My World is No Longer Silent

By Jacqueline Murphy

I have been using the auditory brainstem implant (ABI) for 10 ½ years, and I highly recommend it to anyone who cannot use a hearing aid or a cochlear implant.

I was diagnosed with neurofibromatosis type 2 (NF2) in October 1984, and I lost the hearing in my left ear. I underwent surgery in January 1997 to have a vestibular schwannoma removed from my right auditory nerve, and the operation caused me to lose the hearing in my right ear.

A hearing aid would not have been helpful, so the surgeon performed a promontory stimulation test to help determine whether I was a candidate for a cochlear implant. He said I was a candidate, and in June 1997, I underwent cochlear implant surgery. However, I obtained negligible benefit from the device. The surgeon then told me that the ABI was the only device available that might help me hear. It was still in the clinical trials at that time, and the FDA granted approval for only a limited number of medical institutions to participate. The hospital where I was initially treated for NF2 was not one of them, but New York University Langone Medical Center is one of the FDA approved medical institutions. Fortunately, I live in New York, and it is not a long commute to NYU.

In June 1998, I was referred to Dr. Thomas Roland Jr., at NYU. He told me that some patients are unable to hear with the ABI; others can hear environmental sounds, but they cannot understand speech. Dr. Roland mentioned that the ABI provides a “sensation of sound,” and I would still need to read lips. Although Dr. Roland and my neurosurgeon, Dr. John Golfinos, were able to determine that I was a candidate, doctors and audiologists are unable to tell how much benefit a person will obtain until after the ABI speech processor is programmed.

Dr. Roland gave me literature about the ABI, and I read about some experiences of ABI patients. They said that when they first began using the ABI, “all sounds were the same” and voices were “muffled.” I did not understand how I could distinguish between different sounds if they all sounded alike, or how I was supposed to understand speech if it was muffled.

I was very skeptical that the ABI would be helpful, and I debated as to whether having it would be the right decision. I knew that if the ABI did not help me, I would be very disappointed. I wanted to spare myself that possible disappointment, but I also wanted to hear again. Waking up bilaterally deafened after the surgery in 1997 was traumatic. I was depressed and often cried.

I felt awkward trying to communicate with people who were able to hear, so I stopped socializing. I did not like being outdoors because I felt ill at ease, particularly when I was alone. Since I was unable to hear, I had to constantly look around so that I could be more aware of my surroundings. I spent much of my time in my apartment.

My auditory nerve was not functioning well enough for me to benefit from a hearing aid or a cochlear implant. Therefore, I had only two options: I could continue to live in
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Note from Nancy

By Nancy Kingsley, ALDA News Editor-in-Chief

Although it’s been 11 years since my cochlear implant surgery (which was performed on my birthday!), I can clearly remember the experience. I had been gradually losing my hearing since early childhood and learned to depend on speechreading supplemented by my residual hearing (and later, by a hearing aid). This was effective for one-to-one communication and some small groups, but as my hearing continued to decline, it became harder and harder for me to understand what people were saying. As a result, I figured I should join the Deaf community, so I began studying ASL at a nearby interpreter training program. However, although I got As in all my courses, I soon realized that (1) I hadn’t developed sufficient receptive sign fluency to understand much of what was said at Deaf gatherings and (2) my life experiences were very different from those of people who had grown up in the Deaf community.

Fortunately for me, ALDA was founded just at that point. I attended the second ALDAcon in 1990 and started ALDA-NJ in 1991. Being able to socialize with other late-deafened people was wonderful, but it was still necessary for me to spend most of my time in the hearing world, and my deafness finally reached a point where I could barely function in anything beyond one-to-one conversations with familiar people. (I hadn’t realized how much my speechreading skills had depended on auditory supplementation.) Several hearing loss advocates in my circle had recently obtained cochlear implants and were able to communicate much better as a result, so I decided to get one, too.

How has the implant changed my life? It enabled me to resume activities I had been forced to drop. I could once again participate in small groups (as before, I wasn’t able to hear everything, but I heard enough to make participation worthwhile) and I could once again attend lectures (with the help of an assistive listening system if the acoustics weren’t good). I could understand tour guides if I stood close to them. Because my hearing loss had been misdiagnosed as psychological in my early years, I had never developed sufficient speech discrimination ability to use the phone or understand the radio, and I couldn’t do those things with the CI, either. But anything I had once been able to do I could now do again, and I also found that I could do some things that I had never been able to do, such as occasionally understanding speech without seeing the speaker’s face.

Would I get the CI again? Yes, absolutely. Is the CI the right choice for everyone? No, it isn’t. Whether to get one is a personal decision that people must make for themselves, and one size doesn’t fit all. ALDA’s recognition of this fact is one of our organization’s greatest strengths.

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Eileen Here
By Eileen Hollywood, Managing Editor

Hi, Everyone!

A few years ago, we explored the cochlear implant (CI) decision-making process, and for this issue, we decided to revisit the CI topic from a different angle. We asked people to write about their experiences with CIs/auditory brainstem implants (ABIs) and how these implants have made their lives better or worse.

To start us off, we have a wonderful report from Jacqueline Murphy, “My World is No Longer Silent,” about her experience with an ABI. Martha Mattox-Baker shares the amazing effect her CI has had on her life in “My Cochlear Implant Story,” and another positive account is in “How the CI Has Affected My Life” by Amber Wilhelm. Margreta von Pein provides an open and honest look at her adjustment to a world of sound in “The Transition to Cochlear Implant Hearing.”

You can learn about a bilateral implantee’s experience in Elinore Bullock’s reflections, “One is Good but Two Are Better.” In “My Experience with a Cochlear Implant,” Rick Rutherford shares his responses to many of the commonly asked questions, and Carol Granaldi provides a detailed description of the sounds her cochlear implant has brought back to life for her in “How Do I Love It? Let Me Count the Ways.” In our other articles, Harriet Frankel tells us about what she wishes she could do if she could hear better, Rick Rutherford shares his positive experiences with the “buddy system” for ALDacon newcomers, and Sharon Milian gives us a glimpse of her immediate pre- and post-CI surgery experiences before being hooked up to her speech processor.

And of course we have our regular columns, including “GA to SK,” “Chapter Happenings,” “ALDAAnonymous,” “One of Us,” “Late-Deafened Life—We’re All in It Together,” and “Our World.” This issue also includes ALDA Biz. In the past, the Biz was printed separately, but to conserve on postage and printing costs, we are now publishing it in ALDA News.

As always, I’d like to thank all the writers for their contributions, for without them, there would be no newsletter. If you have any comments or suggestions for ALDA News, please don’t hesitate to contact me at Eileena2@aol.com. And if you have a desire to write for the newsletter, just drop me a line—we are always looking for new stories about any aspect of late-deafness!

ALDA best,
Eileen

Letters to the Editor

In the previous issue, you published my letter about opening a discussion about ALDAs’s future. You also suggested I contact ALDA-ideas@yahoogroups.com to open the discussion there. I have done that and now we have some group members emailing back and forth. Thanks for that suggestion. This is just to say, “COME join the group.” Add your ideas. Let’s talk about what an association of late deafened adults means, can do, is.

However, not many people know about ALDA-ideas, which has lain dormant for several years. To facilitate better communication throughout the entire ALDA family, will the newsletter please publish the e-addresses of all current chat, groups, forums, etc. that ALDA has? That would be a great help.

Thanks,
Margreta von Pein

The editors respond: We are happy to include the information Margreta requested for the benefit of our readers. ALDA, Inc. distributes the e-news (see Christine Seymour’s article about it in the Biz section), is on Facebook, and sponsors a Yahoo Groups list. In addition, some ALDA groups and chapters have their own list. We have provided the active lists below, along with subscription information for them and for e-news. If we have missed anything, please let us know!

ALDA News doesn’t have space to include this information on a regular basis, but it will be posted on the ALDA website.

Sponsored by ALDA, Inc.: ALDA-ideas: ALDA-ideas-subscribe@yahoogroups.com ALDA e-news: e-news@alda.org (enter “subscribe” in the heading)
Below is a response to Margreta von Pein’s letter to the editor in the Spring 2009 ALDA News.

Margreta,

Thank you for pushing forward a dialogue that is long overdue. I’d like to introduce you to the Law of Indirection, which says that what you reach for moves away from you. What you have to do is go in the other direction and lay the foundation to allow what you seek to come to you. An example would be reaching for happiness but being unable to grasp it. The Law of Indirection suggests that you go to the place that is most painful and do the work you need to do, and happiness will then come to you.

In this case, asking about “far-reaching objectives” seems like standing in a valley and trying to see beyond the hill. It feels like reaching for something we can’t even see. If that is the case, then what is “the other direction” and what is the work and foundation, according to the Law of Indirection?

When I talk to hearing people or culturally Deaf people, the same question seems to arise: “Who are you?” To both, there are only two choices, two states of being: either deaf or hearing. To hearing people, I look hearing, not deaf. When I explain I’m deaf (late-deafened), they look confused. To Deaf people, I don’t look culturally Deaf, so they assume I’m hearing. When I explain I’m deaf (late-deafened), they also look confused. This points out our conundrum. We are neither hearing nor culturally Deaf, but almost all of society (hearing and Deaf) expects us to be one or the other! We have to accept ourselves, leave behind that old “hearing” identity and all the pain it caused us, and embrace our late-deafened identity. A few late-deafened people seem to be able to grasp their identity change very rapidly with little, if any, struggle or turmoil. I’m definitely not one of the fortunate few!

Late-deafened would be defined as the loss of a significant amount of hearing usually at the age of 18 or older. That is, late-deafened people grew up either hearing or hard of hearing but not deaf. They lived in the hearing world, went to hearing schools, dated and married hearing people, worked in the hearing world, and judged themselves by hearing standards. They have speech and use English (or another spoken language) as a first language. Some people who became deafened prior to 18 years of age also identify with the hearing community. [Editor’s note: essentially, late-deafened people became deaf after the acquisition of spoken language.] These two attributes, speech and English as a first language, seem to define our world, our culture.

Our new language is voice and sign (with varying degrees of fluency). We have our own “language”, a patois of spoken English and ASL. One of the definitions of a culture is a separate language. In that way, late-deafened people form a separate culture. [Editor’s note: many late-deafened people do not know sign language, and those who do usually use some form of signed English. In contrast, the Deaf community uses American Sign Language (ASL), which has its own grammar. Unlike ASL, signed English isn’t considered a separate language.]

So, that brings us to the first item of action: Define ourselves with clarity and strength. We have a solid, firm foundation with ALDA. But we have yet to start the real work of ALDA. We have to define ourselves before the hearing world and the Deaf world do it for us. We ride on the coattails of others without a voice of our own. So, in other words, our homework is to find our voice. The, “future of ALDA” would be how to present and promote our culture (which we have just defined). But we’re not going to be able to do this on the backs of a few people. It was my privilege to witness and participate in some of the great moments of the 60s. We have another opportunity to hitch up our boots and take giant strides, but we’re going to have to become more of an active group. We’re going to have to expect of ourselves, and others around us, a greater

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Letters to the Editor (continued)...  
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effort at participation.

So, let’s hear what it is to be late-deafened. How are we different from hearing? How are we different from Deaf? If we know who we are, we can more easily work to accept ourselves, and joy and serenity will find us. By going in the opposite direction, away from joy and serenity, and doing the work and laying the foundation, these things will come to us.

Rick Rutherford

READER COMMENTS AND EDITOR RESPONSES

Editor’s note: we will occasionally feature reader comments about ALDA News along with our responses.

No CI for Me!

By Robin Titterington

I became deafened when I was a 19-year-old college sophomore. Let’s just say it was over 30 years ago (but I don’t look it!). I am sure if cochlear implants were available at that time, I would have been first in line. But there were no CIs, no CART, no television captioning, and worst of all, NO ALDA! There’s no need to repeat my journey, but when I moved to Georgia 30 years ago, I only knew “signs.” Surely not fluent and surely not ASL. But I was adopted into the Deaf community, where I was welcomed, taught, and loved. I became very active, I was elected to several positions, and I became (so I’m told) fluent in ASL. Yet my Deaf friends still do not comprehend the sense of “loss” that comes with adult-onset hearing loss.

I have other medical challenges, and not a week (hardly a day) goes by that does not find me in one medical facility or another. I do not plan to undergo any medical procedures that are optional. My head is one of my few parts that is still original (not that that’s a good thing!), and I plan to leave it that way. If you told me a CI could give me perfect hearing like I had 30 years ago, maybe...NAH, probably not!

I am thrilled for my friends who have cochlear implants and are satisfied with the results. I would encourage anyone who wants one to go for it. But I have been a little distressed with recent comments. At least twice at ALDAcon last year, I heard speakers say something like, “everyone should get one.” This is not the ALDA way as I understand “whatever works.” And indeed, a whole issue of ALDA News on cochlear implants seems to be something I would expect from SHHH/HLAA. We have many members who are not eligible for implants or ABIs or like myself, are not interested. I think it’s great to share experiences with them, positive and negative. But I’m discouraged to see an issue with a theme such as this. I suppose we could have another issue on “why I learned sign language” but there is a separateness to that that disturbs me.

Again, to all my friends with cochlear implants or ABIs, HURRAY! But please don’t tell me I need to get one too. It’s not “what works” for me!

The editors respond: We are very glad that Robin brought up this concern, which has no doubt occurred to some others as well. ALDA News has a theme for each issue and includes several articles from different perspectives concerning that theme (along with other articles on other topics related to late-deafness). We understand that all themes will not be of equal interest to all our readers (if we have an issue featuring late-deafened parenting, those without children won’t be able to relate; if we have one on attending college after becoming deafened, those who either didn’t go to college or did so before becoming deafened won’t be able to identify, etc.). However, we always include articles and features that are not on the theme, so everyone should find something of interest.

This publication is firmly committed to ALDA’s “whatever works” philosophy. Because of space considerations, we aren’t able include a sufficiently broad range of articles on each type of communication in a single issue, so it’s necessary for us to address each one separately, but we hope that Robin and others who include sign language in their communication repertoire will be pleased to know that we have already planned to devote an issue to that topic.

NOT A MEMBER?  
Join online at www.alda.org  
Or 
Use the form in this issue of ALDA News
ALDA President-Elect Linda Drattell Runs to Raise Money for ALDAcon!

Linda will run, walk, and crawl five miles for ALDAcon, to help support the programs and speakers it offers. She is asking everyone to sponsor one or more miles by donating $20-$100 per mile. ALDAcon needs our help, and what better way is there for us to give back to the organization that helps us overcome obstacles than by overcoming our own personal obstacles? In Linda’s case, her doctors have informed her that her hearing loss is due to rheumatoid arthritis (RA), which causes painful swelling in the joints. She has decided to run despite the effects of RA on her left hip, left knee, right shoulder, and both ankles.

Please consider sponsoring ALDAcon through Linda’s Run, which will take place on August 15. Names of all contributors will be listed in the Fall ALDA News.

Checks (made out to ALDA, with a note on the check saying “Linda’s Run for ALDA”) should be sent to Linda Drattell, 1702 Nursery Way, Pleasanton, CA 94588 by August 1.

Anyone wishing to join Linda on her run is welcome!

IN MEMORIAM
Salvatore (Sal) Parlato, Jr.

We recently learned of the passing of Sal Parlato on November 12, 2008 due to a stroke. He had contributed poetry about hearing loss that appeared in several recent issues of the ALDA News. Born in 1931, Sal lived in Irondequoit, New York and celebrated 50 years of marriage to his wife Dolores. He served in the Marines during the Korean War and wrote a book about his experiences at the Parris Island boot camp. He recently published A Bad Hear Day, a book of poetry about hearing loss. Sal was the first Director of Instructional Media at the National Technical Institute for the Deaf, and after retirement he taught sign language classes for children and English as a Second Language (ESL) classes for the Catholic Family Center’s refugee program. His many contributions will be missed.
My Cochlear Implant Story
By Martha Mattox-Baker

For many years getting a cochlear implant (CI) was the last thing that I wanted to do. The idea of my head being cut into was beyond imaginable to me. There was a girl in my church who had a CI, and she always asked why I did not get one. I avoided her, as I was just not ready. Also, since I was involved with the Deaf community, I only heard stories of the CI not being successful. It was not until 1999, when I joined an online group called the SayWhatClub, that I started hearing success stories with the implant. I began listening but was still too afraid to get one. I also joined other CI groups as well.

In 2000, I noticed that I was really having problems hearing and figured it was time to have my hearing aids checked, as I thought something was wrong with them. The dispenser where I bought them tested the aids and my hearing and said that the problem was my hearing, not the hearing aids. At the time my daughter was 12 and refused to write things down, repeat what she said, or sign to me. I knew the next few years would not be getting better and realized that I needed to see if I qualified for the CI.

I went for an evaluation in February 2000, and I did qualify. I had to wait for insurance approval, and since I was in several CI groups, I knew that this could take awhile, so I figured I had time to adjust to the thought of having surgery. To my surprise, I received a letter two weeks later saying I had been approved and a surgery date was given to me. I was shocked and not quite ready for this.

I wondered what the Deaf community would say, as I had been a part of it for a while since I had lost my hearing. I knew they were against the implant at this time. One night at a Deaf club meeting I talked to a friend and found out she had the implant also. I told her I was afraid of what Deaf people would say. Her wise words helped me make my decision: “They are not going to have to wear it—you are.” That was so true, and I had the surgery on May 23, 2000. My parents and two of my friends came to be with me. I also asked for an interpreter, who accompanied me to the operating room and was in the recovery room as well as helping the friends who were waiting for me. I spent the night in the hospital and then had to wait six weeks to be connected to the processor because the swelling needed to go down. I had a lot of problems with tinnitus those first six weeks and wondered if the surgery was a mistake. But after the swelling went down I did not have any problems.

When I went back to work two weeks after the surgery, I made the mistake of wearing my eyeglasses. No one had told me to take the ear piece off my glasses and it tore the incision, so I always tell people that if they wear eyeglasses, they should remove the ear piece until the incision is healed. [Editor’s note: Martha’s unfortunate experience with her eyeglass ear piece may have been unusual, as there are many CI recipients who wear glasses but have not had similar problems.]

On my hookup day (June 30th, 2000), my audiologist did what is called a “mapping,” in which I listened to various high and low tones and indicated when I could hear them. Once this was finished, she turned on the external processor and asked me, “What of this can you understand?” I told her I understood everything. She was shocked, as most people cannot understand voices when they are first hooked up. My mom met me in the waiting room and asked me, “Can you hear me?” and I said, “Yes.” After she took me home, I was driving with my daughter and heard the radio. I pulled over to the side of the road because I was in a state of awe. I understood what the DJ was saying!

I never expected to be able to tell what people said, much less on the radio where I could not see their faces. My daughter was just sitting there not sure what to make of all this. I wish she had a camera that could have recorded everything I was dealing with that first day. Later on in the evening I was on my computer and she was sitting on the sofa across the room. She said “Mom,” and I turned around and said “What?” That was the first time she was ever able to just call my name have me respond. Her eyes got as big as quarters and she said, “Cool, I can live with this.” Later she found out it was not so cool, as I could hear her sassing me! I had not known how much she talked back behind my back.

Many people have said they are able to hear music very well after the implant. I still have limitations. I am able to listen to and understand the music from before I lost my hearing (mid ’70s and earlier). After that, I need words to help me. I am involved with a hearing church choir and had to teach myself to be able to hear that music. For the past two years I have been signing for the choir on tours. It takes all the hearing I now have to be able to do this. Understanding the radio does not come naturally to me. On the phone, I can understand some people, depending on their speech.

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My Cochlear Implant Story (continued)...

I still used interpreters for meetings when I worked, and I still request them for concerts, since the interpreters help me when I do not hear. I am still involved with Deaf community activities but not as much. I tried to keep my daughter involved in going to a church, so I switched back to a hearing church, but I am still involved with the Deaf church. I am now living in retirement housing for the Deaf. I was worried about how Deaf people there would react with me having the implant. I see people signing, “She is hard of hearing,” although without my processor I am deaf. But no one has rejected me for having the implant. I have seen the CI accepted more now than it was nine years ago when I got mine.

The implant helps me a lot, though many times when I am alone I take it off so I can relax. I use closed captions on TV. When I am with people I am thankful to have the processor. It’s like having the best of both worlds, which is much better than when I lost my hearing in the ’70s and told my Mom that the Deaf have their sign language and the hearing people have their voices and I had nothing. I felt so disconnected.

When I had the implant, it gave me back my life. My only regret is that I let my fear keep me from getting one sooner. Now I am hearing the first words from my grandsons. It is a miracle to hear again, and I thank God and the doctors for this.

Marty’s mother had rubella while pregnant with her, and Marty may have had some hearing loss due to this or from severe ear infections when she was small. Her hearing loss was detected when she started first grade, but she didn’t need hearing aids then. During her senior year of high school in 1975, her hearing started to fluctuate, and she was diagnosed with Meniere’s disease. She had one year of college at Lynchburg College in Virginia, where she was born, and one year at Ohio State University. Marty was unable to get into the college of education in 1976 due to her hearing loss, and she was employed by Nationwide Insurance for 30 years until a mass layoff in the area. She has three grown hearing children and four hearing grandchildren, and lives in a Deaf housing area with independent living in Westerville, Ohio. Marty is the organizing group leader of ALDA-Midwest (an online group with members in Ohio and surrounding states) and has remained its leader since 2000. She has attended three ALDA conventions and tries to stay active with ALDA and other hearing loss groups as well. She can be contacted at mattoxml@yahoo.com.

Seeking I. King Jordan Award Nominations

This award is be presented to a late-deafened person who has

- had a successful and distinguished career in their chosen field of endeavor
- made significant contributions to their community, profession, and/or nation
- provided an outstanding role model for late-deafened adults everywhere
- clearly demonstrated to the hearing community that a person’s competence, integrity, and human worth are not necessarily diminished by the fact they are deaf

Recipients will be chosen by the ALDA Board of Directors from the nominations that are submitted by members. If you know someone who is deserving of this award, send your nomination today.

Nomination deadline is August 15, 2009.

The ALDAcon 2009 I. King Jordan Award Nomination Form is available online at www.aldacon. alda.org or in PDF file or Word form. If you choose PDF or Word, print it out and mail it to:

Kathy Schlueter
I. King Jordan Award, c/o ALDA, Inc.
8038 Macintosh Lane
Rockford, IL 61107

There is Nothing Like ALDA Karaoke

Where else can you sing your heart out and not have to worry about what you sound like? ALDAcon’s famous Saturday night karaoke party is a one-of-a-kind event. An open stage lets you come up and join the revelers whenever you catch the spirit. Old-timers share the spotlight with newcomers, and a chorus line is not an unusual sight.

On the dance floor no one needs a partner; so twist and shout, do the hokey-pokey, the Macarena, or the Electric Slide—there’s dance you’re bound to know.

ALDA karaoke has a longstanding tradition of providing balloons to help us feel the beat when our ears might miss it. Enjoy the fun and laughter sitting at a table with a balloon between your legs while tapping your feet and you’re sure to have a smile on your face.

No matter how you choose to enjoy, it the ALDAcon karaoke party is an experience not to be missed! Come to ALDAcon 2009 in Seattle (October 14-18) to enjoy this and many other activities designed for stress-free communication!
How the CI Has Affected My Life

By Amber Wilhelm

I got my Nucleus Freedom cochlear implant (CI) 8 months ago. It took me 5 years and 3 different hospitals to finally make the decision to go ahead with the CI. Before getting the CI, I had 6% speech discrimination in my left ear with a hearing aid and none in the right. After receiving the CI in my left ear, I have 92% speech discrimination. It has had a tremendous impact on my life in a positive way.

I lost my hearing 12 years ago and went on to learn sign language and graduate from Gallaudet University. I adjusted to this new life and quit focusing on what I couldn’t do anymore after the first 2 years of losing my hearing. However, I could no longer talk on the telephone, listen to music, go out without making sure there was some kind of accommodation for me at specific events, or enjoy hanging out with people who didn’t use sign language.

Fast forward to the present. I am doing all those things and more, but this has not come without impacting me personally, professionally, and in my relationships with family and friends. It feels unnatural to talk on the telephone again without relay, fly on an airplane and hear the pilot's announcements, listen to the words of music, and sit in church without accommodations. I never thought that I would hear well enough to do any of those things again.

Professionally the CI has impacted me in several situations. Sometimes when I am in meetings that include sign language interpreters, I don’t know whether I should look at the interpreters even though I am hearing the speaker. When I call through voice carryover (VCO) on the videophone at work, I can hear the person on the other end, but I feel like I need to look at the interpreter on the screen. I always had to schedule an interpreter for meetings, and now I don’t need to for small groups. I will be going back to school in the fall and am trying to figure out what accommodations I will need in class and for my internship. This has opened up a whole new way of thinking and can be quite challenging.

My family is amazed at the miraculous turn of events. I went home to see them recently, and communication was so different. Normally they use sign language with me and I have to look at them to read lips. This time we didn’t use sign language as much and I didn’t have to look at them every time they spoke to me. It felt unnatural, but this whole experience has opened up a whole new world for me.

My friends have been supportive both in the past and the present. Most want to know more about my experiences with the CI and how I feel now. My friends who do not use sign language are amazed at how I can understand them without having to look at them. I actually enjoyed hanging out in a hearing group for the first time in a long time when I recently saw some of my old friends. They still see me as me as the same Amber, though with a little more hearing.

The CI has made my life better in some situations; however, I still see myself as a deaf person, since I can go from 92% to 0% in a matter of seconds when I take off the external device. It is a unique feeling to be able to go back and forth between two worlds whenever I want to. Even though the CI has impacted me positively, it doesn’t come without its challenges. This is no easy road no matter which way you go.

Amber recently completed her job with the Hearing Loss Advocacy Network program as an advocate for hard of hearing and late-deafened people. She will start studying for her master's degree in social work this fall at the University of Vermont. She enjoys snowboarding, fishing, hiking, playing with her dog, and volunteering as secretary for ALDA-Maine in her free time. Amber can be reached at wilhelmamber@yahoo.com.
Late-Deafened Life—We’re All in It Together: A CI Story

By Michele J. Bornert

Where were the crickets, darn it! I want to hear the crickets! As I sat in the programming room at St. Louis’ Central Institute for the Deaf (CID), I was greatly disappointed.

It had hit me during my third pregnancy. Deafness, that is. I was born without an ear on my right side, so I was essentially partially deaf from birth. However, my family had decided to take the casual approach and just make sure they walked on my left, let my hair grow long, and ignored the deformity. Of course, that didn’t stop me in grade school from pulling back my hair to gross out Patti Vamvakias. I loved the shock value! But, technically, I could still hear pretty well on my left side, though not 100%. So I grew up hard of hearing in a hearing world and never even knew it. I thought everyone strained to figure out what noises they were hearing and from what direction sounds were coming from.

Then BAM! One day during my third pregnancy, I lost all sound whatsoever, practically overnight. All three pregnancies had been high-risk, and the second one almost killed me. The doctors tried steroids, hearing aids, everything they could possibly think of to do to a pregnant woman, to no avail. I remember going to my specialist’s appointment and asking him if I should learn sign language. His response? “Oh, don’t learn that stupid stuff. Just come back once the baby’s born and we’ll slap one of those cochlear implants in you.” Hmmm. Sounded easy enough.

I struggled through the remainder of my pregnancy, which ended six weeks early (pretty good when compared to my second child being sixteen weeks early), and went back to my specialist. He sent me to CID, which is supposed to be one of the best implant centers in the nation. They gave me lipreading tests and audiograms and quizzed my husband and me about how much ASL I had been using (I had secretly started learning it and found I had a natural ability, so I excelled). But, all in all, the staff approved me as an ideal CI recipient and set the date.

That was it. I was told when to show up at the hospital and what to expect. No x-rays, no MRI’s, no auditory brainstem response tests. I just showed up and wham, bam, thank you, ma’am, I was officially an implantee. But instead of a medal, I was given a card to carry with me in case I set off any metal detectors and to let doctors know that if they attempt an MRI on me now, they’ll be cleaning up the remnants of my head for weeks.

I believe it was six weeks later when I showed up to be programmed. Oh, boy! Now I can hear my babies cry, my other kids laugh, and, of course, those chirping crickets! They started the programming...nothing. “Are you going to start soon?” I asked, unsure of what was happening. Worried looks abounded. “Just a second,” they motioned. Minutes went by. Nothing. I was beginning to become anxious when someone entered the room and informed me that they were getting no response from my cochlear implant. It seemed it had failed. Not the device itself, mind you. That was working just fine. But my brain wasn’t picking anything up.

What happened next was a whirlwind of tests and X-rays, one after another and back again. Could it be true? Regrettably, yes. They’d overlooked checking my auditory nerve. It wasn’t working. The CI was useless. What’s worse, if anything could be, was that the autoimmune disease they’d found that caused my deafness would have actually regenerated the nerve with time and all of my hearing in that ear would have returned. So what does this all mean? It means I had an unnecessary surgery that rendered me stone deaf. I can’t even hear myself scream if I want to—and believe me, I’ve tried.

A few months later, I had the auditory nerve on my right ear severed to try to reduce the tinnitus. It didn’t work, but I now have absolutely 0% residual hearing. A rarity of sorts.

But what’s worse than all of that? Worse than never hearing my children laugh and sing, never hearing music again, and never being able to do musical theatre like I used to? I’m never going to hear those damn crickets again! Now that’s a true bummer.

Michele J. Bornert has since had her CI removed and is now fluent in ASL. She teaches it through her company, Deaf Expressions. She lives in Michigan with her hubby, Kenny, and three kids (all who sign). Visit her online at www.DeafExpressions.net.
I've experienced all aspects of hearing and hearing loss. I was born hearing. In my early childhood, continual ear infections (before penicillin) caused periods of severe hearing loss and some slight hearing loss afterwards. In the ‘60s the noise of rock ‘n roll and single-engine airplanes further damaged my hearing, so in 1973 I began wearing hearings aids for a moderate sensorineural hearing loss. In 2000, Lyme disease caused a profound loss in my right ear and a severe loss in my left. In 2003, the left ear went profoundly deaf, and I lived deaf until 2005, when I got electronic sound implanted in my left ear. Did I miss a stage?

Each stage required me to accept and adapt to the perceptual and cognitive change. The biggest change was becoming deaf. I am a deaf person now. When asked, I say, "I'm late-deafened with electronic sound in one ear." I honor and cherish what I learned those five years without sound. I cannot forget being without sound. If for some reason I could no longer use an implant, I would live quite comfortably as a late-deafened woman.

People ask me, “Are you happy with the CI?” I say, “Before, I had no sound. Now I can be deaf or hearing. I didn’t have that choice before.” But am I happy with it? I'm still in transition.

Being deaf is a more natural state for me than having electronic sound. Being deaf in both ears is more natural than having sound in just one ear. Maybe when I have this CI sound for as long as I had no sound, I will think about it differently. I decided to get the CI because I wanted to hear my family’s and friends’ voices again. I decided that I would not expect to hear music or birds or even have very refined hearing restored. I would be happy if I could just hear what my granddaughter said to me. I can, so for that reason I am happy with the CI.

In the week of the activation, I had a revelation a minute. In the second week it was a revelation an hour. After six months, revelations were still coming daily. The process fascinated me. I loved watching how my brain performed, sometimes top down when I told it nothing, sometimes bottom up when I explained to my brain what that sound was. When the revelations slacked off and my brain had pretty much learned to hear English, I began to notice what I was missing.

Music. Voices on the telephone. Where a sound is coming from. Movie and TV dialog.

I use assistive listening devices where I can, and I speechread. The CI enhances my speechreading. I do not hear as well as I did years ago with two digital BTE hearing aids for a moderate loss. In addition, hearing electronic sound in one ear is not like being hard of hearing, where aids boost residual sound. The sounds I hear are the electrical engineers’ mathematical approximations of that sound. Sometimes I don’t understand because the algorithm is wrong, sometimes my brain is tired and not computing, and sometimes the program in my processor needs adjusting.

We have two ears. Binaural hearing is crucial for listening to music, hearing the pitch center, and telling where sounds come from. Many CI users eventually get two implants, which is only natural. For physiological reasons, I can’t have an implant on my right side. Therefore, my transition from deaf to CI sound may not be optimal.

I am getting used to being a foreigner in my native land. I speak the language but I often don’t understand it. Everyone speaks too fast. They slur their words in ways that I didn’t learn to listen for in language class. I understand when a friend sits opposite and close to me and speaks as if I am new to the language. Family and friends closest to me make an effort to communicate with me. Strangers don’t. Why should they unless I insist? I insist in order to receive instructions, directions, or other functional communication, but I miss the quick, inconsequential speech of everyday life because most speakers don’t even know what they’ve said after it’s passed their lips. To ask to hear those utterances would be fruitless and annoying for them and for me. Our language transmits our culture, and when I don’t hear that language, I lose touch with the culture as it forms, changes, and is expressed around me. I am in the middle of the transition to becoming a foreigner in my own culture.

After 25 years as a college English teacher, Margreta retired and moved to the San Francisco Bay area. She is a writer and has been an ALDA member for 8 years. Margreta had a moderate hearing loss for 30 years, was late-deafened for 9 years, and received a cochlear implant 4 years ago. She has a son and daughter and 5 grandchildren and can be contacted at mvpein@yahoo.com.
“But you’re still deaf!” said my friend.
“Yes, I’m deaf; but I can hear!” I responded.

I am deaf and yet I hear. That sums up the miracle of it for me. I can hear again after 42 years of total silence.

I was born with normal hearing, but at the age of 14, I became profoundly deaf due to a bout with spinal meningitis. My sense of hearing plummeted from normal to profoundly deaf during a span of three weeks. I never saw it coming, hadn’t time to learn to lipread as my hearing declined, had no clue about sign language, and frankly, I was afraid to go that route.

I felt my hearing loss was some mistake, that it would right itself along with my expected recovery from meningitis. I asked the doctor, “When will I get my hearing back?” He moved his lips to respond, but I couldn’t hear him. His expression spoke volumes as he wrote, “Elinore, you will never hear again.” Did I say I was only 14?

Once I recovered from my illness and returned home from the hospital, I found myself unable to follow my family’s conversations. I had been raised to “be seen and not heard” and was still pretty much a child, so did not ask for help. They just didn’t get it. I sat there during meals feeling totally isolated as they chatted away. I had always been a part of the conversation before, contributing my own brand of humor. No more. Big fat THUD!

Those first years involved learning to lipread and to cope and to accept that nothing would ever be the same. Lipreading was my only recourse at the time, as it was felt learning to sign would negatively influence my speech ability. Lipreading without any sound at all to clue me, combined with being rather a greenhorn at it, led me to withdraw and do all I could to avoid people. I later learned that I had set up a mental block against learning to lipread, still nurturing the hope that my hearing would return. I never felt so alone in my life.

My desire was just to get through each day without getting into some kind of difficulty or embarrassment. I hoped for no more. I wanted to get through this life as quickly as possible and be done with it.

Life intrudes, though. I had to start high school. I was mainstreamed (before that was a word), learning on my own by reading the textbooks and sitting like a rock through classes, missing every single thing that was said. I was not considered for deaf school, the thought being that since I was above the age of 12 and had acquired spoken language, going to deaf school would be a step backward. Such was the thinking of the time.

Teachers quickly forgot my situation, stood in front of windows as they talked, walked around the room, and otherwise made lipreading impossible. As at home, I said nothing and just kept my nose in my books. Fortunately, I had learned to read, and it was enough to enable me to make the honor roll, but not enough to enable me to make friends. So it went at school, at church, and at home, and there was nowhere else to go.

Fast-forward now from teenager to grandmother. In 1993, I was implanted in my left ear with the Clarion 1.2 cochlear implant and began the long road to relearning how to interpret sounds, particularly the sounds of speech. It was slow going, since I was dealing with an atrophied speech recognition center in my brain, a whole new world of sounds, and sound memories grown dim, not to mention being a bit long in the tooth. Even with all that working against me, I was overjoyed at being able to hear.

My husband, Jack, was patient with identifying sounds for me: a squeaky door, a plane flying overhead, rustling leaves underfoot, bird calls, chipmunk chips, all the sounds of life. Even before I began to grasp it all, that feeling of isolation, of numbness, lifted. It was still hard to join in lively conversations, but I could do it more and more as time went on. I knew when to speak and when not to, a big thing all by itself. My confidence grew as that underlying tension of deafness lifted.

I enlarged my circles, tried things I’d avoided before (such as joining committees and talking to strangers in stores), and dropped my old desire to avoid people. I actually sought them out now.

I loved being part of the give and take of life wherever I went. All these excursions into the world of sound enlarged my parameters, brought me new joy, and enriched my life.

Still, my speech recognition reached an impasse where I felt I could go no further, and I knew I had further to go, much further. About that time people began discussing the feasibility of getting a second implant. I went for it.

In 2005, I received my second CI, since upgraded to the Advanced Bionics Harmony. It made all the difference, filled the gaps in
my speech recognition, made music enjoyable, and sent my joy and confidence soaring. I could hardly wait for people to say something so I could hear it! I joined the church bell choir, listening and understanding the “ring-leader” without a hitch. Discussion groups were also fair game, and I got to know people so much better and to make new friends.

The radio and telephone are still bothersome, but I can understand whole sentences at times, and I feel certain I will get there if I keep at it. I’m ashamed to admit that I don’t, having gotten used to not having those conveniences and no longer missing them. I just don’t care that much anymore, and I know that’s wrong of me. I want the whole enchilada, but I’m not reaching for it the way I should be.

Life with the family is so much easier and happier, and I can feel and give the love that was so hard for me to do before. Prior to implantation, family events were trials to be gotten through with false smiles and other fakery. I did not enjoy my own family! I could not capture the feeling of closeness that hearing makes easy for others. I felt encapsulated in my little cell of silence. The grandchildren were the hardest. The cute things they said were lost on me, those charming comments that could warm my heart and help me to know and love these new little people in my life.

Conversation these days is mostly with Jack. He took quite a while to realize he could talk to me, to drop signing, to speak to me behind my back, and to be understood without hesitation. Sometimes he tries to talk to me when I’m “not wired,” as I put it. At such times, the struggle is back in all its awfulness. It’s a sobering reminder of where I’ve been…and where I’m going.

Yes, I’m still deaf. But I can hear!

Elinore is coordinator of ALDA-NJ and on the advisory council for ALDA-Garden State. She lives with her husband of 50 years, John, in rural New Jersey. Together they raise puppies for the Seeing Eye and are presently expecting their 20th protégé. When she isn’t wiping up, she enjoys quilting and is a wannabe writer. Readers can contact her at elinorebullock7@embarqmail.com.

My Experience with a Cochlear Implant

By Rick Rutherford

Which CI brand do you have? Advanced Bionics

Why did you pick this brand? It was picked for me. I was referred by my insurance audiologist to UCSF and UCSF had, at that time, only the AB model. I was offered no choice and, at the time, was clueless myself. I felt fine with it, I just followed. Would I change anything today? No.

How long have you had your CI? I have had it since January 1995. It’s the AB C-1, which is the dinosaur. I have a body worn processor, and they apparently have no intention of making a behind-the-ear (BTE) model for me. [Editor’s note: A BTE has been available for C-1 recipients since 2002, and a newer model is expected to be produced shortly.]

Do you have a CI for one or both ears? I have one only for my right ear. I was thinking of getting a second one, but my insurance status just changed for the worse. So, I’ll hobble along, gratefully, on just one.

How long do your batteries last? My batteries are rechargeable and cost $100 each. They start with a charge that lasts for 20+ hours. After a couple of years, this drop to about 12 hours, and after a couple more years, they’re down to 6 or so hours. I have an adaptor that works with 3 AA batteries, which last for about 2 to 2-1/2 days.

How do you feel about using your CI? What works well for you? I have to remember the actual biomechanics of the thing. I started with 30,000 receptors and now I have, what, 15 or so? [Editor’s note: earlier AB models had 8 electrodes; the current one has 16.] I just can’t expect the sound to be the same. When my expectations get out of control, I feel resentment, sadness, anger, frustration, and so on. I’ve come to accept each little thing as a gift, a miracle. For instance, using the phone is an exercise in acceptance. I can use my cell phone, I can use Bluetooth. I accept that I’m not going to hear perfectly. I communicate this to the other person. I do what I can to help, and then I accept the results. Sometimes I have to tell the person that the reception is just not good enough and I’ll call them back when I get to an area with better reception. At home, I use a Phonemate, which plugs right into my old-fashioned body worn

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My Experience with a Cochlear Implant (continued)...

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I understand that telecoils can work as well.

What do you still have trouble with? How do you deal with it? Movies are pretty much out, radio is pretty much out, music is pretty much gone, and TV is pretty much out. I listen to oldies (50s and 60s) in my car. I’ll catch a short musical phrase and my memory fills in the song. I just decided one day to be grateful for the music I had. I had played the trumpet, violin, and guitar. I wrote music and had a much deeper understanding and appreciation for it than most people. I would cry, sometimes, feeling the pain of losing music. Then one day, I realized that I was lucky that I had had music, even for a relatively short time in my life. I had been exposed to a great deal of music, and even my deafness couldn’t take that away. I had something to be grateful for, not something to feel bad about. I had a taste of something most people never have. I go back to those memories and am grateful for the music I had. Gratitude is the antidote for resentment.

What don’t you like about your CI? I resent not being perfect. When I first got glasses (in the 8th grade), I remember feeling that now I wasn’t like other people. I couldn’t just jump into the water—I had to watch out for my glasses. I was really annoyed. I have much the same feeling about my CI. Now, I’m OBVIOUSLY different. But I read an inspirational piece in the Reader’s Digest about a Vietnam veteran who goes around encouraging other wounded vets. He joked that when he took everything off at night, the bed looked like a junkyard. Both legs, one arm, and several other things, too. He said, “They sent me two guys and told me to help get them back on their feet. They had no legs.” In contrast, I find my resentments so petty. This helps adjust my perspective.

Also, being in the hearing world most of the time, I don’t realize how wonderful my CI is. I’m hit again and again with how it DOESN’T work. Then, when I get back into the deaf, hard of hearing, and late-deafened world, I’m reminded again and again how WELL IT WORKS.

What advice would you give to someone who is getting a CI? I guess the main thing is not to try to make yourself into a “hearing person”—it isn’t going to work. The CI will help to make you a better YOU. And what you are is late-deafened. This means you and I and a LOT of other people have certain characteristics that are the same. We’re first and foremost NOT HEARING. We have a different journey. We’re also not Big D Deaf. There are MANY people like us—we’re just so darn
How has your family handled your hearing loss? Have they been supportive and helpful? Shown an interest in new communication modes? Lost all patience?"

My family has been supportive. All of my kids and my hubby sign well. My mother and sisters started to learn, but since I live so far away, they haven’t followed through. It can get frustrating being around those in the family who can’t sign, but I sure appreciate those who can.

My family has had a hard time dealing with my hearing loss. They get very frustrated with having to repeat things for me a lot. My boyfriend has gradually come to accept it, but my 12-year-old son hasn’t. He gets upset a lot and is always making remarks about my hearing loss and how it is getting worse. It makes him mad to have to repeat things. He says I talk too loud, but I can’t judge how loud I talk anymore. It is hard.

I know things could be a lot worse. I still can hear some things instead of deaf. I have problems hearing things in groups and at church, but I am learning how to deal with these issues.

Everyone was gung-ho about learning sign shortly after my hearing loss started. We even had two “family” ASL classes where a teacher came to us. Today (12 years later), the sign for “I love you” is the only thing in this new language that ANY of my family still knows. My husband took three semesters of sign, but, generally speaking, I had to change MY way of communicating with THEM (to lipreading/guessing). They all love me, but my hearing loss isn’t really their problem, it’s mine, and that’s how it’s been dealt with. Repeating goes a long way, though! I only had to throw a few fits when people used the dreaded “never mind.” None of them do that anymore! It would have meant a lot to me, though, if more of them hadn’t given up so easily, especially my parents. The kids in the family adjusted much better than the adults.

When I lost my hearing after NF2 surgery, my wonderful husband was always trying to figure out ways to help me understand. When he read about a speech recognition program, he immediately purchased one and set out to “train” it to his voice. One afternoon, while doing the training, he was interrupted by a phone call and inadvertently left the microphone on. The call was from a new doctor’s office, giving him directions, and he repeated them for clarification: “The doctor is next to the nursery with the pink flamingos” (those flamingos happen to be a very well known landmark). After he hung up he looked at what the speech recognition program had interpreted, and this is what it said: “the doctor is next to the nurse with the painful mangos.” What a metaphor for my life as a lipreader! Now, whenever I get really confused and don’t understand, my code words are “painful mangos.”

When I’m out shopping with my teenaged sons, they will often step into a conversation with a sales clerk or cashier to say, “My mom doesn’t hear well—,” then turn to me and say, “She was asking you ...” They don’t see it as a big deal or an embarrassment, just a matter of fact. I feel so well cared for and also respected as a person with a physical limitation that doesn’t mean I’m stupid or incompetent. They learned this from my husband, who does the same thing

We are doing a major renovation of our home. One of my sons loves to locate new gizmos on the Internet, and he did the research to find a visual alerting system for the phone and doorbell. What he found was really for commercial applications, but the electrician said it would work in a single-family home. It’s hard wired in and can only be ordered and installed by an electrician. It has both a strobe and a piercing 90 dB tone. (Because I have bilateral CIs, I plan to turn off the tone to keep my family from going nuts.) We are putting five strobes in, to be visible throughout the house where I would be likely not to hear the doorbell or phone. We move in this summer, so we’ll see how it works! The smoke alarm system has to be separate according to code regulations, so that requires a whole different setup.

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Chapter Happenings

By Anne McLaughlin, Curator

We have some good reports from our newer ALDA groups. It’s exciting to read about their activities and enthusiasm.

ALDA-Sonora representative and Region IV Director Michelle Lewis reports: “In the summer of 2008, about seven people widely spread through Arizona convened at Marta Watson’s house for our first unofficial in-hopes-of-becoming-an-ALDA-group gathering.

In November we met again with a larger turnout. Many people drove hundreds of miles to participate in our meeting, held at the office of one of our members. There were more introductions, and we decided we were ready to fill out our petition to become an ALDA group. In January 2009, ALDA-Sonora was born. Our attendance has varied from meeting to meeting, but each time we get together we have accomplished more.”

In February the group had its first small but successful potluck, and the April meeting was at a senior center in Surprise. Agenda items included sharing start-up information and delegating responsibilities. Cynthia Amerman is the group leader, Marta Watson edits the newsletter, Lloyd Bently takes care of web design (under construction, but coming soon!), Michelle Lewis handles advertising, and Faye Bently will chair book reviews. For more information about ALDA-Sonora, contact Cynthia Amerman at bigred0822@aol.com.

ALDA-Peach reports via Ann Smith that the chapter held elections in November. Marge Tamas continues as president while Yael Shaner is vice president, Belinda Miller is treasurer, Ann Smith is secretary, and Roxanne Gasaway is member-at-large. In December, the Peaches gathered for lunch at Kacey’s Buffet in Tucker. Ann reports that “as usual we all had a great time enjoying the home-style cooking, the delicious cheesecake, and each other’s company.” January was the annual “un-birthday party,” where all members’ birthdays are observed with cake and ice cream as well as other goodies.

At the February meeting, Belinda Miller, Peach’s resident expert gardener, gave tips on growing spring and summer bulbs. This presentation fused with Peach’s spring fund raiser, the sale of summer flower bulbs. The sale successfully added more than $450 to Peach’s treasury. Karen Sack of Hamilton Relay gave an excellent presentation on the Georgia Relay at the March meeting, covering CapTel, Web CapTel, and Internet Relay via PowerPoint and live Internet demonstrations. Karen also explained the new ten-digit phone numbers for relay calls. Future plans call for a meeting with Dave Litman’s new North Carolina ALDA group in Greenville, SC.

ALDA-Puget Sound is excited to be hosting ALDAcon 2009 in Seattle, WA from October 14 to 18. Chapter members are working hard on registration, silent auction, and hospitality activities. The group celebrated its second anniversary in April. Last autumn, it expanded and now consists of two parts: South Sound and East Side.

In May, the group sponsored a booth at the Taste of Technology, an event put on by the Washington Relay Service, Sprint, and the Washington State Office of the Deaf and Hard of Hearing. Presentations featured the latest information on CapTel and Web CapTel, hearing aid compatible cell phones, wireless telecommunication technology, and the Washington Telecommunication Equipment Distribution Program. In July, ALDA-Puget Sound planned to join the Hearing, Speech & Deafness Center for a night with the Seattle Mariners, with proceeds from ticket sales divided between them.

Thanks for the input from these chapters and groups. How about the rest of our ALDA chapters? Let us know what you are planning and what you have done lately. Send your reports to maumsie@sbcglobal.net by August 18.
Abbie Cranmer describes herself as “a technical abstract work of art, self-sufficient sophisticated woman, a placid creature that unknowingly hunted the knowledge of deafening silence who has nestled herself in the lovely Garden State.” As you can see, Abbie has the gift of writing, but she is so much more than that. She is an advocate, mentor, and friend to many people. We are fortunate to have her as a member of the ALDA family, and if you would like to keep up with Abbie on the Internet, her blog can be found at http://contradica.blogspot.com. Please read her interview and see why Abbie is “One of Us”!

Name: Abbie Cranmer
Where were you born? New Jersey
What is your current residence? Toms River, NJ
What is the cause of your deafness? Progressive sensorineural hearing loss
Age/year you became deafened? I was diagnosed at four with a severe/profound hearing loss. However, there were signs in the earlier years, such as lack of speech development, that indicate I was probably born with a hearing loss or began losing my hearing early on.
Marital status? Single
What is your present job? Full-time bookkeeper and part-time computer technician
What is the worst job you ever had? Working at McDonald’s has to be the worst job for me.
Movies you want to see again? I love Denzel Washington. My favorite movies are Lean on Me and Déjà Vu.
I stay home to watch: The latest Hallmark movie premieres
Favorite pig-out food: My newest is Dark Chocolate M&Ms and Pad Thai; but not together.
Hobbies: I love to work out, garden, and eat. I probably consider my Blackberry a hobby because I pay more attention to that than anything else

(Curator’s note: some people might use the term “addiction” to describe Abbie’s Blackberry use).

If I had more free time: I would probably be able to blog a whole lot more.

The hardest thing about becoming deafened: Was facing the reality that I was deaf. I didn’t have much to lose, since I was already severe/profoundly deaf, but I chose to have a deviated septum surgery in February 2007 and when I woke up in the recovery room I was completely deaf. I had no hearing at all. It was quite a rude awakening because I never thought I would lose my hearing completely. I kept praying that it would come back, but it didn’t.

I began accepting my deafness: About a month after the surgery (as described in the previous question), I performed a repetitive morning ritual of placing my hearing aid in my ear, hoping for some semblance of sound to be pumped into my ear. I just finally accepted the fact that I was utterly and completely deaf and nothing was going to change that. It felt like a weight has been lifted off my shoulders when I finally came to terms with the fact that I was a woman with no hearing and not a woman hiding the fact she has no hearing.

The worst thing about deafness: You feel alone in many situations, especially when you start missing the flow of conversation.

The best thing about deafness: I sleep very soundly! I wouldn’t trade that in for the world.

How did you learn about ALDA? When I attended an HLAA convention

In what ways has ALDA (or deafness) enhanced your life? I loved the fact that you didn’t have to be late—deafened—it didn’t matter what point in your life you became deaf. It also didn’t matter what method of communication you used—verbal, signing, cued speech, or writing. Whatever works to make sure a person understands is truly the motto ALDA lives by. I was amazed at the pleasant and welcoming atmosphere, where all communication barriers were just wiped away.

When I am depressed: I write and eat then I write some more.

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Our World—News from the International Committee

Submitted by Lauren E. Storck, Chairperson

The International Committee (IC) shares international and intercultural news about hearing loss from around the world. As economic headlines have shown, we are all more and more a global interconnected community.

The IFHOH (International Federation of Hard of Hearing People), of which ALDA is a voting member, is already making plans for their next large convention in 2012, in Norway. Save your pennies! And 2010 will see their biennial conference in Sweden. Wouldn’t it be nice for some ALDArocks to meet up at one of those places? We have a lot to learn from each other. See www.ifhoh.org for more information and to read their good Journal, also online. The Journal has an article about cochlear implants, and you may see a familiar face or two in this publication. The editor, Ruth Warwick, lives in Canada and is a pleasure to chat with on emails.

Liisa Sammalpengen of the IC, who lives in Finland, reports that the Nordic Council for deafened people organizes a “Summer Week.” This year, it will be held from June 28 to July 3 in Sweden, and next time it will be in Finland in 2011. She can be contacted about these events via the IC.

Liisa took an enjoyable cruise “very south” around Cape Horn and shared some photos with all of us on the IC, and described some of her experiences with accessibility issues on the cruise. She suggests that anyone planning a cruise get in touch with the company well in advance to learn about, and request, any accommodations needed for hearing loss. If ASL or CART is not an option, Liisa recommends asking for some time from a designated staff person to take notes, and some free Internet time (for communications even on board; there is a charge for this on the cruise, as in many hotels). [Editor’s note: those who can benefit from an assistive listening system should likewise request one from the cruise company well before the cruise.]

Muhammad Akram of Pakistan has also shared photos from his travels to Asian conferences, and sometimes we wish we had our own IC photo album!

As we write this column, the ALDA Board is reviewing the petition for the first official ALDA group outside the USA. Thanks to the interests and energies of ALDA member Muhammad Akram, the ALDA-Asia Group is gearing up. The IC has offered information and encouragement for several months, including communications with others, including a WHO (World Health Organization) contact.

My travels to France this past winter included a visit with Jacques and Sabine Schlosser, f Surdi 13, a French regional hearing loss group. Some of you may remember how much they enjoyed visiting ALDArocks in Chicago a couple of years ago.

As we gear up for the Seattle ALDAcon, we hope more of you will share your international and intercultural interests with us. Email your news to Lauren anytime at drlestorck@gmail.com.

One of Us (continued)...

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My most irrational fear: That while I’m driving over a bridge, something will happen, causing me to go hurtling down into frigid cold water (Curator’s note: I am shivering in more ways than one reading that!).

If I could hear again, the first thing I would do: Well, when I had my cochlear implant activated, I wanted to hear my dog bark again.

The thing I like best about myself: That I can be myself

Nobody knows: How many pairs of shoes I really own

One thing I can’t stand: People who think they are going to get the perfect change award in busy lines at department stores

Favorite memories: I remember growing up and baking with my mom in the kitchen.

Favorite saying: “We are all created equal and each of us deserve no less than others because we all sleep in total silence” by me.

The bottom line is: That there is life after deafness.
My World is No Longer Silent (continued)...

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world devoid of sound, or I could have the ABI, and possibly have some sound perception. So, I decided that I wanted to have the ABI.

On September 30, 1998, Drs. Roland and Golfinos implanted the ABI on my right side. On November 9, my audiologist, Dr. William (Bill) Shapiro, programmed the speech processor with a computer. I heard a sound, but I was not sure whether it was from the computer or if it was just tinnitus. I then heard another sound that was very different from tinnitus, and I knew that I was hearing the sounds from the computer.

I was ecstatic and felt very optimistic that I would be able to hear well again. Although Dr. Roland, Dr. Golfinos, and Bill Shapiro told me that I would not have “normal hearing” with the ABI, I was in denial. I longed for the excellent hearing that I once had, and I did not want to accept the fact that the degree of my hearing loss would always be profound. I set my expectations unrealistically high and was very disappointed. I could not recognize environmental sounds, because all sounds were alike. I was able to hear voices, but speech was garbled and voices were monotonic and mechanical. During one of my follow-up visits, I told Dr. Roland, “I hear your voice, but you sound like a robot.” The quality of the voices, combined with the garbled speech, made it more difficult for me to read lips.

When the ABI did not meet my expectations, I was frustrated and angry. I blamed it for my inability to hear well, and I refused to wear the device. I needed to remind myself that bilateral vestibular schwannomas had rendered me deaf, not the ABI. Since I had a strong desire to hear again, I was determined to obtain as much benefit from the ABI as possible. I wore the device more often, worked with speech/language pathologists to improve my speech reading skills, had several programming sessions with Bill, and became more patient.

Sounds heard through the ABI are different from what they were before I was deafened, so I had to learn to identify them. Eventually, I became accustomed to the new auditory input and realized that all sounds were not alike. I noticed differences in rhythm, duration, and pitch that helped me distinguish between sounds. Some are easier to identify because they sound similar to the way they did before I was deafened, while others are more difficult because they sound very different.

The ABI has helped improve my speech discrimination. Before I had the device, I relied solely on speechreading. However, this can be difficult, because certain speech sounds look identical on a speaker’s lips and some cannot be seen on the lips. With auditory input from the ABI, I can hear the differences in the speech sounds. Over time, voices began to sound more natural and speech sounded more intelligible.

I ask people speak a little slower, which makes it easier for me to read their lips. Often, it’s just one or two words in a sentence that I cannot understand, so I ask the person to repeat the particular word(s) rather than the entire sentence. I also count the number of syllables to help me understand words. If I have too much difficulty, I ask the person to write. I am usually able to understand women’s voices better than men’s, because a woman’s voice is normally higher pitched. I can hear my own voice and tell whether someone is laughing or crying.

In my early days with my ABI, trying to identify sounds and to understand speech required a great deal of patience. Many times, I became very frustrated. However, patience and persistence can pay off. My ABI has assisted me tremendously in adapting to my bilateral deafness by restoring my hearing to a level at which I feel more at ease within the so-called “hearing world.”

My ABI helped me emerge from my self-imposed seclusion and gave me back a part of my life that I had lost when I was deafened. I can interact more easily with hearing people, and I do not feel apprehensive about being outdoors. I am able to hear environmental sounds, including sirens, car horns, and motors.

An incident that happened a few years ago during the winter is vivid in my mind. A car had turned the corner as I was about to cross the street. I did not see it because another car was obstructing my view, but I heard the motor. I rushed back onto the sidewalk, slipped on the ice, and sprained my ankle. I was a bit annoyed that I sprained my ankle, but I was relieved that I was not hit by the car.

Being deaf is not the worst thing that could happen to me, but I am a late-deafened adult, and I prefer not to live in a world of silence. Before my ABI surgery, I often wondered: “Will the ABI help me hear?” Needless to say, the answer to this question is: “Yes… absolutely!”

Jacqueline Murphy lives in Brooklyn, NY. She is currently working as an independent consultant at New York University Langone Medical Center, in the department of Clinical Quality and Effectiveness, where she does data entry and reviews patient charts. She enjoys reading and writing and is assisting her neurotologist, Dr. Roland, on a voluntary basis with writing patient information brochures. Working with him has helped her gain a better understanding of NF2, vestibular schwannomas, and the ABI. Jackie can be contacted at Jmm2299@aol.com.
My Cochlear Implant—How Do I Love It? Let Me Count the Ways

By Carol Granaldi

After more than 50 years of struggling to hear the everyday sounds of our environment and to understand the speech of others, I was implanted in May 2001 with an Advanced Bionics cochlear implant. This opened a long-closed door that had separated me from easily communicating with people and hearing the things that normally hearing people take for granted daily.

When my small grandchildren visit, their high-pitched voices are more understandable. Conversation with my spouse is easier on him and me—I’m not stressed to hear him and he’s not stressed by having to repeat so often. When I’m shopping, I can hear my number called at the delicatessen counter and my name called in a medical facility. I more easily understand what a nurse or doctor or dentist is saying to me—no need to rely on my spouse to listen for me and convey what’s being said. I can mostly understand the speech on radio and TV, although captioning augments what I misunderstand. I can make voice telephone calls using the speaker on my desk and kitchen phones.

I can hear a kitty cat meow and my dog whine. Every morning I walk my dog and hear her paws rustle the fallen leaves. I listen to birdsong and bird calls, the bees that buzz by my “ear,” and the raindrops striking different places—the roof, gutters, and leaves. There are so many sounds to listen to: squeaky door hinges, footsteps in the hall, my dog’s toenails clicking on the kitchen floor, the microwave beeping, the stove timer ringing, the icemaker unloading ice cubes, water flowing from the spigot, food sizzling in the frying pan, water boiling in the pots, the teakettle whistling, the coffee maker pumping and dripping coffee, zippers zipping, paper tearing, a knife cutting crusty bread, salt shaking in the shaker, tableware clinking against plate and cups, doorknobs turning, keys unlocking, car doors slamming outside, wind blowing the leaves in the trees, a doorbell chiming, spray bottles hissing, squirrels chattering, people whistling, flutes and violins, piano chords, the car signal blinking, the car window going up and down, things dropping on the floor.

I’m always in “listening” mode. All these and numerous other sounds were denied me by my profound deafness, but now 21st century technology has enabled me to hear in a way that wasn’t possible only a few decades ago. Many sounds I now hear didn’t exist 50 years ago, like the microwave beeping, the “ready” signal of my electric oven, or the telephone buttons when they are pressed for dialing. All are delicious sounds to me.

At night, I must remove my CI, and then I fall into the deepest silence, which envelopes me like black water into which I’ve plunged. The silence is a deprivation that I feel so keenly that I wish I could wear my CI to bed. If I could somehow tape it to my head so it wouldn’t get dislodged, I would do so. I can’t hear thunder, my dog bark, or my husband call me when he’s had a fall or needs me to take him to the hospital. I get up at night, and the inability to hear myself walk to the bathroom disorients me. I can’t hear the toilet flush or the water run in the sink. Nighttime without the CI is like the soundlessness of death, and when dawn comes, with my CI on again, the sounds of my world becomes the symphony of life.

I’ve written most of this while on a train to Philadelphia on my way to the hospital of the University of Pennsylvania. I have had such a love affair with my CI that I’ve gotten a second one for my other ear! If one CI was so good, I figure, then two is even better and I’m going to be listening in stereo! You can call me the 21st Century “Bionic Granny!”

Carol Granaldi has had a progressive hearing loss since early childhood, eventually resulting in profound bilateral deafness. She resides in an Ocean County, NJ retirement village with her husband Peter and is an active contributor to the ALDA-Garden State listserv. Her email address is cgranaldi@comcast.net.
Link for the phone/doorbell system: http://www.housingdevices.com/ada120.htm

My husband said part of the reason he drank so much was to numb the pain of having to live with me and all my defectiveness. Needless to say, the marriage didn’t last.

My hearing’s been going for years, and I’ve been telling my husband for 15 + years:
• Face me when you talk.
• Give me a “yes” or “no” answer.

He’s a good husband but does not/will not abide by my requests. I figure, OK, if I miss what he says and it’s important to him, tough. It’s his problem.

My sister and brother live far away, but when we visit things are fine. My son explains to his young son that he must face grandma when talking to me (I don’t expect too much at age five).

I am a 37-year-old mother of two adopted kids. I began losing my hearing about the time I got married when I was 25. I remember because I delayed my getting my first hearing aids until after we were married so my husband’s insurance would cover them.

In addition to managing my hearing loss, I am an insulin dependent diabetic and work full time in architecture. In order to accommodate my hearing loss, my family speaks loudly at home and everyone watches TV with the captioning on. The kids don’t even notice it, and my husband says he actually likes it. My husband sometimes speaks loudly in social situations and restaurants, probably because he has adjusted to the volume I need at home. I don’t know how he has the patience when I frequently ask him to repeat things, but he does nonetheless.

I cannot say that we do not struggle. For a number of years I stayed home with my son and worked at his co-op preschool. I did enjoy that experience, but by the time he graduated, I knew I would no longer be able to work with small children other than my own. The energy that I must expend just listening and trying to understand their early speech exhausts me. Also, when my husband is out of town, we are both a bit nervous because I must turn the baby monitor on full blast to even have a possibility of hearing the kids at night. Now that my son is a little older, he helps by alerting me when he hears his sister crying or needing attention. We have all made accommodations, and for now it is working.

Next question: “Are you assertive about your communication needs? Why or why not?” Send your responses to aldanonymous@gmail.com by September 1.
Oh, How I WISH!

By Harriet Frankel

I am aware that there are many wonderful and exciting new products for those of us who are deaf. Thanks to my membership in ALDA, I have met many people who, like me, were not born deaf but have learned how to adjust to life with less than perfect hearing. I have attended innumerable ALDAcon conventions where workshops and various programs and demonstrations of new products have taught me about all the wonderful devices to enable me to lead an almost normal life.

The list is almost endless. Telephones that print out what is being said; cell phones to carry around in your pocket or purse that can send text messages and even take photos that can be printed (all you have to do to use them is retrain your thumbs); medical operations that return sound so that you can take part in conversations. None of these wonders were around when I was a child and my mom became aware that I didn’t hear too well. The only solution was to have my teachers sit me in the front row of my classes.

Now I watch TV (with captioning, of course). Today I can use my telephone by dialing relay and reading conversation on its screen or use a CapTel telephone, which is faster than regular relay because the CA (conversation assistant) uses speech recognition software to re-voice rather than type the hearing party’s comments. I appreciate the protection I receive from the Americans with Disabilities Act (ADA), which kept me from losing my driver’s license.

So what’s my problem? Hardly a week goes by that I don’t read about a wonderful speaker or lecture that I would like to attend. Oh how I wish I could take advantage of the landscape classes at the Botanical Gardens. Oh how I wish I could go to hear a political speaker explain how much I would benefit from voting for him or her. Oh how I wish I could attend classes on Biblical history at my synagogue. Oh how I wish I could attend a neighborhood meeting when they are discussing safety issues. Oh how I wish I could go to that demonstration on baking my favorite cake...on and on it goes until I come to my senses and realize how lucky I am to know about and take advantage of all the help that is available now but not when I was a child or a young adult. [Editor’s note: The ADA requires state and local governments and public accommodations (private businesses open to the public) to provide effective communication for people with hearing loss. Religious organizations are exempt from this requirement. To obtain an accommodation, contact the entity ahead of time and request what is needed—interpreting, CART, or an assistive listening system.]

Oh, how I wish I could tell all the people of my generation who haven’t learned to use a computer that help is available and they don’t need to endure the isolation that becoming deaf usually brings. And lastly, oh how I wish I could personally thank all those who are involved and working tirelessly now and in the past to bring ALDA to deaf and hard of hearing people.

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

SENDING MAIL TO ALDA?

Be sure to use the following address, including “Suite 2,” to ensure delivery:

ALDA, Inc.
8038 Macintosh Lane, Suite 2
Rockford, IL 61107-5336
The Buddy System

By Rick Rutherford

Editor’s note: Rick’s biographical information appears at the end of “My Experience with a Cochlear Implant,” elsewhere in this issue.

I first heard of the “buddy system” from Edna Shipley-Conner. She introduced it as a way to make the ALDA conventions the most positive experience possible for newcomers. I found that the buddy system is more of a year-round thing for me. I go to a lot of different kinds of meetings in the hearing loss community, and I have found people there who became “buddies.”

I’d like to introduce you to one. I met “Buddy” at a hard of hearing support group meeting. We got to talking and stayed in touch ever since. We go to a lot of meetings, events, and socials in the hearing loss community. We’ve taken classes together and done things together that we wouldn’t have done alone. We are in frequent contact (we use text, voice, e-mail, CapTel, etc). We share our feelings with each other about the common issues we deal with around hearing loss, including job, relationships, identity, etc.

We can be honest with each other. By honest, I don’t mean “telling the truth,” although that has to be there too, I mean that we reach down inside to our true feelings. We pull up that feeling and find the right word or words to describe it. This feeling might be fear, shame, anger, resentment, or joy. We now have honesty, and these perfect words give us a language with which we can talk to others about our feelings. Buddy and I don’t bluff with each other—it wastes too much time. There is very little fear between us and thus very little motivation to bluff. Imagine what it would be like to live without this fear that we have lived with for so long, growing up hard of hearing or being late-deafened. Because of Buddy, I find myself participating more in ALDA and other hearing loss groups.

When I first met Buddy, I had been traveling my path in the late-deafened community and struggling with questions of identity, self-esteem, and community for almost 20 years. Buddy was just starting the same journey, working through basic job-related communication issues and showing up for his first hearing loss support group meeting. All the newcomers had the look of a deer in the headlights, glancing around with wide eyes, uncomfortable, uncertain, afraid, but determined to stay. Buddy didn’t have the voice that comes from honesty. The process of asking questions and finding the answers from inside had just begun. But as we first talked, I saw the light come on in Buddy’s eyes. I saw and felt that Buddy was connecting for the first time with other people with hearing loss. Buddy was not alone anymore!

Today, I make sure to let Buddy know about meetings, socials, and events that might be interesting. I share my story with him, I tell what it was like for me, what happened and what it is like now. We talk about how to handle certain situations, what we can control and what we can’t control. We talk about what we should do and how to recognize what we can and we can’t do. We forgive each other for what we can’t do and congratulate each other for the things we take responsibility for. In telling Buddy my story, I explain the mistakes I’ve made and why. I describe the things I’ve learned to do, the things I should do, and the things I can’t do. In this way, Buddy’s journey will be shorter and less painful than mine. It’s a wonderful thing to see this happen and be a part of it.

The first person to benefit from this buddy system is Buddy. He is able to see the road ahead and the person he can become and not have to wonder anymore, “What do I do, how do I do it, and why do I do it?” The future isn’t such a dark cloud. Buddy doesn’t have to wonder “Is this all there is to life?” like I used to. If we have done our work for ourselves well, then Buddy will say, “I want what you have!” In that moment we will give meaning to both our life and Buddy’s life.

The second person to benefit from this buddy system is me. I am going to more meetings and events and I am talking to more people. I am not as isolated as I used to be, and I feel better about myself. When I look into the eyes of a newcomer and see the light of hope, I know why I am here! I know why I have worked through all this pain and done all this work. I call this “The Law of Indirection.” (That which you reach for moves away from you. Instead, go in the other direction, doing the work and laying the foundation to allow what you wish to reach for to come to you.) I lose my pain when I give away my joy. Now that I have a measure of joy and happiness in my life, I see that the purpose is to give it away. But I don’t lose anything—I actually increase my joy.

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The day of reckoning had come. I had spent the past several years in silence, only hearing the loudest rumbles of thunder and garbage trucks. I was beginning to sing to myself all the time, to fill that space where chatter and music should be. I could not hear the doorbell, and remote flashers would not work on the second floor, where my office is. I didn’t know if someone was calling me from downstairs, and most times, people I live with had to come upstairs to talk to me. Music at its loudest became inaudible.

Every day was a challenge, knowing I would not hear instructions, chatting at the checkout, or phones ringing, and that I would leave water running or the disposal or vacuum cleaner on. My stepdaughter had a baby and I wouldn’t hear her cry if I babysat.

I decided to get a cochlear implant. I had heard many success stories, but there were also people who were only partly satisfied and those who had a tough time adjusting to the sound, which is rather artificial. But most CI wearers loved their CIs, especially the more recent versions.

Once I made the appointment with Dr. Christopher Danner (Dr. Bartels’ associate), there was no turning back. Besides the two surgeons, the office at Tampa General Hospital has seven audiologists and a slew of nurses, techs, and receptionists. I saw my audiologist, Dr. Deirdre Hammiker, who tested me for at least an hour and discussed my options. She gave me stacks of materials to study and DVDs to watch. Once we were finished, she said that I looked like a good candidate, but that would be decided by Dr. Danner, who agreed. Once I committed, I started to get nervous. After all, they do drill your skull.

Dr. Danner is a boyish, smiling type whose confidence eased my fears. I knew I could expect dizziness, nausea, and headache for as long as two weeks, and for some, maybe six weeks. But the people I know who have had the surgery had no serious complications. I started hearing from wearers whose lives had changed dramatically.

I had worried about the procedure itself, that the drilling would cause trauma or send fragments to the brain, or that I would have damage to the facial nerve, since the auditory nerve wraps around it. I worried about severe dizziness afterwards, and since I have migraines, I thought the headaches would be killers. But they weren’t.

As part of the prep, I was asked to get an MRI, because I would not be able to do so once the magnetic implant was in place. I also needed a meningitis vaccine (the type that protects from pneumonia as well, called Pneumovax 23). The week before surgery, I went to the hospital for pre-op procedures and checked in the following Monday at 7 a.m. The staff was pleasant and easy to understand, and my surgery went well. I woke up with a plastic dome covering my ear. I left it on for two days, then took it off and showered. I am using bacitracin on the incision, which runs along the back of the ear. It hurts to turn my head or bend over, so I squat and keep my head level. I became nauseous during post-op and that was the beginning of a twelve-hour barf session. I had a prescription for anti-nausea meds. They also gave me a patch behind the ear. I am still pretty light-headed and walking a little bit sideways, but there’s no more nausea. It helps to take pain pills with food.

I am now a week post-op from surgery for a cochlear implant. My pain is mild and is relieved by Tylenol. The pain has been varying from a one-sided headache to an earache to incisional pain to a stabbing pain, and sometimes I can feel it in my throat. I also have a bruise above my right eyebrow. I have felt some pain across the mid-back, perhaps from positioning. After looking at my surgery pictures, it is easy to understand why I have had pain from all directions. I think it looks like an alien encounter. Mostly it just feels like there’s something in my ear.

My light-headedness is leaving me as well. The post-op instructions said that dizziness would resolve sooner the more active you were, so I tried to do my housework although I could not bend over. I was used to squatting because of yoga and Pilates classes, so I was thankful I could still do a lot by myself. I had made sure all the housework, shopping, and laundry were done ahead of time. So I am still not behind yet.

It has not been dizziness exactly. I think of dizziness as what it feels like after you get off the sugar bowl at the fair or drink a six-pack. Maybe that’s worse. But mine has been a listing to the left, kind of stepping when the floor’s not there yet. I have not felt that too
The Buddy System (continued)...

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The third “person” to benefit from this “buddy system” is ALDA. Old-timers will tend to remain and to stay active. We now have a passion and a purpose that can only be met in ALDA. We have a goal (to find new buddies). We have a bottom line (do our words and actions promote the buddy system and ALDA or not?). Newcomers to ALDA will begin and continue their journeys in the hearing loss community with active help from others in this community, and will tend to stay and become active themselves. The ultimate weaning of a newcomer happens when he or she becomes an old-timer to someone new. And in the end, ALDA will grow.

This same commitment to service applies to participation on ALDA boards or committees and to raising money, organizing and setting up events and meetings, and giving support to other groups and individuals. These are all ways we can feel useful and bring purpose to our lives. Someone once said that the purpose of life is to be able to both give and to receive love, and that is exactly what this is all about. Whenever anyone anywhere in the hearing loss community reaches out for help, the hand of ALDA should always be there, and for that, I’m responsible.

My CI and I (continued)...

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much since the first few days. The pain pills covered it up with a wooziness of their own.

Because of the close proximity of the facial and taste nerves to the auditory nerve, the sense of taste can be affected and the chin can tend to quiver. Mine was doing that and my taste sensation has not totally returned, but it’s there. Based on my progress so far, I am hoping to get it back 100 percent.

I was getting bored, so I started a project of going through old pictures, but I had to stop because it made me cry, and I am not supposed to blow my nose.

Everyone has been congratulating me. I am not counting chickens before they are hatched and am trying not to be excited, but I am looking forward to the turn-on date just to see what the big deal is. Meanwhile, I have a few more weeks to heal up and then I expect to be busier than I was before this happened.

(To be continued!)

Sharon Milian is an RN and a freelance writer in Palm Harbor, Florida. She has had a profound hearing loss since the 1990s, joined ALDA in 2000, and works in Tampa scoring standardized tests.

Silent Auction Fun for Everyone!

Every year, ALDAcon features a Silent Auction, and it’s coming to the Seattle ALDAcon from October 14-18! No trying to hear that fast bidder up front. Instead, you can peruse items from art to technology, to...well, not zebras, but pretty much everything else in between, and place your bid in writing. Keep an eye on the bidding, as others will come by and raise the bid. It’s exciting in a very laid-back ALDAan way.

This year’s auction will be housed inside the exhibit hall, which will allow for even more opportunity to keep track of the bidding. We are working hard to make it the best Silent Auction ever, but we need your help. Those delicious goodies on the Silent Auction table arrive via donations from ALDA chapters and individuals. Would you be willing to donate an item representative of your area or one that you know other late-deafened adults would enjoy?

Please contact us at silentauction@alda.org and we will help you get your item to us. Items can be mailed ahead of time or brought with you to the auction, but we need to know details about each item and its value ahead of time. We look forward to hearing from you, and remember to visit our table to make your bids. You’ll be glad you did!

Lu Barrett and Candis Shannon, Silent Auction Co-Chairs
Robin Titterington writes that a good college friend and fellow ALDA member, Gertrude Beal, spent Easter with her in Atlanta. Robin lost her dear old “Elmer-cat” last winter, and she is certain that stock in the Kleenex Corporation rose that week. But her love for animals led her to find a rescued cat at the animal shelter. This one, named Star, is one year old and loves to terrorize Robin’s dogs.

Kim (ALDA Region II director and president of ALDA-Northwest Indiana) and Tahar Mettache became the proud grandparents of Kayden Anthony Biella, who was born February 4, 2009.

Christine Seymour, Yael Shaner, Toni Iacolucci, Gerald Perselay, Paula Sutton, and Joanne Karpowitz graduated from the Gallaudet University peer mentoring certificate program in June after two years of online courses. The program is designed to help train Deaf, hard of hearing, and late-deafened people to assist those who face challenges due to communication inaccessibility. Peer mentor graduates team up with hearing health professionals to provide consumers and their families with practical approaches towards accommodations, use of assistive technologies, and equal access to communications.

That’s a wrap. Don’t forget to send your news items to me by August 18 at maumsie@sbcglobal.net. Hope to see you at ALDAcon!
President’s Report—
Kathy Schlueter

As I type this column, I’m burning the midnight oil. We are at the halfway point of our ALDA year, and the board has been working very hard to meet the challenges of keeping ALDA active. One such challenge is reducing the cost of printing, so we have chosen to incorporate ALDA Biz within ALDA News, and we are also offering members the option of receiving ALDA News electronically.

I’m proud to say that your current board of directors is thinking “outside the box.” We are being creative in finding ways to get more information out to our members and others with hearing loss through the e-news announcements. [Editor’s note: see elsewhere in the Biz section for Christine Seymour’s report about the e-news.] As a result of a letter to the editor published in ALDA News, the ALDA-Ideas Yahoo group (which had been dormant for awhile) has came alive again, with members sharing their thoughts and suggestions about ALDA’s future. ALDA also has a group on Facebook where our members can meet one another, talk, and share ideas. We are working on outreach with our chapters and group leaders and have a very active International Committee. We are excited to announce that we have our first official international ALDA group, ALDA-Asia Pacific. Stay tuned for details to come on the new website that is currently being developed for ALDA, Inc.

The above paragraphs highlight just a few of the projects that we have been working on. I’ve asked some of our board members and committee chairs to tell more of what has been happening in ALDAland. We will hear from others in the next issue of ALDA Biz.

President-Elect’s Report—
Linda Drattell

Hello, everyone!

I am very excited and honored to serve our ALDA membership as president-elect. It has been a busy year, especially in preparation for ALDAcon 2009. I have been wearing many hats, both in my role at ALDA and in my work as hard of hearing/late-deafened support specialist for the Deaf Counseling, Advocacy & Referral Agency (DCARA). I continue to serve on the International and Advocacy Committees, and I have also been acting secretary as needed by the board; liaison for the ALDA-Ideas Yahoo group; and chair of the ALDAcon 2010 bid-solicitation process. In addition, I am working diligently with our president, Kathy Schlueter, and our ALDAcon planning chair, Christine Seymour, to find fundraising opportunities in support of ALDAcon, and I remain on the coordinating committee of ALDA-San Jose.

I am a member of the Bay Area Rapid Transit (BART) Accessibility Task Force, representing the hearing loss community, so if you live in the San Francisco Bay Area, please feel free to email me regarding any accessibility issues associated with our transit system.

We are looking forward to an exciting ALDAcon this year in Seattle! If you are joining us, please introduce yourself to me! And write to me anytime. I look forward to hearing from you.

Warmest regards,
Linda Drattell

Secretary’s Report—Brenda Estes

Major motions for January - May 2009 (motions to accept minutes are not listed); all passed

Motion 2009-01: Accept the group petition for ALDA-Sonora

Motion 2009-02: Accept the treasurer’s report for the end of year 2008

Motion 2009-03: Accept the 2009 budget proposal

Motion 2009-04: Have a drawing for a free one-year membership in ALDA (maximum value $25), open to anyone who signs up to receive the ALDA News electronically by April 1, 2009

Motion 2009-05: Accept ALDA-Boston’s bylaws changes

Motion 2009-06: Accept 3Cube, Inc.’s proposal to develop a new website for ALDA with a management system; provide training to ALDA staff to work with the website; and provide ongoing support.

Motion 2009-07: Include the ALDA Biz in the ALDA News twice a year

Motion 2009-08: Send the ALDA, Inc. president to the HLAA convention in June 2009

Motion 2009-09: Accept the group petition for ALDA-Asia Pacific
Each year ALDA, Inc. holds an election by secret ballot to fill positions on the board of directors that are vacated by the expiration of terms of the current board members. Nominations are solicited and vetted by the nominations committee, which is chaired by the past president and includes at least two other people, one of whom must be a board member and one of whom should be a representative of a chapter. Additional members can be added to increase the geographic and other diversity of the committee and ensure gender balance. If you would like to be a member of this important committee, please contact Christine Seymour at past.president@alda.org.

Nominations for 2010 will be solicited for the following positions:

President-elect—This is the first position of a three-year commitment. During the first year, the president-elect assists the president in the discharge of all functions of that office. In the event of the president’s extended absence or disability, the president-elect performs the duties of that office. During the second year, the person elected to this three-year commitment serves as president, followed by one year as past-president.

Treasurer—The term of office for this position is two years. The treasurer is the principal accounting and financial officer of the Association, has custody of all ALDA funds and securities, and keeps accounts of all receipts and disbursements. The treasurer deposits all moneys and other valuable effects in the name and to the credit of ALDA in depositories specified by the board of directors and distribute ALDA’s funds within limits prescribed by ALDA’s annual budget. The treasurer renders to the president and the board at its regular meetings, or whenever the board may require, an account of all transactions and the financial conditions of the Association. The treasurer also presents to the general membership at the annual general business meeting, chairs the Finance Committee, serves on other committees as assigned, and performs all duties incidental to the office of treasurer.

Region I and II directors—Region directors serve two-year terms. Each represents and is a resident of one of four regions and is elected by members in good standing in that region. The director is responsible for communications addressed to the association by individuals in that region who are seeking information and local resources; provides support and information to groups, chapters, individuals, families, and professionals within his or her region; establish linkages and networks; and represent regional interests and concerns at board meetings.

Region I—Connecticut, Washington DC, Delaware, Massachusetts, Maryland, Maine, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, West Virginia, Virginia, Quebec, New Brunswick, Prince Edward Island, Nova Scotia, Newfoundland, United Kingdom, Finland, Norway, Netherlands, Europe, Middle East.

Region II—Illinois, Indiana, Iowa, Kansas, Kentucky, Michigan, , North Dakota, South Dakota, Nebraska, Ohio, Wisconsin, Manitoba, Ontario Minnesota, Missouri

A member wishing to be nominated or to nominate another member must complete and submit a nomination form, indicating the name of the nominee and the office for which s/he is nominated. If you would like a nomination form, please contact Christine Seymour at past.president@alda.org. Nomination due dates will be announced once the committee is formed, and the election will take place in November after ALDAcon.

Treasurer’s Report—Gloria Popp

ALDA, Inc. began 2009 with $28,041, of which $6,288 was in the operating fund and the balance in restricted accounts. In the first five months of the year, we had income of $16,494, which includes $11,885 for ALDAcon 2009 and $4,609 from 105 new and renewed memberships, as well as some donations and advertising income. Due to the economic situation, the ALDA board voted to not have the usual face-to-face board meeting. Expenses total $7,064 for ALDA News, the website, and communications, leaving the operating fund at a loss of $2,455 for this year to date. If you want further information or have questions, please email treasurer@alda.org.
Hello, Region II ALDA members! It’s been a great pleasure to serve you. At the beginning of the year, with the change to the new ALDA board, I was asked to be region director coordinator. I receive all the documented phone calls from our receptionist Ruth Roldan at our Rockford, IL office, as well as any emails that come to our email address. I then figure out which region each request comes from so the proper director can respond. If it’s my region, I make the calls and answer the questions and emails myself. Many are from people who are looking for support.

I would like to see more chapters in my region. There is a great need for at least one chapter in every state. If any of you in my region are interested in starting a chapter or a social time, please email me, and we will promote your activity in an upcoming ALDA e-news.

I look forward to seeing many of you in Seattle! Feel free to email me anytime at RD2A@alda.org.

Hello, everyone! I became Region III director in January, and it has been a rewarding and exciting experience thus far. We have group start-up activity in the area of Houston, TX and central North Carolina, and we had a wonderful get-together in Greenville, SC in early April that attracted late-deafened individuals from Georgia, South Carolina, and North Carolina. The impetus for this event was the support of ALDA-Peach for the start-up group in North Carolina. People enjoyed getting together so much that we are planning to do it again.

I have received many phone calls and emails seeking information about hearing aids, local deaf resources, and learning to lipread and sign, and I also get queries from students doing research on the topic of late-deafness.

I would like to have contact with all the groups in my region so I will know how ALDA can meet your needs and help you identify other late-deafened individuals in your area. The best way to contact me is by email at rd3@alda.org.

Since January 2009, I have been serving as Region IV director, following Linda Drattell’s term. Among my other duties, I have been helping with the new ALDA-Sonora chapter and hope to find new people to join us and assist in broadening our reach within Arizona.

I have been answering emails sent through ALDA, Inc. Many involve inquiries about local chapter/groups, assistance in finding other ALDA members in the area (if there is no chapter/group), and questions regarding employment or vocational rehabilitation after acquiring hearing loss. Emails have come from Salt Lake City, UT; Denver, CO; Glendale, AZ; Anchorage, AK; Alberta, Canada; Southeast Oregon; California; and Maui, HI. If you are in my region and have not already been in contact with me, please feel free to introduce yourself, especially if you are an area near one in the list above! I can be reached at Rd4@alda.org.

There hasn’t been a lot of recent activity on this committee, except for an important question that came up about how to break a tie in an election for a board position, since neither the ALDA, Inc. nor ALDA chapter bylaws discusses this. One possible solution is to amend the bylaws to have the president only vote in elections for the board when there is a tie for a position, in which case the president would vote to break the tie. This or any other bylaws change would need to be voted on by the membership.
ALDA Launches E-news—Christine Seymour

In January ALDA moved up to the current trend in marketing and public relations by launching the ALDA e-news, an email newsletter that contains up-to-the-minute news of interest to people who are late-deafened, such as national advocacy efforts, technology announcements, and news about ALDA and our events and activities. Unlike ALDA News, the e-news is available to the general public. Members are automatically subscribed, and non-members can subscribe by going to www.alda.org and clicking on the “sign up for e-news” link. Recipients of ALDA e-news are encouraged to forward it to friends and associates who will be benefit from knowing about ALDA, by using the “forward this email” link at the bottom of the page. This gives the recipient a copy of the email with an easy link to sign up to receive the e-news directly.

At this time we are producing two versions of e-news: ALDA e-news, which provides information to the general public, and ALDAcon e-news, which focuses solely on announcements related to ALDAcon 2009.

An added bonus of the e-news marketing tool is that it is also used to generate revenues for ALDA through advertising and information from other agencies and organizations that want to reach our subscribers. (ALDA will never give the information gathered for membership or e-news distribution to any outside agency or organization.)

To protect your right to privacy, e-news has a safe “unsubscribe” link at the bottom of the page. If you do not wish to continue receiving ALDA e-news, simply click on the link. If you unsubscribe and then decide you want to begin receiving e-news again, simply go to www.alda.org and sign up for e-news.

ALDA is very pleased to offer this new publication to help others learn about ALDA and to communicate more effectively with members. As with all its publications, ALDA depends on feedback and suggestions from members to make the best use of our communication tools. If you have questions, comments, or news to share, email e-news@alda.org.

Recently ALDA News, the quarterly newsletter that is a benefit of paid membership, ran a contest encouraging ALDA members to sign up to receive the ALDA News in electronic format. This is not the same as e-news. The electronic format of ALDA News is a full-color PDF file of the regular publication that can be read online or downloaded and printed to read at your leisure. By electing to receive the ALDA News in electronic format, members are helping ALDA reduce the cost of printing and mailing hard copies, with the added bonus of getting the publication in full color. ALDA sends an ePostcard with a link to the ALDA News PDF only to those members who have elected to receive this version. The ePostcard asks that members protect the integrity of this benefit of paid membership by not forwarding, copying, or redistributing the postcard or newsletter in any form without permission from ALDA. If you know someone who would benefit from seeing a copy of the ALDA News, simply email e-news@alda.org with the contact information for the interested party and we will see that an issue is sent.

International Committee (IC) Report—Lauren Storck, Chair

The IC offers a bridge between ALDA nationally in the U.S. and many who are interested in ALDA and hearing loss issues internationally. The committee communicates year-round using an online Yahoo group (moderated by Lauren Storck and Kim Mettache).

The chairperson of the IC serves as the link between the IFHOH (International Federation of Hard of Hearing People) and ALDA (which is a voting member of the federation); responds to inquiries from people in other countries and from ALDA officers and regional directors (representing global areas); invites and welcomes international visitors to ALDAcon’ and encourages the exchange of information and support internationally.

Several IC members travel extensively and distribute information about ALDA, as well as bringing news back to the IC about hearing loss and late-deafened issues from places visited. The IC contributes a regular “Our World: News from the IC” column to ALDA News to share its activities and information with readers. At ALDAcon 2008, the IC sponsored a popular travel workshop, organized by IC member Cynthia Amerman, with panel presentations. An exciting project of the IC during 2008-2009 has been the development of a new ALDA group in Asia, spearheaded by ALDA member M. Akram in Pakistan.

IC members are Geoff Brown (England); Liisa Sammalpenger (Finland); Cynthia Amerman, Kim Mettache, Linda Drattell, Judy Viera, Carolyn Piper (USA); honorary member M. Akram (Pakistan); and honorary member ALDA President Kathy Schlueter.
Join Us at ALDAcon 2009
October 14-18, 2009, Seattle, WA

ALDA is offering registration choices so you can select the package that best suits your interests and budget. Limited scholarships are available; contact wicwas@wcvt.com, Scholarship Chair, for more information.

- Full registration: $265 for ALDA members, $290 for non-members
- Lite registration: $200 for ALDA members, $225 for non-members

Full registration includes all workshops, speakers, exhibits, entertainment, and meals:
- Wednesday Welcome Reception
- Thursday President’s Luncheon
- Friday Recognition Luncheon
- Friday I. King Jordan Award Banquet
- Saturday Awards Luncheon
- Saturday Karaoke Party
- Sunday Brunch

Lite registration includes all workshops, speakers, and exhibits, and the following events:
- Wednesday Welcome Reception
- Saturday Karaoke Party
- Sunday Brunch

Additional meals may be purchased at the time of registration.

Single day rates do not include any social events or meals.

There are three ways to register:
- Register online using your credit card through PayPal (go to http://aldacon.alda.org, click on “Registration,” and click on “Online registration form”)
- Print the online registration form (or the PDF or Word format) and mail to address below; include credit card information or check or money order
- Request a registration packet from the address below or call ALDA at 815-332-1515

ALDAcon 2009 Registration
c/o Paula Titus
7943 13th Ave SW
Seattle, WA 98106
Email: registration@alda.org
Advocating for:
♦ Video & CapTel public phones
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♦ 9-1-1 access with pagers
♦ Captions on all TV programs
♦ Captioned movies
♦ And more... 

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

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

Washington: Where Access Begins

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

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

Renaissance Mayflower Hotel
Washington, D.C.

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

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

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

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

I’d like to: □ Join ALDA □ Give a Gift Membership to: □ General Member, Age 61 or under . . . $25.00
□ Senior Member, Age 62 or over . . . . . . . . . . $20.00
□ Business Membership . . . . . . . . . . . . . . $45.00
□ Tax-Deductible Donation . . . . . . . .. $ _______
□ New □ Renewal

Name ________________________________________________________________
Organization: ___________________________________________________________________
Address: ___________________________________________________________________
City ___________________________________________________________________
State: ____________ Postal Code: ____________ Country: ____________
Home Phone: ________________ TTY □ Voice □ Cap Tel □ VP □
Work Phone: ________________ TTY □ Voice □ Cap Tel □ VP □
Fax _____________________________________________________________
E-mail _____________________________________________________________
URL/Website Address: ___________________________________________________________________
ALDA Chapter (Name/None): __________________

Gender: Male □ Female □

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

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

If paying by check, please mail this member form to:
ALDA, Inc.
8038 Macintosh Lane, Suite 2
Rockford, IL 61107

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

www.alda.org/alda_membership_form.htm

For Credit Card Payment by Mail:
□ Master Card □ Visa
Amount _________________________________
Account # _______________________________
Expiration Date ___________________________
Signature ________________________________
(For Credit Authorization)

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

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

**Why a Lifetime Member?**

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

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

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

* Ann Smith, Lifetime Member

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

**Lifetime Membership Tier**

- **Bronze $500 - $1,499:** receive a personal letter from the President, bronze plaque

- **Silver $1,500 - $2,999:** receive a personal letter from the President, silver plaque and priority seating at future ALDAcons

- **Gold $3,000+:** receive a personal letter from the President, gold plaque, priority seating at future ALDAcons and complimentary registration to a future ALDAcon.

Contact ALDA Treasurer, Gloria Popp
treasurer@alda.org
or visit www.alda.org

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

Association of Late-Deafened Adults

ALDA, Inc.
8038 Macintosh Lane
Rockford, IL 61107

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