that I was literally putting my brain and care into somebody else’s hands without being able to understand, that I finally discovered it was definitely time to request the help I needed.

Here is how it began…

For several years, as my hearing rapidly declined, I “got by” with the use of a personal FM system and reading lips. As my hearing loss worsened, I needed to utilize CART (realtime captioning) for graduate school, which I was very assertive about requesting. Yet when it came to my medical care, I struggled without any captioning. Since my prognosis was fairly predictable every six months (a little bit of tumor growth accompanied by a little more hearing loss) with no real answers on what to do, I passively never requested help.

Then one of the tumors grew significantly over a short period of time, causing substantial hearing loss to the point where I barely had any hearing left. It was time to make a very serious treatment decision. With horribly muffled hearing, I managed to converse with the doctor over the phone by using the voice carryover relay service. Fortunately, I could read the text of the conversation on the phone, as I barely understood anything with hearing alone. Since I responded by voice and could speak very well, I imagine the doctor thought I could still hear sufficiently. We scheduled a week within the next month for me to fly down to California for a consult.

Since I was distraught about the risks of the life-altering event about to take place, it never dawned on me to try to arrange an accommodation. My husband was going with me, so I guess I just assumed he would translate and take notes for me. That was not a good idea, because he was probably just as stressed about the situation as I was! However, I was unable to comprehend or predict his state of mind at the time due to my own inability to wrap my head around what was happening to me so quickly.

I had never met this medical team before and was unfamiliar with their voices or speech patterns. During the first appointment, a nurse practitioner or medical assistant examined me. She had me perform some skills, said some things, and then asked some questions, which my husband answered. Meanwhile, I had no clue what was being said and whether I could provide more important information to answer her questions.

I felt completely helpless and in a
ALDA NEWS

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Note from Nancy

By Nancy Kingsley, ALDA News Editor-in-Chief

Shortly after we selected the theme of coping with hearing loss in medical settings for this issue, I had a personal experience that underscored the need for appropriate staff training in this area and the importance of filing a complaint when the requested accommodation isn’t provided.

I was due for a routine blood test and went to my local hospital’s laboratory testing center, where a sign was posted that stated, “Upon arrival…if you are hard of hearing, please let our registration staff know.” I thought it was very nice that the hospital was already aware of the need to accommodate hearing loss, so I informed the person recording names and requested that someone come over to get me. I also asked how long the wait would be, to make it less likely that I’d miss my turn. I was told about half an hour, so after 35 minutes, I inquired about my status and learned that there were still a few people ahead of me.

After another ten minutes, I started looking around, hoping to see whoever called me in case nobody came over. By doing this, I managed to spot the staff member who announced my name. I went to her, noticing that she had a paper with my name and “HOH” written on it, and explained that I had asked for someone to come over to get me because I couldn’t depend on hearing my name called. She responded that she wouldn’t have known who I was and that the hospital’s policy for assisting hard of hearing people was to speak louder!

I’m on my state Advisory Council for the Deaf and Hard of Hearing, so I emailed the details of my experience to an Advisory Council member from the state’s Department of Health. He forwarded my story to the director of the Department’s Division of Acute and Ambulatory Care (which verifies hospital compliance with state and federal health and safety standards). She then passed my account on to a field office for investigation. (I later learned that the Department had a toll-free phone number for filing complaints about the quality of care received in a hospital or nursing home.) As a result of my complaint, the hospital was cited for violations of state licensure regulations and had to submit a plan of corrective action.

What’s the moral of this story? Be sure to request the communication access you need when you go to a hospital, and if it’s not provided, contact your state’s Department of Health to find out how to file a complaint. By following up in this way, you can help to make future hospital experiences better for both yourself and other people with hearing loss.
Eileen Here
By Eileen Hollywood, Managing Editor

The ALDA News staff would like to wish our readers good health and happiness in the new year. We hope this issue will help get 2009 off to a good start for you.

When Nancy and I chose “Dealing with Hearing Loss in a Medical Environment” as the theme, little did we know that the calls for articles would elicit such an overwhelming response. The number of submissions was so great, and the stories were so compelling, that we had to split them up among this issue and the forthcoming spring issue.

We start off with a great article from Rebecca Dufek, “Medical Communication Breakdown,” in which she vividly recounts her experiences when undergoing a life-changing surgery. In “Coping with Hearing Loss in a Medical Environment,” Marie Drew discusses how she overcomes her communication challenges in doctors’ offices. And “Equal Medical Access? You Deserve It!” by Michele Bornert includes helpful guidance on how to bridge the communication barrier in a medical setting.

A sense of humor can be a big help, and in “Lost: A Front Tooth!” Harriet Frankel presents a lighthearted view of her visit to a dentist that will be sure to put a smile on your face. Mary Clark gives us a personal look at her recent hospital experience in “Dealing with Hearing Loss in a Medical Setting.” In line with our medical theme, Nancy Kingsley includes her report, “Huge Jury Award Penalizes Doctor Who Refused to Provide Interpreters.”

Many readers will relate to Rick Rutherford’s story in “To Sign or Not to Sign, That Is the Question.” Those who were unable to attend ALDAcon can read Nelda Rainey’s and Merna Holloway’s comments about this year’s I. King Jordan Award winner, Tony Yuppa, as well as Tony’s engaging acceptance speech. Having known Tony for many years, I can honestly say that the award could not have gone to a more deserving recipient.

From the international front, we have a great article by Muhammad Akram, “My Life Story,” in which he explains how his hearing loss helped him become a part of the disability movement. In “Chicago Revisited,” Dave Litman shares a moving account of the way his first ALDAcon opened up a new life for him. And to wrap up this issue, we have Jim Keith’s informative and entertaining interview with a long-time ALDAn, Cleo Simmons.

As always, if you have any suggestions, comments, or feedback regarding the newsletter, please be sure to let me know.

ALDAbest,
Eileen

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_

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Contact ALDA Treasurer,
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President’s Message

It is my honor and privilege to serve the membership of the Association of Late-Deafened Adults, Inc. for a second term as President. We are a totally volunteer organization, committed to focusing on making our presence known as the premier support provider not only for late-deafened adults but also for those with any degree of hearing loss. Our doors are open to anyone who supports our goals, and we are looking forward to ALDAcon 2009, “Sound Connections,” which will be held October 14 – 18, 2009 in Seattle, Washington.

In my term of office, I will have the help of a number of new people on our Board. The 2009 Board of Directors is: Linda Drattell, President-Elect; Brenda Estes, Secretary; Gloria Popp, Treasurer; Jane Schlau, Region I Director; Kim Mettache, Region II Director; Dave Litman, Region III Director; and Michelle Lewis, Region IV Director.

We must also say goodbye and give our heartfelt appreciation to outgoing Board members Bernie Palmer, Past President; Lois Maroney, Secretary; and Mary Lou Mistretta, Region 3 Director, who all served on the Board for many years. I personally want to thank them for adding to my growth, for without their support, I would not be where I am today. They will be missed!

My focus for this year will be to encourage others with a hearing loss to join our organization, meet others like themselves, and share in ALDA’s warm family feeling of belonging. We will be working toward the following four goals.

Communication - By using ALDA’s communication philosophy of “whatever works,” I’ll keep an open line of communication between our members and their Board.

Outreach - Our hope is to leave no one outside our doors. Limited scholarships for newcomers to ALDAcon will be made available to provide the opportunity for them to meet others like themselves.

Membership – This is the heart of ALDA, and we will look for new ways to encourage more people to join.

Education – We will continue to provide our members with information about hearing loss and what can be done to help. We will also educate the media, entertainment world, and our government on how to include us.

No goal can be reached singlehandedly, and as your President I am asking for your support. I can be reached at any time by email: president@alda.org or by phone: 866-402-2532, toll free or 815-332-1515.

Happy New Year!

By Kathy Schlueter

Kathy Schlueter

NOT A MEMBER?

Join online at www.alda.org

Or

Use the form in this issue of ALDA News
Medical Communication Breakdown (continued)...

continued from page 1

panic! Had she not read my file, which stated that I had a severe-to-profound hearing loss? If she couldn’t demonstrate that she was familiar with my case by knowing how to appropriately communicate with me, how did I know that I was going to receive good care by the doctor and other staff? If I was not responding and had difficulty understanding, why didn’t she write to me? Since I was the patient, why was she only having dialogue with my husband? It was MY brain they were going to do the procedure on and not his!

Once she was gone, I unleashed my fury at my husband for not diligently writing down everything she had said. Frustrated, angry, and scared, I started crying because I didn’t know what was going on and I couldn’t understand why he didn’t help more with the communication. For years I had been attending appointments on my own, so he really wasn’t prepared for this situation. We were so concerned about what was going to happen—whether I had to have brain surgery, whether I would live, and how I would be affected by the treatment choice I made—that we never made a plan about communication. While waiting for the nurse to come back, we sort of cooled our jets, and I made clear what I was expecting. Fortunately, the consult with the surgeon was the next day, so we were able to have a little time to recover from the initial bad medical-visit experience.

When we met with the surgeon, he was very nice and patient but didn’t seem to understand how to communicate with me. The entire time, I strained to catch words here and there but couldn’t understand the full conversation. I depended on observing the way the doctor presented himself and his mannerisms, my husband taking notes to fill me in later, and my husband’s ability to make a good judgment about the doctor’s character.

It was a frightening experience and one I determined not to repeat again. I am uncertain why I hadn’t been assertive in requesting accommodations. I am sure the office would have arranged for them with the proper advance notification, as we noticed a few interpreters. I think I was struggling too hard to be the hearing person I once was. At school, my success depended on getting all the information, so I made accommodations for my education a priority. Shouldn’t my life have been equally important to me?

The treatment resulted in total deafness on the third day of my stay. The deafness wasn’t a big surprise, but what was a shock was how ill I became from the treatment and the other side effects I suffered. I wondered whether I would have been more prepared for those side effects if I had been more engaged in the consultation by understanding the doctors’ responses. This would have given me the chance to ask more questions and clear up any misunderstandings. Further, it would have provided me with the peace of mind of knowing that I was being included in everything that was about to happen. I would have been assured that I was an equal participant in my care.

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, and Rebecca became completely 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 corresponded with at least 25 doctors (mostly specialists) on the West Coast and countless medical professionals ranging from office staff and nurses to physical therapists. She lives with her husband and two dogs in Redmond, Washington, outside of Seattle. To learn more about how Rebecca manages to survive NF2 and deafness, visit her blog, the “NF2 Odyssey,” at www.diverbeck.blogspot.com. You can contact her at bluediverbeck@yahoo.com.

**ALDA NEWS** NOW AVAILABLE IN FULL-COLOR ELECTRONIC FORMAT

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I find it falls to us to educate the medical personnel, particularly in a local doctor’s office. A sign language interpreter would not help me, I need CART; I realize I have a “legal right,” but you also have to see this through the eyes of the physician. It will cost him more to provide CART than my insurance is going to reimburse him for the visit. So...what is to motivate him to want my business? And as a result, what kind of care am I going to get?

What has worked best for me is to try to reach a satisfactory arrangement, and this differs with each doctor. I have an eye doctor, and the first time I saw him, I brought a “white board” and explained that he needed to write. He does not even talk to me—he just writes. I saw another doctor in the same office recently. My head was in the viewer, he was looking in the opposite end, and he proceeded to TALK to me. Yoo hoo, that doesn’t work, fella!!

On the other hand, my doctor uses what I call “home made sign language.” He taps behind his ear, meaning “focus your eyes here!” When he is done, he gently pushes me back in the chair.

I recently had a physical and asked for accommodation. I explained that if the doctor would just type on a laptop for me, that would be fine. I was informed that they “don’t do that,” to which I replied, “You have no choice. It is the law.” The response was “Nope, can’t help you.” I asked for the supervisor’s name and called her, but she said the same thing, “can’t help you.” I very politely asked if I could have her address, as I would like to send her some information.

I have a small packet that contains the ADA law AND the results of court cases where people did not get accommodation as requested—and I highlighted the ones at a physician’s office. The supervisor called me back, very apologetic, and I got “special care” from the physician. And would you believe that after the appointment, she called me to ask if my appointment was satisfactory!!

I have since purchased my own used laptop, and take it with me to ask a doctor to type for me. This USUALLY works pretty well. However, what do you do when you are deaf and you take your 86-year-old mother to a physician who will not cooperate in typing for you? The ADA protects me when I am the patient. My mother gets very confused, and I explained this to the doctor and told him that he needed to type for me. He gave me a “you are a royal pain” look, proceeded to have a big conversation with my mother (who knows what she told him), and then typed one sentence for me. Now my mother has a fit if I suggest she change doctors. Any ideas on how to deal with this? [Editor’s note: the ADA requirement for effective communication isn’t limited to patients. A Deaf, late-deafened, or hard of hearing person who is helping to care for a child, a relative with dementia, or a sick or injured relative also has a right to effective communication, which the doctor in this case failed to provide.]

Marie is 66 and has neurofibromatosis type 2 (NF2), poor eyesight, and “rotten” balance, joking that she is basically quite healthy other than being unable to hear, see, and walk. She lives in Canonsburg, Pennsylvania and has two sons, one in Georgia and one in Wyoming. Marie has been active in the NF2 community for a long time and was a volunteer resource coordinator for the state in her working years. Her email address is Marie.Drew@comcast.net.
Equal Medical Access? You Deserve It!

By Michele J. Bornert

What happens if you get to the doctor’s office and find there’s no interpreter in sight, even though you had requested one? It’s taken three months to get this appointment—you can’t just leave. So what do you do? You have a number of possible solutions: Whack the secretary with a chair, lie down and kick your feet, use a few choice words, and then go off in a huff. Sure, these methods have their good and bad points, but what’s the best idea?

I became interested in this because of my own bad experience. When I entered the doctor’s office, the first thing I did was write on a piece of paper that I’m deaf and don’t lipread and ask if they scheduled an interpreter (I’d called them three times to remind them). Then, big surprise: No interpreter was hired. “I know a little sign language. I can help.” A “little” sign language was a bit overstated for this woman. Granted, she tried, but, oh, did she not succeed.

Since that wasn’t working, I decided to ask my doctor to please write down what he was saying. He grabbed a pad of paper and started writing one-word “sentences.” Now, who told him he could choose what I need to know or not to know? Much to my chagrin, he uttered that infamous “Never mind” when I asked him a question. Boy, did that grate on my nerves! Never mind?? That’s the ultimate no-no in deaf land.

Unfortunately, many doctors and hospitals are not equipped to accommodate the deaf and hard of hearing population. It’s sad, but true. My suggestion? Contact the administrator. Explain what happened. If he seems unimpressed, politely mention your “lawyer’s” name—that might get his attention.

Other than an interpreter (oral or sign language), there are a few ways to communicate and understand what is happening around you if you can’t hear. Here are some ideas:

- **C-Print** is a computer-aided speech-to-print transcription system developed at the National Technical Institute for the Deaf (NTID), which can be used as a support service option for some deaf and hard of hearing patients. A typist called a C-Print® captionist types spoken comments into a laptop computer. The typed information is displayed simultaneously on a second laptop computer or a television monitor and the printed text is available for review purposes. The system uses word processing software aided by abbreviation software. The captionist receives training in an abbreviation system to reduce keystrokes, and in text condensing strategies. The captionist types as much information as possible, generally providing a more complete representation of what was said than summary notes.

- **CART** (Communication Access Realtime Translation) is the instantaneous translation of the spoken word into English text performed by a CART reporter using a stenotype machine, notebook computer, and realtime software. The text is then displayed on a computer monitor or other display device. [Editor’s note: CART provides a word-for-word rendition, while C-Print provides a condensation.]

- **Notetaker:** There are other less expensive and, unfortunately, less productive ways to interact with your physician or nurse. One option would be to have a nurse or assistant in the room with you and the doctor and have her stand next to you and write down what he says. Or you could even bring your laptop or TTY and let the assistant type what he’s saying. And, just as a warning, you’ll have to remind him several times during your exam.

- **UbiDuo:** The UbiDuo™ is a portable, wireless, battery-powered, stand-alone communication device that facilitates
I’ve been using hearing aids since 1958. In the beginning, I was vain and tried to hide my aid with my hair (didn’t everyone?). So, when I started a new job in 1965, I didn’t tell my new employer about my hearing loss. As luck would have it, my handsome co-worker had his eyes on me as potential “date” material. (Later he confessed that was why I was hired.) Very soon, we started going out for coffee or drinks after work. On Christmas Eve he escorted me to a friend’s holiday party. It was very romantic: The lights were low, the candles glowed, and we danced close together.

Up to that point he had given me no indication that he had romantic intentions. All of a sudden he decided to make his interest known by leaning closer and nibbling on my right ear. He was rewarded by a monumental case of FEEDBACK. Everyone at the party heard it too. We all froze. All eyes were on me and my noise-maker. My date was totally flabbergasted. I could have been embarrassed and humiliated. But instead I burst out laughing and he joined me. That was a turning point for us and the beginning of our love affair, our marrying, and being happily together for nearly 43 years.

I’m a firm believer in the saying, “If you’ve got it—flaunt it.” So I figure that since my hearing loss is invisible, I’ll flaunt my hearing equipment for all the world to see. That’s why I wear my hair super short—my hearing aid and my cochlear implant BTE processor are plainly visible. I’ve even decorated them with holographic stickers resembling shiny jewels.

While I was on a crowded elevator in an Atlantic City casino, I overhead someone on my left side comment, “Boy, that’s a really big hearing aid she’s wearing” (referring to my CI BTE processor). I laughingly turned around and said to him, “It’s not a hearing aid—it’s a computer. This...is...a...recording.”

His jaw dropped just as the elevator door opened, as I stiffly walked robot-like out into the hallway. I don’t know what came over me, but I felt like a kid again.

One day while driving through town running errands in the midst of a rare California rainfall, I took my hearing aid out and placed it on my lap. Shortly thereafter I got out of my car without giving the hearing aid another thought. Unbeknownst to me, it had dropped into a small puddle in the parking lot! I arrived at my next destination when I suddenly realized I wasn’t wearing my aid. I panicked when I remembered that I had removed it because the earmold was irritating me. In vain, I retraced my steps and drove back to my first stop but wasn’t able to locate it.

By the next day the storm had passed, the puddles had cleared, and I made one last-ditch attempt to find my hearing aid. Sure enough, there in the parking lot it lay—only now it was in several odd-shaped pieces. That day not only did I learn the importance of purchasing hearing aid insurance, but I also received quite a lesson in science. For example, did you know that hearing aids do not float or bounce, nor can they withstand the pressure of a 3,000 pound car driving over them? And some people think science is boring!
By Anne McLaughlin, Curator

ALDA-Northwest Indiana hosted a combined picnic with ALDA-Chicago in Dyer, Indiana to end the summer fun. According to Kim Mettache, the weather was perfect and the 23 people who attended had a great time. Kim hopes to repeat this event next year.

In August, ALDA-Chicago officers and board members attended training conducted by Ross Molho, a lawyer. Each participant received a copy of the PowerPoint slide presentation, which covered “The Seven Responsibilities of a Board Member.”

ALDA-Chicago gave two full scholarships (registration and hotel), two partial scholarships (registration only), and one one-day scholarship to ALDAcon to five of its members. The generous benefactor who made this possible is the wife of a former member of ALDA-Chicago.

ALDA-Peach reports that Yael Shaner joined the board as vice president, appointed by President Marge Tamas when the former veep, Kate Seader, resigned for personal reasons. This may be old news because Peach had elections in November, but at this time, I have not received notice of who the new officers are. Yael Shaner is also the highly respected editor of “Peach Fuzz.”

That’s a wrap for this issue. Please, chapter and group leaders, let us know what is happening with you. If you can’t write, assign someone! Many thanks to Ann Smith of ALDA-Peach, Marlene Thometz of ALDA-Chicago, and Kim Mettache of ALDA-Northwest Indiana for their reporting.

Email info to Anne McLaughlin at maumsie@sbcglobal.net. The next newsletter deadline is March 1, so try to get things to me by February 20. I tend to have two speeds: slow and stop.

Our World—News from the International Committee

By Cynthia Amerman

ALDAcon welcomed Guatemalan deaf activist Julio Bamaca, to his first 'con. He made it a memorable occasion for us as well by his enthusiastic participation throughout, and by showing us his salsa skills at the karaoke party. Julio reports that advocacy efforts of ASORGUA, the Guatemalan Deaf and Hard of Hearing Association, were brought to fruition when his country’s congress passed historic legislation on October 8, 2008 that recognized Lensegua (Guatemalan Sign) as an official language, along with Spanish and 21 Mayan languages.

As our Program Chair this year, Miguel Aguayo from Toronto, Ontario was very visible throughout the convention. We thank him for having completed that gargantuan task!

Akram Muhammad from Pakistan is putting together an online ALDA-Asia group, and in February 2009, he will attend an international CBR [community-based rehabilitation] conference on disabilities in Thailand, where he will gather members for the new ALDA group.
Jennifer lives in Tennessee with her husband of 17 years and their five children. While she grew up with hearing loss, it is only recently that she started interacting with others who are deafened. She attended her first HLAA conference in 2007 and, encouraged by others there, attended her first ALDAcon this past September. She enjoyed her ALDAcon experience so much that she is already saving her money to attend next year’s convention in Seattle. Learn more about why Jennifer is “one of us.”

Name: Jennifer Leigh Thorpe

Where were you born? Memphis, Tennessee

What is your current residence? Shelbyville, Tennessee

What is the cause of your deafness? I literally went to sleep and woke up deaf. They tagged it “sudden sensorineural hearing loss” after finding no cause at all. Thirty years later it happened again...in the space of about five minutes. Tests turned up no known reason for the hearing loss.

Age/year you became deafened? Four, although my mother reports that I started having issues with my hearing around the age of two.

How did your family adapt to your hearing loss if at all? My mother sprang into action right away. She had me in speech therapy and SEE (Signed Exact English) classes as soon as possible. I got a hearing aid right away and was mainstreamed into regular school. One of my brothers was born severely mentally retarded less than a year before I lost my hearing, so our family had a lot going on between my doctor’s appointments and his. They couldn’t focus just on one child; they really had to juggle and, in hindsight, that was probably a good thing...I felt rather “normal” in my family instead of “special.”

Marital status? Married, with children.

What is your present job? Full time stay-at-home mom.

What is the worst job you ever had? I worked in the floral department at Wal-Mart for a while. The water that the flowers sits in gets nasty fast...so I had to stay on top of that, and had to cart buckets of water through the store...I was constantly wet and dirty...blech!

Movies you want to see again? I am a die-hard Tommy Lee Jones and Harrison Ford fan. The Fugitive...I have watched it so many times I’ve lost count.

Books you tell others to read? I haven’t sat down to read a book all the way through in a long time, although I love to read and probably own a couple of thousand books. I did read The Shack, and I recommend it wholeheartedly. Ninety-nine percent of my reading is done online...the other 1% is usually spent picking through my cookbook collection.

I stay home to watch: I don’t stay home to watch anything...I love to go places. If I did, though, it would be House, MD...he makes me laugh out loud...he is so terrible! (Curator’s note: I’m happy to know there is more than one person who loves the show for the same reason!)

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Favorite pig-out food: That’s a hard one, really, because I LOVE to eat. When I’m really feeling indulgent, though, I get into the Blue Bell ice cream. And I can eat my weight in sushi, but that’s healthy for you, right?

Hobbies: I am a real computer geek...Facebook, message boards, blogging, instant messaging...I do it all. I love to cook (but hate the dishwashing that it entails), love window shopping and meeting people, LOVE to travel.

You talk about your interest in the Internet. Could you tell us a little bit more about how the Internet has made a difference in your life as a person with hearing loss? I got online in 1998 and knew right away that communicating on the Internet was the way to go for me. It eliminated so many misunderstandings that were common in face-to-face communication. I started meeting people online and my deafness wasn’t an issue for them. Because we had none of the communication issues; the social awkwardness wasn’t there. When I started researching cochlear implants in 2006, I began meeting other deaf and hard of hearing people online. Believe it or not, in the eight years that I had been online prior to that, I hadn’t ever met another deaf or hard of hearing person, and hadn’t even looked. I realize now how much I missed out! I have made so many incredible new friends online. I can’t imagine my life without them. I am so thankful!

If I had more free time: I would probably waste it on the computer!

The hardest things about becoming deafened: When I went completely deaf last year, it was crushing...so quiet, so isolating. The people around me were hearing, and many of them didn’t seem to know how to respond. I found myself staying at home as much as possible...it was so hard to get out and struggle so hard to understand what was going on around me.

I began accepting my deafness: When I finally lost all the hearing in my right ear in March of 2007. Up until then I honestly think I had convinced myself I was a hearing person, despite the fact that I heard very little with my hearing aid. Ah, denial. When you’re stone deaf, you kind of have to re-evaluate. I went to the Hearing Loss Association of America (HLAA) convention in Oklahoma City in June of 2007 and discovered other hard of hearing and deaf people like me. I realized that there was absolutely no shame in being deaf...that we are no less of a person because our ears don’t work like everyone else’s.

What were your feelings as you were getting ready to attend the HLAA conference? To be honest, I dreaded it. I had planned to go, had registered, had a roommate and...almost chickened out. I didn’t know if I really wanted to spend a weekend with a bunch of deaf people. At that time, I was still in a bit of denial and I just didn’t feel like I belonged there. I got there the day before my roommate did and went to a dinner for volunteers that night. I reached out and introduced myself to some of them, and they turned around and introduced me to their friends. I felt at home almost immediately. I spent the entire weekend meeting new friends...it was just incredible!

The worst thing about deafness: I still miss the jokes about half the time and have to ask for a repeat. I don’t get embarrassed about it anymore, though. It is what it is.

The best thing about deafness: Ah, I sleep so well at night! And during my Sunday naps, I take the CIs off. We actually had nine children in our house one Sunday afternoon and I never knew they were there! Awesome!

How did you learn about ALDA? I had some friends who went to ALDAcon in Rochester last year. They talked on and on and on about how much fun they had. I was so jealous and wanted to check it out for myself!

In what ways has ALDA (or deafness) enhanced your life: The people at ALDA accepted me with open arms. It didn’t matter whether I could sign or not...I couldn’t hear, so I was embraced.

When I am depressed: I tend to hibernate. I’m a bit like a bear...I want to just sleep. I do wake up to eat, have coffee, and feed my children, but I prefer to be left alone to grumble and grouch for a few days.

My most irrational fear is: I don’t know that I have a lot of irrational fears...most of mine are based on something rational. I do think a lot about dying young, though. I just can’t picture myself growing old, for some reason. I suppose that’s rather irrational, as I am apparently quite healthy and the women in my family live to be oooooooool.

If I could hear again, the first thing I would do: Actually...I have told several people that if I was offered natural hearing back at this point I wouldn’t take it. I have gained so many new relationships in my life over the past couple of years that I would never have had otherwise and it has made my life richer.

The thing I like best about myself: That I love people and love making new friends. My mother says that when I was four years old I would talk to total strangers on the street. I haven’t ever known a stranger!
Equal Medical Access? You Deserve It! (Continued)

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simultaneous face-to-face communication by means of two displays and two keyboards. The name stems from the words “ubiquitous” and “duo”—ubiquitous because of the desire to see the device become available to deaf and hard of hearing people everywhere and duo because one unit is comprised of two halves.

• Relay: For communicating with the doctor over the phone, you can use any VRS technology. VCO is available, enabling you to use your voice and read the interpreter’s signs or lips. [Editor’s note: Nonsigners can also use other forms of relay, such as Internet Relay and CapTel.]

Hearing loss is a huge challenge to all who experience it. The professionals (doctors, lawyers, teachers) simply do not have the knowledge or (in many cases) the experience of working with a deaf or hard of hearing individual. Be extra sure to call the office at least one week prior to your appointment and explain that you will need such and such (interpreter, notetaker, etc). It’s a good idea to call two or three days beforehand just in case they didn’t grasp the notion (and, believe me, it happens). You might also want to remind them that these services are to be paid for by the doctor and not by you as is specified by the Americans with Disabilities Act.

So the next time you need to go to the doctor or hospital, don’t hesitate to ask for what you need in order to understand and communicate. This is your health; take it seriously. If you have questions, ask away. Don’t let anyone tell you that you do not have the right to equal access. You deserve it as much as any other person.

Michele J. Bornert’s work has appeared in several periodicals. When she isn’t writing or teaching American Sign Language through her company, Deaf Expressions, Michele enjoys reading, movies, and spending time with her family. She resides in Grand Rapids, Michigan, with her husband, Kenny, and three kids, Mollie, Jacob, and Natalie. She can be reached at DeafExpressions05@gmail.com.
Lost: A Front Tooth!  
By Harriet Frankel

Crunch, crunch, this celery with its yummy dip was so-o-o good. Crack! What was that? It felt like a pebble in my mouth. I wiggled my tongue around and spit it out to investigate. Oh, it was a tooth! What tooth? My lower jaw front tooth! It hadn’t hurt—I didn’t have a toothache. I had to go to a dentist real quick. I couldn’t go around looking like an old hag. Old maybe, but not a hag.

I hadn’t been to my dentist in a while and he had moved. Thankfully, he still had the same phone number, so I dialed my relay phone. (What a blessing that phone is. If you can’t hear on a regular telephone, get a relay phone or maybe a CapTel captioned one, but do something.) I got lucky and the dentist could see me in two days, but it wouldn’t be my regular dentist because he was out sick. My dentist had a new partner with a very foreign name, whom I had never met. I thought to myself, “Now, he will probably have an accent and that will make it harder for me to read his lips.”

I’m fairly good at lipreading a casual conversation like “How are you?” “I’m fine,” “It’s a lovely day, but I wish it would rain.” I was a little bit concerned, so I checked my purse to make sure that I had paper and pencil. I also had to worry about a new receptionist and possibly a new dental assistant. The first thing I’d have to remember when I entered the office was to tell them that I was now completely deaf—otherwise, they would probably talk very loud or lean over close to talk into my ear.

The day of my appointment I made it to the new office and into the dental chair. The assistant clipped a bib on me and introduced me to the new dentist, who was very good-looking (that always helps). I was all prepared to read his lips, but then he put on a mask to protect himself from my germs. I told him I was deaf and since I couldn’t see his mouth with a mask on he would have to make motions with his hands. My paper and pen were in my purse, but I was already in the dental chair. Alex (I gave up on that last name), the new dentist, got a paper towel to write on and made signs with his hand when he wanted me to open or close my mouth. Open! Shut! Open! Shut! He gestured with his hands and sometime with his mouth too. It worked out fine and he did a great job painlessly taking out the root that was still in my jaw. Then he took measurements to replace the lost tooth with a bridge because of my being admittedly too old to get an expensive gold crown with all the time involved.

It seemed to take forever to get the bridge, and for a change, while waiting for it I kept my mouth shut. I now have a front tooth (you can’t really tell it’s not mine) and I don’t look like a hag any more than I did before I bit that stalk of celery. I made it through my dental appointment all by myself despite being totally deaf. It was not a real big deal.

Harriet has had a hearing loss since early childhood. She grew up in Indianapolis and later moved to Atlanta, Georgia. When her hearing deteriorated, she received a cochlear implant, which was unsuccessful due to previous ear operations. She enjoys ALDA-Peach now that she is retired, and can be contacted at harrietfrankel@hotmail.com

By Anne McLaughlin, Curator

Everyone must have exchanged news at the ’con, because not many folks have sent information in for these columns. So this will be short and sweet.

Brenda Estes of ALDA-Virginia writes that she has a new member of her family. Calvin, a two-year old Lhasa Apso/terrier mix hearing dog from “Dogs for the Deaf” joined her in August after a long wait. Brenda says her family and friends were just as excited at Calvin’s arrival as she was. Calvin didn’t like the soloist singing at church, so Brenda banned him from Sunday worship. Imagine! A certified hearing dog who is also a music critic! Best wishes to Brenda and Calvin for happy years together.

Carrie Levin of ALDA-San Jose writes that when the San Francisco SPCA’s Hearing Dog Program closed, she was immediately interviewed about her hearing dog Huey. She now has a You Tube video of Huey and her, with a glimpse of her younger son Yuri.

Carrie’s older son Joshua recently competed in the National Youth Rock Climbing championships and won first place in speed climbing and second place in difficulty climbing in his gender/age group. With this high ranking, Joshua earned a spot on the U.S. climbing team and was invited to compete in the Youth World Championship in Sydney, Australia. Joshua is now a six-time U.S. team member.

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I remember the chili. I love chili but barely touched it at the tavern we stopped at in Freeport, Maine after I was picked up at the airport by my dad. I knew something was wrong. I also had a glass of wine and couldn’t finish it...a first for Mary Clark. I had canceled the trip to Maine the day before due to not feeling well, but I chalked it up to nerves and sadness, since my mother had recently passed away and I was going through a divorce. However, it was Father’s Day, my birthday, my “ex” anniversary, and my parents’ anniversary (without my mother), so I wanted to spend time with my dad, as he too was alone. I had trouble eating...I just wasn’t hungry most of the time (a sure sign of depression, I have found out since then), but I thought it would help us get through some of these difficult days if we spent them together.

We then decided to go to Sarah’s, a soup place in Wiscasset on the way home to Camden. I don’t like bricks and can’t walk on them very well, but being a big girl, I said, “Let’s go!” Dad dropped me off quite a ways from the door (I didn’t tell him about my brick phobia), and I knew I would have to walk uphill on the bricks to the door. The sun was in my face and yet I was determined to do this. I wasn’t walking steadily and figured it was a bad balance day, which I sometimes have. My dad, who is 80, parked the car, and I was worried about him. I recall stopping, turning around, looking for him (I couldn’t find him), and looking back toward the sun. I lost my balance and remember saying “oh” and then the “s” word.

The next thing I recall was the ambulance and people standing around and staring. My dad was there and said, “We need to take you to the hospital.” I responded, “No, it’s not necessary...let’s just go home and I’ll wash myself off and we can have soup there.” Blood was on my white sweater, but I didn’t want to go into an ambulance. I even said, “How about you driving and we will stop at the hospital?” I was bleeding from a head wound over my eye, but to me it didn’t seem that big a deal. I also remember telling all the people staring they could go home...the show was over. I lost my balance and remember saying “oh” and then the “s” word.

I was coherent and able to read, so I asked people to write things down for me in the ambulance and ER. I could also lipread fairly well. I wasn’t so worried about me but mostly about my dad (that truly did help me...focusing on someone else). We had just lost my mother and this was all he needed...sigh. I told him to go home after several hours waiting in the ER for the plastic surgeon. It was more important to me for him to be home safely than for him to be there with me. He wrote down everything from “They need your insurance card” to “Are you sure you are not pregnant??” (Dad....you would be the first to know after me.) I had many tests after he left, and I took charge, surprisingly, so I couldn’t have been that bad off. Before the tests, I would say to the doctor, “You need to tell me now what will happen, what you will do...and then I can cooperate better.” They did take the time to do that and then stitched up my head wound.

My heart was beating erratically, and they discovered I had atrial fibrillation or a similar heart problem and put me on a monitor. They also discovered I had a blood clot on my brain due to the fall. This concerned them, so I was immediately transferred to a hospital two hours away in Portland, Maine that could do brain surgery if needed. I really didn’t know all this at the time and was thankful for being deaf at that point. Some things you don’t need to know! I only knew I was being transferred to a larger hospital. I remember that the ambulance was dark (it was midnight at that point). I was very coherent and told the person sitting with me that he would have to turn on the lights if he needed to ask me something, and write it down. I was still the “in charge of it” Mary, but I was getting tired.

I was in the ICU for eight days. I had to ask my dad this recently, as I had become too sick to manage myself and couldn’t recall dates, times, etc. I remember them quizzing me constantly. “Where are you, Mary?” I said, “At a hospital” but could only name it MMA, as I am not from Maine. I kept saying “Maine/Mass Association” or something else that was not right. One day I got mad and said, “Ok, you come to Chicago and I will quiz you about the hospitals there.” (Don’t be afraid to speak up.) They then stopped asking me. I remember Marylyn [Howe] coming to visit me and she and my dad sitting and having coffee my suite overlooking Portland. They said, “Can you believe the view? Look at the view, Mary!” I was like, “Where is the morphine?”

I had wonderful nurses, doctors, support people and, yes, even interpreters. (I was very lucky—I didn’t have to ask for the interpreters,
Dealing with Hearing Loss in a Medical Setting (continued)...  

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although normally patients must do this.) The interpreters were there on the second or third day on a 12-hour basis. I was told I was “a mess”—many things were wrong with me and I couldn’t go home to Chicago for a long time. Just taking a plane ride could make my head explode and of course kill me due to the blood clot. I found that quite funny at the time and remember laughing. They also would not allow me to look at myself...no mirrors. I guess I looked pretty bad. I would also have to have therapy to learn how to walk again, eat again, etc.

I had lost 20 pounds in too short a time, which had affected my heart and the rest of my organs. I remember my father coming to the hospital (two hours’ drive each way every day) and feeding me a spoonful of whatever here and there. At one point. (Stick up for the guest room.

When I give presentations, I emphasize how important it is to find medical folks who cater to YOU! I know many people who take someone with them to appointments, etc. That is ok, but it’s your health, and if the medical staff cannot deal with you as a deaf person, then my feeling is they shouldn’t even be in the medical field. Find someone else who can honor you, your body, and your wishes! My doctors know now to have paper and pen while they are sitting there asking me questions. We don’t always have to have an interpreter, and many times I don’t want one, as many medical issues are intimate and I’m very modest and have no desire to share. My doctors and I laugh a lot. It’s important to make doctors feel comfortable with me as a deaf person. A smile goes a long way, too.

As I write this, I have gotten stronger, gained weight, and not fallen again. I still avoid bricks and have to cover up the “dent” in my head (with makeup). I’m very lucky to be here and blessed with many friends and family members and good doctors!

Mary Clark’s loss of balance and resulting fall occurred on Friday, June 13, an unlucky day for her that gave new meaning to the term “dizzy blonde.” She has been to every single ALDAcon and recently celebrated her 20th ALDAcon anniversary in Chicago. Mary is from Oak Park, Illinois, which is just west of the Windy City, in the middle of the Frank Lloyd Wright district. She enjoys gardening and decorating her 110-year-old Victorian home. Mary is presently busy volunteering for several boards and organizations after working as a teacher of deaf and hard of hearing children for many years, as an administrator for various deaf-related organizations, and as a consultant specializing in deaf-related issues. Her oldest daughter, Lauren (24), resides in Chicago and her middle daughter, Lindsay (21), is a student in Boulder, Colorado. Emily (15), Cooper (a puggle), and Belina (the cat) continue to keep Mary more than occupied. She can be contacted at Ldmpoppins@aol.com.

GA to SK (continued)...  

and earned his sixth consecutive title as national speed champion. He also has three national championships and two North American Continental titles. Carrie signs herself “one proud Mama” and has good reason to be!

Your scribe sailed on the Emerald Princess from Fort Lauderdale to the Eastern Caribbean and had a great time. The only problem was that the date conflicted with ALDAcon. After the cruise, I headed up the East Coast to meet my newest grandson, Donald W. McLaughlin, III and to have fun with his sisters. Then I played Nurse Ratched (my nursing skills are slim!) to my 91-year-old sister Betty, who had a bad spell in early November but has recovered quite well. It was good to get back to my sweet little house in the Glen after five weeks away.

Remember, email your GA to SK news to me at: maumsie@sbcglobal.net by February 20.
I. King Jordan Award Presentation, ALDAcon 2008

Comments by Nelda Rainey

Soon the identity of the recipient of the I. King Jordan Award [Tony Yuppa] will be announced. For now, we will refer to the person as “Angel” because an angel is someone who appears in your life and offers you guidance and hope when you need it most.

Our Angel is the Cogan’s Syndrome Super Guru. I doubt if there is a doctor that knows more about the realistic side of Cogan’s than Angel. CS is an extremely rare autoimmune condition and is thought to be congenital but not hereditary. A medical paper written in 1986 stated that there were 150 known cases in the world. We Coganites are a select group, equally made up of men and women.

Everyone in ALDA probably has had the “being deaf” experience, so they know that feeling. People with CS experience sudden hearing loss along with at least one of the following: painful eye inflammations, Meniere-like vestibulocauditory dysfunction, inflammatory vascular disease, and/or bowel disease. CS is episodic, and flare-ups can occur frequently. Onset can happen at any age but usually presents itself when the person is in the late 20s.

Angel’s CS event happened at the age of 28. He couldn’t find much information about CS even from the medical profession. This was so frustrating that Angel decided to do something about this problem. He knew that the best information would come from other Coganites. But how to find them? It wasn’t easy. Angel put ads in publications aimed at hearing impaired people, and by word of mouth he slowly collected 50 people, some from outside the US. This was the beginning of the Cogan’s Contact Network.

Angel encouraged everyone to share their experiences, did research, and wrote to doctors. Over the years, as frequently as new information became available, Angel copied it and snail-mailed large packages of information to everyone in the Contact group. The information sent out allowed others to know what was happening in the medical profession in regard to CS, what kind of help other Coganites received, whether their treatment was successful, and what questions to ask of their doctors. All this was done on Angel’s own time and mostly with Angel’s own money.

As soon as the Web became popular, Angel took on the task of getting CS out there. Angel contacted such groups at the National Organization of Rare Diseases and other supporting sites for hearing impaired people, requesting to have information about CS included on their site. Today if you search for CS on the Web, you will get many hits, including the Contact page. CS is still very rare, but today new Coganites have a much better chance of finding help and information about CS quickly and easily.

Angel’s most significant accomplishment is that now people with CS know they are not alone and can find the medical and peer support that is necessary for a better quality of life. Today Angel continues to distribute important information by email and by snail mail for those without Web access. Angel has brought together a network of caring people who share their questions and experiences, and welcome newly diagnosed Coganites with support and encouragement. We personally know how important it is to know you are not the only person out there going through a lost and confusing time along with all the physical pain of CS. Here are two emails from members of the Cogan’s Contact group that best describe the typical CS experience, the Contact function, and Angel’s qualifications for this award.

Comments by Merna Holloway

Email from Anna Beltrano (Ontario, Canada): “I wanted to let you know how Angel helped me with the Cogan’s Contact group. It was about eight years ago, at the age of 25, that I was diagnosed with Cogan’s. I was in the hospital for almost five weeks of testing, while a group of doctors tried to diagnose me. I was declared profoundly deaf and was in a wheelchair due to severe balance issues. I had iritis in both eyes, was constantly vomiting from dizziness, had major and constant headaches, and was down from 110 to 95 pounds. I was finally told that I had a rare disorder called Cogan’s Syndrome. I was LOST AND SCARED.

“When I found the Contact group and Angel, it helped me learn so much more than what the doctors and specialists could help me with. Angel was my lifeline and gave me truth and most of all HOPE! I was so confused and terrified. Angel helped me understand that you can live with Cogan’s and at the same time be made aware of ALL the facts of the disease, even the scary aspects. I always received replies to my emails, no matter what time of day they were sent nor how busy Angel may have been when they arrived. Angel genuinely cares and puts others first. I am blessed that Angel put this group together because it has constantly gotten me through so many

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(L-R) Gloria Popp and Robin Titterington

Ken Arcia and Mary Clark

Karaoke kraziness

(L-R) Linda Drattell, Cynthia Amerman, and Christine Seymour

(L-R) Jennifer Thorpe, Dennis Gonterman, Abbie Cranmer, and Tony Yuppa
(L-R) Lois Maroney, Bill Graham, and Christine Seymour

(L-R) Ellen Kaitz, Cheryl Heppner, Kathleen Mannion, Jane. Schlau, and Mark Dessert

Hippie chick (Jennifer Thorpe) meets Barack Obama (Dave Litman)

(L-R) Kathy Schlueter, Robin Titterington, Ann Smith, and Harriet Frankel

(L-R) Sally Skyer and her daughter Melissa
of the problems that come with being a Coganite. I will never forget Angel and this group for helping me through one of the scariest and darkest times in my life. Angel is a wonderful friend with great drive and encouragement! Angel deserves this award!!”

Email from Robyn Limberg-Child, DVM (Michigan): “The difficulty of losing one’s hearing, for many of us in early adulthood when we are just starting careers and families, is an extremely isolating event; and to have it be due to such a rare condition that half the doctors we see have never even heard of it is even more frightening. Finding Angel and Cogan’s Contact opened a door to understanding our condition, as well as giving us a support group of dozens of people who helped each other learn to advocate for ourselves.

“Even for people who have other forms of hearing loss, the medical information that Angel has managed to compile and reference can be very helpful in finding treatment options and names of doctors who are more familiar with different types of hearing loss and immune-mediated disease.

“For those of us who faced that straddling of two cultures—not ‘really’ deaf, but no longer hearing, Angel’s information and support network truly has been a Godsend! Can any of us imagine how lost we might still be if not for all of Angel’s hard work and effort over the many years of running this group?”

Angel not only dedicates time and energy to people with CS—our friend helps everyone. Angel is a big part of ALDA-NJ and often attends ALDA conventions. Here is what the ALDA-NJ founder says.

Email from Nancy Kingsley (formerly of NJ): “I know Angel very well. We met at a hearing loss support group that I organized, and Angel was a great help to me in starting ALDA-NJ in 1991. Angel provided lots of advice and support, and getting the group going wouldn’t have been possible without Angel’s assistance. Angel was always the ‘life of the party’ and has been a big help to ALDA-Garden State as well, coordinating its fundraising Great Adventure ticket sales for a number of years and now also serving as a member-at-large on its board. Angel always goes beyond the call of duty to help others and is very deserving of this recognition.”

Coganites everywhere would like to thank the ALDA Board of Directors for choosing this wonderful young Angel for the I King Jordan Award. Angel really deserves this recognition, and the Board will always be proud of their choice.

(Editor’s note: see p. 21 for Tony’s acceptance speech.)

ALDAnonymous (Continued)

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I was volunteering in a special education class of young students. One girl was playing with my hair and noticed my hearing aids. She asked what those were, and I told her they were hearing aids. She had a petrified look on her face and ran to the teacher screaming, “Teacher, teacher, she’s got AIDS!”

Some years ago, I was at an ALDA chapter meeting where several of us had body processor cochlear implants (this was before the behind-the-ear type became popular). We sometimes plugged the cord of a small hand-held microphone into our processor and gave the microphone end to the person talking. While a few of us were doing this during a group conversation, one CI user grabbed a hand-held microphone and started speaking into it, only to discover that she had selected her own by mistake. She quipped, “Talking to myself, as usual!”

Many years ago, my niece, who was about five at the time, came running into our house with a little friend. She gave me a tight hug, which was appreciated but a little surprising. And yes, there was feedback. She then turned to her friend and said, “See, Susie, I told you my aunt’s ear beeps!”

Now for next month’s question, stop IM-ing and all that for a minute and send us your response to this question: “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?” Send your responses to Bill and Robin at aladonymous@gmail.com by March 1.
I. King Jordan Award Acceptance Speech

By Tony Yuppa

I was having a rough week when Christine [Seymour, ALDA’s President] informed me of winning this award. I asked why was I getting it and wondered how to get out of it. Not your typical response to any award, is it? I was speechless, completely caught off guard. And I am not one for surprises or for being in the spotlight at all. Emails started coming in with “congrats” in the header. My goose was cooked. No secrets in ALDA-land.

Thank you for honoring me with this award tonight. It is truly a humbling experience. Never did I think I would receive such a prestigious honor. I am the 18th recipient of the award. I am proud to be among such worthy people as Ken Arcia, Robin Titterington, and Mary Clark, to name only a few. I was nominated because of Nelda [Rainey]. She’s been with me since the Cogan’s Contact network was in its infancy in 1989. We had an immediate bond. In 1996, I met her at the San Francisco ALDAcon, and we’ve been close ever since. Recently, she sent word to the Network, and they too felt it necessary to nominate me for the work I have done in the last 20 years. She is a wonderful, caring, supportive person. I am blessed to know her.

By now you’re asking yourselves, “What is Cogan’s Syndrome and why haven’t I heard of it before?” These are the same exact questions most doctors are thinking and our members face on a daily basis.

I believe in simplicity and making things easy to understand. Cogan’s is an inflammatory illness that strikes specific organs responsible for hearing, balance, and vision. A support group was needed because there was such a lack of proper information and qualified physicians that people got scared, thinking they were going to die at an early age. So we developed a members list and a database of physicians people could turn to. It’s worked well for everyone to have a contact, an inside person on this illness.

Talking about having a contact person or perhaps an Angel on your side, I feel very fortunate to have one or two close by. I can’t thank these people enough for being my ears. Throughout the turmoil deafness and my illness brought, my sister and brother-in-law, Linda and Ed, have always been there for me 24/7 and are the definition of big sister and brother. Linda is 13 years my senior, a survivor of breast cancer now for 8 years. Unfortunately, Linda and Ed couldn’t be here tonight, but I promised to tape the event. I am thankful and blessed that they never gave up on me, much like the ALDA friends I have made through the years.

Losing your hearing in your mid-20s is a life-altering experience. It alters your friendships, confidence, self-worth, relationships with family members, coworkers, and holidays. You all went through this adjustment period—the isolation, despair, self-pity, the “why me” stage, the always present “I’m sorry” replies, the people whispering into your ears, and let’s not forget the yelling into your face and the m-o-u-t-h-i-n-g of w-o-r-d-s so y-o-u c-a-n understand me responses.

Meeting people at ALDA showed me it’s ok to be deaf. I regained my confidence, made new friends, and instead of losing a family I gained one. Socially, it was what I needed. Emotionally, it was a warm welcome. Physically, it was a blast to be around people just like me. How cool is that?

I am an auto mechanic, the youngest of three children in an average-sized Italian family. When I became deaf, my employer fired me. It seemed they thought I was brain deaf too, but the education you get stays in your head. It’s not in your ears but in your mind. I found another job exactly like my old one. I sued the first employer and am staying with the second. I have a good work ethic. It’s my natural ability to fix things.

After 15 years of deafness, I decided it was time for a cochlear implant, so I got fixed several years ago. It’s helped a lot. I would advise anyone who is late-deafened to get one or two, but do your research first. Attend workshops here, speak to people with various implants, and see for yourself how well they work. If you think explaining your deafness to people is time-consuming and confusing to them, wait till you tell them you can hear them next time you see them.

In closing, I’d like to say to all types of patients, if you can’t find the answer from one doctor, go see another. Do your research. Question everything, just like I did.

I’d like to mention some of our fallen Coganites over the last few years:

Gayle Hayman and Dean Burford of California
Christine Harding of London

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My Life Story

By Muhammad Akram

My name is Muhammad Akram, and I use “Danish” as a nickname. My life was normal like that of other boys in Pakistan. But life is a risk, and I became seriously sick when I was a teenager. With the help of God and the care of my family, the doctors saved me, but unfortunately I lost my hearing. At first I thought I’d get my hearing back soon, as my family and my doctor told me that I would be ok (but that was not true). We tried different treatments and even Chinese acupuncture, but nothing worked. At this stage, I realized that I had lost my hearing forever, and I was disappointed—there was a long life ahead of me, and I wondered, “What will I do? How can I face this? I can’t do anything.” I thought I was hopeless.

During this time, my family always helped me. They knew I was getting bored and found it hard to pass the time, so my brother bought a computer for me—if I’m not mistaken, it was 1989. I started playing computer games and was quite good, but I asked myself, “IS THIS LIFE? There is no cure for my deafness, so am I going to spend all of my life as a dependent?” At this stage, I decided that I should try my best no matter what, even if I failed. I told my family that I was interested in getting a computer diploma. They encouraged me, but the big hurdle was the unavailability of a computer institute for deaf students. I was a little afraid, but I decided to go with hearing students.

Initially, we visited a nearby small computer institute (their response was neither good nor bad). Then I saw an ad from the Pertoman Computer Institute. At that time Pertoman was a pioneer in computer education. We visited the administrative officer, Mr. Shakeel Ur Rehman, who offered me some classes prior to admission. The teacher at Pertoman was cooperative (special thanks to Mr. Javad Akhtar, my instructor). As I was going to learn with hearing students, I thought I might not be able to compete with them and wouldn’t be able to pass, but at least I would learn something new so I should try it. I got admitted and tried my best.

In the first test I got 8.75 marks out of 10, and there was only one other student who got the same marks—none did better than me. This minor test changed my life and my thoughts! I continued to compete with hearing students and was often successful.

I failed in electronic data processing twice, but I didn’t give up until I finally obtained my diploma. This gave me confidence, and I realized that life doesn’t depend on hearing—if you have the will, nothing can stop you.

I’ve met good and bad people in my life; some appreciated me and some laughed at me, but I didn’t care about the latter. Now I knew how to ignore them, how to beat them. After receiving my diploma, I graduated in commerce (B. Com), then got a certificate in computer maintenance, and then became a Microsoft certified professional (MCP). I want to tell all the disabled people that they can compete with able-bodied people and be better than them. And I want to tell able-bodied people that they should not underestimate persons with disabilities (PWDs) or hesitate to give them a chance to prove their abilities.

Here is how I became active in the disability movement.

During my studies in computer science, I worked at Pertoman for NEMES-UNISCO. Then after receiving my diploma, I worked at the Dawn newspaper for three months. In mid-1996, I joined the Pakistan Institute of Quality Control (PIQC) as a computer programmer. One day I met Irene Dine, who was working with the Association of the Physically Handicapped of Thailand (APHT). When I informed her that I was in the computer field, she asked if I could help her in building a website for APHT. I agreed, and after I designed it, she suggested that I should not waste my talent sitting alone at home but should utilize it for local disabled communities. This was good advice.

I visited the social welfare department and asked for the list of NGOs working for persons with disabilities (PWDs). Then I selected the Pakistan Association of the Deaf (PAD) and became a volunteer for PAD in late 2000. In early 2001, I joined Deaf Friends International (DFI) as a remote/virtual volunteer web designer. In September I became junior editor, and in June 2002 I became assistant director at DFI. Later, Irene moved back to the Philippines and started Heaven Care Resource Center, Inc. (HCRCI), and I joined her there. I also had a deaf chat mate from the Philippines named Gilda. Some time ago she decided to leave her job to start Deaf Tour Assistance,
Historic ADA Amendments Act Enacted

On September 25, President George W. Bush signed into law the historic Americans with Disabilities Act Amendments Act (ADAAA) of 2008 (S. 3406). It will take effect on January 1, 2009. This Act overturns certain U.S. Supreme Court decisions that narrowed the ADA's coverage, which excluded from protection many individuals with disabilities whom Congress intended to cover. NCD laid much of the groundwork for this legislation in our 2004 report, Righting the ADA, http://www.ncd.gov/newsroom/publications/2004/righting_ada.htm. The ADAAA requires, among other things, that a disability be determined in its unmitigated state [Editor's note: this means that the right to ADA protection cannot be dismissed because of the use of medication, assistive devices like hearing aids and cochlear implants, or other methods that reduce the disability's impact], and that episodic conditions be evaluated at their worst, not when symptoms are absent [Editor's note: this means, for example, that someone with a fluctuating hearing loss could not be denied ADA protection based on that person's ability to hear well part of the time]. The ADAAA also expressly states that the ADA is to be interpreted broadly to protect anyone who is discriminated against on the basis of a disability.

Following the intense advocacy efforts of an unprecedented alliance of disability and business representatives, the ADAAA passed with overwhelming bipartisan support in the House and by unanimous consent in the Senate. NCD believes that, as a result of this alliance, many more people now have a better understanding of the purpose and scope of the ADA. The ADAAA will reduce the number of incidents of discrimination against people with disabilities, and lead to a more just resolution of disability-discrimination cases.

Following the signing ceremony, NCD [National Council on Disability] and the American Association of People with Disabilities (AAPD) co-sponsored a celebration luncheon that was attended by more than 100 representatives of the disability community and included NCD members Robert Davila, Ph.D., Graham Hill, Young Woo Kang, Ph.D., and Anne Rader. Mike. Collins and Joan Durocher represented the NCD staff. Several members of the community spoke at the event, including Dr. Davila, who thanked past and present leaders and those in attendance for coming together as a political force to win passage and enactment of this historic law.

Reprinted from NCD Bulletin: A Monthly Newsletter from the National Council on Disability (NCD), September 2008. The NCD is an independent agency of the federal government. Thanks to Marylyn Howe for providing this article.

My Life Story (continued)...

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Philippines (DTAP), and asked me to help. Since I love to volunteer, I joined her at DTAP.

The Internet brings miracles—the same way Gilda from the Philippines found me through the ‘net, Galuh Sukmara from Indonesia found me and became my friend. She is also deaf and is a leader of the Deaf community of Yogyakarta in Indonesia. She and Whyu (the president of the Deaf association of Yogya) invited me to visit Yogya as a volunteer, so I enjoyed ten days with the Yogya Deaf community in December 2004, just before the tsunami incident.

During this time, PAD asked me for more support. They first assigned me as an advisor and then also as a special project coordinator. Nowadays I am volunteering at PAD, DFI (USA), HCRCI (Philippines), DTAP (Philippines), Matahariku (Indonesia), ASHA (Rural Sindh in Pakistan), and SDF (an alliance of the Disabled People Organizations of Sindh-Pakistan).

Since I grew up and studied in the hearing community, I might have missed this wonderful Deaf community, which I am now enjoying as a volunteer. I am thankful to Irene Dine for showing me the path of volunteerism. Finally, I would like to say, “If you are deaf or have any other type of disability, don’t feel hopeless—go ahead and give your abilities a chance; select a field and do your best, and then God will do the rest.” Thanks to my family, my God, and all the people who appreciate me.

Muhammad lives in Karachi, Pakistan, and can be contacted at danishkadah@hotmail.com.
Chicago Revisited
By Dave Litman

Apprehension.
Nervousness. Fear.
Excitement. Curiosity.
These were just a few of
the emotions I was feel-
ing as I made my down
Interstate 94 to Chicago.
Having been deaf less than
two years, I was strug-
gling to find my way as a
late-deafened individual.
A therapist I had begun to
see suggested I attend the
ALDA conference. And so
I went. When I arrived, I
was overwhelmed seeing
so many people like me
who had lost their hear-
ing as adults. People were
writing. People were sign-
ing. People were gesturing.
Doing whatever they need-
ed to communicate. Still,
I was alone and did not
know anyone. Fortunately
for me, I hooked up
with an ANGEL, and
he showed me the way
and introduced me to
new people. I thoroughly
enjoyed my experience and
was moved by the speeches
given by Dr. Davila and I.
King Jordan. Going back
home, I promised myself
I would make changes to
my life and strive for new
goals. The year was 1998.

I am happy to say I
did follow through and
make many changes to my
life. The most significant
change was going back to
school for my bachelor’s
degree in Deaf studies and
child psychology. This
experience was frighten-
ing at first because I had
previously failed in college,
and now as a late-deafened
person (with minimal
sign language skills) was
attempting to go back. I
was fortunate to attend the
University of Minnesota,
which had a won-
derful disability office. They
supported me with inter-
preters, note takers, and
CART. Over the next four
years I juggled a full-time
job and school, graduating
in 2002. Not satisfied with
that, I attended Gallaudet
University and received my
masters in social work in
2004.

After a couple years
of working in Rome, NY,
I relocated to Charlotte,
NC and presently work as
a mental health therapist
with deaf youth and their
families. I will be fully
licensed as a social worker
in March of 2009. How I
got to where I am today is
clearly linked to my experi-
ence at ALDAcon 1998. I
remember sitting at dinner
on Friday night listening
to I. King Jordan sharing
with us his personal story
of going back to school
as a late-deafened indi-
vidual. I also met others
who strongly encouraged
me to follow through
with my dreams and not
let any obstacle prevent
me from doing what I
wanted. If it were not for
these experiences I could
only have received through
ALDAcon I do not want
to think where I would be
right now.

Changes I made in my
life were not limited to
establishing professional
goals, however. I also dis-
covered new hobbies and
interests. The best example
relates to entertainment.
As a hearing person, I
loved movies, television,
and music. When I became
deaf, I ended up replac-
ing movies and television
with reading. I often tell
people that I didn’t learn
how to read until I was
28 years old! Outside
of Sports Illustrated or
the autobiography of Bo
Jackson, books held no
interest for me. But after I
became deaf, I discovered
the joy of reading and had
little interest in keeping up
with television and movies.

Music? Yes, I miss it,
but thanks to ALDAcon
I found my “voice.” One
of the best joys of becom-
ing deaf is the freedom
to sing awfully! I love
dancing and being able
to enjoy music through
lyrics. One of my favorite
memories since becoming
deaf is standing on stage
singing “Paradise by the
Dashboard Light” with a
friend. She is a performer
and has a beautiful voice
(so I was told), and we
sang this in front of an
audience of other perform-
ers. Being deaf, though,
it did not matter to me that
I sound awful because I
wanted to experience the
joy of the music. I truly
look forward to Saturday
night at ALDAcon where
I can sing a lot of my
favorite songs at least once
a year.

Clearly my first
ALDAcon experience of
1998 had a tremendous
impact on my life, and
I know I would not be
where I am today if it were
not for the friendships I
have made and the experi-
ences I have encountered.
ALDA has shaped my life
both personally and pro-
essionally and provided
me with so much. I have
been blessed to be a mem-
ber of ALDA for 10 years
and look forward to many
more years and many more
wonderful memories. Once
I learned that ALDA was
returning to Chicago in
2008, I promised myself I
would return as well.

Replace the car with
an airplane. Instead of
going south, I was go-
ing north. And while I no
longer felt apprehension or
fear, I still felt excitement,
curiosity, and nervousness.
Excitement at the oppor-
tunity to see old friends.
Curiosity about what new
things I would learn and
new experiences I would
have. Nervousness about
meeting new people and
how I would communicate
with them. As the days

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Interviewing Cleo Simmons

By Jim Keith

Although our 20th anniversary interviews are focused on ALDA itself, I think everyone would like to know what has happened with you in the past 20 years. Would you tell us about the highlights in Cleo Simmons’ life since 1988?

ALDA and I kind of grew up together. I am deaf since April 1, 1983 when my second acoustic tumor was removed. I worked at Mercy Hospital in the A. C. Buehler Cochlear Implant Department from January 12th, 1988 to June 30th, 1994. I even got to write a column in the Cochlear Implant Bulletin about what I was going through as a late-deafened adult. I then worked at Richard J. Daley College in the Special Needs Department from August 21st, 1994 to June 26th, 2002.

My daughter, Cindy, was working at IHS, Integrated Health Service, and asked if I wanted to work there. I started there in 1999 and I am still there. I work in the Business Office and for the Rehabilitation Director, three days a week.

I now have five grandsons and one great-grandson. Unfortunately, I lost one brother; Tashie died in 1990, Mom died 1992 and Gene my husband of 43 years died in 1995. Brother Bobby died in 2005. Both my sisters lost their husbands. I was very lucky because Mom and Gene were such a big help to getting me to be independent.

You were at the first party at Bill Graham’s, the event that turned out to be ALDA’s beginning. Please tell us about that. How did you get invited? What did you do at the party? How did you feel, both before and after the party, about getting together with a group like that?

I was at the Kennedy Job Training Center with Kathie Hering taking me under her wing. She always tried to get me to go to the Support Group at Ravenswood Hospital that she started. She told me Bill Graham was going to have a party and encouraged me to go. Donna Mc Gladdery offered to go with me; she was my sign language teacher. You have to remember I was still adjusting to being deaf. I never knew another deaf person.

According to the first “letter” Bill wrote, right after the party, he said 22 people attended. I mostly sat and enjoyed watching those who could communicate with each other. It was just a good feeling of belonging.

You were involved with Bill in getting the first newsletters and other things started. What, exactly, was your part in that? What else did you do in those early days to help get ALDA moving and growing?

Bill Graham writing those first “letters” was the primary reason that kept all of us in touch and drew us together. I was working at Mercy Hospital. This is a quote from the 1988 ALDA NL: “The A. C. Buehler Foundation Cochlear Implant Center of Mercy Hospital and Medical Center of Chicago agreed to pay for ALDA’s printing and postage cost...The ALDA-Buehler connection began with charter ALDAn Cleo Simmons, who is a patient of the Buehler Foundation’s director, Dr. Jack Clemis.”

When we first started, Bill Graham, Steven Wilhelm, Mary Clark, Marylyn Howe, or anyone would give me the letters to answer when people would write in for information about ALDA. I would add the person’s name to my ALDA mailing list. When I left, I had over 2000 names. I still have every letter I answered. It was like the late-deafened were coming out of the woodwork. It was all snail mail, no email.

On May 16, 1987, we had our second social, at my house. We sat outside by the pool until the mosquitoes, bugs and darkness came, then we went back...
Cleo Simmons (continued)...

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in, shot pool, and became better acquainted. I've had a pool party every year since. I missed one year when Gene died.

From the beginning, we were a social group. Someone would volunteer to host “whatever” at their home. We relied on snail mail, TTYs, and Bill’s newsletters. Kathie Hering kept us all on track and working for the good of ALDA. I’m sure she is in a special place in heaven for all she did for all of us.

You undoubtedly have, by far, the largest collection of ALDA memorabilia—correspondence, newsletters, pictures, etc.—of anyone. When and why did you start collecting all those things that are in your “informal archives” of ALDA?

Actually, I’m a pack rat, smile. After over 20 years, I started to discard and clean house.

I will always keep the first newsletters. I was even saving all the ALDA National NLs, but running out of room. To refresh this “old” memory, it’s been fun to re-read some of the first newsletters. Surprising how so much still can apply to the present.

You have attended every ALDAcon and may be one of the very few people who have. Let’s talk a bit about the very first ALDAcon. When and where was it held? How many people attended and do you remember any of them in particular? In your own words, what was it like? What stands out in your memory about that first “con”?

The first ALDAcon was at Mercy Hospital October 20-22, 1989. It was actually called, “First ALDA Leadership Workshop.” It was all free. If they could get to Chicago, we would house them. I think 42 or 45 came. Bill Graham, Kathie Hering, Steven Wilhelm, Marylyn Howe, Bob Hawley, Everett Chard, Tom Davinroy, Sr. Maureen Conway, Rick Skyer, Karen Andress, Roy Miller, Mary Skyer, Sid Howie, Andrea Cahill, Bill Fitzgibbons, Elizabeth Ruegg, Ken Begin, Mary Clark, Stan Gadsden, Donna Noland, Diane Tokarz, Barbara Chertok, Tevyen Dorfman, Leonard Hall, Ken Watson, Mary Kay, Vanessa Kramer, Denice Novak, me too! I know that is not everyone, sorry if I missed listing you. Steven Wilhelm set up ALDA “crude.” We would break in small groups and go into different rooms for the “training.” Steven would run from room to room keeping the computers running and helping the typist.


What changes in ALDAcon have you observed over the past 20 years, other than more people attending? Are there any things you, personally, would like to see added or changed to make future cons more worthwhile?

I would say one of the big changes is our communication. Many have learned more sign language, the big screens, all the new technology. More members are getting the CI. Personally, I wish it wasn’t so expensive so more people could come.

What changes have you seen in ALDA itself over the last 10 to 15 years?

I would say the biggest change is members’ attitudes in getting the CI. It is such a big help. Even for those of us who cannot get a CI, it does help with communicating with those that do. And now they are even implanting those with NF2! Jean Richards is the first one that I know of. We were always told, those of us with NF2, that we could only get the ABI, auditory brainstem implant.

I’ve heard some people say that we don’t seem to be very successful in attracting younger late-deafened adults as members. Do you think that’s true, are we becoming an “aging organization”? What do you think we can/should be doing about it?

I think we should continue to reach out to late-deafened adults. That is what ALDA is for. To help and support. I don’t think age matters. True, some of us are 20 years older, but if it wasn’t for some of the “oldies” still doing the work and always volunteering, we’d be in big trouble, smile.

There’s no question that today’s ALDA is a great organization just as it is. BUT…If you had a magic wand and money were no object and you could change anything about ALDA, what would it be? What would YOU do to make it even better for everyone when we celebrate, say, our 30th anniversary?

I would have an ALDAcon for every member and their husband, wife, significant other, or companion if they did not want to travel alone. There are many that have wanted to come but can’t afford it. And wouldn’t it be nice if by the 30th anniversary we had a paid...
To Sign or Not to Sign, That is the Question

By Rick Rutherford

Editor’s note: a version of this article appeared in the January 2008 issue of the ALDA-East Bay newsletter.

This is a three-part answer. The first part is what was it like for me before I studied sign language, the second part is what happened afterwards, and the third part is what it is like now. Also keep in mind that this story is continuing to be written, is undergoing daily evaluation, can change at any moment, may or may not apply to you, and is open to any and all comments. In fact, I encourage you to comment!

What it was like was a growing sense of isolation. Even though I was hard of hearing from my earliest memories (there were always things I missed), it was the continued decline in my hearing, the continued need to adjust and negotiate, that was most difficult. As soon as I worked out a coping strategy, I had to discard it and come up with another. The isolation progressed. I was IN the world but not WITH the world. I felt the wind and the sun. The feeling when you hit the baseball “just right” and it flies over the fielder’s head, the feel of the hammer hitting the nail “just right” and you drive that 16-penny in with one blow, the feel of the steering wheel when the rear end breaks loose and you come to a stop facing 180 degrees from where you started—those feelings grab you and put a smile on your face, and you know you are really HERE. But when it came to people, there was no smile. There was no conversation that was “just right.” There was no feeling that I was really HERE with people.

People and communications were something I worked at, sweated at, and failed at many times. I’m not very good at the little verbal connections that make and maintain relationships—the small talk at a party, that quick snippet in line at the grocery store, the casual banter between people moving and working. I have to either walk or talk—I can’t do both. The commentary from the guide, the bus driver, the directions from the pedestrian, comments in a crowded room or at a movie or at a party, and those sweet things we say to each other in bed, all are missed.

So this sense of frustration grew. I didn’t get what I needed and wanted. The obvious things are those that are immediate and now. The less obvious things are the need to socialize, to have a family, to earn a living, to feel good about ourselves. We need to feel that we are included, that we belong to a group and are valued. With the frustration came anger. I wanted other people to hurt like I hurt. I wanted them to know that I was hurting, but I couldn’t just tell them because I didn’t even understand these feelings myself! This rationalized and justified to me lots of destructive and violent behavior.

What finally happened was that I just got sick and tired of being sick and tired. I got tired of being so angry—it took up so much time and energy. It just wasn’t working for me anymore, and I was feeling worse and worse. I wondered, “Is this all there is to life? Am I going to feel like this forever?” So I started calling around. This was 1988. Finally, I was referred to some strange office in San Leandro, California called DCARA. I called and left a message, and Edna Shipley-Conner and I met. She immediately got me into a weekend coping seminar she was teaching. It changed my life. Edna was the one who showed me, “This is what you do, this is how you do it, and this is why.” I also met other people who personified these things.

Sign language was part of this new view of life. There was also an inner change, with self-esteem being the most obvious. So here I was with a new group of friends (including the Deaf Disability Project in Berkeley, SHHH—now HLAA—and the beginnings of ALDA), and sign language was part of this group. This was part of my motivation to learn ASL.

There are many different ASL classes. There is the casual weekend class as part of a coping class, there is the non-professional adult school class of only a couple of hours a week, and there is the Full Frontal Assault class of schools like BCC (Berkeley City College). I recommend the Full Frontal Assault—it’s lots more fun. At first, I tried the easier, softer way. It’s part of being lazy. It didn’t work for me, but it wasn’t a waste of time—it just whetted my appetite for more. I thought I was doing well. I was encouraged and praised, and I ate it up. Then I tried to talk to a real Deaf person, without voice to fall back on, and I was disabused very quickly about my ASL skills! I began to realize how much work was ahead.

Finally, I made a commitment to follow through on more ASL classes. I didn’t do this for others—I did it for myself. What I didn’t realize was that what I got was

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more were hard of hearing there with CIs, but two I were the only people at the same time. Art and professional all so funny and understand especially Joe. He was just Toothman, were great, Joe Quinn and Charlotte a blast! The teachers, to ASL 1 at BCC and had ism!” So Art and I went opportunity. I can hide my thought, “What a perfect to go to an ASL class. I told me that he wanted (ALDA-East Bay member) two classes. NO! I dropped out after two classes.

In 2007, Art (another ALDA-East Bay member) told me that he wanted to go to an ASL class. I thought, “What a perfect opportunity. I can hide my selfishness under altruism!” So Art and I went to ASL 1 at BCC and had a blast! The teachers, Joe Quinn and Charlotte Toothman, were great, especially Joe. He was just so funny and understanding and professional all at the same time. Art and I were the only people there with CIs, but two more were hard of hearing, and one poor girl had Meniere’s disease (she dropped out because she couldn’t tell when she was going to be sick). What a range of people! One black high school girl, one pediatrician (we called him Dr. Bob), a bunch of twenty-somethings, two older black women, and the oldest of the bunch, me. Watching these people “get it” was inspiring. Art, for instance, seemed to just come alive about half way through the class—that was awesome!

Today, Berkeley has a growing ASL community, a Deaf club, socials, and a community of Deaf and hard of hearing people who are connecting much more through ASL. This shows the effect ASL can have as the glue that forms and binds a community together. I look forward to increasing my connections within this community.

With ASL, the connections I was missing in the hearing world could begin to happen in this brave new world of the hard of hearing and late-deafened adult. Those social connections could now move to a higher level, and my inner journey could progress. Powerful motivations. Simple but not easy. I figure I’ll just keep flailing away, and somewhere in the future, I’ll gain enough ASL to be able to communicate well enough to express all those things I can’t with voice. Small talk at a party, quick snippets in line at the grocery story, the casual banter between people moving and working, and the sweet things we say to each other in bed.

Rick was born hearing, grew up hard of hearing, and became deaf. When he went to college (UC Berkeley, majoring in zoology and physical anthropology), his friends were understanding and helpful, but he grappled with pride, fear, and resentment. In 1988, he met Edna Shipley-Conner, studied ASL, met other people with hearing loss, and realized that he wasn’t alone. In 1995, he received a cochlear implant. Rick is a superintendent with a construction company, interacting daily with contractors, architects, and owners and using the phone (but not willingly) every day. He is divorced and has four children.

Cleo Simmons (continued)...

staff and building? There again the problem would be—WHERE? I guess we will just have to have more than one building.

What would you like to say to ALDA members and others who will be reading this interview?

Bill Graham in his closing statement at Mercy Hospital spoke of envisioning “a time when late-deafened adults have access to communication whenever and wherever they need it.” When I first became deaf, I would write to the TV stations and ask/beg them to caption my program. Now they HAVE to.

I could always request an interpreter from CHS, Chicago Hearing Society. I just had to pay $5 and the rest was paid with a grant. However, my signing was not very good. Now I can request caption and I do not miss anything. With all this new technology, CIs, captions, email, computers, etc., there is hope.

It’s still hard to be deaf. We just have to cope, find new ways. I never thought I could travel by myself to ALDAcon. When Gene died in 1995, I had already registered both of us (he always was with me) my daughter-in-law, Laura, offered to drive me to Rockford and stay with me (such a baby I was/am, smile). After that, I pushed myself to go, with help of family and ALDA friends. I was and still am fortunate because my son-in-law, David, always takes me to the airport and stays with me until I board. Actually, I found out he does not leave until my plane is in the air, such a good boy. When I return either my son, Gary, with Laura, or David will be waiting at the airport.

Finally, I’d like to share a favorite little bit of philosophy: “Life doesn’t consist of holding good cards, but of playing a bad hand well.”

Condensed from ALDA Chicago Style, March-April 2008
Huge Jury Award Penalizes Doctor Who Refused to Provide Interpreters

By Nancy Kingsley

A New Jersey jury recently awarded $400,000 to a deaf patient, Irma Gerena, whose doctor, Robert Fogari, had refused to provide an interpreter for her during her 20 appointments for treatment of lupus. Instead, Fogari wrote information to her partner (who had better written English skills) and communicated through their 9-year-old daughter. The patient said that as a result, she was mostly unable to participate in and understand her medical situation or treatment, including risks and alternatives. When

Fogari told her to go to someone else because of her repeated requests for an interpreter, her new doctor took her off steroids, which had caused her face to swell. She said she hadn’t known that the swelling was caused by the medicine rather than the illness.

In a 2001 case against Jersey Shore Medical Center, the court ruled that auxiliary aids and services for effective communication are required at “critical points” such as requesting a patient’s medical history, explaining treatment, and obtaining informed consent, although not for “routine care,” such as taking blood pressure.

Fogari’s patient sued him under the Americans with Disabilities Act, the Rehabilitation Act (which applies to recipients of federal funding such as Medicare and Medicaid), and New Jersey’s Law Against Discrimination. The award, half of which was for punitive damages, set a national record for such a case. The New Jersey Law Journal published an article about the award, noting that lawyers are likewise obligated to provide communication access and mentioning that in 2007, a lawyer paid $1000 in damages for refusing to provide an interpreter.
Congratulations!
Association of Late-Deafened Adults
on your
20th Anniversary

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- or listings@tdi-online.org

NOTE: All new listings and updates must be submitted to TDI by October 1, 2008 for print in 2009 Blue Book, due out around Spring 2009.

TDI Membership includes:
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- 1 yr. eBlue Book access.
What Is ALDA?

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

To join or renew using credit cards on our secure site, go to www.alda.org. To mail your membership, please complete this form and send with check payable to ALDA, Inc., 8038 MacIntosh Lane, Rockford, IL 61107.

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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).
Keep your mind on the objective, not the obstacle.

-E.B. Fuller