Caregiving comes in many forms. All of them are harder for deaf people, but where there is a need, deaf people jump in and do what’s necessary. I think that deafness heightens our alertness and possibly makes us better at the job than those who depend on their hearing.

Probably the most common form of caregiving is being a mother. Mothers must keep a watchful eye and attentive ear toward their little ones, but deaf mothers like me have to depend solely on eyes. We lived in a waterfront home, and my ever-present fear was not hearing a splash and a call for help. This was in addition to the usual fears of little ones somehow injuring themselves or burning the house down. When they were babies, we had the crib positioned so I could see it from the kitchen and would know if the baby was crying, sleeping, or trying to climb out.

Our two children were born two years apart, so both were small at the same time. At the age of two, Linda understood my problem with newborn John and took it upon herself to alert me to her little brother’s cries. She could even translate his baby talk for me. There’s nothing like a big sister to help with a baby!

Babies were the easy part; toddlers were harder because they used baby talk. It would have been difficult enough to understand them if they spoke normally. And they were all over the place, needing constant supervision as I tried to compensate for the total silence I lived with. Children are keen, and they soon caught on that they could put one over on their mother, but they also devised their own loving little ways of making me understand them. They helped with the phone at an early age, sometimes messing up the message somewhat, but doing their best.

One day John, who was then about three, answered the phone for me because he was right next to it when it rang. Linda was in another room and overheard him. “Mommy can’t come to the phone; she’s death,” he told the caller. Linda ran out and explained to the caller, who by then was expressing condolences. Another time a hearing aid salesman called and was told that hearing aids would not help me because I was “so profound.” Close enough!

The children’s pediatrician told me, “Deaf mothers have the best-behaved children. The kids know that whining will get them nowhere, because it is not irritating if you can’t hear it.” So being a deaf mom did have its perks.

When the children were teens, I took on another caregiver role, that of caring for my ailing father, who, we suspect now, had early Alzheimer’s, and also had colon cancer. He lived with us for five years, all the while impatient with my deafness and insisting that I had to learn how to cope better. He thought I should be better at lipreading, but trying to lipread someone whose teeth wobbled when he talked or were grinning at me from the mantelpiece was more than I could handle. I was unaware when the children were too noisy, and he would awaken from a nap and be quite angry with them and me. During his final week of life, hospitalized but thinking he would be discharged, he declared he didn’t want to live with me again because I was “too hard to live with.” He was referring to my deafness. Since I had cared for him for
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Hi everyone,

This issue is bursting at the seams, thanks to all of you who took the time to share your stories. The theme is “Caregiving and Hearing Loss,” and we have some wonderful articles that are sure to grab your attention. When the responsibility of dealing with hearing loss meets the responsibility of caring for others, the situation can become even more challenging. Hopefully, as you read the stories within these pages, you will draw strength from the experiences of others.

Our first story is “Caregiving from Three Perspectives” by veteran caregiver Elinore Bullock, in which she provides an insightful look at caring for children, an elderly parent, and a brother-in-law. Next, in “Loving an Older Man and Being His Hard of Hearing Caregiver,” Maryruth Dilling provides an account of the difficulties and rewards she experienced in taking care of a loved one. And frequent contributor Carol Granaldi examines caregiving from a different, but no less interesting, perspective—providing care to someone with a hearing loss—in her article “If I Were a Caregiver to Someone Like Me.”

You can learn about Kristen Stansell’s amazing and inspiring recovery following a traumatic brain injury in “A Journey of Recovery.” Those of you who have read Arlene Romoff’s first book, *Hear Again* (as well as those of you who have not read it), will enjoy Margreta von Pein’s informative and candid review of Arlene’s second book in “Sounds Trigger Memory: Review of *Listening Closely* by Arlene Romoff.” And be sure to have a Kleenex handy when you read “Seeing the Singing” by Tess Cruz, which tells us about watching her daughter sing.

If you’ve ever wondered what a cochlear implant recipient experiences during and after the initial activation, you won’t want to miss Tom Hagney’s article, “My Cochlear Implant Activation.” We also feature Karen Griffard Putz’s submission, “Unwrap Your Passion,” which won her an award from the Hot Mommas Project and will inspire you to reach beyond your fears to release your own passion.

In addition to these terrific articles, we also have our regular columns as well as ALDA Biz, which will keep you informed of the accomplishments of our hardworking ALDA volunteers.

We would very much appreciate your suggestions for future newsletter topics. Feel free to contact me with any comments (good and bad) about this issue, as well as your thoughts on how we can make future issues even better.

ALDA Best,
Eileen

Eileen Hollywood

**INSIDE THIS ISSUE:**

1 Caregiving from Three Perspectives
3 Eileen Here
4 Note from Nancy
5 Loving an Older Man and Being His Hard of Hearing Caregiver
6 If I Were a Caregiver to Someone Like Me...
7 Sounds Trigger Memory: Review of *Listening Closely* by Arlene Romoff
8 An Invitation to Join the Collaborative for Communication Access via Captioning
10 A Journey of Recovery
11 One of Us
12 Cinemark and ALDA Announce Greater Movie Theatre Accessibility for Customers who are Deaf or Hard-of-Hearing
13 Life in ALDAland: Seeing the Singing
14 Our World—News from the International Committee
16 ALDAAnonymous
17 My Cochlear Implant Activation
18 Unwrap Your Passion
19 Chatting With Harriet: Educate! Educate!
20 The Late-Deafened Experience—Bagels and Babes: Bonding with My Hearing Children... Kind of
24 Chapter Happenings
26 Some ALDAcon 2011 Highlights
28 ALDA Biz
33 SKSK
34 What Is ALDA?
Some years ago, my late husband’s mother developed Lou Gehrig’s disease (amyotrophic lateral sclerosis), which causes progressive paralysis. As she was no longer able to care for herself, she moved in with us for the last six months of her life. Her speech and swallowing were affected first, so she needed to write down what she wanted to say, and she required a soft diet. I used to say that we were a perfect match, because she couldn’t speak whereas I couldn’t hear, and she couldn’t eat regular foods whereas I wasn’t a fancy cook.

The match with my two children wasn’t as good, however. Since the ADA hadn’t been passed when they were small, there was no telephone relay service, and I needed my small daughter’s help with some phone calls. One time, I asked her to find out when a particular department store opened, and after listening to the recorded message, she told me 9:30, so I arrived at that time only to discover that this was when the store closed at night—it opened at 10. And I didn’t find out until my children became adults that they used to plot mischief behind my back while I was driving them to various places. They knew I wouldn’t have a clue as to what they were saying!

My daughter played soccer at school and was upset because I seldom came to watch her. The reason I stayed away was because the mother of one of her friends liked to chat with me during the games. I could barely understand her but shied away from saying so (I’ve never felt comfortable telling someone that his or her speech is especially difficult for me to follow, which has led to some interesting stories for another time). After my daughter grew up, I explained the problem to her, but she couldn’t fully grasp the emotional strain of bluffing.

Fortunately, I did better when my daughter was in a high school play. CART hadn’t become available yet, so I obtained a copy of the script and glanced at it frequently throughout the performance. Although this wasn’t a very relaxing way to watch a show, I did manage to follow along reasonably well.

As I became deafer, I decided to learn sign language, figuring that I would eventually need to join the Deaf community (this was shortly before ALDA was founded and before cochlear implants became widely available, so there didn’t seem to be any other viable options). My husband and children also took signing lessons, but only my daughter became proficient—my son just learned to fingerspell, and my husband struggled even with that. Ultimately, I didn’t join the Deaf community or use sign language on a regular basis (also a story for another time), but every now and then, my daughter and I find it handy to sign something to one another (such as when we’re positioned too far apart to be able to communicate orally).

Although hearing loss can make caregiving more difficult, misunderstandings can sometimes be quite funny. My most memorable speechreading error occurred when my daughter asked me a question that looked like “Do you know how to define a transsexual?” I was sharp enough to realize that this was unlikely to be what she wanted me to explain, and it turned out that she had actually asked, “Do you know how to find a train schedule?”

One thing is certain—being a caregiver with a hearing loss provides fodder for some pretty interesting stories!
Loving an Older Man and Being His Hard of Hearing Caregiver

By Maryruth Dilling

About six years ago I became involved with an older man. At the beginning of our relationship, I did not consider the health issues that would present themselves over time. I just knew I had found my soul mate, even if the years separated us.

Over the past six years, I have become indoctrinated in geriatric issues such as osteoporosis, heart disease, COPD, and Alzheimer’s. From being someone who would not say “boo” to a doctor, I have become quite assertive in making sure my loved one receives the proper care. During the same period, my hearing loss has become more significant, to the point where I have had to label myself “hard of hearing.”

How has this affected my relationship and caregiving life?

One of the biggest challenges is using the telephone when talking to doctors and nurses. I am almost at the point where I will have to stop using the regular phone to communicate. When calling doctors, I always have to ask them to repeat things several times and to tell them I am hard of hearing. I dread the time when hearing on the phone will not be workable, and I have yet to figure out a communication skill to use when talking to the doctors on the phone. [Editor’s note: A captioned phone such as CapTel enables hard of hearing people to read any parts of the conversation that they have trouble hearing.]

When we are at appointments, things are easier than on the phone. I do have to tell staff members to look at me while talking so I can catch sounds easier, and I have them write things down as much as possible.

Because of my younger age, many people do not realize that I am hard of hearing unless I tell them. Because of my caregiving role, I have become more comfortable in telling people about my hearing loss. I ask them to slow down when speaking, to face me, and to write things down if I am having a hard time understanding them due to the pitch of their voice.

Within our relationship, my hearing loss created a lot of frustration in the beginning. From an attitude of not really believing I had a hearing loss to becoming my champion, my loved one now stands up for me if someone is being rude. He readily explains how the frequency of some voices is easier for me to understand than others. He has even changed his attitude about learning sign language. He used to say he was too old at 67 to learn another language, but he is now willing to try to learn some simple signs. Acceptance makes a big difference.

Caregiving with a hearing loss is difficult to deal with at times. My pride has to take a back seat and I need to self-disclose about my loss to a lot of people I would not normally be open with. But any shame or embarrassment about hearing loss goes away. No one is perfect. In helping with my loved one’s health issues, I have become more comfortable in dealing with mine more openly. I am no longer a doormat. Loving an older man has turned this scaredy cat to a roaring lion.

Maryruth is a transplanted Texan living in the Pacific Northwest. While working on her master’s degree, she keeps busy with home schooling her son, writing, speaking to groups on mental health issues, communication, and goal setting. She is the president of Kindling Dreams, LLC and can be contacted at maryruthdilling@gmail.com.
If I Were a Caregiver to Someone Like Me...

By Carol Granaldi

I’ve not yet had to be a caregiver to my spouse or family, fortunately. Caregiving itself is stressful enough, but doing it with a hearing loss surely will double the stress when one is trying to understand what the patient or the medical or nursing staff is saying and what is being conveyed over the telephone. It’s a huge responsibility, and unless you have your own communication ducks lined up, this could be the most stressful situation you’d ever been in. I do think, however, there are likely more patients with hearing loss that have caregivers who hear normally. In that situation, both the patient and the caregiver will be stressed by the patient’s hearing loss, unless the caregiver is familiar with the nature of the patient’s deafness as well as with the patient’s hearing equipment, if used.

Since I myself am entering elderly status at age 72, I’m facing the possibility of becoming seriously ill (I’m already a heart patient). Over the past dozen years or more, I’ve been hospitalized for a number of surgeries (my hubby calls me “Ms. Slice & Dice”). I’d like to share tidbits of information that will reduce the stress on caregivers if they need to care for someone like me, who cannot hear anything without at least one of my CI processors on my head. Here’s a list of things for caregivers to remember if their patient has considerable hearing loss:

1. Say my name or touch my shoulder and speak to me when you can see me making eye contact.
2. Please respect my inability to understand long sentences, because I can’t hear as fast as you talk.
3. Make sure the batteries in my hearing equipment are working and the earpiece is securely placed.
4. Don’t call me from another room—if I can’t see your face, I may not realize you are calling me.
5. I may ask you to assist me with telephone calls, so let the person on the line know you are acting as an “ear” for a hard of hearing person.
6. If you are with me on a shopping trip, I may have trouble understanding a salesperson or clerk’s speech in a noisy store with overhead music and other voices around us.
7. While I am sleeping, I may startle, so please keep a dim light on in a dark room, and tap my bed to get my attention. Also, be sure there’s sufficient light on your face so I can speechread what you are trying to tell me.
8. Learn how to troubleshoot my hearing equipment, use the battery charger for my CI processor, and check my hearing aid earmold for ear wax or droplets of water that need to be removed.
9. My illness will be more stressful when I can’t hear well, so allow me some “quiet time” to de-stress. If I’m watching TV, make sure the captions are on or I’m using the earphones attached to the assistive listening device, if I have one.
10. Visits to medical sites are frightening to me if I cannot understand the doctor or staff member who is speaking. Please alert staff about my hearing loss and tell them to slow down and speak directly to me, so I can answer important questions myself. If necessary, have a pen and pencil to write down what I can’t grasp, or the doctor’s instructions about medicine or tests.

I hope these tips will help any of us who are patients with hearing loss and cared for by others who most likely hear normally.

Carol has had a progressive hearing loss since early childhood and now has bilateral cochlear implants. She lives in an Ocean County, New Jersey retirement village with her husband and can be contacted at cgranaldi@comcast.net.
Sounds Trigger Memory: Review of Listening Closely by Arlene Romoff

By Margreta von Pein

When I finished reading Arlene Romoff’s Listening Closely (2011), I was ready to go bilateral. Romoff’s closing message is “Cochlear implants, which enable the deaf to hear, are true miracles of Biblical proportions” (p. 168). I had already experienced that because I have a single implant. However, the underlying story of her late-deafened journey to bilateral hearing emphasizes the importance of hearing with both ears.

This is Romoff’s second book. The previous one, Hear Again (1999), tells about her first cochlear implant and introduces the same strong personality that dominates the style in both books. Romoff’s enthusiastic, despairing, self-absorbed, and vulnerable persona in Listening Closely is not too different from the one I had met in her first book, but this time the information far outweighs the distracting character quirks. She admits, “I’m usually terrible at upheavals and new things” (p. 109).

The book is divided into three phases of Romoff’s hearing loss journey: the failure of her first implant; obtaining a second, state-of-the-art implant; and going bilateral. It progresses through time like a journal, with entries from March 14, 2008 to April 26, 2009. Romoff starts with the anguish of being deaf for 24 days after her first implant failed and continues through the joy of hearing with both ears, which had not been part of her life for many years. Her personal philosophy, that a grand design exists in one’s life, motivates her decisions and actions related to going bilateral. This sense of a grand design also charges her with an urge to contribute to the welfare of others, and this book is a result.

Two major discussions develop throughout the three phases of her book. In one, people in any way touched by a hearing loss receive an accurate depiction of the experience. In the other, mostly in the bilateral phase of the book, readers learn how the brain learns to hear with electronic sound. Romoff’s explanations of this subtle and somewhat technical topic are humanized, yet still precise.

Each late-deafened person’s reaction to a hearing loss is bound to be different; our outlooks, personalities, and experiences differ. Romoff’s attitude toward deafness was terror; mine was lack of affect. What a difference! However, her descriptions of what she felt focus on what I call “good counsel” for anyone first experiencing hearing loss in adulthood. She observes, “Trying to communicate all day long is so exhausting that I have to watch carefully how much I take on” (p.46). In commenting on Helen Keller’s “daring adventure,” Romoff offers this advice: “It’s not merely a good attitude that’s required to come through this ordeal with a positive outlook, but the will to make the most of it, and not become a muddle of defeat” (p.51).

She tells it like it is: “That’s what deafness does to your personality and personal interactions—it’s as if you aren’t really there if you can’t hear. Any conversation concentrates on just the facts, ma’am. There’s no energy or inclination left for pleasantries or chitchat—it’s all business” (p. 95). Or “People treat you differently when they know you can hear them” (p. 96). Personal revelations of this kind throughout the book offer a newly deafened person accurate guideposts as well as allowing a late-deafened reader to identify and find welcome solace.

In Romoff’s description of how the brain works with language, she compares hearing with the 10-year-old CI that died to hearing with the replacement CI. However, her description of what the brain is doing fits my different experience, which was hearing-aid hearing to profound deafness to CI hearing. Electronic hearing via a CI is not the same as hearing with a hearing aid; the brain is engaged in different tasks. With her new CI but not yet bilateral, Romoff relates a scene where she seemed to be in a conversation she had years before. It seemed her “brain [was] doing memory searches based on sound” (p.83). She notes that “the improved speech and music capabilities of this processor have evidently enhanced my ability to retrieve memories, short and long term” (p. 85). Romoff had enjoyed playing the piano before her hearing deteriorated, and with the new CI, she was able to recall the sounds of entire pieces she had practiced when hearing. She constantly challenged her brain, and for the most part she reports positive experiences. “My hearing shaped my experiences, and my experiences shaped my behavior” (p. 85). She is courageous in her quest for better and better understanding.

That she was a computer programmer facilitates her understanding of the technical aspects of a CI. This early work experience, albeit in the era of keypunch-card dinosaurs, also enables her to write about the more technical items clearly and accurately. Those of us late-deafened people moving from being deaf to hearing electronic sound recognize how the brain seems to figure out language and other sounds on its...
An Invitation to Join the Collaborative for Communication Access via Captioning

By Lauren E. Storck, Ph.D., Founder of the CCAC

We invite you to join us in the online grass-roots project called the CCAC if you have any interest in more captioning inclusion. A great number of us cannot comprehend speech well in group situations, even with other technologies. CCAC outlines what we call the ten CCAC categories of life, from education, employment and entertainment, to government, healthcare, transportation, and more, where captioning is needed.

In the autumn of 2009, we conferred with friends and colleagues in several circles, and decided that a new focused project was needed for captioning advocacy alone, and this quickly attracted interest internationally. CCAC comprises all volunteer members and uses a very active working community online. It’s an advocacy organization, not a hearing loss group, with members who are deafened, hard of hearing, deaf, and hearing too. CCAC also has a nice balance of consumers and providers who are joining discussions and CCAC “caps”—captioning advocacy projects around the U.S. and globally.

While many fine organizations advocate for captioning, including CART (realtime speech-to-text, with various names in different countries), they have wider agendas by advocating for many additional resources for us, or wider constituencies in advocating for people with many different disabilities.

Consumers are the ones who drive progress, by asking for speech-to-text over and over again, often a long process that requires persistence and a don’t-give-up attitude. CCAC advocacy is not only for millions with deafness or hearing loss. For example, many people with literacy, language, and learning needs also require more quality captioning than is provided now. United, we can advocate, agitate, and legislate.

CCAC itself does not sell any captioning, CART, or broadcasting services or products. The founder is deafened and is also a member of many established organizations. One CCAC goal is to build bridges for a focus on much more inclusion of captioning. As one active member said recently, “CCAC is the place to be for captioning advocacy,” since it welcomes individuals and also other associations and organizations who share interest in the mission of captioning inclusion universally.

In one short year since it was founded, CCAC has some good success stories, which are shared on the website. It has developed an informative public site with useful articles and videos. It also has an active Members’ Forum online. CCAC has helped members in “CCAC Action Requests,” not only for specific information, but also with letters of support when any member is seeking captioning inclusion. CCAC also offers public data-collection documents on the website and invites all to submit information about local and broader captioning advocacy, so others can be inspired and we can share information.

As many who are reading this know—and too many in the hearing world do not—captioning is a mainstream solution because only a tiny fraction of people with hearing loss are sign language users as opposed to the millions who use captions.

A benefit for all members is a creative CCAC plan introduced more recently, thanks to CCAC provider member interest: all members can apply for a free hour of CART or captioning service. With this process to introduce CART or captioning to others, CCAC can expand education and advocacy in members’ regions. CCAC aims to find ways to demonstrate how important CART is and to show that the expense is far more worthwhile than many groups realize. Captioning is our ramp for communication access, similar to wheelchair ramps, which are generally accepted and provided in most countries.

More information is available on the website, including the membership application. Membership is free both to individuals and organizational friends. CCAC is also on Facebook, Twitter, and LinkedIn. We welcome your interest and support! Website: www.ccacaptioning.org. Email: ccacaptioning@gmail.com.
Editor’s note: Holly is deaf-blind from NF2. She has an auditory brainstem implant (ABI), learned sign language, reads Braille, and lives in Arkansas with her son and her husband (who is also blind and has a Seeing Eye dog). Sarah Gorden, who also has NF2, designed the picture based on Holly’s description. Holly’s website is www.hollyalonzo.com and she can be contacted at holly@hollyalonzo.com.

Cure Neurofibromatosis
Poem by Holly Alonzo, May 3, 2011

NF is a genetic disease that
Enables tumors to grow like weeds.
Upon the skin—NF1,
Ravaging the nervous system—NF2,
or a combination of both.

Fighting this disease,
is draining in body and spirit.
Because it’s not considered cancer,
Rarely do people take notice.
Oh, if they only knew.

Malignancy isn’t the worst that can happen.
Abilities lost one by one,
The painful, ugly tumors on the skin,
or going deaf and blind or becoming paralyzed,
Suffering for many years with few treatment options until death finally comes.

It needs awareness and more funding for research.
Spread the word and help us cure NF!
A Journey of Recovery

You may not believe in miracles, but I will give my personal account of what happened to me. At first, I was in a coma so I could not give my thoughts at the time. It is remarkable how much I’ve progressed; I am considered a medical rarity. I have spent many years writing out what I’ve gone through in the process of my recovery, and I want to share my experiences with my hearing with ALDA.

When my auto accident happened six years ago, I was in Scotland near my university. I had driven by British rules (driving on the left instead of the right side of the road) for eight months and was returning from a photo shoot. At that moment, I followed the American rule for passing a truck in the turning lane, and I was on the wrong side. I was trying to be adjacent to the truck but as soon as I started, I realized that trucks make wide turns. I had gone too far forward to get out of the way of the double lanes used by the turning truck, and I was in trouble. There was a rail keeping me from leaving the road, and the result was—crash-boom. The paramedics had to cut me out of my car. I had suffered a traumatic brain injury (TBI) and was comatose for four months. By the third year after my TBI, I had recovered my knowledge and education memories. I did not know why or how I knew, but I would make the correct choice out of instinct.

What’s left for me to heal is my walking balance and auditory ability (ability to transfer what I hear to the brain for recognition). Currently, I use one or two canes or a walker, but I continue to progress with my balance. I’m now 31, and all my life I had been right-handed. But after my TBI, my right hand was ataxic (shaky) and I was forced to learn to use my left hand. It is hard but I do not complain, because things could’ve been worse!

About two million Americans sustain a TBI each year, resulting in 50,000 deaths and 80,000 new cases of long-term disability. I know that I’m not alone, but I do feel alone. My hearing deficit isolates me much more than my physical limitations.

When I was emerging from my coma, I was noted to be tracking people and watching the television. This communicated to my family and healthcare providers that I had not lost my sight. But I was deaf and mute; I could not make noises emerge from my mouth. Being unable to hear is a common temporary deficit, so therapists expected my hearing to improve. I was only mouthing words because I had no idea that no sound was coming out. I wanted to communicate, desperately!

My ears could be hurt by loudness that I was unaware of because it was a brain issue. With extremely loud noises, I would hear a very faint sound and get shocking headaches even though I did not know what was causing this to happen. The brain translates the different noises of words into recognizable meanings. I could sometimes hear things that sounded like loud machinery. I guess I was hearing my brain working to recover my hearing, either that or amplified noises. I was astonished that I could lipread! I remember thinking, “Something is weird! I can’t hear her (my mother) speak, but I can understand what she says! I don’t know how or why.” Actually, I “heard” her from my brain’s projection of my memories of her voice, but it was extremely and abnormally soft.

My nurse-mom had been with me from the very beginning, flying to Scotland after my family was notified of my accident. After four months I was medically flown back (with my mom) to the US. A radio station was going to pay for the trip, but it was too expensive. Therefore, St. Andrews University, which I had been attending, decided to pay for it. We were flown to a healthcare facility in Atlanta. I do not remember any of the flight and just a “wee” bit of Scotland and only those memories that had an influence on me.

I required a “sitter,” who was paid for by the government. I went from one sitter to the next. They often never showed up. It was frustrating to communicate with them because each one spoke in a different way. I was left with my sitters for only a few hours, two days a week. During the other three week days, I went to Emory’s center for rehabilitative medicine. I would try my newly learned sign language, but my words were not clear, so the sitters just ignored me. I know that they were only legally required to make sure I was fed, bathed, and working on my projects like walking, but I desperately wanted to be able to communicate! They made me completely miserable, and my only respite was attending rehab. I could rejoice in the progress I made, which made me extremely happy. During the third year of the dreaded “sitter-ness,” my dad quit his job to stay home with me as my

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1 http://whsc.emory.edu/press_releases2.cfm?announcement_id_seq=10183 (Emory news report)
One of Us

By Karen Krull, Curator

Victor traveled all the way from Kenya to Colorado Springs for ALDAcon 2010. A teacher of French and history by profession, he was very articulate and fit right in. He is currently pursuing a master’s degree in special needs education and is also in charge of career counseling and financial aid for needy students at Alliance High School in Kenya. He lost his hearing at a very young age and has a brother and sister who also have hearing problems, though not as severe as his. I had the pleasure of joining him for dinner one night, along with Carolyn Piper and Selamawit Esthete from Ethiopia. We talked about food, families, culture, weather, and the services, or rather, the lack of services and organizations in their respective countries.

Victor fell in love with CART, and one of his goals is to form an organization in Kenya to fight for the rights of people with disabilities and to reduce the prohibitively high cost of hearing aids. Common interests unite us, and the need for support truly spans all continents. Victor welcomes ALDAns to visit Kenya and says he will take them to Tsavo National Park to see a dancing elephant, and will teach them Swahili. Readers can contact Victor at vodandi@yahoo.com. Read on to find out why Victor is definitely “one of us.”

Name: Victor Nelson Odandi

Where were you born? In a small town called Homa Bay, Kenya

What is your current residence? I currently stay at Alliance High School, Kikuyu, 23 kilometers from Nairobi, the capital of Kenya

What is the cause of your deafness? Childhood sickness

Age/year you became deafened? Two or three

Marital status? Married to Lenny nyar Michael (daughter of Michael)

What is your present job? High school teacher

What is the worst job you ever had? There was no worst job—I’ve been a houseboy, farm boy, building caretaker, and chauffeur and enjoyed all the jobs

Movies you want to see again? Rambo 3

Books you tell others to read? Gifted Hands by Ben Carson

I stay home to watch: Mother-in–Law

Favorite pig-out food: nyoyo (a mixture of dry maize and beans—this food hardens your teeth) and omena (herring)—eating half a plate improves your IQ, he-he-he. As I write this, some have been cooked for me now.

Hobbies: reading newspapers, doing charitable work

If I had more free time, I’d: write articles on disability issues and fight for the rights of people with disabilities internationally.

The hardest thing about becoming deafened is: accepting that you are really deafened—it takes a long time to come to terms with the fact your hearing is fully or partially gone, and adjustment to your new status is sometimes painfully slow. That’s why having a strong network like ALDA is highly recommended.

I began accepting my deafness: after I got tired of wallowing in self-pity.

The worst thing about deafness is: people considering you a bother when you ask them to repeat what you have not heard, and being denied opportunities to prove that you can perform a task. My principal recently made some key promotions in the school administration, but I was bypassed, even for a job I had distinguished myself in: coordinator of financial aid for needy students. Last year one of my colleagues was in charge of this department and I was her assistant. Then she got a scholarship and quit to pursue a postgraduate degree. As a result, I expected to be automatically named to head the department, but somebody else was also appointed. I was discouraged and de-motivated for quite some time. When I later inquired as to why I had been bypassed, I was told it was because of my hearing disability. I decided to let that pass and continue assisting the needy students to get scholarships. Of course, being named to head this post would have boosted my self-esteem, but it wouldn’t have changed my hearing disability.

The best thing about deafness is: some experiences embolden you. The above experience has seriously fired me up to fight for the rights of people with hearing loss and other disabilities. I and a few other deafened people just gave a TV press conference, where I talked about the lack of equal opportunities in Kenya and urged the people and the government to change their attitude towards us. This advocacy battle will continue until employers accord us equal treatment in the workplace and the government provides us with quality education.

How did you learn about ALDA? Through the IFHOH (International Federation of Hard of Hearing People) website

In what ways has ALDA enhanced

continued on page 14
April 26, 2011, Plano, Texas. Cinemark Holdings, Inc. (NYSE: CNK), one of the world’s largest motion picture exhibitors, today announced that it will provide a closed captioning option for people who are deaf or have significant hearing loss in all of its first-run theatres. Cinemark is installing captioning systems on a rolling basis across its circuit in conjunction with the chain’s conversion to an all-digital format. Installation started early this year and about half of Cinemark’s theaters in California already have captioning capability. Cinemark will be able to offer closed captioning at all of its first-run theaters by mid 2012.

Movie captions convey the dialogue, narration, musical cues, and key sound effects, speaker identification and other auditory information, in the form of written text for those viewers who have significant difficulty hearing the movie sound track. Closed captions are relayed—in sync with the movie—only to members of the audience who choose to receive them via a personal display device. The captions are not visible on the screen to the rest of the audience.

The Association of Late-Deafened Adults (ALDA), an advocacy group for those with who have lost some or all of their hearing, applauded Cinemark’s commitment.

Cinemark has worked closely with ALDA in setting the time-table for installation of captioning capability in California. ALDA also agreed to dismiss a lawsuit the organization filed in late 2010 over captioning issues in Cinemark’s California theatres. They were represented by Sid Wolinsky and Kevin Knestrick of Disability Rights Advocates (DRA), a non-profit legal center, headquartered in Berkeley, California, and John Waldo, an attorney whose practice focuses on the needs of those with hearing loss.

“We are pleased with Cinemark’s support for captioning. This decision makes first-run movies available to millions of patrons who are deaf and hard-of-hearing in California. They deserve to participate in this quintessential American experience,” said Mr. Knestrick. “We want to commend Cinemark for the prompt and cooperative way it resolved this case,” Mr. Waldo said. Linda Drattell, a plaintiff in the case, commented “I am delighted that around this time next year people who are deaf and hard-of-hearing will be able to watch first-run movies at Cinemark theaters throughout California.”

Cinemark selected the CaptiView Closed Caption Viewing System (CaptiView) from Burbank-based Doremi Cinemas LLC to transmit the closed captions to audience members who desire the assistance of captioning. CaptiView provides captioning to those who have significant difficulty hearing the movie sound track via an OLED display on a bendable support arm that fits into the theater seat cup holder. This device, provided to movie patrons upon request, operates on an internal wireless system and can be used in any seat in the theatre. The OLED screen provides exceptionally clear captions. The device is also equipped with a privacy visor, which ensures that the captioning has no impact on neighboring movie patrons.

“Cinemark was pleased to collaborate with ALDA,” said Michael Cavalier, General Counsel and Senior Vice President of Cinemark, USA, Inc. “The conversion to digital cinema has facilitated the development of closed captioning systems like CaptiView. We now have a platform that makes full implementation of a captioning system viable. Cinemark has worked closely with our suppliers to make certain that we are providing the highest quality closed caption system,” he added. Laura Franze, a partner with the law firm of Hunton & Williams LLP, who represented Cinemark in working out the settlement with ALDA, commented “Cinemark has long recognized the importance of making the movies it exhibits accessible to deaf and hard-of-hearing audiences and has supported captioning in different forms for many years. With the conversion to digital cinema and the development of digital closed captioning systems like CaptiView, Cinemark was moving ahead to full implementation of closed captioning even before this lawsuit was filed.”

Michael Archer, Vice President of Digital Cinema at Doremi noted, “When we began the in-house design of the CaptiView product two years ago, we worked closely with Cinemark, our long-term partner, to create a viable, high-quality product that displays closed captions for digital cinema. We are pleased to have this opportunity to work with Cinemark to provide captioned movies to their patrons across the country.”
My daughter Julie Ann loves to sing, and when she went to Largo High School in Largo, Florida, she joined the school choir. They have a group of about 20 *a capella* Madrigal Singers who wear Renaissance costumes and have concerts around the area during the holidays. Every year they have an audition to replace seniors who are graduating. When Julie was a sophomore, she auditioned and was happy to learn that she was chosen. (Most of the time, students who get in are juniors or seniors.)

Even though I’m deaf, I never miss these performances. One time, the group had a concert in a small church across from the school, and as usual, I was there to watch Julie. I sat in the back, and toward the end of the concert, my daughter stepped to the front and sang solo. I noticed her looking around, so I waved to let her know I was there. After the concert was over, I headed toward the front of the room to give Julie a hug, but others were going over to her and shaking her hand. I sat down and waited for them to be done, and then she came over to me.

Julie was crying, and I was so worried. I asked her what was wrong, but she just hugged me and continued to cry. I thought she was sick, so we sat down, and she told me that she was hurting because she was singing and I couldn’t hear her. And I told her that even though I couldn’t hear her, I could see. I saw her singing solo, which meant that she was really good, or else her teacher wouldn’t let her do that. Then I saw all these people shaking her hand, and I told her that two came over to me and said that she was really good. So yes, I can’t hear, but I see, and I saw her accomplishments and I was very, very proud of her. And I thanked God that even though I can’t hear, I can still see and I can still be there to watch her. So we just sat there, cried, and hugged each other, and she knows that no matter what, deaf or not, my love for her will always be there.

*Tess grew up in the Philippines and has three children. She was an RN until she lost her hearing as a result of radiation treatment in 1992 for stage 4 nasopharyngeal cancer. Although she was told that she only had two months to live, she survived, but a few years afterwards, she started to lose her hearing and became deaf. When that happened, she lost her job and some friends. At first she was angry at God, wondering why He let her survive cancer and then took her hearing. With nothing to do, she started reading the Bible and books about God, and she says that she had to lose her hearing to hear Him. Tess can be contacted at tesscruz@aol.com.*
One of Us (continued)...

continued from page 11

your life? Many ways! I realized am not alone in my battle. There are others having problems just like me, and through sharing our experiences I got encouraged to trudge on. I had planned to come to the US for my postgraduate studies in the future, but ALDA hastened my coming in order to attend ALDAcon, which I had been hearing members of ALDA talking about. I wanted to attend even if it meant selling my only property, and thanks to a partial ALDA scholarship, I came. And oh, my! I got more than I expected. What a wonderful experience! First and foremost the members were extremely warm and welcoming. I was very surprised to be met by the president herself—Linda Drattell—and her husband, together with Carolyn Piper, who took me out for supper! I didn’t expect to be met by the people in ALDA’s higher echelon. ALDA is indeed a very wonderful family! Now that’s one beauty of being deafened—it makes us warm inside our hearts. Another thing: I didn’t expect the flow of funds during the ALDAcon closing ceremony. The way members responded spontaneously really touched me, and I wished the convention could continue for an extended period. The only solace I had was that at least there will be another ALDAcon.

Through ALDA I also came face to face with superb technology which can go a long way toward ameliorating the problems of people with hearing loss, especially CART and other communication devices. In Kenya, we just dream of these technologies.

When I am depressed, I laugh harder

My most irrational fear is: people’s negative perceptions of me because of my hearing loss. I’m also afraid of snakes.

If I could hear again, the first thing I would do is: pray to God and hear the words I say, how I pronounce them, and the pace at which I pray. I was once asked to say a prayer in a group of people, and after I prayed, one of them commented: “Hey, my friend, you prayed so fast that even God did not hear your prayer!” That comment was discomfiting. From that time I usually decline to pray in a group whenever I am asked to do so.

The thing I like best about myself: I like seeing others prosper. I like encouraging people to do their best and go for their best. I believe in the innate abilities of others.

Nobody knows: that beneath that veneer of seriousness that I project, I have tons of love and I do cry.

What I can’t stand is: pity

Favorite memory: my first ALDAcon in Colorado Springs

Favorite saying: disability is not inability—my wife just informed me it is diverse ability

The bottom line is: Winston Churchill once said: “Never, never give up!” No wonder he was a great British wartime statesman. I urge you to go for your dream, you can do it, I believe in you.

Our World—News from the International Committee

By Muhammad Akram, Chairperson

Nepal is now one of the core members of ALDA-Asia Pacific (which has five dues-paying ALDA members—two from Pakistan and one each from Vietnam, Mongolia, and now Nepal). Maheshwar Ghimire from Nepal was sponsored for a one-year ALDA membership by an ALDA-International Committee member who wants to remain anonymous.

Eight hard of hearing and deafened people in Nepal had their first meeting to discuss the needs of the hard of hearing and deafened movement there. They agreed to start a group and formed a five-member ad hoc committee. They decided to have informal weekly coffee meetings for a few more months and will register later. The proposed name is “Association of Hard of Hearing and Deafened in Nepal,” which will be finalized at the next meeting. The logo will also be proposed at that meeting. Congratulations to Maheshwar and his team! We hope to see him at the Bangkok meeting too in November.

Muhammad Akram is founder and chairman of Danishkadah (www.danishkadah.org.pk), group leader of ALDA-Asia Pacific, and assistant director of Deaf Friends International.
Dear Friend,

The Association of Late-Deafened Adults needs your help in continuing to provide vital support to people with hearing loss. The assistance ALDA provides takes many forms—advocacy, education, and social and emotional support.

ALDA has taken the lead in advocating on behalf of people who are deaf, deafened, and hard of hearing by filing its lawsuit with Cinemark. The settlement we made requires that by next year Cinemark will display captioning of all movies in its first-run theaters in California. For the first time, people who are deaf or have hearing loss will be able to go to the movie theater and choose which movie they would like to see.

People who are deaf, deafened, or hard of hearing need a voice. ALDA fills a special niche for everyone with hearing loss, and especially for people who are late-deafened. Please help us let them know that they are not alone. Help us let them know that we are here to help, advocate, and provide support by sharing our experiences and knowledge. There is still much to do. Your donations will enable us to continue our outreach efforts.

Here are just a few highlights of participating in the life of ALDA:

- Sharing information through our eNews
- Helping those in need through our ALDAcon scholarships
- Providing our official newsletter, ALDA News, in both paper and electronic format to meet the varied needs of our members
- Maintaining and updating our website so that others may find us

Your donations to our FUNDRAISE help us to help others. Here are additional incentives to donate through the FUNDRAISE (you can collect donations from other people toward these amounts):

- The highest donor will receive a free registration to ALDAcon.
- A donation of $2000 will get the donor a free ALDAcon registration and a seat at the speakers’ table at meals (as applicable).
- A donation of $5000 will get the donor a free registration and hotel stay during ALDAcon.

To qualify for these incentives, donations must be received by September 30, 2011. If you have already registered for ALDAcon and are entitled to one of these prizes, ALDA will reimburse you.

Make checks out to ALDA, Inc. and put “ALDA FUNDRAISE” on the memo line. If you want to be considered for a prize by collecting multiple donations, submit the form below with your checks. Mail donations to ALDA, Inc. 8038 MacIntosh Lane, Suite 2, Rockford, IL 61107-5336. Thanks for your support!

ALDA Best,
Cynthia Amerman
President, ALDA, Inc.

ALDA Inc. is a 501(c)(3) nonprofit charitable organization. Donations are tax-deductible.
ALDAnonymous

By Bill Graham and Robin Titterington, Curators

How do you feel around children as a deafened adult? Are you more comfortable communicating with kids than adults, less so or about the same?

Kids scare me now, which is sad, as I used to work professionally with children. I just cannot understand children's voices, and I don't want to look like an idiot in front of a child. There is no bluffing with kids! I was trying to explain how my ears don't work as they should, but sometimes kids can be cruel, especially kids close to me. The annoyance and disdain can be very obvious, and ridicule and taunting are persistent. Although, as the adult, I understand that, it can still hurt deeply enough for me to remove myself from the situation. I admit I miss being involved with children. I had always wanted to be a “safe” place in the world of a child. But I need to feel safe as well.

I love kids, although I do have trouble lipreading them, which can make communication challenging. Then there are some kids like my young nephews, who are CODAs (children of deaf adults). They sign much better than I do (it’s not hard to sign better than me, LOL), so instead of having trouble lipreading them, I have trouble sign-reading them!

I much prefer children. If there is a group with adults and children, I tend to end up with the kids. The adults just leave me out while the kids accept me and are patient with me in trying to communicate.

I feel fine with children. When I tell them I have trouble hearing, they don’t immediately start talking real slow like I am an idiot. Some children are easier to understand than others due to the pitch of their voice. Kids seem to be more accepting, and they don't treat me as an oddity, either. Sometimes it is funny because they start screaming to get me to hear, and then my ability to distinguish words well goes out the door.

My primary reason for getting a CI was that I could not communicate with my granddaughter, who lives in my household. The CI and her getting older (she’s now seven) have both contributed to our ability to communicate, as well as the fact that she understands much more about hearing loss due to our discussions about it and she is more able to handle concepts in general—sometimes she handles them better than adults do!

I also have trouble understanding young women who try to sell me something, tell me about a political situation they think I will want to advocate for or against, etc. When I ask them to lower their voices and slow down, often they are able to do so. Adult males are generally easiest for me to understand, but people with clear diction and slower speech are best able to “reach” me.

The littlest kids are okay and sometimes easier to be around than certain adults. The interaction is largely visual, and I can act goofy without feeling goofy. As kids start to talk a lot, I start to get uneasy around them. When they become teens it’s no different for me than for others: nobody wants to be around them, and vice versa!

Kids are a challenge! Half the battle is getting them to face me so I can take a stab at speechreading. The key is educating the parents. If a parent understands and practices good communication, there’s a better chance she or he will encourage and reinforce it in his or her children.

I don’t have any of my own but I love kids. They’re cute and can say the darndest things…I think. My comfort with kids would generally depend on their age. The younger ones can answer gesturally (e.g., “You really like broccoli, yeah?” <Nod head>). I like to think that they are also more patient than many adults are.

Kids are particularly hard to understand due to the high frequency of their voices, and, depending on their age, poorly formed words. I love the little buggers anyway!

continued on page 17
My Cochlear Implant Activation

By Tom Hagney

Like many of you, I have had a hearing loss in both ears for many years. It progressed from mild to profound over a 32-year period. I had CI surgery on April 22 and was activated on May 20, just 24 hours ago as I write this article. Here are my experiences.

The audiologist turned on the processor and did the initial setup without my having the device on. I looked over the suitcase full of stuff that came with the CI—books, a CD, a DVD, batteries, a charger, a case, a dehumidifier, you name it. The processor was then placed on my ear and initial settings were made, as I listened to tones of varying frequencies and responded with “too soft,” “too loud,” etc. I had to laugh when I felt some tones in my throat and some in my teeth. Weird.

Then the audiologist had me listen to words similar to those in some of the hearing tests that I have had over the years—baseball, hotdog, airplane, etc. To my surprise, I actually heard the words without straining. The sound, of course, is not the normal sound that I have experienced over the years. All the voices sounded like Darth Vader crossed with Mickey Mouse. It was a very high-pitched computerized digital sound. My audiologist said that was normal and would change over time as the brain learned. She didn’t want me to do any training the first week, just to get used to hearing voices and environmental sounds. Training would commence the following week, when several more channels would be turned on and adjustments made.

On a trip to a graduation that evening, my wife conversed with me in the car and I was able to hear her without looking at her to see what she was saying. Both her voice and mine were really weird sounding but understandable. I could identify fan noise from the car’s air conditioning as well as road noise, and I heard and identified cell phone chirps and turn signal tones. Very enlightening.

Things turned bad at the graduation. Acoustics in the church were terrible. There were too many echoes and too much background interference, with several hundred people talking at the same time. I tried several of the program modes and varied the volume and sensitivity modes, but got frustrated and turned everything way down and just gave up trying to hear. I guess I expected too much too soon. At the graduation party afterwards, noise was a problem again, and one-on-one conversations didn’t work. At midnight, we went to a motel, where I took the CI off and got some rest.

This morning, after putting the CI on, I had to retrain myself to some sounds. Listening to my wife was tough at first, but then I fell back into hearing her “new” voice. The sound of the television and air conditioning in the room were very distracting.

I went to breakfast with family members. There was noise and too many voices, and I was unable to locate the voices I was hearing. I did, however, hear sounds that I had not been able to hear for years. The waffle iron alarm had a high pitched chirp that I heard and others could not hear. That was so amazing.

After breakfast, everyone broke up into smaller groups and we conversed in twos and threes. I heard better but still had difficulty when talkers didn’t face me, and I couldn’t pick out the speaking party without looking around to find moving lips. But in a very quiet location, I was able to pick out three different voices, which was encouraging.

There were both ups and downs, but my first day of hearing with a CI indicated that I was off to a good start.

Tom is 64 and became deafened gradually over a 32-year period. He has an 85 to 90% loss in the low frequencies and a 100% loss in the high frequencies. He wears a hearing aid on his left ear and a Cochlear Nucleus 5 CI on his right ear. Tom belongs to both ALDA and the Hearing Loss Association of America and has been married to his wife Mary for 30 “wonderful years.” He can be contacted at tmhagney@earthlink.net.

One of Us (continued)...

continued from page 16

Next ALDAAnonymous question: What is the most difficult challenge related to your deafness at work or in finding a job? How do you deal with it?

Send your responses to Bill and Robin at aldanonymous@gmail.com by August 21.
Unwrap Your Passion

By Karen Griffard Putz

INTRODUCTION I was born with normal hearing. When I was seven, I became hard of hearing due to an illness with a high fever. I received my first hearing aid when I was nine, but I did everything in my power to keep it hidden. I hardly ever wore it except at school. As soon as school ended for the summer, the hearing aid stayed inside a box on a shelf. Group situations were tough for me and I relied on lipreading to comprehend conversation as much as I could. I tried so hard to “fit in” that I would bluff my way through parties, hoping to blend in enough that no one would notice the fact that I was missing out on jokes and teenage banter.

I took up barefoot water skiing and spent my summer days zipping around the lake on my bare feet. I was proud to be the only girl on Christie Lake who could barefoot with the guys. One summer day when I was 19, I turned to cross the wake and caught a toe. I slammed into the water sideways—there was no time to do a normal “tuck and roll.” When I climbed into the boat, I couldn’t hear. I figured that I simply had water in my ear.

In an instant, I had gone from hard of hearing...to deaf.

BACKGROUND Just weeks after becoming deaf, I transferred to a university that had a program for deaf and hard of hearing students. I was clearly uncomfortable at first with the hands that produced rapid-fire American Sign Language. A stranger in a foreign land, I struggled to fit into this new world. I spent my nights crying over my loss of hearing and the frustration of trying to lipread professors that paced across a stage.

My “ah ha” moment came one morning when I was lying in bed and trying to summon the energy to face yet another class with communication challenges. I came to the realization that I could either continue to struggle or I could accept the changes and become the best deaf person I could possibly be. That very morning, I pulled my hair into a ponytail, slapped on my hearing aid, and marched myself to the disability office. I turned in the useless FM system and requested interpreters in every class. That “ah ha” moment was the day I started a new journey of acceptance. Years later, I adopted a quote from the movie, What a Girl Wants: “Why are you trying so hard to fit in when you were born to stand out.” How I wish I had heard that quote as a teenager!

PROFESSIONAL ISSUE One of the things that was lacking on my journey to acceptance was role models and mentors. I wanted to be a labor and delivery nurse, but a counselor discouraged me from seeking a career in that field. “It would be too hard to overcome the communication challenges,” I was told. Years later, I came to find a world of successful deaf and hard of hearing professionals. Deaf doctors. Deaf dentists. Deaf lawyers. And yes, deaf nurses.

I obtained a graduate degree in counseling and went off to work. Four years later, I became pregnant with my first child and was very torn about going back to work. I had wanted to be a mom for so long, and it killed me to leave my baby with someone else. Two months later, I quit my job and stayed home for 15 years. I dove into motherhood with a passion. I had no regrets, as I took complete joy in being able to spend time with my kids and teach them about life. All three were born with normal hearing, and one by one, they lost their hearing. I taught them to communicate and advocate for themselves. When the kids were older, I worked part-time as a college instructor and as a writer for a writing company. I also wrote for Disaboom, Parenting Squad, and the Chicago Moms Blog. In 2003, I became a deaf mentor in the Illinois Early Intervention program, mentoring families raising deaf and hard of hearing kids. I wanted those families to know that there were unlimited possibilities for their children. I joined the international organization, Hands & Voices as a board member and founded the Illinois Hands & Voices as a non-profit organization.

Two years ago, I took a full-time job as a sales manager and dove into the corporate world for Chicago Tribune, TribLocal, and Chicago Now.

Along the way, I learned the value of a mentor as I explored new paths and new skills. When you surround yourself with people who know more than you do, you have a rich pool of resources to tap into and expand your own learning. Kevin Hall, in his book, “Aspire,” shared a quote by Pravin Cherkoori: “Isn’t life magical? Look at what happens when you view yourself as an empty bucket and every person you meet as a well.” Every person that crosses our path in life has something to teach us.

PERSONAL ISSUE While things were going well professionally, over the years, I had put myself on the back burner trying to juggle...
Chatting With Harriet: Educate! Educate!

By Harriet Frankel

Every day when I go about my life I meet someone who is totally clueless about how to deal with a deaf person. I go to the grocery store and line up to pay for my purchases. “What do I owe?” I ask. The cashier will tell me, but I won’t know exactly what she said. I’ve become a member of the invisibly handicapped. This happens to me all the time because I learned to talk way before I became totally deaf. What is her reaction? Since the cashier is a nice person, the answer is probably “I’m sorry.” Well frankly, so am I.

The average response is to talk louder and sometimes lean over to my ear. Most people do not distinguish between hard of hearing people and those who are truly deaf. Sometimes a cashier will turn around the display that shows the dollar amount that I owe, which is most helpful.

Next, I visit the dry cleaner and the clerk turns around to look for the dress or sweater and then voices what I owe. I can’t lipread the back of his head. So, once again, I have to ask. Here’s my chance to be an advocate for fellow deaf people. Almost everything I do in my daily life gives me an opportunity to spread helpful information about ALDA and what that wonderful group of deaf volunteers is doing to make life easier for those of us who are losing or have already lost the ability to hear and understand conversation.

I go to the drugstore to get a prescription and it’s not ready. They say, “I will call you when you can pick it up.” Today I told the clerk she would have to use relay because I am deaf. “Relay! What’s that?” This is our chance to be an advocate and a teacher and educate. Look at your telephone invoice and you will probably see a small charge for relay service. I don’t know why the service is not publicized.

I had a problem recently with AAA auto service. I needed to get my car started and called them for help. I told them I was deaf and said, “Please dial 711 for relay.” I waited and waited for AAA to come and start my car, but no help arrived. I called AAA again and they said, “We told the driver to call you and gave him the number.” When the driver came one day later, I asked him why he didn’t call me and he said, “I called the TTY number, but no one answered.” People do not know that a TTY number is not relay. We have to educate and educate, again and again.

Late deafened adults are not members of the deaf community. We can talk because we learned to talk before we became deaf. That’s why it’s called an invisible handicap. Some of us are sneaky and don’t want to let people know we are deaf. But let’s yell it loud and clear. Tell people about the relay service. It’s even international. I talk to my Swedish cousins using it. Again, I repeat, let us all educate the public.

A version of this article appeared in the ALDA Peach Fuzz, May 2011. Harriet can be contacted at harrietfrankel@hotmail.com.

Unwrap Your Passion (continued)...

continued from page 18

it all. The weight crept up slowly and then one day, I found myself crying. It was my 44th birthday and I weighed over 200 pounds. I had stopped barefoot water skiing long ago and the only exercise I was getting was a weekly volleyball game. A new mentor came into my life, 67-year-old Judy Myers, who was featured on the Today show waterskiing on her bare feet. I unwrapped my passion once again and got back on the water with the world champion Keith St. Onge instructing me. Keith also mentored me for losing weight, and I went from a size 14/16 in jeans down to a 6. This summer, I will enter my first barefoot water skiing tournament. Who says you’re too old to try new things? The new challenge is balancing it all: work, family, exercise, health, and passion.

I’m now paying the ripple forward and helping others to unwrap their passion and discover how full life can be. With passion comes unbridled joy. I’d like to end with another quote from Kevin Hall: “Talents and gifts do not reduce or diminish when shared; they expand and increase like the widening ripples from a pebble dropped in still water.”

This article is slightly revised from the original version at http://hotmommasproject.wordpress.com/2011/04/06/hot-mommas-project-announces-2011-winners. Karen’s blog is at www.deafmomworld.com, and she can be contacted at Karen@deafmomworld.com.
Bagels and Babes is a special time at my kids’ school, where they invite the mothers to come out and bring all their children for a breakfast of…wait for it…bagels for the babes. I, ever the wanting-to-spend-time-bonding-with-her-kids-type mother, decided that this year, we would indeed attend.

I’ve never been very good at estimating arrival times. I always give myself way too much time to get there and then drive like a bat-out-of-hell, only to arrive 45 minutes early. This morning, I did better. I was only a half an hour early. Hey, it’s a step in the right direction.

So when we pulled up in our van that desperately needs a new furnace and some shocks, we were all a little beat up and ready to snack. Unfortunately, we were the only ones in the parking lot, and the only snack I had in the car was a half-eaten Snickers bar with fuzz stuck to it. This surprised me. Not because it was gross or the only thing in the car to eat. But why in the world would anyone only eat half a Snickers bar? That’s just insane.

I had Mollie, my oldest, run into the school to see if we were allowed in yet. We were. So I bundled up my nerves, grabbed my purse, and headed for the school gym, which would double that morning as the cafeteria.

We were, in fact, the first people there. Well, the first people not setting up. The woman behind the breakfast table waved a hearty hello and shouted something to me that seemed pleasant. She could have been saying, “You guys sure are too fat to be arriving so early for food. Can’t you starve a little and give the hungry kids of the world something to chew on for once?” and I wouldn’t have known the difference.

I gave my usual, “Hi! Do you need any help?” Now, why did I ask a question when I knew I wouldn’t know what in the world the answer was? It is a terrible habit I have. Perhaps it’s just me wanting to feel the vibrations of my own vocal cords. I talk quite a lot, actually. I talk to fill up the air, knowing that I sound like some poor, dying animal on the side of the road. But poor, dying animal sounds are better than nothing, right? (I think that may be debatable.)

Thankfully, the woman shook her head as she answered. Even though I realized the answer was no, I did happen to glance at my 10-year-old, Natalie, who, by the way, is the second most fluent signer in the house (behind me, of course), and she interpreted that the woman had been there for 20 minutes and was all set up. Hmmm. If only I had driven a little faster and met my usual 45-minutes-early time pattern, I could have lent a hand. Alas, all I could lend was my mouth and my stomach at this point.

After a couple of minutes of very awkward silence…well, awkward for the woman (everything is silent to me)...I decided to start digging into the donut holes on the far right of the table and get a glass of hot chocolate, located in the middle.

I was so involved in deciding which hole would be the least caloric with the most taste that I failed to realize that more people had accumulated in the gym for the festivities. So when I grabbed the two holes I’d decided on, I moved directly back toward the middle of the table to pick up a glass of hot cocoa. Unfortunately, someone else had already picked up theirs, so when I moved to the left, not looking at where I was going, I hit the woman on her arm and it sent the hot beverage flying.

“Oh, my gosh! I am SO sorry!! I didn’t even realize you were there,” I apologized as I observed where the glass and its contents were going to land. Thankfully, it wasn’t on another person. What’s a wet wall at 7 a.m., anyway? All was OK—except the fact that the woman, who had politely smiled off the collision, had decided to start a conversation with me. She began by introducing herself. I think. Her name was Felicity or Barbara or Veronica. Could have been supercalifragilisticexpialidocious for all I knew. But, because I had absent-mindedly left my paper and pen in the van, I smiled and introduced myself and shook her hand.

She talked and laughed. I laughed and smiled. She talked some more. I nodded. She jabbered on as she started to eat her bagel, which was smothered in cream cheese. (I know this because she ate and talked at the same time.) I smiled and tried not to gag at the grossness. I quickly looked around the gym for one of my three children. Perhaps they could give me an excuse to get away from this bevy of crumbs and saliva and confusion. Nope. They were all busy with their own friends. So I did what any other person would do in this situation: I created a new child. A fictitious child. A child who was always in trouble and was making a ruckus waaaaaaaaay on the other end of the gym.

“Sorry, but I have to go.
Caregiving from Three Perspectives (continued)...

continued from page 1

five years, even changing his colostomy bags (which he didn’t know he had) and answering all his questions over and over (having to lipread them, of course, usually without a clue what the topic might be), his remark stung. I understood, but it still stung.

With the children grown, I experienced an interim wherein my caregiving role was dormant. It was just my husband and me, and he was the one who took care of me! That was a carefree time, but all good things come to an end. For the past year, I have been engaged in still another caregiving role, that of providing compassion and understanding, along with feeding and laundry duties, to my husband’s older brother, Ted. He is extremely feeble, and living alone in his own house became unworkable. He also needs watching over lest he cause himself harm, or, well, do something, shall I say, “unwise”? It’s different this time, though! I now have two cochlear implants and this takes a lot of the strain off. Another difference is that Ted is the hard of hearing one now! My years of silence have equipped me to understand his needs in that regard. He is learning rudimentary sign language and is already proficient with the word “coffee,” his favorite thing, and “cookie,” his second favorite thing. I’m not at all sure, at my grandmotherly age, if I could handle this if I didn’t have my implants. The extra strain of trying to always understand would just be too much.

So there you have three perspectives of caregiving, all demanding a different approach: caring for children, caring for a parent, and caring for a sibling. All of these caring seasons of my life have taught me much about seeking and finding help from God, and I wouldn’t have had it any other way.

Elinore is coordinator of ALDA-NJ and on the advisory council for ALDA-Garden State. She lives with her husband of 50+ years, John, in rural New Jersey, where they raise puppies for the Seeing Eye. Readers can contact her at elinorebullock7@embarqmail.com.

Late-Deafened Experience (continued)...

continued from page 20

Bartholomew is always making a fuss. I need to make sure he hasn’t maimed or killed anyone yet. It was nice to meet you.” I went to leave and the woman with her mouth full spat a few crumbs at me as a goodbye and went about making small talk with another poor victim.

After that…er…situation, I decided that maybe I should eat my holes and drink my chocolate and just sit somewhere. I did so. I acted like I was totally engrossed in the origami book my son has asked me to hold. I’d never found a paper crane so interesting! When I was done with my food and realized that my kids didn’t even know I was there anymore, I went about getting ready to leave. After all, a mother was about to give a presentation on the importance of including your children in your every day activities. Definitely not something I wanted to sit through in silence.

I left knowing that, even though they didn’t give me the time of day, I’m sure my kids appreciated my effort to spend a little more of that time with them. I left knowing that I had done my job and shown my children some extra love. I left knowing that some people just haven’t a clue about the proper eating habits of not talking with your mouth full!…And I left knowing that I had a half-eaten Snickers bar in my car if I crashed in the snow on the way home.

Michele is a totally deaf freelance writer and artist and an ASL instructor. She lives with her hearing husband, Kenny, and three hearing children, Mollie, Jacob, and Natalie, in Grand Rapids, Michigan. Her websites are www.DeafExpressions.net and www.MicheleBornert.com, and she can be reached at DeafExpressions05@gmail.com.
A Journey of Recovery (continued)...

continued from page 10
carer.

I caught my dad working around the house listening to his iPod. I told him that I missed music and he apologized. Music had made such a difference in my life. It conveys such emotion! I can hear percussion, beats, and such, but I really miss hearing the beautiful sounds of the wind instruments. I had played the flute and piccolo and marched in the color guard.

I take a hearing test once a year. In the past couple years; my hearing has stayed the same. Even though this is good news for the doctor, it is disappointing to me. My audiologist wants to continue my yearly hearing tests to make sure that I do not get worse. My psychologist and I think I’m healing but not for precisely what the hearing test picks up. (I initially believed that if I could hear anything, I could not be deaf. This is a common misconception).

For years, I felt like I was in a bubble, unable to hear. I could lipread, but most people in my area speak with a southern accent. I was unable to communicate with anyone other than my parents, so I felt lost. That is a normal feeling for a person who was extremely social and all of a sudden became completely unable to be social. I felt that people were put off and nervous around me because they did not want to hurt my feelings. I became lonely. I know that this is my personal challenge. I have friends and family that I am close to, and that is more than some people have!

SO many people thought if I couldn’t hear what they said, I must be stupid! So I just played with them! Nothing bad, just silly, little things! I thought “well, the joke’s on them!” Then I got tired of playing and wanted people to take me seriously. I was learning sign language, but it is hard, and I didn’t want to show constant frustration. Therefore, I kept a smile plastered on my face. I had taken sign language when I was at Oxford College of Emory University in Atlanta, so I was building on that. I had never been around people who can sign fluently. I sat in the Deaf section at church and the interpreter signed SO fast, but I would catch a word here and there, which indicated that I had learned something and soon would understand more. My family and I stick with the official version of signing for most things, but for others, we use “home signs.” These are fun, but since they are not understood by other people, we have to be careful about using them.

I didn’t have a suitable place where I could learn sign language. Most places use “speech” as a method for teaching. That did not work because—duh—I was a newly deaf individual. Although I once had a Deaf teacher who was really great, at that time, my memory was impaired so I could not learn to sign. As soon as my memory healed, I was back at it! I eventually used a free online sign language program that is highly recommended.

Others cannot understand what I say because it isn’t loud enough for them to hear. I would know how to make the proper noises if I could hear myself. I understand that some Deaf people learned to speak even though they never heard. My brain injury caused irregular functioning in my mouth, lips and tongue, which is slowly healing. But often, six years later, I think, haven’t I given it enough time?! “Time” is a very frustrating word.

Most people do not tell me how I could improve my speech because they are afraid to hurt me. Some people sound out the correct way to say the words, which would work if I could hear them. Some sounds are not visually accessible, so I cannot see how to copy them. But I’ve improved. I started by just mouthing words without any sound coming out but recently, my doctor said that she could understand 70% of what I said! (I’m dancing a little jig—only in my head, of course!)

My many college friends stayed loyal to me. I had told them I would hate for them to say something that I couldn’t completely understand, and I asked them to write down their thoughts for me. I understood that they were going about their lives and had other struggles, but I wanted them to share with me as they once had, and I wanted to share things with them that I couldn’t share with my family (girl talk). Without being able to converse, I am unable to make new friends, and the isolation that I suddenly found myself in is extremely frustrating and lonely.

Even though I can’t hear much, I can “hear” my friends’ voices if I dream about them or imagine them, because I had learned their voices. I anxiously strained to hear their actual voices, and once in a while, I could hear just a smidgeon, which was glorious! I have a DynaWrite by DynaVox, which is a machine on which people can type what they want to say and pass the machine back and forth. Conversations can also be saved. I don’t go anywhere without my DynaVox, since few people understand sign language and I am not fluent in it either (blush).

There are occasions when I was awakened from sleep by “hearing” something I could not describe. It was super loud (to me)! I later recognized the sound and could not believe that I could hear these tiny noises, so my hearing must be improving! For example, when I was getting out of the shower, I “heard” a loud pounding on the wall and thought that my dad was hammering on the house outside. I moved my... continued on page 23...
faucet sprayer over for some reason and was amazed that dad wasn’t hammering anymore. When I moved the sprayer back to where the drips hit my seat, I heard the sound again. It was then that I realized it was just the “drip, drip, drip” from the sprayer.

One time, I heard something strange, listened very carefully, and figured out that it was the air-conditioning coming on. Another time, I was at my desk and heard something loud that scared me. Minutes later, I felt a boom. I have found that my “hearing” is not reliable, but when I felt something, then something was definitely occurring. I was sitting in front of my computer with a window behind it with curtains. I went to get my dad, who drew the curtain, and I saw that a major storm was passing through.

My doctor believes that these strange, weird noises are just amplified by my brain with my heightened hearing and this is a part of “post-traumatic stress disorder” (PTSD). I am not crazy; this is just what happens in the brain after a traumatic episode that was extremely stressful. I have to recognize that these sounds are just amplified; nothing is going to harm me. I then have to figure out how to adjust. For instance, I found that playing “white noise” before I go to sleep relaxes me and I drift off to sleep! The “white noise” completely covers all the tiny little sounds that my brain amplifies.

I decided that I would need to start my “new life” as a deaf individual. I have found that many deaf people, both those born deaf and those who lost their hearing later in life, do fantastic, successful things and help society! I looked up a few people and found that, along with learning other strategies, they actually use their deafness to accomplish things! In college, I was headed to teach photography. However with my TBI and hearing impairment, I knew I had to decide on a new goal. Since my new language is sign language, that is what I would need to teach with. I love teaching, so I will have to get really good at sign language in order to teach with it!

I found out that there is a difference between deaf and Deaf. The lowercase “d” refers to the physical difference of those who do not have the ability to hear speech. The uppercase “D” refers to the Deaf culture that I want to be a part of. I am deaf but working towards becoming Deaf.

I remind myself of how much I can and have achieved since I started my journey. Every journey that I have been on has been exciting! There have been some “adventures” that did not make me feel good, but I definitely learned something that would be of influence in my later days. Therefore, I am NOT going to stay stuck in depression! I will face this adventure open-armed!

Kristin currently lives in Marietta, Georgia and spends her day working on her abilities, reading, writing and cuddling with her puppies. This article is an edited segment of Miracle Girl. Kristin can be contacted at Kristin.Stansell@gmail.com.

Sounds Trigger Memory

I would really like to take time-out from intense listening analysis and just let the sounds flow over me, letting my brain do whatever it feels like doing...allowing my brain to engage in free association, taking in sounds and sights and doing with them whatever it likes. (p. 81)

Now a veteran CI user, she is able to appreciate the brain’s learning capacity. When she goes bilateral, she describes what happens when the second processor comes on board. It eventually activates a specific area of the brain whose task is to coordinate the sounds coming into both ears. It simply doesn’t add the sound input from the second side. The brain actually lays out a second landscape, like a 3-D site plan. With one ear, that isn’t possible, as all sound seem to come from one location and blend together. (p. 128)

Romoff brings the reader as close as possible to the experience even though the reader may not have a hearing loss. She does this with precision and a few imaginative comparisons. When she gets her second processor, she says, “My new ear is like the baby sister getting dragged around by the big sister. It wants to be just like the other ear when it grows up!” (p. 106). Her style is consistent and the book’s organization as laid out in the prologue comes full circle in her epilogue. The reader is never confused or left with unfulfilled expectations. Listening Closely has definitely inspired this late-deafened, single-implant reader.

After 25 years as a college English teacher, Margreta retired and moved to the San Francisco Bay area. She received a cochlear implant six years ago and can be contacted at mvpein@yahoo.com.
Chapter Happenings

By Ann Smith, Curator

Marlene A. Thometz reports that ALDA-Chicago inaugurated a new weekday event called “Coffee Chat” on May 11. This will be held once a month at McDonald’s Restaurant in Oakbrook, Illinois from 6:30 – 8:30 p.m., and all members are welcome to come to meet and share ideas. ALDA-Chicago sponsored an afternoon of bowling at Classic Lanes in South Chicago Heights on May 22. Afterward, bowlers and non-bowlers gathered at a member’s home for submarine sandwiches, chips, cookies, and soda.

ALDA-Boston has been busy, Francine Stieglitz reports. The chapter started off the year with its annual New Year’s Buffet Brunch at the Holiday Inn in Mansfield, Massachusetts. The guest speaker was Geoff Plant, President of the Hearing Rehabilitation Foundation, who has a particular interest in helping those with hearing loss to enjoy music. His dream is to have a Hearing Market Square where people with hearing loss, their families, and their friends could obtain information, receive communication training, and meet other people with hearing loss. On March 19, ALDA-Boston members went to the Hearing Rehabilitation Foundation in Somerville to hear celebrated harpist Aine Minogue perform some fine Irish music for “An Irish Listening, A Celebration of St. Patrick’s Day.” Look for photos at www.aldaboston.org.

April 16 was the Annual ALDA-Boston business meeting and election of officers at the Lexington library. The guest speaker was Jonathan O’Dell, assistive technology manager/training specialist at the Massachusetts Commission for the Deaf and Hard of Hearing. He talked about the Americans with Disabilities Act (ADA) and its implications for those with hearing loss. The members running for re-election were re-elected and then chose to keep the same positions that they had last year. The ALDA-Boston annual Fourth of July Barbecue was scheduled from 3 p.m. to 8 p.m. on July 3 (with a rain date of July 4), at the home of Connie and Charles Barnes in Medfield. This is a double celebration, because it also celebrates ALDA-Boston’s 22nd birthday.

Ann Smith reports that ALDA-Peach joined many Deaf Atlantans in watching the movie “Black Sand” in March. This is an adventure story in ASL with English subtitles. In April, ALDA-Peach members met at the Atlanta Botanical Gardens to enjoy the spring flowers. An added bonus was watching preparations for a wedding to be held at the Gardens later that day. The May event was a service day at the church that allows the chapter to use a rent-free room for meetings. Chapter members showed their appreciation by sanitizing the toys in the nursery. This was an enjoyable job, since members had an opportunity to play with, uh, clean dozens and dozens of cute toys.

Eileen Hollywood reports that ALDA-Garden State presented a very successful spring workshop in April that attracted 35 attendees. Members of the ALDA-GS board were introduced, and ALDA-GS President Doreen Dougherty gave an overview of the organization and the upcoming Walk4Hearing in October. Carol Granaldi then talked about the potential uses of “slash-through-the-ear” self-adhesive stickers and provided information on how to purchase the stickers, which can be used on files in health-care providers’ offices and on driver’s licenses.

After a break for lunch and socializing, a police officer from the local police department’s Community Policing Unit gave a presentation on “Dealing with Law Enforcement Encounters When You Have a Hearing Loss.” The presentation was highly interactive, with a lively question-and-answer session. Discussion topics included how to handle motor vehicle stops; training provided to police officers in regard to dealing with hearing impaired members of the community; and reverse 911 calls. After the presentation concluded, attendees celebrated ALDA-GS’s Sweet Sixteenth birthday with a (very) pink birthday cake.

Diana Pease Fanuel, treasurer of ALDA-GS, recently attended the SWC (SayWhatClub) convention in Baltimore, Maryland. “Hearing on the Harbor” had over 60 attendees from the U.S., Canada, and Australia. Diana reports that it was nice to get reacquainted with Cynthia Amerman, ALDA’s current president, and with others from ALDA and HLAA. Diana loves the crossover of hard of hearing, Deaf, and late-deafened people from different organizations.

Heidi Martin-Coleman received a certificate in deaf studies from Holyoke Community College in Massachusetts. At the graduation ceremony, she addressed over 1000 fellow students, speaking from her wheelchair with Mercury, her black Labrador retriever service dog, by her side. Congratulations, Heidi!

Send your chapter and personal news to Ann Smith at fabsmith@att.net by August 21.
LET YOUR CREATIVE SIDE SHINE!

WE NEED YOU!!

You have a story to tell and we want to know it! Whether it’s an adventure you went on when your hearing loss hit (and haven’t we all been on an adventure?) or the journey of your loved ones’ acceptance of that hearing loss, it’s your story and it’s only yours to tell. Won’t you share it with us? We want to hear...uh, we mean, “see,” what you have to say. So please send it this way!

The ALDA Reader is the official magazine of the Association of Late-Deafened Adults’ convention each year. This year in Indianapolis, everyone will be absorbed in this publication (we can hope), and your story will help make this happen!

Although the crux of the Reader is the articles, we are also looking for and excited to see your artwork, cartoons, hearing loss jokes, captioning bloopers, photography, and poetry! If you have something creative to add spark, educational information, or personal experience to this year’s edition, please send it to us right away.

If you submit something but can’t attend the convention, don’t worry—you’ll still receive a complimentary copy of the 2011 ALDA Reader!

DEADLINE EXTENDED!! Send your creative creation to Linda Drattell at lindra@comcast.net or by snail mail at 1702 Nursery Way, Pleasanton, CA 94588 before August 15, 2011.

Be sure to share this with others who have a hearing loss or an experience with a person with a substantial hearing loss, because we want to hear from them as well.

Thanks for reading, and happy creating!
Some ALDAcon 2011 Highlights

By Kim Mettache, ALDAcon 2011 Planning Chair

ALDAcon Program Chair Terri Singer and her committee have been working hard to plan a VERY fun-filled and informative convention for you. For the first time, a captioned play and a captioned movie will be part of the convention! There is a beautiful playhouse right next door to our host hotel, so we couldn’t pass up the opportunity for a live captioned performance.

Wait till you see where we’re having dinner on Friday night! The Indiana Roof Ballroom, which was opened in 1927, was designed to look like a Spanish village. Presidents, political leaders, actors, and actresses have appeared, dined, and danced here. You can read more about it at www.indianaroof.com.

You will also love the convenience of the upscale mall across the street that is attached to the hotel by a covered walkway. The theater where the free captioned movie will be presented on Wednesday night is located in this mall.

A note about the hotel from Brenda Estes, president-elect: “All the guest rooms overlook the atrium, which has a waterfall. You can stand outside your room and lean over the railing to “people watch” the folks down below and/or wave across to your friends on the opposite side. The breakfast area is HUGE and is separated into various sections for privacy.”

To get to the hotel from the airport, you can take IndyGo’s Green Line Downtown/Airport Express, which provides nonstop service from the airport to locations near major downtown hotels and the Indiana Convention Center. This service runs daily from 5 a.m. to 9 p.m. and costs $7. (IndyGo’s Route 8 provides non-express fixed-route service for $1.75, from the airport to downtown via stops along Washington Street.)

Never before has our convention offered you this much and more both onsite and within easy walking distance. I can’t wait to see you in October!

On Saturday, October 29 at 3 p.m., ALDAcon 2011 is offering an optional 90-minute tour of the Indy 500 Museum and its Hall of Fame. Bus transportation departing the hotel at 2:15 p.m. will be by reservation, which must be made by September 9 (see ALDAcon registration form). Total cost for both transportation and tour is just $20. Reserve early to make sure that a bus seat will be available.

This year marks the 100th anniversary of the Indy 500 Speedway, so this promises to be a very special tour. We expect an Indy 500 race driver to visit during our tour, making it even more memorable.
A Free Movie – Just for You

As a welcoming event on Wednesday night at ALDAcon 2011, you’ll be treated to an open captioned movie!

The movie is expected to begin between 7:30 and 8 PM at the Circle Centre 9 multiplex theatre in the mall attached to Embassy Suites-downtown, our host hotel.

The film title is unknown at this time and will be announced as soon as it’s available. We’ve requested a PG-13 comedy.

ALDA, Inc. and the ALDAcon 2011 planning committee are immensely appreciative of Regal Cinemas’ supportive efforts in arranging the switch to digital screenings in Indy in time for us to provide this special welcome event for our attendees.
**President's Report**

**By Cynthia Amerman**

We lost our treasurer early due to time constraints, and our Region 1 director, Matt Ferrara moved to the treasurer position. Paul Wummer then became the RD1. We especially appreciate our new treasurer's past ALDA experience and our new RD1's knowledge of information technology.

Our focus for the first quarter of the year was the strategic planning committee's goal of continuity. Last year the committee set out to explore five goals for ALDA, continuity and growth being the first two. Since January, we have worked to make changes that will open lines of communication between those who volunteer for ALDA so that they won't be starting at ground zero each year. We have put an editing process in place as policy in order to avoid errors on the website and in eNews, and the Board Manual has been reworked by our secretary, Karen Krull.

Our website has been changed to a national server thanks to our technology chair, Ken Arcia, and we expect further changes in the near future to work out the kinks. The Board would be grateful to have as volunteers any ALDAns who know how to work with websites. If you are interested or know anyone who is (as a volunteer or otherwise), please send the information to me at cynthiaamerman@gmail.com.

The strategic planning committee's recommendation to have an ALDA Ambassador (or ambassadors) is being followed up informally by visits to other organizations to create stronger community ties. Recently I returned from the SayWhatClub convention in Baltimore, having enjoyed meeting a friendly group of people with different kinds of hearing loss. This group offers a variety of online discussion lists for people like us. A corollary ALDA objective is to maintain ties we have already established—such as those formed last June at the International Federation of Hard of Hearing People's (IFHOH's) Biennial General Meeting in Stockholm and at the National Association of Deafened People's Annual Meeting in Liverpool. Late-deafened people in England, Finland, Sweden, and the US have an interest in reviving the Late-Deafened Commission of the IFHOH. Take a look the IFHOH Late-Deafened group on Facebook that has just been started by our European counterparts.

As I write this, I'm headed for the TDI convention in Austin, Texas to learn more about how we can give input toward national legislation on behalf of people with hearing loss and advocate for our communications needs in the 21st century. Past President Linda Drattell and I will gather information there about future technologies to improve our lives, and our Advocacy Chair Cheryl Heppner will also be at this convention. I'll then attend the Hearing Loss of America Convention and Hearing Loop Conference in Washington—your Board members go to these events on a volunteer basis rather than being sponsored by ALDA.

The Board has now begun to focus on a second goal, growth. The volunteer committee, the ALDAcon committee chairs, and others have been planning ways to recruit volunteers. In some cases it is a matter of matching skills to work that needs to be done, when ALDAns have already said they would like to devote time to ALDA. We are also looking for people who would like to write about their rewarding experiences volunteering for ALDA. Contact ALDA News Managing Editor Eileen Hollywood at eileena2@aol.com if you’d like to participate.

ALDAcon Chairs Kim Mettache and Terri Singer have exciting events planned for our October convention in Indianapolis. Click on the ALDAcon button on our website for more information. We will have a variety of workshops, a captioned play, a captioned movie…and our unparalleled (some would say infamous) karaoke party on Saturday night.

ALDA News Editor-in-Chief Nancy Kingsley has been putting together a booklet of Harriet Frankel's ALDA-Peach, ALDA News, and other writing to be published and sold at the convention, where we will celebrate Harriet's 95th birthday on Saturday, October 29. Harriet told us that she would like all proceeds from sale of her wit and wisdom concerning deafness to go to ALDA, Inc. We are very grateful, Harriet!

Concerning advocacy: as you may know, ALDA, along with two plaintiffs, one of whom is our past president, worked with John Waldo, an outstanding attorney and ALDA member, in a California lawsuit against Cinemark movie theaters in conjunction with Disability Rights Advocates (DRA). A successful settlement was reached in which Cinemark agreed to equip all its theaters with captioning capability by June 2012. We deeply appreciate Cheryl Heppner, Linda Drattell and John Waldo for their tireless efforts that led to the success of this undertaking.

**President-Elect's Report**

**By Brenda Estes**

I collaborated with several Board members on updating ALDA, Inc.'s *Board Manual* to ensure continuity for future Board members. As Accessibility Chair of the 2011 ALDAcon Planning Committee, I have been in contact with the Indiana Department for the Deaf and Hard of Hearing to request sensitivity training for the hotel staff so they can be aware of the various modes...
of communication late-deafened adults utilizes and to provide training on how to set up the assistive devices in the ADA hotel kit.

I visited the Embassy Suite hotel in downtown Indianapolis, and the management is very excited about being the convention site and is working diligently with our program and planning chairs to make this a successful ‘con. Inside information: the atrium area has a waterfall, which might be a little tempting for the service dogs. The breakfast area is HUGE and is separated into various sections for privacy, and all the guest rooms overlook the atrium. You can stand outside your room and lean over the railing to watch the folks down below and/or wave across the atrium to guests across from you.

**Past President’s Report**

*By Linda Drattell*

As individual plaintiff and as ALDA’s appointed representative, I worked with our attorneys, John Waldo and Disability Rights Advocates, for the successful settlement of the Cinemark movie captioning lawsuit. By May 2012, all of Cinemark’s first-run movie theaters in California will provide captioning using Doremi CaptiView equipment. Also included in the settlement are the ALDA Board’s positions on an effective complaint process regarding malfunctioning equipment, proper advertisement of captioned movies, and theater staff training.

I am currently working with the ALDA president, treasurer, and ALDA co-founder Bill Graham to determine possible avenues for fundraising. We are hoping to have two presidential fundraisers again this year, in the summer and winter, as well as to increase our sources for funding.

I am co-chairing this year’s ALDA Reader with Michele Bornert. In addition, I chair the Nominations Committee and serve on the ALDAcon Program Committee, International Committee, and ALDA Advisory Board.

**Secretary’s Report**

*By Karen Krull*

Since January, as ALDA, Inc. secretary, I’ve been a busy little beaver. I’ve forwarded the electronic Board Manual to Board members; recorded the minutes of all emailed Board business; tracked and tallied the votes of Board members on motions; and kept an up-to-date listing of all motions of 2011. I have been working on cleaning up and organizing the Board Manual, getting rid of duplicate files and folders, and moving files to their proper place. I’ve compiled and added a list of contents to aid in locating particular files or folders within the manual. Board members received the updated manual in May.

**Treasurer’s Report**

*By Matt Ferrara*

First, I want to thank the Board for their confidence in me for appointing me to finish the current treasurer’s term and to thank Vaughn Shaw for all his work setting up the accounts and fulfilling the treasurer’s functions during the past year as well as for his help in facilitating a seamless transition.

As of May 31, 2011, cash in ALDA’s bank accounts came to $32,907 and in the ALDAcon checking account $6026, for a total of $38,933.

**Balance sheet (for the ALDA bank accounts):**
- ALDA operation expenses: $9356
- ALDAcon (2011) account: $3645
- Scholarship fund: $19,272
- Newcomer fund: $3926

The Federal IRS 990 form for 2010 has been submitted as well as the State of Illinois registered agent report. All outstanding bills have been paid and we are on or near budget with our expenses.

Note that ALDAcon 2011 is a chapter-sponsored event. Detailed finances and status will be in a separate report.

Because of my appointment as treasurer, I could no longer serve on the Board as the Region 1 director. I want to thank Paul Wummer for accepting the appoint-
ment to complete this term.

Remember, ALDA, Inc. is a nonprofit corporation and donations are tax-deductible. Also, some employers have matching donations plans. If you have any questions regarding donations, please contact me.

**Region 1 Report**

*By Cynthia Amerman, President*

Region 1 has had two regional directors (RDs) this year because the first director, Matt Ferrara, was appointed to the vacant treasurer position in March. Paul Wummer replaced Matt as RD1 the following month and is dedicated to seeing that Board members learn more about technology and the Internet.

Matt was also RD coordinator and still handles info@alda.org, which involves sending ALDA inquiries to the appropriate director, board member, or commit- tee. Inquiries came from all over during the first half of 2011, including one about Meniere’s disease from Norway and one about CIs from Argentina. Some people want to find a nearby person to talk with about hearing loss to learn about technological devices. Part of the RD’s work is to point people to organizations where they can find others with hearing loss and/or send them requested ALDA publications.

ALDA-Boston, ALDA-Garden State, ALDA-NJ, and ALDA-Potomac continue to thrive. ALDA-Maine disbanded in the absence of someone willing to take the reins from Lauren Storck. Lauren worked hard to establish ALDA-Maine, which had an exemplary newsletter, and she donated the remainder of her chapter’s treasury to ALDA, Inc. Many thanks to Lauren for her years of service as president of ALDA-Maine.

**Region 2 Report**

*By Marsha Kopp*

I have seen a significant increase in inquiries for financial resources for hearing aids and more requests for networking connection with other deafened people and for a support group in the area. Appropriate contact information was sent. Region 2 (Midwest) is seeing an increase in new memberships.

Region 2 has one group and two active chapters. Martha Mattox is the leader of the ALDA-Midwest (Ohio) group, which she monitors through emails and a Yahoo group. Kim Mettache is president of ALDA-Northwest Indiana (NWI). In March, this chapter hosted a meeting with a deaf coordinator from F.A.C.E.S. (Freedom, Access, Community, Empowerment and Support), a statewide independent living program under Everybody Counts, Inc. The speaker shared her expe-

**Region 3 Report**

*By Rachael Morris*

Hey y’all! I sure have been a busy lady keeping things together with all of your pals in Region 3! Here is what has been going on in this neck of the woods.

After sending out a “Hello” introductory email to all Region 3 members in January, I enjoyed “hearing” back from many and learning tidbits about some of them. This entire experience as a new Board member has been very welcoming!

I have responded to a plethora of emails from individuals seeking financial assistance for hearing technology for themselves or their loved ones. I also referred people to specific chapters, including ALDA-Peach, ALDA-Houston, ALDA-Carolina Flight (two), and ALDA-Suncoast (three). I had communication with a social worker in Texas requesting resources about baby monitors, etc. to pass along to new parents with a hearing loss. I referred a Florida resident services coordinator who was searching for a speaker to the ALDA-Suncoast website as well as a person to contact. I sent friendly guidance and ALDA info to a young woman in Tennessee who is new to the hearing loss world and wants to meet people like herself.

In addition to RD3 inquiries, I had contact with a couple of individuals seeking guidance and resources on NF2. I have NF2 and they were referred to me.

I also serve on ALDA’s volunteer and outreach committees. Be on the lookout at ALDAcon for information about how YOU can become “Volunteer of the Year” for ALDA. The outreachers are also designing a logo for
fun promotional items.

Ok gang, that is all for now. I hope to see your shining faces in Indy! Y’all be good and remember, “Only the strong survive”!

**REGION 4 REPORT**

**By Kathy Evans**

There have been many inquiries for contact with other people who have lost their hearing. Region 4 is the land of wide-open spaces, except in the cities! Many requests for chapters and contacts find us with no ALDAns within 50 or even 100 miles of the person inquiring, so it is challenging to meet their needs. I’ve had emails from people in California, Oregon, Washington, Idaho and Arizona so far this year. Some are interested in starting new chapters, so there is great potential for growth here.

I’ve also received requests for ALDA brochures from some state government agencies and will be connecting with more soon so they’ll be able to refer people to us and be better equipped to meet the needs of late-deafened people in their areas.

I’m just beginning to get to know the people in Region 4, and I hope to make many more contacts in the coming months.

**ADVERTISING DIRECTOR REPORT**

**By Matt Ferrara**

For 2011, I have a continuing ad for Harris Communications and a barter ad for TDI. I also had a one-issue ad for the peer mentoring program at Gallaudet University and a request for ad information from Krown Manufacturing.

Gene Romero volunteered to be on the advertising committee. He has been sending emails and letters to various companies that advertise in other hearing group magazines and newsletters. We have had two responses and are following up on them.

If you know of any potential advertisers, please contact me at mattf812@verizon.net.

**ALDACON PROCEEDINGS REPORT**

**By Carolyn Piper**

At every ALDACon, there are workshop presentations on a wide variety of subjects. The transcripts of those presentations are edited and then placed on the ALDA, Inc. website. ALDA would like to thank our CART chair, Pat Graves of Caption First, as well as her CART providers, who gather the material and do the preliminary formatting. Our editors, Margreta von Pein and Michele Bornert, are also members of our team, for whose help we are very thankful.

**B Y L A W S C O M M I T T E E R E P O R T**

**By Nancy Kingsley**

As reported in the previous *Biz*, Mark Dessert, Roy Miller, and I made a variety of suggestions for updating the ALDA Bylaws, and we also prepared the wording for several Board-generated proposals. ALDA members subsequently voted to approve all 14 changes, and the Bylaws have been revised accordingly.

**MEMBERSHIP CHAIR REPORT**

**By Karen Krull**

With Database Manager Gloria Popp handling the everyday aspects of renewal and recording, I’ve been overseeing and coordinating with her to fill in the gaps as needed. Kathy Schlueter and Brenda Estes also serve on the membership committee. I am presently working on the wording of an exit poll email to all members who did not renew, since one-on-one personal contact with lapsed members might make a difference. The pattern of renewal or nonrenewal seems to be consistent with whether or not the member is planning to attend ALDACon. My goal is to have a membership drive in the near future, as I’d like to see members renewing even if they aren’t planning to attend ALDACon.

**NOMINATIONS COMMITTEE REPORT**

**By Linda Drattell**

An article was published in the Spring *ALDA News* inviting members to join the committee.

To date we have John Waldo, Karen Krull, Fred Heppner, and Rachael Morris. It would be great to have one or two more people, and we especially need a chapter president on the committee.

I will be talking with a couple of organizations to determine the most objective setup for ballot counting. I intend to ask League of Women Voters to oversee the ballot count.

**OUTREACH COMMITTEE REPORT**

**By Brenda Estes, Chair**

The Outreach Committee is creating a list of resources for the ALDA website. The list will be set up by categories, such as organizations, cochlear implant companies/centers, and assistive technology vendors. The committee is also developing ideas for promotional materials and working on creating a “brand” logo that would include ALDA’s name and may also include the “losing my hearing and gaining a family” theme.
**Scholarship Report**

*By Carolyn Piper*

It was gratifying to the committee to be a part of enabling six newcomers to attend ALDAcon 2010 in Colorado. This year, the committee is chaired by Carolyn Piper and includes Karen Krull as member at large and Linda Drattell as Board liaison. As in years past, ALDA, Inc. will provide a limited number of scholarships to help those in financial need who want to attend. Applicants for a scholarship must be members of ALDA, Inc. and be in need of financial assistance in order to attend ALDAcon. Priority in awarding scholarships is given to first-time attendees. Inquiries regarding scholarship applications should be sent to Carolyn Piper at wicwas@wcvt.com.

Scholarships to ALDAcon are made possible through two funds: ALDA Inc’s fund and the Edna Shipley-Conner Newcomer Fund. This second fund was begun by ALDA’s co-founder Bill Graham in 2008, ALDA’s 20th anniversary, in honor of Edna Shipley-Conner. Edna was a long-time Board member and past president of ALDA who worked tirelessly to assist newcomers in learning to deal with hearing loss. She was also the presenter of newcomer workshops at every ’con prior to her death.

To make continuing scholarship awards possible, donations to both funds are needed. Donations can be made at the ALDA web site at http://www.alda.org (click on the link for donations) or sent directly to me at the address below:

82 Piper Place
Huntington, Vermont, 05462.

For further information on scholarships, contact me at wicwas@wcvt.com.

**Strategic Planning Committee Report**

*By Marta Watson*

The focus of our discussion so far this year has been on growth (expanding our membership/recruitment of new members). The following specific actions were recommended.

- Reorganizing the current website committee to include the following chairpersons: advertising, membership, publications, outreach, and technical

- Creating a social networking committee to run and/or follow up social networking ideas including how to utilize blogging, Twitter, Facebook etc. to ALDA’s advantage and what type of information to share on these networks

- Creating an “ALDA elders” committee to develop senior-specific information that takes into consider-

- Creating an official ALDA Ambassador position/chair

- Setting specific, reasonable membership goals for each year

- Redefining the role of regional directors to focus more on members/outreach and less on Board work

- Creating a short “carrot” version of *ALDA News* available to anyone (not just members) who visits the ALDA website

- Developing video advertising (with captions) for placement on YouTube, etc.

- Utilizing already existing “entry points” into the hard of hearing/late-deafened adult population: audiologists, implant manufacturers, hearing technology companies, otologists, university audiology/speech pathology departments, etc. to recruit members

- Reviewing current membership lists to determine whether each RD has at least one contact person per state/high population area who can assist with recruitment

- Personally contacting all nonmember ALDAcon “newbies” who applied for but didn’t get scholarships

Our future discussions will focus on energizing and encouraging the current ALDA membership to participation more fully in local, regional, and national activities.
Your support is essential to help TDI maintain its advocacy work in our nation’s capital, Washington, D.C. Here are some of our goals!

- Current Bills in Congress on Internet Access (HR #3101 & S #3304)
- Mandate for Captioned Telephone Relay Service
- Relay for Deaf-Blind Users
- Universal TV Captioning at All Hours
- Captioning at Movies, Live Events and Online
- National Broadband Plan
- Modernized NG-911 Services
- And much more...

Join TDI as a member and help us fulfill our mission for accessible telecommunications, media, and information technologies!

Contact TDI:
Phone: 301-589-3786; Fax: 301-589-3797; Video: 301-563-9112; TTY: 301-589-3006
info@tdi-online.org; www.tdi-online.org

TDI - Shaping An Accessible World

There are always a few people you do a lot for, and a few who do a lot for you, but they’re not the same people. —Mignon McLaughlin
What Is ALDA?

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

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

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

ALDA provides networking through local chapters and groups as well as our annual 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 Maclntosh Lane, Suite 2, Rockford, IL 61107, 815-332-1515 V/TTY. Membership entitles you to receive the quarterly ALDA News, which spotlights personal experiences of late-deafened people, and to attend ALDAcon at the lower member rate.

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

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

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

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

I'd like to: □ Join ALDA □ Give a Gift Membership to:

Name ___________________________________________________________

Organization: ______________________________________________________

Address _______________________________________________________

City __________________________ State: ______ Postal Code: _______ Country: ______________

Home Phone: _______________ TTY □ Voice □ Cap Tel □ VP □

Work Phone: ________________ TTY □ Voice □ Cap Tel □ VP □

Fax _____________________________________________________________

E-mail ___________________________________________________________

URL/Website Address: _____________________________________________

ALDA Chapter (Name/None): _________________________________

Gender:  Male □  Female □

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

Newsletter preferred format (select one):
□ Electronic (Email) □ Paper (U.S. Mail)

□ General Member, Age 61 or under......$30.00
□ Senior Member, Age 62 or over.........$25.00
□ Veterans Membership $25.00..............$25.00
□ Business Membership.........................$50.00
□ Tax-Deductible Donation..............$ _______

□ New  □ Renewal

If paying by check or money order, payment must be in U.S. funds and drawn on a U.S. bank. If paying by credit card, complete the section below or Renew online by going to: www.alda.org/alda_membership_form.htm

For Credit Card Payment by Mail:
□ MasterCard □ Visa

Amount _________________________________

Account # _______________________________

Expiration Date ___________________________

Signature ________________________________
(For Credit Authorization)

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

ALDA provides networking opportunities through local chapters and groups as well as at the annual ALDA conference (ALDAcon).
Make a Difference! Become a Lifetime Member!

**Why a Lifetime Member?**
A. ALDA and the work it does to support the empowerment of deafened people means a lot to me; I want to support ALDA financially
B. I don’t have to worry about forgetting to renew my dues
C. I plan to live to be at least 130 years old; think what a bargain Lifetime Membership will be!

*Ann Smith, Lifetime Member*

**Lifetime Membership Tier**

- **Bronze** $500 - $1,499: receive a personal letter from the President, bronze plaque
- **Silver** $1,500 - $2,999: receive a personal letter from the President, silver plaque and priority seating at future ALDAcons
- **Gold** $3,000+: receive a personal letter from the President, gold plaque, priority seating at future ALDAcons and complimentary registration to a future ALDAcon.

**Lifetime Memberships**

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

Contact ALDA treasurer: treasurer@alda.org or visit www.alda.org