How NF2 Changed My Life

By Rachael Morris

I was 14 and it was the summer before my freshman year of high school. While away from home, at camp, I started experiencing horrible lower back pain that extended down through my legs. It would initially come at night after I was active all day. At the time, I could not really describe the pain. Now, I characterize it as a sharp nerve pain and deep burning in my muscles. I spent two days in the infirmary sleeping, eating bananas, and sleeping some more. The camp doctor was just treating me as if my body were lacking potassium (this explains the banana binge) and said I had a “charley horse.” I felt better after a lot of rest and was able to finish my camp session.

When I got home I visited my pediatrician. The pain would come and go, appearing mostly after dance class or theater rehearsals. My doctor just agreed with the camp doctor that my body got tired and I needed bananas. Well, eventually the pain got worse. There were many sleepless nights for the entire family and many school days missed. After I was referred to a neurosurgeon at Wake Forest and had MRI scans, I was diagnosed with neurofibromatosis type 2 (NF2). I had a thumb-size tumor putting pressure on my spine, which was causing the pain. My first surgery was in December 1996.

NF2 is a disorder characterized by the growth of benign tumors throughout the nervous system. The hallmark tumors associated with this condition are called vestibular schwannomas or acoustic neuromas. These growths develop along the nerve that carries information from the inner ear to the brain (the auditory nerve). Tumors that occur on nerves in other areas of the brain or spinal cord are also commonly seen with this condition. I have had tumors treated throughout my entire body, resulting in various impairments, some temporary and some permanent.

After my initial diagnosis, I saw my new doctor and had MRI scans every six months in Winston-Salem. I was told all about what COULD happen with this disease, but little did I know that it was what WOULD happen! The warnings of possibly going deaf and having mobility changes were unreal. I pretty much had the mentality of “that will never happen to me.” I really did not think much about it. I was a freshman in high school. There were more important things to ponder like whether the Backstreet Boys or N*SYNC was gonna be #1 on TRL that day!

I was lucky to make it through all four years of high school and two years of college without too many NF2 interruptions. Reality hit when I was 20 and deaf in my left ear due to gamma knife therapy to treat a growing tumor in my brain. Of course, it was an adjustment and I still had good hearing in my right ear. I just had to make sure when I played the childhood game “telephone” to have the person next to me whisper into my right ear, not the left one.

Unfortunately, an acoustic tumor on my right side began to grow when I was 23. My hearing was suffering and I had to get hearing aids. They were pink and very “in-style” (as much as they could be). However, my use of the aids did not last long because the tumor was growing quickly, also causing severe balance problems and dizziness. I was going to be deaf whether or not I had the tumor removed. I needed the TV and radio volume almost on full blast. People talking sounded like Charlie Brown’s teacher to me.

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Hi, everyone!

To help you get the new year started off right, we have a new issue of *ALDA News* that is packed with many enjoyable articles and columns. Our theme for this issue is “Dealing with Hearing Loss in Conjunction with Other Medical Issues,” and you will find inspiring stories of courage, hope, and determination. We have a great cover article by Rachael Morris, “How NF2 Changed My Life,” in which she provides a candid account of living with neurofibromatosis type 2. Holly Alonzo, a deaf-blind wife and mother, is sure to move you with her story, “Deaf, Blind, and Determined,” and “NF2 and Communication” by the late Kathie Hering (ALDA’s co-founder) provides another honest and insightful look at dealing with the challenges of NF2. Rosemarie Kasper’s “Hearing Loss as a Second Disability” enlightens us about the communication obstacles the author encountered.

Moving on to a different topic that will resonate with many readers, Donna Maderer explores the challenges of learning to sign in “Learning Sign Language.” And whether you are a mom or not, you’ll enjoy “ALDA Mom Gets Older and Better,” in which Mary Clark details another chapter in her journey as a late-deafened mother. Roxanne Gasaway provides a brief but vivid account of a personal experience she had at the sea in “Deafness, NF2, and the Sea,” and one of ALDA’s international members, Duong Phuong Hanh, provides a heartwarming account of her first ALDAcon experience in “ALDA—My Big Family.” If you were unable to attend the ‘con in 2009, Nancy Kingsley has written about the awards in “ALDAcon Award Winners,” and you can read Lois Maroney’s I. King Jordan award acceptance speech.

Tim Kimball takes you on an uplifting journey through his life of challenges in “People Say I Am an Inspiration.” Rounding out our issue is “Silent Spotlight,” an eye-opening article by Connie Robinson about the challenges and rewards of living with other people’s invisible disabilities.

As always, we also have some terrific stories from our regular columnists, Michele Bornert and Harriet Frankel, that will make you smile, and the opinions and activities of ALDA members are covered in “ALDAnonymous,” “One of Us,” “Chapter Happenings,” and “GA to SK.”

Many thanks to all the writers who contributed their stories, for without them, this newsletter would not be possible. If you have any comments or suggestions for future issues, please send me an email. We are always looking for feedback, both good and bad, and welcome new and fresh ideas.

Wishing you all a very healthy, happy, and prosperous 2010!

ALDA best,
Eileen
Fran A. Clark once said, “If you can find a path with no obstacles, it probably doesn’t lead anywhere.” And that really hit home for me. Practically all my life, I have battled mental illness. Dealing with that has been quite difficult, but I know that God does everything for a reason. I just wish I knew what that reason was. And as if being mentally ill weren’t enough, God decided to smite me down with total (and I mean total) deafness, too. Smite might be too harsh a word, but, believe me, when I lost all my hearing in 2000, I wasn’t feeling very peaceful. I had a chip on my shoulder the size of Montana. But the fact was that I was now both mentally ill and deaf.

I had stopped therapy a few years before. Just didn’t like it—whether I needed it or not. The idea of some old guy with a Frito catcher around his face listening to my every thought and feeling just didn’t appeal to me. But alas, after deafness knocked me clear out of the ballpark, I was left to deal with this catastrophe alone. People I once hung out with started crossing the street when they saw me coming and stopped inviting me places. I couldn’t hear, couldn’t lipread, and couldn’t seem to keep my friends. That is, until I found ALDA, of course.

But going back, I realized how sick I truly was emotionally, and with newfound deafness, I searched out a therapist. As luck would have it, I found one who specialized in deafness and sign language. It was great until one of my more serious diagnoses started to show its ugly face and I realized I need more extensive help. Fortunately, there was a hospital in Grand Rapids, Michigan that specialized in my ailments, caused by trauma as a kid, and we decided that’s where I needed to go.

Although I had a TTY, I was too scared to call the hospital myself. I don’t know if it was because of my fear of people or just a habit of letting my husband Kenny do things for me. So Kenny gave Forest View Psychiatric Hospital a call and spoke with the intake person. When informed that I would be requiring an interpreter, the man nearly hit the roof. “Do you realize that would cost us $5,000 a week? And scheduling an interpreter’s going to be a real inconvenience!” Kenny calmly explained that if anyone was “inconvenienced” by this, it was I. So the man made a few phone calls, then finally called back and reluctantly sighed that they’d be willing to take me. Gee, thanks.

It was an eight-hour drive from southern Illinois (where we were living at the time). We arrived at the hospital about 2:30 in the morning. Although we had complied with their request to give them two hours’ notice of when we’d be arriving so they could call for an interpreter, they still hadn’t called when we got there. To make things even more frustrating, Kenny couldn’t stay because he had to get back to Illinois for work.

I sat down at the desk, and a man with Albert Einstein hair beamed a smile of extremely yellow and disfigured teeth. “Can you lipread?” he asked me.

“No. Not at all. Please write to me.”

He then proceeded to recite a 15-minute soliloquy about which I had no clue. All I knew was that he needed much stronger toothpaste and maybe a mint or two for his halitosis. Whew!

Finally, about an hour later, my interpreter showed up. Talk about relief! We sailed through intake and got me settled into my room. My roommate, I was soon to discover, weighed about 450 pounds and had only two or three teeth. And no bladder control whatsoever. But I finally got to bed and was awakened at 7 a.m. for breakfast. After the meal, it was medication time. The first day there was no interpreter, but by the next day they had it all worked out.

So after breakfast the second day, we were standing around the nurse’s station. One of the nurses kept eyeballing me and finally said, “Aren’t you grateful for all that the hospital is doing for you? I guess groups might be a little hard to follow, but you can lipread the rest of the time.”

I pointed out that groups would be impossible for me to follow and repeated for the umpteenth time that I can’t lipread! She rolled her eyes, and my interpreter told me later that this nurse pulled her aside and asked her to tell her if she saw me lipreading, because she didn’t believe I couldn’t. How hard could it be, right? Ugh!

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Candis Shannon: In Memoriam

By Nancy Kingsley

The ALDA News is sad to announce that its former editor-in-chief, Candis Shannon, died on November 11 at age 57 after a short battle with mesothelioma, a type of cancer caused by asbestos. Candis’ father was a welder who had worked with this material before its cancer-causing properties were known. She is survived by her daughter Carolyn and a brother.

Candis and I were assigned as roommates at our first ALDAcon in 1990. At that time, we didn’t know that we would later be collaborators in revising a guide to ministry with people who are Deaf, late-deafened, hard of hearing, or deaf-blind, or that both of us would become (at different points) editor-in-chief of the ALDA News and ALDA Publications Chairperson. At the time of her passing, Candis was serving on the ALDA News editorial review board.

Born in Washington State, Candis lived in Alaska since age 10. She was a high school prom queen and obtained a bachelor’s degree from the University of Alaska Fairbanks in 1975 with a double major in music and English. She married her high school sweetheart, and their daughter was born in 1983. Candis traveled with the Arctic Chamber Orchestra (the touring arm of the Fairbanks Symphony) during the ‘70s and ‘80s as principal oboist and English horn player. She was successfully treated for Hodgkin’s lymphoma but was deafened at age 31 by meningitis, which ended her musical career.

Candis then became active in the United Methodist Church as a strong advocate for full communication access and served terms as president of the United Methodist Congress of the Deaf (UMCD) Western Jurisdiction and the national UMCD. In 2000, when the new United Methodist Committee on Ministry with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People was formed, she was selected as vice chairperson and was a contributing author to the second edition of Signs of Solidarity, which I edited.

In 2003, Candis retired from her position as executive assistant for the Laborers Local 942 after 28 years of service. (The union represents workers in the fields of construction, transit, tourism, and pipeline maintenance.) In 2006, she obtained a master’s degree in professional writing from the University of Alaska Fairbanks, where she taught American Sign Language and English, and she also operated a retail business selling assistive technology for deaf and hard of hearing people.

At ALDAcon 1998 in Chicago, Mary Clark presented Candis with the President’s Special Recognition Award, and she received the Able ALDAn award at the ALDAcon in Santa Fe in 2000. Candis will be greatly missed by the many people she assisted and inspired over the years.

ALDA News Says Goodbye and Hello

We offer our appreciative thanks to Dave Litman, who is retiring as curator of “One of Us,” and to Carol Menton, who is leaving the Editorial Review Board (ERB) after many years of service. We welcome Carolyn Piper and Robin Titterington, who have graciously agreed to serve on the ERB, and Karen Krull, who is taking over the reins of “One of Us.”
Being diagnosed with neurofibromatosis type 2 changed everything for me. Not only did I learn that I had an incurable disease, but I also lost my vision a couple of days later because of it.

When I was only 13 years-old, a tumor was found compressing my brainstem. Along with this large tumor, there were many others and I was diagnosed. I needed emergency surgery to remove the tumor. My parents and I were very frightened by all of this, but we knew what had to be done.

The surgery took 14 hours, and the doctors were uncertain that I would survive it. When it was over, I was in the ICU on a ventilator, and I lost the hearing in my right ear. I wasn't sure whether I could see and thought that maybe I was so tired that I had my eyes closed.

Eventually I let everyone know that I couldn’t see. The doctors were not sure what happened to make me lose my vision. I was sent to the ophthalmologist and notified that I was blind. This was such a scary time, but I managed it.

A social worker did everything she could to help. The services for the blind came and talked to me and my parents and I began adjusting to a life without my vision.

Although I was deaf in one ear, I had perfect hearing in the other one. I did exceptionally well for being completely blind and only having one ear. Everything was good—until I got pregnant with my son two years ago and began losing my hearing. An MRI after my son was born showed that the schwannoma on the hearing nerve of my good ear had doubled in size while I was pregnant. But even though my hearing was no longer perfect, it was still manageable.

I was hoping that since I was no longer pregnant, I wouldn’t lose any more hearing, but that wasn’t the case. My schwannoma continued to grow rapidly for the next year or so. Six months after my son was born, my hearing dropped yet again and my speech recognition went down a little, too. I knew that deafness was going to happen in the end. There was nothing that any doctor could do to save my hearing.

I had surgery on my deaf side to remove a tumor that was pressing on my brainstem. I was also supposed to have an auditory brainstem implant placed so that when the hearing on the other side was finally complete-
NF2 and Communication

By Kathie S. Hering

Editor’s note: This article originally appeared in the ALDA News, May-June 1991. Kathie was a co-founder of ALDA and served as president of ALDA-Chicago for many years. She died in 2004.

My hearing loss was caused by neurofibromatosis type 2, which is manifested by bilateral acoustic neuromas (benign tumors on both auditory nerves.) The auditory nerve is just one of the 12 pairs of cranial nerves attached to the base of the brain. These nerves each have a specific function, such as hearing and balance, swallowing, breathing, and facial movement. Acoustic neuromas vary in size, location, and rate and direction of growth. Generally, they grow from within the auditory nerve and swell outward. They often twist around neighboring nerves and damage other neural structures. Treatment of acoustic neuromas invariably means their surgical removal by a neurosurgeon or neuro-otologist.

Because the acoustic nerve lies adjacent to the facial nerve in the brainstem, the tumor’s growth and its subsequent removal often result in damage to both structures. Thus, surgical excision of a tumor on each acoustic nerve often leads to partial or complete facial paralysis. However, current advancements in medical technology now make it possible for the surgical team to sometimes preserve some hearing and/or facial nerve function.

The auditory nerve carries sound information from the cochlea to the brain, where it is interpreted in a meaningful way. Thus, surgical removal of this cranial nerve results in complete deafness. In other words, the organ of hearing (cochlea) is perfectly intact, but the acoustic message cannot get beyond the cochlea to be interpreted by the brain. This type of hearing loss is referred to as “retrocochlear” because the damage occurs beyond the cochlea.

As a result of this total loss of sound, I am noisy. I slam doors and cabinet drawers—not out of anger, but to be sure they are closed. Occasionally, in the “right” rooms, I can feel strong vibrations. Yet I can stand next to the roaring engines of an airplane or train and not know if the engines are on or off. No hearing aids, cochlear implants, or assistive auditory devices can help me hear sounds. It is with this complete absence of sound that we cope daily. And it is this reality that makes it so aggravating when well-meaning “others” suggest that we purchase a hearing aid or at least “test for” a cochlear implant, a device that was developed for people with defective cochleas but intact auditory nerves. With NF2, these conditions are reversed, making hearing aids and implants worthless. [Editor’s note: since this article was written, auditory brainstem implants have been developed for NF2 patients undergoing tumor removal surgery, but they do not provide as much sound information as cochlear implants.]

Like all late-deafened adults, I must rely on my vision to communicate. Speechreading was easier when I still had some residual hearing. At one time, I tried a vibrotactile device, which helped somewhat when I was speaking with one person, and when there was no background noise. But to communicate in everyday situations without auditory or tactile clues, I must rely entirely on visual communication, which for me includes sign language and text reading.

Interactions with other ALDAns can sometimes present a challenge for me, especially if the encounter is with an experienced speechreader. Although I have lost most facial movements, I am not a hostile groucher or as exceptionally serious-minded as I appear to be. I simply don’t have the facial movements required to appear friendly and amused by the jokes people tell me. I am difficult to speechread, and some of my interactions with ALDA friends are slowed down a bit. To compensate for this lack of facial movement, I try to choose my words carefully, sign in a lively fashion, show enthusiasm, and use friendly gestures.

Because NF2 tumors can occur without any identifiable pattern elsewhere in the central nervous system, a person with NF2 can become extremely discouraged after multiple brain surgeries. There is always a life-threatening fear prior to brain surgery, whether it’s the first or fifth operation. Our emotional energy can be depleted by the battle with fear.

For the most part, I’ve learned to deal with NF2, my deafness, and the fear of multiple brain surgeries by cultivating:

- A sense of humor—I’ve learned to laugh at absurd situations, such as entering an operating room and being asked the million-dollar question, “Can you read lips?” Never mind that everyone ahs put on their little blue mask.
- Knowledge—I try to learn as much about the surgery as I can handle.
Hearing Loss as a Second Disability

By Rosemarie Kasper

For most of the first half of my life, being a full-time wheelchair user was my major preoccupation. Searching for accessible entrances to public buildings, many of which did not have one, was both frustrating and inevitably confining. As the lack of physical access gradually lessened—largely due to the ADA (Americans with Disabilities Act) and other laws, a new medical disorder asserted itself: hearing loss.

Both disabling conditions were due to my having osteogenesis imperfecta (OI), a genetic disorder that causes brittle bones, short stature, and related problems. Quite recently, it was determined that more than 50 percent of individuals having OI also experience hearing loss. My loss became apparent in my teens.

Initially, my parents attributed my turning up the volume on radio and TV to a youngster’s fondness for loudness. Ultimately, tests proved otherwise, and at age 18, I received my first hearing aid. It was not a thrill but helped to some extent. Through the years, my hearing aids were upgraded in accord with my needs and with improved technology. I also learned the value of wearing binaural aids and regretted not trying them earlier.

Then in 1985 the unthinkable happened: I suddenly lost total hearing in my right ear. It was a spontaneous medical occurrence and caused me immense anguish by greatly decreasing my communication ability. Whereas earlier I had been commended for my good speech discrimination, this changed dramatically—partly because I could no longer benefit from wearing two aids. With the encouragement of a friend, I registered for a lipreading course and then we both took lessons in sign. Nothing helped significantly, although knowledge of basic sign language has been helpful in certain circumstances.

I learned to expect far more surprises with a hearing loss than with the wheelchair. Normally, if I am able to enter a building, there are no further problems—unless the elevator is down. With a major hearing loss, there can still be a variety of difficulties. An assistive listening system may not be functioning or may not even be set up. Assistive listening devices are not always available for tours, and printed information is frequently lacking. Previously, captioning was rarely available, and I was not capable of benefitting from sign language interpreters.

Even the availability of captioning was—and sometimes still is—not helpful. With Rear Window captioning at the movies, it was difficult to hold the device and watch the movie—so much so that I rarely attended. [Editor’s note: the device was designed to be placed in the cup holder next to the patron’s seat, but a wheelchair user does not have access to a cup holder.] However, my advocacy and especially that of my friend Arlene Romoff, a crusader in theater access for people with hearing loss, helped to alleviate this difficulty, and a special holder was developed for wheelchairs!

The captioning of live theater was a tremendous step forward except for the occasions when I discovered that the captions were not readable from the area designated for wheelchairs! Usually, for safety reasons and as mandated by the fire department, wheelchairs are situated on an aisle near an exit, and the location cannot be changed. On one unforgettable evening, an attempt at relocation was made and my friends and I were led to THREE different areas, each...
Learning Sign Language

By Donna Maderer

Well, I’ve never been tremendously talented in the realm of learning other languages. In high school and college I took German, but there was no conversation practice and none recommended, so after many years the best I could do was read German newspapers. On trips to countries where the language is spoken, I was invariably not understood. A German acquaintance allowed that I was undoubtedly fine, whereas “Austrians don’t speak the language correctly.” Very generous of her, I thought. Generous to me, that is.

The biggest stumbling block I’ve found in learning ASL, or any other language for that matter, is grammar. I’ve a hard enough time stringing a coherent, grammatically correct sentence together in English, let alone doing so in a language with a different bone structure!

As I struggle to learn this new language, I think of my mother’s struggle when she was a child. Her parents were Italian immigrants who lived in an all-Italian neighborhood. She heard English for the first time when she started elementary school. Little Lucia learned by watching other children. When a classmate would say they were going to the water fountain, she came to understand that water equaled agua. Immersion learning is scary and, for us late-deafened folk, not generally possible, but it does seem most effective.

In any case, I knew that I would be losing my hearing completely (I’m 51 and have been completely deaf for about 4-1/2 years now), so I attempted to prepare by enrolling in a couple of ASL classes at the local adult education center. Unfortunately, both classes were geared toward people with hearing, and my hearing had, by that time, degraded to a point where I couldn’t understand what the teacher was saying (I was mostly fine in one-on-one discussions but not in groups). The instructor’s lecture and class discussion were garbled and incomprehensible. I also felt intimidated by all these young, healthy, hearing individuals who were mostly taking the class because they thought ASL was cool. This was a fun class for them but a survival method for me.

My family and I went on to hire a tutor who came into our home to work with all of us. This served to break the ice and put us on similar paths in our learning. Our goal is to gain greater facility with signing so we can have better, more complete communication. In order to avoid becoming overwhelmed—and that state is far too easy to find myself in—I need to remember that this is my primary focus.

We currently communicate using a combination of methods—signed English, notes, and lip-reading. We strive to improve our respective sign vocabularies and refine our grammar, but for now, our mélange method serves us well. I suppose we’ve created our own cobbled-together sort of language.

Unsurprisingly, I’ve found that using professional interpreters for my medical visits is not as helpful as I would have thought. Even though the interpreters I’ve used understand that they need to sign slowly for me, they’re using straight-up ASL. That’s splendid for those who are fluent but not so much for me. I get the essence of what’s being communicated but miss many of the details. To get around this, I either bring along a family member instead or, when one isn’t available, ask the doctors to write down what I can’t lipread. [Editor’s note: interpreters can be asked to use signed English instead of ASL.]

This, amongst many other reasons, is a motivator to learn more and become fluent in ASL. Not too many folks speak my family’s secret language.

Yet.

Donna was born during the “I like Ike”/Lenny Bruce/McCarthy years in your basic large, Eastern seaboard college town. Subsequently, she grew up in about 8,000 other similar towns. After years with a traveling carnival, selling fireworks on street corners, dispatching trucks and, for a seeming eternity, working as an artist’s model, she found her home in the printing industry. She can be contacted at Grantmad@aol.com.
I omitted the fact of my blindness. I did not lie about it, because I was never asked. Now I feel safe knowing that I won’t fall. It’s not hard to use the chair without vision, either. People just need to learn that even though a person is blind, they can still do more than most assume.

Communicating is very difficult now. There is a method called “print on palm,” in which a deaf-blind person holds a hand out flat and the other person uses a finger to “write” the letters on the palm. Another method uses a card with print and Braille letters. The sighted person puts the deaf-blind person’s finger on the appropriate letters. There is also a piece of technology called the deaf-blind communicator. The problem is that it’s very expensive and not available to most deaf-blind people. When I am able to afford one or receive funds to get one, life will be so much easier. Then I won’t feel as trapped in my own little world.

Neurofibromatosis type 2 has taken many things from me, and I am still very young. The only thing I can hope for is a cure some day or at least a way to fix the hearing problems caused by nerve damage. Now, I’m deaf and blind in a power chair, but no matter what happens next, I will manage.

Holly Alonzo lives in Arkansas with her husband and son. She became deaf-blind as a result of neurofibromatosis type 2 but does not let her disabilities hold her back. More information about her is on her website, www.hollyalonzo.com, and she can be contacted at holly@hollyalonzo.com.

NF2 and Communication

ask questions and expect answers. I want to know what to expect. Knowledge leads to assertiveness and the patient (including a deaf one) has the right to know what is happening and a right to communication!

• Faith and a firm belief that everything will be all right—I have developed a philosophy that it’s just another part of living, another of life’s many challenges.

NF2 is just one of the many causes of adult-onset deafness. Yet each etiology brings with it a unique set of challenges. Awareness of these challenges enables us to become more open and supportive toward each other.

But I got through groups and all was well in that area. What wasn’t so well was the propensity for my roommate to be in the bathroom every time I needed to go. We had a rule that, if neither of us were in there, the door was to be left open, since I couldn’t knock to hear if it was occupied. So I sat there, gyrating my hips to discourage an accident, and when she finally stepped out, it felt like victory!

The rest of my four-week stay had its ups and downs, but I learned a lot from that initial hospitalization. I learned that as a deaf woman, I would most likely always have to educate people. I learned that many people don’t believe me when I say I can’t lipread—especially since I have such a clear voice. And I also learned that a human being can hold her full bladder for 3.5 minutes.

Being deaf? Not easy. Being mentally ill? A true challenge. Being both? Justifiably painful. But the fact is that it’s doable. Although it’s not as simple as using a Band-Aid and a lollipop to make it better, with friends like those we find in ALDA, we can get through any obstacles. Even multiple ones.
ALDA Mom Gets Older and Better

Editor’s note: Mary has written a series of “ALDA mom” articles over the years, chronicling her experiences for ALDA News readers.

Boo! It’s Halloween and the holiday I hate the most. I would just get so sick of school parades, parties, making cupcakes the night before Halloween, costumes, trick or treaters, and buying candy (usually having to go out a second time after running out of three bags) that I grew to dislike it! Tonight I skipped it for the first time in 28 years, as both Emily (who is 16) and I had other plans. I did feel a bit sad, though (maybe that’s ALDA mom guilt?). I no longer had anyone who could help me pass the candy out and no longer had children asking when they could go trick or treating. I truly am realizing...the ALDA mom is getting older!

It’s been only a month since I was legally divorced, and it’s been about five months since I was hospitalized for 11 days suffering from many things related to too much unintentional weight loss. Eating was not a priority or a fun activity these past few years, so I did not do it much. I was only at the hospital for a checkup one day and thought they said, “Mary...you have lost four pounds!” I remember saying, “Wow...pretty good for an old lady like me!” But what they really said was, “You have lost 40 pounds!”

As I discovered during my hospital stay, I did not really have 40 pounds to lose. I was anemic, suffering from malnutrition and lack of sleep, and my organs were not functioning up to par. I had actually thought all along, after not feeling great, that it was just part of being an ALDA mom...stress from my mother’s death, divorce from someone I was married to for 28 years, the girls getting older and leaving the nest, everything sagging, wrinkles, and being deaf! The deaf part was last on my list compared to all the other things that were happening in my life (yes, including the wrinkles).

When I was admitted to the hospital, I had the nurse call my dad. He is 80, lives in Maine, and is my best friend and mentor. I asked him to call the girls to let them know where I was and that I was ok and no one was to worry. I was still kind of the ALDA mom trying to look after my family. My girls came immediately. I remember asking stupid questions like “Have you let the dog out? Did you feed the cat? You are hopefully not letting Emily drive my car?” (I had forgotten that it was still in the hospital parking lot, as I had driven to the hospital for my appointment and was not allowed to leave.) They were typical ALDA-mom kids...polite and helpful but thinking that ALDA mom was a bit weird. But now they became my true ALDA mom’s girls, making sure I understood things, giving me flowers, bringing their boyfriends (egad...when the ALDA mom is looking so cute in one of those hospital gowns that tend to fall off the shoulder), and helping me with the TV and the remote for the bed, which I just could not comprehend (I blamed it on my medication).

The ALDA mom’s girls finally brought me home...all three of them (Lauren, 25, Lindsay 22, and Emily, 16). They made sure I had Boost (great for getting your weight back up), a pill box so I could keep track of medication, and lots of home-cooked meals. They also let the dog out and fed the cat, while I slept a lot. Having someone grocery shop for me was luxurious. Never have I appreciated anything more!

Boo! It’s Halloween 2009. I’m still learning how to be an ALDA mom as I become older and more challenged with life events that are not always pleasant for any of us. The girls joined me in Seattle for the 21st ALDA conference, and I couldn’t have been more thrilled. They have grown up with ALDA since Lauren was 3 and Lindsay was 18 months old. Emily has never known me as a hearing person or as not doing something ALDA-related. They have accepted me for who I am, including deafness and wrinkles. I am a very lucky ALDA mom. Growing older...getting wiser...definitely getting better!

Mary Clark has served as ALDA president and Region 2 director. She is a former teacher for the deaf and hard of hearing. She has also worked in social services and served in various administrative positions for agencies and companies that work with people with disabilities. Presently doing consulting, she enjoys hooking (yes, you read that right, but it’s rug hooking), reading, volunteering, entertaining, and traveling. She has lived in a 120-year-old Victorian house for 23 years in the Frank Lloyd Wright district of Oak Park, Illinois and presently resides with her daughter Emily, Cooper (a puggle), and Belina (a cat). Mary’s email address is ldmpoppins@aol.com.
One of Us

By Dave Litman, Curator

Laurie recently attended her first ALDAcon and truly embraced the philosophy of “whatever, works, works!” She lives in Tennessee with her husband and helps run the family business. Laurie has been president of her local Hearing Loss Association of America (HLAA) chapter and works hard to make sure that individuals with hearing loss have access to the tools they need to be successful. Enjoy reading why Laurie is truly “one of us.”

Name: Laurie Pullins.

Where were you born? Columbus, Ohio.

What is your current residence? Maryville, Tennessee (at the foothills of the Smoky Mountains).

What is the cause of your deafness? Unknown.

Age/year you became deafened? My hearing loss was discovered when I was about two years old.

Marital status? Married to a wonderful guy, Steve.

What is your present job? Accountant/chief financial officer for a small company.

What is the worst job you ever had? I never really had a “worst” job...but I did work as a coat check girl in an Italian restaurant where I normally worked as a busgirl, and didn’t like that too much because I worked in a closet!

Movies you want to see again? Dr. Zhivago and old movies that are now captioned.

Books you tell others to read? Same Kind of Different As Me by Ron Hall, The Hole in the Gospel, autobiographies, and books by Nicholas Sparks, James Patterson, and Tom Clancy, just to name a few.

I stay home to watch: The news, Oprah, Law & Order, American Idol, and most recently Glee.

Favorite pig-out food: I only get to name one? Oatmeal cookies, homemade pies, homemade bread, and chocolate (curator’s note: I guess you can name more than one).

Hobbies: Quilting, reading, line dancing, walking my dog, and traveling.

If I had more free time, I’d: QUILT! (Whew, I thought she was going to say she would QUIT!)

The hardest things about becoming deafened are: Not getting the “message,” not understanding every-thing that is being said, having others translate for me (TV shows, movies, speakers, and someone with an accent, beard, or mustache), asking people to repeat or to take stuff out of their mouths (cigarettes, pacifiers, suckers, etc.) so I can read their lips. Nodding my head and laughing at punch lines in jokes when I don’t understand or catch every word, nodding my head in conversations as if I understand what is going on, “faking it,” and the like.

I began accepting my deafness: As a young adult. The turning point was when I got my first cochlear implant in 2005, embraced my deafness, found my group (other persons with hearing loss), and got involved in HLAA. It was then that I realized there were others just like me who had had the same struggles that I did growing up because we did not fit into either the hearing world or the deaf world since we were oral, mainstreamed, and got by with what little hearing we had.

The worst things about deafness are: Trying to hear in a hearing world. Not fitting into either the deaf world or the hearing world but being in between.

The best things about deafness are: The silence when I sleep at night, and being able to selectively “turn off” my ears!

How did you learn about ALDA? Through some friends who went to ALDAcon the year before I did (Jennifer Thorpe and Abbie Cranmer), and through ALDA’s booth at the HLAA convention.

In what ways has ALDA enhanced your life? I gained new friendships, heard some wonderful speakers, and obtained a wealth of new coping skills.

When I am depressed, I: Sleep or vacuum/clean.

My most irrational fear is: Not being able to hear in the dark or not being able to be alerted to an emergency when I have my “ears” off at night.

If I could hear again, the first things I would do are: Call my friends and family on the phone, listen to music and books on tape, and take singing lessons.

The thing I like best about myself: I am perfect just the way God intended me to be, and I have a purpose in life...to pay it forward and help others who struggle with hearing loss because “I’ve been there.”

Nobody knows: That I was a synchronized swimmer in fifth grade. My mother put continued on page 13
ALDA—My Big Family

By Duong Phuong Hanh

I was a newcomer at ALDAcon. What surprised and happy feelings I had! ALDAcon ended some days ago, but I still feel its presence around me. I received much useful knowledge and warm friendship.

This was my first visit to the U.S., and I flew alone from Vietnam to the convention. I faced the pressure of working and the sadness of my Dad’s disease and death during my application for a visa and a scholarship for attending the convention. I went through a period of wanting to give up, feeling that I could not overcome the big loss of my dearest Dad. I was encouraged by Lauren Storck, a beautiful and friendly lady who was always available to assist ALDA-Asia Pacific at any time we have needed her help. I had a friendship with Carolyn Piper, who sympathized with my sadness and helped me with the scholarship process. I am so sorry not to have been able to meet her at the convention so that I could give her a big hug and tell her how much I thank her. I had other ALDA friends who helped me, explained what I did not understand, and, especially, taught me how to dance. I always feel happy when I remember this, and I thank Kathy Schlueter, Christine Seymour, and Linda Drattell.

My first impression of ALDAcon is of being welcomed so warmly. I did not feel like a newcomer but like a child returning to my family. It was easy for me to throw away my shy cover and be outgoing, make friends, and have great communication. I felt touched enough to shed tears when listening to the stories of I. King Jordan and Sue Thomas. As I stated in my report at ALDAcon, someone had said to me that “I don’t believe you are a deafened person because you speak very well.” Now I can tell that person about Sue Thomas, who became instantly and totally deaf at 18 months, and what she has done [editor’s note: she used her speechreading skills in her work with the FBI]. I can also tell about I. King Jordan [Editor’s note: he was deafened at 21 after a motorcycle accident and later became the first deaf president of Gallaudet University] as well as my story of how I strive to live, study, and work in the hearing world. You see, I thought for 32 years that I was just deaf.

Being a nonprofessional social worker, or more exactly, a peer counselor and the only deaf person with this position in Vietnam, I am really delighted with the advanced and useful information that I acquired at the convention. I learned much from the workshops and will write articles in order to share this information with deaf people, their family members, and society—it is my task—in Vietnam.

ALDA—my big family—see you next year!

Hanh lives in Ho Chi Minh City, Vietnam and is a social worker with Deaf/deaf, hard of hearing, and late-deafened people. She says that when she is working with persons with hearing impairments, she feels as if she is seeing her own life. Her hobbies are reading, writing, and researching, and she can be reached at hanhdp2008@yahoo.com.

One of Us (continued)...

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me in swimming lessons to “channel” my active energy. By the time I got to fifth grade, I had taken all the lessons that I could take, so synchronized swimming was the last remaining option. I couldn’t hear the music but learned by watching the others in the water.

What I can’t stand is: Inconsiderate and rude persons. Also, people who enunciate dramatically or talk loudly when talking to me.

Favorite memories: Family times, times with friends.

Favorite sayings: “As long as I live I’ll hear waterfalls, birds, and winds sing,” by John Muir, and also one by Helen Keller that goes like this, “I am only one, but still I am one. I cannot do everything, but still I can do something; and because I cannot do everything, I will not refuse to do something that I can do.”

The bottom line is: “You are special, just the way you are!”
Deafness, NF2, and the Sea

By Roxanne V. Gasaway

At the time I became deaf, I worked in a clerical position at a medical library in Houston, Texas, which is 50 miles inland from the Gulf of Mexico. I loved the sea, so when I received word of a teletype job (perfect for a deaf person) at a steamship company, I was elated. It was my dream job, or would have been if I’d been hired. I have neurofibromatosis type 2 (NF2), and there is so much more to my story than NF2 making me deaf. I’ve also got paralysis on my left side and am a one-handed typist.

In those days, before the arrival of computers and TTYs, big, clunky teletype machines were used, and my one-handed typing was not fast enough on them. NF2 had also caused facial paralysis, meaning that I drove home from the job interview greatly limited in my ability to vent my emotions.

However, the circumstances of our lives can often be a two-sided coin. The flip side of that unsuccessful job interview came a few years later as I stood alone on a wild Texas beach with my hearing dog, Elbert, running around doing his thing. A channel had been cut across the beach from the Intracoastal Canal to the surf of the Gulf of Mexico. My father had said the channel might possibly have been cut to let fish out of a landlocked bay. What happened that one particular day seemed to prove him right.

There was no one else on the beach as I stood by the channel near the surf line. Suddenly a dolphin shot straight up out of the breakers like a rocket. That very large mammal then fell back into the water and disappeared. Perhaps it had been there eating fish from the landlocked bay. I was flattered beyond words and still am when I think about it because I’m as sure as I can be that this dolphin leapt up to greet me, check me out, or both. I was there with my hearing dog nearby because of my NF2, and that experience is a wonderful memory.

Roxanne is a native Houstonian who has lived in Georgia and the Atlanta area for almost 25 years. She has been a member of ALDA-Peach since its beginning ten years ago and has been to one ALDacon. Her email address is ryvang@mymailstation.com.

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ALDAcon Award Winners

By Nancy Kingsley

The awards luncheon was held on October 17. Kim Mettache announced that Mary Lou Mistretta was the recipient of the Able ALDAn award. Kathy Schlueer presented the president’s special award to Patricia and Roy Graves of Caption First, which provides communication access. Pat, a Fortune 500 award winner, began losing her eyesight about 18 months before ALDAcon and said that her experience paralleled ALDAns’ experience in losing their hearing.

Two additional awards were made that night at the I. King Jordan banquet. First, Jane Schlau presented the Bob Davila Angel award to Kathy Evans. Two years ago, Jane was the planning chair for a conference in Rochester, and the program chair dropped out of sight. Kathy took over and helped manage the program to make that conference successful. Kathy and Jane both volunteered for this year’s program committee and when Jane unexpectedly became busy with a new job and a move to another state, Kathy took care of whatever that Jane couldn’t do.

Lois Maroney received the I. King Jordan award, ALDA’s most prestigious. It goes to someone who contributes not only to ALDA but also to others with hearing loss. Lois was originally a foreign language teacher, but after losing her hearing, she became a mental health counselor. Lois was the founding president of ALDA-Suncoast and has served on the ALDA board as region director, secretary, and president. She was a member of the External Advisory Committee of the Department of Rehabilitation and Mental Health Counseling of the University of Southern Florida. In addition, she was appointed to the Committee to Advocate for Persons with an Impairment (CAPI) and became chairperson in 2008, and she was also appointed by Florida Governor Jeb Bush to the Americans with Disabilities Act working group. She is on the Florida Coordinating Council for the Deaf and Hard of Hearing and the Florida Interagency Coordinating Council for Infants and Toddlers. She won the JC Penney Golden Rule award for recognizing a need in the community and responding to the need by initiating services for late deafened people. [Editor’s note: Lois’ acceptance speech is in this issue.]

The evening’s award presentations were followed by ALDA’s first Friday Night Live! Auction, which raised over $1000.

Photos by Ken Arcia
King is a hero to me. He has helped many people to believe that Deaf people can do anything! To be the recipient of an award in his name feels awesome! When my family decided to learn sign, a woman who is deaf came to our home and taught us. One day, she took me aside and said, “Read this,” and with a fierce look of determination, as if her will would now become mine, she signed, “Deaf people can do anything and so can you.” She held a newspaper article in her hand, and I could see it was very precious to her. I read about the students at Gallaudet, who felt the time was right for a deaf president, and they were not afraid to stand up for that belief. And of course, King became that first deaf president.

I remember thinking, “I want to take a stand for things I believe in. I want to feel good about becoming deaf.”

When I told my husband Patrick about this award, he said, “I want to be there, and the children will want to be there, too.” I started to say, “It’s too far” (we live in Florida) and “Everyone is too busy with work to take time off.” He said, “This is a family award.” What could I say! He was right. We, the late-deafened ones, sometimes forget that our family is also dealing with late-deafness and our triumphs and successes are also theirs. My family has often told me how proud they are of me. I want to let them know tonight how proud I am of them as well and share a few memories. My husband and I just celebrated our 35th anniversary this summer! We met in college. We married two weeks after we graduated, and seven years later deafness came knocking on our door.

One of the many reasons I love ALDA is the “whatever works” philosophy. Each family searches for what will work. For my family, sign eventually became the answer. I remember the night my husband started talking and I said “Hold, I will run and get my aids.” My aids were in the drawer. For good reason, too! They stopped being effective for me. He said, “That’s ok—you don’t need them. I will sign to you.” He understood, too, that the aids were just not enough and we would need a new way to communicate. The sign we were learning from books would now become real life for us. I knew at that moment that I would be ok and that we would be ok as a couple. We had problem-solved how we would communicate.

I remember the time I was vacuuming and my son Dan and three of his college friends entered the house. The friends looked at me, and their eyes were open wide because I was pushing a vacuum and it was off. Let’s just call it deaf vacuuming! I then pushed the vacuum to what I thought was “off” so I could greet them. But instead, I pushed it to “on” and was trying to talk to them. Their eyes were now as wide as possible! Dan walked over and hugged and kissed me hello, and I felt his hand reach down and turn off the vacuum. It was then that I realized what I had done, and when I took that deep sigh, he just hugged me even more and introduced me to his friends. No teasing, no look of embarrassment, just a look of love and acceptance, like “This is my Mom!”

When my daughter Meghan was in high school, the local chapter of ALDA asked the teenagers to write about their experience having a late-deafened parent. So Meg sat down, typed up an article, said “finished,” and sent the email off. I asked her if I could read it and she said, “Sure.” I learned for the first time what happened years ago on a family ski trip. We were skiing on Christmas day and a young worker at the ski resort said “Merry Christmas” to me, but I did not know. The person then called me a “witch,” only it started with a “B”! He probably thought this cute girl behind me would agree.

Well, that cute girl was Meghan. Meg told him, “That’s my mom and she is not a ‘witch’—she is deaf. She had no idea you said ‘Merry Christmas’ to her.” When I read that article, I wondered how many others she helped to educate about deafness.

My daughter-in-law Sara is not here tonight and is with our grandchildren. My son-in-law Matt is here. Both of them took sign language before they married Dan and Meg, and both do

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Pictures from ALDAcon 2009

ALDAcon karaoke singers

Bernie Palmer and Robin Titterington at the ALDAcon President's Dance

Bidding at the ALDAcon Live! Auction

Photos by Ken Arcia
I. King Jordan Award Acceptance (continued)...

so well with including me in conversations. What was so amazing is that when they said their wedding vows, they both signed them. They could have just left it for the interpreter to do, but they chose to sign and include me in that very special moment in their lives.

And now I want to introduce my family to my ALDA family. I feel I share this award with my ALDA family, too. I don't know each person in this room, but in many ways I feel like I do. We share the same experiences and many of the same feelings about becoming deaf.

When I was president, I worked hard to increase membership and help the organization to grow, but at the same time I kept thinking, “Be careful—you may get what you pray for.” I say that because there is something so very special about our organization. We are small but very effective. I am in a room full of advocates and leaders. You have taught me, you have role modeled for me, you have inspired me! The advocacy work you do in your community makes the advocacy work in mine so much easier. Together, we are making a difference. We are making this world a captioned one. And why, because we can! The technology is there to do so and the work is ours to make it happen.

I want to share a memory that motivates me to do as much as I can each day. At the time of this memory, I had had two jaw surgeries, was in a lot of pain, and was becoming deaf. I would wake up every morning, help the children get ready for school, drive them to school, come home, and clean up. Then I would go back to bed. I didn't feel there was anything else to do. And I would sleep until it was time to wake up and pick them up from school. At that time, I really had no life beyond being a wife and mother. I am sure my children would say I was a wonderful mother and I am sure my husband would say I was a wonderful wife. But where was I? I was becoming invisible. I had no idea how to live my life deaf. So I slept.

Finally, like King, I had that decisive “I am deaf” moment. I was not looking in a mirror like King; instead, I was looking up at the heavens. I had just left a very frustrating appointment with my doctor, and I knew deafness would not go away. So with a lot of attitude, while looking up at the heavens, I said, “OK, have it your way. I will be deaf, but you better help me.” From that moment on, everything fell into place. All of the things I needed to do I started to do. I started learning sign, went back to school to become a counselor, went to the Deaf service center and volunteered to start services for late-deafened people, and started ALDA-Suncoast of Florida. Then I went to my first ALDAcon. Things just kept getting better and better!

Years ago, when that stranger deafness came knocking on my door, I thought he came empty-handed. I did not realize that he came with many gifts. He brought many wonderful people into my life. He brought me you!

Thank you to the ALDA Board of Directors, and a special thanks to Jane [Schlau] for nominating me, for the support you gave me during my president's year, and for your friendship. Thank you to my husband, my children and my family, for your love and acceptance. Thank you to my ALDA family and thank you to King for inspiring me to believe that deaf people can do anything!

Hearing Loss as a Second Disability (continued)...

with a progressively worse view! We missed a large portion of the first act before finally reaching a place where the captions were marginally readable.

A basic problem is that many theaters do not anticipate that a wheelchair user might also be hard of hearing and thus do not attempt to set up the captioning in a suitable area. Unless the theater is one with which I am familiar, this means that arrangements must be checked out as far in advance as possible.

Overall, coping with hearing loss in addition to using a wheelchair has impressed on me the fact that the most formidable accessibility problems may not be visible. Expecting the unexpected and having the patience to persevere and follow through are invaluable to a fulfilling life.

Rosemarie received her bachelor’s and master’s degrees from Fairleigh Dickinson University, Teaneck and was a senior rehabilitation counselor with the New Jersey Division of Vocational Rehabilitation until retiring. She founded the New Jersey osteogenesis imperfecta (OI) support group 18 years ago and remains its co-chairperson. She is also a co-leader of the Hearing Loss Association-Bergen County chapter and serves on the advisory board of the Bergen County Division on Disability Services. She has received awards from the latter two groups as well as from the national OI Foundation. Rosemarie lives in Hackensack, New Jersey and enjoys traveling, reading, and writing. She has published many articles on disability issues, and her advocacy focus has shifted from wheelchair to communication access. She can be reached at rdkoif@verizon.net.
Introducing Ann Smith, New “Chapter Happenings” and “GA to SK” Curator

*ALDA News* takes pleasure in welcoming our new curator, Ann Smith, whose first columns appear in this issue. (Anne McLaughlin, the previous curator, has retired.)

Ann grew up hard of hearing and finally declared herself “deaf” while in her 30s. By then, she could only hear loud claps of thunder when wearing her powerful aids. She attended public schools, college, and graduate school with no accommodations—this was before the Americans with Disabilities Act. Ann has a supportive biological family but was delighted to find another, “just like me,” family in ALDA. She has served as president, treasurer, and secretary of ALDA-Peach in Atlanta. Ann also loves reading and watching her ten favorite soccer teams play.

**Chapter Happenings**

*By Ann Smith, Curator*

Francine Stieglitz reports that ALDA-Boston has had a busy fall as usual. In October, ALDA-Boston participated in the Hearing Loss Association’s Walk4Hearing. On November 15th, Dr. David Vernick, M.D., an otolaryngologist, gave a talk on hearing, balance, and medication. Because funding for CART services has been drastically cut, ALDA-Boston joined with other HLA groups in the larger Boston area to share CART expenses. This was the chapter’s first joint venture, and others are planned for 2010. On December 6th, Lou and Linda Sakin are hosting ALDA-Boston’s annual holiday party in Framingham. This year, there will be secret entertainment, and details will be posted at [www.aldaboston.org](http://www.aldaboston.org). January 10th will be the annual brunch, which will be held at the Westford Regency.

Cynthia Amerman reports that ALDA-Sonora completed its first year with a meeting in Surprise, Arizona on November 7th. Marta Watson, who attended the convention in Seattle, communicated her enthusiasm for ALDAcon to the group. At the ‘con’s Friday Night Live auction, she sold a beautiful blue hat she had knit when she first became deafened. The same night, representing the International Committee, Cynthia auctioned off a jester’s mask from Venice. Two more ALDA-Sonora members appeared at the ‘con as well: George Ghorpade and his hearing dog, Rover. Marta recently created the group’s newsletter, *ALDA-Sonora Desert Vibes*, which will be published on the website, [www.aldasonora.org](http://www.aldasonora.org), which was designed by Lloyd Bentley and his friend Barry Worrell.

Among ALDA-Sonora’s plans for 2010 are a gathering in the holiday spirit at Marta’s in January, a trip to a captioned performance in Phoenix, a workshop in Tucson in May, and several meetings in and around Phoenix. ALDA-Sonora has been lucky that the city of Surprise funded CART for the group, and CART provider Karla Martin has done pro bono work as well. ALDA-Sonora is considering becoming a chapter but first needs to get its 501(3)(c) status.

Ann Smith reports from Atlanta that ALDA-Peach celebrated its 10th anniversary on November 14, 2009. ALDA President Kathy Schlueter and Regional Director Dave Litman attended; Kathy and her mother drove 830 miles one way from Illinois, and Dave came from his home in Charlotte, NC. Peach member Marie Drew flew down from Pennsylvania. ALDA-Peach President Marge Tamas was mistress of ceremonies. She, Robin Titterington, and several long-time Peach members spoke briefly about the history of ALDA and the Peach chapter and what ALDA-Peach has meant to them. Kathy Schlueter read the President’s letter honoring the chapter and proclaimed November 14th ALDA-Peach Day. Interpreter Thai Morris and CART provider Heidi Thomas donated their services for the event. The chapter presented a special award to Robin Titterington, who worked diligently to establish ALDA-Peach and served on its board as president, vice president, treasurer, and member-at-large, as well as being chair of the anniversary party committee. ALDA-Peach’s refreshment chair, Mary Platt, planned and prepared a fabulous feast, and Belinda Miller baked an especially appropriate dessert: peach cobbler. Dr. Stevie Dirst provided party favors featuring tin, the traditional 10th anniversary gift. Webmaster Steve Tamas created a slideshow of photographs of ALDA-Peach members through the years, and
Bonjour to all, hello!

It was an enormous pleasure for the International Committee (IC) to be part of ALDAcon in Seattle, and we hope many of you enjoyed our truly international presentation.

Hanh from Vietnam offered beautiful greeting cards from the ALDA-Asia Pacific (ALDA-AP) group to all attending, as well as a lovely personal message at the Thursday luncheon. At that lunch, we also were happy to have the ALDA-AP president, Akram, participating via remote CART. In fact, he was with us in real time (although far away in Pakistan) to hear himself receive the “Fearless Leader” award from ALDA this year. Congratulations to Akram! And special thanks to Caption First, which set up remote CART for us (Pat Graves is a wonderful professional, as we all know!).

By the way, why not mention ALDA to any friends or contacts you have in other countries? We’d love to chat with them about ALDA and possibly form a group in another international region.

The IC is currently thinking about loop systems, which are apparently used in many other countries, even in some London taxicabs! There is so much to learn from each other. One informational site we found is http://www.hearingloop.org/.

We are eager to hear from anyone who enjoys international discussions about hearing loss. While the Committee itself is full, there are many opportunities and ways for us to keep in touch all year. Where do you live? Where are you traveling? Talk to us!

ALDA best,

Lauren, chairperson of the ALDA International Committee

Lauren E Storck, PhD
Advocate for Accessibility Equality
drlestorck@gmail.com
http://drlestorck.googlepages.com
Twitter: siglmgga
LinkedIn: L.E.
People Say I Am an Inspiration

From the time I was conceived, I believe God has had His hand on my life. I was born on December 22, 1954 to a 20-year-old unmarried woman in Miami. Her father held an office in the local church, so the decision was made to send her to a home for unwed mothers. When I was born, I had what was termed a “large head.” It was suspected that I was mentally retarded, which made me unadoptable by the standards set up by the state at that time. I was taken to the home of Homer and Ophelia Kimball, a local couple who had been foster parents for years. They specialized in caring for sick babies and had one birth son, Ronald, who was 12 years old.

(My birth parents later married and had two boys and three girls. The marriage lasted 12 difficult years. Alcohol abuse by my birth father was the main problem. After their divorce, my birth father moved to Illinois and was not seen again by his children for many years. My birth mother never remarried. Years later, when I found my birth family, my siblings told me, “If you grew up in a normal family, consider yourself lucky. You were better off where you were than with us.”

One of the agreements foster parents made back then was that they would never try to adopt any of their foster children, an agreement that has long since been done away with. My foster mother told me years later, “I never had an attraction to any other baby I had kept, but from the moment I looked into your eyes, you were mine.” Every three months, the caseworker for the state foster parent system would come to the house to move me to another home to insure that the Kimballs would not get attached to me, and Mrs. Kimball would tell her, “He is sick and I know how to care for him. Leave him here.” This went on for five and a half years.

One day the caseworker took me for an IQ test. The next day she came to tell the Kimballs, “Timmy tested normal and I have the authority to pick him up at any time. He is adoptable.” The Kimballs decided to fight to adopt me. Early in 1961, they had their day in court before an adoption judge, who said, “Mrs. Kimball, when you became foster parents, you and your husband agreed to never try to adopt any of your foster children. Why should I now go against that agreement and let you adopt this little boy?” She looked at the judge with tears in her eyes and replied, “I am the only mother he has known for six years. If you take him away, you will kill him and me.” The judge said, “That’s good enough for me,” and signed the adoption papers. God put me in the home He wanted me to be in.

My father owned an automobile upholstery business, and every summer I would go to work for him. When I graduated from high school, I went to work full time managing the business. The summer after graduation, I moved with a friend to an apartment. At the end of that summer, my roommate told me he was getting married, so I asked my parents if I could move back home. They had begun attending church and told me the one stipulation was that I had to go to church with them.

I agreed and moved back. I did not know at the time that both my Dad and Mom had received Christ into their lives during that summer. The first time I stepped into the Pinellas Park Church of God I was nervous, not knowing anyone or what to expect, but the first people I saw were two of my closest high school friends and their parents, who had been members of the church for years. I eventually began to feel God pulling me toward His Spirit, and at the age of 18, I gave my life to Christ. Soon after getting involved in church, I met my future wife. We were married in 1973 and have two daughters and two grandchildren.

As time went by, Dad became sick with rheumatoid arthritis. His feet would swell until it was impossible for him to put on his work shoes. He would wear bedroom slippers to work and stand at his workbench whistling church songs eight hours a day with tears running down his cheeks. That is where I get my strength today, remembering my Dad at that workbench. I left the shop to try some things on my own. I managed Red Lobster restaurants for a few years, and when the girls got to school age, I went to work managing a concrete plant. Later that year, my Dad could no longer work and I agreed to purchase his part of the business, making my brother and me partners. The only way my brother would agree to being in a partnership with me was for it to be a 51 percent-49 percent split with him holding the majority share. I ended up being nothing more than an employee for my brother for the next 10 years.

In 1988, when I was 29, I began having a stabbing pain in my right thigh just above my knee. After a few visits to an orthopedist, I was told the problem was more neurological than orthopedic, and I was referred to a neurologist, who ran tests and said I had a form of muscular dystrophy called Charcot-Marie-Tooth disease, a non-fatal type with slow progression. Over the next year I began wearing a brace on my right knee, which was beginning to give out without warn-

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ALDAnonymous

By Bill Graham and Robin Titterington, Curators

With several phone choices now available—CapTel, VRS, cell phones, etc.—how do you communicate by phone? Is there a phone application or service that you would like to see available?

I became deafened long before even relay service, so I am thankful for what we have. Yet the more we get, the more I want! Now I wish the voice carryover (VCO) process were easier and did not require “call backs” for video phones.

The service I would like to see available, and that I have been advocating (read nagging) for, is MOBILE CapTel. I want to land in an airport and be able to call for a shuttle from my Blackberry! Getting from the airport to the hotel, or the shuttle to the parking lot—this is the most difficult part of traveling for me. Having mobile CapTel would really give me security and independence. Yes, I know it is available with the I Phone and AT&T. But I just can’t handle that virtual keyboard—I’m not too bright! I do all my own communicating via CapTel, and it has made a tremendous difference to me. I was only deaf a few years before CapTel and never got used to the TTY.

I use voice carryover through the videophone. This allows me to use my own voice on my phone and see what the other person is saying through sign language. My dream would be to have all phone calls captioned automatically when someone calls me on my cell phone.

I recently acquired the new CapTel 800i and it is 200 percent better than previous models. The captioning has few errors. It includes several “bells and whistles,” most of which I haven’t learned to use yet. As a CI user, I’m able to hear on the phone and refer to the caption screen only once or twice in most conversations. My friends say they’ve noticed a big difference in our conversations. The quality of sound is excellent and the volume control is more fine-tuned than in other models. The 800i is $99 and saves me $13 a month for a second line. Since calls go through the Internet, the captioning is there immediately on incoming and outgoing calls, with no need to dial a special 877 number. This is particularly helpful with new voices and business calls, where a customer service person may have a foreign accent.

I use Web CapTel with a cheap phone by the computer, and the new CapTel 800i in the living room. This new phone requires some extra equipment, such as a router if the modem does not have an extra Ethernet connection, plus a Powerline Network Adaptor. Out-of-pocket cost was close to $200. It is worth every penny! I do have some hearing in my hearing aid ear, and the aid can be set to “T,” which works great. But I still like to put the earpiece on my ear. The volume is much better than that of the previous CapTel, and the screen is bigger. Most of all, people can call me direct without going through a toll-free number. EVERYTHING COMES UP IN CAPTIONS! I now have voice mail, and everything is saved in captions. I also connected a lamp flasher (the ringer is turned off) so I’ll be able to answer the phone if I’m home. I am excited to know there may be cell phones in the future that will automatically be captioned. Not everyone has text capability.

Next question: Will you retain your membership in ALDA next year? Why or why not? (And if you’re not a member, why aren’t you one?)

Send your responses to Bill and Robin at aldanonymous@gmail.com by February 21.
How NF2 Changed My Life (continued)...

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My biggest struggles now are that I am completely deaf and have severe balance problems and weakness in my legs. I have taken many sign language courses, but if you do not use signing enough, you lose it (I think we all understand this). I am just not around anyone else who is fluent to the point where I can completely communicate through sign. My friends and family all know some. I lip read mostly and fingerspell. Because of my balance difficulties and weakness, I have trouble walking. I cannot run, jump, skip, or play like I used to. I have a walker that helps me a great deal. When I don’t have it, I need some other kind of support like a wall to lean on or an arm to hold onto. I struggle in crowded, congested, dark areas the most. All of this has not stopped me, though, from driving or going places by myself. I just have to prepare.

I also have difficulty using my right hand and trouble speaking. Not being able to use my right hand well is especially hard, because I am right-handed. My handwriting has suffered some and I have had to learn to sign with my left hand. Both of my facial nerves have been damaged from tumor removal and radiation therapy, and I cannot move my lips. When I speak, I use my hand a lot to move my lower lip so that people can understand me better. I just have to speak slower and clearly.

I go to doctors in Los Angeles, Boston, Winston-Salem, and High Point. I see some kind of doctor at least once a week and have to have periodic MRI scans done to check for growths.

Medical Timeline

• In February 2006, I underwent brain surgery at the House Ear Institute in Los Angeles. I had an acoustic neuroma removed and an auditory brainstem implant (ABI) implanted on my left side.

• In April/May 2006, I received radiation therapy to my brain for other inoperable lesions and went through physical therapy.

• In July 2006, I had unsuccessful surgery to repair my damaged facial nerve.

• August 2006: The hearing in my right ear had been deteriorating. I was hoping it would hang on until I fulfilled my student teaching requirement, but three weeks prior to starting, my hearing was completely gone in both ears. I withdrew from school.

• In November/December 2006, I went through more radiation and physical therapy. I also took a beginner sign language class along with friends and family.

• On January 9, 2007 I returned to LA for removal of the acoustic neuroma on the right side and placement of a second auditory brainstem implant.

• In the spring of 2007, I took another sign language class. I was in and out of the hospital for treatment of hydrocephalus. I had severe headaches, dry and unfocused eyes, and loss of most function and feeling in my right hand. I also had extreme balance and weakness difficulties that resulted in my being unable to walk unassisted. I now used a walker. Life was difficult!

• In September 2007 I began a chemotherapy drug called Tarceva, which I discontinued in May 2008 because the side effects were getting worse and worse. I wanted to feel good for an eventful summer. Fortunately, my tumors have appeared stable since I started Tarceva.

I am 27 now and would say my biggest challenge socially and emotionally is being deaf. Although I received auditory brainstem implants (ABIs) to assist with determining sound, they do not work for everyone. Mine, I feel, are more of an annoyance than anything, and I do not wear them.

Being late-deafened is life changing, far different from being born Deaf! In many ways I feel totally different from the person I was before losing my hearing. I was never a quiet, shy person. I loved being the center of attention (usually entertaining in some way) and being involved in constant conversation. Becoming deaf is lonely! Over time, I have learned to deal with the emotions I face. It has gotten better but will never be easy. I am still adjusting and all I can do is make the best of it. This is how it is going to be from now on.

I miss sound! I really miss music! I have always been one to break out randomly in song or dance. I still do so, around people I know, of course. The song is always something from my past like a “New Kids on the Block” hit or a TV show theme song. It makes people laugh, hard! I love it! I joke and say “Oh, I’m just listening to my iPod, my implanted iPod.” My iPod is constantly in full swing! I have a friend who sends me text messages saying “Ray, what’s play-
How NF2 Changed My Life (continued)...

How NF2 Changed My Life (continued)...

By sharing my story, I think I can make a great role model/mentor. Motivating others who may be struggling with something is what I am most passionate about! I try hard not to dwell on how neurofibromatosis has changed my life. I have been through more than most people go through in a lifetime. It has been a complete turn around, especially in the past four years. I have had to adjust to a life very different from that of my peers and accept a lot of changes. I am very lucky to be blessed with wonderful friends and family, with whom I share a close bond of unconditional love, support, and strength. We have stuck together and fought together. Without them I would not have the motivation, spirit, and attitude I have today.

The support shown through fundraising and donations towards research, encouraging cards from people I hardly know, and kind words shared has been amazing! Thousands of dollars have been donated to the Children’s Tumor Foundation in my name to help fund research. My oldest brother, Rusty and his wife, Crystal started a “Running 4 Ray” NF marathon team in 2006. It began with just a few friends, but in 2008 there were 12 of us participating in the Rock ‘n’ Roll Virginia Beach Half Marathon. I walked (with my walker) the final three miles with the entire NF team right behind me! In 2007 and 2008, my family organized “The Rachael Morris Pro-Am” golf tournament, an event full of familiar faces, as well as lots of strangers! Again, all proceeds were donated for research.

I have been told I am “famous.” Ha. That is because just about anywhere you go in High Point; you are sure to see a “We Love Rachael” magnet. They are big and bright red. Mostly they are on cars, but they are also in some restaurants on visible appliances. A fabulous group of girlfriends surprised me one night just before Christmas in 2006. They came to my parents’ house in the middle of the week, wearing Santa hats, and had a wrapped gift to give me. I was in shock when I opened this gift! It was one of the magnets. The girls told me they were going to be selling them for $5 each and all money would be donated towards NF research. Wow, this really took off and eventually restaurants were selling them, there was an article in the newspaper about them, and people everywhere were getting to know Rachael and supporting a great cause! There was even a MySpace page called “We love Rachael” that some anonymous friend set up. You could see pictures of me and learn my story, as well as order a magnet. I am truly grateful for the phenomenal kindness and loyalty shown to me, and I am still rockin’ because of it!

I am new to ALDA and had the FABULOUS opportunity to attend ALDAcon in Seattle. It is so hard for me to put into words how amazing it was. I gained so much from being there. I became a “confident deaf woman” for sure. I loved mostly learning that I am not the only one who experiences the insecurities and isolation that I do. You all inspired me, and I miss you. I took a piece of you all home with me in my heart! When the pity party
Silent Spotlight
By Connie Robinson

In my particular living arrangement, it seems I am the only member without a cognitive disorder. Both my husband and teenage daughter have attention deficit disorder. In addition, my husband has general anxiety disorder. And my teenage son has dyslexia and learning disabilities.

Therefore, dealing with the school, balancing the checkbook, making out the family budget, planning vacations and holidays activities, managing household repairs, planning menus and shopping, and keeping up with the car maintenance schedule has always fallen on my shoulders.

Yet, when my family and I are out and about, deafness is more visible and therefore, folks see me as the disabled one being “taken care of.”

For years, we have hosted the family Thanksgiving dinner. Family from all over came to town to break bread at our house. However, since none use sign language or are familiar with how to converse with someone who has hearing loss, it has always been assumed that my husband instigated such wonderful festivities when in reality, my husband does not even know when Thanksgiving is.

Indeed, one must grow some thick skin when living with more “invisible” disorders. It can be difficult seeing your credit being given to someone else. However, learning to take your compliments and appreciation vicariously can help. Seeing the handshakes, smiles, nods of approval, and slaps on the back given to others for my accomplishments means that people appreciated what I produced. I can still take joy in knowing that through my talents, creativity, and abilities I made someone’s day a little better.

Although hearing loss is considered an “invisible handicap,” there are quite a number that are even more so. And to that end, everyone should grow more awareness about them. Always appearing tense can be isolating for my husband, whose anxiety can sometimes get the best of him. Losing focus can give others the incorrect impression that my daughter is aloof. And the dependency of doing the simplest of math problems on a calculator can be an embarrassment for my son, who will be graduating high school this year.

Becoming bitter toward family members who are so willing to accept undue credit is wasted negative energy. If it helps them to feel better about themselves to receive approval and esteem from others, regardless of whether or not it was deserved, then shouldn’t I want that for them?

As long as I always know I am capable, not defective, not broken, and not a lesser human being because I am deaf, sacrificing my spotlight is a small price to pay to see my husband and children happy.

Connie Robinson has congenital sensorineural hearing loss and uses both speech and American Sign Language to communicate. In addition to taking care of her hearing husband and two children, she teaches Sign with Your Baby classes and is in the process of forming a new nonprofit deaf service agency in the greater Memphis, Tennessee area. She can be contacted at connie@mempho.com.

How NF2 Changed My Life (continued)...

starts calling my name and I begin feeling like “the dog underneath the table,” I take a deep breath and think of what we learned from each other and the bonds we share.

That’s my story and I’m stickin’ to it.

Rachael is from High Point, North Carolina, which she notes is the furniture capital of the world. She loves to cook, even though what is supposed to be a 30-minute meal turns into a three-hour one. Her favorite thing to do is to just be with her friends and family. Rachael also enjoys reading, crossword puzzles, creative writing, and going to Target.

**NOT A MEMBER?**
Join online at [www.aldanews.org](http://www.aldanews.org)

Or

Use the form in this issue of ALDA News
As with everything else, the meaning of words changes with time. Thanks to technology, when I say I’m “deaf” to my new doctors, they seem to confuse it with being hard of hearing, since everyone walks around with something or other in their ears.

Now, don’t worry about my seeing doctors, because I’m not sick but I’m in my 90s and this old body is not working the way it used to so I’ve had a lot of tests for one thing or another. And since I don’t have a medical degree, I have to have the results explained in plain English the way my old family doctor did.

I have a Medicare hospital insurance policy with Kaiser Permanente, and I get reams of detailed reports for every visit. The problem is that I need a medical dictionary to understand them. When I visit my doctors, I always tell them I’m deaf, but since—as a late-deafened adult—I can talk to them, they just keep on talking to me as if I can hear.

I went to a new doctor and asked her to explain my mammogram. She kept talking, and I begged her to write down what she was saying. “Doctor,” I said, “You have a computer in front of you—please use it.” No! She kept pointing to the X-ray and talking. “I don’t know what you’re saying,” I said. “Please write it down.” Finally I got mad and began stomping out of her office. Then she wrote by hand a half-page explanation and even wanted to shake hands with me. I guess she was afraid I’d sue her. Incidentally, I refused to shake hands, and I changed doctors.

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After that experience I had to go to a rheumatologist, and, again, I told him I was deaf. He proceeded to keep talking and pointing to his computer and a lengthy report. He gave me a prescription for my backache and told me to see his nurse about my next appointment. When I asked him why my legs itched, he said he didn’t know. I could read his lips on that reply, but when I asked him other questions, he started giving me technical answers. I asked him to use the computer in front of him, but he refused and wouldn’t write out what he said. I told him that according to the Americans with Disabilities Act, I was entitled to help. But he left the room, saying to see his nurse about my next appointment. My chin dropped as I saw that my appointment was scheduled for a year later. When you’re in your 90s, you can’t be sure where you’ll be in a year. Sure enough, a year later I got a notice from his office to get a bone scan and come back for another exam.

I went back to the same doctor and reminded him that I was deaf. Did it impress him at all? He just asked me why I was there and when I said, “I can barely walk. What’s wrong with me?” he answered, “osteoporosis” and other medical terms I didn’t understand and couldn’t lipread. Out he walked, saying, “See my nurse for your next appointment.” The next one was not in one year this time—it was in TWO years. I may be in a hospice at 95 if I’m still alive, but I certainly will not go back to him. So on to another doctor.

I told the doctor I was deaf, but this time I explained why I changed doctors. This one said that maybe I needed a better hearing aid. “Would you tell a blind person to get glasses?” I responded. “I don’t wear a hearing aid.” This time I got through to him and he actually used the computer to answer my questions. “Why does my hip ache so badly that I can’t walk?” I asked. “It’s all in your back and you have osteoarthritis.” Why this, why that? and he wrote, “Truthfully, we can only try to make you comfortable. It’s the aging process and cannot be reversed.” So the first rheumatologist had been right—there was no reason for him to see me again. My problem wasn’t life-threatening or some obscure disease. In some cases, a doctor can only try to make you comfortable. But the first doctor wasn’t willing to communicate this information in the way that I needed him to do.
People Say I Am an Inspiration (continued)...

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ing and causing me to fall.

In 1990, I planned a fishing trip with some friends. I left home towing my boat Friday evening after work and drove south over the Sunshine Skyway Bridge into Manatee County. When I got to the exit at S.R. 70, a dark two-lane road, I pulled up under the overpass and got out to make sure everything was tied down. When I got back into my truck, I fastened my seat belt. I bring this up because most of the time I did not wear seat belts. Ten minutes later, an oncoming driver turned left into my path, and I had nowhere to go but straight ahead. I hit his Chevrolet Suburban broadside going 55 mph. The impact sent my boat flying over my truck onto the road in front of me. The trailer ripped off the hitch, puncturing the gas tank, which was full when I left home, spilling gasoline onto the road. The force of the impact caused me to bump my right knee into the dash. Without that slight bump, I could have walked away from what could have been a fatal accident. God had His hand on me that night and spared my life.

Within six months after the accident, my physical condition worsened. I went from wearing a small knee brace on my right knee to wearing leg braces and using crutches to walk. I continued to work every day for years wearing the braces and using the crutches. Finally the physical stress I was putting my body through by using the crutches took its toll on me. I had to stop working and file for Social Security Disability.

Then my mother was diagnosed with terminal cancer. My wife started going through Mom’s personal papers and found my adoption papers from 1961. I was never told I was adopted, and I was 39 when this secret was finally discovered. This totally blew my wife away. There was no way she could tell me the news, so she went to my mother’s bedside and told her what she had found. My mom’s reaction was, “Oh, my God. I KNEW you would be the one to find them. Have Timmy come talk to me this evening.” So my wife called our brother-in-law and asked him to come and tell me the news.

That evening when I got home from work, I was met by a room full of favorite relatives and close friends. My brother-in-law explained, “Tim, I am here to tell you that you are adopted.” I replied,” Oh, come on. That has been a joke for years.” I said that because of the strained relationship between my brother and me. So my brother-in-law slid an envelope with the adoption papers over to me and told me to see Mom because she wanted to talk to me about this.

My mother was my best friend, and I was the person who had told her about her cancer and that she wouldn’t be with us much longer. That evening, she told me that when I came to them in 1954, she had become lonely. My brother and my Dad had developed a strong father-son bond, and she felt like she was missing something. The day I was brought to their home, God created a mother-son bond that would last until she died. The conversation we had that night was very special. She told me she was afraid to tell me about my being adopted because she feared it would destroy our relationship. The more time passed, the harder it became to tell me, until she finally felt it was too late. I will always believe God sent me where He wanted me to grow up. Six weeks after her surgery, Mom passed away.

Soon after Mom died, my brother and I decided to sell our business. With me filing for disability, I could not be a part of a corporation. We also sold our parents’ home and basically went our separate ways. I decided I wanted to find my birth family. With the help of Children and Family Services, which had my adoption records on microfilm, and tremendous assistance from my wife, I was able to find my birth family in less than a year. I had my wife make the call to my birth mother because I was so nervous about her reaction to the news. My birth mother became hysterical. “Oh, my God! I have been waiting for this call since 1954!”

I decided to drive down to Ft. Lauderdale with my wife and children to meet the family. It was Easter weekend in 1995 and very emotional, to say the least. I met the two brothers and three sisters that the week before I had no idea existed. During that weekend, medical histories were discussed, and I said I was diagnosed with muscular dystrophy 10 years earlier. I was told that one sister had a disease that caused her body to produce tumors. I don’t know if the name of her disease was even mentioned. For never knowing each other our entire lives, we were strangely comfortable with each other from the minute we met. In the years that followed, they came to St. Petersburg to attend high school and college graduations and the weddings of both my daughters.

During the next five years, I continued to struggle to walk with braces and crutches. I had gone back to work part time the year after Mom died, to supplement my disability check and to have something to do. On the advice of my doctors, I decided to go from leg braces and crutches to a wheelchair full time. The stress from putting all my weight on my arms to walk was taking its toll—I had had six surgeries on my elbows and hands to correct nerve blockage. Going into the wheelchair was the best move I have ever made. I am NOT disabled in my wheelchair! I live alone (my wife and I divorced a few years ago) and go to work, travel (I have flown to New York City four times in the past

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four years, and last year I went to Las Vegas), and do anything I want to do. I did not stop living when I went into the wheelchair.

In November 2006, I went to my doctor complaining of a sharp hip pain. After two weeks of therapy for sciatica, the pain was no better and I was sent to have an MRI done on my lower spine. The MRI showed three large tumors, and I was diagnosed with neurofibromatosis—the earlier diagnosis of Charcot-Marie-Tooth disease had been wrong. I learned that neurofibromatosis is a disease in which the body produces tumors on nerve tissue. I called one of my sisters to ask what disease my other sister had and learned that it was neurofibromatosis. I found out there are two types. With NF type 1, the tumors can be anywhere on the body, but with NF type 2, they are found exclusively on the auditory nerves, spinal cord, and brain. The auditory nerve tumor symptoms include hearing loss and tinnitus (ringing in the ears). I had gradual hearing loss and tinnitus for 17 years, but this was thought to be caused by the car accident I spoke of earlier.

In December 2006, I went back for another MRI to look at the rest of my spine and brain. The results showed I had bilateral auditory nerve tumors. The one on the right side measured 3.3 cm (approximately the size of a ping-pong ball) and the other one measured 1.2 cm. The MRI also found a problem with my spinal cord at the base of my brain that was not related to NF. That problem had caused severe cramping in my upper body and my arms and hands. On February 7th, 2007, I had surgery to remove the right-side tumor and repair the spinal cord problem. The surgery was performed by Dr. Frank Vrionis at the Moffitt Cancer Center in Tampa. Dr. Vrionis is the head of neurosurgery at Moffitt, which is the number three hospital in the country for the type of surgery I had.

Most of the time when a tumor is removed from the auditory nerve, the patient is left totally deaf in that ear. Also, the facial nerve and the auditory nerve are pretty much intertwined, so when there is damage to the auditory nerve, there is often damage to the facial nerve, causing that half of the patient’s face to be paralyzed. Another side effect in a lot of these surgeries is chronic migraine headaches. But when I woke up in the recovery room after surgery, I could hear out of my right ear and the right side of my face was not paralyzed. And I did not get any headaches as a result of the surgery. God is good!

I was supposed to be in the hospital for four days after surgery, but I developed a complication involving my digestive system, which “went to sleep” because of the amount of anesthesia I was given during the surgery along with the fact that I could not get up and walk. I was in the hospital an extra 10 days because of this and then transferred to HealthSouth Rehab Hospital in Largo for physical therapy. After one week there, I developed a spinal fluid leak at the incision in the back of my neck.

I was sent back to Moffitt, where the surgeons put in a shunt drain tube to relieve the fluid pressure. The tube goes from the middle of my brain, under the skin, behind my left ear, down my chest, and ends up in my belly cavity. Even after this surgery, I still had no headaches! I spent a week at Moffitt recovering and went back to HealthSouth to finish my rehab. Every morning I would wake up and say, “Today is a GREAT day! I will do more today than I did yesterday!” And every day I got stronger. Even the therapists were amazed at how quickly I got well. I kept telling everybody, “I WILL get well and go home.”

My whole outlook is like this. It doesn’t take very long for me to find someone in worse shape than I am. I do NOT consider myself disabled! I am proud when I say I am self-sufficient! God has been very good to me. Some people may say, “This guy is a TRAIN WRECK!” I am here to tell you that I am blessed! I have a Scripture that describes my attitude. It is Philippians 4:13: “I can do all things through Christ who strengthens me.”

I am not disabled. I am blessed!

Tim Kimball is 54 years old, lives in St. Petersburg, Florida, and belongs to ALDA-Suncoast. In November 2006, he was diagnosed with NF2, which caused him to become paraplegic and hard of hearing. He is divorced after 27 years of marriage and has two daughters and two grandchildren. He says his glass is always half full. Tim can be reached at timjk1954@verizon.net.
President's Welcome

By Linda Drattell

I am honored to serve as ALDA’s president this year. My goal is to increase the breadth and quality of services available to ALDA members. To accomplish this, more members need to become involved. Just as kindling is needed to create a roaring fire, ALDA needs its members to spend a few hours a month lending their expertise, ideas, and enthusiasm to make ALDA an organization that meets its members’ needs as late-deafened adults.

Whether you join a committee, start or lead a local chapter, write articles for ALDA News or eNews, or help with fundraising, you will be part of a larger group dedicated to the same mission. No matter how big or small your contribution of time and energy is, that contribution is encouraged and appreciated.

A good place to start is by subscribing to the ALDA-ideas Yahoo group (ALDA-ideas-subscribe@yahoogroups.com). Members come here to share views and add their voices on a variety of issues.

Please let anyone on the board know if there is a particular area that interests you or if you have a special skill, and always feel free to email your thoughts and suggestions to me at president@alda.org.

GA to SK

By Ann Smith, Curator

ALDA-Peach’s Yael Shaner and her daughter, Ananda Melson, went to Johannesburg and Cape Town, South Africa, and on safari in the Okevanga Delta in Botswana. After returning, Yael shared her trip with the ALDA-Peach members at their October meeting with an excellent slide show of her photographs. In August, another Peach, Mary Platt, spent two weeks in South Africa traveling with bell-ringing companions to visit and ring in seven of the eight change ringing towers throughout the country (the eighth was not available). The bell ringers also enjoyed many days of touring wine country, the beautiful coastline, and beaches, going whale and bird watching, and even participating in a safari. Mary also shared wonderful pictures at the October ALDA-Peach meeting.

ALDA members extend their condolences to Tony Yuppa of ALDA-Garden State on the loss of his brother and to Anne McLaughlin, former curator of “Chapter Happenings” and “GA to SK,” on the loss of her sister.

Region 4 director and ALDA-Sonora chapter member Michelle Lewis won the Arizona annual state award from Hamilton Relay for her advocacy efforts on behalf of deaf and hard of hearing people. In case you didn’t see the article in the ALDA News Spring 2009 issue, take a look and learn in more detail about Michelle’s work.

Send your personal news items to Ann at fabsmith@att.net by February 21.

SK SK

Life is not always a matter of holding good cards, but sometimes of playing a poor hand well.

—Robert Louis Stevenson
What Is ALDA?

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

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

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

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

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

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

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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 . . . $25.00
□ Senior Member, Age 62 or over . . . . $20.00
□ Business Membership . . . . . . . . . . . . . . $45.00
□ Tax-Deductible Donation . . . . . . . .. $ _______
□ New □ Renewal

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

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

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

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

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

Ann Smith, Lifetime Member

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

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

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

Don’t Just Be a Member, Be a Lifetime Member!

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

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