This all began with my watching a wonderful TEDTalk given by Dave deBronkart, entitled “Meet e-Patient Dave” (www.ted.com/talks/dave_debronkart_meet_epatient_dave.html), and wanting to share it with others. If you go to the link, make sure to turn on the subtitles, found underneath the pause/play button, to the right of the words: “Subtitles Available in.” Choose your language from the drop-down menu, as several different languages are available. [Editor’s note: TED is a nonprofit that started in 1984 as a conference bringing together people from Technology, Entertainment, and Design. It now offers annual conferences in the U.S. and Great Britain as well as a variety of programs, including the TEDTalks video site.]

I’m a big fan of TEDTalks, as I find them inspiring and informative, but I also like them because they are caption/subtitle friendly. However, patience may be required, as it does take a few days for newly posted TED Talks to be translated/subtitled, since those adding this feature are volunteers, but usually a talk is available in English in just a few days.

At first glance, this talk, given by a man diagnosed with kidney cancer, might not seem relevant to hearing loss, but it is very much so. Dave’s emphasis on taking charge of what’s ailing you, and the need to search for answers beyond those that your doctor provides, is far-reaching. Patients ARE the most under-utilized resource in healthcare, and conferring with other patients (referred to as “the power of patient networks”) who have “been there, done that” can lead you to some of the most effective and cutting-edge treatments available. It’s amazing, the detailed information that e-Patient Dave found on the patient networks he came across. Information that cut through all of the less aggressive and less successful treatments that, had he tried them, probably would have meant a quick demise. We can all benefit from adopting e-Patient Dave’s attitude and forcefulness where our health is concerned, and hearing loss is a health issue.

Speaking of “patient networks,” I consider the SayWhatClub to be one, as we pass on valuable information about hearing loss straight from our own experiences, but we also spill over into providing the emotional support and understanding that a person can’t find in a hearing world, among hearing people. Not even those who love us most know what life is like for us, unless they have a hearing loss themselves.

Dave also asks the question “Why is it that iPhones and iPads advance far faster than the health tools that are available to you to help take care of your family?” and I found myself asking this same question in relation to being able to access information on finding the right technology and the right person to apply and program that technology to treat hearing loss. Why is it so hard?

One of the last stories Dave tells is about Kelly Young, a rheumatoid arthritis (RA) patient (Kelly’s blog is RA Warrior (http://rawarrior.com)—I’ve looked at it briefly and it’s a wonderful blog!),
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Publisher:
ALDA, Inc.
8038 MacIntosh Lane, Suite 2
Rockford, IL 61107

ALDA VOICE/TTY: 815.332.1515 or 866.402.ALDA (866.402.2532)
FAX: 877.907.1738
E-MAIL: info@alda.org
WEBSITE: www.alda.org

Editor-in-Chief:
Nancy Kingsley (Kingsnan@aol.com)
717.394.1391 (2-line CapTel)

Managing Editor:
Eileen Hollywood (EileenA2@aol.com)
732-380-1233 TTY

Editorial Review Board:
Mark Dessert (subvet633@verizon.net), Cheryl Heppner (NVRCheryl@aol.com), Carolyn Piper (wicwas@wcvt.com), and Robin Titterington (furriesmom@comcast.net)

Technology Director:
Ken Arcia (ALDA96Ken@dslextreme.com)

Chapter Happenings and GA to SK:
Ann Smith (fabsmith@att.net)

ALDAnonymous:
Bill Graham and Robin Titterington (aldanonymous@gmail.com)

Advertising Director:
To place an ad:
Matt Ferrara (mattF812@verizon.net)
V/TTY: 815.332.1515 or (toll-free) 866.402.2532

Ad Billing information:
Matt Ferrara (treasurer@alda.org)
V/TTY: 815.332.1515 or (toll-free) 866.402.2532

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Graphic Artist:
Ellen Perkins (eebail@verizon.net)

ALDA 2011 Board of Directors
board@alda.org

Cynthia Amerman, President
president@alda.org
Linda Drattell, Past President
past.president@alda.org
Brenda Estes, President-Elect
president.elect@alda.org
Karen Krull, Secretary
secretary@alda.org
Matt Ferrara, Treasurer
treasurer@alda.org
Paul Wummer, Region 1 Director
rd1@alda.org
Marsha Kopp, Region 2 Director
rd2@alda.org
Rachael Morris, Region 3 Director
rd3@alda.org
Kathy Evans, Region 4 Director
rd4@alda.org

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Note from Nancy

By Nancy Kingsley, Editor-in-Chief

This issue contains a reprint of Willard Madsen’s 1971 poem, “You Have to Be Deaf to Understand.” As I reread it, I realized how much has changed in the past 40 years—and how much hasn’t.

Madsen, who became deaf at age two in 1932, wrote the poem long before the existence of the telephone relay system and cochlear implants. Today, deaf people no longer have to “depend/Upon one who can hear to phone a friend; /Or place a call to a business firm/And be forced to share what’s personal, and/Then find that your message wasn’t made clear.”

Another significant change since Madsen’s boyhood is acceptance of American Sign Language—deaf children are no longer punished for using their hands to communicate. And CIs now enable many to develop functional auditory skills, even to the point of being able to use a voice telephone, a virtually unheard-of feat when Madsen was growing up and struggling painfully to learn to speak and speechread. And when his poem began circulating, closed captioned TV programs and DVDs didn’t exist.

But in certain other important ways, things haven’t changed. Deaf and hard of hearing people who ask for a repeat of something they missed are still often put off with “never mind” (as well as “it’s not important” and “I’ll tell you later”). We’re still shouted at by people trying to make us hear (this even happened to me in a hospital waiting room—it was the hospital’s actual policy to talk loudly if someone indicated that they had a hearing loss!). And misunderstandings due to hearing incorrectly are still with us (I once showed up late for a carpool because I didn’t realize that TWO times had been mentioned—the time the carpool was to leave and the time we were supposed to arrive at our destination).

But when he wrote his poem, Madsen had something that late-deafened people didn’t yet have: organizations like the National Association of the Deaf where he could interact with others like himself. At that time, hard of hearing and late-deafened people had essentially no opportunity to meet their peers and no sources of advocacy, because neither HLAA nor ALDA had yet been founded. Fortunately, we can now connect easily with other ALDAns both in person (through ALDAcon and ALDA chapters) and online.

How much of a difference does it make to be able to interact with others with the same communication needs? You have to be deaf, late-deafened, or hard of hearing to understand.

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As we enter the back-to-school season, we are bombarded, even more than usual, with commercials and advertisements for all sorts of computers and technology gadgets. Whether you are technologically savvy or slow to accept the latest breakthrough, it’s undeniable that technological advances have had a profound impact on how late-deafened people cope with hearing loss. CART, captioned television, email, texting, video relay services (VRS), captioned telephones, and other forms of technology have touched all of us on our journeys in the late-deafened world. And so, for this issue of ALDA News, we bring you the theme of “Technology and Hearing Loss.”

We start off with our cover story, “Meet TED, Dave, Kelly, and Brian,” in which Michele Linder explores how she has drawn strength and insight for coping with her hearing loss through an online resource called TEDTalks. ALDA News editorial review board member and ALDAholic Robin Titterington talks about the joys of being able to use the phone again, thanks to technology, in “Can You Hear Me Now? No, But I Can Use the Phone.” Ann Smith, another well-known ALDA News staff member, provides a “then-and-now” look at how technology has improved the lives of those with hearing loss.

As usual, we also have selections on other aspects of hearing loss. Heidi Martin-Coleman’s graduation speech, “Tempered by Adversity,” shows how personal courage and a supportive environment helped her to triumph over incredible obstacles. Some of you may remember the 1971 poem by Willard J. Madsen, “You Have to Be Deaf to Understand,” which is reprinted here and will still hit home for many readers. Returning to the technology theme, we have two informative articles about the latest in movie captioning: “Lawsuit by ALDA Members Improves Movie Experience with New Technology” by Ken Arcia and “Movie Captioning” by Paul Jacobson.

Linda Drattell makes a convincing argument on the need for broadband advocacy in “Advocating for Broadband? And What Exactly Does that Get Me?” Chelle George provides a vivid account of the positive impact that technology has had in her life in “Technology Ends Isolation.” And in “A Hearing Odyssey” Paul Wummer explores how hearing aids have assisted his journey over the years as a hard of hearing individual.

Frequent contributor Carol Granaldi shares her successes in using DAI devices in “Direct Audio Input: A Low-Tech, Little-Known Assistive Listening Device.” The successes and limitations of technology in the workplace are described in Helen Droitsch’s article, “The Treats and Trials of Technology at Work.” Also on the topic of work is “Job Hunting While Deaf” by Donna Maderer, in which she provides an account of her recent successful search for a job. In “Reflections on Dealing with Hearing Loss,” Deborah Scott explores the challenges of facing and accepting her progressive hearing loss, and this issue also features the regular columns by our entertaining writers Michele Bornert and Harriet Frankel.

As you can see, this issue is bursting at the seams thanks to all of the terrific writers who took the time to share their stories. If you have any comments (positive or negative), ideas for future issues, or an article to share about your hearing loss experiences, please do not hesitate to contact me.

ALDAbest,
Eileen

Several readers have asked why many ALDA News articles continue to another page farther back in the issue. Most magazines and newspapers use this approach to enable more articles to start near the beginning.

We’ve also been asked how to easily get to an article’s continuation page in the electronic version. Acrobat Reader makes it possible to go to any desired page by clicking on “View” and then “Page Navigation” (different versions of Acrobat Reader have slightly different ways of going to a specific page once “View” is selected), and this method may be more efficient than scrolling.

Unlike our print copies, the electronic version is a full-color edition, which we hope offsets any inconvenience in going to the continued pages.

The Editors
I became deafened when I was 19. I was living on a college campus, so losing the ability to use the phone, while frustrating, was not too much of a problem. When I went to graduate school, I got my first TTY, an MCM (kind of a cute little thing!). TTYs required typing what you wanted to say, and there was no relay service, so you could only call other TTY users. Alas, the only place I remember being able to call was, oddly enough, Amtrak, to get train tickets a few times. I worked in Washington, D.C. for two summers, and I don’t even think I had a telephone in my apartment. What was the point!?

Fast forward to moving to Georgia and being truly on my own. Finally, I did have a few friends I could call on my cute MCM! Most of them were hearing, but I was starting to make more Deaf friends. When I needed to make a personal business call (e.g. for a doctor appointment, hair trim, or vet call), I depended on co-workers, which is NOT recommended! Every day I would come to work stressed because I needed someone to make a call. Who didn’t look exceptionally busy? Or “nah, she helped last time but was not happy about it.”

Several years later, I was blessed with a kidney transplant. Anyone who has experienced any kind of severe medical change knows that if you break a fingernail, you are sure you’re going to die. One night there was some little symptom and my phone journey was like this: I called a hearing friend with a TTY and explained. We hung up and she called my doctor’s answering service. When the doctor called back, he asked her some questions and then they hung up. She called me back and relayed the questions, I answered, and we hung up. She called the doctor back, found out I was fine, hung up with him, and then called me back again. That was how telephone calls worked (if you were fortunate enough to have a patient hearing friend).

The day the relay service began, I truly felt like an adult! (I was in my 30s.) A good friend and I stayed up until midnight to use it as soon as it began! I wanted to be the first and found out later that I was the second, but that’s OK. At last, I not only had freedom but most of all, PRIVACY!! I could call whomever I wanted, whenever I wanted.

Recently on LDAchat@yahoo-groups.com (a highly recommended late-deafened group that is not connected with ALDA), some newly deafened folks said, “I would never use a TTY.” I suspect that some of us—er—experienced (I hate to say “old”!) folks were a little defensive. If that’s all you had, you would have used it.

If anyone had told me I would have the ease of using a videophone with voice carryover (VCO), I would have thought they were dreaming. I can call anyone, and often they don’t even know I am deafened. Of course there are still drawbacks: I have to remember to brush my hair before an interpreter pops up on my screen. But I can live with that!

Robin is a past president of ALDA and was originally from upstate New York, but she has lived in Georgia for over 30 years. When not volunteering for ALDA-Peach, she can be found hugging the furries, cheering the Braves, or reading. She can be contacted at furriesmom@comcast.net.
Remember the Good Old Days?

By Ann Smith

As a 60-something who gradually lost her hearing as a young adult, I can remember those “good old days” before the ADA became law and all the current communications technology was developed. We all get frustrated today when our favorite TV show has garbled captions, when the pizza place hangs up on the relay operator, or when the doctor’s office “forgets” to arrange for an interpreter. If you’re my age, though, those frustrations pale in comparison with the ones we faced in the good old days. These are a few of the “coping” skills that were needed in those times.

Accommodations for hard-of-hearing school children consisted of arranging for the child to sit in the front row. This was also the only accommodation I received when I was in college. As a result, it was absolutely necessary to learn to take notes while lipreading, and to carefully study the required reading assignments.

The only way deaf teenagers could chat was face-to-face, so that they could lipread or sign to each other. Joining clubs that met after school, meeting at the local drugstore for sodas, and hanging out with kids who lived nearby were the best ways to make friends. This meant that there was usually a problem trying to follow group conversations, when one-on-one communication was what worked best.

If you dropped your car keys in the parking lot, you couldn’t text for help. I especially remember a long walk on a sweltering afternoon. I apparently dropped my keys when I got out of the car at the train station in the morning, but I didn’t miss them until after work. Naturally, there was no sign of them by that time. The station is only 1 ½ miles from my home, but it seemed much further because I was wearing high-heeled shoes and the temperature was in the 90s.

If the car wouldn’t start, you asked a passerby to make a phone call for you. Doctor’s appointments were made by family members or friends; there was no relay, CapTel, or videophone. I was lucky; I never needed to make an appointment for an embarrassing ailment, not even for an ingrown toenail.

If you were a good lipreader, you might try to watch the news on television. As long as the anchor faced the camera, there was a chance you’d at least know what he was talking about. You could usually follow (or guess) the story in a western or action movie, but dramas were hopeless. You never knew whether the tragic look on the actors’ faces was because someone just died or because they’d remembered that they left the stove on. Watching sports was fine, unless a player got hurt or the officials made a controversial call. You had to wait until the newspaper came to find out exactly what happened. Fortunately, there were lots of good newspapers in those days, so you could rely on them.

Ah, those “good” old days! I don’t miss them at all!

Ann is ALDA’s “Chapter Happenings” and “GA to SK” curator. She grew up hard of hearing and finally declared herself “deaf” while in her 30s. By then, she could only hear loud claps of thunder when wearing her powerful aids. She attended public schools, college, and graduate school with no accommodations—this was before the Americans with Disabilities Act. Ann has served as president, treasurer, and secretary of ALDA-Peach in Atlanta. She loves reading and watching her ten favorite soccer teams play. Contact her at fabsmith@att.net.
“The fire of adversity will melt you like butter, or temper you like steel. The choice is yours.” It’s a quote that makes me think.

I had a rough idea of the course of my life. After earning degrees in nursing and music education, I blended my backgrounds to become a developmental nurse educator for infants and toddlers. I had an amazing husband and two beautiful young children. My schedule was packed to overflowing, and I was proud of it. I liked being busy.

Our third child was born in 2002, following a tenuous pregnancy and frighteningly premature delivery. At first her health problems seemed related to her early birth, but “mother’s intuition” told me that something was wrong. My own health began to falter as well. In 2004, we had our answer: a maternally inherited genetic disease that can vary in severity and presentation, from imperceptible to fatal. The fire-breathing beast was called mitochondrial myopathy, and its flames of adversity were threatening to melt the very core of my being. My precious Heather Grace earned her wings the week before her third birthday, and my comfortable, picture-perfect life came crashing down. Over the next year, the degenerative neuromuscular disease devoured everything I had taken for granted: my strength, mobility, hearing, independence; expectedly, even my life. My task at hand was to prepare my children to live without their mother.

By 2007, my days seemed numbered. After months in the hospital, I was discharged home with hospice. Once I got there, I waited…and waited…wondering when my illness would claim its next victim. Suddenly, it hit me: “I’m still alive!” I had two choices; I could sit at home and spend my days thinking about my illness, or I could be grateful for every new day.

The transition from “hospice patient” to “productive professional woman with disabilities” was not easy. Reclaiming my public, private, and professional roles was more difficult than surrendering them. Deafness, fragile health, and immobility led to the loss of my independence and ability to communicate. With these losses, however, came unexpected blessings. Loss of mobility forced me to slow down. Losing my hearing made me a better listener.

But the most important tool for my survival, next to faith and family, has been education. Holyoke Community College made an indelible mark on my life. I contacted the Office for Students with Disabilities and Deaf Services, and the advisors there played an incredible role in my emotional growth. My illness had nearly destroyed my self-esteem, and I had grown accustomed to being ignored and belittled. The advisors greeted me with eye contact and a firm handshake. I can’t remember exactly what we discussed, but I will remember an unspoken message: what I say and do is important. I am not my disease. This atmosphere of acceptance was not limited to student support services. From instructors to administrators, to the cashier in the cafeteria…they connected with me, not my care attendant. They looked at me and saw a successful, professional woman, not a person in a wheelchair.

When the first day of class finally arrived, I entered the building looking like I was moving in permanently. The back of my power wheelchair was encumbered with bags holding my continuous IV fluid and tube feeding pumps, emergency supplies and medications, laptop and books, and supplemental oxygen. Mercury, my beautiful black Lab service/hearing dog, sat patiently by my side. I felt awkward but knew that I had plenty of support. I needed to do this for my family and myself.

Within a few weeks of attending that initial class, I discovered that HCC not only offered ASL courses, but an entire Deaf studies program as well. I researched the potential for program graduates; it was easy to justify my pursuit of the program to my Massachusetts rehab counselor, my husband, and my doctor. The latter was astounded that I had even taken that initial class. Apparently, most hospice patients aren’t this upwardly mobile.

I’ve been asked more than once, “why?” The answer is that I have completely revised my personal philosophy of education. I believe the day I truly began to become educated was the day I...
**Geoff Brown: In Memoriam**

Geoff Brown, a long-time ALDAan from the United Kingdom who attended ALDAcon every year, died on July 27, 2011 at the age of 84. He was deafened by meningitis at 17, and over 40 years later, he received one of the earliest single-electrode cochlear implants. He subsequently received a multi-electrode CI, which helped him with speechreading and environmental sounds.

He served in many executive committee positions on the UK’s National Association of Deafened Persons (NADP) and was a founding member of STAGETEXT, which provides open captioning for British theater. He was also involved with several UK organizations for cochlear implant users and chaired the Late-Deafened People Commission for the International Federation of Hard of Hearing People (IFHOH). Professionally, he worked as a scientist in the chemical industry before retiring and setting up a bookbinding business, and he was also a lay preacher in the Methodist Church.

Geoff was contacted by a theater group in New York that was planning a London theater trip for their hard of hearing members in 2000 (Arlene Romoff was a pioneer in getting U.S. theater captioning off the ground). The group was bringing its own captioning system and wanted Geoff to help with the arrangements and publicity, and after that experience, he helped to found STAGETEXT. In a 2005 arts accessibility seminar presentation, Geoff spoke about his motivation for promoting theater captioning:

> I tried many times to follow a play by taking the script and a little torch to the theatre with me, but as anyone who has tried this will tell you, it’s well-nigh impossible. All your attention is on the script and you lose track of what is going on on the stage, lose track of where the action has got to. You need to keep an eye on the stage to see how the actors are putting over their parts but you can’t do that and follow the script at the same time.

> Many theatres provide a loop for hearing aid users, and often a performance is interpreted into British Sign Language, but loops are no use for people with no hearing at all, and those who, like me, grew up in a hearing world have no incentive to learn BSL since we know no one who uses it. There are in fact many hearing aid users who can’t understand everything that’s said.

> I suppose learning the entire play by heart might be a possibility for some people, but not me! And anyway, if it’s a whodunnit (like The Mousetrap) you don’t want to know the ending in advance. I gave it up eventually.

NADP noted, “Geoff never let his age stop him [from] doing anything, and he had the energy of somebody 20 years younger. He was at home with new technology, and although he was a quiet and unassuming person he was widely respected and made a significant contribution to the improvement of life for deafened people.” Cicada, a UK CI group, said, “In spite of all his achievements he was a very modest person and always very encouraging and supportive to the efforts of others to help deafened people. No wonder he has so many friends all over the world.”
You Have To Be Deaf to Understand

What is it like to “hear” a hand?
You have to be deaf to understand.

What is it like to be a small child,
In a school, in a room void of sound—
With a teacher who talks and talks and talks;
And then when she does come around to you,
She expects you to know what she’s said?
You have to be deaf to understand.

Or the teacher thinks that to make you smart,
You must first learn how to talk with your voice;
So mumbo-jumbo with hands on your face
For hours and hours without patience or end,
Until out comes a faint resembling sound?
You have to be deaf to understand.

What is it like to be curious,
To thirst for knowledge you can call your own,
With an inner desire that’s set on fire—
And you ask a brother, sister, or friend
Who looks in answer and says, “Never mind”? You have to be deaf to understand.

What it is like in a corner to stand,
Though there’s nothing you’ve done really wrong,
Other than try to make use of your hands
To a silent peer to communicate
A thought that comes to your mind all at once?
You have to be deaf to understand.

What is it like to be shouted at
When one thinks that will help you to hear;
Or misunderstand the words of a friend
Who is trying to make a joke clear,
And you don’t get the point because he’s failed?
You have to be deaf to understand.

What is it like to be laughed in the face
When you try to repeat what is said;
Just to make sure that you’ve understood,
And you find that the words were misread—
And you want to cry out, “Please help me, friend”?
You have to be deaf to understand.

What is it like to have to depend
Upon one who can hear to phone a friend;
Or place a call to a business firm
And be forced to share what’s personal, and
Then find that your message wasn’t made clear?
You have to be deaf to understand.

What is it like to be deaf and alone
In the company of those who can hear—
And you only guess as you go along,
For no one’s there with a helping hand,
As you try to keep up with words and song?
You have to be deaf to understand.

What is it like on the road of life
To meet with a stranger who opens his mouth—
And speaks out a line at a rapid pace;
And you can’t understand the look in his face
Because it is new and you’re lost in the race?
You have to be deaf to understand.

What is it like to comprehend
Some nimble fingers that paint the scene,
And make you smile and feel serene,
With the “spoken word” of the moving hand
That makes you part of the word at large?
You have to be deaf to understand.

What is it like to “hear” a hand?
Yes, you have to be deaf to understand!

In 1971, Madsen (a professor of journalism at Gallaudet University, now retired) wrote this poem, which was subsequently translated into seven languages. Born in 1939, he became deaf at the age of two and attended the Kansas School for the Deaf. In 1975, he helped to establish a certification program for sign language teachers, and he has authored two sign language textbooks, Conversational Sign Language II and Intermediate Sign Language. He is the recipient of numerous awards.
Lawsuit by ALDA Members Improves Movie Experience with New Technology

[Editor’s note: Movie theaters usually avoid displaying open captions for general audiences because some hearing people dislike captions, so the number of OC showings is limited. In addition to the chain discussed in this article, Regal Cinemas recently agreed to start providing closed captioning for virtually all its movies.]

Linda Drattell, the past president of ALDA, Inc., was one of two plaintiffs involved in the lawsuit against Cinemark Theaters last year for not providing access to its deaf customers. As noted on the ALDA website, Cinemark subsequently agreed to start providing captioning at ALL of its theaters across the U.S.

Recently, I joined a friend to watch the Rise of the Planet of the Apes at my local movie theater; I went specifically to try out the new captioning system, CaptiView, manufactured by Doremi (think of “Do-Re-Mi” from The Sound of Music). More information about this system and equipment is available on the company’s website at http://www.doremilabs.com/products/cinema-products/captiview/.

If you are familiar with the Rear Window Captioning (RWC) system, you might think that CaptiView (CV) is similar. It’s not. The only resemblance is that it also uses your cup holder for placing the device in front of you. It has a bright green LED display that shows up to three lines of large, clear, and bright text, so it’s easy to follow. Most deaf people prefer to watch movies with open captions (OC), which are burned onto the film and shown directly on the screen, but the number of movies with OC is very small. When I checked Captionfish (www.captionfish.com) for captioned movies in my area the week before CaptiView started, there were five movies with OC and four with RWC. Now that CaptiView is listed, there were almost 40 with CV alone!

Basically this is what you need to do. First, check Captionfish to see if CaptiView (CV) is available at a theater near you. If it is, then go to the theater, buy your tickets, and ask for the CaptiView display. You might get a few strange looks as you carry this device through the lobby, but with time people will know what it is. Before you enter the movie auditorium (since it’s easier to see outside), turn on the device with the switch on the right side. On the bottom of the display there are three buttons. You can use one to “search for the auditorium” with your movie, then another to “connect.” Make sure you are connected to YOUR auditorium, not the one next door. Then enter and put the CaptiView in your cup holder (sorry if you now have to hold your drink in your lap). Adjust the display so that you can see the movie with the caption display below the screen, then sit back and enjoy! See the photo below for an idea how it looks with the captions and the movie. This shows a scene from the latest Harry Potter film. You can also see how CaptiView works by searching YouTube for “CaptiView.”

CaptiView will be available for almost EVERY movie in Century/Cinemark theaters. Currently it seems to be rolling out from the West Coast to the East Coast in the U.S. The easy availability of CaptiView means that you don’t have to plan your week to be able to see one of the very FEW showings with OC or RWC.

Let me know what you think when you try CaptiView. Of course, I like movies with OC best, but there is a VERY limited selection of dates, times, and titles. I like CaptiView (CV) MUCH better than the big, clumsy Rear Window Captions (RWC), and there are SOOOO many more movies now available to watch. Thank you, Linda and Cinemark, for making this happen. See you at the movies!

Ken was born in Fresno, California and moved to the San Francisco Bay Area after completing graduate school. He is a past president of ALDA and a winner of ALDA’s highest award, the I. King Jordan Distinguished Service Award. Ken loves technology, helps to run the www.alda.org website, and also enjoys travel and photography. He can be contacted at alda96ken@dslextreme.com.
Movie Captioning

By Paul Jacobson

One of my diversions since losing a lot of my hearing has been watching movies. I have found several ways to do that. First, my local library has a number of movie DVDs that provide closed captions. The appropriate DVDs are marked “cc” on the edges of their boxes. [Editor’s note: there are also other ways to designate DVD captions, such as the letters “SDH” for “subtitled for the deaf and hard of hearing” and a square Q.] I’ve found that many DVDs have embedded closed captions that are not accessible through the DVD’s menu. To watch them with captions, one must use a TV set (or perhaps some other device) that has a closed caption setting in its options.

Second, while at the moment very few Puyallup and Tacoma theaters in Washington State provide captioning for English language movies, Century Theaters in Federal Way is equipped with the CaptiView system, which works with almost all of their films. (They are a 16-plex, so there are lots to choose from.) In addition, a website called Captionfish (www.captionfish.com) lists captioned films showing in any designated area, and another website called Hulu (www.hulu.com) shows a number of free films that can be watched on a computer, and their offerings can be filtered for “cc.”

I have tried CaptiView twice, once with True Grit and once with Rise of the Planet of the Apes. The first film is a rather deliberately-paced western drama, while the second is a fast-paced action film. While CaptiView was a big help for me in both cases, it was better with True Grit, since a certain amount of time is required for looking back and forth between the movie screen and the CaptiView screen. If you get too fixated on either screen, you can lose details on the other one. Until they are thoroughly familiar with the CaptiView device, patrons should insist that it be completely programmed by the theater attendant before taking it into the darkened theater. Otherwise, the device’s adjustment buttons are just too hard to work with in the dark.

Paul was born in Kansas City, Missouri and currently lives in Puyallup, Washington. He has a BS in chemistry from the University of Illinois and a PhD in chemistry from Northwestern University. Paul is married with three children and his interests include bowling, gardening, and solar energy. He does volunteer work at his public library and can be contacted at peejay27@q.com.

Tempered by Adversity (continued...)

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realized that everyone I encounter has the potential to impart and acquire knowledge. I used to envision education as a long, winding trail, but I found that education is cumulative, a foundation on which life is built.

As I look back on the past three years, I am aware of the changes in my personal and professional identity and goals. The Deaf studies certificate program introduced me to a culture through its language and people, and that culture welcomed me with open arms. After years of fighting to accept losses due to illness, I discovered that my experiences could be used to teach and inspire others involved in similar struggles. Most of all, I realized that, in my search to locate the population that could benefit the most from my efforts, I was overlooking the very place that was responsible for my rehabilitation and ability to work at all; my own community and my community college.

My graduate classes will likely start in the fall, as I continue my academic journey, step by step. My presence at Holyoke Community College will remain, however, as I continue to tutor Deaf students. Mercury will continue to make his rounds as a self-appointed service dog ambassador, traveling from office to office as he follows a well-worn path. The fires of adversity will continue to ebb and flow. My illness is progressive, but with each change comes the knowledge to compensate for my difficulties.

Heidi Martin-Coleman graduated in May 2011. This is slightly revised from the speech she delivered to her graduating class. Heidi can be contacted at redtape@mitoaction.org.
I am writing from the 19th Biennial TDI International Conference (held June 2-4 in Austin, Texas), where the program theme is “21st Century Communications and Video Accessibility Act: Challenges and Opportunities.” The title is a mouthful, and I hoped I would find the presentations interesting. I didn’t need to worry. By the end of the first session—which was on broadband and communication access—I was racing to my computer to write everything down, having never heard a more compelling keynote speech. Do the words “broadband” and “compelling” in the same sentence sound crazy to you, too?

Simply put, FCC Commissioner Michael Copps talked about the extreme—yes, that’s my summation of the urgency in his presentation in one word, extreme—importance of having functionally equivalent access to Internet broadband. If you don’t have high-speed Internet access, you can’t compete equally, you can’t be an active citizen in a democratic society, and you are at greater risk than the rest of the population in a disaster. So we need to ensure that we have an accessible media landscape to guarantee the flow of news and information to every American. This is the premise of democracy.

Mr. Copps said that Franklin Delano Roosevelt saw one third of the nation not being connected to the communication infrastructure of that time, causing social and economic disparities. Today, deaf and hard of hearing people miss breaking news, weather emergencies, and current events that fuel our society’s conversations with itself.

Take, for example, the information and social culture that is transmitted through YouTube. Ken Harrenstien, a deaf senior software engineer at Google and the lead developer for Google’s captioning technology (he accepted the TDI Engineering Award this year for Google), explained why he was so passionate about making YouTube accessible through captioning. In order to imagine the amount of videos placed on YouTube, he said, imagine Niagara Falls—and each drop of water is one video. After being in existence for only six years, YouTube reached an amazing landmark—each minute, another 48 hours of videos are uploaded. The creation of voice-activated software by Google is helping to make many of these videos accessible to people who are deaf or hard of hearing or who speak other languages.

This is what needs to be done to ensure equal access:

• We need to get access needs addressed at the beginning of technological advances.

• We need to work with other groups to gain access for everyone.

• We need to make sure that decisions are made with us, because those made without us are usually made against us.

Compelling arguments. I was more than hooked. I realized that what the government and industry decide regarding broadband will affect me personally. I’ve taken a closer look at broadband and have decided it’s worth more than a second of my time. We all need to become watchdogs. We must write letters to the FCC when we don’t have the access that is our right and also when we realize that a problem will arise. Contact the ALDA Board if you don’t know who to write to and we will forward your letters. Make your voices heard!

Linda is the past president of ALDA. She can be contacted at lindra@comcast.net.
Technology Ends Isolation

By Chelle George

A hard of hearing or deafened life would be isolating without today’s technology. I can only imagine it as lonely. I remember what life was like before computers. I lived in a small desert town of about 15,000 people, and there were no hard of hearing resources available locally. It was an hour and a half in any direction from a big city. I traveled out of town to get hearing aids and again to get them adjusted. In my late twenties, I was the only person I knew with hearing aids except for the snowbirds who came to town in the winter.

Coping with hearing loss meant faking it—that was my only strategy back then. I tried being hearing because I didn’t know what else to do. There were so many lost conversations during those years and missed connections too. It was a poor strategy.

Along came the Internet and America Online. For months, I had to call long distance to dial in, so my time online was limited, but oh how I loved it. It opened up a new world for me—this was the first place I could socialize without struggling to hear, and I no longer felt like a social idiot. All the words were right in front of me to see. It was beautiful.

Some months later, our small town received local Internet service, and I had unlimited Internet time at long last. I was overjoyed and spent every spare moment online, chatting, emailing, and surfing the web.

After a year of playing around online, where I never had to admit I was hard of hearing, I looked into hearing loss. The first sites I remember finding were SHHH (Self Help for Hard of Hearing People) and ALDA. There wasn’t much on their websites except some basic information and a list of chapters. The nearest one was an hour and a half away, which wasn’t feasible for me to travel.

Keeping up the search, I found the SayWhatClub, an online group. I joined and learned so much from those good people. They said that faking it was bad, so I worked on being honest about my hearing loss. There was a whole world of assistive listening devices (ALDs) out there. The phone company provided voice carry-over phones, and I signed up for one. I learned about resources such as vocational rehabilitation and the disability center at my local community college. I was not alone when I had the SayWhatClub with daily emails of strategies, support, and the chance to rant about our predicaments. I had friends from all over the country who understand what it was like to be hard of hearing. Without the availability of the SayWhatClub, I would have been years behind in technology and awareness and probably wouldn’t have had the courage to be upfront about my hearing loss.

The next big miracle was texting. It started out a teenage activity, and my kids were among those who texted. One night I had my daughter sit down and show me how to do it. She was patient and I learned. The problem was, I seemed to be one of the few adults who texted. How I wished my friends and family members texted back then—it was so much easier and quicker to communicate that way.

A few years down the road, other adults began texting. My mom was among the first, and it elevated our communication to a daily thing. A couple times a day, we would text one another back and forth. If a whole day went by without one of us texting, we would text, “Everything ok?” It was great having my mom at my fingertips, and our relationship grew. Now texting is common, and many of my friends and most of my family text. I even had bosses and co-workers text me. Airlines, my tax preparer, and my own phone company have started using texting. Most people say yes to texting when I ask them.

My phone doesn’t ring much. Instead, it buzzes with text alerts. I discourage phone calls with most people because anxiety builds up in me every time I think about such calls. Even my voice mail tells people to text me instead. (That has gotten rid of unwanted sales calls!) My phone is near me most of the day and I don’t go anywhere without it. The buttons are worn from making words on the little screen, and I can’t go without texting anymore than I could go without email now.

I moved to Salt Lake City almost three years ago, away from those small desert towns. Surely the big city would hold SHHH or ALDA meetings somewhere. A quick Internet search showed me that SHHH had changed to HLAA (Hearing Loss Association of America), and there was an HLAA chapter meeting once a month at the local deaf and hard of hearing center. Not only was I lucky enough to find a meeting with others like me but I also landed at the Sanderson Community Center for the Deaf and Hard of Hearing.

[Editor’s note: This is one of the two locations of the Utah State Division of Services to the Deaf and Hard of Hearing (DSDHH).] continued on page 17
What is the most difficult challenge related to your deafness at work or in finding a job? How do you deal with it?

My most difficult challenge in a job interview is that I get stressed and my remaining hearing almost disappears. I am afraid my answers are not tuned to the question, and I constantly ask the interviewer to repeat. It is embarrassing. Having had severe to profound hearing loss only in the last 10 years, I really don’t know what to do. I’m very thankful my husband is working!

As Meniere’s disease changed my hearing, balance, and stamina, my coworkers froze in their tracks. And our business was mental health! It was a painful scenario: I became the elephant in the agency living room. Their trusted go-to gal who handled all the difficult, different, or medically complicated cases and diverse families became...gasp...one of “them,” a “patient” instead of a “provider” in the medical model. That whole culture is not set up for differences. It has only one right way to be a person, which is why they had me on staff in the first place, to work with all the wiggly cases.

All but one or two of my colleagues simply went blank, couldn’t talk about it, address it, or face what was happening to my body. One would think these professionals who specialize in communication would have rushed forward with empathy. I believe it is just how humans function: Fear turned to avoidance. I got one card after each of my first two surgeries. After the third surgery and the one that left me deaf, there wasn’t even a card from the agency at all, or any information circulated about my change in circumstances or how to reach me. It was as if I’d fallen off the face of the earth.

After four months I came back for a few hours a week, and we navigated forward on how to address my differences. The turning point occurred when a young colleague found me one afternoon, vomiting into my wastebasket from dizziness but struggling to complete chart reviews. He said, “We see you. Well, I see you. You are disabled. You are still so good at what we all need you to do, but you can’t do it the same way. There has to be another way.” I burst into tears of relief. His honesty gave me the courage to confront my boss, the director of this agency, who was distraught but paralyzed with fear and confusion about how to respond, waiting for my lead and plan for solutions.

I left my full-time job, staying on as a consultant, and obtained SSD. I don’t have health insurance because I can’t afford it, and I pay for my own ASL interpreter while working for a grant whose clinical components I wrote and which were funded by our government’s Substance Abuse and Mental Health Services Administration. I work lying at a 30-degree angle because of episodes, use remote systems because travel induces episodes, and on my good days, I travel two hours round trip for a partial day onsite. My brain works when the symptoms abate, and I am offline between times.

It is a very different way to work, and I miss clinical practice. I have had to rethink everything about my expectations and self-worth. But I found ASL, a great gift that has helped me learn, stay flexible, reclaim my work life, and find other late-deafened people. In many ways, my experience is a benefit to my field, but I still have to maintain my optimism, avoid self-pity and stress, look at everything creatively, and stick to “Whatever Works”!

During meetings, I found that I was trying too hard to hear everything. One day, I asked a co-worker what had been said about a particular subject, but he didn’t know because he had been thinking about what he and his girlfriend were going to do that evening. After hearing that, I thought, why am I trying to hear everything when most people aren’t paying attention all the time? In a weird way, I felt better because maybe I was “hearing” as much as everyone else was.

I am a medical assistant, so when I started losing my hearing, I ended up back in the front office because I didn’t realize there were stethoscopes that I could still hear with, and I was too embarrassed and afraid there wouldn’t be to look for them. We used electronic blood pressure (BP) cuffs, so there were no worries...
**ALDAanonymous (continued)...**

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EXCEPT when the cuffs didn’t perform right. Luckily, the doctor and his wife (the office manager and RN) would help me out and take the patient’s blood pressure with the standard cuffs.

When the doctor retired, I went looking for a job, trying to figure out the best time to tell a possible employer about my hearing loss. Then I started working with a new doctor, and lo and behold, SHE had a mild hearing loss and let me borrow her digital stethoscope until I could get my own. She had noticed me leaning in during the interview and figured I was also hard of hearing, but it didn’t matter to her—she saw my experience and my passion for the job and figured we would handle it.

I started doing research on the Internet and found UltraScope stethoscopes. They were not digital/electronic but were supposed to be really good for hard of hearing people and cost a LOT less than digitals, so I ordered one. I was very nervous until I used it to take a BP, but IT WORKED! There are still some BPs that I struggle with, and when that happens, I just ask the doctor or the other medical assistant to double check. This has never been an issue for either of them. The doctor also ordered an amplifier for my desk phone. I can’t use it because it just distorts sound, but she had done it on her own to make things easier for me. As a side note, she also lets me show off my tattoos at work!

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There are both good and bad days with my CI-assisted hearing in work environments, but I don’t keep a count of the number of each type of day. It’s all about attitude in dealing with difficult challenges on the job. I’ve learned to assert myself to understand what it is expected of me to achieve the organization’s goals and then to be understood by showing what I am capable of doing for the company. With previous employers, I wasn’t listening carefully and clearly understanding, using whatever methods were needed—writing, signing, or lipreading. I am at fault for this, clearly. So the quote I found in The Seven Habits of Highly Effective People by Stephen R. Covey, “Seek to understand, then to be understood,” was a profound statement for me. I’ve put that into practice with clear, concise communication and listening skills. While I search for work, I seek to understand the employer’s goals before expressing my needs. I explain what communication mode works best for me and listen to what the employer is looking for to see if there is a match made in heaven where my skills can accomplish the company’s goals.

Next ALDAanonymous question: Do you find it difficult to participate in community activities and events due to your hearing loss? How do you deal with or overcome such challenges?

Send your responses to Bill and Robin at aldanonymous@gmail.com by November 23.

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**Our World—News from the International Committee**

By Muhammad Akram, Chairperson

We received sad news from the United Kingdom that Geoff Brown, a very active member of the International Committee (IC), died on July 28. IC’s members extend condolences to his family and friends. He attended many ALDAcons and mentored many others in ALDA and around the world.

Linda Drattell (the past president of ALDA) also left the IC. We appreciate her hard work and cooperation during her term.

On other hand, we have a new IC member, Victor Odandi of Kenya in Africa. So now we have members from four continents (Africa, Asia, Europe, and North America), and this will help us to raise awareness about the identity of deafened people.
A Hearing Odyssey

By Paul Wummer

It was a summer day in 1963 when I, a six-year-old kid, ran around excitedly showing everyone within eyesight my new hearing aid. It was like Christmas in July; someone had come to my house bearing a special gift for me—a hearing aid with a harness!

Before that my family hadn’t known I had a hearing loss, but there were clues. I’d place my little wooden rocking chair directly in front of the square black and white TV only a few feet away. One day my kindergarten teacher taught the class a fireman song that involved pantomiming a fireman responding to a fire as we sang. The teacher saw that I wasn’t keeping up with the rest of the class. Her remedy? She motioned me to the front to lead the class in another rendition. I didn’t know many of the words and started crying hysterically while going through the pantomime motions (ringing the bell, sliding down the pole, etc).

Wearing the harness strapped around the middle of my chest with the hearing aid in its pocket, I repeated kindergarten. Later, it was explained to me that I needed to catch up on what I missed.

In the early ’70s, smaller hearing aids worn behind the ear (BTE) debuted. I don’t remember hearing or discovering new sounds with the body aid or BTEs. Back then, I guess I was mainly in the business of running around being a kid.

I started college in 1975, and I’ll never forget the first time a group of us decided to go out for pizza. “Yes, pizza!” I said. “No, pizza!” they said. I was confused. After several more rounds of saying pizza, someone finally spelled out the pronunciation for me. “It’s P-E-T-E – sa.” I was saying “PEACE-sa.” When I was back home, I asked my mother why no one had ever corrected me, but she didn’t have an answer.

One day, while I was in class, my battery died. I didn’t have a spare and just sat there until class was over. Even with the aid, it was often difficult for me to follow class discussions, anyway. My hearing depended a lot on what I observed and read (including lipreading)—my eyes assisted my ears. When I asked a classmate afterward about what I had missed, he stared at me in disbelief: “You didn’t hear anything?” With a hearing aid and my eyes, I can pass for a fully functional hearing individual quite often, but without the aid, I hear mostly noise and some words. The hearing aid is my bridge to the hearing world. Many people don’t realize how bad my hearing is—even my audiologist was surprised.

After college, on my first day at work (as a computer programmer in 1979), I was introduced to my co-workers. One was from Michigan. “MiCH-i-gan!” I said to him. Shaking his head and smirking, he said “Nooo, it’s “MiSH-i-gan!” I was mortified.

From the late ’70s through the ’90s, with each new BTE, it took me time to get used to everything sounding different from before. One constant was the noise generated by traffic, which really bothered me. Analog aids cannot closely match their output to a person’s particular hearing loss. In my case, having the volume set high enough for me to hear conversation caused the traffic noise to be boosted by a similar amount. My hearing loss is greater in the speech frequencies, so I heard traffic louder than it really was.

Digital hearing aids debuted in the ’90s. Their major advantage is that they can be more precisely programmed to match one’s hearing loss, but the early models didn’t have enough power for me to hear speech very well, so I stayed with my analog aid.

By 2000, more powerful digital aids were available, and I began hearing and discerning lots of new sounds. Walking up the stairs in my quiet house, I heard a noise. I stopped; it stopped. I started up again; it did, too. The noise turned out to be the sound of my breathing! Reading newspapers became a bit of an annoyance—I hadn’t known that paper rustles a lot. Eating cereal became worrisome—with all that crunching, I thought my teeth might be breaking. Eventually, my brain adjusted to the cacophony. I can calmly eat cereal now, and reading newspapers no longer annoys me. There were also far more pleasant surprises. Traffic didn’t bother me unless it was really loud. I heard more words while watching TV and didn’t need the volume set as high. My neighbor was happy about that!

In 2007, my audiologist mentioned a new, more sophisticated digital aid. The default setting, its advertised feature, was designed to detect different hearing situations and automatically adjust the settings. However, I had the default changed to “act like a normal hearing aid.” Why? With the original setting, when I stopped at a traffic light, the car radio faded. Walking down the street with traffic everywhere felt like being in a ghost town. The aid was programmed to lower the sounds that it thought were (unwanted) background noise that interferes with hearing speech, but it was a bit unnerving to see traffic and not hear it. Maybe too much of a good thing can spoil things (like too many cooks spoiling the broth)? In “normal” mode, the aid is still very impressive. A familiar Eric Clapton song came on the radio in my car and I heard birds chirping. That’s odd, I thought, because my windows were closed. I turned the radio off. No birds. I turned it back on; the birds were back. They were in the song! It seemed as if all music had been remastered and new instruments added. I was also able to hear more words in songs and on the TV.

Nevertheless, in spite of all the advances in technology, there is no device capable of giving a person “20/20” hearing like glasses do for the vision of most people who wear them. There are also “bad hearing” days. Things like too much caffeine, insufficient continued on page 17
A Hearing Odyssey (continued)...

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sleep and many environmental factors can adversely affect hearing. Also, I cannot tell where a sound comes from, since all sound is funneled into the aid’s microphone. And I have trouble hearing consonants (e.g., I cannot hear the difference between “t” and “d”). It is hard to memorize the correct way to say a word when one does not hear how it’s pronounced. It usually takes a memorable event like the pizza exchange for me to remember.

There were other advances in technology over the years that helped me. One that I cannot do without is closed captioning (cc) for TV. My favorite show is “Cheers,” and I had been frustrated about missing much of the dialogue, especially Norm’s (with or without a mug of beer in front of him). Thanks to captions, I know lots of “Normisms” (and now you can Google them, too!):

“Can I draw you a beer, Norm?”

“No, I know what they look like. Just pour me one.”

Years ago, I asked my parents why my hearing loss wasn’t discovered earlier. They said they had thought I was a slow learner. When asked how it was discovered, each gave a different answer. My father stated that the kindergarten teacher told him I was retarded. My mother said that wasn’t true and that she had suspected that I had a hearing loss and tested my hearing by waiting until I went up the stairs. She then whispered, “Paul, do you want some cake and ice cream?” but I didn’t come down. After talking with my younger sister, Sara, I’m inclined to believe that her birth played a major role. She was born in February 1963, and when she was an infant, my parents noticed that she wasn’t responding to loud noises. Banging pots didn’t startle her; something was wrong. They had her hearing checked and learned that she was profoundly deaf. I’d venture that this was when the idea to have my hearing checked occurred to them.

And then came one summer day in 1963 when it felt like Christmas in July.

Paul is the ALDA regional director for Region 1. He is single and lives in Allentown, Pennsylvania. Paul has a degree in accounting and worked at an electric utility company as a computer programmer for 30 years until he lost his job in February 2009. Some of his interests are running, hiking, traveling, reading, classic movies, puzzles, badminton, and bowling. His email address is pwummer@gmail.com.

Technology Ends Isolation (continued)...

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HLAA meetings were advertised on the center’s website, with CART (Communication Access Real Time) provided. I had heard about CART many years before from the SayWhatClub but never experienced it, so it was pure joy to walk into my first HLAA meeting at the Sanderson Center and see everything captioned.

Every meeting I go to at the Center has CART available if I or others request it. It was another miracle as my hearing continues to plunge. I can go to three hours of meetings there (or a presentation) with CART and walk away energized. After two hours in a social situation without CART or any other accommodation, I leave exhausted. I go the Center every chance I get.

Every time I walk in I feel the burden of the hearing world lift off my shoulders and I relax.

A local ALDA group meets informally three or four times a year for potlucks and I have been to a couple of the meetings (date conflicts kept me from going at other times). It’s easy time spent together, talking about anything from captioning woes to the world before and after cochlear implants. Two people from our circle attended ALDAcon in 2010 and gave a report afterwards at an HLA meeting. ALDAcon sounds like a magical place where “whatever works, works” for communication, and I want to attend to experience the magic for myself.

I’m glad I live when I do. Technology has been keeping up with me, and I can’t imagine how separated from the world I would be without it. I try imagining what life would have been like for hard of hearing and deafened people 100 years ago with no technological help, and the only words that come to my mind are “isolated” and “lonely.” Technology continues to improve and expand, and I’m eager to see what comes next.

Chelle lives in Salt Lake City but is originally from Southern California. She raised three children, became a grandma in November 2010, and enjoys skiing and traveling. Chelle is active in the Hearing Loss Association and is co-chair for the local Walk4Hearing. She has a hearing loss blog at http://hearinglosspages.wordpress.com and can be contacted at livinglife fullest@gmail.com.
The Late-Deafened Experience—Fast Food Technology—Is This the Best We Can Do?

With today’s technology, you’d think they’d make more accommodations for deaf and hard of hearing people who want to use the drive-up window at fast food places. Sure, some of them have a sign that states that if you’re deaf or hard of hearing, you should just pull forward to the window. But have you ever tried it? The people at the window get more confused than Ray Charles would be with a “Where’s Waldo” book. But sometimes going into the establishment to get your order just isn’t convenient. Especially on a hot day. Yuck. And thus begins the tale of my latest experience trying to get some eats out of them.

Checkers. She wanted Checkers for lunch. Or in some places they call it Rally’s. Either way, what she wanted was definitely those spicy French fries slathered in warm, saucy cheese and bacon. But it was July. I mean, man, it’s hot outside. The last thing I wanted to do was park and get out of my air-conditioned car. However, she pushed me over by saying “please” so sweetly. It was the least I could do, right? No way. It was too hot, I tell you.

“I’ll help you in the drive thru,” Mollie signed to me as I weighed the options. I mean, sure, I could have gone through the drive thru and just told them at the window that I’m deaf and need to order face-to-face. But I’ve never been one to test waters, so I took her up on her offer.

There I was, face-to-face with the speaker and depending solely on my 14-year-old to let me know when to speak.

“I need an order of French fries with cheese and bacon added, please.” I spoke into the speaker as best I could, but apparently they either couldn’t hear me or couldn’t understand me. I repeated, but Mollie said they still didn’t get it. I raised my voice, “I’m deaf and I’m going to pull around to the window and order there.” I don’t know if they understood me that time, but it didn’t matter, because I was taking the initiative.

Pulling up to the window, I noticed that the girl inside looked extremely confused. When she opened the window, I shouted, “French fries!!! I need French fries!!”

The girl stared at me, looking totally flabbergasted, and then left to take care of my order.

Mollie gently placed her hand on my leg. “Mom? Do you realize that you just screamed at the top of your lungs at that girl?” So that’s why she looked so shaken—

I’d just blasted both of her eardrums out. But we got our fries. Yes, indeedy. Sure, the girl will be deafened for a good two hours, but I had to do it. I needed those fries. Offering her the name of a good ENT, I paid the girl.

“Sorry if I screamed at you,” I sheepishly said.

“What???” she screamed back. Hmmmm. I guess my work here is done.

Michele J. Bornert is a freelance writer and ASL instructor in Grand Rapids, Michigan. She resides there with her hearing husband, Kenny, and three hearing children, Mollie, Jacob, and Natalie. You can contact her at DeafExpressions05@gmail.com. Visit her website at www.DeafExpressions.4t.com.

Candis Shannon Memorial Scholarship Fund

This year we are proud to sponsor our very first scholarship to ALDAcon in memory of Candis Shannon, our dear colleague and former ALDA News Editor-in-Chief. Candis was not only known for her infectious smile and endearing personality, but also for her intrepid excursions to each ALDAcon from her faraway home in Fairbanks, Alaska.

On November 5, Marylyn Howe—who morphs into Marilyn Monroe during ALDAcon’s infamous karaoke parties—is jogging in the Rock ‘n Roll Marathon in Savannah, Georgia. Marylyn seeks your support in helping to raise scholarship funds in Candis’ name. All donations are tax deductible and will go to sponsoring a newcomer to a future ALDAcon. You can help! Please make a pledge either for the entire 13 miles that Marylyn will run or for each mile you think an old washed-up glamour-puss like Monroe can limp.

Email your pledge amount or your questions to Marylyn at juneymoon@aol.com. You may send a check to cover your pledge now or after the race. Checks should be made out to ALDA, Inc. and sent to Marylyn Howe, 39 Log Landing Rd., Savannah, GA 31411. But don’t wait. Pledge today and help a newcomer attend a future ALDAcon in Candis’ memory.
Direct Audio Input: A Low-Tech, Little-Known Assistive Listening Device

By Carol Granaldi

Today, many hearing aid and CI users are aware of wireless FM, infrared, and induction loop assistive listening systems, but few are familiar with a very useful hard-wired device called a direct audio input (DAI) microphone, which is clamped onto one’s lapel or collar and has a wire that attaches to a hearing aid’s internal microphone via a boot. The DAI is most useful in a noisy environment such as a party and can also be used in a car to reduce noise from the road, the engine, and the radio and to bring spoken words closer to the hearing aid or CI processor.

With a DAI microphone attached to my garment or lapel, I found that room noise was reduced by half because my body served as a baffle. It is as though one is cupping a hand behind the microphone to decrease sound and to capture conversation close by. People who hear normally often place their hand on one ear to decrease noise when trying to hear over the telephone or when someone is talking to them.

Few hard of hearing or late-deafened people are aware of the DAI’s advantages, and I’ve seldom seen anyone using the lapel microphone. About a dozen years ago, I wore a DAI to a hearing aid dispenser’s convention and was approached by a couple of dispensers asking why I had a microphone attached to my hearing aid. I learned that dispensers are seldom educated about using assistive hearing accessories beyond hearing aids. When I inquired about this lapse, I was told that many hearing aid users have a vanity problem and don’t want it to be obvious that they have a hearing loss. In addition, most hearing aid customers have mild to moderate hearing losses and do not go beyond the realm of using a hearing aid to hear, despite their complaints that a noisy room poses speech comprehension problems.

At this time, I’m no longer a hearing aid user, having graduated to bilateral CI processors. My previous Phonak hearing aid had a DAI microphone attachment with a boot that attached to the hearing aid’s internal microphone. The equivalent of such a setup is not the same with my CI processor because it has its own attachment apparatus—an earhook connector with an outlet into which a DVD player or other listening equipment is plugged. I decided to experiment a bit, and took the microphone of a Pocketalker [a hardwired assistive listening device], bought a Y jack from Radio Shack into which the microphone fits, and added a microphone clamp that affixes to my garment or that of someone in the car with me. The Y jack is inserted into the earhook connector and I can use either a 48” wire with microphone or a longer cord if I want to attach to another device or person.

This works fine for me, although it’s a bit cluttered looking. But I don’t care because nowadays everyone is walking around with a Bluetooth or other phone attachment, headsets, earplugs, etc. coupled with iPods and DVD players. I feel rather sporting walking around just like everybody else looking so “high tech.” And, when I need to point the microphone when conversing with another person in a noisy room, he or she is flattered that I’ve made a strong effort to understand his or her speech instead of bluffing and responding incorrectly. People feel as though I’m interviewing them (smile).

I also find this setup helpful when visiting a noisy office such as a doctor’s waiting room.

It seems that many hearing aid or CI processor users don’t know about the advantages of a DAI, or, perhaps the “vanity issue” deters them from more fully understanding speech in noisy settings. To them I say: “Get over it. Your vanity may be stressing you or others, if you don’t help yourself by hearing better with whatever assistive listening technology is available so you can participate in the dialogue around you. Remember, a hearing loss is noticed more than a hearing device.”

Carol has had a progressive hearing loss since early childhood and lives in an Ocean County, New Jersey retirement village with her husband. She can be contacted at cgranaldi@comcast.net.
The Treats and Trials of Technology at Work

By Helen Droitsch

Scene – Dallas airport, audit staff convening for last minute meeting.

“Did you text her?”

“Yeah, five minutes ago, she should be here...oh, here she is.”

“Did you line up the conference call in the airport security area?”

“Yes, and it has closed captioning so I can hear and see everything that’s going on, right down to the flicking of pages.”

“That’s a relief, since you’re the lead auditor. What about the satellite link-up?”

“That’s all fixed—all parties in Chile, New York, and DC will be participating—and that’s closed captioned, too!”

“Did you email the audit results to the auditee?”

“Sent just yesterday. I got a text message this morning. ‘All docs received. Talk tomorrow at 9 a.m. MT, 11 EST? Chet.’ All of you should have a copy on your cell—oh, and he sent a picture of their team members in Chile. There will be an automatic translation as well, if we need it.”

“Did you make the changes in the PowerPoint presentation we discussed last night?”

“Absolutely—everything is working, including the sound effects!”

Later, before the flight to Chile took off, one of the auditors came up to me and said, “Hey, I brought a couple of DVDs for the flight—closed captioned even, thought you’d enjoy them.”

Yes, these miracles did occur, not all at once, but gradually in the last five years of my job. I fought for closed captioned phones, for captioned satellite conferences, and for cell phones with international phone and email access for staff auditors on travel. I participated in online training that got me additional accreditations and sometimes even awards. This captioned training would not have been possible had it been in a classroom setting. Sometimes I felt as though I was the only one who cared about the importance of some of these devices. I knew I had to persevere, if only to end the isolation at my job. Otherwise, I would not survive.

Understanding from my co-workers and my boss came slower, and there were the misconnections at airports and the phone and group conferences where I only got a tenth of what was going on. There were those moments when I felt incredibly frustrated and sad that I could not use my speakerphone as often as I wanted to, or could not understand it even if I did—thanks to being in a cubicle! Satellite hookups and closed captioned conferences came only when I could cajole some poor IT staffer into making these things happen. The emotional acceptance of my co-workers and the companies that my teams audited came much more slowly.

There were situations that still had to be dealt with, which technology could not yet address. An example was having to explain to a company CEO that I needed him to face me, when everything had gone so well... because suddenly my hearing aids had stopped functioning. Several times I was the sole member of an on-site audit team visiting a factory where the sound of the clacking machines drowned out the presentation of the floor manager—yet I still had to write up that presentation in detail that same night for my automated work papers, so that I could email these results to my off-site team members and my boss for discussion the next morning. There were a lot of moments like these when I felt a deep despair. Yet now I am extremely thankful I lived and worked in a time where such things as texting cell phones, online training, captioned phones, satellite hookups, and DVDs exist. Without these tools, I would not have been able to keep the job I had, traveled to the exotic places I visited, and enjoyed the friends I met who appreciated me no matter how little I heard.

Helene’s photo was taken at her grandchildren’s piano recital. She no longer plays the guitar or any instruments requiring tuning, but she can still play the piano, although she can’t hear the high notes well. She has a 70% loss in her left ear and 65% in the right one and wears hearing aids. Her hearing loss began in her early 20s and became progressively worse. Helene’s article describes her 22 years with the government (she previously spent four years in public accounting). Because she finds it exhausting to spend hours in group meetings, she prefers to write, paint, and read. She has gone through recent surgeries and is scheduled for more, and she is working on a humorous take-off on visits to hospitals, a la Dave Barry. Afterwards she hopes to get back to serious hiking. Helene can be reached at hel3oise@aol.com.
Job Hunting While Deaf

By Donna Maderer

It’s not as though I had much experience with job hunting during the time when I HAD hearing, so beginning what I’d anticipated to be a profoundly stressful, epic journey without hearing was quite intimidating, to say the least.

I had worked for the same company, a mid-sized Boston-based quick printer, for 27 years and figured that this long stay could possibly make me look less appealing to prospective employers. During that time, though, I had held six very different positions.

Why take on this scary hunt? My job had become uninspiring. The company was shrinking, which meant that my opportunities to learn new things and tackle fresh challenges were shrinking, too. That and layoffs were happening more and more often. It was time to get gone.

Being a pragmatic sort (you know, there ought to be a superhero for that—the Capec Pragmatist or Pragmatic Woman: able to leap tall buildings in 10 easy steps), I started by writing my resume. Doing this gave my ego and spirits a boost. It helped me to see that I had scads of knowledge and experience within the printing industry. I realized that I’d be a good catch for any company but the trick, to my mind, was getting someone to see past my deafness.

My first interview was at the Massachusetts Rehabilitation Commission. I had heard that they had the resources to assist deaf folk find work, but my intake interview was a little frustrating. I got the sense that, since I was employed and this position was in a hearing environment, my case was perhaps low priority. It’s true that I wasn’t in desperate straits, but I still felt utterly lost and afraid.

The rehab commission put me on a three-month waiting list; whatever assistance they could possibly provide wouldn’t be discussed until after that time. I felt let down—I had to wait THREE months? I wanted a new job within three months, and I didn’t want to put off my search for that long.

What I most wanted help with was the following:

1) When and how do I tell a prospective employer that I’m deaf?
2) What industries are, generally speaking, more open to hiring deafies?
3) How does the job search happen in this Internet era? I hadn’t looked for work since resumes were sent off via the US postal service.
4) When (not IF) I got an interview, how would I handle things if I couldn’t read the interviewer’s lips? **panic**

I decided to just jump into the process by talking to a lot of different friends, asking advice of everyone—everyone outside my company, that is. It’s just not smart to let it be known at your place of work, particularly in this horrendous economy, that you’re looking. I was afraid my employers would let me go and I wasn’t keen on the sink–or-swim scenario. After the fact, I realized what I was doing was “networking”—something I never figured I would be able to do. Don’t you need to have smart, pinstripe charcoal grey suits and wear heels for that? Em, no.

I sent one resume via an online career/submit-your-resume-here section of a local hospital. I felt as though I’d thrown a message-filled bottle into the middle of the Atlantic, and sure enough, there was no response.

A fellow I used to work with had connections at a large neighborhood health center, so I asked him if he could give me an introduction to get them to look at my resume. I needed to include a cover letter and thought I should write a brief paragraph about being deaf, mentioning the methods I employed so that this was in no way an obstacle. I figured they’d find out eventually, so it was best to let them know right off. There was no response. I was a little disheartened but understood that this wasn’t going to be easy and that I’d need to do more networking and send off more resumes.

It was then that a friend on Facebook, a woman who had worked for me back when I was the production manager of a large offset pressroom, emailed to ask if I knew a few people who were applying for jobs at the company where she worked. I didn’t have a lot of specific memories of the folks she mentioned; they’d been in different departments and it was well over a decade since I’d seen them. But I took the opportunity to ask, “Can I send you my resume?” Happily, she said yes and I did. The very next day I received an email from the HR manager, asking me to call him with the best times to come for an interview. Realizing that my friend hadn’t told them I’m deaf and fearing that this could be a deal breaker, I wrote back that the phone and I weren’t on speaking terms (and why) and telling him which days were best for me. Happily, he wrote
I first met Terri at ALDAcon in Colorado Springs last year. She was the very enthusiastic person waving the checkered race flag as she talked about plans for ALDAcon 2011 in Indy. Terri’s hearing gradually ebbed from her teen years on, and she was fitted with bilateral hearing aids when she was 36. She opted for a cochlear implant in 2005 after having no usable hearing in her right ear for about eight years. In 2010, she had CI surgery for the other ear, in hopes to one day gain “stereo hearing.” She’s still waiting.

Terri is a travel aficionado, having visited 15 foreign countries and all 50 of the United States. She worked for The Evansville Press and then switched to working in the optical industry, writing Eye-Talk, a magazine for optical dispensers. She has taught classes at OptiFairs held in New York, Chicago, and Los Angeles. That led to a managing editor job for an optical industry magazine in New York State. From there, she moved to Vermont and managed an optical retail shop. When the owners closed it, she moved back to Evansville, where she currently resides.

When I asked Terri for a photo for this article, she said, “I’ve been hiding from cameras for 20 years, so here’s the latest and the greatest. Those of you who know me today can see what 20 years can do to a person.” Read on, and I’m sure you will agree that Terri, with her marvelous sense of humor, is “one of us.” You can contact her at TLSEVIN@aol.com.

Name: Terri L. Singer
Where were you born? Evansville, Indiana
What is the cause of your deafness? Inherited sensorineural
Marital status? Divorced for about 100 years
What is your present job? Putting together ALDAcon 2011; otherwise, retired
What is the worst job you ever had? Gee, that’s about a 10-way tie.
Movies you want to see again? I can hardly bring myself to watch a movie a second time, but my favorite is “The Big Chill” because it’s about friendship.
Books you tell others to read? Anything by John Irving
Favorite pig-out food: Only one? Hmm. Fried chicken? Barbecued ribs?
Hobbies: Traveling, reading, paragliding (kidding), writing, emailing, water exercise
If I had more free time, I’d: Try to fill it. As a retired person, I don’t need more free time. Now, if I had more money… I’d travel more.

The hardest thing about becoming deafened is: The isolation factor.
I began accepting my deafness: When I regained 94% of my hearing with my first CI. Until then, I could not say the word deaf. Now, I readily tell people, “I’m a deaf person.”

The worst thing about deafness is: Besides isolation, it’s having people treat you as if you’re stupid and/or closing you out from group conversations.

The best thing about deafness is: Being able to “turn off” obnoxious people.

How did you learn about ALDA? My cousin, Dennis Gonterman, pushed me for a few years to join, so when ALDAcon was held in St. Louis in 2006, I joined and attended. I haven’t missed one since.

In what ways has ALDA enhanced your life? It’s filled it for the past 22 months as Kim Mettache and I began planning for this year’s ALDAcon. Otherwise, it’s raised my awareness of technology, advocacy, and the value of a great family.

When I am depressed, I: Talk, if someone is available; sleep, if not.

My most irrational fear is: I don’t consider fears irrational. Even if you’re paranoid, that doesn’t mean they aren’t out to get ya!

If you could hear again, what is the first thing you would do? When my CI was activated in my totally deaf ear, the first thing I did was cry. It was like a “Helen Keller” moment. After that, I was anxious to turn on the radio.

The thing I like best about myself: My sense of humor
Nobody knows: I’m such an open book that I can’t imagine there’s anything no one else knows about me.
What I can’t stand are: People who won’t seek the answer before asking me.
Favorite memory: Living in Bennington, Vermont for five years.
Favorite saying: “Can’t see the trees for the forest.” It’s truer than the original—sometimes the tasks are so overwhelming that you can’t see how to break ‘em down.

The bottom line is: Any day above ground is a good one.
As many of my readers know, I have a large old house that I broke up into apartments. This gives me income and company. I have three small apartments: one in my terrace, one in the loft or attic, and one in my spare room. Since I am now in my 90s, my family and friends are happy that I am no longer living alone. In fact, the tenants all look after me.

Since two tenants are students, they are happy to be together, and I furnish laundry and a Wi-Fi connection. They are always helping me with my PC—after all, I didn’t grow up with all these electronic devices like they did. There are also two men who are not students. They all have cars and I have a large lot, so they park here and feel lucky to have a space, since the area is very popular with lots of events in the adjacent park. This is helpful to me, since I can tell when they come home by counting cars.

I noticed that one man’s car hadn’t been here for some time, but since his job involves traveling, I didn’t worry. After awhile I said to my tenant Tara, “Where is Michael? You are so good with your cell phone—maybe you can locate him because I’m worried.”

A few minutes later she came back and said, “I found him. He’s in jail!”

“Jail!” I screamed. Did he have a bad accident? She didn’t know and then we had to find out what jail.

I have a retired lawyer friend and passed the questions on to her. Wanda got the information, which was that Michael was in Gwinnett County Jail for passing bad checks. He was the last person in the world I would have suspected of that. He had lived in my place for three years and always paid his rent early. Now I was cut off from talking to him and he didn’t have access to a relay phone. The best I could think of was to go there. My college students helped again—Phillip found out how to get to the jail and off we went.

As usual, I couldn’t talk to anyone, or rather, I couldn’t hear their answers, so Phillip had to wait in a long line and try to get information for me. He found out that Michael had to request a visit and couldn’t receive letters, only postcards. The next day I got another lesson on what being in jail involves. Michael sent me a letter asking me to post bond for him, but I knew nothing about what that involved. I was shocked to learn how much it would take to get him out on bond, and the fee was non-refundable. Since when does a landlady post bond for a tenant? I still had no idea what was involved, and jails are not set up to accommodate deaf visitors.

My lawyer friend stepped in to help and found out that Michael was arrested in two counties, needed bail in both, and would have to go to court in both places. I wanted to go and hear his public defender argue his case. Michael only has an elderly father to help him, and I have an apartment full of his belongings and his two cars in my lot. I saw this man on and off for three years, but I’ve been unable to talk to his public defender or his father, who can’t use a relay phone. I want to go to his court appearance, but this is the very first time that my deafness has made me feel so helpless.

Chat further with Harriet at harrietfrankel@hotmail.com.
Reflections on Dealing with Hearing Loss

By Deborah Scott

While the phrase “we don’t know what we don’t know” applies to many things, it takes on an entirely new meaning for a hard of hearing person. Perhaps it would be more accurately to say “we don’t know what we don’t hear.” For the hearing person, dropping keys on a floor or sidewalk almost immediately initiates the response of bending over to pick them up. However, for the hard of hearing person, or at least for me, more frequently there is no behavioral response to the sound. We just keep walking and generally don’t respond until we realize our keys are not in our pocket or purse. This occurrence is a frequent part of my reality.

I went for many years not knowing that I was hard of hearing. After being diagnosed with a hearing loss in the mid 1990s, I managed unaided for a number of years until I was finally at the hearing aid stage and was fitted in December 2007. In hindsight, I had previously suffered in silence for a long time, totally unaware of what I had been missing. After all, if I couldn’t hear it, I really had no way of knowing it existed.

With hearing aids, an entire new world began to open for me. People stopped mumbling, music was actually somewhat tasteful and worth listening to, paper crunched, and I could hear my dog Maddison snoring in the corner. Life became a whole lot easier for me. I also became acutely aware of the amount of effort I had previously expended simply to listen. I felt less stressed, had more energy, and actually yearned to be with other people and in group environments. Life was so much better and richer.

I felt elated with this newfound freedom, I began to explore opportunities and experiences I had previously avoided, especially those that involved groups of people. I began volunteering, going out with friends, going to movies, and attending more workshops and public events. I also started graduate school.

However, somewhat like in the boiled frog parable, my environment slowly began to change without my being aware of it. Busy with university studies, I hardly noticed that sounds were no longer quite as clear; people once again began to mumble or speak softly, and my dog didn’t snore as loud. Not being wakened by my alarm was the first clue that something wasn’t right. A trip to the hearing clinic was in order.

Re-evaluation of my hearing diagnosed the problem; I had lost another 10 dB in each ear! With a new set of aids, I could hear again; waves slapped against the shore, paper crunched, leaves rustled, and my keyboard actually clicked when I typed. I went off to a study session in Virginia, feeling pretty confident about my hearing and capable of handling almost anything. After all, I’m just like everyone else now, right?

Our study session began with a personal introduction. I had planned to say that I was hard of hearing and might need some additional support from fellow learners and faculty through the next couple of days, but I left that out.

So what had happened? That question lingered with me throughout the next few days as I learned that my “new ears” did not perform quite as wonderfully as I had expected. In previous group situations, I had always announced my hearing “impairment” (no longer a politically correct term). What was different this time? Did I really think that I was just like everyone else, that this time it would be different, or did I actually believe that my new improved aids were the end-all and be-all?

Throughout the next few days, moments of frustration crept in as I tried to keep up with the conversation and discussions. I could hear Chuck most of the time, although I sometimes missed his jokes, but I hardly ever heard Evelyn and Jeannine unless they were close enough for me to lipread, and Ken’s moustache always seemed to be in the way. There were times when I missed all or part of instructions and was left wondering what exactly we were doing. Did I live in this fog all the time, I began to ask myself.

It was difficult and not always appropriate for me to continually ask people to repeat things and remind them to speak up or not place their hands over their mouths when talking. The lack of flip charts, posted agenda, and written instructions added to my confusion. Without them, I was dependent on the movements of the group or others’ responses to my questions to get me to the next segment. At times, I had a feeling of being “herded” to where I needed to go next, and I spent my energy picking up on the visual clues of activities.

At one point, I even became the focus of the morning chuckle and had to check in with another learner later to find out what had been so funny. Apparently, Evelyn had asked us to say something profound and reflective, and I had simply responded that I was rested, rejuvenated, and ready to go! Evelyn then commented

continued on page 27
Chapter Happenings

By Ann Smith, Curator

Marlene Thometz reports on the activities of ALDA-Chicago. Cleo Simmons held her pool party at the home of her daughter Cindy in Tinley Park. Other ALDA-Chicago summer events included a minor league baseball game between the Windy City Thunderbolts and the Gateway Grizzlies and a day at the Arlington Park Racetrack with a picnic lunch and great live entertainment. A dual chapter picnic with ALDA-Chicago and ALDA-Northwest Indiana was scheduled in Dyer, Indiana in September.

Ann Smith reports that ALDA-Peach is staying busy. Members Xantha Burghardt and Angie Fuoco teamed with CART provider Heidi Thomas and ALDA-Garden State member Arlene Romoff to secure open captioning for several plays at the fabulous Fox Theatre in Atlanta. The Alliance Theatre will also caption several performances this season. Xan, Angie, Heidi, and Arlene worked with the Theatre Development Fund to make this happen; other Peach members supported their efforts with letters and emails to the Fox and Alliance theaters.

In June, ALDA-Peach members met at Kacey’s, a favorite home-cooking buffet in Tucker. July’s outing was a pool party at the home of Rich and Susan Lascek, long-time friends of ALDA-Peach. There were a couple of surprise thunderstorms, but everyone had a great time in the air-conditioned sunroom next to the pool, and the sun also came out to allow lots of swim time. In August, the group went to the Georgia Council for the Deaf and Hard of Hearing (GACHI), which provides services for deaf, hard of hearing, late-deafened, and deaf-blind people. Roger Robb, an advocacy specialist, brought members up-to-date on GACHI’s activities and had several of the latest listening devices on display.

Recently the national Registry of Interpreters for the Deaf held their convention in Atlanta, and ALDA-Peach’s Robin Titterington was thrilled to visit with her “often” ALDAcon roomie, Judy Viera of California. ALDA-Peach’s Yael Shaner returned on August 23 from a visit to her new great-grandson, Luke, and his family in Stuttgart, Germany. Flying deaf to Europe was an interesting experience that she will share with the chapter in the future. (We’re looking forward to reading about it, Yael.) Our thoughts and prayers are with ALDA-Peach’s Angie Fuoco (formerly Fugo), whose mother passed away during the summer.

ALDA members want to know what YOUR chapter/group is doing (for “Chapter Happenings”) and what is happening in YOUR life (for “GA to SK”). Since we can only print what we receive, be sure to send your submission to Ann Smith at fabsmith@att.net by November 23.
who coincidently has a daughter who “wears powerful digital hearing aids.” A large percentage of RA patients (40%) have no visible symptoms (sound familiar? Hearing loss is the invisible disability), which makes it hard to track the disease, causing some doctors not to believe patients when they say they have pain. Through her online research, Kelly found a nuclear bone scan that can reveal inflammation, so she had one done.

The radiologist’s report came back “No cancer found,” but that’s not why she had the scan, so she asked her doctor if the report could be read again, based on her reasons for requesting it. After some back and forth and repeated requests, her doctor fired her, saying “If you don’t want to follow my instructions, then go away,” which launched Kelly on a quest to help others receive better care, to take charge of their own data, and to insist on having their thoughts and wishes heard and considered by the doctors who treat them. I’ve had my own bad experiences with audiologists and doctors, when I’ve questioned their instructions, asked about things we might try, and made suggestions that I thought were reasonable, only to be looked at like I had two heads.

“Let Patients Help,” the end message of Dave’s talk, is a movement I need no encouragement to join, as more “warriors” are needed to take their own raw data into their own hands and make themselves heard. Who is more motivated to make a difference in their disease, disability, or course of treatment than patients themselves? Learning to be responsible for ourselves and seeking to make tools available that will allow us to have more knowledge of those things that directly affect us is always a good idea, no matter what ails you.

The last point of relevance I considered—if you look at the video in the right frame of mind—pertains to times when you are down in that dark place of panic at not being able to function as you once did. A place where nothing seems more frightening than the inability to hear. A place that renders you hopeless at finding a way to live your life with little or no sound, making your loss of hearing seem the worst thing in the world that could happen to you. Considering the whole scope of what might cross your path in life can put hearing loss into perspective, though you really can’t compare adversities, because what is hard for one person doesn’t make what’s hard for another any less valid or troubling.

However, we are able to look at Dave’s disease, one that makes him wonder “What’s my mother’s face going to look like on the day of my funeral?” and whether he’ll be around for his daughter’s wedding, and take a bit of comfort in knowing that in most cases, our hearing loss doesn’t threaten to take our life in a relatively short period of time, if at all.

Many do allow hearing loss to take more than simply their hearing, leaving them isolated and low functioning, but it doesn’t have to be that way. We have a choice in the matter, and, in my mind, to live less of a life than you would if you had your hearing, borders on criminal.

In reading the “about the author” section, of Kelly Young’s blog, I learned of her purpose in becoming a warrior, and she also shares her point of view and passion. Last, she gives us her personal information, which reads: “Kelly lives in Central Florida with her husband and five children. Typically, a list of hobbies and activities would be given here to define the author’s life. Kelly’s list has been confiscated by RA. (It formerly included various sports and crafts.) Instead she now seeks less tangible ways to define herself: She is patient, honest, and kind.”

Hearing loss doesn’t have to confiscate one thing more than you let it. Life is so much more than what can be taken in through our ears. The sights, smells, feelings, and tastes of the experiences that you open yourself up to are many… and that’s the KEY: Remaining open! Constantly fighting the temptation to close yourself off by placing needless limitations on what you can do. It’s not an easy task, but personally, I feel a responsibility to constantly push back against those things that threaten to isolate me. I feel compelled to do everything I can within my ability. To do less seems a slap in the face of those whose disease or disability takes more from them, as on this day.

For Brian, December 20, 1955-July 29, 2011, who fought the good fight and will be sorely missed by all who knew and loved him.

Michele writes for the SayWhatClub newsletter, Online Voices, and also contributes to the club’s weblog. This article is slightly revised from a version that first appeared on the weblog at http://ahearingloss.com. In writing about her own hearing loss experience, which spans more than four decades, Michele has come to terms with all that progressive bilateral sensorineural hearing loss takes away, and she has also learned to appreciate all that it teaches. Michele has four grown children, lives in northern Minnesota with her husband, and enjoys travel and kayaking on the wilderness rivers near her home. She can be contacted at mmlinder@gmail.com.
that this was very deep and profound, and the entire room burst into laughter. At the time, I had no clue as to why they were laughing, so I just took it in stride and laughed along with them. Later, I conferred with another learner to find out what had happened, and once again it became obvious to me that I was still missing things despite my new aids.

The facility also presented challenges for me. As is customary in new settings, I looked for the best places to sit, avoided noisier areas like the large dining room, and tried to remind others to speak up when I couldn’t hear. Acoustically, the library with its shelves lined with numerous books and its floors draped in carpets proved to be one of my better rooms. But during my presentation, the lack of a wall behind me caused sound to move past me like feathers floating in the wind, making it difficult for me to hear comments and questions. Recording my presentation was somewhat helpful, as it allowed me to review it later in a quieter setting.

The schedule was extremely jam-packed with little time for quiet reflection. Whenever possible, I stole a few moments to take a break from trying to listen. Meandering around, walking into town, and listening to the babbling brook helped to restore my sense of peace and allow me to reenergize before heading back to the group.

Airports always pose additional challenges for people who are deaf or hard of hearing, and my connection flight to return home was the closest I had ever come to missing a flight. In the past, when traveling alone I generally found another passenger who was on my flight and then watched so I would know when to follow suit and board, but this time I did not. I thought I was safe, seated facing the attendant and the booth in the holding room. I heard the pre-boarding announcement but missed the general announcement as passengers boarded behind my back through another gate. Fortunately, I got clued in and boarded just in time. (I look forward to the day when all airports implement visual paging services like the one at St. Paul International Airport in Minneapolis.)

On my return home, I was confronted with the pending loss of my dog, Maddison, who had been diagnosed with lymphoma. I live alone, and for nine years, she had served as my second set of ears, my alarm clock, and my doorbell, alerting me when I left something unattended on the stove or the tap running in the sink. I knew that when she was gone, I might need to upgrade my systems or get a hearing dog.

I began to wonder whether I have truly accepted the reality that I am hard of hearing, that my hearing loss is progressive, and that one day I may be deaf. In hindsight, I think I believed that acquiring hearing aids was the “fix” I needed. I would be healed and be just like everyone else.

Audiologist Mark Ross, who is also hard of hearing, writes that “self-acceptance is the essential prerequisite for society’s acceptance.” Self-acceptance begins with accepting reality, but my reality is constantly changing. I am learning that I need to accept those changes as they occur and continue to search for new ways to cope with my hearing loss.

First, I need to continually learn about new advances and seek out accommodations that will serve me best. Second, I need to learn and accept that I operate in two worlds; the hearing world (mainstream) and the non-hearing world, and that it is time for me to connect with others who are also hard of hearing and deaf. Finally, I need to deepen my understanding of hearing loss so I will be better prepared to ask for what I need to support my participation in group activities. Up until now, I have not done this very well.

I spent several days in deep reflection, doing intensive research on hearing loss and lots of journaling. With it came a lot of tears. I have gained a much better understanding of my own situation and needs. I contacted local, regional, and national organizations for people who are hard of hearing and deaf and learned about resources that I hadn’t given much attention in the past. I volunteered to work at a hearing conference in August 2011 and participated in several online chats for hard of hearing people. However, my overriding goal is not to be isolated and restricted to a subculture made up of hard of hearing people but to participate as fully as possible in mainstream society.

Deborah lives in Salt Spring Island, British Columbia, Canada. She entered the health care profession in the mid ’70s and held positions as an optical receptionist, dental receptionist, certified dental assistant, practice coordinator, and office manager. In the late ’80s, she became a software trainer and marketing specialist at Dialog Medical Systems, and her insights into the needs of dental practices led to the creation of the first computer booster course in 1989. In 1990, she left to establish Dentegra Management Services, serving health care professionals in Canada’s western provinces and the Yukon via computer booster workshops, in-house training, and teletraining. Deborah holds a master’s degree from Royal Roads University in leadership and training and is working toward a PhD in human and organizational development through Fielding Graduate University in Santa Barbara, California. Her email address is deborah.scott@shaw.ca.

This article is condensed from “Reflections on Systems Intensive.”
Job Hunting While Deaf (continued)...

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back with a specific day and time.

Now I was freaking out. I’ve gotten someone to agree to give me an interview—what should I do? I’ll walk in there deaf and they won’t talk slowly enough for me to lipread and I’ll have to have them write everything down and I’ll PANIC!

In the days leading up to the interview I asked for and received a ton of advice. The most common was that I should just relax and be myself. My first thought was “Relax????? I really don’t think that’s, in any universe, possible!” and “Be myself??? I’m an odd duck and a deaf odd duck at that. No one will want to hire me if I’m myself! I need to be someone entirely different—preferably someone 15 pounds lighter and with hearing!”

I did actually manage to calm down to somewhere below a full-blown, shrieking panic level. I reread my resume to remind myself that I actually did have lots of valuable and varied printing industry experience. I even made an inroad into accepting that potential employers might just possibly, maybe, feel that I was most qualified for the job.

My first interview was with four men—the owner, the sales/marketing head, the HR manager, and the production manager. Very surprisingly, they all came in with paper and pen, spoke slowly, and didn’t seem put off when I asked them to repeat a phrase, try a different word, or write something down. All this AND the HR guy started fingerspelling some of the words that I missed!

I ended up being myself—which means, in part, that I talk too much, but I suppose that’s a plus when you’re being interviewed. I was cracking wise and telling stories about the first press I ran—an ancient behemoth held together by paper clips and baling wire.

My second interview was with an additional three managers. At the end of this interview they offered me a job. It’s a position with a variety of responsibilities and room for growth, learning, and creativity and it offered more money than I’d been making.

Huzzah!

I went on to the very challenging reality of learning new systems, new computer applications, and new ways of doing things within a hearing environment. During my first week at my new gig, I received a letter from the Massachusetts Rehabilitation Commission telling me when my interview (to discuss if/how they could possibly assist me) would be. I was practically giddy in writing them back saying, “Thank you, but I’ve already found a great new job and no longer need your assistance.”

Donna was born during the “I Like Ike”/Lenny Bruce/McCarthy years in your basic large Eastern seaboard college town. Subsequently, she grew up in about 8000 other similar towns. After years with a traveling carnival, selling fireworks on street corners, dispatching trucks, and, for a seeming eternity, working as an artist’s model, she fund her home in the printing industry. Donna was deafened by neurofibromatosis type 2 and can be contacted at Grantmad@aol.com.

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TDI - Shaping An Accessible World

The reasonable man adapts himself to the world; the unreasonable one persists in trying to adapt the world to himself. Therefore all progress depends on the unreasonable man.

—George Bernard Shaw
The mission of the Association of Late-Deafened Adults (ALDA) is to support the empowerment of late-deafened people.

Late-deafened adults are people who have lost their hearing in any degree after having acquired spoken language. ALDA members may or may not use hearing aids, may or may not use assistive listening devices, may or may not use cochlear implants, and may or may not use sign language. What ALDA members DO is “whatever works.” This is the philosophy that keeps the doors to ALDA wide open to anyone who is interested.

ALDA is committed to providing a support network and a sense of belonging to late-deafened people, sharing our unique experiences, challenges, and coping strategies; helping one another find practical solutions and psychological relief; and working together with other organizations and service providers for our common good.

ALDA provides networking through local chapters and groups as well as our annual convention (ALDAcon). We offer social activities, advocacy, peer support, up-to-date information on new technology, and guidance for late-deafened adults, their families, and their friends on ways to deal effectively with the difficulties arising from losing our hearing. ALDA is inclusive, never exclusive. Members find themselves part of a family, with emotional and social support, and, above all, acceptance.

Membership in ALDA provides support for outreach: newsletters, brochures, mass mailings, public presentations, and participation in local and national events to spread the word about ALDA to the more than 31 million Americans, and other late-deafened people worldwide, who would benefit from our organization. ALDA also assists chapter leaders and regional directors to expand ALDA through more chapters and groups and increased membership.

You can join ALDA via the form in this issue, or go to www.alda.org or contact ALDA, Inc. at 8038 MacIntosh Lane, Suite 2, Rockford, IL 61107, 815-332-1515 V/TTY. Membership entitles you to receive the quarterly ALDA News, which spotlights personal experiences of late-deafened people, and to attend ALDAcon at the lower member rate.

If you are interested in learning about ALDA in your area or seeing ALDA become active there, please contact your regional director (contact information is at “Contact Us” on the ALDA website).
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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:

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

Education 
Advocacy 
Role Models 
Support

ALDA provides networking opportunities through local chapters and groups as well as at the annual ALDA conference (ALDAcon).
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C. I plan to live to be at least 130 years old; think what a bargain Lifetime Membership will be!

*Ann Smith, Lifetime Member*

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- **Bronze** $500 - $1,499: receive a personal letter from the President, bronze plaque
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Contact ALDA treasurer: treasurer@alda.org or visit www.alda.org