IN THEIR OWN WORDS
ALDA PRESIDENTS ● 1990 – 2015

BILL GRAHAM
1990 & 1991

ROY MILLER
1992

MARYLYN HOWE
1993 & 2001

STEVE LAREW
1994 & 2015

TOM DAVINROY
1995

ROBIN TITTERINGTON
1996

CHERYL HEPPNER
1997

MARY CLARK
1998 & 2003

KATHY SCHLUETER
1999 & 2009

KEN ARCIA
2000
IN THEIR OWN WORDS
ALDA PRESIDENTS ● 1990 – 2015

EDNA SHIPLEY-CONNER
2002

LOIS MARONEY
2004

JANE SCHLAU
2005

KAREN KEEFE
2006

BERNIE PALMER
2007

CHRISTINE SEYMOUR
2008

LINDA DRATTELL
2010

CYNTHIA AMERMAN
2011

BRENDA ESTES
2012

MARY LOU MISTRETTA
2013

DAVID LITMAN
2014
I. King Jordan

Foreword

It all began in 1987 with an informal get together – a pizza party! A small group of thirteen adventurous individuals who had become deaf as adults got together at Bill Graham’s apartment in Chicago. Most of the partiers did not know one another. They came from diverse backgrounds. And I am sure they had mixed feelings about how the evening was going to turn out. The one thing that they had in common was the fact that all of them had experienced over and over the difficulty of communicating with long-time friends, family and colleagues at work. They had all experienced the frustrations that come with adult-onset deafness and the craving for clear, easy communications. It is doubtful that any of them were thinking of possibly starting some kind of support group for persons who lost their hearing as adults. And I doubt that Bill Graham was thinking of such a grand venture when he sent out the party invitations – but maybe. Who knows? As well as I know many of the long-time ALDA leaders, I have never really talked with anyone about the rationale behind that first gathering. However, there are some things that we do know. People left the party that evening with a special feeling of camaraderie and a desire to party again. And Bill Graham started sending out a rather humorous newsletter as a way of “keeping in touch” between parties. And eventually, as a result of that first pizza party, a commitment was made to create a formal organization, and the Association of Late-Deafened Adults (ALDA) was born.

I joined ALDA in the early years because I became deaf as an adult and I strongly believe in their mission (to support the empowerment of late-deafened people)... Frequently I have talked to individuals who had very recently become deaf, had learned about ALDA, and had attended an annual ALDA conference, an “ALDAcon.” Regularly they have told me that the sense of belonging they felt at “The Con” and the connections they made with others were truly life saving for them. I never once questioned the need for ALDA or the significance of the group. I did, however, from time to time wonder how the national organization and its many chapters could succeed when all of the leadership was provided on a strictly volunteer basis. The ALDA board, the ALDA officers, the ALDA chapter leaders all do their ALDA work as an add-on to their other responsibilities. I can say now, 28 years after that first pizza party, that ALDA hasn’t just survived, it has thrived!

How did that happen? How did what started as a shoe string operation become a respected, dynamic national organization? In a word, leadership. From the “get go,” the people who have led ALDA, especially the national board members and the national presidents, have been so passionate about the
organization that their work has assured success. The presidents, perhaps more so than any others, have been especially important to the development and success of ALDA.

Here are their stories, in their own words. You’ll read about who they were before they became deaf and who they are now. How did deafness change their lives? How did ALDA change their lives? What took place within ALDA during their presidencies?

Every year I attend the ALDAcon. It truly is the one event of the year where I can (and do) let my hair down and relax. Frequently people talk about those who attend ALDAcon as “family” and about “coming home.” This collection of memoirs by ALDA presidents is testament to those sentiments. I know you will enjoy them as much as I did. Read on!
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Editors’ Note: Unfortunately we were unable to obtain stories from all of the ALDA past presidents for inclusion in this volume. We did, however, want to honor all of the people who have volunteered their time and talents to leading ALDA. For that reason, we have included pictures of all the ALDA presidents on earlier pages and indicated the years in which they served as president.
Growing Up

I grew up in a working class, historically racist neighborhood on the South Side of Chicago. Chicago was and remains one of the most segregated cities in the country. Only whites were welcome in our enclave – people with dark skin walked our streets at risk and were called pejorative names. Even the different ethnicities within our white world weren’t spared. Polish, Lithuanian, Irish, and Italian people were generally referred to by other names. I was half Mick and half Polack.

I lived one short mile from Cook County Jail. My neighborhood could be pretty rough at times. I was afraid to go trick or treating on Halloween because I was a bull’s eye for eggs and blackface. Walking past the public school on the way to my Catholic school could be dicey, and my mom usually drove me the four blocks to school, along with a couple of other Catholic kids from across the alley. About three-fourths of the guys in my neighborhood became day laborers and maybe an eighth served some jail time.

Like everyone I knew (except the nuns and priests…maybe), I had prejudices myself about “other” people. In 1968, when I was 16, my friend Andy and I went downtown to the campaign headquarters of George Wallace, the “law and order” American Independent Party candidate for president. Even though we weren’t yet able to vote, we took home an armful of Wallace stickers and buttons. I don’t remember what we did with them; probably left them on bus seats and under windshield wipers. I’ve never admitted to this before, so I guess I’m not too proud of it, hmm?

I went to a Christian Brothers high school in what had become one of the city’s worst ghettos, three miles directly east of my home and across the tracks. A generation before it had been a white neighborhood and Al Capone lived there. The outside wall of the school had nicks that supposedly were from bullets fired by Capone’s gang. Many prominent Chicagoleans, including the Daleys and a couple other mayors, graduated from the school. And they sent their kids there, even though the neighborhood had changed. By the time I attended, the school was 55 percent black along with a good number of Asians and Hispanics. It was there that my attitude about people who are different began to change.

Becoming Deaf

I had a mild sensorineural hearing loss growing up but it had no evident effect on my life through high school. In college, for unknown reasons, my hearing began to deteriorate rapidly. I attended the Illinois Institute of Technology, majoring in architecture. In my sophomore year I realized I was missing a lot of
what teachers were saying. I didn’t tell anyone I was having trouble coping, not even my parents – pride, fear, and ignorance all coming into play – but inside I panicked.

Much to my father’s dismay, I quit the rigorous architecture curriculum and became an English major, an extremely rare species at IIT. The last two years of college I skipped the majority of my classes. I pretty much hung out all day in the gym, playing basketball, racquetball, and more basketball; hearing didn’t matter much in the games, and the exercise eased my angst. In my coursework, I was good at tests and wrote killer essays, so I was able to eke out B’s and C’s and I graduated. But for many years thereafter, I had a recurring dream that I hadn’t graduated from IIT because I missed so many classes. I woke up sweating sometimes.

By then my self-esteem was pretty much shot. I bluffed my way through hundreds of conversations with friends. In stores I would nod or shake my head at the cashier, whatever seemed appropriate, and sometimes my anxiety to escape the situation was such that I left the store without what I bought. When I walked down the sidewalk and saw someone coming my way, I would often cross the street rather than risk being exposed by an inappropriate passing response or no response at all.

I concluded that since I had trouble understanding people my only recourse was to embrace my blue collar background and get a job working with my hands. I explained this to the foreman when I interviewed for a job at an electrocoating company in the suburbs, and he hired me. I wore a hard hat and operated a crane, transferring long bars of steel on pallets into a vat of chemicals. I hated it. My car broke down a couple weeks into the job, giving me an excuse to quit.

I decided to get as far away from factories as I could. I applied to Colorado State University and was accepted into their graduate English program with an emphasis on creative writing. Moving away from my life of denial in Chicago was something of a relief, but I didn’t take advantage of the opportunity to “start over” in Colorado at first. I bluffed through the whole first semester, and I made no friends. Then during the next semester when people were critiquing a short story I had written and I wasn’t following the discussion, I blurted out: “You’re lucky I can’t hear you or I’d be pissed off!” Everyone laughed and smiled. That warmth of their body language relaxed me. After that, I continued to use humor about not being able to hear and soon I was hanging out with a big group of people, a number of whom became friends for life.

I returned to Chicago and found a job as an editor with The World Book Encyclopedia. Quiet office, working with words; a bit low on the creativity side, but otherwise a good fit. People at work knew I couldn’t hear and were nice about it, but I was on the margins of group interactions. We’d do happy hours and I couldn’t carry on a conversation with anyone, so my colleagues stuck to simple sentences (said over and over) that a five-year-old could field. I was more an endearing mascot who said funny things than an adult who was taken seriously.

By age 25 I couldn’t use the phone anymore. I now date my deafness to that age. At the time, however, I did not relate to the word deaf, especially as a description of myself. I didn’t know any deaf people and didn’t want to know any. Deaf people used sign language and that scared the bejesus out of me. The few times I had seen deaf people in public places signing, I turned away. Another expression of my denial, I suppose.

But in my late 20s a hard-of-hearing artist at World Book – Valerie Nelson – befriended me. She had a Deaf boyfriend and knew ASL and Deaf culture. She encouraged me to learn sign language, but talking with my hands had always seemed to me like an admittance of failure, of not being able to deal with life in the standard way.
Eventually, though, I took a sign language class at the Chicago Hearing Society (CHS). Remarkably, I enjoyed it. I found it fascinating how the Deaf teachers communicated signs without using their voice. And my “good hands,” expressive body language, and general goofiness made me a class favorite.

I took the whole sign curriculum at CHS. One of my capital D deaf teachers, Tom Benziger, took special interest in me. He encouraged me to do field research, and accompanied me to Deaf events—Deaf clubs, Deaf banquets, parties at his house. I made a lot of capital D friends along the way, even though to each other they signed way too fast for me to follow and had life experiences much different from my own. I really enjoyed my Deaf friends, but I bluffed a lot and inhabited the margins of their world, too.

Finding ALDA

In 1987 I learned of a self-help support group for people who become deaf as adults. The group was run by Kathie Hering, a vocational rehabilitation counselor who had a special interest in late-deafened people because she herself was one. I was single and had time on my hands, and the group met not far from where I lived so, mostly on a whim, I decided to go to a meeting.

I remember pacing back and forth in the hall outside the room where the meeting was held. It took courage for me to cross the threshold because I didn’t like unpredictable situations involving strangers. But finally in I went. Little did I know my life would change forever.

There were three people at the meeting: Kathie, Paulette Pounders, and myself. Communication was tortured. Kathie communicated well in sign language but was a poor lipreader, Paulette didn’t sign or lipread, and I didn’t follow sign all that well and I had trouble lipreading Kathie because she had partial facial paralysis from neurofibromatosis tumors. At times the conversation went something like this: “How do you feel?” “What?” “I said how do you feel?” “Six o’clock.” “Sixty cents?” “Yes.”

The first night I went home thinking “Well, that was weird.” But later I thought it actually was something special: I spent time with a couple of strangers and felt comfortable—we had similar life experiences and were in the same boat, communicating badly.

In her counseling job, Kathie had amassed a list of about 25 people who became deaf post-lingually (after childhood). I liked to throw parties—I excelled as a host rather than as a participant—and here was an opportunity to host a new kind of get-together. I sent the people on Kathie’s list letters inviting them to come to my ramshackle apartment in Old Town on Chicago’s North Side and party. I was surprised that 12 people came. Coming into the bad old city to a stranger’s house? Takes moxie. Communication was tough, but we had several pencil-and-paper stations in place. The party lasted well past midnight, so people obviously had a decent time.

Following the party, I sent another letter to the group; Cleo Simmons had volunteered to host a second party. Several more people came and somebody else volunteered to do a third party. So I wrote another letter. More people showed up. Things continued in this way and soon we had a solid social group that met about once a month.

I also took a shot at the self-help group in Kathie’s absence. Kathie had undergone one of her recurrent surgery for NF tumors and couldn’t do the support group while she recovered. I took a new approach to group communication, based on what I saw worked at our parties: some people understood best when they could read the other person’s words. So in the self-help group, we had a hearing person type on a
standard typewriter and provide summaries of what we said. We stuck three or four carbons in with the typing paper and every five minutes or so we’d take a break and pass around the carbon copies and the original and people could read what others had said. Pretty primitive, but it worked.

Then Steve Wilhelm, my closest friend and a computer geek, had an idea: using cables and adapters, connect a computer to a television and have the hearing person type on the computer. The words would then appear on the television screen and we could all read them at the same time; we wouldn’t have to stop and pass papers around. This jerrybuilt system sped up communication considerably and we thought it pretty cool. Steve’s handiwork became known as ALDA Crude and until CART captioning came along it was our primary vehicle for group communication.

Meanwhile, the letters I wrote grew longer and became the group’s newsletter. They got passed around to other people, who read them and asked to be put on the mailing list. And that’s how the group grew. After several months, I held a contest in the newsletter to name the group. Thirteen names were submitted, some of them, um, interesting. They included Happy Organization of Late-Deafened (HOLD), Beginners Organization of Late-Deafened (BOLD), Growing Organization of Late-Deafened (GOLD), and People who Lost their hearing in their Adult Years and Eventually Regrouped (PLAYERS). Association of Late-Deafened Adults won. The name that got the second most votes was UNIted SOciety of the LATE Deafened (UNISOLATED)….Good thing there wasn’t a recount.

**Guiding ALDA as President**

I became the leader of ALDA by default. I wrote the newsletter and that’s what brought people together. When the newsletter got in the hands of people from outside Illinois, the group began to change from a local social circle to a national organization. People such as Marylyn Howe and Roy Miller pushed ALDA toward an increasingly ambitious vision of support for and awareness of deafened adults. Marylyn founded the first ALDA chapter outside of Illinois, in Boston, and contributed mightily to the ALDA News and to outreach efforts. Roy, a political science professor at Southern Illinois University, gave ALDA structure with bylaws and other legal formalities, including incorporation as a nonprofit organization.

Month by month, more and more talented people surfaced in ALDA and put their heart into the organization. My major contribution during that period probably was just to stay out of the way. The organization’s national footprint expanded remarkably quickly and late-deafened adults became recognized as an important new segment of the deaf and hard-of-hearing community.

I became a primary beneficiary of ALDA’s rapid growth. I was invited to speak in many parts of the country and to represent late-deafened adults on a number of disability-related boards. I got to know many, many marvelous people, including hundreds of ALDAns, some who became lasting friends. I also was able to do advocacy work that I think made a difference for other late-deafened people. I wore dress shirts and ties and sports coats. Sure beat operating a crane. It even beat editing encyclopedia articles. I was a very lucky duck.

I left ALDA after five years as its leader. As with any grassroots group, squabbling among the membership increased as the organization grew. The initial euphoria of finding a special place that feels like family gives way to family in-fighting and territoriality. I found myself spending too much time dealing with anger, duplicity, and backstabbing. Well, that’s no fun. Then something happened on the ALDA board that really pissed me off, and I resigned. Fifteen years later, I don’t remember what it was that triggered my departure. Seriously. Karina thinks I’m being disingenuous when I say that, but I’m not. I don’t remember. But whatever it was that happened, I just decided: “I’m mad as hell and I’m not going to take it any more!” And I left.
Afterwards

In 1993, with funding from the state of Illinois, Karina and I started Hearing Loss Link, a social service agency for people who lose their hearing. Link complemented ALDA, if on a local level, providing professional assistance to help late-deafened adults cope better with their hearing loss. Link became a program of the Chicago Hearing Society (CHS) until funding for it ran out.

In 1996 I got a job with Microsoft in Seattle, Washington. It was very tough to move there…Karina and I were both lifetime Chicagoans. At Microsoft my job was Managing Editor of Encarta Reference Library. I worked there ten years, watching paper wealth vaporize in the dot-com bust. But the job was the most engaging, challenging, and enjoyable work I’ve done in my professional career.

During our years in Seattle, we adopted two babies: Eva, born in 1996 in the Republic of Georgia, and Tony, born in 1998 in Kaliningrad, Russia. I became a doting father and didn’t have much of a social life. Between the job and the parenting, my bandwidth for other things was very small.

Other than speaking at a few ALDAcons, I wasn’t involved with ALDA for 15 years, neither nationally nor in Seattle. I didn’t talk or even think about ALDA much. When I did I became emotional, and maybe that’s why I didn’t think about it much. I didn’t exactly regret that I had left ALDA, because my life was full and rewarding in a different sort of way. I did regret the way I had left the organization, which seems rather juvenile in retrospect.

Back to the Future

I got redeployed (in English, laid off) by Microsoft in 2006. Karina and I then moved back to the Chicago area. We live in Cary, about 40 northwest of Chicago on the way to Rockford. For a year and a half, I had no interaction with either Chicago or Rockford area ALDAns. I didn’t contact them, they didn’t contact me. We just weren’t on each other’s radar.

Then in January 2008, out of the blue, Mary Clark emailed asking if I would help with the program book for ALDAcon 2008. The conference was in Chicago, and it would celebrate ALDA’s 20th anniversary. I politely told Mary no.

But Mary couldn’t take a hint. She asked me to help with something else, and I again said no. Then she asked me to do something else…no, no, a thousand times no! But by then I had become somewhat sheepish. After all, the kids are a bit older now and the conference is in Chicago and it is the 20th anniversary, so…the next time Mary asked for help—about having my name connected with the ALDAcon Sponsorship Committee—I said okay, just so I don't have to do much work.

Once I got involved, though, I began to reconnect with people who are very dear to me but who I hadn’t talked with in a long, long time. Fond memories engulfed me, and catching up with these old friends was a powerful emotional rush. Before long I wanted to do all I could to help make ALDAcon 2008 really special. After a month or so I found myself involved with not only the Sponsorship Committee, but the Scholarship, PR, and Program committees as well.

I know a lot of people who were once active in ALDA but who dropped out and never came back. Some of them say: “I don’t need ALDA anymore.” And of course, that’s true. I left ALDA for 15 years and didn’t feel I needed it. There were plenty of other very enjoyable things to occupy my attention, and I did them as time permitted.
But to make a bad analogy, before I moved to Seattle one of my favorite activities was riding my road bike long distances. I took vacations by bike, road in “centuries” (100-mile rides), and I trained for and participated in triathlons. I was, pardon my modesty, a pretty damn good cyclist. But our first year in Seattle, Karina and I adopted Eva and after that I didn’t have time for long rides; besides, Seattle has big nasty hills, an even better excuse not to ride. So my road bike gathered dust. But it was okay: I ran, I swam, I golfed, I played tennis, I did yoga, and I enjoy every one of those activities. I didn’t need biking for exercise or enjoyment.

A couple months after we moved back to Chicago, on the relatively flat terrain of northern Illinois, I started road biking again. Things went pathetically at first – I was in low gear on the slightest hills and distressingly uncertain on turns. It was a hassle to take the bike down from the garage hangers, and each time I did I asked myself: “Why bother?” But gradually my legs and coordination came back. On my fifth or sixth time out, in mid-ride, I realized that I was handling the bike easily and taking some small hills in high gear. It’s a special sort of feeling: the wind against my face, trees rushing by, the road stretching on….special. Yes, maybe I don’t need biking, but for me no other exercise is so exhilarating. So it can sometimes be with ALDA.

Actually it’s not entirely true to say that I don’t need ALDA. Despite two cochlear implants, I still feel socially marginalized most of the time. And that feeling can be exasperating and demeaning, and it affects how I feel about myself and how I deal with everyday life. Mingling with other late-deafened people – people who fully understand what it’s like to be on the margins – can provide a certain sense of wholeness, a feeling that never completely leaves me after ALDA is over.

And should needing ALDA oneself be the only consideration for involvement? I’ve seen deafened adults rebuild their lives through ALDA and make peace with their deafness. It only takes one person, one friend, to change someone’s life in a meaningful way. This happens in ALDA all the time. And it’s a beautiful thing. People who feel they don’t need ALDA should think about that a bit. Maybe somebody in ALDA needs them.
Early Life as a Hearing Person

I was born in Moline Public Hospital in Moline, Illinois, the youngest of four kids. I was indeed a child of the Great Depression and have retained all the survival skills that my parents taught me to this very day (but more about that later). We lived on the out-skirts of town and I spent much of my early years messing around on the farm that was just down the road. I helped milk cows when I felt like it, and when Glen Swanson, the owner of the farm, would tolerate my slowness and limited productivity. I hand cranked the machine that separated the milk from the cream, and helped deliver milk to families in the neighborhood. When I was about 10 years old, and for a few years thereafter, I was allowed to drive the tractor when putting up hay in the late summer. When I was a bit older and could handle a pitchfork loaded with hay, I helped in the loft of the barn scattering the loose hay as it was lifted from the wagon below (which is one of the hottest, itchiest, sweatiest jobs in this world!). In the fall after fresh silage had been cut and placed in the silo, I laughed at the pigs getting drunk from lapping up the 100-proof grain alcohol that seeped from the bottom of the roofless silo after a hard rain. Believe me there is nothing funnier than a drunken pig rolling in the mud! I guess I mention all of this just to let you know that in my roots I have a lot of “down home” experiences in my past, and as the saying goes, “you can take the boy out of the country but you can’t take the country out of the boy.”

I was a precocious kid and a very quick learner. I did all of the things that boys growing up in the forties and fifties were supposed to do (and some that I was not supposed to do). In grade school I played baseball and basketball and received nearly straight A’s on my report cards. But I also was whacked on the butt with a tennis shoe a couple of times for misbehaving in gym, had to fork over my paper route earnings for about six months to pay for the windows in a deserted garage that I had shot out with my BB gun, accidentally set the North Woods on fire while “camping” with my buddy, and helped push over Mr. Kale’s outhouse one Halloween. I had a paper route, rode my hand-me-down bike, played cowboys and Indians while astride my broomstick steed, listened to “The Green Hornet,” “The Shadow,” Jack Benny and Amos and Andy on radio, enjoyed an occasional Saturday afternoon matinee with Red Ryder and Little Beaver or Gene Autry, and religiously went to my neighbor’s house to watch the Lone Ranger and Tonto on what was then a new-fangled technology called television (we didn’t get a TV set at our house until several years later). All in all, my early childhood was rather typical and fun.

Then came high school, girls, and the dreaded teen-age years (as the saying goes, they were the best of times and the worst of times). In high school I dabbled in almost everything. I continued being a jock
playing baseball and basketball for a couple of years, football for three years, and wrestling for one year. But I added new activities, such as participating in debate, theater, and student government. And my nights were spent studying in my bedroom, an effort that helped me graduate as Valedictorian of my class. On weekends I worked with my father and brothers, doing anything and everything to make a dollar – including laying concrete blocks, digging wells, tearing down houses, and unloading coal from freight cars. And during summers I worked wherever I could find a job, including running the swings in a small amusement park, unloading freight cars in a lumber yard (believe me you don’t ever want to unload creosote fence posts from a railroad car in the middle of August), shoving sheet metal into a brake at Buddy-L’s (a toy manufacturer), and chasing a chain for eight hours a day on the 2-M corn picker assembly line at International Harvester Company. Indeed, my teenage years seemed busy, with relatively little time for lying in the grass and dreaming about the future. Besides, my immediate future was rather certain. I was going to college if I could get some financial support, as my parents didn’t have the money to send me.

Fortunately I lived in an era when financial support to attend college was given primarily on the basis of academic performance, and my scholastic record was good enough to earn me some scholarships. So, off I went to Bradley University in Peoria, Illinois. While at Bradley I continued my forensics journey, participating in debate, extemp, and after-dinner speaking. I also acted in a couple of community theater productions, and spit-shined my shoes every week for my time marching with the boys in blue (Air Force Reserve Officers Training Corps). My financial aid was not sufficient to keep food on my table, so I had to work all through my college years. I was a film editor at WMBD and watched almost every film that Hollywood ever made. Bradley was a Greek-dominated school, with almost all social life revolving around the fraternities and sororities on campus. But when I was a junior I teamed up with senior Richard Wagner and we ran as Independents for president and vice-president of the student government. With a little help from the Vet’s Club we pulled off a major upset, and for the first time in the history of the school the student government was led by two Independents who had no affiliation with any Greek organization. It was during my Bradley years that I began to explore a wider world than just the cornfields of Illinois. In particular, my activities on the speech team took me as far east as Ohio and as far west as Hawaii, and the allure of traveling has stayed with me to this very day. I kept my grades up, was awarded a couple of ROTC scholarship medals, was admitted to the Bradley Federation of Scholars, and found my name in Who’s Who In American Colleges and Universities. Like so many others, for me the collegiate years provided an opportunity to grow up a little and grow away from the protective environment provided by one’s parents.

Upon graduation from Bradley I was offered fellowships to attend graduate school at the University of Hawaii and the University of Pittsburgh. At that time, I envisioned myself as a future Clarence Darrow, and a friend suggested that if I seriously wanted to pursue that career path I should move towards the center of power (Washington, DC). So I heeded that advice, and gave up the possibility of surfing on weekends and living the laid-back life of a Pacific Islander (a decision that I have since questioned many times). Instead, I got married late that summer to Bonnie Lou Curless, whom I had been dating for a couple of years. I bought a 1957 Chevy and I drove 8,000 miles throughout the west in two weeks on our honeymoon (this was in the days when some states like Montana had no speed limit) – a honeymoon that was spent in a borrowed tent because we only had enough money for food and gas. Upon returning from our honeymoon, we loaded everything we owned into a small home-made trailer and headed for Pittsburgh and my new office on the 23rd floor of the Cathedral of Learning.

Unfortunately a year of graduate study in the Department of Political Science at the University of Pittsburgh did not satisfy the itch in my bones to groom myself for a career as a barrister. So I applied to and was accepted at a few law schools, and was offered financial support at both the University of Tennessee Law School in Knoxville, Tennessee and Duke University School of Law in Durham, North
Carolina. Being of the opinion that state law schools tended to prepare their students to take that state’s bar exam, and not knowing if I wanted to live forever in Tennessee, I opted for the more general legal education offered by a university with an outstanding national reputation, namely, Duke. So in the fall of 1962 my wife Bonnie and I packed up everything again in our little home-made trailer and headed for North Carolina.

Life in Durham was pretty strange for us as it was our first exposure to the Old South in a time that pre-dated the Civil Rights Law. There were separate water fountains and public restrooms for “negroes” to use, and persons of color still rode in the back of the buses and went to the back door of houses inhabited by white people. There were no bars in Durham, as selling liquor by the drink was illegal. Yet you could buy all the beer you wanted in the neighborhood grocery store. For a person born and raised in the Land of Lincoln much of the then Southern Culture didn’t make sense and was offensive. I did well my first year in law school, but during the fall of my second year an event occurred that made me question my desire to practice law, namely, president John F. Kennedy was assassinated in Dallas, Texas. At the time my only desire was to be a criminal defense lawyer, and I envisioned myself in the courtroom fighting for the rights of the falsely accused. However, when Kennedy was killed I had to face a question that was very upsetting: Did I really want to spend my life defending people some of whom I knew were guilty of heinous crimes? Did I really want to open my office door to rapists, arsonists, and murderers? As time went on, I became very unsatisfied with the life of a law student in Durham, North Carolina. It was not clear whether I was just unhappy living in the South far from friends and family or had I become disillusioned with attending law school. I decided to remove the Southern environment from the question and transferred to the University of Illinois College of Law in Urbana, Illinois. The thinking was that if it was life in the South that was bothering me then by moving back North to my home state, close to my family, my mental health should drastically improve and life as a law student should again become interesting, challenging and desirable. Didn’t happen! It quickly became apparent that I had simply soured on the study of law. So I dropped out of law school and turned my sights in a different direction.

The University of Illinois College of Law was just down the street from Lincoln Hall and the Department of Political Science, so I dropped in there and explored the possibility of returning to graduate school. I was offered a teaching assistantship in the Department of Political Science, quickly accepted it, and resumed my study of the great thinkers of by-gone eras, such as Plato, Aristotle, Machiavelli, St. Thomas Aquinas, Locke, Hobbes and Rousseau. But, while taking a class from a couple of what was then a new breed of political scientists (Denis Sullivan and Milton Hobbs), I was introduced to computers, and thus began a life-long love affair between me and the machine. While at the University of Illinois I finished the work necessary to complete my Master’s degree from the University of Pittsburgh, and a few years later I received my Ph.D. degree in Political Science from the home of the Fighting Illini. I was on a roll. Life was good. And I was ready to get a “real” job!

When I came out of graduate school the job market was great, and I was offered a teaching position at several universities, including the University of South Florida, the University of Nebraska, the University of Ohio, the University of Oklahoma, the State University of New York at Plattsburgh, and the University of Delaware. But when push came to shove I accepted a position at Southern Illinois University at Carbondale. Why? Because it was at a large state university, in a small town, in beautiful Southern Illinois, with several lakes close by where I could go fishing, and only a few hours drive from family. In addition, the position was half-time in the Department of Political Science teaching mostly graduate-level courses and half-time in what was then the Public Affairs Research Bureau doing research largely of my own choosing. None of the other possible jobs offered such a desirable combination of features. So, in 1967 Bonnie and I moved to Carbondale and I began life as a university faculty member.
In the early years of my teaching career I had long hair and a beard, and was viewed by some of my
colleagues as a “radical.” I played on and managed a fast-pitch softball team, held many classes with
my students in a local watering hole, and sucked up tear gas with the rest of the students in May of 1970
when their riots in protest of the war in Viet Nam ended in the closure of the university. It was an
exciting time in my life and gave no hint of things to come.

During the late summer of 1971, I was hit in the head three times during a fast-pitch softball tournament
(seemingly I was the favorite target of opposing pitchers). The next week Bonnie and I went
vacationing on the Grand Mesa in far western Colorado. At that time I began having short but severe
head pains. I attributed the pains to the high elevation, but they didn’t stop when we returned to
Carbondale. So after a time I visited a doctor in Carbondale, who referred me to a neurologist in St.
Louis. The doctor in St. Louis prescribed some pills, which I took for a month and which did absolutely
nothing to relieve my head pains. So back to my local doctor who then referred me to a neurologist at
the Mayo Clinic in Rochester, Minnesota. Bonnie and I made the trip to the Mayo Clinic in March of
1972, and after three days of extensive (and sometimes excruciating) tests, we sat down with a
neurosurgeon to get the results. He looked me in the eye and said “You have a tumor in your head that
has to be removed or you will die.” Needless to say, there were a few minutes of total shock and
numbness as Bonnie and I tried to process that information. Finally, after viewing several films that
showed a walnut-sized growth in the center of my head, I accepted the diagnosis and indicated that I
would be back in early summer for the surgery after the school year was finished. The neurosurgeon
indicated that I should not wait that long as he could not promise that I would still be alive in early
summer. At which time I said “OK, I’ll go home and finish my income taxes and be back immediately
thereafter.” I did exactly that, and a couple of weeks later a 6-centimeter right-side acoustic neuroma
was removed from my head at St. Mary’s Hospital in Rochester.

During the surgery I lost both the 7th and 8th right-side cranial nerves (facial nerve and acoustic nerve),
so two weeks later an 11-7 anastomosis was done. That surgery hooked the facial nerve to a nerve that
previously activated a muscle in my shoulder, and after about six months of electrically stimulating the
new connection I regained some muscle tone on the right side of my face and was able to consciously
shut my right eye by moving my shoulder (a tribute to the plasticity of our brain). I can’t blink that eye
so I forever have to use eye drops to moisten that eyeball. And of course I was completely deaf on my
right side. But the surgery was deemed a “success” and I was sent home with the understanding that I
was “fixed” and perfectly able to return to teaching, go fishing, and enjoy the rest of my life.

Life as a Half-Deaf Person

During the next decade I generally gave little thought to being half-deaf. The surgery and resultant
right-side hearing loss did, of course, necessitate some changes in my style of living. For example,
during the surgery some of my cerebellum was cut away in order to gain access to the tumor, and the
part that I lost controlled fine muscle activities. As a result I had to give up playing softball. I simply
could no longer make the bat connect with the ball. I also gave up playing the guitar as I could no
longer make the fingers of my left hand and the fingers of my right hand make the coordinated precision
movements required in finger picking. I also started printing everything I wrote. My handwriting
looked like a three-year old kid’s scribbling. It was totally illegible! After several thousand practices I
finally regained the ability to sign my name legibly, and to this day that is the only thing that I do not
print.

Being completely deaf in one ear generally is no problem. It usually doesn’t interfere with face-to-face
conversations, and if it does you simply and reflexively turn your head and/or body a little so that your
good ear is facing more towards the person with whom you are speaking. For telephone communications you simply move the phone to your good ear. What one-sided hearing loss does do, however, is make it difficult to impossible for a person to locate the origin of a sound. I may know that there is a bird singing somewhere in my yard, but I cannot tell if that bird is located to my left, right, behind me, or dead ahead. This functional loss made me give up squirrel hunting as being able to locate sound is such an essential component of that activity.

With these few changes my “half-deaf” period passed rather normally. Bonnie and I raised three children (two boys and a girl), we bought a station wagon to facilitate trips to grandma’s, I bulked up my resume with convention papers and an occasional publication, my boys and I spent many hours fishing, and I became active in guiding their scouting careers, first serving as their Den Leader, then Cubmaster, and later as Scoutmaster. All in all, life was progressing rather smoothly. Then in 1982 I awoke one morning and something was wrong. Everyone sounded as if I were at the bottom of a deep well.

I went to a local ENT doctor and he referred me to doctor Michael Glasscock at the Otology Group in Nashville, Tennesee. An MRI clearly showed that I had a 1.5-centimeter tumor on my left-side acoustic nerve, and doctor Glasscock informed me that I had Neurofibromatosis Type II (NF2), also known as Von Recklinghausen’s disease. At that point I was faced with a choice. I could have surgery immediately and remove the tumor when it was as small as it was ever going to be, knowing that it was about 95% certain that I would be completely deaf coming out of the surgery with absolutely no receptive communication skills. Or I could choose to wait, monitor the growth of the tumor, have the tumor removed when it became large enough to be life threatening, and try to develop some receptive communication skills before going into surgery. I chose to wait and monitor the growth of the tumor with annual MRI’s.

My family members were all hearing, my students were hearing, and my colleagues were all hearing. I lived and worked in a hearing world, and I had never met a deaf person in all my life (sound familiar?). So, I decided to try and develop speechreading skills to enable me to function in the hearing world. I worked for almost three years with graduate assistants in the SIUC Clinical Center trying to speechread people on videotape with the sound turned off and trying to speechread a live person sitting on the other side of the glass while I was seated inside a soundproof chamber used to give hearing tests. I struggled and struggled trying to develop speechreading skills, but to date I consider myself an almost total failure in that regard. I am a terrible speechreader!

Regardless of my inability to master the art of speechreading, the tumor continued to grow, and in 1986 it was decided that the tumor should be removed (time and tumors wait for no man!). Soon once again I was faced with a decision. There are three different surgical approaches one can use to remove acoustic tumors, the translabyrinthine, the middle fossa, and the suboccipital. During translabyrinthine surgery the cochlea is destroyed, and it definitely would result in my being totally deaf. The middle fossa approach is only useful for removing small tumors, and my tumor was almost a 3-centimeter tumor at that time, so it was out of the question. But the suboccipital approach could be used, and using that approach would give the surgeon a teeny-weeny chance of saving my hearing (less than 5%). Doctor Glasscock did not do suboccipital surgery, so if I chose him to do the surgery I definitely would be deaf after the surgery. My other choice was to search for a surgeon who used the suboccipital approach and would give me at least a miniscule chance of saving my hearing. All things considered, I felt that I simply had to do everything possible to try and save my hearing. So I went looking for a different surgeon, and in March of 1987 doctor Leonard Malis removed a 3-centimeter left-side acoustic neuroma at Mt. Sinai Hospital in New York City. But my gamble didn’t pay off, and I lost both the left-side 7th and 8th cranial nerves during the surgery. So, at the age of 47, I went to sleep on an operating table a
hearing (half-deaf) person and woke up about nine hours later completely deaf. My world and that of my family had changed!

**Life as a Deaf Person**

Over the next two years Doctor Mark May performed several surgical procedures at the Eye and Ear Hospital in Pittsburgh, Pennsylvania to improve my eye and mouth functions. He did a left-side 12-7 nerve jump, bilateral temporalis muscle transpositions, inserted spring implants in both of my upper eyelids, and placed Gore-Tex slings in both of my cheeks (one of which had to be removed a year later because for some unknown reason my body rejected it). The nerve jump seemed to work well at the beginning as it allowed me to partially close my left eye by wiggling my tongue. The nerve graft was apparently damaged when the Gore-Tex sling was removed from that side of my face, and I have not been able to close that eye ever since – requiring the use of eye drops in that eye also for the rest of my life.

I was fortunate to be working at a major research university and did not suffer occupational displacement when I became deaf. SIUC couldn’t fire me because they came under Section 504 of the Rehabilitation Act of 1973 as amended. If they fired me they would risk a lawsuit for discriminating against a person with a disability and possible loss of millions of dollars in federal grant money. But I obviously could not continue to teach as I could not understand classroom dialogue and questions. So I was moved to a full-time research position in the Office of Institutional Research. But I viewed myself as first and foremost a “teacher,” and I desperately wanted to return to the classroom. But how?

Fortunately my old friend the computer came to my rescue and facilitated my first classroom experience after becoming deaf. I attended a conference in Guelph, Ontario, Canada concerning the “Virtual Classroom,” and upon my return to SIUC I arranged for the university computer center to acquire IBM Group Talk, which was a computer conferencing software program. Then I proceeded to convert a class that I had formerly taught in Data Analysis to a format where it was all taught via computer conferencing. The students only saw me in person the first day of class when they picked up their course syllabi and received a variety of computer-related information. After that, everything was done on the computer. Course assignments were distributed via computer, student work was returned via computer, graded work with comments was returned via computer, student questions were submitted via computer, and my responses were distributed via computer. The course worked extremely well, and I continued to teach it throughout the remainder of my career at SIUC. But it was apparent that the computer conferencing format would not work in small graduate seminars, so my journey back to the classroom was far from over.

I decided that I had to learn sign language and be able to use interpreters in order to ever conduct a substantive seminar again. So, I took two classes in Signing Exact English (SEE) in the SIUC Adult Education program. In the following year, a colleague from the Psychology Department approached me and asked if I would consider team teaching a course in Meta-Analysis with him the next semester. We had team taught several statistics courses together in the distant past and I quickly welcomed the idea. Throughout that course, I lectured every other class period and he answered all of the students’ questions while I tried to figure out what the interpreter was signing. Soon the classroom rhythm got established and I got better and better at understanding the interpreter’s signing, and towards the end of the semester I was starting to feel comfortable working with the interpreter.

In the following year, my friend and I again team-taught a course, this time in “Survey Research Methods.” But this time I was able to participate more than just lecture. I was on the road back to a full-participation classroom experience. And the following fall, I was scheduled to teach my first solo
course since becoming deaf. After five years I was back in the classroom, just me, an interpreter, and the students! PAH!

**Finding ALDA**

Immediately after becoming deaf I had excruciatingly limited communication skills. I did not know sign language and had terrible speechreading skills (even though I had worked on them for several years). In a matter of hours I went from the dynamic world of a university professor to one in which I could neither pick up the phone and order a pizza nor understand my children unless they wrote for me. I knew absolutely nothing about being deaf, and I had nobody to learn from as I had never met a deaf person in all my life. Needless to say, at that point life was a bitch! So I went hunting for information.

During my search a gentleman in Arkansas informed me that there was a guy in Chicago named Bill Graham who was sending out a newsletter for late-deafened adults and was trying to start an organization for those folks. Somehow I managed to get a copy of that newsletter and found the phone number for Bill. I contacted him and arranged to meet him the next time I was in Chicago. So, in the spring of 1989 I met Bill and his then girlfriend Karen at Uno’s Pizzeria in the Windy City. We enjoyed one of Uno’s famous deep dish pizzas and Bill methodically explained what he was up to (while Karen interpreted much of the discussion). I left Uno’s feeling that I had met a special person and that I would like to become involved in his effort (although admittedly I actually understood very little of what was said to me that evening). That fall I attended the First Annual ALDA Leadership Workshop, and as others have said, “The rest is history.”

**Early ALDA Activities**

It’s hard for my aged brain to sort out exactly what happened and when during my early years with ALDA, but some things stand out in my otherwise vague memories. In the beginning the members of the ALDA Board of Directors were elected at the conference; they were not elected by mail ballot. And I served as a sort of “parliamentarian” or “staff” to the earliest ALDA Board. One of my earliest projects was to completely revise the ALDA bylaws, the first bylaws having been developed by my good friend Steven Wilhelm (who also developed “ALDA Crude” – the communication system that was used at the First ALDA Leadership Workshop). The first bylaws had been taken almost intact from a book detailing how to establish a non-profit corporation in the state of California, and they needed to be modified extensively to accurately describe the workings of ALDA. My next big project was to complete the application to the Internal Revenue Service to get ALDA designated as a 501(c)3 tax-exempt organization. That effort took a long time and was more than just a little pain in the butt (dealing with the IRS is never fun).

I was elected to the ALDA Board in the late fall of 1991, and back then the Board chose its own officers. Bill was elected the first president of ALDA in late 1989, and served in that role for two years (1990 and 1991). But at that time the ALDA bylaws limited the president to two terms, so Bill could not be elected president a third time. However, the Board wanted to retain his persona and leadership and created the position of executive director to which Bill was appointed at the unbelievable salary of $1.00 per year (and believe me he was worth every penny). I became the second president of ALDA and served in that capacity throughout 1992, and much of my time in office was spent with the Board continuing to develop organizational infrastructure and materials (a rather mundane effort that nevertheless generated more than its fair share of heat and disagreement at Board meetings).

At that time ALDA was young and dirt poor, but the Board was composed of motivated, dedicated and spirited individuals. One of the funniest things that happened during my presidency was at the Board
retreat that was held in the outskirts of Chicago. I had driven from Carbondale to the retreat site (a distance of about 350 miles) and arrived there very late in the evening (about 2:00 AM). Every door in the building was locked, but I could get in the attached garage (the door from the garage to the building was also locked). Well, I was out of the weather and had my sleeping bag in my truck, so I unrolled it on the concrete floor of the garage, crawled inside, and went to sleep. Later that morning, Mary Clark entered the garage looking for me and saw me lying perfectly motionless on the floor. SHE THOUGHT I WAS DEAD! Needless to say that has been one of our war stories ever since (along with telling about the Pigs Nose Scotch that was “tasted” during the retreat!). Our next Board meeting was held in Carbondale, and one of our favorite pictures from that time is with all the Board members either sitting on or standing beside a trash dumpster (and that was probably an appropriate indication of the status of our fledgling organization back then).

Life as a Senior Citizen of ALDA

I left the ALDA Board in early 1993, but have tried to maintain a relationship with the organization ever since. I have attended every ALDAcon since the First Annual ALDA Leadership Workshop, with the exception of the 1994 ALDAcon that was held in Toronto, Canada and the 2014 ALDAcon that was held in Norfolk, Virginia. In 1994 I had a scheduling conflict and simply couldn’t go, and in 2014 I was recovering from a bit of necessary surgery. I have also been a workshop presenter at most ALDAcons, and some folks probably look forward with anxious anticipation to my annual presentations while others wish I would disappear (can’t please everyone!). I have served on a few ALDA committees over the years, but admittedly have had to largely limit my participation mostly to attending the annual ALDAcon bash because of other professional demands.

For example, I served on the Board of Directors of the Southern Illinois Center for Independent Living (SICIL) from 1989 to 1995, and served as the SICIL president from 1991 to 1994. I served as president of the Association of Late-Deafened Adults in Southern Illinois (ALDA-SI) from 1991 to 1996. I was on the Board of Directors of Hearing Loss Link from 1993 to 1999, and served as the president of that organization from 1993 to 1996. I was the creator, owner and moderator of DEAF-L, an Internet LISTSERV forum for the discussion of anything pertaining to deafness, from 1990 to 2004. I served on the Statewide Independent Living Council of Illinois from 1997 to 2001. I was a member of the Board of Advisors of the Missouri School for the Deaf from 1999 to 2001, a member of the Relay Missouri Advisory Committee from 1999 to 2007, a member of the Missouri State Rehabilitation Council from 2000 to 2007, and a member of the Board of Directors of Telecommunications for the Deaf and Hard of Hearing from 1993 to 2013. All in all, as time passed I just had less and less time to give to ALDA.

I retired from Southern Illinois University on August 31, 1999 as I wanted to work full-time for deaf and hard-of-hearing people. I retired on one day and began working the very next day as the executive director of the Missouri Commission for the Deaf and Hard of Hearing (MCDHH), a position that I held for eight years. I retired from MCDHH at the beginning of 2008 and devoted most of my energy to serving as the president of Telecommunications for the Deaf and Hard of Hearing, a position that I held from 1997 to 2013.

Benefits of Deafness

When I first became deaf life was “hell on wheels.” I never had time to engage in the art of denial, and I never played the “Why me, Lord?” game or tried to negotiate with the Almighty to get my hearing back. Rather I quickly accepted the fact that I was deaf and moved on to learning how to live productively in the world of silence. I, like all other late-deafened adults, faced continual frustration and
communication challenges. But I hasten to add that deafness has over the years provided me with many benefits.

For example, there can be a violent thunderstorm outside my window and I still sleep soundly. The barking of my neighbor's dog doesn't bother me at all. The honking of rude drivers doesn't faze me. I can sit next to the jet engine of an airplane and the roar doesn't affect me. I can terminate an argument by simply “looking away,” for if a person is not within my field of view they can scream their head off and I am not influenced in the slightest. And deafness has allowed me to become more focused, as I am never distracted by air conditioners running, trains passing, people chatting, clocks ticking, and so forth. In addition, deafness has provided many travel opportunities that I otherwise would not have had. Since becoming deaf, I have been fortunate to give presentations related to hearing loss in places as distant as the Czech Republic, Bulgaria, Israel, Germany and Austria – places that I probably would never have seen had I remained a hearing person throughout my life.

The Meaning of ALDA

For me, ALDA satisfied an important need after I became deaf. I had lived and worked most of my life in the isolation of a small office in a large university – so being “alone” was not the end of the world for me. Then too, I was never a crazy party-goer. Outside of family, I could always count the number of my close personal friends on one hand. So I had no craving for a lot of social interaction that needed to be satisfied after becoming deaf. But like all other late-deafened adults I did have a need for personal validation. I needed to know from others like me that I was “OK.” And I needed very much to regain my self-esteem, which had plunged to the deepest of depths when I became deaf (remember, in a matter of hours I went from being a respected college professor to one who could not even order a pizza on the phone). I needed to feel that I was still a worthwhile human being and could still productively contribute to society. And working with ALDA provided that validation, and gave me that opportunity to use my talents in a productive manner. And for that I shall forever be grateful.

Bottom Line

My world is a pantomime world of people silently moving, sometimes in very strange ways (the driver of a car who is boogieing to the tunes on their radio looks very weird if you don’t know there is music playing!). My world is a world where many old friends have drifted away (but many new friendships have emerged – especially in ALDA). My world is a world full of colors, smells and golden sunsets. And my world is a world where I don’t hear the splash of the lure hitting the water any more, but the tug of a fighting fish on the line still gets my adrenalin pumping.

I once was a teenager, a softball player, a college professor, a hearing person – but I’m not any of those any longer. Indeed, my journey into the world of silence has taken me to many fascinating places where I have met many wonderful people and worked with several marvelous organizations. But there will always be a special place in my heart for the organization that was there when I desperately needed it – ALDA.
From Cradle to Tomb . . . Life Is a Cabaret!

As the second oldest of 11 children, I was probably all grown up by the age of 10. I was the secondary mother to my siblings, a role often assumed by older children in a large Irish Catholic family. As a Catholic girl from Boston, I attended a parochial grammar school and a private French secondary school, Fontbonne Academy (“The Good Fountain”) where I graduated with distinction as a “Latin scholar.” That’s what they called it when you can conjugate verbs in French schools that foster Latin where the Iliad and Odyssey take precedence to French. It was like “Vidi, Voici, Vinci” (sic). Go figure.

My Mom was a stay-at-home Mom when she wasn’t on the golf course or shopping in Filene’s Basement for clothes for her brood. My Dad was a hard-working, affable Irishman who was a leather merchant who sold cow hides from the tanneries in the mid-west to the shoe factories – like Sebago and Bass in New Hampshire and Maine. He was also a Brigadier and later a Major General in the USAF who was the wing commander at Otis AFB on Cape Cod.

We certainly weren’t poor. My parents belonged to the local country club; we summered on Cape Cod, and all my siblings went to similar non-public schools, such as Boston College High School or Milton Academy.

But I digress. As a senior at L’Academie de Fontbonne, I applied to a number of all-female Catholic colleges, probably because I didn’t know any differently. I was accepted at Salve Regina College (“Hail, Holy Queen”), a small liberal arts college in Newport, Rhode Island, which was operated by the Sisters of Mercy. Newport, at that time, was the home of Jacqueline Kennedy’s mother, Janet Auchincloss. My girlfriends and I always attended Mass at St. Mary’s on Thames St., where John and Jacqueline Kennedy were married, and we’d take Sunday drives with our boyfriends along Newport’s snooty Ocean Drive. We never failed to point out Caroline Kennedy’s horse, Macaroni, who would be peacefully grazing on the Auchincloss Estate, Hammersmith Farm, oblivious to his equine fame.

Throughout his Presidency, JFK would fly with his entourage into Otis AFB in order to spend weekends at his compound in Hyannisport. My siblings and I would stand at attention outside our cottage and salute our Commander-in-Chief. In the summer of 1963 we had the privilege of boarding Air Force One. What an experience! Alas, that was also the summer Jackie lost her third child, Patrick, in August, followed 3 months later by the assassination of her husband in Dallas.
I define my childhood and my teenage-hood by all these events. The 1960’s was the Age of Camelot and paradoxically, the Era of Chaos. There was the first step on the moon, Vietnam, Haight-Asbury, Woodstock, Newport Jazz Festivals, and in 1967 the Red Sox became “The Dream Team” with Jim Longborg, Carl Yastrzemski, Jim Rice, et al. Up until that World Series with the St. Louis Cardinals, I had perfectly normal hearing. I was a child of privilege and I knew it. I was a student of ballet, a dilettante at piano, a lover of classical and pop music. I equally adored the Boston Red Sox and the Boston Pops. I was good at academics, and I had a lot of friends and classmates who enjoyed hitting the Skoal Room on weekends, a local bar in Newport, to see if we could meet any worthy JG’s (Naval Junior Grades) from the nearby Naval Academy. My dream was to become sufficiently fluent in French to qualify for the U.S. Diplomatic Corps as a translator. At age 19, perky and privileged, I was well on my way to achieving my dream. And then I became deaf.

With a Song in My Heart

The song was “Don’t You Worry ‘Bout Me, Baby” by Franki Vallee and the Four Seasons. I was in Mercy Hall, originally a horse stable from the Vanderbilt Estate that was converted into a freshman dorm at Salve Regina. Kathy, my best friend, was in St. Joseph’s Dorm on Newport’s tony Bellevue Avenue. Neither of us could figure out some of the lyrics. . . “I’ll be true, I’ll always think of you . . . go on and something-something, but don’t you worry ‘bout me, baby.” Kathy and I both had normal hearing. Why couldn’t we figure out what Franki Vallee was singing? So we listened to it over and over, and finally I figured out the missing lyrics . . . I couldn’t wait to call her at St. Jo’s. “Kath,” I exclaimed jubilantly, “They’re singing ‘Go on and be his bride, but don’t you worry ‘bout me, bay..aay..bee.’” She was floored! She said, “My God, what an excellent ear you have.” So true, but that ear only lasted for one more month.

There are a multitude of reasons why I became deaf. The medical reason — and the one I am more comfortable revealing — is that I was admitted to Massachusetts General Hospital with a gastrointestinal condition called Crohn’s Disease. It was there that I entered the emergency room with a body that had gone into shock from septicemia. My physician, trying frantically to save my life, ordered an intravenous feeding of an antibiotic known as kanamycin. Kanamycin turned out to be a highly ototoxic drug. The bottom line is that it presumably saved my life but destroyed the hair cells in my cochlea, thereby rendering me deaf, with a concomitant horrible condition known as tinnitus.

There are other factors associated with my Crohn’s Disease, including being “nurtured” by a mother with a severe psychiatric disorder known as Munchausen’s Syndrome by Proxy, but that’s a whole different essay. The end result was that I entered Massachusetts General Hospital as a very sick young adult with perfectly normal hearing, but left MGH as a recovering Crohn’s disease, Munchausen’s victim with a severe-to-profound sensorineural hearing loss. It didn’t take long before I became suicidal.

Everyone reading this story probably knows what happens next. The depression, the stages of grieving, including denial, bargaining, anger . . . suicidal thoughts . . . we’ve all done it.

And Then There Was ALDA

I cannot remember or pinpoint the exact moment that Bill Graham and I connected. I do recall we were both listed in the 1987 Directory of the American Association for the Advancement of Science. Both of us had self-identified as scientists with deafness, and Bill took the initiative to contact me and ask how I became deaf. We pursued a very lively dialogue in which he described his attempt to host a national conference for people who – like Bill and me – had become deaf as young adults. I was so
desperate for peer support at that time that I pounced upon the opportunity to become involved. Bill’s vision included a self-help module, combined with a social model that would prove that late-deafened teens and adults like him and me could have a social life outside a Deaf Culture model. How radical! But it made perfect sense. We realized we were deaf, not Deaf. We acknowledged that for us, deafness is a sense of loss. We were deaf individuals now living within the fabric of hearing families and hearing culture. Sign language? Sure, we could try it, but most likely we’d never be fluent in it. Speechreading? Forget it. It had its merits, but was not the equivalent of understanding everything that was spoken.

After networking with several people around the country, Bill wanted to host a conference in Chicago. And so we were off and running as conference planners. He built a great team of planners with Mary Clark, Helene Maram, Cleo Simmons, Diane Tokarz, Steve Wilhelm, Stan Gadsden, and Bill’s not-yet wife, Karina Kozlowski. He lined up the fabulous self-help guru, Laurieann Chutis, to lead us through introspection. He secured, with Cleo’s help, the auditorium at Mercy Hospital in Chicago. All systems were go, with one major exception. How would the very first ALDAcon attendees communicate? Our dilemma was that we had the capability to host the best workshops on late-deafness currently available at that time, but we had limited means to make sure that all of us understood what was being said. Enter Jerry Miller, Marty Bloch, B.J. Shorak, and Ben Rogner from the courts and court reporting profession.

We realized that the only common denominator for all of us was reading the spoken word. Steve Wilhelm helped us tremendously by setting up ALDA Crude, a method whereby hearing typists used a cheap Radio Shack computer. Jerry Miller – president of the National Court Reporters Association at the time – and his band of brothers also came forward with help from a few stenographers who were exceptional and skilled in their trade, but in 1989, they were restricted by their professional software to deliver what we now know and appreciate simply as CART. At that time the service was often known as computer assisted real-time transliteration, but it is now generally referred to as communication access real-time translation. For example, take the following sentence: “We now know and realize that there are many sources of information for us to take advantage of.”

This would appear on the screen as:

“We now {know, no} and realize that {there, they’re, their} are many sources of information {for, fore} us {to, too, two} take advantage of.”

Today, we are spoiled with much more sophisticated software and extremely high certification standards for our CART reporters. I count my blessings.

The first ALDAcon was an epiphany for me. I fell in love with all the 42 original attendees, whom we later dubbed as ALDA Pioneers.¹ I cried flying home. I did not want to leave my new-found friends. I schemed for ways to convince my family to move to Chicago so I could have the benefit of support from my late-deafened colleagues. Of course I wasn’t being rational to expect my family to become uprooted for my personal gain, so I decide to do the next best thing and start an ALDA chapter in Boston.

That’s Entertainment!

I was the planning and program chair for the first ALDAcon outside of Chicago – held at the Park Plaza Hotel in Boston in 1992. I realized my life was irrevocably changing as a leader for an association that my heart and soul could identify with. We were young, somewhat reckless, always willing to take a risk. One of our Boston members approached me and asked if I would consider some entertainment at the

¹
Friday night banquet. This was a troupe of dancers called the “Body Language Dancers.” Some were Deaf and some were interpreters. They lip-synched and danced to such numbers as “Stand by Your Man” and “Nobody Knows You When You’re Down and Out.” The entire program was captioned in real-time and projected on a jumbotron in HUGE text for all to read. The audience was enraptured. After the show the dancers asked me why people were not laughing at their slapstick routines. I explained that they were overcome with tears of sadness and joy. It was the first time since most of us became deaf that we could follow the song and dance routine and identify with it. We were simply floored by the ability to follow along. But then the next night we introduced karaoke, and the best was yet to come.

I Could Have Danced All Night

In 1992, the Boston ALDAcon planning committee decided to try out something new in the field of music called “karaoke.” It was a Japanese innovation where a DJ would play music that was captioned on a monitor, and the participants would sing along with the musical artist. It was a lot like following the bouncing ball on TV when Howdy Doody or Mr. Rogers would play a sing-along. My planning committee members were psyched for us to try it, but I was scared out of my wits.

Those of us who become deaf experience a tremendous sense of loss over music. I can remember trying so desperately to hear Elvis again by putting all my 33 1/3 rpms on a reel-to-reel tape deck and listening with headphones . . . to my tremendous disappointment. Elvis’s exquisite baritone in “I want you, I need you, I love you” sounded like a desperate shrill crying, rather than the beseeching love song it was intended to be.

So now at ALDAcon ’92 in Boston, I was forced to make a decision: karaoke or no karaoke? The previous evening’s experience with the Body Language Dancers led me to shoot it down. Will ALDAcon attendees cry and become depressed over this new innovation? Or would they embrace it? In the end, the risk-taker in me took over and said “let’s do it.” And the rest, of course, is memorialized in ALDAcon history.

I cannot begin to describe the euphoria I felt over the years at watching ALDA members hog the microphone to belt out their favorite tunes. I cannot express my incredulity at watching spouses or friends of ALDAns in wheelchairs dance with their mates on the dance floor by whirling wheelchairs around. I cannot do anything but secretly cry with emotion whenever I see someone holding onto a balloon to feel the vibrations during “Proud Mary” or “Jailhouse Rock.”

The Witch of the East

ALDA had its growing pains, for sure. As we were moving more globally and nationally, a very active chapter popped up in California called ALDA East-Bay. Fax communications were becoming quite popular and e-mail was not far behind. I remember being ALDA’s president during a very tumultuous year in 1993 which was wrought with by-law changes and members demanding a re-election. This is typical of organizational growth. However, by the time we held an ALDAcon in Miami in 1997, I was a regular party-goer with most of our West Coast members. One of them, Ken Arcia, and I really hit it off, and we had a blast in Miami. After a fun night of partying, Ken asked me my name. I signed that I was Marylyn Howe. He suddenly looked horrified and signed back, “Oh my God! Rumor has it that you are supposed to be a colossal bitch!” I said, “Ken, trust me. Those are not rumors. I AM a colossal bitch!

What a Day This Has Been, What a Rare Mood I’m In
Since becoming involved, I can’t really summarize the tremendous role that ALDA has played in my life. My involvement has led to multiple opportunities to make a difference. I have served on the National Council on Disability, a 15-member independent agency that advises the United States President and Congress on disability issues. In my day job I have worked at Children’s Hospital in Boston and as the director of public policy for the Massachusetts Developmental Disabilities Council. I currently work for the Federal Emergency Management Agency (FEMA). I am deaf. I am gainfully employed. I married a guy who dated me when I became deaf and we have just celebrated our 47th wedding anniversary. I have three beautiful, healthy children and an adorable, huggable grandson (is there any other kind?).

Does it mean I don’t have bad days? C’mon. I desperately want to use a cell phone like hearing people. I yearn for those radio days of yore. But they’ll probably never happen. I’ll never participate 100 per cent in an all-hearing conversation. However, I am blessed with many, many ALDA friends. With their genuine empathy, passion, friendship, and love, they sustain me.

Although I’m also an Irish citizen, I’m married to a true Brit, and I embrace the words of an old English saying as it reflects on ALDA:

*Shared Joy Is Doubled; Shared Sorrows Halved*
As Bill Cosby once said to open an album: “I started out as a child!” That is stating the obvious, but it brings back memories of what I used to do as a hearing child. Lying on the living room floor and listening to Bill Cosby records was a favorite activity if there was not a sports event on the air. Iowa Hawkeye football and basketball games as well as Cubs games had a higher priority than Bill Cosby, but it was still an enjoyable activity.

I grew up as an Iowa farm boy. I am proud of that. My father still lives on the family farm of 200 acres, or thereabouts. On the farm, we had cows and hogs at various times. We had crops of corn, soybeans, and oats. I will NEVER consider making hay in the summer one of my favorite memories, but it is indeed a memory. The cold lemonade or ice water in between loads of hay is an even better memory.

As anyone in my family will tell you, I am mechanically inept. I did not have the aptitude to be successful on the farm, and attending college to obtain a different type of job was always my goal. It was a goal for my parents too. They successfully managed to get all five boys through at least four years of college. Quite an accomplishment on their part!

I was the oldest of five children and the first to go away to college. Although my family lived 15 miles from Iowa City and the University of Iowa, I wanted to attend a smaller college. I chose to attend Simpson College in Indianola, Iowa, in part because an uncle had previously attended classes there.

**Becoming Deaf**

Being a first-year college student and away from home for the first time was an exciting experience. I went through homesickness temporarily and then adjusted. I made it through the first semester just fine. After returning to school in January, I became sick. It started out as a typical cold with cough, sore throat, and nose-blowing every five minutes. It became worse, and I developed a fever. But I kept going to class, drinking all the fluids I could find, and then going back to bed as soon as class finished.

I soon began to notice that it was more difficult to hear the instructors in the classroom and the classroom discussions. It became more difficult to understand what students in the residence hall said. It became more frequent that students down the hall asked me to turn the radio down. It became more difficult to hear the TV.

I did not tell anyone about it. I would act as if I was not paying attention when people talked to me so I had a reason to ask them to repeat what they said. But people soon figured out something was wrong, and, for the most part, I went into isolation mode. If you do not interact with other people, then you do not have to worry about understanding what they say. That was my approach.
The first real experience I can remember that helped me become fully aware that I could not hear occurred in a restaurant. My father and uncle had driven me back to college after a weekend at home. We stopped to eat nearby before they returned home. I had worked in a steak restaurant so I knew the regular routine for questions the server might ask. I ordered a hamburger, and after she spoke next I replied “everything”. I saw a look of shock on her face as she said something again. I repeated “everything!” Now my father and uncle were looking at me too. Hmmm, what the (bleep) was wrong?

It turned out that the server was asking me what kind of potato did I want. She was supposed to be asking me what I wanted on the burger! That was a poorly trained server, and it was my first embarrassing moment as a deaf person!

The next time I went home was for spring vacation. At the end of one week, it became very obvious to my parents that I was not hearing well, and something must be wrong with my ears. Instead of returning to college on Monday, they took me to the doctor’s office. This doctor had known me since I was a baby. He looked into my ears, and said there must be some fluid in there. He gave me some medication and referred me to an otologist in Iowa City.

The otologist looked in my ears, up my nose, down my throat, in my eyes, and whatever. He then made the startling statement that “I can’t find anything wrong”. Well then, why can’t I hear? My mother said the hometown doc had seen fluid or scar tissue in my ear. The otologist then looked again and said there was no visible problem. This doctor then asked me if I was worried about being drafted into the army. My answer was “NO!” I had a lottery number of 230 or something like that and there was little chance I would be drafted.

That was my first negative experience with ear doctors. I would see many more otologists over the next couple years, but I did not return to his office. My parents were very concerned about finding the reason I could not hear. At that time, I guess I was thinking it would be temporary. I had no experience with hearing loss and had not met any people who were deaf.

Here I was – 18 years old and deaf. What the hell was happening with my life? I was not a happy person during those times. It was very difficult for me to deal with being deaf. I had no perspective. I spent the summer working in the restaurant as a cook/dishwasher as well as doing some work on the farm baling hay and other odd jobs. This was not exactly how I had dreamed of young adult life.

In the spring of 1971, I bought my first hearing aid. I thought that would solve my problems. I could hear sounds but I could not understand speech. It was frustrating because I could not hear as well as expected. I also had to work keeping the hearing aid hidden behind my ear and under the long hair I was growing. I did not want other people to see me as a person who was deaf.

After transferring to a different college for the fall of 1971, I found I was not having any success. My grades were very average and I was not enjoying college life, so I withdrew from college and moved home. I decided to take a lipreading class but did not do well at that either. I had two strikes against me now because I had always assumed that either hearing aids or lipreading skills were the only ways deaf people could be successful in the world.

Over the next 18 months I worked in the restaurant and on the farm, and made plenty of visits to the hospital to have different tests done on my ears. Some of them were not all that pleasant. Anyone else have the test where they put ice water in your ears to test your balance system? It is supposed to make you very dizzy, but I did not feel anything but the pain of the COLD ice water.

**Finding Help**

The good thing about the hospital visits was that a social worker informed me about the State Department of Vocational Rehabilitation. Elmer LaBranche, my VR counselor, was the first person I met who knew that deafness involved more than audiology. He gave me and my parents information about the various college programs in the United States for deaf people.
Mr. LaBranche informed me about Gallaudet College (now Gallaudet University) and gave me information about a sign language class there. I attended the class for eight weeks and felt so proud of myself that I could sign “My name is S-t-e-v-e” when I first showed up at Gallaudet. After the first hour of seeing ASL in action, I knew I had a lot of learning to do.

It took time and patience, especially on the part of others, but I did become comfortable with sign language. I cannot explain why I stayed at Gallaudet. I was slow learning sign language and others dropped out because they could not sign well. All I knew is that the little sign language I could understand was much easier and made me feel more comfortable than lipreading or using a hearing aid.

While attending Gallaudet, I had the opportunity to meet and know two other people who became presidents of ALDA – Robin Titterington and Bernie Palmer. To the best of my recollection, we never discussed our onset of hearing loss. Bernie and I were in the same orientation group at Gallaudet, starting in the fall of 1973. I met Robin during my senior year; she was a wheelchair-using student. I was a part of her reasonable accommodation there. She was able to get to the second floor of her dorm because I carried her up the stairs. She was also able to get in the Rathskellar (Gallaudet student bar) on occasion because I carried her down the stairs. I also got her out of the building by carrying her back up the stairs, although I did threaten a time or two to leave her there.

Attending Gallaudet was a learning experience for me. It gave me an introduction to Deaf people and helped me realize that becoming deaf was not the end of the world. I graduated from Gallaudet with a B.S. in Business Administration with emphasis in accounting. It was my goal to return to Iowa to seek a job in the accounting field. While I enjoyed my time at Gallaudet, I did not feel the need to live in an area with a larger deaf population. It was my intent to seek a job close to “home.”

There were a few things wrong with that plan. One, I had done minimal preparation in seeking a job before graduation. I had developed a resume but had not utilized the Career Office at Gallaudet to participate in interviews and prepare for the job search.

Quite simply, I did not know how to sell myself during a job interview. The Americans with Disabilities Act (ADA) did not exist at that time. I went to job interviews by myself, without an interpreter, and tried to communicate through lipreading. I am a terrible lipreader. (I nominate myself as one of the worst lipreaders ever). I was almost apologetic about having a hearing loss, and not prepared to explain my education and knowledge in accounting.

I was more focused on what I could NOT do than I was on what I COULD do. Today, technology makes it easier to explain accommodations to an employer. With the Internet, pagers, and videophones, accommodations are more familiar and not necessarily as expensive as accommodations in the 1970’s. TTYs were just becoming portable at that time, and I did not know any sign language interpreters who lived in my hometown area. I was not confident enough to push for those things anyway.

Another issue was that I had graduated without taking any computer courses. I could have stayed at Gallaudet an additional semester to take some courses. Businesses were beginning to use various computer languages, and it would have been to my advantage to have that knowledge.

Also, I had assumed Vocational Rehabilitation would find a job for me. WRONG!!! Mr. LaBranche had retired, and there was no counselor available with sign language skills after my graduation.

I worked in a factory for a month before accepting a bookkeeper job. I liked working in an office environment much better than the factory, even though it paid less. But after a year on the job, I decided I could be a better VR counselor than the person working with me. I learned that I had a better chance of becoming employed in the field if I had a master’s degree. I applied for the Deaf Rehabilitation Counseling program at Northern Illinois University and was accepted. Fortunately, my parents were able to provide some financial support, and I was able to convince VR to help pay for tuition.
Starting graduate school at Northern Illinois University (NIU) was one of the wiser choices I have made in my life. It put me in an environment with people who used sign language. It also gave me the opportunity to learn more about deafness itself.

The courses I took at NIU helped me to understand some of my experiences at Gallaudet. I knew that many deaf people did not have good written English skills. I did not know why until graduate school. I learned more about Deaf culture and its traditions. I had experienced some of these traditions at Gallaudet but did not understand them.

I also learned that my hearing loss was probably a combination of viral infection and high fever. I think my doctors made that diagnosis, but I was always looking for a better answer – malaria, meningitis, or whatever. Viral infection and high fever did not seem to fit, but it is the best explanation I have.

While attending NIU, I met two people who would become ALDA stalwarts – Dawn Hicks Maerz and Kathie Hering. We talked some about the needed adjustment to sudden hearing loss, but there always seemed to be other things to talk about too. Both Dawn and Kathie had neurofibromatosis (NF) and I began to learn a bit about the disease. I have always been thankful that my hearing loss was due to other causes and not NF, a devastating disease in which tumors grow continually throughout the body.

I recall having conversations with Dawn and Kathie about becoming deaf and dealing with the various personal issues related to late-onset deafness. I had been using sign language for 5-6 years at that time, and Kathie and Dawn were also able to sign. We talked about learning sign language, family communication issues, and all the other little things where hearing loss can have an impact.

After receiving my degree, I accepted a job as program counselor for the Program for Hearing Impaired at Northern Illinois University. This job put me in an environment where I was working with deaf and hard-of-hearing students and with staff people skilled in sign language. It was comfortable for me, although I still had to deal with nonsigning people at times. I also had to deal with those types during nonworking hours. Even now, more than 35 years after becoming deaf, I am not very good at admitting I am deaf. If people approach me and I see they are talking to me, I often say “I don’t know,” even though I don’t know the question.

Overall, it has always been much easier for me to avoid conversations than it has been to deal with repeated efforts to understand. Every once in awhile, I will meet a person who is willing to write their question and it is always a relief to be able to give an absolute answer. I can then say “I don’t know” because I really do not know!

Finding ALDA

I was employed as counselor for almost seven years. I was becoming bored with the routine of the job and wanted a different challenge. I accepted a job in Lincoln, Nebraska, as executive director for the Nebraska Commission for Hearing Impaired (now the Nebraska Commission for Deaf and Hard of Hearing) in January 1987. That same month, I received a call or letter from Kathie Hering saying she was starting up a group for adults who had lost their hearing in the Chicago area. She invited me to attend. I said no for three reasons: (1) I was moving to Nebraska, (2) I hated driving in Chicago, and (3) I did not see a real need for this type of group. Little did I know that I was missing out on what could be considered a historic event.

I moved to Nebraska and enjoyed the new challenges. However, I did not enjoy life in Nebraska. I missed the daily contact with students and my NIU friends. While attending a conference on deaf and hard-of-hearing issues, I saw Kathie Hering there. She was quick to supply me with copies of the ALDA newsletter and talked about this dude named Bill Graham. I read the newsletters and enjoyed them.

I assume I was like most people and my first thought was Bill Graham, the “evangelist.” Well the ALDA Bill Graham shared a different type of message – beer and pizza for everyone! – and I found it to my liking. Bill has a humorous way of sharing experiences and still getting a message across to people.
In July 1989 I moved back to the Chicago area to take a different job. Kathie soon invited me to a picnic at Bill Graham’s house in Chicago. I gathered up my courage to deal with Chicago traffic and managed to read the map well enough to find the place. Kathie introduced me to Bill and, after offering me a beer, he asked how and why I was interested in ALDA. We started talking and I became interested.

I joined ALDA and started receiving the newsletter. I also remember that most of the newsletters were accompanied by a very nice note from Cleo Simmons, who is the original ALDA Angel I believe, and to me will always be the true ALDA Angel. I remember the excitement about the first ALDA conference and having people from various parts of the country attend. Me, I chose to attend an Iowa football game that weekend. As I recall, Iowa lost to Michigan, and I missed out on another historic event.

I became involved with the planning committee for ALDacon II in 1990. It was an interesting experience, to say the least. Bill Graham, Steven Wilhelm, and I labeled ourselves the Three Stooges, and we acted as such during the planning meetings.

The conference was a success in many ways. I, King Jordan, president of Gallaudet, attended and spoke at the conference. Financial support from the Illinois Department of Rehabilitation Services kept registration at a low cost – something like $25-$30. I remember being nervous about the conference because I did not know what to expect. I quickly became comfortable being among my peers.

Memorable events from the 1990 conference include:

First, listening to King Jordan speak and thinking to myself “I have those same experiences.” King became a role model for me.

Second, being elected to the ALDA board of directors. It was an honor and also became a lot of work as the board began to develop plans for the organization.

Third, and most remarkable, learning what ALDA was doing for people. I met a woman named Barbara Vernon from Wisconsin. Barbara had both hearing and vision loss. She was unable to read the small print that was being provided to caption the meetings. Her hearing made it difficult to interact with others. She was also there alone among strangers. On the first day, she carried her suitcase out of the hotel, planning to go home. Some ALDA Chicago folks stopped her, I cannot recall who. When I saw Barbara she was sitting at a table with Kathie Hering and Cleo Simmons. Crying and apologetic, she was writing notes with others at the table since her sign skills were limited. Kathie and others convinced her to stay and someone tried to accompany her at all times. Barbara did stay, and on Sunday when going home she was crying again. This time it was because she did not want to go home to Wisconsin. She had found a home right there in ALDAland and did not want to leave.

The 1990 conference was the reason I stayed involved with ALDA for the next 13 years. The patience that ALDA members have in communicating with each other, whether it be writing, speaking slowly, signing slowly, trying to fingerspell, typing on a laptop, or using “ALDA Signs” has always amazed me. I have to admit I do not always have the patience to communicate in that manner. I prefer to be among signers, but that is not the “whatever works” communication philosophy of ALDA.

I became president of ALDA in 1994. That was the year when a group of ALDA members, calling themselves Fair Elections Now (FEN), requested a second election as they were not satisfied with the ballot during the first election. My memory is hazy of the exact reasons. I chose to run on the second ballot and became president in the spring of 1994.

1994 was the year ALDA had its conference in Toronto and the only time ALDacon has been held outside the continental United States. I recall giving the opening; I think the theme was “ALDA in the Family.” I remember the karaoke party was held near a Rolling Stones concert, and getting back to the hotel was chaotic since a huge crowd left the concert at the same time.
Reflections

I was actively involved in ALDA from 1990 to 2003. During that time I served as treasurer and president, and also as conference planning chair, business manager, and program chair for various ALDAcons. I drifted away from ALDA for many years, but have become involved again and am now serving my second term as president.

ALDA will continue to exist as there is a core group of people who continually commit their time to the organization. The need for social events for deafened people will always be there. I do think there will be an ongoing turnover as ALDA helps people to move on with their lives and newcomers enter looking for assistance.

ALDA was set up to provide deafened adults with a social network that would allow them to communicate in a comfortable environment. Comfortable means that you can say “Huh?” ten times over and no one criticizes you. Comfortable means that people are willing to take the time to write notes back and forth or, in the case of Roy Miller, being willing to type back and forth on the trusty laptop he always carries. Comfortable is being able to share the frustrations of the lack of communication with family members or co-workers.

ALDAcon in its 27th year still provides a valuable social network for deafened adults. The Saturday night karaoke party is without doubt one of the top social events ever created for deafened adults. I love being able to see the songs I knew as a youth, and to sing/sign/lipsynch them with my ALDA friends.

Why is ALDA not growing? I think there may be several answers. People grow and find they no longer need ALDA. In my case, I married a wonderful woman with whom I can communicate openly. Now, I can go home and express any frustrations I have with her. My family situation has changed with step-children, grandchildren, and in-laws who have accepted me. Through this support, I have also enhanced my relationship with my own family.

My suggestions for ways to increase membership would be to include more of a family focus at the conferences. Most adults attend without spouses or significant others. There are few workshops offered of interest to family members, especially in the areas of understanding hearing loss and coping with that loss. We need to remember that sudden onset hearing loss impacts all family members in some way, not just the person who has the loss.

ALDA needs to hire a professional to help lead the organization. With the constant turnover of board members and officers it is difficult to know what has happened and what needs to happen. Having a professional staff person would provide more consistency in responding to inquiries from newcomers, in planning events, and in seeking outside funds to support the organization.

I am now a professional in the field of deaf and hard-of-hearing services. I was in this field before finding ALDA but ALDA made me explore the effectiveness of these services and extend services to deafened persons that may have not been previously offered. I have made numerous presentations at conferences regarding the needs of deafened adults. I would not be doing that if it were not for my ALDA experiences and watching Bill Graham and King Jordan openly share their experiences as deafened adults.

I am grateful for the opportunity to share these experiences and wish everyone a happy 27th year celebration.
Before Deafness

Amid a blinding snowfall, I was born in upstate New York. Actually, I don’t know if it was snowing but since it was New Year’s Eve, there’s a good chance it was. Due to my father’s work in the newly growing field of nuclear energy, we moved quite a bit and I spent time in New York, Vermont, Illinois and New Jersey. As I grew, my parents always told me I would go to college, just like my much older brothers. That may not seem so odd, but I graduated from high school in 1973 and there were not many college opportunities for those who use wheelchairs. I think it was God’s grace that led me to St. Andrews Presbyterian College (now St. Andrews University) in Laurinburg, Scotland County, North Carolina. Although definitely not a “school for the disabled,” SAPC was opened in the early ‘60s with a commitment to be accessible for all.

My first semester in college, I cried every time I called home. I did well academically and loved the physical freedom of the college campus but I missed my dad so much. When I went home for Christmas, I learned he now had a new “lady friend” and by Easter, they were planning a wedding. That knowledge seemed to free me, because I loved my second semester. The summer began with the wedding and adjusting as a new family. But throughout that summer, I didn’t feel well with the kidney infections that had followed me most of my life.

Just when it was time to return to college, the doctor decided I needed to go to the hospital. To say I was not pleased is a vast understatement. Six weeks later, I had experienced two kidney surgeries, an appendectomy and become deafened virtually overnight from the antibiotic, gentamicin. Years later, driving with fellow ALDAAn, Tony Yuppa, we passed the Trenton, NJ exit and I said, “That’s where I lost my kidney, my appendix and my hearing!” to which he replied, “Couldn’t you be more normal and lose your wallet?”

Attempts to Adjust

I came home from the hospital (I think) in mid-October. I was very weak but by Christmastime I was physically well. Soon after my release from the hospital, my parents took me to an audiologist for a hearing test. I have no idea what she told them since I couldn’t hear it (!) and no one explained anything to me other than that the next stop would be a hearing aid dealer. I did get the hearing aid (only in one ear, the other is “stone” deaf) and she smiled and said, “CAN YOU HEAR ME NOW?!?” and wished me
a nice day. There was no explanation of what I could/could not expect from an aid. My communication was somewhat limited to family, although I knew I couldn’t hear my records (remember those?) or the television, I don’t think we really thought about how it would affect my life. As Christmas approached, there was no doubt that in early January I would be returning to St. Andrews. Partly, that was my dad’s philosophy of “get over it,” but also I think we didn’t have any concept of “adjusting.” This was long before ALDA and how would one adjust? Also, to be honest I WANTED to go back to college, that’s where my friends were.

And then the real world hit. College was not as I remembered. I could understand virtually nothing in the classroom and not much more with my friends. We did get vocational rehabilitation to pay for note takers and I was blessed with good friends who did that and never made me feel badly about asking. (Thank you, Gertrude and Betsy!) I have always been a “people person” and yet now, my social life was non-existent. There were days when I would leave my room, promising myself I would not miss a word by lipreading. Of course one minute in the cafeteria and that was shot. St. Andrews works on a 4-1-4 schedule so during the month of January, one takes only one class and it is something not offered during the rest of the year. I took a literature class under Dr. Carl Bennett. I did not know him before the class but without the late Dr. Bennett’s support, I am sure I would not have stayed in school. I was honored to take his classes again and not only was he always available in his office for class review, but he instilled any writing skills that I have today.

My advisor during my college years was Dr. Robert Urie, an education professor who is also a wheelchair user. During the next many months, I was frequently in his office telling him how my friends had changed in the one semester I was sick. He would calmly ask, “How much of this do you think is related to your hearing?” but I would assure him it was not that. I knew my hearing would not get better and if I said, “Yes, that’s it,” I felt life would always be this miserable. I did go to summer school to make up the missing semester. I was determined to graduate with my class.

During this time, I took two lipreading classes: the first was taught by a woman who told me that if I worked hard, I could go to parties and no one would know I had a hearing loss. She brought out the first practice sentences: “I found a penny in my purse.” “The capital of Japan is Tokyo.” The first lesson was also the last. In the short time I was home that summer, my VR counselor sent another teacher to my home. We practiced with the radio on so I could not use my residual hearing and we practiced in context: one lesson we would be in a restaurant, one at a drugstore and so on. I’m not sure how much “lipreading” I really learned but it did teach me to be more aware of context. Oddly enough, at my request, the teacher also taught me fingerspelling.

In the fall of my junior year, Dr. Urie suggested I take a semester off and go to Gallaudet College (now Gallaudet University). “Horrified” might be the best description of my reaction. Why would I need that? That was for DEAF people and I only had a little hearing problem. Looking back, I suspect there were phone conversations with my parents and before I knew it, Dr. Urie had made arrangements for me to spend spring semester at Gallaudet. My then-boyfriend took me to the airport at Christmas and we both cried.

**Gallaudet**

Gallaudet provided challenges in that in those days, it was not designed for wheelchair users. I not only could not leave my dorm alone, I actually had to be carried to some of my classes. The school arranged for a couple guys to be my “aides” to push me to/from various locations and what now seems almost a miracle, one of the aides had a best friend named Steve Larew! SO, two of your former ALDA presidents met long before there was an ALDA! Steve carried me up and down so many stairs that we
still describe him as “Gallaudet’s answer to ‘reasonable accommodations.’” After we left Gallaudet, we did not see each other for over 15 years until we met again at ALDAcon ’92 in Boston. And we look back in amazement that during that semester at Gallaudet, we never discussed our hearing loss, although our experiences were somewhat similar. We just had no identity as deafened persons.

There is no doubt that the immersion experience at Gallaudet helped me learn sign faster. “ASL” was just becoming “known” and we “signed.” I met my roommate and spelled my name and then asked her what her major was. Her response was “I don’t read lips!” When I went into the cafeteria, there were signs saying, “pointing is not nice.” As I tried to spell “green beans” I found my classmates more than willing to teach me signs. (“Will we ever get to eat with her spelling?!”) I was fortunate that I had no negative feelings about sign although in the beginning, I thought I was learning for “them,” not for me. Before I left Gallaudet, sitting in the Rathskellar with Steve and other friends, I had an epiphany that I had not changed since my hearing loss, only my means of communication had changed.

I spent the following summer working in New York City and living in an un-air conditioned dorm (I just threw that in for sympathy!) And then I returned to St. Andrews for my senior year. At first I tried signing around my friends but was told it was “distracting.” One or two people did know the ABCs. In fact one of my classmates had Deaf parents. He signed to me once or twice but it was so fast, it scared me to death! In the spring of my senior year, as part of a class project, I decided to teach a six-session sign language class. I think I only knew enough signs for six classes! We had to turn people down! And suddenly I had many more friends wanting to practice with me! I had a great ending to my time at St. Andrews and for the first time ever, they had a sign language interpreter at graduation (never mind that I couldn’t understand him!)

**On to NYU**

I’m not sure how I found the booklet about graduate programs at New York University but there was a degree program for “Deafness Rehabilitation.” After working in Washington, D.C. the summer after graduation, I began life in New York City. I don’t think I had any noble goals to rehabilitate deaf people, I thought maybe I could figure out what had happened to me! My roommate, Barbara, knew a little sign and became so immersed; she later became a certified interpreter and remains a dear friend. She also introduced me to the wonderful, diverse world of New York City after my rather sheltered life in rural North Carolina. There were several deaf students in my program and there were interpreters in the classrooms. My first thought was, “EEK, they think I will understand this?!” but I quickly adapted, especially with the extra practice with my classmates. I returned to Washington, D.C. to work the next summer and finished my M.A. in January of 1979.

**Becoming a Southern Belle (Sort Of)**

After experiencing a blizzard in NYC that is talked about to this day, I knew I could not live in the north. I found a job in Rome, GA as a counselor at a new “hearing impaired” program at Floyd College (now Georgia Highlands College) To say Rome, Georgia was a switch from New York City . . . well, I proved I am flexible if nothing else. But just two months after I arrived in Rome, my beloved daddy died unexpectedly. I found small town life was not for me but I can’t say enough about the wonderful people in Rome and Cave Spring who I am sure, helped me stay sane and that is no exaggeration.

About a year and a half after I had moved to Georgia, I got a call asking me to apply for a new job in a new independent living center in Atlanta. I wasn’t sure what that meant, but I was definitely ready for a return to a bigger city. The very first weekend I moved to Atlanta, I was told by my new boss I had to go to a “504 training” and that included staying in a hotel (which seemed odd since I lived ten miles
from there). There was one other deaf person in the training, my dear roommate Mary. She and I still joke about the look on her face (looking downnnnnnnn) when she realized her roommate was also a wheelchair user. We have been like family since and Mary introduced me to Bob and they both welcomed me into the culturally Deaf family where I was welcomed, taught and loved. To this day, I spend Christmas Eve with Mary, Bob, his wife Karen and the “Deaf orphans” they always host. Over the next several years I stayed very active in the Deaf community, improving my ASL and taking several leadership positions including delegate to the NAD convention in Denver. And yet another miracle occurred, I met Cheryl and Fred Heppner (and the late wonder dog, Dana) and this was still before we had discovered ALDA!

So, I thought I was happy. I had no communication at all with my brothers in Denver whom I missed but my Deaf friends always assured me we should be proud to be deaf. I love them dearly but none of us realized I still needed to grieve my loss. There were, however, changes in technology. I often say I didn’t feel like a grown-up until we had the relay service and I could make my own calls. And after seven or eight years with no television, we had captions! It was like coming out of time travel, “They can say THAT on television?” To this day, I don’t really like most television other than the news, the Braves and “Dancing With The Stars”! Also with the advent of computers and email I was able to renew friendships with college friends like Gertrude Beal and Steve Lindsay. Gertrude has gone through the whole “adjustment thing” with me and is a blessing in my life!

And Then There Was ALDA!

To this day, I don’t know how that newsletter ended up on my desk at work. I thought it was the craziest thing I ever read. It was people who had become deaf and they laughed about it! I just had to meet them. The only name I recognized was that of Steve Larew. I did start a correspondence with Jerry Barnhart who was finishing up his Ph.D. at Gallaudet. I went to Washington, D.C. for Barbara’s wedding and spent a day with Jerry. So other than Jerry and Steve, whom I had not seen in over 15 years, I did not know a soul but I knew I had to get to ALDAcon. The newsletter was full of all the fun they had. And the next one was in Boston!

ALDacon ‘92

What can I say? I knew as soon as I checked in I was “home.” I looked over at a table of “ALDAmania” (souvenirs!) and saw a big button with the then logo of balloons. But wait! It was actually two buttons, they were identical but one said, “Sign With Me!” and one said “I Read Lips!” That was my introduction to “whatever works” and to me that still defines ALDA. The hotel room turned out not to be wonderfully accessible but everyone was so helpful and their attitude was so welcoming. I still have my “Sign With Me!” button.

Of course I must relate that Jerry Barnhart and Tony Yuppa, who I met that day, decided to visit the famed, “Cheers” bar which was only a few blocks away. Once we got there, we decided it wasn’t very exciting (only the outside was used in the opening credits) so we had a drink and walked back through the residential section to the hotel. Jerry was pushing my wheelchair and we crossed a street and stopped in the middle of the street. I assumed Jerry was signing something to Tony. I would be embarrassed to say how long I sat there before I began signing and looking around, “Jerry?” And there they were, back on the street corner, I was alone in the middle of the street, looking like an idiot!! But again, adventures like this made me feel a part of the family. I cried on the flight home and told my boss, “I found my own kind!” It was at that first ALDacon that I realized I had reason to grieve; I had suffered a tremendous loss, even if it was not visible. One of my first workshops, the leader asked,
“How many of you have pretended to be hearing in the last week?” I was shocked when my hand joined virtually all the other hands in the room.

I vowed to never miss another ALDAcon and except for one year when I was in the hospital, I never did. I have traveled to many new cities and for five days, I don’t have to stress for a minute regarding communication. I have nearly 300 people with me and I can start a conversation with any of them using “whatever works.” Since that first ALDAcon, going into the hotel every year and starting the hugs makes me feel like I have come home.

Joining the Board

In the early fall of 1994, Jerry Barnhart and Steve Lare both suggested I run for president (via TTY, remember those?!) I felt I could not do it; I had never done anything on a national level other than serving on ALDA’s nominating committee. But they convinced me.

I am so glad we have the position of president-elect because I gained valuable knowledge of how the board worked and what the issues were facing the organization. I also got to know my fellow board members. Our first meeting was in February of 1995 in Rockford, IL with Tom Davinroy as president. The meeting was captioned by the wonderful Pat Graves, I had never been in a small meeting with captions and it was wonderful. Even among that relatively small group, there were diverse communication needs but the goal of helping ALDA was shared by all.

One very positive event came from that planning meeting. Board members were assigned roommates. I was told my roommate would be Judy Viera. I had heard her say in a workshop once that she lived in England so I was a little confused when I realized she was now living in Wisconsin and is a native of California! At any rate, we immediately realized we were kindred spirits and have roomed together many times. I even manage to stay awake long enough to watch Jay Leno’s monologue with her during ALDAcon. I had never even spoken to Judy before that board meeting so I encourage any of you to try the roommate matching service that ALDAcon provides.

My Presidency

What can I say about 1996? It was the best of times, the worst of times. During that year my car died suddenly (more of a challenge due to the logistics of hand controls), I lost my job due to “privatization,” my beloved step-mother told me she had breast cancer and one of my dearest college friends died of cancer. And yet there were good times: I was named the Distinguished Alumni by St. Andrews and spent a wonderful weekend back in North Carolina with an interpreter with me all weekend. That was due to the support of my classmate, noted photographer Billy Howard.

There was another big event in my life that was due to fellow former ALDA president Roy Miller. In the spring, Roy emailed me that a friend of his from Austria would be in Atlanta during August for the Paralympics and would I show her around? Hey, any friend of Roy’s . . . . I had some wonderful email conversations with Petra but somehow until two days before she arrived, it escaped me that she was actually planning to stay with me for three weeks! ARGH! But as I picked her up at the airport, it was obvious we were kindred spirits and we had a wonderful time together. And later, I was able to travel to Austria twice to visit her, my only trips to Europe. Thank you, Roy!

That year ALDAcon ’96 was to be in San Francisco. I don’t know why, but we had our winter board meeting in Fairfax, VA. Usually the board meets where the con will be but for some reason, perhaps financial, we met at Cheryl Heppner’s office. The motel where we stayed was very kind, putting all the
board members together near the elevator. Unfortunately, that was also near the Coke machine and every time someone bought a Coke, all the board members were opening their doors because the doorbell lights started flashing!

The next morning we were greeted with a snow storm. It seemed major to me after so many years in the South but we started the meeting nearly on time. And an hour later, Matt Ferrara arrived from Boston. I still think he came by snowmobile. One of the first major events of my presidency happened at that first meeting when I was greeted with a huge donation from an ALDA member. This was given to recognize how important ALDA was to this member and how life-changing ALDAcon had been to him.

The convention in San Francisco is a little blurry to me, much of my personal life was not very happy at that time and I do know I cried buckets when the Con was over! But as always, we had excellent workshops and keynote speakers and the San Francisco area folks did a tremendous job. During that convention, Shawn Lovley announced that he was publishing *Now What? Life after Deaf* and donating the proceeds to ALDA.

That was the year ALDA changed the make-up of its board from three directors at large to four regional directors. I wish I could say the transition was smooth. It was not and I accept much of the responsibility. But we did make the transition.

The year went by so fast! Soon after I became “past president” my beloved step-mother passed away. The first person I called was Jerry Barnhart and he and his wife, Chris were at the airport when I landed in Newark. The ALDA family was there for me!

I did go to the ALDAcon planning meeting in Miami. I tried to stay involved in the many email discussions but my health was not going so well. In September, my nine-year old kidney transplant failed. I still managed to get to ALDAcon, even though it was a bit shortened. I felt so badly that I was not able to coordinate the next year’s elections which are a responsibility of the past president. MANY thanks to Roy Miller for assuming this job. One of the joys I see as an ALDA board member is the sense of teamwork and if something comes up in our personal lives, someone else will help. To anyone thinking of joining the board “but I don’t have time,” you will never have ENOUGH time. Do it anyway!

**ALDA-Peach**

During my time on the board, I was frequently asked how the Atlanta chapter was doing. It was embarrassing to say there was no chapter so I set that as my next goal. I started discussions with two other deafened women I knew and we somehow “met” (via email) two other women with hearing loss. We had many discussions but were unsure how to have a meeting since we had no access to CART (which was still fairly new in 1998). Finally we decided to just DO IT and 13 brave souls showed up at our first gathering. We used a regular overhead and a white board. As an ice-breaker, we asked everyone to show something from their pockets/purse that said something about themselves but NO voice and NO signs were permitted. I was fortunate to have a Braves’ ticket with me and mimed baseball. I still remember an elderly man pointing to his wedding ring and his wife and letting us know they had been married over 60 years!

That meeting was in October. In December, we decided to have a dinner in a restaurant in Decatur. After it was set up, we thought, “What have we done? How will people communicate?” I still feel, in a sense, ALDA-Peach was born at that dinner. There were a great variety of communication modes needed but everyone found a way to get to know each other.
Soon after, one of our members got a laptop and a projector donated. We still refer to the projector (since replaced!) as “Belinda’s Magic Machine!” Whoever wanted to talk had to type. If they couldn’t type, we had kind of a chain of “interpreters” (someone would read lips, to someone who signed to someone who typed . . .). It worked! A few years later, we were blessed with Beverly Bridges, a certified court reporter who made our meetings accessible for us. Do not let a lack of CART stop you from having a gathering!

And so It Continues

My name is Robin and I am an ALDA-holic. And I always will be. I have found ways to continue to support ALDA with committee work, writing, hosting the Silent Auction with the Peaches and so on. ALDA has given me so much and I hope I can continue to pay it forward. Through ALDA I have been able to gain confidence to tell my family what I need to participate. Things will never be the same as pre-deafness but we still have a good time when we are together. I have so many heroes in ALDA but of course Bill Graham and Kathie Hering are at the top of the list.

If there is one gift I have given ALDA-Peach, I would like it to be my insistence on following “whatever works.” I feel so good when I see our members taking the time to write to those who do not hear/sign or read lips. We all know what it is like to be left out and I am determined that will not happen at ALDA-Peach.

Looking Ahead

Like many, I would like to see ALDA grow. Although I often hear we need an office and staff (true), each member of ALDA can do their part. I don’t believe there is anyone in my life who has spent more than an hour with me who does not know what ALDA is. Even one person in a national office could not reach everyone. I have heard people say the scariest thing they ever did was go into an ALDA event. So, each of us can encourage others to come along. I have also heard people say there are no other LDAs in their area and I find that hard to believe. Unfortunately, many LDA are very isolated and have no communication strategies with strangers so we have to reach out. I remember when I was president I was given the name of a local person who had joined ALDA, Inc. There was a TTY number so I tried it without luck. I called back through the relay and a woman told me to try again. I finally did connect with the man and he said, “you have made me so happy. In the seven years I have been deaf, this is the first phone call I have had!”

As long as I am able, you will see me at ALDAcon, collecting hugs! Won’t you grab a few brochures and try to reach out in your community? Most small papers would love to have an article about your recent trip to ALDAcon. I am reminded of the motto of my lay order, “I cannot do everything, but I can do something.” What will YOU do?
The World Goes Topsy Turvy

I was a music-loving tomboy growing up in Lisbon Falls, Maine and looking forward to my seventh birthday when deafness arrived on the back of spinal meningitis. As I recovered from the illness, phone rings took on an old, hollow tone. Piano keys had a hollow sound when I played them, and voices were faint or completely silent. I couldn't understand any of the people around me when they talked, and the quality of my speech deteriorated. Not even a shiny new Zenith hearing aid helped.

Unable to find professionals to improve my speech and teach me speechreading, my parents uprooted our family to the little town of Woolrich, Pennsylvania after my father was offered a management job there. What sealed the deal was the presence of another town resident, a student just completing his degree in speech pathology. This man, some caring teachers, an older sister who watched out for me, and my serious love affair with books kept the remainder of my elementary and high school years from being completely miserable.

Making Early Connections

College at Penn State University was a great adventure with a few bumps in the road. I loved being able to reinvent myself instead of having an identity that I felt was heavily "the deaf kid" in school. I managed to do well thanks to my strong study habits and ability to secretly copy notes from the people sitting nearby. I could read even sloppy writing upside down and sideways.

One of my best experiences was meeting several other students who had hearing loss. Suddenly I didn't feel so uncool! It was great to have a group to hang out with that understood how hard it was to communicate. But this group was a killer for my self-esteem. I didn't realize that there are different kinds and degrees of hearing loss, and that just because we all wore hearing aids didn't mean we would have the same hearing ability. I felt really inferior because I couldn't understand speech or talk on the telephone as well as they did.

It was at Penn State that I met Fred, my husband of 35 years. He was a shy and serious guy back then – what happened? Of course the craziness must have been already there, since he fell for me. In college, Fred was majoring in zoology, heading toward a career as a Navy officer. He was also a year older, and literally got shipped off to Vietnam while I was about to start my final year at Penn State.
motorcycle to buy my engagement ring. When he came back from Vietnam, we married and lived in Newport, Rhode Island until he fulfilled his service. We have been in Virginia ever since.

**Deafness and Deaf Way**

I was very fortunate to discover a late-deafened man not long after our move to Virginia. Fred Yates had been educated at the state school for the deaf and graduated from Gallaudet University. He was the brilliant first director of what is now the Virginia Department for the Deaf and Hard of Hearing (VDDHH). He taught me my first sign language and became my mentor. Because of his encouragement and the opportunities he created, I met early leaders in the disability rights movement and leaders in the deaf community. Some of them also became mentors and role models for me as I became increasingly active in disability rights advocacy.

Several years later, in 1989, I learned about Deaf Way and decided I had to attend. It was a life changing experience for me. I met interesting, talented deaf people from all over the world. One day I ventured to the exhibit hall. There I spotted the last copy of a newsletter lying forlornly on a table with no banner or sign. It was from ALDA. My curiosity was immediately aroused by the title of the front page story, "Karina's Nose" by Bill Graham. I was completely captivated by it. It was wacky and charming. I loved the idea that there was an organization of people who could make jokes and tell funny stories about being deaf.

**My First ALDacon**

I wrote to Bill Graham after Deaf Way and he convinced me to head with Fred to Chicago for ALDacon. I'll never forget that trip. It was my first time in Chicago and when we left National Airport it was a lovely, sunny, low-70s day. When we stepped outside O'Hare, it was bitter cold with a major wind chill. We had to buy hats and gloves to survive, and I left Chicago having no idea what it really looked like. The entire time we were there, I walked the streets looking down at the sidewalk ahead to keep my face from freezing.

My first day at ALDacon wasn't good. The only person I knew other than Fred was Bill, and he was busy doing a hundred different ALDacon jobs. I went to one workshop that turned out to be about things I already knew. Then I went to two workshops where the people who asked questions and made comments were ones with rewarding careers that had been cut short or become tough to do because of their hearing loss. I felt no connection. Here were people who had already been respected professionals in their field and I had never had that luxury; I had always had to fight to prove myself.

I became increasingly depressed that first day, bitterly disappointed that I still hadn't found a place where I felt I belonged. I believed I'd made a huge mistake. But I had already paid for the registration, flight and room for both me and Fred, so I decided to set aside my own hopes and focus on the positive. I had an opportunity to learn things I could take back home and share for my job. I had been working part-time as a regional outreach specialist for the state, in a new program intended to help meet the needs of deaf and hard-of-hearing individuals.

Am I ever glad I stayed! The second day not only brought lots of good information for me to pass on but many connections with people I felt a bond with. By the time I left, I was definitely an ALDAn. And that was before the karaoke party became an institution!
Pinch Hitting, Reading, Writing, and More ALDAcons

Early on, Bill Graham asked me to write for ALDA News, and soon I was serving on what is now the Editorial Review Board. My residence near Washington, DC also led Bill to request that I represent ALDA at a meeting on TV captioning.

Not long after that, Bill asked me to represent ALDA at a meeting of national organizations for deaf, hard-of-hearing, late-deafened and deaf-blind individuals hosted by the National Association of the Deaf. That was the beginning of my work with what is now the Deaf and Hard of Hearing Consumer Advocacy Network. I helped develop the bylaws and have been proud to represent ALDA in hundreds of meetings, public hearings and other activities in the 17 years since then. The death in March 2008 of my dear friend Jerald Jordan, who represented the USA Deaf Sports Federation, makes me the only individual who has represented their organization in the coalition from Day One.

I have also enjoyed helping with ALDAcons. I’ve served on the program committee, headed sponsorships, assisted with the silent auction, given workshops, and chaired the 1999 ALDAcon in Alexandria, VA.

The most fun I ever had presenting was the year that Fred and I first did a workshop for partners. We asked our audience to pretend we were Phil Donahue and Oprah Winfrey doing a talk show. Fred roamed the audience as we asked questions about how people dealt with things in their relationships. We still laugh over how I gave him a big magic marker and he pretended it was a microphone. Some people grabbed it because they were so eager to speak and never noticed what they were holding.

Certainly high on my list for the most enjoyable volunteering I did at an ALDAcon was the year the "Peaches" took responsible for the Silent Auction and I asked them to adopt me and put me to work.

I wasn’t at the first ALDAcon at Mercy Hospital and I’m not altogether sure if I attended the second or started with the third. I do know that Fred and I have been to four ALDAcons in Chicago and I’ve only missed one since we started attended. That was the 2002 Con in Florida, held while I was at a two-week training in California which led to my being partnered with dream hearing dog Galaxy.

ALDA is my other family. Often when I arrive for the Con I am drained from all the fall activities at my job. I always leave sad yet energized after reconnecting with old friends and meeting so many terrific new people, no matter how wild and crazy I’ve been at the karaoke party the night before.

Here’s a little-known fact: for some years I was ALDA’s postman. When I discovered that all ALDA’s mail was being sent to a post office box less than 2 miles from my home, I volunteered to pick it up, sort it, and send it to the appropriate ALDA person.

Bringing ALDA Home

I have also tried to bring ALDA to where I live. I was one of the individuals who went to Cornelia ("Neil") Keller's house in Washington, DC to discuss setting up an ALDA chapter in the early 1990s. When nothing came of that, I started holding monthly meetings of a loose-knit group in the morning at the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons, where I had become the executive director, for a free-ranging discussion.
This led to hosting mini-conferences, which brought enough interest to eventually start ALDA’s Potomac chapter. Although the group has evolved to one with just four meetings a year, it's still fun to reconnect and all our meetings are some kind of party.

**True ALDA Slavery**

I became an ALDA slave for three years because I met Robin Titterington and I was just crazy about her. When she was up for election as president, I agreed to be nominated as vice-president just for the opportunity to work with her. During my first year, I saw the chaos that resulted from our not having a national office and staff. The lack of records or their being passed on from board member to board member could make things a nightmare. It frustrated me that sometimes we weren't sure if we had the most current edition of the bylaws or what the agreement was for travel reimbursement, if any. We also needed clear policies and procedures for how ALDAcons and ALDA News would be run and so many other things.

I made it my goal as president to complete binders for each of the board members so that all that information would be easy to locate and update. It was a year-long obsession and labor of love. My one big disappointment is that the information wasn’t passed on and used by the succeeding board members.

**Five Things I've Learned from ALDA**

1. As long as ALDA stays true to its roots, it will be home. Who else can brag that their organization started over pizza and beer, has deaf people singing karaoke at its biggest party, and in my case, being first attracted by a story about fingers on a nose?

2. Deafness doesn't destroy a marriage. But the added stresses can break a partnership where communication and shared goals are already weak.

3. One of the hardest things about becoming late-deafened is finding the words to express it – the feeling, the fear, the frustration. ALDA can help you find those words, and it can help you face and cope with the feeling, fear and frustration.

4. Kathy Schlueter has been ALDA's most committed worker over all these years and we just couldn't thank her enough.

5. You can never have too many hugs at an ALDAcon.
“Where are you from Mary?” People would ask me that question all the time and I found it difficult to respond. I grew up all over the country due to my dad’s job and his climb up the corporate ladder. I was born in Saginaw, Michigan, as were my brothers Larry (a year older than me) and John (three years younger than me). My mother was a homemaker and I believe specialized in “moving.” We moved so many times that she could have started her own moving company. From Saginaw we moved to La Grange, Illinois and two years later to Omaha, Nebraska. I recently visited Omaha again while on a trip to Colorado to see my daughter Lindsay who is in college there. While in Omaha I went to look at the house that I lived in while there, and it brought back many memories. For example, I recalled the time that I sat on a bee while watching Larry tool around the driveway in his little sports car (the kind with pedals). My mind flashed back to the time that I got stuck in a mudhole in the middle of the busy street we lived on, and my father ran out and picked me up out of my boots just in time. I was in second grade there when it was discovered that I was deaf in one ear. It was “no big deal” the doctor said. “She does just fine. Just sit her up in the front row at school.” So that is what we did.

We then moved to Mankato, Minnesota where my sister Liz was born (nine years younger than me) and on to Stevensville, Michigan. In Stevensville I had my first dizzy spell. I still remember it some forty years later. I was out on the playground, just standing there and wham it hit me – an attack of vertigo. I went to the office where the school nurse and my mother discussed the situation over the telephone. They decided that I simply had not eaten enough for breakfast that morning. End of discussion. I had vertigo attacks often but I never went back to the office as I figured those adults knew what they were talking about and I had just not eaten enough for breakfast.

We then moved back to La Grange, Illinois where we lived for a mere nine months. I hated the school there and would cry almost every morning while walking to school. I was the “new kid” and really had no friends. I was so happy when we moved again, this time to Cincinnati, Ohio, which was my favorite place while growing up. I arrived in Cincinnati during the middle of my sophomore year in high school. I had tons of friends there and I loved it. To this day I still email my best friend from there.

The frequency of the dizzy spells had increased by that time, yet no doctor could diagnose what was wrong with me. They would tell my mother that it was “all in my head,” and she would sit with me on the edge of my bed after a bad episode and say “Mary, what is bothering you?” I would ask myself that question for many years. I wanted to know what was bothering me as many times the vertigo was
excruciating. Sometimes I just wanted to die, as lying on the bathroom floor and being sick was intolerable.

We moved again in the middle of my senior year to Hinsdale, Illinois. I graduated with kids that I had not grown up with, but by that time I had learned to put a smile on my face and go with the flow. I lost some hearing and was fitted with a bi-cross aid (amplifier in the good ear and wire to the bad ear), and I listened to the coffee maker. I was thrilled! I went to college at Ball State University in Muncie, Indiana. I majored in what at that time they called “Teaching the Mentally Retarded.” Later, as I lost more hearing, I switched majors to “Deaf Education.” And while I was in college my family moved again several times, and I would visit them on holidays – first in Temple, Texas, then in Fort Smith, Arkansas, and finally in Camden, Maine.

**Becoming Deaf**

In my senior year at Ball State I noticed a significant loss of hearing. I could not hear the alarm clock at seven in the morning. Yeah, I know, everyone says that but I truly could not hear the alarm. I could still function as a hearing person most of the time but I was scared. My Deaf Education professor actually went with me (canceled her classes) to the speech and language clinic to have my hearing tested. It was not good. I had a 45 db loss in the good ear and NR (no response) in the bad ear (or should I say the “dead ear?”). But I did OK. I could still talk on the phone and I did not know a single person with hearing loss. So, my life was pretty “normal” but maybe a little strange.

I dated hearing men, and after graduating from college I moved to Chicago where I met Jeff (he had an apartment just below mine). We hit it off and did all the things that hearing couples do, including watching movies, going to comedy clubs, and listening to music together. He knew that I was hard-of-hearing but it did not seem to bother him. After three years of dating we got married.

Fast forward to age 31 and by that time I had a three year old (Lauren) and a one and a half year old (Lindsay). The girls were wonderful additions to my life, but the dizzy spells started again. I remember missing birthday celebrations and wishing I was dead again. I went to doctor after doctor, some of whom were what they call “quacks,” just trying to get some relief. One told me that I had yeast in my ears, gave me anti-yeast pills, and told me that I could no longer have bread and beer (my two favorite things at that time in my life). My hearing was also getting progressively worse. Finally a doctor suggested a CAT scan. That basically saved my sanity! I found out that I had Mondini malformation (also known as Mondini dysplasia or syndrome). Persons with this condition have an incomplete cochlea (one that has only one and a half turns instead of the normal two and half turns), which is related to progressive hearing loss and balance problems. I also had extremely small Eustachian tubes that were close together in my inner ear. I was just thrilled that my condition had a name, that it was not “all in my head” after all (well, it was, but in a different way). I was given Antivert (Meclizine) for my dizziness, which made me depressed but helped with the vertigo. I never knew when the dizziness would hit, so it was not a great drug in preventing the spells but it helped make them tolerable – sometimes.

Accepting deafness was a difficult challenge for me. The story I always tell people concerns when I took Lauren to Day Care one day and she was trying to tell me something. I bluffed and she cried. So I bluffed again and she cried even harder. I took her into the Day Care Center and she was just sobbing at that point. I swallowed my pride, and had to ask another mother what my daughter was trying to tell me. To this day it still makes me cry to think about that day – to not even know what your child needs or wants. I went out to my car and just fell apart. I said out loud to the rearview mirror “Mary you are deaf. You gotta get a grip!!” I went home, called up work, and said “I can't come in today.” I must have cried the entire day. It was grief at its worst! That night I talked to Lauren and I said “We will be
OK! Mommy's ears are broken inside where you can't see them, so I won't always be able to understand you.” I remember that we both cried. She has no memory of that episode, and she is now a beautiful 23-year-old that automatically signs for me. I also had a talk with Jeff. I told him that he could leave or learn how to communicate with me as I did not want to live with someone that I could not communicate with. He signed up for a class at the Chicago Hearing Society the next day.

Little did I know that Mondini syndrome is hereditary. No one in my immediate family has it, and the doctor did not tell me that it could be inherited by your children. I went on to have a third baby – Emily. At about the same time Emily was born it was discovered that Lindsay also has Mondini syndrome. Her symptoms are not as classic as mine and she is now 21 and in college in Boulder, Colorado. She is doing well and is a great communicator as well. I am very blessed!

Finding ALDA

This is where I lucked out. While I was teaching at Whitney Young High School in Chicago my hearing continued to worsen. I had a good teacher friend, Noreen, who was hearing and worked at a health club after her day job as a teacher. Guess who belonged to the health club – Bill Graham and Steven Wilhelm. She said she knew these guys and that they were fun, funny and flirted with her. She was fun and funny too and flirted back. She kept pressing me. “When are you going to call them, Mary?? Do it today because if you don’t I am going to ask you again tomorrow.” She told me to call Bill as she had heard about the self-help group he ran at Ravenswood Hospital. So I called him. I figured he and Steven were just dirty old men chasing after young twenty-something Noreen.

I remember calling Bill on the TTY. I barely knew how to use a TTY but had to resort to it after I could no longer hear on the phone. And I remember asking him, “Are you old?” I figured he was seventy-something (no offense to all you nice seventy-something men out there) as I had tried speechreading classes in the past and everyone was much older than I was. He said, “Well sort of, but come to group.” He then invited me to a party that weekend at the home of Dawn Maerz. I did not know anyone there but was proud of myself for going. I met Bill and he seemed OK, and was not what I expected. (He was not a flirt.) It was a little surprising though because I did not know about NF2 at that time, and the first person who greeted me at the door had NF2. And then I met a second person who had NF2 as well, and I thought “Maybe I am at the wrong place.” Years later I would become educated about NF and I would just forget anyone had it!

Fast forward to a year later. I finally went to Bill's group. Yes, it took me a year to get up the courage to go. I knew that I needed some support. It was great for me and saved my mental well being. I then got involved in ALDA, took a six-week class with Laurieanne Chutis to learn how to become a self-help group leader and started a group out in Oak Park. I learned how to talk in public and at the first ALDAcon I remember I got to tell everyone where the bathrooms were. I was terrified but survived!!!!

Guiding ALDA as President

I basically ran for president as no one else wanted to run. I was president twice (I have no idea why). ALDA had given me a lot. I had gone to self-help groups with Bill Graham as a leader and it helped me so much. I had done grunt work and enjoyed it. I wanted to give back somehow. I remember being on the social committee with Diane Tokarz at that time. I was a teacher so I would bring home carbons and we would write up fun and funny socials for ALDA. I would take them back to my school and run them off when no one was looking. It was hilarious. We were having fun. Stuffing envelopes was fun at that point – believe it or not. So I probably thought being president would be fun!! Little did I know.
I think my biggest strength as president was networking with other organizations and connecting with people who wanted to support ALDA. I wanted very badly to have an ALDA office and an ALDA executive director. Although we did not accomplish that goal in the way I wanted, we did have a basement full of resources here at my house. And at the small office of Hearing Loss Link we had a phone with a separate ALDA line as well as ALDA resources. It was a great experience for me. It was a lot of work too. I would take Sundays off, but the rest of the week was spent on the computer or the phone talking to people that needed to talk. There were still day-to-day things that needed to be done regardless of whether or not there was an office. Every day was a challenge, which I enjoyed for the most part.

Looking Back

I have been involved with ALDA for 20 years and have been to every single ALDAcon. It is said that many people in ALDA learn how to cope with their hearing loss and then move on. I have learned how to cope and accept my hearing loss, but I have no desire to really leave the organization. I love meeting the new people that come into the organization, and I love the friends that I have made over the years. My best friends are ALDA friends. I changed in many ways (not always for the better), which did impact my family and my life, but I would not take it back and don't regret anything at all. It's all part of that put-a-smile-on-your-face-and-go-with-the-flow which I learned growing up.

Every year I say “This will be my last ALDAcon.” I don't get as excited about it as I used to, but I still love to see the people and check out how things are going. We are a different kind of organization in the fact that as late-deafened adults we grow up, learn skills along the way, and then feel like we are OK without ALDA. There are people too, still sitting secluded in their home, that don't know ALDA exists and probably could benefit from ALDA – just as I needed it 20 years ago. Reaching them is difficult unless you have a friend like Noreen who knows a Bill and Steven (smile).

I really don't know what kind of contribution I have made to ALDA. I like to think it is the people part. I was never really good with bylaws or having to write stuff (like this article), but if someone was having a problem with someone, I could negotiate and try to help them work it out. Or if someone was newly deafened, I could write to them and maybe even meet them. That has always been important to me, to show that someone cares. I also think that asking people smarter than me to help with various tasks is a good thing and a contribution. I think I have helped make leaders out of people who have not led before. I like to think that is a contribution too. But my role models have contributed to that – Bill Graham and Marylyn Howe especially. Jerry Barnhart and Kathie Hering (now both deceased) also inspired me. And of course all of my ALDA friends have been important in my life! I could list them all, and say something about each one, but I will tell them in person when I see them at ALDAcon. I'm sending this to the editors, putting a smile on my face, and going with the flow!
Before Deafness

Always loving to attend parties, I crashed my oldest sister’s birthday party when I was born on the same day she turned 8. My family lived in a small, rural farming town in Belvidere, Illinois. I joined my sisters and one brother. I was followed by another sister, Patricia, but she died at birth. Our family members were very close: We worked, played, and cried together. Our parents instilled a love of music, dancing, and sports in us. They encouraged us to challenge ourselves to keep improving and to use our skills.

I was a very energetic child. My family nicknamed me “Dizzy Tizzy” – later to be shorten to “Tiz” because I never wanted to quit talking or stop moving. I guess you can say that I’m still a little that way. I loved music (I played the clarinet and baritone, and danced), gymnastics, baton twirling, volleyball, softball, and bowling. I also turned to crafts – sewing, wood carving, gardening, and graphic design.

I can still remember one fast-pitch softball team I was on with my sisters. Charlene pitched, Darlene caught, Linda was in right field, and I had second base covered. Our parents coached the team and brother Harry was our bat boy. After farm work was done, many of our nights were either scrimmage games or learning different styles of dancing.

As I continued to grow I began excluding myself from family activities at times and went to my room to read. I was hard-of-hearing even then and just didn’t know what everyone was saying or talking about.

After I graduated from high school I attended the Milwaukee Accredited School of Cosmetology. I became a licensed cosmetologist in two states, Wisconsin and Illinois. I was married in 1970 and we raised our family of two sons on a farm in Dakota, Illinois. I still live there 38 years later. I adventured on to Highland Community College and have certification in desktop publishing. I have plans to go back and get my certification in graphic designing as well.

At age 30 I was told that I had a hereditary progressive hearing loss that should have been noted by the age of 7. I cried at that doctor’s appointment not because of the hearing loss but just to finally have someone tell me it wasn’t my fault that I sometimes didn’t understand things people said. I was trying
to listen and I was paying attention, my ears just didn’t work right. It took me three years to convince my husband that I needed a hearing aid. “Why?” he’d say. “You can understand me.” Well, I was told that I had been lipreading for many years without realizing it. To this day, my family still wants me to lipread them.

Attempts to Adjust

Being in a rural area, you can be isolated. Add the hearing loss and not being able to hear the sounds around you adds to this isolation. I needed help, so I went over to a Rockford, Illinois, agency now known as the Center for Sight and Hearing and received some counseling. My counselor took me to the first ALDAcon in Chicago. She met me in the parking lot of a John Deere plant that morning. If I had known how to contact her there, I probably wouldn’t have gone because I was so anxious. I would have stayed home. But, I went, shaking in the knees and nauseous in the stomach, but I made it through the day at ALDAcon. I was fortunate to be included in the rap group session with Bill Graham, co-founder of ALDA. I felt understanding, support, and the beginning of a true friendship with him.

I didn’t want to go home. But you know in reality everyone has to return home to their everyday living conditions. I don’t think a day goes by that I don’t struggle with something, but I have better coping skills now. I’m not too shy to say I am late-deafened, ask for whatever is needed to make understanding better, and YES, darn right, yell at times that I am frustrated and tired of working at communicating.

I love people. I like being very social, and I am willing to help wherever I am needed. This has led me to a larger and larger role in ALDA and eventually to its board of directors. I have a little motto for myself, “Lift Your Wings and Soar.” I can’t get my hearing back, and I can’t change how a person reacts to my hearing loss, but I CAN advocate for myself and for others and serve ALDA so that generations will have a “family” in place to give them the support and understanding they need to cope with their hearing loss. I believe in our philosophy of “whatever works.” I am still a lipreader, I sign a little bit, and I’ll write if you can’t understand me, but I WON’T say “Never mind,” because I do mind! I want to hear what you are saying, what is being talked about, and sometimes I’d like to give the right answer to the question you are asking me....SMILE.

And Then I Couldn’t Stop!

I can’t miss an ALDAcon, nor have I missed one since my first. I don’t know how I managed to drum up the nerve to attend ALDAcon 1992 in Boston, the first Con not in Chicago. I had never flown in an airplane before and due to my ears my ENT didn’t recommend flying. But I HAD to get to Boston for this convention. So, dragging my mother along, I took my first Amtrak train ride. Then came the challenge of ALDAcon 1996 in San Francisco. No matter how I tried to figure out a way to get there on the ground, there was no question – I had to fly. My friend Gloria Popp, who joined ALDA in 1995 from Freeport, was an experienced traveler and offered to make my arrangements and sit with me on the flight. My family was shocked that I was actually going by plane. But nothing was going to hold me back from being with my ALDA family.

When I first joined ALDA, I would sit in the back at ALDA events, just talking with my mother. Then gradually I moved towards the middle to meet a few more people. Now you will see me doing
presentations, and I have received ALDA awards for my work. I’ve also been recognized by other organizations for my advocacy work on hearing loss issues.

To this day, you will usually see me working behind the scenes in planning our convention. I love it! I want to be sure that new people feel comfortable and join in the activities. I want to help solve problems that may arise at the convention so it can run smoothly. Robin Titterington always seems to send out an email message before people leave for ALDAcon saying “If you have a question or problem at ALDAcon, ask Kathy.” I like knowing that people feel comfortable enough to let me help them.

**Joining the Board**

Gosh, I can’t even remember the first term I spent on the ALDA board of directors. I was so scared. I just know that I was approached by some of the board members to run for election. For the first couple of years, I was very quiet at meetings. I watched my fellow board members to learn from their experience and gather all the knowledge that I could. I gradually moved up the board hierarchy – region director, secretary, president-elect, and president. It all happened so quickly. In 1989 I attended my first ALDAcon. In 1999 I was ALDA’s president, and in 2009 I again served as president. This has happened because, with the empowerment and support of my ALDA family, I am able to move forward, set goals, and accomplish the goals I set.

**My Presidency**

Wow! I couldn’t believe. This little country pumpkin was headed to Alexandria, Virginia, for ALDAcon 1999, when I became president of the organization.

I remember giving the opening speech at the convention during my first presidency, telling my story about how I attended my first Con. I mentioned the fear I had, the “what if” questions, and if I would be able to reach out and connect with those who needed me most.

After the speech, as I walked down the aisle to the back of a room, I saw a woman crying. I approached her to ask what was wrong and if I could help her in anyway. She said that nothing was wrong but that everything I had mentioned in my speech she had felt before coming to attend ALDAcon. She had almost stayed home.

I left the room feeling higher than a kite. I did it! By helping just one person I had reached my goal for that day.

I take things in baby steps. I plan many short-term goals and reward myself when I accomplish them and then move on to the next.

Each and every time that I have served on the ALDA Board of Directors has been different. During my terms as president I needed to learn about each board member, how she or he gathers information, and how they process it. As most of you know, we are all unique and what works for someone may not work for another person. We had to work as a “team” to move forward and grow as an organization. Everyone’s opinion is important.
During my first term of office I was a happy wanderer. I traveled to Virginia to visit Cheryl Heppner and ALDA-Potomac members. While in the East, I traveled up the coast to attend an ALDA-Boston Birthday Bash.

In June I attended the SHHH convention representing ALDA, Inc., at our exhibit booth. There I met with the SHHH president, Marcia Finisdore, and Rocky Stone, founder of SHHH. This gave me the opportunity to talk in person about our wonderful organization and how we can work together with other national organizations.

It was an honor and a rewarding experience to serve as president. Here are some of the goals that we accomplished for the year 1999:

1. Established committees and chairpersons to meet the needs of our membership, including a Seniors Committee
2. Redesigned our brochures
3. Developed policy on selling ALDA merchandise and mailing items
4. Dealt with fundraising issues at a meeting of the Former Presidents Task Force, such as those related to development of the ALDA Store and plans for a national office
5. Developed plans for a marketing flier to sell items from the ALDA Store
7. Had a booth at the SHHH convention in New Orleans
8. Formed Advisory Committees under the supervision of the Region Directors
9. Placed an ad in the program book at the Deaf Seniors of America convention in Atlanta
10. Established a national office space that was shared with Hearing Loss Link, a social service agency for late-deafened people in Oak Park, Illinois

**ALDA-Freeport —ALDA-ROCK**

After my first presidency, back at home I began a local chapter called ALDA-Freeport. Was it easy? No, and we continue to struggle today as we are a rural area and people live a great distance apart. Also tie in the factor that many of us live and work on farms where you wake up early and often work well into the night, making it hard to establish a meeting time that would work for all. At our early meetings we wrote on a chalkboard or passed papers around to communicate to each other what we were saying. Then we used a bit of ALDA Crude. My daughter-in-law Tina would type in a Word doc, and then we would show it on a TV. But for the most part my members were happy just receiving our newsletter.
We tried several different locations for our meetings to see if we could attract more members. This led us to the Center for Sight and Hearing in Rockford. The Center graciously provides a free meeting room for us and the use of the facilities if we want to have a party or do some cooking.

With support from Caption First we were able to obtain captioning for our meetings with Cindy Thompson, a CART reporter, volunteering her time. The captions help to make communication easier for all. Even if you have just lost your hearing, you can read what was being said.

We also changed our name. The name ALDA-Freeport became an issue because people felt that they needed to be from Freeport to participate. So we petitioned the ALDA Inc. Board of Directors for a name change. We are now known as ALDA-ROCK. Some people questioned this name as well, saying that we sounded like a band. Our response to that was, “Fine. We may have lost our hearing but we can still rock.” We actually use the word ROCK in different ways – for example, we sometimes say it’s an acronym for Raising Our Communities’ Knowledge on hearing loss.

**Here Lies My Heart**

I’m Kathy, a little bit country, as I still have a no paved road in front of my house. But I’ve found my second family, ALDA. Now over 25 years later it’s still one of the top priorities of my life and will always be.

Beyond participating on the board there is a ton of work that needs to be done, and ALDA needs the volunteers. I have an awful lot of volunteer roles with ALDA. Here are a few: Chapter/Group Coordinator, Advertising Director, Database Manager, ALDAcon 2008 Sponsor/Exhibit Business Manager, and participant on many ALDAcon planning committees.

Won’t you help serve? Just ask for Kathy (that’s me), and I’ll help you find a place to volunteer.

If I can give one piece of advice to remember it would be “Take care of yourself first.” Even though you have lost your hearing you are still YOU. Take the time to grieve, talk to someone if you need to, and go forward and share your experience with others. Not everyone’s skills are the same or developed to the same degree, but it doesn’t matter. This lone country babe is living proof that you can continue to grow. Just plant the seed, give it food and water, and most of all give yourself love.

**What's in the Future?**

I’m not sure anyone can see what lies ahead. As the incoming ALDA president for 2009, I look forward to helping ALDA continue to grow.

I’d like to see that national office filled with a staff, but I’m not going to hold my breath. An office is just a room, but the people inside are the heart of the organization. As volunteers we can continue to raise public awareness about our organization, advocate for ourselves and others, and present to other organizations what ALDA truly means.

We are far more fortunate than past generations in having the new technologies to assist us with our hearing loss, the advantage of the Blackberry, email, Internet, and other technologies to keep our lines of communication open in the hearing world.
You are never too old to learn new tricks. I, for one, am taking advantage of the knowledge that my grandchildren have with software programs on the computer to help me adapt. Plus it’s a great way to stay included in their lives. Check out your community college to see what kind of tech classes they are offering.

On a final note, if you need to talk, call me! I’ll answer as soon as I can.
IN THEIR OWN WORDS
ALDA PRESIDENTS • 1990 – 2015

Ken Arcia – 2000

Growing Up

Did you know that the San Joaquin Valley, and in particular, Fresno County, leads the rest of the state and the nation in food production? The San Joaquin Valley includes six of the top ten agricultural counties in California. Fresno County alone ships approximately $770 million worth of preserved fruits and vegetables every year. I was born in Fresno. Fresno is almost smack dab in the middle of California – between San Francisco and Los Angeles.

I was born in 1962 as the first child of my parents. My parents were very young when I was born. My mother was 16, almost 17, and my dad was 19. I grew up not knowing anyone who was deaf, although I do remember my maternal grandfather wearing hearing aids. I knew when I was in high school that my grandfather was hard-of-hearing due to something that could be passed to me. I never knew exactly what that was. I would eventually find out.

My mom died due to domestic violence when I was only 5 years old, and during her autopsy they also found that she had tumors like my grandfather had. They didn’t really have a name for that when I was growing up.

All during my education, I had completely normal hearing. When I graduated high school and was in college, something intuitive told me to get my hearing tested. I went to our regular ENT (Ear, Nose and Throat doctor) and he did some tests including a BAER (Brain Auditory Evoked Response) test. After that, he said something was abnormal so he wanted me to go to the House Ear Institute (HEI) down south in Los Angeles.

I went down to HEI in the fall of 1981, at the age of 19. I was there at HEI, as it was called, all day for testing, which included an MRI, CAT scan and a test where they measured your eye movements while warm, then cold water was shot into your ears. Not fun! At the end of the day, my doctor, Dr. William House, told me that I had tumors in both ears, with the one in the right ear being slightly bigger. They wanted to do surgery as soon as possible in order to try and save my hearing. They also used a term I had never heard of before – Neurofibromatosis, Type II (NF-2). I was the first in my family with a label
for our disease. As soon as I was given this information, I contacted my sister who is three years my junior. I told her that she needed to get tested ASAP. More on that later.

**My Surgeries**

Being a young man who was still learning to live on his own (I had my own apartment at that time), I put all my faith in the doctors and set up the surgery that was needed. They warned me that I might lose some hearing and maybe have some facial paralysis but I didn’t give it much thought. In April of 1982 I had my first surgery. It was at the St. Vincent’s Medical Center in Los Angeles. It was across the street from HEI. The surgery went well and I was told that they removed most of the tumor and my hearing and facial nerve should not be impacted – much. I had quite a bit of swelling and was released after a week. Most of my hearing came back, and I had minimal facial nerve and balance nerve problems. So far so good.

Meanwhile, my sister had the same testing and they found her tumors were MUCH bigger than mine. If mine were the size of peas, hers were the size of walnuts! When she went in for the surgery on her right side, the tumor was so intertwined with her nerves that they had to cut her hearing nerve in order to get most of the tumor out. She now was completely deaf in her right ear. One cute funny story about her surgery was that when she came out of it, although she was deaf in that ear, she said she “heard” a sound that was like a train chugging along the tracks. My brother and I went shopping and ended up buying her a stuffed “Thomas the Train.” When we gave that to her, she said, “Thanks, but now I don’t hear that anymore. Now I hear…hmm…I think it is a diamond watch…yeah, that’s it.” We all laughed. Nice try, Sis!

Back to me. Since the first surgery was a “piece of cake”, I thought the 2nd would be the same. Big wrong assumption! In April of 1983 I set up the 2nd surgery. I was curious what they were actually doing during the surgery so I asked to view a video of the surgery being done on someone else. Another big mistake! (two strikes…would I strike out?). After viewing the video, I was scared! The first surgery went well and I should have just played along and let them do what they needed to and find out what they did AFTER the surgery, not before! Lesson learned.

So, when they went “in” on this surgery they found that the tumor – like my sister’s – was much more intertwined with my hearing, balance and facial nerves. They had to cut out the tumor and then reattach those nerves. I still (over 30 years later) have some facial paralysis and balance problems, and I do not hear anything in my left ear. Because of the complications, I ended up staying almost two weeks in the hospital. When I was released from the hospital, I noticed that I got dizzy very easily and could not drive. I had to go on disability for a while because I would not be able to drive for almost six months!

**State of Denial**

I also was in a state of denial related to my hearing loss. Never having known anyone who was deaf or who had a hearing loss, I didn’t know what to do. I also didn’t realize what I was missing. I was in denial for almost TWO YEARS! I thought I was “fine.” What made me realize that I had a hearing problem was ironically the TV show called “Cheers.” I loved that show. But because the jokes were so rapid fire, I would catch the first joke but not the second (the canned laughter usually masked the second joke). I also realized I was asking my friends to repeat themselves quite frequently.
I decided to get a closed caption decoder for my TV (this was before they were built in). You kids got it easy these days (sorry, I sound like my grandma)! Once I hooked up my decoder, oh man!! I realized I was missing half the punch lines!!! It was like a slap in the face realizing that I had a hearing loss and had to do something about it. Ironically, my sister was already working on her hearing loss. She told me that I should contact my state Vocational Rehabilitation (VR) office. I did that and thus began a really great relationship with my VR counselor, Linda.

A Hearing Aid and SHHH

Linda set me up with a hearing test at an audiologist’s office. The audiologist’s name was Steve Roberts, and his former career was as a Marriage Family Therapist. I got a hearing aid for my right ear but my left ear was “beyond help”. He had set up weekly meetings for people who were new to hearing loss and hearing aids, and through that group we established the Fresno Chapter of Self-Help for Hard-of-Hearing People (SHHH).

Over the years I got more involved with that group. Linda, my VR counselor, also helped pay for my tuition and books and I was attending college part-time while working full-time. It took me about six years to get my BA degree because it was part-time. When I graduated with my BA, my job at a local bank was eliminated when it merged with another bank. Linda again came to my rescue and set me up with a job at the local deaf services agency. I had already taken one semester of sign language but this was nothing compared to my daily interaction with the deaf staff. I improved DRAMATICALLY and IMMEDIATELY!

I was attending many SHHH events and also the state and national SHHH conventions. It was at the state SHHH convention in Concord, California that I had my first exposure to ALDA. Let me back up. I had been involved with SHHH for about six or seven years. I was a co-founder of the Fresno chapter and had held most positions on the board – sometimes twice! But I also felt there was something missing. As you probably know, SHHH tends to have older members. I was the youngest in my group by far! The average age in our chapter was 60+ and I was still under 30! But it was my only exposure to others with hearing loss. I learned a lot from that group including how to be more assertive, more about my hearing loss and assistive listening devices and how to ask for what I need in relation to communication.

Meanwhile, my sister was still having trouble. She had put off her surgery on the left side because she knew she would be completely deaf. Her hearing nerves would both be cut. She put it off until her health was seriously threatened. I can remember one night back in 1991 when I was at a meeting at the deaf services agency where I worked. She was also there for a sign language class. She had brought her most recent MRI with her and she showed it to me. I tried not to show her how scared I was for her. Over the years her tumor had grown from the size of a walnut to the size of an egg. It was now putting pressure on her brain and she was having blackouts and severe headaches. The doctor told her, “You must have surgery as soon as possible or you will die!” So she no longer had a choice. If she wanted to live, she would be completely deaf.

Interesting coincidence, a co-worker at that same agency had just read about a new type of implant, similar to a cochlear implant, called an ABI. This was for patients like my sister and I who had NF-2. The ABI is an auditory brainstem implant. It connects directly to the brainstem with only a few
electrodes rather than a cochlea implant’s 20+ electrodes. So, during her second surgery, when they removed her tumor, they also implanted an ABI. The results of brainstem implants vary, but my sister only had limited success and the external parts of her ABI now sit in a drawer or box somewhere.

Finding ALDA

Back to me. In 1993, I attended a conference for SHHH in Concord, California. When I walked into the room, I saw several people my age signing!! I rushed up and asked,”Are you with SHHH?” They replied, “Yes, but we are also from ALDA.” Well, I had found my second family!! I had found others like me!

That group included Bill Zitrin, Karin Kasper, Nancy Hammons and of course Edna Shipley-Conner. All were from ALDA East Bay. From that point on, I took the train from Fresno to the Bay Area (a good four-hour trip each way) at least a couple of times a month. I joined in their meetings and social events and eventually Nancy and Edna found me a job at the deaf services agency in the Bay Area, DCARA. I packed up everything I owned and moved to the San Francisco Bay Area in September, 1994.

When I moved to the Bay Area, I immediately joined ALDA East Bay for social activities, meetings, and so forth. I helped with their newsletter and made many new friends. It was such a God-send! I also continued to work with Nancy and Edna at DCARA. I worked with Edna almost daily since her office was near mine and helped her with her “Deafened Adult Program” at DCARA. She had set that up many years before – even before ALDA was established. Through that program, we provided coping skills and also sign language classes for those with hearing loss. I learned so much from Edna and considered her a “second mom” (since I had lost mine when I was five years old).

With her encouragement, I attended my first ALDAcon in 1995 in Rockford, Illinois. I remember thinking “Wow, this is really out in the boonies!” (grin). We had quite a large group representing California. I remember meeting some of my closest friends there including Dennis Gonterman and Mary Clark. Dennis and I are still very close, and I still miss Mary every day!

My ALDA Presidency

After a year or two of being involved with ALDA, Inc., I decided to run for the ALDA, Inc. board. I joined the board in 1996 as Regional Director. It was a new position and through the regional directors, we provided outreach about ALDA to those in our regions. My region included the western United States. After my experience with that, I decided to run for president in 1998. I won and was president-elect in 1999, president in 2000 and past president in 2001.

What I remember from my presidency was the great teamwork we had among the board members. I thoroughly enjoyed working with everyone on the board. I felt I was a good president and was very “fair” and a good “listener” to the discussions, probably because of my counseling training in college (grin). I don’t feel I was a leader but more of a link in the chain – all of the board members being other links that made the ALDA chain strong.

I’m proud to say we established the ALDA website while I was on the board and I’ve been “webmaster” since its inception. We have had countless people find us via the internet and I’m very proud of that – not only personally but also as part of the board that established this vital resource. It’s nice to know we
have “changed the lives” of many people who have contacted us via the website and email. This is also the main source of information for ALDAcon each year. I’m happy to continue that involvement with the website.

During the year that I was president, I also set up an online group. It is sort of a discussion/support group under YahooGroups and is called “LDAchat” for “Late-Deafened Adult chat.” The name may be sort of misleading as it’s not a “chat room” but more of a discussion group via email. I’m proud to say that the group is still going strong and has over 600 members from all over the United States and the world! There are people with varying degrees of hearing loss in that group and the topics range widely but are always in some way related to our dealing with our hearing loss. I have less time to “moderate” the group so now my friend Martha Mattow-Baker runs that group. Thanks, Martha!

One thing I would like to say is that ALDA needs “new blood.” There are many, many people who lose their hearing every day! ALDA needs you! Volunteer to help a committee, start a project or run for a position on the board. You will be glad you did! What you get back is priceless!

Looking Back

I am still very involved with ALDA and in fact am more involved at the national level than I am locally. The local chapter, ALDA East Bay, recently changed to a social organization and now is not affiliated with ALDA, Inc. It is kind of sad this had to happen but I think for many, ALDA East Bay (AEB) filled a need and now that need is no longer there (or is not as great). Many of the officers had been officers repeatedly so I’m sure were burned out. I know for myself, it did fill a need I had for support and social interaction. But now, with my job being busier, I don’t feel I have that need (or the time) for ALDA East Bay – and obviously I was not alone.

As for ALDA, Inc., I am proud to have been president and am happy to still be involved. It still fills a need for me and I get to see my friends (and make new ones) at ALDAcon each year. I always have fun and get my “fill” of ALDAhugs. For those who have never attended, there is nothing like it! It’s hard to describe but it’s like finding your lost family and having a blast with people you feel you’ve known for years (instead of days) all at the same time!

I am also very proud to say I was awarded the I. King Jordan Distinguished Service Award in 2007 at ALDAcon in Rochester, New York. This is ALDA’s highest honor and what makes it so special is receiving it from my peers. I owe so much to ALDA and am very thankful for this honor. As I said in my speech, I know Edna was looking down watching me with a smile on her face and a twinkle in her eye.

Like they say every year… “Come to ALDAcon. It will change your life and you will come again every year!” When you come to ALDAcon, this year or ANY year, please make sure you tap me on the shoulder and say “hello.” I always enjoy meeting new people. We can never have enough friends. Right? See you there!
When asked to write this piece about myself I procrastinated for a couple of months. So, then I started to solve my problem. I invited a special friend to my home for champagne and hors d’oeuvres, creating a soothing, relaxing atmosphere for me to share the information needed to produce a chapter for this book. It was easy to entice this friend to come and visit that day, since it was my birthday. And sure enough, I solved the problem and began writing.

Growing Up

I was born in 1952 in Albany, New York, and grew up there. Having four sisters, and being the middle child, I quickly became the negotiator and peacemaker in the family, which in hindsight was the perfect training needed to become president of ALDA.

My dad owned a scrap metal business, handed down from his father, and my mom was a housewife. My sisters were my friends, and my family was everything to me. Some of my fondest memories involve music the – the Beatles, Bobby Vinton, Elvis, and so forth. My sisters and I gathered around the television and screamed during the Ed Sullivan show when the Beatles lit up the nation.

My seventh grade Russian teacher had a big impact on my life. Using innovative teaching skills, he took a complex language and made it enjoyable. Every Friday we would file out of the classroom with a broomstick bat and play a one-base ballgame called Russian “lapta.” The love for this teacher and for the language inspired me to later become a Russian and French high school teacher.

Onset of Hearing Loss

The question “How did you become deaf?” is never easy for me to answer. If I could point to a specific accident or injury it would be simple. I was in my twenties, married, and pregnant with our second child. While conducting a high school Russian class, I became dizzy and fell against the chalkboard. As I regained my balance, it felt like my head was under water. Thus began many trips to the otolaryngologist. Instead of learning I had an ear infection, I learned I had a slight upper frequency hearing loss. Headaches, tinnitus, and ear pain became a daily part of my life.
After three or four years of searching for a medical reason for my problems, while I gradually lost more of my hearing, the doctors diagnosed temporomandibular joint (TMJ) dysfunction. They speculated that it was a result of an earlier whiplash injury and both TMJs slipped out of place that day in the classroom. It could just be a coincidence that my hearing loss coincided with the jaw injury, or it could be related. There is still no definite answer.

At this point my husband and I moved to Florida with our two children. We undertook this adventure because we had been referred to a doctor there who was a pioneer in the field of TMJ surgery. A six-hour surgery to replace the disks in my jaw was successful (although it did nothing for my hearing loss). Years later the FDA recalled the Teflon jaw implants, which led to another surgery to remove them and replace them with a temporary implant until the joints healed. Two weeks after the temporary implants were surgically removed and all was going well, a car went into an intersection in reverse and hit my car. The whiplash reinjured my jaw, and my hearing loss then turned sharply worse.

The next five or six years were very difficult for me. I have memories of waking up every morning, driving my children to school, and then coming home and sleeping for the day. Between the physical pain that accompanies TMJ dysfunction and the emotional pain of losing one’s hearing, I had no energy. I needed a surgery, but no date was set until the surgeon perfected a technique of using a graft of fat to serve as a disk.

Meanwhile, I was sleeping my life away. One day visiting my surgeon, struggling to understand him, I exploded with frustration and anger. I hit rock bottom that day. That was the turning point for me. My focus shifted from others helping me to me helping myself. I knew that sign language would be part of my future and would be the first step in acquiring the skills I needed to cope with late-deafness. I registered for a class at a junior college and also found a tutor to come to my home and teach my husband and two children sign language. Kay Ann, a culturally Deaf woman, became a dear friend to our family and a mentor to me. Shortly after that, I enrolled in an intensive sign language program at Gallaudet College (now Gallaudet University). There I met people from all over the world, including a woman from Russia. I found that I was not alone.

Acceptance

As I was experiencing hearing loss over the years, someone sent me an ALDA newsletter that told about a conference in Chicago. To this day, I cannot remember who sent it to me or how I met this person. I guess you could say ALDA found me. I remember feeling hope when I read it, but at the same time I remember not feeling ready for ALDA. I filed it away until I was mentally and emotionally prepared to face deafness. After the Gallaudet experience, I was ready.

The local deaf service center was one of the first organizations I had approached. To my surprise, they weren’t sure how to help late-deafened people since their main focus was on the culturally Deaf. The executive director at that time was very willing to serve this population if I would assist the agency by guiding them in providing and developing the programs and services needed by people who become deaf as adults.

The first step was to establish a local chapter of ALDA. This chapter became known as ALDA-Suncoast of Florida. As word spread, a CART provider named Tess Crowder called, offering to provide services
beginning with the second meeting. That was in 1995, and now, 13 years later, she continues to volunteer CART services for our monthly meetings. (Tess became a very special friend, and it was she who came over on my birthday to help me get started with this essay.)

Since teaching foreign languages was no longer an option for me, it was time to explore alternative careers. This marked the beginning of the next stage of my life – going back to school to become a licensed mental health counselor. The university I attended refused to offer CART, so I did the best I could with sign language interpreters. All went well until I took a discussion class, where there was no textbook to follow or notes to borrow. I met with the professor to discuss the stress I was experiencing, and she suggested I consider dropping out. Refusing to give up, I pushed for the university to provide CART. With Tess at my side, CART made all the difference in the world in pursuing and attaining my second master’s degree.

Community Service

As my life evolved into helping those with hearing loss, together with fellow volunteer Kathy Borzell we established programs at the local deaf service center, such as classes in sign language, speechreading, and communication strategies, as well as rehabilitation and mental health counseling. As a result of these efforts, I became the recipient of the JCPenny Golden Rule Award, which recognizes outstanding volunteer services in our community. This was an emotional and poignant moment in my life because I now knew I was on the right track to helping other people.

ALDA Service

I attended my first ALDAcon in 1996. Tom Davinroy, past president and chair of the Nominating Committee, approached me at the welcoming reception. As he noticed “Florida” on my name tag, he asked me right up front to run for the ALDA board as the Region III Director. This is how my relationship with ALDA, Inc. began.

It was about this time that I had my third six-hour surgery. My dedicated surgeon, who I never lost faith in, perfected a fat graft technique to decrease my TMJ pain about 80 percent. This gave me the mental and physical freedom to devote my time to ALDA. I have been serving on the board ever since, and I have never looked back.

In 2003 I was elected as president-elect. In 2004 I served as president. In 2005 I served as past president. In 2006, in accordance with the bylaws, I stepped off the board for a year. As soon as I was able, I ran again for secretary, and I continue to serve as secretary to this day.

During my term as president, my goals were to increase memberships, provide good quality services, and improve communications with members. Although I am proud of those goals, what was accomplished never became more important to me than how it was accomplished. I have my dad to thank for helping me think that way. He rescued a plaque from the scrap yard and hung it in our childhood game room. It read: “For when the One Great Scorer comes to write against your name, He marks not that you won or lost, but how you played the game.” As corny as it sounds, it always stayed with me. People were important, not things.
So I worked to increase memberships, but at the same time I appreciated the beauty of ALDA – an organization that is effective in helping individuals who lose their hearing to find peace with becoming deaf. I recognized that although we wanted to be larger, being small provided the right environment and opportunities for people to heal. I knew the number of people whose lives were impacted by ALDA was far greater than the membership count.

**Advice to Future Presidents**

As far as advice for future presidents of ALDA, I would recommend the following:

- Be sure to use the committee structure by consulting with the chairs when the Board addresses issues that pertain to a committee’s focus
- Follow an agenda even through email discussions, otherwise “around the rosie” you will go
- Send no e-mails in anger; walk away and have a cooling off period
- Get the facts before voicing an opinion
- Value each person by embracing the philosophy “I am OK. You are OK. We are all OK.”
- Control your feelings and don’t permit events or other people to control your emotions
- Refuse to take criticisms personally
- Remember that you can never please all people

**Dedication**

My involvement with ALDA remains strong, and I would not let anything destroy that relationship. I never feel alone because I have friends all over the country I can turn to, people who understand. Friendships are strengthened each year at ALDAcon, and new ones are made. While helping others I am also helping myself, which is the beauty of it all.

By accepting the “whatever works” philosophy of ALDA, deafness has opened doors to a whole new and beautiful world for me, presenting me with opportunities and friendships that have become blessings in my life. My advocacy continues through my work as a licensed mental health counselor and serving on committees and boards related to hearing loss. In addition to my position as secretary for ALDA, Inc., I serve on several boards and committees, including a metropolitan cross-disability advisory committee, appointed by the mayor of St. Petersburg, and the Florida Coordinating Council for the Deaf and Hard of Hearing, appointed by the governor of Florida. Service to ALDA and other persons with hearing loss can be the most satisfying experience in one’s life, and a resultant joy that I hope all of you experience some day.
I Didn’t Hear Him

At the time of this writing, I’m just about “celebrating” my 10-year anniversary of entering the world of hearing loss. It was just about 10 years ago, December of 1998, that I was in a casino in Atlantic City, New Jersey with my family. My husband came up to me, from behind, while I was sitting at a slot machine. He asked me how I was doing (losing of course), and after answering I went back to that one-armed-bandit, trying hard to gain back some of my quarters – or maybe nickels (I’m a sore sport and HATE losing!). The next thing I knew, I turned around and my husband wasn’t there. I was so angry! I not only had lost my money, but now I didn’t know where my hubby went. I walked all over, and finally, in the lobby of this huge hotel he comes up to me. He sees I am NOT a happy camper, and before I can open my mouth to tell him how thoughtless he is for leaving me and not telling me where he was going he said, “You’re going to the doctor.” I asked him why? This was his fault and I was angry. HE was the one who walked away and didn’t say anything!! And then he said, “I TOLD you I was going out for a cigarette. You didn’t hear me – again. You’re going to get your hearing checked.”

I Needed Hearing Aids

That fateful holiday season was my start of a journey that was unimaginable. I remember going to the ENT (Ear, Nose and Throat doctor) who told me I had a hearing loss. He whipped out this little box – the kind of box in which you might find a small gift, like a pendant. In this box were about three or four different “styles” of hearing aids. He told me that I could “improve the quality of my life” by getting hearing aids. (Gee, what was wrong with the quality of my life?) He starts to take out the different aids – the big suckers, I called them – the ones I SWARE I’d never wear; the small ones that fit in your ear but aren’t tiny, and then the killers – the teeny tiny ones that he said “everyone should get these!” Ok, I was willing – how much? I will never forget that first price of $6,000. Was he kidding? Most of us know he was far from kidding. That was the price of digital, in-the-canal hearing aids back in 1998.

I couldn’t afford hearing aids for $6,000, so I began to ask around. As a seasoned shopper, I never settled for the first price of anything! I was very lucky – I had deaf friends. I told my friends I needed an audiologist because I needed hearing aids. I remember we laughed – it seemed so ironic at the time because I knew some sign language; I had deaf friends; I even had a degree in Deafness Rehabilitation, and now I had a hearing loss. My friend sent me to an audiologist I still think of as one of the best. He also quoted me about $6,000 for those tiny little hearing aids, and agreed with my doctor that they would
be the best for me. I remember my hubby and I couldn’t afford $6,000 so we charged the bulk of it. I think my mother helped me pay for the balance.

These were cute little hearing aids – with a teeny tiny thingy that you grabbed to pull them out of your ear. They were barely noticeable, but I felt like they were taking over my whole head! I also remember hearing things that I hadn’t realized I wasn’t hearing anymore. I heard the silliest sounds, such as my audiologist’s pants whooshing. I remember he got up for something, and I heard his pants!! I was so excited – those little-sucker hearing aids were going to be GREAT! And they were great, for about three or four weeks, when I started to complain that they weren’t working so well. So my audiologist adjusted them and off I went, happy again, for another couple of weeks before I again complained that they weren’t working as well. This was the beginning of a great friendship with my audiologist, as well as the beginning of my deafness.

I would visit my audiologist almost every two weeks for the next two years. Every two weeks he’d check my new hearing aids, and every two weeks they needed adjustment. After struggling with the little in-the-canal ones for a few weeks – just a bit over a month, he suggested that we send them back and try small behind-the-ear aids. Those were the ones I swore I’d never use – but these were small ones and my audiologist convinced me to try them. Without going into all the details of two years with the audiologist, suffice it to say that I went through a dozen pair of hearing aids in two years, only to end up deaf – deaf enough to not even bother with hearing aids at all. Just so there aren’t any misconceptions – I only actually purchased about three pair.

My audiologist once “lent” me new, state-of-the-art, programmable digital aids that he got as a sample. These worked for me for quite a while. He never charged me for them because he felt so bad that my hearing was deteriorating so quickly. I paid $6,000 for those first ones and returned them while they were still under “warranty.” I got those little behind-the-ear ones instead. Those worked for a bit, and then I got the samples that I loved. It worked this way for quite a while (relatively, if you consider this whole story takes place in the span of two years), until I needed to buy the BIG suckers, for which my audiologist, feeling very empathetic, only charged me his cost.

*What About My Job*

Throughout this time, I remember being totally panicked. I was working as an Assistant Principal in a New York City high school and just managing to do my job. In retrospect, I not only don’t know how I got that job, but how I became tenured during that time. I was so focused on my ears, and so afraid of losing my job and ending up God only knows where. But somehow I got through that time – thanks to my audiologist, my deaf friends, and my husband, who told me that I had the education, I had the connections and that it was time to use those connections.

I contacted my past professor, who was deaf himself, and told him my saga. He asked me point blank if I was afraid I’d lose my job. I remember feeling funny about that, because well, I was working, and was scared, but I didn’t *FEEL* like I couldn’t do my job. I had to answer “yes” though, because well, the reality is that as we lose our hearing, our ability to communicate changes – and as a school administrator, communication was critical to doing my job. My professor told me, “Jane, go back to school. Get your doctorate.” I did. I don’t know how I did it but I went back to school for five years.

*Back to School*

That first year, I started school and had CART – formerly known as Computer Assisted Real-time Transliteration and now known as Communication Access Real-time Translation. It put me to sleep. I
I struggled so hard to not drift off reading all those notes from those long lectures! I remember that the language was “scholarly.” A lot of the language was new to me – and new to my CART writer, who unfortunately made a number of mistakes. At the point when I realized that there were many mistakes, and that I truly couldn’t keep my eyes open, I went to my teacher, my professor who ended up my doctoral chairperson, and said “I can’t do this.” I was going to drop out. We had an intense email discussion and he asked me if he could present my difficulties to our Learning Community. There were ten of us in that Community and I thought, “Why not just be honest?” In our next class my professor shared part of our email discussion. And I will never forget the people in that class telling me, “Jane, we won’t let you quit!” And I remember clearly saying, “What are you going to do, write my dissertation for me?” And those wonderful people said of course not, but they were there to help me. They’d make sure I was included; they’d help me with notes; they’d do whatever they could so that I wouldn’t feel left behind.

It’s amazing how sometimes one can feel like life is spinning out of control, and how from the least expected places comes the beginning of a new life. This Learning Community, and my experience over five years at Hofstra, was, in retrospect, the beginning of my new life. At about the time this was happening, my deaf professor told me to stop struggling with CART and use a sign language interpreter. I thought that he had lost his mind. I couldn’t sign well enough! He told me not to think that way and just start to work with an interpreter. I di– and haven’t looked back since. I understood maybe 60% of what was signed, and each semester, each year that I went through school I understood more and more. I found a great “pair” of interpreters, who were at the language level I needed in this program, who stayed with me for more than three years through this program, until I graduated, with several others from my Learning Community, with my Doctorate in Education.

I Kept My Job

As I write this I once again marvel at how fortunate I was, and how things just sort of happened this way. How odd that I took an interest in deafness prior to my own hearing loss – enough of an interest to earn a degree in the subject. How odd that I happened to have deaf friends. The fact that I had deaf friends cannot be overlooked. Those friends took me into their home every Friday – once we saw that my hearing loss was rapidly progressing – and “tutored” me in sign language. I had some previous knowledge of sign, and we’d sit every Friday night and just chat, so I could learn new vocabulary and learn enough sign to work with interpreters. And thanks to those Friday nights, I was able to keep my job as an assistant principal.

I was not just an assistant principal. In NYC high schools there are many assistant principals, referred to as APs. There are APs in each subject area – AP English, AP Math, etc. And there are APs of Special Education. I had been a teacher of Special Education for years, and at that point in my life, I was an AP Special Education. I KNEW Special Education laws and laws about accommodation. With the support of my husband, I advocated for myself. This was NOT an easy thing to do. It’s very easy to advocate for someone else, but when it’s coming out and saying,”I can’t hear, I need an interpreter, I need CART, I need … I need… I need…” it’s just very hard to do.

Over the two years of my hearing loss I needed a lot. I used CART at first. I remember going to our School Opening meeting and there was a CART writer. The big-wigs, the superintendent and his deputies, were freaking out! Why? They thought this was something with legal implications! They came to me to ask all about this. I had a friend on each side of me, just sending their psychic support as I explained with a dry mouth what CART was! Later on, I had to go to the NYC Department of Education to document that I couldn’t hear and needed accommodation. I went in to see the doctor. He didn’t know what to do with me because I couldn’t hear him. My interpreter (by now I had an
interpreter assigned to work with me) came into the room and the doctor said, “I guess you’re here because you want to retire?” I looked at him like he was nuts!! I didn’t want to retire – I wanted to work – and I wanted him to document that I needed accommodation to do that. Shocked, the doctor signed the papers and sent me on my way. Once this was completed, I had an interpreter with me all the time – until the day I left that job.

Finding ALDA

As I pause to think about “my story,” I’m thinking that a great deal happened to me during those two years of hearing loss, and the ensuing years of deafness. There are so many stories – so many things I learned – often the hard way. I kept plodding on though, and as I reflect, part of what kept me going – in addition to my family and dear friends, was my ALDA family. I had never heard of ALDA – I had never heard of any support group for people with hearing loss. Why would I have? Earlier I said I was panicked. I didn’t know what to do, even though some may think I was “prepared” for deafness. There IS no preparing to be deaf. It’s shocking, no matter how much you know about it. My way of dealing was to acquire information. I bought books and started to do “research” online. I came across a group called the Say What Club (SWC). This is an internet group of people who talk about hearing loss. Every day, I’d rush to the computer to talk to my “friends” who knew what I was going through. Then there was a change – one of the gals on this list lived in New Jersey – about 45 minutes to an hour from where I lived – and she decided to have a “party.” She invited me and I said “No, but thanks anyway.” She kept inviting me, as did a few others who were going to this party. Finally, I said “I’ll ask my husband if he wants to go,” knowing that he is as far from being a party-goer as one can be. I said to my husband, “You know that internet group of friends I made that all have hearing loss? Well one of them, in New Jersey, is having a party and you wouldn’t want to go would you?” Guess what he said? “Yes, let’s go – you NEED it!”

This was in 1999, and I think that if I’d have to pick the top three events that changed my life in connection to hearing loss, this would be one of them. I made lifelong friends at this party – and it was the first time I heard of ALDA. From that party, I went on to be involved in a number of SWC conferences – one in San Diego. I was a presenter at that conference, on a panel with ALDA’s current president, Christine Seymour. A member of the audience, Edna Shipley Conner, came up to both Christine and I after our talk and asked us to do the same thing at ALDAcon in New Mexico. I believe this was 2000, and both Christine and I went to this life-changing “Con.”

From the moment I arrived and saw people communicating using “whatever worked” from writing to speechreading to sign, and everyone just happy and relaxed, ALDA became part of my life. I cried when I arrived at that ALDAcon, and kept crying for the entire time. I wasn’t hearing well at that time and my hearing aids weren’t helping much. I cried. I went to meals where everything was accessible – speakers, entertainment, everything. I cried. I visited exhibits where I could communicate in whatever way worked. I cried. I went up to Board members thinking, “Wow, these are special people – they are deafened like me and they are leaders and they are happy!” I cried. I went to karaoke – I cried – because I COULD enjoy that music.

Serving ALDA

ALDA has been a part of my life since. The people I met at ALDA changed my life and in some ways saved me. I met people that were working, people that were professionals, people that didn’t let deafness stop them, but used deafness to push them forward. I’d like to think that because of all those I met, because ten years ago Edna plucked me out of another organization’s conference, I also became a leader. I grew into my deafness, my new skin so to speak. I met others like me, who weren’t born deaf
but became deaf, and people who were advocates for those who were deafened. This became my goal – I wanted to be an advocate. I have since presented at ALDAcons often, and I have never missed an ALDAcon since I first went to New Mexico, almost ten years ago.

I’m not sure I’m an advocate, but I am sure I became sort of a leader in ALDA. I ran for the board for no reason other than, “Why not?” I mean, one year I was asked if I’d be interested in running for president of ALDA. I thought of so many reasons why I couldn’t. I doubted that I was ready for so much responsibility. I had a full life – a full time job, two children, and a husband and home to care for. I was going to school. How could I possibly run ALDA? I remembered something I had “heard,” possibly at ALDA, about volunteering, and that thinking of all the reasons why not to do something is easy, but thinking about why one can do something is more positive, and a better way to move forward. I told my husband that I was asked to run for president, and he said, “Go for it!” That was my “why not” moment! Why not volunteer? Why not shoot for the stars – because becoming ALDA’s president to me was shooting for the stars! Why not?

That was a while ago now. I’d like to think I did a good job as president, and I know that I did my best at the time. I had changed jobs, was finishing my doctoral studies, and was swamped with life, but I enjoyed every minute as president. When my term was over, I couldn’t just walk away, so I became the ALDAcon Planning Chair. After that, I again ran for the Board as a Regional Director from Region #1, and unbelievably I won and served another term on the Board.

I have only been involved with ALDA for part of its young life. While no one would ever want to be deaf, I am thankful for a lot that has happened to me since losing my hearing. I advanced my education, earning a doctorate I might not have otherwise sought. I have traveled more than I ever thought I would because I became deaf – to all those ALDAcons over these past years; to many board meetings as a member of the ALDA Board; and to a variety of other places, including Washington, DC as an advocate for children with hearing loss. Without the people I met at ALDA, my life would be so different. The ALDA family is truly a family – where we know each other’s heart. We know what it’s like to lose sound, and we know what it’s like to keep moving forward. When things are down we have each other. When we need advice or an advocate, we know where to turn because someone in our family can help. No one wants to become deaf, but deafness for me brought some remarkably good things, and a lot of that happened through my ALDA family and friends. Not a day goes by that I don’t think of ALDA, or someone from ALDA. May ALDA continue to reach out to those that need ALDA, and may the organization have another 120 years of success and beyond!
IN THEIR OWN WORDS
ALDA PRESIDENTS ● 1990 – 2015

Edgar “Bernie” Palmer – 2007

Growing Up

I was born in Hartford, Connecticut when Harry S. Truman was president of the United States, when Senator Joe McCarthy was dominant in the news, and when JFK married Jacqueline Bouvier. I was fortunate to grow up in a large, blue-collar family of nine children – four brothers and four sisters. My parents were modest people – my father worked for the Balf Construction Company, a company situated in Hartford that primarily produced cement for commercial construction purposes, and my mother essentially was a homemaker who helped make ends meet through a series of home-based jobs, such as a manicurist and a hair stylist/barber. She also, from time to time, hosted social community gatherings at our home, and for a time dabbled in modeling.

Although my hearing loss was first diagnosed in my left ear when I was 9 years old after I was hit by a car, I attended public schools exclusively prior to and after this discovery. My parents were strong believers in education and “The American Dream.” They enrolled us first at Barbour Street School when we were living in Stowe Village back in 1958, and later, when they purchased their first house at the edge of the northwestern part of the city in the early 60s, we attended Vine Street School. After grammar school, I went to the old Northwest Jones Junior High (now demolished), which was situated near Keney Park.

When I was in 8th grade, one of the most important events of my K-12 preparation occurred when I won a scholarship to attend the Hotchkiss School as part of the Greater Opportunities Program. Hotchkiss is a private, preparatory school located approximately two hours west of Hartford in rural Lakeville, Connecticut which is in the western part of the state. Upon arrival at Hotchkiss, the reality of existing in a predominantly Caucasian, small-town, and wealthy environment was immediate and profound. It was at Hotchkiss that I had the opportunity to peer close-up into the lives of some of the wealthy, highly educated benefactors of Hotchkiss. I saw how they lived and what they valued, and I came away not only impressed, but awed. On Sundays, we would visit the homes of these benefactors for dinner and as we sat around the dinner table, there would be lively discussions on a variety of subjects – education, responsibility, perseverance, hard work, self-help, our various interests for which we received feedback,
politics, current events – all those things that lead to a productive and successful personal and professional life.

So it was at Hotchkiss at age 14 that I made the seminal discovery of my life: I came to the realization through my interactions with Hotchkiss faculty, staff and alumni, how important education and hard work would be to any future success. Up until this point in time, I hadn’t really thought much about the ‘future.’ These thoughts were, at times, sobering and scary. At Hotchkiss, I learned how to study and to take personal responsibility for my own education. I also learned about values, respect for others, empathy and importantly, as Henry Ford once said, “Hard work never hurt anybody.”

I spent three wonderful summers at Hotchkiss, and following graduation in 1970 I returned home to Hartford. At HPHS I received support services for “voice and diction” – something I hated then, but for which I am forever grateful now – and lipreading services. Following graduation from Hartford Public High School (HPHS) in 1972 to say I was lost would be a colossal understatement. At that time in my life I was totally listless and I had absolutely no idea what I was going to do with myself. I was truly and literally “lost”. The truth is that I was scared. But things happen in life and often-times, regardless of how painful, frightening or discouraging those experiences may be, we learn from them and are better individuals because of them; an example of what I mean follows.

One day that fall while at work at the Farm Shop where I flipped burgers, my former high school guidance counselor, Mr. Richard Peoples, showed-up for dinner with his family. He was as surprised to see me there as I was to see him. Mr. Peoples was the kind of person who “was always there” – particularly during that last month of high school as I dealt with my newly acquired deafness, and he always seemed to have a personal interest in helping me. During that brief moment in time as he ate dinner with his family, he asked how I was doing and after hearing a feeble attempt at saving-face, being the no-nonsense guy he was, he suggested that I “…stop by [his] office sometime soon to talk and to catch up with what it is you’re doing these days.” After mulling this over for a while, well, it was more like avoidance than “mulling it over,” I finally went ahead and called him with help from my mother. The following week, I stopped by his office and it was there that I learned about both Gallaudet University and the National Technical Institute for the Deaf (NTID). During the time we were together, he suggested that I contact vocational rehabilitation and gave me contact information. Being a professional advisor, and knowing that I was like a lot young people at that age, he did not trust me to follow-up on this advice on my own so he personally contacted my mother, shared resources and information with her about post-secondary opportunities for deaf people and, also, about how I could go about securing funding through vocational rehabilitation (VR) to support whatever educational endeavors I chose. My mother then made an appointment for us to meet with VR, and it was there that I met the woman who would become my VR counselor, Ms. Leslie Waite. Ms.Waite told me more about NTID and Gallaudet, recommended that I begin taking sign language classes at American School for the Deaf (ASD) in West Hartford and later, made arrangements for me to take the Gallaudet qualifying exam at ASD.

During the late fall of 1972 I found myself at ASD in tutoring sessions with Ms. Marilyn O’Leary Brown. That year, the ASD football team won the national championship and I was nothing short of thrilled to see that there were so many seemingly HAPPY young, deaf people just like me out there who
were happy in their own skin. No longer did I feel all alone in the world or as bad about my lot in life – being deaf.

At ASD I met Mr. Fred Sparks, an elderly gentleman who possessed a remarkable collection of stories about deaf people and deaf culture. Mr. Sparks often told me stories about these deaf people and their accomplishments, people like Fred Schreiber, Jerald Jordan and Boyce Williams and others like the deaf baseball player “Dummy Hoy” and the story about the Gallaudet football team’s use of the “huddle.” He also told me a host of other things that are unique to deaf culture such as the National Association of the Deaf (NAD), the Volta Review and the A.G. Bell Association for the Deaf and Hard of Hearing. He told me about deaf clubs and about sports leagues that were composed entirely of Deaf athletes. It was Mr. Sparks who introduced me to Mr. Albert Couthen who is black and deaf. Mr. Couthen is a deaf World Games Olympic champion in track and field, a Gallaudet alumnus and he was the coach of ASD’s national championship football team in ’72 as well as their track and field coach when I first arrived on the ASD campus that fall. Mr. Couthen was my first black-deaf role model.

Finding ALDA

In October 1999 while serving on the Gallaudet University Marketing Committee (GUM), I was approached about the possibility of attending the ALDAcon ’99 in Dr. I. King Jordan’s stead. I was asked because I’m a late-deafened person and some felt I would be a good representative for the university. That year, ALDAcon was held in Alexandria, Virginia under Cheryl Heppner’s astute leadership. Initially, to be honest, I had some strong reservations about attending the conference. That trepidation came from two things: 1) years of a personal struggle to accept myself as a deaf person, and, 2) being privy to the often disparaging statements that at that time had been attributed to ALDA by some Deaf people. I had “heard” a laundry list of curious statements, things like: “ALDA was for deaf people who can’t accept being deaf and want to be hearing.” “ALDA is not for people who sign.” “ALDA is for deaf people who lost their hearing and are clinically depressed about it.” “ALDA is just another support group for whiners.” In any case, derogatory perceptions notwithstanding, but especially because I was asked to represent Dr. Jordan and the university, I decided for myself to go, and so off to Alexandria, Virginia I went for the I. King Jordan Luncheon.

Upon arriving at the conference site, I have to say this: right off, I knew there was something special about ALDA. Contrary to the opinions of some, I didn’t see any “depressed people.” In fact, what I saw, and what I found was a large gathering of people who were just like me - people who had lost their hearing after acquiring the ability to speak. These people were genuinely OK with that and others seeking to find their way. What WAS different, however, was whatever modality I used to express myself was a non-issue. How well I signed or how poorly, for that matter, was moot. These folks were excited to see each other and it seemed like everyone knew everyone. That’s all that seemed to matter. To be succinct, it felt like a ‘family’. At this conference I met the late Edna Shipley-Conner, Cheryl and Fred Heppner, Marylyn Howe, Heidi Adams, Ken Arcia, Mary Clark, Robin Titterington, and Sharaine Rawlinson, and I was happy to see an old football buddy from my college days – Steve Larew, and a friend from my graduate school days at Western Maryland – Rick Skyer. All of these individuals are remarkably accomplished people and they all went out of their way to make me feel comfortable and welcome. Cheryl would remark again and again at how thankful ALDA was for the continued support from Dr. Jordan and Gallaudet University.
During the remaining part of that day, I attended several workshops, but one that really stood out for me was for couples in ‘mixed-marriages’ (deaf – hearing) that was led by Fred Heppner. I found this presentation, the ensuing discussion and participants’ remarks particularly intriguing because I too was married to a hearing person at the time and to ‘hear’ others talk about the challenges, the foibles and the rewards of such relationships was quite enlightening.

So, after what initially was planned as a Friday afternoon luncheon at the Con “representin,” I found myself yearning to find out more about ALDA. So the very next day, I returned to Alexandria and attended the general meeting. Later that evening, at the karaoke party - a tradition at ALDAcons – I had what was an incredibly releasing experience for me: I got to belt-out some ‘oldies but goodies’ with a bunch of other similarly giddy people with nary a worry about carrying a tune! Having made new friends and thoroughly enjoying myself, I left with a sense of excitement. Needless to say, I have not missed a Con since.

Guiding ALDA as President

It was at the ALDAcon in Las Vegas that I was first approached by Edna Shipley-Conner about the possibility of serving on the board. Edna pulled me over after one of the luncheons and suggested that I give consideration for running for the open Region I Regional Director seat. After mulling this over and after much prodding from Edna, and after seriously questioning my sanity, I decided, again at Edna’s behest, to announce my interest in running. Following two years on the board as RD, Region I, I ran for, and much to my surprise, was elected president-elect in 2006.

My goals as president were simple and modest: 1) to increase ALDA national and international membership, 2) to find ways to improve ALDA’s marketing ability through a professional website, 3) to increase ALDA’s resources, and, 4) to increase diversity among membership.

I would hazard a guess and say that my term as president was only moderately successful. During that one year, membership increased – by adding almost one hundred new members. In addition, although there were only moderate increases in the ethnic representation among membership, there were significant increases in members who use American Sign Language.

With Christine Seymour spearheading the web development with early support from Dennis Gonterman and especially Ken Arcia, what I had hoped became a reality. Much of the accolades should be directed squarely at Christine because this was a huge undertaking. I am certain that had Christine known how much time and energy she’d be investing in bringing this “dream” to fruition, she would have had serious pause about taking on this important role. So let me say this for all of us ALDAns: “Thank you, Christine.”

Upon assuming the role of president, almost immediately I learned a hard truth: ALDA’s cupboards were virtually bare. This meant that there could be no grand, costly ideas and that spending would have to be seriously curtailed if ALDA was to remain solvent. Initially, this was disconcerting. However, with Matt Ferrara’s quiet steadiness and astute advice, the board was able to cut costs and free-up funds to help support Dr. Jane Schlau’s efforts to chair the “Roaring to Rochester” ALDAcon in 2007. Because of Jane’s attention to detail and the help of an incredible corps of volunteers that Jane put together, the conference was able to turn a tidy profit and add significantly to ALDA’s coffers. It was through efforts
such as this that the board was able to see the website through from concept to design and finally, to reality.

One of my most memorable images of ALDA is Matt Ferrara’s reaction upon receiving the President’s Award that year. Another was the success of the Rochester conference. Another was that very first karaoke party in Alexandria back in 1999. Another was the memorial services for personal friends like Rick Skyer, the incomparable Edna Shipley-Conner, and more recently, Rachael Morris. The truth is that I have a catalog of memories and enduring friendships that I have been fortunate enough to experience that have accumulated from over a decade of attending ALDAcons.

**Looking Back, an Epilogue**

If there is anything I would do differently as president, if I could do it all over again, it would be to pay greater attention to the sensitivities of human nature and our unfortunate tendency to unwittingly rile-up people as we attempt to communicate by electronic means. What I mean here is that in this age of amazing technological advances, communicating by email and/or other electronic means can be fraught with literal “potholes” and other unfortunate headaches. People take umbrage to things they perceive in email when sometimes what they’re reacting to is not there. Sometimes information that should be in an email is not included in the email – or vice-versa – and the result is confusion, chaos, and misunderstanding. As humans, sometimes, in our zest to get things done timely, feelings may get hurt and tender egos may get abused. In a nutshell, I would be more empathetic and most definitely, more patient.

ALDAcon has been an amazing “find” for me. A “find” that occurred purely by happenstance and, of course, being in the right place at the right time. Had I not served on the Gallaudet University Marketing Committee and had ALDAcon not come to the DC area, it is unlikely I would have, as we say in ALDA, “Lost my hearing, found a family.”
IN THEIR OWN WORDS
ALDA PRESIDENTS • 1990 – 2015

Linda Drattell  2010

Discovering My Deafness

I seemed to have misplaced my hearing beginning in my 30’s. It was a gradual misplacement, one I didn’t even notice at the time though others did. My daughter, now an adult, recently shared with me that when she was young I never responded to her when she called me, and she did not understand why I was ignoring her. Neighbors were frustrated with me as my son, behind my back, would gleefully say swear words without any reprimand from me. Who knew? My husband asked me repeatedly to focus when he was speaking, which I thought I was. Huh!

In 1999, my husband and I, together with our kids, were driving in our car when the air conditioning made a roaring noise that annoyed everyone except me. The initial assessment by my family suggested that I needed to get my hearing checked. I did, and found that I had misplaced it somewhere. I got hearing aids.

I always loved going out to the movies. When we moved to Pleasanton, California in 2000, my hearing was still sufficient enough for my husband and me to enjoy a movie at the Cinemark Theater in Blackhawk. Afterward – or before – we would eat dinner at the Blackhawk Grill. I was able to follow the movie dialogue until a few years later, when my hearing level declined to the point that I could only identify the protagonist in the movie but not the storyline. If I was lucky, I figured out who the antagonist was as well, but that was about it. My husband and I had enjoyed our nights out at Blackhawk – good food, good movie, being together doing something we enjoyed. Then those outings ended because, well, what was the sense?

With a gradual hearing loss everyone suffers because no one realizes what the problem is until it becomes definite – a definitive part of our identity. In my 40’s, around the time when we realized I could no longer understand the movie plot, my hearing level dropped 30 decibels in one night. Doctors could not find a reason. Since then I have self-identified as late-deafened.

Discovering ALDA

That identity – late-deafened – how did I choose that? My audiologist referred me to a self-help group for hard-of-hearing people, SHHH (now HLAA). I attended a meeting and enjoyed a wonderful presentation by Christine Seymour, who would become an ALDA president. I was struck by this person,
the first deaf woman I had ever met. Her professional appearance and presentation left me feeling that I would be okay because she was okay, more than okay, and therefore I would be too. I remember she hugged me and invited me to an ALDA-East Bay meeting. It would be the first of many. Edna Shipley-Conner was at that first meeting, and she took me under her wing as she had done with so many others. I cried at that first ALDA meeting, thankful for the people I met, for the new identity that had true meaning for me, and for a new path to continue to thrive.

I remember Cristina Cordoba asking me, “Why are you crying? We are your family!” I will never forget that and the feeling of belonging she and others created for me.

**My Time With ALDA**

When Edna passed, it was heart-wrenching for everyone who knew her. I was asked to fill her place on the ALDA board, and I thought, how will I ever fill those big shoes? The ALDA board and other ALDA members told me that “Yes, I could make a difference in my own way.” After a year on the board I was encouraged to run for president of ALDA, and it was this decision that I look back on with satisfaction. The ability to serve others with hearing loss, as a board member and president, gave me the greatest feeling of accomplishment that I was giving back to my community. These positions also opened other doors professionally. I became the Hard of Hearing/Late-Deafened Support Specialist, and then subsequently the Director of Community Relations, at the Deaf Counseling, Advocacy and Referral Agency (DCARA), headquartered in San Leandro, California. But most importantly, I look back with pride at what our board accomplished during my tenure as president and past president. We sued Cinemark and AMC Theaters for movie captioning and arrived at historic settlements with both. Deaf, late-deafened, and hard-of-hearing people throughout the State of California would now be able to see first-run movies for the first time just like everyone else.

Which brings me full-circle. I began going to the movies again at the Blackhawk Cinemark Theater, which now provides me with the settlement-mandated captioning equipment to enjoy most first-run movies. My husband and I go out to dinner before or after at the Blackhawk Grill. And every time I go I think of my own personal hearing loss journey and how ALDA helped me to overcome the fact that I have misplaced my hearing.

**My Advice to ALDAns**

What advice would I give to new ALDA members? Here are a few things I have learned:

- ALDA is indeed a family. Be open to new relationships, no matter how far away the person lives or how they communicate.
- There are many ways to effectively communicate. ALDA’s motto is, “Whatever works!” So find what works for you and be content. I chose to learn American Sign Language. Others have chosen from a wonderful array of assistive listening devices in order to effectively communicate. Still others have received cochlear implants. Not every choice works for every individual. Take your time and learn all you can. In the end the choice is a personal one that is only yours to make.
- Get involved! Join a committee for ALDacon, join a chapter or group, or start a new one! It is the most rewarding thing you will have done, and gives you a reason to stay in touch with others.
- Losing your hearing is a journey – it can open you to new skills, new horizons, new goals and new hopes.
It has been five years since I was president of ALDA, and I am still in touch with many of the people I worked with. I continue to volunteer, communicate via Facebook and email, and look forward to each and every ALDAcon. I look forward to meeting those of you who have recently joined ALDA and offer the same warm friendship that was offered me by other ALDAns all these years.
IN THEIR OWN WORDS
ALDA PRESIDENTS • 1990 – 2015

Cynthia Amerman – 2011

How I Became an ALDA

In 1992, friends from New Jersey’s ALDA-NJ group encouraged me to attend ALDAcon in Boston. Edna Shipley-Conner had just started the Buddy Program, and she became my Buddy. She had a couple of reasons for thinking that we might be compatible: (1) we had both just had poetry published in No Walls of Stone: An Anthology of Literature by Deaf and Hard of Hearing Writers, and (2) we both had an interest in learning to sign. At the time, Union County College (UCC) in Cranford, New Jersey had an excellent ASL Studies Program in which I had enrolled that year. My studies took me to many Deaf Community gatherings, including meetings of the Northwest Jersey Association of the Deaf (NWJAD). Given the high level of tolerance by the members of the NWJAD for the poor signing of UCC students, I was allowed to become a member of the Club. My other memberships included SHHH State Chapter (as a founding member) and ALDA-NJ, a social group. Edna liked my “ecumenical” approach to becoming deaf.

Becoming Deaf, Hearing Aids and Cochlear Implants

How did “becoming deaf” happen? Slowly. While attending public elementary schools in Pittsburgh, Pennsylvania, I was embarrassed when, occasionally, I didn’t understand a teacher’s directions. In high school at Ellis, a girls’ day school from which many of my female relatives graduated, I sat at the back of the class. Why? I was tall and/or my last name began with “S.” No one, including me, considered that I might have a hearing loss, even though I understood less of the words to songs on the radio than my contemporaries did. Mostly, I daydreamed in class and only participated if called on. Asking teachers to repeat the question must have indicated solely my lack of attention. As it turned out later, but it’s debatable how much later, I was lipreading at top level and had no idea that I “heard” that way.

Post-graduation daydreaming continued in college, but now I sometimes cut classes during my years at Allegheny College. Nonetheless, a near miracle called college graduation occurred in the mid-sixties. Next, I worked at the University of Pittsburgh for the Director of a Program in Public Health Social Work (what IS an English major to do?). The job was short-lived, due to a sense of adventure that led me to Quito, Ecuador, where I taught all subjects in English in the primary section of Colegio Americano. Having more control in the classroom made being a teacher easier than being a student. During four years spent living in Quito, I married my first husband, a British colonial who had grown up in Africa, and we had our first child in Latin America. When the baby was one month old, he heard the
Apollo moon landing via short wave radio. We moved (back, in my case) to the United States, settling in eastern New Jersey three months after David was born.

After the birth of our daughter Evelyn (Lyn) in Englewood, NJ, my hearing took a dive. My British husband and I later separated, and I moved back to Pittsburgh with the two children. I wanted to know why I couldn’t hear well. Over the course of the next six years I saw four different doctors, asking each to test my hearing because I believed I was becoming deaf. The doctors denied it. Finally, the last doctor gave me hope that I wasn’t hallucinating. “From what you say, there has to be something wrong with your hearing,” he admitted, and referred me to an audiologist. After a few minutes of testing, the audiologist marveled, “No wonder you’re having problems understanding speech — you can’t hear consonant sounds!” Happily, hearing aids could help. Over the next three decades, four different hearing aid manufacturers benefited considerably from my hearing loss. In recent years having bilateral CI’s, one in 2006 and the other in 2013, has dramatically improved hearing in both ears.

During my “doctors-in-denial” years, I got divorced, married my second husband, Peter, who was my high school and college sweetheart, and we had another child, Alex. We were now living in northwest New Jersey at Blair Academy as a family of five. Hilltop Montessori School had hired me to teach English, Spanish and Creative Writing to grades 5-8, and Sussex County College hired me to teach Spanish. After a while, though, it began to be more difficult hearing whether or not students were conjugating their verbs correctly. Sussex would later hire me to teach Beginning Sign Language. Many of the same language teaching principles applied.

**Back to ALDA**

A group of us (3 men and 3 women) decided that we needed an ALDA Chapter in New Jersey. Twenty years ago, in 1995, ALDA-Garden State (ALDA-GS) was born and incorporated. Jerry Barnhart, who had a Ph.D. from Gallaudet in psychology, became our first president. Jerry was so much more than the official leader of ALDA-GS. He inspired us. Many of us gave presentations, advocated and supported all people with hearing loss, not just ALDA-GS members. Our coffers grew from selling Six Flags tickets, and we established a college scholarship fund to help New Jersey people with hearing loss. Following Jerry as ALDA-GS president was tough, but I stayed involved with our chapter over the years through a succession of presidents. Peter and I moved to Tucson, Arizona, in 2007 after his retirement, and I remain an ALDA-GS Advisory Board member. Knowing how this had worked well to keep continuity in my state chapter, during my 2011 presidency, ALDA Inc.’s board voted to have an Inc. Advisory Board. Alas, that has gone by the wayside!

**What I Owe to ALDA for Supporting and Encouraging Me**

Being ALDA-GS president in large part led to an appointment by Governor Christie Whitman to the Division of the Deaf and Hard of Hearing Advisory Council and later to membership in its Speaker’s Bureau. In the late 90’s a deaf-blind ALDA member recommended me for the job as Client Services Coordinator with the New Jersey Association of the Deaf-Blind (NJADB). Subsequently, Gallaudet University accepted me into their Social Work Program on the basis of this work experience with deaf-blind people. My long-term interest in Guatemala combined with an interest in advocacy, so I spent time in Guatemala from 2001-2012 encouraging Guatemalan deaf and hard-of-hearing people in Asorgua (their national association) to advocate for themselves.

In 2008, three of us in Arizona started a group called ALDA-Sonora. That year ALDA gave me the Able ALDAn award. In 2010, when I was president-elect, ALDA, Inc. allowed me to act as delegate to the Biennial Meeting of the International Federation for Hard of Hearing People in Stockholm, Sweden,
and, more informally, I represented ALDA at the National Association of Deafened People’s 25th Anniversary Annual Meeting in Liverpool, England. That year my old girls’ day school honored me with the annual Sara Frazer Ellis Alumnae Award at my 50th high school reunion in Pittsburgh. Although I had been Ellis class correspondent for a record 35 years, the award wouldn’t have happened without figuring in the trust that ALDA and other organizations had placed in me as a leader.

From 2008 on, Liz Booth and I worked together to advance the agenda of deaf and hard-of-hearing people in the state of Arizona in our respective organizations—HLAA and the Adult Loss of Hearing Association (ALOHA)—as well as for ALDA-Sonora. I have been a board member at ALOHA for the last seven years, again on the back of my previous involvement with ALDA. In 2012, Liz and I received the Hamilton Relay Better Speech and Hearing Recognition Award together. The confidence I gained through participation in ALDA translated into increasingly consistent advocacy and education for our benefit. Notice, however, that in every case, these actions were not a solitary effort. Any success, any position, any award involves being a member of a team. This is the most valuable thing that ALDA provides us – the opportunity to become a member of the team and to work together, something we rarely experience in hearing society because, due to our hearing loss, we are often thought incapable of working with others.

**What I Owe to Education, Necessary Adaptations**

Post-college study included a master’s degree in Literature from Drew University, part of a Spanish Master’s at Montclair State University and a Master of Social Work from Gallaudet, as well as ASL studies (UCC) and Spanish-English translation (Montclair) certifications. For the latter, I had to take the final by silently reading, rather than hearing, passages in Spanish and simultaneously translating them into English. I had to forego the Spanish Masters in which I was on full scholarship when my left ear suddenly became totally deaf. Pre ADA three-hour night classes without an interpreter or CART after working during the day were exhausting and frustrating. So I went to sign language school at UCC in hopes that a Spanish-speaking ASL interpreter might help me achieve this goal in the future. Life, however, intervened. Finishing the ASL Studies Program at UCC helped lead to my job at New Jersey Association of the Deaf-Blind. No matter that it sometimes could be a two-hour commute one way, I was ecstatic to have a job in which my hearing loss wasn’t a complete disadvantage.

Because I lived ten minutes from the Appalachian Trail in the wilds of northwest New Jersey, the master’s coursework allowed me to get a job at Sussex County College teaching Spanish, even though my thesis hadn’t been finished and the subject matter was literature rather than Spanish. In 1984, the death of my older son interrupted completion of the M.Litt. Program at Drew. With short extensions, I finished the last two courses I was taking at the time, but found it impossible to separate Margaret Atwood’s tightly interwoven themes while writing my thesis and decided to focus on other things.

Fast-forward ten years. I asked Drew if they would let me write a different thesis, using learning that had taken place during those years in between. My plan was to translate poems from English and Spanish into ASL and to create a video of these poems in translation, to write a journal of this experience, and to compare figures of speech in spoken and signed language. Drew assigned me a professor of German Literature as a thesis advisor who well understood the process of translation.

There was a prevailing attitude at Gallaudet in 1993, the year I attended a two-week summer immersion ASL Program, that non-native signers should not be using ASL creatively. However, in the spring of 1994, when I showed the poems to Clayton Valli, the ASL poet and professor of linguistics at Gallaudet, he told me that he wished he had seen my translations before finishing his Ph.D. thesis, which was just going to press. He said that my signing of the poems was too slow, but that he would have liked to
include my work on patterns of poetry in signed and spoken language. He repeatedly signed “Beautiful” and “Wow!” To know that Clayton, and later another Gallaudet professor, appreciated this work was extremely gratifying, and the process of discovery during my work was enormously so.

During this same 1993-94 school year, my husband and son Alex spent the year in Boston where Alex was attending school. I stayed in New Jersey to write/tape my thesis and sought a job that would not take psychic energy away from my project. The idea of working at the M & M Mars Hackettstown plant nearby appealed to me not only for the psychic energy reason, but also because many Deaf/deaf people end up unemployed or under-employed in factory jobs. As if in solidarity, I went to work in the Flex-Pack and Production sections of the plant. This involved wearing a white uniform, white hard hat and white steel-toed shoes, being able to lift 50 pounds and having the ability to work without talking. In Flex-Pack, during our shifts we made boxes, performed assembly-line tasks, lifted and stacked boxes, and so forth. A truly alien landscape could be found in Production, where there were exposed pipes everywhere, all machinery seemed white in color, and huge carts of coloring water for M & M’s had to be emptied out. On our ten-minute breaks, we could enter a special room where we could eat any product M & M Mars made. We were not allowed to take any candy out of the room. It took only two weeks for me to tire of Snickers, Dove Bars and M & M’s. Unlike most other workers, however, I was too deaf to have conversations even on breaks. After my shift was over each day, I felt a huge sense of relief as I burst out the door into the sunshine and drove away.

It would be accurate to say that I took the “scenic route” through the Social Work Program at Gallaudet from 2000-2004. This involved an adjustment to near total deafness and to “processing problems” not experienced as fully in earlier studies. During the Gallaudet years, I enjoyed a variety of social work internships—at Family Service Foundation, a mental health agency serving Deaf, deaf and hard-of-hearing clients; working at the Center for Global Education, at which I got a grant to take a social work professor to Guatemala to set up internships for myself and two undergrad students; working in Quetzaltenango (called “Xela” in Mayan), Guatemala at the Centro Educativo Para Niños Sordos. I learned enough Lensegua (Guatemalan Sign Language) to sign my farewell speech to students and teachers at Xela’s manual school—a feat never to be repeated!

After I graduated in 2004, a Gallaudet professor, a staff member in the department, a person at International Office that grew out of the Center for Global Education, and I all worked together setting up internships and study programs in Guatemala. It was rewarding to help expand the horizons of Gallaudet students by exposing them to international education and to another culture.

**ALDA Presidency**

The year I was president (2011), ALDAcon took place in Indianapolis. The program committee produced an unforgettable convention, and once in which they kept good control of ALDA’s budget and sought many extra sponsorships. The con made a sizable sum for ALDA that year. We attended a captioned movie, and saw Shakespeare’s “Julius Caesar” with captions. Terri Singer brought in a South African deaf racecar driver and his Indy 500-driver cousin—one of the excursions was a tour of the Indy 500 site. Saturday of the convention marked Harriett Frankel’s 95th birthday. We decided to honor Harriet, a staunch member of ALDA-Peach Chapter in Atlanta, who had grown up in Indianapolis. We created a slide show/commentary on her life with help from Robin Titterington, a past president of ALDA-Peach and former ALDA, Inc. president, and Ellen Matson, Harriet’s daughter. You could hear Harriet (called HARRIET by the Peaches) from just about any corner of a room, and she had some spicy tales to tell. At her birthday luncheon on Saturday, Harriet kept us entertained.
ALDA’s 2011 year went smoothly, and we were able to reach consensus easily on most issues. Many ALDAns had talked with me previously about changing the governance structure, the three-year presidency involving president-elect, president and past president was designed to ensure continuity, though it hadn’t worked as well as planned. A new structure was proposed, but dropped when we couldn’t envision how it could succeed. Late in the year, board member Brenda Estes tapped me on the shoulder to say that Matt Ferrara, Treasurer, had laid out a complicated but doable phase-in plan to allow a president and vice president to serve on the board for two years each—in order that they might better affect change. This year, 2015, is the first full year of the new structure. If it proves more workable than the three-year presidency with only one year as actual president, we members will benefit. If not, we can change the structure again to one better suited to our organization. The 2011 Board was a flexible and resilient one that consistently kept ALDA’s best interests at heart.

ALDA’s Future

Finally, what would I like to see happen in ALDA’s future? Easier to say than to do but, like many others before me, I’d like ALDA to establish a stronger national presence, one feature of which would be an office in Washington where networking with other organizations could be more of an everyday event. Another feature would be to hire an executive director to provide stable long-term leadership. We are small, but we continue to have potential! Funding doesn’t come easily these days but if we could focus more on fundraising perhaps we could realize more of our dreams. On the other hand, ALDAns love to have fun and, as late-deafened adults who have experienced the many pitfalls of hearing loss, we deserve to enjoy life in the present. Maybe what we are already doing is what suits us best. What do you think?
IN THEIR OWN WORDS
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Growing Up

Like many young girls from the 60’s, my dream was to become a nurse, get married, have two or three children and live in a house with a white picket fence. Life doesn’t always work out the way we plan, does it?

In the early 60’s, my brothers and I had the measles, and a few months later, my elementary school teacher noticed I wasn’t always responding in class. Not knowing if I had developed a sudden case of “selective hearing” or perhaps acquired a hearing loss after the recent bout of measles, she recommended that I have my hearing tested.

Mom didn’t want me to feel “singled out” so she arranged for hearing tests not only for me but for my brothers as well. The results showed my brothers had perfect hearing while I had acquired a severe loss in the right ear only. We were poor as “church mice” and as a result couldn’t afford hearing aids. So, in elementary school, I had to start sitting in front of the teacher’s desk, which I refused to do in middle school and high school. I also began attending speech therapy classes two days a week, which I did for the next 10 years. To an elementary school kid, sitting in front of the teacher’s desk was not fun at all. But getting out of class twice a week to go practice rolling your tongue and learning how to talk through your mouth instead of your nose was interesting. I can’t remember why we practiced the tongue rolls but do remember it was fun! We also were taught in speech therapy to take some confetti and lay it on the table, bring your nose level to the table, and start talking. If the confetti moved, it meant you were talking through your nose (nasal twang). Fun you say? You try picking up confetti from the floor and see how much fun it is! To top all this off, for the next few years I had to carry a construction paper booklet with me to and from speech therapy class with pictures of words and names that began with “s”, “sh” and “ch”. This is why to this day, I overly enunciate “sh” and “ch” sounds.

I was mainstreamed in public school. After high school graduation in 1973, I applied to a nursing school program and was denied admission simply because I had a hearing loss in one ear. Wanting to work in the medical field helping people, I then contacted the local emergency medical technician (EMT) coordinator who informed me that preference would be given to returning Vietnam veterans first and then to civilians. Since I already had a hearing loss, I would need to provide a letter from my doctor verifying the hearing loss, and then sign a waiver releasing the city of liability for any future hearing loss that might occur as a result of ambulance sirens.
After making a list of pro’s and con’s, I decided to enroll in a liberal arts program at the local community college while working part-time for an oral surgeon. Like many 18 year olds, I was more interested in socializing than studying. So after one year, I dropped out, switched from part-time to full-time employment, and just enjoyed being a young adult. Eventually, I went back to college to obtain an Associate in Applied Science in Medical Records Technology.

Getting Help

Throughout those early years, my family never treated me differently because of my hearing loss. As a matter of fact, they encouraged me to follow my dreams. Mom was my strongest supporter, she instilled in me the belief that having a hearing loss only meant that I couldn’t hear as well as others; it had nothing to do with my ability to do whatever I wanted in life. In my 30’s, when my hearing suddenly became worse, she was there by my side going to medical appointments with me in hopes of finding a definite diagnosis, a course of treatment and how to prepare for life as a deaf adult.

After calling various state agencies looking for informational resources, mom was referred to the Virginia Department for the Deaf and Hard of Hearing and learned about TTY’s and light signalers. A few years later, when the Simpsons first came on TV, my son kept badgering me to let him watch it and I refused, as I couldn’t lipread the characters and didn’t know if it was a good TV program or not. So he did what most children do; if mom says “no,” go ask grandma. Well, grandma advocated for him and I continued to say “no.” Need I say more? Yep, grandma won that disagreement and brought us our first closed captioned TV. Shortly thereafter, she ordered a vibrating alarm clock for me. And the vibrator that connected to the clock was the most uncomfortable thing ever! It was approximately 8” x 11” and 1” to 2” thick, and when you placed it between the mattress and box spring, it resulted in a hard lump that poked you in the back. The only good thing about it was that it definitely shook you awake in the morning. No more oversleeping for me.

Like many children of hard-of-hearing and deaf parents, my son quickly learned that as my hearing slowly deteriorated he could mumble as he walked away from me, knowing that I wouldn’t be able to hear or understand him. And the frustrating thing for me was that family and friends knew what he was doing and yet never told me. How well I remember on several occasions my cousins looking at me with shocked facial expressions and I asked them “What did he say?” They would just look at me. No matter how many times I reminded them of my progressive hearing loss and needed their help with such situations, it never soaked in. It took me years to realize that they were in denial about my ongoing hearing loss. Occasionally one of them would say, “It’s so hard to remember that you don’t hear as well as you used to.” To which I would respond, “This progressive hearing loss started years ago, and if you really loved me you would make an effort to remember that you need to look at me when talking, as I can’t lipread the back of your head. So hopefully between the hearing aid and lipreading, I can figure out what you’re saying.” This was long before I started taking sign language classes as I thought only Deaf people used sign language. Years later, I would learn how wrong I was.

Problems at Work

Fast forward to the early 90’s. I was working in the medical records department of a mid-size hospital when a human resources manager came to one of our monthly departmental meetings to discuss employee benefits. During the Q&A session, I asked what would happen to me should my hearing continue to deteriorate, and her response was that I would have two choices: either resign or take long-term disability leave. She also pointed out that I was the only hospital employee with a hearing loss. Which I didn’t believe for one second as the hospital was the largest employee in the city and I’d seen
employees with hearing aids. Now in fairness I should say that it’s possible that none of them had asked for accommodations, and thus the hospital had no record of their hearing loss.

Not too long after this, after advocating for two years for a $19.95 portable amplifier to put on the phone so I could hear callers better, the hospital demoted me to a clerical position. Needless to say, my salary would be frozen for many years as I was then making much more than the maximum for the clerical position.

Suddenly, my life had totally changed; it would never be the same again. All I could think about was “I want my life back! How am I going to support my son and me? How was I going to pay for his college education? Suppose his father decides to file for a change in custody from summer visitation to full custody claiming I was no longer a fit parent because of my sudden progressive hearing loss? Will I be able to find another job?” I went to employee assistance counseling services and they couldn’t help me as they bluntly told me they had no experience working with an employee who was being discriminated against because of a hearing loss.

As a result, I became depressed and after my audiologist noticed this she asked what was going on in my life. After explaining to her the situation, she referred me to the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons, which in turn referred me to the Gallaudet Law Center.

After I made an appointment to meet with an attorney at the Law Center, I gathered all of my written requests for the portable telephone amplifier, as well as the date of the department meeting with Human Resources and the date that at my request the demotion announcement was made to my colleagues. I wanted my colleagues to hear it straight from the horse’s mouth that the demotion—she used the word “position change”—was due to my hearing loss and not job performance. To say that the majority of my colleagues were shocked beyond belief is putting it mildly. One colleague though insisted that my salary also be decreased. Fortunately, my salary wasn’t decreased.

As depressed as I was, I am so thankful that I was able to mentally step outside of the fog that I was in to prepare for my meeting with the attorney. The attorney praised me for keeping good notes and copies of everything; as she would often say “If it’s not in writing, it wasn’t said.” That advice has been permanently embedded in my brain. We filed a Title I Employment discrimination complaint and it was settled amicably between the employer and me. The employer immediately provided assistive technology for the two offices I had within the hospital plus space at one of the nurses stations, including TTY’s, portable telephone amplifiers, telephone and doorbell light signalers, a vibrating pager (in those days, text pagers were not available, only ones where you could leave a phone number), and scripts for the five mandatory in-service videos that one was required to watch as part of one’s annual job performance evaluation. Later, the human resources manager told me that the hospital had been deeply concerned that I would go public with the discrimination complaint. My response was “Why in the world would I share my humiliation with the public?” I didn’t want anyone else looking at me as if I didn’t belong or deserve to have a job simply because I was losing my hearing. Needless to say, my thinking changed when I filed a second complaint against them four years later. I didn’t hesitate to go public. Unfortunately, months after filing that complaint I had to drop it as my mother had died and stipulated in her will that in order for me to inherit her house I had to live in it for a specific length of time. So I resigned my job and moved back to my hometown.

A Change of Careers

As a result of the initial discrimination complaint, I decided that perhaps it was time to make a complete career change from the medical field to advocacy. So I began networking and getting the word out, and
even though it took quite a few years, it was well worth it. Now I was able to help others who were struggling with their hearing loss or deafness and the everyday challenges it can present.

For the next 14+ years, I worked at a Center for Independent Living as the Deaf and Hard of Hearing Outreach Coordinator responsible for managing the outreach contract between my office and the state. A such I was responsible for providing outreach services in southeastern Virginia, assisting consumers with applying for assistive technology equipment through the state equipment distribution program as well as installation and training when needed, demonstrating equipment, setting up informational exhibit tables at community events, peer counseling, independent living skills training, and sensitivity training for 911 Centers, businesses and service providers. In addition, I created an email listserv for over 900+ consumers that disseminated information concerning rulings and regulations of the Federal Communications Commission, open captioned movies, local/state/national conventions, and other items of interest. I also responded to requests for information and referrals on funding for hearing aids and cochlear implants, ASL classes, employment, videophones, the ADA, individualized education programs (IEPs), service dogs, and so forth.

Getting a Hearing Dog

It was during this time, that I decided to apply for a hearing dog myself given that on several occasions while staying at a hotel during a statewide outreach meeting I had heard my colleagues talking about the hotel fire alarm going off in the middle of the night. And they didn’t come get me because it was a false alarm. That was NOT reassuring to me at all! After looking at various organizations, I decided to go with one from Oregon that trains shelter dogs to become hearing dogs. There are two classes of hearing dogs: dogs that work for you at home only and “certified” hearing dogs that work both at home and in public. Because I travel so much I felt a certified hearing dog would best meet my needs. What I didn’t realize at the time was that because this organization was so much smaller than another nationally well-known organization that trains labs and golden retrievers, the waiting list for a certified hearing dog (small to medium size) could be 1 to 5 years! Why so long? Shelter dogs are usually mixed breeds and not all mixed breed dogs are comfortable working in an ever-changing environment like a center for independent living where you might have people utilizing wheel chairs, crutches, walkers, elevators, sign language (the dog needs to realize that a person moving their hands and arms while signing is not displaying threatening behavior), and so forth.

After five long years, I finally received my trained certified hearing dog and believe me he was well worth the wait! One look at those soft warm chocolate brown eyes, buff color coat and crooked bottom teeth (just like mine), and I just melted. He loves to travel and doesn’t care if it’s by plane, travel coach or boat. For some reason, the sound of water fascinates him. When near splashing water, he will pull on his leash to the point of my occasionally losing my balance. I can’t begin to tell you how many times, I’ve almost fallen into a noisy pool because of him. I’ve learned not to stop next to a huge outdoor water fountain as he will not hesitate to jump in. And I had to stop taking him to church because he wanted to sing along with the soloist during Sunday morning church service.

Getting a Cochlear Implant

In 2012, I underwent cochlear implant surgery in my right ear and even though I can hear sounds words are still a challenge for me, while music is simply amazing. After hearing no high-pitch sounds in my right ear for 50+ years, it was mind boggling to realize that paper towels crinkle when you dry your hands, unrolling toilet paper from the dispenser makes a sound, my hearing dog makes noise when shaking his fur after coming in from the rain, and the turn signal in the car makes a clicking sound. One of my all-time favorite childhood sounds was that of waves gently lapping along the seashore, and
hearing it again brought me down to my knees, crying like a baby. I thought I would never hear the waves again but due to technology, it was possible.

It didn’t take long for the novelty to wear off with my family and friends as they had expected instant normal hearing and were disappointed when that didn’t happen. For me, sounds initially were high-pitch and painful with the implant. After all, that ear had been totally deaf for 26 years and the brain had to relearn how to decipher the different sounds—kind of like a newborn baby. They don’t understand sounds and words right away, do they? As time went on, the pain went away and the sounds I heard were distorted with the exception of music. I spend hours listening to music because I can actually hear the different scales. Listening to my cousin play the drums in his band is simply amazing as I can also pick out the different musical instruments, whereas before it was just noise.

**Conclusion**

If my mother were still alive, there is no doubt that she would be proud of all I’ve accomplished over the years. She passed away in 2000, and I dearly miss her and her encouraging words “Don’t let your hearing loss stop you from reaching for the stars; anything is possible as long as you set your mind to it.”

Even though my dream as a little girl didn’t come to complete fruition, I did get married, bought a house with a white picket fence, and had one son. Then in 1982, I divorced my husband, moved back to Virginia and went back to college. Eventually I became a foster parent to three boys, worked in the medical field before changing over to working with people who are deaf or hard-of-hearing, faced employment discrimination twice, learned about and joined ALDA (which helped me tremendously in adjusting and accepting late deafness), obtained a certified hearing dog, received a cochlear implant and now have moved clear across the country to Spokane, Washington, to begin a new chapter in my life as executive director of a Deaf and Hard of Hearing Center.

As I embark on this new chapter, I have so much to be thankful for, and I hope to make a difference in the lives of other individuals who have faced or are currently facing challenges in their lives due to their deafness or hearing loss. Life isn’t easy for anyone and it wasn’t meant to be; it’s how you face those challenges that determine the outcome. So go for it! Dream big and reach for the stars! Anything is possible as long as you set your mind to it.
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Mary Lou Mistretta – 2013

When and How I Became Deaf

I was born hard-of-hearing, but no one knew it for a long time. When I was about 2-1/2 years old my sister was born, and I was still not talking. Questions were raised among family members, and the answer they came up with was “She is not talking because she is jealous of the new baby.” I remember asking my mom when I got older “If I couldn't hear and speak, how did you know what I wanted?” Her response was "a mother knows."

I went to kindergarten, then first grade, and by the time I was in second grade there was a new principal who was weeding out all the "undesirables." She sent me home with a note in an envelope that caused my mom to cry. The principal said I could no longer attend Public School #63, and told my mom to send me to the School for the Deaf in New York City.

My parents were upset. They talked it over and decided to enroll me at the local Catholic school. The nuns were so good to me and helped me so much. I always sat in front of the desk by the nun in every grade. One of my fondest memories from fifth grade was when one of the nuns let me join the choir. Can you imagine someone who had a nasal voice and bad speech in a choir? Sister Cecilia told me to mouth the words with no voice. It looked like I was singing. It’s amazing when I think about it now.

The Effects of Deafness on My Life – Family, Friends, Workplace

Back in the olden golden days there was a lot of denial. I was very fortunate that my mom took me twice a week for lipreading and speech therapy, which helped me tremendously. It sure came in handy one day when my parents, sister and I were in the subway in New York City. Somehow my dad was on the other side of the track and trying to talk to my mom but she couldn't hear him. My lipreading came in handy, as I was able to tell my mom what my dad was trying to say.

I was very lucky to have understanding kids in my neighborhood who helped me. For example, I remember going to Saturday matinees with my friend and having her tell me what the movie was about. I feel very fortunate that my childhood years were good. I’m not saying it was all roses. In the schoolyard at recess, there were kids who made fun of my speech. I would fight them and run as fast as my little legs would carry me.
In the workplace, I was lucky and had a good work ethic, which employers took notice of. When the TTY came out my employer bought one for me to use for work, so I would be able to call different departments.

**When and How I Learned About ALDA**

That’s an unbelievable story! A friend of mine had sent me a copy of a sign that she had created. It was a picture of an ear with a line or X across it. The purpose of the sign was for it to be hung over a hospital bed to let others know that the person in the bed couldn’t hear. On the back of the sign was an advertisement about an upcoming ALDA convention to be held in Boston. I read it with interest, and later made a TTY call to Cleo Simmons, someone dear who we all know. She was my first contact at ALDA and she sent me information that further sparked my interest. I finally made it to the ALDA convention the following year in Chicago, and I loved it. I could hardly wait to get back home and start a local chapter in Fort Lauderdale, Florida. After returning home, I did just that. It was a successful chapter, with many members coming to meetings and social events regularly.

**Why I Ran for President of ALDA**

There were many reasons for my decision to run for ALDA president, but the most important one was my desire to help other hard-of-hearing and late-deafened people. I got to do a lot of helping during the six years that I was a regional director of ALDA. It was a very rewarding experience for me. It made me feel good when I helped others, and I still to this day hear from a few of those people.

**The Biggest Challenges and Rewards of Being President of ALDA**

My term as president started out smooth enough, but then my health took a turn for the worse, and I was unable to do much. I kept falling down, so I went to the doctor and found out that I had to have back surgery. It was bad timing to have it happen during the middle of my year as president. It was not ideal, as I could not give ALDA my all. As a result, Dave Litman took over temporarily.

It was an honor to be on the board as president, communicate with the other board members and learn the ropes. It was a very interesting time. I remember letting the other board members know that there would be no work on weekends unless something important came up. Working with the board and getting to know them better was rewarding. Having health problems was not. I guess I could say it was the best of times, and the worst of times.

**What ALDA Has Given Me**

ALDA has given me the power to be who I am, and not be afraid to be deaf. ALDA has given me the courage to speak up, and not hide my cochlear implants. I wear them proudly like a badge of honor. I have them decorated and wear a different cover on my implant to match the clothes that I am wearing. I often get compliments on my "GLITZ."

Many people don’t know what a cochlear implant is, and people would often ask me about it. They sure learned more about cochlear implants after talking with me. I used to hide my hearing aids when I was younger. Thinking about that now, it was not such a good idea to hide them. It’s better to be open about your hearing loss so more people will open up to you.
Advice for New Members of ALDA

My best advice is “Just be yourself!” Don't try to be who you are not. Most importantly, don't BLUFF. We know when you are bluffing. ALDA is there to help you, and we will communicate with you by using pen and paper, or crappy sign language, or even writing on a computer tablet or a smart phone. ALDA's motto is "whatever works". Relax and soon you will feel like you belong. It doesn't take long to begin feeling that “ALDA is family!”
An Unremarkable Beginning

As I write this, I am 45 years old. About half of my life has been as a hearing person with no thought of what living with hearing loss would be like. The other half of my life has been as a completely deaf person with no sound in my life (except for constant tinnitus). If you are reading this, I assume there is not much interest in what my life was like as a hearing person. So let me get that over with quickly and sum it up in one word…unremarkable.

I lived, I worked, I enjoyed sports and music, but my life lacked any real purpose. I was going through the motions, but never really moving forward. In many respects, it seemed I had been waiting for something to come along and say, “Hey you, wake up!” It turned out that being diagnosed with neurofibromatosis type 2 (NF2) and subsequent surgeries was the start of that wake up call. Change did not happen overnight, and I hung onto my hearing identity for about two years. The reality of being a late-deafened adult hit me after I broke up with my hearing girlfriend. She had become my safety net against the hearing world, and when the relationship ended, my true journey as a late-deafened adult began. This was the summer of 1998.

Life Changes

In 1998 I was working at the post office as a newly deafened adult. I had become deaf from NF2 in 1996 and was muddling my way through this new world of silence. I knew a little bit of sign language from working with a deaf coworker, but I was by no means fluent or confident when it came to using sign language. Things changed for me in the fall of 1998 when I was encouraged by my mental health counselor to attend a convention of other people who were late-deafened. Since this convention was only a seven hour drive from my home, I decided to take the plunge and see what would happen. As it turns out, not much happened – just a whole new outlook on life, hearing loss, and making goals for my future. As I said, not much happened. And for those reading this, that was ALDAcon 1998 in Chicago that I was referring to.

While the impetus for this change in my life can be traced to ALDAcon 1998, it was not until I was driving home that I had my epiphany that maybe my life could move in a new direction and I could pursue some professional goals. The first goal I set for myself was making a return to college. At the time, I had attempted college but failed miserably due to lack of direction and motivation. When I was
at ALDAcon I had met several people that inspired me through their stories and encouragement. I contacted my VR counselor, and she was supportive of my goal to attend college. With her support and encouragement, I registered for classes in the spring of 1999. My undergraduate experience at the University of Minnesota was amazing. Amazing the support I received from my advisors; amazing the support I received from the staff of interpreters; and amazing that I actually did well enough to graduate with a BA degree in Deaf Studies and Child Psychology.

As I got close to graduation, I discussed career goals with my advisor. I had identified a desire to work with hearing parents that have deaf babies. My goal was to help them gain the knowledge and confidence that they could raise a happy and healthy deaf child and make unbiased decisions for their child’s life. Social work seemed to be the obvious choice at the time, and I was encouraged to attend Gallaudet to pursue a Master’s in Social Work.

I was accepted at Gallaudet and was able to graduate with an MSW degree. Through my two years of graduate school I recognized that a deaf (even if late-deafened) person would have a difficult time effectively communicating with hearing parents in a neutral way about the needs of their deaf baby. While I still had (have) the passion to do this, I needed to rethink my approach to working with families.

One opportunity that presented itself was to work as a social worker at a deaf school, which I did. While working at that job, I gained valuable real-world, first-hand experience of the challenges parents face in raising a child that is deaf. I learned the value of working with parents where they are at and trying to help them reach the goals they have set for their children. I met so many parents that worked hard to educate themselves and make the best decisions they could for their child. I valued this experience, but also felt limited in my ability to work in depth with families. Therefore I made the decision to move into mental health therapy work with deaf and hard-of-hearing individuals.

For seven years I was a Licensed Clinical Social Worker, providing therapy, advocacy, and case management to a wide variety of individuals with hearing loss. I was able to work with people who used the full spectrum of communication strategies – from Deaf persons that sign natural ASL to late-deafened who only communicate through spoken and text-based English. It was a challenging job that permitted me to see many of the obstacles that deaf people face in the world today.

I left that job and moved to a state agency where now I work with people that are hard-of-hearing in a variety of ways. I truly enjoy the challenges of this job and the multiple opportunities I have to work with people that are hard-of-hearing and late-deafened. I am able to bring to this job many years of professional experience, but I am also able to share my personal experiences as well. Being able to relate to another adult that has hearing loss has made my job eventful, enriching, and meaningful.

**ALDA Influences**

I don’t know what future jobs are waiting for me, but I do know that my work will always have a hearing-loss focus. It is what I know, and it is what I enjoy doing. The foundation of my professional work life can be traced back to that fall ALDA convention that I went to in 1998. I owe who I am today to several people I met at that first ALDA convention. I am not sure if those people know how much their stories and support meant to me, but I will for sure tell them the next time I see them. One of the reasons I am so passionate about ALDA is how much it changed my life and my outlook on life. I went from a guy who was just trudging along getting by to a man who was able to become licensed as a clinical social worker. I am proud of the accomplishments I made, but I also understand that it would never have happened if it were not for my second family of ALDA! ALDA has not only had a big impact on me in regards to my career goals and professional life, but also socially. For those of you that
know me you might be surprised to learn that I have always been socially awkward and shy. I typically do not do well in groups. However being with ALDA has liberated me in many ways, and I now feel more confident when interacting with others. I crave my ALDAcon week as a time where I can let go and embrace others. I never have as much physical contact (hugging people) as I do when with my ALDA family.

I remember vividly in 1998 during my first convention standing around and watching others singing during karaoke night. I remember singing the words to myself of songs I loved, but would never hear again. I remember so desperately wanting to go up on stage to sing out loud with others. Most of all though, I remember how I was terrified to get on stage to sing because as a hearing person people would make fun of me at how bad my voice was. Finally someone dragged me on the stage to sing, and as they say, the rest is history. I think getting on that stage to sing was one of the most liberating moments of my life. I am serious. I have always been shy, especially in groups. I would typically want to hang on the outside of a group and not want to be noticed. That all changed as I am holding the microphone and singing, “Hotel California”! Since that moment my confidence as a late deafened adult increased and my willingness to engage with others also increased.

The difficult thing about ALDAcon is that it lasts only one week. I have experienced the “ALDA blues” after every convention. I leave with so much confidence and vow to myself that when I return to the real world I will continue to be a strong, confident late-deafened adult. This confidence and after-ALDAcon glow will continue for a couple weeks, and with Facebook and the ability to electronically stay in touch with ALDA friends it sometimes lasts a full month. But unfortunately the reality of being late-deafened in a hearing world wins every time.

The simplicity of easy communication people take for granted is often a struggle for someone late-deafened. The fact that I can use sign language and have Deaf friends to sign with does not matter. I identify as a hearing person and always will. When I go to sleep and dream, it is as if I am hearing. When I talk with hearing people (even if they also sign) I use my voice. It is who I am. I struggle with this identity challenge every day, and it is one of the main reasons I have invested so much time and energy with ALDA.

**ALDA Is Home**

ALDA is where I feel at home, and home is often the place we long to be. Whether it is attending ALDAcon, being involved with a local chapter or group, meeting an ALDA friend for coffee, or serving on the board in various capacities it has been important to me to find these opportunities to stay connected with other late-deafened people and specifically to stay involved with ALDA.

Every year that I am blessed to attend ALDAcon and stay connected with ALDA I consider it a blessing. I am thankful for the friends I have made and continue to have in my life. I grieve for those ALDA friends who have touched my life and are no longer with us. I have traveled from Minnesota to New York to North Carolina and ALDA has always traveled with me wherever I might go. I know that if I had never found ALDA my life would be so completely different and much emptier than it is today. From the bottom of my heart, I thank you all for permitting me to join the ALDA family and for helping me change my life from a hearing person who hid in the shadows to a late-deafened person who is not afraid to sing loud, clear, and poorly “Paradise by the Dashboard Light”!
This book was printed with funding from CaptionAccess, providers of live and post-production captioning services. The founder and CEO of CaptionAccess, Bill Graham, was ALDA’s co-founder and first president. For more information about CaptionAccess or to receive a quote on rates, visit www.captionaccess.com, email info@captionaccess.com, or call 847.986.9330.