The year 1964 was a watershed time in my life. I turned 13, saw the Beatles at Hollywood Bowl, and moved to a new city and a new junior high, leaving behind my best buddies. So when my mom noticed a rather odd spongy swelling growing on my left temple and wanted to know how it got there and whether it hurt, I just shrugged. Concerned when it didn’t go away, she dragged me to the doctor, who said it appeared to be a benign fibroma that probably should be surgically removed. Thus began the saga of my life with neurofibromatosis type 2, aka NF2.

Over the next 50 years, my little benign tumor problem morphed from being a spongy swelling, to an unnamed tumor syndrome, to a genetic disease, and finally to what is now called NF2 (not till the mid 80s did I encounter that term). Back in ’64 there were very few diagnostic tools apart from primitive X-rays, biopsies, and going in for a look-see. It wasn’t until the mid to late 70s that things like CT scans (they originally called them EMI scans, as I recall) came along, and not until the late 80s were MRIs available (I had my first one in 1990).

I underwent several minor operations for my temple tumor problem in the 60s, followed over the years by three long and delicate brain tumor removal surgeries in ’77, ’90, and ‘02. In 2012 I had my first radiation surgery, Trilogy, which is similar to the CyberKnife procedure. Every few years I have faced some kind of minor NF2-related surgery, mostly of the “outpatient” type. Several little tumors continue to lurk dormantly along my spine and major nerves, and MRIs are regular events. Because there is no family history of the disease, the geneticists tell me I’m a mutant! So far, my “bad” genes don’t seem to have passed on to my kids.

The disease finally stole all my hearing and vestibular functions in 2002 (in ‘77, I had lost all hearing and most facial nerve function as well as most of my sight on my left side).

All that considered, along with the probability that NF2 is not finished with me, I feel incredibly fortunate to have survived to the age of 63. I’m deaf and I walk funny, smile funny, look like I was in a fight and lost, and can’t taste sugar, but while all these issues are challenging, they are bearable. (Watching my kids go through rough, non-NF2 life-threatening medical crises was much harder.)

When I meet my fellow NF2 survivors, many of them very young and afflicted with a much harsher form of the disease, I realize how blessed I am to have survived to the age of 63. I’m deaf and I walk funny, smile funny, look like I was in a fight and lost, and can’t taste sugar, but while all these issues are challenging, they are bearable. (Watching my kids go through rough, non-NF2 life-threatening medical crises was much harder.)

When I meet my fellow NF2 survivors, many of them very young and afflicted with a much harsher form of the disease, I realize how blessed I am to have made it this far with comparatively little damage and serious life setbacks. I refuse to ask “why me?” because “why not me?” Each of us faces serious issues in life—tragedies, catastrophes, pain, loss, you name it. NF2 is simply one of them. Each time I think my situation is bad, I learn of another person who faces a much tougher challenge and I am chastened.

I have, of course, had my bouts of sadness, fear, depression, self-pity, and frustration. Those emotions have been tempered by my faith in God’s love, the support and love of my husband, my
Hi everyone!

It feels a little odd to be back here again, and as much as I enjoy connecting with you all, I do wish the circumstances under which I’m writing this column were different. Somehow this space seems a bit hollow without the “hey y’all”s and “be good gang”s that were so typical of the sunny and effervescent Rachael Morris. As many of you know, Rachael passed away a few months ago after a courageous battle with NF2. Although the disease took several of her physical abilities, it was no match for her indomitable and buoyant spirit. It is in Rachael’s memory that we chose the theme for this issue, NF2.

Inside these pages you’ll find stories written by those who live/have lived with NF2, interviews of people with NF2, an article about getting an ABI (auditory brainstem implant) and much more. Hopefully, these stories will give you a deeper appreciation of the challenges faced on a daily basis by those who live with NF2. We are all linked by the common thread of hearing loss, and although the causes may be wide and varied among us, learning more about them helps to strengthen the connection between us as late-deafened adults.

As we become engrossed in autumn’s fast pace of school activities, sporting events, and impending holidays, to name a few, let’s not forget the need to take a step back every now and then and rest. I was reminded of the importance of this yesterday while spending the day with my nephew in a rural part of Maryland. As part of his preparation for the sacrament of Confirmation, we were required to make a one-day retreat in the secluded setting of a Franciscan monastery, far from the hustle and bustle of everyday life. I admit that the prospect of sharing this time with a 15-year old who would have preferred to watch paint dry was not too appealing. However, as the day went on, the benefits of being away from all the “noise” for a while became apparent to both my nephew and me. We talked more, forgot about school and work concerns, and became more relaxed.

Dealing with hearing loss daily is tiring, whether we are consciously aware of it or not, and I’ve learned that recharging our batteries can be just what the doctor ordered. It could be accomplished as simply as by curling up with a good book, going for a long walk, or watching some movies on TV. Hearing loss is tough, so it’s important to give ourselves a much-needed break from time to time. ALDAbest!

Eileen

Eileen Hollywood

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INSIDE THIS ISSUE:

1 Fifty Years with NF2
3 Eileen Here
4 Note from Nancy
4 Some Basic Facts About Neurofibromatosis Type 2
5 Just Shy of 30 Years
6 Four ALDAns with NF2 Speak Out
9 How NF2 Changed My Life
12 Life with an Unrecognized Hearing Loss
14 Now, I’m Angry!
15 NF2 and Communication
16 NF2ed
17 One of Us
18 Nancy Kingsley selected for Hamilton Relay 2014 Better Hearing and Speech Month Recognition Award for the State of Pennsylvania
20 2014 OTICON Focus On People Awards Honor Joyce Edmiston of Mount Joy, PA
21 My World is No Longer Silent
23 Frontiers of Communication
24 Nexus Inland NW – Spokane, WA Seeking Executive Director
25 Chapter Happenings
25 SKSK
26 What Is ALDA?
Note from Nancy

By Nancy Kingsley, Editor-in-Chief

I have to thank Yael Shaner, this issue’s “One of Us” subject, for my newest hobby. Although I’ve never met Yael, I learned from her responses that one of her hobbies is taking free online classes through www. Coursera.com, a company that provides MOOCs (massive open online courses). Yael noted that most of the courses offer subtitles in English (as well as in many other languages, since this is an international program).

I went to the Coursera website and found two courses on subjects that have long interested me—social psychology and how to reason and argue. I signed up for the first one, watched the videos, read the readings, and learned a lot. As soon as I finished it, I signed up for the second course, which I’m still taking (you can take more than one course at a time, if you so desire).

Courses vary in length from a few weeks to a semester and are taught by real professors from top universities. From my experience so far, the professors have great senses of humor and know how to make their subjects fun to learn. It’s possible to earn statements of accomplishment by doing assignments, participating on discussion boards, and taking quizzes, but it’s not required—you can do as much or as little work as you want. Although each course has a time frame, you don’t have to adhere to it.

Coursera was started just two years ago and now has seven million users. Courses are available in many fields, particularly health, humanities, and the social sciences. Topics cover quite a range, such as “introduction to Philosophy,” “Nutrition, Health, and Lifestyle,” and “Comic Books and Graphic Novels.” There’s something for everyone with a sense of curiosity, and it’s free and accessible to us, so check it out for yourself.

I discovered a similar free MOOC program, EdX (www.edx.org), which also began in 2012, has over 2.5 million users, and is owned by MIT and Harvard. Because their accessibility information didn’t specifically mention captions, I emailed them for clarification and was told that captions can be activated via a cc button on the video.

Thanks again for the heads up, Yael!

Some Basic Facts About Neurofibromatosis Type 2

By Nancy Kingsley

There are two types of neurofibromatosis, which are inherited from different genes. NF1, which is much more common, does not cause hearing loss, whereas the hallmark of NF2 is the development of nerve sheath tumors called vestibular schwannomas in the region of both auditory nerves. Although the tumors are benign, their location near the brain makes them dangerous, and they or the surgery to remove them causes deafness. Often, the nearby facial nerve is damaged as well, leading to facial paralysis.

NF2 is “autosomal dominant,” which means that if one parent has the condition, there is a 50% chance that each child will inherit it. About half the time, NF2 is caused by a new genetic mutation.

Hearing loss, tinnitus, and balance problems are the main symptoms that first bring patients to the doctor. When it begins before age 20, NF2 typically involves many brain and spinal tumors and rapid tumor growth. Numbness or weakness in the arms and legs can develop as a result.

NF2 tumors can be treated by surgery and radiation. The latter causes less damage but can lead to the later development of cancer. Drug trials are also being conducted.

Because NF2 causes damage to the auditory nerves, cochlear implants usually won’t work, but another device known as an auditory brainstem implant (ABI) may be able to restore some sound perception.
At the dinner table in 1981 when I was 11 years old, a resounding “Awwwww” came from my mom as she pointed at me, causing me to be mortified and embarrassed. She said my right eye wasn’t moving all the way to the right, but a series of eye exams, a CAT scan, and many doctors’ appointments turned up nothing.

My story

In my family there are four of us with NF2—my mom (Jean Richards), sister, nephew, and myself. My mom had one brain surgery when I was around 10 years old. I remember going into her hospital room and seeing her pull up her hair to reveal a snaking scar from her brain surgery. I was speechless.

In 1985 after my first MRI, my mom revealed the outcome: I had two tumors in each inner ear. I ran toward the phone and called my best friend, sobbing. At this time, the average lifespan of someone with NF2 was 35 years, and I thought I only had a short time to live. The teenage years are turbulent anyway, but throw in brain surgeries and uncertainties, and you have a nice traumatic cocktail.

The summer of 1986 proved to be harrowing for my family. My oldest sister and I were due to have brain surgeries at the Mayo Clinic. My family and I rented an apartment and awaited the surgery dates. I was to be first, but then I caught a cold and needed to go after my sister. I cried twice, first when I saw my sister right after her surgery with all the tubes sticking out of her and again when it was my turn for surgery and they shaved off my hair (that sounds funny, but this was the mentality of a 16-year-old). This surgery deafened my left ear and gave me slight facial paralysis. Kids at school said I had a “sly smile.”

Speed up a few years.

My son

At age 21, I gave birth to a baby boy. I had been married briefly, but being so young and having problems with my husband, I left him soon afterwards. I raised my son in line with the African proverb, “It takes a village to raise a child.” We have a strong relationship and he shares a closeness with my parents and is compassionate and caring towards everyone in my family. His presence has helped to heal some of the familial wounds.

Jesus

As I turned 24, my hearing kept deteriorating. A few months before my third surgery I accepted Jesus Christ into my life! It was the best move ever. Now I was fully “armed” to do battle with NF2. Three months later I had the brain surgery that deafened me. My son, who was three years old at the time, thought I would be able to hear when I left the hospital (wouldn’t that have been nice?).

I’m blessed that later in my 20s I went back to college, and at 31 I earned my B.A. degree in liberal arts. I studied magazine journalism, which focused on investigative reporting, perfect for the study of NF2 health care. I now work with online healthcare organizations. It’s very important and empowering for me to bring information about cutting-edge scientific advancements to the NF2 community. I’m thankful I work with dedicated researchers.

For me, the hardest aspect of NF2 (though many of the symptoms vie for top spot) is deafness, for there is discrimination daily. I’ve become an excellent advocate and strong researcher, and I work consistently with legal and advocacy agencies. Not being able to chat effortlessly is isolating, and the sheer weight of silence (broken only by tinnitus) is enough to drive one mad.

Medical community

I have an NF network of experienced NF2 doctors, and Dr. Andrew Fishman (http://www.andrewfishmanmd.com/index.html) at Cadence Health in Winfield, Illinois, is at the top of my list. He is extremely knowledgeable about and experienced with NF2. He became my neurotologist early in 2009, and my NF2 anxieties have been greatly alleviated through him. Cadence Health just merged with Northwestern Memorial Hospital in downtown Chicago, another NF2 power hitter hospital.

NF2 poses complex considerations, but in 2014, there are many more educated and experienced NF2 doctors than there were during my teenage years. By the way, I’m in a tumor growth hiatus! I just had my yearly trip to the National Institutes

Continued on page 8
The National Institutes of Health describes neurofibromatosis type 2 on its Genetics Home Reference website (http://ghr.nlm.nih.gov/condition/neurofibromatosis-type-2) as follows:

Neurofibromatosis type 2 is a disorder characterized by the growth of noncancerous tumors in the nervous system. The most common tumors associated with neurofibromatosis type 2 are called vestibular schwannomas or acoustic neuromas. These growths develop along the nerve that carries information from the inner ear to the brain (the auditory nerve). Tumors that occur on other nerves are also commonly found with this condition.

The signs and symptoms of neurofibromatosis type 2 usually appear during adolescence or in a person’s early twenties, although they can begin at any age. The most frequent early symptoms of vestibular schwannomas are hearing loss, ringing in the ears (tinnitus), and problems with balance. In most cases, these tumors occur in both ears by age 30. If tumors develop elsewhere in the nervous system, signs and symptoms vary according to their location. Complications of tumor growth can include changes in vision, numbness or weakness in the arms or legs, and fluid buildup in the brain. Some people with neurofibromatosis type 2 also develop clouding of the lens (cataracts) in one or both eyes, often beginning in childhood.

Some ALDAns who have NF2 speak openly about their condition while others are reluctant. Their willingness, or lack thereof, has nothing to do with pride or shame. To them, it’s only one part of who they are.

With the recent death of Rachael Morris, a beloved ALDAn with NF2, much attention has been drawn to this condition. Realizing how rare it is (only 1 in 33,000 people have it), many ALDAns may be wondering just what it is and how it affect a person’s life. Below are a few questions I asked of a few of our fellow members about their cases. Participating were Jean Richards (JR), David Litman (DL), Norma Ortiz (NO), and Ken Arcia (KA).

**At what age were you diagnosed with NF2? And where?**

JR: At age 40 at the Mayo Clinic in Rochester, Minnesota.

DL: I was diagnosed at 24. I had developed a ringing in my left ear, and after an audiology appointment did not indicate anything wrong, I had an MRI that showed bilateral tumors, which I learned was from NF2. My diagnosis was made by a local neurologist, but I was fortunate to have treatment at the Mayo Clinic.

NO: I was diagnosed at 25 by a neurologist in a private hospital in Mexico City.

KA: I was diagnosed and had my first surgery at 20 at the House Ear Institute in Los Angeles. I became deaf at 21 after a second surgery.

**Did you inherit NF2? [Editor’s note: half the time, NF2 is inherited and half the time it’s due to a new mutation. NF2 is autosomal dominant, which means that there’s a 50% chance that a child will inherit it from a parent who has it.]**

JR: No, it started with me.
Four ALDAns with NF2 Speak Out (continued)...

Continued from page 6

DL: My NF2 is the result of spontaneous mutation, not inherited.

NO: No.

KA: Yes.

What about NF2 challenges you the most?

JR: Being deaf.

DL: This is difficult for me to answer because I have been very fortunate to only have deafness, a little facial paralysis, and balance nerves severed. So my challenges are nothing compared to what many with NF2 face every day. I enjoy being active and because of balance issues, I can no longer play sports the way I used to. I miss the ease of communicating naturally through language, and I miss my smile.

NO: The most challenging thing about NF2 for me is uncertainty. You can hear and smile, but you don’t know for how long. You can move your arms and legs and feed yourself and see, but you know that one day you might stop being able to do any of them.

KA: The vigilance in watching tumors on my spine and other places.

Which of your symptoms have caused the greatest sense of loss?

JR: Again, being deaf.

DL: Loss of balance has been the greatest loss for me. Bumping into walls, losing my balance and then falling down because I cannot correct it, trying to walk at night, not being able to play sports competitively are part of my everyday life because of the severing of my balance nerves.

NO: After my first surgery I lost sensation and fine movements in my hands; after my second surgery, I developed a dry right eye, so I’m unable to cry on that side. Not being able to cry and feel with my hands is tougher than having a hearing loss.

KA: Hearing loss, since I miss music. I can understand some but can no longer hear in stereo due to my left ear being completely deaf.

Which communication strategies work best for you?

JR: Having a cochlear implant and using sign language. [Editor’s note: Jean is lucky—most people with NF2 cannot use CIs because they don’t have intact auditory nerves. Instead, they can receive an auditory brainstem implant, which is less effective.]

DL: When I was diagnosed, one of the first thoughts I had was that I needed to learn sign language. Since I was going to be completely deaf, communication had to become visual for me. I am willing to work WITH anyone on effective communication, but everything for me has to be visual.

NO: As a general rule, it depends on the person with whom I talk. Most of the time, what works better is lipreading, but I can’t read everybody’s lips, so writing and signing—if he or she signs—helps, too.

KA: I am fluent in sign language, so I prefer that.

Are you ever hesitant to approach new attendees at ALDAcons?

JR: No.

DL: Very much so, but it has nothing to do with NF2. I am socially shy when meeting new people. I know people will say that is not true, but it is. I look back at my first ALDAcon, and if it were not for Tony Yuppa, I would still probably be stuck in the corner of a room with my thumb up my...

NO: My first ALDAcon was in New Mexico, and as a newbie, I was a little shy.

KA: Not since 2000, when I was president of ALDA. Now I approach many, introduce myself, and offer assistance if needed. I believe that we should all reach out to newcomers, since we were in a similar situation at some point.

Do you ever feel that people are hesitant to approach you?

JR: Sometimes.

DL: I am not sure. Most people do not recognize I have NF2, so their fear of me is probably related more to my being crazy, which is completely understandable.

NO: No! Never.

KA: Sometimes, but I try to put them at ease and encourage them to use sign language, lipreading, writing notes—whatever works!

What would you like to share most with our readers to help them understand the ways in which you are different and the ways you are the same?

DL: The biggest way I am different is I that have total hearing loss in both ears. While our individual stories of how we lost our hearing is different, we all share the challenge of being a (former) hearing person who can no longer hear effectively in our environment. The ability to communicate with others and to enjoy music are now VERY different since we lost our hearing, and hearing people cannot
Four ALDAns with NF2 Speak Out (continued)...

Continued from page 7

truly understand what those challenges are like. That is why my time with ALDA is so valuable to me, being able to feel “normal” with hearing loss.

NO: My life is different from others (even other late-deafened adults) because I go to the hospital very frequently. Fortunately, not many people have to be hospitalized at least once a year. However, it is not as bad as it sounds. You can make friends in a hospital and, I must say, very good friends because people in hospitals don’t care whether you are rich or not, whether you have a master’s degree or a PhD, or whether you have a car or a big house. It seems when people face tragedy, they show their best side, their human side. In spite of the tumors, the surgeries, and rehab, I’m still a human being. I have feelings. I laugh at a joke (especially when I hear it, ha ha). I cry when a family member or a dear friend dies or suffers. I dance. I enjoy time with my friends. I’m happy with a big piece of chocolate cake and a good cup of coffee. I love dogs. I enjoy traveling. I feel loved when someone hugs me. And despite NF2, I want to live as fully as possible. For these reasons, I think I am like everybody else.

KA: If you are a late-deafened adult, I am, too! I also experienced loss and struggled with it. Although the reason for your deafness may be different from mine, we have probably faced many of the same obstacles. You are NOT alone. Feel free to contact me with ANY questions at kenarcia@gmail.com. There are no “stupid questions.” We are ALDA family!

Terri Singer writes, “In 2006, Carol Postulka introduced me to Cleo Simmons through email because Cleo had responded positively to my query about sharing a room during the St. Louis ALDAcon. Carol had told me about Cleo’s case of NF2 and a little about the condition. Still, I was unprepared for NF2’s effect on facial nerves, so the barrier that facial paralysis presented to lipreading was a surprise. Since I don’t sign, Cleo used her lipreading skills and I used pen and paper when necessary, and we became fast friends.

Cleo was the first of a number of ALDAns with NF2 who have become part of my friendship circle. On the first night of the St. Louis ‘con, my cousin Dennis Gonterman introduced me to his good buddy, Ken Arcia. Over the past eight years, I’ve gotten to know Ken and learn what a supportive and fun man he is. At ALDAcon 2010 in Colorado Springs, I met Dave Litman, having previously admired his gregarious manner from afar. I’d announced that ALDAcon 2011 would be held in Indianapolis, and Dave came over to volunteer his help. The following year, I made the same offer to him and we worked together a bit on the ‘con in Columbia, South Carolina. This is when I discovered both his wicked sense of humor and his dedication to all things ALDA.

At the ALDA Board’s business meeting in Colorado Springs, I was so impressed with Rachael Morris’ Region 3 report that I had to tell her, and that added another delightful person to my ALDA family. During ALDAcon 2012, I was able to spend more time one-on-one with Rachael. She used her iPad and we shared lots of laughs and some serious work. Since Jean Richards and I both have cochlear implants, the only time we’ve had trouble communicating is in a very noisy environment, but I’m glad that I didn’t let the communication hurdles keep me from getting to know any of the other warm, friendly, funny, and dedicated people with NF2 whom I’ve come to cherish. I found that there always is a way to connect by practicing the ALDA motto: “Whatever works, works.” Contact Terri at TLSEVIN@aol.com.

Just Shy of 30 Years (continued)...

Continued from page 5

of Health, which has a research program specifically designed for NF2. (I go there so they can learn from me.)

I guess you can say that NF2 birthed passion into my soul, for I used to be shy, quiet, and disciplined at holding in my emotions, except for joy. (Our family was not an emotional sort, but NF2 had other ideas.) I stay level-headed, focused, and calm through my strong faith in Christ.

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

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

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

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

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

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

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

I also have difficulty using my right hand and trouble speaking. Not being able to use my right hand well is especially hard, because I am right-handed. My handwriting has suffered some and I have had to learn to sign with my left hand. Both of my facial nerves have been damaged from tumor removal and radiation therapy, and I cannot move.

Continued on page 10
my lips. When I speak, I use my hand a lot to move my lower lip so that people can understand me better. I just have to speak slower and clearly. I go to doctors in Los Angeles, Boston, Winston-Salem, and High Point. I see some kind of doctor at least once a week and have to have periodic MRI scans done to check for growths.

Medical Timeline

- In February 2006, I underwent brain surgery at the House Ear Institute in Los Angeles. I had an acoustic neuroma removed and an auditory brainstem implant (ABI) implanted on my left side.
- In April/May 2006, I received radiation therapy to my brain for other inoperable lesions and went through physical therapy.
- In July 2006, I had unsuccessful surgery to repair my damaged facial nerve.
- August 2006: The hearing in my right ear had been deteriorating. I was hoping it would hang on until I fulfilled my student teaching requirement, but three weeks prior to starting, my hearing was completely gone in both ears. I withdrew from school.
- In November/December 2006, I went through more radiation and physical therapy. I also took a beginner sign language class along with friends and family.
- On January 9, 2007 I returned to LA for removal of the acoustic neuroma on the right side and placement of a second auditory brainstem implant.
- In the spring of 2007, I took another sign language class. I was in and out of the hospital for treatment of hydrocephalus. I had severe headaches, dry and unfocused eyes, and loss of most function and feeling in my right hand. I also had extreme balance and weakness difficulties that resulted in my being unable to walk unassisted. I now used a walker. Life was difficult!
- In September 2007 I began a chemotherapy drug called Tarceva, which I discontinued in May 2008 because the side effects were getting worse and worse. I wanted to feel good for an eventful summer. Fortunately, my tumors have appeared stable since I started Tarceva.

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

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

This is how it is going to be from now on.

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

Because of what NF2 has done to me, yes, my social life has suffered! I do not live like your typical girl in her 20s. Group situations are the hardest. I feel left out of conversation most of the time. I am a great lipreader, so I look around trying hard to lipread the conversation but end up getting lost. It is just as annoying for me to interrupt by saying “What are y’all talking about” as it is for the speakers who have been interrupted! In a lot of situations I get very stressed out and I shut down. This happens with friends and family. It is so hard to see people hysterically laughing together. My reaction is always delayed, and after the moment, the humor is no longer funny.

It hurts deeply, but there is nothing anyone can do. Everyone really does their best to include me. We have ALL learned some signing but are not fluent. We do not live in a strong Deaf community, and I feel like I am the only one. Most of my friends do not live in High Point. We all text and email like crazy, and I just don’t see them nearly enough. I cannot do a lot of things my peers do. For example; concerts, parties, shopping, bars, etc. are all difficult for me. My entire body gets so tired. My stamina has improved a great deal over the years but...
How NF2 Changed My Life (continued)...

Continued from page 10

still is not 100 percent.

I now volunteer several days a week at a local high school, working with exceptional students, and I live at home with Mom, Dad, Smokey (our dog), and Butter Frances (our cat). My world was put on hold my final year of college because of NF2 and I had to withdraw for brain surgery. After ups, downs, and loop-de-loops, I was able to get back into school this past year. In May 2009, I received a BS degree from the University of North Carolina at Greensboro (UNCG), majoring in professions in deafness and concentrating in auditory-oral deaf education. I am kind of lost and don’t know where to go now. When I began college, I was majoring in auditory-oral deaf education. I was unable to student teach, so I lack my teaching license, resulting in the general degree. After the road I have been on, I have gained interest in other hobbies and possible paths in life.

I get bummed, bored, and throw a pity party from time to time, but I strongly believe in keeping my glass half full and staying optimistic. Life is a roller coaster, but still good! I do not like to be sad and would rather celebrate my abilities, everything I have overcome, and who I am NOW. Life is too short and you have to take it one day at a time. By sharing my story, I think I can make a great role model/mentor. Motivating others who may be struggling with something is what I am most passionate about! I try hard not to dwell on how neurofibromatosis has changed my life. I have been through more than most people go through in a lifetime. It has been a complete turnaround, especially in the past four years. I have had to adjust to a life very different from that of my peers and accept a lot of changes. I am very lucky to be blessed with wonderful friends and family, with whom I share a close bond of unconditional love, support, and strength. We have stuck together and fought together. Without them I would not have the motivation, spirit, and attitude I have today.

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

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

I am new to ALDA and had the FABULOUS opportunity to attend ALDAcon in Seattle. It is so hard for me to put into words how amazing it was. I gained so much from being there. I became a “confident deaf woman” for sure. I loved mostly learning that I am not the only one who experiences the insecurities and isolation that I do. You all inspired me, and I miss you. I took a piece of you all home with me in my heart! When the pity party starts calling my name and I begin feeling like “the dog underneath the table,” I take a deep breath and think of what we learned from each other and the bonds we share.

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

Reprinted from the Winter 2010 ALDA News.
Rachael was from High Point, NC and served as ALDA’s Region 3 Director and ALDA News managing editor. She died on July 14, 2014 at age 32.
Life with an Unrecognized Hearing Loss

By John Prokop

I’ve had a hearing loss for my whole life, but I wasn’t made aware of it until I was 19 and about to be drafted for military service. My draft letter notice arrived right after New Year’s Day in 1967, because I had dropped out of college when the semester ended in December. I needed to work full time to earn enough money to take more classes in order to keep my college deferment, but as soon as the university notified my local draft board that I was no longer attending classes, the letter for my draft physical arrived that next week.

The letter told me to report at 6:30 a.m. with proper credentials (birth certificate, draft card, and photo ID). I had heard about the infamous draft physical from other friends who got drafted. I remember hearing that it was thorough, time-consuming, and intimidating and included invading and exploring every orifice and crevice in one’s body. They would also test every body system and its fluids.

After I arrived I was registered, assigned a medical examination folder, and told to strip down to my underwear and tee shirt, place my clothing in a foot locker, and follow the arrows through the various medical examination stations. Luckily the stations were all numbered and I didn’t have to ask where to start. The facility was staffed by US Army personnel, and none were friendly or accommodating.

When it came time to do the hearing test, we were taken to a small portable soundproof room that held about six chairs and a table with headphones and hand-held button testers for us to press when we heard a sound (beep). After the test, people were given their folders back and told to proceed to the next exam station. However, I was not given my folder and was told instead to stand aside and repeat the test with the next group. I thought this was strange, since no one else was held back.

I reentered the soundproof room and retook the test, but when I walked out, I was still not given my folder, and I was told I was to repeat the test again. Now I was getting a little nervous and concerned, because no one else was told to do this. I took the test for the third time, listening so hard for the tones that I felt like I was imagining them in my head rather than really hearing them. I couldn’t figure out why I was being made to repeat this test over and over.

After my third attempt, I was told I must see an ENT doctor because I was unable to pass the test satisfactorily. I was also told if I was trying to deceive the US Army and get out of being drafted, I would be found out and put on a train to the nearest Army boot camp before the day was over. That made me panic and wonder why I was being told this.

The Army ENT doctor was an older man, an officer, and rather stern. I sat in his office in my underwear, with the perspiration running down my arms like a river. He sat at his desk studying my hearing tests and asked me to tell him about my hearing loss. I said I wasn’t aware I had a hearing loss. He asked if I had trouble hearing people talk or understanding what they said. I said some people mumbled or didn’t speak clearly, and those were the only ones I had trouble with, and sometimes I didn’t hear women with soft voices well.

The doctor asked if I any had trouble hearing in grade school, high school, or at home. I suddenly remembered that the nuns in my grade school would sometimes throw an eraser at me in class to make me wake up and pay attention. I couldn’t figure out why they would do that because I really was paying attention. They would say I daydreamed or did not listen when I was called on. Many times I was moved to the first row of the class so I would listen better. It never dawned on me why this was occurring. Of course, when I was moved up to the front I heard better, which just reinforced what the nuns thought I had been doing—not paying attention. My hearing loss was in the upper frequencies, which was why I had trouble hearing the nuns.

I attended an all-male Catholic high school where the entire faculty were priests or brothers of a religious order. I didn’t remember having problems there like I did in grade school. Since I heard lower frequencies well, my hearing loss was not evident to me during my high school years, and I just thought many girls and women mumbled or talked too softly and it was they, not me, who had the difficulty.

At home I had five siblings and my mother was always yelling and hollering, so I never had any trouble hearing her or my Dad. Our house was busy with many people living there (extended family), and everyone yelled to be heard, so no one at home could tell I was hard of hearing.

The doctor personally repeated the hearing test and then said he was going to ask me to repeat words he was going to say. He first asked me the words while facing me and then repeated the words from behind me. When he was finished, he told me I had a profound hearing loss in my right ear and a severe loss in my left ear. I was an excellent...
Unrecognized Hearing Loss (continued)...

Continued from page 12

speech reader, and that was probably how I was able to get by as well as I had thus far in the hearing world.

I sat there absolutely stunned to find out that I was the one who had the problem and that I had such a serious hearing loss that I was truly unaware of. My problem had a name and it wasn’t something I did or caused. This was an epiphany, and suddenly so many things made sense to me.

The doctor told me my hearing loss made me unsuitable for military service, so I wouldn’t be eligible for the draft. He suggested I seek out a qualified audiologist to see if hearing aids could help me hear better.

I was given copies of my hearing tests and ENT consultation by the medical clerk and then escorted to the checkout station to complete my physical and be discharged. I had many conflicted feelings as I left the medical facility. I was happy that I wouldn’t be drafted (although I was expecting to be), but now I had another issue to deal with—my newly diagnosed hearing loss.

For about a month, I didn’t tell anyone, including my parents, about my getting called up for the draft physical. I finally made an appointment to see another ENT doctor, and in February 1967 I was fitted with my first pair of hearing aids. That experience is material for another article at another time.

John lives in St. Petersburg, Florida and is a member of both ALDA and the Hearing Loss Association of America. His email address is jet@ij.net.

Fifty Years with NF2 (continued)...

Continued from page 1

98 year-old-daddy, my family and lifelong friends, and especially in the last 10 years, the NF2 family and ALDA.

I have been befriended and uplifted by wonderful NF2 soldiers including Paula Chapman (my first NF2 buddy), Michelle Lewis, Dave Litman, Heidi Herzog, Sarah Gorden, and of course our wonderful and sorely missed Rachael Morris, who taught me that it is okay to sit for a spell on the pity potty and then “just flush it!” (That is some of the best advice I ever received on coping with NF2.) How can I be down for long with friends like these who understand?

The hardest part has been watching them fight, and sometimes, lose their own battles with NF2 as Rachael did. Each of them has a story, and each of them inspires me to face up to my own battle with as much courage and optimism as they display every day.

The past 50 years have been amazing! Diagnostic tools have improved dramatically, and technological advances in surgery have increased survival rates. Research has discovered just how NF2 develops, and we all look forward to a cure in the not-too-distant future.

Since 1964, besides living with NF2, I have watched some incredible moments in human history, lived in foreign lands, made friends around the globe, AND am still here to enjoy my grandkids. Not a bad 50 years, that!

Now, in 2014, with God’s help (and remembering Rachael’s positive attitude), my goal is to master the art of contentment in all circumstances and to view my glass as half full and ready to be filled to the brim with love and joy.

Marta lives in Montana and is a happily married wife, mother of two, and grandmother of four. Due to NF2 tumor removal, she completely lost her hearing 12 years ago, and her main form of communication is ABI-assisted speechreading (and talking, which she says she does a lot more of). Marta would love to become proficient in signing, but her only opportunities to practice are when she is with other ALDAns. Her hobbies include gardening, knitting, reading, and writing emails, and she has taken a new interest in watercoloring. The things she misses most since becoming deaf are her family’s voices, music, being able to understand sermons and prayers at church, and the sounds of nature. Marta says she tries to focus on all things bright and beautiful and be thankful. Her email address is aldamartacitaw@gmail.com.
For the first time ever, I’m finding that I’m actually really, truly, stratospherically angry about neurofibromatosis type 2. You know, the family curse.

This isn’t a wrist-to-forehead woe-is-me or a Nancy Kerrigan-esque “WHY ME?” kind of thing. Nope, it’s just straight-up rage.

Yep, I’m a little slow. Why wasn’t I in a fury 33 years ago when my Massachusetts General Hospital neurologist, Dr. Parker, and my surgeon, Dr. Ojemann, gave me the news? Shock? Fear? Being lost in wondering what this all meant? How my life would now play out? Yes, plus I was always focused on coping.

In my 20s, I was trying to survive that first surgery and being left by my beau while I was in the hospital. I was also attempting to duck my cousin, who had NF2 too, and her well intentioned yet spectacularly bad advice (“Only God can heal you. Don’t have the operation. Come with me to the faith healers!”) and wretched example. Yes, she died early and tragically from this.

When the print shop where I worked in Cambridge folded, also while I was in the hospital, I needed to scramble to find a new gig that would provide me with health insurance that wouldn’t turn me down for this brand-new-to-me, stunningly large pre-existing condition. Thus, my 20s were pretty action-packed with the coping hurdles.

When I was in my 30s, my symptoms weren’t so bad—some headaches, but not bad as long as I wasn’t weightlifting (my preferred workout back then). I also miraculously experienced only a minor hearing loss from that first surgery, my balance wasn’t so awful yet, and I had a good shrink to help me through the emotional minefield of dealing with everything. And my fabulous husband—the Amazing Bob—and I were a red-hot, going concern. I was able to do pretty much anything that anyone else could (except ditch my job and run away, insurance-less, with the circus). The NF2 seemed sorta distant—certainly not pressing.

So, I kicked up my heels and started solo traveling (Scotland, Eastern Europe, Amsterdam, etc.), since my husband doesn’t enjoy visiting foreign lands. I also started taking in as much live music as possible—after all, my hearing had an expiration date. I’d hit the local clubs at least once a week.

My 40s were still about coping. I clocked in with seven major surgeries plus some near-debilitating radiation in that decade. My best pals, Jen and Oni, and my awesome little sister, Celeste, were there, supporting me throughout. I still traveled but not as much, still took in the occasional show but not like before. This was due to getting older, not being as vibrant due to all the “shootouts at the Massachusetts General Hospital corral” and, eventually, living in the suburbs—“Valhalla by the sea” versus Cambridge.

Now, in my mid 50s, I’m deaf, tippy as all get-out, have a nerve-damaged funny face, and get nasty headaches if I bend over too much. But, all in all, I have a pretty fabulous, happy life.

And now I’m angry? C’mon...NOW? I don’t quite know what to think of this. Maybe I just never had the time or space to be angry about having the family curse before? Dunno. What to do, what to do? (I just love signing that phrase!)

Today’s gonna be sunny and in the mid-60s. A nice long trike ride, for starters, seems like a good plan—a fine distraction.

Donna was born in your basic large eastern seaboard college town and currently resides in Houghs Neck, Massachusetts with her husband of 28 years. After working in a traveling carnival, selling fireworks on street corners, dispatching trucks, and working as an artist’s model, she found her home in the printing industry, “paint and ink feeling pretty similar and all.” She can be contacted at Grantmad@aol.com.

Happy Thanksgiving!
NF2 and Communication

By Kathie S. Hering

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

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

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

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

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

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

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

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

- a sense of humor—I’ve learned to laugh at absurd situations, such as entering an operating room and being asked the million-dollar question, “Can you read lips?” Never mind that everyone has put on their little blue mask.
- knowledge—I try to learn as much about the surgery as I can handle. I ask questions and expect answers. I want to know

Continued on page 16
Someone once said comedy is tragedy. Perhaps. Comedy might also be the icing on the cake of life’s drama and trauma. I have NF2 and swallowing issues, and icing literally makes cake easier to swallow.

A number of times my mother has told me that I was born with my umbilical cord around my neck; it was a traumatic beginning, but I survived in 1954. When I was six months old, I had pneumonia. Also, paralysis developed on the left side of my face. My grandmother noticed that tears were coming out of only one of my eyes. Back then it was thought to be Bell’s palsy, but it never went away, so I grew up with the left side of my face paralyzed, though it didn’t sag. I had a normal childhood and teen years, but I don’t think I would have if the doctors had known to look for NF2. The damage to the left side of my face happened early; deafness in my left ear became apparent when I was nine. A doctor saw something odd in that ear but thought it was an infection. The matter was dropped because his poking around hurt too much.

My parents divorced when I was 12 and Mom met my stepfather when I was 13. Years later, when my hearing loss was more noticeable, NF2 was diagnosed at the House Ear Institute in Los Angeles. That was in December 1972, and I had my first major NF2 surgery in February 1973. The surgery that left me deaf and with both sides of my face paralyzed was in March 1977.

Afterwards, when I went back to work at a medical library, one of the two coworkers I had started going out with after work just disappeared. I saw the other one a few more times, but that friendship was also over. I love the sea and big ships, and I got word of a teletype job at a steamship company. This was a perfect position for a deaf person, but I was a one-handed typist because of NF2, so I didn’t get my dream job because I couldn’t type fast enough on the big clunky machine. (Back then, some deaf people used teletype machines for phone conversations.)

When I was turned down for a promotion at the medical library because I couldn’t use the phone, I quit work to go to Gallaudet University in the autumn of 1978. After one semester, I left because of homesickness and returned to Houston, where I graduated from the University of Houston with a degree in journalism.

The Acoustic Neuroma Association put me in touch with others who had NF2, and that’s how I met Rick Skyer. During the years we corresponded via postal mail, he sometimes mentioned the work that his sister Kathie Hering was doing in Chicago. At the time, I didn’t grasp what he meant—I learned about ALDA, Inc. later.

Now I’m losing ground to NF2. There have been many challenges, but these have been the cake iced with joy and lots of good times. Just to grab a memory, I think about the day I stood alone on a wild beach and a dolphin leapt up out of the Gulf of Mexico to greet me. That was way cool. Life can be hard, but each day has its bright spots and I keep believing in them. I agree with this saying from the Internet: “Laugh when you can, apologize when you should, and let go of what you can’t change. Life’s too short to be anything but...happy.”

Kudos and peace to Rachael Morris. ILY.

Roxanne lives in Georgia with her ex-husband, Mark—they continued to share their condominium after their divorce. Mark is deaf with low vision (deaf-blind) while Roxanne is late-deafened from NF2, and some of the differences between them are interesting. They help each other out when they can.

NF2 and Communication (continued)...

Continued from page 15

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

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

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

Originally published in ALDA News, May-June 1991 and reprinted in the Winter 2010 issue. Kathie was a co-founder of ALDA and served as president of ALDA-Chicago for many years. She died in 2004.
One of Us

By Karen Krull, Curator

This issue’s interview is with Yael Shaner, a long-time member of ALDA-Peach. Read on and you’ll know why Yael is “one of us.” She can be contacted for more information at yaelshaner@yahoo.com.

Name: Yael Shaner
Where were you born? In Dayton, Ohio, on October 10, 1945
What is your current residence? Atlanta, Georgia
Marital status: Divorced
Children/grandchildren/great grandchildren: I have one daughter, five grandchildren, and two great-grandchildren

Education: I received an M.A. in interpersonal communication from Bowling Green State University in 1995 and a certificate from Gallaudet University’s Peer Mentoring Program in 2009.

What is your present job? Bookkeeper for a small nonprofit organization that provides information, training, and support to parents of kids with special needs

What is the worst job you ever had? A VERY temporary job working in a factory putting cardboard boxes together

Movies you want to see again? These are the movies I watch over and over again. They’re all comedies and provide me with PG laughs when I need them!
  • Legally Blond with Reese Witherspoon
  • Galaxy Quest with Tim Allen, Sigourney Weaver, and Alan Rickman
  • Office Space with Ron Livingston and Jennifer Aniston
  • Stuart Saves His Family with Al Franken

Books you tell others to read? The Rise and Fall of the Third Reich by William Shirer

I stay home to watch no TV programs, due to poor captioning and way, WAY too many commercials. I LOVE the re-runs of the ORIGINAL Law and Order with Jerry Orbach, which I watch on Netflix.

Favorite pig-out food: Bread... I love it in any form!

Hobbies: Learning ASL and German, and taking free online classes through Coursera.com. The current class I’m taking is A Brief History of Humankind, taught by Dr. Yuval Noah Harari at the Hebrew University, Jerusalem. This class (like most of the Coursera classes) is captioned in English. Class lengths vary from one course to another. This one is five months long and includes 17 lectures on video streaming online, with about four hours per lecture. This is an amazing class!

If I had more free time, I’d take more Coursera courses.

When I am depressed, I: tend to isolate myself, so I have to make myself reach out to others.

My most irrational fear is: bugs; specifically, those HUMONGOUS water bugs that get into my house.

The thing I like best about myself: My sense of humor
What I can’t stand is: gossipy people.
Favorite memory: My daughter’s birth
Favorite saying: Handsome is as handsome does.

What is the cause of your deafness? Part of it is probably genetic, as there is congenital deafness in my paternal grandmother’s side of the family. I never remember being able to hear out of my left ear. My right ear had a significant loss, which a doctor attributed to the use of antibiotics during childhood.

Age/year you became deafened? I had ongoing hearing loss, about which I was in total denial. Finally, following an ear infection in 2006, most of my remaining hearing went out over the next two years.

The hardest thing about becoming deafened is:

For me, it was being unable to communicate with my younger grandchildren. Also, casual conversations were no longer possible.

I began accepting my deafness: FINALLY, after I lost most of my hearing, I started reaching out to others with hearing loss, including ALDA-Peach.

The worst thing about deafness is: lack of good communication with others

The best thing about deafness is: I don’t have to hear what I don’t want to hear! I like my quiet world.

If I could hear again, the first thing... Continued on page 22
Nancy Kingsley selected for Hamilton Relay 2014 Better Hearing and Speech Month Recognition Award for the State of Pennsylvania

(May 20, 2014)

Nancy Kingsley of Lancaster, Pennsylvania makes a great impression in the deaf and hard of hearing community as being the “go to” person when advocating for the rights of individuals with hearing loss. She lends her knowledge of the Americans with Disabilities Act (ADA) to the many organizations in which she participates.

Nancy serves as the Chairperson for the Lancaster County chapter of the Hearing Loss Association of America (HLAA) and the Director and Advocacy Chairperson for HLAA—Pennsylvania. She also serves on the Advisory council for the Pennsylvania Office for the Deaf and Hard of Hearing (ODHH) where she is influential in enhancing the lives of individuals who provide and receive ODHH’s services.

Nancy also serves on a committee dedicated to educating organizations and event venues on the need for captions, FM systems and hearing loops. Through her work with this committee she was able to bring captions to the Fulton Theater in Lancaster, PA.

Nancy is currently enrolled in Gallaudet University’s Peer Mentoring Program where she learns how to take her passion for advocacy one step further. The program is designed to help students problem-solve and establish goals for improving the quality of life for individuals who are deaf or hard of hearing and ensure that equal and appropriate access to means of communication is available to them.

We commend Nancy Kingsley for her advocacy and dedication to improving the lives of individuals who are deaf or hard of hearing and are pleased to present her with the Hamilton Relay 2014 Better Hearing and Speech Month Recognition Award for the State of Pennsylvania.

This leadership recognition has been brought to you by Hamilton Relay.

About Hamilton Relay

Hamilton Relay provides contracted Traditional Relay and/or Captioned Telephone services to 16 states and the Island of Saipan, and is a provider of Internet-based Captioned Telephone services nationwide. More information is available at www.hamiltonrelay.com.
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- Current Bills in Congress on Internet Access (HR #3101 & S #3304)
- Mandate for Captioned Telephone Relay Service
- Relay for Deaf-Blind Users
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- Captioning at Movies, Live Events and Online
- National Broadband Plan
- Modernized NG-911 Services
- And much more... 

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Growing up with hearing loss, Joyce Edmiston lost many opportunities to interact with others, make friends and advocate for herself. Over time, she gained the courage and wisdom to make her voice heard. Today, she freely shares her hard-won knowledge as a vocal advocate for people with all degrees of hearing loss through her popular blog Xpressive HandZ. Edmiston is among the outstanding individuals with hearing loss honored by the 2014 Oticon Focus on People Awards, a national competition that celebrates individuals who are helping to eliminate negative stereotypes of what it means to have a hearing loss.

This is the third year that Oticon, Inc., sponsor of the national awards program, has invited the public to cast their votes to help determine who among the 12 finalists would be first, second and third place winners in the Adult, Student, Practitioner and Advocacy categories. More than 10,000 votes were cast by people from across the country and around the world.

As the first place winner in the Advocacy Category, Edmiston was recognized on August 14 at a special awards ceremony at Oticon, Inc.’s US headquarters that was attended by hearing care professionals from across the US. As part of her award, Edmiston has designated Hearing Loss of America Association, Lancaster County as her choice for a $1,000 donation from Oticon, Inc.

Edmiston is passionate about the teaching of American Sign Language (ASL) and has also formed a committee to educate local churches the need to provide captioned services for those who do not communicate by sign language. She volunteers with the Telecommunications Relay Service Advisory Board for the Pennsylvania PUC, the Collaborative for Communication via Captioning, and with HLAA at both local and state levels.

“Individuals like Joyce Edmiston are inspiring role models for people living with hearing loss,” states Oticon President Peer Lauritsen. “The remarkable people who are honored in this year’s Oticon Focus on People Awards program have taken their unique circumstances and transformed their lives with a positive outlook that has enabled them to overcome challenges and accomplish goals well beyond what many thought possible.”

The Oticon Focus on People Awards program was created in 1997 by Oticon, Inc., one of the world’s oldest and most respected hearing instrument manufacturers. By celebrating the accomplishments and contributions of individuals with hearing loss, Oticon, Inc. aims to call attention to common misconceptions about hearing loss and motivate people with hearing loss to take advantage of the help that is available to them. The company’s goal is to reach out to the 80 percent of an estimated 28 million Americans who could benefit from hearing solutions, but who fail to seek professional help.
My World is No Longer Silent

By Jacqueline Murphy

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

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

A hearing aid would not have been helpful, so the surgeon performed a promontory stimulation test to help determine whether I was a candidate for a cochlear implant. He said I was a candidate, and in June 1997, I underwent cochlear implant surgery. However, I obtained negligible benefit from the device. The surgeon then told me that the ABI was the only device available that might help me hear. It was still in the clinical trials at that time, and the FDA granted approval for only a limited number of medical institutions to participate.

The hospital where I was initially treated for NF2 was not one of them, but New York University Langone Medical Center is one of the FDA approved medical institutions. Fortunately, I live in New York, and it is not a long commute to NYU.

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

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

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

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

My auditory nerve was not functioning well enough for me to benefit from a hearing aid or a cochlear implant. Therefore, I had only two options: I could continue to live in a world devoid of sound, or I could have the ABI, and possibly have some sound perception. So, I decided that I wanted to have the ABI.

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

I was ecstatic and felt very optimistic that I would be able to hear well again. Although Dr. Roland, Dr. Golfinos, and Bill Shapiro told me that I would not have “normal hearing” with the ABI, I was in denial. I longed for the excellent hearing that I once had, and I did not want to accept the fact that the degree of my hearing loss would always be profound. I set my expectations unrealistically high and was very disappointed. I could not recognize environmental sounds, because all sounds were alike. I was able to hear voices, but speech was garbled and voices were monotonic and mechanical. During one of my follow-up visits, I told Dr. Roland, “I hear your voice, but you sound like a robot.” The quality of the voices, combined with the garbled speech, made it more difficult for me to read lips.
My World is No Longer Silent (continued)...

Continued from page 21

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

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

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

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

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

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

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

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


One of Us (continued)...

Continued from page 17

I would do is: Actually, I CAN hear again . . . well, sort of. I’m a cyborg now due to a cochlear implant. After being activated and chatting with my daughter, the first thing I did when I got to my car was turn on NPR.

How did you learn about ALDA? An online search led me to ALDA.org; that, in turn, led me to our local chapter.

In what ways has ALDA enhanced your life? There are so many ways. . .

• Connection with other people through meetings, email, newsletter, online groups, and personal one-on-one friendships
• Not having to explain that I can’t hear
• Writing and editing the ALDA-Peach FUZZ newsletter since January 2008, which has given me the opportunity to be of service and to learn much about hearing loss and its implications
• Being encouraged to take the Peer Mentoring Program at Gallaudet, which was a life changer for me by giving me great information about the emotional, mental, and physical aspects of hearing loss

The bottom line is: Stay in today, live one day at a time!
Frontiers of Communication

By Bill “Hand-to-Nose” Graham

[Editor’s note: This is one of the most popular articles by Bill Graham, ALDA’s co-founder. It was originally published in the May 29, 1989 issue of ALDA News. Bill’s girlfriend Karina, whose nose is the subject of the article, subsequently became Bill’s wife.]

One sunny day a few weeks ago, as my girlfriend Karina and I lay side-by-side on her parents’ lawn working on our skin-cancers-to-be, I playfully reached over and grabbed her nose. I squeezed the nose lightly between my thumb and forefinger and maintained this gentle pressure until Karina spoke. I don’t remember her exact words—they were probably something insignificant like, “I can’t breathe, Guillermo”—but the important thing was this: I understood everything she said.

Without letting go of her nose, I responded to her remark. Karina then said something else and, once again, I understood her perfectly. We continued in this manner for several minutes with growing amazement. With my hand on her nose, I could lipread Karina much better than I normally do. I experimented with other parts of her body—the top of her throat, the back of her neck, near her Adam’s apple, but none of these locations aided my discrimination as much as having my hand on her nose.

This finding staggered me. I have never been a good lipreader, and my ability and motivation to lipread have dipped even more in the seven years since I learned the comforts of sign language. I do, of course, recognize the practical value of this communication mode, and so I was elated to find this convenient way to improve my skills. For me, Karina’s lovely nose functioned like one of those vibro-tactile devices that pick up speech vibrations and thus help certain deaf people lipread better. But those gizmos are electronic and cost a pretty penny. Karina’s nose is 100% natural, free, and available whenever she is near me.

Although my discovery proved fraudulent, I was hardly distraught. Because in the past year, ALDA truly has crossed into a new frontier of communications. Our use of inexpensive real-time captioning systems at small group meetings represents a tremendous breakthrough for late-deafened adults. It has brought many late-deafened people into group conversations for the first time since they became deaf. Captioning is the “best common denominator” for communicating with late-deafened people because it is something that all of us can understand. More than any other factor, captioning has made it possible for ALDA to function normally as a group.

If you think there’s no way on earth for you to communicate in a group, give captioning a try. In no time, you’ll be holding conversations, not noses.
Nexus Inland NW – Spokane, WA Seeking Executive Director

Nexus is seeking a new Executive Director to replace a long time Executive Director who is retiring. The center is looking for someone who understands the center’s mission and has innovative leadership with which to steer the center into a new chapter of its 30 year history. Nexus recently updated its name: Nexus Inland NW – Serving the Deaf and Hard of Hearing since 1980 and its mission statement: Bridging communication and community.

The Executive Director reports to the Board of Directors and is responsible for the Agency’s overall leadership and operations in accordance with the mission and policies approved by the Board. The Executive Director will lead a highly qualified team focused on serving the deaf and hard of hearing community. Skills and knowledge valuable to the center’s future success include: 1) Leadership and Management: Demonstrates the leadership, initiative and persistence needed to accomplish the goals and objectives of Nexus; has understanding of federal, state and local laws regarding non-profits and ensure compliance with their regulations and a working knowledge of significant developments and trends in the field of deafness and hearing loss issues as well as having expertise in entrepreneurism that include development and marketing which will promote the Center’s mission, values, objectives and reputation. 2) Communication: Ability to develop sound working relationships and cooperative arrangements with community groups and organizations through effective communication with a wide variety of people (written, oral and other possible modalities). 3) Budget and Finance: Knowledge of community foundations, governmental bodies and philanthropic communities, ability to procure funding for the center, contract management by ensuring established funding requirements are maintained as prescribed by the lender, expertise in financial management and understanding financial sources as well as the ability to adapt to ongoing changes. 4) Personnel: Expertise in organizational management and supervision of staff/volunteers, maintain a climate which attracts, motivates and retains a diverse staff of top quality people, ability to manage and or delegate all aspects of the center as well as cross training of the different programs within Nexus.

A master’s degree is preferred, but a bachelor’s or equivalent, with 5 years’ experience, will be considered. Traveling in order to provide training and outreach is required. Salary will be based on experience and qualifications.

Please send a letter of interest with your resume and references to:
Executive Director Search Committee
Nexus
1206 North Howard
Spokane, WA 99201
Chapter Happenings

By Ann Smith, Curator

Francine Stieglitz reports from Boston that the weather was glorious for ALDA Boston’s Fourth of July party on Saturday, July 5. More than 20 people enjoyed the delicious appetizers, salads, desserts, and drinks, and chefs Lou and John barbecued the pork tenderloin, chicken, and Portobello mushrooms perfectly. Guests brought lawn chairs and everyone sat outside, making frequent trips inside to refill their plates. Hosts Lou and Linda Sakin prepared their home both inside and out, just in case the weather didn’t cooperate. September 14 was scheduled for Sundae Sunday in Waltham at Lizzie’s ice cream parlor for an afternoon of fun and fancy desserts.

Francine also sent a clarification of the summer issue report from Boston. Celebration ’14, at which Gael Hannan was the featured performer, was a first-time collaboration between ALDA-Boston and HLAA Boston, not sponsored solely by ALDA-Boston. Because of the success of that evening, ALDA-Boston and HLAA will continue to collaborate on other events. It’s great that ALDA and HLAA are working together.

Jim Stansell reports that the Atlanta Peaches have been busy these past few months. In May they had their annual cookout at the lake. June featured a day of bingo, and July saw the Peaches at Atlanta’s High Museum, which had a special exhibit on concept cars—unbelievable art from really creative minds.

Send news about your chapter (for “Chapter Happenings”) and your personal news (for “GA to SK”) to Ann at fabsmith@att.net. Deadline for the next issue is November 20.

SKSK

The art of living lies less in eliminating our troubles than in growing with them.

—Bernard Baruch
What Is ALDA?

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

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

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

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

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

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

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

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

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

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

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

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URL/Website Address: _____________________________________________

ALDA Chapter (Name/None): _________________________________________

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If paying by check, please mail this form to:

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

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

[ ] Education  [ ] Advocacy  [ ] Role Models  [ ] Support

ALDA provides networking opportunities through local chapters and groups as well as at the annual ALDA conference (ALDAcon).
Be sure to check your address label. It shows the date your dues will expire. Don't let your membership lapse!

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

Make a Difference! Become a Lifetime Member!

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

Ann Smith, Lifetime Member

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

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

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